

**What is the Experience of Primary Eye-  
care for Children with an autistic  
spectrum disorder?  
A grounded theory investigation**

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## **Abstract**

### **Background**

Autism spectrum disorder is a group of lifelong neuro-developmental disorders that influence the way people interact, view and communicate with their world. It is thought that people with autism spectrum disorders have a shorter life span because they do not alert people to health problems that might be treatable. Healthcare in the United Kingdom is intended to be accessible equally by all. Planning for services requires the input of service users to ensure that they are accessible. There is limited knowledge about the experience of eye-care from the service user's perspective.

### **Aim**

The aim of this research is to investigate the experience of eye-care from the perspective of children with autism spectrum disorders.

### **Methods**

A grounded theory methodology was used. Eight primary carer and child dyads and five eye-care professionals were interviewed. Data were analysed and the categories that emerged were integrated to develop theory.

### **Findings**

The overarching category that emerged from the children's data was *feeling in control*. There are facilitators and barriers to this which are dependent on the autism spectrum disorder awareness of eye-care practitioners and the eye-care awareness of primary carers.

### **Conclusion**

The experience of primary eye-care for children with an autism spectrum disorder is dependent on whether they *feel in control* of the situation. The theory generated indicates that a child can be enabled to feel in control if their primary carer and eye care professional work together to reduce the sensory burden, provide continuity, and adapt the process in a person-centred way. This research shows that strategies that enable the child to feel in control can reduce the challenges of the process of primary eye-care. In order for this to be possible the primary carer and eye care professional need effective communication pathways to plan for each individual's specific needs and to prepare the child for the experience.

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## Glossary

Binocular vision	The ability of the two eyes to work together to create depth perception.
CCG	Clinical commissioning group
CVI	Certificate of visual impairment
ECP	Eye-care professional
Enhanced Services	Additional services contracts awarded to optometrists that have accreditation in specialist skills such as Glaucoma management
Functional vision assessment	Observed visual capacity without subjective measurement of acuity
GOS	General Optical Service
Indirect ophthalmoscopy	Method of examining the ocular health that can give longer working distance than conventional means
Kays pictures	Test of visual acuity that employs line drawings that can be named or used in conjunction with a matching card
Lea symbols	Test of visual acuity that employs symbols that can be named or used in conjunction with a matching card
Makaton	Method of communicating with signs and symbols to assist people who are unable to communicate effectively verbally but can be used to support speech development
Ophthalmoscopy	Observation of the health of the inside of the eye
PECS	Method of communicating with pictures to enable conversation for people who are unable to communicate verbally. It is commonly used in educational settings for children with ASD
PC	Primary carer
Phoropter	Head set containing trial lenses for refraction enabling the spectacle prescription to be

	calculated without resting equipment on the patient's nose or ears
PMLD	Profound and multiple learning disabilities
Px	Patient
RAF rule	A ruler used to measure the near focusing ability of the eyes and other binocular vision functions
Retinoscopy	Objective measurement of refractive power of the eye
Rx	Spectacle prescription
Social stories	Story that gives information and pictures to help people with learning disabilities to understand what to expect when they attend a particular appointment

# Chapter 1: Introduction

It is thought that people with Autistic Spectrum Disorders (ASD) may have a shorter life span because they do not alert people to health problems that might be treatable (Datlow-Smith *et al.*, 2012; Mouridsen *et al.*, 2008; Tuffrey-Wijne *et al.*, 2013; Cavill, 2001). They have a less satisfactory experience of health care than people without autism (Lajonchere *et al.*, 2012; Nicolaidis *et al.*, 2012) and according to some research compared with other disabilities (Vohra *et al.*, 2013). Healthcare planning tends to be based on what adults think are the views of children (Carney *et al.*, 2003). The children's voice is often unheard (Notbohm, 2004). This research investigates the experience of children with an ASD when they access primary eye-care services in England.

## 1.1 Autism Spectrum Disorders (ASD)

ASDs are a group of lifelong neuro-developmental disorders that have three common traits (Wing and Gould, 1979; Wing, 1996; Baron-Cohen, 2008; Howlin, 1998). First described by Leo Kanner (1943) and Hans Asperger (1944), they are referred to as a spectrum of disorders (ASD) or conditions (ASC). ASC is the preferred name but this research is using the former name because it is found most commonly in the literature. The diagnosis includes a large range of conditions (including classic autism, pervasive developmental disorders-not otherwise specified (PDD-NOS), William's Syndrome, Rett's Syndrome and Fragile X- Syndrome) and therefore levels of severity and expression are very varied (Howlin, 1998; Wing, 1996). All have the basic traits of ASD with varying degrees of learning disability (LD) and other signs specific to their diagnosis see Table 1.

As a result of these traits they can find the world a frightening, overwhelming and unpredictable place. They may appear aloof, rude, inflexible with very narrow interests and obsessive behaviours. They may have set routines and display repetitive behaviours such as spinning and flapping (Baron-Cohen *et al.*, 1985; Baron-Cohen, 2008). As a result of their communication impairment they may take comments very literally or misconstrue meanings. As a result of their imagination impairment they may put themselves in danger because they cannot predict the outcome of some situations (Morton-Cooper, 2004).

**Table 1: The Three Traits of ASD (Wing, 1996; Baron-Cohen 2008)**

Impairment type	Challenge caused by impairment
Impairment of social communication	Understanding verbal and non verbal communication including facial expressions and body language
Impairment of social interaction	Understanding and recognising other peoples' feelings and knowing how to respond. Respecting social norms and managing own feelings and emotions.
Impairment of social imagination	Understanding the intentions of others and predicting others' reactions. Understanding alternative actions to those of usual routine.

In addition to the three common traits 50-75% have learning disabilities (LD) (National Institute of Clinical Excellence, 2013) and 70% have an additional psychiatric disorder (National Institute of Clinical Excellence, 2013). People who have ASD and LD are referred to as “low functioning” and those without LD are referred to as “high functioning”. There is no specific definition of these classifications but those people with IQ below 70 are considered to be low functioning (Morton-Cooper,2004). Children with ASD are also more likely to have epilepsy and have an increasing risk as they get older. 30-50% of people with ASD have developed epilepsy by adulthood (Morton-Cooper, 2004).

The prevalence in the UK is thought to be 1% (Baron-Cohen, 2008; National Institute of Clinical Excellence, 2013) of the population with approximately half a million diagnosed (National Audit Office, 2009) (400,000 adults and 100,000 children). This represents a large increase in diagnosis since it was first described in the 1940s when the prevalence was thought to be 4 in 10,000. Some recent studies have put this prevalence higher (Coulter *et al.*, 2015). However whether this increase is due to the diagnosis now encompassing more conditions than classic autism and to increased awareness and diagnosis or whether it represents a genuine increase due to environmental factors is extensively debated (Wing, 1996; Whitman, 2000; Baron-Cohen, 2008). Due to the range of conditions exact numbers are not available. The prevalence of ASD is far higher in males than females, up to five times as many males as females. However research shows an under-diagnosis of ASD in females and therefore the difference may not be quite so great. ASD is equally prevalent in all ethnicities (The National Autistic Society, 2014).

In addition to the three main traits there are other associated characteristics that may or may not be present (Wing and Gould, 1979; Wing, 1996). These include: stereotyped movements, unusual gaits, imitating movements, hyper or hypo-sensitivities to sensory stimuli, anxieties and fears, poor concentration span, savant abilities, and challenging behaviour.

Overall the challenges for people with ASD and those caring for them are vast. The range of expressions of the conditions and impact is so large that providing services and support is difficult. All activities of daily living can be affected particularly if these involve interaction with other people. The traits can affect other aspects of daily life such the difficulty giving a balanced diet as there may be restricted diets or a tendency to over eat due to food obsessions and hypo/ hypersensitivity to taste (The National Autistic Society, 2015). Poor nutrition can affect their general health. They also often suffer from sleep disturbances which compounds their difficulties during the day (Morton-Cooper, 2004) and the strain of their carers who also have disturbed sleep. The traits of ASD also impact on the child's ability to make and keep friends and these children are often excluded or bullied (Howlin, 1998). They generally have difficulty with any kind of change which means that family times such as holidays and Christmas can be very difficult for them to manage (The National Autistic Society, 2015b). Children with ASD may not appear disabled and therefore the 'hidden' nature of the condition in many people results in more difficulty with interaction due to the lack of awareness of other people.

Diagnosis is guided by the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders May 2013) which involves assessment against a range of criteria. There is no clear diagnosis point and therefore the process can be long and stressful. First indications of ASD appear in most cases around the age of two but usually diagnosis is not completed until the child is around five and sometimes many years later (Department of Education, 2009). The diagnosis is almost entirely based on observed behaviour but also on delayed speech development (Simmons *et al.*, 2009). It is likely that there are children on the higher functioning end of the spectrum that are therefore not diagnosed but will be coping with the impact of the condition anyway.

It is known that children with an ASD have greater difficulty accessing health and social care (Firth, 2008; Grinker, 2009; Morton-Cooper, 2004; Department of Health,

2009; Department of Health, 2006). Interacting in the world around them is difficult for children with an ASD and healthcare interaction is no exception.

## **1.2 Legislative, policy and strategy background**

The paradigm shift from the medical model of healthcare to the social model of disability in the 1990's (Oliver, 1990; Charlton, 1998) should enable everyone to access the health and social care that they need in the community regardless of their specific needs. The theory behind the shift is that it is society that 'disables' the person because of the design of buildings, services and approach. The old medical model of disability focuses on what the disability is and how to 'fix' that disability. The social care model requires society to design equality into services and resources so that the person is not disabled. This paradigm shift was reinforced by The Disability Discrimination Act (Disability Discrimination Act, 1995) and then The Equality Act (Equality Act, 2010). It follows that services within all areas should be reviewing accessibility and ensuring that the provision does not disable people. The white paper Valuing People (Department of Health, 2001) set out a vision of four goals of service provision for people with learning disabilities: rights, independence, choice and inclusion. The progress made towards these goals was assessed by the white paper Valuing People Now which was published in 2009 (Department of Health, 2009). This was followed by Better Lives For People With An Autism Spectrum Disorder (Department of Health, 2006) which focuses on ASD rather than LD. All these papers seek to enforce an ethos of providing suitable services that include rather than exclude. More recently the Autism Act 2009 (Autism Act, 2009) led to a strategy for adults with autism (Department of Health, 2010a; Department of Health, 2010b).

The autism strategy p19 states that:

“personalisation is about assessing the particular needs of each individual and giving them choice and control to build the right package of care based on those needs. The goal of this strategy is to move from fitting people into services to fitting services to meet people's needs”

The Autism strategy sets out the following recommendations for service provision: increased awareness among professionals, improved clear and personalised diagnosis, national diagnosis pathways, improved access to services, promotion of

independent living in the community, opportunities for work, enabling planning and development of services that meet the needs and priorities of adults with ASD.

The autism strategy is aimed at adults; however The Bercow Report (Department of Education, 2009) reviewed the services for children. This report is not specific to health care and concentrates more on diagnosis and education, therefore service providers only have the adult guidelines to follow for all ages.

Autism spectrum disorders are unusual in that the condition is often hidden by coping strategies and so behaviour in challenging situations, like a clinic, may well be misinterpreted and the patient excluded from the care that they need (Morton-Cooper, 2004). The social care model applies to visible and hidden disabilities. These consultation documents highlight how difficult it is for people with high functioning autism to get the support that they need as they do not fit in with mainstream services or services for people with learning disabilities (National Audit Office, 2009; Portway and Johnson, 2005).

Optometrists therefore need to ensure that their practices, services and approach conforms with the social model of disability and that patients with special needs are offered the same quality of service as everyone else. Staff should have appropriate training and services should be planned and commissioned according to need.

The National Health Service (NHS) constitution recognises the importance of the voice of the service user in service development which in this case is children with ASD. The service user is the expert and therefore listening to what they require and what their priorities are is important in the development of services. Services cannot be person-centred unless the service user is asked their viewpoint.

A recent policy statement (Act of Parliament, 2004; Department of Education., 2003) stresses that children's voices need to be heard in research. The inclusion of child participants in research about services for children is therefore an ideal (Fraser *et al.*, 2004). Society has previously considered children unable to express valid opinions but more recently it has been shown that they can give a better understanding of their own world than adult interpretations of it (Morrow, 2001; Coad and Lewis, 2004; Alderson and Morrow, 2011).

### **1.3 Primary eye-care for children**

Primary eye-care is the service designed to provide routine eye-care and correct refractive errors. In England this consists of tests to detect signs of eye disease or abnormality and tests of ocular function (Opticians Act, 1989; The College of Optometrists, 2014). In order to carry out primary eye-care assessments there are a range of tests that are required. These tests involve the use of a minimum of two sets of bright lights into the eye and a frame or instrument to support glass trial lenses. The child will notice some level of dazzle, touch sensation if a frame is used and may be asked to rest their chin on various machines. In addition it is possible that the optometrist will need to stand very close to them to look inside the eyes and may recommend the use of eye drops that sting and cause blurring of vision. The environment is necessarily clinical and there may be noises from machines and chemical smells from cleaning agents. The child and PC will need to answer various questions and the child may be asked to make preference choices throughout the test.

Primary eye-care for children in England is funded by the NHS through General Optical Services (GOS). The main providers of primary eye-care for children are optometrists. Currently optometrists are allowed to offer a GOS assessment to children under the age of 16 every year and every two years for 16-19 year olds whilst still in full time education. More frequent tests are allowed if there is a clinical finding that requires more frequent assessment. Therefore most children with an ASD are entitled to just one eye examination per year. Typically, optometrists will be allocated 20 minutes to achieve a routine eye examination for a child under 16 years. There is a requirement for optometrists to complete a full eye examination for every service user to include all of the following elements: refraction, internal eye examination and external eye examination. Eye-care professionals can only claim a fee if they have completed all components regardless of whether the service user is able to complete these tests. This financial viability of services for people with special needs are doubtful. This is not the case in other countries such as USA where services such as these are privately funded by each individual. Private funding results in the ECP charging for the time and adaptations required and potentially results in a more flexible and person-centred service.

It has been shown that children benefit from routine primary eye-care assessments because the impact of some eye conditions can be reduced if detected and treated

before the age of eight (Logan and Gilmartin, 2004; Zaba *et al.*, 2007). It is therefore recommended that children should have eye screening at infant school entry and at secondary school entry as a minimum (Thomson and Evans, 1999).

If uncorrected, common childhood eye conditions such as strabismus can lead to permanent visual impairment including lazy eye (amblyopia) and poor binocular vision. This can affect educational progress (Chua and Mitchell, 2004) and also in the longer term impact on career choices (Davidson and Quinn, 2011; Rahi *et al.*, 2009). Career entry criteria for some professions can stipulate good vision in both eyes and demonstrable binocular vision. There is also evidence to suggest that people with amblyopia are particularly prone to lose the sight of the better eye in later life (Chua and Mitchell, 2004).

## **1.4 Primary eye-care and special needs**

It has been shown that people with special needs have various barriers to healthcare generally (Nicolaidis *et al.*, 2012; Alborz, 2005; Firth, 2008; Krahn *et al.*, 2006; Grinker, 2009; Morton-Cooper, 2004) and this will include eye-care (Coulter, 2013). These barriers include:

- Physical barriers for those with additional needs (e.g., wheelchair access)
- Having to wait which is very challenging for people with disabilities
- Lack of flexibility of services which means that appointment times and locations can be an issue if they have to rely on others providing transport or because they feel better at certain times of the day.
- Clinical environments
- Anxiety about the uncertainty of the situation
- Over stimulation in crowded environments

It follows that, if children need early intervention to prevent common childhood eye conditions from causing permanent visual impairment, children with an ASD who find communicating difficult should have primary eye-care services that are fit for purpose. These services need to be adapted for children and for the children's additional needs. Those children with a learning disability and other co-morbidities are more at risk of visual impairment than average (Woodhouse *et al.*, 2000; Woodhouse *et al.*, 2013).

## **1.5 Visual function, ocular health, and ASD**

This section presents the knowledge around ocular health in order to establish whether primary eye-care is a priority for children with ASD. Visual function includes: visual acuity (ability to see detail), peripheral vision, binocular vision (ability to use the two eyes together). Ocular health depends on the risk factors for eye disease and the ability to detect, diagnose and treat eye disease before impairment occurs. A table summarising the literature around ocular health, visual function and ASD can be found in Appendix 1i.

### **1.5.1 Visual function**

#### **Strabismus**

Children with ASD are reported to have a higher than average risk of strabismus. Scharre and Creeden report a prevalence of 21% (Scharre and Creeden, 1992) and Kaplan et al gives a figure between 20 - 50%. (Kaplan *et al.*, 1999). These studies were carried out before the DSM-IV which means that it is likely that the cohort were on the lower functioning end of the spectrum. The sample size was small, in both studies there were 34 students, and the statistical analysis did not consider all possible variables. Kaplan also included data from a survey completed by 7,640 carers of children with ASD. They found that 50% of respondents reported that their child was “cross-eyed”. This was not based on known diagnosis but on parental views.

Another study by Milne et al compared 51 children with ASD to 44 age matched typically developing children (Milne *et al.*, 2009). They found that 10.6% of the children with an ASD had strabismus but none of the typically developing group had strabismus. However this was not a statistically significant result when compared to an average of 5% in the general population.

The data is not robust but indicates that further investigation of the risk of strabismus is indicated. This is particularly important because treatment of amblyopia which is the monocular visual impairment caused by strabismus needs to be carried out before the age of 8 (Thomson and Evans, 1999). If children with ASD are more at risk of strabismus, as the research suggests, then primary eye-care is a priority for them.

### **Near point of convergence (NPC)**

Convergence is the ability of the eyes to turn inwards to the correct angle to ensure that detail closer than the horizon can be viewed with both eyes together. If this does not function accurately then the person may suffer double vision, they may have difficulty with perception of distance, depth and speed, and they may exert extra effort in order to maintain concentration. The closer the object the greater the convergence required, therefore reading requires good convergence. NPC is the limit of comfortable convergence. A poor NPC is likely to cause difficulty with near tasks. Milne et al, looked at a wide range of visual function indicators and found that NPC was significantly reduced ( $p < 0.01$ ) in children with ASD (Milne *et al.*, 2009). Anomalies in NPC can be supported with exercises and spectacles and this risk factor is a further indication for primary eye-care.

### **Visual acuity (VA)**

There is no evidence to suggest that children with ASD have poor visual acuity (Milne et al, 2009; Scharre and Creeden, 1992). Scharre and Creeden were not able to carry out monocular acuities which means that their data indicates binocular acuity which can mask amblyopia.

One study seemed to indicate that children who have hypersensitivity to visual stimuli also have very high acuity, known as hyperacuity (Ashwin *et al.*, 2009). Further studies investigated the possibility of hyperacuity and found no evidence of it (Lievanos *et al.*, 2012; Bolte *et al.*, 2012); however the sample size was small in both. The participants in the study by Bolte are stated as being high functioning. There is no information regarding IQ for the Lievanos study. The tests were quite demanding and therefore it would seem to indicate that these children were high functioning. This bias means that the results may not be transferable to all on the spectrum. Appropriate statistical analysis seems to indicate that there is no difference in VA between typically developing children and children with an ASD in both studies (Lievanos *et al.*, 2012; Bolte *et al.*, 2012).

It is important to note that whilst this seems to indicate children with ASD do not have significantly reduced acuity, these studies were with high functioning children and do not take account of the spectacle prescription required to achieve these levels of acuity.

## **Refraction**

The literature shows no significant risk factors for refractive error but there is a paucity of research in this aspect. Scharre and Creeden found 44% of the children in their study had a significant refractive error but this was defined as + or – 1 Dioptre which is not a recognised evidence based prescribing criteria or based on statistical analysis (Scharre and Creeden, 1992). In addition the median result in the study is plano. No other study included refraction results. The literature seems to indicate that children with ASD have the same risk of refractive error as the general population.

## **Colour vision**

Whilst it is common for children with ASD to have colour obsessions and for colour to be a trigger of challenging behaviour (Ludlow *et al.*, 2006), no research was identified that indicated children with ASD have a higher prevalence of colour deficiency.

Colour blindness is a common issue for males. It is estimated that 8% of the male population are red/green colour deficient whereas 0.08% of the female population has this defect. Franklin *et al* looked at colour discrimination in children with ASD and found that there is a generalised reduction in colour discrimination (Franklin *et al.*, 2010). This study involved high functioning children with ASD and age matched typically developing children. The study was in two parts: the first with a group of 28 children looked at colour discrimination and the second investigated chromatic threshold in a group of 70 children. The children with ASD had higher chromatic thresholds and had discrimination levels equivalent to children 3 years younger. No specific colour deficiency was found. The Farnsworth 100 hue test was used to assess colour discrimination, this is a complex test and it is possible that some of the discrepancy is due to concentration spans rather than a deficit in discrimination.

Colour vision naming and memory was investigated in a study comparing the abilities of 13 children with an ASD and 2 control groups (age matched typically developing, and age and IQ matched mild learning disabilities) (Heaton *et al.*, 2008). The children were given a series of pictures with a coloured tile. They were then asked to pick out the colour that went with the picture out of four possible different tiles. Then they were presented again with a picture and a coloured tile and asked to pick out the colour from four possible tiles all different shades of the same colour. It

was found that children with an ASD relied less on being able to verbally name the colour and much more on perception of the colour. This is something that has been seen in very young children before they have developed language. They use this to identify an object even though they do not know what it is called. As language develops they become more reliant on identifying objects from verbally naming them. Heaton hypothesises that because of delayed language and communication development children with an ASD rely on this early method of using perception of features and not by using the name classification as typically developing children do. This resulted in the typically developing children performing worse than the children with ASD when asked to match from a selection of different shades of the same colour. Children with ASD found this task as easy as choosing between tiles of different colours. The study was relatively small (n=13) and therefore these results are not conclusive but it appears that children with ASD are slightly worse than average in naming a colour out of four options but are slightly better than average at remembering the precise colour so that they are able to pick it out of three similar colours.

### **Sensory overload and visual stress**

The connection between sensory overload (feeling overwhelmed when having to process more than one sensory input) has been reported (Baron-Cohen, 2008). In particular hyper and hypo sensitivities to sensory stimuli are known to be associated with ASD (Rogers and Ozonoff, 2005; Bogdashina, 2003, Ludlow, 2012).

Hypersensitivity is the obsessive focussing on tiny details, dislike of the dark or bright, dislike of sudden flashes of light, and a tendency to look down or covering eyes to protect them from the light. Hyposensitivity is the obsessive focussing on lights, looking intensely at objects, flapping fingers or objects in front of their eyes, interest in shiny objects and touching the edges of objects.

Visual stress refers to the symptoms of discomfort and distortion caused by heavy patterns, and lines and lights (Wilkins *et al.*, 1994). The use of coloured overlays and precision tinted lenses has been investigated and shown to be effective in relieving the symptoms of visual stress (Evans, 2001). These have been found to be of benefit for people with migraine (Wilkins *et al.*, 2002) and reading difficulties (Wilkins *et al.*, 1994). In addition there has been research into the use of these filters that show a benefit for people with photosensitive epilepsy (Wilkins *et al.*, 1999). Researchers Ludlow et al (Ludlow *et al.*, 2006) considered that children with ASD may also benefit from coloured filters because there is a high prevalence of epilepsy

in this population. They further suggest that the other perception issues may be due to cortical hyper-excitability which is thought to be associated with migraine and epilepsy. When compared to age matched controls the rate of reading improved significantly. Fifteen out of 19 children from the ASD group benefitted from coloured filters (their reading rate increased by more than 5%) and in some cases up to 50%. A 5% increase is considered a significant improvement (Wilkins, 1996). In the control group three out of 19 benefitted and the increase in reading was between 8% and 25% faster. The age and IQ was individually matched and care was taken to rule out other variables such as colour vision defects. The sample size was modest and the range of abilities is not stated. It is not certain therefore that this interesting finding is transferable to all on the spectrum. The effect was so significant that there is evidence to suggest that overlays are beneficial to children with ASD.

Ludlow et al investigated the effect on reading speed and visual perception issues associated with ASD and again found evidence in a modest sample that reading speed and visual stress symptoms are reduced by coloured overlays chosen on the basis of clarity (not on colour preference) (Ludlow *et al.*, 2008; Ludlow and Wilkins, 2009). There is however a suggestion that self reporting of visual stress by children with ASD is unreliable.

In a further study Ludlow found that children with ASD who respond positively to overlays for reading also show improvement in their ability to interpret emotions based on images when an overlay is placed over the image  $P < 0.02$  (Ludlow *et al.*, 2012). She refers to this as an improvement in their perception impairment.

These studies suggest that visual stress, and sensory overload are significant and under reported by children with ASD. Additional tests of visual stress therefore may be indicated to identify difficulties and coloured overlays may improve reading speed and comfort. This test is not part of a routine eye examination and therefore is not an indicator for primary eye-care but should be considered when evaluating the services provided for children with ASD.

### **Articles relating to visual processing and perception**

In contrast to research into general optometric measures there is a plethora of research into visual processing and perception in ASD. This research is of great importance in understanding how people with ASD view the world but it is of greater relevance to those who are seeking to understand the processes that cause autistic

behaviour. This is beyond the remit of the present study. However presented here are the salient points that should be taken into consideration by optometrists or clinicians. This section, whilst limited in detail, is included because visual processing may impact on the experience of eye-care and explain some of the visual symptoms associated with ASD. However as indicated by Morton-Cooper (Morton-Cooper, 2004) the published research in this area is only likely to be fully accessible to those familiar with neurological science.

There have been two extensive reviews of the literature in this area (Simmons *et al.*, 2009; Dakin and Firth, 2005). The review methods, inclusion and exclusion criteria or how the literature was appraised are not given in either review, and therefore this cannot be considered definitive. However, these reviews cover extensive literature, and provide a very good overview of this area. This is an area with new research being published almost daily. The limitations of research in this area include that the demands of the tasks tend to restrict participation to high functioning individuals only and the study numbers are small with the exception of studies involving online questionnaires. Whilst the research varies in methodology and is generally inconclusive it does show overall that children with an ASD have difficulties with processing and perception and that:

“Individuals with ASD really do see the world differently, or else, attend in a radically different manner to features of the visual environment” (Dakin and Firth, 2005 p504)

In particular they seem to be able to see detail that others do not because they can either inhibit the global information or the global processing is deficient. This ability to ignore the surroundings and focus on the detail is beneficial in some circumstances but a hindrance in others. Table 2 presents a summary of elements of visual processing that appear to be affected in children with ASDs.

**Table 2: Visual processing and ASD**

Phenomenon	Study	Findings	Relevance
Motion perception (perception of movement based on change in luminance across the retinal detectors or due to higher order interpretation of texture or flicker (motion coherence))	(Milne <i>et al.</i> , 2005; Bertone <i>et al.</i> , 2005; Gepner and Mestre, 2002).	Motion perception is slightly worse in people with ASD. Children with ASD make less postural allowance for motion.	Poor motion perception results in poor performance in activities involving movement.
Visual search	Embedded figure test (Edgin and Pennington, 2005), Block design test (Shah and Frith, 1993) Feature search and conjunctive search (O'Riordan, 2004).	It has been shown in all aspects to be faster in children with an ASD than in typically developing children.	Children are more likely to pick out individual details quicker than typically developing children but less likely to understand the context.

Phenomenon	Study	Findings	Relevance
Face and object perception	(Hobson <i>et al.</i> , 1989).	Children with an ASD seem to process and perceive faces differently to typically developing children. For example an inverted face is processed as easily as a normal face whereas a typically developing child will process an inverted face more slowly. It may be that a child with an ASD processes the face as he would an object whereas the typically developing child use higher processing to treat it as a 'special object'.	This has implications as to why children with ASD may have difficulty with identifying emotions from facial expressions.
Eye gaze	(Swettenham <i>et al.</i> , 2003).	Children with an ASD will not naturally spot the line of gaze of another person whereas a typically developing child will notice the direction someone is looking and naturally be inclined to look in that direction. However children with an ASD are able to follow the gaze of someone if they suddenly change the direction of gaze.	Impaired eye gaze results in children with ASD misreading a situation where there are unspoken instructions, directions or implied meanings.

## **1.5.2 Ocular Health**

### **Visual impairment**

Visual impairment is a term used to describe sight-loss that cannot be corrected with spectacles or contact lenses (NHS Choices., 2010). There are several research studies investigating whether visual impairment is more prevalent in children with autism. Some researchers have found a higher prevalence of visual impairment in children with an ASD (Parr *et al.*, 2010; Pring, 2008; Kielinen *et al.*, 2004; Hobson *et al.*, 1999; Hobson, 2010). However there is debate about whether the children have co-morbidity or whether visual impairment causes ASD-like traits (Andrews and Wyver, 2005). (Pring, 2005) suggests that there are two broad categories idiopathic and non-idiopathic ASD. The idiopathic type might be considered classic ASD in an otherwise healthy child and the non-idiopathic is where the cause can be traced to another condition, in this instance it would be visual impairment. In non-idiopathic ASD the child exhibits enough autistic behaviour so that they meet the diagnostic criteria. However there are also differences in the expression of the condition compared with idiopathic ASD. In particular there is evidence that they are more likely to 'grow out' of ASD (Hobson and Lee, 2010). An explanation for this is given by Pring who suggests that this is because their underlying impairment in social interaction is not so severe and that as they learn to use other modalities to compensate for the visual impairment the ASD traits seem to improve (Pring, 2005).

It is thought that autism or autism like traits occur almost exclusively in children with profound vision loss from birth whereas children with partial visual impairment are very unlikely to show these traits (Pring, 2005). Cass *et al* describe 'developmental setback' in children with visual impairment (Cass *et al.*, 1994) which has some of the hallmarks of ASD but cannot be called ASD.

Cass feels that the tests used to diagnose ASD are not appropriate for visually impaired children (Cass, 1998). Luvyster identified that assessment methods for diagnosis of ASD in toddlers may produce a high rate of false positive diagnosis in toddlers with visual impairment who appear to show less signs of ASD as they get older (Luyster *et al.*, 2011).

There have been several studies of theory of mind in congenitally blind children because impairment of theory of mind is thought to be a strong indicator of ASD. Theory of mind is the ability to understand how other people are thinking in a

particular situation and therefore predict what their behaviour will be. One study indicated that children with congenital blindness are slightly delayed in developing theory of mind but that this is not an indicator of ASD (Brambling and Asbrock, 2010). However this study seems to have excluded children who are congenitally blind and have a diagnosis of ASD therefore it proves only that children with congenital blindness do not all have ASD. Evidence of ASD in this population was found by Hobson *et al* in their study of theory of mind development (Hobson *et al* 1999). Another study of children with a visual impairment (not blind) provides evidence that these children develop normal abilities in theory of mind despite their limited vision (Pijnacker *et al.*, 2012). In this study children with an ASD were excluded from the study. Some of the difficulty in diagnosing autism in this group of children is not having a clear understanding of what is the normal developmental progression for a child with profound visual impairment (Dale and Salt, 2008; Cass *et al.*, 1994).

However taking this into account there is still evidence of a high prevalence of ASD in children with profound visual impairment. One study looked at optic nerve hypoplasia (OHN) and septo-optical dysplasia (SOD) (Parr *et al.*, 2010). Parr *et al* found the prevalence of ASD in SOD 36% and OHN 26%. This does not represent evidence that children diagnosed with ASD are at risk of particular eye conditions as the risk factors for ASD appear to be the presence of congenital eye conditions only.

A published case study highlighted sight loss in a teenager with ASD as a result of vitamin A deficiency due to his restricted diet (McAbee *et al.*, 2009). This does not appear in any other literature and warrants further investigation given the large numbers of people with ASD that do have a restricted diet due to aversions to different foods.

Eye rubbing and poking is an issue for some people with ASD and this is thought to be due to repetitive behaviours and perhaps to create sensory stimulation. This can cause damage to the eye if extreme and advice should be given to ensure that nails are cut short and the behaviour repeatedly discouraged (Kennedy and Souza, 1995).

Research shows that people with LD are more at risk of ocular anomalies than typically developing children (Woodhouse *et al.*, 2000) and as up to 75% of children with ASD also have LD (National Institute of Clinical Excellence, 2013) it follows that

this group maybe at a particularly high risk of visual impairment. Four point seven percent of children with a learning disability are thought to be visually impaired. 13.5% are hyperopic (>3Ds), 7.9% are myopic (>3Ds) and 25.3 % are astigmatic (> 1DC). These findings are higher still for people with specific conditions such as Down's Syndrome (Emmerson and Robertson, 2011). In people with LD and ASD signs of ocular disease can be overlooked because it is assumed that the behaviour is due to their neuro-developmental condition rather than an attempt to communicate pain or blurring. This is known as diagnostic overshadowing (Cavill, 2001). People with LD are known not to attend as regularly for eye examinations as the general population (Emmerson and Robertson, 2011) and therefore they are more likely to develop an ocular abnormality and less likely to attend at an early stage. These studies highlight the need for careful assessment of any child with ASD and LD.

## **Summary**

The literature search shows that primary eye-care is important for all children including those with ASD and even more so for children with co-morbidity or LD. There is a paucity of research specific to ASD and much of the research has been with high functioning children with ASD or as part of a larger study looking at ocular health in the LD population. There is a need for further research into the ocular health risk factors for children with ASD. However, the research seems to indicate that there is greater than average risk of strabismus, NPC weakness and visual stress in children with ASD. It also indicates that they are more likely to have visual processing anomalies resulting in them interpreting the world differently. Therefore the provision of primary eye-care is a priority for children with ASD. In particular the research indicates the need for eye-care below the age of eight.

## **1.6 Position of the researcher**

The researcher has experience in providing primary eye-care for people with complex needs and has observed that children with ASD appear to have great difficulty accessing the services. Some children who appear to be cognitively able to achieve many of the eye examination tests are unable to cope with the process. This research was inspired by a child of eight who had an ASD diagnosis and despite being able to read letters and having verbal communication, became very distressed in the waiting room and declined to enter the consulting room. Over the

space of several visits, using strategies recommended by his PC, he was eventually able to complete his eye examination. It seems, to the researcher, that these children are significantly disabled by the primary eye-care process. An awareness of the child's perspective, how they feel about what is happening to them, should be explored in order to develop more appropriate services.

## **1.7 Primary eye-care provision and ASD: review of the literature**

### **1.7.1 Introduction**

The chosen methodology of the current research was grounded theory and this will be discussed in Chapter 2. In grounded theory research (Corbin and Strauss, 2008) it is common practice for the literature review to be carried out during data analysis so that the emerging data collected is not biased by existing theory. The literature review presented in this chapter was carried out in accordance with grounded theory at the data analysis stage. However in order to establish the context of this research the literature review findings are presented here and discussed in relation to the emerging theory in Chapter 5.

### **1.7.2 Methods**

The literature search was aimed at exploring what is current knowledge on eye-care and service delivery. The last search was carried out on January 31<sup>st</sup> 2015. All English language articles that included the keywords were assessed. It was hoped that systematic reviews would be found but none were. Searches for publications were made on databases (including Pubmed, Google scholar, Department of Health websites, Cochrane database, CINHALL and Ovid), reference lists, citations, books and journals. Search terms entered into search databases were:

{[autism spectrum disorders] OR [autism spectrum condition]} AND {[primary eye-care] OR [primary healthcare]} , {[autism spectrum disorders] OR [autism spectrum conditions]} AND {[healthcare guidelines] OR [ eye-care guideline]}

Table 3 shows a summary of the findings of the literature search.

There is a paucity of research into Autism from the perspective of people with ASD and even less from the viewpoint of children with ASD (Notbohm, 2004; Morton-

Cooper, 2004; National Audit Office, 2009; Department of Education, 2002; Department of Health, 2010; Pellicano *et al.*, 2013). Healthcare services now include patient participation in planning and development, and to an extent, governance (Department of Health., 2013). Transforming patient participation in healthcare is a document that sets out the NHS England pledge to hear the voices of service users (NHS England, 2013). This review found no investigation of the views of service users for primary eye-care and ASD.

The search revealed just two articles one of which was excluded as it was an article about a service and was not evidence based. The second article by Coulter (Coulter, 2013) is in the format of guidelines for practice and contains a three step rule for dealing with children with ASD in an optometry setting. It is noteworthy that all the articles cited are from health and social care AHPs indicating a lack of research on this issue within optometry. This article is primarily based on Coulter's expert opinion. Her recommendations are to improve ASD awareness in the practice team, prepare in advance adapting the test protocol to the child, and give the child more control using a step by step approach.

Several large consultation documents were found that had been commissioned to explore national or local provision of services in healthcare and education. They were all aiming to review current practice and identify good practice (Lajonchere *et al.*, 2012; National Audit Office, 2009; National Institute of Clinical Excellence, 2013; Department of Education, 2009; Dittrich *et al.*, 2011). All these documents were evidenced by large mixed methods studies including surveys, interviews and focus groups from across the country. None of these directly include optometry but make reference generally to healthcare. In some of the documents the methods in data collection and analysis are difficult to follow and as this information is missing the validity of the research cannot be certain (Lajonchere *et al.*, 2012; Dittrich *et al.*, 2011; Department of Education, 2009). These give a broad overview of the difficulties faced in accessing services and in particular the lack of awareness of autism currently in the service planning and at all levels.

Professional guidelines for optometrists were reviewed and fact sheets provided from a national ASD charity were investigated also. Two sets of professional guidelines were found, the professional guidelines from the College of Optometrists and National Autistic Society guidelines for practitioners. These are based on expert opinion and not evidence based.

Two books were identified as particularly helpful for healthcare professionals (Bolick, 2004; Morton-Cooper, 2004) as these give the perspective of the difficulties encountered for clinicians and service users with practical step by step approaches from an expert in the field. One further book was included because it was written by a parent of a child with ASD was reviewed and gave clear advice and guidance backed by examples of the recommendations in action (Notbohm, 2004).

Three smaller studies from AHPs such as dentistry (Stein *et al.*, 2012) and general healthcare (Carbone *et al.*, 2010; Portway and Johnson, 2005;) were included. Although the sample sizes were small and the analysis information limited these did have relevance to the subject and the findings were in line with the other articles identified in the search.

**Table 3: Findings from the literature**

Research article	Approach	Purpose	Relevance to this study
The Bercow Report (Department of Education., 2009)	Mixed methods – survey and qualitative consultation and case studies across England Limited information about methods available	Consultation document investigating the provision of services for children and young people with Autism	The consultation highlights the Every Child Matters requirement for equal access to healthcare. It also deals with child services and early intervention. However it does not cover primary health care and gives no guidelines or recommendations for action
Supporting people with autism through adulthood. National Audit office (2009) (National Audit Office, 2009)	Mixed methods – survey, telephone interviews, focus groups, web based forum, audit of provision 111 (74% response) local authorities surveyed. 1,000 GP's (100% response) 103 disability support officers from further education (28% response) 67 ( 53% response).from higher education 291 third sector organisations Focus groups with the NAS service users and online survey. Government department effectiveness evaluation. Interviews with key stakeholders	To inform the development of a National Autism Strategy for Adult as set out in the Autism Act 2009 (Autism Act, 2009)	Lack of awareness of the needs of people with ASD Lack of evidence based planning for services, only 23% of NHS and 24% of social care training plans included autism awareness Lack of provision for high functioning people with autism Lack of training in healthcare staff, including GP's that indentified 80% feel that more training is needed Applicable to adults and therefore may not be transferable to child services No specific information about eye-care and therefore may not be transferable

Research article	Approach	Purpose	Relevance to this study
Guidelines for providers of services for children and young people with autism. NICE (2013) (National Institute of Clinical Excellence, 2013)	Mixed methods review of evidence set in 5 research questions with individual methodologies including a systematic review of service provision based in GP and dental surgeries	To provide evidence based information for best practice and set out minimum requirements for provision. To form the basis of training for providers	Lack of research in this area Lack of awareness in healthcare results in unnecessary referral to secondary care Flexible appointment times are essential Greater carer recognition in facilitating the care for their child so that the service is person-centred Environmental adaptations and visual supports facilitate access Local autism teams should provide training, advice and support for healthcare workers All health and social care workers should have training
Autism participation – have your say! (Dittrich <i>et al.</i> , 2011)	Validated Survey 255 responses Consultation meetings with key stakeholders 137 attendees. Services evaluation by Hampshire Autism Partnership	To evaluate services in light of the Autism Act 2009	Much of this report was not pertinent to the current study and the audit trail incomplete in that limited analysis detail is given Lack of awareness and training highlighted Children often have to be in crisis before services are accessible Lack of services for high functioning people with autism
Do you know I have Asperger's syndrome? Risks of a non-obvious disability (Portway and Johnson, 2005)	Qualitative, unstructured interviews of 25 families with a member who has Aspergers Limited information about analysis	To explore the risks of being 'on the margins of normality'	The findings are about general day to day life not specific to primary care but highlights the difficulty that people with high functioning autism have accessing healthcare They are 'at risk' because they 'don't fit in'

Research article	Approach	Purpose	Relevance to this study
Services for children with autism spectrum disorders (Dymond <i>et al.</i> , 2007)	Survey 3,500 issued 886 met inclusion criteria Confusing information given as article states a grounded theory approach but no details other than the survey results are given	Service evaluation to investigate a previously identified concern about service provision	4 themes emerged from this study, 3 of direct relevance to the present research Improve the quality, quantity and availability of services Educate and train individuals to work effectively with children with ASD Increase funding for the development of services, training and research Highlights the need to personalise services and to make services accessible and provided by someone qualified and knowledgeable
The medical home for children with autism spectrum disorders: parent and paediatrician perspectives. (Carbone <i>et al.</i> , 2010)	Qualitative. Focus groups. 5 parents of children with ASD 9 professionals involved in service delivery	Investigation of service provision for children with ASD in the American care home service	Small sample with limited information about recruitment and sampling Similar results to other studies Lack of awareness of autism in care professionals Carers advice should be sought by the providers Co-ordinated services and multi-disciplinary working practices recommended as good practice
The code of ethics and guidance on professional conduct. (The College of Optometrists, 2014)	Current practice guidelines grounded in professional experience and accepted practice	To inform optometrists of the minimum provision expected of them	Communication should be appropriate for the patient to understand actions and outcomes Professional integrity places the welfare of the patient above all other considerations and this includes an obligation to maintain their professional competence To adapt routine to ensure it is age appropriate To adapt routine to patient's special needs

Research article	Approach	Purpose	Relevance to this study
<p>Eye-care: preparing for an appointment. The National Autistic Society. (The National Autistic Society, 2012a; The National Autistic Society, 2012b; The National Autistic Society, 2013)</p>	<p>Expert opinion of experienced practitioners.</p>	<p>To provide guidelines for optometrists: how to provide support to carers and service users For carers and services users How to access services, what to expect and how to prepare for eye-care</p>	<p>Recommendations made include Information about child's needs in advance, keeping to time, care in use of questioning, allowing time to respond, use of functional vision tests, the document also sets out what would be the minimum range of tests that should be completed</p>
<p>3 steps to help you examine patients with ASD (Coulter, 2013)</p>	<p>Expert opinion and review of literature</p>	<p>Training article to provide support for practitioners and to improve outcomes of primary eye-care for people with ASD</p>	<p>Recommendations are: improve ASD awareness, prepare in advance and adapt the test protocol to more appropriate techniques, using a step by step approach and giving the patient more control</p>
<p>Desired outcomes for children and adolescents with autistic spectrum disorders (Beresford <i>et al.</i>, 2007)</p>	<p>Qualitative Activity and interviews with children and carers. Interviews with 28 children with an ASD from 25 families. 12 teenagers were observed. 12 teachers and 4 mental health professionals were interviewed</p>	<p>To investigate the desired outcomes for children with ASD in terms of what are the minimum expectations and how are these evaluated</p>	<p>This research found barriers in accessing health care, that carers aspirations for their child are the same as parents of typically developing children, outcomes should be user defined and supported by research involving service users Highlights the lack of research that involves service users</p>

Research article	Approach	Purpose	Relevance to this study
Messages from parents of children with autism spectrum disorder (Bevan-Brown, 2010)	Online survey 137 participants Limited information on analysis and methods	To elicit the views of carers of children with ASD about living with ASD. This included a question that is relevant to accessing healthcare or other similar appointments	Carers want others to accept and accommodate the special needs of their children Preparation in advance would make access easier; time of appointment, telling the provider in advance, pictures of practitioner and office, role-play practice, accept the advice of carers as they know the child best
Autism Speaks. Leadership in Health Care, Research, and Quality Improvement for Children and Adolescents With Autism Spectrum Disorders: Autism Treatment Network and Autism Intervention Research Network on Physical Health (Lajonchere <i>et al.</i> , 2012)	Survey Questionnaires to a pool of 5000 families of service users in the US, no other information available.	To produce downloadable guidelines for aspects of health care for carers and clinicians.	Advice to carers Choose an ASD aware practitioner, use visual supports, tell the practitioner in advance, set the child's expectations Advice to practitioners Limit sensory distractions, demonstrate all equipment, explain what and why, limit clutter, allow several visits, end on positive note
Oral care and sensory concerns in autism (Stein <i>et al.</i> , 2012)	Mixed methods, survey 192 carers of children with ASD and 202 carers of typically developing children. Also interviews with professionals, focus groups with PCs No formal analysis of the focus group data	An investigation of how ASD sensory concerns affect access to oral care at home and at the dentists	Children with ASD have greater difficulty with oral care because of the sensory overload. Use of environmental sensory stimuli control and also support from occupational therapy may help to reduce the fight or flight response.

Research article	Approach	Purpose	Relevance to this study
Practical aspects of managing patients with additional needs: A guide for eye care providers (Gherghel, 2009)	Expert opinion	An article that gives a summary of risk factors and adapted techniques for people with a range of special needs including ASD	This is a summary of information from the NAS information sheet for eye-care. However there appears to be other information without references
Health care for the autism spectrum. A guide for health professionals, parents and carers (Morton-Cooper, 2004)	Expert opinion	A book aimed at providing advice, guidelines and support for healthcare providers working with service users that have an ASD	Lack of research into healthcare provision Four strategies: Safe environment to reduce anxiety; Adapt the examination to avoid sensory overload; Clear sense of structure throughout; Consider the family circumstance and history and how that impacts on their responses.
10 things that every child with autism wishes you knew (Notbohm, 2004)	Expert opinion	This is a book written by a parent of a child with ASD to advise other carers and service providers of key information that may help them to help a child with ASD	10 point guideline that includes: Making your approach age appropriate, allow for sensory processing, allow for communication issues, allowing time and space for processing, visual supports help, learn from what triggers challenging behaviour as it is communicating something, support and encourage, don't judge them.
Asperger's syndrome and adolescence. Helping preteens and teens get ready for the real world (Bolick, 2004)	Expert opinion	A book aimed at supporting carers and service providers who look after teenagers with an ASD. Includes a section on dealing with challenging behaviour	Bolick describes a strategy called 'low and slow' which is designed to help calm a situation that could or has led to a meltdown. This works on the basis that the meltdown is due to sensory overload and therefore the way to counteract this is to slow everything down and create a calm environment. Applying this strategy throughout may reduce the stress of a clinic appointment

### **1.7.3 Findings**

There is very little good quality evidence in the area of experience of primary eye-care and only a fraction more relating to the general primary care services. The findings of the search are shown in Table 3. However key themes can be identified from research and expert opinion guides and these are summarised here. These are shown in Figure 1.

A range of factors emerged from the literature that contribute to the experience of children with ASD of primary eye-care, and these are discussed in the following section. How these factors compare to the emerging grounded theory will be discussed in Chapter 5.

#### **The need for training for professionals**

The lack of awareness and training was highlighted as a significant barrier to healthcare and education (Coulter, 2013; Carbone *et al.*, 2010; Dymond *et al.*, 2007; Dittrich *et al.*, 2011; National Institute of Clinical Excellence, 2013; National Audit Office, 2009). The lack of awareness means that services may not be fit for purpose and training for all professionals involved in eye-care and support staff is indicated, in order to facilitate service development.

#### **Listen to Primary Carers (PCs)**

In several pieces of research the frustration of PCs that their views are often not taken into consideration when their child trying to access a service is mentioned as a barrier to access (Bevan-Brown, 2010; Carbone *et al.*, 2010; National Institute of Clinical Excellence, 2013). ASD is a spectrum with each child being unique and therefore the advice of the PC as to what might help and what will not work is very valuable and very often overlooked.

#### **Preparation**

The literature indicates that preparation for the child is very important. Many authors highlight the benefits of explaining what will happen in healthcare encounters. (Stein *et al.*, 2012; Lajonchere *et al.*, 2012; Bevan-Brown, 2010; The National Autistic Society, 2013; The College of Optometrists, 2014). This might include visual supports such as photographs of the practice and team members (Notbohm, 2004; Lajonchere *et al.*, 2012; The National Autistic Society, 2012a; The National Autistic

Society, 2012b; The National Autistic Society, 2013; National Institute of Clinical Excellence, 2013).

### **Support for high functioning children**

The consultation documents (Dittrich *et al.*, 2011; National Audit Office, 2009) highlighted the need for service development specifically for children and adults that are high functioning and this is reinforced by experts in the field (Bolick, 2004; Morton-Cooper, 2004) and one of the articles (Portway and Johnson, 2005). Often people with ASD do not appear physically to have a disability and the practitioner does not realise that adaptations are required. This results in children with ASD falling out of the mainstream services and as Bolick points out this probably accounts for some of the service users that are considered to be 'difficult' patients (Bolick, 2004). These children are at a particular disadvantage as they are also not eligible to use LD specialist services.

### **The need to treat every child as an individual**

The importance of a person-centred approach was a very common theme throughout the literature. There are recommendations that the services are adapted to the individual's needs (Dymond *et al.*, 2007; The College of Optometrists, 2014; The National Autistic Society, 2013; The National Autistic Society, 2012a). In addition the personal circumstances and experiences need consideration (Morton-Cooper, 2004) not just a generic change to the service. The idea has been raised of an electronic health record accessible to all those involved in the care of the child (Golnick and MaCCabee-Ryavboy, 2010) and this could include the information required to inform providers of the child's specific difficulties, facilitating techniques and could result in reduced time spent in the clinic.

### **Adaptations to the environment**

The literature shows that many of the issues with accessing healthcare are related to sensory overload. The recommendations are for ECPs to think about the environment and limit the sensory impact by minimising lights, sounds, smells, and clutter (Morton-Cooper, 2004; Lajonchere *et al.*, 2012; Stein *et al.*, 2012). Additionally the recommendation that professionals develop strategies to deal with or prevent challenging behaviour was made in two articles (Bolick, 2004; Morton-Cooper, 2004) and another paper suggested that occupational therapy to address this may be helpful (Stein *et al.*, 2012).

### **The use of simple language**

The literature indicates a need to think about the way information is communicated and how instructions are phrased to ensure that the information is meaningful to the service user (Notbohm, 2004; The College of Optometrists, 2014; The National Autistic Society, 2013; The National Autistic Society, 2012a; National Institute of Clinical Excellence, 2013). The literature suggests that the way questions were asked and the time given to process those questions makes a significant difference to the outcome.

### **The flexibility of appointment allocation and timings**

The flexibility of appointments was a common theme in the literature. It is recommended that these children are allocated longer time slots and are flexible enough to avoid the child having to wait (Notbohm, 2004; National Audit Office, 2009; The National Autistic Society, 2013; The National Autistic Society, 2012a; Morton-Cooper, 2004).

### **Multi-disciplinary working**

The recommendation of multi-disciplinary working was raised only by Carbone et al (Carbone *et al.*, 2010). They point out that the stress for carers can be reduced by working together and good communication between care providers.

**Figure 1: Findings from literature search**



## **Guidelines**

The current guidelines for eye-care for children with ASD are very limited. The College of Optometrists (The College of Optometrists, 2014) sets out minimum standards for the provision of eye-care by optometrists. The guidelines are separated into 'types' of patients. The sections that are most relevant are those relating to children, people with LD and the routine eye examination. There is no section specifically for people with an ASD. The guidelines therefore give no recommendations regarding providing for the special needs of high functioning children with ASD or specific adaptations regarding the specific impact of ASD on the process. The recommendations include the minimum range of tests that should be done, the responsibility of the optometrist towards providing the best possible care for each person and putting their needs as the highest possible concern. For all patients there is a requirement that the patient's "dignity and privacy" are respected. There should be no discrimination against patients including age or disability. However support for special needs is implied but the general requirement is to communicate and build rapport. It includes the suggestion that the child is accompanied by an adult that knows them well enough to facilitate the process and also that communication should be adapted to the needs of the child.

In the routine eye examination the optometrist is required to allow enough time to perform a full eye examination but there is no guidance as to what this time would be. The reality in practice is that a standard appointment slot is allocated and therefore this guideline is difficult in practice unless follow up appointments are arranged when appropriate for people who cannot cope with a full eye examination in the allotted time.

The ECP is given the responsibility, to choose an appropriate battery of tests within the boundaries of the minimum legal requirements. The legal requirements according to the Opticians Act 1989 are very prescriptive (Optician Act, 1989) and include tests that some children would not be able to cope with. Therefore the ECP potentially has a dilemma as to whether the patients' needs override the legal requirements.

The guidelines also direct that in an eye examination for a child, the optometrist should: establish rapport with child and carer, address the patient directly and honestly, and make allowance of the anxiety that the child may have.

The guidelines relating specifically to provision for people with LD, states that where possible the carer should be contacted in advance in order to discuss the special needs of the child. The guidelines recommend the use of the SeeAbility pre-test questionnaire which is designed for people with LD to let the practitioner know about their special needs and abilities (SeeAbility, 2010). It also recommends simple adaptations such as speaking clearly, in plain English, directly to the patient. Furthermore it recommends that the practitioner explains and demonstrates equipment first and warns them if they need to touch the patient. Also that the patient is encouraged to visit the practice before the day of their examination so that they are more familiar with the environment (known as an acclimatisation visit).

To summarise these guidelines, the ECP should adapt their communication and tests according to the needs of the patient, which should be discussed in advance, they should not discriminate against anyone, the patient's needs are the most important priority and the patient should be treated with dignity at all times. The guidance is based on legal requirements (Opticians Act, 1989) and one relevant reference from Turner et al is cited, which is a review of literature around ocular health and LD (Turner *et al.*, 2013). No references are cited regarding the guidelines for eye-care for children. Therefore the basis of these guidelines is expert opinion as to how the legal requirements can be met. There is no consideration of the views of the patient or reference to evidence based knowledge regarding children with ASD.

Another set of guidelines can be found on the NAS website (The National Autistic Society, 2013; The National Autistic Society, 2012a). They provide information for PCs as to what might happen and also recommendations for the ECPs to boost their awareness of the needs of children with ASD. There is emphasis on the need for careful communication, for allowing time for processing, explanation and adapting routines to use objective tests where needed. They recommend some specific communication strategies that are used by other allied health professionals (AHPs), such as using the word "again" when they are required to repeat a task, and allowing time for the patient to process information and repeat it several times which will enhance their understanding.

The guidelines give further recommendations about ensuring the child knows what is going to happen, the importance of doing what you say you are going to do, and the use of a count-down technique so they know how much longer the test will take.

The use of visual prompts to help children with communication impairment understand what will happen and when.

The guidelines identify that there is an unpredictability about what can be achieved for each child but unlike the college guidelines, they do give a recommended minimum range of tests that should if possible be completed and suggestions that some of the objective techniques that may be more achievable, such as retinoscopy. These are based on what is achievable rather than legal requirements.

The guidelines also explain that the use of calming techniques may be helpful in order for the child to feel comfortable with the situation and conversely there may be particular dislikes or obsessions that can derail the process. For this reason the guidelines recommend that the PC and ECP discuss the child's needs before the assessment takes place. They also suggest that an acclimatisation visit would be helpful.

In summary, these guidelines recommend adaptations to communication and techniques, based on pre-test information from PCs. They recommend the use of day to day strategies such as phrases that other professionals use, visual prompts, calming strategies and acclimatisation visits. However these guidelines are based on expert opinion and are not evidence based. No research has been done with service users to explore whether these guidelines are appropriate or best practice. They are broadly in keeping with the College guidelines.

The outcome of Coulter's article was a discussion of best practice for eye-care provision for children with ASD (Coulter, 2013). The article gives a three step rule for provision and therefore it is relevant to this section on the literature around guidelines. She recommends: improve ASD awareness, prepare in advance and adapt the test protocol to more appropriate techniques, using a step by step approach and giving the patient more control.

*Improve awareness of ASD* relates to the need for the ECP to understand why the tests may be challenging. Coulter explains that communication needs to be clear and simple and that time is allocated for them to process information, that consideration of the child's possible hypersensitivity to touch and light needs to be made, and an awareness of the difficulty with concentration and attention that these children may have.

*Prepare in advance* refers to the need for the practice team to be aware of how to assist these patients. The allocation of appropriate appointments was highlighted as important, to avoid the need to wait, or to ensure that they do not have to cope with busy waiting rooms. The team also need to be aware of the need to get as much information in advance as possible to prepare for the child's needs and also to avoid any delay from filling on the day of the appointment.

*Adapt the test protocol* is the third step of Coulter's guidelines. She recommends methods and techniques that minimise the use of equipment that touches them or that require advanced communication skills. She also recommends a step by step approach that informs the patient what will happen when, to enable them to feel some control over what is happening.

Coulter is an expert practitioner and these guidelines are based on expert opinion but she also cites AHP based research applied to an optometry setting. This again highlights the paucity of evidence based knowledge around provision for these children. The views are those of experts not of the children receiving the treatment and there is no research that provides evidence that these guidelines are effective.

The guidelines found in this literature search broadly overlap and do cover most of the themes that have emerged from the literature around eye-care and ASD. There is recommendation that ECPs should be aware of ASD and the impact on the eye-care process. There is a requirement that the patient's needs are provided for without discrimination. The guidelines give suggestions as to what adaptations can be made and what factors need to be considered, including communication methods, strategies to gain compliance to the tests, the use of objective tests and the minimum use of any test that causes sensory stimulation such as touch or bright light. Explanation and adaptation are the key points that support a child through the process and enable them to cope with the demands of primary eye-care.

There is however, no formal eye-care pathway for children with ASD and very limited published research around eye-care for children with ASD. No literature around the patient's perspective could be found despite a clear requirement for this from the NHS constitution (Department of Health., 2013).

### **1.7.4 The need for this research**

This chapter has shown that children with ASD have specific difficulties with accessing services due to the impact of their special needs and the lack of flexibility of the UK primary eye-care services, the lack of awareness of ASD, the variation in expression of the condition, and the 'hidden' nature in some cases. In particular it highlights the challenges that an eye examination presents for children with ASD. These include a one-to-one situation that requires communication, abstract tests, eye contact, clinical environment and interaction with people that may not be aware of their needs. It is possible to guess what might be challenging however there is no evidence based knowledge regarding this. Therefore there is a need for research into the patient's perspective of eye-care in order to inform the provision of appropriate services.

It has shown that there is a paucity of research that includes the views of the service users. The present research is needed to fill this gap in knowledge and enable the views of children with ASD to be heard and for theory to be generated grounded in these views. In addition there is a legislative requirement for these voices to be heard.

### **1.8 Outline of the thesis**

This chapter has provided an introduction to the research. The traits of ASD and how they can have an impact on how a child accesses health care have been discussed. It gives an overview of ASD, and the provision and accessibility of services for children with ASD. The legislative background and policies that inform this have also been outlined. The literature review of research into primary eye-care for children with ASD is presented. These topics have been developed further in the discussion of the present research findings in chapter 5.

Chapter 2 presents the methodology and how and why it was selected. It will also give details of research methods, data collection and methods of analysis.

In chapter 3 the findings from the children are presented along with contextual data and how this can be viewed from the perspective of symbolic interactionism. The outcomes are shown in terms of the current service provision and possible adaptations that may improve the experience for children with ASD.

The theory development grounded in the data from the children is presented and discussed in chapter 4. The theory of primary eye-care for children with ASD is discussed in chapter 5.

Conclusions of this research and recommendations for further research is discussed in chapter 6.

## **Chapter 2: Methodology and Methods**

Methodology for any research should be selected for its suitability to answer the particular research question that is being investigated (Greenhalgh, 2001). The research question in this study is:

“What is the experience of primary eye-care for children with an ASD?”

The study seeks to investigate what the experience is like, not primarily from the ECP or PC perspective, but from the viewpoint of a child with an ASD. It is therefore exploratory, descriptive and ultimately theory generating not theory verifying.

The theory developed will be used to help key stakeholders develop and access services. To answer this question the subject needs to be explored, described and interpreted not quantified or measured. Quantitative methodologies are concerned with hypothesis testing, numbers not words, whereas qualitative methodologies are interested in description and discovering. Therefore, for this research question a qualitative methodology is more appropriate than a quantitative approach (Hickson, 2008; Punch, 2005; Hickson, 2008; Holloway, 2005).

Qualitative research is sometimes not considered to rank as high in the hierarchy of knowledge as quantitative methodology. However it is becoming more accepted that some research questions cannot be answered well through large quantitative studies. Evans has developed a hierarchy that rates research in terms of effectiveness, appropriateness and feasibility in which qualitative methodologies are considered appropriate depending on the question (Evans, 2003). Qualitative methodologies are not appropriate to test theory or evaluate effectiveness of interventions but person-centred holistic descriptive approaches are appropriate to learn and explore human experiences (Holloway, 2005). It is becoming more recognised that to evaluate services the views of the ‘expert’ are required and that would be the patient that experiences the service in the case of this study (AHA, 1985; Alderson and Morrow, 2011).

### **2.1 Qualitative research designs**

There are many qualitative research approaches and finding the right design for the research question is as important as deciding between quantitative and qualitative methodologies. In order to select the best approach the aim of the investigation

needs to be examined. Other factors to consider when selecting an approach are the training and philosophical viewpoint of the researcher and, more pragmatically, the time constraints and budget for the research.

The aim of this study was to find out what the experience is of primary eye-care for a child with ASD. To see it from his/ her perspective and understand what causes distress and what makes a 'good' experience with a view to developing a theory of the facilitators and barriers to providing an acceptable and appropriate service. There are a number of possible approaches that could be used and an account of those considered as possible options for the research is presented in Appendix 1ii.

### **Grounded Theory**

Grounded theory is a research approach that uses specific methods to collect and analyse data and develop theory 'grounded' in that data. It is systematic and was initially designed as an inductive process through which theory emerges. It crosses the border between qualitative and quantitative research in that all sources of data can be considered (Glaser and Strauss, 1967).

Data used to generate theory may come from any source that might be relevant to the subject. It is a technique that develops theory and not a theory verification method (Punch, 2005). Grounded theory is an approach that was developed by Glaser and Strauss for their study of *The Awareness of Dying* (Glaser and Strauss, 1967). However it has since been adapted by researchers and several types of grounded theory now exist. There are two main versions, the classic grounded theory developed by Glaser (Glaser and Strauss, 1967; Glaser, 1998) and the modified grounded theory developed by Strauss (Strauss and Corbin, 1990). Although there are other notable versions of grounded theory that have been developed including Charmaz (Charmaz, 2006) and Clarke (Clarke, 2005). The main difference between the versions of grounded theory is the philosophical underpinning. The original work did not state the philosophical underpinning but instead gave details of the methods used in the approach. However later versions have primarily differed according to this. Examples of this would be: Strauss with symbolic interaction (Strauss and Corbin, 1990), and Charmaz with constructivism (Charmaz, 2006).

The classic grounded theory was designed to systematically analyse data to generate theory rather than data being used to test theory (Heath and Cowley, 2004; Charmaz, 2006). To produce theory that is:

“meaningful, relevant and able to explain the behaviour under study.” (Hunter *et al.*, 2011 p7)

It is often used to investigate areas where there is little knowledge currently (Holloway, 2005). The theory developed is grounded in data from ‘inside’ the subject area and has explanatory power (Punch, 2005).

In much of the literature about grounded theory there is strong debate over the two main versions of grounded theory, Glaser vs Strauss. The two versions differ in several ways: shown in Table 4. The use of induction by Glaser and the use of induction, deduction and verification by Strauss, the emphasis on creativity in Glaser and in systematic and detailed evidence in Strauss, and the levels of coding to construct theory are greater in Strauss than in Glaser.

**Table 4: Glaser vs Strauss grounded theory versions (Hunter *et al.*, 2011; Corbin and Strauss, 2008; Charmaz, 2006)**

Glaser	Strauss and Corbin
Substantive coding – initial coding of the data which becomes more abstract as more data is produced.	Open coding- initial coding of the data
No direct equivalent	Axial coding- the use of analytic tools reduce and sort the open codes into groups that are associated
Theoretical coding – integration of coding to develop a core category	Selective coding- defining of codes into categories and a core category
Theory – parsimony, scope and modifiability i.e. less detail but a theory that fits the data and can be generalised.	Theory – detailed and evidenced theory grounded in data with full explanation.

The philosophical underpinning of Strauss grounded theory is Symbolic Interactionism which is based on Pragmatism (Corbin and Strauss, 2008; Holloway, 2005). Pragmatism contends that

“knowledge is created through action and interaction”(Corbin and Strauss, 2008 p2).

People react to different problems by using their experiences, judgement and interpretation, to reflect and resolve the problem and the consequences. They adapt to the situation they find themselves in (Heath and Cowley, 2004). Symbolic interaction is a perspective that considers that individuals interact and react based on meanings that they attach to the actions of others. A person’s social self is made up of their expectations, the context and the behaviour of the people around them. grounded theory investigates the relationship of action, context, and consequences (Holloway, 2005)

“individuals are active, creative and reflective and that social life consists of processes” (Charmaz, 2006).

A process is a term used to describe the movement from action, to reaction and consequences. This is influenced by the context, therefore someone’s reaction may be affected by the circumstances, the person’s previous experiences or how they understand the world. It is therefore a series of linked events that can be analysed to gain understanding of a phenomenon (Corbin and Strauss, 2008). Grounded theory therefore is a theory based in the data collected in terms of the conditions from which process comes and the causes and consequences of change .

“individual definitions of reality shape perceptions and actions” (Holloway, 2005 p175).

### **Case studies**

This approach can be used to gain a greater understanding of a particular phenomenon within its particular context. This involves taking all of the information about a particular situation from any data source and analysing the aspects of the phenomenon. A case can be an individual, a company, a country or any other ‘unit’ that might be identifiable as a unit or ‘bounded system’. The data collected is in depth and from all sources, interviews, focus groups, literature, social media and so on. The aim is to be as holistic as possible and take account of anything that has an impact on how that system functions or how a particular aspect functions in the case of large organisations or systems (Punch, 2005; Yin, 1994). Case studies are low on the hierarchy of knowledge (Hickson, 2008) and even in the newer model developed

by Evans (Evans, 2003) they remain low in the ranking. This is because they are very specific to a given situation and their generalisability is considered limited.

Advocates of this approach will point to the fact that generalisability is not the aim in such research. The aim is to either point out the particular attributes of a special case because it is very important or a 'negative case' which proves a commonly held belief or practice to be wrong. However the data produced can be conceptualised which means identifying concepts that might explain a situation and then using these to put forward as hypotheses for other case studies or further research such as surveys. Therefore case studies, whether stand alone or in combination, can produce trustworthy evidence as long as the cases are carefully chosen, justified and used for the right purposes (Punch, 2005).

A case study approach would be able to give an insight into the experience of individuals and a collection of carefully selected cases would generate some concepts that could then be used in further research. It would also enable aspects such as record cards to be investigated to see how much of the eye examination was completed and the ECP's viewpoint of the experience to see if the understanding of the ECP corresponds with the experience reported by the child. However selecting the cases is crucial to the usefulness of the findings and possibly of more benefit as a further investigation after an initial wider exploratory study.

### ***2.1.1 Chosen methodology***

The research question is:

“What is the experience of children with an ASD of primary eye-care?”

The aim of the research was to find out what their experience is and use it to inform the development of better services for these children. A methodology that enables theory development was desirable.

Providing an eye-care service is an interactive process, like nursing, and as Holloway points out,

“caring involves interaction, communication and active engagement”.  
(Holloway, 2005 p173).

The experience of a child with ASD when they have an eye examination depends on the context and the child, PC, practice staff and specifically interaction with the ECP in a clinical setting whilst taking into consideration the impact of previous experiences of all involved. Therefore grounded theory seems ideal for investigating this question because it enables systematic analysis of interaction to discover the experience and what influences this, and develop theory that can be used to inform service provision. The ultimate aim of this research is to provide a framework for service evaluation and change (Glaser and Strauss, 1967; Hill Bailey, 1997).

The researcher finds that her views are most in line with the symbolic interaction perspective having observed the interaction, action and consequences in the world. It is apparent that the meanings people attach to actions and events colour their perspective of that action. How individuals interpret actions influences how they react and ultimately the consequences. This can be observed on the world stage as well as in a personal day to day context.

Whilst the openness and reduced risk of bias found in the classic (Glaser) approach is attractive, the Strauss and Corbin approach was chosen because of the quantitative background of the researcher. The logical, systematic, structured nature of this approach was thought to be more appropriate for her skill set and inexperience of grounded theory. In addition, optometry as a profession leans strongly towards positivist, quantitative methodology and therefore the target audience of the findings would find alternative approaches harder to reconcile. Using an approach with a clear audit trail will enable the research to hold more credibility and encourage the profession to adopt the findings. This is important as the purpose of the research is to drive service change and therefore the findings need to be in a format that is valued by the target audience.

## **2.2 Methods**

In order to investigate the experience of primary eye care for children with an ASD a qualitative grounded theory approach was chosen. The data collection methods selected were interviews with children with ASD and their PCs, and ECPs.

The methods selected to answer the research question were semi-structured interviews with eight child and PC dyads and five ECP's .The children's interviews

were adapted using a range of alternative techniques to assist them to express their views. The purpose of the interviews is summarised in Table 5.

**Table 5: Purpose of interviews**

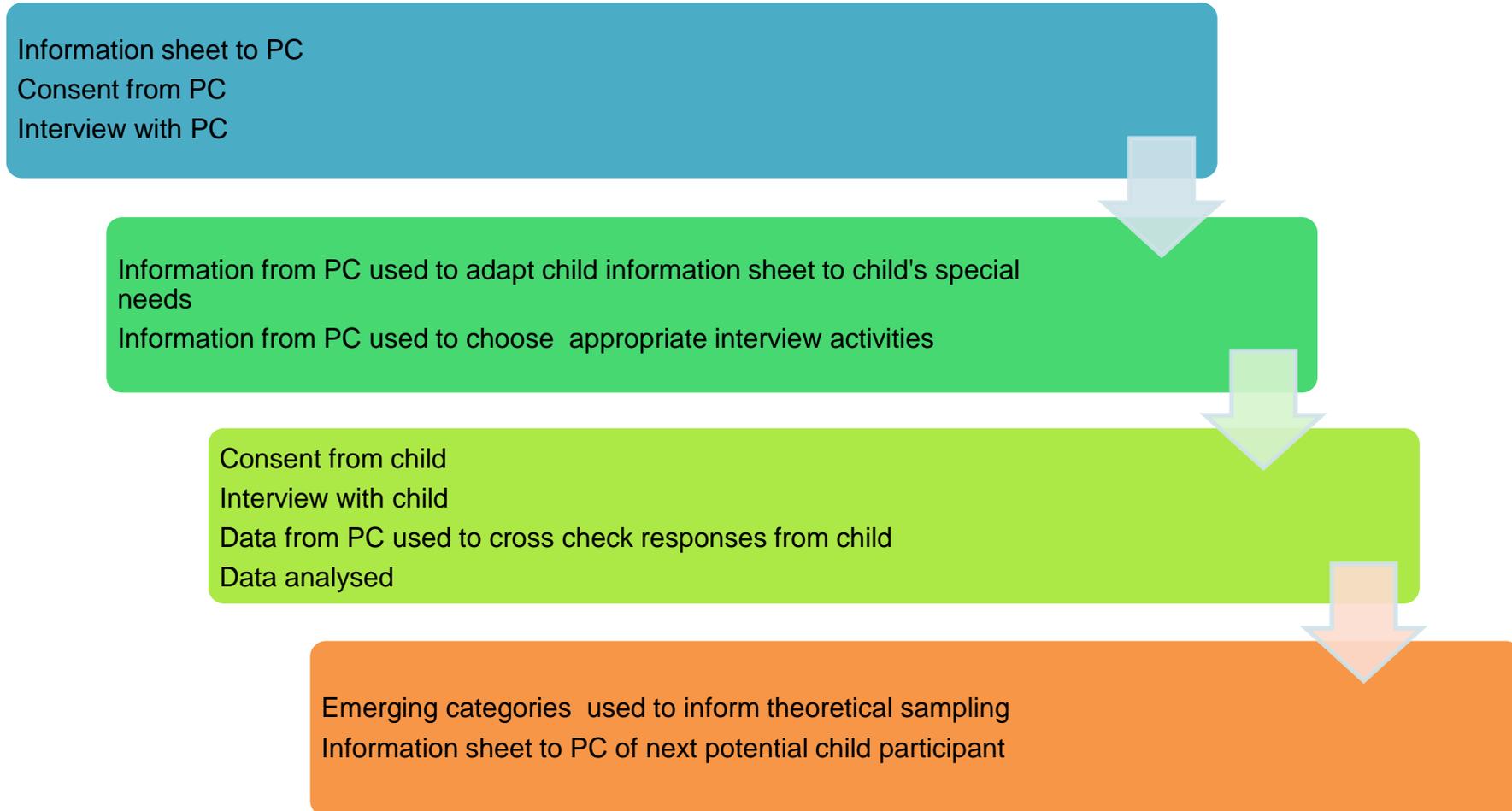
Participant	Purpose of interview
Child	To investigate the experience of primary eye-care from the view of the service user
PC	To investigate the views of primary eye-care of the PCs of children with ASD. To find out the information about the child participants special needs in order to adapt the information sheets and interview methods for the child's specific needs To gain the perspective of the person who knows the child best and observed the eye examination. To add context
ECP	To investigate the views of primary eye-care for children with ASD from the views of practitioners providing the service To add context

The purpose of the child interviews was to elicit views of eye-care directly from the children receiving the service. The purpose of the PC interviews was to gain an understanding of the child's special needs in advance of their interview and also to gain a further, more detailed insight into the experience of the child as viewed by the person that knows them best (Clark and Moss, 2005; Preece and Jordan, 2009). The information about the child's special needs was used to design an appropriately adapted interview for the child. The inclusion of PC data also enables them to give their viewpoint of the experience and finally to provide data as a cross check with data from the children.

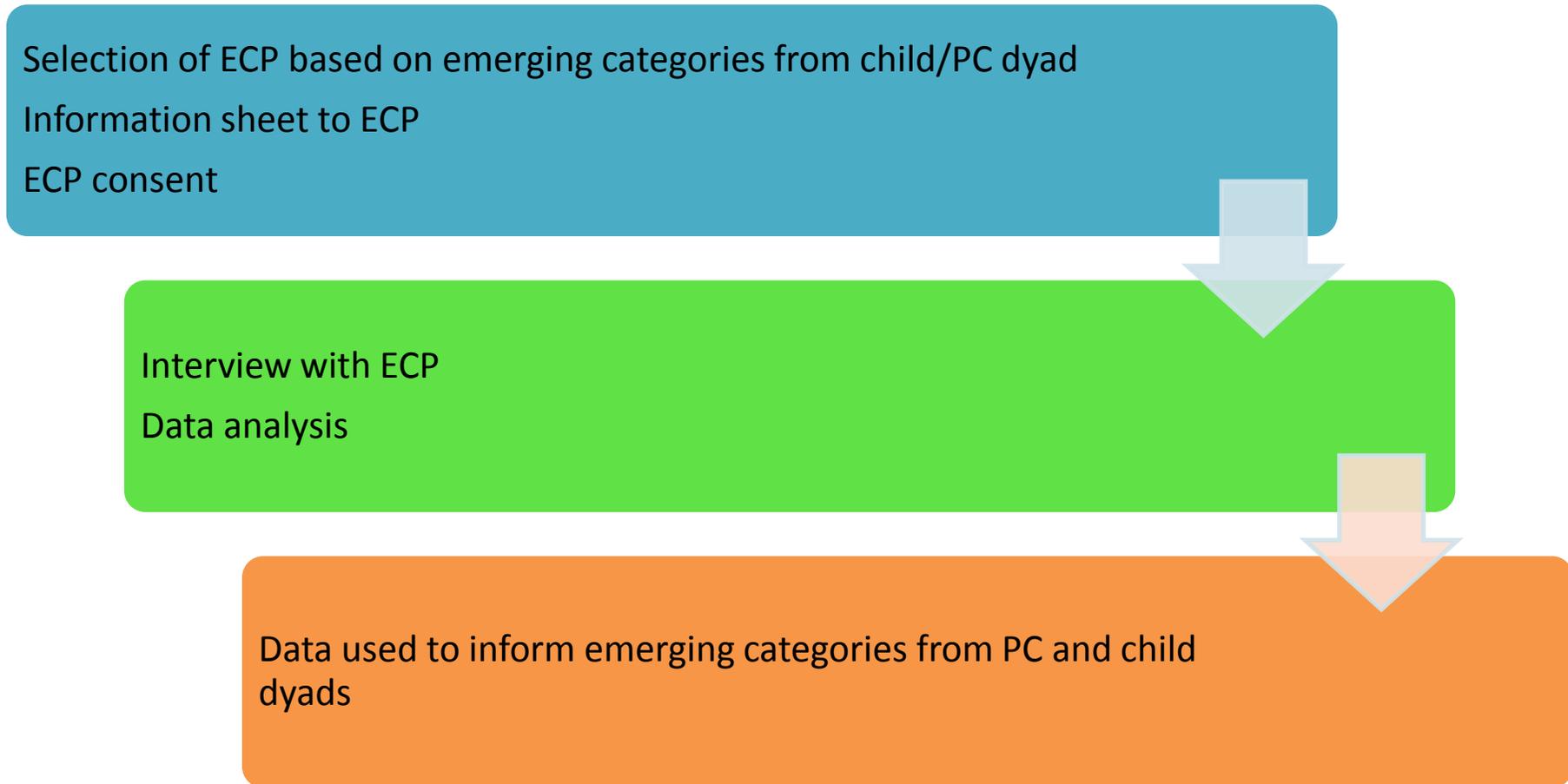
The purpose of the interviews with ECPs was to investigate the emerging data from the perspective of those delivering the service, and to add detail to the context and process and the practicalities of providing services for this group.

The research was primarily concerned with the voices of the children but in order to facilitate this, information from the PCs and ECPs was essential. The flowcharts in Figure 2 and Figure 3 show how the data was used from the interviews with PCs and ECPs.

**Figure 2: Flow chart of child/PC dyad interviews**



**Figure 3: Flowchart of methods for ECP**



### **2.2.1 Data collection methods**

Data collection methods in grounded theory can vary widely. Anything that relates to the subject of interest can be data. This includes interviews, observation, documentation, memos, and literature. However the most common data collection method is the interview (Holloway, 2005; Coad and Lewis, 2004). Grounded theory is an investigation of lived experience and therefore the essential component of data is the perspective of the people involved. However Corbin recommends the use of more than one source of data and in particular the use of triangulation of methods (Corbin and Strauss, 2008).

### **2.2.2 Interviews**

Interviews are a very popular method of collecting qualitative data. An interview is an adapted conversation and conversations are perhaps the most direct way humans communicate. Therefore the process of interviewing is not likely to seem artificial to participants.

“their experiences, feelings, attitudes.... dreams, fears, hopes: hears their views and opinions in their own words” (Kvale and Brinkman, 2009)p xvii.

There are many types of interview and this makes it suitable for different types of research question and purpose (Punch, 2005). They range from structured interviews (such as surveys and standardised questioning) through semi-structured (such as group or face-to face) to unstructured interviews (such as in depth narrative or clinical interviews). The range of interview types is considered by some to be a continuum (Holloway, 2005; Punch, 2005). The selection of the type of interview is very important for the best quality data to be obtained. It needs to be based on the research question and the participants that are involved.

### **2.2.3 Considerations for this research**

Interviews were chosen as the primary data source for this research as it is an investigation of the experience of children with an ASD.

“If you want to know how people understand their world and their lives, why not talk with them?” (Kvale and Brinkman, 2009 p xvii).

The interview process needs to be tailored to the individuals involved and the type of information sought. In this study there were three groups of participants: children with an ASD (and in some cases LD), PCs and ECPs.

### **Interviewing children with ASD**

In the present research further considerations were needed regarding how to best enable children with an ASD, and possibly also LD, to express their thoughts. Children with ASD have impairments of communication, social imagination and social interaction (see section 1.1). Interviews are reliant on verbal communication but the children in this research may use different communication methods such as Makaton, Picture Exchange Communication System (PECS) (see Glossary).

In addition even when verbal communication is used they may have difficulty with meanings of words and are likely to take longer to process information and respond. They have great difficulty with the abstract as they are concrete thinkers, therefore questions need to be straightforward and logical. Beresford discussed this difficulty (Beresford *et al.*, 2007) who found adapting an interview to make the topic meaningful and less abstract was important. Therefore it was decided that in this research the questions would be adapted to their particular needs, kept simple, non-ambiguous and directly relevant. The child would be given time and space to respond to the questions. Fraser suggests that a valid research design is one that ensures that questions and responses are correctly understood (Fraser *et al.*, 2004).

Anxiety in new situations, such as talking to a stranger, and in particular eye contact can be distressing for children with an ASD. Research shows that visual processing is different in ASD including perception of facial expression and the interpretation of the ‘bigger picture’ (Dakin and Firth, 2005; Simmons, 2009; Ludlow, 2012). Facial expressions are used by us all to interpret the intentions of the person (e.g., are they cross, happy and so on) therefore children with an ASD may not be able to judge the situation very well or may misinterpret the intentions of the researcher. In addition they may have impaired theory of mind which results in them missing unspoken instructions or meanings, and not being able to predict how someone else perceives a situation (Baron-Cohen *et al.*, 1985). Processing issues therefore may mean that the child does not perceive the intentions of the interviewer so verbal

encouragement, visual supports and responses are needed. If pictures are used then the understanding of the picture needs to be checked before data are collected.

Some research has shown that children with autism have difficulty with memory in free recall tasks (such as recalling their experience at the optometrists) and do better if they have supports such as words and prompts (Dockrell, 2004; Bowler *et al.*, 2000). The interview venue chosen for the children was an optometry practice to enable observation of them with equipment and to provide visual prompts to aid recall. However, children with an ASD have difficulty with change and if something differs from their expectation it can cause them great anxiety. As the interview is taking place at an optometry practice they may expect to have an eye examination and this expectation needs to be managed in advance. To reduce anxiety interview schedules (written or pictorial) were sent in advance to help the child to understand what is going to happen. See Appendix 2vi. However this sets expectations that must be met, because a change of plan can also cause distress.

### **Interviewing children with LD**

Lewis and Porter highlight the issue that people with LD may not feel that their view is important and low self-esteem can affect their ability to participate (Lewis and Porter, 2004). A valued other person may help to encourage them to participate. Rapport building activities and communication adaptations also facilitate participation. The researcher needs to ensure that questions are meaningful to the participant. The use of alternative techniques such as card sorting, video clips and drawing should be considered. These give the participant a greater range of expression but there is an inherent difficulty with interpreting the data produced. Planning, preparation and triangulation is therefore important (Lewis and Porter, 2004; Coad and Lewis, 2004).

Children are accessed for research through their PC or gatekeeper (this could be a teacher or doctor or other person involved in their care). The need for good relationship building with the gatekeepers has been shown to be important (Duerr Berrick *et al.*, 2000). Poor communication with gatekeepers can significantly reduce the pool of participants.

In view of these recommendations a review of alternative interviewing techniques was made, see Table 6. This gives more information about the methods that were

selected as a result of this review. The methods were chosen to ensure that the needs of each child could be met and a toolkit of options was available. Planning for the interview was made following advice from each child's PC and the PC accompanied their child to the interview so that they had a valued other person to encourage and support them.

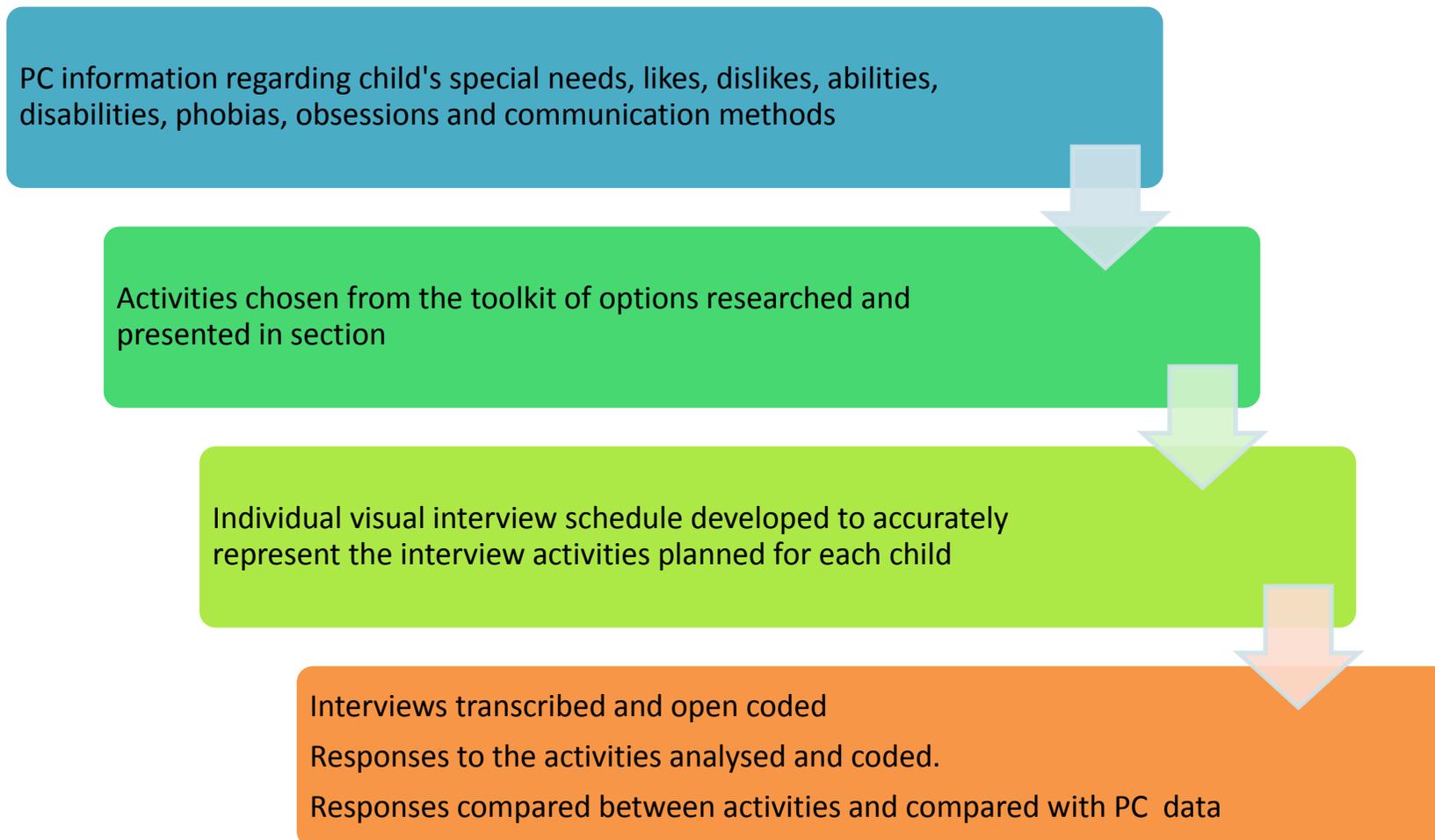
As the researcher did not have access to the child for long enough to build rapport an exercise at the start of the interview was used to establish this. Kelly recommended a rapport building exercise where the researcher and child completed a booklet together that shared information about each other in a relaxed manner (Kelly, 2005).

ASD is a spectrum, there is a wide range of special needs and therefore adaptation needs to be individually planned. In order to plan which methods to use the PC was interviewed first and the child's specific needs and abilities were discussed so that a plan could be formulated. The interview schedule was sent to the PC for their opinion before the interview so that anything could be changed that they felt would not be effective or even distressing (Humphrey and Lewis, 2008; Fraser *et al.*, 2004).

#### **2.2.4 Interview activities**

A toolkit of alternative activities was put together from a range of techniques for interviewing children. Table 6 presents the alternatives along with their benefits and disadvantages. The methods selected for each child were based on the recommendations of the PC and Figure 4 illustrates this process. See also Appendix 5i for further information about the literature regarding alternative interview activities.

**Figure 4: Flow chart to show the planning for each child participant's activities**



**Table 6: Techniques for interviewing children**

Activity	Benefit	Disadvantages	References
Video clips, vignettes and common phrases to start discussion	Act as memory prompts and depersonalises sensitive subjects Use as a start of conversation	Can be a distraction to talk about rather than the topic. May not understand the clips or examples if not relevant directly to them Preparation of clips and cuttings time consuming.	(Punch, 2002)
Draw and Write	Fun Doesn't rely of language so good for expressing feelings Good introduction to a topic Good supplement to other techniques	Open to interpretation. The data from this technique can be more limited than other techniques that produce rich narrative data The focus is on drawing rather than the explanation	(Morgan <i>et al.</i> , 2002; Lewis, 2002; Ogina and Nieuwenhuis, 2010; Mauthner, 1997; Carney <i>et al.</i> , 2003; Backett-Milburn and McKie, 1999)
Photography	Fun Easy Inexpensive	Open to interpretation therefore accurate meanings need to be discussed with the child	(Morrow, 2001)
Spider diagrams	Expands the topic Enables the child to define categories rather than use those imposed by adults Can be used for brainstorming in groups or individually. Enabled the child to take their time to express their thoughts rather than answering questions under pressure.	None reported although the children in the study rated this activity the least liked out of a range of methods used	(Punch, 2002)

Activity	Benefit	Disadvantages	References
Diaries	<p>May provide more information than possible in an interview and reduce the face-to-face difficulties that children with autism may have</p> <p>This also allows temporally arranged information to give greater accuracy.</p> <p>Less intrusive than interviewing</p>	None mentioned in the research	(Humphrey and Lewis, 2008; Lewis, 2002)
Focus groups	<p>Provides consensus opinion</p> <p>Peer support and encouragement</p> <p>Others provide memory prompts</p> <p>Similar to school groups and therefore familiar</p>	<p>Balance of group important</p> <p>Fear of reprisals or bullying may inhibit</p> <p>Personal views may not be represented</p>	(Morgan <i>et al.</i> , 2002; Balen <i>et al.</i> , 2000/2001; Mauthner, 1997; Punch, 2002)
Role play and drama	<p>Gives the child greater range of expression and more control over what they want to say</p> <p>Children were able to act out scenarios in a way that was not personal</p>	<p>Care needs to be taken in the interpretation and meanings</p> <p>Some children may be reluctant to join in</p>	(Coad, 2002; Morgan <i>et al.</i> , 2002)
Card sorting	<p>Effective for young children or children with limited communication skills</p> <p>Fun and keeps child focused on the subject</p>	<p>Questions asked about the cards can be abstract and the task difficult if the child cannot relate it to themselves</p> <p>Questions therefore need to be relevant directly to the child</p>	(Mauthner, 1997; Punch, 2002)
Cue cards	<p>Enable the children to think about the topic. Reduces acquiescence as it gives wider range of responses to people with poor communication</p>	Poor response from children with ASD	(Lewis, 2004; Lewis, 2002)

Activity	Benefit	Disadvantages	References
Poster making	Fun and interactive, focuses on the 'here and now' which is appropriate for children with ASD. The pictures are meaningful to a child who has difficulty with abstract or figurative representations chosen by other people	Not suitable to investigate 'why' and therefore open to interpretation from the researcher. Careful questioning is still required to discover this information	(Beresford <i>et al.</i> , 2007; Beresford <i>et al.</i> , 2004)
Questionnaires	Range of information Large sample Can be designed by children Can be used for mixed methods	Language skills required Responses limited and set by an adult May have a tendency to acquiesce	(Carney <i>et al.</i> , 2003; Dockrell, 2004; Morrow and Richards, 1996)
Visual questionnaires	Good for expressing feelings	Needs clear instructions	(Carney <i>et al.</i> , 2003)
Power point	Gives a wider range of responses for children with limited communication and enables them to have more control and less constraint in their responses	Care needs to be taken in the interpretation of the data produced. The true meanings need to be cross checked with other sources.	(Lewis, 2002; Coad and Lewis, 2004; Lewis and Porter, 2004)
Mosaic method using combination of observation, photographic diaries and stories	Enables children to engage in the research and reflect on the topic. It enables them to visually represent their experiences and can be used to prompt further explanation or as stand alone evidence	The value is found in the interpretation of the images produced by the children not in the image itself	(Clark and Moss, 2005; Morrow, 2001; Clarke, 2002)
Reading stories	Good for young children Helpful prompt where communication is difficult due to lack of vocabulary		(Mauthner, 1997)
Email interviews	Helpful in older children and produces good quality data	Not helpful for young children	(Reid <i>et al.</i> , 2008)

Activity	Benefit	Disadvantages	References
Observation	Suitable for non verbal children A more natural environment that can elicit general narrative of a subject outside of the constraints of an interview	May be limited by the acceptance of the observer by the child	(Lewis, 2002; Morris, 2003; Mauthner, 1997)

## Face-to-face interviews

Whilst it is generally preferred in grounded theory to use a mixture of open and semi-structured questions this is not ideal for children with ASD. Open questions were avoided as several of the PCs commented that their child becomes overwhelmed if the question is too broad. However the approach was flexible and where it was possible to include open questions these were used.

This is illustrated in the following extract from a PC interview:

“Mick(PC) : .So I'll ask Adrian(C) when he come home “how's your day?” so I've been told not to do that because it confuses him, it's too much, although it's only a simple question that we would ask each other and we can answer it, that's too much information for him because he'll expect me, he'll expect, he thinks that I'm expecting him to tell him in one hit how his whole day is so”.

Semi-structured can also be difficult because giving a range of possible options can cause bias. ASD limits their ability to answer questions without prompting or support. The interview questions were therefore structured to avoid: asking questions with more than one part, using figurative language, and questions that require abstract thinking.

The researcher attempted to phrase questions in a simple and straightforward way that was as open as possible whilst still enabling the child to cope with the process. As explained above, for some children the questions had to be at times more closed than is ideal but all questions were cross checked with data from the other activities and from the PC data. A disadvantage of closed questioning (e.g., “Did you like the 3D test?”) is that the child could be led. Interestingly, it seemed that this was not a significant issue. Indeed, the children with ASD answered the questions literally from their own perspective, with their lack of empathy making them resistant to any influence of the interviewer's viewpoint. In effect it was a balancing act between too structured or questions that might lead the child's response, and not enough structure such that they might be overwhelmed with the task.

For example

“LS: What about the big black chair, do you like sitting in the big black chair or would you rather sit on mummy's lap than sit on the big black chair?

Chris(C): I love sitting on the big chair”

This gives the child really only two options, and therefore, limits the quality of the data produced. However, his response was then compared with his response in the card sorting exercise and observation of him interacting with the equipment later in the interview. It would also have been compared with his PC's responses in her interview.

Children with ASD typically do not cope well with abstract ideas and they do not understand the rules of being polite. Therefore it is less likely that a child with an ASD would give an answer simply to please the interviewer. This is often what makes them appear rude but in the context of an interview it is helpful because they would be less likely to worry about disagreeing with the interviewer. The use of more structured questions is therefore, on balance, more effective than giving them less structure.

### **Card sorting**

A range of photographs were printed showing common equipment used in a routine eye examination. These included different versions of the same pieces of equipment and pictures at different angles. There were also pictures of the consulting room environment. Several pictures of each image were included so that the reliability of responses could be checked. There were also cards with symbols for like, dislike and do not know. These were laminated to protect them. The child was instructed as to what the symbols meant and asked to sort the cards onto the symbol that they felt was most appropriate. Each picture was discussed to ensure the child was aware what the picture was. One child did not have a long enough attention span to cope with all the cards and therefore duplicates were removed. Samples of these can be seen in Appendix 3ii.

### **Observation**

Observation of the children in the consulting room environment was another source of data. The children were given the opportunity to walk around the consulting room. They had complete freedom to touch, investigate and play with any of the equipment. The researcher noted which instruments they chose to play with and which they avoided. The child's reactions, verbal and facial, were noted. The way in which they interacted with the equipment was also noted such as what they did with the gadget, how long they played with it, whether they came back to it later.

The option was available to video the reaction of the participants to the equipment in the consulting room. All the children except one were high functioning and video was therefore only used for one child. The camera was held by his PC for the mobile activities. The child understood the purpose of the video and was clearly familiar and comfortable with the process of his PC filming him. The data from this video was transcribed and analysed along with the other data from his interview.

### **Video Clip**

Two video clips were prepared, one of a girl, and one of a boy, having eye examinations. This was a resource available as a visual prompt and could have been used for non verbal children to observe their responses. However it was not required by any of the participants.

### **Draw and write**

Draw and write is an activity that enables children that find expressing themselves verbally difficult. The children were asked to draw and discuss a picture of their favourite test and their least favourite part of the eye examination. Discussion about the picture sought to find out why they chose those items and clarify the meaning of the picture such as for the drawing in Figure 16. Adrian(C) described his drawing as representing how boring it is waiting for the appointment.

### **Photography**

The mosaic technique (Clarke, 2002) seemed a very attractive way to find out more about the child's experience but this would have required recruiting children before their eye examination and asking them to photograph their pathway through the process. The timescale of the project was short, so the technique was adapted. The children were asked, as one of the interview activities, to photograph anything they liked about having an eye examination and everything they did not like about having an eye examination. The photographs were uploaded to the computer and discussed to clarify the response and the meaning where possible. Some of the children were not interested in discussing the photographs afterwards. Copies of the photographs were sent in a booklet to the child and they were given the opportunity to write anything on their photographs that they wanted to. Two children chose to add comments, Freddie(C) and Chris(C). Examples of these can be seen in Figure 14 and Figure 27 also in Appendix 3iii. Steve(C) laid out cards from the card sorting in order to illustrate an eye examination and photographed this as a panorama. He

was then encouraged to pick out the best and least favourite tests and discuss the eye examination. See Figure 19.

### **Modelling**

This activity was designed specifically for Tim(C) because he has a love of plasticine model making. This seemed to be a suitable alternative to 'draw and write' for this individual. He has a specific type of plasticine and particular colours only are acceptable to him. Great care was taken to ensure that this was selected correctly. He was asked to make a model of his favourite part of the examination. Photographs of the model were taken as he wanted to give his model to his ECP see Figure 18.

### **Visual prompts**

A box containing a variety of common eye-care equipment was placed on the table. The child was invited to take out any of the instruments and look at them, play with them, and talk about them. Some pieces of equipment were not recognised by the child and the researcher ensured that they were aware of what these were and their function. In a similar way the child was invited to look around the consulting room, dispensing area and waiting room and touch and play with equipment and talk about it. Their comments, behaviour and interaction were recorded.

### **E-mail questionnaire**

One child was not able to cope with a face-to-face interview and requested an online format as he is more comfortable communicating through computers. The interview schedule was developed into a multiple choice questionnaire with pictures and options which always included a free text box for an alternative response and a 'why?' free text box. This could not be piloted due to time constraints but was developed with the suggestions and approval of experienced researchers and also his PC. The questionnaire can be seen in Appendix 3iv.

## ***2.2.5 Interview method for child participants***

The interview structure for each child was developed from this toolkit of activities, for that individual based on information from their PC. Details of the activities selected for each child can be seen in Table 7. The information given by the PC for each child enabled the researcher to tailor the interview to the needs of each child. The

children were at all times accompanied by their PC. It was important that the PC was present as they acted as their valued other person for support and also enabled interpretation for those children whose verbal communication was limited. Although time was spent at the beginning of each child interview relaxing the child and building confidence and rapport it was nonetheless considered that this might not be enough for some children and that the PC would need to be present.

The PCs were given a choice of location for their child's interview but were requested, unless they felt that it would cause distress, to choose either the researcher's own clinic or a practice local to them (preferably the practice at which the eye examination took place). Four children were interviewed at their own optometrist's clinic, one at the researcher's clinic and one at a practice near to his home. Tim(C) was intending to be interviewed in the practice where his examination took place but unfortunately due to a family bereavement he had to postpone his interview and the opportunity to use the clinic could not be rearranged. The interview took place at the researcher's home. This was satisfactory as he is very high functioning and less dependent on the visual prompts in the clinic environment.

Dylan(C) was considered by the PC to be unable to attend a face-to-face interview. He spends much of his time on a computer and prefers to communicate that way, and will only leave his room once a week, and therefore an adaptation was made to enable an online format. Ethics approval was sought to interview him by email. It was felt that, despite this circumstance, he would be a valuable participant because of his particular extreme difficulty with face-to-face interaction and the bearing it may have on the consultation structure of an eye examination. Also emerging data at that point in the study was indicating that computerisation of the eye examination may be a helpful adaptation and it seemed ideal to explore this with him.

An interview schedule and information sheet was sent to each child ahead of the interview. These sheets were adapted according to the communication needs of the child. See Appendix 2ii. Children with ASD are more able to cope with activities that they are familiar with and do not manage unexpected situations well. Therefore it was important to give accurate information in advance to enable the child to know what to expect in the interview and what was expected of them. They were given either a verbal or visual timetable see Appendix 2iii, and were aware what activities were planned, in which order and when the interview would finish. This limits the element of surprise and helps them to navigate the situation.

Informed consent was given by the PC to enable the child to be approached for the interview and informed consent from each child was sought at the beginning of the interview to indicate their agreement to participate. All but one child gave verbal consent and six children signed the consent form. The behaviour of the child who was unable to give verbal consent was used as evidence of consent. One child gave verbal consent but requested that his PC signed the consent form on his behalf.

All children were reminded that the interviews and associated activities were optional and that they could say they wanted to stop at any point. A calm, quiet room was available in case of challenging behaviour. Simon(C) and Tim(C) became slightly distressed at certain points in the interview. The process was stopped at that point until they were happy to continue and consented to do so. Activities were stopped if the child seemed to be disinterested or became distracted by something else. Disinterest or distraction was considered evidence that they did not want to continue with that particular activity.

The interview started with a rapport building exercise where the researcher and child sat together and filled in a little booklet called 'About me' based on research recommendations from Kelly (Kelly *et al.*, 2000; Kelly, 2007). This booklet allowed the child and researcher to get to know each other and to reduce any power imbalance. The booklet contains information about likes, dislikes, pets, family and jobs or hobbies. The child and researcher completed the booklet and discussed what they were drawing or writing. The child was then given this booklet to keep. This proved a very helpful way of getting to know each other, breaking the ice and also enabling the researcher to explain who they are and why they are asking the child to participate. Dylan(C) declined a face-to-face meeting and therefore the booklet was not used. Freddie(C) was too excited to sit down and draw but grabbed hold of the researchers hand and took her into the consulting room to see all the equipment. It was considered that this was evidence that Freddie(C) was comfortable with the researcher without the need for the booklet.

A 'fact file' format was used with Steve(C) as he was very high functioning and would have found the picture booklet too immature, see Appendix 3i.

The interviews were digitally recorded and manually transcribed. Written field notes were also taken. In addition a video recording was taken of one child's interview

whose verbal responses were limited. Photographs were uploaded into the child's research folder and photographs of their card sorting selections were also recorded in their file.

### ***2.2.6 Interview method for PCs***

Information sheets were sent to potential participants detailing the research and what they would be expected to do and also their child's involvement in the research. Informed consent was requested from each participant. See Appendix 2i.

An interview schedule was sent to each participant giving them a close idea of what was going to be asked in order that they could prepare, see Appendix 2vii. It was made clear that these were broad outlines for discussion and not exactly what would be asked. They were also reminded that they could withdraw from the research at any time or decline to answer specific questions. The purpose of this was to enable the PC to consider the area of discussion ahead of the interview. It was hoped that this would enhance the accuracy of the data.

Semi-structured face-to-face interviews were carried out with all PCs. There were two aims to these interviews. The primary carer chose the location of the interview so that it was convenient to them and enabled them to feel relaxed and comfortable. However two criteria were requested: the location must be quiet and their child must not be present. This was important for the concentration of all involved, for the quality of recording and also so that the primary carer had privacy.

The first two interviews were semi-structured but quite open and exploratory. The questions were in two themes. Theme one was about their child's likes, dislikes, phobias, triggers, communication methods, strengths and disabilities. These questions were very similar for all participants. The second theme was to elicit the views of the PC and also to explore further the data emerging from previous participants.

The interviews were recorded on a digital recorder and transcribed manually. Transcription and analysis was carried out simultaneously. Subsequent interviews became more structured and focused as emerging concepts were investigated.

### **2.2.7 Interviews method for ECPs**

As with the PCs, the ECPs were sent information sheets and written consent was requested. See Appendix 2iv.

Semi-structured interviews and the initial interview was open and exploratory. Interviews with subsequent participants became more structured and focussed. Interview schedules were sent to the participants and they were advised these were guidelines only, see Appendix 2v. The ECPs were given a choice of face-to-face or telephone interviews. The chosen location had to be a quiet environment and private. The interviews were recorded on a digital recorder and manually transcribed.

## **2.3 Sample**

### **2.3.1 Child and primary carer dyads**

Eight dyads of child with a diagnosis of ASD and their PC were recruited. Grounded theory methodology requires recruitment of participants using theoretical sampling until saturation occurs (no new categories emerge). Due to pragmatic considerations related to the professional doctorate a minimum number of participants had to be stated for the purpose of seeking ethics approval. Advice regarding this number was taken from experienced researchers at LSBU who felt that five or six dyads would be appropriate and therefore a sample slightly exceeding this was selected to improve the likelihood of saturation occurring.

Inclusion criteria: Between 4 and 16 years of age and have a diagnosis of ASD using the DSM-IV which was updated to the DSM-5 in April 2013.

Exclusion criteria: Asperger's syndrome or under the care of a hospital eye clinic.

Initially the first exclusion criterion was enforced but a change in the DSM in April 2013 meant that Asperger's Syndrome is no longer recognised as a condition independently. Children under the care of the hospital eye service were not included because this is not primary eye-care and children may be confused as to which eye-care provider is being discussed (e.g. Optometrist, Orthoptist, or Ophthalmologist).

Recruitment was via a wide range of sources. Initially it was hoped that recruitment for the study would be possible through the local special school for children with ASD and their outreach groups in local mainstream schools in addition to advertising at the National Autistic Society. However it became clear that this was not going to be possible due to a significant number of the children not having accessed primary eye –care and many PC’s not having English as their first language in the special school.

The researcher attended many outreach parent groups and parent evenings but after three months it was clear that other recruitment sources would be required. Recruitment was pursued through local support groups for the carers of children with ASD, online optometry forums and also online forums for carers, a national autism conference and through optometry colleagues. Even with this broad approach, recruitment proved highly challenging. Over 200 emails, letters, telephone calls, and one to one discussions were required to recruit the cohort reported in this thesis. Overwhelmingly, the major barrier to recruitment was a lack of engagement with eye-care services for children with ASD. This is discussed further in section 5.3.

The demographics of the sample can be found in Table 7. The sample of children involved in this study represented the mild LD to high functioning region of the autism spectrum. The majority of the children were of white British ethnicity and were in mainstream school. One child was from mixed white and Afro-Caribbean origin. One was home schooled and two were transferring to special school. One child was in private school. All children lived in the south east of England. All children were boys.

The recruitment criteria were applied to the child rather than the PC. Only one father took part in the study, and all other carers were the mothers. The fact that most of the participants were mothers simply reflects the fact that most children attend health care practices with their mother. Both parents of Adrian(C) were interviewed because his father was present at the eye examination but his mother is his PC. It was essential that the dyad was PC and child in order that the child’s data could be compared with the person who knows them best and who was also involved in the process of eye-care.

The method of sampling used was theoretical sampling, which is in keeping with grounded theory. Recruitment would ideally continue until saturation occurred but

given the time constraints of this study it was not strictly possible, however no new codes emerged from the final two child participants and therefore for the region of the autism spectrum that these children represented it is likely that saturation was reached. There was a high level of consensus between the children and triangulation throughout which increased the reliability further.

### **Theoretical sampling**

The recognised method of sampling in grounded theory is theoretical sampling (Corbin and Strauss, 2008). This is the process of selecting the next participant based on emerging concepts. This enables further exploration and verification of concepts by choosing participants that are in a position to confirm or negate the findings. The principles of this were attempted but given the small pool of potential participants and the limited time scale of this project, this was not as closely adhered to as would have been ideal. An example of theoretical sampling was the inclusion of ECPs, as this decision led from data emerging from the interviews with the children and PCs.

Theoretical sampling was carried out by focussing the questions in the interviews to investigate emerging categories. For example it seemed that the children were identifying a good experience with the practitioner's personality and this was also commented on by the PCs. Subsequent interviews included more questions about the practitioner than the initial two interviews. These questions became more focussed on what the elements of the 'right' personality would be and it was decided that interviews with ECPs would add depth to the research. This category was developed further by the professionals who identified that whilst most people are capable of doing this kind of work it suits some personalities and skill bases better than others.

**Table 7: Child Participants and interview plans**

Participant	Source	Primary carer (PC)	Age	Education	Special needs	Interview tools selected based on PC data	Effectiveness of tools
Adrian	Special school outreach team	Mick and Rosie	12	High functioning Main stream school	Verbal communication with symbol prompts but processing impairments therefore needs time to answer questions Concrete thinker Hypersensitivity to noise, lights and crowds Creative – drawing and photography Computers – loves to play on computer Soother – playing with lego bricks	Face-to-face interview Visual timetable with words guiding the interview Photography to make a social story Draw and write Visual prompts Observation Card sorting	Adrian was able to manage face-to-face interview with some visual prompts. However he did struggle if the questions were too open or if there were several parts to the question. He enjoyed the photography and drawing activities. Observation was not required and card sorting added triangulation but did not add any further information.
Freddie	ECP private patient	Daisy	10 ½	Low functioning/ LD Special school	Verbal communication but speaks very quickly and limited range of clear words Symbols used to enhance verbal communication.	Visual timetable with words Observation Photography Card sorting Fast moving pace to avoid boredom	Freddie was lower functioning than had been expected based on the PC data. Therefore at the last minute it was decided that his interview

Participant	Source	Primary carer (PC)	Age	Education	Special needs	Interview tools selected based on PC data	Effectiveness of tools
					Good sense of humour Hyperactive Repetitive behaviours- flicking, spinning and rocking		should be videoed for observation data. He enjoyed the photography but his concentration span was too short to extend this to any further discussion of the photographs. Card sorting was very helpful as this enabled triangulation and cross checking which was valuable given his limited verbal communication. He loves computers and he may have been more engaged with an computer quiz type activity.
Dylan	Local ASD support group newsletter	Sara	13	High functioning Home schooled	Unable to cope with social interaction Unable to cope with face to face interview and in particular being recorded or videoed	Email interview with multiple choice questions and free text options with photographic visual prompts.	Dylan was recruited specifically because of his interest in computers and his difficulty leaving the house. The

Participant	Source	Primary carer (PC)	Age	Education	Special needs	Interview tools selected based on PC data	Effectiveness of tools
					Expert computer operator Needs incentives to interact	Required reward in order to understand why it was beneficial to take part	questionnaire planned could not be validated therefore it has limitations. However it was interesting that he picked out some questions to answer and not others (rather than just answering the first few and giving up). This suggests that the data is accurate as he answered the questions he chose to.
Chris	Local ASD support group newsletter	Zahra	5	High functioning Main stream school	Verbal Hypersensitive to smell, sound and light Perfectionist – not keen on writing or drawing because it isn't perfect Repetitive behaviour – dancing on the spot Hyperactive Good sense of humour Enjoys computers Loves space and Sci-Fi	Interview schedule in the format of a special mission that his help was needed to complete Face-to-face interview Visual prompts Photographs Card sorting Observation Fast moving pace to prevent boredom	Chris has good verbal communication skills but very limited concentration span. Face-to-face interview was limited by his concentration, However he really enjoyed the photograph activity and was one of the few participants that commented on his photos. All activities

Participant	Source	Primary carer (PC)	Age	Education	Special needs	Interview tools selected based on PC data	Effectiveness of tools
							had to move quickly to keep his attention.
Andrew	Local ASD support group newsletter	Marianne	7	High functioning Main stream school	Verbal communicator with symbols to enhance understanding Concrete thinker Good sense of humour Hypersensitivity – touch, sound and light Creative	Face-to-face interview Photography Card sorting Visual prompts	All activities worked very well for Andrew. He was more able than expected and his verbal communication was excellent. Card sorting was very helpful and visual prompts were important. He was not very engaged with photography
Simon	ECP private patient	Anne	10	High functioning Transferring to special school	Verbal communicator Wide vocabulary in subjects that interest him Social interaction very difficult Obsessions Dislike of change Anxiety and phobias Poor self esteem Good at drawing	Visual prompts Observation Drawing (attempted but declined by child) Face-to-face interview Card sorting Required considerable encouragement in all activities	Simon's self esteem and anxiety held him back in the activities. It would have been better to have two sessions with him to build his confidence and understanding of what was happening. The data collected relied on all activities and having a range of activities to choose from helped to

Participant	Source	Primary carer (PC)	Age	Education	Special needs	Interview tools selected based on PC data	Effectiveness of tools
							distract him.
Steve	Local School	Catherine	10	High functioning Main stream school	Verbal communicator Wide vocabulary Keen photographer Likes to draw space aliens Likes science Dislikes being prevented from preferred activities and this triggers challenging behaviour	Interview schedule and about me booklet made into a 'Fact File' to make it more age and IQ appropriate Face-to-face interview Card sorting Photograph visual prompts Use of cards to produce a social story	Steve was the most able child participant and would have been able to cope with only a face-to-face interview. However the photography activity was very helpful and could have been extended to give a social story.
Tim	Local School	Pippa	10	High functioning Transferring to special school	Verbal communicator Wide vocabulary Anxiety and depression Creative – plasticine model making Obsessions Soother- plasticine Strong dislike of computers –these cause hallucinations	Face-to-face interview Plasticine model making Card sorting Visual prompts Encouragement in all activities	Tim was initially anxious and has diagnosed depression and anxiety, He benefited from having a range of activities to express his views and also to enable him to relax.

### 2.3.2 ECPs

The decision to include ECPs was made to investigate categories that were emerging from the data from the dyads. An extension of the ethical approval was made for this additional group.

Inclusion criteria: ECPs working directly with children with an ASD and who are recognised experts in the field.

Theoretical sampling was used to recruit the ECPs. Table 8 gives the demographics of the ECPs, pseudonyms are used to ensure anonymity. The first professional was identified as a frequent contributor to articles published on the subject of eye-care for people with special needs. The subsequent participants were chosen based on the emerging data. They were known opinion leaders and experts in the field of eye-care and ASD. They were from four regions of the UK and worked within hospital, education, specialist clinic and community clinic settings. The exact areas and locations have not been identified in order to protect the anonymity of these participants.

**Table 8: ECPs**

Participant (ECP)	Gender	Reason for selection
Susan	Female	Acknowledged expert in the area of special needs
Beth	Female	Specialist practitioner known to be developing care pathways for people with learning disabilities
Robert	Male	ECP who is involved in specialist care setting and community clinics.
Richard	Male	ECP involved in teaching and training practitioners in ASD awareness
David	Male	Eye-care professional selected because of involvement with community pathways similar to those being recommended by Susan(ECP) and Beth(ECP) but in a different area and also because involved in the teaching of post graduate programs.

The data from one participant was excluded (after the interview) because he had personal experience of ASD as well as professional experience and it was not possible to determine the data that related to his child's experience and his professional opinion.

## **2.4 Analysis**

“the act of giving meaning to data. Our vision of analysis involve taking data apart, conceptualising it, and developing those concepts in terms of their properties and dimensions in order to determine what the parts tell us about the whole” (Corbin and Strauss, 2008 p64)

### **Interviews**

Interviews were transcribed manually rather than using computer software. It was thought this would enable the researcher to fully understand and become familiar with the data and it was possible because of the relatively small number of participants. Digital recordings were transcribed manually and analysis started as soon after the interview as possible (Corbin and Strauss, 2008). This enabled the emerging data to be used in subsequent interviews.

### **Interview activities**

Video, card sorting, draw and write, modelling, photography and observed data was also transcribed manually. Description of reactions of the participant to equipment and the environment were recorded. The responses were triangulated with their responses in other activities such as card sorting see Figure 5. See also Appendix 5xi for an example of triangulation analysis.

Card sorting, photography, modelling and drawing activities were discussed to verify meanings with the child where possible. Data was cross checked with the PC for accurate interpretation and verification.

### **Triangulation and cross checking**

The coding of face-to-face interview data was triangulated with all codes from the interview activities. Memos were an essential part of combining the findings from the range of activities for each individual. This was also used to cross check meanings and develop categories. Figure 5 shows an example of how the elements of the adapted interview were combined.

**Figure 5: Example of analysis triangulation**

**Code :** *likes the Randot*

**Definition:** indicated that the Randot test was acceptable

**Supporting evidence:**

Coding from observation : “ pulls the card from LS hand and moves it backwards and forwards enjoying the effect and making excited noises with a big smile on his face.”

Coding from card sorting:



“He liked: all the charts pictures and letters, all the gadgets including the camera and mallet unit, he liked the big chair, the pictures of children trying on spectacle frames, stereo tests, colour vision charts, stickers and the trial lenses”

This child’s responses to visual prompts in the consulting room,

card sorting and verbal responses were in agreement. This code would have then been compared with any reference to the 3D tests from his PC and also subsequent child interviews.

### **2.4.1 Analytic tools**

In order to analyse the data a range of analytic tools were used. These were based on the methods recommended by Corbin (Corbin and Strauss, 2008).

#### **Transcription**

The transcription was done manually, straight after the interview whenever possible and with field notes and video data simultaneously. This meant the interview was still fresh in the memory of the researcher. Using a manual technique of transcription enabled the practitioner to be fully immersed in the data and completely familiar with all aspects including tone of voice, pauses and hesitations. This enhances the trustworthiness of the data.

#### **Coding**

The analysis took the form of several stages (Corbin and Strauss, 2008). Open coding, was the first stage, and involved the splitting of the data into small sections providing initial concepts. See Appendix 5ii. The first two interviews were analysed closely, line by line, generating many open codes for comparison within the interviews and between subsequent interviews. Open coding of subsequent interviews was carried out to investigate codes already emerging and to search for new codes not identified in previous interviews.

Axial coding, is the next stage of analysis where subcategories and categories (see appendix 5iii and 5vii) are established with axial codes that describe the characteristics, context and consequences of each category. These codes build the picture of the processes that have emerged. Categories and axial codes started to emerge from the open coding after four interviews had been completed.

Integration, is the final stage where the small chunks of data are threaded back together with the development of a core category and the picture of how all other categories relate and connect with this core category. See Appendix 5x. Theory can then be developed grounded in the data. Integration of codes and theory development started after the seventh dyad interviews.

During the analysis those codes that were associated with the individual's own personality were identified and those that recurred throughout the research were considered to be significant to the eye-care experience of children with an ASD.

Triangulation of data from all participants identified those aspects that were common to all.

## **Memos**

All stages of analysis were supported by memoing. Memos were used in the research diary to analyse the approach, views and experience of the researcher, and in all coding levels to explore codes and categories as they developed. Memoing was important to the analysis as it provided a written record of the decision making, ideas emerging and areas for further exploration throughout. It also provides a way of putting the chunks of fragmented data back together to produce the emerging theory.

This study took place over 2 years and therefore memos were used to record thoughts and ideas as they develop and ensure that no data were lost.

The memos took the form of written discussion or annotated diagrams. See Appendices 5iv, 5v, 5vi, 5viii, and 5ix. The researcher found some ideas easier to express in diagram format and this method enabled the researcher to give an overview of how different categories linked together. Often the diagram was a springboard for written memos.

## **Questioning the data**

The data were analysed by questioning what is happening using basic questions such as :“what is happening here?” “why?” “under what circumstances?” “who ?” “how ?” “so what?” and “why is this important?” The analysis was developed further by looking for explanations for the answers to these questions. This method was used to systematically analyse the data to understand what was happening, why and in what context.

## **The analysis of meaning**

The ‘meaning’ behind the responses of the participant was used to assist analysis. Such as: are they personal or can they be applied generally? In particular the researcher questioned the meanings of key words or phrases to ensure that what was interpreted from the data was the meaning intended by the participant. This was important for the children’s interviews as their grasp of verbal communication is impaired due to their ASD. This process requires reflexivity to ensure that the

meanings that are applied are those of the participant and not the researcher. Researcher bias was accounted for by the keeping of a research journal and also in the memos accompanying the data analysis. See Appendix 5vi.

### **The use of personal experience**

The researcher is actively involved in eye-care for people with special needs and the incidents and experiences of the participants were compared with the researchers own experiences and therefore a greater understanding of the meaning and relevance of these concepts could be investigated. Care was taken to ensure it was the experience of the participants that was analysed not the experience of the researcher.

### **Constant comparison**

An important analytic tool in grounded theory, this is the comparison of codes within the interview and between one interview and subsequent ones. Looking for similarity and differences gives an idea if the findings are common to all or personal to one. Constant comparison enables the categories to be further explored in terms of its context, dimensions and properties. Negative cases were used to investigate whether a category was general or personal.

This tool was also used to find patterns in the open coding and inform the interview schedule for subsequent participants. The findings were also used to help make decisions regarding theoretical sampling.

### ***2.4.2 Research diary and reflexivity***

A research diary, see Appendix 5vi, was kept throughout the research which was used by the researcher to reflect on the research at all stages. This was used from the planning, throughout the field work and all the way to analysis and theory development. It enabled the researcher to put in writing the feelings and thoughts that contributed to the development and execution of the research. It was also used to express the limitations and successes of the process.

Researchers using grounded theory are encouraged to use reflexivity (Charmaz, 2006 Birks and Mills, 2011). It is defined by Birks as:

“An active, systematic process used by the researcher in order to gain insight into their work that will guide future actions and interpretations”  
(Birks and Mills, 2011 p175)

In this research reflexivity is achieved by recording feelings, questions and thoughts in the research journal. This was an important way of separating evidence from personal opinion and also the researcher’s reaction to what was being said rather than the true meaning of what is being said.

The use of a research diary throughout enabled the researcher to express opinions and ideas about the data and about the process (Corbin and Strauss, 2008). This was a key way of keeping track of ideas. It also accounts for any concerns about the interview process in order that these could be factored into the analysis. The research diary was also used to reflect upon what did not go as well as hoped in the interview and to develop the process to make it more effective subsequently.

The researcher has experience and views of service delivery for children with ASD and therefore the research diary enabled the researcher to account for these views and the influence on the data analysis. The researcher is actively involved in clinical work in this field and therefore it was important that the personal viewpoints were reflected upon. This ensured that during the analysis what was emerging from data and what was related to the researchers own professional background was transparent.

## **2.5 Rigour**

The concept of rigour in qualitative research is widely debated (Mays and Pope,2000). There is no consensus of opinion as to the most appropriate way of assessing rigour. However there is consensus that it is essential that rigour in research can be demonstrated. The criteria of reliability and validity that are commonly used to evaluate quantitative research do not seem easily applicable to qualitative research. The positivist paradigm of quantitative research enables criteria for rigour to be prescriptive and clearly defined (Birks and Mills, 2011). The qualitative and naturalistic research paradigm however rejects the principle that there is one true answer. Qualitative research is an art and science and there is no consensus of how this can be evaluated (Mays and Pope, 2000; Corbin and

Strauss, 2008). This does not mean however that qualitative research should not be systematic and appropriate criteria are required to demonstrate

“the legitimacy of the research process” (Tobin and Begley, 2004).p 390

### ***2.5.1 Credibility and trustworthiness***

For the purposes of this research the criteria of credibility advocated by Corbin and Strauss (2008) has been adopted to demonstrate the quality of the evidence. Corbin describes this as how well the research findings resonate with the participants and target audience. She sets out 10 criteria that evidence the quality of the research. In Table 9 the ways in which this research addresses these criteria are given.

**Table 9: Trustworthiness criteria in grounded theory (Corbin and Strauss, 2008)**

Criteria	Definition	Research approach
Fit	The ability of the findings to resonate with participants/ target audience	Presentation at 2 key conferences enabled target audience feedback Discussion with carers of people with ASD through the researcher's clinic
Applicability	The findings are useful	Theory developed can be applied to day to day practice User friendly fact sheets developed Theory can be used to facilitate commissioning of services
Concepts	Data organised in concepts that have relevant dimensions and properties	Data analysis was systematic and axial coding and theoretical coding stages clearly define the properties of the core categories and subcategories for each group Audit trail evidence
Contextualization of concepts	Findings need to have context	Information about participant demographics Information about the effects of ASD and LD and how that affects the situation Information about the demands of the eye-examination Information about the circumstances of each participants eye examination (location, chaperone, optometrist practice type, familiarity etc)
Logic	The findings should progress logically	Data analysis is systematic and true to grounded theory methods

Criteria	Definition	Research approach
Depth	There should be rich description of the findings	The use of memos throughout gives depth to the findings The use of interviews as the primary data collection method adds rich description The use of participants words to enhance the findings The use of triangulation of data sources adds detail and context as well as ensuring rigour
Variation	The findings should reflect the variability in life	The analysis investigated those elements of the experience that were unique to the child and which were common to the group. Meanings were compared and cross-checked between participants
Creativity	The research methods and analysis should be creative	The use of a toolkit of interview techniques enabled children to have a voice and therefore add a service user perspective to the topic The use of adapted information sheets in the child's preferred format The use of the 'about me' booklet
Sensitivity	The analysis should drive the research or preconceived ideas should be accounted for	Theoretical sampling of participants and interview questions was driven by analysis of the data from the previous participant Research diary was kept throughout to identify the influence of the researchers experience and beliefs
Evidence of memos	The use of memos is essential to ensure that all data analysis is systematically incorporated	Memos were used throughout from open coding, axial coding and theoretical coding and also in the research diary

### ***2.5.2 Triangulation, member checking and cross checking to enhance rigour***

Member checking has been recommended as a way of improving the credibility of qualitative research (Holloway, 2005; Birks and Mills, 2011). It was not appropriate to member check with the children's data as the analysis becomes relatively abstract and children with ASD find abstract ideas very difficult. However ideas that emerged from each participant were checked at the time for meanings and then fed into subsequent interviews to check whether other participants expressed the same points of view. Each child was sent a summary of the findings and given an opportunity to comment if they wanted to.

The use of a range of activities with the children enabled the researcher to cross check the meaning of comments made or observed data or other findings from activities. The use of PC/ child dyads enabled cross checking.

During the planning stage of the research the proposed toolkit of activities was discussed with a researcher with extensive experience of researching with children and young people with disabilities.

During the analysis stage of the research, triangulation was used at the open coding level. The first two interviews were analysed with open codes and this was then discussed with an experienced qualitative researcher to ensure that the initial coding was appropriate and to provide an opportunity to discuss how this could be developed.

The research has been presented three times at the London South Bank University (LSBU) professional doctorate support group which has proved a useful source of critical appraisal in the planning, execution and analysis of the research. At the theoretical coding level the emerging theory was discussed with the research support group at LSBU as well as with the research supervisors.

The findings and theory were presented at the College of Optometrists conference in poster format and as an oral presentation at the UK Vision Strategy Conference. This provided an opportunity to discuss the findings with the target audience to assess how ECPs related to the findings.

## **2.6 Ethical considerations**

Ethics approval was sought and granted by the Research Ethics Committee at London South Bank University (LSBU) and also from the Institute of Optometry. See Appendix 4i, ii and iii.

Ethical consideration for each participant group was based on the guidance from three types of literature: official codes of conduct (Institute of Optometry code of conduct, London South Bank University research code of conduct), national and global codes based on the Declaration of Helsinki (Act of Parliament, 1998; World Medical Association, 2008) and the guidelines of the National Children's Bureau (Shaw *et al.*, 2011) and on interpretations of these codes (Punch, 2005; Coad and Lewis, 2004; Hickson, 2008; Holloway, 2005; Alderson and Morrow, 2011; Alderson and Goodey, 1996). The areas that they cover are beneficence (is the research worthwhile and justified); respect and rights (consent, human rights, confidentiality, research regulation); and balancing harm with benefit. The research was carried out in accordance with the ethical approval.

### **2.6.1 Child Participants**

There are special concerns about ethical implications of research with children and particularly children with LD (Shaw *et al.*, 2011). Lewis summarises these as consent/assent, confidentiality/anonymity/secretcy, ownership, recognition and feedback, and social responsibility (Lewis, 2002).

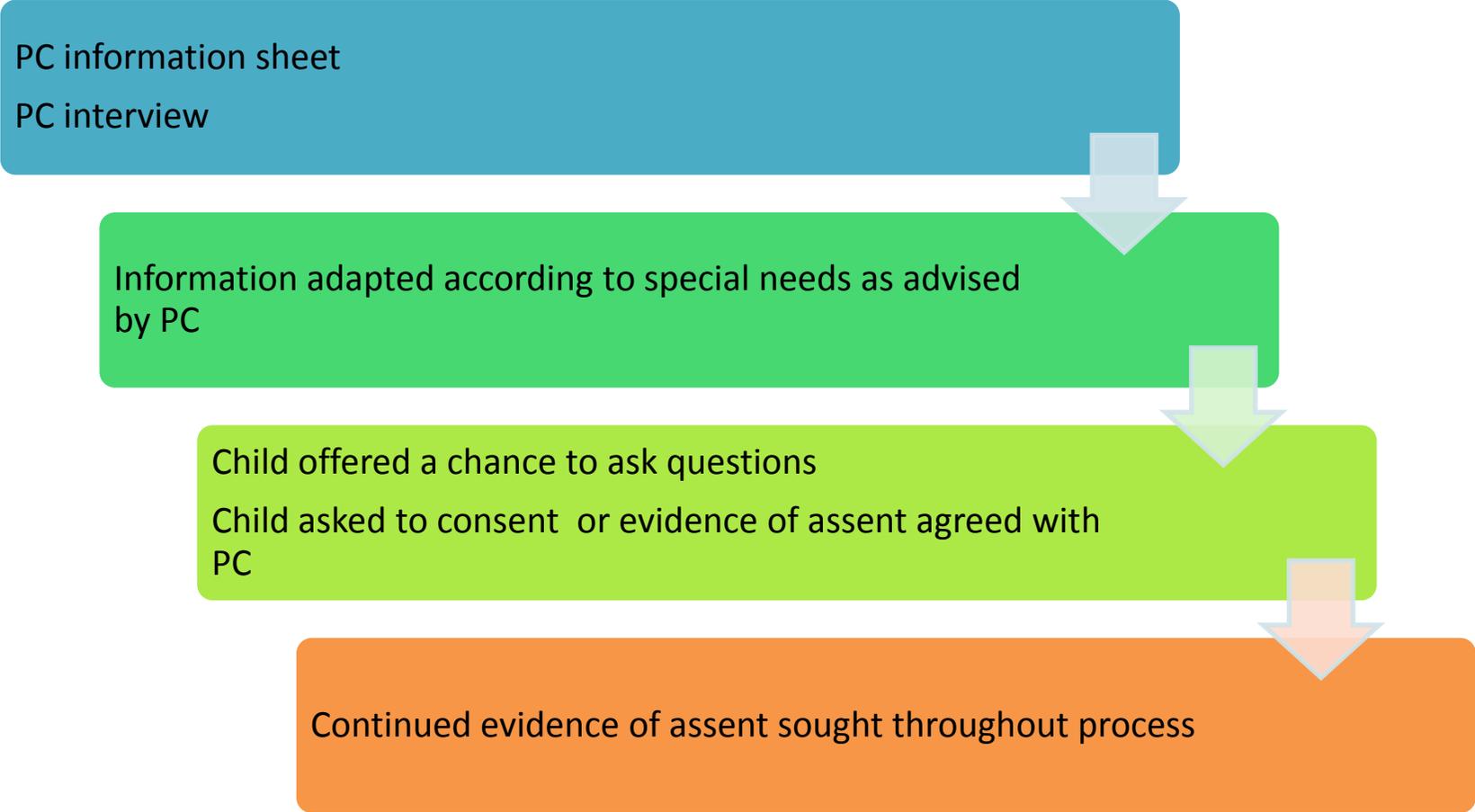
In research the capacity of a child to consent is a significant concern (Alderson and Morrow, 2011; Mauthner, 1997). Do children really understand what they are agreeing to do? What might it mean to them and those around them? The law in England considers anyone under 18 to be a child but acknowledges that people mature at different rates and that if the child can demonstrate that they fully understand and can make an informed decision then this represents capacity to consent (Berrick *et al.*, 2000; UKHL, 1985; Fraser *et al.*, 2004). Capacity is an individual's ability to make a choice, understand the risks and understand their rights. The law is designed to protect children from exploitation, but children's ability to genuinely understand and consent is being more commonly accepted (Children Act, 2004; Mental Capacity, 2005; Disability Discrimination Act, 1995; UKHL, 1985).

In this research all children were accessed either by first level gatekeepers (PCs) or by second level gatekeepers (headteacher, friend of the family or support groups). If a second level gatekeeper was involved permission to contact the PC was sought by the gatekeeper first. Information packs were sent to those that expressed interest. In this way all gatekeepers were able to facilitate informed consent for the child participants.

All child participants were given information packs that were adapted according to their specific needs taking into consideration communication preferences, cognitive ability, interests and age. These information sheets were sent to the PC first to check that they felt that they were appropriately adapted and if not they were amended. See Appendix 2iii.

At the beginning of each interview the child was asked for consent and given the opportunity to ask if anything was unclear or there were any concerns. They were verbally advised that they could stop at any time. There was one child whose communication difficulties made explicit verbal consent from the child impossible. In this case consent was obtained from the primary carer and the child's behaviour (ready engagement in the process and clearly apparent enjoyment of the process) indicated his agreement to participate. The consent process is shown in Figure 6 for the child participants. This shows the stages of consent.

**Figure 6: Flow chart of child consent.**



Two children started to show signs of distress in the interview and for each child a “time out” and an option to stop was given. One child had a calm down breathing routine with his PC which enabled his distress to be resolved quickly and he verbally agreed to continue. His behaviour indicated he was happy to continue. The other child became tearful over mention of his family unit. This was resolved quickly by changing the subject. He also became tearful because he was expecting an eye examination but explanation and a change of activity again resolved his anxiety. Both children and PCs clearly indicated a choice to continue.

Confidentiality for child participants also needed consideration. The child’s details, identity, location and identifying traits must not be revealed. The identity and view of all participants were kept confidential. In the case of a child with unusual circumstances that might be recognisable these details would not be reported in the writing up of the research. Confidentiality was assured for all participants and the use of pseudonyms was used throughout the research.

### **Child participants with special needs**

“Researchers cannot simply focus on researching children and young people who can be readily contacted and are articulate. Children’s perspectives are particular to the childhood they experience; the challenge for researchers is to be inclusive” (Fraser *et al.*, 2004 p45).

Special care needs to be taken for children with ASD not only because of the likelihood of having associated LD but also because the traits of ASD might make them more vulnerable and less able to make informed decisions (Jordan, 1999). It should also be considered that the power imbalance may be perceived as a greater concern in ASD where acquiescence is known to be common (Dockrell, 2004). It is also known that some people with LD are particularly likely to accept the last option given (the recency effect) (Lewis, 2004). This effect needs to be adjusted for when asking participants to make choices at all stages of the research, including the consent process (Stalker, 1998).

### **Recognition, respect and feedback**

The child and adult participants need to know that their views are accurately interpreted, respected and presented. Therefore an accessible format report was sent to the children after the initial analysis of all participants had been carried out. This contained photos of their own creative activities as well as an accessible report

of the overall findings. They had the opportunity to respond to this report but it was made clear that this was optional. In recognition of the child's time and work a small reward was offered (e.g. a small packet of lego). The nature of this reward was discussed with PCs given the serious concerns around obsessions, phobias, colour preferences and dietary requirements of this group of children.

### **Other general ethical concerns**

In line with ethics requirements samples of the information sheets and interview schedules were included in the ethics application. In view of the grounded theory approach it was necessary to inform the ethics committee that the interview schedule was likely to change depending on emerging concepts and findings.

### ***2.6.2 Safeguarding and emotional support***

The researcher is the clinical lead for a primary eye-care service for people with LD and is fully aware of safeguarding procedures for vulnerable adults and children. Primary carers were advised that if safeguarding issues were revealed in the interviews with the child participants the relevant authorities would be notified. The ECPs were advised that if evidence of malpractice was identified this would be reported to the appropriate authorities.

Primary carers may be under a great deal of stress. The researcher works in a multi-disciplinary team that includes emotional support counsellors and is trained in emotional crisis management. If signs of emotional crisis were identified during the interview process the participant were advised that sources of support available for them. One primary carer did become briefly distressed and it was established that she already had access to crisis support services.

### ***2.6.3 Summary***

This chapter has presented the rationale for methodology, the methods chosen and the measures taken to ensure the quality of the research in terms of credibility and trustworthiness. Finally it set out the ethical concerns that were addressed in order to carry out research with this vulnerable group of children. The next chapter will present the findings.

## Chapter 3: Findings

This chapter presents the research findings. The nature of the data produced from the child participants was mostly observation and children's likes and dislikes. They were typically unable to explain 'why', relate details of the context or discuss topics in a more abstract way. Nonetheless, even the child with the most restricted language skills was very able to convey in unequivocal terms their anxieties about eye-care and the features of their consultation that were problematic and those that were facilitators to future eye-care.

Although the research question is "What is the experience of children with ASD of primary eye-care?" the first half of the chapter relates to the context and process of primary eye-care in order that the analysis of the children's data can be fully appreciated. The context and process data is grounded in the findings from the PCs and ECPs who could explain the circumstances, timescales, practicalities and actions in which the children's experience is set. The data from the children is presented in the second half of the chapter.

All codes, subcategories and categories are displayed in italics. This is in order that they can be clearly identified within the text.

### 3.1 Symbolic Interactionism (Corbin and Strauss, 2008)

The data was analysed using the analytical tools discussed in section 2.4.1 and from the perspective of Symbolic Interactionism. Therefore the analysis makes the assumption that the experience of the child of primary eye-care is a combination of the context, the process and their previous experiences, background, beliefs, culture and values. This combination forms the meanings they attach to the experience and therefore how they react to it. Taking an example outside of primary eye-care: an individual in the UK may expect a friend to greet them with a smile, eye contact and a verbal greeting "hello" because their background, culture, previous experience and upbringing tells them that this is the way to greet a friend. If, however that friend walks past them without any of these customs being applied, the individual may be offended. Their reaction is based upon their understanding of what *should* happen and the meaning they apply to what *did* happen which then results in their reaction.

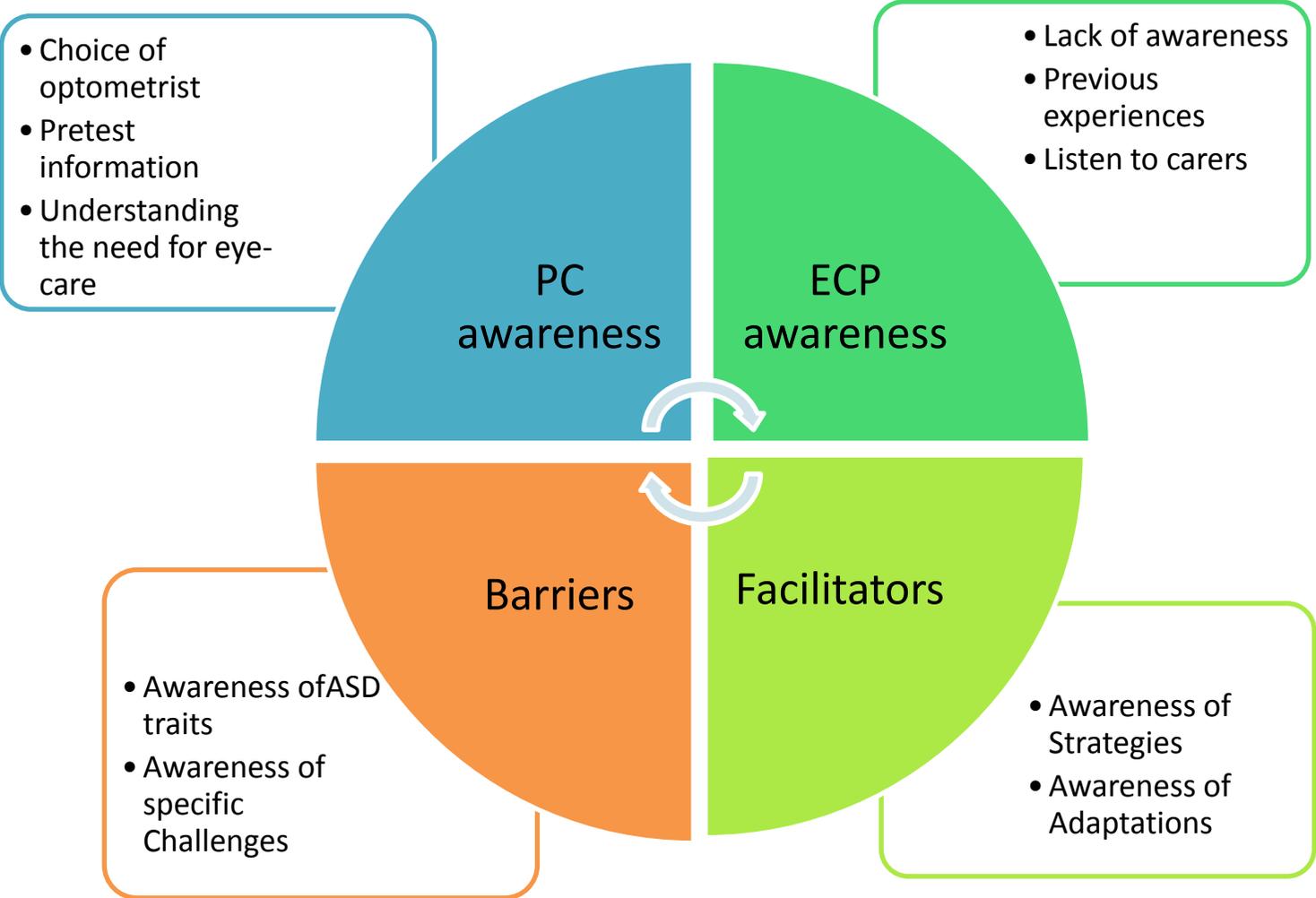
## **3.2 The Context**

In order to understand the data from the children and develop theory of the experience of primary eye-care it is important to understand the context. The context for the primary eye-care experience can be understood more clearly by the use of data from the PCs and ECPs.

### ***3.2.1 PC findings regarding context***

The PCs were primarily interviewed in order to inform the methods and approach used by the researcher to interview the child participants. The PCs were also asked about their views of the eye-care process and these findings are summarised in Figure 7 (see also Appendix 6ii). This data gives a greater understanding of the experience from the perspective of the person who knows the child best which is presented in section 3.4. However it also gives contextual data such as: the choice of optometrist, the child's previous experience, the type of practice, the approach of the ECP, the communication between ECP and PC, the expectations set, the environment of the practice and the special needs of each child. The categories that emerged are shown in the segments and their associated subcategories are attached in the extension boxes. These are presented and explicated and their relevance to the context and process in the following section.

Figure 7: PC findings



### ***ECP awareness of ASD***

The PCs all commented that people generally, in everyday life, *lack awareness* of ASD. This is directly relevant to primary eye-care because if the eye examination is carried out by an optometrist that lacks awareness, in a practice where the staff lack awareness, then the reaction of the child is likely to be different to that of a child attending a practice that has an understanding of the implications of ASD.

“Anne(PC) : he wasn’t um autistic aware.

LS: friendly?

Anne(PC) : no he wasn’t and he, you know, he just saw, he just saw, how old was Simon(C) 4/5, he just saw a boy flipping.

LS: yes, thought he was being naughty?

Anne(PC) : yes and saying, ‘oh come on it will be done in...’ thinking um”

Marianne (PC) pointed out that basic adaptation to the approach could make a difference but many ECPs do not adjust their approach because they are unaware of the needs of these children.

“Marianne(PC) : ...I remember coming out, and I felt really traumatised and I remember ringing [husband] my other half and just, I was really quite upset about it because I felt awful for Andrew(C). No-one wants to see their child like that and I just ‘no, there must be a better way’.

LS: yes

Marianne: surely, you know there’s a lot that could be done really and it’s just practical stuff much of it.”

This lack of awareness means that the ECP may use the same approach for a child with ASD as they would for a typically developing child. The child’s behaviour may be misinterpreted by the ECP as rude or naughty due to this lack of awareness. However this is not specific to eye-care, the PCs were referring to a general lack of awareness in the community as a whole. Several of the PCs had a low expectation of the awareness of the ECPs and this viewpoint seemed to be partially due to their experiences with other professionals that have been involved in their child’s care.

“Mick(PC) : So I can’t expect, I’d like them to have some sort of knowledge of it, but I can’t expect them to train and fully understand it. The teachers at school can’t even do that.”

The effect of any *previous experiences* of eye-care emerged from the data as a subcategory. This could be positive if they had a preferred optometrist, or negative if they had a poor experience. It is interesting to note that two PCs described poor previous experiences and therefore they sought a recommendation to find a suitable optometrist in order to avoid a similar experience at their next visit.

The PCs were in agreement that service providers rarely *listen to carers* and adapt their services accordingly. The PC knows the child better than anyone else and will have useful advice for the ECP. If the ECP does not ask the PC for information they are not able to accurately personalise the examination to that individual's needs.

“Anne (PC): professionals should listen to parents, on ASD friendly [web forums] there are so many threads about this, so many things about ‘I told them it wouldn’t but they insisted’.”

The data highlights that ASD is a spectrum, therefore each individual has specific special needs. ASD awareness enables the ECP to identify the most appropriate approach which is person centred and specific to each child. When Zahra (PC) was asked what information she would like practitioners to have, she said:

“Zahra(PC) : well it would be a very thick book! And of course they are all different aren’t they, spectrum where there are similarities and differences.”

In summary the *ECP awareness of ASD* has an impact on the context of a child's experience by influencing: the approach of the practitioner, the expectations of the PC, the appropriateness of adaptations and by providing a poor or good experience for the child to remember and carry forward to their expectation of the next eye examination.

### ***PC awareness of eye-care***

The PC's are the ‘gatekeepers’ for the child, making the decisions around eye-care access for their children. They often act as interpreters for their child and are most familiar with their likes, dislikes, triggers and challenges. Therefore the *PC awareness of eye-care* has a direct impact on the child's experience of primary eye-care.

The subcategory *choice of optometrist* represented the finding that PCs used various selection criteria when choosing an optometrist. Some chose for convenience, the nearest practice. Some chose the optometrist that was the cheapest and some through recommendations from friends or ASD support groups. None of the carers used guidance leaflets or professional support regarding how to access eye-care.

“LS: OK um and how did you come to choose that particular opticians at [supermarket]?”

Sara (PC) : because it was free ... sorry![laughs]”

The PCs who reported particularly bad experiences were those whose ECP was chosen for convenience or cost and they appeared to have a more limited awareness of ASD.

“Marianne(PC) : I didn’t really [method of choosing optom], I just went to the nearest one. Maybe I should have, in hindsight maybe I should have done some ringing around and asking.”

All but one of the PCs who reported good experiences were those whose children had either a regular ECP that has adapted their tests to the child’s needs or who were recommended experts in the field of eye-care for people with ASD.

“Anne(PC): yes somebody recommended [practice] to us and I said Ok we’ll give them a go and er yes this lady has been absolutely brilliant with him so.”

One PC who had little understanding of what should be involved in a comprehensive eye examination, described the experience as good. However analysis of her comments indicate that in fact the optometrist did not carry out many tests, omitted some important tests, and therefore the process was not likely to have been challenging. The category *PC awareness* included a subcategory of *understanding the need for eye-care* as it emerged that many PCs did not have an accurate understanding of eye-care for children.

“LS: did his test differ from yours in anyway?”

Sara(PC) : only in so far as his didn’t need to be as thorough because he hasn’t got any eye sight problems.

LS: Ok what did they miss out that they do for you?

Sara(PC) : um with this test he didn't even get as far as putting the fake glasses on with the different lenses.”

The experience may have seemed good because the test was shorter and less demanding than average and was therefore a less challenging experience for all. However this impacts on the quality of care, the clinical outcomes and the expectations of eye-care for future visits. The child's expectations are predominantly set by the PC's expectations. The subcategory *setting expectations* was frequently occurring in the PC data. It is known that children with ASD find change difficult and prefer routine, therefore setting appropriate expectations is important.

Catherine(PC) : He likes to know what is going on, what are we doing today? and then, what are we doing?, and then what are we doing? I'm fortunate in the fact that he doesn't throw a complete, go into a complete tailspin if something changes during the day but he does ask quite a lot and I used to get quite fed up with that and I didn't realise how much a part of, he needs to prepare himself for what's coming up so he's got some idea of what he's going to be faced with.”

It is clear from the comments of the PCs that their expectation of the eye examination was based on their own experiences and this meant that the child's expectations were often not set accurately. One PC mentioned that they had warned their child about the air puff test because they were unaware that children rarely have this test. Two of the participants had been taken by surprise by the eye drops as neither had experienced them they had not prepared their child for this to be done.

“Marianne(PC) : and I wasn't actually aware that he was going to have to have drops because I would probably have been able to say there and then, or beforehand he is going to find that really distressing.”

The PCs felt that *setting expectations* reduced the risk of challenging behaviour and distress. One PC said that it was better to assume the worst case scenario so that the child is fully aware of what could happen.

“Marianne(PC) : it’s almost better to say think of the doom and gloom, this is the worst case scenario, as positively as you can, um I always try to reinforce why it needs to be done and what the benefits are of what has to be done.”

Catherine(PC) said that allowing him to ask questions about the process helps him to prepare and reduces anxiety. If the ECP gives the child space and time and answers their questions then the experience is likely to be better than if they have to cope with uncertainty.

“Catherine(PC): So he then starts to ask questions and then you just have to reiterate that yes that’s going to happen and no that’s not going to hurt and things. So for him preparing him for what might occur is the best er is the best way I’ve found. So that he doesn’t get worried and anxious.”

As the children have difficulty with change, *pre-test information* from the ECP to the PC about what will happen is very important, in order that accurate expectations are set. The context of the experience therefore depends to an extent on the paths of communication between ECP, child and PC. In this research, none of the PCs were given information ahead of the appointment to help prepare their child and it is important to note that none had requested this information either. The first PC mentioned that her child had been involved in writing and photographing a social story and it was felt that this may be a useful tool for eye-care. Therefore subsequent PCs were asked about their experiences with social stories. Most had not used social stories previously but several commented that the story needs to be accurate because if the expectation is not met then it might also trigger distress.

“LS: do you think they are a good idea or do you think that they are a bad idea?

Zahra(PC) : they can be helpful in certain situations, but again it’s placing this level of expectation and if anything happens that’s slightly different.

LS: so they have got to be accurate, tailor made?

Zahra(PC) : yes.”

It is interesting to note that none of the PCs had informed the practice of their child’s special needs at their first appointment. Two children were known to their ECP and therefore it was not necessary to inform the practice, however two PCs felt that their

child might be regarded differently as a result and one mentioned that she did not want to cause the ECP anxiety.

“Zahra(PC) : So no, I didn’t but she may have worked it out for herself I guess, some people do if you’ve if they’ve come across them.”

In one case the PC felt that, as their child was high functioning, it was not in his best interests in the longer term for the ECP to be informed in advance or for adaptations to be made. The logic behind this was that he will always need to access mainstream services and therefore it would help him to cope in the future.

“LS: any particular reason why you don’t?

Catherine(PC) : um because I think people will treat them differently and my feeling is Steve(C) has to go out in the world and survive therefore he has to learn strategies to deal with people and I don’t know rightly or wrongly.”

In hindsight most would have given that information in advance. Several commented that they may have had a better experience if they had discussed it with the practice in advance.

“Anne(PC): um no I think really mainly as it is, as it is, what’s that saying er forewarned is forearmed”

One PC commented that she was surprised not to have been asked to fill in information about her child. It might help if the PC is prompted to give this information as they may be unaware of the importance of this in adapting the test and preparing the child.

“Marianne(PC) : I think I’m quite surprised that they don’t do something when they are taking on new patients. That they do some sort of recci, well they didn’t where I went. Anyway anything like that anyway. You know are there any other outstanding medical issues. Are there any learning difficulties etc?

LS: so they didn’t ask you anything like that?

Marianne(PC) : no”

Therefore the *PC awareness* has a direct bearing on the context of child’s eye examination, because it influences the choice of ECP, the preparation of the child

and the information that the ECP has about the child's needs and therefore the adaptations that are made.

### ***Barriers and facilitators***

The PCs expressed many views about factors that they felt influenced the experience, the *barriers and facilitators* of eye-care (and similar consultation) from the perspective of the PC. The children were able to say what they liked and did not like but the PCs were able to give a more objective insight into why the children reacted in certain ways. In this category four sub categories emerged: *ASD traits, adaptations, strategies* and *challenges*.

This first subcategory, *ASD traits* also occurred in the children's interviews (see section 3.3.1) but in this section it is discussed not as part of the experience but as part of the context of the experience. It was evident from the children that some of their experience could be tracked to a specific ASD trait but the PCs data gives more depth to the understanding of how the traits of ASD influence the experience. The findings show that each child is a unique person with many different likes and dislikes, abilities and disabilities, interests and anxieties see Table 7, and this would be expected. However, children with ASD typically react to challenges and experiences that they do not find enjoyable in a more extreme manner than a child without ASD. The exact trigger for the resulting challenging behaviour is unique to the child but the pattern of behaviour is similar.

*Mood swings* was a frequent code from the PC data. All the PCs mentioned that the success of any visit to any professional was dependent on the mood of their child. They felt that the mood swings were far more extreme than typically developing children and not always predictable. The children can be fine with something one day and react very negatively on the next occasion.

“Anne(PC) : who knows with autism one day something's ok and the next day it can freak him out.”

“Mick(PC) : um but one minute with Adrian(C), if he's in a good mood then.  
Rosie(PC) : He will tolerate it more.

Mick(PC) : It won't bother him that much, it just depends on his mood, so one minute he'll say he don't like something and then 10 minutes later he'll like it, so it's hard to fathom with him.”

This implies that some days, no matter how good the preparation is in advance of the appointment, the consultation may not be successful due to the child's mood.

Two other frequently occurring codes were: *being in control* and *centre of attention*. The PCs expressed how their children strive to be in the centre of the situation and that they like to be in control. The children find it challenging if their PC is talking about them to an AHP, such as an ECP, instead of speaking directly to them or including them in the conversation. This need to be centre of attention is not unusual in the population generally but for this group, probably due to their impairment of social interaction, it becomes so severe that it disrupts the process of the consultation. This is linked with *being in control*.

“Zahra (PC): I spent an interview with a social worker with him sitting on my head, and he's 4 stone now [laughs] he was trying to push my face in to clamp me, 'stop talking, stop talking, stop looking at the man...”

If they are in control then the unexpected is limited and they can manage the situation better. Other ASD traits involved in this are likely to be *obsessive* behaviour and the *impairment of social imagination* which causes them to be anxious in new situations. They generally like to take control of a situation and when given a responsibility will do the job very thoroughly.

“Mick(PC) : so it's like if you give him a job, well like if he's doing a job for you.

Rosie(PC) : cos he thinks he's saving the world by doing this.”

*Triggers* are those situations that cause the child to become overwhelmed and display challenging behaviour. This code appears frequently throughout all interviews, child, PC and EPC. The triggers for challenging behaviour and distress are unique to the child but the outcome is similar in all the children. Many triggers were linked to sensory overload and *hypersensitivities* which is relevant to the context of an eye examination where there may be a significant sensory burden.

“Catherine (PC):... if over-stimulated he can't handle that, so lunch halls are not a favourite place for him. Playgrounds with lot's and lot's going on. He gets what I would call sensory overload”

Another trigger of challenging behaviour is feeling trapped or prevented from doing something. This is relevant to the eye examination as consulting rooms are usually small, often darkened and the child may need to sit behind equipment or have to sit still with the ECP in close proximity. This could be perceived by the child as being trapped or confined.

“Daisy(PC) : he doesn’t like being confined, if something’s happening and you have to restrain him I suppose, some sort of danger or something and he can’t see it, and we have to perhaps grab his arm to say ‘no Freddie(C) wait’, he doesn’t like that at all.”

Most of the PCs could say what was likely to cause problems for their child but pointed out that triggers can be unpredictable too which makes situations stressful. The triggers are unique to the child and although ECPs who are ASD aware might have a sensible guess that lights and touch may be triggers they need *person-centred* advice from the PC.

“Sara(PC) : I think it’s a case of, yes it’s acknowledging that there could be issues but not the ones you’re expecting um things like for example, an autistic child might cope with a blood test but freak out about the plaster”

All the children had specific warning signs that they were becoming overwhelmed and challenging behaviour can be avoided if these signs are known and acted upon. Challenging behaviour can take the form of repetitive behaviours, violent behaviour or they may become very withdrawn from the situation.

“Daisy(PC) : Like you can see in his face, that he suddenly comes over all tired, and I have to say to [husband] just be careful because you can just see, it’s like a wave of tiredness, that comes over, if he’s been doing something for so long and it’s just like ‘shump’ and he will just shut down, and then it can blow up with anything we say, but sometimes Freddie(C) will keep pushing it, as they do and we have to keep walking away, otherwise it does blow up.”

*Low self esteem* was an issue reported by several PCs. The carers felt that their children struggle with confidence and easily give up or get frustrated with

themselves. They suffer from frequent knockbacks at school and in out of school clubs. Several of the PCs felt that their children required more encouragement than average to build the confidence that they need to complete tasks that are set.

“Catherine (PC): it is so you know there is a lot of, there is a lot of confidence building with him there’s a lot of reassurance.”

Anne (PC) explained that her child’s ECP managed this very well by her approach, which included praise and a gentle encouraging approach.

“Anne(PC) : she’s very softly spoken very good and very praising.”

*Poor concentration* and distractions were a concern for many of the carers. They found themselves getting anxious about how their child would cope if there are lots of distractions. For example colourful frame displays or gadgets on the work surfaces. This links with sensory overload and therefore challenging behaviour can occur if there are too many distractions and too many demands of their concentration. The children enjoy exploring the consulting room but the PCs reported that during a routine eye examination it made the process more stressful because, the more distractions there were, the poorer the co-operation.

“Daisy(PC) : I just wish it was clear of any sort of gadgets.”

“Zahra(PC) : I just remember sitting and him trying to grab everything around and take it apart.”

Therefore the context of the eye examination is dependent on the ASD traits of the individual and how well these are taken into consideration in the consulting room and the approach of the ECP. Limitation of clutter and sensory stimuli in the consulting room, inclusion of the child in all discussions, encouragement and giving the child choice and control over the process, according to the PCs are facilitators of the process. Negative context would be a feeling of restriction, lack of control of the situation, sensory overload and distractions in the environment.

The subcategory *strategies* refers to the methods that the PCs have developed to help their child cope day to day. These included activities that divert and prevent challenging behaviour or ways of managing that behaviour when signs of distress

are noted. There were several groups of strategies identified from the data. The strategies used are not necessarily the same as those used to manage behaviour in typically developing children.

“Zahra(PC) : you will get people that will look at him and say ‘there there and look at this’ but really if you have got to that point it’s almost like an epileptic fit, you have just got to let them.”

*Calming down* strategies are used by PCs when challenging behaviour or signs of distress occur. This could be changing the activity, breathing techniques or time out.

“Daisy(PC) : Yes and we have to change the subject or change something or make him laugh quickly, do something really quickly, to make it deflate whatever’s going to happen.”

“Pippa(PC) : distraction I think and back off a little bit.”

Some of the children had toys that helped to calm them down but also to keep them calm, similar to comforters. For example, Adrian(C) found fiddling with lego helped him, and Tim(C) liked to play with a piece of plasticine. One of the carers mentioned that their child was calmer when his mother accompanied him to appointments rather than his father. This is an important point because perhaps the choice of chaperone makes a difference for some children.

“Rosie(PC) : He just got angry at me for not taking him.

LS: Do you think he would have got angry at you for not taking him? [to Mick(PC) ] if it had been the other way round though?

Mick(PC) : No, because she treats him completely different to the way I treat him”

*Controlling the environment* is a strategy recommended by the PCs to reduce the risk of challenging behaviour by adapting the physical environment. This involves reducing clutter and distractions, and keeping the continuity and limiting change, so that everything is familiar.

“Marianne(PC) : certainly him being in an uncomfortable environment makes it very clear that he is autistic. So a lot of people might not necessarily realise

that he is but certainly when he's in certain environments he becomes quite scared."

Another strategy that emerged from the PC data was *person-centred approach*. The planning for an activity should be specific to each child's needs because of the wide range of abilities and disabilities.

"Zahra(PC) : yes, it's understanding what works for one child doesn't work for another, and what works today might not work tomorrow. It's the spiky profile, you hear that all the time."

In order to be *person-centred* there needs to be flexibility in the service in all respects (booking, time and length of appointments, equipment, personnel, and approach). Whilst none of the PCs mentioned flexibility as an approach their comments about their individual child's needs led to the code *flexibility*.

Another strategy for avoiding challenging behaviour is *knowing when to stop*. Most of the children can be diverted from a "meltdown" if the early signs of distress are noted. Most of the children show warning signs before challenging behaviour develops. If the ECP knows the signs then they know when to stop. One PC explained that during her child's eye examination the signs of distress were ignored for too long and perhaps there would have been a better outcome had they stopped sooner and resumed the test another day with full explanation for the child to set expectation of the follow up visit.

"Zahra(PC) : if we had stopped a little bit earlier and said you need to do the second part which is different, another time, that might have worked."

Marianne(PC) commented that pushing on regardless of signs of distress was not appropriate. She also recommended stopping and planning a return visit would be fairer for the child.

"Marianne(PC) : I think that was what was quite difficult because it wasn't kind of described as, ok ultimately I'm Andrew(C)'s parent but we are trying to do the best for him, physical health perspective and he needed the glasses he was struggling to see things at school though had someone said look, it was almost as though they were insistent that he had to have those

drops because they could see he was very distressed by it but they still carried on so I was thinking he must need these he must have to do them, it must be integral to what they are trying to do. I didn't have much of an option really.”

Therefore the *strategies* employed by PC and ECP will vary depending on the communication between PC and ECP. Depending on the information shared about the warning signs of distress, the use of comforters, the use of calm down techniques and knowing when to stop, a different context will be created for the process.

The PCs mentioned some specific *Challenges* that they associated with poor experiences. This emerged as a subcategory of *barriers* however it is closely linked with *strategies* because under certain circumstances they might or might not be a problem.

One common challenge noted was that of being *treated normally*. The PCs indicated that they felt that their child was treated the same way anyone else would be treated which they thought was due to their disability not being visible. One PC was happy about this because she felt that it helps to train her child to deal with ‘the real world’ because he is high functioning and needs to be able to learn these skills. The other PCs considered this to be unhelpful as the adaptations that their child needed were not made. It causes people to judge them as naughty and to think that the PCs are not able to control their children.

“Anne(PC) : there’s nothing out there for children like Simon(C) he’s sort of like, mildly autistic and he’s meant to fit in but he can’t obviously, he struggles to.”

“Sara(PC) : with Dylan(C) he looks so normal that people don’t make allowances. If people talk to him and he doesn’t answer they think ‘oh rude child’ ....”

*Parental stress* was another challenge that emerged, this represented the difficulty that PCs face when arranging shopping trips, healthcare consultations and also school activities. They were anxious about their child’s reactions and the possibility

of their child damaging other people's property or hurting someone, and in particular the unpredictability of their reaction.

"Marianne(PC) : so by that point you're thinking 'God I'm dreading going in' because you just don't know. I mean he's never done anything physically to anybody um but it's just that kind of, already you're feeling quite anxious about it."

"Zahra(PC) : well I always have a certain level of anxiety thinking what's going to kick it off, thinking is he going to kick off, is he going to kick off?"

There is also stress resulting from the judgemental attitude of other people. Taking a child out to something like an eye examination is made more stressful by other people treating them as if they do not know how to control their child or that they are bad parents.

"Daisy(PC) : ....because it's just not fair on the parent or on the child especially when everyone is looking at you thinking you can't control your child, when they don't know what's going on."

Marianne(PC) commented that this stress is an issue and has implications around primary eye-care process because the children pick up on the signs of parental stress and this can have a detrimental effect. If the PC is anxious then the child feels less secure.

"Marianne(PC) : yeah, I'm not looking forward to taking him to taking him to the dentist for example and I can kind of feel in myself despite you're best efforts to try and keep that under control um kids are smart and they go and yes they can tell when you're not 100%"

Marianne(PC) and Anne(PC) both had strong links with support groups and found the moral support helps with the stress. Most of the parents mentioned the use of support groups for information and help. However Sara (PC) felt that they were aimed more towards the lower functioning children.

"Marianne (PC): um they are actually invaluable as a support network really, because firstly you are with like-minded people, parents that are in the same

boat as you and some that are in far far more difficult situations, than you know, any of the ones that I've had to deal with Andrew(C). Um but totally understand all of the anxiety, guilt, stress that goes with being a parent.”

The axial code *picking your battles* highlights the difficulty PCs have with persuading their children to cooperate with activities of daily living. The data show that every appointment is stressful and therefore eye-care is avoided if the child's vision appears to be functionally normal. It seems that fear of the battle is what stops many PCs arranging routine eye examinations for children with an ASD.

“Anne(PC): and that is absolutely right. It makes you sound a bit negligent as a parent in a way you can't. I'm just I'm just thinking, oh God can I go through the rigmarole and the stress of taking them somewhere like that. You know it's another thing that you've got to prepare them for. It's another thing that's going to put them outside their comfort zone. So yeah I think that's true”

The subcategory *Adaptations* is the group of codes that highlight those factors that can facilitate the eye-care process. Adapting the routine and environment to control for some of the factors that would create a more distressing experience was discussed by many of the PCs. These include various adaptations to the service design, ASD training, approach and environment that have a positive impact on the process.

The process of booking an appointment produced differing opinions as to what the priorities should be, but there was a consensus that it was an important factor. The considerations were convenience around other commitments, minimising the need to wait, continuity of care and minimising additional sensory burden such as in a busy clinic. This created dilemmas such as having to choose between a preferred time of day and booking with a preferred practitioner. The balance between the impact of the practitioner's personality and the risk of having to wait or choose a time when the child might be tired was difficult. The PCs were in agreement that the appointments need to be scheduled in a flexible manner that suits the individual. The morning is the best time of day for some, or for others not having to wait is a greater priority, so coming at a quiet time of day is important.

“Marianne(PC) : I guess there has to be that element of flexibility if a parent rings up and is genuinely concerned or in advance saying well my child has got ASD and would benefit from having a morning appointment.”

Most of the PCs felt that longer appointments are needed to allow for the adaptations required in the eye examination such as allowing additional time for processing.

“Rosie(PC) : Yeah, longer appointments.

Mick(PC) : The only thing that...

Rosie(PC) : Because you can't always guarantee their mood”

However some implied more frequent short appointments would be better. They felt that breaking things down into manageable shorter episodes might make the process less overwhelming. The key again to this would be that there is flexibility in the appointment length and that it is adapted to the child's needs.

“Marianne(PC) : yes because it was a long time as well, if you think about it really because we were in, they were asking me about what he was struggling with, um, then he had some drops in then he had to sit outside and then the whole examination. So we were in there for quite a long time which I don't think probably helped.”

“Zahra(PC) : if it takes 2 or 3 appointments to get what we need to do that's fine.”

Children with ASD have individual and varied requirements for eye-care services and this means that it is not possible to provide the same service for all. For some children mainstream services are manageable but for others specialist clinics may be required. One child who had severe autism and was the sibling of Simon(C) had not had an eye examination in many years because the specialist clinic he needed was not local. He could not take part in the research because he had not had a recent eye examination but his PC still made this observation:

“Anne(PC) : then if we do want to have another eye test I think it's one over in [town] or somewhere right over there.

LS: right

Anne(PC) : yes ok but er but er [shrugs]

LS: it's difficult isn't it because then you've got to get him there and

Anne(PC) : yes but it's [authority] we don't belong to any authority they just put us off"

All except one of the PCs commented that service providers should have sufficient *training* to be able to help children with ASD. They suggested that ASD awareness training would enable ECPs to have a better understanding of how to provide services for these children.

"LS: do you think practitioners should be trained in awareness of autism?

Catherine(PC) : yes definitely but then I think that everybody should because there are an awful lot of people [with ASD] out there."

One PC felt that special training would be too much to ask of the ECPs. This is because they felt that ECPs should not be expected to train for all the possible variations of general health conditions.

"Mick(PC) : You can't expect someone to train in 10 different things, cos it's not fair, it comes down to cost, it comes down to time, and you have to say look we haven't got time for that."

However another PC suggested that even if it was not practical for all ECPs to have training there could be a designated 'specialist' in each practice.

"Marianne(PC) : I think if you had in every branch a person that was specialised in or had an element of training in dealing with children with ASD I think a lot of parents certainly would welcome that."

### ***Summary of the context grounded in data from the PCs***

The context of the eye examination was thought to be dependent on the training of the staff, the structure of the service given the wide range of cognitive abilities of children with ASD, the appointment booking system, the length of the appointments and flexibility all have an impact. The fact that many children with ASD do not appear as though they have a disability means that they are often treated like

typically developing children without any adaptation to the examination. If the PC is aware that they should give information about their child's special needs in advance then adaptations can be planned. It should also be considered that PCs are under considerable stress and anxiety and this can have an impact on the mood of the child and therefore the outcome.

The experience of the child needs to be seen in the context of the eye-care process for that individual. Each child will have a unique set of circumstances, will have their own unique range of ASD traits and triggers, they will have been prepared for the process by their PC who set the child's expectations based on their own knowledge and expectations, they will be examined by an ECP whose skill set is unique to that practitioner. Therefore the context depends upon the *awareness* of those involved and the resulting approach.

Figure 8 shows the factors that create the context for the analysis of the children's data based on the analysis of the PC data. It shows the factors that surround the experience of primary eye-care for a child with ASD and therefore the variables that have an impact on the process.

**Figure 8: Context of eye-care process identified from the PC data**



### **3.2.2 ECP findings regarding context**

The findings from the EPC's are summarised in Figure 9 See also Appendix 6iii. This data gives us a greater understanding of the experience from the perspective of those that are providing the service. This increases the understanding of the context as it enables an understanding of the practicalities of providing eye-care for these children grounded in the views of those who are opinion leaders for the profession in this specialist area. The categories that emerged are shown in the segments and their associated subcategories are attached in the extension boxes.

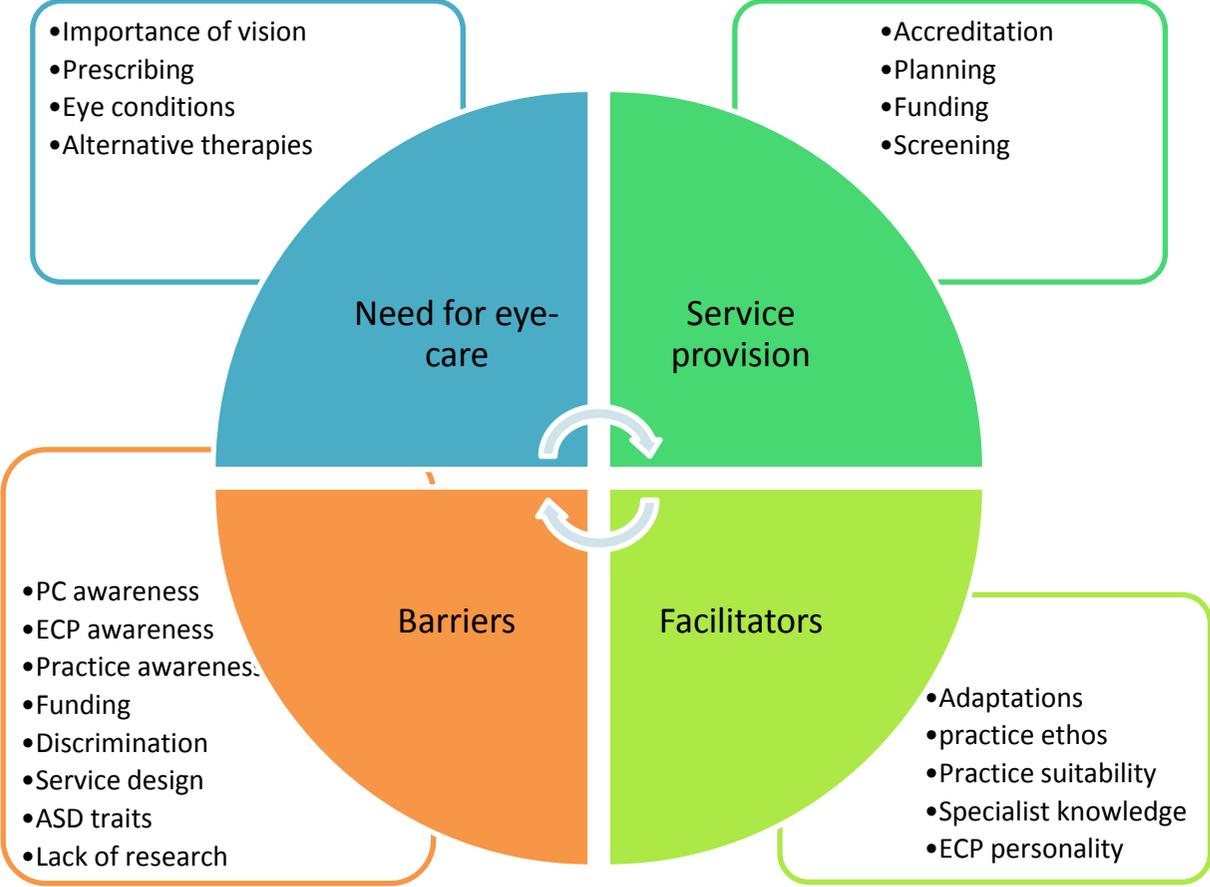
The categories that emerged from this data were: *barriers to eye-care*, *facilitators to eye-care*. Two further categories emerged from the ECP data *service provision* and *need for eye-care*. Whilst the data from the last two categories show how provision could be improved and highlight the need for research into the risk factors for these children, these categories are not directly relevant to the experience of the child currently. As this is out of the remit of this research question detailed discussion can be found in Appendix 6iv for information. The ECPs raise some very important points that are relevant to the quality and provision of eye-care for people with ASD but are suggestions of service development and not general practice now.

The findings from the ECPs that are directly relevant to the experience of eye-care are presented in section 3.5 and those that are relevant to the context and process are presented here.

#### ***Barriers to eye-care***

The ECPs identified several areas that were barriers to a good experience. The findings were very similar to those found in the PC's interviews with much of the data overlapping the PC data. The subcategories relevant to the context of eye-care were: *PC awareness*, *ECP awareness*, *practice awareness*, *funding*, *discrimination*, *lack of research*, and *service design*.

**Figure 9: ECP findings**



The subcategory *PC awareness* overlaps that in the PC findings. However in addition the ECPs felt that PCs need to have more information and support, so that they are aware of the importance of routine eye examinations and how to access appropriate services. The main concern was that PCs may be unaware that children with LD can still have an eye examination. The code *it isn't possible to test children who can't read* emerged from the data from the ECPs. This view point was not given by the PCs interviewed for this study but that may be because they had all accessed eye-care for their children. However it is linked to the low expectations that some of the PCs expressed. The awareness of the PC as to what is possible and what level of service they should expect has implications for the process that is accepted by the PC.

“David(ECP): Probably the biggest barrier is perception of parents and carers that an eye examination may be difficult due to communication skills, behaviour, an abnormal environment and the other perceived barriers rather than real barriers.”

It was felt that children living in residential care tend to have greater difficulty because often they are not accompanied by key workers, or people who really know their history or abilities. The ECPs had encountered difficulty building a rapport with looked after children and providing continuity of care. The ECPs considered the low pay and fast turnover of care staff the likely cause of this.

“David(ECP): education of the care team generally and education of the parents, if the parents are involved. I see more adults with learning disabilities so it tends to be the care team. Why is there a problem with the care team? Because they are generally low paid not particularly well educated and a high turnover.”

Robert (ECP) felt that the general perception of optometrists is of a commercial business not an allied health profession. The code *carers perception of eye-care* therefore highlights the perception that a visit to the optometrist will involve purchasing something or that their child may not be welcome because they do not have the right image for the practice.

“Robert(ECP): a big issue around that we are perceived as selling glasses thinking that someone who is a vulnerable child or vulnerable adult into essentially a high pressure sales situation and its due to the TV advertising, that is the public perception to walk out of a practice with two pairs of specs for the price of one.”

The ECPs also felt that there was a lack of trust between PC and ECP because of previous poor experiences where the system has let them down. This links with the PCs comments about previous experiences but gives a further dimension to this highlighting the need for outreach to PCs to build trust. These findings indicate that the ECPs could facilitate the process if they provided information and built a rapport with PCs.

The *ECPs awareness of ASD* was also thought to be a barrier to eye-care. They highlighted a lack of training regarding the needs of children with ASD and how to provide for special needs. This also emerged from the PC findings but the ECPs gave further insight into the impact of this subcategory.

*Practitioners may be worried about coping* is a code that identifies the nervousness that ECPs may feel when dealing with patients that could display challenging behaviour or may not be able to comply with the full demands of an eye examination. The ECPs felt that there are a significant number of ECPs who feel unable to manage this group of patients.

“David(ECP): ‘our enemy is the person whose story we’ve not heard’ and ultimately that’s what prejudice is all about cultural and experiential problems. So the person who says I can’t see people with LD or I don’t get on with people with autism is probably just terrified that they are not going to do it properly.”

The ECPs also mentioned that inexperienced ECPs may feel anxious about having the skills to comply with the GOS contract and make the adaptations required for children with special needs.

“David(ECP): for the young practitioner is a real challenge and er I think for optometrists generally we are trained that we’ve got to tick a certain number of boxes, not think too much about it, but tick a number of boxes. The less we’ve done of those boxes the more likely we are to be sued and struck off.”

ECPs commented that some do not know how to cope when a child does not have the expected abilities for their age, who might not behave in the way you would expect for their age and who may look ‘normal’. The skill set to adapt tests to the child’s abilities requires training. The code *practitioners need to develop the skills required* emerges from the identification of training requirements such as techniques for examining children who can’t read or cooperate or communicate. This training enables the development of specialist skills required to test children with an ASD effectively, and the awareness that this is a battery of skills rather than a prescription was thought to be required. Every child is different and so the ECP needs a range of tests, techniques, strategies and equipment available. Eye-care professionals are trained to ‘measure’ vision and they may not have a suitable battery of skills to achieve this, therefore the approach may need to be based on observation rather than conventional measurement.

“David(ECP): this is where we as optometrists are poor at examining people with LD and other problems and ophthalmologists are just as bad because we want a number. What’s their vision? We are looking at high contrast acuity, looking at a test chart or a substitution for that and actually we want a number. Well what’s that telling us? Actually very little. We are very poor at sitting and observing the individual and that’s where I gain most information is sitting there observing the individual interacting with their visual environment.”

It was mentioned that optometrists tend not to work in a multi-disciplinary way and the code *awareness of the role of allied health professionals (AHPs)* highlights the benefit in raising awareness of the skills of other professionals. The ECPs felt that very few ECPs were aware of the role of AHPs such as occupational therapists and probably AHPs were unaware that they might be a welcome addition to providing a good service for the patient.

“Susan(ECP): there are barriers there aren’t there, things like you know the other professionals thinking that wouldn’t be welcome to come to an opticians for an eye test they might be in the way um and vice versa we need to know who needs to know what we find about the child and so on.”

However AHPs have been used successfully to facilitate eye-care for people with LD in some parts of the country. As the AHP has prolonged contact with the patient they can build a rapport. This enables the patient to feel more secure because their needs are communicated and supported effectively. In some schemes they are used to do some basic assessments at home such as checking visual acuity or filling in a functional vision assessment. This means that the eye examination can be shortened to just the areas where concern has been flagged. A facilitated examination like this is very different experience for the child to a typical eye examination.

“David(ECP): we don’t get that opportunity unless you have the luxury that I had in [location] having a specialist worker who could do visual acuity assessments and do various other things, point me in the direction and say right these are the 3 things we got to check and do those 3 things.”

Interestingly the role of these other AHPs was not mentioned by the PCs. This may be due to the fact that most of the children were high functioning and in mainstream education and therefore less likely to be in direct regular contact with special needs provision. One ECP expressed a concern that ECPs did not have appropriate pathways to provide for these children in a multi-disciplinary way.

“Susan(ECP): we want better networks with the other professions that work with children and adults with special needs. So we need some reporting pathways in place. So we need schemes do not we, like they have in some places, like Tower Hamlets, that sort of thing. Um but we need that nationwide.”

The subcategory of *practice awareness* highlights the importance of the support staff being aware of ASD and the practice protocol on dealing with patients with ASD. According to the ECPs, the practice receptionists are the front line, first contact point and therefore they need to be welcoming, supportive, flexible and

understanding of the needs of this group. A lack of awareness at the reception can make accessing the service difficult.

“Susan(ECP): Um one particular case history is of a girl who was discharged by the hospital, went to the local optician and she misbehaved in the waiting room and the optician said we can't test her because of her behaviour, and her mum was so embarrassed that she didn't dare take her anywhere else.”

*Practice suitability* was mentioned as a possible barrier to a good experience of eye care. Children with ASD have an increased risk of co-morbidity and therefore might need wheelchair access or hearing loops. Environmental provision for these additional needs impacts on the experience.

“Susan(ECP): there's access barriers for children who, for example, children with severe physical limitations that use wheel chairs.”

This aspect was not discussed by either the children or the PCs. None of the PCs were asked for information about their child's needs by the reception teams but none of the PCs offered information either. None of the PCs commented on the reception team or support staff. This may be due to the fact that none had physical disabilities and because of the PCs expectations of service provision was quite low. However one PC with another child who has PMLD did not seem aware that any optometry practice should be able to provide an eye examination for him and the reason she stated that she had not accessed eye-care for him was that there was not a suitable service local to him.

The subcategory of *funding* was a theme that came up frequently in the interviews with the ECPs. NHS optometrists can claim a fixed fee for each eye examination that they perform. The claim is only valid if a set of compulsory tests have been carried out during that eye examination.

Children with ASD are all entitled to an NHS eye examination. However the ECPs felt that this created a dilemma for ECPs who believe they have to complete a compulsory set of tests to claim a fee for their work but for children with an ASD this is often not possible. Eye-care professionals need to cover their costs and therefore spending 30 minutes or more with a patient and ultimately not being paid for that time is not viable. Most of the ECPs took the view that as long as you had tried all

the tests and demonstrated that they were not achievable then a fee could be claimed.

“David (ECP): I think they need to realise and whilst [optometric advisor] and some of the others are going to say you need to have done everything before you can claim a GOS they need to realise that no you don't, you need to have done, you need to have attempted everything and recorded a reason why you haven't been able to achieve it and sometimes you might not be able to achieve it.”

One ECP felt strongly that 'box ticking' in order to complete an NHS test, puts children under undue stress. He added that instead of it being negligent to omit tests that were not achievable, it was in the child's best interests to do so, especially if estimates could be made using observation of functional vision. Only one ECP, who works in a hospital setting interpreted this differently.

“Beth(ECP): They can't, um they, a sight test from an optometrist is a legal procedure in which they have to record the visual acuity, the glasses prescription that they have found, and the health of the eye, well you know that's not possible in every autistic child if they have not recorded those three things then they can't claim their fee.”

The NHS structure therefore influences strongly the service that they receive and particularly impacts on the flexibility to make appropriate adaptations. All the ECPs agreed that the current funding was a barrier and that there was a case for additional funding in order to provide an appropriate service for this group. This group of children need more time and the ECPs highlighted that working in the area of eye-care for people with special needs is less profitable. Most feel that the fee does not cover the overheads involved in running the clinic if the GOS requirements are completely adhered to.

“David(ECP): Trying to be too hard and fast with GOS is difficult but it does beg the question should there be additional funding available from PCT's CCG's for seeing difficult cases.”

All the ECPs commented that the current eye-care pathway for children with ASD is inflexible, and does not allow the ECP to make the adaptations that would benefit

the child. The subcategory *service design* describes the ECP's concern over the current provision. One participant went further to say that it was not fit for purpose because of the lack of flexibility.

The ECPs illustrated some of the factors that make the service inflexible. The code *frequency of eye examinations* emerged from the views that children with ASD may need more frequent examinations than average. The current eye-care pathway only allows one routine eye examination per year and for some categories of patient that widens to one every two years. If the person is to have another eye examination within that time scale the optometrist has to justify this by indicating why this is necessary within set criteria which do not include special needs. This is inflexible and was considered by the ECPs to be a barrier to providing appropriate care. It prohibits ECPs from recommending more frequent shorter visits for instance to build the patient's confidence or acclimatise them to the clinic environment.

“Susan(ECP): We need to change the rules on how often someone can have an NHS test. Again you can put a code but you should just have a code that says special needs.”

The ECPs commented that PCs often need support to identify suitable community optometrists who have specialist skills for people with special needs. However ophthalmologists are not permitted to recommend individual ECPs that they know to be expert in this area. Currently they often end up taking their children to the nearest or cheapest practice rather than one that perhaps has the skills required to provide a better service.

“Susan(ECP): one of the problems hospitals have is that they are not supposed to recommend are they and they are very wary of that which is why at the moment they don't pass patients on at referral.”

Two ECPs commented on the difficulty of transport to clinics. Access to mainstream services can be limited if the child needs special transport. Unless there is a local school or hospital specialist service they may not be able to access eye-care.

“Susan(ECP): um a lot of children in wheel chairs can't go places with their parents because they don't have transport, they have the school bus or whatever, the taxi or whatever takes them to school, but at the weekends,

their parents don't have that facility to take them out, so they could occasionally be that problem with a child with autism.”

Robert(ECP) made the point that to provide services for children with ASD it required a great deal of commitment. The code *professional's commitment* refers to the investment in equipment, training and clinic time that is required in order to provide for this group. As this is poorly paid then it requires commitment on the part of the ECP. It needs to be something that they want to do rather than something the College of Optometrist obligates them to do, in order for it to be done well. This conversely means that some practices may not make this commitment and therefore impact on the quality of service that they provide.

“Robert(ECP): I'd like to see that you can say I have a skill set that this individual, not because I want to big myself up, not because I want to use it as a money making exercise because its patently not

LS: yes [laughs]

Robert(ECP): but because I want the people that it matters to, the patients with disabilities, to know that they are seeing someone with an aptitude and an interest rather than just someone because they have the right to walk in any practice and not be discriminated against.”

Children are currently entitled to NHS funding for one pair of spectacles per year or when there is a change in spectacle prescription unless special permission is sought from the CCG [see glossary]. *Spectacle voucher provision* emerged from ECP recommendation that funding for spare pairs for these children should be approved. These children are far more likely to damage spectacles. Broken spectacles result in children being without them at times unless they have a spare pair.

“Susan(ECP): We need better provision for spare pairs. At the moment we can apply to the NHS for a second voucher. I think that should be mandatory for children with special needs.”

Two of the PCs had commented on this with one mentioning that her son with severe autism hides spectacles around the house and another PC commenting that her son had broken so many pairs that they are too embarrassed to go back to the optometrist and so she buys ready made glasses from a pharmacist of a power that she believes are approximately the correct strength.

The subcategory of *discrimination* emerged from the data. Unfortunately it was mentioned that some people with ASD still face discrimination from ECPs who would rather not have special needs patients because they are not profitable or do not have the right image for their practice. Fortunately none of the PCs involved in this study had encountered this at any of the practices their children had attended, although this may be due to most of the children in this research being high functioning.

“David(ECP): I would say that is mainly in the high volume corporate environment where examination times are limited and if you present somebody who is going to be more challenging than the average patient then there may be barriers put up and I’ve come across cases where real barriers are put up by generally commercial directors or commercial store managers.”

The final barrier to eye-care was *lack of research*. *Eye-care professionals* referred to the paucity of research in the area of eye-care for people with ASD. Even in the specialist practices of the ECPs interviewed there were too few patients with ASD for them to be able to identify risk factors and trends in ocular health for this group. More information about the eye-care needs, risk factors and treatment for this group is required.

Therefore the context of the eye-care process is influenced by the awareness of PC and ECP which governs the approach of the ECP. The training of staff affects their confidence with children who have special needs and their range of skills. Also, the service design and funding impact on provision, because it affects the ability and willingness of the ECP to provide adaptations to the service, such as acclimatisation appointments, specialist equipment, accessible consulting rooms, and frequent replacement of spectacles. The approach of the ECP and practice management can be, in the worst case scenario, discriminatory due to policies of the practice. Finally the lack of research means that to some extent ECPs do not know what adaptations to make as there is not enough evidence on to which they can build their services.

## Facilitators to eye-care

The facilitating factors mentioned in the interviews were in many ways the reverse of the barriers just described. However the ECPs had some specific ideas about how good eye-care is facilitated

The best *service design* was discussed by all the ECPs and much of their comments have been previously discussed. However, the ECPs also thought that a pathway should be developed to support the needs of all the children. The ECPs discussed *specialist provision* for children with PMLD in addition to ASD. Adaptations to service design in some areas result in children who are well looked after but in others they may have to travel a long way to see a specialist optometrist. This would be a range of locations such as community practice, hospital clinic or screening or testing at school determined by the child's specific needs. Another option suggested would be to include functional vision assessments carried out by PCs such as the tool designed by SeeAbility that enable PCs to run through a check list (SeeAbility, 2012) and seek help if the outcome indicated help was needed. A national pathway could set out the minimum requirements and enable children to get appropriate care.

“Beth(ECP): moderate needs to come to us in [hospital] clinic because they can't have the full sight test but it's unreasonable to expect an optometrist to do that and the severe we probably need to go to them. We probably need to go into school and test them there.”

ECPs recommended many ways to adapt the service design to make it fit for purpose whilst being aware that perfection is unlikely.

“Beth(ECP): that I'd rather try and create a set of standards or things that are achievable, there's no point saying that every optometrist needs to be able to, well that's not, that's not achievable, and then you are setting the parent up with a set of expectations that frankly can't, will never be met.”

The ECPs identified the need to listen to the PCs and children in order to develop a suitable service. Patient involvement in planning echoes the views of the PCs that they are not listened to by ECPs.

The subcategory *practice ethos* emerged from the data from the ECPs who were unanimous in the view that the practices that facilitate good services in this field are those who are altruistic, that see the need and have the conscience to provide it even when it is not financially viable to do so.

“David(ECP): I think it a very um, it depends how altruistic you want to be. GOS [see glossary] doesn’t work for people who fall outside of the normal appointment times but GOS doesn’t work for people who fall within the normal appointment times let’s face it!

LS: [laughs]

David(ECP): so the funding provided by GOS is inadequate in all respects but the Department of Health.....It’s how altruistic you want to be.”

The point was also made that it is the whole practice that needs to make adaptations for this type of work. If the staff have the correct training then they can make sensible adjustments for example to appointment bookings or help make services accessible. This includes the reception team who need to be ASD aware as they are first contact with the PC and child. If they are aware of how to facilitate a visit then the experience is much more likely to be successful.

“Robert(ECP): we went through the process in the past of developing the potential of individuals and making the receptionist aware of what actually goes on in the testing room, we may have a conversation after a patient has gone about anything that was particularly interesting.”

*Practice suitability* depends on many factors. The ECPs felt that small familiar practices in a community setting are, for most children with ASD, ideal. These are better able to provide the continuity, flexibility and familiarity that children with an ASD need. These smaller practices are more able to make individual care plans and adapt the room for the individual by facilitating them having choice. They are also less likely to have noisy waiting rooms. One of the difficulties about providing this service is the impact it might have on other patients. Optometry practices are businesses and the adaptations required for some patients may have disadvantages for other patients.

“Beth(ECP): but there will be some children that, who, with more severe behavioural problems, who a high street optician is not, is never going to

work, not because people don't try, it's just it's not, they are running a business and they can't clear their entire reception of every patient and every sound."

ECPs who have *specialist knowledge* and training are likely to be facilitators of good eye-care. This would include an understanding of the risk factors for children with ASD, evidence based treatment options, specialist techniques and an understanding of the particular needs of children with ASD.

"Susan(ECP): we have talked a little bit about training. We do need training in what the different types of special needs are, because there is a world of difference between a child with autism, well some children with autism, and a child with other special needs."

This knowledge can enable an ECP to determine whether a child's vision is normal even when the number of conventional tests possible is severely limited. Training improves confidence and reduces the concern about doing this type of work.

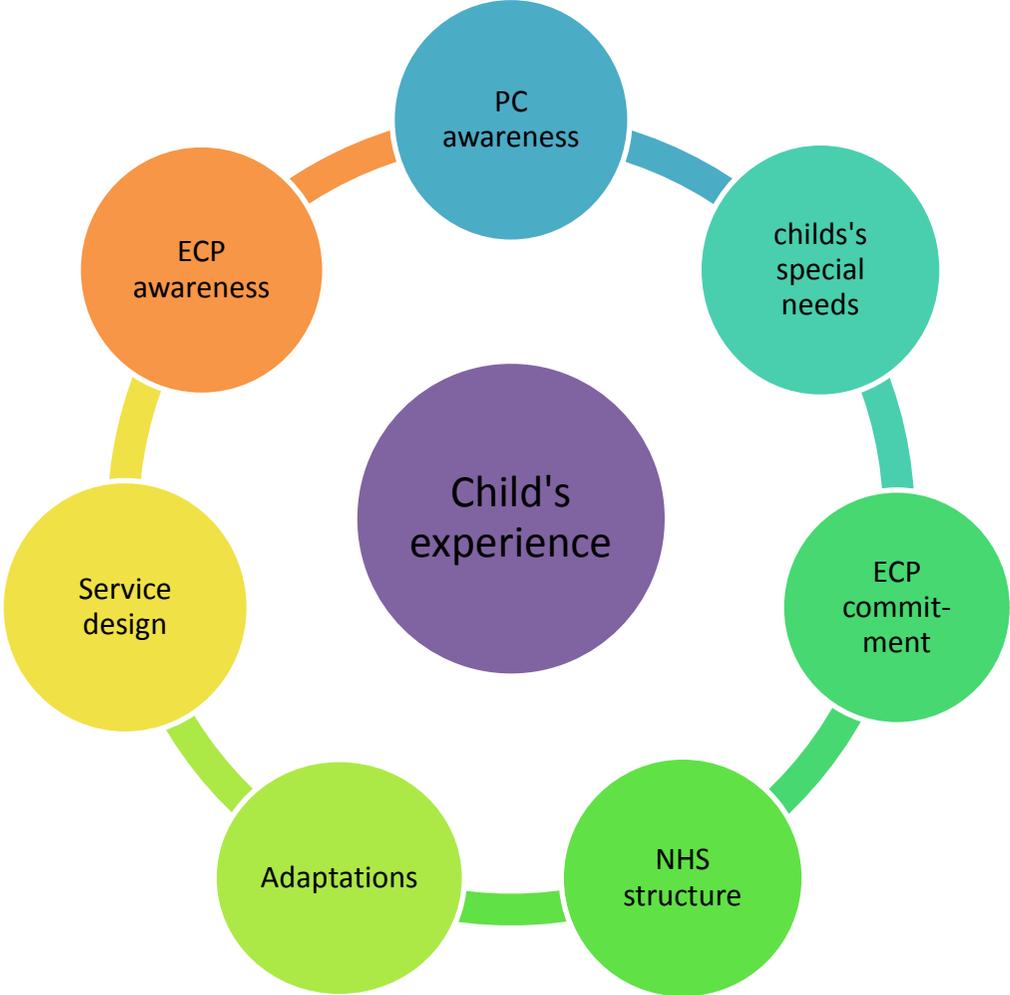
"David(ECP): If you know their vision is normal and they've got normal functional vision, their visual fields are normal and pupil reflexes are normal, generally they are [normal]. Yes they may be on the ASD spectrum but they haven't got any developmental defect that may affect their eyes they are probably going to be normal."

### ***Summary of the context grounded in data from the ECPs***

In summary, the context of the eye examination depends on the practice design and ethos, the training, knowledge and skills of the practice team, the national funding and eye-care pathway, and the altruism of the ECP, and the trust and communication between PC and ECP.

The findings from the ECPs overlap the findings of the PCs considerably. The ECPs however add a further understanding of the constraints of the GOS eye examination and how that affects the provision of eye-care for children with special needs. They also identified the lack of support for PCs in accessing eye-care and understanding importance of it. Figure 10 shows the context in which the child's experience is set grounded in data from the ECPs.

**Figure 10: Context of the eye-care process identified from the ECP data**



### **3.2.3 Combined findings**

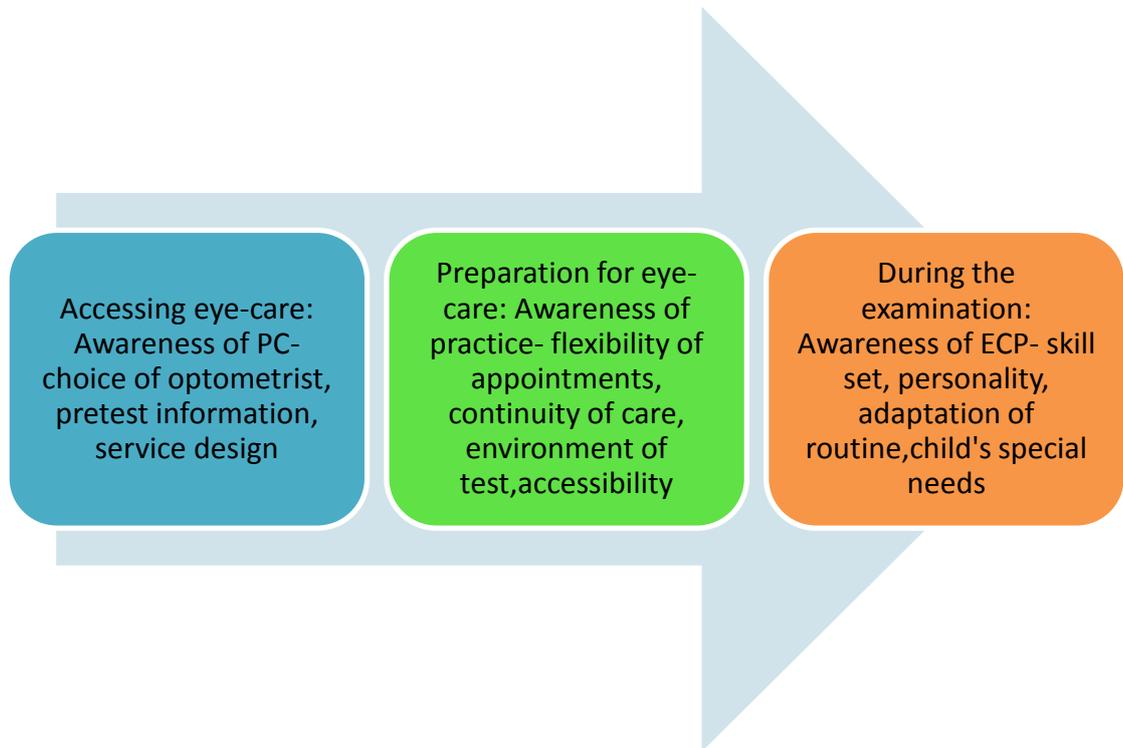
A clear understanding of the context of the eye-care process was important for the analysis of the findings from the child participants. The findings from the PCs and ECPs have provided an insight into this. Figure 8 and Figure 10 illustrate the contextual data that emerged from these two groups of participants. The overlap is considerable but the different perspectives give an in-depth understanding of the setting of primary eye-care. The child's experience depends on many factors but the data show that these stem back to the overarching category *awareness*. The context of the experience of primary eye-care depends on the awareness of the PC and the awareness of the ECP.

The flowchart in Figure 11 illustrates the way the data create the context. The choice of optometrist, the preparation of the child and the setting of the child's expectations depends on the awareness of the PC. The adaptations of the routine and environment, skill set and training of staff, and the approach of the ECP is dependent on the awareness of the ECP. The service design is a result of the constraints of the GOS contract and funding, the interpretation of the requirements of the contract, and the commitment of the ECP to providing an appropriate service regardless of these constraints.

Therefore some children will be attending for primary eye-care in an environment that is adapted, where the system is flexible and their ECP is trained and skilled and whose PC is informed and has set their child's expectation accurately. Whereas some children will be attending for eye examination in a cluttered un-adapted environment, where the system is inflexible and their ECP is not committed to additional training in this area and whose PC may not know what to expect, how to access appropriate services and how to prepare for the process.

This means that the context is not the same for each child and may be different at each visit if they do not have a regular optometrist. Therefore the challenges faced by each of the participants were different despite the aim of the appointment being the same. Thinking of this from the perspective of symbolic interactionism, the experience is different for each child and therefore their responses must be seen in the light of the possible variables and the range of meanings that they may be applying to the situation. The reaction and experience of a child will depend on these meanings.

**Figure 11: Flow chart of the context**



### **3.2.4 The Process**

Process is :

“unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between. The temporal sequences are linked in a process and lead to change.” (Charmaz, 2006)

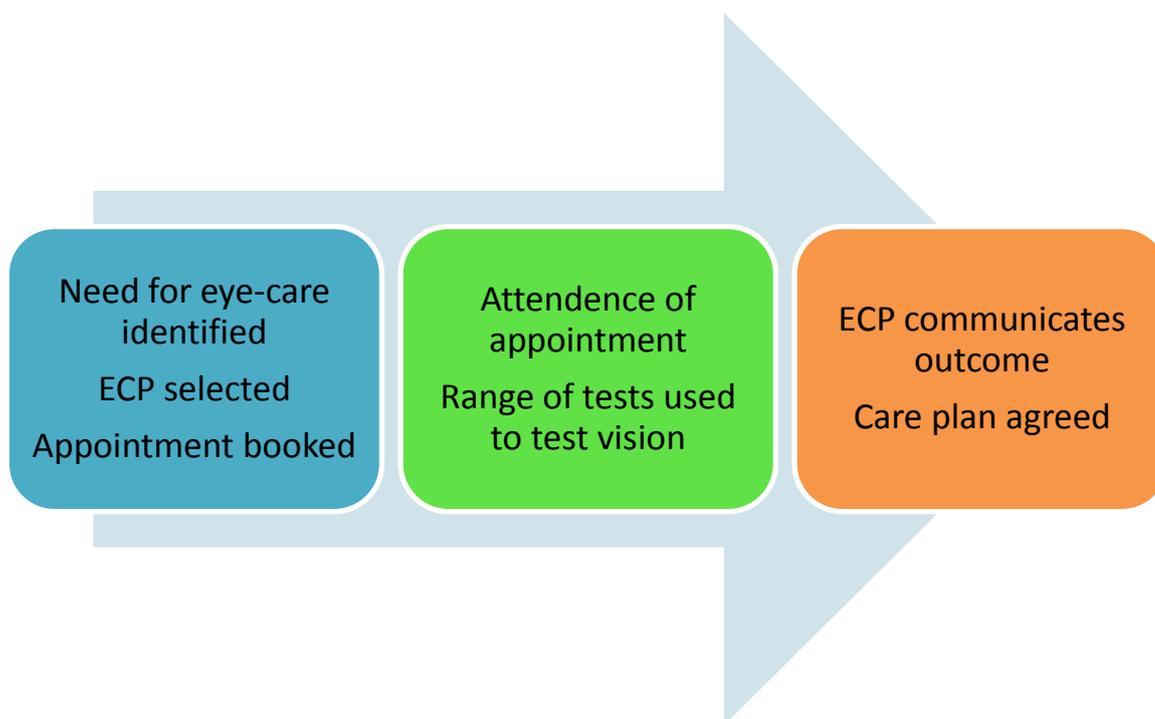
p10

The process of primary eye-care is illustrated below in Figure 12. The PC identifies a need for an eye examination, selects an ECP, arranges an appointment, and prepares the child for the eye examination. The child attends the eye examination, the ECP selects the tests that they feel are indicated, the child attempts the tests and the ECP communicates the outcome.

The process therefore includes communication between PC, ECP and child, as well as decisions made in the planning for the test on an individual basis (PC and ECP awareness), practice basis (practice design) and also national basis (NHS service design). In some cases there may be an AHP facilitator but this was not the case for any of the participants in this research.

Within the main process are multiple stages that contain processes. For example: the ECP decides to carry out a test of vision, a version of the test is chosen (e.g. letter or picture chart, matching cards, preferential looking cards), the ECP instructs the child as to what the test is, what it does and what the child is required to do. The child attempts the test. In this way there is a chain of processes that join together to create the process of primary eye-care.

**Figure 12: Flow chart of the eye-care process**



### **3.3 What is the experience of primary eye-care for children with an ASD? The findings from the child participants**

The previous sections discussed the context and process that form the background to primary eye-care. The aim of this research was to investigate primary eye-care from the perspective of the service user, children with an ASD. Therefore the analysis of the children's interviews was used to develop a theory of the experience of primary eye-care set in the context described in the previous section. Figure 13 illustrates the key findings of the primary eye-care experience from the viewpoint of the children. It shows the categories as segments of the chart and subcategories that relate to these within the segments. These categories and sub-categories are discussed in more detail in this chapter. See also Appendix 6i. In keeping with

grounded theory the categories and subcategories are described by a series of axial codes that determine the characteristics. The key axial codes are described in this chapter.

**Figure 13: Child views of their primary eye-care experience**



### **3.3.1 The impact of ASD Traits**

The open coding revealed that some ASD traits had a significant impact on the eye-care experience reported by the child. Therefore the first category that emerged was that of *the impact of ASD traits*. The subcategories that form this category were: *hypersensitivities, communication impairment, social interaction impairment* and *social imagination impairment*.

#### **Hypersensitivities**

Children with an ASD are known to be hypersensitive to some sensory stimuli (Bogdashina, 2003). These vary for each child but may include any of the senses; lights, sounds, tastes, touch and smells. The children had a range of issues with different stimuli but they all had particular stimuli that could be a trigger. The two most commonly reported by the children in connection with eye-care, and emerged as axial codes for this subcategory were: *light sensitivity* and *touch*.

The use of lights to examine the eyes and test eye movements is routine in eye examinations for children. In some cases there may be additional lights such as cameras to photograph or scan the retina. Many of the children reported at least a dislike of bright lights and flashes and in most cases an extreme reaction to them. Codes relating to this emerged from the verbal and observed data. It was also identified in the card sorting and photographic activities for most of the children.

For example Freddie(C) took the photograph shown in Figure 14 when asked about what he did not like in the clinic.

**Figure 14: Photo of a light by Freddie(C)**



For some children it was the thought of the light that was frightening, for others it was the afterimages (dazzle spots) left by the light, that were an issue and others reported discomfort with the light.

“Simon(C): and it’s like [demonstrates a flash]

LS: that’s it

Simon(C): yes it was big light and I had to close my eyes to get rid of that lighty thing”

“LS: was there anything particularly you were worried about?

Steve(C): um in particular I was worried about, in some opticians they shine a light into your eye to see what’s in it, I don’t like the light shining in my eye”

*Touch* was the other axial code that appeared regularly in the data. Throughout the eye examination there are tests and situations where the child has to tolerate touch. The touch of equipment such as the trial frame, see Figure 15, was mentioned by several of the children.

**Figure 15: Trial Frame**



Other tests that involve touch may be used, such as equipment with chin rests and or physical contact such as examining underneath the eyelid or the ECP raising the eyelid when examining the inside of the eye. The distress caused by touch was indicated by many of the children. In the verbal interview and in the card sorting most of the children reported a dislike of contact with equipment. They also indicated a preference for equipment specifically because it did not require contact.

“LS: do you think that would be better than her touching your eyes or worse?

Andrew(C): yes because that would be better than her touching my eyes

LS: because she's not quite so close, is that right?

Andrew(C): yes

LS: it's still got a bright light on it, so when you switch it on the light comes out of this but she doesn't touch you

Andrew(C): its better when they don't touch.”

The dislike of touch was not unanimous, one of the children liked the trial frame because he associated it with Harry Potter (with whom he had an obsession). The rest of the children indicated that they disliked the trial frame and therefore this negative case was probably just a personality variation rather than disproving the axial code or subcategory.

### **Communication impairment**

The eye examination requires the child to answer questions, follow instructions, and respond to tasks set including making choices. Children with an ASD all have some form of impairment of communication. This is a difficult area to ask the children about because it is not possible for the child to judge how well they understood and responded to the eye examination demands. However evidence of these difficulties can be found in the interviews. The research interview process was, in some respects, similar to the eye-care process and interestingly some of the codes for this subcategory came from the child's approach to the interview but can reasonably be applied to the eye-care process. The axial codes for this subcategory were: *understanding what is required, feeling overwhelmed, literal meanings, and supports.*

The axial code *understanding what is required* emerged from the data as it became clear that the children were anxious about any machine or test that they had no previous experience of. They indicated that good explanation of what it does, why, how long it lasts and what it would feel like, made the situation better. They liked the idea of being allowed to touch and play with the equipment beforehand. If they did not know what the machine does or what they were supposed to do they found the situation challenging.

“LS: ... If your optician said you could touch anything on that machine and try it out first would that be ok?

Andrew(C): yes

LS: as long as you could touch it first and have a play with it.

Andrew(C): yes” [Andrew(C) had previously indicated that this piece of equipment made him anxious]

The axial code *feeling overwhelmed* refers to the point at which the eye-care process has become too difficult for the child to cope. It is known that children with ASD display challenging behaviour when they are overwhelmed by a situation (Notbohm, 2004). During one of the interviews a participant became overwhelmed because he was asked a question that had several parts to it. Whilst this was not a comment on the eye examination it is a good example of how strings of questions and instructions, such as you would typically encounter during an eye examination, can affect a child with ASD. For instance “ Are the circles clearer and rounder with lens 1 or lens 2 or just the same?” Whilst none of the children volunteered this as part of their experience, this research shows that a more effective approach is to use simple language, one question at a time and this would also apply to an eye examination.

The axial code *literal meanings* was again not identified in direct relation to the eye-care process but was observed in the interview and can be directly relevant to any setting where one to one communication is essential. It is known that children with ASD find it difficult to understand a comment that uses figurative language (Baron-Cohen, 2008). Figurative speech is in common use in the English language in everyday situations. Even the most experienced PC and ECP can momentarily forget and use a phrase with an implied meaning. During the interview several of the children demonstrated similar confusion with task instructions, which illustrates the possibility of misunderstanding and difficulty in the eye examination.

“LS: so that’s a picture of the waiting room, do you like that one or not like it?

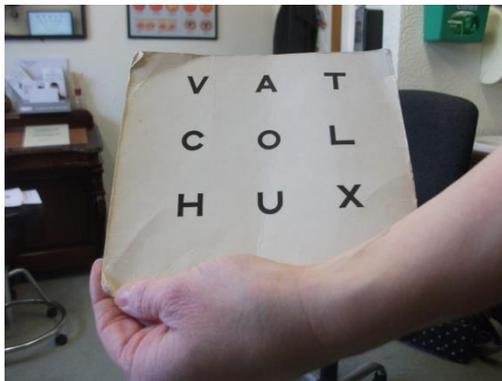
Andrew(C): that doesn’t look anything like the waiting room “

“LS: This is a little card with letters on so if you don’t know your letters very well you can point them out rather than shout them out so you don’t have to say the name of the letter

Simon(C): yes I'm turning into a bit like Dean [sibling with severe LD and an ASD] I don't usually like loud noises in the room"

The axial code *supports* emerged from the data as several of the children indicated a preference for visual supports such as matching cards and picture charts regardless of their age or apparent verbal abilities (The National Autistic Society, 2012b). An example of one of these cards is shown in Figure 16. This was not related to age as the youngest child was an exception to this, indicating a preference for the standard letter chart. Interestingly two of the most able children preferred visual prompts. In the eye-care process children are expected to read out loud letters in a time limited environment which is not ideal given this finding.

**Figure 16: Photo of a matching card by Simon(C)**



### **Social interaction impairment**

The eye examination is an assessment that involves interaction between patient and practitioner lasting for around 30 minutes. Children with an ASD are known to have impairment of social interaction (Wing, 1996) and therefore it is not a surprise that codes relating to this trait occurred frequently in the analysis. This is another area that the codes emerged from participants' responses and also from observation of the way they coped with the interaction of the interview which is a similar situation. The key axial codes that make up this subcategory are: *knowing 'the rules'* and *getting their own way*.

*Knowing 'the rules'* derives from the difficulty understanding the 'rules' of interaction. Data from the interviews shows that this could have a negative effect on the eye-care process. The child can appear rude and uncooperative without realising it and therefore the relationship between ECP and patient could be affected if the ECP is unaware of the child's diagnosis or implications of ASD.

“LS: And my job I’ve already told you I am an optician

Tim: yes obviously

LS: [laughs] and my age umm I don’t know if I’m going to admit to this but I’m  
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Tim: oh that’s a long time”

The axial code *getting their own way* refers to the desire of the child participants to control the situation. During the interview they tended to overrule instructions or requests in order to carry on with a preferred activity. Whilst care was taken to reduce any power imbalance between researcher and child participant it would have been expected that the child would understand that they should follow instructions and respond to the researcher. In the eye-care setting the ECP requests that the child participates in certain tasks, in a reasonably set routine and in a time limited fashion. The two situations are similar and therefore the behaviour shown in the interview is likely to occur in the eye-care setting too.

“LS: Do you like the big chair?

Freddie(C): [looks at all the lenses on the desk, picks up the boxes and looks into them to see what is inside but generally not as much interest as he shows with the other gadgets with buttons to press. This time he appears to listen to the question about the chair but then turns back to the desk.]

Freddie(C): How does it go up? [searching for the button]

LS: Do you like it when it goes up? [no response still pressing randomly at the buttons]

Do you like it when the chair goes up? [no response]

Do you want to make the chair go up?

Freddie(C): [ignores all the questions because he has found the Mallett unit and is pressing the buttons and investigating what it does]”

### **Social imagination impairment**

Social imagination impairment results in the children having a limited understanding of the intentions of others, and having difficulty predicting what will happen and what effect an activity might have on them (Baron-Cohen, 2008; Wing, 1996). There was evidence of fear of the unknown and anxiety around change or lack of continuity. If there is difficulty with imagination and if the expectations that they have are not met, it can be more overwhelming than it might be for others. The axial codes that make

up this sub-category were: *difficulty understanding intentions and predicting reaction to behaviour, dislike of change and the need for routine, waiting, and concrete thinking,*

*Difficulty understanding intentions and predicting reaction to behaviour* is an axial code that was identified in all the child participant interviews. Understanding the intentions of others is not intuitive for these children. For instance when the researcher wanted them to move on to another task, they sometimes did not pick up on the signals that now it was time to do something different. In the example below, Chris (C) had just said that he liked “the middle bit” of his eye examination best but before the researcher had chance to ask him more he became interested in the Ishihara test:

“LS: what did she do in the middle of your test then?”

Chris(C): this is 6 and that is 45 [continues reading numbers from the Ishihara test]

LS: ok [indicating another test]

Chris(C): 5 and 7, 16 and 74”

*Dislike of change and the need for routine* represents the set of codes highlighting the need for continuity and routine which was expressed by all participants. The best outcomes were for children with familiar optometrists in familiar settings. The child entering a familiar setting with expectations set from previous visits seemed more comfortable possibly because they had already processed the situation. Chris(C) illustrated this when asked about the consulting room and tests he said that he liked it all and it was all “fantastic” but when asked if it would still be fun if he had the same tests with someone different:

“LS: if it wasn’t [optom] doing the test do you think it would be as fun?”

Chris(C): it wouldn’t be fun at all.”

“Chris(C): I would be worried that if [optom] wasn’t in the room she worked in”

“Chris(C): I like having [optom] in the room”

Observation of Freddie(C), who was interviewed at the practice where he had his eye examination, shows that he repeatedly went in search of the room that his practitioner used to use. His ECP had recently moved all his equipment into a different testing room which caused Freddie(C) significant confusion.

Situations where unexpected things happen cause distress and what would be considered as an over-reaction in typically developing children. In the example below the participant accidentally let go of the Ishihara book (colour vision test book) which is a concertina of pages which looks like a book but opens out into a long strip if you drop it.

“Tim: [drops the cards from the ishihara] ahahahaha [tries to put them back]”  
[later in the interview further questions about the ishihara came up]

“LS: If [optom] was to do that test with you next time what do you think? Do you think you would like it?

Tim: probably not after, there is no way I would like a book that kept popping out like that.”

After this incident Tim(C) did the card sorting activity and consistently put the colour vision test on the dislike pile. This is likely to be connected to the incident at the interview as he was initially happy to look at the test and all the other children liked the colour vision test.

Freddie(C) was interviewed in the same practice that he usually has his eye examinations. When he arrived he expected to be seeing his optometrist. The example below (excerpt from observation notes for Freddie(C)) shows his reaction to change of expectation.

“I attempt to introduce myself but he pushes past me and walks/ runs into the consulting room. His mother saying to him that [optometrist] isn't there. He comes out of the consulting room and searches the practice for [optometrist].”

Tim(C) demonstrated this also as he too was interviewed in the practice where he has his eye examinations. Despite being told he wasn't going to have an eye examination, and having an accessible information sheet, he still thought he was going to have an eye examination. He was confused and anxious initially because

he just wanted to get on with the test. The quote below was taken whilst doing the rapport building exercise at the beginning of the interview:

“Tim: anyway can we just get on with the test [starting to look slightly tearful again] start already.”

A code that appeared frequently, in all the interview transcripts, was *attention to detail*. This is related to *dislike of change*, in that the children appear to have an ability to spot the tiniest of details, which causes them to notice changes that others might be unaware of. Whilst in the consulting room Adrian(C) noticed a tiny light in the centre of one of the pieces of equipment whilst sitting approximately three metres away from it:

“Adrian(C): How come that light’s there? Will it ever go away? [pointing at a tiny central fixation light on the visual field screener in the far corner of the room] Will that light ever go away?”

LS: which light? [points] oh the little dot, it only goes off when I switch it off.”

In a busy clinic personnel change all the time, there may be locum optometrists, or the order of the tests may change, or they may need a different set of tests depending on their symptoms, there may be a change of consulting room and the equipment may be replaced. This means that patients may have a different set of circumstances each time they go to the optometrist and for someone with autism this means that they have to process the situation every-time they go. Small changes, that others may not notice, can cause significant distress to a child with an ASD.

The code *waiting* results from social imagination impairment. Most people would understand that sometimes you have to wait for your turn even if you have a designated appointment time. It was very clear from the responses that all of the children had an issue with waiting.

“Adrian(C): ... you’re meant to be going in at half past 5, what- ever, but then you have to get there, so you get there at 5 and you have to wait to go in at 5.30 and then you’ve got to wait another 20 minutes because the patients gone over it doing it again [sarcastic voice] ...”

Adrian(C) also produced a drawing see Figure 17 when asked to draw his least favourite bit of the eye examination. It shows him with a thought bubble saying “how long?”

**Figure 17: Drawing of 'waiting' by Adrian(C)**



He explained what the picture was showing:

“LS: [reading the writing on the picture] “how long is it?”

So what was it that you didn't like about that?

Adrian(C): the wait

LS: the wait for it? sitting in the waiting room or sitting in the consulting room?

Adrian(C): sitting in the waiting room

LS: and what was bad about that? Can you describe what it was that was bad about it?

Adrian(C): boring”

The final key axial code for this subcategory was *concrete thinking*. The children demonstrated concrete thinking in many ways and this lack of ability to think flexibly influences the eye examination too. Steve(C), the highest functioning child participant, was unable to cope with the picture acuity charts because the pictures were not accurate and he could not apply what he knows about an object to a line drawing impression of that object.

“Steve(C): I don't know what this is [pointing out one of the pictures on the chart]

LS: oh that's interesting do you know what the pictures are? Do you know what that one is?

Steve(C): apple  
LS: and this  
Steve(C): scissors  
LS: and that  
Steve(C): car  
LS: this  
Steve(C): um not sure clock?  
LS: it is a clock yeah. And that?  
Steve(C): I don't know"

This illustrates why children with ASD need clear instructions for any situation that requires a degree of interpretation such as line drawings that are not to scale.

### **Summary of the category: 'The impact of ASD traits'**

The data show that, unsurprisingly, the traits of ASD have a significant impact on their experience of eye-care.

Setting this in the context discussed in section 3.2: a clinical environment, a one-to-one interaction that requires verbal and non-verbal communication, the following of instructions and the tolerance of excessive sensory stimulation. The individual may need to wait their turn and they may be asked to try some quite abstract tasks.

Consequences: if the traits of ASD are not accounted for in the eye-care process then the outcome is poor. The children have difficulty understanding, interpreting what is expected of them and therefore can struggle with tests that children with the same level of intelligence would find easy. They have difficulty communicating which means that they might not understand what is being asked or have difficulty expressing their responses. They may need longer to process the information which is difficult in a time limited appointment. They do not find the rules of social interaction easy which means that they may appear rude, aloof or uncooperative. They do not cope well with change and the unknown is a cause of anxiety. They are often hypersensitive to sensory stimuli many of which occur in the eye-care process to a greater extent than daily life. Without adaptation to take these needs into consideration the child will become distressed and the eye-care experience poor. Continuity, explanation, time to process and minimising sensory input can help to improve the experience.

### 3.3.2 *The black chair*

The category *the black chair* relates to the reaction of the children to the traditional consulting room chair and what this tells us about how they interpret situations. It is generally assumed by ECPs that children do not like the black testing chair. This is due to the association of the chair with medical examinations and dental treatment. One of the ECPs interviewed for this research, specifically makes the point in his interview that he has taken out his black testing chair and provided a simple waiting room chair instead. However all the children commented that they liked the black chair. Tim(C) was asked to make a plasticine model of his favourite thing in the eye examination and he chose to make a chair, shown in Figure 18.

**Figure 18: Plasticine model of the black chair by Tim (C)**



Andrew(C) initially put a picture of the black chair on the dislike pile in the card sorting and when he was questioned about this he explained it was the equipment attached to the arm of the chair that he did not like but he liked the chair. This means that it was the overall look of the consulting room and the ‘unknown’ equipment that he disliked, not the chair. The reasons given for liking the chair varied from it being comfortable,

Observation of Freddie(C):

“He sat down in the big chair like he is sitting down into a big comfy arm chair.

He shows no fear or anxiety – he enjoys sitting in the chair”

“LS: do you like the chair because it goes up and down? Do you like it because it’s just fun to sit in it?

Tim (C): um no it’s comfortable”

or because it is practical, enabling them to see the letter chart.

“Chris(C): cos it’s a good thing, well and you can see the letter sounds on the mirror”

to the fun of sitting in a big chair,

“LS: What about the big black chair, do you like sitting in the big black chair or would you rather sit on mummy’s lap than sit on the big black chair?”

Chris(C): I love sitting on the big chair”

and the enjoyment of pushing the button to make it go up and down.

“LS: What about the big chair?”

Simon(C): yeah

LS: do you like the big chair? Shall we stand back to take it [photograph]?”

Simon(C): I like going up and down.”

Therefore it emerged from the findings that none of the children appeared to react as expected (by the ECPs) to the consulting room chair. Whilst this is very specific to one piece of equipment it highlights the more significant factor, that nothing should be assumed. The children may not have the reaction that you assume they will and therefore giving choice and listening to them is very important. The assumptions of ECPs about children’s likes and dislikes regarding eye-care equipment and techniques are not necessarily correct. Children with an ASD may apply different meanings to equipment than typically developing children do.

### **Summary of the category *the black chair*:**

From the context discussed in section 3.2 : Primary eye-care requires the use of many different pieces of equipment. The ECP will chose the tests for each individual based on their professional judgement. The awareness of the ECP of the child’s needs will affect how the selection is made.

Consequences: Each individual has a different background and previous experience and unless the ECP asks the child their preferences, then they will be basing their adaptations on assumption not reality. This may therefore result in a poorer experience for the child.

### 3.3.3 *The drops*

The category *the drops* emerged very early on in the research and relates to an extremely negative reaction, that most of the children had, to the use of dilating eye drops as part of the eye examination. The reaction is much greater than would be expected and the emotional trauma long lasting. Andrew(C) was particularly distressed by the drops, which were used without any warning or preparation in his first eye examination. It was the very first thing he wanted to tell me and was repeated several times during the interview.

“LS: Think of all the different tests that you did, what was the one that you think you wouldn’t want them to do?”

Andrew(C): the drops!

LS: is there any other test other than the drops that you didn’t like?”

Andrew(C): ummm

LS: we are going to look at some gadgets in a minute and maybe remind you

Andrew(C): it was probably it was just the drops really”

During the card sorting exercise Simon(C) was shown a picture of drops and he gave a very animated answer:

“Simon(C): what’s this?”

LS: now that’s a packet of drops

Simon(C): don’t like drops, don’t like drops, don’t like drops”

The children gave several reasons for disliking the drops. For example: they cause blurring.

“Andrew(C): no I don’t like, after the drops, guess what?, it was all blurry!”

Another reason given was that they did not like anything touching their eyes.

“Steve(C): and eye drops, I don’t like things on my eyes I don’t like things on my eyes or touching my eyes

LS: so it’s the touching again that

Steve(C): yes too frightening then”

Dylan(C) answered very few questions in his special questionnaire, however despite the question about the drops being towards the end of the questionnaire he decided to answer this question, and clearly stated he did not like drops. The fact that out of all the questions he chose to answer this one and omit many of the others, indicates he had a definite view regarding this element of the eye examination.

### **Summary of the category *the drops*:**

From the context discussed in section 3.2: The eye examination involves the children participating in different tests and activities. Specifically for this category the context includes the use of drops as an objective way of verifying the spectacle prescription by relaxing the focusing muscles of the eyes. They cause blurring for several hours and also sting when they are instilled. There are several tests used that may result in unusual sensory effects and children with ASD are known to struggle when they have to process mutli-sensory situations.

Consequences: if a test or technique is not fully explained then the child can be distressed just like typically developing children. Unlike typically developing children the reaction to disliked tests is much more extreme than might be expected and may have long lasting emotional implications. The drops are an example of this. In the case of the drops the children disliked the blurring and the contact with the eyes. It would be expected that children would comment on the stinging but none of the children stated this as a reason to dislike them. This category therefore could imply that children with ASD may not have the same 'fears' of tests such as the drops, but not limited to the drops, and therefore the effects of tests need to be fully explained in order for the child to accept the test.

### **3.3.4 *The use of computers and gadgets***

The category *the use of computers and gadgets* developed early on in the research process. The love of all things computer and machines with buttons and dials was obvious straight away with the first two participants. The idea of using computerised and automated gadgets was surprising to the researcher whose experience working in primary eye-care has led her to believe that this type of equipment is generally not used for this group of patients. None of the ECPs interviewed used automated equipment with their patients. Therefore it was explored further with the third participant who was chosen because he would only communicate through his

computer. These findings were replicated with all the children (including the children that were lower functioning) except for the final participant. Two of the participants were particularly talented in the use of computers, one of which was the youngest participant. Through observation, card sorting and verbal responses all but one child indicated a fascination of gadgets. However the children did not like gadgets that were unknown to them and the fear of what it might do made them anxious. If the gadget was explained to them and they could play with it first then it was generally accepted. This love of computers was put very well by Steve(C) who seemed genuinely completely confused as to why anyone wouldn't like to use a computer:

“LS: if we designed an eye test that you could do just by looking at a computer and doing different things on a computer would that be more fun than what you did with [optom] ?

Steve(C): er yeah that would be more fun because who doesn't like computers”

The children really enjoyed the interactive element of pressing the buttons. Some children were hard to divert when they had found a gadget that had buttons to press. This was observed in Freddie(C)'s interview:

“LS: [ gives the remote to Freddie(C)]

Freddie(C): [takes the remote straight over to the screen and flicks through all the charts, this time not particularly stopping at any specific screen, he's just playing seeing what he can get on the screen. He finds the picture charts]”

Adrian (C) really enjoyed looking through the box of different gadgets and was very excited about the task:

“LS: We're going to get this box of gadgets from behind mummy ..

Adrian(C): gadgets! [with delight]”

It seems that there may be scope for enhancing the use of computers and automated machines in the eye clinic for children with ASD. In many cases this might keep the child engaged in the process and is within their comfort zone. This is possibly because it reduces the need to interact with the ECP verbally or with facial

expressions, and involves direct simple step by step instructions rather than verbally.

However one child who disliked computers, really disliked them, and found that they made his eyes and head feel strange. He reported hallucinations associated with the use of moving images on a computer screen. This represents an exception to the rule and serves to illustrate the point that eye examinations need to be tailored to the individual's needs and not a one size fits all response. His response to the card sorting picture of computer test charts is shown here:

“LS: It’s a bit like a computer game only a bit more boring.

Tim (C): um no since I don’t like computer games that’s going [onto dislike pile]”

It is notable that despite his dislike of computers he was fascinated by the scanner and also the photographs of the retina. Therefore even with a child who dislikes computers, gadgets were still preferred.

**Summary of the category *the use of computers and gadgets*:**

From the context discussed in section 3.2: The eye-care process involves tests that the child is asked to respond to. Children with ASD have difficulty with social interaction and also find it difficult to follow verbal instructions unless they are simple and concise. Furthermore some parts of the eye examination are better performed using gadgets and computers such as scanning the retina and measuring the peripheral vision. The gadgets are usually large pieces of equipment and require the child to follow instructions, sometimes put their chin onto the machine or lean their head into a machine. They may involve bright flashes and some make sounds or have an electrical hum.

Consequences: the use of gadgets, if appropriately explained, can be fun, and involve less human interaction and therefore may be more effective and less distressing than traditional techniques. The outcome, if designed and controlled for other sensory issues, may be a better experience for the child. Choice is important because children have different needs and the equipment used needs to be tailored to each individual.

### **3.3.5 3D tests and blurring lenses**

The category of *3D tests and blurring lenses* relates to the reaction to tests used in the eye examination that result in an unusual visual effect. The reaction of the children in this study to the 3D effects was much more extreme than those observed by the researcher in community optometry clinic with typically developing children. Many of them liked and enjoyed the tests because they were fun and almost like a game but for some it was uncomfortable. The sub-categories found were: *“It was cool”*, *“Hurts my eyes”*, *dislike the blurring*, and *making choices*.

#### **“It was cool”**

The children were allowed to touch and play with the equipment in the consulting room and their reactions to tests that create a visual effect were generally very positive, with some becoming excitable as a result. The example below from Chris(C) illustrates this:

“Chris(C): what’s that coming up?”

LS: it’s a fly isn’t it

Chris(C): ewww buzzzzzzz [exaggerated laughter]”

The subcategory title “it was cool” came from Steve(C)’s reaction to the 3D test. He seemed to sum up the reactions of the children who were interested and noticeably more engaged in the interview when looking at this group of tests:

“Steve(C): it was cool

LS: it was cool yeah ?

Steve(C): cos you can see everything in 3D.”

Andrew(C) also became very excitable and in order to check the meaning of his reaction He was asked whether he was reacting to it because he did not like it or because it was fun:

“Andrew(C): ohh! Errr! [laughs]

LS: [laughs]

Andrew(C): that’s disgusting!

LS:[laughs] is that fun or is that just disgusting?

Andrew(C): that's fun! [laughs] could do that as a trick for people like they will say like "there's a fly!!! There's a blue fly!!!" and then they will like try and touch it and they won't feel anything [laughs] except the mirror

LS: so you think that would be alright ?

Andrew(C): yeahh"

Some of the 3D tests involved using red green glasses and most of the children found these fun. Chris (C) and Andrew (C) both enjoyed playing with these tests.

"Chris(C): it's fun! Yes because it changes colours of things, it changes the colour of the computer of the letter stand

What about something like this? Do you like that? [red and green filter] it changes the colour, if you look through those it changes the colour of"

"Andrew(C): it's like a rainbow

LS: yes. Do you like that or is that not nice

Andrew(C): it's I like it yes fun!"

One child said that he felt better wearing the red and green glasses, his eyes felt soothed by the colour. This was the child that had previously indicated distress looking at moving images on the computer. It is possible that this could be due to visual stress which is known to be more prevalent in children with ASD (Ludlow *et al.*, 2008).

"LS: Now what do we think of this now. What would happen is he would hang that over there and he would put that on your nose? What do you think of that one?

Tim (C): let me guess [tries them on]

LS: oh very nice. What do you think of that?

Tim (C): weird now I feel better

LS: do you feel better with the red and the green?

Tim(C): yes"

Interestingly the preference was also noticed in tests that produced a sensory stimulation that was not visual. The Lang stereo test is a small card that is grey and black speckled with multiple ridges across the surface. This was liked by most of the

children. Two of the children particularly commented that they liked the feel of the card that has multiple ridges across the surface.

“Chris(C): it’s good well, because, look you can feel some bits, there’s a star,”

### **“Hurts my eyes”**

In contrast, several children found the sensory stimulation too overwhelming. They described the feeling that their eyes hurt because of the effects of patterns or 3D. This is linked to the difficulty with sensory overload and possibly visual stress.

“Steve(C): it was really hard for my eyes and sometimes when something is really hard for my eyes and you use energy it hurts my eyes.”

“LS: does that feel alright?”

Tim (C): not so much because it gets my eye all crazy

LS: does it make it feel funny

Tim (C): no it makes it go crazy”

### **Dislike the blurring**

Some of the tests used in a routine eye examination require the person to look through lenses that are blurred and in the same way that the drops were problematic, this blurring was disliked by some of the children.

“LS: and did you mind them putting the lenses in and out? Better with better without, is that fun or?”

Steve(C): it was strange because your eyesight would be changing constantly.”

“Andrew(C): blurry when I have to have those sort of lenses that go in that sort of glasses there. They give like loads and it’s really blurry”

The children did not like having to choose different lenses because they found that difficult. Tim (C) illustrates this below:

“Tim (C): yeah he did say stuff like that [better one or two]

LS: ok and what did you think of that, did you like that? Or was that difficult?

Tim(C): um yeah difficult

LS: it was difficult, did you enjoy doing it though or did it put you off because it was difficult?

Tim: yeh it put me off ahh”

### **Summary of the category *3D effects and blurring***

From the context discussed in section 3.2 :eye examinations for children need to include some tests to measure vision. This includes depth perception and spectacle prescription and involves the child experiencing different sensory stimuli such as special effects and blurring. In order to measure depth perception optometrists use a range of equipment that create the effect of 3D and children generally find them fun and exciting. Children with ASD can have hypersensitivities and become excitable or distressed by sensory input.

Consequences: if the sensory input is not controlled carefully the child may become overwhelmed, over excited or distressed. However if the child finds the tests enjoyable they may facilitate the process. This category emerged from many codes that related to the over-reaction to sensory stimulation. The over reaction was either very positive or very negative but none of the children were neutral in their reactions. The reactions were greater than those observed in typically developing children. The reactions were so extreme that this could have a significant impact on the child’s eye-care experience.

### **3.3.6 *Practitioner personality***

The category of *Practitioner personality* refers to the comments of the children about their optometrist. This category was pursued because of comments made by the PCs that their children responded well to certain personality types. It was very difficult to ask the children about their optometrist’s personality because this is quite a complex concept for a child with ASD to understand without leading questions. However it was clear from their comments that those who had a regular optometrist were generally happier with the experience and only wanted to see that particular optometrist. This could be due to the practitioner’s personality or maybe due to their

dislike of change it was not possible to determine which of these it was. Several had previous bad experiences with optometrists and the PC had identified another optometrist through recommendations and the result was a better experience with an optometrist that the child indicated preference for. Simon (C) had previously a very bad experience with an ECP but he now had regular ECP that had been recommended and he was very happy with them.

“Simon (C): yes it’s quite fun [laughs] everything is fun when I have an eye test “

Chris (C) had an optometrist that was recommended to his PC from her friends, as being good with children. When he was looking at the equipment he said he liked every test. However, as the quote below shows, when he was asked if someone else did the tests would he still like all the equipment his response was immediate and emphatic.

“LS: if it wasn’t [optom] doing the test do you think it would be as fun?  
Chris(C): it wouldn’t be fun at all.”

Another example of this was with Freddie (C) who, on arrival for the interview, searched the practice for his ECP, who he was looking forward to seeing and whom he associated with the building. When the children were asked about their ECP they could not express what it was they liked about them.

### **Summary of the category *Practitioner personality*:**

From the context discussed in section 3.2: the eye examination is a one-to-one interaction between the patient and ECP. The ECP is as unique as the patient and therefore they have their own personality, approach, background and skill set. This has an impact on how they approach the child, whether they make things fun, whether they explain what they are going to do and how they adapt the routine.

Consequences: the personality, approach and skill set of the practitioner can affect the outcome positively or negatively. The children who were familiar with their ECP seemed to do better and this may be due to the continuity or it could be due to the approach of the ECP. The personality of the ECP seems to have a positive or negative impact on the experience. Although the children could not explain their

likes and dislikes it was clear that the children who had regular ECPs were attached to them.

### **3.3.7 Anxiety**

The category of *anxiety* emerged because there were many codes throughout the interviews that indicated that anxiety was a factor affecting the experience of eye-care. The subcategories were: *fear of the effects*, *fear of the unknown* and *previous experience*.

#### **Fear of the effects**

Two children expressed a significant level of fear of what damage the light could do. One of these caught sight of the light on one of the pieces of equipment when playing with it and then repeatedly commented on the spot in his vision that was left from the dazzle.

“LS: [laughs] the light on it. Did you like it when he put the light on it?”

Tim: no!!

LS: do you like bright lights generally or is it just this light you don't like?

Tim: don't like them, there's a patch in my eye!”

The other child had been told by a friend that the optometrist would use a laser to look at the inside of his eye and was therefore very anxious about the lights used in the test.

“Steve(C): really I was worried about some things and I was happy about other things

LS: was there anything particularly you were worried about?

Steve(C): um in particular I was worried about, in some opticians they shine a light into your eye to see what's in it, I don't like the light shining in my eye”

Simon(C) was clearly very anxious throughout and at one point needed to use some calming strategies.

“LS: do you like gadgets like that or does that make you feel a bit stressed as well?”

Simon(C): mostly everything and everyday and everything I do I feel sick and ... and noise makes it worse.”

All the children seemed to worry about the potential for lasting effects from the equipment used in the test. This may be linked with their impairment of social imagination and therefore the difficulty they have in interpreting situations which has the effect of causing them anxiety. Simon (C) illustrated this as he was worried generally about his health, on the day of the interview he had an injury to his knee caused by an accident on his trampoline, whilst this was not a serious injury he kept referring to it and he was obviously worried about it. During the interview he went to look at the Slit Lamp Microscope (an instrument used to examine the external eye) and although it wasn't even switched on, he thought that it had put a cold draft in his eye. He commented on this intermittently throughout the interview despite reassurances from his PC and researcher.

“Simon(C): still got that little draft in my eye and it gets me worried that”

Restricted spaces were a trigger for anxiety for Andrew(C). He did not like the instrument room (a small dim room) and was so anxious about it that he refused to go in.

“LS: Oh that's the machine I was telling you about.

[instrument room, grey plain walls, low light, 2 large grey machines and several black stalls]

Do you like that?

Andrew(C): nooooo

LS: do you not like this room at all?

Andrew(C): I don't like it at all

LS: tell me what you don't like about it

Andrew(C): I don't like the big machine

LS: if someone explained to you [Andrew(C) interrupts]

Andrew(C): and it's too small”[referring to the room]”

Chris(C) was anxious about the difficulty of the tasks he would be asked to do and for each new task explanation and reassurance was required. When I asked him to look at the pictures and sort them into like and dislike piles he looked very worried.

This anxiety may be linked with low self esteem which is known to be common in ASDs (Baron-Cohen, 2008)

“Chris(C): please do some easy ones!”

### **Fear of the unknown**

*Fear of the unknown* was a code that occurred frequently. It describes those moments where a child expressed a distinct dislike that was related to a test or piece of equipment that they hadn't seen before. When they were frightened of what they did not know or could not predict about the situation.

“Observation of Simon(C)'s interview: When I asked him about a gadget on the worktop in the consulting room. He hadn't seen it before and therefore got quite stressed and his behaviour deteriorated again”

### **Previous experience**

The success of previous experience has a lasting impact on the children. This was shown with one participant who became distressed doing his 'About me' booklet when I asked about TV programs. He mentioned an episode of the Simpsons that had frightened him and just thinking about it now, several years later, made him tearful. He was diverted from the topic quickly but it was interesting to note that he could have talked about any of the TV programs that he does enjoy but instead he chose to discuss the one that he was frightened of. Whilst this is not directly relevant to the eye examination it does illustrate that previous experiences can have a long term impact. The need to get it right from the start appears to be an important factor in the long term confidence in the process.

### **Summary of the category *Anxiety*.**

From the context discussed in section 3.2: Many of the PCs and ECPs commented on anxiety in their children and therefore this as a factor in the eye-care process. Anxiety is known to be an issue for children with ASD (Notbohm, 2004). There are many potential triggers of anxiety in the eye examination such as the need for interaction and communication throughout, the demands of learning new tests and coping with new environments and people.

Consequences: if the triggers of anxiety are not known then a child with ASD may become anxious and unable to cope with the demands of the test which results in a poor experience. Anxiety can be reduced by the awareness of the PC and ECP to ensure that the child has an understanding of what is involved in the tests through preparation, encouragement, familiarity and explanation.

### **3.3.8 Tests and techniques**

*Tests and techniques* is a category that combines the findings regarding the different tests and techniques used in the eye examination. Only one child was able to talk about the tests that were used and recalled details about their order. Therefore this category is a collection of codes of likes and dislikes. The findings were drawn from the children's reactions to the equipment in the room, card sorting preferences and photographs that they took.

The results for different tests were as unique as each individual. The list of tests and equipment that they liked or disliked was different for each child with little overlap. Several codes in this category overlap other subcategories and therefore will not be discussed again here but these include: dislike of touch, bright lights, and drops and the preference towards computers, gadgets and 3D tests. The predictability of the tests that were liked by the children was very difficult and did not seem to be associated with age appropriateness or cognitive ability however most of the preference can be tracked to the impact of ASD such as the hypersensitivities. However one code emerged that requires discussion here, that of *charts*.

#### **Charts**

The children were shown a range of different chart options for measuring vision including: computerised, illuminated, matching charts, letter charts and picture charts. Typically developing children would usually proceed from matching chart and picture charts to letter charts by about the age of five. In this research there was no clear preference although it was noticeable that some of the older, higher functioning children preferred the picture chart rather than the letters. Furthermore, the youngest child interviewed indicated a clear preference for the letter chart. It is therefore important to note that choosing a chart by the age and apparent abilities of the child may not be correct for this group.

### **Summary of the category: *tests and techniques***

From the context discussed in section 3.2: there is a wide range of tests and equipment that could be used as part of an eye examination. Each optometrist selects the tests that they consider to be most appropriate for each patient. Some ECPs have special techniques to enable the child to manage the tests. Some ECPs recommend objective tests rather than tests that require the child to respond and make choices.

Consequences: the preferences of children with ASD may not be the same as would be predicted from their age and cognitive ability or age matched typically developing children. The better experiences cannot be predicted by using a particular battery of tests but by giving the child a choice of different options.

### **3.3.9 Over-arching category for the child participants: *Feeling in Control***

The over-arching category is that which forms the central core to the children's experiences. It can be seen from the data from the children's interviews, and triangulation with data from the PCs and ECPs, that whilst the children have many common traits each individual has a unique set of likes and dislikes, strengths, fears and anxieties. There was no 'rule of thumb' regarding the eye-care routine or battery of tests, no common approach that improves the experience and no particular approach that is detrimental in all cases. The eye examination is a chain of processes and therefore interactions. This was illustrated by Steve (C) in his photo Figure 18 which is a panorama shot of the cards which he had arranged in the order he remembered in his eye examination.

**Figure 19: Panorama of the routine eye examination by Steve (C).**



The most noticeable common factor that emerged was that their reaction to something enjoyable or something not enjoyable is more extreme than one would expect. The eye-care experience therefore can be derailed by triggering challenging or excitable behaviour. The children who reported the better experiences were those who had a regular ECP, who were familiar with the environment and routine, whose eye examination was adapted for their special needs, and who had clear and accurate expectations of the process

Factors that had a stabilising effect were: the continuity of care, an ECP that is ASD aware, adaptations to the examination to avoid triggers (such as having to wait or sensory overload), offering choice where possible and empowering the child with encouragement and explanation. Other factors include the awareness of the ECP that communication might need to be adapted to avoid figurative speech or implied meanings. The use of computers and gadgets was enjoyable for the children when they knew what they had to do and what the gadget was for. The children preferred to be able to touch and play with the equipment first so that they were familiar with it. They had a clear preference to being centre of attention and they did what they wanted to do regardless of other people's expectations of them. Finally the children had various calming strategies or soothers that could be employed to help control an escalating situation.

Conversely, destabilising factors included the unfamiliar or changed environments, unexpected activities such as the use of drops, unexplained equipment, small

enclosed rooms or restrictions, and having to wait in the waiting room. They also found the sensations of blurring (such as after drops), touch (such as the trial frame) and bright lights (such as ophthalmoscopy) distressing. The children tended to be overwhelmed by the recollection of previous experiences which had a negative impact on the process. The children all had unique triggers of anxiety which led to challenging behaviour.

Whilst the children had a unique set of these factors the core to the experience was how well they coped with the process and environment. This depends on whether or not they feel in control of the situation. Therefore the over-arching category that emerged was *feeling in control*. That is not necessarily literally in control, but that they are not overwhelmed, unable to reason and unable to control their behaviour and emotions.

If the child was enabled to feel in control then the experience was better.

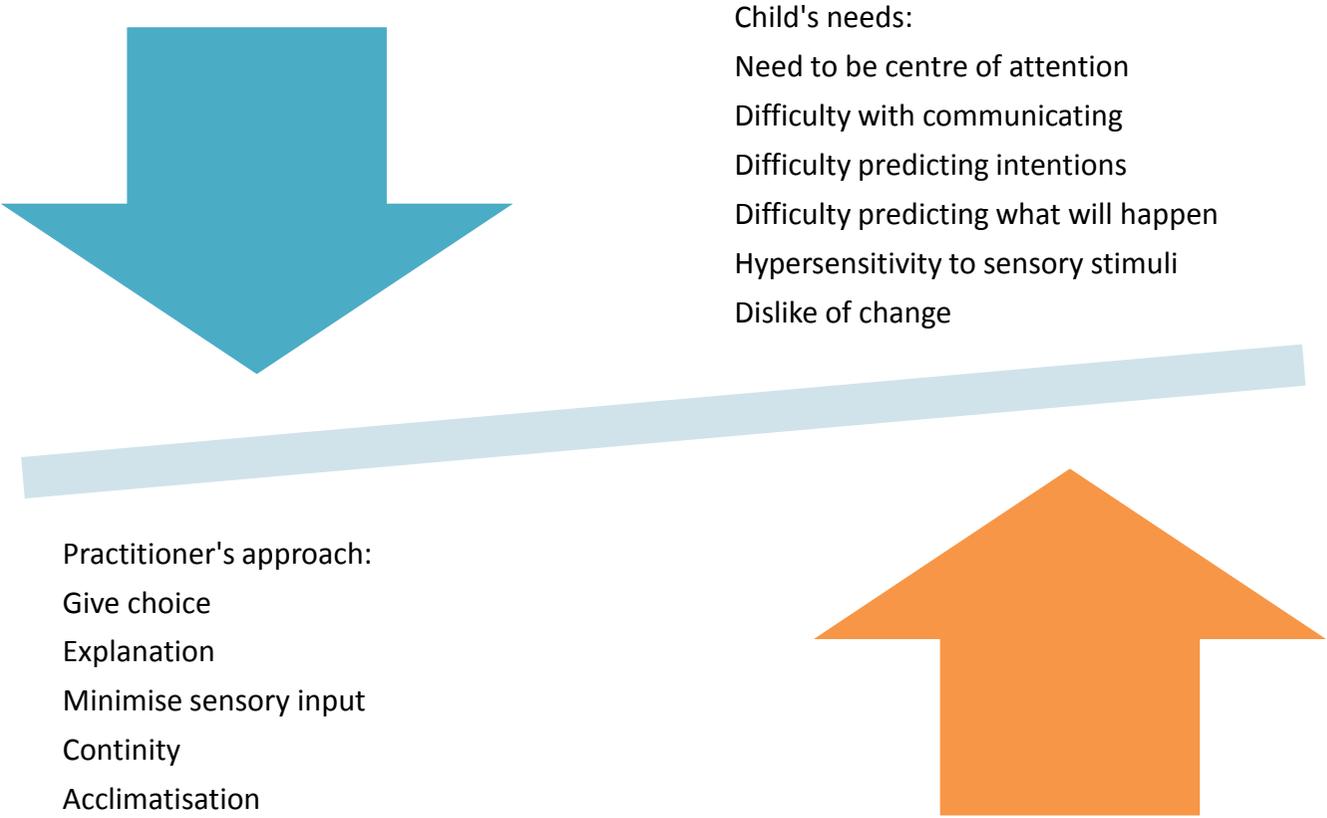
Destabilising factors can cause the child to become overwhelmed and out of control resulting in challenging behaviour. Stabilising factors enable the child to know where they are in the process, what is happening and what is expected of them, reducing anxiety and therefore leading to a positive outcome.

An example of this was Chris (C) who attended for a routine eye examination with an ECP that he was familiar with, in a clinic that he was familiar with and with accurate expectations set in advance. He was very comfortable and enjoyed the test but due to some inconclusive results he was asked to return for a follow up. Unfortunately he had expected the follow up to be a re-run of the first appointment. When the ECP carried out a different battery of tests he became overwhelmed and challenging. His expectations were not met and his reaction was to exhibit challenging behaviour. He no longer felt in control of the situation.

Figure 20 shows the effect of the balance between the approach of the ECP and the special needs of the child. The factors that can be potential sources of distress and the approach that the ECP can take to enable the child to feel in control of the situation. This illustrates the interaction between child and ECP and how this impacts the experience from the child's perspective. This is discussed further in chapter 5 where this relationship is put into context and a theory of primary eye-care experience is developed.

Therefore, the experience of primary eye-care for children with ASD is varied depending on how in control of the process they feel. Many of the elements of primary eye-care were described as fun and enjoyable whilst many were potential sources of anxiety, distress and confusion. The child's experience depends on how well these are managed in order for the child to feel in control and therefore less challenged.

**Figure 20: Diagram to show the adaptation of approach to account for special needs**



### 3.4 PC findings

The data collected from the PCs were used to plan the children's interviews and also to gain a further insight into the children's experiences from the perspective of the person who knows them the best. This data has been used to give context and process information (see section 3.2.1, and 3.2.4). The categories that emerged are shown in Figure 7 and in Appendix 6ii. The categories that are relevant to the context have already been presented, in this section the aspects of the findings that are relevant directly to the children's experiences are explicated.

#### 3.4.1 PC Awareness

The category *PC awareness* is particularly relevant to the context of this research however the axial code *Practitioner personality* from the subcategory *Choice of optometrist* is important with respect to the experience. The PCs were able to give more information about the effect that the practitioner personality has on their child. They were very clear that this made a marked difference to the outcome of the examination. The PCs used phrases such as 'calm', 'puts at ease', 'talkative', 'explains', 'child friendly', 'relaxed', 'fun', 'praising' and 'gentle' to describe the ECPs that were preferred.

"Pippa(PC) : oh I dunno a calm upbeat voice talk to them so they actually know what's about to happen next."

"Marianne(PC) : she was, she explained a lot more what she was doing and she kind of talked pretty much the whole way through it."

"Marianne(PC) : and I do think that was, he warmed to her and he trusted her I think and that made a big difference."

One PC commented that they book their appointments to ensure they see this particular optometrist because she is very good with him. When a rapport has been built, continuity is important for this group of children.

"LS: do you have a particular time of day you choose there or do you just

Anne: no I normally ask for early, first thing appt of the day for Simon(C) as well and with [optometrist at practice] and um she er I think she only works part time not a full week there.”

The children do well when they receive encouragement and praise.

“Marianne(PC) : ..and “oh you’re good at that” quite a lot of positive reinforcement actually which I thought was good. Um “oh I know you are going to get this one done” kids are fickle.”

The ECPs that were selected from recommendations were the better experiences, whereas the poorer experiences were related to ECPs who had been selected for convenience or location. Several had poor experiences when they chose practitioners for ease of location and then subsequently sought recommendations and had far better experiences.

### **3.4.2 ECP awareness**

The category *ECP awareness* has also already been presented regarding the context of primary eye-care. However this category was relevant to the experience too. The PCs all commented on the general lack of awareness of ASD, not just in optometry but in general everyday life. This lack of awareness meant that adaptations could not be made for their child’s special needs.

“Mick(PC) : There was no difference in them [his test and his child’s test] but then I put that down to them not knowing too much about autism anyway.”

“Anne(PC) : say he was sort of like a trendy young lad maybe just qualified, a lot to learn. And I came out quite upset, frustrated and angry [laughs] and that was me, so god knows what Simon(C) was feeling.

LS: yes

Anne(PC): you know and I just felt for him because, oh you know my poor boy.”

### **3.4.3 Barriers and Facilitators**

*Awareness of ASD traits* was a subcategory that emerged strongly throughout the data. In line with the children's findings the range of impairments and traits have an influence on their experience. The axial codes presented here are *hypersensitivity, communication impairment, social interaction impairment, social imagination impairment,*

*Hypersensitivity* was commented on frequently throughout the PC interviews. Whilst in common with the children they all mentioned touch being an issue, many PCs also commented on sound being a negative factor. They reported their child was distracted by sounds that most people would be unaware of, or distressed by, loud noises or crowds.

“Zahra(PC) : he is very very sensory so the slightest little thing, touch, smell, lights can make him flap.”

Only one PC mentioned that the light might have been an issue.

“Zahra(PC) : I do remember being quite anxious about the light coming towards him so I thought he was going to set off but um he didn't really like it too much.”

One PC mentioned that her son was very sensitive to smells. Optometry practices can smell 'clinical' and this can add to the sensory burden.

“Pippa(PC) : he will mention it, he might say what's that strange smell in the house and I think I can't smell anything but [laughs] but he'll he'll he'll notice so annoys him.”

*Communication impairment* is an axial code representing the difficulty that children with ASD have with processing information and expressing themselves. This was an issue mentioned by many of the PCs who felt that their child's communication impairment caused them difficulty with tasks such as following instructions. Several highlighted the need to give information in advance so that they are prepared.

“Zahra(PC) : it can be quite a violent no, it can be a hitting and scratching no, but um later in the day he can walk up to me and say I want to go, I want to go now and then I have to work out what it was I said...No seems to be the default setting that he uses to take time out to process and think about it, rather than have to agree straight away.”

The recommendations from the PCs were to keep the language simple and direct, to allow longer to process what is being said and to avoid figurative speech.

“LS: ok so if optometrists learnt a little bit more about how phrases are interpreted?

Mick(PC) : yes, and not to be so fast I know that would mean a longer appointment time, I know that my appointment was exactly the same as his, um practically word for word, and I you know I’m there so I can say to him, I can basic translate it, although it don’t need translating to us, but just needs a little bit more time, slow down a little bit ...”

The use of visual supports was recommended by all the PCs regardless of how high functioning the child is. Visual prompts can be a visual aid to communication such as picture of activities or instructions in pictorial form. An example of this would be a visual timetable to help the child know what is going to happen, when and how long it will last.

“Anne(PC) : yes and even if you learn the odd makaton sign it’s all just to reinforce verbal communication. You know I think verbal information, he can’t, it’s almost like he’s trying, he’s processing the words themselves rather than the meaning.”

“Marianne(PC) : she talked to him, she explained what she was doing but she was also quite animated and I think when you are asking a child to do something anyway, a small child, there has to be some element of visual direction, it’s never a bad thing but certainly with an autistic child it’s almost key”

.Visual prompts can help to set expectation such as enabling the child to sit in on a sibling’s eye examination. One PC had felt that his child had a better experience

because he had seen his brother have an eye examination in preparation for his own.

“Mick(PC) : He seemed alright, that’s because he knew what was, cos we let [sibling] go first, so he knew it all what was going to happen, he knew we was sitting in a dark room, he was gonna look at the red light, the green light, the bright light.”

Several of the PCs commented that despite their child appearing to be quite able regarding communication, often the child is not managing as well as they appear to be or they are having difficulty expressing what they really mean.

“Rosie(PC) : His auditory processing isn’t very good, so although he’s quite verbal you might actually think he, you are having a full conversation wiv’ him, and he’s taking everything in, but he’ll pick bits and pieces out of what you are sayin’

LS: OK

Rosie(PC) : so and that’s why he’s um, that’s why people are quite, yeah, misunderstand him and get quite confused.

Mick(PC) : because he’ll do the same thing when he’s having a conversation with you, he’ll start talking about one thing but bounce about 3 or 4 different things and expect you to know what he’s talking about.”

The axial code *social interaction impairment* represents the difficulties children with ASD have coping with activities of daily living. This impairment can cause several effects: such as the child appearing rude or aloof, difficulty interacting unless it is on their terms and they are in control, and inappropriate behaviour as they do not understand the ‘rules’ of social interaction.

“Anne(PC) : he wasn’t um autistic aware.

LS: friendly?

Anne(PC) : no he wasn’t and he, you know, he just saw, he just saw, how old was Simon(C) 4/5, he just saw a boy flipping.

LS: yes, thought he was being naughty?

Anne(PC) : yes and saying, ‘oh come on it will be done in...’ thinking um”

*Social imagination impairment* causes the children to see the world differently. It affects their ability to predict what will happen or perceive a situation in the way others would. This can make the world a scary place. Often it results in the child not wanting to be part of whatever is happening as they do not understand why they should be participating. This means that they may not understand why eye-care is important and may need extra explanation about how long it will last and what will happen.

“Catherine(PC) : For example children on the autism spectrum don’t have imagination but that doesn’t mean they are not creative, what, he he [support group speaker] explained this really well is the fact that if we are going into a situation that we have never encountered before we cannot imagine what it will be like.”

An axial code of this subcategory is *Dislike of change* that represents the need for routine, continuity and familiarity.

“Anne(PC) : yes, he’s ok because this lady is lovely but if we went to a different opticians it would be a different kettle of fish.

LS: and you would have to start all over again?

Anne(PC) : yes, he would find it because it was somewhere new he’s find it stressful.”

*Waiting* is another axial code that appeared in all PC interviews. Waiting caused all the children anxiety and is a trigger of challenging behaviour.

“Marianne(PC) : I just think it’s more stressful because he’s getting more anxious because obviously well he’s not knowing exactly what’s happening and what he’s going into. But also I think they just want to kind of go in and get it over with.”

Another axial *poor concentration and distractions* was a concern for many of the carers. This has relevance to the context and is presented in section 3.2 However it is also relevant the analysis of the children’s experience in that some of the PCs commented that they were aware that their child was distracted throughout the eye examination

“Zahra(PC) : I just remember sitting and him trying to grab everything around and take it apart.”

*Challenges* is a subcategory that emerged from the axial codes, *the drops*, *treated the same* and *parental stress*. These are a group of circumstances that create an additional challenge that influence the experience. Under certain circumstances they might or might not be a problem therefore they could be considered a barrier or a facilitator depending on the specific circumstance.

The axial code *treated normally* resulted from the data indicating that PCs felt that their child was treated the same way anyone else would be treated because they did not appear to have a disability. This has been presented in terms of the context however this also has relevance to the experiences of the children All the PCs felt that their child’s eye examination was not adapted to their special needs and the consequences of this are that they may be considered rude or aloof.

“Marianne(PC) : certainly the difficulty you’ve got is that people may look at him and think he is naughty or impolite because he is a lovely looking little boy really. He’s so, he looks healthy and he’s tall so when he does have a bit of a strange episode people are just so...”

The axial code *the drops* represents the distress caused by the use of dilating eye drops. All the PCs mentioned the drops and two in particular commented on the distress that was caused. For one of those PCs it was the trauma of the drops that made her want to become part of the study.

Marianne(PC) : no, well it was bad enough to compel me to contact you so that in itself is kind of, because I just thought, I remember coming out, and I felt really traumatised and I remember ringing [husband] my other half and just, I was really quite upset about it because I felt awful for Andrew(C). No-one wants to see their child like that and I just ‘no, there must be a better way’.

The reaction to the drops is more extreme than with typically developing children who may initially be distressed but are usually won over by a sticker reward, for the children in this study the experience had a long lasting traumatic reaction.

*Awareness of adaptations* is a subcategory of the category *Facilitators*. This subcategory represents the adaptations that enable a good experience of primary eye-care. Axial codes for this have been discussed in section 3.2 as they are relevant to the service design and context. However one of the axial codes is *training* and this includes the ability to select appropriate tests for the child's needs. The use of computers and gadgets emerged from the children's interviews and the PCs also commented on this

All but one PC felt that computerised tests would be well received. They enjoyed the use of computerised tests.

"Daisy(PC) : cos he was using some sort of letters on the television, and I think that because it's a television screen, not television but you know.[computerised letter chart].

LS: yes, it looks like a TV

Daisy(PC) : yeah that's right, um that was all brilliant and he was pressing buttons and things flashing up and things like that was all keeping him amused."

One PC commented that care would need to be taken that the child was doing the test correctly and not getting carried away just playing with the computer.

"Catherine(PC) : I think for some children yes but again it's a very individual thing and yes it could work that you could button pressing and things could be quite fun but the opportunity for pressing the wrong buttons is quite high but I do think it is very much an individual thing."

However one PC explained that her son disliked computers because he cannot cope with the movement on the screen.

"Pippa(PC) : it's like on the computer if things go too fast he gets really annoyed and upset he can't deal with the speed across his eyes but then I don't know because he's actually said I need to stop the pictures mum and I need to rewind"

### **3.4.4 Over-arching category for PCs : Awareness**

From the analysis of the categories shown in Figure 7 an overarching category of *awareness* emerged. Eye-care professional awareness of: ASD and the likely impact of ASD, how to adapt their approach, how to communicate with PC and child, strategies used to encourage and calm the child, how to adapt and develop services that are appropriate and person-centred, and how to create an environment that is appropriate. PC awareness of: how to communicate with the ECP and what information to give, expectations of the service, and how to prepare their child and set their child's expectations. Awareness on both sides supports a good experience of eye-care.

Figure 21 illustrates the factors that influence the experience of eye-care grounded in the data from the PCs.

**Figure 21: Experience of eye-care grounded in the data from PCs**



### **3.4.5 Child and PC dyads**

The findings from the children and the PCs have been presented in sections 3.2.1, 3.3 and 3.4. The experience of the children can be appreciated by combining the findings from the children with the context and experience related data from their PCs. The findings from the PCs were used to plan the approach and activities used in the interview process and also to cross check the responses of the children.

Table 10 shows the overlap between the findings from the children and PC's responses. The categories from the children's data and those from the PC's are very similar but as they represent different perspectives it would not be expected that there would be complete overlap. However it should be noted that there is very little disagreement between the two groups of participants which suggests that the findings are reliable.

The use of child and PC dyads has been a valuable tool in enabling the accurate and reliable interpretation of the children's data. It has also enabled constant comparison to be used more effectively because it was applied within dyads as well as between subsequent dyads. This improved the trustworthiness of the research.

**Table 10: Data from child – PC dyad combined**

<b>Childrens category</b>	<b>PC findings</b>	<b>Combined findings</b>
The use of computers and gadgets	Computers generally very popular	The use of computers and gadgets in eye examination should be considered
ASD traits	Sensory overload due to noise, light and touch Difficulty understanding what is expected Difficulty predicting what will happen Difficulty communicating and processing information	Limitation of sensory input Communication channels between PC and ECP are essential Continuity , familiarity and preparation reduces distress
Practitioner personality	Children preferred the same optometrist each time Children responded well to encouragement Better experiences associated with more time Allow children time to touch and explore equipment	Practitioner personality and the approach of the practice team and design is very important in enabling the child to feel comfortable.
Anxiety	Previous experiences affect how well the child copes Children were anxious if they did not know what was going to happen	All the children suffered from anxiety but this can be controlled by ensuring that they know what will happen, when and why and importantly how long it will take. Previous experiences affect children with ASD significantly.

Childrens category	PC findings	Combined findings
The drops	<p>The children all had great difficulty with the drops.</p> <p>PCs felt that if the child had time to prepare for the drops then they would cope better</p>	<p>The children and PCs both mentioned the drops as an issue. However the children explained that they did not like the blurring after the drops and did not mention the stinging as expected. The PCs felt that the main issue with the drops was that they were not expecting to have drops which caused anxiety and a bad reaction.</p>
Tests and techniques	<p>The use of visual prompts even when the child had verbal communication skills was advantageous</p> <p>Allowing the child to touch and explore equipment helps</p> <p>Training in ASD awareness for ECPs improves the experience</p>	<p>Adaptations to tests can be made to enable the experience to be more acceptable.</p>

### 3.5 ECP findings

ECPs were included in the research as a result of the category *Practitioner personality* emerging early in the analysis of the childrens data. It was included to investigate what factors affect the service provided by ECPs. Much of this data is relevant to the context and process rather than the child's actual experience and this has been presented in section 3.2.2, figure 10 and appendix 6iii. Two further categories emerged *Service provision* and *Importance of eye-care* but these have been omitted from this section because they are more relevant to service development and as such are not directly concerned with the current experience of children with ASD. Discussion of these findings can be found in Appendix 6iv. This section presents those findings from the ECP data that are directly associated with the experience of primary eye-care for children with ASD.

Two of the four categories that emerged were relevant directly to the experience of primary eye-care: *barriers to eye-care*, and *facilitators to eye-care*.

#### 3.5.1 Barriers to eye-care

The subcategory of *ASD traits* was identified in the children's data and PC data and therefore it is not surprising to find it in the ECP data too

The axial code *hypersensitivities* was prominent in the data from the ECPs in line with that from the dyads. The ECPs identified it as a significant issue. They highlighted the use of equipment with lights and that touch the nose, face or ears, explaining that this was a common cause of distress.

“Beth(ECP): that room is full of equipment as they tend to be, different sounds, different smells, different people it becomes such an ordeal to just even walk into the opticians let alone have a test, have the lights turned out, have some things shone in your eye, have a silly pair of glasses put on, have things made blurry and then less blurry with lenses, the whole thing is just too much.”

“David(ECP): Because if you keep a child waiting for 3 hours in a busy waiting room noisy cluttered visually noisy as well then you are not necessarily going to get the best results.”

One ECP felt that it is a particular problem with larger multiple practices such as those based in supermarkets as these tend to be busy, noisy, and have bright displays.

“Robert(ECP): ...but the superstore ones possibly not, they are not the right environment, they are too noisy, they are too busy. They are in busy shopping malls which is probably not the right environment for autistic patients.”

The ECPs mentioned the difficulty with using drops. Unlike the dyads this did not emerge as a subcategory but as one of the codes that developed the axial code *hypersensitivity*. The ECPs commended that if the child has to have drops this is much worse due to the instant sensory impact.

“Beth(ECP): they have this massive sensory thing, their eyes are stinging like mad and then you’ve made them really blurred and it’s a different place again.”

Beth(ECP) uses the phrase ‘a different place again’ in the context that the drops make everything blurry and given the difficulty that children with ASD have processing their environment, the blurring from the drops means that they have to start again. This backs up the children’s comments about the dislike of the blurring rather than the stinging effect that typically developing children complain of.

*Communication impairment* was identified by the ECPs. In order to determine responses to tests and take an accurate symptoms and history, good communication pathways are essential. Children with an ASD will have difficulty expressing what they see and how they feel. Therefore alternative communication techniques may be helpful.

“Robert(ECP): um I started using PECS because the first patients I saw use PECS but I don’t use that very often. Nowadays a lot of the patients I see

seem to have their own communication rather than that but it is still there we need it.”

*Social interaction impairment* was discussed by all the ECPs. One made the point that if the child feels equal to the practitioner then they feel more comfortable and interaction is facilitated.

“Robert(ECP): I like to keep patients on eye level as well. Whether they are on the spectrum or not I put my chair down or get some equality there, get some power balance with them, a bit of control in that respect.”

The ECPs also recommended that the child has choice in the process as this way they feel that they are getting their own way and are more likely to be co-operative. The importance of involving the patient at all stages was mentioned in terms of rapport building and also because the ECPs feel that the children tend to respond better if they are spoken to directly and via their carer. This includes giving them choices as well as making them the centre of the conversation. If the child feels that they have no choice and do not have an understanding of the process they will have a more difficult experience. This finding links strongly with the PC comments about the child needing to be *centre of attention*. It is also in line with the subcategory *adaptations* that is presented later in the category *facilitators to eye-care*.

“Robert(ECP): If I want to talk to mum then I ask them if it’s alright if we talk about them, you don’t mind if I ask some questions things like that.”

“Robert(ECP): I make a point of saying I’m going to turn the lights off and point to the light switch and put my finger on the light switch before turning the lights out. Let them know where it is, um, ask them if they want to turn the lights out give them a mandate for right you are in control turn the light going on or off and things like that.”

Further examples of allowing the child choice and therefore a feeling of control were given by Susan(ECP):

“Susan(ECP): I always give them the choice ok most children choose the pictures but there are some children that choose the letters. But I always like them to make that choice.”

“Susan(ECP): so I might ask mum beforehand or I might take the child in and ask them which room do you like best? and give them the choice because we’ve got another room that has bare walls.”

Another axial code that emerged was *dislike of change*, the ECPs identified change as an issue in the provision of care

“Beth(ECP): one child and it had all gone fine and they took pictures of me and I promised to wear the same clothes that day and have my hair up the same way and we had all this how it was going to be and on the day the child’s notes just went into the general box and another doctor picked them up so it was all just.”

The ECPs accounted for this by the difficulty for children with ASD processing their surroundings especially when the environment is new, changed or busy and there are multiple sensory sources.

“Beth(ECP): and if you fast forward that to coming to a clinic or even to an optician, this is a new environment you don’t know what anything thing is. You have to explore what every single thing in that room, and that room is full of equipment as they tend to be, different sounds, different smells, different people it becomes such an ordeal to just even walk into the opticians let alone have a test, have the lights turned out, have some things shone in your eye, have a silly pair of glasses put on, have things made blurry and then less blurry with lenses, the whole thing is just too much.”

*Waiting* also emerged as an axial code. The ECPs also mentioned the disruptive influence on the process that waiting has. This code emerged in all participant groups.

“David(ECP): Because if you keep a child waiting for 3 hours in a busy waiting room noisy cluttered visually noisy as well then you are not necessarily going to get the best results.”

The ECPs also mentioned that *mood swings* can be a problem and therefore the outcome can be affected by what sets their mood on that day, perhaps on the

activity just before the appointment. For children with ASD these swings can be extreme.

“David(ECP): Although that again changes from day to day I would imagine depends on mood it depends on other stimuli prior to the examination.”

The ECPs also commented that the children tend to have *poor concentration* compared with typically developing children. They indicate that greater success resulted from minimising the distractions. They suggested that children with ASD are likely to do better in rooms with minimal equipment and distractions. This is in contrast to the findings that the children enjoy the tests on the gadgets. This love of computers might be an explanation as to why they are such a distraction. One ECP brings into the room equipment as and when it is required to minimise this distraction.

“Robert(ECP): we’ve got no clinical equipment in there, we don’t keep a slit lamp in there or anything like that.”

“Robert(ECP): If I need to go and get something I’ll go and get it and I’ll bring it in.”

One professional uses a plain chair for the patient rather than the conventional black chair.

“Robert(ECP): I know [colleagues] still have testing chairs in their rooms um but I find that I wasn’t really using the testing chair for anything apart from swinging and going up and down.”

*Practitioner awareness* is another subcategory that emerged from the ECPs. They all mentioned the lack of awareness of ASD in ECPs generally.

“Beth(ECP): I think we need to do more work on everyone having an awareness on how they can assess a child with LD be it autism, be it anything else um and I think for me that is the key and then it can be adapted.”

“Beth(ECP): I think we inflict the same eye care experience on them, I don’t think what we adapt or test in clinic appropriately.”

The ECPs mentioned that they had come across carers who have lost trust in professionals as they have been let down by service providers generally. For example the battle to get their child diagnosed and the lack of support after diagnosis, also perhaps through the school system to get their child the support and understanding they need to succeed at school. Therefore gaining the trust of carers and meeting their expectations can be difficult.

“Beth(ECP): when they do come to clinic it’s a horrendous experience and the parents don’t want to come back and I understand totally why that is.”

“Robert(ECP): I’d rather you held your hands up and said ‘no I can’t do a good job’ than basically screw it up for the future, it’s that long term patient relationship, especially applies to the autistic ones.”

This overlaps a subcategory, *need for eye-care*, which emerged from the category *Importance of eye-care*. This is discussed in Appendix 6iv. Practitioners need to understand why children with an ASD are just as in need of assessment as typically developing children. Poor service may therefore be due to practitioners failing to follow symptoms and signs because they feel that the child will not benefit from treatment or not promoting the need for eye-care to gatekeeper.

David(ECP) recounts a situation where a child with suspected retinal detachment was almost refused treatment because the specialist questioned why you would treat a severely autistic boy with learning disabilities. The treatment went ahead and during the assessment it was discovered that he had bilateral detachments. This means that a possible outcome of not treating is blindness in both eyes.

The ECPs commented that the lack of awareness of practitioners caused the children to be treated the same as typically developing children due to the lack of outward appearance of disability. This was something mentioned by PCs and also demonstrated by some of the children.

“Susan(ECP): one of the difficulties that children with autism face is that they look like typical children, whereas if you take a child with Down’s syndrome, they look like a child with special needs.”

“Beth(ECP): I think we inflict the same eye care experience on them, I don’t think what we adapt or test in clinic appropriately.”

The ECPs agreed with the PCs that training is needed in order to adapt the eye-care appropriately.

“Beth(ECP): I think we need to do more work on everyone having an awareness on how they can assess a child with LD be it autism be it anything else um and I think for me that is the key and then it can be adapted.”

Finally the ECPs felt that another barrier to a good experience is the lack awareness of ECPs regarding the parental stress suffered by the carers and the need to take this into consideration. In particular an understanding that PCs are anxious about the potential for breakages and triggering of challenging behaviour which can be detected by the child and cause the child to become anxious.

“Robert(ECP): in that practice has a lot of expensive equipment that could get broken and then [they will think] I’ll be liable for it.”

### **3.5.2 Facilitators to eye-care**

Facilitators to eye-care are in often shown by the ECPs to be the reverse of the barriers. However the findings presented here show that there are positive steps that can be taken to improve the experience in addition to avoiding the barriers mentioned in the previous section.

The subcategory *adaptations* represents the changes to the service made by ECPs to improve accessibility of the service for children with ASD. On a more practical level the ECPs shared their views on techniques that have been facilitators of eye-care in their own clinics.

Most ECPs use a letter chart or picture chart to measure vision. One of the ECPs pointed out that real targets are better than pictures or letters because they are in the correct perspective and therefore less confusing to a child with ASD who thinks

in a concrete way. The code appropriate tests was used referring to the need for tests that are meaningful for these children.

“Beth(ECP): the pictures we use are fine but for autistic children the pictures are 2D representations of 3D objects.

LS: yes

Beth(ECP): and the size is all wrong and the duck is the same size as the house is the same size as the apple. That can throw an autistic child.”

There was a preference amongst the ECPs for *objective tests* such as Retinoscopy (“ret”)[see glossary]. These give useful clinical information without the need for the child to process the task or respond. The ECPs felt skills were lacking in this area for most optometrists but if the optometrist has these skills the experience would be better.

“Susan(ECP): Um I think that in order to see children you need to be very, very, confident at Retinoscopy.”

“David(ECP): Um other things like dynamic ret. I’d say 95% of optometrists out there if you looked at their records or asked them to demonstrate dynamic ret to me they would say no can’t.”

*The drops* was a subcategory in the findings from the child participants but in addition to the child findings the ECPs suggested potential adaptations to help. Beth(ECP) suggested that drops could be given to the PCs to put into the child’s eyes before they come in. This cuts out the association that the child makes of the drops with the ECP, and reduces the time spent waiting around in the clinic.

“Beth(ECP): the parents put the drops in at home because the drops take 45 minutes to work and that is a long time to wait in the waiting room particularly when they don’t necessarily understand that you are not going to put drops in again.”

Most of the ECPs used *Indirect ophthalmoscopy*. This gives a wide view of the retina relatively quickly compared with standard tests and without the need for very close proximity which can be distressing for the child.

“Susan(ECP): I have access to a head set so I do sometimes but the best one I find is a monocular indirect because it keep you [indicates distance].

LS: you aren't touching are you?

Susan(ECP): no, you are that far away from the child and because you've got a wider field of view, it's easier if their eyes aren't still.”

The use of computers and gadgets had emerged strongly from the childrens data and this was discussed with the ECPS. Most of the ECPs supported the idea of the use of technology but one that tended to prefer to avoid gadgets when possible. There was general agreement that, whilst large pieces of equipment might make the child feel restricted, that there are some patients that do better with them. This is because they are more exciting and they may help to limit the need for eye contact. They may even replace equipment that would rest on their skin such as the trial frame.

“David(ECP): so machines sometimes work better it depends on the individual. Sometimes the machine and being trapped behind the machine anyway but sometimes losing the human contact I find quite helpful.”

“David(ECP): I use a phoropter [see glossary] all the time on most kids anyway but using a phoropter is, they're a robot they're behind the thing with the knobs and gadgets being fiddled and that's easier to use than a trial frame where you have got touch involved and you know sliding things in and out a lot of kids don't like that.”

The ECPs felt that to reduce anxiety of the children they needed to adapt their routine and approach such as allowing the child the opportunity to touch the equipment first so that they were less anxious about it. Children with ASD seem to be more comfortable with tests if they are familiar with them and this group of professionals all recommended allowing them time to touch and explore the equipment.

“David(ECP): so do I make adaptations? I may move some of the equipment out and further back [to] give people more space. Um I will allow children to fiddle um let them touch.”

“Beth(ECP): so maybe they just need to just explore the instrument, feel it touch it.”

Another adaptation that the ECPs recommended was the use of acclimatisation visits to reduce anxiety. All the ECPs agreed that acclimatisation visits are very helpful preparation tools for children with an ASD. These help set the expectation of PC and child as well as enable the child to get used to the clinic gradually. The ideal is for them to meet their practitioner, look at and touch equipment.

“David(ECP): people with autism, once they are desensitised to an environment they will probably feel more comfortable and are able to respond better.”

“Robert(ECP): um I’ve seen patients that I’ve seen perhaps 4 or 5 times in a week, and we won’t even touch them, the idea is to get them used to coming in, getting them into the test room.”

These included strategies such as flexibility, creativity, giving choice and selecting directly relevant tests only to limit the burden for the child.

“Beth(ECP): It’s, it’s, it’s, trial and error you need a great deal of patience of the parents actually on behalf of the child to give you the chance to try and get it right but not going to get it right first time.”

An example of creative adaptation to the examination given by one ECP was a ‘count down’ technique. He tells the child the test will finish at the end of a count down from 10. He finds that this can be built up over several visits until full tests are possible. The idea is built around the need for people with ASD to have structure and explanation in order for them to process what they need to do.

“Robert(ECP): I use counting down so someone knows where they are. I make a point of signposting.”

Another ECP explained that nothing she does is different, it is just that she has a wide range of techniques to choose from so that she can adapt to that child’s needs.

“Susan(ECP): But as regards the tests I use, they are exactly the same as I do for everyone else but then I have a very, very, adaptable routine anyway. Different ways of doing things appropriate to the child.”

Observation of functional vision was mentioned as a key adaptation by all the ECPs. This can be used to estimate what the child can see and also how they use their eyes together or their ability to locate objects in space.

The use of functional vision assessment tools (SeeAbility, 2012) or observation was discussed as a way of limiting the number of clinical tests required. If it can be demonstrated that a child has good vision functionally then it is not justified to measure in the conventional way as well

“Robert(ECP): I’m at that stage that if I can tell by observation, I don’t need to measure it. Why put someone through clinical tests when I already know the answer is going to be?”

Another of these strategies was *person-centred approach*. The ECPs pointed out that each child is different and that with enough information the service could be planned in a person centred way. They recommended a person-centred service that is based on, adapted and funded according to the needs of the individual.

“Beth(ECP): it’s so individual, what is very very exhausting as a health professional, let alone the patient I suppose, is that you can get it cracked for one patient and then the next child comes in and it’s a whole different.”

Several of the ECPs made the point that one important skill is to know when to stop. This strategy of *knowing when to stop* depends on the ECP understanding when does ‘no’ really mean ‘no’ and when is pursuing a test not in the child’s best interest. The ECP should have the confidence to know that sometimes it’s just not possible. It may be better for the patient to choose when they want to stop and leave, even if that is before all tests are completed. Several short appointments rather than one long traumatic visit are probably in the child’s best interest. This is a balancing act between what is in the child’s best interest regarding their health and the distress caused by continuing. This strategy tends not to be applied when testing typically developing children, instead the ECP usually tries to complete all tests to avoid the child having to come back for a test that they may worry about.

“Robert(ECP): they decide when they are ready to go, if they are ready to go, you might not have finished but if they are ready to go and you force the issue then they are not going to come back

LS: yep

Robert(ECP): so call it a day early and say right we’ll see you again sooner, I’ll make a clinical decision on that, we’ve done enough, we’ve done all that you will let me.”

Another strategy used by most of the ECPs was that of adapting the appointment length so that it is flexible for the child’s needs. All the practitioners recommended breaking the assessment into small enough sections to help the child cope. If necessary breaking the test into several visits to achieve this.

“Beth(ECP): knowing we might not get it all but that’s ok. You know it’s like the British cycling team, lots of little 1%’s.”

The axial code *Practitioner personality* was identified as a key to the success of an eye examination. Some ECPS are just not very good working with people with special needs. One ECP explained how he has adapted with time for this group.

“David(ECP): hey the first time I started seeing people with LD I was terrified I didn’t have a clue how to behave and I come from totally the opposite end of the social spectrum in terms of how tactile I am compared to [optom]. [she] will give everybody a hug, she will touch people. I’m anglo-saxon stiff upper lip.... I’ve got used to it and now it’s just becoming more comfortable if somebody wants to touch you, grab my hair, pull my glasses off, do that sort of stuff um that’s fine. Its breaking down that sort of I’m the professional I’m in a suit and this is how I behave.”

This finding is in keeping with the comments of the PCs that some ECPs are better with children with ASD because of their approach. However if practitioners are to get it right then they need to listen to those using the service. The axial code *listen to carers* appeared in the PC data and here one of the ECPs refers to this as a way of ensuring the practitioner approach is appropriate

“Beth(ECP): there’s no magic booklet that tells you what to do with every child, so I think there just needs to be some training, some feedback we need to encourage parents to say to us this works and this doesn’t work.”

*Preparation* is a key axial code under the subcategory of *adaptations*. To an extent it underlies much of the findings already presented but here it is being used to represent the process of preparation on which adaptations can be based. One of the codes from which this emerged was *setting expectations*. This includes use adaptations to the eye-care routine such as explaining tests, likely outcomes and expectations of the child in simple clear terms before the test starts. Setting boundaries and steps of each intervention, how, what, why, how long and how it will feel is important so that the situation can be processed by the child. This enables the child to feel involved and in control of what happens to them.

“Robert(ECP): yes if someone’s anxious then I’ll explain I’m just going to ask you a few questions, have a have a quick look at what you can see at the moment and should they need a pair of specs give them a certain agenda of where they are so that they have a feel for that.”

“Robert(ECP): So he knows that there is a finite limit to what we are actually doing, again it’s timed so he knows where he is, he put up with something because he knows when it’s gonna finish.”

The ECPs also mentioned the importance of accuracy whilst setting expectations. The expectations of the child may be influenced if a practice has the appearance of a shop but it’s activities are not like a shop, which means that the child has to deal with a different situation and process what that means. One of the ECPs picks up this point:

“David(ECP): in a supermarket you wouldn’t you pick up what you want pay your money and don’t have to say a word to anyone. So human interaction is limited. When you go into an optometric practice you are grilled by the receptionist if only to tick boxes on the NHS form when did they last have their eyes tested, what’s your date of birth, what’s your exemption? All these sorts of things. So you’ve got interaction from the moment you get in through the door. And you are then taken into a dark room or taken into a light room

and somebody turns the lights off, while it's off gets very close to you and invades your personal space etc etc.”

One ECP raised the concern that some patients were deliberately obstructive in order to make the point that all services should be adapted for everyone. In a busy clinic it is not viable to make the services fully accessible all of the time and therefore advance information is extremely helpful and enables the practice to provide for everyone. This led to the code *pre-test information* which was used to prepare the routine. This is linked strongly with the findings from the dyads that communication is essential in order to provide an appropriate service.

“David(ECP): One of the barriers to care is people not being very free with information and ..... challenge systems by turning up saying so I've got a disability so cope with it, deal with it, get on with it and whilst I don't get that as much with people with LD it certainly happens with wheelchair users sometimes and you get the occasional person whereas we could facilitate a visit if we were informed beforehand.”

Several of the ECPs use some form of pre-test questionnaire or have relevant questions asked by the reception team or reports from other practitioners to give them information in advance.

“LS: do you use the pre-test questionnaire that Seeability have or do you think it's a good idea?

David(ECP): I think it's a good idea and um I think of these things are a good idea if, the more advance information we can get the better.”

“Beth(ECP): I have letters from the school not the school, from the paediatricians with the general background but what is useful to know is what sort of vision test it's worth me trying so if you have only got 3 minutes of the child's attention, you need to start with the vision test that is most likely to get you a result.”

The advance information enables the practitioner to prepare and also to inform the carers how to prepare their child. This combination would hopefully facilitate the best outcome. PCs can help by discussing possible triggers. The ECP can advise as to exercises at home that might familiarise the child with particularly challenging tasks.

“David(ECP): And whilst it may not be possible to desensitise somebody with or on the ASD it may be and so if for instance somebody doesn’t like individuals invading their personal space give us an indication of how close we can get, can that be broken down a little bit by playing games in advance with a pen torch for instance.”

“Beth(ECP): when I worked in [region] they had a ‘when you bring your autistic child to hospital’ check-sheet that they would go through, it’s very generic to coming to a hospital, it’s not coming to an eye clinic but with very helpful information for us.”

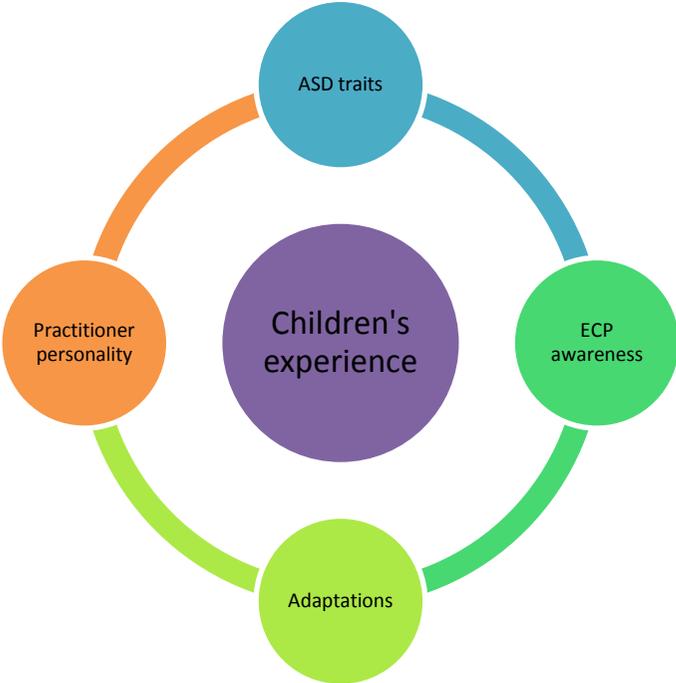
Generally the ECPs felt that they were at a disadvantage because they do not have access to information in advance and therefore did not have the opportunity to prepare. *Preparation* is very difficult for ECPs as often, unlike hospital optometrists, they have no information in advance of the examination on which to plan the approach. PCs are often either reluctant or unaware of the information that is needed in advance of the appointment to enable preparation on both sides.

“David(ECP): sadly the system doesn’t work that well even where there is a formal pathway, and not specifically for people with autism alone but with additional learning disabilities. We’ve got a pathway set up in [location] for instance and probably only 30% of people would fill in a pre-exam questionnaire.”

### **3.5.3 Overarching category from the ECP : awareness**

The overarching category to emerge was *Awareness*. Awareness of the needs and disabilities of children with an ASD, and promoting awareness of eye-care with PCs and ECPs. In addition, ECPs need to be aware of how to make adaptations to the service design and train staff in order to facilitate a good experience of primary eye-care. The experience of children can vary considerably based on the awareness of those commissioning the service, those providing the service, and those that are arranging their appointments. Figure 22 shows the child’s experience grounded in data from the ECPs.

**Figure 22: The experience of eye-care grounded in data from ECPs**



### **3.5.4 Summary**

This chapter has presented the findings from this research. The voice of the children is set in the context of the eye-care process. The combined findings of the dyads and also the findings from the ECPs regarding the eye-care experience are shown and analysed.

The next chapter will show how these findings were used to develop theory grounded in the data from the participants.

## **Chapter 4 Theory Development**

The previous chapter presented the findings of the research. In keeping with grounded theory this data was integrated to develop a theory of primary eye-care grounded in the experiences of the children. This chapter presents the development of the theory. The theory will be presented in Chapter 5.

### **4.1 Theory and symbolic interactionism**

Symbolic Interaction is the theory that people behave in a certain way in reaction to the actions of others, and depending on the context (Corbin and Strauss, 2008). In order to understand someone's behaviour you need to understand the 'rules of the game'. A person's culture and experience, standing in society, gender and age, all might influence how they interpret situations and in turn how they might respond to a situation and the actions of others. To generate theory from this research the findings from the children's data and that of the context and process have been integrated to investigate what enables the child to react positively and what causes them to react negatively in the eye-care situation.

People with an ASD are known to have impairment of their social imagination, social interaction and also communication (Wing, 1996). This causes them to have difficulty understanding other people's intentions, actions and emotions. They are unable to adapt to other people's expectations because they do not understand what is expected. Under particular circumstances this can be even more noticeable, for instance if there are sensory distractions such as lights flickering, or people talking around them, when information is implied by body language or figurative speech, then they quickly become confused and stressed. This affects them in many situations where interaction is required including primary eye-care. It affects how they interpret a situation and then how they respond is unlikely to be how people without an ASD would expect them to respond.

In an eye examination interaction occurs throughout. The process of an eye examination involves the patient going into a place that typically looks like a shop but is not, talking to receptionists, waiting in a waiting room, direct one-to-one interaction with a professional who asks lots of questions and gives lots of instructions, then undergoing tests with equipment that increase the sensory load,

whilst sitting in a small darkened room. This was illustrated by Steve (C) Figure 18 when he was asked to arrange the visual prompt cards into an order that might represent his eye examination. The long string of activities illustrates the range, length and diversity of what is expected in an eye examination, in effect a chain of interactions.

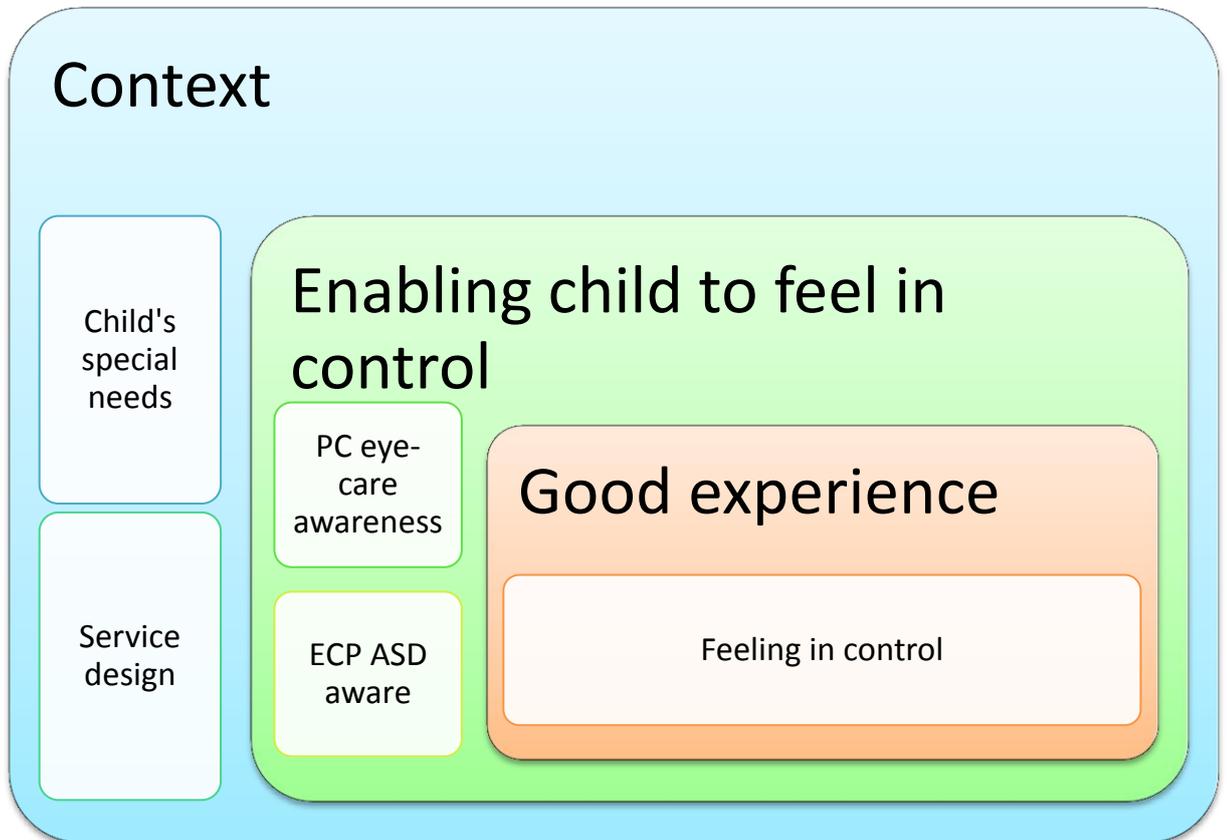
This process is carried out in a time limited appointment slot. The child with an ASD may appear to an ECP who is unaware of their diagnosis to be just like a child who does not have an ASD. The demands can be overwhelming for a child if the ECP assumes that the child knows what is expected in the process and does not modify their routine to allow for the child's special needs. The child may appear aloof or rude which can result in the ECP responding negatively towards the child. It is easy to see how a deteriorating spiral can develop. As the child cannot easily communicate, and may not interpret the situation correctly they may be anxious, stressed and overwhelmed by the primary eye-care process.

## **4.2 Integration of the findings**

Theory was developed using the data from the children regarding their experience and setting it within the context and process which was developed using data from the PCs and ECPs. The literature was used to compare with emerging categories and to gain an understanding of current good practice guidelines.

Chapter 3 presented the overarching categories that emerged. The over-arching category was *feeling in control*. The children's experience was positive when they felt in control. The overarching categories that emerged from the PCs and ECPs was *awareness*. The theory represents the overarching category grounded in the experiences of the children and how that is impacted upon by the overarching category from the PCs and ECPs (the process and context). Figure 23 shows the interconnection between the findings from all participants. The context depends on the *awareness* of the ECP and PC. The awareness (or lack of awareness) influences the service design, the skill set of the ECP, the practice setting, adaptations made for individual's special needs (cognitive abilities, likes, dislikes, phobias and fears, hypersensitivities and severity of ASD), the child's access to eye-care, the preparations made for the experience and the expectations set. Theory emerged from the relationship between these findings.

**Figure 23: Diagram to show the key findings from all participants**

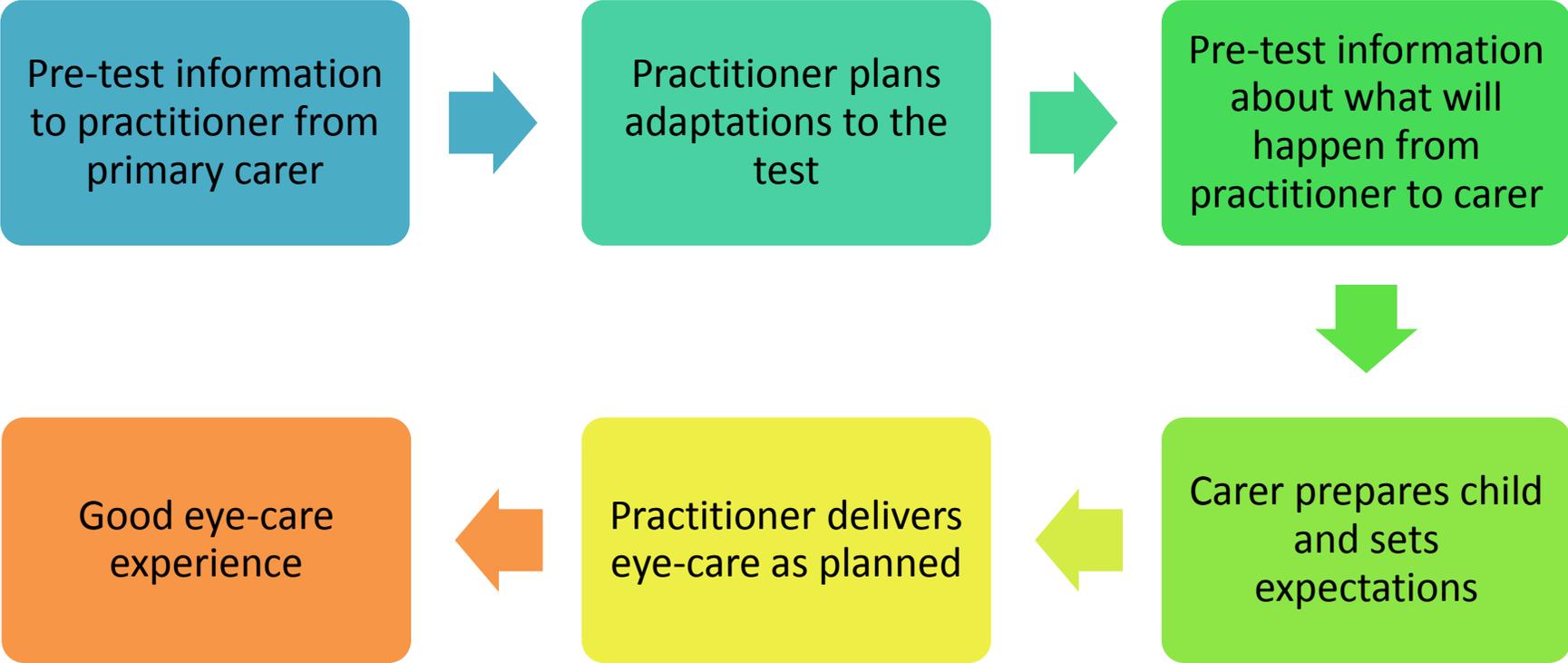


### 4.3 Theory and context

Figure 23 shows the link between context and the experiences reported by the children. The child's access to eye-care is via the PC, and the decisions of the PC are based on their *awareness* of how to prepare their child and how to choose an appropriate practice. The child's experience in the practice depends on the *awareness* and skill set of the ECP and the communication between the PC and ECP. This relationship can be used effectively to enable the child to *feel in control* of the situation. If the child feels in control then the experience is improved.

As one ECP put it, there is no 'magic wand' or prescription to make the experience good for children with an ASD, but there are steps that can be taken to adapt the routine to make it more acceptable. Figure 24 illustrates how the awareness of PCs and ECPs and the relationship between them can facilitate a good experience of primary eye-care for the child. This depends on education of PCs to enable them to access the most appropriate practice for their child, on the PC and ECP communicating the needs of the child and the information that will enable the PC to prepare their child, and finally on the ECP adapting the test to the child's special needs.

Figure 24: The impact of ECP and PC input to eye-care



## **4.4 The theory of primary eye-care grounded in the views of children with an ASD.**

This section presents the theory that has emerged from this research grounded in the views of children with an ASD. It shows that the experience of primary eye-care depends on how *in control* of the process that the child feels. Theory was developed based on the overarching category and the perspective of symbolic interactionism. A person will respond to an interaction based on what they know of the situation, what meanings they attach to the situation and the context in which it is set. In primary eye-care this is a three way process involving the interaction between child, ECP and PC. Children with an ASD may not attach the typical meanings or have the typical understanding or expectation of a situation, their response is likely to be different to that expected by ECPs and PCs. The eye-care process detailed in section 3.2.4 which shows that it is a series of interactions, and therefore a series of stages that may be challenging to children with ASD.

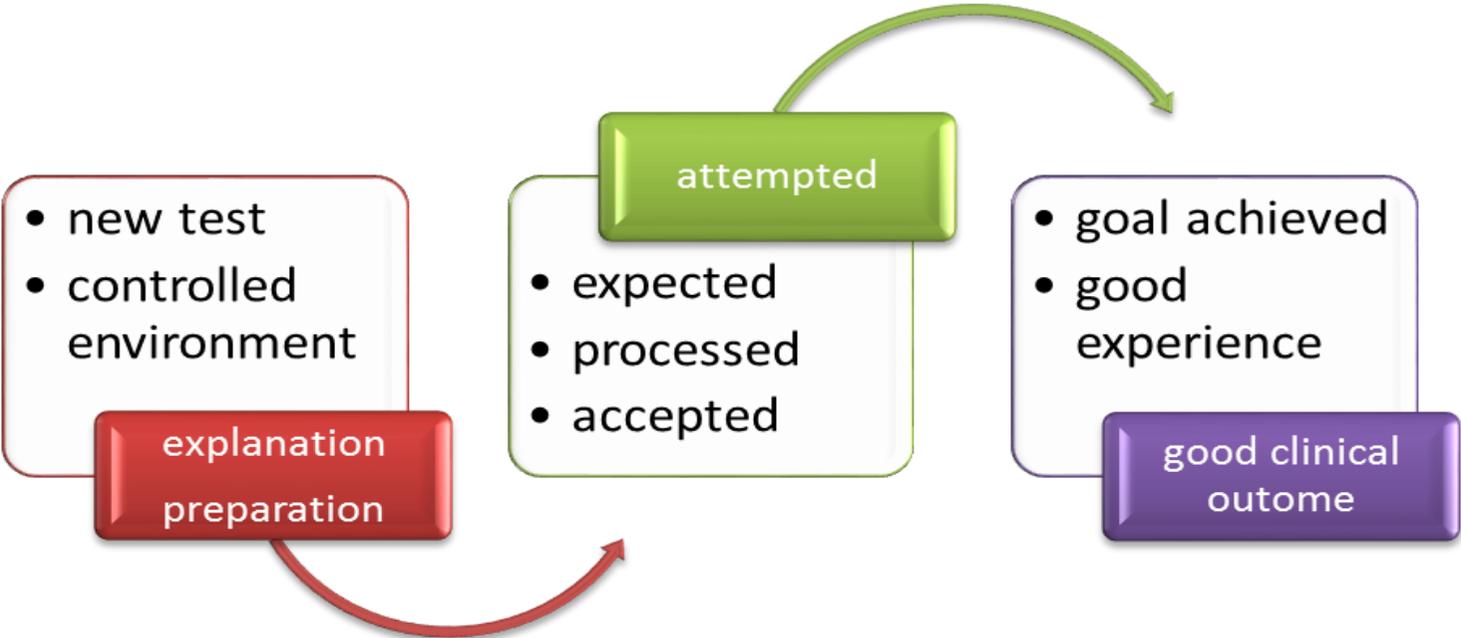
### ***4.4.1 Theory of a positive experience of primary eye-care***

An accessible service appears to be one where the child is enabled to *feel in control*. This is achieved where the ECP is ASD aware, PCs are educated in eye-care and informed and the child's special needs are known and accounted for in a person-centred way. This involves outreach, support and education for PCs; multi-disciplinary, flexible and adapted approach from the ECPs which is proactive rather than reactive.

The theory of positive primary eye-care is illustrated in Figure 25. Grounded in the data from children with ASD, the process for a positive experience would be: A need for eye examination identified by the PC. The PC is provided with information and support in locating a suitably trained ECP. The PC contacts the ECP to arrange an appointment. At the initial contact they discuss with the ECP the child's special needs. The ECP informs the PC as accurately as possible of what is going to happen so that the PC can prepare their child. An appointment is made that will limit the risk of having to wait in the waiting room. The ECP adapts their approach for the child's special needs (including communication methods, triggers, hypersensitivities and cognitive function). The child attends for their appointment. The ECP explains step by step and with alternative methods of communication where needed, what is expected of them and what each piece of equipment is. The ECP gives them time to

process and respond, the child is given the opportunity to touch and explore the equipment before it is used. The tests are attempted, follow up appointments are arranged when needed and expectations set of what will happen at these appointments. Continuity is kept in terms of the consulting room and ECP. The outcome is that the child feels less challenged, anxious and overwhelmed and therefore *feels in control*. This child's expectations, fears and uncertainties are accounted for in a person-centred way. The resulting experience is positive.

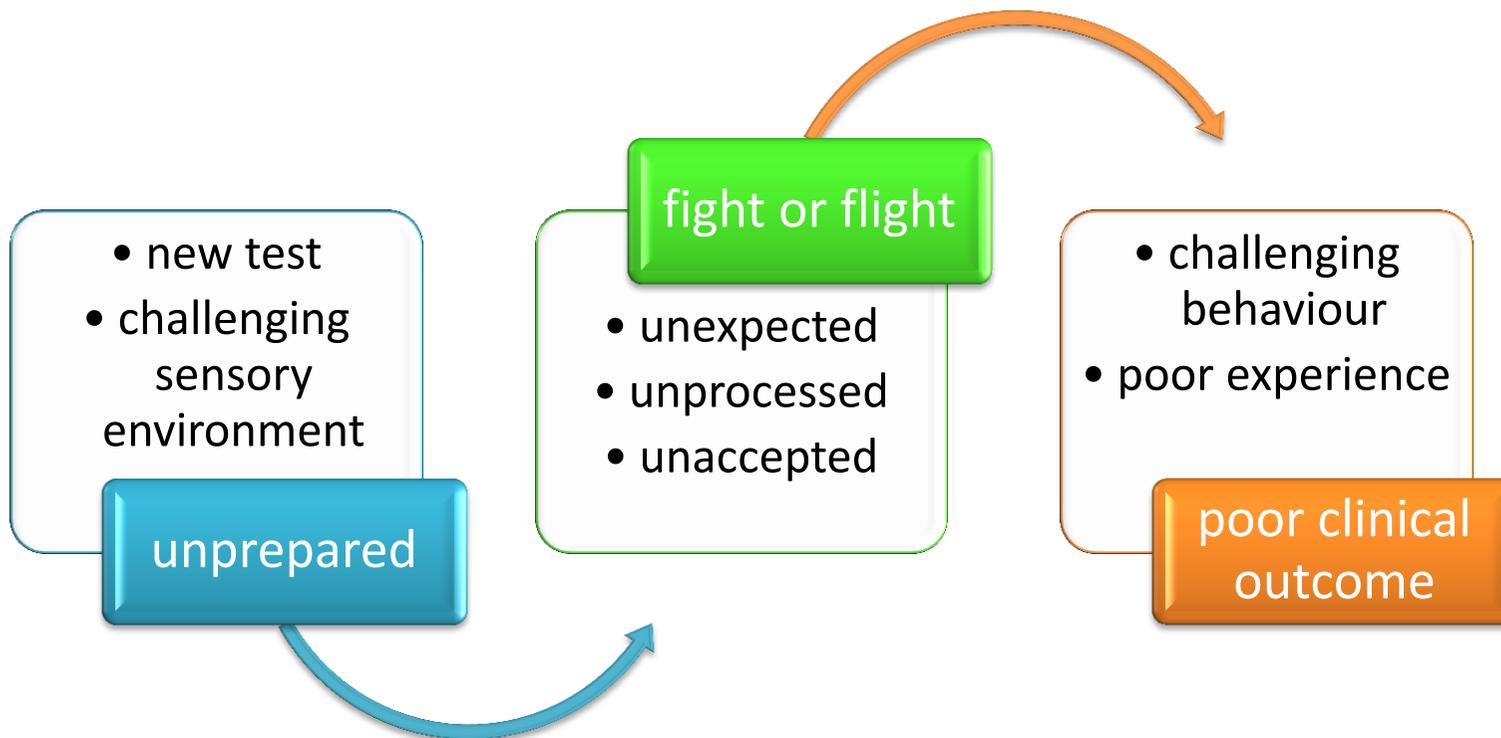
Figure 25: Theory of positive eye-care experience



#### ***4.4.2 Theory of a negative experience of primary eye-care***

Conversely the theory of negative primary eye-care experience is illustrated in Figure 26. This shows the pathway that causes the child to report a poor experience grounded in the data from this research. The PC identifies a need for eye-care. They book an appointment at an optometry practice based on locality and cost. The ECP has no awareness of ASD. The PC does not give any information about their child's special needs before the appointment. The ECP may be running late and the child has to wait in the waiting room. The ECP assumes that the child is typically developing as they do not appear to have a disability. The ECP asks questions, gives instructions verbally with no visual supports. The appointment is time limited and therefore the ECP expects fast responses from the child. The child cannot process this and becomes anxious, confused or frightened. The ECP puts equipment on the child's nose and ears and uses bright lights to examine the eyes. There maybe distractions in the background such as an instrument that is switched on that emits an electrical hum, or maybe the ECP has used sterile wipes to disinfect chin rests or trial frames and so there is a chemical smell. The child is overwhelmed and experiences the fight or flight reaction to fear. The child does not interact in the way expected. The child does not attempt the tests and the ECP does not know why and interprets this as the child being naughty. The child displays challenging behaviour or 'shuts down' and does not co-operate. The child's expectations, fears and uncertainties are not accounted for in a person-centred way. This results in a negative primary eye-care experience

Figure 26: Theory of negative eye-care experience



### **4.4.3 Summary**

The experience of primary eye-care for children with ASD depends on how in control they feel. The eye-care process is a string of interactions and therefore in order for the experience to be a positive one the providers of the service need to be aware of how to facilitate this. The interactions between all three stakeholders in the process are the key to its success. The next chapter will discuss the findings and emerging theory and how this relates to current knowledge and practice.

## **Chapter 5 Discussion**

Chapter 4 has presented the emerging theory of the experience of primary eye-care for children with ASD. This chapter will discuss theory, current practice and knowledge. It further develops the connection between the child's experience and the context within which it is set in order to illustrate the emerging theory.

### **5.1 The experience of primary eye-care for children with ASD.**

It can be seen from this research that the experience of primary eye-care for children with ASD is influenced by many factors. This section discusses these in relation to the experience and the theory that has emerged.

#### ***5.1.1 Current service structure***

The current service structure is set around the GOS eye-care contract. The literature shows that optometrists must carry out a set range of tests in order to claim a fee for their work (Opticians Act, 1989). The ECPs indicated that as the fee is low the optometrist needs to limit the time taken with each patient in order for the service to be viable. The findings of this research and the literature (Turner *et al.*, 2013; The National Autistic Society, 2012a; The College of Optometrists, 2014) indicate that the children benefit from having longer to process information, or may require several visits in order to cope with the full range of tests required for the ECP to claim a fee. This means that the ECP struggles to adapt the eye examination and maintain its financial viability. The requirements of the children do not appear to be compatible with the current GOS eye-care provision and therefore service provision and funding needs to be reviewed in order to provide these adaptations.

#### ***5.1.2 Adaptations to the test***

The children found the examination challenging when adaptations were not made and when ECPs were not aware of their needs. The tests that they disliked were different for each individual but there were some challenges that were in common. They found unfamiliar equipment frightening, they disliked equipment that caused a

sensory overload such as blurring, dazzle or contact with skin. They also disliked change in the routine which caused them to have to reprocess the situation.

It has been shown that each child is unique and therefore adaptations need to be person-centred. This means that each child's specific special needs are accounted for, and therefore the child feels comfortable. The literature strongly supports this (Dymond *et al* 2007; The College of Optometrist, 2014). Unfortunately the structure of the NHS eye-care does not easily support the flexibility that this would require.

The PCs are likely to have developed a range of strategies that they know are successful for their children such as diverting them to another activity if they are becoming distressed. If ECPs can liaise with carers to discover these strategies then this will improve the experience for the child, and for the ECP. The literature supports this need to listen to carers (Carbone *et al* 2010; National Institute of Clinical Excellence, 2013). Many of the PCs use calming strategies for their children when they become overwhelmed and two of the ECPs mentioned the need to factor these into services. One ECP has a 'count down' technique to facilitate test procedures and another commented on the need for a quiet time out area for children with ASD. The use of calming strategies such as 'low and slow' (Bolick, 2004) are mentioned in the literature and are applicable in teaching and healthcare settings.

However taking into account the general traits of ASD, some simple general adaptations and policies can make a significant difference to the experience of any child with ASD. It is important to note here that these adaptations would not have a detrimental effect on other service users. These include minimising the use of equipment that contacts the skin or uses bright lights or causes blurring, giving clear explanation with no element of surprise, and once expectations are set they should be met.

To make the child centre of attention and include them in the decision making process enables them to feel they are part of the process and that they genuinely have choice. Specifically, ECPs should, wherever possible, talk to the child rather than to the PC. There is no specific mention in the literature of the importance of making the child centre of attention, however the current guidelines do recommend that the child is addressed directly and communication is appropriate for the individual (The College of Optometrists, 2014; Coulter, 2013). The children have

difficulty processing situations and therefore building rapport, ensuring familiar surrounding and setting expectations are all extremely important.

Notbohm highlights the importance of giving time and space to process information (Notbohm, 2004) and there is advice regarding the use of visual supports to enable communication on the National Autistic Society website. It is clear from this research that preparation can reduce the anxiety of the children significantly and eye-care awareness training for primary carers as well as ASD awareness training for ECPs seems to be the key to this. The literature shows that there is a significant lack of training and awareness for professionals planning, running and commissioning services (National Audit Office, 2009; National Institute of Clinical Excellence, 2013) and a need to fund this appropriately (Dymond et al, 2007). It is notable that whilst there is eye-care information on the National Autistic Society website none of the PCs in this research had accessed it.

The following adaptations to the practice would facilitate a good experience : collecting information about the child's needs in advance, allowing short frequent appointments or longer appointments depending on the individual to allow for acclimatisation and processing, minimising distractions particularly background sensory stimuli such as equipment buzzing and clinical smells. The sensory overload of general clinical environments was highlighted by the literature (Morton-Cooper, 2004; Lajonchere *et al* 2012; Stein *et al* 2012) However the data from the ECPs in this research show that this is difficult to achieve in the current eye-care setting.

### **5.1.3 Team work**

The data show that the PCs have an extremely important role to play in facilitating their child's eye examination. ASD is a spectrum and whilst the above section sets out 'rules of thumb' for adaptations, each child is different and the service can only be person-centred if the ECP knows about each child's special needs.

PCs or support workers are best placed to provide this information. Communication between them and the ECP is very helpful in advance of the appointment. This communication needs to go both ways to enable the ECP to adapt the service, and to enable the PC to set the correct expectations and prepare the child. The inclusion

of other AHPs as facilitators in some services to fulfil this role has been successful. The literature (National Institute of Clinical Excellence, 2013; Bevan-Brown, 2010; Carbone *et al.*, 2010) highlights the feeling of PCs that generally professionals do not listen to them. In this study this view was expressed by some of the PCs too.

#### **5.1.4 The use of computers and gadgets**

A category that emerged early in the research was the enjoyment of computers and electronic gadgets. The only barrier to using them was the fear of what they did. When a gadget was explained and the child allowed to touch and explore it, all but one child found them a positive element of the eye-care process. This illustrates very well that when fear of the unknown is accounted for and the child empowered then the experience is better. The child feels in control because they understand what will happen and why. The recommendations of Coulter also indicate the need to allow the child time to understand and explore their environment (Coulter, 2013).

Whilst most of the ECPs (who all worked successfully with children with ASD) did not routinely use electronic aids they all mentioned that they offered the child an opportunity to touch and play with equipment first.

The use of computers potentially reduces the need for interaction between the child and ECP therefore the child may feel more comfortable as a result. There may be some concern by PCs that this reduces normalisation and that adapting in this way will impact on their longer term abilities to cope in 'the real world'. There was no reference to the acceptability of computerised equipment and tests in the literature.

#### **5.1.5 ASD traits impact on the experience of eye-care**

The findings given in section 3.3.1 highlight the categories that arise regarding the impact of ASD on the process. The context data given in section 3.2 shows that many aspects of the eye-care process have the potential to be challenging given the range of impairments that a child with ASD might have. The process involves interaction, communication, sensory stimuli and a certain level of assumed knowledge about what is going to happen. Children with ASD view the world differently (Simmons *et al.*, 2009), they find interaction difficult and have limited understanding of what is expected or implied in any situation that they are not

prepared for (Baron-Cohen, 2008). They take longer to process a situation because they find it difficult to see the 'bigger picture' and they pick out details that are not pertinent to the process whilst missing the important points.

The children's reactions to situations that they found challenging were extreme and therefore very disruptive. Most of the children had known 'triggers' and mood swings. This was illustrated by the reactions of the children to the drops and also to the discomfort of the trial frame. The theory of primary eye-care that has emerged suggests that if the child feels in control then their ability to cope is greater. Therefore if strategies are used that avoid the triggers, and when necessary calm the child, it follows that the experience is better.

A subcategory from the children was that of *waiting*. This illustrates the emerging theory very well because the difficulty the child has with waiting is that they do not understand the reason for waiting and therefore quickly become distressed. The feeling of being in control is outweighed by frustration and anxiety.

Waiting is not discussed in any of the literature but minimising waiting is mentioned in the guidelines (The College of Optometrists, 2014; The National Autistic Society, 2012a). One of the ECPs suggested that it might not be as simple as booking the child into the child's preferred time slot as this may not be practical in a clinic setting. Whilst it may not be possible to give complete flexibility on times available but simply informing the carer of the times in the day that waiting is unlikely would result in the child not having to cope with a wait.

"Beth(ECP): we have two selections of appointments the appointment they can either come at 8.30 or 11.30 which I know doesn't seem to be much choice but actually if they come in the middle of the clinic it is really busy. So if they come at 8.30 there are very few people there I get them straight in and out done. If they come at 11.30 again they've not got to queue at reception, there are far fewer people in the waiting room because most people have gone, and then by 11.30 I've usually caught up with myself and I can get them in and out and they are not waiting in the waiting room."

### ***Impairment of communication***

If a person has impairment in communication skills then they have difficulty understanding and being understood (Wing, 1996). They may struggle with instructions and responding to instructions. This causes frustration, anxiety and confusion. In the eye examination the child may need to read letter charts, describe what they are seeing, express opinions and make choices. Children with ASD also have difficulty with commonly used phrases that are not literal and figurative speech and also non verbal communication such as facial expressions and gestures (Notbohm, 2004; Morton-Cooper, 2004). In addition some children with ASD do not develop verbal communication and some that have verbal communication apply different meanings to words and expressions (Wing, 1996).

In order for the child to feel in control there needs to be an agreed method of communication. The ECP needs to be aware of the child's communication impairment and allow for this by giving time to process and respond, and by careful consideration of the demands of each test. Where necessary alternative techniques can be used (The National Autistic Society, 2012b). This is possible if the child communication needs are discussed in advance of the examination.

The following are general adaptations to communication that can help: the use of closed questions but cross checking responses, the use of visual prompts and supports, asking one question at a time and the avoidance of figurative speech.

### ***Impairment of social imagination***

Impairment of social imagination results in difficulty being able to predict what others are thinking or what the intentions of others are (Baron-Cohen, 2008). If an individual has difficulty interpreting the intentions of others and situations they may not know what to expect and may result in them feeling confused and anxious. If they cannot imagine what will happen they may imagine the worst case scenario and therefore they will be frightened or overwhelmed. An example that illustrated this from the research was the fear expressed by some of the children, of some of the larger pieces of equipment. If they were not aware of what a piece of equipment does then they were very anxious. However when they had explanation, and were allowed to touch or play with the gadget, they tended to enjoy the more complex pieces of equipment such as the fundus camera shown in Figure 27 which is a photograph taken by Chris(C) when he was asked to photograph things he liked. He

was initially anxious about the machine but when he found out it was the machine that takes photos of the inside of his eye he was very excited.

**Figure 27: Photograph of a fundus camera by Chris(C)**



Understanding what will happen, when and why results in the child feeling in control and makes an otherwise unacceptable test seem acceptable. Relating this to the theory shows that facilitating the understanding of the child reduces the anxiety and increases the feeling of control over the situation.

### **Impairment of social interaction**

Impairment of social interaction causes the individual to have difficulty understanding the 'rules of the game' as far as the interaction with other people is concerned (Baron-Cohen, 2008). As shown in the discussion of the process (section 3.2.5) eye-care involves interaction with an optometrist and various other people in the practice such as dispensing opticians and receptionists. The interaction in an eye examination is intense one-to-one in a closed consulting room. Children with ASD may not understand how people behave in the clinic and being restricted to sitting down or waiting they may find challenging. Eye-care professionals and support staff may perceive the child's behaviour as rude or naughty because they do not behave in the way most typically developing children would behave.

The comfort of the child in the eye examination can be affected by the pressure of interaction between optometrist and child. In order for the child to feel in control of the situation this difficulty needs to be accounted for.

## **Obsessions and repetitive behaviours**

Individuals with ASD can exhibit obsessive or repetitive behaviours (Wing 1996). The participants in this research had various expressions of these such as obsessions with: Harry Potter films, Lego, plasticine modelling, Skylanders, spinning movable parts of toys, and flapping. For some of the participants these obsessions could be used by their PCs in calming strategies such as one child who takes a piece of lego with him as a soother wherever he goes. If the ECP was unaware of the importance of this piece of Lego and takes it from them in order for them to hold a reading chart then the child might feel challenged or distressed. However an understanding of the depth of these obsessions and behaviours can be used to help keep the process running smoothly and enable the child to feel comfortable and in control.

## **Phobias, self esteem and anxiety**

One of the participants (Anne (PC)) referred to her son (Simon (C)) as:

“fears and phobias boy”

Most of the difficulties expressed by the children result in anxiety and in the child lacking confidence or pride in their abilities. The children had phobias that cause them to feel extremely anxious. Many of the children were reported by their PCs as being anxious and from the children’s interviews it could be seen that they struggle with anxiety about much of life. These anxieties and phobias need to be taken into consideration to enable them to feel in control of the situation. Low self esteem and anxiety result in the child feeling that they are unable to do what they are being asked to do and therefore encouragement in the approach will empower them. Notbohm explains in her guidelines that encouragement and a non-judgemental attitude makes a significant difference to children with ASD when they are being asked to attempt any activity (Notbohm, 2004). Encouragement to attempt the tests is more likely to produce a good outcome. In order for a good experience to be achieved information in advance between PC and ECP should be given so that the child is empowered and not frightened.

## **Hypersensitivities**

Hypersensitivities are commonly reported in ASDs (Bogdashina, 2003) and this research highlights the derailing effect of sensory overload. One ECP explains very

well the difficulty that children with ASD have with hypersensitivities everyday, even before the ECP adds to this bright lights and equipment that touches the skin:

“they can be acutely aware of how their legs feel inside their socks, how their bottom feels on the chair, there’s just too, you know, their clothing touching their skin, there’s such an over load”

The experience of the child is improved if the sensory burden is reduced.

In summary, the traits of ASD can cause difficulty with communication, interaction and understanding what will happen. In addition to this the children may have phobias, anxieties and hypersensitivities. If these are not factored in to the consultation process the child may feel overwhelmed, out of control and their behaviour can deteriorate quickly.

### ***5.1.6 Acceptable and unacceptable tests***

The children’s data highlighted that the ECPs may not be able to predict what tests are acceptable or unacceptable to the child. The category *the black chair* shows that features of the consulting room environment may be interpreted by children with ASD in unusual and idiosyncratic ways. From the researcher’s experience it is a commonly held view that children find the black chair frightening. One of the ECPs (Robert) also mentioned this and commented that he had removed the black chair from his consulting room and has replaced it with a waiting room chair.

However, overwhelmingly, the children in this research indicated a preference for the black chair. They did not associate it with bad things, they described it as comfortable, they thought it was important otherwise one would not be able to see the letter chart, it was fun because it goes up and down. It was indicated as a dislike by one child during the card sorting but when this was investigated he explained that the chair was not frightening but the equipment next to the chair in the picture was what made it look frightening.

Another example of this was during an interview one child was shown a small room with a visual fields machine inside to ask his opinion of the machine, however he would not go into the room because the room was too small. He was frightened by

the room not necessarily the equipment. The reaction of the child is based on their perception of the situation not the expectation of the ECP. If the child is given a choice then they may choose differently to the ECP. If they have choice then they have more control over the situation and they are more likely to comply.

Whilst considering the acceptability of tests the unexpected reactions to tests shown by this research also needs consideration. It was found that children with ASD seemed to react differently to some of the tests than typically developing children. An example of this was the use of the drops. The experience of the researcher is that most children react to the stinging of the drops and are frightened that the drops will hurt. This may be true of the children with ASD but when asked about the drops, of the children that had experienced them, none commented on the stinging, and most commented on the blurring effect that lasted for a long while afterwards. The blurring was a strange and frightening sensation to them. This causes anxiety and confusion especially as they may not understand information given to them, may not be able to predict the effects of the drops or understand that the effect is transient.

Communicating what will happen, why and when it will end is important and therefore one PC suggested that her child would have been better if he had been told in advance and prepared for that test. This again goes back to the need for the child to feel in control and to know where they are in the process. It is important to note that in most primary eye-care settings the drops are used as part of the initial appointment where possible.

Related to this finding is the general observation that the children responded more acutely to the effects of blurring and visual effects such as 3D images. The children generally found all of these tests very enjoyable. Their reactions were exaggerated and they became hard to redirect to another question or activity. These responses are linked to sensory overload, where there is too much input for them to process and they can become overwhelmed quickly and this can trigger challenging behaviour. If these tests are spaced through the primary eye-care routine (battery of tests) then the effects will not be so overwhelming and the child will feel more comfortable.

There was no particular battery of tests that can be prescribed to give a good outcome. The findings show that every child is unique in their likes, dislikes and the disabilities resulting from their ASD. However giving them choice, explanation and

preparing them enabled them to feel in control and improves their experience. There is no reference in the literature to this lack of predictability in preference for particular types of tests or in the expected reactions to them. It is a particularly important finding given that optometrists usually have a set routine and will have an expectation of what children might be anxious about or enjoy. An understanding that with children with ASD might react differently is very important.

### **5.1.7 Continuity**

The need for continuity and meeting the child's expectations was another finding that contributes to the development of the theory of the eye-care experience. Children with ASD were more comfortable with the process if they were familiar with their ECP and the environment. They were acutely aware of changes to routine, environment and personnel. A change from expectation caused them to feel anxious and therefore it is important to set expectations and stick to them. If they attend the same practice, the same room, have the same ECP and are given explanation of what will happen then they are likely to feel less anxious. If they know what to expect and there are no surprises then they will feel in control and not overwhelmed. The difficulty with managing change is highlighted in the literature but there is no reference to it in terms of continuity in a clinical setting. This may be a reflection of the paucity of literature regarding eye-care for children with ASD.

## **5.2 Current knowledge and the emerging theory**

As discussed in section 1.7.3, there is a paucity of research regarding primary eye-care and ASD. A summary of the current guidelines is presented in section 1.7.3 and it can be seen that the current guidelines when combined together are very much in line with the grounded theory that has emerged from this research. Whilst this gives resonance to the findings of this research, it can also be seen that these guidelines are not evidence based, they are based on expert professional opinion. Therefore the present research provides evidence on which to base the guidelines.

### **Current guidelines and the emerging theory**

Based on the emerging theory service provision is optimum when planned and delivered in an ASD aware setting. This requires the service to be person-centred

and flexible. Knowledge of alternative communication methods, alternative tests and techniques, and a proactive approach to avoid discrimination are all key. Several visits in order to achieve a positive outcome may be indicated. In order for the service to be person-centred communication pathways between PC and ECP is essential.

The literature search produced three sets of guidelines (Coulter, 2013; The College of Optometrists, 2014; The National Autistic Society, 2012a; Opticians Act, 1989). These are discussed in section 2.2. The guidelines set out by the College of Optometrists are minimum standards expected of ECPs and the Coulter and NAS guidelines are practical recommendations and suggestions.

Whilst the College Guidelines do not state explicitly a minimum standard of provision for children with ASD, a combination of guidelines for children's eye-care and eye-care for people with learning disabilities and the code of conduct would imply the minimum standard for children with ASD. The guidelines prohibit discrimination, and require adaptations to the service such as alternative communication methods, gathering enough information in advance to adapt the service to the needs of the person. It also includes the need to treat each person as an individual, with dignity. However the population with ASD is very large and their difficulties with eye-care so profound that the lack of a specific set of guidelines is significant.

This research shows that the needs of children with ASD deserve a specific section in the guidelines to raise awareness in the profession of the general principles of service provision for this group. In particular those that are high functioning and therefore do not fall into the category of LD but yet certainly benefit from adaptations to the test. An example of this is the recommendation to use a pre-test questionnaire such as that from SeeAbility for children and adults with LD (SeeAbility, 2010). This research shows that this communication pathway is important and whilst the SeeAbility questionnaire is helpful it is not appropriate for children on the high functioning end of the spectrum. In particular it does not cover some of the relevant elements highlighted by this research such as an individual's obsessions, phobias and calming techniques. An output of this research is a pre-test questionnaire based on the emerging theory and this can be found in section 6.3.

The National Autism Society have guidelines published on their website for ECPs and PCs (The National Autistic Society, 2012a; The National Autistic Society, 2013).

These give the ECP an understanding of what adaptations may be beneficial in a practical way that enables these standards to be achieved. They are in agreement with the research findings in many aspects. They recommend that PCs and ECPs discuss the child's needs and that the ECP adapts all aspects of their approach to accommodate these needs. The guidelines acknowledge that all tests may not be possible for all children. It sets out the minimum range of tests that should be attempted and gives some tips as to how this can be achieved. The present research shows the diverse range of likes and dislikes, phobias and obsessions therefore means that the tests need to be person-centred.

Coulter's guidelines are designed as a practical guide too (Coulter, 2013). She is based in America where funding and eye-care structure is different to the UK. The eye-care service in the UK for children is primarily funded by the NHS and therefore the service has to comply to the requirements of the NHS optometry contract. In America the services are privately funded and therefore there is much more professional freedom regarding adaptations to the routine and methods employed for each individual. However her guidelines are very much in keeping with the findings of this research. She emphasises allowing the child some control in the process. This is not the same as enabling them to feel in control but is allied in principle. One can feel in control without actually being in control. Eye-care professionals are required by their NHS contract to complete a full eye examination and therefore the child cannot be in control of that process but the way that it is approached can enable them to feel in control.

These three sets of guidelines are in line with the theory of eye-care from this research but none of them give support or advice as to how this is achievable within the NHS structure. The Opticians Act which sets out the requirements on which the NHS contract is based (Opticians Act, 1989). It does not acknowledge the differences in the requirements of a child with ASD compared to a typically developing child. The NHS contract is more concerned about ensuring that everyone receives the same service without considering that some people require an adapted service to achieve equality. The findings of this research indicate that the NHS provision for children with ASD is not appropriate or fit for purpose and should be reviewed in order for children with ASD to receive the eye-care that is appropriate for their needs.

The literature review and the data from the ECPs in this research show there is a paucity of research regarding the need for eye-care. None of the children in this research had been diagnosed with eye disease and those that had spectacles had mild prescriptions. There is no evidence based knowledge around the risk factors eye anomalies carried by children with ASD. This lack of research may be linked with difficulties recruiting participants and the vast range of expressions of the autism spectrum. However it may also indicate that there is a very poor uptake of eye-care in this section of the population. The ECPs commented on the fact that there is a much higher prevalence of ASD in the population than the numbers of children with the condition that attend their clinics would indicate. They make the point that the more children with a condition you see the more you build up knowledge of the risk factors attached to that condition, but they are not seeing enough children with ASD to have formed any particular conclusions. It is very important that children with ASD are encouraged to attend for routine eye-care because at the least they carry the same risk of eye anomalies as typically developing children. This risk has been shown to be higher if they have learning disabilities in addition to the ASD (Turner, 2013).

### **Summary**

The theory that has emerged from this research is in line with current professional guidelines and expert opinion. However applying this theory to enable a good experience of primary eye-care for children with ASD requires service change.

### **5.3 Limitations**

The main limitation of this study is the demographics of the cohort. The recruitment of participants was very difficult and therefore created a limitation regarding true theoretical sampling.

The sample of children consisted entirely of boys, because no girls with ASD came forward. It would have been interesting to find out if girls experiences are the same as the boys. However given that there are approximately five times more boys than girls with ASD (The National Autistic Society, 2014) the findings are still relevant and useful. The sample consisted of children with mild learning disabilities and ASD up to very high functioning children with ASD. This resulted in the data being skewed away from the lower functioning children.

One PC had two sons with ASD. The child that participated was high functioning. The child that did not take part had severe LD as well as ASD. The reason he did not participate was because he had been unable to access eye-care for many years due to lack of specialist provision locally. The views of the ECPs and this particular PC seem to indicate that the difficulties for this group are quite different from those that are higher functioning. Whilst they share similarities there are additional difficulties with communication and ability to do the tests as well as logistical difficulty with location, transport and wheelchair accessibility. The findings of this study touch upon some of these issues. This case illustrates an important point apparent from the PC and ECP interviews. The inability of the researcher, despite great efforts, to identify potential participants who were more advanced on the autistic spectrum is likely to result from the very sparse uptake of community optometric eye-care by this cohort of children. Given the findings of the present research concerning the difficulty that higher functioning children with ASD have with eye-care this is not surprising. However, it does highlight the need for the present research and for the findings of the present research to be taken seriously so as to improve accessibility especially give that people with PMLD are at a much higher risk of visual impairment than average (Woodhouse *et al* 2013). However the aim of recruitment was not for greatest variation, but to explore the experience of children with ASD. As the spectrum is very varied and the research was time limited the sampling was directed towards the group of children that are most likely to be accessing mainstream optometry practices. This has been at the expense of capturing the experience of children with severe LD combined with ASD.

The age range of the children was skewed towards the 10 to 13 bracket with only two children below the age of eight. The critical period of eye development is under the age of eight (Logan and Gilmartin, 2004). It is possible the data may not be representative of the experience of children during the years where eye-care is particularly important. This results in a theory that may not be generalisable to all children and specifically those at greatest need of eye-care. High functioning children with ASD acquire coping strategies as they grow and therefore some of the difficulties experienced by younger, or lower functioning children may not be represented by this research. In view of these limitations it should be considered that the findings indicate the minimum adaptations required to give a good experience.

Another limitation is the lack of accurate context details. Whilst the data from the PCs and ECPs gave a general context and process background, each child had a unique set of circumstances around the examination. Therefore theory has been developed based on an assumed context rather than the exact context for each child. Also the approach of the ECP has been derived from the child and PCs comments and this may not be an accurate representation of actually what happened. The children needed to have had an eye examination in the last six months and be able to prove that they can remember it, but even with this requirement, details of the context and process may have slipped their minds. The theory therefore needs to be seen as an approximation based on the data presented that requires further testing in real life situations.

This chapter has discussed the theory of primary eye-care experience grounded in the views of children with ASD. It has also discussed how the findings relate to current knowledge and practice. The next chapter presents the conclusions of this research and recommendations for further investigations of eye-care for children with ASD.

## **Chapter 6 Conclusions**

### **6.1 What is the experience of primary eye-care for children with ASD?**

The research question was 'What is the experience of primary eye-care for children with ASD?'

The findings of this research show that children with ASD from the mild LD to the high functioning end of the spectrum commonly have a poor experience of primary eye-care. They find the process challenging because of the lack of awareness of their special needs and in particular the sensory overload, time limited and abstract nature of the eye-examination. They feel overwhelmed, confused and anxious. The research also shows that the current service design is not fit for purpose for these children because of the lack of flexibility and funding resulting in the adaptations resting on the altruism of the practitioner. The research also shows that children often have different expectations of the process than the reality because the carers are also unaware of what to expect and how to set expectations for their child.

The children who reported better experiences were familiar with their ECP, had accurate expectations and had been prepared in advance. They felt comfortable, tended to engage with optometric instrumentation as interesting gadgets rather than frightening instruments, and felt in control. This can be further enhanced by ECPs limiting sensory overload, adopting a flexible approach and communicating carefully.

Factors that led to poor experience were: lack of preparation in advance, unmet expectations, sensory overload, ECP lack of awareness of ASD, eye-care practice service design and environment, and PC lack of awareness of the process of primary eye-care. These destabilising factors led to the child not feeling in control and therefore overwhelmed.

### **6.2 Recommendations for further research**

This section is a discussion of the research needs that have been highlighted by the findings of this exploration of eye-care for children with an ASD. The lack of research around eye-care and ASD was evident when the literature search was carried out. However there are some specific areas that have emerged as research

needs. The most obvious of which is the need to investigate whether this grounded theory is accurate but others that are discussed here include investigating the uptake of eye-care, the eye-care experience of children on the LD end of the autism spectrum, the eye health risk factors for children with ASD, and the possible development of computer based eye examinations.

### ***6.2.1 Testing the theory***

Grounded theory is an approach that generates theory. The research does not start with a hypothesis, instead a theory with explanatory power emerges grounded in the data (Holloway, 2005), it does not prove a theory. Therefore further investigation is indicated to test the theory. If the theory is accurate the reported experience of a child with ASD should be good if they have as much of the process managed by their PC and ECP in an attempt to reduce the anxiety and enable the child to feel in control of the process.

Initially it was considered that this study could be carried out in a case study methodology. Section 2.1.1 gives details of why this was not chosen as the methodology for this research. However as a follow up to this research, a selection of case studies could be investigated for evidence that proves or disproves the ability of this theory to predict the circumstances that produce a good eye-care experience. This would involve looking for cases that fit with the theory, negative cases and cases from across the autism spectrum to see if the theory is generalisable. Each case could be investigated from adapted interviews with the child, interviews with the PC and also ECP, as well as assessment of the clinical records. Detailed investigation of the ethos of the practice, the environment, the previous experiences of the child and the communication between ECP and PC, and ECP and the child. This would build a picture of how different eye-care approaches can affect the outcomes and the reported experience. The present research gives general information regarding the context of the eye-care however a case study can give the exact context of each individual and therefore the theory can be accurately tested. Details such as how clinically 'successful' the eye examination was could be collected. This would include what tests the child was able to complete, what challenges the child had to manage, how the ECP went about achieving this and whether or not the child coped with the process.

A further study to investigate whether implementing this theory improves the experience of eye-care would be the natural next step. This could be done by using mixed methods. A quantitative RCT could investigate the outcomes of eye examinations for those whose treatment followed the recommendations from this study and those who did not. The eye examination would be designed specifically for the individual based on their needs, communication between the ECP and PC would be as recommended by the theory, and the outcomes compared with those of children whose eye examinations were not designed specifically for the individual but in a generic way for a child with ASD. A qualitative concurrent study could be made by interviewing children about their experience of the process or asking them to carry out a photo journal of the process such as in the mosaic technique (Clarke, 2002). This would require the recruitment of age and ability matched children with ASD to be allocated into two groups, one whose PC and ECP are trained in the theory and one whose PC and ECP are unaware of the recommendations. Whilst this would enable the theory to be accurately tested it may be difficult to recruit for this given the difficulties encountered recruiting for the present research and the diverse nature of the autism spectrum.

The PC and ECP resources that have been developed as an extension from the present research, see section 6.3 need further investigation to see how user friendly they are and whether the information gathered by them is sufficient to support the PC and enable person-centred planning the eye examination for each individual. The resources need to be tested by stakeholders and modified according to their comments in order for them to be a useful tool for PCs and ECPs.

### ***6.2.2 Uptake of primary eye-care for children with ASD***

One of the most significant barriers to recruiting for the present research was the number of potential participants that had to be excluded because they had not had an eye examination. The ECPs also commented that they see very few children with ASD in their clinics and significantly fewer than the prevalence of the condition would predict should be accessing service.

There is a paucity of knowledge of the uptake of primary eye-care for children with ASD. This research has highlighted an urgent need to investigate this. This could be then used to help determine the most effective way of providing services for all

children and understanding how best to educate PCs about the need for primary eye-care. It would also help ECPs to know how to support PCs to access appropriate services.

The ECPs and literature highlighted a paucity of research into the optometric correlates of ASD. Whilst there are studies that have investigated the risk of visual impairment in children with LD (Salt and Sargent, 2014; Woodhouse *et al.*, 2000; Woodhouse *et al.*, 2013), little is known about the risk of visual impairment in children with ASD but not LD. There has been a great deal of research into the processing and perception issues in ASD (Simmons *et al.*, 2009) but much more needs to be done with regard to functional vision in order to plan appropriate services for this group of children.

### **6.2.3 Children with severe LD and ASD**

Children with PMLD and ASD seem to have a very different experience of eye-care and a range of different factors that affect their ability to access eye-care. These children are at the highest risk of visual impairment (Salt and Sargent, 2014) and therefore investigation of the access to eye-care for this group is of high importance. The literature indicates that children with ASD but without LD have difficulty accessing services that are mainstream and are not eligible to use services that are commissioned for children with LD. Therefore they fall through a gap in service provision, however they are also likely to be at lower risk of eye health issues. Whereas the literature and the data from the ECPs and PCs all indicate that despite some enhanced services, the provision for the most at risk is still too restricted. In particular there is limited access to eye screening services in special schools (Woodhouse *et al.*, 2013). The ECPs recommended a three tier service that enables all children regardless of their position on the autism spectrum to access eye-care. Further research into how services could be commissioned that are suitable for all the children in the autistic spectrum is an urgent need.

### **6.2.4 Computer based eye examinations**

In recent years, considerable progress has been made in automated computerised vision screening (Jessa *et al.*, 2012; Thomson and Evans, 1999). This research

seems to suggest that most children with ASD respond well to computerised technology and might find computer-based assessment more acceptable. It may be that these children would benefit from the paradigm shift towards automated computerised screening. Therefore research investigating the potential development of computer based eye examinations, that minimise the social interaction and verbal communication components of the eye examination, would be very helpful. This could be compared with the outcomes of conventional testing to evaluate which is more effective and acceptable to the child.

The present research indicated that there is a large burden on PCs regarding encouraging their child to cooperate in medical and allied health assessments. This type of computerised screening may help PCs to identify whether their child has an eye-health or visual issue that should be pursued further or whether in fact this is one battle they do not need to fight.

### **6.3 Dissemination plan**

In order for the outcome of this research to be used to develop services a plan has been prepared for dissemination.

Two papers are planned for peer review journals. One will be targeted at an optometry journal as this will promote the findings to those providing services for children with ASD. The second paper will be targeted at a journal for Allied health professionals involved in the care of people with ASD. The research indicates that a multi-disciplinary approach may facilitate eye-care and therefore knowledge of these outcomes may help to foster this. However more significantly it may be that the theory generated by this research could be applied to other similar situations such as dentistry, general practice and medical assessments.

Optometrists also refer for professional training articles to a magazine produced by their association. This is not peer reviewed but it does reach the majority of the profession. As series of articles are planned for this magazine that include the results of this research and how to apply it to clinical work, ASD awareness training and also an article explaining qualitative research and how this could and should be used to evaluate and develop services to enable optometrists to provide services that are person-centred.

Figure 28 below show three output documents from this research that will be published in order for service users and service providers can communicate more effectively and therefore enable appropriate services for individuals. It is intended that these will be taken up by websites nationally and also for local ASD support groups. During the research the PC's indicated that most of their support and information came from local groups not the national charities. However it is likely that the local groups look to the national charities for their resources. The documents include information for PC, ECPs and also communication tools to help PCs and ECPs exchange the information that this research has shown to be key in adapting the eye-care provision.

The researcher has already been working with the Royal College of Ophthalmologists, RNIB and also SeeAbility regarding the development of eye-care services for children with ASD. The work has been presented at the UK Vision Strategy conference (2014) and as a poster at the College of Optometrists conference (2014).

***Figure 28: Patient and practitioner online and paper resources  
consisting of four information sheets***

This package consists of four information sheets:

- Information sheet 1: Recommendations for practitioners - A guide to help optometrists achieve a good outcome when examining children with ASD.
- Information sheet 2: For carers and service users - Information sheet for people with an ASD, parents and carers
- Information sheet 3: Pre-test questionnaire
- Information sheet 4: Examination outcome feedback form

These four information sheets are on the following pages

**Information sheet 1: Recommendations for practitioners**  
**A guide to help optometrists achieve a good outcome when examining children with ASD.**

Autism spectrum disorders (ASD) are a range of neurodevelopmental conditions that have 3 common traits.

- Impairment of social communication
- Impairment of social interaction
- Impairment of social imagination

As a consequence of these traits, people with ASD have difficulty communicating and understanding verbal and non-verbal communication, also difficulty understanding and taking into consideration other people's feelings and predicting how someone else will react. They can seem aloof and rude or uncooperative.

ASD is known as a spectrum because of the diversity of ASD's, ranging from high functioning individuals to people with profound and multiple learning disabilities (PMLD). It can be associated with epilepsy, ADHD, Down's Syndrome and other conditions. Some people with ASD can be very high functioning which means that it can be a 'hidden' disability and therefore the practitioner can inadvertently cause distress.

Many people with ASD have severe difficulties with sensory processing and can become overwhelmed by sensory input (noises, lights, touch, smells etc) that other people may not even be aware of such as the hum of a machine in the consulting room. When they become overwhelmed and are unable to communicate their behaviour can become very erratic or challenging. In some cases they may just 'shut down' altogether and withdraw from interaction.

Given the range of tests and sensory input in an eye examination this can be a very stressful experience for children with an ASD.

People with ASD can display repetitive and obsessive behaviours.

In order to adapt the eye examination for a person with an ASD the following guidelines should be considered (the most important points have been highlighted):

- Get as much information in advance as possible by sending a pre-test questionnaire
- Train the whole practice team so that they are aware of what autism is and how it can impact on what we do in the waiting room, consulting room and dispensing area.
- Book appointments in such a way that the person is unlikely to have to wait in the waiting room (eg either at the start of the day or just after lunch)
- Consider offering familiarisation visits
- For some children several short appointments are better than one long appointment
- Give information about what to expect in advance so that the child can be prepared for the routine. It is important that you do what you say which means you may need to arrange a follow up appointment for any additional tests that are required.
- Remember that the child will assume it will be the same as last time or as they have been told, unless further instruction is given. Do not change the routine unless it is unavoidable.
- Do not change personnel without informing the child, if they expect to see a particular optometrist or dispensing optician then it will be challenging if it is someone else on the day of the appointment.
- Adapt the routine to use tests appropriate to age and ability
- Use short simple language: literally, say what you mean
- Always explain what you are doing, why you are doing it and the effect it might have. This is particularly important if you are using drops or new equipment
- Give them time to answer questions and only ask one question at a time
- Do not ask broad questions: be specific or give options to choose from
- Check that they understand
- Minimise any sensory stimulation including noise, smells, lights and touch
- If possible, arrange home visit or a school based test for low functioning individuals if this would be less distressing
- Give as much control over the process to the patient as possible and even when this is not possible help them to feel in control by explaining what will happen
- For people with quite profound difficulties, photocopy letters and pictures used in optotypes so that the child and carer can practice matching activities at home.

**Suggestions for adaptations:**

Make a set of letters or pictures that can be placed on a prompt card rather than pointing as this is a task they will be familiar with

Use hand held equipment where possible to avoid touch as much as possible

Some children may prefer a phoropter to a trial frame: ask the child which they would prefer.

Offer familiarisation visits

Get the carer to help practice at home some of the sensations that might happen – covering one eye, spectacle frames on the nose and ears, shining a light in the eye, close proximity

When explaining what will happen use the phrase structure “now X then Y” as they are familiar with this from other professionals.

## **Information sheet 2: for carers and service users**

### **Information sheet for people with an ASD, parents and carers**

Why are eye examinations necessary?

When you have an eye examination the optometrist carries out a range of tests, including:

- Measuring how well you see things in the distance.
- Measuring how well you see things that are close up.
- Measuring if spectacles are required and if so the power of spectacles you need to correct your vision to see well at all distances.
- Measuring your peripheral (side) vision
- Assessment of the health of the inside (retina, nerve, lens) of your eyes.
- Assessment of the health of the outside (lids, lashes, conjunctiva, cornea) of your eyes.
- Assessment of how well your eyes work together (by testing the actions of the muscles).

These tests are important for children because some eye conditions can cause permanent sight impairment unless treated before the eye is fully developed (around age 8).

Children may not report problems with their vision because they may not be aware that what they are seeing is subnormal. They may be unaware that one eye is blurred compared with the other eye because they never compare one with the other.

Children with communication impairments are less likely to be able to report eyesight difficulties.

People with learning disabilities are more at risk of eye conditions than people without learning disabilities.

It may be that you are unaware of a problem with your child's vision if they have one eye that sees well enough to compensate in day to day activities.

What might make the eye examination stressful for your child?

- Waiting in the waiting room.
- They may be asked to make rapid decisions about which of two lenses is clearest.
- The use of eye drops that sting and cause blurring.
- The touch of the spectacle frame that is used to try different lens powers (known as a trial frame).
- The blurring effect of some of the trial lenses used.
- The need to have the room dark at times.
- The use of bright lights to look inside the eye.
- Your child may need to put their chin onto the chin rest of some instruments.
- The look of the consulting room which has lots of gadgets and medical equipment.
- Distractions such as computer screens, flashing lights and brightly coloured spectacle frame displays.
- The noise of the instruments.
- The smell of cleaning products.
- The close proximity of the optometrist when they are examining the inside of the eyes.
- The need to cover one eye.

Whilst this is a long list of possible sources of challenge there are several easy steps you can take in order to make the eye examination process better for your child.

How can you help to make eye examinations effective and less stressful for your child?

Eye examinations can be adapted appropriately if you consider the following steps:

- Always tell the optometrist in advance of the appointment that your child may need some support and adaption to the tests. This is just as important if your child is high functioning as for those with a learning disability. If you do not tell the optometrist it may take them a while to work it out. First experiences of eye-care are very important and if the right approach is not taken initially it may affect your child's ability to cope in the longer term.
- Arrange the appointment to be at the beginning of the day or straight after lunch so that your child is less likely to be kept waiting for their appointment.
- Ask the optometrist what they are likely to do during the test so that you can accurately set your child's expectations of the test.
- Familiarisation visits can be helpful. This is a time when you can take your child to see the clinic and meet the staff without having to cope with the tests as well. Another appointment would then be made to come back and do the tests. For some children several short appointments can be better than one long appointment. If this is not offered and you think it would help then ask the optometrist if this can be arranged.
- It is possible that your child may need a test involving drops that sting for a moment or two and blur their vision for a few hours. It is worthwhile asking specifically about this in order to prepare your child or alternatively declining drops on the day and arranging a return visit when your child is prepared properly for them.
- Give the 'practitioner information' leaflet to the optometrist in advance. Not all optometrist will have experience of testing people with an ASD.
- If you think some of the tests may be difficult you could prepare your child by practising some activities such as covering one eye, reading out letters or matching letters or pictures. The optometrist can supply you with photocopies of letters and pictures for this purpose.
- Look at the list above and consider, in advance, knowing your child's profile, what aspects of the test might be a trigger and advise the optometrist. The optometrist can then plan the range

and order of tests to make the experience less stressful.

Optometrists, like all healthcare professionals, are very busy and the best way of communicating with them might be to send them this information in an email.

**For parents and carers of children with an ASD and learning disabilities:**

It is possible to test the vision of children and adults who are unable to read letters or respond verbally to tests.

It is important to know about a person's ability to see even if they are unable to read or use a computer because we use our vision for so much. We use it to recognise faces, locate food on our plate, for mobility and for leisure activities.

If it is unlikely that your child will tolerate wearing spectacles it is still important to know whether they are long or short sighted because it will help you plan how far away objects of interest need to be placed in order for them to see them. It will help when planning how to teach some aspects of self-care and feeding.

For some people with an ASD coming into a clinic environment and breaking their daily routine is too difficult. If you feel that your child could cope better in their home or school environment then please discuss this with the optometrist. Only a few optometrists do home or school visits but all should be able to refer you to another practitioner who can offer this.

### **Information sheet 3: Pre-test questionnaire**

Dear Parent/ primary carer,

Please answer the following questions about your child. This information is very important as it will enable the optometrist to plan an appropriate eye examination for your child.

- 1) Name
  
- 2) Address
  
- 3) Date of birth
  
- 4) Are there any particular concerns that you have about your child's vision?
  - discomfort
  - redness
  - blurring
  - double vision
  - eye rubbing
  - eye poking
  - headaches
  
- 5) When was the last eye examination and how did it go?

- 6) Does your child communicate well verbally?  
If not what method of communication do they use?
- 7) What might your child find challenging or stressful?
- bright lights
  - noise
  - waiting
  - clinic smells
  - putting chin on instrument chin rests
  - things touching their nose and ears
  - other
- 8) Does your child have any phobias?
- 9) What is your child particularly good at and/or likes very much?
- 10) Do you have a particular reward for good cooperation?
- 11) Does your child have learning disabilities?

Could your child manage any of the following tests?

- naming letters on a letter chart
- matching letters on a chart with a prompt card
- naming pictures on a picture chart
- matching pictures on a picture chart with a prompt card

And which would be best for them?

12) Does your child have any other medical conditions or take any medicines?

- epilepsy
- ADHD
- diabetes
- gastro-intestinal conditions
- other

13) Do you have a family history of eye problems?

- squint ( turn in the eye)
- lazy eye (amblyopia)
- astigmatism
- short sightedness
- long sightedness
- glaucoma
- other

Please use this page for any additional comments that you think might help us to provide a good eye examination for your child.

#### **Information sheet 4: Examination outcome feedback form**

Eye examination results for optometrists to complete for children with special needs

Date

You will have been given a copy of your child's spectacle prescription if this is required. This information sheet is for you to keep with your child's medical notes or give to anyone else involved in the care of your child that might find it helpful.

Name

Address

Date of Birth

Spectacles:

- are not required
- should be worn all the time except
- should be worn only for
- new spectacles are required and a voucher from the NHS has been issued

Eye health:

- is normal and your child is able to see very well
- a letter for your GP is enclosed explaining that
- your child has a long standing eye condition that does not need treatment. This is called
- your child needs to do exercises to help the two eyes work better together
- your child has inflamed eye lids (blepharitis)
- your child has a 'lazy eye' and this means that they do not see so well as normal from their right/ left eye

**Actions:**

- enclosed is a sheet explaining the exercises I have recommended
- enclosed is a sheet explaining how to clean your child's eye lids
- some tests were not completed today and another appointment will be needed
- assessment with coloured overlays has been recommended and the information sheet is enclosed about this
- The next eye examination will be due

**Other comments:**

## 6.4 What is new from this research?

The present research provides evidence grounded in the views of service users. The findings indicate that if the approach of the ECP enables the child to *feel in control* by adapting to their special needs in a person-centred way, then the experience is better. The adaptations by PCs and ECPs should aim to minimise anxiety and distress and to enhance the child's perception of being in control. These changes are often very simple and benefit all children such as developing better communication pathways between PCs and ECPs. Current practice is based on the requirements of the GOS contract which has been shown by this research to have limited applicability for this group of children.

The research is broadly in line with current guidelines (Coulter, 2013; The National Autistic Society, 2012a; The College of Optometrists, 2014) however it has highlights a paucity of research underpinning these guidelines. It provides evidence on which to build appropriate services in addition to the expert opinion of experienced ECPs that are the current basis of service provision.

Whilst the research has not found an ideal eye-care routine for children with ASD it has shown that contrary to current practice computerised and automated technology could play an important part in screening and testing the vision of children with ASD. The research indicates that this is may be more acceptable to the children than some of the conventional tests and techniques. It has also shown that it is important to give choice and not attempt to predict the preferences of children with ASD because they have a different view of the world that is not always predictable.

As an output of this research evidence based resources have been developed to assist PCs, ECPs and children, see figure 28, providing and accessing primary eye-care. These include a pre-test questionnaire to help with planning, advice to the PCs about accessing services and preparing their child, and also awareness training for ECPs.

This research has also shown that children with ASD need adaptations in a person-centred manner in order to have fair access to primary eye-care. Furthermore they are more in need of eye-care and significantly disadvantaged by the current service due to the structure, funding and inflexibility of the current provision. Services rely on

the altruism of the individual practitioner because of the particular needs of these children.

The theory generated indicates that communication between PC, child and ECP result in the child *feeling in control* and could be applied to other allied health professions that are providing services that involve one-to-one consultations in clinical environments.

The theory generated can be applied to service planning, commissioning and provision, to ensure that every child's special needs can be accommodated appropriately, and that children with ASD can have access to the eye-care services that they deserve, grounded evidence from service users, because "Every child matters" (Department of Education., 2003).

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## Appendices

## Appendix 1 Literature search findings

### Appendix 1i Literature search findings on ocular anomalies and ASD

Ocular function	Studies	Findings	Relevance
Hypersensitivity	(Bogdashina, 2003)	Dislike of extremes of light and dark, flashes of light and a tendency to look away or shield their eyes. This is thought to be due to a hypersensitivity to visual stimuli which causes pain and discomfort	Children with ASD may be distressed by the bright lights and dark testing environment of the eye examination.
Hyposensitivity	(Bogdashina, 2003)	Symptoms of being obsessively attracted to visual stimuli looking intensely at objects and lights, movement of hands and objects in front of their eyes is thought to be due to hyposensitivity	Children with ASD may be less aware of the damage that sunlight can do. They may develop repetitive behaviour to create more visual stimulation.
Reduced near point of convergence (NPC)	(Milne <i>et al.</i> , 2009)	This study looked at a wide range of visual function and found only NPC to be significantly reduced in the participants with ASD.	NPC is a key component of prolonged close work and if this is reduced it can create problems with learning and concentration. This should therefore be assessed for all children with ASD
Reduced visual acuity	(Bolte <i>et al.</i> , 2012; Scharre and Creeden, 1992; Milne <i>et al.</i> , 2009)	Several studies looking at visual acuity have shown no difference between the visual acuity of children with ASD and typically developing children.	Further research is required to investigate visual acuity and ASD, current evidence is inconclusive.
Hyperacuity	(Ashwin <i>et al.</i> ,	This study found that in children with	Further research into hyperacuity would be beneficial

Ocular function	Studies	Findings	Relevance
	2009)	ASD and hypersensitivity the visual acuity was in excess of normal visual acuity. This has subsequently been shown to be a flawed study.	as this study suggests that children with ASD could have hyperacuity but due to the design of the study this is not evidenced currently.
Strabismus	(Milne <i>et al.</i> , 2009; Scharre and Creeden, 1992; Kaplan <i>et al.</i> , 1999)	These studies found a high prevalence of strabismus in children with ASD. The percentage with strabismus was between 20% and 50%	There are some methodological issues with these studies and a paucity of research in this area generally. However it seems that children with ASD should be screened for strabismus as they are probably at a higher risk than average. Therefore eye examination at an early stage are indicated.
Colour vision	(Heaton <i>et al.</i> , 2008; Franklin <i>et al.</i> , 2010; Ludlow <i>et al.</i> , 2008)	No difference in the prevalence of red/green colour deficiency was found	Children with ASD appear to be no more likely to be colour blind than typically developing children.
Colour naming	(Heaton <i>et al.</i> , 2008)	This study found that children with ASD tend to rely more on perception of colour than colour naming. They found it easier to match a shade of red when given 4 different shades of red than typically developing children who named the colour and then got confused because all the options were also called red.	Children with ASD may struggle to link the names to the perceived item and therefore appear to have poorer vision whereas this may be a deficit in communication rather than vision.
Visual stress	(Ludlow <i>et al.</i> , 2008)	Visual stress causes a range of ocular and neurological symptoms including headaches and reading	There is evidence that children with ASD may benefit from overlay screening.

Ocular function	Studies	Findings	Relevance
		difficulties. It is triggered by some patterns, lines and lights. This has been shown to be reduced by using precision tints and coloured overlays, in children with dyslexia, migraine sufferers and photosensitive epilepsy. There is a high prevalence of epilepsy in ASD and this study shows a significant and profound improvement in reading rate with coloured filters in children with ASD.	
Visual processing	(Dakin and Firth, 2005; Simmons <i>et al.</i> , 2009)	Vision has many stages, the detection of light followed by several systems of processing the information that is gathered by the retina and maculae. The research indicates that in several respects that information is processed differently by children with ASD. The areas highlighted are motion perception, visual search, face and object perception, and eye gaze.	Children with ASD process what they see in a different way to others. This causes them to appear to have difficulties with their vision and understanding what they see. These processing issues can be considered a visual impairment and may affect how they interpret objects of interest, facial expressions, interpret the intentions of others, and spatial awareness and motion. Researchers are interested in these studies because the clues it might give to what causes ASD.
Visual impairment	(Parr <i>et al.</i> , 2010; Pijnacker <i>et al.</i> , 2012; Brambring and Asbrock, 2010;	There is no consensus of opinion regarding a link between ASD and visual impairment. These studies indicate that children with a visual impairment are more likely to have a	Further research is needed into the links between visual impairment and ASD. The current data is confused by the diagnosis process of ASD.

Ocular function	Studies	Findings	Relevance
	Luyster <i>et al.</i> , 2011; Cass <i>et al.</i> , 1994; Hobson <i>et al.</i> , 1999; Hobson and Lee, 2010; Pring, 2005; Kielinen <i>et al.</i> , 2004)	diagnosis of ASD and show impairment of theory of mind. However this may be due to the assessment process for ASD being difficult for visually impaired children and also may be due to developmental delays due to sensory loss which later resolve.	
Vitamin A deficiency related sightloss	(McAbee <i>et al.</i> , 2009)	Restricted diets can cause vitamin deficiencies which result in poor retinal function and visual impairment.	Many people with ASD have restricted diets due to hypersensitivities to taste, smell and texture. This research was just one case study but needs to be considered when assessing children with ASD given the lack of research.
Eye rubbing and poking	(Kennedy and Souza, 1995)	Eye rubbing and poking is a repetitive behaviour found in people with ASD and LD. This can cause permanent damage to the eye and the paper recommends guidelines to help discourage this activity	Children who develop obsessive eye rubbing and poking can suffer visual impairment that might go undetected if they are not having regular eye examinations. This behaviour can indicate eye problems also and the behaviour can overshadow a need for urgent care.
Optic nerve hypoplasia and septo-optical dysplasia	(Parr <i>et al.</i> , 2010)	A high prevalence of ASD was found in children with optic nerve hypoplasia and septo-optical dysplasia	There may be a link with visual impairment and ASD but more research is required to find out whether children with ASD are more at risk of these two conditions.
Co-morbidity and visual impairment	(Emmerson and Robertson, 2011)	The prevalence of visual impairment is higher in people with LD and particularly associated with some	Up to 70% of people with ASD also have a LD therefore this group of people with ASD are at the highest risk of visual impairment

Ocular function	Studies	Findings	Relevance
		conditions such as Down's Syndrome.	
Diagnostic overshadowing	(Cavill, 2001)	People with learning disabilities can suffer delayed diagnosis because they are unable to communicate symptoms and behavioural indicators are misinterpreted by their carers	Children with limited verbal communication and learning disabilities are at risk of having eye conditions that are not detected early enough for treatment

## **Appendix 1ii Qualitative research methods review**

There are many qualitative research approaches and finding the right design for the research question is as important as deciding between quantitative and qualitative methodologies. In order to select the best approach the aim of the investigation needs to be examined. Other factors to consider when selecting an approach are the training and philosophical viewpoint of the researcher and, more pragmatically, the time constraints and budget for the research.

The aim of this study is to find out what the experience is of primary eye-care for a child with ASD. To see it from his/ her perspective and understand what causes distress and what makes a 'good' experience with a view to developing a theory of the facilitators and barriers to providing an acceptable and appropriate service. There are a number of possible approaches that could be used and below is an account of those considered as possible options for the research.

### **Phenomenology**

Phenomenological research stems from the philosophy of phenomenology which is associated with Husserl (Creswell, 2007). It is concerned with the study of 'consciousness' and 'how we know' and a person's consciousness of the world. Within phenomenology there are several research approaches that have evolved. Descriptive phenomenology provides rich description of an experience in order to achieve an understanding of the 'essence' of it while Hermeneutic phenomenology looks at understanding through interpretation (Holloway, 2005). Phenomenology is the study of lived experience and what it means to be human. The researcher investigates commonalities between others' experiences of everyday life, and in particular the things that we do not notice or take for granted. Phenomenological research looks at the essence of the subject and is rich in description (Holloway, 2005; Hickson, 2008; Silverman, 2011). It produces an understanding of the phenomenon from the view of the individual not from the view of others. It is an ideal approach to produce a deep understanding of the experience of life for people within certain areas of interest and facilitates empathy with the lived experiences of others and therefore gain a greater understanding of the decisions they make and actions that they take (Holloway, 2005).

This approach could have been adopted for this study as it would generate rich description of the experience of primary eye-care. However, the aim of this research is to understand the primary eye-care experience from the child's perspective not the researcher's and to generate a usable theory. Whilst Phenomenology would be able to inform practitioners about the experience it the burden would be left to individual optometrists to interpret that for action in everyday practice.

### **Case studies**

This approach is used to gain a greater understanding of a particular phenomenon within its particular context. This involves taking all of the information about a particular situation from any data source and analysing the aspects of the phenomenon. A case can be an individual, a company, a country or any other 'unit' that might be identifiable as a unit or 'bounded system'. The data collected is in depth and from all sources, interviews, focus groups, literature, social media and so on. The aim is to be as holistic as possible and take account of anything that has an impact on how that system functions or how a particular aspect functions in the case of large organisations or systems (Punch, 2005; Yin, 1994). Case studies are low on the hierarchy of knowledge (Hickson, 2008) and even in the newer model developed by Evans (Evans, 2003) they remain low in the ranking. This is because they are very specific to a given situation and their generalisability is considered limited.

Advocates of this approach will point to the fact that generalisability is not the aim in such research. The aim is to either point out the particular attributes of a special case because it is very important or a 'negative case' which proves a commonly held belief or practice to be wrong. However the data produced can be conceptualised which means identifying concepts that might explain a situation and then using these to put forward as hypotheses for other case studies or further research such as surveys. Therefore case studies, whether stand alone or in combination, can produce trustworthy evidence as long as the cases are carefully chosen, justified and used for the right purposes (Punch, 2005).

A case study approach would be able to give an insight into the experience of individuals and a collection of carefully selected cases would generate some concepts that could then be used in further research. It would also enable aspects such as record cards to be investigated to see how much of the eye examination was completed and the ECP's viewpoint of the experience to see if the understanding of the ECP corresponds with the experience reported by the child.

However selecting the cases is crucial to the usefulness of the findings and possibly of more benefit as a further investigation after an initial wider exploratory study.

### **Action research**

Research that is aimed towards influencing service change can be achieved through teamwork in Action Research (Marshall and Rossman, 2011). This involves members of a team working together to identify a need for research, planning and participating in the research. The outcomes of the research are implemented and then re-evaluated in a cyclical manner. This might be feasible in a large hospital unit or organisation but optometry tends to be on relatively small scale and therefore the practicalities of this approach means it would not be possible. It could also be said that this methodology is not so much about the child's perspective and more about the service itself.

### **Grounded Theory**

Grounded theory is a research approach that uses specific methods to collect and analyse data and develop theory 'grounded' in that data. It is systematic and was initially designed as an inductive process through which theory emerges. It crosses the border between qualitative and quantitative research in that all sources of data can be considered (Glaser and Strauss, 1967).

Data used to generate theory may come from any source that might be relevant to the subject. It is a technique that develops theory and not a theory verification method (Punch, 2005). Grounded theory is an approach that was developed by Glaser and Strauss for their study of the awareness of dying (Glaser and Strauss, 1967). However it has since been adapted by researchers and several types of grounded theory now exist. There are two main versions, the classic grounded theory developed by Glaser (Glaser and Strauss, 1967; Glaser, 1998) and the modified grounded theory developed by Strauss (Strauss and Corbin, 1990). Although there are other notable versions of grounded theory that have been developed including Charmaz (Charmaz, 2006) and Clarke (Clarke, 2005). The main difference between the versions of grounded theory is the philosophical underpinning. The original work did not state the philosophical underpinning but instead gave details of the methods used in the approach. However later versions have primarily differed according to this. Examples of this would be: Strauss with

symbolic interaction (Strauss and Corbin, 1990), and Charmaz with constructivism (Charmaz, 2006).

The classic grounded theory was designed to systematically analyse data to generate theory rather than data being used to test theory (Heath and Cowley, 2004; Charmaz, 2006). To produce theory that is:

“meaningful, relevant and able to explain the behaviour under study.” (Hunter *et al.*, 2011p7)

It is often used to investigate areas where there is little knowledge currently (Holloway, 2005). The theory developed is grounded in data from ‘inside’ the subject area and has explanatory power (Punch, 2005).

In much of the literature about grounded theory there is strong debate over the two main versions of grounded theory, Glaser vs Strauss. The two versions differ in several ways: shown in the table below. The use of induction by Glaser and the use of induction, deduction and verification by Strauss, the emphasis on creativity in Glaser and in systematic and detailed evidence in Strauss, and the levels of coding to construct theory are greater in Strauss than in Glaser.

***Glaser vs Strauss grounded theory versions (Hunter et al., 2011; Corbin and Strauss, 2008; Charmaz, 2006)***

<b>Glaser</b>	<b>Strauss and Corbin</b>
Substantive coding – initial coding of the data which becomes more abstract as more data is produced.	Open coding- initial coding of the data
No direct equivalent	Axial coding- the use of analytic tools reduce and sort the open codes into groups that are associated
Theoretical coding – integration of coding to develop a core category	Selective coding- defining of codes into categories and a core category
Theory – parsimony, scope and modifiability i.e. less detail but a theory that fits the data and can be generalised.	Theory – detailed and evidenced theory grounded in data with full explanation.

The philosophical underpinning of Strauss grounded theory is Symbolic Interactionism which is based on Pragmatism (Corbin and Strauss, 2008; Holloway, 2005). Pragmatism contends that

“knowledge is created through action and interaction”(Corbin and Strauss, 2008p2).

People react to different problems by using their experiences, judgement and interpretation, to reflect and resolve the problem and the consequences. They adapt to the situation they find themselves in (Heath and Cowley, 2004). Symbolic interaction is a perspective that considers that individuals interact and react based on meanings that they attach to the actions of others. A person’s social self is made up of their expectations, the context and the behaviour of the people around them. Grounded theory investigates the relationship of action, context, and consequences (Holloway, 2005)

“individuals are active, creative and reflective and that social life consists of processes” (Charmaz, 2006).

A process is a term used to describe the movement from action, to reaction and consequences. This is influenced by the context, therefore someone’s reaction may be affected by the circumstances, the person’s previous experiences or how they understand the world. It is therefore a series of linked events that can be analysed to gain understanding of a phenomenon (Corbin and Strauss, 2008). Grounded theory therefore is a theory based in the data collected in terms of the conditions from which process comes and the causes and consequences of change .

“individual definitions of reality shape perceptions and actions” (Holloway, 2005 p175).

## **Appendix 2 Information sheets and interview schedules**

### ***Appendix 2i Information for PCs***

Study Title:

What is the experience of a child with Autistic Spectrum Disorder when they have an eye examination?

Date:

Dear

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which is shared with others (eg. in reports and publications or is shared with a supervisor) will have your name and address removed so that you cannot be recognised from it.

Thank you for reading this.

Yours sincerely

Louise Stalker  
Researcher

**Study title: what is the experience of a child with Autistic Spectrum Disorder when they have an eye examination?**

***What is the purpose of the study?***

The purpose of the study is to try to find out what an eye examination is like from the viewpoint of a child with an ASD. To find out how easy or hard it is, how much fun or how distressing it is and to ultimately look at what we have found out and try to form a theory as to whether eye examinations need to be adapted to make them more acceptable to children with an ASD and if so in what ways. Hopefully this will lead to better eye-care for this group of patients.

***Why have I been chosen?***

You have been chosen because you have specialist knowledge in the field of Austistic Spectrum Disorders.

***Do I have to take part?***

It is up to you whether or not you take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

If you decide to take part you are free to withdraw at any time and without giving a reason.

***What will happen to me if I decide to take part?***

Your involvement would be an interview with the researcher. The interview will be digitally recorded. All information is confidential and stored securely without reference to the names of the participants. The interview will be very informal with general questions about Autistic Spectrum Disorders, how you feel the diagnosis might affect a child when they have an eye examination, and your views of best practice. You will be sent a sheet of example questions before the meeting to give you a chance to think about them in advance.

You do not have to answer all questions if there are some that you object to. Your professional judgement is not being tested in anyway. The interview will last no more than 1 hour.

Only one interview will be necessary although it may be that the researcher will call you to clarify information later on in the analysis stage. This is will only be a brief contact and you can decline to comment further.

The interview will be at a mutually agreeable location such as a private space within your organisation or at my workplace, the Royal National Institute for the Blind, Judd Street, London.

The entire study will take 3 years but your involvement will just be to attend for your own interview.

***What are the possible disadvantages of taking part?***

The interview will take up one hour of your time.

***What are the possible benefits of taking part?***

There is no intended direct benefit to you however participation will hopefully help us to make sure that eye-care services for people with an ASD are appropriate and effective in the future.

***What if something goes wrong?***

If you are unhappy about some element of the study and need to complain there is a procedure arranged for you to be able to do this:

In the first instance contact the researcher Louise Stalker

[louise.stalker@yahoo.co.uk](mailto:louise.stalker@yahoo.co.uk)

If you need to pursue it further then you can contact the project supervisors :

Dr Martin Benwell    [martin.benwell@lsbu.ac.uk](mailto:martin.benwell@lsbu.ac.uk)

or

Professor Bruce Evans    [bjwe@bruce-evans.co.uk](mailto:bjwe@bruce-evans.co.uk)

If you are still unhappy that the complaint has not been dealt with or you consider the complaint to be of a serious nature you can contact the university ethics committee at the address below.

***Will my taking part in this study be kept confidential ?***

All information that is collected about you will be kept strictly confidential. Any information that is shared with others (e.g. in reports and publications or is shared with the project supervisor) will have your name and address removed so that you cannot be recognised from it. Any audio recording will be kept securely and will not be accessed by anyone other than the researcher.

Data will be kept by the researcher for 5 years. It will then be deleted from the computer and any paper records shredded.

***What will happen to the results of the research study?***

The results of the study will be written up in a doctoral thesis available at London South Bank University Library and will also be published in a peer reviewed scientific journal for optometrists. Your information in the thesis and written papers will be anonymous and you will not be identifiable from this. You will receive updates each year of the research and an optional opportunity to feed back your views will be provided.

***Who is organising and funding the research?***

The researcher is self funding.

It is being jointly organised by

London South Bank University Faculty of Allied Health Professions, 90 London Road, London. SE1 6LN

0207 815 6100

and

The Institute of Optometry, 56 – 62 Newington Causeway, London. SE1 6DS

0207 407 4183

***Who has reviewed the study?***

London South Bank University Research Ethics Committee

The Institute of Optometry Research Ethics Committee

The code of conduct of the College of Optometrists will be observed.

Thank you for taking the time to read this

Yours sincerely

Louise Stalker

## ***Appendix 2ii Information sheet for child participants***

Study name:

What is the experience of a child with Autistic Spectrum Disorder when they have an eye examination?

Dear

My name is Louise. I am a student at university in London.



I would like it if you would help me in my study. I am learning about how you feel when you have your eyes tested.

I am trying to find out what you like



about having your eyes tested



and what you don't like.



Why have I been chosen?

I have chosen to ask you because you have just had your eyes tested and will be able to tell me what it was like.



What do I have to do?

I would like you and Mummy to visit me at the opticians just to have a talk.



I will ask you questions about the eye test that you had and you can show me the things that the optician used.

I will record what you tell me on a little digital video camera so I can watch or listen to it again later.



I will not show the video to anyone else unless you tell me to.

I will not ask you to do any tests.

If you would rather not answer some questions then this is fine.

What you tell me is private and no-one else will know what you tell me.

What could go wrong?

Nothing that we will do will hurt you and nothing can go wrong.

You can ask to stop at any time.

Why should I help ?

Hopefully with what you tell me I will be able to help Opticians make eye tests easier and more fun for you and other people in the future.



I hope that you will help me but it is important that you know that you don't have to.

Thank you

Louise Stalker

## ***Appendix 2iii Example of adapted information sheet for child participant***

### IMPORTANT MISSION: CAN YOU HELP?

My name is Louise, I am a student and I have been given the very important job of making eye tests better for children. I want to make eye tests as good as they can be so everyone will find them fun. I have heard that you had your eyes tested by Genevieve and I think that you would be the best person to help me with my mission!

For this mission I need you to help me complete the following stages :

- 1) Meet up at my friend, Deacon's, opticians in Tonbridge. We can talk and you can ask me anything you want to know about the mission and about me.



- 2) Look at some things that opticians use to test people's eyes so that you can tell me what are fun and what are not fun



- 3) Look at some photos of things that opticians use to test people's eyes and you will need to sort the photos into pictures of tests you like and tests you don't like.



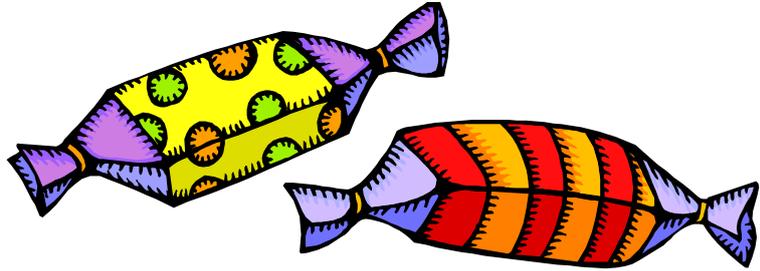
- 4) Have a look in the opticians room and talk about what Genevieve did when she tested your eyes.



- 5) If we complete the mission we can take some photos of the opticians, put them on the computer and type into the computer whatever you want to say about the photos.



- 6) If we do the mission well we might be able to print this out so it can be used by opticians to give to children when they go to have their eyes tested.



When we complete the mission you will receive some sweets as a well deserved reward

## ***Appendix 2iv Information sheet for ECPs***

### **Study Title:**

**What is the experience of a child with Autistic Spectrum Disorder when they have an eye examination?**

Date:

Dear

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which is shared with others (eg. in reports and publications or is shared with a supervisor) will have your name and address removed so that you cannot be recognised from it.

Thank you for reading this.

Yours sincerely

Louise Stalker

Researcher

## **Information sheet for participants**

### **Study title: what is the experience of a child with Autistic Spectrum Disorder when they have an eye examination?**

#### **What is the purpose of the study?**

The purpose of the study is to try to find out what an eye examination is like from the viewpoint of a child with an ASD. To find out how easy or hard it is, how much fun or how distressing it is and to ultimately look at what we have found out and try to form a theory as to whether eye examinations need to be adapted to make them more acceptable to children with an ASD and if so in what ways. Hopefully this will lead to better eye-care for this group of patients.

#### **Why have I been chosen?**

You have been chosen because you have specialist knowledge in the field of Austistic Spectrum Disorders.

#### **Do I have to take part?**

It is up to you whether or not you take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

If you decide to take part you are free to withdraw at any time and without giving a reason.

#### **What will happen to me if I decide to take part?**

Your involvement would be an interview with the researcher. The interview will be digitally recorded. All information is confidential and stored securely without reference to the names of the participants. The interview will be very informal with general questions about Autistic Spectrum Disorders, how you feel the diagnosis might affect a child when they have an eye examination, and your views of best practice. You will be sent a sheet of example questions before the meeting to give you a chance to think about them in advance.

You do not have to answer all questions if there are some that you object to. Your professional judgement is not being tested in anyway. The interview will last no more than 1 hour.

Only one interview will be necessary although it may be that the researcher will call you to clarify information later on in the analysis stage. This is will only be a brief contact and you can decline to comment further.

The interview will be at a mutually agreeable location such as a private space within your organisation or at my workplace, the Royal National Institute for the Blind, Judd Street, London.

The entire study will take 3 years but your involvement will just be to attend for your own interview.

**What are the possible disadvantages of taking part?**

The interview will take up one hour of your time.

**What are the possible benefits of taking part?**

There is no intended direct benefit to you however participation will hopefully help us to make sure that eye-care services for people with an ASD are appropriate and effective in the future.

**What if something goes wrong?**

If you are unhappy about some element of the study and need to complain there is a procedure arranged for you to be able to do this:

In the first instance contact the researcher Louise Stalker  
louise.stalker@yahoo.co.uk

If you need to pursue it further then you can contact the project supervisors :

Dr Martin Benwell martin.benwell@lsbu.ac.uk

or

Professor Bruce Evans bjwe@bruce-evans.co.uk

If you are still unhappy that the complaint has not been dealt with or you consider the complaint to be of a serious nature you can contact the university ethics committee at the address below.

**Will my taking part in this study be kept confidential ?**

All information that is collected about you will be kept strictly confidential. Any information that is shared with others (e.g. in reports and publications or is shared

with the project supervisor) will have your name and address removed so that you cannot be recognised from it. Any audio recording will be kept securely and will not be accessed by anyone other than the researcher.

Data will be kept by the researcher for 5 years. It will then be deleted from the computer and any paper records shredded.

**What will happen to the results of the research study?**

The results of the study will be written up in a doctoral thesis available at London South Bank University Library and will also be published in a peer reviewed scientific journal for optometrists. Your information in the thesis and written papers will be anonymous and you will not be identifiable from this. You will receive updates each year of the research and an optional opportunity to feed back your views will be provided.

**Who is organising and funding the research?**

The researcher is self funding.

It is being jointly organised by

London South Bank University Faculty of Allied Health Professions, 90 London Road, London. SE1 6LN

0207 815 6100

and

The Institute of Optometry, 56 – 62 Newington Causeway, London. SE1 6DS

0207 407 4183

**Who has reviewed the study?**

London South Bank University Research Ethics Committee

The Institute of Optometry Research Ethics Committee

The code of conduct of the College of Optometrists will be observed.

Thank you for taking the time to read this

Yours sincerely

Louise Stalker

## ***Appendix 2v Interview schedule - Expert eye-care professional***

Thank you for agreeing to take part in this study. As you know already one of the ways we are finding out this information is by interviewing you. The interview will last no more than 1 hour and you can ask to stop the interview at any time. You do not have to answer any questions that you don't want to. All information is confidential. The following is an outline of the interview but not necessarily the exact questions or order. You do not need to do anything before the interview, but if you would like to prepare then it may help to think about the questions below before the interview.

- 1) What do you think are the main barriers and facilitators of primary eye-care process for children with an ASD?
- 2) Do you think that children with an ASD have the same eye-care experience as typically developing children?
- 3) What tests do you as a practitioner find the most difficult to do with children with an ASD?
- 4) Do you think that there are some specific adaptations to the eye examination routine that are needed for children with an ASD? (Different to those that you would make for children generally).
- 5) Do you think that children with an ASD are more at risk of eye sight problems?
- 6) Do you think that children with an ASD are as likely as typically developing children to have attended for a routine eye examination below the age of 8?
- 7) Do you think that all optometrists should be expected to offer primary eye-care for children with an ASD?
  - If not, In what way do you think it should be delivered?
  - If yes, Do you think that there should be specific training for optometrists and if so what type of training do you think is needed?

- 8) What changes to the provision of primary eye-care would improve the care of children with an ASD?
- 9) Is there a difference in the ability to provide a suitable eye examination for children with an ASD between England, Wales and Scotland ?
- 10) Any comments that you would like to make that you feel would add to the study that have not be covered in the interview.

***Appendix 2vi Interview Schedule – Child Participants***

Thank you for helping me.

When we see each other I will be asking you some questions. It's not a test so it's OK if you don't want to answer some of them or you think that you don't know the answer.

This leaflet is to tell you some of the questions that I might ask.

I'd like to know about your eye test so I will ask you some of these questions:

What you can remember about your eye test?

What you liked about the eye test?

What the optician was like?

What you didn't like about the eye test?

What you think opticians can do to make the eye test better?

Do you want to have your eyes tested again next year?

Next, you can have a look at all the things in the optician's room and tell me what you think about them. I've got some pictures I'd like you to sort into pictures of things you like and things you don't like.

Finally, I'd like you to take some pictures of the opticians that I can put in a booklet to help explain to other children what it is like to have your eyes tests.

At the end there will be a little treat to say thank you for helping me.

I hope that will be OK – but you can miss out any bits that you don't want to do.

Best wishes

Louise

## ***Appendix 2vii Interview schedule for PCs***

### **Interview guide – parents/ carers interviews**

Thank you for agreeing to take part in this study which will look at your child's experience when they have their eyes tested. As you know already one of the ways we are finding out this information is by interviewing you. The interview will last no more than 1 hour and you can ask to stop the interview at any time. You do not have to answer any questions that you don't want to. All information is confidential. The following is an outline of the things that I will ask you. You do not need to do anything before the interview, but if you would like to prepare then it may help to think about the questions below before the interview.

#### **Part A)**

To get to know your child:

- 1) Please could you describe your child, their likes, dislikes, things that make them happy, things that make them sad, things that they find exciting, things that make them frightened?
- 2) What are their strengths and what do they find difficult?
- 3) How old are they and how are they educated (home, mainstream, special)?
- 4) How do they communicate best?
- 5) What do they do to overcome difficulties that they have?
- 6) Do you have any other children that do not have an ASD?

#### **Part B)** To find out about the eye test:

- 1) What was their reaction to the news that they were going to the optometrist (opticians)?
- 2) What would their reaction be next time?
- 3) Did they talk (depending on communication) about the eye test afterwards – if so what did they say or indicate?
- 4) Overall was it a good experience or a bad experience for them?
- 5) Do you think that your child's vision is good- why?
- 6) In what way was the eye test adapted to your child's needs?
- 7) Do you think that the optician understood your child's needs?
- 8) Do you think that the result of the eye test was accurate?
- 9) Do you think that eye tests are important?

**Part C) About you:**

- 1) How did you feel while your child was having their eyes tested?
- 2) How likely are you to arrange another test when your child receives their reminder?
- 3) Do you find it easy to book an appointment with an optician for your child?
- 4) How did you choose the optician?
- 5) Is the eye test easier or more difficult than other appointments that he/she has to attend?
- 6) What information were you hoping to get from the test and did you get this?
- 7) Did s/he have all the tests done that your child that doesn't have an ASD had done – and if not which ones can you remember were not possible or omitted?

## **Appendix 3 Interview adaptations**

### ***Appendix 3i Fact file for Steve(C)***

Thank you for helping me!

I am trying to make eye examinations better for children. So that I know what children like and don't like about eye examinations I would like to ask you some questions. I hope that is OK with you.

Outline of what we are going to do:

- 1) We fill out a fact file so you know what this is all about and who I am.
  
- 2) I will ask you all about your eye examination, what you like and what you didn't like. What you would like to change if you could. It is important that you know that you do not have to answer any question that you don't want to. There are no right or wrong answers. This is not a test.
  
- 3) We will look at some photographs of pieces of equipment and I will ask you to put them into piles of things that you like and things that you don't like. We may look at some pictures on the computer too for you to tell me what you think of them.
  
- 4) If we have enough time we will look at a little video of someone having an eye examination and you can tell me what you like and what you don't like about the tests that the optician does.
  
- 5) I will give you a little gift to say thank you for helping me.



***Appendix 3iii Examples of photographs taken by the children***



### ***Appendix 3iv Questionnaire for Dylan(C)***

I am a research student at London South Bank University, my name is Louise Stalker. I would be grateful if you could help me with my research study.

Study Title : What is the experience of children with an autistic spectrum disorder when they have an eye examination?

As you have recently had an eye examination your answers would be very helpful. It is hoped that the results of this survey can be used to develop training for opticians. This will make the eye test a better experience for people with autism.

The survey should take no more than 10 minutes, it looks long but there are only 2 questions on each page and you will receive a reward to say thank you for completing it. For most of the questions there are suggested answers that you can choose, if you don't agree with any of these answers then please type in anything else that you think is better. If there are any questions that you don't want to answer that is OK.

#### Question 1)

How did you feel when you had your eyes tested? Circle any that apply to you

Happy

Excited

Frightened

Confused

Unhappy

OK

Other: ( any other words that you want}

#### Question 2)

The eye test was : circle any that apply

Fun

Boring

Difficult

Easy

Exciting

Annoying

A waste of time

Enjoyable

Uncomfortable

Over-whelming

frightening

Other:

Question 3)



Look at the picture - did you have this test done?

If yes, did you think it was :

a) good

b) OK

c) Bad

d) Very bad

Question 4)



Look at the picture- did you have this test done?

If yes, did you think it

was :

a) Good

b) OK

c) Bad

d) Very bad

Question 5)

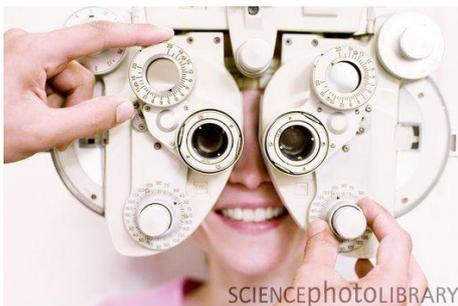


Look at the pictures did you have to put these frames on ? If yes , was it

- a) Good
- b) OK
- c) Bad
- d) Very bad

If no , do you think you would mind if the optician had asked you to wear them for some of the tests?

Question 6)



Did you look through this machine?

If yes, was it

- a) Good
- b) OK
- c) Bad
- d) Very bad

If no, would it have been OK if the optician had asked you to look through this machine ?

Question 7)



Look at the pictures did you do this test ?

If yes, was it

- a) Good
- b) OK
- c) Bad
- d) Very bad

If yes, did you mind putting your chin on the chin rest?

If no, would it have been OK if the optician had asked you to do this test (you would put your chin on the rest and the optician uses it to shine a light onto the front of your eyes to check that they are healthy)?

Question 8)



Look at the picture, did the optician use a light like this? If yes, was it

- a) Good
- b) OK
- c) Bad
- d) Very Bad

If yes, was it Ok when the optician came up close to you to look at your eyes?

If you didn't have this test done, would it have been OK if the optician had used this light ?

Question 9)

Did the optician ask you to read letters from a chart?

If yes, was it

- a) Good
- b) OK
- c) Bad
- d) Very bad

Would you prefer to look at a chart with pictures instead of letters like the one in the picture below?



Question 10)



Look at the picture , did you have to wear red and green coloured glasses similar to these?

If yes, were they

- a) Good
- b) OK
- c) Bad
- d) Very Bad

If no, would it be ok if an optician asked you to put these on for a special test that checks whether your eyes work together?

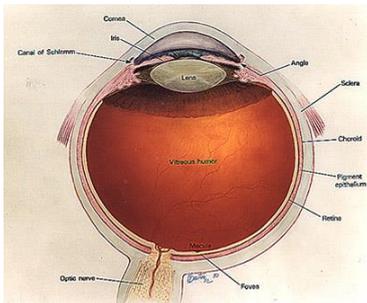
Question 11)



Look at the picture, did the optician cover one of your eyes with a patch similar to this one? If yes, was it

- a) Good
- b) OK
- c) Bad
- d) Very Bad

Question 12)



Did the optician have a picture similar to this of the human eye on their wall?

If yes, was it

- a) Interesting
- b) Not very interesting
- c) Boring
- d) Frightening

If no would it have been

- a) Interesting
- b) Not very interesting
- c) Boring
- d) Frightening

Question 13)

If the optician said you need to wear spectacles would it be good or bad?



Question 14)

If the optician put drops in your eyes would it be

a) OK

b) Bad

c) Very Bad ?



Question 15)

If you had to wait in the waiting room for more than 5 minutes because the optician was delayed by the patient before you would it be OK, how would you feel about it?

Question 16 )

Was there any test that the optician asked you to do that you would not want to do again? (please describe the test if you do not know what it was called)

Question 17)

Please put anything below that you think would help make eye tests better for people with autistic spectrum disorders :

Thank you very much, your help is important to us.

## Appendix 4 Ethics approval letters

### Appendix 4i LSBU



Direct line: 020-7815 6024  
E-mail: [dippenas@lsbu.ac.uk](mailto:dippenas@lsbu.ac.uk)  
Ref: UREC 1121

Louise Stalker  
31 Stacey Road, Tonbridge  
Kent  
TN10 3AP

Dear Louise,

**What is the experience of a child with Autistic Spectrum Disorder (ASD) when they have an eye examination?**

Thank you for submitting the documents from the review and acceptance of your study from the Institute of Optometry's Research and Ethics Committee.

I am pleased to inform you this application has been approved and upheld by Chair's action on behalf of the University Research Ethics Committee.

I wish you every success with your research.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Sharon Dippenaar".

Sharon Dippenaar  
Secretary, LSBU Research Ethics Committee

cc:

Prof Joan Curzio, Chair, LSBU Research Ethics Committee

## **Appendix 4ii LSBU amended approval**

**London South Bank  
University**

Direct line: 020-7815 6024  
E-mail: [dippenas@lsbu.ac.uk](mailto:dippenas@lsbu.ac.uk)  
Ref: UREC 1121

Louise Stalker  
31 Stacey Road  
Tonbridge  
Kent  
TN10 3AP

Dear Louise,

**Re: What is the experience of a child with Autistic Spectrum Disorder (ASD) when they have an eye examination? (UREC 1121)**

Thank you for submitting this proposal and for your response to the reviewers' comments.

I am pleased to inform you that your request to the University Research Ethics Committee to include specialist health care professionals in your above study has been reviewed. The Chair is able to confirm that the study was completed in keeping with the London South Bank University Code of Practice for Research with Human Participants.

I wish you every success with your research.

Yours sincerely,



Sharon Dippenaar  
Secretary, LSBU Research Ethics Committee

cc:

Prof Joan Curzio, Chair, LSBU Research Ethics Committee

## **Appendix 4iii Institute of Optometry**

**Ronald Rabbetts, MSc, FCOptom, SMSA, DCLP**  
31 Warblington Street  
PORTSMOUTH, PO1 2ET

Phone: 023 92816571  
Email: ronald.rabbetts@virgin.net

14 September 2011

Ref:

**Research application to LSBU by Mrs Louise Gow (Stalker)**

**What is the experience of a child with Autistic Spectrum Disorder (ASD) when they have an eye examination?**

To whom it may concern:

As Chairman of the Institute of Optometry's Research and Ethical Committee, I am writing to confirm that this application has been considered by the IoO REC.

Our various comments and suggestions have been taken into account, and the various documents revised accordingly. She has answered our main query on the number of subjects to our satisfaction – Grounded Theory is not something with which we are familiar, but obviously the advice from her tutors at LSBU is that eight subjects should be sufficient.

Hence the IoO REC approves her application for this research project.

Yours sincerely

*Ronald Rabbetts*

## **Appendix 5 Methods review and analysis examples**

### ***Appendix 5i Review of adapted interview methods***

The aim of the interview is to gain an understanding of the participant's interpretation of the subject. The interviewer is there to

“listen, to observe with sensitivity and to encourage the person to respond”  
(Charmaz, 2006)

Structured interviews enable the researcher to ask specific questions with a limited range of possible answers (Punch, 2005). This type of interview is prescribed and standardised and is more suitable for survey research than grounded theory.

Semi-structured interviews have some standardised or focused questioning and some open questions (Charmaz, 2006). This enables the researcher to cover a range of questions that they are interested in as well as having some flexibility for the interview to change direction where needed.

Unstructured interviews have an open format allowing the participant freedom to say what they want to say rather than be constrained to specific questions or ranges of possible answers. This enables the collection of rich data (Holloway, 2005; Charmaz, 2006)

“a flexible, emergent technique; ideas and issues emerge during the interview and interviewers can immediately pursue these leads” (Charmaz, 2006)

Corbin is not specific regarding the type of interviews she recommends but does suggest that unstructured interviews tend to give the most data (Corbin and Strauss, 2008). Holloway recommends an unstructured approach initially to gain a grasp of the subject and then subsequent interviews should become more structured to focus on the emerging concepts (Holloway, 2005). In order to build rapport Charmaz recommends that the interviewer starts with ‘warm up’ questions (Charmaz, 2006) and leaves the most important questions to later. Charmaz considers this to be important as the participant is more likely to be open if this rapport is established first (Charmaz, 2006).

Kvale and Brinkman highlight the need to consider the power relationship and how this affects the perception of the situation and outcome from both sides (Kvale and Brinkman, 2009). This includes the need to account for differences in age, gender

and social status (Holloway, 2005; Kvale and Brinkman, 2009). The choice of location can reduce any perceived power imbalance and therefore this needs careful consideration (Barker and Weller, 2003).

A further consideration is how an accurate understanding of the meanings of words and phrases used can be ascertained. This ensures that the data is accurately analysed and not forced (Charmaz, 2006).

### ***Interviewing children***

The interview process is different for children than for adults and in order to collect accurate data literature of interviewing techniques with children was studied. Coad and Lewis (Coad and Lewis, 2004) carried out an extensive review of literature on engaging children in research. This review shows that interviews with children can be very effective if the structure and schedule are planned and the child is given full information in advance. It is possible to adapt qualitative interviews effectively for children to participate and enable their voices to be heard (Lewis, 2002).

Kvale and Brinkman (Kvale and Brinkman, 2009) identify several points that need to be considered when interviewing children. The power imbalance is significant (also (Mauthner, 1997; RW.ERROR - Unable to find reference:240). Children may attempt to answer questions even if they don't understand them because they feel that they must answer. Kellet & Ding in (Fraser *et al.*, 2004) suggest that this is because children are 'conditioned' to think that not answering would be rude. Ogina suggests that this can be reduced by asking them to elaborate on their answer avoiding the yes/no options (Ogina and Nieuwenhuis, 2010) (Fraser *et al.*, 2004) highlight the need for rapport and trust building. This enables the child to feel comfortable enough to give their complete views (Mauthner, 1997).

Questions should be age appropriate and long complex questions avoided. Coad and Lewis add to this that if communication skills are limited rephrasing may help to increase understanding (Coad and Lewis, 2004) (Fraser *et al.*, 2004) suggest that children may expect more guidance from the interviewer as they do from their teachers. They also recommend giving them longer to answer than you might expect them to need. The location should be chosen that is familiar to the child to make them feel more comfortable. Finally they suggest that the use of a different context such as drawing or story telling may be more child friendly.

Lewis and Porter (Lewis and Porter, 2004) recommends the following adaptations to facilitate interviews with children; ensuring the child knows it is ok to say that they don't know or don't understand, avoid repetition of questions, aiming for uninterrupted narrative rather than yes/no responses and the use of statements to discuss rather than questions.

There is no consensus of opinion regarding the best type of questioning with some recommending direct, structured questions Carney et al (Carney *et al.*, 2003) and others such as Balen et al (Balen *et al.*, 2000/2001) suggesting open questions. Balen suggests open questions as this gives the child greater freedom in responding whereas direct questions require understanding (receptive language) and the ability to answer (expressive language) which may be difficult for some. It is important that the child is given space and privacy so that their views are not influenced by those people around them that might expect them to respond in certain ways (Mauthner, 1997).

It has been shown that the use of variety of innovative techniques can help engage children in qualitative research (Lewis and Lindsay, 2000; Lewis, 2002; Lewis and Porter, 2004; Mauthner, 1997; Balen *et al.*, 2000/2001; Carney *et al.*, 2003; Ogina and Nieuwenhuis, 2010; Punch, 2002). These techniques add an element of fun and they reduce boredom and increase cooperation. The views of children whose verbal skills are limited can also be recorded through these methods. In particular pictures can help children express fear and anxiety better than words. A range of activities enable the child to have time to think and also takes accounts of different personalities and abilities (Punch, 2002). Using a combination of techniques also adds an element of triangulation which improves the rigor of the research (Balen *et al.*, 2000/2001). The use and interpretation of the findings from these methods required caution (Backett-Milburn and McKie, 1999). They recommend that the researcher appraises these techniques first and also that interpretation involves reflexivity so that the true meanings are drawn out taking into consideration issues such as the child's abilities and setting and understanding of the task.

Therefore the use of additional techniques need to be planned specifically for the participants considering their age, needs and the setting of the interview.

### Appendix 5ii Examples of Open coding

Code	Definition	memo
Finds it difficult to understand what people mean	He is sometimes a bit slow in understanding what people mean when they talk to him	<p>This is the processing issue that several of the carers have commented on. They might not get it straight away it might take a little while to cotton on despite the cognitive ability being high. Perhaps too much information at once or too many other distractions.</p> <p>“He’s a lot better at adults than he is children but he can’t quite work out, he is always behind as in working out what they mean and what have you. LS: the processing of it PIPPA(PC) : the processing, now he’s getting frustrated”</p>
He loses his temper	He gets frustrated and loses his temper much more now than before	<p>He used to be calmer but recently his behaviour has become much more aggressive and abusive, He gets frustrated and throws paddies but he didn’t before – hopefully this is just a phase due to everything else going on in his life.</p> <p>“ now he’s getting frustrated. He’s got volume to his voice and he’s shouting ‘you’re not f... listening to me, you’re not ‘ which is good because he is developing but it isn’t in a 10 year old. The 5 year old next door ‘sort of went [face]’ because he’s never seen him like that TIM’s having paddies”</p>

### Appendix 5iii Examples of Axial coding

Category	Code	Definition
Personal traits	Humour	Sense of humour – tends to be slap stick or silly sometimes inappropriate not knowing when to stop. Playing tricks and laughing excessively at other peoples misfortunes ADRIAN(C) FREDDIE(C) and CHRIS(C)
	Stands out	Noticeable compared with other children – not the same as other children. ADRIAN(C) and CHRIS(C) are good at sport
	More flexible now	As he has got older he is more able to cope in different situations – it has got easier
	Interested in the pictures of the inside of the eye	STEVE(C) liked the pictures of the inside of the eye because he had learnt about it all at school and found it interesting. TIM(C)also found it interesting
	Interested in some of the tests	CATHERINE(PC) asked a lot about the colour vision test and was interested in some of the other tests.
	Outdoors	Enjoys all activities outside running off energy and enjoying playing
	Gets anxious about things that peers have told him about eye tests	
	Creative	Enjoys making things or designing things
	Dislikes costumes or disguises	Doesn't like it if someone changes their appearance by wearing something they wouldn't normally wear – such as borrowing someone's coat. I wonder if this is linked with dislike of change and having to

		connect what they know of one person to the person looking different to usual. FREDDIE and DYLAN(C)
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### **Appendix 5iv Examples of open code memos**

<b>Code</b>	<b>Definition</b>	<b>Memo</b>
Likes the trial frame because it looks like Harry Potter's	He said that the trial frame was his favourite thing in the room because it reminded him of Harry Potter	When given a free choice of everything in the room he said he likes the trail frame best because he has an obsession with Harry Potter. This required a bit of imagination. It was good that he liked to wear them as so many of the participants did not like them. He didn't seem worried about touch and thought they were ok because Harry Potter wore them. If he can identify with things he seems more comfortable, more in control and less anxious.
Perfectionist	He wanted to do the task perfectly and got stressed when it didn't go to plan	He had previously said he was good at drawing but when he found it difficult he started to go into a meltdown such that I paused the interview and thought it might have to be stopped. He got disproportionately stressed about the drawing because he couldn't get it right – maybe because I was watching him he lost confidence. "SIMON(C): the Harry Potter glasses LS: do you want to draw them for me then? [SIMON(C) starts to draw but can't do it and starts to show signs of frustration] Doesn't matter if they are not

		<p>right just draw how you like, are there any in here ? “</p> <p>... “Its just so I can remember what you like that’s all</p> <p>SIMON(C): [starts to show signs of a meltdown, breathing quickly and rocking]</p> <p>LS: its ok don’t worry [calms down a bit]”</p> <p>...”ANNE(PC) : that’s it</p> <p>SIMON(C). Do you want mum to draw it?</p> <p>LS: or do you want to just write it. You don’t have to do any drawings sweetie.</p> <p>SIMON(C): just can’t seem to get it right, bash my head on the door some times. [very quiet hard to hear]”</p>
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## ***Appendix 5v Analysis memo of card sorting Simon(C)***

“Over all he liked the ‘fun’ tests that did not require bright lights-stereo tests and colour vision tests.

If he didn’t recognise an instrument he was afraid of it, and imagined it did things that it doesn’t. He decided that the SLM puffed air at him – but it wasn’t even switched on so it didn’t even shine a light at him. He was frightened and therefore got worried about it.

He liked the idea of having a fundus photo taken but not the idea of looking at the photo. He likes computers generally so maybe that is why he liked it. He was ok with the normal picture of the eye on the wall but the room also had a textured diagram of the eye and he really didn’t like that at all.

He seemed very anxious generally but interestingly there were only a few tests that he said he didn’t like – obviously drops was there – this is a common theme throughout all the children’s interviews. He doesn’t like bright lights. He was clearly anxious of things he hadn’t seen before – such as the RAF rule – it looked scary – unfortunately there wasn’t one in the clinic for him to play with. I think this should be considered fear of the unknown. He also didn’t like the look of the combi- unit – I think this is fear of the unknown too because he likes the chair on its own- it just looks scary.

I felt that the results were reliable as he chose not to place some cards and some similar cards he made the same selection for.

Considering how anxious he is I think that practitioner personality – and trust in the practitioner plays a big part in the success of his test as I think under normal circumstances all of these tests would be a challenge to him. This is the same with CHRIS(C) who thought his practitioner was marvellous and he managed very well despite having big problems in other settings. If he trusts the practitioner then all the tests are easier.

## ***Appendix 5vi Example of Research diary entry***

Diary Entry 20/05/2012 research journal

I have now finished transcription of the first interview. It was so difficult. I really wasn't expecting it to be that difficult. I think possibly it was complicated by the conversation being 3 way rather than 2 way. Also Mick(PC) had most to say and as I thought I was interviewing Rosie(PC) I had the Dictaphone in the wrong place which meant I had to check and double check some of his comments especially when they were both speaking together.

I am worried about the details of the interview – the pauses and times when people spoke over each other, as to whether the transcription reads exactly as it should. I will go back over it.

In the next interview I will amend my techniques in 3 ways particularly:

- 1) If more than one person – interview them separately
- 2) Check that Dictaphone is really in the right place
- 3) Slow down so I don't speak over them – I need to give them more space to speak

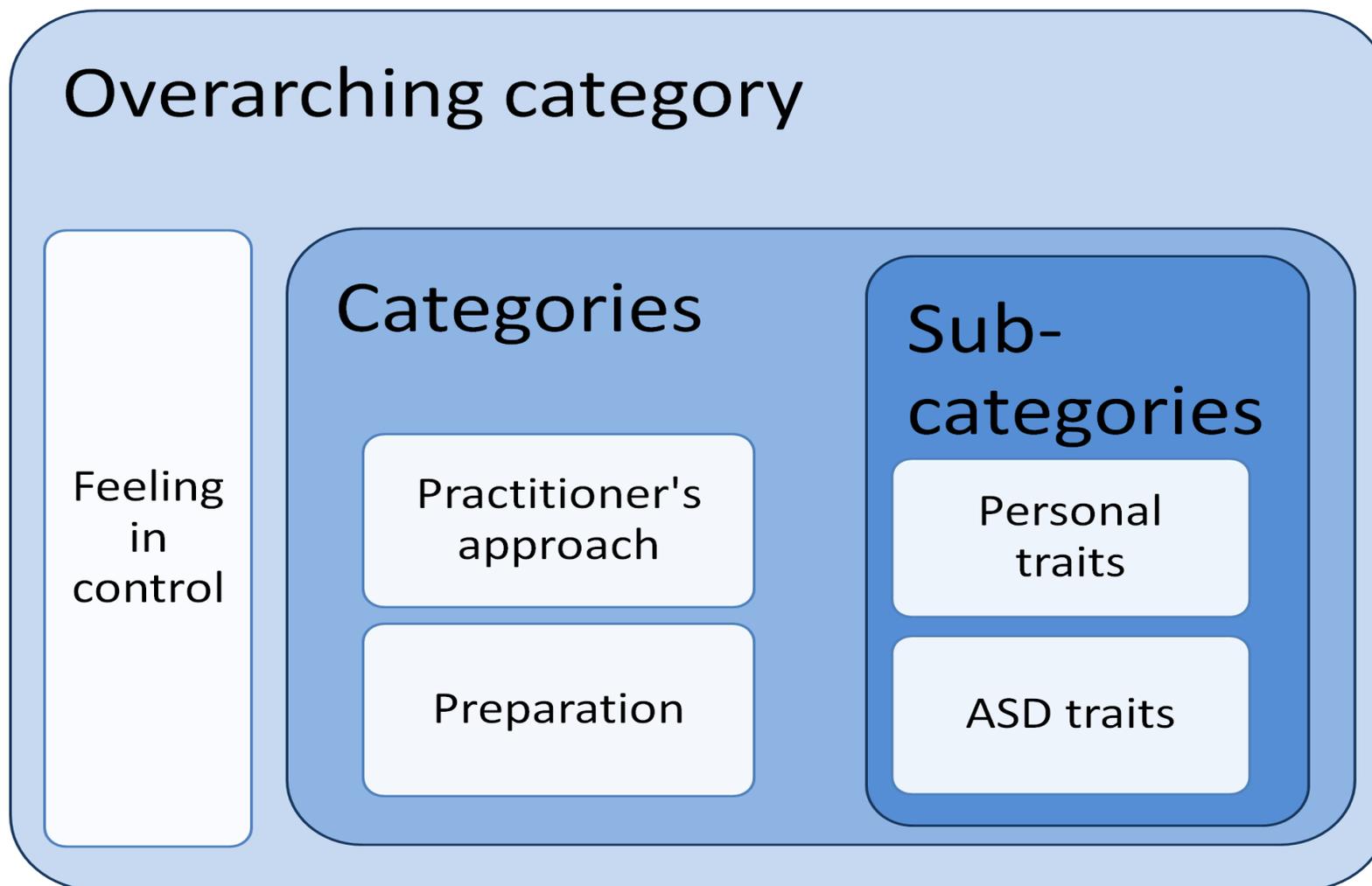
Having done this first interview I spoke to Martin Benwell about the difficulty of interviewing people who have difficulty with the questions due to cognitive function – was I posing too many leading questions. He said that this was fine in areas that I really need an answer (ie the section where I find out about the child for purposes of planning the interview) but not when trying to elicit views of the research question. Reviewing the transcript in the light of this – I think that I did pose too many leading questions. I will be more careful next time.

**Appendix 5vii Example of tables used to group axial codes for analysis**

Code	Sub category	Category
Very perceptive	Perceptive	Personal traits
Sense of humour	Humour	
Curious	Curious	
Slightly worried about eye test	Anxiety	
Observant	Attention to detail	
Grown up vocabulary	Grown up	
Aware of others feelings	Perceptive	
Robot helper	Innovative	
Straightforward	Literal thinking	
Good recall of the test	Memory	
“Don’t like the light shining in my eye”	Hypersensitivity	Sensory
3D tests cool	The effect	
Changing vision with lenses is strange	The effect	
“hurts my eyes”	The effect	
Touch	Hypersensitivity	
Doesn’t like wearing glasses	Hypersensitivity	
Things go blurry close up	The effect	
Scared of the dark	Frightened	
Prefers the phoropter head	Other gadgets	Gadgets
Prefers the SLM to direct	Other gadgets	
“who doesn’t like computers”	computers	
Camera frightening	Other gadgets	
Dislikes waiting	Waiting	Challenges
Explanation helped but also made it worse	Explanations	Practitioner approach
Not the test necessarily that is off putting	Overwhelming	
Growing out of stickers	Rewards	
Ok with going to the optometrist	Good	Overall perception of experience

<b>Code</b>	<b>Sub category</b>	<b>Category</b>
Experience is mixed	Mixed	
Lots of things I don't like	Bad	
I wouldn't say any were enjoyable	Bad	
Frisby 3D test looks a bit boring		Specific tests
Likes the look of the consulting room		
Least favourite test is the eye patch		
Likes trying frames on		
Images on the picture chart not recognisable		
Picture chart is hard		
Liked the colour vision test best		
Good understanding of colour vision		
Motility was hard		
Picture matching is easy		
Advanced card sorting		
Likes the big chair		
Model eye freaky		

*Appendix 5viii Example of the use of diagrams in the theoretical analysis*



## ***Appendix 5ix Axial coding memo***

Emerging categories analysis up to Andrew(C) memo

Andrew(C) was not so keen on his eye test. He had been to 2 different optometrists in short succession and had a bad experience with one and a reasonable experience with the next.

Andrew(C) had 2 particular issues with the eye examination and he kept returning to these points over and over. He doesn't like the feel of anything touching his face – even the occluder- even if he holds it himself. He really doesn't like drops – the blurring effect and the burning discomfort. It was particularly noticeable that he was nervous of any gadget he didn't know – his fear of the unknown was the greatest of all of the participants.

Further to the categories already developing

Sensory – Sensory overload – this was evident only in Andrew(C) when he said he could not decide and there were too many questions. Sensory overload was greater in others. Hypersensitivity- on the other hand this was very evident due mostly to his repeated comments about touch – the touch of the trial frame, the touch of the chin rest, the occluder etc etc. His experience of the eye examination was significantly the poorer for this sensitivity not being identified by either of the practitioners who saw him.

Traits- in Andrew(C) there was no evidence of dislike of change but I think that would not be possible to demonstrate because he hasn't had the consistency of an optometrist to get used to in order to worry about change, however this category still stands until proved otherwise. Andrew(C) additionally really demonstrated the impairment of communication – the difficulty with all the questions, reading letters as words, preferring upper case letters, misunderstandings in the interview highlighted his communication issues. Obsessions are still evident although in Andrew(C)'s case I think this is likely to affect his experience in the eye examination.

Gadgets- Andrew(C) does like computers but not so much as the others. He will play on the computer but isn't so obsessed with them. I suspect that is also why he is a little more scared of the larger pieces of equipment we use –

simply because he is not so familiar with technology. He suffers more from the fear of the unknown than the others do but I think that when familiar with them he would be fine with it all.

Patient behaviours- still not quite convinced this is the right title – I think that it seems to imply they are doing something wrong but what I'm trying to collate here is that range of behaviours / reactions to the situation that are not quite as you would expect. For Andrew(C) there were less 'behaviours' of note – but in addition to previously there is the sub-category of frightened. Curious was also in the list for Andrew(C) but many of the other ones were missing. Again that doesn't rule them out it just means that these behaviours are individual. The ASD profile is known as the spiky profile because of the variability in the condition and because of the unpredictability of it. This links well with the person – centred approach to planning an assessment taking into account the individuals set of concerns rather than a rule of thumb.

Judging by the data from the children so far curiosity and anxiety are common and need special consideration in the planning and preparation for an eye examination. On the up side sense of humour so far is across the board – something that could be used to put the child at ease as they all seem to have a good sense of humour.

Practitioner approach – this is the manner in which the tests were carried out and adaptation or no adaptation was made. In Andrew(C)'s case the latest optometrist (the more successful test of the two) he describes as talkative and nice. It would sound like she involved him and tried to relax him. This obviously has an impact on the experience. They seem to like rewards but quite specific rewards, one liked some stickers but not others, another didn't like stickers at all. Dylan(C) would only do anything if there was a financial reward attached! I suppose this will vary with age and IQ. However in common is that they like encouragement from the practitioner- that adds to a good experience if they feel that their hard work was being rewarded.

Familiarisation – I've added this category in because it doesn't seem to sit well in any other section. By this I mean the flexibility to allow a child to touch and hold and play with the equipment. To meet the practitioner to sit in the chair and to see the scary instrument room etc. If the child has explanations and a chance to touch the equipment they may be able to overcome the fear

of the unknown. The experience is definitely worse where a child hasn't been allowed to become familiar with the set up first. This category would probably contain such things as explanation, preparation, and hands on. Andrew(C) experienced explanation and hands on. The others had varying degrees of explanation offered. The drops experiences being classic examples.

Challenges- This is unchanged from the previous memo. Waiting is an issue that has a large bearing on the experience of the eye examination for children with an ASD

**Appendix 5x Integration of coding for Professionals**

Overarching category	Category	Sub-Category	Axial codes	Memo
Enabled to feel in control				<p>Over arching theme of the findings are a need for the child to feel in control: to feel comfortable with the environment, with the practitioner and to only do tests that they are comfortable with. There is no particular group of tests that cause a problem. When they are disliked the reaction is far more acute than it would otherwise be. Computers are generally liked and drops generally not liked. Hypersensitivities need to be considered and the test needs to be planned around the child's needs. Fear of the unknown and change are major factors in the success of the test and therefore the practitioner's approach needs to be tailored to the child's individual needs. The categories are those broad areas that support a good experience or create a bad experience and the subcategories and axial codes are the components of these categories. If you tailor the test taking these into consideration the child will feel that they are in control all the time and the test will be a better experience.</p>

Overarching category	Category	Sub-Category	Axial codes	Memo
	Impact of practitioner		Personality	<p>The practitioner's personality seems to be key to the experience for the children.</p> <ul style="list-style-type: none"> <li>• Fun and funny</li> <li>• Welcoming</li> <li>• Familiar</li> <li>• Explains things</li> <li>• Bossy</li> </ul> <p>3 of the children had regular optometrists that that they felt very comfortable with. One child said that any test would be ok with his practitioner but not with anyone else. 1 child had been to many practitioners trying to find a suitable one and this time had such a good experience that his mother has decided to stick with this practice.</p>
			Practice	<p>The children stated several things that they didn't like about practice environment</p> <ul style="list-style-type: none"> <li>• Don't like the combi units</li> <li>• No scary textured pictures or models (anatomical diagrams ok)</li> <li>• Like leaflets</li> <li>• Like rewards</li> <li>• Like the black chair</li> <li>• No waiting</li> <li>• Don't like restricted spaces</li> </ul>

Overarching category	Category	Sub-Category	Axial codes	Memo
			Continuity	Continuity is reassuring they know where they are and what will happen. Change causes anxiety and then challenging behaviour
	Preparation	adaptations	Training in ASD awareness	Practitioner and staff need to be aware of ASD and what impact it might have on the success of eye examinations
			Pre-test information about special needs	Information in advance as to what might be challenging and what are the abilities of the child so that the test can be tailored appropriately so the child does not feel challenged <ul style="list-style-type: none"> <li>• Abilities</li> <li>• Fears</li> <li>• Previous experience</li> <li>• Communication</li> <li>• Triggers</li> </ul>
			Equipment according to needs	Prepare equipment according to the need of the child so that it is ready and appropriate and so that the test flows well so the child does not end up waiting or attempting things that are too difficult or too easy, also so that the child has as much done in as short a space of time as possible
		Impact of ASD traits	Fear of the unknown	All the children indicated in some way fear of instruments that they did not recognise or of

Overarching category	Category	Sub-Category	Axial codes	Memo
				rooms that had gadgets in that looked scary. If they do not know what the machine or test does then they tend to be frightened and this can trigger challenging behaviour
			Dislike of change	Nearly all the children indicated that when things change they don't like it or when things stay the same they are more comfortable. They all showed attention to detail and observational skills which meant that when things are not quite as they expect they notice it and also notice details that are not really that important
			Own way	All the children wanted their own way and to be in control of the situation.
			Hypersensitivities	Hypersensitivities showed up throughout the interviews with children expressing a dislike of <ul style="list-style-type: none"> <li>• Touch (nearly all the children disliked touch)</li> <li>• Light</li> </ul> The eye examination involves lights and touch right through and therefore this is difficult to avoid but giving instructions and options should help to control the distress and help them feel in control because they know what is happening and how long it will last

Overarching category	Category	Sub-Category	Axial codes	Memo
			Anxiety	<p>The children expressed anxiety in many ways</p> <ul style="list-style-type: none"> <li>• Getting it wrong</li> <li>• Change</li> <li>• Lights</li> <li>• Health</li> <li>• Doing tests</li> <li>• Having to do things they can't such as reading</li> <li>• Choices</li> </ul>
			Confidence	<p>This links with the anxiety. Several of the children exhibited negativity and lack of confidence with a tendency to give up too quickly or to say they couldn't do it.</p>
			Concrete thinking	<p>Takes phrases and comments literally. This means that if you ask them to describe something they will give every detail, if you use an analogy they will get confused. They may not understand what you are saying.</p> <p>This also affects the picture charts that are representative and therefore they may struggle to recognise</p>
			Concentration	<p>Easily distracted and therefore tests need to be done that</p> <ul style="list-style-type: none"> <li>• Are interesting to the child</li> </ul>

Overarching category	Category	Sub-Category	Axial codes	Memo
				<ul style="list-style-type: none"> <li>• Short</li> <li>• Relevant</li> </ul> <p>The room needs to have as few distractions as possible.</p>
			Obsessions	<p>Obsessions and repetitive behaviour is common in ASD. The children show a range of obsessions</p> <ul style="list-style-type: none"> <li>• Particular toys</li> <li>• Interests</li> <li>• Behaviours – flapping, fiddling, dancing , spinning</li> <li>• Routine – calming routines</li> </ul>
			Processing	<p>Thinking longer than usual before answering a question was commented on by most of the children's carers. Processing visual information and other stimuli especially when more than one input at a time means that their response takes time – this time needs to be allowed otherwise the communication is hampered and they will get frustrated and out of comfort zone.</p>
			Sensory overload	<p>Sensory input can overwhelm quickly. Minimise the lights, tactile and auditory information should help.</p> <p>Should be considered when using blurry lenses several of the children commented they didn't</p>

Overarching category	Category	Sub-Category	Axial codes	Memo
				like the feeling and didn't like the fluctuation of the vision.
			Social interaction	Lack of social skills <ul style="list-style-type: none"> <li>• Knowing how to request things politely</li> <li>• How to react to others</li> <li>• How to express a dislike effectively</li> <li>• Cope with other people</li> </ul>
		Impact of personal outlook	Likes	This covers a range of their particular likes as well as specific to the test <ul style="list-style-type: none"> <li>• Things that they like obsessively</li> <li>• Tests that they enjoy</li> <li>• Sensations that they like</li> <li>• People</li> <li>• Computers</li> </ul> Things that they like can be used to interest and engage them and improve the outcome and reduce risk of meltdown or reward them
			Dislikes	As above only the opposite <ul style="list-style-type: none"> <li>• Dislikes</li> <li>• Fears</li> <li>• Worries</li> <li>• Obsessions</li> </ul> Things that they don't like will cause lack of interest, frustration, fear or anxiety

Overarching category	Category	Sub-Category	Axial codes	Memo
			Experience	<p>What has happened before influences how they will approach this test</p> <ul style="list-style-type: none"> <li>• Good experience</li> <li>• Bad experience</li> <li>• Continuity</li> <li>• First test</li> <li>• Input of friends</li> </ul>
			Characteristics	<p>Every individual has a set of characteristics and these will affect how they respond to the test</p> <ul style="list-style-type: none"> <li>• Sense of humour</li> <li>• Hobbies</li> <li>• Moods</li> <li>• Talents</li> <li>• Abilities – reading etc</li> <li>• Curious</li> </ul>

**Appendix 5xi Example of the triangulation of data in category development**

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
Impact of ASD traits-  : if the traits of ASD are not accounted for in the eye-care process then the outcome is poor. The children have difficulty understanding, interpreting what is expected of them and therefore can struggle with tests that children with the same level of intelligence would find easy. They have	Hypersensitiv ities	Children with ASD can be hypersensiti ve to sensory stimuli and sensory overload	<p>“LS: was there anything particularly you were worried about? Steve(C): um in particular I was worried about, in some opticians they shine a light into your eye to see what’s in it, I don’t like the light shining in my eye” “Simon(C): and it’s like [demonstrates a flash]</p> <p>LS: that’s it Simon(C): yes it was big light and I had to close my eyes to get rid of that lighty thing”</p> <p>“LS: do you think that would be better than her touching your eyes or worse? Andrew(C): yes because that would be better than her touching my eyes</p>	<p>“Pippa(PC) : more like touch, er light touch he might say you are burning you’re very very hot. He says that about the tooth paste, had the same toothpaste for years and it still burns mum he reacts overreacts to is but we’ll get there [laughs].”</p> <p>“Zahra(PC) : he is very very sensory so the slightest little thing, touch, smell, lights can make him flap.”</p> <p>“Zahra(PC) : I do</p>	<p>Beth(ECP): that room is full of equipment as they tend to be, different sounds, different smells, different people it becomes such an ordeal to just even walk into the opticians let alone have a test, have the lights turned out, have some things shone in your eye, have a silly pair of glasses put on, have things made blurry and then less blurry with lenses, the whole thing is just too much.”</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
<p>difficulty communicating which means that they might not understand what is being asked or have difficulty expressing their responses. They do not find the rules of social interaction easy which means that they may appear rude, aloof or uncooperative. They do not cope well with change and the unknown is a cause of anxiety. They are often hypersensitive to sensory stimuli</p>			<p>LS: because she's not quite so close, is that right?            Andrew(C): yes            LS: it's still got a bright light on it, so when you switch it on the light comes out of this but she doesn't touch you            Andrew(C): its better when they don't touch."</p>	<p>remember being quite anxious about the light coming towards him so I thought he was going to set off but um he didn't really like it too much."</p>	<p>"David(ECP): Because if you keep a child waiting for 3 hours in a busy waiting room noisy cluttered visually noisy as well then you are not necessarily going to get the best results."</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
<p>many of which occur in the eye-care process to a greater extent than daily life. Without adaptation to take these needs into consideration the child will become distressed and the eye-care experience poor.</p>					
	<p>Communication impairment</p>		<p>LS: so that's a picture of the waiting room, do you like that one or not like it?            Andrew(C): that doesn't look anything like the waiting room "</p> <p>"LS: This is a little card with letters on so if you don't know your letters very well you can point them out rather</p>	<p>LS: ok so if optometrists learnt a little bit more about how phrases are interpreted?            Mick(PC) : yes, and not to be so fast I know that would mean a longer appointment time, I know that my</p>	<p>"Robert(ECP): um I started using PECs because the first patients I saw use PECS but I don't use that very often. Nowadays a lot of the patients I see seem to have their own communication</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>than shout them out so you don't have to say the name of the letter</p> <p>Simon(C): yes I'm turning into a bit like Dean [sibling with severe LD and an ASD] I don't usually like loud noises in the room"</p>	<p>appointment was exactly the same as his, um practically word for word, and I you know I'm there so I can say to him, I can basic translate it, although it don't need translating to us, but just needs a little bit more time, slow down a little bit and..."</p> <p>"Zahra(PC) : he was going up a travelator thing in Tesco's and it suddenly stopped and I looked at him and he had pressed the stop button. He said it said 'stop' or 'press to stop' so he did!"</p>	<p>rather than that but it is still there we need it."</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				<p>“Daisy(PC) : They have to digest things first before they report back to you don’t they! [laughs]</p> <p>Pippa(PC) : pictures with words because he has difficulty reading words, yes, yes.</p> <p>LS: that’s easily done, so timetable with pictures [writing on notes]. I didn’t want to sort of patronise him if he didn’t want pictures.</p> <p>Pippa(PC) : but no, no, no, I think this is what he is having trouble dealing with, everyone says oh you’re clever Tim”</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				<p>“Anne(PC) : so but keep the language simple and straight forward....  Anne(PC) : they do PECs at school.  LS: that’s what I’d like to get in my clinic in London is a PEC’s board.  Anne(PC) : Oh I think that would be brilliant a PEC’s board you know for children perhaps more severe than Simon(C)”</p> <p>“Anne(PC) : yes and even if you learn the odd makaton sign it’s all just to reinforce verbal communication. You know I think verbal</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				<p>information, he can't, it's almost like he's trying, he's processing the words themselves rather than the meaning. LS: yes"</p> <p>"Rosie(PC) : His auditory processing isn't very good, so although he's quite verbal you might actually think he, you are having a full conversation wiv' him, and he's taking everything in, but he'll pick bits and pieces out of what you are sayin' LS: OK Rosie(PC) : so and that's why he's um, that's why people</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				<p>are quite, yeah, misunderstand him and get quite confused.  Mick(PC) : because he'll do the same thing when he's having a conversation with you, he'll start talking about one thing but bounce about 3 or 4 different things and expect you to know what he's talking about."</p>	
	Social interaction impairment		<p>LS: And my job I've already told you I am an optician  Tim (C): yes obviously  LS: [laughs] and my age umm I don't know if I'm going to admit to this but I'm 43  Tim (C): oh that's a long</p>	<p>Sara(PC) : interaction with the other kids OK as far as I could tell. Um but the teachers would say it always has to be on his</p>	<p>Robert(ECP): I like to keep patients on eye level as well. Whether they are on the spectrum or not I put my chair down or get some equality</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>time”</p> <p>LS: Do you like the big chair?  Freddie(C): [looks at all the lenses on the desk, picks up the boxes and looks into them to see what is inside but generally not as much interest as he shows with the other gadgets with buttons to press. This time he appears to listen to the question about the chair but then turns back to the desk.]  Freddie(C): How does it go up? [searching for the button]  LS: Do you like it when it goes up? [no response still pressing randomly at the buttons]  Do you like it when the chair goes up? [no response]  Do you want to make the chair go up?  Freddie(C): [ignores all the</p>	<p>terms.”</p> <p>Catherine(PC) : it’s a difficult one because you could look at him and say he’s absolutely normal and then you realise when you are talking to him that oh he’s not looking at me that’s a bit rude isn’t it. I remember his Tai Kwando instructor saying Steve(C) needs to look at me when I’m addressing him. And I said to him I know that but Steve(C) cannot take on board what you are saying to him if he is looking at you.”</p>	<p>there, get some power balance with them, a bit of control in that respect.”</p> <p>David(ECP): when they realise ‘well what about me’ [laughs] you can sometimes get a result.”</p> <p>“Robert(ECP): If I want to talk to mum then I ask them if it’s alright if we talk about them, you don’t mind if I ask some questions things like that.”</p> <p>“Robert(ECP): I make a point of saying I’m going to turn the lights off</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>questions because he has found the Mallett unit and is pressing the buttons and investigating what it does]”</p>	<p>Zahra(PC) : I mean he’s, this is the sort of character of him, he will run up, get in the pulpit and go ‘hello my friends’ and if they laugh which of course most of them do, he does it again [laughs].”</p> <p>“Mick(PC) : You know, um, he’s got a pretty good sense of humour, it’s just that he doesn’t realise or know when to stop.</p> <p>Rosie(PC) : Or when to use it.”</p> <p>“Zahra(PC) : I spent an interview with a</p>	<p>and point to the light switch and put my finger on the light switch before turning the lights out. Let them know where it is, um, ask them if they want to turn the lights out give them a mandate for right you are in control turn the light going on or off and things like that.”</p> <p>Susan(ECP): I always give them the choice ok most children choose the pictures but there are some children that choose the letters. But I always like them to make that choice.”</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				social worker with him sitting on my head, and he's 4 stone now [laughs] he was trying to push my face in to clamp me, 'stop talking, stop talking, stop looking at the man.'	"Susan(ECP): so I might ask mum beforehand or I might take the child in and ask them which room do you like best? and give them the choice because we've got another room that has bare walls
	Social imagination impairment		<p>"LS: what did she do in the middle of your test then?  Chris(C): this is 6 and that is 45 [continues reading numbers from the Ishihara test]  LS: ok [indicating another test]  Chris(C): 5 and 7, 16 and 74"</p> <p>Adrian(C): How come that light's there? Will it ever go away? [pointing at a tiny central fixation light on the</p>	Catherine(PC) : For example children on the autism spectrum don't have imagination but that doesn't mean they are not creative, what, he he [support group speaker] explained this really well is the fact that if we are going into a situation that we have never	"David(ECP): Because if you keep a child waiting for 3 hours in a busy waiting room noisy cluttered visually noisy as well then you are not necessarily going to get the best results."

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>visual field screener in the far corner of the room] Will that light ever go away?            LS: which light? [points] oh the little dot, it only goes off when I switch it off.”</p> <p>LS: if it wasn't [optom] doing the test do you think it would be as fun?            Chris(C): it wouldn't be fun at all.”</p> <p>“Chris(C): I would be worried that if [optom] wasn't in the room she worked in”</p> <p>“Chris(C): I like having [optom] in the room</p> <p>Observation of Freddie(C) shows that he repeatedly went in search of the room that his practitioner used to use because recently he has</p>	<p>encountered before we cannot imagine what it will be like.”</p> <p>Anne(PC) : yes, he's ok because this lady is lovely but if we went to a different opticians it would be a different kettle of fish.            LS: and you would have to start all over again?            Anne(PC) : yes, he would find it because it was somewhere new he's find it stressful.”</p> <p>“Marianne(PC): so I mean, he's comfortable, he likes routine, he likes knowing what</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>moved all his equipment into a different testing room. The change of room caused Freddie(C) distress and confusion.</p> <p>Tim: [drops the cards from the isihara] ahahahaha [tries to put them back]"</p> <p>“LS: If [optom] was to do that test with you next time what do you think? Do you think you would like it? Tim: probably not after, there is no way I would like a book that kept popping out like that.”</p> <p>Observation of Freddie (C):I attempt to introduce myself but he pushes past me and walks/ runs into the consulting room. His mother saying to him that [optometrist] isn't there. He comes out of the consulting</p>	<p>he's doing. I wouldn't say like he's not inhibited but if he's comfortable in his environment doing what he likes doing he's fine.”</p> <p>Sara(PC) : they were doing their class assembly that the teacher sort of said, well he doesn't want to be part of it. I said well that's ok. She said but he doesn't want to be part of it at all. He doesn't even want to sit on the edge and I thought that's a bit not quite right, and it just sort of plummeted downhill from there, well</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>room and searches the practice for [optometrist].”</p> <p>Tim(C)demonstrated this also as he too was interviewed in the practice where he has his eye examinations. Despite being told he wasn't going to have an eye examination and having an accessible information sheet he still thought he was going to have an eye examination. He was confused and tearful initially because he just wanted to get on with the test.</p> <p>“Adrian(C): ..you ‘re meant to be going in at half past 5, what- ever, but then you have to get there, so you get there at 5 and you have to wait to go in at 5.30 and then you’ve got to wait another 20</p>	<p>something’s wrong.” [referring to when her child first showed signs of ASD in that he didn’t understand why you would want to be part of the school play].</p> <p>“Beth(ECP): one child and it had all gone fine and they took pictures of me and I promised to wear the same clothes that day and have my hair up the same way and we had all this how it was going to be and on the day the child’s notes just went into the general box and another doctor</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>minutes because the patients gone over it doing it again [sarcastic voice] ...”</p> <p>“LS: [reading the writing on the picture] “how long is it?”</p> <p>So what was it that you didn’t like about that?</p> <p>Adrian(C): the wait</p> <p>LS: the wait for it? sitting in the waiting room or sitting in the consulting room?</p> <p>Adrian(C): sitting in the waiting room</p> <p>LS: and what was bad about that? Can you describe what it was that was bad about it?</p> <p>Adrian(C): boring”</p> <p>“Steve(C): I don’t know what this is [pointing out one of the pictures on the chart]</p> <p>LS: oh that’s interesting do you know what the pictures are? Do you know what that one is?</p> <p>Steve(C): apple</p>	<p>picked them up so it was all just.”</p> <p>Beth(ECP): and if you fast forward that to coming to a clinic or even to an optician, this is a new environment you don’t know what anything thing is. You have to explore what every single thing in that room, and that room is full of equipment as they tend to be, different sounds, different smells, different people it becomes such an ordeal to just even walk into the opticians let alone have a test, have the lights turned out,</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>LS: and this  Steve(C): scissors  LS: and that  Steve(C): car  LS: this  Steve(C): um not sure clock?  LS: it is a clock yeah. And that?  Steve(C): I don't know"</p>	<p>have some things shone in your eye, have a silly pair of glasses put on, have things made blurry and then less blurry with lenses, the whole thing is just too much."</p> <p>Zahra(PC) : he was getting anxious waiting because he cannot wait he always goes to the front of a queue."</p> <p>"Marianne(PC) : I just think it's more stressful because he's getting more anxious because obviously well he's not knowing exactly</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				<p>what's happening and what he's going into. But also I think they just want to kind of go in and get it over with."</p> <p>"Daisy(PC) : I just think that if a special needs child has an appointment, that um and if you know that's going to happen, you make sure you finish your appointment earlier, that you give them an appointment that you've got 10 mins spare in between, just in case someone does go over that you've got a bit of time so that you are free, so as</p>	

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				soon as they come in they can be take straight in.”	
The Black Chair- unless the practitioner asks the child their preferences then they will be basing their adaptations on assumption not reality. This may therefore result in a poorer experience for the child			<p>“LS; What about the big chair?  Simon(C): yeah  LS: do you like the big chair?  Shall we stand back to take it [photograph]?  Simon(C): I like going up and down.”</p> <p>Andrew(C) initially put a picture of the black chair on the dislike pile in the card sorting and when he was questioned about this he explained it was the equipment attached to the arm of the chair that he didn’t like but he liked the chair.  The reasons given for liking the chair varied from it being comfortable,</p>		

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>Observation of Freddie(C):            “He sat down in the big chair like he is sitting down into a big comfy arm chair.            He shows no fear or anxiety – he enjoys sitting in the chair”</p> <p>“LS: do you like the chair because it goes up and down? Do you like it because it’s just fun to sit in it?            Tim: um no it’s comfortable”</p> <p>“Chris(C): cos it’s a good thing, well and you can see the letter sounds on the mirror”</p> <p>LS: What about the big black chair, do you like sitting in the big black chair or would you rather sit on mummy’s lap than sit on the big black chair?            Chris(C): I love sitting on the</p>		

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			big chair		
<p>The Drops –</p> <p>The reaction to disliked tests is much more extreme than might be expected and may have long lasting emotional implications. The drops are an example of this.</p>		<p>: if a test or technique is not fully explained then the child can be distressed just like typically developing children but unlike typically developing children this distress is much more extreme and long lasting.</p>	<p>Andrew(C) was particularly distressed by the drops which were used without any warning or preparation. It was the very first thing he wanted to tell me and was repeated several times during the interview.</p> <p>“LS: Think of all the different tests that you did, what was the one that you think you wouldn’t want them to do? Andrew(C): the drops! LS: is there any other test other than the drops that you didn’t like?” Andrew(C): ummm LS: we are going to look at some gadgets in a minute and maybe remind you Andrew(C): it was probably it</p>	<p>LS: so overall the experience wasn’t great? Marianne(PC) : no, well it was bad enough to compel me to contact you so that in itself is kind of, because I just thought, I remember coming out, and I felt really traumatised and I remember ringing [husband] my other half and just, I was really quite upset about it because I felt awful for Andrew(C). No-one wants to see their child like that and I</p>	<p>“Beth(ECP): they have this massive sensory thing, their eyes are stinging like mad and then you’ve made them really blurred and it’s a different place again.” Beth(ECP) uses the phrase ‘a different place again’ in the context that the drops make everything blurry and given the difficulty that children with ASD have processing their environment, the blurring from the drops means that</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>was just the drops really”</p> <p>“Simon(C): what’s this? LS: now that’s a packet of drops Simon(C): don’t like drops, don’t like drops, don’t like drops”</p> <p>“Andrew(C): no I don’t like, after the drops, guess what, it was all blurry”</p> <p>“Steve(C): and eye drops I don’t like things on my eyes I don’t like things on my eyes or touching my eyes LS: so it’s the touching again that Steve(C): yes too frightening then”</p> <p>Dylan(C) answered very few questions in the questionnaire however despite the question about</p>	<p>just ‘no, there must be a better way’.</p>	<p>they have to start again. This backs up the children’s dislike of the blurring.</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			the drops being towards the end of the questionnaire he decided to answer this one and clearly stated he did not like drops. The fact that out of all the questions he chose to answer this indicates he had a definite view regarding this element of the eye examination.		
<p>The use of computers and gadgets –</p> <p>The use of computers and gadgets may facilitate the eye-care process as the children find them enjoyable.</p>		<p>: the use of gadgets, if appropriately explained, can be fun, and involve less human interaction and therefore may be more effective and less distressing</p>	<p>LS: if we designed an eye test that you could do just by looking at a computer and doing different things on a computer would that be more fun than what you did with [optom] ?</p> <p>Steve(C): er yeah that would be more fun because who doesn't like computers"</p> <p>LS: [ gives the remote to Freddie(C)]</p> <p>Freddie(C): [takes the remote straight over to the</p>	<p>Marianne(PC) : something digital um is never a bad thing for a child with ASD [laughs]. They seem to like that."</p> <p>Daisy(PC) : cos he was using some sort of letters on the television, and I think that because it's a television screen, not television but you know.[computerised</p>	<p>David(ECP): so machines sometimes work better it depends on the individual. Sometimes the machine and being trapped behind the machine anyway but sometimes losing the human contact I find quite helpful."</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
		<p>than traditional techniques. The outcome may be a better experience for the child.</p>	<p>screen and flicks through all the charts, this time not particularly stopping at any specific screen, he's just playing seeing what he can get on the screen. He finds the picture charts]            LS: you know I was trying to do that the other day and I couldn't do it"            "LS: We're going to get this box of gadgets from behind mummy ..            Adrian(C): gadgets! [with delight]"</p>	<p>letter chart].            LS: yes, it looks like a TV            Daisy(PC) : yeah that's right, um that was all brilliant and he was pressing buttons and things flashing up and things like that was all keeping him amused."            Catherine(PC) : I think for some children yes but again it's a very individual thing and yes it could work that you could button pressing and things could be quite fun but the opportunity for pressing the wrong buttons is quite high but I do think it is</p>	<p>"David(ECP): I use a phoropter [see glossary] all the time on most kids anyway but using a phoropter is, they're a robot they're behind the thing with the knobs and gadgets being fiddled and that's easier to use than a trial frame where you have got touch involved and you know sliding things in and out a lot of kids don't like that."             Beth(ECP): yes there are auto refractors and things aren't there. So I think they are great to try."</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				<p>very much an individual thing.”</p> <p>Pippa(PC) : it’s like on the computer if things go too fast he gets really annoyed and upset he can’t deal with the speed across his eyes but then I don’t know because he’s actually said I need to stop the pictures mum and I need to rewind”</p>	
3D and blurring tests			<p>“Chris(C): what’s that coming up?  LS: it’s a fly isn’t it  Chris(C): ewww buzzzzzzzz  [exaggerated laughter]</p> <p>“Steve(C): it was cool  LS: it was cool yeah ?  Steve(C): cos you can see everything in 3D. “</p>		

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>“Andrew(C): ohh! Errr! [laughs] LS: [laughs] Andrew(C): that’s disgusting! LS:[laughs] is that fun or is that just disgusting? Andrew(C): that’s fun! [laughs] could do that as a trick for people like they will say like “there’s a fly!!! There’s a blue fly!!!” and then they will like try and touch it and they won’t feel anything [laughs] except the mirror LS: so you think that would be alright ? Andrew(C): yeahh”</p> <p>Some of the 3D tests involved using red green glasses and most of the children found these fun.</p> <p>“Chris(C): it’s fun! Yes because it changes colours</p>		

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>of things, it changes the colour of the computer of the letter stand</p> <p>What about something like this? Do you like that? [red and green filter] it changes the colour, if you look through those it changes the colour of"</p> <p>"Andrew(C): it's like a rainbow</p> <p>LS: yes. Do you like that or is that not nice</p> <p>Andrew(C): it's I like it yes fun!"</p> <p>One child said that he felt better wearing the red and green glasses, his eyes felt soothed by the colour.</p> <p>"LS: Now what do we think of this now. What would happen is he would hang that over there and he would</p>		

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>put that on your nose? What do you think of that one?  Tim: let me guess [tries them on]  LS: oh very nice. What do you think of that?  Tim: weird now I feel better  LS: do you feel better with the red and the green?  Tim: yes</p> <p>Chris(C): it's good well, because, look you can feel some bits, there's a star.</p> <p>Steve(C): I remember them  LS: did you like them?  Steve(C): not very much [laughs] because one side was green and one side was blue  Catherine(PC) : red  Steve(C): red  LS: did you feel wonky in it or something?  Steve(C): it was really hard</p>		

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>for my eyes and sometimes when something is really hard for my eyes and you use energy it hurts my eyes.”</p> <p>“LS: does that feel alright Tim: not so much because it gets my eye all crazy LS: does it make it feel funny Tim: no it makes it go crazy</p> <p>“LS: and did you mind them putting the lenses in and out? Better with better without, is that fun or? Steve(C): it was strange because your eyesight would be changing constantly.”</p> <p>“Andrew(C): blurry when I have to have those sort of lenses that go in that sort of glasses there. They give like loads and it’s really blurry”</p> <p>“Tim: yeah he did say stuff</p>		

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>like that [better one or two]            LS: ok and what did you think of that, did you like that? Or was that difficult?            Tim: um yeah difficult            LS: it was difficult, did you enjoy doing it though or did it put you off because it was difficult?            Tim: yeh it put me off ahh”</p>		
<p>Practitioner personality –</p> <p>The personality of the practitioner seems to have a positive or negative impact on the experience. Although the children couldn't explain their likes and dislikes it was clear that</p>	.	<p>: the child's comfort in the setting is a result, to a large extent, of how comfortable they are with the practitioner and how the practitioner makes them feel.</p>	<p>“LS: if it wasn't [optom] doing the test do you think it would be as fun?            Chris(C): it wouldn't be fun at all.”</p>	<p>Pippa(PC) : oh I dunno a calm upbeat voice talk to them so they actually know what's about to happen next.”</p> <p>“Pippa(PC) : yes I suppose this one makes it more of a game a lot more humour to it.”</p> <p>“Anne(PC) : he had that with [optom] he</p>	<p>David(ECP): hey the first time I started seeing people with LD I was terrified I didn't have a clue how to behave and I come from totally the opposite end of the social spectrum in terms of how tactile I am compared to [optom]. [she] will give everybody a hug, she will touch people. I'm anglo-</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
the children who had regular optometrists were attached to them				<p>was so good, he was so chatty and it was funny he didn't mind [optom] leaning right in."</p> <p>"Marianne(PC) : she was, she explained a lot more what she was doing and she kind of talked pretty much the whole way through it."</p> <p>"Marianne(PC) : and I do think that was, he warmed to her and he trusted her I think and that made a big difference."</p> <p>"LS: do you have a particular time of day you choose there or do you just Anne: no I normally</p>	<p>saxon stiff upper lip.... I've got used to it and now it's just becoming more comfortable if somebody wants to touch you, grab my hair, pull my glasses off, do that sort of stuff um that's fine. Its breaking down that sort of I'm the professional I'm in a suit and this is how I behave."</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
				<p>ask for early, first thing appt of the day for.Simon(C) as well and with [optometrist at practice] and um she er I think she only works part time not a full week there.”</p> <p>“Marianne(PC) : ..and “oh you’re good at that” quite a lot of positive reinforcement actually which I thought was good. Um “oh I know you are going to get this one done” kids are fickle.”</p>	
Anxiety –		: if the triggers of anxiety are	“LS: [laughs] the light on it. Did you like it when he put the light on it?	“Anne(PC) : Simon(C) is so placid but the fear	David(ECP): so do I make adaptations? I may move some of

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
		<p>not known then the child may become anxious and unable to cope with the demands of the test which results in a poor experience.</p>	<p>Tim: no!!            LS: do you like bright lights generally or is it just this light you don't like?            Tim: don't like them, there's a patch in my eye!"</p> <p>"Steve(C): really I was worried about some things and I was happy about other things            LS: was there anything particularly you were worried about?            Steve(C): um in particular I was worried about, in some opticians they shine a light into your eye to see what's in it, I don't like the light shining in my eye"</p> <p>"LS: do you like gadgets like that or does that make you feel a bit stressed as well?            Simon(C): mostly everything and everyday and everything</p>	<p>just takes him. He would never hurt anyone it's just the fear."</p> <p>"Anne(PC) : Oh he [Simon(C)] gets very anxious, very anxious lots of anxiety er low self esteem but a lot of it comes from the lack of knowledge from school."</p> <p>"Anne(PC) : we were in Waterstones and Simon(C) has decided that all the age 9-12 books are scary and if they've got a scary cover, and it's not necessarily a scary cover but to him it's</p>	<p>the equipment out and further back [to] give people more space. Um I will allow children to fiddle um let them touch."</p> <p>"Beth(ECP): so maybe they just need to just explore the instrument, feel it touch it."</p> <p>"David(ECP): people with autism, once they are desensitised to an environment they will probably feel more comfortable and are able to respond better."</p> <p>"Robert(ECP): um</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>I do I feel sick and ... and noise makes it worse.”</p> <p>“Simon(C): still got that little draft in my eye and it gets me worried that “</p> <p>“LS: Oh that’s the machine I was telling you about. [instrument room, grey plain walls, low light, 2 large grey machines and several black stalls] Do you like that? Andrew(C): nooooo LS: do you not like this room at all? Andrew(C): I don’t like it at all LS: tell me what you don’t like about it Andrew(C): I don’t like the big machine LS: if someone explained to you [Andrew(C) interrupts] Andrew(C): and it’s too small” [referring to the room]</p>	<p>a scary cover, he can’t look at any of the books in that section.”</p>	<p>I’ve seen patients that I’ve seen perhaps 4 or 5 times in a week, and we won’t even touch them, the idea is to get them used to coming in, getting them into the test room.”</p> <p>“Beth(ECP): We let them touch every piece of equipment the first time they can do what they like we don’t try and test anything.”</p>

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
			<p>Chris(C) was anxious about the difficulty of the tasks he would be asked to do and for each new task explanation and reassurance was required. When I asked him to look at the pictures and sort them into like and dislike piles he looked very worried.</p> <p>“Chris(C): please do some easy ones!”</p> <p>“Observation of Simon(C)’s interview: When I asked him about a gadget on the worktop in the consulting room. He hadn’t seen it before and therefore got quite stressed and his behaviour deteriorated again quite dramatically”</p>		
Tests and techniques		Each child has a unique set	See table of card sorting results		

Category	Subcategory	Definition	Evidence from Child	Supporting evidence PC	Supporting evidence ECP
		of likes and dislikes regarding the different tests used			

## Appendix 6 Summary of categories, subcategories and axial codes for all participants

### *Appendix 6i Child participants table of categories, Subcategories and axial codes*

Category	Subcategory	Key Axial Codes
Impact of ASD traits	Hypersensitivity	Light, Touch, Sound, Taste, Smell.
	Communication impairment	Understand what is required, Feeling overwhelmed Literal meanings Supports
	Social interaction impairment	Knowing 'the rules' Getting their own way
	Social Imagination impairment	Difficulty understanding intentions, Predicting reactions to behaviour Dislike of change Need for routine Waiting Concrete thinking
The black chair		Comfortable Likes pressing the buttons Practical

Category	Subcategory	Key Axial Codes
The drops		Blurring Touch Unexpected
The use of computers and gadgets		“Who doesn’t like computers” Pressing the buttons Dislikes the effect
3D tests and blurring lenses	“It was cool”	Liked the effect, Fun effects
	“Hurts my eyes”	Sensory overload, Dislikes the effect
	Don’t like the blurring	The blurring effect, Fluctuation in vision
Practitioner personality	Personality	Fun, Calm, Friendly, Explains
	Practice	Likes environments, Dislikes environments
	Continuity	Familiar with personnel Familiar with practitioner, No changes
Anxiety	Fear of the effects	Doing tests Lights Health

Category	Subcategory	Key Axial Codes
	Fear of the unknown	Change Unknown equipment, Unknown tests Unknown location
Tests and techniques	Charts	Types of charts Matching Picture charts Letter charts
	Likes	Obsessions Sensations
	Dislikes	Fears Worries Obsessions
	Characteristic	Hobbies, Humour, Moods, Curiosity

**Appendix 6ii PCs table of categories, Subcategories and axial codes**

Category	Subcategory	Key Axial Codes
Practitioner Awareness	Lack of awareness	Adaptations not made Naughty child Treated the same
	Previous experience	“there must be a better way” Low expectations Trendy image
	Listen to carers	Taking advice from carers Think they know better
PC Awareness	Choice of optometrist	Local Cost Recommendations Regular practitioner Child friendly
	Expectations	Low expectations Setting expectations
	Pre-test information	Info to practitioner Info to PC Explanation Preparation
	Understanding the need for eye-care	Reason for booking Picking your battles Risk factors

Category	Subcategory	Key Axial Codes
Barriers and facilitators	ASD traits	Moods Being in control Triggers Low selfesteem Poor concentration Dislike of change
	Strategies	Calming down Controlling environment Person-centred approach Flexibility Knowing when to stop
	Challenges	Treated normally Parental stress The drops
	Adaptations/ preparations	Appointment booking Appointment length Service design Training

**Appendix 6iii ECPs table of categories, subcategories and axial codes**

Category	Subcategory	Key axial codes
Barriers to eye-care	Carers awareness	It isn't possible to test a child that can't read No point if they won't tolerate spectacles Looked after children Carers perception of eye-care
	Practitioner's awareness	Practitioner may be worried about coping Practitioner need to develop skills required Awareness of the role of AHP
	Practice awareness	Welcoming Flexible Understand the needs Suitability
	Funding	NHS contract structure Poorly funded Box ticking
	Discrimination	Not the right image Not profitable Lack of awareness
	Service design	Frequency of eye exam Specialist provision Professionals commitment Spectacle voucher provision

Category	Subcategory	Key axial codes
	Lack of research	Too few children to get risk factor data Don't know the risks Evidence based therapies
Facilitators	Adaptations	Step by step Specialist facilitators Preparation Adaptation to routine Specialist knowledge
	Practice ethos	Altruistic Whole practice commitment flexibility
	Practice suitability	Small familiar Quiet Continuity Impact on other patients Specialist equipment Choice
Service provision	Accreditation	Post grad training Specialist skills Reassurance and support for carers Commissioning Opt out List

Category	Subcategory	Key axial codes
	Planning	Accreditation and audit Avoid failure of service National referral pathway Legislative background Defining special needs Normalisation
	Funding	Flexible Enhanced fee Viable service
	Screening	In school screening Neuro-developmental referral pathway
Need for eye-care	Importance of vision	Just as important if not more so Adapt environment to visual impairment Explanation of behaviour
	Prescribing	Alternatives to specs Specialist skills in prescribing
	Eye conditions	Processing Visual impairment Risk factors
	Alternative therapies	Colorimetry Behavioural optometry Other therapies

## ***Appendix 6iv Further findings from ECPs regarding service provision and the need for eye-care***

### **Importance of vision**

One of the findings under the category of *Barriers* section 3.2.3 was the lack of awareness of carers and optometrists that despite a child not having verbal skills vision is still important. The ECPs suggested that good eye-sight is as important and possibly more so for this group because it helps people to interpret the world around them and interact with it. If there is already one disability that affects this adding a visual impairment to it will make things even more confusing.

“David(ECP): For a 14 year old boy with autism really challenging behaviour poor socialisation add onto that

LS: no vision

David(ECP): blindness would be a real handful for the rest of his life. But he is actually now I think he is about 6/18 in one eye and about 6/24- 6/36 in the other eye so he’s retained some sight so yes there was a point to operating and doing it.”

“Susan(ECP): children with special needs, need good eye-sight more than normal children do, which is an odd way round to think but when she explained it, she’s absolutely right, that if you’ve got poor eye-sight but you are very very bright you can reason what it is you are seeing. And you can reason, oh that’s green, so it’s a field. And there’s a big brown lump in the middle, that’s probably a horse or a cow and and there’s another lump on this animal’s back so that’s a rider, that means it’s a horse. But if you don’t have that reasoning power you just see a brown blob on a green background and you’ve got no idea what you are looking at.”

One of the barriers to eye-care that was mentioned earlier was that carers felt that their child would not wear spectacles. This emerged also as a concern of the ECPs. They highlighted the need for carers to be informed as to the importance of eye-care regardless of whether their child would comply to spectacle wear. Carers need to know whether their child is long sighted, short sighted or has any type of visual impairment in order that they may assist them, either by changing their environment or by encouraging them to wear their spectacles.

“David(ECP): The importance of eye examinations, the importance of making sure somebody is visually normal or correcting any visual deficit or knowing about any visual deficit so you could adapt the environment the teaching environment or the methods of teaching because we all assume that people can see as well as us.”

“David(ECP): that’s the problem with encouraging people to wear glasses afterwards sometimes it’s the physical presence of something on or around on their nose they trying to, it’s trying to educate optometrist but struggling to, you know, that + 0.50 / -0.50 right and left is really not going to make enough difference to the child’s life that they are going to wear the prescription. Whereas -6 might. [laughs]”

Treatment options for children with ASD may not be just spectacles. If the problem is due to the processing of information then a clear explanation to carers and teacher helps for adaptations to be made and for their potential problems to be understood.

“Beth(ECP): We can give the parents ideas of ways to help their children use their vision better, you know, have an uncluttered environment. There are loads of things.”

Beth(ECP) explained that the information an optometrist can give to carers and teachers might help explain some behavioural issues that had been put down to challenging behaviour rather than a vision processing issue. This understanding will enable the teacher or carer to adapt their activities to avoid unnecessary stress for all concerned.

“Beth(ECP): they can’t understand facial gestures, you have to say that you are pleased or cross

LS: yes

Beth(ECP): they can’t process every child’s face, so they may not know who their classmates are or not that might be a very difficult thing for them to understand.

LS: yes

Beth(ECP): go and stand in Arminers group, well actually who Arminder is could be quite difficult.”

One of the ECPs said that based on the literature there is probably a higher risk of squints, refractive errors, reduced visual acuity, and reduced accommodation. The axial code *Eye conditions* emerged as the ECPs gave their views of the risk factors for eye conditions in ASD.

“Susan(ECP): if you look at the literature, then squints are more common, reduced acuity is more common and refractive errors is slightly more common than in the general population.”

Three of the ECPs commented that accommodation was found to be poor in other conditions such as Down’s syndrome and that research was needed to investigate this in ASD. They highlighted that reduced accommodation affects all near vision tasks.

“Beth(ECP): their accommodation is the thing, you need to know whether the kids can accommodate properly so that comes as part of the hospital assessment.”

This was not unanimous though with one ECP commenting that they felt the vision was likely to be just the same as any child in terms of risk factors unless they also have LD.

“LS: Do you think that children with autism have more eye problems than average or do you think that they are just the same as any other children in their risk factors?”

Robert(ECP): I suspect it’s just the same um I don’t keep epidemiological data.”

“Robert(ECP): there probably is because of the co-morbidity with other learning disability is higher and there are more conditions in other LD’s so yes if you tried to crunch the numbers then yes.”

The prevalence of visual impairment was mentioned by two of the participants who felt that they had not seen much evidence of it and that perhaps sometimes children were wrongly diagnosed as having ASD when in fact they have ASD type traits due to a visual impairment.

“David(ECP): yes and what I would immediately question with those is that it’s probably nothing to do with the ASD it’s probably to do with the underlying conditions.”

“Beth(ECP): I think a lot of children with what we think of as this cerebral visual impairment have been labelled erroneously as being autistic because they like things to be in the same place and their shoes have to be lined up they don’t like new environments. But it’s not they are not autistic it’s just that they have this visual processing problem.”

One ECP felt that the processing of visual input is impaired in children with an ASD and that this should be considered for sight impairment registration as it is as limiting as visual acuity reduction or fields loss. The impairment of processing and the inability to filter out the information around them that is not relevant causes everything to become overwhelming.

“Beth(ECP): Understand that children with autism their vision is normal, you know if you measure it on the letters in the chart, it’s normal, but it’s the way they use their vision do you know.”

“Beth(ECP): We know a lot about children with cerebral visual impairment so they can’t use the vision, there’s too much going on, they can’t like do Where’s Wally puzzles. They can’t see the page and pick out individual parts of it. It’s the same with a child with autism, they can’t use their vision they can’t look at something and know it’s a cup, they have to touch it.”

She also thinks that the processing issues have developed to help the child deal with sensory overload caused by the ASD.

“Beth(ECP): They have found a way to make their life easier, so they keep doing it. No-one has taught them that, it’s an instinctive thing.”

Beth(ECP) suggested that adaptations might include central suppression. The child would use eccentric viewing in order to reduce input and visual stress.

“Beth(ECP): The other alternative it that they don’t use their central vision, they only use their peripheral vision, so that’s why the kids may not look you straight in the face, it’s just too much information so they look to side of things cos your peripheral vision is much hazier than central vision.”

She also mentioned another adaptation called Tunnelling, which is suppression of the periphery, is adopted. This causes them to scan constantly only processing one bit at a time but causing them to miss 'the bigger picture'.

"Beth(ECP): The other alternative is the kids who tunnel they only use the central part of their vision when they are looking at something so that they can only see the very very centre bit."

She felt that these adaptations would account for the lack of eye contact, the obsession over details and the inability to use vision in a systematic way to pick out the important bits of the visual scene also might explain their lack of concentration and resulting challenging behaviour.

"Beth(ECP): one of the reasons autistic children don't like things to be changed and this makes a lot of sense really if you think about it. You know what your lounge looks like at home, you walk in the door and sofa's on the right, and the TV's in front of you, if you are an autistic child the context of what a sofa is and where things are is quite difficult anyway but actually if you've got a photographic, your brain takes a picture, you know what the lounge looks like, you've got over the whole what the sofa is, you don't have to do that every-time because you've got that picture in your head of where that sofa is and you know it's going to be soft and how to go and sit on it and you know the telly will be opposite so you've not got to think about it every-time.

LS: process it.

Beth(ECP): Well if you move the sofa and put it in a different place then your brain just doesn't know what to do because it can't, it doesn't know that it is a sofa because it's not where it should be and have to go through that whole, what is this, where is it, how far away is it, what do I do with it again. And so the autistic child will either go and try and sit where the sofa used to be or get very distressed because this isn't right."

Beth(ECP) also commented on the possible reading problems that might stem from the child looking at the page of print and not being able to systematically start at the beginning and read through, they try to read it all at once and then get overwhelmed. They might find identifying the important details difficult.

“Beth(ECP): they can’t do that they can’t scan a page and look to count so they are processing a busy scene. So go to your bedroom and find your socks, well that’s really difficult because they have to look individually at every single bit in order to say is this a sock or not a sock.”

“Beth(ECP): And if already your brain finds it difficult to interpret if something is a sock or not a sock but it’s so much having to be done that the brain just, you can see that avoid doing it altogether.”

The difficulties that impaired processing can create on the way the world is interpreted were also discussed. In particular how it affects the way that they cope interacting in the world.

“David(ECP): and I would say that probably because of differences within the brain which may or may not be the cause of the ASD or a factor could also be causing problems with visual perceptual problems and the way certainly psychologically interpret their world is different.”

Beth(ECP) feels that these processing issues are significant enough that registration could be considered but she is unaware of any child that has been registered.

However all of the ECPs commented that relatively small numbers of children with ASD are attending for eye care and therefore it was not really possible to be certain.

### ***Alternative treatments***

The range of visual therapies and treatments were discussed with the participants. None of the professionals felt that there was enough evidence to offer or recommend any of the various visual therapies such as behavioural optometry or visual stress treatments such as colorimetry. They were open minded about the relative benefits and provide information to carers when it was requested.

The use of coloured overlays and tinted spectacles was mentioned by two practitioners. They both felt that this was not mainstream but were aware that some children seemed to be assisted by using overlays. Neither were actively encouraging patients to investigate this treatment. One ECP suggested that the child’s ability to do the colorimetry test was doubtful but would arrange for colorimetry if requested. The other ECP suggested that there is anecdotal evidence

that it is helpful but was not aware of evidence and therefore felt recommending it was not appropriate.

“Susan(ECP): I know that some children with autism benefit from tinted lenses and things like that but..

LS: do you do that here? Colorimetry?

Susan(ECP): yes

LS: and do you recommend that autistic youngsters? or just base it on ...

Susan(ECP): no it's usually in response to a parental request.”

“Beth(ECP): So do I think that autistic children should have overlays, well why not give it a go, I think there is nothing to say it makes it any worse but again you have got to balance the time spent doing the assessment and the expectation against what else they could be doing so no I don't specifically talk to parents about overlays.”

“Beth(ECP): I don't have an adequate explanation in my head for why that works, so I can't let myself prescribe something when I don't have an adequate explanation for why it works.”

The discussion about vision therapy was very similar. There was considered to be a lack of evidence and although elements are in use in mainstream optometry it was not generally considered to be something that mainstream clinics should offer. One practitioner pointed out the wealth of online blogs by carers who feel that such therapies had changed their child's life but this could not be considered evidence and should be seen in the context of how much school time was lost and the intensity of the treatment.

“Susan(ECP): no no we draw a real distinction between ourselves and behavioural optometry because we get a lot of phone calls saying that “can I get an appointment please I've been told I need to see a behavioural optometrist” and I really distance myself from that, and I always go through the spiel I'm a mainstream optometrist, behavioural optometry is not evidence based, you come to me for mainstream stuff.”

“Beth(ECP): it's difficult, there's plenty of testimony of websites that the parents or teachers say this has revolutionised my child's life, this has totally

changed the way everything is. The difficulty is that there are no randomised trials.”

### **Summary of *Need for eye-care*:**

Context: the need for eye-care for people with ASD is not fully understood because of the lack of research. Carers often find taking their children to any type of consultation stressful and tend to avoid taking them to appointments that they perceive as not being essential. Carers may not know what can be done to test the eyes of children who can't read. They may not feel that their child would tolerate spectacles and therefore understand that it is still important to be aware of the refractive error that their child has.

Consequences: carers often do not access eye care and therefore problems with the child's vision are undiagnosed, untreated and not accounted for in daily activities. The full extent of the ocular risk factors associated with ASD may not be known as many are not accessing eye-care.

### ***Service provision***

The ECP participants spoke about how to standardise and regulate good practice. The viewpoints varied considerably but there was general consensus that the current provision is not standardised but should be. The subcategories were: *Accreditation, Screening, Funding, Planning and Normalisation*.

### **Accreditation**

The idea of *accreditation* would be that all ECPs involved in this work would have specific training and evaluation of their skills on a regular basis. This did not produce a unified response. Two ECPs were very enthusiastic about accreditation as a way of identifying practitioners who are genuinely interested and qualified to provide a good quality service for people with ASD. All ECPs were in favour of helping carers identify skilled practitioners though not necessarily through accreditation.

“Susan(ECP): I think we should have accreditation for optometrists to see children with special needs.”

“LS: do you think that optometrists should be accredited to do that so that they can take the more specialist end of the spectrum?”

David(ECP): I think they have got to be interested. Strictly everything they are doing is core competence however we both know that some of the things that are core competence are not core.”

One participant felt that the accreditation should not apply just to service provision for children with special needs but to all below the age of 12 because the skill set benefits all children.

“Susan(ECP): Um so it would be much easier if you said anybody under the age of 12 you cannot see unless you are accredited.”

They recommended that an accreditation course should be a post graduate training course with practical experience and also an element of ongoing training to keep up to date.

“Susan(ECP):... the accreditation should be post graduate simply because the undergraduate course is expanding all the time and there are so many other things that go into it, that we just would not have time to, or the facilities to get undergraduates up to standard.”

The benefit of accreditation would be to reassure and help carers make good choices, and also enable special enhanced pathways with correct funding to be implemented. However they felt that accreditation needs to be regulated otherwise the benefits are minimal.

“Beth(ECP): I hesitate to provide or choose a specialist optometrist because I think it's not beyond the scope for any optometrist to do it but I think if you are going to not waste the time of the child and give the parent of the child a good experience then we do need to highlight people who have experience, who have some training, who have a contact at the hospital.”

Currently there exists a list of specialist practitioners through a charity called SeeAbility. They do not need to be accredited. Whilst all ECPs interviewed agreed this was helpful, one practitioner felt that it might be abused and suggested that the list should include user reviews and was monitored to ensure that these practitioners have the correct skills.

“Robert(ECP): do you think it would help if um an online directory that parents could access and to find optometrists that are interested in looking after youngsters with autism, a bit like the SeeAbility?”

“Robert(ECP): if its user reviewed, yes I do. If it’s a case that you can do this training course and sign up that register I don’t um.”

Another participant however felt that whilst this is an ideal it is not viable, it would seriously limit the choice for patients and it would be very difficult to police.

“David(ECP): I think it is a marvellous idea and there will be 2 practices in the country probably that would meet the

LS: criteria

David(ECP): rigid criteria that somebody could set down. I think ideally yes we should all aim to achieve 3 Michelin Stars but what you are asking people to do is try and achieve excellence in an area where there is not likely to be any financial reward and the only reward that you will get is in heaven. So if you set the bar too high um you are going to find that you are going to get few people applying to go on the list.”

Currently all practitioners are obliged to see children with ASD. However all the participants felt that this should not be the case. If a practitioner feels unable to provide a suitable level of care then good practice should allow a referral to a colleague or alternative provider.

“Susan(ECP): and I think it’s quite wrong that the college expects everyone to see children and adults with special needs. They hate this idea of specialising but the thing is if you are not really interested in a field within optometry but you have to do it because the law says you’ve got to do it, you will do it badly.”

“Robert(ECP): my argument would be that I don’t mind if you turn around and say I haven’t got the skill set to see this particular person with learning disabilities but as long as you say but I know a man who has.

LS: yes

Robert(ECP): I’d rather you held your hands up and said no I can’t do a good job than basically screw it up for the future.”

## Screening

All practitioners were clear that special schools need to implement vision screening. Currently there is no requirement for this and yet these children are at much greater risk of visual impairment but unlike mainstream schools no screening scheme exists.

“Robert(ECP): and there are several reasons for that. Children age 4 or 5, certainly in England, have their eyes tested in school when a lot of special schools don't have that facility.”

Two practitioners felt that pre-screening in the community was beneficial in identifying those children that might need help and also help to support the child through the eye-care process.

## Funding

The appropriate *funding* of services was discussed and the ECPs recommended that funding should be flexible. Ideas for achieving this varied between the participants with one mentioning that an increased fee may attract practitioners for the wrong reasons. This participant felt that if practitioners get paid more there should be some audit to ensure they are actually adapting their services appropriately and not just claiming the fee. Suggestions varied between payment per hour rather than per appointment or a fixed fee that reflects the longer chair time. The payment could be based around the hospital model of payment per session regardless of what was possible to achieve in that time.

“David(ECP): um however if you want to make it work generally the wider optometric setting to get more people involved you really need to have a setting where somebody is either paid by the hour.”

“Susan(ECP): we would need, well I would extend this for children and adults, we need appropriate funding, because children and adults with special needs need longer chair time and maybe two separate visits, it maybe one extended visit, it doesn't matter what it is, um but the fact that you need longer needs to be reflected in the NHS.”

“Beth(ECP): Whereas in the hospital we have a lot more freedom you know, if we get nothing we get nothing, we still get the appointment, if they come for the appointment we still get paid even if we've managed to get no

concrete information, but actually that doesn't bother me that we've got no concrete information because you know that might have been the first visit when we've just seeing how things are."

"Robert(ECP): um if you were to say right an eye test for someone with autism is worth £80 as opposed to the £20 something you get might actually get quite a lot people doing the training and because I'll have them in the practice for 20 minutes and I'll have them in and out because autistics are not going to stay, because they will not be going that extra mile for that patients that need it. Yes I think we need to fund it differently but how we would do it well and monitor I don't know."

## **Planning**

The subcategory of *planning* investigates the possible ways that services can be developed specifically for this group. One ECP commented that planning is required to prevent services failing in the way that the community dental service has. This service was designed to provide for those that can't cope with mainstream services but not with specific groups in mind therefore it has become unmanageable. The axial codes to this subcategory were: *National referral pathway, Legislative background, Defining special needs, and Normalisation.*

A *national referral pathway* was recommended such as exists for children with other neuro-developmental conditions. One ECP favours setting up a national eye-care pathway for children with ASD that would enable them to have a mandatory ophthalmology screening just like children with other neuro-developmental conditions. .

"Beth(ECP): So for paediatricians to be aware and parents to be aware I don't think it is necessary for every child with autism to have a visit to an eye clinic, but they need know how they can access eye-care. So be that at a local opticians or and be that some awareness amongst the optometry community about how they can facilitate a visit of a child with autism to their practice, and then an assessment by a paediatrician as part of their annual overview of the child in clinic whether that's done in school if the child is in specialist school."

The *legislative background* of provision for these children was discussed by one ECP. The Hall report (Hall, 1996) recommends that children with neurological

disorders should have a full eye examination rather than just a school screening. He pointed out that this means if the CCG declines to make provision for this then they are not complying with legal requirements and action may be taken against them. This has implications for the funding of services too.

“David(ECP): so I think there is a place to argue with LD trusts and the mental health trusts whatever label there attached and the CCG’s that there’s a need to develop that service and as was said by [omitted] in one of their reports recently if you don’t provide that or make that provision you are likely to fall foul of 5 different Acts (human rights, and all the others) so the threat to commissioning boards if they don’t is quite strong.”

All ECPs agreed the fundamental point that people with ASD have the right to services that are as good as services for those who do not have ASD.

One ECP raised the issue of how you define ‘special needs’ and how you define the criteria for using the pathway particularly as some people have an ASD but no diagnosis. *Defining special needs* is required in order to plan services.

“Susan(ECP): The problem with that is trying to decide who’s got special needs.”

Whilst accreditation has already been discussed above, the axial code accreditation and audit occurs in this subcategory too because of the way services are commissioned. Care pathways always include the use of accredited providers and clinical audits. Therefore without accreditation referral pathways can be difficult.

“Susan(ECP): You see once you’ve got accreditation those sorts of things are smoother, one of the problems hospitals have is that they are not supposed to recommend are they and they are very wary of that which is why at the moment they don’t pass patients on at referral. If you had an accreditation system then that would be fine wouldn’t it, you would just have the list.”

It is also important for commissioners to be able to measure the outcome of any pathway implemented. This requires agreement as to what and how to measure the outcomes. One ECP suggested quality of referrals, increase in visual impairment

registrations (CVI), the increase in numbers accessing the services, patient feedback and ultimately how many children are helped to use their vision better.

### ***Normalisation***

*Normalisation* is the encouragement of children with a disability to access mainstream services (Whitman, 2000). One ECP commented that if these children are directed to specialist services then they will not be empowered to access the mainstream. The carers and practitioners need to decide whether normalisation will ever be achievable or if it is very unlikely and the only way to a positive outcome is to use a specialist service. When services are planned this needs to be considered.

“David(ECP): so I can see the argument for a hospital setting but when we come back to normalisation and trying normalisation went a bit too far I think. Normalisation has come back to well normal should be as normal as possible where you get a good result and for most people with autism alone um I think normal should be in a high street environment because most kids on the ASD spectrum we are hoping that they are going to be able to cope in the wider world with some support.”