Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD): Experiences of Parents, Young People and Professionals in Scotland
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Study aim
Over the years ENABLE Scotland has become increasingly aware of the gap in services to meet the challenges faced by parents at the early stages of a child’s diagnosis of a learning disability. The aim of this study was to explore the extent and nature of challenges faced by the parents of children with diagnosed and undiagnosed learning disabilities and access to support after initial concerns about a child’s development are raised.

Research methods
The research utilised qualitative research methods and employed an online survey, interviews and group discussions. Views from three target groups were sought: parents or primary carers of children who have learning disabilities; professionals identified by the parents as making a positive change in their journey around the period of diagnosis; and the young people who have a learning disability.

Key findings
The study shows that while in majority of the cases (60%) parents raise initial concerns about the child’s development, in the remainder of cases (40%), they are made aware of a child’s developmental issues by others. The route to diagnosis is tortuous with multiple referrals, and parents are provided with little or no targeted information and advice on benefits or social work support. Most parents seek an early diagnosis as it enables them to look for information on the condition. Diagnosis is also seen as a gateway to support and services.

The time taken for a diagnosis varies with the condition: for ASD the mean period was found to be 36 months and for global developmental delay (GDD) 25 months. GDD diagnosis can mislead parents into believing that the child will eventually ‘catch up’. Parents with children identified with GDD are far more likely to find the route to diagnosis unclear in comparison to those diagnosed with other known conditions.

In a majority of cases the information provided to parents was seen to be generic and not tailored to the needs of the specific child and family.

Application for benefits requires specification of ‘what the child cannot do’, which is found to be traumatic by the parents. Most parents were strongly critical of the social work assessment process, but parents who have a social worker allocated to them were very appreciative of their help and support.

The education sector is most involved and most supportive in taking care of the child in the period around diagnosis. The involvement of the voluntary sector in supporting parents is very limited.
Diagnosis was seen by the professional service providers as an important factor in facilitating access to support and services. According to the professionals, parents can take a long time to accept a diagnosis. Professionals often find it difficult to balance the need for an honest appraisal, with the requirement of being sensitive when discussing the child’s situation with the parents. Managing expectations of many parents can be challenging for staff in schools. It can be challenging for parents who are required to balance ‘what the child can do’, as is the approach of the education system, against the need for identifying ‘what the child cannot do’, to access welfare benefits and social work support.

Multi-agency and joint working between professionals and parents is generally perceived to have a positive impact on the child and the family.

Interviews with young people who have a learning disability indicate that while they did not immediately understand the meaning of their diagnosis, they did recognise if it had made a difference in how they were treated by others. Diagnosis also helped them understand themselves better. The role of teachers within the specialist unit providing additional support needs in the school were identified as most important by young people specifically around transitions (e.g. from primary school to secondary school) where the young people need much support to gain confidence and support for independent living. Young people interviewed had a very positive outlook for the future.

**Recommendations: 10 point plan**

The findings of this research make strong policy and practice recommendations to support implementation of the Children and Young People (Scotland) Act 2014.

1) The Scottish Government should commission a practice guidance document for commissioners and practitioners on implementation of the Children and Young People (Scotland) Act 2014 for disabled children and young people.

2) Training and clear referral pathways for learning disability/cognitive delays/global developmental delay diagnosis should be available in every local authority area.

3) Lead professionals with expertise in additional support for learning and disability in each local authority area should be identified to support the named person role where a child is presenting with a learning disability, or where there is a concern around development.

4) Named Person professionals should have relevant training and knowledge to enable them to support and signpost family carers to access information and advice around parenting a child who has a learning disability and the social work, education and welfare systems to maximise access to rights and support.

5) Under the new duty to develop Children’s Services Plans, the relevant planning authorities should consider family support services as a key part of the Children’s Services provision for disabled children.
6) A toolkit for named persons should be developed and issued to ensure that named persons are equipped to ask families the right questions at the right time to inform support strategies.

7) The public bodies should consider the role of the local and national voluntary sector as an important source of information, advice and support for families, and actively support referrals.

8) Sources of information and advice should be developed for families who are in the process of accessing a diagnosis of a learning disability.

9) The Scottish Government should develop and issue practice guidance for education authorities on delivering inclusive education to support the implementation of Section 15 in the Standards in Scotland’s Schools Act 2000.

10) Research should be commissioned to assess the long term impact of the Children and Young People (Scotland) Act 2014 on outcomes for disabled children; and the impact of a lack of formal diagnosis of a learning disability for young people transitioning into adult life and service eligibility.

About the study
The study was funded by the Third Sector Early Interventions Fund managed by the Big Lottery. The research was conducted by Dr Vibha Pankaj (ENABLE Scotland) from September 2013 to July 2015.

The study was conducted through a survey for parents of children (up to 16 years of age) with or without a formal diagnosis of a learning disability (including ASD). Face to face interviews were conducted with parents, professionals and young people.
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Introduction

1.1 Background

ENABLE Scotland has been in existence for more than sixty years and has been supporting children, young people and adults who have learning disabilities and their families to exercise their rights to achieve greater equality and better opportunities. ENABLE Scotland believes that people who have learning disabilities¹ should be valued as full and active members of the community.

Over the years through interaction with parents and through feedback from practitioners ENABLE Scotland became increasingly aware that there was a gap in services to meet the challenges faced by parents at the early stages of a child's diagnosis of a learning disability. The current public policy, legislation and service delivery environment provides a fertile ground to deliver services that respond to the challenges and meet the diverse needs of all parents and children.

This report provides an account of the experiences of parents², service providers and the young people around the early stages of child's diagnosis of learning disabilities. The aim of this study was to identify the key issues and concerns so that these can inform the delivery of the GIRFEC framework for children who have a diagnosed or undiagnosed learning disability. The experiences of parents and carers along with that of the professionals (practice that worked well for parents and carers) is hoped to provide insight into their perspectives. This research project has been funded by the Third Sector Early Interventions Fund of the Scottish Government.

¹In this study the term "learning disabilities" includes Autism Spectrum Disorder.
²In this study the term ‘parent’ implies the primary carer of the child. This includes natural parents, adopted parents and guardians.
1.2 Learning disability

The Keys to Life (Scottish Government, 2013:6-7) defines people who have learning disabilities as those having a significant lifelong condition that started before adulthood, which affected their development and which means they need help to understand information, learn skills and cope independently. A similar definition of learning disability is provided by the Department of Health (2001) as a “significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood”.

According to the British Psychological Society (2001), the medical diagnosis of a learning disability requires meeting three core criteria: a) a major impairment in intellectual functioning (typically an IQ of 69 or less); b) a major impairment in adaptive/social functioning, i.e. how well a person can handle common demands in life and how independent (includes safety) they are; and c) age of onset is before adulthood.

The terms associated with learning disability have evolved over time within the health, social care and education sector to help identify need and plan and deliver services. Learning disability and learning difficulty are often used interchangeably but have different meanings within health, social care and education sectors. The term learning difficulties is used to include those who have specific learning difficulties such as dyslexia but might not have any or significant impairment to intelligence and therefore cannot be categorised as having learning disabilities as per the definitions in the policy documents. The Doran committee in their Strategic Review of Learning Provision for Children and Young People with Complex Additional Support Needs (2012b) and the Report of the National Review of Services for Disabled Children (Scottish Government, 2011a) also find that the definitions around learning disability and learning difficulty are overlapping and have continued to attract a lot of debate and interpretation.

Increasingly the term intellectual disability is being used across Europe (e.g. Inclusion-Europe, no date), USA and Australia and also amongst some professional groups within the UK (Mansell, 2010). According to the World Health Organisation (no date), intellectual disability implies a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.
The diagnosis of a learning disability can be complex. In some cases the diagnosis can be made at birth or prior to birth, e.g. Down’s syndrome, foetal alcohol spectrum disorder. The diagnosis can take place early in child’s life; in primary school where the child’s progress may not be compatible with his/her peers; at transition stage when the child moves from primary school to secondary school; or at a stage when the child moves from childhood into adulthood where their peers become more and more self-reliant and independent. There are a wide range of conditions that could result in a learning disability and each has a detailed list of criteria whose application results in a diagnosis. For example, NICE Clinical Guideline, 128 (2011:8-10) provides a detailed list of criteria that would result in a diagnosis of autism spectrum disorder (ASD).

Gillberg et al. (2013) in their paper highlight the complexity associated with a learning disability and services.

“The children are reported to have problems in the fields of (a) general development, (b) communication and language, (c) social interrelatedness, (d) motor coordination, (e) attention/"listening," (f) activity, (g) behaviour, (h) mood, and/or (i) sleep. Children with major difficulties in one or more (usually several) of these fields will be seen by health visitors, nurses, social workers, education (including preschool) specialists, paediatricians, GPs, speech and language therapists, child neurologists, child psychiatrists, psychologists, neurophysiologists, dentists, clinical geneticists, occupational therapists, and physiotherapists, but, in the vast majority of cases they will be seen only by one of these specialists, when, in fact, they would have needed the input of two or more (occasionally even all) of the “experts” referred to”.

It is not uncommon to diagnose the child as having Global Developmental Delay (GDD). It is described as a condition that occurs between birth and 18 years of age where the child does not reach the key milestones of development which include learning to communicate, to process information, to remember things and to organise their thoughts (Foundation for people with learning disabilities, no date).

There are a range of factors that can contribute towards the causes of a learning disability (Gillberg and Soderstrom, 2003). For example, a learning disability could be linked with a genetic mutation (e.g. Prader-Willi and Angleman syndromes, Down’s syndrome), or a defective gene syndrome (e.g. fragile X, 22q11 deletion syndrome). It can also be a consequence of environmental factors such as maternal intake of neurotoxins (e.g. alcohol, thalidomide) and also through prematurity at birth or suffering from meningitis and encephalitis or a brain injury. Smoking and alcohol in pregnancy have been associated with attention deficit hyperactivity disorder (Milberger et al., 1996). Foetal alcohol spectrum disorder is a continuum of permanent and lifelong defects caused by maternal consumption of alcohol during pregnancy.
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

In this report, the term learning disabilities includes those with a diagnosis of Autism Spectrum Disorder (ASD). ASD is an umbrella term that is used to describe symptoms and behaviours which affect the way in which a group of people understand and react to the world around them. It is also recognised that some of those who have a learning disability can also have ASD. ASD includes Asperger syndrome which is sometimes referred to as a hidden disability (Foundation for people with learning disabilities, no date).

Further, the term diagnosis is used to imply that a person has been assessed as having a learning disability/disabilities and this has been communicated to his/her parent/carer. This may subsequently, with the consent of the child, be communicated to professionals in education and social care.

1.3 The numbers

There appears to have been a steady rise in the number of children being diagnosed with learning disabilities, which is often associated with improved diagnosis and increased reporting from parents and more children surviving longer. For example, commenting on a Cochrane review by Oono et al. (2013), the Editor’s Note (2013) suggested that the steady rise in the number of children diagnosed with Autism (ASD) at increasingly younger ages is likely to be related to an increased focus on, and interest in parent mediated interventions for children with Autism. Demographics associated with people who have a learning disability vary widely. Mencap estimated that there were approximately 1.5 million people in the UK (around 3%) in 2001 living with learning disabilities of which more than 210,000 had a severe or profound learning disability (Mencap, no date). The Learning Disabilities Observatory (Emerson et al., 2011) estimated that in England there were 286,000 children (180,000 boys, 106,000 girls) who had a learning disability in the age range of 0-17. As per the 2011 census there were approximately 12.5 million children under the age of 19 in 2011 in England. This implies a prevalence rate of approximately 2%.

Data on learning disabilities for Scotland is patchy and not wholly representative of the actual numbers of people who have a learning disability. As per the 2011 census there were approximately 1.2 million children and young people under the age of 19 years in Scotland. Using a 2% estimate this implies approximately 24,000 children and young people under the age of 19 years have a learning disability. The healthcare needs assessment conducted in 2004 (NHSHS, 2004) also estimated that 2% of the population of Scotland had mild to moderate learning difficulties, while 0.3% to 0.4% had severe to profound learning disabilities. It suggested that 18,000 adults were known to have learning disabilities by local authorities; an estimate which is significantly lower than 2%. The Keys to Life (Scottish Government, 2013) strategy estimates that there are 16,000 school-aged children and young people who have a learning disability and require support.
Community Paediatricians and other healthcare professionals based in Community Child Health Departments conduct assessments to enable early identification, assessment and monitoring of children (0-19 years) with additional support needs across Scotland and capture it on the Support Needs System (SNS). The SNS system captures information on any learning disability, language or communication impairment, emotional problems, behaviour disorders and physical problems. In 2011 there were 15,541 children and young people on the SNS system of which 78% were recorded as having at least one impairment (of any severity) and 26.8% as having at least one severe impairment recorded. Of all children and young people on SNS, 98.6% were recorded as requiring at least one service (newly identified or ongoing). The most commonly required service type recorded was the involvement of the speech therapist (Information Statistics Division, 2012).

The study Growing up in Scotland (GUS) (Bradshaw and Hall, 2013) published an analysis of the experiences of children with all kinds of disability (data emerging from responses for 5217 children born in 2004/05). The study asked parents if the child had any longstanding illness or disability. The analysis suggested that 13% of children had a disability at 10 months of age which increased to 15% by the time the child was 3 years old. This had further increased to 19% by the age of 6 years suggesting that by the age of six, 1 in every 5 children (20%) has some kind of long term disability (which includes learning disability).

1.4 The strategy, guidance and policy framework

A number of principles, policies and guidance documents have been enunciated to provide children with their rights. In some of these, learning disabilities have been specifically mentioned while in others they emerge from a more generic position.

Under the Convention on the Rights of the Child, the UN specified 54 articles (UNCRC, 1990), where all rights apply to all children without exception, and that best interests of the child should be taken into account. With specific reference to this study, Articles 23 and 24 deal specifically with disability and health services respectively. Article 23 (children with disabilities) suggests that a child who has a disability has the right to live a full and decent life in conditions that promote dignity, independence and an active role in the community. Governments must do all they can to provide free care and assistance to children who have a disability. Article 24 (health and health services) suggests that every child has the right to the best possible health.

\[^{3}\text{Here “longstanding” meant to be anything that had troubled the child over a period of time or that it is likely to affect him/her over a period of time.}\]
Additionally the UN Convention on the Rights of Persons with Disabilities which came into force in 2008 (UN, 2008) requires the parties to the Convention to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that they enjoy full equality under the law. The convention comprises of 50 articles of which articles 4 to 32 define the rights of persons with disabilities and the obligations of states parties towards them. Article 7 relates specifically to children with disabilities:

- states parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
- in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
- children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Further, Article 30 requires that the parties take appropriate measures to enable “children with disabilities to have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system”.

In the Scottish context, The Children (Scotland) Act (1995) (The Scottish Office, 1997a) provides the regulations and guidance to support and protect children and their families. Chapter 6 (volume 1) introduces a legal framework for assessment, services and support to children who have disabilities (includes learning disabilities), children affected by disability and their families. It requires services for these children to be designed to minimise the adverse effects of disability and to enable them to lead lives which are as normal as possible. It defines disabled children as children in need. The local authorities have a duty to safeguard and promote their welfare and are required to assess a child’s needs when requested to do so by a parent or guardian. This is generally known as a Section 23 assessment. Volume 2 (The Scottish Office, 1997b) provides regulations and guidance for local authorities with respect to children that are looked after by them. It puts forward duties and guidance for local authorities to work in partnership with the parents and families, health services and the voluntary sector amongst others.
The Early Years Framework (Scottish Government, 2008 a,b) provides a list of actions to promote children's rights as defined by the UN Convention on the Rights of the Child (UNCRC) discussed above (Scottish Government, 2008c). It puts forward ten overlapping elements that need to come together to deliver a radical improvement in outcomes for children during early years. Three of the ten elements deal with developing systems that provide coherent, joint and streamlined delivery of services. As part of a coherent approach it includes development of single outcome agreements, i.e. agreements between local service delivery partners such as the health, social care and the voluntary sector. For planning and delivery it mentions the “Getting it right for every child” (GIRFEC) (Scottish Government, 2012a) agenda.

Getting it Right for Every Child (GIRFEC) framework builds upon the above policy background, the promises made in the Children's Charter - ‘Protecting Children and Young People’ (Scottish Executive, 2004) and the requirements of the UN Convention on the Rights of the Child discussed above. Though GIRFEC is a universal approach that can be applied to all children in all circumstances, the format is expected to work well for children who have learning disabilities and complex needs (arising from both learning disabilities and from other difficulties such as sensory impairment, mental health problems and behavioural difficulties). The GIRFEC approach works through:

- a single coordinating point of contact;
- shared language across professional groups and organisations;
- single assessment framework;
- single plan with clear actions, outcomes, responsibilities and timescales;
- prioritization and co-ordination of actions;
- reduced duplication in assessment, meetings and reviews; and
- reduced chance of confusion over responsibilities to address needs.

Central to children who have a learning disability is the issue of additional support for learning (ASL) which is underpinned by the Additional Support for Learning (Scotland) Act 2004 and 2009 (Scottish Government, 2009). The Act allocates duties to education authorities to identify, make provision for, and review provision for the additional support needs of children and young people for whose education they are responsible. It also places duties on education authorities, (and in certain circumstances health, social work and Skills Development Scotland) to work, to plan and make joint provision for children and young people with complex or multiple additional support needs.

Where their needs are significant, and require support from education and another partner agency, and will last more than one year, children and young people may have a statutory co-ordinated support plan to bring together all of the support to be provided to meet their learning needs (Scottish Government, 2012c).
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

The Scottish Government’s strategy, the Keys to Life (2013), aims to improve the quality of life of people who have learning disabilities. It is not limited to children and young people and has considerable emphasis on adults who have learning disabilities. There are more than 50 recommendations most of which are related to health; one is solely for local authorities and the rest involve varying degrees of participation and working with other agencies. It recognises the role of ENABLE Scotland and with respect to children it points to the GIRFEC agenda.

The National Parenting Strategy (Scottish Government, 2012d) was put forward to “act as a vehicle for valuing, equipping and supporting parents to be the best that they can so they, in turn, can give the children and young people of Scotland the best start in life”. It recognises the UNCRC’s rights of the child and mentions the GIRFEC agenda for achieving these.

Better Health, Better Care (Scottish Government, 2007a) provided an action plan to help people to sustain and improve their health. Its section on “The best possible start” deals with action on learning disabilities and also specifies the GIRFEC programme as the vehicle for achieving this.

The Children and Young People (Scotland) Act 2014 (Scottish Government, 2014) is the main policy contexts for the future. It brings forth the principles of the UNCRC in influencing the design and delivery of children’s services. The Act places duties on the Scottish Ministers to keep Children’s Rights under consideration when exercising functions. Part I of the Act requires the local authorities to prepare a Children’s Services Plan every three years in consultation with service providers. It also requires the local authorities to report every three years on what they have done to further uphold children’s rights. The Act provides impetus to the integration of services provided to children from the “point of view of recipients”.

Co-ordination in design and delivery of service provision is strengthened through having a single point of contact, the named person for every child and young person. It requires the development of a Child’s Plan (with multi-agency input including those of the child and the child’s parents) where the child has a well-being need (i.e. well-being is at risk). The Child Plan helps identify the need for a “targeted intervention” to meet the well-being needs of the child that are not capable of being met fully by the mainstream services (those which are generally available to all children). The Act increases the entitlement of early learning and childcare provision for 3 and 4-year-olds from 475 hours a year to a minimum of 600 hours. The Act also defines children’s services as any service provided in the area of a local authority for the benefit of children generally; or children with needs of a particular type (such as looked after children, children with a disability or children in need for additional support for learning).
The Social Care (Self-directed Support) (Scotland) Act (SDS, 2013), that came into force in 2014 is also relevant to providing need-specific support for children who have learning disabilities and their families. It places a duty on social work departments to offer those eligible for social care a range of choices around how they would like to receive their social care and support. It provides flexibility and choice on how their individual budget is used to meet the outcomes they have agreed.

1.5 Aims of this study

The aim of this study is to provide insight into the experiences of parents around the early stages of a child’s diagnosis of a learning disability and parent expectations of support and services available. This is to inform implementing the GIRFEC framework for children and families with learning disabilities. It is also expected to inform campaigns for improved services and support for children and families.

The specific objectives of this study are to investigate:

- the challenges and issues faced by parents before diagnosis (when early concerns are raised about the child’s development), during and after the child’s diagnosis of a learning disability;
- gaps in awareness, availability and access to support and advice, pre and post diagnosis period; and
- aspects of practice that work well for parents.

The research utilised qualitative research methods to facilitate reflection from three target groups; a) Parents or primary carers of children with learning disabilities; b) professionals identified by the parents as making a positive change in their journey pre and post diagnosis; and c) the young people’s recollection of their life following a diagnosis of a learning disability.
It is important to ask what is and what is not known about the early stages of diagnosis of learning disability and the experiences of parents and carers and their needs. In this section, literature is examined for answers to the above question.

2.1 Raising early concerns

It is important to identify children who may have developmental disabilities. Parents’ observations of speech, language or cognitive skills of their child can be an important source of information for screening for a learning disability and service referrals for early intervention (Diamond, 1993; Chung et al., 2011).

Once early concerns are raised, the parents want to know about the causes of their child’s learning disability. A study conducted by Makela et al. (2009) investigated the value placed by parents on an etiological diagnosis (causes of intellectual disability) for their child. The study found that the intensity to find out about the causes of an intellectual disability was often felt by the parents when developmental concerns were first noted, and that it diminished over time. All parents included in their study felt that they would have preferred to have an etiological diagnosis however, for some it was more of a curiosity.

2.2 Timing of diagnosis

The time at which diagnosis of a learning disability is made depends on the condition. Some of the conditions can be diagnosed early (prior to birth) e.g. Down syndrome (DS), while others may take considerable time for diagnosis.
A brief review of literature

Hedov et al. (2002) collected data from 51 departments of paediatrics in Sweden and found that 75% of families were provided a diagnosis of Down's syndrome within 24 hours of a child's birth. The study found that more than half of the parents were dissatisfied with the timing of the disclosure; more families felt that they were informed too late rather than too early. The authors opine that parents of children born with DS may need some time for themselves before being provided the diagnosis. The study also suggests that there is probably an optimal time for the first information after delivery. Information given immediately after the delivery might disturb the bonding and recovery of the new, possibly fragile, family. On the other hand, the information cannot wait too long after the birth, leaving the parents in anxiety and loneliness.

Keenan et al. (2010) reported that the mean age at the diagnosis of Autism Spectrum Disorder (ASD) in Ireland was just over four years. An earlier study, by Howlin and Moore (1997), found that the average age before the child is formally diagnosed with ASD was between 5 and 6 years in the UK and that many children experienced long delays and multiple referrals before the diagnosis was made. Keenan et al.’s (2010) study in Ireland found that the amount of time between first referral and diagnosis was around 15 months.

Baird et al. (2000) examined issues around disclosure of diagnosis of cerebral palsy. They found that dissatisfaction with diagnosis was greater when it was delivered late. They also found that dissatisfaction with how the diagnosis had been disclosed was greater where children had been premature and/or of low birth weight and where they developed more severe degrees of physical disability.

2.3 Delivery of diagnosis

Davies et al. (2003) in their study with parents of children diagnosed with Turner syndrome found that initial experiences of the diagnostic process with a professional can have a major and long-lasting influence on parents’ ability to cope. In cases where the parents had some doubts about their child’s development and wanted answers about the condition, they described the diagnosis as confirmation of their suspicions. For some parents the most important reason for wanting a diagnosis was validation and the legitimacy it provided for the child’s appearance and behaviour (Makela et al., 2009). A study conducted in the US (Garwick et al., 1995) examined the issues associated with “breaking the news” to parents and caregivers of infants born with Down’s syndrome and or congenital heart disorder. They found that families who did not suspect a problem prior to diagnosis particularly accentuated their feelings of shock and surprise. Carers placed more emphasis on how they were informed than specific details about the condition. Families responded positively to professionals who kept them informed about their child’s condition and focused on their child as a whole, rather than only the negative aspects of the child’s condition. Negative reactions were associated with hearing the diagnosis on the phone, hearing it in the presence of strangers and with receiving outdated or inadequate information. The study suggests that those providing such information to parents should also manage the psychosocial aspects correctly.
A similar study on Down’s syndrome (DS) conducted in Sweden (Hedov et al., 2002) found that parents had a “traumatic crisis reaction” on being informed of the DS diagnosis. A majority of the parents (70%) felt that the information had been insufficient and a majority (60%) also felt that they had been unsupported. The major criticism concerning the way in which the information was provided was that they received too much negative information about DS and that both the communication skills and the knowledge of DS on the part of the professionals could have been better.

Baird et al. (2000) developed recommendations for good practice related to the delivery of a diagnosis of cerebral palsy. They recommended that diagnosis should be conveyed by a consultant paediatrician, accompanied by a person such as a health visitor who will be involved in the child’s continuing care and that no other person should be present. Parents should be provided medical details clearly and directly and given as much time as they wish to ask questions. The authors suggested that, in the case of cerebral palsy, many parents feel a strong need to understand the reason why their child has impairments. They also recommended that the manner in which diagnosis is provided should reflect sympathy, honesty and openness. It should provide a balanced viewpoint rather than a catalogue of possible problems. Whitehurst (2011) in her study with parents of children with Foetal Alcohol Syndrome Disorder reported similar parental sentiments.

Chua (2012) conducted an integrative literature review on parental experience of having a child diagnosed with ASD. The study considered 20 papers originating from eight different countries. The review found that a majority of parents had hoped for a more structured and timely diagnosis. The parents were dissatisfied with the professionals’ poor manner and with the fragmented information they received. The study reported that the communication of the diagnosis needed to be more co-ordinated and professionally managed. The review quotes a study conducted in Scotland (Brogan and Knussen, 2003) in which more than half of the 126 Scottish parents included were satisfied with the diagnostic process; they were pleased with the professionalism and timeliness of diagnosis, and the amount of information received.

### 2.4 Coping with diagnosis

A number of studies have investigated the experiences of parents immediately following the diagnosis of a disability. Graunngard and Skov (2006), through their longitudinal study, provide an insight into parental experiences and ways of coping following the realisation that their new-born child has a disability (which includes learning disability). This study uses a grounded theory approach in which 16 parents were each interviewed twice over a period of two years, the first time soon after the disclosure of a disability. They quote the definition of coping as:

> The constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. (Lazarus and Folkman, 1984)
A brief review of literature

The above definition incorporates two strategies: a) problem-focused coping, i.e. coping that is directed at managing or altering the problem causing the distress; and b) emotion-focused coping, i.e. coping that is directed at regulating the emotional response to the problem. The problem-focused coping used by the parents included looking for relevant information, learning new skills and being able to control the health professionals’ actions and decisions. The parents felt that they were in a constant fight to establish and support the rights of their child and that the diagnosis would help the healthcare system in influencing the child’s recovery or cure. Emotion-focused coping strategies identified were: retaining hope, creating future images, ignoring the seriousness of the condition, seeking social support and concentrating on possibilities (as opposed to disabilities) in the child.

Graungaard and Skov (2006) found that diagnosis had a key role in the parents’ search for certainty and that diagnosis plays a strong role in influencing their emotional and problem-solving strategies. The meaning ascribed by the parents to a diagnosis was related to finding coping possibilities that would help them in reducing the immense stress that they experienced.

Burr and Klein (1994) suggest additional coping strategies used by parents and families to deal with the stress following diagnosis. Having good relationships (increased cohesion and co-operation), effective communication (listening, openness), and advancing spiritual and individual development through keeping active were named as avenues for coping. Taanila et al. (2002) used the Burr and Klein’s coping framework to examine families that coped well (high coping) and those that didn’t (low coping). A comparison showed that high coping families had greater acceptance of information, engaged in hobbies and had an optimistic attitude towards the child’s life. Having good family co-operation and social support through formal and informal services including personal resources helped in coping.

Hugger (2009) examines the emotions of parents after the delivery of diagnosis. She suggests that “mourning the loss of an ideal child” is an inherent part of the emotions. She quotes the classic stages as: grieving, denial, anger, bargaining, depression and acceptance.

The manner in which the diagnosis is received and the way in which parents cope is also strongly dependent on cultural and religious norms. In other words experiences from one culture cannot be directly applied to another. For example, Huang et al. (2010) in their study on mothers of children born with cerebral palsy in Taiwan suggested that the Taiwanese mothers not only felt the loss of the “idealised child” when the child was diagnosed with cerebral palsy, but they also lost their expectations of ‘normal’ motherhood and fulfilling the societal anticipation of having given birth to a healthy child. They felt loss of face, self-blame or being blamed by the husband’s family. Within the UK the experiences of minority ethnic parents were said to be influenced not only by their own cultural and religious backgrounds through which they interpret learning disability, but also by “minority experience” which includes social factors such as poverty, class and discrimination (Heer et al., 2012).
2.5 Post-diagnosis services

A number of studies have examined the long-term needs of families with a child who has a disability. The literature suggests that the parents go through considerable struggle to access appropriate support and information. For example, Stalker and Moscardini (2012) conducted a detailed literature review on the experiences of children in Scotland who have disabilities and also examined the relevant policies in this context. They found that despite high levels of need there was inadequate provision of services for children across Scotland who have learning disabilities. They suggest that children who have learning disabilities are often seen as lying outwith the remit of both community learning disability teams and child and adolescent mental health services. They also found that in relation to social inclusion, parents are the child’s main advocates “fighting” to secure mainstream services and “ordinary” opportunities. The National Review of Disabled Children (Scottish Government, 2011a:15) also quotes fSDC Diary Project feedback suggesting an overwhelming number of parents and families having to “fight, battle or struggle” when seeking need-specific specialist services. Quine and Pahl (1992) in their longitudinal study on children growing up with severe disability found that families’ needs fell into three categories: information needs; help with communication, and other skills and practical help. The greatest need they found was for information.

There have also been some studies that focus on the requirement for services in the period immediately following the diagnosis, a period which is of most interest with respect to this report. Baird et al. (2000) suggest that parents should be offered the chance to discuss the diagnosis again shortly after disclosure. They should be provided with written information that is easy to understand and contains some optimistic points. They suggest that the report should mention early support programmes and a contact name and telephone number that parents can use for support. The study also suggests that once a firm diagnosis is made parents appreciate learning about the feelings that other parents may have had at such a time, and about support groups. They suggest that an offer should be made for arranging an introduction to another parent of a child with similar difficulties. Graungaard and Skov (2006) in their study on parents’ experiences and needs found that the parents required: an equality in co-operation between parents and physicians; an individual and specifically designed information strategy; an empathic personal approach; treatment of a child as a child and not a case; and consideration of the child’s possibilities despite disabilities. Similarly Huang et al. (2010) in their study on Taiwanese mothers suggested that in order to promote better understanding of the child’s condition, emotional support and information should be provided to the mother and the family. They suggest that home visits following the diagnosis to assess the mother’s and the family response to diagnosis should be conducted with particular consideration to cultural background and influences on beliefs about disability.
A brief review of literature

Timmins (2006) finds information-seeking behaviour of individuals as a response to a stimulus that is perceived as either a challenge or a threat. She defines the information needs as:

“Thus, information needs are personal expressed needs of the client/family/nurse for specific condition-related information. Information needs are therefore expressed needs, rather than normative (defined by the professional)” (Timmins, 2006:378).

She suggests that a lack of clear understanding of the term “information need” exists amongst professionals and service users. The general understanding of this term is biased towards the professional perspective (service based) as opposed to that expressed by the service user. Allen et al., (2012) in their study with parents during early years, found that the parents responded best to personalised information and support build upon trust and supportive attitude. Birch and Martin (2010) suggest that parents who lack confidence, have low literacy levels, have language issues or a limited ability to absorb complex information require support to access and utilise information materials.

Some studies have suggested gender differences in the nature of information support needed by the mother and father. For example, Graungaard and Skov (2006), in their study find that mothers and fathers of a severely disabled child differed in their emotional state at any one point in time as well as in nature of information they needed. They suggest that fathers were more likely to need information that provided a firmer idea of what the future might bring as well as scientific material that provided them with greater understanding of the condition and alternate treatments. The mothers were primarily concerned about the information related to normal caring duties for the child.

2.6 Support for the whole family

The wellbeing of the parent or the primary carer of the child cannot be neglected. Their health and wellbeing is vitally important for ensuring that the needs of their children are met. It has been suggested that issues such mental illness, problem with drugs and alcohol misuse, learning disability and strained partner relations can have a negative impact on the parent’s capacity to care for their child and increases the risk of the child being maltreated or neglected (Clever et al., 2011). Healthy child development depends on the child’s relationships, and particularly their attachment to the primary caregiver. The process of attachment begins at birth.
Bruns and Foretser (2011) suggest that parenting a child who has developmental disabilities can be a positive experience if appropriate support is available to the primary carer at the time of diagnosis and ongoing support following diagnosis from their immediate and extended family members. They suggest that support from immediate family (spouse, sibling) and extended family members is seen as extremely important and that it can be varied from being very positive to having difficulties with the grandparents and extended family members. Assuming the mother as a primary carer, Trute et al., (2012) in their study suggest a positive relationship between the mother’s positivity as a psychological coping resource and that of positive adjustment of families of children who have a disability.

Rahi et al. (2004) in their study provide an insight into the impact of “key worker” services within tertiary settings to help provide a link person to promote information provision, support, and liaison for the assessment and diagnosis of children with serious visual problems and suggest its applicability in other settings too.

Lancaster (2012) in their study found that social work services take a holistic approach in assessing the needs of the child and their family and look at needs, urgency and risks. They suggest that there is some variation in the use of eligibility criteria in different local areas and that the use of these criteria is complex when used to determine service provision for disabled children and young people. However, they found little evidence of tightening eligibility criteria, reduced levels of support or cutbacks in services. Stalker, et al. (2013) on the other hand in their study suggested a tightening of eligibility criteria which meant that increasingly support for disabled children was available only to complex cases, at higher risks or in crisis situations.
Research methods and data sources

The research utilised a range of methods to help define the scope and remit of the investigation. The overall assumption was that there are challenges faced by families at early stages of diagnosis of a learning disability which need to be met. The data was collected using an online survey, interviews and facilitated group discussions. The study was progressed through the following stages.

3.1 Stage 1 - Scoping exercise

To inform the research process discussions were held with a range of professionals who provide services, directly or indirectly, to children and young people who have learning disabilities and to their families. These included staff from the health services, the local authorities and the voluntary sector.

Facilitated group discussions were organised with in-house ENABLE Scotland staff. Interaction in all other cases was in the form of face-to-face meetings. Overall around 40 professionals and 8 parents/close family members were engaged as part of the scoping study.
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

The key questions used to facilitate these discussions were:

- what in your opinion are the challenges/problems experienced at early stages of diagnosis by parents, families and young children?
- what are the needs and where are the gaps in services?
- who all should we be talking to as part of the research?
- what questions would you like answered that would make this research a success?
- are there any unintended consequences (risks) of the research process?
- what change would you expect following implementation of findings of this research?

The themes emerging from the policy review, literature review and facilitated discussions were collated within the scoping study report (Pankaj, 2013) to be further investigated through survey and face-to-face interviews.

3.2 Stage 2: National survey with parents

To explore the experiences of parents and carers on the themes identified by the scoping study, a survey questionnaire was developed. The questionnaire included a range of themes such as:

- raising concerns about the development of the child;
- the first point of contact;
- time taken in diagnosis;
- professionals involved in the process of diagnosis and support;
- impact of learning disability of child on family finances;
- coping strategies; and
- ease in accessing benefits.

Of particular interest were aspects of support which worked well for parents.

The questionnaire (Appendix 1) included a range of question types. Closed questions were asked to obtain factual information. A number of questions used the rating scales to elicit level of agreement on aspects of services, support from professionals and different coping strategies. Additional boxes were provided for many questions to allow respondents to add comments. Open-ended questions were also included to capture individual experiences on a range of issues.

The questionnaire was piloted with parents for content, sensitivity, clarity and feasibility. A number of multi-agency, front-line service providers, including ENABLE Scotland staff, who supported parents of children with a learning disability, were provided the link to the survey. Feedback from piloting was collated and shared with the research advisory group and amendments were made.
The survey was placed on an online survey platform QuestionPro (www.questionpro.com) and was distributed using databases of addresses available with different organisations and networks. Hard copies were also made available to agencies on request. A number of agencies and networks supported the dissemination of the survey through their networks and some also provided links to the survey through their websites. Social media was also used to advertise the survey. Some individuals forwarded the survey email to service providers in local Community Health Partnership areas and relevant specialist healthcare professional groups/networks. A further 200 hard copies were distributed to parents on ENABLE Scotland’s database who were accessing Keys to Life funding or had registered interest in it. Another 50 hard copies were sent to a carer organisation on request. Some professionals such as nurses, speech and language therapists forwarded the link to the questionnaire to their professional networks.

As the intention was to examine recent experiences (within the current policy framework), only those parents whose children were below the age of 16 were included. A total of 125 fully completed responses were received that met the survey inclusion criteria. A further 51 responses were incomplete. Only fully completed survey responses have been used for analysis. However all open-ended responses were included in the study. A conscious attempt was made to include all geographical locations across Scotland. Responses received represented 27 of the 32 council areas of the country (Figure 3.1).

For the purposes of this research the term “parent” is the primary carer of the child (or young person) and includes natural parents, adoptive parents, step-parents and guardians.

![Figure 3.1: Percentage of responses received per local authority areas (Scotland) (n=125)](image-url)
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

Of the survey respondents, 90 per cent were natural parents of the child, the remainder were adoptive parents, foster parents or step-parents. A small percentage of parents (13%) were still going through the process of diagnosis while a majority of them had received a firm diagnosis of a learning disability for their child (87%).

A learning disability can be linked to a range of symptoms and conditions. Of the total 125 responses, most respondents (51) had children diagnosed (or suspected with) ASD, many in conjunction with other conditions. Amongst other conditions diagnosed or suspected the largest numbers were for Asperger syndrome (13), Attention Deficit Hyperactivity Disorder (15) and Global Developmental Delay (14). Other conditions included Down’s syndrome, Angleman syndrome, Williams syndrome, Dorsal stream dysfunction, Dravet syndrome, cerebral palsy, Foetal Alcohol Spectrum Disorder, 22q11 deletion syndrome and spina-bifida. In many cases learning disability was associated with physical disabilities with some suggesting learning difficulties such as dyslexia.

3.3 Stage 3: Semi-structured interviews

With parents

Through the survey, more that 100 parents and carers provided their contact details agreeing to take part in face-to-face interviews. Additionally, information about the research was disseminated widely through networks and membership databases. The researcher attended networks/workshops/networking events for parents and conducted workshops with relevant information about the research at these events. From those who volunteered a diverse set of 10 parents and carers were interviewed that were from across Scotland representing both urban and rural areas. Of the parents, eight were natural parents (7 mothers and 1 father), one was a step father and two were adoptive parents. Their children’s diagnosis comprised a range of conditions that included, for example, ASD (included high functioning and regressive autism); attention deficit hyperactivity syndrome (ADHD), global development delay (GDD), genetically linked learning disabilities and complex physical and behavioural issues.

When contacting parents/carers for an interview, information about the research was sent to them as per ethical guidelines and informed consent was sought. Key prompts and open questions were developed to facilitate open responses. The interviews were conducted in their homes and at a time and date suitable to the parents. Interviews typically lasted one to one and a half hours. As part of the interview the parents were asked about their experience on what worked for them. They were then asked to identify professionals that played a role in providing need-specific support. The named professionals were contacted for an interview to get their perspective on the identified area of good practice. The interviews were recorded and later transcribed by a professional transcriber.
With professionals – what worked well
The key professionals identified by the parents as those who provided need-specific support primarily included professionals from the education sector, a head teacher of a mainstream school, a head teacher of a special school, a preschool outreach visiting teacher and a support worker of a special needs unit within a mainstream school.

Other professionals included a general practitioner, a physiotherapist and a learning disability nurse. Contacts were made with all the professionals identified. Some had moved on and could not be contacted and one other health professional identified had retired. The questions for professionals were open-ended. In total eight professionals were interviewed. These interviews were also recorded and transcribed.

With children and young people
A small number of young people (12 to 17 years of age) who had a firm diagnosis of a learning disability (including ASD) were recruited to take part in the interviews. School teachers and project leads within ENABLE Scotland who run support groups for children who have learning disabilities distributed information about the research to schools and parents. Those parents who responded and were happy for their children to take part in the research were then contacted for consent. The young people were also provided information about the research as per ethical guidelines and their consent was sought prior to conducting the interview. The questions asked were open-ended and explored the children's experiences in general and about the people in their lives who offered support to them. They were also asked what they thought support looked like and what kind of support they felt they needed. Talking Mats (no date) was used to facilitate discussions. Five children (three boys and two girls) were interviewed of whom two had been diagnosed with Asperger, two with ASD and one with global developmental delay. These discussions were also recorded and transcribed for analysis.

3.4 Stage 4: Analysis
The data emerging from the surveys was exported to Excel (Microsoft Office) for further analysis. The qualitative data from the survey was collated. The interviews were recorded and professionally transcribed verbatim and included pauses and utterances. The researcher read through the transcripts in conjunction with listening to the recordings. The interview data was analysed for emerging themes. The themes emerging from the survey and the interviews were compared and combined to develop themes for presentation in the report.
3.5 Ethical considerations and informed consent

Ethical considerations and guidelines were routinely assessed and followed throughout the conduct of the research. The survey provided parents information about the project, it proposed outcomes and confidentiality and anonymity of the data collected. They were also asked to volunteer for face-to-face interviews by providing their contact details. Parents who volunteered to take part in one-to-one interviews were contacted via email or telephone. Opportunity to ask further questions was also provided. They were asked to complete a Project Participant Consent Form. This explained how the data would be used, confidentiality and anonymisation of results and findings. Consent was also sought from young people themselves and their parents prior to interviews.

3.6 Summary of the research process

The overall process employed in this research is summarised in Figure 3.1. The emerging findings are presented in the following chapter.
Research methods and data sources

Figure 3.1: Flow Chart of research process
4.1 Introduction

This chapter presents the findings that emerged from the analysis of survey data and the face-to-face interviews with parents. The key themes emerging in this chapter begin from the time when early concerns are raised about the child, leading to seeking a diagnosis, receiving the diagnosis and follow-up support. The experiences relate to parents of children who had been diagnosed with a learning disability as well as those who were still awaiting a diagnosis but had received an informal confirmation that there were development concerns about their child. A wide range of conditions were reported in the survey as discussed in the previous chapter. Some of these conditions also had related co-morbidities such as ADHD, FASD, cerebral palsy, detachment disorder, dyspraxia and wheat intolerance, to name a few. Those without a formal diagnosis reported having an informal diagnosis of global developmental delay, ASD, chemical imbalance, learning and behaviour issues, ADHD, FASD, allergies and sight problems.
Experiences of parents

4.2 Raising early concerns

The survey reveals that in a majority of cases (over 60%) it is the primary carer (parent) who raises concerns about the child’s development (Figure 4.1).

When my son was less than 18 months old, I knew things weren’t right. My health worker told me to leave it till he was 2. But in my heart, I knew he needed help.

(Parent of child diagnosed with ASD and learning disabilities)

However, a significant proportion of those surveyed (23%) indicate that the early concerns are raised by primary care professionals, who are mainly the health visitor, midwife, the GP and the paediatrician.

The child minder and the nursery nurse raised early concerns in a minority of cases.

If it wasn’t for my son’s health visitor noticing that there was something wrong I wouldn’t have found out as quick……

(Parent of child with global development delay)

Our child was diagnosed when he was 4 years old, due to the sharp eye of a paediatric consultant when we were on a routine hospital visit. We were immediately sent for genetic/urine blood testing.

(Parent of child diagnosed with ASD)

But my neighbour is a consultant paediatrician. She spent five minutes and then she went, make an appointment – don’t wait ‘til he’s two.

(Parent of child diagnosed with ASD)

The nature of concerns raised ranged from behavioural issues such as wasn’t sharing, wasn’t interacting with other children, was not picking up common words/numbers in school, had communication, speech or irregular sleeping patterns, hyperactivity, was very difficult to deal with, was self-harming or had feeding problems.
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

Up till two and a half, three, he was a perfectly normal, happy child. He could communicate, he could do imaginary play, and say words and repeat things off TV. And then just about near three years, a few things were picked up in nursery, his behaviours. He wanted to play on his own, he didn’t want to participate in the group, with the other children, and he’d often wander off.

Parent of child diagnosed with ASD)

In some cases the children’s behaviours are described as having severe temper tantrums or destroying property. In other cases the observed patterns are a complex mix of physical and behavioural symptoms which parents are unable to understand at that point in time. Some parents also said that their child had a delay in physical development.

The feedback suggests that some concerns are raised by chance. For example, a mother recalled her son being undiagnosed till the age of seven. One day when he was “put out of class” he was identified accidentally by a specialist as needing to be investigated for a learning disability.

……she (the educational psychologist) seen (saw) him outside the classroom, with his behaviour, which was obviously… She knew, right away, what was wrong with him.

(Parent of child diagnosed with ASD and ADHD)

The survey also establishes that for more than a third (36%) of the respondents the health visitor is their first point of contact for help and support (Figure 4.2). Slightly more than a quarter (28%) had contacted their GP for information and advice, followed by nursery and school staff (14%) and the paediatrician (9%). Family members, educational psychologists, speech and language therapist, neurologists and social workers are also noted as a first point of contact by a small number of survey respondents. This indicates that the health visitors and the GPs are the professionals who need to be well equipped to guide the parents in these cases.

Figure 4.2: Professionals (percentages) that were identified as first point of contact by parents
4.3 Route to diagnosis

The feedback illustrates diverse journeys for individuals with diverse needs and family circumstances. Parents with children born with a genetically linked learning disability are informed either prior to the birth or soon after birth about the child's condition. In such cases the assessments were conducted through hospitals and specialist units. For others, the route to diagnosis varied from the primary health care system (the Universal Pathway for All Children) as the starting point leading to range of specialist centres or professionals such as Child and Adolescent Mental Health Services (CAMHS), Community Early Assessment Team (CEAT), Southbank Child Centre, Lanarkshire Autism Diagnostic Service (LADS), Yorkhill Hospital, Edinburgh Sick Kids Hospital, the educational psychologist, the speech and language therapist and the community paediatrician.

The responses show that in most cases at least some support from the various service providers from health, social work or the education sector is available, and is used by the parents as they navigate through the system for a diagnosis.

As shown in Figure 4.3, the survey finds that a majority of the respondents either disagree (23%) or completely disagree (34%) that the route to diagnosis is clear. About a fifth (19%) of the respondents agree and a further 7% completely agree that the route to diagnosis is clear. Sixty three percent of respondents agree (30% completely agree and 33% agree) that they were actively involved in the process of diagnosis.

![Figure 4.3: Parent experiences of the route to diagnosis](image-url)
The interview feedback provides insight into the struggles faced by parents with children with different levels of perceived needs. Parents whose child who was deemed as “not being bad enough” or was a high functioning (ASD) child with social and adaptive issues, or has global developmental delay, struggle to find information or support or to navigate their way towards a diagnosis. In cases of a rare genetic condition the parents struggled to get relevant support and advice.

Experiences associated with having clarity about the route to diagnosis varies considerably. Of parents whose child has had no formal diagnosis, only 18% (n=16) feel that the route to diagnosis is clear to them. For those parents whose child has been given an overarching diagnosis of global developmental delay, a vast majority (93%, n=14) suggest that the route to diagnosis is not clear to them. Interestingly, a third of parents (30%, n=64) of children with a diagnosis of ASD and/or Asperger syndrome feel that the route to diagnosis is clear. Parents who get referred to different specialist centres (often located in different geographical locations across Scotland) for assessments feel that an unplanned approach to referrals and assessments can be frustrating for the parent involved.

Initially, we were getting referred to the wrong people. We had so many appointments. There wasn’t a day without at least one or two appointments. And you would get sent to the wrong place or you would get sent to something and they would say, oh, no, you shouldn’t be here, this test won’t work for your child….. and then it’s another re-referral, which is another three months down the line.

(Parent of child diagnosed with a rare condition)

He (specialist) thought that [the child] may potentially have cerebral palsy, and they booked [the child] in for an MRI scan for further exploration – and we were expecting that to be pretty soon, and we didn’t get… I had to chase up the MRI scan. And then they also took blood tests as well, at the same time. So [the child] was over two, at that point, for diagnosis.

(Parent of child diagnosed with a rare condition)

There is also a perception that the pathway is much clearer for well-known and established conditions such as ASD.

So there’s an autism pathway here. So if they think your child is autistic, you go through that pathway, or if they think your child has got cerebral palsy, you go to this service, etc., etc. But when they don’t have a clue what’s wrong with your kid, there doesn’t seem to be a pathway, you just seem to get referred all over the place, randomly, to different professionals. And if they come back and say, oh, no, it’s not me, then you have to get referred to somewhere else, and then they say, oh, no, that’s not us, and then you get referred to somewhere else.

(Parent of child diagnosed with complex disabilities)

It is not always specialist centres associated with learning disabilities that the parents had to steer through to obtain a diagnosis. Their struggle lies in the fact that the parents do not appear to be fully engaged in what was going on.
Experiences of parents

Mainstream school wasn’t interested and said he could have been blind, so we got his eyes checked out. Then they said he could be deaf, so I got my GP to refer him to get a hearing test, which came back fine. Then they told me he could be autistic so back to the GP, I went to have her refer him to X [diagnosis service] and they knocked the referral back and then my GP got the child and family centre involved…which was a waste of 9 months in my eyes as I got no information and felt as though I and his dad where in the spotlight, not my son.

(Parent of child with global development delay)

However, there were parents and carers who had a positive experience with respect to the route to diagnosis. The feedback suggests that a co-ordinated approach led by the professional, with parents being involved and informed, worked well.

We were very lucky we had everyone on board from the start ie nursery, health visitors, speech and language team, doctor. Yes it took 3 years but they were all doing tests and watching X all the time before I went to (X) hospital’s autism language unit to assess X and get a diagnosis for [the child].

(Parent of child diagnosed with Asperger syndrome)

Our GP did a referral to speech and language therapy, but he also did a referral to the community paediatric service because we were talking about so many different issues. And both those referrals came through, and he had a full assessment at the community paediatric service, which was to do physio and occupational therapy, etc. And speech and language identified very quickly that, yes, there was quite a significant developmental delay with his communication.

(Adoptive parent of child with global development delay)

So they isolated him – they came in and had a look at him and decided to give him a little play area for himself. And as they progressed and studied him, he was then recommended to go not to the mainstream nursery but to a specialist nursery….So he spent a morning in one place, and it was the afternoon in the other, and they just continued to study him. And, at that point, we also had a learning/educational development officer… She came out to the house and worked with him. And, at that age, he was about four he went there (the Child Centre), and they did some tests and stuff, and we didn’t get the full… or the diagnosis until he was about four.

(Parent of child diagnosed with ASD)
4.4 Getting a diagnosis

The survey shows that 85% of the respondents agreed they wanted a diagnosis. A majority of respondents (64%) felt that it had taken too long for them to get a diagnosis (Figure 4.4).

Comments in the survey indicate that the time between the raising of early concerns and that of some certainty about the diagnosis can be difficult for parents and carers. The survey provides varying timescales for different conditions. Table 4.1 gives the average time taken to get a diagnosis for children who have different learning disabilities.

Table 4.1 Time taken for diagnosis (from raising of early concerns) for different conditions

<table>
<thead>
<tr>
<th>Learning disability (number of respondents)</th>
<th>Time taken for diagnosis in months: mean (median; range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Spectrum disorder (n=64)</td>
<td>36 (30; 6-120)</td>
</tr>
<tr>
<td>Global developmental delay (n=14)</td>
<td>25 (24; 0-66)</td>
</tr>
<tr>
<td>Attention Deficit Hyperactive Disorder (n=15)</td>
<td>61 (60; 12-108)</td>
</tr>
<tr>
<td>Average time taken for those who are waiting for a firm diagnosis (n=14)</td>
<td>38 (24; 9-144)</td>
</tr>
</tbody>
</table>
Experiences of parents

A variety of reasons were provided by the parents to explain why the diagnosis took time. The parents feel that in some cases if the professionals are not convinced that the development of the child will be delayed in the long term, they have to ‘wait and see’ to review ongoing progress of the child through the periodic six-monthly reviews of the child (Universal Pathway for all children) and assessments leading to the 27-30 month review of the child. The parents find the waiting periods difficult as there is no support forthcoming, and that they have to deal with the child’s condition and needs on a day-to-day basis. The desperation to obtain help and support for the child has meant that the parents persistently looked for alternate routes that could lead to a diagnosis.

But, by that time, I knew there was something not right, and I knew that my child was suffering, because he was struggling. So, over the summer, I got in touch with his speech and language therapist, and she did a profile on his language skills, communication skills, stuff like that, and she said that there was enough pointing towards the autism spectrum that we needed to get it investigated further.

( Parent of child diagnosed with ASD)

Parents noted that sometimes if children had issues specifically related to social and adaptive behaviour rather than intellectual disability, they could be seen as merely badly behaved. They feel that due to lack of understanding of the spectrum (e.g. ASD), the symptoms can go unnoticed as they are hard to identify.

I think a lot of it in school was, because X was bright, it wasn’t picked up sooner. It was all just behavioural issues. There was no learning disability or speech or anything. I think that has been why it’s taken longer, because it’s solely just been behavioural issues. He was later diagnosed with having Asperger syndrome.

( Parent of child diagnosed with Asperger syndrome)

He is very bright, but, socially and emotionally, he is years behind his peers – years behind. So the work that he’s able to cope with, he can cope with it on an academic level – he can’t cope with it on a social and emotional level.

( Parent of child diagnosed with ASD)

The diagnosis of global development delay was found to be misleading as it sometimes gave parents hope that the delay was temporary and that the child would catch up on the developmental milestones in due course. Some parents feel that the professionals provide the diagnosis of global development delay as a soft diagnosis and perhaps they do not want to break the news. In other cases the perception is that the professionals are reluctant to label the child too early. The survey and the interviews indicated that the information available on global developmental delay is scant and leaves parents worrying about the future of their child.
Our son was not reaching milestones and at age 4 was more like a 2 year old development wise. We felt we were given ‘global development delay’ as there was nothing else they could label him with. 6 monthly meetings at child clinic where he underwent checks like playing with blocks, cars, etc, but no assistance/advice was provided, and apart from school meetings, no other input received. For 3 years we have felt that we were the only parents dealing with this condition. (Parent of child diagnosed with GDD)

But if your child is undiagnosed for years, or diagnosed with something like global developmental delay, which is the generic catchall for we haven’t got a clue, there’s nowhere to go with that. (Adoptive parent of child with GDD)

When our son was diagnosed with this we were told and we weren’t given any information. I worry about his future, if he will be able to hold a job down if he is lucky to get one, if he will be able to live independently etc. This is a great concern. (Parent of child diagnosed with GDD)

In cases where there is no diagnosis or uncertain diagnosis the parents feel powerless and distraught.

She doesn’t have ADHD, but she does have ADHD traits. So it is very difficult, because we are in this no man’s land. But I just feel that early intervention would have stopped a lot of issues that our family have gone through. (Parent of child with no diagnosis)

It was also suggested that the identification of a learning disability can get delayed if the child's mother tongue is not English.

So she had to learn English, so to speak, which she did, but I think these health professionals and psychiatrists, in particular, put her learning difficulties down to the fact that she was behind a couple of years [with learning the language], so she had to gain that. So I think that’s the way they looked at it. (Parent of child diagnosed with ASD)

There is a strong feeling that diagnosis empowers the parents by providing them with tools and techniques for understanding the situation and needs, and managing their day to day life better which is unavailable otherwise.

We needed to know what exactly… Why he’s like this. And if the professionals can diagnose him, then at least you’ve got a point where you can accept and study and understand what the condition is that he’s got, and how to cope with it, and what the future would hold. (Parent of child diagnosed with ASD)

The data shows that parents find it beneficial to “put a name to” what was wrong rather than being in denial of the situation. A late diagnosis can make it difficult to compensate for the positive difference that an early diagnosis makes for the child.
Experiences of parents

The parents feel that the diagnosis helps them accept, study and understand the condition. It enhances their ability to cope with it. It helps them bond better with the child and plan, not only the current support needs but also for the long term.

Having the diagnosis has made X (the child) and I, much, much closer... If you’ve got that bond, and if you’re having constant sleepless nights and problems and difficulties, it’s easier to cope with it.

(Parent of child diagnosed with genetic disorder)

Diagnosis also enables them to ask specific questions of the specialists as they are more informed. It also permits them to meet with other parents of children with a similar condition and work out the best way forward for the child and the family. It helps in linking parents and carers to relevant support groups that the child can avail of, as well as for the parents who could avail informal support and counselling from peers at times when they needed a listening ear. There is a strong perception that all this support is a consequence of the certainty through diagnosis which they would not have accessed otherwise.

And when I found a support group for my eldest son, it was like, oh, my God, all the pressure gets lifted off, because you’ve got somebody you can phone if you’ve got a question, somebody you can phone if you’re upset. But, of course, when your kid is undiagnosed, there was nothing.

(Adoptive parent of child with complex needs)

I just feel that, for me, I just wish there had been early intervention, because I don’t think it would have escalated to the stage that we are at. I just feel that CAMHS is good, but the waiting list… It’s just a constant wait. It’s a wait for everything. You’re put on the waiting list for everything, and it’s so long.

(Parent of child with ASD and ADHD)

This feeling of isolation was also amplified for those whose child did not have a firm diagnosis.

Because we don’t have a diagnosis… a lot of these forums are for people who have ADHD, who have autism. There are a lot in this area: there are help groups for ADHD; there are help groups for autism; there’s help groups for all different types – but when you don’t have a diagnosis, that is the issue, and you’ve nowhere to turn.

(Parent of child who is awaiting diagnosis)

The diagnosis helped the parents to seek out the right education and the right school to meet the child’s needs, and to help them progress further.

Well, he has got a learning disability, but I think he’s a lot more able, and I think the problem has been that he wasn’t being taught in a way that he could understand, because he didn’t have a diagnosis – and that’s Dr. X’s[GP] view as well, is that, with the right education, he should be catching up.

(Parent of child diagnosed with GDD)
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

The knowledge of the specific condition provides certainty and clarity of the situation. It helps them take control and makes it easier for them to access support and benefits.

You don’t have to argue with DLA [Disability Living Allowance] over whether or not they’re disabled when you’ve got a diagnosis. You don’t have to argue with school about support when they’ve got a diagnosis. But, more important, you can go and… You feel more in control, because you’re like, do you know what, this is the situation, I can manage this, I know where to look for information.

(Adoptive parent of child with FASD and complex needs)

I think, always, at the back of my mind, I had this, well, we might not have her for long, the things they were testing for and things, and I didn’t have any expectations for the future, so when we got the diagnosis, it was just a huge, huge relief to (the father) and I – I think, firstly, because we knew what we were dealing with; we knew what help we could try and get for her, what we had to do to make the most of her abilities; we could get in touch with a support group specifically for children with (genetic disorder).

(Parent of child diagnosed with genetic disorder)

4.5 How diagnosis was delivered and its impact

The long-term impact of how diagnosis is delivered has been considered extensively in the literature. The survey showed that a majority of parents (66%) either agreed or completely agreed that in their experience the diagnosis of their child was conducted with care and consideration (Figure 4.5). Out of the parents with children diagnosed with ASD and Asperger syndrome (n=64), 76% agreed and only 14% disagreed that diagnosis was conducted and delivered with care and consideration. However, similar data for those with a diagnosis of GDD (n=14) suggests that only 31% parents agreed, 31% disagreed and a further 38% responded as being neutral to the statement that the diagnosis was conducted and delivered with care and consideration.

Figure 4.5: Experience of parents on how diagnosis was delivered
Experiences of parents

A minority (37%) of all parents surveyed (n=125) agreed (agreed or completely agreed) that they were given an opportunity to ask questions following a diagnosis (Figure 4.5). Around half of those surveyed either disagreed or completely disagreed with the statement that they were given an opportunity to ask questions. Interestingly, for those with the diagnosis of GDD (n=14) more than 93% feel that they were not given the opportunity to ask questions.

Getting a diagnosis was identified as a crucial moment that parents and carers reported as remembering even after a number of years. The sensitivity with which the diagnosis was delivered and subsequent engagement of parents with the professionals were described as key factors that made the diagnosis a positive or a negative experience.

The doctor was very honest with us from the beginning and explained that our daughter was likely to have a condition or syndrome and that diagnosis can take some time. This really helped us understand the process. This honestly was refreshing and I think a lot of parents are told their child will catch up when doctors don’t always know this.

(Parent of child diagnosed with rare genetic condition)

Specialised knowledge and understanding of the condition, engagement of the parent and providing parents with an opportunity to ask any follow-up questions were also associated with a positive experience of receiving a diagnosis.

She (the geneticist) was lovely – straightaway she was chatting to (the child) and started asking quite specific questions, which all linked in with (the child) – constipation, sleeping, …..., all sorts of different attributes that she had. And I said, “Are you thinking of something specifically?” And she said, “Yes. I think she’s got X (specific syndrome)” – and she explained it to us.

(Parent of child diagnosed with rare genetic condition)

The negative experiences seem to stem from parents not being involved and informed about what was going on. This makes them feel belittled and patronised. There were examples where lack of involvement of parents in the assessment process lead to further anxiety and distress experienced by them.

Our 1st paediatrician was so unhelpful and uncaring. She said she didn’t want to tell me what she was testing for as I would just ‘google it’!

(Parent of child diagnosed with genetic disorder)

I just felt so frustrated. I didn’t really understand what was going on, because, as I say, the child that I could see was not the child that they saw or described [in the assessment report]. They wouldn’t know him as well as me, so the report wouldn’t necessarily be everything that he was. The fact that there were these big, glaring mistakes [in specific observations about the child] just completely confused me.

(Parent of child diagnosed with ASD)
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

In general getting a diagnosis of a learning disability for the child is reported to be traumatising by parents. Some parents described it as a sense of bereavement, shock, or shattering of hopes and dreams.

I suppose you’re in a state of… almost like bereavement. You feel helpless and you don’t know what’s going to happen. Your aspirations and dreams are shattered. Your child isn’t going to be what you’d hoped for. And you just want to do everything you… And it takes a while for it to sink in. It’s like a bereavement that never ends, it just continues. It is quite a shock.

(Parent of child diagnosed with ASD)

**Impact on mental health**

The study finds that the parents/ carers experience extreme stress and mental health issues. At least 90% of interviewees of this study reported some kind of mental health issues that were directly related to the experiences, and caring for the child with diagnosed or undiagnosed learning disability. Parents report a range of emotions associated with a diagnosis that include, mental distress, clinical depression, trauma, despair, anxiety, frustrations, exhaustion, and nervous breakdown. Parents cited a variety of reasons for their stress, mental health and well-being. While for some, their problems were associated with getting a diagnosis and caring for the child, for others the cause was the struggle in getting access to DLA or finding support for the child in school. In some cases mental health was affected by the stress of having to go through tribunals and appeals in an environment perceived to be unsupportive

And, unfortunately, I ended up with depression, because of everything that I had to go through, and the way I was made to feel, and sometimes not respected.

(Parent of child diagnosed with ASD)

But my partner, [mother of child]. I think she took it quite badly. She was a bit in denial and depression. We had some problems at home with the whole thing. Again, it was just the unknown, especially since he’d developed normally. It was a big shock.

(Parent of child diagnosed with ASD)

Some parents reflected on the impact of their mental health on their capacity as the primary carer of the child. For example, a mother’s campaign for social work support resulted in her having a nervous breakdown.

That was in the process of an appeal, and then I had my breakdown – and what happened when I had my breakdown was really, really awful and terrible. I went to the GP’s to basically say to them, “I think I’ve got depression.” After I came out of my depression, breaking down the barriers is difficult, because even if somebody gets referred, then they still have to pick up the phone or send an email – and sometimes that’s too hard.

(Parent of child diagnosed with complex needs)
Experiences of parents

The uncertainty of not knowing what is wrong with the child adds to the distress and impacts on the well-being of parents. Many find this uncertainty difficult to cope. Uncertainty is sometimes exacerbated when the disability is not seen as being “bad enough”. The impact of not knowing about the condition, or not having financial or social care support for the child can have a detrimental impact on the family and, importantly, on the siblings of the child who become indirectly affected by the ongoing struggles being faced by the family.

There’s been days where I’ve just been on the floor, just crying all day, because I just don’t know how to cope, I don’t know where to go, I just don’t know what to do. And the fact that we probably won’t get a diagnosis, there has to be support for people who are in this situation. And I know it is very difficult when you don’t really know yourself what’s wrong with your child. There has to be support for family, and especially siblings – there really has.

(Parent of child with no diagnosis)

Feelings of not being heard and not being trusted

Many parents feel that they are not heard by the professionals when they raise early concerns about their child’s development. In other cases the feeling is that the parents’ views are not welcome even when their child’s education and development plans are discussed. They feel that professional interpretations of the child’s needs are seen as the only source of knowledge, and that the parents are not seen as equal partners in contributing to their child’s plan. Being asked to attend parenting classes is perceived by many parents to imply that they have poor parenting skills. Many parents feel that their efforts to access support and information are seen by the professionals as them being too pushy, an inconvenience, and as individuals with mental health issues.

No one listened to my concerns for 9 months. I believe my child should have diagnosed at birth given she is partially sighted with profound and complex needs. Health visitor should have picked up my child not developing.

(Parent of child with complex needs)

A mother, having gone through the struggle for a diagnosis for the first child, had to go through a similar experience with her second child. She felt that, in spite of her experience with the first child, her concerns about her second child were not taken seriously and she had to push hard for a diagnosis. Parents describe their time as ‘rough and rocky’ as they try to raise issues with professionals within healthcare and school settings. In many cases the parents feel that they are not trusted.

So I had a bit of a rough time, and a rocky road. I was basically insinuated to be a neurotic mother. They didn’t like to hear what I had to say or anything like that. They were very much that they were the professionals and they knew what they were doing.

(Parent of a child with ASD)
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

Those four years in between me getting him at two and his diagnosis at six, all I had was people saying to me and writing in reports… that say, in our opinion, there’s nothing wrong with him, his mum is bonkers, mum’s parenting skills are lacking. They never actually came and watched me do any parenting, but that was their assessment.

(Adoptive parent of child with complex needs)

The interview feedback also suggests that being labelled as a “neurotic or bonkers” parents had meant that on any further referral or re-referral, the professionals would continue to treat the parents as such, and their input would continue to be seen as unreliable.

**Impact on sibling and wider family**

The parents report direct/indirect impact of what’s going on within the family on the sibling as they feel isolated.

She’s [the sibling] has got a lot of anger towards her sister. When she was a little bit younger, she used to say, “You’ve ruined my life”. I think it’s been very, very, very difficult for [the sibling], especially because she’s been so isolated, because we’ve not been able to go out anywhere; she can’t have friends over, because the little one just… [The sibling] is very embarrassed, because [the child] will just come in and start her screaming… she basically just ruins the experience for [the sibling]….and she has just lost all self-confidence and needs somebody to speak to.

Family and friends are seen as important support systems for the parents in caring for the child (discussed later). However, there were instances where family members did not quite understand the specific needs of the child.

My mother hasn’t seen the boys for 14/15 months now, because she fell out with us because I asked her to make less noise at New Year, because [the child] couldn’t take it.

(Parent of child with ASD)

My Dad is 82, and my Dad didn’t really understand the condition, because it was just whatever, being brought up in a different generation.

(Parent of child with rare genetic condition)
Experiences of parents

**Impact of not having the right professional input**
Parents report experiences of being assessed and supported by workers who, in their opinion, do not have the right qualifications or skills to identify specific issues related to learning disability.

So if a referral comes in, they [mental health workers] will go out, visit the family, make a sort of assessment, which isn't a formal paper assessment that you get, it's just their opinion, essentially – and if they think there's a problem, you will then see either a psychologist or a psychiatrist, or they can just say, nothing to do with us, and get rid of the referral. They may have some training, after they’re taken on, but they’re not nurses, they’re not learning disability qualified, they’re not mental health qualified, which beggars belief, and they’re certainly not psychologists or psychiatrists…..So as soon as we saw a qualified professional, the diagnoses started rolling in, but it took four years.

(Parent of child with complex needs)

The parents feel that the role of the professionals with the right skills and experience is crucial to early identification and timely intervention.

And it’s a lottery, isn’t it? It is. Let's be honest. If the ‘right person’ [person with right skills and competences] had taken [the child] on, a psychiatrist or a healthcare professional dealing with mental health issues – they would have picked it [autism] up straightaway. That’s my feeling on it. Because, again, I ask myself, why can a head teacher or an assistant teacher pick it up before they could? So those two years that she was actually getting so-called psychiatric help were really a waste of time and money.

(Parent of child diagnosed with ASD)

Some parents also emphasise that not having skilled professionals right from the start, meant having reports following their child’s assessments that did not match up with their observations of their child’s condition or needs. It was only when an experienced professional conducted the assessments that the picture became clear.

She [the paediatrician] was assessing him for autistic spectrum and the X dysfunction. And then, for the first time, we actually got a report that I read that sounded like it was about my child.

(Parent of child diagnosed with ASD and complex needs)
### 4.6 Information and advice

The survey finds that about 40% of parents agreed (15.5% completely agreed and 24% agreed) to receiving information that was clear and understandable. Interestingly only 18% of respondents agree (7% completely agree and 11% agree) that they had received advice and information on services available after a diagnosis (Figure 4.6).

![Figure 4.6: Experiences of parents receiving information and advice following diagnosis](chart)

The feedback from the survey and interviews suggests that a majority of respondents did not get the required information and they had to find it from books or online resources. In some cases they were directed to sources of information, such as the library, a specific website or were added to the mailing list of local learning disability centres (e.g. an autism centre). A number of parents feel that the information provided is generic and, consequently, not helpful in dealing with the aftermath of receiving a formal or informal diagnosis.

I was handed a book with a list of organisations along with numbers and left to get on with it. The isolation was and still is unbearable at times. At least 90% of the numbers given could not help A [the child] either due to out of catchment area or age or lack of funding.

(Parent of child diagnosed with ASD)

I found most of my information on the web and googled like mad to find support online etc. I do feel it’s a bit like “here’s your diagnosis, now you know what’s up, bye bye”, and left us to get on with it.

(Parent of child diagnosed with Asperger syndrome)

Some parents describe generic information about the condition as “harsh reading” or “too scary”, and consisting of many symptoms and issues that were too generic and did not apply to their child.
Experiences of parents

A majority of respondents of children with specific known conditions (e.g. Down's Syndrome, cerebral palsy, Weaver syndrome, 22q11 deletion syndrome, Angleman syndrome and dorsal stream dysfunction) feel that since their child had been either diagnosed before birth or soon after birth they had received good information and advice. They were, for example:

- provided with access to physiotherapy or occupational therapy;
- directed to a network of families; provided with information about DLA;
- put in touch with a voluntary sector organisation that specialised in supporting families; or
- provided with access to services before and after diagnosis on a needs basis.

However, in a minority of situations parents' experience was contrary to the above, even in a case of early diagnosis of a known genetic condition.

Our daughter was diagnosed with a genetic disorder at 11 weeks - that day we were given the bombshell and then sent home with no support, told to come back to see paediatrician in another week.

(Parent of child with a rare genetic condition and associated learning disability)

4.7 Involvement and engagement of different sectors

It is clear that a number of professionals and multi-agency services are involved with the parent and the child pre and post diagnosis. The key professionals who are known to play a role during the process of diagnosis and follow up support are:

a) the primary care services (pre and post birth): midwife, and the health visitor (generally the named person for GIRFEC ), the general practitioner, the paediatrician;
b) pre-school and early years: nursery nurse, child minder, pre-school learning assistant, nursery teacher;
c) primary and secondary school: school teacher, educational psychologist, head teacher, learning assistant; special education needs teacher;
d) voluntary sector: support workers from organisations such as ENABLE Scotland; and
e) specialist staff: workforce providing need specific services related to learning disabilities e.g. social worker, local area coordinator for learning disability, hospital nurse.

The survey asked the respondents to identify the extent of involvement of professionals from each of the above sectors in the period around diagnosis. The extent of the involvement of these professionals is described by the parents as follows (also see Figure 4.7):

- for 51% of respondents, the primary care sector (e.g. GPs, health visitor, midwife) were involved (20% often involved and 31% sometimes involved) in the process of diagnosis. These professionals were also identified as those raising early concerns about the child’s development (discussed earlier);
- around 59% of respondents noted the involvement of pre-school and early years professionals e.g. nursery teacher, pre-school learning assistant, child minder (34.9% often involved and 23.8% sometimes involved);
• a majority (71%) of respondents noted the involvement (52% often involved and 19% sometimes involved) of the school/education professionals (e.g. school teacher, educational psychologist, head teacher, learning assistant);
• just over 17% of respondents said that the voluntary sector was involved (5.5% often involved and 11.9% sometimes involved) in the diagnosis process. Interestingly 21% of the overall respondents did not perceive the involvement of the voluntary sector as applicable to their situation; and
• more than half of the respondents (52%) said that the specialist workforce was involved (25% often involved and 27% sometimes involved). This included the specialist workforce, such as hospital nurse, social worker, local area coordinator.

Figure 4.7: Involvement of multi-agency professionals pre and post diagnosis

The response to the question on which professionals supported the parents with patience, care and consideration provided in Figure 4.8 reveals that:

• 47% of respondents found staff from the primary care sector (midwives, health visitors, GP, paediatrician) as supportive;
• a higher percentage of respondents 58% said that preschool/ early years sector and 70% from the school sector supported the respondents; and
• a smaller percentage, 24%, of parents had experienced support from the voluntary sector. Interestingly a quarter (25% N/A) of respondents did not feel that the voluntary sector had any role in this aspect with an additional 42% suggesting that the voluntary sector has never supported them during this period. It was noted by 46% of respondents that they were supported (often supported 17.5% and 28.5% sometimes supported) by the specialists.
As has been discussed in earlier sections, the involvement of primary care and pre-school professionals was identified as being vitally important in raising early concerns, as well as in supporting the parents and their families through diagnosis. However, with respect to day-to-day support, it is the school sector which was identified by a majority of parents as being primarily involved. The role of social workers was identified as being crucial in establishing need through social care assessments and providing need-specific support to children and families. A specific question was asked within the survey and in face-to-face interviews to establish how parents feel about their engagement with social workers and the service they provided. This is discussed in the next section.

The parents feel supported through the school system by the educational psychologist, the speech and language therapists, teachers and the head teacher who were the primary source of day-to-day support for the child and the parents.

Well, once he was in the school, we kind of lost touch with the professionals, so it’s really the school just dealing directly. I would say the deputy head, or his teachers at the school, because that’s my main point of contact now for all A’s needs. I don’t really have a professional that comes to the house or deals with A anymore – all that is now being handled at the school.

(Parent of diagnosed child with ASD)
He’s very settled, very happy there, and he achieves the tasks that they’ve set out for him – every year, they give him work to do at school – and his behaviours there are much better, I would say… I don’t know if it’s because he’s in a different environment, but he seems to perform better at school than he does at home – or maybe he knows that, at home, he can get away with things and we’re a bit more soft with him.

(Parent of child diagnosed with global developmental delay)

Only a very small number of parents suggest that the voluntary sector (including ENABLE Scotland) is either involved in or providing support to them.

4.8 Involvement of social work

The role of social work is crucial in assessing and providing need-specific support to parents and the child who has a disability. A specific question on the involvement of social care was included in the survey, and was explored further in face-to-face interviews.

The system

Amongst those surveyed, 53% report not having had social care assessment of need for their child (Figure 4.9). These include a number of respondents who said that they were not aware of this assessment and the availability of support through it. There are others who were aware but have never contacted the social work department in this regard. There are others whose child has not received a referral to a social work disability team because of the absence of a firm diagnosis or because the child was not classed as “severe risk” or “disabled enough”.

In this [geographical] area, you cannot get a social work service if your child is undiagnosed, which is utterly ridiculous, because what if they’re never diagnosed? So X [the child] was entitled to nothing. We were entitled to absolutely nothing.

(Parent of an undiagnosed child with complex needs)

The responses show that not receiving a referral to the social work team was disappointing for some parents. There is also a sense that this process is perhaps easier for children with a physical disability as opposed to those having a learning disability, which may not be apparently visible. Some had been persistent in trying to access some support but were denied any. A mother not being able to cope with the care of her child with complex disabilities asserted that the assessments were only carried out when she had a nervous breakdown and the family was seen as being at substantive risk. Similar frustrations are conveyed by many other parents.

Apparently my son didn’t qualify to be assessed by the (social work) disability team. It took 17 months for the assessment to be done and it was still all wrong information at the end. I wasn’t given the full option of social care services available. i.e. I was told I wasn’t entitled to direct payments.

(Parent of child diagnosed with Asperger syndrome)
Experiences of parents

The survey finds that around 30% of the respondents received support based on health and social care assessments of need from the social work department (Figure 4.9).

There is a strong feeling that the eligibility criteria for social work support is difficult to meet. Further, the boundary between those eligible for support and those who were not was sharp, and access to any support from social work is not available if the child falls short of the eligibility criteria by a single point.

Some parents find the whole process of assessments difficult and tiresome. Many such parents seek support during the assessment process from professionals such as the advocacy worker. There is a feeling that they have to persistently chase social work. In many cases the respondents did not feel supported by social work due to the delay in being assessed. If they subsequently did not qualify for support it resulted in additional frustration. Delay in response following an assessment was also a source of annoyance for many parents. There were respondents who had not heard back from social work for more than two years after the assessments. There was a feeling of not getting support when it was most needed.

"I contacted social work when my son was going through a very difficult time. By the time social worker visited about 6 months later, the crisis was over and nothing they would/could help with. Useless and wouldn’t return phone calls."

(Parent of child diagnosed with Asperger syndrome)

The parents felt that the delay in assessments and support was due to a bureaucratic and poorly-run system with staff who had a heavy workload and high turnover. Constant change of staff was found to be stressful by parents.
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

I have now withdrawn my child from social work. There was lack of consistency with the social workers (3 in 2 years) each one had a different approach. In the end I withdrew as it was too stressful.

(Parent of child diagnosed with learning disability and cerebral palsy)

I’ve had three social workers in a year. People stay for six months and then they just leave – they’ve had enough and they just get out. So I’m on my third social worker. I did ask for SDS [self directed support] this time last year. The first one ignored it for six months. And then the one after that said I would need to wait– and then it got refused. So, yeah, at the moment, I’m miffed at that, because I’m not asking for a lot, I’m asking for something that will benefit him [the child]. But I’m just trying to work out how to go forward.

(Parent of child diagnosed with ASD)

There were a few parents who said that the negative reputation of social work had held them back from requesting support.

I have not requested this as I have heard so many bad stories from other parents. Mostly being told their child doesn’t fit the criteria. I feel like I could do with support but don’t need to go through this awful process.

(Parent of child diagnosed with Down’s syndrome)

However, those who did receive support from social work feel valued and supported by the workers, while finding the system slow and bureaucratic.

The assessment process was limited [fast] and reviews were minimal but I know where to ask for help and although I had to wait for shared care and for respite I now have a good support package. I also received massage and reiki via social services which was very helpful.

(Parent of child diagnosed with Down’s syndrome)

Whilst our Family Support worker is very helpful and knowledgeable, I do find the whole system slow and bureaucratic.

(Parent of child diagnosed with rare genetic condition and learning disabilities)

There is a feeling that some of the services they were entitled to were not being provided due to limited budgets and cut backs.

We are meant to get two overnights [respite] a month as she has severe sleep problems but have problems accessing that due to the carer’s other work commitment. We maybe get one night every 4-6 weeks.

(Parent of child with rare genetic condition and learning disabilities)

Been trying to move forward with this for over a year we just get told there are no services in our area or no money!! Desperately need a break.

(Parent of child diagnosed with GDD)
Experiences of parents

Some parents feel that the support provided by social work is not sufficient and that they had to find extra support themselves.

Received 5 hours of supported respite per week. Usual tick box system.

(rgent of child with brain injury and learning disabilities)

We have been put in as a priority since he was in class 2 but has a life-limiting condition, so he now gets more respite through [voluntary organisation], so that has improved.

(Parent of child with complex needs)

Local area differences in availability of support from social work were also reported.

We have had good support from X city council in the early stages of diagnosis. But we have had limited poor support when we moved to Y [council area], we no longer have a social worker in this area.

(Parent of child diagnosed with Asperger syndrome)

There is some dissatisfaction experienced by parents who wanted a greater level of support than they had received.

We scored highly enough to be considered for respite, however as our son is at a small mainstream school out of catchment and does not receive transport, we would have to transport him to and from respite to school and back which is hardly the point of respite.

(Parent of child with complex needs)

Generally, social care assessments of needs are seen as holistic and take account of family needs. However, the survey shows that many parents are unaware of carer assessments, which primarily focus on the support needs of the parents. The parents and carers clearly express the positive experience of being supported by a social worker. Some parents were content that though it had taken some time to get social work on board, the support they provided has been valuable.

Eventually, after being desperate for 2 years, I phoned social services and got a family support worker who has been very good, helping me get respite.

(Parent of child with GDD and ADHD)
The social worker

Although the social work system is seen as slow and bureaucratic, a large number of respondents who were allocated support, praised individual social workers for their commitment, ability and effort.

So, because of my social worker, I have a fantastic team now – worked hard on it, but X [support worker] is in my team, and she’s a key player and works very hard with him [the child]. And it’s also my respite as well, because I know that he [the child] is having a great time.

(Parent of child diagnosed with ASD)

Parents feel that getting a social worker was a big help as they provided relevant information about benefits and potential sources for funding that parents could apply for. The social workers helped in filling forms and in getting respite. Some parents had built trusting relationships with the social workers, who they could contact any time for advice and support.

I’ve got my social worker’s mobile number – and I just phone her. And if I want her to turn up at a meeting, because somebody is not playing ball, because CAMHS or the school have let us down, she will come, and she will make phone calls.

( Parent of child with complex needs)

One parent reflected on joint working between the social worker and a member of a CAMHS team. The parent felt that joint working had meant shared understanding of needs, and provision of support that was practical and helpful for both the mother and the child.

So I had a lot of help, because the two of them worked together, so each knew what the other was doing, which is really, really good. And then they would come out together for a home visit, which is even better.

( Parent of child diagnosed with Asperger syndrome and ADHD)

Apart from the direct support provided by the social workers, some parents presented other reasons for having an allocated social worker. One of the reasons was to ensure that their child was “in the system” which in turn would establish their child’s disability and need for long term care.

I decided that I really needed to have a social worker, so that my child was in the system and known, because there’s a disability part of the social work, and because… Basically, it was after I had to fight for the DLA it became obvious to me that I needed to fight more, that I needed to get recognition, because I had to go to tribunal to get the DLA for my son, and it was because of the education department.

( Parent of child with ASD)
Experiences of parents

And it was only after a few meetings at the school, maybe a year ago or so, that social work came up again. And they asked me if we had a social worker, and I said, well, we used to have, but we don’t have now. So it was felt that we should get back in touch because, as X’s [the child] needs become more, as he’s getting older, we should have a social worker or we should have somebody assigned to him to access the council’s facilities and different things that X [the child] will need in the future – although they’re happy that he’s happy at home and everything is okay at home, but they still feel you need to have social work aware of him and assigned to him. Because at some of the meetings I’ve been to, [carer support services] they’re talking about self-directed support and financial help and other things, so that operates directly through the social work, so that was why I got back in touch with them.

(Parent of child with ASD)

For many parents social work support had primarily helped them get respite care.

I think it is beneficial but the only reason I got a social worker was I asked for one to help get respite.

My child has received Respite Care through his assessment of need.

4.9 Accessing state benefits

The survey finds that a substantial majority (87%) of respondents agree (58% completely agree and 29% agree) that having a child who has disability has impacted on their finances (Figure 4.10). For a majority of parents, caring for a child who has learning disabilities has meant providing full time care, which is sometimes shared with partners or with other family members. For many parents these caring responsibilities meant reduced employment opportunities; some had given up work due to high child-care costs. The responses indicate that finances are also impacted by the need to purchase equipment, respite or support to provide care for the child.

![Figure 4.10: Impact on finances and access to state benefits](image-url)
Parents and carers of children who have a learning disability can be entitled to a variety of support including financial benefits depending upon need. These could include disability living allowance, employment support allowance and attendance allowance, income support, carer's allowance, disability equipment allowance and school transport allowance amongst others.

The survey investigated parents' awareness and access to these benefits.

As shown in Figure 4.10, only 31% parents reported having received advice on possible benefits through professional sources around the time of diagnosis. There is a clear sense that for many parents this information has taken a long time (sometimes several years after the diagnosis) to reach them. It is interesting to note that 80% of respondents report being aware of their possible entitlement to receiving state benefits. For a majority of these respondents this awareness is limited to disability living allowance (DLA), which they received primarily through informal sources such as other parents who were in a similar situation or through friends. The health visitor, local specialist voluntary sector organisations/groups, carer centres, local charities, schools/nurseries are also noted by some parents as sources of information about benefits. A small number of other professionals who provided information are listed as being the welfare rights officer, social worker, and local area coordinator, nurse and community paediatrician. Some parents had learnt about the benefits through their own reading or had come across the information almost accidentally.

And when I was on Employment Support Allowance, I was told that the government was changing the rules and that I needed to be on DLA, so that we wouldn't be paying the extra bedroom tax. And that was the first time I was informed that we should have been on DLA – we should have been on it for a long time. I feel that things like that would have helped us so much, because I'm now in so much debt because I’ve been unable to work.

(Single parent of undiagnosed child with challenging behaviour)

Access to benefits is suggested to be rather difficult and challenging for parents and carers. Figure 4.10 shows that only 21% find it easy to access benefits. The qualitative response from the survey and the interviews highlights the challenges faced when attempting to access benefits.

A majority of parents find filling in forms torturous due to their layout and content. The stigma around claiming benefits made form-filling even more difficult.

It is not easy to access some of the financial benefits as they [the claim form] are quite intrusive and often ask many questions about financial situation even down to asking about child's own savings and those of their siblings.

(Parent of child with physical disabilities and ASD)
Experiences of parents

Claiming DLA is difficult - the forms are horrendous and it is so upsetting having to justify every bit of support your child needs and having to write in minute detail all the things your child can’t do. Then feeling you are viewed as a waster for claiming financial support for your child.

(Parent of child with genetic condition and associated learning disability)

Many parents find the process of claiming benefits “mind-numbing”. The general feeling is that the emotional upheaval following the diagnosis meant that they were ill-equipped to fill forms. Some parents are of the view that children with a hidden disability are more likely to miss out on the benefits as it is more difficult to provide evidence of the disability.

The parents find the support provided by the professionals very helpful. These professionals were named as health visitors, social workers, nursery staff, charities, colleagues, friends and welfare advice officers. At the same time many parents reported to being treated insensitively or being judged by the professionals who helped them complete the forms.

Community Paediatrician referred us to social work benefits officer to help fill in DLA forms and look at what we were entitled to. It was extremely useful and took a lot of stress off.

(Parent of child with rare genetic disorder)

Someone from the local authority came to fill out the DLA claim form - she was very insensitive and handed me a leaflet on my child’s condition and asked me to “tick” what’s wrong with the child from the list.

(Parent of child with learning disabilities and genetic disorder)

Some parents also reported their continued struggle to making their claim after the benefits were initially refused.

And, yes, it was upsetting, filling out that form, but I thought it was worth it to get the recognition my son deserved. Worst mistake I’ve made, because that caused so much stress in my life that, after 3 appeals, I ended up having to go to tribunal, where I won.

(Parent of child with complex disabilities)

The responses make it abundantly clear that those who receive benefits (primarily DLA) find it extremely helpful as it supported them in: purchase of equipment (motability car, special pencils, books); providing lessons (e.g. swimming lessons) for the child; organising outings for the child; creating a suitable environment; and going on day trips or holidays. Those parents who had given up their jobs to care for the child felt that receiving Employment Support Allowance has helped in reducing the stress of financial pressures, worries of debt and poverty.

The DLA has made a big difference, it’s the little costs that add up to a huge part of the household budget. Special pencils, books and environments suitable for day trips they all cost.

(Parent of child diagnosed with Asperger syndrome)
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

4.10 Coping strategies

The trauma and stress of receiving a diagnosis was discussed earlier in this report. The survey and interviews find that the parents and carers employ a range of strategies to cope with the diagnosis of a learning disability. A substantial majority of respondents suggest that keeping an optimistic attitude and maintaining hope (95% and 91% respectively) for the future is important for coping (Fig. 4.11). For an overwhelming majority, having the right kind of information and knowing where to get support is crucial in helping them remain positive and cope better. Having time to pursue interests and self-development were important coping strategies (50% and 70% respectively).

More than three quarters of the survey respondents (76%) feel that the family is an important source of support (48% very important and 28% important) in helping them care for their child (Figure 4.12). More than a half of the respondents see their friends as supportive. A majority (71%) of respondents find people with children in a similar situation (peers) as important (33% very important and 38% important) in providing help and support during this stage. It is interesting to note that less than half (47%) of the respondents see the role of the voluntary sector as being important (very important 25.6% and important 21.6%) in providing support and care.

![Figure 4.11: Importance of different kinds of informal support](image-url)
4.11 Other issues

Focus on supporting the parents’ needs too

Although each journey described by parents was unique and distinct, a common theme that clearly emerged related to the mental health and well-being of the parents themselves. The survey makes it clear that many parents experience trauma and stress following the diagnosis. The time taken to accept the situation and move forward is variable and often strongly dependant on the support they receive. Parents can go through various emotional stages of grieving, denial, anger, bargaining, depression and acceptance of the diagnosis itself; these stages have been previously highlighted in the literature (Huger, 2009). The study shows that many parents find themselves ill-equipped to deal with the realities of managing their child’s physical, psychological and educational needs, and that there was a need for professional support for parents. In these circumstances the professionals should not only provide parents with guidance about the support available for the child, but also take on the role of an advocate and a counsellor for the parents themselves.

In terms of the health visitor, I wish that she could have been a bit more, “Mary [disguised name] you need to go and see a community paediatrician.” I know it’s up to me to… But I think I needed a bit of a shove. I think the penny wasn’t dropping.

(Parent of child diagnosed with a genetic condition)
Inclusion of the child in mainstream schools

A number of parents reported experiencing stress and anxiety when sending their child to a mainstream school. The child’s often reduced ability to cope with the social aspects of day-to-day life, in addition to educational expectations, are the key stressors. Parents who have children who have a hidden disability (e.g. higher functioning autism) feel that the child’s social, emotional and psychological needs should be catered for, as these can sometimes be masked by the good academic performance demonstrated by some of these children. The parents feel that a child who has a learning disability wants to “fit in” the mainstream environment but feels “mixed up” and anxious and depressed.

You hear all the time that children are getting excluded from schools, because they’ve got a hidden disability and they’re not the norm. So mainstream school, and the way it’s funded, and things like that, you really have to be the norm. And some people, if you’re not the norm, well, you just need to change to be like the norm – but that damages the child.

But he doesn’t have the processing skills that we have, and unless he’s explicitly taught things, he will never learn it – never – because it’s just not wired there – it’s just not there, and so he feels that he’s faulty, that he’s broken. And that’s the way society makes him feel.

It’s hard to put your child into an environment that you know doesn’t get it, and it’s like putting your child into the lions’ den, knowing that, yeah, there’s a good chance he’s going to get hurt, because he doesn’t understand the hidden social curriculum, he doesn’t understand about what you should and shouldn’t do to be a friend, and things like that.

There is a clear feeling that the parents and the professionals should be working together to meet the educational needs of children who have learning disabilities. Parent experience suggests that the professionals should be interacting and communicating better, and that parents’ opinions need to be valued and not treated as an inconvenience.

Lack of communication is a huge thing. Education and health don’t speak, and health and education don’t speak, and health and social work don’t speak, and… Do you know what I mean? There needs to be transparent, open communication. …… but all I’m saying is, my experience would have been different if I had a head teacher that understood.

Changes need to happen is, professionals need to respect parents – all professionals need to respect parents, and listen to them, and not dismiss them as, you don’t know what you’re talking about, I’m the professional here. And I was hoping that GIRFEC would do that, but it’s taking a while to filter down.
Experiences of professionals

The professionals directly involved in providing services to children and their families were contacted for interviews. Many of these were named by the parents who had been interviewed for this study as providing positive support to them. These included an additional support needs outreach teacher, outreach worker, a head teacher of a mainstream school, a physiotherapist, a general practitioner and a learning disability nurse. This chapter presents the perceptions of the professionals on the general concerns experienced by the parents, and what worked well for them.

5.1 Issues around diagnosis

The professionals feel that getting a diagnosis of a learning disability is beneficial for the parents and the child in many ways. It facilitates access to services, helps identify sources of information through books and online resources, and helps them build networks of peers to understand and manage the disability of their child. They also accept that sometimes there can be reluctance on the part of the specialists in delivering a firm diagnosis, and that in some cases the only diagnosis that is provided is that of global developmental delay.

And sometimes, even after all these different assessments have come back, diagnostic terms will be ‘developmental delay’, usually…. But, often, during this whole early assessment, the only term that will be used is ‘speech delay’ or ‘delayed motor development’, for example – very rarely would they use the term ‘learning disability’.

(General practitioner)
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

The best label is the one that actually explains the situation. So I don’t think we’re against labels, and we can totally see why parents… in an ideal world, you wouldn’t attach labels to people, but while that’s the only way to attract attention and get proper respect and treatment.

(Support worker)

It was noted that in the long run the diagnosis of global developmental delay is not helpful. The diagnosis of developmental delay is limited to childhood years but seems to be carried by the individual even when they are adults. A child with this diagnosis is well looked after in terms of education and developmental needs through the various annual reviews conducted through health and care systems. However, since this diagnosis does not go beyond 16 years of age, when the child ceases to be defined as a child, the individual can be left without any individualised support.

So I’ve seen parents come to me, and they’ve suddenly lost all the benefits they were getting before, have just suddenly stopped, and they’ve got to apply for benefits where a diagnosis is required.

(General practitioner)

The professionals reflected that a diagnosis of global developmental delay can be misunderstood by parents as being a delay in development with an expectation that the child will catch up in time. It is often not understood as a disability that will persist in the long-term and that the parents should be provided this information.

The doctors or other medical staff involved doesn’t change the diagnosis from global developmental delay to learning disability, so the families have no idea they’ve got a learning disabled child – they don’t understand. So then they get referred into our service [provided by the learning disability nurse], and they maybe are appropriate for our service, but the family is really distressed and upset because nobody has sat down and told them that their child or young person has got a learning disability.

(Learning disability nurse)

Some professionals also suggest that not having a firm diagnosis limited parents’ access to information and support. In many cases the parents may simply be denied access to services that would be available with a diagnosis. They expect that a firm diagnosis, such as that of Down’s syndrome, can help practitioners provide appropriate referrals to services and also link the parents to established supports networks, which the parents find difficult in cases where there is no diagnosis or a diagnosis of global developmental delay.

Even if I was asked where to suggest a parent goes, I don’t think I’d tell them… I think I’d tell them to go to the special needs place at the Sick Children’s Hospital, the SNIP [Special Needs Information Point], where they have lots of information about lots of places. But I wouldn’t immediately say, oh, these are the best people to go to – I wouldn’t know that.

(General practitioner)
Experiences of professionals

The practitioners are aware of the stress and emotional strain the parents go through during the early stages of a diagnosis. They feel that when early concerns are raised, parental instinct would primarily want everything to be alright for the child i.e. they would hope that the child’s condition does not require a name. However, as the diagnosis process progresses, the parents in retrospect start feeling that they could have got a diagnosis earlier.

This time can be very challenging to them because the otherwise perfectly healthy child, all of a sudden, presents symptoms that were not what the parents expected and that other professionals start to get involved. (Outreach support worker)

A lot of mothers worry it’s something they’ve done. Did they eat the wrong thing or did something happen when they were pregnant? Whereupon, sometimes, if they get a diagnosis and they get an answer, they know it was a syndrome, they know it was going to happen regardless – that's just that child – then they can get a bit of acceptance and a bit more understanding.

You hear a lot of stories – and I've seen it – where the child has just been labelled as a naughty child, especially in a school environment or a nursery environment. And then the parents can say, no, hang on a minute, this child actually has autism, or whatever their diagnosis, it’s how we’re handling him – we need to handle this child better and put procedures in place, and then this child will manage better. (Physiotherapist)

It was also acknowledged that the process for diagnosis can be overwhelming for parents because they see a number of different professionals at different times. The professionals felt that for conditions such as ASD and ADHD, the pathway to diagnosis was a bit clearer. There was a clear protocol for filling in specific questionnaires, conducting observations and assessments, and that these were concluded at a final meeting where the decision was made clear to the parents. However, even in these cases until the final coming together, the process could appear quite disjointed to parents.

5.2 Helping parents to get to terms with the diagnosis

The professionals within school settings were clear that once early concerns were raised, supporting parents and carers can be challenging and that it needed to be done sensitively. They describe the stage when parents are still struggling to come to terms with the diagnosis and working out their child’s abilities.

At this time the parents can appear very challenging to the staff in terms of their expectations around what their children can do and what they want their children to be able to do. This stage can be very difficult for both the school staff and the parents. The staff try to be very sensitive to the parents who might be experiencing additional support needs for the first time.
And it’s up to us, as a professional, to maintain being professional, even when the parents are being unrealistic or if they’re not being sensitive to the staff. We have times where they will be quite unpleasant to us, and it can be quite difficult for us to work our way through…

(Head teacher)

The school professionals suggest that sometimes parents continue to see their child as having deficits and expect professionals to provide solutions and treatments that were unproductive. There is a recognition that parental acceptance and “coming to terms” with their child’s disability can sometimes take a long time. They suggest that only a positive outlook can help parents be less stressed and “enjoy the child for who she/he is”.

He would do things on a one-to-one level, but, actually, out there, life is not like that, so he needs to learn to do things in small groups and on a two-to-one level, and to cope. And I think the idea that there is a programme or there is an intervention or there is a therapy that can “fix” our children is really unhelpful – and I think that’s what that parent is finding unhelpful, and I think [the parent] beginning to realise… I think [the parent] just at that stage of thinking, actually, they don’t have an answer – but I think it will still take [the parent] another year or two to come to that.

(Deputy head teacher)

Some professionals feel that the dilemma of providing best support to the child and family can lead to having “hard conversations”, which can be difficult for the parents but helped the parents in coming to terms with reality and moving forward.

I’ve had lots of conversations with A [dad] around skills that B [child] will have. I have had conversations around things that the child used to do that he now won’t do. And this is difficult – that journey for A and for the family about what their expectations of B [the child] are, is very difficult, and they’re still going through that journey. Slowly, very slowly, there will be hard conversations with them around what their child can or cannot do.

(Head teacher)

The professionals were clear that there were many children whose level of need might not be apparent at an early stage but could benefit from early intervention.

I suppose our feeling is that these families that are muddling along, if they don’t get the right support, things can become more complex, and parents can get a bit burnt out.

(Learning disability nurse)
Experiences of professionals

The professionals from the educational setting suggest that they create opportunities for parents to speak to other parents who have made this journey in bringing up a child with additional support needs. Activities include organisation of evening get-togethers, with a focus on providing information and specialist talks from behaviour specialists. The parents and young people who were identified as positive role models also delivered talks to share their experiences and provide information and coping strategies. Such events, it was suggested, provided a positive experience to many parents while for some others, who had not accepted the situation, these events can be traumatic. Thus planning and delivery of these events needed much thought and consideration.

They got up and left, these parents that I remember, because they just didn’t want to know, they didn’t want to consider that as a possible future for their son. But a lot of the parents were grateful for it as well because it showed that there were elements of independence that could be. Some of our parents, I have to say, saw it as very dark and very black and they didn’t find it useful to them at all – whereas a lot of the parents did find it useful because it let them… But that’s all about where parents are on their own journey in coming to terms with their child.

(Deputy head teacher)

Additionally these schools have also created informal peer support networks for parents that met regularly.

5.3 Need for a supporting environment and appropriate competences

It was noted that not all professionals within the mainstream schools were equipped with the knowledge and understanding of learning disabilities and their impact on the family. It was emphasised that providing the right support for children who have a learning disability required the right kind of knowledge, understanding and attitude, specifically that of empathy. It was suggested that attracting teachers into the area of additional support needs has been difficult. The fact that more and more children with complex needs are being educated in mainstream schools means that a workforce within schools with the relevant competences is extremely important. Updating of the generic teacher training programme can be an important and effective solution to ensure effective mainstreaming of the education system for the future.

Commenting on the present situation in schools, some of those interviewed suggested that there is an increasing demand being placed on class teachers without much support for them to do so confidently. The environment of the schools does not lend itself to help teachers provide need-specific support to children with additional support needs.

But it’s a big ask for a class teacher to take on board their class, and their children with additional support needs, and then the other bit with the family as well.

(Outreach visiting teacher)
Often it is the experience and skills of the staff concerned that comes with time. This experience helps professionals develop an understanding of parents’ emotional and support needs. The professionals interviewed reflected that due to their long-term experience they were able to manage expectations of parents sensitively even when there was a conflict in views of the parents and the school staff. The everyday conflicts when supporting a child who has a learning disability are described as, what their children can do, or what the parents wants their child to be able to do and what the best support should look like (from a professional perspective and that of the parent). The professionals are concerned that a workforce that does not have appropriate training and/or experience would have difficulty in providing help and advice sensitively.

This can be challenging for staff who without appropriate training and education will have little or no understanding and experience of additional support needs and how to deal with these situations sensitively.

(Head teacher)

5.4 Child and parent focussed support

Most of the professionals interviewed are clear that although the child is the focus of services, supporting parents was a vital part of the big picture.

It was 50:50...You’re supporting the child in school, but, actually, you’re supporting the parents out with that. Our role in supporting these children, I would say, or these parents, is about the professionals coming together and working together as a team to make it happen for them, to try and make that easy. So it’s about creating forums where parents are getting access to everybody [professionals involved, e.g. social work, educational psychologist, health] at the one time to try and reduce the demand on their [parent’s] time for lots of different appointments, having to do lots of different things. So that’s the way we try and work round it.

(Outreach Visiting teacher)

I see my job….very much as supporting the parents and availing them of as much information as possible. Because what I have to be very aware of in school, is that our children can’t go home and tell their parents things, so all sorts of things could happen in this school, and, actually, nobody would ever know – but the parents have to know.

(Head teacher)

Professionals interviewed are of the view that, within a child-centred education system, their role includes managing support for the parents. They acknowledge that the concerns and observations of the parents need to be heard sympathetically, and interventions explained appropriately. This, they felt, could be managed by being approachable and responding to any kind of worry the parent might have. Some suggested that they extended the support to parents by providing them an option to phone them at any time they needed support or advice.
Experiences of professionals

I think it takes a certain professional to be able to sit with the mum and say, right, I hear you – I hear that you’re saying little Johnny vomits after this food, or doesn’t sleep, or does this, or does that – but these are the things, that are important to me that I think are to do with what’s going on with them; these other things are by-products, it’s not something... Quite often, nobody listens and no-one explains to them why they’re not listening to those things.

(Physiotherapist)

First of all, be the ear that listened, and then, secondly, be the person that they knew that they could come to, that if I couldn’t do something about it, I could link them up with the person that maybe could, and try to pull all that together.

(Outreach visiting teacher)

Many interviewees note that while supporting a child who has a learning disability they have noticed health and well-being issues of the parent who is the primary carer. In such cases, the view is that it is not easy to raise health and well-being issues of the parents as their primary role is to provide support for the child. However, they suggest that where the child support needs are being considered by multi-disciplinary teams, parent support needs should also be brought to the fore.

It’s a very difficult thing, because it’s the child that we are treating, it’s not the parent that we are treating, but we definitely support a parent to go and seek help from their GP, if they choose to.

(Physiotherapist)

It is also suggested that multi-agency meetings should be used to raise concerns about parental health.

“I’m a bit worried about that mum”, then you’d mention it to the consultant, and then the consultant could then say to the mum... “Right, you need to go and see your GP. You need a bit of help.

(Outreach worker)

The professionals are clear that co-ordinating support for the child and making links with the right professionals and services is an important aspect of their role. Building relationships with parents is important to ensure that they feel comfortable to discuss concerns and seek support, and implement interventions that support the child.

So I suppose, you have got to engage and build a relationship with the parent before you can encourage them to make the changes that are necessary. And you’ve also got to be able to listen to all the other things that are going on and be really holistic, because if it’s not the right time for you to say, we’re doing stuff on sleep, when a child is not going to sleep, you could recommend things for the parent to do – if they’re not in the right place to do them, they’re not going to happen. So you have to be really active about thinking about what’s right for the parents, at the time, and listening to what’s going on for them.

(Physiotherapist)
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

He [the father] would meet me properly; although I would have met him maybe on school visits before X [child] had started. And then, on top of that, you have got the educational psychologist, who he was also familiar with. So you’re building that relationship up very early, and doing it in a supportive way.

(Deputy head teacher)

The practitioners believe in an ethos that takes care of the family needs, and feel that the system does not recognise the role of practitioners in supporting the parents.

We would say our education is child-centred, but, actually, I think if it’s more family-centred, then that just shifts the focus slightly… if you’re family-centred, you know the family. It’s that kind of knowledge and understanding about the dynamics of the family that I think sometimes helps.

(Outreach visiting teacher)

The professionals reflected that the responsibility of supporting parents, support workers and families as much as the child in a mainstream school setting can be challenging. Many of the professionals interviewed for this study were either specialists in learning disabilities or were working in a mainstream school setting that had specialist disability provisions and an environment that supported the 50:50 approach.

That’s a big ask, because, actually, as educationalists, you’re responsible for the education and progress of that individual child, and I think, in education, my feeling is that that other part (supporting the family), I think that there’s no recognition, really. That other half of the job, for me, is and always will be just as important as supporting the individual child.

(Outreach worker)

5.5 Managing expectations

Most professionals felt that managing the expectations of parents and supporting them can be difficult and can take some time. The parents also need time to accept their child’s disability. Progressing through primary school, the parents appear to maintain hope that the child will be able to catch up from the developmental delay as the child grows up. For many parents the realisation that the learning disability is going to persist in the long-term only comes when the child enters secondary school.

By the time a lot of our youngsters hit S1 [first year at secondary school], a lot of the parents are then starting to realise that they’ve now hit the secondary phase of their education, that there are six years left, and that they’re now looking at post-school planning, and that can quite often be a flip of a switch in their heads that the child that they have in front of them is the child that they have, and they should be enjoying their child.

(Deputy head teacher)

They acknowledge the difficulties arising from differences in the perceptions and opinions of the professional and the parent. For example, there can be a difference in opinion on what classifies as progress in a child’s development and the kind of education the child should receive.
Experiences of professionals

The level of positivity we may feel about some progress that’s been made with a child, the parents may not see that as being big leaps forward, and they’ll be disappointed with that. So it just takes time.

(Head teacher)

The professionals agree that managing parental expectations can be very challenging for the professionals, and that communication and relationship building requires patience and skill. It was suggested that some parents can acquire an attitude of helplessness and were consequently unwilling to take control of the situation. Such parents can expect support and services for every aspect of the child’s life. It was only after a professional has built a good relationship and trust with a family can they tell the parents that they should try and be more empowered by taking on responsibilities and not feel that they needed support for everything.

And I think I can get away with saying that to some of our families, particularly ones with whom I’ve formed really positive relationships. I can say, “Oh, that’s just what you do – you have to be a taxi yourself”.

(Head teacher)

Some practitioners are of the view that sometimes the step parents had to be headstrong and persistent to obtain the right support and services. However, this attitude can also lead to them being perceived as aggressive and neurotic.

And if a parent with a child with disabilities isn’t determined and headstrong when they start, then they become that way, because they have to fight their corner; they have to fight for things; they have to fight for equipment; they have to fight for respite – and it’s wrong, but they do have to do it. And if they don’t put their head out and say, I want this, I want that, then they don’t always get it. And they wrongly, sometimes, as well, get labelled as a troublemaker – it’s that mum; she’s always complaining; she always wants something. And you think, well, no wonder she always wants something – look at the [poor] lifestyle she’s got, and look at the issues she’s got.

(Support worker)

A number of reasons were suggested as causes of stress and anxiety amongst parents:

- lack of understanding of the condition;
- having to explain the child’s condition again and again to different practitioners;
- lack of appropriate housing;
- financial strain; and
- the need to constantly fight for the support.
5.6 GIRFEC and multi-agency working

For most of the practitioners interviewed, multi-agency input is vital to providing needs-led services. Though all practitioners feel that GIRFEC was a positive way forward, a need to develop the right attitudes in society towards children who have learning disabilities was seen to be important.

I am confident in saying that we are a GIRFEC school. But I don't think society is GIRFEC yet, and I don't think systems like the health board, police, education, social work, I don't think they're GIRFEC yet.

(Head teacher)

All practitioners are committed to involvement of the parents in developing their child’s plans. However, some feel that involving parents in multi-agency meetings (as recommended by GIRFEC approach), had limited benefits and was fraught with difficulties for children with complex needs. Experience of professionals suggests that parents can find such meetings threatening and are sometimes unable to cope emotionally with the nature of discussions about their child in a setting where so many professionals are present.

There's a real misunderstanding by the Scottish government about the worth of multi-agency meetings. Parents, on the whole, find them very threatening; they feel as if everybody is talking about their child. I think we have to have them, and we do have them – we've got very good practice in the school – but I think if there are difficult messages to be delivered to parents, they need to be delivered in a setting where parents are comfortable, where they don't feel they're being judged, where they have a relationship with somebody, they can either challenge somebody, like me, or they can come back and say, well, explain that further, or they can just say, I don't agree.

(Outreach Visiting Teacher)

It was also suggested that there were sometimes expectations from parents to be “more professional than the professionals” as they were expected to respond to queries, have an opinion, not show their emotions and even make a decision in the multi-agency meeting there and then, allowing them very little time for reflection and thought.

Multi-agency working can also sometimes lead to different professionals having varying views on the needs of the child.

I think, despite GIRFEC and despite the Early Years Collaborative… there are still big pockets of professional mistrust. So social work says to me, Mrs. so-and-so, your parent in question, says she needs that, and I say, well, actually, I would agree with her. “Oh…” and there's a look of astonishment on people's faces.

(Head teacher)
Many professionals raised concerns about the role of the named person, and the vast number of children allocated to one such person. They feel that it is unrealistic to expect every named person to have an understanding required for co-ordinating the needs of children who have learning disabilities. There is also a feeling that the named person allocated to disabled children should be looking after the needs of fewer children to be able to co-ordinate support and address their needs in a holistic way.

My understanding of GIRFEC always used to be that, for our children that have disabilities and additional needs, your named person would be someone the parents knew, like a nurse or someone, that they could phone up and would be making sure that they were seeing the physio, they were seeing this, they were seeing that – but it doesn’t work like that. Your named person still stays as the head teacher. Or if there are huge needs, then the social worker will be your named person. But all these people have lots of people on their books.

(Physiotherapist)

And I think the idea of a named person for every child is utopia – I think it’s unrealistic – and why are we not just saying, you’ve got a health visitor who has got 600 families in their caseload, how can they be experts on 600 families? But if 4 of those 600 families has a child with ASD, how can they have the knowledge that is required to take that forward and know the pathways to take that forward?

(Learning disability nurse)

In cases where the children have complex needs, and are in specialist schools, the role of the named person can be well defined as the number of children they support is comparatively smaller, and the school system is geared towards supporting children’s specialist needs. It is suggested that this kind of specialist support from the named person can be challenging in mainstream schools.

I’ve always taken on that role in the school. I think the whole thing is because we see so much of the children because they’re in our care for such a long time – to me, it’s logical – so, as a school, we accept and embrace a lot of that responsibility. But I think, when you’ve got busy secondary schools, with quite disparate departments, who are all doing a really good job, it may be quite hard to see your way through who the lead professional would be, and is it realistic that the head teacher, who has got 1500 kids in his school…

(Head teacher)

The professionals feel that although the policy and implementation of GIRFEC implies that the systems will be joined up, in reality there was still scope for synchronisation of systems to avoid duplication of effort.
5.7 Social work issues

Practitioners see social work as an integral part of their multi-professional team and suggest that positive working relationships with colleagues from social work. In cases where they are providing one-to-one support to parents, they feel that having a diagnosis has helped in getting access to support from social work as it provides an idea of the nature and extent of support needed. They feel that although support is provided by social work the parents in some cases do not perceive it as helpful, partly due to waiting times.

I think, in our local authority, there are fairly direct routes of access to, for example, speech and language therapists, and all the rest of it. There’s always a waiting time, which parents find difficult. I think there’s a fairly direct route of access to social work.

(General practitioner)

The support workers often communicate with social work on behalf of parents to help them understand the role of social work in providing services and facts around waiting times.

I think we’ve got in-depth knowledge, and we’ve got what I call the knowledge about the knowledge, which is not merely that there is a social work team, but, for example that they are very helpful or that they have a waiting list of 6 weeks, at the moment, so don’t panic if they don’t get back to you straightaway – and that can be very helpful to parents, to have that kind of contextual knowledge as well.

(Support worker)

Professional support workers helped parents with assessments for social work services and self-directed support for the purpose of respite. They feel that managing expectations of parents around access to support is sometimes challenging. There are differences in perceptions between the parent and the practitioners on what should be available through state funds, and what the parents could take on as their overall parental responsibilities.
I think, across Scotland, what local authorities are finding hard, and systems are finding hard, is to make that [support] entirely accessible, in the true sense of the word. And I think the biggest thing people are finding difficult is to make it fair and equitable. So, in our local authority, and in my school, different parents have different packages, for which there doesn’t seem to be a very logical set of criteria, so parents quite often feel, rightly or wrongly, hard done to that they’re not getting something [which other parents might be getting].

(Deputy head teacher)

And I know [the mother] was away off to have a fight about her direct payments being used to pay for skiing lessons, which she saw as having very positive outcomes for her son – which social work saw as something that any parent would pay for themselves, because if you’re a typically developing child who wants to go for skiing lessons, a parent would have to pay that.

(Head teacher)

Practitioners agreed that sometimes there is stigma attached to seeking support from social work. At the same time there can be a long waiting list for assessments and allocation of support, which the parents can find taxing.

I think, generally, as well, people feel that they’re always having to ask for support from social work. And I think there is still a stigma about going to social work and asking for help, because it’s about you saying that you’re not managing, as opposed to the offer coming of what’s available for you. So you’re going to have to be assessed on your level of support that you require, so there’s equity, which is fair enough.

(Learning disability nurse)

I think they [social work] have huge demands on their time. I suppose, from our point of view, if we start working with a family and they’ve not got social work contact and they’ve never had a Section 22... They’ve not had a Section 23 completed. We’re very aware how long that actually then takes for families, which I think can be really hard for families to wait, because they’re very triaged in the waiting list, so even though you’ve referred, they’re not on a standard waiting list – they then… I think someone from social work makes contact to see how great their need is. And even to wait for a Section 23 [duty of local authorities to assess needs of the child and/or parent when requested], they can be quite low down the list.

(Support worker)

Joint working (e.g. learning disability nurse and the social worker) and partnership working are suggested as ways in which the practitioners can support parents. Practitioners report positive outcomes of joint working between social work, health and education.

Over the past 12 years that I’ve worked with them, we’ve had some amazing social workers who have just gone above and beyond, all the time. The last couple of years, they’ve had real problems. They’ve been understaffed – that’s coming good again. Because I think it’s important that our families all do have a named social worker – and whilst some of the families haven’t been allocated, then I think [the social worker] and I have taken on that role that if there’s any difficulties or any issues, we’ve dealt with that between us. But I do know that a number of families find it very, very helpful to have a named social worker.
We see social work in the same way as we view therapists – they’re an essential part of the team. Because respite is such a huge issue for our children, for the families – a huge issue. So we do joint LAC and school reviews and a huge amount of sharing of information.

And we’ve had some really, really high tariff children and we’ve found solutions. And I know, for instance, we have a young person who is 13 now, who is a looked after accommodated child, and it was just so important… She has very, very challenging behaviour, but she is a wee girl who is of the [x] community – her family are [x] generations – and it was not right that that wee one should go anywhere else apart from be supported within her own local community.

It was two years, to turn the family home into a care home so that our young lady could be supported 24/7 within her own home. And mum and siblings moved out of the house and were re-housed elsewhere, and she became a looked after and accommodated child.
Experiences of young people

Five young people who had a firm diagnosis of a learning disability shared their reflections on experiences of having a diagnosis and its impact on their lives and their future. Two children had a diagnosis of ASD (high functioning) and expressed their views eloquently. One child had Asperger syndrome. The other two interviewed had been diagnosed with GDD and learning disabilities. Those with ASD and Asperger were able to recall having a diagnosis while the who have with learning disabilities shared their views about support and life in general. The questions were open-ended and explored how they felt about their lives at present and their support systems.

6.1 Response to diagnosis

Most young people feel that following diagnosis they were generally not sure what it meant for them.

I had no idea what it was. I was kind of confused. For about three nights on end, I couldn’t sleep, because I had no idea what this is. I’d just been told that I had this Asperger’s syndrome – what is it, what does it involve, how does it affect me. She (mother) couldn’t really explain it, because I was so young at that time – I was just coming up for ten – so it was quite confusing for me.
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I’m not sure how the diagnosis came along, but when I was younger, it was very hard to explain to people – very hard.

Some young people were unable to recall the time they received the diagnosis as they were too young, but remembered becoming indirectly aware of it in school, or through difficulties they experienced in day-to-day life.

I didn’t understand, at the time, my diagnosis, but what I did understand was that, simple things such as picking up a knife and fork, listening, talking, having eye contact, was very hard – very, very hard.

Some children feel that having a name to their condition meant that they could understand their own stress and behaviour better, and that others could understand them better too. For example, one young person said that only after the diagnosis could she/he make sense of why she/he was in detention regularly at school. Diagnosis meant that her/his behaviour (throwing tantrums and reactions to situations) was better understood by the school staff and she/he was not put into detention.

If I didn’t have the name and if I didn’t have the support... I would be a completely different person from I am today. If I wasn’t diagnosed, then I would be in so much trouble, myself, and my parents wouldn’t be able to help me. They would think it would just be attitude problems or whatever. I’ve had that problem in the past, and once I told certain people, it then got easier. But without the name, I wouldn’t be able to be here today.

Before the diagnosis, I was very loud – I still am, even after it, but knowing now… Everyone was confused and everyone just thought I was badly behaved. In primary school, we used to get tracking sheets, which are like you had a warning, and it would go 1, 2, 3, 4, 5, and then you’d get detention after that for misbehaving. And, every week, I was on it, all the time.

Following a diagnosis young people noticed a difference in the behaviour of their parents, who became more understanding.

I can’t really remember much about it, but I can remember my Mum and Dad acting differently. I wasn’t getting shouted at as much. I was still getting shouted at for the odd thing. Although I’m not very high on the spectrum, I still should know some of these things, even though… But it did make quite a difference to my life when I was diagnosed.

There was also a feeling that their teachers had a better understanding of their needs. In many cases this resulted in teachers adopting a different approach with them in comparison to other children.
They would have us segregated into our own spaces, and they would explain to us or they would give us instructions to say, “You’ve to fit these jigsaw puzzles in the right order. Now, if you’re struggling, please put your hand up” or whatever.

And they did find a way to get around it, and, eventually, I was getting used to it and starting to understand it.

I’ve had many reports from my school saying that I need to speak up in class and I need to speak up whenever I’m asking for help. And just now, in my year, in 5th year, I struggle with that. And whenever I was in a classroom, or whenever I was outside, I struggled to ask for help. And when I didn’t ask for help, I then realised, whenever I got into the activity, I was struggling; I was getting myself wound up – and, eventually, someone would have to come over and ask if I’m alright and, “Do you need a hand?” or, “Do you understand what you’re doing?”

The young people also felt that diagnosis had led to their neighbours becoming more empathetic towards them.

I used to jump about my living room floor, above my neighbours, who have a chandelier on the roof (laughter), so it wasn’t really the best... And, after that, there wasn’t as much complaints.

Young people felt even visitors to the child’s house reacted differently to the child’s behaviour.

When, normally, I would have annoyed the life out of them, they just wouldn’t react to it. And, in all honesty, I like a little bit of reaction, but just not too much....But because I’d been given this diagnosis – “Oh, my God. You need to be nice to him. You can’t get annoyed at him”....So when my Mum and Dad told them, they understood 100%.

There was also a feeling that, following the diagnosis, there was a clear change in the attitude of peers.

And I’m like, it’s just me, I can’t help it. Just if they don’t like me, don’t like me – it doesn’t bother me. And the school, some teachers are just the same as my friends – some teachers didn’t understand. Apart from X [the school] has been really helpful, but primary school hasn’t been very helpful.

They felt that, following diagnosis, access to support was also easily identified and made available.

Just, after diagnosis, I went to X [charity for ASD]... They had just started, because a lot of kids had been diagnosed and the rate of diagnosis was growing and growing – and it still is growing, because of the technology they have now. And my mum knew some of the girls over there. She took me over and they basically helped me to feel more confident about myself.
6.2 What helped

The young people talked about the vital role of their school in providing them need-specific support. They felt that it had been instrumental in helping them develop as confident and independent individuals. Some felt that this was achieved by providing them the flexibility when they needed it.

The teachers in X [the school] have given me freedom, if I feel confident enough, to go to classes myself, or if I need support in the classes, or if I just don’t feel like going to class, they give me the options to do so. They let me go out for my lunch, but if I don’t feel like it… They’re always here if I need them. And that’s the good thing about it. There’s no pressure to do anything, it’s always just do everything at my free will – so there’s no pressure.

They’ve helped me through different ways of thinking – they help me get my way about thinking about other people’s thought and going, “Aye, your opinion is just as good as mine.” They also helped some of my… Like if I’m getting angry, they help me have flexible thinking, like what I could do instead of doing something else. So just things like that.

And then, when the college applications came out in March, I never applied for any. I didn’t know what to do, and I had to go and see the careers adviser, [X]. And I applied for all these different courses that I didn’t even know if I wanted to do. So when it came round to actually thinking about it, I thought, I don’t know what I want to do, I just want to stay on at school, so I stayed on at school. And, now, I’m doing an Advanced Higher in Higher Maths.

It’s much better. I think it’s much better. During my mainstream school, I can go to classes now and again – and it’s becoming on a daily basis now, just going to classes or whatever. But whenever there is something bothering me or there is something that is worrying me, this is just at the corner of the school, and I can always come up here, and it’s just a little private corner that no-one can come into, and I can have a talk with any teachers or anyone I like.

Some young people felt that it was their own determination that had helped them achieve what they wanted.

My last year… in 3rd year, I was going to leave at the end of 4th year, just to say that I’d left school... It wasn’t that I didn’t like school, it was just I couldn’t be bothered with school. But towards the end of 4th year, I manned up and studied for my exams and done my exams and went into 5th year. In 5th year, it was the same as the start of 4th year – I was just kind of laidback and no done anything. And then, halfway through 5th year, I said I was going to leave.

Many young people felt that transitions (e.g. change of school) which were required as they grew up were difficult, but the teachers helped them gain confidence by providing the right support.
But when I came into primary school, I had two teachers helping me get through it, and they would push me in the right direction to stay in class. I would complain at first, and it would continue that way, but, eventually, they knew the teachers were doing the right thing, because I then quickly adapted to being in mainstream school and done very well at it.

As soon as I came to high school, I was at the very peak of what I was doing. I understood everything; I could talk to people without having to stand close to someone or hide behind someone’s back – and I was very pleased with myself. However, coming up to high school was a completely different thing to me, and so… For anyone, it’s very scary, coming up to high school, because you’re a big teenager and you can’t just run home to your parents and start saying this person done that to me – you need to be able to deal with it yourself. Coming up to high school was a very, very hard thing to do, and it took me quite a long while to even get used to it. I was promised to go to another high school, and then they changed it to here, since it was local – the reason being, it is local, and plus I don’t… It gives them a lot more freedom to use different abilities.

I’ve grew in confidence, moving through transitions, but, from the very beginning, it was very hard – very hard – and everyone pushed me and pushed me and pushed me, but it came out certain in the end.

Some young people complimented the help provided by ENABLE Scotland in getting them through transitional periods, particularly with respect to work placements and work-related skills. The organisation was identified for having helped young people gain confidence and become independent individuals.

They [Enable staff] definitely have helped me gain my confidence. I was speaking to my Mum on Saturday – even… If someone had to tell her, in six years’ time, your son will be able to drive and he’ll be able to go on a bus himself, he’ll be able to train himself, my Mum would have went, pfft, no – because I wasn’t… I couldn’t do it. I couldn’t even go in a taxi myself.

They’ve [Enable Staff] always been there to help me. And even if I couldn’t talk to my parents about anything, I would certainly go to my teachers and the school and I would look for in-school services, which I could use. And it’s brilliant that they could help me out in any way possible.

I did a link course at my local college, and he helped me go from my house to my local college. He’d meet me just down the hill from my house, at McDonald’s, and he would take me to the college, and then he would go to school, where he would work, and then come back at 4 o’clock and work with me there, and he got me home and all that – and it really, really helped. So it was until his boy was born, and I did it myself. So that, I think, really benefited me for getting the confidence to travel myself.

He showed me how to think differently, how to handle distress if I had a lot of stress, how to just walk away from situations that were stressing me out.
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Other young people mentioned how the apparent joint working and interaction between their parents and professions had helped them gain confidence.

6.3 Looking towards the future

All young people expressed a very positive outlook for the future.

I feel absolutely ready to hit the world of work. Still very unsure reasons, some very sure reasons, but everyone is going to have that very unsure reason, and there’s always going to be that little glint of despair, of having doubt. Looking back now, I couldn’t believe I was a little moaning child that was scrawny and couldn’t even speak to other people other than shouting at them just because I couldn’t get my chicken nuggets (laughs). But I just can’t believe how far I’ve came now – I really can’t believe it.
Conclusions

7.1 Introduction

The aims of this study were to explore and identify the key issues and concerns of parents, professionals and young people around the early stages of a child’s diagnosis of a learning disability. This was to inform delivery of the overarching GIRFEC framework for children who have a diagnosed or undiagnosed learning disability. The scope of this research included parents who did not have a firm diagnosis of a learning disability for their child.

The key conclusions that emerge from the study are as follows.

7.2 Experience of parents

The study reveals that there are a number of weaknesses within the implementation of GIRFEC for all children. There is a lack of clarity on what should be done, and how, when such concerns are raised by the parents or carers. This period appears to be a blind spot where professionals supporting the children and families during these early years could make a difference through appropriate support, advice and early intervention.

7.2.1 Raising early concerns: While in majority of the cases (60%) parents raise initial concerns about the child’s development, in the remainder of 40% cases they are unaware of any developmental issues. Although a significant number of times (24%) concerns are first raised by the professionals, there is still scope for early concerns to be raised by professionals such as the health visitor as the named person (GIRFEC), and through early years assessments (The Universal pathway for all children, 0-3 years).
7.2.2. **First point of contact:** For a majority of parents (64%) the health visitor and the GP are the first point of contact for information and advice once early concerns have been raised. First point of contact for other parents includes professionals such as nursery and school staff. The role of the Early Years Professionals and the named person is important in listening to the concerns raised by parents and providing information and support.

7.2.3. **Route to diagnosis:** Most parents (57%) find the pathway to diagnosis complex, tortuous and frustrating. Two thirds (63%) feel that although they are actively involved in the process, they struggle to navigate through the system, sometimes having multiple referrals. There were area-based variations in the kind of support available to parents.

7.2.4. **Wanting a diagnosis:** Most parents (85%) are keen on diagnosis, which is perceived as a prerequisite for obtaining support; a diagnosis empowers and equips them with information and facilitates access to services. However, it should be noted that wanting a diagnosis is seen as a need due to parents experience of struggle in getting support and services without it.

7.2.5. **Time taken for diagnosis:** The time taken for a diagnosis is expectably variable for different conditions. For ASD the mean period is 36 months from the time when early concerns were raised and for GDD it is 25 months. As diagnosis is seen as an important factor to accessing support, the parents and families can be without much support during this period.

7.2.6. **Diagnosis of global developmental delay (GDD):** Global developmental delay diagnosis can mislead parents into believing that the child will eventually catch up. Parents with children identified with GDD are far more likely to find the route to diagnosis unclear in comparison to those diagnosed with other known conditions. A much smaller proportion in comparison to other conditions agrees that their child’s diagnosis has been conducted with care and consideration.

A vast majority feel that they have not received clear and understandable information following the diagnosis. The GDD diagnosis is a child’s diagnosis (till 18 years of age) and can lead to the individual not realising that they might not have any support provision available to them following this age as adults. This can impact on support needed at the transition period, financial benefits and social work support needed in the long term, and might require further assessments of need or a diagnosis for ongoing support.

7.2.7 **Experience of diagnosis:** The diagnosis in most cases (66%) was provided with care and consideration. However, opportunities for parents to ask follow-up questions are limited.
Conclusions

7.2.8 **Information and advice:** Some parents (40%) agree that information provided is clear and understandable; most information provided is seen to be generic and not tailored to the needs of the specific child and family. Information related to support and services is not provided routinely.

7.2.9 **State benefits:** In a majority of cases the child's disability can impact on the finances of the family. Most parents are aware of the state benefits that they could or do receive. However, only a minority are provided with advice on these by the professionals; others become aware of these through informal sources. Most parents find it difficult to access benefits. The application form requires the parents to specify ‘what the child cannot do’, which was traumatic for them. Support in filling in forms was found helpful.

7.2.10 **Social care assessments and support:** A significant proportion of parents are unaware of the existence of social care assessment of need and the ensuing support. Most parents are strongly critical of the assessment process, specifically with respect to the eligibility criteria. Most parents feel that there are long delays in assessments and subsequent follow-up support. For many, social care only became available following a crisis situation. However, most parents who receive social care value and appreciate it.

7.2.11 **Support from social workers:** Although the social care system is perceived to be bureaucratic, most parents who have a social worker allocated to them are very appreciative of their help and support.

7.2.12 **Support from different sectors:** The education sector is most involved and most supportive in taking care of the child in the period around diagnosis. The involvement of the voluntary sector in supporting parents is very limited.

7.2.13 **Coping strategies:** Having access to relevant information and maintaining hope are seen as the key coping strategies by the parents. However, many parents report that they do not have access to it. Knowing parents of children with similar learning disabilities (peers) is an important part of informal support. Approximately half the parents receive peer support through parent support networks.

7.2.14 **Impact on siblings:** The siblings suffer directly or indirectly within a family environment focused on fighting for adequate support for the child who has learning disabilities. The sibling can feel neglected or their needs compromised. They might be directly or indirectly supporting their parents in caring for their sibling who has a learning disability.
7.3 Experience of professionals

7.3.1. Diagnosis: Diagnosis is seen as an important factor in facilitating access to support and services. GDD is a child's diagnosis and is applicable only till the child is 18 years old. With a GDD diagnosis parents require to pursue assessments for a diagnosis at this stage to access any benefits and support for the young person in the long term.

7.3.2. Supporting parents: It can take a long time for many parents to accept a diagnosis. Many parents could benefit from support and advice from the professionals. Professionals often find it difficult to balance the need for an honest appraisal, with the requirement of being sensitive when discussing the child’s situation with the parents. Managing extreme expectations of many parents can be challenging for staff in schools. Building trusting relationships with parents and meeting the needs of the child and the parent is important. A better understanding of challenges faced by the parents can enhance professional capacity to provide sensitive support. For example, having an understanding that ‘what the child can do’ (the education system) versus the need for identifying ‘what the child cannot do’ when accessing welfare benefits and social work support, can be challenging for parents.

7.3.3. Competences of workforce: Providing the right support for children who have learning disabilities requires professionals with appropriate competences which include listening skills, empathy and trusting relationships which allow for open communications between professionals and the parent.

7.3.4. GIRFEC: Multi-agency working and joint working between professionals and parents is generally perceived to have a positive impact on the child and the family. A range of issues related to effective implementation of GIRFEC for children who have learning disabilities that exist are:

- the systems (information sharing and assessments) is not synchronised and in many cases the experts do not agree with each other;
- parents can experience multiagency meetings as challenging and overwhelming and need support to participate;
- the capacity and capabilities of the Named Person (e.g. health visitor and head teacher) dictates whether the child with learning disabilities will get the right kind of coordinated support.

7.3.5. Social work: Partnership working with social work is important to provide support and respite to parents and families.
7.4. Experiences of Young People

7.4.1 Young people and diagnosis: While most young people did not immediately understand the meaning of their diagnosis, they did recognise if it had made a difference in how they were treated by others. Diagnosis also helped them understand themselves better. The role of teachers within the specialist unit providing additional support needs in the school is identified as most important by young people specifically around transitions (e.g. from primary school to secondary school) where the young people need much support to gain confidence and support for independent living.

7.4.2 The support role of ENABLE Scotland is identified in helping young people gain confidence, particularly with respect to work placements and work related skills.

7.4.3 Young people interviewed have a very positive outlook for the future.
Recommendations

10 Point Plan: Getting it right from the start for children who have learning disabilities

The findings of this research lead to some strong policy and practice recommendations to improve the experiences of families, children, and professionals alike. In particular, the implementation of the Children and Young People (Scotland) Act 2014 provides a timely opportunity to address issues raised through direct recommendations around children’s services planning and developing specialist skill set for professionals around an individual Child’s Plan for a disabled child.

The universal principle of monitoring wellbeing indicators for all children (GIRFEC) should mean that a formal diagnosis should not be a barrier to accessing support, both for the child as an individual, and for the family around the child. This should promote a significant positive shift around the experiences of families of children who have/may have a learning disability in those early years.

The research has also identified gaps around what statutory sector services currently provide, and what families identify as making a positive difference to their lives in the journey to diagnosis, which gives clear direction to the voluntary sector around the development of support and services for families.
In order to make sure that the Children and Young People (Scotland) Act 2014 delivers for children with learning disabilities in the early years and beyond, this research points towards ten key recommendations to ensuring that this universal policy and legislation is enacted to the best advantage of disabled children and their families.

1. **Children and Young People (Scotland) Act 2014 in the context of disabled children**

   In order for the implementation of the Children and Young People (Scotland) Act 2014, to deliver the best possible outcomes for disabled children and address the issues raised by this research, there is a need for:

   1.1 The provisions within the Act to be understood in the context of disability, and for disabled children properly recognised as ‘children with needs of a particular type’.

   1.2 It is essential that the wellbeing indicators (Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included) set down in Part 18 of the Act, are properly articulated within the context of disability. For example, the ‘Achieving’ indicator should include ‘not meeting developmental milestones’. This would trigger an appropriate and timely response around emerging evidence of a learning disability.

   1.3 Furthermore, for wellbeing indicators to be suitably applied to the experiences and the learning journey of disabled children, it is essential that these are framed positively in associated statutory and practice guidance. For example, ‘Included’ should recognise a disabled child as ‘a child who may need more support to overcome barriers to participation’ rather than a negative framing that suggests familial failings i.e. ‘child has limited support to overcome barriers to participation’. This nuanced approach to translating policy into practice in a more positive manner would improve parental confidence in the system as a supportive intervention, and encourage professionals to consider the support strategies that are likely to be successful, which include a holistic, family support programme, with the child at the centre.

   **Recommendation 1:** The Scottish Government should commission a practice guidance document for commissioners and practitioners, which makes clear how to implement the Children and Young People (Scotland) Act 2014 for disabled children and young people.
2. Early intervention and diagnosis
The Named Person Service created by the Children and Young People (Scotland) Act, provides
a potentially excellent framework to facilitate an early intervention approach to identifying early
concerns, and implementing an appropriate and timely response, irrespective of the presence
of a formal diagnosis. This is a significant step in a system where, this research concludes,
that a formal diagnosis is currently seen by parents as the key to accessing supports and
services. Specifically:

2.1 The Named Person system, once implemented, should trigger an appropriate and
timely response, providing that early developmental concerns are properly identified
as a ‘wellbeing need’ which triggers the development of a Child’s Plan, thus remedying
the current delays experienced by families in access to supports and services; and
lessening the perceived need to chase a formal diagnosis, as well as the stress and
anxiety that this process brings for families. If the named person and wellbeing indicator
system works well in this way, in theory, lack of diagnosis should not be a barrier to
accessing support.

2.2 In practice, in order for the Named Person provision to meet the needs of families at
the point of ‘raising early concerns’, named person professionals will require a solid
understanding of the wellbeing indicators in the context of learning disability.

2.3 Named person professionals should also be capable of, or have early access to other
specialists who can support with, identifying developmental issues and concerns around
both physical and cognitive development of the child; as well as responding to concerns
raised by parents. The appropriate response would then be for the named person
to support the parents to access a specialist for further assessment, and to refer to
appropriate sources of information and advice to reduce and minimise parental anxiety
and familial stress.

The positive experiences of parents interviewed via this research, clearly indicates that where
the system works well, their key professional had a background in additional support for
learning or in a specialist setting.

**Recommendation 2:** Training and clear referral pathways for learning disability/cognitive
delays/ global developmental delay diagnosis should be available in every local authority
area. Every area should ensure access to a learning disability specialist who has appropriate
knowledge of the referral pathways and the support required for families during this journey to
diagnosis.

**Recommendation 3:** Consideration should be given to identifying lead professionals with
expertise in additional support for learning and disability in each area to support the Named
Person role where a child is presenting with a learning disability, or where there is a concern
around development.
3. Support for families

Information and advice, and peer support opportunities are identified by this research as key coping strategies by parents, pre and post the child’s diagnosis. The research highlights that for parents to participate as ‘equal partners’ in their child’s care, the systems that they then have to engage with, such as multi agency meetings about their Child’s Plan, mean that they are expected to take on an increasingly professional role – or at least engage in a manner which professionals consider to be constructive. The research demonstrates that the system can currently entrench a ‘them and us’ dynamic, where parents can find it difficult to air concerns or frustrations in a non-confrontational way.

The research concludes that this support for families is required, not only at the point of diagnosis, but in fact, in keeping with the principle of early intervention, throughout the journey towards a diagnosis, and indeed throughout the child’s life; including at points of transition. The research identifies the following as key requirements of support for families as they progress through their journey of identifying concerns and achieving support for themselves and their child.

3.1 The Named Person Service provides the ideal framework to ensure families have access to the advice, information, support and services they need. The research suggests that the parent already identifies professionals who will take on the role of named persons and are the first point of contact for information and advice, which is a positive indicator for the practical application of the legislation. The Children and Young People (Scotland) Act 2014 therefore places that relationship on statutory footing and defines the responsibilities entailed.

3.2 The Carers (Scotland) Bill 2015, presents opportunities to address some of the current gaps in family support by identifying parents and siblings as carers and young carers. Parent and sibling carers do not always identify as being ‘carers’, and this is one of the key challenges in the journey for a parent of a disabled child – recognising the shift from ‘mummy’ or ‘daddy’ to ‘carer’ can be a challenge, and one that many parents will not readily want to explore. It is therefore important that named persons are equipped to make that identification as part of the Child’s Plan considerations, and make appropriate referrals to appropriate supports and services. The Carers (Scotland) Bill 2015, will provide for every parent and sibling carer to have an Adult Carer Support Plan or Young Carers Statement respectively, on request or when identified as a carer by the local authorities. Furthermore, the Carers (Scotland) Bill 2015, also requires each local authority to establish and maintain an information and advice service for carers in its area. To meet the information and advice needs of family carers, identified by this research, these services should be equipped with information and advice specifically relevant to parent and sibling carers.
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

3.3 Information and advice services, including the Named Person Service, should be equipped to inform parents of their rights including access to Social Work Assessment of Needs, as provided by section 12A of the Social Work (Scotland) Act 1968 and/or an Additional Support for Learning Needs Assessment, as per Section 8 of the Education (Additional Support for Learning) (Scotland) Act 2004.

3.4 There is a need for professionals to achieve a greater awareness of the additional stress that parenting a disabled child can bring to the family dynamic, and design engagement strategies that minimise this, and support parents and carers to engage with the planning system and maintain their own health and wellbeing. Advocacy services and self-advocacy resources should form part of support for families. The support for families should include provision to help them to prepare for this role and support to do so effectively. Provision for peer support opportunities should be made available to parents.

3.5 The research concludes that the majority of families find the welfare system complex and tortuous. In order to remedy this, parents and families should have access to specialist welfare advice and routinely offered the opportunity to access this by professional points of contact; particularly by Named Person professionals.

**Recommendation 4:** Named Person professionals require to be equipped with the relevant training and knowledge to enable them to support and signpost family carers to access information and advice around parenting a child who has a learning disability, navigating the Children and Young People (Scotland) Act 2014, the Additional Support for Learning (Scotland) Act 2004, the Social Work (Scotland) Act 1968, the Equality Act 2010, the forthcoming Carers Bill, and the benefits system to maximise access to rights and support.

4. **Children and young people’s services planning**

A key principle of primary prevention is supporting and assisting parents and families at least as much as the child directly. Family stress contributes to a risk to a child’s wellbeing. A holistic approach to Children Services Planning is needed, as follows:

4.1 A holistic approach to children’s services planning should ensure that local community based peer support services are commissioned, which properly meet the needs of the wider family; including by providing as a minimum the key requirements of support for families identified by this research – sources of advice and information, peer support, access to counselling if needed, parenting support, advocacy services, information about benefits, and respite opportunities.

4.2 Under the new duty to develop Children’s Services Plans, this research recommends that relevant planning authorities should map out existing provision of support for families of disabled children and engage directly with parents to inform service development and commissioning strategies.
Recommendations

4.3 The requirement to prepare Children and Young People’s Services Plans provides planning authorities with an opportunity to map out children’s and related services, and identify gaps which should inform future children’s services planning. In line with the ambitions of the Christie Commission, children and young people’s services and service plans should be designed with and for disabled children and their families; informed by people who will use the services.

4.4 The duty to prepare Children and Young People's Services Plans should be underpinned by the principles of prevention and early intervention. This requires service planning to take a holistic view of children’s services ensuring they meet the needs of parents and families as much as they meet the needs of children.

4.5 Children and Young People’s Service Plans should recognise and seek to address the particular needs of children with disabilities, among other groups, recognised in the Children and Young People Act as ‘children with needs of a particular type’.

4.6 In line with the principles of the Christie Commission, effective children’s services planning will require taking a ‘long-term’ view and being able to anticipate emerging and changing needs, informed by the lived experience of children, young people and their families. Early identification of disability as a wellbeing need will assist forecasting needs and facilitate long-term children services planning.

Recommendation 5: Under the new duty to develop Children’s Services Plans, this research concludes that relevant planning authorities should consider family support services as a key part of the Children’s Services provision for disabled children. In order to meet the family support needs identified in this research, commissioning bodies should map out existing provision of support for families of disabled children and engage directly with parents to inform service development and commissioning strategies.

5. Skills of children’s workforce
This research highlights some of the tensions that exist in current parent-professional relationships. The health and social care and education workforce should continue to develop skills and competencies that facilitate the recognition of parents as equal partners in their children’s care; further embedding Common Core of Skills, Knowledge & Understanding and Values for the “Children’s Workforce” (Scottish Government, 2012e) in Scotland. Skilled and competent practitioners should have a level of awareness that enables them to recognise where parents need more support to participate in increasingly professional environments; and the knowledge to make appropriate referrals to meet that need.
Furthermore, professionals working with families should be equipped with competencies to manage difficult conversations; including medical professionals involved in the diagnosis process and education staff. Specifically:

5.1 Diagnosis should include follow-up time allocated by the specialists for parents to ask further questions about the diagnosis. It should be made clear that this allocated time is available to them. At the point of diagnosis the named person has a role to play in ensuring parents have access to that opportunities.

5.2 Named person professionals will require a good understanding of wellbeing indicators in the context of learning disability. This will enable them to trigger an appropriate response to the wellbeing need; in particular to support the family to access supports, services and specialists. In order to fulfil the statutory functions of the Named Person Service for children who have learning disabilities and their families.

5.3 In order to address the gaps identified in this research in terms of parental access to information and advice, named persons should be equipped with the appropriate questions to ask in order to identify and meet the needs of the family by making appropriate referrals to supports, services and specialists. For example, asking about family finances and making an appropriate referral to specialist welfare advice would ensure that families of disabled children have access to the specialist welfare advice required to support them to navigate the ‘complex and tortuous’ welfare system, as identified by this research. Appropriate questions should be defined in practice guidance for the Named Person Service.

5.4 Named persons will also require being aware of appropriate referral pathways in the context of disabled children. This would mean that named persons should be equipped to inform parents, among other things, of their right to request a Social Work Assessment of Needs for their child and/or an Additional Support for Learning Needs assessment. Furthermore named persons should be equipped to recognise parents and siblings of disabled children as carers, and therefore entitled to a Carer Support Plan.

**Recommendation 6:** Within the context of the practice guidance recommended above, a toolkit for named persons to guide through appropriate issues and key considerations for parents of a disabled child should be developed and issued to ensure that named persons are equipped to ask families the right questions at the right time to inform support strategies.
Recommendations

6. Voluntary sector
The research identifies 70% of families do not receive a formal social work support package. Therefore the voluntary sector has a significant role to play in filling the gaps in the provision of family support. Specifically:

6.1 The voluntary sector can lead the way in developing whole family support and creating opportunities for shared-experience peer support, as well as supporting professionals to develop the skills and expertise around specific conditions.

6.2 This provision should be mapped out and inform appropriate referral pathways that families can be linked in to by statutory services.

6.3 Whilst the Children’s Services Planning process can only consider ‘children's services’ or ‘related services’ contracted on behalf of the local authority formally, mapping out other sources of support for parents and children locally provided by the voluntary sector and supporting referral pathways to these would support families to access sources of advice and support earlier, rather than at crisis point.

6.4 Further, whilst this research should reassure parents that a firm diagnosis should no longer be seen as the passport to services and support, the process of establishing a diagnosis does leave families with no clear indication of where to turn for support. At present, the research identifies that there is no obvious point of contact.

Recommendation 7: As part of the practice guidance recommended above, public bodies should consider the role of the local and national voluntary sector as an important source of information, advice and support for families, and actively support referrals.

Recommendation 8: The Scottish Government and the voluntary sector in Scotland should work together to pilot sources of information and advice for families who are in the process of accessing a diagnosis of a learning disability, or who are monitoring ongoing concerns.

7. Inclusive education
The research identifies parents and families apprehensions about mainstream schooling for their child. The following need to be considered for inclusive education:

7.1 The Scottish Government’s renewed focus on raising attainment for all pupils via the National Improvement Framework for Scottish Education, and a focus on multi-disciplinary working via the Children and Young People (Scotland) Act 2014, presents a timely opportunity for the Scottish education system to consider a progressive approach to delivering a truly inclusive education system. Families and professionals identify plenty that is positive about the principles of mainstream education, but considerable apprehension and anxiety about whether the current system is equipped to deliver a truly inclusive education experience.
The research identifies good practice which should become universal practice with regards to meeting the educational needs of children, young people and their families. As a minimum these include; creating opportunities for shared-experience peer support for children with additional support needs, and for their parents or families; Education staff equipped with the training and skills to meet the needs of children who have learning disabilities, working alongside parents and other professional input (social work and NHS) to plan for inclusion in school trips and out of school activities, reduce informal exclusions, and create more opportunities for specialist input in school as often as is required to support children who have a learning disability to achieve their full potential.

**Recommendation 9:** To compliment the practice guidance recommended above to support the implementation of the Children and Young People (Scotland) Act 2014, the Scottish Government should develop and issue practice guidance to education authorities on delivering an inclusive education to support the implementation of Section 15 in the Standards in Scotland's Schools Act which introduced the legal presumption to mainstream. This should include a balance of ensuring that support is available to staff to create an inclusive learning environment, as well as recognition of continued investment in specialist support when needed.

8. Further research

The effective implementation of the Children and Young People (Scotland) Act 2014, has been identified by this research as a timely opportunity to remedy many of the issues identified. But ultimately, time will tell if this approach will deliver improved outcomes for disabled children in Scotland. Further research is therefore required to review the implementation and assess how effective it has been in doing so.

Furthermore, whilst this research should reassure families that the absence of a formal diagnosis should not be a barrier to supports and services in childhood; further research is required into the experiences of those who lack a formal diagnosis or have a childhood diagnosis of global developmental delay; at the point of transition to adulthood. At this point, the presence of a firm diagnosis does become important when accessing certain benefits and other types of support to live an independent life.

**Recommendation 10:** The Scottish Government should actively monitor, report and evaluate the long term impact of the Children and Young People (Scotland) Act 2014 on outcomes for disabled children; and should commission further research into the impact of a lack of formal diagnosis of a learning disability for young people transitioning into adult life and service eligibility.
References


Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)


Inclusion-Europe (no date). Increasingly the term intellectual disability is being used across Europe: http://inclusion-europe.eu/.


References


Scottish Executive (2012b) The right help at the right time in the right place. Strategic review of learning provision for children and young people with complex additional support needs. The Scottish Government: Edinburgh.
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

Talking Mats (no date) Communication tool used to overcome communication difficulties for people with learning disability or dementia: http://www.talkingmats.com/about-talking-mats/.
References


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Who is this survey for?
This survey is for carers (mother/father/guardian) of a child (under 16 years of age) who has any kind of learning disability (Autism Spectrum Disorder is included). The learning disability could be diagnosed formally or informally or might still remain undiagnosed, or the child could have a diagnosis of global developmental delay. Thank you for taking time to fill in the survey.
The information you provide will be very valuable in helping us improve and develop support services for the carers that best meets their needs, both, before and after diagnosis of a learning disability for their child. The survey should take roughly 15-20 minutes to complete.
We will also be conducting in-depth research as part of this study. If you are interested in taking part please leave your details at the end of this survey and we may be in touch.
All responses will be treated confidentially in accordance with the Data Protection Act and your individual feedback will not be traced back to you. You will not be contacted again as a result of filling in this survey unless you have offered to help us with further research.

Purpose of the survey
The survey seeks your experiences around the early stages of a diagnosis of a learning disability of your child. We are specifically investigating positive examples of support experienced by carers that will help us in learning lessons on what worked.
Scottish Government (Third Sector Early Interventions Fund) is funding this project. The findings of this research will be available from this website on completion.

Survey instructions
A carer should fill a separate questionnaire for each child with a learning disability within a family.
The closing date for this survey is 10th of June. Please fill this questionnaire and post it back to ENABLE Scotland in the self addressed envelope provided.
When filling in the questionnaire, please follow the instructions provided.

Section 1: ABOUT THE CHILD

Q1. Please ✓ the local authority area you currently live in

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<tr>
<th>Local Authority area</th>
<th>✓ Tick one that applies</th>
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<td>31. Orkney Islands</td>
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<td>32. Western Isles</td>
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Appendix

Q2. What is the current age of your child? Please provide approximate age in years and months.

Q3. Has your child been diagnosed with a learning disability? Please mark as appropriate

1. YES, the child has been diagnosed (Please go straight to Section 3 Question 16)
2. NO, the child has not been diagnosed (Please continue to Section 2 Question 4)

SECTION 2: YOUR CHILD HAS NOT BEEN DIAGNOSED: Views and experiences of parents/carers

Please note: This Section should be filled in by parents/carers who have answered NO to the previous question. If you have answered YES then please go to Section 3, QUESTION 16 (page 9).

Q4. If your child has not been formally diagnosed, then what is the informal diagnosis or what concerns have been raised about the child’s development?

Q5. If you are still waiting for a diagnosis, then please estimate approximately how long (years and months) it has been since early concerns about the child were raised.

ABOUT YOU

Q6. Are you the primary care-giver for the child?

1. YES 1. NO

Q7. How is the child related to you? Please tick that applies.

1. Natural son/daughter
2. Adopted son/daughter
3. Foster child
4. Stepson/stepdaughter
5. Natural brother/sister
6. Half-brother/sister
7. Step-brother/sister
8. Adopted brother/sister
9. Foster brother/sister
10. Grand-child
11. Other relative
12. Other non-relative
13. Any other, please specify

Q8. How would you describe yourself as?

1. Single, that is never married
2. Married and living with husband/wife
3. A civil partner in a legally-recognised Civil Partnership
4. Married and separated from husband/wife
5. Divorced
6. Widowed
7. Cohabiting (living together with partner but not married)
8. Other, please specify

Q9. Do you have other people (e.g. family, friends) who you can rely on for support when caring for the child?

1. YES If you have ticked Yes, then please specify who they are
2. NO If you have ticked No, then please elaborate

Q10. Who first raised concerns about your child’s development (for example, when you first noticed changes in behaviour or lack of progression to childhood milestones)?

1. Myself
2. A professional
3. My partner
4. Other family member
5. Other, please specify

Q11. When early concerns were raised about your child’s development, who did you first seek help from? Please specify (for example, mother, health visitor, partner, GP, a friend).

Q12. Please state your level of agreement with the following statements. (Please TICK as appropriate)

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<tr>
<th>Statement</th>
<th>Completely agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Completely disagree</th>
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<tr>
<td>It is taking too long to get a diagnosis</td>
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<td>I am/ was not ready for any professional intervention around diagnosis for my child</td>
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<td>I do not/ did not want a diagnosis</td>
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<td>My child’s diagnosis is being conducted by professionals with care and consideration</td>
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<td>The information I have received with respect to the process of diagnosis has been presented in a clear and understandable manner</td>
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<td>I have/am receiving advice regarding the services available to my child and family</td>
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Q13. To what extent have the following been involved (have put effort into, engaged) in the process of diagnosis for your child. (Please TICK as appropriate)

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<thead>
<tr>
<th></th>
<th>Often involved</th>
<th>Sometimes involved</th>
<th>Seldom involved</th>
<th>Never involved</th>
<th>N/A</th>
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<tr>
<td>Initial contact services professionals (e.g. GP, Health visitor, midwife)</td>
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<td>Pre-school/Early Years professionals (e.g. nursery teacher, child minder)</td>
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<td>School/Education professionals (e.g. school teacher, head teacher, additional support for learning staff, learning assistant)</td>
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<td>Voluntary sector staff (e.g. ENABLE Scotland support workers)</td>
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<td>Specialists (e.g. hospital nurse, social worker, local area coordinator)</td>
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Q14. To what extent have the following supported you (provided for, served you with patience, care and consideration) in the process of diagnosis for your child. (Please TICK as appropriate)

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<th>Often involved</th>
<th>Sometimes involved</th>
<th>Seldom involved</th>
<th>Never involved</th>
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<td>Primary care/Initial contact services professionals (e.g. paediatrician)</td>
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<td>Pre-school/Early Years professionals (e.g. nursery teacher, pre school learning assistant, child minder)</td>
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<td>Specialists (e.g. Autism specialist, hospital nurse, social worker, local area coordinator)</td>
<td></td>
<td></td>
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</tbody>
</table>

Q15. What kind of support has been provided to you before and or during the process of diagnosis? (e.g. if you were provided respite, counselling support, information about learning disability, financial support etc.) Please use the space to elaborate on your experiences on support and challenges.

**NOTE:** Now please go straight to SECTION 4 – Supporting my child, Question 28, page 92.

Section 3: IF YOUR CHILD HAS BEEN DIAGNOSED WITH A LEARNING DISABILITY: Parental experiences and views

Q16. Please state what specific learning disability has your child been formally or informally diagnosed with?

Q17. Please state how long (estimate of years and months) it took for a formal or an informal diagnosis since early concerns about the child’s development were raised.

ABOUT YOU

Q18. Are you the primary care-giver for the child?  1. YES  2. NO

Q19. How is the child related to you? Please tick that applies.

1. Natural son/daughter
2. Adopted son/daughter
3. Foster child
4. Stepson/stepdaughter
5. Natural brother/sister
6. Half-brother/sister
7. Step-brother/sister
8. Adopted brother/sister
9. Foster brother/sister
10. Grand-child
11. Other relative
12. Other non-relative
13. Any other, please specify

Q20. How would you describe yourself as?

1. Single, that is never married
2. Married and living with husband/Wife
3. A civil partner in a legally-recognised Civil Partnership
4. Married and separated from husband/wife
5. Divorced
6. Widowed
7. Cohabiting (living together with partner but not married)
8. Other, please specify

Q21. Do you have other people (e.g. family, friends) who you can rely on for support when caring for the child

1. YES If you have ticked Yes, then please specify who they are
2. NO If you have ticked No, then please elaborate

Q22. Who first raised concerns about your child’s development (for example, when you first noticed changes in behaviour or lack of progression to childhood milestones)?

1. Myself
2. A professional
3. My partner
4. Other family member
5. Other, please specify
Appendix

Q23. When early concerns were raised about your child’s development, who did you first seek help from? Please specify (for example, mother, health visitor, partner, GP, a friend).

Q24. Please state your level of agreement with the following statements. (Please TICK as appropriate)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Completely agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Completely disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>It took too long to get a diagnosis</td>
<td></td>
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<tr>
<td>I was/was not ready for any professional intervention around diagnosis for my child</td>
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<tr>
<td>I do/did not want a diagnosis</td>
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<tr>
<td>My child’s diagnosis was conducted by professionals with care and consideration</td>
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<tr>
<td>The information I received pre- and post-diagnosis was presented in a clear and understandable manner</td>
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</tr>
<tr>
<td>Following my child’s diagnosis, I received sufficient support and advice regarding the services available to my child and family</td>
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</tr>
<tr>
<td>I was given the opportunity by the professionals to return and ask questions after the diagnosis was made</td>
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</tr>
</tbody>
</table>

Q25. To what extent have the following been involved (have put effort into, engaged) in the process of diagnosis for your child. (Please TICK as appropriate)

<table>
<thead>
<tr>
<th>Role</th>
<th>Often involved</th>
<th>Sometimes involved</th>
<th>Seldom involved</th>
<th>Never involved</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care/Initial contact services professionals (e.g. GP, Health visitor, midwife)</td>
<td></td>
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<tr>
<td>Pre-school/Early Years professionals (e.g. nursery teacher, child minder)</td>
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<tr>
<td>School/Education professionals (e.g. school teacher, head teacher, additional support for learning staff, learning assistant)</td>
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<tr>
<td>Voluntary sector staff (e.g. ENABLE Scotland support workers)</td>
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<tr>
<td>Specialists (e.g. hospital nurse, social worker, local area coordinator)</td>
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</tr>
</tbody>
</table>

Q26. To what extent have the following supported you (provided for, served you with patience, care and consideration) in the process of diagnosis for your child. (Please TICK as appropriate)

<table>
<thead>
<tr>
<th>Role</th>
<th>Often supported</th>
<th>Sometimes supported</th>
<th>Seldom supported</th>
<th>Never supported</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care/Initial contact services professionals (e.g. paediatrician)</td>
<td></td>
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<td></td>
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<tr>
<td>Pre-school/Early Years professionals (e.g. nursery teacher, pre school learning assistant, child minder)</td>
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<tr>
<td>School/Education professionals (e.g. school teacher, educational psychologist, head teacher, learning assistant)</td>
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</tr>
<tr>
<td>Voluntary sector staff (e.g. ENABLE Scotland support workers)</td>
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<td></td>
</tr>
<tr>
<td>Specialists (e.g. Autism specialist, hospital nurse, social worker, local area coordinator)</td>
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</tbody>
</table>

Q27. What kind of support has been provided to you after diagnosis? (e.g. if you were provided respite, counselling support, information about learning disability, financial support, membership of parent networks etc.) Please use the space to elaborate on your experiences.

Section 4: SUPPORTING MY CHILD

Q28. In your being able to provide good care for your child, please state how important the following have been to you. (Please TICK as appropriate)

<table>
<thead>
<tr>
<th>Role</th>
<th>Very Important</th>
<th>Important</th>
<th>Neither important nor unimportant</th>
<th>Of Little importance</th>
<th>Unimportant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other family members</td>
<td></td>
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<tr>
<td>Friends</td>
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<tr>
<td>People who have children in a similar situation</td>
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<tr>
<td>Staff of voluntary sector organisations, e.g. ENABLE Scotland</td>
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</tbody>
</table>
Exploring Concerns Around a Child’s Diagnosis of a Learning Disability (Including ASD)

Q29. How important have the following been in helping you to provide good care for your child? (Please TICK as appropriate)

<table>
<thead>
<tr>
<th></th>
<th>Very Important</th>
<th>Important</th>
<th>Neither important nor unimportant</th>
<th>Of Little Importance</th>
<th>Unimportant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having relevant information</td>
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<tr>
<td>Knowing where to go for support</td>
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<tr>
<td>Having time for myself to pursue my interests</td>
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<tr>
<td>Self development and learning new skills</td>
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<tr>
<td>Maintaining hope for the future</td>
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<tr>
<td>Having an optimistic attitude towards the child’s life</td>
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<tr>
<td>Access to child centred planning</td>
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</tbody>
</table>

Q30. Please state your level of agreement with the following statements. (Please TICK as appropriate)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Completely agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Completely disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was or have been provided with support and guidance during the diagnosis/assessment process</td>
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<tr>
<td>I have been actively involved in the diagnosis process</td>
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<td>I have received life coaching support</td>
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<tr>
<td>I have received counselling support</td>
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<tr>
<td>The route to diagnosis was clear to me</td>
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<tr>
<td>I received peer support through parent support networks</td>
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<tr>
<td>I have been encouraged to be involved in the review of my child’s care plan</td>
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</tbody>
</table>

Section 5: FINANCES AND BENEFITS

Q31. With respect to your financial situation and benefits, please state how much you agree with the following statements. (Please TICK as appropriate)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Completely agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Completely disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am aware that I could be entitled to benefits</td>
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</tr>
<tr>
<td>Having a child with disability has impacted on my finances</td>
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<tr>
<td>I was provided benefits advice</td>
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<td></td>
</tr>
<tr>
<td>I have found it easy to access benefits I am entitled to</td>
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</tbody>
</table>

Q32. Please use this space to expand on your experiences of the above (e.g. who provided you with benefits advice; what difference did it make to you being able to support your child and whether there were challenges in understanding your entitlement to benefits etc.)

Q33. With respect to your experiences relating to social care assessments, please answer the following questions. (Please TICK as appropriate)

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has your child been through social care assessment of need?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you requested a social care assessment of need for your child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you received an allocation of support through social care assessment of need?</td>
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<td></td>
</tr>
</tbody>
</table>

Q34. If your child has been or is going through social care assessment of need (via a social worker) tell us about your experience (e.g. what difference did that make to you in getting the support needed to support your child; whether your child’s assessment met the required criteria for social care support; and if there were any challenges etc.).
Appendix

Section 5: What can be done better – YOUR SUGGESTIONS AND COMMENTS

Q35. Please use the space below to elaborate on your experiences around early diagnosis of a learning disability for your child. Was there any aspect of the journey through to diagnosis which you would say made the difference? Who/What was it that made a positive difference. (e.g. the professionals; the named person/ the lead person; your family; information provided; meeting other people in similar conditions etc.).

Q36. This research is particularly interested in finding from you what could be done better and what worked well for you. Please use this space to provide your comments and recommendations.

NOTE: We will be conducting one to one interviews with parents and carers as part of this research. If you are interested in sharing your experiences then please provide your contact details below. We might get in touch with you shortly.

Name: ____________________________ Phone number: ____________________________

Email Address: ____________________________