



Parents with learning disabilities in Newcastle upon Tyne

Carried out by:



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Acknowledgements

There are a number of people to thank for their contributions to this research, not least those parents and professionals who gave up their time and spoke freely.

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Finally, the commissioners of the research, Northern Rock Foundation, their trustees, Louise Telford and Carol Candler, must be thanked as without their intent and support, this particularly hidden, marginalised and disadvantaged group would continue to be so.

About Northern Rock Foundation

Northern Rock Foundation is an independent charity which aims to tackle disadvantage and improve quality of life in the North East and Cumbria. The Foundation gives grants to organisations which help people who are vulnerable, disadvantaged, homeless, living in poverty or are victims of crime or discrimination. It also supports training, research and demonstration work and seeks to share learning from the activities it funds.

More information: www.nr-foundation.org.uk

About the authors

Barefoot Research and Evaluation is a social research organisation based in Newcastle upon Tyne, working across the North East and Cumbria. They have particular expertise in work with vulnerable children, families and at-risk groups and on projects and strategies to support them. Barefoot Research and Evaluation has carried out work on family intervention initiatives and parenting programmes in the voluntary and public sector. Dr. Christopher Hartworth, who set up Barefoot, has 20 years' experience of research and evaluation, beginning in developing countries in poverty alleviation programmes and continuing in the North East of England in work with disadvantaged communities.

More information: www.barefootresearch.org.uk

i Executive summary for professionals

Introduction

Northern Rock Foundation, under its Enabling Independence and Choice Programme, commissioned an independent organisation to undertake research in Newcastle using a case study approach to explore existing service provision for parents with learning disabilities and to look at possibilities for improvement.

The objectives of the research were to:

- Examine current statutory and voluntary sector provision
- Investigate need and scale of need
- Identify models of best practice within the local authority area
- Identify gaps in provision
- Support the development of services for parents with learning disabilities in Newcastle.

It is important to note that this study focuses on adults, their experiences and the experiences of professionals working with those adults and their families. It does not look at the outcomes of the children of parents with learning disabilities, either those who stay with their parents or those who have been looked after.

Definitions

Although there are other more comprehensive and inclusive definitions, for the purposes of this report and to remove any confusion between the terms 'difficulty' and 'disability', we are using the medical definition of learning disability which relates to any individual with an IQ under 70. Learning disability is diagnosed through an IQ test, which determines IQ scores regardless of educational background.

Key findings

Existing provision

In relation to provision in Newcastle, there exists considerable expertise in working with parents with learning disabilities; much of which is held within the Community Team for Learning Disabilities (CTLTD) service of Northumberland, Tyne and Wear NHS Foundation Trust (NTW). Others in the voluntary sector such as Children North East, Families in Care and Skills for People also have expertise in this area. There are existing resources, such as the parenting assessment tool and a training manual for professionals developed by CTLTD, which have been delivered locally and nationally. There have also been a number of services and initiatives aimed at parents with learning disabilities in the recent past such as advocacy services, parenting courses and drop-ins.

Currently, services that work with parents with learning disabilities in Newcastle tend to be focused round the Child Protection process, such as Children's Social Care and to a lesser extent Adult Specialist Services. There are some good examples of support provided, such as CTLD and Children North East, and there is a wealth of expertise that can be built upon to create supportive provision for parents with learning disabilities in Newcastle, which is an area where there is currently significant scope for improvement.

Views of parents

Many parents with learning disabilities generally have a poor experience of services in Newcastle. Many parents end up in complex Child Protection Proceedings, which they neither understand nor can contribute to, and often these parents have their children ultimately removed from their care. They then often return to their communities alone and unsupported. The types of issue that were raised during this research included:

- **Dissatisfaction with service contact:** many parents were generally unhappy about their contact with statutory services in Newcastle, although those that were provided support (opposed to enforcement) spoke of it highly.
- **Unfulfilled support requirements:** parents reported that they wanted support but none was given.
- **A condescending and patronising approach:** parents reported that their contact with statutory services was characterised by professionals talking down to and treating people with little respect.
- **Contact characterised by the experience of fear and suspicion:** parents reported that much of the contact with statutory services was characterised by fear and they were worried about the things they say.
- **Poor and inappropriate communication:** parents reported that they did not understand what professionals were trying to say to them.
- **Untimely support:** there were reports from parents that even when support was offered, it was either not when it was promised or too late.

In relation to support needs, parents spoke of their desire for: support to help them overcome their isolation; advocacy; parenting support; and general help and support.

Views of professional agencies

In relation to issues raised by professional agencies, it became apparent that different agencies had different viewpoints and concerns with regards to parents with learning disabilities, including responsibilities, family support, advocacy and strategic direction. These perspectives are grouped into those of the local authority, the health authority, the voluntary sector and community family support agencies.

Perspectives of local authorities

From a local authority perspective, there appears to be three main issues. First is the difficulty of diagnosis and the subsequent knowledge of numbers. This is because no agency routinely carries out IQ tests on all those parents suspected of having a learning disability, so we do not know how many parents there are in Newcastle who are undiagnosed. Also, as there is no central record of numbers of parents who have been diagnosed, we also do not know how many diagnosed parents with a learning disability there are. Secondly, amongst professionals working for the local authority there was a difficulty in deciding whose responsibility is it, i.e. Adult or Children's Services, to provide support services to parents and their children. Thirdly is the difficulty associated with the assessment of capabilities versus the need to protect children, i.e. making the choice between providing support to enable the parent to continue parenting and removing the child to ensure safety.

Perspectives of the health authority

From the health authority perspective, the issues include deciding which agency, health or local authority, is best placed to provide services to parents and subsequently deciding which professionals should provide such support services, i.e. should it be Nurses, Social Workers, Health Visitors or others. The question exists, is NTW best placed to provide this service?

Perspectives of the voluntary sector

From a voluntary sector perspective the dominant issue was the lack of access to advocacy for parents with learning disabilities. There were several voluntary sector agencies that provide advocacy for people with learning disabilities in Newcastle but only one of these continued to provide advocacy support for parents. The main reason for this was the time consuming nature of advocacy for parents who mostly needed advocacy to support them with Child Protection Proceedings. If support was given by advocates then this used so much of their time that they were unable to provide an equal service to other people who needed support. One of the reasons for this was because of general funding shortages and cuts that meant that there were less advocates employed.

Perspectives of the community family support services

There is one predominant issue from the perspective of community family support services that have the view that the family is the best place to bring up children, if they are safe and free from harm. This is the need to reshape existing family support services to be able to provide longer term support, likely to fluctuate over time, which will be able to respond to the changing needs of the child. Such a service thus needs to be made up of support workers that understand child development and the corresponding family needs. A service must also go beyond practical responses, such as keeping babies warm, clean and fed, and incorporate nurturing and emotional support which can be modelled and therefore 'taught'. Similarly, when the child starts to assert the self and

exhibits more challenging behaviour, this is something which can also be managed through modelling behaviour in a similar way.

The implication of such issues for a family support service is to create a service that can follow the family as it develops using a key worker or support worker type approach, sometimes providing intensive support, sometimes providing very limited support. Currently however, family support services are not configured to provide such a service and this may have implications for the Council's Families at Risk Intensive Support Service (FRISS).

Conclusion and recommendations

It was apparent from this research that there is clear willingness and intention from across the local authority, health authority and voluntary sector, to develop policy and services in Newcastle. There have already been efforts in the recent past to create a strategic location for the workstream but unfortunately they have stalled. It is hoped that, using this report as impetus, efforts can be revived and realised.

We think that the benefits to both services and families are clear: a more equal and accessible range of services; more effective and skilled services; cost savings and keeping families together. With these issues in mind, we provide a number of recommendations to consider, which include:

1. **The creation of a policy 'home'**: the first recommendation we make is the need to create a policy home to locate the workstream – a place where issues are discussed in a multi-agency context with the local authority as the lead agency. As the following summary for parents states, someone needs to take charge of the work. One of the main weaknesses in this workstream has been that there has not been one single forum or mechanism which has representation from Adult and Children's Services, health and the voluntary sector, whose responsibility it is to make decisions about parents with learning disabilities. To this end, we would like to pose the question, is the best place for such a home the Think Family Commissioning Partnership or would it be elsewhere? The objectives of such a group would need to include the creation of a lead strategic responsibility and also it would need to create an operational group to coordinate services.
2. **Better estimates of numbers**: the second recommendation is to attempt to more accurately estimate numbers of parents, particularly those with a service need and there are a series of actions associated with this. Simply put, we do not know how many parents with learning disabilities there are in Newcastle – and we need to know. There are a number of ways in which this could be done. As a first step, we suggest carrying out a survey of all Health Visitors and questioning them about their caseloads and how many parents with learning disabilities they have on their books. It may make sense that this request comes jointly from Adult and Children's Services and the health

authorities. Although this would not provide definitive answers, it would at least provide an idea about numbers of parents with learning disabilities with children under five with a service need. Similarly, a survey could be sent out to community based organisations such as the Family Intervention Programme, Social Work area teams, Children North East etc, asking them how many parents with learning disabilities they work with who have children over five.

3. **Estimate costs:** our third suggestion is to undertake an estimation of Looked After Children costs associated with children of parents where there is a learning disability. We think that looking after the children of parents with learning disabilities has significant cost implications to the Local Authority. In the main body of the report we attempt to provide an illustration of how much it costs. We also think that if support services are put in place and are accessed by parents then less children will need to be looked after and so cost savings will be made. We think that if the Local Authority can estimate currently how much looking after children of parents with a learning disability costs then service development decisions will be made more straightforward. In the event of service development (see next recommendation), this would also provide a baseline of information that can be used to monitor impact.
4. **Service development:** our fourth suggestion is to look into service development and reshaping to make services better at providing support for parents with learning disabilities. We think this can be done through the following:
 - **Reshaping existing family support services:** we think that this relates primarily to Children's Services, their parenting services and FRISS and also to commissioned family services. We have mentioned here about the need to both skill up professionals in existing services and also for a longer term family support service, which is responsive to the needs of parents, sometimes with intensive support, sometimes with little support and a 'watching brief'. The emphasis here would be on early intervention and on specifically designed interventions, such as parenting programmes. It may be that such services could be developed from existing family intervention programmes and other community services. Within such a service we think that it is important to have an emphasis on continuity and coordination of services. We think that there is significant potential to develop this continuity and coordination based on learning from how existing services for families with complex needs are coordinated, such as the Team Around the Family approach. There may also be an existing structure to be able to do this, via the Think Family Commissioning Partnership. There are significant cost saving advantages to departmental budgets in reduction in looked after children costs, thus there should be demonstrable annual cost savings.

- **Improving intra agency cooperation:** again there is much scope for improvement in the coordination and cooperation of agencies who currently deliver services to parents with learning disabilities. For example, coordination could be improved if there is more clarity of purpose and a demonstrable willingness to engage. For example: the Clinical Psychologists at CTLD could provide IQ assessments for the parents with learning disabilities who have a service need; Adult Social Care could improve how they cooperate with other community services (both reshaped and existing family support services) and put in place processes to make this easy; Children's Social Care also have the potential to become more supportive in their approach and could cooperate better with Adult Services, providing support to the parent and child. All these three agencies would have much to gain in a constructive and coordinated dialogue about the support needs of families, which could be complemented by an effective family support service.
5. **Improve advocacy facilities:** our last recommendation concerns the need for advocacy services for all parents with learning disabilities who are involved with Child Protection Proceedings, including at Case Conferences and at the courts. Currently there is almost no advocacy available to parents who are involved with Child Protection Proceedings. Without advocacy, people with learning disabilities do not understand the processes which are acting upon them and their children, which is ultimately a Human Rights issue. This will be a challenge in the current climate of austerity although there may be options in up-skilling the Citizens Advocacy Service, or leveraging in charitable funding. It is expected however, that the more effective community based services are for parents, the less people will need advocacy. We also think there could be several zero cost quick wins in improving parents' understanding of the Child Protection process and at court, including ensuring all reports are submitted five days in advance of meetings, properly explaining proceedings, reintroducing court protocols already developed and having court hearings in Newcastle.

ii Summary for parents

We were asked to find out what it is like for parents with learning disabilities in Newcastle – what is easy for them, what is difficult for them and what would make life better for them and their children.

The Council wanted us to do this and so did the health service. A charity called Northern Rock Foundation gave us money to do the work.

We looked at what types of things were there for parents with learning disabilities if they need help. We also tried to find out what things were not there which people needed.

We looked at what happens at Child Protection meetings and what it was like for parents at meetings. We looked at what people could understand and what was confusing for them. We looked at what help they needed.

We also talked to lots of workers and asked them what they thought about things for parents with learning disabilities. We asked them what they thought the biggest problems were and what they thought would make things better for parents.

After we had found out what was there and what was not there and what life was like for parents and what workers thought, we made suggestions to make things better.

Our first suggestion is that there needs to be some people in the Council and the health service to take charge of things for parents. At the moment no one is in charge so people cannot make decisions together and make things better.

Our second suggestion is that people need to count the number of parents with learning disabilities in Newcastle. At the moment no-one knows how many parents there are, so people don't know how much they need to do - a little or a lot.

Our third suggestion is for the Council to work out how much money it costs them to look after the children of parents with learning disabilities. At the moment lots of children of parents with learning disabilities are taken into care. We think that if people help you more with being a parent, not as many children will be taken into care. If the Council works out how much it costs them to look after children, it will show them how much money they can save if they help parents more.

Our fourth suggestion is for the Council and the health service to see if they can make the help they give to parents better. We think that they can make the help

they give to parents better. This will help parents look after their children better so they can become better parents and have happier and healthier children.

Our last suggestion is to make advocacy (this means having someone to help you understand and speak at meetings) better for parents at Child Protection meetings and at the Courts. This is more difficult as someone will have to pay for more advocates.

Who did the work? Barefoot Research and Evaluation is the name of a research organisation in Newcastle. We do lots of work about people who are often ignored or who are not as strong as other people. We are independent.

Who paid us to do the work? Northern Rock Foundation in Newcastle is a charity and funds different types of things to make life better for people.

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Acronyms used in this report

Acronym	Description
CSC	Children's Social Care
CTLD	Community Team Learning Disabilities
FIP	Family Intervention Project
FRISS	Families at Risk Intensive Support Service
JSNA	Joint Strategic Needs Assessment
NEPSS	North East Parents' Support Service
NHS NTW	Northumberland, Tyne and Wear NHS Foundation Trust
SALT	Speech and Language Therapist
VPSS	Valuing Parents Support Service

1.0 Introduction

Northern Rock Foundation, under its Enabling Independence and Choice Programme, commissioned Barefoot Research and Evaluation to undertake research in Newcastle into existing service provision for parents with learning disabilities. Permissions to carry out the study in Newcastle were provided by both Adult and Children's Services within the Local Authority.

Both directorates agreed that Newcastle would be the detailed case study of what is intended to eventually be a regional study looking at provision for parents with learning disabilities. Accordingly, those directorates deserve credit for allowing access to their services and opening themselves up to external scrutiny. The findings therefore in this report pertain to Newcastle only. It is suspected that many issues will be similar across the region.

The objectives of the research were to:

- Examine current statutory and voluntary sector provision
- Investigate need and scale of need
- Identify models of best practice within the local authority
- Identify gaps in provision and provide recommendations for the creation of a local policy framework
- Support the development of services for parents with learning disabilities in Newcastle.

A more general objective was to raise awareness of the issues faced by parents with learning disabilities across statutory (local authority and health) and voluntary sector services in Newcastle.

It is important to note that this study focuses on adults, their experiences and the experiences of professionals working with those adults and their families. It does not look at the outcomes of the children of parents with learning disabilities, either those who stay with their parents or those who have been looked after.

1.1 Methodology

The methodology used for this research consisted of: interviews with professionals who had any level of contact or role to play in the provision of services to parents with learning disabilities; interviews with parents with learning disabilities; and a review of secondary information and national research.

In total, we interviewed a total of 24 professionals from a range of services across Newcastle (there were two professionals interviewed from Gateshead although this did relate to their experience in Newcastle where they had

previously worked). The services and their representatives are presented in appendix one. The semi-structured interviews were structured around a set of questions (see appendix two), which were loosely based upon the 2007 Department of Health good practice guidelinesⁱ.

We also carried out a small number of interviews with parents themselves and held one focus group at a parent support group at Skills for People in Newcastle.

We recorded the data through taking transcripts of interviews which was then thematically analysed

Narrative data were analysed using the grounded theory constant comparison method, where each item is compared with the rest of the data to establish and refine analytical categoriesⁱⁱ. Themes emerged within individual interviews and across different interviews. Recurring themes across transcripts were taken to reflect shared understandings of the participants and the report is structured according to these recurring themes. As with any qualitative social research methodology which uses an analysis of narrative, we are using opinion to generate data; both professional opinion and client group opinion (i.e. parents with learning disabilities). The results presented in this report is therefore such; the professional and personal opinion of those interviewed.

Finally, we undertook secondary research and carried out an examination of the literature (i.e. project reports, evaluations and published and unpublished research, including re-examinations of primary data). A list of references can be found at the end of this report.

Note: Endnotes are presented on the last page of the document and contain the references. Footnotes are used to add detail or notes to the main text.

2.0 Context and background

There is a wealth of research, policy and practice literature about parents with learning disabilities (see reference list) and it is not our intention to summarise or re-cover the content of that body of knowledge; it is voluminous and others have done it in much greater detail than we can here. There is also much good guidance from organisations ranging from the Department of Health to the Norah Fry Research Centre at the University of Bristol.

However, what we would like to say is that there is ample evidence and public policy guidance which indicates that, with the right support parents with learning disabilities can be good parents. For example, the work by McGawⁱⁱⁱ and Tarleton^{iv} show what type of support is required and the Government's 2001 Valuing People Strategy explicitly states that people with learning disabilities 'can be good parents'^v. Also, there is current good practice evidence, which include a service run by the charity Family Action in Leicester^{vi} and the Valuing Parents Support Service, based in Kent (see box 6.2).

What we found valuable in carrying out this study was to try and understand the situations of parents with learning disabilities and what life was like for them. From a non-learning disabled parent's perspective, this was obviously difficult to achieve. We were pointed in the direction of the Clinical Psychologist Sue McGaw's work and also to the substantial body of work done by Booth and Booth from the University of Sheffield. This national and detailed research proved very useful and it was also complemented by local viewpoints. For example, like the work of a local Speech and Language Therapist Caroline Wills who points out such issues as 'many parents need encouragement to talk to or look at their baby while feeding them and I have often needed to stress the importance of nursery rhymes and play but this is not unique to parents with learning disabilities'^{vii}.

All of this material helped us to understand the situations of people with learning disabilities as parents and their disadvantage. Briefly, we find that educational disadvantage occurs in three main ways in relation to how people learn about parenting: direct experience; observation; and reading^{viii}; all of which may be missed by people with learning disabilities. But disadvantage is not only caused by people lacking the skills to be parents. There are a range of situations which lead to people with learning disabilities being judged to be unfit parents and ultimately having their children removed. For example, Booth and Booth^{ix} categorised parents with learning disabilities into the following groups:

1. Parents whose only child was taken away at birth or very soon after and placed for adoption or put into permanent care: parents were judged simply unfit to be parents.
2. Parents whose first child was removed but who have successfully raised subsequent children: these parents were not given the opportunity to

demonstrate their parenting capabilities and this was based more on prejudices than on the behaviour of parents.

3. Parents who received no help or support with the problems that eventually led to the removal of their children: one reason for this was a misconception that as parents with learning disabilities, they learn more slowly and need more reinforcement, they cannot learn at all.
4. Parents who were compromised in their caretaking role by competence-inhibiting¹ support: this is support based on the assumption that the parent is incapable of managing on their own and intervention is necessary for the child's sake – it is unresponsive to parents' needs, denies them the opportunity of overcoming problems on their own, undermines their self worth and provides little motivation for them to improve their parenting skills.
5. Parents who lost their child(ren) because of the behaviour of a partner without learning disabilities or with additional problems: in these cases children were put at risk by factors such as mental health problems, alcohol or substance misuse, violence or sexual offences.
6. Parents whose children present management problems of a severity that would tax the coping abilities of any family: for example, behavioural problems, criminal behaviour and other special needs.
7. Parents whose children were removed as a precaution in anticipation of problems arising in the future: for example, because previous children were removed and in spite of no current issues, further children were removed 'just in case'.

The cumulated work of Booth and Booth point towards the similarities between people with learning disabilities being denied the right to bring up their own children and other categories of people, whose behaviour is judged detrimental to the well-being of their children, such as people with substance misuse issues or those with mental health problems^x.

They conclude that:

People with learning [disabilities] are doubly disadvantaged in providing good-enough parenting by the legacy of discrimination that, among other things, denies them any preparation for parenthood (Marsden, 1979). Parental rights should only be terminated after determined efforts have been made to remedy the parents' problems and these efforts have failed (Gilhool and Gran, 1985)^{xi}.

Again, for the purposes of context and background, we present the following table, which shows the key features of good and bad practice relating to services for parents with learning disabilities.

¹ A distinction has been made between 'competence-inhibiting' and 'competence-promoting' support where the latter is understood to allow parents to be in control whilst at the same time developing their caretaking skills (Booth and Booth, 1994a).

Table 1.1 Key features of good and bad practice for parents with learning disabilities

Good practice	Bad practice
<ul style="list-style-type: none"> • Workers with a genuine liking or feeling for the families concerned, who understand their point of view, are not seen as interfering and respect them as people • Practical support that is sustained over the longer term and directed towards teaching, maintaining or reinforcing parents' own skills • Recognition of the emotional needs of parents • The mobilisation of community supports including extended family • Close integration of formal services and informal support networks • Independent advice or advocacy especially where the worker is unable to represent the interests of both the parent and the child. 	<ul style="list-style-type: none"> • Inconsistency of treatment between different families or by different practitioners working with the same family • Lack of continuity in service delivery and a high turnover of support workers • Poor coordination and collaboration between different agencies and different workers • Failing to notice problems before a crisis erupts • Usurping parents' authority in their own home • Treating the parents as less than fully adult • Failing to involve parents in decisions affecting their lives or to respond to parents' concerns • Using parents' fears of losing their child to secure their acquiescence • Judging parents by inappropriate standards and values • Seeing parents and children as individuals and diminishing the importance of their relationships

Source: After Booth and Booth, 1994a.

It may be useful to conclude this section by mentioning that since the publication of the Department of Health's 2001 Valuing People White Paper and its follow up, Valuing People Now in 2009, parents with learning disabilities now have a higher profile compared to previous policy documents. However, these were initiatives of the previous Labour Government and perhaps the most relevant policy stream of the Coalition Government is that of the Department of Communities and Local Government's Families with Complex and Multiple Problems initiative.

2.1 Definitions

There is much discussion about definitions of learning disability^{xii} and again the purpose of this research is not to reiterate this debate. Indeed, Newcastle's Joint

Strategic Needs Assessment, which is carried out by the Local Authority and the Primary Care Trust, recognises that there is no single accepted definition of learning disability. The Valuing People White Paper, which is the 'industry standard' definition, is reported to be that which is followed in Newcastle. This is:

'Learning disability includes the presence of: a significantly 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, with a lasting effect on development'^{xiii}.

However, for the purposes of this report and primarily to remove any confusion between the terms 'difficulty'² and 'disability', we are using the medical definition which relates to any individual with an IQ under 70 (an average IQ is around 100)³. Learning disability is diagnosed through an IQ test, which determines IQ scores regardless of educational background. The test is carried out by a Clinical Psychologist.

Thus, all the references and discussion in this report relates to a parent with an IQ under 70 who is therefore agreed to have a **learning disability**.

2.2 The problems with diagnosis

We do not know how many people in Newcastle are diagnosed as having a learning disability. This is because an absence of a central database; information is held by a number of different agencies, such as GPs, Social Work teams, schools. There is also the issue of diagnosis: many people with learning disabilities go through life without being diagnosed.

The reasons for this often start at school, where a child will not be tested unless there is a specific need or requirement, such as a need to attend a school for Special Educational Needs. Otherwise children may commonly be referred to as 'slow learners' or having learning difficulties but they are unlikely to be IQ tested. As an adult, there is no reason to test someone unless they have a specific health need, or problem, or are unable to work and are denied disability allowances. And if there are no reasons to be diagnosed as having a learning disability then the individual 'just carries on'.

If that person then had a child and was struggling to care for the baby there would also be no reason for that person to be diagnosed as having a learning

² The term learning difficulty relates to someone having special educational needs, such as dyslexia or difficulties in one particular area.

³ The World Health Organisation defines learning disabilities as 'a state of arrested or incomplete development of mind'; an individual with a learning disability is said to have 'significant impairment of intellectual functioning' and 'significant impairment of adaptive/social functioning' (British Institute of Learning Disabilities, 2004).

disability. Again however, if there was an identified health issue or problem, a clinical psychologist from Northumberland, Tyne and Wear NHS Foundation Trust (NHS NTW) would carry out the test. Note: such tests are provided for people with learning disabilities generally and not just for parents with learning disabilities.

Parents with learning disabilities would be identified generally by a health professional and judged as being unable to cope/in need of support and a referral to Social Services would be made. Up to 2009, Social Services have requested a test from NHS NTW, which had been provided. A screening tool (called Strap-LD - Screening Tool Relating to the Assessment of Parents with suspected Learning Difficulties) was developed in 2007 to be used by professionals outside of CTLD as NHS NTW was receiving too many inappropriate referrals. The referrals subsequently went down.

NHS NTW stopped carrying out assessments in 2010 as they felt they were acting as gatekeeper between Social Services and its service users. It was also felt that assessments should be carried out because of a health need opposed to a social care need, as they were being provided by NHS NTW not the Local Authority. If there is no underlying health need and if Children's Social Care wish to have an IQ test carried out, they must privately purchase that service (the only assessment that currently exists in terms of a statutory assessments is the parenting assessment, see later, that is carried out by the Community Team Learning Disabilities – CTLD, which is a service of Northumberland, Tyne and Wear NHS Foundation Trust).

Thus, if you become a parent with learning disabilities you are unlikely to already have a diagnosis. Unless you have a health need, NHS NTW will not carry out a test and Social Services cannot provide one (because they do not employ clinical psychologists). The latter are able to 'spot purchase' tests (thought to be approximately £1500) from private providers in critical cases (such as at Child Protection Conferences), although this is uncommon: one professional knew of only two cases when this had happened in the last two years.

This situation can make the use of the Strap-LD problematic; if the Screening Tool indicates the likelihood of a learning disability, unless Children's Social Care will purchase a test or unless there is a health need, the person's level of disability will remain unknown. CTLD reported receiving five Strap-LDs recently in a week with three strongly indicating a learning disability and it was reported "*in each case the Social Worker asked where do I go from here?*".

Therefore, the Local Authority will not know how many parents with learning disabilities it has unless it tests each parent with suspected learning disabilities (which some local authorities are reported to do by employing their own Clinical Psychologist). We have attempted to estimate numbers in Newcastle, which is

presented in the following section. This issue is also covered in the recommendations (page 56).

2.3 Numbers

The estimation of the number of parents with learning disabilities in Newcastle has been a key factor for a number of agencies. If services do not know numbers then it is difficult for them to make plans for services. Estimation of numbers essentially determines need and thus scale of provision and ultimately has a bearing on costs and budgets. Unknown numbers has been used almost as a justification for inaction; for example, one Local Authority representative said that there are so few parents with learning disabilities that there are “*no strategic conversations*”. Within this issue lies not just the numbers of parents with learning disabilities but also the numbers of parents with learning disabilities who both need support and who qualify support under the Fair Access to Care Services (FACS).

A key variable in determining numbers is diagnosis – in that we cannot count people who have not been diagnosed. Because of the issues outlined in the section on diagnosis, only a relatively small number of people in Newcastle have been diagnosed as having a learning disability and this obviously translates onto people who become parents (i.e. so only a small number of parents are diagnosed). The 2011 JSNA presents the following table, although we do not know if these adults have received a diagnosis.

Table 2.1 Number of adults with a learning disability who are known to the Local Authority in 2011

Description	Number
Age 18 to 64	848
Age 65+	92
Male	521
Female	419
Total number	940

Source: JSNA, 2011

As a result of this, numbers of parents with learning disabilities remain unknown and currently unknowable^{xiv}. At the time of writing, Adult Social Care’s Specialist Services have only between five and 10 that are known to service and some of these are being worked with. The CTLD work with around 15 parents with learning disabilities at any one time and these may also be in receipt of support from Specialist Services, but equally may not.

In short, the numbers of parents with learning disabilities known to specific services is small. In the light of an absence of data required by statutory services

to determine numbers (i.e. those with a diagnosis), let us turn to other approaches of estimating numbers in a given population.

One method is based upon a detailed examination of the caseloads of Health Visitors (as these will visit almost all babies and their parents in a given local authority area) as was carried out in Sunderland in 1995. This study used a set of criteria^{xv} to judge whether parents had a learning disability. They estimated that 7.3 percent of Health Visitors' caseloads included parents with learning disabilities, which equated to 1564 families with a parent with a learning disability with a child under five. There will, of course, be reasons associated with this high number; perhaps the sample was carried out in an area with a disproportionately high number of parents with learning disabilities and thus when extrapolated it produces skewed figures. English (2000) employed the same methodology in Newcastle and came up with a figure of 1757.

Another method was developed by Mirfin-Veitch *et al* (1999) whose findings produced a prevalence rate of 2.51 families per 1000 families in the general population. If we apply that to Newcastle we get a figure of 77 parents with a learning disability⁴.

Another method of calculating parents with a learning disability was derived from a recent study^{xvi} which arrived at a figure of one in 15 people with learning disabilities will become parents. In relation to how many adults with learning disabilities there are in Newcastle, the JSNA 2011 presents a series of estimates. One of these in addition to the figure in table 2.1 was provided by the CTLD in 2007 which took numbers from General Practitioners' practice lists. This provided a figure of 1525 adults with a learning disability. If we use the above method this produces a number of 101 parents.

However the JSNA provides other estimates of adults with a learning disability which use approaches that have been used across England and Wales (and these take into account people not known to services and also types of learning disability). Using a national method arrives at a figure of 4250 people between 18 and 64 with a mild to moderate learning disability. If we use the one in 15 method on this figure, we arrive at 283 parents with learning disabilities.

Thus, using different models produces very different results; anywhere between 77 to over 1700.

If we look at the experience of community-based services (such as GPs, Health Visitors, family intervention projects, family support agencies, solicitors, etc.), contact with parents with learning disabilities is relatively common. Although, for this piece of research, a comprehensive review was not carried out, there was sufficient evidence gathered from our networks and through the knowledge of other professionals^{xvii}, to indicate that service contact with parents with learning

⁴ Based on a total of 30,815 families in Newcastle (Office of National Statistics: Child Benefit Families, 2010, HM Revenue & Customs).

disabilities is reasonably common. For example, one such agency commented: *“you only have to go to one GP practice and talk to the Health Visitors there and they will have parents with learning disabilities on their books”*. Another example is from Newcastle’s Anti-Social Behaviour Family Intervention Project (FIP) who said that parents with a learning disability formed a *“significant chunk”* of their caseload.

To conclude this section, we can say that community service contact with parents with learning disabilities who have a service need is relatively common. We could also discount the higher estimate of 1757 as it is significantly higher than the three other estimations. This leaves three figures of 77, 101 and 283. We could also say that not all people who have learning disabilities who are parents will have a service need. We leave it to the reader to make their own conclusion about numbers but we think that based on the cumulative evidence in this report, it is reasonable to estimate that there are at least 50 parents with learning disabilities in Newcastle with a service need.

As a comparison, the three Family Intervention Projects in Newcastle (the Anti-Social Behaviour FIP, Changing Trax and the Community FIP) had a combined caseload of 109 families^{xviii} in 2010.

3.0 Expertise and provision in Newcastle

3.1 Existing expertise in Newcastle

There exists considerable expertise in parents with learning disabilities in Newcastle; most of which is held within the CTLD service of Northumberland, Tyne and Wear NHS Foundation Trust. This is demonstrated, by among other things, the number of publications about parents with learning disabilities by professionals working in Newcastle, including:

- Elvish, J., Hames, A., English, S. and Wills, C. 2004. Parents with learning disabilities: an audit of referrals made to a learning disability team, Learning Disability Review
- English, S. 2010. The importance of specialist advocacy services for parents with learning disabilities, Learning Disability Practice
- English, S. 2002. The family way, Learning Disability Practice
- English, S. 2000. Parents in partnership, Learning Disability Practice
- Hames, A. and Noble, C. 2009. Christine Noble's story, British Journal of Learning Disabilities
- Wharton, S., English, S. and Hames, A. 2005. Assessing parenting skills when working with parents with learning disabilities, Learning Disability and Practice
- Wharton, S., English, S. and Hames, A. 2005. Training for parents with learning disabilities, in Primary Health Care
- Wills, C. 1999. Fighting over a toy, RCSLT Bulletin.
- Wills, C. 1999. Learning to be a parent, RCSLT Bulletin

One of the current CTLD Community Nurses was awarded the Nursing Standard Award in 1997 for her work with parents with learning disabilities.

CTLD has also developed a parenting assessment tool and a supporting training manual for professionals (see boxes 3.1 and 3.2), which has been delivered locally and nationally^{xix,xx}. Parenting assessments are carried out by a community nurse and a SALT. The latter looks at issues around the parents' language abilities and their level of interaction with a child^{xxi}. An assessment takes between four and six months. Recommendations are then given to Children's Social Care together with any support requirements. The assessment that the CTLD carry out is one which "*looks at the things that they can do with support*".

Box 3.1 Content of the parenting assessment

The parenting assessment is broken down into the following areas:

- Acknowledgement of problems and cooperation
- Practical skills
- Preparation for baby
- Housekeeping skills
- How safe is your house?
- Establishing routines
- Understanding the process
- Stability
- Diet
- Personal hygiene
- Health care issues
- Budgeting
- Interaction between mother/father and baby/child
- Emotional attachment
- Communicating with other people/professionals
- Decision making
- Timetabling – appointments for self and child
- Play stimulation
- Awareness of child development
- Behavioural management and consistency
- Coping with stress
- Developing networks

The training manual was developed after consultation with a range of key health and social care professionals and is designed to cover the critical areas affecting parents with learning disabilities. It can be delivered by non-specialist professionals in the context of a parenting support group.

Box 3.2 Sessions in the parenting support manual

- | | |
|--|--|
| 1. Introduction and ground rules | 10. Dental hygiene |
| 2. How to play with young children | 11. Health related issues – smoking, alcohol and drugs |
| 3. Healthy eating for young children | 12. Exercise and relaxation |
| 4. Understanding abuse and Child Protection related issues | 13. Safety in the home |
| 5. Communication with children | 14. Fridge and kitchen hygiene |
| 6. When to access medical help | 15. First aid |
| 7. Healthy eating for adults | 16. Sun protection |
| 8. Bullying | 17. Sexual health |
| 9. Helping children to be well behaved | |

There have also been a number of events in Newcastle, attracting national, citywide and neighbourhood interest. For example, in 2003, Newcastle's CTLD organised a well attended national conference entitled, Parents with Learning Disabilities – Evidence Based Practice, with attendance from 110 professionals. There have been more local events such as in 2007, there was a focus group with service managers to attempt to develop services for parents with learning disabilities and in 2011, there was another focus group facilitated by the Parenting Commissioner to look at good practice.

Box 3.3 Good practice in Newcastle: Community Team – Learning Disabilities

Community Team – Learning Disabilities or CTLD is a service of Northumberland, Tyne and Wear NHS Foundation Trust. It is commissioned by Newcastle Primary Care Trust. It is a multi-disciplinary team made up of a Behavioural Assessment and Intervention Team, Community Nurses, Occupational Therapists, Physiotherapists, Psychologists, Psychiatrists, Speech and Language Therapists and Support Workers. They support a range of people with learning disabilities where there is a health need including parents. The team has over 10 years of experience and expertise working with parents with learning disabilities, although certain members of the team have considerably more experience. They have developed specialised parenting programmes, designed bespoke parenting assessments, created targeted training programmes for professionals and have written publications in specialist and popular journals and newsletters to spread that expertise. They have become a centre for local expertise and are commonly the agency that is consulted when there is a problem or a need concerning parents with learning disabilities. Not only do they support individual parents, they have also coordinated services to provide a seamless and effective service for families. In any future development of services, their input will be invaluable.

3.2 Current provision for parents with learning disabilities

There have also been a number of services and initiatives aimed at parents with learning disabilities in the recent past. These have included:

- In 2000, CTLD including Psychologists, SALTs⁵ and Community Nurses ran parenting course over 10 weeks for 10 parents with learning disabilities, which was reported to have been very successful.
- Between 2004 and 2006, CTLD ran a rolling programme of training to other professionals including Midwives, Health Visitors and Family Support Workers across the public and voluntary sectors. The training was one hour a week for three months and was run by the Community Nurse, a SALT and a Consultant Psychologist. A key reason for carrying out the training was CTLD was receiving referrals too late, when the parent was already in crisis. The Community Nurse said “*we were getting referrals from Social Workers when they were already going through Care Proceedings*”. The training had an impact as they started receiving referrals earlier which improved the work they did with parents with learning disabilities. Currently, other professionals receive no training on working with parents with learning disabilities.
- In 2009, CTLD ran a drop-in for parents with learning disabilities at Riverside Library in Benwell. It ran for three months and had two facilitators.

⁵ SALTs play an important role in service delivery to parents with learning disabilities, particularly in providing the basic principles of alternative and augmentative communication⁵ to professionals working with parents with learning disabilities (to be used when teaching practical tasks and advising on parents’ understandings of concepts).

Possibly, the most noteworthy and comprehensive of historic services was the North East Parents' Support Service (NEPSS) implemented by Mencap which ran between 2003 and 2008 with funding from Northern Rock Foundation. Although, this service was initially intended to be a regional family support service, it predominantly provided advocacy services around Child Protection Proceedings in Newcastle. The NEPSS was a highly effective and valued service^{xxii} (also see box 3.4) and resulted in a series of key achievements including the development of guidelines for Child Protection Conferences involving parents with learning disabilities and protocols for family courts. The NEPSS was reported to be "*stretched beyond belief*"^{xxiii} and it was reported to have helped the work carried out by the CTLD ("*it helped us a lot*"). It did this as it removed the advocacy-related element of the CTLD's work, i.e. the support to parents who were in Child Protection Proceedings. It was reported that the service developed a successful protocol for the Crown Family Court. When the service was coming to an end the views of associated professionals were canvassed to attempt to secure succession funding (although these efforts were ultimately unsuccessful).

There are currently the following services available to parents with a learning disability in Newcastle:

- Advocacy services: there are some advocacy services available from voluntary sector organisations such as: Newcastle Council for Voluntary Services and their Citizens Advocacy Service; Skills for People who provide a professional advocacy service and they have a self-advocacy group for parents with learning disabilities; and Families in Care which is the only organisation that offers advocacy to parents with learning disabilities in the Child Protection process. The first two organisations will offer generic advocacy, such as for housing, benefits and debt management issues: Citizens' Advocacy do not provide advocacy for Child Protection as they use lay volunteers who lack the necessary expertise; and Skills for People no longer provide the service for Child Protection (see section 5.2).
- Community Team Learning Disabilities (CTLD)⁶: consists of a Behavioural Assessment and Intervention Team and a range of departments including Clinical Psychology, Community Nursing, Speech and Language Therapy, Psychiatry, Occupational Therapy and Physiotherapy. Their remit is to work with adults and children with learning disabilities who have a health need. CTLD provide a range of services to parents with learning disabilities from formal assessments (e.g. parenting assessment, see box 3.1) to general support and training (see box 3.2). They have an active caseload at any one time of around 15 parents to whom they will provide a range of support services. The Community Nurse will also present reports to the courts at Care

⁶ Newcastle and Sunderland local authorities are the only areas which have Community Teams for people with Learning Disabilities (CTLD) which are services of Northumberland, Tyne and Wear NHS Foundation Trust (NTW).

Proceedings about the parenting ability of the parent based on the Assessment. This report will be presented together with the reports of other professionals, such as Social Workers and Health Visitors. It is widely reported that “*if Sue [English – the Community Nurse] was not here then there would be no service*”^{xxiv}. There are two support workers who are currently supporting two parents attend the parenting courses at Walker Library and St Martins Church. Since the end of the NEPSS and the advocacy services they provided, parents with learning disabilities in Newcastle have required more support from existing services and CTLD in particular has seen a rise in the number of parents they support, particularly those involved in Care Proceedings^{xxv}. This has also added to a longer term pattern where CTLD have seen an increase in referrals since 2003^{xxvi} (although by how much is not known), which could mean a number of things, including: the numbers of parents with learning disabilities are increasing; parents with learning disabilities are increasingly being picked up by services (mostly by tier 3 and 4 services); or there is an increased awareness amongst agencies of parents with learning disabilities.

- Adult Services Learning Disabilities Team: this team currently works with six parents currently who are assessed as having a Substantial or Critical Need. They work approximately two to four hours a week to support the parent as an individual, depending on need. Although there is no limit to the duration of that support, they are conscious about not developing dependency between Social Worker and person with learning disabilities. Therefore they rarely provide support after two years.
- Children’s Social Care (CSC): although a statutory agency with a responsibility to ensure the safety and welfare of children, they do provide a limited family support service, within the Assessment and Monitoring section⁷. Here, Family Support Worker is a generic term which refers professionals doing very different jobs at different levels of need, for example in one locality there are four posts which are only used for time limited pieces of work as part of a Child Protection or Child with Complex Needs Plan, or as part of a plan for reunification. There have been occasions where Assessment and Monitoring have also ‘spot purchased’ support for parents with learning disabilities. In one case, United Response⁸ was commissioned by CSC on the recommendations of CTLD to provide a period of support.
- Children North East’s Families Plus service: Families Plus Integrated Family Support Service uses a mix of paid Family Support Workers and volunteers and is available city-wide. In the West of Newcastle Families Plus is commissioned through Sure Start West Riverside Children’s Centre as part of their targeted family support offer.
- Safe Newcastle’s Anti-Social Behaviour Newcastle Family Intervention Project delivered by Your Homes Newcastle: although not specifically in their

⁷ Children’s Social Care is divided into two basic sections: Initial Response; and Assessment and Monitoring.

⁸ These are a charity who supports people with disabilities.

remit, they provide services to a number of families where the parents and children have learning disabilities, although they are generally not diagnosed. These families can both be victims and perpetrators of anti-social behaviour, in debt, with tenancies under threat as a result of multiple problems.

Box 3.4 Professional reactions to the end of the NEPSS project

A consultation was carried out by CTLD and the Newcastle Learning Disability Partnership Board with a total of 29 professionals that included (Solicitors, n=11, Social Workers, n=8, Barristers, n=3, Social Work Team Managers, n=2, Community Nurse - Learning Disabilities, n=1, Independent Review Officer (Child Protection), n=1, Psychologist, n=1, CAFCASS worker, n=1).

The majority of professionals **used the service frequently**, with a total of 18 professionals scoring a four or five (from a scale of one to five, one being occasionally and five being very frequently).

Most of the professionals **rated the service as excellent** (using a sliding scale of one to 10, one being poor and 10 being excellent) scoring eight or above (25 professionals rated the service as nine or 10). The positive aspects of the service that were reported are shown in figure 1. All professionals said that if the service was withdrawn it would negatively impact upon their clients. When asked how it would negatively impact, responses are shown in figure 2.

Figure 1

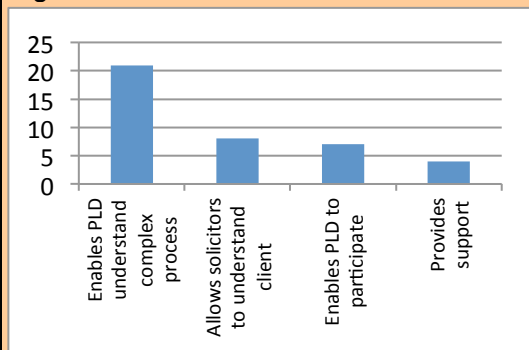
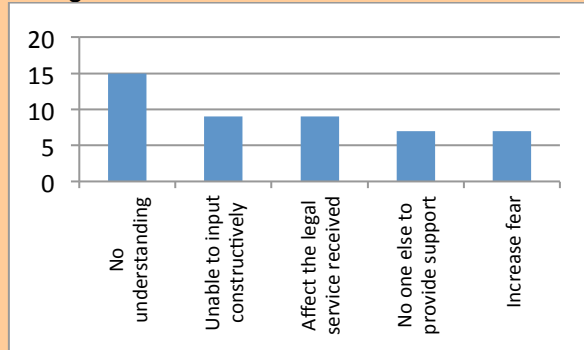


Figure 2



Solicitors' responses presented a particular viewpoint on services for parents with learning disabilities. Two illustrative comments included the following.

“My clients face losing their children through Care Proceedings. The legal process is complex, frightening and confusing. The anxiety and distress of parents is real. Advocates provide an invaluable service to clients (and indeed to solicitors, barristers and judges) making communication effective and ensuring that the client is able to participate effectively in the proceedings”.

“The loss of this service would be disastrous ... it supports the most vulnerable in our society and would leave them without this provision. In my area of work I have no doubt that families would suffer unnecessarily and that the risk of injustice would be very real”.

All professionals consulted wanted the service to continue.

4.0 Parents with learning disabilities

4.1 Who are parents with learning disabilities in Newcastle?

Despite the problems with numbers, there has been significant service contact between parents and community-based agencies and thus we do have a considerable level of knowledge about parents with learning disabilities in Newcastle.

From this research and from existing local research, we know that:

- The majority are single mothers (85 percent in one audit^{xxvii}).
- Parents with learning disabilities experience a number of vulnerabilities and risk factors (one service audit in Newcastle found that approximately 10 percent of total referrals had associations between themselves and Schedule One offenders, almost 40 percent had been abused as a child, 30 percent had been in care)^{xxviii}. Added to this the majority of parents with learning disabilities have been bullied at school^{xxix} and often suffer abuse, hate crime and anti-social behaviour in the communities in which they live.
- Around three quarters of parents with learning disabilities have their children removed^{xxx}. Of those parents with learning disabilities referred into the CTLD between 1994 and 2003, almost 60 percent of their children were on the Child Protection Register, most of them under the category of neglect (70 percent)^{xxxi}. Parents that do not have their children removed tend to have very strong family relationships.
- Most parents with learning disabilities are referred into CTLD's services by Children's Social Workers (53 percent in one audit), followed by Health Visitors (20 percent), then community nurses (11 percent)^{xxxii}.
- Often, when parents present themselves at (any) community services they already have a number of professionals involved, including Police and housing officers, and when it goes to Child Protection Conference then the numbers increase.
- Most parents experience significant isolation both socially and from services. One Advocacy Worker illustrated this by saying: "*Parents with a learning disability are usually so isolated, they've had loads of doors shut in their faces ... by the time they come to us, they're really at the end ...*".
- Many parents are unhappy with the label as having a learning disability and some people do not want a diagnosis. For example, during the fieldwork for this study, one Senior Support Worker from an advocacy service gave an example of a female with an IQ of 65 that was supported during a Child Protection Conference. This parent attended a state school and was reported to say of the agencies at the Conference, "*they think I'm mental*".
- Many parents with learning disabilities think they are good parents and therefore find it difficult to both comprehend why they are the subject of Child

Protection Proceedings and understand the nature of the concerns of authorities.

4.2 The experience of parents

We also know about the experiences of parents with learning disabilities in Newcastle, not only from current qualitative research, but also from current self-advocacy groups and the experience of community-based agencies who work with parents with learning disabilities. All of these issues presented here are similar to the experiences of parents with learning disabilities across the country as is presented in the research literature, for example, Booth and Booth, 1994.

4.2.1 Contact with services

The following issues were raised by parents with learning disabilities in Newcastle:

- **Dissatisfaction with service contact:** many parents were generally unhappy about their contact with statutory services in Newcastle, particularly relating to 'Social Services' (parents did not define which elements of Social Services they were dissatisfied with). These related to a number of areas including punctuality, communication and approach. Comments from parents included:

"They don't do their job".

"They turn up when they feel like, and don't explain things".

"My Social Worker doesn't come when she says she will, doesn't turn up and sometimes I don't see her for ages ... she doesn't come out very often".

"They need to come out more".

"They should have a better attitude".

"They came into the house and they weren't nice".

- **Unfulfilled support requirements:** parents reported that they wanted support but none was given. Other parents who received support both provided by Social Services' Family Support Workers and United Response spoke highly of the assistance. For example, comments included:

"I get help once a week for four hours week ... I'd be really bad off if I didn't have my support worker".

"My support worker's lovely".

“I’ve asked for a support worker but they’ve said there’s no funding”.

- **A condescending and patronising approach:** parents reported that their contact with statutory services was characterised by professionals talking down to and treating people with little respect. Comments included:

“They criticise you and make you feel like you’re stupid”.

“They judge you because you have a learning disability”.

“They think you’re incapable of learning”.

- **Contact characterised by the experience of fear and suspicion:** parents reported that much of the contact with statutory services was characterised by fear and they were worried about the things they say. For example:

“I’m frightened of saying or doing anything wrong”.

“You have to watch what you say and do with Health Visitors”.

Additional fear is also created as parents often do not understand what is expected of them and this is often exhibited through aggression.

- **Poor and inappropriate communication:** parents reported that they did not understand what professionals were trying to say to them. They said that information was presented to them in formats that they did not understand or was not explained adequately. For example, parents made the following comments:

“They make rotas that I can’t follow”.

“They write things down but I can’t read so I have to have pictures ... the only thing I know is pictures”.

“They say things to you then they write it down in a big report that I can’t understand”.

- **Untimely support:** there were reports from parents that even when support was offered, it was either not when it was promised or too late. For example, one parent said:

“When they do say they’ll help you, they don’t do it in time, they promise things and they take a long time, like help and support when you need it, then it’s too late. And this makes the kids struggle because of that”.

“They don’t put things in place on time”.

4.2.2 Support needs

Parents in Newcastle were asked what things were difficult for them and what support needs they have. There were a range of responses, some which were common for all parents, such as choosing the right school, and others which were more specific to parents with learning disabilities.

- **Overcoming isolation:** a recurring theme both from parents in Newcastle and in the research literature was isolation relating to them and their children. Parents with experience of a support worker said that this was a key function of a worker; helping them and their children to go out. For example, comments included:

“Going out on my own ... it’s really difficult, I need my mam to go out with me, if she doesn’t come then I can’t go out”.

“I feel like I’m trapped in my own home ... I’ve got no life”.

“The kids need to go out”.

- **Advocacy:** the need for such a service came up several times during conversations with parents. Particularly those who had experience of Child Protection Proceedings. For example, one parent said:

“I’ve got no advocate and I need one for court”.

“It would help to have someone like a support worker or advocate by your side through the [Child Protection] process”.

“I wouldn’t be able to get a house without support ... you need people behind you”.

- **Parenting support:** there were a series of reports from parents with learning disabilities in Newcastle about the need for specific support around parenting issues. Comments included:

“You need support for parents with learning disabilities to raise their kids”.

“Need more help with parenting skills”.

“Some groups don’t work for parents with learning disabilities ... you need more groups where parents with learning disabilities feel comfortable to learn”.

“Need more information about what you go through when you’re pregnant ... and knowing what your rights are”.

- **General help and support:** this ranged from routine issues with universal relevance to more specific problems including keeping the family together. Comments included:

“Things like finding the right school, what happens if [name of child] is poorly, things to do with the kids”.

“If I don’t get help then [name of son] will go into care ...the kids need their mam”.

“It’s hard to get information about what’s on for kids”.

“I need clear information and [telephone] numbers where to go for help”.

“It would be good to know why you get support and why you don’t”.

4.2.3 Why universal services are not currently meeting needs

As was alluded to in the previous section, parents with learning disabilities do not generally access universal services. For example, one professional from a support service said *“Few of the parents I work with access generic services such as Sure Start or Children’s Centres, despite much encouragement from a number of sources”^{xxxiii}*.

There are several reasons why parents do not attend such services in Newcastle including:

- A lack of knowledge and awareness of community services: parents are reported by professionals to simply not know what provision is available for parents or children.
- An inability to understand the content of parenting and children’s services: for example, ‘information is too hard to understand, or they [parents with learning disabilities] do not feel able to attend with people they do not know, or other parents make negative and derogatory comments about them’^{xxxiv}.
- Attitudes (either real or imagined) of professionals and peers.

Existing universal services are generally reported by both professionals and parents to be inappropriate for their needs. For example, in relation to parenting programmes, ‘they may not be able to read the letters [of invitation, etc.] or organise themselves in order to attend, they may feel uncomfortable in a workshop format ..., they may have difficulty analysing their own behaviour and making changes and they may not understand or retain information given’^{xxxv}.

Also, most parents with learning disabilities find it difficult or impossible to attend mainstream pre- and post-natal groups^{xxxvi}. As a result of non-attendance at

ante-natal classes, they do not get identified as having additional needs early in their pregnancy.

One professional had this to say about the need for specifically tailored services: *“Parents with learning disabilities have generally had a rubbish childhood and we are trying to change that for their children – and we are trying to provide appropriate and adequate services – so we are not providing generic services but rather those that are specifically tailored towards people with learning disabilities^{xxxvii}”*.

There is also scant feedback on services from parents with learning disabilities which makes it difficult for services to adapt. One of the reasons for this (although there will be others such as a lack of means) was reported by one professional as, *“People don’t like to complain because they think things will get worse if they do^{xxxviii}”*.

In summary, one professional from the Primary Care Trust reported *“services that say they are inclusive aren’t, unless they make themselves inclusive to people with learning disabilities ... they have to do specific things to do that ... otherwise no matter how inclusive they say they are ... they are not”*.

5.0 Child Protection, advocacy and legal issues

5.1 Child Protection and the importance of advocacy

We feel it is important to include a specific section in this report which focuses on issues of advocacy in and around the Child Protection process. Clearly, it is highly charged area because of the subject (i.e. the removal of children from parents where there is felt to be risk of significant harm), the client group and the issues that they experience which predominantly relate to an inability to understand the current situation (i.e. why they are there in the first place) and ongoing proceedings.

As was previously mentioned a high proportion⁹ of parents with learning disabilities find themselves involved with the Child Protection process and a significant proportion of these will have their children removed permanently either into foster care or through adoption. There will be others whose children enter into partial and semi-permanent care, either voluntarily or through Court Orders.

Parents whose children are identified as being at-risk^{xxxix} (ultimately via Children's Social Care Social Workers) become the subject of Child Protection Conferences (often referred to as Case Conferences). At these Conferences, a number of professionals from a range of organisations (for example, Children's Social Care Social Workers, family support agencies such as Children North East or Family Intervention Projects, Community Nurses, Health Visitors, etc.) monitor and report on the family situation; parents also attend these meetings. Child Protection Conferences generally take place every six months. They are sometimes brought forward if there are concerns or if an assessment is due. There is a Core Group formed from the Conference and they meet every four weeks to monitor the family situation. Alternatively if the Conference decides a Child in Need plan is required (opposed to a Child Protection Plan), a Care Team is formed and they meet every six weeks.

If action plans are not followed and if the professionals and specifically Children's Social Care are not satisfied that the child(ren) are no longer at risk, then formal Child Protection Care Proceedings will be initiated. This can either be voluntary or through an enforced court-led process (carried out by dedicated Family Courts), either way both involve a complex legal process. The courts and ultimately the judge will then decide on what is in the best interests of the child(ren).

Both processes (the Case Conferences and the court/legal process) can be protracted and may occur over periods of up to 12 months.

⁹ As was discussed in section 2.3, it is very difficult to identify definitive numbers of parents with learning disabilities including those involved in the Child Protection Process. Thus we are unable to give numbers here.

Parents with learning disabilities suffer disproportionately (compared to other non-learning disabled parents) during these proceedings for a number of reasons, most of which revolve around their capacity to understand a complex set of processes. In the following bullets, we have attempted to illustrate the level and nature of their disadvantage.

- **The high number of involved professionals increases fear and miscomprehension and is intimidating:** there can be as many as 20 professionals involved in Child Protection Proceedings, representing different organisations, with different viewpoints and agendas, presenting 20 reports. One advocacy organisation reported that when parents approach them for support, they will already have a number of professionals involved with them and when their cases go to Child Protection Conference then the numbers increase. They commented *“it is so intimidating and confusing for them to have so many people scrutinising them”*. It was also identified that Proceedings are dominated by Children’s Social Care in format, atmosphere and agenda. One Advocate reported *“they’re [Child Protection Proceedings] loaded in favour of Children’s Social Care ... even the Independent Chairs are all generally ex-Social Workers”*. They continued, *“it’s very difficult to change the agenda from one of the removal of the child”*.
- **The information that is presented at Case Conferences, Child Protection Proceedings and at the courts is very complex** and without advocacy support cannot really be understood by people with learning disabilities. Not only is the information complex but also the way it is presented can often lead to misinterpretation. There were many reports from professionals about the difficulty of understanding information and the complexity of the presentation of information. These ranged from reports which should be presented five days before Conference but were often not, the complexity of language used verbally, in reports and Proceedings and information and evidence presented when in court. For example, one family support initiative commented, *“Even the material in the Child Protection Plans is unsuitable for parents with learning disabilities ... for example, it says ‘the parent must acknowledge that ... and the parent must acknowledge that ...’ so we can say that the conditions of the plan have been met because we’ve asked mum and she has acknowledged it, but she doesn’t understand ... so when it comes to it, it seems like the parent has broken all of the things that she acknowledged and agreed to, so removing the child is easy”*. It was pointed out that information was often presented as ‘Do you understand’ as opposed to ‘What do you understand’. It was also highlighted that the NEPSS did introduce protocols which were agreed by the Local Authority and by the Family Courts and were to be used (such as the submission of reports five days in advance and the use of frequent breaks and a ‘translating’ service permitted in court). However, these protocols are often not followed. As one advocacy service commented, *“the process is complicated and inconsistent”*.

- **Inappropriate timing for court hearings:** there were reports from advocacy services about a number of issues concerning the locations and timings of court hearings. For example, court cases being rearranged at the last minute and being re-located to outside of Newcastle including courts in Gateshead or even Middlesbrough. Without support parents with learning disabilities would not be able to attend these and be party to the decision which would ultimately result in the removal of their children. Also there were reports where court cases were heard on a Friday afternoon where children would be removed and the parent would face a weekend alone.

In short, as one community agency report, “*the Child Protection process is not fair [to parents with learning disabilities]*”^{xli}.

5.2 Who supports parents through these processes?

Currently, in Newcastle there is effectively no advocacy service for parents with learning disabilities who are involved with Child Protection Proceedings (with the exception of Families in Care who support a handful of parents with a resource of one full time and two part time Advocate/Support Workers). Up until recently, there were one or two other voluntary sector organisations who would also provide support but they were forced to withdraw the offer of support as it was proving too time consuming and using up all their small human resource capacity. As one advocacy service reported “*Our biggest time consuming issue is child protection cases [sic] where a child is being removed from parents who have a learning disability*”.

The reasons for this was that as one advocacy service illustrated “*it takes up so much time supporting parents through Child Protection proceedings ... a minimum of four times as long dealing with a parent with learning disabilities Child Protection case than with a routine case [i.e. dealing with the advocacy needs of an adult with learning disabilities]*. Another advocacy service reported, “*you’ve got all the reports to go through, the meetings, Case Conferences ... the final Child Protection meeting can take one whole week ... if a child is granted an Interim Care Order, you have to go to court every 28 days*”.

It is also not uncommon for advocacy services to provide support to people with learning disabilities over a long time period as issues in their lives, often stemming from the Child Protection Process, evolve. For example, one service reported that they have been working with one mother for three years who has had three children removed, mostly supporting her at Child Protection Conferences. Now they are supporting her on housing issues as she has been evicted from her three bedroom house as she is now a single person and has had her Child Tax Credits and Child Benefit stopped, is in rent arrears and has debt problems.

Thus the main advocacy services for people with learning disabilities in Newcastle have withdrawn from providing support for parents with learning disabilities involved with Child Protection. As one service commented, "*if we didn't we would be able to help people with what is our high volume work which is housing, rent arrears and anti-social behaviour*".

The alternatives to advocates (and the preference is for specialist advocates who have experience of the Child Protection process as was with the case with the NEPSS project, opposed to generic advocates who lack the necessary skills and expertise) is solicitors or support workers, such as the Community Nurse or Family Support Workers. However, the latter two cannot compromise their position as professionals providing evidence, so their ability to advocate is limited to simply attempting to ensure that the individual understands what is being communicated.

The role of solicitors varies and is dealt with in the following section on the legal process. Briefly however, the input of the solicitor depends on the Solicitor's Practice and their procedures and the commitment of the individual Solicitor (whether they are sympathetic and go 'above and beyond' their professional duty). In some cases Solicitors will accompany parents to some Case Conferences and Child Protection Proceedings, in other cases not. They will however always be present at court but not necessarily spend time with their clients after or before court explaining things. In other words, support from Solicitors is piecemeal and *ad hoc* and largely dependent on the luck of being allocated a good and sympathetic Solicitor.

In 2008, Newcastle City Council published an Advocacy Strategy, within which one of the identified gaps was advocacy for parents with learning disabilities. However, advocacy for parents with learning disabilities involved in Child Protection Proceedings is effectively non-existent. As one advocacy service put it, "*The advocacy need at Child Protection proceedings is paramount – but no-one is providing the support in Newcastle ... not Skills for People, nor Citizen Advocacy [a project of Newcastle Council for Voluntary Services], not no-one*".

The following boxes present the contrasting experiences of a parent who did have support from an advocate and the experiences of someone who did not.

Box 5.1 The experience of a parent who did not have an advocate

The following is an excerpt from a letter from a parent in Newcastle to a Social Work Team Manager about her experiences of a Child Protection Process. She did not have access to an advocate.

“I was devastated, packing the bag and thinking my child was gone forever. I did not understand what was happening and why my child was being taken away. I had to sign forms and I did not understand what I was signing.

I feel if I had understood fully then this situation would never have been as devastating as it was. I am still recovering from it and have lost my confidence and have been scared of what might happen to the kids.

I think I should have had someone with me to make sure I understood what was happening and to help me understand what I was signing, and that I was made aware of my rights. I was in a situation I didn't understand and would hate things to happen in this way again to me or someone else. I want to think that if I was in this situation again it would be handled differently and that all Social Workers would know what to do”.

Note: This parent received help writing the letter from a community advocacy service.

Box 5.2 The experience of a parent who had an advocate

Helen [ex-Mencap Advocacy Manager] went to the Family Court with mums and dads when they had to go about their children, so they were not on their own. Court is quite frightening as it is a big place and there are lots of people and you do not know where to go when you get there. When you go into the court room there is a place you have to sit and you need to know when to stand up and what to do.

Helen helped with all of this. She also sat beside parents and told them what was happening if people speaking were using big words and mums and dads did not know what they meant. She made sure everyone had a solicitor to help them. Social Services inform mums and dads that they need legal representation, but how do we all know what that is and how to get it? I think people talked to me properly when Helen was with me as they tried hard to make sure I understood better.

Child Protection Conferences can be scary because there are lots of people there and some people you do not know. Helen used to make sure that everyone who wrote a report for this meeting came and shared it with me a week before the meeting. This was good because it meant that mums and dads knew what people were saying about them or what people thought should happen with their children before mums and dads went to the big meeting.

I have talked to other mums and dads who have a learning disability at a parenting drop-in that the Community Nurses ran. They want someone like Helen to help them as they do not know all the things they should know.

Helen came to all my appointments with me and helped me a lot as she knew about child protection and could explain things to me in a way that I could understand. Lots of mums and dads who have a learning disability find it hard to speak up for themselves. Helen used to check with me which bits I felt I could say myself and what I wanted her to say for me. She was good in meetings and if I wanted to say more she let me.

Source: This letter was written by a parent with learning disabilities in Newcastle with help from an Advocacy Support Worker.

5.3 Legal issues

In relation to legal process, if the local authority has concerns about the safety of a child, they will invoke a Section 47¹⁰ enquiry (of the Children's Act). They then will issue a Public Law Outline and letter to the parents, it then goes to a Pre-Proceeding Meeting.

Solicitors receive a fixed fee for representing parents involved in Pre-Proceedings and do not get paid for the time they spend with the client. The fee from the Legal Services Commission is £147 if there is no letter issued on behalf of the client to the Pre-Proceeding Meeting and £347 with an issuing letter. In court, the fee structure changes. For the former two fees, the solicitor meets the client and prepares subsequent letters.

There are a series of problems and barriers which relate to access of legal assistance and of progress once within the legal apparatus. One of the first problems faced by parents involved in Child Protection Proceedings is where to find a solicitor. For some parents, they are directed by sympathetic support workers, such as the Community Nurse with CTLD, who know of solicitors who are experienced in issues pertaining to parents with learning disabilities. Such Solicitors are more sympathetic, they may spend much longer than is (financially) budgeted for on explanations and they may have legal resources which are in accessible formats for people with learning disabilities (picture books for example). They may also take people for pre-court visits before the hearings. Sympathetic Solicitors may also be in constant contact with the parent and a relationship builds with the client.

Other Solicitors from different legal firms may not provide similar services and parents may simply be allocated whichever Solicitor is appointed on that day from a particular law firm. Parents who are not in contact with community services such as CTLD will not be directed to known sympathetic Solicitors and it is not known how they broker access or identify a relevant Solicitor. It was also reported that if parents are dissatisfied with their legal representation, they find it difficult to change Solicitors.

One of the first issues faced by representing Solicitors is gaining the necessary documentation. Parents with learning disabilities generally do not work and so they can claim legal aid. However, they often do not have the necessary documentation as proof of an inability to work and many also do not have any ID. In these common cases, parents must give authority for the solicitor to gain such documentation on their behalf, which takes additional time.

If the Solicitor is unsure that the client can understand the legal process, they will request a Capacity Assessment carried out by a Psychiatrist, this determines if a

¹⁰

www.childrenslegalcentre.com/Legal+Advice/Child+law/childprotection/Whatisasection47enquiry

parent has the capacity to instruct a solicitor. The Psychiatrist will then prepare a report which will indicate whether the client has capacity to understand the legal process; the report may also indicate a learning disability. If they do not have capacity the Solicitor will notify the 'Official Solicitor' based in London who will appoint a representative to act on behalf of the parent. The representing Solicitor (generally the original Solicitor approached) will interview the client and write down what they say and then send the transcript to the Official Solicitor in London. If the latter agrees then the Solicitor will represent the parent throughout the legal process. This happens in approximately half the cases in one legal practice which represents a relatively high number of parents with learning disabilities.

There are a number of concerns that have been raised about parents with learning disabilities and the legal process^{xi}. The overriding concern is that parents with learning disabilities simply are unable to understand the complex and serious set of circumstances that they are involved in. Despite *"trying our best within the set of constraints we find ourselves in"* as one Solicitor put it¹¹, without independent advocacy support, clients find themselves at a *"disadvantage and are on a severely unequal footing"*. One Solicitor said *"people don't understand what's happening ... before the courts, at the courts, if conditions of the court are given ..."*.

This has a number of implications which go beyond simply not understanding proceedings. It means that clients cannot constructively input into the process and dialogue is difficult, as clients do not understand the points of Solicitors and *vice versa*. Again this raises the issues of inequality and also of basic Human Rights; as parents are unable to equally and effectively participate in a process that effects them and their children.

There are also other concerns such as consistent levels of understanding (amongst Judges), locations of court hearings, other legal issues such as precedent and concerns that other representing Solicitors may be less that sympathetic. Comments included:

"We need the same judge so they become familiar with the issues ... if there are different judges we keep having to remind them the clients have learning disabilities which is not good".

"We'd also like the same location ... we can be allocated any court, for example Durham Magistrates court – I mean how are people going to get there?".

"There are problems with precedent – if someone has already had two children removed then it is likely that the third will also be removed".

¹¹ i.e. Insufficient fees to cover time required to adequately explain and cater for clients with learning disabilities and a lack of skills.

“We’ve seen the impact of the Legal Aid cuts ... solicitors just hot-footing it out of the court as soon as the case is finished ... and the parents are left not knowing what to do and what are the next steps”.

6.0 The experience of professionals

We interviewed a number of professionals from a range of different types of organisations, including support and enforcement-type agencies. The findings have been thematically analysed and are presented in this section. It is important to note firstly that there are a number of agencies in Newcastle who have experience of working with parents with learning disabilities in a variety of situations and contexts. Many of these are involved in and around the Child Protection process but equally there are also those which are involved in supporting parents.

However despite this, in Newcastle it was estimated that proportionally, most of the work that is done with parents with learning disabilities is taken up by Child Protection Proceedings and with only a fraction being estimated to be support work and training to parents with learning disabilities^{xlii}. Whilst, among professionals there is clarity about Safeguarding processes, the opposite is true with regards to support provision.

Most professionals describe services for parents with learning disabilities in such terms as 'sporadic', 'piecemeal', 'ad hoc' and 'uncoordinated'. For example, 'sometimes' or 'sporadic' were common responses to the following questions. Is there:

- Access to independent advocacy?
- Accessible information and communication?
- Long-term support where necessary?
- Support available that is designed to meet the needs of parents and children based on assessments of their needs and strengths?

One example of uncertainty is the situation with regards to methods of diagnosis; in 2009 CTLD stopped carrying out IQ assessments but recently these were reported to have started again, but professionals reported that the process is no longer clear.

The lack of clarity for professionals was felt to reflect an increased lack of clarity for parents themselves. Certain professionals who were interviewed for this study professed to not knowing what was available for parents with learning disabilities. Indeed, a common feeling amongst such professionals was:

"If professionals don't know about available services, then what help for service users?"

6.1 Identification of parents with learning disabilities

One difficulty expressed by professionals was how parents with learning disabilities are identified, both in terms of receiving a diagnosis and being identified early enough to ensure effective and timely intervention. Currently, parents with learning disabilities come into contact with services in a number of ways. This may be through a GP who may refer into Children's Social Care's Initial Response Service when the individual presents at pregnancy, or a Midwife may refer to CSC who may become involved at 16 weeks into the pregnancy. However, early intervention by any services, particularly CSC is the exception rather than the norm and services may only become involved either just before birth, just after, or when the Child Protection process has already been initiated. This has implications on the ability to provide timely interventions which have further implications on the ability of parents to comply with conditions laid down by Case Conferences.

The late referrals into support or advocacy services was raised on many occasions and was reported to have a number of negative impacts not only on parents (through affecting the level and type of service they receive – less supportive, more supervisory/enforcement) but also on the services they are referred to. These latter impacts generally affect the type of relationship between parent and support service and also impacts on the type of support they can offer.

There was also some confusion about the meaning of the terms: learning disability; learning difficulty; and mental health problems. It was felt that some agencies used these interchangeably.

There were a series of concerns about diagnosing learning disabilities. The main one was generally an absence of a diagnosis and this led to common perceptions of community services 'suspecting' that the parent has a learning disability. This leads to the situation where most parents with learning disabilities on the caseload of certain community services (e.g. FIP) have not been diagnosed and parents with learning disabilities often do not meet the eligibility criteria to qualify for an IQ test/diagnosis (compounded by agencies not knowing what the eligibility criteria is for a test). This leads to agencies reporting working with a high number of parents with possible learning disabilities, described as a "*significant chunk*" of their caseload but "*being unsure of their diagnosis*".

This also limited the services available for the parent because of an absence of a diagnosis. For example, one Family Support Worker said "*we try and refer them onto Adult Services but unless they have a diagnosis they won't do anything ... we try and get a Children's Social Worker but they say it's the adult and not the child so they won't do anything ... it's nearly impossible to get any help at all [from Adult or Children's Services] so you just have to try as best you can yourself*".

There are other reports about an unsatisfactory response from Adult Services. For example, one family intervention initiative reported *“they are very difficult to engage with”*. They continued *“We’re always nervous when a case comes in ... because we haven’t got the necessary specialisms and it’s hard to get other services involved”*.

There were also concerns raised about the contradictions in demonstrating the capabilities of parents: on one hand that they are sufficiently disabled to qualify for support; and on the other that they are sufficiently competent as to be allowed to parent their children. One Senior Advocate reflected this by saying: *“Increasingly, the onus is on the person to prove how dire their situation is [to Adult Services] but then they must prove to Children’s Services that they can parent but they must also prove to Adult Services how incapable they are, so they can get support”*.

The situation is further clouded by people’s perception of their own disabilities. For example, one Social Worker reported *“A lot of people [with learning disabilities] don’t think they’ve got learning disabilities and they think they can parent OK and that Social Services are wrong ... so the parents perceive they’re OK. Then other services become involved and it later dawns on them [services] that there’s a learning disability but at that point it’s too late [as children may have already been removed]”*.

There was also an expressed worry about the ability of some individuals to be correctly diagnosed as having a learning disability, particularly in the context of disadvantage. For example, it was felt that as a result of an historic lack of engagement with educational and other community services that people would fail IQ tests regardless of having a learning disability or not. However, this is categorically not the case as is testified by Clinical Psychologists; IQ tests measure IQ score independent of other variables.

6.2 The need for a different type of support

Many professionals felt that parents with learning disabilities needed a different type of support; one that was provided to the family over a longer period. This means providing services in a different way to those which are currently delivered. It was reported that services are currently provided either to the adult or the child and do not and, indeed it was reported, cannot respond to both. One Senior Parenting Practitioner said *“services are either delivered to the adult or the child and not to the family”*.

Another professional reported, *“They need long term support, someone who can cater for their long term needs, with an emphasis on early intervention”*. It was raised on a number of occasions that the way many community services are currently configured is inappropriate for longer term support. It was reported that

current brief intervention models do not work for parents with learning disabilities. One professional said “*Services are very happy to put in short term intensive support but that’s not what’s needed [for parents with learning disabilities]*”^{xliii}.

One professional said “*we need a ‘vision’ when we’re working with parents [with learning disabilities] ... a different way of looking at the support we provide ... we need to know what we want to achieve*”^{xliv}. The same professional reported “*There is a lack of understanding about what people with learning disabilities need ... they [community services] think they can provide an intervention, do some training and then they’ll know what to do ... they don’t realise that having a learning disability is a lifelong condition ... if they provided services for people with a physical disability it would be different because there is a recognition that people live with a physical disability for life. So like support to people with physical disabilities, support to people with a learning disability needs to be long term*”.

One professional commented, “*There also needs to be a recognition that support needs will vary over time, with some periods needing a lot and sometimes not much*”^{xlv}.

Taking such a long term approach would also counter the critique from certain professionals who have concerns over the ability of parents with learning disabilities to provide for the changing needs of children, particularly the change from catering for physical and then emotional needs.

Box 6.1 Christina’s story – lessons for service

The following is an excerpt from an article that looked in detail into a successful intervention into family life where there were parental learning disabilities. The case study highlighted what made the intervention successful, and provides useful lessons for a service for parents with learning disabilities:

- A package that fosters independence and development of parenting skills rather than ‘propping families up’
- A robust package, with sufficient hours, meeting Christina’s needs as well as her children’s needs
- An active and valued involvement from the parent
- The involvement of the advocate
- The involvement of the parent’s family
- A case coordinator
- Specialised learning disability social work support
- A support team manager who is an active member of the support team
- Psychology support and training
- Regular supervision and support
- Opportunities to learn parenting skills before Assessment
- Good housing in a safe neighbourhood

Source: Hames and Noble, 2009.

It was also felt that professionals who work with parents with learning disabilities require a specific skill set to allow them to work effectively. These skills range from ways to communicate effectively to how to work in difficult family situations. In relation to the latter, an example was given by a FIP worker: *“We wanted to see what it was like going out with a family on a routine/mundane task, such as going to the shops with the family; it was described as carnage, with the kids screaming ... FIP doesn’t have the skills to work with parents with learning disabilities”*. About the former, one agency who has provided professional support to other organisations working with parents with learning disabilities commented, *“We do lots of explaining to other services about families where there is a learning disability ... about understanding and how to communicate differently”*.

One of the common reasons attributed to inappropriate support (poor communication, attitudes and a culture of brief interventions), was professionals’ high caseloads (particularly Social Workers). For example, one Advocacy Worker said; *“Because people are overwhelmed by caseloads and are so busy, so they don’t have time to spend with people ... people are treated with disrespect by professionals”*. Another Support Worker said, *“People need more face to face contact – and that is not going to happen when people are overwhelmed by caseloads”*.

Several professionals identified the need for a specific service. For example, *“To have a team with specialist knowledge would be invaluable”^{xlvi}*.

6.3 Accessible information and communication

The amount and standard of appropriate information and methods of communication was reported to vary significantly depending on both the service but more importantly the individual professional. There appeared to be no standards applied to how parents with learning disabilities were communicated with or the offer of the nature of communication (i.e. how parents with learning disabilities preferred to be communicated with). If the individual professional was motivated and sympathetic, then they often developed their own portfolio of materials – this was the case from Solicitors to Family Support Workers.

It was reported by an experienced Advocate that the best way to communicate with an adult with learning disabilities is by getting to know them and developing a relationship with the person. They said *“it’s less about using pictures and other techniques and more about being able to find out what people understand and retain”*. However, it was noted that as a result of often receiving referrals (from agencies such as Social Services) *“so late in the day”* that it is difficult to develop such a relationship.

6.4 Strategic issues

6.4.1 Integration of services, including commissioning

One of the main recommendations of the government guidance is that services should be integrated, particularly Adult and Children's Services, including clear referral pathways and protocols. In Newcastle, the level of integration is weak; there is currently no integration at a strategic or operational level. There are some instances of operational working but this is reported to be uncoordinated and *ad hoc*. Illustrative comments include:

"Sometimes there is on an operational level but it depends on the professionals involved".

"Adult and Children's Services are not joined up".

"Children's Services staff only really talk to other Children's Services staff".

"In general, there are case discussions where there is good communication but this is often limited to critical stages of intervention. Outside of that communication is a generally poor".

It was unanimously reported that there was no commissioning strategy for parents with learning disabilities services. This was reported to be due to several issues including different commissioning priorities and an absence of leadership and/or responsibility for the issue. Comments included:

"The key issue is who should take the lead ... there is the will but not the way"

"The main problem is there is no-one to lead the workstream in health or in the local authority".

"The problem was that no-one in Newcastle is accountable".

6.4.2 Policy

As is implied from the section above, there is no strategy, policy or strategic mechanism in Newcastle that covers parents with learning disabilities, either in the local authority or in the local health services. We suspect this is the same in many other local authority areas.

There have been some attempts in the past to attempt to create some policies, including in 2005 there were unsuccessful attempts made by the Local Authority

to create referral pathways between community agencies and through the 2010 Advocacy Strategy that identified parents with learning difficulties as a priority (this Strategy is currently under review). Following background work considered by the Learning Disability Partnership Board, in late 2009 meetings were held between senior representatives in the Local Authority's Adult and Children's Services about the need to develop policy but this has not progressed.

A major issue is locating the workstream in a logical and identifiable place, in other words '*finding it a home*'. One possible area has been the Learning Disabilities Partnership Board, which exists under Newcastle (Local) Strategic Partnership's Wellbeing and Health Executive Group. Indeed, the Learning Disabilities Partnership Board convened a Rights and Equalities Sub Group which has occupied itself with a range of related issues including advocacy. It is currently being decided how learning disabilities issues and voices will be reflected most effectively in the emerging Health and Wellbeing Board (known as Wellbeing for Life Board in Newcastle).

However, the Learning Disabilities Partnership Board is made up of purely adult services and contains no representation from Children's Services, which is clearly vital. The Children's Trust¹² in Newcastle does link to the Rights and Equalities Sub Group particularly around transitional issues (i.e. from child to adult) but that is the limit of its influence.

Whilst there is effective partnership working at sub group level on some issues such as transition and employment between Children's Trust members and the Learning Disabilities Partnership Board, there is no consistent strategic relationship and no reciprocal membership.

There is a Think Family Commissioning Partnership made up of health, the voluntary sector, Safe Newcastle, Local Authority and their remit is to deliver the Parenting Strategy. The Partnership provides the governance arrangements for the Families at Risk Intensive Support Service (FRISS) and Newcastle's parenting initiatives. Funding for both areas comes out of the Early Intervention Grant (EIG) and parents with learning disabilities have been identified as an area which requires support. There are also strong links between the Partnership and other strategic groups in Newcastle, most notably the Parenting Commissioner attends the Adult Commissioning Group and also the Carers Strategic Group.

There is currently the intention and a structure that allows for both strategic and operational provision for parents with learning disabilities. The Parenting Commissioner commented, "*We have created structures over the last year which lays out universal services, Integrated Targeted Support and Children's Social Care and Child Protection ... now there needs to be a focus on improving*

¹² A local partnership that brings together the organisations responsible for services for children, young people and families in a shared commitment to improving children's lives (www.newcastlechildrenservices.org.uk/mcs_childrens_trust).

practice". They continued "*support for parents with learning disabilities would fit within the Families at Risk Intensive Support Service*".

There is a recognition amongst senior professional in Newcastle that there must and needs to be a multi-agency approach to working with parents with learning disabilities, again both operationally and strategically.

6.5 Proposals from professionals

There were a series of proposals from professionals about operational and strategic development. These included:

- **Capacity development amongst mainstream services:** one professional commented "*they [professionals] need skilling up*". Another said "*you need more and better training ... a rolling programme - Adult and Culture Services has a training and workforce development unit ... such a thing could be located there*". And another said "*There needs to be awareness raising amongst professionals about what it means for them to work with parents with learning disabilities*". Capacity development has specific connotations in relation to the development of specialist parenting programmes for parents with learning disabilities. There are many professionals across a range of public and voluntary organisations that deliver a variety of parenting programmes. If such professionals are to deliver specific programmes 'in-house', either in groups or via one-to-ones, there is an associated training need. It would also be helpful if there could be clarity on the terms of learning disability, learning difficulty and mental health problems.
- **Referral pathways and protocols:** this issue is clear in the Department of Health (2007) guidance and incorporates where parents can be referred to for a variety of support and assistance. One professional said "*we need to identify where people [services] fit together*". Another said "*There needs to be a protocol and specific guidance*". There is also the corresponding requirement for better and more available information.
- **A point of coordination:** there were many reports about the need for both clarity of leadership and a point of coordination for services, on both an operational and strategic level. For example, "*There's not joined up working ... you need someone to coordinate the support around a family and take a longer term view*". This also related to specific services such as advocacy, for example, "*you need a coordinator and an advocate who is specialised in Child Protection as soon as possible ... then many people often just need a low level of support*".
- **An emphasis on early intervention:** there were many critiques of the enforcement-type focus of intervention and late referrals. For example, one professional said, "*If there is potential, then intervention needs to be early and more preventative work needs to be done*". Indeed, there is evidence from professionals that the absence of preventative work will inevitably result in more intensive and costly interventions later on. It was reported that people

with learning disabilities can quickly move from receiving no support to requiring critical and intensive services. For example, one person received no support to the point where they needed to go into adult foster care. The involved professional reported *“Because of the lack of low level support, they then needed high level, intensive support”*. It is generally accepted that support needs will vary over time; some times requiring intensive support, other times needing very little. For example, a Social Worker at the Valuing Parents Support Service (VPSS) in Kent which is a joint Adult and Children’s Services project, says ‘the level of input goes up and down and we will always try to steer families back to mainstream services where we can, but some families need support for some time’^{xvii}.

- **The development of services:** there were a series of reports about the need for services for parents with learning disabilities, including the need for independent and regular support, parenting programmes and advocacy. In particular it was felt necessary to reduce the isolation of parents with learning disabilities and increase and strengthen social networks. One professional stated *“A big problem is isolation and being vulnerable to isolation and not having any regular support ... if they had friends their lives would be better”*. One professional said *“You need a comprehensive service consisting of psychologists doing parenting assessments and IQ tests, SALTs carrying out comprehension assessments, Community Nurses doing assessments of support and training needs and Support Workers providing the support and advocacy”*. Also it was felt that as currently there are effectively no services for parents with learning disabilities, if services were developed then they could act as almost demonstrator projects which could illustrate impact. For example, one professional said *“if we had a service that works well with parents with learning disabilities, you could show other professionals that it can be done ... that positive outcomes can be achieved”*. It was reported that if specialist resources were developed then these would have to directly involve both Adult and Children’s Services and the resource would have to ‘straddle’ both services. An equivalent example was provided by the FIP who had previously had a seconded CAMHs¹³ worker. The FIP Manager said *“we had a seconded CAMHs worker in 2010 into the FIP team which worked really well and there were similar problems that existed between FIP and CAHMs as does now between FIP and Adult Social Care Services”*.

¹³ Child and Adolescent Mental Health Services.

Box 6.2 Practice example: Valuing Parents Support Service

A useful model of good practice is the Valuing Parents Support Service (VPSS) run by Medway Council in Kent. It is made up of three family support workers, which takes all referrals of parents with learning disabilities from both Adult and Children's Services and who provide parenting support and help parents engage with health and well being services. The VPSS carries out expert assessments rather than the individual council services and where common themes are identified, such as drug and alcohol, housing and debt, they are referred to other community services. Workers receive supervision from Adult and Children's Services and any issues are fed back to those departments. An evaluation of this service found that it helped keep families together - 84 percent of children were living with their parent(s).

7.0 Benefits of support

We think there could be two main benefits to providing improved services to parents with learning disabilities. These are:

- **Keeping families together and reducing the number of children in the looked after system:** a high proportion of parents with learning disabilities have their children taken into care. There are a series of estimations about percentages, ranging from 70 to 20 percent depending on the study^{xlviii}. An audit of the CTLD caseload in 2006 found that almost 60 percent of children were removed from the family home: 22 percent were adopted and 38 percent taken into care. In real numbers this was: 183 children removed: 68 adopted and 115 into care.
- **An associated reduction in costs:** it is always difficult to accurately attribute costs or savings to looked after children. Local Authorities only really know during placement and at the end of financial years and the subsequent analysis. However, one thing is indisputable; costs for looked after children are high and any effort to reduce these numbers is therefore welcome. Here, we can attempt some rough calculations. A 2009 Government Select Committee^{xlix} on Looked After Children had this to say:

Despite falling numbers of children in care, the rising unit costs of placements has led to a substantial increase in expenditure^l. Total gross expenditure on children in care in 2007–08 was £2.19 billion, 51% of which was spent on fostering services and 41% on children’s homes. The average cost per looked-after child per week across all placements was £774. For children in residential homes the average was £2,428, and for foster care £489ⁱⁱ [the latter equates to £25,428 per year]. 71% of looked after children are cared for in foster placements.

There were different local costings which estimated the total cost for a looked after child in a foster placement was between £45,000 and £55,000 per year with an independent foster agency, such as Foster Care Associates or SWIIS Foster Care.

Carrying out a cost calculation using the figures from the 2006 CTLD auditⁱⁱⁱ would show that the audit identified 115 children entered the looked after system. If we attribute foster care costs using Government figures, those 115 children cost the local authority a total of £2,924,220 each year.

The subject of cost of a support intervention was raised during this research and one commissioner commented, “*A package to keep people together is expensive ... but you can’t base a decision on price*”. However, it would seem from rudimentary calculations that one almost cannot afford not to fund

support interventions (the experience from Kent in box 6.2 showed that 84 percent of children stayed with their parents).

There are direct links between the provision of a support service and a reduction in looked after children, not just from other areas (see box 6.2) but also from local judicial experience. For example, it was reported that Courts have said at Child Protection proceedings that the more support that can be provided in the community to parents with learning disabilities, the less likely they will recommend custody for the child.

To conclude, it would appear that the following comment has validity: ‘The earlier services become involved, the less likely children are to have developmental problems and there is an increased likelihood that the children will remain in the family homeⁱⁱⁱ’.

8.0 Discussion

During this research, it became apparent that different agencies had different viewpoints and concerns with regards to parents with learning disabilities, including responsibilities, family support, advocacy and strategic direction. These perspectives are grouped into those of the local authority, the health authority, the voluntary sector and community family support agencies.

Perspectives of local authorities

From a local authority perspective, there appears to be three main issues. First is the difficulty of diagnosis and the subsequent knowledge of numbers. This is both because no agency routinely carries out IQ tests on all those parents suspected of having a learning disability, so we do not know how many parents there are in Newcastle who are undiagnosed. Also as there is no central record of numbers of parents who have been diagnosed, we also do not know how many diagnosed parents with a learning disability there are. Secondly, amongst professionals working for the local authority there was a difficulty in deciding whose responsibility is it, i.e. Adult or Children's Services, to provide support services to parents and their children. Thirdly is the difficulty associated with the assessment of capabilities versus the need to protect children, i.e. making the choice between providing support to enable the parent to continue parenting and removing the child to ensure safety.

Perspectives of the health authority

From the health authority perspective, the issues include deciding which agency, health or local authority, is best placed to provide services to parents and subsequently deciding which professionals should provide such support services, i.e. should it be Nurses, Social Workers, Health Visitors or others. The question exists, is NTW best placed to provide this service?

Perspectives of the voluntary sector

From a voluntary sector perspective the dominant issue was the lack of access to advocacy for parents with learning disabilities. There were several voluntary sector agencies that provide advocacy for people with learning disabilities in Newcastle but only one of these continued to provide advocacy support for parents. The main reason for this was the time consuming nature of advocacy for parents who mostly needed it for support with Child Protection Proceedings. If support was given by advocates then this used so much of their time that they were unable to provide an equal service to other people who needed support. One of the reasons for this was because of general funding shortages and cuts that meant that there were less advocates employed.

Perspectives of the community family support services

There is one predominant issue from the perspective of community family support services that have the view that the family is the best place to bring up children, if they are safe and free from harm. This is the need to reshape existing

family support services to be able to provide longer term support, likely to fluctuate over time, which will be able to respond to the changing needs of the child. Such a service thus needs to be made up of support workers that understand child development and the corresponding family needs. A service must also go beyond practical responses, such as keeping babies warm, clean and fed, and incorporate nurturing and emotional support which can be modelled and therefore 'taught'. Similarly, when the child starts to assert the self and exhibits more challenging behaviour, this is something which can also be managed through modelling behaviour in a similar way.

The implication of such issues for a family support service is to create a service that can follow the family as it develops using a key worker or support worker type approach, sometimes providing intensive support, sometimes providing very limited support. Currently however, family support services are not configured to provide such a service and this may have implications for the Council's Families at Risk Intensive Support Service (FRISS).

9.0 Conclusion and recommendations

9.1 Conclusion

Currently, services that work with parents with learning disabilities in Newcastle tend to be focussed round the Child Protection process. Supportive provision for parents with learning disabilities in Newcastle is currently an area where there is significant scope for improvement. Indeed, there are some good examples of support provided, such as CTLD and Children North East, and there is a wealth of expertise. In other words, there is expertise to build upon.

It is also apparent from this research that there is clear willingness and intention from across the local authority, health services and voluntary sector, to develop policy and services in Newcastle. There have already been efforts in the recent past to create a strategic location for the workstream but unfortunately they have stalled. It is hoped that, using this report as impetus, efforts can be revived and realised.

We think that the benefits to both services and families are clear: a more equal and accessible range of services; more effective and skilled services; cost savings and keeping families together. With these issues in mind, we provide a number of recommendations to consider, which are presented in the following section.

9.2 Recommendations

Whilst we concur with the guidance presented in the Department of Health 2007, we have a number of suggestions which are more specific to Newcastle:

6. **The creation of a policy 'home'**: the first recommendation we make is the need to create a policy home to locate the workstream – a place where issues are discussed in a multi-agency context with the local authority as the lead agency. As the following summary for parents states, someone needs to take charge of the work. One of the main weaknesses in this workstream has been that there has not been one single forum or mechanism which has representation from Adult and Children's Services, health and the voluntary sector, whose responsibility it is to make decisions about parents with learning disabilities. To this end, we would like to pose the question, is the best place for such a home the Think Family Commissioning Partnership or would it be elsewhere? The objectives of such a group would need to include the creation of a lead strategic responsibility and also it would need to create an operational group to coordinate services.
7. **Better estimates of numbers**: the second is to attempt to more accurately estimate numbers of parents, particularly those with a service need and there are a series of actions associated with this. Firstly, we suggest carrying out a survey of all Health Visitors and questioning them about their caseloads

(there are currently 114 Health Visitors in Newcastle and approximately 15,000^{liv} children under five, giving a theoretical caseload of around 130 children per Health Visitor – though clearly this would be much smaller as only a small proportion of those would require support). It may make sense that this request comes jointly from Adult and Children’s Services and the health authorities. Although this would not provide definitive answers, it would at least provide an idea about numbers of parents with learning disabilities with children under five with a service need. Similarly a survey could be sent out to community based organisations such as the FIP, Social Work area teams, Children North East, etc. asking them how many parents with learning disabilities they work with who have children over five (and none under five as these would be captured by the Health Visitor questionnaire).

8. **Estimate costs:** our third suggestion is to undertake an estimation of Looked After Children costs associated with children of parents where there is a learning disability. An estimation of annual costs would make service development decisions more straightforward. In the event of service development, this would also provide a baseline of information that can be used to monitor impact.
9. **Service development:** our fourth suggestion is to look into service development and reshaping. We propose that there is much to be gained in both adapting existing services and what they already do and improving intra agency cooperation and coordination:
 - Reshaping existing family support services: we think that this relates primarily to Children’s Services, their parenting services and FRISS and also to commissioned family services (from internal budgets and external resources such as the Newcastle Fund). We have mentioned here about the need to both skill up professionals in existing services (in their awareness of issues and ability to communicate effectively – this is something which was successfully done in the past through a rolling training programme delivered by CTLD) and also for a longer term family support service which is responsive to the needs of parents, sometimes with intensive support, sometimes with little support and a ‘watching brief’. The emphasis here would be on early intervention and on specifically designed interventions, such as parenting programmes for parents with learning disabilities. It may be that such services could be developed from existing family intervention programmes and other community services (Families Plus’s Family Support Volunteers provides a useful model where they are currently used across Newcastle as a way of providing long term maintenance and ongoing support and supervision). Within such a service we think that it is important to have an emphasis on continuity and coordination of services. We think that there is significant potential to develop this continuity and coordination based on learning from how existing services for families with complex needs are coordinated, such as the Team Around the Family approach. There may also be an existing structure to be able to do this, via the Think Family Commissioning

Partnership. As was demonstrated in section 7.0, there were significant cost saving advantages to departmental budgets in reduction in looked after children costs, thus there should be demonstrable annual cost savings.

- Improving intra agency cooperation: again there is much scope for improvement in the coordination and cooperation of agencies who currently deliver services to parents with learning disabilities. For example, coordination could be improved if there is more clarity of purpose and a demonstrable willingness to engage. For example: the Clinical Psychologists at CTLD could provide IQ assessments for the parents with learning disabilities who have a service need (we estimate between 50 and 100); Adult Social Care could improve how they cooperate with other community services (both reshaped and existing family support services) and put in place processes (for example, Single Point of Contacts or referral pathways) to make this easy; Children's Social Care also have the potential to become more supportive in their approach and could cooperate better with Adult Services, providing support to the parent and child. All these three agencies would have much to gain in a constructive and coordinated dialogue about the support needs of families, which could be complemented by an effective family support service.

10. Improve advocacy facilities: our last recommendation concerns the need for advocacy services for all parents with learning disabilities who are involved with Child Protection Proceedings, including at Case Conferences and at the Courts. Currently there is almost none available and it is essentially a Human Rights issue where without advocacy, people with learning disabilities do not understand the processes which are acting upon them and their children. This will be a challenge in the current climate of austerity. However, there may be options in up-skilling the Citizens Advocacy Service or leveraging in charitable funding.

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Appendix one: Services and their representatives interviewed

Agency	Position interviewed
Caris Robson	Solicitor
Children North East	Head of Service Families and Parenting, Lead Practitioner Families Plus, Senior Family Support Worker Families Plus
Ex-Mencap North East Parents' Support Service	Advocacy Manager
Families in Care	Senior Support Worker/Advocate
Gateshead Council	Children's Commissioning Learning and Children – SEN Officer
Mental Health Trust	Clinical Psychologist
Newcastle City Council	Service Manager, Specialist Teams, Adult Services
Newcastle City Council	Lead Specialist Family and Parenting Support, Integrated Targeted Services, Children's Services
Newcastle City Council	Senior Practitioner
Newcastle City Council	Strategic Partnership Coordinator - Transformation Team (ACS)
Newcastle City Council	Assessment and Monitoring Team, Service Manager and Social Worker
Newcastle City Council and NHS north of Tyne	Joint Health Commissioner for Children
Northumberland, Tyne and Wear NHS Foundation Trust	Community Clinical Manager Learning Disabilities - Planned Care
Northumberland, Tyne and Wear NHS Foundation Trust	Community Services, Planned Care Group
Northumberland, Tyne and Wear NHS Foundation Trust	Community Nurse
Skills for People	CEO, Advocate, Support Worker
United Response (support service for people with disabilities)	Area Manager
YHN, Family Intervention Project	FIP Manager
Your Voice Counts (advocacy service for people with learning disabilities)	Senior Practitioner (Social Worker)

Appendix two: Questionnaire for parents with learning disability research

Definitions, numbers and overview of services

1. How would you define parents with learning disabilities?
2. How many parents with learning disabilities do you work with?
3. What support services exist for parents with learning disabilities in Newcastle?
 - e.g. (self) advocacy
 - parenting programmes
 - Service user groups, etc.
4. Can you say how are these services staffed and funded?

Accessible information and communication

5. What accessible information is available for parents with learning disabilities in Newcastle
6. Is this customised or commissioned for Newcastle or is it mainly national information?
7. What formats is the information available in?
8. Do professionals know enough about how to communicate with parents in easy to understand ways

Clear and coordinated referral and assessment procedures and processes, eligibility criteria and care pathways

9. What are the eligibility criteria for parents with learning disabilities?
10. What type of assessment is used?
11. When does identification of need occur (e.g. when pregnancy is confirmed)
12. What type of support does your service offer?
13. How long do you generally provide support for?
14. Do you think that people with learning disabilities who become parents know about the support available?
15. Do you think there are clear referral procedures and care pathways?

Support designed to meet the needs of parents and children based on assessments of their needs and strengths

16. Are there examples of support designed to meet the needs of parents and children based on assessments of their needs and strengths in Newcastle?
If yes, are there particular circumstances or conditions that have facilitated such support to be put in place?

Long-term support where necessary

17. What long term support can be made available to parents with learning disabilities in Newcastle?

Access to independent advocacy

18. Is independent advocacy available to parents with a learning disability in Newcastle

19. What are the benefits of access to independent advocacy
20. What sort of independent advocacy services should ideally be developed e.g. should they be dedicated/specific or be part of wider generic teams with perhaps specialist knowledge?

Joint working

21. Is there any joint working between adult and children’s services, health services and voluntary sector organisations? e.g. jointly agreed protocols for referrals, assessments and care pathways?
22. Is there a joint commissioning strategy for parents with learning disabilities services (adult and children’s services, health services)?
23. Is there good communication between agencies? e.g. are there practice development meetings or networks?

<p>The Department of Health (2007) guidance says there are five key features of good practice in working with parents with learning disabilities:</p> <ul style="list-style-type: none"> • Accessible information and communication • Clear and coordinated referral and assessment procedures and processes, eligibility criteria and care pathways • Support designed to meet the needs of parents and children based on assessments of their needs and strengths • Long-term support where necessary • Access to independent advocacy. <p>To what degree do you think these exist in Newcastle?</p>	yes	no
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Capacity and knowledge

24. Do you feel adequately equipped to do work with parents with learning disabilities? Yes/no – explain
25. Do you receive any training? (Is there joint (agency) training?)

Experiences of parents with learning disabilities

26. How often in Newcastle do children of parents with learning disabilities get returned to their families after being removed?

Proposals

27. What services would you develop in Newcastle for parents with learning disabilities?
28. What would be the priorities to develop and why
29. Any other comments?

Endnotes

- ⁱ Department of Health, 2007.
- ⁱⁱ Pope *et al.* 2000.
- ⁱⁱⁱ McGaw, and Newman, 2005.
- ^{iv} Tarleton *et al.*, 2006.
- ^v Department of Health, 2001, pg 81.
- ^{vi} Carson, 2011.
- ^{vii} Wills, 1999b, page 13.
- ^{viii} Booth and Booth, 1994a cited in Wills, 1999a.
- ^{ix} Booth and Booth, 1994a.
- ^x *Op.cit.* 1994a.
- ^{xi} *Op.cit.* 1994a: page 53.
- ^{xii} See Department of Health, 2007, pg. 36.
- ^{xiii} Department of Health, 2001, pg. 14.
- ^{xiv} Booth and Booth, 1993.
- ^{xv} Based on Whitman and Accardo, 1990, cited in English, 2000.
- ^{xvi} Emerson *et al.*, 2005.
- ^{xvii} This is both through existing fieldwork and published local information such as Wills, 1999a.
- ^{xviii} Newcastle City Council, Senior Performance Analyst, pers. comm. October 2011.
- ^{xix} Wharton *et al.*, 2005.
- ^{xx} English, 2002.
- ^{xxi} Wills, 1999b.
- ^{xxii} Norah Fry Research Centre, 2007.
- ^{xxiii} Mencap's ex-Advocacy Manager, pers. comm. October 2011.
- ^{xxiv} Family Support Worker, Children North East, pers. comm. October 2011.
- ^{xxv} English, 2010.
- ^{xxvi} Elvish, J. *et al.*, 2006.
- ^{xxvii} Elvish, J. *et al.*, 2006.
- ^{xxviii} Elvish, J. *et al.*, 2006.
- ^{xxix} English, 2010.
- ^{xxx} Senior Practitioner, Your Voice Counts pers. comm, October 2011.
- ^{xxxi} Elvish, J. *et al.*, 2006.
- ^{xxxii} Elvish, J. *et al.*, 2006.
- ^{xxxiii} English, 2010.
- ^{xxxiv} English, 2010.
- ^{xxxv} Coleman, 1990 and Tymchuk, 1990 cited in Wills 1999b.
- ^{xxxvi} Wills, 199a.
- ^{xxxvii} Mencap's ex-Advocacy Manager, pers. comm. October 2011.
- ^{xxxviii} Advocacy Support Worker, Skills for People, pers. comm. October 2011.
- ^{xxxix} It was reported that "*most Child Protection [for PLD] is about neglect which relates to poor parenting and poor housing, no routines, inappropriate behaviour, anti-social behaviour, rent arrears ...*" (FIP Manager, pers. comm, October 2011).
- ^{xl} FIP Manager, pers. comm. October 2011.
- ^{xli} This evidence originates both from the current study's interviews and also the consultation with 11 Solicitors about the cessation of the NEPSS.
- ^{xlii} Community Nurse, pers. comm. September 2011.
- ^{xliii} Senior Parenting Practitioner, October 2011
- ^{xliv} Child Psychologist, pers. comm. September 2011.
- ^{xlv} Head of Service, Children North East, pers. comm. September 2011.
- ^{xlvi} FIP Manager, pers. comm. October 2011.
- ^{xlvii} Hunt, 2011.
- ^{xlviii} For the former, Booth and Booth, 1994b and for the latter, Pixa-Kettner. 1998.
- ^{xlix} House of Commons, 2009, Children, Schools and Families, Committee Looked-after Children, Third Report of Session 2008–09, Volume I

ⁱ Beyond Care Matters, para 28; Care Matters Green Paper, para 1.13

ⁱⁱ NHS Information Centre, Personal Social Services Expenditure and Unit Costs England, 2007.

ⁱⁱⁱ Elvish, J. *et al*, 2006.

ⁱⁱⁱⁱ Elvish, J. *et al*, 2006., page 32.

^{iv} Office of National Statistics: Child Benefit Families, 2010, HM Revenue & Customs.

Contact details for the report's author:

Dr Christopher Hartworth
Director, Barefoot Research and Evaluation
Tel: 07813 789529
Email: christopherhartworth@barefootresearch.org.uk

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The Old Chapel, Woodbine Road, Gosforth, Newcastle upon Tyne, NE3 1DD
Tel: 0191 2848412
Email: generaloffice@nr-foundation.org.uk
Registered charity number: 1063906
Company limited by guarantee: 3416658

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