



Summary

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.

We would firstly like to thank Newcastle City Council's Adult and Children's Services for supporting this study and for agreeing to be the detailed case study local authority in what is hoped will eventually be a regional study. There are particular individuals here to thank including Bill Norman who has tirelessly supported parents with learning disabilities and made sure they remain on the agenda. Thanks also to Mick McCracken, Jonathan Jamison and Sue Miller.

We also would specifically like to thank Sue English who has been extremely helpful in providing us with information and answering our constant stream of questions. Again her and the team at CTLD have demonstrated an enduring commitment to parents with learning disabilities, which must be congratulated. We would also like to thank Sylvia Copley, Lesley Davies and Maria Hood from Children North East, Helen Robson from Caris Robson and Helen Newton for their help and support with the study.

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

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 (CTLD) 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 CTLD, 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 levering 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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