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Fair Deal For Families?

learning from the experience of parents
with a learning disability





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The Baring Foundation

Acknowledgements

There are seven families' experiences in this report. Five parents and four children told us their stories of what it is like to be part of a family where at least one parent has a learning disability. I would like to thank them for their honesty, openness and courage in trusting us with their life experience.

Thanks are due to People First Scotland and ENABLE Scotland for making contact with some of these families and supporting them to tell their stories. People First is the national self-advocacy organisation for people with learning disabilities. ENABLE Scotland is a national service provider for people with learning disabilities.

Lesley Henderson is a social worker in a Children and Families team, and is also a member of the Working Together with Parents Network. She and a colleague carried out the work with the four children that you will read about in the section "What children said".

This publication is part of the Working Together with Parents project, which is lead by the Norah Fry Research Centre at Bristol University. Thanks to the Baring Foundation and the Esmée Fairbairn Foundation for funding the work of the Working Together with Parents Network, of which this is a part.

Andrew Miller
October 2008

References

- Tarleton, Ward and Howarth (2006) Finding the Right Support, Norah Fry Research Centre www.right-support.org.uk
- Joint Committee on Human Rights (2008) A Life Like Any Other? Human Rights of Adults with Learning Disabilities, TSO Limited



The best example of support from these stories is that of ENABLE Scotland for Amanda, Ross and Alieesha. This support has focussed on the needs of the family – its aim has been to enable Amanda and Ross to be good enough parents for Alieesha. With this support in place, the parenting has been successful. One of the key points about this support is that ENABLE Scotland, who have the expertise in providing support to adults with a learning disability, are working along with the Children and Families social work team to ensure that the outcomes for the child are good. This joint working is often crucial. It was absent, for example, in Mary and Jack's story, with disastrous consequences.

What the research suggests, and these stories illustrate, is that there is not an established culture for providing good support for families where the parents have a learning disability. The one change that would help make most difference at this stage is the production of national guidelines for supporting parents with a learning disability. These guidelines should cover the following areas:

- Accessible information and communication
- How to make a clear "way in" for parents that gets round the problem of their fear of social work
- Assessments that identify a family's strengths and support needs, and a way for all agencies to plan using the same assessment
- Providing support for the parents and children that meets their needs, and is well-coordinated between all the agencies involved
- Access to advocacy
- Good practice when safeguarding procedures are necessary
- Good practice in commissioning services for parents

Such guidelines have been in place in England since 2007. Similar guidelines in Scotland, that take account of our own laws and policies, would give confidence to frontline workers, managers and commissioners to develop good practice in their own work. Without them, many families are being let down daily by failures in our services. The cost in human terms is matched by the financial cost of many children growing up unnecessarily within the care system. With Good Practice Guidelines, and support at every level to implement them, there is the chance that the support will be there to keep families like Mary and Jack's, John's, Amanda and Ross's, and Bianca's, together in homes that allow the children to thrive and develop into confident, happy and secure adults.

Introduction

Families where one or both parents have a learning disability get a raw deal. That statement is supported both by research (Finding the Right Support, 2006) and by anecdotal evidence. Many families do not get the support they need, and as a result the children suffer. An extraordinarily high number of these children, around 50%, do not get to grow up in the family home, either because they are taken into care or because they are brought up by a relative.



Behind these statistics are the families whose lives are affected by such actions. The impact on families who do not get the support they need can be staggering. It can send even strong, well-rounded families spiralling into crisis. The stories in this report illustrate some of the consequences of not providing the right support.

This report comes from the Working Together With Parents Network in Scotland. This is part of a wider UK network that was established in 2006 with funding from the Baring Foundation and the Esmée Fairbairn Foundation. Its aim is to collect and share good practice in supporting parents who have a learning disability, and also to identify where good practice is lacking and change is needed. This may be policy change, or change in practice. Here in Scotland the Network has met regularly to hear the experiences of parents and practitioners.

We spoke to parents from four families who were known to members of the Network. Importantly, we knew a number of families who were not willing to share their stories for this report, even with the promise of anonymity. Their reason was always fear that they would somehow be recognised, and that their family would pay the price.

In addition to these stories, we have included a piece of research conducted by a social worker who is a member of the Network. She spoke to four children, from three different families, whose parents have a learning disability. Although the aims of this work were modest, the results complement what the parents have said. We hope that more work will follow that allows the voice of children to be heard.

We soon realised that the experience of families in Scotland was very similar to that in England, as described in Finding the Right Support, for example. The stories you are about to read will show that many parents are too scared to approach social work for support, in case they lose their children (a very reasonable fear, judging by the statistics). If they do ask for support they are often turned down. Even if they do get support it is often too late: the situation has become critical and there is a Child Protection issue. Organisations who should work together to support parents often



lack the policies and protocols to make this co-working effective. Parents find it hard to get helpful information. Many agencies and set-ups, including schools and the Children's Panel system, are very poor at taking account of parents' learning disability. The result is that the challenging enough job of being a parent can become next to impossible.

There are many things that could be done to improve the situation. A significant first step would be national guidelines on supporting parents with a learning disability. These would provide the practical help that many organisations need to change their practice to provide the support these families need. These guidelines should have backing from the highest levels to ensure that they are put into practice.



These stories do not make comfortable reading. But if they result in better support for the hundreds of families in Scotland who need it, then the parents and children who have been brave enough to allow their stories to be used here, will be satisfied.

John

"My name is John. My partner and I have five children. I have learning difficulties, and so do two of my children. We don't have any support at home to help us with the kids. My wife won't allow it. She is terrified of the social workers. She won't go and ask them for help, even if we need it. She is terrified that they will judge us for needing help, and decide to take our kids away. She hears other parents talk at the school gates. And she reads it in the papers.

It's a bit of a struggle as you can imagine.

It was okay until our youngest was born. He has a learning difficulty but it wasn't diagnosed early. We knew within months, but people wouldn't listen to us. That's quite an extra strain. The midwife said to us 'You've had four already, you don't need anything else from us'.

There is a very good organisation called First Hand. It gives parents a break. We got

Conclusion

Being a parent is a huge responsibility. The well-being of children in a family is paramount, and it is important that families receive the support they need to bring their children up in a safe and nurturing environment. People with learning disabilities have the right to support in their parenting role, just as their children have the right to grow up in a safe and supportive environment.

The families that we have spoken to have had numerous difficulties in raising their children, above and beyond the challenges that all parents might expect to face. They have not had the support they needed and deserved. The impact that these difficulties have had on the families is obvious – stress and mental health problems, and in some cases the break-up of the family.

These stories are small in number, but we believe are worthy of our attention, because they highlight serious issues that need to be addressed. It was not hard for us to find parents who have had huge difficulties finding the right support to bring their families up: the problem was finding parents willing to have their stories told publicly, so scared were they that there would be consequences for them and their children. All but one of the families insisted that their stories should be heavily anonymised for this reason.

The main conclusion to be drawn is that things should change. The way these families and others have been treated is not right or fair. This discriminatory treatment has been highlighted in "A Life Like Any Other", a report by the Joint Committee on Human Rights (2008). The report recommends proactive and positive action to make sure that the right of both children and parents to a family life is upheld.

In all these stories, parents found it difficult to get the information they needed, from schools, Social Work Departments, Children's Panels, or anywhere else. Communication was often poor, which left parents feeling excluded and powerless to make the decisions they needed to make. It is not always easy to make all written information accessible, but it needs to be recognised that this is important, and in many cases is a legal obligation.

Parents found it difficult to get the support they needed, and some of them found it too difficult even to approach the Social Work Department for help. They were too afraid that the spotlight of suspicion would fall on them. Others who wanted support were denied it, apparently without an assessment having been carried out. There needs to be a clear way for people to ask for and get the support they need. This needs to be co-ordinated so that all agencies can work together from the assessment onwards.



The girl who was also the eldest drew a poster with her wishes:

- "To have more confidence in myself
- To make everything for everyone better
- Be a really good singer
- When I'm older be an actress/singer/hairdresser
- Money
- To go to school all the time and get good grades
- Have more time to do stuff and go out with friend's/family
- For there not to be such a thing as bullying"



"My wish...to make everything for everyone better...
for there not to be such a thing as bullying"

Key points:

1) Common experiences

This exercise was particularly useful because it has been rare to hear the voices of children whose parents have a learning disability. Although only a small number of children took part, it was striking that they had a number of experiences in common.

The main one of these was that all four children had been bullied. Not only that, but their homes had been targeted. All of them felt that this was because they were seen to be different as a family.

2) What would help

Although all the children had had contact with social work at some point, none named social work as an agency that they could approach for help about the bullying or harassment.

The children had a number of ideas about what might help with their worries. Many of these were to do with people outside their immediate family and community groups: friends, gran, Scouts, Beavers etc. Social workers offering support to a family might have an important role to play in facilitating these relationships to begin and be maintained.

help from them when we only had four children. When you've got five they need to provide two sitters so it costs more so we can't use them.

It was at this time that I got depressed. I had stopped doing anything in the house and I was worried I was going to start taking out my feelings on the kids. That's why I walked out. I didn't go to the Social Work Department for help. You can't say 'I'm shouting at my children, I need support'! Not if you have a learning difficulty. That's asking for trouble.

I was suicidal actually. My G.P. gave me anti-depressants and told me they would help me mentally. He didn't tell me anything about side effects or how addictive they are. But I'd heard something about them, so I looked into it, and I decided not to take them. I was disappointed though – I felt he'd rather give me drugs than give us the support we needed.

This is how it got to be so bad: everything is harder when you have a learning difficulty. It takes me a day to do things it might take you an hour to do. You can't get the information you need when you need it. When B (my second child) was in primary school I tried to get the Additional Support for Learning Act on tape. I wanted to know what his rights were. I was told that it would take six months. I gave up because I needed it in two weeks for a transition meeting. He didn't have a social worker or a key worker, and the meeting was a disaster. So it's been a battle to get him the right level of support in his school. If you can't read and write you can't make a complaint: phone complaints mean nothing – you can't follow it up a year later and say 'I phoned to complain a year ago', because they don't have it on record.

The different departments are all over town: Education Department, Social Work Department, Children and Families. I see them all to try and get my youngest into a pre-school programme. That was a nightmare – we got him a place but no-one would pay for the transport: Children and Families said it was Education, Education said it was Children and Families, so I would go from one building to another.

That was hard because I had to travel all over town. My memory's bad and I'm not good at finding my way around. I started making trails in the grass from the bus stop to the offices, so I could find my way back, but the birds started eating the trail! So I tried marking the trees instead.

Then what happens is they change the structure or move offices, and don't tell us. Or if they do tell people it's written somewhere and I can't read it. So everything takes even longer to sort that out.





I spend so much time trying to sort things out for my two kids with learning difficulties that I end up neglecting the other three. It's not fair on them. But it is draining taking on the system and caring for my family and working.

The schools are another thing on top of that. When our kids started, the schools took no notice of our learning difficulty. Parents' evenings were a nightmare. Most of the communication with the school is done by letter. The writing is tiny and they don't make an effort to make the language easy. My wife reads a little bit, so what we do is look for dates and amounts of money, and ignore the rest. So outings and things that need to be paid for, that gets dealt with. But if the letter says swimming classes are starting and you need to bring your swimming costume on such and such a day, they keep missing out on that, and we just remember the next week. Those are small problems compared to all the rest of the stuff. If I let myself get too worked up over things like that I'd get depressed all over again.

"Asking for support from the same organisation that takes your kids away is always going to be difficult."

The big stuff is making sure the other two get the support they need. Information is really hard to get. Different places tell you different things: The Social Work Department, Citizen's Advice. And to get anything, you have to tell your story over and over again.

Attitudes of social work, teachers, learning assistants, council staff – they all judge us by our label. You know from their faces when they're not listening. You can see them writing us off or switching off.

All of that is why I felt like putting an end to it all. I couldn't see an end to it.

But...I managed to refer myself to a specialist. It took six months but I did it. He helped me a lot. He told me about People First, and through them I met other parents in situations a bit like mine.

I'm feeling better than I was, and I'm back home now. But I won't pretend we don't have problems, because we do. We could really do with some support with the kids, but there's no chance. Asking for support from the same organisation that takes your kids away is always going to be difficult. So we just get on with it".



Group 2 – What helps?

- Scouts
- Clubs
- Lock on door
- Tell a teacher/tell Mum or Dad
- Beavers
- Cleaning
- Pizza (make it myself)

As bullying seemed to feature quite heavily we explored this a little further. We did a session with all the children after we had had a break with some juice and cakes. We asked what sort of bullying they had experienced. These were the responses:

- Pushed down stairs at school
- Slagging
- Nasty things said – what you look like
- Hitting/kicking/fights
- Gangs of teenagers at the door/smashed windows/shouting/eggs thrown at house (one comment made was that other neighbours get the same because of their colour)
- Going home from school – people shout at us

The children said that the reasons for them being bullied at school and in the community were that they were easy targets. They felt that people considered them and their parents to be weak and so could pick on them. They said they were aware of other families in the neighbourhood that had been targeted, for example because of their race.

We talked about what could be done to improve the situation. They all said you could tell a teacher at school and you could phone the police. Their view was that something would happen at school but the police wouldn't do anything to help. No-one mentioned a social worker.

We finished by asking the children a "magic wishes" type of question.

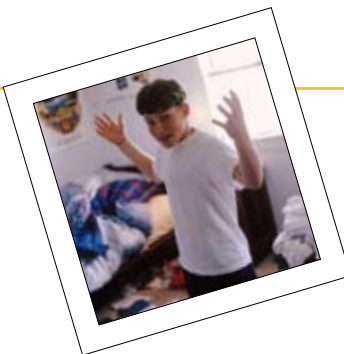
Two of the boys took that to mean what they wanted to be. Both said they wanted to be professional footballers, one for Hibs and one for Hearts, and they drew the club shirts. Another boy drew pictures of American cars and said that was what he wished for.



- Food
- Helping
- Fun
- Getting peace and quiet
- Car
- Dogs peeing and pooing

In Group 2's Worry Sack

- Difficult to have fun
- No smacking
- Egg at window
- Smashed windows
- Cleaning
- Housework
- Can't find stuff in my room
- Food
- Cooking
- Bully
- Clothes
- Playstation



We then drew some balloons and asked the children to put what would or does help them with their worries. They stayed in the same groups.

Group 1 – What helps?

- Having friends that help and understand
- Getting out to clubs with friends
- Having gran to help or other family members
- Tell people if you are getting bullied
- More money
- Getting locks on doors
- Being able to have times for your friends
- Getting away from each other (family) as being around the same people doesn't help



Key points:

1) The fear barrier

The perception that the Social Work Department is an agency that takes your children away is an enormous barrier to these parents' legitimately asking for support (for parents with a learning disability this perception is fairly accurate, as around 50% of children born to parents with a learning disability are indeed removed from the family home). The result of this avoidance was that the family's situation went from difficult to critical. Without the resourcefulness or resilience of both parents, it is easy to understand how the family could have broken down completely, with the result that the children would be taken into care.

2) Accessible information when and where it is needed

Time and time again this family's need for good, clear information has simply not been met. From the various schools they have dealt with, to different Social Work Departments to G.P.s, they have been faced with a lack of information, inaccessible information, inconsistent information, or just plain wrong information. The impact on this family cannot be overestimated. It made them feel powerless and frustrated. It directly affected John's mental health and the stability of the whole family. Parents with learning disabilities need clear, accessible information, available in the right way at the right time. With good information, the whole course of the last fifteen years would have been different.

3) Agencies not working together

The numerous agencies and departments that parents have to deal with are not set up to work well together. This father had to spend enormous time, energy and money going from one to another to sort out problems.

Not only were these different departments not designed to work together, any clear guidelines on how they should work together are not consistently followed.

4) Communication with support agencies

This is a problem that would face any parent, but for parents with learning difficulties the problem is much greater. Physically accessing buildings and offices can be difficult. Moreover much of the communication is done in writing: for people who cannot read or write this is as much of a barrier as physical access. Complaints procedures that rely on the written complaints do not present a level playing field for those who need to make their complaints verbally.



Sandra

Sandra is a single parent with two children – Katy who is 16 and Chris who is 14. When she was pregnant she asked the midwife for help and was told “Just get on with it!”

She and her partner split up when Katy was 5 and Chris was 4. That’s when she found she needed more support, and unfortunately there wasn’t any.

At that time she didn’t have any social work involvement and because of that she couldn’t get any support. She asked health visitors and school for support but she was just expected to get on with it.

She was living in a house where she had problem neighbours but she couldn’t get help with that either. It all got too much, and she found she couldn’t cope with having the children on her own and bad neighbours. So she went to Blackpool for about two months while the children stayed with their grandparents. However, that arrangement became too much for them, so they contacted the Social Work Department.

The children went into foster care. Sandra was told if she did not come back home they would go into permanent foster care. So she came back, and lived in a hostel for four months until she got a council flat. She had a choice of two, and the other one was “horrible”, so she took this one, even though it wasn’t much better.

“The support just isn’t there when it’s needed”

For the next eighteen months Sandra had a lot of contact with the children while they remained in foster care. After that they came back to live with her full time. Sandra found it hard to support her children through school. Although she could read, it was still difficult to meet the expectations the school had of parents. “Parents’ nights were hard. There was too much information and you had to hold it all in your head. It was too rushed.”

At this point she still was not offered any regular support, because the children were no longer on the child protection register. She was going through a difficult divorce and under a lot of stress. She did have some contact with social workers at this time, but they were all temporary workers. Then about five years ago she got a regular social worker. To begin with he only saw the family about once a month, which was



What children said

I am a social worker in a very busy Children and Families team based in the east of Scotland. I am a member of Working Together With Parents Network.

A colleague and I wished to speak to children who live with a parent or parents who have a learning disability to try to find out what this is like for them. We wanted to know specifically what their experiences were like to be on the receiving end of social work services, and to find out what improvements they could suggest.

We identified ten young people between the ages of ten and sixteen who were known to our team, although not all were actively receiving services. In discussing these young people with other professionals we further narrowed this to eight. We then sent out letters to these eight children and separate letters to their parents. We followed this up with a phone call to each of the parents. Following on from this six children agreed to participate. We also contacted each of the schools to seek their permission as we planned to hold two group sessions during school hours.

Group Session

On the day of the first meeting of the group two children were unable to attend. One, who was in S4 and about to sit her prelims, did not feel she could miss her classes, and the other chose not to come.

On the day then we had four children, one girl and three boys. They were aged 11, 12, 13 and 14. Two of these were siblings.

We began by again explaining the purpose of the group and started with some ice breakers as the children did not know each other.

We then split into two groups. We had on the wall a rucksack and asked the children to work in their pairs and place their worries into the rucksack.

In Group 1’s Worry Sack

- Playing
- Washing
- Shopping
- Friends
- Money
- Bullying
- Clean
- Can’t go out
- Clothes
- Looking after people in family

**Key points:****1) The difference the right support can make**

These parents have been able so far to raise their child successfully because they have had the right support. This success is doubly emphatic because of the environment they have had to live in. Yet their first child was removed, without a formal assessment having been made, on the basis that they were unfit parents. This seems to indicate clearly that it is possible to achieve more, with the right support, than some social workers believe.

2) The poverty factor

Living in poverty makes it much harder to bring children up safely and well. Statistically, a higher proportion of people with learning disabilities live in poverty, and so they are more likely to have to bring up their children, a hard enough task in itself, with the additional difficulties that poverty brings. In this family's case, these included poor quality housing and a physically threatening environment, both of which jeopardise the health and safety of their child.

3) The Children's Hearing System

The Children's Hearing System is not an accessible or inclusive process for some parents with learning disabilities. The information they are given is not clear and the hearings themselves are difficult to follow. These parents certainly felt excluded from the process. They felt that others involved in the process, namely social workers and the foster mother, are listened to more than they are. The parents were not able to communicate clearly with the decision makers at the hearing, and so they felt they had no voice. The need for better information and better communication is acute.

nowhere near enough. He used to be the social worker for the children rather than for Sandra, but later on she was told he was for the whole family.

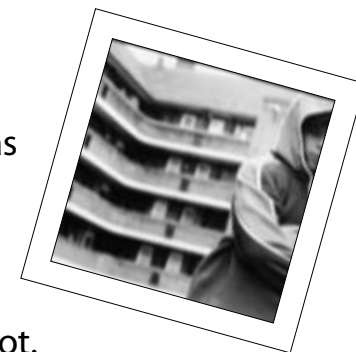
About 2 years ago the children ended up back on the child protection register because Chris was running away and putting himself at risk, and Katy was going out and drinking a lot. The children ended up staying part-time at a young persons' unit. They ended up getting in with a bad crowd there. Katy started drinking even more and ended up in a close support unit where she still is. At fifteen she got pregnant, and was encouraged to have an abortion. Later on, in a respite unit, she met someone else there on respite, who was a drug dealer.

Katy now has one overnight at home per month. Chris has three overnights at home at the moment. He has more in the holidays.

Things have moved on and the children are now off the child protection register.

Sandra was supposed to be getting some parenting support and outreach work from the unit but this hardly ever happened. What she is looking for is practical, hands-on support with a number of different issues. For example, she knows she needs support with setting and keeping boundaries, especially now the children are older. However, this kind of support is not what is being offered. Instead, it is advice from a distance. "They only phone up every so often, and they have said 'Just give us a call when you need us'".

More support at home would have helped Sandra, but just now, at this critical time, the support just isn't there when it's needed.

**Key points:****1) Becoming a parent doesn't make you eligible for support**

As a person in her own right, Sandra did not want or need social work support. When she became a parent, her circumstances and her support needs changed dramatically. However, this change was not recognised by social work, or by her health visitor. In many parts of the country, having a learning disability and becoming a parent does not meet the eligibility for receiving a service.

Even when it was very clear that the family had ongoing support needs, support was not available. It was only made available when the children were placed on the child protection register.

**2) The right support not available**

The type of support that is now available to Sandra does not meet her needs. She is not used to phoning anyone when she has a problem, and she worries that each time she phones it is an admission that she is not coping. The fear that this might be held against her makes it an unsuitable service and an ineffective use of the council's resources.

3) The poverty factor

Many people with learning difficulties live in poverty. A lot of the problems they face as parents are made worse by having to deal with other problems that are caused by poverty. For Sandra, having to live with bad neighbours, not being able to move house, and later on having to accept a horrible flat made it extremely hard to be a good enough parent.

4) The risks of being placed in care

It is wrong to assume that being placed in care is a safer option for children. Sometimes it is, but in this case the older child came to significant harm through the other people she met while in care.

5) When schools don't support parents

The school was not geared up to meet the needs of parents who had a learning disability. Accessible information was not available, and there were no adjustments made to normal school routines such as parents' evenings.

Mary and Jack

Mary and Jack have worked hard to build a family life. Today, their modern flat is spotlessly clean and stylish too, with wooden floors and a brand new kitchen. The only clutter is what you would expect in a household with a seven year old girl – toys everywhere that seem to have exploded from her bedroom. There is no indication, from a brief visit to their home, that this was a family nearly destroyed.

When Leona was born, Mary and Jack had already figured out how they could best raise their daughter together. Because Mary had serious problems with her balance, Jack did all the bathing, feeding and changing. Mary gave Leona all the nurturing a



new baby Alieesha went home the same day.

Nearly two years later, the family are still doing well. The support they have had from the service provider has been consistent and positive. However, none of it has been paid for by the local authority, and everyone is well aware that this is an exception; an exception that is very puzzling. "The main difference between the family when Melissa was born and the family when Alieesha was born, is us", said D, the manager of the support service. "If support had been available for the family the first time around, there's no reason why it couldn't have worked out. Why can't they see that this support is an investment?"

Not that there aren't any problems. Amanda is desperate to move house, but this is proving difficult. Being parents with learning difficulties doesn't give them any extra housing points. They are just like everyone else who is trying to move away from the street.

They do their best. They are re-decorating their flat room by room. But because of the damp, the wallpaper starts peeling almost as soon as it's hung.

"I'm not going to bond with her because who's going to have her on Monday?"

Meanwhile, Ross and Amanda continue to have contact with Melissa. This means ongoing Children's Panel meetings. Amanda finds these very difficult. "They're upsetting. Last time I tried to explain what I meant. I could tell they didn't understand... They talk down to you like you're stupid. They listen more to social work and Jean (Melissa's foster mother) than they do to me." However, for the sake of gaining more hours of contact with Melissa, it's an ordeal worth going through.

The future is uncertain for this family. So many decisions are out of their control. "If I could wave a magic wand, I would have Melissa back home, be a complete family. But then, I worry that I've lost my mother instincts for her." The consequences of removing Melissa from her parents without any parenting assessments being made are likely to be felt for years to come. The council are still not paying for the support that enables the parents to provide a good upbringing for Alieesha. Without that support, history could repeat itself, and one more child would be taken into care for the most avoidable of reasons.



Amanda and Ross

Squeezing past young men injecting in the close with Alieesha in the buggy, used needles scattered on the ground. They've had their windows smashed, and they have been burgled, and regularly feel unsafe. But this is nothing to do with the parents' having a learning disability – they don't feel targeted. It is just life in this street for young parents.



Amanda and Ross have had a bit of a tough life. They got together when they were young, and within a couple of years their first child - Melissa - was born. However, because the hospital had concerns about the couple's abilities to bring Melissa up safely, they contacted the Social Work Department. Although Amanda and Ross never had an assessment of their parenting abilities, Melissa was taken away and placed in foster care. Amanda wasn't even allowed to hold her when she was born.

Amanda and Ross were distraught. No-one offered them any support to make sense of what had just happened to them. What made it worse was a social worker telling Amanda "If you ever get pregnant again, you must have an abortion".

So when Amanda found out she was pregnant again in 2007 she was very frightened. She knew she needed support, but also knew she couldn't go to the Social Work Department. Instead she contacted a service provider that she'd heard of, ENABLE Scotland. She also found a lawyer. The lawyer instructed a report of the couple's parenting needs. ENABLE asked the local authority to address the recommendations in this report, so that Amanda and Ross could have the support they would need to take their baby home and raise her successfully. The authority, however, did not respond. So ENABLE stepped in and provided unpaid support for Amanda throughout the rest of her pregnancy.

When the child was born, Amanda was not allowed to take her home. An emergency meeting was called by social work. Because the baby was born on the Friday, Amanda and Ross had the whole weekend to worry about whether they would be able to keep their child or not. It was terrible being in limbo for that length of time. Ross refused to hold his baby, saying "I'm not going to bond with her because who's going to have her on Monday?"

At the meeting, ENABLE proposed supporting the family at home, and liaising with the Children and Families social workers. This was agreed, and Ross, Amanda and their

mother could give. This division of labour worked well for all three.

Not only that, but the couple had lots of informal support from family, friends and neighbours. They also got regular advice and guidance from services as and when it was needed. Jack gave up his work to become a full-time carer for both Mary and Leona, an arrangement that suited everyone well.

So Leona grew up healthy and happy. She started at the local primary school at five and joined the Brownies. Then in 2006, things began to unravel. Two allegations were made against Jack, in close succession. Both came as a result of remarks that Leona made at school. The first time this happened, a social worker arrived at the house and took Mary and Leona to the social work offices. Jack was called to go to the local police station, where he was questioned. There was also an Appropriate Adult there. Someone at Leona's school had heard her saying that Jack got into bed with her and gave her a cuddle. "I told them that that was right, or nearly. I did get into bed with Leona most mornings. She hated getting up out of bed, so I used to turn it into a game. I'd get in, then roll over, holding onto the blankets so she was left without any. When I told the police that they just didn't seem to listen." Jack got frustrated, then frightened after a while, not to be believed. However, after the interview Jack was allowed home. "Afterwards the Appropriate Adult told me it had been a big misunderstanding".

"We're scared to death of the Social Work Department. We're scared to say 'boo' to them in case they interpret that as something else."

Meanwhile the social worker and a police officer were asking Leona questions at the social work office. They took her away from Mary, and questioned her for an hour and a half. After these interviews they were allowed to go home.

The second allegation came just six weeks later. This time they took Leona away for two hours to be questioned by a male police officer and the social worker. Again Jack was asked to go down to the police station. This time it was more like an interrogation. "It was very intimidating. Eventually they asked me if such and such had happened and I said 'maybe' when I knew the answer was 'No'. It was just because I was so confused with the speed they were asking the questions."

After that Mary and Jack were told there would be a formal investigation. Arrangements were made for Leona to stay with her gran. They were told the investigation would take eight weeks. Communication was poor. The social worker



told Mary “You have to pick Leona or Jack”. Mary thought that meant: divorce Jack or you’ll lose your daughter. Naturally that was terrifying. In fact, the social worker had meant that Mary could stay with Leona or with Jack, but she didn’t make that clear. So Leona continued to stay with her gran. As part of the investigation, Leona was examined by a child doctor. He found no sign of abuse.

At some point after this, Mary and Jack got an advocate to help them say what they wanted. Although this support felt important to them, the advocate herself felt frustrated. “I felt I couldn’t do enough for them,” she said. “When I first met them Leona was already with her gran, and the interviews with the police had taken place. Jack was fearful of the social worker and not wanting to rock the boat, for obvious reasons, and I had to take my lead from him. If I’d met them earlier I could have done more, but the Children and Families Team didn’t make a referral.”

In fact, the eight week investigation took nine and a half months to complete. At this point, they got a letter saying that there was no case to answer. There would be no children’s hearing. And so Leona came home.

Key points:

1) Perceived discrimination against people with learning disabilities

Jack and Mary both felt strongly that they had been ‘picked on’. As Jack said “I spoke to my G.P. at the time. He said he gets into bed and cuddles his kids. I spoke to my brother and other people. They all do what I do.” Mary felt that the attitude of the Children and Families social worker did not believe that keeping the family together was the best option: “A lot of people think that parents with learning difficulties can’t cope, and they’re just waiting for a slip so they can step in and do something about it. That’s not what we need.”

2) The investigation took too long

The eight week investigation took nine and a half months. The parents were not told why it took so long. In all that time, Leona and her parents were kept apart.

3) The parents were not listened to

Neither Mary nor Jack felt listened to by the police or social work. They had support from an advocate and from a service, but still felt that these agencies had made their minds up very early on. The result was an extended investigation that led to a terrible and long-lasting strain on the family. Jack now suffers from a number of stress-related health problems. “I used to be the calmest, most laid

back guy you could find. Now I’m a bag of nerves. I think some marriages might not have survived that pressure. But I need to be strong so I can keep being the main carer for Mary and Leona.”

4) Poor Communication/Information

In this story the social worker did not check that Mary had understood a really important piece of information. Mary thought this poor communication was typical of this social worker. “She wasn’t very good at explaining things” said Mary. “She didn’t know how to communicate with people with learning disabilities.” Children and Families social workers are not given enough training in working with people with learning disabilities.

5) Support for the family

There was no recognition of the fact that Jack was the main carer, not only for Leona but also for Mary: “Each day I would walk Mary up to the house. I had to stop 100 yards from the house and let Mary make the rest of the way there herself. She would ring me on her mobile to let me know when she’s got there safely. I’d leave her there for a few hours, then come back and walk her back home.” The ongoing strain of the investigation was not recognised and he was offered no support. If he had not been able to stay strong, the family unit would have collapsed.

He was offered no support even after the investigation was completed, and the allegations shown to be untrue. And yet, Jack is someone with a learning disability – he has had to make sense of all that has happened without counselling or any other professional help. His relationship with Leona has been affected. “When she first came back, I couldn’t be the dad that she wanted me to be. I was scared to hug her or kiss her or be affectionate.”

And there has been no attempt to repair the loss of trust in the Social Work Department. The legacy of their involvement has been fearfulness and anger. “We’re scared to death of the Social Work Department. We’re scared to say ‘boo’ to them in case they interpret that as something else.”

6) Advocacy

An existing relationship between the Children and Families Department and the local advocacy service did not lead to a referral being made at the time that people first became concerned about Leona’s wellbeing. If ever parents might need advocacy support, it is at a time like this. If there was no policy in place to make an automatic referral to an advocacy service, there should have been.