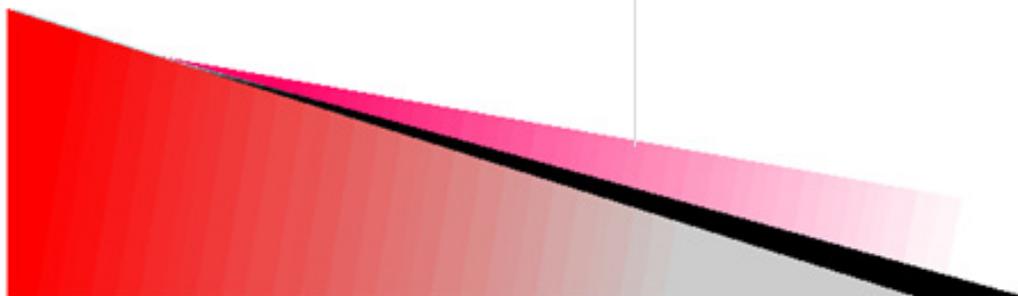




Learning Disability Wales
Anabledd Dysgu Cymru

**Being a Family: Parents
with Learning
Disabilities in Wales**



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Joyce Howarth
(Researcher and Report Author)

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Learning Disability Wales
41 Lambourne Crescent
Cardiff Business Park
Llanishen
Cardiff
CF14 5GG
029 20681160
enquiries@learningdisabilitywales.org.uk

www.learningdisabilitywales.org.uk

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Chapter 1: The context

This research was commissioned by the Vulnerable Children Branch of the Department for Health and Social Services at the Welsh Assembly Government.

The department was aware of the work of Learning Disability Wales and of other organisations in raising concerns about the experiences of parents with learning disabilities. Prior to considering the development of appropriate guidance, the department wished to secure more information about the nature of these experiences and the number of parents with learning disabilities in Wales. The department were bringing forward the Stronger Families policy and the Children and Families (Wales) Measure 2010 and envisaged using some of the powers in the measure to benefit parents with learning difficulties 'whose children may be in need or at risk'.

In particular the department were considering whether the remit of the new Integrated Family Support Teams could be extended to parents with learning disabilities.

The Welsh Assembly Government's policy document 'Statement on Policy and Practice for adults with a learning disability', 2007, states that 'All people with a learning disability are full citizens, equal in status and value to other citizens of the same age.' It is recognised in the document that people with learning disabilities may become parents and will need support from various agencies to fulfil this role. This report aims to show how this has been successful for some parents, and makes recommendations to ensure that all people with learning disabilities who become parents are given the support needed to fulfil that role.

The literature

There is a considerable and growing body of literature on issues affecting parents with learning disabilities. There are three major sources of reviews of literature and research:

- SCIE (Social Care Institute for Excellence) research briefing 14: *Helping parents with learning disabilities in their role as parents* (SCIE 2005)
- A chapter by Gwynneth Llewellyn and David McConnell 'You have to prove yourself all the time: people with learning disabilities parenting' (Llewellyn & McConnell 2005)
- Sue McGaw and Tony Newman's 'What works for parents with learning disabilities' (McGaw & Newman 2005)

The key messages from these reviews are as follows:

- There are no accurate and reliable figures on the number of parents with learning disabilities.
- Most children born to parents with learning disabilities do not have learning disabilities themselves.
- Most of what we know relates to mothers with learning disabilities; we know very little about fathers.
- A range of interventions are needed from which service providers can 'pick and mix' to suit the individual needs of each family.
- Parents with learning disabilities can and do learn child care, home safety, child health and how to interact with their children. Home based programmes are more successful than others.
- Parents with learning disabilities are up to 50 times more likely to have their children removed than other parents.
- Children are usually removed due to concerns about the risk of harm due to neglect rather than abuse.
- Lack of support services are a key factor in influencing court decisions.
- The most effective support is that which helps parents to achieve and learn. Parents themselves are the best people to judge the usefulness of support services. Families respond well to services that provide consistency and continuity in staff support and resources.

- Parents with learning disabilities are likely to be supported by generic, community based services with additional specialist support only when necessary. Services need to be:
 - ♦ family, rather than child or parent, centred
 - ♦ emphasise prevention rather than crisis intervention
 - ♦ emphasise parents' strengths
 - ♦ be tailored to the individual needs of each family
 - ♦ understand the specific needs of parents with learning disabilities
 - ♦ be long term and flexible.
- Barriers to the development and maintenance of services include limited funding, lack of skills in professionals to assess and support parents, negative attitudes about parents with learning disabilities and lack of co-ordination between children's and adult's services.
- Most of the evidence focuses on parents with learning disabilities bringing up babies and young children. There is little evidence of the experiences of parents with older children.
- Parents with learning disabilities need information that is accessible, in appropriate formats, and communicated clearly to them.
- Many professionals do not feel equipped to work effectively with parents with learning disabilities.
- Parents tend to be reluctant to approach statutory services for support because of fears of negative responses to their parenting if they do.
- The views and experiences of parents themselves have only recently begun to be heard in the literature and elsewhere (Tarleton, Ward & Howarth 2006, SCIE 2005, Llewellyn & McConnell 2005)

'Finding the Right Support' (Tarleton, Ward, Howarth 2006) marked a greater understanding of the rights of parents with learning disabilities and their families to remain together, and the work of the professionals who were trying to support this. Parent's voices were key in the pictures painted of children's services having very negative views of their abilities to parent, and the lack of skills in communicating what was needed for the children and what was happening. Professionals and parents involved in this study agreed that co-ordinated multi-agency support was vital to ensure that parents were supported appropriately.

Buchanan and Gunn (2007) argued that the structures of social work services can adversely affect practitioners' abilities to uphold service user rights and prevent workers delivering a service that is grounded in an equality of opportunities and rights-based approach. In particular the rights of parents with learning disabilities are not upheld. Elvish (2006) found that the earlier services

became involved with a family whose parents had learning disabilities, the better the outcomes for the children.

‘Working together to support disabled parents’ (SCIE 2007) sets out the principles and key features of good practice. This valuable document underlines the importance of adult services taking a lead role in responding to parent’s needs, and that good working relationships and partnership working with joint protocols are key to success. It also discusses a ‘continuum of prevention’, rather than crisis intervention, whereby unnecessary problems are prevented by meeting specialist needs of parents and post crisis support is offered which looks to prevent future problems.

A chapter on ‘Parenting and family life’ was included in ‘A life like any other’ (Joint Committee on Human Rights) which examined how the Human Rights of people with learning disabilities were being supported and enacted. They found that, overall, the right to respect for family life was not being supported, and emphasised the importance of accessible information for parents with learning disabilities. As this is being written, a mother with learning disabilities in Nottingham is taking her local authority to the Court of Human Rights over the removal of her child.

CSCI (2009) *Supporting disabled parents: a family or fragmented approach?* found that disabled parents generally have problems accessing all services, and that the extra effort needed to ensure no gap between adult’s and children’s services is not always happening. They found particular pressures for parents with learning disabilities: lack of accessible information, low expectations on the part of professionals about their ability to parent and an expectation that parents with learning disabilities plan for every practicality of having children – a much higher standard than is expected of others.

Children’s services

While the research was being carried out, there were several child abuse cases reported in both the Welsh and UK national press. In Wales, there was the report of a review of services for children in Swansea, which reported serious concerns in service provision and the setting up of an Intervention Board to oversee improvements. There was also the ongoing case in the Vale of Glamorgan of a vulnerable young man who had sexually assaulted the children of an adult placement foster family he was with. In the UK, the terrible story of Baby Peter’s life continued to dominate the media, with children’s social workers often being scapegoated as responsible through lack of actions. Since this incident, there has been a recorded rise in the numbers of children removed from their families.

Lord Laming’s (Laming 2009) review of child protection in the light of the death of Victoria Climbié was published, making recommendations to increase

communication between services on concerns around children, increase training for all professionals and improve Serious Case Reviews. Although this was not immediately applicable in Wales, the lessons learnt were heard and made workers aware of their practice obligations.

It would seem that over the life of this study, pressure has been growing on children's social workers to guarantee the safety of children, surely an impossible task. Parents with learning disabilities have voiced their revulsion at the abuse Baby Peter suffered, and their fear that they may now be more likely to lose their children.

Services for people with learning disabilities

This background in children's services needs to be set against the rise in awareness in services for people with learning disabilities of the rights and needs of parents with learning disabilities. A UK wide network of both parents and professionals has been established over the last 2 years, which aims to spread positive practice and to promote policy change, so that parents with learning disabilities and their children can get better support. Networks have also been established in Wales, facilitated by Learning Disability Wales, which meet regularly (see Appendix 3). The network in North Wales began only recently and already has 36 members, both parents and professionals. The network in South Wales has been campaigning for change in service provision for parents since it began in May 2007. The parents in South Wales planned the first Welsh conference on supporting parents with learning disabilities (Give us a Chance to be Parents 2009) and advised this study on content and resources being used.

The right to parent is also part of the changes in the way services are planned and delivered – a person centred approach is now expected from services, with each individual with learning disabilities being encouraged to consider the life they want to lead, and to find ways to lead it. For many people, this means doing what everyone else of their age is doing, and becoming a parent. The self-advocacy movement has championed both person centred approaches and awareness of human rights.

Some of the work on scoping the numbers of parents with learning disabilities was based in Caerphilly. Work here has also moved on in the course of the research. The adults' and children's services there are together developing a policy on supporting parents with learning disabilities and Carmarthenshire's Family and Children's Team are beginning this process, as well as looking at local research that is needed to inform the process. Other services are developing new ways to support parents with learning disabilities (see Appendix 4)

England

England has had 'Good Practice Guidance on working with parents with a learning disability' since 2007. This sets out clearly a summary of relevant legislation and policy, and how adult and children's services should work together to improve support to parents with a learning disability and their children. The guidelines have raised expectations of both people with learning disabilities and services, and have been used as a checklist to challenge unsupportive services when court proceedings occur. Guidelines on commissioning services for parents with learning disabilities are being written and are due to be published this year.

Scotland

The Scottish Consortium for Learning Disability have conducted a small scale research project to look at the lives of parents with learning disabilities, 'A Fair Deal for Families?' which records the difficulties parents have with services and lack of accessible information, the way in which services do not work together, and the fears parents have of losing their children. The Consortium are also producing new guidelines for Scotland on supporting parents with learning disabilities, based on the English guidance, due for publication in July 2009.

The parents

This study has been about finding good support that has worked for parents who live with their children. It must not be forgotten that this does not apply to all parents with learning disabilities in Wales; perhaps it applies to a small majority. The stories below have been collected from parents I have met in my travels around Wales who have had their children removed. I have only chosen 3 to represent the pain and heartbreak that is suffered.

Bron and Tom

Bron and Tom were 20 when they had Aaron. They were known to learning disability services, and Aaron was put on the child protection register when he was 2 months old; there were concerns over their ability to care for the baby. Bron is not very confident, finds reading very difficult and finds it hard to ask for help. She's a mum who carries her baby's picture round with her, and loves talking about what a beautiful baby he was, and how he smiled and giggled. Sure Start helped Bron learn how to bathe, feed and dress Aaron, but there was no other support. Bron found it increasingly difficult to know what more to do for Aaron and who to ask for help. Her relationship with Tom was also going through a very difficult time. After an assessment where Bron did not understand what was happening nor the implications, Aaron was removed from his family at 6 months old. Bron still grieves for his loss, and descended into an ongoing depression. She was given no support to cope with this appalling loss and is truly heartbroken. Tom found it more and more difficult to cope with her grieving, trying to keep his grief to himself so as not to upset her. 2 years later the relationship

broke up and Bron found herself homeless. She is currently under psychiatric care.

Heather' story

Heather's little girl was taken into care in a voluntary foster placement as a close relative had smacked and marked her; Heather had not done anything wrong.

Heather's daughter was placed on the child protection register; she was only allowed limited contact with her daughter. Heather's little girl's name is no longer on the child protection register, but she is still in foster care. The Children's Team have now applied for care proceedings, due to the smacking incident and they also think that the little girl's development is delayed.

Heather says:

'I feel upset not having my daughter here. I feel like I have failed as a parent.

I don't like going to the council offices to see my daughter. I don't like being supervised at the contact and don't like the situation. I don't like that they have to watch what we are doing with our own daughter. I don't know what they are writing down. I don't like it when they accompany me and my daughter to the toilet. I can't take my daughter out on my own.

I don't know if my daughter will ever come home.

I can't get to speak to my daughter on the phone at the foster parent's house. I only get to speak to my daughter on the phone when she is having contact at my cousin's house. I'm not able to take my daughter to any appointments as the foster parents do this.

I don't like going in or near my daughter's room. She isn't here with us.

I don't go to church when my daughter is not with me, I only go to church when my daughter can come. (I have unsupervised contact with my daughter at church). I don't know what to say to people when they ask where my daughter is.

I miss being able to take my daughter out for a meal, a walk, a drink. I miss talking to my daughter and playing with her in the garden and the paddling pool.

I used to do some housework with her, such as doing the hoovering and dusting, making some cakes, dressing up with her, doing colouring with her and doing some jigsaws and reading books with her.

My daughter asks about coming home when we have contact in the council offices. I don't feel like the local authority has listened to our views in their decision, such as the plans we made at the family group conference.

Getting out of the house and going to the “Give us a chance to be parents” conference in Llandrindod Wells, helped me to talk about my situation to other people. I did not have to tell them lies about where my daughter was.

I hope things will get better and things will get back to normal sometime.’

Julie’s story

“Over a year ago I was feeling unwell, so I went to the doctors and found out that I was pregnant. 3 weeks later I went into hospital and the baby was born 2 months premature. The new baby boy had to stay in hospital for a long time because he was only 3lbs when he was born.

I already had a little boy who was 3 years old at the time and I knew that I would find it really hard to cope with a new baby. I told my social worker that I wanted my new baby boy to be adopted by a new family to give him a better life. The social workers were very helpful and supportive. When he was let out of hospital my baby was put into temporary foster care and I knew it was best for him to be adopted.

My family started putting a lot of pressure on me to keep the baby. I didn’t want to see him because I knew it would be so hard but my family kept pressuring me, so I decided to try and look after him. I found it very difficult with the new baby and told my social worker that I was sure that it would be best for the baby to be adopted. The social worker was really supportive and helped me a lot.

I told my family that I wanted the baby adopted and they started putting even more pressure on me to change my mind again. It was really difficult dealing with my family when they were putting so much pressure on me, but I knew that it would be best for the new baby if he was adopted and had a better life than I could give him.

I have stopped contact with my baby boy and want him to be happy in a new life. My social worker and advocate are still being very supportive and always listen to me and the problems I need to talk about.

It was very upsetting and painful. It was a hard decision to make. It was a brave decision but a hard decision. It’s not easy to cope with, a very depressing thing. Not a day goes by when I don’t think of him. It’s still painful now, it’s quite hard. I’ll get there but it’s going to take time. It takes time to mend a broken heart at the end of the day.

Life could be better than it is, I suppose. I just want to get back to normal with my toddler son, and get on without Social Services. What I want most is to be a good mum to him, to be here for him 24/7, and to keep ourselves to ourselves.”

These are typical of the lives of many parents with learning disabilities in Wales. This research aims to begin to end this by showing what good support is, how it can be provided and ensure the information goes to people with learning disabilities, to enable them to campaign for the change they feel is needed.

Chapter 2: How many parents?

This short research study aimed to scope, for the first time, the approximate number of parents with learning disabilities in Wales. It is acknowledged (Booth 2002) that it can be difficult to count how many parents there are because services have diverse providers with no specific lead, records can be poor, and there are no common definitions of what a learning disability is due to the invisibility of many parents to official agencies. This is not therefore a definitive study, but a beginning in trying to ascertain the numbers.

Work took place in Conwy and Caerphilly. Through the networks of the researcher and Learning Disability Wales, contacts were made with senior managers in statutory and voluntary organisations and short articles were published in a variety of local newsletters. Meetings were held with various service providers, including social service teams and voluntary organisations such as Homestart to discuss the issues around parents with learning disabilities and how the research would be conducted. Where it was not possible to meet, telephone conversations took place to establish the need for the research and the importance of completing the questionnaire on the numbers of parents the service had worked with. (See appendix 1)

As some of the services to be contacted were within the NHS, the All Wales Primary Care Research Management and Governance Centre was approached to enquire about ethical approval. After some discussion, it was decided that this was an audit so ethical approval was not required.

A questionnaire was developed which asked for basic information such as the number of children, and the initials and age or date of birth of one of the parents, to prevent double counting. This was sent to services along with a short assessment tool (See appendix 2) for recognising a person with learning disabilities, aimed at professionals working in mainstream services. This was developed from a tool used in Norfolk (Morgan & Goff 2004).

Conwy

The questionnaires were sent out, and slowly the replies came back. Unfortunately the only responses received from Conwy were from the adult learning disability service, and a voluntary organisation that stated they had not worked with any parents with learning disabilities. The midwives I approached contacted their Clinical Governance Office, to check on completing the questionnaires. The department were satisfied with the responses to their data protection queries, but were not happy to immediately release the information which would prevent double counting. Permission was granted as this report has been written, to speak with their Information Governance Department, but unfortunately this was too late. This meant that no information from midwives or

health visitors was forthcoming from Conwy. To encourage responses from other Conwy services, telephone calls were made and emails were sent, but nothing more was received. Responses from only one service produced too little data to be of use, so results from Conwy are not included.

As the Conwy response was so different to the Caerphilly response, it is important to consider why this was so. Caerphilly is close to the author's base, so it was easier to access and more visits were made than to services in Conwy. Caerphilly children's and adult's services have been working together over the last 3 years to find ways forward in supporting parents with learning disabilities. This included a day's training by Dr Sue McGaw from the Special Parenting Service, Cornwall NHS Trust; all services with any involvement with children or parents were invited and this resulted in a much greater awareness of the existence and needs of parents with learning disabilities. The joint work has continued, with a draft of a 5 year strategy on supporting parents with learning disabilities completed. There has been no similar joint working in Conwy, so it can be assumed that services are not at the same level of awareness.

Caerphilly results

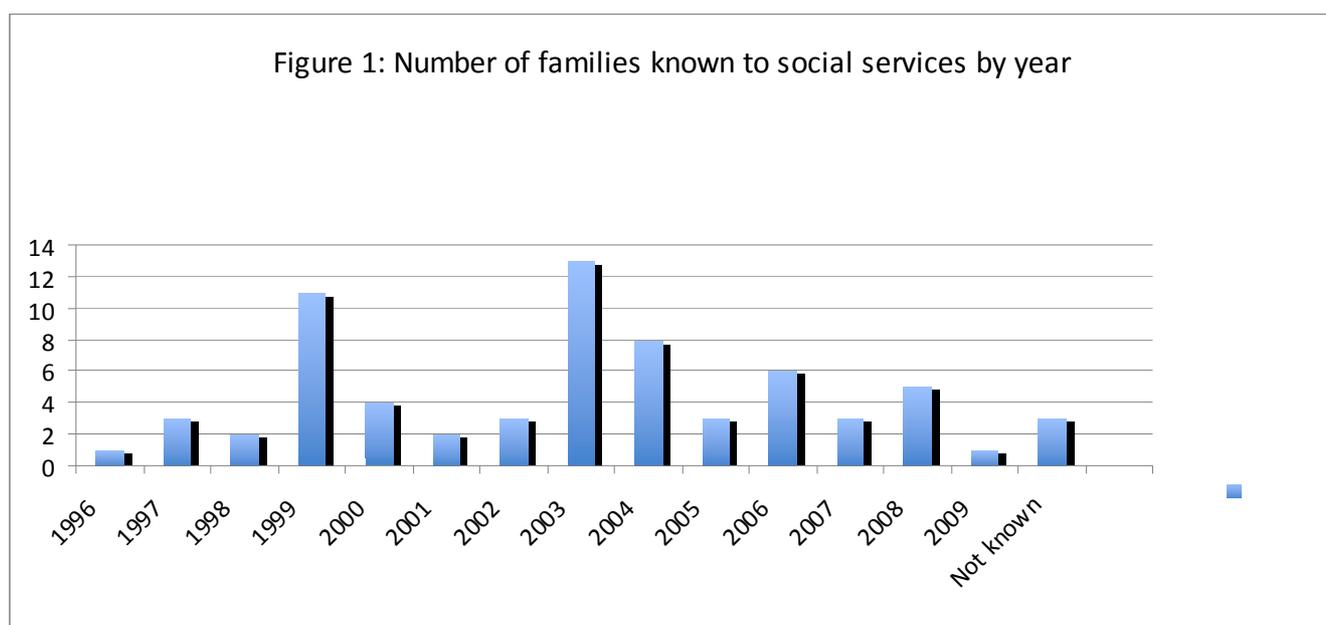
15 questionnaires were sent to services in Caerphilly, with 8 responses. The children's and adults' social service teams worked together on the data they provided. Of the non responders:

- two services which are not based in Caerphilly, but are contracted to support parents and children around sexually harmful behaviours, said over the phone they had not worked with parents in Caerphilly in the last year
- one service said 'We work with people living with domestic violence, not people with learning disabilities' – this seems to assume that people with learning disabilities do not have any part in domestic violence.
- 2 were small local charities who didn't answer the phone.
- finally a midwife and health visitors; this seemed to be due to pressure of work, as the individuals concerned were very interested in the research when spoken with.

A total of 91 families with at least one parent with learning disabilities were identified: 68 from social services and a further 23 from voluntary groups such as Homestart records. Overall, just over half (54%) were single parent families. A much higher proportion of the families known to voluntary organisations were single parents (70%) compared to social services (49%).

Source	Number of single parent families	Number of two parent families	Number of parents not known	Total number of families
Social Services Total	33 (49%)	27 (40%)	8 (11%)	68 (100%)
Voluntary organisations Total	16 (70%)	7 (30%)	0	23 (100%)
Grand Total	49 (54%)	34 (37%)	8 (9%)	91 (100%)

Social service records went back to 1996, although for 3 families, the year they were first known to services was not recorded. Between 1 and 13 families became known to social services per year, with peaks in 1999 and 2003/4. There seemed to be a slight increase in the number of families becoming known post 2003, but no clear trend was evident. The information from the voluntary organisations did not include the dates from which families were known.



Forty-six (68%) of the families known to social services were still on the active caseload.

- 10 (22%) were on the child team's caseloads only
- 15 (33%) were on the adult team's caseloads only
- 21 (46%) were on both.

Thirty (65%) of the 46 families on the active caseload still had children living with them. In seven of these families, however, siblings had been removed. All except one of the families known to the voluntary organisations (96%) still had children

living with them, and in only one of these families had a sibling been removed. Of the 22 families no longer on the active social services caseload, 10 (46%) still had children with them, with this information not known for 4 (18%). Overall, of the families known to social services, 40 (59%) had children removed; this is in line with previous findings (Tarleton et al 2006).

One voluntary group, which was managed by a person who provided an adult placement for a woman with learning disabilities, reported that 75% of the parents they worked with had learning disabilities – a total of 230 in 2008. However, details of only 8 families were completed, so this was all that were included in the final data.

All those listed by social services are on the register of people with learning disabilities. This means that they have been formally assessed as having an IQ below 70, the health service definition of learning disability. Those listed by the voluntary organisations will not all have been formally assessed, and so some may have an IQ over 70. However, to those supporting them, they still present as having similar needs to people who are formally assessed as having learning disabilities. As there is no evidence of a relationship between parenting ability and IQ, this may not be a suitable way to decide level of need (Booth and Booth, 2005).

Therefore their inclusion in the overall numbers would appear to have some validity in terms of identifying the preferred type of service support to parents with learning disabilities.

What this means for Wales

There is no reason to think that Caerphilly is unusual in the numbers of parents with learning disabilities who live there. The county has the fifth highest teenage pregnancy rate in Wales (Statistics for Wales 2008), at 53.7/1000 in under 18's, so there is a possibility that the figures for parents with learning disabilities may be slightly higher because of this. However, the effect would be minimal in the numbers we are looking at.

The 2001 census shows that Caerphilly's total population is 169,521. Lowe et al (2007), in looking at the prevalence of people with challenging behaviours across a total population of 1.2 million in South Wales, used the estimated administrative prevalence of learning disability as 0.45% of the general population. Applying this formula gives the estimated population of people with learning disabilities in Caerphilly as 763.

This study has identified that 91 families with parents who have learning disabilities are known to services in Caerphilly. If this is taken as 91 individual parents, this represents 12% of people with learning disabilities in Caerphilly,

which could be a conservative estimate, as in some of the families both parents may have learning disabilities.

According to the 2001 census (Office for National Statistics 2002) the adult population of Wales is 2,240,306. Using the above formula, this gives an estimated 10,081 people with learning disabilities in Wales. The study's results extrapolated across Wales would give a total of 1,210 parents with learning disabilities.

Summary

- Joint working, training and planning across social service departments, and all other services involved with children and parents, can result in a greater awareness of the existence of parents with learning disabilities.
- 59% of families known to social services had children removed.
- 65% of families still on social services active case load had children living with them.
- 23 families not known by social services were thought by voluntary organisations to have learning disabilities.
- 12% of people with learning disabilities in Caerphilly are parents.
- Extrapolated across Wales this would give a total of 1,210 families where at least one parent has learning disabilities.

Chapter 3: The parents

I interviewed a total of 11 parents across Wales:

- 2 married couples
- the wife in a married couple
- 6 single mothers and a single father

Their children ranged from 10 months to 24 years old. During the 10 months of this project, I travelled widely around Wales, meeting as many parents as I could in a variety of settings, to find participants. All except one of the interviewees were found this way; parents were generally unwilling to speak with someone they had not met at all, as they were wary of another stranger asking about their parenting – they felt they were continually judged, and did not want to invite more of that. Some feedback from professionals who asked parents to take part also suggested that parents are always worried that they may have their children taken into care, and were concerned that I might disclose information to children's services.

Methodology

The 2 couples were interviewed together; the other parents were interviewed by themselves in a variety of settings, including advocacy offices and their living room. It was important it was somewhere they felt comfortable and happy to meet with me. One mother whose first language is Welsh was interviewed with a supporter who also had Welsh as her first language. The supporter played an entirely appropriate role, only speaking when the mother spoke to her and as far as I know this was on questions of translation, not encouraging responses.

The interviews lasted between 50 minutes and an hour and a half. A semi-structured topic guide was used which covered their children, their feelings about being a parent, what made it easy to be a parent, what made it difficult and advice for workers. I was very clear both in information material provided before the interview and again at the beginning of the interview that the information provided would be confidential unless the person told me about any previously undisclosed abuse. I also made it clear that they did not need to answer the questions and could stop the interview at any time they chose.

Interviews were recorded and transcribed. The transcripts were read and re-read to identify major themes and issues. These were cross checked with my research supervisor. The names of the parents have been changed.

Being a parent

All the parents I met loved being a parent, their children were the centre of their lives. None would want to be without their children and have a life free of ties and responsibilities. Cerys was very clear about this

I think that when you are a parent, you've got a responsibility to be a parent, not to go out drinking and things like that. If you are a parent, you're a parent full stop.

When talking about Rachel, she smiled incessantly and loved showing off her photos. She couldn't imagine life without her daughter

The joy of seeing my daughter and of playing with her and seeing her having good mates. Seeing her grown up like a, well she was a baby, now she is like a young lady.... To start off with, its scary to be a Mum, but now because I am getting used to being, well actually a Mum, it's quite a nice feeling. Seeing her coming up to me at night and giving me hugs, cuddles and kisses It's a nice feeling to know I am there for her and she knows that as well. It's a nice feeling.

When asked what was good about being a parent, Jo said simply

It may sound daft, but just to have someone saying 'dad'. .. I'm happier than I have been in years.

Tony smiled when he said

Best thing is watching them growing up, yes, that's right, watching them.

Amy sees her daughter and herself as a team

She helps me and I help her; we both work together.

Dawn, who shone when she spoke about her daughter's achievements, just enjoyed being with her

I like being a parent. She's company.

Tracy was realistic about family life, and probably speaks for most families in the country

I love them both to bits, like, and I get on well with them. I know we argue and I know we fight and stuff, but I wouldn't be without them.

Dawn, who is also carer for her physically disabled husband, proudly told me that when her daughter was born there were

people telling us we would never cope but we have.

All the parents I spoke with would agree with that – they often weren't expected to cope but with varying levels of support they have.

Common experiences

Children in care

The parents I interviewed are living with their children. However, for 5 of the families, their children had at some stage been in care and 1 child in one of the families continues to be; this was because of a family emergency or when the parents parted. Jo had what he saw as a battle to have his son returned to his care some years later, when he was in a position to offer a stable and supportive home. The parents were always worried that they would not be able to have their children returned and were willing to do anything to enable this. Tracy said

I done everything that Social Services asked me to do. I ... literally gutted the house, got it a little tidy, they came and checked the house and they said, well we haven't got a problem, the kids can come back. So I was quite happy that the kids could come back.

For Tony and Karen their children were taken into care when their baby daughter became dangerously ill

Christine had meningitis and the kids were taken into care.

Some went to Tony's mum and dad. Christine was in hospital, and they went to mum and dad's and they went to my sister's. They went to social services then.

Tony came back from hospital to get a change of clothes for Karen. Nothing could have prepared him for what he found social services children's team had done while they were with their ill child

Everything in the house, in a skip, the whole lot went in there. Belongings, kids' toys, teddies. Everything went. Came back to a strange house, stripped the whole house. ...

Gutted the whole house. They blamed the house ...

It wasn't the house at all. He had meningitis. He took it, caught it out somewhere else. It wasn't the house at all. ...

they blamed our home. They took our home.

As well as worrying about a dangerously ill child, he now also had to try to get the house in a fit state for their family to come back to and to satisfy social services.

They relate that no-one spoke to them about it, that Tony just found it in this condition. While remembering this, Tony was very agitated; Karen felt that they had been very badly treated, and was upset that

We had no apology. No apology from social services at all.

It was proved that Christine had meningitis, not an infection caused by the condition of the house.

Sexual assaults

Three of the families had to deal with the sexual assault of one of their children. One of the fathers (who was not assessed as having a learning disability) raped his severely disabled daughter; an uncle raped a niece temporarily in his care and a neighbour sexually assaulted a young teenage boy. All of these cases have been to court and the perpetrators convicted. Only one of them felt that the child's social worker had helped them through this trauma.

Jo thought it had all taken too long to deal with, and didn't understand why a teacher who was told did not report it immediately.

He was sexually abused by a 39 year old woman. Not just my son, other kids in the area as well. I heard rumours from other kids and asked my son if it was true, but he said no. Then a teacher was told the rumour, but nothing seemed to happen. My son told the truth when he had a falling out with the woman. He told me then and I phoned the police. She's been to court now, and is waiting sentencing.

Karen recalled the moment when

My daughter came in, started hitting me, and kicking me and saying 'I hate you. I hate you for leaving me.' We understand why now, because she was abused ... by Tony's brother. Now it's all coming out.

For a third of the families interviewed, to be trying to support their children through sexual assaults and to deal with their own emotions and the repercussions within the family seems too much to bear, but somehow they are all coping. A greater understanding is needed of how families deal with this situation where one of the parents has learning disabilities.

Problems with letters

Under the Disability Discrimination Act 1999 (DDA), service providers have a legal duty to take reasonable steps to make it easier for disabled people to use their services. It is known that many people with learning disabilities have literacy and general communication problems, and that this is part of their impairment. However most local authority workers in children's services seem to ignore this

law and continue to send letters and professional reports to parents in a format that is inaccessible to them.

Four of the parents talked about the poor support they had received, most of which centred around their inability to understand the letters they were sent and the jargon often used. When asked what made his life difficult, Jo said simply

Sometimes getting letters, I don't read well. No-one checked if I understood the letters before I came here.

Cerys encapsulates the thoughts of the other parents:

I don't understand the big words, I don't understand the meaning of them. ... the letters they were sending to me there were like big words that make me panic, made me worry a lot.

Professionals seem to give little thought to whether parents have literacy skills, and have no idea how their letters can affect people who don't understand them. Parents learn quickly what logos are used by services, so know where they've come from. For those who are going through care proceedings, it vastly increases the stress, to know it is a letter from children's services, but not to be able to fully understand it or not be able to read it at all. Although supporters can help them to understand, they may not be there for some time after the letters arrive, and certainly reports can take more time to explain than a supporter may be allotted.

For Cerys there was an added difficulty; her first language is Welsh. Her English is extremely fluent, but when she becomes stressed she finds it more difficult to both understand and express herself. During the interview with me she had a Welsh speaking supporter with her, and often stopped to check the meaning of a word I had used, or how to say something in English. All the child care proceedings that took place were in English; this was because the children's social worker was English, and this disadvantaged Cerys immensely. Even with a Welsh speaking supporter by her side, the main business of the case conferences, where she knew she was facing the possibility of losing her daughter, was happening in a language she did not always understand. Cerys is a woman whose disability includes impaired communication, yet she was expected to play her part in proceedings that were dreadfully stressful, in a language that she is not comfortable with.

Extended families

All except one of the families had been supported by their own extended families to some extent. Although this occasionally brought tension, it proved to be the most consistent, loving and practical support available at all hours

If I've got any problems and I can't get hold of my social worker, I just go over and tell my mum. And then my mum comes over and sorts whatever the problem is.

The parents often acknowledged that without their family's support they may have had their children removed. Sometimes they had to swallow their pride and accept that they were seen as failing by their family

If the family wasn't around probably Rachel would be in care now. It was either asking the family for some help or leave her go to a care home, which I didn't want to happen.

The support given by families varied from very practical help with budgeting, shopping and decorating to respite during school holidays. The parents usually appreciated the support, not taking it for granted

If I want a break she'll take her. ... Stay overnight. ... Stay. In holidays though, like Summer holidays, I have three weeks then she have three weeks. We share it.

Without this ongoing support, it is possible that a number of these families would not be together.

Views of children's service

The comments made by the parents about the way children's services worked with them were extremely negative. These included

Over the years we've had all different social workers telling us off.

the amounts of hoops I had to jump through.

now and then I thought they were being nosy.

Seven of the families had difficult times with children's services, and often had a low opinion of the social workers. Although this is to be expected when a department has considered removing your children, it would seem it is also down to children's social workers not having an understanding of learning disabilities, nor the way support is usually offered. From the parents' accounts, they feel that social workers from children's services treat them as children themselves because they have the label of learning disabilities. Karen reported that

Over the years we've had all different social workers telling us off. ... One social worker bollocked me off for kids drawing on the wall! She shouted at me!

It is unacceptable for social workers to shout at their clients for choosing different lifestyles to their own. It is also poor practice for clients to perceive the way feedback is given as being told off. There seems to be little empathy to how a parent may be feeling, or flexibility in demands on the parents. Karen and Tony seemed to have pressures piling up:

- their new born baby had a life threatening illness
- their young daughter was recovering from meningitis, and they were recovering from the stress of this
- their house had been gutted, so everything in their home was new to them and unfamiliar
- they had 4 other children to look after.

We weren't sticking to no appointments. Like going to Family Centre, we had to; we automatically had to go to Family Centre. I wasn't going to Family Centre, I had things to do, I was too tired.

It does feel that there was no flexibility in expectations regardless of exhausting and unusual circumstances.

Other parents talked about how they could not rely on children's service social workers to do what they said they would, and the problems this caused. Tracy especially felt

she doesn't sort out the problems... So then it gets worse and worse.

Margaret, as a new mother, had feared the involvement of social services in her family's life. Along with other parents, she thought she was being harshly and negatively judged on no evidence because she had learning disabilities. Although her worst fears of losing her baby were unfounded, she still thought that

Social service made it hard. The hoops I had to jump through. They said I had to spend 5 days in hospital, wanted an inspection of the house and it had to be immaculate. I had to know lots by 1 month, or she'd be put on the At Risk register; they thought I was going to hurt her!

Margaret thought that giving birth and being with a new born was already enormous pressure for any new parents, but this added pressure of perfection was terribly trying. She considered that

Giving birth and this first year with her has been easier than dealing with services at the beginning. All the stuff I had to go through.

These are, of course, only the participants' views of their relationship with children's services. They may seem overly strong, but they do suggest a depth of feeling that requires attention.

A totally different view came from Amy, whose daughter has severe learning disabilities and after her divorce has moved into a flat for herself and her daughter. She has received ongoing support from the Disabled Children's team over the years, as well as from the Learning Disabilities team. Her experience was

They are all really nice, they are, they're lovely.

Both teams look at support as long term, unlike children's services generally, and have a good understanding of disabled people and their needs, including easily written resources. The result for Amy has been good, appropriate support, an understanding of her impairment and how this affects her life, and good ways to work with her.

Summary

- 11 parents from across Wales were interviewed
- All the parents loved being parents; their children were the centre of their lives.
- 5 of the families had children taken into care. They had met the conditions imposed for the return of the children to their family.
- 3 of the families had children who had been seriously sexually assaulted. All 3 families had involved the police.
- Parents had problems with literacy, and were worried by letters they could not understand. No adjustments to methods of communication were made for their impairments.
- A parent interviewed whose first language is Welsh reported that child care conferences and reports were in English. This disadvantaged her.
- Extended families provided support to all but one of the parents interviewed. This support was vital in helping to keep the children and parents together.
- Most parents had received poor support from children's services; they felt they were treated badly because of their learning disability.

Chapter 4: What is good support?

This chapter examines what parents with learning disabilities regard as good support. Overall, what they value has minimal cost implications, as it is mainly about attitude and approach. Different individuals and organisations were referred to, and when the reasons for the praise were explored, it was because:

- the parents were treated in a manner that made them feel listened to
- service professionals were reliable in doing what they agreed to do
- support was given with problems – they were not made to feel everything was their fault
- choices were offered in how to approach anything from problems to housework
- they felt their home was their own and not under the control of a service worker

The only service provided that some parents thought important, and would like more of, was respite care. This is exactly the same as what is wanted by many parents with a disabled child.

Respite

The parents with disabled children value respite care enormously, as it gives them time to themselves, to recharge their batteries and to catch up on chores. It has been shown that respite can help relieve stress for parents of disabled children (Chan & Sigafos 2001). Tracy again felt not listened to about both her and Lee's needs.

I was hoping, like, there was a place where my son could have gone for respite. But Lee's social worker does not agree with that. ... he wants to go back to the foster mum, she was brilliant I said, look, well one weekend, would it be possible just for Lee just to stay with her just for one night or something? But she said no, it's not a good idea.

Tracy does not remember being given any reasons why it was a bad idea, just being told it was. This shows the need for advocacy for parents as ongoing support, not just around crisis points such as child care proceedings; an advocate would have been able to argue Tracy's case, and if reasons based around Lee's needs were given for refusing the request, to explain it later to Tracy, in ways that she could understand. As it stands, Tracy has been left feeling her opinion on her child's needs count for little and this has undermined her role as a mother.

One of the main supports that the parents interviewed needed, was to establish routines – whether this was regular eating and sleep routines with the child or

routines that enabled them to see how to do all the housework and shopping necessary. School holidays upset those routines and some parents can find it very difficult; this may be linked to their impairment. Cerys was one who enjoyed her child's company, but found it difficult to do all the necessary chores by herself as well

the school holidays I have to take her everywhere with me like shopping on a Monday ... On the Wednesday usually we're meant to do housework, but because the school holidays is coming up I can't do housework because I have to take her out, or whatever. It's not easy to be a single parent when the kid's always around. It's quite hard. I've got a routine ... So normally she's quite good, but I can't do everything at once when the school holidays are here.

Many parents find school holidays a difficult time; it is no different for some parents with learning disabilities, and it is a time, especially for one parent families, when they may need extra support to relieve the stress.

Amy recognises the importance of the respite care that Hannah received, and acknowledged that it gave her time for herself. As Hannah was coming up to 18, she would be moving to adult services, and there were many concerns for Amy around choosing a new respite place for her daughter that would suit her as much as the one she had been using. For both of them, it meant new people, places and routines. Amy was not clear if it would mean changes to the amount of respite that her daughter would be offered, and was especially worried that it may be less than the current respite entitlement

She goes for respite. She goes once a month for one night; not enough is it?

This is one area that extended families excelled in; taking children on holiday, having them regularly for an afternoon or babysitting. Tracy's mum loved being a grandmum, and spent a lot of time with her grandson

He goes over there quite regular. He goes over there every day, because she only lives across the road from us.

Margaret said

I'm lucky with my mum. If I have to do anything at the weekends, a big clean or anything, she has her.

Often their families were the only people that the parents would trust to babysit, even though this limited their own options; their child's safety and the peace of mind this brought came first.

the whole family I trust most.

Being listened to

It is worrying that parents' concerns about their children are not listened to; a number of the parents thought this was because they have learning disabilities and are not expected to know anything. It is especially concerning when you consider that where parents with learning disabilities do have their children removed, it is because of neglect (Booth et al 2005). Here, parents have been asking for help with difficult issues, but are being ignored by professionals.

Karen and Tony have 6 children; 3 of them have now been statemented as having special educational needs. Matt spent his education until secondary school in trouble; Tony says this was because he was frustrated; he couldn't do the work, not because he was just a naughty child. However, the school and social worker disagreed. Karen had tried to be heard

I've been saying over the years and they just wouldn't listen to me ... He was statemented, they did listen in the end. Just hard getting them to listen. They called us overprotective parents, over anxious parent. It's like go away and leave us alone. They're right, that's it.

Tracy's son, who was disabled and had ongoing health needs, went to clubs that were arranged by his social worker – as he was a young teenager, both he and his mother needed space away from each other to enable him to develop healthily as an independent young man. The clubs met this need well. He also had a support worker he saw once a week, but

Now they're on about cutting support down for Lee which I don't agree with but if that's what they want then I can't really go against that, because it's Social Services.

Tracy worried that Lee's behaviour, which had become very difficult and at times violent since he became a teenager, would worsen if the extra support was removed. She felt this concern was ignored by Lee's social worker. Tracy found it very difficult to oppose her son's social worker – her learning disability made it more difficult for her to marshal arguments, and she worried that she would lose all services for Lee if she disagreed.

Being reliable

Many of the parents talked about professionals saying they would do something, then not doing it. They found this very frustrating, and often difficult to challenge, as they were often dependent on the person doing other things. They felt very much let down. Tracy found

With my son's social worker, I've asked her to do things and she hasn't done them, so it's quite difficult.

Tracy knew her own social worker could be relied on to help her sort things out, if she'd tried to speak to her son's social worker nothing seemed to happen

I go back to my social worker and tell my social worker I've been to Lee's social worker and told her what the problems were and nothing's been done. So then my social worker gets hold of her and then sorts it out then. So my social worker's brilliant, like.

Obviously this does nothing to help the communication and respect between departments.

Jo had previously experienced a similar lack of reliability, which he read as lack of respect towards him, that he was not seen as worth doing things for. He was much happier when people were clear about their abilities

if she can't help she'll say then find someone who can help.

A large case load cannot be taken as a reason for failing parents, and being well-meaning is not enough. A parent said to me

If I don't do what I said, I get trouble. If she doesn't do what she said, nothing happens.

Again the lack of equality and respect comes through.

Sorting out problems

Baby Ann arrived earlier than expected. David and Margaret had only had the keys to their new house for 2 days, and nothing was ready for the new baby. Margaret had got to know Flying Start before Ann's birth, and they came in and helped the young couple get the house ready

Everyone in Flying Start was really good.

They sorted out the problems that the extended family were unable to tackle.

Dawn's daughter was being bullied at school. She knew there was something wrong for a while, but Sarah wouldn't say anything. When Dawn finally found out the problem, she went to see the Head, but felt he wasn't interested and didn't help. In desperation

I phoned the school nurse and she came out to help me.

Sarah changed schools and was much happier. The new head also seemed more understanding

They told me "If you got any problems, come and see him, he will sort it out for me."

It is vital that this sort of problem is sorted out immediately, and the school should have policies to support this. However, the child's welfare was left at risk until Dawn could find someone who would sort it out.

With 2 teenagers in the house, Tracy often found herself in situations that were difficult and felt unsure what to do; she needed help quickly to retain her position as head of the house, especially with the ongoing problems with Lee. Her own social worker recognised this

If I've got a problem I just go down and see my main social worker and she'll sort it out there and then or, if not, then a couple of days after.

Tony and Karen often found dealing with children's services very stressful; they did not always understand what was being asked of them and felt they were treated in disrespectful ways. They knew they had to comply, but were not always sure exactly what was needed. Tony's support worker Michael began to act as a filter between them and children's services

What happens now, if they've got any problems with the house now, they speak to Michael first. Michael tells us you'd better do something with the house. Michael said at the meeting, if there's any problems with the house, just let me know then he tells us.

This relieved the stress for these parents in dealing with children's services. They found Michael respectful towards them, used language they could easily understand, spoke with them rather than writing letters and supported them to choose what actions to take.

The family are again a source of great help with problems. When Tracy's social worker was not easily available

I just go over and tell my mum. And then my mum comes over and sorts whatever the problem is.

As new parents, Margaret and David found themselves up against a host of things they've never had to cope with before. Margaret has realised, like many new mums

Mum is on hand, I can ask her about anything. Mum knows lots.

Choice and control

Four of the families had support workers going into the house to help with a variety of practical tasks. Tony and Karen had this support for some years, but then it had stopped

We had support in the mornings as well, in the mornings. Now it's been withdrawn. They're happy now with the house and we don't need no help.

This support was from children's services, and was regarded with suspicion by Tony and Karen as they had been through assessments where everything they did was written down. They felt that often they were being watched rather than supported. Karen also thought that she had the morning routine sorted, and the support workers were just sat watching her, not offering anything constructive. Tony, however, still saw his support worker Michael from the learning disabilities team

He comes out once a week now. On Monday, half past 10. Any problems, I talks to him. Any problems, phones. He asked me do I have any problems? Yes, he's very good.

Tony felt that Michael helped him to be a dad, and that he could talk about anything with him without being judged. If Michael offered any advice, Tony knew he was free to choose whether to take it or not. This is one of the important differences for the parents between support from adult and children's services – they feel they have to do everything asked of them by any worker in children's services, whereas workers from adult services they feel treat them in a more adult way

Tracy's support worker was employed by her residential support provider. She found this support invaluable in helping her to stay on track with her chores, and learning the new skills she needed as her children developed. What she valued most about this support worker was

it's up to me, like, she comes in and she says 'right, what're we doing today?' Well I say, Monday's we tidy up the house.

Tracy felt she was in control in her own home, and this helped to increase her confidence in her own ability to cope.

Peer support group

Only one set of parents belonged to a support group for parents with learning disabilities. At the time of the interviews it was the only one in Wales, and gave evidence to the Parliamentary Committee (Joint Committee of Human Rights 2008). At the time of writing there is a new group in North Wales, with another 4 being planned across Wales. Tony and Karen were amongst the first members of their group

Jenny got a list of people with learning difficulties with families, and she does a support group now. Jenny done a support group, advocacy work after that.

Through the group they met other parents in similar situations, so broke their isolation and shared coping mechanisms. They valued the group, as they could relax and talk about whatever they needed to, without feeling judged.

Advice

The parents were asked what advice they would give to supporters. The following from Cerys and Amy encapsulated the accumulated advice

What they have to think about is how does the person feel inside them. How is their brain thinking, how's the feelings, because everybody's got feelings haven't they? I think they have to think that we've got feelings as well not to think (asked support worker for translation) ... not to be discriminating.

Think about me and Hannah together.

The parents saw themselves as part of a family, not the separate entities that services seemed to view them as.

Summary

- Parents regard being listened to, reliability, sorting out problems, choice and control of their own home as being the top factors in good support.
- Respite care is a service greatly valued by parents with a disabled child.
- Extended families can often be relied on for respite.
- Some parents have not been listened to over worries concerning their child's welfare. This has resulted in a lack of diagnosis of educational problems and continued stress over service provision.
- Parents feel let down and disrespected by workers not doing as they agreed.
- Some problems, such as their children being bullied, feel insurmountable. It is important that all professionals take these concerns seriously.
- It can be useful to have one point of contact for professionals to cut down on the number of people parents are dealing with, and thus decrease stress.
- Extended family can be relied on to help sort out problems.
- Parents feel they are being treated in a more adult manner if they are given choices around how to do things. It also gives them back a feeling of control over their own homes which can be lost with a number of supporters giving instructions.
- A peer support group of parents with learning disabilities has offered a way out of isolation and new ways to cope to one set of parents.
- Parents advise workers not to forget their feelings, think about how their brains work and not to discriminate against parents with learning disabilities.
- The final advice was to think of the parents and children together, not separately.

Chapter 5: How is support provided?

At the end of each parents' interview, I asked the parents who had given them the best support, and asked for permission to approach the people to interview them. The findings here reflect the findings of 'Finding the Right Support' (Tarleton et al 2006), which covered Great Britain.

Extended Families

The parents all agreed to me contacting professionals, but none wanted their families interviewed. The reasons for this ranged from

I don't want them bothered, they do enough.

to

I don't want them knowing all my business.

This has unfortunately meant that there are no views from extended families in this report. From the interviews with parents, the support offered by families was similar to that given the world over

- Cerys' extended family had Rachel over for tea 3 or 4 times a week
- Karen and Tony's families helped decorate and furnish the house after it had been gutted by children's services
- Dawn had no professional support at all; her mother-in-law baby sat regularly and had her grand daughter to stay a lot over school holidays
- Amy's parents had Amy and Hannah living with them during one difficult period, and were the only people Amy allowed to look after Hannah
- Tracy's mum only lived across the road, so often had her grandson for tea – and in the early days had helped Tracy with shopping
- Margaret and David felt able to call on their parents for whatever support they needed – whether decorating or babysitting

Professional support

I interviewed a total of 16 paid staff; none of these were social workers from child care teams as the parents did not view them as sources of good support. Staff interviewed were:

- 4 support workers
- 4 independent advocates
- 2 social workers from a learning disability team
- 1 social worker from long term care children's team
- 1 social worker from disabled children's team
- 1 supported living manager
- 1 residential home manager
- 1 care manager
- 1 health visitor

For half of these staff, this was the first time they had worked with a parent with a learning disability, although some had experience in a related field, such as child care. All of the independent advocates had worked with a number of parents, generally having 3 or 4 on their current case load. One of the social workers in the learning disability team had 9 parents on her current case load – although only 3 of these had their children living with them. She talked about the mental health problems of the parents whose children had been removed.

Training

The experience of professionals working with parents with learning disabilities was therefore very varied. Only Tracy's care manager had participated in specific training on working with parents with learning disabilities, and this was only

conferences and seminars where we have gone...just touched on brief(ly).

The only example of good training was from the Flying Start health visitor who thought that the training her team had been offered was

a lot more accessible to us because we're Flying Start and because of the nature of the caseloads that we're working, we've been able to access (it) and we really have had an amazing amount of training and it's been fantastic to be honest.

Much of this training had relevance to the parents with learning disabilities she supported.

The number of parents with learning disabilities that professionals are working with is sizeable. However, there is little or no good, relevant training open to professionals.

Support for workers

Qualified workers and advocates reported good and regular supervision. For the unqualified workers interviewed, who are not office based and so less likely to regularly see colleagues, it was a different story. These staff are working with people all the time and reported no supervision, but just asked for support if they had a problem. One person commented

I've been at it so long, they just leave it to me anyway.

The assumption seems to be that they will cope – and it can be difficult to admit when you're not coping in these circumstances. There is also a quality issue, as without good, regular supervision it is difficult to quantify the standard of the service they are providing and offer development opportunities that could enable them to improve.

For everyone, the main source of support was the team they worked in and colleagues

I put a lot into colleague discussion, to be honest (laughs). And I reckon that's something you're going to find everywhere because I think colleagues support each other more than anything. And as I say, our team is quite strong now and we've got a good team in place.

This support was informal and available whenever it was needed, not on a monthly or 6 weekly basis as for supervision. It could also be given in return to colleagues who needed it, so the worker did not feel they were burdening others, and thus helped build the team.

This also was considered to have benefits for the parents, as often

We tend to work as an open team; although we've all got obviously our own clients we tend to be a bit nosy and get to know each other's clients so if anything happens they haven't always got to see the generic duty worker they can actually contact someone within our team.

One advocate was a member of a large network of parents and their supporters, which met quarterly (see Appendix 3). She found this a valuable source of support

through the network and other advocates outside the county. So you can offload, you know you're not struggling alone. We're all dealing with the

same issues. Certainly my understanding from talking with other advocates is that (the) issues they face I'm facing here, we get the same problems very often, and the same answers. Yes, it's good to have the network and get to know other advocates who work specifically with parents cos they are a different group to other people with learning disabilities.

What makes support for parents difficult?

Everyone interviewed spoke about different issues that made supporting parents with learning disabilities more difficult for them, and at times made the service received by the parents not as good as it could be.

The emotional impact of the work could be difficult for those supporting parents through care proceedings, especially if they are at risk of losing their children. Tracy's social worker said

I think Tracy's case affected me in the beginning a lot emotionally because of why her children were taken away ... you question yourself as a parent and you question your home-life and you imagine somebody coming in and making judgements about how your garden looks or how your house looks or how you reprimand your children or what you give your children for tea at night. So in that respect I think in the beginning it really did affect me ... that kind of thing was really kind of emotionally charging.

Tracy's family support

Tracy had

- her own social worker
- residential support worker
- residential service manager
- her eldest child's social worker
- young carer's support worker
- her son's social worker
- her son's support worker
- her son's respite care provider
- her son's teacher
- her son's learning assistant at school
- the health care staff involved with her son's ongoing health issues

This was a total of more than 10 different professionals from different services, with different ways of working, different agendas, different jargon, different paperwork, different offices and different phone numbers. However, this was the smallest number of professionals that had worked with her family since the children's services had become involved 3 years previously.

Cerys' social worker commented

It's definitely one of the cases you think about at home and you can't switch off.

Too many people

There seemed to be little liaison and negotiation between services about what support was being provided. This sometimes led to a large number of people being involved, all with different agendas. When she became involved, Tracy's care manager found

she had so many people coming in and out doing different jobs ... I think she was over-fed too much information and too many people going in and telling her different things so I tried to be the only contact that she had because I think she was a bit overwhelmed.

Checks were done on exactly who was providing what service to Tracy and her family, and agreements were made as to what could be cut down. There was also an agreement that no new services would be provided without checking first with the care manager. Her son was approaching transition, which would bring yet further changes to cope with. It is a complicated system with complex relationships to be dealt with, confusing at the best of times.

Amy's social worker had similar feelings about the numbers of people concerned with Amy and Hannah's lives, and felt that everyone was providing everything possible to try and support the family through a crisis.

I think with parents with learning disabilities you can't overload them as well and I think everybody was thinking "This support would be good, this support would be good." But it is about getting the right support and not just providing any support because it's there.

She recognised the problems this was causing for Amy, and how her confidence and belief in her own abilities were being threatened by well-meaning services

A lot of the control was taken away from Amy and Amy was looked at as a bit of a child really and it's like "Hang on, this mum's going to have to care for this child on her own you know, with not this amount of support in the long-term." So it's about kind of making her more independent, not dependent on services.

One of the reasons for this happening seemed to be that no-one had overall responsibility for ensuring that the family had appropriate services according to their need. The disabled children's team social worker commented

there's a lot of little pieces going in and that's, I think, what the problem is, there's no links between them all. ... it is very difficult for me to understand all the separate graduations of involvement that people have, so if you're in the middle of it, it must be intensely difficult at times.

Lack of communication

Everyone spoke of how their work was made more difficult by the lack of communication between the different departments and individuals who were involved with the parents. Information on meetings that were due to happen and agendas for these meetings could be difficult to get. An advocate stated

when I asked the social worker for more information they felt it was very invasive.

Another advocate had similar experiences, and although she tried to be understanding, was frustrated that her support for a parent in child care proceedings was hampered

I haven't found communication very good on their part. Quite often they've kind of forgotten to ring me up and tell me about something that's going on, or haven't returned my calls; I'm not sure if that's probably because they're busy or whatever but, it's a case in point.

There seemed to be assumptions from outside social services that the different departments would liaise; one residential support worker said

Child & family team and learning disabilities team don't know what each other are doing.

There was also a feeling from the independent service providers that they were not included in any discussions about service provision. One manager told me that her efforts to ensure good support for a tenant had been ignored, that statutory services seemed to want to work in isolation and not have to negotiate needs.

Teams within the same department do not seem to communicate with each other over what they are doing; at times different teams barely recognise each other's existence. This leads either to a waste of resources and increased confusion for the parents, or to a lack of needed services. There should be one person or department that sees the family as a whole, not as separate beings, and be informed by all services of what is happening and how the support is being provided. They could also ensure that different professionals had information about what was happening and the support going in.

I think we work in very different ways

There seemed to be no reciprocal understanding between adult and child services about how each other works, and little effort seemed to be made to remedy this. One social worker did try to bridge this gap, by giving a seminar for health visitors locally

Two of us went and there was about 15 of them (Health Visitors). We didn't expect to be bombarded quite as much, but we were trying to explain and some of them were going, "Well they haven't got any education. They shouldn't be parents", "They can't read." "They can't do this" and they're quite judgemental and we had to challenge them on a few issues.

This comment seemed to be in direct contrast to the health visitor from Flying Start

we're not there to judge. We're not there to trip her up or to say 'you did that wrong' ... because there's no right or wrong, is there? ... But we're there to support her... them, the family, when they need us.

This far more open approach to a family in need is not a common experience of children's services, and perhaps one that should be considered. It is working well for the Flying Start team, who are welcomed by all types of parents as supporters rather than critics. The health visitor also summed up an important point in these differing approaches

There are safeguarding issues that we can't support that are having a negative impact on that child's well-being or welfare or developmental outcomes or whatever, in which case that then comes into the safeguarding arena and we have to address that. ... there are parenting issues that can be supported so that they don't have a massive and negative impact on a child. ... we often don't need to enter that safeguarding arena because we can put the support in sooner to improve the outcomes, really.

The care manager voiced what is experienced as a more typical approach by children's services towards parents with learning disabilities, and the approach that her training and professional practice led her to

"we must remove the child straight away" and I understand why they initially say that, obviously... but I come at it from a different angle, "hang on, let's look at the scenario, let's look at the adult involved, let's look at how we can support them". Kids need their parents you know and let's see how we can support that relationship, first of all. I don't want to keep a kid in a risky situation ... I don't mean that at all but let's see what we can do first. ...

Let's try and be a bit more supportive from that angle first before we go heavy-handed.

The residential service manager found that Tracy was criticised because

the youngest one had nits a couple of times and the house was very... messy.

For her, the important issues when looking at Tracy's parenting were

they were still fed, they were washed, they were watered, they were loved, they were given cuddles every day. ... We can put people in to help her to maintain her tenancy, let's look at how we teach her some new skills, get her on some courses. Does she even know how to read her washing machine? Does she know how to read a cookery book? ... No, she doesn't. So how do we support her to learn these skills?

These two workers seemed to emphasise that supporting people with learning disabilities is a long-term commitment. It appeared that children's services work in very different ways; the disabled children's social worker said of children's services in general

there is nothing really that will go into families long-term.

The supported living manager observed, from her 6 years experience of supporting parents

Some health visitors give people stuff to read or only show people once how to do something. They don't know good ways to work with people with learning disabilities, they have limited approaches; their lack of time plays into this. They can also have a 'I've shown you once, you can't do it, you can't learn' attitude. Parents are given written plans they can't read, there are no creative attempts, using videos or magazines. They don't try to find other ways.

There were issues here around the ignorance of, or ignoring of, the Disability Discrimination Act. Workers in children's services did not appear to think that they could ask for advice on ways to work with people with learning disabilities from those professionals or individuals who already support them. When a children's social worker was asked how she could improve the service she had offered, she commented

I think to get advice really from someone who has either worked with learning disabilities or knows that field. I think I could have possibly spent more time with Adult Learning Disability team to get a feel from them of how

they work and what support they've got, that they could offer, and I don't think you get the opportunity to do that though really, do you?

Opportunities to learn from individuals with expertise in given fields need to be built in by senior managers as part of a strategic way to support parents with learning disabilities. Workers on the ground find it hard to fit more into their working days unless an action like this is prioritised by management.

Lack of knowledge of Childcare Procedures

Every worker interviewed who had to support a parent through childcare procedures felt at a loss to know what that procedure was. One advocate, who thought she had learnt procedures through previous experience, said in despair of a current case

there doesn't seem to be any logical process that anybody seems to be following at this moment in time.

A learning disability social worker related

I trained as an adult social worker so I didn't really have a huge knowledge of the childcare system but other social workers in the team at the time did, so they helped me through my first lot of care proceedings and you just pick it up as you go along really.

Another social worker found

initially it took a lot of time, even though I'd done child protection and things in college and looked at the laws and everything. But the way they worked, it's not the same as we worked, so it was difficult at the beginning to understand what was going on and having to ask the right questions and getting support from others in the team as well. Just to make sure are they doing what they are supposed to do and is that right.

Legal processes can devastate a number of lives if the child is removed, yet workers outside children's services have to 'pick it up as you go along' and 'ask the right questions'. This appears to be a system that is balanced against parents and there is a lack of information accessible to social workers in different teams and other professionals. Information on these critically important procedures should be open and easily available to those who need to know about them and training on local protocols should be offered to anyone who works with parents.

A very experienced advocate found that parents were not informed of what was happening

Very often the parents haven't been told they're being assessed, never been told how or when or why or anything. Never ever said. One she texts me and says when's the assessment starting? It had started, already started. Nobody was ever clear about it to her and then when I asked the social worker for more information they felt it was very invasive.

As an assessment can lead to a parent having their child removed, it is hard to understand why the parent was not informed that every action will be recorded and could be reported in court. It may be again that the social worker had informed the parent – but in jargon that the parent did not understand. As this advocate reported

There's no plain talking, there's no talking at a level that somebody with a learning disability can understand, and say why we're doing this assessment and what tool – they talk about a specific tool, and that doesn't mean anything to my parents. What does it mean? It would be easier if they said part of the assessment is supervised and check how you make the bottles or check how you change somebody's nappy, or check how you hold somebody. Cos they don't realise that all that's being looked at. Parent does not realise – how I'm turning this out, holding the baby, doesn't realise that to play and talk and all that is being assessed.

Again, it appeared that the Disability Discrimination Act was being ignored at what could be the most important time in the life of parents and their child.

A social worker who had talked about the problems of finding her way round childcare procedures, kept the parent as her focus in it all, because

It's not easy because you're facing losing your children and it's not easy for her, not at all.

Lack of consistent standards

Many of the professionals found it difficult to know what standards the children's services were expecting of parents. It seemed that what was regarded as an acceptable standard of housework, childcare or hygiene differed from professional to professional, and was based on the professional's own personal values rather than an agreed set of standards within a department. An advocate found

It's one of the big issues with parents isn't it, one person saying this is good and another saying it's not good. You never know if you're right or wrong.

For a worker trying to support a parent to attain an acceptable standard so that their children can continue to live with them, was reported to be terribly frustrating – and confusing for the parent. An independent living manager reported that

It all depends on the community worker's own personal standards – they are often unrealistically high, but everything that doesn't reach the standard is reported. And the parents aren't told in advance what that standard is.

This manager, who had recently had a baby herself, was pleased when Margaret told her that now she had a daughter she wanted to get qualifications and get a job, so that she was a good role model. She was astounded when a child care worker's response to Margaret's ambition was

She can't work, she's had a baby.

In a world where parental leave for a birth is a clear expectation, and with most women going back to work after the birth of a child, this attitude appears a very unprofessional and restrictive one.

There seemed to be frequent changes of social worker for some parents, due to either staff sickness or moving to another job. A disabled children's social worker agreed with this

A lot of staff sickness has been an issue in getting meetings together. There's high levels of sickness ... There's been changes in staff, that's the problem, you know. .. I think that can cause periods of instability for the family.

This is an issue that should be explored – are rates of sickness higher in children's teams than other social service departments? The disabled children's social worker was perceptive in recognising the effect a change of personnel can have on a family. The advocate noted that it can mean

a change of social worker and change in attitude.

It would be very helpful for all concerned if there were a set of standards for each family stating what the minimum expectations are in parenting. This would mean that an individual person's own values would not be transposed to the professional setting, allowing parents and professionals to know what they need to do to be able to bring up their child. With these standards, it is important not to lose sight of the things essential to a child's development. The disabled children's social worker was clear on this

It's the love they've got for their kids, because I have never met a family who have got so much love for their kids.... we know that it's chaotic,

hygiene standards aren't always brilliant in the home, you know, but the love that they show to those children is absolutely astounding! Isn't it? ... at the end of the day, they're such lovely children that Tony and Karen are doing things right, otherwise they wouldn't be such lovely children! You know, their needs are met.

Policies

No-one who was interviewed knew of any learning disability policies or joint protocols in their locality for working with parents with learning disabilities. Caerphilly Social Services children's and adults teams have a draft protocol, and Carmarthenshire has just begun work on one. This vacuum left all workers unsure what they are supposed to do or can do. One social worker said

If we do come across to work with the children's team they've got their legal documents, haven't they. They've got their protocols and policies.

Supporters of people with learning disabilities felt powerless in comparison to their counterparts in children's services, as protocols set out the way things need to be done, ensure everyone understands their role and responsibilities and what they can expect from other professionals. This social worker had a copy of the English guidelines (Dept of Health 2007) which she was using to inform her own practice and to try to educate and challenge others if necessary.

There is no doubt that everyone interviewed felt the absence of some official backing for their work, and would welcome joint protocols from their local authority and guidance from the Welsh Assembly.

The family

There was concern from people working in all services that often the family is lost sight of – it becomes the parent and separately the child, as they are dealt with by different services. A children's social worker commented

when you're dealing with a family, it's a family isn't it? ... the family is not worked with as a family.

She was concerned that this fragmentation of a family led to needs not being met, especially of children in a family who did not have a social worker

I think that's the problem, is that you work with two of the children but I think there's more, maybe, that I should be... could be... should be doing with the other children, but it's because they're not open, they don't get that support.

This concern for the family led one learning disability social worker to suggest

I would like more joint working, joint assessment that maybe it would be nice sometimes to have maybe a family meeting, to ensure that we are supporting them appropriately.

Another learning disability social worker came back to the family throughout her interview, concerned that there seemed no way to support parent and child together

it would be nice if the children's team were able to share the funding with us and get a support worker to do things with Rachel and Cerys together ... The children's services can sometimes be seen as inflexible, both in their approach to assessments and child care, as well as funding things for parents to do with their children, which surely would be for the child's welfare?... we are constantly trying to get more support for Rachel and Cerys together.

To show that it can be done, and that it makes a difference, the health visitor from Flying Start was clear

that's what Flying Start is, it's very much about looking at the family and the family dynamics.

What support has worked well?

The professionals I interviewed enjoyed their work on the whole in supporting parents. It was frustrating at times, and other times they were made angry or sad by the treatment of parents by services. Most of them were passionate about families staying together, and enabling parents with learning disabilities to live with their children.

Empathy

Many of the workers interviewed displayed an incredible depth of empathy towards the parents they supported. Sometimes this could be painful, when parents were going through child care proceedings. It was also something that helped motivate them to continue to support the parents, and understand what was needed. The care manager had learnt she was not welcome in the school holidays and commented

I know what my house is like in the children's holidays and I respect that and then I make another appointment to go. And then the house is fine, it's lovely. But, you know, she's not trying to hide anything from me, she's just being a mum in those holidays, "And I'm doing painting and messing round and I can't be bothered and I'm having lazy days." Isn't that what we all do?

One of the social workers voiced a similar thought to others

when you're then trying to teach certain skills you are then all of a sudden getting home to your messy house where you haven't put your dishes away and "God, how can I go and tell somebody to clean..." you know...it made you look at every aspect of your life as well as working with somebody.

This level of empathy was felt by a number of the workers, who compared their own parenting standards to those that appeared to be expected of the parents

One health visitor said 'I went to the house and there were pots in the sink' – pots in the sink! She'd just had a baby 2 weeks previous. The health visitor said this was neglect and reported it to social services. Good job she didn't come round my house when I had mine. Now tell me, why should that happen to her and not to me?

This illustrates again the different standards that appear to be used for parents with learning disabilities.

An advocate who had worked with a number of parents who have lost their children spoke movingly about

the longing for a child that I have experienced myself, you know, these people are experiencing just that same level of longing and intensity and you have some group of professionals who just come in and make a decision.

Another advocate remembers the first time she accompanied a parent to a case conference

In a room with 12 people talking about your parenting, I'd be terrified. I'd be more terrified if it was me. ... Some of the stuff motivates me to work even harder.

It is not possible to order workers to be empathetic towards the people they work with, but it does appear to give a greater understanding of the situation the parents are in and some of the coping strategies they use. It certainly motivates a number of the professionals to keep going and try to improve services.

Peer support

During the period when this research was undertaken, there was only one peer support group for parents in Wales. The advocate who facilitated the group spoke at length about its value for the parents

We have a parents group where there's a number of parents who come together every fortnight. So they have a lot of peer support. Also in the group we invite professionals in, so parents as a group think of things to ask these professionals – such as child care workers, managers – about their rights and things like that. ... but mainly they get peer support. They understand. I don't have learning disabilities and I'm not a parent of children with disabilities either so I think what I've done mostly is give them a support network, of people they recognise that I'm not the only one in this boat.

The parents seemed to benefit from using the group

They get a lot from each other I find, more than they do from me. It's user led, the group decide on everything. ... It's building self esteem, self confidence, they feel worthier. It's difficult, I mean they're disclosing really heart-rending stuff but also they're able to laugh. They come in the group and very often they do laugh. ... It's knowing there are people there with the same or similar problems, and they are fantastically helpful to the other parents, and what they get out of the group more than anything is self confidence, self belief. Certainly with the group when it started they were quiet, didn't say a lot. The fact is now that people come in and it's a very relaxed meeting place really. I think that's what they get from the group really, is each other. I don't know how to put it any other way, just that feeling of belonging, self worth, that they're doing something positive.

A support worker spoke in a similar vein about a parents' group she had worked with in England. She talked about the isolation that parents can feel, and that the parents' group helped break this isolation, gave them a place where they could share what was happening and find others who had experienced that.

A lot of them are so lonely. They need a peer group, where they know they can call on someone when things get hard.

Using peer support groups to increase self-esteem and skills has been shown to be effective in a variety of circumstances (Naylor, P & Cowie H 1999, Funck-Brentano, I et al 2005). It has clearly worked for parents with learning disabilities and should be replicated across Wales.

Advocacy

It was very evident that in child care proceedings advocates were vital to ensure the parents' voices were heard and that parents understood what was happening. Although learning disability social workers can perform part of this role, they do not have the independence of most advocates and find it harder to challenge colleagues who work within social services. As an advocate said

we do challenge services and their rights...individual's rights and the local authority's responsibilities.

Advocates require skills around a large number of areas: One has done a lot of work around debt, as her experience is that

they need a lot of support around finances; they get themselves into a lot of debt, they always want to buy nice things for their baby, which is fair enough, we are pummelled by advertising all the time and so we sort of do debt management with them, budgeting, that kind of thing.

Dawn specifically needed support from her advocate with her daughter's school

the other thing was around her daughter moving schools because of bullying issues.

A social worker in learning disabilities commented

advocacy is essential. There is not enough, there should be more.

Many advocacy services in Wales are reliant on funding from the Welsh Assembly Government in a grant scheme administered by British Institute for Learning Disabilities (BILD). Advocacy groups have been informed that the current round of funding may be the last of its kind, and other ways need to be found to fund advocacy services. The need for advocates for parents with learning disabilities is considerable, especially around child care proceedings when complex legal issues are debated. A children's social worker agreed that

What we could do with is more independent advocacy. We don't have enough of that.

Practical support

For the majority of parents, practical support has been essential. This has included debt management as well as housework and healthy eating. Some of this has been provided by children's services and some by learning disability services. The Flying Start health visitor did

Everything from feeding, bathing, changing's, everything – safety, the lot.

She was aware that all this had to be done in as practical and accessible way as possible, and spent more time with these new parents than perhaps she would normally, to make sure they had fully understood instructions

We had to be a little bit creative, in that we used lots of pictures and we drew lots of posters and we stuck things up in the kitchen ... and that seemed to work.

One learning disability social worker found her tv viewing habits useful

So we've been through all the toddler stages. She would ring up for some practical support because she had nowhere else to go. So I was kind of like Supernanny on the other end of phone, talking her through tantrums and sitting her on the stairs and time-out.

Cerys found people in positions of power overwhelming, and could not always take in what was said at school about her daughter, so her learning disability social worker had given

support with school reviews for Rachel.

When she first became a single parent, many things were difficult for Cerys, and she had no regular routines. A community support worker was put in, and found that initially she was

someone for Cerys to talk to, because there were some things at the start that she didn't know about, and wanted to have someone to talk to and ask, and maybe afraid to show that she didn't know.

This support became more practical when Cerys' confidence in the worker grew, moving to skills with housework and hygiene. The support worker was very aware that she was going into someone else's home, and was careful in the way that she worked

She doesn't want anyone to boss her around and tell her what to do. She just wants someone there to help her do things, but to do it in a way that's positive. Yeah, and you don't want someone judgemental going there.

The learning disability social worker knew that some practical support from children's services did not work too well and was clear

our support workers have had training around learning disabilities so I think that's important.

This highlights again the importance of training for all professionals on what it means to have a learning disability and best practice ways of working.

Tracy's care manager was specific that they needed to teach Tracy skills that would help her cope with all sorts of situations, not just housework. Tracy was taught how to do a risk and choice plan. This gave her skills in assessing what risks different people and situations could bring to her family, and the possible consequences of her choices based on this. The choices were vitally important for Tracy

"Yeah, so it's my home and it's my choice?" "Yes", "Right!" And she was really positive then and got on board to signing up to things and learning new skills.

Her care manager summed up the approach that all the workers had

let Tracy be an adult and teach her the skills to be in control.

Building confidence

Some of the parents had grown immensely in confidence and self belief, since good support had started to be provided. The common thread in this support appeared to be that the parent had been viewed in a holistic way, with person centred planning philosophies behind it. These parents had particularly difficult events to deal with in their lives, which had led to them becoming more isolated. One learning disability social worker thought changes had begun in the mother when she was given the opportunity of

seeing there was a different life as well, because she's having all these opportunities with the support workers ... giving her experience of going to the local town and going to different places, going to eat somewhere different, going shopping.

One mother's needs were carefully assessed by the community learning disability team, and with her they decided

it had come out about possible self-advocacy training for her to build her confidence ... once she had gone through that training, which was about a four week session, she started coming to our social groups then as well, it led onto our social groups then as well, which we run once a month so she was coming regularly to those.

Since then

She has been on various courses for numeracy, literacy, cooking, all sorts of things. Some of those courses have been certificated which she is immensely proud of because it's qualifications and she has never had anything like that before ... the stronger she is getting, the more skills she is learning; she is becoming more confident and assertive and able to cope with certain situations herself. ... I think the person-centred approach is definitely the way forward.

This indicates that growth in confidence and assertiveness can lead to success in coping with new situations. If this type of support is given, the ongoing support needed around parenting decreases. Another single mother was supported to go to

Lots of different groups, where she's meeting other young women or women of a similar age and she's made contacts through that group then where she's friends outside and meets people ... and build her confidence.

It is especially important to bear this in mind for parents whose children are getting older, as they will probably leave home at some stage and the parents will need help to readjust to a new time in their lives. So it can be key to help someone find a role

which gives her purpose outside the role of being a mum.

Parent's achievements

For all the workers, what helped them in their support activities was seeing how the parents developed and achieved as a result of that support. As Tracy's care manager remarked

I can't help being very fond of Tracy and feeling proud of what she has achieved and just flourishing herself, being confident and accessing the local college, learning to read and write and building more social networks, having friends, just growing in confidence. Always been a beautiful mum.

Amy's social worker observed

She's so come out of her shell. And she's so capable and so really enthusiastic about things.

Tony and Karen's advocate had seen them work through some terribly difficult times, and now saw her role with them diminishing

I'm proud of them. They can certainly speak up for themselves now. A couple of weeks ago I went out to see them and said I've still got you down as my clients, but I'm not sure what there's left for me to do here.

Jo's supporter was full of admiration for the way he fought to regain the custody of his son, and changed his way of life to enable this.

Jo, he's brilliant (tearful). He was never diagnosed as having learning disabilities, spent 32 of his 52 years in prison. He had no coping skills – he would get drunk, then break into places to sleep. He's now got himself straight – got a job, did it all himself for his son. And his son is determined now to stay with his dad.

One social worker, asked what helped with the support she offered, summed it all up

The thing that makes it most easy to support the parents, is the parents themselves, and the relationship they have with their children.

Summary

- Parents did not want their extended families interviewed.
- 16 professionals who supported parents with learning disabilities, in a variety of services, were interviewed.
- Those professionals who supported parents through child care proceedings were adversely affected by the experience.
- All professionally qualified staff received regular supervision; unqualified staff needed to ask for support when they needed it.
- There were often a large number of paid workers from various agencies involved with a family. There was little communication between these agencies.
- The Disability Discrimination Act is frequently disregarded by professionals in children's services.
- Children's services and adult services work in very different ways, and appear to know little about each other's working methods.

- Adult service staff find it very difficult to gain information on child care procedures and relevant legal processes
- None of the services interviewed currently have policies or protocols to guide staff when working with parents with learning disabilities.
- There were no consistent standards on what constitutes good-enough parenting. The expectations appear to change according to the worker's personal values.
- No service appears to work with the family; the family unit and the needs of the family are not considered.
- Those involved in supporting parents with learning disabilities tend to be empathetic towards the parents, and this helps to motivate them in their work.
- Two workers spoke about a parents peer support group, which seem to offer substantial development and relaxation opportunities.
- There were calls from professionals for improved availability of independent advocacy to be funded.
- All parents had benefited from practical support. It was thought that family support workers who had received training around learning disabilities offered better practical support.
- Risk and choice plans were found valuable and empowering in working with one mother.
- A person centred approach worked well for parents, as support was then made available to increase self advocacy and socialising skills, which led to an increase in self esteem and confidence.
- Parents' growth in skills and confidence helped motivate the supporters to continue with their work.

Chapter 6: Management view

I interviewed 3 senior managers:

- a regional manager from a residential support service across North Wales
- a service manager for a residential support service in Mid Wales
- a manager of a Family and Community Team (FACT) in South Wales.

Their experience of managing staff who support parents with learning disabilities varied from just 2 parents to

recently between 50-60% or even more of our referrals have involved a parent with a learning difficulty of some sort.

in the FACT. The issue of criteria for eligibility for services from adult teams was one that concerned them. The service manager's staff support a single mother with learning disabilities who had received no services until concerns were reported about her teenage daughter. It became obvious that her impairment meant she had a number of needs, but without a formal IQ assessment she could not access services. She agreed to a formal assessment and was judged to meet adult service criteria. The concerns of the manager were about what would have happened if she had not quite met the criteria – her needs would have been the same. Her children had been removed on a temporary basis while assessments were going on - it was clear that without the extra support her children would not have been returned. The service manager was left wondering how many parents do not quite meet the necessary criteria, therefore do not receive the extra support and so lose their children.

The FACT manager had similar experiences and said

I think I am avoiding using learning disability because we are not necessarily talking about people who fit within the adult team criteria. ... I know that it's people who don't necessarily fit that criteria who can have quite a lot of difficulty because they are not necessarily entitled to any services from that side ... while it is an important factor it is rarely the only factor.

Approaches to support

The 3 managers work in very different organisations with different client groups and obligations. It is not possible then to compare their work in any way, but just to convey what they do.

Regional Manager

This organisation had

a professional support worker who goes and supports you, who helps you out with everything. We then believe that there's lots of people out there in the community who can help you with things, so we try to signpost people to the right direction.

This signposting was the key to their work, as staff recognised they couldn't know everything, and were funded to work a limited number of hours with each person they supported

we don't have the expertise, but we'll look for other organisations who can help out and try and get them involved.

The approach was based in empowerment. Dependency on their support worker was discouraged and it was recognised that other people with learning disabilities may have the skills to help out

We believe in mutual support, that's what the network is founded on, each member helps each other out, at very basic levels sometimes. For example, in North Wales we have an embryonic stage of a parenting group, where all the members who've got children get together and help each other out.

Service Manager

In Mid Wales communities tend to be small and spread out. This has implications on service provision, as in areas where there is no public transport, the support worker may be the only person a client sees. The organisation aimed to support people to maintain family connections and become involved in their communities to try to break this isolation. Floating support was provided to enable people to live independently in their communities. The support was person-centred and

Varies to meet the needs at the time, it's needs led.

Support to maintain a tenancy was central to the service provided, and as the service was person centred a lot of the support could be seen as building a social life. This was essential to enable people to have full, rounded lives and to break the isolation they may have been feeling

We find out what people's interests are and encourage them to join groups in their communities. It may be going to church or a drama group; self advocacy groups are always welcoming. ... We hope the support will help them build friendships.

As they were experienced at maintaining family connections, when working with parents with learning disabilities they were very aware that a parent

Comes as a package – you can't just look at the parent, you need to look at the family as a whole.

The parent may officially be the person they were contracted to support, but this recognition of the family was important as a way of working.

FACT manager

The FACT team had 4 staff who tended to work with parents with learning disabilities. They, and other staff, worked with a whole range of families with various support needs

It's a holistic approach I think. And the parenting is very much a holistic approach as well. ... we look at every family individually anyway when we set up a contract and we agree with the family what the work is that we are going to do and then we review it regularly with the referrer so that we've always got in mind Where are we going? What are we doing? How are we going to achieve it?

This clear, family centred approach fitted well with the person centred approach in services for people with learning disabilities. The team did not work in isolation, but with all those involved with the family

they might be going to corporate meetings, child protection review meetings, whatever and information shared along the way with the parent and others involved, and then hopefully you get to a point at which you feel the family have moved on enough that you can pull out. ... you set out clearly what you are hoping to achieve, you involve the family every step of the way.

There had been much discussion in the team, and with professionals from across the county, on the best way to work with parents with learning disabilities. They decided that they are going to adopt a

solution-focused intensive support approach where you start by getting the people you work with to identify positives, however small, and then building on those positives ... I think it is a case of, if you like, realising the potential that can be achieved and having the time and patience to achieve it and working out the best ways of actually maintaining it then.

This again reflects the ways many professionals work to teach people with learning disabilities new skills – accept there is potential there and use current strengths to progress from.

A development the team were considering was peer support groups as

I got the impression from Circles on a training day that one of the things that does work is mutual support, maybe mentors that wouldn't replace our work but would be in addition to it. ... people having time to assimilate information, learn to use it, get good at it and then share with others who are in similar situations about what they do and how they do it.

Issues in the work

The 3 managers struggled with issues common to any manager:

- Time
- Resources
- Inter-agency working

Time

Supporting parents with learning disabilities took more time than supporting other parents or people without children. This could cause a variety of problems for a manager when support hours are limited

My staff will come to me and say 'I'm spending an inordinate amount of time on the telephone to Miss X who's worried about her child being taken away from her, and reassuring her about social services and talking through with her the processes.'

It was difficult for a support worker not to spend time with the parent when there seemed to be no-one else who would give this support. Viewing the entire service, rather than one person's needs, the manager saw that

it takes away from the rest of the service we're supposed to provide. So I have to be really quite firm with my staff. If they're spending 16 hours on one person cos they've got a child and need that extra support cos no-one else is supporting them, then the rest of the people are dipping out.

The FACT team would usually

aim not to be involved with families for a long period of time ... we don't want to stay involved on a very long-term basis because you are creating dependency.

However the manager accepted that where the parents had learning disabilities, the team may have to be involved for much longer than usual, as people with learning disabilities needed time to learn

sometimes the involvement will be over a number of years in supporting families. There was one family where we supported them for years; two at least, waiting for a social worker from the adult team to become involved so that you could then attempt to kind of build from both sides the skills of the family.

The concern was often that parents would become dependent on the support, and experience had shown that other families can learn and move on quickly when they are motivated. However, experience had shown this manager that

You just do it by the needs of the individual family and possibly we are getting better at it because there is a family that we have worked quite intensively with over the last year, and we have just pulled out of the family and they've done really well. I wouldn't be surprised if we have a re-referral but in the meantime they've done really well and they are empowered to get on and look after their children themselves without outside support.

She also knew that if workers were supporting parents with learning disabilities

They need more time to work out the resources that they are going to use with the family. Potentially they need more time to prepare the material they are going to use with the family. They often need more time to write up what they have done because detail is important in those write-ups, so, yes, it takes more of people's time to achieve the same outcomes.

This obviously had implications for funding the work to support parents with learning disabilities to bring up their children.

Resources

One of the resource issues, especially in rural areas, was that services are not always available. This could mean that residential support staff began to take on roles beyond their own, to try to ensure that parents had the support they needed

I've had to pull my team back a wee bit, say this is not our role. ... We often get dragged into things like being advocates for people, especially in child care conferences. Just because there's no-one else to do that.

Lack of advocates with the skills to support parents in court had implications for other services. This manager had also found that there were not always services there to support the child, and again had to remind staff of their roles

I have to clearly start saying to them at some point that we're there to support the member and not the child. That becomes quite a big demand, as quite often there's no formal structure in place for the child, which is surprising. We try and help wherever we can, but we're a very low level support service.

The cost implications of the extra time needed by parents with learning disabilities were something that the managers worked with

There's always some cost to these sort of things, but it's just time costing.

The FACT manager had been creative in the ways she finds funding for the work, as not all of it could be covered by the core funding from county.

We work in partnership with a lot of people which means we spend an awful lot of time accounting for what we do and justifying what we do. Which is probably quite good for you.

The extra time needed by workers and the specialist resources that were useful, as well as the transport issues people faced in rural areas, all combined to increase the cost of providing a service to parents with learning disabilities

All that kind of thing would need to be resourced and that's probably the issue. ... So everything is resource driven isn't it?

All the managers admitted that supporting parents had resource issues for their organisations, but as all were committed to keeping families together where it was safe for the child, they had found ways to ensure that the needed work was funded.

Inter-agency working

All three organisations worked in partnership with a variety of other services. There were always possible areas of conflict in this work, as well as possible enrichment. For both residential support services, it was the basis of the way they worked

We work really hard at partnership working, it's part of what we do. ... it's something that we're genuinely trying to develop.

The FACT manager saw partnerships as a way to develop new ways of working, and do things they would not otherwise have had opportunities to

It's a good county, I think, for partnership working. People do tend to see links quite well. ...so we're hoping to take forward ... action research bids that would look at how we improve work with parents with learning

difficulties. So it seems that once you make a link you get that kind of flowing effect that more links come through.

However, for all 3 there were possible problems in partnership working that were based in attitudes and lack of clarity on what the priority needed to be. These problems tended still to be between adult and children's services. The managers from adult services reported

The problems occur when people want different things. So one side thinks that the parents can't cope and the other side thinks that with some support and training that parent would be able to do it. There's that big gulf there. And there never seems to be a middle ground.

It's difficult with children's services as there seems no clarity on who has overall responsibility for the family – not just the parent or the children. There seems to be no willingness to discuss the issues, to negotiate and clarify so that we can all move forward.

And to the children's service manager

It doesn't work where ... you've got other organisations involved who have got different outcomes in mind. There needs to be a much closer link between adult services and children's services in recognition that the welfare of the child is paramount, not the rights of the parent.

This last point does seem to focus on what can be the nub of this problem – that the welfare of the child must be seen as the priority. Often adult services did not voice this, as

There are times when we think it's just not safe and not fair. It puts us in a really difficult position, because we do want to do what's best for the parent, because ultimately we're there to support the parent, but by suggesting that the child moves out of the family home it is not doing the best by the parent, but it is doing the best by the child. That can potentially break down the relationship between us and that member. So we do get ourselves in sticky situations sometimes. ... So we let social services be the bad ones. It's the way it has to be sometimes, so that you can be there supporting the parent afterwards. And that's when they need our support more than any other time.

However, this lack of acknowledgment to other professionals of the priority concern has led to greater divisions between services. It must be acknowledged by adult service workers that a child's right to being safe and to enjoy the best possible physical, mental, social and emotional health, part of the Welsh Assembly Government's 7 core aims (WAG 2003), comes before any adult's

rights. It also should be acknowledged that often the best possible mental, social and emotional health for a child comes from living with their family.

New work

Little is known about the needs of fathers with learning disabilities, especially if they have parted from their child's mother. FACT had a dad's group

We've got a dad's worker and sometimes we get referrals through relating to dads with learning difficulties and it might be that they may be having contact with a child that has been removed, to improve the quality of contact or whatever. And the worker, because there is only one of him, hasn't got a lot of scope for one to one but he has a lot of groups running and they quite happily assimilate dads, any dads, into the groups. So they've got the mutual learning and he can then maybe top up with a few one to one sessions on top of what they are picking up from the dads groups. And that works quite well. It's an effective way of working. ... If there was a pot available we would probably go for money where we could support fathers and promote parenting work with fathers who had less ability, if you like, to promote parenting skills and the whole thing about health service information being geared towards fathers - not, and then fathers with limited literacy skills - not at all.

What's needed

The organisations these managers worked within all had a strong value base that was openly acknowledged

The values that I think we work within are inclusive and they don't work to a blame culture ... I just believe that values flow from the top in an organisation. ... there has been a kind of positive approach to the work people do and the way that they do it.

This was felt to be important in supporting any work that was happening, but especially work that may lead into conflict with other services.

The regional manager thought that one thing that would help enormously would be to have good sex education for children and young people with learning disabilities

I think we need to start way before that, to talk about contraception and birth control and all those things beforehand. ... just people having the same availability of information that you or I have got. ... So back to basics, to let people understand what they're letting themselves in for, to understand that it's not the only option, that they can do other things.

It does seem incredible that basic information and advice about sex education is still so absent.

The service manager thought that families needed help to stay together

That's what they want, and what they should have – support as a family to be together. At the moment it seems to be support for the parent and support for the child separately. ... This is a family, and it needs to be seen as a whole.

The FACT manager thought

Under the Strengthening Families programme they have focused on families with drug and alcohol issues haven't they? Maybe if the focus was with families with learning difficulties, then you'd look in the same way as they have kind of promoted the community first areas for community development. Maybe, you know, a more resource intensive approach that was also partly community based. Where you've got a county like this, where you've got rural areas that wouldn't necessarily be inexpensive because you've got people all over the place who could do with, no doubt, mentors and other help.

This is a snapshot of a limited number of management views. All 3 managers were passionate about supporting parents and families. All worked in services that were supportive of their work, and could be confident that working in the way that individual families needed was accepted. All would welcome a policy guidance lead from the Welsh Assembly Government.

Summary

- 3 senior managers from services across Wales were interviewed; 2 from residential support service providers, 1 from a Family and Community Team (FACT).
- Their experience varied from 2 parents to over 50% of referrals being parents with learning disabilities.
- There were concerns around IQ assessments possibly excluding parents from the support they needed.
- Supporting parents with learning disabilities takes more staff time than supporting other parents, or supporting people with learning disabilities without children.
- The time needed for parents to learn new skills is contrary to the usual expectations in children's services.

- Lack of advocates can lead to residential support services staff taking this role.
- Managers find ways to resource and justify this extra time.
- The 3 managers saw partnership working as central to their work.
- One point of conflict in partnership working can be the rights of the parent against the safety and well being of the child.
- Adult service staff do not acknowledge that the safety and well being of the child must come above the rights of the parents.
- FACT have a dad's worker who does work to help dad's with learning disabilities to maintain contact with children when the relationship with the mother has broken down.
- Basic sex education work is needed for children and young people with learning disabilities.
- There is a need for services to view the family as a whole, not separate entities.
- WAG need to highlight the work needed with parents with learning disabilities.

Recommendations

- Consideration is given to the value of IQ assessment when supporting parents who may have learning disabilities – an IQ of 72 may lose them services offered to someone with an IQ of 70. The support needs are probably similar.
- Adult service staff need to acknowledge that a child's right to safety and physical, mental and emotional health is the most important principle to work to.
- Resources are made available by WAG to support work with parents with learning disabilities and to recognise that this work needs more time.
- Support for fathers with learning disabilities to maintain quality contact with their children when they have been removed from the family home or the relationship with the mother has broken down, needs to be provided.
- Services need to work towards a blame free culture to enable growth and development for their workers.
- Sex education needs to be a necessary part of the curriculum for children and young people with learning disabilities.
- WAG needs to highlight the importance of work with parents with learning disabilities as it did with The Strengthening Families programme when families with drug and alcohol issues were focused on.
- More needs to be known about areas where social services managers see their staff as working with very few parents with learning disabilities. Are there fewer parents with learning disabilities in these areas? If so why? Are the parents not recognised as having learning disabilities?

Chapter 7: Conclusion and Recommendations.

Perhaps the main finding in this study has been that there are more parents with learning disabilities needing support than were previously thought. Previous estimates had put the figure at 6% (Emerson et al 2005), while this study found a prevalence of 12% in Caerphilly. Extrapolated, this gives an overall total in Wales of 1,210 parents with learning disabilities. Services need to be planned with this figure in mind. The planning needs to be done on a multi-agency basis, including statutory and voluntary children's services and health; this cannot be seen as purely the responsibility of services for people with learning disabilities. Service delivery also needs to be multi-agency with co-operation between agencies on policies, protocols and resources.

The study shows that where good support is provided, families can live together and children flourish and grow. There needs to be an acceptance that support for parents with learning disabilities will be long term, throughout the childhood of their children. The support will not need to be at the same level all the time, but vary according to the needs of the moment.

This provides challenges for child care services, who usually expect a focussed short term input will enable parents to learn the needed skills or behaviours. In general support is needed at different stages of a child's development, so can be predicted to a degree:

- Being a new parent, understanding how to care for a baby (eg bottles, coping with crying, bathing and routines)
- Weaning and crawling
- Toddlers and the tantrums
- Going to school, routines necessary for this
- Changing schools, coping with homework
- Adolescence and living with a teenager

Each family may have its own crises or confusions when extra support may be needed. What it is important to focus on is that "When problems are seen as rooted in people's personal deficits and limitations they may seem intractable and out of reach. Shifting the focus onto features of people's lives that can and should be changed, challenges the negative stereotypes that inform such thinking and opens up possibilities for social action in support of families" (Booth & Booth 1997)

Many of the findings of this study mirror those found in the British study 'Finding the Right Support for parents with learning difficulties' (Tarleton et al 2006). This study found that:

- There needs to be a raising of awareness of how support can be offered to parents with learning disabilities, especially amongst child care professionals.
- The lack of clear communication between social services departments about the support being provided to parents, and between agencies about child care proceedings is evidently disabling to parents' abilities to parent.
- There were no consistent standards on what constitutes good enough parenting.
- There was a need for more independent advocacy to be funded
- There was a strong feeling from many of those involved in this study that an ability for a social services' department to support the family, rather than individuals, would improve the support being offered to parents.
- Joint training is needed for all professionals working with parents with learning disabilities. Parents need to be involved in the delivery of this training.
- Parents are recognised as extremely loving and completely committed to their child, wanting the best they can provide for them.
- Where support that is appropriate and suitable for the family is provided, the families can flourish and parents can just be parents.

This study has also progressed the understanding of what is regarded as good support by the parents, as their views were central. From the parents' perspective, good support is not costly, as most of it is based in attitudes rather than extra services. The main things they want are:

- Professionals to listen to them properly, without prejudgement
- Professionals to be reliable
- Support to be given to help in sorting out problems
- Choices to be offered by supporters in how things such as housework can be done
- Letters and reports to be made more accessible
- Easier access to respite is needed by those who have disabled children

These are similar to the guidelines produced by Change in the English guidance (DoH 2007).

There has also been more detail from professionals on what barriers there are to support being improved. These include:

- Professionals in adult services supporting parents feel hampered by their lack of knowledge of child care procedures, and the difficulties in discovering what these are.
- Child care departments in social services seem to ignore their duty under the Disability Discrimination Act to make their reports and other forms of written communication accessible to people with learning disabilities.
- Parents and their supporters felt that there were often too many professionals involved with the families. This increases stress for parents and can waste resources.

One finding is particular to Wales; that parents whose first language is Welsh are expected to go through child care proceedings that are in English. Communication skills are often impaired in people with learning disabilities, and extreme stress can increase this impairment. The language issue needs to be carefully considered, to ensure that using English in these possibly life changing procedures does not disempower the parent further.

Recommendations

Policy

- The Welsh Assembly Government should produce similar guidelines to Good Practice Guidance on working with parents with a learning disability (DoH 2007).
- Local authorities should produce their own protocols on working with parents with learning disabilities, in conjunction with all services who offer this support. A useful example of this is the Suffolk Accord. (<http://www.suffolk.gov.uk/CareAndHealth/ChildrenAndFamilies/ACCORD.htm>)
- Eligibility criteria for services should be based on an holistic assessment of need. They should replace the current IQ assessment when supporting parents who may have learning disabilities – an IQ of 72 may lose them services offered to someone with an IQ of 70. The support needs are probably similar.
- Data should be collected locally on the numbers of parents with learning disabilities from all services that support families, and the numbers of their children taken into care each year.
- All parents with learning disabilities should be offered a person centred plan.
- Sex education needs to be a necessary part of the curriculum for children and young people with learning disabilities.

Those supporting/working with parents

- Literacy levels of parents need to be established.
- Once the literacy level is known, all written material needs to be produced so that parents can understand, making reasonable adjustments as demanded by the Disability Discrimination Act 1996.
- Adult service staff need to acknowledge that a child's right to safety and physical, mental and emotional health is the most important principle to work to.
- Professional staff should work from a family viewpoint rather than an adult and a child perspective.
- Specific support around managing timetables and people needs to be considered, to enable the parent to feel in control of what is happening, and give a competent image to professionals they deal with
- Workers need to try to imagine how the person they are working with thinks and feels, to be able to discern possible misunderstandings.

Service development

- Services need to be family, rather than adult or child centred. The needs of the family as a whole unit are currently often ignored.
- Funding should be made available for work with families as a whole.
- One person in one department should have the overview of what support is needed and what is provided, with the family's needs at the heart of this.
- Multi agency meetings of all involved in supporting parents with learning disabilities should take place, to look at support as a whole.
- Extra support should be available if needed during school holidays.
- Planning ahead should take place with the parent for the transitions known about eg children moving out, school changes. It needs to be recognised that transition is a time of stress, so there should be preparation to prevent stress.
- A designated person in the adult team should act as a central point for comments from the children's services on aspects of parenting, to ensure that the parent fully understands what is being said and asked for, and help relieve stress from misunderstood demands.
- Children's services should regard working with parents with learning disabilities as working in partnership. This can reduce a dictatorial approach and increase the parents' confidence in their ability to cope. Standards on partnership working need to be set, so that all workers understand what is wanted and work to the same criterion.

- Children's services need to be seen to be considering the support needs of the family. The current perception is that they first consider removing the child.
- Adult's services should voice their belief in children's safety before parents' rights. The current perception is that rights are valued above children's safety.
- Every children's social service department should make available their childcare procedures on the local authority website as a flow chart.
- Children's services should consider and outline the standards that are necessary for parents and children to continue to live together. This may not be possible on a generic basis, but is feasible for individual families. Once these standards have been set, they should be shared with the family and with all working with them. Agreement/s are needed that the standards will be worked to by all concerned regardless of change of personnel.
- Parent support groups should be set up locally.
- Services need to work towards a blame free culture to enable growth and development for their workers.
- Regular supervision that is not problem based should be the norm for unqualified staff, especially those who work mainly alone.
- Senior managers in children's services need a strategic overview of how support offered in their localities works for parents with learning disabilities.
- Fathers with learning disabilities may need support to maintain quality contact with their children, when they have been removed or the relationship with the mother has broken down.

Advocacy

- Specialist parents' advocacy workers are needed, to work with parents with learning disabilities, so that the parents' voice can be heard around issues concerning their children.

Further research

- Research is needed on how parents with learning disabilities cope with and are treated within the transition process as their children get older, especially those whose children will transfer to adult services.
- Evaluations of school bullying procedures should be evaluated with parents who have had to complain. Evaluation should include parents with learning disabilities.
- More needs to be known about the perceptions workers in children's services have of parents with learning disabilities and where these originate.

- More needs to be known about areas where social services managers see their staff as working with very few parents with learning disabilities. Are there concentrations of parents with learning disabilities in specific areas?
- There should be research into the sexual assault of children whose parents have learning disabilities.
- There should be research into how parents with learning disabilities deal with sexual assaults on their children, and the support they receive.

Welsh Language

- Child care case conferences must take place in Welsh where that is the first language of the family at the centre of the conference.

Training

- All social service employees must have training around the Disability Discrimination Act and all departments should examine how to enact this locally.
- Joint training between those working in adult services and those in children's services should take place to gain an understanding of the other's legal obligations and values base.
- Staff in children's services should receive training on the impact on the individual of having learning disabilities to enable them to offer a more effective service
- Staff in all services not trained in working with people with learning disabilities should undertake training that is presented in partnership with parents.
- Training should cover listening to parent's concerns, and answering those concerns.
- Speaking up training for parents with learning disabilities should be made available.
- Practical skills training including risk and choice planning should be offered to all parents with learning disabilities.

Welsh Assembly Government

- Guidelines on working with parents with learning disabilities, similar to Good Practice Guidance on working with parents with a learning disability (DoH 2007) should be produced and strongly disseminated and backed by WAG.
- Resources should be made available by WAG to support work with parents with learning disabilities, to recognise that this work needs more time.

- WAG needs to highlight the importance of work with parents with learning disabilities, as it did with The Strengthening Families programme when families with drug and alcohol issues were focused on.
- Funding for advocacy services for parents with learning disabilities should be provided by WAG, to enable services to exist and be completely independent.

References

Booth T (2002) *Parents with intellectual disabilities*.

http://www.intellectualdisability.info/lifestages/ds_parent.htm

Booth, T. and Booth, W. (1997) *Exceptional childhoods, unexceptional children*, London: Family Policy Studies Centre.

Booth, T. and Booth, W. (2005). *Parents with learning difficulties in the child protection system: experiences and perspectives*. Journal of Intellectual Disabilities, 9(2), 109-129

Booth, T., Booth, W. & McConnell, D. (2005). *The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts*. Journal of Applied Research in Intellectual Disabilities, 18(1), 7-17

Buchanan, I & Gunn, R (2007) *The interpretation of human rights in English social work: an exploration in the context of services for children and for parents with learning difficulties*. Ethics and Social Welfare, 1(2), July 2007, pp.147-162.

CSCI (2009) *Supporting disabled parents: a family or fragmented approach?*
CSCI 2009

Department of Health (DoH) and Department for Education and Skills (2007) *Good Practice Guidance on working with parents with a learning disability*

Emerson E., Malam S., Davies I. & Spencer K (2005) *Adults with learning difficulties in England 2003/4*. www.ic.nhs.uk/pubs/learndiff2004

Elvish, J et al (2006) *Parent with learning disabilities: an audit of referrals made to a learning disability team*. Learning Disability Review, 11(2), April 2006, pp.26-33.

Funck-Brentano, I et al (2005) *Evaluation of a peer support group therapy for HIV-infected adolescents*. AIDS: September 2005 - Volume 19 - Issue 14 - p 1501-1508

Joint Committee of Human Rights *A life like any other? Human Rights of adults with learning disabilities*. TSO 2008

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K. & James, W. (2007) *Challenging Behaviours: Prevalence and Topographies*. Journal of Intellectual Disability Research, 51 (8), 625 – 636.

Llewellyn, G. & McConnell, D. (2005) 'You have to prove yourself all the time: people with learning disabilities parenting.' In Grant, G., Goward, P., Richardson, M. & Ramcharan, P. (eds) *Learning Disability: A life cycle approach to valuing people*, Maidenhead, Open University Press

Laming (2009) *The Protection of Children in England: a progress report*. TSO 2009

McGaw, S. & Newman, T. (2005) *What works for Parents with Learning Disabilities?* Ilford, Barnardo's

Merkel-Holguin L, Nixon P, Burford G, *Learning with Families: A synopsis of FGDM Research and Evaluation in Child Welfare* in Protecting Children Vol 18 www.americanhumane.org

Morgan P & Goff A (2004) *Learning Curves: The Assessment of Parents with a Learning Disability. A Manual for practitioners*. (Norfolk Area Child Protection Committee 2004)

Morris, J *Good Practice Guidance on Commissioning Services for Families Affected by Parental Learning Disability: Focusing on children's services*. (Due for publication www.right-support.org.uk summer 2009)

Morris, J *Good Practice Guidance on Commissioning Services for Families Affected by Parental Learning Disability: Focusing on adult's services*. (Due for publication www.right-support.org.uk summer 2009)

Morris, J & Wates M (2007) *SCIE Resource guide 9: Working together to support disabled parents*. SCIE 2007

Naylor, P & Cowie H (1999) *The effectiveness of peer support systems in challenging school bullying: the perspectives and experiences of teachers and pupils*. *Journal of Adolescence* Volume 22, Issue 4, August 1999, Pages 467-479

Office for National Statistics (2002) *Census 2001: first results for Wales*. London TSO 2002

Scottish Consortium for learning disability *Fair Deal for Families? Learning from the experience of parents with a learning disability*'. SCLD 2008

Smith L and Hennessy J (1999) *Making a Difference: Essex Family Group Conference Project, Research Findings and Practice Issues*, Chelmsford: Essex County Council

Social Care Institute for Excellence (SCIE) research briefing 14 (2005): *Helping parents with learning disabilities in their role as parents*. SCIE 2005

Statistics for Wales (2008) *Teenage Conceptions in Wales, 2006*.
<http://www.statswales.wales.gov.uk/tableviewer/document.aspx?FileId=1971>

Tarleton B, Ward L & Howarth J (2006) *Finding the Right Support for parents with learning difficulties*. Baring Foundation 2006

WAG 2003 *Children and Young People: Rights to Action*

Questionnaire



‘Finding the Right Support for Parents with Learning Disabilities in Wales’

The Welsh Assembly Government has commissioned this research to gain an idea of the number of parents with learning disabilities in Wales, and the kind of support these parents view as useful to them. The results of the study will inform ministers in considering how to ensure appropriate support is available to all parents with learning disabilities in Wales.

This is the first piece of work in the UK aiming to assess the numbers of parents with learning disabilities. The aim of this questionnaire is to identify the approximate numbers of parents with learning disabilities known to services. It is going to Child and Family teams, adult learning disability teams, health visitors, midwives and voluntary groups who offer support to families. No personal data is being asked for. The mothers’ or fathers’ initials and date of birth are being requested only so that the completed forms received from different professionals can be cross-checked to avoid double counting.

There will be no follow-up to this questionnaire. That is, no request will be made for direct contact with any of the parents or families listed here. Direct contact with a small number of parents with learning disabilities does form part of the overall study, and this is being arranged through other contacts.

If you are not sure about whether a parent has learning disabilities, please refer to the enclosed Assessment Tool as a guide.

If you have any queries about completing this questionnaire, please contact project leader, Joyce Howarth on 01633 838672 or joyce.howarth@tpfirst.org.uk

Thank you very much for your help

***'Finding the Right Support for Parents with Learning Disabilities in Wales'* questionnaire**

Your name

Job title

Organisation & Place of work

Phone no/email

Have you worked with parents who have learning disabilities?

Yes **No**

If yes, how many did you work with in 2008?

Single parents **Couples**

Please indicate how many children, mother's and father's initials and dob and whether the children are still with the parents for each of the families you worked with in 2008, by using the form below.

Family 1

No of children	
Mother's dob/age in 2008 and initials	
Father's dob/age in 2008 and initials	
Are the children still with the parents?	

Family 2

No of children	
Mother's dob/age in 2008 and initials	
Father's dob/age in 2008 and initials	
Are the children still with the parents?	

Family 3

No of children	
Mother's dob/age in 2008 and initials	
Father's dob/age in 2008 and initials	
Are the children still with the parents?	

Family 4

No of children	
Mother's dob/age in 2008 and initials	
Father's dob/age in 2008 and initials	
Are the children still with the parents?	

Family 5

No of children	
Mother's dob/age in 2008 and initials	
Father's dob/age in 2008 and initials	
Are the children still with the parents?	

If you worked with more families than this in 2008, please continue on separate sheet; just copy and paste the table above.

How many other parents with learning disabilities did you work with prior to 2008?

Single parents **Couples**

Please indicate how many children, mother's and father's initials and dob for each of the other families you worked with prior to 2008, by using the form below.

Family 1

No of children	
Mother's dob/age at birth and initials	
Father's dob/age at birth and initials	
Are the children still with the parents?	

Family 2

No of children	
Mother's dob/age at birth and initials	
Father's dob/age at birth and initials	
Are the children still with the parents?	

Family 3

No of children	
Mother's dob/age at birth and initials	
Father's dob/age at birth and initials	
Are the children still with the parents?	

Family 4

No of children	
Mother's dob/age at birth and initials	
Father's dob/age at birth and initials	
Are the children still with the parents?	

Family 5

No of children	
Mother's dob/age at birth and initials	
Father's dob/age at birth and initials	
Are the children still with the parents?	

Family 6

No of children	
Mother's dob/age at birth and initials	
Father's dob/age at birth and initials	
Are the children still with the parents?	

Family 7

No of children	
Mother's dob/age at birth and initials	
Father's dob/age at birth and initials	
Are the children still with the parents?	

Family 8

No of children	
Mother's dob/age at birth and initials	
Father's dob/age at birth and initials	
Are the children still with the parents?	

If you worked with more families than this prior to 2008, please continue on separate sheet

In the families you worked with prior to 2008, where the children still live with their parent(s), how old are the children? (Please put total numbers, not per family)

No of children

Under 3

Under 5

Under 10

Under 14

Under 16

Over 16

Thinking of all the families, what support did you provide?

Did you identify/suspect at the time that they had learning disabilities?

Yes, all **Yes, some of them** **No, all of them**

If yes, how?

What were your actions based on this knowledge/suspicion?

Thank you for completing this questionnaire. Once it is completed, please either return to your manager if requested, or email to joyce.howarth@tpfirst.org.uk .

Assessment tool



‘Finding the Right Support for Parents with Learning Disabilities in Wales’

Thinking about whether a parent has learning disabilities.

The Welsh Assembly Government describes people with learning disabilities thus: ‘The term ‘learning disabilities’ was adopted by the UK Government in 1991. It replaced previous terms used in the UK that now seem very pejorative such as ‘mental handicap’ or ‘mental deficiency’, and is an alternative to pejorative terms such as ‘mental retardation’ used in other countries.

From birth or early childhood they will have had an impairment of intellectual function that significantly affects their development and leads to difficulties in understanding and using information, learning new skills and managing to live independently. They are, therefore, more likely to require support and services to lead an ordinary life. Common difficulties concern:

- Understanding and using information
- Making choices and decisions
- Learning and using symbolic forms of communication
- Being independent at home and getting around in the community
- Dealing with social situations.’

Statement on Policy and Practice for Adults with a Learning Disability WAG 2007

What follows is not a conclusive assessment of whether someone has learning disabilities. It is a tool that covers the sort of areas that are useful to think about if you are querying whether a parent has learning disabilities. Please try to ensure that when you are considering someone you have worked with, any issues highlighted in the assessment tool are due to their cognitive/intellectual capacity, and are not due to emotional or mental health problems.

If you use the assessment tool with a parent you are currently supporting, please be aware that some these questions may be received as very negative. It is a problem focused tool, and does not look at the person’s skills and strengths (eg very loving, asks when not sure about something). It may be better to try to think about this away from the parent, and ask only the questions you’re not certain of the answers to.

Assessment Tool

Tick box if relevant

1. HISTORY

Self reported

- Attended Special school (learning disabilities/ SEN)
- Attended special unit in mainstream (learning disabilities/ SEN)
- Needed extra help at school

Family/Other Agencies

- Give information about parent's Special Education
- Say the parent needed lots of help at school

2. BACKGROUND INFORMATION

Can provide only vague or naïve information about basic facts (eg not certain which hospital their child was born in, how long partner has been around, birth dates of children, type of schooling child receives)

3. LEVEL OF SUPPORT

Another person has a major role in providing help/advice to the family (eg help with filling in forms, reading letters, shopping, arranging housing, using public transport, budgeting)

4. LITERACY

- Significant problems with writing
- A reluctance to write in presence of others
- Writing address, but misspelled, postcode absent
- Reading words but with limited understanding only
- Avoiding reading/writing tasks ("I haven't got my glasses")

5. TRAVEL

- Problems travelling on public transport (eg finds timetables and bus routes hard to understand, confused by bus numbers)
- Always comes to appointments with another adult

6. APPOINTMENTS

Erratic appointment keeping (eg early, late, wrong day, odd excuses)

7. FINANCE

- Problems managing money
- Difficulty giving accurate change for a note
- Problems estimating cost
- Running out of money quickly on a regular basis

8. ROUTINE

- Being overwhelmed by day to day routine
- Difficulty in sending child to school with kit needed
- Difficulty in coping with household routine
- Difficulty prioritising demands and activities

9. COPING STRATEGIES

Uses lots of explanations/excuses for problems - eg "his glasses are at home" or "I lent my thermometer to a friend"

10. CHILD CARE

- Difficulties with:
 - following a routine
 - predicting dangers
 - giving praise to child
- Seeming to be always telling the child off
- Inappropriate feeding
- Child appearing to look after parent/other siblings

11. SIGNIFICANT ILLNESS OR INJURY

Physical trauma that occurred under the age of 18 which may have caused a problem with cognitive functioning, ie head injury, meningitis oxygen starvation

12. IQ

of 70 or under

If several boxes have been ticked you may want to discuss with the parent whether finding support through the Community Learning Disabilities Team may be helpful. If the parent is in agreement, contact the Team Leader to discuss the individual and explore whether a referral would be appropriate.

Questions are based on an assessment tool by Penny Morgan and Andy Goff in 'Learning Curves. The assessment of parents with a learning disability' Norfolk Area Child Protection Committee, 2004

Appendix 3

When children in care grow up

It is important to remember that many parents with learning disabilities have had their children removed. Some of these children have been adopted, others placed in foster care. Yvonne's story is one that has given some hope to young parents, that perhaps when their child is an adult they may be able to contact them and possibly, like Yvonne, get to know them.

Yvonne is a mother in her 40's. Her three children were removed about 16 years ago when the eldest was 6 and her son was a baby. Yvonne explains

I was having me epileptic fits and his father wasn't looking after him properly. His father wasn't looking after him. ... Well, not looking after any of us.

She was finding it increasingly difficult to cope and her epilepsy was worsening. Over time this has had a severe impact on her memory. The father's drug taking increased, Social Services became involved and removed the children

(Social Services said) It's best for them, to go into care. ... Well at first I didn't want them to cos they was my children. ... In the end I said it would be fair for them to go.

The three children were split up. The baby boy was adopted, his youngest sister went into foster care and the eldest girl went to live with extended family members.

Over the years Yvonne would occasionally talk about her children; she would talk continually about them for a few days, then she would go quiet again. Fourteen years after they were removed, she began to say that she would like to find them. She was referred to an advocate who supported Yvonne in this.

First, the advocate contacted the social service departments that had been involved with the children. This was complicated by the fact that the local authorities had changed, and there were uncertainties about where the files were kept. However, they were eventually tracked down with help from social workers and Yvonne wrote letters to her children, with photos, so that if they asked to access their files they would be able to see that she would welcome contact. The advocate remembers

the letters she wrote were absolutely heart-wrenching. And I think all the years she had been without her children they had been in the forefront of her mind.

They then realised that the eldest was now 18, and Yvonne could contact her if they could find her. Various attempts were made to get in touch with the extended family members her daughter lived with, but to no avail. They had moved and no-one knew where they were. Then the advocate had the idea of trying the Salvation Army Family Tracing Service (FTS) They sent the minimal details they had along with a payment (£25 today for those on benefits), and waited without much hope. The FTS will try to trace known and named family members who are 18 years of age and over; they say that due to limited resources they do not normally become involved in searches where adoption has taken place. After a few weeks FTS contacted Yvonne to say they had found her daughter, but could not give more details without the daughter's consent. They needed to know that both parties wanted contact. Yvonne wrote a letter to her daughter saying that she wanted to see her, and this was forwarded by the FTS. After a few letters between them there were phone calls, which went well, so a meeting was arranged. At this stage the advocate withdrew – as she says, her job was done. It had taken about 2 years to get to this point.

The residential staff where Yvonne lived took over the support for the meetings. Although they had been placed separately, Yvonne's two daughters lived near to each other and were in close contact, so both wanted to meet their mother. Yvonne was very excited about the first meeting, which was to take place in a coffee bar near where the girls lived. The staff were more reticent. They tried to talk with Yvonne about how she would feel if the meeting did not go well, combating her excited dreams about the meeting with 'Yes, but what if ...'

We didn't know their backgrounds, what sort of lives they'd had. So it was a double edged sword – you had to get her ready for meeting them, but at the same time, possibly this may not go as well as you like.

However, it did go well and contact has been maintained over the last 5 years.

From the staff's viewpoint there are continual possible problems. Yvonne is a vulnerable adult they have a duty of care towards. A supporter is always with her when she meets her daughters:

I don't know what Yvonne would say to them, and she would quite openly tell them about how much money she's got ...I wouldn't feel safe leaving Yvonne with them, as I don't know what they'd say to her. So, it's always a supervised visit. ... I feel responsible to make sure nothing untoward comes of the visit.

They remember that families are not always easy and family members may manipulate each other. They have also watched the daughters coming to terms with Yvonne's learning disabilities, and accept that she cannot support them in the ways that they had perhaps dreamt of.

The learning disability ... at the beginning they didn't understand it. They didn't appreciate what effect it had on Yvonne. It was a while before they started to change their attitude to her slightly from this sort of why don't you understand? To sort of, yeah, we understand.

They advise anyone else supporting parents to contact their children in this way to

Just take it slow, know what you're dealing with. Try and find out as much about the history of what's gone on before those meetings take place, so that nothing suddenly takes you by surprise. Just be extremely understanding and supportive.

Yvonne meets with her daughters about 4 times a year, and certainly beams when she talks about them and shows off her photos of her daughters – and of her 2 grandchildren. She still talks about her son, how he has just reached 18, and hopes that he will read his file and get in contact with her. Her advocate pondered

So after years of heartache really she now has that contact with two girls and two grandchildren. I wonder how many parents with learning disabilities whose children are perhaps coming up to 18 know about this family tracing service?

<http://www2.salvationarmy.org.uk/familytracing>

Appendix 4

Other support ideas

This section gives outlines of ways that some organisations in Wales are working with parents with learning disabilities that may be useful for others to know about.

Working together with parents network

Learning Disability Wales received funding from the Baring Foundation to facilitate networks for parents with learning disabilities and their supporters. There are network meetings in both North and South Wales. There are often more parents than supporters at the meetings, with a mix of information sharing, discussing relevant issues and sharing experiences and worries. The reasons people give for coming to the meetings are:

- To meet other parents
- To meet people who have gone through similar things
- To improve services for parents with learning disabilities
- To talk about important things – there is nowhere else to talk about parents
- To meet new people and get advice
- To know you are not alone

Members of the network planned the first conference in Wales on issues for parents with learning disabilities – ‘Give us a chance to be parents’, which was seen as extremely successful with 85 participants from services across Wales.

For more details please contact Simon Rose at Learning Disability Wales
simon.rose@learningdisabilitywales.org.uk
029 2068 1160

Action for Children specialist

Action for Children have a worker in Neath/Port Talbot who specialises in working with parents with learning disabilities. The work is funded by Cymorth and is part of their outreach service for families. Criteria for referral are that either there are child protection concerns or the child has high needs. Referral can only be made by social services.

Funding was initially gained 10 years ago as part of the Sure Start work. The manager at that time was aware that parents with learning disabilities were often subject to care proceedings. She thought that with the All Wales Strategy for learning disabilities there was a new generation of adults with learning disabilities

who wanted an ordinary life which included parenthood, but the support was not there for this.

Julie Lewis works with parents with learning disabilities and parents with mental health problems. Usually clients have 12 weeks support from the outreach team, but the service accepts that longer is needed for parents with learning disabilities. They find that the same families tends to be referred repeatedly over the years. Generally in working with families there is an expectation that parents should be able to sustain any changes made to their way of life after a short period of intensive intervention. However, it is accepted that parents with learning disabilities need longer term input with repeated interventions as the child's needs change.

There has been no formal evaluation of the service, but a social worker from the learning disabilities team told me that it was obvious which parents had received this service, as their skills improved immensely, and they felt more confident of their abilities as a parent.

Julie works with up to 8 families on a 1:1 basis. With a new referral she meets the family with the social worker, looks at what the social worker wants addressed and what the family feels they need support with. She then sets up a scheme of work. Assessments are done in an amenable way alongside the parents to decide whether there are ways that routines could be approached differently (eg breakfast routine) and a pictorial timetable is made to help with this. Julie tries to do things in ways that all the family can understand so that the parents don't feel their lack of literacy skills are being highlighted as they are often embarrassed about this. The work is specific to individual family needs.

Progress reports go to children's case conferences. Before the case conferences she checks with the parents what they want to know, and reassures them that the reports going in are what they have seen with her, but they have been written in official words this time. After the case conference she makes sure they understand what has happened. Sometimes in conferences parents misunderstand the questions asked, and give a response that puts a negative light on them. Julie advises them of the response needed to the question actually asked, which often gives a more positive picture.

At the end of the input, Julie evaluates the support with the parents. With the social worker and the parents she considers whether their concerns have been met. All of this is done with resources suited to the parent's understanding.

One of the ongoing difficulties experienced by Action for Children in this work is the separation of adult and children's teams in social services, and the difficulties each side has in focusing on the other's agenda. They have tried to tackle this, including organising joint workshops several years ago. However little seems to

have changed. Even when parents have been referred by both adult and children's departments, the communication between the two is not good.

The other problem she meets is that some parents may not have a diagnosed learning disability but do have additional support needs. They do not seem to meet the criteria of the adult team even though their support needs are the same as others supported by the team. Some parents have additional mental health problems, but the mental health teams do not work with them, asserting that the parents are eligible for support from the learning disability team. This can be detrimental to the parents as the learning disability team do not have specialist mental health training, especially in post natal depression.

For more details contact Julie Lewis:
Julie.Lewis@actionforchildren.org.uk

Family Circle

Family Circle is part of Tros Gynnal, a children's charity. They facilitate family group meetings in Cardiff, Pembrokeshire and Bridgend. These are similar to family conferences, but the major differences are that Family Circle are completely independent, so to parents they are more attractive than a social services led meeting, and their attitude is that family holds the key to problems, not any professional.

The idea for family group meetings was developed in New Zealand in the 1980's and is now used successfully in countries around the world. It has been evaluated in a number of countries and shown to have positive outcomes in child protection cases (Smith and Hennessey, 1999; Merkel-Holguin et al, 2005). Family group meetings lead to greater feelings of empowerment by families, are usually able to produce a plan that is acceptable, and mobilise greater informal and formal support for families. Plans produced were assessed by social workers as having:

- prevented children going into public care in 32% of cases
- prevented court proceedings in 47%
- made no difference in 21% of cases

(Smith and Hennessey, 1999).

Family Circle primarily work with families where social services are involved and thinking of removing children. They believe that every family has strengths, and can find ways to make situations better. Families have better ways, when brought together, of protecting children, making sure the child goes to school. Families can find ways to remedy the things that concern social services. One family that Family Circle worked with had chaotic lives and a very dirty house but obviously

loved their children. The social worker was looking at placing the children with another family member. The family meeting planned that each member of the family would take a role and broke all the identified problems down into small achievable steps. 6 months later the children were off the child at risk register. The meeting harnesses and draws on the strengths of a family; it's their plan, they are not being told what to do by a professional. The process is about empowering people and families to deal with their own lives, the power is not with professionals.

The Process - A referral is made either by children's services or any other professional or family member. The allotted Family Circle Co-ordinator immediately contacts the carers of the children (mum/dad) and asks if they can meet them, to properly explain what a family meeting is. It needs to be completely voluntary.

The Co-ordinator meets with the carers and explains how the meeting works, and with the carers begins to identify who is part of the family's network. Some families say they don't have anyone/no-one will want to come and it can take a few visits to produce a list. A wide view is taken of 'family' – it does not need to be a relation, but someone who cares about the focus family. Then either the carers or Family Circle can make contact.

The Co-ordinator meets with everyone on the list and it is seen as important to talk face-to-face, as people can be unsure or defensive on the phone. Usually it is only necessary to meet these people in the network once.

The children are always involved in the meetings. The Co-ordinator will try to identify someone from the family who can advocate for them, but if necessary, Family Circle can provide an advocate. The children always attend as it is about them and focuses everyone on why they are there.

It is important to always offer places that are possible for meetings that the family are comfortable with. There must be comfy chairs and no central table. The meeting is held at a time to suit the family, so often they are held in the evening or at weekends. Only professionals have a problem with this. The families recognise that their needs are being taken into account. There is always food as it helps people to relax and it is harder to argue with a full mouth. The family are given as much time as they need.

The meeting has 3 stages:

1. Information sharing. The referrer is asked why they made the referral, what their concerns are and what they hope to achieve. If there are conditions that need to be met, these are spelt out. There is also a chance for the family to ask them questions. A lot of social workers say they find

this very difficult. Usually they are at meetings with up to 20 professionals and 2 family members, this is the other way round. It can be a difficult time, but it is important that professionals stay with it. Professionals only come to the meeting as information givers, it is not a time for them to have a discussion about the family. The Co-ordinator ensures this happens correctly. When the family network are happy that they have got all the information they need, the professionals leave, and wait in a separate room. The Co-ordinator spends another 10 minutes or so with family, making sure they have everything they need (pens, paper, food, drink) and they are clear they know what they are doing.

2. Family time. This can be as long as is needed. Sometimes meetings have taken up to 5 hours, or more. Often families have started talking before the meeting, and the meeting can be completed fairly quickly as the ideas are part way there. When the family are happy they have made a plan, the professionals are called back in.
3. Action plan Everyone goes through the plan and makes sure it is written down in the way that they want. It is only changed if the social worker says it does not address their concerns. A date is made to come back to see what progress is being made and have a review, perhaps 3 months later. There is only one other meeting after that, if at the review changes are made to the plan.

Family Circle have had a minimal number of referrals for families whose parents have learning disabilities over the last 5 years. This is possibly because families are not aware of Family Circle or because social workers make assumptions that parents wouldn't understand/be able to cope.

I know that there are some individuals out there who will harm their children and action needs to be taken. But you need to distinguish between that person and a genuine caring loving parent. Some of those caring, loving parents do need additional support and help. They're trying their best but perhaps their best isn't quite good enough. With family and friends help and support it can be made good enough.

Mike Clark, Project Leader, Family Circles

For more details contact Mike Clark:
Mike.Clark@trosgynnal.org.uk
029 2034 4681

Family Empowerment Project

Circles Network is best known for its work in facilitating the establishment of 'circles of support' for vulnerable people. A circle of support is made up of individuals known to a particular person who meet together on a voluntary, unpaid basis to help the person achieve their goals. The Family Empowerment Project is a service run by Circles Network that offers support, educational packages and assessments for disabled parents.

The service works with parents who are experiencing difficulties in parenting their children, helping them to recognise the difficulties they face and to overcome these issues. The Family Empowerment Project is a flexible service, which is needs based, and delivered in the home or local community. The project is independent of statutory organisations and works to a person centred philosophy.

Assessments - A referral is made to the project by someone in the legal system (a solicitor or barrister) to undertake an assessment for a court hearing, of the parents' support needs. The Family Empowerment worker may work with the family in their home for 40 – 60 hours preparing the assessment. As it can be difficult for parents with learning disabilities to transfer their skills to other settings, this can often show their skills and strengths to a greater advantage.

Teaching/ongoing support – Parents are referred by social service departments who have concerns that they are not fulfilling certain parenting criteria (eg house becoming very dirty) and recognise that with extra individual support the parents may cope. The Family Empowerment Project can provide a person-centred teaching plan that enables parents to understand what is needed of them and how to achieve this. The workers are very adept at making resources accessible to people with low literacy skills.

The Family Empowerment Project also provides flexible contact supervision support, where specialist trained staff can supervise family contact sessions. Their work is very much person centred.

For more information please contact:

Deborah Hill - Wales Co-ordinator

Tel: (029) 20487575

Mobile: 07779 626886

Email: deborah.hill@circlesnetwork.org.uk

Torfaen's Circles

An Assistant Team Manager in the Childcare Management Team (south) and the Team Manager of the Family Support Team developed a system for one family in Torfaen where both parents have learning disabilities. The children are 13 and 9 years old, (ages approximated to provide anonymity) obviously well loved but with ongoing problems that necessitated continuing interventions from various teams and a stream of support workers going into the home. For the Assistant Team Manager, her base lines of

- the children being loved
- developing their potential emotionally, academically, socially and physically
- the parents being motivated to change and
- having the capacity to learn new skills and behaviours

were met. Putting the children into foster care did not seem to be a positive step, but over the years the continual crises and the mother's spiralling anxiety sometimes appearing as aggression with unfamiliar people, showed that the family's needs were not being met. Concern was being expressed by all the teams involved – Education, Health, Children's services and Adult services.

The Assistant Team Manager decided to take a radically different approach for this particular family, and began by talking with colleagues in other services about trying to find an approach that worked long term. Eventually the professionals involved agreed to meet together, facilitated by a psychologist from children's services and another from adult services. At the first meeting, there were a lot of professional issues, people saying 'We don't do that (work with children, provide parenting classes, work with adults, provide support for adults with learning disabilities), that's your job.' This was slowly and painfully worked through. It took 4 meetings of the professionals involved (probably about ten people) for everyone to begin to understand how the others worked, their philosophical approach, legal obligations and agree to what would be a successful outcome. Training needs were acknowledged by all the services. It was important for all to be open to accepting their weaknesses.

To some extent they examined together what had worked in the past, what did not work and from that came to understand what may work in the future. It was obvious that if the family were to be enabled to stay together, support would need to be ongoing, not the short interventions the children's services, and other services, were used to. The following strategy was agreed:

- all the services would stay involved until the children reached adulthood
- different services would take the lead as required, according to the family's need at the time
- crucially no re-referrals would be needed as was normal for children's services, as this took valuable time and resources

- fewer people would go into the family home, trying to limit it to those the family trusted and were comfortable with

It came to be understood in the meetings that the mother's aggression was fuelled by anxiety that she would lose her children. So support was led by the community learning disability team for health, and her community nurse successfully worked with her on anger management. It also became clear that the parents' relationship was under strain from the ongoing interventions, fear of losing the children and trying to cope with children becoming teenagers, together with a lack of ability to work as a team. The psychiatrist in the health team was skilled in relationship work and successfully worked with the couple, together with the mother's community nurse and they are now seen as a stronger couple. The family support worker was liked and trusted by the family, and was willing to listen to their current needs and be flexible in the way she worked with them. She was supported in this by her manager, who helped to develop creative ways to work with the family. Homecare were removed as their work was seen as superfluous to the ongoing work at the time.

The family still have their occasional crises, the last because their usual support people were on leave, and a duty social worker went in with no prior knowledge of the family. However, it is acknowledged that the parents have worked hard to do whatever has been asked of them, and the children are happy and healthy. A success.

So, why did this happen? Because of the determination of 2 professional workers, who took identified and containable risks.

1. The Assistant Team Manager was supported by her immediate Manager and the Group Manager, as well as the Family Support Team, to work on an exceptional needs basis with this family, by way of a pilot. She did not accept the lack of policy as a barrier to action. She is clear about the importance of supporting families in staying together, when the child protection assessment base lines (see above) are met. She is willing to be flexible in approaching this area and open to new ideas. Some of the thinking about multi-agency working was informed by the English guidelines (DoH 2007), and by Dr Sue McGaw's work.
2. The Family Support Team Manager found new and creative ways to work with families, worked with the parent's strengths and needs, matched the support worker with the family and supported her, in extending her role as required at the time.

In services for people with learning disabilities this would be seen as person centred working – here it is very much family centred working. There are cost and resource implications. Agencies and services involved in this situation at different times included:

ADULT SERVICES

Social care: social worker, family aide re mother's needs, homecare

Community learning disability team: community nurse, psychologist, psychiatrist, support worker re appointments for the mother (eg took family as a whole for dental appointments).

CHILDRENS SERVICES

Social care: social worker, sessional worker for the children and father, family support team social worker and support worker.

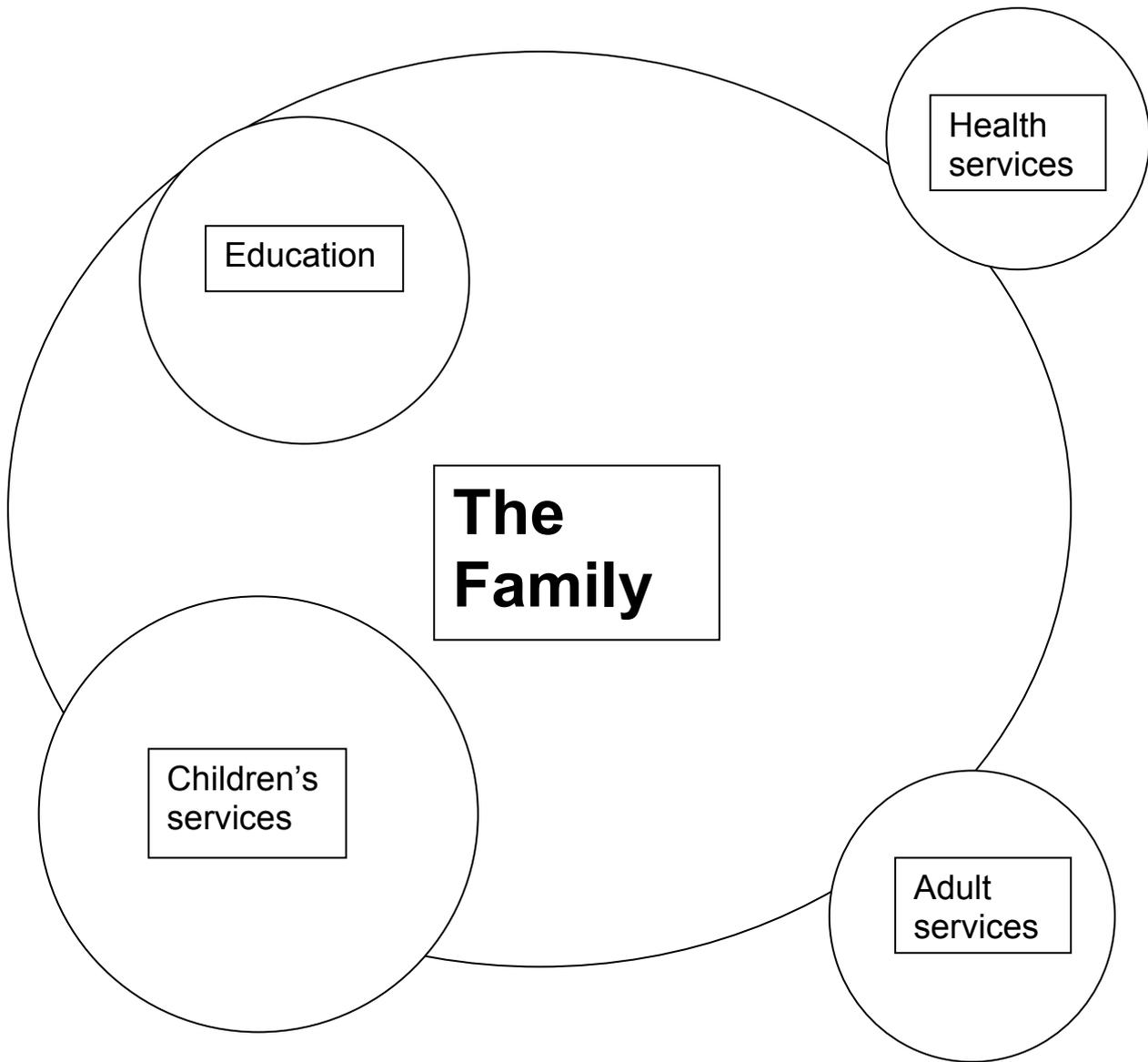
Education – schools

Independent visitor

OTHER

Young carers

Community-based activity providers locally: art club, local organisation working with families where children have disabilities.



Services vary in the amount of time and resources they are giving, and at times this will be minimal. In the above diagram, Health and Adult services are shown as giving little input, but this could change according to the family's needs. The family is shown as central to all input and services.