Positive Parenting: Supporting parents with learning disabilities - Transcript

1: Introduction

'You know the meaning of life is about having relationships, someone who loves you and someone who you love'

'And also to make sure that the people in this world today understand what special needs people are actually saying and what they want to do in life'

'Just take the time to talk to us and respect us as individuals'

Welcome to **Positive Parenting: Supporting parents with learning difficulties**, a collaboration between Research in Practice and Research in Practice for Adults. Over the next hour or so we will be taking a look at the support which is needed for this vulnerable group. We will be looking at parenting and ways in which professionals can work alongside parents to ensure good outcomes for the whole family. In particular, the CD highlights the need for adults and childrens' services to work together to ensure the best for parents and that children do well in their care.

Nicola Smith The term learning disability is a technical word because you are born with a learning disability so I will refer to a learning disability because that's in my title, but I will respect whatever they want to be called

Narrator: Nicola Smith, Co-Chair of the Learning Disability Task Force, raising the issue of terminology.

Sally Hodge: It can be confusing because a learning difficulty tends to refer to a specific area of difficulty and it tends to be used for school based difficulties so things like dyslexia and dyspraxia, minor difficulties that don't fall into the disability range, tend to be called difficulties. I think the term disability is much more global.

Beth Tarleton: Most people with learning difficulties or disabilities in the UK would prefer organisations and people to use the term learning difficulties but generally practice in adult health and social care is to use the term learning disability.

Eric Emerson: I tend to talk in the language of the people I am talking to - it's about communication in a sense, so better to communicate than get into 'too much of a tizzy' about particular terminology.

Jenny Morris: Obviously it is very important to respect the terms that people use to describe themselves and if somebody is describing themselves as a person with a learning difficulty I would always use that terminology with them. However, guidance uses the term people with learning disabilities because it is set within a legal framework where the term 'learning disability' has a legal definition and confers certain entitlements in terms of access to an assessment and to services.

Jo Williams: In MENCAP we talk about disability and I know that some people who themselves I would say have a learning disability prefer the term difficulty. So we have to be sensitive in the terms we use and respond to that individual and that is the issue.

2: The context

Narrator: So, we are not going to get 'into a tizzy' about the terms used. The terminology we will be using reflects individual contributor's preferences. Eric Emerson, Professor of Disability and Health Research, helps to set the context.

Eric Emerson: Historically in the UK the majority of people with learning disabilities always lived within the community. When they didn't live with their families – historically we put them in large scale institutions.

Jo Williams: You know people with a learning disability were described as moral defectives and so a young woman who became pregnant without a partner now could find herself now locked in an institution with child removed and we know of people who spent the next 40 years in what was then a sub-normality hospital. Shut away from the world.

Eric Emerson: So we relied on institutions in terms of providing support (which is probably the wrong word), but providing services or support for people who were not living with their families, but even at the peak of the institutionalisation period, the majority of people were outside institutions.

Jo Williams: If you kind of fast-forward to the movement to help people into the community which start in the 80's and 90's what was happening then was people were saying of course we shouldn't lock people up in large institutions but move them into the community. But people were really very reluctant to acknowledge that they were individuals with the same sex-drives as others, so it's a big taboo area. The idea that people with a learning disability should form a close relationship at the day centre and then want to get engaged and get married was actually very unacceptable.

Eric Emerson: People with learning difficulties are now more likely to be living in the community either with their families or outside of their families - you know in terms of providing residential support in community based residential services.

Jo Williams: I think it's only in the last decade with very few exceptions that people have begun to realise that their hopes and aspirations are just like anyone else's. You know the meaning of life is about having relationships, someone that who loves you and someone who you love.

3: What is a learning disability?

Narrator: That was Jo Williams, Chief Executive MENCAP. So what is a learning disability and how many people have a learning disability?

Eric Emerson: The traditional way we measure this kind of stuff is IQ - These are very general, broad based measures of intellectual functioning and most of the formal classification systems, like the ones used by the World Health Organization, have specific cut-offs on IQ tests. So that if you fall below that and you did since childhood then you are classified as having an intellectual disability or learning difficulty or whatever term you wish to use.

Sue McGaw: Well it can mean different things to different people, but the technical answer to that is that it means that three criteria have to be met.

Narrator: Sue McGaw is a Clinical Psychologist who founded and led the Special Parenting Service in Cornwall.

Sue McGaw: The first criteria is that the person is assessed as having a significant impairment of intellectual functioning, which basically means they have probably got an IQ of below 70. The second criterion is that they have a significant impairment of adaptive and social functioning, and the third criteria is that both are present before onset of adulthood. Someone who has a borderline disability would have an IQ between 70 and 80 and that would represent 6.7% of the general population and below an IQ of 70 we are talking about having a diagnosed learning disability which would comprise 2.2% of the general population. Within the 60 – 70 bracket comprises mild disability and we know that below an IQ of 60 parents with learning disabilities do have significant problems, more so than parents above that IQ of 60.

Sally Hodge: It is not a specific difficulty in for example – for example reading. It's a much more widespread and general difficulty. Yes, they will have difficulty learning to read but they will also have difficulty in understanding other things in life as well.

There is a group of people who have organic damage and there is no doubt that they have organic damage. There was deficiency of oxygen at birth, a common reason for having a learning disability, or they have a genetic condition which has learning disability associated with it, and those people tend to be very clear cut in the group of learning disabilities and their IQ's place them firmly in that range.

Narrator: Sally Hodge, Clinical Psychologist**.** So what else do we know about the incidence of learning disability?

Approximately 3% of children will have a learning difficulty/disability. That is pretty consistent and that is what we would expect given the distribution of intelligence and that is what we find approximately when we look at children who are identified as having educational needs associated with learning disability. Because people with learning disabilities have shorter life expectancy than other people, then in the adult population the number is lower and our best guess is that around about 2% that is 1 – 50 people in Britain are adults who have a learning disability.

Sally Hodge: Having a genetic condition can happen to any parents of any class, whereas I think and I come across this second group much, much more in care proceedings is that there is a group of people who come from backgrounds where they are just full of dreadful life experiences, and parents have similarly had dreadful life experiences and they perpetuate and perpetuate. I think that that group of people tend to present themselves much more around the borderline, so say between the 65 to 80 range, but struggle to use the intelligence they have, they struggle to use their cognitive skills because of their life experiences.

Eric Emerson: 200 of the adult population are identified as having a learning disability because they at some time or other have used the disability services, which means of course that 75% or the vast majority of people with a learning disability in this country do not use disability services. They are identified as having a learning disability whilst at school but then suddenly vanish. Two possibilities here, the first is that the finish of school suddenly cures them of having a learning disability which is a bit implausible actually, but more likely is that people choose not to identify themselves with a learning disability once they become adults and if you talk to adults with mild or less severe learning disabilities they don't identify themselves as having a learning disability – they may identify themselves as someone having difficulty in reading or something like that, but not as having a learning disability. It is not a badge that many people want to wear quite frankly.

The other issue of course is that social care agencies have increasingly strict eligibility criteria about who can use their services and are excluding many adults with less severe intellectual disabilities from accessing services.

Narrator: So access to services for this group may be difficult .What does research tell us? Hedy Cleaver is Professor Emeritus of Royal Holloway, University of London.

Hedy Cleaver: The research tends to have looked at the adult and when you look at studies of the family - when I tried to research what had been done before and you look at families - is the family of the person who has the disability. So it's the parent of the adult who may have a learning disability. There is very little research on parents who have learning disabilities, partly because at one time there was a great fear of adults with learning disabilities who had children, and we tended to keep them separate and segregated, secondly, there was a huge taboo about adults with learning disabilities having a sex life and becoming parents. To some extent of course the fears were driven because of the genetic issue of parents with learning disabilities and - this is a reality - they are far more likely to have a child with a learning disability or other disability and fears that these parents will not be able to parent adequately. There is no evidence to suggest that they cannot parent adequately providing they receive the correct support.

Eric Emerson: We did the first national survey in which we interviewed 3,000 people with learning disabilities in England in 2003/2004 and we did ask people whether they had children or whether they were still looking after their children. I think approximately half of the people who had children were still looking after them, but it is one of those things which you always regret when you were doing the survey, that you didn't ask the very important question - why weren't they still looking after their children? Was it perhaps because they had grown up and left home or because they had been taken away from you and perhaps someone else is looking after them. We just don't know. I don't think anyone knows the answer to that question. What we do know is that there are a significant number of parents with learning disabilities looking after their children, and also that parents with learning difficulties are at greater risk of having their children removed from them. Pinning down the numbers – we just can't do that.

4: Challenges to Parenting

Narrator: So we are not sure exactly how many parents with learning disabilities there are, nor how many of their children are living with them. However, there is clearer evidence about the challenges they face.

Jo Williams: Parents who themselves have disabilities or learning difficulties would say that they feel very isolated and often very alone and very afraid. They are facing the unknown. Some of them may have very good family support but often they don't and if they don't have good family support the authority of local government in all its guises is pretty scary – you know if you think about benefits in itself. So we know that half of the families who have a disabled child live in poverty and so for those parents who themselves have a disability actually the chances are that they will be in extreme poverty.

Eric Emerson: The chances of having a child with severe learning difficulties are just as great, whatever segment of society you come from, the extremely rich to extremely poor – it really has no bearing whatsoever on having a child with a severe learning disability. But that is not true at all in the terms of the probability of children having mild or moderate learning difficulties. There is a very, very strong link to social position or social class, or social-economic status or whatever term you wish to use and the rates of having a child with mild learning difficulties are around about five times higher amongst the poorer 20% of the population than they are amongst the 20% richest part of our population. Which of course means that those people with mild learning disabilities are much more likely to be exposed to poverty and disadvantage whilst growing up and as adults.

Jo Williams: Many families are also likely to have fairly poor housing; the environment they are living in may be difficult, so judgements will be made about that as well.

Narrator: Poverty is therefore crucially important, but how might other life experiences have an impact?

Sally Hodge: We know also from the research and I produced a paper last year that was published looking at the level of psycho-pathology amongst parents with learning disabilities. What I found was that 79% of the population I interviewed were reporting abuse and neglect in childhood, so in itself that is going to present in some way in their own parenting. I also found that in their adulthood of that population 45% also indicated that there was some level of psycho-pathology in there. So they are prone to clinical depression, poor self esteem and a number of other symptoms.

I think parents are so out of touch or unaware of how awful their own life experiences are, and how they have impacted on them and how much that they are then repeating a pattern. I think often it is very unconscious. If you haven't experienced as a child good enough emotional parenting, if you never felt wanted or you felt always that you have been a nuisance or you have been exploited or abused it is very difficult to summon up the energy to be able to parent in the best possible way your own children. It's just not there - one hasn't learned that experience of being unconditionally loved.

Narrator: There is also another significant way these parents can be vulnerable.

Hedy Cleaver: What the research seemed to show when we followed the children through was that a key factor that distinguished children who remained living safely with their parents from those who were either removed or who didn't show satisfactory progress was the day to day support of a caring safe adult, a relative or a partner. You have to remember that word - a 'safe' adult living with them - because many of these women with learning disabilities who have children can be targeted by paedophiles that are very good at supporting the mother and making sure that her life runs well, the house is clean and that there is enough money coming in. She is looked after, but this is at the expense of the children. So a 'safe adult' is a very important thing to remember.

Sue McGaw: The research that I am currently involved which I hope will be published this year is showing that within the partners of many mothers with learning disabilities there is a huge risk factor, and I think we are just starting to tap into that. In particular what the findings are showing is that mothers with partners of IQ's of more than 80 are 8 times greater in terms of risk to the child in terms of the child being on the Child Protection Register, or removal of their child, then for mothers with partners with IQ's less than 70. So therefore where both parents have learning disabilities actually they have an awful lot in common, sharing a lot of their past difficulties and their current difficulties and it is much more reciprocal than when you have a huge discrepancy in the level of IQ. We have to be careful with that too, because we cannot generalise too much.

Eric Emerson: There are also a group of people who have been almost certainly subjected to high levels of social exclusion, bullying, victimisation. In a sense they are living in a society which is continually telling them that they are actually not very good people. You know these are the group of people who have grown up and lived in the understanding that they are actually not particularly valued in the society in which they are living. They are the butt of jokes and there are continuous messages being sent to people with learning difficulties that they are either second class citizens or not citizens at all.

Glen Rollings: When I was at normal mainstream schools I was bullied a hell of a lot with the kids all calling me thicko, or whose got the D hat on and until I moved to a special school and then the bullying stopped because we were all the same. All the kids at special school some had the same kind of symptoms in a similar way.

Narrator: Glen Rollings, a parent, highlighting the issue with personal experience.

5: Guidance and joint working

There is clearly much policy relevant to work with parents and children in this area, including Every Child Matters; The Common Assessment Framework; Valuing People and more recently Putting People First. All of these sit as a backdrop to the Good Practice Guidance on working with parents with a learning disability. Jenny Morris was commissioned by the Department of Health and the then department for Education and Skills to write the Good Practice Guidance.

Jenny Morris: The Guidance identifies that there are five key features of good practice for both children and adult services. These are: accessible information in communication, clear and co-ordinated referral and assessment procedures and processes, clear eligibility criteria, support that is designed to meet the needs of parents and children that is based on the assessment of their needs and strengths and long term support where necessary and access to independent advocacy.

How that translates for children's services is that it is really important that they start by considering what support parents might need and in doing that recognise the possible impact of cognitive impairment on, for example, the ability to read letters or the ability to read instructions or how to make up a baby's feed, those kinds of things and to recognise that parents might need support with these tasks, rather than leaving them to fail at what are quite basic tasks. This 'failure' often gets labelled as child neglect and often at that stage the family is in crisis and it is often quite difficult to provide support.

Glen Rollings:Just treat us like humans with no more jargon. Just treat us normal instead of looking down at us. Parents would like support, as we said, from people who really understand how to work with parents with learning difficulties.

Narrator: Beth Tarleton is a Research Fellow at the Norah Fry Research Centre in Bristol

Beth Tarleton: Support can come from mainstream services or special parenting services - there are some around the country – parents would like to be able to access mainstream services and for those services to be trained and be able to support them, so that they can go to the family centre that everyone else goes to – goes to all the same services like breast feeding groups and all those sorts of things. At the moment parents are still feeling scared to enter the environments with all different mums, without support and feel that they might not understand what is going on, so there needs to be a greater awareness of parents with learning difficulties in all the mainstream services, so that they can access the same support that anybody else can.

Jenny Morris: It's really important that children's services recognise that parents as adults have entitlements under adult legislation and those assessments of their parenting capacity should not be made until those support needs have been addressed. It is very easy to see cognitive impairment as the cause of the difficulties the children and the family are facing, rather than addressing the barriers that the parent might be experiencing like lack of access to accessible communication and that kind of thing. Or just lack of knowledge about what they should be doing as a parent. What is important to recognise, if children's services take that approach, is that it actually opens up possibilities for supporting families. You can't actually change somebody's cognitive impairment - they have that for life - but what you can do is change the environment that they are experiencing that impairment in and the support or lack of support that is currently available to them.

Sally Hodge: Because local learning disability services tend to be overwhelmed they tend to use IQ as a cut off for eligibility for their services, which means that people who I think, in reality, are the really high risk group which is people who are cognitively impaired and significantly cognitively impaired and often function at a level below their IQ because of their emotional and personality difficulties. This group are not eligible for the more appropriate service, which would be the learning disability service. They are only eligible for the local adult mental health service.

Narrator: Eligibility for services is clearly very important with a number of legal obligations.

Jenny Morris: It's very important that adult learning disability services recognise that parents like these, do have entitlements to an assessment as disabled people. And that parenting roles are covered under Fair Access to Care Services and Practice Guidance and that the parenting role should be addressed when assessments are carried out. It is also really important to recognise that it is not appropriate to use IQ as a method of determining eligibility and that although is very common, it could be easily challenged in Court because it is actually going against their statutory responsibility to make such a blanket exclusion.

Glen Rollings: They just don't know how to treat us; also they don't know to treat people with mental illnesses as well. We want to go forward and just have freedom and support as individuals because we are the same as everyone else.

Eric Emerson: As eligibility criteria for social care gets tightened up then it is quite clear that we are not supporting a group of adults who are quite vulnerable so what tends to happens is that no support is provided until they are in crisis. The ways in which that crisis can manifest itself is when they become parents – when social care agencies become involved in child protection - whereas previously have not given them any support whatsoever. It's a kind of crazy social policy. We know this is a vulnerable group of people who may have difficulties in accommodating to the demands of life. We say they are not eligible for social care services because they are not disabled enough to meet our criteria and then when things go wrong then the Fire Brigade comes out.

Beth Tarleton: There was one Adult Learning Disability Service that had a Children's Social Worker attached to it and that had been very helpful.

Jenny Morris: One additional thing about linking between Children and Adult Services is that it is really, really important that they agree and have very clear referral and assessment processes in order to prevent parents falling between the two.

SCIE – the Social Care Institute for Excellence - has produced a resource guide on joint local protocols. The process of writing those joint local protocols is usually as valuable as the protocol, because it is the writing of it that enables adult and children’s services to come together and to try and get better co-ordination between their services and their referral procedures etc. Part of those protocols will usually be identifying somebody in learning disability services who has particular expertise or experience around parenting issues and somebody in children’s services who has particular expertise or experience around learning disability issues. Or if those people don’t exist to set up communication processes so that they can get access to that help from the respective services.

Narrator: And then, there is the issue of resources

Jenny Morris: One of the key things that joint local protocols can do which is the most effective in enabling joint working is to deal with the financial issues, pooled budgets or similar arrangements, because the classic situation is that parents like these fall between adults and children’s services because neither wants to call on their budget and if you have a pooled budget then it mitigates against that.

Jo Williams: We need to skill people to understand learning disability and who also understand safeguarding children and they are a rare breed, and with the structural changes in the social care sector there may be some big challenges there. How do we equip people that understand the world of learning disability to really truly understand the safeguarding agenda and the child protection system and all that that means. In our experience if you can find a person or skill them up they are the best support the family can have, because they can explain the systems to the families but also help the families to get an advocate. So you know there is something there about practice on the ground. In policy terms we just have to make sure all the rhetoric about keeping children with their birth families applies just as much to our children as it does to every other child.

6: Support for parents

Narrator: Now let's turn our attention to supporting Parents. Here is Glen Rollins

Glen Rollings: Social workers should be a bit more supportive to parents with learning difficulties. I'm not saying every social worker but some social workers we see, they only think of one thing. OK, the job is for the child but they have to look at the other end of the scale at what's causing it and why they are having problems with the child. Look at the parents – have they got some type of learning difficulty? Instead of just taking the child away from their parents, instead of thinking and using their heads – hold on – let's take a step back and have a good look at what's going on and help the parent.

Narrator: So what do we know from research about what supports parents?

Beth Tarleton: There is not a lot of research, but from the information and the work that we have been doing at MENCAP and others have been doing – often it is the very practical things that make a difference and that is about helping people to understand some of the difficulties of running a home really with a child, and getting into routines and people can do that, if they have a little bit of guidance and support.

We did the survey in 2004 and there were at least 85 services that we found that were trying to be pro-active in the way they were working. Some services were doing really innovative things like adapting mainstream parenting courses into easy English and pictures and things and putting it on tape. They can work through that with parents and one had negotiated with a local college to do a cooking course and had negotiated that the parents could qualify by submitting their work in photos, rather than a written assignment. So there are lots of really, really interesting ways that people are working with parents to help them understand the new things they want to learn.

Communication skills are obviously really important for anybody in contact with parents with learning disabilities. They need to know how to use the accessible language; they need to know how to get access to communication expertise if they require that. I think parents would like professionals who work with them to have experience of working with adults with learning difficulties or training about how you can support people in very basic easy information and breaking concepts down, so that they have got an awareness.

Then they also like professionals to work with them at their level, something like making a baby's bottle, parents could be supported through the different steps by taking photographs of each step to making the bottle so that parents can refer to that and practice and get it right, or perhaps find a container that's the right size for the water so that they don't have to do the measuring of the little gradients on the bottle. Lots of really practical concrete ways of explaining things so that the parents could get to grips with things.

Glen Rollings: The idea we want is for this jargon to be stopped and just to be written down in simple common words we can understand. We were talking the other day on CD, like you are doing now, putting it into words and playing it back so that a learning disability person can understand by listening and then you do not use jargon. It's got to be simple and the learning difficulty people will understand it.

Beth Tarleton: Like the books that have been made by Change about you and your baby, and you and your little child, with pictures and very short sentences or skill cards or breaking down the things they have difficulties with into easy steps so that they can master them and practice them so that they are developing skills, rather than being viewed as people who can't but actually working towards being the best they can. Lots of the services that are trying to work this way often use a key worker and try to reduce the number of workers going into a family, so that they can all be consistent in how they support people and have the same idea of the goals that they are working for. In the places we talked to parents they were very pleased with this sort of support when it was co-ordinated and consistent and was helping them to do things for themselves and learn that they could improve.

Christopher Rollings: More respect to disability people and more communication and understanding to special needs people, also to make sure that the people in this world today understand what special need people are actually saying and what they want to do in life.

Narrator: So good communication is vital to support and accessing mainstream services

Jenny Morris: Mainstream health services have a really important role to play for these families, GP's, midwives, health visitors etc. but they are not always delivered in a way that is very accessible to parents, because the assumption is that people can read, people can understand jargon and that people are confident to go into a strange building for an appointment. Really the health services like all public services should be looking at how to fulfil their disability duty in terms of pro-actively looking at how they can be equally accessible to these groups of parents. They need to know about the relevant services that are available, particularly independent advocacy services. The evidence is that they don't but again the process of writing joint local protocols could highlight the need to know about these things and to make sure that they do know about it.

Beth Tarleton: Support should be available whenever parents need it - whether it's a little baby or whether it is a child at school needing help with their reading.

Parents with learning difficulties are always going to have learning difficulties so that they may need to have different supports at different times. Parents have found that they have often had support and that when they have tackled that issue it has gone away. We need to a new way of thinking or it needs to be available throughout the parenting journey I suppose.

Families need different kinds of support at different periods of time – most of the research and the services we know about are actually providing support to parents with young children, but those parents are likely to be experiencing particular problems when their children become adolescents so they may need long term support.

Jo Williams: The other thing I think is working well is peer support – some of the families say that the best support they have had is from someone in similar circumstances so pulling those together.

Debbie Moseley: I think there is one thing that Parents2Parents do is support parents with learning disabilities, listen to what they have to say and answer them the best way that they can.

Narrator: And what is Parents2Parents?

Momotaz Begum: It's a parents group that supports parents with learning disabilities. What they do now is support other parents who are going through the same thing and explain to them this is what is going to happen and this is what you can expect and they also point out things that the parents have a right to access. They were not aware of those things when they were going through the process so now that they know that they can have an advocate straight away and they should have that referral straight away, not the day before and that is not fair for the parents, because they don't have fair access to the information that they can challenge, and the Parents2Parents help them with that.

Debbie Moseley: Parents which are in the same predicament as me and we talk about all our problems together and I don't feel alone anymore as I use to because other families are going through what we have been through and some are at the beginning and some are in the middle and some are at the end.

Narrator: That was Debbie Moseley and before that we had Momotaz Begum
Other support can also help

Jenny Morris: One of the things that does make a very big difference to the individual family is if there is good extended family support and you can't put a price on that really. Good support can enable someone to parent and look after their child effectively and there is certainly evidence from Australia that parents with learning disabilities are more likely to be able to keep their children where they have good support from an extended family member. However, there are instances where parents have felt excluded by the way the support is provided because the extended family member effectively takes over the childcare, rather than facilitating the parent to look after their child.

It seems to me that for local authorities they do have to think very carefully about how they support that extended family and get into partnership with that extended family as well as that nuclear family because that can make a very big difference to those people's ability to parent.

Narrator: Here is Christopher – Glen's son with first hand experience.

Christopher Rollings: I've never had a disability in a way and I am always a confident person, for instance you have found out about my Dad who has special needs and Mum has got special needs as well and my brother and my little sister and really with my sister and my brother when I am around the house and everything else and they have wanted my help, for instance I have actually been there to help them.

7: Assessment

Narrator: Assessment in essential to providing meaningful support.

Sue McGaw: What strikes us over a period of time when you are working with many parents with learning difficulties is that how complicated each one is.

Narrator: Sue McGaw developed the Parenting Assessment Manual, now used widely to help practitioners in their work.

Sue McGaw: I know when I am trying to discuss this with other professionals, the way that I liken it, is like putting your hand into a bag of marbles each time you are asked to complete a Parenting Assessment and each time you get a different combination of colours and marbles coming out. So at no one time are the marble colours the same, so what you are having to apply is a systematic approach to the assessment and the approach you are providing, which is versatile enough to take in all the different factors that we are trying to consider.

What we are looking at, in particular, are the known, the things that we know from the research and from our experience, and if we start off looking at the level of cognitive functioning as something we know is problematic the rate and level of ability of these parents to take on board information is going to be limited. Their ability to problem solve and also to generalise information is going to be fairly limited as well, and by that if we are asking them or telling them or advising them to do something their ability to take something in and then to apply it may also be fairly limited.

It is really important to assess what support is needed on an individual basis and that one can’t say that because someone has a learning disability that they are going to need X or Y, and I think that a good baseline assessment and there are quite a few tools that are out there that do baseline assessments in the area of learning disability to see where strengths and weaknesses are. I also think it is helpful wherever possible when there is a question about ability to do a full psychological assessment actually, to look at cognitive functioning. I find often when people come to me in proceedings that hasn’t happened and when I do an assessment I discover that there is a particular area of difficulty which would make it difficult for that parent to access the information in the way it has been presented. So we are working against them right from the start.

As far as I know there is no one parenting tool that does the job, because it would have to be standardised on a huge population of parents, so we, as professionals, are doing the best job we can to get this right.

Sally Hodge: What I am I saying what I think needs to happen is a three-pronged approach to assessment, to use a functional assessment – looking at how parents manage their own affairs and independent living skills and adaptive behavioural skills on a daily basis. We have to look at a diagnostic approach which is looking at can we identify that this parent definitely has a learning disability? – what are their numeracy or literary skills like, have they got mental health issues? what is their self esteem like? have they got an anger management problem? - and the third approach is an ecological one, where we are look at each member of the family individually but also as a family unit, living within their own community, and it is looking at how much support they get from other people. Do they get on with their neighbours, do they have extended family support nearby, and do they access the resources that they need? All these three elements come together in any one assessment.

It is not just the person, it is the environment they live in and it is there support network whether their partner is able to make up for the difficulties they have, they work together and whether their difficulties compensate for each other, or whether their strengths compensate for each other.

Glen Rollings: My partner, she's got learning difficulties but she ain't got it as severe as me she can read but as she is slow on her maths, so if there is any paperwork – like reading or anything she will read it to me, and vice versa if she needs something added up I will calculate it for her. So we work as a team in that kind of way.

Sue McGaw: It is the neighbourhood and whether neighbours are supportive, whether there is family around that provides the emotional back-up that parents need when they are parenting, I think one needs to take into account things like the education and the support for the children and whether that is available and whether they are able to access it.

Narrator: The Parenting Assessment Manual is a vital tool to ensure that this happens.

Sue McGaw: What is offers is a theoretical approach to conducting a parenting assessment which looks at 312 parenting skills across child domain and parent domain, looking at both children's needs and parents needs at the same time, and expands the child's age range from 0 to 19 and it looks at the whole family as a unit as well. The model that it is based on – there are several - but the main model is that we are looking systematically at assessing parenting knowledge, skills and frequency of practice across those 312 skills. At the end of it we end up with a needs profile which is graded and also a risk profile so a risk of poor parenting to the child, but also a teaching programme comes out of it and, because it is all electronic now, it should assist professionals to get there sooner, but for the information to be very accurate.

Sally Hodge: For me the things that need to be most considered are emotional and the personality functioning of a person and I think this is really important that there is a thorough assessment of those areas. Often when parents themselves have had a poor experience they are not necessarily consciously aware of the impact that this is going to have on their own parenting and patterns we know are repeated and repeated. Being able to explore that and provide them not only with support, or the teaching and training where needed, the psychological support could make a big difference to whether they will be able to successfully mitigate against the risk factors that are around.

Sue McGaw: What we found from our perspective within the Special Parenting Service is that we have to be very practical. If we can look at parenting routines as the mainstay of parenting, that is a really good starting point for any professional. Parenting hangs on the back of those routines, and for many of these parents they have not been subjected to, nor had the benefit of parenting routines in their own life. Do they understand that they have to get up in the morning and wash the child and feed them and get them off to school and make sure that they are clothed appropriately and have got all their books?

Then we get down to targeting particular skills just on an everyday basis or weekly basis with a parent just to keep it simple, to target three or four skills at any one time, to make sure that we are evaluating those skills in terms of measuring them and that we know as professionals how to do that. We need to to remember that professionals get trained to apply our skills in a particular way and forget how we come across sometimes to very vulnerable parents.

What we would like to do when we are assessing or carrying out interventions is have the parents alongside us so that they can see us writing it down, or they can see what we are putting onto the laptop. If we write a report we offer them a simplified version of that report and they always hear the results of the report first before we share that with anybody else. We also have an open door policy so that parents can access our services as and when they need to, and that is quite a difficult thing to do these days.

If we can ensure that we have continuity of services it’s going to help these parents.

Narrator: So some important practice guidance for assessment.

8: Child protection and the Court

Mark Moseley: When you get in there that's the first thing that is in your mind, you ain't any good, your rubbish, you ain't worth anything and it's not worth living, so it is very important to have a good advocate with you. Support is the main thing you need somebody to tell you, you have some good things. My lawyer done that to me – he said 'Mark you got some good things mate, you are a good bloke, don't let people put you down'

Narrator: So what kind of support do parents need when child protection procedures come into play – a formidable prospect for any parent?

Momotaz Begum: Parents2Parent are very good because of lot of these parents like Grace and Debbie when they first started going through the proceedings for child protection, they were not aware of what to expect and their social worker didn't take the time out to explain to them that, OK this will happen and that will happen, and this is what you should expect so a lot of the time it was a huge shock for the parents and obviously it would have made them more distraught.

Mark Moseley: Case Conferences are very intimidating. As soon as you walk in you are intimidated as soon as you walk in that door you start going down into your box, because that is how they make you feel, even the secretaries in that office make you feel that you are nothing.

Debbie Moseley: The thing that really irritates me with the Case Conferences is that they use all this jargon that you don't understand. They want to make it more simpler, like either easier to read to use pictures for people who cannot read it would make it a lot easier.

Grace Kendall: They should sit and listen to you and get the facts right, before they jump into the deep end – they speak too quick for people to understand who doesn't understand that well.

Damian Griffiths: Some of the disadvantages of the Child Protection Conference system I would say that it is intimidating for families and for professionals in some cases. It's very formal, it is problem saturated in that it focuses much more on the negatives and the problems than it does on the possible solutions. Families by and large don't understand it and they feel attacked and the business meeting around a table doesn't really lend itself to a collective task approach.

Narrator: Damian Griffiths from Oxfordshire County Council. Before him, Debbie Moseley and Grace Kendall talking about their experiences. So how can this intimidating process be improved for parents?

Debbie Moseley: We want to have the report, possibly a week before. When you go to a Case Conference you get the report on the day, which is not good enough, because we have not got the time to challenge the report or what they are saying about us, and we need to talk and have more time with an advocate and also have a private room. They have a private room to discuss all their things, why can't we have our own room to talk to our advocate instead of sitting in a hallway with everybody walking past and whatever you have to say they are listening and they are going to tell this and this to them and they are not giving us chance to have our say. I think the Case Conferences should be shorter because they are too long. I have been to Case Conferences where they have been three hours and you just sit there for three hours and it's not good.

Narrator: In cases where there are serious concerns about a child's welfare, parents may become involved in Court proceedings.

Sally Hodge: We know that when parents are referred to our particular service, just prior to going through care proceedings, that we are reaching them at the worst possible moment in their life. They are at risk of having their children removed from their care. In the past research has shown that on the basis of IQ alone that parents have actually lost their children through court proceedings which evidently shouldn't be happening and that more sophisticated assessments need to be completed before we get to the point of care proceedings with this population.

It is extremely anxiety provoking and anxiety itself has an impact on cognitive functioning. You know there is a double disadvantage to people who are struggling in going through the court system. Having somebody that they trust with them who is not part of the proceedings, who could help them go over what has happened and help them understand what is happening is essential. I think it is not the job of somebody who is within the proceedings to do that, because I think if there is anxiety or paranoia around, they are not going to be able to work with that person, so it needs to be an independent advocate and I think that is absolutely essential.

Mark Moseley: Parents need a bit more of a chance to keep the kids, because I truly believe that children are damaged in the mind once they are removed from the house and they go to foster parents - they are with complete strangers - they are not Mum and Dad and never will be - so that is the first thing that I think should be changed. I think the parents should have a bit more of a chance to keep the kids.

Sally Hodge: A lot of the resources are channelled into getting through the hearing process. In a way it might be a bit easier if the result is that the child has been placed with the parent but that there is a recognised need for support, but often that doesn't happen because it has been come at too late. I think there is very, very little recognition about what it does to people who have lost their children. It can be devastating and what I see in proceedings is people going off and having child after child because they haven't been given the help that is needed to process what has happened to them. It really is very, very important that people are given post-removal support, counselling and therapy if that is needed in order for them to be able to recognise and learn, its not just about what has happened it's about putting them in a better position for children that they may have in the future. Understanding what went wrong, what they contributed to that as well as helping them through what is a really devastating event.

Narrator: Sally Hodges bringing us to the end of our brief look at parenting for adults with learning disabilities.

9: Conclusion

We hope you have enjoyed this CD which is also available to download from our websites. There is also a list of resources, a transcript and further information. We would like to thank all of our contributors. in particular those parents who shared their experiences with us and will leave you now with some final comments from our contributors.

‘I wanted to be heard, because I don’t think I was being heard and that I am talking for hundreds of parents in this country, their voice is not heard’

‘It is important to have it in their format, disc or tape or it might be in film but it has to be down to the person’s individual needs’

‘They like to pick on me and they do, like when I was at school they did, I have a disability and I had to leave school, just treat people normally instead of looking down at us’

‘What the parents tell us themselves is that they are really frightened to ask for support because if they do, they are afraid that there children will be removed and if they don’t ask for support they get themselves into difficulties and it’s a downward spiral’

‘There are improvements in support and guidance that we are giving our parents but we still as professionals need to be in a position to be able to say for some parents it’s still not right and for other parents they need ongoing parents and for the other remaining parents they need occasional support’

‘Adults and Children’s Services should work together’

‘All new Mums need support and we are no different’