

# Getting Things Changed

Successful professional practice when  
working with parents with learning difficulties



Beth Tarleton, Danielle Turney, Wendy Merchant and Nadine Tilbury (2018)

With huge thanks to all the parents and professionals involved.

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# Successful professional practice when working with parents with learning difficulties

## Key messages:

### Parents:

- Spoke of professionals who treated them with respect and supported them to learn. They had positive relationships with most professionals they were engaged with.
- The positive professional practice had, for some parents, enabled them to understand the children's social workers' role and to engage more effectively with them. Parents who had previously lost children, had kept later children, with support.

### Professionals:

- Started from the Children Act 1989 presumption of enabling children to remain with their families, where possible. However, they recognised that successful practice was defined by process - how parents were worked with and the nature of the support offered - and could still take place even if, in the end, the child was removed from the parents' care.
- Understood that:
  - Parents' learning difficulties did not automatically result in inability to parent and that any neglect was usually unintentional and often based on a lack of understanding of the child's needs.
  - Parents need support to overcome a wide range of difficulties and to ensure the well-being of their children.
  - The quality of support provided, contributed to positive outcomes for children.
  - Parents may need support recurrently and/or over the long-term.
- Developed positive relationships with parents, were honest about their concerns and tailored how they worked to the individual parents.

Working with parents requires:



Time

Trust

Tenacity

Truthfulness

Transparency

Tailored response

#### Local policies:

- Operationalised the key principles in the *Good practice guidance on working with parents with a learning disability* (GPG) (DH/DfES, 2007, WTPN 2016).
- Some professionals were not aware of their own LA's policies detailing how to support parents with learning difficulties, or the GPG, even though they were in fact working in accordance with local policy and the GPG.

#### Different models of specialist provision to support parents were observed:

- **Consultation model:** parental learning disability specialists were called in to support or advise other practitioners such as health visitors / school nurses;
- **Hub model:** specialists co-ordinated other practitioners' involvement with the family.

#### Planning for anticipated need:

Systems to measure and plan for anticipated numbers of parents with learning difficulties who might need support were lacking.

# Successful professional practice when working with parents with learning difficulties

## Aims

We wanted to find out ‘what works’ when working with parents with learning difficulties where there are concerns regarding neglect, in order to support the development of effective, fair and positive practices. So our guiding questions were:

- What are successful practices when working with parents with learning difficulties?
- How is success defined by professionals, parents with learning difficulties and children?
- What facilitates successful practices?

We did not have a preconceived definition of ‘success’. We recognised this is an extremely complex area and that ‘success’ could mean very different things to different people. We were interested in understanding the ways in which success is perceived when working with parents with learning difficulties.

The term learning difficulties is used here to include parents with a diagnosed learning disability and those without. Parents in this wider group may not meet the threshold for support from the adult learning disabilities team as they do not meet the criteria for a formal diagnosis of learning disability, but struggle with similar issues in everyday life and ensuring the welfare of their children.

## How we investigated ‘successful’ practice with parents with learning difficulties

The research was carried out in three Local Authorities in England. Members of the Working Together with Parents Network ([wtpn.co.uk](http://wtpn.co.uk)), which supports professionals working with parents with learning difficulties, were asked to recommend areas where there was ‘successful practice’. Once sites had agreed in principle to take part, NHS ethical approval was obtained and local research governance approval. The University of Bristol was the research sponsor. We were advised by parents with learning difficulties at Greenwich Advocacy, and by a group of parents with learning difficulties and their adult children at SpeakUp Rotherham. This group has also made a video giving their view on the project findings see <http://www.bristol.ac.uk/sps/gettingthingschanged/>. We were also advised by a group of professionals and academics.

We used a case study approach interviewing three parents (nine in total) and, with the parents' agreement, the professionals (38 in total) involved with them in three Local Authorities where there were specialist parenting services for parents with learning difficulties. We then developed eight case studies including the views of the parent and the professionals involved with them. We were unable to interview the professionals involved with the final parent. We asked the parents what they understood about neglect and being involved with children's services, as well as what was good and bad about how they were supported. It should be noted that the parents were actually all mothers; unfortunately, no fathers were interviewed in this study, even though this was desired. Mothers were the recipients of the professionals' support, and they were the parents introduced to us by the services. See Dugdale and Symonds (2017) for recent research on fathers with learning difficulties. There is a film about those findings at: <https://www.youtube.com/watch?v=pNe133YO5S0>

We asked the professionals involved with parents what they understood by the term 'learning difficulties' and what they thought when the term 'parents with learning difficulties' was used in conjunction with the term 'neglect.' This was particularly insightful as it gave an understanding of the beliefs and assumptions that underpinned the professionals' approaches to parents. We also asked professionals how they worked with the parent and with each other. Service managers and commissioners were asked about the local policies guiding practice in the area and the arrangements for specialist parenting services, including how they were financed.

## Who were the families involved in the research?

The three anonymised composite case studies on the following pages have been drawn together to provide an insight into the families' situations. The mothers could all be described British and living often in poor circumstances. Some details have been changed to ensure participants' anonymity.

All the mothers interviewed had at least one child living with them. For two of the mothers, this was their only child. The other seven mothers had more than one child, and in five of these families the older children had been removed from their care. They were often living with kinship carers. Six of the mothers had family support, usually the family member who was caring for their older children. One family had support from their child's previous foster carers while another, with a disabled child, had access to respite/short breaks.



## What sorts of issues were the families facing?

The concerns regarding the child/ren's welfare that had brought the parents into recent contact with Children's Services included: grubbiness of child reported by nursery; a child whose health had been affected by poor diet; a child being very underweight; unrecognised serious medical condition; concerns regarding father/partner/uncle; concerns regarding inappropriate friends; homelessness; poor housing. In some cases, 'historic' concerns related to the care of previous children appeared to be the driver for present referral. Two mothers felt the concerns were linked directly to their learning difficulties. One mother spoke of abuse in her own childhood.

The report now presents a summary of the key findings, including Nikki, Chloe and Janine's stories illustrating how professionals worked with parents in each of the three sites. These stories are composites drawing on the eight case studies.

## Findings

### Parents relationships with Children's social workers

The parents' understanding of the role of social workers varied from believing that their child's social worker did not understand them and wanted to remove their current child, to understanding their role in ensuring the welfare of the children. Some parents had had a number of social workers with whom they had relationships of differing quality. Most of the parents had negotiated a more positive relationship with their child's current social worker whom they saw as supportive of them. One parent recognised that having their previous child removed was '*our fault*' as they not listened and responded to their child's social worker's concerns and was determined to show the social worker that they had changed:

*'But this time we had a lot of support with my daughter. And it was...how it feels was different. I didn't sweat the social workers – always helping each other, basically. It was like we needed a new cooker, we told them we needed a new cooker, we needed a new fridge and freezer; they sorted everything out for us. We told them what we needed.'*

The parent felt that their child's current social worker was supportive and helped them in a direct and practical way.

## Parents' positive relationships with professionals

All of the parents had positive relationships with **most** the professionals involved in their case. They all spoke positively of the professionals from the specialist parenting services. Parents described their professionals as 'nice', 'helpful', 'patient', 'friendly'.

*'They understand where I'm coming from. They sit there, actually sit there and listen and hear me, before they tell me what to do.'*

Parents identified situations where professionals had 'understood' their situations, advised, taught and empowered them: *'I got to see what I was good at.'*

*'She is very understanding. I can talk to (special parenting worker), like I'm talking to you. She puts me on the right road.'*

Relationships were often long-lasting, with parents feeling they could contact professionals even if they were not currently being actively supported by them.

*'... Because I've had [Name of professional] for, like, over ten years now... [She] will turn up saying, 'How's things?'*

## Professionals' views of parents with learning difficulties and concerns regarding neglect

Professionals in all three sites shared some common understandings regarding parents with learning difficulties. They understood that the parents who have an intellectual impairment 'don't set out to be bad parents'. Professional saw parents as having 'a higher need for support and information in a way that suits them'

*'Parent has difficulty processing information, and may have difficulties with their own literacy, numeracy, and speech and language, that sort of thing really.'*

*'That they don't have a good understanding of what their child needs. Sort of not educated as well as other people, in terms of parenting. I don't know. And that people that can be taught, and can learn, if the right teaching is in place. I wouldn't necessarily write anybody off because of a learning disability, you know.'*

Professionals did 'not automatically make the link between learning difficulties and neglect', and believed that in most cases, the neglect of their children was not intentional - 'there might be identified areas of neglect. However, potentially, probably, not intentional'. They

sought to understand each family's situation and the impact of the learning difficulty, while recognising the wide range of additional challenges/difficulties parents face:

*'Parent with learning difficulties need a large network of life-long support because of their vulnerability which comes from a mixture of things- having a LD, being victims of domestic violence, sexual abuse and vulnerable to being groomed by sex offenders. However, there is hope if the parents have the right level of support and are given the opportunity to learn.'*

*'If you've got a parent whose mind is completely preoccupied with, you know, not having enough money, fear, maybe mental health issues, then it's very hard to sort of prioritise, and be thinking about your child's needs. So I would say that a percentage of the parents that we see with learning difficulties and neglect, it's actually because of those broader, social, mental health issues, that prevent all parents, actually, from being able to prioritise'*

Professionals focused on the need to provide effective support to ensure parents and children had the best chance to remain together. Commenting on situations where children were removed, one professional said:

*'... I would wonder whether those parents had been appropriately supported in a way that they could access and understand, to parent their children effectively.'*

## Parenting after children have previously been removed

All of the professionals were asked a question, which came from the parents' advisory groups, about whether they believed in 'second chances' for parents with learning difficulties. Professionals, from all backgrounds, said that parents deserved a 'second chance' but that it needed to be in the context of a discernible change in circumstances: *'Yes – but something needs to have changed for children's services to be convinced.'*

*'Particularly if there's been a gap, and people have made some changes in their lives. You know, I've seen a lot of people who had a first child maybe when they were 16, and they were in a kind of, you know, really chaotic, difficult relationship, and there was a baby removed. Six years later, they're in a settled relationship, they're mature, they're well able.'*

Parents' ability to change was linked to the provision of appropriate support while keeping a focus on the child/ren, their outcomes and time frame.

*'I believe that everybody has the right to appropriate support to parent their children effectively. And if they have had access to that and things haven't worked out, that doesn't mean that they shouldn't have the opportunity to try again with different, more...differently shaped support, or whatever, as long as the child is safe in the meantime. I think people can*

*change. People can change. And also that sometimes where people talk about having a second chance, it's because the first chance wasn't appropriately supported in the first place, and that was why things went wrong. So yes, I do believe in second chances.'*

## Successful support for parents with learning difficulties

Professionals were clear that successful practice was about providing parents with appropriate support whilst retaining a focus on the welfare of the child.

*'So I think for successful practice to happen, you need to have all of those markers that are in the Good Practice Guidelines: it needs to be collaborative, it needs to be positive, it needs to completely have the child's needs at the heart of the plan, of the practice, as well as the parent's needs, so there needs to be a good balance.'*

*'Our focus is understanding what the best we can do to optimise how this parent can successfully parent.'*

*'It could be successful practice that you've identified that a parent can't do it, and that child is in a place where it is now having all of its needs met...'*

*'We absolutely sit on the fence whether the good outcome is the child being removed, or the child being taken – sorry, the child being removed, the child staying... Whatever is right for the child. There's no... You know, they can both be really good outcomes...'* (Professional from specialist parenting service).

It was recognised that professionals in teams supporting parents could come to the realisation, at different times, that a child could not remain at home and that this could cause difficulties within the team.

## Relationship-based practice

Successful practice was relationship based, with professionals knowing and understanding the parent's situation and adapting their approach to meet the parent's needs. Many of the professionals in mainstream services were working in accordance with the *Good practice guidance on working with a parent with a learning disability* (DH/DfES, 2007; WTPN 2016) and making 'reasonable adjustments' (Equality Act, 2010) in their practice, even when they had not heard of the guidance or, in some cases, their own local policy on working with parents with learning difficulties.

*'But for me it was about getting in [Mother's] shoes, knowing where she's coming from, knowing her capabilities, and just getting to know [Mother]. And being very diplomatic, showing empathy, and just having that friendly approach with [Mother]'*

*'...Because we've known each other for a long time, and I think that helped. I think it may have been very different if someone brand new had come onto the scene, and, you know, was asking Mum to meet, and, you know, observing her in her own one-to-one time with her daughter, and, you know, all that protected time, she was happy for me to be there. And I guess that might have been difficult if she didn't know me...'*

### Multi-agency team work

Professionals from the different agencies involved with the family worked as a team in which *'Everyone played their part'*, including the parent.

*'... It has to be working as part of the team, but with the parent with learning disability as part of the team. Not 'the client', and not 'the person with LD', it's just all being a team and working together....'*

*'Working with children there has to be an incredible amount of information shared. So we do talk a lot between professionals, about, sort of, what's not working. Quite clearly, very quickly, you know, if something isn't working, it's picked up and discussed as a group.'*

At a multi-agency level, clear and timely referrals, joint protocols and shared positive understanding facilitated successful practice:

*'I also think it's successful when there's...all the agencies are working to the same agenda, going back to that challenge, that we all believe that, yes, this is do-able. This parent can do, and be safe, and be good enough to be able to do that. And I think that attitude is...you know, adds to the success of it.'*

Nikki, Chloe and Janine's stories illustrate how professionals worked with parents in each of the three sites. These stories are composites drawing on the eight case studies. The quotes are from parents and professionals we spoke with.

## Nikki

Nikki is in her early 20s and has a diagnosed learning disability and mental health issues – she has been diagnosed with borderline personality disorder (BLPD). She lives with her son Liam, now 6½ years old, and her current partner, Ed. Nikki is currently pregnant and the baby is due in about a month. She came to the attention of the specialist parenting service about 18 months ago when the designated teacher at Liam’s School referred him, then aged 5 years. At that point, Liam was quite overweight as a result of poor diet. His teacher also described him as regularly coming in to school looking grubby and noted he had not had regular dental care. On investigation, social workers identified concerns with Liam’s general standard of physical care, but also raised concerns about some of the adults with whom Nikki was spending time.

Nikki had been homeless for a time after she broke up with Liam’s father, and had been living in temporary accommodation; she moved into her present flat when Liam was 4, but there are problems with the accommodation and she would like to move somewhere more suitable for Liam and the new baby. Her parents do not live locally and she has little contact with them.

Her relationship with Liam’s Children and Families Social worker was not positive initially - Nikki felt he was just checking up on her, and was not really supportive of her as a parent. However, the case was transferred after the initial assessment and she now has a different SW who she describes as ‘more down to earth’ – and with whom she is more comfortable, despite the fact that a Child Protection Plan was put in place in response to the identified concerns about Liam’s safety and well-being. The first social worker referred her for a **PAMS assessment**. The PAMS assessor also referred Nikki to the local authority’s specialist parenting team who undertook a **cognitive assessment** and identified that Nikki had a mild learning disability. She found the input from the specialist Parenting Team helpful as they confirmed what she and her parents already knew: *“I’ve always known, since I was a young age. Like my mum knew. But obviously they found out that I was like a bit behind and stuff”*. However, they had not previously sought or been given a formal diagnosis of learning disability until the parenting team became involved.

As a result of the various assessments, she was provided with a **Family Aide worker** who worked with her to address concerns about Liam’s physical care and dental hygiene, and to help her with meal planning; additionally, she helped Nikki with money/budgeting issues, with her housing problems and other practical activities. She found the PAMS assessment a positive experience - the PAMS paperwork had an **Easy Read** summary in a different colour

### **Children and Family Intervention Service:**

*“She just trusts people too easily. She’s quite...she’s vulnerable. So she trusts people too easily, people will smile at her and, you know, that’s her friend, and ... .you know. So we did – I did a lot of work with that. The health – oh, also, health; we done a lot of stuff with her, training on health”*

which showed tasks that were required. The PAMS workers also used pictures and helped devise a system to help Nikki remember her appointments with them, as the cognitive assessment by the specialist parenting service had highlighted this as an area Nikki struggled with. They created a **calendar as a visual aid**, but also made sure their appointments were at the same time on the same day each week.

Nikki commented that the PAMS worker spent time observing her and how she and Liam interacted, and how she coped with daily tasks like planning and cooking meals. She liked that fact that the PAMS assessor gave positive feedback on what she was doing well, while also noting areas where she was struggling and needed additional help or guidance. The positive feedback helped build Nikki's confidence and self-esteem which encouraged her to

**Professionals involved:**

- Children and Family social workers
- School Nurse
- Clinical psychologist
- Mum's GP
- Child's GP
- Family Centre
- Family Aide
- Health Visitor
- Speech and Language Therapy (SALT)
- Community Learning Disability team,
- including support worker
- School
- PAMS assessor

engage more fully with the PAMS worker, make an effort to attend the appointments and ultimately enjoy meeting with her. She noted that she liked to have Easy Read (pictures/large print/simple words) information, but not all the professionals she encountered used it with her. It seemed it was not something that was automatically produced, and this could be a barrier for her in her contact with professionals.

Nikki's diagnosis of BLPD, in addition to her learning disability, seems to have been a factor affecting her relationship with some professionals. The specialist parenting service coordinated a **meeting of professionals** as quite a pejorative view of Nikki had emerged and she was seen by some as 'manipulative' and possibly also deceitful in her dealings with Social Services. This perception had particularly affected her relationship with her first C&FSW. However, detailed discussion of the different responses to Nikki's behaviour enabled the specialist parenting Service to offer alternative interpretations in light of her diagnosis and also previous experiences. It was clear they were not providing 'excuses' but explaining and offering a different perspective.

Through their work, and the local authority's use of a **Signs of Safety approach**, Nikki has been able to understand better that

some of the people she had previously befriended were not necessarily good for Liam and that she needs to take her time to get to know people before trusting them in her home and with Liam. Support from the Family Aide has helped Nikki to manage Liam's physical care, food intake and dental hygiene and the Child Protection Plan has now been 'stepped down' and she receives on-going help through a Child in Need plan. This will be kept under review once the baby arrives, but at this stage, there are no significant concerns about the family, and they appear to be managing well with the current level of support.

*Adult LD team Social worker says: 'It's sort of taking one step at a time for her, rather than bombarding her with lots of different services. Because I think it will just...more likely to disengage again, I think, rather than working with her where she's up to at the moment, with the goals that she wants of...of, you know, finding a new accommodation, getting her money, accessing the right benefits that she needs. And her new goal now of wanting to do a hair and beauty course...'*



## Chloe

Chloe is the mother of three children aged 10, 6 and 2 years old, she has a diagnosed learning disability and experienced significant abuse in her childhood which resulted in many different foster care placements. Chloe's two older children are no longer in her care. Chloe recognised that she hadn't engaged with Children's Services in the past as she had felt that her children would be removed anyway. Chloe had a change of heart and told social services when she became pregnant a third time, but the baby, Isla, was removed at birth and was in foster care for seven months before being placed on a supervision order. There were a number of concerns for Isla's welfare including whether Chloe had a good understanding of her needs, as well as concerns regarding her relationship with her partner, which was believed to be violent, and the fact that there were often inappropriate people in her home which was considered to be unhygienic and very messy. Chloe also struggled with her mental health and the loss of her older children. Chloe had a positive on-going relationship with the Occupational therapist (OT) from the Special Parenting service, which was based in the learning disabilities team. The OT acted as a '**Care co-ordinator**' regarding Chloe's support needs as a disabled adult and the OT had been involved in her case when her other children were removed. She provided a helpful hints sheet for working with parents with learning difficulties and was available to provide advice and support to other professionals working with the mother. The OT also **explained the cognitive assessment** to the rest of the team, explaining how its conclusions would impact on the mother's understandings and interactions with them. She also explained **how to break down information** so that Chloe was able to understand it.

A **PAMS assessment** was ordered by the court. This was undertaken by the assessment team who also undertook an assessment of the mother's attunement while Isla was in foster care. Joint visits were undertaken with the OT and the PAMS assessor and the OT often supervised her contact with Isla and used the time to role-model positive interaction with her. The PAMS assessor also discussed with the clinical psychologist in her team, how to work with Chloe. Chloe did a few sessions of **Video Interaction Guidance** to support her to understand when she was engaging positively with her daughter.

### **Mix and match resources used with Chloe:**

- DVD showing a dramatization of child protection procedures
- Diary/calendar with meetings written on
- Easy read information breaking down task and in relation to meetings
- Note book for Chloe to record what she was doing.
- Communication book in which all professional wrote when they visited
- Printed time table for the parenting assessment
- PAMs I need help questionnaire
- Change book 1-5
- Kids Need...: Parenting Cards for Families and the People Who Work With Them (Mark Hamer)

Chloe said her daughter's social children's social worker 'listened to me'.

The Children's social worker said that she did not judge Chloe, but was 'empathic' and 'listened to her' in order to take her concerns seriously. She made **additional visits** so that she could discuss one topic per meeting with her so as not to confuse her, rather than the three or four topics that she would usually cover.

While Isla was returned home on a supervision order, the Children's Service outreach team visited regularly for the first few months to ensure that Chloe's needs were being met and to support Chloe in learning the skills needed. A Family group conference was organised to garner support from her partner's family resulting in increased contact with her partner's mother. The health visitor and OT from the specialist parenting

The learning difficulties support worker was a *consistent person that can provide her with that emotional and psychological support.'*

service both continued to visit Chloe regularly. Chloe had a **personal budget** which allowed her to employ a **support worker** who worked three days a week. The support worker supported Chloe with household chores, child care routines, meal planning and shopping etc. Chloe also had **art therapy** weekly for a number of years and Isla went along and joined in when she was old enough.

**Professionals involved:**

- Child and Family Social Worker
- Worker from the assessment team
- Children's services outreach team
- OT from Special Parenting Service
- Art therapist from LD service
- Advocate
- Learning Disability support worker
- Health Visitor
- Family Group Conference Coordinator

The professionals involved had a meeting every six to eight weeks to review the plan. Chloe attended the meeting and they reviewed what was working well and what needed more support. Chloe was asked what she thought of the support. In between meetings, there was '**open communication**' between the professionals. They communicated by group email, shared reports with each other and had telephone discussions when needed.

Once the child protection concerns had decreased, the Care co-ordinator continued to organise the on-going support for Chloe using a person-centred approach focused on supporting Chloe to do her best for Isla. Targets were written in a person-centred way such as: I know my plan is working because.....

Risks were also discussed with Chloe using a 'risk matrix', bringing in the perspectives of all the different professionals.

Chloe was 'signposted' to the **children's centre** so that Isla could have more contact with other children and she could meet and observe other parents.

The support worker continued to be in regular contact with the OT and would report any areas of difficulty. The OT from the specialist parenting team would then make **joint visits** with the health visitor and make a plan with Chloe about how to proceed.

As Isla grew, workers continue to '**demonstrate**' to Chloe how to be with and play with Isla. Chloe liked it when the OT did puzzles with her and Isla and when they played skittles together.

When Isla was two years old she started to attend nursery. Isla's key worker developed a **close relationship** with Chloe and would also '*prod her along*' in terms of Isla's care, often showing her how to do things.

## Janine

Janine is in her twenties and has mild learning difficulties. She is a single mum to her four-year-old daughter - Bella. She has an older boy who was removed from her care when she was a teenager. He now lives with her mother due to concerns for his welfare as he was underweight and his father was violent towards Janine. Janine is supported by her sister and there are currently no concerns regarding Bella's welfare. Janine came into contact with services again during her second pregnancy, although she had had intermittent contact with the health visitor from her first pregnancy, who then became her health visitor again.

### **Health visitors regarding Bella:**

*'She's just absolutely flying. She's brilliant'. 'She's having a really, you know, positive childhood experience, as far as we can see, you know, in good physical health, is developing in every way we'd expect.'*

**A Parent Assessment Manual (PAMS) assessment** was undertaken by the specialist parenting services and led to the development of a detailed support plan which involved pre-birth teaching regarding practical parenting skills. A cognitive assessment was also undertaken and the results of this assessment explained to the multi-agency team by the clinical psychologist from the Specialist parenting service so that support could be tailored appropriately for Janine. Midwives and the health visiting services provided a lot of input and **worked jointly** with the specialist parenting services and early help worker, often going on joint visits, as well as keeping in contact by phone and emails in addition to attending the Team around the Child and then Child in Need meetings, which were attended by all the professionals, as well as Janine and her family. Bella's social worker oversaw the work of the early help worker. The **health visitor has remained involved with the family throughout**, visiting regularly throughout the four years; the early help worker was involved throughout the assessment and Child in Need plan and continued supporting Janine, for longer than she *'should'*, once the level of concern regarding the baby's welfare was reduced. Janine was referred to advocacy by the worker from the specialist parenting services and the advocate supported the mother in Child in Need meetings. She supported Janine to speak up for herself and ensured reasonable adjustments had been made to meet her needs.

*'But with Janine we actually, you know, took a doll and took it into the sleep environment, and put it down in the cot, and showed her how to make the cot up, and what things to think about and so on, and were much more hands-on and practical with that.'*  
**(Health visitor)**

Initially, Janine's **family** were concerned about her pregnancy and didn't feel that they could offer much support as her aunt was already caring for the elder son. However, the early help worker developed a good relationship with Janine's family and had some *'frank conversations'*. Bella's social worker made it very clear to the family that if family support was not available, when the baby

was born Janine would be placed in a mother and baby placement. Janine's sister is now providing regular support to Janine.

The **Signs of Safety approach** was used in Team Around the Child (TAC) and Child in Need (CiN) meetings to ensure Janine understood: *what we were worried about, what's working well, and what needs to happen*. After CiN meetings an easy read summary of the meeting was sent, and explained to Janine, which was slightly more formal. The worker from the specialist parenting services also used the **I-Thrive approach** to structure their support. The 'success' of support was judged in relation to the professionals' concerns and goal-based targets included in the Child in Need plan. *'A whole team approach'*

The focus of the work with Janine was to ensure positive outcomes for Bella. This involved pre-birth input on how to keep well in pregnancy and how to start parenting and keep baby

*'She does it step by step and if I don't understand she'll say it again and again and again and again.'* (Janine)

safe. This teaching of parenting skills by the health visitor and specialist parenting services was achieved through developing positive relationships, explaining using **'non-judgemental plain talk'**, using 'easy resources' and practical teaching about looking after a

baby. When Bella was born, the breast feeding co-ordinator made extra visits to support her to get Bella to latch on.

As Bella grew up, work was done to enable Janine to understand Bella's emotional needs and to enable her to play appropriately with her. Janine was recognised as being *'grabby'* with the baby and missing Bella's cues. **Video interaction Guidance** was used help Janine *'learn how to communicate with Bella'* and interact with Bella. Psychological support was also provided for her mental health, to enable Janine to *'reflect on past experiences with her*

*'Whenever I need help, they step in'* (Janine)

*older child'* and to support her on-going contact with her son.

Janine was shown how to do her cleaning and supported with her finance and budgeting. Janine has been attending a **college course** for parents with learning difficulties and young mums, for three days a week for three years. Transport and a crèche are provided and there is a low staff: parent ratio. Janine learnt about child care, literacy and numeracy and employability skills. A personal advisor provides individualised support to mothers. This course provided Janine with a peer group and she made a close friend. It was funded by Care to Learn.

Janine had a **positive relationship** with all of the workers with whom she has been involved for the last five years. She says they *'sat down and talked to me'*. Even though there are now no concerns about Bella's welfare, she is still in frequent contact with the health visitor and knows she could ring the health visitor or worker from the specialist parenting services

if she needs help or is worried about something.

**'Mix and match' resources/techniques used to support Janine:**

- Demonstrations with and use of doll for practicing child care.
- Change resources – My Baby 0-1
- The Social Baby video
- Breast feeding video
- I need help questionnaire from the Parent Assessment manual
- Easy read leaflets and worksheets

## 6Ts

Themes within the professionals' discussions of their practice with parents with learning difficulties can be summarised in relation to '6Ts' (adapting a framework developed by Turney and Tarleton, 2015).

### Time

(Extra time is needed to get to know parents and communicate appropriately - in easy ways - with them. Parents need more time to take on board information / new skills / knowledge. Parents may need support *through* time, i.e. long-term or recurrent support)

*'Just putting that extra time to ensure that they – that we're offering the advice in a format that they understand. So it – and it does take more time; it's attending more meetings, it's ensuring that the people around them have the information that they need to apply at home, you know, then to guide the family at home. So it does take more time, it's more communication, because of the bigger team around the family.'*

### Trust

(Parents and practitioners need to trust each other for the support to be effective; time is needed to develop this trust.)

*'Clinical skills are obviously important, **but without a relationship with families, then all is lost**, in my opinion. So a great deal of effort needs to go into building relationships, building trust, in order to get the best outcome for families.'*

### Tenacity

(Workers need to keep working on issues with parents over the longer-term, as necessary.)

*'We sort of do a little bit of problem solving now and again with her... because I know her, and I know that she will just not say, 'I need this. I need help with this'.*

### Truthfulness

(Practitioners need to be honest with parents and be really clear what the issues are. Parents should be honest with professionals.)

*'I think it's being really clear and in plain language, parents know what we're worried about...it's all in bullet points, so it's not like long.'*

*'We try to always be honest with the families we're working with, and to explain to them processes and the reasons for those processes, without it becoming, sort of, adversarial kind of experience for people. I think that's really important. At the same time, there's a balance with trying to explain to people how serious Child Protection proceedings are. So finding the balance between making sure that people understand that it's not an accusation or a telling-off process, but it is a serious process that can lead to steps being taken to protect children where necessary. So I think through starting with honesty, right from the very beginning with all of our clients, and as necessary, offering information in a way that they can understand and relate to, that emphasises the seriousness of the situation, while at the same time continue to try to work with the parents to help them, support them to be the best parents that they can be, and the parents that they want to be.'*

### **Transparency**

(Practitioners and parents need to be really clear about what is happening and what needs to be done when and by whom.)

*'We did it around the Signs of Safety: what we were worried about, what's working well, and what needs to happen. So that Mother was clear, you know, what, as professionals, what we're worried about, what was working well, and what needs to happen. Because actually the concerns that we had, they weren't Mothers and Mother's partner's concerns.'*

### **Tailored response**

(Understanding and working with parents in a way that works for them. Good communication is key to this.)

*'I think it's having a clear understanding of their difficulties, and knowing what works and doesn't work for them ... communication is key in my job, so it's finding out what's best – what tools are best to use, what format is best to use, what approach is best to use.'*



## Role of specialist services

Specialist services were operating in the three local authorities that participated in the research. The special parenting services were seen as a resource for practitioners across the Local authority. Professionals in these teams provided leadership at strategic level and an on-going resource for local professionals. Other professionals could say to the team:

*'I'm really struggling, I'm not getting this right for this parent, we're not moving forward, please come and help me.'*

While actively involved in cases, workers did joint visits with other professionals and role modelled working with parents. They also provided advice, consultancy and training in order to support other professionals in working with these parents.

*'We've done some training on learning disability with midwifery, health visiting, as well as children's social services as well. So it's just actually sort of going out there and saying, 'This is a need of a parent with a learning disability', and then really to address that whole issue of timely referrals. It can enable people to understand that people with learning disabilities need extra support, and need extra time, and need extra – you know, or different ways of communicating. Then, sort of like, when they come across someone in their work, then they might actually refer to us a lot more timely.'*

The specialist services appeared to be working in two ways:

- **Consultation model** - parental learning disability specialists were called in to support or advise other practitioners such as health visitors / school nurses;
- **Hub model** - in which specialists at the centre co-ordinated all other practitioners' involvement with the family.

All three specialist services were driven by health professionals. They were based in both adults and children's services and supported other professionals in their relationship-based approach and tailoring their support to the needs of the parents. In one area, professionals from the specialist parenting service spoke of supporting other professionals to understand parents better through meetings in which the detail of the case was discussed. This allowed sometimes negative assumptions about a particular parent to be explored and, on occasion, challenged or re-framed, allowing a more positive, helping relationship to be established:

*'It was really positive. And I think, because people were being open about how they felt, that they felt manipulated, and they felt like they were being lied to, and then when you looked at the personality disorder that the person had been given a label in court, and the level of learning disability, and just really thinking about those labels, and what they might mean for a person, and their attachment difficulties through abuse, once you then open out and, like,*

*really start thinking about the person, it just felt in the room that there was a better understanding... You can say someone's manipulative, but actually are they? Look at what they're dealing with.'*

## Ways in which support was provided in each area

### Location 1

- Assessments offered by the specialist parenting service, which includes a clinical psychologist and Speech and Language Therapist.
- The specialist service has a key role in liaising with and between professionals, offering advice and guidance; they also run training sessions for social workers to equip them to work with parents with learning difficulties.
- They work closely with parents to help them understand themselves and their individual challenges, strengths and difficulties.
- Community Learning Disability Team (CLDT) professionals can refer parents with whom they are working, for expert assessment and to get advice on how to support the parent most effectively.
- The LA has an advocacy service that is open to any adult with a learning disability
- The Child and Family Assessment and Intervention team work with families where children are the subject of a Child Protection Plan and undertake PAMS assessments when parental learning difficulty is suspected. Families are referred to them by the C&F Intervention Service (CFIS). They work closely with the specialist parenting service. The C&FAI Team take a needs-led approach and use their own budget (rather than the CLDT's) to provide or develop resources on the basis of individual needs.
- The CFIS works collaboratively with Education, Health and Social care professionals but often takes the lead on advising professionals how best to communicate/interact with parents with LD.

### Location 2

- Joint protocol has been developed. The development was led by the specialist parenting service.
- Specialist service located within children's services and provides regular training to professionals across the Local Authority.
- Specialist service was seen as a resource, that would offer advice and support when not actively involved in cases.
- Champions have been located and supported across the county.

- Regular pre-birth skills teaching and use of video interaction guidance to support development of parent-child interaction.
- Early help team works closely with the specialist parenting service and health visiting service, undertaking joint visits when appropriate.
- Provision of a college course for parents with learning difficulties.

### Location 3

- Care Co-ordination is provided in relation to the parent's personal support needs by the Learning Disabilities team. They would ensure the parent's Core Assessment (Adult Social Care) is up to date, plan support for areas where the parent has difficulties due to their disability and refer to other services as appropriate.
- Long-term relationships had been developed between the specialist parenting service and parents. Parents are not discharged from the service. If parents do not have a package of support, their case would be reviewed on an annual basis.
- Key professionals at the special parenting service have been in post for a long time providing a consistent and enduring presence.
- Joint protocol in place to ensure a joined-up approach to parents from both children's' services and the learning disability team.
- Use of cognitive assessment to support others to understand the parent and, as needed, case meeting to discuss parents and understand the impact of their LD and other diagnoses on their parenting and engagement.
- Specialist parenting service situated as part of the learning disability team which gives them access to colleagues, resources and services.
- If parents have a diagnosed learning disability, access is provided to a range of therapies such as art therapy. This support can be long-term.

These lists are not exhaustive but give an indication of the range of ways that LA support was provided.

## Local policies and commissioning strategies

The *Good Practice Guidance on working with parents with a learning disability* was recognised as a driver for positive practice. In one area, it was noted that their local policy on working with parents with a learning difficulty '*operationalised*' the Good Practice Guidance:

*'Some time back when the original Guidance came out, we did some audit around our service, kind of breaking down each area and looking at how we were performing. So that involved...yeah, looking at each area, looking at what we were able to do, looking at what we weren't doing so well, and then also it involved, like, a parents' feedback bit as well, so we were interviewing parents that were known to our service, and looking at what was working well, what wasn't working well, and kind of getting them to rate how they found things. And then as a result of that, we then set up the parents working party with children's here, and then that's when we started developing, like, the tools and stuff. And also we'd use the parents tool kit that we'd developed at the parents' network, to kind of use that as an audit tool.'*

In two areas, pressure from the courts and local authority legal teams were a clear driver for positive practice:

*'In child number four's case the court directed that my team needed to meet with the OT from the learning disability team, who she had a social worker from, and ... the learning disabilities team for the children.'*

*'In terms of guidance, what would be widely known amongst our social work teams is the Good Practice Guidance, ... which is very much driven by our legal services, and saying, you know, you should be really familiar with this, and making sure that ...'*

## Lack of awareness of numbers of parents

Even though there had been a major investment made in PAMS expertise in more than one area in terms of training, finance and systems, there were no statistics available about anticipated numbers of parents with learning disabilities. None of the interviewees in the three sites was able to point to any local systems for co-ordinating multi-agency data that would provide a rough indication of potential future need.

*'We have xxx children currently on child protection plans; it's interesting that I can say lots of data, but I don't know how many of those children's parents have got a learning difficulty.'*

*'We rely on the service provider to identify need and to notify us as commissioners as and when they see that need shifting significantly.'*

Lack of understanding of potential needs inhibited forward planning:

*'If we don't know what the needs are, and the potential need is...If we get some facts and figures, we can plan more accordingly, to be able to meet that.... I don't think we probably collate the unmet need, things that we're not able to provide, in a formalised way, so that we can then put our case to our commissioners in order to say, 'Look, can we address this need that we're finding at the moment?' So I need – yeah, perhaps I as manager need to change that.'*

## Funding support

Funding for parent support varied between the sites, from pooled budgets to negotiation in individual cases. In one site, a section 75 (NHS Act 2006) pooled budgets arrangement for learning disability services had been set up between the local authority and the NHS, which also specifically included a contribution from Children's Services to help ensure a focus on the **family** as a whole.

More generally, it was found that adults and children's services were both saying it was the other's responsibility:

*'We commission jointly from the pooled LD budget ... whilst there will be some health outcomes, quite often the outcomes are around parenting function and independent living. [When asked about midwives, health visitors, maternity services, antenatal care] at the moment we don't really have a joined up approach to commissioning in that context.... That's something to develop I think.'*

*'So for children, or for parents with learning disabilities, following the assessment, if there was a need for ongoing support, it would be a discussion with children's about why is that support needed. So if it's support around the parents' needs, under the Care Act, then that would clearly come from me and my purchasing budgets. If the need is around support for the child, and isn't around the parenting of the adult, then Children's would pay for it. Or from time to time, I know in the past we have got into – because it's quite hard to disentangle that sometimes – we have got into some joint funding arrangements. But it's on a case-by-case. We don't have a pooled budget that automatically funds it.'*

There was a lack of awareness of the amount spent on supporting parents, coupled with an awareness that the successful support saves money for other services.

*'Raising those questions about, well, OK, if we're going to start doing that, what numbers are we looking at, and what impact would we hope that that would achieve? And what would be the cost?'*

*Can't really say how much we spend on supporting parents with learning disabilities because it's a sort of needs-led thing.'*

*'and that's all out of my budget (the PAMs team). It makes savings in other people's budgets.'*

## Strategic overview

Commissioners, policy makers and senior managers did not seem to have a strategic or joined-up overview of local needs and resources.

*'We work on two completely different systems'*

[professionals from health and social services on sharing information]

Specialist leads, teams or hubs were regarded as key to providing this information.

*'I almost feel you need a champion in there, somebody who's very passionate about the issues, but you also need somebody more senior at the strategic level, who can take things forward and make service-level changes. So when we've got the right people in post, it's really, really good.'*

*'I certainly think that that's been a key thing with the success of [name of parent], is that there has been consistency within the team. We do think outside the box and are quite creative in the way things can be done. But whether that's ... you know, is that a system or is that an individual?'*

*'I think the long-term impact in providing a better service to our families is to have a multi-disciplinary team in-house, for example. So we can align all our services to make the best use of each other's budgets, you know, and service provision.'*

## Conclusions

- Professionals did not automatically link the parent's learning difficulties with an inability to parent. However, they recognised that parents were likely to need support and education.
- Understanding the parent and their situation was key to working successfully with parents with learning difficulties.
- Parents engaged with professionals who they felt respected and helped them.
- Successful support aimed to support the parent while focusing on the outcomes for the child. Professional practice was viewed as successful, whether the child/ren remain with their parent or are removed from their care, if it had empowered and enabled the parent to do their best.
- Successful support was relationship-based and required: Time, trust, tenacity, truthfulness, transparency and tailored support. Families had received recurrent or on-going support that recognised the parent's learning difficulty was lifelong and that their needs and circumstances change with time.
- Specialists in working with parents with learning difficulties, whether individuals, in teams or in hubs, were a key resource. They gathered and shared expertise, drove activity, set the appropriate speed and direction of family work, and linked with every practitioner involved in a case, to ensure a holistic, family-focused approach. They also provided consultancy or training for other professionals.
- Commissioners, policy makers and senior managers did not always have a strategic or joined-up overview of local needs and resources. Specialist leads, teams or hubs were regarded as key to providing this information.
- Support for parents was either funded on a case by case basis or through a pooled budget.

## Recommendations

- Commissioners, policy makers and senior managers should ensure they have a strategic, joined-up overview of local needs and resources. Specialist leads, teams or hubs are key to providing this information.
- Local authorities should resource specialists in working with parents with learning difficulties, whether individuals, in teams or in hubs, who can gather and share expertise, drive activity, set the appropriate speed and direction of family work, and link with every practitioner involved in a case, to ensure a holistic, family-focused approach. They can also provide consultancy or training for other professionals.
- Parents require long-term or recurrent support. Support should be consistent and flexible as a parent's learning difficulty is lifelong and their needs and circumstances change over time.

- Practitioners should build and maintain mutually trusting relationships with parents so that, where possible, ongoing light-touch support can be provided, reducing the need for repeated crisis-driven interventions. Senior managers in health and social care should endorse multi-agency protocols and appoint champions who promote coordinated practice and quicker resolution of case-management issues.
- Managers should also ensure specific named contacts are identified and that systems are in place to embed effective practice which is not wholly reliant on particular individuals.
- Adults and Children's services should pool budgets to enable effective joint working with families.

A range of legal and policy provisions can support the implementations of these recommendations such as the Human Rights Act 1998, Children Act 1989, Equality Act 2010, Children and Families Act 2014, Care Act 2014, United Nations Conventions (Rights of Children, Rights of Persons with Disabilities).



## Resources and further Reading

- Working Together with Parents Network ([www.wtpn.co.uk](http://www.wtpn.co.uk)) - Supports professionals working with parents with learning difficulties and learning disabilities, and their children.
- WTPN (2016) Working Together with Parents Network (WTPN) update of the DoH/DfES Good practice guidance on working with parents with a learning disability (2007) <http://www.bristol.ac.uk/sps/wtpn/policyessentials/>
- Turney, Tarleton and Tilbury (2018) Supporting parents who have learning disabilities - Strategic briefing for service leads and commissioners. Dartington: Rip/Ripfa. <https://www.rip.org.uk/resources/publications/strategic-briefings/supporting-parents-who-have-learning-disabilities-strategic-briefing-2018/>
- The President's Guidance: Family proceedings: Parents with a Learning Disability. <https://family-proceedings-parents-with-a-learning-disability>.
- Case law: Re G and A (Care Order: Freeing Order: Parents with a Learning Disability) [2006] NI Fam 8; Medway v A & Others (Learning Disability: Foster Placement) [2015] EWFC B66 (2 June 2015); Kent CC v A Mother [2011] EWHC 402 (Fam); A Local Authority v G (Parent with Learning Disability) [2017] EWFC B94.
- The Scottish government has shown legislative and policy leadership on supported parenting <http://www.gov.scot/Resource/0051/00511327.pdf> and [https://www.sclد.org.uk/wp-content/uploads/2015/06/Supported\\_Parenting\\_web.pdf](https://www.sclد.org.uk/wp-content/uploads/2015/06/Supported_Parenting_web.pdf)
- Tarleton, Howarth and Ward (2006) Finding the Right Support. Bristol; Norah Fry Research Centre, University of Bristol. <http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/rightsupport.pdf>
- Dugdale and Symonds (2017) Fathers with learning disabilities and their experiences of adult social care services. SSCR: <http://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/FWLD%20SSCR%20Findings%204%20page%20summary%20FINAL.pdf>

## Getting Things Changed project

This research was part of a large grant funded by the Economic and Social Research Council (ESRC) ES/M008339[LP3] [BT4] /1 called Tackling Disabling Barriers: Co-Production and Change. The project was known as the Getting Things Changed project. Find out more at: <http://www.bristol.ac.uk/sps/gettingthingschanged/>.

Contact: [Beth.Tarleton@bristol.ac.uk](mailto:Beth.Tarleton@bristol.ac.uk).

## Pointers for practice

### 5 main principles of the Good

#### Practice Guidance:

- Accessible information and communication
- Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways
- Support designed to meet the needs of parents and children based on assessments of their needs and strengths
- Long-term support where necessary
- Access to independent advocacy

We have found that in order to follow the principles in the Guidance, working with parents takes:

↓  
Time  
Trust  
Tenacity  
Truthfulness  
Transparency  
Tailored response

Here are some questions to support you in your work with parents:

#### Local context

- Do the parents have support needs under the CARE ACT? I.e. can they be provided with support in their own right?
- What does your local policy say about referrals and support for parents with learning difficulties?
- Is there a specialist team or professionals who can provide advice or consultancy about /joint working with these parents?

- How will long-term or re-current support be provided to parents?

#### Relationship

- How much extra time do you need to allocate to this parent to fully understand their situation and develop their trust?
- How can parents feel respected and empowered and part of the team around their child?

#### Communication and teaching

- Have parents understood what you are telling them? Are you using short questions and concrete terms? Are you avoiding or explaining jargon? Can they tell you in their own words what the 'problems' are or what it is you are expecting of them?
- Are your letters / reports / agendas in a format the parent understands?
- Does one of the team need to show the parents how to .... ? Might they need to show the parent on a number of occasions, breaking the task down into small steps?
- Would video interaction guidance help the parent to see their positive engagement with their child?

#### Meetings

Do the parents:

- Know where the meeting is and how to get there?
- Know who will be there and why?
- Have an easy read version of the papers?
- Have an advocate, so they can participate fully?
- Get an easy read summary afterwards setting out discussion, decision, and actions required?



Norah Fry Centre for Disability Studies  
8 Priory Road  
Bristol  
BS8 1TZ

**Contact details:**

GTC-SPS@bristol.ac.uk

**Lead researcher:**

val.williams@bristol.ac.uk

[bristol.ac.uk/sps/gettingthingschanged](http://bristol.ac.uk/sps/gettingthingschanged)

In memory of Dr. Sue Porter, 1953-2017.