

Good Practice in Parenting Support for Parents with a Learning Disability: project report.

Introduction

It is acknowledged that estimating the numbers of people who have a learning disability in the population is difficult. The Learning Disabilities Observatory estimate that in 2012 there were “908,000 adults aged 18+, of whom 199,000 (22%) are known to GPs as people with learning disabilities” (Emerson et al 2012). However, the true numbers of parents who have a learning disability are unknown, definitions have been difficult to apply and many people do not have this label attributed until they access health and social services. A number of agencies are involved in the support of parents who have a learning disability and the impact of effective support is both an education and practice issue.

This report sets out the results of a joint education and practice project that was designed, delivered and evaluated between November 2012 and November 2013. The project initiated between De Montfort University and Leicestershire Partnership Trust (LPT) had a focus on the following:

- To map those involved in the assessment and support of parents with learning disabilities
- To seek good practice examples locally and nationally
- To evaluate an assessment tool and pilot its use locally
- To disseminate and publish good practice in parenting assessment and support

Background and Context

The project developed following ongoing informal links between Community Nurses (LD) in Leicestershire Partnership Trust and the School of Nursing & Midwifery, De Montfort University. These links had provided opportunities for knowledge sharing and joint teaching around parenting by people with learning disabilities. A small project fund through the East Midlands Local Education & Training Board (LETB) enabled this project to be formalised and develop.

Whilst the work of the group is locally focused in Leicester, Leicestershire and Rutland, it is set within an international and national context of the published literature.

Literature Review

The concept of parenting, or of being a parent, is one that the vast majority of people are aware of. Kitzinger defines parenting as a biological and social process, one that bestows adult status (Kitzinger 1992, cited in Gould and Dodd 2013). However, parents with learning disabilities are exposed to negative stereotypes before they have a chance to prove themselves worthy of being parents. They are often seen as 'eternal children' who do not mature sexually, socially or emotionally (McConnell and Llewellyn 1998, cited in Gould and Dodd 2013). This can leave parents with a learning disability feeling as though they are being unfairly judged: they are judged by stricter criteria than other parents and they are more likely to be accused of being a failure as a parent rather than the failure to lie with the support offered (Tarleton 2008).

A critical review of the literature would indicate that it is unclear what constitutes adequate or inadequate parenting (MacDonald 2009; McGraw and Sturmey 2006; Gore 2010; Barkby et al 2009). Currently, there is no agreed definition of adequate care, with the legal interpretation being left up to individual practitioners (Gould and Dodd 2013). There appears to be a lack of consistency of what constitutes 'good parenting'. Ward and Tarleton (2007) indicate that parents with a learning disability feel they must prove themselves to be 'good enough' to be parents to professionals whereas those without a learning disability do not; this is mirrored in Gould and Dodd's (2012) article which explores the effect on birth mothers of having their children removed, and what support is given to them. The preconception that professionals have about people with learning disability can be that they are not sexually or emotionally mature and are childlike. Women were reported to have been encouraged by professionals to have their pregnancies terminated and were made to feel they would not make 'good mothers'.

Some discussion has been raised about the suitability of assessment tools for parents with learning disabilities to assess their self-efficacy (Bloomfield et al 2010). Macdonald focuses on the needs of the child when assessing parent competency in order to achieve the best outcome for them (Macdonald 2009). However McGraw and Sturmey offer an assessment tool that focuses around three primary areas that concern the parent: parents' life skills, familial history and access to support/resources (McGraw and Sturmey 2006). Ward and Tarleton argue that assessments should be completed by multi-disciplinary team as well as being informed by informal visits to parent's homes and not left up to individuals to pass judgement (Ward and Tarleton 2008). The process also needs to balance the rights of the child against the rights of the parent/s (Gould and Dodd 2013).

It is generally agreed that parents with learning disabilities are more likely to have to go through a Child Protection court case than parents in the general population (Tarleton 2008; Gould and Dodd 2013). This is mainly due to allegations of emotional abuse and neglect (Bloomfield et al 2010). It is also reported that parents with learning disabilities often lack the necessary skills to be parents; have reduced support networks and a mistrust of social

services (Ward and Tarleton 2007; Pemberton 2010). However, there have been examples of success in teaching parents with learning disabilities the skills they need to be a good parent and in gaining the trust of parents so that they do not feel afraid to ask for help (Pemberton 2010).

The Department of Health and Department for Education and Skills has issued guidance for supporting parents with learning disabilities in England (Department of Health 2007) however a gap has been reported between policy and practice when it comes to supporting parents with learning disabilities (Ward and Tarleton 2007). Parents with learning disabilities report that support is seen as added stress and they are therefore less likely to seek help due to increased fear and anxiety or being usurped, de-skilled and disempowered (Gould and Dodd 2013).

A common theme throughout the literature was that there needs to be an improvement in the communication between child services and adult services (Gore 2010; Selbie 2012; Tarleton 2008; Ward and Tarleton 2007). Nick Gore's article (2010), discusses a study carried out in 2009 to investigate the number of parents with a learning disability in Wales, their experiences and the experiences of professionals who work with them. Gore comments on the 'lack of communication between professionals' and the limited knowledge they have of each other's role, particularly adult learning disability Social Workers and children's services. The article reports on negative experiences had by parents in their contact with professionals, even though the parents interviewed had not had their children removed. Gore reports that at the time of the study, guidelines for good practice on working with parents with a learning disability had been released in England, but not in Wales.

Gore suggests to view situations from a 'family' perspective rather than to focus on the needs to the child or the needs of the parent separately (Gore 2010). Tarleton discusses the role of an advocate and how they can empower parents with learning disabilities to feel more confident and make informed choices (Tarleton 2008). Practical support offered by professionals was wide-ranging but a person-centred and holistic approach was recognised as essential to build confidence for parents (Gore 2010).

The best support offered to parents with learning disabilities centres around removing barriers to communication. It is generally agreed that more easy-read literature is needed to allow parents to access information so that they can learn new skills and make informed choices about their parenting (Gore 2010; Pemberton 2010; Ward and Tarleton 2007). Parents struggled with reading letters, understanding formal court proceedings and with over-long meetings; this is classified as intuitional abuse by Tarleton (Tarleton 2008). These factors that contribute to barriers to communication could be removed or lessened through appropriate training.

In order to better support parents with learning disabilities, professionals need to be trained in how to support individuals with learning disabilities. Gore identifies that training for professionals was lacking concerning working with individuals with a learning disability (Gore 2010). Pemberton agrees that specialist nurse training should be developed to help

parents with learning disabilities become good parents (Pemberton 2010). Barkby et al suggest that a greater knowledge within Health Visiting services will help parents with learning disabilities (Barkby et al 2009). Ward and Tarleton also argue that this should be extended to midwives, as they are not equipped to assess people with learning disabilities (Ward and Tarleton 2007). Training may also help professionals to empathise with parents with learning disabilities and allow them to be more understanding that people do not choose to be poor parents but need better support in order to learn the skills to become good parents.

In conclusion, parents with learning disabilities are more likely to go through court proceedings to have their children removed than compared to parents from the general population. This is due to unclear definitions of what constitutes good parenting, a lack of quality support due to gaps between policy and practice as well as poor communication between inter-agency working.

There are examples of good practice that involve the use of independent advocates, education programmes and training that focuses on gaining knowledge of working with adults with learning disabilities. Much of the literature mentioned above reports on predominantly negative experiences of parents with learning disabilities, however, there are clear areas of good practice, as mentioned in Ward and Tarleton's article, and also in Pemberton's report published in Community Care, 2010, 'Family Action Service helps Parents in Leicestershire'. This report describes the work of a service that provides hands on, practical support for parents with a learning disability. It uses the service to provide an example of good practice and to provide evidence that through this supportive approach, effective parenting skills can be acquired and applied. This report is one of the most recent pieces of literature along with a spate of others from the Community Care Journal, namely; Carson 2011, Hunt 2011 and Fox, 2011 that use the Leicestershire service and another similar service in Gillingham to provide examples of good practice.

(Jane Reynolds, Sarah Lindsay, Charlotte Hings & Lucy Johnson - Learning Disability Student Nurses De Montfort University)

The work of the project group

In order to map the agencies involved in the assessment and support of parents with learning disabilities an initial email request was sent to all agencies that, from experience, we knew worked with parents with learning disabilities. This meeting took place in November 2012 and twenty seven participants attended representing a wide range of local organisations.

This meeting enabled us to highlight some of the issues facing services and individual practitioners when working with parents, both barriers to effective working and good practice examples were shared (See Appendix 1). This initial group felt that face to face meetings would be beneficial for sharing good practice examples, sharing knowledge and to focus on three key areas:

- Assessment
- Resources
- Networking

The group then developed into a 'core group' with representation from key agencies including; Advocacy Services; Speech and Language Therapy (SALT); Community Learning Disability Nursing (CLDN); Health Visiting (HV); Children and Young Person's Service (CYPS); Higher Education (Learning Disability Nurses, Health Visiting and School nursing students) and Occupational Therapy (OT). Additionally, agencies that were unable to attend regular meetings were engaged through email communication including Adoption services, Psychiatry, Psychology, Children's Services and many others.

The regular meetings used the focus of the three key areas of **assessment**, **resources** and **networking** to share good practice and discuss opportunities for multi-agency working to enhance the experience of parents who have a learning disability.

A number of local agencies work with parents who have a learning disability however it was clear that these agencies often did not understand each other's role in relation to parenting or (in some cases) have formal links or communication pathways. The project offered the opportunity for agencies to meet together, share good practice and some of the challenges they face.

Core members identified their work in relation to parents who have a learning disability:

Leicestershire County Council (LCC) – Children and Young Peoples Service (CYPS), Child Protection Team

LCC CYPS provides county wide services to children and families, through a range of provision to those children identified as requiring universal services, 'Child in Need' or 'Child Protection'. As part of the Child Protection Service, it is our role to safeguard and protect children who have been deemed at risk of Neglect or Abuse (Physical, Emotional or Sexual).

This involves working collaboratively, where possible, with the parents and families to identify the cause of risk, highlight risks and protective factors and work to address these so that the balance of safety is on a positive level.

With regards to parents who have a learning disability, we have a duty to provide the same level of support that all parents access. It is recognised that parents with a learning disability need to have their individual needs and requirements addressed, whether through words / pictures / symbols or a higher level of physical demonstration.

The service recognises the need to work with partner agencies to achieve the best outcomes for the children and families involved.

Daryl Clarke (Leicestershire County Council (LCC) – Children and Young Peoples Service (CYPS), Child Protection Team)

Mencap Leicester Advocacy Project

An advocacy project working in Leicester City, with adults with a learning disability, who provide 1:1 issue based advocacy to individuals. Many referrals are to support parents with a learning disability who are going through child care proceedings with their unborn baby, baby or child.

Parents are supported to have their say and help them to understand information being given to them and information being asked from them. The service works alongside other professionals for example solicitors and barristers, child care & adult social workers, Sure Start, family support agencies and learning disability services to support parents to engage effectively with these services. Advocates meet with parents regularly to ensure that they understand processes and procedures provide independent support for parents to talk to and liaise with other professionals on their behalf.

Bindya Mistry & Laura Clifford (Mencap Advocates)

Community Learning Disability Nurses, Leicestershire Partnership Trust

Community Learning Disability Nurses (CLDN) are employed by Leicestershire Partnership Trust (Health) and covers all areas of Leicester, Leicestershire and Rutland. CLDN work within a multi-disciplinary team comprising of Consultant Psychiatrists / Occupational Therapists / Speech & Language Therapists / Physiotherapists / Outreach Nurses and Psychologists.

CLDN work with adults (18 years +) with a learning disability who have additional health care needs and their role may include:

- Promoting optimum mental & physical health whilst working in partnership with other agencies & services

- Address any health inequalities and work with agencies to ensure reasonable adjustments are made where possible
- Facilitating referrals to other services to ensure individuals needs are met (for example referral to Speech & Language Therapists for a communication assessment)
- Carry out therapeutic work including relationship work, anger management, assertiveness, understanding mental & physical health, anxiety management, self-esteem, talking therapies which can include Cognitive Behaviour Therapy
- Assisting a person to manage their physical health for example diabetes, epilepsy, blood pressure monitoring, weight management
- Follow Care Programme Approach (CPA) process for people with complex mental health needs

In addition the CLDN works with parents with a learning disability in various ways including:

- Working in an inclusive manner with parents and in partnership with others from primary, secondary & tertiary care
- Supporting parents through the Child Protection / Safeguarding process & liaising with all involved to ensure all information is shared as needed
- Attending & participating in pre-birth, core group and case conference meetings
- Refer to Advocacy services to ensure parents have access to independent support.
- Liaise with Children's services and contribute to meetings as necessary
- Explore with parents if past experiences can impact on their parenting assessments & explore how any experiences such as previous abuse, anxiety, domestic violence, relationships impacts
- Work with parents to identify their needs & help them access other services
- Support parents to accept support & explain benefits & consequences of intervention from others
- Contribute to assessments needed including capacity assessments and those required for Court
- Child Protection Plans either through observations and / or direct work
- Support parents regarding Keeping Safe (physically & emotionally)
- Clear understanding of the importance of healthy relationships & and how this can impact on the relationship between child & parent
- Contraception and sexual health
- Support parents through any conflict which may arise when working with numerous agencies
- Signpost to access Community resources for example Sure Start / pre & post natal sessions at health centres

- Help parents to recognise that all families have difficulties at times & to encourage coping strategies

Heather Crozier & Sarah Morris (Community Learning Disability Nurses, Leicestershire Partnership Trust)

Community Nursing Assistant (Learning Disability)

The key role of the Community Nursing Assistant is to support the qualified nurse which includes:

- Developing good therapeutic relationships with parents after they have been assessed within the learning disability service
- Problem solving and signposting with parents
- Liaising with a range of professionals, both within generic and learning disability services
- Support parents to identify any needs or support they may need and inform the named nurse (liaising with other agencies when needed)
- Supporting parents with their appointments – for example midwife, health visitor, GP, domestic violence counsellor, sexual health clinics (for contraception advice)
- Desensitisation work regarding attending appointments
- Reporting concerns to named nurse
- Carrying out plans of care devised by named nurse
- Support parents if their child has been removed and they need support
- Support at contact sessions to ensure reasonable adjustments have been made
- Support parents with information they have been given regarding how to develop healthy relationships with their child and / or family members
- Attending meetings/case conferences and provide support to parents (if needed)

Joe Brailsford, Shiera Rathor & Sue Swanwick (Community Nursing Assistants, Leicestershire Partnership Trust)

Speech & Language Therapist (Learning Disability), Leicestershire Partnership Trust

Speech and Language Therapists (SALT) work as part of the Community Learning Disability Team and their work includes:

- Completing a communication assessment of the individual's ability to understand information and how they communicate
- Complete a SALT report or Communication Passport to summarise the individual's communication skills and how others can best communicate with them
- Using the information gained from the assessment to support the individual to:
 - Understand the information given regarding the parenting assessment, any parenting advice or other issues
 - Express their views

- Ask questions
- Using the information gained from the assessment to support other professionals to make reasonable adjustments to ensure their communication is effective with the individual. This may include:
 - Supporting others to make their written information accessible using simple text and appropriate symbols/pictures
 - Advising on alternatives to written information
 - Advice on how to involve the individual in meetings
- Using the information gained from the communication assessment to contribute to assessments carried out by other professionals such as capacity assessments

Pauline Ndigirwa (Speech & Language Therapist, Leicestershire Partnership Trust)

Student Nurses (Learning disability) De Montfort University

Whilst as an organisation De Montfort University do not have a specific role in working with parents with a learning disability students nurses are involved in both placements and in exploring the theoretical concepts around parenting. Student nurses were involved in the project through the following:

- Active involvement in the group including attendance at meetings and contribution to the project report.
- Networking with agencies who support parents to understand their role.
- Sharing the work of the project group in a range of student forums
- Co writing a literature review for the final project report

Jane Reynolds, Sarah Lindsay, Charlotte Hings & Lucy Johnson (De Montfort University)

Health Visiting, Leicestershire Partnership Trust

Health visiting is a universal service available for all families with pre-school children. Health Visitors offer health assessments, and share information with parents regarding positive physical and emotional health choices for themselves as well as their children and support them with these choices. Health Visitors are in the process of introducing an antenatal contact to all families.

Health Visitors work in partnership with other agencies for example Sure Start / Home Start / CYPS to support families with additional needs. In some areas, Early Years Support is available where Health Visitors have caseloads of approx 25 families which enabling them to offer more intense visiting and support to families who have been identified with more intense needs.

Chrissie Matthews (Health Visitor, Leicestershire Partnership Trust)

Specialist Health Visitor Leicestershire Partnership Trust

The service uses an holistic assessment and referral process, works with families who have a young person (0 – 19 years) who has a disability (antenatal support can also be provided where needed). The specialist health visitor works closely with social care, education and health colleagues.

The role includes supporting parents with their child's diagnosis, change in condition, support through family crisis, management of constipation & continence, sleep management and equipment ordering.

Debbie Bromley (Specialist Health Visitor)

Psychologist, Leicestershire Partnership Trust

The team carry out Intelligence Quotient (IQ) assessments to clarify learning disability and complete recommendations on how best to work with parents, psychological assessments and support families to understand why parents respond in a particular manner. Psychologists carry out psycho-therapy; provide emotional support to understand anger / relationships / previous experiences and how these may impact on keeping their child with them.

The psychology team work in a pro-active manner and try to engage with prospective parents prior to conception, working through their concerns, anxieties and fears in relation to previous life experiences.

Dr Bridget Cryer-Rolley (Consultant Clinical Psychologist Leicestershire Partnership Trust)

Occupational Therapist, Leicestershire Partnership Trust

Identifying and meeting the needs of parents with learning disabilities is one of the key tasks set out in the White Paper, Valuing People (DoH 2001). It is the aim of OT's working with adults with a learning disability who are, or are to be, parents to ensure the needs of the individual are met whilst taking appropriate responsibility to ensure the welfare of any child in their care. The OT's role will be determined by the needs of the adult with a learning disability. It is not the role of the OT to give advice about childcare and they should never be in a position of having direct responsibility to the child's welfare.

- To be involved as early as possible in looking at the parents' functional skills
- To explore the parents ability to learn and apply new skills and identify any support, adaptations or recourses which would improve their functioning
- To assess the parents functional skills and independent living skills
- To look at the home environment and how it meets parents needs
- Where appropriate to assist and enable parents to develop their routines of daily living (not the child's care)

- Liaise with Child and Adult Services, refer on as appropriate
- If Health Visitor or midwife identified a particular issue they could liaise with us for advice using our learning disability expertise
- OTs should be flexible in developing their role in response to client's needs, but should be done within the limits of professional competence and the role of adult LD services
- We do not assess the parents' parental skills – that is the job of midwife, health visitors etc
- Open ended support cannot be guaranteed OTs will be involved as long as the parents have need for OT and when those needs are met the case will closed accordingly
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It is important for OTs to promote good joint working with all services involved to help safeguard the welfare of both the child and the adult.

Provided by Rachel Sinclair (Occupational Therapist, Leicestershire Partnership Trust)

Consultant Psychiatrist, Leicestershire Partnership Trust

- Assessment of Learning Disability, Autism and any associated psychiatric / behavioural needs and epilepsy; management of those conditions using Psychotropic medication
- Assessment of capacity around mental health / cognitive issues; advice and support to other professionals on the above area
- Referral / joint working with Learning Disability Multi-Disciplinary Team on mental health / behaviour management / Autism / epilepsy related issues
- Named Doctor for Adult Safeguarding – lead for Think Family Approach / Think Family Audit in Learning Disability
- Undertook Trust wide survey on current involvement and interest in parenting work which was presented to Trust Safeguarding Committee

Dr Mary Barrett (Consultant Psychiatrist (Adult Learning Disability), Leicestershire Partnership Trust)

Locality Manager, Local Authority

Leicestershire County Council is a statutory authority which provides support to adults via the Adult and Communities Department. The team I manage is called the Personal Care and Support Team and is based at 3 High Street, Coalville, Leicestershire, LE67 3EA. This is a generic service providing longer term support to adults over the age of 18 with support needs that meet the Substantial/Critical category of our eligibility criteria. Parents with a learning disability would fall within our remit as they are likely to require longer term involvement. Our involvement with parents who have learning disabilities usually relates to providing on-going support to the parents (often but not solely) during the carrying out of

child care proceedings relating to their child. The allocated worker liaises closely with the person, their significant others and the Social Workers from the Children and Young Persons Service (CYPS). The role of the worker is to ensure that the needs of the parent are taken into account and that any information and assessment is carried in a manner that maximises the opportunity for the parent to engage with, contribute to and gain from the process. This would include using appropriate communication methods when exploring parenting skills etc so that the parent is able to render a clear and accurate picture of their abilities and areas where support is required. We would also support with attendance at external assessments for example to psychologists at the request of the Court.

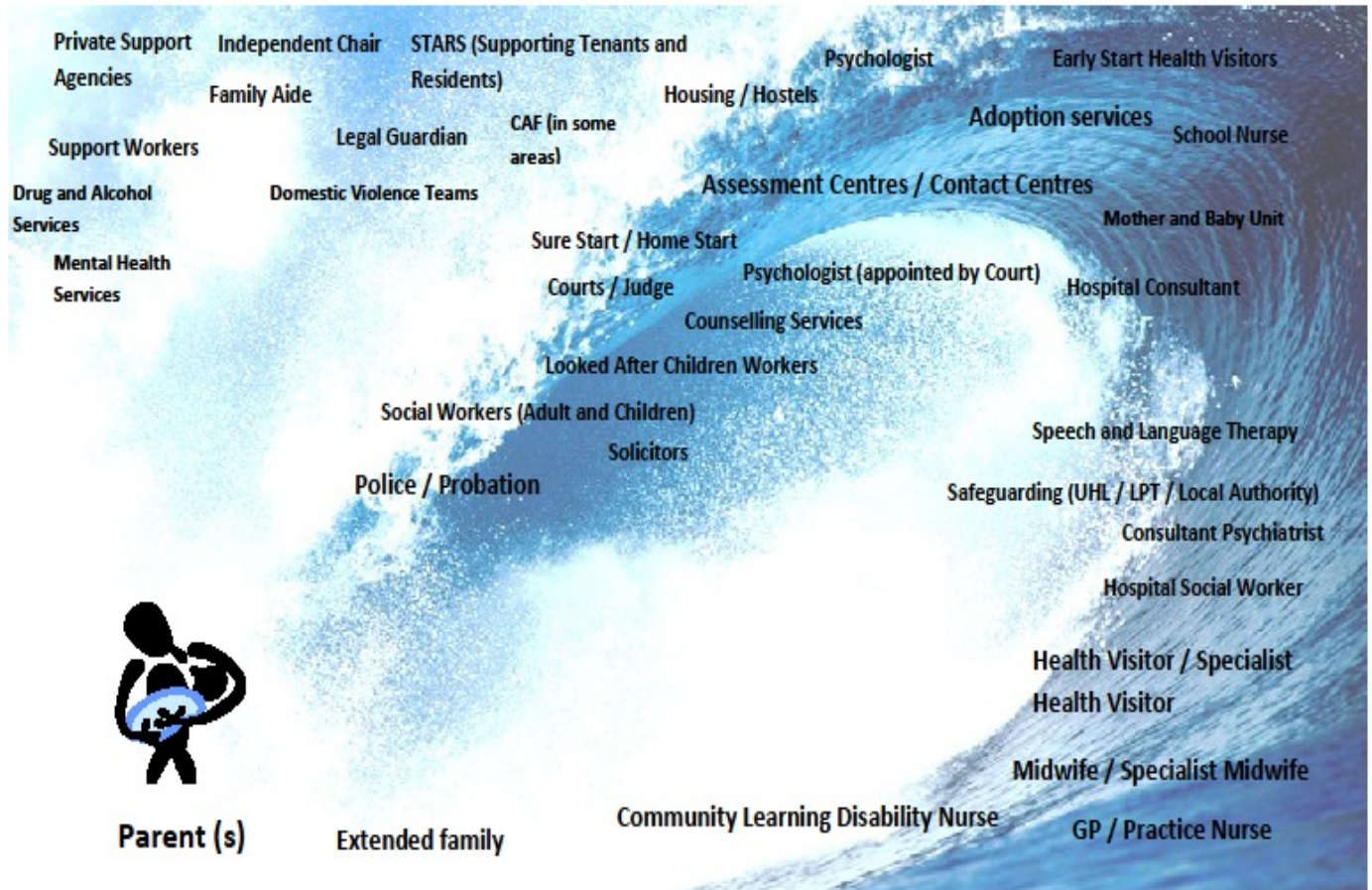
We can provide packages of support to the parent to assist them with their parenting role (but not to the level where someone is required to act in loco parentis). This is usually via a personal budget.

Liz Clarke (Adult Social Care, Leicestershire County Council)

Whilst a number of agencies became key to the work of the project there are many more that were unable to engage. Some of these were represented at the launch of the project and have maintained contact via email whilst other agencies and practitioners have been more difficult to engage.

For families where there are complex issues around health, housing and Child Protection many agencies may be involved. Practitioners have described working with families where up to forty different agencies have input. Fig 1 uses an example of a family where there may be a Child Protection issue to illustrate the agencies commonly involved with parents.

Fig 1: The 'wave' of agency involvement



Case study approach to understanding parents needs

This case study was developed during the project to give an insight into the complexities of working with parents with a learning disability; written jointly between the two Community Learning Disability Nurses, Sarah and Heather, and a couple who have chosen to be known as Luke and Chloe.

Case Study

Luke and Chloe are a couple who both have learning disabilities and have had a baby. Chloe attended all her ante-natal appointments independently supported by Luke and his mother and she stated her pregnancy had been “a positive experience”. Chloe has had a previous child removed from her care and she only has ‘Postbox’ contact once a year. Chloe had a difficult childhood with lots of bad experiences involving abuse and neglect.

Luke and Chloe currently live with Luke’s mother and she is supportive of the couple.

Luke and Chloe had known one another from school but had not been in a relationship until recently and were not together long before Chloe became pregnant. When they first found out they were expecting a baby, Chloe was told that they would not be able to keep their baby. Luke and Chloe were involved with various different organisations during and after pregnancy.

The Community Learning Disability Nurses working with Luke and Chloe quickly realised that the services involved were disjointed and communication between services was limited. Joined up working between services was required as the range of agencies involved with Chloe and Luke were wide ranging.

The following agencies became involved in supporting Luke and Chloe through the pregnancy, the birth and after discharge from hospital:

Support Agency – to support

- Chloe with her finances

Mencap Advocate –to ensure Luke and Chloe were receiving

- independent support to assist them through the process

Solicitors – to ensure

- Luke and Chloe received the correct independent legal support

Social Workers – to assess and support

- from Adult Services

Social Workers – to assess and support

- from Children's Services

Community Learning Disability Nurse – to assess and address

- emotional and physical health needs (Improve low self-esteem which has arisen from previous difficult relationships including domestic violence and emotional abuse)
- acknowledging previous abuse and to support accessing psychological therapy and services
- developing skills for independence
- supporting Luke with understanding Chloe's previous history
- Complete Emergency Grab sheet, Traffic Light Hospital Booklet and Who Am I? Assessment

Acute Liaison Nurse – to ensure

- Chloe received support within the hospital where she would receive ante-natal care and give birth

Occupational Therapist – for assessment

- of Activities of Daily Living Skills

Speech and Language Therapist – for assessment

- of Luke's communication skills to ensure workers would be communicating in the most appropriate way
- for assessment of Chloe's comprehension skills

Midwife – to provide

- care during pregnancy, labour and birth and during the post-partum period

Health Visitor – to promote

- good health, prevent illness and offer practical health and advice

Ante-natal Group - to prepare

- Luke and Chloe for the birth of their baby through classes with other prospective parents

Contact Centre – to provide an environment for

- regular contact with their baby

Luke and Chloe's Story (this story has been created in discussion between Luke and Chloe and their community nurses)

Chloe and Luke said that the Midwives during pregnancy were “helpful and nice” and “it went really well”; Luke said he “asked questions and she answered them”.

Chloe said her experience was “good”. The midwife who delivered the baby “had a sense of humour “and it had been “alright....I done it before; she also said the midwife had been “nice”.

Chloe said the nurses on the ward were “helpful and nice” but she also said they “didn’t explain much after the baby was born”. They felt they had been treated with respect.

Chloe felt “happy” being a mum and she felt “happy holding him (her baby) in my arms”.

Luke said “it feels great to be a dad”, “the love will always be there” and he “wants to be more protective of the baby”. In talking about their relationship Luke stated the situation has brought him and Chloe “closer together”.

Luke and Chloe explained how they felt when they left their baby at the hospital; “I held him for 10 minutes”, “.....there was a security guard and 2 Social Workers” and they felt “devastated when we left the hospital”.

Luke and Chloe feel very “sad” and “upset” that their baby is not with them and they talk through a lot of different emotional feelings. They didn’t feel they had any support after the baby was removed and “no-one rang to see if we were ok”.

Both Luke and Chloe said that its “difficult getting up early in the morning”, “walking by the bedroom and seeing the baby’s bedroom empty”, “it’s horrible” and “it’s sad”.

They have both expressed that they are “.....not sleeping” and they “.....cry a lot”.

Luke has expressed that he feels “angry” and that he has not felt it useful to be told to “....calm down” when he talks about his feelings of anger at the situation.

Luke and Chloe have said that some people “don’t understand”, “people don’t listen” and they feel people “don’t return their phone calls”. Luke’s mother has to contact people for them sometimes.

Luke and Chloe have found the communication with agencies difficult at times, saying the situation is “confusing – saying one thing and then another”; Luke has said “I think they have made their decision” and “...they are doing everything so fast”.

Luke and Chloe have said “we want help....no-one gives us trust”, “no-one has explained what help is available to us” and “no-one has explained what support is available”.

Chloe also finds it difficult to understand why people keep talking about “the past” because “it was in the past”. Luke and Chloe have found it difficult to understand reports provided by services if they haven’t been in accessible format; accessible information would help them to “understand what’s happening”.

What Luke and Chloe Think Helped

- “Having an advocate”
- “Having good legal advice”
- “Having Community Learning Disability Nurse to talk to and explain so we understand”
- Being listened to by the Advocate, Solicitor, the Judge and the Community Learning Disability Nurse
- Having phone calls from Foster Carer

What Luke and Chloe Think Didn’t Help

- No-one explained what support is available
- Lack of accessible information
- Lack of practical support given
- “Being watched by cameras”
- “No instructions are given to us”
- To keep talking about, and bringing up “the past”.

What Luke and Chloe think could have helped

- If Community Learning Disability Nurses had become involved earlier
- Clarity of feedback content
- Having feedback from contact visits
- Having emotional support
- Having help with “the past”
- “Just give us loads of support and help to get our lives back on track”

People Involved In This Case Study Highlighted

- The family need to be looked at holistically
- The emotional impact of Luke and Chloe being separated from their baby needs to be recognised and support needs to be given to access support services
- Lack of home visits and communication between workers needs to be improved
- Workers need to return phone calls
- Level of understanding and capacity needs to be clarified earlier
- Accessing services in a timely manner is needed
- Workers need to have a positive relationship with parents despite any pre-conceived ideas
- Practical support and advice needs to be available
- Explanation of the concerns needs to be shared
- Multi-disciplinary risk assessment needs to be available

Key findings of the project

Assessment tools

It is acknowledged that few standardised tools exist to measure adequate parenting however the Parenting Assessment Manual Software (PAMS) (McGaw 2012) is recognised by some services as providing a screening tool or comprehensive specialist assessment. Whilst it is noted that any assessment of parenting will require the assessor to make subjective decisions about capacity to parent the use of a tool which assesses within the domains of parental knowledge, quality of parenting skills and frequency of parenting practice (McGaw 2012) offers a structure to support assessment. It is also suggested that:

“PAMS has been developed to present complex information within a format that interfaces well with the Framework for the Assessment of Children in Need and their Families (2000) and the Common Assessment Framework (CAF) for children and young people (DCSF 2010)” McGaw 2012.

Two of the project leads, Heather Crozier and Sarah Morris (Community Learning Disability Nurses) undertook training in using PAMS in order to assess its relevance to cases within health care, to pilot its use and share this within the group (further details of the assessment tool are at Appendix 2). After the initial training some difficulties in accessing the software have meant that this pilot has been delayed.

One of the key findings of the group, which is also reflected in the national and international literature, is that agencies use a range of assessments to assess the parenting skills of people with a learning disability. Many of these will be specific to the agency and not necessarily shared. Agencies also identified that there are issues around late referrals and their involvement in parenting assessment. Problems in identifying people who have a learning disability and differences in terminology add to some of these difficulties.

Resources

Many services use a range of resources to support parents who have a learning disability. Good practice examples have been found within the project group from Speech & Language Therapy focussing on accessible communication, further examples of resources used by organisations have been shared (Appendix 3). A key finding of the group is that many resources exist but these are often web based and not always accessible to parents or professionals.

The Learning Disability Register is a key resource for agencies. This register identifies those adults who have been acknowledged to have a learning disability in Leicester, Leicestershire & Rutland and whilst not a completely accurate picture the group was able to work to ensure all agencies could contact the register holders to check the ‘status’ of someone should they need to.

Networking

This area of the projects work focussed on professional networking. Working Together Parenting Network (Bristol) is a multi-agency network and has four regional groups who meet regularly to share information. Members of the group have joined the regional Working Together Parenting Network and have hosted a regional group in Leicester and shared the work of the group. This link with the regional group has generated a generic invite to be involved in the review of the DH (2007) Good Practice Guidance on Working with Parents with a Learning Disability.

Additionally, international professional networks exist, Healthy Start network (Australia) have a range of accessible resources including teaching materials and run webinars around key issues facing parents and those supporting them. A key success of the group has been making links with national and international networks. We also acknowledged our own group as a multi-agency networking group for Leicester and Leicestershire.

Summary of key findings

- A large number of agencies are involved in supporting parents who have a learning disability. In some cases, parents can have over forty different agencies working with them where there is a Child Protection issue and on-going support. These agencies have differing criteria for referral and inclusion and work with parents across differing timeframes. This raises issues around the number of agencies involved with parents, their focus and consistency for the parents.
- Agencies were often working in isolation and without an in depth understanding of other agencies working with parents with a learning disability.
- Agencies use a range of assessments to assess the parenting skills of people with a learning disability. Many of these will be specific to the agency and not necessarily shared.
- Agencies weren't aware of the Learning Disability Register and the ability to access this information.
- Excellent resources exist within agencies that would be beneficial across other organisations.
- Networks exist to support professionals nationally and internationally. Involvement in these networks offers opportunities for wider knowledge sharing.
- Whilst it is acknowledged that the 'core group' for the project met regularly a limitation of the group is that there are many more agencies who would work with parents who have not been involved in this project.
- The legal support for parents who are involved in Child Protection proceedings is complex but it has been difficult to engage representation from these organisations
- There is often a lack of awareness of learning disability amongst those agencies involved with parents.
- There is little evidence of collaborative working between adult and children's services despite government guidelines supporting joint working and information sharing.

Recommendations from the project group

Assessment:

- Consideration is made to a local agreement for the recognition of specific assessments used in organisations.
- Full pilot of Parenting Assessment Manual Software 3.0 (PAMS) within Leicestershire Partnership Trust.
- Consider the development of a Leicestershire parenting assessment tool

Resources:

- Development of a Directory of services and resources, web based materials and a process for sharing
- A repository for resources (web based) – this has already been discussed at Leicestershire Partnership Trust Senior Management Team meeting
- Explore the development of social media applications to support parents
- Develop a Pathway and protocol for effective working between Leicestershire Partnership Trust and other agencies (including the local acute Trust) around maternal health care and parenting
- Develop a 'grab sheet' for pregnant women accessing GP services, antenatal and maternity services
- Develop training packs for learning disability awareness
- Explore the potential of 'modules of learning' with the faculty of Health & Life Sciences of De Montfort University around parenting by people with learning disabilities
- Limited transitions work across agencies around sexual health education, parenting preparation and relationships with young people who have a learning disability

Networking:

- Continue to meet regularly as a networking group to share good practice examples, problem solve, avoid isolation and promote proactive interventions. Networking also offers support for professionals dealing with sensitive issues around pregnancy, parenting and relationships.
- Continue to work with regional, national and international networks to inform and influence
- Ensure the future involvement of parents who have a learning disability to gain their views on what works well, what difficulties they experience and what they would like to tell professionals to improve the support they receive.

Conclusion

The project has been a catalyst for a number of organisations to come together and focus on their work around supporting parents who have a learning disability. Practitioners in this area of work are often isolated and developing a local network of interested and committed practitioners has enabled information and resource sharing, better understanding of each other's organisations work and ways to enhance the experience of parents. This has also developed a sense of confidence and meaningful direction.

The project has identified gaps in services and areas where further development is needed. Many of these are listed within the recommendations and additionally:

- Sexual health
- Transitions work
- Multi-agency assessment
- Development of a parenting 'pathway' for local use
- Clarity of the role of practitioners within organisations working with parents, the lines of communication between agencies and who is the lead agency at a specific point in time.

The project group are keen to move this forward for the future to address some of these gaps.

The partnership approach to this project between education and practice has also enabled students to engage both within the project itself and within the classroom setting. Joint teaching sessions with practitioners and education staff have enhanced the students understanding of some of the issues facing parents who have a learning disability.

The project leads, Heather Crozier, Nicky Genders and Sarah Morris, would like to thank the project team for their involvement and look forward to working together in the future to enhance the experience of parents with a learning disability.

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Appendix 1

The following is an amalgamation of the comments made by the groups on their flips charts at meeting held in November 2012.

Issues for professionals/organisations

(Grouped into themes)

Referrals:

- lack of
- to the wrong service
- too late
- not always appropriate
- people sometimes fall between services
- people may get 'batted between' services

Services:

- lack of understanding re the nature of learning disability
- Where is 'Think Family'?
- lack of support post removal of children
- difficulties with transition services – support for pregnant teenagers with learning disabilities
- Is there a service at all?
- generic social working
- difficulty accessing solicitors for legal advocacy
- lack of 'joined up' service between adult and child services
- no agreed assessment framework
- lack of understanding of professional roles
- overlap between services and gaps in services
- cultural issues
- some services focus on a deficiency model not a competency model
- 12 week assessment not long enough
- child may become the carer as the children grow older
- lack of communication between services
- meetings involving the parents can be too long and complex
- learning disability professionals not always accessible
- different criteria for accessing services
- lack of a parenting pathway

Resources

- difficulty in accessing appropriate resources
- lack of resources for parenting
- accessibility of information across services
- lack of staff support and training
- learning aids
- lack of assessment tools/skills

Role expectations:

- Screening for Learning Disability – who screens?
- Whose role is assessment?
- professionals may not necessarily be trained in assessment
- confidentiality and information sharing
- lack of role clarity
- different priorities for health professionals
- preconceived ideas and stigma
- social isolation

Examples of good practice

- where joined up working occurs this works well
- resources that are available in different formats for example easy read, DVD
- 12 week assessments can be extended - can request an extra two weeks and easy format information
- use of Sure Start/good networking
- breaks in meetings and time to ensure parent understands
- involvement of the parent
- meaningful dialogue with children's services
- joint assessment
- Common Assessment Framework
- Speech & Language Therapy
- Barnardo's young carers project
- Think Family approach
- good working relationships with solicitors & Advocacy (Mencap)
- some good Multidisciplinary working
- befriending schemes for example scheme in Coalville

Way forward

- examining referral criteria for learning disability services
- children and adult services working better together
- early referrals
- training available for professionals
- pre pregnancy workshops
- what are the priorities for women with a learning disability
- mapping services/what each service does
- positive risk taking
- accessible information
- timely referrals
- preventative work to be acknowledged
- directory of services
- virtual network of interested individuals
- an information hub
- enabling parenting approach
- parenting pathway

Appendix 2

Parent Assessment Manual Software (PAMS 3.0)

The PAMS is based on 3 models:

- Parent Skills Model
- Parent Multi-Dimensional Skills Model
- Knowledge – Skills – Practice Contingency Model

The assessment consists of:

- Initial screening tool
- 'I need help' tool
- Parent questionnaire
- Skills index
- Core skills assessments (worksheets)
- Observations

The assessment has 31 parent and child domains which are divided into 312 skills (383 including sub-skills).

Observations within the home are rated as:

- Good skill
- Adequate skill
- Poor skill

In terms of need for a teaching programme, the priority ratings are:

Low priority – programme recommended as there is low risk of harm and minimal concerns relating to the child's health, safety and general wellbeing.

Medium priority – Programme recommended in 4 – 8 weeks as there is a medium risk of harm relating to the child's health, safety and general wellbeing. These concerns are not life threatening.

High priority – Programme needed immediately as there is a significant risk of harm relating to the child's health, safety and general wellbeing. An intervention needs to be delivered urgently as some situations are, or may become life threatening.

All scores are automatically calculated after you have inputted the information.

The assessments can be carried out as a single or joint assessment.

4 reports can be created from the PAMS:

- Single report
- Joint report (joint profiles take the best parent skills into account)
- Capacity teaching report
- Updated capacity teaching report

Appendix 3

Resources (selected)

ACTing to Support Parents with Learning Disabilities – Pamela Cooke (research project funded by the Home Office Family Support Grant Programme 2001 – 2004
(www.anncrafttrust.org)

A Jigsaw of Services, Social Services Inspectorate (SSI) – DoH, Mental Health & Disability –
(www.disabledparentsnetwork.org.uk/dpndocs/jigsaw-of-services.pdf)

Ann Craft Trust Centre for Social Work. University of Nottingham, University Park,
Nottingham. NG7 2RD

Barnardo's A Practitioner's Guide to Interagency Working in Children's Centres (a review of literature) March 2007 – Karen McInnes, Barnardo's Policy and research unit –
(www.barnardos.org.uk)

Birth to Five – NHS 2001 (www.publichealth.hscni.net/publications/birth-five)

Enabling Parenting with Support. Effective Working with Parents with Learning Disability –
Deborah Chun, Pavilion 2012

Every Child Matters 2004 – Department for Education & Skills – (www.education.gov.uk)

Finding the Right Support (a review of issues and positive practice in supporting parents with learning difficulties and their children) – Beth Tarleton, Linda Ward & Joyce Howarth 2006. The Baring Foundation (www.baringfoundation.org.uk)

Good Practice Guidance on Working with Parents with a Learning Disability – DOH 2007
(www.gov.uk/government/organisations/department-of-health)

Improving Outcomes for Mentally Ill Parents & their Child: Think Child, Think Parent, Think Family – www.scie.org.uk/publications/atagance/atagance09.asp

Inspection of Services to Support Disabled Adults in their Parenting Role – Sarah Googinge 2000 DoH – (www.gov.uk/government/organisations/department-of-health)

Is it legal? A Parent's Guide to the Law. 3rd Edition 2007 Family & Parenting Institute

I Want To Be A Good Parent. Book 2, 3 and 4 by Sue McGaw –
(www.pillcreekpublishing.com/publications)

Making The Difference (a training pack for organisations working with parents with a learning disability) – MENCAP (www.mencap.org.uk/)

Parents with Learning Disabilities – Northgate & Prudhoe NHS Trust Community Learning Disability Team

Parent training Support for Intellectually Disabled Parents (Review) – The Cochrane Collaboration. Coren.E, Hutchfield,J, Thomae.M, Gostafsson.C 2011 Issue 2, published by John Wiley & Sons Ltd

Pregnancy & Childbirth - BILD (www.bild.org.uk)

RCN Pregnancy & Disability – RCN Guidance for Midwives & Nurses – (www.rcn.org.uk/)

Supported Parenting for Mothers & fathers with Learning Disabilities – (www.supportedparenting.com)

Supporting Disabled Adults in their Parenting Role – (www.jrf.org.uk)

Supporting Parents with Learning Disabilities & Difficulties; a starting point – Disability, Pregnancy, Parenthood International 2011

Social Care Institute for Excellence (SCIE) – (www.scie.org.uk)

Working Together with Parents Network – (www.bris.ac.uk)

You & Your Little Child 1 – 5. A Guide for Parents in Pictures & Easy Words – Change 2007 (www.changepeople.org)