

Vulnerable parents with and without a learning disability:
Long-term outcomes for families with and without prior
involvement in a parenting skills programme.

Project Report

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Sharon McGregor, Dominic Jarrett, Ailsa Stewart

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Dominic Jarrett (Chief Investigator)
December 2016

Research Team

Chief Investigator

Dominic Jarrett
Research and Information Officer
Learning Disability Service
34 Lister St
Kilmarnock KA2 0BE
Tel. 01563 826423
Email dominic.jarrett@aapct.scot.nhs.uk

Investigators

Dr Ailsa Stewart
Course Lead PG Certificate in Mental Health Social Work
University of Strathclyde
Glasgow School of Social Work
141 St. James Road
Glasgow G4 0LT
Tel: 0141 4448655
Email: ailsa.e.stewart@strath.ac.uk

Dr Gillian MacIntyre
Senior Lecturer
University of Strathclyde
Glasgow School of Social Work
141 St. James Road
Glasgow G4 0LT
Tel: 0141 4448655
Email: Gillian.macintyre@strath.ac.uk

Sharon McGregor
Research Assistant
University of Strathclyde
School of Social Work and Social Policy
based at NHS Ayrshire and Arran
Arrol Park Resource Centre
Doonfoot Road
AYR, KA7 4DW

Study Sponsor

Dr. Karen L. Bell
NHS Ayrshire and Arran
Flat 60 Lister St
Crosshouse Hospital
Kilmarnock, KA2 0BB
Tel: 01563 825856
Fax: 01563 825806
Email: karen.bell2@aapct.scot.nhs.uk

Steering Group Members

Dominic Jarrett, Research and Information Officer, North Ayrshire Health and Social Care Partnership
Dr Ailsa Stewart, Course Lead PG Certificate in Mental Health Social Work, University of Strathclyde
Sharon McGregor, Research Assistant, University of Strathclyde
Karen Bell, Head of Research and Development, NHS Ayrshire and Arran
Nicky Jenkins, Team Leader, East Ayrshire Health and Social Care Partnership
Ann Cathro, Community Learning Disability Nurse, East Ayrshire Health and Social Care Partnership
Kathleen Winter, Public Health Practitioner (Child Health), NHS Ayrshire and Arran
Elaine Markham, Childcare Team Manager, East Ayrshire Health and Social Care Partnership
Janey Smith, Occupational Therapist, East Ayrshire Health and Social Care Partnership
Marlyn Nicol, Child Protection Advisor, NHS Ayrshire and Arran
Allyson McDougall, Clinical Psychologist, NHS Ayrshire and Arran
Carol Fennell, Team Manager/ Mental Health Officer, Adult Learning Disability Social Work Team, East Ayrshire Health and Social Care Partnership

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Executive Summary

Families including a parent or parents with a learning disability can often have complex needs linked to issues such as poverty and mental health, and are known to be over-represented in child care proceedings. Previous local project work with 12 families had demonstrated the potential of providing intensive support to parents with a learning disability, as well as others without a learning disability who were vulnerable for other reasons. A follow-up project 16 years later sought to re-engage with those families in order to explore their outcomes. Parents, children, and 3 key professionals involved with each family were to be interviewed; however, following recruitment issues, only parents from 3 of the original families participated, with parents with a learning disability from 2 other families being recruited to provide an additional perspective.

Interviews with the parents and 11 professionals affirmed much that is familiar from the existing literature, including services being slow to offer support, but at times quick to judge. However, very positive experiences were described of professionals acting flexibly in an ideal realization of their role (e.g., long-term involvement from a general practitioner with a whole family; hands-on, respectful support from a Social Worker), as well as the love for their children evidenced by the parents interviewed. Of the 5 families interviewed, only 1 had their children within their own custody, affirming the high rate of removal of children identified elsewhere in the literature. However, all the parents interviewed maintained an active role in their children's lives.

The achievements of the parents were recognized by those professionals interviewed, who also offered a wide variety of insights into how they aim to work with parents with a learning disability. These reflected issues such as the need to be respectful of the parent and their experiences; to take a broad perspective on the family circumstances, and not just focus on the parent; to understand their communication and support needs, and adapt information and training as appropriate; to aim for consistent, long term, flexible support; and to listen.

In many respects, the observations of parents and professionals underlined the importance of achieving and sustaining a positive, trusting relationship with parents. This, rather than the need for input from any particular profession or service, was one of the key findings for the project. While this is less readily discussed or perhaps realized than the need for additional resources or new pathways, it is none-the-less a fundamental element of successful partnerships, which needs to be considered. Reflecting the project's findings, the following recommendations are offered:

- Basic awareness of the support needs of people with a learning disability, and parents with a learning disability in particular, should be provided to all those working with children and families. This should be promoted on the basis of a social systems definition of learning disability: the relevance of this training for other individuals who may exhibit similar needs in relation to learning and support, but who do not have a 'learning disability' label, should be emphasised.
- Positive messages in relation to the successful realisation of distributed parenting should be promoted across communities. Parenting by communities/extended networks as opposed to solely by biological parents is not a new concept, and should be recognised and welcomed as a valid option. Where distributed parenting is being employed, attention should be paid to ensuring the continuing, meaningful involvement of the supported parent(s) themselves.
- Partnerships between parents and staff should be informed by more than just a consideration of needs and relevant roles. While a commitment to long-term involvement, such as that recommended within the Scottish Good Practice Guidelines, provides opportunity for positive relationships to emerge, creating the right conditions for those relationships from the outset is a legitimate area to focus on. Realising this within resource constrained services will be challenging, but can be enabled by positive practice in team leaders (knowing their staff as individuals as well as practitioners); flexible responding to referrals (allocating on a more measured basis than the basic fitting together of needs and roles); and encouraging staff to recognise when they are not the right fit for a family, and act on it.
- Further work should be undertaken to explore the outcomes for children of parents with learning disabilities, specifically in relation to: frequency and nature of their role as young carers; college experiences and the impact of stigma/isolation; employment outcomes.
- Staff should be encouraged to reflect and act on the wellbeing of the broader family, where they become involved with parents ostensibly for reasons other than parenting. It is recognised that the current dialogue in relation to the implementation of the Named Person role has highlighted real concerns with regard to the perceived excessive intrusiveness of services. This highlights the need for sensitivity when practising holistically in relation to the needs of an individual and their family.
- Staff should be encouraged to consider the needs of parents not just as parents, but also as individuals in their own right, and to explore with the parent opportunities in relation to this.

Contents

1	Introduction	1
1.1	Background: Service experiences and outcomes	2
1.2	Support tailored for each family's needs and strengths.....	3
1.3	Longer-term outcomes	4
1.4	Impact of parenting interventions on children.....	5
1.5	Provision of accessible information and communication.....	6
1.6	Access to long-term support and independent advocacy.....	7
1.7	Partnership working between agencies involved with the family	7
1.8	Training for those supporting parents with learning disabilities.....	8
1.9	A whole-family approach to support and service provision	8
1.10	Aims of the current research project	9
2	Method	11
2.1	Steering Group.....	11
2.2	Background research	11
2.3	Recruitment.....	11
2.3.1	Families involved in the original parenting programme:.....	11
2.3.2	Contacting Families	12
2.3.3	Families not involved in the original parenting programme	12
2.3.4	All families.....	12
2.3.5	Immediate family members	13
2.3.6	Professionals	13
2.4	Interview materials.....	13
2.4.1	Parent interview schedule	13
2.4.2	Interview prompts for parents from original project	14
2.4.3	Professional interview schedule.....	14
2.5	Focus group materials	15
2.6	Ethical approval.....	15
2.7	Description of analysis.....	15
3	Results: Parent Interviews.....	16

3.1	Theme 1: Parent experience of natural networks	16
3.2	Theme 2: Parent memories of support from parenting project.....	17
3.3	Theme 3: Experiences of parenting	19
3.4	Theme 4: Transfer of custody	20
3.5	Theme 5: Parent experiences of support from services	21
3.5.1	Positive experiences of services for parents as individuals in their own right..	23
3.5.2	Negative experiences of services	24
3.6	Theme 6: Parents' experiences of working with service professionals	25
3.6.1	Barriers to supportive relationships	26
3.7	Theme 7: Parent experiences of information provision	27
3.8	Theme 8: Outcomes for children	28
3.9	Theme 9: Changes as children mature	30
4	Results: Professional Interviews	31
4.1	Theme 1: Perceptions of natural networks	31
4.2	Theme 2: Perceptions of family needs and strengths.....	32
4.2.1	Needs associated with parenting.....	32
4.2.2	Parents' needs as individuals	33
4.2.3	The strengths of the family.....	33
4.3	Theme 3: Experience of providing support.....	34
4.3.1	Support provided to parents as individuals	35
4.3.2	Support relating to immediate family member	36
4.3.3	Support relating to whole families	37
4.3.4	Experience of multi-agency / partnership working	37
4.3.5	Training undertaken by professionals	38
4.3.6	Insights about parents with learning disabilities and effective relationships ...	39
4.3.7	Specialist support for parents with learning disabilities	40
4.4	Theme 4: Challenges to providing support	41
4.4.1	Wider family related challenges in providing support	42
4.5	Theme 5: Supports provided by other services.....	43
4.5.1	Supports provided by other services for parents in relation to parenting	43
4.5.2	Supports provided by other services for parents as individuals.....	44

4.5.3	Others supports provided for immediate family members	44
4.6	Theme 6: Changes as children mature	45
4.7	Theme 7: Experiences of transfer of custody	47
4.8	Theme 8: Parent outcomes.....	48
4.9	Theme 9: Outcomes for immediate family members.....	49
4.10	Theme 10: Gaps in support for parents.....	50
4.11	Theme 11: Gaps in support for immediate family members	52
4.12	Theme 12: Gaps for professionals and services.....	53
4.13	Theme 13: Experiences regarding information provision	53
5	Focus Group	55
5.1	Support from family	55
5.2	Involvement in social networks outwith the family	55
5.3	Support with parenting.....	56
5.4	Experiences of concerns	56
5.5	Support from services.....	56
5.6	Positive and challenging aspects of parenting.....	57
6	Discussion.....	58
6.1	Support for parenting skills following the original project.....	58
6.2	The extent to which supports were informed by the original project's outcomes ...	63
6.3	The extent to which skills/supports developed in the original project were sustained during the intervening years.....	64
6.4	The extent to which supports changed as children aged.....	65
6.5	The experiences of immediate family members	66
6.6	The experiences of parents involved in the original project, and those who were not	67
6.7	The impact of inaccessible information	70
6.8	Study limitations.....	71
6.9	Importance to services and recommendations.....	72
6.10	Dissemination.....	74
7	Conclusion.....	75
8	References.....	76

1 Introduction

In 2001, the Learning Disability Service based in NHS Ayrshire and Arran reported on the outcomes of a pilot parenting programme implemented in East Ayrshire with vulnerable parents, with and without a learning disability (Denny et al., 2001). The project involved 12 families: each family had a parent who either had a learning disability, or who did not have a learning disability but were vulnerable for other reasons, e.g., were living in poverty and isolation. For the purposes of reporting the research findings only, families were allocated to 3 groups, namely a learning disability group (consisting of 4 families), a vulnerable group (consisting of 5 families) and a control group (consisting of 3 families: 2 with a learning disability and 1 without), who received normal services.

The interventions trialled within the programme were developed from evidence-based research (e.g., Feldman, 1998; Kelly et al., 1996; McGaw, 1996), and involved a combination of group and home-based interventions, supported by the use of modelling, role-play, illustrations and handouts. The programme had a dedicated support worker who worked extensively with the families, as well as input from learning disability and primary care services.

Whilst Denny et al. advise that the results should be treated with caution due to methodological limitations (e.g., the projects small sample size), overall, parents receiving the interventions showed more improvements than those from the control group. The improvements achieved were in a number of areas including parenting skills, symptom recognition, the quality of the home environment and a reduction in parental stress. The project also achieved its target of helping each family achieve at least four of their training goals. At the beginning of the programme, there was an average of 15 training goals set for families within the learning disability group and an average of 19 for the vulnerable group. At the end of the programme, an average of 45% of training goals were met (range: 33-72%). In all cases, the learning disability group met fewer targets than the vulnerable group. Behaviour management (e.g., bedtime routines, toilet training and dealing with tantrums) was the area where both groups struggled most to achieve their goals. Six of the families from the intervention groups were followed up 6-months later by telephone, to explore whether training goals had been maintained. Feedback from the parents indicated that 77% of the goals for the learning disability group and 61% for the vulnerable group were maintained.

1.1 Background: Service experiences and outcomes

The work by Denny et al. reflected an awareness that families with a parent who has a learning disability can often have very complex needs due to a large variety of factors including poverty, discrimination, depression, poor self-esteem, and unemployment (Macintyre & Stewart, 2012; Wade et al., 2007). In addition to having complex needs, there is a propensity for parents with a learning disability to be over-represented in care proceedings (Cox et al., 2015). However, many such families are involved with social services and child protection agencies due to the parent not possessing the skills and knowledge necessary to parent effectively, rather than them being purposefully neglectful or abusive (Feldman, 2004). Tarleton (2007) suggests that parents with learning disabilities may have to meet a stricter criteria within parenting capacity assessments than other parents. One possible consequence of this is seen in the estimate that between 40% and 60% of parents with learning disability have their children removed due to them being assessed as unable to meet an adequate standard of parenting (Wilson et al., 2013).

This standard of parenting is often referred to as 'good enough parenting' (Choate & Engstrom, 2014). According to the Scottish Government (2008), this requires parents to be able to provide basic physical care, love and affection, security, guidance, boundaries, and age-appropriate responsibility and independence. Several of the skills and knowledge synonymous with being a 'good enough parent' have been found to be lacking in some parents with learning disability including the ability to provide a safe home environment, adequate nutrition, positive and nurturing interactions, being able to recognise and treat medical emergencies and having a basic understanding of child development (Feldman, 2004). Yet, when provided with enough support, many parents with a learning disability can improve their skills and knowledge, and learn to parent more effectively (Murphy & Feldman 2002; Coren et al., 2011). This essential point is supported by a growing body of evidence, however, all too often services continue to fail to acknowledge this, with the consequence that they in turn fail parents with a learning disability. Yet frequently, this failure is attributed to the parents themselves.

The National Parenting Strategy (Scottish Government, 2012a) and Getting it Right for Every Child (GIRFEC; Scottish Government, 2012b) both acknowledge that parents and families should be provided with the support they need at the earliest opportunity. The Children and Young People (Scotland) Act, 2014, also places a duty on Local Authorities to secure services for children deemed at risk of becoming looked after. However, unlike the Keys to Life (Scottish Government, 2013) and the refreshed Scottish Good Practice (SGP) Guidelines for Supporting Parents with Learning Disability, entitled '*Supported Parenting*' (SCLD, 2015),

there is no specific mention of (or guidance for working with) parents with learning disabilities.

The SGP Guidelines advise that the main features of good support provision for parents with learning disability are: 1) support that is tailored for each family's needs and strengths, 2) the provision of accessible information and communication, 3) having access to long-term support and independent advocacy, and 4) partnership working between agencies involved with the family (SCLD, 2009). Yet in practice, this level of support does not tend to happen (Scottish Government, 2013). The Getting It Right For Every Child (GIRFEC) legislation is one means by which the Scottish Government is seeking to address this, however for all families, let alone those involving parental learning disability, the impact of this remains to be seen. As part of GIRFEC, the implementation of the Named Person role (an individual identified for every child who has a key role in co-ordinating their support where needed, such as a Health Visitor or Head Teacher) also represents efforts to nurture better collaboration in the interests of children and young people.

1.2 Support tailored for each family's needs and strengths

The need for tailored support for families described within the SGP guidelines had previously been identified in the first wave of the Growing Up in Scotland study. This longitudinal study (tracking the lives of thousands of children from early-years and beyond) found that taking a one-size-fits-all approach to parenting support could disadvantage key groups (Anderson et al, 2007). Reflecting this, evidence-based parenting programmes, tailored for parents with learning disability, have been shown to be effective in helping them parent more effectively. Examples include home-based learning programmes, e.g., Self-directed Learning (SDL; Feldman, 2004); group-based learning programmes e.g., Supported Learning Parenting Programme (Booth & Booth, 2003); and a programmes incorporating a combination of both, e.g., Mellow Futures (Tarleton, 2014).

Feldman (2004) demonstrated the successful use of illustrated self-directed learning materials, accompanied by audio tapes, in relation to 25 basic childcare skills. The vast majority of parents quickly met a performance level comparable to known competent parents. However, the potential reach of self directed learning comes at the loss of peer support within groups, as well as having an unknown impact on other aspects of the parents' lives (e.g., their parent-efficacy, self-esteem) or additional skills (e.g., managing their child's behaviour), or indeed their children's lives.

In contrast, interventions such as the Supported Learning Programme (SLP: Booth & Booth, 2003) and Mellow Futures are built around group-based interventions. Positive outcomes have been identified for both of these. Booth and Booth (2003) suggested that whilst most of the progress made as part of the SLP may have appeared minor e.g., being able to shop independently, going on holiday or taking driving lessons, its true impact can only be fully understood when considered within the context of each parent's life. Mothers involved in the programme evaluated by Tarleton (2014) felt it helped them understand their babies better, address past and current issues in their lives, and increase their confidence. In addition, they also valued the peer support from other mothers in similar situations.

The common outcome running through each of the parenting programmes discussed above is that they have all shown positive results in helping parents with a learning disability to develop the skills they need. However, the successes being reported are short term with some results being reported during the intervention (e.g., Tarleton, 2007) and others being reported around 7 months after completion (Feldman, 2004).

1.3 Longer-term outcomes

Whilst there is an increasing, albeit limited, evidence base surrounding the short-term benefits of supporting parents with learning difficulties, there is a dearth of research regarding the longer-term outcomes, especially for programmes specific to parents with learning disabilities. One study reporting both short-term and long-term outcomes (follow-up 1 year later), albeit not specific to parents with learning disability, was the Parenting Early Intervention Programme Evaluation (PEIPE) conducted by Lindsay et al (2011). They aimed to evaluate the effectiveness of five parenting programmes that were selected by the UK Government to be implemented within 150 local authorities in England between 2008 and 2011; 43 local authorities participated in the evaluation.

The programmes were aimed at parents of children aged 8-13 (either with behavioural problems or at risk of them) due to that age range being judged as tending to have lower levels of support available to them than younger or older age groups. The parents involved were considered to be more disadvantaged than the general population, e.g., living in poverty and isolation, single parent and low education. These disadvantages are similar to those frequently experienced by parents with a learning disability.

The four programmes for which complete data was available (Triple P; Strengthening Families Programme; Strengthening Families, Strengthening Communities; and The Incredible Years) showed improved outcomes for parents and their children, which were

maintained up to 1 year after the project ended, and the outcomes were positive for parents of both older and younger children. Short-term outcomes saw improvements in parent's mental well-being (79% of parents), in parenting 'laxness' (74% of parents), a reduction in over-reactivity (77% of parents) and a reduction in the number of parents that had previously considered their child as having serious behavioural issues (19% less parents). The majority of parents found the group helpful (98%). The programme helped them deal with their problems (95%), helped with their children's behaviour (95%) and they experienced fewer problems since the programme completed (98%). At the 1-year follow-up, positive outcomes in relation to parent 'laxness' and child behaviour were maintained, and parent's mental well-being still remained higher than at the beginning of the programmes, but had shown a small reduction. .

1.4 Impact of parenting interventions on children

While some evidence exists with regard to short and longer term outcomes for parents, research generally has been criticised for being deficient regarding the impact of parenting programmes on children (Wilson et al., 2013). What evidence does exist regarding outcomes for children of parents with a learning disability is limited and unclear. Whilst a few studies suggest that living with a parent with a learning disability can have adverse consequences for children, such as an increased risk of child developmental delays and speech and language problems (Emerson & Brigham, 2014), health, developmental and behavioural problems (Feldman, 2004), these outcomes can be dependent upon a number of other factors and not necessarily related to parental learning disability.

Collings and Llewellyn (2012) note the impact of disadvantage and isolation in general on children's wellbeing, and the difficulty in disentangling the impact of parental learning disability from these. Indeed, a recent large scale American study which followed up families with and without a mother assessed as having an intellectual disability (Powell et al., 2016), found that for young children (aged 3), there was no difference between their health outcomes on 3 variables (mother's rating of child's overall health; diagnosis of asthma; and obesity as indicated by reference to national indicators) between the two sets of parents, once a variety of sociodemographic factors had been controlled for (e.g. education involvement, income, support networks).

Whilst one of Collings and Llewellyn's (2012) main findings were that children experienced social exclusion, bullying and stigma, only one study cited by them included reports from children themselves, all-be-it a small number. Faureholme (2010) conducted a longitudinal qualitative study on 23 Danish children of parents with learning disabilities over a 10-year

period (1994 to 2004), aged between 8-12 and the time of the first interview. Six children were moved into permanent foster care and most received an element of special education, which was held separately from peers. Some children reported feeling 'humiliated' at being removed from the classroom and 'degraded' for not learning the same subjects at the same time and pace as peers. This resulted in many expending additional effort in an attempt to help their siblings avoid similar outcomes, e.g. encouraging siblings to do their homework. The children also spoke about experiencing bullying, isolation and stigma at school.

Overall, existing evidence exploring the possible impact of having a parent with a learning disability is inconclusive. Similarly, research that looks at the outcomes of parenting programmes for children has also yet to be established (Wilson et al, 2013).

1.5 Provision of accessible information and communication

Other disadvantages parents with learning disability can face are not having access to information that they can understand, and information not being issued timeously. The importance of this is reflected in the SGP guidelines stating that services should make communication and information accessible to parents with a learning disability. Indeed, under the Equality Act (2010), services have a legal obligation to do so.

NHS Scotland provides three easy-read CHANGE resources to parents with learning disability free of charge (Lewis et al., 2011). The CHANGE resources, '*My pregnancy, my choice*' and '*You and your baby 0-1*' were available from 2009 and '*You and your little child 1-5*' from 2010, and they are the easy read equivalent of '*Ready Steady Baby!*' (pregnancy to 1 year old) and '*Ready, Steady Toddler!*' (1 to 5 years old), which are free resource guides already provided to mothers by midwives and health visitors (Lewis et al, 2011; Reece & Porter, 2011). An evaluation on the use and implementation of the CHANGE resources was conducted by Lewis et al (2011). They found that parents were not getting access to the CHANGE resources as readily as NHS Scotland intended. However, all parents were positive about the resources and most commented on the inaccessible nature of the 'Ready Steady...' resources. Lewis et al. (2011) also found that professionals involved with parents had a lack of awareness regarding the resources, and there was no clear distribution pathway for them.

The lack of accessible resources means that parents with learning disability may not be as informed as other parents. Furthermore, the lack of accessible information also has the potential to have considerable implications for parents to understand and fully engage with

processes that can have life-altering outcomes for them and their children, such as child protection proceedings.

Dale (2004) and MacIntyre and Stewart (2012) report that information issued to parents regarding the child protection process can be high in volume, difficult to understand and issued at short notice, with some information being handed over during meetings. Information being handed over for comment during meetings of such importance is very concerning considering the parent receiving it may not be able to understand it or have time to absorb it or its implications. To this end, MacIntyre and Stewart (2012) not only recommend the input of services such as advocacy to support parents through the child protection process but also for supports to be long term where needed.

1.6 Access to long-term support and independent advocacy

Access to advocacy services is also a recommendation of the SGP guidelines. Advocacy can help parents in many aspects of their lives including the child protection process, and has not only been shown to be cost effective (Bauer et al, 2014) but has also been shown to help improve outcomes for parents with learning disability. MacIntyre and Stewart (2012) conducted a mixed methods study to investigate the role of advocacy on the lived experiences of parents with learning disability. They found that advocates played a key role in helping parents understand information, have their voices heard, and challenge decisions.

However, access to advocacy for parents with learning disability has been found to be lacking. Hartworth (2012) found there to be a reduction in the number of advocacy services available to support parents with learning disabilities within Newcastle upon Tyne. They found that this group of parents primarily need support with child protection proceedings, which are lengthy and time intensive for advocacy staff. However, funding cuts and the scarcity of available funding sources has meant advocacy services are less able to take on lengthy advocacy cases (Hartworth, 2012). This can leave parents to navigate the complex child protection process on their own without independent support.

1.7 Partnership working between agencies involved with the family

All services supporting parents, whether it is advocacy, social work, NHS or education, should be working in partnership together. As well as being one of the main features of the Scottish Good Practice Guidelines, partnership working between agencies is also one of the ten key components of GIRFEC (Scottish Government, 2012b) and is promoted legislatively by the Scottish Government in the Public Bodies (Joint Working) (Scotland) Act 2014, and

the Children and Young People (Scotland) Act 2014. Partnership working helps professionals to develop a shared understanding, within their own organisations and across other agencies involved, of the needs of the children and their families. In addition, effective communication and shared recording across all partners helps in reducing the overall risk as all services are informed of the overall picture and not just of their own snapshot. However, effective partnership working takes time to develop that is not necessarily afforded to staff, especially in times of austerity, and can result in relationships between social workers, other services and service users being underdeveloped, contributing to poor decision making (O'Connor & Leonard, 2014).

1.8 Training for those supporting parents with learning disabilities.

As well as partnership working within their own organisations, staff should be trained in the needs of parents with learning disabilities in order for them to understand and appreciate the issues they face and their complex needs. In a study by Cox et al. (2015), legal professionals raised concerns about the key role social workers and their assessments play in care proceedings as it was felt that, whilst there were some excellent social workers, there were also those with a negative attitude who lacked knowledge and experience of working with parents with learning disabilities, which influenced their assessments.

It was also suggested that the process was prejudiced against people with learning disabilities, and that some social workers seemed to be biased in their evidence selection by tending to choose evidence supporting their case whilst ignoring that which did not. The study recommended that professionals involved with parents with learning disabilities undergo relevant training. This not only highlights the relevance of the role independent advocacy could have in the child protection process (as mentioned earlier), but also highlights the importance of partnership working so that a fuller picture of the family circumstances can be established, rather than just relying on one viewpoint.

1.9 A whole-family approach to support and service provision

GIRFEC guidelines stipulate that partnership working between professionals is essential for enabling early intervention support for families when they first experience difficulty, rather than when they have reached crisis. GIRFEC also recommends the selection of a lead professional to 'co-ordinate and monitor multi-agency activity' (p.7). However, deciding on who the lead professional should be is not necessarily straightforward, and even more basic issues can exist with regard to identifying appropriate sources of support.

Hartworth (2012) found that health professionals based in Newcastle upon Tyne found it difficult to decide which agency should provide services (i.e., health or local authority) to parents with a learning disability and which professionals within those organisation should be involved, e.g., nurses, health visitors, and social workers. Similarly, the local authority professionals reported difficulty in deciding which local authority service was responsible for providing support to families (i.e., Child or Adult services), and raised concerns about the conflict between addressing the support needs of the parent and safeguarding the child.

This safeguarding/support conflict experienced by professionals is also reported in more recent research, e.g. Tarleton and Porter (2012) who refer to the valley between adult and children services as 'no-man's land'. Tarleton and Porter (2012) conducted an evaluation of the role of the Valuing Parents Support Service (VPSS), a specialist Parent with Learning Disability Team which is a joint project between child and adult services in Kent. It is aimed at parents with a learning disability with children under 8 years old, with a view to providing support that considers the needs of the whole family.

The service evaluation compared the outcomes of children and families receiving support from the VPSS to those receiving standard support from children's Assessment Services. Focus groups with parents highlighted that parents received support in a range of areas including parenting skills, household support (e.g., shopping, safety and cleanliness), advocacy, facilitating access to mainstream parenting groups, helping parents engage with factors influencing their ability to parent (e.g., domestic violence, housing and grief of having children removed) and signposting to external services where needed. The evaluation also found that children supported by the VPSS had better outcomes than those supported by the Assessment Services, partly due to the tri-level positive partnership working that was implemented in the project, i.e., between the VPSS team and parents, between parents and other services, and between services.

The success of the partnerships was attributed to VPSS staff being matched to parents, who described the staff as 'respectful, honest and kind'. VPSS staff were also able to support parents to engage with a wide range of mainstream services including play groups, mother and baby groups, housing and legal services and counselling.

1.10 Aims of the current research project

Much progress has been made since the work by Denny and colleagues 15 years ago regarding the support of parents with a learning disability, and other vulnerable groups of parents. However, gaps remain in the evidence base (particularly regarding longer term

outcomes of involvement with parenting programmes). Reflecting these, the current research project looked to establish the long-term outcomes and experiences of the 12 families involved in the original parenting programme run by NHS Ayrshire and Arran between 1998 and 2000. By exploring each family's subsequent experience of service involvements (and those of key professionals involved with them), the project sought to inform the provision of support generally to families not only of parents with a learning disability, but also of those who are vulnerable for other reasons, as well as identifying valued aspects of the original project. The current project also hoped to develop the evidence base in relation to supporting parents with a learning disability in general, and with regard to the challenges of raising older children in particular, as well as providing insight into the experiences of immediate family members themselves. Specific secondary research objectives were as follows:

- To find out about the nature and extent of the support for parenting skills that families have received since the completion of the first project.
- To find out the extent that supports received were informed by the outcomes of the first project.
- To find out the extent that skills/supports developed in the first project were sustained during the intervening years.
- To find out whether the supports and interventions offered to the families changed and/or developed as the children have aged.
- To find out about the experience of the other immediate family members with regard to the supports and interventions offered to the family throughout their lives.
- To explore how do the experiences of families not linked in any way to the project compare with those who were.

2 Method

2.1 Steering Group

The project was overseen by a multi-disciplinary steering group consisting of 12 professionals. This included researchers from education and health, and members of the local Community Learning Disability Team and Adult Learning Disability Social Work Team. The involvement of the steering group was invaluable, particularly in highlighting key personnel and organisations that would be beneficial to visit to build up a background knowledge of services, designing project materials, and resolving recruitment issues.

2.2 Background research

The researcher met with 3 individuals involved within the original research project including the support worker, the community learning disability nurse and an administrative assistant. This provided insight into the original parenting intervention and to some of the difficulties parents faced, e.g., bedtime routines and nutrition. The support assistant advised that they took an approach of 'never assume', and provided an example of asking one parent how they sterilised their bottles. The parent answered (appropriately) that they used the microwave. However, only by asking the parent to demonstrate was it established that they had not realised the bottles had to be cleaned first.

A number of organisations and services within the local East Ayrshire area were also visited to build a picture of the services and resources that families could have had/currently have access to and to explore their experiences of supporting vulnerable families.

2.3 Recruitment

2.3.1 Families involved in the original parenting programme:

One of the initial priorities was to locate the 12 families involved in the original parenting programme. This entailed the research team liaising with the local Community Learning Disability Team Leader (who along with Social Work colleagues, searched their team databases) and with the Primary/Acute Liaison Nurse for the Learning Disability Service (to liaise with GPs where there was a lack of service involvement for parents). Parents and immediate family members were to be excluded from involvement if they were experiencing crisis, presented a risk to the researcher, or did not have the capacity to consent to involvement. No parents were excluded. Five of the 12 families were located through the

Learning Disability Service and 6 via the GP. A letter was issued to the remaining family via the GP but it was returned as addressee unknown.

2.3.2 Contacting Families

The 5 families located via the Learning Disability Service were contacted by a Learning Disability Nurse via a telephone call and, where this was unsuccessful, via an appointment letter. Initially 4 families agreed to be interviewed, but 1 family subsequently withdrew their participation.

Of the 6 parents located via the GP, each received a letter from their GP advising about the research project and that they would be contacted after 3 days by a Learning Disability Nurse to check whether they were happy for the researcher to contact them. One family subsequently met with the researcher, but decided not to participate.

2.3.3 Families not involved in the original parenting programme

The research project had an initial criteria that specified a minimum level of recruitment of 8 families from the original project. However, as this minimum was not met, recruitment was extended to include parents who were actively involved (or had been involved within the last 2 years) with a Community Learning Disability Team in North, East, or South Ayrshire, and who had at least 1 immediate family member aged 16 or over. Two additional families were recruited this way

2.3.4 All families

The recruitment process for all families entailed initial contact being made via a professional familiar to them. If willing, a meeting was arranged with the project researcher to allow them to explain the project further, following which, a period of 3-days was allowed for the parents to consider their participation. Parents were also asked for their consent to allow for members of their immediate family (children now aged over 16) to be approached regarding involvement, and to identify 3 key professionals to be contacted about participating. Parents were also to be given the opportunity to participate in a focus group discussion with other participating parents.

2.3.5 Immediate family members

The 5 participating families had 9 children between them, with an average age of 21 years (ranging between 15 and 25 years old). None of the immediate family members were recruited to the project: for 4 families, the parents or guardians did not consent to them being contacted. While one family did agree to this, their children either could not be contacted, or chose not to take part. An overview of the participating families is provided in Table 1. below.

Family	Participated in Original Project?	No. of Children	Care status of children
1	Yes (LD Group)	3	Kinship care
2	Yes (Vulnerable Group)	1	Local Authority Guardianship
3	Yes (Vulnerable Group)	3	With parents
4	No	1	Kinship care
5	No	1	Kinship care

Table 1. Profile of participating families

2.3.6 Professionals

The 3 key professionals identified by the parents were to be ones who were involved with the family in the last 10 years (between 2005 to 2015). Of the 5 families participating, the parent of one family was unable to identify professionals within this time frame due to their children being in kinship care for that duration and having no contact with other services. Three professionals from each of the remaining 4 families were identified by the parents themselves, all were contacted and 11 were interviewed.

2.4 Interview materials

All interview and focus group materials (consent forms, participant information sheets, focus group schedule and interview schedules for parents, immediate family members and professionals) were developed from the project's research objectives, the literature review and feedback from the multi-disciplinary steering group. Three semi-structured interview schedules were prepared, one for parents, immediate family members and professionals.

2.4.1 Parent interview schedule

This consisted of 12 main questions that explored what parents remembered about the original parenting programme and whether recommendations from it were implemented;

their perceptions of the changing needs of their children as they matured; their experiences of services since the parenting intervention both for themselves as parents and their children; their experiences of employment, parenting support received since the project, and the people that have supported them; and their experience of written information provision. The 2 questions relating to the original parenting intervention programme were omitted from the interviews with the additional families recruited from the Community Learning Disability Teams.

2.4.2 Interview prompts for parents from original project

At the end of the original parenting programme, individual reports were prepared for the families which outlined the areas where parents received support, listed services that were involved with the families and provided recommendations for continuing/future support. The recommendations made were individual to each family, but examples included recommendations for continued support in relating to their children (e.g., children's hygiene, child development and child guidance) or recommendations particular to the parents as individuals (e.g., assertiveness training, counselling and continued home help support). Initially, the individual reports were to be shown to the families as a reminder of the original parenting programme. However, as staff members involved in the original parenting intervention advised that parents did not receive the reports, information from them regarding the family's involvement in the project and the recommendations made at its end were used to focus discussions with parents. In addition, and to act as a memory prompt, photographs of the support worker and team leader involved in delivering the programme were included in the information sheets. These prompts were not used for parents from the additional families recruited via the Community Learning Disability Teams.

2.4.3 Professional interview schedule

This consisted of 15 main questions relating to: their role in supporting the family; the main strengths and needs of the family; what services they were aware of being involved with the family or that the family were excluded from; their multi-agency working experience; assessment and intervention approaches taken with the family; any age-specific issues in relation to the children; and their experiences of written information and training. All professionals were asked the same questions.

2.5 Focus group materials

The focus group interview schedule consisted of 10 main questions that explored parents experiences of the parenting programme; what support parents receive from others (peers, friends, family and community); experiences of services for themselves and their children; experiences of parenting in relation to their proudest, most challenging and best thing about being a parent; and if they experienced any differences in raising their children as they matured.

Two families were excluded from an invite to the focus group, one due to their declining to participate in the group at the interview stage and the other family due to changes in their family circumstances preventing involvement. The remaining three families (4 parents) were invited to attend a focus group and 2 participated (2 from additional families). The focus group was facilitated by the researcher and a Community Learning Disability Nurse. One parent was supported by a Community Support Worker from their local Community Learning Disability Service.

2.6 Description of analysis

All interviews and focus groups were digitally recorded and were transcribed as soon as reasonably practicable. A thematic analysis of the data was then undertaken, informed by the General Framework Approach (Gale et al., 2013).

2.7 Ethical approval

The project was approved by the West of Scotland Research Ethics Committee, and also had Research Management approval from within NHS Ayrshire and Arran.

3 Results: Parent Interviews

Seven parents from the 5 families participated in an interview, consisting of 5 mothers (Parents 1 to 5); 2 of whom were supported by their partners consisting of one step-father (Parent 6) and one father (Parent 7). Two parents remained together, 2 parents were living on their own, one parent had re-married, one parent was living with their own parents and their child. As previously outlined, 1 family maintained custody of their children, the other 4 families had custody transferred. In relation to parent experiences of employment, one parent was in paid employment, whilst another was in part-time voluntary work. Themes identified from the interviews are described below.

3.1 Theme 1: Parent experience of natural networks

Natural networks relates to family, friends or people from the wider community that parents mentioned during the interview. Parents provided a number of examples of positive experiences in relation to natural networks. For one parent, these ranged from family members acknowledging their role as a parent to actively encouraging them to be involved in the parenting role and to have parental responsibilities. Some of the examples shared by the parent included family members seeking their permission to hold their child or to take their child on an outing. Encouragement was given by family members in the form of praise, and reassurance:

"He [Brother] goes, 'I'll take him out' and he was going out with his friend... and I said to mum, 'he'll need his milk with him'. So I went in and made his milk and made sure to my mum it was, you know, the right temperature and that. And I showed and I asked mum to check and she said, 'Oh!, that's good, you've done it perfect!'" (Parent 5)

Some parents also spoke about the practical support they received from family in relation to parenting, such as family members undertaking babysitting or helping the parent with other practical childcare tasks. Emotional support was another type of support that a couple of parents valued, as well as advice on parenting:

"Emotional support [from her own parents]. They helped me a lot with making me understand a lot about parenting and things like that. They've just been, they've just been there all the way through it." (Parent 1)

Sometimes, the emotional support was just about knowing there was someone available to help:

"My sister-in-law..oh she's gid, I go doon and sit and talk to her and that and she helps me and that and if I need any help she'll give me some help." (Parent 2)

For most parents their families were their greatest, or indeed only, source of support. For others, it was not just families that were a good source of support: one parent in particular spoke about their ex-partner still maintaining a relationship with themselves and their child. Parents also spoke about the support they received from the broader community and how friends supported them with relationship difficulties, to community activities, and in the acquisition of literacy skills. One parent advised that being known within the community allowed their family to be alerted to the parent being suddenly unwell.

As well as being sources of support, natural networks could also be sources of tension. One parent spoke about not being listened to, and about a family member sometimes using the threat of contacting services to control the situation:

*"But see when you're trying to say to her something, something else, she does nae listen...And then she says, 'I'm phoning', and you're feart in case she phones *CLDN SW* in case she thinks I'm calling her something..." (Parent 4)*

Networks were also described as breaking down in some instances. Difficulties in dealing with a child's behaviour were described by one parent as contributing to a break up, while another spoke about their experience of an abusive relationship, which they left after seeking help.

3.2 Theme 2: Parent memories of support from parenting project

Despite the 16 year time frame since its completion, those parents who were involved in the original parenting project still remembered it. Two parents remembered different aspects of the group based interventions: one remembered participating in group-based workshops relating to nutrition and cooking; the other spoke about their enjoyment of the group environment, and the social aspect that went along with it. However, for all parents the peer support element of the project was not maintained. Only one parent advised that whilst they knew a couple of parents, they did not see much of them.

The support that parents received at home was the aspect of the original parenting project that parents seemed to remember most. Memories included receiving support around housekeeping, health, nutrition and budgeting, establishing bedtime routines, and coping with multiple children. Parents also spoke about the new skills they had learnt within the

project, e.g. in relation to nutritional aspects and learning to cook. One parent mentioned that it was particularly helpful to know what food types their child should avoid due to the impact on their behaviour. The parenting project was also beneficial for one parent who not only learned about first aid but also passed their first aid test. Another parent noted that their involvement in the parenting project helped them gain access to a college course.

The relationship parents had with the support worker on the original project was obviously an important aspect of that project's success. Among the valued aspects of the relationship were the close bond they had, the support worker being available when needed, providing guidance and having the ability to make parents feel better:

*"I loved *Support worker from Parenting Project* coming...I just loved that how eh, I could talk to her and she was really supportive...Yeah. And I think we come, very close to being friends so, I really did like *Support worker from parenting project*." (Parent 1)*

During the interviews, the recommendations from each family's individual report were read out, and the parent was asked whether they remembered the recommendations being put in place. Home help support was a recommendation for 2 families, for one family it was recommended that the home-help be maintained and for the other, that it be reinstated. The parent that already had home help in place advised that their children were removed from their care shortly after the original project ended, so there had been no opportunity for any recommendations to be put in place. For the other family, it was confirmed that home-help was indeed not only re-instated, but that it was also long-term support that lasted up until their children began secondary school (which was a couple of years after the project ended). The third parent spoke about input from a Psychologist in relation to a recommendation for ongoing support on child control. They also remembered a recommendation for continued health visitor support being implemented (regarding feeding), as well as a recommendation around child safety, which resulted in new window locks being put in place.

Parent recollections of recommendations for support in relation to their children were more vivid than their recollections of recommendations that were particular to themselves as individuals (e.g., counselling, coping with stress). One parent advised that the recommendation for them to receive support around stress had been implemented, but did not provide additional detail of what this entailed. Another parent had no recollection of ever receiving the assertiveness training that had been recommended. Similarly, another parent had no recollection of every having received counselling, nor it being continued as per the recommendation noted in their report.

With regard to possible improvements to the original parenting project, one parent noted that while support around child behaviour was provided, more support in this area would have been helpful as they really struggled with this. For another parent it was more about them wishing they had taken the opportunity to attend the group sessions offered by the project, as social situations were still an issue for them. This parent was also asked what advice they would give to encourage other parents to take up such opportunities, if a similar parenting project was to be run in the future:

"Just to give them more encouragement [to attend group work]. Tell them a lot about it...A lot more information [to encourage other parents to go to group work]...I would tell them to give it a try." (Parent 1)

3.3 Theme 3: Experiences of parenting

Interviewees were asked about their experiences of parenting. The positive experiences they shared included playing with their children, going on trips together, participating in celebrations (e.g. birthdays) and enjoying a cuddle together. Two families described sharing skills with their children: for one, this involved them baking together as a family, and helping their child implement the skills they were learning in their college course by sharing their knowledge of baking; for the other, this related to teaching their child to swim.

Positive recollections of participating parents tended to reflect the same range of experiences that are valued within families in general, although the circumstances of some compounded their significance. One parent cherished just being able to spend time with their children, and highlighted that this was more important than anything due to them not having custody. Poignantly, for one parent the most enjoyable aspect was helping their children so they could avoid experiencing what the parent had:

"Helping them [children] out with the help that they need. To stop them going through what I went through." (Parent 3)

Although initially prompted by the intervention of services, this parent also spoke positively about their insight into their situation. As a result, they were able to take control of their life and turn things around for themselves and the family they had been at risk of losing:

"I was depending on them [services] and it was just one day I got up and I says, 'I cannae depend on other folk, I've got to pull myself up or I'm going to loss the wains', ken what I mean, somehow. And eh, I just decided that's it and I went and done it aw." (Parent 3)

Along with describing the same positive experiences of parenting as many would, the parents also discussed the same type of challenges any parent could face, including their experience of post natal depression; the difficulties of adjusting to being a parent; and how they handled childhood scenarios, such as bedtime routines, bed wetting, managing multiple children, and keeping an eye on young children when they are out playing with friends.

3.4 Theme 4: Transfer of custody

This was a major theme in that 4 of 5 mothers had experience of losing custody of their children. Three parents lost their children (5 in total) to kinship care and one to their spouse initially, and then, approximately 5 years later, into local authority care. The average age of the children at the time of their removal from their parent's custody was 4 years old (ranging between 2 and 7 years old), based on the 3 families for whom this information was available. It should be noted that these ages are approximate and were ascertained from either the individual project reports for each family that participated in the parenting project or from the parents themselves.

Parents were asked if they understood the reasons why custody of their children was transferred. Whilst the reasons for the transfer of custody, such as neglect, child safety and child abuse, differed for each parent, they did share a consistent belief that the decision to remove their children from their care was unjustified. For one parent, the safety of their child was a concern for the local authority and an underlying reason why custody was transferred from the parent to their spouse, this being something they completely disagreed with.

For another parent, custody of their child was transferred to kinship care following their leaving an abusive relationship. The transfer of custody was something the parent could not understand, particularly as they had permanently removed themselves from the abusive situation:

"He [Son] lives with his Gran...He had to be with his Gran all the time...Because of his Dad, what his Dad did...but he still had to stay with them [even though Parent had split up from the father]...That would have been, he was still a little baby at the time...He was about 2, 3, about 2 and a half and he stayed with his Gran for the rest of his life... We saw somebody, they said he had to go and stay with mum and dad...No [didn't understand why Son had to live with his grandparents]." (Parent 5)

The third parent shared that 'neglect' was the reason cited for the transfer of their children into kinship care, but they felt that social work had jumped to conclusions in relation to this, and did not fully understand the family situation. At that time the parent had moved into a new home, was decorating and as such had been getting their meals at the grandparents' house:

"Well the neglect part bit they [social work] were talking about ken, they were expecting a mother to just move into a house and have everything done ken, for them coming and I'm going, ken, who does that? Who has a house already repaired for them coming. So yeah, I did think they jumped to conclusions a lot. And they weren't listening, ken, they wanted it done and it was their way or no way." (Parent 1)

Despite the custody of the children of 4 parents being transferred, all parents still remained in contact with their children and retained their parent identity. For 3 parents, it was the support of their families that facilitated the contact. As mentioned earlier, one of those parents still remained in the family home, with their parents and their child. One of the other parents spoke about being able to visit their child every night. The third parent spoke about seeing their children regularly, being actively involved in their lives, and still being able to do every day things with them, such as take them to school or nursery.

The experience of the fourth parent was different in that whilst it was unclear how much contact they were able to maintain with their child whilst their spouse had custody, it was clear that it was the support from services that enabled contact with their child to be maintained after the child was removed into residential care. This parent came up against a few different challenges that included feeling that the father had more contact with their child, which in their view was unjust:

*"He [Dad] got more access than I did...They were all for *Dad* that's why. That's what I don't understand. He hits the wain and yet they are all for *Dad*." (Parent 2)*

3.5 Theme 5: Parent experiences of support from services

All parents were asked what support they had received from services over the years while their children were growing up. Whilst a couple of parents from the original parenting project intimated that they did not feel they had received any further parenting support from services since the parenting project ended, all 5 families provided examples of positive experiences of supports from services, including support from Advocacy, Education, Health,

Police and Social Services. One parent reported having received support from advocacy, in relation to family review meetings:

"Aye I did [have advocacy]...I had yin from (local advocacy service)...They would go to meeting with me. Speak up for me and that and explain things...They were awright. Nice staff. They helped me with a lot...Brilliant [at explaining things]... They were brilliant with me." (Parent 2)

Education was another source of positive support that parents mentioned. The range of supports described included support for a child in relation to dyslexia and anger management in school; access to a summer school placement for another; and advice in relation to benefits a family was entitled to.

The NHS was another source of support for parents, some of which exemplified 'traditional' NHS activity e.g. successfully prescribing medication for the management of a child's behaviour, or support to understand the impact of a child's diet on their behaviour. However, other examples demonstrated NHS services taking a broad perspective on what was an appropriate role for them. One parent received support from the Community Learning Disability Team regarding a rota of appropriate contact with their child. Another family spoke about the support they received in relation to their application for their child's disability payments:

*"It was *Paediatrician* that telt us to go and get *Child*'s disability cos he was entitled to it because of his health problems. And we done that. Well, we went for the forms and they said that they would fill it oot and they got *Nurse* from *Child Development Centre* to help, she's been with us for years" (Parent 3)*

Flexibility was also exemplified, and valued, in the support of the local GP practice for one parent. The practice recognised the needs of their child, and the issues created by their having to wait within the waiting area, and worked to remove or minimise this when the child attended the practice. A GP acting as an advocate for a family was also described: one parent spoke about how their GP intervened and put in a complaint against a social worker who was causing the family distress. The same family also described Police intervening on their behalf following threats by a Social Worker to remove their children as result of accusations of an incident. Investigation by the Police subsequently found that the incident had not actually occurred.

Social services were also a source of positive support for one family in particular who advised that the only person that they felt had helped them as a parent was their Child &

Family Social Worker:. The same parent spoke positively about how social work and health both worked well together in providing them with support with their child's behaviour:

"They come out and listen tae me when I had problems and that. They helped me great, so they did, so they did, they helped to calm her doon and that. They just used to come out, folk used to come out and play games and everything for her tae play games and that. Show me what to dae with her to get her to calm down and that." (Parent 2)

3.5.1 Positive experiences of services for parents as individuals in their own right

Parents also spoke of the positive experiences they had of services providing support to them as individuals in their own right. Frequently, this support was in relation to the health of a parent. One parent spoke about getting help with medication use from their local Community Learning Disability Team and how that helped to take the stress off them taking medication. Another spoke about the medication and emotional reassurance they received from their GP in relation to post natal depression. There was also an example shared where a member of the local Community Learning Disability Team helped a parent choose a suitable house, and others of NHS staff supporting access to recreational activities.

The experiences of one parent demonstrated how the separate contribution of agencies combined to bring them new opportunities and greater independence. For this parent, Social Work was of particular help in securing them a voluntary work experience placement (which also provided them with a top-up to their benefits):

"I asked my first social worker if she could get me a job just to help my mother out. And she marked it down and before I knew where I was, I was going to (Work placement)...Kitchen, artroom, publishing [lists what they do at placement]." (Parent 4)

The same parent described how input from Occupational Therapy helped them with independent travel, as a result of which they were now independently travelling to their voluntary work placement:

*"*OT*...was the one who helped me get on and off buses, but I was doing that well that *OT* thought 'I think we'll make this our last appointment because you are doing that well'...Just like, making sure that I go in the right, there's a bus ticket, just to make sure I'm getting off at the right stop and aw that...At first I was nervous...but now I'm great."* (Parent 4)

3.5.2 Negative experiences of services

As well as sharing their positive experiences of supports from services, parents also shared their negative experiences, mainly in relation to education and social services. In terms of education, one family spoke of their child not being diagnosed as having dyslexia until they reached secondary school. As a result of the delay, their child had struggled at primary school. The same family described their child's primary school as not being equipped to provide appropriate behavioural support to them, which resulted in their having to move schools. A key issue for the family in relation to primary school was its lack of support for the successful dietary routines they managed to establish to improve their child's behaviour:

*"At *Primary School*, I was always getting *Child* into routines. And the minute he stepped into that school, bin!, 'you're not allowed that in here'... But the energy drinks was doing what Ritalin was doing... He was going into the school like a normal person in the morning...And he was sleeping at night!" (Parent 7)*

A similar experience was shared in relation to secondary school where the school were only providing half-days for their child because of their behaviour. This led to concerns about their child not only missing out on an education, but also putting extra pressure on them coping at home.

The NHS was another area where parents had negative experiences. One parent spoke consistently of struggling with their child's behaviour issues, and that it was not until their child was in their twenties that they were diagnosed with ADHD:

"I kent this years ago that my wain hud it [ADHD]. I goes, I told you fae years ago what's wrang with my wain.. It took from then [aged 2] until she was 21 to tell us she had ADHD. I goes, I could have telt you that years ago what was wrong with my wain." (Parent 2)

Social work was perceived by some parents as having acted inappropriately, on the basis of partial information. One family spoke about seeking help from services, but as soon as they did they felt social work jumped to conclusions and things spiralled out of control. This was linked to the scenario described above in relation to the loss of custody of children, as a result of social work perceptions of a home which the family had just moved into, and were still preparing:

"I don't like the social services...Well, the reason I, the first time I got in contact, ken I did it through my health visitor, cos I wanted a little help with, ken with the children and that...I asked the health visitor for help... it all went downhill after that. ." (Parent 1)

Another parent described social services appearing at their house with the police in relation to accusations of abuse, issuing threats to remove the children, before any sort of investigation had been conducted. As mentioned earlier, the police intervened and their investigation found the abuse accusation to be unfounded. Services failing to deliver on promised support was also described: one parent spoke of professionals not following through on promises of support to visit their child in hospital.

3.6 Theme 6: Parents' experiences of working with service professionals

The quality of the relationships which parents established with professionals were obviously of critical importance in allowing for positive change within families. Examples of the features of supportive relationships included professionals being respectful of the parental role, such as seeking permission from the parent before lifting their child; having a good temperament; and communicating effectively. Effective communication covered a wide range of aspects, and included listening to parents. Professionals being willing to help, as well as listen, was also greatly valued, as evidenced in the comments of a parent regarding their relationship with their GP:

"So the doctor got me in every so often and I spoke to him. He was the only person that just sat and listened. Naebody else round about me did nae. That's what I felt....And if it was nae for him, I says, I would nae have been here the day." (Parent 3)

For another parent, it was their Children and Families Social Worker that they felt was supportive and approachable:

*"The only person I got on with was *C & F Social Worker*. *C & F Social Worker* was nice. *C & F Social Worker* was a lovely woman...Ken, she understood what we were going through. Ken, she used to come up and see us at the house and any problems I could go up and see her at *Town*." (Parent 2)*

Just having the knowledge that there was someone they could turn to if they needed help was a valued aspect of support. For another parent, the family having knowledge of staff working with their child (and vice versa) was helpful. Finally, effective multi-agency working, and including parents, was valued by one family:

"Well it was a learning support group [the meetings held about child]. The teachers that worked with him, social works department, health visitors, eh, and us. There was usually about 8 or 9 of them sitting in at the meetings and they were held every 3-months or

something like that just to see how he was progressing and aw that kind of thing....They always said that they would wait till they were at the meeting and we were there before they discussed anything about what tae dae....There was always great outcomes after they meetings.....they bent over backwards just to help us the best they could...I was coming home with a smile on my face and saying, 'something's getting done noo'." (Parent 3)

3.6.1 Barriers to supportive relationships

As well as describing features of supportive relationships, parents also spoke about aspects of support they received from professionals that could be potential barriers to establishing a supportive relationship. One parent spoke of their dislike of particular professionals, which was borne out of the parent's prior experience of them being unsupportive of the routines they had set up for their child to assist with their behaviour. Another family spoke about disliking the attitude of a social worker who they felt was authoritarian in their approach. Parents' past experiences with professionals could also influence their openness to others from the same service. One family spoke about their experience with one social worker causing distrust in another.

Professionals not providing explanations about the support they were there to provide left one parent unclear as to reasons for their involvement. Another highlighted staff turnover and inconsistency of support as being a barrier to building a relationship:

"I don't remember all the social workers, there were quite a few.. .Very uncomfortable because you get to ken someone then they change it to someone else and you feel uncomfortable again. So no, I didn't like it very much." (Parent 1)

The same parent spoke about there being a number of services involved at the same time and there being too many of them to remember. Related to this, another parent spoke of the adverse effect of having so many different professionals coming and going from the house.

Professionals being involved in child protection reviews also negatively affected relationships that had previously been deemed to be supportive. One parent spoke about how this impacted their relationship with their GP:

"He [GP] was great. Eh, I didn't like him at some points...Eh, maybe because he's been involved with the social workers and that. I didn't like him at the point, I wasn't going through a very good time at that time." (Parent 1)

A number of parents spoke about the unequal power-balance in their relationship with social work which made them feel intimidated and powerless:

"She lifted the wain oot the walker wae his arms. Up in the air. And I was nae happy about that but I could nae say nothing in case I got the blame of it...I was so terrified fae that eh woman." (Parent 3)

The need to respect the wishes of the parent was evident in feedback from another interviewee, who described how other family members being around was a barrier to open communication with the health professional supporting them:

*"Well she says, well my mother will say-, she thinks *CLDN SW*'s a good laugh you see...I don't. *CLDN SW* is supposed to be in to see me. No her...Because it's me *CLDN SW* is seeing. Because *CLDN*'s sent her to see how I am or whatever...Well so I can get chatting to her [why parent would prefer to see CLDN SW on her own]."* (Parent 4)

While the behaviour of some staff obviously presented barriers to the establishment of a supportive relationship, there was some acknowledgement of the need to get the right fit, between staff and parent. Parents also had to be receptive to receiving support. One parent spoke about how their spouse being in a calm mood resulted in them being more open to receiving support from their new social worker.

3.7 Theme 7: Parent experiences of information provision

Accessing information was challenging for parents, and 3 spoke about not receiving enough information. For one parent the lack of information was in relation to their own health condition. For another, information about how to cope with their child's behaviour was lacking. Difficulty in finding information on appropriate courses for their child was also described by one parent.

During the course of the interview, parents were asked to provide an example of written information they had received that was easy to understand, and an example of one that was difficult. One good example was the head lice information that was provided from a school, due to the use of pictures within it. Another good example was 'My Personal Child Health Record', issued by health visitors to parents after the birth of their child. This again was due to the pictorial element of the information. There was, however, a suggestion that some of the other information provided by health visitors (and midwives) could be considered bad examples. Information provided regarding meetings of various types was also noted as

being difficult. For one parent, this related to Children's Panel meetings, and for another, it related to school meetings.

Some parents spoke about the sources of support they had to understand inaccessible information. Three parents spoke about the support they received from family members. One parent received support from their own parents to understand reports from the Children's Panel. Similarly, another parent spoke about helping their spouse to understand information from school review meetings. One parent spoke about their dyslexia and getting support to understand a letter, which resulted in the whole family trying to work out the wording. It is a telling reflection of the kind of information routinely provided to families, that even with this collective effort, it remained problematic.

As well as family members, professionals were also described as providing support in relation to understanding written information. One parent spoke about the support she received from a member of her local Community Learning Disability Service to understand health appointment letters and to remind them of appointment times.

3.8 Theme 8: Outcomes for children

Parents spoke about their children's school experiences, and what they had been doing since leaving (for those who had left). Some described their children receiving additional support in relation to education. For one parent, this involved their child attending a school that had particular skills in supporting children with behavioural difficulties. Another parent had some recollection of their child receiving a home visiting teacher. A third parent spoke about the secondary school supporting their child with their dyslexia, which was not sustained due to funding issues:

"Em, some of the classes that he was in he had somebody reading oot things tae him. But he did nae have that support right through the whole school. He only got it for so long. Eh, because the funding for that was nae there to do it right through." (Parent 3)

Other positive aspects of the school experience for some children included the establishment of long lasting friendships, and it being a place where their children 'thrived' (Parent 1). School was also a source of opportunities for children from 2 families. For one, this included their child going horse riding through their school. For the other, one of their children became a qualified boat crew member via a school opportunity, and subsequently volunteered with the project that provided the opportunity for them.

The outcomes for children since leaving school varied. Some parents spoke about their children's experiences of college, which were frequently less productive than could be hoped for, often as a result of factors unrelated to the family. One parent mentioned that their child had gone to college but did not last long, and was unsure of the reasons for it. A couple of parents also noted that courses did not work out for their children due to various reasons outwith the families' control. One parent spoke about the courses being discontinued so there was no opportunity for onward progression, while cessation of funding curtailed the college placement of a child from another family (for reasons which the parent did not know):

*"Well she [daughter] was working in *College* but they stopped paying her [to attend college as a student]. So she had to come out of it...Oh different things like, transport or something [what daughter was doing in college]...I don't know [why college stopped paying daughter to attend], maybe she had used up all the money [suggesting an explanation of why college stopped daughter's money]." (Parent 4)*

Another parent spoke about their child attending college but then being asked to leave due to their attendance. The parent attributed this in part to the college's running of the course, i.e. the turnover of teaching staff and the content of the course not keeping their child interested. Overall, for the 8 children no longer in education, outcomes were as follows:

- One became a full-time carer for their parent after struggling to find a job.
- One was being supported to travel independently, cook and learn everyday skills.
- One had become a parent, and was self-employed
- One was in receipt of benefits
- One had a series of different jobs, and had only recently become unemployed again.
- One was being supported to live in their own accommodation and also had experience of undertaking a work experience opportunity.
- One was waiting to hear about whether a referral to an organisation that provides contextualised learning and work experience opportunities was successful.
- One was undertaking voluntary work.

In the same way as a willingness to participate in college appeared to have been undercut by 'system issues' for some of the children, so too one child's willingness to work appeared to have been unrealised as a result of an employer's perceived risk averseness:

*"So, where do you stand. You go somebody, *Child* was interested and dain a job, they'll no take him on because their's fear he's a health and safety risk." (Parent 3)*

3.9 Theme 9: Changes as children mature

Some issues continued for families along with a child's maturation, for example, the management of difficult behaviour. However, significant change had also occurred. One set of parents, who had become grandparents, spoke about looking after their grandchildren. This was not only to give their child a break, but also with a view to try and help them avoid what they had experienced:

*"Well, I ken what I was like when I went through the postnatal depression and everything else. I would nae like to see *Oldest Daughter* go through it. That's why I take the wains [grandchildren] and that for her. "* (Parent 3)

Relationships between parents and their children changed in other ways. A couple of parents spoke about friendships becoming important for their children. One parent commented on the maintenance of school friendships in relation to this, while another described having to adapt around their children's new priorities in this respect:

"Oh no, mummy cramps their style when they're older! They're not wanting anything to do with mummy, their friends are more important than mummy right now!" (Parent 1)

Increasing independence and responsibility were, unsurprisingly, also features of the changing relationships between parents and children. One parent described visiting their child in their own home. Children taking greater responsibility for their own health was described by one parent, while another described their child taking on greater responsibility for the parent's health, including putting them to bed after the parent had had an epileptic fit. Children were also described as now taking an active role in the maintenance of the household, including cooking meals for family members.

4 Results: Professional Interviews

Eleven professionals participated in an interview, consisting of the following professions:

- A Support Assistant for Community Learning Disability Mental Health Team
- Two GP's
- A Social Work Assistant for Adults with Learning Disability Team
- A Community Learning Disability Nurse
- A Community Support Worker for Community Learning Disability Team
- A Support Assistant for Community Learning Disability Team
- A Respite Carer
- A Paediatric Nurse
- A Children and Families Social Worker
- A Deputy Head Teacher.

The main role of 6 of those professionals was to support the parents (primarily as individuals), 4 professionals were in place to support the immediate family members and 1 was supporting the whole family. Themes identified from the interviews are described below.

4.1 Theme 1: Perceptions of natural networks

The natural networks of parents were seen by professionals as evidencing positives and negatives, including the need to deal with issues such as bereavement, break-ups, and even abuse. The membership of natural networks reflected that outlined in the Parent interviews (primarily grandparents, but also step-dads, and ex-partners). Significant involvement from grandparents in one family (who were acting as kinship carers) was described by one professional, whose comments underline the potential importance of a distributed approach for realising the parenting role across a network:

*"*Parent* obviously had her daughter and *Parent*'s mum [Grandparent] was a massive support to her and her stepdad's been a massive support and I think together they've just, you know, gelled." (Family 4, P2)*

Similarly to the parents, professionals described networks as providing emotional and practical support, e.g. with transport to exercise classes for a parent, or undertaking child-minding. However, for some professionals, the extent of involvement of networks heavily influenced how they perceived the parent's actual role in parenting their own child(ren).

One saw a parent's relationship with their child as more of a friendship. Another professional saw the parent they were supporting as a parent in name only, with the bulk of support coming from elsewhere. Another professional spoke about it appearing on the surface that the parent was hands-on, but in reality that was not necessarily the case:

"I do feel for the guys that, you know, you see them with their kids and you think, that's brilliant because it's the same as you. You know, that big bit of work that we done, but then you think, but it's not, because you're looking behind the scenes and they're only puppets because they're only getting a wee shot at it [parenting] and they don't deal with the whole thing, do you know what I mean. And it's a shame because they are missing out in so much. It really is." (Family 4, P1)

The extended network being able to step in and provide assistance was described by one professional, who spoke of a parent's mental health initially impacting on their ability to parent, leading to the grandparents taking over care of the child. While the grandparents lack of understanding of the parent's mental health issue initially led to them being somewhat excluded from this transition process, it was observed that over time their active involvement in the parenting of their child had improved.

4.2 Theme 2: Perceptions of family needs and strengths

The needs of families identified by the professionals tended to fall under two categories or, more specifically, two identities: the needs associated with their parenting role and the needs of the parent as an individual.

4.2.1 Needs associated with parenting

The parenting need for one family was to be supported in order to maintain contact with their child who was under local authority care. This entailed supporting the family to work through the requirements for maintaining contact, which involved repetition of information, explaining the reasons for the differences in the level of contact for each parent, and the requirements needing to be met to increase contact with their child. For other parents, support in relation to nutrition, cooking and housekeeping was described.

For 2 families, managing and coping with their child's behaviour was their most significant need. Professionals for these 2 families described instances of when the child's behaviour was posing a risk to the child themselves and others, and the impact of that on the parents' wellbeing. Another professional involved with one of these families, who was familiar with

their child's behavioural difficulties, questioned whether services can actually meet all the needs of a family:

"I think em, as a parent of any child with special needs, whatever they might be, at the end of the day the parent still has the 24/7 responsibility for the child and regardless of how much support goes in, you know, in terms of medical support and educational support and social work support and all these things, regardless of that you've still got a child living at home, not sleeping well, chaotic behaviour and so, I, I have no doubt that all of their needs could never have been met from that point of view." (Family 3, P3)

As well as identifying existing needs, 2 professionals for one parent spoke about having identified potential future needs of the parent, primarily due to the health of the Grandparent (who was a kinship carer) deteriorating, and spoke about the difficulty of being able to plan now for when the grandparent was no longer around. This included getting around the issue of the grandparent's reluctance to allow the parent to be more active within the home, and supporting the parent to learn the life skills they would require.

4.2.2 Parents' needs as individuals

In terms of the needs of parents as individuals, one professional spoke about undertaking an advocacy role to educate and guide the parent they were supporting. For another parent, their significant need was gaining access to services and opportunities. This created a need for professionals to work with wider family members in order to facilitate the parent's access to services, and work around the over-protective input of the wider family.

Most parents were also identified by professionals as having needs in relation to particular vulnerabilities. For a couple of parents, they were vulnerable due to their ongoing health conditions including epilepsy or mental health, or a combination of both. For another parent, they were deemed vulnerable by a professional due to them being perceived to have been taken advantage of within the broader community. Support in relation to assertiveness and confidence was identified as needed for one parent.

4.2.3 The strengths of the family

As well as discussing the needs of the families, the professionals interviewed also identified them as having a number of strengths. The part that families themselves play in the creation of successful partnerships with services was highlighted by one professional who described the strength of a parent as being the courage to seek support when they needed

it, and in others describing the willingness of a family to engage with offered supports. One professional spoke about how the latter family's compliance with everything they suggested was excellent, while another spoke of how willing the family were to meet with them whenever there was an issue with their children.

Personal qualities of parents were highlighted by some professionals. For one parent, these were qualities which they had developed through being offered support and new opportunities, as a result of which the parent was seen as having significantly transformed their own confidence and wellbeing. For another, their understanding and ownership of their health needs, and their assertiveness in relation to these, was noted.

The only family whose parents remained together, and who retained care of their children, were praised for this, especially in the context of the behavioural difficulties they had faced with a child. For two families whose children were residing elsewhere, managing to maintain contact with their children was identified as a major strength:

*"They wanted to get involved. They were always there and they were loving towards *Daughter*, *Daughter* just need to-, she'd 'Can I phone my mum?', and certainly, mum would be on the phone and chatting away, about *Mum's Husband*, her husband and the birds and-, and Dad, you could just see that the relationship was there."* (Family 2, P2)

Notably, professionals also spoke about there being strength in parents' love for their children:

*"She clearly had a strength of character and a love for *Youngest Son* that allowed her, you know, I've seen other parents break when dealing with behavioural issues not as bad as *Child*'s. But *Parent* never, you know, there was never anything other than, you know, 'I just want *Child* to be okay', you know, 'I love *Child*', she would do anything for him. And she did. And I think that's probably the greatest strength actually,"* (Family 3, P3)

The children within the families were also identified as demonstrating strength, in their resilience and ability to adapt.

4.3 Theme 3: Experience of providing support

A key role that some professionals identified for themselves was conveying information, including keeping the parents updated on the support they were providing to their child, and explaining the nature of and reasons for interventions that were being undertaken.

Similarly, another professional spoke about being the intermediary between the family and the consultant supporting their child, and being a contact for the parent when required.

Another professional responsible for supporting the child of one family who was in residential care, provided an example of how they included the parent by keeping them informed of any appointments their child was due to attend, such as health appointments and school reviews, and providing the option for the parent to attend as well. Similarly, for the same family, another professional spoke about how they kept the parents involved when their child was moving from residential care to living more independently in their own home, and inviting them to transition meetings:

"I've been at plenty of transition meetings as well. Mum and Dad were invited to go to the transitions meetings...Mum and Dad got to see the house and I think they bought things for it as well." (Family 2, P3)

As mentioned earlier, one of the parents' strengths identified by professionals was them being able to maintain a relationship with their children. Examples provided by professionals of the role they had in supporting one particular family are demonstrative of the key role that services can play in the maintenance of family relationships, especially when the child is no longer residing with their parent(s). This included providing supervision for contact visits with accommodated children; explaining the boundaries in relation to contact; and working with parents around requests for increased contact.

4.3.1 Support provided to parents as individuals

Parents were asked to identify professionals who had supported them within the last 10 years and as the children of some parents were in their twenties, some of the professionals chosen were selected for the support they provided to the parents as individuals. For one parent in particular, the support provided allowed them access to opportunities, which included learning to travel independently, undertaking voluntary work and accessing leisure activities. The professionals spoke about the work they were involved in with wider family members to help facilitate opportunities for this parent:

"That was another thing mum [Grandparent] didn't want her [Parent] doing was going on a bus, and we're like, 'well why not? How else is she going to get places?', 'That's how she ended up pregnant', and we were kind of like, 'right, okay, but you know, a bit more education now, you know, she's not got the daft head on, she's no a young girl anymore, she's an adult'. 'Can

*we try it', and it did, it took us a wee while, but now, I think *Mum* travels independently from the house to *Café* where she does her work and back again."* (Family 4, P1)

Financial matters were something that a number of parents required support regarding. One professional spoke about organising an advocate for a parent who was separating from their partner and needed help with settling financial matters. Another described helping the same parent to understand their financial situation and its implications. For another parent the financial support was about helping them complete the form to continue receiving their benefits.

Professionals also appeared to have a key role in nurturing the wellbeing of some of the parents. Some were providing support in relation to issues such as nutrition and diet, monitoring medication to ensure it was taken appropriately, supporting access to exercise groups, and supporting parents to health appointments. One health professional spoke about supporting a parent with their housing needs, including the use of technology (such as bed sensors, for seizure monitoring), the outcome being that the parent was now living in their own home.

4.3.2 Support relating to immediate family member

A number of those professionals interviewed were selected by parents to participate because of the support they were providing to their child(ren). Professionals for 3 families spoke about supporting the child(ren) to access opportunities, whether that was organising access to local resources, finding solutions that work for the individual when a service was no longer providing activities that were of interest to them, and helping them with job applications.

A couple of professionals who were supporting one particular parent with their individual needs spoke about flexibility in their practice, by looking at the needs of the immediate family member too, as it was recognised that the family itself was perhaps not supporting the child sufficiently in relation to social opportunities. One professional spoke about signposting services to the child's situation, and it opening up opportunities to help build their confidence and social skills:

*"We had highlighted that to social services to say we felt *Daughter* needed input to signpost her, because the family would be quite happy just to let that happen and she would just end up in the house and ken, no really do much....[]... But, I think *Parent*'s social worker at the time, put *Daughter* in touch with the Prince's Trust and all that, ken, because it was*

recognised she did have limited opportunities and limited skills and she had quite a wee cosseted life.” (Family 4, P3)

Other areas of support for immediate family members were behavioural support; management of a care package (including seeking to reduce it in order to maximise independence); and supporting an individual in relation to social skills and other activities of daily living.

4.3.3 Support relating to whole families

When some professionals described the support they were providing, it was relating to the whole family. This was particularly the case for a family GP, who spoke about their long-term involvement with a parent and child, spanning 10 years. The 3 professionals involved with another family indicated that whilst they were in place to support the parent with their individual needs, their input involved significant work with the whole family in order to facilitate access to opportunities for the parent, for example:

“It’s very hard when you do this job to just support the person you’re there to support because you’ve got the parents, you’ve got the sibling and you’ve got different hats for each person that you’re dealing with and you can’t just work with that person, without touching on a wee bit of everybody.” (Family 4, P1)

4.3.4 Experience of multi-agency / partnership working

All professionals discussed elements of their support provision that involved working in partnership with families, and other services/agencies. There were a number of ways in which professionals worked in partnership with families. One professional reported liaising with family members who were living in another country to provide updates on the health of the parent at their request. Three professionals who were supporting 2 different parents spoke about their partnership working with family members in monitoring the parents’ ongoing health conditions. This included asking for their assistance in monitoring and supporting a parent’s medication use; and advising family members of signs of a parent’s health deteriorating, to allow them to be proactive in getting support .

Partnership working between agencies was also discussed at some length by interviewees. Some of the benefits attributed to this, where it was successful, included:

- The provision of a unified response to identifying the needs of families;

- A good access point for referral;
- Facilitation of a timely response;
- Information sharing with the child at the centre,
- Provision of training to other professions,
- Intensive support,
- Multiple-perspectives and expertise contributing to the overall picture of the family
- The provision of co-ordinated support:

*"And so, em, for instance, you know, going back to the likes of the *Family*, when you liaise with the school, when you liaise with the OT at *Child Development Centre*, you know, everybody is bringing their own, within their professional experience, their own piece of information and their impression of what's going on. And if you understand all these different aspects, it makes your overall management much more effective." (Family 3, P3)*

Professionals also highlighted some challenges with multi-agency working, including:

- Having large workloads that could impact on the capacity to engage with other agencies;
- Family members not engaging with or being open to support;
- Communication between services being challenging at times;
- Short-notice of meetings making attendance difficult to organise;
- Not getting a timely response from services.

4.3.5 Training undertaken by professionals

While interviewees were able to identify a range of training with some connection to supporting parents with a learning disability, all 11 professionals advised that they had not received specific training for working with parents with learning disabilities . One professional indicated that it was just common sense and that they would access the services that are available. Another professional spoke about conducting their own learning around the needs of parents with a learning disability through independent reading:

"I've read stuff off my own back, ken, just to, you know ,develop my understanding about it but no actual, like, formal training.... But certainly it [parenting] wasn't something we covered in our training [during BSc]." (Family 4, P3)

Outside of those interviewees who were trained learning disability practitioners, some others indicated that they had received training in relation to people with a learning

disability. A couple of professionals indicated that they had received training in relation to different communication aids to help make information accessible. Professionals also identified other relevant training they had received, including bereavement training, training relating to children with learning disabilities and health and wellbeing related training.

4.3.6 Insights about parents with learning disabilities and effective relationships

During the course of the interviews, professionals identified a range of factors that they incorporated into their practice when working with parents including:

- Being aware of the needs of parents and being mindful that some parents need extra support with understanding, including adapted information and appointment reminders. Non-compliance may actually be down to lack of understanding, rather than deliberate non-compliance.
- Parents should have access to appropriate ongoing support, with continuity.
- Social inclusion and a good support network within the parent's own community is important.
- Spending one-to-one time at appointments that are within a family home.
- Including and listening to the parent, and respecting their perspective:

*"Listening to what they had to say to you was the most productive, I felt, because that was really vital. Because I think they'd previously experienced not getting listened to...Just some things that *Mum* had said like, 'it doesn't matter what I say because nobody listens anyway'..[]....And so I think it was very much about listening to what she has to say and involving her in it." (Family 2, P3)*

Providing support on the basis of needs, as opposed to a diagnosis, was highlighted. As one interviewee outlined, pushing for a diagnosis of learning disability where one is not in place can potentially upset a relationship:

"I do think that the bit is that they maybe have got an unknown diagnosis and that is a struggle then. I have a mum the now and I had asked her, 'can I get a cognitive test done?' and I thought, I'm just going to ask outright here. She went mental at me, and I said, 'no, I'm not saying anything', and I thought how do I get back out of this. How do I get back out of this now. But what I use with her, I just use sheets and I just laminate them, just of the things I want her to do. But I do believe that she's got a learning disability." (Family 2, P3)

Other factors that helped professionals establish and maintain positive relationships were being available as a point of contact, setting boundaries, being non-judgemental and providing holistic and flexible support. Consistency of involvement was key, as it helped professionals to cultivate a supportive relationship, monitor the individual's health and wellbeing, and recognise when something was not right.

Comments from one interviewee highlighted the need for reciprocity within relationships, and introduced the importance of getting feedback from parents as to what was working, particularly as this was usually not received:

"As I say it was em, it's interesting to hear that kind of feedback that they thought it was, we were being well supportive. It was good. You know, I like to hear that as a school because we do try and do that. We all do. It's nice to hear something positive like this...And sometimes it does feel like fire-fighting...[]...But it's nice to hear that some parents appreciate it." (F3, P1)

There was some evidence of professionals making assumptions about parents with a learning disability, including that having a diagnosis of learning disability can unlock access to supports for those who need them. Although supporting different families, the two participating GPs shared similar insights about how a learning disability or physical disability can make parenting more difficult. While recognising the challenges that go along with being a parent with a disability, the interviewee below also makes assumptions regarding the likelihood of a child of a parent with a learning disability being more likely to also have a learning disability:

"It's a challenge for anybody with a significant learning difficulty. Or any significant even major physical disability being a parent. If you're challenged because of learning disability, then that may make the challenges of parenting more difficult. If you have a learning disability yourself, I presume your child's more likely to have a learning disability which is another issue." (Family 5, P2)

4.3.7 Specialist support for parents with learning disabilities

Knowledge of available specialist support for parents with a learning disability was variable. One professional was unable to identify any specialist services; among those identified by the other professionals were:

- The local Community Learning Disability Team.

- Pre-5 supportive nursery placements (for children that need earlier integration into education).
- Psychology for conducting parenting assessments.
- Mainstream parenting services / support-work and parenting skills (albeit no specific resources identified).
- Aberlour Child Care Trust for parenting support:
- District Nursing and Midwives are *"all kind of are good at liaising with each other and working together."* (Family 5, P1)

One professional advised that sometimes parenting groups would not be accessible to families unless the child has an allocated social worker due to child protection issues, and that resources for parents were limited. Another professional spoke about looking to the NHS and then education services for support, and thereafter to third sector services, to fill any gaps identified.

4.4 Theme 4: Challenges to providing support

There were a number of challenges that the 11 professionals described, relating to parents, immediate family members, services themselves, and the wider family. Parent-related challenges that professionals identified included not immediately knowing a parent's understanding or communication needs when they were working with a parent for the first time. Other parent related challenges were working with parents who were separated to keep them both included in their children's lives; and keeping in contact with a parent when their mobile telephone number constantly changed. One professional described dealing with a parent not being at home at the time when contact with their child was arranged, and the fallout from review meetings when the parent was disappointed and stressed that decisions did not go their way due to them being unable to make the changes that were expected of them.

Three professionals supporting different families spoke about family distrust of social services, and their being seen as enemies instead of allies, for example:

"They don't want social workers, but you're trying to say to them, 'if you don't get a social worker, you don't get the services that you're needing'. Because I think some folk think social work come in, see what's happening and go, 'oh no, that's no right, we're taking your daughter away from you' or 'we can't have you all living here together'. You know, it's really hard, because there's so much bad press with social work." (Family 4, P1)

Another interviewee described challenges stemming from a parent's apparent lack of motivation to help themselves, this being linked to their experience of post-natal depression and the long-term behavioural difficulties of their youngest child:

*"There was quite heavy social work involvement over the years, em, and I think they found it was an intrusion in their house although it was helpful initially for the likes of *Child* to get help. Because mum wasn't motivated enough to have a regular routine, I would say, for *Child* but *Child* would nae comply so there was difficulties in the morning getting him up to go to school and such like. So somebody was put in then to help him get up, washed and dressed to go to school."* (Family 3, P2)

In relation to support being provided to immediate family members (children), professionals indicated that the challenges they had experienced were the mood of the individual impacting on interactions; supporting the immediate family member to deal with major lifechanging events (i.e., moving from local authority care to their own home); and dealing with challenging behaviour:

*"*Daughter* was quite hard to gauge because she was so, she was really chaotic when she moved out of *Respite Care*. Em, and it was a huge move for her coming from this to her own tenancy. A massive move. But it's took, maybe, 3 to 4 year to settle doon, but, she's, she's made a massive progress."* (Family 2, P1)

A challenge of note for services and staff was lack of awareness of a family's needs until crisis hits. The response of services could be constrained by this, and by assessment processes which did not accommodate working in crisis situations. Professionals also described instances of poor joint-working, which impacted on the parent they were supporting:

"Her [Parent's] benefits hadn't been changed to her new address. That was a job social work were supposed to do. And didn't...Slipped through the net..." (Family 5, P1)

4.4.1 Wider family related challenges in providing support

All the wider family related challenges in providing support related to the situation of the family previously described, where 3 generations lived in the same home (grandparent, parent and child). As noted previously, the professionals working with this family reported difficulty in getting the Grandparent and their partner on board with the support to the parent, including access access to opportunities outwith the family home. A range of

factors were identified as shaping this, including the Grandparents fear of social work, and of their Daughter and Grandchild being taken away. Other aspects included them being used to providing the support on their own; their over-protection of the parent, shaped by restricted views of their abilities: and the financial implications of support provision. In one example, the need for a financial contribution from the family towards respite for the parent proved a disincentive for the Grandparents.

4.5 Theme 5: Supports provided by other services

While the interviewees themselves represented a broad spectrum of service input to the 5 families, they in no way depicted the full extent of the variety of inputs that were in place. The professionals interviewed described supports from a range of other services for the families they worked with. This included support provided for the parents themselves, and immediate family members.

4.5.1 Supports provided by other services for parents in relation to parenting

Involvement from Social Services was described in relation to all of the families for whom professionals were interviewed. Their involvement had obviously been significant and long term for most of the families, for all that it was described as intermittent for one family (*'...they've kind of dotted in and out of their lives'* (Family 3, P2)), or being from *'afar'* (Family 5, p1) for another (reflecting the stability of the parent's life currently). For these 2 families, concerns of one sort or another were mentioned as informing the involvement of Social Services, be it in relation to the level of care given to the children for one family, or in relation to transfer of guardianship and the vulnerability of the parent for the other.

Two families were receiving support from psychology about managing child behaviour, but a professional for one of those families indicated that this was not overly successful, possibly (in part) as a result of limits on the parent's capacity to comply with that input at home (in terms of implementing behavioural strategies). Another professional spoke of the parent they were supporting attending parenting classes, and although unsure of who ran those, the professional indicated that they thought it might have been the local authority.

Professionals for 3 families spoke of advocacy involvement. One family had been advised of advocacy, but it was reported that it was not something they were interested in. Both parents (albeit separated) from another family had different experiences of advocacy, with one parent receiving advocacy support for review meetings. Another family had had temporary input from advocacy in relation to the resolution of financial issues following

separation. Other professions identified as working with parents include Health Visiting for one family (in close collaboration with Social Work), and Home Helps.

4.5.2 Supports provided by other services for parents as individuals

All 4 of the families for whom professionals were interviewed were described as having multiple involvements with support services. This included health services, social services, and the third sector. In relation to health, professionals spoke of the supports parents had received from professions such as Psychology, CLDNs, GPs, Dieticians, and Occupational Therapy. Some of these were described simply in relation to the work they had carried out (e.g. Dietitian input in relation to weight management; OT input in relation to assessment for and installation of aids and adaptations), however others were described in very positive terms, specifically input from a CLDN, and from a GP. The CLDN was generally recognised by one participant as having had a positive impact for the parent concerned, while one parent's support from GPs was highlighted by another participant in relation to their accessibility, their interest in the wellbeing of the individual, and in their communication with the parent:

Other supports received included input from Support Workers regarding upkeep of the home environment, independent travel, and cooking. A comment from one participant highlighted the multiplicity of one parent's needs, and how the range of support accessible via the Learning Disability Service had helped in meeting these:

*"I think she got, well, with *LDS* and what not, I think she got some education in terms of being able to cook and prepare meals. Also the reading and writing thing. I think there was an element of support from the dietetic point of view as well. And all of this has largely come from *LDS* rather than I think from the social work department."* (Family 5 P2)

In terms of the literacy support needs of the above parent, it was highlighted that they were accessing a mainstream group in relation to this, rather than anything specifically targeted at people with a learning disability. For 2 families, supports were described as providing access to everyday aspects of 'normal' life, this being holidays and work experience for one, and developing social networks for both.

4.5.3 Others supports provided for immediate family members

Support for immediate family members was generally described in relation to 2 of the families: involvement with multiple support services was, again, described. For both

families, Health Visiting was described as having a positive role, in relation to the identification of health problems at an early age. Psychology was also involved with both in relation to the management of behaviour, and awareness of risk. Indeed, both families were described as having involvement with the CLDT, with one family receiving support not only for the immediate family member, but also their staff team. Occupational Therapy, Physiotherapy and a Paediatrician were also involved in providing support to one family, through paediatric services; CAMHS was also mentioned in relation to the same family. The support from paediatric services was positively described as being 'pragmatic':

*"Yeah it was a pragmatic approach that was taken, yeah....[]...I think the priority as time went on was establishing support and enabling *child* develop the best that he could. And helping the family to manage as best as they could." (Family 3, P3)*

As one of the immediate family members was living in their own home with support, the care team in place around them was identified as a key source of support. This was founded on very positive work undertaken to support the individual's transition into their new home. This individual's involvement with a day centre was also described very positively, including their involvement with a wide range of the activities available there.

For the other family, the support of education in relation to 2 of their children was described very positively. For one in particular, the professional interviewed noted,

"The school again, not that I'd had much involvement, but I know that they were very hands-on and very supportive." (Family 3,, P3)

For the other child, a member of staff from the school described providing them with access to a range of taster opportunities for different courses, to encourage them to go to college. Pro-active and supportive engagement appeared to very much characterise the support from the school.

4.6 Theme 6: Changes as children mature

Some issues were described as arising as children matured, and services and parents had to adapt around these. For one individual, services had had a role in relation to helping them to understand the changes they were undergoing, develop sexual awareness, and promote age-appropriate behaviour. Services also adapted around the individual, nurturing their independence through the reduction in intrusive elements of their support package, such as sleepovers, and the introduction of supportive technology. It was, however, also noted that

services can struggle to recognise the emerging independence of a maturing child, particularly where issues of learning disability or mental health are involved.

The individual themselves was also shaping their support environment, through the choices they made about the supports they accessed:

*"So she goes to that and I know she did go to *Youth Project* but she kinda, I think she's outgrown that. She's moved on from being like a young person, she's kinda moved away from the *Youth Project* type of stuff."* (Family 2, P1)

In tandem with this, support was provided to the parents, to assist them in respecting and adapting to their child being an adult in their own right. This included accepting their decisions and making arrangements to visit them in their own home, as opposed to just turning up. At the same time, there was a recognition that the boundary issues addressed were not a specific issue for parents with a learning disability:

"And that's what no just parents with learning disability struggle with, loads of parents and carers struggle with that concept, that this person has a learning disability and special needs but they still have rights as an adult. And a lot of parents don't, find that difficult. Especially kids coming through, transition fae children to adult services." (Family 2, P1)

Whilst there were specific issues in relation to maturation for one family, those experienced by another were described as, *'Nothing beyond normal teenage troubles, you know.'* (Family 3, P1). It is of note that this quote came from an education professional, and that they were able to place the experiences of the family concerned (as regards maturation) on the spectrum of normal variation.

Where the experiences of two of the families perhaps differed from the norm, was in the early adoption of the caring role by immediate family members. For one family, the mother's health concerns in relation to epilepsy necessitated her family member taking on various aspects of the caring role, including providing prompts in relation to personal hygiene. The capacity of the family member was described as surpassing that of the parent: this, and the assumption of caring responsibilities, had resulted in a perceived shift in the parent-child relationship:

"...he indeed became her, I think, he maybe became son and brother in terms of the support that he was offering her." (Family 5, P2)

While the issue of the child's capacity surpassing that of the parent was less clear in relation to the other family, it was apparent that the immediate family member had adopted a protective role in relation to their parent:

*"But, although, I do think the roles are sometimes reversed when *Daughter* takes over and she's the mummy..." (Family 4, P1)*

Shifting roles and emerging challenges were only part of the picture for the families within the project. For one of the professionals, who had the advantage of having been involved with the family over many years, there was a clear sense of progress and achievement on the part of the child and family:

*"It's been a real privilege being involved with *Mum* and *Youngest Son* and it's also been wonderful to see how *Youngest Son* has come through and, from a child who, you know, literally, you know, would be on the desk, would be climbing on the examination couch, he'd be literally in and out of everything. He would be in the sharps bin, he'd be in, you know, to being a young man who you can have a conversation with." (Family 3, P1)*

While the above professional was careful to acknowledge the significant contribution of services to the success of this family, they were also clear that it was the environment and love provided by the mother in particular that was critical to this:

"...if it wasn't for that stability and that acceptance and that love over the years, I've no doubt that anything else that would have been put in to help wouldn't have, you know, ended up with the same outcome." (Family3, P1)

4.7 Theme 7: Experiences of transfer of custody

While 4 of the families in the project had had experience of children being placed under the care of others, experiences of this process were only extensively described in relation to one. This encompassed a discussion of the circumstances giving rise to the process (marital breakdown, behavioural issues, and child protection concerns), how protection measures were implemented (supervised visits, phone contact over loud speaker), and how the input of the parents was successfully maintained.

The complexity and significance of the process was clearly articulated in the account of this professional. While the need to constantly consult with the parents was noted, it was also acknowledged that the process can be *'quite intimidating'* (Family 2, P1). Reconciling the

wishes of a parent with the views of professionals also posed challenges at times, particularly where Social Services staff felt unable to support these due to the parent's failure to meet required criteria. Advocacy did have a supportive role for one of the parents within Children's Hearings.

Despite an apparent focus on recognising the choices of the individual, there was some suggestion of tension between the individual, and the limits put in place around them:

*"I think everything [careplan] has been about *Daughter* as an adult and her choices...they might not have been the right ones and some of the powers in the order, 'well, naw, you need to have this service because it's to protect you'. She might not like it, but it's part of her care plan. Because she's not able to make that, you know, make that decision."* (Family 2, P1)

Review of the circumstances of the individual's guardianship under the local authority, and the need for its maintenance, was a regular process, and was at the time of the interview described as considering the possibility of greater contact with one of the parents. Again, the wishes of the individual themselves appeared to be a significant consideration here.

4.8 Theme 8: Parent outcomes

A wide range of positive outcomes were ascribed to the parents. Some were described as being happier, more confident or more assertive, as a result of actions such as moving into their own home, or volunteering in a café. Financial issues did continue to have an impact on one parent, but progress had been made in relation to this. Of note in this context was the recognition by one NHS worker of the legitimacy of their dealing with financial matters:

"Definitely [financial matters can impact on health]. And that's a way we get round it, in our supervision. Because we're very, you're in a for a health, if she needs support social work need to put support in for her. I just do it." (Family 5, P1)

Some of the NHS and primary care staff interviewed commented on improvements in the health and wellbeing of the parents they supported. This related to such things as positive weight gain, better medication management, and management of epilepsy. For one interviewee, the improvements seen were clearly linked to the input of their service.

Home modifications which had been secured for one parent were seen as having had a positive impact. Greater independence for two of the parents was also a significant

achievement, particularly for one who had previously been significantly constrained by the influence of their own parent.

Opportunities available to 2 of the parents were seen as extremely positive by the relevant interviewees. Social inclusion was a significant part of this success, either in the collaboration with others within a work placement for one parent, or through participation in a mainstream exercise group for the other. For the latter parent, the inclusiveness of the exercise group was clearly described:

*"And *Mum* really enjoys all the different people [at the exercise group], she'll go round and speak to everybody. You know, it's a wee social gathering as well as, you know, having the benefit of exercise. But she'll go round and, 'Hi! How are you doing today? I haven't seen you, were you alright last week?' And it's just lovely to see"* (Family 4, P1)

4.9 Theme 9: Outcomes for immediate family members

Outcomes for immediate family members were identified for 3 of the 5 participating families. Some of these were similar to the outcomes identified for parents: one family member was seen as making more positive choices, and being more assertive in their decision making. For this individual, significant improvement had also been seen in relation to the appropriacy of their behaviour, resulting in part from the significant involvement of services.

Education was described as a positive experience, or as having provided access to positive experiences, in relation to children from 2 families. For one family, the individual was described as doing extremely well at school, and having loved it. For the other, one family member was described as having accessed a development opportunity (helping to sail a tall ship from New York to Scotland), and having benefited greatly from it; another was described as accessing 'taster sessions' of various college courses, to encourage them to move on to one; a third member of this family was described as continuing to demonstrate literacy and numeracy issues, but as having attended school more frequently due to the input of a homehelp, who assisted in getting them ready for school.

Extensive involvement of services was no guarantee of the successful resolution of an identified issue, as evidenced in services failing to effectively control one family member's epilepsy. For others, significant improvements in the wellbeing and overall life quality of the individual were attributed in part to services engaging in active planning with them:

"She's amazing. Absolutely amazing. From people thinking that she couldn't do things, to see her where she is today...Yeah, it was brilliant. It was absolutely brilliant. And I think that that was because there was a good transition." (Family 2, P3)

The success of this individual was also seen in the range of activities they were engaged with in the community.

Life for one individual was shaped to a large extent by their role as a carer for both their mother and grandmother. Despite the considerable responsibilities this entailed, it was felt that they took everything 'in their stride', and still managed to maintain links with friends. The management of this role had been supported in part by services facilitating a successful application for carers allowance for the individual.

4.10 Theme 10: Gaps in support for parents

For all the success that was evident across the participating families, the interviewed professionals were also able to identify a variety of ways in which support for parents could have been improved. Some participants highlighted issues around access, both in terms of physical access to groups, but also in terms of knowing what support to tap into: one of the roles that was identified for the involved services by one interviewee was signposting the family on to other supports. While open days around developments such as SDS were viewed positively, it was questioned whether many parents with a learning disability would go along to such events. Another interviewee identified services as also having to contend with access issues, in as much as they had to 'fight' for supports:

"...she's got her day services and things like that, but we had a fight and I think we have a fight for the majority of the guys that we support.....to try and find services." (Family 4, P1)

For 3 of the families, there was a clear sense that services had missed opportunities to effect positive change at an earlier point. One interviewee commented on a parent having to give up a job they enjoyed, in order to look after their child; the same interviewee also reflected on not being aware of respite ever having been offered to the family. Another interviewee reflected on the possibility that their previous involvement with a parent had been overly focused on the ostensible reason for referral (in relation to mental health), and had missed opportunities to address broader issues within the family, including scope for drawing in support from social services:

*"I suppose in a way, we didn't actually fully consider the needs of *Parent* being a parent, and the needs of *Daughter*, ken, having a mum with these, ken, having a learning disability and having a mental illness. So, the kind of statutory thing, if there had been, or if it had been flagged up at that point, I think things could have been different." (Family 4, P3)*

Social Work and care providers were both identified as having had scope to intervene earlier for some families. The transition between child and adult services was seen as a potential area for development, in that it could draw in the whole family and better prepare them in relation to the changing needs of the child and their growing independence. Good joint working between all agencies was seen as necessary in relation to this: the development of a transition team within one locality was noted as an example of good practice.

One interviewee suggested that part of the issue lay in individuals with milder learning disabilities being overlooked. While services were good at mobilising in relation to the needs of people with more profound learning disabilities, those at the other end of the spectrum could be overlooked as they could appear to be doing 'ok' – until the point when they clearly weren't:

*"...it takes a crisis, for something to happen, so like with *Parent* and then that's when you think, right okay, well we really need to get her out the house then. So then that's when we start approaching the services and saying, well what can we do for this lady?" (Family 4, P1)*

Some of the gaps described related to the efficacy of services: one interviewee reflected on the experience of one parent within a work placement, and the fact that their supervisor could have benefited from some learning disability awareness training, so as to be better placed to support them. A lack of resolution to the investigation of one parent's health complaints was described within another interview. Absent services were also identified as playing a part in an ongoing dispute between separated parents: the folding of an advocacy service which they had been involved with was described as having left the parents 'in limbo' (Family 5, P1).

A comment made within one of the interviews captured a complex array of issues:

"I think there's been a lot of input to that end [addressing the family's needs], but have we really achieved anything at the end of the day...I think part of that would be mum's abilities, you know..I think mum in particular had a wee hard life and I think it's never going to be any different. I'm not sure why because, because it's just the way things are with learning disability I think." (Family 3, P2)

On the one hand, an aspect of this is celebrating the strengths of the parents, and questioning whether services really achieved anything additional to this. At another point, it introduces a sense of inevitability to the outcomes for the family (and possibly the broader population of people with a learning disability), again reinforcing the futility of services. Rather than asserting the irrelevance of service input, in the context of the previous discussion regarding missed opportunities, this can perhaps be taken as illustrating the failure of services to build appropriately on the strengths of an individual.

The role of grandparents as kinship carers in one family gave rise to reflections on their support needs. As it stood, there was no peer or support group which the grandparents could access to assist them in coping with their role, which, combined with a reluctance to become involved with services, had the potential to create preventable vulnerabilities for the family.

4.11 Theme 11: Gaps in support for immediate family members

While there was good evidence of schools and other services effectively supporting immediate family members, there was also some discussion of ways in which they could improve. For one interviewee, the experiences of the child they supported, in relation to going through a number of failed foster placements, highlighted the need for a greater range of options in this respect within the community, particularly as such experiences were not unique to the individual discussed:

*"It was just, it was horrendous. I think we've learned from that as well. Care commission, they'll no stand for it anymore. Cos we had to obviously inform Care Commission and they said, well, what are you doing to work towards, social work trying to get her fostered but that broke down and, it was just horrendous for *Daughter*, I felt for *Daughter* being in here for 3 years without-, seeing other kids coming and going and I was just proud of her because I think she coped tremendously well." (Family 2, P2)*

For another individual, their not meeting the criteria for learning disability services, but being seen as having learning difficulties which would benefit from similar support, meant that mainstream services were perceived as inadequate. Inadequacy was also seen in the range of development opportunities available to this individual (and another) within college, and subsequently.

4.12 Theme 12: Gaps for professionals and services

While much of the discussion in relation to support gaps was focused around the families at the centre of the project, some broader observations were made by interviewees, regarding the needs of services and professionals in relation to better supporting parents with a learning disability. Among these was an acknowledged tendency for Children and Families Social Workers to perhaps focus overly on the needs of the child and neglect to properly consider the support needs of the parent. A lack of knowledge was suggested as contributing to this.

Another interviewee also acknowledged a lack of training, but in relation to learning disability services, where appropriate responding to parents with a learning disability could be undermined by the infrequency with which they might be encountered. For this interviewee, one of the benefits of participation in the project was the opportunity it afforded to reflect on past practice regarding a parent, an opportunity which might not otherwise have been created. Part of this individual's reflection on their role included a recognition that Nursing, or Occupational Therapy, may be a less threatening first contact for a parent with a learning disability, than Psychology:

"Because I think well it's less formal and we would make it less formal. I think Psychologists going in it makes people quite nervous, kind of creates a barrier straight away and they're thinking, 'oh my God', cos somebody's coming in to check how I'm looking after my baby, whereas we would do it very informally and just spend time with the person." (Family 4, P3)

4.13 Theme 13: Experiences regarding information provision

Interviewees all demonstrated an awareness of the potential challenges for individuals in receiving complex information. Some interviewees considered the issue in relation to the family they supported, but were unclear as to the extent to which it actually impacted on them. The benefit of a multi-agency perspective in helping to recognise and accommodate individual information needs was suggested by one interviewee, on the grounds that they themselves would not necessarily have a detailed awareness of an individual's information needs. Another interviewee, from an education setting, commented on the general assumption that parents can read correspondence sent out to them, and that no alternative is put in place unless an individual identified themselves as needing this, which they may be embarrassed to do. Considering this highlighted the value in looking at how information was provided generally by a school.

Good practice was identified in the materials (such as accessible appointment letters) provided by the Learning Disability Service, and was evident in interviewee's descriptions of their reinforcing and repeating messages, to support understanding. Use of resources such as Talking Mats was also described, as was use of pictorial information. Simplifying or limiting the amount of information provided was also mentioned:

*"... in terms of *Parent*, any sort of information that I was to send out or anything like that, I would always try and keep it quite simplified so that *Parent* wouldn't get herself upset or stressed that I think a lot of information can be, em, not entirely targeted for people with learning disabilities." (Family 4, P2)*

Other support approaches adopted included involving advocacy, or reading out forms and assisting with their completion. Having someone an individual felt comfortable approaching for such help was obviously key. One interviewee (a respite carer) described assisting the father of the individual they supported:

"Aye, ken like social work, any kind of form he would come doon, 'can you help me fill this in?'. Cos I did nae mind, 'aye, nae problem, just come doon' and I'd tell him when I was available." (Family 2, P2)

A variety of examples of inaccessible information were provided by interviewees:

- Legal documentation (specifically linked to child protection proceedings)
- Reports of assessments
- Medication leaflets
- General appointment letters
- Benefits forms
- Mainstream parenting course materials

Some examples of good information were also provided:

- SDS information pack sent out by local authority(?)
- Appointment letters provided by some services (e.g. Learning Disability Service)
- Visual prompts on calendars
- www.patient.co.uk (source of verified information in relation to a wide range of health conditions, with 'patient friendly' sections)
- Change resources (You and Your Baby; You and Your Little Child)

5 Focus Group

As mentioned earlier in the report, two parents participated in the focus group discussion, with one being supported by their support worker from their local Community Learning Disability Team. The focus group facilitators were the researcher and a Community Learning Disability Nurse.

It should be noted that the parents did not both remain in the group for the whole period of discussion, therefore this method of data collection could be considered as a joint or concurrent interview rather than a traditional focus group.

5.1 Support from family

Both parents indicated different levels of support from their families including their now adult children. For Parent 5 this included being cared for by her son, who was a source of comfort and support during her ill health as well as a significant part of her social network. He was also recognised as a source of help for the professional staff in Parent 5's life due to his ability to check on his mother if they had concerns. For Parent 4, she noted support from her mother, step-father and Aunt as being important, particularly in household tasks and routines around mealtimes. Support with managing finance was also noted as being helpful and important. Making and taking to appointments for various activities was also an area that the parents had required support with at various times.

Both parents highlighted the importance of family members as social support with examples of shared mealtimes, company and outings being particularly enjoyed and appreciated. Introducing parents to and helping them attend other social activities was also a feature of family support, for example for Parent 5 who attended a leisure centre for weight loss classes.

5.2 Involvement in social networks outwith the family

Whilst there was clear evidence of the parents using mainstream resources such as a local reading club, weightloss classes and local hairdressers, there was very limited evidence that this had led to their involvement in social networks outside the family. Parent 5 noted that she had in fact sometimes travelled to a class with one of the other members and enjoyed their support within the class. This had unfortunately not led to their meeting outwith this environment.

5.3 Support with parenting

The parents both noted the difference in their requirements to provide support to their children as they got older and how this in fact now meant their children could provide support to them as noted above.

Both noted significant support from family in parenting, for example Parent 5 had to leave a violent marriage and return to her parents' home when her child was very young. They provide a home and support with parenting until she moved into her own flat. Family support was also provided by extended family member, for example taking the children out on trips or providing advice on parenting.

5.4 Experiences of concerns

The parents were able to recall and describe the experience of having concerns expressed about their parenting skills by others. For Parent 5 this related to concerns about bruising on her son's body and a concern that she was unable to protect her son from her ex-partner. Intervention by her parents enabled the child to remain within the family, rather than being accommodated by the local authority. However, despite this largely positive outcome, Parent 5 still had concerns that she was not believed by the relevant authorities and that they had not communicated their concerns to her effectively during the process when her son went to live with her parents. In particular this related to being given clear information about the circumstances that would have to exist for her living situation to be considered safe for her son to live with her, i.e. living on her own without her partner who had previously been violent.

The description of her experience of being asked to take all of her son's belonging to a particular centre to hand him over to others to care for him was particularly challenging for her to recall.

5.5 Support from services

The parents found it very challenging to identify supports from services around their parenting skills. This was rather to be expected given the time lapse between the original project and the focus group. Also as the 'children' concerned were now in their 20's recollection of support can be considered to have faded.

There was some discussion of the nursery experience of both parents, although again this primarily focused on support being provided by their families, e.g. *'it was mum that helped me.'*

Discussions around experiences of schooling more generally, focused on the parents securing time with their children from their parents or with their parents, including day trips and having the opportunity to pick them up from school or cook them a meal.

5.6 Positive and challenging aspects of parenting

The parents discussed the things they most valued about being parents. Examples of physical affection and pride in their children were discussed by the parents, particularly in how caring they now were towards their parents and grandparents. It was evident from the data that the parents both valued the relationships they had with their children despite the challenges in the early days of parenting them.

Parent 5 had suffered significant issues with ill health and she had found this very difficult to explain to her son and had wanted to protect him from being concerned about her health. There was some evidence that the parents were concerned about the care they might require from their children and did not want to overly impose.

The parents were able to identify challenges from early parenting experiences and this largely focused on managing behaviour (including recognising crying triggers). There were also concerns about the extent to which the parents were trusted to parent their children when small, even by family members. Offers to help or intrusion when the parents were trying to feed, bathe or change their children could be perceived as preventing the parent from developing her own skills.

6 Discussion

The starting point for this project was the implementation of a linked piece of research 16 years previously. The elapsed time offered real scope for obtaining unique insight into the lives of the families from the original piece of research, but it also carried significant challenges, with regard to tracking down families, establishing recollection of the previous involvement, and drawing links between that activity and the families' subsequent involvement with services. These challenges were acknowledged by the steering group at the outset and as previously noted contingency plans were put in place to deal with the likelihood of low recruitment rates.

As it transpired, the recruitment of families proved to be a sizable hurdle, with only 3 of the original 12 families being recruited to this project, and only 1 of those having a parent diagnosed as having a learning disability within the original project. The inclusion of two additional families brought much of value with regard to exploring the experiences of parents with a learning disability who had older children, but did not strictly address some of the original project aims. The multiple strands of data within the project address some of these aims more effectively than others, but offer rich insight in relation to all.

6.1 Support for parenting skills following the original project

While the families within the project received support from a wide range of services and professionals, the extent to which these were addressing specific parenting issues was variable. Some support did indeed relate to issues such as managing behaviour, cooking, household and financial management, but there seemed to be little that was presented in terms of providing support in relation to overall parenting issues and reducing risks identified. Indeed, only one parent was described as accessing a parenting group.

Most professionals did evidence a wide breadth of perspective in relation to the needs of the parent and their family, reflecting, perhaps, their professional role and/or their length of involvement. The support of a GP to one family, who had known them for over 10-years, was obviously key, and in many respects exemplified much that is expected from the 'classic' GP role (in contrast to the primary care experiences of many people with a learning disability, (MacIntyre, 2008)). The involvement of a learning disability nurse, for all that it encompassed some historical missed opportunities to look more broadly at the needs of the family and not just the parent, went on to effect profound change in the wellbeing of the parent, their relationship with their daughter, and the influence of the extended family.

Most families perceived their natural network as being the main source of support in relation to parenting generally. This included providing respite through child minding; modelling parenting skills, such as bathing and feeding; and providing emotional support. For 2 families, the extent of this involvement reflected the fact that the grandparent(s) were acting as kinship carers. However, this support had not resulted in the parents themselves being excluded entirely from fulfilling their role (for all that for one family, this inclusion had evolved over time from an initial position of being somewhat exclusive).

It is of note that, particularly in relation to the previously mentioned family, there was perhaps some evidence of a divergence in the view of professionals, and those of the parent themselves, with regard to the extent of the parenting role. Some of the former suggested that the parent was one, to an extent, in name only, engaging to only a limited extent in what they themselves would consider to be the role of the parent. A similar observation was made in relation to the second family, within which the grandmother had been fulfilling a kinship care role. This suggests that for some professionals there are clear limits to the role that parents with learning disabilities might play in the lives of their children which could lead to discriminatory practice.

In contrast to this, all of the parents interviewed clearly saw themselves as such, and their love for and pride in their children was readily evident. While the notion of distributed competence is not a new one in relation to parents with a learning disability (Booth and Booth, 1994, 1998; Goodley, 2001), the above contrast might suggest that it is one that has still to find traction in some places, particularly as a valid form of parenting with benefits for both the child and parent.

One area of parenting which some of the families evidenced significant needs in relation to was behaviour management. For one family in particular, the challenges presented by their youngest son's behaviour were a significant source of stress, for a range of reasons, including a failure of health services to arrive at a means for successfully managing his epilepsy. Psychological services had significant input to this (and another) family in relation to behaviour management, but its impact was unclear.

Evidence suggests that children's behaviour is a significant area where parents require support (not only those with a learning disability, but also those without). The impact of limited or ineffective support can be significant, even to the point of the child being removed. While the information provided within the interviews suggests that factors other than the child's behaviour contributed to the transfer of custody for one family, it is telling that it is the perseverance and love of the parents within the other (Family 3), rather than the provision of effective supports, that is highlighted as being the key factor by one

professional, in managing the behaviour issues. It is, however, legitimate to speculate that the long term, committed, and valued input of that professional (a GP) could well have been a key factor itself, in supporting the family to make best use of its own strengths, and the supports made available to it. This however does suggest that for a number of these families the likelihood of their children remaining with them is dependent upon the extent to which professionals invest in and have the knowledge to support them effectively.

The existing literature in relation to parents with a learning disability stresses the importance of effective multi-disciplinary and multi-agency support (MacIntyre and Stewart, 2012). Services and professionals, along with the parent(s) and others (e.g. extended family), can comprise part of the network across which parenting competence is distributed, and from which nurturing physical and social environments can emerge. Complexity and reciprocity are undoubtedly inherent aspects of such networks, and disentangling the contribution of one part from another is a futile task. It is perhaps more productive to look at how effective connections between the various parts of the network are fostered.

For the professionals interviewed, a range of factors were identified as contributing to positive working relationships with parents. Effective communication, including recognition of the need to adapt information, was one part of this; one interviewee suggested that providing a needs-led service, as opposed to a diagnosis-led one, was another. Other aspects included being non-judgemental and holistic in perspective, and flexible in provision, respectful and accessible, while also aiming for continuity of support.

Multiple involvements with services can be wholly appropriate and positive, but they can also work against the establishment of effective, sustained relationships. As some of the parents here described, it could be difficult to remember what their purposes were. Furthermore, there is the potential for this to be compounded by a failure to explain the purpose of a particular involvement. Attitudinal barriers can also be significant: there was evidence within the parent interviews of professionals being authoritarian or over-bearing and, in effect, exacerbating the power differential already present. Current ideas in relation to co-production of services and service response are as relevant here as they are in relation to any realm of care. Services and professionals no doubt have a crucial role in providing assistance, but parent contributions also need to be valued, and they themselves considered as equal partners in the creation of solutions to issues within the family.

Parents were excluded from that kind of partnership for a variety of reasons. Barriers described by them included staff turnover, unreliable services, lack of communication (poor explanation), and staff attitudes, all of which are familiar issues from the existing literature.

A lack of trust was also evident in some of the comments from parents, specifically of social services, as a result of their potential role in the removal of a child.

Similarly, the components of service delivery which professionals saw as valuable were also familiar, chief among these being accessibility and flexibility. In part, this flexibility was demonstrated in staff being prepared to take on tasks because they needed done, and not be bound by the apparent remit of their service. NHS staff and schools assisting with or suggesting benefit applications were examples of this, and demonstrated instances of services listening to and supporting the view point of parents. The latter examples can be contrasted with those instances parents described where services failed to listen to or consider a parent's situation, e.g., in a school electing to not comply with a parent's successful approach to managing their child's behaviour through diet, the NHS apparently failing to respond to a parent's concerns regarding their child having ADHD, and social services arriving at decisions perceived as being hasty, or misinformed.

One of the distinguishing features of the original project on which this one was based was its inclusion of parents with a learning disability, and those without one, but deemed vulnerable for other reasons. The make-up of the present project reflected this, in having one parent with a learning disability, and 2 vulnerable parents involved from the original project. It is in keeping with the experiences described within the literature to note that all of those parents with a learning disability had their children removed from them, into kinship care. Without a detailed examination of the circumstances surrounding those decisions, it is only possible to speculate as to the extent to which these reflected parenting skills which could have been improved by the provision of earlier, more appropriate support, or acceptable parenting which was perceived as inadequate due to the application of stricter than normal criteria, or presumptions regarding ability.

It is, however, of note that 2 of the parents were able to trace these decisions back to incidents which they disputed. For one, the absence of food within a house which was being prepared for living in was understandable and had been accommodated, however it appeared to have factored into the decision to have their children removed. For the other, a specific safety concern raised by the local authority was seen as inaccurate. Even less information was available in relation to the removal of children in the other 2 families. However, all 4 perceived this decision as having been unjust.

The existing literature already illustrates in detail the potential for services to fail to listen to or support parents with a learning disability. It also describes many aspects of services which contribute to positive supports. It is striking that many of the positive attributes described by parents and professionals here appear to be characteristics of relationships, as

opposed to features of services or professional roles. Positive input from professionals evidenced respect and a willingness to listen to and advocate on behalf of the family, while professionals themselves described a need for respectfulness and a holistic perspective. Even those more service oriented descriptors (flexibility and accessibility) are not in themselves tied to a service function, but to how it is delivered, i.e. how it relates to the people it supports. Indeed, a limited number of comments remarked on the concerns which can accompany some professional roles: the distrust which can be felt towards Social Work, and the anticipation of being assessed which can be evoked by Psychology.

The involvement of multiple services and professionals was very evident in the support of some families, and professionals were able to describe the benefits of this. Families, however, were also able to describe the negatives, making reference to a lack of clarity around the purpose of input, and the challenges of keeping track of who was who. Consistency was obviously a valued aspect of support, in some instances being evidenced in the involvement of GPs, in another by the stable involvement of staff in a residential setting.

The complex and multiple needs described in relation to some of the families clearly led naturally to the involvement of varied professionals. But given the clear importance of positive, respectful relationships (as evidenced, for example, by parents recollections of their relationship with the Support Worker from the original project), and the potential significant consequences of their absence, it is legitimate to question whether at times, the 'solutions' applied to some situations are more reflective of service structures and habits (multiple disciplines with varied specialist roles) than they are of what may actually be of use: a positive, sustained relationship with someone a family can trust. From that perspective, responding to vulnerable parents may be less about bolstering services with a multitude of varied professionals, than it is about services attending to how they can create the space for positive relationships to emerge.

It should also be noted that practical observations were made with regard to the need for professionals to receive training in relation to supporting parents with a learning disability. There is evidence to suggest that professionals are not well supported to work effectively with parents with learning disabilities. In addition, that professional training in both health and social care does not focus sufficiently on this area, which means that professionals do not possess the relevant knowledge and skills to support parents (MacIntyre and Stewart, 2012). Within the current project, this was not identified solely as an issue for staff without a background in learning disability, but also for those with one. Indeed, it was telling that recognition of missed opportunities to address broader issues within a family in the past was expressed by a learning disability nurse who had been involved with the parent for a number of years. Others saw missed opportunities for earlier intervention from social work

or care providers, with the transition between child and adult services being one point with the potential to involve and better prepare the whole family.

6.2 The extent to which supports were informed by the original project's outcomes

There was some evidence of recommendations from the original project being acted on, and to a lesser extent, of them having a positive impact. The home-help support put in place for one family following the project recommendations was long term and positive. Other recommendations in relation to Health Visitor and Psychologist input were also acted on. It should be noted that 2 of the 3 families from the original project had their children removed. For one, this occurred shortly after the end of the project, and there was no opportunity for recommendations to be put in place. For the other, recommendations were actioned (in relation to infant feeding), but it is a question whether supports continued to evolve appropriately in line with the changing needs of the child and parent.

The extent to which input from the original project continued to shape the support given to the 3 families over time is unclear, beyond the above noted immediate response to recommendations. Given the elapsed time, it is unsurprising that direct links are difficult to identify. Indeed, it is of note that the parents could recall with some detail (with some prompts, such as photos of the project staff) elements of the original project, and topics addressed within it (e.g. play, nutrition, bedtime and school routines), including the fact that support in the home was an aspect of what was offered.

Perhaps the strongest recollection of the original project (particularly for one parent) was in relation to the Support Worker attached to it, and the relationship they established with the parents. Their accessibility, their guidance, and their encouragement, appeared to have been key aspects of their involvement, and undoubtedly were a large part of the project's positive impact on the families. This impact included skill acquisition beyond the project itself, with one parent describing the acquisition of a first aid certificate following on from the project's work on that topic, and another describing how the project led to them subsequently accessing a college course.

While the limited engagement with parents from the original project severely restricts the opportunity for making observations regarding its long term impact, it is worth looking at what information is available, in relation to what evidence and available guidelines consider positive approaches in relation to supporting parents with a learning disability. The importance of sustained and consistent long-term involvement, for as long as a family

needs, is often stated (MacIntyre and Stewart, 2012; SCLD, 2009; Tarleton et al., 2006). In this respect, the fact that Home Help involvement was not only reinstated for one family, but remained in place for a period of years following the project's end, is of note.

Some recommendations were made within the final reports regarding support to the parents as individuals. One of the 3 parents could provide some information in relation to this being implemented (support regarding causes of stress), however the other 2 had no recollection of the support recommended for them being implemented. It is not clear whether this is reflective of the support not being offered, or not being remembered. Given the elapsed period of time, the latter is very possible. Parents also described positive support for themselves as individuals, in relation to issues such as health and employment

6.3 The extent to which skills/supports developed in the original project were sustained during the intervening years.

The opportunity for skills to be maintained was constrained by the removal of children in 2 of the 3 families. For the 3rd family, the multiple challenges they experienced and overcame were linked in some areas to topics covered within the original parenting project (e.g. behaviour management), however, their management appeared to have emerged out of the ingenuity of the parents themselves, with some assistance (and some interference) from services. Indeed, it is telling that one of the professionals interviewed in relation to this family described the mother, and their love for their children, as a key strength, rather than any specific aspect of their care.

In terms of skill maintenance, the possible issues in relation to home safety for one family suggest that, at least for some, those aspects of the original family which addressed home safety were not maintained (or possibly, never had the impact intended). In addition, evidence of supports established during the original project being sustained was minimal. Again, this highlights the challenges in conducting follow-up work after such a lengthy period. However, it may also be reflective of the challenges faced by many parents with a learning disability (and indeed others), with regard to the provision of short-term support. While it was in the nature of the original project that it was short-term, and while so many aspects of its delivery evidenced positive practice in relation to parents with a learning disability, it is possible that the approach taken to support parents to exit from the project could have been developed further. Specifically, it was noted within the interviews and in conversations with staff from the original project that none of the families received any version of the final report on their progress and future support needs. The extent to which this might have helped to shift ownership and awareness of the recommendations to the

families themselves is uncertain, but its absence is of note, particularly in light of current guidance in relation to empowerment, and information provision (Scottish Government, 2011).

6.4 The extent to which supports changed as children aged

While the span of the intervening period undoubtedly impacted on the ability of participants to reflect on the experience and impact of the original project, it did afford ample scope for illustrating the families' and services' responses to the maturation of the children involved. In some instances, there was evidence of services failing to adapt around needs, for example, in not recognising the needs of one child in relation to ADHD, and in failing to resolve or effectively understand the health problems of another.

However, there was also evidence of positive service experiences. For one individual in particular, it was evident that those supporting them fully recognised the changing needs of the individual, and were working with both them and their family to understand these. This included support in relation to appropriate behaviour for the individual, and respecting boundaries for the parents. The support environment itself was also changing around the individual, as evidenced in their transition into their own tenancy, the reduction of staff sleepovers, and choice making in regards to community activities during the day.

The involvement of Nursing staff with one family afforded them the opportunity to observe the potential isolation of the child, and initiate discussions with social services to address this. For other families, education played a crucial role, as a place where their children 'thrived', or where considerate, flexible responses and the affordance of opportunities to their children were in evidence.

Indeed, it is telling that one of the key professionals identified by a family was the head teacher from their children's secondary school, who evidently demonstrated many aspects of the positive relationships discussed earlier, in their accessibility, willingness to listen, and respect for the family. It may be the case that their ability to place the experiences of this family's children on the spectrum of normal behaviour (*'Nothing beyond normal teenage troubles'*) played some part in this. It has to be noted that the same family encountered significant issues with a child in relation to the management of behaviour, and a perceived lack of support from their primary school in relation to managing this. Key to this was the school's refusal to accept the successful routines the parents had established for supporting their child.

The same family was described by one professional as having received home help input in relation to their care of their children, which had come to an end as a result of the friction created by the perceived intrusion into the household. One parent in this family described themselves as coming to a realisation that they needed to change in order to ensure that they retained their children. With this in mind, it may be that part of their having a successful relationship with the secondary school head was attributable in part to them themselves being in a position where they were better able to engage. Whatever part this may have played, it still speaks to the importance of creating successful relationships, and suggests a need for investment to achieve this. Possibly, this may be less to do with linking families with appropriate professionals, than it is about identifying the appropriate individuals for them to be working alongside.

For other families, it was not so much changes in support received by children that was evident, as it was changes in the support given. In one family, the immediate family member was acting as a full time carer, while in the other the daughter was described as being protective of the mother (to the extent of being overly so). The challenges facing young carers are increasingly recognised across services, along with the need to effectively support them in this role (Scottish Government, 2010). It is a question whether this role is one that occurs more often among the children of people with a learning disability. Outside of the fact that their capacity may outstrip that of their parents (as described here, and by Woodhouse et al., 2001), the frequently greater (often as a result of being unidentified) health needs of people with a learning disability may carry with it the greater likelihood of care responsibilities for their children. Indeed, it is of note that the full time care provided by one family member was in relation to their parent's epilepsy, the prevalence of which is considerably greater among people with a learning disability than it is in the general population (Scottish Government, 2013).

6.5 The experiences of immediate family members

It had been hoped that those individuals who had been children at the time of the original project would prove to be a key source of insight for this one. As it is, their lack of involvement leaves some gaps in relation to the original project aims, but suggests avenues for further activity.

What was apparent from the information gathered was that outcomes for the children of the 5 families had been varied. Employment, including self employment, had been an outcome for some; others were involved in or awaiting work experience or voluntary work. The majority appeared to have been linked to opportunities of some kind, however the role

which college played in this was questionable. Those parents who spoke about their child(ren)'s experiences of college did so fairly negatively, noting that their attendance ceased for reasons such as funding withdrawal; courses being discontinued; their child being asked to leave due to attendance; or other, unspecified reasons.

For adults whose parents have a learning disability, a limited number of narrative studies have highlighted the experience of social exclusion and stigma, it being suggested by some that this may lead to poor educational, psychological, and behavioural outcomes (Collings and Llewellyn, 2012; Faureholme, 2010). The extent to which this applies to the children connected to the families here is unclear. Social isolation was definitely mentioned as a risk in relation to the child from one family (which triggered a response from services involved with the parent), but for others there was clear mention of friends, or of the children having a place within their local community. While practical issues were identified in relation to the college experiences of some children, for others the reasons for their leaving college were less clear.

The opportunity to listen to these individuals themselves would have been the ideal outcome, however in its absence, questions remain. As Collings and Lewellyn (2012) observe, work to date in relation to the children of parents with a learning disability has tended to focus on early developmental outcomes, or child outcomes as a secondary concern in relation to assessing parenting competence. The latter authors comment on the need for research to look at the long-term outcomes of children of parents with a learning disability. The present study sought to address the issue, and has done so to a limited extent, however in doing so it has perhaps raised more questions which would benefit from a focused exploration, including:

- Frequency and nature of their role as young carers
- College experiences and the impact of stigma/isolation
- Employment outcomes

6.6 The experiences of parents involved in the original project, and those who were not

Within the results section of this report, the experiences of those families involved in the original project and those who were not, were examined together under common themes, reflecting the relevance of the majority of the themes identified to all the families. While the small sample for this project limits the extent to which any distinction between the two groups can be explored, it is none-the-less informative that it is the shared qualities of their

experiences that proved to be most apparent. The two families recruited from outwith the original project were distinct in the extent of their active involvement with their own parents, who were acting as kinship carers, and there were some experiences that were unique to these situations (for example, in how their own parents facilitated or restricted their involvement as a parent). However, particularly in the absence of a clear thread of support from the original project over the intervening period for the other 3 families, it would be inappropriate to attribute any aspect of the families' situations to their involvement or not in the original work.

Indeed, rather than seeking to learn from differences between the two groups of families, it is potentially more relevant to look at each family individually, to identify what can be learnt from it. Key points to note would be as follows:

- The experiences of Family 1 can be taken as illustrating the value in sustained, long term support. Their experiences following the cessation of the original parenting project, with regard to assumptions made by social services, and the removal of their children into kinship care, may reflect in part the absence of a positive, valued relationship such as that established by the parent with the Support Worker from the original project.
- The experiences of Family 2 are illustrative of what can be achieved when services collaborate effectively with parents, in this case, maintaining meaningful contact between parents and child throughout the various living arrangements experienced by the latter. Involvement of a consistent staff group was also evidenced.
- The experiences of Family 3 encapsulate a complex variety of issues, including behavioural issues in a child, mental health issues for a parent, and caring for multiple children. Long term support again appeared to be a key element here: from a home help, and from the GP, but it is telling that the greatest part of the success was attributed by one professional not to the support of services, but to the parents themselves
- The experiences of Family 4 provide a positive example of the potential of service support to transform an individual's life, including their relationship with their child and their own parents, who were acting as kinship carers. With the support of services, the parent took up independent travel, accessed an exercise group and day services, commenced voluntary work in a café, and began attending a local disco. At the same time, their experiences illustrate the way in which services can miss opportunities: in this instance, much earlier involvement to support the parent in

relation to their mental health could also have been used to understand and support their broader family life, but was not.

- The experiences of Family 5 are richly illustrative of the positive impact of kinship care by grandparents who were very much focused on encouraging and reinforcing the continuing role of the parent themselves. While sustained, consistent service involvement was also a feature here (e.g. from a GP), there is a sense very much of the family sustaining itself and the wellbeing of its members, through acting as a supportive network.

Indeed, it is striking that for all of the families, success was evident in their maintenance of positive relationships with their children, often despite the input of services. Distributed parenting was very much a factor in achieving this success for some, and proved a successful and legitimate mode of parenting which allowed those parents to maintain a valued parenting role, for all that some professions seemed to question their identity as 'real parents'.

How the parent identity emerged for those parents was complex and evidently (at times) challenging. However, it is also important to reflect on the other roles the parents evidenced, particularly as individuals in their own right. Stets and Burke (2000) discuss the way in which individuals carry and fulfil multiple identities within their lives. Acquisition of multiple roles can be a positive growth, and help reinforce the sense of meaning and purpose within an individual's life, particularly if those roles are positively verified by the actions of others. However, the access to multiple identities is not spread evenly across society, in that those higher within the social structure, or who have access to more resources, will have access to more identities.

In this respect, some of the parents spoken to here appeared to evidence this inequality (unsurprisingly perhaps, given the general inequities experienced by people with a learning disability and others in similar situations). A parent in family 3 had to give up their job due to health issues; in contrast to this, the support provided to a parent from Family 4 clearly evidenced the dividends which flowed from looking at the wellbeing of the parent as an individual, and supporting them to access new opportunities (in effect, to forge new identities for themselves).

6.7 The impact of inaccessible information

Arguably, one of the ways in which the parents were prevented from taking on new, or successfully developing existing identities, was in the provision of inaccessible written or verbal information. In the context of the Named Person legislation which the Scottish Government is seeking to implement, it is of note that some of the examples of poor information provision were linked to midwives, health visitors, and school meetings. The potential responsibilities of Health Visitors and Head Teachers with regard to the Named Person role create a clear imperative that they communicate clearly and effectively, in a manner which accommodates the needs of the parent. In this respect, it is of note that the Deputy Head Teacher interviewed within this project commented on the scope for the school to consider to a greater extent the literacy needs of its parents, in the information it routinely sends out.

Gaining support from others to read information (including children's panel reports) was described by parents, with the support coming from sources such as Learning Disability Nurses, or other family members. Professionals responded to the needs of individuals by adapting resources or correspondence, developing visual approaches to accompany other resources, and reinforcing and repeating information. Advocacy was also described as being of assistance in supporting understanding.

It is striking that the examples of bad information provided by professionals were generally materials provided for the mainstream, while the good examples are ones which evidence efforts to deliberately improve accessibility. An understanding of the information needs of an individual is something that can emerge over the course of establishing a good relationship with them, although (as noted by one professional), the effective merging of multi-agency perspectives can also foster understanding in this regard. In the absence of these, parents can be left dealing with mainstream materials which may well be too complex for many who are accessing them (as Protheroe et al. (2015) found when looking at information leaflets provided within GP surgeries in England).

The potential consequences of this are significant, and increasingly acknowledged. However, solutions to date have continued to focus on generating alternative versions of documents. In the context of a broad inequalities agenda, which encompasses more than just parents with a learning disability, it would appear relevant to reflect on whether it is sufficient to accept mainstream information provision, and shore up its shortcomings with alternatives, or whether it is more productive and equitable to challenge what constitutes mainstream information provision in the first instance.

6.8 Study limitations

The small sample of families involved in this project necessarily limits the extent to which any insights can be generalised. However, the conversations which took place with those families, along with the accompanying perspectives of the various professionals, generated a richly informative set of insights of great relevance, none-the-less. More significantly, the low involvement of families involved in the original project on which this one is based restricts the capacity of the project to address those original aims which were described with reference to experiences in the original project. As has been stated throughout, the length of elapsed time would have posed a challenge under any circumstances, and it is reasonable to speculate (given what is known of the service experiences of parents with a learning disability and others) that people's experiences over that time may well not have been ones they would seek to re-visit, or share with a researcher.

The lack of involvement of those 'children' within the 5 families is a disappointing outcome, and one which invites the adoption of a different approach to involving those individuals, and any in similar situations. Given that all of the 'children' to be approached would have been aged 16 or older, it may have been more appropriate to approach them directly as individuals in their own right: while we were properly respecting the roles and responsibilities of the parents, we were perhaps failing to respect the rights and growing autonomy of the immediate family members themselves. Indeed, a piece of work focused solely on the experiences of the children would have been a legitimate endeavour, and one which may be pursued as a supplement to this project (all-be-it focusing on families other than those from the original parenting project).

Another limitation may relate to the use of the label of learning disability. Within the original parenting project, ascription of the learning disability label to a parent was informed by the use of the Wechsler Adult Intelligence Scale – Revised (Wechsler, 1981), with those individuals obtaining a score of below 70 being assigned to the Learning Disability group. For those individuals recruited to this project who were not part of that project, the Learning Disability Teams that they were involved with operate to a criteria that includes reference to IQ, but notes that IQ in isolation is not sufficient to assign the label.

Collings and Llewellyn (2012) note the frequent use of a social systems definition of learning disability, which includes reference to considerations such as whether the individual attended special schools or classes; whether they receive a disability allowance; and whether they are regarded by themselves or service providers as a 'slow learner'. On the basis of such criteria, it may well have been the case that some of those not labelled as having a learning disability within the original project would have satisfied a social systems based

definition. To the extent that this is an issue, the distinction employed within that project may well have been an artificial one, which doesn't reflect what we would now consider as good practice, and which might not reflect how the additional 2 parents recruited to the project acquired their label.

Any subsequent work would benefit from a more consistent use of the label; alternatively, on the basis of a social systems perspective, there may be arguments for exploring outcomes within families first and foremost on the basis of their experience of health inequities such as poverty, isolation, and lack of employment, with any additional diagnostic labels being factored in as a secondary consideration.

The parenting evidenced by the families within this project is as much part of a spectrum as they themselves are. Indeed, the challenges described by the parents here would challenge anyone, and are not unique experiences to parents with a learning disability. The supported parenting approaches some demonstrated are only grades different from any family who receives childcare support from a grandparent, they are not something qualitatively unique. The added element is the way in which services and professionals fail to practice flexibly in relation to individual needs.

6.9 Importance to services and recommendations

The experiences of parents in this study confirm much that is already familiar from the existing literature, with regard to the challenges of multi-agency working, the negative impact of attitudes and assumptions made by services, the frequency with which children are removed from parents with a learning disability, the challenges of communicating effectively with parents (and the continuing frequency with which services fail in this regard), and the complex social situations and experience of disadvantage frequently seen among parents with a learning disability.

While the organisation and mobilisation of services were undoubtedly issues noted within the various project discussions, the importance of positive relationships between workers and individuals is perhaps one of the more striking aspects. But service re-configuration, or the addition of new professional roles, are in some ways more realisable challenges than addressing the issue of how staff can be supported to forge better relationships with individuals. A basic awareness of learning disability is undoubtedly part of this, but so too is an understanding of the impact of health inequities. Successful connections are not a necessary consequence of 'clicking in' the right professional role, they are about the right individual, possibly regardless of their role. In this respect, it is of relevance to note the

positive relationships within the Valuing Parents Support Service described by Tarleton and Porter (2012), and the fact that within that service, staff were matched to parents.

The Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities recognise the importance of relationships, and describe the use of Person Centred Planning as a positive tool for understanding individual strengths and helping trust to emerge. The positive example of the voluntary sector and community organisations, and of advocacy, in relation to building successful relationships are noted. So too is the need for relationships to be long-term, and informed by mutual respect. Yet it is arguable that greater emphasis could, and perhaps should, have been laid on this.

It is with this in mind that the following recommendations are made:

- Basic awareness of the support needs of people with a learning disability, and parents with a learning disability in particular, should be provided to all those working with children and families. This should be promoted on the basis of a social systems definition of learning disability: the relevance of this training for other individuals who may exhibit similar needs in relation to learning and support, but who do not have a 'learning disability' label, should be emphasised.
- Positive messages in relation to the successful realisation of distributed parenting should be promoted across communities. Parenting by communities/extended networks as opposed to solely by biological parents is not a new concept, and should be recognised and welcomed as a valid option. Where distributed parenting is being employed, attention should be paid to ensuring the continuing, meaningful involvement of the supported parent(s) themselves.
- Partnerships between parents and staff should be informed by more than just a consideration of needs and relevant roles. While a commitment to long-term involvement, such as that recommended within the Scottish Good Practice Guidelines, provides opportunity for positive relationships to emerge, creating the right conditions for those relationships from the outset is a legitimate area to focus on. Realising this within resource constrained services will be challenging, but can be enabled by positive practice in team leaders (knowing their staff as individuals as well as practitioners); flexible responding to referrals (allocating on a more measured basis than the basic fitting together of needs and roles); and encouraging staff to recognise when they are not the right fit for a family, and act on it.

- Further work should be undertaken to explore the outcomes for children of parents with learning disabilities, specifically in relation to:
 - Frequency and nature of their role as young carers
 - College experiences and the impact of stigma/isolation
 - Employment outcomes

- Staff should be encouraged to reflect and act on the wellbeing of the broader family, where they become involved with parents ostensibly for reasons other than parenting. It is recognised that the current dialogue in relation to the implementation of the Named Person role has highlighted real concerns with regard to the perceived excessive intrusiveness of services. This highlights the need for sensitivity when practising holistically in relation to the needs of an individual and their family.

- Staff should be encouraged to consider the needs of parents not just as parents, but also as individuals in their own right, and to explore with the parent opportunities in relation to this.

6.10 Dissemination

The methodology and results of this project are to be published by Sage online in a case study article (McGregor et al., (In press), Exploring the Long-Term Outcomes of Vulnerable Parents With and Without a Learning Disability Using Interview Methodology). The wide variety of partners within the project steering group provides accessible routes for dissemination across the Ayrshire Health and Social Care Partnerships, Universities, and third sector. Involvement of steering group members in the Scottish Parents with Learning Disability Network will ensure that its outcomes are shared across the country.

7 Conclusion

The unacceptably high rate at which children are removed from parents with a learning disability creates an imperative to look specifically at their needs, and how services and professionals fail them. Frequently, that failure arises out of a narrowness of focus, which precludes a rounded appreciation and understanding of a family's circumstances. Children and families services focus on the child, at the expense of exploring the parents support needs; adult services might focus on the parents own needs, but fail to explore those of the wider family; Learning Disability Services may exclude those who fail to meet their criteria, the result being that they remain unsupported by any service.

Some of these issues were evident in the feedback of professionals and parents within this project, but so too was a willingness to engage beyond the confines of traditional role concepts, and to act flexibly and respectfully in the interests of families. That flexibility and role blurring is not something which services are naturally set up to accommodate, yet they are features which are increasingly necessitated by the growing realisation that services as they stand are failing individuals and communities in many ways, and must change (ALLIANCE, 2014).

Potentially, part of that change must entail an acceptance of complexity, and a concerted effort to refrain from oversimplifying service and life experiences into linear pathways which can frustrate and restrict as much as they can clarify. The distributed parenting demonstrated by families within this project and elsewhere exemplifies this complexity; and the response of services at times exemplified a preference for a simpler, more traditional model of parenting. A recent report from the International Futures Forum (2016), regarding transformative change in health and social care, remarks on the inevitability that a new system structure will be more complex than the existing one, but recognises this as a natural and positive evolution. Just as there may be some way to go in the acceptance of distributed parenting approaches among parents with a learning disability (and others), so too there may be some way to go in the acceptance of the need for services to adopt a similar, networked approach to their competence.

Many of the challenges faced by parents in this project were ones any family would struggle with. Indeed, outside of the (at times) perverse response of services, it is the commonality of their experience that is one of the striking things. The life experiences of parents with a learning disability lie on a continuum with those of all parents. It would behove services to remember that, and seek to adapt their practice accordingly.

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