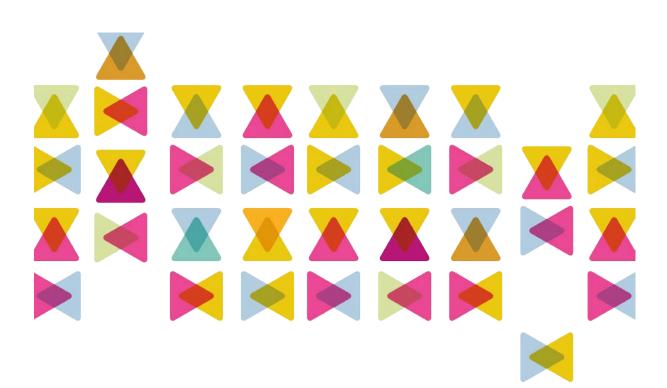


A practical and strategic guide to developing a supported parenting approach for parents with learning disabilities

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An increasing body of evidence demonstrates that providing the right support at the right time can lead to positive outcomes for children and parents alike. The aim of this document is to describe the range of supports that parents with learning disabilities might need, and to suggest ways that this support could be delivered. It is for service commissioners and professionals from the NHS, local authorities and the voluntary sector; anyone indeed who has a role in developing or delivering support for parents.

What do we mean by a supported parenting service? We mean that parents with learning disabilities are able to access the right support at the right time to produce the best possible outcomes for them and their children. It is likely that this support will come both from universal services (i.e. for all parents) and from specialist services (i.e. for people with learning disabilities). Some aspects of a supported parenting service may be specifically commissioned for that function, or alternatively it will be delivered via existing services. So when we refer to a supported parenting service we mean the collective activities of all agencies working together to supported parenting principles.

#### This Guide

- Outlines important issues inherent in developing a supported parenting approach
- > Highlights key factors of a supported parenting approach
- Outlines good practice in supported parenting

#### **Setting the Context**



A number of national policies and strategies

propose support for families aimed at producing positive outcomes for children. Key features of this support are that it is flexible, family-centred and preventative:

"We recommend that... parents with learning disabilities should have access to local supported parenting services based on the principles of supported parenting, and that the Scottish Good Practice Guidelines for Supporting Parents With Learning Disabilities are being followed by professionals working with parents with learning disabilities to ensure better outcomes for families. (Recommendation 38, The keys to life, National Learning Disability

Strategy, 2014)<sup>1</sup>

Research with Scottish families highlights that different parents have different support needs and we want to ensure that, whatever the issue and wherever they live, the support they want is readily available to them, proportionate to their needs and those of their children." (National Parenting Strategy p.25)<sup>2</sup>

No matter where they live or whatever their needs, children, young people and their families should always know where they can find help, what support might be available and whether that help is right for them. The Getting it right for every child approach ensures that anyone providing that support puts the child or young person – and their family – at the centre. Practitioners need to work together to support families, and where appropriate, take early action at the first signs of any difficulty - rather than only getting involved when a situation has already reached crisis point." (A Guide to GIRFEC. p.3)<sup>3</sup>

<sup>&</sup>lt;sup>1</sup> The keys to Life, Scottish Government (2013) http://www.scotland.gov.uk/Publications/2013/06/1123

<sup>&</sup>lt;sup>2</sup> The National Parenting Strategy (2012) http://www.scotland.gov.uk/Publications/2012/10/4789

In addition, the Children and Young People (Scotland) Act 2014 places a responsibility on local authorities to provide services to families where the children are at risk of becoming looked after.

These national strategies, policies and pieces of legislation indicate the importance of taking a supported parenting approach, in order to achieve positive outcomes for the children of parents with learning disabilities. This guide has been written to facilitate the delivery of this kind of support.

# What we mean by learning disability

The Scottish Government's Learning Disability strategy, The keys to life<sup>4</sup>, defines learning disability like this:

People with learning disabilities have a significant, lifelong condition that started before adulthood, which affected their development and which means they need help to:

- Understand information
- Learn skills; and
- Cope independently

<sup>&</sup>lt;sup>3</sup> A Guide to getting it right for every child (2012) http://www.scotland.gov.uk/Resource/0045/00458341.pdf

<sup>&</sup>lt;sup>4</sup> The keys to life, Scottish Government (2013) http://www.scotland.gov.uk/Publications/2013/06/1123



But this is only a part of a description. It does not capture the whole person who can be much more – a friend, a family member, a community activist, a student, a parent, an employee or employer to name just a few roles." (keys to life p. 6)

The Working Together With Parents Network believes that supported parenting services should be available both to parents with a diagnosed learning disability and also to parents with a milder or undiagnosed learning impairment which causes similar struggles with everyday life.

## What is supported parenting?

**'S**upported parenting' is the term used to describe supports adapted to the particular needs of parents with learning disabilities. There is no organised system of supported parenting nor is there a designated funding source. Supported parenting is an approach more than a specific programme, similar to supported living or supported employment approaches.

Supported parenting can be found within agencies providing services to a wide range of individuals and families, and it can be found in programs with the single specialty of serving families headed by parents with disabilities. When specialized support for parents with disabilities is available it can come from a wide variety of systems.

So when we talk about 'supported parenting services', we refer to the whole system and cluster of services from whom parents with learning disabilities might get support. Supported parenting is based on a number of principles:

- > Support should be available right from the start i.e. from pre-birth onwards
- ➤ Families might need ongoing support i.e. support at every stage of the child's development
- > Support must be based on respect for the parents and for the emotional bond between the parents and their children
- > Parents should be seen as a resource, not a problem
- > Support should be for the family as a whole rather than individuals
- ➤ Parents should be supported to feel in control and to experience being competent
- > Support should focus on building strengths
- Making mistakes as a parent is forgivable: support should help parents learn from them
- Families are best supported in the context of their own extended families, neighborhoods and communities

All the decisions made about developing supported parenting services should be based on these principles.



Supported parenting developed from two key beliefs:

- That it is legitimate to give parents support, and that this does not mean the parents are incompetent or bad
- That flexible support based on what parents actually need results in better outcomes for children and parents

Some areas have put supported parenting programmes into practice for some time. For example, <u>Healthy Start</u> is a national supported parenting strategy in Australia.

A range of organisations in Wisconsin USA have adopted a supported parenting approach.

In Scotland, some voluntary sector organisations use a supported parenting approach in their work with families with parental learning disability, for example:

- Aberlour Child Care Trust
- > The Action Group
- A partnership programme between NHS Fife, Barnardos and Fife Council

The reasons why a supported parenting approach is needed are that:

- It helps children to achieve GIRFEC's eight indicators of wellbeing
- Communication with parents is key to effective practice
- > Input from multi agencies has to be coordinated



# Why have a dedicated supported parenting service?

- Some specialist skills are required
- Early intervention has to be intentionally built in/ protected
- > It is a human right of parent and child
- > It helps parents to parent better
- Preventative support makes better use of public money

As stated above, the function of a supported parenting service can be delivered in different ways, and by a number of agencies working together, as long as services are working to the principles of supported parenting, and staff have the skills and confidence to work with people with a learning disability. An essential component of this is flexible support in the family home which has the capacity to meet the longer term needs of the parents. It is unlikely that universal health services will be able to provide this on their own, because:

- Any one family may need a significant number of support hours per week
- Some parents will need support over many years, beyond the point where they are able to work with the family

Long term, intensive support may be uniquely offered to parents with learning difficulties, but this is justified when it builds the capacity of the parents, and achieves good outcomes for the child.

Therefore, it can be useful to think of a 'supported parenting service' as being a discrete component within a broader supported parenting approach provided within a locality.

The question of who should provide this service, and which funding stream(s) fund it, has been addressed in different ways by different local partnerships. It is not the intention of this Guide to prescribe any one model, but rather to emphasise the importance of this element of the supported parenting approach: flexible support at home based on the principles of supported parenting listed above.

## What do we mean by 'support'?

A supported parenting service will recognise parents may need support with a wide range of tasks, not all directly related to parenting, but all aimed at producing better outcomes for children. The People First (Scotland) Edinburgh Parents' Group produced a list to illustrate what they mean by 'support'. This list is not meant to be prescriptive, but rather to show the wide range of support activities to be considered.

Firstly, the values base that underpins any support must be in line with the principles listed above. So the following values are fundamental:

- Listen to us
- Get to know us
- Have a positive attitude
- Do not judge us
- > Trust us and work to build up trust

Based on the principles of supported parenting above, features of the service will be:

- Support might be everyday it depends on the person and what they need
- > Support will be individualised, not off the shelf
- Support will be flexible. It may be at different times of the day - it needs to be available at times that are important to the family
- Support will involve working with the family to build up their skills, rather than to take over
- However, it is also expected that staff may undertake some tasks that parents are not good at e.g. some parents might struggle to help a child with homework, but support for the child with their homework would enable the parents to do other tasks that they can do well

Therefore, support might include any of the following tasks (and others besides):

- Accessible information
- One to one and group advocacy
- Reading letters
- > Filling out forms
- Making appointments health and other and developing systems to keep them



- Attending appointments with the parent
- Budgeting, paying bills
- Linking with council services e.g. housing
- > Linking with the school e.g. parents' evenings
- Developing parenting skills practical (making food, changing nappies, setting routines) and emotional (understanding behaviour, setting boundaries, meeting needs). Reminding and prompting these learned skills
- > Supplementing what parents do e.g. supporting children with their homework
- Addressing the emotional wellbeing of parent and child
- Supporting parent and child to make connections with the community
- Understanding the child's needs

The above list of possible support needs is fairly extensive. It is likely that some of these needs can be met by universal services taking a supported parenting approach.

Based on the available evidence, these kinds of support have good outcomes for children and parents:

- ▶ Parenting programmes where self-directed learning is key have better outcomes that are maintained longer<sup>5</sup>
- Parenting programmes and home support are both effective, and providing these in combination produces better outcomes than either in isolation<sup>6</sup>
- ► Long-term support<sup>7</sup>

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<sup>&</sup>lt;sup>5</sup> Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities, Feldman et al (2002)

<sup>&</sup>lt;sup>6</sup> What works with parents with learning disabilities?, McGaw and Newman (2005)

<sup>&</sup>lt;sup>7</sup> Ibid.



# Planning and Commissioning a service/ support

This section outlines some of the key issues to be considered

when planning or commissioning services for families where the parents have learning disabilities. As stated previously, a major part of taking a supported parenting approach means that current mainstream services for parents or families are aligned to meet the particular support needs of parents with learning disabilities.

This section relates to the commissioning of individual packages of support, but also has relevance for the planning and commissioning of services at an area wide level, should resources and opportunities be available locally to support such development.

It is not intended to provide exhaustive guidance in relation to commissioning services from a supported parenting perspective, and should be read in conjunction with the more extensive commissioning guidance provided within:

- ➤ Commissioning Social Care<sup>8</sup>
- Joint Strategic Commissioning Learning Development Framework<sup>9</sup>
- ➤ Self-directed Support: A Strategy for Scotland<sup>10</sup>
- ➤ Supported Parenting The Refreshed Scottish Good Practice

  Guidelines for Supporting Parents With a Learning Disability¹¹

Because support is for the whole family, and positive outcomes will be achieved for both children and parents, it is important that adult and children's services take joint responsibility for planning and commissioning services to meet the needs of parents with learning disabilities. The following areas of activity are comprised within a supported parenting approach:

Identifying parents that might need support should happen as early as possible. Unless families are already known to services, GPs and health visitors are in the best position to do this. A number of screening tools have been developed to help identify parents with learning disabilities where a formal diagnosis has not been made.

Training may be required to administer this screening effectively. It is important that:

- Professionals are skilled in using a screening tool
- Are confident about working with someone with a learning disability once identified

<sup>&</sup>lt;sup>8</sup> Commissioning Social Care, Audit Scotland (2012) <a href="http://www.audit-scotland.gov.uk/docs/health/2012/nr\_120301\_social\_care.pdf">http://www.audit-scotland.gov.uk/docs/health/2012/nr\_120301\_social\_care.pdf</a>

<sup>&</sup>lt;sup>9</sup> Joint Strategic Commissioning Learning Development Framework, Institute of Public Care (2012), <a href="http://ipc.brookes.ac.uk/publications/pdf/Learning\_Development\_Framework.pdf">http://ipc.brookes.ac.uk/publications/pdf/Learning\_Development\_Framework.pdf</a>

<sup>&</sup>lt;sup>10</sup> Self-directed Support: A Strategy for Scotland, Scottish Government (2010) http://www.scotland.gov.uk/Resource/Doc/329971/0106962.pdf

<sup>&</sup>lt;sup>11</sup> Supported Parenting, SCLD (2014) <a href="http://www.scld.org.uk/wp-content/uploads/2015/06/Supported">http://www.scld.org.uk/wp-content/uploads/2015/06/Supported</a> Parenting web.pdf

Know where to signpost/refer parents once identified as needing extra support

It is vital that the purpose of this process is to provide a route for parents with a significant learning need to be given extra support as needed.

#### Assessment

Service planning should be based on assessment of need.

Key features of this kind of assessment are:

- They take account of parents' strengths
- They take account of other informal supports already available e.g. relatives
- > They recognise families' needs and circumstances in the broadest sense e.g. poor housing
- They are carried out, where possible, in the home where surroundings are familiar

More detail about good practice in assessment can be found in the Scottish Good Practice Guidelines in Supporting Parents With a Learning Disability or Parenting Assessments for Parents With Learning Difficulties.<sup>12</sup>

#### A Coordinated Response

As stated above, a multi-agency response is required to provide an affective supported parenting approach. These agencies will include the NHS and social work department, and

<sup>&</sup>lt;sup>12</sup> Parenting Assessments for Parents With Learning Difficulties - Key Messages, WTPN (2014) http://www.bristol.ac.uk/sps/wtpn/resources/

will probably also include other local authority departments and third sector agencies. For these agencies to work together effectively, the following elements must be in place:

- Shared values and objectives
- Openness and honesty
- Trust
- Complimentary skill bases
- Understandable and effective information sharing processes
- A clear and shared understanding how services are resourced to provide this kind of support

Ideally, all agencies will have been involved in developing an interagency protocol that makes explicit roles, responsibilities and lines of communication. The Social Care Institute for Excellence has a template of local, joint-working protocol for supporting disabled parents. It is available online <a href="here">here</a>.

A commissioning strategy should be based on an audit of current service provision and an identification of gaps in provision. It may be that some of the support activities listed above for parents with learning disabilities are already in place from a number of agencies e.g. midwifery, health visitors, Home Start. In this case the first step is to identify service gaps. When doing this, take into account whether the current services:

Can offer the long term support required by many parents with learning disabilities



- Can offer the flexible support that parents need
- > Can offer the intensity of support that some families need
- Can offer support for activities that may not be seen as 'parenting activities'
- Have the experience to support people with learning disabilities

For example, health visitors will offer an enhanced level of support to families that are identified as needing it. However, health visitors cannot see the family beyond the child's fifth year, may not be able to provide support in the evenings or weekends, cannot offer daily support, may not be able to address housing problems, debt management problems etc., and may not feel confident about supporting parents with learning disabilities. So there is a range of 'gaps' that need to be identified in mapping current provision.

The views of parents with learning disabilities should inform all stages of the commissioning of services, namely:

- > Identifying gaps in provision
- Design of services
- Monitoring and review of services

As well as commissioning the right services, it is important that within mainstream and specialised services, staff have the training they need to provide the appropriate level of support. This advice on commissioning recognises that the move towards self-directed support means that parents will increasingly have more choice over the support services they use. However, the vital importance of commissioning good quality service will remain.

#### **Key messages**

#### from parents

The People First (Scotland) Parents' Group has developed key messages for any supported parenting service:

#### What?

- ➤ A 'Team Around the Family' is best: one team that can meet all our needs
- > Independent advocacy is very important.

#### When?

- > Support as long as we need it (even if that's a long time)
- > Needing long-term support doesn't mean you are a bad parent.

#### Where?

➤ In our own home, our own environment with our own stuff so that we can relax

#### Who?

- ➤ In line with self-directed support, we should have a choice about who provides our support
- ➤ Home support should not be provided directly by Children and Families Social Workers because these social workers have the powers to remove children where necessary, it is hard to trust them to support us
- There needs to be a shared commitment and budget between Children and Families Social Work and Adult Services.

#### How?

- ➤ Treat us equally: any other parent is allowed to fail without being labelled a failure.
- > Show not tell
- > Repeat as needed if we need things repeated it doesn't mean we can't learn

#### Research/Good

#### **Practice**

#### **Examples/Resources**

The Refreshed Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities gives further information about supported parenting. It also has sections on:

- The evidence base for the kinds of support that lead to good outcomes
- Good practice examples from Scotland and England
- Available resources for professionals and parents, including training providers

The link for the Good Practice Guidelines is <a href="http://www.scld.org.uk/scld-projects/working-with-">http://www.scld.org.uk/scld-projects/working-with-</a>
<a href="parents/parenting-guidelines">parents/parenting-guidelines</a>

#### **Good Practice**

#### **Example**

As stated throughout this document, a 'supported parenting approach' will look different in each locality, depending on its current services, structures and systems, as well as on the particular support needs of its local population. This is an example of how one locality, Fife, developed a pre-natal pathway following supported parenting principles

#### Pre-natal pathway for parents with a learning disability

#### **Partners**

NHS Fife, Barnardos and Fife Council

#### **Main Aims**

To develop a care pathway to improve service delivery for pregnant women and parents with a learning disability.

To deliver a *supported parenting model* with input from Barnardos to ensure we maximize the joint skills and knowledge of the voluntary sector, NHS Fife and Fife Council.

#### **Outcomes**

The overall outcome we wanted this to achieve was that parents feel better supported to fulfil their roles as parents and understand the key emotional and physical needs of their babies

Other broad outcomes we aimed to achieve, as described and measured using Barnardo's Outcomes Framework were:

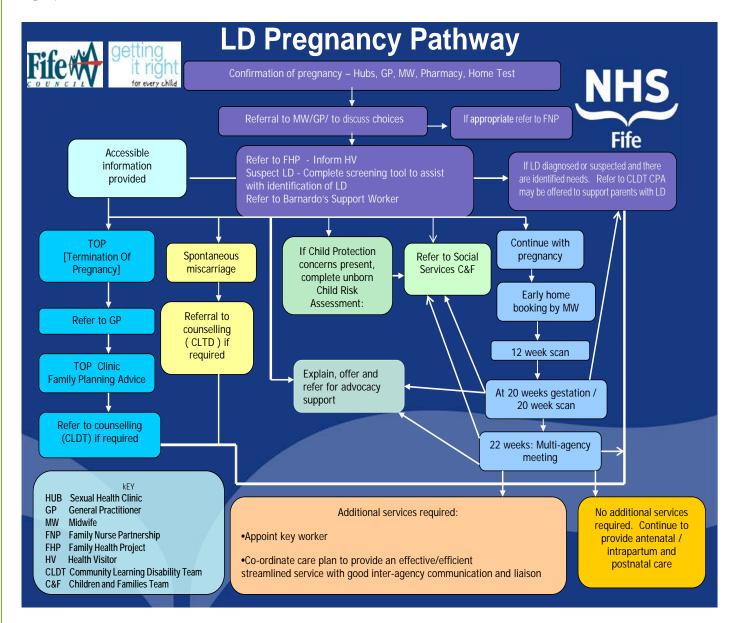
- Improved Parental Confidence
- Improved Parenting
- Improved Access to Support Services

In developing this pathway we wanted to ensure that each component of the pathway was confident in fulfilling its own part of the 'support jigsaw', and were confident about referring and signposting appropriately to other agencies for other, complementary, support.

The pathway provides pregnant women and families with a more practical, 'hands on' approach, for example help in relation to parenting issues, meal preparation, shopping, etc.

#### **Components of Project**

The pathway is led by the Family Health Project and supported by a Support Worker employed by Barnardo's. It links to other services, principally NHS Adult Learning Disability Community Service, Advocacy services and Health Visiting services (see graphic below).



#### **Key features of this pathway include:**

- Close working links between NHS Fife Family Heath Team, Barnardo's support worker and NHS Fife Adult Learning Disability Community Service
- Undertaking needs-based, asset-based assessments of families' support needs
- Accessible Parenting resources, especially the Parenting Resource Pack, My Pregnancy, My Choice and You and Your Baby. Making sure these were given to families in good time, and that parents were supported to understand the key messages

- Supporting and developing flexible and responsive services that provide advice, support and guidance to parents with learning disabilities
- Working in partnership to assist in the development and implementation of intensive 1:1 provision for families
- > Supporting and developing childcare, play and early learning opportunities
- providing a role model for parents in promoting and supporting good practice
- providing an advocacy service as identified through the needs assessment process, and making appropriate referrals to this service
- working in a non-discriminatory, culturally-sensitive manner which encourages all families to access support services
- working closely with other agencies and the local community to promote collaborative working
- working in partnership with the team leader, to cascade 'on the job' learning and share knowledge/skills amongst services

#### **Outcomes**

Over the last 2 years (to April 2015) supportive work has been undertaken with 21 mothers. The three outcomes outlined above were achieved in all cases.

An additional outcome in 12 of these cases was that the male partners fully participated in the pathway and were able to develop their skills and learning in terms of their role as a father.

Of particular note is that at commencement of the pathway 12 mothers' unborn children were already on the Child Protection Register. At the completion of their engagement with the programme 9 of these unborn children had been removed from the register. We cannot categorically prove that the impact of the programme was the major factor in these removals form the register however we can assume that the programme was a significant factor in these decisions.

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The Working Together With Parents Network is funded by the Esmee Fairbairn Foundation. This Network aims to achieve better support for parents with learning disabilities by addressing current policy and practice. Members include parents and a wide range of social workers, health and education professionals, and workers from the voluntary sector.







