

Scoping Exercise: Supporting Parents with Learning Disabilities: Challenges and Opportunities

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Principles of Supported Parenting

- Support should be available from pre-birth onwards
- Support may need to be ongoing at every stage of the child's development
- Support must be based on respect for the parents and for the emotional bond for the parent and child
- Support should be for the family as a whole rather than individuals
- Parents should be supported to be in control and to experience being competent
- Support should focus on building strengths
- Families are best supported in the context of their own extended families, neighbourhoods and communities.

Overview of Session

- What we asked
- How we did it
- What we found

What we asked



- What range of services is available to supporting parenting for parents with learning disabilities across Scotland?
- To what extent do parents with learning disabilities have access to services based on the principles of supported parenting?
- To what extent are professionals following the Scottish Good Practice Guidelines for supporting parents with learning disabilities?
- What outcomes are being achieved for parents with learning disabilities from the perspectives of key contacts?

How we did it

- Looked at the available evidence of what works
- Electronic Survey across Scotland including network members, SWS learning disability and children and families sub-groups, heads of midwifery services and lead nurses group
- Interviews with key stakeholders across key geographical areas, (Glasgow, Edinburgh, Fife, Tayside and Ayrshire)

Limitations

- Not known how many people received the survey due to secondary circulation
- Lack of a voice for parents with learning disabilities themselves.
- Lack of evidence over outcomes for parents being effectively recorded
- Lack of data on outcomes for children

What do we already know?

- Evidence based parenting support programmes work
- Limited evidence of the long term effectiveness
- Limited evidence on outcomes for children
- Limited availability of accessible information
- Importance of advocacy
- Importance of joint working

Findings (1)



- Numbers of parents with learning disabilities is unknown - problems with data that is collected
- Lack of clear and consistent data collection across agencies – who counts what and how this is recorded
- Inconsistent use of language

Findings (2)

- Type of assessment of learning disability
- Progress in early identification
- Challenges:
 - impact of stigma
 - lack of understanding of need
 - need for self-referral
 - poor joint working
 - perceived costs

Findings (3)



- Referrals – how decided and where from?
- Trigger point primarily CP concerns
- Generic v specialist services: learning disability only or vulnerable parents?
- Benefits of multi-disciplinary team to support parents with learning disabilities

Findings (4)

Assessment of parenting capacity, for example PAMS, specialist v's generic v's adapted.

Awareness growing but not widespread use

Challenges:

- time taken to complete the assessment
- purchasing a license
- training staff

Findings (5)

Support available

- Prenatal and postnatal services, e.g. around the birth of the baby, toddler
- Services focusing primarily on the development of parenting skills – parenting programmes
- Services that support the parent with issues around parenting in its broadest sense – including tackling the impact of poverty and deprivation
- Advocacy and representation – including legal representation
- Support for children – primarily focused on child development and attachment.

Findings (6)

- **Key features of accessible information:**
 - provision of graphic or other visual information
 - avoid too much information at one time
 - repeat key messages
 - provide verbally also
 - materials and processes should be translated through the use of advocacy

Findings (7)

- Impact of poor joint working
 - Adult and children and families services
 - Parent often not eligible for service provision in their own right
 - Importance of input of third sector organisations
 - Focus on CP process undermines strengths based approach

Discussion (1)

Scottish Good Practice Guidelines

- 87% aware of guidelines, 79% used in their everyday practice
- Influential in practice development
- Useful in raising awareness of the issues faced by parents and promoting a rights based approach

Discussion 2

- Progress towards supported parenting
- Pre-birth support – progress has been made
- Ongoing support – lack of progress in this area
- Strengths based approach – respect for parents, viewing the family as a resource, parents being in control, building on strengths

Discussion (3)

Support for the whole family:

- Narrow focus unlikely to result in positive outcomes
- Importance of looking more broadly at the families circumstances, including tackling social issues and the needs of the child
- Reducing perceived conflict of interest.

Conclusion



- Parents can and do become good enough parents
- Support required to do so needs to be long term and intensive but flexible
- Whole family approach required
- Appropriate assessment tools required
- Accessible information needs to be provided to ensure meaningful participation
- Specialist parenting programmes should include: appropriate teaching and learning methods using visual and graphic material, opportunities for repetition, modelling of behaviour and longer timeframes for learning.