



What Works For Parents With Learning Disabilities?

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Barnardo's has been promoting an evidence-based approach to children's services since the mid-1990's. During the past 12 years we have commissioned leading academics and expert practitioners to review research about 'What works?' for children in a wide range of subject areas.

In 2005 Barnardo's re-launched the series of 'What works?' publications, bringing the material up to date and also including new titles.

What works for parents with learning disabilities? is a revised and updated version of a report first published in 2000. Parenting is a difficult task under any circumstances. When parents have intellectual limitations, especially where their situation is compounded by poverty, poor housing and lack of social support, providing an adequate standard of care for their children may prove an insurmountable task. The book addresses the following questions:

- how can we support adults with learning disabilities in their parenting?
- which assessments are most effective in assessing a family's strengths and needs?
- how can interventions be tailored to the needs of the family?
- how can we enhance the likelihood of better outcomes?

What works for parents with learning disabilities? will offer all professionals in statutory agencies, voluntary agencies and health services useful information to provide the best service. It emphasises the importance of inter-agency work in enabling parents with learning disabilities to access effective and relevant services.

Contents of *What works for parents with learning disabilities?* include:

1. Learning disability and parenting

2. Why parents with learning disabilities are of concern to health and social care services

3. Assessment

4. Services

5. Interventions

6. The future

Key messages about learning disabilities and parenting

- The primary task of health and social care services is to provide parents with learning disabilities with the support they need in order to care adequately for their children.
- As with all childcare practice, the welfare of the child remains paramount and must precede any consideration of parental rights.
- Parents' rights and children's welfare are best supported through a combination of positive attitudes and evidence-based practice.
- While a precise division cannot be made between parents who are and who are not affected by learning disabilities, parents with learning disabilities share a sufficient commonality of need which may require a specialised response.
- Many health and social care services perceive themselves as insufficiently well equipped to deliver this response.

Key messages on why parents with learning disabilities are of concern to health and social care services

- While the association is ambiguous, there is strong evidence for a genetic link between parental learning disability and child development delay.
- Where families receive insufficient support, any genetic vulnerability to development delay in children may be compounded by a paucity of environmental stimulation.
- Behavioural problems, particularly in boys, and corresponding difficulties in parental management may arise when the child's intellectual capacity exceeds that of their parents.
- The prevalence of childhood abuse is likely to be greater among parents with learning disabilities than in the general population.
- In the absence of adequate support, a maternal IQ less than 60 can be considered a factor predictive of inadequate parenting.
- The main predictor of competent parenting is an adequate structure of professional and informal support.

- Poverty and disadvantage cannot entirely account for the difficulties disproportionately experienced by parents with learning disabilities, hence remedial interventions must address individual, environmental and wider social problems.

Key messages on assessment

- A combination of diagnostic and functional assessments are available which are tailor-made to suit the specific needs of the family. Avoid battery assessments using a block approach (the same combination of tests applied each time to all parents). This can be a crude process and potentially damaging to vulnerable parents and children who are subjected to indiscriminate testing, regardless of their clinical presentation.
- Use assessments which have been selected discretely (standardised on adults with learning disabilities) and which will not be re-administered in another format during an assessment phase. Tests or questions which are repeated within a short time-frame are vulnerable to distortion.
- A holistic approach is necessary when assessing a family's strengths and needs. However, this does not mean that each member of a family should be assessed. Where just one child or one parent within the family appears to be experiencing difficulties, a single assessment may be indicated.
- Assessments should ideally include fathers or other men involved in the family (even when they are not the child's father) to establish any positive or negative contributions they are making to the household and the extent to which they are promoting or inhibiting the well-being of the child or children.
- An inter-agency plan is crucial as it can identify who is best suited to assess the family. Such an approach will avoid repetition and will be effective in terms of professional time and 'wear and tear' on the family.
- Assessments must take account of environmental factors, social stressors and the support available to families, all of which may be determining parental competencies.
- Assessments are inevitably intrusions into the life of parents and children; unless mandated by a court, informed consent is essential and the information collected should be no more than is necessary to achieve the intended task.

Key messages on services

- A range of interventions are needed from which service providers can 'pick and mix' to suit the needs of the families they serve.
- Interventions should be designed in association with a diagnostic and functional assessment (see Chapter 3). The intensity of the programme and mode of intervention (whether group work, individual programme, combinations of both, or residential) will be determined by the findings of this assessment.
- Where indicated, long-term support should be provided for those families who need it. Families respond well to services which provide consistency and permanence in terms of staff support and resources.

- Long-term funding is required to enable service providers to build up a range of effective interventions and to have the skilled staff in place to use them.
- Resources should be used that match the level of understanding and preferred approach (e.g. pictures, modelling, role playing) of each parent who is involved with the service.
- Interventions should promote transfer (otherwise known as generalisation) from one skill to another, or from one setting to another.


Key messages on interventions

- Interventions should build on parents' strengths as well as their vulnerabilities.
- Interventions should be based on performance rather than knowledge and should incorporate modelling, practice, feedback and praise.
- Tangible rewards may promote attendance at programmes, rapid acquisition of skills and short-term commitment. Other methods of engagement are needed long term. Intensive service engagement is more demanding than intermittent service engagement, though it may be more effective.
- In order for generalisation to occur, programmes should be adaptable to provide training in the actual environments in which the skills are needed.
- If teaching must be provided out-of-home, it should be in as home-like an environment as possible.
- Factors which promote resilience in the children's environment should be identified and enhanced.
- The importance of family ties should be recognised and no actions taken that damage such ties.
- Interventions should diminish, rather than cause or contribute to, the social exclusion of the child and parents.

Key messages on the future

The following will enhance the likelihood of better outcomes for parents with learning disabilities and their families.

- Clinics that provide health checks, sex education, contraceptive advice and support to adults with learning disabilities.
- Parenting education in schools, specifically designed to meet the needs of children and adolescents with learning disabilities.
- Training to professionals, especially those working within the primary care services (midwives, health visitors, community nurses, GPs) to enable them to identify vulnerable prospective or actual parents with learning disabilities and to prepare them for parenting.
- Training to generic service providers to increase their understanding and skills regarding the complexities of engaging vulnerable parents with services.
- Multi-agency working across services using a standardised approach to assessment, intervention and support, including long-term support, with service protocols and performance indicators in place to raise and maintain clinical standards.

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- Service design, delivery and maintenance that is characterised by partnership with parents.
 - Research that is of clear use to families.

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The full report is available to purchase on-line from www.barnardos.org.uk/resources

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