

What Works for Parents with Learning Disabilities? – Summary

Author: Susan McGaw
Report Published: 2000

The 'What Works?' series

Some ways of dealing with problems work better than others. Every child has the right to expect that professionals intervening in their lives will do so on the basis of the best available knowledge. But the majority of interventions in social care are not evaluated before they are introduced. In that sense, much of the work done with children is an uncontrolled experiment.

Barnardo's has a special interest in evidence-based practice, that is, finding out what works, and ensuring that the interventions we and others make in children's lives are as good as they possibly can be.

As Roy Parker and his colleagues have pointed out:

'A hundred years ago, the benefits of providing separate care for deprived and disadvantaged children were thought to be self evident. It has since become increasingly apparent that unless outcomes in childcare can be adequately measured, we have no means of justifying the actions of social workers, which may have far reaching and permanent consequences for individuals.'

Qualitative work, and user studies, for which the UK has a good record, are important in understanding the processes which enable interventions to work well, and understand what service users most value. They do not, however, help us to know what interventions work best, or why.

In order to understand cause and effect - the relationship between a particular intervention and an outcome - randomised controlled trials are important. RCTs in the UK and North America include studies of day care, home visits, accident prevention, and other early childhood interventions.

The cohort studies, such as the National Child Development Study (NCDS) enable us to see who does well after a poor start in life, and understand what factors may lead to resilience.

Barnardo's What Works reports draw on a range of research designs and evaluations which suggest that particular interventions are worthwhile.

This report in brief

Attitudes to parents with learning disabilities have changed considerably in recent decades. There is much more acknowledgement than before that while many such parents face specific and challenging problems, they remain parents, with the same hopes and fears as others. *What Works for Parents with Learning Disabilities* is a review of what we know about the most effective ways of providing support. It draws on empirical evidence and research to establish a knowledge base for practitioners and those charged with developing services.

The report falls into six parts:

- A general discussion about learning disability and parenting.
- Why parents with learning disabilities are of concern to health and social care services
- Ways of assessing families.
- Ways of intervening
- What is known about effectiveness
- Current service issues

Learning disability and parenting: general comments

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 child care 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 many common needs. Service providers need to be wary of the argument that all parents should be treated alike and offered the same services as the mainstream population. A specialised response is often required. Many health and social care services do not feel they are equipped to deliver this response.

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

Work with parents with learning disabilities is challenging. American studies report that as many as 50% of their children are estimated to be at risk from abuse/neglect and 25% may be taken into care. Some families are so vulnerable that no single agency can address all their needs. Support services can feel overwhelmed by the demands placed on them, which in turn can leave families suspicious of health and social welfare services, fearing in particular that their children will be taken into care.

Despite the vulnerability of both parents and children, there are few support services for parents with learning disabilities and a lack of specialist training for professionals. Often the strengths of the parents remain unidentified and basic information about whether they need help with, for example, reading, writing or counting is unknown. Research suggests that:

- There is evidence for a genetic link between parental learning disability and child developmental delay.
- Where families do not get enough support, any genetic vulnerability to development delay may be compounded by lack 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.
- Parents with learning disabilities are more likely than the general adult population to have been abused as children.
- Adults with IQs below 60 are unlikely to be able to parent adequately unless they receive effective support.
- The main predictor of adequate parenting is a firm structure of informal and formal support. Inadequate parental support includes untrained staff using interventions designed for other populations, confused multiple agency involvement, no parenting models, no parent support or a husband/partner with an emotional disorder who is abusive. A lack of friends, neighbours, family and community may be even more disabling.
- Poverty and disadvantage cannot entirely account for the difficulties disproportionately experienced by parents with learning disabilities. Remedial interventions must therefore address individual, environmental, and wider social problems, such as lack of social support.

Assessment

A careful assessment is essential before starting work with parents with learning difficulties. A number of issues must be borne in mind:

- A combination of diagnostic and functional assessments can be used to suit the specific needs of the family.
- A holistic approach is necessary when mapping the family's strengths and needs. However this does not mean that each member of the family should be assessed. Where just one child or one parent is having 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), especially when children are affected by their presence or thought to be 'at risk' from them in some way.
- An inter-agency plan is crucial. This can identify who is best suited to assess the family, thus avoiding repetition, saving professional time and reducing 'wear and tear' on the family.
- Assessments must take account of environmental factors, social stressors and the support available, all of which may be determining how well parents cope.
- Assessments inevitably intrude into the life of parents and children. Unless mandated by a court, informed consent is essential and the information collected should be only what is needed for the intended task. Helping parents with learning disabilities say 'no' may be as useful a learning experience as encouraging them to say 'yes'.

Interventions and services

Once an assessment has been done, there are a number of ways of working. How effective they are is largely determined by resources and the extent to which the intervention chosen meets the families' needs.

Group work

In the UK group work is a favoured method. Parenting groups tailored to the special needs of such parents, with practical activities included, can be a powerful catalyst for change. Programmes which build in concurrent home based interventions as well as individual work with the client before the group begins seem to be particularly effective.

Home-based one-to-one teaching

Parents with learning disabilities generally respond well to individual teaching programmes but standard parenting teaching packages need to be modified.

Combinations of home-based and group programmes

These programmes need substantial resources but can be a very effective form of support, particularly when help is offered long-term.

Residential programmes

Residential placements may be necessary when the home environment is unsuitable for teaching purposes, the child is at risk in the home setting, or resources at home are inadequate. But residential programmes should be used with great care. Parents often do not maintain newly learnt skills once they are back at home. The disturbance to the family and child caused by taking them out of their home and neighbourhood must be weighed against the possible benefits of an intensive programme in a safe environment.

The report outlines other resources for professionals - manuals and booklets for parents, board games and equipment (such as an electronic doll which looks, cries and demands attention like a real baby).

Implications for practice

Some general implications for practice emerge:

- A range of interventions are needed from which service providers can 'pick and mix' to suit the families whom they serve. Long-term funding is required to build this up and to have the skilled staff in place.
- Interventions should be designed in the light of a diagnostic and functional assessment. The intensity of the programme and approach (whether group-work, individual programmes, combinations of both, or residential) will be determined by the findings of this assessment.
- Long-term support should be given when needed. Families respond well to services which provide consistency and permanence in terms of staff support and resources.
- Resources should be used that match the level of understanding and preferred approach (e.g. pictures, modelling, role-playing) of each parent involved.
- Interventions are needed which help parents turn knowledge into skills in the home setting.

Effective interventions

Attempts to measure the effectiveness of interventions with parents with learning disabilities are often dogged by methodological issues. For example in looking at existing research it is important to consider:

- How families were recruited
- The research design used
- Moral issues such as the ethics of establishing control groups among 'high-risk' families and the concern that some of the parents studied may not fully understand the purpose of the research.

Few long-term outcome studies have been conducted into the health and well being of grown-up children of parents with learning disabilities. One small retrospective study however concluded that children's destinies are not fixed by having a parent with learning difficulties.

Despite the paucity of robust studies existing research offers some useful findings for practitioners:

- Interventions should build on parents' strengths as well as their vulnerabilities.
- They should be performance rather than knowledge based and include 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.
- In order for generalisation to occur, programmes should be adaptable to provide training in the actual environment 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.
- The longer and more intense the training the more chance of the improvement being maintained. It is important to continue teaching throughout parenthood as parents encounter different challenges during different stages of their children's development.

Current service issues: implications for practice

The final section of the report takes a broader look at services aimed at the whole community and concludes that the following services would benefit parents with learning difficulties and their families:

- Clinics that provide health checks, sex education, contraceptive advice and support to adults with learning disabilities
- Parenting education in schools designed to meet the needs of children and adolescents with learning difficulties. The psychosexual development of people with learning difficulties mirrors that of other adolescents. They therefore need school-based sex education as much as their peers, particularly as girls with mild to moderate learning disability are at increased risk of early pregnancy and dropping out of school.
- Teaching on sexuality, adulthood and parenting as part of the curriculum within special education.
- Training to professionals, especially those working in primary care (midwives, health visitors, community nurses, GPs) to help them to identify vulnerable prospective or actual parents with learning disabilities and prepare them for parenting.
- Training to generic service providers to increase their understanding and skills in 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
- Service design, delivery and maintenance that is characterised by partnership by parents.
- Research that is of clear utility to parents.

Conclusion

The task of balancing the rights and responsibilities of parents with learning disabilities and the welfare of children is highly complex. Although there are gaps in the research on what works best in supporting such families, some clear messages for practitioners emerge.

First, research and service delivery must be done with sensitivity and respect. Vulnerable and powerless populations are always easier to research than rich and powerful ones. Parents with learning difficulties often receive attention from too many professionals rather than too few and are often over rather than under assessed.

Second, there are as yet few specialist services and more specialist training is needed.

Third, careful assessments followed by interventions which are intensive, reliable and where necessary long-term are most likely to give the best outcomes for both parents and children.

To order a full report

To purchase a copy of the full report please contact:

Barnardo's Publications,
Barnardo's Trading Estate,
Paycocke Road,
Basildon,
Essex, SS14 3DR

Tel: 01268 520 224
Fax: 01268 284804

Or email your order stating the title of the publication(s) together with your full name, billing address and contact telephone number to: jo.barnes@barnardos.org.uk