







### **Acknowledgements**

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#### This evidence summary is based on the following systematic review

Wilson, S., McKenzie, K., Quayle, E. and Murray, G. (2014). A systematic review of interventions to promote social support and parenting skills in parents with an intellectual disability. *Child care, health and development* 

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# Interventions to promote social support and parenting skills for parents with an intellectual disability

## What is the intervention?

This systematic review covered two types of intervention for parents with intellectual disability; interventions designed to teach parenting skills and those aimed at strengthening social relationships. Parents with an intellectual disability are at an increased risk of losing custody of their children (Booth and Booth, 2005). While the exact number of parents with intellectual disability is not known there has been an increase in the number of social care referrals in this group where an estimated 40-60% fail to meet the standards required for 'good enough parenting (Department of Health and Department of Education and Skills, 2007; Cleaver and Nicholson, 2005; McConnell et al., 2000). Most referrals are made based on concerns about neglect or emotional abuse.

Research findings show that parents with intellectual disability may experience difficulties parenting effectively due to limited cognitive ability, environmental factors such as poor support networks, the negative attitudes of others and the increased risk of poverty, inadequate housing as well as poorer mental and physical health than parents who do not have an intellectual disability (Aunos et al, 2008; O'Keefe and O'Hara, 2008; Mayes et al, 2006; Cleaver and Nicholson, 2005; Kroese et al, 2002; Feldman et al, 1992). Nevertheless, it has been argued that with adequate support, parents with intellectual difficulty can parent appropriately. This systematic review by Wilson and colleagues (2013) examined interventions designed to promote social support and parenting skills of parenting with intellectual disability.

The systematic review included seven studies, covering six different interventions. Two studies (McGraw et al 2002; McConnell et al 2009) reported on interventions aimed at social relationships and five studies (Feldman and Case, 1999; Feldman et al, 1999; Llewelyn et al, 2003, Mildon et al, 2008; Brisson et al, 2010) reported findings for interventions designed to improve parenting skills. Interventions varied from individual home-based self-directed learning to group interventions. Wilson



and colleagues (2013) highlight the paucity of research for intervention effectiveness and as such only two of the included studies met quality criteria. Therefore, findings must be treated with caution.

## Which outcomes were studied?

- Improved social support networks
- Improved parenting skills

# How strong is the evidence?

The evidence base is relatively weak.

The review included seven studies relating to six interventions where only two studies met the quality criteria the review authors employed (the Scottish Intercollegiate Guidelines Network, 2008). Of these two, one study (Llewellyn et al, 2003) adopted a randomised controlled design and one study (McGaw et al, 2002) adopted a between-group repeated measures design. Of the remainder, two studies included a within subject multiple baseline design, and four included a single group repeated measure design.

Sample sizes were small, ranging from four to 45 participants (mean = 22). The majority of participants were mothers, so there is little evidence of whether these interventions are appropriate or effective for fathers with an intellectual disability (Wilson et al, 2014). Included studies are also limited by the use of different definitions of intellectual disability. Four of the seven studies specified the IQ range of participants whereas other studies relied on a combination of official diagnosis, IQ, attendance at special educational needs classes in school, and self-diagnosis. This range of definitions means that findings cannot be generalised to all parents with intellectual disabilities. Further, in Mildon et al.'s (2008) study, all participants had existing involvement with child protection services, further reducing the generalisability of findings. The review is limited by small sample sizes, limited use of follow-up measures and a lack of child outcome measures.

Acknowledging these limitations, the authors state that findings relating to the strengthening of social relationships are inconclusive. While the evidence was slightly more robust for interventions that taught parenting skills, these results must also be treated caution due to the limitations outlined. Nevertheless, Wilson and colleagues (2013) highlight that given the increasing referral rates for



parents with intellectual disability and the paucity of available research data this review offers important preliminary findings.

## Effectiveness: how effective is the intervention examined?

#### **Outcome 1: Social relationships**



#### **Outcome 2: Parenting skills**

Effect rating	0
Strength of Evidence rating	0

Findings for impact on social relationships were inconclusive (McGaw et al, 2002; McConnell et al, 2009). McGaw et al.'s (2002) pilot study of a group intervention aimed at improving the self-concept of parents and the quality of relationships was conducted with 22 parents in a special parenting service in the UK. Findings showed a significant improvement in self-concept for the intervention group from post group to follow-up (p < 0.05). No significant differences were found regarding feelings about their children or judgements about their child's capabilities (p > 0.05). Positive changes were found for 64% of the intervention group. McConnell et al.'s (2009) pilot study of 42 mothers participating in the Australian Supported Learning Programme across six sites found intervention participation led to small but positive effects (d = 0.35) on mothers' social support networks.

Findings from Llewellyn et al's (2003) randomized controlled trial of a Home Learning Programme with 45 parents found that behaviour-based skills interventions may be more effective than less intensive interventions such as lesson booklets or normal service provision. Successful elements included increased ability to recognise home dangers and precautions (p < 0.001), understanding symptom recognition and illness (p < 0.025), knowledge of skills need to manage emergencies (p < 0.001), and knowledge about using medicines safely (p < 0.001). Findings showed a decrease in improvements for home safety precautions and health understanding from post to three-month follow-up.



In the remaining studies, mixed findings emerged. Feldman et al. (1999) found that based on a sample of 10 mothers, childcare skills increased as a result of using illustrated instruction manuals, with a significant increase on test scores from baseline to treatment and treatment to follow-up (p < 0.001). Mildon et al. (2008) found that the home-based intervention pilot with 24 parents led to a positive, but non-significant improvement in parents' home environments.

## Mechanisms: how does it work?

The authors briefly comment on the causal pathways that might lead to improved outcomes. They note that mothers with larger, more helpful social networks report better psychological wellbeing (Kroese et al, 2002). Hence, they suggest that social support has a key role in successfully performing the parenting role (Wilson et al, 2013). Further, interventions that adopt a behavioural skills-based approach within a home-like environment facilitate the adoption and generalisation of parenting skills.

# Moderators: When, where and who does it work for?

The majority of studies were conducted in Australia followed by Canada and USA. Only one of the 7 studies took place in the UK.

Most studies focused primarily, or solely, on mothers. Across all seven studies, 138 participants were mothers, whereas only 19 fathers were included across the studies. Samples are therefore not sufficiently large to suggest whether outcomes will differ according to gender.

A number of moderators were suggested across the different interventions, all of which may have affected outcomes. McGaw et al. (2002) noted that some parents in their study had previously attended a similar group programme, meaning that outcomes may have been the result of a cumulative effect of multiple interventions. Similarly, Llewellyn et al. (2003) suggested that an inconsistent level of input received by parents may have affected the success of the intervention.

McGaw et al. (2002) found that single parents had a higher level of negative self-concept, which may lead to interventions being less effective for this group.

Across two different studies (Feldman et al., 1999; Feldman and Case, 1999), intellectual ability was highlighted as a moderator. Feldman et al. (1999) suggest that reading ability and comprehension



levels may impact the effectiveness of interventions based on the use of pictorial manuals to help improve parenting.

# Implementation: How do you do it?

Included interventions adopted a variety of methods including individual home-based approaches and group interventions. Individual interventions involved self-directed learning at home. Two interventions (Feldman and Case, 1999a; Feldman et al., 1999) used pictorial manuals and accompanying audio description which outlined 25 specific skills related to childcare. Two interventions (Llewellyn et al., 2003; Mildon et al, 2008) used trained parent educators who visited parents at home to teach childcare skills. Home visits in Llewellyn et al.'s (2003) study were supplemented by illustrated guidance booklets with the intervention delivered over three months. Whereas the intervention period was longer in Mildon et al (2008) at six months but no additional materials were used.

Two interventions adopted group-based approaches (McGaw et al, 2002 ; McConnell et al, 2009). McGaw et al.'s (2002) study focused primarily on parents' social skills and understandings, where parents took part in semi-structured group activities over 14 weeks (similar detail is not provided regarding McConnell et al.'s study).

## **Economics: What are the costs and benefits?**

No economic analysis was included in the study.

## What are the strengths and limitations of the review?

Wilson and colleagues assessed studies using the Scottish Intercollegiate Guidelines Network (SIGN, 2008). While only two studies could be assessed using this tool, the authors provide a detailed description of the strengths and limitations of all eight studies. In doing so the review highlighted the limitations of existing studies relating to lack of comparison groups, small sample sizes and sampling strategies, including the variation in definitions of intellectual disability employed



by studies which limit the generalisability of findings. This means that no definitive conclusions can be drawn from the studies reviewed. However, the authors note that preliminary findings suggest there may be positive changes in social relationships and that behavioural interventions may be effective in improving parental skills amongst parents with intellectual disabilities. The authors suggest that large-scale, controlled studies are needed to determine which components are effective for whom and for how long.

# Summary of key points

- There is a lack of robust studies of interventions aimed at social support and parenting skills of parents with intellectual disability.
- Existing studies are limited by small sample size, lack of generalisability, limited follow-up measures, limited information on intervention intensity and a lack of child outcomes measures
- Findings relating to social support are inconclusive although there was some evidence that positive change may be possible.
- There are preliminary findings that behavioural interventions may be more effective for improving parenting skills than less intensive interventions such as normal service provision or lesson booklets.
- Large-scale, controlled studies are needed to determine which interventions ae effective and to identify which components are most effective for whom and for how long.



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