

EVIDENCE SUMMARY

Peer support interventions for parents

KEY MESSAGES

- Parents and carers of children with special needs often have health and wellbeing challenges due to the demands of high-intensity care.
- These parents can become socially isolated and miss out on the health and wellbeing benefits of social support. They may also have difficulty accessing services.
- Peer support interventions provide a support network, and the opportunity to access knowledge and resources.
- The organisation of a peer support group and the skill of the group leader contribute to the success of the group for its members.

What is the evidence around peer support interventions for parents and carers raising children with special needs?

CHALLENGES FOR PARENTS AND CARERS

Raising a child with special needs can be stressful and isolating. The day-to-day practicalities of care can be emotionally and physically demanding. It also takes time and energy to attend appointments, follow up with therapy at home, advocate for the child, and navigate a complex service system. There can also be financial demands due to therapy or medical expenses, or if the carer must work fewer hours or in a lower paid job.

Parents and carers of children with a disability, a developmental delay, learning difficulties, or other chronic conditions often have to juggle competing needs. The needs of the child must be balanced against the needs of other family members. Carers may have less time and energy for social and leisure activities for themselves.

It can be difficult to take a child with special needs out because of:

- the child's physical needs (such as needing a wheelchair)
- behaviour that is frustrating to the carer (such as tantrums)
- behaviour that is unsafe for the child (such as running away).

Parents and carers can feel that their community or family don't understand their child's condition. They may feel they have to explain things, or educate people. They may even feel stigma, either because of what other people say or do, or because they are worried about what other people may be thinking.

As a result, these parents and carers may go out less. They may even be excluded from social gatherings. They can feel isolated and lacking in support.

WHAT ARE THE EFFECTS ON PARENT AND CARER WELLBEING?

One consequence of isolation is that parents and carers of children with special needs may have difficulty accessing services and support. Yet these parents have challenges of their own. Life-long informal care-giving is associated with increased physical problems such as back pain and migraines, and

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psychological problems such as depression, anxiety and stress. Carers can have short-term emotional distress such as guilt, sorrow and frustration. They may experience loneliness, uncertainty and lower life satisfaction. This may be particularly so in families with younger children and children with behavioural problems. When a carer is ill, he or she may be less able to manage the child's condition, setting up a cycle of negative outcomes.

HOW DOES SOCIAL SUPPORT HELP?

Social support – sharing the company of someone who is emotionally concerned with us, who tries to understand our situation and offers help or advice – alleviates stress and isolation. Social support is good for everyone, whether or not they are under stress. Social support helps families with special-needs children cope (Hogan et al. 2002).

Parents and carers of children with special needs may benefit particularly from the social support of their peers: people who they see as their equals, who share their experiences and challenges. Peers can ask each other questions, and provide emotional support and advice.

PEER SUPPORT INTERVENTIONS

Peers can support each other in many ways. Some peer support is informal, such as a gathering of parents in a local park, a phone call between friends or a Facebook group.

There are also more formal peer support interventions for parents of children with special needs. These may be professionally developed, and led by paid staff, but they differ from other professional interventions because the knowledge and skills shared by the parents are practical, and derived from personal experience rather than formal training.

Peer support interventions can:

- take place in person, by telephone or online
- be one-to-one or in a group
- be peer-led or facilitator-led.

They all aim to foster peer-to-peer interactions and increase social support in a form that is most useful and acceptable to participants, thus improving their wellbeing. As well as providing social support, peer support interventions can support participants by increasing access to local social and health services, and providing them with resources relevant to their child's condition and other family issues.

EVIDENCE FOR PEER SUPPORT INTERVENTIONS

There is some good evidence for the health and wellbeing benefits of particular peer support interventions. For example, randomised controlled trials of two different programs (the Family-to-Family Network, and the A-PLUS program) found that telephone, face-to-face and group peer support reduced anxiety in mothers with children with chronic illness (Chernoff et al. 2002; Ireys et al. 1996).

Overall, parents and carers in peer support interventions report improved wellbeing – feelings of belonging, support and empowerment, for example. They feel less isolated, and they expand their social and support networks by meeting outside the program. They feel more able to cope, and less depressed, guilty or lonely. Participants also report they learn more about caring for their children from being involved in peer support programs.

The findings of randomised controlled trials have been more mixed. One review examined the evidence around peer support for parents of children with chronic disabling conditions (Shilling et al. 2013). It found that, overall, controlled trials were not able to detect differences in outcomes for parents receiving peer support.

EVIDENCE FOR FACILITATED PEER SUPPORT GROUPS

Compared with peer support interventions in general, there have been fewer studies on formally facilitated peer support groups.

One model for providing facilitated group peer support is to train facilitators who come from the same community as the group members. The Empowering Communities, Empowering Families program is designed for groups of parents with children with problem behaviour. Parents receive training delivered by the facilitator from the course manual, and also receive peer support from a discussion component.

There is good evidence that this model improves positive parenting practices and reduces children's problem behaviour. The program had a very low dropout rate, probably because these parents felt comfortable receiving information from someone who was similar to them (Day et al. 2012).

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MyTime is a facilitated peer support intervention for parents and carers of children with special needs that is not structured around a formal course manual. In this model, trained facilitators manage the groups' processes but do not provide counselling, although they do provide evidence-based resources to the groups as necessary. Play helpers engage children in appropriate play activities while the groups are in progress.

In an evaluation of MyTime, group members expressed high levels of satisfaction in the program, and reported very positive experiences and impressions (Department of Families, Housing, Community, Services and Indigenous Affairs 2013). Parents and carers gained access to more information about how to care for their children, through practical knowledge derived from the experiences of their peers, as well as the resources provided by the facilitator. Members received the advantages of a peer social-support network, and their links to the community also increased as they often met outside of group times.

WHO BENEFITS FROM PEER SUPPORT?

It has been suggested that effective social support must be reciprocal. But this does not mean that everyone in a peer support group must be at the same stage, and not all families with children with special needs have the same requirement for support.

Qualitative research on MyTime found benefits for participants with a range of family circumstances (Hammarberg et al. 2014). Positive views on the value of the social and practical support offered by the program were expressed even by people who were no longer attending or whose participation was only short term.

There is some evidence that families with special-needs children display similar levels of functioning to families with typical children. Having time and resources to adjust to a diagnosis, and being part of a support group, have both been suggested as factors contributing to the functioning of these families (Van Riper 1992).

Parents who are in the early stages of adjusting to a diagnosis may benefit from the expertise of these 'veteran' parents, who are more used to their situations and have learned ways to manage their children's conditions. And veteran parents providing peer support can also experience enhanced quality of life and a validation of their experiences.

As well as the general beneficial effects for a family when the primary carer's wellbeing improves, peer support groups can benefit the siblings of children with special needs. The evaluation of MyTime found that siblings attending the group became more understanding and accepting of their brother or sister's condition through playing with similar children and interacting with the play helpers.

ARE THERE ANY RISKS?

In some cases, social-support interventions may damage participants' self-esteem by reinforcing their self-image as a member of a stigmatised group. Hearing too many negative experiences as part of the intervention can actually cause anxiety or depression in some participants through mood contagion, and the perception of available social support can worsen. There is also the danger of negative group interactions, such as difficulty fitting in or bullying within the group. However, this is one reason for providing facilitators: recognising and averting potential mood contagion and other negative group dynamics is a key skill for facilitators.

WHAT MAKES A GOOD GROUP?

Organisation and leader capability are associated with the wellbeing improvements from belonging to a support group. The MyTime evaluation found that good groups had good staff. When the facilitator was seen by parents as being skilled and empathic, parents reported that group discussions were productive and that they benefited from being part of the group. But when facilitators were seen to be too controlling, or were unable to manage the groups effectively, parents found the groups to be unproductive. Also, children not effectively managed by the play helpers were disruptive to the parent groups.

The research around peer support can indicate how the balance of a group may also affect the benefits received by its participants. For example, the Parent to Parent peer support program for parents of children with special needs was less successful when the parents considered that their children's challenges were different to those of their peer partners' children (Singer 1999). Similar issues around differences in parent education and the child's level of disability came out in the qualitative study of MyTime. Cultural and language barriers can also make groups unsuccessful for some participants.

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SHARED SOCIAL IDENTITY

In many peer support groups of parents of special-needs children, simply having similar problems and experiences was enough to form a shared identity and feeling of support. A shared social identity fosters a sense of belonging and the feeling that support is at hand. This feeling – as much as any actual support received – is one of the most important reducers of stress in parents and carers raising children with special needs.

MYTIME

MyTime is coordinated nationally by the Parenting Research Centre in partnership with 14 state-based agencies. There are 214 MyTime groups across Australia.

FURTHER READING

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MyTime: www.mytime.net.au