Department of Social Services Summary report: Peer support for families with young children with disability and developmental concerns

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Summary report

Good social supports are critical to the wellbeing of parents/carers, their ability to parent responsively and to successfully navigate the health, education and disability systems that support their children.

> *Just as the core thing that a child needs is attachment, bonding, security, people who are totally committed to them and respond appropriately to them, someone needs to be able to give to the family. Someone has to be crazy about that kid, and someone has to be crazy about their caregiver. The quality of your parenting will be affected by your support network. The majority of people have people who can share the load, and provide them with emotional support. If they don't and they are resourceful enough they find them, through mothers' groups or whatever. However, that is not a system that works consistently. Some people don't have support and this is where government can step in.* Academic/researcher

Australia's Disability Strategy 2021-2031 (the Strategy) is Australia's national disability policy framework. The *Early Childhood Targeted Action Plan* (EC TAP) sits under the strategy and focuses on children from infancy to school age with disability or developmental concerns, their families, and carers.

This research study was commissioned by the Department of Social Services to support implementation of Australian Government EC TAP Action 3.1: *Analyse existing community support models of peer networks, to identify inclusive, innovative and adaptable approaches and to support participation of all parents and carers. This includes, but is not limited to support models tailored for rural and remote locations, Aboriginal and Torres Strait Islander and culturally and linguistically diverse parents and carers*. The methodology comprised:

- A review of the literature
- Qualitative and quantitative fieldwork with parents/carers of young children with disability and developmental concerns, including 10 small group discussions and 16 in-depth interviews, and an n=323 online survey
- Qualitative fieldwork with people working in peer support, the disability and early childhood sectors and in research and policy roles, including 35 interviews and 7 online workshops.

Fieldwork was conducted in June and July 2022. This report summarises key findings and recommendations.

Key findings

Mapping peer support options available to parents

The literature review found that peer and social supports have increasingly been adopted across the health and community service sectors as a means of increasing social connectivity, reducing stress, and addressing unequal power relations between professionals and individuals. Research shows that beneficiaries value peer support and describe benefits that include increased confidence, a sense of belonging and a positive sense of community. Peer support has also been found to increase families'

capacity and skill development, including how to access information and services and advocate when their needs are not being met.[1]

The review identified three categories of peer support (1:1, group, and online) which were then validated through the primary research. The peer support categories, and models of support under those categories are:

- 1:1: Telephone information and lines; support to navigate systems
- Group: Short-term information and capacity building; ongoing parent support groups; supported playgroups; events/activities
- Online: Websites; online communities/Facebook; podcasts; apps.

The review found little evidence for how different peer support categories or models contribute to outcomes for families, including with respect to attracting and retaining diverse families and families with more complex needs. The primary research also explored what parents/carers of young children with disability and developmental concerns value with respect to peer support. It found that the benefits of peer support are not tied to particular delivery modes or programs, but rather linked to opportunities for emotional support, insider insights and information, system navigation and social connection. These benefits can equally be derived from 1:1 or group, online or in person, one off or prolonged engagements – depending on the design of the program and the preferences and needs of parents/carers.

Limitations/Gaps

Whilst comprehensive, the current peer support system for families with young children with disability and developmental concerns is fragmented and lacks connections to the broader early childhood service sector. Substantial gaps exist with respect to providing 1:1 and online supports, and supports for:

- families who are pre-diagnosis, who are not connected to the National Disability Insurance Scheme (NDIS), and who are waiting to access services
- families navigating access to the NDIS and education systems
- fathers and male carers
- First Nations and culturally and linguistically diverse families, including migrants on temporary visas
- families experiencing significant life challenges
- families living outside metropolitan areas.

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[1](Hammarberg et al., 2014) (Meltzer et al., 2020)

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However, there appear to be broader issues with the reach of peer support programs, and barriers to engagement. In addition to gaps for specific population groups, there are also issues of loneliness and isolation at the population level. A significant proportion of parents/carers of young children with disability and developmental concerns do not have access to good emotional supports, or the opportunity to talk about their child's needs and strategies for addressing these. Some described a vicious circle where feelings of anxiety or anger put up further barriers to engaging with other people in their lives.

To illustrate, of the parents/carers surveyed:

- 58% would like more connection with other families with children like theirs but don't know where to find this
- 66% have someone they can talk to when they have questions about their child's needs
- 60% have someone to workshop problems and solutions with
- 48% say that they often can't get help when they need it
- 31% don't have anyone they can confide in
- 29% have no one to lean on in times of trouble.

I feel like I've no one I can turn to if I have a problem, no one to delegate things that need to be done so I feel overwhelmed and under stress everyday. I feel like it makes me less patient when raising my child, and I fear this will have an impact on them as they develop. Parent/carer

Opportunities

Our analysis has suggested that there is an opportunity to better meet the needs of parents/carers of young children with disability and developmental concerns through providing more consistent opportunities to engage in peer support, and tailoring opportunities to better meet the needs of families. However, achieving this would require changes to funding arrangements, how programs are delivered, and significantly more coordination and cooperation between peer support delivery agents than currently exists. The following design issues will also need to be addressed.

No one peer support model will meet the needs of all

Parents/carers with young children with disability and developmental concerns express a preference for a variety of peer support models (group/1:1, face-to-face/online/telephone/ text, ad hoc or ongoing). They note that these preferences might change over time and with situational need. In addition, many families may not be looking to *formal programs* for emotional connection, and may prefer peer supports to come through their natural networks. These varied preferences emphasise the need to offer a range of peer support options, and that there is no 'one size fits all' approach to meeting needs – rather, a peer support system is required.

Effective peer support design requires co-design and deep listening

Whilst the different peer support models have strengths and weaknesses, it is not possible to predict what options will be most appropriate for any given population cohort. To illustrate, some culturally and linguistically diverse and First Nations parents/carers in this research study preferred peer support options that sat within their cultural community, whilst others wanted to engage with families in their geographic community. Co-design of peer support, and deep listening, are required to determine what will best meet the needs of individual parents/carers – by definition, this involves place-based supports rather than a strict model imposed at the national level. Local communities and organisations are best placed to support translation of good peer support practice in a meaningful way.

Low awareness of the available peer support options and lack of interest in 'reaching in'

Many parents/carers of young children with disability and developmental concerns are not aware of what peer support is available or would not reach in if they were. The benefits of peer support aren't immediately obvious to parents/carers, who tend to put their own emotional support needs last. This again emphasises the need to work through existing relationships of trust – and through local communities and organisations.

A broader role for peer support than 'programs'

The literature specific to peer support for families with children with disability and developmental concerns typically focuses on programs. This emphasis is reflected in the service system. Other sectors – notably mental health – use the concept of lived experience to frame the role of personal experience. The benefit of this frame is that it helps shape a broader role for lived experience – where people with lived experience are central to the design and delivery of the overall disability sector, rather than merely program recipients or facilitators.

It is also possible to think about the role of peer support for parents/carers beyond the disability sector. Moore, for example, argues that the starting point for designing peer support interventions should be mapping families' broader social ecosystems, and that these may encompass a variety of service sectors – not just disability.[2] This lens considers connection to peers and the broader community as a social determinant of child and family wellbeing, and prioritises natural networks, including existing child and family services connections. In this context, professionals could note that the role of peer support as an enabler of good parenting is not limited to parents with young children with disability and developmental concerns – and that many families would benefit from more support with respect to parenting. This includes parents of children with disability and developmental concerns pre-diagnosis.

Monitoring and evaluation

As mentioned, there is little evidence for the effectiveness of peer support interventions in the literature and a need to think about how to more consistently measure the success of peer support. Developing a national monitoring and evaluation framework would provide a basis for more consistent measurement.

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[2] Personal communication as part of an interview for this study.

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A consistent, coordinated peer support system

This research study has suggested the need for a tiered approach to developing peer support interventions. This acknowledges that not all families require additional intervention, and for those that do, different levels of support are likely to be appropriate. The table below illustrates this continuum of support.

TABLE 1. TIERS OF PEER SUPPORT

	Family descriptor	Support needs
Tier 1	Families with children with disability and developmental concerns	Additional support required with respect to disability/developmental concerns: e.g. system navigation, goal setting and supporting children in natural environments
Tier 2	As above, and with poor social connection/means to create connections	As above May also need social and emotional supports May need support to engage
Tier 3	As above, and experiencing serious life challenges or cultural barriers to engagement	Disability peer services layered through existing (place-based and culturally specific) service delivery

The requirements for a peer support system are outlined in more detail in the table overleaf.

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TABLE 2. REQUIREMENTS OF A PEER SUPPORT SYSTEM: KEY FEATURES OF A WELL-FUNCTIONING AND HIGHLY VALUED PEER SUPPORT MODEL

Identified needs	Why this is needed	What this looks like	Role of peer support
A 'way in' to peer support	There is a need to create ways for parents/carers to understand the peer support options 'menu'	Multi-dimensional universal touchpoints (e.g. baby bag, mothers' groups) as well as soft entry points (e.g. warm referrals from early childhood and community services) and social media advertising to interrupt online searches	Create an understanding of the full menu Community Champions as connectors
Responding to a diagnosis	Parents/carers tell us that initial diagnosis can be devastating, and they don't always get good support at this time	Universal peer support offered at the time of diagnosis that is closely connected to health system This is a 'sitting with' service that doesn't demand anything of families – may be face-to-face or linkage service	Support for distress and providing a sense of hope and optimism (parents/carers and children can lead thriving lives post-diagnosis) Permission to 'feel as you feel' through empathy/ understanding
1:1 system navigation	Whilst there are many group offerings supporting system navigation, there is little 1:1 peer support at key transition points	A universal 1:1 system navigation service	Peer workers can provide advice on navigation with a 'ground up' perspective, as well as emotional support
Family goal setting	Goal setting that promotes family centred participation can support engagement with the NDIS	Peer-led positive vision planning is encouraged before engaging with the NDIS planning process	As per above
Connection with peers	Whilst this isn't often a primary driver for parents/carers to engage, the consensus amongst those who have engaged with peer support is that it is much needed	Multifaceted programs to meet different needs: e.g. low-pressure opportunities to trial support options; socialisation for children; action focus for men and so on….	Peer workers as per above Peers as participants (parents/carers, children, siblings, extended family)
Information, advice and skills building	A key driver for parents/carers to engage	Meeting a variety of parent needs via universal and more tailored approaches (e.g. from websites to group supports)	Peer workers and participants as per above
Mainstream inclusion	The mainstream (e.g. service system and other families) is not genuinely accessible and inclusive	Social marketing campaigns targeted to families, capacity building for the early childhood, community and recreation sector workforces	Encouraging families in the general community to be more inclusive to make natural peer support a more viable option
A safe space	Whilst mainstream services/the general public can be judgemental or not a good fit developmentally, there can be a need for safe spaces where families with young children with disability and developmental concerns are naturally included	Supported playgroups, recreation opportunities, including family activities/days out specifically for those with children with disability/developmental concerns	Peer workers and participants as per above

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Options for short-term funding

The following section outlines discrete actions that could be undertaken under EC TAP Action 3.2. *Pilot a peer-led support program. Develop and trial innovative new approaches for peer-led supports tailored for particular cohorts, co-designed by parents and carers of children with disability or developmental concerns, and people with disability.*

This evidence base has not suggested that there is one specific model that should be implemented. Instead, the need is to learn from and build on existing good work and incorporate the design principles outlined above.

Option 1. Promote peer support options – mainstream workforce capability building

Key issue	There is an opportunity to build the capacity of the early childhood workforce to make warm referrals to peer support.
Role of peer support	Warm referral to peer support.
Example activity	Include a focus on peer support in workforce capacity building programs (existing and new).

Option 2. Fill system gaps via peer support

Key issue	Families have emotional needs that are not being met through the current service system. This includes through key transitions, such as waiting for a diagnosis or access to services. Service gaps are likely to be particularly acute or exacerbated in rural and remote areas.
Role of peer support	Where there are thin markets or service gaps, there appears to be an opportunity to build capacity in the community to meet families' practical and emotional support needs.
Example activity	An example workshopped with stakeholders in the study is to recruit and train paid peer workers in rural/regional/remote areas who would be based in local hubs (e.g. neighbourhood houses, child and family hubs) to create social opportunities and support goal setting and development strategies.

Option 3. Support equitable access

Key issue	A number of useful peer support options have good coverage in some jurisdictions but not others.
Role of peer support	Differs depending on the nature of the peer support activity.
Example activity	An example is 1:1 system navigation, which is currently offered in some but not all jurisdictions.

Option 4. Layer service delivery

Key issue	Families with multiple challenges and in culturally specific settings will likely benefit from layering supports that are usually offered through disability-specific peer support programs.
Role of peer support	Varies depending on the nature of the peer support activity.
Example activity	A way to do this would be to fund existing programs that use peer support or have strong community connections or place-based approaches. Ideally these

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Key issue	Families with multiple challenges and in culturally specific settings will likely benefit from layering supports that are usually offered through disability-specific peer support programs.
	programs would be mentored and supported by disability-specific peer support organisations.

Future considerations

Option 5. Promote peer support options – communication campaign

Key issue	A key barrier to families accessing peer support programs is that parents/carers simply do not realise these programs exist.
Role of peer support	Promotion of peer support options.
Example activity	A multifaceted government campaign directly communicating the availability of peer support options to parents/carers.

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