

# Why family leadership is important

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Some parents of children with a disability or developmental delay may stand back and let service providers do the work. That's understandable because therapists and other professionals are important—but they are a part of a bigger picture.

When children are little, family leadership plays a big role in building a good life. Parents see themselves as experts, too, with many skills that help their child develop. They understand that service providers are one part, not the focus, of achieving positive outcomes. Parent peer workers are an emerging workforce with training and lived experience in disability who can help families nurture these leadership values.

Peer workers, other professionals and families of children with disability or developmental delay attended an IIDL workshop, hosted by Plumtree to discuss how family leadership can be activated during the early childhood years. IIDL (International Initiative for Disability Leadership) is a global forum dedicated to building effective leaders among disability peer networks, service providers and policymakers and sharing innovative practices and resources.

Activating family leadership involves a system-wide change. Messages of hope and possibility upon diagnosis instead of the deficits and a connection to a peer worker or peer-led service can be life-changing for families.

Peer supports are valuable because all families can access them, regardless of NDIS funding. With lived experience in raising a child with disability, parent-peer workers can establish an authentic connection and help in areas such as emotional support and sharing practical information. Their work complements the services of therapists and other professionals.

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## Why family leadership is important

The following statement was written by and for peer workers, other professionals, and families of children with disability or developmental delay. It was developed at the IIDL Match Building family leadership through peer work in the early childhood years: Activating family participation, hosted by Plumtree in June 2021.

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### Family leadership means parents and carers

- See themselves as an expert on their child
- Feel equipped to take the lead in partnerships with professionals and communicate their child and family's needs
- Understand that service providers are one part, not the focus, of achieving positive outcomes
- Are confident about making the right choices

### Empowering families of children with disability or delay is valuable because

- Big picture visioning is vital when children are very young
- It enables families to navigate a life of citizenship, acceptance and purpose for their child
- A family-centred, strengths-based approach helps align school and other services to desired positive outcomes
- After building agency and expertise through professionals and peers, families go on to empower other families as a part of a peer-led organisation or network
- Strong family leaders nurture leadership skills in their children

### Peer supports are valuable because

- With lived experience in raising a child with disability or delay, peer supports complement the work of professionals
- Peer workers help in areas such as emotional support, building family agency, and sharing practical information
- They are available for all families, including those without funded support
- Through an authentic connection, they help transform families from focusing on a child's deficits to a positive outlook
- They take families from a surviving mindset to a thriving mindset

### Family leadership and peer-led services can be further developed by

- Promoting the value of parents as peer workers and family leadership to families, and encouraging their participation
- Engaging and training more diverse peer workers to support Indigenous communities and ones where English is not the first language
- Service providers and peer workers creating and supporting peer-led programs and organisations with communities of people with disabilities
- A system-wide approach to ensure that families experience consistent messages of hope and possibility