ACD

Snapshot: Carer Supports

May 2025

Background

ACD is the Victorian advocacy service for children with disability and their families. We are a not-for-profit organisation led by, and for, families of children with disability.

Our vision is an inclusive community where children with disability and their families thrive.

In May 2025, ACD ran two *Have Your Say* consultations with parents and guardians of children with disability. The sessions focused on supports within the scope of Victorian and local governments.

This snapshot highlights the perspectives and distinct needs of families of children with disability, with a focus on paid work and financial security, access to respite, and social connection and isolation.

These findings are particularly timely with the Victorian Carer Strategy currently undergoing a refresh — a whole-of-government approach aimed to recognise and support carers.

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Executive summary

ACD ran two *Have Yor Say* consultation sessions with families on the topic of Carer Supports. The consultation primarily focused on supports within scope of the Victorian and local governments and the topics:

- Employment and financial security
- Respite
- Social connection and isolation

Families shared a wide range of social, emotional and practical supports they value as parents and guardians of children with disability. This included formal disability and carer services, such as NDIS-funded support workers and family-led workshops, as well as support from their family, friends and peer networks.

The marginalisation carers experience in the workforce was a consistent challenge raised by families. Many had left paid work entirely, while others described working fewer hours, accepting lower-paid roles, or working beyond paid hours to meet both work and caring responsibilities.

Those who remained in the workforce said that understanding employers and flexible work arrangements, such as working from home or flexible hours, were essential in enabling them to continue working. In contrast, a lack of flexibility from employers was seen as a major barrier to maintaining employment.

Families also identified inclusive schools as a factor that would make a difference to families' financial security. They spoke about how the need to pick up children early, homeschool due to a lack of appropriate schooling options, or the inability to access out-of-school hours care made it difficult or impossible to maintain paid work.

Families called for easier access to respite support. This includes more information about what supports are available, reduced wait times, and less burden of proof on carer status and 'need' for support. Many emphasised the importance of flexible respite offerings to meet the individual needs of the family. For example, offering in home support for children who find it distressing to leave their familiar environment.

Events, retreats, and activities delivered by family-led, grassroots and not-for-profit organisations were described as valuable forms of respite. Families expressed the desire for these opportunities to be more widely available and offered more frequently, particularly in remote and regional communities.

Beyond carer supports, the capacity of mainstream systems and community services to support and meaningfully include children with disability was viewed as crucial in supporting the respite of families. For example, holiday and after school care and recreational activities.

Families shared the importance of connecting with other families with similar experiences and how isolating it can feel when you don't have others in your network who understand your circumstances. Families emphasised the importance of peer support activities and groups, the immense loss when these programs were defunded, and the need for greater access for these supports in regional and remote areas.

Families emphasised how they viewed their social connections as being inseparable from the inclusion of their entire family unit. They wanted to see more inclusive community activities as a means for their children to increase their social participation and build friendships, as well as for parents to engage in community activities as any other family would.

Finally, families expressed the need for greater access to mental health supports, as well as resources that help them plan. They spoke about the emotional weight of caring and the pressure of making complex decisions. They called for more supports that recognise and respond to the ongoing nature of this role.

1. Valuable supports for carers

Families shared what supports they found most helpful – practical, social and emotional.

Many highlighted the important of family, including "*chosen family*", and friends, especially for help with caregiving responsibilities, family logistics, and emotional support through non-judgemental listening.

> *"I know that my mum, personally just has made a huge difference to just having the extra set of hands sometimes. … Even just sometimes having an extra set of hands in the house or put on a lot of washing … I think that's hugely important."*

Participants also shared how beneficial support workers and formal family, disability and carer services had been to their family, particularly when support could be accessed without having to jump through hoops to prove their carer status and need for support.

> *"I think it was really nice when I called them … there was no need to sort of prove that I was a carer. [Their] sort of stance was that you wouldn't be contacting us for fun."*

Grassroots and family-led groups, as well as workshops, were identified as essential sources of information and support.

Schools also played a significant role when they demonstrated understanding, creativity, and flexibility. Families valued schools that took a holistic approach to student wellbeing and worked with them to find solutions.

2. Paid work and financial security

Impact on paid work

It is well-established that carers are one of the most disadvantaged groups in the workforce. This was evident when talking with families in the *Have your Say* sessions. Parents and guardians, overwhelmingly women, shared that they had been forced to leave work entirely or struggled to re-enter the workforce.

The time needed for their caring responsibilities, the lack of understanding and flexibility from employers, and inadequacies of systems, such as schools, transport and out-of-school hours care to meet the needs of children with disability, and balancing the emotional cost of caring with workplace stress were all raised as challenges for families.

Families described several challenges, including:

- Time-intensive caring responsibilities
- A lack of flexibility and understanding from employers
- Inadequacies of systems (e.g., schools, transport, out-of-school hours care) to meet the needs of children with disability
- Balancing the emotional cost of caring with workplace stress

> *"I found it difficult to get the hours that suited me as a carer and lost shifts because I couldn't start work at nine or take shifts at school pick up times. I have had to resign from paid work due to school not being able to support my child."*

> *"Unable to work a permanent job caring for all in the family as single parent. Lost a good job once having to attend son's medical so often with no other support or extra help."*

For those who remained in the workforce, many reported reduced earnings due to part-time hours or working in lower-paid roles.

> *"I believe that although this is unspoken, I have likely missed on promotion."*

Participants also shared that they found there were fewer job options, with not all employers or job types offering the flexibility needed.

> *"Not being too popular for employers that do not like to offer flex working time."*

> *"It has been difficult to get a job with the flexibility we need to care for our kids. So, I don't work. The emotional cost of caring for a child with a disability also impacts my ability to work."*

> *"I have not been able to pursue my professional dream [of] running my own business."*

In contrast, many families raised the immense, positive impact that trusting and understanding employers had on their ability to balance work with their family's needs. This included capacity to work from home, flexible hours that allowed for conflicting demands, such as attending medical appointments and school pick up, and flexibility to take time off.

One participant added that the combination of both her and her partner's employers offering flexible work solutions was essential in helping their family balance childcare duties and needs.

> *"Having a supportive understanding workplace has made all the difference for me."*

Supporting families' employment and financial security

Families were asked to rank seven supports based on what they believed would be most helpful to families' financial security.

Participants voted inclusive kinder, schools and childcare, including out-of-school hours care and flexible work arrangements as the factors likely to make the biggest difference to their financial security.

> *"After school care won't accept my child."*

> *"I've tried to get my daughter registered at her mainstream outside-school-hours program, but it keeps getting put in the 'too hard' basket by the company who runs it."*

> *"I found it difficult to get the hours that suited me as a carer and lost shifts because I couldn't start work at nine or take shifts at school pick up times. I have had to resign from paid work due to school not being able to support my child."*

The option most frequently voted as making the least difference was sessions with a financial planner.

See Appendix A for the full list of options and results.

Families also mentioned maintaining their skills through volunteering and online courses. They suggested that increased access to free education for carers would be highly beneficial.

Additional recommendations to support families' financial security include greater awareness of Carer Card entitlements (i.e., the same as the Seniors Card) among businesses, and payments for those not entitled to Commonwealth carer income supports (e.g., not an Australian citizen, above income and asset thresholds).

3. Respite

Families shared what supports were needed to support carers to have respite, or in other words, take a small break from their caring responsibilities.

Accessing timely and appropriate respite services

A consistent theme was the difficulty in accessing formal respite services, particularly for those who are not eligible through the NDIS.

Families expressed the need for:

- Increased funding for, and availability of respite
- Reduced waitlists
- Simplified access processes
- Less burden of proof of need

"Supports that you don't need to fight so hard for … the way you need to speak about how bad your life is to prove you require assistance."

"We have been on [the] waiting list for Victorian Support for Carers for ages - no options."

Rigid processes and definitions, such as 'parental responsibility' and who is the 'primary' caregiver are not reflective of the dynamics and complexities of the lives of families of children with disability and create barriers to respite.

"A change of mindset that although young children are mainly parents' responsibilities, [but] young children with a disability require a lot more additional support from their parents comparing to able body peers."

"Include immediate family members on respite not just the main carer [because if respite is only offered to the] main carer then they can't really rest unless they get funding for a support worker to care for the child too."

Respite support needs to have flexible offerings to meet the individual needs and preferences of children and families. For example, some raised how respite support outside of the home environment or separated from their family would not work for their needs.

"Being able to have joint respite where care[r] and child [are] in [the] same facility where they can be under [the] same 'roof' but in parallel groups. My child struggles to be away from me."

"We've started to use more online groups and activities for our kiddo - this gives us small windows to get things done!"

"Respite away from home is not always easy."

Others mentioned that they were not aware of what respite support and activities there are in their community, if any.

Support for the entire family unit

Family retreats and activities, typically run by not-for-profit, grassroots and family-led organisations, were frequently cited as a valuable form of respite. Families wished to see increased availability (including in remote and regional areas) and frequency of these programs, as well as subsidised family holidays.

"Funding for individuals, families, for weekend retreats with other families - including connection and support for mental health, educational sessions for parents and feel-good activities for children."

"Camps or something similar for [the] family to go away at no cost so [the] family can have break but have availability with a support work[er] available to give you a break also."

"Give vouchers out to families for accommodation"

Support for siblings was also highlighted as a key gap in carer supports.

"Programmes for us to spend time with the sibling who might be neglected because of the care required for their affected sibling."

"Workshops and webinars for siblings."

Further, families emphasised the importance of making mainstream services more inclusive and accessible, recognising this as a crucial form of respite. They want better access to the same services and activities that families of children without disability regularly use and rely on. Many families highlighted the urgent need for more inclusive out-of-school hours and holiday care programs.

"Outside-school-hours care for kids with disability & school holiday programs."

"School holiday activities that [are] available to be accessed kids with wheelchairs."

They also raised the need for more locally delivered activities where staff are skilled and trained in working with children with disability.

"Local council funding inclusive activities/programs where we can drop off and staff are trained in supporting the child without need[ing] parent/support worker present."

"Training and education for complex self-care needs. Toileting support major barrier for accessing any program."

"More mainstream services and activities after school that actually are neurodiversity affirming and accessible!"

4. Social connection and isolation

Peer support

Carers are more likely experience social isolation and face distinct challenges to participating in community life. Families were asked what forms of social connection and wellbeing support were working and what was missing.

Some families discussed the importance of their family and friends in their lives, while others shared it can still feel lonely when those around them can't fully understand their circumstances.

"Not many people understand the struggles we go through parenting the kids… Workmates, study mates and even family don't actually know what it's like and often

trying to chat with them or explaining things makes me feel more isolated, so I don't speak about our challenges to others very often."

However, there was consensus among families of the significance of in-person and online peer support groups and family activities. How valuable it was to have inclusive events and connections with families with similar experiences, how damaging it was when these programs were defunded, and the need for greater access for these supports in regional and remote areas.

"We are remote, so it feels as like compared to the whole Melbourne metro area, there's close to nothing. … Then we only got told about a not-for-profit organisation … and as soon as we got the connection with them, like, … finally, we found somebody. It was such a good feeling. And unfortunately, because we're so far away, it doesn't really make sense to drive down 3 hours for like a 2-hour meeting."

"Peer support online helps me not feel isolated as it can be accessible at all times of the night (and day), and this way you're able to find groups that align with your own values, as opposed to a [face-to-face] group where it's difficult to find our 'tribe'."

Many had built peer networks through carer activities or disability-specific activities or settings (e.g., specialist schools). One contributor added that they wished there was more awareness and inclusion in mainstream peer settings, such as Parent and Teacher Associations, so that families of children with disability can feel more included.

"I think often there can be a lack of disability awareness [of parents in mainstream schools] and how to embrace kids who are a bit different and [they] probably aren't going to get you."

Inclusive communities

Families discussed how they viewed their social connections as inseparable from the inclusion of their entire family unit. Families wanted to see more inclusive community activities (e.g., sport and 'relaxed' arts events) and settings (e.g., inclusive playgrounds and venues with accessible toilets). These are both a means for their children to increase their social participation and build friendships, as well as for parents to engage in local, community activities as any other family would.

"More availability in terms of resources of social groups, activity groups, including sport groups, will be important for my child … because I [have] struggled [for] a long time to try to find a group that have accessibility in mind when they organise activity."

"More inclusive spaces and sports/social activities to connect with other families from the beginning."

Decision-making burden and mental health supports

Families spoke about the heavy emotional and decision-making load of caring for a child with disability, and the lack of support to navigate this. They called for more future planning and mental health supports.

"An information pack sent upon diagnosis with support groups, treatment suggestions. Those first weeks after diagnosis are so daunting."

"Include planning resources for parents for how to best plan for their children."

"I would love more support to care for the carers physical and emotional health."

“Have mental wellbeing support and workshops for both the carers and the children with disability who might [be] struggle in coping.”

“Supporting us with our emotional health caring for others.”

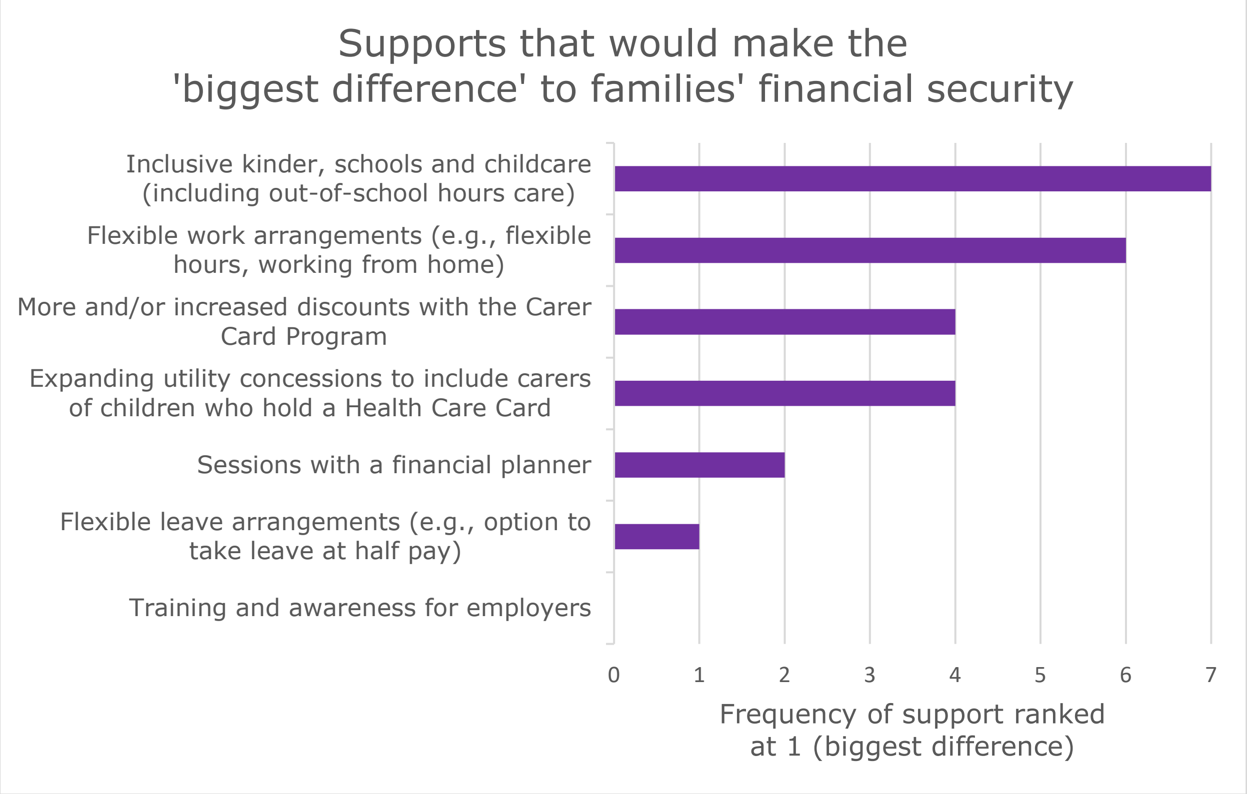
Families who participated

Twenty-nine families participated in the sessions. Their children ranged in age from 0 to 19 years, with an average age of 9. Autism was the most represented primary diagnosis. Nearly all participants were female (96%).

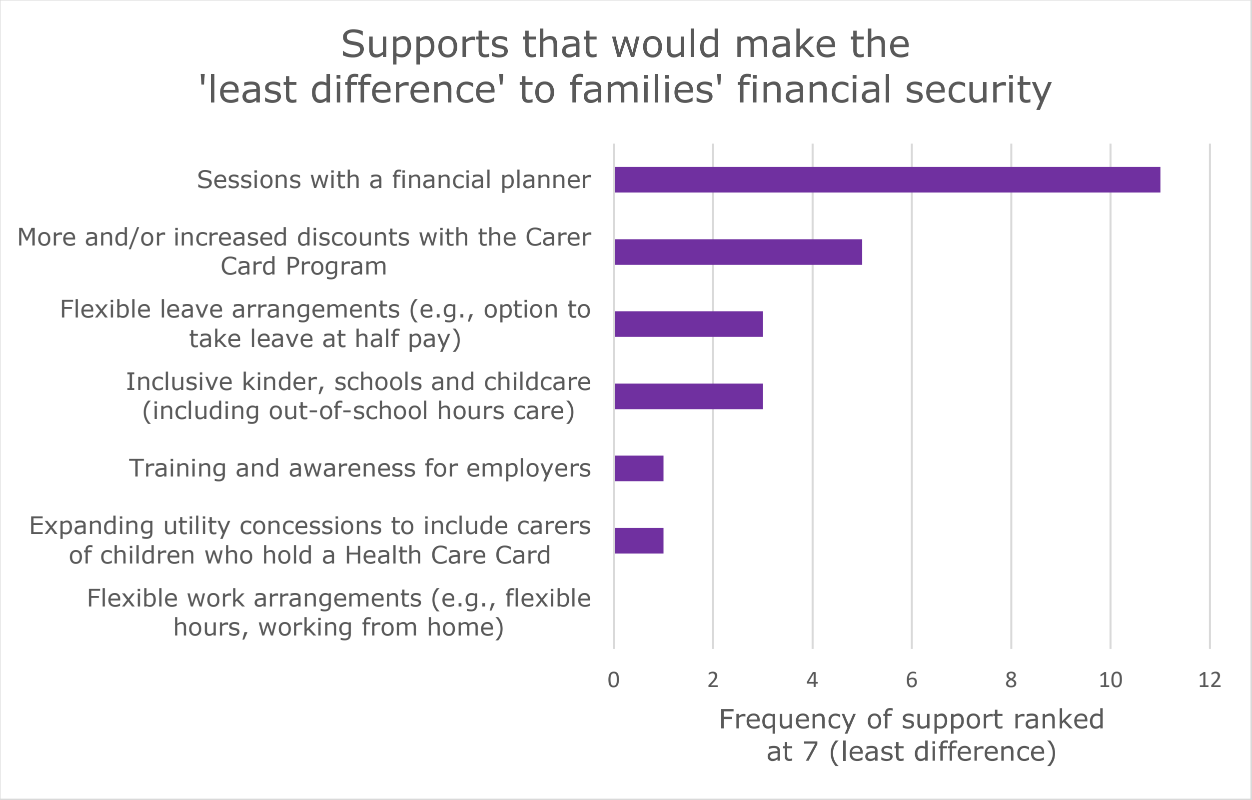
41% of participants identified as culturally and linguistically diverse. Most families lived in urban regions (85%) and 15% lived in regional Victoria.

Appendix A: Financial security supports

Families (n=24) were given a list of seven support options and asked to rank them from 1 (biggest difference) to 7 (least difference) based on what they believed would make the most difference to families' financial security.



Inclusive kinder, schools and childcare (including out-of-school hours care) was the option most frequently ranked by families as making the biggest difference to their financial security, followed by *Flexible work arrangements.*



Sessions with a financial planner was the option most frequently ranked by families as making the least difference to their financial security.