REPORT ON THE DISABILITY ASSEMBLY WA (DAWA) SUMMIT HELD ON 27 MARCH 2026

Care Succession and Planning

For Families with Intellectual Disability

Contents

DAWA Summit on Care Succession and Planning for Families with Intellectual Disability

Foreword

The vision of Disability Assembly WA (DAWA) is to unify, support and champion a thriving disability ecosystem in WA to ensure world leading and sustainable outcomes for people with disabilities, their families and carers.

A key initiative to achieve this vision is through convening a number of 'Summits' each year, bringing together people with disability, families, carers, peak bodies, advocates, providers and experienced stakeholders from diverse backgrounds to generate informed, impartial discussion and debate 'the big issues'.

The 2026 DAWA Summit program is focusing on the topic of "**Care Succession and Planning for Families with Intellectual Disability"** in Western Australia."

For people with disability, particularly those with intellectual disability, there is focus on the early years right up to leaving school, and rightly so.

The next two phases of leaving school and finding community activities and then maturing at home as parent carers are ageing are both challenging too.

Finding, discussing and planning solutions beyond this is often left until later or until it is forced upon families and carers. Often late in the piece, if at all.

What happens when parent carers can no longer provide care? For too many families, this question is deferred, avoided, or only confronted in crisis. Planning is inconsistent, often ad hoc, and almost always dependent on parent carers who are already stretched and navigating systems alone. There is no predictable timing, no coordinated pathway, and no assurance that the future will be safe, stable, or dignified for their loved one.

Western Australia is entering a pivotal moment with the peak of the baby boomer carer bubble. For decades, parent carers, many now in their seventies and eighties have carried the primary responsibility for safeguarding, advocacy, and daily decision making for their adult sons and daughters. Their dedication has been extraordinary. But the demographic reality before us is clear as thousands of families are approaching a transition point for which our systems are not yet prepared. This is no longer a distant issue.

We have reached the point where both housing arrangements and lifelong care leadership must be transferred, documented, or urgently re-designed. The risk is clear, without structured, State government supported care succession pathways, many families will face avoidable crisis, and people with intellectual disability and high and complex support needs will be left vulnerable.

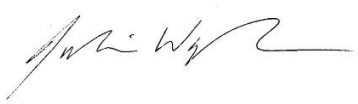
Very few plans exist. That is the warning signal. The care and safeguarding of our most vulnerable citizens and the wellbeing of the ageing carers who have supported them for decades must now be urgently treated as a priority issue.

The Care Succession and Planning for People Living with Intellectual Disability in Western Australia Summit, convened by the Disability Assembly WA (DAWA) on 27 March 2026, brought together 128 parent carers, siblings, service providers, and representatives from local and state government. Their collective insight forms the foundation of this Report. It reflects the lived experience of families, the operational realities of organisations, and the shared commitment across sectors to ensure that people with disability can live safely, securely, and with dignity throughout their lives.

This Report outlines the priority actions identified by the disability community to strengthen care succession pathways in Western Australia. It highlights the need for coordinated planning, clearer guidance for families, and system settings that support stability rather than crisis response. The recommendations presented here are powerful and grounded in evidence, shaped by lived experience, and informed by the expertise of those who work every day to support people with intellectual disability.

The work ahead is significant, but the opportunity is equally great. By acting now, Western Australia can lead the nation in building a care succession framework that honours families, safeguards individuals, and strengthens the disability ecosystem for the future.

This Report will guide ongoing collaboration, including a follow-up Summit hosted by DAWA and its partners, focused on achieving measurable and lasting outcomes for families across our State.



Julie Waylen
Chair, Disability Assembly WA

DAWA Summit Sponsors

As a volunteer organisation DAWA appreciates the support of its sponsors who enabled the Summit to occur.

Sponsors & Supporters

DAWA also appreciates the support from our partners for this Summit on Care Succession and Planning for Families with Intellectual Disability.

Summit Partners

Australian Inclusion Group

Future Living Trust

Microboards Australia

Steppin Stones (Parent to Parent)

Valued Lives

Siblings Australia

EXECUTIVE SUMMARY

Introduction

The 2026 DAWA Summit program is focused on Safeguarding and aims to address a critical issue in Western Australia: **Care Succession and Planning for Families with Intellectual Disability** in Western Australia.

There are an estimated 1.2 million primary carers in Australia (around 10% of whom are estimated to live in Western Australia) and the majority are over 45 years of age. The selection of the Care Succession and Planning topic for the 2026 summit program therefore reflects its strategic and state-wide importance, the potential to impact on a significant number of people with disability, particularly those with intellectual disability, and their families.

The care succession needs of people living with intellectual disability are urgent and growing and the imperative for a structured, government-supported Care Succession and Planning process is becoming ever more pressing.

The first part of the program was held on Friday 27th March and was attended by 128 invited guests in Perth (118), Broome and Bunbury (10).

Following brief introductory presentations by "Spotlight Speakers", the broad discussion topics for group (POD) discussions across the day were:

POD Focus Group (1) | Reflecting on your own experience and knowledge:

What are the main issues currently facing older families who cannot/will not be able to sustain a caring role for their adult children who live at home; and what initiatives or services currently exist (or previously existed) to support older families to plan for the future and put the plans into action?

POD Focus Group (2) | What is required to make enduring progress a reality?

POD Focus Group (3) - | How do we ensure the message gets through to most families, with encouragement to take the personal futures journey?

A detailed account of the Summit process and the key themes that arose within the POD discussions is provided in Appendix 1 of this report. A summary is provided below:

1) The Current Landscape: A Crisis of Carer Anxiety and Exhaustion

Aging primary carers are currently facing a crisis of anxiety and exhaustion as they attempt to transition from being the "executive managers" of their children's lives

to securing a sustainable future for them. Many families feel they have effectively become "the system" themselves due to a default reliance on their personal persistence as "the system", leading to pervasive burnout and a sense of overwhelm. A "double whammy" occurs as parents' physical and emotional capacities diminish while the system remains difficult to navigate, often forcing families into crisis-driven responses rather than allowing for the intentional, relational succession planning they desperately need.

Significant economic and systemic hurdles also impede this planning process, particularly regarding the legal and financial advice required for estate management, e.g., the high cost of specialised legal help - such as testamentary wills and trusts – is prohibitively expensive.

Furthermore, carers expressed deep concern over safeguarding gaps and the potential for abuse or neglect in formal systems that lack independent oversight. There is a widespread fear that paid supports may only provide for basic bodily needs while failing to protect the quality of life, continuity of care, and the unique "finer details" of the person's life that parents have managed for decades.

Securing safe and permanent housing remains a central concern, as many adult children remain at home because there are no realistic, high-quality alternatives that offer independence and belonging. Families are calling for "safe and forever" housing with security of tenure, expressing a profound fear of their children being "plonked" into group homes with co-residents they did not choose.

Ultimately, these families are seeking a system that provides coordinated planning and stable funding to ensure that their children's needs, routines, and preferences are understood and maintained long after the family can no longer provide direct care.

2) Concern over Passing the Care Responsibilities to Siblings

The "sibling burden" represents a significant source of anxiety for parents of individuals with disabilities, who fear passing the responsibility of care to other children by default. This concern stems from a fundamental tension between a sibling's role as a family member and their potential role as a primary carer, particularly when they may already be managing the care of ageing parents.

While parents often view siblings as essential long-term advocates who understand the "finer details" of a loved one's needs, there is a clear consensus that succession planning must be "normalised" to ensure siblings retain their own life opportunities rather than being expected to take over caregiving by default. Many parents expressed a preference for external mechanisms, such as independent advocates or visiting services, to handle financial and planning roles to preserve the family relationship.

Current systemic gaps leave adult siblings without adequate support, a situation exacerbated for those living in rural areas, overseas, or in households where English is not the primary language. To address these deficiencies, families recommend the implementation and support of sibling-specific support groups and peer-to-peer networks to facilitate practical knowledge sharing and proactive succession planning before a crisis occurs. Strategic initiatives should also focus on creating "intentional support networks," such as microboards or Circles of Support, which distribute responsibility across a formalised structure rather than leaving it to a single family member. Furthermore, providing external guardianship or decision-making support is seen as vital to ensuring siblings are not left to navigate complex systems alone.

3) The loss of Relationship-Based Support has added to the Anxiety of Families and Carers

The transition to the National Disability Insurance Scheme (NDIS) has been characterised by many older carers as a shift from a human-centric, relational model to an impersonal and bureaucratic transactional system. Participants report that the "humanity" of previous state-based systems has been replaced by a "constant churn of paperwork" and administrative compliance, which significantly detracts from their primary roles as carers and advocates and limits their capacity for proactive long-term planning.

This systemic shift has created a perceived loss of connection, with the current model often described as "combative" and "traumatic" for those navigating complex needs, where individuals are frequently treated as "receipt numbers" within an algorithm rather than people with unique social ecosystems.

To address these failings, there is a clear consensus among families on the need for the government to rebuild local, relationship-based navigation based on the proven features of the former WA created Local Area Coordination (LAC) model. This previous approach was highly valued for providing a single point of contact with deep personal knowledge of the individual and their family, facilitating a continuous and supported planning process rather than an administrative hurdle. By maintaining manageable caseloads and focusing on proactive, long-term connections, the LAC model successfully fostered capacity building and the development of informal community networks that acted as vital, grounded safeguards for the individual's future.

Furthermore, the current system has created a void in family leadership investment, with service providers often focusing exclusively on individualised funding transactions rather than working collaboratively with the family unit. Families advocate for a return to a "village" approach that prioritises intentional support networks, peer-to-peer mentorship, and relational support over a total dependency on the funding. Reinvesting in family leadership - including dedicated

support for capacity building and sustainable futures planning - is seen as essential to restoring the humanity and connection necessary for long-term stability and effective advocacy within the disability sector.

4) State Stewardship and Ownership

As thousands of families approach a critical transition point, there is an urgent need for improved stewardship and accountability by the State government to address care succession and planning. Summit participants advocate for a "Care Succession and Planning Strategy" (3-5 years) with clear timeframes and funded priorities that moves beyond the disability sector to include mainstream services and the broader community.

Crucially, this requires a "horizontal project approach" rather than a siloed one, demanding cross-ministerial buy-in from portfolios such as Health, Housing, Communities, Treasury, Local Government and the Attorney General to ensure comprehensive system coordination.

The State government is also called upon to lead the development of proactive personal futures planning models and to use local structures to bridge service gaps and foster community inclusion. This systemic integration should also involve public authorities, such as the Public Trustee, to track estate planning uptake and provide a secure repository for essential documents.

Sustainable change requires a commitment to permanent, stable State government funding, with specific attention directed toward the unique challenges faced by families in regional and remote areas. Without such a commitment, the Summit highlighted the significant cost of inaction, warning that failing to implement these proactive measures will lead to increased system costs and high-cost crisis responses, including emergency hospital stays and homelessness.

Further, to move from reactive to proactive support, participants recommend the Minister for Disability Services should write to her federal counterpart to advocate for integrating futures planning into the NDIS as core business, including specific funding line items for transition mapping and the provision of planning "checklists" at key milestones.

5) Office of the Public Advocate, the NDIS and the need for Independent Advocates

The Office of the Public Advocate (OPA) is identified as a central actor in a permanent safeguarding framework for people with intellectual disabilities and high and complex support needs, though current systemic tensions exist between the OPA's "least restrictive" approach and the NDIS' preference for formal guardianship.

To better support families during the transition to adulthood, there is a strong call for the OPA to be better resourced to adopt a more active, relationship-based guidance role. This would involve integrating the OPA's functions into comprehensive safeguarding plans for those under guardianship that proactively address physical and digital safety, carer succession, formal guardianship, and emergency crisis planning to ensure long-term stability for the individual.

Independent advocacy is highlighted as a critical but severely under-resourced component of the disability support system, essential for ensuring individuals with intellectual disability and high and complex support needs are not left "alone in the ecosystem" once family carers are no longer able to be there. Families advocate for a significant increase in trained, robust, and independent advocates who can navigate the often "combative" and "traumatic" NDIS appeals and review processes. Options proposed for consideration include a model similar to the Mental Health Advocate Services (MHAS) – State government-funded but independent of service providers - to protect the individual's rights and "vision for a good life," including for those facing language barriers or technical challenges.

Finally, the urgent introduction of a Community Visitor Scheme in Western Australia is presented as a vital safeguarding priority to provide a "reliable and consistent" check on the entire home ecosystem.

As recommended by the Disability Royal Commission, this scheme would offer independent oversight of care and well-being through personal relationships, rather than just administrative standards monitoring. Such a scheme is viewed as a necessary layer of protection to ensure that "someone is watching over" vulnerable individuals.

6) Consolidate and Expand the Network of Providers of Support for Care Succession and Planning

The Summit participants identified a diverse range of existing and historical models for care succession and planning - such as the Future Living Trust, Microboards Australia and Carers WA - noting that these organisations and others for young families too are highly effective but require significant investment.

There is a strong recommendation to not only retain these successful models and build on their knowledge and presence but also to significantly expand them to reach vulnerable populations, including Aboriginal communities, LGBTIQ+ communities, those for whom English is not a first language, and families in regional or remote areas. Expanding the reach of these services is considered essential to ensure that support is available to all, including those currently in the justice system or experiencing homelessness.

To prevent care planning from becoming a crisis-driven response, the participants further advocate for the strategic resourcing of existing disability services

organisations and models to integrate futures planning into their standard pathways. This approach focuses on early intervention, specifically targeting younger families and sole parents who often do not receive information about long-term planning until their children are much older. By funding these organisations to promote the tangible benefits of proactive planning, the system can move toward a model where families are empowered to build sustainable futures well before the primary carer is no longer able to provide support.

Furthermore, participants emphasised the role of mainstream community infrastructure in normalising succession conversations as a standard part of life. Schools are identified as critical early entry points that can act as "libraries" for referrals and hubs for building social capital, while medical professionals - including GPs and hospital social workers - are seen as trusted figures who can introduce care succession as a standard health care consideration.

Finally, participants proposed the use of Community Legal Centres to provide cost-free support for legal mechanisms like Guardianship and Enduring Powers of Attorney, alongside a greater role for local governments in hosting information and fostering community-level inclusion.

7) Establish Knowledge Hubs

The current disability landscape is marked by a poorly resourced and fragmented information ecosystem, leaving even highly educated carers to "shop around" for critical legal, financial, and relational advice. Families frequently discover essential tools, such as Microboards or Special Disability Trusts, only by chance due to the lack of a "single source of truth". This fragmentation and lack of central hub impose a heavy "executive load" on already burnt-out carers, who must navigate a complex system without holistic support to manage their adult children's integrated physical, emotional, and financial needs.

To bridge this gap, Summit participants advocate for the urgent establishment of centralised "Knowledge Hubs" that function as a "tourist information place" for families. These hubs would provide a holistic navigational map of available services, offering "compare the market" tools and practical "cheat sheets" to translate complex legalese into accessible resources.

Crucially, to ensure equity for older carers who may not be tech-savvy or for whom English is a second language, these resources must be delivered through multi-channel support, including face-to-face services and diverse formats, rather than relying solely on digital portals.

A defining feature of the proposed model is the employment of paid peers as experts to serve as a "dependable backbone" for families. These hubs would move beyond mere information provision to facilitate peer-to-peer mentoring and educational workshops, helping families build social capital and intentional

networks, such as Circles of Support. By learning from those with lived experience, families can reduce isolation and gain the confidence required to document the "internal management" details - such as intimate routines and preferences - that are vital for effective long-term safeguarding.

Strategic implementation requires a State government-funded, non-government organisation (NGO)-run model to ensure the hubs can "speak truth to power" while remaining independent of NDIS service providers. As a starting point, participants recommend a proof-of-concept pilot, using a co-design approach to develop a model as a blueprint for multi-channel support and community-based planning. Success depends on intentional outreach to the "most vulnerable" - including First Nations, LGBTQIA+, and rural communities - and ensuring that both families and service providers access the same information paths to create a coordinated, rights-based safeguarding framework.

8) Make it Happen…… and Potential "Quick Wins"

The transition from high-level discussion to immediate, practical action is the primary demand of families seeking a coordinated system for care succession and planning. Participants advocate for the urgent establishment of an integrated, rights-based safeguarding framework that bridges the interfaces between the NDIS, State government mainstream services, and legal and housing systems.

To ensure long-term stability, the State government must provide clear stewardship and a "Shared Strategy" (3–5 years) with actionable priorities and clear ownership. Families expressed a genuine sense of desperation for a "dependable backbone" of support that is not "stymied" by bureaucratic silos or jurisdictional gaps.

Encouraging families to begin the planning journey requires a focus on authentic storytelling and early intervention to build hope and normalise these conversations. Using lived experience and success stories - shared through podcasts, schools, and broad media campaigns - can help reach families before a crisis occurs. Integrating succession planning into standard life milestones through community settings such as schools and medical professionals is seen as essential for engaging younger families and the "most vulnerable" who are often marginalised by the current system.

A critical "quick win" identified is the development of tangible resources and "Knowledge Hubs" to provide a "single source of truth" for families. This includes the creation of standardised "Futures Planning Kits," easy-read process maps, and practical "cheat sheets" for complex legal and financial mechanisms. Furthermore, the introduction of paid peer "buddies" is viewed as vital to providing a human-centred support structure that can help families navigate the heavy "executive load" of long-term planning.

Finally, enduring progress requires a shift toward permanent, stable State funding rather than a reliance on short-term grants. Strategic investment must include immediate financial assistance for professional legal services, such as grants for wills and Special Disability Trusts, alongside robust funding for independent advocacy. System capacity must also be built by expanding the range of organisations equipped to provide care succession and planning supports to families and training NDIS planners to include succession planning as core business, ensuring that the system remains proactive and accountable to the individuals it serves.

9) Funding support will be required

While the POD discussions focused almost entirely on strategies required to address the significant gaps that exist in relation to Care Succession and Planning for Families with Intellectual Disability in Western Australia, many of the themes and calls for action documented in this Report will require funding support if they are to be realised.

The implementation of robust care succession strategies requires targeted State government financial support to remove the significant barriers families face when attempting to navigate complex systems. A critical priority is providing support for specialised legal and financial advice, allowing families to engage professionals for drafting testamentary wills, establishing Special Disability Trusts, and setting up Enduring Powers of Attorney. Alongside this, funding is needed to develop practical "Futures Planning Kits" and Easy Read resources to simplify the administrative burden on ageing carers.

To ensure long-term stability, Summit participants advocate for State government-led housing and safeguarding frameworks. This includes funding to protect individuals' housing rights and security of tenure, and an urgent need for a "sizeable increase" in independent advocacy and the establishment of a state-funded Community Visitor Scheme (CVS) to provide independent oversight and regular well-being checks for vulnerable individuals once their primary family carers are gone.

A major theme is the call for centralised "Knowledge Hubs" and relationship-based navigation. These hubs, envisioned as State government-funded but NGO-run, would serve as a "single source of truth," offering holistic advice and employing paid peer experts to mentor families. Families also demand a return to a state-funded navigation model approach that prioritises deep personal knowledge and a single point of contact over transactional, faceless systems.

Finally, achieving these goals requires high-level State government stewardship and a 3–5 year "Shared Strategy" with clear, funded priorities. This must be a horizontal, cross-ministerial effort involving Health, Housing, and Treasury to

ensure systemic integration. Crucially, the strategy must provide permanent block funding rather than short-term grants, with specific resources dedicated to the unique challenges of isolation and lack of service models in regional and remote areas.

Messages for the State Government and Key Decision-Makers

- There are an estimated 120,000 primary carers in Western Australia and the majority are over 45 years of age.
- Many of these ageing families and carers are feeling "abandoned" by the system as they enter the later stages of their lives and seek to transition from being the 24/7 "executive managers" for their children to securing a sustainable future for them. They are desperately seeking a system that provides "forever" homes, coordinated planning and stable funding to ensure their children's needs, routines, and preferences are understood and maintained long after they can no longer provide direct care.
- The loudest calls from this Summit are for the State Government to acknowledge this huge gap in the safeguarding lifecycle for families with intellectual disability and assume both responsibility and accountability to address Care Succession and Planning.
- The State Government is called upon to:
    - **Establish a 3–5 Year State-Led Shared Strategy:** Families call for a "Shared Strategy (3–5 years) with clear ownership, timeframes and funded priorities" and warn that without it, WA will face "high-cost crisis responses, including emergency hospital stays and homelessness."
    - **Create State-Funded Knowledge Hub(s) (Single Source of Truth):** Centralised, multi-channel hub(s) offering legal, financial, housing, and planning guidance, staffed by paid peers. Families report a "poorly resourced and fragmented information ecosystem" and call for hubs that act as a "tourist information place" with "cheat sheets" and peer mentors.
    - **Rebuild Relationship-Based Navigation (LAC-Style Model):** Reintroduce a human-centred, local, relational navigation system with manageable caseloads. Carers describe the current system as "combative" and "traumatic" and want a return to the LAC model that provided "deep personal knowledge of the individual and their family."
    - **Provide Permanent, Stable State Funding:** Provide long-term State government block funding for navigation, advocacy, housing pathways, and succession planning supports. The report stresses that enduring progress requires "permanent, stable State Government funding".

- **Expand and Resource Proven Care-Succession Models:** Invest in Future Living Trust, Microboards, Carers WA and others such as Valued Lives for younger families, and culturally appropriate models for Aboriginal, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTIQA+ communities, regional, and remote families. Participants emphasise that these models are "highly effective but require significant investment" and must be expanded.
- **Invest in Early Intervention Care Planning for Younger Families:** Normalise succession planning through schools, GPs, hospitals, and community settings. Schools are described as "libraries for referrals," and early intervention is essential to avoid crisis-driven planning.
- **Strengthen and Expand Independent Advocacy:** Significantly increase funding for independent, skilled advocates who can navigate NDIS, safeguarding, and crisis systems. The report states advocacy is "severely under-resourced" and essential to ensure individuals are not left "alone in the ecosystem."
- **Fund Legal and Financial Planning Support:** Provide grants or subsidies to families for wills, Special Disability Trusts, Enduring Powers of Attorney, and estate planning. The document notes that specialised legal help is "prohibitively expensive," preventing families from planning.
- **Support Siblings Through Dedicated Programs:** Establish sibling-specific supports, peer networks, and external decision-making mechanisms to avoid defaulting care to siblings. Parents fear the "sibling burden" and want supports so siblings "retain their own life opportunities."
- **Establish a WA Community Visitor Scheme:** Provide independent oversight and regular wellbeing checks for vulnerable individuals. Families call this a "vital safeguarding priority" to ensure "someone is watching over" individuals once carers are gone.

APPENDICES

APPENDIX 1: SUMMIT REPORT IN DETAIL

Section 1 – Disability Assembly WA, and the Summit Program

About the Disability Assembly Western Australia

Disability Assembly Western Australia (DAWA) is a Collective Voice comprised of Western Australians with disability and their families, carers and people from the broader disability sector who volunteer their time to improve the connectedness of the disability ecosystem.

DAWA evolved to help fill a void that developed in the State with a loss of local system stewardship and leadership after the introduction of the NDIS.

Over the past few years, DAWA has grown to become a local community of local people who know disability. Supported by more than 800 advocates and followers reflecting the diversity of our State, DAWA is a safe place for meeting and sharing diverse perspectives, knowledge and expertise and for working together to contribute real life experience with local ownership and respect on the issues that matter.

Our vision is to unify, support and champion a thriving disability ecosystem in WA to ensure world leading and sustainable outcomes for people with disability, their families and carers.

About the Disability Assembly WA Summit Program

A major initiative of DAWA is bringing together people with disability, families, carers, peak bodies, advocates, providers and experienced stakeholders from diverse backgrounds to generate informed, impartial discussion on the big issues affecting people with disability, their families and carers and the broader disability ecosystem.

A feature of DAWA's approach is a program of 'Summits' each year tackling topics of scale and concern for people with disability.

Each Summit is invitation-only to ensure the participation of a cross section of people with disability, families, carers, peak bodies, advocates, service providers, experts and government representatives. Attendees contribute their experience, understanding, expertise and research to the key topics under discussion.

Throughout each Summit, attendees generally hear briefly from specialists on the topic and then participate in facilitated 'POD' (focus group) discussions to explore the topic in detail. Findings, key themes, preferences and recommendations are collated, and a report prepared, to be presented to government representatives and other influencing or decision-making bodies that are empowered to make change for good.

These decision makers are then invited to respond to the report findings and recommendations at a follow-up Summit later in the year, which focuses on gaining commitments to action and the achievement of real and lasting outcomes.

Selection of the 2026 DAWA Summit Topic

The 2026 DAWA Summit program aims to address a critical issue in Western Australia: **Care Succession and Planning for Families with Intellectual Disability in Western Australia.**

There are an estimated 1.2 million primary carers in Australia (around 10% of whom are estimated to live in Western Australia), and the majority are over 45 years of age. The selection of this topic for the 2026 Summit program therefore reflects its strategic and state-wide importance, the potential to impact on a significant number of people with disability, particularly those with intellectual disability, and their families.

The care succession needs of people living with intellectual disability are urgent and growing. As the population of carers ages e.g. the baby boomer generation is now into their sixties and seventies, the succession of care for their loved ones living with intellectual disability needs careful and specific planning.

The imperative for a structured, government-supported Care Succession and Planning process is becoming ever more pressing.

A message and endorsement from a parent and DAWA Summit lead, Bruce Langoulant:

"For our daughter and her many peers across WA who are living with significant intellectual disability – and us too - this topic is important!

Safeguarding aging carers and their family members living with significant intellectual disability and often related physical disabilities as they separate from their co-existence with family and look to their future care and security in later life beyond their parents, is vital but often a missing piece in the lifecycle.

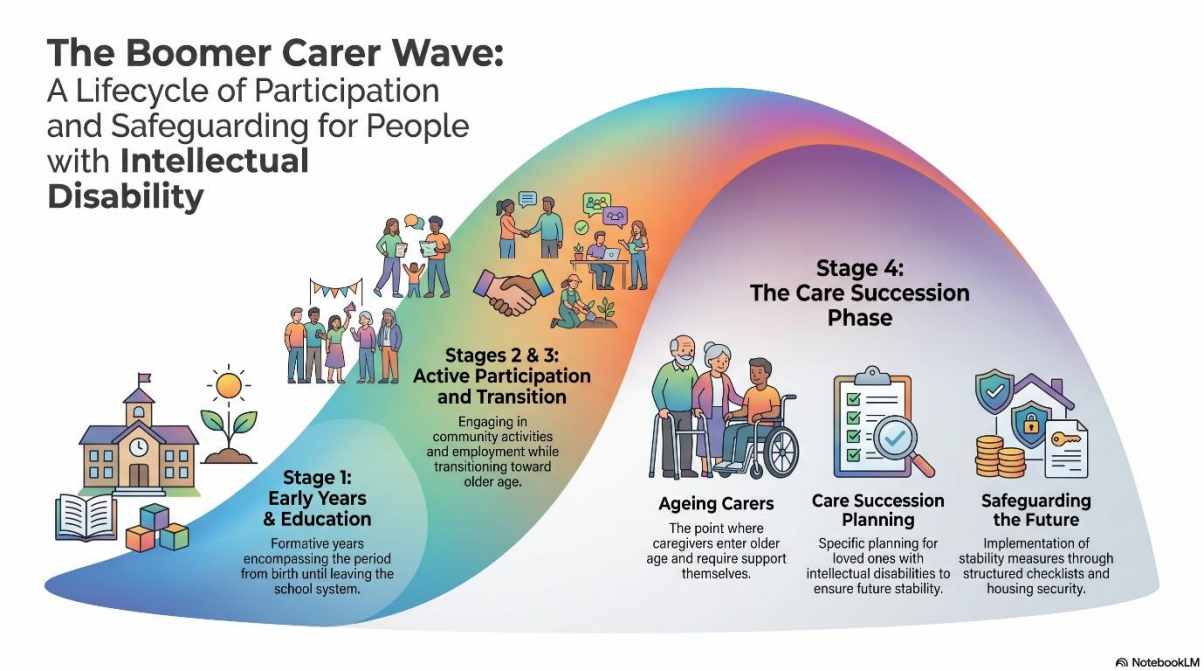
There is a lot of focus on the early years right up to leaving school. Taking an early intervention approach in phase one of the journey for a person with intellectual disability is a worthy strategy and with years ahead there is optimism a plenty.

The next two phases of leaving school and finding community activities and maybe employment and then maturing at home as your parents are aging, while challenging, becomes a way of life.

But 'Stage 4', while predictable, is not adequately recognised, talked about or serviced, yet it attracts much anxiety and uncertainty when it should offer so much peace of mind for all.

Discussing and planning solutions beyond the first three phases is often left until late in the piece or until it's forced upon you, if it happens at all.

With a preference and encouragement for their family member to live in the community, with an appropriate and secure housing and support arrangement, stable future care leadership and safety responsibilities and an agreed and documented final transition point, for many, including those in the 'baby boomer' generation, Stage 4 is imminent.



With the 'Meet and Greet' interviews we conduct at My Place Foundation, of which I am Chair, the carer parents of the mostly maturing participants with complex needs consistently ask the following three questions:

1. What support can you provide?

2. Where will (the consumer) live?

3.Who will be there (for the consumer) when I/we are not?

The care and support needed for our very vulnerable and their aging carer families should be a priority. We know the journey will end and we need more than paper to direct it. Establishing clear and documented plans with identified people involved for this important and known stage with State support is a worthy project and would add the missing piece - the completion of preparations for the emotional and important final stage – Stage 4.

To date it has been shaped and advocated for by a locally led 'Stage 4 Working Group', members of which were among the Partner organisations at the Summit: Future Living Trust: Developmental Disability WA: Microboards Australia: Valued Lives: My Place Foundation and the Australian Inclusion Group.

Sharing the theme with a wider audience of parent carers, siblings, service providers, advocates and local and State government representatives at the 27th

March 2026 DAWA Summit was designed to obtain input from each of these key segments of the disability care eco system.

Having the combined feedback now because of the DAWA Summit is empowering for this Report and its recommendations.

With the feedback and overwhelming support you have provided, the project team will continue to underline the urgency and need for action to safeguard this special and dependent cohort. Creating greater awareness of this hidden stage and the very vulnerable family members who require tailored services and care is essential. Also essential is to make it easier for families to connect and readily obtain reliable advice and support with planning the vital care succession arrangements needed as they all grow older.

We look forward to the opportunity of continuing to expand on this project with you."

Section 2: Summit Process and Proceedings

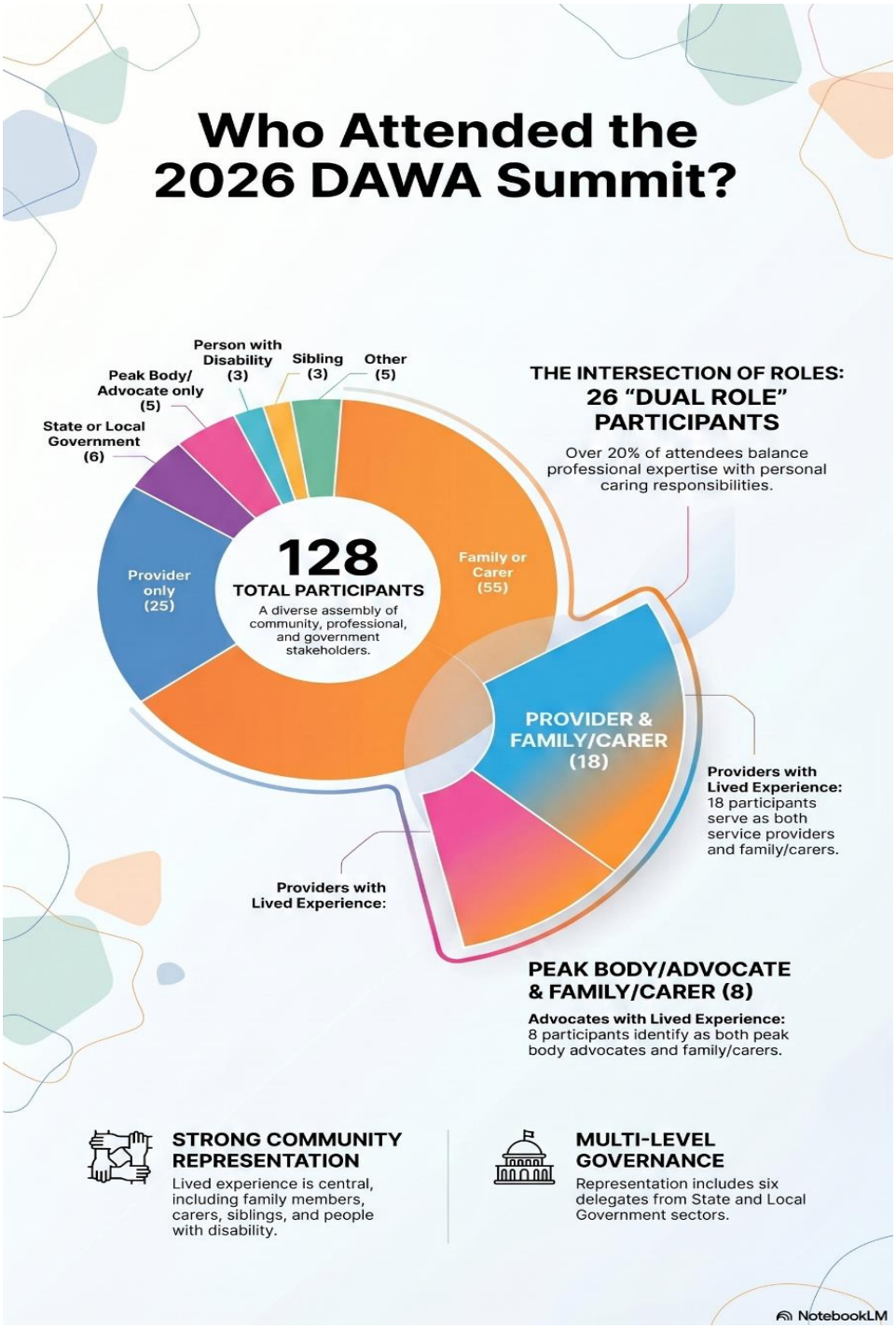
The DAWA Summit on '**Care Succession and Planning for Families with Intellectual Disability'** in Western Australia, was held on Friday 27th March 2026 at the Telethon Speech and Hearing Function Centre, 36 Dodd Street, Wembley. The venue was selected because of its ability to meet parking and other accessibility requirements for the participants and the range of conference and 'break out' rooms available.

118 invited guests attended in Perth and an additional 10 participated online in the Broome and Bunbury.

The participants' primary role indicated in their registration was:

- 55 - family or carer of a person with disability
- 43 – service provider
- 13 – peak body or advocate
- 3 – person with disability
- 3 – sibling of a person with disability
- 6 – State or local government representative
- 5 – other

In should be noted that 18 participants who registered as a provider and 8 who registered as a peak body or advocate representative also indicated they were a family member or carer of a person with disability. The infographic below illustrates the breakdown of the categories against which participants registered for the Summit and clearly shows the level of interest in the Care Succession and Planning topic across the disability ecosystem.



The agenda for the Summit (see following page) was designed to include a brief 'spotlight speaker' presentation from a sibling who, in conjunction with her brother, has successfully navigated the Care Succession and Planning journey for their family member (sister). It also included a facilitated 'spotlight panel' in which four panellists helped to set the scene by providing brief perspectives as a sibling, carer parent, service provider and representative of the Office of the Public Advocate, before engaging all Summit participants in in-depth discussions within small working groups – named 'PODs' – over the rest of the day.

Care Succession and Planning

For Families with Intellectual Disability

DAWA Summit Program
Friday, 27th March 2026

8:15am	**Doors open**
8:30am	**Registrations open**
9:00am	**Acknowledgement of Country & Introduction |** Julie Waylen **DAWA Chair** Welcome to regional participants online and in-person attendees
9:15am	**Ministers Speech |** Hon Hannah Beazley MLA
9:40am	**Spotlight Speaker | 'The Issue Firsthand'**– Jo Turner, Successful Outcome-Sibling Perspective
9:50am	**Spotlight Panel** I **'Setting the Scene':** Carer Parent/ Sibling/ Service Provider/ Office of the Public Advocate – Moderated by Amy Clark DAWA
10:20am	**How the PODs will work |**Neil Guard DAWA
10:30am	**Morning Tea** - Mini break
10:55am	**POD Focus Group (1) | Reflecting on your own experience and knowledge** What are the main issues currently facing older families who cannot/will not be able to sustain a caring role for their adult children who live at home? What initiatives or services currently exist (or previously existed) to support older families to plan for the future and put the plans into action? How effective are/were these initiatives and what needs to be resurfaced/retained?
11:45am	**Comfort Break**
11:55am	**POD Focus Group (2) | What is required to make enduring progress a reality?** • What are the key components of an effective solution to the issues identified in the first POD discussion? • What quick start initiatives are needed? • How do we ensure effective pathways to meet varying needs including economic and diversity? • What else needs to happen?
12:45pm	**Lunch and networking**
1:40pm	**POD Focus Group (3) | How do we ensure the message gets through to most families with encouragement to take the personal futures journey?** • How do we continually promote and demonstrate the benefits and opportunities and successful examples? • Who can play key roles to ensure futures planning is valued, encouraged, integrated into existing planning pathways and funded? • How should we track progress and measure success? • What are the most important next steps?
2:30pm	**Recapping Summit findings |** Neil Guard DAWA
2:50pm	**Conclusion and next steps |** Bruce Langoulant DAWA
3:00pm	**Day concludes**

The opening addresses were provided by:

- **Julie Waylen, DAWA Chair**, who provided an Acknowledgement of Country, a welcome to the Summit participants in Perth, Broome and Bunbury and a thank you to DAWA's Summit sponsors and supporters. Julie specifically acknowledged the presence in the audience of Dierdre Croft, a remarkable Western Australian mother, advocate and changemaker who recently appeared on Australian Story talking about her journey with her son Richard, including Care Succession, Safeguarding and long-term Planning.

  Julie outlined the process for the day and then spoke about the significance of the Care Succession and Planning topic to families and carers across the State, who shoulder extraordinary and increasing responsibility in a highly transactional and often fragmented system.

  For older carers, particularly ageing parents supporting adult children with intellectual disability and high and complex needs, Julie highlighted that the profound question that sits quietly but growing louder behind every decision is "Who will care for my loved one when I no longer can?" It is not an abstract concern, but a daily reality for thousands of families, but is a question that no family should have to face alone - and yet way too many do.

  Julie reminded the audience that this DAWA Summit was about bringing the insights of families and carers to the forefront, naming the challenges honestly, and working together to shape solutions and design a system that enables coordinated planning, early intervention, and long-term safeguarding, such that no family is left wondering what will happen when they can no longer provide care.

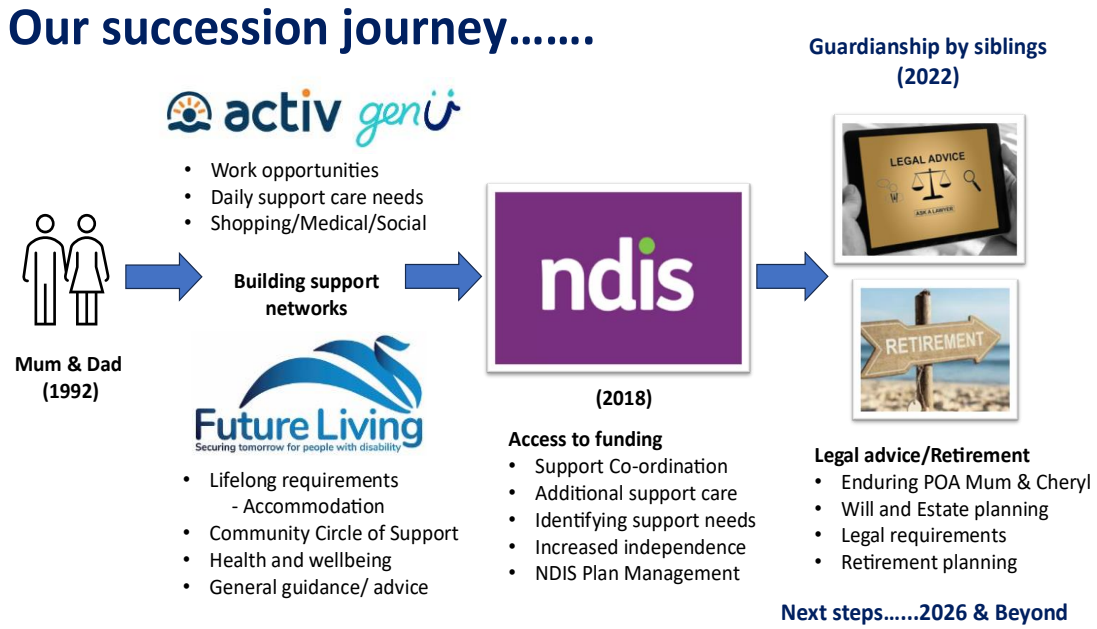
- **Hon Lauren Cayoun MLC, Government Whip in the Legislative Council and Member for Western Australia,** who spoke on behalf of Hon Hannah Beazley, Minister for Disability Services.

  Lauren acknowledged the role of families and carers across the State and acknowledged the importance of the Care Succession and Planning topic. She thanked DAWA and its supporters for planning and convening the Summit and advised that the government is keen to listen to the concerns of ageing carers with families with intellectual disability and those with high and complex support needs, and that she and the Minister looked forward to receiving and discussing the Report in due course.

- The opening addresses were followed by a presentation by **spotlight speaker Jo Turner** on "The Issue Firsthand," providing a sibling perspective on Care Succession and Planning, where a positive outcome has been achieved.

  While based in Sydney and working with the Leukaemia Foundation, Jo also has enduring Power of Attorney over her mother (89yrs), now in Aged Care, and her sister Cheryl (64yrs) who has an intellectual disability, supported by her brother Colin.

Jo spoke about her family's succession journey with her sister, as depicted in the diagram below. While the journey has not yet finished, the support of Future Living, access to funding through the NDIS and obtaining good legal advice have given Jo and her family considerable comfort that Cheryl will continue to be safe, well supported and continue to lead a good life as they all move into retirement.



Jo's presentation was followed by a **spotlight panel** to further assist in setting the scene. Facilitated by **Amy Clark, DAWA Board member and sibling advocate** for her brother David, the panel included:

- **Amy Clark** herself, who spoke about the concerns and fears of herself and her family when they read things like reports from the community visitors' schemes in other States that paint an environment where people with disability can go unseen, unheard and unsupported in their own homes. The reports include examples of:
    - Residents lacking funding and support avenues to participate in the community.
    - Their basic health, medical, mental, and nutritional needs not being adequately addressed or monitored by services.
    - Support staff disrespecting and belittling residents and keeping them in the dark about significant changes that affect them.
    - Residents feeling disrespected, belittled, and also kept in the dark about their staffing rosters and critical reports and plans.

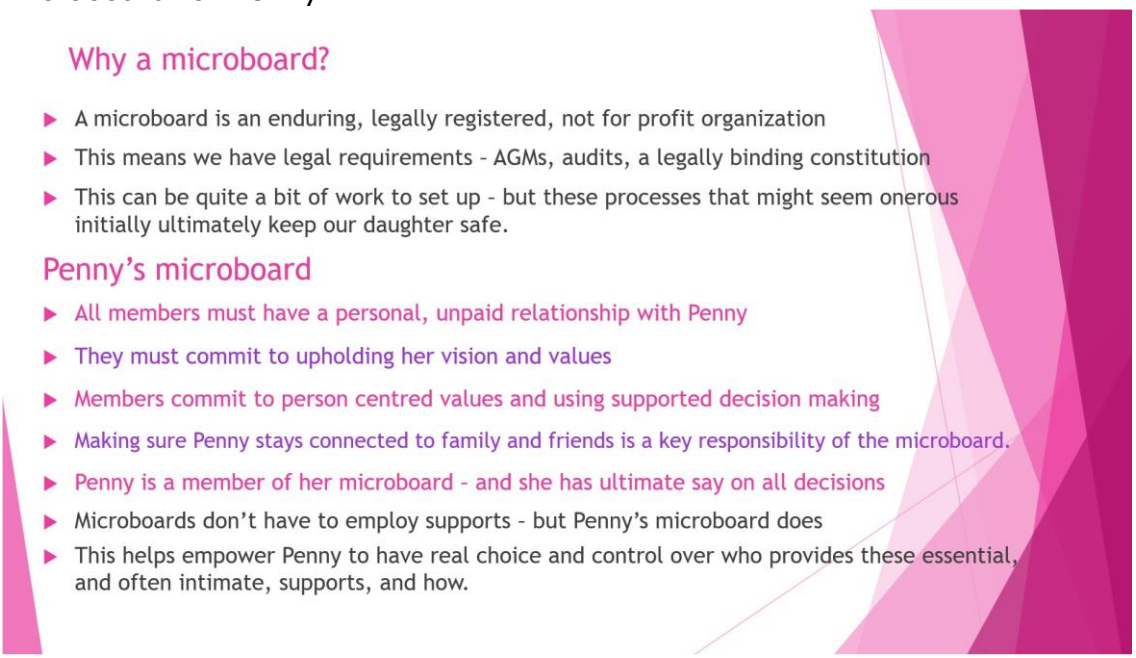
Amy described her mother as an everyday full-time 'shield' for her brother, with restrictive leave and excessive overtime – a role that looking to the future, siblings feel impossible to accept.

- **Liz Manning, a retired academic and parent/carer** with four adult children including her daughter Penny, who is the focus person of a 'microboard' that incorporated in 2021.

  Liz outlined that when asked about "What has worried you when thinking about your future?", Penny's answer was:

  "Something that makes me worried about the future is my parents getting older. When it is their birthday, I get a bit worried because they do a lot for me still. I am worried about who will help me in the future with some things. I am happy that my parents are helping me start my microboard and they have helped me to have other people around me who care about me and know me well."

  Liz then described what a microboard is, and the reasons for establishing a microboard for Penny:



- **Darren Ginelly, Managing Director, My Place Foundation,** which has recently been established, focussing on individualised and personal housing options for people with disability.

  Darren spoke about the concerns that people with disability and their families and carers most frequently raise when seeking support from the Foundation, including most commonly "Where will (the consumer) live?' and "Who will be there (for the consumer) when I/we are not?"

  Darren then outlined the range of supports the Foundation intends to provide to eligible people with disability. Particularly relevant to the Summit topic are:

  - Encourage, promote and support people with disability maintaining choice and control over their lives and living arrangement.

- Support people with disability to be assisted into home ownership through shared home ownership arrangements.
- Operate as and undertake the activities of a specialist disability accommodation provider.
- Act as an advocate being a socially responsible landlord.
- Act as a trustee for a person with disability and their families or significant others, as required.
- Collect funds and accept donations, bequests and devises of real and personal property for all or any of the Foundation's objects.

- **Debra Casey, Manager Advocacy Investigation and Legal, Office of Public Advocate,** who outlined the role of the Office of the Public Advocate (OPA) in provision of access to advocacy, guardianship and administration services which protect and promote the financial interests and welfare of adults with a decision-making disability.

  The functions include:

  - Advocacy and investigation services, including assessing referrals from community members concerned about people who may be experiencing neglect or abuse and managing the team of people who investigate these concerns.
  - Advocacy for the appropriate appointment of guardians and administrators and appropriate interventions in relation to Enduring Powers of Attorney and Enduring Powers of Guardianship.
  - Guardianship and administration services provided through the appointment of the Public Advocate by the State Administrative Tribunal.
  - Community education services regarding the guardianship and administration system.

  One of the concerns of OPA that particularly resonated with the audience is that OPA and the NDIA appear to have conflicting positions on guardianship and financial administration matters. OPA generally defaults to the "least restrictive" approach while the NDIA appears to default to recommending formal guardianship.

The introductory spotlight presentations were followed by Summit participant discussion in small focus groups, named 'PODs,' the composition of which was designed to include a mix of stakeholders and experience, placing the person(s) with disability at the centre.

To ensure the individual perspective and lived experience was front-and-centre for each discussion, each of the 14 PODs (including Broome and Bunbury) comprised up to ten Summit participants pre-allocated into groupings to enable a mix of perspectives and encourage open conversation.

Each discussion lasted 50 minutes and was facilitated by a passionate DAWA or partner volunteer - not necessarily a 'professional facilitator' but a person with a range of involvement in the sector, briefed and provided with facilitation tips to manage the process of discussion and ensure all voices were heard.

The facilitator was supported by a nominated 'scribe' to ensure each group's discussion was fully and accurately recorded (for later collation in the Summit report) and to help summarise the key messages from each discussion that stood out most in the group conversation.

The broad discussion topics for each of the PODS were:

POD Focus Group (1) | Reflecting on your own experience and knowledge:

- What are the main issues currently facing older families who cannot/will not be able to sustain a caring role for their adult children who live at home?
- What initiatives or services currently exist (or previously existed) to support older families to plan for the future and put the plans into action?
- How effective are/were these initiatives and what needs to be resurfaced/retained?

POD Focus Group (2) | What is required to make enduring progress a reality?

- What are the key components of an effective solution to the issues identified in the first POD discussion?
- What quick start initiatives are needed?
- How do we ensure effective pathways to meet varying needs including economic and diversity?
- What else needs to happen?

POD Focus Group (3) |How do we ensure the message gets through to most families with encouragement to take the personal futures journey?

- How do we continually promote and demonstrate the benefits and opportunities and successful examples?
- Who can play key roles to ensure futures planning is valued, encouraged, integrated into existing planning pathways and funded?
- How should we track progress and measure success?
- What are the most important next steps?

Following the three POD focus group discussions, participants regrouped to receive a recap of some of the broad themes and messages gathered from the POD discussions during the day.

In closing the Summit, participants were advised that the next steps would involve consolidation of all the POD discussions into a Report on the Summit, which would be provided to Ministers, government departments and other key stakeholders and would then form the basis for a final event to be held in August 2026. At this final event, the intention would be for the 'decision makers' to respond to the Report

findings and recommendations and make commitments to action towards the achievement of real and lasting outcomes.

Section 3: Key Themes from the DAWA Summit on "Care Succession and Planning for Families with Intellectual Disability" in Western Australia.

This section of the Report provides a consolidated documentation of the key themes that arose within the POD group discussions. While the flow of the discussion differed to reflect the composition and experiences of each POD, the key themes arising across the discussions were generally similar, as follows:

1) The Current Landscape: A Crisis of Carer Anxiety and Exhaustion

Executive Load of Caring

As primary carers age, they face a critical juncture: transitioning from being the sole "executive managers" of their children's lives to ensuring a sustainable, safe, and advocated future after they are gone. **While desperate for systems settings that support stability rather than crisis response, and which provide for coordinated planning and clearer guidance for families, perhaps more than ever, many are finding the system to be a major barrier and facing a range of challenges in making the transition.**

Overwhelmingly, the first POD discussions exposed that older carers face a complex array of challenges when attempting to plan for the future of their adult children with disabilities. These challenges included the significant anxiety and exhaustion felt by many ageing parents who provide long-term care for adult children with disabilities. Decades of providing 24/7 care without adequate respite have left many older carers grappling with the long-term support and in a state of chronic fatigue and deteriorating health.

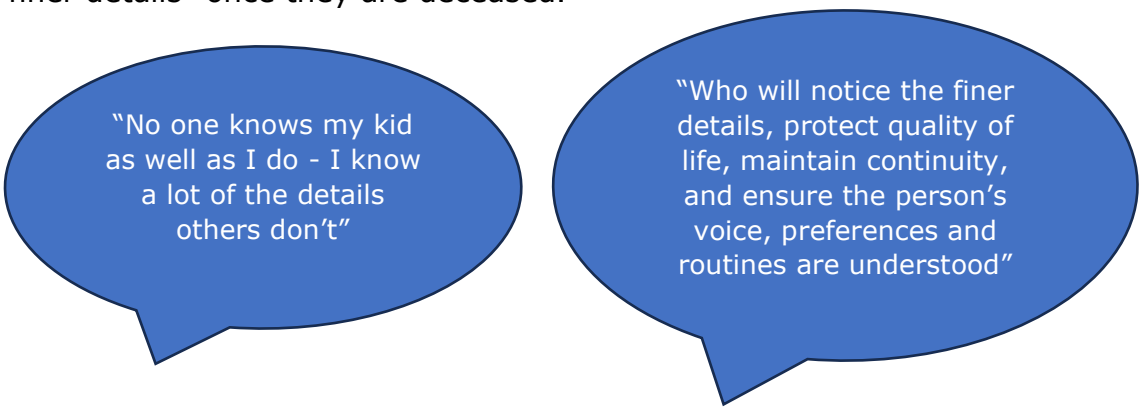
Participant Quotes:

"Carer fatigue is very real!"

"We older families are deeply worried about the future because too much still depends on us. Our biggest concerns are long term NDIS funding, housing and living arrangements, and who will hold the detail, quality and continuity of the person's life when family can no longer do so."

Central themes, particularly from families of a person with intellectual disability and other complex needs, included feeling alone, the high risk of carer burnout, diminishing capacity, the physical, emotional, and intellectual toll on their lives and a sense of overwhelm. **The message from many families was that they have been carrying too much, for too long, in a system that's only getting harder to navigate and is too dependent on their persistence – "We are still the system."**

Many parents currently manage every dimension of their child's life - physical, emotional, intellectual, and financial. They have deep anxiety about what will happen when they can no longer provide the day-to-day support and there is no clear or trusted alternative who will hold the "subconscious knowledge" or notice the "finer details" once they are deceased.

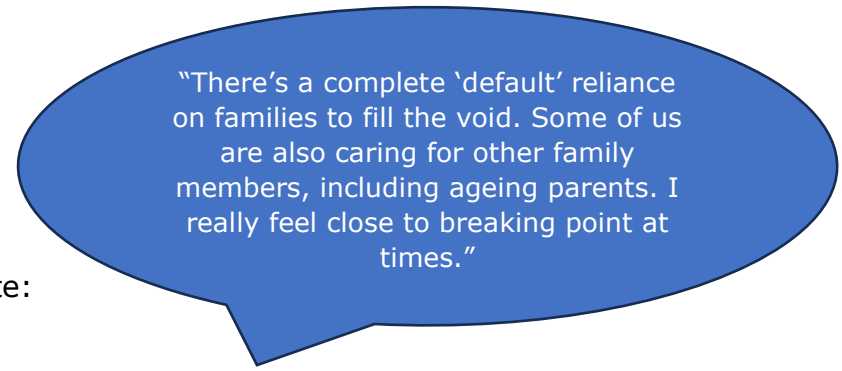


Participant Quotes:

The Double Whammy

Some of the Summit participants described a "double whammy," where they are simultaneously caring for an adult child and their own ageing parents; while a few also described how the stress of caring has contributed to marriage and family breakdowns, leaving them as sole carers.

Participant Quote:



The Expense of Legal and Financial Advice

Financial planning for the future was one of the most significant hurdles identified by many older carers, primarily due to a combination of high costs and the long-

term economic disadvantage caused by decades of unpaid caring (a "full time" unpaid job). For many, this means they have lower lifetime incomes and superannuation available in their own later life stages, due to their caring responsibilities.

Many participants expressed concern at how they would ever be able to afford the cost of the expensive legal and financial advice required for succession planning, including structures like testamentary wills or Enduring Power of Attorney. Some families advised they simply do not have the financial means to pay for the professional help required to manage complex estate planning.

There is a noted need for a program that recognises the pressure on families and carers and provides much easier access to these specialised services (legal, financial, etc.) without families having to "shop around" and pay multiple high fees.

Participant Quotes:

"Accessing specialised legal and financial help for estate planning, such as testamentary wills or trusts, is 'difficult and expensive.'"

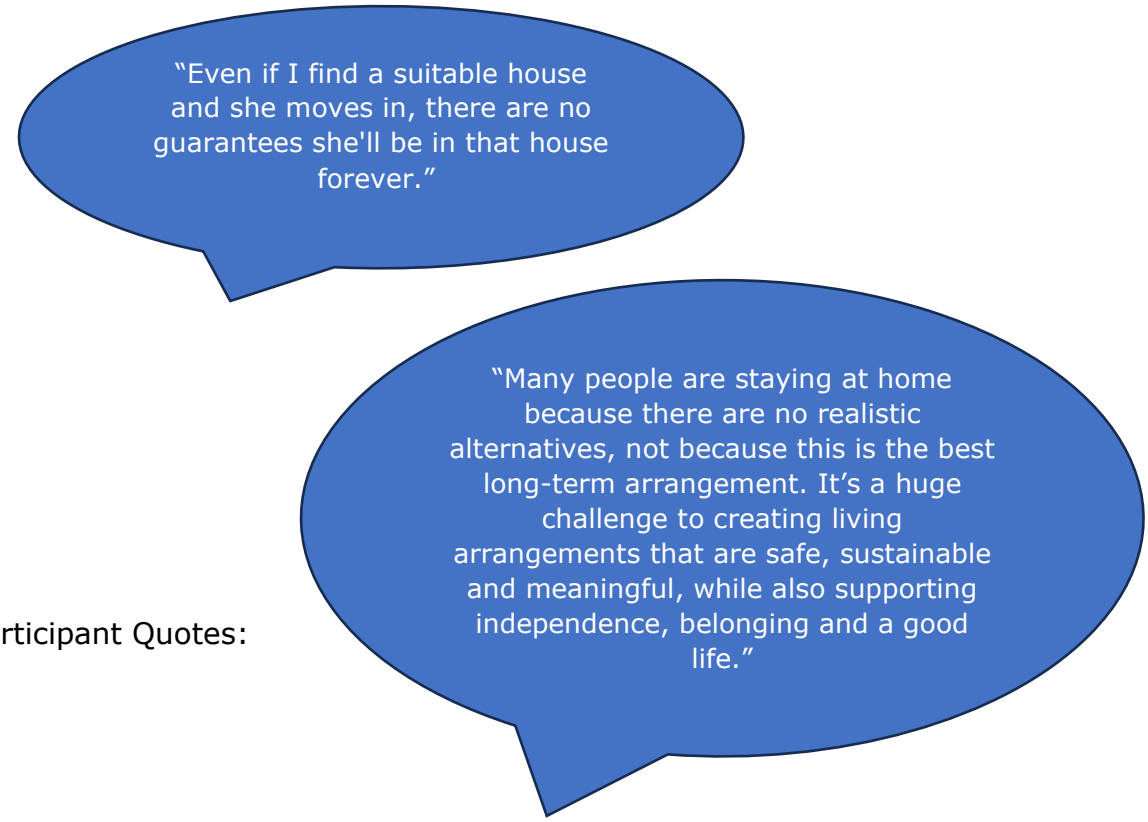
"For most of my 30 years of caring, I have endured stress every day. This has also affected my health. I worry all the time about my children's future, especially knowing that all 3 of my adult children require housing & care in the future."

Housing

Securing safe, sustainable, and independent housing was a central planning concern for many families at the Summit, often due to the lack of alternatives. Many described how their adult children had no option but to remain at home because there are no realistic alternatives, and parents fear "plonking" their children into group homes where they may not get along with co-residents. Others were clear that solutions must include housing that offers security of tenure -

described as "housing that is safe & forever" - and goes beyond traditional wheelchair-accessible stereotypes to be truly fit for purpose.

Participant Quotes:



There is a very real fear that even if Specialist Disability Accommodation (SDA) is secured, the funding or the ownership of the building may not be guaranteed in the long term.

One participant referred to the Disability Royal Commission which found that new housing alternatives are essential to ensure people with disabilities are not placed at risk of harm, abuse, and neglect, which is a concern in some current Supported Independent Living (SIL) options. Indeed, the same participant cited the Commission's "Voices of People with Disability" report that documented over 200 examples of where abuse and neglect have occurred within the system. Others vented their frustration that while the Commission and NDIS Reviews had addressed many of these issues, there is currently "no sense of how the government is actually responding" to the recommendations.

A specific message from some Summit participants was that SDA should be owned and run by the State to protect the rights of individuals to live independently, rather than leaving housing security to the "mercy of the open market". Others saw accommodation providers as potential prompters, suggesting SIL/SDA providers and public housing authorities should integrate futures planning into

their onboarding processes, prompting families to begin care and succession planning at the point of entry.

Ultimately, securing safe, suitable and sustainable housing for their family member is one of the most significant and central planning concerns for many families, to ensure that they retain their independence rather than "being plonked in a group home with someone they have not chosen to live with."

Participant Quote:

"Imagine if you came home to a new husband or wife. It's so hard to share domestic space with other people. How is their quality of life sustained to the same or better standard?"

Other Family/Carer Concerns:

In brief, other carer concerns raised in some of the POD discussions included:

- *Safeguarding Gaps*: Some families fear their children will be vulnerable to abuse or neglect in formal systems that lack "teeth" or independent oversight like a Community Visitor Scheme.
- *Quality of Care:* Carers are concerned that paid supports only provide "a roof, food, and basic bodily care" while ignoring the child's quality of life and meaningful activities.
- *Crisis Responses:* A lack of early planning pathways means many families are forced into "crisis responses" only when the carer can no longer function.

Participant Quote:

"The state has pulled out of the crisis care, so there's no last resort"

- *Estate Management Anxiety:* There is significant worry about the lack of independent oversight for financial trusts once parents pass away.
- *Systemic Hurdles:* Carers often face barriers when trying to empower their adult children to manage their own finances.
- *Capacity Assumptions:* Banks frequently make assumptions regarding a person's capacity to understand or perform their own banking. As a result, there are barriers to a person with a disability being able to have their own home or repay a mortgage, as banks may not recognise their ability to make independent financial decisions.

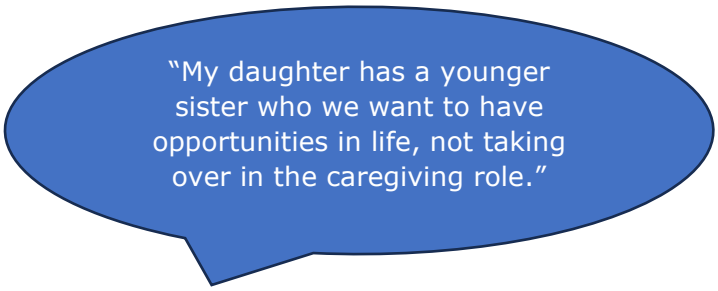
- *Regional and Remote Families*: Families outside of metropolitan areas face extra disadvantage, where funding may be approved but remains unusable due to a lack of local providers and specialist supports. This isolation makes the decision-making process even more difficult, as there are fewer alternatives to explore.
- *Crisis Responses:* Some families indicated that the current environment often forces older families into crisis responses rather than allowing for intentional, relational, and supported succession planning.
- *Respite:* For families already experiencing burnout the lack of access to respite often compounds their issues.
- *Online Shift:* The shift toward online systems can be a barrier for older carers who are not tech-savvy or live in regional areas with poor internet.

2) Concern over Passing the Care Responsibilities to Siblings

The "sibling burden" represents a significant source of anxiety raised by many parents of individuals with disability who fear passing the responsibility of care to other children by default. **While siblings are often viewed as the natural successors to parents in supporting a person with a disability, many parents highlighted a fundamental tension between their role as a family member versus their potential role as a primary carer.** Parents are frequently reluctant to simply hand the baton over to them, especially when siblings may already be facing the "double whammy" of managing the care of their own ageing parents simultaneously.

Ultimately, most participants felt that the conversation about succession planning needs to be "normalised" to ensure that siblings are supported to have their own lives and opportunities rather than simply being expected to take over the caregiving role by default.

Participant Quote:



Many parents articulated their worry that while a service provider might handle basic needs like food and housing, only a family member like a sibling will "notice the finer details" or "fight" for the individual's quality of life. Therefore, while they may not directly take on daily care, there remained some expectation that siblings would likely be the ones to provide long-term advocacy and be part of intentionally created support structures. However, some parents stated that they would prefer

to secure external mechanisms (such as independent advocates or "visiting services") to handle financial and planning roles so that siblings are not left to do it alone.

Some also noted that support must also account for siblings who live overseas or rurally and cannot realistically be expected to "reorganise their lives" to provide local support or day-to-day care. Others noted that services are primarily geared toward those whose first language is English, making the already complex system nearly impossible to navigate for others.

Ultimately, participants agreed there was a gap in the system regarding support specifically for adult siblings. Families suggested that future initiatives should include:

- "Sibling groups" to help them understand what they "want and need" in their future roles and to normalise conversations about succession planning before a crisis occurs.
- Peer-to-Peer Networks to connect siblings with others in similar situations to provide reassurance and practical knowledge that they are "not alone in the system".
- Some families even suggested that guardianship or decision-making support should ideally be handled by someone other than a sibling to preserve the family relationship
- Intentional Support Networks, such that rather than siblings carrying the responsibility alone, they are involved in formalised structures, such as microboards or Circles of Support (see later in this Report).

3) The loss of Relationship-Based Support has added to the Anxiety of Families and Carers

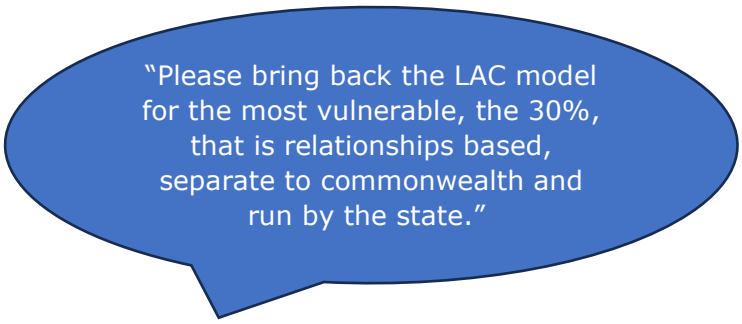
Landscape Shift

While acknowledging the transition to the National Disability Insurance Scheme (NDIS) has been empowering for some, it was widely described by many of the older carers, particularly of people with intellectual disability and other complex needs, as impersonal, transactional, and bureaucratic. Many of these Summit participants reported that the "humanity" of the previous state-based system has been lost, replaced by the administrative burden of a "constant churn of paperwork" and significant time on NDIS compliance, which was detracting from their primary role as carers and advocates and limiting their capacity for long-term proactive planning.

These participants also testified that the NDIS has significantly shifted the landscape of disability services from a relational model to an impersonal,

transactional, system-focussed model, leading to a perceived loss of connection within the support system.

Building on the theme of a shift in the local landscape and while acknowledging its time had likely passed, the loss of the former WA created relationship-based WA Local Area Coordination (LAC) model under the former state-based system was bemoaned by many.



Participant Quote:

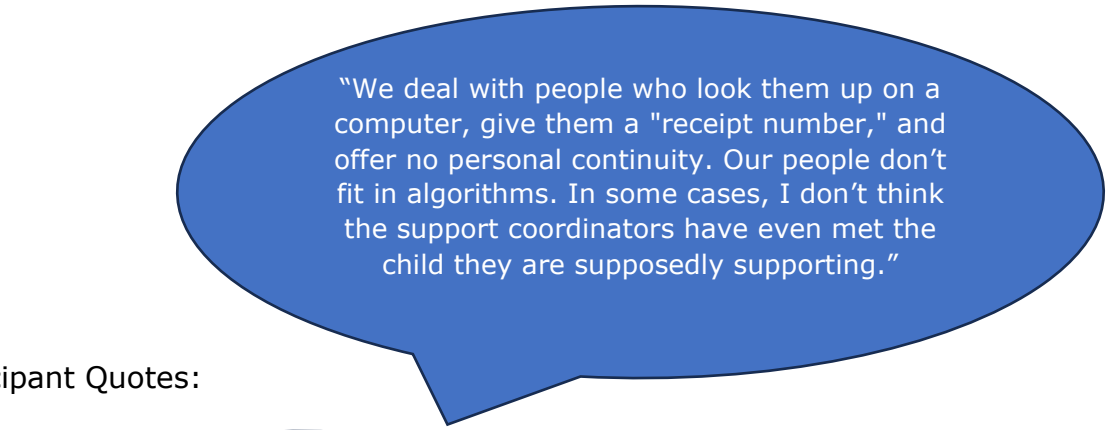
The LAC approach was praised for having "personal knowledge of the person with disability" and Summit participants described other highly valued features of the model, including:

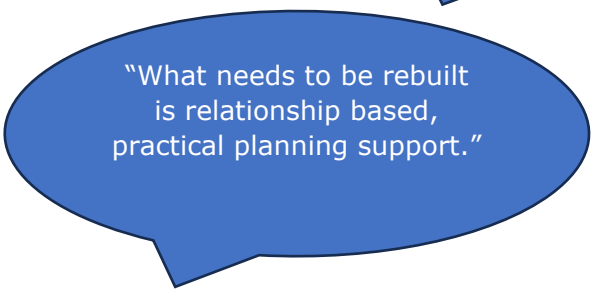
- *A Single Point of Contact:* It provided families with a dedicated person to communicate with, avoiding the need to navigate multiple fragmented systems.
- *"Deep Personal Knowledge":* The LAC really knew the person with disability and understood the "whole eco-system" of the family.
- *Long-term Connection:* They "followed families" as they went through their lives, supporting them through various milestones and transitions.
- *Manageable Caseloads:* The model supported approximately 250 LACs across the state, ensuring coordinators had the time to know their families well and understand the "whole ecosystem" around the person.
- *Facilitator of Informal Networks:* Coordinators emphasised the importance of intentional networks and helped facilitate families to build more local community focused networks, which in turn created informal safeguards that would remain in place after the primary carers were gone.
- *Continuous and Separate Funding:* Unlike the current model, the LAC resource was described as continuous and with funding support not tied to specific transactions or "fee for service."
- *Proactive Planning:* LACs facilitated early and intentional conversations and sustainable succession/futures planning. They engaged families in futures planning in a "grounded and consistent way."
- *Capacity Building:* The LAC approach focused on capacity building and parent education of both the person with disability and the family.

- *State-Funded Oversight:* The program was state-funded and regulated by the Disability Services Commission (DSC), which trained the coordinators and maintained a "local lens" on service delivery.

In contrast, while again acknowledging the NDIS system had proved a blessing for some, for others it was described overly focussed on processes rather than the individual, often "combative" and "extremely traumatic".

Participant Quotes:





Perhaps not surprisingly, one of the loudest calls from Summit participants to decision-makers is the need to rebuild local relationship-based navigation, based on the features of the previous WA created LAC model, because it "provided a trusted intermediary who acted as a conduit between the family, funders and planning supports, ensuring that planning was a continuous, supported process rather than an administrative hurdle."

Family Leadership

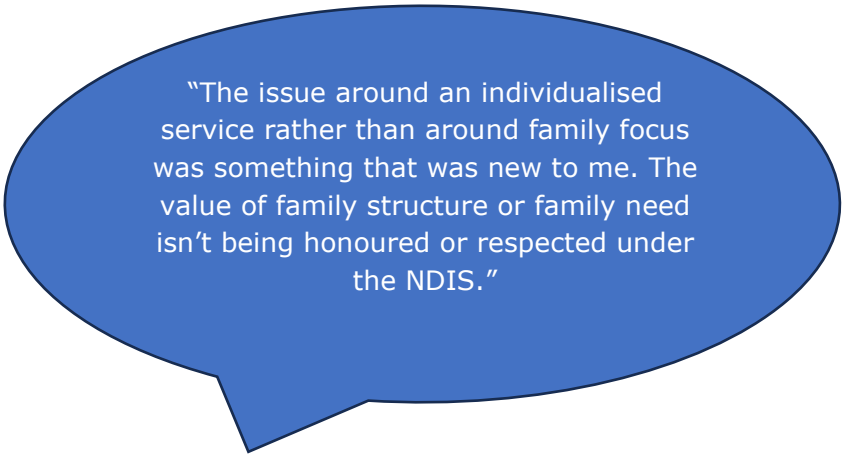
In a similar vein, some families described a void of recognition and investment in family leadership (time, services or financial) when the NDIS came in, and State and community services pulled out.

Many families talked about how their providers had been pushed by a transactional and systems focused model, driven by individualised funding, to focus solely on the provision of services to the person with disability, rather than being part of a network and working with families. A few described how in their view, this has

created a "dependency on the funding" and moved away from the "village" approach that fostered informal community relationships.

Considering this, many advocated strongly for a return to the family leadership approach, also a previous Western Australian initiative they considered a highly effective and grounded model for supporting families, arguing that the shift to transactional NDIS funding has led to a loss of "connection" that the model previously provided.

Participant Quote:



Specific features and values of the family leadership approach were described as:

- Helping families connect with peer networks, resources, and futures pathways, allowing families to learn from those with lived experience and find mentorship within the system.
- Being built on relational support valued for being "grounded" and providing a "single point of contact" that prioritised human connection over impersonal processes.
- Focussing on building the capacity of both the family and the person with a disability, including through helping families understand how to use funding effectively and advocate for their needs.
- Facilitating and guiding families through proactive, intentional and sustainable futures planning, rather than waiting for a crisis.
- Building intentional networks, such as Circles of Support or peer groups, to ensure that the individual with a disability was surrounded by a "village" rather than just paid providers.

Ultimately therefore families and carers at the Summit strongly advocated for resurfacing of these family leadership features, including dedicated investment to support capacity building of the family and to restore the "humanity and connection" that the state-based model previously provided.

4) State Stewardship and Ownership

The demographic reality before us is clear, as thousands of families are approaching a transition point for which our systems are not yet prepared. This is no longer a distant issue. All Summit participants identified that a systemic approach to Care Succession and Planning is desperately required. **They identified an urgent need for improved stewardship and accountability from the State government to ensure no person is left without the support they need simply because their life does not fit neatly into a jurisdictional box.**

In this respect, Summit participants demanded immediate support from the State government to support the growing cohort of older carers attempting to plan for the future of their adult children with disabilities. Specifically, they called loudly for an acknowledgement that the State government sees futures planning as a priority for families and that this moves beyond just the disability sector to include the broader portfolios of government, mainstream services, and the community.

Participants called for the development of a "Care Succession and Planning Strategy" of 3-5 years with clear timeframes and funded actionable priorities, rather than trying to address everything at once.

This Strategy **would entail an approach in the State government takes a leadership role in funding, amplifying voices, and building inclusive systems and would be aligned with the State Disability Strategy and State Carers Strategy consultations to ensure cross-departmental coordination.**

They also identified that, at the State level, succession planning should not be siloed or the sole responsibility of the Minister for Disability Services; rather it requires a "horizontal project approach" with buy-in from the Ministers for Health, Housing, Communities, Treasury, Local Government and the Attorney General to ensure comprehensive system coordination.

Participant Quote:

> "This issue needs cross-Ministerial prioritisation with buy in from more that just the Minister for Disability Services because it cuts into so many other portfolios. It has to be a horizontal approach"

In relation to initiatives that should be led by the State government, suggestions included, but were not limited to:

- Assume leadership responsibility for the development of the State Strategy, a proactive personal futures planning model, and the provision of block funding to support and sustain implementation of the initiatives proposed e.g., for advocacy and the establishment of "Knowledge Hubs" (see below).
- The Office of the Public Advocate and the Public Trustee were identified as entities that should be part of a coordinated mechanism to track the uptake of estate planning and provide a repository for key documents.
- Partnering with Local Government, which was repeatedly emphasised as an underused partner that could help bridge gaps in the existing service system, e.g., coordinating support services at the local level and using local structures to host information, connect people to resources, and foster inclusion – as part of their "public services".

In addition, Summit participants urged the Minister for Disability Services to write to her federal counterpart to advocate for:

- The systemic inclusion of specific funding line items for futures planning in the NDIS to ensure it is proactively addressed and tracked during plan reviews, rather than just in response to a crisis. The NDIS could also provide "future planning kits or checklists" once a participant reaches a certain age e.g., 30.
- The roles NDIS Planners and Support Coordinators, to include transition mapping and navigation when a person reaches significant milestones, such as turning 18 as core business (with associated NDIS Goals), integrated, resourced and with personnel trained to provide the necessary support.

A priority action identified by all Summit participants was to present the Report from the Summit to the Minister for Disability Services with a view to gaining a commitment to action some, if not all the messages and recommendations from the Summit and to direct permanent, stable funding to ensure the actions remain ongoing and sustainable. Specific attention and resources were identified as necessary to respond to the added challenges faced by families in regional and remote areas.

If necessary to gain such a Ministerial and Government commitment, potential actions identified for DAWA and other advocates (including Summit participants), included:

- *Politicians as Champions:* The "Adopt a Politician" program was proposed as a way for families to directly influence decision-makers by showing them the real-life impacts of planning (or a lack thereof).

  The grassroots advocacy initiative was categorized as an "Action from Lived Experience" and would be designed to ensure that the findings of the Summit lead to tangible systemic change, by:

- Families and Summit participants bypassing bureaucracy and engaging directly with their local politicians.
- Taking the report from the Summit to these meetings to make politicians aware of the issues firsthand.
- Creating a groundswell of support for action.

This approach was seen as a way to ensure that the focus stays on a "good life" for people with disability, while reflecting a broader theme that enduring progress requires building personal relationships and "speaking truth to power" to ensure the system remains accountable to those it serves.

- *Highlighting the Cost of Inaction:* A further vital step to be considered commissioning research to demonstrate the consequences of doing nothing, such as increased system costs and high-cost crisis responses like emergency hospital stays or homelessness.

5) Office of the Public Advocate (OPA), the NDIS and the need for Independent Advocates

Office of the Public Advocate

The Office of the Public Advocate (OPA) plays a critical, though sometimes conflicting, role in the oversight and decision-making structures for adult children with disabilities, including determining the appropriate level of formal decision-making support for an individual.

Their involvement is primarily focused on guardianship, safeguarding, and navigating transitions into adulthood, in respect to which some Summit participants highlighted a significant systemic tension – while OPA defaults to the "least restrictive approach", the NDIA often defaults to recommending formal guardianship orders. The OPA position aims to protect the individual's autonomy through supported, relationship-based decision-making, rather than families being forced into legal structures.

The Public Advocate is seen as a key "actor" in a necessary, permanent safeguarding fixture and there is a strong call for the OPA to be better resourced to adopt a more active, relationship-based guidance role during the transition to adulthood.

To ensure long-term stability for the individual **Summit participants advocated for a comprehensive plan that links the OPA's work, as part of a safeguarding plan for those under guardianship, with other areas such as:**

- **Physical and digital safety.**
- **Carer succession planning.**

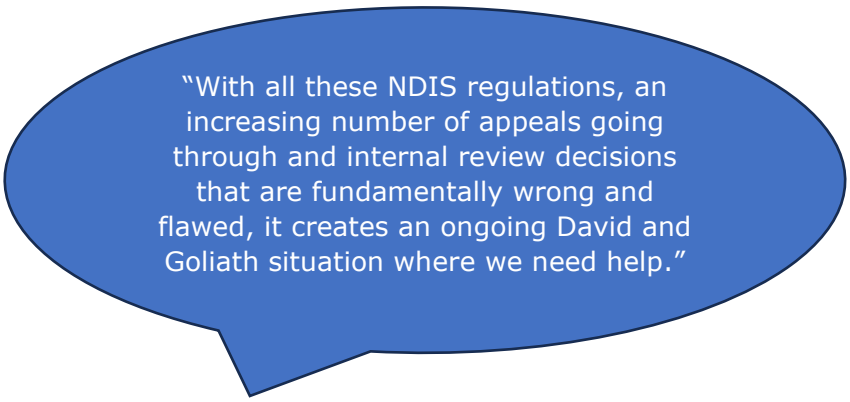
- **Formal guardianship.**
- **Crisis Planning** (e.g., in the event a parent is suddenly incapacitated).

Independent Advocacy

Existing Advocacy Organisations such as People with Disabilities WA (PWdWA), Developmental Disability WA (DDWA), Advocacy WA, and Citizen Advocacy were cited by many participants as excellent providers of independent support to help families navigate systemic barriers and fight for appropriate funding. However, despite the critical work of these organisations, independent advocacy support was identified as a severely under-resourced component of the disability support system, yet essential to ensure that no person with a disability is left "alone in the ecosystem" once their family carers are no longer able to provide that oversight.

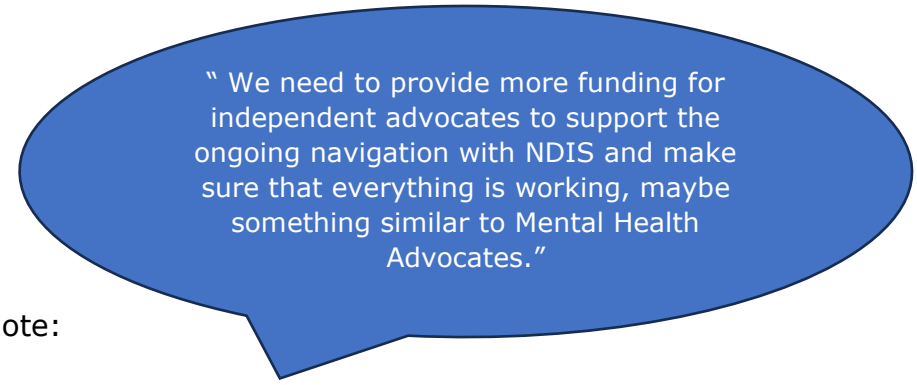
Coupled with the previous discussions concerning the need for alternatives to guardianship and support to deal with often "combative" and "extremely traumatic" situations with the NDIS, families therefore advocate a need for more professional oversight and a sizeable increase in the number of trained, independent and robust advocates, who are trained to fight for the individual's rights and quality of life.

Participant Quote:



Ultimately, families strongly believe that individual and systemic advocacy must be resourced well as part of a safeguarding system for a person with disability once their family carers are no longer present. Independent advocates are a vital structure to watch over and fight for the most vulnerable individuals and hold the "vision for a good life". Advocates can also help those who are not tech-savvy, do not speak English as a first language, or find the system's "robots on the other side" dehumanising.

Key components of independent advocacy sought include ensuring that decision-making for care succession is done outside of service provision systems - operating under a State government-funded "fee-free-service" model, and "independently run."



Participant Quote:

As an option for consideration, **some families expressed a strong desire for a model of independent, trained advocates similar to the existing Mental Health Advocate Services (MHAS)** (albeit the MHAS service only supports people who are receiving or referred for involuntary mental health treatment).

This type of support would be **focused entirely on the individual, helping them navigate the ongoing complexities of the systems and ensuring that their specific needs and quality of life are being met**. Such advocates are seen as essential because they provide a layer of independent oversight that is not "monetarily incentivised" by service provision.

In addition, Summit participants identified the need for urgent introduction of a Community Visitor Scheme (CVS) in Western Australia, as recommended by the Disability Royal Commission, as a further safeguarding mechanism to provide a "reliable and consistent" check on the entire home ecosystem.

Most Summit participants identified that while such a scheme is operating in most other jurisdictions, Western Australia does not currently have a formal CVS, and they highlighted its establishment as a critical priority to address perceived gaps in the current safeguarding system. They described it key features as providing:

- *Monitoring Care and Well-being:* Intended to "oversee the care of the actual carer and what's happening to the actual person," providing a check on the quality of services and the individual's overall safety.
- *Continuous Review Process:* The sources contrast this model with standards assessment (e.g., as under the previous "standards monitoring" scheme under Disability Services Commission (DSC)).
- *Reliable Personal Connections:* Effective oversight is linked to "personal relationships" with visitors who are "reliable and consistent," offering a human element that helps families feel their loved ones are being watched over by someone who truly knows them.
- *Independent Safeguarding:* It acts as an independent safeguard, which families believe is necessary because current bodies like the NDIS Quality

and Safeguards Commission lack "teeth" or only cover formal service providers rather than informal support networks.

In summary, **older carers see a Community Visitor Scheme as a way to ensure that "someone [is] watching over" their vulnerable adult children once they are no longer able to provide that oversight themselves.**

6) Consolidate and Expand the Network of Providers of Support for Care Succession and Planning

When asked to identify initiatives or services that currently exist (or previously existed) to support older families to plan for the future and then put the plans into action, approximately half of the Summit participants were able to able to identify at least one organisation, historical model, or specific tool. A full list of the initiatives or providers identified through the POD discissions is documented in Appendix 2 together with a brief summary of their key function. The list includes

- *Existing or past Organisations and Advocacy Groups:*
  - Future Living Trust
  - Developmental Disability WA (DDWA)
  - Valued Lives Foundation
  - Microboards Australia
  - Bespoke Advocacy Groups
  - Carers WA
  - Wanslea
- *Historical and Relational Models:*
  - WA Local Area Coordination (LAC) Approach
  - WA Individualised Services (WAIS)
  - Family Leadership
  - Circles of Support
- *Planning Tools and Financial/Legal Structures:*
  - Planning Books
  - Legal Mechanisms
  - NDIS Roles
  - Guardianship and Trustees
- *Informal and Peer Support:*
  - Peer-to-Peer Networks
  - Community Connections
  - Sibling Support Initiatives
  - Specialist Help
  - Specific Navigational Apps.

    - Identification Tools
- *Specialised Respite and Community Hubs:*
    - Niche Respite Models
    - Community Infrastructure
- *Guidance for Specific Transitions:*
    - Medical and Developmental Guidance
    - Ripple Ability
- *Legal and Financial Nuances:*
    - Testamentary Wills
    - Centrelink Representation
- *Workforce and Global Perspectives:*
    - DAMA Visas for Immigrants
    - Travel Support
- *Key Planning Frameworks:*
    - 8-Point Plan
    - Planned Individual Networks
    - Informal "Grapevines"
    - Natural Safeguards

Summit participants who have accessed any of these services argued strongly that they were (or had been) highly effective and should be retained (or resurfaced where they no longer exist).

They also advocated strongly that these services should be significantly expanded through State government funding to increase accessibility, service regional and remote areas and specific and more population groups (e.g., Aboriginal populations, those for whom English is not the first language, and LGBTIQ+ communities) and reach the most vulnerable (including those who are homeless or in the justice system).

To prevent care planning from becoming a crisis-driven response, the participants further advocated for the strategic resourcing of existing disability services organisations and other models to integrate futures planning into their standard pathways. This approach focuses on early intervention, specifically targeting younger families and sole parents who often do not receive information about long-term planning until their children are much older. By the State government funding these organisations to promote the tangible benefits of proactive planning, the system can move toward a model where families are empowered to build sustainable futures well before the primary carer is no longer able to provide support.

The following potential additions to current Care Succession and Planning support bodies were identified through the discussions:

- *Existing Disability Services Providers:* Already have significant reach across the disability ecosystem and should be resourced to ensure futures planning is valued and integrated into existing service pathways.

Participant Quote:

- *Schools:* Conversations about succession and care planning need to be normalised as a part of life and initiated early, particularly when children are young. In this respect, schools were identified as critical early entry points for these conversations, especially during transition points when families are actively seeking information.

  Beyond just providing information, schools were seen to play a vital role in bringing families together, which helps build social capital and peer to peer networks, and acting as "libraries" to refer families to specialised services.

  Examples of similar "successful" models included Chalice, an integrated service model acting as a hub where families can access various other services; and Kiind, which serves as a method for starting the personal futures journey when children are young, ensuring the planning is not left until a crisis occurs.
- *Community Legal Centres:* These centres are identified as essential partners for managing the legal components of the journey, including Enduring Powers of Attorney (EPA) and Guardianship. Some participants suggested consideration should be given to establishing a dedicated community-based legal service specifically focusing on futures planning, at the same time removing the cost barrier for many families.
- *Medical Professionals:* GPs, child health nurses, and hospital social workers are seen as trusted referral points who can normalise the conversation about succession as a standard part of health care.
- *Local Governments:* Many participants suggested that local councils are an underused resource that could host information, foster inclusion, and even oversee care coordination.

7) Establish Knowledge Hubs

Many Summit participants were able to identify that future succession planning for older carers involves a complex set of financial, legal, and relational arrangements designed to ensure the long-term safety, advocacy, and quality of life for adult children with disabilities. Some described the process as moving from a daily care role to management style role that covers physical, emotional, intellectual, and financial needs.

Core Components of Succession Planning were less easy to describe, and different carers outlined a variety of tools and structures they had used or considered to prepare for a time when they can no longer provide care (see previous theme on Existing Providers).

Key components identified across the PODs included:

- *Safeguarding through Rights and Community:* Participants emphasised an integrated safeguarding framework grounded in human rights, dignity, and autonomy.
- *Legal and Financial Structures:* These include testamentary wills, Enduring Power of Attorney, and Special Disability Trusts (particularly noted for their rules that allow families to secure a child's financial future without affecting the carer's pension).
- *Intentional Networks:* Models like Microboards (requiring a minimum of six people in WA) and Circles of Support designed to hold the "vision for a good life" and provide safeguarding when parents are gone.
- *Documentation of "Internal Management":* To tangibly record the intimate details of a child's routines, preferences, and needs.
- *Professional Oversight:* Some families engage services paid for from an estate to provide a special person who checks on the individual during significant occasions like Christmas and birthdays.
- *Independent Advocacy and Dedicated Navigation:* Effective solutions must include navigators or coordinators who help families manage the "executive load" of different systems. Crucially, this advocacy should be independent of service providers to avoid conflicts of interest and should not follow a fee-for-service model.
- *Co-Design and Lived Experience:* An effective solution must be built through co-design and co-production with people with disabilities and their families. This ensures that initiatives are informed by lived experience and address the actual realities of the community.
- *Building Social Capital:* Support should focus on helping families build a "circle of support" around the individual. This ensures that decision-making is shared among a broader group of people who care about the person.

- *Peer Support and Mentoring:* Peer-to-peer and family-to-family groups were identified as powerful "quick start" initiatives. Hearing from others who have lived through similar transitions helps build confidence, reduces isolation, and allows for the sharing of practical, lived-experience strategies.

Even for educated carers, the Summit clearly exposed that finding the "right" information is a major challenge due to the lack of a "single source of truth", meaning families are left to "shop around" between various organisations, often discovering tools like microboards only by chance. Issues identified included, but were not limited to:

- *Awareness of Tools:* Some carers reported having never heard of options like Special Disability Trusts, Microboards, Planning Books and Apps until participating in community planning sessions, or the Summit itself.

Participant Quote:

"I really don't know what services are available and how to access them. There's no central source for advice or services. We really need a central point of contact for mentoring and to help join up the system."

- *Navigational Complexity:* The system was described as a "nightmare" to navigate, with information often fragmented across different financial advisors, lawyers, and advocates. This creates a situation where "what you don't know, you don't know".

Participant Quote:

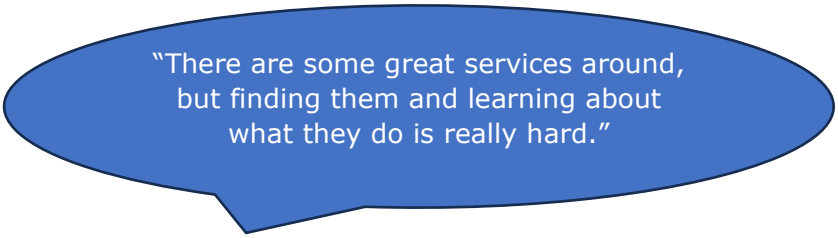
"There's no one place to go anywhere. You can get a bit of information from a financial advisor, a bit of information from an advocate, a lawyer who can add another bit. There's no holistic support."

The current fragmentation of information was identified as a major barrier, leading to a call for centralised "Knowledge Hub(s)" to provide:

- *Accessibility:* The hub should provide a "single source of truth" or central portal for financial, legal, and service delivery information and key

documents (e.g., a "futures planning kit"), making it easier for families to understand their options without having to "shop around".

- *Format Flexibility:* Participants emphasised that this information must be available in diverse formats (face-to-face, different languages) and not just online, as many older carers are not tech-savvy.
- *A Navigational "Map":* Families want an "overarching or summarising website" or a "tourist information place" to make it easier to see all available services and community organisations in one place.
- *A "Compare the Market" for Services:* Families suggested the creation of a "compare the market" tool or an overarching website that acts as a holistic map of all available community organisations and services.
- *Paid Peers as Experts.* These individuals could help others navigate the system based on their direct experience and provide "buddies" who can provide a "dependable backbone" and walk alongside families on their succession and future planning journeys.
- *Educational Forums and Workshops:* Peer networks utilise workshops and forums where families can get practical guidance and learn from others who have lived through similar life transitions.
- *Translation of "Legalese" into Practical Tools:* The Hub would offer practical resources such as process maps, "cheat sheets," and Easy Read factsheets.
- *Targeted/Preventative Outreach for the "Most Vulnerable":* Intentional outreach is required for those facing multiple layers of disadvantage, including homeless people, those in the justice system, and CALD, First Nations, and LGBTQIA+ communities.
- *Equal Access for All Stakeholders:* A vital component of symmetry is that "providers and [the] whole ecosystem access the same hub paths as participants". This ensures everyone - from the family to the service provider- is working from the same baseline of information.



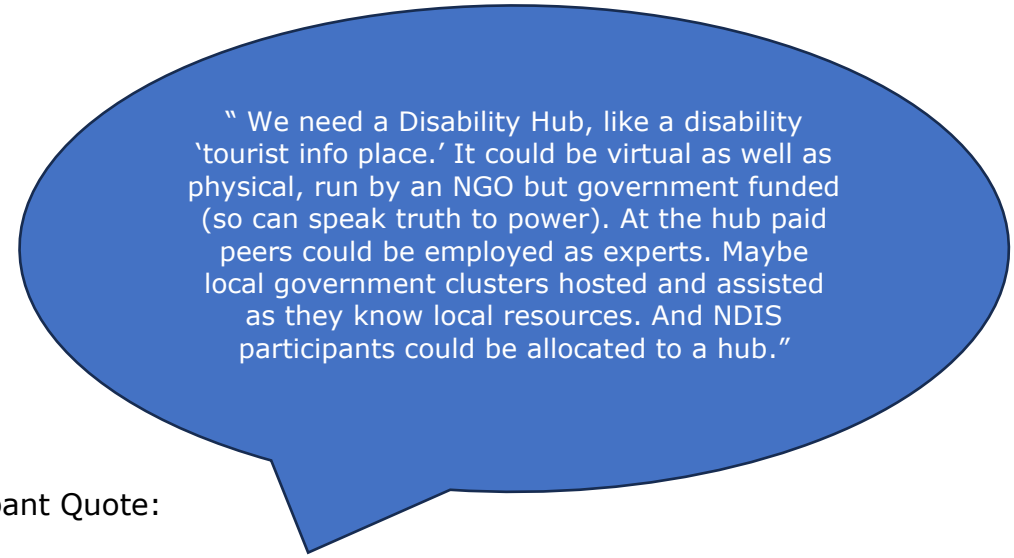
Participant Quote:

The creation of "Knowledge Hubs" was a primary recommendation from families and carers in most of the PODs, to address the current fragmentation of information, "join up the system" and help them to navigate complex legal and financial succession planning.

One POD reported that consistent information is available in NSW and South Australia, leading also to a loud call by families for the WA State government to fund and promote such a central source of reliable, contemporary options to remove the burden of research from burnt-out carers and the need to pay multiple high fees for aspects such as financial planning and legal advice.

Strategic implementation requires a State government-funded, non-government organisation (NGO)-run model to ensure the hubs can "speak truth to power" while remaining independent of NDIS service providers. It should be part of a concerted and coordinated approach by the State government, with funding provided as a matter of urgency to "at least establish a proof-of-concept pilot."

Participant Quote:



While acknowledging it currently focuses on helping parents navigate challenges to give children the best start in life, the Ngala model and structure was suggested by a few Summit participants as a possible blueprint for supporting older carers through care and succession planning, through the following adaptations:

- *Utilising Multi-Channel Support:* Just as NGALA provides a free parenting line, a succession-based version could offer a dedicated helpline for carers.
- *Residential Planning Services:* To help families explore and transition into future housing and supported living options for adult children with disability.
- *Community and Parent Centres as Planning Hubs:* The sources suggest the NGALA model of child and parent centres could be reimagined as local hubs where families receive practical guidance, attend workshops, and build skills for long-term planning.
- *Capacity Building and Training:* NGALA's focus on upskilling parents can be adapted to provide tailored workshops for estate planning, establishing Special Disability Trusts, and creating "life plans."

8) Make it Happen…… and Potential "Quick Wins"

The final Summit discussions focused on how to make sure the message gets through to families and encourages them to take the personal futures planning journey; and what are the most important next steps?

Encouraging Families to take the Futures Planning Journey

Not surprisingly given the previous discussions, the re-creation of Relational Local Coordination, Institutional Support and Funding, Expanded Advocacy, Expanded Provider Networks and the establishment of Centralised Disability Hubs were highlighted as systemic high priorities for action, but other main themes and messages from the responses centred on authentic storytelling, early intervention, and systemic integration.

Specifically, these themes, which sometimes repeated previous commentary included:

- *Storytelling and Lived Experience:*
  - Lived experience is considered the most powerful way to reach families, as they respond better to relatable human stories than to bureaucratic language.
  - Promotion should include sharing success stories and "the hard parts" of the journey to normalise the experience and build hope.
  - Specific suggestions include:
    - Creating podcasts of success stories to capture the hearts and minds of the broader community.
    - Using schools as venues for seminars and awareness campaigns to share successful lived-experience stories and practical planning tools.
- *Diverse and Multi-Channel Communication:*
  - Promotion must be early and consistent, using various mediums such as social media, forums, promotional materials, and word of mouth.
  - Broad media campaigns are recommended, including television stories, print media, social media advertising.
  - Approaching universities to create marketing campaigns was suggested to help elevate the message.
  - Tying promotion to high-visibility events such as International Day of People with Disability (IDPwD) and Carers Week in WA.
  - Targeted Outreach and Regional Roadshows to reach diverse and vulnerable (the "most vulnerable") communities.
- *Early Intervention and Normalisation:*

  - Conversations about succession and care planning need to be normalised as a part of life and initiated early, particularly when children are young.
  - Schools are identified as critical early entry points for these conversations, especially during transition points when families are actively seeking information.
  - It is vital to engage younger families and sole parents to ensure they are not left until a crisis occurs.
- *Collaborative Advocacy:*
  - Promotion should involve influencing politicians through programs like "Adopt a Politician" to keep the message visible to decision-makers.
  - Collaborative efforts should extend to GPs, child health nurses, and social workers at hospitals to act as referral points for futures planning.
  - The message should emphasise that proactive planning provides a return on investment for the state by avoiding high-cost crisis responses like emergency hospital stays or homelessness
- Alternative Media and Public Space
  - Beyond digital media, participants suggested very visible public promotion, such as using the Yagan Square billboard or placing posters on buses to keep the message in the public eye.
  - Engaging specific media personalities (e.g., ABC's Nadia Mitsopolous) was suggested as a way to champion the issue and hold systems accountable.

Next Steps and Quick Wins

A clear message from participants in the final POD discussion was the need for "less talk, more action <u>now</u>" to urgently establish a system that enables coordinated planning, early intervention, and long-term safeguarding.

Participant Quote:

> "Quick start initiatives should include hubs, outreach, peer networks, educational forums, and practical technology tools that help families connect, share knowledge, and keep important information, routines and safeguards in one place."

Participants advocated strongly for the urgent establishment by the State government of an integrated, rights-based safeguarding framework that bridges the interfaces between the NDIS, State government mainstream services, and legal and housing systems.

"We urgently need a coherent, rights-based safeguarding and planning system that families can actually navigate."

Participant Quote:

The discussions in many PODs highlighted a genuine sense of desperation for the State Government to provide leadership, through resourcing the disability eco-system to meet the gap that currently exists for Carer Succession and Planning, including independent advocacy and dignified public infrastructure - a desperation to ensure that families can rest reassured that there is "a dependable backbone around their family member, before the family can no longer be that backbone."

"Enduring progress needs an integrated safeguarding framework - embedding dignity, autonomy, will and preferences. It needs clear pathways; consistent information; human-centred engagement (not a "faceless system"); and recognition that people live within families, relationships and communities. Effective solutions must bridge NDIS–state–legal–housing interfaces and respect economic and cultural diversity."

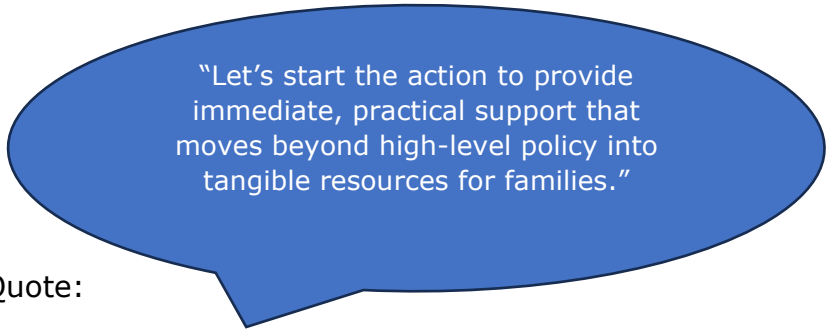
Participant Quote:

The most important next steps therefore focused on moving from discussion to practical action, establishing clear ownership, and securing sustainable funding. Key themes and messages from these discussions, many of which were considered potential "Quick Start" initiatives, were:

- *Policy and Government Accountability:*
    - A priority is to present the report to the Minister for Disability Services (and Minister for Communities with responsibility for Carers) and secure a guaranteed commitment to action the discussed outcomes.

- Next steps should include leveraging the presence of several ex-disability ministers in parliament and using programs like "Adopt a Politician" to keep the issue on the legislative agenda.
- A further step is demonstrating the consequences of doing nothing, such as increased system costs and crisis responses like emergency hospital stays.
- The work should be explicitly linked to the State Disability Strategy and State Carers Strategy consultations to ensure cross-departmental coordination.

- *Strategic Mapping and Coordination:*
  - A critical gap is the lack of clear ownership, so an immediate next step is to identify exactly who will lead, coordinate, and take responsibility for progressing this work.
  - There is an urgent need to map what organisations exist in Western Australia, what they do, and where the gaps are to reduce duplication and ease navigation for families.
  - Participants again called for a longer-term strategy (3–5 years) with actionable priorities to make a difference.
- *Practical Tool and Resource Development:*



Participant Quote:

  - A key next step is to develop standardised "Futures Planning Kits", templates, process maps, "cheat sheets," and Easy Read guides and checklists tailored to different life stages. This includes developing individualised process maps that cover guardianship, administrative options, and wills.
  - The development and roll-out of Knowledge Hubs was again proposed as a vital way to provide central information sources, with a recommendation to allocate additional funding specifically to research their effectiveness.
  - Plans should be designed to tell a "story of need" that serves as a triage tool, identifying exactly what is required at different stages of the journey.

  - Practical tools need to include facilitators or "buddies" who can "walk alongside" families to keep them on track with their planning journey by providing grassroots, human-centred help.
  - Resources should include practical technology tools to help families connect, share knowledge and obtain key information and routines.
  - New initiatives should be trialled through proof-of-concept pilots that utilise co-design and co-production with the disability community from the outset through to evaluation – essentially designing around continuity, rather than crisis.
- *Sustainable Funding and Resourcing:*
  - Succession planning cannot rely on short-term grants; it requires permanent, stable funding to remain ongoing and sustainable.
  - Specific attention and resources must be directed toward the added challenges faced by families in regional and remote areas.
  - Families require immediate financial assistance to overcome the high costs of professional services, specifically grants to engage lawyers for wills, estate planning, and setting up Special Disability Trusts.
  - Sustainable funding is required for both systemic and individual advocacy to ensure the message continues to be amplified and is not "stymied" by bureaucratic conflicts of interest. This includes individual advocates who can "speak truth to power" and challenge system failures.
  - An investment is needed for peer-to-peer and family-to-family groups, as a powerful way to reduce isolation and share practical lived-experience strategies.
- *Workforce and System Capacity Building:*
  - There is a need to build the capacity of system workers to raise expectations of what is possible for people with disabilities and to work against the "commoditisation" of care time.
  - Specifically, this should include advocacy to the Commonwealth to train NDIS planners on succession planning so they can support families through the process during annual reviews.
  - Health, housing, and employment systems should have disability awareness built-in so they can naturally prompt and support futures planning.
- *Personal and Family Action:*
  - Families must be encouraged to "just start" the process, beginning with identifying their specific journey stage - whether they need all components of planning or just one (e.g., legal or financial).

- A next step for families is ensuring they have a plan for where information is stored and who it will be passed on to in an emergency

In addition to the primary themes already discussed, other potential "Quick Start" initiatives suggested for consideration by a few of the PODs included:

- Developing specific crisis management plans for families, covering scenarios like bushfires or fuel crises to ensure continuity of care and access to medical appointments.
- Prioritising the development of crisis accommodation that is fit for purpose.
- Moving to a blended funding model (including block funding) for respite houses to ensure they remain viable, as the current individualised approach is seen as "broken".
- Signing up to the National Agreement for Liveable Housing to improve the stock of accessible homes.
- Increasing the focus of Legal Aid on assisting people subject to guardianship orders.
- Translating complex "legalese" documents into Easy Read layman terms and user guides.
- Launching education campaigns that support families with free wills, free EPOA (Enduring Power of Attorney), and planning.

9) Funding support will be required

While the POD discussions focused almost entirely on strategies required to address the significant gaps that exist in relation to Care Succession and Planning for Families with Intellectual Disability in Western Australia, many of the themes and calls for action documented in this Report will require funding support if they are to be realised. The implementation of robust care succession strategies requires targeted State government financial support to remove the significant barriers families face when attempting to navigate complex systems.

The primary areas for funding include, but are not limited to the following:

- *Legal and Financial Planning Services:* Families identified a significant financial barrier to accessing the specialised professional advice needed for complex estate planning. For example, financial assistance to engage lawyers and financial advisors for drafting testamentary wills, establishing trusts (such as Special Disability Trusts), and setting up Enduring Powers of Attorney.

- *Development of Practical Tools:* Resourcing the creation of "Futures Planning Kits," templates, process maps, and Easy Read guides to help families navigate legal and administrative options.

- *Housing and Crisis Accommodation:* To ensure long-term stability, Summit participants advocate for State government-led housing and safeguarding frameworks. Securing "safe and forever" housing is a central concern and funding needs include State-Owned Housing.

  Suggestions included that Specialist Disability Accommodation (SDA) should be owned and run by the State to protect rights and ensure security of tenure rather than relying on the "open market". They also included that the State could increase the stock of accessible homes by signing up for the National Agreement for Liveable Housing.

  In relation to Crisis and Respite Care, funding may include developing fit-for-purpose crisis accommodation and moving to a "blended funding model" (including block funding) for respite houses to ensure their viability.

- *Independent Advocacy and Safeguarding:* Participants emphasised that advocacy must be independent of service providers and adequately resourced. Key funding areas are:

  - Increased Advocacy Workforce: A "sizeable increase" in trained, independent advocates to fight for an individual's rights and quality of life once family carers are gone.
  - Community Visitor Scheme (CVS): Establishing a formal, state-funded CVS in Western Australia to provide independent oversight and regular checks on the well-being of vulnerable individuals.
  - Systemic Safeguarding: Permanent funding for both individual and systemic advocacy to ensure voices are amplified and system failures are challenged.

- *Centralised "Knowledge Hubs":* There is a "loud call" for a "single source of truth" to replace the current fragmented information landscape. Funding is therefore needed for:
  - Establishment of Hubs: Funding for virtual and physical "Disability Hubs" (run by NGOs but government-funded) that provide holistic advice, mentoring, and a "navigational map" of services.
  - Proof-of-Concept Pilots: Initial investment to trial these hubs, including research into their effectiveness.
  - Paid Peer Experts: Funding to employ peers with lived experience within these hubs to walk alongside families as "buddies" or mentors.
- *Relational Support and Navigation Models:* Families advocated for a return to relationship-based models rather than the current transactional NDIS approach. Funding may be required for rebuilding a state-funded,

relationship-based navigation system that provides a single point of contact and deep personal knowledge of the individual's "ecosystem".

Investing may also be required for models that build the capacity of families and people with disabilities to advocate for themselves and use funding effectively.

- *Peer, Sibling, and Community Networks:* To avoid the "default" reliance on siblings to carry the full burden of care, the sources suggest funding for:
    - Sibling Support: Specific initiatives including sibling peer groups and networks to help them understand their future roles and avoid burnout.
    - Intentional Support Networks: Resourcing the establishment of formal structures like "Microboards" or "Circles of Support" to ensure decision-making is shared among a broader community.
- *Strategic Implementation and Regional Support:* Finally, participants repeated their call for high-level State government stewardship, including:
    - Shared Strategy Funding: Developing and funding a 3–5 year "Shared Strategy" with funded and actionable priorities and cross-departmental coordination.
    - Regional and Remote Resources: Directing specific resources to address the unique challenges of isolation and lack of local providers in regional areas.
    - Block Funding: Providing stable, permanent block funding for implementation to ensure initiatives remain sustainable beyond short-term grant cycles.

Section 4: Messages for Governments and Key Decision-Makers

- There are an estimated 120,000 million primary carers in Western Australia and the majority are over 45 years of age.
- Many of these ageing families and carers are feeling "abandoned" by the system as they enter the later stages of their lives and seek to transition from being the 24/7 "executive managers" for their children to securing a sustainable future for them. They are desperately seeking a system that provides "forever" homes, coordinated planning and stable funding to ensure their children's voices, routines, and preferences are understood and maintained long after they can no longer provide direct care.
- The loudest calls from this Summit are for the State Government to acknowledge this huge gap in the safeguarding lifecycle for families with intellectual disability and assume both responsibility and accountability to address Care Succession and Planning.

- The State Government is called upon to:
  - **Establish a 3–5 Year State-Led Shared Strategy:** A whole-of-State government plan with clear ownership, timeframes, and funded priorities. Families call for a "Shared Strategy (3–5 years) with clear timeframes and funded priorities" and warn that without it, WA will face "high-cost crisis responses, including emergency hospital stays and homelessness."
  - **Create State-Funded Knowledge Hub(s) (Single Source of Truth):** Centralised, multi-channel hub(s) offering legal, financial, housing, and planning guidance, staffed by paid peers. Families report a "poorly resourced and fragmented information ecosystem" and call for hubs that act as a "tourist information place" with "cheat sheets" and peer mentors.
  - **Rebuild Relationship-Based Navigation (LAC-Style Model):** Reintroduce a human-centred, local, relational navigation system with manageable caseloads. Carers describe the current system as "combative" and "traumatic" and want a return to the LAC model that provided "deep personal knowledge of the individual and their family."
  - **Provide Permanent, Stable State Funding:** Provide long-term State government block funding for navigation, advocacy, housing pathways, and succession planning supports. The report stresses that enduring progress requires "permanent, stable State Government funding".
  - **Expand and Resource Proven Care-Succession Models:** Invest in Future Living Trust, Microboards, Carers WA, and culturally appropriate models for Aboriginal, CALD, LGBTIQA+ communities, regional, and remote families. Participants emphasise that these models are "highly effective but require significant investment" and must be expanded.
  - **Invest in Early Intervention Care Planning for Younger Families:** Normalise succession planning through schools, GPs, hospitals, and community settings. Schools are described as "libraries for referrals," and early intervention is essential to avoid crisis-driven planning.
  - **Strengthen and Expand Independent Advocacy:** Significantly increase funding for independent, skilled advocates who can navigate NDIS, safeguarding, and crisis systems. The report states advocacy is "severely under-resourced" and essential to ensure individuals are not left "alone in the ecosystem."
  - **Fund Legal and Financial Planning Support:** Provide grants or subsidies for wills, Special Disability Trusts, Enduring Powers of Attorney, and estate planning. The document notes that specialised legal help is "prohibitively expensive," preventing families from planning.

- **Support Siblings Through Dedicated Programs:** Create sibling-specific supports, peer networks, and external decision-making mechanisms to avoid defaulting care to siblings. Parents fear the "sibling burden" and want supports so siblings "retain their own life opportunities."
- **Establish a WA Community Visitor Scheme (CVS):** Provide independent oversight and regular wellbeing checks for vulnerable individuals. Families call this a "vital safeguarding priority" to ensure "someone is watching over" individuals once carers are gone.

APPENDIX 2 – Existing or Past Case Succession Organisations, Models and Services

Key existing or past Organisations and Advocacy Groups identified in Summit POD discussions

- **Future Living Trust:** Provides financial planning, wills, estate management, and a paid "Visiting Service.
- **Developmental Disability WA (DDWA):** Offers "on the couch" sessions, seminars, links to lawyers and "What if I die tomorrow" workshops.
- **Valued Lives Foundation:** Specifically focuses on Futures Planning and "Shaping Tomorrow" initiatives.
- **Microboards Australia:** Helps families set up Microboards, which create a network of at least six people to provide long-term oversight and safeguarding.
- **Bespoke Advocacy Groups:** Includes Advocacy WA, People with Disabilities WA (PWdWA), Citizen Advocacy.
- **Carers WA:** Offers support groups like Carers Connect and navigational help through the Carer Gateway**.**
- **Wanslea:** Offers "Plan for the Future" services.

Historical and Relational Models

- **WA Local Area Coordination (LAC) Approach:** This previous state-funded model provided a single point of contact with manageable caseloads and personal knowledge of the family.
- **WA's Individualised Services (WAIS):** Previously supported families with Individualised Living and Futures Planning.
- **Family Leadership:** A historical approach that helped families connect to peers, resources, and futures pathways in a grounded and consistent way.
- **Circles of Support:** Predating the NDIS, these networks helped build informal community connections around a person.

Planning Tools and Financial/Legal Structures

- **Planning Books:** The "Before You Die" book and Future Living Trust's "Safe & Secure" book are used to document the "internal management" and intimate details of a person's care.
- **Legal Mechanisms:** Enduring Power of Attorney (POA), testamentary wills, and Special Disability Trusts are key financial planning tools.
- **NDIS Roles:** Families utilise Nominee status as a less restrictive alternative to formal guardianship, as well as Support Coordination and Supportive Independent Living (SIL) pathways.
- **Guardianship and Trustees:** Engaging the Office of the Public Advocate (OPA) or external trustees to act on a person's behalf.

Informal and Peer Support

- **Peer-to-Peer Networks:** Often cited as a "game changer," these include mentoring from parents who have lived experience.
- **Community Connections:** Leveraging local businesses, neighbours, and church memberships to build a natural "village" of support around the individual.
- **Sibling Support Initiatives:** Groups designed specifically for adult siblings to explore their future roles and needs.
- **Specialist Help:** Utilising family accountants with disability experience or GPs who can assist with the extensive paperwork required for the NDIS.
- **Specific Navigational Apps:** The **AbilityAid App** was mentioned as a tool that links families directly to NDIS-related information.
- **Identification Tools:** The **Sunflower lanyard** is used as a simple but effective way to help others identify hidden disabilities, which can assist in community safety and understanding.

Specialised Respite and Community Hubs

- **Niche Respite Models:** Beyond standard respite, families noted the effectiveness of SWAN's "mum and dads' weekends away," which focus on carer relaxation, and DDWA's "side-by-side" camps.
- **Community Infrastructure:** The availability of sensory rooms, hubs, and toy libraries, as well as buildings provided through local councils, were identified as existing assets that support the broader ecosystem of care.

Guidance for Specific Transitions

- **Medical and Developmental Guidance:** The KIIND (formerly Kalparrin) initiative was praised for helping families with kids in medical situations by guiding them toward the next steps in the system.
- **"Ripple Ability":** This service was noted for its ability to "follow families" through their lives, providing consistency across different milestones and transitions.

Legal and Financial Nuances

- **Testamentary Wills:** Participants specifically identified testamentary wills (rather than standard wills) as a critical tool for estate planning, though they noted the high cost of the legal advice required to set them up.
- **Centrelink Representation:** Having a designated representative at Centrelink who can talk on the person's behalf was listed as a practical way to manage administrative interactions.

Workforce and Global Perspectives

- **DAMA Visas for Immigrants:** Families and providers discussed using **DAMA Visas** to sponsor full-time immigrant workers to ensure workforce

consistency. However, recent federal increases to the required salary levels have made these workers ineligible for the visa, creating a new barrier.

- **Travel Support:** It was noted that the NDIS will fund **support workers to travel overseas** with a person with a disability, which can help maintain care consistency during travel.

Key Planning Frameworks

- **8-Point Plan:** A specific **"8-point plan"** developed by DAWA was cited as a useful framework for families.
- **Planned Individual Networks (PLAN):** The **Canadian model** of Planned Individual Networks was mentioned as a resource-intensive but effective example of structured network building.

Informal "Grapevines"

- **Natural Safeguards:** For those living rurally or in tight-knit areas, community support often builds naturally through **local businesses, neighbours, and church memberships**, creating a "grapevine of people who care for the individual. However, families caution that while these connections provide safety, they do not replace the need for professional oversight or the "executive management" of care.

APPENDIX 3

DAWA Board

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Charmain FitzGerald
Erin Marshall
Carolyne Franklin
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Paul Fleay
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DAWA Council

Julie Waylen (Chair)
Amy Clark
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Esme Bowen
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