Disability Assembly WA

A collective voice for people with disability

Living with Significant Intellectual Disability.
Challenging the Gaps

What We Heard...

The report from the Disability Assembly WA (DAWA) Summit held on 22nd March 2024

Disability Assembly WA (DAWA)

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About the contributors to the work

DAWA sincerely thanks the families who shared the complex world of navigating life with, and for, a person with significant intellectual disability and our sector colleagues who took part in the Summit, the subsequent conversations, information sharing and report creation.

54 of the 96 participants consented to be named as contributors to this work:

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Disability Assembly Western Australia (DAWA) is an independent not-for-profit systemic advocacy organisation governed by a Board of Directors. DAWA's vision 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 major part of our purpose is bringing together people with disability, families, carers, peak bodies, advocates, providers, experienced stakeholders from diverse backgrounds and the policy- and change-makers of the day.
We generate informed, impartial discussion and debate on the big issues. We are a team of innovative people with lived experience and/or professionals in the disability field who hold a diversity of perspectives.
DAWA is a safe place for meeting and sharing knowledge and expertise.
DAWA is your local community of local people who know disability.
We are the collective voice…the power of one.

If you would like to know more about DAWA and how you can get involved please email us at hello@disabilityassemblywa.org
https://disabilityassemblywa.org

Foreword from the CEO

DAWA has convened its third successful Summit. Our topic was **Living with Significant Intellectual Disability in WA: Challenging the Gaps**

Disability Assembly Western Australia (DAWA) is the collective voice of the disability ecosystem in WA. It comprises a collection of Western Australians made up of people living with disability (PWD), their families, friends and carers, people from the broader disability sector, and representatives of some government agencies.

As part of our systemic advocacy work, DAWA gathers data and collective opinion. Our Summits and the subsequent Summit Reports constitute key pillars of this vision and aim to inspire and facilitate informed discussion and debate on the big issues faced by PWD. DAWA welcomes and connects people from across the disability ecosystem to discuss and debate a priority topic. The topic of each Summit is determined through consultation with key stakeholders, is based on strategic priority and state-wide importance, and very importantly, on the potential to impact the lives of PWD in WA.

The Summit held on 22 March 2024 was further evidence of DAWA delivering on its vision to unify, support and champion a thriving disability ecosystem in WA to ensure world-leading and sustainable outcomes for PWD and those who care for and about them. At this event, DAWA connected the disability ecosystem in WA, and generated informed and impartial discussion on the big issues in the lives of Western Australians living with significant intellectual disability. This report is an outcome of the day in our role as the conduit to convey and amplify the collective voice, experiences and concerns, as well as to offer potential solutions to service providers, the governments and changemakers.

The program for the day included multiple breakout sessions of facilitated ‘PODs’ of 8-10 people, which allowed participants to speak freely within a guided conversation. I am humbled by the allyship that was demonstrated. The POD-scribes collected direct information from the conversations, which is collated, reviewed phenomenologically, and presented as themes and insights in this report. A full description of our objectives, methods and processes is contained in the accompanying supplementary Appendix.

DAWA’s two previous Summits have attracted participants with lived experience of the disability related to each Summit topic. For this Summit, where we sought to identify the gaps, barriers, challenges and solutions for a person living in WA with significant intellectual impairment, most of whom are unable to represent themselves, DAWA targeted our invitations to the people most appropriate to speak on their behalf.

The 69 people in the room, and a further nine who constituted a face-to-face POD in the Kimberley, came together to advocate on behalf of people with significant intellectual disability (PWID). Most were parents of adult children. Some were parents of younger children; some sector providers; and carers and guardians. They shared important insights into the current and future challenges and gaps, and the inequities, and offered solutions to the barriers that PWID and their families face. They gave up their time in the hope that their stories can be the foundation for optimal WA state planning and a better future for all PWID living in WA. Their suggested areas for increased advocacy, their visions and solutions for a good life…. for ‘thriving in life’….. form a sound platform from which to approach this important and exciting time of change in the disability ecosystem.
On review of our scribed notes of the day, we identified that the demographics in the Summit rooms, whilst broad and varied, seemed to be missing a subset of important information

holders. There was a paucity of siblings of adults with intellectual disability, and we believed they may be an important and unique voice. DAWA immediately convened two separate online PODS, which were held across the two weeks following the Summit Day. We invited siblings of adults with significant intellectual disability to join our facilitated conversation. Their information, stories and opinions are included in this report

The findings and recommendations from this Summit will guide and focus DAWA in our advocacy efforts. Our main objective in preparing and distributing this report is to contribute to a sustainable, evidence based and realistic transformation of the issues and services that assist PWID to live a good life in WA. We are, therefore, deeply grateful to the families and community members who joined us and contributed so generously.

On behalf of the Board and Council of DAWA, I also wish to express my gratitude to the Stan Perron Foundation, Tolchard Consulting, Partner&Prosper, My Place, Far North Community Services, and PeopleKind, all of whom funded parts of this day and this work.

As the NDIS Independent Review and the changes to the Legislation unfold, this report strives to identify, highlight and define the work we, as community members and government officials of an inclusive Western Australian society, need to address.

We look forward to the second part of the DAWA 2024 Summit process where change makers, service providers, and Government Ministers and Officers are invited to join the March 2024 participants and contributors to share the higher levels of vision, their plans and their proposals that articulate with the issues, address the gaps and meet the recommended outcomes within this report.

All within the Disability Assembly hopes that after that day, 22 August 2024, we will share a clear set of actions and recommendations that not only guide our advocacy work, but articulate and collaborate with all levels of Government working in the same space to improve WA's disability ecosystem.

Again, deep gratitude to all those who attended and participated, sharing in the spirit of optimism and hope for a better future.

Dr Sarah Love
Chief Executive Officer

Disability Assembly WA
A collective voice for people with disability

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"The power of one….

…….one collective voice."

DAWA acknowledges the original custodians of the lands on which we live and work.

We pay our respects to the Elders, leaders, educators and advocates past, present and emerging, and commit to working together for a better and more inclusive future.

EXECUTIVE SUMMARY

This report summarises, groups and defines the experiential qualitative data gathered from 96 people who have lived experience of significant intellectual disability (ID), support and care for a person living with intellectual disability, and/or who work professionally within the West Australian disability ecosystem.

In March 2024, Disability Assembly Western Australia (DAWA) held a Summit Event focused on the topic, **'Living with Significant Intellectual Disability: Challenging the Gaps'**. This topic was chosen because DAWA received multiple communications from families living with significant ID, stating they believe they are being overlooked and misunderstood. A concerted effort was made to ensure the inclusion of a broad range of people with intellectual disability (PWID) who could speak for themselves. The cohort was largely parents, carers, and siblings of PWID who could provide informed input on behalf of those who could not speak with their own voice, and a small number of representatives from a range of disability service providers, advocates, peak bodies, and other subject matter experts.

In this report we present the data gathered from facilitated conversations in small 'POD' groups on the topics of:

1 | Thriving in Life (including Employment or Alternatives to Employment)
2 | Thriving at Home
3 | Thriving Relationships

DAWA engaged Tom Tolchard from Tolchard Consulting and the expert assistance of skilled POD facilitators to help us capture:

- the experiences of families and others who care for and about people with significant intellectual impairment,
- the challenges and gaps, and the impact these have on thriving for the PWID and for their family, and
- the suggested opportunities to mitigate the challenges and fill the gaps.

We gathered the information and qualitative data and grouped it into themes and insights. In this report we present a summary that forms a solid platform for our advocacy work around the needs of people with significant intellectual impairment. This report identifies and articulates the challenges and gaps as identified by families, highlights these issues with stakeholders at all levels in the disability ecosystem, and shares the families' suggestions, requests and recommendations about how services and processes can be improved to deliver better outcomes for PWID. Our Summit process is described and attached as an APPENDIX at the end of this document.

The POD conversations generated valuable insights and DAWA looks forward to engaging with stakeholders across the disability ecosystem - including all tiers of government, the public sector, peaks, advocacy organisations and service providers - to share these insights as we discuss, debate, co-design and transform the disability ecosystem.

DAWA wishes to harness the power of the collective voice, and work with all tiers of government to achieve better outcomes for those living with intellectual disability and all the people who care for and about them.

Theme One

Investment in formal and informal daily supports directly correlates to better quality of life for people with intellectual disability

"The best way (to live their best lives) is for people with severe intellectual disability to be supported by the wider community and this hasn't happened yet – we need greater access and inclusion, and dedicated support workers are instrumental to this."

Source: DAWA Summit family member

"My sister is deaf, and she has a deaf support worker who she is much more engaged with (sic). It's the skills and the relationship that count the most."

Source: DAWA Summit family member

Insight 1. Rewarding and recognising the crucial role of Support Workers

Support Workers have significant influence over the well-being and future outcomes of the PWID they support. There is a need for greater recognition and appreciation of the profound responsibility and positive impact of the well trained and well supported Support Worker.

A major issue is the perception of support work as a transient job rather than a dedicated career with pathways to training, skills development and career progression. The workforce shortage is noted. The current 'casualisation' of support work employment contracts has resulted in reduced employment and financial security for the Support Worker and a worrying trend toward a greater number of different Support Workers in one-off interactions with the PWID and a dilution of the relationship between Support Worker and participant.

It is acknowledged that disability support work is a popular job with student nurses and allied health therapists while they are studying, and although the support work role for students typically has a duration of only two to four years, the benefits to the PWID, to the students themselves and to the professions for which they are studying, outweigh some of the disadvantages of short tenure. However, there does need to be a base of stability and growth in the profession of support work. The long term, professional, dedicated Support Worker who fosters learning and independence, builds capacity, facilitates positive relationships and meaningful daily activities while ensuring ongoing safety and security is invaluable to the PWID and the family. It is longevity of care/of relationship that is crucial to supporting the PWID to thrive and this can only be achieved if we back Support Workers to become skilled clinicians and valued leaders in their field.

The need for initiatives to attract and retain 'career' Support Workers is unanimously supported. There is an identified need for incentives including training and professional development, credentialing, defined career pathways, review of remuneration (to be, at least, in line with Aged Care rates), and greater public recognition of the role as a vocation.

Insight 2. Clarifying the role and responsibilities of the Support Worker

Concerns are shared about the dilution of the caring role with examples of Support Workers in group homes and residential settings now being responsible for integrating cleaning and other domestic duties into their role. The growing variability in daily task skill sets of many Support Workers is resulting in reduction of core skills. This reduction in skill in key areas is a concern that is amplified where the PWID is unable to communicate their personal care needs adequately. Examples of Support Workers having to complete domestic duties such as cleaning, cooking and grocery shopping, while also supporting the person with a disability (where these are not skills the PWID is needing to learn/capable of learning) leads to a dilution of the caring role, with Support Workers consequently lacking sufficient time to support their clients in the essentials of a thriving life. Essentials include being able to leave the home regularly and frequently to socialise and learn new skills. The additional workload is reported to lead to lower job satisfaction and/or burnout for Support Workers in many cases.

Variability in skills is another area of concern, with staff shortages meaning many people with disability are supported by people who are inadequately trained in areas of care required by the individual PWID. This is compounded when a person with complex needs doesn't have the support and/or ability to adequately verbalise their personal care needs to a support person. Many families are resorting to arranging and personally funding Support Workers to complete extra training. Many Support Workers report being asked to train in their own time and at their own expense.

Training, and even credentialing, is mooted as a solution, for example, training in effective methods to support communication with a non-verbal PWID. Allowing Support Workers to focus on delivering support, including communication support, is seen as critical to the life outcomes of the PWID.

Insight 3. Parent, sibling, and family carers need support: “You can’t fill from an empty cup”

Parent-carers spoke widely about the ‘fight’ for respite funding, of decreasing options for respite, and of inconsistent outcomes. We heard stories of how family relationships are severely tested and life for each family member is feeling more restricted when compared with a few years ago. The respite options in WA are reducing. Siblings discussed advocating for their siblings’ right to live independently and enjoy the same quality of life as themselves, for the ‘right of passage’ for the PWID to experience some social separation from their parent, with the lack of availability of safe respite being one of the constant barriers.

This gap in services is even more pronounced for the PWID who demonstrates violent or challenging behaviours, in which instance parental well-being is challenged and availability of regular respite can be considered essential. There is now a paucity of WA facilities and organisations that are able to offer skilled help. This lack of safe, reliable respite opportunities speaks further to the lack of appropriate training in so far as understanding that challenging behaviours are almost always caused by an unmet need.

Support for the parent-carer is waning, and the system is now urgently required to develop a greater understanding of, and ability to deliver, safe services with respite that use evidence-based responses during and after an incident of challenging behaviour.

Championing Change and Potential for Advocacy Support

1. What would enable the profession of disability support work to attract and retain highly skilled career Support Workers?
2. What processes and resources are required to refocus Support Worker Role Descriptions on the valuable parts of disability support work?
3. How might Western Australia support, facilitate and enhance the role of the unpaid carer as identified in the NDIS Review?
4. What does good respite look like and how can access be improved?
5. A revision and common sense approach to restrictive practices.

The desired sustainable outcomes for PWID and their families and carers include

- continuity of care that recognises and adequately supports the unique needs of the PWID as well
- accredited educational opportunities for Support Workers,
- a career pathway for Support Workers that includes tenure and appropriate employment contracts.

Theme Two

Policy and legal frameworks aim to support the person with an intellectual disability, their family or carer…. however they don't always have a positive impact.

"(recent change) has reduced common sense, dramatically increased reporting and paperwork. The guidelines have lost the plot, gone over the top, yet they are helping less in a practical way"

Source: DAWA Summit family member

"It's hard to contribute to good planning when the timing for any long term goal is the next election cycle, and the short term goal is not to be on the front page of the weekend newspaper".

Source: DAWA Summit family member

Insight 4. Future planning affords peace of mind

As a society we continue to experience increasing numbers of PWID outliving their parents. Families and carers are experiencing high levels of anxiety when future planning for their PWID. There is little guidance available to plan for a time when "the parents are no longer here/able to care for them".

There is a strongly expressed need to know that systems and processes that are working for the PWID and for the whole extended family unit will continue long after the primary carer (usually a parent) is no longer alive or capable. An important nuance to future planning is that the needs of all people change with age. Families want reassurance that there will be recognition that behavioural responses change over time and that an assessment 'in time' should not be an assessment for 'all time'. That is to say, the future needs of the PWID should be addressed by continual, ongoing evidence-based assessments, rather than on a guarantee that what is delivered now will continue.

There is a paucity of information and/or support on how to link into or establish systems to ensure the future security and safety of PWID who may no longer have active family around them.

Insight 5. Who watches the watchers?

The question repeatedly arose of how best to protect the PWID who may be living within challenging family dynamics, in situations where there is not an ongoing cross-generational sense of belonging, safety and empowerment.

The systems and processes for efficient and effective continuous, recognised, legal status and the legalities of guardianship for those without the ability to self-advocate are not well known or well-publicised. The need for ongoing protection from physical, emotional, social, and financial abuse means specific legislation, policy and frameworks are required for PWID.

Insight 6. The real-life impact of government policy

Multiple examples were shared of the difficulties encountered by changes in services, policy, and support provision.

One current example occurs in the change in the independent living options system from Supported Independent Living (SIL) to Specialist Disability Accommodation (SDA). Many PWID currently living in SIL with housemates who have physical disability are finding the housemates fit the criteria to move to SDA, leaving the PWID requiring support of 1:1 without adequate funding, and/or being ineligible for SDA and finding no suitable alternative.

The expectation that families are required to understand, navigate and undertake new processes with each change in government and/or policy is causing family stress.

There is great efficiency as well as peace of mind in protecting the PWID from the consequences of the typical and normal political cycle. There is a strong need to be assured that policy and regulatory frameworks protect the PWID and the family from unscrupulous providers, at-risk processes and mis-use of funds regardless of the politics of the day.

Bipartisan cooperation and long-term agreements have the ability to reduce the stressful impact of change of government, as does specific systems assistance during periods of change of government policy.

Insight 7. A voice for the voiceless … advocating and amplifying their voice

Ensuring responsibility and accountability for those who have limited opportunity and ability to advocate for themselves will always remain a requirement of an inclusive society.

Catering to the needs of PWID, especially those with limited communication, is viewed as a moral imperative and one which the wider community needs help to address. While awareness and acceptance in the community of people living with physical disability is growing, there is lesser understanding of people living with intellectual disability. The difficulty surrounding this issue is now critical and urgent as accommodation and living options are changing, and attention and resources are required to address accommodation and living options specifically for the most vulnerable of PWD, those with severe intellectual impairment, especially those who are currently in long-term hospital accommodation with nowhere to transition, or those living alone after transitioning from institutional settings some decades ago. The sub-cohort of people at the most severe end of the spectrum of intellectual impairment need specific attention, plans and processes within the new Independent Living Options that are being explored for the whole cohort of PWD.

Championing Change and the potential for Advocacy Support

1. What State-wide planning services, tools, platforms and processes are needed to deliver coordinated, safe support for PWID when their parents (or other unpaid carers) are no longer capable. The system of guardianship vs public advocacy.
2. Safeguarding against abuse and misuse of power or resource.
3. Collection of/access to (more transparency) in data surrounding the important metrics in disability to allow us to propose data-driven, safe and reasonable options for sub-cohorts. (eg geography/location of planned independent living homes).

The desired sustainable outcome for PWID and their families and carers includes

- having a freely available Government resource that mandates and ensures the safety and security of PWID
- establishment of a Specialist Disability Office /access to a Specialist Disability Officer at State level addressing issues of people with significant and severe intellectual impairment
- an easy-to-navigate system (easy for the layperson) related to guardianship.

Theme Three

Creation of thriving inclusive West Australian communities

"You can't be what you can't see. If more people can see what people with intellectual disability are capable of in recreation spaces and workplaces, we lift the expectations and opportunities for all".

Source: DAWA Summit family member

"We want to be in groups of like-minded people. There used to be sports groups that the kids and young adults could go with others but the advent of NDIS funding brought about a heap of hurdles. He had a great social life – now that has gone. He doesn't just want to walk around shopping centres."

Source: DAWA Summit family member

Insight 8. The stewardship role of Local Government Authorities

The Summit findings recognise the extraordinary influence of Local Government Authorities (LGA) in improving inclusion for PWID in their local communities.

Examples of high quality, well used, valued programs across LGAs are inconsistent in delivery and/or are often abolished without communication.

The strong stewardship role of the LGA requires appropriate funding for initiatives to continue which have a positive impact on the quality of life for PWID. The 'Neighbourhood Model' which is supported by evidence, is not fully optimised in WA.

Insight 9. Cognitive Access: moving beyond physical access to ensure people with intellectual disability thrive

A theme uncovered in DAWA's 2023 Summit: 'Living a Good Life in My Community' is reintroduced and reinforced in today's findings: - Community access continues to be considerate largely of people with physical disability with little regard for, accommodation of, or inclusion of the needs of those with lives deeply impacted by cognitive and /or sensory disabilities.

This cohort, while smaller than other disability cohorts, carries the greatest vulnerability and as such needs greater attention within access and inclusion plans across the state. A strengthening of the regulations surrounding Disability Access and Inclusion Plans (DAIPs) is required. A system to accredit and endorse DAIPs will go some way toward this, as will ensuring true co-design of DAIPs with PWD by all State Government agencies (staff and citizens) and Local Government Authorities (staff and residents).

Insight 10. Variety is the spice of life

As with us all, PWID have diverse interests and choose to spend their time pursuing many different activities. PWID are not a homogenous group and, whilst there are many needs of the whole cohort, the severity of intellectual impairment makes for many sub-cohorts.

True community inclusion by everyone including sports clubs, pubs and restaurants, parks, libraries, cultural and public spaces, and religious and community organisations needs to be supported and facilitated by Government policy and resources.

The Companion Card Program is cited as a successful initiative that has broadly increased accessibility; however, a decreasing availability of options for peer group activities that meet the needs of people with little or no verbal communication due to intellectual/ cognitive ability impacting all aspects of life is noted.

These activities and programs that provide opportunity for friendships and overall physical and mental wellbeing are considered by families to be essential for the wellbeing of PWID. The reducing availability of safe transport options and of transport funding is a further limiting factor to social wellbeing.

Insight 11. A home for life

A stable home/ ongoing continuity in a physical abode, is noted as a crucial component of wellbeing for PWID.

People with severe or profound disability are less likely to own their own home – 56% (or 692,000) compared with 67% (or 2.0 million) of people with other disability, and the need to improve housing choices, availability and options for support provision are called for. This data is supported on the Australian Institute of Health and Welfare website where ABS data from 2019 is cited[1], revealing non-dependent people with sensory or physical disability were more likely to own their home than those with intellectual disability.

There remains, in many situations, no option for the PWID but to live with parents. Necessity often sees parent carers living with the PWID well into their child's adulthood in both metro and regional areas, limiting development of all parties due to the financial, emotional and physical strain on the parents and lack of independence for the PWID. A report released in June 2021[2] identified WA as a 'thin' market for SDA, a term used to describe a gap in the market that still exists.

Furthermore, there is a gendered breakdown whereby women are more often the carer and carry the 'mental load'. Men are more often the 'breadwinner'. These gender related impacts create significant strain on relationships and finances.

Insight 12. Engaging our school communities

The power of our already high-quality education system to improve community inclusion cannot be understated.

There is a strong belief that PWID and the whole education system will benefit from more disability awareness resources and training to inform and support teachers and students of **all abilities** in the school environment.

Insight 13. Local Connectors and Family Liaison – a lost piece of the puzzle

Having consistency is a recurrent request. Consistency in this instance refers to 'consistent point of contact', even 'single point of contact' where possible. It is the consistency in relationships that is most valued by families of PWID, and there is a nervousness amongst families created by the 'transactional feel' of services that has emerged and is increasing in WA.

The previously mentioned development and support for career Support Workers somewhat addresses this request, as does the establishment of a trusted local connector who will know the local programs and opportunities in the community, who 'knows' the PWID, and on whom families can rely for their expertise, wisdom and guidance.

The introduction of the Navigator Role is creating a new temporary issue/gap as services that presently provide Support Coordination are predicted to exit the industry before Navigation Services are established.

Insight 14. Transitioning to adulthood: employment for people with intellectual disability

Employment (or suitable alternatives to employment) is imperative to ensuring future wellbeing, security, and independence of PWID. There is a requirement for education at a societal level to ensure people understand that most PWID are capable of work and have the right to fulfilling employment.

Currently, there is no nationally consistent framework for young people and their families to follow when leaving school and attempting to find employment or a suitable alternative to employment.

Data is not collected at the national level to provide evidence of outcomes. Research undertaken in this space recommends shifting focus from short term 'planning' to a broader perspective of 'transition-focused education'.
A consistent framework is called for, with multiple options at program level. There cannot be a one-size-fits-all approach. The post-school period is a significant transition

period that requires greater focus from all stakeholders including policy makers, education providers and employers.

Insight 15. People with intellectual disability in medical settings.

Some of the greatest health disparities in Australia are experienced by PWID due to mainstream health services being ill equipped to meet their needs. The poor health profile and health disparities experienced by this vulnerable population mean that they have a life expectancy 27 years less than people without intellectual disability. Individuals with intellectual disability often encounter barriers accessing services due to a lack of awareness and accommodation from healthcare services.

This, along with lengthy waitlists and geographical barriers mean that people with intellectual disability face challenges in accessing services. Whilst there are some best practice examples of how positive cooperation and genuine consultation between health professionals and the supporters of PWID has led to excellent outcomes, these are individualised and dependent on the people involved. Reduction of inequity can be achieved by Screening Services, Dental and Allied Health Services and hospitals by creating/ increasing the role of a specialist disability liaison officer to facilitate these interactions.

There is a gendered aspect in the interface with the preventative health and medical systems, in that women carers (often mothers) carry the greatest load in seeking/ attending medical care for the PWID.

Championing Change and the Potential for Advocacy Support

1. Specific Independent Living Options for people who require complex 24 hour supports due to severe intellectual impairment.
2. Planning for the changing geographic need of housing for PWID.
3. Employment and alternatives to employment for PWID
4. Addressing accessibility to preventative health, wellness and screening services and addressing competency levels of health practitioners when caring for PWID.
5. Greater involvement of (greater funding for LGAs in planning and delivery of community programs for PWID.
6. Regulatory control of DAIPs
7. Ensure the Navigator roles meet the complex needs of the sub cohort of PWID: those with severe intellectual impairment

The desired sustainable outcomes for PWID and their families and carers include

- having the full range of choice in the options for independent living, including but not limited to style of home and geographic location.
- disability awareness at all levels of education: from school curricula to the tertiary training of medical, allied health and hospital workers.
- a system that includes trusted advisors who know and understand the unique needs of PWID and their family and carers.
- a dedicated system that prioritises the individual needs of PWID in primary care, preventative health screening and wellness services.
- transition-focused secondary education integrated with a sustainable post-school pathway for PWID enabling access to a range of options including vocational training, supported and open employment.
- strengthened DAIP Regulations with meaningful monitor and auditing. Institution of an Accreditation Process by WALGA, Development WA or The Offices of the Ministers (Disability, Planning) ensuring effective co-design, innovation in practice and community connectedness.

[1] *https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/housing/living-arrangements*
[2] *https://assets.summerfoundation.org.au/pdf_offload/2021/06/SDA-in-Thin-Markets-JUNE-2021-web.pdf*
[3] *https://www.everyonecanwork.org.au/wp-content/uploads/2020/11/Fostering-employment-for-people-with-intellectual-disability-Accessible.pdf*

Theme Four

The challenges of the metropolitan area are amplified in rural, regional or remote areas.

The Summit included a POD of Kimberley representatives, including Indigenous Australians, who met in Broome. Where their insights align with those of the eight metro PODs, they are included in the collective voice. However, this is where they differed.

"This is the first time in 20 years…the first time in my life of caring for my grandson who is in his early 20's that I have felt a part of something…. felt valued…. and that I have been listened to and heard. I want to continue to be involved"

Source: DAWA Summit family member

Insight 16. Regional choice and support provision

Living in regional areas of WA as a PWID is particularly challenging. There is an even greater perceived gap in community awareness about PWID outside of the metropolitan area. There is less choice in every notable area including but not limited to allied health (including social work), community support, and hospital pathway services.

The irregular availability and connectivity of technology adds to the difficulty in coordinating and delivering services. The lack of safe and appropriate local accommodation facilities results in the need to accommodate young people with disability in aged care facilities or choosing no support at all.

There is a need for a focus on resources to support local training, on the viability of disability support work as a career for those living in regional and remote WA, and for support and resources for skilled culturally-safe drive in/drive out specialist service delivery.

Insight 17. Regional travel

Long term evidence strongly supports ecologically sound service delivery in metropolitan as well as rural and remote areas. That is to say, service is best delivered where the PWID lives, plays, recreates or works.

Being On Country is an additional requirement for the well-being of PWID who identify as Aboriginal. Travel is described as an extremely challenging item and often a barrier to good care, especially for those with complex disability and/ or high support needs. Examples included a lack of wheelchair-accessible taxi services in the regions, and a myriad of difficulties pertaining to air travel, including poor assistance and communication in airports, and less safe transportation of essential mobility equipment when compared to metropolitan areas.

Travel to Perth for any part of care is difficult and less than optimal, but where local care is not available, it is essential that funding of travel and subsistence for the PWID and their supporting person are accessible and adequately resourced.

Insight 18. Accommodation

Lack of safe, culturally appropriate and geographically appropriate land and housing is evident. The risk of homelessness is higher for PWID living in rural and remote areas, and the pressure then is transferred to the local hospital systems at greater cost per day than provision of suitable community housing with support.

It is economically unsustainable, as well as inequitable. This is one of the examples of siloed thinking and systems, and siloed funding must be broken down to allow this to be addressed.

Families can often identify suitable unoccupied land close to family / owned by family, but responsibility for planning and resourcing supply of the housing, even temporary demountable accommodation, falls between the jurisdictions/ departments/funding bodies.

Collaborations between jurisdictions, between providers and between industries have the ability to create solutions.

Championing Change and the Potential for Advocacy Support

1. Specific Independent Living Options for people who require complex 24 hour supports due to severe intellectual impairment and whose families wish for them to be geographically close to family or On Country.
2. A less siloed version of assisted travel
3. Equity of service for PWID across the state of WA.

The desired sustainable outcomes for PWID and their families and carers include

- having choice about where to live in rural and remote areas.
- access to decentralised service and traveling services.
- having the same access and inclusion spaces as metro people

CONCLUSION

These insights, and the opportunities for change and advocacy presented alongside them, present a rich deep dive into the issues that are faced by families of people with significant intellectual disability. This is their everyday life.

These insights also create a road map on which Disability Assembly WA can focus our future advocacy and collaborative solutions. It is our hope that by adding the power of systemic advocacy to the existing advocacy services for individual families, we can help to lessen a little of their workload and amplify their voices. The intention of providing the collective impartial voice in this report is to support the redesign and development of a functioning system that meets the needs of all living with disability in WA, including this very important sub-cohort of people with significant intellectual disability (PWID).

We will continue to work with and for PWID and families across Western Australia, to collaborate with our colleagues, communicate with our governments and to effect system-wide change to the benefit of all.

We look forward to engaging proactively with stakeholders across the disability eco-system to seek out positive change for those living with intellectual disability, and especially look forward to the follow-up Summit meeting to be held on 22 August 2024 where the Minister for Disability, decision-makers and other changemakers at all levels of Government will join us to address the issues, questions and requests tabled in this report.

The Next Steps …

DAWA commits to work collaboratively and constructively with all stakeholders to ensure progress towards sustainable solutions.

The key people in changemaker and decision-maker roles in WA have been invited to the follow-up summit on 22 August 2024 to address the points in the report.

We are particularly interested in working with:

The Hon Minister for Disability, the Shadow Minister for Disability and the West Australian Government

1. **to build on our Connectedness**:
    a. Whilst the evidence supports the efficiency of call centres and online contacts, these remain services for the more able PWD. Is there any plan for the Office of Disability to create a local centre for knowledge translation and assistance for our most vulnerable people, those living with intellectual disability?
    b. DAWA welcomes the opportunity to be part of a national push, led by WA, for each state to take a targeted approach to this cohort, and work with their carer families and support circles

2. **to strengthen the Disability Access and Inclusion Plan (DAIP) program:**
    c. Agree to actions that ensure the co-design of DAIPs with people living with disability by all State Government agencies (staff and citizens) and Local Government Authorities (staff and residents);
    d. Increase or mandate focus on functional and social levels of inclusion;
    e. Increase accountability of commitments made within DAIPs by organisations, agencies and LGAs,
    f. Enhance transparency of outcomes of DAIPs in public records: - communicating the attainment of DAIPs, celebrating successes and showcasing best practice.

Minister(s) for Local Government and WALGA

3. **to create a connectedness and consistency of standard across local authorities in relation to disability to allow families to be known and feel secure.**
    a. What needs to be established for true co-design to occur?
    b. Is there a mechanism to strengthen State Government and Local Government disability award frameworks and include recognition of effective co-design, innovative practice, effective inclusive design, and community connection practices?

c. Are resources available to LGAs to take a lead role in engaging people with lived experience (people living with disability, their families and carers) to ensure a vibrant community of engagement and understanding in local communities.

d. Knowledge of the needs of people with physical disability has improved greatly over the past decade. Elevation of knowledge about sensory and intellectual disability requires more attention to strengthen accountability for Access and Inclusion (A&I) for all PWD in all LGAs (including but not limited to inclusion of A&I in new Councillor and staff induction programs).

Minister for Planning

4. **to create a focus on Government policy to ensure all major infrastructure (including transport arrangements) are effectively co-designed with people living with disability and use best practice in infrastructure design for accessibility.**
    a. Commission a review of all public transport hubs for effective inclusion practices.
    b. Ensure all apps and websites include key accessibility features (ensuring that “accessibility” includes physical, sensory, intellectual and other features of disability)

To all changemakers and decision-makers, we ask

…….as you build a legacy of support for our state, is there opportunity for DAWA to support you to bring home a range of local services to better know and support PWD and their families?

ACKNOWLEDGEMENTS

We are grateful to the following sponsors and corporate partners who offered financial or in-kind support to enable us to host the summit: Stan Perron Charitable Foundation, Partner&Prosper, GT Communications, Tolchard Consulting, PeopleKind, Far North Community Services and My Place.

APPENDIX

This Appendix describes the process deployed by Disability Assembly WA (DAWA) for the Summit held in Friday 22nd March 2024.

The Appendix forms part of the report entitled 'What We Heard' distributed in July 2024.

Overview of DAWA

DAWA Board of Directors

CO-CHAIRS	Bruce Langoulant, Grace Mills
DEPUTY CO-CHAIRS	Charmain Fitzgerald, Erin Marshall
BOARD MEMBERS	Esme Bowen, Neil Guard, Sally Hollins, Susan Male, Tony Vis

DAWA Council Members

Mary Butterworth	Kathy Hough
Michael Chester	Victor Djugadi Patrick
Amy Clark	Monique Power
Carrie Clark	Gina Price
Mark Fitzpatrick	Katie Rodwell
Paul Fleay	Barbara Goodwin

Our Sponsors

Stan Perron Charitable Foundation, People Kind Group, My Place, Far North Community Services, Tolchard Consulting , GT Communications and Partner&Prosper.

FOREWORD

Disability Assembly WA (DAWA) has made great strides in the first half of 2024.

Much of this progress has been to clarify strategic direction and to strengthen our back-of-house foundational structures, sustainability and governance to support our high-quality systemic advocacy.

A Stan Perron Charitable Foundation Grant allowed establishment of the inaugural DAWA CEO role which I was honoured to accept in a part time capacity in January. Since then, we have established a stronger committee structure led by Directors and Council Members which includes friends of DAWA as well as skilled, interested members of the public, and our Customer Relationship Management database shows strong growth.

Our committee structure is healthy and aligned, with small teams focusing on the following:

- Communications and Advocacy;
- Marketing and Events;
- Fundraising;
- Finance and Risk; and
- Best Practice.

The office of the CEO is emerging. A Policy and Administrative Officer commenced with DAWA in May 2024 and is a very welcome addition to our team, bringing qualifications in Commerce and Law. In April, DAWA entered into an agreement with the McCusker Centre for Citizenship at the University of Western Australia and welcomed McCusker Interns in the UWA Winter term to assist in operationalising our Communications and Fundraising Strategies. As always, DAWA continues to be strongly supported by the expertise and generosity of Partner and Prosper in all we deliver, especially in events such as this Summit.

In writing the Summit Report ‘What We Heard’ and this Summit Process Appendix on behalf of the Board and Council of DAWA, I wish to take this opportunity to thank them for their extraordinary support and trust in me across this first five months. In my 40 years of professional practice, I have never known a Board or Council so highly reputed, skilled and dedicated, and so willing to roll up their sleeves when required in the operational space. They embody the true spirit of DAWA and I acknowledge their tireless work to amplify the collective voice of disability in WA.

It is thanks to their hard work that the Summit Program is entering its third year. The style of our summit shape-shifted somewhat in 2024. Firstly, a full regional POD was included in the Summit via audiovisual link to represent the rural and regional voices of Western Australians living with disability; and secondly, in lieu of a morning for POD breakout sessions to gather data and information followed by an afternoon focused on immediate response to that data, DAWA implemented a more robust and research-based two-step Summit process.

The entire Summit program on the 22nd of March was allocated to identify what living in WA is currently like for individuals with intellectual disability…… and what it could look like. The underlying question throughout the day was “How can we address the gaps?” We identified that there was an important and unique voice missing from the demographics filling the rooms, and in order to deliver a thorough report with a sound research approach, DAWA immediately convened two online PODs, both for adult siblings of adults with significant intellectual disability to discuss the Summit topics.

The other big change in the process has been to remove the requirement for immediate response-without-notice requested from service providers, policy- and change-makers, and government officials including the Minister for Disability, which was achieved by publishing the Summit Report on DAWA’s website as well as distributing it widely, allowing DAWA and attendees to reconvene for Part II of the Summit, scheduled for August 22 2024, to discuss and address the gaps and barriers, and put forward potential solutions that will allow Western Australians with intellectual disability to thrive in life. I thank all these people in advance for their willingness to read and digest our report and to join us to address the content in August.

I would also like to thank the supporters of this first Summit of 2024, without whom it would not have been possible: Stan Perron Charitable Foundation, PeopleKind Group, My Place, Far North Community Services, Tolchard Consulting, GT Communications and Partner&Prosper.

This section of the document is the Appendix to the March 2024 Summit Report, “What We Heard….” and aims to communicate the processes and procedures which allowed the comprehensive information in the report to be gathered and collated.

DAWA looks forward to working with our supporters, collaborators, stakeholders and governments of all levels in August 2024 to contribute to the WA co-design of a better disability ecosystem for all.

Dr Sarah Love
Chief Executive Officer
Disability Assembly WA
A collective voice for people with disability

SECTION 1 | Introduction to the DAWA Summit Program

A key pillar of DAWA's approach to fulfilling its purpose is through convening a number of Summits each year.

By invitation, DAWA assembles and connects people from across the disability ecosystem in Western Australia to discuss and debate a priority topic. Topics are identified through consultation with DAWA stakeholders based on their strategic and state-wide importance and the potential to improve outcomes for people living with disability in WA.

The Summits take a person-centred approach at all times to ensure the individual perspective and lived experience is front-and-centre for each event. Summit participants are engaged in a facilitated, solution-focused process to

- leverage, build, and share knowledge to support effective local market stewardship; and
- provide the contemporary opinion and data which allows DAWA to:
    - amplify the voice of PWD and those who care for and about them,
    - champion a healthy, aligned disability ecosystem in WA,
    - be an impartial honest data-driven broker, collaborator and advocate for people living with disability,
    - be the connection between disability and other systems such as education, health, justice and corrections, child protection, mental health, and aged care;
    - collect and disseminate information relating to people living with disability,
    - display leadership and provide evidence-based insights, narratives, and data; and
    - provide, through active and informed discussion and debate, impartial advice and recommendations on complex challenges in disability.

A written report is produced following each DAWA Summit which contains a summary of the process and highlights, together with key findings and the insights participants' agreed messages, recommendations, or outcomes.

The report is published on the DAWA website, but more importantly is provided to key people in the Office of Disability and the WA Minister for Disability Services as well as other relevant state and federal Ministers; Local Government Authorities; the WA Local Government Association (WALGA); other relevant organisations; policy- and change-makers; and all stakeholders with an ability to influence and/or support the implementation of the report recommendations.

SECTION 2 I 2024 Event Overview

The third DAWA Summit was held on Friday 22 March 2024 at the Telethon Speech and Hearing Function Centre.

People from across the disability ecosystem including parts of regional WA were invited to discuss and debate the topic Living with Significant Intellectual Disability: Challenging the Gaps.

The selection of this topic reflects comments, questions and concerns shared with DAWA across the previous year. Families who care for and about people with significant intellectual disability reported feeling disenfranchised and overlooked by the current system and shared a combination of:

- concern that this may worsen as the new system emerges in response to the outcomes of the NDIS review and the subsequent redesign of the NDIS, and of State-based services; and
- desire to be part of the co-design process and wanting to find a way to be heard.

The participants of previous DAWA Summits have been almost all people with disability (PWD). The selected topic at this Summit impacted the demographic, as people living with significant or severe intellectual disability are often unable to advocate for themselves. These individuals were represented at the Summit by families, carers, guardians and a small number of participants from Provider organisations.

Eight representatives of the DAWA Board and Council were joined by 69 participants at the Perth location, nine participants via video link from Broome to represent regional WA, and a further 10 participants in two separate online pods specifically designed for siblings of people with intellectual disability (PWID). These sibling POD sessions were convened in the two weeks immediately following the Summit when review of the participant list and scribes' data showed the sibling voice was not strongly represented. DAWA believes the adult sibling of an adult PWID is a unique and important voice and extended our demographic to include them.

Following the introduction and welcome by DAWA CEO, Dr. Sarah Love and DAWA Board Chair, Bruce Langoulant, the scene for the day was established by our guest speaker, the Manager of Developmental Disability WA Advocacy Services, Leticia Grant. The proceedings of the day were expertly led by our Master of Ceremonies, Tom Tolchard of Tolchard Consulting.

The facilitated working groups, which we refer to as PODs, gave participants the opportunity to provide their own experiences and perspectives in small groups within a safe and supported environment. The day consisted of three separate POD Sessions.

All sessions focused on providing and listening to context, facts, lived experience, and available research evidence, all pertaining to what is currently working well for PWID and those who care for and about them; what main barriers, gaps and challenges exist; and what possible solutions could be considered.

SECTION 3 I The agenda of the day

Summit Meeting

Living with Intellectual Disability: Challenging the Gaps

22 March 2024, Telethon Speech and Hearing Centre, Dodd St, Wembley

AGENDA

8:30am **Meet the DAWA Council**
Networking

9:00am **Registrations open**

9:30am **Acknowledgement of Country & Introduction**
Dr Sarah Love, CEO, DAWA
Acknowledgement of Country and welcome

9:40am **Spirit of DAWA**
Bruce Langoulant, Chair, DAWA

9:45am **Setting the scene**
Leticia Grant, Advocacy Services Manager with Developmental Disability WA

10:00am **How the PODs will work**
Tom Tolchard, Consultant CEO, Tolchard Consulting

10:10am **Morning Tea**

10:25am **POD Focus Group 1 | Thriving in Life:** What are your biggest concerns that you want to talk about today? What is working well in life that you don't want to lose?
Morning Tea served to the tables.

11:25am **Comfort Break**

11:40am **POD Focus Group 2 | Thriving at Home:** Where do you live and with whom do you live today and in the future?

12:40pm **Lunch and networking**

1:40pm **POD Focus Group 3 | Thriving Relationships:** What do you do all day and with whom do you do it?

2:40pm **Recapping summit findings**
Tom Tolchard, consultant specialising in the social enterprise sector

3:10pm **Conclusion and next steps**
Sarah Love, CEO, DAWA

3:20pm **Day concludes**

SECTION 4 | Outline of the POD Process

The first POD session focused on the theme **Thriving in Life**, with the following guiding questions:

- What does life look like for you and your person with an intellectual disability?
- What are the biggest concerns that you want to talk about?
- What is the impact on you and your PWID and how might we address that?
- What is working well for you and your PWID?
- What is the impact on you and your PWID, and how might we see more of that?

The second POD session focused on the theme **Thriving at Home**, with the guiding questions being:

- What has positive impacts on you, your PWID and the others around them and how might we see more of that?
- Where does your PWID live at the moment? Is that working for you and them, and why or why not?
- Where do you and /or your PWID want to live in the future? Are there any barriers to that and how might we overcome them?

The theme of the third and final POD session focused on **Thriving Relationships**, with the following guiding questions:

- Are there any current barriers to thriving relationships and how might we overcome them?
- What activities does your PWID enjoy doing?
- What makes these activities valuable or meaningful to them?
- What are the benefits of these activities to you and your family?
- What does your PWID want to do (or do more of)?
- Why can't they do (do more) of these activities and how might we facilitate more of these activities?
- What does your PWID want to stop doing (or do less of)?
- Why can't they stop doing these activities and how might we overcome these barriers?

Following each POD discussion the entire participant group regrouped for a summary of the information from each and every POD and to begin the task of identifying key themes and insights.

A detailed discussion of the themes and insights is included in "What We Heard….", the Summit Report that this Appendix Process document supports.

SECTION 5 | Themes and Insights

1 | Theme One

Investment in formal and informal daily supports directly correlates to better quality of life for people with intellectual disability

2 | Theme Two

Policy and legal frameworks aim to protect and support the person with an intellectual disability, their family or carer - but they don’t always have a positive impact.

3 | Theme Three

Creating inclusive West Australian communities

4 | Theme Four

The challenges of the metropolitan area are multiplied when living in rural, regional or remote areas.

Insight 16: Regional choice and support provision

Insight 17: Regional travel

Insight 18: Accommodation

Next Steps from DAWA

DAWA has distributed the Summit Report titled “What We Heard…” and this appendix process document to all Summit participants, all office holders related to disability in all levels of State Government, and all people in the DAWA customer relationship management system.

Please forward widely to your own networks.

The follow-up Summit is to be held on 22 August 2024, at which people with lived experience of significant intellectual disability along with those who care for and about them, service providers, and government officers including the Hon Don Punch, WA Minister for Disability will address these report findings.