

See Me, Know Me: Building Trust and Sustainability in the NDIS

By

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EMBARGOED UNTIL 9AM, 11TH OCTOBER 2022

Abstract

The NDIS is not working for everyone in Western Australia. This costs governments, taxpayers and, most importantly, people with disability and their families and friends who are left holding the bag. In this paper, three of Australia's deeply experienced people in the delivery and use of disability services examine the development of the disability services system in Western Australia in order to frame the deficiencies demonstrable in the NDIS as it currently stands.

They then identify three fundamental proposals constituting a call to action designed to result in the building of a more trusted and sustainable NDIS in the West, also providing a platform for scalable national improvements. In essence, local collective leadership and collaboration, trusting and enduring relationships with people with disabilities, their families and communities and stronger partnerships with mainstream and community organisations across the state are critical to achieving an NDIS in Western Australia that will better meet the needs of all people with disability and their families.

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Introduction

The NDIS is not working for everyone in Western Australia. This costs governments, taxpayers and, most importantly, people with disability and their families and friends who are left holding the bag. The primary causes include ignoring WA's significant and world leading experience over 60 years in disability service delivery and a lack of true collaboration. Choice and control have been at the centre of Western Australian disability services policy for over 30 years with policy and practice developed to meet this focus but this experience has been largely ignored in the NDIS roll out in this state. The fix is in leveraging that experience and for government, service providers and people with disability to truly work together to re-invent the NDIS as an articulated part of the disability services system that truly meets the needs of people with disability living in WA. WA can reshape the NDIS to be more effective and efficient.

Every person deserves a good life. And every person with a disability deserves a good life. Often, this takes some extra help. This is where the concept of disability support has come from: society's humane response to the challenges disability can pose. There is a spirit of commitment to humanity and human rights in every person who takes part in the support of a person with disability, be it the person themselves, their family, their wider community or those with a formal role in disability support. All these people are driven by this spirit and it is in this spirit that we provide this paper in which we seek to reflect on the experience gained since the NDIS began rolling out in Western Australia.

In this discussion, we stand back and assess what developed in Western Australia over decades and compare it to what we have today via the NDIS. It is the spirit of humanity and human rights that drives us to identify where the two different approaches—the Western Australian capacity and the NDIS—could merge to deliver the best support for all Australians living with disability and their families as broad community views say that we are not there yet.

Further, there is a common desire for confidence and peace of mind in disability support—felt by people with disability and that broader community. And it is commonly understood that Western Australia had a strong disability support environment which started from a good place with individual and family connection at its heart.

This article comes from the same place. It focuses on delivering a future view of a good life for the person with disability and is written to inform future custodians and people who need to access disability support. It aims to provide a balanced account of disability services arrangements in Western Australia which evolved over a century—the evolution of an effective and responsive support environment for individuals and families living with disability. This knowledge is relevant to the implementation of the NDIS but is not well understood by the NDIA.

As such, this article describes key policy, administrative, governance and program arrangements and then analyses and articulates some key features of a successful, connected disability services system. It reflects on the strengths and weaknesses of current arrangements post the NDIS transition and recommends key strategies that will help realise new benefits of the NDIS yet build in the highly valued features from the previous WA system. We are not throwing out the baby with the bathwater. In doing so, we aim to create a helpful public policy resource to guide debate and future decision making by governments and the disability sector. It calls potential collaborators to action.

The development of disability service provision in Western Australia

The Western Australian disability services experience was developed over decades, involved significant community inclusion and collaboration with the state government. It was built up with outcomes at the forefront and considered the needs of individuals with disability, their families and friends (natural supports) and the wider community's needs. As these needs evolved, the lack of a strict market ideology and close co-operation between people with disability, their natural supports, service providers and governments meant that improvement was able to be made locally, effectively and in a timely manner. It was certainly not perfect but the close working relationships and the constant innovations developed, meant that the system was effective and efficient for all parties and in touch with community.ⁱ

Importantly, as will be seen below, ideas such as choice and control via personalised funding have been at the centre of Western Australian disability services policy for more than three decades, starting in the late 1980's.

Disability services in Western Australia evolved substantially since 1945. Following WWII, disability supports grew, in part because of ex-service men and women returning to Australia with war related injuries. Families seeking a better life for their children established community groups. These groups, usually run by private efforts, offered schooling, therapy and accommodation.ⁱⁱ Many were established for people with physical and sensory disability—disability cohorts not provided for by the state government, which instead focussed on support for people with psychiatric services and intellectual disability through accommodation in a psychiatric hospital. While some government facilities were established for people with significant acquired disability – the Quadriplegic Centre was established in 1969ⁱⁱⁱ for people with spinal cord injury – most service provision for people with disability without intellectual disability remained with the non-government sector.

In 1964^{iv}, a distinction was made between mental health and intellectual disability. The Mental Deficiency Division was established within the state government's Mental Health Services. Children were transferred from Claremont Mental Hospital to Pyrron hostel – a significant improvement. Disability supports focussed on helping those with intellectual or cognitive disability to learn functional skills in more home-like and community settings. Nurses were replaced by social trainers helping people to live productive lives. The leadership and credibility of Physician Superintendent Dr Guy Hamilton, who had a son with a disability, was essential – a medical expert leading the way from a medical to a developmental social training approach.

The 1980s were a watershed decade in the maturation of the disability services system in Western Australia. We have reproduced a timeline in Figure 1 which provides the main stages of funding and policy developments from 1980 onwards. In 1981, the International Year of Disabled Persons raised awareness about the rights and needs of people with disability.^v The newly established national Home and Community Care program^{vi} offered home and community support. Mainstream services were urged to include people with disability as clients. The Commonwealth Disability Services Act in 1986^{vii} provided a national framework for reform.

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Figure 1: Timeline of Significant Funding and Policy Developments Supporting Disability Services in Western Australia^{viii}

34 Years Ago	1988	Local Area Coordinators (LAC) – LAC model introduced in 1988. The program started in Albany in 1988 and was expanded to other country areas in 1989-90. It was introduced to Perth in 1991 with full WA coverage in 2000.
29 Years Ago	1993	Individualised Funding – WA government introduces individualised accommodation support funding.
26 years Ago	1996	Objective Funding Model – Estimate of Resident Staff Support Instrument (ERSSI) introduced to balance individuals' needs with population support requirements.
21 Years Ago	2001	Mixed Funding for Flexibility (Unit Pricing) – Business Rules, based on funding principles and the analysis of actual costs; where direct care costs represented 85% and program support costs 15% of the total allocation.
19 Years Ago	2003	Realistic Funding – The Fair Level of Funding Policy was established by the WA government to provide a baseline of the funds required for the provision of accommodation and community-based support services.
18 Years Ago	2004	Certainty of Indexation – A regular indexation process was established by the government for state funded services. Staff wages identified as significantly under-funded.
17 Years Ago	2005	Shared Management Model – policy, principles and pricing developed to support individual's managing their own supports with assistance as needed.
16 Years Ago	2006	Service User Choice – The disaggregation of block funding to enable service users to exercise their right to choose an alternative service provider / service model if desired.
14 Years Ago	2008	Evidence-Based Funding – Audit of service provider costs undertaken to allow the government to better understand the costs of service delivery.
14 Years Ago	2008	Data-Rich Feedback – WA government funds the annual production of the "State of the Disability Sector Report".
11 Years Ago	2011	Fair Pricing, Individualised Funding & User Choice All Human Services in WA – WA government establishes the Delivering Community Services in Partnership Policy (DCSP). Additional funding to meet historical underfunding provided in two tranches with Component 1 applied during 2011 and Component 2 funding in 2013 to address historical underfunding, rural and remote issues, challenging behaviours and people with changed needs. The DCSP Policy replaced the Funding and Purchasing Community Services Policy (2002) and was effective from 1 July 2011.
8 Years Ago	2014	NDIS – Trial sites commence with individualised funding.
8 Years Ago	2014	WA-NDIS – Price Guide developed following a tender process building on more than 20 years of cost and funding experience.
Completed 5 Years Ago	2014-17	Only State with three Disability Funding Systems – State funding, WANDIS and NDIA trial sites.
Bilateral Signed 4.5 Years Ago	2017	Bilateral signed with Commonwealth – WA government makes decision for a Commonwealth administered NDIS in WA.

This was followed in 1991 by the first Commonwealth State Disability Agreement (CSDA), later the Commonwealth State Territory Disability Agreement (CSTDA). This clarified the roles and responsibilities of jurisdictions in funding and service provision.^{ix}

In Western Australia in 1986 a new government agency, the Authority for Intellectually Handicapped Persons (AIH), was established^x. AIH oversaw services for people with intellectual disability and led reforms for better community services. Leadership was provided by a community-based board. From the late 1980's significant innovations were introduced including Local Area Coordination and Post School Options. These were both underpinned by a commitment to personal, local and accountable support arrangements and individualised funding—the establishment of choice and

control in the hands of people with disability. Innovations were grown carefully and scaled up in following years. These nation-leading innovations were recognised by the Steering Committee for the Review of Commonwealth/State Disability Service Provision.^{xi}

Following the appointment of the state's first disability minister in 1991, the Hon Eric Ripper, a second government agency, the Bureau for Disability Services (BDS)^{xii}, was established. Both AIH and BDS had governance boards comprising disability professionals and consumer representatives reporting directly to the Minister. BDS's role was the oversight of services not affiliated with AIH, along with increasing awareness of the needs of people with disability. BDS funding was primarily for people where the main disability was not an intellectual one. AIH and BDS also assisted in establishing community-based supports where families administered funding and made the decisions—the realisation of choice and control.

A single disability agency for government

In 1993, these two government agencies were merged under legislation to form the Disability Services Commission (DSC) – a department which both operated and procured disability services, including accommodation, therapy, supported employment, alternatives to employment, medical services, individual coordination and advocacy.^{xiii} The Act defined disability:

...a disability – which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment or a combination of impairments and which is permanent or likely to be permanent... and which results in a substantially reduced capacity of the person ... and a need for continuing support services.^{xiv}

The Act also called on all state government agencies to develop disability service plans. While the Act applied to all Western Australians with disability, those over 65 and those with psychiatric disability remained within the health or aged-care system. Services for this older group of people were primarily through aged-care and nursing homes. Younger people with acquired disability were also in such places and, in the early 2000s, many were offered community housing instead. DSC continued to provide accommodation for people with intellectual disability while the non-government sector provided services to those with other disabilities. Throughout the existence of DSC, the charitable human services sector played a significant role in service delivery, especially for people with physical and sensory disability.

Some individuals and families chose self-managed options or working with their choice of organisation. Others preferred government services. There was always a role for government, especially as a provider of last resort: an especially significant resource in a state where isolated communities are unable to attract service providers. Critical need can demand rapid response from government and poor planning and implementation, without collaboration with the service providers and those people with disability impacted by the services, can be very expensive. It is almost uniformly cheaper to get the service right through collaboration.

Accommodation supports included nursing homes, hostels and shared housing/community homes through to individual arrangements often located in the person's own or family home. Funding was provided via block funding and individual funding arrangements by DSC. Nursing homes were also funded by the Commonwealth government.

As flexibility increased for living arrangements, so too did costs. Dormitory accommodation of the 1950s and 1960s was cheaper per person than a four-person community home. Similarly, a four-person community home was often cheaper than individual options. Most people, given a choice

between congregate care or individual living would opt for the latter, usually in the community or a family home. These costs were mitigated by the flexible and innovative culture of Local Area Coordination in conjunction with creative human services providers which enabled many individuals to live in the community with modest levels of funding due to the added creative combinations of informal, community and mainstream supports.

Configuration of accommodation influenced the budget as did demographics. Many people with disability lived at home with ageing parents. In 2003, DSC observed that 70% of care was provided by friends and family members.^{xv} As family members aged, demands were placed on community services. Similarly, as people with disability aged, their support needs increased. ^{xvi}Advances in medical technology and society improved life expectancy.

A constrained budget meant that DSC had to balance its response to those in greatest need, while also supporting others in other ways. Funds available were never adequate for demand. However, the acknowledgement and recognition of the criticality of and informal and community supports to quality outcomes in service delivery and cost control has been to a significant degree lost in the roll out of the NDIS.

Accommodation services – humanity meets budget reality

In 1999, the Board of the Disability Services Commission, under the leadership of Chair Barry MacKinnon, was concerned about growth in demand for accommodation supports indicating a rise in unmet need well beyond the forward estimates in the budget. A sound business case and business plan submission to the Western Australian Treasury for the 2000-2005 outyear forecast sought additional funding for unmet need.^{xvii} This business plan, updated annually, served as the cornerstone for funding growth over the forward estimates and beyond and confirmed the importance of forward planning.

While the average annual cost for accommodation for each service user in 2002-2003 was \$42,931^{xviii}, the actual distribution of funds was varied. Some annual individual packages were as high as \$230,000. A new “Fair level of funding” policy limited newly allocated funding to a quarter share of the costs of four-person accommodation, encouraging those seeking individual accommodation arrangements to work within a budget which Government could afford.^{xix} Other policy approaches to community living coupled with good financial management included the Community Living Plan (2008) which identified creative alternatives to group homes for people with significant support needs.

As new funds became available, new accommodation places were allocated according to relative need through the Combined Application Process and community-based panel.^{xx} Vacancies were managed collaboratively, increasing the number of people in accommodation. Some older DSC facilities were replaced with modern homes providing greater privacy and access. An arrangement with the government housing authority saw a commitment to build additional dwellings with better accessibility. DSC housing was transferred to the housing authority resulting in better use of land.

More to disability funding than accommodation

Over time, there were significant budget increases, in part the result of well-coordinated action across the Western Australian disability sector. A parent-led campaign, sponsored by the Developmental Disability Council (DDC) and launched in 1998, drew attention to the needs of ageing parents.^{xxi} “The adopt a politician scheme” matched members of parliament with people with

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disability. In May 2003, the Accommodation Blueprint Steering Committee released a report with sixty recommendations setting new goals in accommodation including better ways for support.^{xxii}

The Board and senior staff from DSC worked with the Western Australian Treasury to develop a new multi-year business plan, which under the direction of subsequent committed Ministers and Cabinets, was funded. Funding for disability services in Western Australia grew from \$225 million in 2001 to \$788 million in 2014,^{xxiii} with significant growth from new disability agreements in the following years.

This constant growth is testimony to the commitment and cooperation of government with service users and service providers.

Other personal and community supports

While accommodation service provision has a high public profile, other supports are just as important in ensuring a good life and appropriate supports for people with disability. Services such as medical, early intervention, family support, individual coordination, direct advocacy, alternatives to employment, and access and inclusion reforms all contribute to a better life for a person with disability.

The capacity to live and work independently can be related to the severity of the disability. But it should be noted that people with severe and multiple disabilities are able to live a better life engaging in their local community than being isolated in special facilities. This also widens their sphere of engagement to economic activities and widens their network of natural supports, thus reducing formal needs.

It was with this philosophy in mind that Local Area Coordination commenced in 1988 by AIH as a service to assist people with intellectual disability in the local community.^{xxiv} This was expanded to a broader service group in the early 1990s to include people with physical, sensory and neurological disability. Local Area Coordinators helped individuals and families to access community supports and to design their own services. They struck a balance between direct assistance and advocacy. They partnered with community and mainstream organisations and increased access to supports and services. Their work over many decades led to a good life for many with disability. Their engagement with, and direct connection to, people with disability, families and local communities throughout the state meant that Local Area Coordinators provided both intelligence and the “connecting glue” in the disability support system.

One important element of reform which led to ongoing service improvements was that of the relationship between the DSC Board, DSC staff and local communities. Board meetings in and visits to regional towns and suburban areas facilitated by Local Area Coordinators ensured that Board members were visible and listened directly to family and individual views. Relationships between local government authorities and the DSC Board and staff meant that community access became a feature of local design — both of built environment and attitudes and supports to people with disability.

The role of the community – Disability Access and Inclusion

Community support relates not just to individual support specifically for people with disability, but also to access to mainstream community support, services and facilities. Disability Access and Inclusion Plans^{xxv}, a legislative provision, require government agencies to include people with disability in their planning—looking beyond the built environment and considering inclusion in a

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wider sense. Public awareness resources and campaigns remind all services to include people with disability as their customers, which also made sound business sense.

Barriers to mainstream services still exist. Health, accessible housing, transport and aged care are some areas where services can be inaccessible. Universal access is essential in a society where the ageing population – and the increased life expectancy of people with disability – places pressure on mainstream services to cater for potential service users. Community awareness action such as DSC's *Count me in* public-awareness campaign demonstrated the benefits of including all people within a customer group, not just for reasons of community but also for economic reasons.

The importance of community cannot be understated. It enhances the quality of life for people with disability and their families.

Understanding and Supporting the Disability Services Sector

Another critical aspect of managing resources and ensuring the effective and efficient provision of services and community supports was the sustainability of the disability services sector in Western Australia. Long experience tells us that unplanned termination of services—say, because of a service provider being unsustainable—increases costs to government significantly. The stabilisation of the service followed by the development of a replacement plan and the transfer of clients and staff are expensive and time-consuming activities that are able to be managed effectively, if not avoided entirely, by undertaking the collection of appropriate data and analysing the ongoing financial sustainability of the sector. The DSC undertook this process on an annual basis by reviewing the four key sustainability indicators, termed the “Four Pillars of Sustainability” as:

- Service Quality
- Human Resources Management Maturity
- Governance Maturity
- Financial Sustainability

These pillars were assessed for each funded service provider and plans were made to respond to apparent risks in the short-, medium- and longer-terms. This process saved considerable financial resources but also allowed for the managed retreat from service delivery of those organisations that were not likely to remain sustainable and which represented a risk to those service users that were the organisations clients. A timely, well thought out plan allowed costs to be reduced but also support greater personal choice and control to be enacted by service users and natural supports.

The balance between two approaches

We have presented some approaches to the support of people with disabilities – accommodation or residential support, and other community supports which have applied over the last two decades. It is important to appreciate the necessary balance between these two service types.

Some people with disability will never require nor seek accommodation support. This may be because their needs are such that they are able to live independently, or perhaps they have family or friends or community who provide support. Other people with disability have needs such that supported accommodation is the only workable approach.

By offering a range of service types, each with a different cost, society can support many people with lower cost services, while at the same time giving high support to those most in need. This is illustrated through DSC budget papers for 2013/14 which reported average costs per service user for

each of Accommodation support (\$165,000), Community-focussed supports (\$54,000), Coordination and individual supports (\$6340) and Family supports (\$11460).^{xxvi}

This balanced range of supports was the result of decades of service delivery work from professionals, feedback from consumers and advocacy from families and carers. Each shift in policy and practice was hard fought. No gain was taken for granted, and once new ground was broken, it was never willingly relinquished. By the second decade of the current century, disability supports in Western Australia were largely focussed on the needs of the individual as part of their family and community. Despite there still being significant unmet need, the disability sector was typified by a collaborative team of supports which sought to support the person with the disability to have a good life. Importantly, collaboration and integration of services were corner stones for this successful, efficient system.

Analysis of strengths and weaknesses of the WA disability support and services system

It is helpful to identify some of the key strengths and weaknesses of the previous system as a benchmark when considering the new National Disability Insurance Scheme (NDIS) implementation.

At a high level, we group four key areas of strength as follows.

- *Governance and collective leadership* — The Disability Services Commission was a separate entity established through legislation with clear focus on disability rather than being just part of a larger multi-function department. There was strong system-wide ownership of the Commission with community governance through the Board and Advisory Council and a strong sense of unity across the disability sector. This wide ownership reflected inclusive strategic planning and a focus on individualised funding and support, rather than services based on diagnosis. Significant progress was made because of sustained and collective leadership, including by specific Ministers for Disability in Cabinet with strong links to other Ministers.
- *A strong and trusting connection to people with disabilities, families and local communities across the state* — The progressive development of a quality state-wide Local Area Coordination (LAC) system and commitment to individual choice and control as well as connection to local communities provided community cohesion. Local Area Coordinators were employed by the DSC and provided direct intelligence to the Commission both at individual client and community levels. This connection and its results informed system and individual decision making. The purpose and culture of the Commission included a strong focus on the rights and contributions of people with disability, positive and trusting relationships and a personalised approach supporting choice and control through individualised funding. There was also a strong early intervention and school-aged approach with support to children at risk of disability, school leavers and a focus on ageing carers. These were important features along with the capacity of LAC and funded organisations to provide information and short-term capacity building supports. LAC was seen as a gateway to community, not just the disability services system.
- *A strong partnership with disability service providers and key community and mainstream organisations* — together with the strong individualised funding approach enabling choice and control, the Commission also had a partnership with disability services providers and balanced Individual with block funding, consistent with a WA government approach to

working in partnership with the disability services sector. Importantly, DSC was proactive in addressing service gaps in remote areas such as the Pilbara and analysed the sectors sustainability to forecast and plan for service gaps and change. The State Disability Services Act's Disability Access and Inclusion Plans, along with the state-wide LAC network, led to strong and connected supports through mainstream services. This included key partnerships with health, housing and education authorities. Importantly, the Commission's Director General was able to collaborate and advocate as a peer with other departmental heads to progress and resolve complex interface issues.

- *A system which builds and sustains strong organisational capability* — Due to the stability of leadership and strong partnerships, the DSC and sector were able to build and sustain strong organisational capability. Inadequate funding forced disciplined decision making and innovation. However, control, collaboration and local decision making were critical structural requirements to allow for this innovation to be realised. A series of comprehensive five year strategic and business plans provided a balance between early intervention, capacity building and crisis intervention. A multiyear timeline allowed the sector to plan and implement with confidence. This sustained period of evolution of support was based on connection and evidence, an investment in international knowledge exchange and innovations, leadership training and individual service design which included the provision of technical capacity and resources. Families were valued and their leadership nurtured as natural and informal networks were seen to be an important key to a good life for the person with a disability. Stable leadership with the Commission and its own role in service delivery saw the development and retention of skilled staff and capacity to support challenging situations, stabilise crises and keep support arrangements within funding benchmarks.

Gains in capability by the Western Australian disability services system were verified by independent reports, which compared data on Western Australian disability system performance against national benchmarks and made highly favourable conclusions. Western Australian disability programs were also becoming progressively replicated in other Australian states and internationally.^{xxvii}

Of course, nothing is perfect and there were several key structural problems:

- Waitlists, especially for accommodation support, and an insufficient funding base, left many families waiting in crisis despite best efforts in temporary support. This was well documented as a national problem by the Australian government report "Shut out: the experience of people with disabilities and their families in Australia".^{xxviii}
- Psychosocial disability related to a long-term mental health condition was included in the United Nations Convention on the Rights of Persons with Disabilities but in WA was administered separately in the mental health system and not part of the DSC. People with a psychosocial disability received less direct attention in the acute service focussed mental health system and did not experience the same access to community-based services and benefits as those people with disabilities covered under the DSC.
- Interstate portability was a problem for people with individual funding leaving Western Australia. They could not take that funding with them. Similarly, for those entering Western Australia, there was a need to newly qualify for support for funding in competition with

others. An arrangement between the state and territories for temporary supports gave minor relief but did not outweigh the funding continuity problem.

- Under the Commonwealth/State Disability Agreement, there became a progressive disconnection between the Western Australian system and Commonwealth funded employment services. This resulted in a loss of community connections for people with significant disabilities versus the substantial gains made when the state administered the joint State/Commonwealth Post School Options program. This issue of joint planning and commissioning is discussed again later in this paper.

It was expected that the transition to the NDIS would have enabled the strengths of the Western Australian disability services system to be retained. The additional benefits of a fully funded national scheme could have been a significant and positive step forward for people with disability, their families and the sector in Western Australia. Unfortunately, this has not been the case.

The Transition phase to the NDIS

Following decades of fighting for disability support, people with disability and their families observed that it should be possible for disability supports to be an entitlement and not a battle. After discussion and lobbying for such a scheme, the NDIS was legislated in 2013. It is administered by the National Disability Insurance Agency (NDIA). Western Australia was vigorous in its support of the concept. However, the 12/13 WA State Budget papers note that:

[t]here is a current lack of detail on implementation and funding from the Commonwealth. The Commission will remain actively involved at all levels of policy development to ensure that any future scheme will be responsive to the needs of Western Australians with a disability, and not dilute current services.

The DSC commenced a trial in Western Australia in July 2013 to ensure alignment with the NDIS and to enhance Western Australia's readiness to join. During a protracted period of negotiation with the Commonwealth government, the Western Australian government advocated for a federated approach. The state-based My Way project, with eight trial sites, sought to use relationship-based support, local decision-making and flexible funding to increase choice for people with disability, their families and carers. This trial ran concurrently with NDIA-run trial sites for comparison.

In December 2017, Commonwealth and Western Australian governments agreed that Western Australia would join the NDIS, resulting in Western Australian disability funding being transferred to the NDIS and a much-reduced role for the DSC in new machinery of government arrangements.^{xxix} Formal transition to NDIA began mid-2018 and by 2022 was largely complete.

In summary, after two decades of relative stability, the WA disability sector is now facing its two greatest challenges – a change in host department to the multiple-purpose Department of Communities, and a change in funding and administration. Many Western Australians are concerned about the loss of state engagement in service delivery. Similarly, families felt that the proximity of the DSC gave them comfort. They now observe that most communication is through a phone service where many issues and concerns remain unaddressed. The reputation of Centrelink as a personalised service for people with disabilities is deservedly not strong. Some now comment that the NDIS call-centre approach to service advice and assistance does not address the needs of the disability sector.

Disability Services Today

Western Australian machinery of government changes in July 2017 following the Labor government's election created new arrangements for disability administration in the state ahead of the decision to join the NDIS in December 2017.

The standalone Disability Services Commission department created in 1993 was amalgamated along with the functions of Child Protection, Housing, Local Government and Communities into the multi-purpose Department of Communities.

Key disability administration and decision-making transitioned from the state to a shared responsibility with the Commonwealth: a situation where responsibility does not seem to be clearly taken by either government. Funding the new arrangement was also shared via agreement: the combined funds provided more people with services via their personal approved plans.

The NDIA offices and their externally sourced "Partners in the Community"^{xxx} have become the primary contact points for all Western Australians living with a disability — that is, people with a NDIS plan or people who may need a plan, and those who live with a disability but don't require regular funded support.

The "Partners in the Community" program in WA is outsourced by the NDIA to three organisations. This includes an Early Childhood Intervention partner and two Local Area Coordination partners. The NDIS LAC program aims to provide a personal connection via a Local Area Coordinator for people with funded plans and a contact point for others via the Information, Linkages and Capacity Building component of their work.

Feedback from the sector about the new WA disability governance arrangements indicates that the greater number of people now in the system and the lack of LACs available is testing the functioning and personal connection of the system. Telephone is still the common method of contact. Though, even speaking directly with the NDIA can be a problem.

The Disability Services component of the Department of Communities is now named The Office of Disability. This office is significantly smaller than the previous DSC. Its scope has changed from a high level of client contact, strategic planning and system management and maintenance to an oversight role assisting the Minister with the NDIS relationship and the new State Disability Strategy.

The impact of the downsizing saw many experienced and committed employees made redundant. They have left the system, taking years of experience with them. This in turn saw the loss of the personal connections which people living with disability in Western Australia had with their DSC contacts. Familiar and experienced staff have been replaced by new personnel who are often newly trained and still finding their feet—they are unaware of the history, what has worked and what has not. Others provide only a phone number.

The old state system had a comprehensive state-wide footprint with personnel and connections in the metropolitan area, major regional centres and local communities. These have been replaced with the new NDIS national office based in Geelong, with a state office in Midland with contracted partner organisations providing a version of Local Area Co-ordination that lacks key elements necessary for the Local Area Co-ordination system to operate as originally intended.

Transfer to NDIS was conducted with a focus on meeting unrealistic deadlines. This in turn created a lack of confidence and peace of mind for many, a feeling which has not yet been dispelled. Individuals and families report discontent from other participants and service providers across the

state. This is being addressed by the NDIS. But there are many agendas. Because of the size of NDIS and the complexity of decision-making processes, the national organisation moves slowly.

Disability in WA is still finding its new self.

Many people, previously with unmet or unrecognised needs, have now been included to receive services. This is a major positive, along with the new entitlement to national portability and the inclusion of people with psychosocial disability.

But are previous clients satisfied and confident in their service? Informal feedback from people with disability and their families indicates considerable dissatisfaction. Because of the dispersed nature of service supports, it is no longer easy to assess the attitudes of people who use these services. The loss of most experienced Local Area Co-ordinators and their regional and metropolitan offices has removed the opportunity for direct feedback and timely rectification where possible.

The approachability and responsiveness of the old system is missed by many. This was how people with disability and their families connected to the community. This was their source of incidental assistance and advice. It was also the framework within which timely and effective solutions were found to problems and, importantly, where the innovative capacity described above was deployed. This shortfall has not yet been addressed.

While many Western Australians have now received funding through NDIS, widespread informal feedback is that many people are struggling to make plans work. The lack of advice and connection to experienced people is evident. A common theme is that there is no one person who sees and knows me in the system.

People with disability and their families are increasingly left to negotiate and act for themselves in what are often emotional and complicated circumstances. Further, this can be a complex and new substantial challenge over and above existing responsibilities.

Family leadership and networks are emerging as a new and strengthening dimension for families and their service providers, ironically through consumers struggling to cope with change. These new networks equip and empower families to prepare and connect with the best in the system, and to build on the common connections between family arrangements. They also provide advocacy for families and balance the views of professionals.

NDIS promotes choice and control as a key feature. This is welcomed by all. But working towards this outcome is challenging.

The NDIS system itself is significantly bigger than the former DSC. Provider numbers in Western Australia alone have increased by a multiple of 13. At the end of 2016-2017, there were 161 registered DSC service providers^{xxx} while the NDIS Quality Safeguards Commission reports that in Western Australia on 30 June 2022, there were 2053 active providers.^{xxxii} New providers are entering the system as NDIS registered providers with tailored service offerings. They are joining traditional whole-of-service organisations which were formed decades ago. This change has impacted the fabric and size of the sector. It has diluted the connections and relationships which held it together in the past.

Importantly though, the risk to people with disability here is that we are unable to assess the extent that the service mix is adjusting effectively in response to need. Service mix is a critical risk factor in assessing programs like the NDIS. Changes in the number of service providers does not imply that the service provider sector is responding effectively to the service needs of people - indeed, it is one

of the key proxies for risk that governments and the community should be analysing.^{xxxiii} With the ability of service providers to cherry pick services they deliver to remain financially sustainable, the likelihood is that the service mix is changing. This proposition is borne out in the 2020 Western Australian Charities Landscape Report.^{xxxiv}

It has also resulted in confusion of leadership. For NDIS participants and the vast number of others living with a disability there is now a distinction between what the state and the Commonwealth roles are as they relate to their circumstances. Once a local state-based person employed by DSC would be either your Local Area Co-ordinator or provide office-based advice. Direct, in person access was readily available. Today the state-based Office of Disability is not where Western Australians take their NDIS enquiries. The Office has oversight of the state's NDIS agreement with the Commonwealth and is actively involved in the delivery of the State Disability Strategy – a strategy about how people with a disability can live more inclusively. It will not assist with the structure and funding of their NDIS plans. The lack of connection and personal relationship adds further confusion and anxiety.

Solving this requires more listening by decision makers, especially listening to those with a disability and those caring for them who know what more cohesive service support was like. It also requires more people on the ground with direct connection to people.

Looking Forward

It is widely held that the Western Australian disability system is now so fragmented that many people are struggling to make their plans work. They do not know who to contact when things need attention and timely response. Service providers themselves, used to being paid in advance, are now paid in arrears once services have been delivered. They report that they are struggling with viability and sustainability. These are not signs of a healthy system.

Without urgent attention, there will be significantly increased cost to the state and Commonwealth government and a loss of confidence and reputation ahead. Those impacted will need extra support, whether they be participants or providers. An effective system depends on all, including governments, playing their part. In a humane society, failure is not an option for vulnerable people or the organizations on which they rely.

Earlier, we commented on four elements which we believed were key strengths of the Western Australian disability sector before the introduction of NDIS. It is in these key areas where we recommend the NDIS and overall disability system need to change.

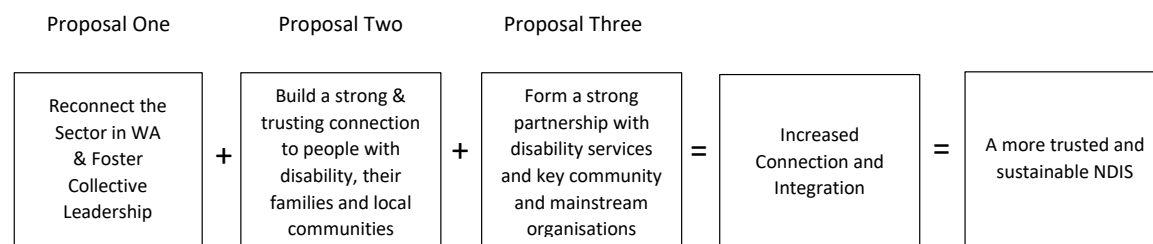
These four elements would also benefit other states and territories. Although the history of disability services in other states and territories may be different, we believe that today's experience of NDIS is largely consistent throughout. NDIS is a well-funded mechanism which is yet to provide a fully responsive approach to its clients.

These four elements are neither exclusive nor exhaustive.

We now translate these into three key practical conjoined proposals. We believe that, if these proposals are pursued, the result will be a more trusted and sustainable NDIS (see Figure 2 below). We also believe that, if these three key design elements are introduced, staff will then be attracted to work and stay as part of a more connected and productive system. Attracting and keeping capable and committed staff at every level will lead to a progressive rebuild and sustainability of the deep leadership and capability that was a feature of the previous disability system in Western Australia.

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Figure 2: The Formula for Building Trust and Sustainability in the NDIS



Proposal one — formalize a new movement to reconnect the sector in WA and foster collective leadership

History tells us that the better you know the past, the better prepared you will be for the future. Why don't we listen to those who have gone before us? And how can any office of disability stay relevant to the population if it doesn't have a relationship with it? There must be a formal mechanism which feeds intelligence from the system through to the national organisation.

We now have two governments directly involved, but neither consistently provides people living with disability with a central and reliable source of information tailored to their personal circumstances. And most importantly, neither government can currently provide receptive and well-informed staff members with whom individuals can have ongoing relationships, so that someone in authority *can see them and know them and their journey*.

Adding to this gap is that the broad and active knowledge base in disability which existed previously in government has been diminished. Instead, it is now found primarily in the sector and the community— those who provide the personal support on the front line. This bountiful group of people includes family and makes up most of the state's population. It includes many business leaders and industries. Family leadership is also a critical component of this broader network requiring strong investment. The previous intergenerational leadership, mentoring and capacity building which typified the WA Disability Services Commission and the professional disability sector is at risk of being very significantly lost.

Assembling representatives from across the system and the state to determine priorities and progress for this whole system to function well and provide peace of mind is a worthy endeavor to be pursued. What it might reveal could either be gold or dynamite depending on one's position.

Those with strong views about the need to assemble have established the Disability Assembly Western Australia (DAWA), with its first meeting held in July 2022. The assembly is an apolitical movement with a key objective to create long lasting reform and a collective voice for people with a disability to positively impact generations of people with disabilities and their families. DAWA was established to bring together people with experience, knowledge, and expertise from all backgrounds to work together to ensure the delivery of a world-leading, effective and sustainable system for people with disabilities living in WA.

DAWA is administered by a council of people with disability, carers and experienced service sector professionals who passionately share the common goal of improving the lives of people with disabilities and their families/carers. DAWA has many supporters including individuals with disability, families, carers, advocates, leaders and experts reflecting diversity and Western Australia's geography. Its supporters are passionate advocates who want to help create an effectual and sustainable service

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system for the benefit of people with disabilities, their families and the broader Western Australian community.

DAWA plans to host disability system summits to provide a place and platform for people with disability, families, carers, peak bodies, advocates, service providers, experts and government to help shape the future of service delivery to people with disability in the WA community. DAWA's forums are an opportunity for the disability system and contributors to come together and share lived experiences, understanding, expertise and research which informs government policy, improves service delivery and highlights individual and group achievements which benefit people with disabilities in our community.

This assembly approach is based on a model successfully used in the WA Health Department and has been adapted for the disability sector and NDIS context. It has strong community grass roots support and is a promising innovation.

Proposal two — a strong and trusting connection to people with disability, their families and local communities

National implementation of Local Area Coordination within the NDIS is through “Partners in the Community” with 13 separate organisations across the country. It has been critiqued as lacking cohesion and the integrity provided by evidence-based service design.

A Productivity Commission 2011 study led to the design of the NDIS^{xxxv}. Following a rigorous process of examining all the evidence, the Commission identified a range of core features. One such feature was Local Area Coordination, with this concept based on that from Western Australia. But the highly valued state-wide Western Australian system has been replaced with a national system with the same name but lacking many of the key evidence-based design features. Unlike the former Western Australian Local Area Coordination, this new approach is currently unable to demonstrate delivery of a reliable personal connection for NDIS participants and the broader population of people with disability.

In their 2021 book “Power and Connection – The international development of Local Area Coordination”, Bartnik and Broad outline the key design and implementation factors.^{xxxvi} A wide range of independent studies across population groups and international settings demonstrate that these lead to consistent outcomes at the individual, family, community and system levels and supported financial and system sustainability.

The current approach is very different to the successful Western Australian Local Area Coordination model. The current approach through “Partners in the community” has led to a range of issues with quality and consistency problems. Our analysis on the key design features is as follows.

- The NDIS participant to staff ratios are higher and not comparable to the evidenced based ratios previous working effectively in Western Australia. This would mean that the nature and frequency of contact is more task-based and infrequent.
- Individuals and families do not experience an ongoing relationship with a consistent Local Area Coordination so personal knowledge and connection is not the same. Local Area Coordinators are also not necessarily based in their local communities, as previously, and so much of that local connection is lost.
- Partners often separate out the connected features of the Local Area Coordinator role. Some ‘Community LACs’ do community work while other Local Area Coordinators do funding plans and implementation. This leads to another level of disconnection.

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- Most previous Local Area Coordinator staff from the state system have been lost to the new 'Partners'. There has been a major loss of capability and knowledge.
- The 'Partners' do not cover all regional and remote parts of the state as before. It is no longer a state-wide comprehensive approach.
- The direct intelligence from the Local Area Coordinator network is not connected to the State Office of Disability in any formal way. The previous direct connection of the state government to real issues and people in local communities throughout the state has been lost.

Two key issues facing the NDIS currently include overall scheme sustainability and trusted connected relationships with people with disabilities and their families. This is essential so that public confidence in the scheme is maintained.

While there would need to be some additional funds to improve ratios and capability, evidence from the full range of international studies is that relationships, trust and overall scheme sustainability would all be improved. Value for money is guaranteed by evidence-based work.

The value proposition to sustainability of the disability services system is clear – Local Area Coordination has a history of supporting people with disability and their families to build and pursue a good life in the community through individual, family and community capacity. This approach results in outcomes for individuals and families, local communities and the service system overall: the increased amount of informal, community and mainstream support leads to optimal use of funding and specialist disability services.

Proposal three — forming a strong partnership with disability services and key community and mainstream organisations

Currently, the Commonwealth government through the Department of Social Services (DSS) oversees the Australian Disability Strategy and the funding for national Information, Linkages and Capacity building (ILC) grants program of \$134 million per annum. State and territory governments complement this through their own strategies and funds.^{xxxvii}

The WA State Government through the Office of Disability oversees "A Western Australia for Everyone: State Disability Strategy 2020-2030" and an associated Action Plan with funding for access and inclusion initiatives^{xxxviii}. In addition, there is also state based philanthropy and fundraising.

While we understand there is a level of consultation with WA colleagues as part of the national ILC allocation process, there is clear room for a more structured local joint commissioning approach with some pooled national and WA funds. This could usefully also involve the local NDIS "Partners in the Community" network to inform the planning process, given their funded activity in the ILC area.

A more joined-up "commissioning" approach for ILC grants including joint planning with the states and NDIS "Partners in the Community" would help improve the connectedness and value-for-money of these largely currently separate and parallel approaches. In this way, the system could build organisational capacity, and establish a sustainable and valuable support base for people with disability and their families in WA and throughout our nation.

Currently, various initiatives often seem disconnected with organisations and community groups having to continually apply for short term funding from various sources. This often results in the loss of community capital as staff leave projects which are unsure of ongoing funding and a lot of stop-start activity. The results and outcomes of funded projects are not easily shared and disseminated so

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that maximum demonstrated value is not gained. Funded projects often result in one-off initiatives rather than being part of a strategic and system effort.

A state-based trial of joint commissioning would be a welcome building-block of a more connected and grounded disability approach within our nation.

Conclusion

We have presented the evolution of the Western Australian disability system, from its earliest days in the previous century through to its phasing out as part of the new NDIS. We identified four key elements which were features of the system hailed Australia wide as a leader in results and reputation. We report on anecdotal evidence from individuals and families and to a lesser extent from their service providers. This information presents a fragmented system.

Despite a significant injection of funds in recent years, it shows a shortfall in expectations. Of even greater concern, an observation from many is that the heart of the disability system is being lost along with peace of mind for the future for many ageing parents.

Finally, we propose adding the key elements of what brought connection and success to the Western Australian experience prior to the NDIS. We propose ways to transfer this nationally to the new system. We believe that only then will there be value-for-money which represents a valuable return on the significant investment of today's NDIS. From the point of view of a person with a disability, "Only then will you truly see me and know me".

And this is a leadership challenge for a new government.

Authors' Biographies

Eddie Bartnik

BA. (Hons), M. Psych. (Clinical), M. Ed. Studies, GAICD, FAIM, FASID

Mr Eddie Bartnik has a unique long-term view on disability/ mental health services, Local Area Coordination and individualised funding/personalisation reforms based on 35 years of local, national and international experience.

Mr Bartnik was appointed as Strategic Adviser to the National Disability Insurance Agency between 2014 – 2019 and Chair of the Agency's National Mental Health Sector Reference Group. He provided national level expert advice on mental health/psychosocial disability, Local Area Coordination and the Information, Linkages and Capacity Building (ILC) strategy.

Prior to this, Mr Bartnik was Western Australia's first Mental Health Commissioner for the period 2010-14, the first position of its kind in Australia. He led mental health reform and oversaw the commissioning of public, private and community sector mental health services. He joined the mental health sector from his previous position as Acting Director General of the Department for Communities in WA. This followed a long career and various state-wide, country and metropolitan director positions with the WA Disability Services Commission over the period 1987 – 2010.

Mr Bartnik has worked extensively and published across Australia and overseas in areas of human services reform, Local Area Coordination, individualised funding and personalised support. He is Fellow of the Australian Institute of Management, a Fellow of the Australasian Society for Intellectual Disability, a graduate member of the Australian Institute of Company Directors and International Lead for the International Initiative for Disability Leadership. In 2018 he was a Salzburg Global Fellow. He currently works as an independent consultant in disability, mental health and community services and is actively involved in NDIS implementation in Western Australia and nationally.

Bruce Langoulant AM

Mr Bruce Langoulant is a Western Australian father who has developed an extensive history in providing advice to families who are impacted by disability and death due to experiencing meningitis - the most serious infectious disease affecting children since polio. His advice skills come from over 30 years of working directly with families and businesses to produce and oversee plans which provide the protection needed for their financial resilience. His personal disability experience has been as a co-carer for his daughter who suffered extensive and permanent disabilities from pneumococcal meningitis she contracted at Christmas in 1989 when she was just six months old. She is now a mature woman requiring 24/7 care while residing at home with her parents.

This personal experience of the daily challenges for families with sons and daughters who are voiceless and invisible in our society due to their disabilities has fueled Bruce's wider interest in making their lives count. He has significantly contributed to the disability services landscape in Western Australia as a member of the Disability Services Commission Board for 21 years 2001-2022 and as its Chair since 2007.

Mr Langoulant has over 40 years of small business experience in the advertising and marketing and financial services industries. Further he was instrumental in the formation of the advocacy and

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support organization Meningitis Centre Australia Inc. with Prof. Fiona Stanley in 1992 and has been its Chair for over 30 years. He has been directly involved in the lobbying and introduction of a range of childhood and teenage vaccines on to the national immunization plan to protect Australians against disability and death from meningitis causing bacteria. He was a Sydney 2000 Olympics Torch Relay Community runner, a Fiona Stanley medalist of 2001, a finalist in the Western Australian of the year in 2019 and was awarded a Member of the Order of Australia for his work in 2019.

His continuing personal lived experience of disability along with his statewide DSC Board role visiting families across the state of Western Australia in their homes and workplaces over decades has added the key element of understanding the past and present nature of the delivery of disability services here.

Dr Ruth Shean AO

MEd PhD FAICD FGIA FCGI FIPA AWA

Dr Ruth Shean first encountered disability in 1967 when volunteering during school holidays at the Sir James Mitchell Spastic Centre where her sister worked as an occupational therapist. Twenty years later, after public turmoil for the Spastic Welfare Association, Dr Shean was appointed CEO in 1990. She reestablished stability and introduced a client focused service where decision making was transparent and defensible. In 1991, Dr Shean was appointed to the Ministerial Advisory Committee by the first Western Australian Minister for Disability, the Hon Eric Ripper. Later, she served as Deputy Chair of the National Disability Advisory Council, and also as National President of the Cerebral Palsy Association.

In 1993, Dr Shean was appointed to chair a State Ministerial Government Task Force on the Education of Students with Disabilities and Specific Learning Difficulties. The recommendations from The Shean Report are relevant today with a focus on individual planning and advocacy for each student.

After nine years leading the Cerebral Palsy Association, Dr Shean was appointed as Director General of the Disability Services Commission in 1999. In this role, she worked across Western Australia to listen to the concerns of people with disability and their families. One special interest was the needs of Aboriginal people with disability and addressing the dearth of support for those in remote communities. Dr Shean made significant changes to transparency in funding decisions, especially with allocations to individuals and families for accommodation needs.

Dr Shean also advocated for better funding from State Treasury, inviting Treasury officials to meet with families living with disability to better see funding shortfalls. Nationally, Ruth actively participated in COAG committees, chairing the senior officers' disability network and addressing national disability matters.

Dr Shean is a Trustee of the Jon and Barry Brealey Trust which disperses a deceased estate to benefit people with disability.

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