Towards an inclusive future for
PEOPLE WITH DISABILITY IN AUSTRALIA:
PERSPECTIVES FROM HISTORY, THEORY AND POLICY

A MONOGRAPH COMMISSIONED BY LIFE WITHOUT BARRIERS

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June 2021

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EXECUTIVE SUMMARY

The disability sector in Australia has undergone many reviews, investigations and inquiries in the four decades since the International Year of Disabled Persons (IYDP) in 1981.

The creation of the Disability Royal Commission (DRC) in 2019 is, however, the first of its kind for the sector. Royal Commissions are serious legal undertakings. They can call witnesses, make recommendations to governments, and have a lasting impact on the issues under scrutiny. They are guided and, in some cases, limited, by their terms of reference. They are also, given their nature of scrutinising issues of national importance, lengthy.

In the case of the DRC, it will be 2022 before final recommendations are made. This, more often than not, means that its recommendations will be made to a different government to that which set up the Commission. We also note that governments do not necessarily accept all recommendations made by inquiries.

Like many stakeholders over the past 18 months, Life without Barriers (LWB) has been both participant and observer as the DRC continues its hearings. LWB has commissioned the reports included in this monograph to assist in considerations for future submissions and planning.

This monograph consists of five major sections. The first is a historical analysis of the disability services sector from 1992 until 2020. We chose 1992 as a key marker as it was the year in which the Commonwealth Government transferred responsibility from its jurisdiction to state jurisdictions of all aspects of disability programs and services, except employment and advocacy. While this is not a detailed history, it does provide a representative overview and gives the necessary background to the Sections of the monograph that follow.

Sections II and III then address the following questions:

> Which key practice models or theoretical approaches have shaped the Australian Disability sector; how has this impacted service delivery; how has practice changed over time; what were staff trained in then vs. now? How do the introduction of the NDIS and marketisation of disability services fit into this picture?

Theories help us make sense of our world and guide human services to explain phenomena and support approaches to service delivery and practice. Over the past three to four decades, the Australian disability sector has embraced many theoretical approaches and models that influenced policy, shaped disability programs and guided practice.

We outline how different theories such as Normalisation, Social Role Valorisation, system-based theories, and a human rights focus were embraced, tested, implemented and changed over time. New theories and practice approaches require new knowledge and skills for the disability workforce and are often accompanied by training, education and even new degree programs.

These changes then bring significant impacts on disability service providers in terms of their staffing profiles, recruitment, training and development and support models. We would suggest that the need to be both adaptive and flexible as a human service organisation has become a defining characteristic within the disability sector in Australia over the past decade.

Section III also considers how the introduction and roll-out of the National Disability Insurance Scheme (NDIS), as the largest social policy initiative since Medicare, brought considerable disruption to the sector and its workforce. The scale and scope of this national scheme has required exponential growth in the workforce, and the subsequent shift to a market model has brought new private-for-profit providers to the sector. Additionally, the central agency administering the scheme, the National Disability Insurance Agency (NDIA), has also employed thousands of staff.

We discuss how the sector has witnessed the creation of new roles, changes to former ones, growth in certain staff and diminishment of others. We conclude this section with some reflections on considerations for the Australian disability workforce in the coming years.

Section IV offers some insights into the pathway towards the establishment of the DRC. To do this, we have taken six reports – three national, three state-based, which can be seen as leading towards the DRC. Two of these were specifically focused on abuse or neglect of people with disabilities (Case Studies #3 & #4). Three are federal reviews that dramatically altered the sector, and have had lasting legacies (Case Studies #1, #2, #6) and one which gives an insight into a review which resulted in none of the recommendations being adopted (Case Study #5).

Our chartered pathways highlight the critical role of the media in taking up issues on behalf of people with disabilities. It also demonstrates how the sector has changed over time and what an important role advocacy (and staff whistleblowers) play in ensuring that issues are not 'swept under any carpet'. We conclude this section with some reflections on the possible impact of the DRC over time, and its potential legacy.

Section V is a service provision environmental scan with a 5–10 year horizon. From the perspective of a service provider such as LWB, it discusses what a 'good life' for a person with a disability could be and how it could be advocated and supported within the context of the current service sector in Australia. It considers some domestic and international service delivery models that may offer useful pathways for LWB in its future planning. It concludes with some positive opportunities for future planning.

OUR BRIEF

Over the past twelve months, Life without Barriers (LWB) commissioned several major reports from the authors. These have been collated into this document as follows. The first was a historical overview of the national disability sector from approximately 1992 to the present, including:

- Key federal and state-based legislation and policies
- Jurisdictional differences and nuances
- Key developments concerning research, best practice and sector specific knowledge
- Service delivery standards and requirements
- Key players in the sector & changes over time
- Other factors that may have influenced the disability service sector (e.g. outcomes from enquiries)
- Governance arrangements (federal and state-based)

This was published in-house as Chenoweth, L (2019) *A brief history of the Disability Services Sector in Australia: 1992 – present day* and forms Section I of this document.

The second had two parts: first, it undertook an analysis of key theoretical models that have influenced disability policy and practice in Australia. The second part considered the fragmented nature of the disability sector workforce and its implications for the NDIS. These were presented as a draft to LWB and now form Sections II and III of this document.

The third report, as commissioned, presented a 'pathway' towards the Disability Royal Commission by a focus on several major government reports into violence and abuse towards people with a disability. This report was presented as a draft to LWB and now forms Section IV of this document.

Section V is a newly commissioned piece responding to several questions as asked by LWB:

- What does community living for people with a disability mean in the third decade of the 21st century?
- How can a service provider [continue to] support a 'good life' within the current sector frameworks? and
- What practical and beneficial models of service delivery, domestic or international, can assist LWB in future planning?

USE OF LANGUAGE

In this monograph, we use the terms: people with a disability or person with a disability as the preferred descriptor. We are aware of the contested nature of language, and particularly of the language that is used about vulnerable people, much of which, historically, has become pejorative. When citing from other texts, however, we have not changed such language, and note here that when different terms are used, it is because they appear in the original text.

GLOSSARY

mana

In Maori culture, *mana* is many things: It is honour. To have *mana* is to have great authority, presence or prestige. It is respect.. For some, *mana* is a legacy handed down by generations of *tupuna* (ancestors). For others, it is bestowed on them for their great words and deeds.

whānau

Literally, whānau translates into the English word: family. However, in Māori society a family is not the nuclear family as defined in the West. *Whānau* is the collective of people connected through a common ancestor.

ACRONYMS

CSDA   Commonwealth/State Disability Agreements

DSA   *Disability Services Act 1986*

DDA   *Disability Discrimination Act 1992*

CAA   Carers Association of Australia

NDIA   National Disability Insurance Agency

NDIS   National Disability Insurance Scheme

NGO   Non-Government Organisation

PDAA   People with Disabilities Australia

DSSA   *Disability & Sickness Support Act 1991*

HOW TO REFERENCE THIS DOCUMENT

Chenoweth, L. & Stehlik, D. (2021). Towards an inclusive future for people with disability in Australia: Perspectives from history, theory, and policy. Melbourne: Life Without Barriers.

HOW TO READ THIS MONOGRAPH

In response to our brief (above), this analysis adopts the perspective of service provision, i.e., through the lens of disability service providers as much as possible. It is important to note that this is a *partial* view of this period. The narrative offered here is mainly from the perspective of policy and service providers. The stories and perspectives of people with disabilities and their families are important and powerful but, unfortunately, are not within the scope of this document.

To keep the monograph as manageable and accessible as possible, it includes references, a glossary, and several appendices. The various reports consulted are included in appendices as follows:

- Appendix A – Federal government and its agencies
- Appendix B – State governments and agencies
- Appendix C – Non-government organisations – Australia and International

For those interested, we have also included some detail about the methods adopted in undertaking this research. These are included in Appendix D.

- Appendix E – offers further material on Active Support and Individualised Funding
- Appendix F – offers additional material on Workforce data.

ACKNOWLEDGEMENTS

CONTENTS

INTRODUCTION

This monograph has emerged following the commissioning, by Life without Barriers (LWB), of several 'think pieces' – reports seeking to respond to specific questions asked of the authors by LWB. In bringing these together in one document, they provide a solid foundation of our detailed investigation into the legislative, regulatory and policy frameworks that currently support the Australian disability services sector.

This research was conducted as the Disability Royal Commission (DRC) was beginning its hearings. The establishment of the DRC, and the pathways to its creation, form the basis of Section IV of this monograph. However, to more clearly appreciate the context within which the DRC is currently operating, this monograph also contains a historical overview of policies since 1992 (actually since 1981 the International Year of Disabled Persons) in Section I; an analysis of the many theories which have, and continue to, inform the sector and influence its workforce (Sections II and III); and also discusses how, given this complexity and history, a service provider can continue to provide a 'good life' to those it serves drawing on the potential offered within some domestic and international approaches (Section V).

We have deliberately taken a service provision perspective, or 'window', through which to undertake this analysis. We consider the impact of the constant policy change has had, specifically on practice. We ask does the sector benefit, or is it weakened by this political turbulence? We consider that one way in which it is weakened is that scrutiny of issues of abuse and neglect can be 'over-bureaucratised' – in other words, they can be deferred to a review (and there have been many, many reviews) and therefore actually not dealt with in the moment.

In undertaking this work and considering the plethora of literature that now surrounds the issues, we have been struck, again, by the need to safeguard our most vulnerable citizens. For providers such as LWB, the DRC offers a real opportunity to influence the 'agenda' for the next decade and beyond. However, as we note here, federal royal commissions, while powerful bodies, can become less so if their recommendations are not adopted. This is a salutary historical lesson. It means that while we have hope for the DRC's long-term vision, and its recommendations, we must continue to build alliances with people with disability and their allies, safeguard supportive, safe services, and advocate for more inclusive and welcoming communities.

1. THE SECTOR IN AUSTRALIA: A BRIEF HISTORY

Introduction

This section follows a roughly chronological path, referring briefly back to 1981 and the United Nations International Year of Disabled Persons (IYDP), and then forward across the critical policy issues of the time: Deinstitutionalisation; Community Living; Person Centred Practice; the crisis of Unmet Need and the development of a National Disability Insurance Scheme. The shift across several decades to a marketised sector and its current difficulties are covered in the sections *Marketisation and Market Failures*. The seven timelines developed alongside these periods of history are included for ease of tracking how events unfolded and in which jurisdiction.

Some additional sections are included to address important initiatives and developments that have impacted the sector and service delivery. These are a brief history of Local Area Coordination, a section on Restrictive Practices and brief coverage of the interface between disability and the justice system. Each section has an internal framework that includes: Legislative/ Policy contexts; Inquiries/Reports/Research Evidence; Drivers for Change, and responses.

While such a chronological view appears to be smooth and rational the past decades can be characterised as having 'two steps forward/one back' approach. As this monograph details, not all those involved, either parents or service providers, or even government agencies, could strategically plan for a future which was envisioned but lacked detail. A 'backwards' look, such as this monograph undertakes, can also identify missed opportunities, particularly the many reviews and reports of the sector that were not actioned on, or were left to lapse over time.

Deinstitutionalisation

Any discussion of the disability services sector in Australia usually marks the year 1981, which the United Nations determined as the International Year of Disabled Persons IYDP); however, because such a determination was made in 1975, following the Declaration of the Rights of Disabled Persons, the decade prior to the 1980s can now be seen as foundational towards the changes that were to impact the sector subsequently. This was a decade of civil rights movements globally, and in Australia, the demands for recognition of human rights for vulnerable citizens, including those with a disability, should be viewed as a part of this global trend.

Central to this social awakening were the many emerging stories of how people with disabilities were living within large-scale, highly structured institutional settings in all states and how many of these settings were well below the standards society now expected. Leading this movement for change were some of the parents, not only of those family members who lived in institutions, but also those still living at home, but facing a possible institutionalised future. Australia began to realise that these 'baby boomers' were not being offered the same opportunities afforded their peers in the nation's post-war growth.

Institutional settings were late 19th and early to mid-20th century responses to care for vulnerable people. At the time, such institutions (globally in western countries) were built 'in the countryside' to ostensibly enable fresh air and exercise to be part of their 'treatment' – the concept of an 'asylum'. While beyond the scope of this review, the now discredited 'science' of eugenics was fundamental to this approach (see Bowman & Virtue, 1993 for Victoria; Stehlik, 1997 for Western Australia and Chenoweth, 1998 for Queensland).

By the 1980s, the growing suburbs in Australian cities had caught up with many of these large complexes, and some, for example, like Claremont in Western Australia, built in 1903 and 10 km from the city centre, were now located in highly desirable future suburban development locations. This was one factor central to the Commonwealth government's decision, taken in the early 1980s, to close down its Rehabilitation Centres in all states and move to a community-based model of care.

The Commonwealth Rehabilitation Service (CRS), established in 1949 to directly provide services to war veterans and their families, also operated from major institutional settings in each state. By the 1960s the CRS had begun to expand its 'back to work' services beyond veterans to a broader population of people with a disability.

This transition from institutional 'care' to care within the community became known as 'deinstitutionalisation', and this process (which some would argue has not been completed to this day) commenced in the early 1980s and forms the narrative of this first period from the early 1980s until 1992.

It would be hard to overstate the profound impact IYDP had on Australian society. Many were moved by the media stories and the powerful imagery associated with advertising. Many others were surprised (and shocked) to read that Australian citizens were still 'locked up' in large institutions. Some had been there all their lives, having little personal decision-making; choice of activities (let alone work) or companionship. These settings were managed according to rigid timetables and staff needs, than those for whom this was, ostensibly, their home.

With the election of the Hawke Labor Government in 1983, the energy and vision held by many in the sector began to take shape through Federal policies. A first, and critical step, was the Federal Handicapped Programs Review, which released its Report in 1985, and which led directly to the milestone legislation which still frames the sector today, the Commonwealth *Disability Services Act, 1986* (DSA). The Review, in which 3,000 people nationally participated (Soldatic & Pini, 2012: 184) documented stories of institutionalisation from all states, and its findings gave much hope to parents (and some service providers) who had been lobbying and advocating for change. It was the first national review of its kind that also included the voices of people with a disability.

The legislative changes at this time also included the Commonwealth *Home and Community Care Act 1985*, and these two pieces of legislation, together with a parallel Review of aged care services, formed the basis of the Hawke Government's legislative, social welfare platform of change. Policies rapidly followed. The DSA changed how the Commonwealth was planning to fund the sector in the future. Direct service delivery by the Commonwealth would remain with employment (utilising the CRS network) and advocacy (which resulted in the growth of advocacy NGOs). All other services would be the responsibility of the state governments – in particular, and urgently, accommodation in community based settings, as the closure of institutions was a major recommendation of the Review.

The DSA also legislated fundamental Principles and Objectives, which were built on the civil rights agenda of the 1970s and the global trends then being enshrined in legislation worldwide. By the end of the 1980s, all Australian states had passed versions of disability services legislation and signed up to the Commonwealth agenda. This was subsequently enshrined through the five year Commonwealth State Disability Agreements (CSDA), which ensured that the Commonwealth continued to support the Disability Services Pension (which replaced the Invalid Pension in 1991) and employment and advocacy services and contributed to the funding of State government services and programs. These legislative and policy statements opened up the sector to more national scrutiny than had been the case in previous decades, as the subsequent many Reports and Reviews (see Timelines) demonstrate.

For many, however, the deinstitutionalisation process underway was too much, too soon. The Federal Minister who led the legislative and policy changes, Don Grimes, recalled in 1992 that:

> … there was also a general feeling in the community that we really didn't need to do much. There were people providing services who were seen as public spirited citizens relieving the rest of society of a burden. The recipients weren't complaining *because there was no one to complain to.* So why change anything?
> (Grimes, 1992: 3 italics added).

For others, the opening up of these institutions to public scrutiny and the subsequent transitions to community-based living meant, for the first time, that complaints about how people were treated, *were* being taken seriously. Each state had legislated for a Public Advocate as a component of their own DSA legislation, and it was to the Public Advocate in Victoria, in May 1991, that 'serious' allegations (including sexual and physical abuse) were made about the treatment of residents in a Victorian institution, Aradale. These resulted in a major Review and subsequent recommendations, which included closing that institution. At the time, the sector in Victoria was legislated with its revised post-1986 legislation: *Intellectually Disabled Persons Services Act, 1986* and the *Mental Health Act, 1986* and therefore offers a useful case study to provide a focus to this section.

'Aradale' was located in Ararat, Victoria and had opened in 1867. Located nearly 200 km to the west of Melbourne, it offered the 'countryside' and isolation then considered essential for such institutions. Similar to other places around the country, the history of Aradale can be seen as that of having many name changes (Ararat Lunatic Asylum; Ararat Hospital for the Insane; Ararat Mental Hospital; Aradale Mental Hospital; Aradale Training Centre); many different societal 'purposes' and, inevitably, over-crowding and abuse. Residents included people with intellectual disability, a maximum-security facility for the criminally insane (until 1991), as well as a psychiatric hospital. It was, therefore, a major employer in the region. In fact, to this day, Ararat of that time was known as 'a city of asylums'.

The Public Advocate presented a letter detailing 'five issues of concern', including physical and sexual abuse, at Aradale, and the Victorian government responded by establishing a Review in May 1991; the Task Force Report remains disturbing reading (Parliamentary Paper 198/1988–91) today.

The Review found that the average stay for psychiatric patients was 22.3 years, and that '… Aradale provided neither a home-like environment nor conformed with legislative principles …' (7). It was found to be in breach of legislation. In the early 1960s, there had been 800 people in Aradale, however, 30 years later, there were only 245 residents and 455 staff – in other words, nearly two staff per resident; despite this, for 12 hours each night shift fewer than 20 staff were on duty, and all the wards were locked.

The Review investigations determined that in the previous year 1990–1991, it had cost the Victorian government $18m. (nearly $35 m. in present-day dollars) to run Aradale (9) and '… a casual observer of the clients would have trouble understanding where the money (nearly $70,000 pa. per client) went to …' (9). Comparisons were made with 24-hour aged care ($35,000 per annum) at the same time. Disturbingly, the Review also found that '… 20–50% of some items of food purchased … did not reach the clients' plates' (10). Fundamental to the Review's findings was the statement that:

> … staff have a vested interest in maintaining clients' dependency. There is a clear perception by staff and the local community that further reduction of existing client numbers will actively threaten employment (7).

This finding summarises the tensions underpinning the entire national deinstitutionalisation project. Some five years after the DSA legislation, the first CSDA and the changes in societal attitudes, the issue for those still residing in institutions became that of workers' rights. The Review Report cites the Human Rights Commissioner, Brian Burdekin, who had asked, rhetorically: '… whether union rights and industrial rights take precedence of human rights …' (11). It was a vexed political issue as the Hawke Labor government had prided

itself on its record of positive industrial relations and had established a Prices and Incomes Accord to underpin this position in 1984.

Aradale closed in 1993, and this decision '… polarised the community' (Burin, 2011) with many echoing one former Aradale employee's view that: '… closing institutions wasn't the right thing to do'.

> I was very sceptical about the closing of Aradale. I thought that this would never work, they'll have to build institutions again and lock these people away' **(cited in Burin, 2011, 2).**

Across Australia, the more than 100year old large scale institutions were closed at this time, but their legacy still lingers, as societal demands, and the costs associated with community care shifted. Many of the 'community based' centres opened at this time are now viewed as being essentially institutions. In 2011, advocates called for the closure of Colanda House in Colac (100 residents), some 170 km south of Ararat, where many those from Aradale had been moved in the early 1990s. Media at the time highlighted the evident resistance to a proposed transition to community supported units, as '… parents and friends of Colanda residents say this type of care isn't suitable for their children who have moderate or severe intellectual disabilities' (Burin, 2011, 5). The Ararat Institution itself remains as an exhibit for tourists, offering the visitor an experience of a 'ghost town' with '70 interesting historic abandoned buildings'.

Shift to the community and supported living

As large institutions began to close under deinstitutionalisation policies, Australia joined many other jurisdictions in mobilising what has been termed the 'shift to community'. This movement remains ongoing as some people stay in hospitals, nursing homes and other residential facilities accommodating groups well above that of family size. It is now well established that the move from institutional to community settings has delivered positive outcomes for people with disabilities.

The evidence shows that improvements in well-being, more leisure activities and social outings, more opportunities to make choices and social interactions (e.g. Chowdhury & Benson, 2011).

Disability agencies, both state and non-government, were charged with making these shifts and closing the large institutions. With some early initiatives, for example, in Queensland in the 1980s, this was required to be on a cost-neutral basis. With the changes post-1986 and into the 1990s, various funding streams under the *DSA 1986* were made available to achieve the closures.

These community-based options were based mainly on forms of shared living, and the group home became the universal "standard". This type of group home accommodated up to up to six, sometimes eight people, in a shared house. These dwellings included ordinary houses obtained through ordinary rental markets, purchased outright or purpose-built clusters of homes on one site. In Queensland, for example, most people moved to ordinary suburban home rentals, whereas, in New South Wales, the government purchased homes for this purpose.

The group home model allowed for shared support delivered to all the residents by workers employed through the disability provider organisation. While there were certainly some improvements for people, the carry-over of institutional cultures into community settings (sometimes referred to as re-institutionalisation) was widely critiqued (e.g. Bigby, et al 2012). Rigid practices and rules limited choices and activities for individual residents. One example illustrates how an established routine of 3 x 8 shifts in 24 hours meant that all residents had to be home by 2 pm every day thus ruling out any all day activities. After considerable advocacy and persuasion from management, staff agreed to trial a 2 x 12-hour shift model. This had a positive impact not only on residents' experiences and opportunities but also on staff satisfaction.

SEPARATION OF HOUSING AND SUPPORT

From the first moves to community living, concerns emerged about the connections between housing and the provision of supports. Having one agency that provided both housing and employed the staff delivering care and support limited choices for the person with a disability and embedded control over their life by the service provider. The path to achieving this separation was driven by several factors as the momentum around self-determination within the disability movement increased. More people with disability (with their families) aspired to have their own home rather than live in group settings, develop friendships and to have more meaningful activities in the community (Garcia Iriarte et al., 2014). There was a desire to realise more individualised options that then led to a reconceptualisation from shared group living to supported living.

SUPPORTED LIVING

'Supported living' is an umbrella term originally coined by Kinsella (1993) to cover models that offer greater choice and control. It separated housing from support offering '… more flexibility, focused on one person at a time, could be tailored to anyone regardless of their level of disability and was concerned with building social connections' (Bigby et al: 310).

Supported living covers a range of options where the person buys or rents their home and receives personalised supports and has become a dominant model across many Western jurisdictions (see Emerson, 2012 et al for UK and Larson et al. 2013 for USA). With the subsequent shift in the last decade to new funding arrangements such as budgets assigned to individuals through disability service providers across several states (eg, Growing Stronger) and now the NDIS nationally, demand for supported living arrangements has increased.

Evidence around whether such arrangements deliver better outcomes for people with an intellectual disability is still sparse (McConkey etal. 2016) and often mixed (Bigby, Bould & Beadle-Brown, 2017). It appears that people with mild and moderate levels of disability in supported living do have more control over their lives though many still admit to feeling lonely and face restrictions on their activities because of low incomes (Bigby et al. 2017).

UNMET NEEDS

As more and more people, including those with complex needs, received supports through supported living models, demand rose, and services systems were stretched beyond capacity to meet it. The level of unmet need and government costs rose dramatically, leading to a situation where many people simply missed out. Across the jurisdictions, most funds went to people with high support needs and left thousands of people on long waiting lists.

FIGURE 1. DEMAND VS FUNDING AVAILABLE

Service demand

Funding allocation
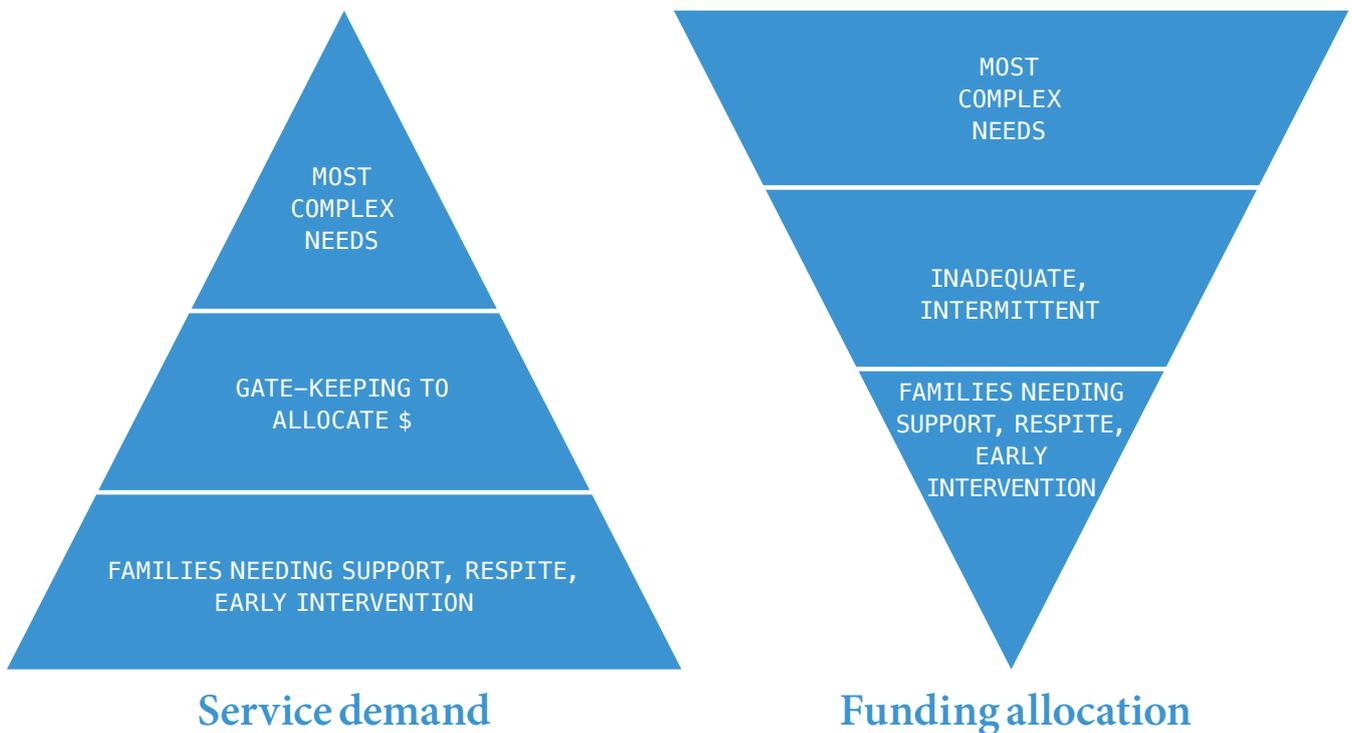
As one manager interviewed reflected on this time commented:

The government got stalled by money [in the 1990s]. There just wasn't enough to deliver person-centred supported living.

Funders and service providers were grappling with what became known as the inverted triangle dilemma, as depicted in Figure 1 above. The whole system became completely unbalanced and was criticised as unfair and inadequate.

Unmet need continued to rise through to the early 2000s prompting a sense of urgency to find answers. The responses to unmet need involved a range of measures by governments. Additional funding was made available by Australian governments, totalling $519 million over the two years 2000–2001 and 2001–2002. The Commonwealth contributed $152 million on the proviso that the states would at least match this. Several states contributed even more funding to address the shortfall. For example, in 2001–02, Victoria provided approximately an additional $30 million and New South Wales a further $29 million (AIHW, 2002). State governments put further budget bids forward for additional funding to help 'fix' the system. Over the ten years post-2000, state governments' investment in disability services rose substantially.

Disability was advanced as a priority. For example, in New South Wales the Carr government (1999–2003) separated ageing and disability from the Department of Community Services, setting up a new department to focus on ways to fund better support for people with disability. The Timelines identify other strategies adopted.

At the Federal level, carers' voices became more prominent in both the aged and disability sectors. The Howard government (1996–2007) made significant changes resulting in the sector becoming more privatised. As a result, community sector became more engaged in state-market contractual arrangements (Soldatic & Pini, 2012). There was a notable shift from disability advocacy and consumer representation in the policy process which promoted representation of families and service providers to advisory committees. This was further strengthened by Commonwealth investment in direct support for carers and families through initiatives such as the National Carer program and the Commonwealth Respite for Carers program. For example, in the 2004–2005 Budget, the Howard government announced an additional $461m. to support carers (see https://formerministers.dss.gov.au/wp-content/uploads/2012/06/Fact-Sheet-6_Support-for-Carers.pdf. Retrieved: 10th October, 2019).

As the unmet need became more widespread and was experienced across the country, a groundswell movement calling for change gained momentum. The National Disability and Carer Alliance was formed in 2009 and included many peak bodies such as National Disability Services (NDS) – the peak body for specialist disability service providers; Australian Federation of Disability Organisations (AFDO) peak body for organisations representing people with disability, and Carers Australia peak body for families and carers.

People with disabilities, families and advocates who became increasingly aware of the possibilities of different approaches in other countries began to form alliances. These included existing organisations such as Family Advocacy NSW, People with Disability Australia, Community Resource Unit in Queensland, Julia Farr in South Australia and many others. Lobbying gathered for a national insurance scheme and intensified after the 2020 Summit in April 2008. Every Australian Counts (EAC) was launched in 2011 with the express aim of fighting for an NDIS type scheme. EAC is still operating as a watchdog to ensure the NDIS stays on track.

Person-centred planning (PCP)

Since the shift from institutions to community living, the disability sector has adopted different approaches to planning for the future for a person with a disability. Over time these have evolved from the initial focus on individualised program planning to more person and family-centred approaches. This reflected the shift from planning from a service perspective – i.e. make the person fit the service or program – to an emphasis on the *person* within the family and the community. PCP is fundamentally different from traditional planning, as it shares power and works towards community inclusion (Sanderson, 2000), and it is now widely accepted as the key approach in planning for a 'good life' for people with a disability (see further below).

It is well established in the disability research literature that community connections and participation in ordinary activities are central to the inclusion project, thereby yielding positive outcomes for people with disability and families. Over several decades, community integration, as it was previously termed, emerged as the primary goal of community-based service provision for people with intellectual disability (Pretty, Rapley, & Bramston, 2002). This was regarded as a crucial response to isolation, loneliness, and poor quality of life. Pioneering work in this arena aimed at the importance of going beyond what John O'Brien called 'mere community presence' to real community participation (see for example his Five Service Accomplishments at https://www.optionsforsupportedliving.org/blog/john-obriens-five-service-accomplishments).

However, there are still ongoing debates within inclusion policy and research where less attention is given to social connections and relationships (Hoskin, 2010 cited in Robinson & Notara, 2015, 726) than physical presence.

There is some evidence that PCP works better for some people than others. In reviewing several studies, people with mental health issues, emotional or behavioural problems or complex health needs, appear less likely to get a plan (Robertson, Emerson et al., 2007) and have it implemented. The overwhelming barriers however seem to reside within organisations. A key factor here is the vital importance of committed facilitators (in Australia read: service delivery coordinators) in the success of PCP. In the UK, Robertson, Hatton et al. (2007) found that the commitment of facilitators to PCP was *the* most powerful predictor of whether people would receive a plan and was also related to increased chances of benefiting in the areas of choice; contact with friends; hours per week of scheduled activity and size of social networks. They concluded that the most common reason for the failure of PCP to be implemented was problems related to facilitators (64%) – e.g. leaving their position or not being available. Other barriers to PCP included time, the availability of services and appropriately skilled staff. This points to an implementation gap (Mansell & Beadle-Brown, 2004) wherein plans are not carried out due to a lack of resources and fiscal restraints in the support allocation.

As disability services and support have shifted to person-centred approaches, funding models have similarly shifted to more individualised and self-directed approaches. Following changes in the sector, specifically in Australia after the introduction of the Commonwealth *Disability Services Act, 1986*, an active campaign by lobbyists and families commenced for the right for people with a disability to be given the cash to purchase their support (D. Leece & J. Leece, 2006). Individualised funding (IF) of disability supports can be seen as a mechanism for ensuring genuine options and increased control for individuals and families becomes a reality, rather than a vision (J. Leece & Peace, 2010). The alternative to traditional modes of funding and service provision for people with disabilities – to support people to make choices and to be included – goes under many different names.

This includes person-centred services; self-directed support, person-directed service, independent living, consumer control, self-determination, self-directed services; consumer-directed services and Individualised Funding (IF – see also Appendix E).

These models are all based on the same principle: if people with disabilities are to participate and contribute as equal citizens, they must have choice and control over the funding and support they need to go about their daily lives (Netten et al., 2012). In the Australian context, literature is largely looking at IF from as policy standpoint (for example, Dew et al., 2014; Purcal, Fisher, & Laragy, 2014), which means that evidence of first-person accounts of consumer experiences with self-direction in supporting people with disabilities in the Australian context are extremely limited (Ottmann, Laragy, & Haddon, 2009). This limited research indicates that families need adequate preparation and support over a longer period. The challenges in self-directed support can include practical tasks of finding and hiring workers and financial management, the higher order issues of ensuring safeguards, sustainability over long periods of time (i.e. a life course) and dealing with changing needs and transitions. It also means that families and people with a disability need to become 'experts' in managing the human service sector, a task that can be beyond many due to time and financial constraints.

The movement to person-centred approaches and broader social inclusion fostered innovations in supporting people with disabilities and families. One of these was Local Area Coordination.

Local Area Coordination

Local Area Coordination (LAC) in Australia can be viewed historically as having three distinct iterations. The first model was established, trialled and evaluated in Western Australia in the 1980s. While remaining essentially based on the WA approach and with subsequent international interest (for UK see Lunt & Bainbridge, 2019; Hall & McGarrol, 2013; Broad, 2012; Vincent, 2010); for New Zealand see (Roorda et al, 2014) the second model expanded around the country from around the late 1990's. The third, as it was taken up by the NDIS, post-2016, has now become one component of the National Disability Strategy. The current national model deviates from the original WA approach in significant ways.

To understand these transitions over the past thirty years is to know how the growth of a 'people-centred' approach to disability services in Australia, which had its genesis in the civil rights movement in the 1970s, slowly, but inexorably, began to shape service delivery programs.

The WA LAC model can be seen as an early and exciting (at that time) innovation in placing the person at the centre. Stimulated by ideas from North America, including the service brokerage model being adopted in Canada (Bartnik & Chalmers, 2007:22) the WA LAC model also took advantage of the Commonwealth program for sector change as embedded in the *Disability Services Act, 1986*, and the subsequent funding re-arrangements with individual state governments. Along with other states, Western Australia took full responsibility under this arrangement for its accommodation services. Costs associated with that responsibility were also considered as alternative pathways emerged, that is: keeping people at home or as near to home and their community as possible (p, 22). In the mid-1980s, anything seemed possible in the sector, and for the first time, service providers and their clients began working together to forge partnerships for service delivery.

The WA LAC model was also, importantly, a response to the 'tyranny of distance' that continues to challenge human service delivery in the vast state of Western Australia, with its small, highly dispersed population with over 80% of the population living in greater metropolitan Perth. Up until the mid-1980s, all services for people with a disability and their families were offered in Perth: including all accommodation services, largely in institutional settings. There was little or no regionalisation of service delivery. Specialists did visit some of the major regional centres, but this was irregular and relied on funding, so it proved very costly to maintain. Notably, such visits were also not timed to the needs of individuals or families and were often out of their reach, both geographically and financially.

The WA LAC model was, therefore, a *geographic* one, first and foremost. In 1988, a pilot (for people with an intellectual disability only) was undertaken in Albany, a major rural centre and a four and a half hour drive south of Perth. Following an evaluation of this pilot, the formal program was expanded to other regional centres. At the same time, a major formative evaluation and training program was established for the new coordinators in partnership with a University research team. These early coordinators were drawn from the WA public service and were experienced staff who had been working alongside their clients for some years in various other settings, and as Vincent (2012: 207) notes they were '… from a range of service professions. The key issue was their capacity to work creatively with people, families and communities'.

At the time, one of the surprisingly successful innovations was enabling the coordinators to have access to modest funding pools that could assist their clients in overcoming some of the barriers to living a 'good life' (Bartnik & Chalmers, 2007, 24). This approach was the first of its kind within the human service sector. It met many challenges, not least that the state treasury was not equipped to manage this form of 'investment'. Eventually, through perseverance, the potential of this approach was realised. This transition period of some 3–4 years ran in parallel with the deinstitutionalization program (see above), the closure of the Commonwealth Rehabilitation Centre at Melville (in suburban Perth), and the opening up of CRS community-based locations in major regional settings across the state.

By 1993, there were 27 coordinators located in the state's regional areas, and a decision had been made, following the success of this rural outreach, to locate some coordinators in metropolitan settings. This was highly controversial at the time, as a major impetus of the regional trials had been the *lack* of a service system to support clients. While the metropolitan areas at that time (early 1990s) had nowhere near the number of NGOs now available, some felt the move to the metropolitan diminished the investment in the regional areas.

By 1993, the Commonwealth began to take more of an interest in the WA approach, and funding was provided to expand the service from intellectual disability to include physical and/or sensory disability. The following three years saw growth across the Perth metropolitan area and in some additional regional centres, and by 1996, 2,478 people accessed the service (Bartnik & Chalmers, 2007, 23). It should be noted that key to the growth of LAC was the dual role of the coordinator, both as broker of services for individual clients, but also as community development activist to encourage the burgeoning NGO sector.

Following this success, rapid growth continued, and by 1998 the WA Government funded a doubling of the '… existing service size, aiming to make LAC available to all people with disabilities across the State by 2000' (23) – that is within two years! By the early 2000s, the structure which framed the WA LAC model was well established, with a Vision Statement and a Charter to underpin it. These were developed in full consultation with the clients and their families, and the concept of 'a good life' was then agreed to (as discussed further below).

Further Federal investment followed, and reviews and evaluations found the coordinators' experiences were beginning to challenge some of the assumptions that still beset the sector at that time about the capacity and ability of the clients being served. On the issue of vulnerability, Bartnik & Chalmers (2007), from their perspective as involved senior officers in the Commission, the approach taken by the LACs was that:

> … care and protection issues [are approached] from a strengths, self-determination and preventative perspective. This doesn't mean being naïve about limitations and risks, rather it means starting with positive ideas and then introducing safeguards as required. [LAC's] work closely with specialist services around vulnerabilities, reporting of critical incidents as required by legislation and any necessary safeguards (30).

As the program broadened, clients and their families became its strongest supporters. In addition, according to Bartnik & Chalmers (2007) the service sector more broadly was also being challenged, as they put it, LAC had

> … progressively replaced case management and social work/service coordination as the front line of the disability system in WA It is not just another layer and there has been a systematic process of readjustment and major reform (30).

Other states began to take an interest, and a pilot program of eight sites was established in Queensland in the early 2000s, with a deliberate focus on rural and regional settings by Disability Services Qld (DSQ). This program was based on the WA model but adapted for local conditions (Chenoweth & Stehlik, 2002). It was also subject to a formative evaluation and included training for individual coordinators. Some already lived and worked in their geographic locations, and others were relocated as part of the trial. The evaluation found the model was cost-effective for rural areas and had the potential to foster inclusion, build social capital, and encourage the use of technology in rural practice. A feature of the Queensland pilot was the ability of coordinators access to modest funds for each client, over time. This bypassed layers of red tape and allowed a prompt response to specific needs that would make a real difference – for example, purchasing a new washing machine for a family of a child with high support needs where clothing and linen needed to be washed daily. Over time, however, this proved a challenge both for the Department and for Qld Treasury.

A further, more localised version of LAC, was also introduced into New South Wales as a pilot program in 2002–2003, again, mainly in rural and regional settings, and formally evaluated on behalf of the NSW Department of Ageing, Disability and Home Care. Subsequently, additional coordinators were established in the following year in rural/regional settings with a plan, at the time, dependent on funding to expand this to some metropolitan sites.

The Qld and NSW approaches did not have the long-term success enjoyed in WA, primarily because the programs were seen as 'add-ons' rather than fundamental within the existing system. It was also due to the different ways the sector had grown in those two states, with a regional focus to service delivery more highly developed than that of WA and therefore more services available 'on the ground' than had been the case in WA.

An interesting observation perhaps worthy of further exploration is the relatively few enquiries and reports of abuse in the system in WA compared with states such as Victoria, NSW and Queensland. LAC was the central model for disability support in WA, whereas other states retained more traditional models that involved institutional care. A question to ponder is whether a place-based local approach somehow is more of a safeguard protecting vulnerable people.

With the introduction of the NDIS in 2014, change to the LAC model as established became inevitable. The National Disability Strategy, at first resisted by Western Australia, but then finally accepted in December 2017 (WA Department of Communities, n.d.), meant that future service delivery would be shaped by external, rather than local, factors. By 2017, this difference in the role of NDIS-funded (but re-named as) '*local* coordinators' (no longer place-based) became the focus of one submission to the Productivity Commission's Review of NDIS funding undertaken in that year. The Queensland Capricorn Community Development Association's submission to the Review, written by John Homan, a parent and long-time disability advocate, highlighted where that organisation saw the differences in models:

In the Western Australian model, Local Area Coordinators are not mere messengers. To their customers they **are** the NDIA. They can make decisions with the customer on behalf of the NDIA, as their authority matches their responsibility. Local Area Coordination, and direct funding have created the dynamic where the person with a disability, the NDIA through the LAC, and service providers are now equals at the table. Ownership of decisions made is shared (2017, 3).

For Homan, this raised the question of whether 'the governance of NDIS is based on relationships, or just another version of the traditional, institutional model' (p. 1).

In Western Australia, the innovative Local Area Coordination project has changed dramatically in two ways, thirty years after its inception. The first, the previously fully independent Disability Services Commission, established under the *WA Disability Services Act 1993*, has been subsumed within the Department of Communities and the CEO of the Department, is now also the CEO of the Commission (see *DSC Annual Report 2017–2018*). The second is that the NDIS, signed onto by the WA Government, has changed the way in which local coordination will now be managed in the state. These two very recent changes have yet to be fully evaluated, and their impact on the sector fully understood. A generation of LAC services will have left a significant legacy, and it is hoped this will form the basis of future, vital research.

Marketisation

As briefly outlined in a previous section, the Commonwealth's influence in the sector grew from its initial involvement largely with employment and the *Sheltered Employment Assistance Act, 1967* until it became the dominant causal agent and funder, involved in all aspects of the sector in the mid-1980s with the *Disability Services Act 1986*. Five areas of action were identified: accommodation, community support services, early intervention and education, employment and income maintenance, and self-determination and advocacy.

While the policies underpinning the DSA argued they were founded on social justice and equity principles, an overriding economic framework shaped this new future. In the lead up to 1986, and almost immediately after the election of the Hawke Labor government in 1983, Australia was gripped by recession and inflation. The new government's response was to deregulate the financial markets and attempt to manage increasingly high interest rates. The burgeoning growth of the disability sector's demands on the Federal Government, and the subsequent COAG arrangements under the DSA were almost immediately subjected to a 'fiscal ruler'.

The decade of the 1980s can be viewed in hindsight as one in which the growth of a new form of 'welfare state' developed. While not a total rejection of the Keynesian model of earlier decades, it nevertheless influenced all political parties in most Western democracies, to a greater or lesser degree. In the early 1980s, for example, the then Minister for Social Security in the Fraser government, Senator Fred Chaney summarised this view as him being personally 'disappointed' in the '… increasing dependence on the state to provide services, in a decline in personal responsibility and a decline in family interdependence …' (Hardwick & Graycar, 1982, 3).

This response to societal upheaval, which came to be called 'economic rationalism' or 'neo-liberalism' began to challenge (or 'counter-attack') the social justice principles as espoused in the early 1970s, particularly by the Whitlam Labor government (Graycar 1983, 3). It needs to be plainly stated this approach to 'welfare' (and by extension, to the disability sector itself), was adopted by *both* the major political parties in Australia from the 1980s onwards. At this time there was an overt transition to 'family care' 'care at home' 'staying at home as long as possible'; an approach which assumed that individuals had families, and that those families were structured on agreed principles, with women staying at home, and men going out to work. The *Home and Community Care Act 1985* and subsequent HAAC program was a clear indication of this trend (for more detail see: Stehlik, 1992).

The welfare state in Britain (Margaret Thatcher), America (Ronald Reagan), New Zealand (Roger Douglas) and Australia (Paul Keating) was deemed to be in 'crisis' at this time of rising unemployment and increasing demands on the system (Mishra, 1984). The relatively 'new' disability sector, initially excited by the possibilities offered by the *Disability Services Act 1986*, became caught up in this trend to individualisation, community care, and professionalisation and *cut-backs*. The language within the sector changed: where patients had become clients, they were now customers – and a 'consumer focus' became central to policy developments. Alongside the growth of the consumer, was the growth of standards and monitoring in its various forms. A brief glance at the timelines attached to this monograph highlights the many, many reviews, audits, reports and evaluations undertaken nationally and within states over this next decade. Having just 'learned' to become a 'client' the individual with a disability now had to learn to become a 'consumer'. Such language elides the reality that for many consumers, there were few choices in either services, or supports.

However, this neo-liberal approach did support growth in the market (being the sector), and one immediate impact of this new approach was the initial funding, by the Commonwealth through its State agencies, of new NGOs, designed to provide 'improved conditions' to people with a disability (WA Authority for Intellectually Handicapped Persons, 1990, 17). The social history of this growth in NGOs in the sector has yet to be written. However its legacy can be seen today, with many non-for-profits, as well as for-profit agencies in the field – a field which has been termed 'fragmented' (Bigby, 2014, 93). The great paradox of this growth is that in our desire for individual supports (later to be known as 'self-management'), we have created a national, professional class that actually 'manages' the sector on behalf of the Commonwealth.

Elsewhere the 'unmet needs' campaign of the early 2000s were discussed, however in the 1990s, under the influence of these neo-liberal frameworks that increasingly controlled the sector, need became attached to policy development, and the concept of 'consumer' and 'need' can be seen to have clashed as a result. Watson (1995, 166) explains that as the '… state attempts to regulate and intervene in the aspects of everyday life of selected members of a social community via discourses of need: and needs discourse are used to legitimate claims for the distribution of resources and benefits …', the 'consumer' gets caught up in this paradox. Market efficiency and effectiveness became watchwords. This market 'ethos' '… affects how people as workers, as agents of the state, and as citizens relate to themselves, to one another, and to the major public institutions around them' (Muetzenfeldt, 1992a, 191). At the time, there was no sense of how this ethos would permeate and then dominate the sector, and how, after thirty years following the DSA, it has now become institutionalised and normalised to the point where it is difficult to imagine alternatives, let alone implement any.

The second Keating ministry, and the subsequent four Howard ministries, embedded this ethos into the disability sector, along with the rest of the human service landscape. Disability became a 'business' and we began to hear of 'customers' of 'bottom lines', of 'purchasers' and increasingly, the 'purchaser/provider split'. We began to have reviews of the sector by the Productivity Commission, as if the sector was another arm of industry. Indeed the concept of 'sector' and the language used in this monograph, can be seen as a legacy of this ethos.

At the *Australia 2020* Summit, held by the Rudd Labor government in the first six months following its election in December 2007, the marketization of the disability 'industry' reached its maturity with the concept of an insurance scheme to enable future care needs of individuals to be met accepted as a plank in the new government's future social policy platform. Following the Productivity Commission's 2011 (No 54) Report that

had argued the sector was 'inadequate, under-funded and broken', planning for an insurance scheme, similar to that of funding the health care system (Medicare) was underway. As a result, some thirty years after the promises embedded in the DSA, the sector again blossomed with ideas, visions and promises of a future where the disability became secondary, the person – a full citizen – would be central. It would be 'transformational', it would finally be the instrument through which '… choice and control' would be placed in the hands of people to '… choose their own supports and goals' (Bonyhady, 2016).

The marketization of disability support has reached its apogee in the National Disability Insurance Scheme. The consumer (person with a disability) would now be able to access the 'market' (NDIS) through the supports and programs offered by the sector (NGOs and for-profits) because each individual would have the necessary funding made available personally, and it would be their individual choice how they spent it, and on what they spent it. This was the vision. However, as David & West (2017, 332) cogently argue, there is a flaw here as they cite from the literature:

> The 'citizen consumer' construct that places the consumer and their choices at the centre of service delivery systems reflects neoliberal governments' values and priorities (Clarke et al., 2007). However, the assumptions underpinning the notion of the service user as a key player in, and shaper of a human services market, have been critiqued as problematic and contradictory. Many are concerned that true market forces may not operate well in a human service context and that the 'profit motif' associated with market competition is 'antithetical' to human services values and purpose
> **(see also Meagher & Goodwin 2015; Quiggan 2016).**

Today, the NDIS has replaced the DSA as the guiding policy and program delivery agent, although the DSA legislation remains. The administration aspect to the NDIS is far-reaching and highly technologised, based on computer modelling and 'e-technology' or 'on-line' as outreach – if the innovation is in the technology, research is urgently required to answer the question: how can this be safeguarded? As David & West ask: 'who wins and who loses' in this 'new market landscape of consumer control and choice' (2017, 333). The detailed answers to these questions are yet to be determined.

Early implementation challenges however, do not bode well for future success as recent, public concerns regarding not only the access to the system, but also the ability of individuals to have 'real' choice shows. The funds allocated to the NDIS remain under scrutiny. For the states who have signed up to the CSTDA there are never enough funds For the Commonwealth these funds offer opportunities too irresistible not to access, as the recent decision to transfer NDIS funding to drought support has shown (McCauley, 2018).

Abuse, violence & restrictive practices

The theme of violence and abuse perpetrated against people with disabilities has been a constant feature of their history. It has been well documented that people with intellectual and cognitive and psychosocial disability experience higher rates of violence than non-disabled people and the general population (Hughes et al. 2012; Cadwallader, Kavanagh & Robinson, 2015). The closure of many institutions was in response to findings of numerous inquiries that those who lived in them were the victims of physical and sexual abuse, neglect and maltreatment. Responses to recommendations of such inquiries have heralded changes in service standards, new legislation, guardianship arrangements and the creation of new service models.

It is beyond the scope of this monograph to provide a detailed history of these events and consequent measures in the disability sector. Abuse and violence in the lives of people with disabilities are multifaceted and involve many factors. However, there is a complex relationship between residential care, complex needs, so-called challenging behaviour and the use of restrictive practices. This section introduces some of these issues.

INSTITUTIONALISED SETTINGS

Much of the violence against people with disabilities occurs in institutional settings such as group homes, nursing homes, mental health facilities, and hospitals. Some of this includes criminal offences such as assault, sexual assault perpetrated by members of staff, other residents or outsiders (Steele, 2017). Others constituted abuse that was "condoned" within the service as "necessary" to manage the person.

Some forms of institutionalised care included measures that involved maltreatment, seclusion, physical restraint, often for long periods of time and later the use of chemical restraints psychotropic drugs. For example, the exposure of the shocking treatment of children at a respite centre in Queensland in 2009 was reported to the House of Representatives Standing Committee on Legal and Constitutional Affairs. This led to the establishment of accreditation quality standards for human services, Human Services Quality Framework, in Queensland. Queensland also introduced criminal history screening for staff of facilities.

COMPLEX NEEDS AND CHALLENGING BEHAVIOUR

People with complex needs and disabilities have historically posed challenges for families and services providers in how to provide the best support. It is this group who are typically labelled as having high support needs and consequently require higher levels of funding. This group includes people who have several intersecting conditions: intellectual or cognitive disability, other physical or sensory impairments, autism or psychosocial disability. Many exhibit what has been termed 'challenging behaviour' which historically, was defined as:

> Culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy; or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson 1995, 3).

As research into causes and understanding of challenging behaviours progressed and developments influenced our understanding of disability in social theory, such as the social model of disability, old conceptualisations were regarded as disempowering and deficit focussed. More recent understandings and explanations include behaviours of concern or behaviours that challenge the system (Chan et al 2013). Such behaviours are now known to be attributed to a constellation of issues: for example, neurological, effects of drugs, communications breakdown, no appropriate opportunities to learn and failure of support systems. Positive behaviour support and active support have become more widely adopted by services as effective support strategies for people with complex needs and behaviour.

Service responses have often been, and some still are, crisis-driven for several reasons. Families can find they are no longer able to cope when their child reaches adolescence, funding packages may not be sufficient to provide the support needed for the person to be safe or staff may not have the skills and training to understand and best support them.

For many people in this situation, behaviours that were harmful to themselves or others heightened their risk of being subjected to restrictive practices. The inquiries and reports of abuse in service settings, the consequent development of safeguards and service standards shaped the development of regulatory frameworks for the use of restrictive practices.

RESTRICTIVE PRACTICES

Restrictive practices refer to interventions that limit a person's right to freedom of movement and include mechanical, physical and chemical restraint, seclusion, and detention or containment (Chandler, White & Willmott, 2017). They are used across several settings such as mental health facilities, aged care and disability support services. Because restrictive practices involve the limitation of a person's human rights, in recent decades, their use has been subject to some form of authorisation by the state by a substitute decision maker. From the 1980s, most Australian states began to develop legislation for the appointment of substitute decision-makers across different spheres of a person's life – e.g. personal matters, finances, health and medical care where the person was deemed unable to make the decisions. These took the form of various guardianship regimes and or public advocates.

These systems provided safeguards and a degree of protection for people with impaired decision-making capacity in that major decisions about the use of restraints could not be decided by disability service providers. Instead they required referral to an independent authority charged with responsibility to make decisions in the best interest of the person. Managing those processes differed across state jurisdictions. Chandler, White & Willmott (2017) provided a comprehensive summary for the authorisation of restrictive practices as at 2017. This is summarised in Table 1 below:

TABLE 1. RESTRICTIVE PRACTICES AUTHORISATION SUMMARY

AUTHORISATION OF RESTRICTIVE PRACTICES UNDER EXPLICIT STATUTORY PROVISIONS	
• Within guardianship legislation	Queensland Tasmania
• Outside the guardianship system through an administrative model	Victoria Northern Territory

AUTHORISATION OF RESTRICTIVE PRACTICES AS MEDICAL TREATMENT/HEALTH CARE	
• By 'person responsible'	New South Wales South Australia Western Australia Victoria Tasmania
• By the Statutory Health Attorney	Queensland
• Health Attorney	Australian Capital Territory

SPECIFIC ISSUES	
• Physical restraint	Differing approaches across different state tribunals
• Chemical restraint	Conflation of therapeutic and restraint effects Different interpretation across jurisdictions

It is apparent that restrictive practice is an area of concern, especially as the NDIS achieves its full roll out across different states and territories, raising issues for service providers. The consensus appears that the law is unclear, uncertain, inconsistent, and raises profound questions about the capacity of current guardianship regimes to safeguard a person's human rights and safety (Australian Law Reform Commission, 2014; Steele, 2017).

The NDIS released its Restrictive Practices and Behaviour Support Rules in 2018, detailing how the Quality and Safeguarding Commission will regulate and monitor the use of restrictive practices. These rules applied from July 2018. Like child protection, criminal justice and health, restrictive practices under guardianship processes is another site where Federal and State jurisdictions are currently conflated and have the potential to create gaps and dilemmas for service providers. One particular point of intersection is in the use of restrictive practices with a behaviour support plan. The rules require that behaviour support plans be developed by a registered specialist behaviour support provider and any use of restrictive practices must be authorised by the relevant authority. The rules also require service providers to lodge monthly reports to the Commission. Given the delays within the NDIA for plan reviews and "thin markets" for behaviour support specialists in some areas, it is unclear how this will unfold.

Restrictive practices have been a contested area of service provision for many years, formerly outside any regulatory authority and increasingly over the past twenty years, subject to more safeguards and legal processes. At best this can be described as a work in progress.

INCARCERATION & DOMESTIC VIOLENCE

Well beyond the scope of this monograph, it is worthwhile noting that early research in Western Australia undertaken as a longitudinal study before the DSA and up to and including the period just after the DDA, found that people with an intellectual disability, charged with a criminal offence, were given custodial sentences in greater number than their non-disabled peers. In addition, some 16% of those for whom this was a first arrest were given a custodial sentence, compared to 7% of the general population. These figures, drawn from police records and the WA Disability Services Commission database (see Cockram, 2005), could be reasonably extrapolated to the general population. Such incarceration increases if the individual is also of Aboriginal heritage.

The Women with Disabilities Australia (WWDA) website has an extensive, and detailed publications archive documenting gender and disability issues, including violence and abuse (http://wwda.org.au). There were many attempts made by WWDA in the late 1990s to improve access to women's refuges and violence services for women with disabilities. Attempts were also made to ensure the Federal Government's Partnerships Against Domestic Violence Strategy (1998) included the voices of women with a disability.

A project was undertaken in early 2000 in Western Australia in order to provide the detailed statistics and evidence required for policy change. The report found that '… there is a paucity of research undertaken on the extent and nature of family and domestic violence and women with disabilities' (Cockram, 2003 n.p.). The report detailed the types of violence experienced and the length of time such violence was experienced. The report concluded that a greater availability of targeted services was urgently needed, as was greater public awareness, and awareness within the service sector, including in the justice system. It should be noted that it was only during the late 1990s the police recordkeeping system in Western Australia kept a record of disability, as the following quotation from one participant highlights:

> … police typically regard violence against a woman with disability within the "medical model" of disability, which describes the difficulties of people with disability in society as stemming only from the person's limitations, rather than from the social context of discrimination …' (Cockram, 2005, n.p.).

Towards a National Disability Insurance Scheme

While it is usually regarded as being established in 2013 with the passage of the *National Disability Insurance Scheme Act 2013*, as briefly outlined above, the notion of an insurance-based scheme to support people with disabilities was introduced to the Australian policy platform much earlier. The Whitlam government commissioned an inquiry into a national accident compensation and rehabilitation scheme in 1972. The inquiry recommended a system of no-fault compensation for *all* injuries, beyond motor accidents and workers' compensation, to be funded from previous earnings and included access to rehabilitation. The legislation was before Parliament, but with the dismissal of the Whitlam government in 1975, the proposal was abandoned by the incoming Fraser government.

It was another 40 years before ideas of an insurance-based scheme was on the table. In the ensuing years, as discussed earlier this paper, problems with disability support arrangements, increasing and prohibitive costs, and an urgent call for reform escalated. The Senate Standing Committee on Community Affairs Inquiry Report into the Funding and Operation of the CSTDA in 2007, highlighted the lack of clarity in the CSTDA agreements and inconsistency in how they were implemented across different states and territories. Along with general confusion and insecurity about the future, the key concerns for people with disabilities and the sector were issues such as the lack of portability of funding from state to state and how disability support interfaced with other sectors such as health, aged care etc. The committee made two main recommendations: 1) a National Disability Strategy to act as a high level national policy to better coordinate the delivery of services and 2) a review of alternative funding arrangements to include the costs and benefits of individualised funding, how similar schemes had been implemented internationally and provisions and tools for people with disabilities and families to make choices and informed decisions.

AUSTRALIA 2020

As mentioned briefly above, in 2007, the Rudd Labor government came to power. It quickly held the *Australia 2020* Summit, a convention of some 1000 delegates to help shape the nation's long-term future in ten key areas. The summit provided the ideal platform to bring forward innovative, bold proposals and ideas. Disability advocates Bruce Bonahady and Helena Sykes (2008) in their submission, urged that time was 'right to reform the disability sector: to shift from the current crisis driven welfare system to a planned and properly funded national disability insurance scheme'.

PRODUCTIVITY COMMISSION REPORT

The agenda moved quickly. The Productivity Commission was charged with conducting an inquiry into disability care and support in December 2009 to investigate and the feasibility of new approaches, including a social insurance model for funding and delivering long term disability care and support to people regardless of how those disabilities were acquired. It was tabled in 2011 and was a pivotal moment in disability policy. The Report findings ricocheted around the sector and, more importantly spoke directly to the Australian community. It found that the disability sector was 'under-funded, unfair, fragmented and inefficient', a system marked by 'invisible deprivation and lost opportunities'. The Commission recommended that the current system be replaced with a National Disability Insurance Scheme.

Interestingly the rhetoric that accompanied the DSA in the 1980s is surprisingly similar to that which accompanied the NDIS. Both motivated people with a disability, families and professionals towards the ideals of human rights, social inclusion and participation. The DSA made many gains; nevertheless, it ultimately failed to deliver, leaving people with a disability with a service system that was described as ' … irretrievably broken and broke, chronically under-funded and under-resourced, crisis driven, [and] struggling against a vast tide of unmet need' (see Kendrick, Ward & Chenoweth, 2017).

With the passage of the NDIS Act 2013, and the creation of the National Disability Insurance agency (NDIA), the implementation of the Scheme was underway. It launched a pilot phase across four sites from 1st July 2013, a year ahead of schedule. The full roll-out, with the exception of Western Australia, was achieved by the 1st July 2016. WA was included from July 2018 (see above). This was to be one of the largest and most complex policy/ program roll-outs in the nation's history. The NDIS was forecasted to provide supports to over 450,000 people by 2019, (from just over 30,000 in 2016). Not surprisingly, there were implementation issues and subsequent debates, as all stakeholders grappled with the new system.

MONEY/FUNDING

Money has occupied the attention of all stakeholders from the outset in two significant areas: first, from the standpoint of *funding* of the scheme and second, from the view of service users and service providers about the perceived *(in)adequacy* of costing and pricing of services and supports.

Funding debates emerged almost immediately from 2013. In Federal Parliament, concerns were expressed as to whether the funding arrangements (set up under the Labor government in its 2013–2014 budget) were properly costed and adequate to the task. The Opposition (later the Abbott government of 2013–2016) argued there would a gap of $3.8 billion by the full rollout in 2010. While the Opposition enthusiastically embraced the scheme during the 2013 Election campaign, there was some early conjecture the scheme could be privatised, either partly or completely, under a Liberal/Coalition government, as the human services sector as a whole is increasingly being privatised, as a recent ANAO audit identified (Dingwall, 2019).

Later the Turnbull government its 2017–2018 budget, increased the Medicare Levy by 0.5 percentage point to fund the Scheme. In June 2017 the Productivity Commission released a position paper on NDIS costs and found that costs were broadly 'on track' with modelling and that basically, participants' lives had

improved. However, that Report identified the speed of implementation as a future risk as well as workforce shortages and 'thin markets' (see further below). Funding arguments have continued with the most recent criticism by the sector of the Morrison government's underspend of $4.6 billion, which then contributed to a better overall bottom line (Probono Australia, 2019).

Costing and pricing have similarly been major concerns as the approved prices for many services were argued as being too low, causing many providers to leave the scheme. Participants and service providers lobbied strongly for better pricing, and this along with the Productivity Commission Report, prompted the NDIA to engage McKinsey & Company to undertake pricing review in 2017. The key issues raised in their final report (March, 2018) were: the transactional costs incurred by service providers in shifting to the NDIS model, the additional costs of providing supports to people with complex needs, and gaps in pricing to cover service delivery in regional areas. The NDIA gave in principle support to all 25 recommendations, and the Morrison government later supported 18, one partially and another in principle.

IMPLEMENTATION ISSUES

With any new national scheme and especially one with the scope and magnitude of the NDIS, early 'teething' issues were to be expected. However, the NDIS has had considerable problems in its rollout. The scheme was launched a year ahead of schedule, a timeframe that some now argue was too rushed with insufficient preparation time to get the system 'right'. From the initial rollout in one of the trial areas in Geelong (Victoria) there were some complaints from other states, anxious to have the NDIS start-up in their area. Other states and regions felt that it was better to be further along in the implementation time period so that early teething problems could be sorted before they were to enter the Scheme. The speed of the rollout and the pressure agency staff were under to achieve higher participant numbers inevitably led to difficulties.

A major early setback was that the ICT system and the My Place portal were found to be inadequate for the task. In mid-2016 the Turnbull government announced another Inquiry to review the IT system. The consultants, Pricewaterhouse Coopers found multiple compounding problems in the ICT system that adversely impacted the participants.

The Joint Standing Committee for the NDIS is the Federal government entity charged with investigating matters relating to the implementation, performance and governance of the NDIS. It has heard evidence about long wait times between plan approval and supports being delivered, dissatisfaction over planning processes (including planning over the phone), inconsistency in decisions, skills of planner staff, and the NDIA's lack of transparency (Buckmaster & Clark, 2018). The committee also held inquiries into the early childhood early intervention approach and service supports for people with psychosocial disability.

These problems have received considerable and ongoing coverage in the media and this, in turn, has arguably led to an erosion in the confidence of participants, service providers and the general community. Despite feedback from the NDIA, most participants expressed satisfaction with the scheme and that they are better off. However, the narrative remains problematic.

Concerns had been voiced about safeguards and quality assurance in a market-based scheme even prior to the scheme's launch. The NDIS Quality and Safeguarding Framework was developed to address these issues, and later, the NDIS Quality and Safeguards Commission was established in 2017. This brought together various quality and safeguarding functions under a single agency.

Market failure?

The challenges for both participants and service providers to transition to a market-led service delivery model cannot be underestimated **(Parliament of Australia, 2018, n.p.)**

The critical, and as yet, unresolved issue within the NDIS project, is the question of 'market failure' – or, in layperson's terms – whose responsibility is the care and support of those people whose disabilities are the most challenging to serve? Or who live in places where there is a shortage of, or limited services? Or, in many cases, where there is only one service available – thereby undermining the very premise of the NDIS project, that of personal choice and decision-making. For Australian society, currently embedded within a 'market ethos', such 'failures' within the market explain why there is currently a debate within the NDIS regarding its 'market readiness' for the provision of services.

Within this market ethos, the person with a disability becomes what Marston et al. (2016) term a 'quasi-market citizen subject' a term they consider 'hollow' when compared with 'solidaristic conceptions of citizenship' (2016, 402). They examine the Productivity Commission's report of 2011 as the basis for the NDIS and consider its stated concept of 'self-directed funding' was 'couched in terms of social norms such as self-determination and human rights' (407). However, by creating a disability 'market' there is an assumption the 'market will provide' but, in fact, as Fawcett & Plath (2014) argue ' the market is under no obligation to respond to the wants and needs of individuals' (754 as cited in Marston et al. 407), and in the nearly five years the NDIS has been in place, the fact that 'thin markets' has now emerged as a critical issue, underlines this important point.

In addition, and importantly, it appears that some service providers within this market environment are opting '..not to engage with the NDIS, delaying (or refraining! (sic) their registration with the scheme' (Souza, 2019, 2). Taking this service provider approach and considering the parameters within which they are required to operate suggests that a more 'provider-centric NDIS would facilitate provider engagement' (3). It appears the thin markets within which the disability sector now finds itself require more intervention than was originally envisaged when the scheme was first promoted.

A report based on a Review conducted by the Federal Parliament (Chair: K Andrews) in September 2018, specifically focusing on the market within which the NDIS was operating, concluded that '… most participants are not ready to engage confidently and navigate the market' and that '… the roles, responsibilities and activities of all those responsible for market stewardship (read the Agency: NDIA) are unclear'. The committee report talks of 'Provider of Last Resort' policy, within the context of 'thin markets' as not being released, and of therefore remaining 'unclear'. While this present document does not wish to reiterate the committee's findings, nevertheless, the urgency with which the recommendation on thin markets was stated speaks volumes:

> The committee recommends the NDIA publicly release its Market Intervention Framework as a matter of urgency (5.62).

The NDIA subsequently released this Framework in October 2018 and describes what it terms a 'light touch' should intervention be required (NDIS, 2018: 4) if services are not available, or are hard to access. However, the document recognises the paucity of services in some areas, and the increasing demand for these non-existent services, means that the NDIS may need to undertake what it terms as 'direct commissioning' as an 'effective intervention' (7) however this will only be undertaken following the development of an intervention plan (10).

Following the Federal election in May 2019, for the first time in the history of the disability sector, a Minister for the NDIS was appointed. In August 2019, a Review of the NDIS legislation and rules was announced, which '… will inform the development of the NDIS Participant Service Guarantee' (Robert, 2019) – no time limit for this Review or when a report is likely was available at the time of finalising this monograph.

Conclusions

This section has provided an overview of the Australian disability sector from 1992 to the present day. It has been a period of major change in the sector. It can be said that we have witnessed the devolution of responsibility for disability services from the Commonwealth to the states and return to the Commonwealth in less than 30 years. It has also been a period of major shifts in the role of government in the provision of public good. The move from universalist welfare models and largely state funded services to the non-government and business sectors gained its greatest momentum over this time. Privatisation, competitive tendering and the shift to market-based systems affected almost all arenas of service delivery; for example, privatisation of energy and water resources, prisons, refugee detention, and areas of health and aged care.

In disability, this period has marked the transition of people with disabilities previously viewed as inmates and patients to being people with the same human rights as others. People with disabilities and their families have become clients then customers, service users and are now 'purchasers' of services under the NDIS. The shift to a market-based system has proved to be problematic as this monograph has attempted to highlight. Systems that become overly bureaucratic are rarely able to respond well to people's needs. They become bogged down in red tape, long waiting periods, high transactional costs and a centralist worldview. The evidence is growing that better outcomes can be achieved for people with disabilities through programs that can deliver locally (i.e. are place-based) and via interventions that are relationship-based.

It still may be too early to forecast whether the NDIS can achieve this. However, the current practices of increasingly looking to technological 'fixes' and more external reviews, along with contractors and privatisation, are not promising.

This period has brought many challenges to the sector as a whole. For service providers this has meant a significant turnaround, a reshaping of almost every aspect of their operation: how they are structured, how they market and to whom, how they remain accountable to multiple stakeholders and how they can make their funding and funding guidelines deliver for people, and on their objectives.

It appears that such challenges have been too difficult for some as organisations optout of disability services. There has always been a tension between the capacity of government funding to meet the needs of people with highly complex needs, for people who live in remote and regional areas, for people who face oppression or marginalisation as members of other oppressed minority groups. Many service providers, like LWB, have supported vulnerable people to achieve decent lives – this lies at the heart of their mission. Thus far, many have managed to uphold those values. Although it appears this is increasingly difficult, there is hope there is likely support from allies within and outside the sector to face the challenges ahead.

1980–1991
New directions

1991–1996
Continuing social change

1996–2003
"most able of the disabled"

2003–2007
"no strings … on handout"

4th Fraser Ministry
(Inner Cabinet)

Senator Fred Chaney
03.11.1980–07.05.1982
Social Security

1st Hawke Ministry
(Inner Cabinet)

Senator Don Grimes
11.03.1983–13.12.1984
Social Security

2nd Hawke Ministry
(Inner Cabinet)

Senator Don Grimes
13.12.1984–16.02.1987
Community Services

Universalism' abandoned as an income security policy

International Year of Disabled Persons (IYDP) launched by UN 1981: Theme – Full participation and Equality

Disabled Peoples' International (DPI) established 1981

Citizen Advocacy established in WA 1980

Citizen Advocacy established in Victoria 1981

Elizabeth Bowey Lodge Inc established in SA 1981

Minister writes to ACROD calls for 'independent body to represent the views of disabled people as consumers' (Soldatic & Pini, 2012: 184)

Established in 1981

UN Decade of Disabled Persons commences (1982–1992)

Victoria: Intellectual Disability and Mental Health Services separated

Victorian Code of Rights (Force Ten) presented to Minister at 5th Strand Conference 1981

In a home or at home: Home Care and Accommodation for the aged (McLeay) 1982

WA: *Review of Services to people with intellectual disabilities* (Beacham). Recommendations not acted on

Prices & Incomes Accord 1983 (social wage)

Review of Handicapped Persons Assistance Act commences, 3000 people participated nationally

Social justice policy responses often poorly funded

1st International Self Advocacy Leadership Conference, (People First) US 1984

Equal Opportunity Commission established 1986

Vic: *Intellectually Disabled Persons Services Act 1986*

Mental Health Act 1986

Australia has second highest level of child poverty in OECD (16% 1985)

NSW Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled (Richmond) 1983

New Directions: Reports of the Handicapped Programs Review 1985

Senate: *Private Nursing Homes in Australia: Their conduct, administration and ownership* 1985

Children in Institutional and Over Forms of Care: A National Perspective Parliament of Australia 1985

Home and Community Care Act (HAAC) 1985

Disability Services Act (DSA) 1986

All State governments to enact Disability Services legislation as component of DSA

NSW: Disability Council of NSW 1987

Qld: *Intellectually Disabled Citizens Act 1985*

Qld: Intellectually Handicapped Services transferred to Family Services from Health

Social Security Review (Cass) 1986

WA: Review of WA AIHP Act 1985

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2007–2013
"underfunded, unfair, fragmented …"

2013–2016
Underlying assumptions, stereotypes, myths

2016–2019
Many are struggling

Chris Hurford
16.02.1987–24.07.1987
Brian Howe Social Security

Dr Neal Blewett
24.07.1987–04.04.1990
Community Services & Health
Brian Howe (Social Security)

Brian Howe
04.04.1990–07.06.1991
Community Services & Health

Brian Howe
07.06.1991–20.12.1991
Health, Housing & Community Services

3rd Hawke Ministry (Inner Cabinet)

4th Hawke Ministry (Inner Cabinet)

Family Assistance Supplement 1987
Family Support Program 1989
'New Managerialism'

Convention on the Rights of the Child, ratified 1990

Historical Development of the Commonwealth's Statement of Principles and Objectives 1989
Social Security Review (Cass) 1989

First Trienniel Review of Home and Community Care Program 1988
Towards Social Justice for Young Australians 1989

Responsibility for Disability Services moved from Health to Family & Community Services NSW 1989

Vic: Violence at Caloola 1988
Home and Community Care Program National Guidelines 1989
Residents' Rights in Nursing Homes and Hostel: Final Report (Ronalds) 1989
Qld: *A Place for Everyone* Report (Allison & Poulton)
Qld: First child sterilisation case in Family Court: Refused.

ABS: *Disability and Handicap. Australia 1988*

Disability & Sickness Support Act 1991 (DSSA)

Disability Support Pension (DSP) replaces Invalid Pension 1991

Vic: *Services for Older People with Intellectual Disability* 1990

Productivity Commission: *Aids and Appliances for People with Disabilities* 1991

Disability Discrimination Act 1992 (DDA)

1980–1991
New directions

1991–1996
Continuing social change

1996–2003
"most able of the disabled"

2003–2007
"no strings … on handout"

Brian Howe (DPM)

04.04.1990–11.03.1994

Health, Housing & Community Services (to 1993 then) Health, Housing, Community Services & Local Govt.

1st Keating Ministry (Inner Cabinet)

Dr Carmen Lawrence

25.3.1994–11.03.1996

Human Services & Health

2nd Keating Ministry (Inner Cabinet)

Employment of People with Disabilities. Government Response. April 1992

Cwlth Respite for Carers Program
ABS: Disability, Ageing and Carers
National Mental Health Strategy 1992

UN Decade of Disabled Persons concludes (1982–1992)

Carers Assn of Australia launched (CAA)
People with Disabilities (NSW) launched

HRC *National Inquiry into the Human Rights of People with Mental Illness* (Burdekin) 1993

Qld: *Commission of Inquiry: Psychiatric Unit Townsville Hospital 1991*

Qld: *Cabinet approves closure of Challinor, and eventual closure of Basil Stafford*

WA: *Disability Services Act 1992* & WA Disability Services Commission established

WA: Review of Accommodation Services for People with Disabilities 1993

WA: Review of Local Area Coordination Pilot Trial 1993

SA: *Supported Residential Facilities Act 1992*

NSW: Disability Services Act 1993

NSW: *Community Services (Complaints, Appeals and Monitoring) Act 1993*. Ombudsman to received complaints about disability services

Evaluation of Hostel Options Care Packages. Report 8. AGPS: Canberra

Home but Not Alone: Report on the Home and Community Care Program 1994

Modifications to DSA 1994

Working Nation 1994 includes: Case Management and Reciprocal Obligation

Australian Disability Consultative Council replaces DACA

Commonwealth Disability Strategy launched (10 year framework)

Modifications to Disability Services Program

Introduction of the Supported Wages system

Evaluation of Disability Reform Package

Evaluation of CSDA

Life without Barriers established

NSW: Creates new Department of Ageing, Disability and Home Care 1995

NSW: Disability Strategic Plan launched November 1995

Qld: Basil Stafford Inquiry commences

Qld: Draft policy statement and planning framework for Institutional reform

Qld: *Report of an inquiry into allegations of official misconduct at the Basil Stafford Centre* (Stewart) 1995

Productivity Commission: *Workers' Compensation in Aust 1994*

Strategic Review of Disability Services Program (Baume) 1995

Australian Law Reform Commission (1995) *Review of DSA*

Productivity Commission: *Charitable Organisations in Aust* 1995

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2007–2013
"underfunded, unfair, fragmented …"

2013–2016
Underlying assumptions, stereotypes, myths

2016–2019
Many are struggling

Dr Michael Wooldridge

11.03.1996–21.10.1998

Health & Family Services

1st Howard Ministry (Inner Cabinet)

Senator Jocelyn Newman

21.10.1998–30.1.2001

Family & Community Services

2nd Howard Ministry (Inner Cabinet)

Senator Amanda Vanstone

20.01.2001–07.10.2003

Family & Community Services

3rd Howard Ministry (Inner Cabinet)

Commonwealth Disability Policy 1983–1995. Background Paper 2 1995–1996

Social Security (Prospective Determinations for Newstart Recipients) Guidelines 1 of 1996

Commonwealth Services Delivery Agency Act 1997

Social Security Department split; Centrelink created; purchaser/provider split; Review of National/disability Advocacy Program (NDAP); National Carers Program integrated all programs into one; National network of carer resource centres estab

Working Nation abolished

1997 Governor-General accepts role as patron CAA

WA: *Disability Services Amendment Act 1999*

Qld: New Coalition Govt makes decision to halt deinstitutionalisation program

Qld: HACC services largely provided to aged care clients

Working Solution: Strategic Review of the DS Program (Baume) 1995

NSW: *The Integration/Inclusion Feasibility Study* (McRae) 1996

Report on Proposals for Changes to the Welfare System November

Unmet Need in Disability Services: Shortfall or Systematic Failure September 1999

Mid Term Evaluation of Commonwealth Disability Strategy 1999

Revised Strategy launched 2000

Minister at National Press Club identifies 2 kinds of citizens with disabilities (1) could not work at all and need support (2) could participate in rapidly expanding part time labour market

NSW: Disability Policy Framework 1998

5 Year Review of Act by NSW Law Reform Commission. Recommendations not adopted

NSW Govt closure of all large residential centres by 2010

A Matter of Priority: Report on Disability Services – Second Report

NSW Parliament, Report 23, December 2000

Participation support for a more equitable society (McClure) 2000

Disability Discrimination Amendment 2002

National Family Carers Voice established

OECD *Transforming Disability into Ability*

(Fed DDA) Developed national standards especially for transport

SA: *Volunteers Protection Act 2001*

NSW: Concern raised re cost shifting in CSDA

NSW: New Dept created: Disability Services; Ageing and Home Care (largely focused on intellectual disability) 2001

NSW: first Childrens' Policy developed 2002

NSW: Additional funds to focus on early intervention and family support

Cost Benefit Analysis of Rehabilitation Services 2003

Productivity Commission: *Report on Government Services*. Ch. 13. 2001

1980–1991
New directions

1991–1996
Continuing social change

1996–2003
"most able of the disabled"

2003–2007
"no strings … on handout"

Senator Kay Patterson
07.10.2003–27.01.2006
Family & Community Services

3rd Howard Ministry
(Inner Cabinet)

Mal Brough
27.01.2006–03.12.2007
Families, Community Services & Indigenous Affairs

4th Howard Ministry
(Inner Cabinet)

Children in Institutional care. March 2005

Forgotten Australians: A report on Australians who experienced institutional or out of home care as children August 2004

A hand up not a hand out: Renewing the fight against poverty March 2004

Disability Employment Programs split across 2 Depts (DEWR) October 2004; 2005–2006 Budget Major Review of DSP

Disability Advisory Council disbanded; Established Carers Advisory Council

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UN Convention on the Rights of Persons with Disabilities (CRPD) adopted 2006

Inquiry into Equal Opportunity in Employment for People with a disability 2005

WORKability II: Solutions – People with disability in the open workplace – Final Report of the National Inquiry into Employment and Disability, December 2005

WA: *Disability Services Amendment Act 2004*

SA: *Carers Recognition Act 2005*

SA: *Commission of Inquiry into Children in State Care* 2004–2008

SA: *Commission of Inquiry into Children on the APY Lands* 2004–2008

Productivity Commission *Review of DDA 1992* – Government does not implement recommendations 2004

Family & Community Services: *Evaluation of Cwlth. Disability Strategy.* Erebus. September, 2006

Review of DSP from July 2006 new entrants to DSP = mutual obligation (like work for the dole); Curtailment of advocacy through funding agreement; 1.8b funding for Disability Services announced by PM on 28.06.2007

NDAP reviewed for second time

Key eligibility halved from 30 hours work text to 15 hours

CRPD opened for ratification by member states (2007)

All NGOs funded had to report media to Government agencies

Vic: *Disability Act 2006* Established Disability Services Commissioner (replaces *Intellectual Disabled Persons Services Act 1986*)

SA: *Julia Farr Services (Trusts) Act 2007*

Qld: *Disability Services Act 2006*

NSW: *Stronger Together* launched – 10 year Strategy

AIHW: *Disability and Disability Services in Australia.* January 2006

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2007–2013
"underfunded, unfair, fragmented …"

2013–2016
Underlying assumptions, stereotypes, myths

2016–2019
Many are struggling

1st Rudd Ministry (Parliamentary Secretary)

Bill Shorten
03.12.2007–24.06.2010
Disability Services

1st Gillard Ministry (Parliamentary Secretary)

Bill Shorten
25.06.2010–14.12.2011
Disability & Childrens' Services

2nd Gillard Ministry (Parliamentary Secretary)

Senator Jan McLucas
15.12.2011–25.06.2013
Disability & Carers

Planning Options and Services for People Ageing with Disability September 2010

Senate Inquiry into Funding and operation of the CSDA 2007

Australia 2020 Final Summit Report: Establish an NDIS

The Way Forward: a new disability policy framework for Australia 2009

Who cares….? Report on the inquiry into better support for carers 2009

National Disability Strategy 2007 released as ALP Platform

Social Inclusion Unit established in PM&C. – priority: a labour market for people with a disability

Reactivation of support for Advocacy nationally. Withdrawal of requirement for media notification; Australia 2020 NDIS is announced as a 'Big Idea'

National People with Disabilities & Carers Council established – Rhonda Galbally Chair

Disability Investment Group established (B Bonyhady)

CRPD entered into force globally on 03.05.2008 and Australia ratified on 16.08.2008

Vic: *Disability Amendment Act 2007* – enhanced powers of DSC

Pension Review (Hamer) 2009

Shut Out; the experience of people with disabilities and their families in Australia. FaCHSIA. 2009 proposed new National Disability Strategy and new funding mechanisms

Productivity Commission: *Contribution of the Not for Profit Sector* 2010

Disability and Ageing: lifelong planning for a better future. July 2011

National Disability Strategy signed off in COAG 2011

Sheltered workshops rebranded as 'social enterprises' (Shorten)

Disability Commissioner established in own right (Graeme Innes)

Qld: Public Advocate report on Restrictive Practices

Australia's Future Tax System Review (Henry) 2010

Productivity Commission: *Caring for Older Australians* 2011

Productivity Commission: *Disability care and support.* Report No 54. 2011

Senate Standing Committee on Community Affairs Ref. Committee: Inquiry into the involuntary or coerced sterilisation of people with a disability in Australia commences

National Disability Insurance Scheme (NDIS) 2013

NDIS commences in stages: Pilot phase

Vic: Social Inclusion Unit established

SA: Royal Commission into Independent Education 2012–2013

Vision for Sustainable Supported Employment Report 2012

ABS: *Unmet Need for Formal Assistance* 2012

ABS: Intellectual Disability Australia 2012

ABS: Caring in the Community 2012

ABS: Young People with Disability 2012

ABS: Aboriginal & Torres Strait Islander People with a Disability 2012

ABS: Disability and Labour Force Participation 2012

1980–1991
New directions

1991–1996
Continuing social change

1996–2003
"most able of the disabled"

2003–2007
"no strings … on handout"

Jenny Macklin
26.06.2013–18.09.2013
Disability Reform

Senator Marise Payne
18.09.2013–23.12.2014
Human Services
Kevin Andrews, Social Services
Senator Mitch Fifield, Assistant Minister for Social Services

2nd Rudd Ministry
(Inner Cabinet)

1st Abbott Ministry
(Outer Cabinet)

Royal Commission into Institutional Responses to Child Sexual Abuse (2013–2017)

Involuntary or coerced sterilisation of people with disabilities in Australia. October 2013

NDIS commences in 4 Trial sites – July.

National Standards for Disability Services (NSDS) 2014

SA: *Not-for-Profit Sector Freedom to Advocate Act 2013*
Qld: Child Protection Commission of Inquiry 2012–2013
Vic: Betrayal of Trust: Inquiry into the Handling of Abuse by Religious and Other Non-Government Organisations November 2013

NSW: *Disability Inclusion Act 2014*

Making Welfare Work: submission on the Interim Report into Australia's Social Security system. National Welfare Rights Network August 2014
ABS: *Autism in Australia* 2014

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2007–2013
"underfunded, unfair, fragmented …"

2013–2016
Underlying assumptions, stereotypes, myths

2016–2019
Many are struggling

Scott Morrison

23.12.2014–21.09.2015

Social Services

Senator Marise Payne, Human Services

Senator Mitch Fifield, Assistant Minister for Social Services

Christian Porter – Social Services

Stuart Robert

21.09.2015–18.02.2016 (resigned 12.02.2016)

Alan Tudge, Assistant Minister, Social Services

Alan Tudge

18.02.2016–02.07.2016

Human Services

2nd Abbott Ministry (Outer Cabinet)

1st Turnbull Ministry – Outer Cabinet

Adequacy of existing residential care arrangements … young people with disabilities June 2015

Commissioned by Attorney General to undertake a Review of Employment Discrimination (March 2015)

SA: Child Protection Systems Royal Commission 2015–2016

Vic: *Reporting and investigation of allegations of abuse in the disability sector: Phase 1 the effectiveness of statutory oversight* June 2015 Ombudsman

Productivity Commission: *Report on Government Services Vol. F: Community Services* 2015

Senate: *Violence, abuse & Neglect against people with disability in institutional settings.* November 2015

PwC: Review of NDIS ICT problems and failures

National Disability Insurance Scheme Amendment Act 2016

Act creates: National Disability Insurance Scheme Transition Agency (NDIA)

New ICT system launched July 2016

Disabled People's Organisation Australia (DPOA) established: consists of National Ethnic Disability Alliance (NEDA); First Peoples Disability Network; Women with Disabilities Australia (WWDA); People with Disability Australia (PWDA)

Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability (HRC) May 2016

SA: *Child Safety (Prohibited Persons) Act 2016*

NSW: Parliamentary Inquiry into Elder Abuse

1980–1991
New directions

1991–1996
Continuing social change

1996–2003
"most able of the disabled"

2003–2007
"no strings … on handout"

2nd Turnbull Ministry (Outer Cabinet)

Alan Tudge
02.07.2016–20.12.2017

Sarah Henderson
18.02.2016–24.08.2018
Assistant Minister, Social Services, Housing and Disability Services

Michael Keenan
20.12.2017–24.08.2018
Human Services

Joint Standing Committee on NDIS: Progress Report 2017

Senate: Violence, abuse and neglect against people with disability in institutional settings November 2017

Indefinite detention of people with cognitive and psychiatric impairment in Australia. November 2016

Vic: *Disability Amendment Act 2017* (Vic)

Vic: Royal Commission into Family Violence 2015–2016

Qld: Barrett Adolescent Centre Commission of Inquiry 2015–2016

Productivity Commission: *National Disability Insurance Scheme (NDIS) Costs* October 2017

Vic: *Disability Services complaints data*: (2007–2015)

Royal Commission into Aged Care Quality and Safety established 08.10.2018

Royal Commission into Violence, Abuse, Neglect & Exploitation of People with Disability established 04.04.2019

Qld Public Advocate: *Reshaping the Disability Services Act 2006: An inclusive and accessible Qld* November 2018

NSW Ombudsman: *Abuse and neglect of vulnerable adults in NSW – the need for action* November 2018

Delivery of outcomes under the NDS 2010–2020 to build inclusive and accessible communities December 2017

Vic: Mental Health Royal Commission 2018

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2007–2013
"underfunded, unfair, fragmented …"

2013–2016
Underlying assumptions, stereotypes, myths

2016–2019
Many are struggling

Sen. Linda Reynolds CSC
30.03.21 – present
Minister for the National Disability Insurance Scheme

Michael Keenan
28.08.2018–
29.05.2019 (retired)
Human Services

Stuart Robert
29.05.19 – 30.03.21
Minister for the National Disability Insurance Scheme

Sen. Anne Rushton
30.03.21 – present
Minister for Social Services (incl. National Disability Strategy)

1st Morrison Ministry (Inner Cabinet)

2nd Morrison Ministry (Inner Cabinet)

3rd Morrison Ministry (Inner Cabinet)

SA: *Disability Inclusion Act* 2018 (SA) Domiciliary Care outsourced

Independent Pricing Review. National Disability Insurance Agency. Final Report February 2018 (McKinsey & Co)
ABS: *Experiences of Violence & Personal Safety 2016*

Senate: Charity Fundraising in 21st Century Inquiry

Joint Standing Committee on NDIS created July 2019 – Chair: Kevin Andrews – Reviews on: Implementation & Performance of NDIS; Independent Assessments; NDIS Quality and Safeguards Commission; NDIS Workforce.

Review of NDIS Act – David Tune. Review Report Released: Dec. 2019

COAG Disability Reform Council: Extends NDIS Planning for 2 years. March 2020

Re-Commits to National Disability Strategy (2010–2020).

Fed.Dept.Health: issues Management Plan as Emergency Response to Covid-19. April 2020

NDIS Commission releases 2nd *Annual Report* – September 2020

Digital Partnership Program – announced February 2020.

National Disability Strategy position paper released for comment – July 2020

Federal Court rules on use of NDIS funds for access to specialized sex worker services – May 2020.

Mavromaras, et al 2018. *Evaluation of the NDIS: Final Report* 2018

Education & Learning – Oct.2019

Group homes – Nov. 2019

Health care for people with cognitive disability – Dec. 2019

Criminal justice system – March 2020

Emergency planning and response – April 2020

Rights and attitudes – April 2020

Employment – May 2020

Restrictive practices – May 2020

First Nations People with disability – June 2020

Safeguards and quality – November 2020

Violence and Abuse … at home – Dec. 2020

Promoting inclusion – Dec. 2020

Culturally and linguistically diverse – March 2021

Vic: Department of Families, Fairness and Housing – created: Feb 2021 (incls. Disability services)

2.

SHIFTS IN THEORETICAL APPROACHES: IMPLICATIONS FOR THE NDIS

Introduction

Australian disability services and supports have undergone extensive and rapid changes over the past four to five decades. In the previous section, we have reflected on these changes in legislation, policies and practice. To a large extent, these decades also experienced shifts and changes in theoretical approaches that resulted in different models of support and care, all of which required a disability workforce that had the necessary knowledge and skills to provide that care.

This section tracks the changes in theoretical approaches and practice models over this period. It highlights the profiles of staff and workers needed and how they were prepared for working in this field and has three major parts:

- The first part lays out the genealogy of theoretical approaches covering the period. This covers the fundamental ideas, the main theorists and writers, and the main countries implementing the model;

- The second explores roles in the disability workforce, their education and training and how this changed over time; and

- The third examines the current situation under the NDIS and how marketisation of the sector has impacted the way people are supported, the essential practice approaches currently utilised and an overview of the staff required to provide supports in these contexts.

In finalising this monograph, we became aware of a research report commissioned by the Disability Royal Commission (Clifton, 2020) *Hierarchies of power: Disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability* and published in October 2020. This document offers a further detailed analysis of many of the theories and practice implications we cover in this section. Our contribution was written and presented to the LWB as a draft in February 2020.

Theoretical models shaping the sector

EARLY INSTITUTIONS

From early colonisation of Australia, people with a disability were largely congregated in asylums run either by the early charities or by the state. These contained people with mental illness, intellectual disability and a host of other conditions of unknown aetiology. 'Treatment' was based on congregate and segregated models. Institutions became the dominant accommodation in most states, where large, foreboding (to those living within them, and those outside) estates were built usually on the outskirts of major centres. Staff consisted of custodial wardens, perhaps a medical administrator and some nursing personnel, and ancillary staff for the kitchens, gardens, maintenance etc. These institutions provided employment for the staff rather than proper care for the residents (see Cocks & Stehlik, 1996).

From Post WWII to the present day, many theories, ideas and approaches have emerged, been adopted, adapted and then discarded (or buried) as new innovations came into the field. On exploring these shifts in more detail, we can track a genealogy of frameworks from the 1950s to the present day. These are discussed in more detail later. Some of these were specific to disability such as normalisation, while others had a broader application in human services, for example, ecological frameworks. This is in no way an exhaustive list. It focuses on the key approaches that were universally adopted and implemented. However, over this time various innovations appeared that were adopted in relatively small pockets of practice. These were often therapeutic interventions, with little evidence on their efficacy but nevertheless were taken up in some sectors. These have not been included[1].

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1 An example was the Doman-Delacato method of 'patterning' introduced in the 1960s. This involved repeatedly moving children through various development mobility phases. It was subsequently found to have no evidence of success. (American Academy of Pediatrics, 1982).

INDIVIDUAL, SOCIAL AND INTERACTIVE MODELS

A rudimentary distinction of theoretical approaches can be explained as follows:

- Individual models where disability is seen as the result of some attribute of the individual. The dominant manifestation of individual models is the medical model, where disability is viewed as a defect or pathology of the person, and medical interventions are needed to 'fix' them. Other and historic individual models include viewing disability as a random personal tragedy or as a moral punishment for past sins;

- Social models frame disability as a result of social factors or barriers. Their central tenet is that individual limitations are not the cause of the problem but rather, it is the failure of societies to provide proper supports and environments to include people with disability on the same footing as everyone else;

- Models focused on individual-environment interaction. The binary distinction of individual and social models did not adequately address the experience of disability, prompting the development of bio-psychosocial models. The World Health Organisation (WHO) has developed this schema since 1980 to the current International Classification of Impairments, Disabilities, and Handicap (ICIDH), which uses the domains of impairment, disability, and handicap to incorporate individual *impairments*, the functional limitations that consequently arise, *disability* and the resultant disadvantage and discrimination, *handicap*. The latest revision is the International Classification of Functioning, Disability, and Health (ICF, 2002).

These three conceptualisations provide a framework with which to explore the following history of theories and ideas that informed and guided services and practice across the disability sector.

Theoretical frameworks Post WWII to the present

The period from postwar to the present, some seventy years, has witnessed many changes in theories, models of care and the different workforces that provided services and supports. This section traces this history and discusses in detail foundational concepts and ideas within theories and how they were applied in practice. It also briefly outlines the main theorists and researchers who promulgated the theory, and how ideas changed even within a particular approach. This is summarised in Table 2 below.

TABLE 2. A GENEALOGY OF THEORETICAL MODELS: 1950 TO PRESENT DAY

CRITICAL DECADE(S)	TITLE OF THEORY	PRINCIPAL THEORIST	COUNTRY	DISCIPLINE	FUNDAMENTAL PRINCIPLE
	Medical Model	Various	Western societies	Medicine	Exclusion Congregation/Segregation/Institutional Care
1950s	Normalisation Principle (NP)	Niels Bank-Mikkelson (1919–1990)	Denmark	Law	Lives of PwD should resemble, as much as possible, the lives of ordinary people
	Symbolic Interactionism (SI)	Irving Goffman 1922–1982	Canada	Sociologist/ Social Psychologist	SI as Everyday actions and interactions; people's behaviour; stigma; dramaturgy; institutionalisation
1960s	Normalisation	Bengt Nirje 1924–	Sweden	Medicine	NP into policy and practice; extensive international influence of 1969 publication
1970	Ecological Systems Theory	Urie Bonfonbrenner (1917–2005)	USA	Psychologist	Human Development; Influenced US Policy on child development; Argued for ecological rather than biological approaches; systems approach has influenced more recent thinking beyond child development
1970s/1972	Normalisation	Wolf Wolfensberger (1934–2011)	USA	Psychologist	Publication of US based text drawing on Mikkelson/Nirje: focused largely on Intellectual Disability.
1975–present	Social Model	Union of the Physically Impaired Against Segregation (UPIAS) Mike Oliver Vic Finklestein	UK		……. Society disables physically impaired people. Considers to be historically the point at which people with physical impairments began to argue for their own voice ' standpoint' or 'lived experience'.
1980s/1983	Social Role Valorisation (SRV)	Wolf Wolfensberger	USA	Clinical Psychologist	Further developed NP to broaden reach beyond Intellectual Disability. Enhanced competency and image aspects.

CRITICAL DECADE(S)	TITLE OF THEORY	PRINCIPAL THEORIST	COUNTRY	DISCIPLINE	FUNDAMENTAL PRINCIPLE
1980s/1986	Person Centred Planning (PCP)	John O'Brien	US	Social Scientist	Developed practical tools to assist in introducing Normalisation/SRV
1980s	Social Model from Lived Experience	Carol Thomas 1958– Jenny Morris 1950–	UK		Response to social model not engaging with embodied experience. Highlighted the bodily experience of impairment
1982	Minority Group Model	Irving Zola 1935–1994	USA	Medical Sociologist	*Missing Pieces: A Chronicle of Living with a Disability.* Influenced 'lived experience' sociologists
1990s	Marxist Approach to Social Model	Tom Shakespeare (1966–2006) Mike Oliver (1945–2019)	UK	Sociologist Sociologist	Moral responsibility on society to remove the 'burden' of disability
	Feminist Approach to Social Model	Adrienne Asch (1946–2013) Michelle Pine (1952– Sally French	USA USA UK	Philosopher Psychologist Sociologist	BioEthics/Genetic Testing Critique Education/Minorities
2000s	Neo-Liberalism/ Marketisation				
	WHO ICF framework				

Codes:
▮ Individualised Theories; ▮ Structuralised Theories; ▮ Combination of Individual/Structural; Other

Medical and individual models

The medical model is the most prevalent individual model in scope of application and its longevity over many years. In the past the "problem" of disability was firmly located in the province of medicine. The medical model defines disability as the result of some physiological impairment due to disease or intrinsic damage to the individual's body. The model stems from the disease model in medicine, where a "condition" is diagnosed and then treated through various interventions that all focussed on the individual's impairment. The goal in medical models is to cure or at least manage the condition and this rests on the basic assumption that the person needs to adapt to the environment. Determining the causation and nature of the disease or condition and its subsequent treatment is the domain of scientific and clinical investigations by health care professionals.

While historically the management and care of people with disability was undertaken by medical and nursing staff, the medical model was the foundation for other professions, including psychology, physiotherapy, speech pathology and other therapists. Psychology uses clinical diagnostic criteria often determined by standardised tests to determine a person's intelligence, self-concept, motivation, mood etc. This quantification of the problem then provides a basis for interventions to change behaviours, to improve performance or ameliorate deficiency.

It is important to note here that the medical model has many significant contributions to the improvement of the lives of people with disability. Aids and modifications such as prosthetics, cochlear implants, medications, early diagnostic tests etc have greatly reduced the incidence and impact of many impairments.

However, the dominance of the medical model led to stereotyping and defining people with disability by their condition or limitations. This is sometimes referred to as the personal tragedy view of disability, whereby bad things have happened to the person furthering the negative view of the impairment as associated with the whole person (Retief & Letsosa, 2018). Terms such as cripple, invalid, spastic, retarded all stem from the medical model creating an identity limited to negative labels and stereotypes.

It also set up a dualism wherein able-bodied people could be categorised as somehow better or superior to people with disabilities (Johnstone, 2012).

The close alignment of the medical model with sickness and a cure agenda brings other difficulties for disabled people. First, within the medical model there is a requirement for the person with the disability to play the "sick role" if they are to receive continued help and support and keep them in a powerless position with regard to making their own choices. Second, many people with disability do not regards themselves as sick but have ongoing impairments that are not really health problems per se. As a result, the medical model fails to consider the crucial distinction between impairment and sickness.

Normalisation and SRV

The Normalisation Principle as initially included in Danish law by Bank-Mikkelsen from as early as 1959, was more comprehensively developed by Bengt Nirje (1969) in Sweden. Nirje's work was to have international impact on policies, legislation and services for people with disabilities. In the late 1960s, Sweden was concerned with the status of the rights of those labelled 'mentally handicapped'. Nirje was head of the Swedish Association for Retarded Children and developed the principle to influence policy and the conditions for people with disability in institutions and the community.

THE ELEMENTS OF THE NORMALISATION PRINCIPLE

In conceptualising the idea of 'normal', Nirje proposed that the normal rhythms of the day, the week, the year and the whole life cycle were important for all people and should be available to those with disability. He then extended this to reflect the "normal conditions of life' including economic and environmental conditions.

The formulation of the principle of Normalisation meant ' … making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society …" (Nirje, 1985, 67).

Nirje travelled to the United States and Canada and worked with others, notably Wolf Wolfensberger who further developed Normalisation in North America and later reformulated it as social role valorisation (SRV).

Normalisation had a significant effect on the way services for people with disabilities were structured and delivered throughout much of the developed world. It was a major influence in Australia and led to a new conceptualisation of disability as not simply being a medical issue where the person was indistinguishable from the impairment. Interestingly, Nirje's ideas were picked up in Australia initially in Queensland where he visited in the late 1970s. Wolfensberger visited several states in Australian in the late 1970s and early 1980s, and had significant influence, particularly within the public sector (Millier, 1999).

The main impact of Normalisation was in driving reforms in services, in education systems and in practice generally. These drivers of change are evident in government reports and policies during the 1970s and early 1980s. For example, the NSW Anti-Discrimination Board Report (1981) made recommendations on the rights of people with intellectual disability to receive appropriate services, to assert their rights to independent living so far as this is possible, and to pursue the principle of normalisation. The Federal Government adopted the Normalisation principle as a theory for policy and systems change through the late 1980s, particularly evident within the Commonwealth Rehabilitation Service which began closing institutions and rehabilitation centres and moving to community-based rehabilitation models of support on the election of the Hawke Labor Government in 1983.

BOX 1. WOUNDS EXPERIENCED BY DEVALUED PERSONS

Relegation to low ('deviant') status and rejection, perhaps by family, neighbours, community, society, service workers, leading to:

- Cast into one or more historical deviancy roles;
- Symbolical stigmatising, 'marking', 'deviancy-imaging', 'branding';
- Being multiply jeopardised, scapegoated;
- Distantiation: usually via segregation and also congregation;
- Loss of control, perhaps even autonomy and freedom, leading to:
  - Discontinuity with the physical environment and objects;
  - Social and relationship discontinuity, even abandonment;
  - Absence or loss of natural/freely given relationships, and substitution of artificial/'bought' ones;
  - Deindividualisation, leading to:
    - Involuntary material poverty, material/financial exploitation;
    - Impoverishment of experience, especially that of the typical, valued world;
    - Exclusion from knowledge of, and participation in, higher order value systems (e.g. religion) that give meaning and direction to life, and provide community;
    - Having one's life 'wasted';
    - Being the object of brutalisation, 'killing thoughts', and death making.

SOCIAL ROLE VALORIZATION (SRV)

The reformulation of Normalisation by Wolfersberger in the early 1980s resulted in a new theory: that of Social Role Valorisation more commonly referred to as simply SRV. This approach focused on the social devaluation of certain groups of people through being poorly treated, being assigned low-value roles, often even at risk to their health and survival. Wolfensberger identified how devalued people suffer a process of 'wounding' whereby bad things happened to them (Thomas & Wolfensberger, 1999). These wounds are listed in Box 1.

SRV offered a way to understand the long-term effects of social devaluation on individuals and how human services themselves contributed, often unconsciously, to these processes. The goal of SRV was to raise consciousness about societal devaluation and offer ways to promote more valued roles for people. SRV was addressed to a wide range of groups at risk of being devalued by society: including people with mental health issues, intellectual disability, physical impairments, from different ethnic or racial groups and criminal. However, its greatest impact can be seen in service systems for people with intellectual disability.

SRV promoted two broad strategies to counter devaluation and promote valued roles: improving the *images* surrounding people with disability and working to improve their *competencies*. Image referred to all aspects of the person and their environments: their personal appearance, labels ascribed to them, the settings in which they lived, and the roles that these conveyed. Competency enhancement was regarded as the other crucial tool in supporting a person to function as well as possible in their environments, thus improving their status and perceived value. Both aspects had a significant impact on service systems and on the workforce involved.

Wolfensberger's work was part of a major systems reform in the US and Europe of how individuals with disabilities would be served, resulting in the growth in community services in support of homes, families and community living (Wolfensberger, 1991).

In Australia, as mentioned above, it had a direct influence on legislation, policy and services models. In parallel with other reforms of the 1980s, SRV provided one of the theoretical underpinnings to the closure of institutions, the shift to community living and individualised approaches. It was widely promoted through training workshops for public servants, services providers, professionals and family members for many years. For example, in Western Australia, the first group of employed Local Area Coordinators were all supported in attending training based on SRV principles (see also Section I).

Taking a retrospective view, it would appear that while SRV and Normalisation did impact at the policy level, in practice its impact was more visible at the local or personal level. Some agencies, parent and advocacy groups embraced it, adopting the strategies of promoting valued roles to achieve better lives for people with disability. These groups were largely associated with a nation-wide SRV movement that provided the training workshops accredited by Wolfersberger's Institute in the United States. Many smaller services based on SRV principles were often set up by parents for their own family members, usually including community living and support. Many are still operating. See, for example, Homes West and Avenues Lifestyle Support in Queensland. SRV also underpinned advocacy efforts again, many started by parents. For example, Family Advocacy NSW still works from an SRV theoretical model. Some larger organisations adopted SRV though there were fewer. Aged Cottage Homes (now ACH Group) in South Australia for example, adopted SRV in the design and delivery of all their services to older people.

There were, of course, many criticisms of Normalisation and SRV at the time. The major weaknesses identified included the lack of evaluation and critique, confusion about language and jargon and the demanding training schedule. However, it remains a powerful influence on disability services and is still active in the sector today.

Social models

The social model emerged from the Union of Physically Impaired Against Segregation in the mid-1970s. This was a movement that consisted of people with severe physical disabilities who found themselves in segregated institutions where their views were ignored, and authoritarian regimes ruled their lives. They proposed that disability was a:

> … disadvantage or restriction of activity caused by a contemporary social organisation that takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1975).

The initial proponents of the social model were people with physical disabilities, based in the UK. Mike Oliver, a social work academic, is usually credited with promoting the social model in the academe (Oliver, 1983, 1990). As well as teaching individual models, Oliver wanted to offer his students a way to make their practice more relevant to disabled people. The social model came at a time when the disability movement was taking off in the UK and so the social model "took on a life of its own and became a big idea" (Oliver, 2013, 1024). Fundamentally the social model is usually understood as sitting in stark contrast to the medical model as defined by People with Disability Australia:

> The social model sees 'disability' is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others (See PWDA at www.pwd.org.au).

In its simplest form, the social model requires a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment. These are more readily applied to physical and sensory impairments. For example, a person may have an inability to walk (physical impairment) but not being able to enter a building because of the stairs is a disability.

The social model has been a rallying cry for action and change and was adopted by many disability movements across the world. It is now accepted and recognised internationally as a way to address "disability" The United Nations Convention on the Rights of Persons with Disabilities (CRPD) 1992, represented a major paradigm shift in attitudes and how disability was approached.

Disablement is a form of social oppression that operates at both the public and personal levels, affecting what people can do as well as what they can be (Reeve, 2004, p 83). The social model seeks to change society to accommodate people with impairment rather than seeking to change people with impairments to fit into society.

Critiques of the social model came from several quarters; for example, it was argued that the model was created by white males with physical impairments. Many other groups, including disabled women, people from minority ethnic and cultural communities, people with learning and intellectual disability questioned the model's relevance. Other people with disabilities argued that it did not sufficiently take into account the psychological impacts of disablism or the complexities around individual identities (Morris, 1991,2001; Shakespeare, 1994, 2006). Still, others argued that it was fine at a theoretical level, but it did not apply in practice. The social model provided a feasible framework for making policy and legislative changes and offered another way to think about the experiences of people with disability and address ways to change the environmental, communication and attitudinal barriers they faced.

Ecological and systems models

As discussed above in Section I, person-centred approaches are widely accepted as fundamental to planning and supporting good lives for people with disabilities. At the fundamental level, person-centredness is based on ecological or systems theoretical frameworks. These models sit within the individual-environment interaction group of conceptualisations of disability.

Ecological approaches originated in the field of child development and are largely attributed to the work of Urie Bronfenbrenner, a co-founder of Head Start (USA). His model outlines a framework to examine an individual's relationships through different environmental systems in the community and wider society (Bronfenbrenner, 1979). It outlines five ecological systems as illustrated in Figure 2 below.

FIGURE 2. BRONFENBRENNER'S ECOLOGICAL SYSTEMS THEORY MODEL

CHRONOSYSTEM
Changes over time

MACROSYSTEM
Social and cultural values

EXOSYSTEM
Indirect environment

MESOSYSTEM
Connections

MICROSYSTEM
Immediate environment

CHILD

(C) The Psychology Notes Headquarters https://www.PsychologyNotesHQ.com
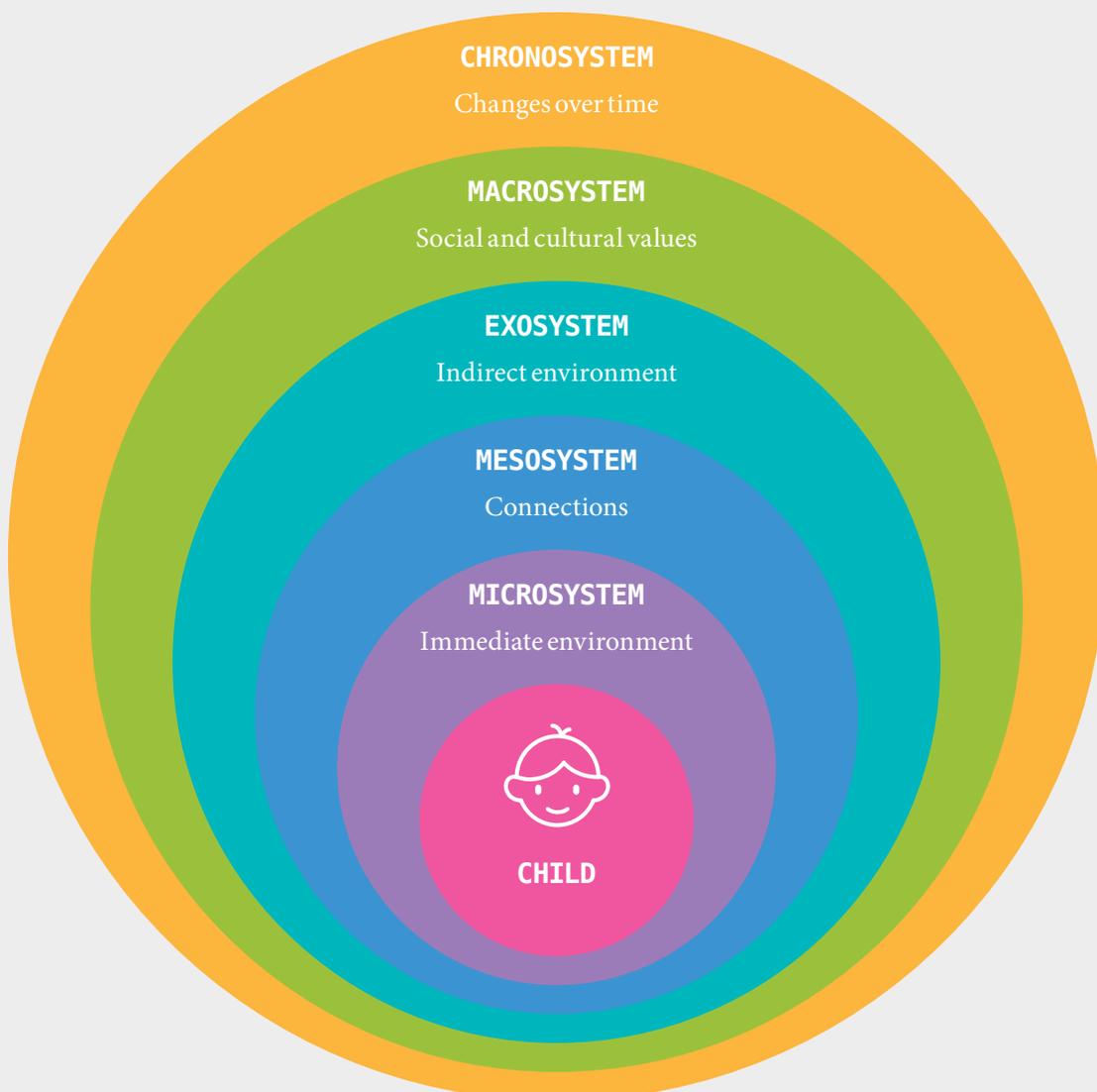
This theory has been applied to various fields beyond child development including mental health, children with physical disabilities, inclusive education and deinstitutionalisation (Berry, 1995). Ecological/systems models have been adopted as a framework for practice by many professionals as well as guiding policy (Eriksson et al. 2018).

Applying the five systems in a disability context, placing the person at the centre, then possible relationships in these systems include:

- Individual: the person, age, gender, health, impairment
- Microsystem: family, peers, school, day-care, neighbourhood, church
- Meso system: relationships between the individual, family and service system
- Exosystem: family friends, parent's connections at work, service agencies, mass media
- Macrosystem: overall attitudes and ideologies of the culture – including attitudes about disability
- Chronosystem: sociohistorical conditions and timespan of life events

Ecological or systems approaches require that any assessment or intervention needs to be understood and interpreted in light of the culture or sub-culture in which the person lives and a de-emphasis on objective testing. They can also take into account the service system and the interactions between personnel and the person and their family.

We return to this model in more detail in Section IV where we utilise it to consider how to provide a 'good life'.

Behaviour theories

Theories of behaviour have had a place in disability services for decades. As behavioural psychology developed in the first half of the 20th century, theories and practice about learning continued to be developed. As services and the care of people with intellectual disability saw a need for ways to teach new skills, to foster more appropriate behaviours, psychology developed interventions based on learning and behaviour modification.

POSITIVE BEHAVIOUR SUPPORT

Behaviour theories are still employed in positive behaviour support for people with complex needs and challenging behaviour. This practice approach gained momentum in the early 2000s as many disability services were stretched fining appropriate ways to support people with challenging behaviour.

Positive behaviour support is an evidence-based approach with the primary aim of improving a person's quality of life. Decreasing the frequency and severity of the challenging behaviours is a secondary goal. It is argued as a person-centred approach based strongly within a human rights framework.

> In the current international context positive behaviour support is defined as:
>
> An approach to behavior support that includes an ongoing process of research-based assessment, intervention, and data-based decision making focused on building social and other functional competencies, creating supportive contexts, and preventing the occurrence of problem behaviors. PBS (positive behaviour support) relies on strategies that are respectful of a person's dignity and overall well-being and that are drawn primarily from behavioral, educational, and social sciences … PBS may be applied within a multi-tiered framework at the level of the individual and at the level of larger systems (Kincaid et al, 2016, 71).

The ongoing process of assessment, planning and intervention takes into account the person's needs, their environment and works with families, carers and support staff to develop a shared understanding of the person, their needs and how they can enjoy a better quality of life. PBS involves the development of behaviour support plans and focuses on developing the person's skills and communication. Importantly PBS requires staff training and development for all levels of staff in an organisation from frontline support workers to coordinator and managers.

The National Disability Insurance Scheme Quality and Safeguards Commission (NDIS Commission) has developed a Positive Behaviour Support Capability Framework to guide the NDIS Commission's work on behaviour support capability and to consider the suitability of behaviour support practitioners to deliver specialist behaviour support services.

Within the NDIS context, PBS is described as the "integration of the contemporary ideology of disability service provision with the clinical framework of applied behaviour analysis. Positive behaviour supports are supported by evidence encompassing strategies and methods that aim to increase the person's quality of life and reduce challenging behaviour" (NDIS Commission, 2019).

ACTIVE SUPPORT

An increasingly prevalent approach to supporting people with intellectual disability that draws upon behavioural theories is Active Support. Active Support uses a range of approaches aimed at enabling people to participate in meaningful activities and relationships to gain more control over their lives, develop more independence and become included as a valued member of their community irrespective of degree of intellectual disability or presence of challenging behaviour (United Response, 2014). At Appendix E we provide some further detail of Active Support from the literature analysis.

Active Support was initially funded on technological skill development but found that this was not enough to consider the complexity of ordinary lives. It therefore focuses much more broadly on whole of life. And uses the concept of 'engagement' which is regarded as 'experience a life as close as possible to the life of people without intellectual disability' – a 'good' life (See Section V).

Key elements of Active Support are 1) the development of staff skills in promoting engagement and 2) the capacity of the service to provide accessible opportunities in a structured and predictable fashion.

From a theoretical standpoint, Active Support draws upon theories of behaviour support, person-centred and ecological approaches, social inclusion and quality of life. The approach integrates perspectives of the person or individual, the wider social networks and the organisational context and leadership (Bigby et al, 2019). In common with Positive Behaviour Support, Active Support has been widely researched and evaluated. It has been shown to increase participation in ordinary life, social relationships and community activities. It has also been shown to be an important approach in supporting people with challenging behaviour.

ICF framework

The International Classification of Functioning, Disability and Health, usually referred to as the ICF, is a classification of health and health-related domains. It has had a long history through the World Health Organisation's processes for development through various versions. As mentioned earlier, the initial WHO framework, the International Classification of Impairments, Disabilities and Handicaps was proposed in 1980. It was originally applied to understand the effects of long-term conditions such as arthritis and rehabilitation impacts. It is now widely adopted across many countries in disability programs and public health.

The ICF was later introduced in 2002. The framework, essentially a biopsychosocial model, sits in the interactive models of disability theories in that it incorporates both individual characteristics as well as environmental factors and context: see Figure 3 below.

FIGURE 3. BIOPSYCHOSOCIAL MODEL
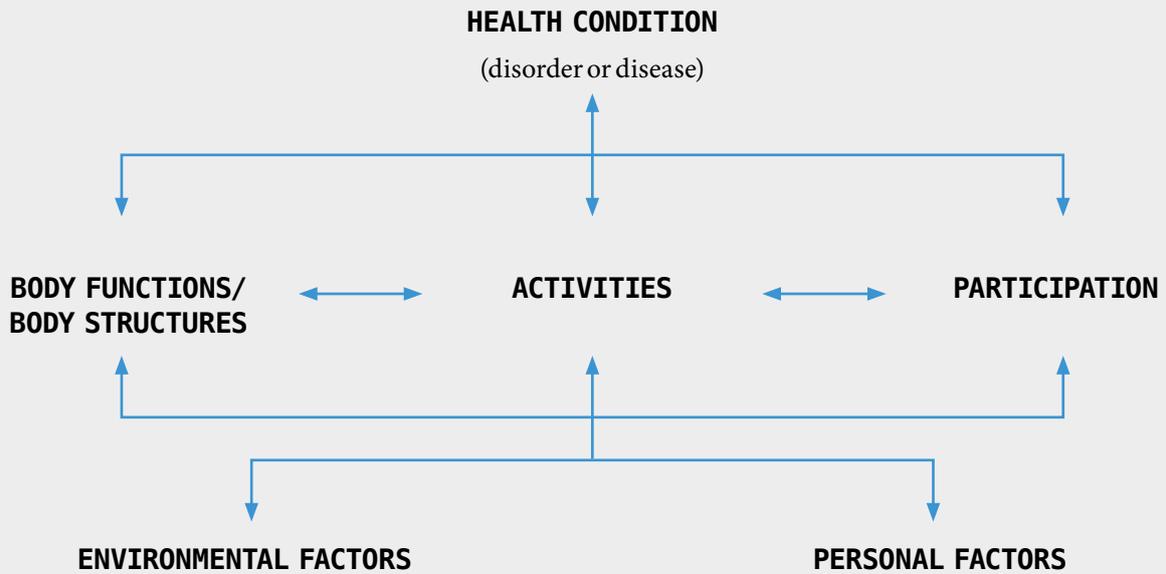
The biopsychosocial model was originally developed by George Engel (1977) who argued a crisis in the biomedical paradigm in illness and psychiatry left no room for social and psychological aspects of illness. It is now widely used in illness, chronic disease, mental health and disability contexts. The ICF is explicitly related to the biopsychosocial model and its application in developing clinical guidelines to influence person-centred care (Wade & Halligan, 2017).

In practice in Australia, the ICF/biopsychosocial model is the foundation for most health and rehabilitation services. Its application to people with a disability includes allied health and therapies, rehabilitation post severe injury, stroke, etc. Its wider application as a neutral classification system is at a whole of population level as a tool for measurement, assessment and statistical records to monitor countries' progress. It is here that the links between the ICF as a measurement and monitoring tool and the philosophical vision of UN Convention on the Rights of Persons with Disabilities become apparent (Madden et al. 2011).

Disability rights frameworks

The quest for human rights and inclusion as ordinary citizens for people with disability emerged from the general civil rights movement initially in the United States but is now a universal and worldwide framework. In the USA, the *minority group model* argued that people with impairments were a minority, subjected to stigmatization and exclusion like other marginalised groups on the basis of race, ethnicity or gender. This view led to the advancement of anti-discrimination laws such as the *Americans with Disabilities Act 1992* and Australian Anti-Discrimination legislation.

The culminating instrument through the United Nations is the Convention on the Rights of Persons with Disabilities (CRPD) adopted in 2006, which provides standards of protection for the civil, cultural, economic, political and social rights of persons with disabilities on the basis of inclusion, equality and non-discrimination. It makes clear that persons with disabilities are entitled to live independently in their communities, to make their own choices and to play an active role in society. The CRPD has formed the foundation for policies and legislation across many states and jurisdictions. This, in turn, has greatly influenced services and practice.

This human rights model is closely aligned with the social model of disability though there are some important differences summarised from Degener (2017):

- the human rights model goes beyond the social model's explanation of social factors, by offering a framework for disability policy that emphasises the human dignity of people with disability;

- it incorporates both first and second generation human rights, i.e. it encompasses both human rights, civil and political as well as economic, social and cultural rights;

- the social model does not fully appreciate the reality of pain and suffering in the people's lives whereas the human rights model acknowledges that some people are confronted by real challenges and argues that such factors should be taken into account in the development of relevant social justice theories;

- the human rights model addresses questions of cultural and minority identity whereas the social model does not really include identity issues;

- the human rights model does acknowledge that policies aimed at the prevention of impairments are examples of human rights protection; and

- again the human rights model goes beyond explanation of poverty and offers constructive proposals for improving peoples life situations.

Human rights frameworks have brought changes in services and practices for people with disability over several decades. Reflecting on the history of people with disabilities, the experiences of institutionalisation, forced sterilization, and, in some cultures, extermination have marked the battle for rights or people who had been denied such rights for centuries – from inequality to equality, prejudice to tolerance, and from exclusion to inclusion (Glicksman et al. 2017).

What these changes have meant at the coal face of services and support is that people with disabilities are people first, that they have a say in decision making in matters that impact on them, that they are entitled to grievance processes and generally should have choice and control of their lives. Yet despite this, we still encounter marginalisation, exclusion and maltreatment for some, particularly those with intellectual and cognitive disabilities.

Conclusions

The disability field has witnessed a range of theories and approaches to practice and interventions. This section has provided an overview of the main theories. We offer several summary points here for consideration in adopting the most appropriate practice frameworks:

- The development of theory is an ongoing organic process rather than a linear progression from one theory to the next;

- Not all theories have been tested or evaluated for their efficacy. While very difficult in human services settings, evaluations of programs are often minimal or lacking altogether. In addition, evaluation of the theory underpinning specific programs or interventions are rarely evaluated;

- Remnants of "older" theories can still be found in practice in pockets of services or programs;

- Over time many theories become diluted or corrupted in their use. This can lead to perversions of what the original theory intended;

- Practitioners may be unconscious of the theoretical frameworks they are a using in practice but have adopted interventions as required;

- Many disability services practices are heavily driven by policy and legislative requirements which may be contrary to preferred theoretical approaches;

- Supporting people with disabilities can be complex whereby one single universal theory cannot adequately explain and guide actions. Usually, practitioners need to draw upon a range of theories needed to inform their practice; and

- There are differences between ideologies and theories yet often these are conflated which can lead to distortions.

3.

THE FRAGMENTED LANDSCAPE OF WORKFORCE DEVELOPMENT[2]

Introduction

The creation of a national agency to create, develop and then manage a national scheme such as the NDIS, and the changes the NDIS brought about in service delivery, had an immediate and direct impact on the disability sector workforce. (For further details about the current workforce and its characteristics, see Appendix F).

Prior to the creation of the NDIS, the sector included a mix of private for profit; NGOs; state government and self-employed 'entrepreneur professionals' with an emphasis on state government service delivery. This mix has now changed dramatically, and it is useful to begin this discussion with a brief overview of the landscape prior to the NDIS legislation being enacted in 2013.

In the lead up to the 1980s, the workforce can be seen to be a familiar medical model approach. This meant not just professional medical staff (doctors, nurses, allied health professionals) but also orderlies, porters, kitchen staff, gardeners, drivers etc. As Section I describes, the institution at Aradale in Victoria in the late 1980s had over 455 staff for some 245 residents (2019, 8). This imbalance (with 2 staff per resident) was not unusual at the time. For many small communities such as Ararat, the institution was a major employer and economic driver.

From the 1990s, as changes began to be more rapid, the workforce also changed, and as group homes became common, the staff needed became less 'medically oriented', and more focused on providing care 'in the home'. This transition period needs to be viewed as being one where the workforce was being changed both 'internally' and 'externally'. The 'external' influences being the increased role of formal tertiary education: as allied health, education, and nursing all entered university curricula.

As a result, we would suggest that the workforce can be seen to have 'split' into the 'in home care' group and the 'out of home' care group. 'Out of home' would include the professionals that were still involved in people's lives. These were often employed centrally – say, for example, as those by The Authority for Intellectually Handicapped People (AIH), a state government agency in Western Australia, which had 4,500 clients in 1992, and a budget of $58.6m. It had 1,650 staff and provided the following services – largely 'in house': early intervention; school support; residential and sheltered employment; professional and specialist health services (AIH Irrabeena, 1990, 8). It also managed group homes, as well as providing support and policy guidance to statebased NGOs. Western Australia offers a clear example of the direct involvement of the state government and the more 'hands off' federal role at this time.

Workforce and training

As models of care and support for people with disabilities influenced by the theoretical developments (see Section II above) changed over time, so did the workforce employed in services and organisations. This section provides an overview of the range of staff and professions who worked in these services and the training and education provided. These are summarised in Table 3 following.

This is not an exhaustive or complete account. It is beyond the scope of this monograph to provide an exhaustive coverage of all training, as historically much of this was statebased in line with the various authorities responsible for services. Later, as universities and colleges provided diplomas and degrees for many occupational groups, these also varied in nomenclature and, to some extent, content. However, we have endeavoured to summarise the key roles and corresponding education and training they received.

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2   Productivity Commission (2011) *Disability Care and Support*. Inquiry Report Vol. 1. 54. 31 July. Canberra. p. 2.

TABLE 3. DISABILITY THEORY INFLUENCES ON AUSTRALIAN WORKFORCE PLANNING

CRITICAL DECADE(S)	TITLE OF THEORY	DISCIPLINES	TRAINING	EDUCATION	NOTES
	Medical Model	Nursing	In-house		Focussed largely on psychiatric models
		Medicine		Universities	Psychopedic nursing NZ
1950s	Normalisation Principle (NP)				Tended to remain largely European centred around Denmark
	Symbolic Interactionism (SI)	Sociology		Universities	Initially focus on Institutions for people with disabilities, then became more widely discussed.
		Education			
1960s	Normalisation				Tended to remain in-house (Sweden) until taken up by Wolfensberger in his 1972 publication (in English).
1970	Ecological Systems Theory	Child Educators	In-house		Child development theory
		Pediatricians		Universities	
1970s/1972	Normalisation	Social Work	Universities		Some limited special education courses
1980s/1983	Social Role Valorisation (SRV)	Occ.Therapy	Vocational Education		
		Psychology			
1980s/1986	Person Centred Planning (PCP)	Allied Health			Specialised training associated with SRV model from USA. Introduced by Federal Government and taken up by NGOs nationally.
		Speech Therapy			
		Residential care workers	Qld. government. Diplomas TAFE		

Codes:

█ Individualised Theories;   █ Structuralised Theories;   █ Combination of Individual/Structural; Other

CRITICAL DECADE(S)	TITLE OF THEORY	DISCIPLINES TRAINING	EDUCATION	NOTES
1980s	Social Model from Lived Experience	Sociology Social Psychology Allied Health disciplines Nursing Local Area Coordinators	Universities	Nursing became part of University education by the early 1990s.
1982	Minority Group Model			
1990s	Marxist Approach to Social Model		Universities In House	WA Qld. & NSW governments arranged in house training.
	Feminist Approach to Social Model			
Early 2000s		Bachelor of Human Services – became more common. Eg Griffith University.		
2010 on wards	Neo-Liberalism/ Marketisation	Contraction of University degrees Contraction of TAFE courses		'Repackaging' of degree courses more common

Codes:

■ Individualised Theories; ■ Structuralised Theories; ■ Combination of Individual/Structural; Other

WORKERS IN INSTITUTIONS

Large institutions or asylums provided for all life needs on one site. As well as medical and nursing staff, they employed cooks, kitchen hands, cleaners, gardeners, maintenance people, laundry workers, and office staff.

Medical staff

These facilities were headed by a medical superintendent, medically qualified and usually a government employee. There may have been other medical doctors who visited or more junior residents. Many of these earlier medical practitioners specialised in psychiatry, which included intellectual disability within the mental health system. In some institutional settings, allied health staff may have been employed offering physiotherapy, occupational therapy, speech pathology and vocational training.

Nurses

The day-to-day care and supervision was provided by nursing staff, organised hierarchically and headed by a matron or senior nurse. These were typically larger estates or campuses on the outskirts of major centres drawing much of the workforce from the surrounding area, thus providing the main industry of the town.

Nursing staff were hospital trained up until the 1980s and covered general registered nurses and enrolled or nursing aides who had less training. In some jurisdictions, a specialist mental health/intellectual disability training was offered. In New Zealand, for example, three-year training in psychopedic nursing was offered from 1961 until the early 1980s (Burgess, 1982).

CARE AND SUPPORT – COMMUNITY SETTINGS

Residential care workers

In some jurisdictions, there was a shift away from the medical model of care in institutions to residential care. In Queensland, for example, this shift occurred from the late 1970s to the early 1980s in state government facilities. This change was prompted by staff influenced by Normalisation and lobbied for community-like settings and activities. In Western Australia, the focus shifted to a training model where people with disability were encouraged and supported to learn new skills through individualised plans, albeit in congregated and segregated settings. This required a workforce oriented to training rather than nursing care.

Nursing staff were gradually replaced by new Residential Care Workers trained in-house until Colleges of Advanced Education began offering diploma courses. These were two to three-year programs that were oriented to training and supported lives more oriented to the normal rhythms of the day/week etc. (based on the Normalisation principle) than the medical model. While these staff worked within institutional settings for many years, they also formed the workforce of group homes and community care as deinstitutionalisation proceeded.

Towards an army of Personal Support Workers

As institutions closed or diminished, increasing numbers of people with disability were living in community settings. Many were accommodated in group homes either run by the state or NGOs, and more families were able to keep their children at home with support. Over the ensuing decades, the role of the support worker shifted from state employed officers to staff within service providers to smaller brokerage operators and solo private practitioners.

This workforce assumed many names and many roles that included:

- Residential care officer
- Residential care worker
- Residential support worker
- Community support worker
- Personal care worker
- Personal care assistant
- Personal support worker
- Support worker
- Direct care worker
- Carer
- Disability support worker

Here we adopt the term 'personal support' worker to include all of the above.

Personal support workers were employed to be with a person in their (usually, group) home and could provide personal care (e.g. bathing, toileting, grooming), domestic assistance (cooking, cleaning, shopping), social support (outings, community connection). They could also be required to plan and implement activities and support programs under the direction of other staff.

The training of support workers has changed considerably over time. Initially trained within government institutions, support workers now have options to undertake TAFE training to Certificate 3 or 4 level, a diploma in community services (or similar) usually 18 months to two years with a TAFE or private provider or a degree in human services, community welfare for three years. Some employers do not require any formal qualifications, especially when employed directly by the person with a disability or family.

Support workers form the largest workgroup in the disability sector. This workforce is growing exponentially and was forecast to constitute 71% of newly created jobs in the disability workforce under the NDIS (Commonwealth Department of Social Services, 2019).

PSYCHOLOGY & BEHAVIOUR SUPPORT

Psychology has had a long-standing role in the disability field. Alongside medicine, psychology became a core profession in the diagnosis of what was then termed mental retardation, through the development of psychometric testing, the development of interventions to modify behaviour and develop learning skills.

Psychologists were the earliest profession outside medicine and nursing to be engaged in institutional settings. This discipline was to play an important part in dealing with complex and challenging behaviour, a significant problem within institutions and community settings. People with intellectual disability have a higher incidence of challenging behaviour (Emerson & Einfield, 2011) that, while arguably exacerbated by brutal treatment in institutions, continues to be of concern in the support and management of clients. Behaviour support became a large component of service provision and hence required a suitably qualified workforce.

The expansion of behaviour support was principally the domain of psychologists who assumed practice leadership, but the models developed have required many support staff to implement them. Disability service providers have provided increased behaviour support services for several years, especially as jurisdictions mandated them as a requirement to reduce restrictive practices. Service providers have increasingly had problems recruiting appropriate support staff (National Disability Services, 2017).

The workforce issues in providing positive behaviour support have expanded with the rollout of the NDIS. Organisations and practitioners will need to acquire specified capabilities to improve outcomes incrementally over time. The NDIS Quality and Safeguards Commission (2019) has outlined a capability framework which, while not specifying formal qualifications, will require specific training for some staff.

ALLIED HEALTH

Allied health encompasses a broad group of trained professionals who provide health-related services in rehabilitation, dietary and nutrition, chronic disease management. Definitions vary across different countries. However, this group typically refers to a range of health professionals who use scientific principles and evidence-based practice in the identification, management and prevention of disorders.

Allied health includes the professions of physiotherapy, occupational and speech therapy, podiatry, dietetics, optometry, rehabilitation counselling, radiography and others. In Australia, the peak body, Allied Health Professions Australia, includes 19 peak membership bodies and 10 affiliates. All are university qualified, often requiring post-graduate level degrees for membership and/or registration. (See AHPA, https://ahpa.com.au/about-ahpa/).

In the disability sector, from the 1970s, allied health professions were involved in institutional settings and in rehabilitation units to provide physiotherapy and speech therapy for people with specific mobility or speech difficulties. Occupational therapists were also employed to develop activities for daily living and work skills.

Many were employed directly by the Commonwealth Government and worked in the Commonwealth Rehabilitation Service.

Allied health professionals were engaged in early childhood settings to assess children with developmental delay, intellectual and learning disabilities. Non-government organisations devoted to care and support for children and adults with cerebral palsy, spina bifida, intellectual disability, vision and other impairments also employed teams of therapists who were central to assessment and intervention regimes.

Similarly, educational settings such as special schools, education support units also employed allied health professionals, many as government employees. Allied health still forms a large part of the hospital and health workforce, in the rehabilitation of spinal and brain injuries, psychiatric units and in the transition from hospital to community.

Over time, there has been a shift of many therapy services to private practice, which has paralleled the shift to community living and individualised programs and funding. This is discussed later in the section on the NDIS workforce.

In Appendix F, we offer a brief outline of some of the key positions currently within the sector as outlined by the NDIA.

Is the future personal care?

This brief analysis highlights that while the workforce may appear to have the same characteristics in the present as it did in the past, nevertheless, the changes to legislation, both federally and state-based, have directly impacted the *balance* within the sector. This balance is now 'tipped' towards personal care/personal support workers. This category was unknown prior to these major changes. It now forms the foundational basis of the sector and is likely to continue to grow exponentially.

A further change work noting is the shift in both education and training within the sector. As we have highlighted, the transition from diplomas to degrees from TAFE/CAEs to Universities, has meant a more technical, more professional workforce. This has come at a price however, as the tertiary courses are focused primarily on 'getting jobs' and courses in values clarification, theoretical frameworks or philosophical appreciations play a very small part, if at all. These highly educated career-focused professionals are less likely to be interested in being employed as personal care workers.

While the allied health professions are still common throughout the sector, they are more than likely to be 'private for profit' employed, either as single entrepreneurs or within a for-profit agency. The Commonwealth no longer employs such individuals as they were once within the old Commonwealth Rehabilitation Services (CRS).

Such training as is done in the sector is left to 'on the job'. However, where this often falls short is the NDIS does not necessarily provide funds for training (taking people off their jobs to provide intense activities). Training may be 'on the job' but rarely is offered in the way the WA Government did in the early 1990s, with a two-week intensive live-in program which focused on SRV principles for Local Area Coordinators (see Section I). In today's transactional environment, this would tend to be viewed as indulgent.

The exponential growth of the direct care (personal care) workforce has resulted in a tightening or shortening of qualifications. As demand outstrips supply, it is often the training of such individuals that falls short. In some case, the pressure to employ is such that no training is required. Learning 'on the job' has some immediate impacts on vulnerable people, as does the lack of any detailed enquiries into previous employment histories.

Furthermore, to ensure that no time is wasted on the job, training can now be accessed as a private for-profit activity, particularly online. Diplomas can be granted without even needing to be 'hands on'. Such courses have few standards, little monitoring and, we would argue, can be compared with some of the more unreliable 'English-language' courses being offered in the early 1990s.

Some new roles within the new 'fragmented' workforce have emerged over time. The WA model of Local Area Coordinator is one such example. While the term continues to be used within the NDIS system, the NDIA LAC is not the same as the WA LAC, either in training, in management or in activity. Other new roles have emerged by transitioning to a behaviour support model, particularly within those agencies supporting the 'hard to service' people. This latter group may not have benefited at all from the transition in workforce characteristics, but that analysis has yet to be undertaken.

The NDIS: markets & models of support

The creation of the NDIS had an immediate impact on the then-existing workforce. As the sector came to grips with the extensive changes, people with a disability, their families and their advocates focused on the most important aspect of the new system to them: the freedom to 'choose' their care. This freedom to choose was based on the principle of human rights and on the theoretical approaches associated with 'person-centredness', as a driver for change.

Almost immediately, it became obvious there were not enough people in the system to provide the kind of choices demanded. These tended not to be the allied health/professionals described above, but rather personal care workers. One estimate was that demand would mean an additional 90,000 EFT positions in the next five years, far exceeding the projected growth for the NBN or the Snowy Hydro Scheme (Commonwealth Department Social Services, 2019).

This growth in workforce of people with limited training and education opportunities is also predicated on a vibrant TAFE/VET sector. However, this sector has suffered major funding cuts in past years, and its transition to an on-line learning platform is slower than that of the tertiary sector. The tertiary sector is not set up to take up this 'slack' and, as a result, we anticipate that increasing numbers of personal care workers will have little or no training at the time of employment. It remains to be seen whether agencies will be able to access funding to offer them training.

The transition to a market-model insurance-based system of disability support has also seen a growth in private-for-profit agencies. Where once the sector was largely within the purview of state governments, charitable organisations and parent-managed services, the private-for-profit (offering a 'choice' within the 'market') has now stepped in. These agencies are more likely to be focused on offering allied health services, such as speech therapy, occupational therapy and counselling. They may be visiting services to people's homes or may be offered in a central location. They are funded through the complex web of finances associated with personal choice. They are registered with the NDIA, and that agency 'manages' their standards and monitoring. They may also be Partners in the Community (PITC) (see further below).

The NDIA itself is a new player in the fragmented workforce model the NDIS now offers. As an agency that reports to the Department of Social Services, it now has its own Minister and a staff of nearly 3,000 nationally.

It should be noted the 3,000 figure is 'capped' by legislation, but this is currently being challenged. It should also be noted the NDIA has utilised 2,000 labour hire contractors over a two-year period. It is not possible from the data provided in the public annual reports to identify the characteristics of this consultant workforce, but one assumption may be that it was employed to set up the highly complicated and expensive computer system that underpins the NDIS[3].

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3 At the time of publishing this Monograph, data emerged that more than a quarter of the NDIA total workforce are labour hire staff: some 1,497 temporary staff out of a total of 3,169 (Sadler, 2021).

The data also highlights the Partners in the Community (PITC) workforce that totals 5,288. This PITC workforce is both private for-profit providers as well as NGO agencies. The PITC model is a new aspect of the NDIS.

The central component of the NDIS is the individual 'plan'. This plan once approved (by the NDIA) is then funded. The costs for all services are drawn from this fund. Developing such a plan has become a complex and sophisticated new aspect of the fragmented workforce. Planners are more likely to be individuals with market/financial skills – the first time such a component can be visible within the disability sector. These planners are highly likely to be within the private-for-profit aspect of the workforce, or one of many professionals that can be accessed through one agency. They offer 'accounting' services. Of interest would be to evaluate such advice as to its efficacy and efficiency. Planners also must register with the NDIA. It is noted that pricing of services has been contentious, placing pressure on relationship-building so central to high quality care (Cortes et al, 2018).

The NDIS has also changed some existing workforce characteristics. One is that of the Local Area Coordinator. In the WA approach, these front-line service providers were highly trained, usually also university graduates, whose purview was restricted geographically, and whose relationship with their clients was to act as a mediator between the service system and the individual and to work as creatively as possible to ensure needs were met. WA LACs were allotted a small 'fund' which they could use on behalf of the client, without having to resort to grants.

In the case of the NDIA LAC, this individual steps in once the individual's 'plan' has been agreed to and funded. According to one agency, the NDIA LAC

> … helps you understand your plan …' but does not 'provide case management support'. There is another individual called a 'Support Coordinator' who 'coordinates services … and … develops the capacity and resilience of your support network … **(Barkuma, 2020).**

Both individuals have to be funded through the same complex individual financial arrangements.

While the NDIS offers a national scheme there have been parts of Australia which have had less opportunity for access to it since its inception This has been given the economic term of 'thin markets' and was discussed in the *History* in some detail. The neo-liberal marketization of the disability sector has resulted in a congregation of services back to highly populated areas. If you live in a city, you are much more likely to be able to have a 'choice' than if you live in a rural location, or remotely. The cost of offering services in remote areas has yet to be fully appreciated. The early pilots of the NDIS in 2013 included a remote location in the Northern Territory. To scale up that undertaking nationally will require not only increased funding, but also political will.

Finally, one aspect of the NDIS workforce system that is not possible to quantify is the employment of family members or friends as personal care workers. This may be a direct response to the 'thin market' dilemma discussed above, or it may be that it is a direct and personal choice. It is unlikely these individuals have the training, although they may have years of direct experience. It is not possible from public data made available by the NDIA to even guesstimate this aspect of the workforce, but we would expect it to be large and growing.

4.

THE DISABILITY ROYAL COMMISSION: FOUR DECADES IN THE MAKING

Introduction

The first part of this section comprises of analysis through a case study design of several critical reports which are presented in a chronological order. The framework analysing the case studies undertaken here was developed focusing on the following pertinent questions:

- Why was this report chosen?

- What were the terms of reference of the review as reported?

- What was its 'significant impact'.

- What was the scope (i.e. national/state) of the review.

- What were the critical precursors or the pathways that led to the review being commissioned?

- What was the level of authority of person/persons undertaking/conducting review?

- What were their recommendations?

- Were these adopted? How? Where? When?

- What were the changes that the review/report instigated – if any

- Have these changes held over time?

- What is the current status of the issue/s under review?

The second part of this section is an analysis of media reports, government legislation, reports and inquiries that can be seen, in hindsight, to have contributed to the establishment of the DRC as follows:

- A chronology of the lead up to the establishment of the DRC and where the pressures for such a Commission can be identified was prepared;

- Role of media.

It should be noted that while the DRC may now be seen as 'inevitable' given the weight of reportage and public attention documented here, nevertheless, its announcement in March of 2019 was a surprise to many, as up to that point, the Federal Government had indicated that a Royal Commission was not on their agenda.

The announcement and funding in the 2019–2020 budget for the Commission and support for those participating was welcomed overall. Twelve months later, at the time of writing, its breadth and potential are still yet to be realised. The current pandemic has interrupted proceedings somewhat though it is hoped these will continue soon.

Context

In Section I of this monograph, we developed a timeline from 1981 to the present day, which includes the many reports (Federal and State and NGO) that the sector has experienced over this period.

From a Federal Government perspective, this highlights how, with each change of Government, the sector became the subject of further investigations.

Over time, and with the adoption of a neo-liberal approach to 'welfare' with a shift to a 'from welfare to work' approach, such investigations were undertaken by authorities that had previously not been involved with disability services such as, for example, the Productivity Commission.

Our analysis also shows how the State governments followed the Federal lead, and began undertaking state-based reviews, often as a result of media pressure or parent advocacy.

Reviews and reports with long term impacts

We have identified the following reviews that have had long-term impact on the sector for more detailed analysis here:

- Two federal reviews, one undertaken by the Coalition government in the early 1980s established a foundation for the 'decade of change' to come; one undertaken by the newly elected Labor government in the mid-1980s then set the scene for the next four decades;

- A major review conducted by the Queensland Government following complaints of abuse staff harassment undertaken in 1995;

- A further review of a Queensland facility which ultimately led to changes in legislation and the establishment of quality standards for disability services;

- A review of the NSW Disability Framework by the NSW Law Reform Commission in 1998 is offered as an example of recommendations *not* adopted – and why; and

- Finally, a review conducted by the Federal Department of Families, Housing, Community Services and Indigenous Affairs in 2009 which proposed a new National Disability Strategy and new funding mechanisms, leading directly to the establishment of the NDIS.

CASE STUDY #1:

House of Representatives Standing Committee on Expenditure Inquiry into Home Care and Accommodation for the Aged – Review Sub-Committee. 'In a Home or At Home' Accommodation and Home Care for the Aged. Chair: L (Leo) B McLeay MP (ALP). 28th October 1982.

Why was this review/report chosen?

This Review, which commenced in December 1980 post the Federal Election, promoted the concept of 'new Federalism' as a method by which the Commonwealth became more directly involved in developing policies regarding targeted services to the aged (and then, by extension, to people with disabilities more broadly). It particularly focused on transferring financial support from institutional to community-based care.

The Review, while established by the Fraser Coalition Government, more directly then led to the major policy changes enacted by the Hawke Labor Government as elected in 1983 (see further below).

While the McLeay Review was focused on aged care programs, its recommendations heavily influenced the subsequent review of disability programs, and the establishment of a 'whole of issue' policy and program response within the previously fragmented Commonwealth programs.

What were the terms of reference of the review as reported?

While no specific terms of reference were identified by the Expenditure Review Committee, the sub-committee had the broad remit to 'conduct an inquiry into Accommodation and Home Care Programs for the Aged' (McLeay, 1982, p.183).

What was its 'significant impact'?

The Review Report was tabled in October 1982, a matter of some months before the March 1983 Federal Election. It was, therefore, a critical piece of national research and evaluation that directly led to the new Labor Government's policies and programs post-1983.

Because the Review Committee was bipartisan, and because the sector had for many years been, if not neglected, in a state of *statis* regarding policies and programs, it was a critical lever in the changes brought about in the subsequent decade.

Importantly, the Review also began to question the 'institutionalised' nature of care to vulnerable people, and particularly to those who were not 'sick'. This opened up the debate followed up in the Handicapped Programs Review (1984/5) discussed further below.

What was the scope (i.e. national/state) of the review?

The Committee visited all states; received over 220 submissions and 125 witnesses. It also visited many facilities. A criticism at the time was that the Review did not directly seek the input of general practitioners (Hemer, 1983, 3).

What were the critical precursors or the pathway that led to the Review being commissioned?

There had been a general public disquiet about service delivery, particularly as the generation that had survived the Depression and WWII were now reaching their retirement ages. The aged care sector was largely based on what the Review termed 'a voluntary principle': that is, it relied heavily on charitable organisations – including churches. In 1975 the Social Welfare Commission reported that: '… care for the aged *and the handicapped* is haphazard, expensive and inadequate' (McLeay, 1982, p.3 italics inserted).

Hemer argues that people were '… increasingly questioning the inadequacies, expense and mismatch of services' (1983, 3).

It should be noted that while the Review was underway, the Fraser Coalition Government did little or nothing to make any changes, instead arguing it was '… waiting for the report …' (1983, 3).

What was the level of authority of person/persons undertaking/conducting review?

The Review was bipartisan, and the sub-committee that undertook the Review consisted of members from three major parties, chaired by Leo McLeay MP (ALP). Mr McLeay was Deputy Chair of the Parliamentary Committee and later became Speaker of the House of Representatives. The Review took two years and was assisted by a secretariat.

Key recommendations.

The Review recommended the reduction of current anomalies in the financial arrangements between the Commonwealth and State governments; the Review also made recommendations for transfer of responsibility for the administration, delivery and financing of accommodation and home care programs to the States (McLeay, 1982, ix).

The Review foreshadowed the development of funding for respite care (McLeay, 1982, recommendation 4.15, xiii).

This approach subsequently led directly to future recommendations made in the mid-1980s.

Were these adopted? How? Where? When?

The Parliamentary Committee (now chaired by Leo McLeay) developed a follow up Report in October 1984, eighteen months after the Federal Election that established the Hawke Labor Government.

Subsequently, the new Government established a Working Party on Aged Care Policies, which was chaired by the Social Welfare Policy Secretariat and included membership from various relevant Departments (note the fragmented nature of programs at this point, as mentioned above), including that of the Prime Minister and Cabinet.

At the time of preparing the Follow-Up Report, 'no formal action' regarding the McLeay Report itself had been taken. The Report also stated that:

> 1.15 Concern has been indicated by the States on the need to know the Commonwealth's position so as to enable their own planning to proceed, in an orderly manner **(Parliamentary Paper 292/1984, 2).**

What were the changes that the review/report instigated – if any?

In 1985, the Hawke Government established a Department of Community Services (Minister, Senator Don Grimes) (which also included programs for people with disabilities see further below); as well as an Office for the Aged and undertook a '… complete overhaul of Federal funding for nursing homes …' (Le Guen, 1993, p. 12). This had direct and immediate impact on funding, standards and monitoring and ongoing reporting to the Federal government.

In July 1985, the *Nursing Homes and Hostels Programs Review* was established, with a subsequent major shift away from residential towards community-based care. It based much of its direction on the recommendations made in the McLeay Report (Le Guen, 1993, 13). These recommendations directly changed existing policies and procedures and had a significant impact on service delivery and by extension, on workforce participation.

Have these changes held over time?

The critical recommendations associated with the McLeay Report can be seen as having stood the 'test of time'. The Commonwealth funding into aged care services remains primarily at the level of community-based care, rather than expanding nursing homes.

The McLeay Report can be seen to have also led directly to the establishment of 'one Minister' which was also adopted for the disability sector by the Federal Government (same Minister initially) and the McLeay review can also be seen as a principal precursor to the subsequent establishment of the Home and Community Care (HACC) program.

What is the current status of the issue/s under review?

The sector, in line with the history of disability services, has become one which is now dominated by 'privatforprofit' nursing and aged care accommodation services.

CASE STUDY #2.

New Directions: Report of the Handicapped Programs Review (HPR Report). Tabled in Federal Parliament: 30 May 1985.

Why was this report chosen?

First,

it laid the foundations for the legislation that followed: the *Commonwealth Disability Services Act (DSA) 1986*, which dramatically changed the sector's landscape, and still influences it four decades on;

Second,

it was the first Federal review of the sector that called for, and then took into account, very seriously, the contribution of people with disabilities, their families and advocates;

Third,

it was a national review, over-riding the 'voices' of state governments in its reach beyond their jurisdictions, to the sector 'on the ground' – signaling that the Commonwealth was taking leadership;

Finally

the Principles and Objectives, which underpinned the subsequent legislation, were developed as a result of this review's findings and were themselves based on international standards, specifically, the United Nations.

These Principles and Objectives were 'gazetted' that is, they were brought ' … within the ambit of the legislation … [to] … form the basic yardstick for the development of the [future] program … (Grimes, 1985a, *Second Reading Speech*, Senate 12 November.

What were the terms of reference of the review as reported?

The seven areas of examination by the Review's terms of reference were guided by the 'principle of the least restrictive alternative'[4].

They focused on effectiveness, needs, suitability, adequacy, efficacy, changes needed and measure of accountability (see Appendix, *HPR Report*, 1985, 136).

> The terms of reference were deliberately made very broad to allow for as wide an expression of views as possible, and by not circulating submission guidelines it was intended that people be free of the usually formal procedures of a government review … (*HPR Report*, 1985, 5).

What was its 'significant impact/s'?

The process the review adopted signaled the far-reaching changes that the Commonwealth Government would be proposing for the sector.

By immediately describing people who were being provided services within the national programs as 'consumers' (rather than 'patients', 'inmates' or many other more derogatory descriptors) a clear signal was made that there was to be 'choice' within a 'market approach' as the following quotation highlights:

The review process adopted was quite unlike most public inquiries undertaken by the Commonwealth Government [as] the major focus of the Review was to establish appropriate long-term goals and develop program options based on the aspirations of consumers. This consumer outcomes approach is a most important development and *will form the basis of new programs* for people with disabilities to be established by the Commonwealth (see: DARU http://www.daru.org.au/resource/new-directions-report-of-the-handicapped-programs-review Retrieved, 21 March, 2020 (italics inserted).

Unlike many other reviews of the sector, either before or since (see Section I) this review purposefully led directly to new, groundbreaking legislation.

What was the scope (i.e. national/state) of the review?

The review's scope was national and the new Labor Government made it clear that it would be taking this opportunity to fundamentally alter the foundations of the sector towards a 'person-centred approach' that had, for too long in its opinion, been dominated by what could be better termed an 'institution-centred/or 'workforce centred' approach.

The review's scope was based on an 'outcomes' perspective for those service users. This meant that the benefits for people with disabilities was to be paramount, not the maintenance of the 'bricks and mortar' of institutions (Cocks & Stehlik, 1996, 25).

> Close to 1700 submissions were received and over 5000 people participated in an unprecedented program of open public consultation, covering sixty-five cities and provincial centres throughout Australia. … Review staff presented papers or gave oral reports to numerous conferences, seminars and workshops in the past twelve months, attended by over 3500 people …
> (Grimes, *New Directions*, 1985b, p iii).

In addition, and importantly, Senator Grimes also personally wrote '… directly to 900 organisations and individuals inviting submissions …' (1985b, 5).

What were the critical precursors or the pathway that led to the review being commissioned?

During the lead up to the International Year of Disabled Persons (IYDP) in 1981 (see Section I), Tasmanian Senator Don Grimes GP, then shadow Minister for Social Security, commissioned and released two important Discussion Papers.

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4   Chih-Yuan Lin (2003) offers a brief history of the philosophical underpinnings of this principle.

The first, *Physically Disabled People in Australia: A Discussion of Present Provisions and Directions for Future Policies (1980)* and the second: *A World in Which Slowness is Suspect. Intellectual Handicap in Australia. Background and Areas for Action (1981)*[5].

These documents were broadly circulated at the time and deliberately targeted to '… reach a wide audience, to gain interest and understanding; and to examine the areas in most need of attention …' also recognised the challenges that any future changes would face:

> The problems are so deep-seated, the changes required so radical, and the potential resistance so strong that, at best, 1981 can only be the beginning … **(Boorer/Grimes, 1981, i).**

The Boorer reports directly influenced the thinking of the new Labor Government, and more specifically the terms of reference of the Handicapped Programs Review. One of the more prescient conclusions was that:

> For leaders in the field of [disability] it is no longer a question of whether to phase out the large institutions, but of how to organize the phase out. The problems are two-fold: firstly, governments have to be won over, because, by erecting buildings they are seen to be doing something, whereas a community service is essentially invisible. Secondly, extra resources must be found so that community services can be developed before the process of discharging people begins … **(Boorer/Grimes, 1981, 20).**

At the time of writing these Discussion Papers, the McLeay Review (see above) was underway. In the lead up to, and following IYDP, there had also been several high-profile state-based reviews, the findings of which

the Commonwealth only too acutely aware. For example, in New South Wales, the Richmond Review[6] (1983) '… recommended closure of many large institutions for both people with disabilities, and people with mental illness …' (Cocks & Stehlik, 1996, 23) and specifically recommended that this closure of institutions be followed by a transition to community-based models of accommodation.

> In September 1983, six months after the election of the Hawke Labor Government the Handicapped Programs Review was initiated by Senator Grimes, as the then Minister for Social Security. It was called 'Handicapped Programs' because, at that time, current Commonwealth programs and policies were underpinned by the *Handicapped Persons Assistance Act 1974.*

What was the level of authority of person/persons undertaking/conducting review?

The Review was conducted 'in house' by officers of the newly created Department of Community Services (created in December 1984 following a second Federal Election) that Senator Grimes now headed (see also McLeay discussion above).

As Minister, Senator Grimes had previously established the Disability Advisory Council, the first of its kind, and this, as well as international expertise (for example, Professor Tom Bellamy[7] of the University of Oregon), informed the Review Secretariat, led by Brian Luby. Luby was a senior member of the Executive Service of the Department with long experience in the public service, and was well known within the networks of the sector. Such networks gave the review immediate access, and keeping it 'in house' meant having direct access to Departmental expertise and data sources.

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5   These Discussion Papers, while 'authored' by Senator Grimes, were researched and written by Ms Jan Boorer, his adviser and a woman with lived experience of disability.

6   The 1983 Inquiry into Health Services for the Psychiatrically Ill and Intellectually Disabled was led by David Richmond (see https://nswmentalhealthcommission.com.au/richmond-report Retrieved 21st March, 2020).

7   'In September 1984, the Review took advantage of his participation in a conference in New Zealand to invite Professor Tom Bellamy to be a special consultant for a short period. Professor Bellamy, who is Director of the Specialised Training Program (STP), College of Education, University of Oregon, USA, provided many insights and perspectives on consumer outcomes which have assisted in the development of this report' (HPR Report, 1985, p.5). Tom Bellamy had developed STP (Specialized Training Program) promoting the idea that the '… capabilities of individuals could be greatly enhanced by the competency of their employment specialists' (US Senate, 2013, p. 35). This also highlights where the review's focus was placed.

By December 1984 the review had changed from its original purview in September 1983 to a ' … review of all Commonwealth programs by the Minister himself, not by a committee reporting to the Minister …' (HPR Report, 1985, 4). In other words, the 'buck' stopped with the Minister.

What were their recommendations?

The Review report was shaped around the issues raised during the consultation process. It was therefore focused on those aspects of quality of life for people with disabilities that they themselves had highlighted. The report was written in such a way as to ensure that those reading it understood that it was based on evidence gathered through the consultation process. The discussion around each section, drawing on that evidence, then concluded with recommendations[8].

The Report made recommendations in areas of accommodation; home and community based support (which led to the establishment of HACC); respite care; employment; education; training; rehabilitation (then primarily a Commonwealth responsibility); income support; transport; aids and appliances; sport, recreation and leisure (see Table 4 below).

In the interests of brevity, here we have taken two particular recommendations and highlighted how these then 'played out'. The first 'accommodation' and the second, 'income support'.

Accommodation:

The discussion in this section had reflected on the fragmented nature of the sector at that time, and the first recommendation made was that all existing Commonwealth funded programs be 'rationalised'.

There was also a recommendation to provide recurrent funding for 'community-based accommodation' specifically 'capital funding channeled through State Housing Commissions' (1985, 27–28). Low interest loans were flagged to enable entry into open rental housing markets.

Critically, this section also recommended that the new DSA legislation specifically fund respite services and a deinstitutionalisation demonstration program (more on this further below).

Income support:

At the time of the review and the release of the *New Directions* report, the Commonwealth had 'split' service delivery from income maintenance by creating a new Department in December 1984. This 'split' had far reaching consequences for the sector. Most importantly, it meant that Senator Grimes was no longer responsible for income maintenance for either the aged or those people with a disability. His new department (Community Services) was specifically created to ensure high quality *service* delivery as well as to '… coordinate all Government social security, community services and health and welfare *policies* … (Hawke, 1984, 5 italics inserted). An Office of Disability was also created. The Department of Social Security (under Brian Howe) retained the income maintenance (i.e. Pensions/Benefits) responsibility. In short, this meant that the Minister who had taken overall responsibility for the review, could not then be responsible for ensuring the safe passage of those recommendations regarding income support.

Were these adopted? How? Where? When?

The following table highlights the breadth of the 52 recommendations, and the themes reported on.

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8   For the first time, the Commonwealth employed a cartoonist – Simon Kneebone – to add immediacy and texture to the report itself. Kneebone was a psychologist who worked as a youth worker before becoming a cartoonist. He went on to illustrate much of the Commonwealth's subsequent publications in this period.

TABLE 4. NEW DIRECTIONS. REPORT OF THE HANDICAPPED PROGRAMS REVIEW, 1985. RECOMMENDATIONS

ISSUE	NUMBER OF RECOMMENDATION
Legislation	1, 2
Coordination	3
Funding	4, 5
Research & Development	6, 7, 8
Consultation	9
Human Rights	10
Accommodation	11, 12, 13
Home & Community Based Support	14, 15
Respite Care	16, 17
Employment	18, 19, 20, 21, 22, 23
Education	24, 25
Training	26
Rehabilitation	27
Income Support	28, 29, 30, 31, 32, 33
Transport	34, 35
Aids & Appliances	36
Sport, Recreation & Leisure	37
Information Services	38
Community Education	39
Access to Generic Services	40, 41, 42, 43
Prevention of Disability	46, 47, 48*, 49, 50, 51
Implementation [of the Report]	52

Accommodation – Recommendations 11, 12 and 13:

While there was general acceptance of the need to move to more community-based accommodation, nevertheless this transition was slow and often, painful. Those NGOs that had been providing institutionally based accommodation were particularly stressed about this transition which, for many of them, was 'too much, too quickly'. Many parents agreed with them, and it became a struggle for the Commonwealth to achieve the high aims of the review.

Some of this tension can be seen in a powerful speech by the then Minister (subsequent to Senator Grimes), Dr Neal Blewett to a conference in Melbourne in November 1988, some two years after the promulgation of the DSA when he argued that:

> We want service providers to accept that the more people they lose to outside employment or independent living the greater their individual and corporate achievement; that preventing or discouraging such transition is as damaging and destructive to service providers and their services as it is to the people they are ostensibly trying to help (1988, 4).

A summary of these changes and their impact was made by the Social Policy Group in the Parliamentary Library in 2008, which asked the question: have these [the Review/the Legislation] noble aspirations been realised? It concluded that:

> The balance of opinion suggests that they have not. Indeed, even the aspirations themselves are now in question. Some service providers and carers, for example, are concerned that government programs (both Commonwealth and State) are attempting to integrate into community-based accommodation and into open employment, people with severe or multiple disabilities for whom these are not realistic or even preferred options. They opposed the Commonwealth's proposed phasing out of sheltered workshops on these grounds in the early 1980s and some years later were successful in having the value of these organisations acknowledged by government.

> Furthermore, the move from large institutions and sheltered employment into community-based and mainstream services was not accompanied by a commensurate move of the financial resources essential to its successful implementation. The result has been that the quality of life of people moving into community settings has often deteriorated rather than improved. This is said to be particularly the case for people with more severe disabilities (Phillips, 2008, n.p.)

Income Support – Recommendations 28, 29, 30, 31, 32, 33

The creation of the Disability Support Pension in 1991 was a direct outcome of the review and the report and has 'stood the test of time'. Its passage through Parliament was lead by Brian Howe, previously Minister for Social Security, and later Minister for Community Services (and disability). The transition from an 'invalid' pension to a 'disability' pension also signaled a critical change in philosophy that, people with a disability were not 'sick' and should not, therefore, be treated as 'patients'.

The consolidation of the fragmented nature of previous support income was also largely realised, as was the somewhat 'vexed' issue of eligibility. However, the Social Policy Group concluded in 2008 that

> The rhetoric about the focus on individual consumers rings a little hollow in the face of recent findings (by the Baume Review [see *History*]) that 60% of the potentially eligible population had no access to any Commonwealth disability services. Among the 40% who did use Commonwealth services, the level and quality of services provided tended to be influenced by location and historically determined funding arrangements rather than by the needs of the person concerned. These were the very inequities which the Commonwealth Government set out to overcome in 1983 (Phillips, 2008, n.p.).

Perhaps with the clarity of hindsight, it would be fair to conclude that given that the breadth and scope of the review and the changes recommended in the subsequent report were so fundamental, that a 100% achievement on all recommendations was very ambitious. Nevertheless, the Commonwealth persisted in cajoling, encouraging and, sometimes, pressuring the sector to adopt the reforms over the next few years.

Funding of NGOs became dependent on change in practice, and the Commonwealth adopted a program of what were termed 'demonstration projects' which experimented '… with alternative disability support models of care and work, all via the non-government sector …' (Soldatic & Pini, 2012, p. 184). These demonstration projects were undertaken in each state, and were supported by the Department, and subsequently, evaluated. One such project was the

> … funding of the Hornsby Branch of the Challenge Foundation of NSW to close its hostel and move all residents to community-based accommodation. In 1987 its doors closed. Whilst some of the women who moved from there have since passed away, those remaining have continued to live successfully in the community … **(Van Dam, 2007, 2).**

In his Second Reading Speech, Senator Grimes made it very clear that future funding under the new legislation would be subject to 'upgrading and restructuring obligations' on behalf of those 'prescribed services' (i.e. NGOs receiving Commonwealth grants). Such obligations *not* being met would result in those NGOs no longer being funded beyond 30 June 1992 (Grimes, 1985a, 6). This set a deadline for transition arrangements, and also gave a timeframe for the necessary state government interventions. It also created a great deal of angst within the sector.

Also, of interest here, given the changes that impacted the sector following the election of the Liberal/Coalition Government in 1996, was Recommendation 48 that focuses on intellectual disability and is worth repeating in full at this point. It set up a proposal to enable advocacy to be an important platform in the Commonwealth leadership for the sector.

It is recommended that relevant Commonwealth and State Ministers:

- Provide finance for a range of citizen advocacy programs;
- Give support to self-help groups to develop self advocacy training programs and
- Consider the introduction of time limited and partial guardianship provisions under relevant legislation in all States and Territories (*HPR Report*, 1985, p. 133).

This recommendation also led to growth of positions as well as an increase in the role of the Public Guardian/Ombudsman offices in various States.

What were the changes that the review/report instigated?

Principally, the review and the *New Directions* report led directly to the development of a new, groundbreaking legislative response: the *Disability Services Act 1986 (DSA)*.

In Section 24 the report outlined this legislative reform and its components and importantly, the first recommendation set the foundation for this historic legislation. It recommended that:

> … the Commonwealth Government's role with respect to services for people with disabilities – [would] … involve a clear statement of philosophical direction, recognizing the focus on consumer outcomes within the legislation. Contribution to positive consumer outcomes will become the basis for policy initiatives, program development and evaluation (*HPR Report*, 1985, 100).

In this way, the Government signaled that it would be oversighting, monitoring, evaluating and funding programs that had 'positive consumer outcomes'. The determination of what this actually meant for those NGOs and state governments delivering such services would become the focus of subsequent Acts as well as of the Baume Review a decade later (Baume, 1995). This leadership would be underpinned by a 'clear statement of philosophical direction' that subsequently became the Principles and Objectives of the legislation (see above).

As the Section I highlights, the introduction of the *DSA 1986* began a process of growth in the NGO sector, and the creation of a number of advocacy organisations, such as, for example, Disabled People's International (Australia), which was supported by the receipt of a government grant (Soldatic & Pini, 2012, 184) at this time.

Have these changes held over time?

The Principles and Objectives that underpinned the *DSA 1986* were designed to encourage '… their use across all relevant programs and services for people with disabilities …' (Grimes, 1985a). They have achieved this aim in the decades since. They are still a component of the legislation. They are central to most of the NGOs in the sector and are regularly referred to in review and evaluation studies.

They, and the legislation itself, stand as a legacy of their champion: Senator Don Grimes. As Minister, he began the process of change a decade earlier, steered the review and the legislation through Parliament, and on his retirement in 1987, could look back with some pride as to this achievement. The struggles to achieve the high aims of the legislation and the review were then left to others to lead. He foreshadowed this in his Second Reading Speech as follows:

The Government has set the stage, and it will be up to all the players – Parliament, government, departments, service providers, people with disabilities, parents of people with disabilities and the community at large – to ensure that the spirit of the legislation is kept to the fore and acted upon. We have sought to establish a dynamic, responsible process which the community at large and all levels of government can use to meet the needs and aspirations of people with disabilities in positive and creative ways **(Grimes, 1985a, 8).**

While the 'consumer' focus remains central, in the years immediately following the introduction of the DSA, the growth in advocacy across the sector meant that, for the Commonwealth, service delivery often became a struggle between new models and old systems. Soldatic & Pini cogently argue that this advocacy was 'harnessed by the Hawke government' as a way to ensure that its planned 'restructure' across jurisdictions would be a success (2012, 185).

This in turn culminated in the establishment of five year administrative agreements between the Commonwealth and States and Territories (CSTDA) (see *History*) in which the Commonwealth maintained responsibility for income support and labour market programs, as well as shared responsibility for advocacy. This left accommodation services to the States and Territories. The focus on labour market programs also

…. reflected the growing prominence of neoliberalism and its attendant concern with re-regulating the nexus between the social security system and the labour market in that the aim was to move disabled people from welfare to employment…
(see Soldatic & Pini, 2012, 185).

In 1992, Brian Howe, Deputy Prime Minister and also Minister for Health, Housing & Community Services (which included disability services) introduced the *Disability Discrimination Act 1992* in part to ensure that discrimination in the workplace was not a barrier to open employment goals. The *DSA 1986* was also modified in 1994 with the introduction of the Commonwealth Disability Strategy (CDS) which 'was intended to encourage Australian Government departments to ensure equal access … in the development and delivery of policy, programs and services … (Phillips, 2008 n.p.).

What is the current status of the issue/s under review?

In the decade following the introduction of the DSA, there was remained an energy and enthusiasm in the sector that saw the introduction of various Federal and state Acts, the establishment of many NGOs supporting people with a disability, and the creation and adoption of alternate models of care, such as, for example, Local Area Coordination in Western Australia (*see Section I*). Many were both innovative and successful.

The disability sector responsibility remained within the inner cabinet during the period immediately after Senator Grimes' retirement, however his championing of reform and the review recommendations was missed. Subsequent Labor ministers continued to focus on 'welfare to work' (Dr Neal Blewett, Mr Brian Howe) (see Soldatic & Pini (2012) for a summary of these neo-liberal approaches) but as they became responsible for even larger portfolios, following the Hawke/Keating Ministries models of larger and more centralized Departments, disability reform became less front and centre. The Office of Disability, created with much fanfare in 1984, also became subsumed within this centralization.

The *DSA 1986* has itself undergone a number (at least five) major amendments since its first promulgation. It continues to stand however, and the Principles and Objectives remain.

CASE STUDY #3.

Care Independent Living Association, Bribie Island

Why was this report chosen?

The Federal House of Representatives Standing Committee on Legal & Constitutional Affairs conducted an Inquiry into Crime in the Community in 2002–2004.

While focused on crime and fear of crime nationally, the second volume of their report investigated several accounts of abuse in Queensland institutions. This report is an example of a Federal Inquiry investigating specific accounts of crimes against people with disability and had significant impact at a State level. It is also an inquiry that was **not** specifically about abuse and disability.

What were the terms of reference of the review as reported?

The inquiry investigated the extent and impact and fear of crime within the Australian community and effective measures for the Commonwealth in countering and preventing crime.

It was to consider but not be limited to:

(a) the types of crimes committed against Australians

(b) perpetrators of crime and motives

(c) fear of crime in the community

(d) the impact of being a victim of crime and fear of crime

(e) strategies to support victims and reduce crime

(f) apprehension rates

(g) effectiveness of sentencing

(h) community safety and policing

The inquiry was referred to the Committee on 21 May 2002 by the Minister for Justice and Customs, Senator the Hon Chris Ellison.

What was its 'significant impact'?

The Inquiry was conducted by a Federal parliamentary standing committee in a Federal Coalition government.

While some members of the committee were from the Labor Opposition, the majority were from the Coalition. It could be argued that the Inquiry was used to rebuke and castigate the Labor State Government's perceived inaction and coverup from years earlier. This did lead to significant legislative, policy changes and more accountable practices.

What was the scope (i.e. national/state) of the review?

This was a federal review of crime in the community nationally.

What were the critical precursors or the pathways that led to the review being commissioned?

This specific inquiry by the Standing Committee on Legal & Constitutional Affairs included hearing submissions about abuse of children and other vulnerable people.

As part of this process, the Committee pursued the investigation into cover-ups of abuse at the John Oxley Youth Detention Centre in Queensland that occurred in the late 1980s some 14 years previously. The scandal known as 'Shredder-gate' involved the destruction of documents and evidence by representatives of the Goss government in 1990.

The Committee noted that:

> Evidence to the Committee has exposed a culture of concealment and collusion – a culture that has effectively covered up abuse of children and placed the welfare of those entrusted with their care ahead of that of the victims. There is evidence of abuse taking place at the John Oxley Youth Detention Centre in the late 1980s and continuing today at the replacement for the John Oxley Centre – the new Brisbane viii Youth Detention Centre: physical abuse including beating of children while handcuffed. Had action been taken in 1990 to clean up instead of cover up, subsequent abuse could have been avoided and the culture changed (2004, viii).

During the Inquiry the Committee received a number of exhibits in relation to Care Independent Living Association, Bribie Island a non-government organization that ran a care facility. A public hearing took evidence in Brisbane on 18 June 2004 and also received evidence on a confidential basis. The committee noted that the Forde inquiry into the abuse of children in state care (1999) did not extend to abuse more broadly – i.e. it did not include children or adults with disabilities.

This evidence prompted the committee to reflect on how "cultures of concealment" continue:

> A shocking example of how the culture remains was illustrated by evidence of practices in a care facility for the intellectually and physically disabled on Bribie Island. Such evidence included a description of punishment meted out to a boy whereby his artificial leg was removed to force him to crawl. This incident and more was revealed in evidence given to the Committee (2004, viii).

Other precursors included:

- a number of repeated complaints to the government by parents about treatment of their family members;
- The Queensland Office of the Adult Guardian investigated the centre early in 2004 and found a culture of unfair punishment and maltreatment.

What were their recommendations?

The Committee made specific recommendations in relation to the Abuse at Bribie:

> Recommendation 5
>
> The Committee recommends that the Commonwealth gain a commitment from the Queensland Government within the framework of the Council of Australian Governments to introduce an accreditation system for disabled care facilities similar to that introduced by the Commonwealth for aged care (p. xvii).

Recommendation 6

The Committee recommends that the Commonwealth gain a commitment from the Queensland Government within the framework of the Council of Australian Governments that the Queensland Auditor-General be given the power to conduct performance audits of Queensland public sector entities comparable to the performance audit power available to the Commonwealth Auditor-General (xvii).

Were these adopted? How? Where? When?

The uncovering of the abuse at the Bribie facility prompted the Queensland government to develop the Disability Quality Service System in 2004. The then Minister Warren Pitt announced the *Queensland Disability Services Act 1992* would be reviewed with a view to improving 'mechanisms for preventing abuse of any kind against anyone' (Pitt, 2004).

The subsequent *Queensland Disability Services Act (2006)* included provisions for:

- Monitoring and Compliance
- Complaints and Governance
- Restrictive Practices and Positive Behaviour Support
- Criminal History Screening

The mechanism for implementing these provisions was the Queensland Human Service Quality Standards and later the Human Service Quality Standards Framework (HSQF). The HSQF provided the basis for accrediting disability services and these have been revised and amended a number of times. These standards now apply to all community services in Queensland.

What were the changes that the review/ report instigated?

The review led to the establishment of quality standards for services in Queensland providing mechanisms for accreditation, monitoring standards for services, lodging and responding to complaints and screening of staff. Later iterations also provided oversight of the use of restrictive practices.

Police also laid criminal charges against eight former staff members at the facility. The lead perpetrator and three other staff were later found guilty and sentenced to community service in 2009 five years after the offences were committed. This drew public criticism and coverage in the media.

Outcomes

> BOX 2. THE TRIAL FIVE YEARS LATER
>
> The trial and sentencing of the staff members was not finalised until 2009.
>
> At the hearing it was revealed that a five-year-old autistic boy was bitten by carers and a teenage patient was hit around his genitals with a fly swatter. Defence lawyer Brendan Ryan accused the defendant of locking up a young female patient, who was also autistic, in a 'cage' while she ate her lunch.

This inquiry and subsequent actions led to criminal charges against the staff and the closure of the facility in October 2004. The state government used funds from the liquidation of the organisation to offer compensation to the victims and their families. However, the victims and their families were still dealing with the trauma some decades later (*The Courier Mail*, 2006). There is an increased level of accountability of services which may contribute to some level of prevention. Reports of abuse of people with disabilities in Queensland have continued, despite this inquiry. The Queensland Office of the Public Advocate (2015) reported concerns at ongoing institutionalisation in Queensland health facilities. The Office was also critical at the lack of transparency around the use and efficacy of restrictive practices, noting that

> … highly vulnerable people continue to be subject to practices that impact significantly on their human rights without proper transparency. When you consider the impact of such practices on vulnerable people, this transparency is crucial … (14).

CASE STUDY #4.

Inquiry into Allegations of Official Misconduct at the Basil Stafford Centre 1995 (Stewart Inquiry).

Why was this report chosen?

This inquiry was conducted by the Queensland Criminal Justice Commission (the Commission) following a series of complaints made to the Commission about the abuse and severe neglect of residents by staff and the intimidation and harassment of staff who reported incidents of abuse at the Basil Stafford Centre.

Basil Stafford was a state residential facility in Greater Brisbane and home to 122 people with intellectual disability. Like all state institutions Basil Stafford was subject to a broad state policy of Institutional Reform was instigated by the Goss Labor government in May 1994, with the agenda of closing all state institutions (Chenoweth, 1998).

This inquiry is of importance in that it:

1. exposed the cultures of abuse that existed for many years in institutions;

2. was conducted during a period of major policy change;

3. highlighted the resistance to that change by some staff who intimidated and bullied whistleblowers;

4. was conducted by the Queensland's first agency charged with investigation into police and public sector misconduct.

What were the terms of reference of the review as reported?

The Commission resolved to:

- Conduct an investigation into cases of alleged or suspected official misconduct by persons holding appointments at the Basil Stafford entre concerning:

    a) the abuse of clients;

    b) the gross neglect of clients;

    c) the harassment or intimidation of those persons who have complained or would be likely to complain of the abuse or gross neglect of clients.

    for the period 1 January 1985 to 31 December 1993.

- As part of the investigation referred to in paragraph 2 hereof to consider generally and make recommendation concerning any statutory provision, policy, practice or procedure relevant to the clients of the Basil Stafford Centre or the reporting of treatment of such clients, and any related matters; and

- To engage the services of an independent qualified person pursuant to section 2.55 to the Act, that person being The Hon. D G Stewart to conduct the investigation and to report thereon to enable the commission, the Commissioners and the officers of the Commission to discharge the functions and responsibilities imposed by the Act.

What was its 'significant impact'?

This Inquiry marked the first major expose of abuse of people with intellectual disability in state care. It also shone a light into the 'insidious institutional culture' of the Centre and cover-ups and silencing of staff who made complaints about how people were treated.

The Inquiry attracted adverse media attention which in turn impacted negatively on staff morale, especially those who were committed to providing good care and who tried to stand against abusive practices.

There were some improvements in staff recruitment, a slow movement of people into community-based care and some prosecution of perpetrators. In terms of real and sustained change however, it is difficult to see how this Inquiry made a difference on a systems scale.

Even after a follow-up Inquiry into the implementation of the recommendations (Carter, 2000), it could be argued that the changes made were minor and did not actually address the insidious culture. The inertia of organisations and their imperviousness to change ultimately made the road to better lives a long an arduous one.

What was the scope (i.e. national/state) of the review?

This was a state inquiry by its own Criminal Justice Commission into misconduct by state's own officers.

What were the critical precursors or the pathways that led to the review being commissioned?

The Inquiry was commissioned following a series of complaints concerning staff at the Basil Stafford Centre and the treatment of residents to the Criminal Justice Commission. These complaints centred on three areas of concern:

1. Abuse of clients including physical assaults so called "thump therapy", sexual abuse and neglect;

2. Intimidation of staff who witnessed such acts of abuse and violence; and

3. The lack or inadequacy of procedures relevant to the reporting and prevention of abuse.

The gravity of these complaints were amplified by the prosecution and trials of several Residential Care Officers employed at the Centre.

These included:

- In February 1991 a former RCO was found guilty of rape of a 22 year old resident with severe and profound intellectual disability. The young woman was pregnant and was delivered of a baby boy in September 1990. The staff member was sentenced to a term of imprisonment which was increased following appeal by the Attorney General;

- In January 1991, another male RCO was arrested and charged with assault of a resident. The matter did not proceed through the courts but was later referred to the Misconduct Tribunal. The staff member was dismissed;

- In August 1991, another male RCO appeared in the Inala Magistrates Court charged with assault causing bodily harm. The victim was a 17 years old boy with intellectual disability who suffered lacerations to his mouth requiring six stitches, two lost teeth and another broken tooth. The RCO pleaded guilty and was sentenced to 150 hours community service; and

- In the course of these proceedings, it was reported that several staff who witnessed these events chose not to report them, lied about what had transpired and/or expressed fear of reprisals from other staff if they did report them.

What were the recommendations?

There were 20 recommendations. The first and primary of these were that the problems at the Centre were of such a nature that the only practicable solution was to close it.

Other recommendations included:

- the referral of matters regarding particular staff members to the Director of Public Prosecutions or other disciplinary tribunals (Rec. 2, 3 & 7)

- procedures and actions to improve health and hygiene as well as medical facilities on site (Rec. 4, 5, 13 & 14);

- recruitment of more suitable staff with minimum educational qualifications; the provision of formal training especially in values and attitudes for all new staff and ongoing raining. (Rec. 8, 9 & 11);

- adoption of rigorous and fair standards of performance and creation of a career path for staff (Rec. 10, 11);

- Improved staff/client ratios and more stringent supervision of Residential Care Officers. (Rec. 12);

- Diligent and rigorous investigation of all suspicious client injuries and any observed inappropriate activities. These should be referred to outside bodies (e.g. Queensland Police Services of Criminal Justice Commission) and disciplinary action taken. (Rec. 15, 16 & 17);

- Changes to legislation: Amendment to the Queensland Coroners Act 1958 to provide for compulsory inquests into any death in a state run or administered residential facility. (Rec.6) and amendments to the Criminal Law (Rehabilitation of Offenders) Act 1986 requiring applicants for positions be required to disclose any previous crimes of offences. (Rec.9);

- The department consult with eternal advocacy bodies (e.g. Queensland Advocacy Incorporated) to seek advice on how to improve conditions and individual advocacy for clients. (Rec. 18,19);

- The department establish a methodology for periodic review to ensure these recommendations have been implemented. (Rec. 20).

Were these adopted? How? Where? When?

Adopting these recommendations was a long and tumultuous process. The key recommendation that the Centre should close was not achieved. In May 2000, the Beattie government mounted another Inquiry led by Justice Carter to review the implementation of recommendations of the Stewart Inquiry.

Closing the Centre

Before the report was released the then Labor government, obviously disturbed and concerned by the public disclosures forthcoming in Stewart's report, announced in 1994, that the Centre would close within 'three to four years'. However, the Centre did not finally close until 2013, nearly ten years later.

The closure or not of the Centre was subject to competing political decisions as the State government changed over 1994 to 1997. In 1996 following a change of government and the election of the Liberal/National Borbidge government, it was announced that the Centre would not close. This was largely a political response to the robust and vigorous support for the Centre by a group of relatives who wanted the Centre to remain as it was (Carter, 2000).

With yet another change of government in 1997 with the election of the Beattie Labor government, the situation again changed. The closure was not a public undertaking. Instead, the department worked towards supporting more residents to move into community-based care through what was termed the BSC Relocation Project. This saw numbers reduce to approximately 25 in 2001. The remaining residents were those whose families wanted centre-based care.

Criminal Prosecution

Recommendations 2, 3 and 7 which related to the institution of criminal prosecution proceedings, an investigation into misconduct and departmental action against certain Residential Care Officers (RCOs) were all complied with. One RCO was charged and sentenced to two years' imprisonment (DeMaria, 1999).

The Misconduct Prevention Unit was established prior to the release of the Stewart report initially proposed to run for one to two years. However, this continued until the mid-2000s.

What were the changes that the review/ report instigated?

As already discussed, there were few changes initially from this review. Change took many years and was incremental rather than revolutionary.

Outcomes

The Centre ultimately closed in 2013 though it operated as a smaller unit within the facility for more than a decade after the Inquiry. Alternative community living options were developed especially for those with severe and profound disabilities and challenging behaviour.

The culture was seemingly impenetrable to scrutiny and change. For example, the follow up Inquiry in 2000 found staff still unwilling or uncomfortable to provide information even anonymously. A confidential survey to 200 staff yielded just 74 responses, none of which were from those employed at the time of the Stewart Inquiry.

Even years later, the Centre was the subject of media attention for the treatment of people still living there. For example, in 2007, it was reported that a young 19 year old man was subjected to shocking mistreatment, being kept caged, with no face to face contact and food delivered through a slot in the door (*The Courier Mail*, 2007).

The Basil Stafford Centre remains a sobering memory for many. As a review process it did not bring about immediate positive change, which was to take many years. It did bring to public scrutiny however, the appalling abuse and neglect of vulnerable people and the power of insidious cultures of silencing those who speak out.

CASE STUDY #5.

NSW Law Reform Commission Review of New South Wales Disability Services Act 1993–1998.

Why was this report chosen?

The review of the *New South Wales Disability Services Act 1993* (NSW DSA) by the New South Wales Law Reform Commission (the Commission) in 1998, and its subsequent report of 1999, allows a 'window' into the sector in one state, at a critical decade of great change.

The *NSW DSA* was enacted by the Greiner Coalition government in 1993, as a response to the Commonwealth State Disability Agreement of 1992 (CSDA) (see Section I).

The CSDA had a powerful influence on all states, as not only were old Acts repealed and new Acts, with human rights foundations enacted, but also the way in which services by the State Governments were delivered changed, as did the relationships between the State Government Departments and those NGOs which were providing front line services.

This 5 year Review was enacted in the 1993 NSW Legislation (Section 29), and the NSW Law Reform Commission was the natural 'home' for such a review, as it was focused on legislative frameworks, rather than on service delivery. Nevertheless, the Commission did undertake a wide-ranging review of the sector, and its report raised a number of critical issues for the future of service delivery in NSW.

For reasons that will become clear below, a decade after the Review, these recommendations were still *not* adopted.

What were the terms of reference of the review as reported?

There were four terms of reference, all of which focused on the *NSW Act*, its regulations and whether there were any 'resource or financial implications' (NSW Law Reform Commission Report, 1999a, x).

What was its 'significant impact'?

The Commissioners undertook a wide-ranging consultative process within the State (see next section) and this enabled a reflection on the successes or challenges posed.

The opportunity to provide feedback direct to government (or so those consulted believed) within the framework of a legal review, outside of government or its departments, meant that the evidence gathered had both immediacy and honesty.

Those consulted had every reason to believe that the government would accept the Commissioners' recommendations.

What was the scope (i.e. national/state) of the review?

It was a statewide review. The Commission established a 10 person Reference Group, with the assistance of the Disability Council of NSW, to 'provide advice on the conduct of the review'. This Group met on four occasions, and 'provided comments' on an early released Issues Paper and on the Report itself (1999a, 3).

The Commissioners called for submissions, visited a number of centres and held meetings with particular agencies as well as with the responsible two state government Departments: Ageing and Disability Department (ADD) and Department of Community Services (DOCS). The Commission utilised the print and radio media to advertise its review widely.

96 submissions were received, including one from the Minister for Community Services, the Hon Faye Lo Po' MP.

In September 1998, the Commission released its Issues Paper, and this was followed up with public seminars during November and December. These seminars '… allowed the Commission to see how the *NSW DSA* [was] working in practice …' (1999a, 4).

15 focus groups were conducted with groups both in Sydney and in the Illawarra and Broken Hill districts. The Commission went to some lengths to ensure diversity within these groups (1999a, 6).

What were the critical precursors or the pathways that led to the review being commissioned?

The transition of some previously managed Commonwealth programs to State governments was the focus of the 1991 CSDA (see *History*). In their consultations, the Commissioners heard that this was 'a matter of major concern' as in New South Wales parents, advocates and services felt they would '… lose the benefit of the major philosophical and policy progress that had been made in service provision at Commonwealth level under the DSA 1986 …' (1999a, 8).

In the period since the introduction of the NSW DSA, there had been six Ministers, and the government had changed from Coalition (conservative) to ALP (centre) in those eight years. Until the election of the Carr ALP government in 1995, there had not been a 'specific' Minister for Disability Services, and at the time of the Review of the *NSW DSA*, this was Faye Lo Po', who had been appointed the previous December (1997) with a portfolio that also included Ageing, Women and Community Services.

As the Section I highlights, like most states, New South Wales was also attempting a deinstitutionalisation process at the same time that this review was being conducted.

In February 1998, with Lo Po' as Minister for less than six months, *The Australian* ran a series of reports on the sector, and specifically her Department (DOCS), headed '*Inside the Department of Disorganisation*' (Wynhausen, 1998). The details in these reports were shocking to say the least, and so by the time the Commission's review got underway, the Department and its Minister felt under severe public pressure.

What was the level of authority of person/persons undertaking/conducting review?

Four Commissioners signed off on the Review Report. The Hon Justice Michael Adams QC as Chairperson of the Commission; and as Commissioners: Professor Neil Rees (Commissioner in charge of Review, and at that time, Professor of Law at Newcastle University); Professor Reg Graycar (subsequently, Director, NSW Women Legal Service) and Professor David Weisbrot (subsequently, President of Australian Law Reform Commission).

The Commissioners were assisted by a small team of Commission officers, and employed external agencies to undertake a wide-ranging consultative process with particular emphasis on focus discussions.

What were their recommendations?

There were 40 recommendations in all – however, for the purposes of this case study, Recommendation 12 was critical. This recommended

> … that the NSW DSA be amended to '… require the Minister to prepare and publish a four year plan within six months of this amendment coming into effect. It should require the Minister to review, update and publish the plan every year … (1999a, xvi).

Were these adopted? How? Where? When?

The disability sector was 'split' between two Departments in New South Wales: Ageing and Disability Department (ADD) and Department of Community Services (DOCS). This was largely historical however despite the newly elected Carr Government enabling one Minister to manage both Departments, there was no attempt to rationalise this anomaly. We can compare this directly to the Western Australian experience, where the CSDA enabled a new Department to be established, and all aspects of disability services were then rationalised into this new entity. This also meant that the relationship with the Commonwealth in WA was managed on a 'one to one' basis.

The way in which this 'split' was managed in NSW was that ADD held the funds, while DOCS delivered the services – largely accommodation and support – a classic 'purchaser/provider' split (see *History*). ADD also funded the NGO sector in NSW, which in the 1996–1997 financial year the Commissioners noted were 700 agencies receiving $176.2m funding. DOCS received $220.2m the same year. It is not clear from the report how much of this funding was actually Commonwealth monies (1999, 10) but a subsequent estimate shows it to be likely between 70% (NSW) and 30% (Commonwealth) (Roth, 2007). These arrangements made what was already a complex system, even more so.

The Commission made it clear that, within its terms of reference, they had identified some 'non-conforming' services that continued to be funded. 'Non-conforming' to the *NSW DSA* as well as, most likely, the *Commonwealth DSA 1986*. (1999a, 11). The Commission put the estimate of 'non-conforming at 30% of non-government agencies and 86% of those managed through DOCS' (1999b, n.p.). However, the Commission was clear that simply 'closing these services down' was hardly a sensible option, as there were few alternatives for people.

Importantly, the evaluation and monitoring of *NSW DSA* standards was not possible to ensure any compliance as there was little funding and fewer resources for this. The Commission found that there was '… widespread community dissatisfaction with the Disability Services Standards as a measure of quality' particularly as most services were 'self-assessing' rather than there being an independent review process (1999b, n.p.).

In NSW, reviews of government departments were a constant reality. The early 1990s was a period of economic recession. It was also a time when the neo-liberal policies associated with welfare service delivery became popular with governments of all political persuasions (see *History*, and also see above case studies). In NSW this had a direct impact on the sector, and its very public 'face' was DOCS. Wynhausen reported that:

> … if there was a time the public sector needed drastic restructuring, that time never seemed to end for community services … the department's work restructured again and again to save money … **(1998, 1).**

In fact, DOCS had been restructured *7 times in 10 years*, and in one restructuring during the Greiner government (1988–1992) over 1,000 staff had taken voluntary redundancies.

Critics of the Department, such as Community Services Commissioner Roger West, also pointed out that this constant restructuring and '… loss of skilled, experienced people has left the department without sufficient expertise to do the work it's there for …' (cited in Wynhausen, 1998, 1).

In January 1998, a representation of 70 welfare agencies and unions to Minister Lo Po' argued that DOCS urgently needed an 'infusion' of $100 m. However, the Minister responded by creating an expert task force. Critics such as John Jacobson of the NSW Council on Intellectual Disability were not impressed with this, which he viewed as a way of pushing the issue into the future (1998, 1) and not dealing with it at the moment.

What were the changes that the review/ report instigated?

For the Commissioners, who crafted their report recommendations '… to significantly affect the way in which services are provided and administered …' the only way this could be possible would be '… if sufficient funds are made available to implement them …' (1999a, 12).

The Commission considered that access to mainstream services as provided by State and local governments needed to be considered a 'right' for people with a disability. While this was a principles under the NSW DSA nevertheless, the Commission found that this '… process had largely failed to achieve its aims and produce real change'. The only way to strengthen this for the future, in the Commission's view, was to 'improve the quality of plans' as per their recommendation to the Minister (1999b, n.p.).

Outcomes

In 2007, a summary of government policy and services to support and include people with disabilities, was prepared for the NSW Parliament by the Parliamentary Library Research Service (Roth, 2007). It is this report that states:

The NSW Government has not yet implemented the [Law Reform] Commission's [1999] recommendations (2007, 17).

The report itself does not give any reason for this outcome.

In the decade between the release of the Commission's report, and the summary above, there had been three Ministers. The Government had remained ALP in this period. The Department had undergone several name changes, and at the time of writing this summary was now called Ageing, Disability and Home Care (ADHC). There had been any number of service reviews, evaluations and monitoring, but the Commission's recommendation that a four-year plan be released by the Minister, and then action judged against such a plan, was not implemented.

The legislation was again reviewed in 2003 by the Law Reform Commission, as per the legislative requirements.

While a detailed history of the NSW experience remains to be written, this case study offers a reflection on a decade of change, of constant 'churning' and, it has to be said, of missed opportunities. For example, the authors of this report were involved at this time in the 'brief' introduction of Local Area Coordination into New South Wales in 2002–2003 as a pilot program (see *History*). This pilot lapsed due to lack of funding, and changes in management direction. The Commission's Report can also be seen as a casualty to this particularly turbulent time in the history of the disability sector in New South Wales.

CASE STUDY #6.

Shut Out: The Experience of People with Disabilities and their Families in Australia (2009). National Disability Strategy Consultation Report (NDSC Report) as prepared by the National People with Disabilities and Carer Council. (Published by Commonwealth Government: Canberra).

Why was this report chosen?

This was the first major national review of the sector since the Handicapped Programs Review (see above). In the two decades since the HPR the sector had undergone many changes, many smaller reviews, much evaluation and several significant changes to legislation and policies. It had also been the subject of a regular ABS Census. However, the fragmented nature of the sector remained a critical issue, as did the question of eligibility, access to funding and unmet needs (Section I).

This consultation and its subsequent report were supported by the recently (December 2007) elected Rudd Labor Government as it moved to take up issues that had been raised during its election campaign.

What were the terms of reference of the review as reported?

On 17 October 2008, less than a year after its election, the Rudd Labor Government released a Discussion Paper seeking responses to three key questions about peoples' direct experiences of disability. These questions, specifically focused on what was being called The National Disability Strategy (NDS), were as follows:

- What do you think should be included;

- We are interested to know about your personal experience;

- Do you have any other comments, thoughts or ideas about the NDS? (*National Disability Strategy Consultation Report* NDSC Report, 2009 Appendix A, 64).

There were *no* formal terms of reference and this 'review' can therefore be seen as echoing the way in which the HPR had been conducted – with a broad, national mandate and in an attempt to 'by-pass' more traditional sources of information going directly to those people with a lived experience, their families and advocates.

What was its 'significant impact'?

This consultation and the report as released played an important part in the preparation for the National Disability Insurance Scheme (NDIS) that the new Government was proposing as its centrepiece welfare reform.

However, unlike the *HPR Report*, it should *not* be viewed as solely leading to legislation, rather it should be seen as one significant component of the strategic planning and public relations aspect to the lead up to the NDIS announcement. It was central to that strategy in that it publicly demonstrated to the broad sector (as well as the nation at large) the Government's commitment to a future reform of disability programs.

What was the scope (i.e. national/state) of the review?

It was a national review. It was supported by and funded by the Federal Government. However, it was designed to be viewed as being at 'arm's length' from Government by the direct involvement of the National People with Disabilities and Carer Council (NPDCC). This Council was established early in the life of the new Government.

Public consultations were held in all capital cities and 'selected' regional locations between 27 October to 26 November 2008 – less than 10 days after the release of the Discussion Paper. The capital city consultation events were chaired by Dr Rhonda Galbally AO, Chair, of the NPDCC. The Australian Federation of Disability Organisations (AFDO) 'facilitated' consultations in 52 regional and remote locations (*NDSC Report*, 2009, Appendix C, 76).

750 submissions were received, 'more than half of which were from individuals and the remainder from a range of organisations' (*NDSC Report*, 1). 2,500 people attended consultations. The extensive number of submissions resulted in KPMG being commissioned to analyse these (76).

What were the critical precursors or the pathways that led to the review being commissioned?

The DSA and CSDA had put employment firmly in the Commonwealth jurisdiction, and therefore, from the Keating government onward (see Section I), employment of people with disabilities became the central focus of all Commonwealth programs and planning. The recession of the early 1990s ensured this became an even more pressing aspect.

With the election of the Howard Liberal/National Coalition Government in 1996, there was an immediate move towards more stringent 'neo-liberal' approach to disability programs – what Soldatic & Pini (2012) refer to as a 'reconfiguration'. They summarise this as including:

> … the marginalization of consumer representation from the policy process, the widespread adoption of privatization, including the engagement of the community sector in state-market contractual relations and the reworking of the welfare and labour-market nexus (2012, 187).

To the dismay of many parents and advocates, the new Government began changing, as well as reversing some of the previously hard-fought-for reforms. The language describing the sector also changed. As well as 'consumers', there was talk of a 'market'. Disability became a business, with 'bottom lines'; 'purchasers' and, to much consternation, the 'purchaser/provider' split, which became code for an increased privatisation and marketisation of the sector (as discussed in Section I).

While employment was the 'face' of the neo-liberal agenda, the Howard Government was also quietly moving to dismantle advocacy, particularly, systems advocacy. It reviewed the National Disability Advocacy Program (NDAP) during its first Ministry (1996–1998) and subsequently re-focused on 'carers'. This resulted in a 'plethora of consumer representative bodies [being] reconstituted' (Soldatic & Pini, 2012, p. 187). In its third Ministry, it abolished the Disability Advisory Council and created a Carers Advisory Council and it began to explore ways in which regulation could more effectively silence advocates (187).

At the same time, Disability Employment Programs were split across two Departments, and in the 2005–2006 Budget a major review of the Disability Support Pension was announced.

For those in the sector who were at the front line of these major changes, it became increasingly difficult to criticize, as the Commonwealth made its grants subject to a 'no criticism' clause. For the Family Advocacy editor of *Families for Change*, writing in the Autumn of 2007 – the previous decade had been a challenge, to say the least. She/he writes:

> The political environment, in which we current exist, has done much to silence and still the activists among us. A number of recent reports and articles have pointed to the 'silencing of dissent' across the not for profit sector in Australia. As the heavy hand of government is being felt across many quarters and the public purse strings are pulled ever tighter, so too are the lips that used to form the words of activism. They are falling silent for a number of reasons – fear of funding loss, frustration at calls for change falling on the deaf ears of governments, unwieldy and unresponsive bureaucracies, and 'biting the hand that feeds you' syndrome (*Families for Change* (2007), 3. 1. 1.)

In 2007, the Senate, with the pressure of the Opposition, agreed to an Inquiry into the primary government funding and coordination mechanism for the provision of disability services and supports across Australia (Soldatic & Pini, 2012, 188). This bi-partisan report of February 2007, had, as Recommendation 4:

> That in the life of the next CSTDA [i.e. in next five years], signatories agree to develop a National Disability Strategy which would function as a high level strategic policy document, designed to address the complexity of needs of people with disability and their carers in all aspects of their lives (Senate, 2007, x).

It was at this time that the Federal Government signed the newly formed *United Nations Convention on the Rights of Persons with Disabilities*.

What was the level of authority of person/persons undertaking/conducting review?

The Federal Election in December 2007 was one fought on a number of fronts, not least, the need for a 'new' alternative approach to disability programs. In Opposition, Labor had signaled that it would be making disability the centrepiece of its welfare reform, and when the Australia 2020 Summit was called in April 2008, the proposal for a National Disability Insurance Scheme (NDIS) was one of the 'great ideas' that made the final report.

Subsequently, the new Government also instigated 'community consultation forums' in each state, and disability reform became a regular topic for discussion (see Marsh et al, 2011).

Leading this agenda for change were two Labor 'heavyweights': Jenny Macklin and Bill Shorten. Jenny Macklin had been a leading researcher in the Keating Government, and had been Deputy Leader of the Opposition, and of the Labor Party since entering Parliament in 1996. Bill Shorten had been Secretary of the AWU and understood the challenges facing the labour market when he was elected in 2007. Both were powerful advocates for change, with Shorten as Parliamentary Secretary for Disability in the first Rudd Ministry (2007–2013) and Macklin as Minister for Families, Community Services and Indigenous Affairs in the inner cabinet.

The NDIS therefore, was the goal to which the consultation process (and its subsequent Report) were working towards. The consultations were critical to this, as it was important to ensure the future safe passage of new legislation which depended on a bi-partisan approach, one which was firmly based on public perceptions and support for change. The appointment of Rhonda Galbally as Chair was also critical, as the Report then appeared, when published, to be 'from the ground up' and not a 'Federal report'. Indeed, the Commonwealth, when publishing it made a series of disclaimers including that:

> This report should not be read in isolation, nor will it be the only source of data to inform the development of the National Disability Strategy. Rather, the report is a useful way of bringing together the voices of those people with disabilities, their families, friends and carers and the organisations that support them who provided submissions and participated in consultations. **(2009, iii)**

However, to balance this, both Macklin and Shorten co-wrote and co-signed the Foreword to the report. In this they summarise the findings as follows:

> The task that falls to us is to make the political, social and economic changes necessary to enable this to happen. We have been told we need to tackle issues and barriers around disability services, we need to ensure an adequate standard of living for all our citizens, and we need a society in which all people are included and are supported as citizens and leaders in the community **(2009, iv).**

In summary, these consultations and the subsequent report carried much weight, was central to the subsequent development of the NDIS and continues to be referred to and cited (for a more personal reflection of the lead up to the consultation process see Galbally, 2013).

What were their recommendations?

The Report did not have recommendations, instead, it concluded with 'Implications for the Development of the National Disability Strategy" (NDS) and that '… all participants made it abundantly clear that much is expected from the NDS …' (2009, 61) it concluded.

Here the National People with Disabilities and Carer Council concludes that a future NDS needed to address four strategic priorities:

- increasing the social, economic and cultural participation of people with disabilities and their families, friends and carers;
- introducing measures that address discrimination and human rights violations;
- improving disability support and services; and
- building in major reform to ensure the adequate financing of disability support over time (2009, 61).

There was a call for the rights 'enshrined in the UN Convention' be imbedded in the Strategy; the creation of an Office of Disability, and increased funding for advocacy, among other conclusions.

Were these adopted? How? Where? When?

Immediately following the *2020 Summit* (see further below), Shorten created the Disability Investment Group, a handpicked group of 'prominent Australians with a wealth of experience and knowledge in philanthropic investment', working with Price Waterhouse Coopers to undertake a feasibility study (costs, benefits and governance) into a national disability insurance scheme. It reported in 2009.

The National Disability Strategy (an initiative of the Council of Australian Governments, COAG) was launched in 2010 and draws directly on the NDSC Report as it cites from it in its Overview (COAG, 2011, p. 8). The COAG document reported on the Productivity Commission being asked to examine '… a range of options and approaches, including a social insurance model on a no-fault basis' (p. 51). The Report also cited the PriceWaterhouseCooper report (see above) on a National Disability Insurance Scheme (NDIS) (2009). All the various parts of the strategy were coalescing.

A Bill to establish the NDIS was then introduced in Federal Parliament by Prime Minister Julia Gillard in November 2012. This was subsequently passed as the *National Disability Insurance Scheme Act 2013* the following March. This legislation did not override or negate the *Disability Services Act 1986*. The NDIS Act created the NDI Agency, and 'roll-out' began with demonstration projects in several states. There was a sense of urgency in the establishment of the administrative structure associated with the legislation, as the election of September 2013 drew nearer.

On the subsequent election of the Abbott Liberal Coalition Government at that election, disability policy was relegated to the outer cabinet, and there was a consolidation of 'human service' departments federally (*see Section I).*

Have these changes held over time?

The *'Shut Out'* Report has become a critical milestone in the recent history of disability services in Australia. In the decade since this national consultation, there have been several changes of Federal Government (10 Ministeries) and 12 Ministers.

The NDIS has become a 'household' term in this decade, but nevertheless concerns are held that welfare reform in this sector remains stagnant. While the NDIS was hailed as an 'epochal reform' and an 'iconic' change in Australian social policy at the time (see Goggin & Wadiwel, 2014, 1) it is increasingly being argued that the COAG NDIS has 'stalled'.

What is the current status of the issue/s under review?

The next section of this monograph now details the lead up to the creation of the Disability Royal Commission, and the role this report played in that process.

Case studies can be instructive in highlighting key issues, pivotal events and drawing out themes and learnings. We propose that these six review reports offer us the tools to unpack the path to the DRC, what its potential contribution might be and how we might do things differently in the future.

The pathways to the DRC: an introduction

Two distinct pathways can be observed towards the announcement of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission, DRC) on 4th April 2019.

The lead up to the legislation that created the National Disability Insurance Scheme in 2013, and, in particular, the consultation process which preceded this, is one pathway. These consultations were national, broad and raised many issues, not all of which could be addressed through the establishment of the NDIS (see Case Study #6 above). These consultations, and the evidence gathered, gave the Federal government an insight into the scale and breadth of the issues raised.

The second pathway, and the one is explained in more detail below, was through the establishment of the Royal Commission into Institutional Responses to Child Sexual Abuse (Institutional Response RC) in 2012 by the Gillard Labor Government, and subsequent events. This RC acted as a signal to the broader disability sector that the Federal Government was taking the issue of abuse of its vulnerable citizens seriously, and the decision to create a Royal Commission, with all the legal powers that such a body holds, raised the hope that a future investigation could be created to focus more specifically on the cases raised in the disability sector.

In addition, and importantly, the personal stories explored through a number of media investigations in the years prior to 2019, were also central in keeping the matters before the public eye and ensuring that politicians of all persuasions 'didn't forget by sweeping the issues under the carpet'.

The following provides a brief outline of the central pathways towards the establishment of the DRC.

A BRIEF HISTORICAL SCAN

The issue of abuse – both physical and sexual – of people with disabilities has a long and sordid history in Australia.

Until the creation of the *Disability Services Act 1986* and its Commonwealth/State service agreements (CSDA) in 1992 (see *History*), state governments had primary responsibility for the care of people, and to ensure the standards and monitoring associated with their accommodation, which, had been, for nearly 100 years, primarily large institutions more often managed and run by charitable organisations.

In some cases (for example, Queensland and Western Australia) where these institutions were actually directly state government managed, we would argue this 'management' was 'at a distance' and there was little, if any, direct intervention in cases of abuse or neglect as these tended to be 'managed' 'in-house', and not made public, as our case example below highlights.

The Handicapped Programs Review consultations (see Case Study #2) opened the sector up, and gave parents, advocates and people with lived experience a unique opportunity to 'speak truth to power' for the first time. At the same time, Australians were becoming aware (through the IYDP in 1981, and then in the media) that people with disabilities must be accorded the same rights as non-disabled citizens, including the right to a life without abuse or neglect. The public deinstitutionalisation of the large accommodation services into smaller 'group' homes during the 1980s and 1990s gave the wider public the hope that such abuses would stop, as the carer/client relationship, it was argued, could become more 'like a normal family'.

However, this new intimacy raised other issues associated with abuse, and those people with a cognitive impairment, or who were not mobile, remained vulnerable. Many group homes still bore the hallmarks of institutions with similar routines and practices, but in community settings. Often the combination of five or more unrelated residents led to conflicts and inadequate staffing exacerbated abuse and assaults (Victoria Office of the Public Advocate, 2019).

It is often asked why people did not/do not speak out more loudly.

In fact, all investigations report that people try to speak out, but are often silenced by more powerful individuals, or by the fact that there would not be any alternative to their present living arrangements. In the case of Western Australia, for example, there was only one institution – Claremont Hospital in Perth – and up until the early 1960s, only one paediatrician who advised all parents with a new baby born with a disability to place that child in the care of Claremont. Those parents who did not, for fear of abuse or neglect, were risking a future without any state support (see Stehlik, 1997). While many rejected the institutional option, it was at a cost.

In Section I we highlight the number of reviews and reports released following the 1992 changes in Federal legislation. As we discuss above, there were Reviews in Queensland and in New South Wales, an Ombudsman was created in 1993 to take complaints. Such offices were also created in other states following new legislation. In Queensland in 1995, a Review of Basil Stafford Institution raised issues, and in 2004–2006 South Australia conducted a Commission of Inquiry into Children in State Care. In August 2003, *ABC Four Corners* reported on what were then called 'Homies', people who, as children, had experienced abuse in 'charitable' homes. At the time, the President of the Queensland Children Services Tribunal commented that the 'repercussions' of having this experience '… are enormous and they ripple out to every facet of a person's life …' (*ABC Four Corners* transcript, 2003, 1).

In 2009, People with Disability Australia (PWDA) released a research study *Rights Denied: Towards a national policy agenda about abuse, neglect and exploitation of persons with cognitive impairment* which investigated barriers encountered to the realization of human right to freedom from abuse (French et al, 2009; Senate, 2015, 37).

Despite the growing evidence, the state reviews and reports did not appear to result in the structural changes essential to ensure people's ongoing safety. Cases continued to emerge, and advocates and parents continued to call for 'something to be done'.

YOORALLA

The cases of abuse, sexual, physical and emotional, experienced by the residents of Yooralla group homes in Victoria[9] came to national public notice through an *ABC Four Corners* report screened on 24th November 2014 entitled: 'In our care'. It was advertised as '… lifting the lid on a major scandal involving one of the country's biggest disability providers …' (*ABC Four Corners*, 2014).

The program drew on previous investigations by *The Age* and *The Sydney Morning Herald*, and from the personal experiences of Sandy Guy, a reporter, and her 31-year-old son, who was a resident at one of the Yooralla homes.

Ms Guy spoke of years of trying to get the management at Yooralla focused on the abuse being experienced by residents, and the impact of a recent 'restructure' which 'shed' house-managers and left 'residents and staff … largely unsupervised' (Guy, 2012).

The Victorian Department of Human Services had had identified 112 cases of alleged 'staff to client' abuse, and had commissioned an external inquiry, specifically focusing on Yooralla where '… a male carer had been the subject of several sexual assault and misconduct allegations …' (*Gippsland Carers News*, 2012). The management of Yooralla was accused of 'seriously mishandling' these complaints, and the external inquiry resulted in an individual being charged in March 2012 (DARU, 2012) and subsequently sentenced to 18 years in prison (*ABC News*, 2013). However, concerns remained.

The 2014 *ABC Four Corners* program resulted in the CEO of Yooralla resigning, and demands being made for an 'inquiry into Victoria's disability sector'. At the same time, former National Disability Commissioner Graeme Innes called for a 'national inquiry' stating that he believed that there were '… dozens or hundreds of similar abuse and neglect cases throughout Australia …' (Michelmore et al, 2014, 1). He presciently argued that:

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9   A thorough case study of Yooralla was written by M Ryan & M Jackson in December 2013.

> We will have a wave of these cases which are going to emerge over the next few years and we need to be preparing for that … we need to be ready to address it and proactively change the culture in these organisations, or changing the organisations themselves … (2014, 2).

In 2014–2015 there were 495 reports of alleged assault in disability services to the Department of Health and Human Services (*The Age*, 2016). With an election in Victoria imminent, both sides of politics promised an inquiry if elected. However advocates called for a broadening of any review as '… countless past complaints … have done nothing to stop the continuing abuse …' according to the Chair of Disability Advocacy Victoria (*The Guardian*, 2014, 1) and that it was '… distressing to see the prevalence of [this] abuse and neglect … crisis' (Blackwood, 2014, 1).

The Victorian Ombudsman then announced an investigation, saying that: 'The Public Advocate has told me that the high-profile cases [i.e. Yooralla] are only the tip of the iceberg'. She continued:

> Concerns about abuse will never be alleviated if people do not report allegations – or if those reports are not taken seriously and investigated thoroughly … (Victorian Ombudsman, 2014).

The matter re-emerged in the public domain as legal processes took their course, and alleged abusers began being sentenced in courts. The Victorian Ombudsman released her report *Investigation into disability abuse reporting* mid-2015. She found that people were not reporting abuse '…because they fear they will not be believed, no action will be taken, or they will be punished …' (*The Age*, 2015, 3). Despite this publicity, and the reviews, the incidents continued, and *The Age* reported on a 'grim repeat of history' in April 2016, when more cases in Yooralla emerged.

At the time, the Victorian Parliament itself was undertaking an inquiry. Its interim report was tabled in August 2015, but Victorian advocates continued to express their '… frustration at the federal government's silence on holding a Royal Commission on the issue …' (*The Age*, 2016).

Concurrently, the Australian Human Rights Commission presented its report: *Equal before the law: towards disability justice strategies* in February 2014, recommending that each jurisdiction 'implement a disability justice strategy' (Senate, 2015, 35).

THE FEDERAL SCENE

Our pathway towards a Disability Royal Commission federally had developed a number of fronts that can now be seen as beginning to coalesce.

In 2011, the Report of the United Nations Human Rights Council Working Group on the Universal Periodic Review for Australia '… identified issues around Australia's human rights protections for people with disabilities …' (Senate, 2013) and called for a Human Rights Act. This was rejected by the Government which instead announced the development of a Human Rights Framework (see Human Rights Commission, 2013).

In September 2012, the Senate referred the involuntary or coerced sterilisation of people with disabilities in Australia to a select committee of inquiry, which reported in July 2013. This review consulted widely and subsequently made 28 recommendations including recommendation 5:

> 2.127 The committee abhors the suggestion that sterilisation ever be used as a means of managing the pregnancy risks associated with sexual abuse and strongly recommends that this must never be a factor in approval of sterilisation (Senate, 2013, ix).

Prime Minister Gillard had announced the Royal Commission into Institutional Responses to Child Sexual Abuse on 12 November 2012. At that time, media stories of historical abuse in religious institutions made most of the front pages, specifically in New South Wales and Victoria, but cases also emerged in other states.

However, this Royal Commission, while it focused on children, was broader than the religious charitable institutions, it was also focused on '… offences against children in state care … [and] … also not-for-profit organisations …' (*ABC News On-line*, 2012). The Royal Commission, which took five years, began to hear harrowing evidence of historical abuse in state-run and NGO-run institutions.

At the same time, the NDIS began with pilot sites in several locations nationally in July 2013 to much publicity, and in September 2013 a federal Coalition coming into power, and the sector again saw immediate policy changes.

The Interim Report of the Royal Commission into Institutional Responses (2014) stated that

> … children with disabilities are more vulnerable to sexual abuse than children without disabilities, and are often segregated, to varying degrees, from the mainstream community for long periods, which increases the risk of abuse (Senate, 2015, 36).

In August 2014, the Australian Law Reform Commission released its report: *Equality, Capacity and Disability in Commonwealth Laws* (No 124). In December 2014, the Senate undertook an inquiry into the adequacy of existing residential care arrangements available for young people with disabilities, with Senator R Siewart as Chair.

The new Government's response to the Senate Inquiry on sterilisation was delayed until May 2015, and then pointed to the fact that regulations associated with sterilisation of people with a disability was '… primarily a state and territory issue …' and that laws regulating these issues have '… been significantly reformed …'. It concluded by stating that the Government was '… considering the recommendations in the report …' (Senate, 2013). This issue of 'whose responsibility' became central to a subsequent Senate Report in 2015 (see further below).

As we described earlier, while the Commonwealth did not have direct responsibility for accommodation under the CSDA arrangements, it did fund them indirectly. It also continued to have joint responsibility for advocacy, despite a 'watering down' of this during the Howard Coalition

government and its subsequent re-strengthening during the Rudd-Gillard governments (see also Section I) and then watering down again following the Abbott Coalition election.

In January 2015, a Coalition of peak disability advocacy bodies wrote to the Prime Minister, calling for a national inquiry. Endorsed by '… over 95 state and territory-based disability organisations … with over 11,000 signatories …', this petition was in direct response to the Yooralla case, and others that were emerging (Senate, 2015, 1).

The petition was responded to within the Senate, with the creation on 11th February 2015 of a select committee of the Community Affairs References Committee chaired by Senator R Siewart (Greens). In its report, the Senate directly referenced the Yooralla cases, Graeme Innes' comments and the petition. It also made it clear that, under the National Disability Agreement, enacted in January 2009, the jurisdictional 'split' between the Commonwealth and States was clear. Crucially, the Senate concluded that

> …. as a signatory to the U N Disability Convention, the Australian Government retains ultimate responsibility to ensure that the treatment of people with disability in Australia is compatible with the provisions of .. [the] Convention … (Senate, 2015, 2).

In other words, in the Senate's opinion it was not an issue that could be 'handed back' to the States, it was a Commonwealth responsibility, and the Senate argued its case throughout this report in which it '… examines the issue of violence, abuse and neglect of people with disability from a whole of issue perspective …' (2015, 3).

The Senate advertised its review on 15 April, 2015 and wrote to 140 organisations nationally inviting submissions of which it received 160. Six public hearings were held, and witnesses called.

In its conclusions, the Senate committee felt it was clear that '… a coordinated, well-resourced national response is required to address the issue of widespread violence, abuse and neglect …' (2015, 267) and to this end, it recommended the establishment of a Royal Commission.

On release of its comprehensive report in November 2015 (a remarkable achievement given a review of only six months), the disability sector had every reason to believe that the issue was now 'front and centre' and an early response from the Federal government was anticipated. However, Senate recommendations are only that: recommendations. It is up to the government of the day whether to accept or reject these.

In March 2017, some fifteen months after the release of the Senate report, the Government responded that it would *not* be establishing a Royal Commission. By this time, the Abbott Coalition had become the Turnbull Coalition, and the sector had had several Ministers, with their primary focus being on 'rolling out' the NDIS nationally. In its argument for this rejection, the government '… cited the development of the National Disability Insurance Scheme Quality and Safeguarding Framework …' which had earlier been agreed to within a COAG meeting.

The Chair of the Senate committee, Senator Rachel Siewart, stated that this agreed Framework, while useful, would '… not [be] sufficient for the rigour that we need to ensure quality, and to ensure that we have a very rigorous process …'. In addition, despite the care with which the committee's had made its case that this was a national issue which required a Federal government response, the government in rejecting the recommendation also stated '… State and Territory Governments needed to take some responsibility for the quality of care to some of Australia's most vulnerable people …' (*ABC News On-line*, 2017).

WHAT HAPPENED NEXT?

On 27th March, 2017 *ABC Four Corners* screened a further report on alleged abuse and neglect of people with disabilities, entitled: *Fighting the System*, which argued that one story from NSW '… typifies everything that is going wrong in group homes around Australia …' (Branley, 2017) where people are 'locked away … behind the walls of suburbia'. The program focused on the vulnerability of people who are reliant on the service system to maintain their rights, and how advocates and parents are 'physically exhausted after decades of fighting bureaucracy', with the NDIS just a 'new version' to negotiate.

In May 2017, Disabled People's Organisations Australia coordinated a 'civil society statement' to the then Prime Minister, Malcolm Turnbull. This Statement, endorsed by 160 organisations and 3783 individuals, called for the immediate establishment of a Royal Commission into all forms of violence, abuse and neglect. It was formally presented to Prime Minister Turnbull on 7th June 2017 and he responded in July 2017. His reply stated that the matter had been put before COAG and the Disability Reform Council (DRC) had been asked for its comments. He referred again to the NDIS and ' … existing universal complaints and redress mechanisms …' (Disabled People's Organisations Australia, 2017).

In December 2017, the Royal Commission into Institutional Responses delivered its final report, five years in the making and with thousands of allegations of abuse, this Royal Commission had kept the issue of institutional abuse front and centre in the public imagination, and while its focus was children, its historical perspective meant that many of those giving evidence were adults. This Report gave impetus to the Senate Greens, who continued to call for a Royal Commission into Disability. 'If the Government can change its mind on a Royal Commission into the banks, it can on the abuse, violence and neglect of people with disability' they argued (Steele-John, 2017).

These findings and recommendations did not change the government's mind about a Royal Commission as Greens spokesperson Senator Jordan Steele-John made clear in a press release in February 2018 '… the Government continues to do nothing' (Steele-John, 2018a).

A National Disability Abuse and Neglect Hotline was established, and by September 2018 had already received over 200 complaints (Steele-John, 2018b).

On October 22nd, 2018, in response to the Royal Commission on Historical Abuse, the new Prime Minister, Scott Morrison, gave a National Apology in Parliament and accepted, in principle, 104 of the remaining 122 recommendations related to the Commonwealth's responsibilities. Morrison announced a National Redress Scheme and stated, ' … the Commonwealth, as our national Government, must lead and coordinate our response'. He concluded: 'We can never promise a world where there are no abusers. But we can promise a country where we commit to hear and believe our children' (Morrison, 2018).

On 2nd November 2018, the New South Wales Ombudsman released a special report to the NSW Parliament entitled: *Abuse and neglect of vulnerable adults in NSW – the need for action*. This report covered the 206 cases of alleged abuse and neglect that had come before the Ombudsman's office since 2016. It stated that the inquiry

> … has shone a spotlight on the appalling living conditions of some of the most vulnerable members of our community, including some individuals who have been hidden from society and prevented from accessing the supports they need (NSW Ombudsman, 2018, n.p.).

In March 2019, the Morrison government called for consultation on a Draft Terms of Reference for a Royal Commission. It received 3,700 responses – a measure of how much the issue was front and centre for the sector.

On 5th April 2019 the Prime Minister announced a Royal Commission which, importantly, included funding to support people to participate. This had been a major recommendation of the 2015 Senate inquiry. The RC was given a three-year timeframe and its six commissioners were announced.

For the Senate Greens this was both an 'opportunity for justice' as well as a 'win for the disability rights movement' (Steele-John, 2019).

SOME CONCLUDING REFLECTIONS

In conclusion, we offer some reflections on what we can learn from the history of inquiries, the road to the current Royal Commission and what future impact it may have.

Investigative journalism and media freedom

With the cultural changes post IYDP (Section I has details) and the transformation of the sector in the subsequent decades, policies which encouraged advocacy – as defined within the *Disability Services Act 1986* – resulted in an increasing use of the media as a strategy to inform and hold governments (and NGOs) to account.

While a detailed analysis of the relationship between the media and the sector has yet to be written, it is clear from the research undertaken for this monograph, that the media (in all its forms) must be viewed as critical to ensuring that matters which would tend to be 'managed in house' are now being made public.

As the pathway to the DRC shows, the two *ABC-Four Corners* programs in 2014 and 2017 were vital in ensuring that abuse and neglect was brought to public attention. The media and the matters raised also speak directly to politicians, and our chronology shows just how quickly their responses can be observed.

In a sense, the *DSA 1986* opened a pathway for parents, advocates and people with lived experience of disability to 'step over' the institutional structures that previously ensured silence. As our two Queensland case studies show, this advocacy does result in change. It gives hope that issues raised will not be swept under any carpets.

We would suggest therefore that this is likely to become increasingly common. Indeed, with the extensive use of social media, and of the ease with which we can now photograph and video images, and upload them, we would argue for the hope that any abuse or neglect is less likely to be 'hidden' or 'secret' in future. We note that family members have taken cameras into aged care facilities, which have exposed shocking abuse to their elderly relatives which have then been made public.

Speaking out and speaking up

As well as the voices of families and advocates, our research has also highlighted the role of staff in speaking out about issues. While the role of the 'whistleblower' continues to be a contentious one judicially, nevertheless some staff (see Queensland case studies) have felt strongly enough on matters to speak out, despite the threat of losing their jobs. These examples highlight how the resultant publicity ensures a change in complaint procedures and ensures that matters are brought out into the open, outside of the agency or the institution, and resolved by external third parties.

The case studies reveal how the persistence of systems and entrenched cultures allowed cover-ups of abuse and neglect for many years. This has been apparent in other inquiries in other sectors and in the Royal Commissions into sexual abuse of children, and aged care. Why does abuse persist and re-emerge after inquiries have released their findings and made recommendations?

The road to this DRC has been characterized by long and sustained advocacy from people with disability, families and others in the sector. Many have spoken out and continued to lobby government over many years. Advocacy is a hard process and brings significant personal as well as systemic costs.

Political turbulence

Through the case studies described above, this monograph highlights just how the political turbulence affects the sector. Our case study from New South Wales (# 5) is particularly apposite in this, as changes in government and in ministers meant that the Law Reform Commission's recommendations could be side-lined for nearly a decade.

There can be no other sector that is so vulnerable to the political vagaries of the Australian federal system – except perhaps that of Indigenous Australians.

We also highlighted, in our Queensland case study (# 3), the manner in which a Federal government can 'chastise' a state government.

Does the sector benefit or is it weakened by this political turbulence? One way in which it is weakened is that scrutiny of issues of abuse and neglect can be 'over bureaucratised' – in other words, they can be deferred to a review (and there have been many, many reviews) and therefore actually not dealt with in the moment.

While we would not go so far as to state that there has been a systematised 'culture of cover ups', nevertheless it remains disturbing to see that despite all these reviews, recommendations by Commission and Ombudsmen, Public Advocate reports and media stories, over more than four decades, abuse and neglect continues. As Robinson et al (2019) argue:

> … entrenched abuses in service systems and poor evidence of change in response to various inquiries following the uncovering of abuse and neglect indicate that something different is needed (26).

To achieve real and positive change for people with disabilities, many spheres of society must come together. The prevention of and response to abuse requires changes to service cultures, strong and ethical leadership and robust judicial processes (Robinson & Chenoweth, 2011). As we pointed out in the introduction, the DRC is a serious legal undertaking and a powerful instrument for change. Already it has (uncharacteristically) made recommendations about the need for additional supports for people with disability in the face of COVID-19 pandemic. We are hopeful this response is indicative of its future final recommendations and ultimately safer and better lives for Australians with disability.

5.

COMMUNITY LIVING: TOWARDS A GOOD LIFE IN THE 21^{ST}C

Community living: national and international perspectives

Person-centred approaches to community living were developed in many jurisdictions as we discussed earlier. This section has two parts.

The first reviews several domestic and international models of care that are striving to provide a good life as a guiding principle. In describing these, we also consider what each model has to offer service providers and some implications for practice.

The second considers the following question: can a service provider (continue to) provide a 'good life' within current sector frameworks? It addresses this by describing the value of a planning framework that offers an opportunity to explore what a good life means to an individual currently in care: from the perspective of that individual.

We conclude with some reflections.

INTRODUCTION

Predictably, given the history of global disability movements, there are common elements in all of models of care. For example, all set out core principles and values that underpin the approach. Notions of choice, control and rights to an ordinary life are widely espoused. However, there are also differences in models and their implementation. The cultural and historical context of the jurisdiction, the availability of other generic supports such as affordable housing, access to health care, education etc. all have an impact on what kind of life can be achieved and sustained for the person with a disability.

Here, we present an overview of selected models from Australia, Aotearoa/New Zealand, United Kingdom, Canada and Scandinavia. This is a small and partial sample selected against broad criteria of relevance to people with intellectual disability, larger service providers and commitment to person-centred community living.

The final selection of examples is predominantly based on a desktop review, published research and follow-up consultations with known informants. The examples include national government initiatives setting policy and funding parameters through to local organisational models focused on supporting individuals and families.

COMMON THEMES ACROSS ALL OF THESE

Reviewing these examples, a number of values and principles can be identified across all of them as inherent for supporting a good life. These include propositions such as:

Relationships are central to the good life:

Examples all identify how crucial relationships are and the importance of linking with families, friends and other ordinary people.

Focus on human rights:

Many agencies refer to the UN Convention CRPD and identify specific articles that relate to the supports being provided.

Having choice & control:

Central to the NDIS in Australia, choice and control feature prominently across all examples.

Person at the centre:

While all examples were selected as person-centred approaches, there were specific details of how the person was central to the planning and variously involved throughout the process across all examples.

Engaging with the community:

This was a feature of many examples with some offering detailed community connections aims.

Finally, the jurisdictions of all the examples had disability policies and funding models that allowed some level of direct funding, from direct funds to the person through brokerage and contractual models.

AUSTRALIA

Summer Housing

https://summerhousing.org.au

Originally established to provide alternatives to young people with disabilities living in nursing homes, Summer Housing has developed an ambitious model of housing and support based on co-located apartments within large developments. These are now based across most states and the ACT. The core element is the provision of accessible housing based on leading edge technology and design. Summer Housing does not provide disability support services but can assist the person to secure services through an NDIS provider of their choice.

Implications

- Accessible innovative housing options;
- Use of smart technologies;
- Designs and locations geared to independence and community connections;
- Focus is on young people with complex needs rather than people living in group homes
- Model relies on and is strengthened through partnerships with private sector, government and other organisations;
- Specialist disability accommodation funding seems to be essential at this stage;
- Separation of housing and support;
- Strong focus on working with local services to provide individualised bespoke support packages.

My Place

https://www.myplace.org.au/

My Place was established by some of the founders of Local Area Coordination in Western Australia. It is a not-for-profit provider of individualised and flexible supports to people with disability and their families. My Place supports over 400 people with disability to live in their own homes, or remain in their family home, and become valued and contributing members of their community. Importantly, the organisation does *not* provide any group home, day centre or other congregate care services.

Core values:

- Autonomy – Promotion of independent thought and action through exploring, choosing and creating;
- Individuality – Acknowledging and respecting … unique needs and desires;
- Equality – Promotion and protection of equal rights and opportunities for all;
- Accomplishment – Personal success, growth and fulfilment;
- Security – Stability of desired lifestyle and confidence about the future; and
- Humanity – Preservation and enhancement of the well-being of all.

My Place offers three levels of support for funding and support arrangements:

- Do it all yourself: total control of funds and supports. My Place acting as a banker.
- Do it together: funding administered by My Place but control over employing own supports. My Place assists with planning, navigating the system etc.
- Do it for you but not without you: My Place co-ordinates services and employ support people on behalf of individual. In other words, least administrative and legal responsibility. Common approaches include home sharing with another family, couple or individual, providing flexible supports wherever needed and mentoring where the person may not need flexible supports but rather has access to a mentor to help with decisions, connect them to local community and assist in developing skills.

Implications

- Does not use group homes or any congregate models;
- Arrange of support options to suit different needs and situations;
- Could be suited to those people already semi-independent and needing only drop in support;
- Strongly oriented to local community options;
- Innovative in its approaches; and
- Large scale – 400+ people supported.

AOTEAROA/NEW ZEALAND

Enabling good lives

https://www.enablinggoodlives.co.nz/

Enabling Good Lives (EGL) is a national partnership between government agencies and the disability sector in Aotearoa/New Zealand. The need for a new approach was initiated from late 2011, and the first demonstration project in Christchurch commenced in 2013 and a further project in the Waikato in 2014. It is aimed at long-term transformation of how disabled people and families are supported to live everyday lives. It is focused on supporting people to be in everyday places rather than focusing on "special" places. EGL is based on the following principles:

Self-determination	Disabled people are in control of their lives.
Beginning early	Invest early in families and *whānau* to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
Person-centred	Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
Ordinary life outcomes	Disabled people are supported to live an everyday life in everyday places. They are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life.
Mainstream first	Disabled people are supported to access mainstream services before specialist disability services.

Mana enhancing	The abilities and contributions of disabled people and their families are recognised and respected.
Easy to use	Disabled people have supports that are simple to use and flexible.
Relationship building	Supports build and strengthen relationships between disabled people, their *whānau* and community.

Under this scheme, service provider organisations are asked to:

- operate with a clear set of principles and expected outcomes;
- negotiate how they work on a person by person and/or family by family basis. Note: This will initially be informed by the disabled person's plan.
- experience one monitoring and evaluation process that is developmental;
- operate according to a facilitation-based approach i.e. make it easier for individuals and families to achieve their goals by tailoring supports rather than the provision of a set range of service types;
- work to ensure community (generic) options are exhausted before specialist services are considered;
- operate with significantly reduced bureaucratic restrictions; and
- experience the "system" as being supportive of innovation.

Implications

- Similar broad national approach such as NDIS though no mechanisms for direct funding outlined as yet for implementation;

- EGL is perhaps more comparable to the Australian Disability Strategy in that it adopts a whole of government approach to achieving better outcomes for people with disability;

- The focus on community/mainstream options is strong; and

- Outcomes from the pilots may be useful for future planning.

UNITED KINGDOM

The United Kingdom has a long history of disability rights having pioneered the social model (see Section I) with consequent early adoption of anti-discrimination policies and improvements in access to housing, transport, education etc.

Support for people with disabilities is available through social care. Social care is a general provision that includes older people, children in care as well as people with disabilities. It is administered through local authorities who contract the support to local providers – including charities and not-for-profits as well as private businesses.

There have been increasing difficulties in social care provision under austerity policies. Support for vulnerable people has been described as a "fragile sector" as numbers needing support increase; numbers receiving it decline and spending rising though still below 2010–2011 levels (Bottery & Babalola, 2020). Social care is means tested and has become more stringent recently.

In such a context, quality supports for people with learning disabilities to achieve a good life may be difficult to find. Many local authorities report providers are leaving the sector, citing "provider distress", difficulty in attracting and retaining workforce, and many options for community living and residential support are no longer feasible. However, we found one model, available in both England and Scotland, of personalised and effective service support that may be worth considering. There are other examples however, outside of the service context, with a focus on building community connections and capacity to welcome and include people with disabilities included here.

Real Life Options

https://reallifeoptions.org/

Real Life Options is a registered charity established in 1992 supporting people with learning disabilities and autism in England and Scotland. It offers a range of services based on supporting more choice and greater control in their lives, enabling individuals to achieve their potential.

Real Life Options supports approximately 1600 people and employs over 2,000 staff across almost 50 local authorities. Their model of support and enablement is based on key essentials that contribute towards living a full and happy life as shown in Figure 4 below.

Two core principles are '… having a voice that is heard and choices in the way we live our lives …'. The role of the agency is to support people to live a life where they enjoy positive relationships and have a sense that they belong; where they have a safe place that they call home and are enabled to enjoy good health and wellbeing.

FIGURE 4. REAL LIFE OPTIONS MODEL
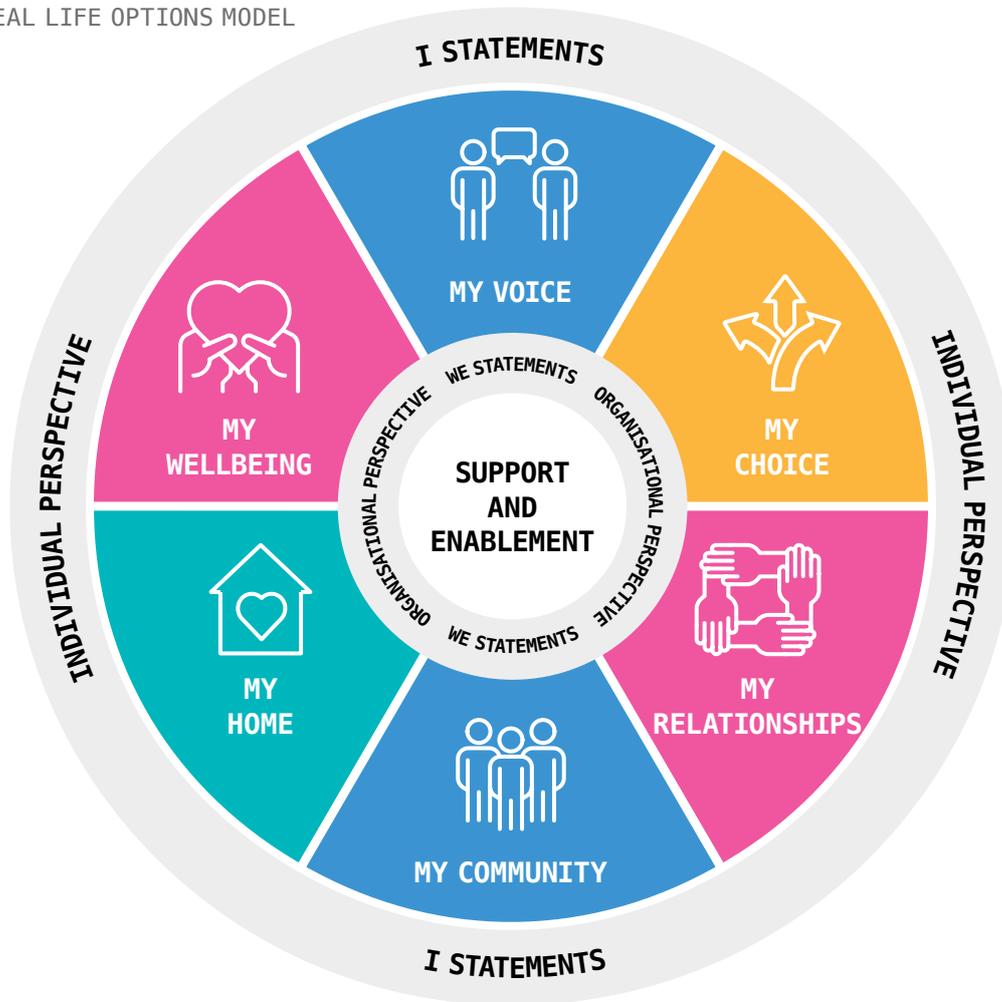
Copyright 2019 Real Life Options

Implications

- A large organisation similar to many service providers with national footprint;

- Appears to be an integrated model encompassing all parameters of having a good life in an holistic way;

- Relationships with families and others are values and facilitated;

- No evaluation reports are available as to how this translates for the person;

- May be useful in scaling up person-centred and individualised supports; and

- Operating in a context of markets with some similarities to Australia.

Other community building programs in the UK

A network of organisations focussed on building communities and connecting people works together to develop useful and practical projects to welcome and include all citizens including people with disabilities. These organisations are strongly aligned in values and approaches and collaborate on various projects through partnerships. Three key organisations a have strong track record in undertaking projects that put community first and develop connections across individuals, neighbourhoods, groups, businesses and other organisations.

Inclusive Neighbourhoods Ltd.

http://inclusiveneighbourhoods.co.uk/

Based in Sheffield, Inclusive Neighbourhoods Ltd. led the early development of Local Area Coordination in England and Wales as an approach to supporting individuals, families and communities to build their resilience, nurture and share their gifts and skills and build and pursue their vision for a good life. It also undertakes international projects in partnership covering other LAC initiatives and person-centered active support.

Local Area Coordination (LAC) Network UK

https://lacnetwork.org/

The LAC Network was established to support the ongoing development of the LAC model in England and Wales. It is comprised of member groups.

Community Catalysts

https://www.communitycatalysts.co.uk/

This organisation's focus celebrates the strength of people and community. It offers a range of skills and experience in helping local people help other local people to live a good life, to be connected to and contributing to their community. Projects include working with people to develop community enterprises, helping organisations to create the conditions where people can follow their dreams.

Implications

- All focus on good lives for people with origins in disability movements;
- Focus is communities not services;
- Depth of expertise in community capacity building and connecting people;
- Linked to LAC and NDIS in Australia;
- Many innovative examples; and
- Projects are evaluated.

CANADA

While overarching disability policy and income support rests with the central government, disability support services in Canada are provided at the provincial level. It is fair to assume that all provinces offer personalised services and supports and support individual funding to some degree. There are, however, differences in the extent to which this is realised for all citizens with disability. Canada has been very interested Australia's NDIS with a view to implementing a similar scheme nationally.

Individualised approaches have been underway in Canada for decades so there is considerable practical experience and shared learning in organising supports around a good life. Several provincial and local organisations have fostered and supported people with disabilities and families in person-centred approaches and community inclusion for many years. These organisations typically act as resource hubs rather than provide direct services.

Vela Canada

https://www.velacanada.org/

Vela is a non-profit organisation that provides information and mentoring to individuals with disability and their families or allies, to take greater control of his/her life by exploring ideas and options that can lead to customised, inclusive and creative supports.

Vela was established in 1990 in British Columbia. Vela is a leader internationally, in the creation and support of microboards having created more than 1100 of these. A Microboard™ is a small (micro) group of committed family and friends (a minimum of 5 people) who join together with the individual to create a non-profit society (board). This group then guides the process to:

- plan his/her life;
- brainstorm ideas;
- advocate for what they need;
- monitor services and ensure they are safe;
- connect to his/her wider community; and
- do fun things together.

In 2009, Vela embarked on supporting people to access and manage Individualized Funding through Community Living BC. This allows the person to choose someone to receive the funds directly and then organise the supports needed.

Implications

- Based on vision of a good life for the person;
- Strong on choice and control for the person;
- Aligned to individualised person-centred approaches;
- Long standing and proven positive outcomes;
- Supports the navigation of complex systems (like NDIS);
- BUT largely geared towards people with family/ allies; and
- May have useful ideas, approaches for people with few or no family contacts.

Innovative Life Options Manitoba

http://www.innovativelifeoptions.ca

Established in 2000, Innovative Life Options Inc. (LIFE) is a province-wide non-profit organisation that serves as a resource hub offering information, guidance and support to individuals living with an intellectual disability and their supporters. Engaging in a person-centered approach, LIFE empowers individuals to create the quality of life that they desire within the framework of valued and meaningful relationships. LIFE believes that relationships and community connections are integral to a person's success and satisfaction in their life. LIFE is founded on the following core values:

- All people deserve to have opportunities to explore interests and design the life of their choosing;
- People with disabilities belong in the community;
- All people deserve to be treated with respect and dignity;
- All people should have opportunities to explore personal growth;
- All people change and thus shouldn't be restricted due to previous choices or life circumstances;
- Focusing on relationships, gifts, capacities, and celebration leads to connectedness and increased safety;
- Relationships are directly related to quality of life. More rich and diverse relationships result in increased quality of life; and
- People flourish when gifts and capacities are recognised.

Similar to Vela, LIFE supports people to access individualised funding offered by the provincial government through their In 'The Company of Friends' (ICOF) model. This model is available to those who wish to self-direct and manage their own lives rather than receive residential or day services from an agency. These funds have been used to support people to move into their own home.

Implications

- Similar to Vela – provides information and support;

- Aligned to individualised person-centred approaches;

- Core focus is on relationships and being in the community;

- Geared to families but do support individuals; and

- Some aspects may be useful for those providers supporting people in group homes with few community connections and relationships.

NORDIC COUNTRIES

Scandinavian countries were amongst the earliest adopters of policies to close institutions and shift to community living options for people with disabilities. As outlined in the earlier section on theories, Normalisation theory underpinned these efforts. Nordic countries (Scandinavia and Finland) are considered to be distinct examples of well-developed welfare states (Kuznetsova & Yalcin, 2017) and have strong traditions of equality and inclusion of vulnerable people in society. Essentially these are social systems that value social cohesion and connectedness.

Currently, disability support is funded nationally and administered through local authorities. Support includes income benefits adequate to meet the person's needs, housing support through social housing and support for employment and day activities. Essentially these address the value of social structures and arrangements that provide universal access to housing, healthcare etc.

There is a note of caution to be taken here. Recent policy shifts to more marketised services in Nordic countries have raised concerns for people with intellectual disability. Some commentators argue that the contracting of services to private operators by some local authorities in Sweden has reduced the freedom of choice for people with disability and the staff supporting them (Trygged, 2020). A further study from Norway reported that the number and quality of services has declined and was found inadequate for 45 of 57 municipalities (Dahl, 2018).

Implications

- Generic supports – housing, education health are key to a good life for people with disabilities. Nordic countries have historically provided access to these for all;

- Social equality and connectedness as core value;

- People with disabilities access the same supports as the general population;

- BUT difficult in Australian context where access to generic supports is uneven, partial and problematic;

- Can large service providers facilitate better access/supports across these domains? and

- Marketisation of services may not always deliver the best outcomes and need to be monitored for quality.

CONCLUSIONS

Many common themes are evident across all these examples. These resonate strongly with the UN Convention on the Rights of Persons with Disabilities, as expected from countries who are signatories to the Convention. These themes are more prominently expressed as underlying values and principles and include:

- Relationships are central to the good life;

- Focus on human rights;

- Having choices;

- Having control over one's decisions;

- Person at the centre for planning and providing supports; and

- Community connections are vital.

Other commonalities can be found in many of the examples. Most jurisdictions now embrace personalisation, individualised budgets and direct funding. How these translate into a good life for the person and what impact they have, is less clear. For example, few evaluations are available in the public domain.

No one system is perfect

In canvassing many examples, it became clear that there is no single model to achieve the outcomes being sought. Elements of some services support people with disabilities to have more choice in who supports them or have more relevant and appropriate activities in their local community. However, there are many challenges to getting it right for everyone.

Changing from group home models is difficult

There were very few examples in the approaches we found where large organisations made the shift from group homes for better individualized good life models at scale. It is therefore suggested that building from scratch may be easier than 'retro-fitting' a large and complex system. As discussed in Section I above, the closure of institutions was complex, difficult and fraught with tensions across different stakeholders. Any future transition is also likely to be challenging.

Not everything is within a service purview

A good life resides in a holistic context. It rests on being loved and cared for within family and friends, having relationships and connections, having a secure home, having purpose, being safe. All this requires a community and society that welcomes and includes everyone. Not all these aspects sit within the purview of the service provider and they are not funded to do so. Yet, many vulnerable people with disabilities are isolated with few relationships, and so rely on their service for almost every aspect of their lives. The question then arises – *what is the responsibility of a service to promote and support a good life?*

Lifetimes of limitations

Historically, many people with intellectual disability currently living in group homes have lived most of their lives in service settings. Many have had a whole lifetime of limitations – limited or lost connections with family, few opportunities to engage with ordinary activities in their community, to go to work and generally to build a network of supportive relationships. Therefore, for many, the starting point is already behind and more intensive supports are needed to 'catch up' to their peers in the general community.

The review of models presented here suggests there is an opportunity for thoughtful and innovative work for large service providers in Australia to provide the leadership through partnerships to explore and test out approaches to shifting from large group homes to more individualised supported lives. This requires embarking on a journey, engaging with allies and partners along the way and learning (through evaluations) from the processes. The challenges are large and complex but starting with each person is central to this undertaking. We discuss ways to approach this in the next section.

Can a service provider [continue to] provide a 'good life' within current sector frameworks?

CONTEXT

The NDIA Report of 2017 uses 2010 Census data, now over a decade out of date. At that time, a total of 1 per cent of people with a disability in Australia aged to 64 years, lived in care accommodation: approximately 13,500 individuals. One in five of these (ie 21.2 per cent), or some 2,862 people were considered to have 'profound limitations'.

In this NDIA context 'care' means 'living in as a resident for 3 months or more at time of census'. It can be assumed that for some of these residents, that care has been life-long.

Given the history of disability in this country, as we have described in previous sections, changes resulted in a shift from institutions to group homes for many people. This population has lived in such accommodation for many years. Some lived within state run group homes which were later transferred to disability service providers. Many found themselves transferred to service providers when these government homes closed, often living away from their natural family networks, placed in homes with other individuals with whom they had little in common.

This group home arrangement is now considered by many as unsuitable for their needs (see for example, Kendrick, 2017). Research also shows that efforts to improve models of supported living have mixed and varied results (see for example Bigby, Bould & Beadle Brown, 2017). Developing "better" group homes is therefore a complex undertaking (Bigby & Bould, 2017).

FOUNDATIONS

The concept of a 'good life' for people with a disability is a recognised measure of service efficacy. It emerged at the time of transition from a service-centred approach to service delivery towards a people-centred approach as we discuss in detail above.

> What makes a good life is a personal and individual matter but most people would agree it includes opportunities for valued relationships, a secure future, choices, contributions and challenges (WA Government, 2017)

This statement became the guiding principle that established the foundation of Local Area Coordination (see above sections) in Western Australia. It goes on to describe the planning process as personalised, future-focused, responsive and reviewable. It is underpinned by a trusting relationship between the person with disability, their family, carers and a Local Coordinator. The relationship may take time to establish and requires ongoing engagement. The person with disability can choose to involve others in this process (for example, family/carers, friends, support workers, local community members, and trusted staff from specific service providers or mainstream organisations).

Importantly, the person with disability is central to the process and takes control of their plan to the extent that they wish. Their plan for a good life will be developed from their responses to the following guiding questions:

- How would I like my life to be? (Vision)
- My/our story? (Current situation)
- What would I like to build on? (Long-term goals and Plan goals)
- How can this happen? (Support strategies)

In Western Australia, the 'plan' was designed to '… reflect the individual's aspirations and goals, their current circumstances, and clear pathways to achieving their goals …' (p 4).

These 'good life' principles have formed the foundations of service delivery domestically and internationally. As we discuss earlier in this section, service providers in Canada have adopted the principles. See for example, the Plan Institute's summary of these in Etmanski et al (2014).

For Duffy (2003) a Good Life can be structured around seven aspects of what he terms 'citizenship':

Purpose – a sense of direction that is unique to us;

Freedom – the ability to shape our life to suit ourselves and our own needs;

Money – enough financial security;

Home – a place of our own;

Help – practical assistance, security and support;

Gifts – making a contribution;

Love – valued relationships, friendships and family.

A Good Life – means flourishing, not just surviving and with personal goal setting towards the next 5–10 years.

This people-centred approach remains the foundation for the *UN Convention on the Rights of People with Disabilities*, in particular:

> … the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices (Section n)

> … that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them … (Section o).

(https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf 6 December 2006, p.2).

The Australian Government has reaffirmed the following in its *Disability Services (Principles and Objectives) Instrument 2018*: https://www.legislation.gov.au/Details/F2019L00035

> People with disability have the same right as other members of Australian society to exercise choice and control in relation to the decisions that affect their lives. **(Section 5)**

> People with disability receiving disability services have the same right as other members of Australian society to receive those services in a manner which results in the least restriction of their rights and opportunities. **(Section 6)**

In the section prior to these (Section 4), the Australian Government states that:

> People with disability have the same right as other members of Australian society to services which will support their attaining *a reasonable quality of life* (Italics added).

In this context 'reasonable' may be understood as being 'fair' or 'sensible' when compared with 'other members of Australian society'. In this statement, the Australian Government places the responsibility of the attainment of this fair, sensible quality of life, on the service system.

> We would argue that it is in this fundamental aspect – that the two concepts of 'quality of life' and a 'good life' – can be seen to have different sources.

'Quality' implies a measurement is possible. It connects with the service system by suggesting that this system itself can be measured in the manner and services which it supplies. Quality can also be determined by external sources, such as those who provide funds for services, or by an auditing process. Once agreed with, quality tends to remain relatively static. It also tends to be determined for the 'common good' rather than for the 'individual'.

A 'good life', on the other hand, rests on the individual determining a definition for themselves. It is very personal, very individualistic, and while it may have external influences, is not determined by anyone other than the individual concerned. It is dynamic, that is, it changes over time. It requires regular updating, through agreed processes.

Each of us would most likely determine a different definition of a 'good life' for ourselves. Such definitions are influenced by our age, our gender, our life experiences and our current personal circumstances. Such a definition should be considered as 'dynamic' rather than 'static' and as our circumstances change, so our concept of the good life, for us, changes with them.

CHALLENGES

This individualistic approach to determining a good life, while it is a great strength, is also its greatest challenge.

For people with a disability, living in group accommodation, and whose lives are bound up with a service system designed to contend with the many, rather than the few, articulating individual needs becomes a challenge for them and for the service that has been established around them.

It is a challenge for the service system to offer individual approaches to care and support. The funding for such intense, personalised approaches is simply unavailable. How to support an individual's desire for a good life, when funds are restricted?

A GOOD LIFE WITHIN A SERVICE SYSTEM

As we discuss in detail above, a people-centred, individual approach underpinned the growth of Local Area Coordination (LAC), first in Western Australia, and then later in other Australian states.

In Western Australia, where the concept of a 'good life' was the foundation for all LAC undertakings from the early 1990s until recently, the service system developed an approach in which services were built around the person's individual pathways. These pathways were determined through a processing of planning (see further below), and were supported by a flexible approach to service delivery and to funding.

LAC, as it grew outwards from Western Australia, changed within its new contexts. For the purposes of this section, however, we shall continue to draw on the LAC WA Model, rather than others that emerged domestically and internationally. Over time, definitions of a good life were called for from people with disabilities themselves, and the WA LAC program then adopted the following statement:

> What makes a good life is a personal and individual matter but most people would agree it includes opportunities for valued relationships, a secure future, choices, contributions and challenges.

What is important here is that a good life is not determined by bricks and mortar, or by wealth. Security is critical, as are valued relationships (see further below), and the capacity for choice, for making a contribution and for having challenges in life. This is a definition to which we can all subscribe – it does not mention 'disability' 'impairment' or any other physical or psychological conditions. It also does not measure itself against any other criteria, as it is very personal.

For WA LAC, this approach became the guiding framework for their planning for service delivery to people with a disability. We discuss one approach to this planning further in more detail below. It is this planning, and taking the time to do it right, which enriches the individual and the service system, while at the same time seeking alternatives beyond the system itself.

In Part 5.1.3 above, we describe a service developed from this LAC model, My Place.

TOWARDS A GOOD LIFE (WITHIN SUPPORTED ACCOMMODATION): SOME ASSUMPTIONS

Here we take some of these principles and consider some assumptions to 'fit' with the people presently living within Australian service provided accommodation.

We have developed the following assumptions about an individual who may be planning for her/his 'good life':

> They have few or no family connections and have been 'in care' within the service system for most of their adult lives. They may have been 'moved around' this system prior to coming to their current provider, and in that process, may be carrying a 'story' about themselves, such as that they are 'hard to serve'. They may have few, if any, external connections, other than those arranged by their service provider; and their primary human contact remains with staff. They may be co-located in accommodation that includes some people with profound limitations, and this may mean that their own opportunities are more limited.

These remain assumptions – they need testing. Our discussion now turns to how planning for the people currently in situations as described above, can be undertaken while holding 'true' to the purpose of enabling a good life.

GUIDING QUESTIONS

Four broad questions that underpin the whole planning process are as follows:

- How would I like my life to be? (My personal vision of the future);

- My story (Current situation);

- What would I like to build on? (Long term goals and plan goals); and

- How can this happen? (Support strategies/ decision making).

While the WA LAC program was designed primarily for people who were living at home with their family members, we would suggest that planning for a good life can also be fundamental to people living in supported accommodation, if the service system supports the process at all levels and maintains the person as central.

STEP 1: TOWARDS A GOOD LIFE — PLANNING

As the WA LAC experience highlighted, this planning for individuals became central to the capacity of the service system to enable a good life.

First and foremost, individuals were supported in their deliberations and conceptualisations of just what a good life would mean for them. It becomes a challenge, when one's own goals have, in the past, largely been determined by others, to consider anything is possible. It is also a tendency to determine 'need' by what is on offer. This form of planning should encourage thinking 'outside the box' – rather than remaining fixed to what the service system as it is currently designed, can offer.

Much time needs to be taken to ensure that free choice and free decision-making are truly supported.

This planning is designed to be jointly undertaken with the individual concerned and relies on the service system taking the process seriously, expending funds to ensure it is done well, and then following through with agreements made.

We suggest a two-step process to this planning. The first draws on Uri Bronfenbrenner's ecological systems model. The second then develops the individual considerations using the four questions process as above.

Step 1: Ecological Systems Approach

As mentioned above, even if an individual has been within a service for some time, changes in staffing, and personal circumstances may mean that the service does not actually 'know' that individual well enough to begin to plan for a good life with them.

We therefore suggest that an ecological systems framework be developed for each individual. Using the Bronfenbrenner model (1975) as described in Figure 5 below:

FIGURE 5. ECOLOGICAL SYSTEMS MODEL
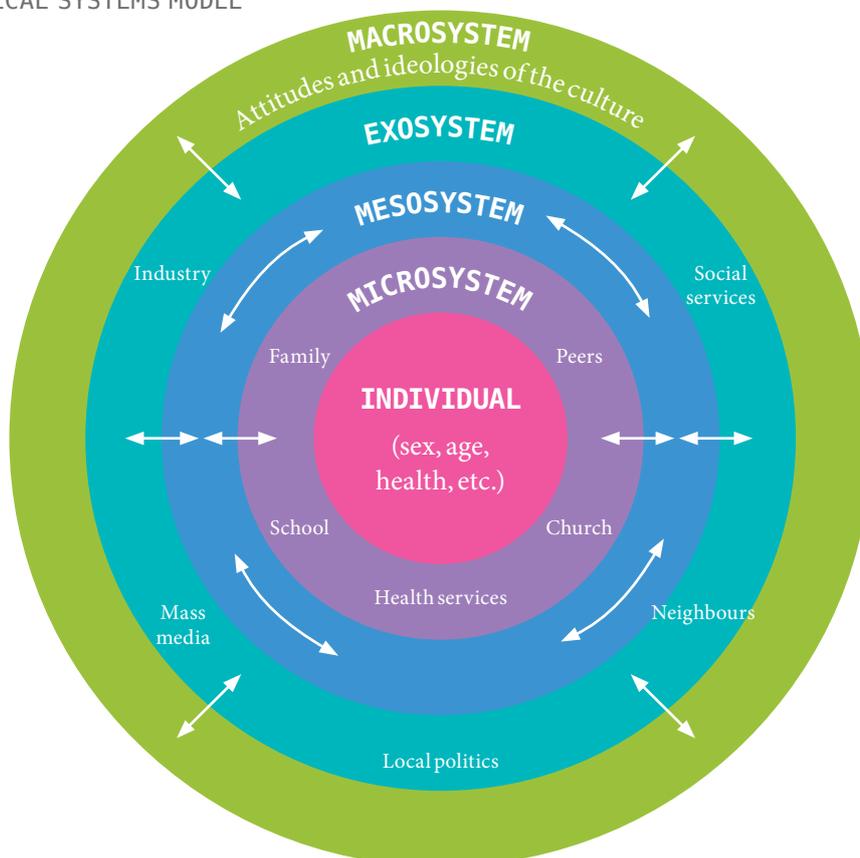
Bronfenbrenner originally created this model for children, hence the focus on 'school, church, family'. However, this model has been expanded subsequently, and is now more commonly utilised across all age groups.

The microsystem has the most direct impact on the individual. The mesosystem locates where these influences link and interconnect around the individual. The greater the connections – largely developed through family and parents – the greater the impact of the mesosystem. The exosystem has impacts on the individual but through links that are not direct. These include events where the person is not an active participant but which affect them. For example, a staff member with whom a person had trusting relationship may be transferred to another role, thereby causing some grief to the person.

As the model highlights – moving from the individual at the centre – outwards – enables consideration of the many influences that may impact on the individual's life.

While undertaking a major evaluation of disability programs in New South Wales in the mid-2000s, we used this approach to enable a centering of the individual within the then service system, and to determine where the strengths and weaknesses of that system were located.

In our direct experience, the paucity of influences is often the determining feature. In considering the assumptions detailed above, it is highly likely that our individual has few, if any, family members, may have no peer support, no longer attends school, or even work-related activities, and therefore the microsystem may be limited to activities arranged and determined by the service provider alone. This then impacts directly on the mesosystem, which has few, if any, interactions outside of those organized by the service system. *It is here that opportunities lie to begin to build a 'good life'.*

QUESTIONS TO BUILD THE MODEL

Building from the model begins around the *Individual*. These questions may be answered from information held by the service system.

> Who is the person and what are their needs and abilities?
>
> How old are they?
>
> How long have they lived in the current setting?
>
> Where did they live previously?
>
> What is their gender?
>
> Do they currently live communally?
>
> If so, who are the people with whom they live?
>
> What is their health status?

The next series of questions will draw on information within the service, and through interaction and conversation with the individual concerned.

What interests does the individual have? Do they follow a particular sports team (for example); what do they enjoy doing most?

Family members: who are they? Where do they live? How often are they in touch? Or visit? Do they take a direct interest in the individual – i.e. enabling external activities etc.

Peers: Who are the individuals that share the accommodation? Are they friends? Do they seek to do activities together? Or separately? Has the individual shared with them for a long time, or just recently? Are there other people that may be considered as peers? Who are they? How do they keep in touch? Do they visit? Do they take a direct interest in the individual – i.e. enabling external activities etc.

School/Work/Church: Is the individual still a student? What peers are connected with school? Are there activities arranged outside of the service by the school? If the individual undertakes work activities or attends church services – similar questions can be posed.

Health services: Is the individual connected with health services? If so, which ones? How often do they attend? Or do they visit the site?

In considering the *mesosystem* – do any of the above interconnect? For example, are peers located within work places? Or within schools? Do volunteers at church also visit at home? Who organises external activities (outside of the service)?

In this way, a schematic of interactions can be identified. In our evaluation project, we undertook this with the individual and a large sheet of butchers' paper – some textas and gave the process the time it needed.

As the interview/conversation develops, connections may also be identified with the *exosystem*. For example, external human services may be interacting with the individual on a regular basis; or there may be neighbours to the home accommodation who interact with residents, through barbeques etc. etc.

WHO ASKS THE QUESTIONS?

The response to this is: who knows the individual best? If there is a family member or peer who is identified as being this person, they should be involved in the conversation/discussion focusing on the questions above. Their knowledge of the individual will enable 'gaps' to be filled in, and their presence will add to the sense of trust and security necessary to enable a positive outcome.

In addition, this known peer/family member is also then involved in ensuring that the 'good life' being planned for has some future. He/she can begin to take responsibility for some aspects of any decision-making. They can act as a safeguard, to ensure that any decisions are acted on in the future.

It is highly recommended that there be an 'external' individual included in this process if possible. While it may be that the most trusted person is a staff member, this can limit the possibilities to what the service can provide rather than a broader vision. Having another 'ordinary citizen' perspective can bring ideas not thought of.

STEP 2: TOWARDS A GOOD LIFE – ACTIONS

We now return to our overarching questions. We have built up a substantial body of evidence about our individual. We have involved her/him in a series of conversations about the present day, and about goals/dreams/ideas about the future. We now need to shape in more detail responses to our four overarching questions:

How would I like my life to be? – Are there any other issues/goals/plans that have not emerged during conversations?

My story – While this should be reasonably clear from material already gathered, have we missed anything?

What would I like to build on? Are there goals that are short term/medium or long term? Is there any priority being given?

How can this happen? Who needs to be involved? How often? What needs to happen next? How will goals be achieved? What resources are required? Does anything (current) need to change?

An agreement as to next steps is then finalised. This will reflect the individual's aspirations and goals, their current circumstances and clear pathways to achieving their goals (WA Disability Services Commission, 2017). It will be a dynamic agreement, one that will be reviewed on a regular basis. It will form the framework that guides service delivery to our individual and will support a strengths-based approach to self-determination and goal achievement. With permission, it will be shared with key decision makers to ensure that everyone involved with that individual is aware of actions agreed to and how the person might achieve their goals.

IMPLICATIONS

Scaling up this approach will prove a challenge for a service provider with a large number of clients.

There will be issues associated with resources (ie: staff to do the planning; time constraints, inviting peers to participate etc) as well as issues associated with reform challenges: such as alterations to existing programs, and will these then affect others? The financial cost associated with an approach such as this may also prove a challenge.

As it is now a decade since the Productivity Commission report, it is timely to reflect and take action. It may be prudent to build alliances, partnerships of service providers, community groups and/businesses to undertake a small, discrete pilot adopting these approaches with a view to generating new ideas and innovations. This could be evaluated formatively as well as for outcomes and cost/benefit. While it may be a complex undertaking, a pilot or demonstration project could develop new ideas and learning.

The path to good lives in 2030: opportunities and challenges

This section explores the question of what community living and having a good life means for people with disabilities in the coming decades?

Our review of many examples in this monograph and from our own involvement over several decades in Australian and international settings, certainly confirms many people with disabilities *are* living a good life. People have been supported to make choices about where that want to live; to have their own homes, to be part of their communities and to have meaningful relationships with families and friends. For many, this has been the case for years. They are supported to make choices about their life, and to have considerable say in the delivery of supports.

It can also be argued however, that for a large population of people with disabilities, this has not been their experience. The current challenge faced by the disability sector in Australia is how to move forward to supporting more choices, how can the current system engage with families and ordinary citizens, garner support from wider community and create more inclusive and cohesive society for all?

We offer the following issues for consideration, representing opportunities as well as challenges.

A GOOD LIFE IS MORE THAN A SERVICE

In considering what makes a good life, many elements have been described: a sense of belonging, being respected, having a broad network of relationships that enrich and support. Much of this sits outside the domain of services and involves families and other friends and allies as well as the wider community. Yet many people with disability do not have these relationships or connections. Parent advocate Margaret Ward describes the good life as a 'three-legged stool'. It rests on having families and friends, a welcoming and inclusive community as well as a paid service. If any one of these is missing, the good life cannot be realistically achieved. No one 'leg' of the stool can provide the good life. Services alone cannot do this; families cannot meet all the needs, and the community may lack the knowledge and skills.

Services however, are often the only presence in a person's life and are then they are left with the moral and practical challenge of trying to facilitate for all three domains – a challenge that is usually not acknowledged or funded.

STARTING FROM SCRATCH

As outlined earlier, many people currently supported in services have lost connections with family, few relationships, have little experience in being part of the community – having lived a life of relative isolation with few opportunities to imagine what their good life might look like.

They may also not be able to express their wishes verbally or have complex needs. Here, a service will be starting from scratch getting to know the person, offering new experiences and developing opportunities. This requires patience but can provide positive experiences for the person from which to grow.

TRANSFORMING SERVICES IS A JOURNEY NOT A QUICK FIX

Transforming a service system to achieve sustainable and positive change requires developing a vision and planning at many levels. Pursuing a good life for everyone takes time and invariably involves setbacks as well as progress.

A good life is also often described in aspirational terms, but a service then must transform this into operational actions. In reality, this is more like a marathon journey rather than a one-off project. We need to keep at it, one person at a time.

THERE ARE OPPORTUNITIES FOR LEARNING ALONG THE WAY

Embarking on such a transformative process will inevitably generate new ideas, new issues and new problems. All of these provide opportunities not only for learning within, but also for others who may follow.

Tracking, recording, and reflecting on these should be an integral part of the process. Involving other partners, forming alliances and sharing knowledge and ideas widens the perspectives from which all stakeholders can benefit. By working within alliances and partnerships, such learnings are shared by all involved, saving resources.

While there are gaps in disability research in Australia, there is considerable evidence about models of support, about what works and what does not. Part of the learning journey, therefore, should incorporate the building of evidence through partnerships with researchers and the translation of that evidence to practice.

CURRENT POLICY SETTINGS ARE PROMISING

For a considerable period, Australia has been embracing policies of individualisation, person-centredness, choice and control. The objectives and aims of the NDIS are strongly aspirational for a good life for all people with disability within the scheme. There remain many complexities and difficulties in the implementation of the Scheme and some concerns the original intent is slowly being eroded. However, at its core the NDIS is founded on people with disability having control over and choices about their lives. It was also a shared project involving, people with disability, families, allies, service providers and policymakers along the way. There is still a strong will and commitment to make the scheme work.

6. CONCLUSIONS

This monograph has covered a range of issues and perspectives covering the history, policies and challenges in the disability sector. As stated at the outset, these have been presented from the perspective of service providers hence offer only a partial picture.

In considering the future it will be crucial to ensure people with disabilities and families are considered front and centre to the conversation.

By way of conclusion, we offer some thoughts on the current challenges and possible opportunities for the sector as a whole.

Article 19 and independent living

Article 19 of the UNCRPD outlines the right to live independently in the community. It sets out the steps towards achieving this life – making choices about where to live, having access to a range of services and support as well as to mainstream services and facilities in the community. In short, it argues for the same choices and opportunities as for all citizens. This lays down a challenge for those jurisdictions where segregated services and institutionalised care are still the default option, when individualised personal care is the required norm. Change in these situations requires a complete paradigm shift, a shift it can be argued, that started in this country with the NDIS.

It should be noted here that even decades earlier, the cash payments for care programs in Europe arose through an alliance of the independent living movement seeking choice and independence and the neoliberal "new right" seeking efficiencies through the development of markets – indeed a paradigm shift (Edwards, 2019).

In ratifying the convention, Australia, like many other countries, has also set the bar for how people with disability should live. We have seen examples in our research where signatory countries have also undertaken cuts to budgets for support, reduced eligibility parameters for receiving support in an attempt to deal with flagging economies.

The question now arises: is Australia's implementation of the NDIS facing similar pressures – both fiscal or ideological?

Competing discourses in disability and public policy

As discussed throughout this monograph, the discourses of rights, personalisation, choice and control, globally, have been evident in the disability movement for several decades. Many jurisdictions have formulated policies that reflect these goals, developed funding systems that aim to deliver better outcomes for people with disabilities. This has driven greater advances in possibilities for people with disability in how they live their lives and their position in wider society.

As we have argued however, this same period has also heralded and later entrenched public policies based on neo-liberal ideologies, new public management theories and their associated applications in the marketisation of the human services. This too is a global phenomenon. These marketisation and human rights discourses tend to collide. They appear to have little in common. For those vulnerable in society, these discourses impinge on their daily lives within the service sectors that have been designed to provide care and support.

The issue to unpack here is the nature of competing discourses wherein these two ideas rival for dominance. The devolution to markets to provide services to vulnerable people has been found wanting in sectors such as aged care, corrections, childcare etc. Disability services have been similarly under scrutiny. We would argue that leadership *within* the sector is urgently required. Further to our analogy of the three-legged stool (p. 103 above), waiting for one part of the sector (i.e. government) to set the agenda may not be the response to the challenge required. Safeguarding against the apparently hegemonic power of the market is in the hands of the service sector – particularly that not-for-profit, person-centred component.

The ongoing challenge will be to continue to support the human rights approach to care, while ensuring that the marketisation approach does not dominate.

Ongoing tensions

It is apparent that disability issues have always brought tensions and dilemmas for those living and working within the sector. Tensions of competing policy intents as outlined above, differing perspectives on theory – as fundamental as seeing the "problem" of disability as individually determined or socially constructed, all play out by impacting on people with disabilities, and on those who work with them as well as the system itself.

For most people with disabilities, the options of choice and control have been key in improving living options and lived experiences. Self-direction brings freedoms but it also brings a devolution of risk and responsibility to the individual as well.

This can be particularly risky for people with cognitive impairments, such as those with intellectual disability or brain injury, who may be vulnerable to unscrupulous markets. The choice versus care tension is another debate that requires further analysis. Thill (2015) argued that choice and control, rather than voice and listening, as the main strategy for service reform, can actually be burdensome for many people with disability.

The NDIS market has also created tensions for the disability workforce. As the system moves more towards "cash for care", markets will inevitably drive cost-cutting exercises and underpricing of service. We are continuing to witness a steady decline in conditions for disability workers. Lowering prices translates to lower wages, fewer skills and less training and increased casualisation. In the long term, this runs the risk of diminishing the flexibility and quality of services. For example, the recent COVID pandemic revealed problems of casual support workers working across several sites and organisations in the aged care sector. David and West (2017) propose such a scheme could become an "Uber-style wild west", whereby participants use on-line platforms to recruit and roster support workers.

This could also bring benefits for many people offering flexibility and control over their supports. The risks of inaccessibility for people who perhaps are not IT literate or who have cognitive impairments are certainly a factor, but also provide new opportunities for developing user-friendly and inclusive technologies that are manageable for everyone. With appropriate training such innovations could increase competencies and skills, and capacity for choice and decision making.

While new forms of technology – including social media – have had dramatic impact on users, and offer opportunities for better forms of communication, it should also be recognised that the regulators (in particular, governments) are increasingly keen to use technology in order to create what are perceived to be 'efficiencies' but are effectively cost cutting exercises. The recent 'robo-debt' experience in Centrelink, with all its associated impacts on individuals, is a case in point.

We would argue that all technological responses to human demands need to be tempered with appropriate safeguards, and should always involve a form of evaluation, to ensure that such responses are not creating further challenges.

There is also a tension for those service provider organisations which traditionally came from the very communities they sought to serve but now find themselves somewhat detached from those communities. Growing dependence on government funding, with increasingly contractual arrangements constrain what can and cannot be done can absorb an organisation's resources to be overly focused on meeting funding obligations and lose the sense of accountability to the community. This is especially so for those not-for-profits that were set up by ordinary community members and parents. A for-profit business is more likely to be accountable to shareholders or the fiscal bottom-line.

Beyond systems and funding?

As we have argued, living a good life where one is supported in everyday choices, to be safe, to participate in one's community and above all to have loving supportive relationships, means more than being a consumer or participant in the service system.

Building better lives for people with disability will entail all sectors of Australian society. Many examples of good lives for people with disability include informal relationships and supports alongside those provided by services and funded through government.

The challenge ahead is to develop ways to garner support from ordinary Australians, community groups, neighbours and businesses. This needs to occur both at the level of individual support as well as through to the systems level. For those people with few ordinary relationships, be that with family, friends or currently totally reliant on services, current NDIS arrangements will need expansion.

It will require leadership from the disability research sector, universities and vocational education providers to join with service providers and community organisations to build the necessary alliances for this goal. This would facilitate bringing together the research evidence, to inform better programs and supports, to prepare an effective and committed workforce and create more inclusive communities. We recognize that this is not a short-term agenda. It requires long term planning and unwavering commitment. It will require safeguarding against the tendency to efficiency, as opposed to effectiveness. It will need to ensure that we learn from the past and continue to support all those who work towards an inclusive future.

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APPENDIX A

Key reports: Federal Government and agencies

PARLIAMENT OF AUSTRALIA

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DEPARTMENT OF SOCIAL SERVICES

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A New System for Better Employment and Social Outcomes. Report of the Reference Group on Welfare Reform. (McClure P, Chair). https://www.dss.gov.au/sites/default/files/documents/02_2015/dss001_14_final_report_access_2.pdf

February 2009
Pension Review Report (Harmer) https://www.dss.gov.au/about-the-department/publications-articles/corporate-publications/budget-and-additional-estimates-statements/pension-review-report

2000
Participation support for a more equitable society: final report of the Reference Group on Welfare Reform. (McClure, P Chair). https://catalogue.nla.gov.au/Record/533643

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DEPARTMENT OF FAMILIES, HOUSING, COMMUNITY SERVICES & INDIGENOUS AFFAIRS

2012
Vision for Sustainable Supported Employment. Report by an Advisory Group. https://www.dss.gov.au/sites/default/files/files/disability-and-carers/policy_research/EE_version_%20Vision_for_Sustainable_Supported_Employment.pdf

AUSTRALIAN BUREAU OF STATISTICS

Experiences of Violence and Personal Safety of People with Disability. 2016. Released: 28/11/2018. https://www.abs.gov.au/ausstats/abs@.nsf/0/7F8F3ECBBA976E2CCA258352000F295E?Opendocument

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Released: 18/10/2016.
https://www.abs.gov.au/ausstats/abs@.nsf/0/C258C88A7AA5A87ECA2568A9001393E8?Opendocument

Disability, Ageing and Carers, Australia: Summary of Findings, 2012
Released: 13/11/2013
https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/5968BE956901DD79CA257D57001F4D89?opendocument

Disability, Ageing and Carers, Australia: Additional data cubes, 2012
Released: 13/11/2013
https://www.abs.gov.au/ausstats/abs@.nsf/0/82127C9F2A7B7CABCA257C21000D8B26?Opendocument

Unmet Need for Formal Assistance, 2012.
Released: 15/09/2015
https://www.abs.gov.au/ausstats/abs@.
nsf/0/1FE57ED300CC4F76CA257EC00012BB44?
Opendocument

Intellectual Disability, Australia. 2012.
Released: 30/06/2014
https://www.abs.gov.au/ausstats/abs@.
nsf/0/437CAC7624D4150CCA257D0400129092?
Opendocument

Caring in the Community, Australia. 2012.
Released: 25/06/2014 https://www.abs.gov.au/ausstats/
abs@.nsf/0/E243871471015E4BCA256943007F0603?
Opendocument

Autism in Australia
Released: 04/06/2014
https://www.abs.gov.au/ausstats/abs@.nsf/0/
C7E33200027E52C1CA2578D900154327?
Opendocument

Young People with Disability, 2012
Released: 30/04/2014
https://www.abs.gov.au/ausstats/abs@.nsf/0/
FCF8C781B2CB45AFCA257CC9001442E3?
Opendocument

Aboriginal and Torres Strait Island People with a
Disability, 2012.
Released: 18/04/2017
https://www.abs.gov.au/ausstats/abs@.
nsf/0/176B7899CCE3B173CA257D9E00112463?
Opendocument

Disability and Labour Force Participation, 2012
Released: 05/02/2015
https://www.abs.gov.au/ausstats/abs@.nsf/0/
C7C72D7706E9BED0CA257DE2000BDC60?
Opendocument

Disability Variables, 2006
Released: 03/10/2006
https://www.abs.gov.au/ausstats/abs@.nsf/0/
CCEAE13918629FB0CA2571F40020A8DC?
Opendocument

*Disability, Ageing and Carers, Australia: Summary of
Findings, 2003*, Category 4430.0, Canberra, 2004, p33,
Table 14.

Disability, Ageing and Carers, Australia: Summary of
Findings, 2003.
Released: 15/09/2004
https://www.ausstats.abs.gov.au/Ausstats/subscriber.
nsf/0/978A7C78CC11B702CA256F0F007B1311/$File/
44300_2003.pdf

PRODUCTIVITY COMMISSION

July 1990
Aids and Appliances for People with Disabilities
https://www.pc.gov.au/inquiries/completed/disability-
aids-appliances/03aapwd.pdf

1994
Workers' Compensation in Australia.

June 1995
Charitable Organisations in Australia
https://www.pc.gov.au/inquiries/completed/
charity/45charit.pdf

July 2004
Review of the Disability Discrimination Act 1992
https://www.pc.gov.au/inquiries/completed/disability-
discrimination/report

March 2009
Contribution of the Not-for-Profit Sector
https://www.pc.gov.au/inquiries/completed/not-for-
profit/report/not-for-profit-report.pdf

August 2011
Caring for Older Australians
https://www.pc.gov.au/inquiries/completed/aged-care/
report

AUSTRALIAN NATIONAL AUDIT OFFICE

(all reports can be found on website at: https://www.anao.gov.au)

April 1996
Competitive Employment Training and Placement Services

November 1999
Special Benefit

March 2000
Home and Community Care

February 2002
Home and Community Care Follow Up Audit

March 2005
Centrelink Audit

June 2005
Helping Carers: the National Respite for Carers Program

October 2005
Administration of the Commonwealth State Territory Disability Agreement

June 2006
Funding for Communities and Community Organisations

May 2007
Distribution of Funding for Community Grant Programmes

May 2007
Administration of the Community Aged Care Packages Program

December 2008
Disability Employment Services Performance Audit

April 2011
Service delivery in CRS in Australia

May 2013
The Award of Grants under the Supported Accommodation Innovation Fund

June 2013
Cross Agency Coordination of Employment Programs

May 2015
Management of Smart Centres Centrelink Telephone Services

January 2016
Qualifying for the Disability Support Pension

March 2016
Early Intervention for Children with Disability

October 2017
Decision making controls for Sustainability – National Disability Insurance Scheme Access

November 2018
Disability Support Pension Follow On Audit

June 2019
National Disability Insurance Scheme Fraud Control Program

2019–2020 (proposed)
Administration of the Home Care Packages Program National Disability Insurance Agency's management of outsourced Partners in the Community

AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE

(All reports are available on website at: https://www.aihw.gov.au)

April 1998
Disability support services provided under the CSDA 1996.

1999
Australia's Welfare.

November 2000
Disability support services provided under the CSDA 1999.

July, 2002
Unmet need for disability services: Effectiveness of funding and remaining shortfalls.

2003
Australia's Welfare

November 2004
Disability support services 2002–2003: the first six months of data from the CSTDA

February 2006
Disability and disability services in Australia.

September 2009
Life Expectancy and Disability in Australia 1988–2003.

November 2008
Disability in Australia: Intellectual Disability.

April 2009
The geography of disability and economic disadvantage in Australian capital cities.

November 2010
Health of Australians with disability: health status and risk factors.

January 2011
Disability support services 2008–2009: report on services provided under the CSTDA and the NDA.

July 2011
Younger people with disability in residential aged care: update from the 2009–2010 Minimum Data Set.

October 2011
Disability support services 2009–2010: report on services provided under the NDA

September 2012
Disability Support Services: services provided under the National Disability Agreement 2010–2011.

June 2014
People using both Disability Services and Home and Community Care in 2010–2011.

February 2016
Health status and risk factors of Australians with disability 2007–2008 and 2011–2012

April 2017
Life expectancy and disability in Australia: expected years living with and without disability

April 2017
Autism in Australia

June 2017
Disability in Australia: changes over time in inclusion and participation fact sheets: community living, education and employment.

July 2017
Submission to Productivity Commission Human Services Inquiry

December 2017
Access to health services by Australians with disability

August 2018
Submission into Charity Fundraising in the 21st Century

October 2018
Poverty in Australia 2018.

October 2018
Chronic conditions and disability 2015.

May 2019
Disability support services: services provided under the NDA 2017–2018.

July 2019
Pathways of younger people entering permanent residential aged care.

September 2019
People with disability in Australia.

APPENDIX B

Key reports: State Governments

NEW SOUTH WALES

NSW Law Reform Commission, *Review of the Disability Services Act 1993* (NSW), Report 91, July 1999.

People with an intellectual disability – giving evidence in court. June 2000
https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclrd/lpclrd_publications/lpclrd_reports.aspx

NSW Department of Ageing, Disability and Home Care, *Living in the Community: Putting Children First*, July 2002.

NSW Government,(2003) Government's response to the *Final Report on Disability Services, Making it Happen*.

NSW Ombudsman, *Report under Section 11(c) of the Community Services (Complaints Reviews and Monitoring) Act 1993*, 16 September 2004.

NSW Ombudsman, *DADHC – The Need to Improve Services for Children, Young People and Their Families: A report arising from an investigation into the Department of Ageing, Disability and Home Care*, April 2004

NSW Auditor-General, *Auditor-General's Report – Performance Audit – Home Care Service*

– Department of Ageing, Disability and Home Care, NSW Audit Office, October 2004, p17

NSW Parliament, Legislative Council Standing Committee on Social issues, *Making it Happen: Final Report on Disability Services*, Report 28, November 2002, p50-51.

Coalition for Disability Services, *An End to the Silence: The Crisis in Supported Accommodation for People with a Disability in NSW*, October 2005.

NSW Ombudsman, *DADHC: Monitoring Standards in Boarding Houses – A special report to Parliament under s 31 of the Ombudsman Act 1974*, June 2006,

NSW Ombudsman, *Services for Children with a Disability and Their Families: Department of Ageing, Disability and Home Care (DADHC): Progress and Future Challenges*, May 2006, foreword.

July 2007
Intellectual disability and the law of sexual assault
www.lawlink.nsw.gov.au/crld
https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclrd/lpclrd_publications/lpclrd_reports.aspx

September 2018
Feedback on development of a new Disability Inclusion Action Plan.
https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclrd/lpclrd_consultation/disability-inclusion-action-plan-consultation.aspx

November 2018
Abuse and neglect of vulnerable adults in NSW – the need for action. A special report to Parliament under section 31 of the Ombudsman Act 1974. NSW Ombudsman. November.

VICTORIA

August 2010
Supervised Treatment Orders in Practice. How are the Human Rights of People Detained under the Disability Act 2006 Protected? Office of the Public Advocate.
https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/supervised-treatment-orders/52-supervised-treatment-orders-in-practice-how-are-the-human-rights-of-people-detained-under-the-disability-act-2006-protected

December 2010
Supervised Treatment Orders. Office of the Public Advocate.
https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/supervised-treatment-orders/43-supervised-treatment-orders

February 2011

Position Statement: Restrictive Interventions. Office of the Public Advocate

https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/restrictive-interventions/44-restrictive-interventions-1

December 2011

Sterilisation of children with disability.

https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/sterilisation/42-sterilisation-of-children-with-disability

June 2012

Learning from complaints: safeguarding people's right to be free from abuse.

https://www.odsc.vic.gov.au/wp-content/uploads/OccasionalPaper1.pdf

August 2012

Restrictive Interventions in Victoria's Disability Sector. Office of the Public Advocate.

https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/restrictive-interventions/44-restrictive-interventions-1

January 2013

Submission to the Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia.

https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/sterilisation/46-submission-to-the-senate-standing-committee-on-community-affairs-references-committee-inquiry-into-the-involuntary-or-coerced-sterilisation-of-people-with-disabilities-in-australia

November 2013

Betrayal of Trust: Inquiry into the Handling of Abuse by Religious and Other Non-Government Organisations.

https://www.parliament.vic.gov.au/images/stories/committees/fcdc/inquiries/57th/Child_Abuse_Inquiry/Report/Preliminaries.pdf

February 2014

Learning from Complaints: Families and service providers working together.

https://www.odsc.vic.gov.au/wp-content/uploads/OccasionalPaper2.pdf

June 2015

Reporting and investigation of allegations of abuse in the disability sector: Phase 1 – the effectiveness of statutory oversight. Victorian Ombudsman.

2017

Disability Services complaints (2007–2015)
What have we learnt so far?

https://www.odsc.vic.gov.au/wp-content/uploads/FINAL-DSC-Complaints-Data-Paper.pdf

QUEENSLAND

May 2000

Carter, W.J. The Basil Stafford Centre Inquiry Report: Review of the Implementations of the Recommendations. Key Findings. Queensland.

November 2013

People with intellectual disability or cognitive impairment residing long term in health care facilities. Office of the Public Advocate.

https://www.justice.qld.gov.au/public-advocate/activities/past/people-with-disability-residing-long-term-in-health-care-facilities

May 2014

Inquiry into the use of electronic monitoring at disability accommodation sites in Queensland. Office of the Public Advocate.

https://www.justice.qld.gov.au/public-advocate/activities/past/inquiry-into-the-use-of-electronic-monitoring-at-disability-accommodation-sites-in-queensland

June 2019

Upholding the right to life and health of people with a disability in Queensland.

https://www.justice.qld.gov.au/public-advocate/activities/current/deaths-of-people-with-disability-in-care

SOUTH AUSTRALIA

January 2005
Social Inclusion in S.A. Preschools and Schools.
https://www.education.sa.gov.au/sites/g/files/net691/f/
social-inclusion-education-2005.pdf

August 2009
*Families experience of child care services for children
with a disability.*
https://www.education.sa.gov.au/sites/g/files/net691/f/
families-disability-childcare-report-2009.pdf

June 2015
Quality Systems and Outcomes Measurement Project
https://dhs.sa.gov.au/about-us/publications/quality-
systems-and-outcomes-measurement-project

2018 –present
Ministerial Advisory Council of South Australia –
current projects

- Least Restrictive Practice
- Distinguishing trauma from disability
- Connecting parents of children and students with disability
- Funding for disability services (continuing project)
- Professional Learning for the team of educator and support officer working with children and students with autism (continuing project)

https://www.education.sa.gov.au/department/about-
department/minister-education-and-child-development-
decd/ministerial-advisory-committee-children-and-
students-disability/maccswd-projects

APPENDIX C

Non-government organisations: some links

Autism
https://www.autismspectrum.org.au/about-autism/our-research/research-findings

FASD
https://www.nofasd.org.au

Facilitated Communication
http://www.annemcdonaldcentre.org.au/facilitated-communication-training

Post Polio Syndrome
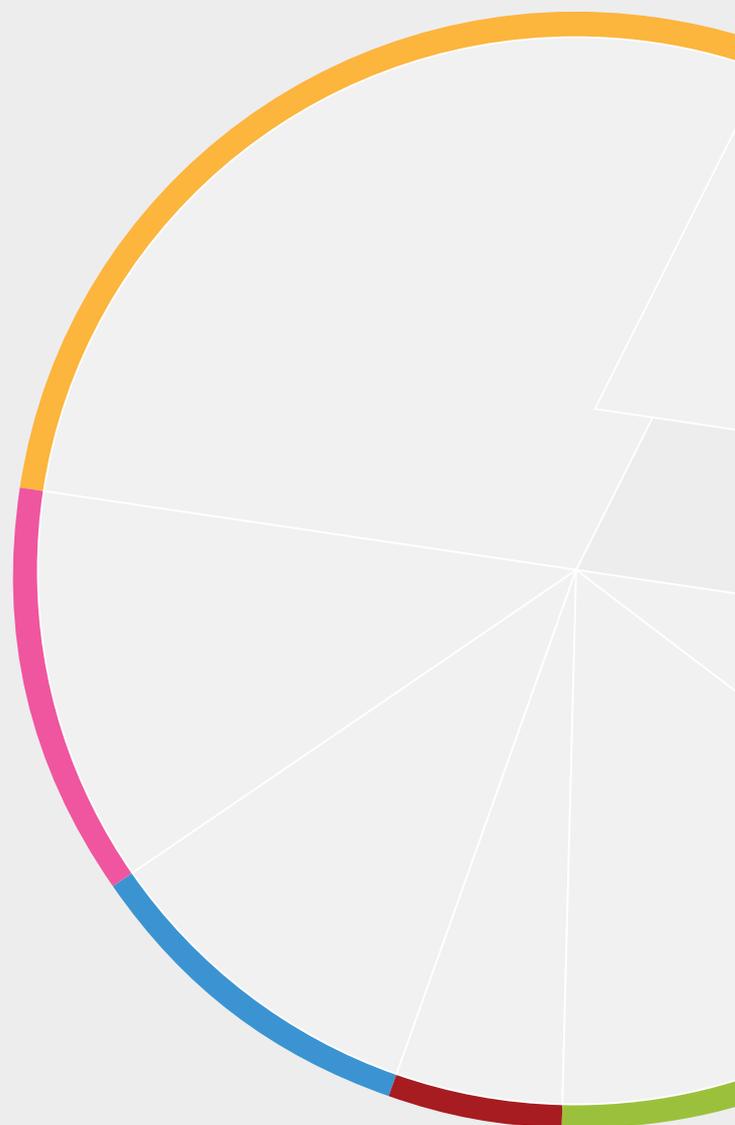https://www.poliohealth.org.au/late-effects-of-polio/

International reports

OECD 1992 *Employment Policies for People with Disabilities.*

OECD 2003 *Transforming Disability to Ability. Policies to promote work and income security for disabled people.*

https://www.oecd.org/els/emp/transformingdisabilityintoability.htm

APPENDIX D

Methods

The following methods were adopted for the major sections of this report.

DOCUMENT SEARCHES

A legislation and policy scan were conducted for the period from 1992 to the current day. This included reports, policies, legislation for the Commonwealth and State jurisdictions focused largely on New South Wales, Queensland and Victoria (including other states where possible).

A search was undertaken for all inquiries relating to people with disabilities and the service system, both Commonwealth and State. Such inquiries were often in direct response to growing concerns about abuse, mistreatment or lack of access to services and undertaken by Ombudsmen, Public Advocates as well as state or Commonwealth government agencies.

A timeline was then created which places these Inquiries, subsequent reports, major Federal reviews and other matters relating to the topic, into context. While it is not exhaustive, it does provide a useful and rapid overview.

Finally, a limited scan of published research was conducted. Given the extensive number of research articles relevant to disability published over the almost 30-year period, this was restricted to research specifically related to the provision of services and supports. Again, while not exhaustive, it should provide a useful starting point.

It is important to note here that the scan of publications includes much of the so-called "grey" literature. This includes reports from government agencies, peak bodies and community organisations. Grey literature is not subjected to peer review so its rigour cannot be guaranteed, though it is important and useful from an historical point of view.

INTERVIEWS WITH STAKEHOLDERS

Several interviews were conducted with stakeholders identified as involved in the sector during the period under study. The purpose of these interviews was to clarify the sequence of events drafted from the document scan and to add any other significant policies or events not covered. The timeframe for this report limited the number of interviews, however this approach proved a successful 'member check' of the evidence gathered.

CONSTRUCTION OF THE TIMELINES

A preliminary systematic review of all documents yielded large amounts of information and these are organised within a timeline of all events from 1992 to the present. This provides a "helicopter" snapshot of the various periods thus enabling deeper analysis for historical purposes. Given the importance of the decade preceding 1992, when the *Commonwealth Disability Services Act 1986* was legislated, and the first of the five-year Commonwealth/State Disability Agreements signed, a timeline from 1980–1991 is also included.

THEMATIC ANALYSIS

Deep dive analysis was then undertaken for the final report format. Key overarching themes within the time period emerged. These guided the integration across legislation, policy and research and the consequent impact on service delivery.

CASE STUDIES

A framework to analyse the case studies undertaken here was developed focusing on the following pertinent questions:

1.   Why was this report chosen?

2.   What were the terms of reference of the review as reported?

3.   What was its 'significant impact'.

4.   What was the scope (i.e. national/state) of the review.

5.   What were the critical precursors or the pathways that led to the review being commissioned?

6.   What was the level of authority of person/persons undertaking/conducting review?

7.   What were their recommendations?

8.   Were these adopted? How? Where? When?

9.   What were the changes that the review/report instigated – if any

10.   Have these changes held over time?

11.   What is the current status of the issue/s under review?

The case study analyses are presented in chronological order.

APPENDIX E

Further material on Active Support and Individualised Funding

1. DEFINITIONS

What is Active Support (AS)?

Is founded on principle of Positive Behaviour Support (PBS) and on values associated with a Person Centred Approach to service.

Has previously had a background in technological skill development.

More recently, has come to mean 'engagement' rather than technological support.

'Engagement' has come to mean 'experience a life as close as possible to the life of people without intellectual disability' – a 'good' life.

Includes 'moment to moment' experience of activity.

Has been 'adopted in principle' by most services in Australia, but has been found 'difficult to embed' in practice (Bigby et al, 2019(a), 2.

What is Individualised Funding?

Builds on a Person Centred Approach to service

Supported by principles associated with a Human Rights perspective.

Provides 'personal budgets … to increase independence and quality of life' (Fleming et al, 2019, 5.

Has long been goal of parents and advocates.

Has its foundational roots in Independent Living Movement.

Now a primary objective of NDIS – 'supporting the independence and social and economic participation of people with disability'

Can take a variety of practical forms – including: direct payments; brokerage; social benefits systems.

What is practice leadership (PL)?

Focuses on all aspects of service user's quality of life

Managing and organizing work loads of service staff to achieve AS principles

Ensures a shared understanding which places person at centre of service system

Is different to management practice

### 2. AS BLUE PRINT – POSSIBLE PREDICTORS OF GOOD AS

1. Staff training in AS using classroom and in-situ methods;

2. Strong practice leadership of individual direct support workers and their team through regular coaching, observation and feedback about their practice; discussion of AS in team meetings and individual supervision, shift planning, and support to maintain focus on the quality of life of the people they support as core to everything they do;

3. Practice leadership structured so leaders are close to every-day practice, and their tasks are not split across different positions;

4. Staff having confidence in the management of the organisation;

5. Services not supporting more than six people under one roof;

6. People sharing accommodation having support needs that are not too different, and not all having challenging behaviour; and

7. Senior leaders having a shared understanding of AS and recognizing and value high-quality practice.

From: Bigby et al, 2019(c).

3. IF BLUE PRINT — POSSIBLE PREDICTORS OF GOOD IF

1. Decision makers, senior staff etc. need to shift from 'scepticism' to 'enthusiasm';

2. Little evidence of need for safeguarding or perceived risks associated with IF;

3. Opportunity in relation to future employment, rather than focusing on potential job losses;

4. Staff Training must include background and history associated with IF;

5. Training for volunteers and family support networks essential;

6. Transition of service system to IF and values associated with person-centred practice needs time and financial support to be successful;

7. Transition may include using traditional supports while moving to IF approach;

8. Such transitions need to be closely evaluated and supported.

From: Fleming et al, 2019.
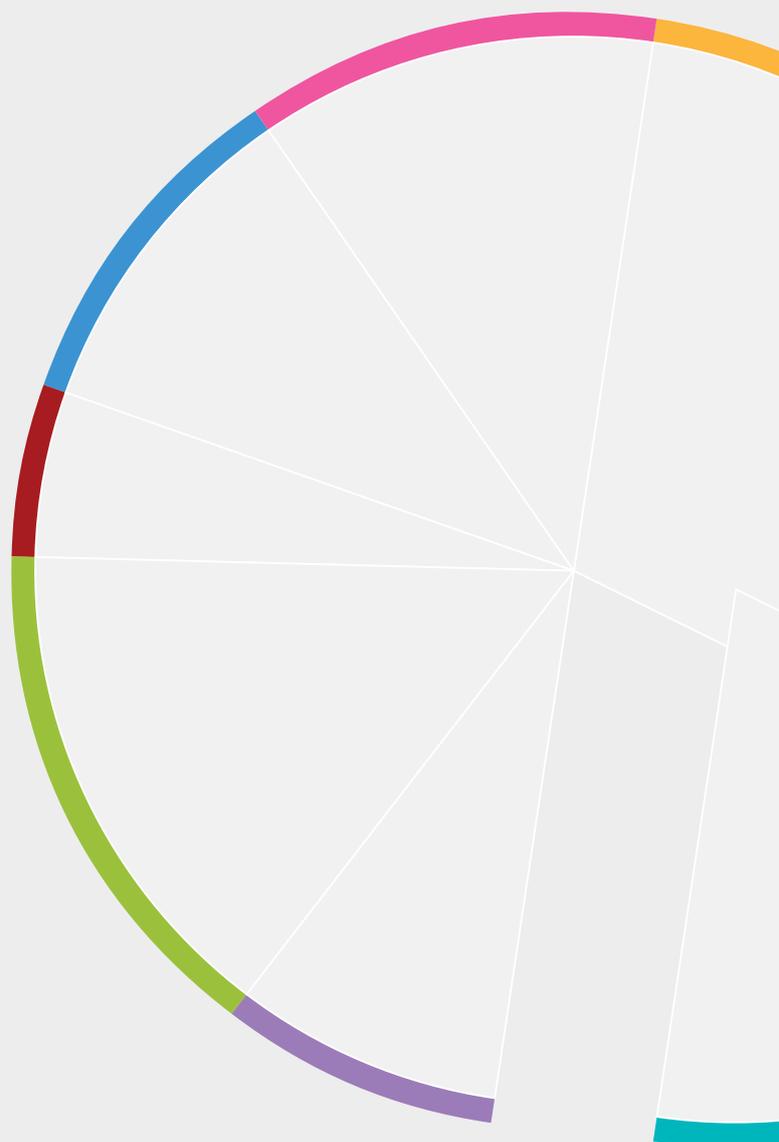
4. SWOT ANALYSIS OF ACTIVE SUPPORT (AS) — FROM THE RESEARCH LITERATURE

STRENGTHS

- Supports a Person Centred Approach
- Best activated and supported with strong practice leadership (PL)
- Can support front line staff job satisfaction
- Can support a reduction in front line staff turnover
- Can add value to organisational structures, policies etc.
- Can mitigate against hierarchical approaches to management
- Some evidence that AS works well in smaller 6–8 service settings

WEAKNESSES

- Little evidence of value to service users with challenging behaviours
- Little real research evidence from perspective of service user
- Of no value (rhetoric only) if not support by senior staff and through PL models
- Tends to a hierarchical approach
- Doesn't appear to get tailored well to individual needs, and therefore little evidence of real change in practice at service user level
- Very fragile and highly exposed to diminishment in use over time
- Tends to support a more homogenous grouping within service setting
- Little evidence that solutions lie in having more staff

OPPORTUNITIES

- More empirical research essential – particularly from service user perspective
- Research vague as to relationship between staff training and AS maintained over time
- However, staff training in AS principles essential to ensure use over time
- Senior personnel in organisation need to support and encourage practice leadership, but each organisation needs to have an individual who has specific responsibility for PL

THREATS

- Service providers are failing to realise AS full potential
- Tends to rhetoric rather than reality – means it is rarely questioned
- If management doesn't support, then front line service fails
- NDIS tends to focus on compliance rather than on AS
- Lack of funding for training and supervision within NDIS model
- Tends to be at 'early stages' even if 'adopted' by service over many years
- Little empirical evidence associated with change at service user level

5. SWOT ANALYSIS OF INDIVIDUALISED FUNDING (IF) – FROM THE RESEARCH LITERATURE

STRENGTHS

- Strongly supported by service users, families and advocates
- Positive effects with respect to quality of life indicators, client satisfaction and safety
- Shifts 'power' from agency to individual
- Supports concept of 'flexibility'

WEAKNESSES

- Has difference meanings and different policies associated with these
- Paucity of evidence as to impact on physical functioning, unmet need and cost effectiveness
- Long delays evidenced in accessing and receiving funds
- Tendency to highly bureaucratized processes
- Tendency to complexity
- Tendency to lack of clarity
- Inconsistencies in approach
- Hidden costs and administrative charge add to concern and stress
- If staff turnover high – factors outweigh advantages

OPPORTUNITIES

- MSupported by strong, trusting and collaborative relationships in support networks
- Facilitates information sourcing, staff recruitment, network building and support with administrative and management tools
- Works well if agency supports it in principle
- Service agencies release role of 'gatekeeper' which tends to 'disabling practices' – instead adopt positive attitude to IF
- Cost effectiveness less well understood through empirical literature
- Future employment opportunities for staff rather than potential job losses

THREATS

- Socio-demographic differences
- Rural and Remote factors such as lack of choice of services and fragmentation of services
- Focus by governments on compliance rather than outcomes
- Can be a major additional stressor in lives of individuals and their families
- Some users can be discouraged by well-meaning staff
- Can mean that unpaid (volunteer/family) expectations of 'free support'

APPENDIX F

Further material on workforce statistics

1. COMPARISON OF NATIONAL WORKFORCE OF NDIA 2017–2019

On–going Australian Public Service Employees

	YEARS				TOTALS	
	2017–2018		2018–2019		%INCREASE	
	F/T	P/T	F/T	P/T	F/T	P/T
Male	483	19	613	40	19%	52%
Female	1,155	265	1,550	399	25%	34%
Sub Totals	**1,638**	**284**	**2,163**	**439**	**24%**	**35%**
Totals	**1,922**		**2,602**		**26%**	

On-going employees compared by year.

There was a 24% increase in full time on going staff in the twelve months between 2017–2018 and 2018–2019 with the largest increase in female full-time on-going staff.

Non on–going Australian Public Service Employees

	YEARS				TOTAL	
	2017–2018		2018–2019		% INCREASE	
	F/T	P/T	F/T	P/T	F/T	P/T
Male	179	11	205	16	12%	31%
Female	452	70	580	91	22%	23%
Sub Totals	**631**	**81**	**785**	**107**	**20%**	**24%**
Totals	**712**		**892**		**20%**	

Non on-going employees compared by year.

There was a 20% increase in full time non on-going staff in the twelve months between 2017–2018 and 2018–2019.

Figures derived from Appendix I. *NDIS Annual Report 2018–2019.*

The following **summarises the complete workforce** as at 30th June 2019:

Australian Public Service employees (f/t, p/t on-going and non on-going):	3,495
Labour Hire Contractors and secondees:	2,278
Partners in the Community (PITC):	5,288

Figures derived from Chapter 2.5 workforce management in *NDIS Annual Report 2018–2019.* p. 65.

On–going Australian Public Service Employees

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Figures derived from Chapter 2.5 workforce management in *NDIS Annual Report 2018–2019*. p. 65.

2. ROLES IN THE SECTOR

Local Area Coordinator

Local Area Coordinators (LACs) work closely with people with disability and their families to identify current and future supports that are needed to realise the person's goals and aspirations and to have a good life. This work often involves complex conversations and a deep understanding of the impacts of disability. LACs also work alongside people with disability and families to build capacity to exercise choice and control and strengthen networks with local organisations and communities. Part of this work also involves working with mainstream and local organisations to raise awareness and improve opportunities for people with disability to participate in their local community.

Planner

Planners work with participants and their families or representatives to gather information, identify support options across mainstream, informal and community networks and determine NDIS funded supports that can be included in participants' plans. Planners work cooperatively with all partners to ensure plans are successfully implemented. They also undertake plan reviews.

Other NDIA roles

Other roles in the agency may include working in quality assurance, leading teams and policy work.

3. ROLES FOR REGISTERED PROVIDERS

The NDIS has created many new roles more broadly in the disability sector.

Registration Groups

The NDIS provides a comprehensive list of registration groups covering many roles and services. Registration Groups are based on the skills and compliance obligations required to deliver the support. Social workers are eligible to provide many services such as:

1. Assistance to Access and Maintain Employment or higher education [Assist Access/Maintain Employ]. Supporting participants to secure employment, provide necessary support and training to maintain their job or provide supports for specialised Supported Employment.

2. Group and Centre Based Activities [Group/Centre Activities] Supporting people to participate in group-based community, social and recreational activities.

3. Assistance in coordinating or managing life stages, transition and supports [Assist-Life Stage, Transition]. This involves assisting people to coordinate their supports, to make the transition to living independently and participating in community.

4. Accommodation/Tenancy Assistance [Accommodation/Tenancy This involves providing assistance and advocacy to secure and maintain housing.

Professional Registration Groups

In addition to the general registration groups, the NDIS includes several professional groups that can be provided only by people with a higher level of qualification (e.g. social work, psychology, occupational therapists and other allied health professionals. These professional registration groups are specifically well suited to Accredited Disability Social Workers.

1. *Specialist Positive Behaviour Support [Behaviour Support].*
   Behaviour support creates person-centred and individualised strategies for people with disability to reduce the occurrence and impact of behaviours of concern and minimises the use of restrictive practices. Key to this support is safeguarding the dignity and quality of life of people with disability who require such specialist support.

2. *Early Intervention Supports for Early Childhood [Early Childhood Supports].*
   These supports are for children aged 0–6 years who have a developmental delay or disability and their families and/or carers. The practitioner supports families to help their children develop the skills they need to take part in ordinary daily activities in order to optimise the best possible outcomes later in life.

3. *Support Co-ordination.*
   This is designed to assist people to get the most out of their NDIS funding plan. Support coordinators help participants to build capacity to connect with supports and to coordinate these supports by building skills, ensuring the right mix of supports are being provided for the person to achieve their goals. Specialist support coordination is a higher level of service for people with more complex and specialist needs.

4. *Therapeutic supports.*
   These supports cover a range of therapy services provided by health professionals including physiotherapy, speech pathology, dietetics etc. Accredited Disability social workers are qualified to provide to provide specialist counselling, specific supports in finding and keeping a job and in multidisciplinary teamwork.