

A brief history of the  
**DISABILITY SERVICES SECTOR  
IN AUSTRALIA:**  
1992 – PRESENT DAY

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## ACKNOWLEDGEMENTS

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## GLOSSARY OF TERMS

CSDA	Commonwealth/State Disability Agreements
DSA	<i>Disability Services Act 1986</i>
DDA	<i>Disability Discrimination Act 1992</i>
CAA	Carers Association of Australia
NGO	Non-Government Organisation
PDAA	People with Disabilities Australia
DSSA	<i>Disability and Sickness Support Act 1991</i>

# 1. INTRODUCTION

## The brief

Life Without Barriers requested an historical overview of the national disability sector from approximately 1992 to present including:

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

The draft report was to be delivered by 14th October, 2019.

The rationale for the timeframe commencing in 1992 was to include the transfer from the Commonwealth jurisdiction to state jurisdictions of all aspects of disability programs and services, except employment and advocacy. This transfer in 1992 marked a key point in transition for national disability service provision and subsequent delivery of these services.

This period also reflects the early history of Life Without Barriers from its inception in the early 1990s and official launch in 1995.

## Methodology

The approach to the research consisted of several distinct but interrelated phases:

### 1. Document search

First, a legislation and policy scan was conducted for the period from 1992 to the current day. This included reports, policies and legislation for the Commonwealth and State jurisdictions focused largely on New South Wales, Queensland and Victoria, (including other states where possible).

Second, 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.

Third, a timeline was 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 refined to research specifically related to the provision of services and supports. Again, while not exhaustive, it is intended to provide a useful starting point.

It is important to recognise 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.

## 2. Interviews with stakeholders

Four 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.

## 3. 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.

## 4. 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.

## How to read this report

This report contains several sections organised around an overall timeline covering events impacting on the sector in the timeframe as agreed. In response to the brief, 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 largely from the perspective of policy and service providers. The story from the perspective of people with disabilities and their families is important and powerful but, unfortunately, is beyond the scope of this report.

To keep the report as manageable and accessible as possible, it includes references, a glossary and several appendices. This is to allow Life Without Barriers to further follow-up any significant issues or events that are specifically relevant to the organisation. 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.

## Overview of sections

The report 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 on the sector and service delivery. These are: a brief history of Local Area Coordination, a section on Restrictive Practices and a brief coverage of the interface between disability and the justice system. Each section has an internal framework which includes: Legislative/Policy contexts; Inquiries/Reports/Research Evidence; Drivers for Change and responses.

While such a chronological view appears to be smooth and rational, in fact, the past decades can be characterised as having a ‘two steps forward, one step back’ approach. As this report details, not all those involved, neither parents nor service providers, or even government agencies, could strategically plan for a future which was envisioned, but lacked detail. A ‘backwards’ look, such as this report undertakes, can also identify missed opportunities, in particular, the many reviews and reports of the sector that were not actioned on, or were left to lapse over time.

## Limitations of this report

This report should be considered a detailed overview rather than an exhaustive presentation. The central, and critical aspects to the three decades are covered, as are many of the inquiries that were held over this time. This places the current Royal Commission Inquiry into the context of three decades of reviews, reports, extensive consultations, legislative and policy changes. References as well as Appendices offer further reading.

## 2. 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 actually 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 subsequently impact the sector. 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 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 and 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, like Claremont in Western Australia, built 10 kms from the city centre in 1903, 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 1941 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’. This process (which some would argue has not been completed to this day) commenced in the early 1980s and forms the narrative of the first period of this report 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 that accompanied the Year; many others were surprised (and shocked) to read that Australian citizens were still ‘locked up’ in large institutions, some having been there all their lives with little personal decision-making; choice of activities (let alone work) or of companionship. These settings were managed according to rigid timetables and staff needs, rather than the needs of 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 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 many of the stories of institutionalisation from all states, and its findings gave much hope to the many 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*. 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 the manner in which 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 non-government organisations (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 built on the civil rights agenda of the 1970s and on the global trends then being enshrined in legislation around the world. By the end of the 1980s, all Australian states had passed versions of disability services legislation and had signed up to the Commonwealth agenda. This was subsequently enshrined through the five-year Commonwealth State Disability Agreements (CSDA). This 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 the sector nationally to more scrutiny that 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 the way in which people were being treated, *were* being taken seriously. Each state had legislated for a Public Advocate as a component of their own DSA legislation. 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 for 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 kilometres 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 included 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 not only people with intellectual disability but also those from a maximum-security facility for the criminally insane (until 1991) and 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 ...’ (p.7). It was therefore 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 \$18 million (nearly \$35 million in present-day dollars) to run Aradale (p. 9) and ‘... a casual observer of the clients would have trouble understanding where the money (nearly \$70,000 pa. per client) went to ...’ (p. 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’ (p.10). Fundamental to the Review’s findings was the statement that:

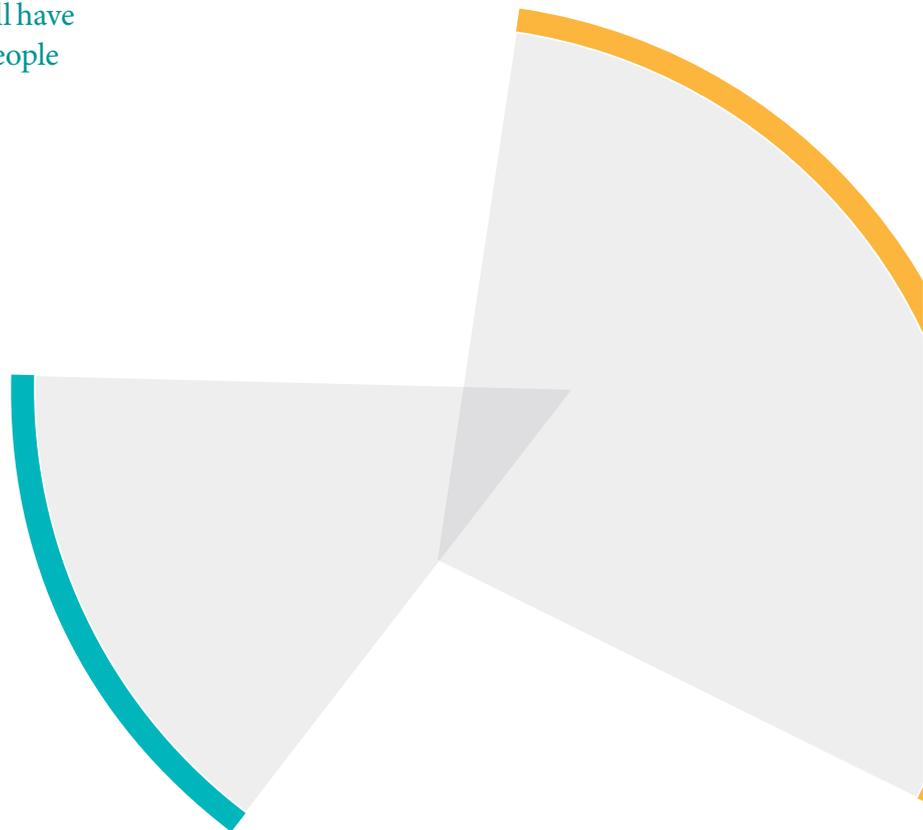
... staff have a vested interest in maintaining clients’ dependency. There is a clear perception by staff and the local community that further reduction of existing client numbers will actively threaten employment (p. 7).

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 ...' (p. 11). This became 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 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, p. 2).*

Across Australia, the more than 100-year-old large scale institutions were closed, 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 were calling for the closure of Colanda House in Colac (100 residents), some 170 kilometres south of Ararat, where many 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, p. 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'.



# 3.

## 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 remain in hospitals, nursing homes and other residential facilities accommodating groups well above that of a 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 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 largely based on forms of shared living and the group home became the universal 'standard'. This type of group home accommodated up to six, sometimes eight, people in a shared house. These dwellings included ordinary houses obtained through ordinary rental markets, purchased outright or as 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 by the disability provide 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

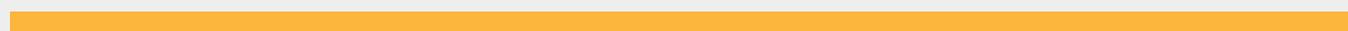
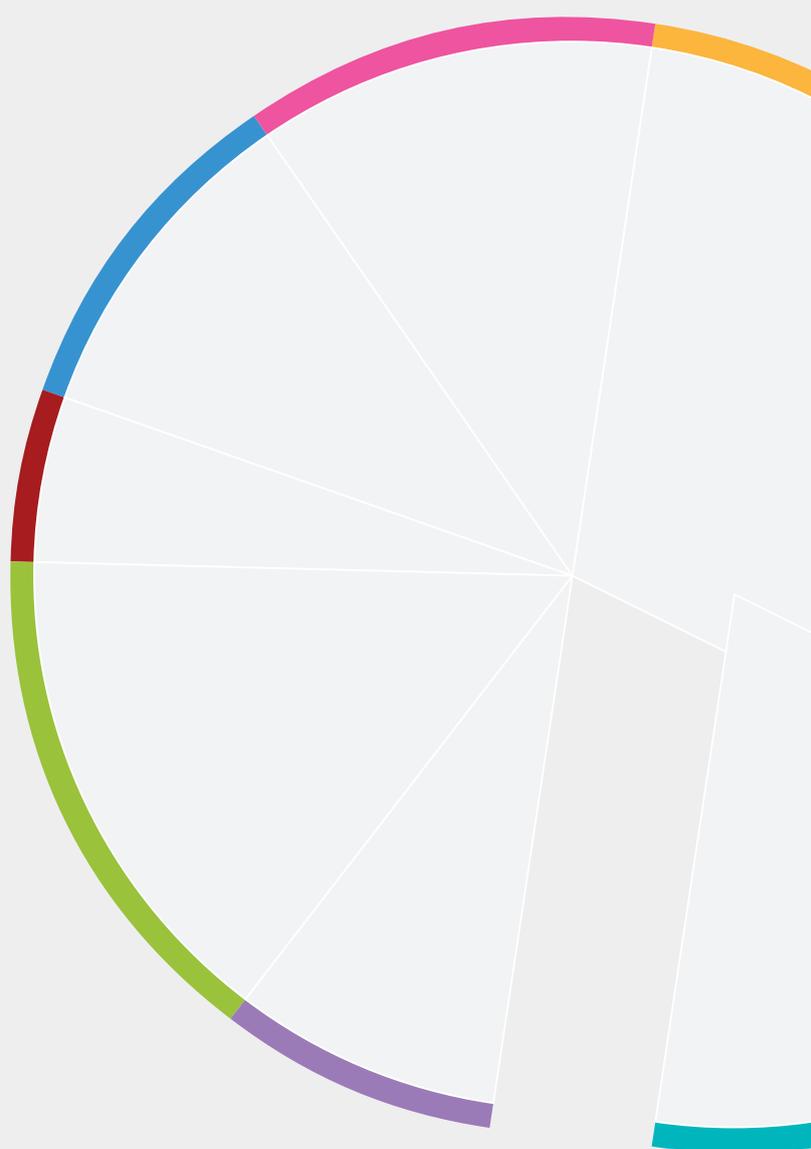
From the first moves to community living, concerns emerged about the connections between housing and the provision of supports. Having the one agency that provided both housing and employed the staff delivering care and support, was found to be limiting choices for the person with a disability and embedded control over their life with 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, to develop friendships and have more meaningful activities in the community (Garcia Iriarte et al., 2014). There was a desire to realise more individualised options which 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 (e.g. Growing Stronger) and now the National Disability Insurance Scheme (NDIS) nationally, demand for supported living arrangements has increased.

Evidence around whether such arrangements actually deliver better outcomes for people with intellectual disability is still sparse (McConkey et al., 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 report feeling lonely and face restrictions on their activities because of low incomes (Bigby et al., 2017).

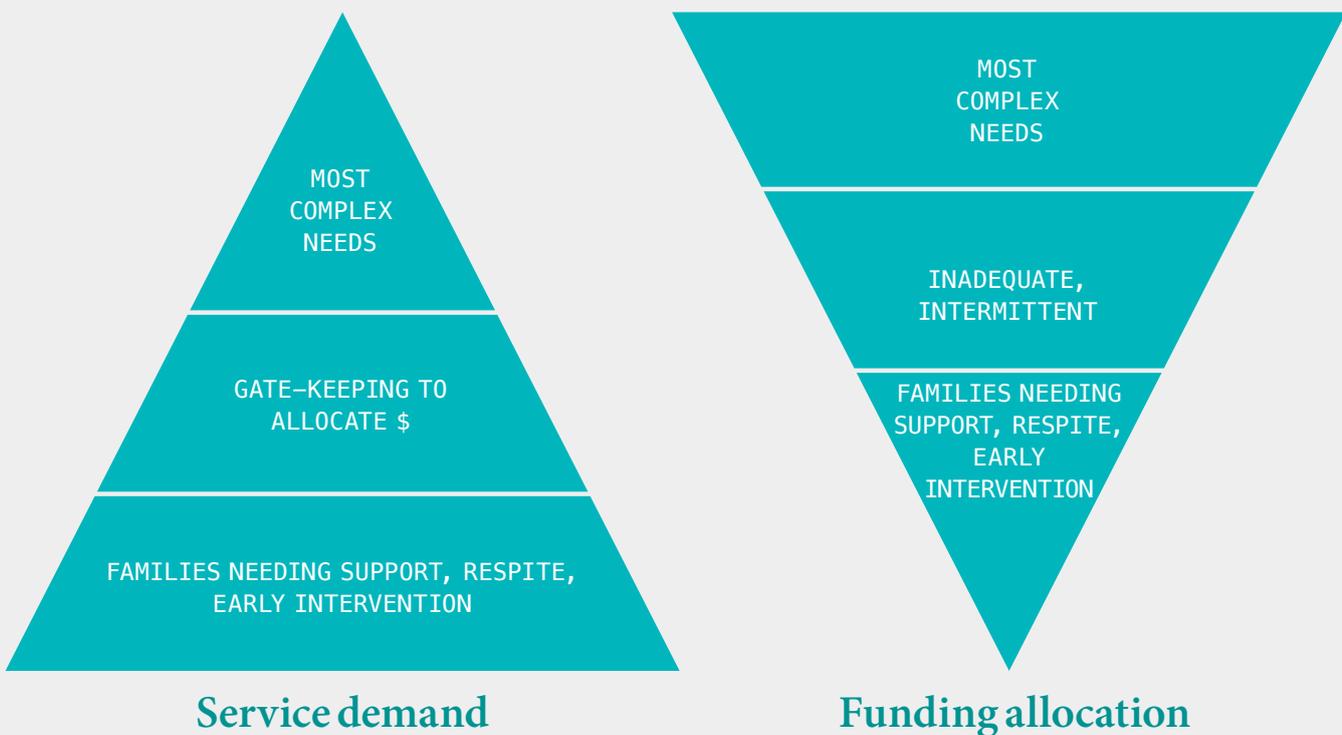


## Unmet need

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, the majority of funds went to people with high support needs and leaving thousands of people on long waiting lists. As one manager commenting on the 1990s put it:

The government got stalled by money. There just wasn't enough to deliver person-centred supported living.

FIG. 1. DEMAND VS FUNDING AVAILABLE



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.

Funders and service providers were grappling with what became known as the inverted triangle dilemma as depicted in Figure 1left. 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 2000–01 and 2001–02. 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 an additional \$30 million approximately and New South Wales a further \$29 million (AIHW, 2002). Other budget bids were made by state governments for even further funding to ‘fix’ the system. Over the ten years post-2000, the investment by state governments in disability services rose substantially.

Disability was advanced as a priority. For example, in New South Wales the Carr Government (1995–2003) 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, the voices of carers became more prominent in both the aged and disability sectors. The Howard Government (1996–2007) made major changes resulting in the sector becoming more privatised. As a result, the 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 to a promotion of families and service providers and 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 2004–05 Budget, the Howard government announced an additional \$461 million to support carers (see [https://formerministers.dss.gov.au/wp-content/uploads/2012/06/Fact-Sheet-6\\_Support-for-Carers.pdf](https://formerministers.dss.gov.au/wp-content/uploads/2012/06/Fact-Sheet-6_Support-for-Carers.pdf). Retrieved: 10th October, 2019).

As unmet need became more widespread and 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, formed alliances. These included existing organisations such as Family Advocacy, 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 a NDIS type scheme. EAC is still operating as a watchdog to ensure the NDIS stays on track.

## 4. PERSON-CENTRED PLANNING

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. These have evolved over time 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. Person Centred Planning (PCP) is fundamentally different from traditional planning as it shares power and works towards community inclusion (Sanderson, 2000). It is now widely accepted as the key approach in planning for a ‘good life’ for people with a disability (see Appendix D).

It is well established in the disability research literature that connections to community 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 was 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 paid to social connections and relationships (Hoskin, 2010 cited in Robinson & Notara, 2015, p. 726) than physical presence.

There is some evidence that PCP works better for some people than others. In reviewing several studies, it appears that 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/or have it implemented. The overwhelming barriers however seem to reside within organisations. A key factor here is the vital importance of committed facilitators (called service delivery coordinators in Australia) in the success of PCP. In the United Kingdom, 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 appropriate 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 own support (Leece & 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 (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, including 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).

All these models are 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 a policy standpoint (for example, Dew et al., 2014; Purcal, Fisher, & Laragy, 2014), which means that evidence and 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). What this limited research does indicate is that families need adequate preparation and support over a longer period of time.

The challenges in self-directed support can include practical tasks of finding and hiring workers and financial management as well as 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.



## 5. LOCAL AREA COORDINATION

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

To understand these transitions over the past thirty years is to understand 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 Western Australian LAC model can be seen as an early, and exciting (at that time) innovation in putting 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 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. It also began to consider the costs associated with that responsibility, and turned to the alternative, 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 model was also, importantly, a response to the 'tyranny of distance' that still continues to challenge human service delivery in the vast state of Western Australia, with its small, highly dispersed population and over 80% of people 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. Importantly, 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 Western Australian model was therefore a *geographic* one, first and foremost. A pilot (for people with intellectual disability only) was undertaken in Albany, a major rural centre and a 4.5 hour drive south of Perth, in 1988. Following an evaluation of this pilot, the formal program was expanded to other regional centres, while 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 which could assist their clients to overcome some of the barriers to living a 'good life' (Bartnik & Chalmers, 2007, p. 24). This approach was the first of its kind within in the human service sector. It met many challenges, not least that the state treasury was not equipped to manage this form of 'investment'. However, the approach was persevered with as its potential was realised.

This transition period of some 3–4 years ran in parallel with the deinstitutionalisation 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, nevertheless, it was felt by some that the move to the metropolitan settings diminished the investment in the regional.

By 1993, the Commonwealth began to take more of an interest in the WA approach, and funding was provided to expand the service from just intellectual disability to include physical and/or sensory disability. The following three years saw a growth across the Perth metropolitan area and in some additional regional centres. By 1996, 2,478 people had 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 a 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' (p. 23) – that is within two years! By the early 2000s, the structure which framed the Western Australian 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 (see Appendix D).

Further Federal investment followed, and reviews and evaluations found that the experiences of the coordinators 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 and 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 (p. 30).

As the program broadened, clients and their families became its strongest supporters. In addition, according to Bartnik and 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 W.A. It is not just another layer and there has been a systematic process of readjustment and major reform (p. 30).

Other states began to take an interest, and a pilot program of 8 sites was established in Queensland in the early 2000s with a deliberate focus on rural and regional settings by Disability Services Queensland (DSQ). This program was based on the Western Australian model, but adapted for local conditions (Chenoweth & Stehlik, 2002). It was also subject to a formative evaluation, and included training for individual coordinators, some of who already lived and worked in their geographic locations, others who were re-located as part of the trial. The evaluation found that the model was cost-effective for rural areas and had 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 to access modest funds for each client, over time. This bypassed layers of red tape and allowed 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 Queensland Treasury.

A further, more localised version of LAC was also introduced into New South Wales as a pilot program in 2002–2003, again, largely 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 Queensland and New South Wales 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 in which the sector had grown in those two states. A regional focus to service delivery was more highly developed than in Western Australia, with more services available ‘on the ground’.

An interesting observation perhaps worthy of further exploration is the relatively few enquiries and reports of abuse in the system in Western Australia compared with states such as Victoria, New South Wales 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 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 ‘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 [National Disability Insurance Agency (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 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 30 years after its inception. The first is that 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 an important legacy, and it is to be hoped that this will form the basis of future, vital research.



## 6. 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, in fact, 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 and 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 therefore 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 last 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 that this approach to 'welfare' (and by extension, to the disability sector), 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 along 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 the United Kingdom (Margaret Thatcher), United States of 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, 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 Report 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.

This neo-liberal approach did support a growth in the market (being the sector) and one immediate impact 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 which actually ‘manages’ the sector on behalf of the Commonwealth.

Elsewhere the ‘unmet needs’ campaign of the early 2000s was 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 not only of ‘customers’ but of ‘bottom lines’, of ‘purchasers’ and increasingly, of 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 very language used in this Report, 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 marketisation of the disability ‘industry’ reached its maturity. The concept of an insurance scheme to enable future care needs of individuals to be met, was 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 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 marketisation 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. This was the vision. However, as David and 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, np).

Today, the NDIS has replaced the DSA as the guiding policy and program delivery agent, although the DSA legislation remains in place. 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 and 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. In addition, 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).

# 7. ABUSE, VIOLENCE AND 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, 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 report 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 is multifaceted and involves 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).**

As research into causes and understanding of challenging behaviours progressed and our understanding of disability was influenced by developments in social theory such as the social model of disability, old conceptualisations were regarded as disempowering and deficit focused. 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 supports needed for the person to be safe; or staff may not have the skills and training to understand and best support the person.

For many people in this situation, behaviours that were harmful to themselves or to others heightened the risk of them 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 or 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, for example, 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. Major decisions about the use of restraints could not be decided by disability service providers but required referral to an independent authority charged with responsibility to make decisions in the best interest of the person. How those processes were managed differed across state jurisdictions. Chandler, White and Willmott (2017) provided a comprehensive summary for the authorisation of restrictive practices as at 2017. This is summarised in Table 1 right:

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 to be that the law is unclear, uncertain, inconsistent and raises deep 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 area where Federal and State jurisdictions are currently conflated. This has 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 delays within the NDIA for plan reviews and 'thin markets' for behaviour support specialists in some areas, it is not clear how this will unfold.

Restrictive practices have been a contested area of service provision for many years, formerly outside any regulatory authority, and over the past 20 years, increasingly subject to more safeguards and legal processes. At best this can be described as a work in progress.

## Incarceration and Domestic Violence

While well beyond the scope of this Report, 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 that 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 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 np). 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, that the police record keeping system in Western Australia kept a record of disability). The following quotation from one participant highlights the issue:

*... 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 np).*

## 8.

## 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 were on the table. In the ensuing years, as discussed earlier in 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

In 2007, the Rudd Labor Government came to power and quickly held The Australia 2020 Summit, a convention of some 1000 delegates aimed at helping 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, specifically to investigate 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. This report was tabled in 2011 and was a pivotal moment in disability policy. The Report 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', and a system marked by 'invisible deprivation and lost opportunities'. The Commission recommended that the current system be replaced with a National Disability Insurance Scheme.

It is interesting to note here that 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, but 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 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 1st July 2016. Western Australia was included from July 2018 (see above). This was to be one of the largest and most complex policy and program rollouts in the nation's history. The NDIS was forecast 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 major areas: first, from the standpoint of **funding** of the scheme and second, from the standpoint of service users and service providers about the perceived **(in)adequacy** of costing and pricing of services and supports.

There were debates about funding almost immediately from 2013. In Federal Parliament debates, concerns were expressed as to whether the funding arrangements (set up under the Labor government in its 2013–14 budget) were properly costed and adequate to the task. The Opposition (later the Abbott Government of 2013–16) argued that there would be a gap of \$3.8 billion by the full roll-out in 2016. While the Scheme was enthusiastically embraced by the Opposition during the 2013 Election campaign, there was some early conjecture that the Scheme could be privatised, either partly or completely, under a Liberal/Coalition government, just as the human services sector is being increasingly privatised, as a recent ANAO audit identified (see <https://www.smh.com.au/politics/federal/benefits-of-centrelink-s-serco-contract-unclear-auditor-20190221-p50zel.html>).

Later the Turnbull Government in its 2017–18 budget, increased the Medicare Levy by 0.5 percentage points 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 a 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 roll-out. 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 who were 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 roll out and the pressure agency staff were under to achieve higher participant numbers inevitably lead 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 there were multiple compounding problems in the ICT system which impacted adversely on 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 on-going, coverage in the media and this in turn has arguably led to an erosion in confidence of participants, service providers and the general community. Despite feedback from the NDIA that the majority of participants express satisfaction with the scheme and that they are better off, 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.



## 9. 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: np).

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 as to 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’ (p. 407). However, by creating a disability ‘market’ there is an assumption that the ‘market will provide’. In fact, as Fawcett and Plath (2014) argue, ‘the market is under no obligation to respond to the wants and needs of individuals’ (p. 754 as cited in Marston et al., p. 407). In the nearly five years that 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’ (p. 3). It appears that 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 confidently engage 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’ (p. 7). This will only be undertaken following the development of an intervention plan (p. 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 writing this report.

# 10. CONCLUSION

This report has provided an overview of the Australian disability sector from 1992 to the present day. This has been a period of major change. It can be said that we have witnessed the devolution of responsibility for disability services from the Commonwealth to the states and its return back to the Commonwealth in less than 30 years. This 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 government 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 report 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 major 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 actually deliver for people and on their objectives.

It appears that such challenges have been too difficult for some people as organisations opt out of disability services. There has always been tension around 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 Life Without Barriers, have supported vulnerable people to achieve lives where dignity and choice does exist – this lies at the heart of their mission. Thus far, many have managed to uphold those values, and although it appears increasingly difficult, there is hope for support from allies within and outside the sector to face the challenges ahead.

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## APPENDIX A

### Key reports: Federal Government and agencies

#### Parliament of Australia

Senate (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability. Community Affairs References Committee*. November. Background Paper 2 1995–1996. Commonwealth Disability Policy 1983–1995. Social Policy Group.

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##### February 2015

*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](https://www.dss.gov.au/sites/default/files/documents/02_2015/dss001_14_final_report_access_2.pdf)

##### February 2009

*Pension Review Report* (Harmer).

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*Participation support for a more equitable society: final report of the Reference Group on Welfare Reform*. (McClure, P Chair).

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Cass, B 1988 *Towards Enabling Policies; Income Support for People with Disabilities. Issues Paper No 5*. Social Security Review. AGPS: Canberra.

#### Department of Families, Housing, Community Services and Indigenous Affairs

##### 2012

*Vision for Sustainable Supported Employment*. Report by an Advisory Group.

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## 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*.

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### 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

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<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/lpclr/lpclr\\_publications/lpclr\\_reports.aspx](https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclr/lpclr_publications/lpclr_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](http://www.lawlink.nsw.gov.au/crld)

[https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclr/lpclr\\_publications/lpclr\\_repor%20ts.aspx](https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclr/lpclr_publications/lpclr_repor%20ts.aspx)

#### September 2018

*Feedback on development of a new Disability Inclusion Action Plan.*

[https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclr/lpclr\\_consultation/disability-inclusion-action-plan-consultation.aspx](https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclr/lpclr_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](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 – 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

### Towards 'A Good Life'

'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'.

Western Australia Disability Services Commission.  
*Local Area Coordination*. August 2012.  
[http://www.disability.wa.gov.au/Global/Publications/For%20individuals%20families%20and%20carers/2010\\_lac\\_leaflet\\_brochure\\_2012\\_ver\\_02\\_web.pdf](http://www.disability.wa.gov.au/Global/Publications/For%20individuals%20families%20and%20carers/2010_lac_leaflet_brochure_2012_ver_02_web.pdf)  
Retrieved 1st October, 2019.

'The planning process is 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).

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:

1. How would I like my life to be? (Vision)
2. My/our story? (Current situation)
3. What would I like to build on? (Long-term goals and Plan goals)
4. How can this happen? (Support strategies).

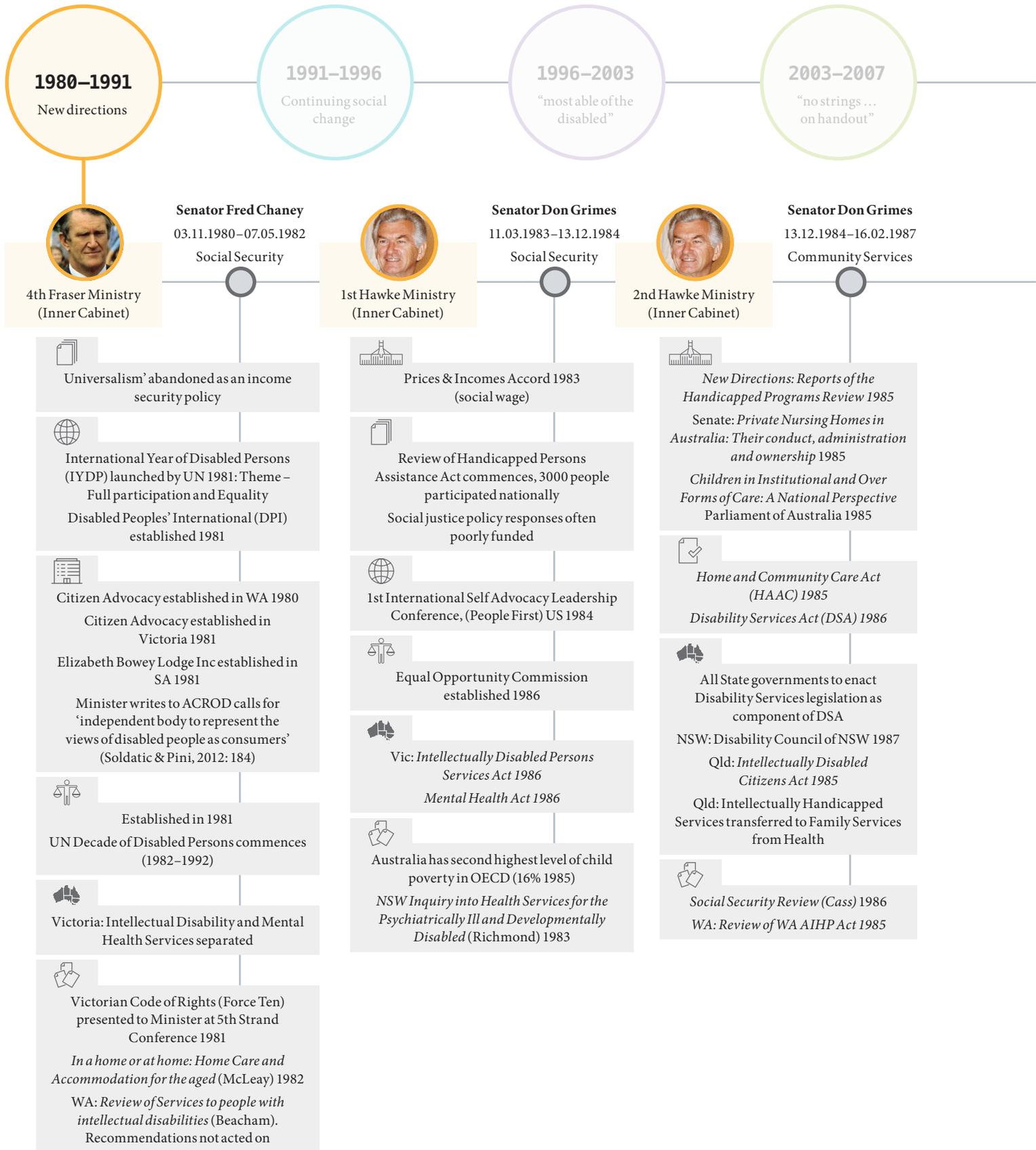
The plan will reflect the individual's aspirations and goals, their current circumstances, and clear pathways to achieving their goals' (p 4).

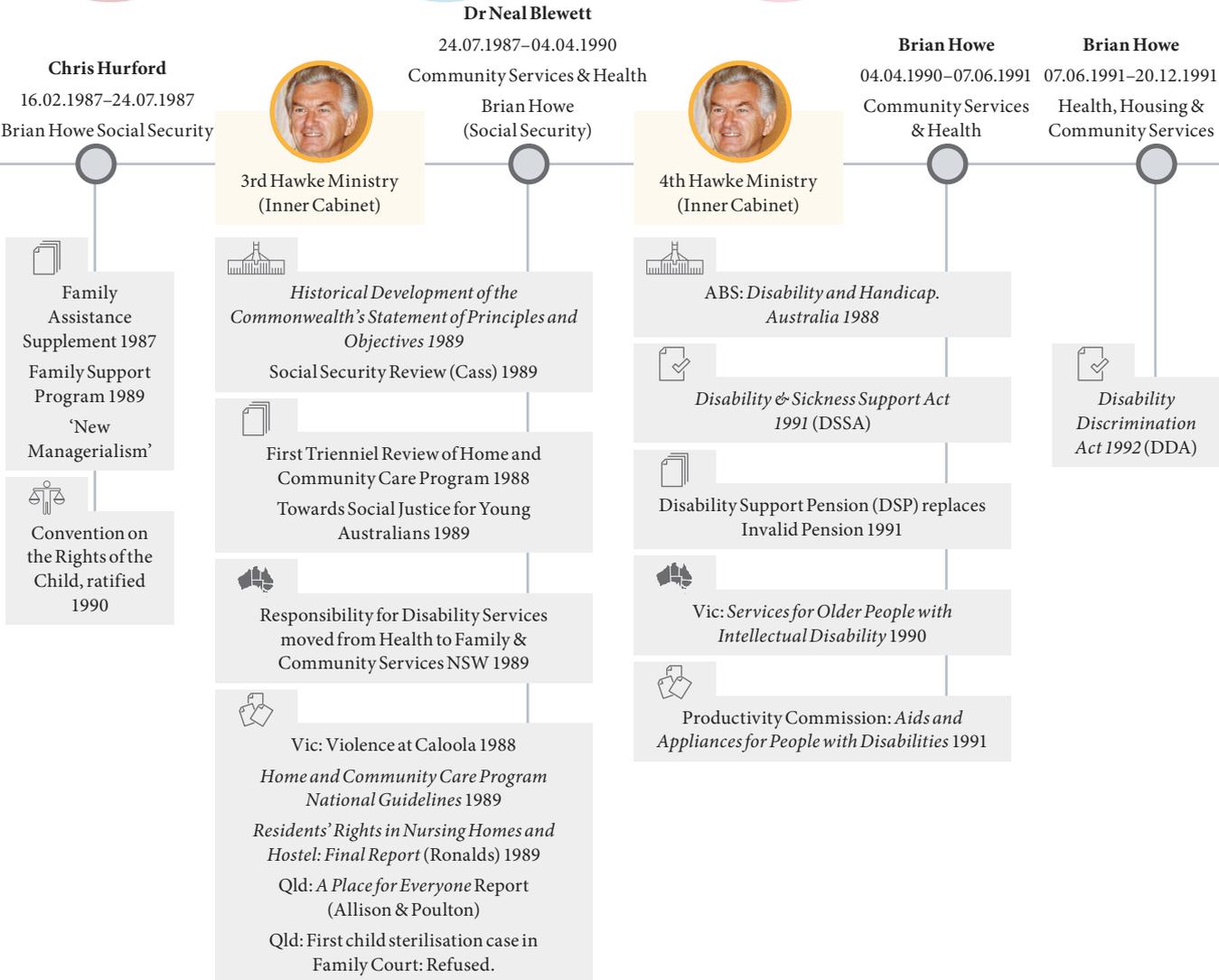
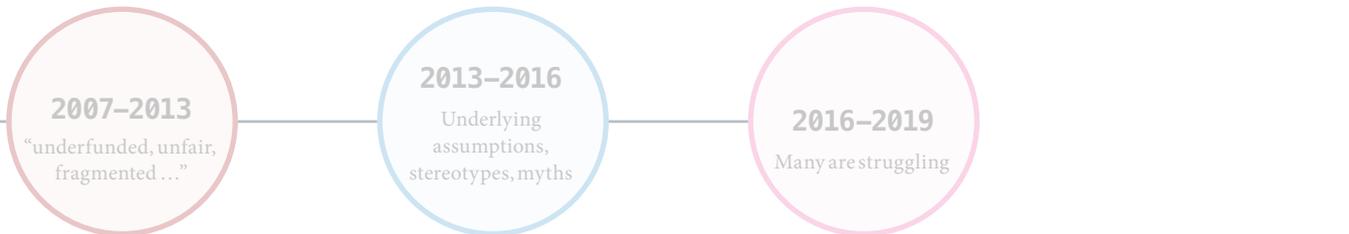
Western Australian Disability Services Commission.  
*Local Coordination Planning Framework*. February 2017.

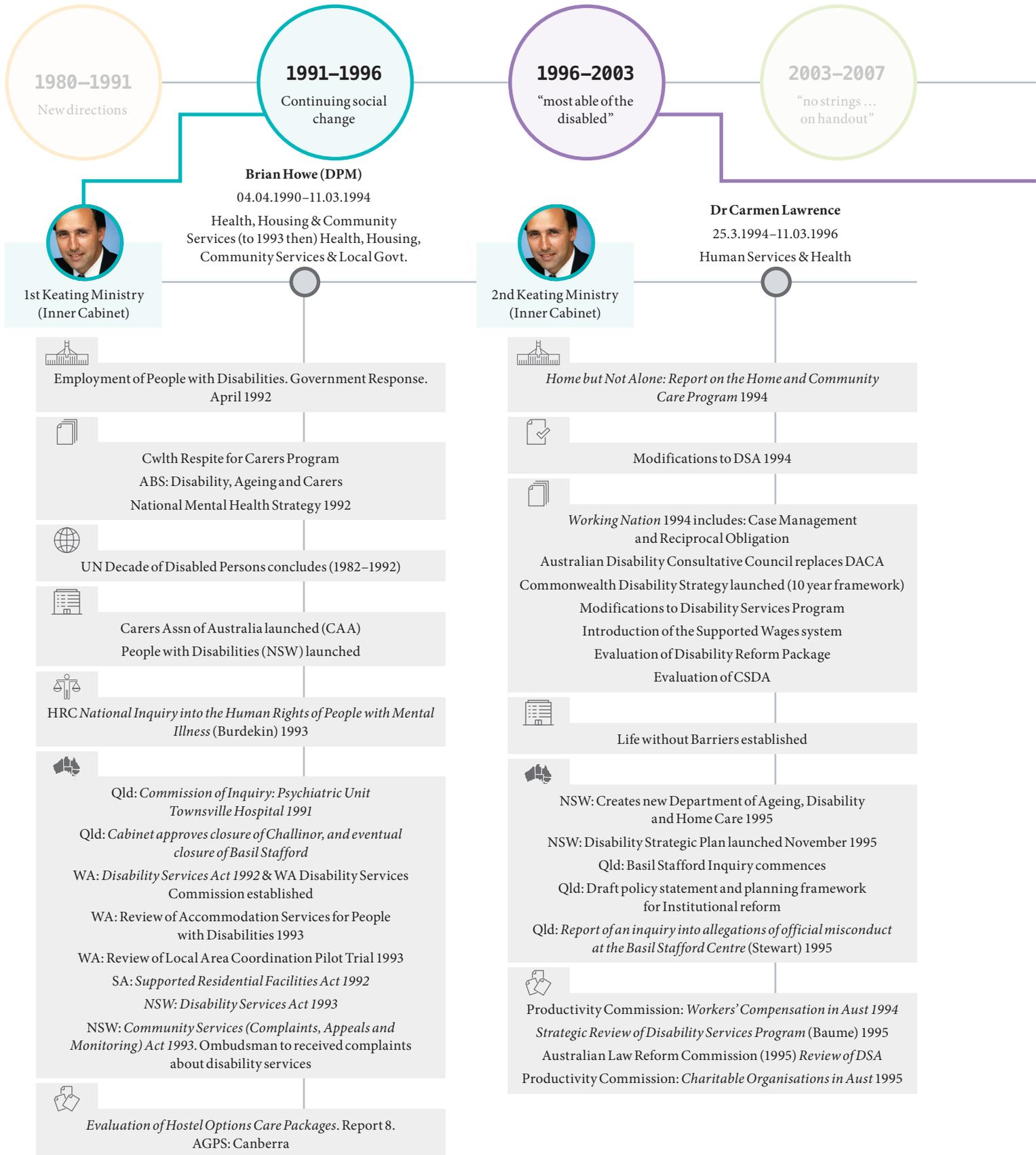
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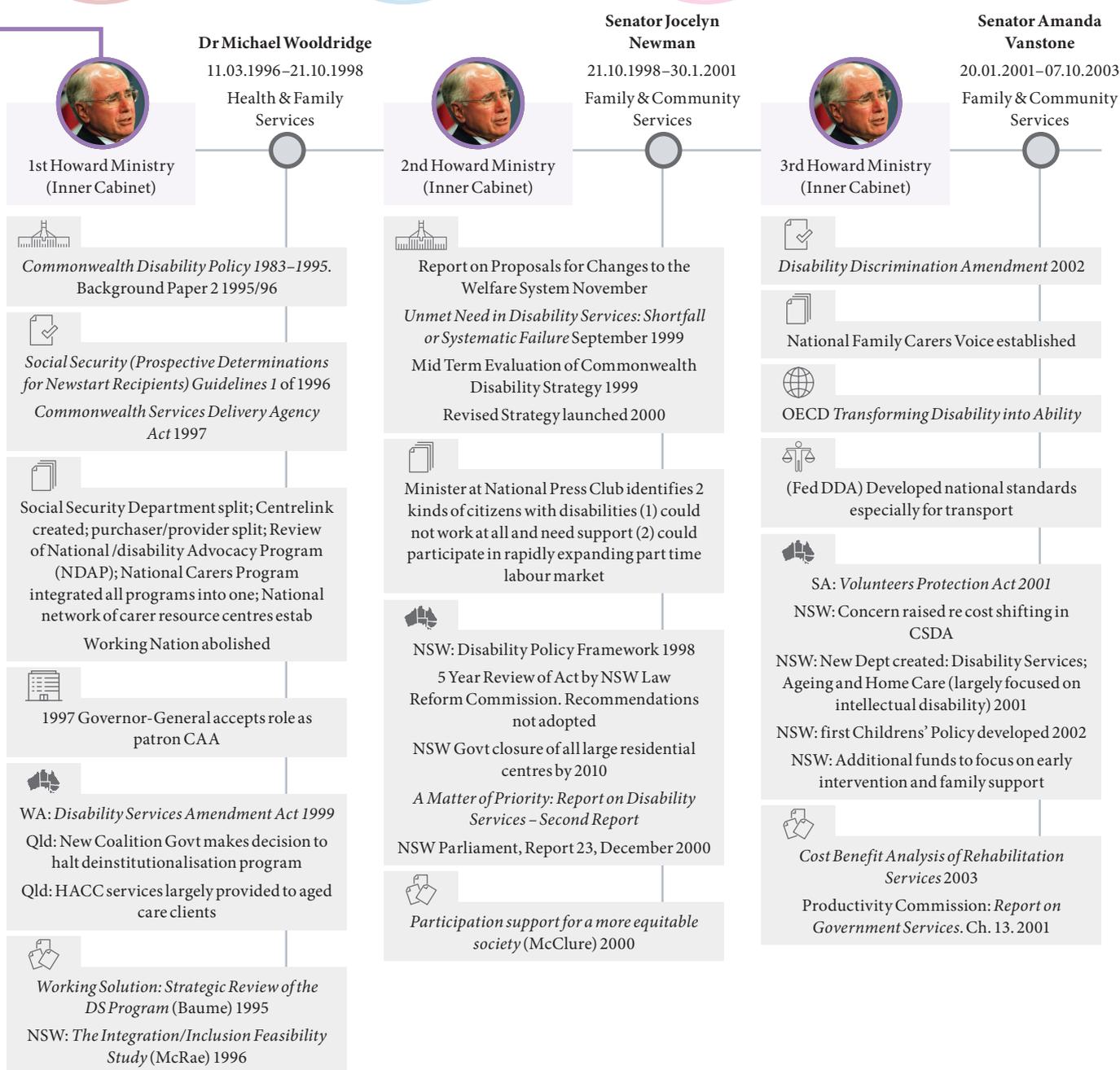
A Etmanski, A, J. Collins, J & V Cammack, V (2014)  
*Safe and Secure: Seven Steps on the Path to a Good Life with Disabilities*. Plan Institute: Vancouver, BC.

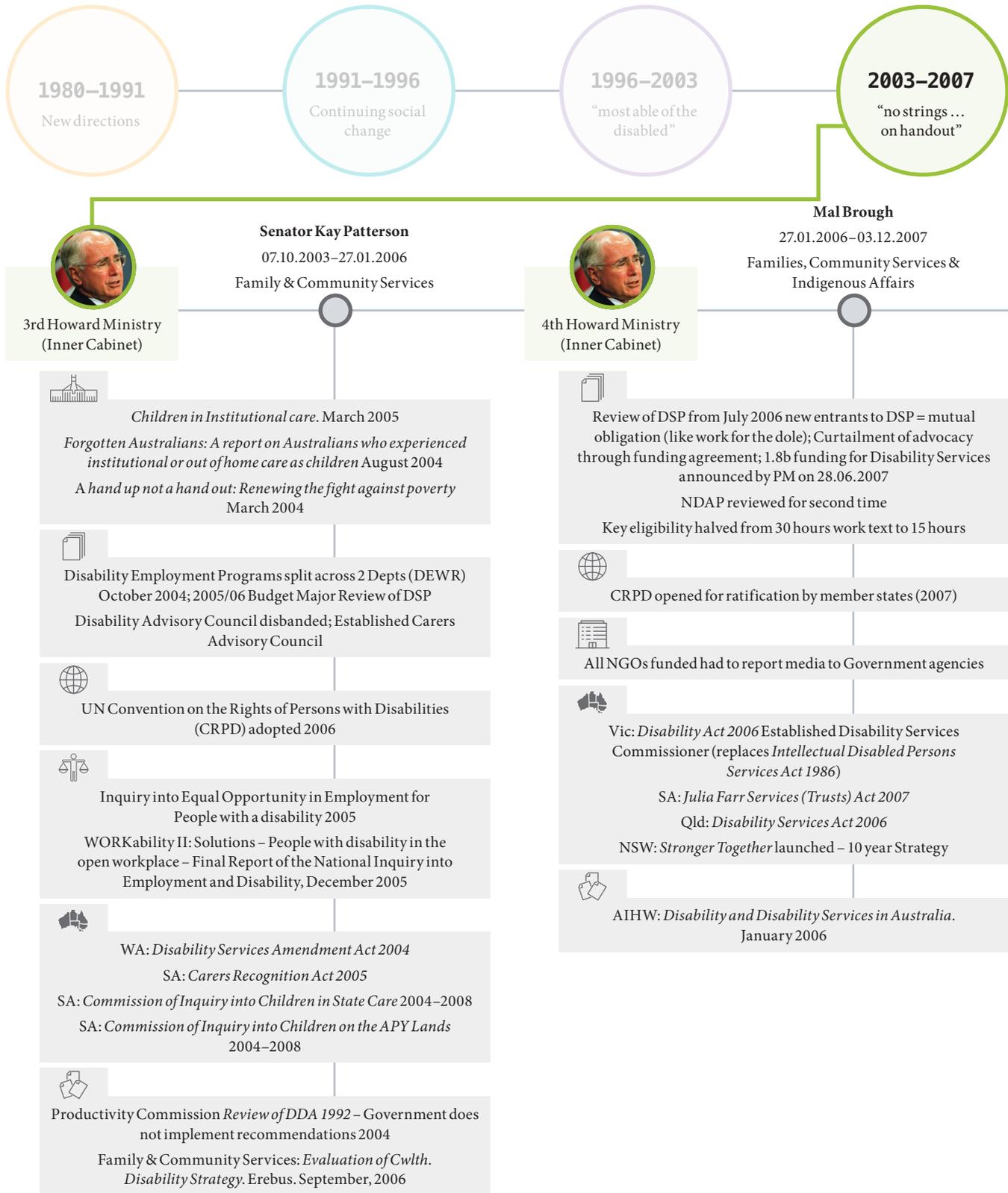
# APPENDIX E

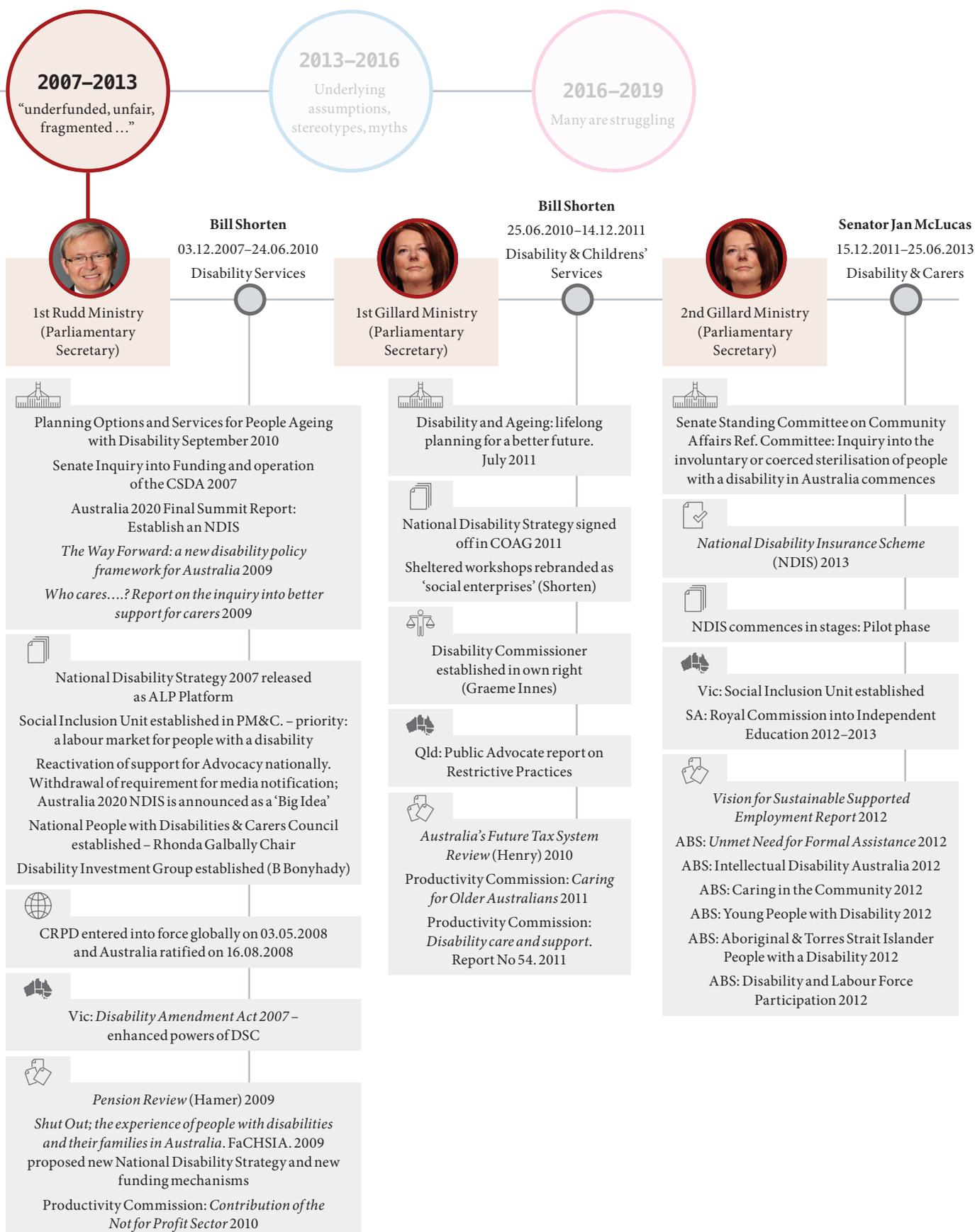


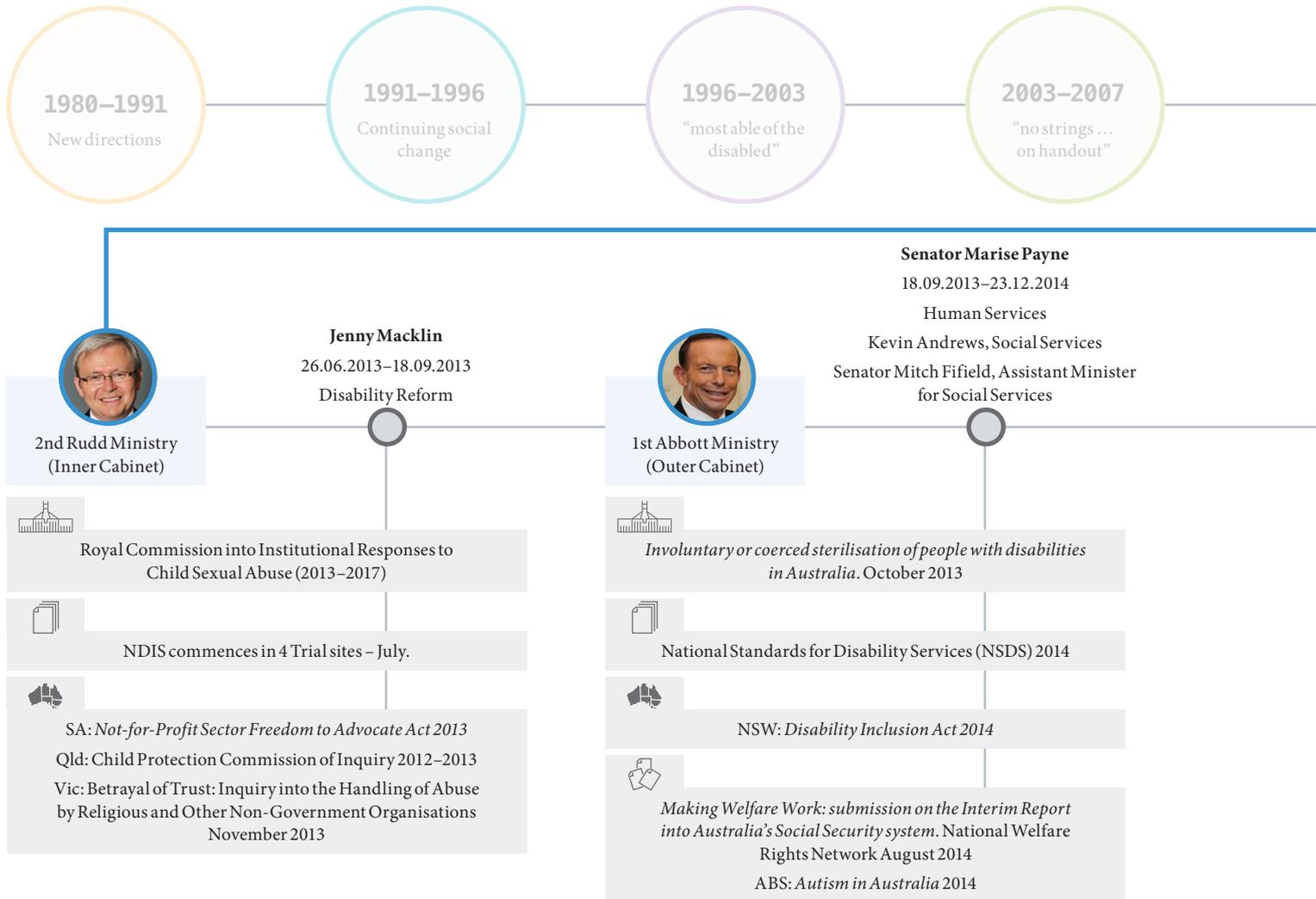


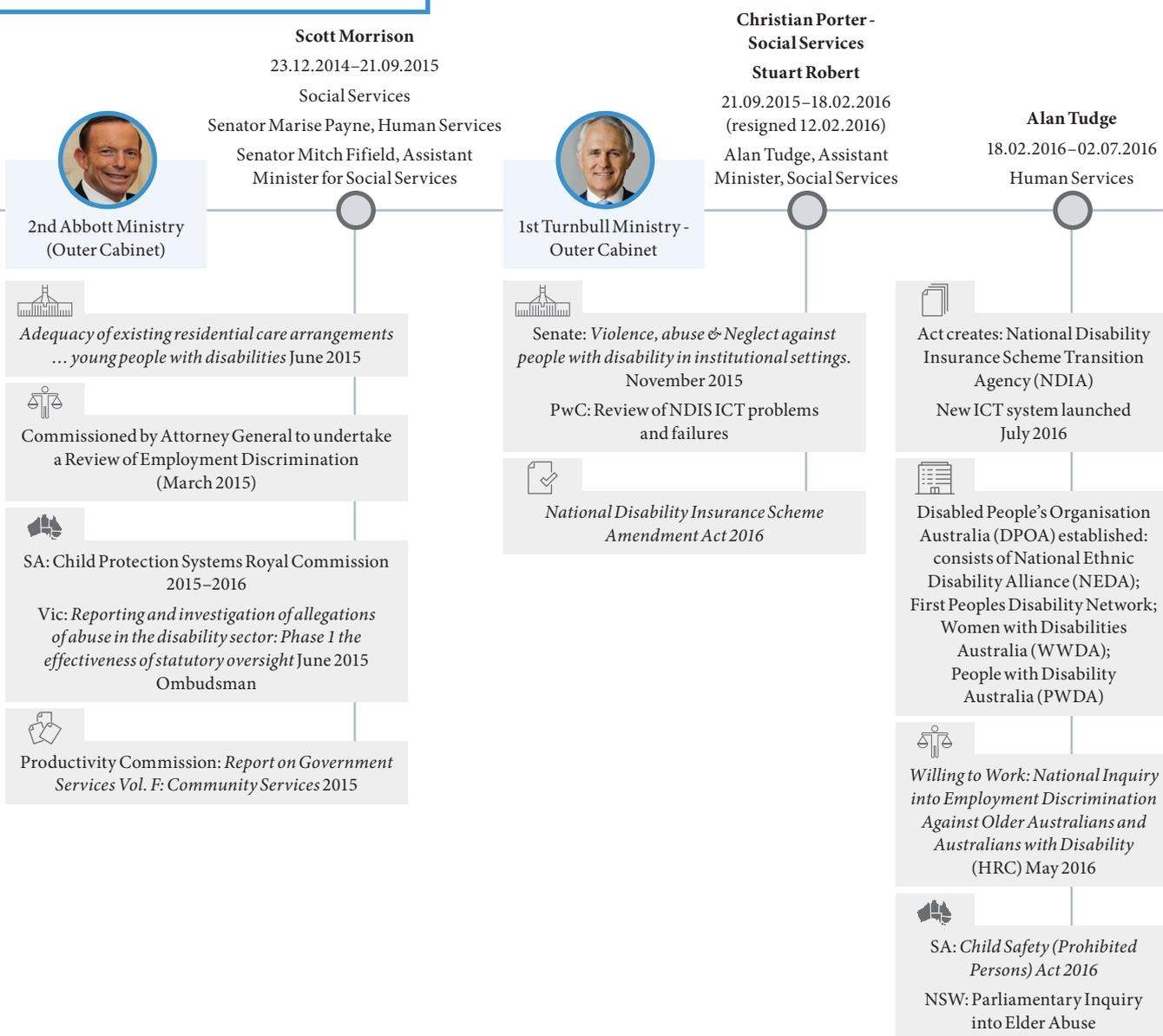
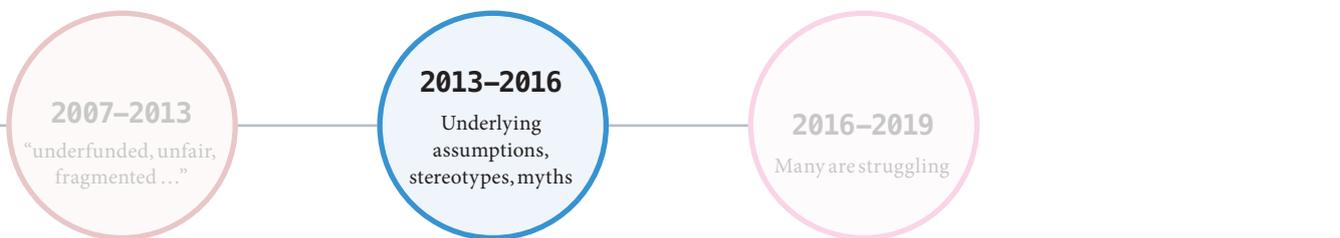


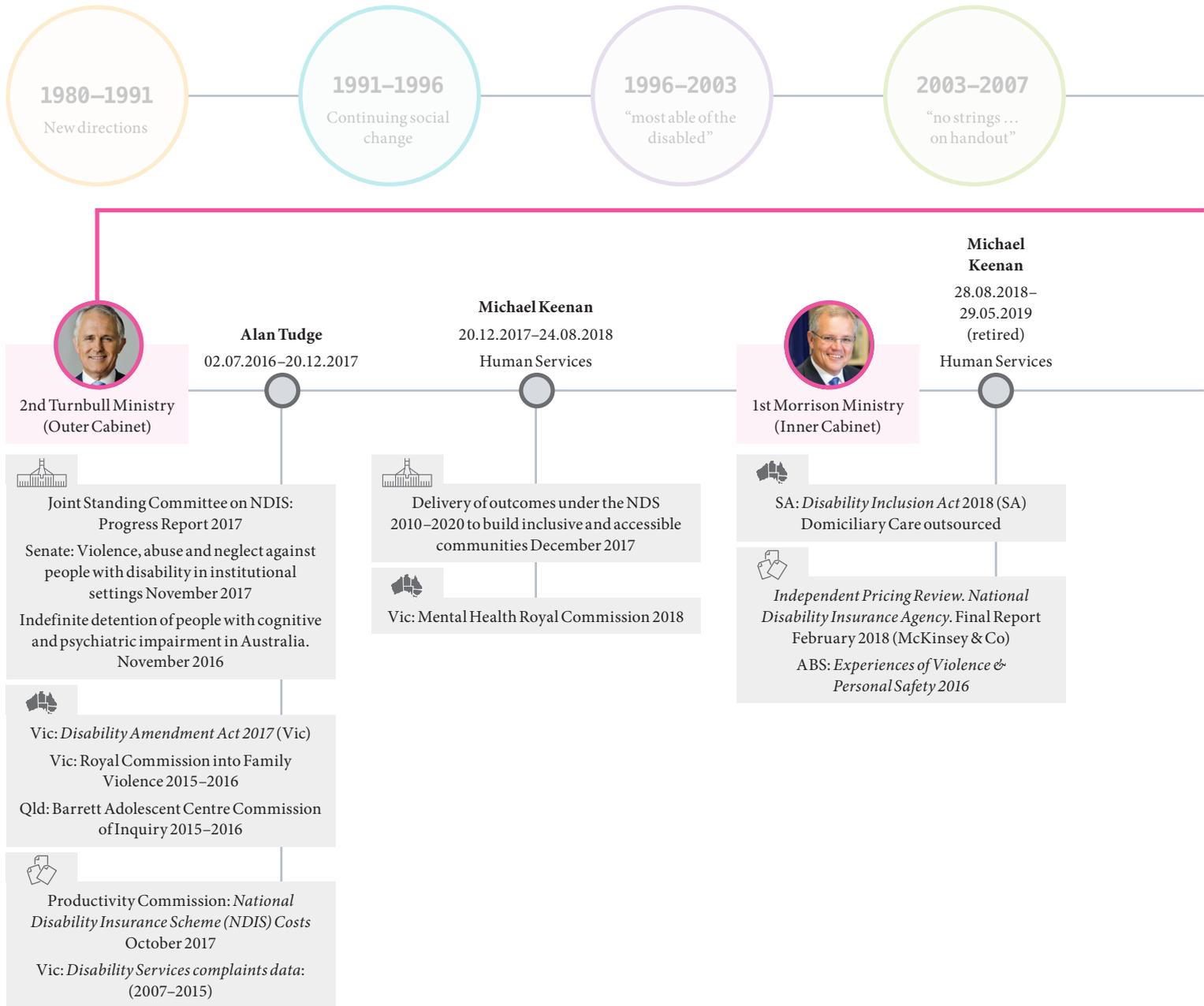


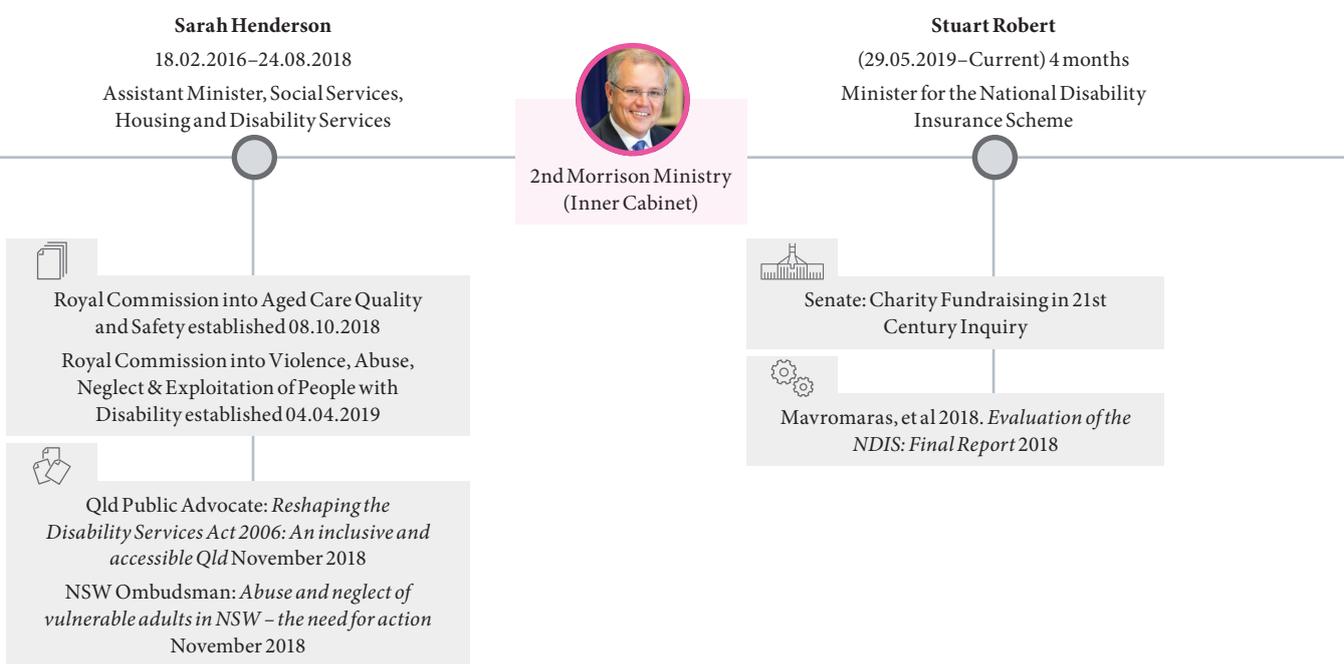












A brief history of the disability services sector in Australia:  
1992 – present day

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