

For better or worse -

How have people with intellectual disability fared in a whole of disability service framework?

Dierdre Croft

Since the early 1990s, Australian jurisdictions have progressively moved towards a more integrated approach to disability services provision in place of policies and practices of the past that were based on the support needs of different disability groups.

This article explores the impact of a “whole of disability” service framework on the provision of services to people with intellectual disability, with a particular focus on the provision of accommodation support services to people with intellectual disability in Western Australia.

The article was written by Deirdre Croft who has been investigating the historic provision of accommodation support services for Western Australians with intellectual disability as part of her PhD research. Deirdre is the mother of a 29 year old son with severe intellectual disability. She currently works as a Collaboration Manager at the Australian Research Alliance for Children and Youth (ARACY) responsible for managing ARACY's Preventing Youth Violence project.

From there to here

Twenty four years ago, in 1986, two policy developments occurred in Australia that were based on very different assumptions about how the formal disability services system could best meet the support needs of people with intellectual disability.

At a national level, 1986 saw the passage of the Commonwealth Disability Services Act which had the stated aim of creating an integrated disability services system that was “*more flexible and more responsive to the needs and aspirations of (all) people with disabilities*”¹ no matter the cause or consequence of their disability.

While the legislative principles proclaimed that “*people with disabilities are individuals*”, the broad targeting of the legislation to “*people with disabilities*” as a generic group suggested that disability, in itself, could be considered a unifying experience, for which more encompassing policies and procedures could also be applied.

In the same year, the establishment of the Authority for Intellectually Handicapped Persons in Western Australia created a clear distinction between the policies, practices and administrative arrangements for meeting the needs of people with intellectual disability relative to those for people with other disabling conditions.

Administrative responsibility for the provision of services to Western Australians with intellectual disability had previously come within the ambit of Mental Health Services (within the WA Health Department) which was also responsible for supporting the needs of people with a psychiatric disability (at the time described as having a mental illness).

Writing in the first annual report of the Authority for Intellectually Handicapped Persons, the inaugural Director, Haydn Lowe noted that the establishment of the Authority on 1 January 1986 “*was the culmination of many years work by service providers, consumer groups and Government and followed three reports recommending on the form and structure of a separate agency*”.

He went on to say that the creation of this separate agency “... *acknowledged that services to the intellectually handicapped are most appropriately regarded as socio-educational rather than health or welfare in nature*”.²

The Authority’s 1986-87 Annual Report commented on the development of a first Strategic Plan for the new agency based on four objectives: client rights; client development; client integration; and community acceptance.

The strategic priority on client development was “*to ensure (that) the development of personal and life skills of people with an intellectual handicap are promoted, acknowledged and protected at all levels in the community*”.³

A strong personal development focus across the life course “*to achieve the highest level of independence possible*” was also reinforced under the Authority’s principles of operation, as was an acknowledgment of the potential vulnerability of people with intellectual disability, with an associated need for measures to assure their protection (in the least restrictive manner possible).

Five years later in 1991, Western Australia established the Bureau for Disability Services which assumed broad responsibility for policy development and service funding for Western Australians with disabilities (other than intellectual disability for which the Authority for Intellectually Handicapped Persons remained responsible; and mental illness which continued to be a Health Department responsibility). The appointment of a dedicated Minister for Disability Services at the time was acclaimed as an Australian first.⁴

In the same year, the Commonwealth, State and Territory Governments agreed to adopt a national framework under which the administration and funding of disability service provision throughout Australia would be rationalised. The intent was to achieve greater service efficiencies, less duplication and better accountability, and, most importantly, better outcomes for Australians with disability.

Under the first Commonwealth State Disability Agreement (CSDA), State and Territory Governments committed to enact complementary disability services legislation in their own jurisdictions incorporating the principles and objectives of the Commonwealth Disability Services Act of 1986. The legislative principles were underpinned by an acknowledgment of the equal human rights of all Australians with disability, which brought with it a right to services that would support them achieving a “*reasonable quality of life*” (with the qualification that the right to services equated to the same rights enjoyed by “*other members of Australian society*”).⁵

In 1993, Western Australia’s Disability Services Act provided for the amalgamation of the Authority for Handicapped Persons with the Bureau for Disability Services to form the Disability Services Commission as a dedicated public service agency with an exclusive focus on disability service policy, funding and provision - another Australian first.

Seven years after the celebrated creation of the Authority for Intellectually Handicapped Persons as a separate agency to meet the unique “socio-educational” needs of Western Australians

with intellectual disability, services to meet the needs of people with intellectual disability would now be met under the auspices of an agency with a more expansive disability agenda and a substantially expanded client base.⁶

The question posed in this article is: how have people with intellectual disability fared under this “whole of disability” service framework?

How many people with intellectual disability are getting support?

Monitoring the impact of these policy and administrative changes on the lives of people with intellectual disability has been made more difficult by the paucity of officially published data specific to people with intellectual disability that would enable reliable comparisons to be made over time.

Since the Disability Services Commission was established in 1993, for example, only the total number of service users with intellectual disability per year has been published in the Commission’s annual reports, with no distinction made as to the disabling condition of people accessing different service types. Published national data have been similarly generalised.

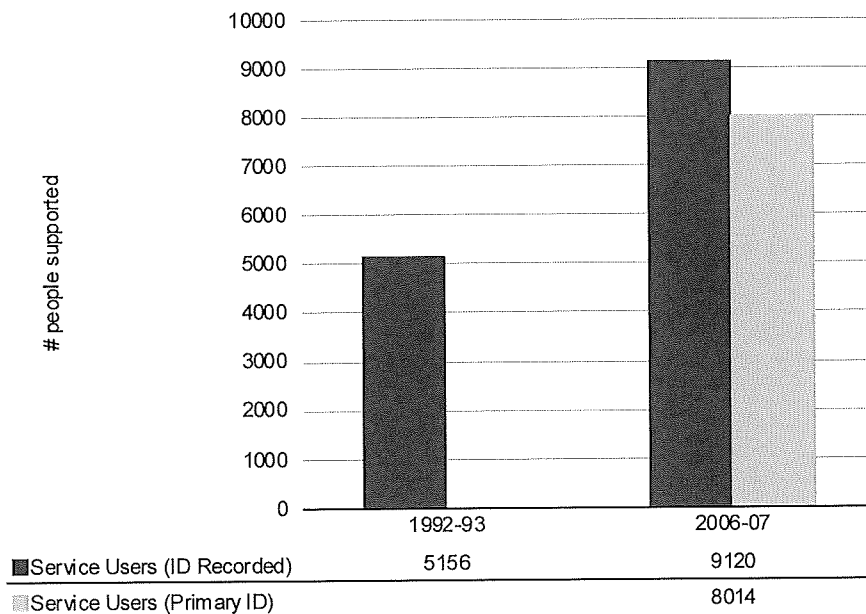
Much of the analysis below is based on data specifically sought from the Australian Institute of Health and Welfare, the WA Disability Services Commission and WA’s Intellectual Disability Database. Due to different timeframes of data available from these sources, to ensure comparability, the data reported below are current at 2006-07.

In 1992-93, figures cited in the last annual report of the Authority for Intellectually Handicapped Persons indicated that 5,125 Western Australians with intellectual disability were provided with services during the year (or 65% of the 7,909 people with intellectual disability registered with the Authority as being eligible for specialist service support at the time).

According to data supplied by the AIHW, by 2006-07 the number of people with intellectual disability accessing services funded or provided by the Disability Services Commission had increased to 8,014 (if you count only those for whom intellectual disability was recorded as their primary disability) or 9,120 (if all those with a recorded intellectual disability are considered).

Either way, between three and four thousand extra people with intellectual disability (either primary or recorded) were being supported in 2006-07 than was the case 14 years previously in 1992-93.

Western Australians with Intellectual Disability
Service users 1992-93 to 2006-07
 (AIHP Annual Report 1993, AIHW MDS Tables 2007)

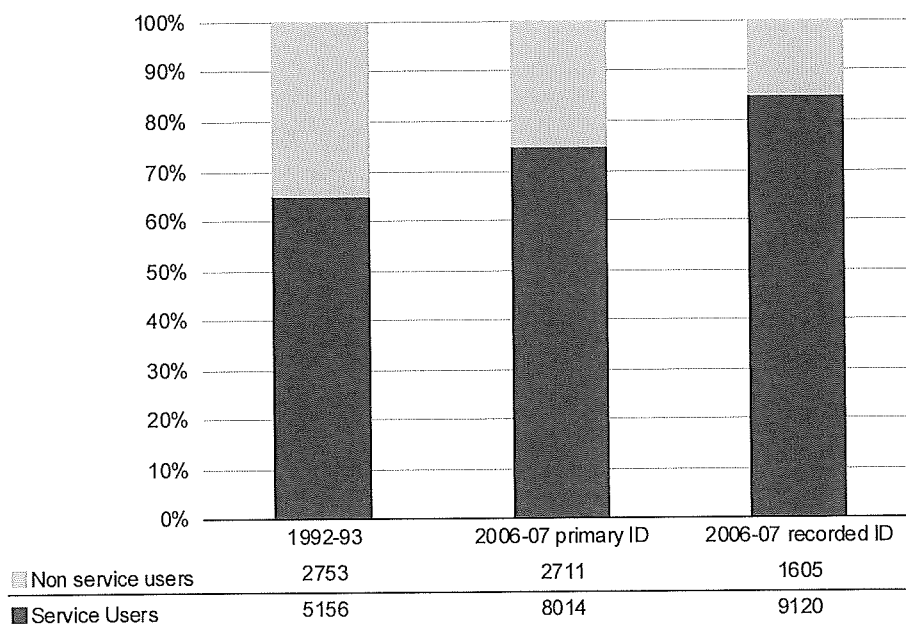


Over the same time frame, the proportion of people registered as eligible for support who actually received support also increased.

Depending on whether the calculation is based on primary or recorded intellectual disability, between 75% and 85% of the 10,725 people with intellectual disability registered with the Commission as eligible for support in 2006-07 were in receipt of some sort of service support from the formal system, compared to only 65% in 1992-93.

So far... so good...

Registered Western Australians with Intellectual Disability
% service users and non-service users 1992-93 to 2006-07



How much support are people getting?

The data cited above suggest that, under the whole of disability service framework in Western Australia, the number of Western Australians with intellectual disability accessing services has indeed increased since 1992-93, both in absolute terms and relative to the number of people with intellectual disability registered with the Commission.

But perhaps a little caution is called for before we crack open the champagne bottles.

Could it be that the type and level of support people have been receiving has changed over time and, if so, might this also be having an impact on how people with intellectual disability are faring under the whole of disability service regime?

Again, the available data do not provide a ready answer to the question.

However, a guestimate of the level of support provided may be made, based on dividing the allotted budget by the number of people supported within that budget.

On this basis, in 1992-93, the budget for the Authority for Intellectually Handicapped Persons was \$84.9 million. The budget was expended exclusively to provide service support to 5,125 Western Australians with intellectual disability. This translates to an expenditure of \$16,566 per person supported.

In 2006-07, the budget of the Disability Services Commission was \$334.4 million (nearly four times the budget of the Authority for Intellectually Handicapped Persons in 1992-93).

According to the Disability Commission's 2006-07 annual report, the number of service users for the year was 20,750 (again around four times the 5,125 people supported through the Authority for Intellectually Handicapped Persons in 1992-93). Of the total number of service users, about a half had an intellectual disability.⁷

The Commission's 2006-07 annual report stated that the average cost of providing support to the 20,720 service users was \$16,115 per service user.⁸

Based on a whole of disability service accounting framework, it is not possible to separate out the dedicated expenditure on services to support the needs of people with intellectual disability in 2006-07 relative to expenditure on people with other disabling conditions.

However, it would appear that, despite substantial increases in cost of living expenses and salary costs over the past decade and a half, the average amount expended per disability service user in Western Australia has not increased above the levels reported for service users with intellectual disability in 1992-93.

What kind of support are people getting?

Under the former Commonwealth State and Territory Disability Agreement (now National Disability Agreement), since the early 2000s standardised whole of year data have been collected from the different jurisdictions on the number of people with disability receiving different types of disability support services.

Data are collected and reported under five broad service categories, with between three and eight service types under each category. The five broad service categories, together with the types of services provided within each, are:

- **Accommodation support** (services that provide accommodation to people with disability and services that provide support needed to enable a person with disability to remain in their existing accommodation or move to more suitable or appropriate accommodation)
- **Community support** (services that provide the support needed for a person with disability to live in a non-institutional setting).
- **Community access** (services designed to provide opportunities for people with disability to gain and use their abilities to enjoy their full potential for social independence)
- **Respite** (providing a short-term and time-limited break for families and other voluntary caregivers of people with disability, to assist in supporting and maintaining the primary care-giving relationship while providing a positive experience for the person with disability)
- **Employment** (including open employment, supported employment and targeted support).

The disabling condition of people accessing different service types within each category is not identified in the officially published data which means it is not possible to track how different disability groups are traveling relative to each other, nor relative to previously established benchmarks.⁹

In most of the service categories, the number of reported Western Australian services users with disability is about what would be expected (or just under) given Western Australia's population size at just over 10% of the national population.

However, the number of "community support service" users in Western Australia for different service types appears to rank well above the population based expectations.

For example, in the 2006-7, Western Australia had:

- 7,958 service users for "case management, local coordination and development" (18% of the national total of 44,409)
- 4,673 service users for "therapy support for individuals" (21% of the national total of 21,558)
- 1,766 service users for "behavior/specialist intervention" (29% of the national total of 6,135)
- 1,971 service users for "other community support" (35% of the national total of 5,604).¹⁰

In the data collection days of the Authority for Intellectually Handicapped Persons, many of these service types were not classified, nor data collected for them in the same way as occurs today, such that it is now not possible to make meaningful before and after comparisons in many areas of service provision.

Over the same period of time, however, services that are now categorised as accommodation support appear to have been a more consistent category.

As such, and for the purposes of this analysis, the number of Western Australians with intellectual disability specifically receiving accommodation support services has been further investigated.

At first glance, it would appear that the numbers look good (even though overall, in 2006-07, Western Australia performed much as would be expected from the size of its population providing accommodation support to 3,807 Western Australians with disability, or 10.1% of the

national total of 37,473.

On request, the Australian Institute of Health and Welfare has provided service data specifically identifying the number and characteristics of Western Australians with intellectual disability accessing accommodation support services.

The data for 2006-07 indicate that:

- 2,580 Western Australian service users with a recorded intellectual disability were classified as receiving accommodation support services representing 68% of the total 3,807 Western Australian accommodation support service users for the year. (Intellectual disability was recorded as the primary disabling condition for 2,209 or 58% of the total number of accommodation support service users in Western Australia).

By way of comparison, the Authority for Intellectually Handicapped Persons reported that in 1992-93 there were 1,705 people with intellectual disability receiving accommodation support (1,210 accessing residential support and 495 receiving support to live in the community).

Based on these figures, the increase in the number of service users with intellectual disability receiving an accommodation support service over the 14 year timeframe from 1992-93 to 2006-07 was 875 (or an additional 62.5 service users with intellectual disability per year).

A closer examination of the official data on accommodation support service users, however, shows a very high number of younger people with intellectual disability aged 5-14 and 15-24 were classified as receiving “in-home” accommodation support.

Given the long-stated policy of promoting family based care for children with disability, these data seem to require further clarification.

The Disability Services Commission provided a more detailed breakdown of the data which showed that a high proportion of people with intellectual disability classified as receiving in-home accommodation support were actually in receipt of services classified as “intensive family support” or “IFS”.

In other words, while for the purposes of national data collection and reporting, the person with intellectual disability was classified as being in receipt of “accommodation support”, in actual fact support services were being provided to enable the person to continue to live within the family home. According to the Disability Services Commission website, the Intensive Family Support program:

“... assists people with disabilities to remain with their family and provides families with a break from caring... Support may include someone coming into your home to provide personal care for your family member with a disability, providing opportunities for community inclusion and socialisation, and at the same time giving families a break from the caring role.

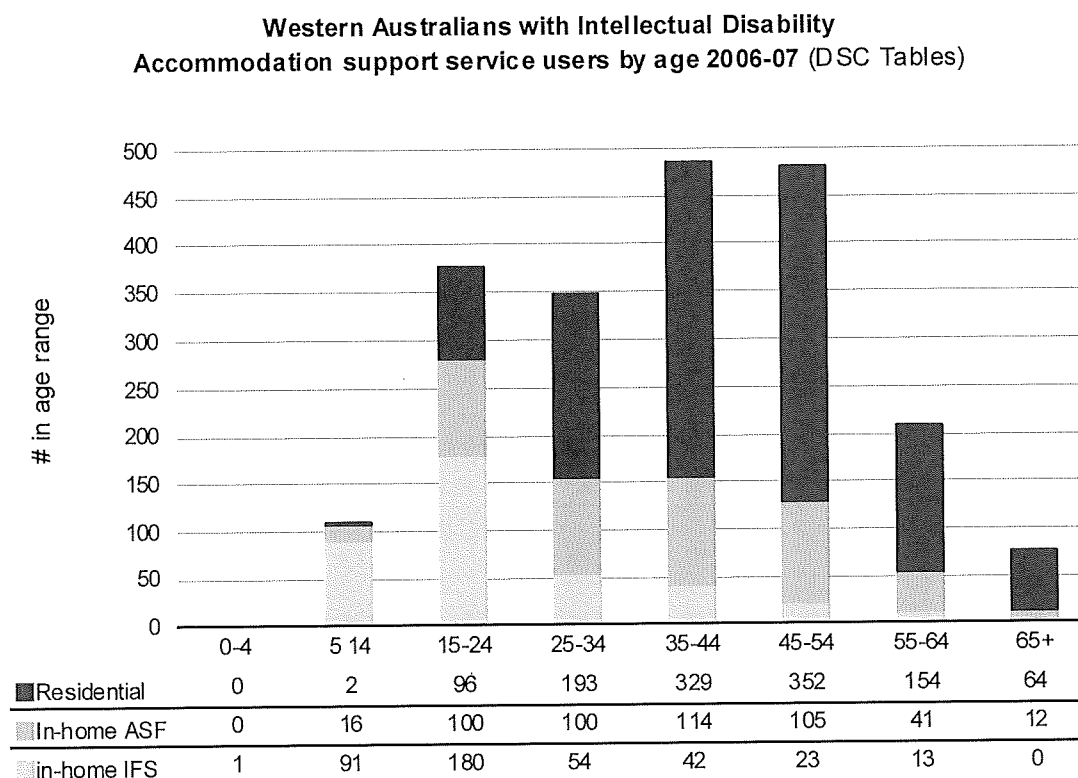
Funding is allocated to people who have been given the highest priority by an independent panel, and is allocated specifically to the person with a disability”.¹¹

No doubt many parents with a younger son or daughter with intellectual disability would applaud a service priority focused on providing intensive support to families in their caring role.

However, the understanding of many parents whose children are moving into their adult years

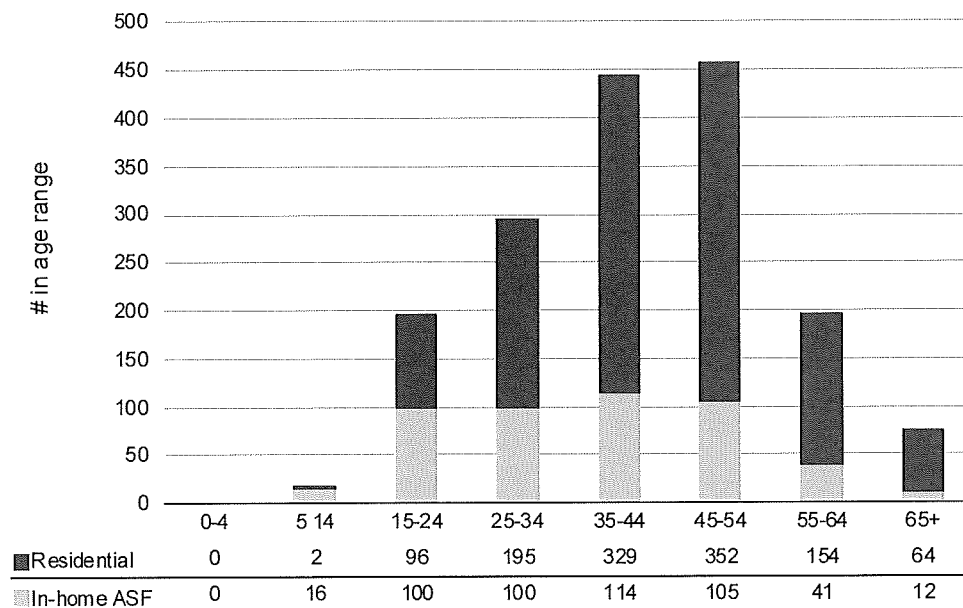
is that “accommodation support” refers to support that is provided to enable the person to live in the community, rather than to continue living within the family home.

The diagram below shows the number of people with intellectual disability classified as receiving accommodation support services in 2006-07 and the type of support they received according to age.¹²



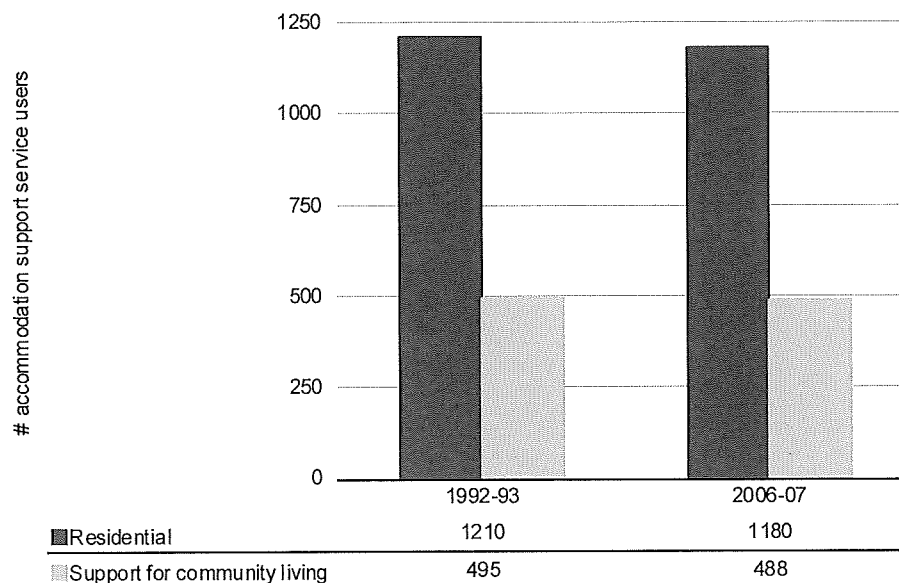
If the number of people with intellectual disability receiving intensive family support funding is discounted so as to show only those people receiving accommodation support in the community, the age distribution and numbers receiving accommodation support within each age range changes quite markedly.

Western Australians with Intellectual Disability
Accommodation support ID service users by age 2006-07 (DSC datatables)



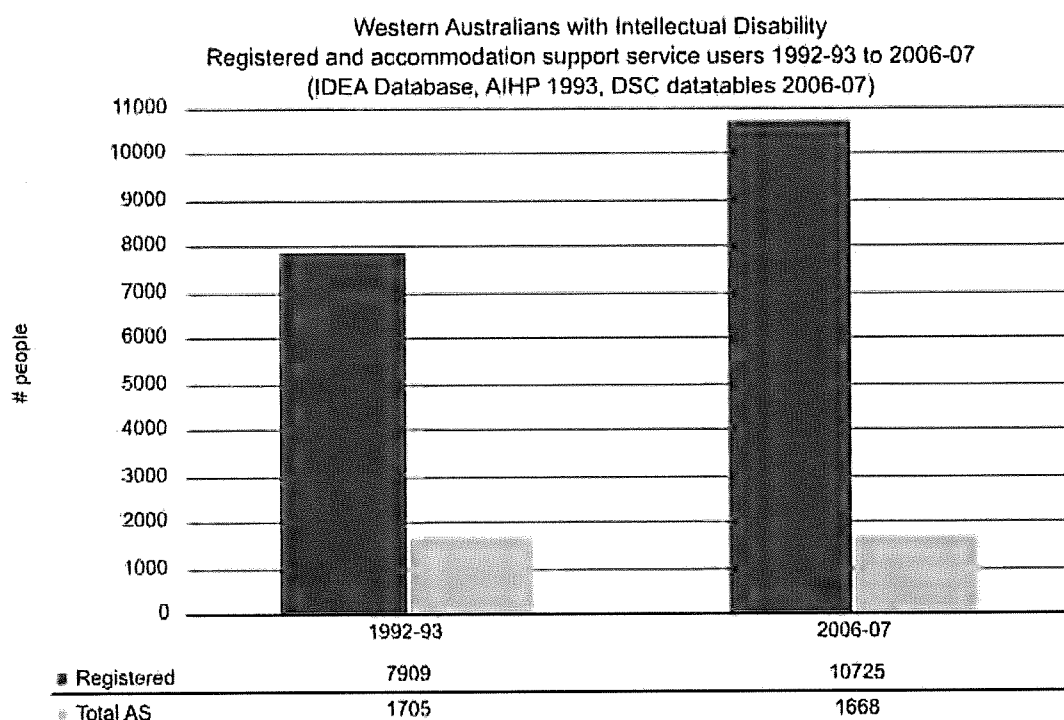
Now, when the figures are re-examined, a less positive picture emerges of the number of Western Australians with intellectual disability accessing out of home accommodation support in 2006-07 (either residential support or support to live in the community) compared to the number of people receiving accommodation support in 1992-93. Despite the 14 year interval, it would appear that the number of people receiving accommodation support out of the family home has actually gone down (albeit only slightly).

Western Australians with Intellectual Disability
accommodation support service users 1992-93 to 2006-07
 (AIHP and DSC datatables)



By aggregating the number of people receiving residential support and those accessing support to live in the community, a figure can be derived for the total number of people with intellectual disability accessing accommodation support outside the family home. When this figure is compared to the total number of people with intellectual disability registered with the Disability Services Commission, the picture changes yet again.

As can be seen from the diagram below, the number of people with intellectual disability registered with the Commission has increased by 2,816 or 36% since 1992-93, while the number of people receiving out of home accommodation support appears to have fallen slightly over the same period.



How many people are not getting the support they need?

Over the past decade or so, the high level of so-called “unmet need” has dominated public debate about disability service provision in Australia. In such a climate, the political defence has typically been to counter with an account of how much extra funding has been allocated to disability services over time. As, indeed, funding has certainly increased.

But increased expenditure, in itself, does not necessarily translate into better outcomes for people with disability, and performance measures should surely include the number of people who are not receiving the service support they seek, as well as those who are. (It makes sense that a person whose needs are not being met will find little comfort in the knowledge that someone else is getting the support they need.)

In the health care system, waiting lists for the delivery of services are frequently cited as an indicator of performance, irrespective of the number of people for whom a service has been provided. As indeed, the extent of the failure to provide services to people who need them may

be considered just as potent a performance indicator as success in doing so to a more limited number.

In the national, whole of disability services system, jurisdictional “waiting lists” are not routinely maintained nor reported.

The need for “better data” both on current unmet need and on likely future need has been a recurring theme in the many jurisdictional and national inquiries that have been conducted since the review of the first Commonwealth and States Disability Agreement in 1996. Yet still the data seem illusive.

In the absence of reliable data, over the years, statisticians have pored over the available numbers, and their implications, to come up with “estimates” of the level of unmet need, which is often also referred to as “unmet demand”.

In 2008, the AIHW extrapolated from the results of the 2003 ABS survey of Disability, Ageing and Carers to generate a national estimate of unmet need for different service categories specific to people with intellectual disability.¹³

- For employment services, the estimated level of unmet need ranged from 1,400 people (most conservative) to 17,700 people (least conservative).
- For community access services, the estimated level of unmet need was estimated to range from 1,400 to 10,300.

The highest level of unmet need for people with intellectual disability, however, applied to accommodation and respite services where 22,800 Australians with intellectual disability were estimated to have an unmet need for these service types. The analysis showed that, of the estimated total number of 26,700 people with disability who had an unmet need for accommodation support or respite, the vast proportion (85%) had an intellectual disability.

The reported data would seem to indicate that, at a national level at least, unmet need for accommodation and respite services has disproportionately impacted on people with intellectual disability and their family carers relative to people with other disabling conditions.

In addition, according to the AIHW analysis, of the people with intellectual disability who needed help with core activities (self help, mobility or communication) to support their daily living or with other activities (such as cognition and emotion) to support their participation in Australian society, only about half had their needs fully met.

What distinguishes the needs of people with intellectual disability from those of people with other disabling conditions?

By definition, people with intellectual disability have significant deficits in their intellectual functioning, as well as significant deficits in their capacity to adapt to the requirements of their physical and social environment.¹⁴ The website of the American Association of Intellectual and Developmental Disabilities (AAIDD, 2009)¹⁵ describes how the capacity for adaptive behaviour enables a person to meet their own day-to-day living needs:

“Adaptive behaviour is the collection of conceptual, social, and practical skills that all people learn in order to function in their daily lives”.

The AAIDD website provides further details on the importance of capacity in each of these

three domains if a person is to be able to maintain an independent, personally healthy, socially connected and economically productive lifestyle.

The skills identified by the AAIDD are presented below:

- **Conceptual skills:** literacy; self-direction; and concepts of number, money, and time
- **Social skills:** interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, following rules, obeying laws, and avoiding being victimised
- **Practical skills:** activities of daily living (personal care), occupational skills, use of money, safety, health care, travel/transportation, schedules/routines, and use of the telephone

It follows that the likely impact of significant deficits in these adaptive skills will be pervasive, affecting all dimensions of the life of the person with intellectual disability the consequences of which will call for a much higher level of personal and social support, guidance and protection than would be the case for people whose disability is specific to the sensory or mobility restrictions their disability may impose.

In this respect, it is important to acknowledge that many people with intellectual disability also have other disabling conditions which compound the impact of their diagnosed primary disability.

According to the 2003 ABS Survey of Disability Ageing and Carers, 57% of people with intellectual disability also had a concurrent psychiatric disability and almost 60% had severe communication limitations.

On the basis of all of the above, it may be assumed that most people who meet the Disability Services Commission's intellectual disability eligibility criteria will require at least some measure of ongoing support if they are ever to leave the parental home and live more independently in a community setting.

In its 2008 bulletin on intellectual disability¹⁶, the AIHW reinforced the distinguishing characteristics of people with intellectual disability that would most likely necessitate the provision of supports which people with other disabling conditions may be less likely to require in similar circumstances.

“People with intellectual disability encounter special challenges that are different from people with other types of disabilities in a number of important aspects. For example they have difficulty learning and applying knowledge and in decision making. They may have difficulty identifying and choosing options at key life transition points. They often have difficulty adjusting to changed circumstances and unfamiliar environments and therefore need high support during times of change” (AIHW, 2008, p.1).

Why personal planning is especially important for people with intellectual disability

A decade or so ago, a Western Australian mother who was applying for accommodation support for her school leaver son with intellectual disability distributed to other intellectual disability advocates the lengthy submission she had prepared in support of her application. At the time, the mother was facing serious health problems. Her submission was headlined

“By planning or by tragedy”. The case she put was that, one way or another, her son would need to be accommodated away from the family home. The transition could be managed in a timely, planned way to minimise any trauma he might experience in adjusting to a new home environment, or it would be required at a time of family tragedy which would compound the trauma he experienced in the process of relocating.

As a mother with years of experience in meeting her son's needs, she recognised that his severe intellectual disability made it difficult for him to adjust to change, even at the best of times, let alone having to cope with multiple changes occurring at a time of family crisis.

In a resource constrained service system, however, it is the level of crisis in a person's life that determines how people's needs are prioritised for the rationing of scarce service support.

An Accommodation Support Funding Fact Sheet published by the Disability Services Commission in November 2000 advised on the criteria for assessing the criticality of a person's needs:

“Eligible people will be assessed against specific criteria to establish their priority or immediate need, that is, the extent to which their current support arrangements are at risk of breaking down. This process ensures that funding is provided to the people who need it most.

Typically, immediate need is due to one or more of the following factors:

- *ageing carers*
- *illness, poor health or stress of the carer*
- *the carer is supporting more than one person with a disability*
- *changing support needs of the person*
- *risk of exploitation/abuse*
- *the person is living in a temporary arrangement that cannot continue”.*

The criteria for prioritising the relative criticality of people's need are no longer published on the Commission's website. However, it is notable that the first three priority criteria listed above relate to the capacity of carers to continue to provide care, rather than reflecting the need for support of the person with disability or on providing developmental opportunities for the person to live more independently in the community.¹⁷

Various inquiries into the provision of accommodation support in other Australian jurisdictions¹⁸ have reached a common conclusion: that the service system is “crisis driven” and that the limited resourcing available has made it possible to provide accommodation support only in the event of a breakdown in the person's existing living arrangements.

For the majority of people with intellectual disability whose support needs are being met within the family home¹⁹ it follows that a breakdown in existing arrangements would most likely occur as a result of a breakdown in the capacity of the person's parent/s to continue to provide home-based care and support (due to death, ill-health or other family trauma).

A service system in which accommodation support is provided only when the ordered world of the person in need of support falls down around them would seem to be especially insensitive to the special needs of people with intellectual disability who, by definition, experience limitations in their capacity to adjust to changes in their living circumstances and/or environment.

Otherwise expressed, a service system which rations support according to the level of crisis in a person's life would appear to have a far more deleterious effect on the quality of life of a person who is limited in their capacity to adjust to change than it would on a person who is not so limited.

Given the unique characteristics that differentiate people with intellectual disability from people with other disabling conditions, it would seem all the more important, and humane, to plan and implement an orderly and gradual transition from one set of living arrangements to another, so as to enable the person's parent carers to provide emotional continuity and support while they are still alive and capable of doing so.

Pre-requisites for disability service planning

At a systemic level, the plethora of official inquiries and reviews that have been conducted into the needs and unmet needs of Australians with disabilities over at least the past two decades have typically been justified with reference to establishing a better basis for service planning.

In 1992 (a year before Western Australia's Authority for Intellectually Handicapped Persons ceased to exist and Disability Services Commission was established) a review was conducted into the provision of accommodation services for people with disability in Western Australia. Even then, the review report commented that inadequate data was impeding planning for the orderly provision of needed services:

"The Committee noted the absence of appropriate information either systemic or anecdotal for a number of ... disability groups which would adequately support the planning of services".²⁰

Notably, the Committee also remarked on the quality of data then available in the intellectual disability field:

"The Committee noted the extent of information available in the intellectual disability field, and the role of the Authority for Intellectually Handicapped Persons and other key non-government agencies in planning and advocating for services for people with intellectual disabilities and their families and carers".

Nine years later, in 2001, the then Minister for Disability Services in Western Australia, the Hon. Sheila McHale commissioned two reports: one to review the process for allocating accommodation support funding; and the other to identify the current and likely future demand for accommodation support services in Western Australia.

As the Minister said at the time:

"The peak disability organisations, families and the Disability Services Commission will work together to ensure that we all have a clear picture of the level of need for accommodation support. We need to plan for people with disabilities, just as we plan for growth in schools and our ageing society".²¹

And then again in 2003, Western Australia's Accommodation Blueprint Steering Committee identified the need for better data - both quantitative and qualitative - to enable *"a more informed framework for planning"*.

The quest for better data to inform service planning was also being expressed at a national level.

The 1996 report of the review of the first Commonwealth State Disability Agreement argued that proper planning for disability services funding and provision depended on the availability of... “better data”:

*“Without putting a figure on unmet demand for services that currently come under the CSDA, it is impossible to plan for the development and more adequate resourcing of the disability services system”.*²²

Ten years later, in 2006, the Senate Standing Committee on Community Services inquiry into the funding and operation of the Commonwealth, State and Territory Agreement cited the lack of jurisdictional data on the level of need and unmet need as an impediment to service planning.

Referring to the claim of State and Territory Governments that they lacked the capacity to provide further resources to address unmet need, the inquiry report stated:

*“The Commonwealth, while acknowledging that there is still a level of unmet need, has stated that the ‘data collected and made available by the States and Territories does not allow an accurate assessment of the level and nature of this need’”.*²³

Yet again, here we are, 18 years after the 1992 review of accommodation services for people with disabilities in Western Australia called for better data to support accommodation support service planning, still bemoaning the fact that the data are inadequate, and that data inadequacies inhibit a planned approach to disability service delivery.

Except that, these days, the data available on the needs and unmet needs of people with intellectual disability would appear to be just as inadequate as those available on people with other disabling conditions, especially compared to the situation in 1992 when the WA accommodation services review commended the quality of intellectual disability data presented.

In the meantime, why, we might ask, do intellectually capable policymakers find it so difficult to come up with reliable measures of current and future need?

Could it be that they’d prefer not to know... just in case the numbers reveal a seemingly overwhelming task ahead?

But would the data really be so overwhelming?

What lies ahead?

Planning assumes some measure of predictability. It stands to reason that a service system based on responding only to crises in people’s lives will inevitably defy the best laid plans of orderly service delivery. Crises, of their very nature, are unplanned and unpredictable. (Otherwise, we would presumably put in place plans to stop crises from happening in the first instance.)

One of the difficulties in quantifying demand for disability service support is that the majority of people with disability do not seem to need, or seek, support from the formal service system.²⁴

In a whole of disability service framework, identifying who will seek support and who won’t, and under what circumstances, is perhaps one of life’s great imponderables, lying well beyond the statistician’s reach.

If, however, we narrow our focus to the disabling condition of people who are already the main users of different disability support services, and especially to the disabling condition of the main service users of accommodation support services, a clearer picture of potential need may begin to emerge.

And if we narrow our focus still further to the unique characteristics, and likely support needs of people with intellectual disability, estimates of need, unmet need and likely future need for this population group may become even more readily quantifiable.

According to data supplied by the Australian Institute of Health and Welfare on the living arrangements of Western Australians with intellectual disability, three years ago in 2006-07, close to 3,500 Western Australians disability service users with intellectual disability aged 15 and over were living at home with family.

In 2009-2010, those same people would now all be classified as adults aged 18 and over.

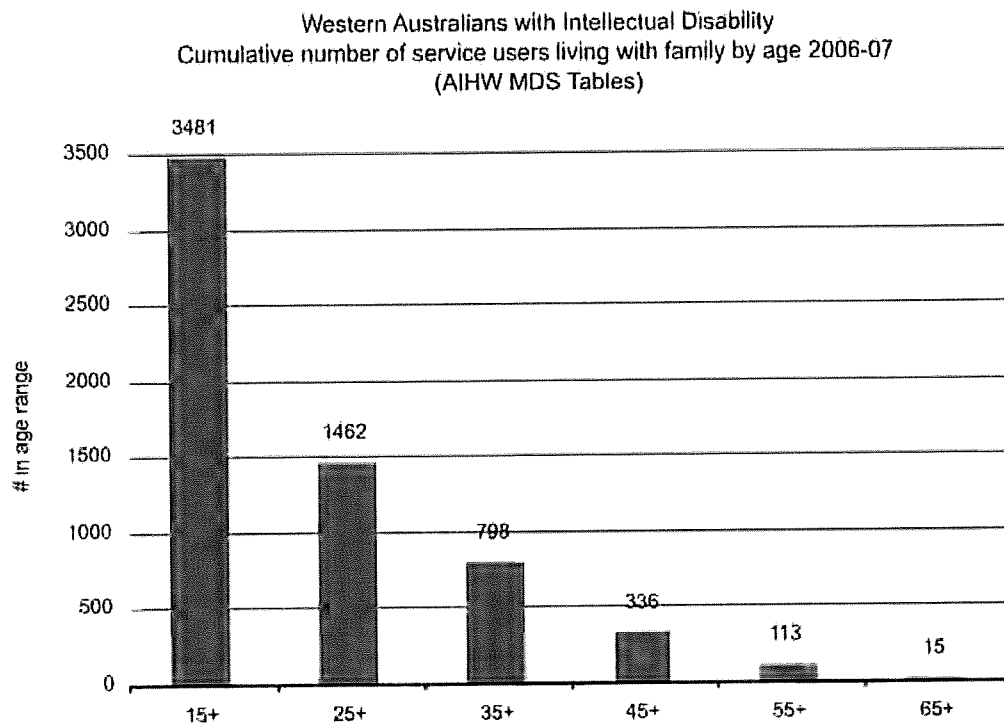
The 2006-07 annual report of the WA Disability Services Commission (p. 38) reported against a five year target set in 2003-04 which sought to:

- eliminate the backlog in unmet need for accommodation support (estimated at 225 people in 2003-04)
- keep up with projected population growth (estimated at 3.73% a year).

2006-07 was the fourth year of the plan. According to the Commission's annual report for the year, in the four years from 2003-04 to 2006-07 inclusive, accommodation support had been provided to an additional 455 people with disability, averaging out at an additional 114 people supported per year.

Assuming that about two-thirds of this increased capacity went towards meeting the needs of people with intellectual disability, approximately 75 additional people a year would have been provided with the accommodation support they sought.²⁵ At the same rate, it would take around 46 years to meet the accommodation support needs of the 3,481 Western Australians with intellectual disability aged 15 and over who were living at home with their families in 2006-07 (who would now be aged 18 and over).

On the same basis of calculation and considering only those service users aged 25 and over living at home with family in 2006-07 (who would be aged 28 and over in 2009-10), a close on 20 year time frame would be required to provide out-of-the-family-home accommodation support for the 1,462 people in this older cohort.



Has a change of focus meant a change in priorities?

In a whole of disability service framework in which the promotional focus is on people's "abilities" rather than the impact of their "dis-ability", it would no longer seem to be politically correct to highlight the differential impact of a particular disabling condition on a person's capacity to cope with life's challenges.

Nor does a whole of disability service framework seem to make special allowances for the differential impact of policies and practices on the lives of people with different disabling conditions and/or on their family carers (with particular reference, in this instance, to the impacts on people living with intellectual disability).²⁶

Except for the substitution of "intellectually handicapped person" with the more generic reference to "people with disabilities", many of the provisions of Western Australia's Authority for Intellectually Handicapped Person's Act (1985) are reflected in the principles of the Commonwealth Disability Services Act (1986) and in the complementary Western Australian Disability Services Act (1993).

The more targeted Authority for Intellectually Handicapped Person's Act, however, included additional principles that:

- reinforced the preference for the education of a person with intellectual disability to be provided through the mainstream system (principle: d)
- established the requirement for a clear definition of responsibilities for oversight treatment and training "*when an intellectually handicapped person is in the care of the Authority*" (principle: j)
- highlighted the importance of enabling people with intellectual disability to lead "normal" lives:

“The living conditions of intellectually handicapped persons should be as close as is possible to those considered normal in the mainstream of society” (principle: e).²⁷

Given the similarities between the legislative principles across the different Acts, to further investigate how people with intellectual disability have fared under a whole of disability service framework, it may be instructive to also examine how the strategic priorities have changed over time.

As reported in the 1986-87 Annual Report of the Authority for Intellectually Handicapped Persons (p. 11), the Authority’s first and only fully-fledged strategic plan was developed in December 1986 which defined the Authority’s mission as being:

“To advance the rights, responsibilities, dignity, development and community participation of people with an intellectual handicap”.

The strategic plan included four strategic objectives: client rights; client development; client integration and community acceptance – all of them specific to the rights and needs of people with intellectual disability.

Seven principles of operation, many of which identified and expanded on issues likely to impact on the lives of people with intellectual disability and their families, were adopted as “corporate philosophy”.

For example, the text accompanying the principle of operation headed “**development**” (p. 10) included the statement:

“It is essential that developmental programs, attuned to the needs of the individual, are commenced early and continue throughout life”.

The text accompanying the principle of operation headed “**normalisation**” included the statement:

“The interests of both the person with an intellectual handicap and society are best met when the conditions of everyday living are as close as possible to the norms and patterns in the mainstream of society”.

And again:

“On attaining adulthood people with an intellectual handicap who are capable of doing so should have the opportunity to live independently if they so decide”.

Under the principle of operation headed “**rights, freedoms and responsibilities**” was included the statement:

“Parents, advocates, guardians, caregivers and others with a responsibility for the care of a person with an intellectual handicap should be aware of the rights of that person and also the extent and limit of their authority to act on behalf of that person”.

And under the principle of operation headed “**protection**” was included the statement:

“The taking of reasonable risks is important for development, and the environment of the person who has an intellectual handicap should eliminate only unreasonable risks”.

The same mission statement, strategic objectives and principles of operation applied until 1992-93 when planning for a new strategic plan got underway. However, further development

of the Authority's new strategic plan was superseded by the establishment of the Disability Services Commission in December 1993.

Operating on a whole of disability service framework, the Disability Services Commission's first annual report in 1993-94 (p. 12) described the Commission's mission as being:

"to enable people with disabilities and their families to achieve a quality of life commensurate with that of the rest of the community".

The objectives for the three program areas were listed as being:

- *To ensure an environment which facilitates access and participation for people with disabilities and their families and carers* (**Program 1: Community Development and Services Improvement**)
- *To assist people with disabilities and their families to achieve individual and family wellbeing through the provision of supports and services* (**Program 2: Individual and Family Support**)
- *To provide support for a positive home environment which best meets the individual needs and aspirations of people with disabilities* (**Program 3: Accommodation and Community Home Support**).

The key strategies listed under each of the programs were strongly oriented towards the Commission's role in direct service funding and provision.

Fast forward to 14 years later, the 2006-07 Annual Report of the Disability Services Commission (p. 17) reported on the development of a new strategic plan (the Commission's third) to cover the period from 2006-2010 with the vision that:

"All people live in welcoming communities which facilitate citizenship, friendship, mutual support and a fair go for everyone".

To achieve this vision, the 2006-2010 strategic plan expanded on five strategic goals:

- **Goal 1 - individuals and families:** *"promoting citizenship for people with disabilities and the important role of families, carers and friends"*.
- **Goal 2 - communities:** *"strengthening communities to welcome and include people with disabilities, families and carers"*.
- **Goal 3 - mainstream services and the business sector:** *"building partnerships and working with mainstream services and the business sector so that people with disabilities are welcomed and included"*.
- **Goal 4 - services funded and provided by the Commission:** *"building partnerships which strive for high quality, flexible, sustainable and responsive services"*.
- **Goal 5 - research, planning and policy:** *"influencing the strategic direction of governments and decision makers through research, information and planning"*.

Under each goal is listed a series of strategies in which the dominant terminology used reinforces the importance of relationships, partnerships, positive community attitudes and opportunities to enhance "access", "participation" and "inclusion" of people with disabilities in the social and economic life of the Western Australian community.

In the Executive Summary to the 2006-07 Annual Report (p 2-3), these priorities are reinforced in the list of major achievements documented for the year.

While the annual report highlights the production of the Sector Health Check Report²⁸ as “one of the Commission’s most outstanding initiatives” for the reporting year, six of the ten other “significant achievements” refer to community education initiatives (either targeted or more broadly based) and other initiatives aimed at improving physical or social access.

The achievement of a more welcoming, accessible and inclusive community for people with disability is unquestionably an important and worthy social goal.

However, in a hierarchy of human needs, and in a service climate in which there are high levels of unmet need for service support, it may also be questioned as to whether community inclusion would rate as Priority One for people with intellectual disability and their family carers who, the numbers suggest, are disproportionately affected by the shortfall in specialist disability support services – and more particularly for accommodation support and respite services.

Annual reports of the Authority for Intellectually Handicapped Persons (1986-87 to 1992-93) also referred to the importance of “client integration” and “community acceptance” (which were listed as two of the Authority’s four strategic objectives) towards achieving a better quality of life for people with intellectual disability.

But the Authority’s strategic plan also gave weighting to the need for the provision of programs and opportunities which “*commenced early and continued throughout life*” that supported “*client development*”, promoted “*normalisation*”, secured the person’s “*rights, freedoms and responsibilities*” and assured adequate “*protection*”.

One wonders whether people with physical and sensory disability would feel comfortable if similar strategic priorities were to be applied to a more generic, whole of disability, service framework.

On the other hand, for those of us who have had direct experience of living with intellectual disability (as individuals, parents, friends, supporters, advocates and/or specialist professionals), the operational priorities identified in the strategic plan of the Authority for Intellectually Handicapped seem just as relevant and required today as they did then.

If intellectual disability is to be defined as occurring in the developmental years, resulting in significant deficits in intellectual functioning and adaptive capacity, it may be assumed that intellectual disability has lifelong and pervasive developmental impacts which cannot simply be addressed by creating a more accommodating physical, social or attitudinal environment.

By definition, the limitations to intellectual functioning and adaptive capacity imply a need for lifelong support and guidance which must necessarily be provided either informally (by family and friends) and/or through the formal service system if people with intellectual disability are to be enabled to lead a reasonable quality of life over the course of their life.

Gains and losses for people with intellectual disability in a whole of disability service framework

Based on this analysis, it is encouraging to note that services are being provided to a greater number and proportion of Western Australians with intellectual disability than was the case in 1993 when the Authority for Intellectually Handicapped Persons was absorbed into the Disability

Services Commission.

It is more difficult to identify where other gains have been made.

Intellectual disability advocates and parent carers of people with intellectual disability to whom the author has spoken have, however, been more ready in their assessment as to what has been “lost” over the same period of time. As variously conveyed, these reported losses can be summarised as follows:

- **loss of identity** (where the unique characteristics and special needs of people with intellectual disability have been generalised to accommodate the sensitivities and lifestyle aspirations of people with other disabling conditions)
- **loss of service focus** (which recognises the lifelong developmental needs, support for learning and problem solving, and likely increased social vulnerability of people with intellectual disability)
- **loss of professional and service expertise** (based on an in-depth understanding of the unique characteristics and support requirements of people with intellectual disability and their family carers)
- **loss of a distinguishable advocacy voice** (where previously intellectual disability specific service organisations now operate within a more generalised whole of disability service provision framework)
- **loss of bargaining power** (where the capacity to present the case for support based on clearly defined and quantified needs of a distinct population group is diminished)
- **increased competition for scarce resources and service support** (in competition with other, more articulate, disability groups advancing their own agenda)
- **loss of public and political impact** (due to the diffusion and generalisation of whole of disability messages)
- **increased individual, family and social disadvantage** (due to all of the above).

While this analysis has primarily reported on the disability service system operating in Western Australia, international expert on intellectual disability, Professor Jim Mansell (2006) suggests that a similar “de-differentiation” of intellectual disability services based on “*the loss of special, separate policies and service structures with intellectual disabilities and their replacement by general policies and structures*” is a phenomenon that has occurred simultaneously throughout the western world.²⁹

Mansell also notes that “*the consequences of de-differentiation may include greater competition for priority of resources and a lack of recognition of special issues*” while “*the idea of developmental intervention to help people overcome their intellectual disability has almost completely disappeared as a priority*” (p. 72-73).

What is required to reclaim lost territory?

The antidote for many of the losses above would seem to lie in redressing the issues identified.

The core requirements are:

- **A distinct intellectual disability identity:** There is a need to reclaim and define a distinct intellectual disability profile in which the unique characteristics and needs of people with intellectual disability can be clearly articulated and promoted.
- **Intellectual disability specific data:** data are required to enable monitoring, informed advocacy and evidence-informed action to address the unique needs of people with intellectual disability.
- **A dedicated advocacy focus:** recognising that many people with intellectual disability cannot speak for themselves or speak well themselves, there is a need to strengthen and adequately resource a strong intellectual disability specific advocacy voice which can represent the needs of people with intellectual disability and their family carers based on the best available data and evidence.

A concluding personal comment

As a journalist/wordsmith by professional training, I am interested in how we use language and the meaning we attribute to the language we use.

On which basis, I experience a certain inconsistency in the use of the word “dis-ability” as a generic label to describe people who are limited in their physical or intellectual capabilities, compared to the more precise definitions we apply to people with superior physical and intellectual “a-bilities”. It seems ludicrous to assume we would group elite sportspeople with high flying academics into a singular category as if superior ability in either domain created a unifying experience. Yet we have no problem grouping people who have a physical or intellectual disability on the assumption that the experience of disability must also create a common cause. To my mind, it’s lazy language and conceptually flawed.

Some years ago, a highly intelligent colleague with severe vision impairment reported to me that the only thing she had in common with a person with intellectual disability was “humanity”. Surely, it is the same quality that unites us all.

Endnotes

¹ Disability Services Act (1986), Section 3, objects of the Disability Services Act

² Authority for Intellectually Handicapped Persons (1986), Annual Report, p. 1.

³ Authority for Intellectually Handicapped Persons (1987), Annual Report, p. 10.

⁴ In a brief history posted on the WA Disability Services Commission website, the appointment of a Minister for Disability Services was reported to have “*added political clout and ensured that the disability sector finally had its own voice in the Cabinet room of successive State Governments*”.

⁵ Disability Services Act (1986), Principle 4 states that “*people with disabilities have the same right as other members of Australian society to services which will support their attaining a reasonable quality of life*”

⁶ According to the AIHW (2008) in 2006-07, the number of Western Australians with disability under the age of 65 who were potentially eligible for specialist disability services was estimated to be 71,000 or 6.6 times the 10,725 people with intellectual disability registered with the Disability Services Commission at the time.

⁷ There is a variation between the number of service users with intellectual disability reported in the Commission’s Annual Report and those provided through AIHW. Advice from DSC indicates that

the AIHW data which are provided later in the year are likely to be more accurate. According to the AIHW, 9,120 service users for the year had a recorded intellectual disability and 8,014 had a primary intellectual disability.

⁸ Disability Services Commission 2006-07 Annual Report p. 23

⁹ Australian Institute of Health and Welfare (2008), *Disability support services 2006-07, National data on services provided under the Commonwealth State/Territory Disability Agreement*

¹⁰ Australian Institute of Health and Welfare (2008), *Disability support services 2006-07, National data on services provided under the Commonwealth State/Territory Disability Agreement*, p. 10.

¹¹ <http://www.disability.wa.gov.au/forindividuals/disabilityservices/familysupport.html>

¹² According to figures supplied by the Disability Services Commission for 2006-07, a further 21 Western Australians with intellectual disability were recorded as being supported in an "alternative placement" and 34 classified as receiving "other support".

¹³ Australian Institute of Health and Welfare (2008), *Disability in Australia: intellectual disability* available from <http://www.aihw.gov.au/publications/index.cfm/title/10582>

¹⁴ The WA Disability Services Commission *Policy for Eligibility Appeals in Respect of Intellectual Disability and Autism Spectrum Disorder* specifies "that to be eligible for Commission Services available to people with an intellectual disability a person must have significantly below average intellectual functioning; significantly below average adaptive behaviour; and the condition must be manifest prior to 18 years of age" (p. 2) available from http://www.disability.wa.gov.au/search.html,svNC_DoWordSearch=Y,svSearch_Reset=Y

¹⁵ The AAIDD definitions on adaptive behaviour are available at http://www.aamr.org/content_106.cfm?navID=23

¹⁶ Australian Institute of Health and Welfare (2008), *Disability in Australia: intellectual disability* available from <http://www.aihw.gov.au/publications/index.cfm/title/10582>

¹⁷ Notably the WA Disability Services Commission has announced the introduction of a new Community Living Plan "which will contain and promote a range of alternative pathways to enable people with disabilities to live with appropriate levels of support within the community" (Disability Services Commission Annual Report, 2006-07, p. 6).

¹⁸ For example, the New South Wales Legislative Council Standing Committee on Social Issues Inquiry into the Residential and Other Support Needs of People with a Disability: Making it Happen (2000); the South Australian Legislative Council Social Development Committee *Inquiry into Supported Accommodation* (2003); the Victorian Parliament's Family and Community Development Committee *Inquiry into the Provision of Supported Accommodation for Victorians with Disability or Mental Illness* (2009).

¹⁹ According to data supplied by the AIHW, of the 9,120 service users with intellectual disability in Western Australia in 2006-07, 6,376 or 70% lived at home with family.

²⁰ Bureau for Disability Services (1992), *Review of accommodation services for people with disabilities in Western Australia*, p. 77.

²¹ Unmet Needs Working Group (2002) *Identifying the Need*, p. 6

²² Yeatman, A., (1996) *Getting Real: The Final Report of the Review of the Commonwealth/State Disability Agreement*, p. 3

²³ Senate Standing Committee on Community Affairs (2006), *Inquiry into the funding and operation of the Commonwealth, States and Territories Disability Agreement*, p 63-63

²⁴ According to the 2008 AIHW report on disability support services provided under the Commonwealth State/Territory Disability Agreement (p. 12), in 2006-07, 721,253 Australians with disability were potentially eligible for specialist disability support services. Of the potential population, 225,600 or 31.3% received some form of support from the formal service system. However, the proportion of the potential population receiving services varied markedly across service types e.g. 5.2% for accommodation support services up to 13.7% for community support services. Of the 354,720 people with disability potentially eligible for employment services, 80,008 or 22.5% of the potential population

were in receipt of services.

²⁵ This may be considered a generous assumption given that the increase in the number of accommodation support service users between 1992-93 and 2006-7 (including a proportion of those receiving intensive family support) averaged 62.5/year (see page 10).

²⁶ Acknowledging that, in a disability service system based on meeting people's "individual" needs, this would not be perceived to present a problem.

²⁷ This principle was translated to an objective for service provision in the Disability Services Act (1993)

²⁸ *"The report.... examined the workings of the sector to determine whether Government resources were being used effectively, efficiently and in the best interests of people with disabilities in Western Australia. A total of 67 recommendations were made, including the development of a WA State Disability Plan".* (Disability Services Commission Annual Report, 2006-07, p. 2)

²⁹ Mansell, J., (2006), *Deinstitutionalisation and community living: Progress, problems and priorities*, Journal of Intellectual and Developmental Disabilities, Vol 31 (2), pps 65-76

Centre for Welfare Reform

The latest report from the Centre for Welfare Reform, 'Personalised Transition' has just been published. Personalised Transition describes how the most radical extension of personalisation into health care, education and social care was achieved.



Personalised Transition was commissioned by the Yorkshire & Humber Region and describes a radical new reform of public services. The report describes and evaluates the success of a new model of personalised transition to help disabled children leave school and move into adult life. But the implications of this reform go much wider, suggesting the possibility of radical reforms in health care and education. Developed in Sheffield by Talbot Specialist School, in partnership with Sheffield City and NHS Sheffield, this model is the most radical form of personalisation in the UK. The model was first implemented in 2007 and is now being extended across the whole of the City.

- For the first time ever young people and families have been able to control individual budgets from social care, health care and education.
- Families have experienced marked improvements in their lives and the lives of their sons and daughters.
- Young people with severe disabilities are finding work, getting more involved in community life and having better lives.

For a copy of the full report www.centreforwelfarereform.org/ <<http://www.centreforwelfarereform.org/>>