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national council on
intellectual disability

It’s my life … I’ll do it my way

Submission to the
Long Term Disability Support
Productivity Commission Inquiry 2010

Version 1.0

16 August 2010

The National Council on Intellectual Disability (NCID) was established over 50 years ago by parents and friends, in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.

National Council on Intellectual Disability
PO Box 771 Mawson ACT 2607
61 2 6296 4400
ncid@ncid.org.au
ncid.org.au

Rob Allen President	Mark Pattison Executive Director

National Council on Intellectual Disability

Statement of Principles

for the establishment of a National Disability Long-term Support Scheme

For the National Council on Intellectual Disability to support any National Disability Long-term Support Scheme the scheme must ...

1. Be an entitlement scheme which is enshrined in legislation for ALL people with an intellectual disability
2. Be a funding scheme and not a model of service delivery
3. Meet the support needs of ALL people with an intellectual disability
4. Meet ALL the support needs of people with an intellectual disability over their lifetime
5. Ensure that people with an intellectual disability and where appropriate their families, have direct control over the resources allocated to meet their specific support needs over their lifetime
6. Ensure people with an intellectual disability have access to full social, economic and community inclusion and participation
7. Ensure there are no impediments, financial or otherwise to people with an intellectual disability gaining employment
8. Ensure that any adopted scheme is not bureaucratic or process driven

Adopted by NCID's Board on 18 December 2009

Table of Contents

I planned each charted course -
Each careful step along the byway,
And more, much more than this,
I did it my way.

Yes, there were times, I'm sure you knew,
When I bit off more than I could chew,
But through it all, when there was doubt,
I ate it up and spit it out.
I faced it all and I stood tall
And did it my way.

(Paul Anka and Frank Sinatra, 1969)

Introduction

The key questions for the Productivity Commission Inquiry into the long-term support needs of people with intellectual disability are:

1. How much funding is required to meet all the support needs of all people with intellectual disability?
2. How is the required funding to be raised?
3. Does the Australian Parliament and all political parties have the will and courage to introduce a new levy/tax.

All other questions are of secondary importance, or of no importance, if these three questions are not addressed positively. In fact, other questions are a distraction from these three central questions.

For people with intellectual disability the first question is easily answered, see sections below of this paper; it is acknowledged that for other ‘types’ of disability this may not be the case.

The second question can only be answered by the Productivity Commission and by Treasury. It is within these two government agencies that the expertise and resources sit for a decision to be made on the best manner for the funding to be raised.

The third and most important question for this Inquiry is not even raised by the Productivity Commission. **Does the Australian Parliament and all political parties have the will to introduce a levy/tax to fund all the support needs of all people with intellectual disability?**

Without this commitment, nothing will change. A scheme which only addresses some of the support needs of some people with intellectual disability does not change the current situation. People with intellectual disability and their families will still be faced with unmet need, and the pressure on the support ‘system’ will be such that people with intellectual disability and their families will continue to have no control over their lives.

If the outcome of the Productivity Commission’s Inquiry and the political response to it is to be truly transformational, then both must ensure that all the support needs of all people with intellectual disability are fully funded.

Until this happens there is little point in discussing governance, infrastructure, the design of a new system, the nature of services, who makes the decisions, etc, etc. These dissipate our energies and focus.

The emphasis of this submission will be on demonstrating that the definition of intellectual disability includes all people with intellectual disability who need support in daily activities, that we know how many people with intellectual disability there are within the Australian community and that there are easy to use tools which give an accurate assessment of their support needs.

All this knowledge enables us to accurately predict the funding required to meet all the support needs of all people with intellectual disability.

In addition to this submission, NCID has submitted two others in areas where we have particular expertise, and a major policy paper:

a. Health (with NSW CID and Australian Association on Developmental Disability Medicine)
b. Employment
c. Developmental Support (with SA Council on Intellectual Disability)

When the Productivity Commission sets out the best way to raise the funds needed to ensure that all the support needs of all people with intellectual disability are met then NCID will make representations to the Australian Parliament for them to adopt the recommendations; and, NCID will also provide comment on the best system for ensuring that the funds are spent in an effective and efficient manner.

NCID has participated in the drafting of two submissions — by the Australian Federation of Disability Organisations (AFDO) and In Control (NSW) — that provide alternative funding allocation schemes. NCID endorses these submissions and acknowledges the combined expertise that went into their drafting.

The Productivity Commission has received a very important submission from people with intellectual disability — from the Speak Out Reach Out Committee of NSW Council on Intellectual Disability. NCID recommends that the Productivity Commission gives priority to that submission.

I'll do it my way - its about people not services

In Australia, we have historically talked about services not people with disability; for example, we have State Ministers for Disability Services not Ministers for Disability Issues (as in NZ) or Ministers for People with Disability or Ministers for Inclusion, etc. The problem is that the focus is not on people with disability and their equal participation in the life of the Australian community but on the needs of service providers that only support a minority of needs for a minority of people with disability.

The Productivity Commission continues this focus by talking about services and systems. To its credit, the Productivity Commission does ask us to tell them when they 'get things wrong' (p4).

In this spirit, we must all change our language and talk of the lives of people with disability and acknowledge the many ways in which people with disability will meet their needs to enable them to participate in the life of their community.

UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities explicitly includes people with intellectual disability;

> (P)ersons with disabilities include those who have long-term physical , mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others,.[i]

And,

> Recognizing the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive supports.[ii]

A key right for people with intellectual disability is the right to self-determination, ie, to make choices about 'how I live my life and how I am supported to do this'.

That this 'right' has been historically assumed by government officials and delegated to service providers is no longer acceptable or 'legal' as Australia has ratified the UN Convention on the Rights of Persons with Disabilities.

> Recognising the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.[iii]
>
> The principles of the present Convention shall be: (a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.[iv]

The submissions by AFDO and In Control address this issue. NCID supports self-directed funding and planning and makes the point that people with intellectual disability must not be excluded from these arrangements due to their disability. Article 12 of the UN Convention of the Rights of Persons with Disabilities affirms the equality of people with intellectual disability and the importance of support in making decisions.

A short history of the treatment of people with intellectual disability[v]

An understanding of the history of how society has responded to people with intellectual disability is important to separate historical habit from the research evidence[vi] [vii] [viii]. Such an understanding helps raise our consciousness to the daily experience and assumptions that people with intellectual disability and their families continue to face.[ix]

The movement towards an inclusive society is predicated on the fact that people with intellectual disability have generally been, and continue to be at risk of being, segregated from society. Many models of service today continue to echo this historical practice. Many children are still organised into separate schools or classes. Many adults are still grouped into separate workplaces or non-work day programs. And many adults are still grouped in institutional accommodation settings.[x]

Inclusive models of disability service that support children and adults to participate alongside their peers, at day care, school, work, or where they live, are still emerging as we attempt to respond to a new agenda of equal rights and equal opportunity.[xi] [xii]

One of the unfortunate by-products of the history of segregation of people with intellectual disability is that many in the community still inadvertently believe that segregation must be something good, something that must provide a benefit to this population. Otherwise, why would we continue to do this into the 21st century.

The research evidence is, however, confronting. There is no comparative research which finds a beneficial advantage when people with intellectual disability are grouped and segregated for education, employment or living purposes. In contrast, the comparative research finds significant benefits when this population is included.[xiii] [xiv] [xv]

Two and half thousand years of human history, however, has left its mark on our habit of segregating people with disability. And we are still recovering.

From ancient times, people with intellectual impairment were frequently subjected to responses based on a “killing thought”. The ancient Greeks and Romans believed that any physical or language difference was a mark of inferiority. Plato and Aristotle wrote that people with disability should not be allowed to live.[xvi] And Spartans passed laws to kill infants with impairments. Early Romans mutilated children born with impairments and threw them into the Tiber River. The foundation of Roman Law, the Twelve Tables, mandated the killing of infants with impairments. These laws remained in effect for a thousand years as the first codified western laws until Christianity took a stronghold in the 4th century of the Common Era.[xvii]

People with intellectual disability have been particularly targeted by modern social policies aimed at devaluing individual human differences. Hitler’s mass sterilisation program from 1933 included people with intellectual disability as the first category in the Reich Statute. The international eugenics movement of the late 19th and early 20th century which influenced our early human services, listed people with intellectual disability as number one on the list of people that should “be eliminated from the human stock”.[xviii]

Such beliefs drove policies of sterilisation and mass institutionalisation of people with intellectual disability throughout the world including Australia. While many institutions have been closed since the peak of such practice in the 1960s, there are still over 7,000 people with intellectual disability living in institutions in Australia. And we are still at the very beginning of moving to a system of inclusive education, employment, and supported living.[xix]

As a nation, in 1986 we chose a *new direction,* to move from segregation to the integration of people with intellectual disability as citizens with equal rights.[xx] Recently, we have also signed the United Nations Convention on the Rights of Persons with Disabilities which sets out comprehensive obligations on Australia to *promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity*.[xxi]

The National Council on Intellectual Disability (NCID) seeks the Productivity Commission to ensure that our nation's response to the needs of people with intellectual disability is in the provision of support for their inclusion and equal participation in Australia society. To safeguard against our historical habits, we implore the Productivity Commission tounderpin its investigation with an evidence-base so that good intentions alone are not the basis for how we respond to our domestic and international obligations.

Disability inequality in Australia

Comparison of people with intellectual disability, other disabilities, and people without disability in Australia:

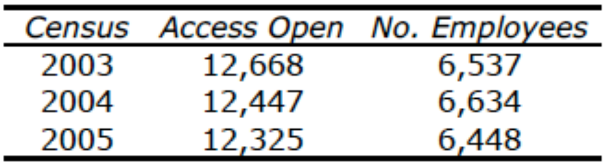
Measure	People with intellectual disability	People with other disabilities	People without disability
Complete year 12	19.2%	30%	49%
Left school year 8 or younger	unknown	16%	5%
Complete a diploma or higher education	0%	13%	20%
Complete a bachelor degree	0%	13%	20%
Labour force participation	11.9%	53%	81%
Income through wage	22.6%	35%	63%
Receive government pension or allowance	57.1%	43%	14%
Home owners with mortgage	<5%	33%	43%
Live in public housing	unknown	7%	2%
Unemployment rate	17.4%	9%	5%
Gross median weekly income	$255	$255	$501

Sources:
1. Australian Bureau of Statistics, Disability, Ageing and Carers; summary of findings, Australia, 2003
2. AIHW, Disability in Australia: intellectual disability, Bulletin 67, Australia, 2008

For people with intellectual disability:

… (L)ife expectancy is much lower than the general population, and approximately twenty years lower for people with severe disabilities. (Bittles, AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ, Montgomery PD (2002) "The influence of intellectual disability on life expectancy" *J Gerontol A Biol Sci Med Sci* 57:7; M470-M472)

… **(T)he work participation rate has stagnated.** We have reached a crisis in the unemployment of people with intellectual disability. The number of new people with intellectual disability getting jobs in open employment has stagnated (Source: Australian Government Disability Services Census. Commonwealth Department of Family, Community Services and Indigenous Affairs. Australian Government).



Census	Access Open	No. Employees
2003	12,668	6,537
2004	12,447	6,634
2005	12,325	6,448

There are over 6,000 people with intellectual disability employed in the open labour market. Most school leavers, however, face lifelong unemployment. Many are in day programs (Source: Disability support services 2004–05. National data on services provided under the Commonwealth State/Territory Disability Agreement, August 2006. Australian Institute of Health and Welfare: Canberra). Very few, if any, move from these day programs into open employment. In 1995, there were 4,240 workers with intellectual disability. In the 10 years of the Hawke/Keating governments from 1986 to 1996, there was an annual average increase of 424 new workers with intellectual disability. In the first six years of the Howard government from 1996 till 2003, a further 2,297 jobseekers with intellectual disability found work. The average increase, however, slowed to an annual increase of 328 new workers.

From 2003, the increase of workers with intellectual disability has plateaued. **The number of workers with intellectual disability hasn't increased since 2003, despite a growing population.**

The 2008 FBI statistics show that people with **intellectual disability were victims of Hate Crimes** at twice the rate as people with physical disability (no such statistics are kept in Australia).

Definition of Intellectual Disability

The definition of intellectual disability is important as it sets the foundation for determining the population that we are concerned with, and respond to, in the design of policy and support services.

> *Definition is important, as significant consequences can result from the way a term is defined. A definition can make someone eligible or ineligible for services, subjected to something or not subjected to it, exempted from something or not exempted, included or not included and/or entitled or not entitled.*

The authoritative definition of intellectual disability is that of the American Association of Intellectual and Developmental Disabilities (AAIDD). According to the 11th edition of the AAIDD definition manual:

> "Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18."

This definition is consistent with Commonwealth and State government program definitions of intellectual disability. For example, in Schedule 1B of the Commonwealth Social Security Act 1991, the Guide to the Impairment Tables for the Assessment of Work-Related Impairment for Disability Support Pension (DSP):

> "Intellectual disability indicates a significantly below-average level of intelligence functioning (as measured by standardised Intelligence Quotient (IQ) scores) and associated problems in adaptive functioning which begins prior to the age of eighteen."

Further, all State education programs for students with disabilities typically use an intellectual disability definition to determine qualification for assistance. For example, in the Victorian Program for Students with Disabilities Guidelines 2009, "intellectual disability" is defined as:

> "Sub-average general intellectual functioning which is demonstrated by a full-scale score of two standard deviations or more below the mean score on a standardised individual test of general intelligence; and
>
> Significant deficits in adaptive behaviour established by a composite score of two standard deviations or more below the mean on an approved standardised test of adaptive behaviour".

All other States use a similar definition for eligibility to special education programs on the basis of *intellectual disability*.

In summary, a label of intellectual disability involves meeting three criteria:

- significant limitations in intellectual function (a significance determined by two standard deviations below the mean of the population);
- significant limitations in adaptive behaviour (a significance determined by two standard deviations below the mean of the population); and
- age onset before age 18 (during the developmental period).

There has been consistency in these three elements of the definition of intellectual disability for the last 50 years.

Eligibility for long-term essential support

An assessment of *intellectual disability* is a strong indicator that ongoing support for life will be required to participate with substantive equity in community settings and activities.

AAIDD have stated that:

> "Providing supports to people with intellectual disability enables their functioning in typical life activities in mainstream settings but does not eliminate the possibility that they will continue to need ongoing supports. Put another way, if supports were removed, people with intellectual disability would not be able to function as successfully in typical activities and settings."[xxii]

In this regard, *support need* is about what it will take to accommodate a person's inclusion in typical settings to achieve substantive equity in terms of a standard of living comparable to people without disability.

Additionally, we must be wary of references to "mild" within a discussion about *intellectual disability*. Earlier classification systems of *intellectual disability* provided a hierarchy of classification within the *intellectual disability* category, (i.e. mild, moderate, severe, profound) based on IQ score ranges. This has had the unfortunate consequence of misleading the support needs of those with the label, "mild intellectual disability". The challenges faced by all people who are assessed as having intellectual disability are *significant*.

> "By definition, all individuals with intellectual disability have significantly impaired intellectual abilities and adaptive behavior;"[xxiii]

NCID proposes that an assessment of "intellectual disability" is sufficient evidence for eligibility for assistance under a new program of support for people with disability.

A definition of *support needs*: "Support needs refer to the pattern and intensity of supports necessary for a person to participate in activities linked to normative human function." Whereas all people with intellectual disability have substantive support needs, the nature and degree of this support will vary from individual to individual.

There are two important concepts within a framework of support needs.

First is the notion that *support needs* assumes that there is a disparity between a person's current competence and the behavioural expectations of the environment. The provision of support is therefore those things that enable a person with intellectual disability to participate in a meaningful way - to learn, to work and to live. We may refer to this as the achievement of *substantive equity,* because we have implemented supports that achieve an equality of opportunity and participation as compared to people without disability.

Second, the nature or degree of *support needs* is based on that which enables a person with intellectual disability to be included in a typical setting - a typical classroom, workplace or home. In this respect, a measure of *support needs* is based on what it would take to include a person with intellectual disability in an environment or activity that is typical for a person without a disability. This is an important element given the UN Convention on the Rights of Persons with Disabilities imperative to move from segregation to inclusion. The quantum of *support needs* must therefore be judged by equal participation in an inclusive environment.

Conclusion – the cost

In 2010, the population of Australia is 22,500,000. Statistically 2.5% of this population has an intellectual disability — 562,500 people. Of these ,528,800 will have an IQ between 70 and 55; 33,700 will have an IQ of < 55.[xxiv]

As stated, the main question for the Productivity Commission and the Australian Parliament to answer is, 'how will the necessary funds be raised to support 562,500 people with intellectual disability?'

The Productivity Commission has the intellectual and other resources to arrive at a good 'estimate' of how much funding will be required to meet all the support needs of all people with intellectual disability and also the best way to raise these funds.

In 2010 Productivity Commission published the 'Report on Government Services' that provides detailed information on the number of people receiving support, the cost of that support and the potential population that could have support provided.

An example of the additional funding required: we can use information available to ascertain the amount of funding to provide support to all people with intellectual disability in a job,

- the working age population is 61.8% of the total population[xxv], which equals 347,625 people with intellectual disability
- 4,400[xxvi] students with intellectual disability leave school each year and need support to find a job
- the cost for supporting a person with intellectual disability into a job is between $13,370 and $39,118
- the cost of supporting a person in a job is between $5,280 and $13,200
- as an indication of how the costs should be apportioned, the split is currently 30% at the lower end to 70% at the higher end.

Therefore to support all people with intellectual disability in a job (or similar) is going to cost $3.7 billion; the Commonwealth currently spends $237.5 million on providing support to 25,600 people. The difference is borne by State and Territory governments, individuals and families, State and Territory governments currently spend $576 million on supporting 38,343 number of people in employment and non-employment day activities.

In addition, given a split of 30% level 1 funding, 30% at level 2 funding and 40% at level 2+, $73.3 million is required each year in addition to the funding needed to support this group and those already in employment (or similar).

It has been demonstrated that a real job has a net cost of $1,692 (due to reduction in DSP and PAYE taxes). This reduces the cost to $.6 billion that is less than we are spending at the moment. This is based on leading support practice with an emphasis on outcomes.[xxvii]

In this example the BIG questions are:

1. Are governments willing to make changes to ensure they only purchase evidence based support? if not,
2. how is the $2.7 billion additional funding to be raised? and
3. will the State, Territory and Commonwealth governments be prepared to transfer all their current funding to a new independent and national agency?

For an ongoing discussion on statistics, number of people with intellectual disability receiving support, the support funding they receive and the potential population and associated funding – www.ncid.org.au.

Endnotes

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[i] UN Convention on the Rights of Persons with Disabilities, Article 1.

[ii] UN Convention on the Rights of Persons with Disabilities, Preamble (j).

[iii] UN Convention on the Rights of Persons with Disabilities, Preamble (n).

[iv] UN Convention on the Rights of Persons with Disabilities, Article 3.

[v] For an extensive study of the history of people with intellectual disability see: National Council on Intellectual Disability (July 2004). People with Intellectual Disability and Employment: History, Knowledge, Outcomes and Policy - An Australian Perspective.

[vi] Prime Minister of Australia. Address to Heads of Agencies and Members of Senior Executive Service (30 April 2008). "A third element of the Government's agenda for the public service is to ensure a robust, evidence-based policy making process. . . . "The Government must receive the best advice, based on the best available information and evidence. . . . Policy design and policy evaluation should be driven by analysis of all the available options, and not by ideology. . . . Policy innovation and evidence-based policy making is at the heart of being a reformist government. . . . . Service delivery should be contestable, and decisions about the mix of the public and private sectors should be based on the available evidence on how to deliver services efficiently and effectively."

[vii] Productivity Commission. (2009) Challenges of Evidence-Based Policy Making. "It is as important that we have a rigorous, evidence-based approach to public policy in Australia today as at any time in our history."

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Mank, D.; Cioffi, A.; Yovanoff, P. (1997). Patterns of Support for Employees With Severe Disabilities. Mental Retardation, 35, (6) 433-447.

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Mank, D.; Cioffi, A.; Yovanoff, P. (1999). Impact of Co-worker Involvement With Supported Employees on Wage and Integration Outcomes. Mental Retardation, 37, (5) 383-394.

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[xv] Interaction, Vol.21/1, 2007. Deinstutionalisation: A review of the literature.

[xvi] Plato The Republic, Book III, 409e-410a. "This then is the kind of medical and judicial provision for which you will legislate in your state. It will provide treatment for those of your citizens whose physical and psychological constitution is good; as for the others, it will leave the unhealthy to die, and those whose psychological constitution is incurably corrupt it will put to death. That seems to be the best thing for both the individual sufferer and for society."

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[xxi] The United Nations Convention on the Rights of Persons with Disabilities. Australia ratified the Convention on 17 July 2008

[xxii] AAIDD (2010). Intellectual Disability. Definition, Classification and Systems of Support. 11th Ed.

[xxiii] AAIDD (2010). Intellectual Disability. Definition, Classification and Systems of Support. 11th Ed.

[xxiv] For more information on intellectual disability statistics see, AIHW, Disability in Australia: intellectual disability, Canberra, November 2008

[xxv] Taken from, ABS, Population by Age and Sex, Australian States and Territories, Canberra, Jun 2009

[xxvi] The number of people with intellectual disability applying for the DSP, Characteristics of DSP Recipients, FaHCSIA, June 2008.

[xxvii] See NCID's submission to the Productivity Commission on Employment

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to the
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Version employment 2.0

24 August 2010

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Table of Contents

It’s my job …

Introduction

The National Council on Intellectual Disability is providing a second submission to the Productivity Commission Inquiry into Long Term Support. The purpose for making a second submission is to highlight the importance of the issue of employment support for people with intellectual disability.

If people with intellectual disability are to become 'true' citizens, then they must have the financial capacity to participate in community life. This cannot be achieved on welfare!

In addition, a real job gives a person a valued role and places a person within their community. This has enormous social and health benefits, and leads to a reduced dependence on government-funded support.

So the question for the Productivity Commission Inquiry is, based on research evidence (level of pay, hours of work and job duration): What employment support methodology(s) must the new long-term support scheme fund?

Background

NCID is seeking policy and support for people with intellectual disability to choose to work in typical business and industry settings among people without disability, and enjoy wages and working conditions the same as their co-workers.

An International Labour Organisation (ILO) meeting in March this year at Lukasa, Zambia, of governments, employers and workers organisations from six African countries and the United Kingdom, stated that the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) signals a move away from practices that segregate people with disability to practices that include people with disability in all areas of society.

The report of the ILO meeting at Lukasa begins by stating:

> "A new era of opportunity for persons with disabilities is heralded with the entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in May 2008. This Convention requires States to move away from an approach that caters to people with disabilities in separate facilities towards an inclusive approach that opens doors to training opportunities in general training centres and employment opportunities in the open labour market alongside non-disabled people."[i]

The policy consideration of nations is thus not whether we should or shouldn't support people with intellectual disability to participate in the open labour market, but what assistance we should put in place to ensure that all people with intellectual disability of working age have the opportunity to do so.

Professionals in the early and mid-twentieth century perceived people with significant intellectual disability as not having the capacity for productive work.[ii] We are, however, indebted to the US researchers who challenged this perception in the late 1960s and throughout the 1970s, particularly the research by Marc Gold.[iii] In 1979, Bellamy reported the general findings of the research on productivity:

> "In addition to being desirable, productivity is possible for severely handicapped adults. There exists a rapidly expanding professional literature that documents the learning of difficult, lengthy, and intricate vocational skills by severely handicapped individuals. During the last few years research has left little doubt that severely handicapped adults can become vocationally competent persons."[iv]

This research revealed two important associated findings on the nature of employment assistance to people with intellectual disability.

First, that it is both our willingness and competence that is pivotal to the inclusion of people with intellectual disability in the open labour market. Systematic instruction to train people with intellectual disability on the job to complete job tasks to a level of productivity of economic value to employers is critical to success. This technology assumes a capacity to learn and places no limits on what is possible.

Second, the successful demonstrations of competitive employment for this population questioned the basis for employment programs that *group* people with intellectual disability in non-work programs and segregated employment settings. Segregation, justified on the basis of 'support need', 'incapacity to work' or as a 'preparation for open employment', is not supported by the research.[v]

Evidence of good support practice

If the United Nations Convention (CRPD) provides a *rights* basis for inclusion, then the research evidence finds that inclusion is not just a *right*, it is good practice. And the evidence-based practices to assist people with intellectual disability in the open labour market are readily available.

The US vocational research had a significant impact on Australia. In 1983, the then Minister for Community Services, Senator Don Grimes, undertook a landmark consultation with Australians with disability.[vi] In 1986, the Australian Parliament approved the Disability Services Act. This legislation set out a 'new direction' - and not unlike the UN CRPD - signaled a move away from segregation to the integration of people with disabilities in Australian society. The object of the legislation included;

1. *to assist persons with disabilities to receive services necessary to enable them to work towards full participation as members of the community;*
2. *to promote services provided to persons with disabilities that:*
    - *(i)* *assist persons with disabilities to integrate in the community, and complement services available generally to persons in the community;*
    - *(ii)* *assist persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community;*

An employment service in Sydney, *Jobsupport*, was funded in 1986 to demonstrate the application of the new models of open employment assistance to people with significant intellectual disability. This was the first open employment service for people with significant intellectual disability in Australia and the demonstration found that the US research could be replicated in Australia. *Jobsupport* placed 14 people with moderate intellectual disability within the first year of this demonstration. Jobsupport currently supports over 520 people with moderate to severe intellectual disability in the open labour market. And some people have recently celebrated 20 years in employment. A significant result given that few, if any, people with moderate to severe intellectual disability moved from school to work before 1986.

What is happening to people with intellectual disability?

It is now 24 years since the Disability Services Act. What has been the impact of this legislation on the inclusion of people with intellectual disability in the open labour market? Have we achieved our objectives? Let's take a look at some data.

The Australian government collects data[vii] on every person with disability who receives funded disability services.

- For the year 2007-2008, 16% of people with intellectual disability of working age were employed in the open labour market.
- 47% or about half of this population are not participating in the workforce.
- 23% work in institutional employment settings (i.e. sheltered workshops, now known as ADEs).
- 84% of people with intellectual disability of working age are either segregated or excluded from the open labour market.

With 16% of people with intellectual disability in the open labour market, it is an indication that we have made just a small step in the right direction from a very low inclusion rate in 1986.

The vast majority of people with intellectual disability between the ages of 15 to 64 (82,368, June 2008) are in receipt of the Disability Support Pension (DSP). The DSP is a government income support payment for people with disability deemed not able to work for 15 hours or more per week at or above the minimum award wage.

- 88% of people with intellectual disability on the pension (72,484) earn either no income or less than $71 per week.[viii]
- Of the 12% that earn above $71 per week, just 2.8% earn income above $306 per week.[ix]

A high percentage of people with intellectual disability are therefore unemployed and in poverty.

While we have made a small step forward since 1986, the data indicates that the participation of people with intellectual disability in open employment programs is in gradual decline. The number of people with intellectual disability accessing open employment assistance has declined by 8.5% since 2003-04; whereas other disability groups, such as people with psychiatric disability, have increased significantly.[x]

We are currently witnessing a worrying shift in the Australian open employment assistance program away from people with intellectual disability. Despite a substantial increase in the overall number of people with disability accessing this program, the declining numbers of people with intellectual disability indicate an employment program that is losing its effectiveness for this population.

Economics, participation or ideology?

The Australian government tracks the employment outcomes of its program of open employment assistance for people with disability. In November 2009, the national average 26-week employment outcome was approximately 34%. On average, this means that one out of every three jobseekers with disability get a job that lasts at least 26 weeks. The national average hours of work per week is 19, and the national average weekly wage is $307.[xi]

The best performing open employment service for people with moderate intellectual disability (IQ <60) in November 2009 achieved an average 26-week employment outcome of approximately 75% — considerably higher than the national average for all people with disability (34%). The average weekly hours of work was 22, and the average weekly wage was approximately $348.[xii] These employment outcomes were achieved by an employment service focused on evidence-based practices. It is a benchmark of practice and performance that the National Council on Intellectual Disability would like to see offered to all people with significant intellectual disability throughout Australia.

Supporting people with intellectual disability to work in the open labour market is economically efficient when compared to segregated work programs or adult day programs. In 2005, Econtech, an economic modelling provider, conducted an analysis of the cost and benefit of open employment compared with sheltered employment and day programs for adults with intellectual disability. The report found that the outcomes achieved by open employment deliver a higher net national benefit at a lower cost to government than segregated employment or non-work day options. This is due to the significantly higher wages achieved in open employment providing savings from pension payments, the payment of income tax, and the resulting higher disposable disposable income (a net benefit of $5,810 to the national economy and a net cost to governments of $1,692).[xiii]

Policy must create the capacity for real jobs …

In our review of the literature and our analysis of high performing specialist employment services, we have identified service characteristics associated with positive outcomes for people with intellectual disability.

- Strong leadership that has a focus on evidence-based practice.
- Direct engagement with youth with intellectual disability and their families
- An assessment of jobseeker preferences, strengths and weaknesses - which determine the supports that will be required
- Job marketing that includes customisation for jobseekers that do not fit neatly into employer advertised positions
- Finding a good match between the needs of the jobseekers and the needs of the employer
- Systematic training that meets the employer agreed quality and productivity

- The setting up of a structure of support that is carefully monitored over the long term.

It is these areas of competence that NCID would like to see as a core component of what the Australian government purchases on behalf of jobseekers with intellectual disability.

The Australian government has this year launched a new program of open employment assistance for jobseekers with disability - the Disability Employment Services. There are some critical changes that NCID has identified as significant decisions by the current Minister for Employment Participation, Senator Mark Arbib, which will assist Australians with intellectual disability.

First, the Australian program will now be demand driven. The program used to be “capped” whereby funded services were limited by the number of people with disability for whom they could provide employment assistance. This resulted in a number of people simply missing out on an opportunity to join the workforce. This barrier is now removed.

Second, the Minister has provided additional funding for services that work with people with significant intellectual disability. This decision recognises that the number of support hours to find a job and provide systematic training on the job was considerably high in the first year of support for this jobseeker population. This decision will enable specialist intellectual disability open employment services to have adequate funding to apply best practice open employment assistance.

Third, the Minister has made it easier for school leavers to move smoothly from school and *school to work* transition programs to open employment assistance. “School leavers” will be able to register directly with employment assistance providers without having to attend an assessment to determine eligibility for assistance.

Our challenges

The new system has only just begun and we will be watching carefully to see if this results in an increase in open employment participation of people with intellectual disability. There are clearly still many challenges as we move towards an inclusive society. There are five areas that NCID see as important challenges for Australia if we are to provide all people with intellectual disability the equal opportunity to participate in the open labour market as equals.

- Australian governments need to recover from its habit of funding segregation via adult day programs and sheltered workshops (ADEs). Many within the government, unfortunately, still believe that this population cannot work in open employment despite the demonstration and research to the contrary.
- Australian governments need to address its low expectations that youth with intellectual disability will move from school to work in the open labour market. Many students leave without any knowledge of what work is, or have employment goals. Many educators still operate on the basis that open employment is not possible and therefore not a goal that they should work towards
- Australian governments urgently need to replicate good open employment practice so it is a prevalent option for youth with intellectual disability and their families. We

have some specialist services that are high performing and operating at world's best practice; however, these services are few and far between.

- Australian governments need to build service and staff competence via training and technical assistance. Australia has yet to implement a program of service staff training and development linked to the employment research. The Australian government has taken a first step and funded an innovative project of training and technical assistance.
- Australian governments need a national plan for youth leaving school that is based on the high expectation of open employment as a goal that is attainable with the right support. This plan will require national leadership to bring together families, self-advocates, and National and State governments to envisage a system of school-to-work where all school leavers are supported to participate in the open labour market.

We have made a start. Our challenge is to offer inclusive employment to all people with intellectual disability as a matter of course so that inclusion in the open labour market is the 'default' or dominant approach and outcome. It is what the UN CRPD requires.

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[i] International Labour Organization. (2010). People with intellectual disabilities: opening pathways to training and employment in the African region / International Labour Office, Skills and Employability Department. - Geneva: ILO, 2010

[ii] Hermelin (1956) Studies of learning and trainability in imbeciles. University of Reading. Thesis. unpublished.

[iii] Gold, M. (1980). Did I Say That. Articles and Commentary on the Try Another Way System. Research Press.

[iv] Bellamy, G. T., O'Connor, G., Karan, O. C. (1979). Vocational Rehabilitation of Severely Handicapped Persons. University Park Press: Baltimore. Note: Important to note that this population was characterised by Bellamy as people with intellectual impairment of IQ scores below 40 - a group that rarely finds work in open employment in Australia.

[v] Wehman, P. (1981). Competitive Employment. New Horizons for Severely Disabled Individuals. Paul H Brookes: Baltimore

[vi] Commonwealth of Australia. (1985). New Directions. Report of the Handicapped Programs Review. AGPS

[vii] AIHW. CSTDA 2007-2008, Disability Support Services.

[viii] Correspondence from Minister Jenny Macklin to NCID, 6 October 2009

[ix] Correspondence from Minister Jenny Macklin to NCID, 6 October 2009

[x] AIHW. CSTDA 2007-2008, Disability Support Services.

[xi] DEEWR Health Check Data. Note: Data provided to contracted services only. Not Published.

[xii] DEEWR Health Check Data. Note: Data provided to contracted services only. Not Published.

[xiii] Econtech: An analysis of alternative methods of government funding of employment services for people with disabilities, 2005

National and NSW
Councils for
Intellectual Disability

Australian Association of
Developmental Disability Medicine

Australian Productivity Commission
Submission on the health of people with intellectual disabilities
National and NSW CID & AADDM

There are over 500,000 Australians who have intellectual disabilities. This is a similar proportion of the population as Indigenous people and "with health outcomes at least as bad" (RACGP, 2006). The Australian research shows:

- Only 29% of health conditions being diagnosed and appropriately treated in people with intellectual disabilities.
- Very high rates of dental disease and both obesity and being underweight.
- Life expectancy up to 20 years lower than the general population.

This stark inequality arises from a range of factors including challenges to communication between health professionals and patients, high rates and complex ranges of health problems, problems with skills and available time in the mainstream health workforce, a lack of specialised intellectual disability health services to back up the mainstream, health promotion and research tending to ignore people with intellectual disabilities, and lack of co-ordination within and between governments. Furthermore, poverty and inadequate supply of free and subsidised health services further reduces the accessibility of health and allied health services for people with intellectual disability.

People with intellectual disability have high rates of co-morbid physical and mental health problems. Physical health problems include high mortality (late 50s for people with Down syndrome and early 60s for people with intellectual disability) and high morbidity with an average 5.4 medical conditions per persons, two conditions of which are unrecognised or poorly treated. Hidden health issues include pain, sensory impairment, infections, osteoporosis and epilepsy. Additionally, many people with intellectual disability are over-medicated. They have considerable lifestyle and nutritional issues including obesity, gut problems, constipation, H. Pylori bacteria, and reflux; neither do they receive regular immunisation, blood pressure checks, breast and Pap tests, skin checks, medication reviews, weight reviews and hearing and vision reviews. Mental health issues include not only schizophrenia (which is more common in people with intellectual disability), but also the highly prevalent conditions of depression, anxiety and post traumatic stress disorder. They also have lower rates of accessing appropriate services. Their risk is further compounded by difficulties accessing the health system, reliance on others as carers and high rates of poverty.

Many of the current Australian Government's health reforms benefit the wider community but they leave out people with intellectual disability, e.g. hospital funding allocations will be based on "efficient price" of services and this will create yet another barrier for people with intellectual disability to access crucial services. Specific health care planning for people with intellectual disability, despite many years of lobbying, has not appeared on the national health agenda.

Additionally, people with intellectual and developmental disability as a population of interest are excluded from most current Australian research agendas. Researchers cannot derive data from a national dataset because it doesn't exist and where national and population surveys are undertaken people with intellectual disability are usually excluded. We continue to urge the National Health and Medical Research Council (NH&MRC) and Australian Research Council (ARC) to specifically address the systemic neglect of research that specifically examines the unmet physical and mental health needs of people with intellectual disability.

As an example of the invisibility of this population in the health provision context, the Australian Government recently changed the Medicare item numbers which clearly identified health assessments for this population by merging the items for intellectual disability health assessment items into generic items. This means that the data that researchers had been accessing since July 2007 when the Medicare items came into play, is now lost. This was the one piece of data collected by the Commonwealth on the health of people with intellectual disability. Obviously the needs of this population are yet again being minimised.

Without good healthcare, a person's health suffers and puts them at risk of consequent problems in employment, daily living, learning, participating in society and more. The lives of people with intellectual disability are already impoverished by discrimination (Emerson, 2007; Wagstaff, 2002), and yet as a society, we continue to accept their poor health status.

We urge attention to the healthcare of people with intellectual disability by this current inquiry into disability care and support in Australia, and ask the Australian Productivity Commission to examine the cost of poor healthcare to this group of Australians. We commend the Australian Productivity Commission for initiating the debate.

Professor Nicholas Lennox, Director of the Queensland Centre for Intellectual and Developmental Disability (School of Medicine, the University of Queensland) and President of the Australian Association of Developmental Disability Medicine, n.lennox@uq.edu.au

Jim Simpson, Advocate, National and NSW Councils for Intellectual Disability, jcsimpson@optusnet.com.au

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national council on intellectual disability

Early Intervention – too little too late?

OR

Developmental Support – support for life!

NCID policy paper for comment

March 2010

The National Council on Intellectual Disability (NCID) was established over 50 years ago by parents and friends in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with intellectual disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee, the membership of which is exclusively people with intellectual disability representing all States and Territories.

National Council on Intellectual Disability
PO Box 771 Mawson ACT 2607

+61 2 6296 4400

ncid@ncid.org.au

ncid.org.au

Preamble

This policy paper is written in response to a request from a number of our members who raised questions about the adequacy of early intervention support. While government policy and rhetoric represents a system that is supportive of the development of children with intellectual disability, the everyday experience of families is different.

Following the initial representations from families in South Australia, NCID conducted a family survey and then undertook a survey of policy in Australia and internationally. This paper is based on that work.

The beginning

For most parents, having your baby or young child diagnosed as having a disability is a fairly traumatic and distressing experience. All your previously held assumptions, beliefs and aspirations for your child are likely to be challenged. Most disturbingly, even today, many parents are given "well meaning" advice from family, friends and professionals not to "get too attached", have "too much hope" or high expectations of their child and, in many instances, families are still told what their child won't be able to do as in "don't expect him/her to ever talk, be able to go to school, have a job, look after themselves" etc. This all serves to reinforce what is already a very disorientating experience. Frequently, there is no one on hand to provide clear, practical and supportive information and advice. Parents often speak of having no one to talk to who understands and is able to provide them with a positive picture.

Frequently, the only people on hand in the earliest days of diagnosis are from a medical or health background and, though often well-meaning and intentioned, can be less than positive about the future and frequently do not have good information or the necessary expertise on managing and living with disability. As stated by D. Spiker and M. R. Hopman "*Physicians and other professionals typically have limited experiences with individuals with Down Syndrome, increasing the importance of parents acquiring information to share with the professionals.*"[i]

One consequence of this is that mothers (and fathers) are emotionally separated from their children and the process of maternal bonding is suppressed, if not permanently delayed.

It is at this moment that 'Early' Intervention needs to begin. This needs to be the starting point for a life-long process of ensuring (and enabling) prompt, appropriate and expert services and supports are available as and when required and needed by both the person with a disability and their family.

For some families with children with an identifiable condition, there are some excellent early information and support services in place — examples of this are the Down Syndrome Association which provides an information pack to families of newborn children with Down Syndrome. The Down Syndrome Association attempts to ensure that this information is available through the staff on maternity wards and provides comprehensive information on both the syndrome, how to access further information and support and positive stories written by families with children with Down Syndrome.

Similar information is available through other associations.

For families who have a child diagnosed with Autism, similar information is available. However, as this is frequently at an older age, many years can pass for families frustrated at not being able to identify the problem or access help.

However, for very many families with children with an intellectual disability (with or without other associated physical or medical conditions), there is frequently no timely information, no readily available support and no clear process for tapping into early intervention services. Many families spend many distressing and difficult years trying to identify and access appropriate support and services for their child. It is frequently only through the considerable diligence and perseverance of families that relevant and appropriate information is found. Access to early information, support and advice is patchy, ad hoc and varies enormously both within States and from State to State, and is frequently dependent on both the child's diagnosis, the geographic location of the family and luck in tapping in at the right moment to appropriate information or services.

Currently in Australia, there is no national legislation that identifies the rights of every child with a disability and their family to access prompt, appropriate and funded early intervention support from the moment of birth or diagnosis of disability. This leaves families frequently floundering and expending enormous amounts of time, energy and resources in trying to identify and locate appropriate supports for themselves and their child.

Advice and Information

In the early days, often families speak of wishing they had the opportunity to talk to other families about their experiences and how they have coped/managed with the range of issues and difficulties confronting them and their child. It has been well documented both anecdotally and within the literature that linking families together to offer support, advice and information is one of the most valuable early intervention strategies, particularly in the early stages. This has been the policy underpinning the implementation of playgroups, particularly for vulnerable and at risk families. Families with babies and young children with intellectual and multiple disabilities face a higher risk of social isolation, increased poverty and family breakdown. Access to support, information, advice and other parents' experience can be invaluable in the early days in assisting parents to cope with the enormous challenges facing them. As stated by D. Spiker and M.R. Hopman *"It is generally assumed that early intervention is beneficial for children with Down Syndrome and their families – both in the ways it serves to improve the child's rate of early development and in the opportunities it provides for parents. ... providing particularly helpful companionship to assist the parents in their early emotional adjustment to the birth of a baby with Down Syndrome through parent support groups..."*[ii]

However, for many families there is great difficulty attached to attending the regular local playgroup or mothers group. Having a child who is "different" carries with it a range of complex social and emotional difficulties. Many parents are not confident in the early days to confront a group of other parents who may be either pitying or providing more of the "well meaning" advice. Parents need to be equipped with sufficient information and support before attending such places. Without access to some disability specific information and support, many families will remain isolated, increasing the possibility of family breakdown and reducing the opportunity for their child to access vital and appropriate engagement with other children and therapeutic services. It is at this stage that it is vital for families to become linked into appropriate disability specific support, advice and information services. These can be formal or informal but need to have sufficient expertise and resources to enable families to acquire the necessary knowledge and confidence to commence down the path of supporting and enabling their child with a disability to lead a full and fulfilling life.

Therapy Support

Once parents start on the road to accessing information and gaining knowledge of their child's condition and needs, the requirement for therapeutic services quickly follows and this is the point at which, traditionally, the concept of early intervention commences.

However, once again, the experience of many families is of an ad-hoc, uncoordinated system which is largely dependent on the family's capacity and ability to advocate strongly and vocally for their child. Systems vary greatly from State to State and within States as to how families access early intervention services, how those services are delivered, what therapeutic services are actually available and the length of time and extent to which those services are available. In every State, there are examples of excellence; but these examples are isolated and not replicated in any way and are only available to the few dependent on geography or being able to pay for services privately.

Currently, in Australia there is no mandate for all children with intellectual disability to have a comprehensive assessment and individualised family service plan developed in the early years. In addition, there is no mandate for all children with intellectual disability to be enrolled in and have access to appropriate and expert early intervention services.

Many families talk of their frustrations in trying to access adequate and appropriate therapeutic services. For many families, the opportunity to develop a clear plan outlining clear goals and the necessary services and supports required to achieve these would be invaluable in ensuring their child has every opportunity to reach their full potential. In tandem with this is needed a clear articulation of the necessary resourcing required for families to access the services and supports identified. If all this was clearly laid out from early on, it would prevent an enormous amount of wasted time, energy and resources, both on the part of families seeking services and for services and government in providing services and support where there is frequent duplication and repetition. Families speak of the frustrations in attempting to have their children accepted through the range of different intake systems that exist for different services, the repeated assessments and provision of information required.

For many families with children with intellectual disability, the experience of much early intervention services is less than optimal. There is little in the way of expert programs available that are based on any evidential background. Where such programs exist, both in Australia and overseas, there is no funding available to replicate such programs on a more extensive basis or to provide the opportunity for training for therapists and families. For example, the DownsEd Institute in the UK has a comprehensive literacy program for teaching young children with Down Syndrome.

After Early Intervention – What Next?

Early Intervention services and support are traditionally provided for the years 0 – 6. Once a child goes to school, the access to services and support changes completely. Families once again have to negotiate a whole new maze of systems and services. Support with negotiating one's way through the school years varies again enormously from State to State. However, the experience for many is one that is disjointed, disorientating and frequently distressing.

In some States, there are organisation such as the Association for Children with a Disability (Victoria) and Family Advocacy (NSW) which develop resources that provide families with information on how to negotiate the bureaucratic systems.

What is singularly lacking is a mandated system which ensures all families with children with disabilities have access to appropriate and skilled transition support services which are focused around the person's individual support plan.

Transition through different life stages are periods of particular sensitivity and vulnerability for families and children with disabilities. Early planning, with all appropriate service providers to clearly identify the supports, services and resources required for the person with disability to progress smoothly through the next stages of life, is critical and imperative.

Future life stages for a person with disability should be part of the ongoing process that builds on early planning and intervention. Whole-of-life planning that is focused on the person with disability's opportunities, needs and desires scaffolded by the necessary supports, services and resources has to commence at the earliest possible opportunity and continue throughout life.

Developmental Support is essential for a good life

Internationally, there has been an increasing recognition of the importance that the early years of childhood make in people's future development as they set the foundation for learning, behaviour and health.

Across Australia, there is a body of work being amassed regarding the value and importance of early intervention support and services. It is clearly documented that governments agree that timely, appropriate and quality early childhood services and support can be critical to the long-term positive outcomes for both children and society.

"Decades of research in Australia and internationally have demonstrated the benefits of early interventions for children, families and communities. Early intervention has been shown to achieve, at relatively modest cost, changes to prevent harms that are very

expensive to remediate." (Report prepared for the Qld Council of Social Service Inc by The Social Policy Research Centre UNSW, Kylie Valentine & Ilan Katz)[iii]

The Tasmanian Government document *"Whole of Government Policy Framework for the Early Years "* (Dr Sue Jenkins Policy Division, Department of Premier and Cabinet Aug 2005) outlines the range of policy papers and plans regarding Early Intervention developed across Australia in recent years:

"In Australia, the Federal Government has demonstrated its commitment to investing in early childhood through the Stronger Families and Communities Strategy (Australian Government, 2000).

More recently, the publication of the draft National Plan of Action for Children and Young People within the National Agenda for Early Childhood (2004) sets out future directions with four broad action areas: Healthy young families; Early learning and care; Supporting parents and families; and child friendly communities.

Other significant national initiatives include:

- *the establishment of the Australian Council for Children and Parenting (ACCAP)*
- *the Australian Research Alliance for Children and Youth (ARACY)*
- *the Child and Youth Health Intergovernmental Partnership (CHIP) set up within the National Public Health Partnership.*

At State Government level, early childhood strategies and programs for prevention and early intervention are in place in Victoria (Best Start, 2001 and Putting Children First, 2004), New South Wales (Families First, 1998), Queensland (Putting Families First, 2001), ACT (included in The ACT Children's Plan, 2004), and are currently being developed in South Australia (Every Chance for Every Child, 2003) and the Northern Territory, while Western Australia has amalgamated existing programs for children into the Children First Strategy, which includes their early years framework.

Three years ago, Tasmania began to bring a more strategic and coordinated approach to the early years with development of the Our Kids Strategic Policy Framework, and subsequently the Our Kids Action Plan 2004 – 2007 (Department of Health and Human Services, 2003)." [iv]

The importance of the early years is extensively documented and uncontested and each State and Territory has plans or has in place policies to implement strategies to improve services to children and their families. The World Health Organisation has concluded that early childhood is the most important developmental phase throughout life and inequities in economic resources result in inequities in early childhood development, and argues that 'the overarching goal of the global community should be to find the means of providing universal access to effective early childhood development programs and services'. (S. Jenkins 2005)

This is no less true for children with disabilities and in fact has greater impact as disability has a very high private and public cost.

Article 7 of the United Nations Convention on the Rights of People with Disabilities further spells out that "*Governments agree to take every possible action so that children with disabilities can enjoy all the human rights and freedoms equally with other children. They also agree to make sure that children with disabilities can express their views freely on all things that affect them. What is best for each child should always be considered first.*"

Early intervention is described as a *"process of providing services, education and support to young children who are deemed to have an established condition, those who are evaluated and deemed to have a diagnosed physical or mental condition (with a high probability of resulting in a developmental delay), an existing delay or a child who is at risk of developing a delay or special need that may affect their development or impede their education."* (*Wrightslaw, What is Early Intervention, USA*)[v]

In Australia at the national level, there is no policy or legislative document that provides an overarching framework for the implementation of early intervention support and services to children with disabilities and their families.

The Policy Framework

The only National legislative document that outlines the provision of services to people with disability in Australia is the Disability Services Act (Commonwealth) 1986. This makes no provision or mention of any early intervention services or any statement regarding the right of people with disability to access appropriate and timely support and services.

The National Disability Agreement 2009 (NDA) likewise makes no overarching statement regarding the rights of people with a disability to access appropriate and timely support and services. The key objective is that the NDA "***contribute to***[vi] *... People with a disability and their carers to have an enhanced quality of life and participate as valued members of the community."*

The Reform and Policy Directions of the NDA 26(f) outlines as one of the key priority areas "*Early Intervention and Prevention, Lifelong Planning and Increasing*

Independence and Social Participation Strategies – An early intervention and Prevention Framework will be developed ***to increase***[vii] *Governments' ability to be effective with early intervention and prevention strategies and to ensure that clients receive the most appropriate and timely support by mid 2011".*[viii]

It is clear that all Australian Governments do not have a commitment to ensuring that all people with intellectual disability get the development support that they need.

By contrast, in the USA the *Individuals with Disabilities Education Improvement Act of 2004 (IDEA)* makes a series of statements regarding the status and rights of people with disabilities:

"Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities."

"(d) PURPOSES —The purposes of this title are to:

(1)(A) ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living;

(B) ensure that the rights of children with disabilities and parents of such children are

protected; and

(C) assist States, localities, educational service agencies, and Federal agencies to provide for the education of all children with disabilities;

(2) assist States in the implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families;[ix]

(3) ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting: systemic change and system improvement activities; coordinated research and personnel preparation; coordinated technical assistance, dissemination, and support; and technology development and media services; and

(4) assess, and ensure the effectiveness of, efforts to educate children with disabilities."

As part of the IDEA, there is an obligation on the States to provide at no cost to families evaluation and assessment of children with disabilities to determine eligibility for services.

Following eligibility, there is the requirement to develop an Individualized Family Service Plan (IFSP) which documents and guides the early intervention process for children with disabilities and their families. The IFSP *"contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate the child's development. Through the IFSP process, the family members and service providers work as a team to plan, implement and evaluate services specific to the family's concerns, priorities and available resources."* A Service Coordinator assists the family in coordinating the services identified in the Plan. In addition, the Plan will outline the transition process for the child's transition from early intervention services into preschool and thence into school. The Plan will outline the transitioning process and identify the services needed after transition.

The IDEA legislation provides for a comprehensive framework for supporting families with children with disabilities particularly in the early years and in transitioning into and out of school. There are aspects of the implementation of the legislation that are left to the discretion of the States and therefore is open to some inconsistencies and discrepancies between the States. However, the Congress has established a body for monitoring the implementation of Federal legislation called the U.S. Government Accountability Office (GAO) which is an independent, nonpartisan agency that works for Congress. Often called the "congressional watchdog," GAO investigates how the Federal government spends taxpayer dollars. This agency has undertaken a range of reviews on how the States are implementing IDEA and have made an extensive range of recommendations to Congress on ways in which the States could improve services under IDEA.

Currently, each of the States and Territories in Australia are left to independently interpret and implement disability services policy under the Disability Agreement 2009. This leads to a lack of consistency in the scope and quality of services provided across the country. **It also means that there is little in the way of any evaluation at the national level of what is being achieved and particularly what and where any quality outcomes may be.**

A group of families in NSW provided valuable insight into policy and government rhetoric — their comments are valuable as they go beyond the common complaints of lack of funds, lack of flexibility and lack of trained therapists.

The NSW Disability Services Act (1993)[x] underpins the policy development of the office of Ageing, Disability and Home Care (ADHC), the key department responsible for the implementation and delivery of disability support services for children with disability aged 0 – 17.

Stronger Together: A new direction for disability services in NSW 2006 – 2016 is ADHC's latest policy document which outlines the system and service delivery for young people with a disability in NSW. This policy document is important in that it outlines provision of lifelong support and services to people with disability and their families. The policy focuses on two key areas:

"*Strengthening Families"* through *"enabling children with a disability to grow up in a family and participate in the community;"* which includes *" increasing the investment in early intervention services; providing training and intensive support for parents, including families with children with challenging behaviours; and building information and networks to support families."*

and *"Count me in ... promoting community inclusion – supporting adults with a disability to live in and be part of the community;"*

This should mean, through the policy's reference to case coordination, case management and service plans, a seamless, coordinated process which provides the range of supports and services required to ensure a person with disability achieves their maximum potential across the whole of their life.

However, there are still some glaring gaps and deficiencies in the policy and implementation. There is, despite mention of streamlined entry and access points and a review of all assessment tools, no explicit incorporation of transition processes and ensuring that all planning processes incorporate adequate and timely strategies for transiting into and out of services and life stages.

There is no explicit mention of collaboration with education, particularly around early intervention and ensuring children with disability have access to quality early education as well as coordinated approaches to transition into and out of school and provision of assessments and therapy services to children whilst at school.

Finally, there is no process in place for independent evaluation of the implementation of the policy and service delivery. There is no independent process for families to feed into the system to provide either advice or feedback on the implementation and outcomes of the policy. Whilst organisations such as Family Advocacy provide policy advice and information to the NSW Government, they are not resourced or equipped to undertake any comprehensive evaluation of implementation or service delivery.

Conclusion

In conclusion, NCID would make the following points:

- As part of the development of the National Disability Agreement, there should be a clear statement on the right of children with disabilities and their families to access comprehensive, timely developmental support/early intervention and lifelong support thereby ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.
- It is essential that all legislation and policy pertaining to disability acknowledges that the wellbeing, growth and development of very young children with an intellectual disability (or the risk of an intellectual disability) occurs best:
  - **within a loving, supportive and empowered family;**
  - where the child is able to experience all the developmental opportunities available to all children; and
  - when additional supports are given within those settings.
- That legislation and policy stipulates that families are assisted with life-long planning and goal setting to be implemented as early as possible in the life of a person with intellectual disability. That all planning is individualised, person and family-centred and is based on the goals, aspirations, needs and wants of the person with an intellectual disability and their family.

- That based on the evidence and research to date the most effective early intervention service provision for families with multiple or intensive needs take the form of programs that include centre-based early education and care with home visits to provide parent support and education. The development of a family visiting programme where the key message would be that, irrespective of the level of disability, the child could lead a successful life, i.e. a life where he/she can be happy and achieve to the best of his/her ability. **The chance of that happening will be enhanced if parents can dream of possible futures and be supported in making those dreams come true and understand the additional support and training the child might need to maximise his/her potential**. Such a programme would be developed and conducted by experienced parents of older children with disabilities and ideally would be the first information the family would have – a positive but pragmatic message delivered in the maternity hospital or as soon as the disability is recognised.

- **Effort be put in at both the systemic and personal levels to maximise the attachment between the child and parents.**
- The organisations within jurisdictions that have a responsibility for early childhood services should have the carriage of providing all early intervention services. That policies clearly outline processes for collaboration and linkage between disability specific departments and services and other departments and services such as education to ensure seamless transition.
- That governments and policy makers recognise there are no "quick fix" solutions and developmental supports need to go beyond the first couple of years of the life of a person with intellectual disability and do not stop with school or other transitional times and that there be a concept of continuous support.
- Families should have access to self-managed packages to buy the supports that make sense to them.
- Every venue of service delivery for young children, every group and every programme for young children should be truly inclusive of all children including those with disabilities.
- Parents who are socially disadvantaged or who themselves have a disability have access to additional support to undertake the parenting role as required.
- That a mechanism for independent evaluation of the implementation of policies and services regarding developmental support/early intervention be established nationally and include a process for measuring long-term outcomes.

Footnotes

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[i] The Effectiveness of Early Intervention, ed Michael J Guralnick, Chapter 13 The effectiveness of early intervention for children with Down Syndrome, Baltimore MD,1997.

[ii] ibid

[iii] Review paper on the cost effectiveness of early intervention programmes for Queensland, Kylie Valentine and Ilan Katz, Social Policy Research Centre UNSW, Nov 2007

[iv] Whole of Government Policy for the Early Years, Dr Sue Jenkins, Policy Division, Department of Premier and Cabinet, 2005.

[v] What is early intervention?, Wrightslaw, www.wrightslaw.com accessed 11 March 2010.

[vi] Highlighting has been added by the author to indicate that the objective is not to achieve a positive outcome for all people with disability but a lesser goal.

[vii] Again, the objective is not to achieve a positive outcome for people with disability but a lesser goal.

[viii] Individuals with Disabilities Education Improvement Act USA 2004

[ix] IDEA not only places a legal obligation on States but it places traditional early Intervention within a educational context which places it firmly within a development model that strands the important transition points of a person's life.

[x] In NSW, policy has been developed under the Disability Services Act (NSW) 1993 which includes provision to:

(a) ensure the provision of services necessary to enable persons with disabilities to achieve their maximum potential as members of the community,

(b) ensure the provision of services that:

> *(i) further the integration of persons with disabilities in the community and complement services available generally to such persons in the community,*
>
> *(ii) enable persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, and*
>
> *(iii) are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self-esteem,*

(c) ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services,

(d) encourage innovation in the provision of services for persons with disabilities,

(e) achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, for persons with disabilities, and

(f) ensure that designated services for persons with disabilities are developed and reviewed on a periodic basis through the use of forward plans.