RESPONDING TO PRODUCTIVITY COMMISSION

DISABILITY CARE AND SUPPORT (FEB 2011)

"The concept of 'mild cognitive limitations' as applied to adults with mild mental retardation (intellectual disability) is a 'gross misnomer'. Functioning at the lower extreme of the intelligence range they have 'mild' limitations only in comparison to those of individuals with 'moderate' to 'profound' mental retardation (intellectual disability)." (What is Mental Retardation? Ideas for an Evolving Disability in the 21st Century – Harvey N. Switzky and Stephen Greespan – American Association of Mental Retardation Books 2006)

The Productivity Commission report both recognises (1.3 Overview) and promotes (p24 Introduction) this 'gross misnomer'.

That the Productivity Commission both recognises and promotes this 'gross misnomer' is a reminder that assessment certainty will be particularly difficult in relation to this group and less clear than for others who may have a more easily observed disability.

Where other people with a disability are likely to accurately report functional impairments associated with their disability a person with an intellectual disability is likely to stress their sameness to everyone else and their ability to successfully perform certain functions which they in fact cannot.

I have observed an Occupational Therapist undertaking a functional assessment of a person with an I.D. and cerebral palsy and asking them a series of questions such as, "Can you cook?" The person with an intellectual disability replying in the affirmative to each of these questions even though they were things the person could not do or only with considerable support. I have been present when a 'psychologist' administering a functional assessment asked questions such as, "Could you paint a house, can you organise a dinner party?" and the person with an intellectual disability responds in the affirmative even though they would be severely challenged to even begin these tasks. I have also on occasion after occasion heard professionals and bureaucrats of every stripe say, "Oh that's only mild intellectual disability," and in saying this automatically negating and downgrading the needs of the person.

The 'severe difficulties' that people with an intellectual disability face in relation to mobility, self-care and/or communication are in many ways quite different to the difficulties that other people with a disability face and may need to be assessed differently. For example a person with an IQ in the range of 55 to 70 may be able to speak clearly and be understandable to others. However, they are likely to have 'significant difficulties' with communication which include:

- Finding it difficult to understand what others are saying particularly if they use complex concepts or words or speak quickly.
- Finding it difficult to tell others that you don't understand and therefore appearing to agree.
- Agreeing out of anxiety to be accepted, even if it is not what you want.

- Finding it difficult to read written language and comprehend, even if able to read individual words.
- Finding it difficult to relate to numerical concepts e.g. time and money.
- Finding it difficult to engage in more sophisticated communication, for example discussing feelings, or personal issues, or following humour.

These 'significant difficulties' lead to people with intellectual disabilities in the range 55-70 experiencing 'confusion and anxiety' in everyday life, experiencing 'rejection and isolation' in social situations and work places and experiencing 'manipulation and exploitation' in financial and other like dealings.

People with an IQ in the range of 55-70 are likely to have 'significant difficulties' in self-care which include:

- Keeping self safe from sexual exploitation;
- Keeping self safe from financial exploitation and other exploitation; and
- Keeping self physically healthy rates of obesity, poor dental hygiene are high in this group. Substance abuse is becoming a growing issue for people with IQ 55-70 range (Dickson et al, 2005). Age of death is much lower than for the population average.

The 'severe and profound' social disadvantages that people with an IQ 55-70 face are demonstrated by their gross over-representation as:

- victims of sexual assault;
- victims of crime; (Jackson, et al, 2006; Lindsay et al, 2010)
- offenders; (Jackson, et al, 2006; Lindsay et al, 2010)
- in the care of child safety; (Fudge Scholmans and Rooke, 2008)
- having their children taken into care of child safety; (Hill, 2009)
- homelessness:
- mental health diagnoses and disorders; and (Baludesian, 2005/2006)
- unemployment and poverty. (Geener and Powers 2007)

These gross over representations are the direct result of the inherent difficulties of attempting to negotiate our world with an intellectual disability.

The impact of disability is different for people with an IQ 55-70 than for many other people with a disability. While for other people with a disability difficulties around self care may lead to almost immediate physical harm for a person with an IQ 55-70 it will be a slower grinding down into disadvantage, exploitation, poor health and early death.

The 'severe and profound' difficulties that people with intellectual disabilities face can be dramatically de-escalated if people have appropriate support. Many people with IQ 55-70 live very safe if sometimes circumscribed lives in caring family environments. It is likely that the ultimate support needs of this group go largely unrecognized while such secure family support exists. If, however, this family support falters they are very vulnerable. However, many people with intellectual disabilities come from family backgrounds that expose them to severe disadvantage. If a young person with an intellectual disability is born into a family that experiences homelessness, drug use, poverty, mental illness, exploitation and child safety interventions, then their social outcomes are severely compromised.

These people with an intellectual disability from the most socially disadvantaged families are not likely to present seeking disability service support. All available research shows that they do not do well with mainstream service support. In many ways people with IQ 55-70 who come from disadvantaged family background are exhibiting similar social outcomes to Aboriginal and Islander populations.

The Productivity Commission floats the idea of re-allocating Disability Pensions from some people with intellectual disabilities to the support services of other people with a disability as a way of financing the N.D.I.S. As an alternative to Disability Pension the report talks vaguely of creating more flexible job markets for this group.

This vague talk of more flexible job markets is hardly a guarantee of fair and equitable dealing for this group. More so as technological change creates job markets that people with an intellectual disability may find increasingly difficult to access.

It is estimated that between 1% and 3% of the Australian Population have an intellectual disability. This is between 220,000 and 666,000. Of these some 90% have an IQ in the range 55-70. Comparing these figures to the Productivity Commission figures it is clear that the Productivity Commission believes that a sizeable percentage of this group will not be eligible for Tier 3 supports and will need to rely on Tier 2 supports. However, all available evidence points to how poorly mainstream services are responding to this group.

In conclusion I note:

- The Productivity Commission has bought into the 'gross misnomer' of presenting 'mild intellectual disability' as of being something 'gentle in effect'.
- This 'gross misnomer' has led the Commission to reduce its estimates of how many people with intellectual disabilities will require Tier 3 supports.
- The Commission will need to utilise assessment tools which properly and adequately chart the 'significant difficulties' of people with intellectual disabilities and that these may be different tools from other people with a disability or this group may be unfairly disadvantaged.
- The Commission should consider how the N.D.I.S. will relate to people with intellectual disabilities from disadvantaged background who may be unlikely to approach on their own behalf.
- The Commission needs to move beyond vague statements before it advocates stripping of Disability Pension from one disadvantaged group to provide support to another group.
- The Commission should consider 'early intervention' Tier 3 supports for groups such as young people with an intellectual disability exiting child safety. (Queensland Child Safety figures show one in four people exiting Child Safety have a disability with Intellectual Disability being one of the most common reported disabilities) (Commission for Children and Young People and Child Guardian 2009).

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