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**Susan Hayes** AO PhD FIASSID  
Professor of Behavioural Sciences in Medicine

SUBMISSION TO THE AUSTRALIAN PARLIAMENT'S JOINT STANDING  
COMMITTEE INQUIRY INTO IMMIGRATION TREATMENT OF DISABILITY

**1. Background**

I am a clinical forensic psychologist and I specialise in the area of people with intellectual disabilities (PWID) interacting with the justice system. I conduct research in this field, and I also engage a clinical forensic psychological practice. I have practised in the area for over 25 years.

In this role I have conducted a number of assessments of individuals with an intellectual disability (ID) who are seeking to obtain a visa for permanent residency in Australia. I also conduct many assessments of people with intellectual disabilities who have been charged with offences or found guilty of offences, and also those who have been victims of crime. This is the background against which I make this submission.

The points which I wish to make in this submission are:

- a. Currently, only visa applicants with readily recognisable conditions (such as syndromes including Down Syndrome, or cerebral palsy) or with a history indicative of disability (such as special schooling) are being identified; therefore, these applicants are being discriminated against compared with other applicants who do not have these obvious conditions.
- b. The present criteria for assessing the cost to the Australian community and the use of services are outdated and do not reflect the evidence base concerning people with disabilities' involvement in and financial contribution to the community.

This submission will use the internationally accepted definition of intellectual disability:

**Intellectual disability** is characterised 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.

For practical diagnostic purposes, the criteria for diagnosis are an Intelligence Quotient (IQ) score that is approximately two standard deviations below the mean population score of 100

Behavioural Sciences in Medicine  
Sydney Medical School  
Lvl 6, Blackburn Building D06  
The University of Sydney  
NSW 2006 Australia

and a Standard Score (SS) on a standardised measure of adaptive behaviour that is also approximately two standard deviations below the mean. This is usually interpreted to mean an IQ or SS of 70–75 or below, derived from performance on appropriate individual psychometric assessment instruments.

The following five assumptions are essential elements of this definition<sup>1</sup>:

- (1) Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
- (2) Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioural factors.
- (3) Within an individual, limitations often coexist with strengths.
- (4) An important purpose of describing limitations is to develop a profile of needed supports.
- (5) With appropriate personalised supports over a sustained period, the life functioning of the person with an intellectual disability will generally improve.

This classification system intends to replace the terms “mildly”, “moderately”, “severely” or “profoundly” intellectually disabled with description of the level of support the person needs – intermittent, limited, extensive, or pervasive. The classifications, *mild*, *moderate*, *severe* and *profound*, are nevertheless still widely used in Australia and elsewhere; usually the ranges for these categories are as follows:

Category	IQ or SS points
Mild	50–69
Moderate	35–49
Severe	20–34
Profound	under 20

## 2. Is the current process for assessing a visa applicant against the health requirement fair and transparent?

The current process for assessing a visa applicant against the health requirement is not fair or transparent. The Commonwealth Medical Officers tend to only recognise disabilities which involve a genetic abnormality (such as Down Syndrome) or which result in noticeable physical abnormalities (such as cerebral palsy).

In my forensic practice with offenders with ID, I have encountered many instances where the offender has an ID, and has migrated to Australia with his or her family, or the family may be

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<sup>1</sup> American Association on Intellectual and Developmental Disabilities, *Intellectual Disability: Definition, Classification, and Systems of Supports* 11th ed, (Washington, DC: American Association on Intellectual and Developmental Disabilities, 2010), p. 7.

refugees, and the ID has not been noticed because the individual “looks normal”. In my practice, such individuals mainly come from Middle Eastern, Pacific Island or Asian nations where they would not have been in special schools or classes or received any special support at school, as those facilities and services are not generally available in many countries. Furthermore, a history of having left school early, not having attended school regularly, or not been employed after leaving school, which would usually be markers for the possibility of ID, similarly may not attract the attention of the CMO because education facilities in some countries do not have provision for special education or support.

Therefore, there are many PWID who are granted visas because the condition of ID is not recognised and diagnosed.

### **3. What types of contributions and costs should be considered?**

In my experience with visa applicants with intellectual or other disabilities which have been identified by CMOs, the family is usually a business or professional family, which has made provision for the family member with ID. Such support measures often include employment in the family business, a family trust to support the PWID, and plans for the future care and housing of the PWID, usually with a member of the extended family.

By contrast, in those families that I have encountered in my practice with defendants/offenders where one or more family members have ID, I cannot recall a family where adequate provision has been made for the ongoing support of and care for the family member with ID. In many instances the family member with ID receives a welfare benefit or payment such as Disability Support Pension or unemployment benefit. Owing to the deprived background of many of these families, and the evidence-based link between poverty and ID, it is not unusual for there to be several members of the family with ID.

The contributions of PWID to the Australian society cannot and should not be measured by the rather limited list of criteria which are currently used, and which are often used erroneously, because the use of services and indeed the availability of services for PWID are frequently over-estimated.

#### Use of services and resources by people with an intellectual disability and costs

##### **3.1 Education**

When the PWID uses primary and high school education services, they will in all likelihood require special assistance in mainstream classes or placement in special classes. Whilst this is undoubtedly a cost to the Australian community there are other areas apart from ID where new migrants may use educational resources to a greater extent than an individual born in Australia, for example, English language classes, educational support for psychological/psychiatric disorders (including those arising as a result of being the victim of torture or trauma), special education for students with behavioural problems, or students with other learning disabilities which are not diagnosed as ID.

Late adolescent or adult applicants with ID may be unlikely to use school education services. They may wish to enrol in a TAFE course, especially a TAFE courses designed for PWID, or

courses which have open entry. If the PWID enrolls in a mainstream course he or she would pay fees similar to any other student. Therefore the major "drain" on post-school education resources would be the few who enrol in special ID TAFE courses (or equivalent) and who are not charged fees.

### 3.2 *Pension-welfare benefit*

Many PWID receive no pension or benefit, and earn a weekly wage in open employment. As with any other person or migrant in the community, there is a possibility that the PWID may become eligible for a welfare benefit in the future, although there does not appear to be a higher than average likelihood that the individual will become eligible for a pension or benefit. Many PWID applicants are in good health and rarely visit a medical practitioner.

One study of a post-school population found that of those in the borderline and mild-moderate range of intellectual disability, only 12.3% were receiving a Disability Support Pension<sup>2</sup>. This finding provides some evidence to support the argument that access to a pension is not the norm amongst the population of PWID, especially if the individual has no behavioural problems, and does not need regular help with daily activities or routine financial transactions.

### 3.3 *People with ID in open employment*

Research with people with intellectual disabilities in open employment<sup>3</sup> showed that in the study group, the average IQ score was 53, a level which may be lower than that which would usually be assumed for PWID in open employment. The study sample worked for 28 hours per week on average and received an average wage of \$228 per week, with the salary range being \$70-\$402 per week. In this study sample the categories of employment which employed the highest proportion of PWID were the food industry (30%), factories (25%) and clerical work (35%). I know of other PWID working as cleaners, actors, kitchen-hands, housekeepers in hotels, and child care assistants.

A study of people with **severe** intellectual disabilities<sup>4</sup> emphasised the importance of a supportive family in locating work opportunities, and improving work habits (punctuality, work ethic, good relationships with other employees) of the PWID. Hence, those PWID with a supportive family and good work skills are more likely to be able to locate and persevere with employment. Furthermore, those individuals with IQ scores above the severe range, with good family support, would have greater opportunity for learning complex vocational skills, earning a wage, and working successfully in an integrated community environment. A

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<sup>2</sup> Hayes SC (1996) *People with an intellectual disability and the criminal justice system; two rural courts*, New South Wales Law Reform Commission, Research Report 5: Sydney.

<sup>3</sup> Tuckerman P, Morgan J, Smith B, Delahunt R (1992) The relative costs of supported employment: job support six years on, *Australian Disability Review* 4: 49-60.

<sup>4</sup> Ford J, Ninnes P, Parmenter T (1995) Attitudes towards supported employment of parents and primary care givers of individuals with severe intellectual disabilities, *Australia and New Zealand Journal of Developmental Disabilities* 20(4) 245-261.

South Australian study<sup>5</sup> found that social competence and higher IQ were predictive of higher earnings amongst people with an intellectual disability in open employment.

### **3.4 Family support and future planning**

A Melbourne study examined adults with intellectual disabilities who had remained at home with their parents until at least the age of 40. An intensive case finding strategy in 12 municipalities was employed to ensure that “the sample included some older people with intellectual disabilities who are ‘hidden’ in the community, unknown to specialist disability services”<sup>6</sup>. Within the sample, 53% were known to intellectual disability services, although only 34% were actively using those services. This finding adds to the argument that it is erroneous to assume that all PWID will be known to specialist services or will use those services.

The average age of leaving home was 52.5 years. Most families had planned the future of the family member with ID. The most common forms of future planning were to nominate a key person to take over from the parents (26%), or a combination of a key person and financial arrangements (24%), or a combination of a key person, plus residential and financial plans (15%). Only 5% of families had no plans. This study indicated that most families with a member with ID make plans for that person’s future and do not necessarily rely upon government services, even when parents age and are unable to look after the PWID, or after parents have died. In many instances, siblings take over the care giving role when parents die. A five year follow-up in this study demonstrated that financial plans were successful in 77% of cases, key person plans in 82% of cases, and residential plans in 63% of cases, indicating that there is no reason to assume that this type of planning will fail later.

### **3.5 Under-use of Resources by People with an Intellectual Disability**

Many people with intellectual disabilities and their families choose not to use specialist resources, because of the lack of perceived need to do so, or dearth of such resources. People with mild-borderline disabilities are often ineligible for specialist services. Estimates of older people with intellectual disabilities who are not in touch with specialist services range from 28% to 75%<sup>7</sup> depending on the method used for case-finding this population. When people with intellectual limitations have remained at home with their family for considerable periods

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<sup>5</sup> Rusch F R, Heal L W, Cimera R E (1997) Predicting the earning of supported employees with mental retardation: a longitudinal study, *American Journal on Mental Retardation* 101 (6): 630-644.

<sup>6</sup> Bigby C (1996) Transferring responsibility: the nature and effectiveness of parental planning for the future of adults with intellectual disability who remain at home until mid-life, *Journal of Intellectual and Developmental Disability*, 21(4); 295-312.

<sup>7</sup> Jacobson J, Sutton M, Janicki M (1985) Demography and characteristics of aging and aged mentally retarded person. In M Janicki and H Wisniewski (Eds) *Aging and developmental disabilities: Issues and approaches*. (pp 115-143) Brookes: Baltimore; Krauss M, Seltzer M (1986) Comparison of elderly and adult mentally retarded persons in community and institutional settings, *American Journal of Mental Deficiency* 91: 237-243; Bigby C (1995) Is there a hidden group of older people with intellectual disability and from whom are they hidden?



of time during the developmental and young adult stages, their service needs are lower and their informal networks are more developed<sup>8</sup>. Good social skills are a positive predictor of self-sufficiency and lack of service use.

Amongst the clients that I have assessed for visa applications, in my expert opinion many will not require specialist resources in Australia and will be able to live independently in the community.

### **3.6 Costs to the Australian Community**

#### **3.6.1 Possible eligibility for the Disability Support Pension (DSP)**

As indicated above it is likely that many PWID will be employed full- or part-time in open employment and may therefore not be eligible for the DSP, or if eligible, may have the amount of their pension reduced owing to their earnings. In my experience with PWID in open employment, it is highly likely that they will be able to maintain employment over a lengthy period of time, presumably for their full working life, particularly if there are no behavioural or social difficulties which would impede or impair their vocational abilities. Therefore, it appears likely that PWID may not receive the DSP or the full DSP at any point in their life, or at least this is no more likely than for any other person who migrates to Australia.

#### **3.6.2 Eligibility for carer's pension on the part of a family member**

It is my understanding that a carer's pension is available only to a carer who has to give up paid employment in order to stay at home to take care of a person with a disability. To the best of my knowledge, in my practice with PWID and their families, no person in the family is in receipt of a carer's pension unless the family member is so disabled physically as to need full time care and assistance with all of the activities of daily living including their personal hygiene. Therefore a member of the family remaining at home to look after the PWID will be likely to occur in a very small percentage of cases.

#### **3.6.3 Use of services, precluding other citizens from the services**

The assumption that there would be any prejudice to the access to specialist health care and community services of Australian citizens and permanent residents if families who a member with ID were to be granted a visa is grossly over-stated by migration reviews. The major services which would possibly be utilised would be:

(a) school education, if the individual is of school age: as pointed out above, other visa applicants may require special education support.

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Lessons from a recent case-finding study, *Australian and New Zealand Journal of Developmental Disabilities*, 20(1): 15-24.

<sup>8</sup> Bigby C (1995), op cit.



(b) post-school education if they wish to continue their education or engage in vocational training (perhaps at a TAFE college): attendance at a course would enhance the individual's employability and can be compared with any visa applicant who wishes to engage in post-school education in order to enhance their career prospects.

(c) medical services for any physical/health problems that may exist or arise: there is evidence that PWID have higher rates of physical and psychiatric/psychological health problems than non-disabled peers. However, PWID like all other visa applicants will presumably have to pass a medical examination. The major issue is that at present the condition of ID is regarded as a medical condition in itself, whereas it should be considered separately from any physical or psychiatric/psychological health issues that the individual suffers from.

(d) other services or supports for PWID available within the Australian community: the provision of services for PWID in Australia is parlous, and most families contribute substantially to the services which their family member receives. This might include paying extra tuition fees at school or for extra-curricular education or coaching; private fees for interventions such as speech, occupational or physio therapy; respite care fees; carer payments; transport costs for special taxis or modifications to vehicles; and fees for social and recreational activities. In reality the extra costs of disability are usually borne by families, rather than by the Australian community.

#### **4 How do we measure these?**

There needs to be a realistic assessment of the costs and contributions. At present there are two major drawbacks to the formula for assessing costs –

- first, the criteria are out of date and old-fashioned, based upon notions of the PWID as an “eternal child” and dependent throughout their lives, and
- secondly, the criteria tend to be “one-size-fits all”, with little consideration being given to the individual's strengths and impairments.

The American Association on Intellectual and Developmental Disabilities (AAIDD)<sup>9</sup> publication “establishes an advanced paradigm that professionals will use when evaluating and delivering the support services that a person with intellectual disability needs at school, at home, in the physician's office or the courts, if the need arises. Rather than look at individual deficits, this model is based on evaluating the support services someone needs to reduce the mismatch between a person's capabilities and skills so that they can participate fully in all aspects of daily life”<sup>10</sup>.

The Australian government must take a similar approach to evaluating realistically the support services that are needed by each individual applicant.

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<sup>9</sup> AAIDD, op cit.

<sup>10</sup> [http://www.aaidd.org/IntellectualDisabilityBook/content\\_2351.cfm?navID=270](http://www.aaidd.org/IntellectualDisabilityBook/content_2351.cfm?navID=270); accessed 9 April 2010.

## **5 Are there additional factors that should be considered?**

I submit to the Joint Standing Committee that discrimination exists in the current practice of identifying and excluding PWID who have a readily identifiable disability, which is noticed by the CMO, whilst applicants without obvious signs/symptoms of ID are not excluded.

If there is to be a non-discriminatory approach to the treatment of visa applicants and the application of provisions pertaining to intellectual disability, an assessment of the intellectual abilities of all visa applicants must be undertaken using IQ and adaptive behaviour assessment instruments which are culture-specific and culture-fair, and normed for the applicant's culture. The tests must have demonstrated reliability and validity and be published, in order that the test characteristics can be evaluated.

The Australian Government must either exclude all applicants who have an intellectual disability, a practice which can only be achieved if all visa applicants are assessed, or it must cease the current discriminatory practices of targeting only a few applicants who have specific and noticeable syndromes or conditions.

Assessment of the intellectual abilities of all visa applicants will be a very costly process, and the Australian Government may decide that the benefits are outweighed by the difficulties.

A second major issue is that psychometric assessment of IQ and adaptive behaviour is difficult and costly in many countries because of the lack of appropriately skilled psychologists, dearth of culturally appropriate psychometric instruments that are normed for that country, and lack of awareness of the concept of, and diagnostic criteria for ID.

I have viewed a number of reports from psychologists or psychiatrists in nations such as India, Bangladesh, African nations, Cambodia, Vietnam and Laos. In my experience, psychometric assessments conducted in many countries are inadequate because they assess only IQ and do not assess adaptive behaviour skills; therefore a diagnosis of ID cannot be made according to the internationally accepted diagnostic criteria. Furthermore, the tests used are not properly developed and normed, and there are no data concerning the reliability and validity of the tests.

Therefore, if the Australian Government were to opt to assess all visa applicants for the possibility of ID, there would need to be guidelines for such assessments, including lists of accepted tests, and details of the qualifications of accepted test administrators. However, such a process may in itself become discriminatory owing to factors such as cost and availability of testers in some nations, especially those suffering war or civilian disturbance.

## **6 Do you have personal experience of this?**

As mentioned above, I have assessed a number of PWID who have applied for visas and I have extensive experience in the area of ID especially the issues of the rights of PWID. I also have encountered in my forensic practice many defendants or offenders with ID who have migrated to Australia (mainly with their families), and for whom the condition of ID was not diagnosed at the time of migration.





**7 What principles should apply to the assessment of visa applications against the health requirement? Should there be exceptions?**

In my opinion, the health of PWID should be assessed independently of the condition of ID; ID should not be regarded as a medical condition in itself.

**8 Other issues**

As members of the Committee will be aware, on 18 July 2008 Australia ratified the UN Convention on the Rights of Persons with Disabilities, and on 21 August 2009, ratified the Protocol. I submit that the guiding principles of the Convention should apply to visa applications. These guiding principles are:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- b. Non-discrimination
- c. Full and effective participation and inclusion in society
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e. Equality of opportunity
- f. Accessibility
- g. Equality between men and women
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

I submit that the present immigration policies and practice regarding visa applicants with ID may be in contravention of Principles (b), (c), (d) and (h). Furthermore, I consider that the following Articles of the Convention may be contravened:

Article 8 – Awareness-raising – current immigration policies and practices do not effectively combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life, or promote awareness of the capabilities and contributions of persons with disabilities.

Article 18 - Liberty of movement and nationality – current immigration policies and practice are inconsistent with the obligation of States Parties to recognise the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability, and are not deprived, on the basis of disability, of their ability to utilise relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement.

Australia has not demonstrated an enviable capacity to nurture full and effective participation and inclusion in society for those citizens with ID who are born here. As mentioned above, the costs, both financial and emotional, of providing a respectful and autonomous environment for the PWID usually falls to the family.



Given the prevalence of ID, health, welfare and human services funding is far below that for other conditions with similar prevalence. It is not generally recognised that the prevalence of ID is roughly the same as the prevalence of many other chronic health conditions which have higher public and medical research profiles. Approximately 588,700 people, or 3% of Australians, have ID or a developmental disability and 436,200 of those were aged under 65 years; this figure compares with the prevalence of diabetes (2.2% of the population), hypertension (2%), depression (2.8%), heart disease (2%) and stroke (1.8%)<sup>11</sup>. For many reasons beyond the scope of this submission, PWID are discriminated against in many areas of Australian society; I submit that it is unworthy of this nation to discriminate against the small proportion of visa applicants with ID whose conditions are recognised by CMOs.

We can do better for PWID, both those who have been born here and those who seek to join our society.

Susan Hayes

9 April 2010

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<sup>11</sup> Australian Bureau of Statistics (2006) 4102.0 - Australian Social Trends, 2006. Chronic conditions and disability.