



Down Syndrome NSW

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***Submission to the Joint Standing Committee on Migration  
– Inquiry into the migration treatment of disability***

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**Down Syndrome NSW** is a not-for-profit family support organization, established in 1980, supporting families with a member who has Down syndrome across NSW, from birth or prenatal diagnosis onwards. Membership includes people with Down syndrome, immediate and extended family members, interested individuals and professionals, and a range of agencies, such as schools and disability support services.

Down Syndrome NSW is the only NSW organization specifically and exclusively representing the interests of people with Down syndrome and their families.

Down syndrome (Trisomy 21) is a congenital condition, caused by the presence of an extra copy of chromosome 21. Its features are well known and easily distinguishable in most individuals. It is usually diagnosed, before, at or soon after birth.

The impact of Down syndrome on an individual is variable, but usually includes an intellectual impairment categorized as mild-moderate on currently available psychometric assessment.

A number of known and manageable health conditions occur somewhat more frequently amongst people with Down syndrome, although some people with Down syndrome enjoy remarkably good health throughout their lives. All the health problems that might be encountered by a person with Down syndrome occur amongst all the population in general. Down syndrome itself is not a disease.

People with Down syndrome are valued members of their families. They generally do need support throughout their lives. Families willingly provide the most significant support, and rightly anticipate that they can count upon a measure of community support as well. The contributions people with Down syndrome make to their families and the communities in which they live may include, but are not limited to any economic contribution they can make.

Down Syndrome NSW is pleased to have the opportunity to express the views of families of people with Down syndrome on the current immigration practices that affect them and their peers.

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During its almost 30 years of supporting people with Down syndrome and their families, Down Syndrome NSW has received a constant and increasing level of inquiry from families located in Australia and overseas who have encountered often unexpected difficulty with immigration applications based on Commonwealth Medical Officers' assessments and recommendations about a family member with Down syndrome. The enquiries are usually about whether Australia's laws are really framed and intended to exclude people with Down syndrome, as that is the apparent response to their applications.

We understand that Down syndrome is not specifically mentioned in the Migration Act, but the implementation of the regulations has affected many applications for visas by people with Down syndrome.

Applications have been regularly refused, and families have often been given advice that under any circumstances would be regarded as unthinkable, including abandoning a child so that rest of the family can migrate. Some families have had the resources, resilience and stamina to appeal, often several times, and have eventually won approval for their applications. Many more have given up in despair and disgust. This history of the treatment of families applying to immigrate is shameful, indefensible and unjust.

The recent history of families of people with Down syndrome applying to immigrate, including those making on-shore applications after the birth of a child with Down syndrome in Australia, has been well documented by Dr Jan Gothard of Down Syndrome Association of WA and Ms Sharon Ford, who are making their own submissions to this Inquiry.

Most of the reports assessing visa applicants against the health requirements that we have seen (and continue to see) reflect a woeful ignorance of the current outlook for people with Down syndrome. Down Syndrome NSW has repeatedly supplied the Department of Immigration (in its many guises) with up to date information, and none of it appears to have been utilized.

Even when the health of the person with Down syndrome has been documented and acknowledged to be excellent, absurd and wildly variable estimates of potential future costs have been made on the basis of the diagnosis of Down syndrome alone.

People with Down syndrome have routinely been viewed in the context of immigration as only a "charge" or "cost" to the Australian community. Little or no consideration has been given to their potential contributions, economic or otherwise. There has been no acknowledgement that they are valued members even of their families. Children and adults alike have been devalued and objectified. No consideration has been given to the mental and emotional health of unnecessarily separated families

In one current case, a young woman with Down syndrome has been denied a visa (a joint application has been made for her and her elderly mother - whose application would have otherwise been accepted - to immigrate as refugees) even though she is actually her mother's daily carer. Other family members' applications have been approved but their resettlement has been made more difficult by the separation from their elderly mother and sister, and anxiety about their safety in a Middle East displaced persons' facility. Such situations are barbaric and cannot be allowed to continue.

Recent cases highlighted in the media, including the very high-profile case of the Moeller family in 2008, have demonstrated the stark inadequacies of current regulations, and the Australian community's rejection of the status quo. The regulations are out of step with the values of the Australian community.

The public interest is not served by rejecting the families of those whom Australia wants to attract or accept as immigrants.

The public interest is not served by separating families, especially leaving vulnerable family members without their primary supports.

The public interest is not served by amplifying disadvantage by refusing visas to legitimate refugees who have disabilities, including Down syndrome.

The public interest is not served by a Migration Act and its regulations that regularly forces families of people with Down syndrome to endure Migration Appeals Tribunals solely on the basis that one member has Down syndrome.

The public interest is not served by the exemption of the Migration Act from the Disability Discrimination Act, nor by immigration practices that breach the United Nations Convention on the Rights of People with Disabilities (ratified by Australia, July 2008).

Neither the public interest nor the personal interests of Australians with Down syndrome is served by any law or regulation that systematically devalues and objectifies their peers with Down syndrome.

The position of Down Syndrome NSW is simple:

*The current practice that Down syndrome is documented as a "health", or any other criterion for non approval of an application is objectionable and unacceptable. If a family satisfies the other requirements for a visa (such as business, family reunion or refugee criteria), the presence of Down syndrome as a characteristic for one of its members should be irrelevant.*

There is therefore, no need to present a case based on the value of people with Down syndrome reduced to a listing of abilities or achievements, and no need to argue fine points about the absurd estimates of costs, an equally flawed consideration.

Social justice, legal and ethical considerations which will be argued forcefully by experts in those fields, will be sufficient to see these shameful and outdated practices against the human rights of people with Down syndrome end, and end soon.