ABOUT DOWN SYNDROME AUSTRALIA

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change, and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission.

Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 13,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.¹

Down syndrome is the most common cause of intellectual disability and everyone who has Down syndrome will have some degree of intellectual disability. In the past, many people with Down syndrome have not had the same opportunities as their peers. Often, they have been separated from the rest of the community, living in segregated settings such as care institutions. Low expectations were placed on them and there were limited opportunities for learning and participation in inclusive activities.

With better early intervention and medical care, as well as the increased inclusion and integration of people with Down syndrome into society, the quality of life with Down syndrome has increased. Children with Down syndrome often attend childcare settings, pre-schools and primary and high schools alongside other children of their age. Adults with Down syndrome are involved in their communities including through paid employment (open or supported) and voluntary work. An increasing number are living independently, with some level of support, within the community. The life expectancy of a person with Down syndrome has increased from only 25 years of age in 1983 to approximately 60 years in 2016 due to better support and health care, with one in 1 in 10 living to their seventies.²

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EXECUTIVE SUMMARY AND RECOMMENDATIONS

Down Syndrome Australia welcomes the opportunity to provide feedback to the Disability Discrimination Commissioner as part of his national consultation on future priorities. This submission will primarily focus on the specific issues facing people with Down syndrome in Australia. Representatives from Down Syndrome Australia have also attended consultations in Perth and Canberra.

Down Syndrome Australia was established in 2011 as the peak body providing support and advocacy for more than 13,000 Australians who have Down syndrome and their families. Down syndrome is the most common cause of intellectual disability and everyone who has Down syndrome will have some degree of intellectual disability. In the past, many people with Down syndrome did not have the same opportunities as their peers. Often, they were separated from the rest of the community, living in segregated settings such as care institutions. Low expectations were placed on them and there were limited opportunities for learning and participation in inclusive activities.

The increasing inclusion and integration of people with Down syndrome into our communities has considerably improved the quality of life and life expectancy of those living with Down syndrome. This has occurred in several key areas including early intervention and medical care, education, and supported employment to facilitate the active participation of people living with Down syndrome in society.

Despite the progress which has occurred, considerable barriers remain. Many of our members have expressed their deep concerns regarding the limited knowledge of the broader community and some health and education professionals regarding Down syndrome and other intellectual disabilities. This leaves some people with Down syndrome and their families feeling unsupported and marginalised and, in extreme cases, the subject of prejudice. There are also a range of challenges around access to inclusive education, appropriate employment, and independent housing. Down Syndrome Australia also has significant concerns around discrimination against people with disabilities who are attempting to migrate to Australia.

People with Down syndrome today are living full, satisfying lives like other people in the community. But there remain challenges in terms of full inclusion in the community. There is a clear need for additional work in these important areas, to ensure the rights of people with Down syndrome and their families. We therefore make the following recommendations to the Disability Discrimination Commissioner:

- **Recommendation 1** - the Commissioner work closely with DSA and other representative organisations of people with intellectual disabilities, to develop a public awareness campaign to tackle stigma and raise awareness of the importance of social inclusion.

- **Recommendation 2** – the Commissioner to recommend the need for information and training for health professionals to increase their knowledge of intellectual disabilities to ensure appropriate, non-discriminatory health care and advice is provided to families, particularly with regards to pre-natal screening.

- **Recommendation 3** - the Commissioner work with advocacy organisations to promote awareness of inclusive education and information regarding recourse to parents and families who may experience discriminatory decisions regarding entry to schools and institutions and the provision of year level curriculum once enrolled.
Recommendation 4 – the Commissioner to document barriers to inclusive education and to develop strategies to address these barriers.

Recommendation 5 - the Commissioner to work with Government to ensure appropriate investment in schools to support children with disabilities to have access to the supports required for inclusive education.

Recommendation 6 – the Commissioner work closely with disability advocacy organisations, the Fair Work Commission, and the Fair Work Ombudsman to develop resources for people with intellectual disabilities outlining their options, rights and wages in the workplace and legal avenues available if people with disabilities believe their rights are being infringed.

Recommendation 7 – the Commissioner work closely with disability advocacy organisations, employer representative bodies (e.g. Australian Chamber of Commerce and Industry), professional bodies (e.g. Australian Human Resources Institute) and employers to develop a national education program to increase awareness about, and the benefits of, employing people with disability, reduce misconceptions and reduce stigma regarding disabilities, the importance of valuing the contributions of people with disability, and promoting workplace equity.

Recommendation 8 – the Commissioner conduct a public inquiry into the health assessment process undertaken as a part of the Migration Act 1958 in relation to people with a disability and the subsequent denial of entry to Australia of migrants on the grounds of their disability. This inquiry should include recommendations to Government on how to improve the process and provide early opportunities for consideration of contextual issues.

Recommendation 9 - the Commissioner to promote alternative housing models to increase the independence of people with disabilities.

Recommendation 10 - the Commissioner to work with tenancy tribunals and tenancy advocacy organisations to develop information regarding the rights of tenants with disabilities and where they can obtain advice if they are experiencing problems around renting properties.

Recommendation 11 – the Commissioner should work with the National Disability Insurance Agency (NDIA) and other government agencies in advocating the need for additional funding for Information, Linkages and Capacity Building (ILC) to ensure that people with disabilities and their families are adequately supported in the community.

Recommendation 12 – the Commissioner to recommend additional resources to ensure people with intellectual disabilities have access to supported decision making, and appropriate support and training to successfully self-manage their NDIS plan.
AWARENESS/UNDERSTANDING

“If people don’t listen to you it can be a real disappointment. If this happens I encourage you to keep going, keep talking, sooner or later they will listen it may just not happen overnight. Do not give up”
(Michael Sullivan NSW Centre for Intellectual Disabilities)

The rights of people with disabilities have advanced significantly in Australia, particularly through the adoption and ratification of the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD), and the introduction of better support systems through the implementation of the National Disability Insurance Scheme (NDIS). Despite significant progress, many people with disabilities still experience stigma and discrimination. Social exclusion, marginalisation, feeling ignored and in extreme instances abuse have been cited as barriers to meaningful participation in the Australian community (FaHSCIA, 2009) (for full report, please click here). For people with disabilities and their family members, the consequences of stigma, exclusion and marginalisation can be considerable, including feelings of social isolation, depression, negative self-perceptions and suicidal ideation (Green, Davis, Karshmer et al., 2005) (for full research article, please click here).

This issue is even more problematic for people with an intellectual disability. The portrayal of life with Down syndrome is often negative with some community members having negative attitudes and false perceptions including (Gilmore, Campbell, & Cuskelly, 2003; Gilmore, 2006) (for Gilmore et al., 2003 article, please click here). Some myths include:

- children with Down syndrome are aggressive, unresponsive, moody, solitary and inattentive;
- Down syndrome only occurs in children of older mothers;
- all people with Down syndrome have severe cognitive deficits;
- all people with Downs syndrome are the same; and
- children and adults with Down syndrome cannot be educated or employed.

Many parents of children with Down syndrome, indicate that these myths are propagated by some health professionals who have limited knowledge about Down syndrome and who do not have a modern understanding of the social concept of disability. A 2014 survey of women who had a child with Down syndrome found that nearly half (48%) believed that health professionals were giving biased or incorrect information about Down syndrome at the time of diagnosis. Approximately a quarter of women surveyed believed that this biased information was leading to more terminations of pregnancies affected by Down syndrome (Kellogg, Slattery, Hudgins, et al., 2014). The attitudes of health professionals when women opted not to terminate their pregnancy based on screening results were in some instances negative, with some women feeling harassed and constantly having to defend their decision to continue their pregnancies (Kelly, 2016).

Further training for health professions is an important first step in breaking down the stigma and misconceptions that surround Down syndrome. This training should target a range of areas including:

- ensuring that health professionals are providing women with up-to-date, accurate information about Down syndrome both prior to screening and after receiving their results;
- the use of balanced language in relation to Down syndrome and other intellectual disabilities when discussing results of prenatal screening and diagnostic testing;
• the nature of results (often expressed as a numerical probability estimate) and the offer of a follow up diagnostic test if an ‘increased probability’ result is obtained;
• that continuing or not continuing the pregnancy are both options in the event that a foetal genetic or structural condition is diagnosed; and
• resources and supports that are available to parents carrying a child with Down syndrome or other intellectual disability, so that they can make an informed decision about whether to continue with their pregnancy.

Some positive initiatives are already in place which may be beneficial for health professionals in their role with expectant mothers and families. For example, the University of Sydney is utilising the Down Syndrome International “Dear future mom” video (https://www.youtube.com/watch?v=Ju-q4OnBtNU&feature=youtu.be) to provide medical students with information about life with Down syndrome. Similarly, resources including the ‘Discussing Down syndrome: A Physician’s Guide’ website and the webinar already developed by Down Syndrome Australia for the Australian College of Midwives in 2015 should be broadly disseminated.

A greater community awareness of Down syndrome can also be achieved through promoting the voices of people with Down syndrome and their families. Research conducted by Skotko, Levine, and Goldstein (2011), challenges the common false beliefs held by community members regarding Down syndrome. For example, nearly 99% of people with Down syndrome indicated that they were happy with their lives; 97% liked who they are; and 96% liked how they look. The participants with Down syndrome emphasised how good their own lives were and sought to encourage parents to love their babies with Down syndrome. They further encouraged healthcare professionals to value them, not label people with Down syndrome, recognise that people with Down syndrome can make valuable contributions, and emphasized that they share similar hopes and dreams as people without Down syndrome (Skoto et al., 2011).

DSA recommends the following to build community and health professional awareness and understanding of Down syndrome:

• **Recommendation 1** - the Commissioner work closely with DSA and other representative organisations of people with intellectual disabilities to develop a public awareness campaign to tackle stigma and raise awareness of the importance of social inclusion.

• **Recommendation 2** – the Commissioner to recommend the need for information and training for health professionals in increasing their knowledge of intellectual disabilities to ensure appropriate, non-discriminatory health care and advice is provided to women and families, particularly with regards to pre-natal testing.
EDUCATION

_Inclusive education is central to achieving high quality education for all learners, including those with disabilities, and for the development of inclusive, peaceful and fair societies._

_(Convention on the Rights of People with Disabilities, General comment No. 4 (2016))_

In the past, the standard approach to education for people with intellectual disability was segregation in special schools. In the last few decades, there has been an increased awareness about the benefits of taking a more inclusive approach to education, where children with an intellectual disability are supported in the same class as typically developing peers. There is considerable evidence regarding the benefits and positive outcomes of inclusive education, including academic and social benefits for children with and without disabilities.

Research conducted by Sirlopú, Gonzalez, Bohner et al. (2008), found that inclusion programs were effective in improving prejudice and intergroup anxiety; and in promoting positive attitudes, affect and trust amongst children without a disability. Children with disabilities also benefit from being educated in mainstream classes including gains in expressive language, literacy skills, better reading comprehension, higher levels on tests of mathematical skills, and fewer behavioural difficulties compared to segregated students (Blackorby, Knokey, Wagner, et al., 2007; Hehir, Grindal, Freeman et al., 2016).

These results were further supported in a review of inclusive education conducted by the Alana Institute (for full report, please click [here](#)). Researchers followed children with Down syndrome over a two-year period (Dessemontet, Bless, & Morin, 2012). Children in inclusive education demonstrated a significantly greater growth in the development of literacy skills than their otherwise similar peers (see graph below) (Dessemontet, Bless, & Morin, 2012; Hehir, Grindal, Freeman et al., 2016).

![Graph showing the growth in literacy skills of students with Down syndrome in inclusive versus segregated settings.](image-url)

(Source: Dessemontet, Bless, & Morin, 2012)
Similar results were obtained in research conducted by Buckley, Bird, Sacks & Archer (2006). In the United Kingdom, 46 teenagers with Down syndrome were examined by researchers on academic and social outcomes. These students were either attending inclusive or separate special education schools. Students in inclusive education outperformed their segregated peers on measures of academic development. The researchers estimated that when compared to the students in segregated programs, students from inclusive educational environments were approximately two and a half years ahead on measures of expressive language, and more than three years ahead in reading, writing, and literacy skills (Buckley et al., 2006; Hehir et al., 2016). It is important to note that the students were from different educational districts and placement in schools was a factor of educational policy rather than intellectual attainment of the student.

Despite concerns by some parents and educators regarding inclusive education negatively impacting on the quality of education for typically developing students, evidence indicates that typically-developing students in inclusive classrooms receive the same level of teacher attention as students in non-inclusive classrooms and have similar levels of academic achievement (Salend & Duhaney 1999). A review conducted by Kalambouka, Farrell, Dyson & Kaplan (2007) of 119 papers reported no adverse effects on typically developing students from the inclusion of children with disabilities, with positive effects reported in 81% of studies (Jackson, 2008; Kalambouka et al., 2007). Although there has been a global shift towards inclusive education, many children with disabilities and their families in Australia report numerous barriers to accessing inclusive education.

The attitudes of some teachers towards inclusive education in Australia have been positive. Research looking at the developmental expectations, personality stereotypes and attitudes towards inclusive education with a sample of Australian teachers, showed that many recognised the benefits of inclusive education (Gilmore et al., 2003). The results, however, also showed that a large percentage (85%) endorsed stereotypical beliefs about Down syndrome including that the average child with Down syndrome is ‘happy’ and ‘more affectionate than others’ (Gilmore et al., 2003). These stereotypes fail to recognise the individuality of children with Down syndrome and may result in certain expectations of children with Down syndrome which, if unmet, may impact on inclusion (Gilmore et al., 2003).

Forlin (2006) argues that although the attitude of teachers regarding inclusive education has been positive, there is a need to acknowledge that teachers work in schools that have an embedded culture such as school characteristics, traditions and organisational dynamics which often pose obstacles in effective inclusion of children with disabilities.

Since 2010, the Zero Project has measured the implementation of the UNCRPD with social Indicators, country by country. In 2016, experts from 129 countries including Australia contributed to this process, with a focus on education. When considering whether a person with disability has the right to receive free and compulsory primary education within the mainstream educational system, global respondents stated Yes in 39% of cases, 52% stated ‘Yes with qualifications’, and 8% indicated ‘No’. One of the most mentioned comments of experts both internationally and in Australia was the fact that governments still highly promote and favour segregation and special schools over inclusive mainstream schools. Governments also often highlight to parents the benefits and advantages of special schools compared to inclusive ones (Fembek, Heindorf, Kainz & Saupe, 2016) (for full report, please click here).
These issues are exacerbated by a clear lack of funding for students with disabilities. In 2015, the Nationally Consistent Collection of Data on Disability (NCCD) data showed that 12.5% of students needed supplementary, substantial or extensive support for a disability or learning difficulty but just 5.1% of all students received funded support for their disability in 2014 (Productivity Commission, 2014). This was also reflected in the 2011 Review of School Funding Report (Gonski). The review identified that ‘(t)he existing resourcing provided to the government and non-government school sectors for students with disability remains an issue. Students with disability in non-government schools receive substantially less public funding than their counterparts in government schools.’ (DEEWR, 2011 p. 32, 135).

Our members have shared their experiences with the education system which similarly reflects the results outlined above. As a part of the Senate Education and Employment References Committee Inquiry in 2015, members highlighted some of the issues they faced within the education system, including a lack of knowledge and understanding of Down syndrome, limited support available within the school, children with Down syndrome being excluded from class activities and being denied choice when selecting education programs, and an unwillingness on behalf of some schools to offer a place to a child with Down syndrome (Down Syndrome Australia, 2015). Others acknowledged positive experiences including provision of support in class by para-professionals, schools seeking input from external professionals (e.g. speech therapists, occupational therapists), open communication between school staff including Principals and parents, the initiation of clubs to facilitate peer support, positive and inclusive attitudes by all school staff, and encouraging independence using learned routines, visual supports and social stories.

To ensure that students with Down syndrome and other disabilities have access to education in mainstream schools, DSA recommends the following:

- **Recommendation 3** - the Commissioner work with advocacy organisations to promote awareness of inclusive education and information regarding recourse to parents and families who may experience discriminatory decisions regarding entry to schools and institutions and the provision of year level curriculum once enrolled...

- **Recommendation 4** – the Commissioner to document barriers to inclusive education and to develop strategies to address these barriers.

- **Recommendation 5** - the Commissioner to work with Government to ensure appropriate investment in schools to support children with disabilities to have access to the supports required for inclusive education.
“I got knocked back a lot because of employers. That was a bit more challenging. Maybe because of people’s attitudes ... just looking at my disability, thinking that you’re not able to do the job. Not listening. That kind of stuff”. (34-year-old woman, urban, currently working in an ADE).

There is considerable evidence highlighting the important benefits employment can have on the psychological and economic wellbeing of people with disabilities, including improved life satisfaction, feeling useful, developing new skills that can be used in other areas of life, easing social isolation, and protecting against poverty (Schur, 2002). Similarly, employers also reap benefits from hiring people with disabilities. Evidence indicates that workers with a disability have higher rates of retention, better attendance and fewer occupational health and safety events than those without a disability (Hindle & Phillips, 1999) (for full research article, please click here).

The Results from the National Disability Survey conducted by the Australian Human Rights Commission in 2014 showed that access to employment was the second biggest human rights issue facing people with disabilities. For people with intellectual disabilities (ID) access to employment can be even more difficult. Evidence from the ABS Survey of Disability and Carers suggests that people with an intellectual disability have worse employment outcomes (ABS, 2012) than other disability groups including:

- higher rates of not being in the labour force (60% for people with ID vs 50% for those with other disabilities and 18% for people without disabilities);
- amongst those in the labour force - being less likely to have full-time employment (12% for people with ID compared to 32% for those with other disabilities); and
- higher rates of unemployment (20% for people with ID vs 8% for those with other disabilities).

For people with disabilities, the type of employment available generally falls into two categories: open employment and supported employment. In open employment, the person with an intellectual disability is employed on the open labour market by an employer which is not in the disability sector. Supported employment refers to employment where the individual with ID engages in streamlined work for reduced wages based on their level of capability, often receiving high level support (Melzter, Bates, Robinson et al., 2016) (for full report, please click here).

For many people with ID, there is often limited choice regarding the type of employment particularly in open employment (Melzter et al., 2016). This may be due to others such as parents making choices regarding where the person with ID works, limited options of where to work, lack of information about options and other external circumstances which influenced decisions regarding employment type. This frequently results in people with ID working in supported employment positions (Melzter et al., 2016).

There are many positive examples of people with ID engaging in open employment with good benefits to both the worker and the employer. However, there are a range of barriers for people with ID in engaging and maintaining open employment (Australian Human Resources Institute, 2013; Melzter et al., 2016). These include:
• lack of funding/support for upskilling and education opportunities for people with disabilities;
• difficulty with the application process;
• attitudes of employers;
• limited awareness on behalf of employers regarding Disability Employment Services;
• Disability Employment Services not considering preferences for types of work; and
• unstable labour market - people with ID were working in entry-level and/or low-skilled positions and thus were more vulnerable to turnover and lack of clear employment pathways.

Other barriers that people with ID may experience in open employment include low levels of awareness of their rights at work, lack of availability of jobs, and difficulties in accessing flexible work arrangements (Human Rights Commission, 2015). Employment outcomes for people with intellectual disabilities could be improved through the adoption of Disability Discrimination Act Action Plans in organisations. The development of action plans has a number of benefits for employers including accessing a wider job market, improving corporate image, and better service delivery (Australian Human Rights Commission, 2016). For people with disabilities, action plans help to breakdown misconceptions and discriminatory practices and attitudes commonly experienced in the employment market (Australian Human Rights Commission, 2016). There is a need to increase corporate and community awareness of Disability Action Plans to facilitate the employment of people with disabilities (for further information about Disability Action Plans, please click here).

Several issues have also been reported by people with intellectual disabilities in supported employment. These include poor wages, limited autonomy and choice of work, and less mainstream community connections (Melzter et al., 2016). The use of the Business Services Wage Assessment Tool (BSWAT), developed by the Australian Government for use by Australian Disability Enterprises (ADEs) to assess the wages of supported employees has resulted in considerable economic loss for people with disabilities. In particular, the BSWAT has resulted in substantial discounts in the wages of people with disabilities based on competency rather than productivity and was recently ruled as discriminatory by the Federal Court. In response to the ruling, the Australian Government has established the BSWAT Payment Scheme, however, the Scheme will only entitle supported employees to 70% of the money owed to them.

Employment is integral for people with disabilities in improving quality of life, lowering social isolation, and facilitating meaningful activity. DSA has the following recommendations:

• **Recommendation 6** – the Commissioner work closely with disability advocacy organisations, the Fair Work Commission, and the Fair Work Ombudsman to develop resources for people with intellectual disabilities outlining their options, rights and wages in the workplace and legal avenues available if people with disabilities believe their rights are being infringed.
• **Recommendation 7** – the Commissioner work closely with disability advocacy organisations, employer representative bodies (e.g. Australian Chamber of Commerce and Industry), professional bodies (e.g. Australian Human Resources Institute), and employers to develop a national education program to increase awareness about, and the benefits of, employing people with disability, reduce misconceptions and reduce stigma regarding disabilities, the importance of valuing the contributions of people with disability, and promoting workplace equity.
MIGRATION

Australia has signed multiple treaties that support the basic human rights of migrants including the Universal Declaration of Human Rights, the Convention and Protocol relating to the Status of Refugees, and the International Covenant on Civil and Political Rights. In addition, the Australian Government signed the CRPD which recognises that discrimination against any person because of a disability is a direct violation of the inherent dignity and worth of the human person. Despite this, there have been various examples of migrants with ID and their family members being denied entry to Australia and, in some cases being asked to leave Australia, due to their disability. Although some people with a disability may be granted an exemption under the current arrangements, the decision-making regarding such waivers is often inconsistent and subject to lengthy waiting periods.

Australia’s signing of the UNCRPD was made subject to the declaration that “*it understands that the Convention does not create a right for a person to enter or remain in a country of which he or she is not a national, nor impact on Australia’s health requirements for non-nationals seeking to enter or remain in Australia, where these requirements are based on legitimate, objective and reasonable criteria.*” The implementation of this clause, however, has been problematic.

The Migration Act 1958, which is exempt from the Disability Discrimination Act 1992, mandates that potential migrants to Australia must undergo a health assessment to determine their eligibility. The health assessment process takes into consideration a range of factors including the assumed future costs associated with the individual’s health condition or disability. This process has many shortcomings including:

- failing to distinguish health and disability as distinct concepts, specifically that people with disabilities can have good health;
- including costs associated with special schooling and community supports when inclusive schooling is the preferred model and significantly less costly; and
- failing to take into consideration the economic and societal contributions made by people with disabilities and their families.

For people with Down syndrome, research has shown that most health-related costs are borne within the first two years of life and rapidly decrease thereafter. In particular, the demands on health services declines significantly with age to approach population levels during adolescence, indicating the general level of good health of people with Down syndrome (Geelhoed, Bebbington, Bower et al., 2011).

Denying migrants entry to Australia on the grounds of the individual’s disability is discriminatory and unfair. DSA recommends the following:

**Recommendation 8** – the Commissioner conduct a public inquiry into the health assessment process undertaken as a part of the Migration Act 1958 in relation to people with a disability and the subsequent denial of entry to Australia of migrants on the grounds of their disability. This inquiry should include recommendations to Government on how to improve the process and provide early opportunities for consideration of contextual issues.
Access to housing is an important human right. In the past, people with Down syndrome often lived in segregated housing such as group homes or even in institutions. Today more and more people with ID are choosing to live independently. The UNCRPD recognises the right of people with disabilities to live independently in their community, at a residence and with people of their choosing, with access to appropriate in-home and community support services.

Unfortunately, some barriers remain to independent living arrangements including:

- limited support services to facilitate living independently;
- inadequate design of housing;
- affordability of private rentals particularly in urban areas; and
- limited housing availability (FaHSCIA, 2009; French, 2009).

As a result, some people with Down syndrome and other disabilities live in aged care facilities, group homes, and other segregated housing effectively isolating them from participating in the community (French, 2009). It should be noted that some people with Down syndrome find living in group housing beneficial, but that is not the case for everyone. The lack of choice and alternative housing also means the individual has little chance of moving from unsuitable accommodation resulting in a compromised quality of life (FaHCSIA, 2009). Many individuals with Down syndrome have the necessary skills to live more independently, in a unit or house with some support.

Discussions with consumers as a part of the National Disability Strategy Consultation highlighted that people with disabilities want to live independently in the community (FaHCSIA, 2009). Several solutions were proposed by consumers including alternative models of housing, additional funding to increase availability, and greater availability of individual support packages to assist some to purchase services to enable them to live a more independent life in their own home (FaHCSIA, 2009).

One example of a different approach to housing designed to promote independence for people with intellectual disability is Project Independence (http://www.projectindependence.com.au/) which is being rolled out in the ACT. This project aims to provide a new model of home ownership for people with disabilities and the opportunity to acquire equity in property. This social model of housing will provide accommodation in three houses for a small number of residents. The initiative provides some people with disabilities their first opportunity to live independently and own their own home.

**Recommendation 9** - the Commissioner to promote alternative housing models to increase the independence of people with disabilities.

**Recommendation 10** - the Commissioner to work with tenancy tribunals and tenancy advocacy organisations to develop information regarding the rights of tenants with disabilities and where they can obtain advice if they are experiencing issues in rental properties.
“So they gave me a list of everything that NDIA funds because NDIA didn’t tell me and my support service didn’t tell me. So there’s packages for people to try and get them into work but no one ever told me that it’s available...But [the NDIA] don’t tell you what they’re offering”.

(Person with a Disability, NDIS participant, Evaluation of the NDIS, Intermediate Report)

The National Disability Insurance Scheme (NDIS) heralds a significant social shift in how people with disabilities and their families are supported. The Scheme aims to eliminate the disadvantage many people living with disabilities experience ensuring they are better supported to fully participate in the community and workforce. The Scheme is the first of its kind in the world giving people with disabilities greater choice and control over their supports and managing their disability, but also in receiving the right supports to facilitate them in reaching their goals.

Evidence to date indicates that NDIS participants have benefited in a range of areas including improved choice and control over supports, access to a larger number of supports, and reported increased positivity and wellbeing since entering the Scheme (Mavromaras, Moskos, & Mahuteau, 2016) (for full report, please click here). Despite the best intentions of the Scheme, some consumers have highlighted issues (Mavromaras et al., 2016) including:

- lengthy and complicated process of establishing NDIS eligibility, which is exacerbated by the initially unresponsive administration of the Scheme on the part of the NDIA. This results in delays between first and subsequent contact, feedback on access enquiries and telephone enquiries remaining unanswered;
- variability in the quality of the planning meetings or “first plans” with some participants finding that planners do not have sufficient understanding of the impact of the disability;
- inappropriate use of standardised tools such as the PEDICAT to determine levels of funding;
- high workloads of NDIA staff which reduces contact with individual participants and prevents a more customised service;
- choice and control for NDIS participants is frequently impeded by a lack of service providers and long waiting lists;
- funding for family supports is inconsistently included in plans and limited in scope;
- NDIS participants who are unable to effectively advocate for services on their own behalf, including some people with psychosocial disability and/or those who struggle to manage complex NDIS processes, are experiencing poorer outcomes under the NDIS and receiving a lower level of services than pre-NDIS;
- time consuming paperwork associated with the Scheme;
- ineligibility to the NDIS for some individuals including those who may experience episodic or temporary impairments or illnesses;
- some NDIS participants and their family members report feeling more isolated and unsupported – mostly because the individualised model provides less opportunity for engagement with other people with disability and carers to that which were available to them pre-NDIS; and
- NDIS participants need initial support and guidance in managing funds before engaging in self-management of funding.
There have also been concerns raised regarding the level of funding provided for the Information, Linkages and Capacity Building (ILC) component of NDIS. The ILC aims to support those who may not be eligible for the NDIS and those seeking activities not covered in NDIS packages by building personal capacity for people with disabilities and their families, and developing community capacity to become more inclusive of people with disabilities. The concerns regarding the resourcing of ILC were reiterated by outgoing Chair, Mr Bruce Bonyhady, who indicated a need for additional funding. At this time, only $132 million has been allocated to ILC which is insufficient given the scope of work needed in this area and the number of people who require support. This will have significant consequences for people with disabilities and their families who may not be eligible to receive NDIS packages and who are receiving inadequate support in their community.

**Recommendation 11** – the Commissioner to work with the NDIS and other government agencies in advocating the need for additional ILC funding to ensure that people with disabilities and their families are adequately supported in the community.

**Recommendation 12** – the Commissioner to recommend additional resources to ensure people with intellectual disabilities have access to supported decision making, and appropriate support and training to successfully self-manage their plan.
CONCLUSIONS

The national consultation currently being undertaken by the Disability Discrimination Commissioner provides an important opportunity to highlight the need for work in several areas which profoundly impact the everyday lives of people with Down syndrome and their families. This submission provides a number of recommendations which have the potential to improve the quality of life of people with Down syndrome and other intellectual disabilities and facilitate greater community participation. These areas need to be addressed not only by the Disability Discrimination Commissioner but by the Australian Government to ensure that the basic human rights of people living with disabilities are realised.
References


