

Inquiry into Social Inclusion and Victorians with a Disability Submission from Down Syndrome Victoria

Down syndrome is the most common genetic disability, occurring in one of every 700 to 900 births in every country of the world, covering all ethnic groups and nationalities. Approximately 3000 people in Victoria have Down syndrome, with between 50 and 70 new babies born each year.

Down Syndrome Victoria (DSV) is the statewide peak membership organisation representing people with Down syndrome and their families. It is a not-for-profit organisation established in 1978 to provide support, information and resources to people with Down syndrome, their families and the broader community, with the mission to empower individuals with Down syndrome for a lifetime of meaningful inclusion in the community.

As the mission of the organisation suggests Down Syndrome Victoria promotes inclusion in all aspects of its work. Meaningful inclusion can be challenging and difficult to achieve for people with Down syndrome, and to assist its members and all people with Down syndrome with this lifelong goal, DSV delivers a number of programs designed to maximise potential and develop skills that will lead to independence, involvement and ultimately meaningful inclusion in the community.

The term “meaningful inclusion” is important to Down Syndrome Victoria. People with Down syndrome often experience gestures of tokenistic inclusion, resulting in a negative impact on the person and family, and potentially a reluctance to continue with the activity. Thought and planning needs to be applied to the process of inclusion to ensure that the experience is positive and advantageous for all. Meaningful inclusion is not just about having a person with Down syndrome being present in a mainstream school, a workplace, a sporting club or a community group, it's about welcoming that person, reducing the barriers, and allowing the person to participate genuinely in the activities of the group. The work of Down Syndrome Victoria assists this process by providing strategies and services to support members throughout this life long journey.

The Down Syndrome Inclusion Support Service (DSISS) delivered by Down Syndrome Victoria, is a program offered to mainstream schools in Victoria. Specialised, experienced Education Consultants visit schools, meet with students, teachers and parents and assist the school to create an individualised program for the student with Down syndrome that will focus on the strengths and skills of the student. DSV's Education Consultants suggest strategies that foster inclusion and encourage teachers to embrace the experience of teaching a child with Down syndrome as a positive one that can benefit the whole school community. Successful, meaningful inclusion in schools relies on a commitment from all involved, supported by the specialised resources and experienced advice provided by the DSISS and other specialised services. Unfortunately for some though this service is not accessible.

The DSISS is predominantly a user pay service, although it has received some partial funding over the past 3 years from DEECD. DEECD funding has been given to students starting Prep in a government school or transitioning to a new government school and has been gratefully utilised by schools with a student with Down syndrome meeting the eligibility criteria. Unfortunately ineligible students are required to pay \$1800 to receive this service. Many school and families are not in a position to afford this beneficial but costly service. DSV constantly explores alternative funding options for this program, but unfortunately is unable to reduce the fee of this statewide service. There is a considerable need for his service in regional

Victoria and DSV uses any additional funding received from philanthropic sources to cover the increased costs of delivering this service to remote areas of Victoria. One of the significant barriers to meaningful inclusion therefore is the cost of the support that is required. Further investment in every child with a disability in school is required to ensure that the inclusion process in (government and non-government) mainstream schools is fully equipped with the resources and support it needs.

It is worth noting, that in 2013 the DSISS was awarded the National Disability Award for Excellence in Improving Education Outcomes. The prestigious National award acknowledges and recognises the value of the work of the DSISS and Down Syndrome Victoria as Best Practice in delivering a meaningful inclusive education program, but unfortunately the financial barriers of accessing this service still exist.

Down Syndrome Victoria provides a whole of life service for new parents after the birth of baby with Down syndrome, throughout the school years and beyond into adulthood. Promoting inclusion in the community is a priority for DSV that needs to be facilitated throughout the whole of life experience. For example, to encourage adult participation and inclusion in the community, in 2009 DSV established a social, peer support group called Club21 (for adults aged 18+). This highly popular group meets fortnightly at Federation Square and then travels as a group to an activity of interest to the participants. A number of volunteers and staff of DSV support the group, maximising the opportunities for the adults to socialise and participate in fun, interesting and inclusive activities. An important element of inclusion is access, although Club21 is disability specific, it enables the group of adults to experience activities in the community without the barriers that may exist if they were to individually participate. The Club21 presence in the community is a positive one, demonstrating that groups of adults with Down syndrome can join in events and activities like other members of the community.

Club21 has become so popular in recent months that most fortnightly activities now have waiting lists and there is a real need for this program to expand. In particular adults with Down syndrome living in regional Victoria find it difficult to travel to Federation Square for fortnightly activities. DSV has plans to establish additional Club21 groups in Geelong and the Mornington Peninsula to cater for the need in these areas. The independent skills developed through the Club21 program are essential to enable adults with Down syndrome to participate in the economic, social and civil dimensions of society.

Not surprisingly, the Club21 program receives no regular source of funding. DSV is currently unable to expand the program as the financial resources are not available.

Down Syndrome Victoria is committed to empowering individuals to achieve a lifetime of meaningful inclusion in the community. DSV appreciates this opportunity to make a submission to the Family and Community Development Committee's inquiry into social inclusion. It is hoped that a cohesive plan, that is well resourced, can be implemented in Victoria that will appropriately respond to the needs of all people with a disability and their families. Down Syndrome Victoria would appreciate the opportunity to collaborate further in the establishment and implementation of this plan.