

30 May 2019

Ms. Vicki Rundle
Acting Chief Executive Officer
National Disability Insurance Agency

Dear Ms. Rundle

We, the Short Statured People of Australia Incorporated (SSPA), a recognised national genetic support organisation representing individuals of short stature (dwarfism), their families and/or carers over the past 52 years are, very concerned about the ongoing number of reports from our members' being denied access to the Scheme and on some occasions even after appeal. These concerns also exist within our health professional's advisory board, a group of Australia's leading medical and allied health experts in Skeletal Dysplasia.

Dwarfism herein referred to as short stature, is defined as when individuals standing less than 150 cm tall (men) and 140 cm tall (women). Recent advances in genetic research have led to the identification of in excess of 350 different types of short stature. People with these conditions have day to day difficulties because of the impacts of their physical disability. These conditions vary in severity, the necessity for major medical and surgical interventions and the level of adaptations required for functioning in society, particularly in relation to mobility.

The multiple conditions causing skeletal dysplasia are genetic so will be present from birth. Most individuals would have confirmation of the genetic mutation causing their skeletal dysplasia. There is currently no treatment available in childhood which improves either growth or the specific bone and joint deformities. For our community of adults who have finished growing it is too late for any treatment to influence the underlying condition. Limb lengthening is generally not feasible for these conditions and not available for adults.

The conditions cause significant mobility issues, stride length is short and walking speed impaired; children and adults are unable to keep up with their peers. Common community-based activities which other individuals use to maintain physical health are inaccessible to the group. They cannot use gym-based exercise equipment built for an average statured body frame. They will need ongoing access to physiotherapy for early intervention support to maintain physical function on a lifelong basis and many need mobility aids such as orthotics and car modifications.

Communication challenges due to short stature can include cleft palate, respiratory and hearing complications, resulting in delays in language and speech development, requiring speech therapy and hearing aids. Some skeletal dysplasias include global learning difficulties.

Throughout school these challenges may adversely affect educational outcomes, contributing to low academic results, diminished self-esteem and reduced employment opportunities. Some employment opportunities can also be restricted due to stature, for instance short statured people are less able to manage some trades. Nor may an employer be willing to take on someone with a disability to work in a commercial kitchen, as foot stools may be seen as a hazard.

Social participation is more difficult due to mobility issues; problems with participating in activities with average statured peers such as team sports, and limits to activities where equipment is designed inappropriately and needs modification (i.e. pushbikes), requiring OT assessments and recommendations. Some members due to their height or joint limitations, have issues accessing public transport.

Self-care/management is challenging for physical tasks. As a result of living in a world built for average height people, people of short stature require modifications to areas in the home, especially the kitchen and bathroom to be able cook etc. and undertake personal care safely and efficiently. Independence in self-care requires appropriate bathroom modifications, assistive technology and more complex conditions need caregiver support.

Garden and yard maintenance is a challenge, also heavier household responsibilities such as windows and gutter cleaning are all very difficult and potentially unsafe for the majority of members.

Before some items of clothing such as school uniforms, business suits and dresses can be worn, they may need to be modified by a professional seamstress. Due to the small and disproportionate size of the feet, problems can be encountered when buying comfortable shoes to fit, resulting in additional costs if shoes have to be made or modified.

To assist with getting information across about the impact of short stature on daily living, we have attached 3 case studies of current NDIS participants who have 3 types of short stature/skeletal dysplasia and have obtained access to the scheme. Each one highlights the impact of their condition and the current supports they receive from the NDIS.

To help lessen the numbers of people with short stature/skeletal dysplasia being denied access, we strongly recommend that the NDIA considers short stature disorders/or skeletal dysplasia for inclusion in the Access automatic eligibility lists, particularly in list A.

Moving forward we are happy to support this process and to contribute further if needed.

Yours truly,

A handwritten signature in black ink, appearing to read 'S. Milliard', with a long horizontal flourish extending to the right.

Sam Milliard, President of SSPA,

A handwritten signature in black ink, appearing to read 'David Sillence', written in a cursive style.

Professor David Sillence, on behalf of SSPA Professional Advisory Board (PAB)