

Education, employment and social inclusion

Persons with spinal muscular atrophy (PWSMA) have and are encountering barriers in these three areas that prevent them from achieving their full potential.

“The ability to lead a normal life is particularly imperative for parents with adult SMA children and the PWSMA themselves.”

– Living With Spinal Muscular Atrophy in Malaysia: A Study

BARRIERS TO EDUCATION



> The misconception that PWSMA are intellectually challenged.

One common experience had by both PWSMA and caregivers is the assumption on the part of education officials that a child with a physical disability should be placed in the special education class (i.e. due to learning disability), even though the risk of learning disabilities for PWSMA is the same as the general population.”

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> Discrimination against persons with disabilities

She said they couldn't have [my daughter] unless I have someone or a full-time PA (personal assistant) look after her. The teacher reasoned that if she assists [my daughter], the class would stop midway, disrupting it. The teacher even mentioned that the PIBG had complained that it would interrupt the class if [my daughter] continues to be there. I was shocked! So shocked! I felt like it was not fair for my kid, but if I let [her] stay in that school, I was afraid they might do something to my daughter, so I took her out from that school immediately.”

– A mother of a woman with SMA type 3

> Lack of understanding and compassion

I think that primary school was the hardest time of my life because I faced many challenges. For instance, my classroom was on the first floor and the teachers weren't very ... I would say, supportive. My parents talked to them, but they still didn't put my class downstairs, so I had to climb up the stairs.

Sometimes I was so tired and my dad had to carry me up.”

– A man in his 20s with SMA type 2

> Bullying

There was one incident (long silence) of bullying because ... because of my condition, I couldn't lift my head up. If I fall down now, I can't lift my head up. Yeah, so ... my classmates when I was in primary school in normal class ... one of them pushed my head down ... and ... and pressed. Well, of course, as my head was down, I couldn't lift it up (silence). Yeah ...”

– A man in his 20s with SMA type 2

BARRIERS TO EMPLOYMENT



> The misconception that PWSMA are intellectually challenged

One common experience had by both PWSMA and caregivers is the assumption on the part of education officials that a child with a physical disability should be placed in the special education class (i.e. due to learning disability), even though the risk of learning disabilities for PWSMA is the same as the general population.”

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> Lack of adequate infrastructure

From the point of view of the infrastructure, public facilities like public toilets are not disabled-friendly. The whole list can go on and on whichever place you go. And of course, the working place – if he starts working, we of course would expect that environment to be disabled-friendly.”

– A father of a young man with SMA type 2

BARRIERS TO SOCIAL INCLUSION



> Lack of awareness about SMA

When they see us, they think we can do things by ourselves, they think that we are normal, but we really do not have much strength to do that – we need their assistance.”

– A woman in her 40s with SMA type

> Lack of adequate infrastructure

In Malaysia, a lot of places are still not accessible to wheelchairs – this is one of the concerns. Even if we want to bring her to as many places as we wish, because wheelchair accessibility is very poor in Malaysia, sometimes we won't bring her there. We can't, so we don't go because of the inconvenience.”

– A mother of a woman with SMA type 22

> Lack of compassion

A huge problem with the lifts ... if people are trying to get in the lift, even though they see there is a [person in a] wheelchair there, they don't wait for me [to go in]. So I just drag myself to the side, and I just let them all go in, and I will just wait for the next one ... The facilities are not maintained [and] the inconsideration of people parking in the disabled spot.”

– A woman in her 20s with SMA type 30



POLICY RECOMMENDATIONS

- > Ensure that the principle of inclusive education is fully implemented in all schools.
- > Enforce the Zero Reject Policy that guarantees every child in Malaysia access to education.

- > Train all teachers in disability awareness and the basics of special education needs.
- > Propose a law that prevents discrimination against persons with disabilities when it comes to

- employment.
- > Reintroduce the proposed amendments to protect job seekers against discrimination to the Employment Act 1955, which were withdrawn in 2019.

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