



SOCIAL CONNECTEDNESS
FELLOWSHIP PROGRAM

**Policy Brief:
Inclusion for Individuals with Profound/Multiple
Disabilities**

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ISSUE AND EVIDENCE

Individuals with intellectual disabilities (ID) are often not considered a priority for governments and communities, and the needs of those with profound/multiple disabilities (PMD) are even further pushed aside. This neglect may be because of negative attitudes towards their inability to be active and engaged citizens. As a result, government officials and the general public will not necessarily advocate for or support their rights. Special Olympics (SO) has been a strong advocate for providing sports training and competitions for those with ID since its founding in 1968.¹ The next challenge for this organization is to better include those with PMD in their programs through the expansion and enhancement of their Motor Activity Training Program (MATP). However, multiple barriers to the implementation of MATP continue to exist across the globe and reproduce differently in each region.

BARRIERS

A major barrier to the inclusion of those with PMD is the lack of incentive to provide funding and support inclusive policy.² Governments have overemphasized the economic benefits of service provision for people with PMD, rather than the needs of the relevant individuals.³ Another barrier to inclusion is the persistence of segregated special schools, or a lack of schooling altogether for those with PMD. There is also a lack of data and research available on this population, as well as a lack of distinction made between the levels of severity

1 "Eunice Kennedy Shriver," Special Olympics, <https://www.specialolympics.org/about/eunice-kennedy-shriver>.

2 United Nations, "Chapter V: Persons with disabilities: breaking down barriers," United Nations, last modified 2018, <https://www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2018/07/Chapter-VPersons-with-disabilities-breaking-down.pdf>.

3 Kenneth K. Poon, "Context, Service Provision, and Reflections on Future Directions of Support for Individuals With Intellectual Disability in Singapore," *Journal of Policy and Practice in Intellectual Disabilities* 12, no. 2 (2015): 106, <https://doi-org.proxy3.library.mcgill.ca/10.1111/jppi.12121>.

of ID. Some other barriers include a country's level of political development, poverty, socioeconomic class, immigration, race, culture, and opportunity. These are all factors that apply to the broader population, but when combined with other disability-focused barriers, they exacerbate the challenges faced by those with PMD and their families. Families may not have the financial resources to access quality care and assistive devices for their children due to poverty, immigrants may face discrimination from nationals who view them as competition for services,⁴ and cultural attitudes can contribute to negative views of individuals with PMD.⁵

STAKEHOLDERS

The population primarily affected by the issue are the individuals with PMD, as well as their families/caregivers. Governments have a vital role to play but have only occasionally taken into account their needs thus far. Government departments simultaneously are decision-makers as well as barriers to change. Typically, the relevant departments include education, social welfare, and/or health. The catalysts for change at this point in time include NGOs and non-profits like SO and its national chapters across the globe, disability organizations as well as families/caregivers and the general public.

PROGRAM RECOMMENDATIONS

Overcoming many of the barriers to the social inclusion of those with PMD requires both changes in attitudes and changes in law and policy. SO and non-governmental organizations (NGOs) can aid in catalyzing such changes. These recommendations may also be relevant for anyone or any organization that works with and/or provides services for those with PMD.

⁴ Anonymous Professor, telephone interview by the author, Montreal, QC, June 11, 2019.

⁵ Eleni Rossides, telephone interview by the author, Montreal, QC, July 11, 2019.

Consider changing the name of MATP to a term that is more concise, clear, and inclusive

SO is competitive and fun, and fosters the development of skills such as teamwork, sportsmanship and relationship building. However, the name MATP suggests it is a medical program or service, rather than a program that is recreational, supportive and encouraging.⁶ The name should be changed to one that can be easily recognized by the general public, and something that is more-or-less self-explanatory. MATP is not an ideal name for a program that is trying to foster inclusion.

Work towards designing Unified Schools/Sports Models for MATP

Unified Schools and Sports models should be developed specially for those with PMD. Increasing the exposure between individuals without PMD and those with PMD is essential, but should be done with young teenagers rather than young children. Inclusive middle schools and high schools would be better suited for individuals with PMD in particular, because families/caregivers may be more open to this model. Older children may be more responsible than younger children when interacting with those with PMD, who have additional health conditions and higher dependence on others. Classes would not be unified, but pupils could share the same building and property, which would give students the opportunity to interact with those with PMD during recreational periods. Moreover, the schools could hold unified gym classes.

⁶Anonymous Professional, telephone interview by the author, Montreal, QC, July 2, 2019.

Consider bringing MATP to existing residential institutions or to special schools to eliminate transport costs/issues

One of the most frequently cited barriers to inclusivity is transportation.⁷ SO could consider expanding MATP to schools and institutions to save on transport costs, time and money, as the athletes would not have to be transported to another place to attend training sessions. Moreover, SO could provide training to SO employees in regions to operate transport. For example, in countries such as India where many areas already lack services and transportation,⁸ it would be especially challenging to run a program like MATP. A first step would be to conduct surveys for the transportation needs in a given region to get an idea of where the eligible candidates are located.

Increase overall public awareness of those with PMD

More awareness raising needs to be done among the public on those with PMD. Inclusion can be fostered through exposure and sustained interaction. Bernhard Schmid of Lebenshilfe Vienna, an organization that provides services to those with disabilities explains that, "The first glimpse and the first contact with an individual with profound/multiple disabilities is never sufficient. Only when the interaction becomes more intense and deeper will you see the personality behind the disability, and you learn how to reach each individual."⁹ More opportunities for peer-coaching need to be advertised at community centers and in university settings. Awareness needs to be raised on those with PMD through social media, to

7 Rossides, telephone interview by the author.; Bernhard Schmid, e-mail interview by the author, Montreal/Vienna, QC/AT, July 19, 2019.; UN, "Chapter V Persons," United Nations.

8 "WORLD REPORT ON DISABILITY," last modified 2011: 11, https://www.who.int/disabilities/world_report/2011/report/en/.

9 Schmid, e-mail interview by the author.

reduce the potential discomfort or surprise people feel when encountering them for the first time. Trust needs to be built between those with PMD, their families, and others in order to build communities of inclusion. This is trust that others will not harm the individual, and trust that others will give the individual the respect they deserve.

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