SOCIAL CONNECTEDNESS
FELLOWSHIP PROGRAM

Building Social Connectedness for Individuals Living with Profound/Multiple Disabilities and their Families

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EXECUTIVE SUMMARY

The Motor Activity Training Program (MATP) is Special Olympics' (SO) adapted sports training program for individuals with profound/multiple disabilities (PMD). MATP faces numerous barriers as SO works to expand its reach around the world. The following barriers are not exclusive to each region, but can be common to all the regions. They reproduce differently depending on their interactions with other barriers. The barriers are organized in this way because some are more potent in certain regions.

In Latin America, Africa and Middle East/North Africa, the notable barriers include:

- a lack of resources and policy programming due to poverty and political development
- the existence of a hierarchy of needs in disability advocacy
- a lack of data and research
- tensions between the medical and social models of disability

In East Asia and the Asia Pacific:

- a lack of a regional tribunal for human rights
- the unreliability of studies
- a lack of parental consultation and informing
- a lack of accessible services

In North America and Europe/Eurasia:

- a lack of funding and resources
- a lack of training among professionals
- gaps in the transitions between services
- misconception of costs by governments and an inability to comprehend by outsiders
- the persistence of segregated schools
- class, immigration, race, and opportunity

Negative attitudes continue to be a barrier in all regions. Overcoming these barriers will help foster social connectedness of those with PMD.

RECOMMENDATIONS:

CHANGES TO MATP AND SO PROGRAMMING:

1- Consider changing the name of MATP to a name that is more concise, clear, inclusive and fun
2- Work towards designing Unified Schools/Sports models for MATP athletes/candidates
3- Consider looking into alternate ways to engage MATP athletes by making use of assistive devices and other technologies
4- Consider putting together a manual targeted at ageing SO athletes with dementia
5- Consider bringing MATP to existing residential institutions or to special schools to eliminate additional transport costs

POSSIBLE AVENUES FOR RESEARCH AND ADVOCACY:

1- Improve data collection and research by pursuing relationships with academics who research intellectual disabilities (ID) and PMD, and inform them of MATP
2- Increase overall public awareness of those with PMD
3- Frame MATP as a necessary program for skills development, physical health, social inclusion and well-being
4- Encourage community-based approaches which focus on bringing those with PMD out into the community to increase interactions with others

KEY ABBREVIATIONS

Special Olympics (SO)

Profound/Multiple Disability(ies) (PMD)

Motor Activity Training Program (MATP)

Convention on the Rights of Persons with Disabilities (CRPD)

Intellectual Disability(ies) (ID)

Middle East/North Africa (MENA)

Quality of Life (QoL)

INTRODUCTION

According to the World Health Organization (WHO), more than one billion people in the world live with some form of disability. Of that, almost 200 million people experience many difficulties on a daily basis.[1] Individuals with disabilities typically have poorer health, lower levels of education, higher rates of unemployment, and higher rates of poverty than those without.[2] The world is primarily designed for those without disabilities. However, with an aging population, an increased life expectancy of those with ID and more importantly of those with profound/multiple disabilities (PMD), politicians and lawmakers need to further explore how we can make the world not just accessible and accommodating, but welcoming too. Policies should foster an environment of inclusivity in which those with intellectual disabilities (ID) and their families/caregivers feel like they belong.

Fostering inclusivity on a global scale has been spearheaded by Special Olympics' (SO) adapted sports programming for individuals with ID. SO was founded in 1968 by Eunice Kennedy Shriver, whose sister Rosemary had an ID.[3] SO runs Unified Sports and Unified Schools programs, in addition to international Olympics competitions. The former involves individuals with and without disabilities competing in sports together, while the latter involves pupils attending inclusive schools. SO is currently working at improving the inclusion of those with PMD, through the expansion and enhancement of its Motor Activity Training Program (MATP). However, many legal and domestic barriers stand in SO's way. For example, article 1 of the

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[1] "WORLD REPORT ON DISABILITY," last modified 2011, https://www.who.int/disabilities/world_report/2011/report/en/. 5.

[2] "WORLD REPORT." 5.

[3] "Eunice Kennedy Shriver," Special Olympics, https://www.specialolympics.org/about/eunice-kennedy-shriver.

Convention on the Rights of Persons with Disabilities (CRPD) makes no mention of inclusion, but rather focuses on ensuring the enjoyment of human rights and promoting human dignity.[4] These two provisions are critical, but provide evidence that international lawmakers and national governments have yet to go beyond those two facets to advocate for a sense of belonging.

This report will look at the variety of barriers (legal, political, capacity, social, cultural, attitudinal, and financial) to the implementation of MATP, SO's adapted sports programming for individuals with PMD. Furthermore, this report will examine the availability and scarcity of services and disability policies, which may present challenges to fostering inclusion across the seven different regions in which SO operates. The seven regions include North America, Europe/Eurasia, Latin America, Middle East/North Africa, Africa, East Asia, and the Asia-Pacific. Recommendations will focus on how barriers can be overcome by SO and other actors in order to foster social connectedness and eliminate social isolation for individuals with PMD and their families/caregivers. Social connectedness refers to a society where everyone feels valued, has their basic human rights upheld and the chance to belong,[5] whereas social isolation refers to a state in which individuals lack access to people, places, power, and agency.[6]

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[4] United Nations, "Convention on the Rights of Persons with Disabilities (CRPD)," United Nations - Disability, 10. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.

[5] "About Us," Samuel Centre for Social Connectedness, https://www.socialconnectedness.org/about-us /.

[6] About Us," Samuel Centre for Social Connectedness.

METHODOLOGY

To complete this research, a landscape analysis was conducted by looking at the available academic literature on the population with PMD, along with a review of special reports compiled by international organizations such as the United Nations (UN) and the WHO. Next, a review of domestic policies and commitments to the CRPD was carried out. The second phase consisted of an outreach process where academics, non-governmental organizations (NGOs) and SO regional coordinators were contacted to gain insights on regional policies and challenges they have witnessed and affronted in promoting the inclusion of those with PMD. Ultimately, thirteen interviews took place in total. The last part of the report features a set of recommendations targeted at SO, NGOs and governments to overcome the barriers to social inclusion and social connectedness faced by those with PMD and their families/caregivers.

MATP AND DISABILITY

Created in the 1980s, MATP focuses on training seven different motor skills, which include mobility, dexterity, striking, kicking, manual and electric wheelchair, and swimming.[7] Determining who is eligible for MATP is not always black and white. Individuals may have conditions that limit physical disability such as cerebral palsy. They are also usually dependent on others for all aspects of daily living. The murkiness surrounding who qualifies as an MATP athlete is also observable in other areas of disability policy and advocacy. Generally, there is an absence of national policies for those with ID. If there are some policies in place, they make no distinction between those with physical disabilities and those with ID. Furthermore, the

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[7] "Motor Activity Training Program: Special Olympics Coaching Guide," Special Olympics, last modified 2005, http://digitalguides.specialolympics.org/matp/index.php?_ga=2.115241550.817659290.1564416622-2137436788.1559658800.

academic literature primarily focuses on those with mild-to-moderate ID and thus, those with PMD remain understudied as a population.[8]

An interesting finding reveals that it is not always clear whether researchers take into account the geographic location of those with ID, despite this factor being quite important. Those living in rural areas will typically be of lower socioeconomic background and have reduced access to services.[9] An analysis of 428 articles in the Journal of Intellectual and Developmental Disability since 2000 found that only 6 percent of the articles focused on rural participants.[10] The gaps in disability research for those with PMD need to be filled to better understand how we can better foster their inclusion.

MATP AND AGING SO ATHLETES

SO has also begun implementing MATP for aging SO athletes who have acquired dementia. The program, according to Eleni Rossides, MATP advisor for SO Europe/Eurasia, is primarily recreational, in which the athletes compete in sports such as bocce.[11] The increased promotion of MATP for elderly individuals is evident when looking at the evolution of their care. A 2005 cross-national study looked at group homes for aging individuals with ID in Japan, Australia, Canada, and the United States. The study found there was no increase in funding to take into account the residents' changing support needs.[12] MATP sports are more appropriate

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[8] Stuart Wark, "Does intellectual disability research consider the potential impact of geographic location?," Journal of Intellectual & Developmental Disability 43, no. 3 (2018): 362, https://doi.org/proxy3.library.mcgill.ca/10.3109/13668250.2017.1310826.

[9] Wark, "Does intellectual," 362.

[10] Ibid.

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

[12] Christine Bigby, "Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability," Journal of Intellectual and Developmental Disability 33, no. 1 (2008): 78, https://doi.org/10.1080/13668250701852433.

for aging SO athletes with dementia, who may also acquire physical mobility limitations and become more dependent on others for daily care and basic needs.

The mental health of ageing SO athletes is another dimension to be examined. A 2013 study found depressive and anxiety symptoms in 990 participants with PMD over the age of 50.[13] About a third of these participants were assessed with standardized psychiatric interviews.[14] Studies show that SO athletes experience many positive feelings when participating in SO, including a sense of achievement, improved self-concept, higher self-esteem, higher quality of life, and lower stress levels. [15] Given the positive outcomes of SO for younger and middle-aged athletes, it is viable to believe these feelings are felt by ageing athletes as well. Furthermore, ageing SO athletes face a transition in which they may outlive their families/caregivers. Providing them with adapted sports activities tailored to their needs would combat social isolation and monotonous routines.

ISSUES, EVIDENCE AND KEY FINDINGS: REGIONAL OVERVIEWS AND KEY COUNTRIES

The following section will highlight barriers in each of SO's regions. The regions are grouped together based on common barriers and the potency of the barriers' consequences. However, some barriers are present in all the regions. They manifest in different ways and have differing levels of severity and importance depending on the regions' contexts, history and

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[13] Heidi Hermans and Heleen Evenhuis, "Factors associated with depression and anxiety in older adults with intellectual disabilities: results of the healthy ageing and intellectual disabilities study," International Journal of Geriatric Psychiatry 28, no. 7 (2013): 691, https://doi-org.proxy3.library.mcgill.ca/10.1002/gps.3872.

[14] Hermans and Evenhuis, "Factors associated," 691.

[15] Suzanne Robinson et al., "Individual and Contextual Correlates of Frequently Involved Special Olympics Athletes," American Journal on Intellectual and Developmental Disabilities 123, no. 2 (March 2018):164, https://doi.org/10.1352/1944-7558-123.2.164.

characteristics. They will also interact with other barriers, exacerbating the effects and making overcoming social isolation more difficult.

GROUP A: LATIN AMERICA, AFRICA and MIDDLE EAST/NORTH AFRICA

Negative Attitudes and Different Priorities

Negative attitudes and discrimination continue to persist towards those with ID in these three regions. Studies conducted in six African countries (Botswana, Lesotho, Nepal, Mozambique, Eswatini, and South Africa) reveal that roughly 46 percent of persons with disabilities experience some form of negative discrimination.[16] It was not specified whether these people had ID or other forms of disability. However, in public and community spaces, adults with ID are continuously exposed to prejudice and threats of aggression such as physical abuse and degrading stereotypes.[17] Because of this discrimination, these individuals typically have limited social networks.[18] Their social relationships are primarily composed of their families/caregivers and other professionals who manage their health conditions.

In Latin America, Armando Gomez, the region's MATP advisor explains that the main barrier to the social inclusion of those with PMD in Latin America is social attitude, as their well-being is not considered a high priority for their governments. For example, Chile was one of the fastest-growing economies in the region[19] 10 years ago but only recently established MATP in

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[16] "Disability and Development," United Nations, last modified 2018, https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/07/disability-report-chapter2.pdf.

[17] Danae Van Asselt, Angus Buchanan, and Sunlia Peterson, "Enablers and barriers of social inclusion for young adults with intellectual disability: A multidimensional view," Journal of Intellectual & Developmental Disability 40, no. 1 (2015): 38. https://doi.org/proxy3.library.mcgill.ca/10.3109/13668250.2014.994170.

[18] Van Asselt, Buchanan, and Peterson, "Enablers and barriers," 38.

[19] Georgia C. Frey and Viviene Temple, "Health promotion for Latin Americans with intellectual disabilities," *Salud Pública de México*, 2008, 169. https://www.scielosp.org/article/spm/2008.v50suppl2/s167-s177/.

2019. The allocation of economic resources is based on government priorities and the provision of disability services was not seen as being highly important.

Lack of Resources and Policy Programming Due to Poverty and Political Development

The Latin American, African and Middle/East North African regions lack resources to promote disability policy and services. [20] In Africa, the overall summary rankings for the disability policies of the countries studied were as follows: Namibia–High, Malawi–Low, and Sudan–Low. The rehabilitation policy of South Africa ranked Low. According to Judith McKenzie, a professor at the University of Capetown, "There are free health service for these children but they are not very suited to their needs. Despite government efforts to offer better services, individuals with PMD are not yet included in the education system and often stay at home quite isolated or attend makeshift care centres where they receive care but limited development activities."[21]

Gomez outlines that in Latin America, the "main barriers are economic and human resources, since MATP requires more specific training and more personalized attention."[22] Overall, even if governments in these regions are willing and capable of providing some services, poverty is widespread. Poverty and disability reinforce one another; poor health and nutrition, poor living conditions, poor access to health services, environmental risks, and injuries pose additional challenges to those living with PMD. Individuals with PMD are more likely to be faced with these challenges along with a lack of proper resources, and are thus

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[20] Hasheem Mannan, Joanne McVeigh, and Mutamad Amin, "Core Concepts of Human Rights and Inclusion of Vulnerable Groups in the Disability and Rehabilitation Policies of Malawi, Namibia, Sudan, and South Africa," *Journal of Disability Policy Studies* 23, no. 2 (2012): 67, https://doi.org/proxy3.library.mcgill.ca/10.1177/1044207312439103.

[21] Judith McKenzie, e-mail interview by the author, Montreal/Cape Town, QC/WC, June 17, 2019.

[22] Gomez, e-mail interview by the author.

more likely to not have a high life expectancy. Furthermore, McKenzie explains, "Households with disabled people tend to be poorer than others and they might be struggling with issues of food and housing and not interested in these activities."[23]

Hierarchy of Needs in Disability Advocacy

Many priorities take precedence in these regions concerning political, economic and social development. For disability advocacy, there also exists a hierarchy of needs. Advocates will push for a number of necessities ahead of the recreational and physical education needs of those with PMD. First, there is a lack of schooling available for this population and segregated schools continue to persist. In Latin America in 2008, those with PMD were often denied school admission and students with various conditions were restricted to elementary education.[24] Unfortunately, this is still the case in 2019, as revealed by Gomez:

> In some countries, people with ID are excluded by the insurers or have challenges with the Health or Education departments. Many schools are not architecturally prepared to receive people with severe motor disabilities. Participants who have the profile to participate in MATP are excluded from the education system and require personalized therapy.[25]

Second, those with mild ID who are employable will take precedence, as others will view them as capable of being contributors to society while those with PMD are unemployable. Third, access to quality healthcare is an important resource for those with disabilities. Individuals with PMD have complex healthcare needs, such as epilepsy, which requires special attention.[26]

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[23] McKenzie, e-mail interview by the author.

[24] Frey and Temple, "Health promotion," 169

[25] Gomez, e-mail interview by the author.

[26] Paula Jacobs, Kenneth MacMahon, and Ethel Quayle, "Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis," Journal of Applied Research in Intellectual Disability 31, no. 6 (November 2018): 977. https://doi.org/10.1111/jar.12466.

Lack of Data and Research

Overall, there is a lack of data and evidence on this segment of the population in these regions. A barrier to this is the fact that getting information directly from those with PMD is extremely difficult, as many are non-verbal or unable to communicate effectively. As a result, quality of life (QoL) researchers have often avoided researching those with PMD and have zeroed in on the experiences of individuals with mild and moderate ID.[27] In the Latin American region, there is data on the prevalence of ID, but it is inconsistent and unreliable. On the Pan American Health Organization (PAHO) website, Georgia Frey, a professor in the Public Health Department at Indiana University Bloomington critiqued the International Disability Rights Monitor (IDRM) report on the status of disability rights in the Americas. Only Chile, Paraguay, and Mexico provided estimates on the number of people with ID, and this data was deemed unreliable.[28] Moreover, Frey's study reveals that Brazil, Costa Rica, and Jamaica were the only countries in the region that had achieved Most Inclusive Nation status. Belize, Bolivia, El Salvador, Guatemala, Guyana, Honduras, Nicaragua, and Paraguay were classified as Least Inclusive, which means they lacked the basic elements of social inclusion for people with disabilities.[29]

Medical and Social Models of Disability

The medical and social models present challenges for advocates because they influence how people conceptualize the rights of those with PMD. In the Middle East/North Africa region,

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[27] Katja Petry and Bea Maes, "Quality of Life: People with Profound Intellectual and Multiple Disabilities," in Profound Intellectual and Multiple Disabilities : Nursing Complex Needs (John Wiley & Sons, Incorporated, 2008), 15, digital file.

[28] Frey and Temple, "Health promotion," 168.

[29] Frey and Temple, "Health promotion," 169.

the WHO reports that the medical model of disability dominates over the social model, which promotes a rights-based approach.[30] Despite this, the majority of MENA countries have included articles on disability in their constitutions. The period from 2003 to 2012 is known as the Arab Decade of Disabled Persons, which began with the Economic and Social Commission for Western Asia's (ESWA) conference on "Disability and Conditions in the Arab World: Towards an Arab Decade of Disability."[31] During the Arab Decade, most country governments in the region devised new laws, strategies and policies that reflected the changing understanding of disability and sought to bring national frameworks in line with the provisions of the CRPD. In fact, half of the MENA countries reported that they had or were developing a national strategy or plan on disability.[32]

COUNTRY HIGHLIGHTS: GROUP A

BRAZIL

Table 1: Brazilian Disability Policies and Services[33]

Benefits/System	**Description**
Benefício de Prestação Continuada de Assistência Social	Minimum wage benefit for 2.3 million persons with disabilities (no distinction made between those with physical disabilities versus ID)
Previdência Social	Disability pension for partial and full disability and sickness (seems to be for those with milder ID or physical disabilities)

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[30] "Disability Rights in the Middle East & North Africa," last modified December 2014, PDF. 2.
[31] "Arab Decade of Disabled Persons, 2003 –2012," United Nations, last modified 2004, https://www.un.org/esa/socdev/enable/disarabdecade.htm.
[32] "Disability Rights." 4.
[33] UN, "Chapter V Persons," United Nations. 64.

Transport Costs	Reimbursed, but not clear if this includes those with PMD

Brazil has ratified the CRPD and its Optional Protocol. They have also enacted many domestic laws to protect the rights of those with disabilities, but lack specific policies for those with ID.[34] Some of these laws include:

- Decree 3298/99 (National Policy for the Integration of Persons with Disabilities, Consolidates protection Standards, and Other Measures)
- Law 7853/1989 (Provides support for people with disabilities and their social integration through the National Coordination for the Integration of Persons with Disabilities)
- Law 8213/91 (Social Security Benefits and Other Provisions)
- Law 10048/2000 (Legal Proceedings for persons with disabilities)
- Law 10436/2002 (Brazilian Sign Language)
- Law 10216/2001 (Provides for the protection and rights of people with mental disorders and redirects the Mental Health Care Model)
- Decree 4360/2002 (Benefits for the elderly and individuals with disabilities)
- Decree 7037/2009 (National Human Rights)
- The Act on National Education Guidelines and Bases

SOUTH AFRICA

According to Judith McKenzie, the population with PMD is highly neglected in South Africa. Prof. McKenzie explains, “There is a specific government project that is trying to address the fact that these children are out of schools and not receiving any education at all. The aim of this project is to provide support for caregivers to provide daily learning programmes for these children in special care centres and moving ultimately into the formal education system as they are not included in that much at this stage.”[35] Moreover, medical officers hired by the South African Social Security Agency often have no specialized training to conduct disability assessments.[36]

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[34] International Laws," Disability Rights Education and Defense Fund, last modified 2019, https://dredf.org/legal-advocacy/international-disability-rights/international-laws/.

[35] McKenzie, e-mail interview by the author.

[36] UN, "Chapter V Persons with disabilities: breaking down barriers," United Nations, https://www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2018/07/Chapter-VPersons-with-disabilities-breaking-down.pdf. 72.

South African Barriers[37]

- Transport
- Finance
- Lack of parental involvement
- Poverty
- Services that are not adapted to their needs
- Exclusion from the educational system
- Low levels of public awareness
- Patchy data collection

McKenzie's Recommendations to the Government[38]**:**

- "To work with the therapeutic teams that have been set up in the provinces through the provincial departments of education. They visit care centres on a regular if infrequent basis and would be able to develop strategies that could work."
- "Parent support groups would also address some of these challenges and reduce the isolation that some mothers experience."

South Africa has ratified both the CRPD and its Optional Protocol, and have some domestic laws in place for persons with disabilities (see below). However, a closer examination of the academic literature and an interview with Prof. McKenzie reveals that those with PMD have yet to benefit from these laws.[39]

- Ratified CRPD
- Ratified CRPD Optional Protocol
- Constitution – Bill of Rights (1996)
- Employment Equity Bill (B60–98)
- Blind Persons Act, 1968
- Disability Grants Act, 1968
- Employment Equity Act 1998
- Second Pension Laws Amendment Act, 1970
- Special Pensions Act
- Special Pensions Amendment Act, 1998
- Welfare Laws Amendment Act, 1997
- Workmen's Compensation Act, 1941

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[37] McKenzie, e-mail interview by the author.

[38] McKenzie, e-mail interview by the author.

[39] "International Laws," Disability Rights Education and Defense Fund.

SAUDI ARABIA

There is a lack of academic literature on the MENA region, though a significant study was conducted that revealed the attitudes of Saudi students towards those with disabilities. Overall, the outcome of the study suggests that individuals exposed to those with ID had more positive attitudes than other students who had not interacted with people with ID. Furthermore, older students were more likely to hold positive attitudes than younger students, though the study did not give a reason for this result. An interesting finding is that having a relative with a disability had no effect on attitudes towards inclusive schooling.[40] However, this study reveals that normalized interaction between those with ID and those without instills positive attitudes among students, rather than negative ones. These results point to a future that is more accessible, accommodating and welcoming for those with ID and PMD.

Saudi Arabia has ratified the CRPD and its Optional Protocol. However, only one article of their constitution mentions persons with disabilities[41]:

- Constitution, Article 27

GROUP B: EAST ASIA AND ASIA PACIFIC

Lack of Regional/International Enforcement for Human Rights

Disability rights advocacy is especially difficult in East Asia and the Asia Pacific due to the absence of a regional court or commission.[42] In 2012, the Asia Pacific region had the lowest levels of signature and ratification of the CRPD in the world, with 36 signatories and 27 states

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[40] Ghaleb Hamad Alnahdi, "The positive impact of including students with intellectual disabilities in schools: Children's attitudes towards peers with disabilities in Saudi Arabia," *Research in Developmental Disabilities* 85 (February 2019): 1. https://doi.org/10.1016/j.ridd.2018.10.004.

[41] "International Laws," Disability Rights Education and Defense Fund.

[42] Michael L. Perlin, "Human Rights Law for Persons With Disabilities inAsia and the Pacific: The Need for a DisabilityRights Tribunal," *Journal of Policy and Practice in Intellectual Disabilities* 10, no. 2 (June 2013): 96. https://doi.org/proxy3.library.mcgill.ca/10.1111/jppi.12032.

parties that accounted respectively for 72 percent and 54 percent of eligible states.[43] The reasoning for these regions' lack of international commitment to disability rights is clear by looking at how their governments understand the costs associated with disability services. For example, the Singaporean government has focused on "the economic merits of the [service] provision rather than a response to the needs of individuals with disabilities and their families."[44] The government sees services as a way to make a profit, rather than for addressing the needs of those receiving the services. The Singaporean government needs to find a balance between economic motives and social impact. The case of Singapore is further highlighted on page 22.

Unreliability of Studies

Domestic studies in East Asia are prone to response bias because cultural factors may prevent respondents from truly disclosing their needs. Families may perceive need for help differently due to strong cultural values related to family pride, and the desire to not lose face. In result, there is a tendency for East Asians to give moderate responses on rating scales.[45] Gathering data and research on the population with PMD in these regions thus presents a challenge for academics, due to potential inaccuracy in responses from their families/caregivers.

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[43] "Disability News for Asia and Pacific Regions," Disabled World, last modified December 23, 2017, https://www.disabled-world.com/news/asia/.

[44] 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.

[45] Seok Han Tan, "Assessing the needs of caregivers of children with disabilities in Penang, Malaysia," *Health and Social Care in the Community* 25, no. 2 (March 2017): 456. https://doi.org/10.1111/hsc.12325.

Lack of Parental Consultation and Informing

In East Asia and the Asia Pacific regions, there is also an overall lack of consultation with and involvement of the parents in the process of promoting the inclusion of their child. The development of services for children with disabilities and their families/caregivers is largely in the hands of professionals or therapists working in government agencies and NGOs. This has often resulted in services that meet the needs of the professional, therapist or organization rather than those of the child or family.[46] The emphasis on providing services with the professionals in mind reflects a medical model approach to care rather than a social model. The medical model may be essential for service provision, but incorporating the social model would ensure a more inclusionary and sensitive method.

Moreover, parents and those with disabilities are generally unaware of the existing policies and programs. A study conducted in rural India in late 2005 revealed that 94 percent of households with persons with disabilities had not heard of the Persons with Disabilities Act and its entitlements, and that 60 percent of persons with disabilities in rural areas had not heard of the country's disability pension.[47] Disability benefits play an important role in the lives of people with PMD and their families/caregivers. However, only 28 percent of persons with severe disabilities receive disability benefits globally and the reach of such benefits varies across regions. For example, benefits reach more than 90 percent of persons with severe

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[46] Amar-Singh HSS, "Meeting the Needs of Children with Disability in Malaysia," *Med J Malaysia* 63, no. 1 (March 2008): 2. https://www.researchgate.net/profile/Amar-Singh_Hss/publication/23399309_Meeting_the_needs_of_children_with_disability_in_Malaysia_Editorial/links/56b1338c08aed7ba3feb0e76.pdf.

[47] UN, "Chapter V Persons," United Nations. 72.

disabilities in developed regions but only between 10 and 11 percent in East Asia and the Asia Pacific.[48]

Lack of Services

There is a shortage of services particularly in Africa and the Asia Pacific. For example, in 2011, only 17 to 37 percent of people with ID who needed assistive technology received the devices they needed, while only 5 to 24 percent who were eligible for welfare support received the funds.[49] Research in the Uttar Pradesh and Tamil Nadu states in India found that a lack of services was the second most frequently cited reason for people with disabilities not being able to access adequate health facilities.[50]

COUNTRY HIGHLIGHTS: GROUP B

TAIWAN

Primarily, academic studies in Taiwan have focused on caregivers, rather than on the individual with PMD, or on the family unit as a whole. One study reveals that if caregivers of adults with PMD are employed, have a higher level of education, and have a higher family income, they are more likely to have a higher QoL.[51] Moreover, having a higher level of education means the caregiver is more likely to have a higher level of social support and better access to social services information.[52] In the same study, it was found that most respite users are parents who have joined parental organizations and are from a middle-class background.[53] However, the majority of respite care users do not access other

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[48] UN, "Chapter V Persons," United Nations. 72.
[49] "WORLD REPORT." 7-10.
[50] "WORLD REPORT." 9.
[51] Yueh-Ching Chou, Chi Chiao, and Li-Yeh Fu, "Health status, social support, and quality of life among family carers of adults with profound intellectual and multiple disabilities (PIMD) in Taiwan," *Journal of Intellectual and Developmental Disability* 36, no. 1 (2010): 76-77, https://doi.org/10.3109/13668250.2010.529803.
[52] Chou, Chiao, and Fu, "Health status," 77.
[53] Ibid.

welfare services,[54] those who do have some notable characteristics. Respite care users who access additional welfare services typically have a religious belief and live in a metropolitan city, suggesting they have better access to knowledge and social networks.[55] Overall, the key reason for the low utilization rate of welfare services in general was the fact that families had not heard about these services.[56]

Taiwan has two domestic policies related to disabilities, but like other countries, no distinction is made between those with ID or PMD[57]:

- 身心障礙者權益保障法 (Law on the Protection of the Rights and Interests of the Disabled)
- People with Disabilities Rights Protection Act 1980

MALAYSIA

The focus for academic research in Malaysia has been on the training of professionals who serve people with PMD. Similar to the barrier faced in Group A, there is a need for Malays to distance themselves from the politics of disability.[58] It is argued that there needs to be improved individualized attention in terms of meeting the needs of the families/caregivers and the individuals with PMD.[59]

Malaysia ratified the CRPD in 2010. However, the ratification was made with reservations to Article 15 (prohibition of torture and ill treatment) and Article 18 (the right to liberty of movement and nationality), in which the government does not consider itself bound.[60] A number of European countries have objected and continue to object to this reservation. They include Austria, Belgium,

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[54] Chou et al., "Respite care," 18.
[55] Chou et al., "Respite care," 19.
[56] Ibid.
[57] "International Laws," Disability Rights Education and Defense Fund.
[58] HSS, "Meeting the Needs," 3.
[59] HSS, "Meeting the Needs," 3.
[60] UN, "15. Convention on the Rights of Persons with Disabilities," United Nations Treaty Collection, https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en.

Germany, Sweden, Switzerland, and Portugal.[61] Malaysia has only one piece of domestic law that addresses those with disabilities:

- Persons with Disabilities Act (2008)

SINGAPORE

According to Kenneth Poon, a professor at the National Institute of Education in Singapore, supports remain limited in Singapore and there is a disparity between the goals outlined in the World Report on Disability and the available options for most individuals and their families.[62] Social services are run by NGOs known as voluntary welfare organizations (VWOs), as there is a belief in Singapore that social services are to be jointly funded and supported by public and private interaction. It is only in recent times that policy and legal frameworks have begun to hold more importance.[63]

Recommendations from Kenneth Poon[64]:

- There needs to be a "re-examination of the diffused responsibility for disability services within the government."
- There is a need to "evaluate the way services are being delivered."

Singapore has ratified the CRPD, with two pertinent reservations to[65]:

- articles 12(4), in which they reserve the right to apply their own legislative framework for review of the CRPD
- article 25(e), in which they assert the provision of national health insurance over private insurance for those with disabilities

Singapore also only has one legal framework relevant for people with disabilities:

- 1990 Barrier Free Accessibility Code

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[61] UN, "15. Convention," United Nations Treaty Collection.
[62] Poon, "Context, Service," 100.
[63] Poon, "Context, Service," 101.
[64] Poon, "Context, Service," 100.
[65] UN, "15. Convention," United Nations Treaty Collection.

INDIA

In India, there is very little federal support for those with disabilities.[66] However, individuals with physical, visual, and hearing impairments have more rights than those with PMD. Furthermore, Aesha John of Texas Christian University explains people typically share their homes with extended family, but due to discrimination and negative attitudes towards those with disabilities, families will often shift to living in nuclear-sized homes. [67] John recommends more research needs to be done on families as a whole.[68]

India is a State Party to the CRPD and has two relevant legal documents pertaining to those with disabilities[69]:

- Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act,1995 (no. 1 of 1996)
- The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999

GROUP C: NORTH AMERICA and EUROPE/EURASIA

Lack of Funding and Resources

Generally, in these regions, there is a lack of funding available for those with PMD. Caitlin Beavis-Hardy a lecturer in the Department of Occupational Therapy at St-George's, University of London explains the costs of caring for those with disabilities: "They just require so much funding per person to facilitate the kind of assistance and resources they need. Obviously, it makes a huge difference for that person and for that family, but if you are thinking

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[66] Aesha John, videoconference interview by the author, Montreal/Fort Worth, QC/TX, June 13, 2019.

[67] John, videoconference interview by the author.

[68] Ibid.

[69] "International Laws," Disability Rights Education and Defense Fund.

about population sense, it doesn't go very far. [...] It's really hard to reach everybody."[70] Furthermore, policy- and decision-makers are unaware of assistive technology and the possibilities they bring or do not care to know.[71]

Another vital resource that is often lacking is transportation. In fact, academics, service providers and SO employees cited transportation most frequently as a barrier to being able to participate in social activities for those with disabilities.[72] Furthermore, there are challenges within existing transportation services and policies. For example, in Austria, if an individual *only* has an ID, but no mobility impairment, then the person is not eligible for a discount.[73]

Negative Attitudes

Aside from discrimination and degrading and negative attitudes, families/caregivers of those with PMD do not always believe their family members are capable of participating in MATP.[74] Moreover, sensitivity, precaution and distrust in others for the care of their children are continuous feelings evoked by caregivers of those with PMD. Getting access to families/caregivers for interviews for this report was especially difficult as intermediary organizations were cautious about confidentiality.

There is an overall persistence of a culture of disability because of the prevalence of the medical model. According to the Commissioner for Human Rights, children with disabilities are continuously denied their educational rights because schools are not equipped to meet their

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[70] Caitlin Beavis-Harvey, videoconference interview by the author, Montreal/London, QC/UK, June 12, 2019.

[71] UN Disability and Development 241-242

[72] 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.

[73] Bernhard Schmid, e-mail interview by the author, Montreal/Vienna, QC/AT, July 19, 2019.

[74] Professor, telephone interview by the author, Montreal, QC, June 11, 2019.

needs.[75] Moreover, a number of Council of Europe member states such as Slovenia hesitate to close down residential institutions.[76] In addition, some European countries refuse to develop community-based services for persons with disabilities as they argue that institutional care is necessary for persons with PMD.[77] In Bulgaria, for example, caregivers believe those with PMD are to be treated like "babies who should be protected from any harm." [78] Moreover, people may feel those with PMD do not need nor want exercise.[79]

Furthermore, many students and health professionals have negative perceptions towards working with persons with ID in general. In some cases, "While professionals were willing to treat people with an ID, they were not willing to spend more time or to complete additional training necessary to effectively treat persons with ID."[80] Moreover, Rossides provides insight on coach training for MATP:

> We get physiotherapists from different types of school backgrounds that have different approaches. […] We try very hard to standardize the approaches for MATP. […] And a few months later, although they sign up to do it, you find out that they don't want to do it anymore and the reason for it is because it's challenging. Challenging in terms that they will not show result unless you really work hard with them maybe for one or two years. On average, 25 to 30 coaches are trained, […] and maybe five of them who stay within this program will carry on with the program in the country.[81]

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[75] "Human Rights of Persons with disabilities," Council of Europe, https://www.coe.int/en/web/commissioner/thematic-work/persons-with-disabilities.
[76] "Disability Watchdog: Slovenia Builds New Institutions," European Network on Independent Living, https://enil.eu/news/disability-watchdog-slovenia-builds-new-institutions/.
[77] "Human Rights," Council of Europe.
[78] Slavka Kukova, e-mail interview by the author, Montreal, QC, July 4, 2019.
[79] Schmid, e-mail interview by the author.
[80] Luis Salvador-Carulla et al., "Training on intellectual disability in health sciences: the European perspective," *International Journal of Developmental Disabilities* 61, no. 1 (2015): 21. https://doi.org/proxy3.library.mcgill.ca/10.1179/2047387713Y.0000000027.
[81] Rossides, telephone interview by the author.

Lack of Training

In tandem with an unwillingness to engage in the necessary training to work with individuals with ID, service providers' skills are insufficient. In 51 countries, people with disabilities were more than twice as likely than individuals without disabilities to report health care provider skills as being inadequate.[82] They were also four times more likely to be treated badly and nearly three times more likely to be denied health care. Many personal support workers are also poorly paid and have inadequate training. For example, a study in the United States found that 80 percent of social care workers had no formal qualifications or proper training.[83]

Transitions between Services

A lack of coordination between various services also presents a barrier. Beavis-Hardy explains the gap of services during the transition phases of an individual's life: "It's not just the transition from children to adults, but also the transition from adult to senior and [...] how to keep things consistent, how do we make sure the standard of care remains high?" [84] Typically, youth are eligible for special education schools until the age of 21 in most places. However, after this age, funding for school attendance ends, forcing families to change their routines. Another transition consists of the transfer from paediatric health and rehabilitation services to adult services.[85] Service provision spans "the whole life course of young people and their families from the time of birth and diagnosis to the far future when parents might cease to be

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[82] "WORLD REPORT." 9.
[83] "WORLD REPORT." 9.
[84] Beavis-Harvey, videoconference interview by the author.
[85] Camille Gauthier-Boudreault, Melanie Couture, and Frances Gallagher, "How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability," Journal of Applied Research in Intellectual Disabilities 31, no. S2 (March 2018): 215, https://doi.org/10.1111/jar.12394.

able to care for their adult children."[86] Even further, little information is available in accessible formats, and many communication needs of people with disabilities are unmet.[87]

<u>Misconception of Costs/Inability to Comprehend</u>

The lack of funding for disability services and programs is a major barrier; however, the over-emphasis on money is also a barrier. According to a parent who was interviewed, "The big cost is not the funding, but time in the family's life and time in the child's life."[88] Moreover, the same parent said, "Social isolation is really very, a very real thing. On the other hand, social enrichment is also very real. And when you know other people who experience disability and various kinds of disability, it's very much enriching and helps you build a very strong social life."[89] This demonstrates the importance of not just unification between those with ID and neurotypical people but also with others in the disability community. Moreover, social isolation is stronger when an individual is non-verbal and even more so when an individual has PMD. The parent continued, "Those are the people who are most likely to be living at home with their parents forever. And that's not a good platform for social inclusion and being part of the community."[90]

<u>Segregated Schools</u>

Another barrier to the inclusion of those with PMD is the persistence of segregated school systems. Research reveals the following practices and beliefs: children with PMD are often relegated to a separate place in society, they are considered by the majority to be

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[86] Jacobs, MacMahon, and Quayle, "Transition from," 670.

[87] "WORLD REPORT." 23.

[88] Anonymous telephone interview by the author, Montreal, QC, July 2, 2019.

[89] Ibid.

[90] Ibid.

inferior, their segregation is rationalized as being “good for them,” and they are evaluated based on having an ID rather than their individual characteristics.[91] Through Unified Champion Schools, the segregation of people with disabilities has been steadily decreasing across the United States. However, segregated school systems remain across the globe, and children with PMD are sometimes rejected from attending school altogether. Bernhard Schmid of Lebenshilfe Vienna, a non-profit organization that provides services for those with ID, explains that inclusive schools in Vienna in particular are open to “a wide range of pupils with disability, including ID, but not for pupils with profound disability.”[92] According to Schmid, “There is no law that forbids them from participation, but the whole system is not ready for them, and nobody even tries to be ready for them.”[93] Moreover, parents are usually happy that they have this choice and fight to preserve special schools[94], which inadvertently perpetuates segregation and social isolation.

Class, Immigration, Race, and Opportunity

Other barriers include class issues, immigration, race, and opportunity. This is particularly relevant in countries that have large immigrant populations, such as the United States and Canada. Some families have more resources and are thus able to afford activities, daily events and trips.[95] Furthermore, they may live in close-knit communities with better access to services. For example, those living in the suburbs in Chicago tend to be of middle-class background families, where parents can devote more time and resources to providing high

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[91] Milton Seligman and Rosalyn Benjamin Darling, "All Families Are Not Alike: Social and Cultural Diversity," in *Ordinary Families, Special Children, Third Edition: A Systems Approach to Childhood Disability* (New York, NY: The Guilford Press, 2009), 39, digital file.

[92] Schmid, e-mail interview by the author.

[93] Ibid.

[94] Ibid.

[95] Anonymous Professor, telephone interview by the author.

quality of life to their children, whereas the inner city kids' families cannot provide the same level of care.[96] A professor who wishes to remain anonymous describes their experience growing up in Colombia: "People with money get all kinds of stuff. People without, they get nothing. There's another dimension for Latino immigrant families that I work with. They don't know about resources or opportunities. Also, some people see them as competition."[97]

Moreover, low education levels affect the ability of parents to access and maximize health services for their children. For example, El Salvadoran immigrants to the United States lack the necessary finances for transportation and gathering more knowledge. Furthermore, American Hispanics without high school educations are more prone to folk beliefs related to causes and cures for disabilities, which may prevent them from accessing quality health services.[98] These studies on the El Salvadoran immigrants and American Hispanics did not make a distinction between families of those with PMD versus milder forms of ID, but it is conceivable that such challenges are exacerbated for these families with members who have PMD.

COUNTRY HIGHLIGHTS: Group C

CANADA

Canada, along with the United States, is considered a global leader in disability policy. This past June, Canada passed Bill C-81, or the Accessible Canada Act, where the government is committing to further working with disability communities across the country to provide environments that are more accessible. However, the Canadian government is not unlike other constituents as those with PMD are left out. MATP is not widespread nor firmly established in the SO provincial and territorial chapters in Canada. Instead, SOC makes use of the Active Start and FUNdamental programs targeted

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[96] Ibid.
[97] Anonymous Professor, telephone interview by the author.
[98] Frey and Temple, "Health promotion," 174.

at young children with ID. Furthermore, they also feature a functional testing program, which measures “fitness and foundational movements.”[99] There lacks any organized adapted sports programming for those with PMD.

Canada has ratified the CRPD with a couple of reservations to procedural mechanisms.[100] Canada has the following legal frameworks related to disability policy[101]:

- Constitution – Charter of Rights & Freedoms (1982)
- Human Rights Act (1977)
- Employment Equity Act (1995)

UNITED KINGDOM (Great Britain)

The United Kingdom (UK) recently released a policy framework for healthcare and social services, known as the NICE Guidelines. According to Beavis-Hardy, “It’s the new overarching policy that sort of governs all aspects of health and social care over here in the UK.[...] The government invested a lot of money into it, to try and make sure it covered all aspects of health and social care. But as the policy is coming into implementation, a lot of academics and clinicians and all the different kind of people it applies to are starting to notice the gaps in the policy. There are some kids who have gotten used to a certain level of care but there is no system set up to help with the adult transition.”[102]

The United Kingdom has ratified the CRPD and its Optional Protocol. The government placed three reservations on the CRPD, only one being relevant for those with PMD[103]:

- Education: “Reserves the right for disabled children to be educated outside their local community where more appropriate education provision is available elsewhere”

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[99] "Functional Testing," Special Olympics British Columbia, https://www.specialolympics.ca/british-columbia/functional-testing.

[100] UN, "15. Convention," United Nations Treaty Collection.

[101] "International Laws," Disability Rights Education and Defense Fund.

[102] Beavis-Harvey, videoconference interview by the author.

[103] UN, "15. Convention," United Nations Treaty Collection.

Domestics Law and Policy[104]:

- Disability Rights Act 1999
- Northern Ireland, Disability Discrimination Regulations 1996
- Disability Discrimination Act 1995
- Disability Discrimination Act 2005
- Special Educational Needs and Disability Act 2001

SCOTLAND

Table 2: Relevant Scottish Policy and Programs

Principles of Good Transitions[105]	This framework looks at the continual improvement of support for young people with additional needs between the ages of 14 and 25 who are in transition phases, especially from child to adult life.
Getting it Right for Every Child	This program looks to support families by "making sure all children and young people can receive the right help, at the right time, from the right people."[106]

PhD candidate Paul Jacobs of the University of Edinburgh explains that a significant barrier to the inclusion of those with PMD in Scotland "are the politics of austerity," in which "funding has gone down in recent years."[107]

Barriers to Social Inclusion in Scotland According to Paula Jacobs

- Move towards individualized support and thereby increasing isolation
- Closure of day centres
- Funding provided is short-term
- Small number of people with PMD within the country, and they live far from one another

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[104] "International Laws," Disability Rights Education and Defense Fund.

[105] "DOWNLOAD 'PRINCIPLES OF GOOD TRANSITIONS 3,'" Scottish Transitions Forum, https://scottishtransitions.org.uk/summary-download/.

[106] "Getting it right for every child (GIRFEC)," Scottish Government, https://www.gov.scot/policies/girfec/.

[107] Paula Jacobs, videoconference interview by the author, Montreal, QC/Edinburgh, Scotland, June 25, 2019.

Table 3: Countries That Have Not Ratified CRPD

Bhutan	Cameroon
Lebanon	Solomon Islands
Somalia	St. Lucia
Tajikistan	Tonga
United States	Uzbekistan

RECOMMENDATIONS

Overcoming many of the barriers to the social inclusion of those with PMD requires new laws and policies, and changes to old ones. However, changes in attitudes within general society need to occur as well. The following recommendations are targeted at SO and NGOs, as they are best positioned to aid in catalyzing such changes.

#1 - Consider changing the name of MATP to a name that is more concise, clear, inclusive and fun

Special Olympics 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 something that is recreational, supportive and encouraging.[108] The name should be changed to one that can be easily recognized by the public. The new name should also be more-or-less self-explanatory. MATP is not an ideal name for a program that seeks to foster inclusion.

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[108] Anonymous Professional, telephone interview by the author.

#2- 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 with and without PMD is essential, but should be achieved with younger teenagers rather than young children. Inclusive middle schools and high schools would be better suited to engage with individuals with PMD 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 they could share the same building and property, which would give students the opportunity to spend time with those with PMD during recreational periods. Moreover, the schools could hold unified gym classes. This recommendation can be applied in regions such as North America and Europe/Eurasia at first.

#3 - Consider looking into alternate ways to engage MATP athletes by making use of assistive devices and other technologies

Making use of individuals' current assistive devices in MATP programming would also be a useful way to train athletes. Rather than placing a sole emphasis on the person's physical and motor capabilities, there are ways to engage the person in a creative manner that makes use of their assistive devices. For example, an occupational therapist at Peter Hall Ouimet in Montreal, Quebec designed an adapted target shooting activity using a switch and hair-dryer. The participant presses the switch, activating the hair-dryer which propels the ball onto a target. The participant has control over how far the ball goes, depending on the length of time the switch is held down for, and how much pressure is applied. This adapted activity was tested successfully with individuals with PMD by the author of this report and thus can be applied in regions where the use of assistive devices is already widespread, such as North America and Europe/Eurasia.

#4 - Consider putting together a manual targeted for aging SO athletes with dementia

A special manual designed for aging SO athletes would be helpful in terms of determining a clearer vision for their programming. As many MATP athletes are wheelchair users and aging SO athletes with dementia are not, the programming should be adapted to suit their needs and capabilities. As previously mentioned by Rossides, the current MATP program for aging SO athletes is mainly recreational sports-based rather than intensive motor training. More research needs to be conducted on aging SO athletes to convince governments of the physical and inclusionary benefits of programs like MATP. This recommendation can be applied in North America and Europe/Eurasia first.

#5 - 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.[109] SO should consider expanding MATP to schools and institutions, to save on transport costs and time and money, as the athletes would not have to be transported to another place to attend training sessions. This recommendation is relevant for all regions. Moreover, SO could provide training to SO employees in regions to operate transport. In particular, in countries such as India where many areas already lack services and transportation[110], it would be especially challenging to run

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[109] 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.

[110] "WORLD REPORT." 11.

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.

#6 – Improve data collection and research by pursuing relationships with academics who research ID and informing them of MATP

Numerous academics interviewed for this report were very interested in MATP, and in the population with PMD in particular. Considering partnerships with them in the future would be beneficial for this community and SO overall. Informing academics of MATP would also help facilitate advocacy and awareness raising in any region. Future fellows paired with SO should also include the population with PMD in their research, regardless of their focus.

#7 - Increase overall public awareness of those with PMD and begin fundraising initiatives

More awareness raising needs to be done among the public on those with PMD. Inclusion can only be fostered through exposure and sustained interaction. Bernhard Schmid of Lebenshilfe Vienna explains, “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.”[111] More opportunities for peer-coaching needs to be advertised at community centers and in university settings. Awareness needs to be raised on those with PMD through social media, to 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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[111] Schmid, e-mail interview by the author.

#8 – Frame MATP as a means of skill development, physical health and social inclusion and well-being

Many academics interviewed for this report were curious about whether the athletes truly benefitted from MATP. The important thing to emphasize to academics and professionals is that sustained, consistent training needs to be completed in order to see any real benefits.[112] In addition to skill development and physical health, MATP's goal is to foster social inclusion and well-being, which enables athletes to collaborate with people without disabilities and instill pride in themselves and their families/caregivers.

#9 – Encourage participatory community approaches, which focus on bringing those with PMD out into the community by increasing interactions between them and others

Communities need to be better involved and aware of PMD. In areas where there may only be one individual with PMD, everyone should be aware and rally around this individual to support their rights and promote social connectedness with others. The broader community should offer support through community-based programs and support groups that connect those who do not have a family member with PMD with those who do.

IMPACT

Stakeholders can use these recommendations in a variety of ways. For academics, they may serve as a guide and inspiration for further research. For NGOs, the recommendations may reinforce or suggest new ideas for advocacy and programming. For SCSC, they can further include this population and their families/caregivers in their outreach work of building social connectedness, and by reaching out to parents of these individuals and working at building support and network groups. For Special Olympics, this research and its resulting

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[112] Rossides, telephone interview by the author.

recommendations can help key actors in the organization further understand the challenges faced everyday by those with PMD and their families/caregivers.

This research report was carried out in tandem with a community engagement initiative. The author organized an Olympics competition for Day Camp Massawippi in Montreal, Quebec. 25 campers with a variety of disabilities including those with PMD participated in a torch parade, sports stations (target shooting, javelin, shot put, bowling and relay) and a closing ceremony featuring the distribution of certificates, ribbons and sports bags. A photographer and videographer documented the event and the products were shared via a number of social media platforms, reaching over 200 people in Montreal and the SO communities.

CONCLUSION

This report sought to identify the barriers to the social inclusion of those with PMD and to the development of MATP, SO's adapted sports training program for such individuals. The path towards social inclusion begins with overcoming these barriers. The barriers are legal, political, capacity, social, cultural, attitudinal, and financial in nature. The recommendations include changing and creating new programs within SO to ensure the organization enhances its inclusive practices. Furthermore, the recommendations suggest new avenues of research. Studies of families as whole units should be conducted, and parents need to be better informed and consulted in service provision. Moreover, MATP needs to be framed differently in order for the program to be more welcoming. Lastly, more awareness needs to be raised on the population with PMD, through campaigning and increased interaction through community-based approaches.

CONSTRAINTS:

Originally, this project sought to gain a lot of insight from families/caregivers of those with PMD, though due to privacy and consent, this process was halted. Future research should focus on hearing the voices of families/caregivers, while potentially hearing from those living with PMD as well. Moreover, further original quantitative research needs to be done as the majority of this report consists of qualitative research and a review of literature. With a larger time frame, various politicians who consider themselves advocates of those with disabilities should be contacted as well to hear their thoughts on the policy process and the blockades they face.

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