Intellectual disability: advocated or neglected by the physical therapy profession?

Session description and objectives

Historically people with Intellectual Disability (ID) are a disadvantaged group, attracting few general public health policies and initiatives. A person with ID’s health and safety from harm is frequently dependent on other people’s actions, due to their powerlessness and other disadvantages associated with their disability, and how they are perceived in society. As a result this population experiences major inequalities in a wide range of health conditions, many of which can be mitigated by carefully prescribed exercise and facilitated engagement into physical activity. Physical therapists are thus well placed to play a crucial role in enabling and advocating for the health and wellness of both children and adults with intellectual disability. But is there evidence that physical therapy can make a difference? Are physical therapists working in, and do they have the necessary skills, to work in this area of practice? As a profession have we neglected our responsibilities to people with intellectual disability, have we placed them in the “too hard basket” or are we staunch advocates.

Objectives

1. To raise awareness of the health issues of people with ID through the lifespan and the impact on health and wellness.

2. Consider strategies to work with people with ID through the lifespan to improve health, function and well-being.

3. Describe validated assessment tools and interventions to improve health, function and well-being.
Special Olympics transforms lives through the joy of sport, every day, everywhere. We are the world’s largest sports organization for people with intellectual disabilities: with more than 4.7 million athletes in 169 countries – and more than a million volunteers.

Special Olympics Health Programs

Despite severe need and higher health risks, people with ID are often denied or have limited access to health services. Despite a mistaken belief that people with intellectual disabilities receive the same or better health care, they typically receive sub-standard care, or no health care at all. There is a misconception that poor health of people with ID is due to their disability. Research has shown that this is the result of a breakdown in health education, health promotion, and health care that can and should be addressed.

Special Olympics has become the largest global public health organization dedicated to serving people with intellectual disabilities. Over the years, Special Olympics health programs have improved the health of our athletes - either profoundly changed--or saved—lives. [http://www.specialolympics.org/healthy_athletes.aspx](http://www.specialolympics.org/healthy_athletes.aspx).

- **Healthy Athletes**
  
  Officially launched in 1997, Special Olympics Healthy Athletes® offers health services and information to athletes, families, and coaches. Seven free health screening events are offered in a welcoming, fun environment. Athletes are educated on healthy lifestyle choices and behaviors. In addition, problems that may need additional follow-up are identified. More than 1.7 million health exams have been conducted in more than 130 countries.

  Healthy Athletes has the world's largest database of health data for people with intellectual disabilities. Through Healthy Athletes, more than 155,000 health care professionals and students have been trained to treat people with ID. These health care professionals provide improved care to millions.

  The physical therapy component of HA, called FUNfitness, is a fitness screen and education performed by physical therapy professionals. Data has indicated that flexibility and balance are the two over-riding global concerns, followed by consistent physical activity.

- **Healthy Communities**
  
  Healthy Communities is a model Special Olympics Health program that addresses the health disparities faced by people with ID through immediate and long-term solutions developed in their own communities. The ultimate goal is INCLUSIVE HEALTH.

  A Healthy Community is a location officially by recognized for efforts in creating year-round access to quality health care. Through partnerships, fitness and wellness programs, as well as robust Healthy Athletes programming, dozens of Special Olympics locations throughout the world are paving the way for inclusive health. Special Olympics has a goal of having 100 recognized Healthy Communities by 2020.
Children with Intellectual Disability: The role of Physiotherapy

Intellectual disability (ID) is defined by the World Health Organisation (WHO) as “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence), and which results in a reduced ability to cope independently (impaired social functioning), begins before adulthood, and has a lasting effect on development” [1]. As is the case with many countries, South Africa does not yet have standard definitions and terminologies and a nationally accepted measuring tool for ID, and as a result, the estimates of ID prevalence in children from different sources are not comparable because of differing definitions and methods of data collection [2].

Prevalence of Intellectual Disability in children
Disabilities acquired in childhood, including ID, are believed to arise in 5-17% of children in developing countries worldwide [3]. There is a lack of prevalence studies among youth with ID using measures of adaptive functioning [4]. The prevalence of ID has been estimated at 10.4 per 1000 globally, with increased rates among children and adolescents in lower income countries [5]. In the sub-Saharan region, there has been no large scale epidemiological study to define the magnitude of childhood ID [6]. The estimated prevalence of ID in the South African population varies considerably, based on the method and cut-off points used to identify and define ID [7]. Prevalence estimates of children aged 3-17 years with ID in Europe were calculated to be 1.10% [8]. In Finland, the cumulative prevalence is reported to have reached 1.2% by age 17 years [9]. A study conducted in France yielded a prevalence rate of 18 per 1000 [10].

Weight status and Intellectual Disability in children
There is a scarcity of evidence on the weight status of children with ID, with studies conducted mainly in adults [11]. However, a recent report from the US revealed that ID is associated with increased risk for obesity [12]. This is associated with an increased frequency of several health conditions and impairments, with supportive evidence that these health disparities are associated with preventable environmental determinants [13]. There is ample international evidence on the increased prevalence of overweight/obesity in children with ID [12][13] [14], however there is little to support this for South Africa. It is uncertain whether the risk factors for adults with ID apply to children with ID [15]. Childhood obesity may progress to diminished cognitive and physical development, which can translate into negative social and economic consequences such as social segregation and poor academic performance at school, and which may compound the already negative impact on children with ID [69][1] [406]. In addition, if the extent of the problem is not well documented, there may be inadequate efforts to address the problem.

Physical activity, Fitness and gross motor skills
Children with ID have been shown to engage in less PA compared to typically developing (TD) children [16-18]. Regular participation in PA by all children, enhances body composition, bone health, psychological health and promotes social engagement [19-22]. Key facilitators for PA participation are enjoyment and unstructured activities, social interactions, parental support and increasing level of independence. However, children with ID may be further inhibited in their PA participation as they have been found to have delayed gross motor skills (GMS) development, poor cardiovascular fitness and show less proficiency in balance and coordination compared to their TD peers [23]. The barriers to participation include lack of knowledge, skills, fear, parental behaviour, adverse attitudes to disability, scarce facilities, lack of transport, deficient programmes and staff capacity, increased cost, functional limitations, unsafe environment and lack of facilities or programmes at close proximity to facilitate access [24-25].

Role of Physiotherapy
Childhood obesity is an extremely complex condition in which prevention and intervention are challenging, yet essential. The medical and psychosocial effects extend beyond the personal level and into the economic, social and public health levels. Lifestyle modification of children, parents, teachers and all stakeholders is necessary to produce vital outcomes. Physiotherapists, who are skilled stakeholders in the management of children and adults, are well-positioned to develop evidence-based intervention programmes for implementation to address these problems, in order that all children may enjoy an enhanced health-related quality of life.
References

The role of carers in physiotherapy services for people with intellectual disabilities

1. Who attends to the needs of people with intellectual disabilities?

Physiotherapy is critical as a component of health promotion programmes for persons with intellectual disabilities but not many of them are currently included in any health promotion programmes at all, especially in developing countries. Early intervention programmes by rehabilitation professionals for children with intellectual disabilities which include intensive physiotherapy are common but there is lack of evidence of habilitation programmes beyond the age of five. Huge gaps exist in transition services from early intervention to school aged services, primary to high school, and post school to adult life. From school-going age, children and adults with intellectual disabilities are mainly seen by general practitioners or paediatricians for their medical needs. In well-resourced settings, there are occupational therapists who focus on learning and activities of daily living in schools and facilitating employment for adults with intellectual disabilities.

2. People with intellectual disabilities’ living arrangements

Most people with intellectual disabilities require ongoing care and support from others in order for them to perform adequately in different life settings. The lifetime care responsibility is usually taken up by family carers especially in low to middle income countries where formal out of home living options are minimal. In some affluent settings, adults with intellectual disabilities live in group homes facilities where they are cared for and supported by paid carers. However, there is evidence that most people with intellectual disabilities remain under lifetime care of their families even in developed countries.

People with severe to profound intellectual disabilities usually have other impairments co-existing with the intellectual impairment like physical and communication impairments which make them more dependent on their carers. In modern, urbanised societies, lack of out of home services for those with mild to moderate intellectual disabilities who are higher functioning means most of them remain at home playing games and watching television from dawn to dusk with almost no physical activity in their day and seldom going out. Some are in supported employment or go for day activities at sheltered workshops where they mostly do activities that do not involve much physical movement. In remote and rural settings, those who can are involved in agrarian activities but there are many who just sit at home, fully dependent on family carers.

Family and paid carers of people with intellectual disabilities restrict their movements due to vulnerability to sexual abuse and other risks and for some, challenging behaviours and fear of negative societal attitudes. Their activities are also limited by lack of services like affordable transport and programmes for transition from school to adult life. Hence, obesity resulting from the sedentary lifestyles is common among people with intellectual disabilities.

3. What should physiotherapists do?

The sedentary lifestyles led by people with intellectual disabilities and their dependence on carers make physiotherapy pertinent for health promotion to enhance their quality of life (and that of their carers). Prolonged (lifetime) engagement with each individual does not seem feasible but it is crucial to involve both carers and people with intellectual disabilities in health education programmes and encouraging the carers to facilitate physical activity. Physiotherapists need to widen their scope of practice by being more cognisant of what happens in their clients’ social settings (social model) rather than focusing on individual deficits (medical model). Also, rural and remote areas need to be given attention by providing improved subsidised transport and outreach physiotherapy services.
Is falling a problem for adults with intellectual disability?

Falling is a frequent and serious problem for many adults with intellectual disability (ID). Studies to date report similar findings; approximately 30% of adults with ID will experience a fall in one year and many will have numerous falls. Not only is falling a recurrent problem, it frequently results in serious injury (e.g. fractures to limbs, head and face, head injuries, broken teeth). Of concern is that an increase in risk of falling starts at a younger age in people with ID than that reported in older adults without disability.

The reasons for frequent and serious falls in the ID population are multiple and complex. Identified fall risk factors to date are: having arthritis, having a seizure disorder, taking more than four medications, concurrent medical problems, using walking aids, having difficulty lifting or carrying greater than 4.5kg, abnormal patterns of walking, decreased motor responses to balance perturbations, increased impulsiveness and distractibility, and visual deficits.

Also of concern is that fallers’ participation in everyday activities within their home and community can be greatly restricted as a management approach to reduce risk of falling that may then contribute to a vicious cycle of declining strength and balance contributing to regular falls. People with ID are known to already have reduced participation in physical activity. It is well known that reducing physical activity leads to reduced fitness and health, confidence and community participation. In the case of adults with ID, this can eventuate in increasing workload for support staff and family as the person becomes progressively more immobile, and may necessitate early admission to aged care facilities that can cope with mobility-dependent people.

Are there evidenced based interventions to reduce falling and increase physical activity participation in adults with intellectual disability?

Although studies are starting to investigate interventions to prevent falls in adults with intellectual disability, this research is still in its infancy, so at present there is minimal robust evidence for any one approach. That said, enough work has been published for us to start to implement interventions based on best available evidence as well as learn from the vast knowledge available in preventing falls in older adults. Similarly there is a growing body of evidence in increasing physical activity participation for this population group.

What can I do as a physiotherapist?

A structured review of risk factors for falling in people with ID recommended supervised exercise programmes as one method for preventing falls. As physiotherapists we are well placed to provide strength and balance exercises for adults with intellectual disability to prevent falling, the debate now focuses on how best to deliver such an exercise programme. Encouraging people with intellectual disability similarly attracts debate on how best to do this. Current options will be critically discussed in the Discussion forum. The following references will be of interest to the reader:

References


