### **Autism**ontario

# Accessing Inclusive Personal Training Programs for Young Adults with Autism:

Strategies for Overcoming Barriers

No. 51, December 2012

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#### **Background**

In Canada, studies have shown that only approximately 3% of individuals with a disability are actively engaged in organized sport<sup>1</sup>. However, educators and others are becoming increasingly aware of the benefits of personal fitness for students with special education needs and typically developing children alike<sup>2</sup>. And some are convinced that physical education has a central role to play in building self-esteem and social skills that in turn lead to a more active and inclusive lifestyle for young people with autism.

Although more and more young adults with autism are showing interest in accessing personal fitness opportunities, there are few programs outside school settings that are accessible. In addition, few fitness professionals are systematically trained to include people with disabilities in their fitness programs. And few Day programs for adults with disabilities offer inclusive fitness activities.

This article is therefore intended to raise awareness of barriers that people with ASD face in accessing fitness opportunities, offer strategies for designing individualized fitness programs, and suggest the need for future research that explores the impact of personal fitness on people with autism and their communities.

### Identifying and Understanding Fitness Barriers

Why do we need to identify and understand fitness barriers as a first step towards overcoming them? Identifying and understanding barriers helps to clarify difficulties experienced by disabled individuals with disabilities who are becoming self-determined and who wish to be part of a particular community.

Sensitivity to barriers experienced by adults with ASD who are accessing fitness opportunities helps caregivers, developmental service workers, and fitness professionals design and implement useful programs.

Emergent data from case study research by the authors suggest that common obstacles to fitness include:

- environmental accessibility
- socio-behavioural; and
- economic barriers.

#### Environmental Accessibility Barriers

#### **Programmatic**

The existence of an ASD does not automatically place an individual at risk for physical activity participation. Fitness professionals are able to provide services to "apparently healthy" individuals (individuals with no known medical condition which place them at risk for physical activity participation). Unfortunately, misconceptions about disability and ASD and its relationship to health status remain commonplace. Through awareness and initiative, fitness professionals can play a significant role in increasing the involvement of individuals with

<sup>1 2001</sup> Statistics Canada Participation and Activity Limitation Survey Changing Minds, Changing Lives <a href="https://www.paralympic.ca/en/Programs/Changing-Minds-Changing-Lives.">https://www.paralympic.ca/en/Programs/Changing-Minds-Changing-Lives.</a><a href="https://www.btml">httml</a> [retrieved August 31st, 2012]. NB. We have not found studies that itemize general physical activity levels or fitness experiences of people with autism.

<sup>2</sup> The Ontario Curriculum, Grades 1-8: Health and Physical Education, Interim Edition, 2010 (revised)

ASD in regular physical activity programs<sup>3</sup>. But first they need to overcome the possible misconception that autism is a disease and that only health care professionals are qualified to work with people with ASD.

#### **Physical Accessibility**

Individuals with ASD have many of the same strengths and weaknesses that individuals without ASD have when it comes to cardio and strength training abilities. Along with other groups of individuals, such as older adults and those with physical disabilities (e.g., CP, MS, and amputations), people with autism may need adapted equipment to accommodate physical impairments, i.e.:

- low weight machines and dumbbells;
- medicine balls with hand straps;
- and other universally-designed equipment (e.g., recumbent elliptical)

When seeking out a personal trainer, a fitness class, or a fitness facility, it is important that parents and professionals know the right questions to ask to clarify that a particular person or environment is going to meet the needs of the individual with ASD and that the requisite equipment or adaptations are made.

#### **Sample Questions**

- Can my personal assistant attend the facility with me without extra charges?
- What are the busiest times for the facility? What areas are most crowded and when?
- Does the facility provide orientation and instructions on how to use equipment?
- Have any of your personal trainers/fitness specialists supported an individual with ASD or other disability?

For a list of additional helpful questions see http://www.ncpad.org/exercise/fact\_sheet.php?sheet=359&view=all.

#### Socio-Behavioural Barriers

#### Misconceptions/ Stereotypes and Attitudes of Others

Although fitness professionals might believe that ALL people are being encouraged to be active, stereotypes and misconceptions about autism may impede potential clients with ASD from accessing fitness facilities. And former teachers, caregivers, and adults with ASD themselves may

not realize that special fitness needs can be accommodated at public facilities.

For individuals with ASD, participating in a fitness program is often a new experience. New experiences hold social and behavioural challenges, such as:

- meeting new people;
- negotiating a new setting; and
- participating in a new setting with others.

Social accessibility for clients with ASD may take time, but the key to accommodation is flexibility on the part of fitness professionals and others at the fitness facility.

Individuals with ASD who experience behavioural outbursts that include screaming or vocalizing can cause tension and apprehension amongst the trainer, support staff and also other clients or members present at a gym. It is important for fitness facilities and professionals to be open to allowing knowledgeable support workers or caregivers into their facilities to help create optimal outcomes, especially at the beginning of a program when routines are being established. At times it may mean that a person with ASD has two support people and the personal trainer working with him or her simultaneously.

For many individuals with ASD it is important to develop routines, and these routines may need to be established gradually, i.e., shorter, more frequent visits to the fitness facility may be necessary. Further, fitness professionals need to be patient, flexible and satisfied with incorporating small changes within established routines to promote successful training.

The Ontarians with Disabilities Act passed in 2005 makes Ontario the first jurisdiction in Canada to implement and enforce mandatory accessibility standards which apply to both the private and public sectors. Many businesses are making efforts to become accessible; however, there needs to be a corporate buy-in by the fitness industry if people with disabilities are to feel they have opportunities for fitness in an inclusive atmosphere.

#### **Economic Barriers**

#### **Dependence on Supporters**

Many adults with ASD remain dependent on their caregivers (parents or other supporters) for basic needs in many spheres of life, from housing to mental health. This reality means that caregivers are called upon to

<sup>3</sup> Inclusive Fitness and Lifestyle Services for all (dis)Abilities(2002). Canadian Society for Exercise Physiology (CSEP) <a href="https://www.csep.ca">http://www.csep.ca</a>.

orchestrate opportunities for fitness. Adults with ASD who live in rural areas face different challenges from those in urban areas, where there are more choices of transportation systems, fitness facilities, and trainers.

#### **Systems Issues**

Associated with the dependence of many adults with an ASD upon caregivers is the need to advocate for funding to cover the costs of participation in fitness training. Unless caregivers approach officials about using individualized funds to promote fitness, this area of health and social inclusion is largely ignored.

Persons with an ASD who require intensive supports incur higher costs than other disabled persons. Such costs include:

- hiring support personnel to mediate a gym membership and bridge communication with a personal trainer; and
- arranging and paying for transportation to a fitness facility (i.e., especially if the person with an ASD lives in a rural area)

To convince officials to allow government funding to be used for fitness needs, persons with an ASD themselves, their caregivers, and supporters need to raise awareness of the benefits of fitness.

For example, Ratey (2008) reports research linking aerobic exercise with improved brain function; Hillman, Erickson and Kramer (2008) suggest that physical fitness improves cognition in school children; and, research on the links between physical fitness and mental health has been active for decades<sup>4</sup>.

## Strategies for Designing Inclusive Fitness Programs

The suggestions below offer starting points for creating inclusive fitness programs at home, in fitness facilities, or in community groups. Although the components listed below are not exhaustive, we believe that the keys to developing viable programs include acknowledging the role of caregivers in initiating and sustaining programs,

4 Hillman, C.H., Erickson, K.I. & Kramer, A.F. (2008). Be smart, exercise your heart:exercise effects on brain and cognition. Nature Reviews Neuroscience, 9, 58-65; Ratey, J.J. (2008) Spark: The revolutionary new science of exercise and the brain. New York: Little, Brown and Company; Paluska, S.A. & Schwenk, T.L. (2000). Physical activity and mental health: Current concepts. Sports Medicine, 29 (3), 167-180.

identifying assumptions about disability, and aligning assumptions with practices. For more information on strategies for accessing inclusive programs, we recommend the following web sites:

www.allabilitiesfitness.ca www.topshapeinc.com www.ncpad.com www.ala.ca http://paralympic.ca

#### Role of Parents/Caregivers

- Key to seeking and creating an environment of inclusive fitness
- Good role models
- Initiate community relationships, friendships, access to associations
- Participate in group exercise
- Staff at group homes or in day programs must be committed
- Seek caregiver/staff workshops
- Understand benefits of fitness

#### Attitudes

 Teach personal trainers and fitness instructors the social model of disability (i.e., acknowledge and itemize socio-cultural barriers, and understand that disability is distributed within a social structure)

#### Individualize for Success

- Use positive terminology
- Never underestimate a client's intellect
- Address specific behaviours and functional limitations by evaluating equipment, environment and teaching exchanges
- Make programs accessible for clients, i.e., include picture schedules, and provide adapted equipment
- Offer alternative formats for instruction
- Use repetition
- Build in positive reinforcement

#### **Exercise Guidelines**

If necessary, obtain physician consent

- Understand effects of medication
- Provide supervision
- Label machines with pictures
- Allow time to master a skill
- Use prompting and task analysis
- Consider length of activity
- Model technique
- Use video to demonstrate
- Start slowly and increase frequency, intensity, time, type
- Teach to practice safety

#### Find Model Programs

- Examine existing programs and practices by visiting local programs while they are in session
- Tailor new programs on such models, but adapt these for specific environments, individual needs, and logistical constraints
- For some it is helpful to start a home-based program
  with a personal trainer who is then able to support
  skill transfer to a new setting, such as a gym or a
  community program

#### Future Research

We believe that all people with ASD benefit from personal fitness, and that it is possible to develop inclusive programs that accommodate a diversity of people with ASD. However, systematic research is needed to track general physical activity levels and fitness experiences of adults with autism, and the impact of personal fitness on people with autism of varying ages, interests and abilities.

We also believe that an emphasis on physical education during the high school years needs to be represented in transition planning for young adults. We argue that it is important to take full advantage of school-based resources in the fitness domain to plan for the personal fitness needs of adults with autism who are leaving school. Research is needed to answer the question of whether transition plans that include fitness programs are in fact carried out beyond school. Further, if training does continue in adulthood, fitness programs that are implemented require evaluation.

Finally, fitness professionals require training to be able to include individuals with autism in public and private personal training settings. It is imperative that professional training programs in Education, Developmental Services, and in the Fitness Industry include adapted and inclusive fitness in their certification curricula.

NB. Since 2010 Dawn Campbell and Karin Steiner have been collaborating to provide access to personal training and fitness programs to adults with autism and other disabilities. Together the authors have developed case studies of the fitness experiences of adults with a range of developmental disabilities. This article emerged from conference presentations to the OADD's Research Special Interest Group (RSIG) in April, 2012 and IMFAR in May, 2012.

To view video of a young man completing his workout routine using a visual schedule and with the aid of a coach visit: <a href="http://www.allabilitiesfitness.ca/#!video">http://www.allabilitiesfitness.ca/#!video</a>.

#### About the Authors

Karin G. Steiner (Ph.D.) began her career as an English instructor at universities in China and Japan. When her son was diagnosed with autism, she embarked on a second academic career focussed on cognitive theories of autism and developmental psychology. Karin's publications include articles on teaching theory of mind concepts to young children with autism and her doctoral work explored social understanding in the friendships of adults with developmental disabilities. Karin is the founding Executive Director of New Leaf Link (www. newleaflink.ca), a rural charitable organization dedicated to the community inclusion of adults with developmental disabilities.

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