



## Maximizing the use of Special Olympics International's Healthy Athletes database: A call to action

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### ABSTRACT

There is a critical need for high-quality population-level data related to the health of individuals with intellectual disabilities. For more than 15 years Special Olympics International has been conducting free Healthy Athletes screenings at local, national and international events. The Healthy Athletes database is the largest known international database specifically on the health of people with intellectual disabilities; however, it is relatively under-utilized by the research community. A consensus meeting with two dozen North American researchers, stakeholders, clinicians and policymakers took place in Toronto, Canada. The purpose of the meeting was to: 1) establish the perceived utility of the database, and 2) to identify and prioritize 3–5 specific priorities related to using the Healthy Athletes database to promote the health of individuals with intellectual disabilities. There was unanimous agreement from the meeting participants that this database represents an immense opportunity both from the data already collected, and data that will be collected in the future. The 3 top priorities for the database were deemed to be: 1) establish the representativeness of data collected on Special Olympics athletes compared to the general population with intellectual disabilities, 2) create a scientific advisory group for Special Olympics International, and 3) use the data to improve Special Olympics programs around the world. The Special Olympics Healthy Athletes database includes data not found in any other source and should be used, in partnership with Special Olympics International, by researchers to significantly increase our knowledge and understanding of the health of individuals with intellectual disabilities.

### What this paper adds

This paper is a “call to action” paper developed after a consensus meeting regarding the utility of the Special Olympics International Healthy Athletes database. Priorities are identified and recommendations for improvements to the database are presented.

### 1. Introduction

Decision makers need high quality data to make informed choices; whether their decisions are made at a broad policy level affecting whole populations, or at the level of the individual (Lin et al., 2014). Furthermore, the data used to drive health promotion

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agendas, health treatment plans, or health policy initiatives needs to be directly relevant to the population of interest. For example, there are physical activity guidelines for children and youth 5–17 years of age (World Health Organization, 2010), which differ significantly from the guidelines for individuals over the age of 65 (World Health Organization, 2010). However, for people with intellectual disabilities, health decisions both at a policy level and at an individual level are often made based on data or information from the general population. One reason for this is a lack of high quality, population level, data on the health status of individuals with intellectual disabilities (Lin et al., 2014; Lunskey, Klein-Geltink, & Yates, 2013). Much of what is known about the health status of people with intellectual disabilities comes from small scale studies conducted in developed countries (e.g. United Kingdom, USA, Australia, Canada) (Emerson & Hatton, 2014; Lloyd, Foley, & Temple, 2014; Temple, Foley, & Lloyd, 2015). Quality population-level information is needed to fully understand the health status, including health disparities, of various sub-sets of the population, and to develop health promotion initiatives that can be measured over time.

While people with intellectual disabilities make up a relatively small portion of the overall population, the proportion of people with intellectual disabilities in the population is rising (Lunskey et al., 2013; Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011; Westerinen, Kaski, Virta, Almqvist, & Iivanainen, 2007). Additionally, people with intellectual disabilities consistently experience high levels of health disparities (Cooper, Melville, & Morrison, 2004; Emerson & Hatton, 2014; Krahn, Hammond, & Turner, 2006; Lunskey et al., 2013). These health disparities include, but are not limited to, high rates of obesity (Lloyd et al., 2014; Temple et al., 2015), and diabetes (Balogh, Lake, Lin, Wilton, & Lunskey, 2015), high rates of congestive heart failure, chronic obstructive pulmonary disease, and asthma (Lunskey et al., 2013). Females with intellectual disabilities also have even higher health risks than their male counterparts (Balogh et al., 2015; Foley, Lloyd, & Temple, 2013; Lloyd, Temple, & Foley, 2012; Temple, Foley, & Lloyd, 2014), and receive fewer preventative health screenings than the general population (Lunskey et al., 2013). Further, people with disabilities use health care services far more than the general population, especially emergency rooms (Lunskey et al., 2013; Meerding, Bonneux, Polder, Koopmanschap, & van der Maas, 1998; Newacheck & Kim, 2005; Ward, Nichols, & Freedman, 2010); yet this population consistently experiences challenges accessing health care services (Ali et al., 2013). The patterns of health needs, and causes of death, differ for people with intellectual disabilities (Cooper et al., 2004). While there is convincing evidence of health disparities; there is little high quality scientific evidence relating to the health of people with intellectual disabilities, particularly from an international public health perspective (Lin et al., 2014; Lunskey et al., 2013). A meeting hosted by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (Bandini et al., 2015) resulted in a consensus statement highlighting the importance, and need, for high quality health research to develop the evidence base and identify best practices for both health promotion activities, and healthcare service delivery for individuals with disabilities.

### 1.1. Existing health surveillance of individuals with intellectual disabilities

Important health policy decisions are often informed by evidence from large cross-sectional or longitudinal surveillance; for example the National Health and Nutrition Examination Survey (NHANES) in the United States, the Canadian Health Measures Survey (CHMS) in Canada, or surveys distributed by the World Health Organization. However, individuals with intellectual disabilities are often under-reported, excluded, or inaccurately identified in national and international health surveillance (CDC/NCBDDD, 2009). In current large-scale health surveys, people with intellectual disabilities may be significantly under-represented due to sampling strategies (Emerson & Hatton, 2014). For example, the CHMS only samples people "...living in private households at the time of the survey. Residents of Indian Reserves or Crown lands, institutions and certain remote regions.... are excluded" (Tremblay et al., 2010, p. 8). While the CHMS does not specifically *exclude* people with intellectual disabilities, it does exclude people who live in community based assisted living homes (group homes) and does not account for proxy reporting if an individual with an intellectual disability is not able to answer a question or perform a particular measurement in a traditional format. Consequently, this limits the number of people with an intellectual disability who participate.

Analysis of administrative health records is an alternative to large-scale health surveillance, where available (Lin et al., 2014; Safran et al., 2007). However, this method is also wrought with identification issues and often focuses on health care utilization and prevalence of specific medical conditions (e.g. diabetes prevalence or emergency room visits) (Lunskey et al., 2013; Safran et al., 2007). The recent release of the *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* is an excellent example of how administrative health databases have been used to greatly further our understanding of the health individuals with developmental disabilities (Lin et al., 2014; Lunskey et al., 2013). This document focuses on prevalence estimates in Ontario, Canada describing the health status of adults with a developmental disability, health care utilization, and it examines how consistent their health care is in relation to the primary care guidelines. However, this document has focused on adults only, and is limited in its scope to Ontario (just one province in Canada) (Lunskey et al., 2013). Finally, large administrative databases are usually not able to examine the effects of health promotion initiatives (e.g. healthy eating, physical activity promotion, etc.), due to the constraints of what data is included in administrative health databases. Consequently, this limits the ability to use this data to understand how best to promote the health of individuals with intellectual disabilities, or to evaluate the effectiveness of a given health promotion program.

### 1.2. Special Olympics International Healthy Athletes database

Special Olympics is an international sport organization that provides year round opportunities for individuals with intellectual disabilities to engage in sport and physical activity opportunities (Special Olympics International, 2012, 2016b). For more than 15 years, Special Olympics International has been conducting free "Healthy Athletes" screenings to participants. The Healthy Athletes program conducts screenings in seven discipline areas: *Fit Feet* (podiatry), *Healthy Hearing* (audiology), *Special Smiles* (dentistry),

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