



Mini Review

Toward Healthy Living: Enabling Physical Activity among Adults with Intellectual and Developmental Disabilities

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Abstract

Adults with intellectual and developmental disabilities (I/DD) have a higher risk than the general population of engaging in sedentary behaviors and acquiring health issues associated with physical inactivity. To promote research and best practices related to active living and enhancing wellbeing among adults with I/DD, this mini review aimed to identify potential barriers of full community participation (physical, social, and emotional engagement/inclusion) among adults with I/DD. The literature gap highlights a need for building evidence-based research and practices, which may provide a better understanding of physical activity participation with adults with I/DD living in group homes and in the community in order to improve their health and wellbeing.

Keywords: Intellectual disabilities; Developmental disabilities; Physical activity promotion; Public health; Adults

Mini Review

According to the Center for Disease Control and Prevention (CDC), intellectual and developmental disabilities (I/DD) are disorders that are typically present at birth and, to varying degrees, adversely affect intellectual, physical, and emotional development [1,2]. Specifically, intellectual disabilities are characterized by problems with intellectual functioning, including the ability to learn, reason, and solve problems, as well as with adaptive behaviors involving daily social and life skills, which manifest before the age of 18 years and are likely to be lifelong. Additionally, developmental disabilities encompass a broader category that includes intellectual disabilities, but also includes physical conditions that may affect multiple body parts or systems [3]. The inclusive term I/DD is often used in situations where multiple disabilities are present [3]. Individuals with I/DD have a higher risk than the general population of developing chronic conditions, such as obesity, heart disease, hypertension, depression, and anxiety [4-7]. Many individuals with I/DD lead sedentary lifestyles and do not meet the minimum physical activity (PA) recommendations for promoting their health and wellbeing [5,8,9].

Based on the National Core Indicators Adult Consumer Survey (NCI-ACS) 2017–2018 data, researchers reported that only 19% of adults with I/DD who live in the community did PA/exercise three or more times per week for more than 10 minutes at a time [10]. Specifically, the rate for adults with I/DD meeting PA guidelines (~13.5%) was less than half that of the general population (~30.8%) [11]. It is a significant concern that more than 60% of adults with I/DD spent over three hours a day engaging in screen-based sedentary behaviors [12]. Obesity, overall physical and psychosocial

health and wellbeing, and community participation among adults with I/DD have received limited attentions and investigations [11,13,14].

It is well-documented that there are positive relationships between PA and health and wellbeing in adults. The Global Recommendations on Physical Activity for Health recommends 150 minutes per week of moderate intensity PA such as, brisk walking, jogging, cycling, or swimming for the general population aged 18 and above [15]. However, limited assessments of PA participation of adults with I/DD indicate their PA participation is not sufficient [16,17]. Adults with I/DD are at great risk of developing diabetes, heart diseases, and osteoporosis [18,19]. This population is also at great risk of becoming overweight or obese due to insufficient PA participations, significant amount of sedentary activities, and nutritional deficiency [9,20]. In addition, it has been recognized that adults with I/DD demonstrated high rates of fall [21,22] and poor functional health including balance, joint pain, and motor function, and these health risks increase with age [23,24]. However, regular PA or exercise has not been advocated or conducted as an effective medical and lifestyle interventions with adults with I/DD, and the effects of regular PA or exercises on fall prevention are not clear in the literature [25].

There is a need to determine appropriate methods for promoting PA and identifying exercise prescriptions such as “dose” of exercise program in order to maximize the positive effect of regular PA or exercises on adults with I/DD. For instance, according to Texas Biennial Disability Report, over 41,000 Texans with disabilities with different ages have moved from institutions to the community since the development of the Texas Promoting Independence Plan in 2001, where services on average cost significantly less than in

institutions [26]. Adults with I/DD along with their families and caregivers, for the most, receive limited support services such as PA opportunities and face a high risk of developing sedentary lifestyles [17]. An urgent need exists for adults with I/DD to have access to quality PA supports that address their overall health and wellbeing, especially for those whose families and caregivers may have no or limited knowledge of the benefits of PA [27]. The primary purpose of this mini review was to identify the barriers of full community participation (physical, social, and emotional engagement/inclusion) among adults with I/DD. Then, practical strategies and evidence-based implementation models are introduced from a public health perspective in order to promote their PA and health status.

Public policies have increasingly supported the rights of adults with I/DD to live in communities of their choice. Making this relevant to adults with I/DD requires a corresponding increase in environmental supports to promote full community participation. Until the age of 21 years, adults with I/DD are eligible to receive support services (i.e., education, training, health promotion) through the Individuals with Disabilities Education Act (IDEA, PL 101-476). When eligibility for these services ends, the task of securing support shifts from educational systems to the individual, family, or other caregivers. It was noted that the health status and needs of adults with I/DD living in the community who are not receiving support services are often unknown to state and local agencies [28,29]. Compared with the general population, researchers' and practitioners' knowledge and understanding of adults with I/DD levels of PA participation and accessibility to PA programs are limited. If health and wellbeing of adults with I/DD are reduced due to physical inactivity or being sedentary, then independence will be limited in this population even though they are dwelling in the community. Health and well-being becomes more challenging over the lifespan as aging-related changes impact both the adults with I/DD and supporting family members. Key challenges that must be addressed by communities, families, and adults with I/DD include the following: (a) improving the health and functioning of adults with I/DD and their families; (b) enhancing consumer directed and family-based PA; (c) reducing barriers to health and community participation; and (d) reinforcing training systems/networks of health and PA professionals, family members, and home caregivers [18,30].

Adults with I/DD are more likely to develop chronic health conditions at younger ages than other adults due to biological factors related to syndromes and associated developmental disabilities, limited access to adequate health care, sedentary lifestyles, and environmental issues. This population also has higher rates of obesity (79.6%) [31], sedentary behaviors, and poor nutritional habits compared to the general population [32]. Many health care providers, adults with disabilities, and families are unfamiliar with current and accurate information about the age-related health issues for individuals with I/DD. A need exists not only for more research in this area, but also for disseminating data and information related to preventative and surveillant strategies across the lifespan for adults with I/DD. These strategies include targeted health education programs, appropriate screening, and community health promotion programs.

Research has documented the physical and psychosocial benefits of community-based PA and exercise programs for adults with I/DD, as well as their caregivers [33]. In-home health services and self-directed support (centering services on the individual needs of persons with I/DD) were proposed as important strategies to increase opportunities and quality of the services for adults with I/DD [34,35]. However, most intervention research did not have follow-up studies, and the resources and services were discontinued after intervention programs were completed as well.

Although more than half of individuals with I/DD live with family (71%), the numbers of services provided directly to individuals with I/DD in the community was decreasing from 5.5% in 2000 to 3.3% in 2012 [36]. This gap between need and public services/resources is likely to increase with more individuals with I/DD living longer, more dual-income families, lower fertility rates, and more families living in poverty in the U.S [36]. Another important trend includes the increase in the number of minority families with individuals with I/DD. The percentage of non-Hispanic Caucasians is estimated to drop from 62.2% in 2014 to 43.6% of the population in 2060 [37]. Cultural caregiving norms and language barriers, along with poverty, affect access to services and well-being of adults with I/DD and their families, especially related to PA [38]. Community First Choice Option and the Balancing Incentive Program, which are designed to help states move people needing long-term services and support from institutional care to home- and community-based care, were developed according to the 2010 Affordable Care Act.

Williamson and Perkins (2014) conducted a systematic literature review to identify U.S. family caregiver outcomes and their association with existing services and supports for family caregivers of individuals with I/DD [30]. They indicated that the current status of the U.S. disability service system is complex and variable making implementation of evaluation measures challenging. With increasing financial pressures and an aging population (7.3 million individuals with I/DD in the U.S.), policy makers and service providers need to pursue and evaluate innovative practices related to PA and well-being. The on-going involvement of family members in the lives of individuals with I/DD should be encouraged by the system, and emphasis on home- and community-based services means understanding the needs of adults with I/DD and their family caregivers. Comprehensive assessments of formal and informal caregiver needs and supports are needed, which can help prioritize formal resources and services more effectively [30,39].

Models of consumer-directed supports (e.g., personal assistance, supported living, and cash subsidies) have grown, stimulated by the Real Choice Systems Change grants of the 2000 New Freedom Initiative and the Robert Wood Johnson Self-Determination Initiatives [40]. Outcomes of consumer-directed supports for families of adults with I/DD have included greater service satisfaction, fewer unmet needs, better access to health care, fewer out-of-pocket disability expenses, reduced feelings of stress and burden, greater self-efficacy, more opportunities for employment (both caregivers and adults with I/DD), and improved social and leisure opportunities and community participation [30,33]. However,

in many of these programs, family members often make the decisions rather than the adults with disabilities. Further, in many cases funds are used to pay family members. Little is known about the impact of using consumer-directed funds to pay family members to provide care, and how this effects PA, well-being, health, and self-determination of adults with I/DD [40,41].

The concepts of "livable communities" and "healthy homes" have been promoted for persons who are aging with disabilities [42]. As people age and require more supports for their activities of daily living, work, or recreation, they may require modifications to their homes and communities that allow them to remain in their current settings. Environmental interventions (EI) to adapt or modify home/living environments and assistive technologies (AT) have shown positive effects on physical and psychosocial functioning of along with reduced mortality for individuals with Alzheimer's disease and decreased stress for their caregivers [43,44]. In home environmental modifications have been confirmed to be beneficial (e.g., increased function, fall prevention) for individuals with different special needs [45], especially for adults with dementia [43,46]. Research shows that age-related health problems among people with intellectual disabilities are similar to those in the general population, including the development of dementia in later life. However, the prevalence of dementia in people with Down syndrome and other developmental disabilities at mI/DDle and early elderly ages is higher than in the general population. For older adults with I/DD, families and service providers have the challenge of adapting the environments so that individuals can maintain functioning and continue desired activities as long as possible [33].

Conclusion

In conclusion, while this generation of adults with I/DD has generally had limited opportunities to make their own choices regarding their daily lives, and have had restricted options regarding supports in the community as they were growing up, the next generation of individuals with I/DD and their families are likely to have higher expectations from the service system. This generation of adults with I/DD and their caregivers have received mandated school services and grown to expect more options in the community, more consumer-directed services, and more support for aging in one's home setting. More person-centered planning and interventions [33] are needed for adults with I/DD and their caregivers, given that the National Task Group on Intellectual Disabilities and Dementia has called for including developmental disabilities in the "National Plan to Address Alzheimer's Disease" [47].

Increased partnerships between academic institutions and community organizations who serve adults with I/DD are critical to expand future research and develop evidenced-based practices to meet national goals (i.e., Healthy People 2020) among adults with I/DD living in their communities. A key aspect of developing and implementing personal support plans for adults with I/DD will be focusing on the individual's health and wellbeing needs. PA, dietary/nutritional, and community engagement will need to be key elements of a system of support with adults with I/DD. [48]. The gap in the

literature highlights the need for building a community-based participatory research model, which may provide communities with an exemplar approach that might be used to ensure the early identification and effectiveness of interventions related to health disparities among adults with I/DD. Furthermore, community-based participatory research efforts may provide better understanding of PA participation among adults with I/DD, and identifying factors relating to PA behaviors in order to improve risk factor identification and better target health promotion in adults with I/DD. This form of research and practice will allow practitioners and researchers to evaluate the PA needs, design positive change and cost-effective PA interventions, and promote sustainability of successful PA interventions and implementation strategies [49].

References

1. Center for Disease Control and Prevention (2012) Facts about intellectual disability.
2. Phillips KG, Houtenville AJ, Reichard A (2019) Using all-payer claims data for health surveillance of people with intellectual and developmental disabilities. *J Intellect Disabil Res* 63(4): 327–337.
3. Schalock RL, Borthwick-Duffy SA, Bradley VJ, et al. (2010) Intellectual disability: Definition, classification, and systems of supports. (11th edn), American Association on Intellectual and Developmental Disabilities, 444 North Capitol Street NW Suite 846, Washington, DC.
4. Flygare Wallén E, Ljunggren G, et al. (2018) High prevalence of diabetes mellitus, hypertension and obesity among persons with a recorded diagnosis of intellectual disability or autism spectrum disorder. *J Intellect Disabil Res* 62(4): 269–280.
5. Hsieh K, Rimmer JH, Heller T (2014) Obesity and associated factors in adults with intellectual disability. *J Intellect Disabil Res* 58(9): 851–863.
6. Lauer E, McCallion P (2015) Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. *J Appl Res Intellect Disabil* 28(5): 394–405.
7. Taggart L, Truesdale M, Dunkley A, et al. (2018) Health promotion and wellness initiatives targeting chronic disease prevention and management for adults with intellectual and developmental disabilities: Recent advancements in type 2 diabetes. *Curr Dev Disord Reports* 5(3): 132–142.
8. Piercy KL, Troiano RP, Ballard RM, et al. (2018) The physical activity guidelines for Americans. *Jama* 320(19): 2020–2028.
9. Scott HM, Havercamp SM (2016) Systematic review of health promotion programs focused on behavioral changes for people with intellectual disability. *Intellect Dev Disabil* 54(1): 63–76.
10. Human Services Research Institution (HSRI), National Association of State Directors of Developmental Disabilities Services (NASDDDS) (2019) In-Person Survey 2017-18 Final Report National Core Indicators.
11. Stancliffe RJ, Anderson LL (2017) Factors associated with meeting physical activity guidelines by adults with intellectual and developmental disabilities. *Res Dev Disabil* 62: 1–14.

12. Hsieh K, Hilgenkamp TIM, Murthy S, et al. (2017) Low levels of physical activity and sedentary behavior in adults with intellectual disabilities. *Int J Environ Res Public Health* 14(12): 1503.
13. Dairo YM, Collett J, Dawes H, et al. (2016) Physical activity levels in adults with intellectual disabilities: A systematic review. *Prev Med Reports* 4: 209-219.
14. Hsieh K, Heller T, Bershadsky J, Taub S (2015) Impact of adulthood stage and social-environmental context on body mass index and physical activity of individuals With intellectual disability. *Intellect Dev Disabil* 53(2): 100-113.
15. World Health Organization (2011) Global recommendations on physical activity for health. Switzerland.
16. Bodde AE, Seo D-C (2009) A review of social and environmental barriers to physical activity for adults with intellectual disabilities. *Disabil Health J* 2(2): 57-66.
17. Dixon-Ibarra A, Lee M, Dugala A (2013) Physical activity and sedentary behavior in older adults with intellectual disabilities: A comparative study. *Adapt Phys Act Q* 30(1): 1-19.
18. Krahn GL, Fox MH (2014) Health disparities of adults with intellectual disabilities: What do we know? What do we do? *J Appl Res Intellect Disabil* 27(5): 431-446.
19. Mcvilly K, McGillivray J, Curtis A, et al. (2014) Diabetes in people with an intellectual disability: A systematic review of prevalence, incidence and impact. *Diabet Med* 31(8): 897-904.
20. Sohler N, Lubetkin E, Levy J, et al. (2009) Factors associated with obesity and coronary heart disease in people with intellectual disabilities. *Soc Work Health Care* 48(1): 76-89.
21. Finlayson J, Morrison J, Jackson A, et al. (2010) Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. *J Intellect Disabil Res* 54(11): 966-980.
22. Ho P, Bulsara M, Downs J, et al. (2019) Incidence and prevalence of falls in adults with intellectual disability living in the community: A systematic review. *JBHI Database Syst Rev Implement Reports* 17(3): 390-413.
23. Heller T, Fisher D, Marks B, et al. (2014) Interventions to promote health: Crossing networks of intellectual and developmental disabilities and aging. *Disabil Health J* 7(1): S24-S32.
24. Oppewal A, Hilgenkamp TIMM, van Wijck R, et al. (2013) Cardiorespiratory fitness in individuals with intellectual disabilities-A review. *Res Dev Disabil* 34(10): 3301-3316.
25. Crockett J, Finlayson J, Skelton DA, et al. (2015) Promoting exercise as part of a physiotherapy-led falls pathway service for adults with intellectual disabilities: A service evaluation. *J Appl Res Intellect Disabil* 28(3): 257-264.
26. Texas Council for Developmental Disabilities, Texas Office for Prevention of Developmental Disabilities (2014) Texas biennial disability report.
27. Taliaferro AR, Hammond L (2016) "I don't have time": Barriers and facilitators to physical activity for adults with intellectual disabilities. *Adapt Phys Act Q* 33(2): 113-133.
28. Emerson E (2011) Health status and health risks of the "hidden majority" of adults with intellectual disability. *Intellect Dev Disabil* 49(3): 155-165.
29. Hatton C, Emerson E (2015) Introduction: health disparities, health inequity, and people with intellectual disabilities. In: *International review of research in developmental disabilities*. Academic Press.
30. Williamson HJ, Perkins EA (2014) Physical activity in a large sample of adults with intellectual disabilities. *Intellect Dev Disabil* 52(2): 147-159.
31. Barnes TL, Howie EK, McDermott S, et al. (2013) Physical activity in a large sample of adults with intellectual disabilities. *J Phys Act Heal* 10(7): 1048-1056.
32. Havercamp SM, Scott HM (2015) National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disabil Health J* 8(2): 165-172.
33. Heller T, Gibbons HM, Fisher D (2015) Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellect Dev Disabil* 53(5): 329-345.
34. Carmel E, Orbach I, Zinger-Vaknin T, et al. (2008) Physical training and well-being in older adults with mild intellectual disability: A residential care study. *J Appl Res Intellect Disabil* 21(5): 457-465.
35. DeCarlo MP, Bogenschutz MD, Hall-Lande JA, et al. (2019) Implementation of self-directed supports for people with intellectual and developmental disabilities in the United States. *J Disabil Policy Stud* 30(1): 11-21.
36. Larson S, Hallas-Muchow L, Hewitt A, et al. (2014) In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2012.
37. Colby SL, Ortman JM (2015) Projections of the size and composition of the US population: 2014 to 2060: Population estimates and projections. *Curr Popul Reports* pp: 25-1143.
38. Anderson LL, Humphries K, McDermott S, et al. (2013) The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellect Dev Disabil* 51(5): 385-398.
39. Lunskey Y, Tint A, Robinson S, et al. (2014) System-Wide information about family carers of adults with intellectual/developmental disabilities-A scoping review of the literature. *J Policy Pract Intellect Disabil* 11(1): 8-18.
40. Dean EE, Dunn W, Tomchek S (2015) Role of occupational therapy in promoting self-determination through consumer-directed supports. *Occup Ther Heal care* 29(1): 86-95.
41. Gross JMS, Wallace L, Blue-Banning M, et al. (2013) Examining the experiences and decisions of parents/guardians: Participant directing the supports and services of adults with significant intellectual and developmental disabilities. *J Disabil Policy Stud* 24(2): 88-101.
42. Kochtitzky C, Cracchiola M (2016) Built environments for improving human development and promoting health and quality of life. In: *Health care for people with intellectual and developmental disabilities across the lifespan*, pp: 373-391.

43. Jensen L, Padilla R (2017) Effectiveness of environment-based interventions that address behavior, perception, and falls in people with Alzheimer's disease and related major neurocognitive disorders: A systematic review. *Am J Occup Ther* 71: 7105180030.
44. Kales HC, Gitlin LN, Stanislawski B, et al. (2018) Effect of the WeCareAdvisor™ on family caregiver outcomes in dementia: A pilot randomized controlled trial. *BMC Geriatr* 18(1): 113.
45. Carnemolla P, Bridge C (2018) A scoping review of home modification interventions – Mapping the evidence base. *Indoor Built Environ* 0(0): 1420326X1876111.
46. Padilla R (2011) Effectiveness of environment-based interventions for people with alzheimer's disease and related dementias. *Am J Occup Ther* 65(5): 514-522.
47. Bishop KM, Hogan M, Janicki MP, et al. (2015) Guidelines for dementia-related health advocacy for adults with intellectual disability and dementia: National task group on intellectual disabilities and dementia practices. *Intellect Dev Disabil* 53(1): 2-29.
48. Schalock RL, Luckasson R, Tassé MJ, et al. (2018) A holistic theoretical approach to intellectual disability: Going beyond the four current perspectives. *Intellect Dev Disabil* 56(2): 79-89.
49. Schalock RL, Gomez LE, Verdugo MA, et al. (2017) Evidence and evidence-based practices: Are we there yet? *Intellect Dev Disabil* 55(2): 112-119.

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