Title: Leisure Activity Participation of Middle-Aged Adults with Down Syndrome: Initiators, Social Partners, and Settings

Authors: Iulia Mihaila1, Benjamin L. Handen2, Bradley T. Christian3, & Sigan L. Hartley3

1University of Illinois at Chicago, 2University of Pittsburgh Medical Center, 3University of Wisconsin-Madison, Waisman Center

Introduction: Despite the increase in lifespan for individuals with Down syndrome (DS), research to date has largely examined the earlier life stages of individuals with DS, with little focus on the daily lives of middle-aged adults with DS. In the general population, leisure activity is an aspect of daily life that has been found to contribute to healthy aging, including psychological well-being and physical health (e.g., Pressman et al., 2009). Yet, only a handful of studies have examined the leisure activity of individuals with DS during middle adulthood (e.g., Carr, 2008), and all have utilized global measures of participation, limited by retrospective reporting over lengthy periods of time. The present study provided an in-depth description of the leisure activity of 40 middle-aged adults with DS and examined factors (i.e., initiators, social partners, and settings) associated with participation.

Method: Analyses were based on 40 adults with DS who completed a 7-day daily diary with their caregivers. The adults with DS were Caucasian, aged 25-53 years (M = 37.8, SD = 8.6), and had an average mental age of 7.9 years. Half were male and the majority (67.5%) lived with family. For 7 consecutive days, the adults with DS and their caregivers completed an open-response leisure diary based on the Victoria Longitudinal Study activity questionnaire (VLS; Jopp & Hertzog, 2007). Each evening the adults with DS and their caregivers checked each of the leisure activities that the adult with DS had participated in that day (from a list of 42 items). Leisure activity was then broken down into four domains – physical, social, cognitively stimulating, and passive. For each leisure activity checked, the adults with DS and their caregivers then reported the time frame during which the activity occurred, who initiated the activity (i.e., self, family, friend, or staff), who engaged in the activity as a social partner (i.e., no one, family, friend, or staff), and where the activity occurred (i.e., home vs. community).

Results: Descriptive statistics indicated that on average, middle-aged adults with DS spend roughly 38 minutes/day in physical leisure, 80 minutes/day in social leisure, over 2.5 hours/day in cognitively stimulating leisure, and just under 2.5 hours/day in passive leisure. One way analysis of variance (ANOVA) models with Bonferroni post-hoc corrections indicated that middle-aged adults with DS were self-initiating the greatest percent of their leisure activity across all domains, and were most frequently engaging in physical, cognitively stimulating, and passive leisure activity on their own, without a social partner. Family was the second most common type of initiator and the second most common type of social partner in all domains of leisure activity, except physical. Staff were more likely to initiate physical leisure as opposed to other types of leisure and more likely to engage as social partners in physical leisure as opposed to other types of leisure activity. Finally, one-way ANOVAs indicated that a greater percent of physical leisure occurred in the community (as opposed to the home), an equal percent of social leisure occurred in the home and the community, and a greater percent of cognitively stimulating and passive leisure occurred in the home (as opposed to the community).

Discussion: On average, middle-aged adults with DS met standards for physical activity (i.e., 150 minutes/week) set by the US Department of Health and Human Services (2008), exceeded rates of social leisure activity reported for adults in the general population (United States Bureau of Labor Statistics, 2017) and engaged in passive leisure activity (i.e., watching television) at rates comparable to adults in the general population (Dempsey et al., 2014). Findings indicate that middle-aged adults with DS most frequently self-initiate and self-engage in leisure activity, perhaps as the result of well-established daily routines, and point to the importance of building daily routines that promote participation in adaptive types of leisure activity. Incorporating leisure into daily routines may reduce reliance on caregivers to facilitate leisure activity. Additionally, findings indicate that family members support middle-aged adults with DS by initiating and engaging as social partners in social leisure activity, whereas support staff and agency providers allocate their resources towards supporting physical leisure activity. These findings have implications for the development of low-cost interventions and educational trainings that engage caregivers in promoting the leisure activity participation of middle-aged adults with DS. Finally, support services should continue to promote participation in community-based leisure activity, while simultaneously developing routines for home-based physical leisure (i.e., treadmill while watching TV), as this could enhance daily physical leisure activity for middle-aged adults with DS who face barriers to community-based leisure.

References/Citations:

