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Equity in active living for people with disabilities: Less talk and more action^{*}



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People with intellectual, developmental, physical, psychiatric and sensory disabilities are often on the fringe of society that disposes them to pockets of isolation living with family members, in supported living facilities funded by local, state and federal agencies, or in low resource communities where access to active living opportunities is limited or nonexistent. In the aggregate, people with disabilities make up one of the largest minority groups in the U.S. with prevalence data ranging from 15 to 20% of the U.S. population (CDC, 2013). Recent statistics show that they have one of the highest rates of unemployment (Brucker and Houtenville, 2015), physical inactivity (Carroll et al., 2014), and poorer health status (Dixon-Ibarra and Horner-Johnson, 2014; Krahn et al., 2015) compared to any other subgroup in our society. And many people who acquire a disability never make the switch from 'patient' to 'participant.' They are often anchored to a healthcare system that does an excellent job of diagnosing the condition and providing rehabilitation and medications to treat and manage it, but upon discharge, healthcare professionals are not given the time nor resources necessary for connecting their patients to active living programs in their community, leaving a huge gap between rehabilitation and the 'life after' rehabilitation (Rimmer, 2012).

Individuals born with a disability do not fare much better, facing similar challenges in accessing recreation, sports and physical activity programs (Rimmer and Marques, 2012). The key attributes of success among children and youth – strength, endurance, power, agility and coordination – are often a notch below children without disabilities, and most communities are unaware or uninterested in adapting their programs so that children with and without disabilities can play together in the same park or on the same sports field or playground (Rimmer

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and Rowland, 2008). Meeting certain regulations required by federal laws have allowed for growth in many special recreation programs (Wachter and McGowan, 2002), and while an excellent adjunct to the many more opportunities offered to non-disabled youth, can never be a replacement for promoting inclusive active living programs for all children.

1. Disability-associated active living barriers we've been talking about for years

Dozens of papers on barriers to physical activity have been published over the last two decades on various subgroups of people with disabilities (Martin Ginis et al., 2016). These papers consistently report that the built environment creates substantial limitations in accessing outdoor and indoor physical activity programs and venues (Scelza et al., 2005; Becker and Stuifbergen, 2004; Zalewski, 2007; Phillips et al., 2009). Outdoor exercise may be unavailable because neighborhoods either lack sidewalks or have surfaces that are badly damaged (Clarke et al., 2008); high traffic volume makes it problematic and possibly dangerous to get across streets (Vasudevan, 2016); and hilly terrain may be too difficult to traverse (Scelza et al., 2005). In terms of getting to an indoor facility such as a fitness center, lack of accessible transportation is often the number one barrier to using these facilities followed by cost of the membership (Vasudevan, 2016).

People with disabilities who can afford to join a fitness facility and have transportation to get there often find that exercise professionals have very little knowledge about how to adapt programs or make reasonable accommodations to facilitate access to group exercise classes, exercise equipment or other areas of the facility (Scelza et al., 2005; Phillips et al., 2009; Rimmer et al., 2004; Stuifbergen et al., 1990; Rimmer, 2005; Rimmer et al., 2000). Some of the more enjoyable forms of exercise that have higher rates of adherence because of their

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socially engaging elements – Yoga, Pilates, dance, aquatic classes – are often not accessible or available to people with physical disabilities (Rimmer et al., 2016a). There is also a general perception/attitude among providers that children and adults with disabilities need 'specialized' rather than integrated services, that feeds into a culture of isolation and separation (Rimmer, 2005; Murphy and Carbone, 2008; Dunn and Leitschuh, 2006) and exposes them to higher rates of physical inactivity, poor nutrition and obesity (Carroll et al., 2014; Iezzoni, 2011; Fox et al., 2013).

2. Let's stop talking about disability-associated active living barriers and do something about it

While population-specific health promotion efforts are important for evaluating the efficacy of interventions and for tailoring information unique to the physical, cognitive, learning and sensory characteristics of the end user, the long-term strategy must be to identify the core elements of success and use those elements to promote greater levels of inclusion in integrated settings. Thus, providing guidance to health professionals on effective strategies for including people with disabilities in existing active living programs is necessary for building greater connectivity between specialized, disability-specific health promotion programs where individuals are taught how to be physically active, eat well, and manage their weight, with programs offered in their own neighborhoods and communities where they can apply those skills on a day-to-day basis among their neighbors and peers. This effort requires a framework that builds the evidence by capturing successful strategies at the local level, finding innovative ways to translate successful practices to other communities, and ultimately upgrading and maintaining their applicability and currency.

The National Center on Health, Physical Activity and Disability (NCHPAD, www.nchpad.org) has a cooperative agreement with the Disability and Health Branch in the Division of Human Development and Disability at the Centers for Disease Control and Prevention (CDC) since 1999 to build the infrastructure to support the accessibility and inclusion of people with disabilities in existing and future public health promotion programs in physical activity, nutrition and healthy weight management (Rimmer et al., 2016b). NCHPAD is currently supporting local, state and national organizations in adopting a trustworthy set of guidelines, recommendations and adaptations that will promote inclusive public health/active living practices for children and adults with disabilities. The target audiences include (a) community leaders who affect policy and organizational change at the local, state and national levels; (b) key stakeholders representing state and local groups in each community sector (schools, healthcare facilities, fitness and recreation centers, public health/active living programs) who can offer support for *community health inclusion* initiatives; and (c) disability and aging service providers who can promote active living and healthy eating in their communities and advocate for inclusive programmatic, policy, systems and environmental change.

Fig. 1 illustrates NCHPAD's Knowledge Adaptation, Translation and Scale Up framework (N-KATS). N-KATS contains four sequencing phases. In Phase I, extensive searches are conducted and evidencebased models, programs, practices, policies, etc. are identified and adapted for children and/or adults with mobility disability. In Phase II, the tools and resources created in Phase I are effectively disseminated to key stakeholders in customized sets of training materials tailored to their specific need and aligned with the contextual factors of the community. In Phase III, Center staff serve as facilitators in assisting local providers in implementing adaptations to their existing programs, practices, policies and services. And in Phase IV, successful programmatic, policy, systems and environmental changes are captured, archived and scaled to a growing number of communities involved in similar active living activities. Phases II and III in the N-KATS framework have the word Translation between them to reflect that dissemination and implementation form the core elements of knowledge translation.



Fig. 1. NCHPAD knowledge adaptation, translation & scale up framework (N-KATS).

Around the outside of the N-KATS framework are the overarching outcomes associated with each phase: Customized Knowledge (Phase I) promotes greater Community Awareness (Phase II) of the needs of local citizens with disabilities; increased awareness leads to Knowledge Uptake (Phase III); and successful 'best practices' are archived and prepared for Scale Up (Phase IV).

3. Conclusion

With growing efforts by such organizations as the Centers for Disease Control and Prevention, the Robert Wood Johnson Foundation, Kaiser Permanente and others to transform communities into healthier places to live, work, and recreate, now is the time for active living programmers and researchers to work closely with disability organizations to ensure that active living communities are inclusive of the needs of children, adults and seniors with disabilities. The current state-of-thescience in active living research that historically runs on two parallel tracks - one designed for the general population where most of the financial and human resources are directed, and the other track for disability-specific research with significantly less resources - must no longer operate in the future within their own separate spheres. The National Center on Health, Physical Activity and Disability (NCHPAD) is starting to capture the best elements from both sets of active living program and research initiatives and is infusing them into an existing framework (N-KATS, NCHPAD Knowledge Adaptation, Translation & Scale up). NCHPAD provides a unique opportunity for active living programmers and researchers to work hand-in-hand with disability programmers and researchers in building the foundation for promoting inclusive active living practices that reach all community members, including people with disabilities.

Increased participation in active living programs offered in communities across the U.S. can have an enormous positive impact on reducing secondary conditions and improving health in people with disabilities. As rates of obesity and physical inactivity continue to remain persistently higher among children and adults with disabilities compared to the general population, an even greater and more coordinated effort is needed to ensure that active living programs recognize and respond to the specific adaptations that must be embedded in communities in order to make them safe, secure and accessible for people with disabilities.

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