

The Missouri Disability and Health Collaborative Needs Assessment

Report on the Three-Phase Needs Assessment on Strategies to Increase Participation of People with Intellectual Disabilities in Public Health Nutrition and Physical Activity Programs

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Executive Summary

People with intellectual disabilities (ID) are at significantly greater risk for inactivity and related health problems when compared to both people without disabilities and people with other disabilities (Havercamp & Scott, 2015). In Missouri, only 28% of adults with ID engage in moderate physical activity for at least 30 minutes three times per week (HSRI and NASDDDS, 2014). Inactivity and poor nutrition can lead to health consequences that make it more difficult for people with disabilities to participate in community life (Ravesloot et al., 2007). Also, given the well-documented risk of social isolation for people with disabilities, and the established links between physical health, emotional/mental health, and quality of life (Havercamp & Scott, 2015), the need to make public health programs more accessible and inclusive becomes even more compelling.

In an effort to begin addressing this situation, the Bureau of Community Health and Wellness at the Missouri Department of Health and Senior Services collaborated with the University of Missouri Kansas City, Institute for Human Development (UMKC-IHD) to conduct a three-phase needs assessment. The Centers for Disease Control and Prevention (CDC) fund this collaboration through the Disability and Health Program in the National Centers on Health Promotion for People with Disabilities (CDC-RFA-DD16-1602). The purpose of this report is to present the results of the needs assessment, which identifies strategies to implement inclusive public health programming in Missouri and assesses the readiness of Missouri public health programs to do so. The needs assessment occurred in three overlapping phases:

Phase 1: Comprehensive literature review on health and wellness supports for people with ID. The comprehensive literature review identified common barriers to promoting

nutrition and exercise programs for people with ID, with special attention given to methods for overcoming barriers to participation.

Phase 2: Community-based systems modeling. The purpose of the system-modeling sessions was to gain insight into the conceptual and causal relationships community members attribute to policies and practices that impact participation of individuals with ID in public health nutrition and physical activity programs. This process included adults with ID, family members, and public health professionals.

Phase 3: Community Health Inclusion Index Organizational Assessment. Lastly, the assessment team used the Community Health Inclusion Index (CHII) Organizational Assessment to collect data from county and municipal public health organizations that receive funding from/participate in Bureau of Community Health and Wellness public health programs.

Key Findings

The phases of the needs assessment resulted in five key findings, which we briefly describe here. We provide an in-depth description for each of these in the chapters that follow. Finally, the key findings are those that appeared in more than one phase of the needs assessment. However, there were additional, important findings specific to each phase.

1. Relationships are important for people with ID. Many people with ID cannot participate in community programs without someone to take them to the site, and many need a support person with them during the activity. The support person may be a family member, a service professional, and could be a staff member at the public health organization. Recognizing this and making accommodations for a support person will help increase the participation of people with ID.

2. People with ID cannot benefit from programs if they have difficulty understanding the materials or concepts. To make nutrition and physical activity programs fully accessible, public health programs should implement Universal Design principles. Universal Design refers to a broad spectrum of practices meant to produce materials and environments that are inherently accessible to all. This includes both making environments physically accessible and using Universal Design for Learning principles to make written materials and instructional techniques accessible (see Appendix B for a full description).
Interventions/strategies that effectively increase the participation of people with ID in community-based public health programs design all aspects of their programs to be physically and cognitively accessible.
3. Training for staff and volunteers is vitally important. Any effort to make public health programming inviting to people with ID must ensure that the people running the programs understand the importance of including people with ID and have the knowledge and resources to do so. Each phase of the needs assessment identified training as a means to address primary barriers such as accessibility of materials/programs, motivation, and general attitudes about people with intellectual disabilities.
4. Outreach and information placement strategies influence participation of people with ID.
In all three phases of the needs assessment, data showed that people with ID often do not know about available programs or do not think those programs will welcome them. Targeting family members, partnering with disability service providers to disseminate information, and including imagery of people with disabilities in promotional materials are important ways to ensure that information about inclusive public health programming reaches people with ID.

5. Public health agencies across Missouri are willing to become more inclusive. Data from Phase 2 and Phase 3 of the needs assessment clearly indicate a high level of interest in accessibility and inclusion. However, there is a gap between intention and practice. Focusing efforts on activities that arise out of the four previous Key Findings will help shrink that gap.

Phase I: Comprehensive Literature Review

The aim of this comprehensive literature review is to enhance our understanding of the barriers and facilitators that determine the extent to which people with ID access healthy living resources and programs. Furthermore, we are interested in identifying characteristics of interventions that increase access to mainstream healthy living resources and activities. To this end, two questions guided our work:

1. What barriers and facilitators affect the decisions that people with ID make about participating in fitness and nutrition programs in their community?
2. What characteristics are shared by interventions/strategies that have been most effective in increasing the participation of people with ID in community fitness and nutrition activities?

A Brief Review of Health Disparities

A solid body of evidence has established that people with ID experience disparities not only in health status, but also in access to health promotion information and activities. As a group, people with ID engage in low levels of physical activity (Rimmer et al., 2010; Stanish, Temple, & Frey, 2006), eat unhealthy diets lacking in essential nutrients (Johnson, Hobson, Garcia, & Matthews, 2011; Draheim et al., 2007), and have high levels of obesity and related chronic disease (NCD, 2009; Rimmer et al., 2010; Sutherland, Couch, & Lacono, 2002). In fact, the CDC places people with ID in the highest risk category for obesity. Recent research also shows that overweight adults with ID are more likely to be obese or morbidly obese as compared to overweight adults without ID (Hsieh, Rimmer, & Heller, 2014). People with disabilities use more health care resources than the general population, but they also receive less preventive care and are less likely to access health promotion programs and services (NCD, 2009).

The evidence-based interventions that seek to address these disparities are disability-specific curricula facilitated by disability professionals in residential or day programs for people with ID (Boehm & Ravesloot, 2014; Marks, Sisirak, & Heller, 2010). Less evidence exists for what works to make community-based, non-disability specific healthy living resources and programs accessible for people with ID. In other words, we have learned quite a bit about how to support healthy choices within a disability services context, but there is a gap in knowledge about how to support healthy choices for people with ID within a mainstream public health context (Brooker et al., 2015; Anderson et al., 2013). This distinction is important for two primary reasons. First, most people with ID do not participate in formal disability services such as day programs or group homes. An estimated 87% of individuals with ID live on their own or with family, and many of these individuals may receive case management services only or may be completely unconnected to the service system (Braddock, et al., 2015). The movement toward less restrictive settings and home-and-community-based services has indisputably improved quality of life and independence for people with ID. It has also shed light on health as an area of stark inequality. In fact, those people with ID who live in the least restrictive settings are less likely to exercise regularly and more likely to have poor nutrition than other adults with ID (Rimmer & Yomaki, 2006). This is due in part to the lack of accessible health promotion activities available to adults with ID and the people who support them.

Without access to health information they can understand and act upon, individuals with ID have not been able to make gains in health status even as they have made gains in other domains of equality. Beyond these compelling concerns about equality and discrimination, there are also fiscal drivers for inclusive and integrated public health strategies and programs. Duplicating services across systems is unsustainable; understanding how to adapt public health

fitness and nutrition programs to be accessible to broader audiences can promote greater efficiency as well as reducing inequality (Anderson et al., 2013).

Methodology

This literature review combines findings from three types of studies: quantitative studies, qualitative studies, and reviews such as systematic, scoping, or comprehensive literature reviews. The rationale for including both qualitative and quantitative studies was to capture important data about the experiences and preferences of people with ID and their caregivers as related to participation in healthy living activities. We also chose to include systematic reviews that have already applied criteria tests to existing studies and synthesized findings in ways that are helpful to the specific goals and aims of the project for which this literature review was conducted. The article selection process is discussed below and Figure 1 depicts the decision-making process.

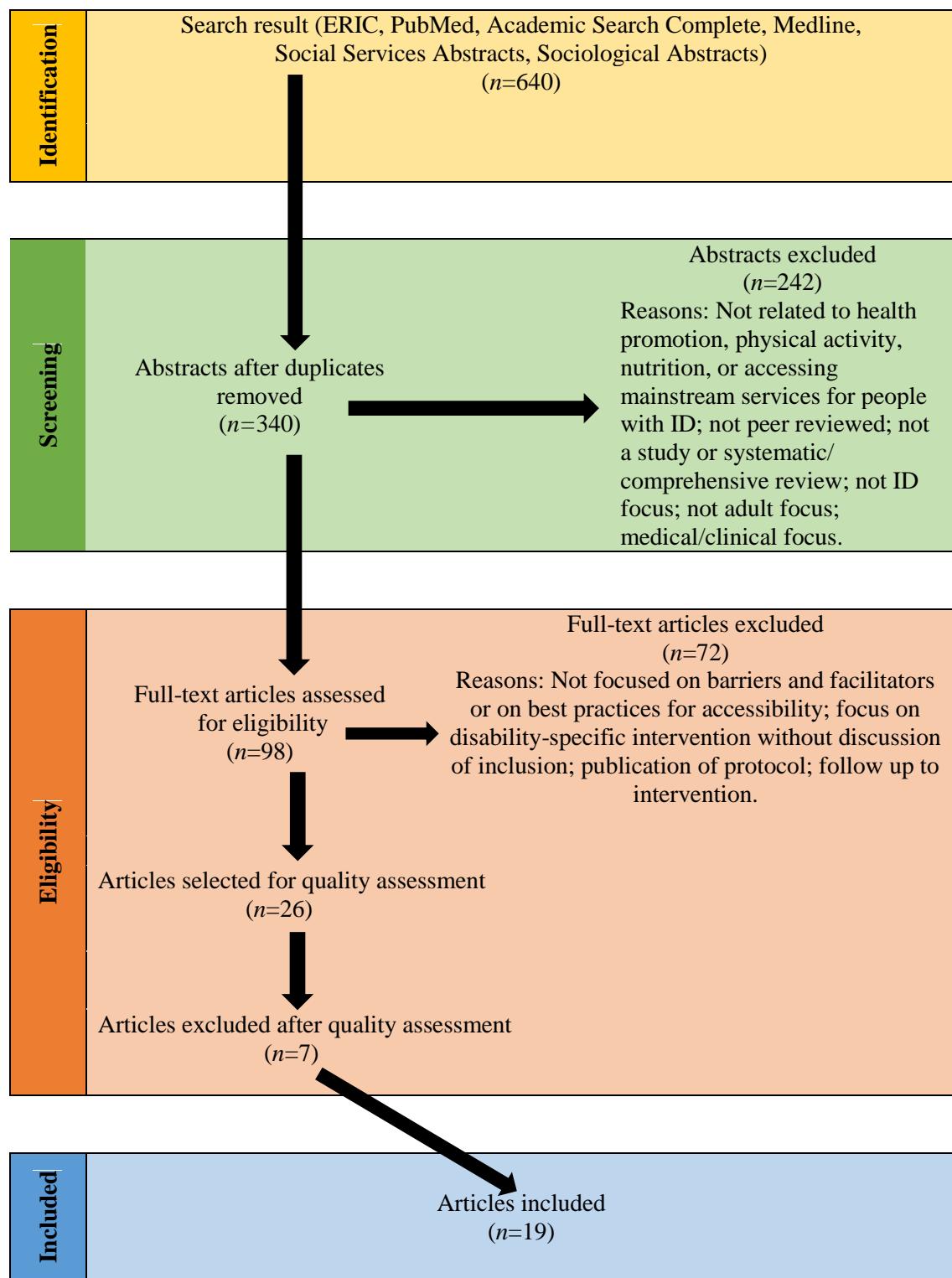
Identification. A computerized search using the ERIC, Medline via OVID, Academic Search Complete, PubMed, and Science Direct was undertaken. Key words used to search for relevant literature related to nutrition included a combination of “intellectual disabilities” with “food, nutrition, meal, food service, meal planning, or meal service.” To search for key words associated with physical activity we used a combination of “intellectual disabilities” with “exercise, physical activity, walking, motor activity, sports, or physical fitness.” Finally, we searched for literature relevant to “intellectual disabilities” and “health knowledge, health behavior, health education, health promotion, or preventive health services.” In addition, we searched the reference lists of articles returned from our database searches.

Screening. Any peer-reviewed research articles, published after 2000, with a focus on inclusive health promotion, healthy eating, physical activity, and/or community participation for people with intellectual disability, were eligible for inclusion. Participants could be adults with

ID, family members, and/or professionals who serve adults with ID. Articles were not excluded based on study design, as discussed earlier. We ultimately included a few studies that took place in and recruited participants from disability service programs (rather than inclusive settings) because they offer valuable data and insight about the factors that influence successful and sustained participation in healthy living activities. These findings can inform the way in which public health and other community agencies adapt strategies to be inclusive and accessible.

Eligibility. We used three different quality assessment tools for the different types of studies included in the review. Each tool is a validated instrument selected in consultation with an expert from the University of Missouri-Kansas City Health Sciences Library. For quantitative studies, we used the *Quality Assessment Tool for Quantitative Studies*, developed by the Effective Public Health Practice Project. This tool addresses the need for reliable evidence to guide the development of public health practice and policy across a range of topics. For qualitative studies, we used the *Quality Assessment Check-List for Qualitative Research Studies – Patients' Perspectives* developed by the Swedish Agency for Health Technology Assessment and Assessment of Social Services. Upon the recommendation of the Health Sciences Librarian who consulted on this review, we selected this tool because although ours is not a review of clinical health literature, the patient-centered approach used by SBU reflects the person-centered values driving the project for which this review is undertaken.

Figure 1. Flow Chart of the Article Selection Process



We used the AMSTAR (A Measurement Tool to Assess Systematic Reviews) tool to assess the quality of systematic and other literature reviews. Developed to aid decision-makers in using systematic reviews to identify evidence-based practices for use in health-related fields, this tool has excellent reliability, good inter-rater agreement, and good face and construct validity (Shea, et al., 2007).

Three staff from UMKC-IHD read the 26 articles selected for quality assessment and scored them using the tools described above. We then met to discuss the articles and each person's justification for the scores they assigned to each article. If we determined that a score needed to be adjusted, we did it at this time. We averaged the scores of the three reviewers and assigned a final score to each article. As a result of this process, seven more articles were excluded from the final review, leaving 19 remaining articles.

Included. Of the final 19 studies (see Table 1), eight originated in the U.S., three in the U.K., three in the Netherlands, two in Australia, two were multinational, and one in Sweden. In terms of quantitative studies, the final group of articles included one randomized control-group trial, two cohort pre-post designs, one observational study, two cross-sectional studies, and one cluster randomized trial. The articles based upon qualitative data included two studies that used focused individual interviews, one that employed interviews and observations, one based on focus groups, two that used both interviews and focus groups, and one that used surveys and focus groups. Each of these used validated qualitative data extraction, coding, and analysis methods. Finally, the systematic literature reviews included one scoping review, and one structured literature review.

Of the 19 studies, eight had a primary focus on physical activity, and six focused on both physical activity and nutrition. An additional two focused on health promotion or health

education in general, two on community participation, and one on the relationship between health perception and neighborhood characteristics. A total of four articles studied the impact of a particular intervention targeting adults with ID. While just eight studies explicitly addressed barriers and/or facilitators as part of their research design, all researchers identified barriers and/or facilitators in the discussion, implications for future research, implications for practice, or similar sections of their papers.

Lastly, adults with ID were the participants in 18 of the studies. Of these, two studies focused specifically on adults with Down Syndrome, and the participants in one study were nurses who work with adults with ID. Participants in four studies included family members and/or support staff.

Table 1. Studies included in the review

| Study | Design | Description | Outcome measures | Findings highlighted in discussion |
|----------------------------------|---------------------------------------|---|-------------------------------------|--|
| Qualitative Methodologies | | | | |
| Caton et al. (2012) | Qualitative Semistructured interviews | Study to explore knowledge and experiences about health in people with ID. 13 adults with ID participated. | | Thematic analysis identified moderation, wellbeing, tobacco and alcohol, medication, and exercise as themes in health understanding. Barriers to healthy lifestyles included inadequate support due to staffing levels and staff interest, inadequate opportunity to apply health knowledge in community settings, perception of risk, motivation. Caregiver knowledge about health and barriers to health is critical as a facilitator. |
| Bergstrom et al. (2014) | Qualitative In-depth interviews | Study to understand barriers and facilitators to implementing a course to improve health literacy and health related behaviors in adults with ID. 83 adults with ID participated. | Health literacy Health behaviors | There is a need to involve participants in planning interventions. It is critical to involve caregivers who can support and facilitate healthy lifestyle choices in everyday settings outside of the class. A focus on health knowledge should be balanced with a focus on empowerment. Instructors need to know how to match teaching strategies to the needs of adults with ID. |
| Kuijken et al. (2016) | Qualitative Focus groups | Study to gain insight into (1) perceptions of own health, (2) what participants consider as healthy living and (3) factors be related to the ability to live healthily. 21 adults with ID participated. | | Existing mainstream projects can be adapted to include people with ID by getting direct input of participants with ID to identify problems and solutions. Knowledge sources can be difficult for people with ID to interpret. Knowing what is unhealthy does not translate into making healthier choices. Support from others, motivation, healthy food available at home, and available facilities in the community were identified as resources by participants. |

| Study | Design | Description | Outcome measures | Findings highlighted in discussion |
|-----------------------------------|--|--|-------------------------|--|
| van Schijndel-Speet et al. (2014) | Qualitative Interviews and focus groups | Interviews and focus groups with 54 older adults with ID to determine facilitators and barriers to PA | | Facilitators were (a) enjoyment, (h) perceived benefits for physical comfort, (c) knowledge about benefits for health, (d) Physical activities as part of the daily routine, and e) being active for a useful purpose. Barriers were lack of self-confidence, fear of activities being too difficult, transportation, and perception of risk by staff or participants. Social support from relatives, staff, and peers seemed to be a prerequisite as well as a motivation. |
| Taliaferro & Hammond (2016) | Qualitative Surveys and focus groups | Study to identify the barriers, facilitators, and needs influencing physical activity participation of adults with ID within the framework of a social ecological model. 6 adults with ID and 6 family members participated. | | Personal level barriers such as lack of skill or motivation may result from constraints at the policy or environmental level such as lack of education, limitations imposed by attitudes of others, or lack of opportunity. It is important to consider the needs of family members as well as needs of person with ID. Having support people as "champions" for PA is an important facilitator. PA staff and leaders need the understanding, skill, and knowledge to provide support to adults with ID. Information dissemination is a barrier that crosses the interpersonal, organizational, and community levels of the social ecological model. |
| Mahy et al. (2010) | Qualitative Structured interviews | Study to identify the barriers and facilitators for participating in PA for adults with Down Syndrome. 6 adults with DS and 12 support people participated. | | Facilitators: (1) support from others; (2) activity was fun or had an interesting purpose; and (3) routine and familiarity. Barriers: (1) lack of support from others; (2) not wanting to be physically active; and (3) medical and physiological factors." Strategies should include educating support people about the importance of activity, encouraging them to be more physically active themselves and assisting them to minimize any associated burdens such as time constraints and transportation |
| Focht-New (2012) | Qualitative Naturalistic inquiry with surveys, focus | Study to explore 1. experiences of RNs providing health teaching to adults with ID, 2. teaching | | Exposure and experience were critical to nurses' development as teachers of people with ID. Teaching strategies included developing easy to understand materials, use of repetition and review, use of humor, demonstrations, opportunities to share, extra time for complex concepts. Caregivers are gatekeepers of opportunity. Success with gaining access through caregivers |

| Study | Design | Description | Outcome measures | Findings highlighted in discussion |
|-----------------------------------|---------------------------------------|---|---|--|
| | groups, and observations | topics and how they are selected and 3. what teaching strategies are used. 23 nurses participated. | | required social approaches of building trust, developing relationships, using various teaching strategies to engage caregivers, increasing caregivers' knowledge and experience, and being responsive to them. |
| Quantitative Methodologies | | | | |
| Melville et al. (2015) | Quantitative Cluster randomized trial | Walk Well behavior change program to support adults with ID to walk more, to increase levels of physical activity and to reduce time spent sedentary. | Primary (mean steps/day) and secondary (moderate vigorous-vigorous physical activity, overall physical activity, sedentary behaviours, body mass index and wellbeing) | There was no significant effect on either primary or secondary outcomes. Lack of effect in the Walk Well trial may be due to a lack of availability of social support to make walking accessible, facilitate community participation and moderate social disadvantages. Lack of time to walk, complicated behavior change techniques, and inability of participants to use/fill out the scales may have contributed to lack of effect. |
| Chng et al. (2013) | Quantitative Observational | Study to evaluate program to train peers without ID to support retirees with ID to participate in community groups. 3 pairs participated. | Activity engagement, Social engagement | Activity engagement increased strongly at post-test and follow-up combined, (PND = 95%). There was no effect on social engagement. Both supported (PND = 65%) and independent engagement (PND = 71%) increased. Based on observing social interaction in both supported and independent activities, authors concluded that all three participants experienced substantial social inclusion. |
| Heller et al. (2003) | Quantitative Survey | Study to assess the determinants of exercise participation in adults with Down Syndrome. 44 | Exercise participation | Instructional material needs to be designed for people with limited reading and comprehension skills. The significant determinants of exercise participation were carers' perceived outcomes of exercise for persons with DS and access barriers such as transportation, "no one to exercise with," "no one to show me how to exercise," and inaccessible facilities. |

| Study | Design | Description | Outcome measures | Findings highlighted in discussion |
|-----------------------|----------------------------------|--|---|---|
| | | adults with DS filled out surveys. Support people filled out informant surveys. | | Professionals who work in community-based fitness centers need training on accommodation issues. The training should also focus on family and staff attitudes and expectations for exercise. |
| Bazzano et al. (2009) | Quantitative Cohort pre/post | Community-based peer-led health promotion intervention for adults with DD. 85 participants. | Changes in weight, BMI, abdominal girth, access to care, and self-reported nutrition, physical activity, self-efficacy, and life satisfaction | Positive outcomes of significant weight loss, improved nutrition, increased exercise frequency, increased self-efficacy, and improved access to care. Carer motivation impacts the effectiveness of weight loss interventions. Carers may be better able to support weight management in the longer term if they are included in the intervention learning process. Peer mentors were especially effective in supporting individuals with developmental disabilities in making changes and building community capacity. |
| Ewing et al. (2004) | Quantitative Two groups pre/post | Study to compare the impact of an 8-week cardiovascular disease risk reduction group teaching program for 92 individuals with ID and 97 normal learners. | Changes in weight, BMI, and self-reported exercise and eating habits | Two thirds of participants who completed the program lost or maintained weight, with statistically and clinically significant decreases in BMI and abdominal girth. Follow up calls indicated that people with ID made sustained changes in exercise and diet patterns, so authors felt that the impact was greater than just BMI change might suggest. Improving education and motivation for carers would improve outcomes for people with ID. |
| Emerson et al. (2014) | Quantitative Cross sectional | Secondary analysis of longitudinal data. Examines the relationship between social connectedness of people with ID and health. Data from 279 people with ID and 22,979 without. | | The sample was households in the general population and included people with mild to moderate ID who may not receive disability services. There is a great need for more data on this population. Health inequalities may be partially attributable to less favorable perceptions of important neighborhood characteristics and lower levels of social and civic participation. |

| Study | Design | Description | Outcome measures | Findings highlighted in discussion |
|---------------------------------------|-------------------|--|--|--|
| Systematic and Scoping Reviews | | | | |
| Brooker et al. (2016) | Systematic review | Review of interventions designed to increase PA in adults with ID | Increased levels of PA in adults with ID | Public health officials should find ways to target and include people with ID. We should amend interventions to suit the lives of people with ID, rather than requiring them to fit into programs that are not tailored to them. Some evidence that goal setting strategies, health education focusing on the benefits of PA, incorporating PA into the intervention and using group and individual delivery modalities are effective. Most studies are not high quality and there is a lack of measurement tools validated for use with people with ID. |
| Heller et al. (2011) | Scoping review | A scoping review of studies on physical activity and nutrition health promotion interventions for individuals with intellectual disabilities | Weight loss, BMI, fitness, PA levels, knowledge, life satisfaction | The interventions that were most effective in reducing weight were those with health behavior education incorporating both healthy eating and exercise. Key challenges include developing programs that take into account intellectual limitations (e.g., difficulty understanding, lack of knowledge), other cognitive and social emotional barriers (e.g., lack of motivation, lack of self-efficacy, poor outcome expectations), and issues of accessibility (e.g., transportation, accessibility of equipment, money). |
| Verdonschot et al. (2009) | Systematic review | A review of the literature concerning the influence of environmental factors, as defined in the ICF (WHO 2001), on community participation for adults with ID. | Varied | Factors with positive influence: choice making, variety and stimulation of the environment of facilities, vocational services, family involvement and social support factors with negative influence: lack of transport, attitudes of people in the community and staff. |
| Bodde & Seo (2009) | Systematic review | A review to analyze the barriers to PA for adults with ID | Varied | Lack of support from others, cost, and transportation were frequently identified as barriers. These are all modifiable. Residential staff, managers, service providers, and policy makers can collaborate to alleviate barriers so that people with ID are able to make choices about their health. Battling the perception of risk is critical and caregivers should be trained in promoting PA as a part of normalization and integration. |

| Study | Design | Description | Outcome measures | Findings highlighted in discussion |
|---------------------------|------------------------------|---|-------------------------|---|
| Hutzler & Korensky (2010) | Systematic review | Review to identify motivational correlates that both contribute to, and can be assumed to be effects of, participation in sport, recreation, or health-related physical activities in persons with ID | Varied | Improved fitness and skills can increase self-efficacy, which is a factor in both initiating and sustaining PA. Social support from peers, family, and staff is an important determinant of motivation for PA. Peer-based modeling, training for instructors/coaches, and involvement of family and staff, and video-audio aids help to sustain participation over time. More research is needed to understand the different benefits or negative aspects of segregated versus integrated sport environments. |
| Naaldenberg et al. (2013) | Structured literature review | Review to provide insight into the main characteristics of published health promotion intervention studies for people with ID and, in, doing so, to identify best practice and knowledge gaps. | Varied | Findings suggest that the field of health promotion research is underdeveloped for this group. This is consistent with commentary that people with ID represent a marginalized and too often overlooked population group in public health. There is a “need for research that...actively bridges the gap between mainstream and ID health promotion research by building on existing mainstream knowledge and theories, tailoring mainstream projects toward the needs of people with ID.” |

Findings

The aim of this review is to gain understanding into the barriers and facilitators that affect how and to what extent people with ID participate in healthy living resources and programs, as well as into characteristics of interventions that have increased participation by people with ID in mainstream healthy living resources and activities. To that end, we read each paper with the purpose of not only understanding the research outcomes presented but also to record the researchers' insights, recommendations, and findings about such barriers and facilitators. We discuss the chief factors affecting the participation of people with ID in community-based healthy living resources in the following sections. Each section includes findings about the characteristics of programs/interventions that have been successful in increasing accessibility and participation.

Support from family, peers mentors, and staff (16 studies). Many people with ID cannot participate in community programs without someone to take them to the site, and many need a support person with them during the activity. Even public health strategies such as informational campaigns about healthy eating may not be fully accessible to people with ID without support from family and/or staff. Researchers repeatedly mentioned that if the support person is not willing, does not understand the importance of nutrition and fitness, or simply doesn't have time, then the person with ID does not have the opportunity to access community resources (Bazzano et al., 2009; Bergstrom et al., 2014; Caton, et al., 2012; Taliaferro & Hammond, 2016; Heller et al., 2003; Van Schijndel-Speet et al., 2014). This is relevant to mainstream community organizations seeking to become more inclusive

"Participants told us they were dependent on staff or their relatives to go outside or to take part in an activity. However, [support persons] did not always have enough time to support them in physical activities."

Van Schijndel-Speet, et al., 2014

because it can inform their collaboration with disability service providers as well as the way they structure both programs and outreach strategies. For instance, Bazzano et al. (2009, p. S206) point out that people with ID often make lifestyle choices collaboratively with their caregivers, suggesting that programs need to take into account the needs, preferences, and schedules of support persons.

Many of the findings about support apply to both staff and family, but some distinctions became apparent:

1. Staff support is often dependent on organizational policies and budget (Verdonschot et al., 2016; Taliaferro & Hammond, 2016; Heller et al., 2011). Participants in a qualitative study about health knowledge among adults with ID (Caton et al., 2012) said that staff did not have time to take them for walks, and that staff did not know how to prepare fresh healthy food and did not have time to do it. In their analysis of the interview data, the authors wrote that “inadequate staffing levels restrict what people with ID can do, eat and drink, and also where they can go.”
2. Family involvement is consistently linked with greater community participation for people with ID, (Verdonschot et al., 2009; Hutzler & Korensky, 2010; Bazzano, 2009), but family caregivers often face time constraints, stress, and mental or physical health issues of their own. Three of the articles in this review cited feedback from parents on the difficulty of finding the time to take their adult children with ID to fitness activities, as well as the challenge of finding accessible programs that the person with ID enjoyed. Taliaferro & Hammond (2016) reported that family members were more motivated if the community programs met their needs as well as those of their relative with ID.

A number of other articles reinforced the importance of involving and educating support people. Heller et al. (2003) found caregivers' perception of the benefits of exercise to be a significant predictor of participation for adults with Down Syndrome. Similarly, people with ID are more likely to make healthy choices at the grocery store if accompanied by a support person who is "informed and motivated" to support new skills and behaviors about food (Bergstrom et al., 2014, p. 169).

Motivation and preference (14 studies). The motivation of people with ID to participate in healthy eating and/or physical activity was mentioned as a barrier or facilitator in 14 studies. Many researchers specifically identified factors that influence motivation, positively or negatively. These factors have been grouped into the categories of "social support" and "fun and enjoyment" as described below.

Social support. In their 2010 systematic review of motivational correlates for physical activity in adults with ID, Hutzler & Korensky (2010) identified social support as a strong contributor to motivation, and Taliaferro & Hammond (2016) found "camaraderie" with peers to be a predictor of motivation. While the concept of social support is clearly linked to the caregiver issues discussed above, it also applied more broadly to the need for people with ID to have opportunities to socialize and build relationships in their neighborhoods and communities. Melville and colleagues (2015), in exploring the disappointing results of a physical activity intervention for people with ID, found one factor was a lack of this broader social support. They suggested that "increased participation...is likely to require

"While support and encouragement from others helps bolster participation in the general population, it appears to be a critically essential factor for adults with ID who have no option but to depend on tangible social support to be able to participate in physical activity."

Bodde & Seo (2009)

specific social support that is over and above existing support from family and paid carers” (p. 9). In a similar finding, Van Schijndel-Speet and colleagues (2014) reported that key facilitators of physical activity for older adults with ID include social contact and friendship, and support from others. In a study on the relationship between social connectedness and health for adults with ID, participants were more likely to report their own health as “good” or “very good” if they also reported “regular social contacts with friends” (Emerson, 2014).

WHAT WORKS

One promising approach to increasing social support is *Active Support* mentoring, in which volunteers without ID are trained to support people with ID to participate in community activities. A recent study, although small, resulted in significantly increased participation of adults with ID in community center programming (Chng et al., 2013). The data on social support may be especially relevant to public health agencies striving to become more inclusive. Melville (2015) points out that cooperation among various community entities can help “reduce the social capital/networks barriers to adults with intellectual disabilities participating in community activities...for example, social enterprises, volunteer organizations, and buddy programmes may all have a role to play in supporting adults with [ID] to become more active” (p. 9).

Enjoyment and rewards. Put simply, fun is a strong motivator for participation. While this is true for the population in general, it has particular implications for health promotion strategies that are effective for people with ID. Several studies identified fun and rewards as facilitators for motivation (Bodde & Seo, 2009; Hutzler et al., 2010; Heller et al., 2003; Heller et al., 2011; Naaldenberg, 2013; Taliaferro & Hammond, 2016;). Mahy (2010), in a study of

barriers and facilitators to physical activity for adults with Down Syndrome, identified fun and socializing as a primary facilitator for participation, noting that participants “generally had a negative attitude to formal exercise, but had a more positive attitude to social activities that included an element of physical activity” (p. 802). Similarly, Taliaferro and Hammond found both fun and social support to be key facilitators for physical activity: “Adults with ID identified their motivation for participation as revolving around the importance of fun, getting to be with other people, and friends” (p. 126). In a study of barriers to physical activity for adults with Down Syndrome (Heller et al., 2003), participants reported motivation-related barriers including “lack of energy (46%), too difficult (41%), boring (39%), and too lazy (30%)” (p. 169). These findings, according to the authors, suggest that fun and stimulation may influence motivation more than education about the benefits of exercise.

Accessibility of health promotion materials and programs (13 studies). Nearly 70% ($n=13$) of the studies identified accessibility of health promotion materials as a barrier to participation. Naaldenberg and colleagues (2013), in a review of challenges to health promotion for people with ID, wrote that “health promotion activities for the general population often assume a certain level of independence, can be difficult to understand, expensive, inaccessible, or invisible to people with ID or their supporters” (p. 4535). Researchers cited specific concepts that people with ID had difficulty with, such as portion size and moderation (Kuijken et al., 2016; Naaldenberg, et al., 2013), as well as a broader need for adapted materials appropriate for low literacy or low health literacy users (Heller et al., 2003; Brooker et al., 2015). Both written materials and presentation techniques need to be appropriate for people with ID. Bergstrom and colleagues (2014), in evaluating a health education intervention for people with ID, found that when participants did not “grasp what was expected” they could become insecure

and therefore resistant to continuing the activity. Nurses describing their experience learning to provide health education to people with ID recommended using repetition and review, humor, concrete demonstrations, opportunity to interact, and extra time for complex concepts (Focht-New, 2012). People with ID can also have difficulty understanding how to use exercise and fitness equipment/technology, which creates a barrier to participation and relates to the need for support people during fitness activities (Heller, et al., 2003; Bazzano et al., 2009).

WHAT WORKS

Naaldernberg (2013) found some evidence that goal-setting strategies, health education focusing on the benefits of physical activity in both group and individualized formats, and incorporating physical activity into the intervention are effective, but that was based on only six studies with weak study design and small samples. Heller et al (2011), looking specifically at reducing obesity in people with ID, found that the most successful interventions combined health education components with physical activity components. They cite the *Health Matters Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities*, an evidence-based intervention using best practices for health literacy, universal design principles, and adult learners. This curriculum has consistently produced positive outcomes in fitness level, health and wellness knowledge, and self-efficacy for participants, but has not been tested or adapted for use in inclusive settings outside of the disability service context (Marks, Sisirak, & Chang, 2013).

Self-efficacy (7 studies). Lack of self-efficacy can be a barrier to participation for people with ID who may feel uncertain trying new things or may have experienced failure or

rejection (Bazzano et al., 2009; Verdonschot et al., 2009; Hutzler & Korensky, 2010). As defined in Bandura's Social Cognitive Model, self-efficacy refers to one's own belief in one's ability to do things (Bazzano et al., 2009). The insights and data from the seven studies that included findings on self-efficacy and the additional three that discussed self-efficacy may be especially relevant to public health or other community agencies. In striving to make strategies accessible, it is important to consider how to support self-efficacy and empowerment and how to mitigate initial fear or insecurity (Bergstrom et al., 2014; Van Schijndel-Speet et al., 2014; Heller et al., 2011). Hutzler & Korensky (2010), in their review of motivational correlates for physical activity participation, noted findings from Peterson et al (2008) that peer support was significantly correlated with self-efficacy ($r=.028$), which in turn was correlated with participation ($r=.024$). This finding aligns with other work showing that perceived lack of skill competency can inhibit participation in physical activity for people with ID (Taliaferro & Hammond, 2016). Overall, Hutzler & Korensky (2010) found that the “improved physical fitness and elevated skill levels” from participation in sport or exercise mediated increased self-efficacy

WHAT WORKS

A community-based intervention to increase physical activity resulted in significant gains in self-efficacy related to nutrition and healthcare access. The study authors attributed the gains in self-efficacy in part to the use of community-based participatory research, in which people with ID were meaningfully involved in the design, development, and evaluation of the intervention (Bazzano et al., 2009). Heller et al. (2011) reviewed 11 health promotion interventions and found that the ones that included a physical activity component were more likely to result in increased self-efficacy.

for participants. Indeed, a review of health promotion interventions concluded that “lack of motivation, lack of self-efficacy, [and] poor outcome expectations” were among the greatest challenges to effective health promotion for people with ID (Heller et al., 2011).

Attitudes about disability (7 studies). Lack of acceptance by the general public and by staff at community sites was identified as a barrier in seven studies. Nearly a quarter of adults with Down’s Syndrome listed “people might make fun of me” as a barrier to participation in physical activity (Heller, 2003). In a 2010 study, support people identified “a lack of community awareness, a lack of acceptance of adults with ID, [and] a lack of understanding about disability” as barriers (Mahy et al., 2010, p. 801). Perceived negative attitudes of people without ID can hinder participation in community activities by people with ID, while feeling accepted can increase participation (Verdonschot et al., 2009, Van Schijndel-Speet, et al., 2010).

In the Active Mentoring study (Chng et al., 2013), the researchers found that “members from...three mainstream community groups responded favourably when approached to support” people with ID, and that the program increased social inclusion of the participants with ID as well as both their supported and independent engagement in community activities. (It should be noted that the acceptance by community members in this study is in contrast to findings from other research on resistance among the general public to including people with ID (Chng, et al., 2013).

“Doing activities that were the norm among fellow group members set the stage for community acceptance and ultimately, social inclusion.”

Chng, et al., 2013

Staff and volunteer training (8 studies). Staff training, along with volunteer or peer mentor training, was mentioned in eight studies. Professionals, family members, and people with ID tended to identify training as a means to address primary barriers such as accessibility of

WHAT WORKS

In a qualitative study of teaching methods used by nurses to educate people with ID about health, Focht-New (2012) found that exposure and experience were critical to changing the nurses' attitudes. The nurses said that "unlearning" past perceptions about ID was as important learning specific teaching strategies. They also reported that their acceptance of people with ID and respect for their abilities and skills grew with exposure.

materials/programs, motivation, and general attitudes about disability (Heller et al., 2011; Heller et al., 2003; Taliaferro & Hammond, Focht-New, 2012; Verdonschot et al., 2009; Naaldenberg et al., 2013). As one study summed it up:

"There is a need for program instructors, staff, and physical activity leaders to have the understanding, skill, and knowledge to provide support to adults with ID to maximize participation, motivation, and safety. Policies are needed within organizations to address the perceived lack of staff and administrator training and support" (Taliaferro & Hammond, 2015).

Cost (4 studies). Just four of the studies cited cost as a barrier to participation in healthy living activities. However, one of these was a systematic review (Bodde & Seo, 2009) that found personal and/or agency financial constraints to be a barrier in six of the seven studies included. Heller and colleagues (2003) reported that 36% of adults with Down Syndrome and 39% of support people cited cost as a barrier, and Mahy and colleagues (2010) cited cost as a barrier but did not indicate the significance. One review cited "financial constraints" on the part

of agencies as a barrier to implementing accessible health promotion programs (Naaldenberg et al., 2015).

Perception of risk (7 studies). Several studies mentioned that safety regulations, caregiver protectiveness, fear of injury, or uncertainty about medical professionals' approval prevent people with ID from participating in healthy living activities. Participants in one study said they could not learn healthy cooking skills in their group home because they were not allowed near a hot stove (Caton et al., 2012). Bodde & Seo (2009) found "risk assessment" by support persons to be a significant barrier. They note "adults with ID may be physically able to participate in PA but are either prohibited from doing so by concerned caregivers, or may have learned over time that they are to be careful to 'not overdo it' because they see themselves as fragile when it comes to PA" (p. 63). The two studies on barriers for adults with Down Syndrome also cited concerns about health limitations and fear of injury (Heller et al., 2003; Mahy et al., 2010). Older adults with ID listed fear of falling as a barrier to physical activity, and many of them also said that support people discouraged them from activity because of safety or health concerns (Van Schijndel-Speet et al., 2014). Bodde & Seo (2009), after analyzing barriers to physical activity for adults with ID, concluded: "battling this perception [of risk] is critical and caregivers should be trained in promoting PA as a part of normalization and integration" (p. 63).

Transportation (15 studies). Transportation is consistently mentioned as a challenge or barrier for people with all kinds of disabilities. For example, 15 of the 19 articles included in this review make some mention of transportation. Of these, six identify transportation as a significant or primary barrier to participation. Interestingly, family members mentioned transportation as a greater barrier than did participants in three articles, saying that their adult child with ID could participate in more community activities if the family member was not the

only source of transportation (Bodde & Seo, 2009; Taliaferro & Hammond, 2016; Mahy et al., 2010). Heller et al. (2011) included transportation as a key accessibility challenge for effective health promotion activities for people with ID. No articles included recommendations or data on solutions to transportation issues.

Discussion

The importance of personal relationships. The articles included in this review demonstrate that relationships are perhaps the most important mediating factor in determining whether a person with ID is able to participate in community-based fitness and nutrition programs. The majority (16, 84%) of the articles listed in Table 1 (see pages 15-20) indicate that a person's relationships with a support person (family, peers, or staff) can serve as either a facilitator or barrier to full participation. For example, as Van Schijndel-Speet (2014) noted people with ID who participated in their study were often dependent on staff or relatives to "go outside or to take part in an activity." Furthermore, Bazzano et al., (2009) indicate that people with ID tend to make lifestyle decision collaboratively with the people who provide support. Even the motivation to participate in fitness and nutrition programs is impacted by social support. For example, Taliaferro & Hammond (2016) found "camaraderie" with peers to be a predictor of motivation.

The importance of personal relationships points to a few things public health programs can do to make their programming accessible to people with ID. First, recognize that people with ID will often be accompanied by a support person. It is important to welcome support people, as they will play an important role in determining continued participation. Second, train public health staff to work with people with ID. As we mention above, seven (37%) of the articles we reviewed discuss the importance of staff training and volunteer or peer mentor

training. Perhaps as Chng and colleagues (2013) suggest, public health staff could be trained to provide *Active Support* mentoring, in which people without ID are trained to support people with ID to participate in community activities. Training may also help alleviate any fears or negative attitudes related to ID. Multiple articles [37% (7)] indicated that perceived negative attitudes about ID and the abilities of people who have ID create a barrier to participation.

Accessibility of health promotion materials and activities. An important characteristic of interventions/strategies that effectively increase the participation of people with ID in community-based public health programs is accessible written material and presentation techniques. As we noted above, Bergström and colleagues (2014) found that when participants did not “grasp what was expected” they could become insecure and resist continuing the activity. Similarly, people with ID can have difficulty understanding how to use exercise and fitness equipment/technology, which creates a barrier to participation (Heller, et al., 2003; Bazzano et al., 2009). Some solutions for making health promotion materials and activities accessible include:

1. Using repetition and review
2. Using humor
3. Providing concrete demonstrations
4. Providing opportunity to interact
5. Allowing extra time for complex concepts (Focht-New, 2012).

Lastly, Mahy et al. (2010) found that a number of barriers and facilitators to activity are quite similar for people with or without ID. Everyone has time constraints. Everyone likes to have fun. Most of us do not want to be bored and many of us worry about the costs of activities. Making a program or activity accessible will not only make it inclusive of people with ID but

will very likely make it more fun and useful for people without ID (Jenson, Peterson-Besse, Fleming, Blumel, & Day, 2015).

Phase 2: Community-Based Systems Modeling

The purpose of the system-modeling sessions was to gain insight into the conceptual and causal relationships community members attribute to policies and practices that impact participation of individuals with ID in public health nutrition and physical activity programs.

These sessions occurred in six regions of the state and with adults with ID ($n=25$), family members ($n=8$), and disability support and public health professionals ($n=41$).

Systems modeling is based in a methodology called fuzzy cognitive mapping (FCM), long used for compiling expert knowledge in a network of causal links (Kosko, 1986). FCM is a reliable knowledge-based model that facilitates “sense-making” by helping program partners and stakeholders communicate about strategies and decisions (Jetter, 2006). Through the systems modeling sessions, the project team gathered the viewpoints of multiple stakeholders to develop a better understanding of causal patterns between specific variables (Gray, Chan, Clark, & Jordan, 2012; Jetter & Schweinfert, 2011). In essence, the process leads to a person’s hypothesis about how to achieve the best results based on the personal experience.

This methodology is highly participatory and fosters social learning between participants. The FCM process begins with individual participants developing a map which depicts the most efficient way for a system to achieve a goal—inclusive health and nutrition programs in our case. In the map, concepts are connected using arrows that indicate causality. A positive or negative arrow indicates that an increase/decrease in the first concept leads to a corollary increase/decrease in the second concept (Jenson et al., 2017).

Procedures. Each of the modeling sessions followed a script to ensure fidelity of implementation across our three participant groups (Table 2). We gave participants a blank systems-modeling template similar to the one depicted in Appendix A. Next, the facilitator

described the Missouri Disability and Health Collaborative and explained that we were conducting the sessions in order to create a model that would inform targeted actions with the goal of improving the health of the people with ID and their inclusion in public health programming. Following a short question and answer period, the facilitator led participants through a series of questions that helped each participant complete an idea map (see Table 2). Groups were limited to 10 or fewer participants. The facilitators provided as much support and took as much time as was needed by individual participants.

We limited the number of concepts participants could list for each question for two reasons. First, we wanted to force participants to choose the concepts that were the most important and not simply provide a list of ideas. Second, as Borgatti (1996) noted, some people are “lumpers” and some are “splitters.” Two such participants could have identical views about making community fitness and nutrition programs accessible, but we would not be able to discern this because their data would look quite different. Therefore, each of the participants was required to identify the same number of concepts. Once they identified these concepts, we asked participants to identify directional and weighted relationships between concepts. This enabled us to analyze the direct and indirect effects of each concept that participants believed support healthy lifestyles for people with IDD. Following the development of the maps, we asked each participant to describe their maps and explain the meaning and importance of each concept. This provided context for our analysis of each concept and enabled us to code each map accurately (Petri & Corwin, 2015). Using the added directional and weighted relationships, we merged the maps from multiple participants to show a dynamic display of direct and indirect effects.

Table 2. System Modeling Instructions

1. As you see here, our ULTIMATE GOAL is Accessible Community Fitness and Nutrition Programs for people with developmental disabilities. You will draw a map that describes how to reach our goal.
2. In the ovals, under each question:
 - a. List 2 – 3 things that make it hard for community fitness and nutrition programs to make their resources and activities accessible.
 - b. List 2 – 3 things that make it hard for people with ID to access fitness and nutrition programs.
 - c. List 2 – 3 things that community programs should do to make activities accessible.
 - d. List 2 – 3 things community programs should do to make resources and information accessible.
3. Draw arrows between all items that are related to one another.
4. Rate the strength of each connection using the following scale:

| Strong | Moderate | Mild |
|---------------|-----------------|-------------|
| 3 | 2 | 1 |

Participants

The participants included individuals with ID (25), family members of people with ID (8), and professionals (41). The professionals included people who provided disability supports [29% (12)] and people who worked in public health [56% (23)]. Five (12%) of the professionals did not provide information about their field. Table 3 provides a summary of all participants.

Table 3. Systems Modeling Participants.

| People with Intellectual Disabilities (n=25) | |
|---|-----------|
| Race/Ethnicity | |
| American Indian/Alaska Native | 1 (4%) |
| Black/African American | 2 (8%) |
| White | 19 (76%) |
| Missing | 3 (12%) |
| Gender | |
| Male | 8 (32%) |
| Female | 17 (68%) |
| Age Range | |
| Average age is 41 years old | |
| Age Range between 19 and 68 years old | |
| Disability Status (9 people listed more than 1 disability; 4 people listed more than 2) | |
| Autism | 5 (20%) |
| Cerebral Palsy | 2 (8%) |
| Down Syndrome | 1 (4%) |
| Epilepsy | 1 (4%) |
| Intellectual Disability | 17 (68%) |
| Learning Disability | 8 (32%) |
| Traumatic Brain Injury | 3 (12%) |
| Other | 2 (8%) |
| Family Members (n=8) | |
| Race/Ethnicity | |
| Asian or Pacific Islander | 1 (12.5%) |
| Black/African American | 1 (12.5%) |
| White | 6 (75%) |
| Gender | |
| Female | 8 (100%) |
| Relationship to Person with ID | |
| Mother | 5 (62.5%) |
| Other | 3 (37.5%) |

Table 3. Systems Modeling Participants.

| Professionals (n=41) | |
|------------------------------|----------|
| Race/Ethnicity | |
| Black/African American | 3 (7%) |
| Hispanic/Latino | 1 (2%) |
| White | 33 (81%) |
| Other | 1 (2%) |
| Missing | 3 (7%) |
| Gender | |
| Male | 6 (15%) |
| Female | 32 (78%) |
| Missing | 3 (7%) |
| Professional Role | |
| ID Support Professional | 13 (32%) |
| Public Health | 24 (59%) |
| Missing | 4 (10%) |
| Years in the Field | |
| Average of 16 years | |
| Range between 1 and 45 years | |

Analysis

We used an item level analysis (Lecompte & Schensul, 1999) to code the data. Two members from the needs assessment team from UMKC-IHD read the maps and together developed a codebook. Our process included discussions about the contents of the maps that led to consensus on the names and definitions for individual codes. Ultimately, we identified 18 core concepts that emerged from the maps (see Table 4). Once the codebook was complete, we individually analyzed maps and then met weekly to compare the coding structure of data across team members. Anytime there was less than a 100% level of agreement across all codes, we discussed areas of disagreement, and recoded the data until agreement level reached 100%. We repeated this process until we had coded all the maps.

Following the coding process, we used Microsoft Excel (2007) to create an adjacency matrix for each map. We used the directionality of the connecting arrows and the strength score assigned to each connection to develop each adjacency matrix. We coded the connections with numerical weights, which represented the scale ranges of “strong,” “moderate” or “mild” strength (see Table 2). We then merged the individual matrices into one data set, which we exported to R (R Core Team, 2016) for the final analysis.

Table 4. Concepts, Definitions, and Frequencies Represented in Participant Maps.

| Concepts | Definition | Prof. (n=41) | Fam. (n=8) | Ind. (n=25) | Total (N=74) |
|--|--|-----------------|---------------|----------------|-----------------|
| Advocate | A person's ability and willingness to advocate for the opportunity to participate. | 3 | 0 | 3 | 6 |
| Cost | Barriers associated with the cost of community fitness and nutrition programs for people with ID and their support persons. | 68 | 7 | 14 | 89 |
| Desire & Motivation of People with ID | The level of interest in fitness and nutrition programs among people with ID. | 24 | 4 | 14 | 42 |
| Desire & Motivation of support person | The level of interest in fitness and nutrition programs among support persons. | 5 | 1 | 0 | 6 |
| Health & Wellness Knowledge | Level of knowledge about healthy choices in a person's life. . | 10 | 1 | 1 | 12 |
| Inclusive Development | Include people with ID in the development of programs and promotional materials. | 11 | 0 | 0 | 11 |
| Interagency Partnerships | Partnerships between organizations that allow them to provide accessible fitness and nutrition programs | 24 | 4 | 0 | 28 |
| Location | Location of community and fitness and nutrition programs and the impact that has on accessibility. | 29 | 3 | 6 | 38 |
| Outreach and Information Placement | Creative ideas about how to reach people with ID and their families with program information, as well as where to place information. | 49 | 6 | 9 | 64 |
| Program Knowledge | Awareness of what programs are available in the community. | 32 | 5 | 6 | 43 |
| Public/staff Attitudes | Refers to general public's level of acceptance of ID; Stigma; attitudes of staff. Refers also to the perception by | 11 | 2 | 1 | 14 |

Table 4. Concepts, Definitions, and Frequencies Represented in Participant Maps.

| Concepts | Definition | Prof. (n=41) | Fam. (n=8) | Ind. (n=25) | Total (N=74) |
|------------------------------|--|-----------------|---------------|----------------|-----------------|
| | people with ID that they might not be welcome or that a program will not be inclusive. | | | | |
| Representative Images | Using imagery in promotional materials that includes people with ID. | 8 | 2 | 0 | 10 |
| Schedules | Refers to the times when a fitness or nutrition program is offered. | 11 | 1 | 2 | 14 |
| Staff Training | Offer specific training about ID awareness, fitness and nutrition, universal design, accommodations, and/or health disparities. | 36 | 4 | 1 | 41 |
| Support Person | Individuals need a support person (staff or family) who will attend fitness and nutrition programs. This can include volunteers and peers who may be matched with an individual. | 19 | 8 | 11 | 38 |
| Time | Refers to having the time to participate or support fitness and nutrition programs | 3 | 0 | 1 | 4 |
| Transportation | Refers to transportation issues that impact access to and from community fitness and nutrition activities | 61 | 3 | 16 | 80 |
| Universal Design | Refers to a broad spectrum of ideas meant to produce products and environments that are inherently accessible to all people | 89 | 13 | 30 | 132 |
| TOTALS | | 493 | 64 | 115 | 672 |

We employed a confirmatory factor analysis (CFA) to examine the latent constructs within the mapping data. As a part of the structural equation modeling (SEM) family, CFA plays an essential role in model validation (Brown, 2014; MacCallum & Austin, 2000). CFA helped us understand the relationships among the mapping concepts and the underlying factor structure for creating accessible community fitness and nutrition programs. (Yang, 2003).

Upon examining the data, we excluded concepts mentioned fewer than 20 times, which left ten remaining core concepts: Cost, Desire and Motivation of People with ID, Outreach and Information Placement, Program Knowledge, Interagency Partnerships, Location, Staff Training,

Support Person, Transportation, Universal Design. Based on the global model fit indices and the factor loadings in each model, we removed variables with the lowest factor loading from the model until we achieved acceptable model fit. Ultimately, four concepts remained in the final model structure (see Table 5 and Figure 2).

Model fit. For the final model, the Chi-square statistic was not statistically significant, which means that the model's implied and observed matrices are the same. The absolute model fit index, Standardized Root Mean Residual (SRMR; Bentler, 1995; Joreskog & Sorbom, 1986), which represents the standardized difference between the observed and implied variances and covariances, was found to be a close fit (SRMR =.03). Therefore, the absolute fit statistic (SRMR and Chi-squared) shows a close fit. We used the Root Mean Square Error of Approximation (RMSEA; Kelley & Lai, 2011) for comparative fit, which was within the borderline for a close fit ($RMSEA <.05$). In addition, the Comparative Fit Index (CFI; Bentler, 1990) indicated a close fit ($CFI =1.00$), and Tucker-Lewis Index (TLI; Tucker & Lewis, 1973; Bentler & Bonett, 1980) indicated a close fit ($TLI =1.07$). Therefore, we conclude that the model has a close to perfect fit, which lays the basis of reliable item level estimates and leads to valid result inferences. Table 5 presents the item level estimates and factor loadings, which range from .42 to .70, with significant p-values. Additionally, Figure 2 presents a path diagram for accessible community fitness and nutrition programs.

Table 5. Factor Loadings for Each Concept

| | <i>N</i> | λ | <i>S.E.</i> | <i>p-value</i> |
|----------------------------------|----------|-----------|-------------|----------------|
| Outreach & Information Placement | 64 | .45 | .17 | <.001 |
| Interagency Partnerships | 28 | .42 | .16 | .03 |
| Staff Training | 41 | .70 | .30 | <.001 |
| Universal Design | 132 | .50 | .17 | .01 |

Figure 2. Path Diagram for Accessible Community Fitness & Nutrition Programs.



Discussion

As we mention in the introduction of this section, the systems modelling process leads to a community-based hypothesis about how to achieve the best results based on the personal experiences of the participants. Using the FCM methodology, we identified four statistically significant community-based strategies (Figure 2). Because the identification of these strategies is based on the experiences of a broad range of Missourians, we propose that they are strategies worth pursuing. Furthermore, they are strategies that are relatively easy to implement. These four strategies (Staff Training, Universal Design, Outreach & Information Placement, and Interagency Partnerships), were not necessarily the concepts that were mentioned most often. They were, however, the concepts that the participants linked strongly to multiple other concepts,

meaning that they believed these concepts were likely to have the greatest impact on making community fitness and nutrition programs accessible.

Through the systems modeling process, we identified other strategies or concepts that were important to the participants even though we were not able to demonstrate statistical significance for them. These concepts included concerns about cost, location, and transportation. Participants mentioned these concepts more than the statistically significant items “Staff Training” and “Outreach and Information Placement.” This indicates that while people were concerned about cost, location, and transportation, they did not perceive them as integral to making public health programs accessible to people with ID. This is appropriate given that two of these concepts (Cost and Transportation) are not concepts that public health programs could change. In terms of cost, the strategies currently implemented by public health programs are free to community members. Lastly, transportation is not a system that is widely controlled by the DHSS or public health agencies and there is very little that they could do to improve it. On the other hand, they can train their staff, implement universal design, improve outreach and information placement, and create new interagency partnerships.

Phase 3: Community Health Inclusion Index (CHII) Organizational Assessment Survey

About the CHII Organizational Assessment

The Organizational Assessment Survey is one component of the Community Health Inclusion Index (CHII), created by the National Center on Health, Physical Activity and Disability to collect information about inclusive healthy living resources in a community. The survey asks questions across five topic areas: healthy eating programs and policies; physical activity programs and policies; staff training and incentives; healthcare; and inclusion attitudes. Results identify barriers to inclusion for people with disabilities and indicate the kinds of training, resources, and technical assistance that community nutrition and fitness organizations need to become fully inclusive.

Local Public Health Agencies in Missouri already implement a number of successful evidence-based strategies to increase physical activity and healthy eating habits in our communities. The Missouri Health and Disability Collaborative will use the CHII Organizational Assessment Survey, along with other needs assessment data, to develop new toolkits and training that will extend the reach of these programs so that people with ID can participate and benefit alongside their neighbors, colleagues, friends, and family who do not have disabilities.

Survey Participants

Statewide, 56 (49%) of 115 local public health agencies completed the survey. The majority of participating professionals (40) identified themselves as supervisors, with two HR Coordinators, two Communication Liaisons, and 20 who selected “other.” (Because the survey is designed to be completed by teams, the total number of professional roles selected exceeds the total number of agencies.) Of the 56 agencies that completed the survey, 44 (79%) identified as a

“healthcare site,” eight (14%) identified as a “worksite,” and four (7%) identified as a “community institution/organization.”

Promoting Healthy Eating Through Policies and Programs

Nearly three quarters [(73% (41)] of agencies reported having at least one policy that promotes healthy eating. Most frequently, these respondents cited policies encouraging staff to serve as role models for healthy eating [70% (39)], while just 18% (10) had policies about offering healthy food at company events.

70%
Have policies
encouraging
staff to serve as healthy
eating role models



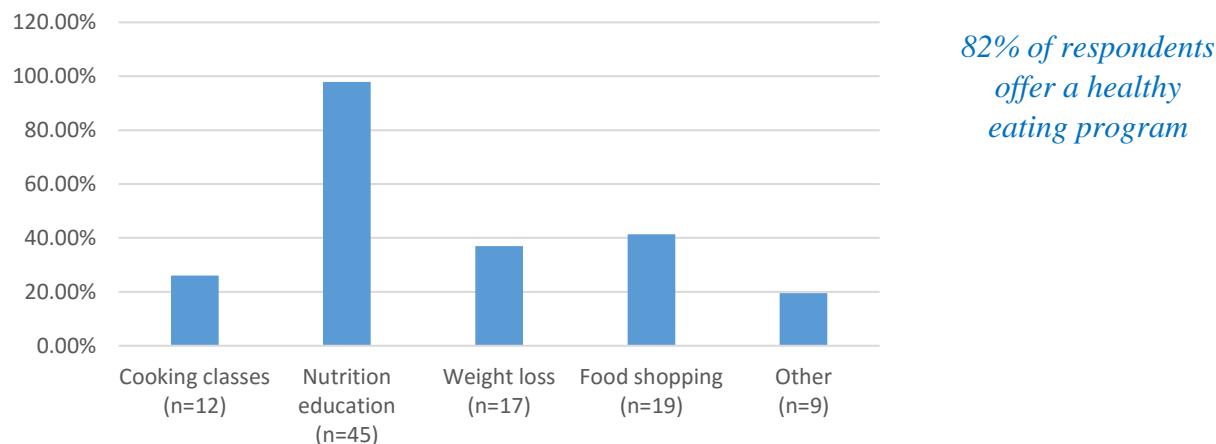
18%
Have policies about
offering healthy food at
company events



Eleven (20%) agencies reported having food for sale at their site, with the majority (8) through vending machines. Of these, eight (72.3%) have policies about stocking healthy items and involving stakeholders in food policy decisions. Just five (45%) have a policy that healthy items are priced comparably to unhealthy items, and four (36%) reported that meals provided meet nutrition standards.

Healthy eating programs. A total of 46 (82%) agencies reported that they offer at least one healthy eating program. The types of programs offered are shown in Figure 3.

Figure 3. Healthy Eating Programs



Notably, while the majority of these agencies offer some type of accommodation [85% (39)] and hold programs in accessible locations [98% (45)], just 56% (26) reported having a policy about inclusion and only 23% (11) offer adapted equipment.

Over 90% of agencies (42) offer nutrition programs at no charge or provide subsidies/discounts for low-income participants. Adapted equipment available included accessible scales for weight loss classes (3) an accessible room (1) and general declarations of accessibility (5).

91%
Charge no fee or offer subsidies

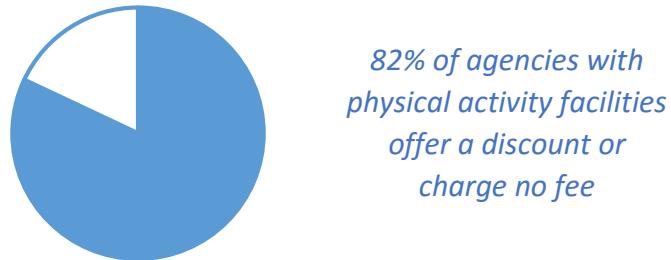
70%
Provide accommodations such as allowing a support person to attend

56%
Have a policy that nutrition programs be inclusive

Participating in Physical Activity

Overall, 48% of agencies (27) reported at least one facility available for physical activity at the site (e.g., gym, pool, outdoor walking track, indoor activity room, etc...). Most of the sites either charge no fees for use of these facilities [56% (15)] or offer discounted memberships/fees [26% (7)].

Figure 4. Cost of Participating in Physical Activities



Physical activity programs. Of the 27 agencies with physical activity facilities on site, 12 (44%) offer at least one physical activity class or program on site. While this is a small sample of agencies with programs, the data about accessibility and inclusion still offers valuable insight:

- 10 out of 11 respondents hold physical activity programs in an accessible location
- 10 out of 11 also said that physical programs are designed so that people with or without disabilities can participate equally
- 3 agencies have adapted equipment, such as a seated elliptical trainer and an all-abilities playing field

Accessible programs specified by respondents include yoga class (1), cardiac rehab (1), stretching programs for those with arthritis (1), aerobics (1), and all classes/programs available (5).

Program materials. Most participants [80% (45)], use some kind of instructional/educational materials for nutrition or physical activity programs. Among these, 25 (56%) indicated that they make their program materials available in alternative formats such as braille, pictographs, ASCII, video with captions, large print, or audio.

Staff training. Only 39% of participants (22) reported that staff receive some type of disability awareness training either onsite or through outside education. These organizations covered key disability awareness concepts to varying degrees:

36%

Train staff on communicating with people with different types of disabilities (*n*=8)

32%

Train staff on providing services to people with different types of disabilities (*n*=7)

23%

Train staff on first-person terminology and on adapting the environment for people with disabilities (*n*=5)

Training policy. Among the 22 respondents (39%) who reported some disability training for staff, 18 (82%) indicated their agency had at least one policy about such training.

- 13 agencies (59%) reported a policy that staff at all levels receive disability awareness training
- 12 (55%) indicated that disability awareness training is part of human resources policy
- 3 respondents (14%) said that people with disabilities are involved in the training

A few agencies (6) also indicated they provide disability awareness training for physical activity program staff at their sites. This training included “*using written and electronic resources for reference when working with persons with disabilities*” (3), “*providing adapted physical activity programming*” (2), and “*training persons with disabilities on using exercise equipment*” (1).

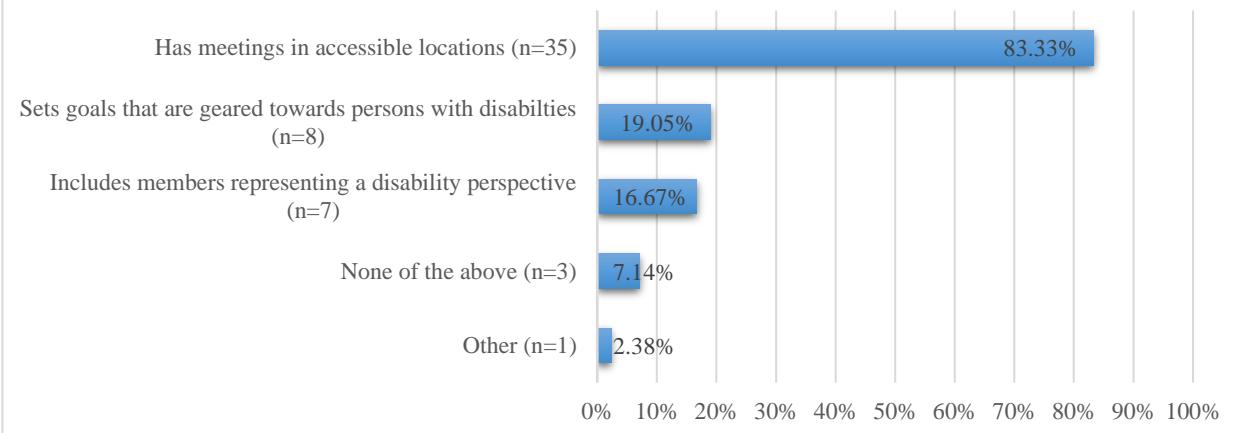
Disability Awareness Training –

Training provided by employers to inform staff of how to work with and be sensitive to the special needs of persons with disabilities that will enable such persons to function and thrive in the given environment. Training includes the dismantling of stereotypes and misconceptions.

Inclusive Wellness and Health Promotion

Over 75% of agencies (42) reported that they are part of a wellness committee/work group/coalition. People with disabilities have varying opportunities to participate in and contribute to such groups; while 85% of agencies (35) hold meetings in accessible locations, only 16% (7) include members who bring the disability perspective, and just eight (19%) set goals that are geared toward people with disabilities.

Figure 5: Activities to Promote Participation of People with Disabilities in Wellness Coalitions (n = 42)



Transportation

Just one agency reported that they provide transportation to their site. This agency indicated that the transportation is used for students with disabilities to attend extracurricular activities and that it includes a “ramp or lift for entering the vehicle.”

Questions Specific to Healthcare Sites

Out of 44 respondents who identified as a healthcare site, over 60% (27) indicated that they offer obesity screenings for patients with disabilities, and over 65% (29) also record physical activity levels of people with disabilities. The table below further illustrates policies and practices related to healthcare screenings for patients with disabilities.

62% Offer obesity screenings for patients with disabilities (27)

66% Ask patients with disabilities about their level of physical activity (29)

9% Have a roll-on or lift scale to weigh a patient who uses a mobility device (4)

18% Have ASL interpreters available at the site (8)

Employee health. Agencies answered questions about promoting employee health as part of their overall health and wellness promotion effort. A total of 59% (33) offer incentives for engaging in healthy lifestyles (e.g. healthy eating, weight loss, or physical activity). The most frequent incentives offered are shown on the following page.



37% offer prizes such as merchandise or gift cards

(21)



32% offer physical activity breaks during the day

(18)



23% offer resources to promote healthy lifestyles (exercise equipment, cookware)

(13)

In addition, 16% (9) offer time off as an incentive, 23% (13) offer discounted gym memberships, 12% (7) offer discounted insurance, and 7% (4) offer funds for healthy eating or weight loss programs.

Readiness for Change

This section of the survey explores the extent to which organizations see inclusion of people with disabilities as a goal and are committed to improving their capacity for inclusive health promotion.

Inclusion

"The active engagement of people with disabilities in all aspects of health promotion. Programs, policies and environments are inclusive when they go beyond accessibility and encourage full participation, where people with disabilities are valued contributing members with a sense of belonging."

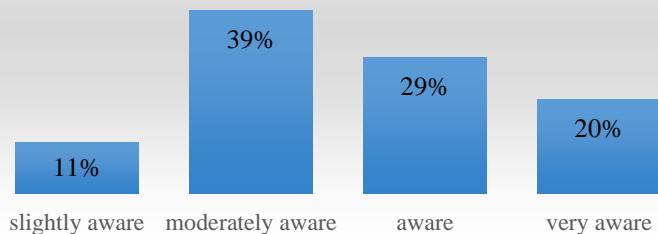
Five indices determine organizational readiness for change: Awareness about inclusion of people with disabilities in health promotion, concern about inclusion in health promotion, leadership support for efforts to increase inclusion, plans for new efforts toward inclusion, and adoption of plans to improve building site accessibility. Among the 56 local public health agencies that took the Organizational Assessment Survey, 21% of agencies (12) stood out for

high scores across all five indices. An additional 20% (11) scored highly on at least three indices.

The distribution of scores on all five indices is represented below.

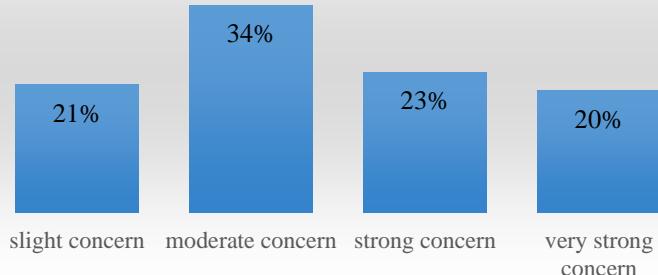
Agency Responses to the Readiness Index Questions

Figure 6. How aware is your organization about inclusion of persons with disabilities in health promotion?



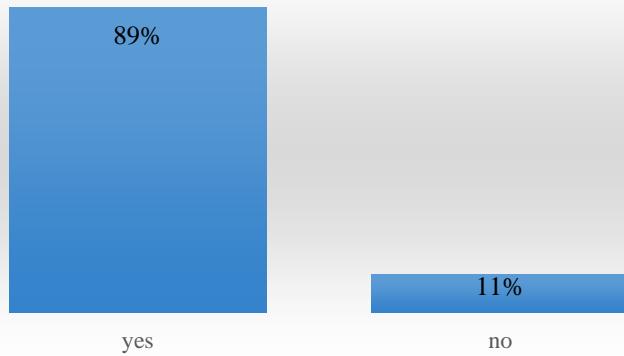
Nearly half of respondents [49% (27)] rated their agency's awareness of disability inclusion as "aware" or "very aware," with an additional 40% (22) reporting "moderate" awareness. One did not answer.

Figure 7. How much of a concern is inclusion for your organization?



Over half (53%) of respondents said inclusion was a "strong" or "very strong" concern. A surprising 21% (12) said it was a "slight" concern. Two did not answer.

Figure 8. Does agency leadership support efforts to increase inclusion?



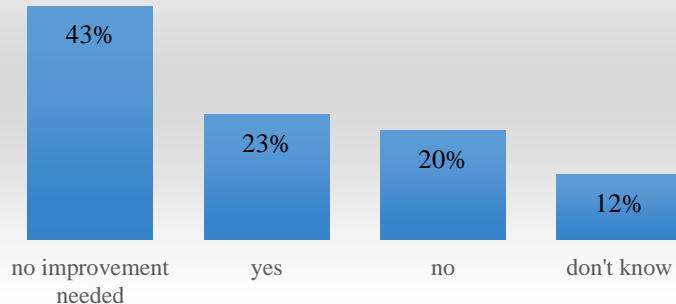
A large majority of agencies reported that leadership supports efforts to increase inclusion [89% (50)]. Just 11% (4) of leaders do not support such efforts. Two organizations did not answer.

Figure 9. Is agency planning inclusion efforts?



Just 23% (13) mentioned that they are currently planning additional efforts/services toward inclusion. Most [73% (41)] reported no plans, and 4% (2) did not answer.

Figure 10. Has agency adopted plans to make building more accessible?



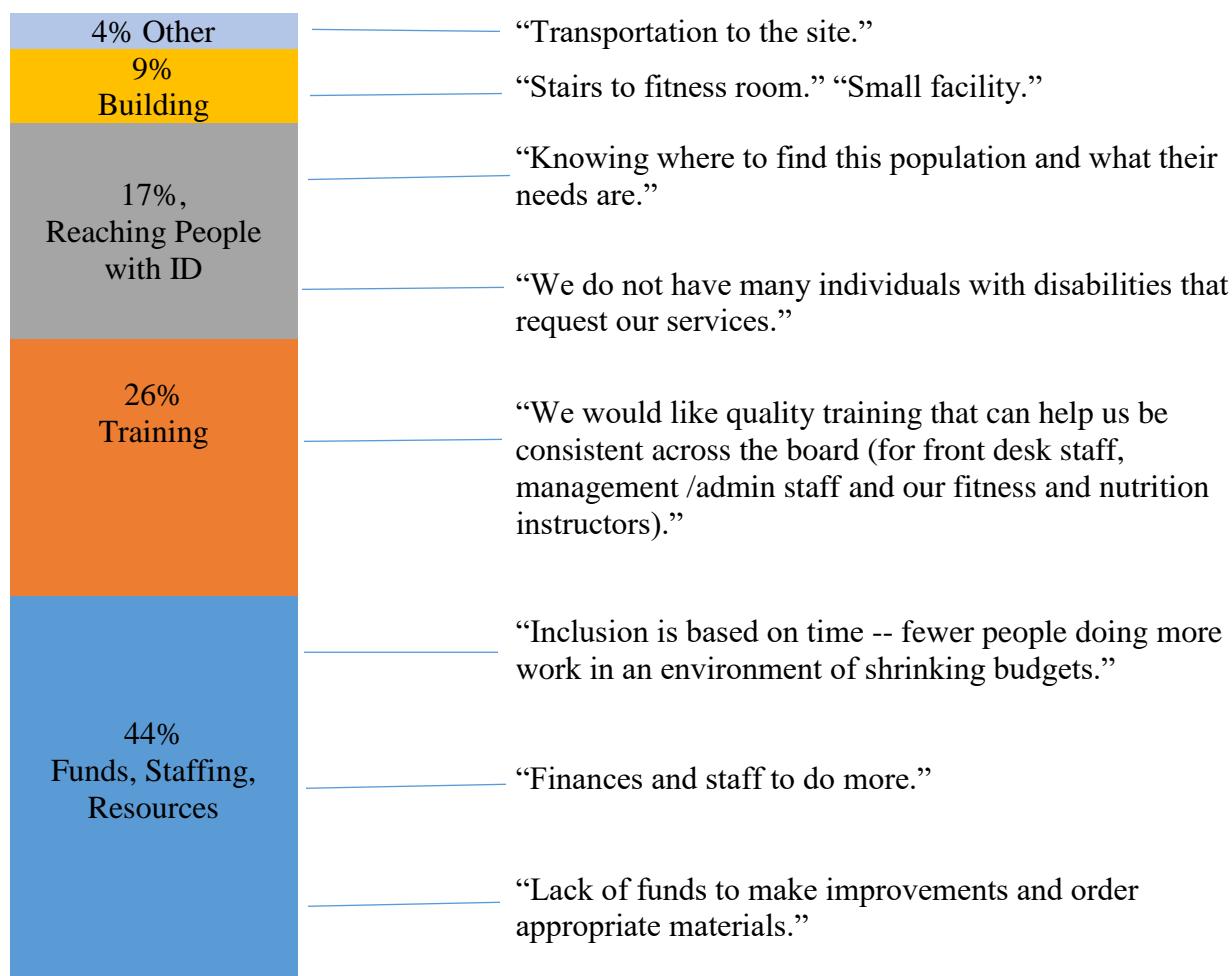
Asked about plans for making the building site more accessible, 43% of agencies (24) said that no improvements were necessary, while 23% (13) indicated they have adopted plans for improvement, 20% (11) have not, and 12% (7) answered “don’t know.”

Specific plans to enhance inclusion included:

- Adding new facilities to the building such as installing a lift (3)
- Changing policies such as making strategic plans and using regional community health assessment data to identify needs (3)
- Others including drive-through flu clinic, combatting obesity, and free support group for mental health (5)

Participants also had the chance to identify obstacles their organizations face regarding inclusion of people with disabilities in health promotion (Figure 11). Among the 37 who provided feedback (each respondent could provide more than one comment), funding was the most frequent [44% (19 comments)]. Participants specifically mentioned funding for added services, more staff, capital improvements, and/or resources such as a wheelchair scale. Another 26% (11) referenced training for staff, and seven respondents said they did not know how to identify people with ID in their communities or find out their needs.

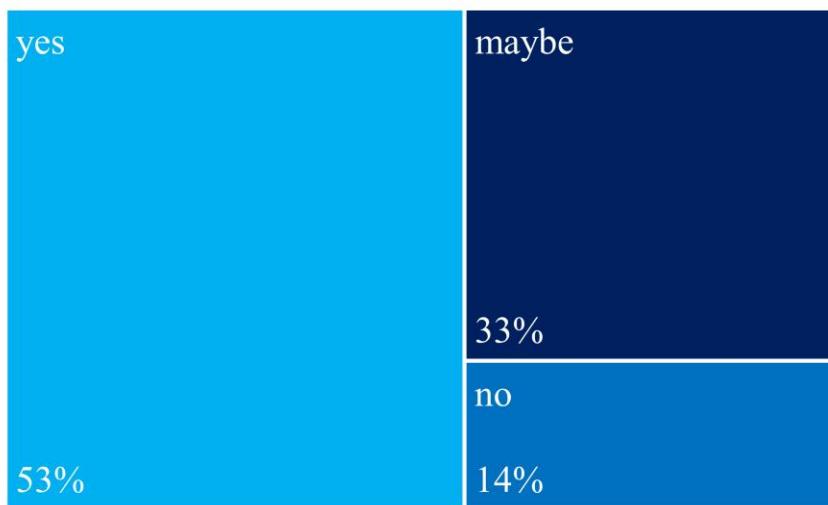
Figure 11. Obstacles to Full Inclusion



Need for Technical Assistance

Of the 48 agencies who responded to the question about technical assistance, just over half [53% (25)] indicated interest in receiving technical assistance or resources to help them become more inclusive of people with disabilities. Another 33% (16) responded “maybe and only 14% (7) expressed no interest in additional assistance (see Figure 12).

Figure 12. Agencies Interested in Technical Assistance to Increase Inclusion



Conclusion

Public health agencies across Missouri clearly indicate willingness to become more inclusive and accessible for people with disabilities and have provided a candid and thorough assessment of their strengths and challenges regarding inclusion. While just 39% of agencies surveyed have disability awareness training in place and 56% have policies about inclusion, agencies told us that their leaders support efforts to increase inclusion and many said they would like technical assistance to do so.

One indicator of the gap between intention and practice is the finding that nearly 90% of agency leaders support increased inclusion, but just 23% of agencies have current plans for additional efforts/services that would enhance inclusion/accessibility. The professionals who completed the surveys shed some light on this discrepancy in their comments about the obstacles they face (see Figure 10). The bulk of the 44 comments [44% (19)] related to funding/resources and staff training. Respondents wrote, for instance, that they “already run with a limited number of staff who all do many different jobs” and that they “may not always know there is a need for

better accommodation.” A further obstacle they identified is how to identify the ID population and understand the needs. One respondent mentioned the challenge of reaching “those in our community who are not necessarily part of a formal group or interact with a local service agency,” and another said that it was “hard to get the group homes to participate.”

Finally, among the 56 local public health agencies that took the CHII Organizational Assessment Survey, 21% of agencies (12) stood out for high scores across all five indices. Nearly all of these 12 agencies (10) indicated that they would like to receive technical assistance. Additionally, almost all of these 12 agencies (11) had at least one policy that promotes healthy eating, seven of them had at least one inclusion policy, and six of them provide disability awareness training. Based on these encouraging results, we recommend that these 12 organizations be allowed to participate in the pilot phase of the Missouri Disability and Health Collaborative activities.

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Appendix A
Systems-Modeling Template

Community Fitness and Nutrition Programs

Missouri Disability and Health Collaborative

Community Fitness and Nutrition Systems-Modeling Project

Professionals

1. Race/Ethnicity

- American Indian or Alaska Native
- Asian or Pacific Islander
- Black, not of Hispanic origin
- Hispanic/Latino
- White, not of Hispanic origin
- Other

2. Gender

- Female
- Male

3. Your professional role

- Public Health Professional
- IDD Support Professional
- Other _____

4. How many years have you worked in your field? _____

What makes it hard for community fitness and nutrition programs to make their resources and activities accessible?

What makes it hard for people with IDD to access fitness and nutrition programs?



What should community programs do to make activities accessible?

What should community programs do to make resources and information accessible?

Appendix B

Universal Design

Universal Design (UD) is an approach to the design of environments, communication, services, and policies to work well for the widest range of people, taking into consideration the widest range of situations. It is not about “special design” for a particular set of people. Rather, it acknowledges that designing for the widest range of users will benefit all users in some way, and often in unexpected ways. The seven principles of UD are equitable use; flexibility in use; simple, intuitive use; tolerance for error; perceptible information; low physical effort; and size and space for approach and use.

As a concrete example, a lever door handle rather than a knob improves accessibility for a person with mobility disability. The same lever could also improve accessibility for someone without a disability whose arms are full when trying to open the door. Another example: removing excess information and using plain language on an agency’s brochure may improve accessibility for a person with intellectual disability. The streamlined brochure will also improve accessibility for a person without a disability who recently experienced trauma. In a related example, simple signage with clear pictures eases the navigation of buildings for all users, including those with low literacy skills.

UD is not a set of specifications or a checklist for compliance, nor does it dictate that one size should fit all. It is a design approach based on seven broad principles that can be used by any organization, program, or facility to enhance experience and outcomes for users (Jenson, et al., 2015).