

Human Development Institute · University of Kentucky

RESEARCH BRIEF

An update on HDI's research in the field of developmental disabilities

Health Matters: From Research to Practice

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Health and wellness for persons with intellectual and developmental disabilities (IDD) is a national issue, and there are compelling data that persons with IDD have poorer overall health, a higher incidence of obesity, as well as fewer opportunities for regular exercise and health promotion activities (Anderson, Humphries, McDermott, Marks, Sissarak, & Larson, 2013). While these overall data are disconcerting, National Core Indicator data present an even bleaker picture for our own state.

In Kentucky, National Core Indicators (NCI) data annually document the outcomes and life satisfaction for over 400 randomly selected individuals with IDD receiving services state-funded Developmental Disabilities services (e.g., Supports for Community Living, Michelle P. Waiver, Money Follows the Person, state general funded programs). Developed in 1997 by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI), NCI has now expanded to include 39 states (National Core Indicators, 2014). Kentucky was one of the early adopters, having participated every year since 1998. This continuous participation in National Core Indicators has allowed the state to track performance on key indicators for persons with IDD (health and safety, employment, rights, service planning, community inclusion, and choice), and to compare performance as a state with the national data set.

In Kentucky, we have been especially focused upon improving outcomes for individuals receiving Supports for Community Living (SCL) Waiver services. SCL is our state's residential Medicaid developmental disabilities waiver; the SCL waiver provides a broad array of services for waiver recipients (residential, supported employment, transportation, community access, etc.) As a part of that focus on improved outcomes, HDI has worked with the KY Division of Developmental and Intellectual Disabilities to create a Quality Improvement Committee to address the life areas in which our state is falling short, including health and wellness, for SCL waiver recipients.

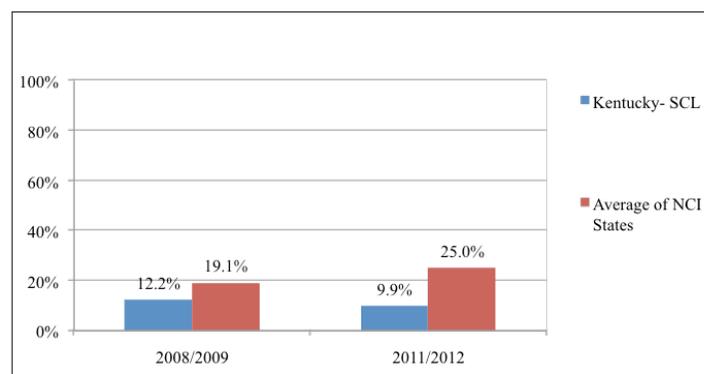


Figure 1: KY Percentage Who Engage in Regular Moderate Exercise Compared to National Core Indicator Average

Figure 1 demonstrates why health and wellness is such a compelling issue for our state. Whereas, at the national level, the number of individuals with IDD who participated in moderate exercise (such as brisk walking, bicycling, cleaning, gardening, or swimming), 30 minutes a day for at least three times per week, increased from 19.1% to 25.0% between the 2008/2009 and 2011/2012 data cycles, the percentage of SCL recipients in Kentucky who met this recommended level of physical activity actually decreased

from 12.2% to 9.9%. While the national data can hardly be considered a positive picture in themselves, the fact that a random sample of KY's SCL recipients were rated as having substantially lost ground in terms of physical activity clearly indicates a clear call for action for our state.

Method and Research Questions

A State Survey of Providers: The Perspective of Service Agencies

While our National Core Indicator data have strongly indicated the need to emphasize health and wellness for individuals receiving SCL services, we wanted to get the perspective of provider agencies, as to what they perceived as the key barriers and potential strategies. Further, we wanted to know if agencies were considering *both* the health and wellness of the individuals they serve, as well as health and wellness for the direct support professionals who work with those individuals. We know that the attitudes of caregivers impact food choices and physical activity (Heller, Hsieh, & Rimmer, 2004). If direct support professionals are not *themselves* knowledgeable of health and wellness, it is doubtful that they can or will encourage individuals with IDD to adopt healthy choices and lifestyles. Thus, in early Spring 2013, we collaborated with the KY Division of Developmental and Intellectual Disabilities to conduct a statewide survey of agencies providing services to individuals on the SCL waiver. We were interested in three basic questions:

1. To what extent were agencies offering health and wellness initiatives for the individuals they serve, as well as similar initiatives for their direct support staff?
2. What are the perceived barriers to putting health and wellness programs into place?
3. Could we identify innovative strategies/promising practices that agencies are currently using?

Results

We received a total of 136 agency responses (representing 54.1% of all SCL provider agencies in Kentucky). Approximately half (49.6%) of the responding agencies reported that they did not offer any health and wellness programs for staff, 35.6% offered occasional programs (1 to 4 per year), and only 14.8% reported offering on-going programs for their staff. For the individuals with IDD served by those agencies, respondents noted offering more frequent programs, with 48.1% stating that they offered on-going health and wellness programs, and only 23.3%

indicating that they did not offer any health and wellness programs to the individuals that they serve.

Interestingly, providers in our survey self-reported a much higher percentage of individuals with IDD who engaged in ongoing regular exercise (moderate exercise, at least 30 minutes per day for three times per week) than our National Core Indicator data (40.1% vs 9.9%). This discrepancy may have reflected a sampling bias (providers who were already addressing health and wellness were probably more likely to fill the survey out to begin with versus the National Core Indicators sample that is drawn randomly), and/or a tendency to put "one's best foot forward" and to report all individuals who were exercising at least occasionally (as opposed to the more rigorous criterion of at least 30 minutes per day 3 times weekly). Incidentally, our National Core Indicator survey found that approximately the same percentage of individuals with IDD – about 40% – were reported to engage in physical exercise *at least occasionally*; thus, the discrepancy in the provider survey may have been that agencies interpreted that item as simply whether the person engaged *periodically* in moderate physical exercise and that they did not respond to the question as it was actually written.

Barriers to Ongoing Health and Wellness Programs.

Agencies reported a range of barriers to ongoing health and wellness programs *for staff*, including 1) cost (for both agencies and individual direct support professionals); 2) time and scheduling, including staff working across multiple shifts; and 3) at least at times, a lack of interest and motivation on the part of staff. Perceived barriers for health and wellness programs for *individuals served* included: 1) Cost and staffing; 2) Individual characteristics (level of intellectual disability, presence of additional disabilities, medical issues); 3) Lack of awareness of the importance of health and wellness on the part of individuals served, as well as motivation to engage in health and wellness activities; 4) Difficulty arranging transportation; and 5) Poor staff role models. Lack of financial and staffing resources along with negative attitudes toward health promotion were common themes across both groups.

Promising Strategies for Health and Wellness Programs.

Agency respondents identified a number of strategies to encourage health and wellness initiatives *for staff* including: 1) Financial incentives/discounted health club and gym memberships; 2) Enfolded health and wellness into a broader program of "stress management", since stress is a significant job element for many direct support

staff; 3) Creating informal competitions to make health and wellness fun (e.g., “Biggest Loser” Contracts); and 4) Developing programs for direct support professionals and individuals served to participate *together*. Promising strategies for health and wellness for *individuals served* included: 1) Establishing funds for health club and gym memberships and/or discounted memberships; 2) Encouraging staff to cook healthier meals; 3) Using established curricula (e.g., Health Matters, Marks, Sisarak, & Heller, 2010); 4) Building exercise programs into daily routines (morning exercises, regular participation in community YMCAs, low impact exercises on a daily basis); 5) Walking to things when possible; 6) Gardening (which also addresses both recreation and healthy eating).

Moreover, we identified several innovative practices from our respondents. These included:

- Enlisting *UK Extension Services* (mentioned by two respondents) to teach classes; it is noteworthy that UK Extension Services are provided in every county in the state.
- Partnering with University Horticulture Programs to teach gardening, landscaping.
- Teaching and providing opportunities for individuals to shop for their own food at local Farmer Markets.
- Cooking classes taught by volunteers.
- Walking groups (and monitoring how much each member walks!).

It is also important to recognize that all of the proposed strategies could be offered in inclusive community environments, and not within a congregate setting for people with IDD.

Implications and Action Plan

In order to improve health and wellness outcomes for individuals with IDD in our state, the Human Development Institute is collaborating with the KY Division of Developmental and Intellectual Disabilities and the University of Illinois-Chicago, University Center of Excellence on Developmental Disabilities, on a series of steps that incorporate the results of our KY National Core Indicator data, our provider survey, and the evidenced-based Health Matters Curriculum (Marks et al., 2013). Over the next year, we will:

- Create a Health Matters Curriculum pilot across 14 provider agencies, including the provision of Certified Instructor training to 4-6 staff members at each pilot agency, who will, in turn, act as Health Matters trainers for the individuals whom they serve.

- Work with each pilot agency to provide the Health Matters Curriculum to 18 to 24 individuals with IDD per agency; the curriculum will be provided in 3 twelve-week Health Matters courses within each pilot agency across the year.
- Work with each pilot site to conduct an Organizational Capacity assessment (including Organizational Culture, Organizational Resources, and Perception of Health Promotion Knowledge and Self-Confidence) at 3 time periods (at baseline, 6 months into the project, and at 12 months). The purpose of the Organizational Capacity assessment is to ascertain the degree to which organizations perceive that they have developed the capacity and resources to sustain a comprehensive health and wellness program.

In addition to the random sample of 400 plus Core Indicator interviews we conduct each year in Kentucky, we will also collect specific health and wellness measures from the National Core Indicators for all of the participants in the Health Matters research study. This will enable us to compare a global measure of health wellness for participants in the Health Matters curriculum in comparison to the population of individuals with ID/DD receiving SCL services in KY as a whole.

We will continue to develop *Health Messaging* pilots throughout Kentucky, which we had started, in collaboration with the KY Division of Developmental and Intellectual Disabilities and the University of Illinois-Chicago, in 2012-2013. In Health Messages, provider agencies nominate a coaching team consisting of one direct support professional and one individual supported by the agency. Each team then receives training to become Healthy Lifestyle Coaches (HLC) and learns ways to effectively deliver health messages to up to 10 people at their agency. The HLC Teams introduce a new health message each week for a total of 12 weeks. Peers are then encouraged to both adopt and to pass onto others that weekly health message. Health Messaging thus encourages the development of unique leadership opportunities for individuals with IDD. The Healthy Life Style Coaches themselves, as well as the administrators of the participating provider agencies who participated in the 2012-2013 pilot, found substantial individual and agency benefits to their participation, including the opportunities for individual with IDD to take a lead role in creating this change within both their own lives as well as for others within their agencies.

Through the process of implementing activities around nutrition and exercise, it is anticipated that there will be a

positive impact upon the culture of how organizations and individuals with IDD perceive health and healthy choices. Central to those changes is the increased self-esteem and self-efficacy toward health behaviors. In providing programming at both the individual and provider level, we will work with stakeholders across the state to create a vision and plan for systemic adoption of health promotion opportunities for people with IDD.

Conclusion

Sustained and systemic change is never easy –but it *is* possible. This Research Brief has attempted to 1) describe the parameters of a significant health issue for individuals with IDD in our state; 2) show how we have attempted to identify both the barriers as well as potential strategies for addressing that issue; and 3) outline the creation of a plan of action – with measurable outcomes – to develop a sustainable and effective vehicle for change. What we have illustrated is a start, but it is a very important beginning to improving the health and wellness status of individuals with intellectual and developmental disabilities in Kentucky.

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You can find more examples of our research on our website at www.hdi.uky.edu.