# RESEARCHBRIEF

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

# Nothing about us without us: Asking Kentuckians with disabilities about what they need to thrive

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## Background

In spring of 2015, the Commonwealth Council for Developmental Disabilities (CCDD), Kentucky Protection & Advocacy (KPA), and the Human Development Institute (HDI; University of Kentucky) developed a needs assessment to identify areas of high need for people with disabilities in Kentucky. The purpose was to gather data in an effort to assist the above agencies in planning future programs and initiatives to benefit people with disabilities.

A needs assessment may serve various roles in the public sector, including identifying unmet needs, assessing a specific population's needs, evaluating the effectiveness of services, providing evidence of community support, increasing public involvement, guiding decisions, designing logic models, making changes, or informing policy (Engle & Altschuld, 2014; Stevens, 2004; Witkin & Altschuld, 1995). In this needs assessment, the goal was to identify areas of high need for people with disabilities in Kentucky and then to develop practice, policy, and service solutions at the systems level, organizational level, and consumer level. A community participation approach was used to disseminate the data and enable persons with developmental disabilities (DD) to develop a capacity to contribute to their own development as well as the development of the community.

In this Research Brief, we describe the process by which the results of this survey are being translated into policies, practices, and services that address the needs of Kentuckians with DD and their families.

## Method and Research Questions

The target populations for the survey were individuals with DD, their families, service providers, and administrators. The needs assessment survey asked for demographic information (including race/ethnicity, gender, county, and whether the participant was a person with a disability, a family member, or a professional). Respondents were asked to rate ten areas of life needs on a Likert-type scale. The survey also included open-ended questions to gather information on specific issues that individuals faced within a particular area of need.

The needs assessment survey was provided in both paper and electronic format, and was made available in both English and Spanish. The paper survey was disseminated at family and advocacy events, as well as at conferences, along with a pre-paid envelope so that respondents could mail the completed surveys directly to the HDI evaluation unit. The electronic link was primarily disseminated by the three organizations, and was hosted by HDI. The survey link was activated in April 2015 and was open until June 2015.

## Results

The majority of respondents were white, non-Hispanic females between 40-59 years of age (53%). Forty-one percent of the respondents resided in Daviess, Fayette, Jefferson, and Kenton counties (Figure 1).

The ten areas of life need were: self-advocacy, education and early intervention, childcare, healthcare, health and wellness, employment, housing, transportation, recreation,

and community supports. Respondents were asked to rate the ten areas on a five point scale (1-very high need, 2-high need, 3-moderate need, 4-low need, and 5-very low need). The areas identified as highest need (rated as a 'high' or 'very high' need) were transportation (48%), employment (46%), and housing (46%). Five major themes arose for transportation: accessibility, affordability, availability, dependency, and reliability. Three major themes surfaced for employment: inefficient systems, limited opportunities, and misconceptions about benefits. Five major themes emerged for housing: accessibility, financial considerations, inefficient systems/laws, support, and unsuitable alternatives.

The results of this analysis were used to help analyze needs, develop programs, and inform policies for persons with DD in order to close a necessary gaps. In addition to the traditional dissemination methods, a multi-pronged stakeholder engagement strategy was employed to identify practices and policies that will address specific issues within the areas of high need. This included engaging state leaders, organizational staff, self-advocates, and families.

### Figure 1: 2015 Respondent Demographics—Region
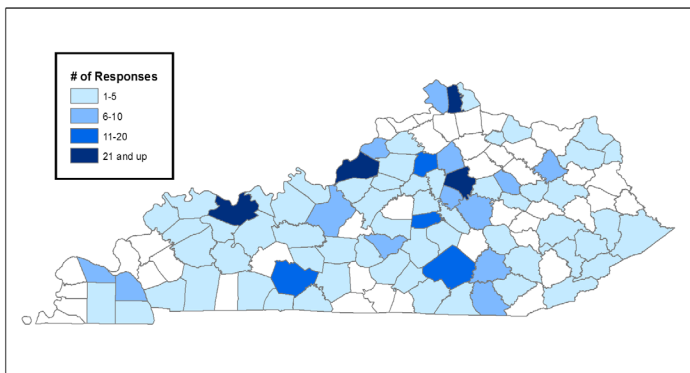


## Engaging State Leaders

This needs assessment was one part of a large state wide collaborative comprised of different organizations. In addition to the DD needs assessment, focus groups were conducted by the CCDD. The Martin School (University of Kentucky) compiled the current status of various Kentucky programs for comparison to other states using several national data sets and then shared the compiled report with the CCDD.

The CCDD Five Year Planning Committee, comprised of state leaders from organizations across the state, examined the data from each source—needs assessment, focus groups, and policy status report. An in-depth presentation was made about the needs assessment results by HDI's Executive Director to the Five Year Planning Committee. The CCDD drafted a preliminary five year plan for review at its October retreat. The plan was further refined at the Council's November 2015 meeting, and then finalized at the February 2016 Council meeting in anticipation of public comment by organizational and advocacy groups. Therefore the results of the

needs assessment played a key role in informing policy and future direction organizations serving individuals with DD.

## Engaging Organizational Staff

In order to explore ways through which HDI could address the areas of high need, the HDI staff assembled to review and discuss the Needs Assessment during the December 2015 all-staff meeting. The major themes and findings of the needs assessment were presented, and then staff were organized into small groups to discuss findings related to transportation, employment, and housing, and to brainstorm about potential solutions. Transportation themes that arose from this discussion included exploration of ride sharing services (like Uber), carpooling, and other transportation alternatives; financial issues; public transportation; and miscellaneous topics. Figure 2 displays the broad strategies and specific solutions identified by the all staff activity.

### Figure 2: Transportation Solutions identified by staff
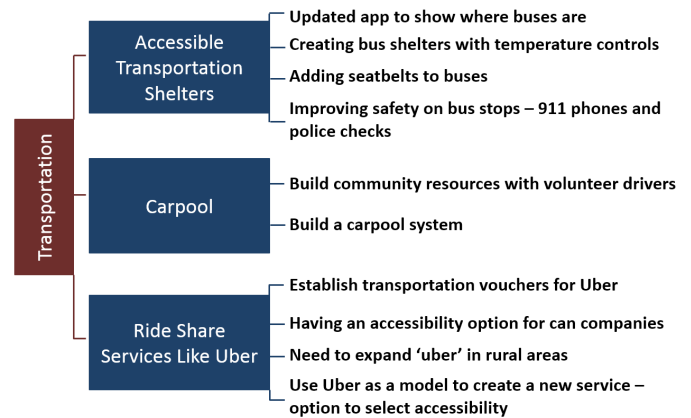


Solutions identified for housing fell under four broad categories: 1. Advocacy and education solutions, 2. housing policies, 3. Caregiver issues, and 4. accessibility. Advocacy and educations solutions included advocating for more resources for housing, raising awareness about available resources and rights about accessible housing, educating case workers about housing resources, educating realtors on accessibility, developing a resource guide for families, and educating pre-service students on accessible housing. Solutions related to housing policies included examining housing policies adopted by other states and exploring partnerships to evaluate affordable housing within the community. Solutions related to caregivers include promoting shared living, increasing the pay rate for personal care attendants, and exploring options for backup caregivers. Solutions related to accessibility included developing builder modules on how to expand the market for their houses, develop and disseminate a list of specialized architects and builders, streamlining the legal process for home modifications, utilizing smart home technology,

and offering incentives like tax credits for making home modifications.

Solutions identified for employment fell under three broad categories: 1. Education/training, 2. Advocacy and information dissemination, and 3. Partnerships. Solutions related to education/training included creating trainings for coworkers on working with someone with a disability, educating about SSI and employment, and educating job coaches, employment professionals, and potential employers about the underused labor market. Solutions related to advocacy and information dissemination included creating a network of employers who will advocate for people with disabilities as employees, creating and promoting an accessible website explaining employment and benefits, disseminating employment and benefits related materials at family resource centers, training self-advocacy skills to help employees problem solve work issues, and working with legislators to ensure KY becomes an Employment First State. Solutions related to partnership included developing communities of practice to help employment specialists and families partner with local businesses to identify employment opportunities, developing a network of mentors for people who are interested in self-employment, and exploring ways to re-establish the business leadership network.

## Engaging Self-Advocates and Families

The HDI Consumer Advisory Council (CAC) seeks to provide "advisement and direction to the HDI, advocating for systems change, assisting with evaluation of HDI effectiveness, [and] reviewing and assisting in the development of HDI proposals," (HDI, 2016a). The CAC officers are individuals with disabilities and/or their family members. CAC members discussed the needs assessment data as part of their quarterly meetings. To date, two areas of need have been discussed—transportation and health care.

Major healthcare themes that arose from the CAC discussion included awareness, advocacy, accessibility, empathy, education/training, self-advocacy, and transition/transfer improvements. The CAC recommended mandatory training that included accessibility, sustainability, and sensitivity training for persons with DD for providers, nurses, and all healthcare staff. The CAC suggested improved self-advocacy skills, such as encouraging the patient (rather than just the parent) to plan ahead for doctor visits, communicating directly with the provider, and also asking for extra time with the doctor during office visits. The Council proposed improved transitions from pediatric to adult healthcare as well as improvements with transfers between healthcare facilities. The CAC recommended more accessible rooms and medical equipment for persons with DD. The CAC discussed raising awareness for healthcare reform through multi-level advocacy measures and also a need
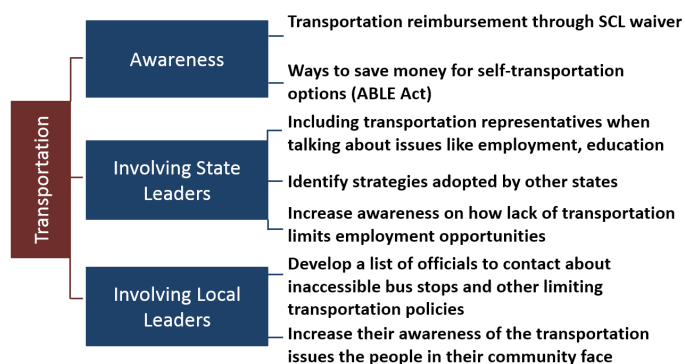
to address violations for persons with DD. The CAC agreed that changes were needed in healthcare for persons with DD.

The solutions identified during the discussion on transportation included training activities to increase awareness about the transportation waiver under the Supported Community Living waiver program, inviting and engaging public transportation coordinators from urban regions and mayoral offices (including representative from the Transportation Department) concerning ways in which transportation could be a barrier to accessing services (employment, education), developing a list of officials to contact regarding transportation issues, increasing awareness about ways to procure self-transportation, and identifying strategies used by other states. Figure 3 displays the major themes identified.

## Conclusion

Clear strategies and conversations about identifying solutions based on the needs assessment is as important as the needs assessment itself. The solutions identified by each group were quite different, as evidenced by the different foci of the organizational staff and the self-advocates and their families on the transportation theme, illustrated in Figures 2 and 3. Embedding the needs assessment data discussion in existing meetings increased the number of people who could participate in such discussions. Important next steps include consolidating the themes from the discussions to create a plan for immediate and long-term solutions to the areas of high need, and working with Kentuckians with disabilities who have identified and experienced these needs in order to ensure that the responses identified will indeed lead to meaningful solutions.

### Figure 3: Solutions identified by self-advocates and family members



Transportation

**Awareness**
- Transportation reimbursement through SCL waiver
- Ways to save money for self-transportation options (ABLE Act)

**Involving State Leaders**
- Including transportation representatives when talking about issues like employment, education
- Identify strategies adopted by other states
- Increase awareness on how lack of transportation limits employment opportunities

**Involving Local Leaders**
- Develop a list of officials to contact about inaccessible bus stops and other limiting transportation policies
- Increase their awareness of the transportation issues the people in their community face

## References

Engle, M., & Altschuld, J. W. (2014). Needs assessment: The perspective from the public sector. In J. W. Altschuld & R. Watkins (Eds.), Needs assessment: Trends and a view toward the future. New Directions for Evaluation, 144, 33-45.

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Witkin, B.R., & Altschuld, J.W. (1995). Planning and conducting needs assessments: A practical guide. Thousand Oaks, CA: Sage Publications.

## About HDI Research Briefs

**HDI Research Briefs** were initiated to highlight the research activities at HDI. Projects at HDI focus on individuals with disabilities and include projects with emphases in early childhood, school age persons, adults, and issues across the lifespan. Many of these projects have significant research components and involve HDI staff, students in graduate programs, and other faculty at UK. With each issue of **HDI Research Briefs**, we will try to provide a cross-section of HDI's research activities. The brief reports are typically "mini" versions of more involved studies. The brief reports are intended to give an overview of the research project and emphasize the implications of the studies.

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