

RESEARCH BRIEF

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

Exploring and Understanding the Advocacy Needs of Kentuckians with Developmental Disabilities

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In this research brief we present the results of a recent needs assessment evaluating the advocacy-based needs for Kentuckians with developmental disabilities and their families. Results highlight the different levels and types of supports needed to build self-advocacy capacity and to inform effective planning and services and the individual, local, and state levels.

Background

Advocacy is the deliberate process of managing information and knowledge with the clear goal to influence and/or change the policies, practices, power dynamics, attitudes and/or actions that directly and positively affect lives. Advocacy can be employed by a directly or indirectly affected population, or by a third party on behalf of an affected population, including those inside and outside of government or other positions of power (Naeve, Fischer-Mackey, Puri, Bhatia, & Yegbemey, p. 1, 2017).

Disability advocacy has played a central part in creating laws, policies, and programs that recognize the rights of persons with disability and provide opportunities for people with disabilities to live in communities. Advocacy can happen at any of four levels—self, individual, system, and legislation. Self-advocacy occurs when a person with a disability speaks up for their rights and for access. Individual advocacy occurs when an individual speaks out against the unfair treatment of a person with a disability. System advocacy is advocating for changes in programs, policies, or procedures. Legislative advocacy is advocating for changes in laws. It is important to identify specific needs at each one of these four levels to ensure that people with disabilities are able to advocate for

their rights as well as ensure that programs and laws provide equitable opportunities for people with disability.

“A need in the simplest sense is a measurable gap between two conditions—what currently is and what should be” (Altschuld & Watkins, 2014, p.6). Needs assessment is a “systematic set of procedures that are used to determine needs, examine their nature and causes, and set priorities for future action” (Witkin & Altschuld, 1995). Advocacy needs assessment informs both how to use resources judiciously to empower individuals to advocate, as well as get a ‘fresh look’ on the issues based on current socio-political climate. This research brief describes the findings related to advocacy based on two recent statewide needs assessments. Kentucky’s Developmental Disability network agencies, including the Human Developmental Institute (University Center for Excellence in Developmental Disabilities), Kentucky Protection and Advocacy, and the Commonwealth Council for Developmental Disability, jointly administer a needs assessment every two-years to inform program planning and delivery for individuals with developmental disabilities and their families.

The survey asks respondents to rate their level of need across 10 lifespan areas, including advocacy. Other lifespan areas addressed in the survey included education and early intervention, childcare, employment, housing, transportation, community supports, health and wellness, healthcare, and housing. In addition to rating needs in these life areas, respondents are also encouraged to write in comments about specific issues within each life area. These comments provide a rich textual data and add depth to our understanding of

specific issues. This research brief presents the qualitative analysis of the textual data as it relates to advocacy.

Method & Analysis

The needs assessment survey includes both demographic and Likert-type scaled questions. The demographic questions included age, sex, role (i.e., individual with developmental disability, family member, provider, administrator, and other), and county of residence. Respondents were asked to rate each life area on a 5-point scale (1- very low need, 2- low need, 3- moderate need, 4- high need, and 5- very high need). As mentioned previously, respondents were asked to provide specific areas of need within each life area. A brief definition for each life area was also included in the survey. The needs assessment survey was administered both in paper and online format. The Internet link to the online survey was sent to agencies, advocacy, and family groups across the state. Self-advocates, providers, and families across the state were invited to complete the survey. The survey was administered in the Summers of 2015 and 2017 respectively. The survey administration window was open for at least 3-months to allow for promoting the survey across communities. Responses from the paper surveys were merged with the online survey responses to create a central dataset.

An inductive thematic analysis approach was employed in analyzing the textual data (written in) by respondents in response to the advocacy needs question. Thematic analysis is a flexible qualitative analysis approach and can be used to 'unpick or unravel the surface of reality' (Braun & Clark, 2006). For the purpose of the analysis, a theoretical framework was not used, and textual data were used to report on the needs of respondents. A priori codes were not used, and themes were derived based on emerging patterns from the textual data. Results from both the 2015 and 2017 surveys are presented in the following paragraphs.

Results

Table 1 displays the major themes and examples of textual data under each theme. The major themes were as follows: (1) providing current and relevant information; (2) need for more advocacy groups; (3) training and coaching on self-advocacy; (4) providing transportation and communication supports for advocates to participate in events; (5) educating guardians, community members, and professionals on issues faced by individuals with developmental disabilities.

Theme	Examples of textual data which fall under theme
Need for more advocacy groups	<p>“There are not enough support and advocacy groups available.”</p> <p>“Not enough self-advocacy resources in rural areas.”</p> <p>“Not enough programs for individuals with autism or their family members.”</p> <p>“More active and visible advocacy groups needed.”</p> <p>“In my area there is only one program that is available to individuals with disabilities. I would like to see more training and advocacy groups in my area.”</p>
Training on self-advocacy	<p>“Individuals need support, training, and people who are willing to listen.”</p> <p>“Services teaching how to self-advocate.”</p> <p>“Self-Advocacy starting in IEP process with more intention, training, and coaching.</p> <p>“Lack of leadership skills, lack of leadership mentors, [and] lack of disability pride.”</p> <p>“Individuals do not know how to advocate for themselves or what resources to access.”</p> <p>“There are NOT enough resources, opportunities, placements, education, trainings, etc. for people with disabilities to be able to be independent and be self-advocates.”</p> <p>“Being able to self advocate - empowered with correct information, understanding processes related to policy change, processes and procedures related to services and assistance received.”</p> <p>“Communication/Assertiveness, learning negotiation rules, more opportunities to practice self-advocacy”</p> <p>“Understanding all of the issues that affect their lives - Income, Medicaid, transportation, housing, etc. Understanding that they have choices and how to make the choices best for them. “</p>

Theme	Examples of textual data which fall under theme
Transportation supports to participate to events Transportation supports to participate to events	<p>“Transportation to different local meetings and events to help promote and assist in developing self-advocacy. Support and assistance from caregivers, family, [and] house personnel supporting in several ways to help the advocates in support, encouragement, understanding of the importance, and transportation to the local meetings to allow meeting with other advocates to participate in events and to learn ways to be a self-advocate!”</p>
Communication supports to enhance participation	<p>“Communication issues limiting their ability to express for themselves their needs and wants. Advocates attempt to fill these roles, but advocates have limitations in their ability. We need earlier intervention and education in alternative means of communicating from an early age, so individuals may learn an effective system to communicate with others around them.”</p> <p>“Ability to have an appropriate voice - access to technology that gives non verbal persons a voice”</p>
Educating families and guardians	<p>“Some parents/guardians think they know what is best for that person and limited what the person can express or be involved in/speak up for themselves.”</p> <p>“They don’t know how to take up for their selves. It’s hard for families of them to let go of charge.”</p> <p>“True participation in meetings. Many that I attend, family members speak for the individual or speak over the individual. Also an issue when a guardian disagrees with a choice the individual makes.”</p> <p>“Adults with guardians are often unheard because the guardian trumps the individual’s decision with what they think it best. Good intentions do not always promote growth and development. Life is a journey, and everyone should be allowed to experience the positives and negatives that shape who we are and who we become.”</p>

Theme	Examples of textual data which fall under theme
Educating legislators	<p>“There is just so little support outside home or staff that support them. It is a population that is still overlooked. Persons with disabilities rights still have to be brought to the forefront of some government officials for them to fully understand.”</p> <p>“Disconnect from the participant and the people who can make a change.”</p> <p>“They do not have the interest or ear of state legislators.”</p>
Educating communities	<p>“Shift in mentality of all. Valuing self-advocacy and seeing its need. Both with the individual and the community.”</p> <p>“I think many of them want to self-advocate but feel like no will listen to them due to their disability”</p> <p>“The general public is not educated on this issue.”</p>
Educating professionals	<p>“Self-advocates are concerned about repercussions of speaking out about areas that concern them”</p> <p>“I do not think agencies are encouraged or given any incentive to help adults with self-advocacy. “</p>

Discussion

Results of the qualitative analysis show varied level of supports are needed to build self-advocacy capacity among individuals with developmental disabilities—training and providing opportunities to practice advocacy, more local and regional advocacy groups, and providing supports so that people can participate fully at events and forums. Transportation continues to pose a major barrier for individuals with developmental disabilities to participate in the community. Furthermore, the results show how the lack of communication devices impedes individuals with developmental disabilities ability to ‘voice’ their needs at advocacy events. The themes also highlight that advocacy is not a solo endeavor and it requires the continuous engagement and education of legislators, guardians, community members, and professionals.

Results from the needs assessment present opportunities for the three Developmental Disability Network agencies to build capacity at each level of advocacy, including: (a) Self-advocacy: training and education on self-advocacy, providing

timely and accessible information, (b) Individual: providing timely and accessible information, training and education for families and guardians, (c) Systems: providing transportation and communication supports to participate at events, creating venues for advocacy, educating community members and professionals, (d) Legislative: educating legislators, professionals, and community members. These needs show that a multi-level, multi-pronged approach to building advocacy capacity is needed to influence practice, policies, and laws.

This study has a few limitations. The purpose of the study was to examine the need across all life areas and not just advocacy. A need assessment solely focusing on advocacy might reveal more specific areas of need. The analysis does not differentiate the comments by respondents (i.e., family member versus individual with developmental disability versus a provider). Finally, while the current survey methodology allows for a broad snapshot of needs, it also ‘dilutes’ the needs voiced by individuals with developmental disabilities. These limitations should be taken into consideration when using these findings from this study.

References

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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.

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