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Support Needs of Adults with Intellectual Disability Across Domains: The Role of Technology

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Abstract

People with and without disabilities universally value the goals of greater control and self-determination, inclusion and participation in their school or community, and enhanced social inclusion. Technology is an important support in achieving these goals. In this manuscript we examine the intensity of support needs, as measured by the Supports Intensity Scale, of persons with intellectual disability (ID) by severity of their intellectual deficit, as well as examining the level of support needs of individuals with co-occurring autism, mental health problems, and physical limitations. We compared the profiles of support needs of persons with ID and particular concomitant conditions and discussed the implications from these findings for the use of technology to address the support needs of people with intellectual disability.

Keywords

Assistive Technology; Intellectual Disability; Support Provision

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The "promise" of technology that was presented in the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (Tech Act) was that use of such technology would “enable individuals to: (A) have greater control over their own lives, (B) participate in and contribute more fully to activities in their home, school and work environments, and in their communities, (D) interact to a greater extent with non-disabled individuals, and (C) otherwise benefit from opportunities that are taken for granted by individuals who do not have disabilities” (Technology Act, p. 1044). Progress has been made in achieving this promise for adults and students with intellectual disability (Wehmeyer, Palmer, Smith, Davies, & Stock, 2008), although there remains much to be done to ensure that people with intellectual disability achieve the full benefits of technology.

There are a myriad of reasons technology is underutilized by people with intellectual disability, including the complexity of most devices and low expectations for people with intellectual disability. As has been emphasized in this special topic issue, the American

Association on Intellectual and Developmental Disabilities definition and classification of intellectual disability (Schalock et al., 2010) emphasizes on the interaction between the capacities of the person with the disability and the context in which that person lives, learns, works or plays. Disability, and in this case intellectual disability, exists only in the gap between those capacities and the demands of the context. Why is this important for consideration by educators interested in technology? By defining the *disability* as a function of the reciprocal interaction between the environment and the student's functional limitations, the focus of the "problem" shifts from being a deficit within the student to the identification and design of *supports* to address the individual's functioning within that context, with an enhanced focus on adaptations, accommodations and modifications to the context. Technology, in such a model, becomes a critical support tool not only to accommodate for a student's limitations but to provide supports across domains that reduce the gap between the person's capacity and the demands of the context. The purpose of this paper is to examine the profiles of intensity of support needs generated by the Supports Intensity Scale (SIS) for adults with intellectual disability with and without concomitant impairments across domains to provide direction for consideration of the use of technology to address these support needs.

Methods

Participants

Study participants were 274 adults with intellectual disability receiving funding from a state ID/DD agency. Participant mean age at time of testing was 41.6 years (range = 19 to 83 years, *SD*=14.3). Approximately 61% (*n*=167) of participants were male, and 39% (*n*=107) were female. The mean age for males was 41.5 (range = 19 to 79 years, *SD*=14.4). The mean age for females was 41.8 (range = 19 to 83 years, *SD*=14.2). Seven percent of participants were African American (*n*=19), one percent were Native American (*n*=3), and approximately 90% (*n*=246) were White, with all other ethnicities represented at less than one percent of the sample. One hundred and thirty participants (47%) had at least one psychiatric diagnosis identified, 32 (12%) had two psychiatric diagnoses, 11 (4%) had three, and 144 (53%) had no psychiatric diagnoses. Across the sample, 24% of participants had mild levels of intellectual impairment, 23% had moderate, 14% had severe, and 37.2% had profound levels. Eight-two percent of the sample had hearing within normal ranges, 8% had a mild hearing loss, 5% a moderate loss, 1.5% a severe loss, and 3% a profound hearing loss. Sixty-five percent of the sample had normal vision, 19% had a moderate vision loss, 7% had a severe vision loss, 6% could only perceive light, and visual ability of 3% of the sample was undetermined. Twelve percent of the sample lived alone, 24% were living with two or fewer persons with developmental disabilities, 47% were living with three to seven other persons with developmental disabilities, 2% were living with eight or more people with developmental disabilities, 14% were living with relatives, and living arrangement was classified as "other" for the remaining 3%. With regard to current day activities for people in the sample, 5% were receiving special education services in school settings, 2% were competitively employed (either greater or less than 20 hours per week), 7% were working in congregate settings fewer than 20 hours per week, 23% were working in congregate setting more than 20 hours a week, 7% were involved in agency-based, non-work activities, and the rest were involved in "generic community activities."

Participants were randomly selected from the population of all people receiving services from the state agency. Participants were restricted to persons 18 years and over because the SIS was normed for use with adults. Informed consent was obtained from all participants and/or their parents or guardians. Using procedures described subsequently, SIS interview data were completed for all participants and demographic data were obtained for all participants with a completed SIS.

Procedures

All data collection was conducted by a doctoral student and three graduate research assistants (GRA) trained by the doctoral student, all of whom were trained to mastery on the administration of the *SIS*, as described in the SIS Manual (Thompson et al., 2004). Research staff collaborated with state agency personnel to schedule interview dates, times, and locations. All interviews were conducted at a location convenient to the person with the disability and informants and were arranged in conjunction with the cooperating direct support providing agency. A primary contact at each local direct support agency was designated who was responsible for coordinating the location for all SIS interviews. Respondent teams, ranging from two to four persons, were configured with the following parameters pertaining to who should participate in the interview: (a) The person served, to the maximum extent possible and based upon the person's preferences; (b) A direct support professional who had experience working with the person on a daily basis and knew the person served; (c) A representative from the person's community support provider; and (d) The person's case manager, guardian, and/or a family member. In all interviews, at least one direct support person served as a respondent. In 16% of interviews (*n*=44), a parent or guardian also served as a respondent.

Inter-rater Reliability—For 34 participants (12.4% of all participants), two interviewers completed SIS protocols while interviewing the same respondent. In all 34 reliability analyses, the doctoral student served as the primary rater and one of the GRAs served as the second interviewer. Data on inter-rater reliability were entered into an SPSS for Windows version 13.0 data base with the participant as the case and each item and rating type (frequency, duration, type) as variables for analysis. Percent agreement for each item and for each indicator of support need (e.g., frequency, duration, type of support) for the *Section 1: Support Needs Index* (SNI) ranged from 88% to 100% for individual items and from 95.12% to 99.62% on total section scores. Overall, agreement was 97.75% for Frequency ratings, 97.90% for Daily Support Time ratings, and 98.83% for Type of Support ratings, for an overall reliability of 98.16%. There were 4,998 unique opportunities for agreement/ disagreement (49 items × 3 ratings per item × 34 participants). Of these 4,998 ratings there were disagreements between the primary rater and the student rater on 92 ratings in the *Section 1: Support Needs Index* section. Of those 92 disagreements, 83 (90%) were by one rating point either way. For the *Exceptional Medical Support Needs* section there was agreement on ratings for 11 of the 15 items (the "Other" item was not included in the calculation) and for each of the four items on which a disagreement occurred (Parenteral feeding; Turning or positioning, Protection from infection, Ostomy care), there was only one interval during which a disagreement occurred. The overall inter-rater reliability for the *Exceptional Medical Support Needs* section was, then, 99.2%. For the *Exceptional Behavioral Support Needs* section there was agreement on all ratings with one exception, the “maintaining mental health” item, on which there was one interval for which a disagreement occurred. The overall inter-rater reliability for the *Exceptional Behavioral Support Needs* section was 99.75%, resulting in an overall reliability rating for *Section 3: Exceptional Medical and Behavioral Support Needs* of 99.48%.

Instrument

Supports Intensity Scale—The Supports Intensity Scale (SIS) was developed to measure the level of support adults with intellectual disability require to participate in everyday life and community-based activities. The SIS is composed of three sections, only two of which were relevant to this study. The primary section from which norm referenced indices are generated, the *Support Needs Scale*, involves 49 life activities grouped into six subscales or sub domains: Home Living Activities, Community Living Activities, Lifelong Learning Activities, Employment Activities, Health and Safety Activities, and Social Actvities. Section 3, Exceptional Medical and Behavioral Support Needs, lists 15 medical conditions and 13 problem behaviors. An underlying assumption is that certain medical conditions and challenging behaviors predict that people will require increased levels of support, regardless of their relative intensity of support needs in other life domains. For example, people with high support needs in terms of respiratory care need maximum support in their daily life regardless of their level of support needs in specific activities associated with Home Living, Community Living, and so forth. Likewise, a person who engages in physical aggression will require additional support, regardless of the person’s level of independence in other areas of life. A 0–2 scale is used to rate the relative significance of supports needed to manage the medical conditions and challenging behaviors: zero (0) = no support needed; 1 = some support needed; 2 = extensive support needed. The SIS was normed on a sample of 1,306 people with intellectual disabilities in 33 states. The scale has adequate internal consistency reliability, with alpha levels of .94 or higher for each subscale or sub domain, adequate test-retest and inter-rater reliability, and adequate content and criterion-related validity (Thompson et al., 2004).

Data Analysis

Descriptive analyses of the data were conducted on support needs as indicated by SIS domain standard and percentile scores. Because the SIS was developed for and normed with people with intellectual disability, all participants were identified as eligible for services within the state system based upon their intellectual disability. In addition, portions of the sample had concomitant disabilities in social and communication (autism), mental health, and physical impairments (cerebral palsy, uses wheelchair). The analyses enabled us to examine “profiles” of support needs by specific limitations (or degree of limitations) and to consider the types of technology use that might be important in such circumstances.

Results

Tables 1 through 4 provide descriptive data (minimum, maximum, mean, and standard deviation) for standard scores and percentiles for each SIS domain (e.g., home living, community living, lifelong learning, employment, health and safety, and social) for the entire sample (people with intellectual disability, Table 1), people with intellectual disability and autism (Table 2), people with intellectual disability and one or more psychiatric diagnoses (Table 3), and people with intellectual disability with concomitant physical disabilities (e.g., has cerebral palsy or uses a wheelchair). Figures 1 and 2 depict data for mean standard score (Figure 1) and mean percentile (Figure 2) by type or level of impairment. These figures provide data for people with intellectual disability by level of impairment (mild, moderate, or severe/profound.

Looking particularly at Figure 2, which provides information on percentile scores for the population, there are a couple of general observations that can be made before discussing impairment-specific support needs. First, as might be expected, the general pattern of support needs was similar across levels of intellectual impairment and ID with a concomitant disability. Participants with mild intellectual disability had the lowest intensity of support needs, followed by participants with moderate intellectual impairment, participants with intellectual disability and a psychiatric disorder, and participants with intellectual disability and autism. Participants with severe/profound intellectual impairments and participants with intellectual disability and a concomitant physical impairment had the highest levels of intensity of support needs. Across most groups, lifelong learning was the domain in which the highest intensity of support needs was reported, except for participants with severe/profound levels of intellectual impairment and participants with intellectual disability and physical impairments, for whom the home living and health and safety domains (respectively) were higher.

The level of intensity of support needs in the home living domain varied most widely among groups, being the lowest for participants with mild intellectual impairment and participants with intellectual disability and autism, but the highest for the aforementioned groups. Health and safety was generally higher, proportionally, across groups.

Discussion

The intent of these analyses is to provide information with regard to areas of support needs as a function of the particular needs that might be experienced by people with intellectual disability, overall, and people with intellectual disability with particular concomitant impairments or limitations and to consider what types of technology might be of particular benefit.

Technology to Address Specific Areas of Support Need

First, as noted previously, across all groups there were high levels of intensity of support needs (relative to other domains) for the *lifelong learning* domain, a domain that would correlate directly with school-based learning for school-age students with intellectual disability. One of the primary means that technology can be applied to promote success in learning environments is to make instructional materials more usable by all students by applying principles of universal design to the design and development of curricular materials. The presentation of most content, particularly in core academic areas, is through print-based mediums (textbooks, worksheets) and through lectures. Students who cannot read well or who have difficulty with memory or attention, including students with intellectual disabilities, will not have ‘access’ to the content presented through these mechanisms and, thus, will not have the opportunity to learn the content. Applying principles of universal design to curriculum development can address this barrier by providing curriculum adaptations (e.g., modifications to how the content is represented, how it is presented, or how students engage with the content) (Rose & Meyer, 2006).

Designing educational materials and technology used in instruction with principles of universal design in mind is critically important for students with intellectual disability and presents an obvious role for technology in promoting learning. Additionally, however, technology can be used to ‘augment’ the curriculum (Wehmeyer, Sands, Knowlton, & Kozleski, 2002) as a means to promote learning. Curriculum augmentation involves expanding the curriculum to teach students cognitive strategies or learning-to-learn strategies that better enable them to engage in the academic task. Technology can be applied to support these types of activities for students with intellectual disability.

Mutliple technology-based supports have been examined to promote these objectives. Douglas, Ayres, Langone, Bell and Meade (2009) examined the use of eText supports to reading and listening comprehension for students with intellectual disability, determining that recorded voice or text-to-speech supports and graphic organizers improved text comprehension. Mechling, Gast, and Thompson (2008) found that the use of SMART board technology in combination with flash card instruction improved acquisition of sight words, both targeted and through observational learning. Sorrell, Bell, and McCallum (2007) showed that students with intellectual disability improved reading comprehension when using a computer-assisted reading device. Bouck, Bassette, Taber-Doughty, Flanagan, and Szwed (2009) found that the use of a pentop computer improved acquisition of two digit math facts for students with intellectual disability.

Participants with physical disabilities had higher levels of intensity of support needs, in general, and relatively higher support needs in the *home living*, and *health and safety* domains. Mobility issues are obviously of relevance here, and limitations in mobility have implications for other domains, including employment, recreation, and community inclusion. Despite the important mobility limitations in this population, there is little research literature evaluating the use of technology applications to the problem. Research that has been published on the issue describes use of automated systems that guide the user to a destination, and use of robotic assistance for ambulation (e.g., Lancioni, Olivia, & Gnocchini, 1998; Lancioni, Olivia, & O’Reilly, 1997). In fact, the available of “mobility technology” (e.g., walkers) is often as much a function of concerns about health and safety as actual mobility (Nochajski, Tomita, & Mann, 1996). It is best, as such, to consider mobility in its broadest sense, including personal navigation, when considering technology supports for students with disabilities, and not just personal ambulation. For example, GPS-enabled navigation devices, now readily accessible on smartphones or standalone devices for use in automobiles, provide the potential to enable greater community inclusion/living and social inclusion. Davies, Stock, Holloway, and Wehmeyer (2010) showed that people with intellectual disability could successfully and independently navigate a fixed-route downtown bus route using a PDA-based GPS system. Further, research has shown that highlighting landmarks along navigation routes in indoor settings can be a useful strategy during travel repetition priming (Stankiewicz & Kalia, 2007; Foo, Warren, Duchon, & Tarr, 2005).

Furthermore, the ubiquitous availability of cell phones, which are increasingly serving as a life line not only for people with disabilities traveling in the community (Bryen, Carey, & Friedman, 2007; Stock, Davies, Wehmeyer, & Palmer, 2008), but also for mainstream populations such as younger children or older adults, illustrates how common technology supports can be employed to address domains such as community living or social engagement.

Along with participants with intellectual disability and concomitant physical impairments, people with severe/profound intellectual impairments also had high support needs in *home living*, *community living*, and *health and safety*. It is not unusual for a person with intellectual disability to have difficulties with everyday activities such as eating, dressing, using the bathroom, and a number of other functional tasks that, in turn, limits his or her independent living and community integration or impact health and safety. Technology can improve functional abilities, to support greater independence in activities of daily living, control over one's environment, and, in the end, to enhance community integration (Felce & Emerson, 2001; Mendelson, Heller, & Factor, 1995; Stock, Davies, Wehmeyer, & Lachapelle, 2011). Ayres and Langone (2008) and Canella-Malone, Sigafoos, O'Reilly, de la Cruz, Edrisinha, and Lancioni (2006) have provided evidence of the importance of video supports to teach students with intellectual and developmental disabilities critical functional home and community living skills. Taber-Doughty, Patton, and Brennan (2008) established the utility of simultaneous and delayed video modeling to teach students with intellectual disability community inclusion (library) skills. Bramlett, Ayres, Douglas, and Cihak (2011) found that computer simulations to teach skills related to clothes shopping enabled students to acquire and generalize skills.

Lancioni, Dijkstra, O'Reilly, Groenweg, and Van den Hof (2000) determined the efficacy of a computer-controlled audio prompt device, with prompts delivered through an earpiece, to enhance task completion of setting a table and cleaning tasks for two young adults with intellectual disability. Riley, Bodine, Hills, Gane, Sanstrum, and Hagerman (2001) showed that the use of a reminder system that includes a modified pager to help people manage their own activities, by a young woman with Fragile X syndrome enabled her to independently complete more daily living tasks than when she was not using the device.

Other means to support independence include problem solving, decision making, and being able to ask for help when needed, and other cognitive and social capabilities. Davies, Stock, and Wehmeyer (2003a) demonstrated the efficacy of a palmtop-based intelligent aid for people with intellectual disability to increase independent decision making. Davies, Stock, and Wehmeyer (2003b) provided evidence of a computer-simulation program to teach ATM and independent money use skills to individuals within intellectual disability.

There are a number of technologies that might be important for *employment* support. Wehmeyer, Palmer, Smith, Parent, Davies and Stock (2006) conducted a meta-analysis of single-subject design studies to examine the impact of technology use on employment-related outcomes for people with intellectual and developmental disabilities and found that the use of technology to promote employment outcomes was generally effective, in particular when universal design features were addressed. The technology devices implemented in this review included audio prompting devices, palmtop and desktop computers, and communication devices. Outcome areas targeted included vocational and employment skills, work-related social skills, and computer use.

Van Laarhoven, Johnson, Van Laarhoven-Myers, Grider, & Grider (2009) evaluated the efficacy of a video iPod to prompt a participant with developmental disabilities to complete employment-related tasks with fewer prompts from adults. Similarly, Davies, Stock and Wehmeyer (2002) evaluated the impact of a palmtop application that allows a user to view step-by-step picture sequences along with audio instructions at his or her own pace, which was used by students to support learning through antecedent cue regulation, self-instruction, and self-monitoring/evaluation strategies. Davies et al. examined the use of the *Visual Assistant* with 10 participants with intellectual disability receiving community-based vocational supports or enrolled in a community-based transition program. Participants were more independent (requiring fewer external prompts) and more productive (making fewer errors) when using the palmtop PC-based software program. This device served, in essence, as an accommodation to enable students to augment the curriculum and apply strategies that enable them to succeed in the curriculum.

In an employment-related domain, transition, Lee, Wehmeyer, Palmer, Williams-Diehm, Davies, and Stock (in press) investigated the impact of student-directed transition planning instruction using the *Whose Future Is It Anyway?* curriculum, using a computer-based reading support program, *Rocket Reader*, on the self-determination, self-efficacy and outcome expectancy, and transition planning knowledge of students with disabilities. A two-group pre-post design with random assignment was used and demonstrated that self-determination, self-efficacy and outcome expectancy for education planning improved through the application of the technology.

An area of particular support need for persons with intellectual disability who also had autism was, not surprisingly, the social domain. Obviously, technology that supports community inclusion, such as that discussed previously, will enhance opportunities for socialization. An area of potential to increase social interactions involves the use of technology in the area of sports, recreation, and leisure. Wehmeyer et al. (2004) highlighted a number of technology supports to improve social inclusion in sports, recreation, and leisure, from using simple switches to palmtop technology devices.

Limitations—We should note a number of limitations to this analysis. First, although the sample was randomly selected from a population of people with intellectual disability receiving services in one state, there is no assurance that this population is typical of the population of people with intellectual disability as a whole. Also, we are inferring the potential for technology supports for students with intellectual disability from a population of, primarily, adults with intellectual disability. The types of supports, however, that students with disabilities will need across domains will be similar to those addressed within the adult population described here, and we believe these findings provide helpful information in both thinking about technology as a form of support to address support needs for students with intellectual disability, as well as providing direction for future research.

This study showed that the intensity of support needs across domains of persons with intellectual disability varied based on the severity of their intellectual deficits and the presence of concomitant conditions such as autism, psychiatric disorders, and physical impairments. We discussed these findings related to these needs in relation to the possible contribution technology supports can mitigate the gap between the individual's support needs and the demands in the environment. We have a small body of science in the area of assistive technology but there remains a pressing need for more investigations to better understand the contribution of ever changing technology and how it can be effectively used to support individuals with intellectual disability across life domains.

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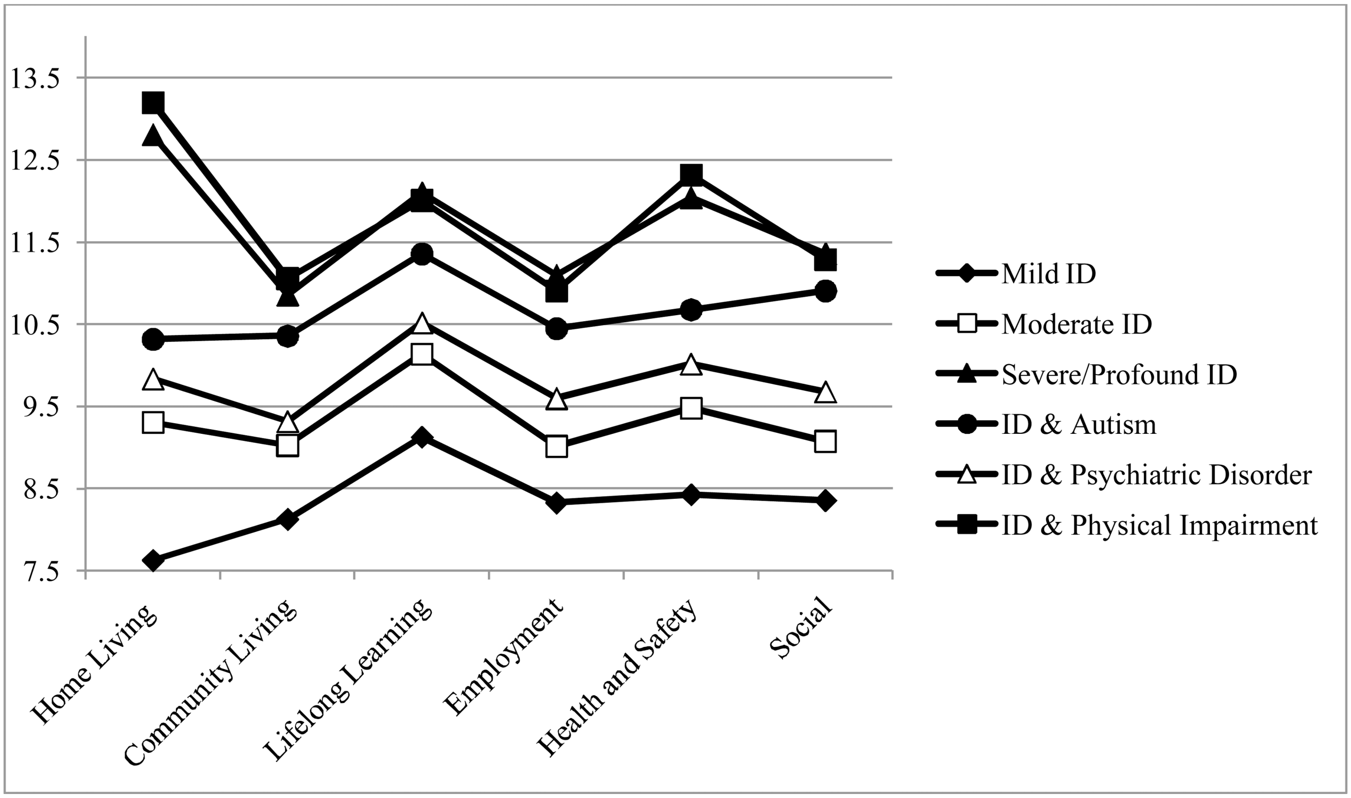

Figure 1.
Mean Standard Score by Type of Impairment and Domain

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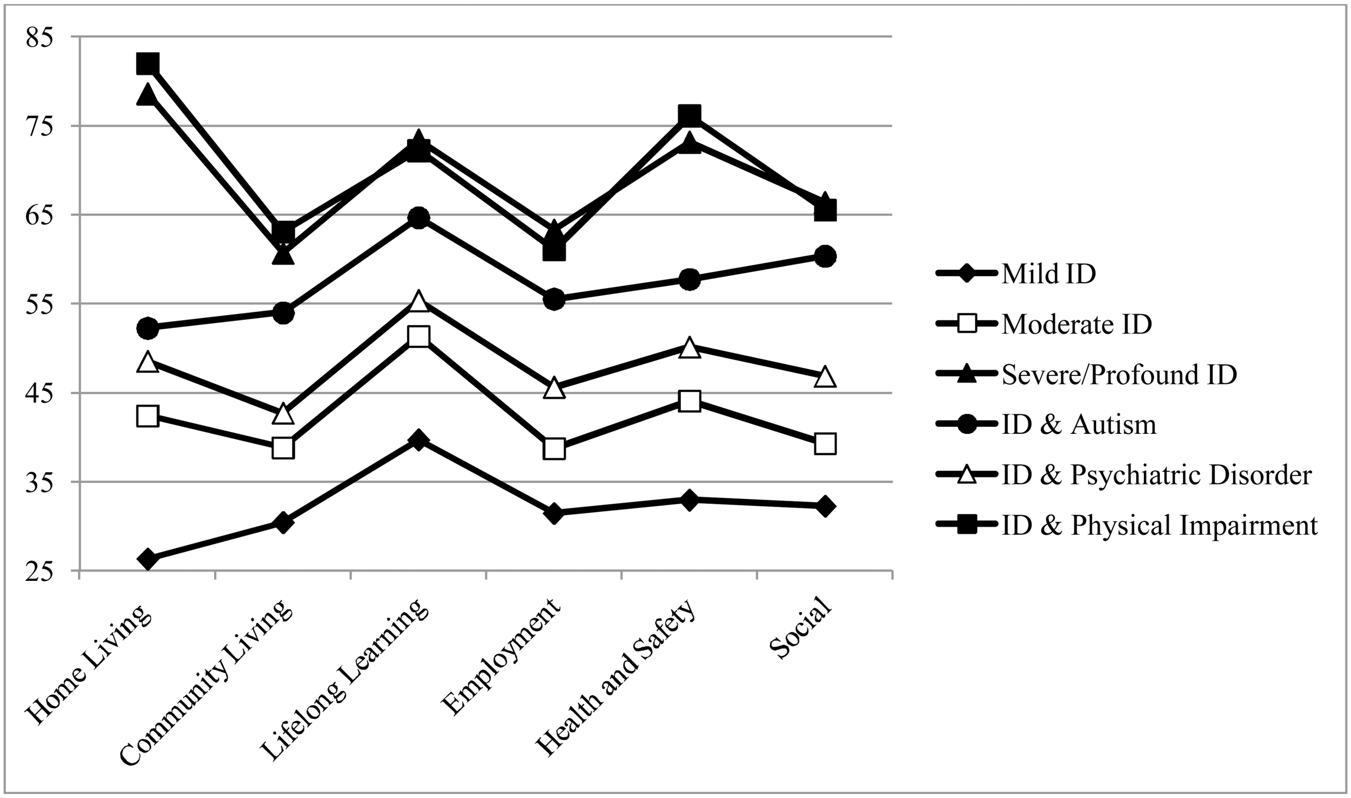

Figure 2.
Mean Percentile Score by Type of Impairment and Domain

Table 1

Support needs by domain for people with intellectual disability

Descriptive Statistics: Intellectual Disability (n −274)				
	Min	**Max**	**Mean**	**SD**
Home Living Standard Score	4	16	10.72	3.10
Home Living Subscale Percentiles	2	98	57.33	30.89
Community Living Standard Score	4	15	9.77	1.93
Community Living Subscale Percentiles	2	95	48.17	21.27
Lifelong Learning Standard Score	6	16	10.89	2.02
Lifelong Learning Subscale Percentiles	9	98	59.78	22.09
Employment Standard Score	5	14	9.92	1.97
Employment Subscale Percentiles	5	91	49.58	22.49
Health and Safety Standard Score	4	14	10.54	2.27
Health and Safety Subscale Percentiles	2	91	56.37	25.15
Social Standard Score	5	15	10.08	2.09
Social Subscale Percentiles	5	95	51.58	23.60

Table 2

Support needs by domain for people with intellectual disability and autism

Descriptive Statistics: Intellectual Disability and Autism (n = 22)				
	Min	**Max**	**Mean**	**SD**
Home Living Standard Score	7	16	10.32	2.30
Home Living Subscale Percentiles	16	98	52.27	24.41
Community Living Standard Score	8	14	10.36	1.36
Community Living Subscale Percentiles	25	91	54.00	15.82
Lifelong Learning Standard Score	9	16	11.36	1.76
Lifelong Learning Subscale Percentiles	37	98	64.68	16.89
Employment Standard Score	6	14	10.45	2.06
Employment Subscale Percentiles	9	91	55.55	23.62
Health and Safety Standard Score	8	14	10.68	1.55
Health and Safety Subscale Percentiles	25	91	57.77	18.22
Social Standard Score	8	15	10.91	1.63
Social Subscale Percentiles	25	95	60.36	18.13

Table 3

Support needs by domain for people with intellectual disability and psychiatric diagnoses

Descriptive Statistics: Intellectual Disability and Psychiatric Diagnoses (n=130)				
	Min	**Max**	**Mean**	**SD**
Home Living Standard Score	4	16	9.84	2.90
Home Living Subscale Percentiles	2	98	48.50	29.36
Community Living Standard Score	5	15	9.32	1.98
Community Living Subscale Percentiles	5	95	42.73	21.17
Lifelong Learning Standard Score	6	16	10.50	1.96
Lifelong Learning Subscale Percentiles	9	98	55.37	21.53
Employment Standard Score	6	14	9.60	1.91
Employment Subscale Percentiles	9	91	45.65	22.02
Health and Safety Standard Score	5	14	10.02	2.14
Health and Safety Subscale Percentiles	5	91	50.15	24.20
Social Standard Score	5	15	9.68	2.03
Social Subscale Percentiles	5	95	46.88	22.90

Table 4

Support needs by domain for people with intellectual disability and physical impairments

Descriptive Statistics: Intellectual Disability and Physical Impairment (n=104)				
	Min	**Max**	**Mean**	**SD**
Home Living Standard Score	6	16	13.20	1.97
Home Living Subscale Percentiles	9	98	82.01	17.84
Community Living Standard Score	8	14	11.06	1.11
Community Living Subscale Percentiles	25	91	63.07	13.12
Lifelong Learning Standard Score	6	16	12.01	1.74
Lifelong Learning Subscale Percentiles	9	98	72.23	17.45
Employment Standard Score	6	14	10.91	1.48
Employment Subscale Percentiles	9	91	61.09	17.49
Health and Safety Standard Score	7	14	12.32	1.47
Health and Safety Subscale Percentiles	16	91	76.12	14.99
Social Standard Score	7	14	11.29	1.45
Social Subscale Percentiles	16	91	65.54	17.17