

Intellectual and Developmental Disabilities

Training Medical Personnel to Work with Persons with Intellectual and Developmental Disabilities

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Abstract

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Key words: Healthcare professional, disability training, health disparities, treatment, experience, comfort, competence, modes of training

Training Healthcare Professionals to Work

with Persons with Intellectual and Developmental Disabilities

Although individuals with intellectual and developmental disabilities (IDD) are increasingly included in their communities, they face persistent difficulties accessing healthcare. Characterized as encountering a “cascade of health disparities” (Krahn, Hammond, & Turner, 2006), persons with IDD experience high rates of comorbid, complex health conditions. In this population (and given less access to preventative healthcare), common health problems can present as more severe (Ward, Nichols, & Freedman, 2010). Such commonly occurring problems include gastrointestinal problems for individuals with Autism Spectrum Disorder (Buie et al., 2010) and, for those with Down syndrome, cardiac problems and early onset dementia (Roizen, 2010). Beyond medical issues, those with IDD also show high levels of maladaptive behavior and psychopathology (Dykens, 2016). Compared to those without IDD, individuals with IDD have poorer health outcomes, with shorter life expectancies (Emerson & Baines, 2011).

Faced with a population that has complex health conditions, comorbid conditions, and difficult behaviors, treatment for persons with IDD often requires more time and is considered by some to be more difficult. Since persons with IDD tend to be of lower socioeconomic status (Dejong et al., 2002), many individuals require public insurance coverage, even as many healthcare providers do not accept public insurance or limit their IDD patient caseloads (Ward et al., 2010). Among those healthcare providers who do treat these individuals, many cite difficulties providing care to patients with IDD (Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012).

To alleviate health disparities for persons with disabilities, it is imperative to increase the numbers of disability-trained healthcare professionals, preferably beginning during the pre-professional years. Unfortunately, there appear to be disconnects between the actual training

provided, the experiences and desires of medical students, and the values of the medical school deans and program directors that administer training programs. Holder, Waldman, and Hood (2009) evaluated the content related to IDD training included in medical and dental schools' curriculums. Among 427 students in residency programs, 81% responded that they had not received any clinical training with the IDD population; as a result, 56% felt “inadequately prepared” to provide treatment. Yet among the 198 medical and dental school deans surveyed in the same study, more than half (58%) stated that curriculum content on individuals with disabilities was not a high priority. Although these students are not receiving training in their programs, many report the desire for training on IDD (Ryan & Scior, 2016).

Still, though few in number, a small cadre of healthcare professionals do provide care to individuals with IDD. In studies of these disability-oriented healthcare professionals, the main aspects typically examined include their IDD-related levels of experience, comfort, and competence. Concerning disability-related experience, physicians, nurses, dental service providers, and mental health providers have all discussed lacking experience both in treating patients with IDD and in exposure to the population during their pre-professional training (Appelgren, Bahtsevani, Perrson, & Borglin, 2018; Auberry, 2018; Morris, Greenblatt, & Saini, 2019; Ummer-Christian et al., 2018). Similarly, many healthcare providers report that, when treating patients with ID, they lack confidence and feel uncomfortable (Wilkinson et al., 2012; Carter, Simons, Bray, & Arnott, 2017; Zerbo, Massolo, Qian, & Croen, 2015; Pelleboer-Gunnink, Van oorsouw, Van Weeghel, & Embregts, 2017; Robey, Gwiazda, & Morse, 2001). Consequently, healthcare professionals often report a lack of competence in treating those with IDD (Appelgren et al., 2018; Carter et al., 2017; Zerbo et al., 2015).

Levels of experience, comfort, and competence may also vary across different IDD groups. As concerns for treating persons with intellectual disabilities more generally, Australian healthcare providers in one large hospital considered themselves broadly competent, although less confident in utilizing specific skills (Ong et al., 2017). Similarly, mental health practitioners were confident in their general counseling skills, but less confident in terms of assessments or specific interventions (Hronis, Roberts, & Kneebone, 2018). In neither study, however, were care providers asked about their abilities to treat persons with different types of disabilities. In one of the few disability-specific studies, Pace, Shin, and Rasmussen (2011) reported that 76% of U.S. physicians felt comfortable providing medical care to patients with Down syndrome. With only a few exceptions, then, studies remain to be performed of healthcare providers' levels of experience, comfort, and competence in treating persons with different types of disabilities.

Additional concerns relate to continuing education and future recruitment-training. In the United States, healthcare professionals are required to obtain an average of 50 credit hours of continuing education per year, with hours varying across states and healthcare disciplines (Davis & Willis, 2005). Yet to be established within continuing education programs, however, is a national curriculum encompassing IDD. Even lacking such a curriculum, studies have documented the search to discover which modes of training are effective (e.g., case studies, clinical experiences, online modules). In fact, positive attitudes and perceptions for treating persons with IDD have been fostered by virtual patient trainings for physician assistant students (Boyd et al., 2008), interactions with simulated patients with ID for medical students (Watkins & Colgate, 2016), lectures on special healthcare needs for dental students (DeLucia & Davis, 2009), and clinical training modules for nurses (Sanders et al., 2008). Even so, for either professionals in practice or in their training years, it remains unclear as to which modes of

training are most preferred by those in the field and which practices or experiences constitute the most effective ways to prepare healthcare students to treat individuals with IDD.

In considering training more broadly, it is also important to examine the perspectives of disability-related healthcare professionals. To date, such perspectives are lacking. Indeed, while Havercamp et al. (2016) and Tracy and Iacono (2008) have explored training methods that utilize the perspectives of individuals with IDD, few studies have yet examined provider recruitment and training from the perspective of those individuals already working professionally with the IDD population. These professionals are relatively uncommon, in that they are committed to serving people with disabilities, lack (in most healthcare disciplines) disability-specific subspecialties, and have only a few disability-related organizations overall. Nevertheless, these in-the-trenches healthcare providers might provide invaluable, first-person guides to future recruitment, training, and retention efforts.

This study, then, examined the broad issue of disability-related training of healthcare professionals, from the perspective of those who work professionally with persons with IDD. We aimed to answer three sets of questions. First, to what extent do disability-oriented healthcare professionals feel experienced, comfortable, and competent to treat patients with different types of IDD; are experience, comfort, and competence unitary constructs; and how do they compare across disability types? Second, which venues of continuing education do these professionals consider optimal, and are any of these venues more or less beneficial to healthcare professionals with particular personal-professional characteristics (older-younger, male-female, etc.)? Third, which strategies and approaches do these providers identify as potentially working best to recruit and train future healthcare professionals to work with the IDD population? For the purpose of this study, the disability types used are a mixture of broad category disabilities and specific

conditions. The ten disabilities to which respondents evaluated were based on general diagnostic categories as well as a few of the main, or high incidence, diagnoses of intellectual and developmental disabilities. We were primarily interested in professionals who work with people with developmental disabilities, or disabilities that begin during childhood years, are covered under the special education categories, or include conditions with disability-specific healthcare clinics (e.g., Down syndrome).

Methods

Participants

Respondents included 155 health professionals from nine health-related disciplines, all of whom currently work or have worked in the past with persons with disabilities. Of the sample, 74% were female (N=113), 26% male (N=39). The mean age for female respondents was 40.37 years and for male respondents was 48.77 years, $t(148) = 29.94$, $p < .0001$.

To participate in this study, respondents must have been working (or at one time have worked) in a professional capacity with individuals with disabilities. Respondents were eligible to participate if they worked professionally in any of the following disciplines: clinical psychology; dentistry; family medicine; nurse; nurse practitioner; pediatrics; physician's assistant; psychiatry; and social work. As shown in Table 1, many respondents were nurses (roughly 30% of sample when combining nurses and nurse practitioners), as well as pediatricians or psychologists (both above 20%); we had few physician's assistants (1), dentists, family medicine physicians, or psychiatrists (each 7% or below). All individuals responded to a national

survey that asked “Are you a health professional who, as a part of your professional practice, treats individual(s) with a disability?”

Procedure

An anonymous web-based survey was developed to understand the characteristics and experience levels of disability-oriented health professionals. The survey included six sections: demographics of the respondent; demographics of their professional practice; professional experiences; potential benefits and barriers; career influences; and open-ended questions. Before distribution, the survey was piloted with at least one professional from each discipline. Based on pilot-participant feedback, we made necessary changes and submitted the study to the University Institutional Review Board (IRB). Upon receiving IRB approval, the survey was then transferred to REDCap, a secure web-based application to create and manage the survey along with the data (Harris et al., 2009).

Efforts to recruit study participants included sending flyers and emails targeting disability-oriented health professionals in each of the nine disciplines. Specifically, we recruited through such national and state-based associations and organizations as the American Academy of Developmental Medicine and Dentistry, American Psychological Association- Division 33, Developmental Disabilities Nurses Association, International Developmental Pediatrics Association, Special Care Dentistry, and The Sibling Leadership Network. In addition to these associations and organizations, we also contacted numerous Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs across the United States. These groups then disseminated the flyer electronically through their respective email lists, websites, and newsletters.

The online survey was active and collecting data from February 2019 until mid-September 2019. All surveys were completed electronically and recorded anonymously. Surveys took approximately 20 minutes to complete. All responses were stored in REDCap, before being transferred to IBM's Statistical Package for Social Sciences (SPSS). The final set of questions was open-ended; analyses of these questions were conducted by exporting responses from REDCap to Microsoft Excel.

Questionnaire

The survey consisted of a web-based questionnaire that respondents accessed through clicking an active link on the (electronic) recruitment flyer. Respondents were asked roughly 90 questions. Respondents were not required to answer any question. Many questions were on a Likert-scale; others included "select all that apply", single answer, drop-downs, with a few written fill-ins. If respondents selected "Other" as an answer choice, they were then asked to write in the additional information. The survey was made up of the following six sections.

(1) Respondent's Profession and Training

Respondents were first asked to describe their basic demographic information, including profession, any sub-specialties, gender, age, and practice setting. Additional questions regarded the length, in years, the respondent has held a license in his or her profession and how long he or she has been practicing, as well as the length of time (in years) treating patients with IDD.

(2) Pre- and Post- Professional Training Related to IDD

Questions next centered on the respondents' years of formal schooling and credentials (e.g., residency, certification exam). We also asked the extent to which eight modes of training helped them in working professionally with persons with IDD. Respondents were presented with

the question “To what extent has each the following helped you to be trained in working professionally with persons with disabilities?”, to which they rated eight different training venues. Rated on a 5-point scale (from 1-“Not helpful at all” to 5-“Extremely helpful, a main training source”), those modes included day-to-day professional experiences; case studies; clinical examples; course work; continuing education talks; journal articles; professional talks or conferences; and online modules.

(3) Professional Experience

The third section asked questions regarding the respondent’s professional experience and activities related to persons with disabilities. Respondents were asked to indicate participation in any professional activities including individuals with disabilities (e.g. Special Olympics' Healthy Athletes/Healthy Communities initiatives), or other professional activities with persons with IDD that fall outside of their formal practice; percentage of all of their professional activities involving individuals with disabilities (including Special Olympics or other unpaid activities); and percentage of their professional practice that includes individuals with disabilities. This section also asked a series of questions regarding experience, competence, and comfort in treating persons with each of ten specific disabilities. These disabilities included: autism spectrum disorder; deaf-blindness; deafness; Down syndrome; other genetic syndromes; intellectual disability; motor disability; psychological disorder/ psychiatric condition; speech or language impairment; and visual impairment. Respondents rated the degree to which they have treated individuals with each disability (experience), as well as their levels of comfort and competence, on similar 5-point scales (1-Never to 5-Often for experience; 1-Not competent/Not comfortable to 5-Extremely competent/Extremely comfortable for competence and comfort).

(4) Benefits & Barriers to Treating Persons with IDD and (5) Professional Influences

The next two sections concerned benefits and barriers experienced when medically treating persons with disabilities (Section 4) and influences that fostered respondents to enter into a disability-related sub-field of their profession (Section 5). Respondents rated potential benefits of their work with the IDD population (e.g., My work with this population makes a difference; This work challenges me), as well as potential barriers (e.g., More difficult to see success; Financial compensation is not enough). Section 5 focused on potential influences on the respondent's career choice, including having a sibling or family member, attending specialized camps, and pre- or post-training exposure to individuals with IDD.

(6) Open-Ended Responses

Under the general heading of "Reflections," the final section included four open-ended questions. Questions related to how the respondent chose to work professionally with people with disabilities, advice they would give others in this regard, and any additional information or thoughts they wanted to share. The second of these questions asked "What should be the ways/strategies used to recruit greater numbers of professionals in your field to work professionally with people with IDD?" We analyzed this question in detail and present findings below. For all four questions, adequate space was provided to type out written responses.

Analyses

After performing basic analyses related to respondent demographics (Table 1), we performed subsequent analyses following the study's three main goals. We first compared the levels of experience, comfort, and competence across the 10 disability types. We then performed Cronbach's alphas to determine whether experience, comfort, and competence held together as unitary constructs. Using these factors, we then compared levels of these three constructs.

A second set of analyses focused on the preferred modes of training. In addition to comparing levels across the eight training venues (via a one-way, repeated measures ANOVA), we examined whether specific training modes were differently beneficial for respondents who were females vs. males, or who were of different ages or had different amounts of time in their profession or in their professions working with persons with disabilities, or of different types of professions. Given the different numbers of respondents in each profession, we limited this last analysis to comparisons of nurses (including nurses and nurse practitioners, $N = 45$); pediatricians ($N = 40$); and mental health professionals (including clinical psychologists, social workers, and psychiatrists; $N = 49$).

Finally, we examined the responses of those who answered the open-ended question concerning ways/strategies to recruit greater numbers of healthcare providers to work professionally with people with IDD. Using phenomenological qualitative analyses, the first author began by coding all responses; this approach allows the coder to categorize and assign a descriptive code to individual responses (Creswell, 2013). Once codes were determined, they were organized into five major themes. To operationalize each theme, a clear definition was described, and examples and non-examples were provided. To determine coding reliability, a graduate student then served as a second coder, independently coding all respondents' answers as to the presence or the absence of that theme for each response. Kappas were used to evaluate reliability between coders. Across the five themes, the median coefficient was .628 (ranging from .447 to .941). Using Cicchetti's (1994) guidelines, inter-rater reliabilities ranged from "fair" ($\kappa = .40$ to $.59$) to "excellent" (.75 to 1.00), with most falling within the range of "good" reliability (.60 to .74). When the two coders disagreed, they discussed the case, and each response was ultimately assigned its appropriate theme.

Results

Experience, Comfort, and Competence

As shown in Table 1, the study's respondents were experienced in both their respective professions and in working professionally with persons with IDD. The length of time in the profession and in working professionally with persons with IDD was moderately correlated, $r(147) = .643, p < .0001$. There was also, however, a small subset of long-term professionals who had only recently begun treating persons with disabilities; among those healthcare providers who had been in their professions for 10 or more years, 11.1% (10/90) had served persons with IDD for five or fewer years.

For each disability type, respondents also rated their levels of experience, comfort, and competence. Using one-way repeated measures ANOVAs, differences occurred in treating individuals with different conditions in terms of Experience, $F(9, 141) = 38.66, p < .001$, Comfort, $F(9, 141) = 20.26, p < .001$, and Competence, $F(9, 143) = 30.59, p < .001$. Respondents most frequently treated individuals with Autism Spectrum Disorder and with an Intellectual Disability; they least frequently treated persons with Deaf-Blindness. This pattern of highest levels for those with ASD and ID and lowest for those with Deaf-Blindness held as well for both Comfort and Competence. See Table 2.

Using Cronbach's alphas, we also found that unified constructs existed for experience, comfort, and competence (alphas = .868, .922, & .905, respectively). Using total scores for each construct, levels of experience exceeded comfort levels, which in turn were greater than levels of competence, $F(2, 145) = 63.37, p < .0001$. Ranking (for each participant) the three constructs from lowest (1) to highest (3), levels of experience exceeded levels of the other two constructs

for 58.5% of all participants and was lowest in 16.3% of respondents. Conversely, levels of competence (compared to the other two constructs) were lowest in 47.6% of all participants, highest in only 1.4% of respondents. Experience exceeded comfort, which exceeded competence.

Training Modes

Respondents also differed in their sense of the helpfulness of eight training modes, $F(7, 139) = 62.57, p < .0001$. The most helpful venues of training were Accumulation of Day-to-Day Professional Experiences and Clinical Experiences, with Online Modules rated as least helpful (see Figure 1). These differences varied slightly by profession, with Nurses (= nurses + nurse practitioners) rating Online Modules higher (4.23) than did Pediatricians (3.45) or Mental Health professionals (3.40), $F(2, 129) = 8.51, p < .0001$. The helpfulness of other venues did not differ by types of healthcare providers, nor were different training venues' levels of helpfulness rated higher or lower by professionals of different genders, or who were of different ages, lengths of time in their field or who had worked for different numbers of years with patients with disabilities.

Voices of Respondents

Across the entire sample, 66% (103/155) of respondents provided a response to the question "What should be the ways/strategies used to recruit greater numbers of professionals in your field to work professionally with people with IDD?" From these responses, we identified the following five themes (Table 3).

(1) Need for exposure

Answered by 45.6% (47/103) of those respondents answering the open-ended question (above), healthcare professionals stated the need or advantage of first-hand disability exposure.

In almost all cases, the respondent cited increased exposure as an ideal way to both understand and serve the IDD population. As one healthcare provider noted, “Expose students to people with IDD and their families. There is always fear of the unknown, so healthy exposure to people with IDD will help students be more comfortable with people of all abilities.”

(2) Need for resources/training

The second most common theme focused on resources and training in IDD. This theme, volunteered by 37.9% of those providing an open-ended response, expressly noted the need for more resources and/or training opportunities to better support and serve their patients and families. “More content about disabilities other than mental health...” noted one healthcare professional.

(3) Financial Considerations

The next most common theme (28.2%, or 29/103), which arose in both positive and negative statements, related to issues of compensation, expenses related to disabilities, or healthcare access. One respondent proposed to “Create opportunities for providers to receive a reasonable compensation to provide quality care while working with patients with disability. Cannot focus on number of visits since most visits for children with disabilities take much longer to accomplish.”

(4) Positive feelings towards career and (5) IDD as Underserved Group

A small subset of respondents, comprising 11.7% (12/103), noted that their career was rewarding or more generally expressed positive statements toward their disability-related sub-field. In terms of recruiting others in their discipline, one respondent offered that one should recruit healthcare professionals by continuing “...to expose people to the joys of working with

these patients while healthy to improve the desire to help them while sick.” Finally, a few respondents (4.9%, 5/103) commented on the IDD population not receiving appropriate care or opportunities for care.

Discussion

Although persons with disabilities encounter barriers to accessing healthcare, a small subset of community healthcare providers do treat this population. This study is among the first to explore the experiences of these disability-oriented professionals, especially as they pertain to their experiences, comfort, and competence in treating persons with different disabilities, their perceptions of the helpfulness of various training venues, and their advice as to how to attract and train future healthcare providers to work with persons with disabilities. This study had three main findings, each of which has both research and practical implications.

Our first finding involved the disability-oriented professionals' levels of experience, comfort, and competence. Overall, our sample consisted of experienced providers, and most providers had started treating persons with IDD early on in their professional careers. Although some longer-term providers had more recently begun treating persons with IDD, this sub-group was relatively small (about 10%). It was also notable that, across the ten disability types evaluated, professionals differed in their degrees of experience, comfort, and competence in treating persons with different disabilities. Across all three constructs, professionals rated highest autism spectrum disorder and intellectual disability, with lower ratings for persons with deaf-blindness.

Overall, however, experience, comfort, and competence did hold together as unitary constructs that, when compared to each other, showed interesting patterns. Specifically, levels of

experience exceeded levels of comfort, which in turn exceeded levels of competence. This pattern held overall and for most individual respondents. Although prior studies have usually focused on one of these constructs (e.g., Hronis et al., 2018; Ong et al., 2017), this study is among the first to compare all three, and how experience may pave the way to comfort, which might ultimately lead to competence.

Second, this study found that, from the perspective of disability-oriented healthcare providers, training venues differ in their levels of helpfulness. Across the eight modes of training, respondents identified accumulation of day-to-day professional experiences and their clinical experiences as most helpful; online modules, in particular, were judged less helpful. For unclear reasons, our nursing group, compared to both pediatricians and to mental health professionals, showed higher (albeit still relatively lower) scores on online modules. No other differences emerged based on personal characteristics. For example, our younger professionals did not show any preferences for online trainings; this finding (or non-finding) occurred even when we defined younger by age, by years as a professional, or by years working professionally with persons with disabilities.

Third, using an explicitly open-ended question that focused on training, these disability-related healthcare providers identified five themes, including the critical role of increased experiences as fostering the recruitment of disability-related healthcare professionals. Indeed, from both quantitative analyses and from the open-ended responses, increased exposure to those with IDD was valued by these healthcare providers. Increased exposure was also the most helpful mode of training; experience levels were highest (vs. comfort and competence) across the ten disabilities; and the most commonly-expressed theme related to the need for increased IDD exposure as important for attracting new professionals into working with this population.

Taken together, these findings have implications that may begin to lessen the healthcare disparity for persons with disabilities. From a strictly research perspective, it may be beneficial to assess in greater depth those healthcare professionals who already treat persons with IDD. Although a small subgroup within each discipline, these providers know intimately the benefits and challenges involved in caring for the IDD population, and it is important to understand their perspectives. Future studies and policy initiatives might explore in greater depth the advice-competence of those committed healthcare professionals, who have the most day-to-day experience serving those with IDD.

A second implication concerns the role of experience. In both our quantitative (i.e., ratings) and qualitative (open-ended) questions, respondents repeatedly emphasized the value of accumulated professional experiences with persons with IDD. Healthcare providers suggested that training programs “might make training and exposure mandatory” and that these individuals and their families needed to be “purposefully integrated” into training experiences. Such seamless training experiences with IDD populations reinforce earlier findings related to reducing stigma toward persons with IDD among clinical psychology students. Specifically, trainee engagement in positive, informal experiences appears to reduce stigma and improve attitudes towards those with intellectual disabilities (Ruedrich et al., 2007; Werner & Stawski, 2012). Such purposefully integrated experiences may parallel the impact that exposure to positive out-group exemplars can have on reducing individuals’ implicit biases towards out-group members (i.e. persons with disabilities) (McIntyre, Paolini, & Hewstone, 2016).

But practical experiences alone may not be enough. From this study, most respondents noted that they were more experienced as opposed to comfortable in treating persons with IDD, with competence lagging further behind. In short, there may be a role for information; note, for

example, Viecili, MacMullin, Weiss and Lunsky's (2010) finding that clinical psychology graduate students who took an elective course in developmental disabilities were six times more likely than their counterparts to include people with intellectual disabilities in their future career plans. This finding also aligns with findings in which professionals report that, when working with persons with IDD, they have general but not specific skills (Hronis, et al., 2018; Ong et al., 2017).

Ultimately, to become fully competent in treating individuals with disabilities, it may be necessary to experience both hands-on clinical training and specific, disability-related didactics. This combination recalls a classic idea, borrowed from the world of cognitive psychology, of how many human achievements feature both a "hot" (i.e., emotional, affectively laden) and a "cold" (intellectual, cognitive) component (Lepper, 1994). In this case, comfort might be considered the hot or emotional component, the one most fostered by increased contact and experience. But aspects of cold components might also operate when providing healthcare to persons with disabilities; it might also be important to take classes, attend talks, and in other ways receive IDD-specific information. Additional continuing-education resources that could further knowledge of individuals with disabilities include tip sheets, modules, and/or webinars. Each provides initial interaction tips, appropriate communication, and common misconceptions to foster health professionals to have positive experiences with these patients. Many national and international initiatives already exist to provide professionals with beginning information as it relates to healthcare for persons with disabilities (Smith, McCann, Dykens, & Hodapp, 2020). Such initiatives, however, are probably not widely known by most community-based healthcare professionals.

Indeed, in summarizing the literature on training mental health professionals to treat mental illnesses among those with IDD, Dykens (2016) highlights disability-specific didactics (about ways in which mental illnesses present, as well as therapeutic approaches and psychotropic medications), extensive supervised clinical experiences with persons with IDD, and engagement in positive, informal experiences. This combination, then, includes both the experiential and the intellectual, and future research and intervention efforts might operate on both the “heart” and the “mind” aspects of competence.

Beyond the study’s findings and implications, we also acknowledge its limitations. All recruitment efforts were web-based and limited to organizations that were willing to disseminate our flyer. However, due to the ways in which modern healthcare professionals operate, we assume that having a web-based survey should not have greatly impeded the participants’ ability to participate. Although we recruited a large and national sample, we were also unable to determine the study’s response rate (as we did not know how many recruitment flyers were disseminated by each organization). An additional limitation resulted from our over-representation of pediatricians and nurses, our under-representation of some of the other healthcare disciplines. When asking the respondents to evaluate their levels of experience, comfort, and competence across ten different disability types, we also acknowledge that our terminology may be problematic in that the ten proposed disabilities are not comprehensive in terms of all specific conditions or all categories.

Still, this study begins the process of understanding training experiences and needs as seen by those disability-oriented healthcare providers who work every day with persons with IDD. Although much remains to be known, this study provides information about these professionals’ levels and interplay of experience, comfort, and competence; about preferred

modes of training; and about specific recommendations and advice. Ultimately, we need to increase the numbers of well-trained healthcare professionals who work with persons with disabilities, and this study begins to point the way to strategies that might increase our society's capacity to serve this important, but underserved and rewarding, group of individuals.

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Table 1. *Demographics of Healthcare Professionals*

		% (N)
Profession	Clinical Psychology	20% (30)
	Dentistry	5% (7)
	Family Medicine	7% (10)
	Nurse	22% (34)
	Nurse Practitioner	7% (11)
	Pediatrics	26% (40)
	Psychiatry	3% (4)
	Social Work	10% (15)
Age	20-29	7% (10)
	30-39	20% (30)
	40-49	20% (30)
	50-59	27% (40)
	60+	26% (39)
Years in Profession	<1-3	9% (13)
	4-9	18% (27)
	10-15	12% (18)
	16-20	8% (11)
	21-30	27% (40)
	30+	25% (37)
Years in Profession with IDD	<1-3	13% (20)
	4-9	22% (33)
	10-15	16% (23)
	16-20	11% (16)
	21-30	27% (39)
	30+	10% (14)
Setting of Practice	Private	11% (17)

	Group	14% (22)
	Public (Community Clinic)	6% (9)
	Hospital/ Emergency Room	32% (49)
	School	5% (8)
	Other	31% (48)
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Educational Level	Associates Degree	7% (12)
<i>(Check all that apply</i>	Bachelor's degree	21% (33)
<i>% > 100%)</i>	Master's degree	19% (30)
	Doctoral / Professional Degree	58% (90)
<hr/>		
Credentials	Residency	22% (50)
<i>(Check all that apply</i>	Fellowship	33% (52)
<i>% > 100%)</i>	Certification Exam	52% (81)
	Internship	30% (47)
	Other	10% (15)
<hr/>		

Table 2 *Health Professionals' levels of Experience, Competence, and Comfort*

Disability Type	Experience Mean (SD)	Comfort Mean (SD)	Competence Mean (SD)
Autism Spectrum Disorder	4.63 (.795)	4.18 (.980)	4.00 (1.01)
Deaf-Blindness	2.87 (1.24)	2.98 (1.29)	2.63 (1.15)
Deafness	3.09 (1.18)	3.09 (1.29)	2.72 (1.14)
Down Syndrome	4.01 (1.12)	4.05 (1.04)	3.85 (1.07)
Other Genetic Syndromes	4.24 (1.01)	3.86 (1.10)	3.61 (1.09)
Intellectual Disability	4.63 (.697)	4.25 (.943)	4.09 (.946)
Motor Disability	4.24 (.965)	3.87 (1.06)	3.61 (1.07)
Psychological Disorder / Psychiatric Condition	4.51 (.804)	3.89 (1.09)	3.68 (1.02)
Speech or Language Impairment	4.51 (.836)	3.88 (1.09)	3.66 (1.06)
Visual Impairment	3.55 (1.16)	3.28 (1.26)	3.02 (1.18)
Total	40.22 (6.73)	37.32 (8.59)	34.86 (7.83)
N	150	150	152

*** 5-point scales. 1-Never to 5-Often for experience; 1-Not competent/Not comfortable to 5-Extremely competent/Extremely comfortable for competence and comfort.*

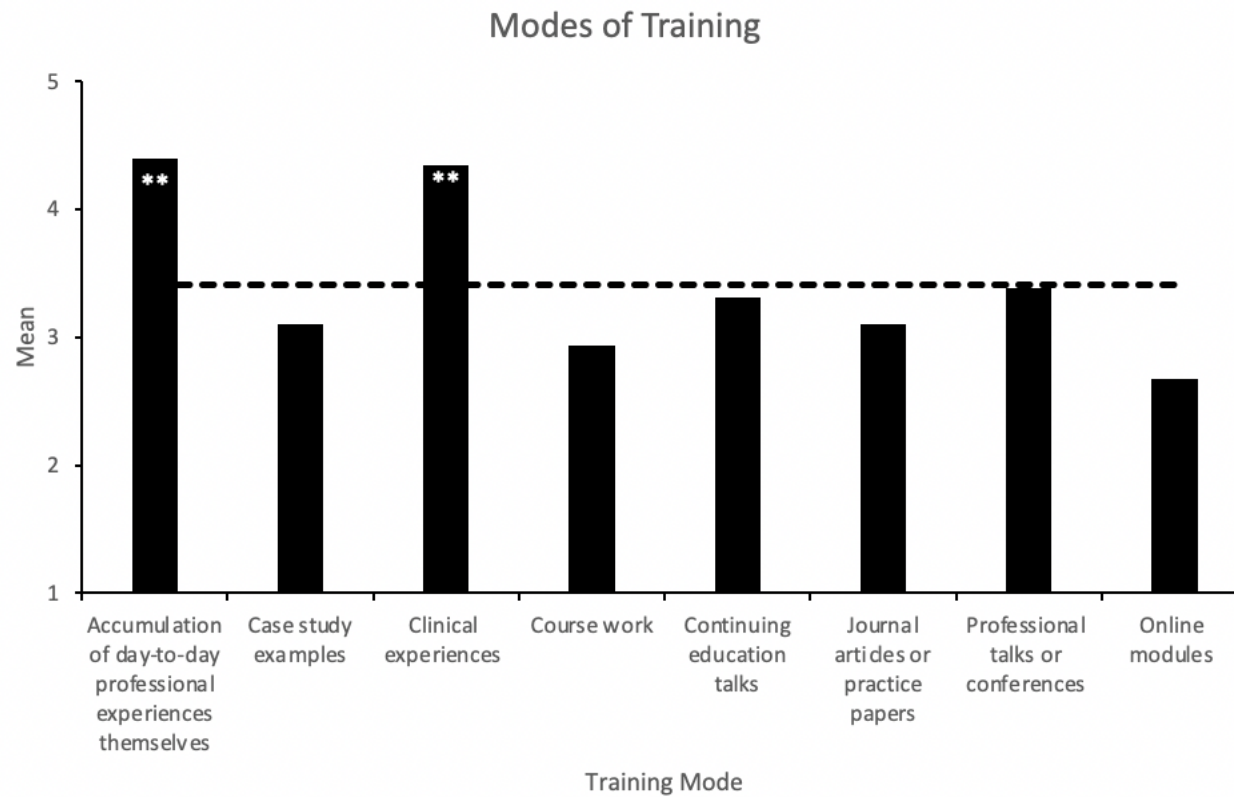
Table 3: *Voices from the Respondents*

Theme	Voices from Respondents
Need for exposure	<p>“Make training and exposure part of mandatory professional development and change the culture of choice to necessity – all professionals need to be trained to work with this diverse population.”</p> <p>“More exposure and experience in working with students or clients in low-stakes settings such as recreational programs to learn more about this population from a strengths-based model rather than deficit based, as this allows the neuro-typical individual to see the personality of the individual with IDD.”</p>

<p>Need for Resources / Training</p>	<p>“These children and families need to be purposefully integrated into training program clinics from day #1. The commonalities they share with other children need to be emphasized and not just all the ways that they are different.”</p> <p>“Increase exposure and meaningful interactions in NON-clinical scenarios --- allow medical students and other health professionals to have frequent, meaningful interactions that expose them to people with disabilities outside of emergency/healthcare situations.”</p> <p>“In my opinion we have to make it an integral part of training through medical school and residency and expose young trainees to people with IDD.”</p> <p>“Education and advocacy are the very best tools to help us. The more comfort in assessing, treating, and referring these patients, the more doctors will embrace seeing them.”</p> <p>“Increased exposure to evidence-based treatments and guidelines to help gain confidence.”</p> <p>“1. Pre-professional training programs for health professionals which intentionally include practical didactic and clinical experiences with individuals with IDD 2. Settings in which individuals with IDD are provided service should reach out to pre-professional training programs to offer opportunities for clinical placement during training.”</p> <p>“More information on this population and how to work with them in professional education.”</p>
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<p>IDD as an Underserved Population</p>	<p>“Let more people know that the IDD community needs more help. Right now, diaper banks won't carry larger size diapers for IDD & insurance limits diagnoses covered for diapers, also respite won't take the children with moderate to severe IDD.”</p>
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Figure 1: *Level of helpfulness for commonly occurring modes of training*



** Modes of training were significant above or below the grand mean

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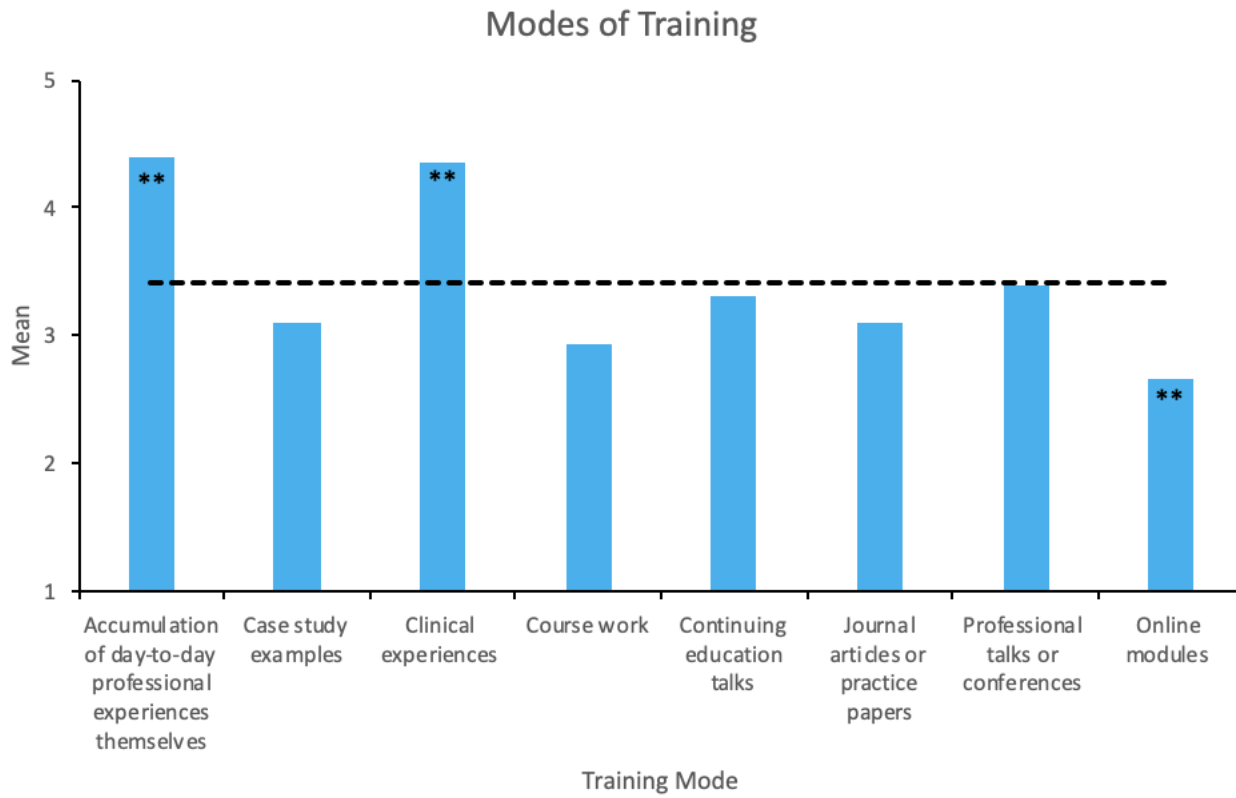
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<p>Positive or Negative views towards Finances</p>	<p>“More information on this population and how to work with them in professional education.”</p> <p>“More resources available to the IDD population so clinicians/professionals feel as though they have support to offer the families”</p> <p>“Pay them better. It's awful to be in such a rewarding field that is so unrewarding financially.”</p> <p>“Appropriate compensation for time and competence needed to care for people with IDD.”</p> <p>“Remove the reimbursement caps on our services.”</p>
<p>Positive Feelings Towards Career</p>	<p>“I feel that the only thing to promote is the feeling of love, compassion, and family that you give to persons with DD that may not have it.”</p> <p>“Putting a face and a story on families with special needs and indicating the rewards that treating them brings.”</p>
<p>IDD as an Underserved Population</p>	<p>“Let more people know that the IDD community needs more help. Right now, diaper banks won't carry larger size diapers for IDD & insurance limits diagnoses covered for diapers, also respite won't take the children with moderate to severe IDD.”</p>

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