

Research Article

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Virtual Nutrition, Socialization and Stress Reduction Intervention for Adults with Disabilities: A Feasibility Study

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Abstract

Objective: Assess feasibility of a virtual intervention to improve dietary habits, social interaction, and stress management among adults with intellectual and developmental disabilities (PwIDD), led by college students as part of a health curriculum.

Methods: Eight 75-minute virtual sessions led from home kitchens were assessed using pre- and post-intervention surveys; post-intervention focus groups.

Results: Participants were adult PwIDD (n=49 at T1, n=27 at T2) and their caregivers (n=28, n=15 at T2), 5 faculty mentors, and 12 college student instructors. Reliability scores were high for distress and loneliness measures; low for dietary measures. PwIDD program completers differed from non-completers on several variables, including employment and living situation.

Conclusions and implications: The online intervention, facilitated through a college curriculum for health-related disciplines, was feasible for PwIDD and caregivers who completed the program, most faculty and all students. Valid and reliable assessment tools are needed for PwIDD.

Keywords: Stress reduction; Intellectual and developmental disabilities; Diet; Socialization; Incorporation into health-related college curriculum

Introduction

People with Intellectual and Developmental Disabilities (PwIDD) experience more health conditions, worse mental health, and less access to support than those without disabilities [1]. These heightened risks can be reduced through lifestyle changes, social integration, increasing access to support and participation in evidence-based interventions [1,2].

Health conditions of particular concern to PwIDD include obesity and overweight, diabetes, and cardiovascular disease. Thirty-eight percent of adults with intellectual and developmental disabilities have obesity [3,4]. While this is less than the 42% obesity rate of the overall American adult population, both obesity and overweight put PwIDD at risk for type 2 diabetes, high blood cholesterol and hypertension [3,5-8]. PwIDD also have higher premature mortality rates compared to the general population [9]. One factor that can help reduce risks for obesity and cardiovascular disease is eating fresh produce [10-12]. PwIDD consume well below recommended levels of fresh produce [13-15]. Being sedentary and drinking sugar-containing soda is also associated with weight gain among PwIDD [4].

The presence of chronic health conditions, such as cardiovascular disease or type 2 diabetes, has been associated with increased isolation, being sedentary, and distress [16]. In a cross-sectional study comparing PwIDD to those without disabilities, PwIDD demonstrated significantly lower levels of overall well-being and a strong association between loneliness and reduced well-being [17]. PwIDD demonstrated significantly lower levels of overall well-being and a strong association between loneliness and reduced well-being. Anxiety levels are also high in this population and most prevalent among PwIDD with Autism Spectrum Disorder, hearing loss, and/or seniors [18]. The COVID-19 pandemic decreased social opportunities for PwIDD, increasing anxiety, depression, and perceived isolation [19-21]. Residential schools, day services, and relief care were limited during the pandemic, creating

a need for innovative resources to provide support for PwIDD and their caregivers. New ways of working with this population, including technology-based interventions, were recommended during and after the pandemic [22].

Students preparing for careers in the health professions will be expected to work with PwIDD, but they have few opportunities to learn about this population in their academic preparation [23-25]. The unique nutritional needs of the disability population require physical therapists, occupational therapists and dietitians to work collaboratively to provide effective care [26]. Dietitians lack the preparation to work with people with disabilities and need communication skills and the ability to engage clients with disabilities as primary tools for supporting dietary improvements in disabled clients [27]. Training college and graduate students in these disciplines through inter-professional education that is embedded into the curriculum is recommended [26]. Simulated patient encounters have been effectively used to prepare undergraduate nursing students to serve PwIDD [28].

Self-efficacy theory can be used as a framework for interventions in this population. The theory identifies four essential factors to increase one's confidence in making a specific change: Role modeling, verbal persuasion, mastery experiences and a positive somatic (physical) state [29]. Increased self-efficacy allows individuals to exercise personal

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agency over their habits and choices [30]. The present intervention incorporated Self-efficacy constructs as participants observed the instructor prepare a healthy snack, prepared a snack themselves, received verbal encouragement for eating the snack and engaged in a relaxation exercise to reduce physical distress symptoms. Both the social and physical environments are social determinants of health that are essential to supporting the health practices and status of individuals and communities [31]. In this study, social determinants included the social support from the instructor, fellow participants, and caregivers who frequently assisted PwIDD in the program. Environmental determinants were enhanced and utilized as participants engaged in the activities virtually from their own kitchens.

The overarching goal of this study was to create and determine the feasibility of a replicable virtual intervention to improve dietary habits, increase social interaction, and reduce distress among PwIDD that was led by students as part of a college curriculum in a health-related field. The aims and evaluation of this intervention have been guided by recommendations by Teresi and colleagues, who have delineated comprehensive and specific guidelines for the evaluation of the feasibility of pilot studies with small samples [32]. The specific research questions examined in this study were:

1. What is the feasibility of the protocol for data collection, particularly for PwIDD? What is the evidence of the reliability of the measures?
2. To what degree was the fidelity of the intervention maintained over the course of the program? Were student instructors able to implement the program as intended?
3. To what degree were PwIDD able to remain engaged throughout the intervention period? How did non-completers compare with completers of the intervention?
4. What is the feasibility of incorporating the delivery of the intervention into a college curriculum for students in health-related academic programs? To what degree of success were student instructors recruited, trained, and mentored throughout the intervention?

Materials and Methods

Design

This feasibility study used a pre- and post-intervention survey and a post-intervention focus group discussion to evaluate Snack, Chat & Chill, an 8-session online program delivered through a virtual meeting platform. All participants completed a university-approved online informed consent process using a secure survey software system by clicking an "I agree" button prior to participation in the study. A unique version of the consent form was developed for participants who were PwIDD, which incorporated short phrases and simple sentences. Assistance by telephone or video chat was offered by the study team to any participant who requested it, although all needing assistance preferred to receive it from their caregivers. We obtained Institutional Review Board (IRB) approval from the university of the lead author prior to collecting data for this project (PRO-2022-186) through an expedited review process.

Participant samples

Five faculties from 3 universities and 1 community college across four southern NJ counties formed the planning team. The faculty disciplines included general Psychology, Health Psychology, Nutrition and Dietetics, Nursing, and Public Health/Wellness. A total of 12

college student instructors were recruited to receive training and lead the program over the duration of the study. Eight student instructors (2 from each institution) were recruited in the fall 2022 semester. The program was offered again in the spring 2023 semester by the 3 universities and was offered once more in the summer 2023 semester by the lead university in an attempt to reach the desired number of program participants. During the spring 2023 semester, 2 of the 3 universities recruited and trained 4 new student instructors. No new instructors were recruited for the summer 2023 program. Student instructors were invited to join the research study the first time they served as an instructor; data were not collected from instructors beyond the first time they led the program.

Program participants were PwIDD who were age 18 or older residing in southern NJ and their caregivers. They were recruited by email using lists managed by providers of services to PwIDD in the area. Program participants who completed the program once were allowed to join a second or third time, but were not enrolled in the research study more than once. G*Power was used to determine a required sample size of 71 PwIDD to detect significant changes in dietary behaviors from T1 to T2, using an alpha of .05, power of .8 and effect size of .3 [33]. In the absence of this sample size to detect change, we needed 30 participants for establishing feasibility [32].

Measures

Surveys for all participants (PwIDD, caregivers, student instructors and faculty researchers) and focus groups for PwIDD and for student instructors were the primary means of data collection for this study. Three surveys were developed and administered electronically through the Qualtrics software system pre-post intervention (T1 and T2): 1 for PwIDD, 1 for caregivers and 1 for student instructors. One post-intervention (T2) survey was developed and administered to faculty researchers through Qualtrics. Existing validated measures were incorporated when possible. Study team members reviewed and took the surveys prior to their use as part of the development process, but surveys were not formally pilot-tested. Table S1 provides a summary of the questions and reliability scores for the participant and caregiver surveys. All surveys used in this study are included in the Supplementary Files.

The survey for PwIDD assessed 1) nutrition knowledge, attitudes and behaviors, 2) sleeping habits, 3) perceived loneliness, 4) perceived levels of stress and coping confidence, and 5) the self-reported biometric measures of height, weight and blood pressure [34-35]. We used the unpublished Nutrition Knowledge, Attitudes and Behaviors Survey to assess the nutrition component of the program for this study, which was developed by the Family Resource Network of New Jersey in 2017. All food-related questions were accompanied by a picture of the food. An abbreviated version of the Pittsburgh Sleep Quality Index was adapted for use in the survey, as sleep quality is related to perceptions of mental and emotional well-being [36]. The 3-Item UCLA loneliness scale was used to assess perceived levels of loneliness [37]. The 10-item Kessler psychological distress scale was used to assess levels of distress [38]. Finally, two items from the Perceived Stress Scale were used to assess perceived stress and coping confidence [39].

Modifications were made to the response choices for the questions from the adapted Pittsburgh Sleep Quality Index items, UCLA Loneliness Scale, Kessler Psychological Distress Scale, and Perceived Stress Scale items based on recommended guidelines [40]. In addition to verbal response categories, pictures and images were added to better enable PwIDD to understand and respond to the questions. For ordinal

responses, we used “not at all,” “a little,” and “a lot,” with each response accompanied by a graphic of a drinking glass that was empty, half full, or almost completely full. For ordinal response choices of “good,” “fair,” or “poor,” the accompanying graphic was a smiling face, neutral face, or frowning face.

A unique 3-question nutrition knowledge survey was developed and administered at the end of each program session that was based on content presented during the session. In the final 5 minutes of each session, participants accessed a link to the survey from the Zoom chat box and answered the questions.

The caregiver survey assessed the caregiver’s perceptions of the nutrition habits, sleep quality, loneliness, distress, and stress levels for their care recipient who was a PwIDD using the same questions in the participant survey, but without the accompanying pictures and graphics. The caregiver’s own nutrition knowledge and personal dietary habits were assessed using the nutrition knowledge, attitudes and behaviors survey. Questions related to cooking confidence, barriers to cooking, and food resource management for caregivers were adapted from the cooking matters for adult’s survey [41].

In the T1 student instructor survey, students were asked about their previous experience working with PwIDD and their intention to serve PwIDD in their future careers. Both T1 and T2 surveys assessed students’ negative attitudes about PwIDD were using the 20-item interaction with disabled persons scale and their interest and comfort level in working with PwIDD using questions created for this study [42]. In the T2 survey only, students also answered questions about perceptions of their professional development using 6 items we created for this study, which assessed public speaking, leadership, time management, teamwork/collaboration, confidence/comfort in serving PwIDD, and overall professional development. Students also indicated whether they would participate in a program like this again and whether they would recommend the experience to other students.

Faculty planning team members completed a survey at T2 to assess the feasibility of offering the program as part of a curriculum and reflect on their perceived impact of the program on the student instructors and/or research assistants. Questions included the time required to mentor students, challenges they faced, and their perceptions of students’ skill development and professional growth on this project.

Two 1-hour, live, virtual focus groups 1 week after program completion were conducted by a research team member, one for PwIDD and one for student instructors. Focus groups for PwIDD were offered at the end of every 8-week session in the fall, spring, and summer. A focus group for student instructors was only offered at the end of the fall 8-week session due to scheduling challenges. Questions and responses for the focus group for PwIDD are in Table S2 and for student instructors are in Table S3. Questions for PwIDD were reviewed by 2 professionals directly serving PwIDD (but not part of the study team) for appropriateness and feasibility. No additional review was deemed necessary for questions for student instructors. A note taker was present at each focus group to capture participant responses for each question. Caregivers served as a proxy if their care-recipient was non-verbal.

Intervention development and implementation

A team of 4 of the 5 faculty researchers, 2 graduate research assistants, 1 undergraduate research assistant, and 1 stakeholder family (a parent and 3 adult children who are PwIDD) developed the content for 8 program sessions and a 4-hour training program for

instructors. The community college faculty member chose to engage in implementation only.

Instructors were students in nutrition and dietetics, occupational therapy, public health/wellness or psychology and the program served as part of students’ clinical requirement, internship, or course project. Students from these majors were recruited because these are programs of study which prepare graduates for health-related professions. Instructors completed a 4-hour, live virtual training program led by 1 faculty member and 1 graduate assistant. Throughout the 8-week program, they met 3 additional times for 1 hour to discuss the program’s progress and address concerns.

Dietary interventions for PwIDD have demonstrated successful behavior changes in 8-12 weeks guiding our decision to make this program 8 weeks in length [43,44]. Nutrition topics were selected to address the health risks for PwIDD and to support the USDA dietary guidelines for Americans 2020-2025 [12]. For each 75-minute session, participants and instructors connected from their home kitchens *via* Zoom. Instructors guided the preparation and consumption of a healthy snack, facilitated interactive nutrition games, and led a 15-minute relaxation activity. Each session focused on a unique nutrition topic, recipe and game, with a relaxation activity that was repeated two sessions in a row to increase familiarization with the relaxation skills.

Socialization was encouraged, and participants shared thoughts on the session content. Participants received session details a week in advance of each session to enable them to purchase snack ingredients and prepare for the session. Each site offered the same lesson in each week of the program. Participants were encouraged (but not required) to join the program geographically nearest to them. Table S4 contains an overview of recipes and activities.

Data analysis

Quantitative data were analyzed using SPSS (version 29). For the post-session knowledge survey, we examined percent correct for each item. We examined descriptive statistics at T1 and T2, including time to survey completion, possible and observed ranges, frequencies, means, standard deviations, skewness, kurtosis, and missing data.

Qualitative data from the PwIDD focus group were independently summarized by two research team members. Notes from each focus group meeting were combined into a master document. The two researchers compared summaries, reconciled differences, organized them into unique categories and reported them as frequencies. Student instructor focus group data were summarized by one member of the research team, as it was a smaller group and all data were collected in a single meeting.

Results

We examined the reliability of the pre- and post-program surveys completed by PwIDD and caregivers. Table S1 reports the internal consistency reliabilities of all multi-item survey measures. For PwIDD at T1 and T2, Cronbach’s alphas were 0.85-0.90 for psychological distress and loneliness scales, suggesting high reliability. For caregivers’ perceptions of PwIDD at T1 and T2, Cronbach’s alpha for the same measures was 0.64 to 0.88, suggesting a lower reliability for caregiver reports of PwIDD. For measures from the cooking matters survey, Cronbach’s alphas ranged from 0.50-0.87, indicating low to good reliability.

Forty-nine PwIDD completed the T1 survey with 34 corresponding caregiver T1 surveys; 31 PwIDD completed the T2 survey with 19

corresponding caregiver T2 surveys. Of the 49 PwIDD who completed the T1 survey, 4 did not attend any program sessions, 18 attended 1 or 2 sessions, and 27 completed 5 or more sessions and the T2 survey. Fifteen caregivers of PwIDD attending 5 or more sessions completed the T2 survey. Although we could not test for significant change from T1 to T2 due to the limited number of participants completing all assessments, we had a large enough sample (>30) to establish feasibility [32].

Of PwIDD who completed 5 or more sessions, most were male (66.7%), White (81.5%), and were 34.97 years old, on average. Average Body Mass Index (BMI) was 31.01, which is classified as obese; self-reported blood pressure averaged 124.40 (systolic)/77.90 (diastolic), which is classified as clinically healthy. Most PwIDD were not employed (55.6%); those who were employed averaged 12.73 hours of work per week. A majority lived with family (63.0%) and most had not participated in organized fitness activities (55.6%). The predominant disability-related diagnosis of participants as reported by caregivers was autism spectrum disorder (40.0%). In comparing those who completed 5 or more sessions versus those who completed 0-2 sessions, there are several differences between the two groups (see Table S5). Completers were more likely than non-completers to be male, employed, work fewer hours per week, live with family, participate in organized fitness activities, have slightly higher blood pressure, and have a caregiver report their disability diagnosis.

Descriptive data about PwIDD's survey responses are presented in Table S6a. We calculated time to survey completion for PwIDD using the total time logged into the survey software. For the T1 survey, removing five outliers, time to completion was 2.97 to 73.27 min, with an average of 12.16 min (SD=10.88). For the T2 survey, removing three outliers, time to completion was 2.81 to 49.48 min, with an average of 12.27 min (SD=11.15). One question about confidence in making dietary changes had a notable number of PwIDD (n=18 at T1 and n=16 at T2) with missing responses; the remaining questions had few or no missing responses.

Post-session knowledge surveys for PwIDD ranged from 66.67% (portion sizes) to 89.58% (mindful eating) correct. Percentage of correct responses was above 80% for 5 of the 8 knowledge surveys and also included nutrition labels, macronutrients, healthy beverages and healthy snacking. Full results are in Table S7.

Caregivers of program completers were female (100%), White (93.3%) and were 60.40 years old, on average. Most were retired (53.3%), held a college degree (66.7%), and reported a household annual income of \$100,000 or more (53.3%). Most were mothers (67.9%), siblings (14.3%) or fathers (10.7%) of PwIDD versus paid staff in a residential or day program (7.1%). Mothers provided an average of 30.17 hours of direct care to the PwIDD, had other sources of help (66.7%), and did not have care responsibility for other individuals (60.0%).

Descriptive information about caregivers' survey responses, both perceptions of PwIDD and their own experiences, at T1 and T2 are presented in Table S6b. For the T1 survey, removing three outliers, time to completion ranged from 5.07 to 12.30 min, with an average of 18.89 min (SD=10.17). For the T2 survey, removing three outliers, time to completion ranged from 4.42 to 40.37 min, with an average of 9.10 min (SD = 2.14). The amount of missing data for any of the survey items was nominal and is noted in Table S6b.

Twenty-two PwIDD and 7 caregivers attended one of the PwIDD focus group sessions. While they were intended for PwIDD with caregiver assistance only, some caregivers expressed their own opinions and these are noted in Table S2. Participants enjoyed the program,

especially making and eating the snack. Few PwIDD reported a least favorite activity, although some felt sleepy after the relaxation activities. Most participants, including 1 who was non-verbal, enjoyed the social interaction, reporting they had fun during the sessions, had a chance to speak and felt their voice was heard.

Several expressed the desire for more choices within the program, such as varying the times program is offered, allowing participants to vote on the weekly snack, and having break out rooms during sessions to choose between different nutrition or chill activities. Some asked to receive all recipes at the start of the program, providing more cost effective options for ingredients, and offering dinner recipes because the program was held in the evening. Participants were highly satisfied with the performance of the instructors, noting their knowledge, sincerity, and ability to provide clear instructions and create an inclusive group atmosphere. Of 12 student instructors, 9 completed the T1 survey and 6 completed both the T1 and T2 surveys. Reliability of the interaction with disabled persons scale was good (T1 $\alpha=0.80$, T2 $\alpha=0.73$) and the 6-question perceptions of professional development was good ($\alpha=0.86$) [42]. Student instructors were female (100%), white (89.9%) and did not identify as having a disability or being neurodivergent (100%). One third were graduate students in either dietetics, psychology or occupational therapy; the remainder were undergraduate students in nutrition, psychology, nursing or public health/wellness. Seventy-eight percent had "some" or "a lot" of experience working with PwIDD prior to participating in the program. Two-thirds anticipated serving PwIDD in their careers. Students' average negative attitudes toward PwIDD (on a scale of 1="disagree very much" to 6="agree very much") was 2.93 (SD=0.49) at T1 and 2.76 (SD=0.45) at T2. On a scale of 1="very uninterested/uncomfortable" to 3="very interested/very comfortable," students interest in working with PwIDD averaged 4.00 (SD=0.87) at T1 and 4.45 (SD = 0.93) at T2; their comfort in working with PwIDD averaged 3.44 (SD=1.33) at T1 and 3.91 (SD=0.83) at T2. In terms of perceived professional growth, students reported an average of 2.44 (SD=0.44) on a scale of 1= "skills stayed the same" to 3="skills changed a lot" finally, 100% of students indicated that they would serve as a facilitator for a similar program again and would recommend the experience to other students.

All 8 student instructors from the initial program offering participated in the focus group (it was not offered after the spring semester for the 4 new instructors). Responses are summarized in Table S3 and indicate a high degree of satisfaction with the training they received and their level of preparation to lead the program. They developed a better understanding of PwIDD and how to communicate with them, increased patience, improved group management skills, and greater adaptability in teaching. Challenges included unstable internet connections, client behaviors (such as losing focus or talkativeness), and not being able to see and guide participants in snack preparation. They found that participants liked most of the activities and recommended a few changes for future program offerings.

Four faculty representing the three university partners completed the T2 survey; the community college faculty partner did not. Half reported their students' involvement as a research assistant and half reported it as part of a required course or clinical experience. All reported spending between 30 minutes and 1 hour each week in mentoring the students. All found the students to be prepared and reported that their ability to work with PwIDD improved "a lot" and their leadership, teamwork, public speaking/communication, and overall professional development improved "some" or "a lot". All but 1 faculty member observed "some" or "a lot" of improvement in time

management skills and all but 1 believe the program “is sustainable and can continue to be implemented as-is”. Faculty identified the professional development opportunity for students, the valuable service to the PwIDD community and the organization of the intervention as strengths. They reported the recruitment and retention of PwIDD as participants as a challenge. One suggested offering a support group for caregivers to help them encourage healthier eating for their loved one with a disability.

Discussion

The first aim of this study was to explore the feasibility of the data collection protocol for PwIDD and the reliability of the measures. One challenge to the evaluation of interventions for PwIDD is the accuracy with which evaluation tools measure the self-reported knowledge, attitudes and behaviors of this population. Prior research has identified limitations in assessing dietary habits, independent living skills and self-reported anxiety [45-49]. The average survey completion time of approximately 12 minutes with minimal missing data for all but one question suggests that use of an electronic survey with assistance from a caregiver is feasible for PwIDD.

The high focus group participation rate among program completers (81%) and number of comments suggests that focus group discussions are very feasible for PwIDD. The reliability of the established survey instruments used in this study were acceptable to good; however, insufficient sample size limited our ability to accurately measure the reliability of the scales assessed.

The second study aim was to examine the fidelity of the intervention over time and the degree to which student instructors were able to implement the program as intended. All program meetings were implemented by all student instructors as planned, following the established schedule and content. Training appeared to be adequate for student instructors, who indicated confidence in their ability to implement the intervention as planned. All program materials were created as planned and were readily available to students and participants. The virtual platform (Zoom) functioned well for each session with few challenges for participants or instructors.

The third study aim was to assess the degree to which PwIDD were able to remain engaged in the intervention and how non-completers compared with program completers. PwIDD enjoyed preparing and consuming healthy snacks, participating in interactive nutrition games, and engaging in relaxation activities. Of PwIDD who took the first survey, 55% completed the program and second survey. Program completers differed from non-completers on several variables, suggesting that factors other than interest in the program may have affected their participation.

The program appeared to be most feasible for caregivers who are the mothers of PwIDD, most of whom had help in caring for their loved one. Paid caregivers who were responsible for gathering 2-4 PwIDD to participate together in a virtual meeting connection from one tablet or laptop were less likely to complete the T2 survey. They may not have found it possible to complete the extensive surveys for each PwIDD under their care, even though it was feasible for them to facilitate 2-4 PwIDD in the group home to participate in the program together.

The fourth study aim was to explore the feasibility of incorporating the delivery of the intervention into a college curriculum for students in health-related academic programs. Faculty and student instructor data indicate that building the facilitation of the program into a college curriculum for health-related academic programs at the bachelor's and master's degree level is a sustainable model for recruiting, training,

and supervising students to serve as instructors and for faculty to serve as mentors. It did not appear to be feasible for the community college partner, who stopped participating beyond the initial planning meetings and launch of the program.

The study had several limitations. While it was important to address the reliability of the surveys for PwIDD, the small sample size was a limitation in conducting this analysis. The small sample size also limited our ability to explore content validity through an analysis of survey items. Modification to existing surveys for sleep, loneliness and distress were not pilot-tested prior to use in this study. While the nutrition knowledge, attitudes and behavioral items were reviewed by several members of the study team, they were not pilot-tested with PwIDD. We did not attempt to conduct follow-up interviews with program non-completers.

Conclusion

Snack, chat and chill was an enjoyable virtual intervention for adults with intellectual and developmental disabilities and their caregivers, providing greater accessibility than in-person programs, as participation is from home kitchens. While feasible for some PwIDD and caregivers with resources such as help from other support persons and availability of time, attendance and survey completion rates suggest it appeared to be less feasible for PwIDD who work more hours outside of the home and for those who live in more independent settings, such as group homes. The intervention was feasible and has shown to be sustainable for 4-year college faculty in the health professions to facilitate as part of the required clinical and professional experiences for students in bachelor's and master's degree programs. It may be less feasible for 2-year college faculty who do not facilitate clinical and professional experiences as part of the curriculum. Student instructors and faculty found the intervention to be beneficial in developing students' professional skills, knowledge and attitudes toward PwIDD.

The creation of evidence-based interventions requires valid and reliable evaluation tools, which are limited for this population, particularly for PwIDD who have lower levels of cognitive functioning. Assessing PwIDD poses unique challenges, necessitating one-on-one support for survey access, comprehension, and response selection. Exploring caregivers (both family members and paid staff) as reliable proxies for PwIDD in completing surveys and other assessment methods that are not survey-dependent is recommended for future research.

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