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Professional Development Strategies for Treating People with IDD and Mental Health Needs

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Professional Development Strategies for Treating People with IDD and Mental Health Needs

Cover Page Footnote

The University of New Hampshire (UNH) recognizes the decades-long contributions of Dr. Joan Beasley, to the field of therapeutic interventions for individuals with intellectual and developmental disabilities and mental health needs. Beginning in 1992, Dr. Beasley and co-authors published a series of papers describing protocols that would ultimately become the Systemic, Therapeutic, Assessment, Resources, and Treatment (START)/Sovner Center Model. The National Center for START Services™ (NCSS) was founded in 2011 at the University of New Hampshire's Institute on Disability. Through the efforts and dedication of Dr. Beasley and her colleagues, the National Center for START Services™, provides technical assistance, training, evaluation, and certification to START programs and resource centers in more than 15 states, serving the mental health needs of thousands of individuals with intellectual disabilities. Today, START is an evidence-informed and evidence-based model which strives to build capacity across systems to meet the needs of individuals with IDD-MH. Dr. Beasley is a Research Professor at the University of New Hampshire where she conducts research on the mental health aspects of intellectual and developmental disabilities. She currently leads the National Research Consortium on Mental Health in Intellectual and Developmental Disabilities at UNH.

Professional Development Strategies for Treating People with Intellectual/Developmental Disabilities and Mental Health Needs

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Plain Language Summary

People with intellectual and developmental disabilities have a hard time getting the mental health support they need. There are not enough programs to teach mental health professionals. Our team created a virtual education series. In this study, we describe the series. We asked providers to fill out surveys before and after. After finishing the series, providers felt more knowledgeable and comfortable. They also reported feeling more connected to other providers caring for people with intellectual and developmental disabilities. Overall, the providers were highly satisfied with the sessions and series.

Abstract

People with intellectual and developmental disabilities (IDD) experience significant health and mental health inequities and difficulties accessing care. There are few initiatives that train mental health professionals to care and advocate for the health and mental health care needs of people with intellectual and developmental disabilities.

We developed a Mental Health and Intellectual and Developmental Disabilities

The University of New Hampshire (UNH) recognizes the decades-long contributions of Dr. Joan Beasley, to the field of therapeutic interventions for individuals with intellectual and developmental disabilities and mental health (IDD-MH) needs. Beginning in 1992, Dr. Beasley and co-authors published a series of papers describing protocols that would ultimately become the Systemic, Therapeutic, Assessment, Resources, and Treatment (START)/Sovner Center Model. The National Center for START Services™ (NCSS) was founded in 2011 at the UNH's Institute on Disability. Through the efforts and dedication of Dr. Beasley and her colleagues, the National Center for START Services™ provides technical assistance, training, evaluation, and certification to START programs and resource centers in more than 15 states, serving the mental health needs of thousands of individuals with intellectual disabilities. Today, START is an evidence-informed and evidence-based model that strives to build capacity across systems to meet the needs of individuals with IDD-MH. Dr. Beasley is a research professor at the UNH where she conducts research on the mental health aspects of IDD. She currently leads the National Research Consortium on Mental Health in Intellectual and Developmental Disabilities at UNH.

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Professional Learning Community (PLC) with Clinical Education Teams (CET) training components through The National Center for START (Systemic-Therapeutic-Assessment-Resources-Treatment) Services® to further educate providers in the U.S. The National Center for START Services® utilizes multiple training and collaboration forums to build the expertise and capacity of community members and service providers caring for people with IDD and mental health disorders. The PLC and CETs are two of these forums.

In this study, we describe the development of, and examine outcomes related to, a 9-session virtual series for doctorate-level psychologists and psychiatric prescribers. Anonymous pre- and post-surveys assessed knowledge, self-efficacy, and self-reported practice behaviors. Session satisfaction surveys were collected after each session. One-hour focus group feedback meetings were held 1 month, and 6 months post the virtual education series and were coded utilizing a modified content analysis approach.

A total of 16 participants consented to be a part of the research evaluation of this virtual education series. Upon completion of the series, the participants reported improvements in various domains including utilizing a strengths-based biopsychosocial approach, comfort in caring for people with mental health conditions and IDD, and self-reported knowledge about the mental health aspect of IDD. Additionally, the providers noted an increase in access to a national network of participants who care for people with IDD. Overall, the participants endorsed a high level of satisfaction with the sessions and series.

The Professional Learning Community using Clinical Education Team training components is a model for connecting and educating medical professionals. Building a professional learning community that unites practitioners who care for people with IDD offers valuable opportunities to increase comfort and knowledge, connect providers, and help improve wellbeing of people with IDD.

Introduction

People with intellectual and developmental disabilities (IDD) experience significant health and mental health inequities and difficulties accessing care. Some of these health inequities include elevated rates of asthma, diabetes, obesity, cardiovascular disease, and decreased health screening (Emerson, 2011; Ouellette-Kuntz et al., 2005; Reichard et al., 2011; Stancliffe et al., 2011; Stirling et al., 2021). The mental health inequities include elevated rates of mental health disorders that are twice the national average (Buckley et al., 2020; Mazza et al., 2020) and difficulties accessing a range of mental health services. People with IDD with co-occurring mental health disorders have higher rates of emergency room visits and poorer service outcomes compared to those with chronic health conditions (Gilmore et al., 2021). There are few initiatives that train mental health professionals to care and advocate for the health and mental health care needs of people with IDD (Adirim et al., 2021; Marrus et al., 2023; Weiss & Lunsky, 2010)

START (Systemic-Therapeutic-Assessment-Resources-Treatment) is a lifespan (ages 6+) service model for people with IDD (Beasley et al., 1992). START provides 24/7 intervention services, cross-systems linkages, and capacity-building technical assistance to promote health and wellbeing for people served and their communities (Kalb et al., 2021). There are currently

over 20 regional START programs across the country. Regional START programs consist of independent providers funded through local entities. START programs receive referrals from case managers, mental health providers, families, schools, and a range of other community providers.

In 2011, the National Center for START Services[®] (NCSS) was established at the University of New Hampshire's Institute on Disability, a University Center for Excellence in Developmental Disabilities (UCEDD). NCSS has three primary functions. First, NCSS facilitates START program implementation including quality assurance and expert training and technical assistance to START programs. Second, NCSS provides training and technical assistance to the broader national network of professionals who work with people with IDD and mental health needs (IDD-MH) through its professional development initiatives. Third, NCSS conducts research and evaluation activities to evaluate efficacy of the START model, outcomes related to training and professional development offerings, and a range of IDD-MH interventions.

Clinical Education Team (CET) Meetings

NCSS utilizes multiple training and collaboration forums to build expertise and capacity of community members and service providers caring for people with IDD and mental health disorders (Beasley et al., 2016). One such forum is the Clinical Education Team (CET) meetings, which are learning forums designed to improve the capacity of the local community to provide supports to individuals with IDD and mental health needs by learning together in the context of anonymous case-based discussions. The CET was first referred to as the "clinical team meeting" which was developed in the mid-1980s for the community of providers and clinical specialists to improve their understanding of and capacity to support people with serious mental health conditions. In 1988, clinical team meetings became part of the START model. In 2013, this became the CET through the guidance of Dr. Anne Hurley, who believed that formalizing the process and providing continuing education credits would improve participation. Dr. Hurley is a prominent leader in the field of IDD-MH, founder and editor of *the Mental Health Aspects of Developmental Disabilities Journal* (1998-2009), and START's founding Clinical Director.

CETs are facilitated by START program members and include local mental health clinicians, IDD, emergency, and/or inpatient service providers. Representation from clinical, medical, and systems experts is expected. Active engagement and interaction among CET attendees are integral aspects of the forums. Cases presented are always reframed to include their strengths and capabilities. This includes recommendations that come from CETs to enhance access to rewarding and engaging experiences to increase meaning in the person's life. Each START program typically hosts one CET per month for 10 months a year.

In preparation for each CET, one participant collects and reviews records, observes and interviews the person and system of care to determine their concerns and priorities, and communicates the purpose of the CET. They then obtain permission to share deidentified information to gather others' ideas and possible solutions. This information is used to develop a patient-specific deidentified presentation that includes standardized information. The interdisciplinary forum of the CET offers an open dialogue and brainstorming around complex

issues presented. The in-depth discussion identifies innovative interventions and potential solutions from a variety of disciplines. It also includes a brief (10-15 minutes) topical didactic related presentation that expands upon one of the issues addressed.

Professional Learning Communities

Another training forum used by NCSS is Professional Learning Communities (PLCs). PLCs are evidence-based adult learning models (Nelson et al., 2010; Servage, 2008). They are an effective model for developing a community of practice amongst like-minded professionals motivated to create positive change. PLCs are intended to reduce a feeling of alienation amongst professionals in the field (Servage, 2008), fostering a community of practice in which committed professionals can engage in critical inquiry, which is defined as a “process of discovering our hidden assumptions, evaluating the worth of what we are doing now, and imagining possibilities for the future” (Servage, 2008, p. 74).

PLCs, hosted by NCSS, are time-limited (typically 6-12 sessions) and provide professionals with training, facilitated discussion, and tools to improve knowledge of mental health disorders and IDD across a local or regional system of care. Since 2013, NCSS has hosted more than 25 PLCs across the U.S. and Canada, training over 490 professionals from various disciplines on various aspects of mental health and IDD.

While both CETs and PLCs are training forums focused on building professionals’ capacity around the mental health aspects of IDD, there are several notable distinctions between the two. START CETs are offered by START programs to build the capacity of their local community of providers. Attendees of CETs are not the same from session to session. PLCs, hosted by NCSS, are national or regional training forums that have the same group of participants for the duration of the PLC. CETs are singular events, with each session offering a different training topic related to IDD-MH. PLC schedules represent a series of interrelated topics that collectively contribute to overall learning objectives of the PLC. While CETs build capacity, PLCs build capacity and *community*.

ECHO Model

There is existing data around outcomes of adult learning communities. Extension for Community Healthcare Outcomes (Project ECHO) is one model, developed in 2003 by Dr. Sanjeev Arora, which has been widely used and extensively studied (Arora et al., 2010, 2011; Zhou et al., 2016). ECHO utilizes telehealth technology, best practice protocols, and case-based learning to train and support healthcare providers in developing the knowledge and self-efficacy needed to treat a variety of patient populations. These methods closely align with those of CETs but differ in two main aspects; (1) CETs provide structured follow-up to previously discussed cases and (2) typically occur in the context of the START service delivery model.

There are numerous articles reporting outcomes related to ECHOs and autism in primary

care, mental health, and multiple medical specialties (Mazurek et al., 2020; McBain et al., 2019; Sohl et al., 2017; Zhou et al., 2016). We identified four ECHOs that specifically focus on the mental health care needs of people with IDD. A Project ECHO in North Carolina increased mental health provider knowledge, self-efficacy, and problem-solving regarding caring for individuals with ASD (Dreiling et al., 2022). Similarly, a New South Wales, Australia, Project ECHO engaged behavioral support practitioners, nurses, psychologists, social workers, and occupational therapists who reported an increase in self-reported knowledge and confidence in mental health and intellectual disability care after participating in an ECHO (Bessell et al., 2023). In Canada, a Project ECHO focused on supporting providers caring for mental health of people with intellectual disability during the COVID-19 pandemic (Thakur et al., 2021). Providers reported improvements in self-efficacy, support, and coping (Thakur et al., 2021). Meanwhile, a different virtual education course in Canada informed by ECHO practices taught family caregivers about mental health and well-being for adults with IDD during the COVID-19 pandemic (Lake et al., 2022). Caregivers reported an increase in self-efficacy and well-being after this course (Lake et al., 2022). We did not find any ECHOs in the literature from the U.S. that focused on the co-occurrence of mental health disorders and intellectual disabilities.

In recognition of training best practices for health professionals and to reflect existing training paradigms offered by NCSS and START programs, NCSS developed a Mental Health and Intellectual and Developmental Disabilities Professional Learning Community using CET components. We assessed self-efficacy, knowledge, self-reported practice behaviors, and satisfaction with the virtual education series.

Methods

Series Development

Series content and evaluation tools were developed by subject matter experts in IDD and mental health needs. Didactics for each session were developed by nine clinical experts who specialize in specific topics. Of the nine clinical experts, four also have duality in their role as a family member of a person with IDD. Table 1 contains the topics and learning goals for each session. The learning sessions were held remotely using Zoom, a web-based teleconferencing platform. Sessions were held once monthly from September 2021 through May 2022. These virtual education sessions utilized a CET format: anonymous case-based learning with an expert panel, didactic presentation, and discussion to increase expertise and capacity of its participants. Each session was 60 minutes and consisted of a 10-minute case presentation, a 10- to 15-minute corresponding didactic training, and a 35- to 45-minute group discussion. Each participant had access to a cloud-based folder that contained PLC materials and group contact list (if consent was provided). All the sessions reflected the guiding principles and approaches of the START model including evidence-based, strengths-based, and positive psychology approaches, prioritizing the wellbeing of people with IDD-MH and their families.

Table 1*PLC Outline: Topics and Learning Objectives*

Session	Topic
1	<p>PLC Welcome and Introduction to Systemic Therapeutic Model</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Describe the benefits of the systemic therapeutic model for people with IDD-MH and their families. 2. Describe how the systemic therapeutic model informs assessment for psychiatrists/prescribers and psychologists. 3. Identify at least three (3) strategies for implementing a systemic therapeutic approach.
2	<p>Autism and Behavioral Complaints</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Describe the most common complaints by caregivers for people with autism. 2. Describe common medical conditions that often present as behavioral complaints. 3. Describe common mental health conditions that often present as behavioral complaints.
3	<p>PTSD and Trauma-Stressor Related Disorders</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Describe the prevalence of stressful and traumatic life events and the diagnosis of PTSD in people with IDD. 2. Identify the symptom presentation of PTSD in people with IDD. 3. Explain trauma informed approaches and evidence-based treatments of PTSD in IDD
4	<p>Common Medical Concerns in IDD</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Describe three (3) common medical issues individuals with IDD may have. 2. Explain common health promotion and disease prevention strategies. 3. Identify how medical comorbidities may affect an individual's mental health and behavioral presentation.
5	<p>Movement Disorders</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Recognize common movement disorders in individuals with IDD and the terminology used to describe them. 2. Identify specific patterns of movement disorders linked to Autism Spectrum Disorder, Rett's syndrome, Down syndrome, and cerebral palsy. 3. Describe the role of various treatments in individuals with IDD with movement disorders and complications of neuroleptic therapy.

(table continues)

Session	Topic
6	<p>Working with Families</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Describe three (3) key points that have been learned from research about families of people with IDD. 2. Identify at least three (3) challenges with the IDD and MH systems that families face. 3. Identify at least (3) strengths of families. 4. List at least three (3) essential practices in the positive support of families
7	<p>Alternatives to Medication: Supplemental Therapies and Supports</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Identify changes to environments, which will create an increase in quality of life. 2. Select areas of wellness to include in supplemental supports. 3. Describe a positive psychology intervention to use in their practice.
8	<p>Gender Non-Conformity in Children and Adolescents with Developmental Differences: Parent Reactions</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Identify terminology and concepts pertaining to gender variation in neurodiverse children. 2. Discuss the range of parent reactions to gender variation in neurodiverse children. 3. Discuss supportive parenting for gender non-conforming/neurodiverse children.
9	<p>The Assessment and Treatment of Psychiatric Disorders: Where the Neurosciences are Leading Us</p> <p><i>Learning Objectives:</i></p> <ol style="list-style-type: none"> 1. Apply the concepts of gene-environmental interactions and pharmacogenomics to clinical practice. 2. Integrate these data in the diagnosis and treatment of psychiatric and behavioral symptoms among individuals with developmental disabilities. 3. Merge these ideas with novel approaches to adjunctive use of psychotropic medications in the treatment process.

Recruitment

Our study involved voluntary participation from various psychiatric prescribers and doctorate-level psychologists, including those from START teams in California and Tennessee, as well as community-based professionals. Participating individuals were eligible to receive free continuing medical education or continuing education credits.

Recruitment occurred via a flyer that was emailed by the National Center for START Services® and START programs in California and Tennessee. Research consent was obtained from all participants at registration, which was online via Qualtrics. The research involved minimal risk to subjects, as it was de-identified and did not adversely affect the rights and welfare of subjects. Participants were asked to acknowledge they reviewed the informed consent at registration, which served as an e-signature. The informed consent in Qualtrics (software licensed by UNH)

was not tied to survey responses.

Measures

Prior to and after the educational sessions, participants completed electronic surveys. The surveys assessed participants' self-efficacy, knowledge, and practice behaviors. All data were collected anonymously. The initial survey also asked about the demographic information of participants. Additionally, after each educational session, participants completed a brief survey regarding their satisfaction with that session. For each session, participants were asked to rate their satisfaction on a 5-point scale (1 = not satisfied to 5 = very satisfied).

After completing all the educational sessions (1-month post-PLC), feedback was further obtained from participants in 1-hour feedback groups at 1 month and 6 months post-training. The input from these groups was incorporated into the overall qualitative review of satisfaction.

The following five primary questions, with follow-up prompts outlined for facilitators (see Appendix), were posed at the 1-month post-PLC focus group.

1. Describe your experience with the educational sessions.
2. What was helpful?
3. What else would be helpful?
4. What was challenging about participating in this learning community?
5. How has your participation in the educational sessions impacted your practice?

The following 4 primary questions, with follow-up prompts outlined for facilitators (see Appendix), were posed at the 6-month post-PLC focus group.

1. How has your participation in the educational sessions impacted you and your practice?
2. What's one thing you learned that you have carried with you from the educational sessions?
3. What other learning experiences or resources would be helpful to you?
4. Have you been in contact with other members of this PLC? If so, what was the nature of your contact?

Analyses

Pre- and post-surveys, as well as satisfaction questionnaires, were analyzed to determine any changes. The analysis involved a combination of descriptive, qualitative, and quantitative methods. Qualitative data from the focus groups were collected via transcription. The focus groups transcriptions were examined using a modified content analysis approach where major themes were identified, and frequent views were grouped into themes. This method allowed common ideas to emerge and provided evidence to support those ideas.

Results

Participants

A total of 29 participants were enrolled in the PLC. Attendance varied with a range of 9 to 22 participants per session, with a mode attendance of 14. Attendance data was not collected for the final session. Table 2 depicts session attendance. Demographic characteristics of participants were gathered from the pre-survey ($n = 16$) and are summarized in Table 2. The post-survey was completed by 13 participants.

Table 2

Session Attendance

Sessions	Number of participants
Total participants enrolled	29
Session 1	22
Session 2	19
Session 3	14
Session 4	14
Session 5	13
Session 6	14
Session 7	9
Session 8	12
Session 9	Not collected

Regarding profession, 15 participants were psychiatrists, 4 were doctoral-level psychologists, and the remainder included: medical doctors, licensed clinical social workers, Doctor of Education, licensed mental health practitioners, board-certified behavior analysts, and nurse practitioners. Nine participants worked with a START program. Eight participants were from California, six were from Tennessee, and nine other states were represented, including five states that do not currently have START programs but learned of this opportunity through colleagues.

Regarding age groups served, 50% of participants ($n = 8$) treat all ages while 31% ($n = 5$) treat children ages 0-17. Participants represent an experienced group, with 95% of respondents ($n = 10$) reporting 16+ years of experience as a practitioner. While 25% ($n = 4$) reported working in community-based clinic settings, another 19% ($n = 3$) worked at a university/teaching institution and 13% ($n = 2$) worked in a hospital setting. The largest proportion of respondents (31%; $n = 5$) selected the “other” option, indicating roles in state government, insurance companies, and private academic-affiliated roles.

Participants were also asked to respond to demographic questions about themselves. All

participants identified as non-Hispanic and English-speaking. A majority (88%; $n = 14$) identified as female. Most participants identified as White (69%; $n = 11$) with 25% ($n = 4$) identifying as Asian. One participant selected “other” but did not elect to share additional information. Table 3 summarizes participant demographics.

Table 3

Participant Demographics (n = 16)

Demographic characteristics	<i>n</i>	%
Gender		
Male	2	13
Female	14	88
Race		
Asian	4	25
White	11	69
Other	1	6
Years of experience as a practitioner		
0-5	1	6
6-10	3	19
11-15	2	13
16-20	5	31
21-30	3	19
31+	2	13
Age groups treated		
Children (0-17)	5	31
Adults (18-60)	2	13
Older adults (60+)	1	6
All ages	8	50
Current work setting		
Clinic (community-based)	4	25
Hospital	2	13
Residential	1	6
Private practice	1	6
University/teaching institution	3	19
Other ^a	5	31

^a Those who selected “Other” identified their primary work setting as state oversight, government, insurance company, academic-affiliated/private, START.

Satisfaction

A total of 96 session satisfaction questionnaires were completed throughout the study. About 89% of respondents were satisfied or very satisfied with the sessions. Almost half (four of nine) total sessions (2, 7, 8, & 9) reached a 100% overall satisfaction rating while only one session (5) dipped below an 80% rating.

After completion of the series, 83% of participants noted they were overall “highly

satisfied” with the entire series. All respondents ($n = 13$) agreed that they plan to share what they have learned with others and that they would recommend this PLC to colleagues.

Respondents were asked what they liked most about the PLC and what they would change. Interestingly, much of the feedback about improvements would be addressed if we had implemented the CETs as they are typically designed, extending the time to 2 hours to include much more time for discussion and some time for follow-ups to past presentations. One-hour sessions were used to garner more participation, given feedback received previously from professionals regarding available time commitment to ongoing training.

Open-ended feedback from the survey included positive comments regarding the following components: case presentations, structure, collaborative nature, structured presentations, group discussion, share access to articles and resources, and the experts involved. Many of the participants expressed a desire for more sessions. Quotes included the following.

“I’m sad this series is over. I’ve learned a lot and would like to continue to build my knowledge and skills working with patients with neurodevelopment disorders. This series has really helped so far.”

We also asked participants about recommendations on how to improve the virtual education series. Participants noted the desire to include child-based cases, as the focus was on adults, more didactics for people with less background, longer sessions for more discussion, and a follow-up regarding cases presented in past sessions.

Knowledge

Interestingly, 50% of participants reported receiving formal training on IDD-MH prior to their participation in the series. Of the eight respondents who received formal training, five offered an average number of training hours received. The minimum number of hours reported was 3. The highest number of hours was reported as “thousands” because of one participant’s IDD-MH internship/fellowship. The remaining three responses indicated a range of 5 to 500 hours. Despite the strong representation of formal training, 77% ($n = 10$) rated their current level of knowledge regarding the mental health treatment of people with IDD as “some but not all I want or need.” As illustrated in Figure 1, there was a shift in people feeling more knowledgeable at post-series compared to pre-series.

Self-Efficacy and Self-Reported Practice Behaviors

Participants were asked to rate their self-perceived abilities regarding each of the PLC’s learning objectives, which relates to self-efficacy and self-reported practice behaviors. Figure 2 illustrates pre- and post-education series self-ratings.

Figure 1

Pre & Post Self-Rating of Current Level of Knowledge Regarding the Mental Health Treatment of People with IDD

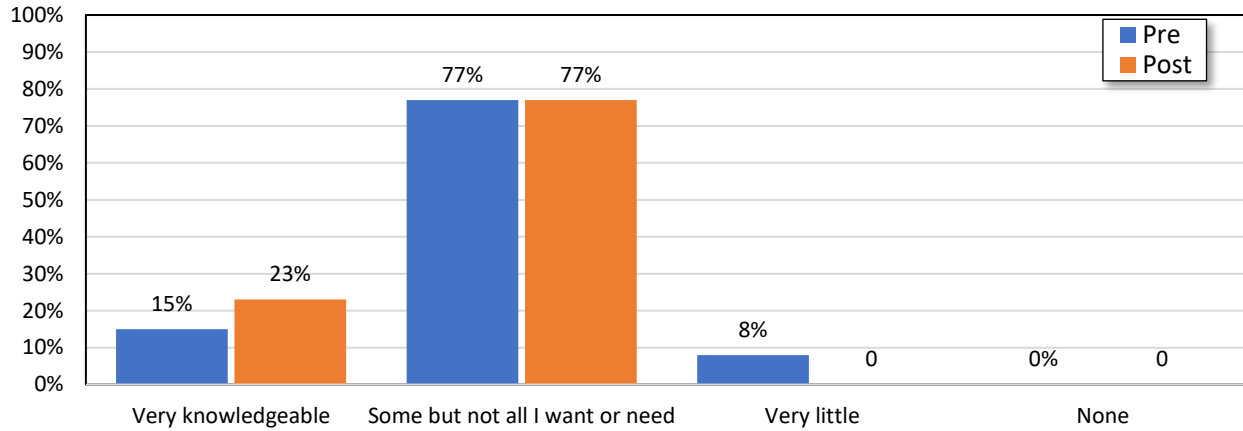
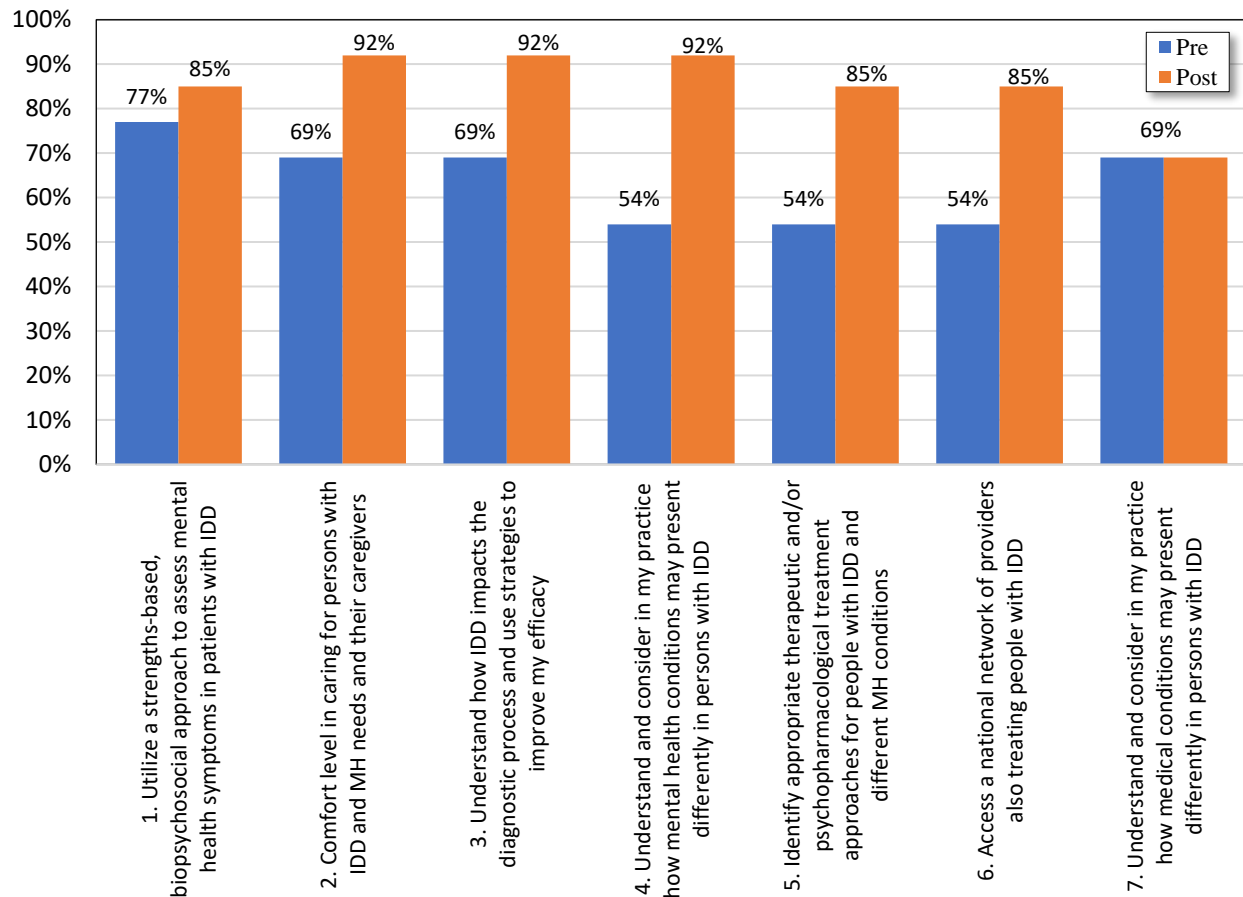


Figure 2

Pre and Post Self-Reported Agreement Ratings with PLC Learning Objectives



1-Month-Post Focus Group

Primary feedback from the three-person focus group was that they wanted more time for discussion. The group was unanimous in stating that they would recommend shorter case and didactic presentations, reserving the final 30 minutes for group dialogue. The group agreed that (a) an hour is easier to fit into their schedule (versus a 90-minute session); (b) providing mechanisms for corresponding in between sessions would be useful; and (c) receiving session materials 1 week in advance would offer time they needed to be prepared.

This is like the last bias in medicine that it's not uncommon for this population to be refused treatment by having a practitioner say; I don't know how to treat this person.... But it's quite common, not just people in behavioral health, but people even in primary care to say, I don't know how to treat this type of person.

6-Month-Post Focus Group

Three participants participated in the 6 month-post focus group, only one of the same participants from the 1-month focus group. Participants again unanimously called for continuation of the training group and reinforced that preserving group discussion time is a paramount priority.

What is one thing you learned that you have carried with you from the educational sessions?

One of the participants valued learning more about interdisciplinary, biopsychosocial, systemic approaches reviewed in various sessions, specifically citing the utility of ecomaps and family systems theory.

Make a visual map in the head to ask who interacts with this person and how that drives different behaviors or symptoms. How does that help or hinder? They pay me to do meds, but I really feel that meds are a small piece most of the time, so I do ask this. The other one was the parent-child dyad and see it was a family problem...traditional model of psych is so dependent on verbalization so it's so hard to work with people or families that don't communicate that way. There's a lot to bringing these other modalities in.

What other learning experiences or resources would be helpful to you?

"Haven't seen anything else like this since training. Reminded me about being a resident and how I learned psychiatry in the first place and that's really nice. It's better than a 2-day conference where it's in one ear and out the other. The speakers might be engaging but it's not what you're doing. It was highly applicable and timely and nice to use a case-based methodology. The reason it isn't done is because it's hard."

“Very beneficial for the learning process; the national team has so many resources but watching a video is so much different than having the presentation and discussion and brainstorming and hearing other ideas and having those ‘I never thought of that’ moments. If there was another opportunity I would participate again even if it was the same topics!”

Discussion

We describe the development and evaluation of a virtual education series that was structured as a Professional Learning Community using Clinical Education Team components for connecting and educating medical professionals. This is one of the first virtual education series in the literature from the U.S. that focuses on the co-occurrence of mental health disorders and intellectual disabilities.

Upon completion of the series, participants reported improvements in various domains including utilizing a strengths-based biopsychosocial approach, comfort in caring for people with mental health conditions and IDD, and self-reported knowledge about the mental health aspect of IDD. Additionally, the providers noted an increase in access to a national network of participants who care for people with IDD. Overall, the participants endorsed a high level of satisfaction with the sessions and series.

There were two sessions/topics that garnered 100% overall satisfaction ratings and highest agreement that objectives had been met: (1) Gender Non-conformity in Children and Adolescents with Developmental Differences: Parent Reactions; and (2) Alternatives to Medication: Supplemental Therapies and Support. This indicates a clear desire or need for more education and information on these topics for medical and mental health practitioners and can guide our focus for future and ongoing training.

This group of participants reported relatively high levels of prior training in working with people with IDD (50% of respondents), which is higher than anticipated given that the medical field provides minimal training on caring for the needs of those with IDD, including the judicious and suitable use of psychotropic medications (Adirim et al., 2021; Marrus et al., 2023; Weiss & Lunsy, 2010). The evaluation of the series shows that upon completion, participants reported improvements in all seven areas assessed except for *understanding and considering how medical problems may present differently in people with IDD*. Participants already had a high level of medical expertise and knowledge in this topic before the session. Positive changes in ratings of understanding how mental health conditions may present differently in people with IDD and identifying appropriate therapeutic/pharmaceutical treatments were notable. These are core competencies in this work, and an important outcome of this training.

Additionally, the participants noted an increase in access to a national network who care for people with IDD as well as a desire to keep this professional learning community intact and communicating. Overall, the participants endorsed a high level of satisfaction with the sessions, the entire series, and the resulting professional community. Building a professional learning

community that unites practitioners who provide treatment to the same underserved populations offers valuable opportunities to improve practice.

Limitations

There are some limitations to this study to consider. First, there were a small number of participants and smaller number of respondents to the pre- and post-surveys and post-series focus groups. The limited number of participants is considered beneficial to the level of engagement during the sessions, but do not lend themselves to large-group statistical analyses.

The survey tools are not validated and are self-report assessments. However, these tools are the typical tools utilized to evaluate continuing education programs and ECHO programs (Ghosh et al., 2021; Mazurek et al., 2020). Reports on self-efficacy and knowledge, as well as those on changes in personal practice, are pragmatic given the nationwide reach of this PLC. It is not known if any actual changes in practice occurred because of the PLC sessions. However, better participation in the three post-series focus groups would lend more information about longer-term effects of participation.

Ratings indicating increased abilities and focus group feedback were important indicators of the value of the series to participants. However, there may still be a need for longer-term, ongoing learning communities to lead to high levels of confidence and skill in serving this population. Next steps could include longer sessions to include more discussion and opportunities for follow-up on previously presented case examples (75-90 minutes). Means for continuation of the PLC for ongoing networking, sharing of resources, and supporting one another may also be useful and helpful to participants, increasing the community of those who serve this population.

Conclusion

This paper describes a highly replicable model that can be operated at low cost. Means for keeping costs to a minimum include utilizing internal resources and engaging participants with more expertise as case presenters. Offering it online increases the reach and broadens accessibility for busy prescribers and professionals who are otherwise unable to dedicate much time for ongoing continuing education.

Blending PLC and CET training components is a model for connecting and educating medical professionals. Building a professional learning community that unites practitioners who care for people with IDD offers valuable opportunities to increase comfort and knowledge, connect providers, and help improve the wellbeing of people with IDD-MH.

References

- Adirim, Z., Sockalingam, S., & Thakur, A. (2021). Post-graduate medical training in intellectual and developmental disabilities: A systematic review. *Academic Psychiatry, 45*, 371-381. <https://doi.org/10.1007/s40596-020-01378-8>
- Arora, S., Kalishman, S., Thornton, K., Dion, D., Murata, G., Deming, P., Parish, B., Brown, J., Komaromy, M., Collieran, K., Bankhurst, A., Katzman, J., Harkins, M., Curet, L., Cosgrove, E., & Pak, W. (2010). Expanding access to hepatitis C virus treatment—Extension for Community Healthcare Outcomes (ECHO) project: Disruptive innovation in specialty care. *Hepatology, 52*(3), <https://doi.org/1124-1133>. [10.1002/hep.23802](https://doi.org/10.1002/hep.23802)
- Arora, S., Thornton, K., Murata, G., Deming, P., Kalishman, S., Dion, D., Parish, B., Burke, T., Pak, W., Dunkelberg, J., Kistin, M., Brown, J., Jenkusky, S., Komaromy, M., & Qualls, C. (2011). Outcomes of treatment for hepatitis C virus infection by primary care providers. *New England Journal of Medicine, 364*(23), 2199-2207. <https://doi.org/10.1056/NEJMoa1009370>
- Beasley, J., Kroll, J., & Sovner, R. (1992). Community-based crisis mental health services for persons with developmental disabilities: The START model. *The Habilitative Mental Healthcare Newsletter, 11*(9), 55-58.
- Beasley, J. B., Klein, A., & Weigle, K. (2016). Diagnostic, treatment and service considerations to address challenging behavior: A model program for integrated service delivery. In I. L. Rubin, J. Merrick, D. E. Greydanus, & D. R. Patel (Eds.), *Health care for people with intellectual and developmental disabilities across the lifespan* (pp. 129-137). Springer. https://doi.org/10.1007/978-3-319-18096-0_129
- Bessell, E., Kim, J. S., Chiem, L., McDonald, A., Thompson, D., Glozier, N., Simpson, S., Parcsi, L., Morris, R., & Koncz, R. (2023). Effectiveness of project echo programs in improving clinician knowledge and confidence in managing complex psychiatric patients: A waitlist-controlled study. *Academic Psychiatry, 47*(1), 25-34. <https://doi.org/10.1007/s40596-022-01701-5>
- Buckley, N., Glasson, E. J., Chen, W., Epstein, A., Leonard, H., Skoss, R., Jacoby, P., Blackmore, A. M., Srinivasjois, R., Bourke, J., Sanders, R. J., & Downs, J. (2020). Prevalence estimates of mental health problems in children and adolescents with intellectual disability: A systematic review and meta-analysis. *Australian & New Zealand Journal of Psychiatry, 54*(10), 970-984. <https://doi.org/10.1177/0004867420924101>
- Dreiling, N. G., Cook, M. L., Lamarche, E., & Klinger, L. G. (2022). Mental health Project ECHO Autism: Increasing access to community mental health services for autistic individuals. *Autism, 26*(2), 434-445. <https://doi.org/10.1177/13623613211028000>
- Emerson, E. (2011). Health status and health risks of the “hidden majority” of adults with intellectual disability. *Intellectual and Developmental Disabilities, 49*(3), 155-165. <https://doi.org/10.1352/1934-9556-49.3.155>

- Ghosh, S., Roth, B. M., Massawe, I., Mtete, E., Lusekelo, J., Pinsker, E., Seweryn, S., Moonan, P. K., & Struminger, B. B. (2021). A Protocol for a comprehensive monitoring and evaluation framework with a compendium of tools to assess quality of Project ECHO (Extension for Community Healthcare Outcomes) Implementation using mixed methods, developmental evaluation design. *Frontiers in Public Health*, 9. <https://doi.org/10.3389/fpubh.2021.714081>
- Gilmore, D., Harris, L., Longo, A., & Hand, B. N. (2021). Health status of Medicare-enrolled autistic older adults with and without co-occurring intellectual disability: An analysis of inpatient and institutional outpatient medical claims. *Autism*, 25(1), 266-274. <https://doi.org/10.1177/1362361320955109>
- Kalb, L. G., Beasley, J. B., Caoili, A., McLaren, J. L., & Barnhill, J. (2021). Predictors of mental health crises among individuals with intellectual and developmental disabilities enrolled in the START program. *Psychiatric Services*, 72(3), 273-280.
- Lake, J. K., Volpe, T., St. John, L., Thakur, A., Steel, L., Baskin, A., Durbin, A., Chacra, A., & Lunskey, Y. (2022). Mental health and COVID-19: The impact of a virtual course for family caregivers of adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 66(8-9), 677-689. <https://doi.org/10.1111/jir.12965>
- Mazurek, M. O., Parker, R. A., Chan, J., Kuhlthau, K., Sohl, K., & ECHO Autism Collaborative (2020). Effectiveness of the extension for community health outcomes model as applied to primary care for autism: A partial stepped-wedge randomized clinical trial. *JAMA Pediatrics*, 174(5), e196306. <https://doi.org/10.1001/jamapediatrics.2019.6306>
- Marrus, N., Koth, K. A., Hellings, J. A., McDonald, R., Gwynette, M. F., Muhle, R., Lohr, W. D., & Vasa, R. A. (2023). Psychiatry training in autism spectrum disorder and intellectual disability: Ongoing gaps and emerging opportunities. *Autism*, 27(3), 679-689. <https://doi.org/10.1177/13623613221112197>
- Mazza, M. G., Rossetti, A., Crespi, G., & Clerici, M. (2020). Prevalence of co-occurring psychiatric disorders in adults and adolescents with intellectual disability: A systematic review and meta-analysis. *Journal of Applied Research in Intellectual Disabilities*, 33(2), 126-138. <https://doi.org/10.1111/jar.12654>
- McBain, R. K., Sousa, J. L., Rose, A. J., Baxi, S. M., Faherty, L. J., Taplin, C., Chappel, A., & Fischer, S. H. (2019). Impact of project ECHO models of medical tele-education: A systematic review. *Journal of General Internal Medicine*, 34, 2842-2857. <https://doi.org/10.1007/s11606-019-05291-1>
- Nelson, T. H., LeBard, L., & Waters, C. (2010). How to create a professional learning community. *Science and Children*, 47(9), 36.
- Ouellette-Kuntz, H., Minnes, P., Garcin, N., Martin, C., Suzanne Lewis, M. E., & Holden, J. J. (2005). Addressing health disparities through promoting equity for individuals with intellectual disability. *Canadian Journal of Public Health*, 96, S8-S22. <https://doi.org/10.1007/BF03403699>

- Reichard, A., Stolze, H., & Fox, M. H. (2011). Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disability and Health Journal*, 4(2), 59-67. <https://doi.org/10.1016/j.dhjo.2010.05.003>
- Servage, L. (2008). Critical and transformative practices in professional learning communities. *Teacher Education Quarterly*, 35(1), 63-77. <https://www.jstor.org/stable/23479031>
- Sohl, K., Mazurek, M. O., & Brown, R. (2017). ECHO autism: Using technology and mentorship to bridge gaps, increase access to care, and bring best practice autism care to primary care. *Clinical Pediatrics*, 56(6), 509-511. <https://doi.org/10.1177/0009922817691825>
- Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Bershady, J., Taub, S., Fortune, J., & Ticha, R. (2011). Overweight and obesity among adults with intellectual disabilities who use intellectual disability/developmental disability services in 20 US States. *American Journal on Intellectual and Developmental Disabilities*, 116(6), 401-418. <https://doi.org/10.1352/1944-7558-116.6.401>
- Stirling, M., Anderson, A., Ouellette-Kuntz, H., Hallet, J., Shooshtari, S., Kelly, C., Dawe, D. E., Kristjanson, M., Decker, K., & Mahar, A. L. (2021). A scoping review documenting cancer outcomes and inequities for adults living with intellectual and/or developmental disabilities. *European Journal of Oncology Nursing*, 54. <https://doi.org/10.1016/j.ejon.2021.102011>
- Thakur, A., Pereira, C., Hardy, J., Bobbette, N., Sockalingam, S., & Lunsy, Y. (2021). Virtual education program to support providers caring for people with intellectual and developmental disabilities during the COVID-19 pandemic: Rapid development and evaluation study. *JMIR Mental Health*, 8(10). <https://doi.org/10.2196/28933>
- Weiss, J., & Lunsy, Y. (2010). Service utilization patterns in parents of youth and adults with intellectual disability who experienced behavioral crisis. *Journal of Mental Health Research in Intellectual Disabilities*, 3(3), 145-163. <https://doi.org/10.1080/19315864.2010.490617>
- Zhou, C., Crawford, A., Serhal, E., Kurdyak, P., & Sockalingam, S. (2016). The impact of project ECHO on participant and patient outcomes: A systematic review. *Academic Medicine*, 91(10), 1439-1461. <https://doi.org/10.1097/ACM.0000000000001328>

Appendix

Pre-Survey

- Ethnicity
 - Hispanic
 - Non-Hispanic
 - Unknown
- Primary language
 - English
 - Spanish
 - American Sign Language
 - [open entry]
- Race
 - African American/Black
 - American Indian/Alaskan
 - Asian
 - Hawaiian/Pacific Islander
 - White
 - [open entry]
- Years of experience as a practitioner
 - 0-5
 - 5-10
 - 10-15
 - 15-20
 - 20-30
 - 30+
- Gender
 - Female
 - Male
 - Not Listed [open text]
- Age groups you treat:
 - Children (0-18)
 - Families
 - Adults (18-60)
 - Older adults (60+)
 - All ages
 - Other [open text]
- Current work setting
 - Clinic (Community-based)
 - Hospital
 - Residential
 - Private practice

- Hospital
 - University/teaching institution
 - Other [open text]
- Did you receive formal training on IDD/MH during your pre-practice training? YES/NO
 - If yes, about how many hours of pre-practice training in IDD/MH did you receive?
- Rate your current level of knowledge regarding the mental health treatment of people with IDD.
 - Very knowledgeable
 - Some but not all I want or need
 - Very little
 - None
- What do you hope to gain as a result of your participation in this course? [open text box]

Session Survey

Which session are you evaluating?

[dropdown list of all session #s & corresponding dates]

Overall, how satisfied are you with this session?

- Highly satisfied
- Satisfied
- Somewhat satisfied
- Not satisfied at all

Please rate your satisfaction with today's session

	not satisfied 1	2	3	4	very satisfied 5
Zoom webinar technology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Content of session	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Facilitation of session	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your overall experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What would have improved your experience?

[open text box]

What questions do you have from today's session that were not answered?

[open text box]

What topics addressed during today's session would you like to learn more about?

[open text box]

After submitting this survey, you will be auto-directed to a separate page where you can register to receive CMEs & CE for today's session. The information shared within this survey is not connected to the CME/CE registration.

Thank you!

Post-Survey

Overall, how satisfied were you with the IDD-MH PLC?

- Highly satisfied
 - Satisfied
 - Somewhat satisfied
 - Not satisfied at all
-

General Feedback

	Strongly Agree (1)	Agree (2)	Neutral (3)	Disagree (4)	Strongly Disagree (5)
I plan to share what I've learned with others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would recommend this IDD-MH PLC to others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What did you like most about the IDD-MH PLC?

[open text box]

What would you change to improve the IDD-MH PLC?

[open text box]

- Self-efficacy & knowledge ratings (pre & post)

Please rate your ability before and after training to...

(1 = low ability/not very good to 5 = high ability/excellent)

	BEFORE THE IDD-MH PLC	AFTER THE IDD-MH PLC
--	-----------------------	----------------------

- Utilize a strengths-based, biopsychosocial approach to assess mental health symptoms in patients with IDD.
- Comfort level in caring for persons with IDD and MH needs and their caregivers.
- Understand how IDD impacts the diagnostic process and use strategies to improve my efficacy.
- Understand and consider in my practice how mental health conditions may present differently in persons with IDD.
- Identify appropriate therapeutic and/or psychopharmacological treatment approaches for people with IDD and different MH conditions.
- Access a national network of providers also treating people with IDD.
- Understand and consider in my practice how medical conditions may present differently in persons with IDD.

Rate your current level of knowledge regarding the mental health treatment of people with IDD.

- Very knowledgeable
- Some but not all I want or need
- Very little
- None

One-Month Post PLC FOCUS GROUP Questions and follow-up prompts

1. Describe your experience with the educational sessions.
 - a. What was it like to be part of the learning community?
 - b. What was the format like in terms of case/didactic/discussion?
 - c. What worked/didn't work?
 - d. Did they leave the session feeling like they learned something?
 - e. Were expectations clearly outlined for your participation?
 - f. Did you feel like it was an open learning environment? (thoughts/ideas were respected and welcomed)
 - g. Do you feel like you got what you signed up for?
 - h. Tell us how the sessions addressed a multidisciplinary audience.... Was there something in it for you?
2. What was helpful?
 - a. Were you able to take what you learned and apply it in practice?
 - b. Were you able to share your new knowledge with others?
 - c. Did your learning change preconceived notions you already had?
 - d. What best met your learning needs- didactic/discussion/case/combo of both?
 - e. When did you feel you were most actively learning? When were you most engaged?
 - f. Was an hour enough time? Did you feel like you needed more time?
3. What else would be helpful?
 - a. What would you change to improve the sessions/format? – more time? More discussion? More didactic?
 - b. Should there be more interactions between sessions? (i.e.: Listserv/sharing resources)
 - c. Did you like emails with questions/did you utilize the materials in Box?
 - d. Was there too much communication about the PLC? Too little?
 - e. Additional speakers/topics that you'd like to see?
 - f. We provided a list of topics and presenters- would you prefer a more open session where you bring a case and from that case a topic is developed (learner-led)
4. What was challenging about participating in this learning community?
 - a. Was the time of the meeting/length of the meeting good for you?
 - b. Was the format of the meeting helpful?
 - c. Did you feel like the virtual format worked in terms of your learning & engagement?
 - d. Do you feel like your voice was heard or that you were able to share your thoughts?
 - e. What would you do differently? What would you change?
 - f. If you had questions about the PLC, were they answered in a prompt and clear fashion?

5. How has your participation in the educational sessions impacted your practice?
 - a. Tell us about connections you made with others in the field?
 - b. Do you intend to maintain connections/contact with those you met? How so?
 - c. How did your participation impact your knowledge of IDD-MH?
 - d. Tell us more about how your confidence and adequacy in caring for people with IDD-MH changed or what impacted by the PLC sessions.
 - e. Has your willingness to see people with IDD changed at all?
 - f. Do you think there's been any change in your own belief in your capacity to care for people with IDD-MH?
 - g. Are there ways that you are more involved in the care of people with IDD-MH? If so, what?
 - h. (Follow up) do you think/has there been any change in your practice of who you see or what clinical capacity you work in– (ex: might be more willing to work in a clinic for people with IDD-MH, take on additional patients with IDD)
-

Six-Month Post PLC FOCUS GROUP Questions and follow-up prompts

1. How has your participation in the educational sessions impacted you and your practice?
 - a. Tell us more about how your confidence and adequacy in caring for people with IDD-MH changed or what impacted by the PLC sessions.
 - b. Has your willingness to see people with IDD changed at all?
 - c. Do you think there's been any change in your own belief in your capacity to care for people with IDD-MH?
 - d. Are there ways that you are more involved in the care of people with IDD-MH? If so, what?
 - e. (Follow up) do you think/has there been any change in your practice of who you see or what clinical capacity you work in– (ex: might be more willing to work in a clinic for people with IDD-MH, take on additional patients with IDD)
2. What's one thing you learned that you have carried with you from the educational sessions?
3. What other learning experiences or resources would be helpful to you?
 - a. Such as: ongoing PLC/community of practice, newsletter, quarterly meetings....
4. Have you been in contact with other members of this PLC? If so, what was the nature of your contact?
 - a. Was the time of the meeting/length of the meeting good for you?
 - b. Was the format of the meeting helpful?
 - c. Did you feel like the virtual format worked in terms of your learning & engagement?
 - d. Do you feel like your voice was heard or that you were able to share your thoughts?
 - e. What would you do differently? What would you change?
 - f. If you had questions about the PLC, were they answered in a prompt and clear fashion?