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Optimizing Telehealth Delivery for People with Intellectual and Developmental Disabilities and Mental Health Service Experiences

Jessica M. Kramer[a], Joan B. Beasley[b], Andrea Caoili[c], Luther G. Kalb[d], Tawara D. Goode[e], and Micah Peace Urquilla[c]

[a]Department of Occupational Therapy, University of Florida; [b]Institute on Disability, College of Health and Human Services, University of New Hampshire; [c]National Center for START Services, Institute on Disability, University of New Hampshire; [d]Center for Autism, Services, Science, and Innovation, Kennedy Krieger Institute; [e]Georgetown University National Center for Cultural Competence & University Center for Excellence in Developmental Disabilities, Georgetown University Medical Center

ABSTRACT

Introduction: The aim of this study was to identify strategies to support the delivery of mental health services for people with intellectual/developmental disabilities via telehealth. This occurred within START (Systemic Therapeutic Assessment, Resources and Treatment), an evidence-based mental health crisis prevention and intervention model.

Methods: Focus groups and interviews were held with 82 people from START: 47 providers, 16 service recipients, and 19 family caregivers. Analytical memos were used to identify the main ideas. Selective coding ensured interpretation was grounded in participants' perspectives.

Results: Telehealth was acceptable and accessible when everyone worked together to prepare for sessions; START providers used specific strategies to engage people over telehealth; and when there was ongoing assessment and monitoring modified for the telehealth environment.

Conclusion: The Prepare, Engage, and Assess (PEA) Framework may be used to provide mental health services via telehealth for people with intellectual and/or developmental disabilities.

KEYWORDS
Intellectual disability; mental health teletherapy; community engaged research

INTRODUCTION

The COVID-19 pandemic and subsequent restrictions necessitated a shift in the way all services, including mental health services, were provided to people with intellectual and/or developmental disabilities (Andino et al., 2023). Since the end of the public health emergency, slightly more than 25% of services remain available through teleservice and telehealth delivery for people with intellectual and/or developmental disabilities (Friedman, 2022). Telehealth delivery provides an opportunity to expand access to qualified mental health services for people with intellectual and/or

CONTACT Jessica M. Kramer ✉ Jessica.kramer@phhp.ufl.edu Department of Occupational Therapy, University of Florida, College of Public Health and Health Professions, University of Florida, PO BOX 100164, Gainesville, FL 32610-0164, USA

developmental disabilities, who have identified challenges receiving appropriate community-based mental health care (Kramer et al., 2019). Reported benefits of telehealth services include convenience, reliability, and access, while barriers include technological and engagement challenges (Ali et al., 2023; Bundy et al., 2023; Harris et al., 2022; Kramer, Beasley, et al., 2023; Lunsky et al., 2021; Selick et al., 2021, 2022). However, most studies about telehealth experiences were conducted during the height of the pandemic, a time of extraordinary stress and uncertainty in which telehealth was a largely untested means of service delivery. Therefore, the findings may not generalize to the post-pandemic environment.

Policy makers and funders require that the use of telehealth be evidence-based to remain a viable and funded service provision option (Andino et al., 2023). There is a need to develop and evaluate telehealth delivery protocols that are effective and inclusive for people with IDD and mental health needs (Valdez et al., 2021). There are established guidelines for telehealth delivery (Joint task force for the development of telepsychology guidelines for psychiatrists, 2013; National Quality Forum, 2021). However, these guidelines do not consider the modifications needed to facilitate therapeutic activation of people with intellectual and/or developmental disabilities who have communication, cognitive, and sensory differences. A recent study by Selick and colleagues (Selick et al., 2023) identified strategies that enhance the quality of patient-provider communication when delivering primary care teleservices to people with intellectual and/or developmental disabilities. Strategies included forming trusting relationships, using video features that allow for non-verbal communication, providing sufficient time to share one's thoughts, and meeting in a comfortable setting (Selick et al., 2023). However, the extent to which these strategies translate to mental health services is unknown.

The first step to generating quality evidence for telehealth-based mental health services for people with intellectual and/or developmental disabilities is to develop acceptable and accessible telehealth protocols, as grounded in the experiences and needs of those using delivering and receiving of those services (Byrne, 2019; Kramer et al., 2019, 2024; Schwartz et al., 2020). START (an acronym for Systemic Therapeutic Assessment, Resources and Treatment) is an evidence-based model that employs mental health best practices for assessment and treatment to promote effective cross-systems' crisis prevention and intervention and improve well-being for persons with intellectual and/or developmental disability services across the U.S. (Beasley et al., 2018; Kalb et al., 2019). Since the COVID-19 pandemic, some START services have been provided via telehealth, most notably coaching and consultation services. Importantly, telehealth delivery within START has continued beyond the pandemic response, which aligns with national trends of telehealth use (Andino et al., 2023; Shaver, 2022). There is an opportunity to learn from their experiences using telehealth during the provision of "usual care," which may be different from experiences using telehealth during the COVID-19 public health emergency (Thomas et al., 2022).

The aim of this study was to identify strategies that support the acceptability and accessibility of mental health services delivered via telehealth within START. The long-term goal was to formalize methods of telehealth delivery for evaluation in a non-inferiority trial comparing telehealth to in-person START services (Kalb et al., 2023). To accomplish this aim, the perspectives of START providers, persons with intellectual and/or developmental disabilities receiving START services, and their family caregivers were elicited to address the research question: What strategies facilitate the acceptability and accessibility of mental health crisis prevention and intervention services when delivered over telehealth for people with intellectual and/or developmental disabilities?

METHODS

Focus groups and individual interviews were conducted to elicit experiences with telehealth delivered within START. Focus groups and interviews were used to elicit individual's experiences with telehealth, which broadly aligns with a phenomenological approach (Bradbury-Jones et al., 2009; Bush et al., 2019; Love et al., 2020), and grounds the development of protocols in the preferences and experiences of people for whom the intervention is intended to benefit (Byrne, 2019; Kramer et al., 2024; Schwartz et al., 2020; Walmsley, 2004). All study procedures were completed after IRB review and approval.

Participants

Recruitment of participants occurred from April to December 2022 through the distribution of flyers at START program sites to people who received START services within the past year and their family caregivers. Inclusion criteria for all participants were prior participation of in-person START services with at least three months of experience with START services via telehealth and three months experience with START services in-person. START providers had at least one year of experience delivering START services, including telehealth. People receiving START services were required to be between 13 and 35 years old with the ability to participate in a virtual meeting for at least 30 minutes. Family caregivers were required to be the primary caregivers of someone receiving START services ages 13–35.

A total of 82 people participated in this study: 47 START providers, 16 people with intellectual and/or developmental disabilities receiving START services, and 19 family caregivers (see Table 1). The geographic distribution across all participants was North Carolina (34.2%), New York (25.6%), New Hampshire (18.3%), Texas (13.4%), Iowa (4.9%), and other states that provide

Table 1. Demographics of telehealth focus group participants.

		People with IDD % ($n = 16$)	Family Caregivers % ($n = 19$)	START Providers % ($n = 47$)
Gender Identity				
	Female	56.3% (9)	89.5% (17)	83.0% (39)
	Male	37.5% (6)	10.5% (2)	17.0% (8)
	Non-Binary	6.2% (1)	0.0% (0)	0.0% (0)
Race				
	Asian	0.0% (0)	0.0% (0)	2.1% (1)
	American Indian/Alaskan Native	0.0% (0)	5.3% (1)	0.0% (0)
	Black/African American	5.9% (1)	10.5% (2)	34.0% (16)
	White	82.4% (14)	68.4% (13)	53.2% (25)
	Two or more races or race not listed	5.9% (1)	15.8% (3)	8.5% (4)
	Prefer not to answer	0.0% (0)	0.0% (0)	2.1% (1)
Ethnicity				
	Hispanic/Latinx/Spanish Origin	12.5% (2)	21.1% (4)	10.6% (5)
	Non-Hispanic	87.5% (14)	73.7% (14)	85.1% (40)
	Not listed	0.0% (0)	5.3% (1)	2.1% (1)
	Prefer not to answer	0.0% (0)	0.0% (0)	2.1% (1)
Age (in years)				
	Range	17–40	43–74	24–73
	Mean (sd)	27.75 (6.32)	59.32† (9.9)	39.7 (11.9)

IDD: Intellectual and/or developmental disabilities.

START services (3.6%); these states include both rural and urban- based START programs. All participants spoke English; 21.1% of family caregivers ($n = 4$) and 17% of START providers ($n = 8$) spoke more than one language. One participant with an intellectual and/or developmental disability also used American Sign Language.

START providers had between 1 and 33 years of experience in the field ($M = 11.82$ yrs, $sd = 7.79$) and were trained in the disciplines of social work (36.2%), psychology (21.3%), mental health counseling (12.8%), education (8.5%), and others (21.3%) such as public health, nursing, criminal justice, speech language pathology, and marriage/family therapy. START providers in the study were experienced in implementing telehealth. Our enrollment focus was on START providers due to their direct experiences with diverse telehealth conditions and populations served within START; this helps ensure that the data gathered and subsequent interpretations reflect a broad range of telehealth strategies.

Within the study, most of the people with intellectual and/or developmental disabilities (68.8%, $n = 11$) and family caregivers (89.5%, $n = 17$) had received START services for more than one year. In this manuscript, we use the term intellectual and/or developmental disabilities to describe a heterogenous group of people receiving START services. Developmental disability is a condition that is attributable to a mental and/or physical impairment, manifested before the age of 22, long-term, results in significant limitations in multiple areas of functioning, and requires specialized supports (The

Developmental Disabilities Assistance and Bill of Rights Act of 2000). A broad range of conditions such as autism spectrum disorder, cerebral palsy, and intellectual developmental disorder may be identified as a developmental disability. All people receiving START services also receive services through their state's Department of Developmental Disabilities and have been determined to be at high risk for mental health crisis.

Procedures

The informed consent materials and semi-structured questions were developed in collaboration with a team of two persons with intellectual and/or developmental disabilities and mental health service experiences, two family caregivers, and one START provider. During a series of video conference meetings, the team reviewed materials to ensure transparency in the description of study risks and benefits, that the text (consent/assent, interview questions) was easy to understand, and identified images to support the understanding of the text. Informed consent (or parent permission and assent) was obtained from each participant using a universally designed consent form that included images to enhance understanding.

People with intellectual and/or developmental disabilities and family caregivers could participate in focus groups or individual interviews using Zoom™. This flexibility reduced barriers to participation and accommodated participants' communication and scheduling preferences. Three members of the research team served as primary facilitators, and six START providers served as co-facilitators. Seven focus groups were conducted with START providers, each with 5–9 participants. The team also conducted six focus groups and six individual interviews with family caregivers and three focus groups and nine individual interviews with people with intellectual and/or developmental disabilities.

All focus groups and interviews began with a review of study aims, risks, and benefits, and ground rules (e.g., respect each others' experiences and keeping information confidential). The semi-structured question guide aligned with core components of START (therapeutic coaching, outreach, and assessment and monitoring; Kalb et al., 2023) and were targeted for each stakeholder group (Appendix A). For example, questions for people with intellectual and/or developmental disabilities were projected in large text with images using the Zoom™ share screen feature. All questions included follow-up prompts to elicit details regarding access to technology, accessibility for persons with disabilities, and how telehealth services were tailored to family values and culture. The same guide was used for focus groups and interviews. Participants could respond verbally or in the chat, to accommodate communication preferences and allow for greater interaction among participants; for example, participants were encouraged to use live chat to share if and how their perspectives differed from the person speaking. A live CART transcriptionist attended all focus groups; individual interviews used the Zoom™ auto-transcription feature. All focus groups and interviews were recorded, professionally transcribed, de-identified and integrated with chat text, and checked for accuracy against the original recordings.

Analysis

The analyses used a two-phase process. The analytical team was directed by an occupational therapist and experienced qualitative researcher (author J. K.) with no affiliation with the National Center for START Services. The analytical team included staff associated with the National Center for START Services. Three had professional training in social work, education, mental health care, and research (including authors A. C. and M. P. U.); one person also identifies as a multiply disabled self-advocate (author M. P. U.), and one was a student completing a social work internship. The use of these team members helps to triangulate the interpretation of the data (Vaismoradi et al., 2016) and bracket potential professional assumptions influencing the interpretation of the data.

Phase 1 focused on the rapid identification of the main ideas to identify and define telehealth strategies and integrated the data reduction and data interpretation process. Alternative approaches to line-by-line coding are appropriate in qualitative research as long as those approaches are described and justified (Sandelowski, 2010). This study's aim to identify and define strategies for telehealth delivery necessitated an approach that combined qualitative analysis with clinical expertise. To do this, we used a structured analytical memo template pragmatically organized into practice-oriented concepts identified a-priori as related to the core components of START and to our research question (Brooks et al., 2015; Bush et al., 2019; Hammond et al., 2022): two broad categories of what worked and what did not work; and six focused content areas: materials, technology, therapist strategies and actions, accessibility, responding to family needs, and cultural/linguistic considerations. One member of the research team reviewed a transcript (e.g., one focus group or interview) and extracted information using the memo template, and a second reviewer triangulated the extraction. Reviewers stayed close to the meaning expressed by the participants, but some interpretation was necessary to summarize the main concepts within each transcript (Birks et al., 2008). Next, all memos were reviewed by two team members, both within (e.g. all people with intellectual and/or developmental disabilities) and across (e.g., people with disabilities compared to family caregivers and START providers), to identify frequently occurring strategies. This ensured that the identified strategies had salience and acceptability across groups and START program contexts (e.g., urban and rural, state). The team created figure drawings to represent the relationship of those strategies in different ways (Hunter et al., 2002). The content from the memos was mapped back to the figures to "test" different conceptualizations of the main ideas (themes) (Bush et al., 2019). This output of this phase was the broad Prepare, Engage, Assess (PEA) Framework.

In phase two, to ensure the generated framework stayed close to the original data and to enhance the credibility of our results (Chun Tie et al., 2019; Whittemore et al., 2001), original transcripts were coded line-by-line using selective-coding. Selective coding is the application of abstract and conceptual codes generated from previously identified concepts (i.e., from the memos and framework) that integrate the data back into a cohesive whole (Chun Tie et al., 2019). Codes were organized into categories of common meaning (Prepare, Engage, and Assess) and were reviewed and triangulated by additional members of the research team (author J.B.B.) using the coded data. Finally, the team examined how strategies used across the PEA framework interacted with each other (in the results, these are indicated with an "interaction" note). The final themes are grounded in the perspectives of young adults with intellectual and/or developmental disabilities (YA), family caregivers (FC), and providers (SP), as reflected in the provided quotes in the results.

RESULTS

Mental health services provided by START teams via telehealth were accessible and acceptable when: all people actively prepared for sessions; when START providers used explicit strategies to engage people with intellectual and/or developmental disabilities and their family caregivers over telehealth; and when there was ongoing assessment and monitoring modified for the telehealth environment.

Prepare

START providers, people with intellectual and/or developmental disabilities and family caregivers took action to prepare for telehealth sessions that would facilitate success during the session. This included scheduling telehealth sessions for optimal engagement; making the most of technology; and balancing comfort, privacy, and support.

Schedule for Optimal Engagement

START providers needed to schedule sessions when people with intellectual and/or developmental disabilities and their families were most able to engage. Factors considered included limiting the amount of screen time each day; identifying a time that fits with the regular routine, with cultural and religious practices (e.g., observing the Sabbath on Saturday and abstaining from technology); and scheduling a session when help was available. Family caregivers requested a consistent time for telehealth to create structure to facilitate more consistent engagement. One family caregiver described, “[telehealth] has worked pretty well for [my daughter] because it’s routine, repetition, and practice” (FC5).

An important aspect of scheduling was to ensure the availability of needed materials prior to the telehealth session. These materials were delivered or mailed by the provider, sent electronically, or a list of materials needed for a session was provided in advance. One family caregiver described how the START provider “would let me know in advance, make sure he has got three red pencils and stuff like that… We were able to make sure that he had all the things he needed to participate in whatever activity was being presented” (FC23). Having the right materials readily available made it easier to engage in telehealth therapeutic coaching sessions.

Making the Most of Technology

The implementation of telehealth requires access to equipment, software, and knowledge of how to use it. The experiences of people with intellectual and/or developmental disabilities and family caregivers with technology ranged from familiarity and acceptance to frustration and rejection. For those less comfortable, participants could become frustrated when using the technology, which could interfere with the success of the session. One provider shared, “when you’re supporting individuals that may have older parents, guardians, loved ones that are their support, that may not be as comfortable or have the working knowledge of how to utilize that type of technology. [They need] a lot of guidance to help connect and work through … and the rural areas tend to need more assistance to be creative on how to get them to that” (SP5). Providers noted that for those living in rural areas or families with limited resources, telephonic telehealth may be more available and reliable than internet-based video conferencing software.

It was important to match the telehealth delivery platform with people’s preferences; people with intellectual and/or developmental disabilities and family caregivers felt most comfortable with familiar platforms, such as Zoom or Facetime (interaction: Engage). One provider described how video communication apps provided multiple modalities for interaction: “FaceTime where I’m able to use my iPhone to actually speak with them and have that visual, but sometimes he’ll just like text me what he really wants to say, rather than saying it on camera” (SP20). Similarly, START providers and families discussed the value of integrating various features of the telehealth platform into the session including share screen, backgrounds, emoji reactions, and chat. A family member described the benefits of video conferencing platforms: “You’re able to focus in on really what you’re doing… when that screen is up, and everybody’s looking at the same thing” (FC8).

Telehealth was most feasible when family caregivers and providers anticipated and had solutions for challenges like poor internet connections, low device battery, and problems with software updates. A family member described her process of planning ahead: “So don’t wait till the last minute to check this stuff, check it the night before … avoid those frustrating moments where the technology, at least on my side, isn’t working correctly” (FC16). Such technical difficulties could contribute to frustration or interrupt the provision of care (interaction: Assess). By creating a back-up plan, the telehealth session could continue, even when encountering technical difficulties.

Although not mentioned as frequently, some family caregivers and providers noted the importance of ensuring that people with intellectual and/or developmental disabilities could be safe while using devices. If people were upset, devices were at risk of damage, and a provider expressed concern that “we can no longer be of any help … and we’ve cost them a good deal of money” (SP59). Since telehealth sessions required internet connection, supervision was also needed to ensure the internet was used safely, as described by this family member: “He likes computers, but we just have to make sure he [doesn’t] look at … scary movies and stuff that really bothers him” (FC09).

Balance Comfort, Privacy, and Support

Providers, family caregivers, and people with intellectual and/or developmental disabilities all took actions to enhance their physical space in which the telehealth session occurred. The space needed to be free from distractions, familiar, and comfortable. The setting needed to be private, so people could feel safe sharing freely. One young adult shared “In a private room. … I’m more open” (YA8). Finally, adequate physical space may be needed for the device, materials, and a support person. One family caregiver described, “I have the computer I need to put it where both of us can see it and it makes it a little difficult because it takes away the space where we can both sit and work at the same time. So, I brought in a tray table, I put all the supplies … and then brought them over as we needed them (F13).”

Many acknowledged that being in one’s home could facilitate more open sharing compared to an office setting. One provider explained, “we’re meeting [them] where they’re at. So, it makes them want to engage more because … they’re in a safe place at their homes” (SP33). The virtual environment allowed people to have favorite objects or familiar location while engaging with provider, which not only contributed to physical and emotional comfort, but also provided opportunities for START providers to get to know people’s interests and observe their environment (interaction: Assess).

Privacy did not exclude a preferred person or support from being present. Local supporters helped with technology, provided hands-on assistance for activities as needed, and could monitor to ensure safety during the session. For some young adults with intellectual and/or developmental disabilities, having a trusted supporter could help them feel more comfortable during the telehealth session. As shared by one young adult, “So my mom knew that I felt some type of way. So she had a conversation with them… and I ended up talking to them for myself … and they understood how I felt” (YA4).

Engage

START provider actions to engage people over telehealth included identifying and sharing interests, active listening, demonstrations of accountability to the person with an intellectual and/or developmental disability and their family member, using positive engagement techniques, and providing accommodations.

Identifying and Sharing Interests

START providers worked with people with intellectual and/or developmental disabilities and family caregivers to identify meaningful activities and interests in telehealth sessions. One family member described this initial interaction as “a telehealth version of … a cup of coffee” (FC08) that allowed people to get to know one another and contributed to the development and maintenance of positive rapport. START providers also integrated people’s interests into telehealth sessions. “I’m thinking of one person, he loved to travel and go different places and kind of do a lot of visualization to that, so, we’ll do a [virtual] museum tour. {Another person] loved Disney movies. So, we will watch little clip of Disney movie [using shared screen on videoconferencing] and kind of talk about what was the lesson there? What can she apply to her own life?” (SP07).

In some instances, service providers shared the same interests as people with intellectual and/or developmental disabilities and their families. In these instances, the providers noted the additional value of taking off their “professional cap” (SP58) through these shared interests. Highlighting shared interests, such as animals or hobbies, through conversation or activities over telehealth, further strengthened the relationship and rapport.

Active & Reflective Listening

People with intellectual and/or developmental disabilities and their family caregivers felt a strong connection with providers who listened, observed, and responded in a way that promoted and expressed understanding via telehealth. This included START providers’ use of strategies, including their tone of voice and facial expressions on video conferencing. One family member shared, “you’re talking and there’s no pressure… it feels more like you’re talking to your friend and you’re like venting…. But at the same time, you know that this friend knows things that you can do to prevent or help diminish the situation … their tone of voice, the warmth and sincerity… they’re just genuine.

I don't feel like I'm being told what I want to hear" (FC30). Being "face to face" (as described by several YAs) on telehealth via video call allowed for a stronger sense of connection. Another family member explained, "It's just easy, accessible, and you can actually see somebody and talk to somebody" (FC09).

Receiving teleservices on the phone, when necessary, was acceptable, but video conferencing was preferred by most. One young adult stressed "You get to like see people's face, their body language, and because you can always tell by somebody's reaction and their body language by looking at them. On the phone, they can be fake and you can't really tell what they're doing" (YA04). It is important to note that most people with intellectual and/or developmental disabilities felt the strongest connection with providers when meeting in-person when compared to telehealth via video (interaction: Assess).

Accountability

START providers demonstrated that people could count on them to be there when needed over telehealth, demonstrating accountability to people with intellectual and/or developmental disabilities and their family. Telehealth made it easier to quickly schedule meetings in response to requests for services, as described by this provider: "The only way our schedules matched up was a quick hour… we were able to do it, like, the following day… if we had planned it in-person, it would've been pushed out way longer, but the fact that we were able to do it through telehealth … we were able to do it pretty quickly" (SP42). START providers used phone, text, e-mail, and video conferencing to follow up on identified needs and action steps, as described by this parent: "It's nice accountability to connect with them regularly, for them to check in … because it does really make you want to complete the things you said you would… So there's a bit of accountability when they're calling constantly … and giving them the update." (FC1)

Using Positive Engagement Techniques

START providers used strength-based, person-centered methods grounded in positive psychology with people with intellectual and/or developmental disabilities and their family caregivers as part of their practices, including when using telehealth. This provided hope to family caregivers who often felt discredited or disregarded by other service providers. One family member reflected, "[The START providers] always show how I'm a go-getter parent, I'm not going to take no for an answer… [they] also recognized the strength of my grandson, learning how to be an advocate of his own" (FC02). Fostering hope via telehealth through positive engagement contributed to a strong sense of rapport between family caregivers and providers.

Accommodations for Virtual Engagement

Accommodations allowed for effective engagement when they considered each persons' strengths. Accommodations used by START providers included taking breaks and providing opportunities for movement; this accommodation was especially important in a virtual environment where sustained attention could be difficult. Visual cues helped people with intellectual and/or developmental disabilities with cognitive support needs, and communication supports included American Sign Language (ASL) for video, closed caption, and pictures. Some individuals felt more comfortable engaging with the camera off. The ability to provide timely accommodations was enhanced through the use of direct conversation with young adults and their family caregivers about their preferences and needs and ultimately reduced frustration during telehealth (interaction: prepare, assess).

Assess

The appropriate delivery of any mental health service includes ongoing observation of the person to evaluate engagement and monitor changes. START providers used creative strategies to gather information via telehealth, learned how to identify and respond to difficulties during telehealth sessions, and supplemented telehealth with in-person visits.

Gathering Information Over Telehealth

START strategies employed during in-person visits were also used in telehealth sessions to learn more about a person's preferences, interests, and needs (interaction: engage). For example, START providers asked targeted questions to help family caregivers share things they may have otherwise overlooked. One family member emphasized, "they'd ask me certain questions, and they will want to know certain things... because they know what to ask and... how to do it in a way that would help me to answer (FC26)."

When using video conferencing, START providers noted and reported what was going on in the background and periphery of the screen. Some used the flexibility of video conferencing to invite the family to "... give me a tour of the place- can you show me around? (SP48)?" Despite the use of these strategies, START providers recognized that what was shared over telehealth could be limiting.

Identify and Respond to Difficulties

Telehealth presented a unique challenge for observing signs of mental health difficulties. START providers attempted to attend to subtle cues such as how much someone talked, facial expressions, body movement, and changes in camera use. One provider explained, "On the telephone... I just have to be very conscious of the tones of voice and other noise you may hear in the background (SP29).” Other times, a family member or other supporter reported signs of distress that the START providers could not view on the screen. One family member described, “letting her [know] he’s starting to hunch over he’s starting to poke his eye … he’s done (FC 30).” Knowing how to gather this information in creative ways was a key aspect of monitoring over telehealth.

Sometimes START providers had difficulty monitoring the level of engagement during telehealth sessions, especially if cameras were turned off. When this occurred, START providers attempted to encourage people to turn on their cameras and interact. Despite video contact, sometimes providers found themselves unable to intervene and manage the session effectively, as one provider shared, “when uncomfortable situations come up, it’s easier for them to shut down because [they] could just close the computer versus working through that in-person (SP51).” When START providers identified signs of difficulty or limited engagement, they took action to address the needs of the person with an intellectual and/or developmental disability and their family caregivers by reconsidering the platform used, the time of the sessions, (interaction: prepare), or strategies to enhance accessibility (interaction: engage).

Supplemental In-Person Observation and Training

START providers conducted in-person sessions in the home to gain a better understanding of the person within their environment. One family member described the benefits of supplementing telehealth with in-person visits: “Some of the challenge is getting a better view of the person-where they live, the interaction with, if they have any siblings or with the other family. If you come into the environment in the home, you will get a better picture of that” (FC2). In-person sessions were also important when engaging in in-depth therapeutic interactions. One young adult shared, “When we’re on the phone, you’re just ‘how is your day, how is work?’ Those things aren’t super personal, but if you’re trying to make some progress and you’re talking about personal stuff, [in-person] is easier.” (YA10).

START providers conducted in-person and telehealth sessions in a complimentary way, to practice skills and further reinforce what was learned, as described by one provider: “We talked about the coaching strategy on telehealth, make a copy of the strategy, create guidelines and instructions … We did some telehealth and some in-person, just to kind of bridge that gap a little bit (SP7).” Similarly, a family member explained how “[The provider] did some strategies during an in-person visit. But then, during coaching, [on] video, she would re-emphasize and reference back to when she was here (FC25).”

DISCUSSION

This study identified specific strategies that can enhance the acceptability and accessibility of mental health crisis prevention and intervention services delivered via telehealth for youth and young adults with intellectual and/or developmental disabilities. Drawing upon these findings, our research team developed the “Prepare, Engage, and Assess Framework for Telehealth

Table 2. Prepare, Engage, and Assess Framework for telehealth service activation manual examples.

PEA Framework	Example guidance in the PEA Manual
Prepare	
Scheduling	• Along with scheduling needs and preferences of the person and caregivers, it is also important to be strategic with your own telehealth schedule. Time should be built in between meetings, when possible, to head off-screen fatigue and avoid meeting overlap.
Optimize Technology	• Each person has a preference regarding camera use, which may be affected by how the person is feeling, their environment, or the activity. . .. Please keep your camera on at all times unless specifically asked to turn it off. • Identify a secondary backup way to connect (e.g., phone number) if a virtual/web-based meeting is not possible • Provide hands-on instructions for selecting and using microphones and cameras, as well as viewing and using chat.
Comfort and Privacy	Ideally, the person should identify a designated, private, or semi-private space (as appropriate) in their home for telehealth services. A consistent space for the person’s telehealth equipment and materials creates a familiar, consistent setting to promote full engagement. Having materials readily available, like fidget devices or a cozy blanket fosters comfort.
Identify a trusted supporter	Having a trusted supporter to call on can reduce anxiety and help the person remain resilient and engaged if technology or other challenges arise. You can also ask the trusted supporter to assist by looking for signs of dysregulation or distress that may not be readily apparent onscreen
Engage	
Build rapport	• Like meeting for a cup of coffee, or at someone’s kitchen table, build in time for conversation that is unrushed and less structured with minimal expectations. Spend this time getting to know those you are working with. • To identify interests, ask the person to show you around their home using an iPad, smartphone, or tablet. Point out things you notice that may be of interest to the person. • Each session should include a note and follow-up activities to be shared with everyone involved and revisited during the next session.
Strength spotting	You can use a word cloud generator to create a visual image of the individual’s strengths. Then share with the person how you noticed they used those strengths during the session or identify a “Word of The Day” to facilitate a discussion on how the person may activate their strengths.
Provide accommodations	Gather information about the person’s expressive and receptive communication preferences and needs ahead of time so you can plan accordingly. Invite the person to communicate in ways that work best for them (chat features, writing, drawing, keeping camera off/on, or a combination of methods).
Assess	
Assess Well-Being on Telehealth	• Ask the person targeted questions to gain a better understanding of their environment (ex: “What is your favorite room in your home?”). • Speak to family caregivers and other team members to gather additional information that may be difficult to gather via telehealth.
Monitor for Engagement and Dysregulation	Be mindful of any sudden changes in camera usage and what that might mean for the person. For example, someone may abruptly turn their camera off if they become upset during a session or someone who typically has their camera on has not had it on recently.

Service Activation Manual" (Table 2). Although the manual was developed in the context of START services and for a specific research purpose (Kalb et al., 2023), the PEA Framework may help provide a foundation for telehealth-based mental health service delivery in a broader range of mental health service programs serving people with intellectual and/or developmental disabilities. The findings from this study highlight that a planful approach when delivering mental health crisis prevention and intervention services over telehealth can facilitate an environment in which people with intellectual and/or developmental disabilities and their families can actively participate in their treatment toward that very important goal (Evans & Randle-Phillips, 2020; Sucala et al., 2012).

First, the mental health provider, the person with intellectual and/or developmental disabilities, and their support system must be *prepared* to get the most out of their telehealth services. Findings in this study contribute to the growing body of evidence highlighting the importance of ensuring the safety, convenience, and privacy of telehealth for people with intellectual and/or development disabilities and their families (Gilmore et al., 2023; Kramer, Beasley, et al., 2023; Valdez et al., 2021). In this study, people with intellectual and/or developmental disabilities and family caregivers took an active role to ensure their physical environment was comfortable and that their technology was set up for a successful telehealth session. These strategies may be used to facilitate the feeling of comfort and convenience other people with disabilities and their family caregivers have expressed when attending sessions from home via telehealth (Ali et al., 2023; Harris et al., 2022; Kramer, Beasley, et al., 2023).

An equally important component of *preparation* was the technology used and the activities conducted during telehealth sessions in response to the preferences and needs of people receiving telehealth services. Importantly, this preparation must consider the needs of those living in rural settings, with reduced access to telehealth equipment and infrastructure, or those with limited information and community technology literacy (ICT). Other studies have identified that those caregivers who were less fluent with technology or had difficulties with telecommunications infrastructure during sessions reported feeling frustrated, overwhelmed, or anxious when using teleservices (Ali et al., 2023; Gilmore et al., 2023; Kramer, Beasley, et al., 2023), which is not conducive to a positive therapeutic environment. It is the professional responsibility of the mental health provider to ensure people with intellectual and/or developmental disabilities and their families are equipped to engage in telehealth, and if not, to link the family to resources to gain access (e.g., hot spots) and build information and communication technology literacy (Kramer, Beasley, et al., 2023; Kramer, Guerrero, et al., 2023).

Second, professionals must *engage* people with intellectual and/or developmental disabilities and their families by building rapport, providing accommodations, and promoting trust and engagement. Rapport is the foundation of successful therapeutic relationships, including relationships enacted via a telehealth platform (Selick et al., 2023). In this study, START providers established rapport using evidence-based practices provided both in-person and via telehealth.

Third, continual assessment is required to further refine telehealth-delivered services to meet the needs of each person with an intellectual and/or developmental disability and their family. This study, like others, found that there is a need to address concerns of the loss of "hands on and eyes on" a person when using telehealth delivery (Ali et al., 2023; Harris et al., 2022). Monitoring mental health symptoms via telehealth required providers to use more active strategies compared to in-person monitoring, including targeted questions, virtual home tours, and careful observation of nonverbal cues. Effective monitoring sometimes required assistance from caregivers present during telehealth sessions. Further, in this study, providers, family caregivers, and young adults with intellectual and/or developmental disabilities all endorsed a hybrid approach that combines video conferencing, phone calls, and occasional in-person visits, suggesting the need for flexibility in service delivery. The strategies identified in this study could be implemented to mitigate potential risks, such as safety, associated with delivering mental health services to people with intellectual and/or developmental disabilities via telehealth (Bundy et al., 2023).

This study has several limitations and strengths. First, a convenience sample was employed. People who chose to participate in this study may have had more positive experiences with telehealth, biasing the findings in our study. However, our semi-structured question guide elicited both positive and negative experiences with telehealth. In addition, individuals receiving and providing START services may not generalize to a larger population of persons with intellectual and/or developmental disabilities and their caregivers, although participants represented multiple regions of the United States, as well as urban and rural contexts. Furthermore, because START employs mental health best practices using standardized approaches, the results may be similar for other mental health services that use best practices. A second limitation was that people with intellectual and/or developmental disabilities who engaged in this study predominantly identified as White, non-Hispanic. As a result, their perspectives regarding telehealth may not be representative of people from other racial, ethnic, ethnic, and cultural groups. It should be noted that family caregivers and START provider participants represented a wider range of racial and ethnic backgrounds. Third, while focus groups and interviews elicited experiences of participants, as broadly aligned with a phenomenological approach, our procedures were designed to gain a high-level understanding of shared perspectives. While a traditional phenomenological approach typically requires "thick"

- We wanted to learn what can be done to make mental health services work for people with intellectual and/or developmental disabilities using telehealth (the computer or phone). We talked with adults with intellectual disabilities, family caregivers, and mental health providers across the U.S.
- One way to make telehealth work for people with intellectual and/or developmental disabilities is to follow three steps: 1) prepare, 2) engage, 3) assess. Each step is described below.
- Step one is “prepare.” Telehealth can work better when everyone gets ready before the meeting starts. Getting prepared includes scheduling the session at a time that works best for the person. The technology must be available and easy for people with disabilities and their families to use. It is also important to attend the telehealth session from a comfortable and private space. Some people with disabilities might want someone to sit with them during the telehealth session.
- Step two is “engage.” During a telehealth meeting, mental health providers can get people with disabilities more involved by asking about their interests and listening to them. They can ask about things that happened since the last meeting. People with disabilities can also be more involved when there are accommodations to make telehealth accessible.
- Step three is “assess.” There are a few things mental health providers can do find out how a person is doing over telehealth. Mental health providers can ask questions and notice things they see in the camera. Mental health providers may need to talk to a family member to make sure the person with a disability is doing okay. Sometimes it helps to have a visit in- person.

Figure 1. Plain language summary of project and findings

description, which can be challenging to obtain in focus groups and one-time interviews (Bradbury-Jones et al., 2009; Bush et al., 2019; Love et al., 2020), our two-phase analytical approach ensured our interpretations were grounded in participants’ shared experiences with START telehealth.

CONCLUSION

This study proposes the application of the Prepare, Engage, and Assess Framework as an approach that may maximize telehealth experiences for people with intellectual and/or developmental disabilities receiving mental health crisis prevention and intervention services (Figure 1). Further research is needed to determine if the PEA framework can be used to guide the provision of effective START services over telehealth for people with intellectual and/or developmental disabilities.

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Statement of Authorship

All authors contributed to the writing of this manuscript and approved the submitted version. Additional contributions include contributions to the study design: Kramer, Beasley, Caoili, Kalb, and Goode. Contribution to data collection and analysis: Kramer, Caoili, and Peace Urquilla.

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Appendix: Focus group and interview semi-structured questions for participant groups*

Topics related to core START practices	START Service Users	Family Caregivers	START Providers
General telehealth practices	One thing you like about meeting with your START coordinator or coach over the phone or video. One thing you don't like about meeting with your START coordinator or coach over phone or video.	Tell us about a time when START provided telehealth to your family. What went well, and what didn't go well?	Describe a time when you provided START telehealth services. What went well, and what didn't go well?
Assessment of needs and preferences	Think of a time when your START coordinator or coach helped you feel better. Finish the sentences: I feel listened to when . . . . I feel respected when . . . I feel comfortable when . . .	Think about a time when the START team was helpful to you when using telehealth. What did they do that was helpful?	Describe how you assess needs and preferences of START recipients and their families when using telehealth.
Therapeutic coaching	Tell us about an activity you liked doing with START over the phone or video.	Tell us about some START coaching activities that you think were really helpful when using telehealth.	What are some ways you provide therapeutic coaching activities when using telehealth?
Positive psychology practices	Finish this sentence. The strengths my START provider helped me identify are . . .	Give an example of how the START team helped you to recognize your strengths and/or the strengths of your family member when using telehealth.	How do you use strengths spotting to form a positive, therapeutic relationship with a START recipient and their family when using telehealth?

*All questions included follow up prompts to elicit details regarding access to technology, accessibility for persons with disabilities, and how telehealth services were tailored to family values and culture.