Creative Technology-Based Strategies for Engaging Young People with Serious Mental Health Conditions in Longitudinal Mental Health Services Research

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Abstract
A better understanding of the transition from child to adult community mental health services is important given the high rates of service drop-out. Conducting longitudinal research is challenging during a major service provider change. Developmentally-typical transition-to-adulthood instability can deter study engagement. This study examines the efficacy of creative technology-based strategies to recruit and engage adolescents and young adults (AYA) with serious mental health diagnoses in a qualitative study during their transition from child to adult services. Participants were recruited from one agency to complete three in-depth qualitative interviews and monthly surveys exploring mental health service experiences over 12-months. Participants received a smartphone and data plan for 6-months at initial interview, $50 at 6-month interview and $55 at 12-month interview. Four research assistants used a shared Google Voice account to text monthly online surveys and to communicate with participants. 19 participants enrolled; 74% remained enrolled across the 12-months. Smartphones and data plans were not effective in recruiting nor sustaining study engagement for most participants. Participants preferred a mix of texting and phone calls to prompt study engagement; 60% of online surveys were completed. Unanticipated participant-researcher communication outside of research scope suggests that the formation of strong relationships and additional support during this transitional time is critical for sustained study engagement. Study findings have practical implications for social work longitudinal research design and effective study implementation. Future social work research is warranted on innovative strategies to boost study and service engagement among AYA with serious co-occurring mental health and developmental instability.

Keywords Technology · Community mental health · Service transitions · Adolescents and young adults · Longitudinal research

Serious mental health conditions (e.g., schizophrenia spectrum and bipolar disorders) emerge in late adolescence when young people “age out” of child system services and transition into adult mental health service systems. This “transition” between child and adult systems is typically wrought with problems and considered a key contributor to service disengagement (Singh & Tuomainen, 2015). A deeper understanding of transition experiences is critical for designing practices, programs and policies that prevent disengagement and support wellness. Yet, engaging young people in longitudinal research during this transitional time is inherently challenging due to (1) the formal system support changes and disconnection; (2) the episodic nature of serious mental health conditions and; (3) developmentally-typical instability in living situation, school, work, relationships, and community. Creative use of technology shows particular promise for effective young adult recruitment and sustained longitudinal research participation during times of immense instability and system disconnection.

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High Prevalence of Mental Health Conditions and Low Service Engagement

Approximately 75% of adults with serious mental health diagnoses report their symptoms emerged between adolescence and young adulthood (Kessler et al., 2007). The most serious conditions, including schizophrenia spectrum and bipolar disorders, onset in late adolescence (Kessler et al., 2005)—a time of immense social-emotional change that is critical for future adult quality of life, stability and wellbeing. The high incidence rates of very serious conditions observed during adolescence and young adulthood makes this a critical time to address mental health needs. However, compared with middle-aged and older adults, adolescents and young adults (AYA) with mental health diagnoses have the lowest treatment-seeking rates and highest early treatment exit rates (Huey et al., 2014; McGorry et al., 2013; Singh & Tuomainen, 2015; Substance Abuse and Mental Health Services Administration [SAMHSA], 2019). Although 20% of AYA have a psychiatric and/or substance use disorder diagnosis, less than 25% of those diagnosed engage in mental health treatment (Center for Behavioral Health Statistics and Quality, 2016; Kessler et al., 2012; McGorry et al., 2013). Approximately 60% of youth enrolled in child mental health services exit care once they reach the age of 18 (Cohen et al., 2020a, 2020b; Paul et al., 2013; Singh & Tuomainen, 2015).

Child and adult mental health service systems and programs are typically separate (Abidi, 2017), have different methods for engagement (Munson et al., 2012), and do not coordinate with one another—even within the same agency (Cleverley et al., 2018). Those who transition into adult services do not feel that these new services meet their age-specific needs, which include evolving social roles and responsibilities with family, partners, and peers, balancing education and employment engagement, and navigating independent living (Cleverley et al., 2020). Additionally, perceived stigma regarding help-seeking, poor mental health literacy, and lack of culturally responsive services also negatively impact AYA service engagement (Cohen et al., 2016; Davis & Butler, 2002; Davis et al., 2012). There is an urgent need to better understand the multiple individual, social, and provider factors and processes that together prevent successful child to adult service transitions. Longitudinal research on the transition from child to adult mental health systems is sparse. A recent study leveraged semi-structured interviews with youth pre- and post-transition (n = 22) from child to adult services, illuminating complex processes, multiple opportunities for intervention and the need for additional longitudinal research of young people’s experience of the transition from child to adult mental health services (Cleverley et al., 2020).

Using Technology to Boost AYA Longitudinal Research Engagement

Longitudinal research participation is susceptible to the same factors impacting AYA mental health service engagement. In particular, the multitude of developmentally-relevant changes that occur during the transition to adulthood thwart study participation (Eyrich-Garg, 2011). Most longitudinal research designs include a mix of retention strategies. A meta-analysis of 141 longitudinal studies (n = 3585) that included adolescents and adults found a mean study retention rate of 73.5%, and identified 95 different retention strategies (mean of 6.2 strategies per study). Successful retention strategies included: increasing flexibility in study participation (e.g., either in person or phone), securing location details (e.g., another person who knows the participant’s whereabouts), and leveraging reminder phone calls (Teague et al., 2018).

Successful retention strategies require cultural sensitivity (Abshire et al., 2017). One promising approach to boosting longitudinal research participation of AYA with serious mental health diagnoses is leveraging mobile technology for study communication and activities. Mobile technology is easy to use, cost-effective, and suitable for large-scale longitudinal surveys (Kuntsche & Robert, 2009). AYA, regardless of sociodemographic and risk characteristics, have consistent and recurrent access to mobile technology (Pollio et al., 2013): about 89% of AYA have a smartphone (North et al., 2012; Pollio et al., 2013; Rideout & Robb, 2018). AYA prefer texting over other types of communication via technology (i.e., e-mail, social media), and frequent study staff contact is critical for sustained AYA longitudinal research engagement (Bender et al., 2014; Eyrich-Garg, 2011).

Despite limited research on the use of technology to engage AYA with serious mental health diagnoses, there is evidence that mobile technology (e.g., texting messaging, mobile applications) increases service utilizations, referral access, and communication between youth and providers (Sheoran et al., 2016; Tyler & Olson, 2018). Mobile-based technology has potential to support wellness among AYA. For example, text message-based services are promising in addressing AYA suicidal thoughts whereas web-based applications (that are mobile friendly) support AYA in tracking, gaining awareness of and self-managing depressive symptoms (Niendam et al., 2018; Robinson et al., 2016; Välimäki et al., 2017). More importantly, AYA specifically endorse the use of mobile-based technology for mental health assessment and intervention (Aschbrenner et al., 2019). Although mobile-based technology (e.g., calling, texting, mobile applications, social media messaging) can prevent longitudinal research attrition, there is
limited research examining its use with AYA with serious mental health diagnoses. This study aims to operationalize mobile engagement strategies for successful longitudinal research engagement and examine the impact of these strategies with this particularly vulnerable population.

**Research Questions**

Research questions included: (1) Which mobile communication methods and related incentives do AYA with serious mental health needs prefer in longitudinal research and why? (2) How effective is mobile-based technology in recruiting and retaining AYA participation in longitudinal research? (3) What unexpected situations and experiences in longitudinal research help leverage mobile technology to prevent attrition?

**Method**

**Study Site**

One large urban public mental health provider in Texas served as the recruitment site. This non-profit agency has approximately 900 employees and 45 locations. This agency was recruited because it provided both child and adult mental health services; and was interested in learning directly from AYA how to improve transitions and retention in adult services. The agency serves approximately 29,000 individuals each year; approximately 6500 are children and families, and 22,500 are adults. Agency service participant demographics are 60% White, 18% Black, 2% Asian, 16% other or unknown; 33% identify as Hispanic; services are funded through a mix of Medicaid, grants, State of Texas general revenue, and sliding scale payments (Integral Care, 2020).

**Researcher Description**

One of the authors with expertise in qualitative methods provided training for the research assistants. Training included interviewing techniques and the method of content analysis. One research assistant had a clinical license (LPC), and the remaining were pursuing degrees in social work and related mental health degree. Interviewers also received training on discussing sensitive material with AYA with mental health issues. Research assistants were part of all phases of the project, including recruitment, data collection, and analysis.

**Sample Eligibility Criteria and Recruitment**

Providers in Texas use a state-mandated level of care (LOC) system to prescribe services. Since this study aimed to understand transition experiences for those with the greatest need for continued services into adulthood, recruitment targeted those enrolled in the two highest levels of care (e.g., LOC 3 and LOC 4). For this study, we recruited a purposive sample of 17 to 19-year-olds with a serious emotional disturbance or mental health diagnosis who were either: (1) preparing to age out of child services within the next six months (upon their 18th or 19th birthday, depending on their funding) or (2) had aged out of services within the last year. The agency had 247 enrolled youth turned 18 during the study period, 64 of whom were enrolled in the two highest LOCs in children’s mental health services, 18 of those individuals obtained at least one service in adults services within the next year, displaying a disengagement rate (64%) similar to another recent state-wide analysis by the authors (Cohen et al., 2020a, 2020b).

The research team employed four waves of recruitment over a 10-month period, approximately every 2.5 months. The research team attended program/team meetings once during each of the recruitment waves to: (1) share study goals, purpose and eligibility criteria, and (2) train staff on how to introduce the study to AYA and complete the “consent to contact” form. Twenty-five staff (e.g., program managers, child therapists and case managers, and adult service intake specialists) were trained over the 10-month recruitment period. As an incentive, staff who recruited a participant were entered into two $20 gift card drawings.

If AYA were interested in study participation, staff supported AYA in completing the consent to contact form. This form read at a 5th grade level and described study purpose and expectations. If the AYA consented to future contact, they provided their phone number, e-mail address, birthdate, and signature. Staff who supported form completion added their name and e-mail to the form and then sent it to the research team via encrypted email. The research team responded to staff with a thank you email and added the staff’s name in the $20 gift card drawing. Every month, the research team emailed program managers with the number of ‘consent to contacts’ received, recruitment materials, and to answer to any questions.

A research assistant called potential participants to schedule an initial meeting within seven days of receiving the consent to contact. If the AYA did not respond, the research assistant sent a follow-up text message with study information. If the AYA did not respond to the follow-up text, a research assistant attempted three more times over the next three weeks by call and follow-up text. Attempts were made at different times of the day to increase chances of response. The research assistant also e-mailed when AYA provided an e-mail address. After four attempts, the research assistant contacted the agency staff who supported consent to contact form completion to verify contact information and assess AYA’s interest in study participation.
If the AYA expressed continued interest, the research assistant provided a short description of study participation expectations and compensation via phone or text—and set up an in-person meeting time to review the study consent form, obtain written consent, and conduct the first interview. During the consent process, the research team assured participants that engagement in the study would not impact their services with their mental health provider and that the information they shared with us would not be distributed back to their provider. All in-person interviews were scheduled at convenient times and locations (e.g., participants’ homes or public places: library, school, park, or coffee shop).

**Smartphone Distribution**

To promote study recruitment and retention, each participant received a smartphone with unlimited text, minutes, and data for six months at their initial interview (total value $180). In order to address concerns with privacy, we reassured participants that smartphones distributed to them would not track their location nor any data from the phone. Due to participant feedback, cash stipends were offered as an alternative to prepaid cellular data plans at 6-months. Most owned their own smartphones and preferred cash as compensation.

The research team created a Google Voice account with a local phone number for all communication with participants (i.e., calling, texting, sending surveys, and making interview appointments). Two research assistants shared access and management of the Google Voice account but maintained different responsibilities. One managed initial recruitment calls and follow-up attempts to potential participants. The other sent monthly surveys via text and scheduled in-person interviews. Both responded to participant texts as quickly as possible during business hours. The Google Voice account provided continuity in communication for research participants. The research assistants also provided tailored, personal communication (e.g., addressing participants by name, asking how they are doing, using exclamation marks and emoji’s, and sharing requested resources and information).

**Data Collection**

**In-Depth Interviews**

Research assistants conducted approximately 60-min semi-structured interviews at three time points: enrollment, six months and twelve months. Interviews were primarily open-ended, exploring previous and current service experiences, service barriers and facilitators, perceived mental health needs, future plans, and current research study experiences. Interviews also included selected elements from the Center for Mental Health Services National Outcome Measure scale, a 10-min demographic and wellness survey, to compare study participants to AYA in other SAMHSA grant funded projects (SAMHSA, 2014). Interviews took place at mutually agreed upon safe locations identified by the participant and research assistant. Interviews were audio-recorded and transcribed for analysis. As previously stated, participants received a smartphone and pre-paid data card (worth $180) at the first interview. Originally it was planned to provide individuals another pre-paid data card at 6-months, however all participants requested cash due to having their own phone. For this reason, participants received $50 at the six-month interview and $55 at the 12-month interview.

**Monthly Surveys**

In months when an in-depth interview did not take place (i.e., months 2–5 and 7–11), participants completed brief monthly online surveys on their smartphone. Surveys were in Qualtrics, took approximately five-minutes to complete, and explored medical and mental health service use, employment and education participation, housing status, justice system interaction, mood, and substance use in the past 30 days. Mid-month, a research assistant sent the online survey link through an individualized text message in the afternoon or early evening (based on participant preference) to every eligible participant (i.e., completed baseline interview at least two-weeks prior, and not due for a 6-month or 12-month interview that month). One to three days after the first text message, the team member sent a text reminder to eligible participants who had not yet completed the survey for that month. A week after the first text message was sent, a research assistant sent a third and final text message to remind participants to complete the survey.

**Rigor**

Throughout data collection, several procedures were utilized to monitor and enhance the quality of the collected data, including systematic review of interview transcripts and audit trails and debriefing meetings with the research team and a qualitative research expert (Mack et al., 2008). Member-checking, also known as participant or respondent validation, was also incorporated as a tool to enhance trustworthiness (Harvey, 2015). As we were drawing conclusions about our research questions, we would follow up with participants and check for accuracy and resonance with their experiences. For example, researchers spoke to four of our participants at a follow-up interview about how we were finding that smartphones with data plans were not an appealing incentive. Most participants shared that they already had a smartphone and preferred cash. In this case, we used member checking as a validation technique for our results as well as a method to make necessary changes to recruitment during the data collection phase.
Ethical and Practical Considerations

The present study explored the experiences of AYA with serious mental health needs, and as such, AYA could experience emotional distress during or after an interview. To mitigate this, the research team had a list of mental health resources to provide for participants. To provide additional support, the researchers also debriefed with participants after the interview. The research team also acknowledged how their experiences in the mental health field could impact the data collection and analysis of the data. Therefore, researchers applied a reflexive approach by having repeated check-in conversations with the rest of the team and the team’s supervisor. These conversations focused on preconceptions and assumptions about the research topic and the outcome of the investigation and on mitigating those biases (Holmes, 2020).

Analysis

The research team used descriptive analyses to summarize interview and survey response rates and patterns. The research team used content analysis to identify themes and patterns in the interviews, open-ended survey responses and documented text and call communication between participants and research assistants (Krippendorff, 2004). Inquiry types were identified based on characteristics (e.g., mental health, resources, emotional support) and summed for each of their frequencies across participants.

Participants

From December 2017 to November 2018, the research team received 45 signed consent to contacts. Thirty-five AYA responded to initial research team outreach, and 19 enrolled in the study, completing an initial interview. Mean age at enrollment was 18 years (SD = 0.74). Eleven (58%) identified as women, five (26%) men, and two (11%) gender non-conforming. Eleven (58%) identified as Latinx, three (16%) as White, three (16%) as African American/Black, and two (11%) as Asian. Twelve (63%) identified as LGBTQ+. Eight participants (42%) identified as bisexual, seven (37%) heterosexual, 1 (5%) homosexual, and three (16%) selected other, specifying asexual or pansexual.

At study enrollment, 12 participants lived with parents (63%), seven (37%) lived with romantic partners, friends, or roommates. At study enrollment, 100% reported having experienced at least one “household dysfunction” (i.e., parental mental illness, incarcerated relative, mother treated violently, parental substance abuse, or divorce) in their childhoods with eight (50%) reporting childhood neglect and seven childhood abuse. At enrollment, six (32%) were employed and one (5%) was enrolled in school.

Participant EHR-listed current DSM-5 diagnoses were primarily mood disorders, including: major depressive disorder (89%) and bipolar disorder (11%); 59% also had a substance use disorder. Eighteen (95%) were diagnosed early in their youth and had participated in child system services for 5–10 years. One had experienced a psychiatric crisis at 17 that resulted in child system treatment. In the year before aging out of child mental health services, participants received, on average, 77 (SD = 47.5; Range = 9–134) services. Child services were multi-faceted including therapy, psychiatry and non-traditional supports such as equine therapy. After transitioning to adult services, participants received on average 13 (SD = 16, Range 0–57) services. Adult services were primarily assessment, psychiatry, case management, and crisis services. The primary reason for individual to receive more than a handful of time-limited services was the presence of a psychiatric crisis including the deployment of the county mental health crisis response team. At study enrollment, 100% reported anxiety as their primary mental health concern; 89% reported substance use.

Results

Recruitment Response Rates

The research team received 45 consent to contact forms during 10 months of recruitment. Nineteen AYA responded to recruitment wave 1 efforts. The research team initiated contact via phone call, but 15 responded via text message. Of the nineteen, 17 (89%) scheduled an initial interview. Of the 17 who scheduled an interview during wave 1 efforts, 9 (53%) completed an initial interview. 5 (29%) rescheduled and completed interviews, and 3 (16%) did not show and never responded to research team outreach efforts. Wave 1 efforts resulted in successful recruitment of 9 (47%) of study participants. In recruitment wave 2, ten AYA responded to initial phone calls. Eight (80%) scheduled an initial interview; four (40%) completed an interview, three (30%) rescheduled and completed an interview, and one (10%) did not show. In recruitment waves 3 and 4, six young people responded to initial phone calls; three (50%) completed initial interviews; and three (50%) completed rescheduled interviews. Reasons for rescheduling the first interview included conflicts with employment schedule or a need to confirm participation with parents/caregivers. Of the 35 AYA with consent to contact who responded to the research team’s recruitment strategies, 19 (54%) enrolled in the study and completed an initial interview. See Fig. 1 for participant recruitment and enrollment process.
The Use of Technology: Recruitment and Retention

Smartphones

Smartphones with data plans were not an attractive incentive because most \( n = 14 \); 74\% \) participants already owned a smartphone that they preferred to use for participation in the study. Among those who preferred to use their own phones and data plans, two had their smartphones disconnected due to missing phone payments. With participant consent, the research team communicated with participants’ parents to schedule interviews and send monthly surveys. Of the five provided smartphones and data plans, one participant initially used the study-provided smartphone, then lost it and resorted to using her old smartphone. The rest relied on the study-provided smartphones to participate in the study.

Leveraging Both Texting and Calling

During the initial interview, the research team inquired about participant communication preferences with the research team. Most participants reported being comfortable with and preferred both, texting and calling: 68\% \( n = 13 \) had no preference between texting or calling, 26\% \( n = 5 \) preferred texting, and 5\% \( n = 1 \) preferred calling. No participants preferred e-mail. (The few times the research team used e-mail to engage participants, it did not yield a response.) The team then tailored their communication with each participant based on their preferences.

Early in the study, the research team observed that automatic “push notifications” did not result in survey completion. Push notifications are generic, automated application-generated. The research team used “Hi this is the team at UT. Hope you’re doing well. Just wanted to send you a friendly reminder about quickly filling out the monthly survey link. Thank you!” Upon sending the first texts prompting monthly survey completion, the research team received simple, but custom, requests from participants, for example: “Please use my other phone number instead,” “You might have to email me if I don’t respond,” “Please email me if I don’t respond after two texts,” and “Please text my mom if I don’t respond.” Accommodating the personalized requests from participants would aid in survey completion response rates, so the research team opted to send personalized survey reminder texts by including the names of participants, a personalized statement (e.g., “hope school is going well”), and including the research team member’s name with the

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**Note.** Of the 250 youth who turned 18 while enrolled in a community mental health agency during the study period, 64 were in the 2 highest levels of care at age 17.

**Fig. 1** Participant recruitment and enrollment flowchart
text. It is interesting to note that despite requests, emailing the survey link did not result in survey completion, but additional texts did.

Participants valued the flexibility of communicating with the research team via both text and phone. For example, one participant, Lucy, described appreciating initial and follow-up texts to complete monthly surveys: “It’s good that I get the text to do it, because I don’t think I would remember if I didn’t get the text to do it.” While others, like John, appreciated follow-up phone calls prompting completion:

Sometimes I feel like people answer the phone. Like I always answer my phone. So, if you were to catch me at the right time, I would definitely have a conversation with you all. The thing with text messages is that I would just like look at them, and say that I will respond to them later, and then it has been like 5 days.

Measure Completion and Experiences

Interviews and Monthly Surveys

Nineteen participants completed initial interviews, 15 (79%) completed six-month interviews, and 14 (74%) completed 12-month interviews. Participants who completed a final interview reported that consistent communication with the same research team member (in texting, scheduling, and in-person interviews) encouraged them to continue study involvement. One participant, Ashley, said, “it definitely helped to get reminders from y’all, and also the check-ins.” Monthly text reminders to complete the survey became a meaningful interaction for some participants. Participants could complete nine online surveys during their 12 months of enrollment. Participants (n = 19) completed 102 monthly surveys, a 60% response rate. On average, participants completed 5.37 surveys (SD = 3.44; Range = 0–9); 58% completed at least half of the surveys; 37% completed all nine surveys. Figure 2 shows attrition in monthly survey completion: 89% completed month one survey, while 42% completed month 11 survey.

Most (68%) described online surveys as easy to complete. For example, Jorge said, “they are not overly complicated. That’s what I like about it. I just click it and you just do it. That’s why it is so easy for me to always do it.” When asked what might make survey completion easier, participants said the surveys and team prompting were not the issue, rather it was their own personal capacity, motivation and organization related to their mental health and the competing demands of young adulthood that got in the way of survey completion. Here is how one participant, Sarah, described why they forgot to do the surveys despite research team prompts:

It was lack of energy. Having to do the whole thing every time, I was just like, I couldn’t even brush my teeth. It just felt like a lot. It was because my depression was so bad, that if I had answered to questions, it would be extremely, extremely, extremely [in regard to survey questions about mental health]. You know what I mean. It wasn’t you all. It was just me. It was definitely my own lack of energy and forgetting. I tried to do it at first and just kept forgetting.

For others, an inability to complete monthly surveys occurred because their smartphone was disconnected, broken, lost, or stolen. As Marla mentioned, “…to be honest I thought, I think I need a phone [reason for signing up for study]. And then my phone got stolen!” Additionally, some participants, like Ashley, expressed guilt for not completing surveys:

Again, I feel bad for not keeping up every month with this. All I can say is that it has mainly been the same, it mainly has been that I’ve been depressed most of the time. Cause I signed up for this, but it has been a tumultuous time.

Fig. 2 Survey completion by month

Note. Surveys for months 1, 6, and 12 were replaced by in-person interviews.
This is particularly important for researchers who aim to sustain participants in longitudinal research using online methods.

Strong Connections and Additional Support

While analyzing interviews and posing the analytic question, “why did some complete the final interview, while other did not?” the research team identified the strength and closeness of the relationships between the research assistants and participants as critical for sustained study engagement. Of the 19, the research team formed strong bonds with 14 participants, feeling a sense of closeness with participants, having engaged in mutual sharing and connecting over shared interests and life experiences that was noted during data collection and during analysis. Research assistants described these connections as, “I remember so much about some participants who I felt closer to or I could relate to; I really wanted to mentor her; she was so intelligent and self-aware—I looked forward to connecting; I worried about her and was relieved when they reached out.” Of the 14 who had built strong bonds with the research team, 13 participants completed their final interview; the one who did not was struggling immensely with maintaining her independent living situation, engaging in significant substance use, and lacking sufficient social support.

In support of participant resilience and strong connections to research assistants, 47% of participants unexpectedly contacted the research team for reasons unrelated to study activities (seven via text; two via phone). Participants most frequently inquired about where and how to get mental health support. The research team provided information for how to access walk-in clinics, low-cost counseling and medications, and resources for domestic violence. The research team unexpectedly became an important AYA service connector and emotional support. Two participants sought support during serious mental health crisis. Jackie texted: “I’m sorry to bother you I just wanted to ask you if you know any walk-in clinics around [location], I don’t feel good and I really need to talk to someone.” The research assistant (a clinical social work master’s student) employed counseling techniques and directions to the nearest walk-in mental health clinic. The other participant, Greg, explained that he did not like asking for help and had ceased services immediately after his agency intake, yet he felt comfortable texting the research team for support: “I want some counseling and medications. I’m paranoid and it won’t go away.” The research team conducted a safety assessment, employed a grounding exercise, and connected the participant to a local mental health clinic.

Two participants asked for concrete adulthood and career-related tasks, assistance with how to pay their electricity bill and help with applying to colleges. Mikaela texted: “I need help could you give me a call ASAP. I’m still struggling with my lights wondering if y’all can help me out with that.” The team provided information on how to access emergency funds to cover household bills, and resources for applying to colleges. Three participants shared updates on their personal successes with school, work, and mental health access. For example, Jimena shared her recent successful college acceptance that she had described her hope for during her six-month interview. After the study concluded, three participants continued to reach out with inquiries or updates. Two months after completing the last interview, Kate reached out to ask about early voting at her college campus. The research team sent her early voting resources and locations. This participant replied with an update and thank you message when she completed early voting. Another participant, Veronica, updated the team on her continued intake process on the adult side of services and felt comfortable with sharing her experience:

I had my appointment yesterday. And, it was okay. I don’t know if I actually got to see a caseworker or not so I think I still need to go back and do that. But I did get to see my new psychiatrist and that went okay…I’m scheduled to see them next month to go back to the financial aid and see my caseworker and also to see my psychiatrist again so I’m hoping that they will prescribe me to medicine and stuff.

Study Dis-Engagers

Of the five who the research team did not feel that they built a strong bond with, who ultimately did not complete the 12-month interview, three were female and identified as White (n = 2) and/or Hispanic (n = 3); two were male and African American/Black. All had immense housing, income and social support instability. None connected successfully to adult services. One ceased study participation because he experienced psychosis and believed the research team was connected to the provider he did not want to receive services from. The other four passively exited the study, ceasing communication with the research team despite the team attempting contact via phone, text, and email, contacting previous providers (from consent to contact form), and any family or social supports that the participants consented that the research team could contact.
Discussion

This study highlighted how technology can be used in creative ways to engage AYA with serious mental health conditions in longitudinal qualitative research during a forced shift in mental health provider. Study recruitment and retention rates are similar to other research with AYA with serious mental health needs. Study findings have particular implications for social work researchers and providers who aim to successfully engage traditionally “hard-to-engage” populations in research and services. The unanticipated relationship development that appeared related to study engagement should be considered in planning and supporting qualitative longitudinal research with this population, and warrants further research. Also, given COVID-19 shelter-in-place mandates, study methods and findings can inform the adaptation of in-person data collection to safe, socially distanced virtually-based study protocols.

One important study takeaway was that a free smartphone and data plan participation incentive did not successfully recruit nor sustain participant engagement. Despite receiving public mental health services and having limited to no income, participants had better smartphones and data plans than the ones offered in the study. Some participants were also part of a family smartphone and data plan. Despite having prior access to smartphones and data plans, participants’ phone numbers changed multiple times throughout the course of the study. Phone number changes resulted from participants who initially did use the smartphone provided by the study but (a) did not schedule their follow-up interview in time to keep the same prepaid data plan, and thus same phone number or (b) did not schedule follow up interviews at all. In two cases where participants already owned smartphones, the participants changed from their family’s data plan to their own plan, therefore changing their phone number. Future research providing a smartphone and data plan incentive should carefully describe the benefits of the incentive they will be providing to participants and suggest to participants that accepting it does not mean they need to use it immediately—it can be a back-up plan in case their current phone or data plan backfires.

A different incentive to recruit participants may have resulted in more than 42% (19 of 45) successfully enrolling in the study. Researchers should consider cash incentives, or other types of technology, such as a tablet or laptop, to support both study engagement and success with mental health service engagement. Of the 19, 74% completed 12-month interviews, which is similar to the 73.5% longitudinal research rate found in a meta-analysis of 141 longitudinal studies (Teague et al., 2018).

Flexibility in data collection methods for this population is key. Research teams must prepare for and expect AYA to change their communication preferences, phone numbers, interview meeting locations, and for various family and other social supports to be present or nearby during interviews. The research assistants conducted interviews in pairs, initially for safety. However, having a second interviewer present allowed for one interviewer to engage with the AYA during the interview while the other interviewer engaged with others who were present (e.g., a parent). Engaging with others typically occurred by moving to another space and talking. Inclusion of the additional option to complete interviews virtually may have increased interview completion, allowing for increased AYA privacy in interview completion. More surveys may have been completed if research assistants collected survey data verbally over the phone or via videoconference for those who did not complete the online survey via the texted link. In addition to phone and text communication, Facebook messaging has shown promise with engaging a similar population in longitudinal research during the transition out of child mental health services (Klodnick et al., 2020). All of these research methods are challenging for social work researchers to get efficiently and effectively approved by Institutional Review Boards. More researchers who effectively use such methods (as described above) must publish their work to provide evidence for the effectiveness of these methods for particularly vulnerable, hard-to-engage populations.

Proactive, rapid, and tailored interactions are also critical to sustained AYA longitudinal study engagement. Generic push notifications via text did not result in successful online survey completion. Conducting initial interviews in-person with research assistants was important. Participants liked “knowing” who was calling or texting them. The research team’s (1) flexibility; (2) rapid response rates; and (3) use of personally tailored texts and calls appeared critical for sustained study engagement. Service providers who aim to engage AYA in mental health services should consider texting and brief check-ins as adjunct services/supports to mental health counseling. Texting is increasingly used as an engagement strategy in mental health care with AYA (Summerhurst et al., 2018; Tolou-Shams et al., 2019). Automated text-based appointment reminders are common and effective in mental health treatment (Schwebel & Larimer, 2018) and texting is identified as one of a number of effective longitudinal attrition prevention strategies (Teague et al., 2018). Research and clinical teams that aim to be effective with flexible, rapid, tailored text-based engagement strategies like this must be in communication frequently, and be motivated and flexible enough to respond to participant contact. Two of the research assistants were social work graduate students with flexible schedules and able to respond to participant texts during breaks from class or fieldwork, which ultimately made this approach feasible.
The relationships that the research team and participants developed appeared to prevent study attrition. Frequency of contact and study experiences of sharing what one was experiencing with the mental health system (and being heard by an interested near-age research assistant) paired with text prompts (which felt like a “check-in” experience for participants) resulted in strong participant-research team connections with some participants. Other longitudinal studies with monthly check-ins found that AYA participants expressed a desire for new relationships and someone to talk to (Cleverley et al., 2020; Singh et al., 2010). The research team’s flexibility in when and how they connected with study participants, as well as their consistent and personalized communication with study participants demonstrated care and “being there” for a vulnerable population. The research team’s (1) clinical engagement skills; (2) non-judgmental approach; (3) neutral status as people who want to understand but not fix or change AYA; and (4) promotion of self-determination kept participants engaged in the study.

The research team also responded proactively to participants who reached out for support (47% of the sample), providing emotional support and connections to mental health service providers. There is a general assumption that AYA do not want mental health support given their new adult status and right to discontinue services. However, some participants did reach out for support when they perceived it was needed. Additionally, many used the support that the research team provided. Findings from this study examining service experiences are detailed elsewhere (Emerson et al., 2019). Most participants had negative child-to-adult service transition experiences resulting in service discontinuation. Thus, the research team served a critical role for some participants, facilitating reconnection to needed services and resources, and supporting in times of mental health crises. Because the research team was led by PhD-level researcher with a background in public mental health practice, and research assistants that included former master’s level clinicians turned researchers, and social work master’s students, the team was able to effectively respond and communicate with participants in ways where they felt heard, validated, and effectively connected to needed resources. Furthermore, the team had a close, reciprocal relationship with the referring agency which allowed the research team and agency to develop proactive psychiatric crisis mitigation plans prior to the deployment of the study. This speaks to the importance of having trained clinicians either conducting or supporting data collection efforts of such vulnerable populations.

However, it also speaks to the challenges facing research teams who aim to study service engagement and experiences effectively. Yet, the very design of the study and necessary interaction with participants made the research team an intervention. It was easy for participants to text or call the research team, and by design, to receive a prompt, tailored response to address immediate needs. It is challenging to untangle the extent to which the research team and relationships truly helped participants with their mental health and developmental needs, or connection to, and engagement in, community mental health services. Among those who had unanticipatedly contacted the research team for support, two were enrolled in mental health services at study end. It is critical for social work researchers to remain reflexive, consider their role in influencing research participant behavior, and report these factors in research publication.

### Study Engagement Barriers

Technology-based strategies helped with retention for most participants in this study, but there were still barriers to a subset of the sample. When the research team lost contact with participants, it was because participants were experiencing exacerbated mental health symptoms paired with challenging life circumstances threatening basic needs (e.g., housing or job loss or change). Also, research assistants were 100% female-identifying, 2 were White, 1 Latinx, and 1 Filipino. All were between the ages of 20 to 35, had at least a bachelor’s degree, and at least middle socio-economic status. It is possible that research assistants who identified as male and/or African American/Black would have improved participant study engagement. Social work researcher teams may benefit from increased diversity in order to increase mutual relatability, and thus foster stronger bonds among research assistants and participants to prevent study attrition.

### Limitations

This study relied on a small convenience sample of AYA with serious mental health conditions at one public mental health provider in Texas. Study findings are not generalizable to AYA with mild to moderate mental health needs, nor private mental health service settings. This study lacked text and phone conversation transcripts between the research assistants and participants, which would have shed further light on research team engagement strategies—and should be captured and examined in future research. The study lacked a standardized measure of relationship strength and quality between the research team and participants, nor participant perspective on how strong of a bond that they felt they had with the research assistants. This study also lacked assessments of both technological competence and issues of privacy and paranoia. For example, the present study argued that push notifications were not effective, yet the research team did not assess if participants turned off push notifications or if they simply did not engage with the notification. It could be that the participants did not fully understand how to use their phones or simply only used the most basic features. It could also be that the researchers assumed that because participants had access to
a smartphone or grew up with technology that they had the technological capacity and knowledge to use their phones for study engagement. Lastly, the present study did not assess for issues of privacy and paranoia. One participant disengaged because he thought the research team was part of the agency where he was once receiving services despite the consent process clearly stating this was not the case. It begs the question as to what levels of paranoia could impact the research participants and their engagement with the study.

**Conclusion**

Future social work research is warranted on innovative strategies to boost study and service engagement among AYA with serious co-occurring mental health and developmental instability. This study provides helpful insights and practices for study recruitment and retention methods for AYA with serious mental health conditions. Social work research teams that aim to support sustained study engagement, must be prepared for participants to engage with the team beyond planned study activities. Examining interactions between the research team and participants can yield important insights for effective social work research methods to engage vulnerable and marginalized populations in longitudinal research.

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**Data Availability** Data is available upon request.

**Declarations**

**Conflict of interest** We have no conflict of interest to disclose.

**Ethical Approval** The study was approved by the Institutional Review Board at the University of Texas at Austin.

**Informed Consent** All participants provided written consent to participate in the study. All participants consented to have their data used for publication purposes. All authors consent to the publication of this manuscript.

**References**

Abshire, M., Dinglas, V. D., Cajita, M. I. A., Eakin, M. N., Needham, D. M., & Himmelfarb, C. D. (2017). Participant retention practices in longitudinal clinical research studies with high retention rates. *BMC Medical Research Methodology, 17*(1), 1–10. https://doi.org/10.1186/s12874-017-0310-z

Center for Behavioral Health Statistics and Quality. (2016). 2015 National Survey on Drug Use and Health: Summary of the Effects of the 2015 NSDUH Questionnaire Redesign: Implications for Data Users. Substance Abuse and Mental Health Services Administration, Rockville, MD. Retrieved from https://www.samhsa.gov/data/sites/default/files/NSDUH-TrendBreak-2015.pdf

Aschbrenner, K. A., Naslund, J. A., Tomlinson, E. F., Kinney, A., Pratt, S. I., & Brunette, M. F. (2019). Adolescents’ use of digital technologies and preferences for mobile health coaching in public mental health settings. *Frontiers in Public Health, 7*, 178. https://doi.org/10.3389/fpubh.2019.00178

Bender, K., Begun, S., DePrince, A., Haffjee, B., & Kaufmann, S. (2014). Utilizing technology for longitudinal communication with homeless youth. *Social Work in Health Care, 53*(9), 865–882. https://doi.org/10.1080/00981389.2014.925532

Cleverley, K., Rowland, E., Bennett, K., Jeffs, L., & Gore, D. (2018). Identifying core components and indicators of successful transitions from child to adult mental health services: Scoping review. *European Child & Adolescent Psychiatry*. https://doi.org/10.1007/s00787-018-1213-1

Cleverley, K., Lenters, L., & McCann, E. (2020). “Objectively terrifying”: A qualitative study of youth’s experiences of transitions out of child and adolescent mental health services at age 18. *BMC Psychiatry*, 20, 1–11. https://doi.org/10.1186/s12888-020-02516-0

Cohen, D. A., Klodnick, V. V., Stevens, L., Fagan, M. A., & Spencer, E. S. (2020a). Implementing adapted Individual Placement and Support (IPS) supported employment for transition-age youth in Texas. *Community Mental Health Journal, 56*(3), 513–523. https://doi.org/10.1007/s10597-019-00508-3

Cohen, D. A., Klodnick, V. V., Kramer, M. D., Strakowski, S. M., & Baker, J. (2020b). Predicting child-to-adult community mental health service continuation. *The Journal of Behavioral Health Services & Research*. https://doi.org/10.1007/s11414-020-09690-9

Cohen, D. A., Lopez, M., Klodnick, V. V., & Stevens, L. (August, 2016). A guided pathway to success: Addressing the needs of youth and young adults with serious mental health conditions in Texas. Texas Institute for Excellence in Mental Health. School of Social Work, The University of Texas at Austin. Retrieved from https://tsxsystemofcare.org/wp-content/uploads/2019/06/Texas-TAY-Policy-Paper-Final.pdf

Davis, M., & Butler, M. (2002). *Service System Supports During the Transition from Adolescence to Adulthood: Parent Perspectives*. Implementation Science and Practice Advances Research Center Publications. Retrieved from https://escholarship.umassmed.edu/psych_emhsr/435

Davis, M., Koroloff, N., & Ellison, M. L. (2012). Between adolescence and adulthood: Rehabilitation research to improve services for youth and young adults [Editorial]. *Psychiatric Rehabilitation Journal, 35*(3), 167–170. https://doi.org/10.2975/35.3.2012.167.170

Emerson, K. R., Cohen, D. A., & Klodnick, V. V. (2019, November). Adolescent experiences of the transition from child to adult public mental health services. American Public Health Annual Meeting, Philadelphia, PA, United States. Retrieved from https://apha.confex.com/apha/2019/meetings/Handout/Paper450330/APHA%20handout.pdf

Eyrich-Garg, K. M. (2011). Sheltered in cyberspace? Computer use among the unsheltered ‘street’ homeless. *Computers in Human Behavior, 27*(1), 296–303. https://doi.org/10.1016/j.chb.2010.08.007

Harvey, L. (2015). Beyond member-checking: A dialogic approach to the research interview. *International Journal of Research &
