Mental health supportive services during COVID-19: Proposing an online, self-guided Acceptance and Commitment Therapy program for parents in the disability community

Ty B. Aller  
*Utah State University*

Elizabeth B. Fauth  
*Utah State University*

Sarah Hodgskiss  
*Utah State University*

Jeff Sheen  
*Utah State University*

Follow this and additional works at: [https://digitalcommons.usu.edu/ddnj](https://digitalcommons.usu.edu/ddnj)

**Recommended Citation**
DOI: [https://doi.org/10.26077/8307-528b](https://doi.org/10.26077/8307-528b)  
Available at: [https://digitalcommons.usu.edu/ddnj/vol1/iss2/14](https://digitalcommons.usu.edu/ddnj/vol1/iss2/14)
Mental Health Supportive Services During COVID-19: Proposing an Online, Self-Guided Acceptance and Commitment Therapy Program for Parents in the Disability Community

Ty B. Aller,1 Elizabeth B. Fauth,1 Sarah Hodgskiss,1 Jeff Sheen,1 and Michael E. Levin1
1Utah State University, Logan, UT

Plain Language Summary

Parents of children with intellectual and developmental disabilities (I/DD) often experience significant stress from physical, cognitive, and behavioral characteristics of their child, balancing their child’s needs with that of other family members, and support factors including navigating complicated service systems for their children (Marquis et al., 2019). These stressors are exacerbated in the context of COVID-19 where new financial and social challenges arise, coupled with an environment where many I/DD and mental health services have been canceled or adapted into telehealth modalities (Bradley, 2020; Pierce et al., 2020). Accordingly, this paper describes the effectiveness of mental telehealth options for parents of children with disabilities. Next, we discuss several challenges of service-delivery models, explaining how online, self-guided programs may provide a viable and effective option to meet the growing psychological needs of these parents, particularly during COVID-19. Last, we introduce our online program that targets stress and wellbeing in parents and propose a call for collaboration with clinicians, therapists, and advocates working with parents of children with I/DD.

Telehealth Services

Across the U.S., telehealth services provide a socially distanced and safer solution in the wake of COVID-19 (Adalja et al., 2020). Telehealth services use technology to communicate with

Correspondence concerning this article should be addressed to Ty B. Aller, Center for Persons with Disabilities, 6800 Old Main Hill, Utah State University, Logan, UT 84322-6800. Email: ty.aller@usu.edu
clients remotely, often provided synchronously, using videoconferencing or telephone calls (Hilty et al., 2018). Most commonly, appointments are scheduled a priori, take place during normal business hours, utilize similar amounts of service provision time, and are available to individuals, families, and groups (Pierce et al., 2020). Telehealth services can be asynchronous, allowing individuals and service providers to interface at different times, or for clients to access resources independently (i.e., self-guided). Examples include “patient portal” models where clients upload materials or information at their convenience and the provider reviews and responds later. Self-guided education and supportive services are also asynchronous options in which individuals review resources on their own delivered through text, audio, video, or interactive modules. Telehealth programs have addressed mental health needs of parents of children with autism spectrum disorder (ASD), parents of children with life-threatening illnesses, and parents of children with other health conditions (Bearss et al., 2018; Hinton et al., 2017; Muscara et al., 2020; Nieto et al., 2019; Vismara et al., 2013).

**Effectiveness of Synchronous Telehealth Services**

Even prior to COVID-19, synchronous telehealth services were available for parents of children with I/DD, targeting behavioral symptoms and parenting skills, and reporting positive outcomes (Bearss et al., 2018; Muscara et al., 2020; Xie et al., 2013). In a program for parents of children with autism (Bearss et al., 2018), therapists trained parents via video conferencing. Participating parents reported increased confidence when managing behavioral symptoms and endorsed recommending the program to others (Bearss et al., 2018). In another program, parents of children with ADHD improved their disciplinary practices and other parenting skills after 10 small-group videoconference sessions with a therapist (Xie et al., 2013). This program evaluation included a face-to-face therapy comparison group; levels of improvement were positive and similar across both modalities, suggesting that telehealth services can be as effective as in-person services (Xie et al., 2013).

Telehealth has been studied in highly stressed parents, not limited to parents of children with I/DD. Muscara et al. (2020) studied the effects of an acceptance and commitment therapy (ACT) group intervention delivered via video conferencing. Parents had children who were recently diagnosed with a life-threatening illness or injury. Parent groups met with a mental health facilitator to build skills in reducing posttraumatic stress symptoms (PTTS). Over six sessions, parents significantly decreased PTSS and had greater improvements in their subjective experiences of their child’s illness, as compared to a control group (Muscara et al., 2020). This is promising evidence that telehealth services, specifically ACT-based services, can reduce parental stress.

**Effectiveness of Telehealth-Online Hybrid Programs**

While some telehealth services are completed entirely in real time with a service provider, others implement combinations (a hybrid) of synchronous and asynchronous delivery (Bai et al., 2015; Hinton et al., 2017; Vismara et al., 2013). One example is the Triple P Online–Disability (TPOL-D) program, which helps parents of children with disabilities increase parenting skills and
self-efficacy, while also decreasing behavior symptoms in their children (Hinton et al., 2017). The program included self-guided modules, an online parent-support group, and an optional weekly call with a facilitator. Parents who participated in TPOL-D significantly increased their self-efficacy and positive parenting practices (Hinton et al., 2017). Similarly, in a program for parents of children with ASD, synchronous and asynchronous hybrid delivery included live video conferencing combined with self-guided work online. Improvements were identified in building parents’ confidence in addressing their child’s needs and in teaching parents effective ways of relaying that information to other caretakers (Vismara et al., 2013). Another hybrid program for parents of children with ADHD used online lectures and group sessions led by a facilitator. Compared to a control group, participating parents reported increased knowledge of ADHD and intention to adhere to medication (Bai et al., 2015).

The emphasis for the above programs is primarily helping parents manage behavioral symptoms. While these programs effectively reduce exposure to stressors and improve parents’ self-efficacy, other programs specifically target mental health and overall wellness of these parents. Pennefather et al. (2018) tested an online program for parents of children with ASD that not only covered topics about reducing certain behaviors in children through applied behavior analysis (ABA) but also used ACT principles to reduce parents' stress. Parents attended weekly synchronous sessions, accessed a webpage with additional resources and a group support feature, and completed homework. The program was associated with improved behavior symptoms in children and decreased parental stress.

Considerations of Delivering Synchronous and Hybrid Telehealth Programs

While telehealth-delivered supportive services for parents of children with I/DD offers clear advantages from face-to-face programs in terms of convenience, and minimizing travel and risk of viral exposure, four main limitations remain for synchronous telehealth: quality and consistent internet access, scheduling, scaling, and cost. Infrastructure to support internet access, while beyond the scope of this paper, is an issue that still exists throughout the rural U.S. and needs to be addressed to support access to telehealth services (Greenberg et al., 2018). Scheduling appointments is also challenging for any parent but may be more so for parents of children with I/DD. Dowling and Dolan (2001) report numerous barriers including waitlists, scheduling conflicts when managing multiple providers, and appointments conflicting with work/school schedules.

The service ratio of synchronous services (one provider for one client) and the need to hire trained therapists creates issues with scaling and cost. Unmet needs are a known problem; long waitlists are documented in the Medicare system where the mental health needs of individuals with I/DD and their families are often unaddressed (Slayter, 2010).

Asynchronous Self-Guided Online Programs

Asynchronous self-guided (online-only) programs overcome burdens of scheduling, scaling, and cost (but not internet availability) by providing resources that parents can access at
their convenience, without a provider, and at low cost. There are minimal provider cost-differences in offering self-guided resources to one parent versus 1,000 parents; thus, services are highly scalable. While these programs are costly to develop, once available they can often be offered at low-cost.

Effectiveness of Self-Guided Online Programs

The evidence for online, asynchronous interventions for mental health in the general population, albeit not specific to parents with I/DD, is compelling (Andersson, 2016). In a systematic review and meta-analysis, Cuijpers et al. (2010) included 21 studies of 810 participants with anxiety and depressive disorders and determined that online self-guided therapies are equally as effective as face-to-face therapy, even in studies with up to 1 year of follow-up (Cuijpers et al., 2010). Lorenzo-Luaces et al. (2018) reported that these kinds of findings are not an artifact of sample differences; participants across 21 studies completing internet-based Cognitive Behavioral Therapy (CBT) programs were comparable to participants included in studies of antidepressants and face-to-face therapy.

ACT and other therapeutic models have been used to teach parents of children with health issues or disabilities particular parenting skills (Lock et al., 2017; Nieto et al., 2019; Wainer & Ingersoll, 2012). These online programs have been implemented with parents of children who have anorexia nervosa (Locke et al., 2017), functional abdominal pain (Nieto et al., 2019), and ASD (Wainer & Ingersoll, 2012). A program using lectures, practice examples, videos, and quizzes to help parents and professionals address behavioral symptoms of children with ASD identified that users increased their knowledge of behavior strategies (Hamad et al., 2010). In a study of an asynchronous gaming platform, vulnerable parents were incentivized by the game to learn positive parenting skills by offering virtual rewards for practicing a variety of parenting and stress-reduction skills. The program was effective, with parents reporting lower stress after completion (Love et al., 2016). The success of these studies supports that online, self-guided therapies targeting mental health symptoms and stress management must be considered a viable option for vulnerable persons, including parents of children with I/DD.

A Novel Online Self-Guided Program to Reduce Stress in Parents of Children with Intellectual and Developmental Disabilities

The stress faced by parents of children with I/DD is well-documented and already considered an important target for intervention (Marquis et al., 2019). The COVID-19 pandemic has forced clinicians, therapists, and researchers of parents with I/DD to adapt quickly to virtual formats to safely address the increased parental stress. Online asynchronous delivery is an effective option for therapeutic stress management, with this modality overcoming barriers of scheduling, scaling, and cost. Here we introduce our program, ACT for Parents: an online self-guided program building ACT skills, specifically adapted for parents of children with I/DD. We first explain ACT principles, as these are core to the program and make it unique from online CBT. We then present evidence of the effectiveness of online ACT in similar populations. We briefly
describe our program, and we end with a call for collaboration.

ACT is a modern form of CBT that focuses on increasing psychological flexibility (i.e., engaging in meaningful patterns of activity while accepting whatever internal experiences arise) through a combination of acceptance, mindfulness, and values-based skills (Hayes et al., 2006). Psychological inflexibility, the opposite of psychological flexibility, is when behavior is rigidly controlled by cognition, emotions, and internal experiences, or when attempts to avoid these experiences result in less meaningful or ineffective behaviors (Hayes et al., 2006). ACT uses six core components to facilitate psychological flexibility: (1) acceptance, (2) cognitive defusion, (3) present moment awareness, (4) values, (5) self as context, and (6) committed action (Hayes et al., 2006). Acceptance and cognitive defusion emphasize decreasing the maladaptive behavior regulatory effects of internal experiences. Acceptance focuses on experiencing aversive internal experiences for what they are, rather than attempting to avoid them. Cognitive defusion involves relating to thoughts as “just thoughts,” rather than true facts. Other skills aim to shift clients’ sensitivity to meaningful parts of their environment by more flexibly attending to the present moment and developing a more flexible sense of self-as-context (i.e., a sense that self is not the rigid, evaluative self-narratives we create, nor a “container for experiences”). A third subset of skills focus on increasing meaningful, effective patterns of behavior through values (i.e., identifying what one wants their life to stand for) and committed action (i.e., developing patterns of activity linked to one’s personal values).

ACT is well-established and well-supported in robust empirical studies. A review of 20 meta-analyses, summarizing results from 133 Randomized Control Trials (RCTs) with 12,477 participants, found strong empirical support for ACT in treating a wide range of mental health concerns (Gloster et al., 2020). Specific to parents of children with I/DD, ACT has helped mothers of children with autism improve emotion regulation (Salimi et al., 2019). In a meta-analysis restricted to 24 studies of diverse caregiving roles, such as caregivers of individuals with dementia and children with disabilities (Han et al., 2020), ACT had small but significant effects on reducing anxiety, small-to-moderate effects on reducing stress, and moderate effects on reducing depression and improving quality of life.

**Online Acceptance and Commitment Therapy**

ACT has been adapted to online, self-guided delivery in a range of populations, demonstrating effectiveness in multiple RCTs. Levin et al.’s (2017) RCT found online-ACT to reduce depression and anxiety in college students. An RCT of a mobile app-based ACT program identified improved wellbeing and valued action in people seeking self-help, compared to a general population (Krafft et al., 2019). One meta-analysis of 10 RCTs identified that online ACT was effective in managing depressive symptoms (Brown et al., 2016); another meta-analysis of 17 RCTs supported effectiveness of online ACT for reducing depressive symptoms and anxiety (French et al., 2017).

Our own team at Utah State University recently developed and tested ACT for Caregivers—an online, self-guided ACT program for caregivers of people with dementia. Pre/post
follow-up analyses of 51 caregivers identified statistically significant improvements across all care-related outcomes: decreased depressive symptoms, care-related burden, and stress reactions to behavioral symptoms, and increased positive aspects of caregiving and quality of life. ACT-specific outcomes also improved, with decreased cognitive fusion and psychological inflexibility, and improvements in living according to personal values (Fauth et al., 2019, 2021). Population similarities are noted here. Like parents of children with I/DD, dementia caregivers face behavior symptoms and chronic stress from their family caregiving role and have limited ability to schedule and attend appointments.

Based on promising results from ACT for Caregivers and other ACT programs, we developed online ACT for Parents. This program is specifically tailored to build psychological flexibility, stress-management skills, and well-being within the context of parenting a child with I/DD, via 10 self-guided sessions of 20-30 minutes each. Each session focuses on one or more ACT concepts, building skills through practicing techniques, and applying concepts learned.

In developing ACT for Parents, we were purposeful in addressing limitations we have identified in many online programs. We note that many online programs are “text-heavy,” requiring users to spend considerable time reading about concepts, potentially contributing to skimming instead of internalizing the material, and general disengagement. Our modules use short-text formats—phrases, bullets, and graphic layouts that minimize visual fatigue. We also employ interactive exercises to reduce passive text reading. For example, rather than providing large blocks of text explaining a concept, we ask users to write in how the concept presents itself in their life. This interactive format is unique, providing multiple opportunities for participants to learn the important processes that increase psychological flexibility.

We also noted that some online resources are “watch and learn” or “read and learn,” with interaction only in the form of quizzes. We purposefully vary the content delivery, engaging the user in a variety of media, but avoiding quizzes. Users interface with material at multiple occasions in the module—allowing them to select options that resonate with their own challenges, and/or type in examples from their own life, which are carried through to examples later on. For example, in one activity participants actively engage with a metaphor titled, “passengers on the bus.” After reading the metaphor, participants select multiple options for how a bus driver could respond to unruly passengers and what the outcomes might be for each response, thus informing the concept of cognitive defusion. In another defusion activity, participants type a thought that “hooks” them. They then use the software interface to change the size, color, and shape of the text to practice noticing “the thought is just a thought.” These activities provide variety for participants while encouraging active practice of ACT processes.

A Call for Collaboration: Online Service Delivery and Program Evaluation

ACT for Parents was developed before and during the COVID-19 pandemic, and we seek collaborators to provide this program to their networks of parents with I/DD. We have developed the program with the Center for Persons with Disabilities at Utah State University, who have content experts in parents of children with I/DD, and mental health and therapy; however, we
would like to “beta test” this program with parents or other focus groups with lived and professional experience. We feel strongly that creating and adapting programs requires additional involvement of more individuals and professionals with the lived experience. In line with this, we have worked to create relationships with parent groups throughout the rural west and plan to collaborate with these groups to compete for future funding opportunities while also working with these respective groups to find more effective ways to disseminate information through their established networks.

We also foresee opportunities for collaborative funding development. If a network or provider wants to seek external funding for their program and thinks ACT for Parents might enhance their portfolio of service options/modalities, we could include this program, assisting with grant preparation, and building in program evaluation components that could empirically examine the translation of this program into this population. We also seek further development of the program, specifically for individuals living with I/DD, to address their own mental health needs; collaborations for further modifications in this regard would be impactful. Importantly, we emphasize that this program is not “for sale”; it was developed in a clinical academic setting for clinical and research applications, and not developed for private, for-profit purposes. Our goal is to present this program as a novel, empirically based option, with opportunities for collaboration with networks and providers serving this population who are likely seeking “already developed” programs suitable for the COVID-19 environment. This approach could lead through future collaborations with the Association of University Centers on Disability through educational or awareness campaigns, as it is likely that the program is unknown and, in our experience, dissemination largely depends upon healthy and active relationships to spread information across silos.

Conclusion

In general, the mental health and disability fields often function “in silos,” creating and adapting services for clients independently— with overlap, but without collaboration. Parents of children with I/DD are at the intersection of these fields—under chronic stress from their role, and more recently facing additional context-specific stress from the pandemic. Now more than ever, this population needs empirically supported telehealth options that embed mental health supportive services within the I/DD context, and which overcome barriers of social distancing, scheduling, scalability, and cost. Our program offers an extension of existing I/DD parent stress programs and of traditional ACT programs from other populations, teaching ACT skills in a fully online asynchronous interactive platform. To our knowledge, ACT for Parents is the first program to offer this. Being newly developed, we seek collaborators for understanding the program through the lived experience of users and providers. We also seek for networks or providers for scalable service delivery to foster program evaluation and sustainable funding. Through online, self-guided, and empirically validated programs, including but not limited to ACT for Parents, both the mental health and disabilities fields can offer support to parents of children with I/DD, in this unique COVID-19 pandemic, and in the future.
References


Hamad, C. D., Serna, R. W., Morrison, L., & Fleming, R. (2010). Extending the reach of early intervention training for practitioners: A preliminary investigation of an online curriculum for teaching behavioral intervention knowledge in autism to families and service providers. *Infants and Young Children, 23*, 195–208. [https://doi.org/10.1097/IYC.0b013e3181e32d5e](https://doi.org/10.1097/IYC.0b013e3181e32d5e)


