

Enhancing Access to ABA for Rural, Remote, and Underserved Families

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Background

Traditionally, core clinical autism services for children have been provided in-person. Yet, in rural and remote communities across Ontario, access to vital core clinical autism services can present enormous challenges for families. There is a notable shortage of service providers outside larger population centres and families often face lengthy waitlists for in-person services along with long, costly, and disruptive travel when a provider becomes available. The sudden shift to virtual services during the pandemic has opened minds to the potential for virtual options to dismantle longstanding barriers to service, and research into the effectiveness of telehealth continues to expand.

Before the COVID-19 pandemic forced ABA practitioners to reconsider service delivery options to avoid disruption to critical services for people with autism, research illustrating the benefits of telehealth as an alternative to in-person services had already begun (see, for example, Peterson et al., 2017). The primary motivation behind this earlier research was to improve access to service, particularly for those with limited resources in their own communities. At Kinark, as many as 40% of our client families have told us that they face significant challenges accessing autism services for reasons related to geography, transportation, and childcare. Virtual services offer flexibility and can help families overcome these barriers and participate in programs in ways that better meet their needs and preferences (Nohelty et al., 2021). As research continues to support the effectiveness of virtual ABA for children with autism, and service providers embrace the potential of telehealth platforms, families in underserved communities across the province will have opportunities to access crucial therapies that were previously limited to those living in or near urban centres.

Family Experience in Ontario

Creating an optimal therapeutic setting is challenging given the diverse and individualized needs of each child with ASD. Families have told us they encounter barriers like transportation, childcare, wait times, and expenses for in-person therapy; they also grapple with challenges often overlooked by the literature and by practitioners, such as sensory sensitivities, disruptions to routines, and difficulties with transitions – factors inherent to participation in clinical and in-person settings. Moreover, the learning environment offered by traditional in-person therapy does not resemble the day-to-day lives of children and families. Families may feel they are expected to replicate the clinic environment in their homes for treatment to be successful – without the materials used by therapists and with the constant disruptions that are present in their everyday lives. These differing environments pose challenges for the generalization of skills and, for many families, incorporating and accommodating the distractions present in the home environment, which can be more easily done when using telehealth service options, would create a more realistic and supportive treatment environment. Fostering equitable healthcare means the responsibility lies with the service provider to tailor their services, utilize tools and resources available to the family, and acknowledge the unique circumstances of each household.



Virtual services can be used in ways that offer sensitivity and respect for the entire family in home-based care, adapting to the realities of the family's daily living and eliminating the need to have service providers – who might change frequently – in the family home. In the context of virtual services, the home environment is transformed into an extension of the clinical setting. Drawing a parallel with the shift to online learning platforms during COVID-19, where the computer became the child's school space while the rest of the home retained its privacy, virtual ABA offers a similar dynamic. While not ideal for everyone, it can offer more privacy for the family and reduce stress while facilitating effective and respectful therapeutic engagement.

Our Purpose

At Kinark, it is our mission to help children and youth with complex needs achieve better life outcomes. We strive to provide inclusive services that respond to the diverse needs of the children and youth living in our province. The enormous challenges families face when trying to access essential autism services, combined with mounting evidence on the effectiveness of virtual ABA, underscore an urgency for innovative and collaborative approaches to service delivery across the province.

We believe that autism service providers have an obligation to adapt their service offerings and invest in technologies that can enhance access to ABA and other core clinical services for families. Many thousands of families across Ontario experience lengthy gaps in service as they sit on waitlists and struggle to find providers close to home. The expansion of our virtual services is a necessary next step to ensure we continue to meet the needs of families in rural and remote communities, as well as those who struggle to find providers close to home or simply prefer to receive services virtually.

The Evidence

In a recent synthesis of research focusing on the efficacy of virtual ABA therapy during the COVID-19 pandemic, Li (2023) summarized three virtual service delivery models that vary depending on the symptoms and support needs of the child participant. The first approach provides training directly to the caregiver and supports them with implementing the intervention. This caregiver training model is suited to children with more severe levels of ASD and those who don't yet have the skills needed to participate independently. This approach is not new and has substantial empirical support: in a systematic review of 28 studies of telehealth and ABA, Ferguson et al. (2019) concluded that using telehealth technology to train caregivers in the delivery of ABA-based interventions is feasible and yields positive results. Research has demonstrated that virtual caregiver training can effectively be used to increase caregiver knowledge and implementation of skills, achieve improvements in child social communication skills and imitation, and reduce problem behaviours (see also Meadan and Daczewitz, 2014; Parsons et al., 2017).

Direct delivery models are more recent and emerged widely during the pandemic to support continuity of service. These approaches provide virtual ABA directly to the child, with or without caregiver involvement. The child might participate independently, or a caregiver is present to assist with techniques like prompting, reinforcement, and redirection to help the child attend to the clinician. Research has shown that when ABA is delivered via direct therapy, children with autism acquire their target skills to mastery and maintain the skills after treatment (Knopp et al., 2022; Nohelty et al., 2021). These results are observed across a range of skills (e.g., social, language, adaptive) and among clients with varying ASD severity levels (Li, 2023).

Caregiver involvement during virtual ABA therapy offers several advantages. Virtual models enhance transparency in treatment, which allows caregivers to observe skill acquisition and behaviour management strategies that they can apply in their home environment (Nohelty et al., 2021). For



children who require more support, caregivers are trained to implement ABA-based interventions; studies suggest that caregivers are able to implement strategies with up to 95% accuracy, while children experience improvement on 85% of their target skills and behavioural goals (Li, 2023). Generalization of skills to family members in the home setting is also evident. Nohelty et al. (2021), for example, reported an 89% success rate in the generalization of skills to family members, which may be attributed to children participating in service in their home environment.

Though research into the efficacy of direct service delivery models is new and emerging, evidence suggests that, overall, virtual ABA yields positive outcomes for children and caregivers and offers a promising alternative to in-person services. The gaps in research related to the benefits of virtual ABA become more apparent when families share their lived experiences. Virtual ABA can help families access services that are otherwise unavailable to them. They can benefit families facing transportation and childcare barriers, reduce or eliminate the difficulties associated with in-person visits for children with ASD, and allow for teaching and skill acquisition in a natural environment that is comfortable for the child and the family. The flexible nature of virtual services provides a comprehensive range of modalities that can allow families to interact at their convenience and enable them to navigate the balancing act of family life more effectively.

Limitations and other considerations

When considering virtual services, assessment, consultation and planning with the family and provider is necessary to determine which interventions can be realistically implemented through a virtual platform, as well as which skills can be effectively targeted. Specific domains, such as play skills, may be challenging to target virtually, and the appropriateness of the targeted skills for the virtual environment must be considered (e.g., toileting, dressing, bathing). Access to technology devices, connectivity, privacy, and the family's comfort and proficiency with technology must also be taken into account when deciding whether virtual ABA is a suitable option. Considerations of how to deliver virtual ABA have been published by the <u>Ontario Association for Behaviour Analysists</u> (2021) and <u>The Council of Autism</u> Service Providers offer practice parameters for the delivery of virtual ABA services.

When deciding the modality of service, research suggests that virtual ABA should be included as an option for families who don't have access to in-person services, as well as for those who prefer to receive treatment in their home. Virtual ABA is likely not a solution for every child or every family; however, it offers a viable alternative for the many families who face access barriers to in person services.

This research review was produced by Kinark's Research and Evaluation team in consultation with Kinark's Autism Services Program.

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For questions on this research review, please contact communications@kinark.on.ca



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