



Developing Workforce Skills and Capacity in Telehealth: What LEND Trainees Need to Know

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Abstract

Introduction The COVID-19 pandemic significantly impacted the way health-related services are delivered, rapidly shifting from in-person to telehealth visits. To ensure that future healthcare providers are fully prepared to deliver services to families of youth with neurodevelopmental disabilities (NDD), understanding telehealth's advantages and barriers is vital. To this end, data were gathered to inform the development of a nationally available telehealth curriculum aimed at training future healthcare professionals from the Leadership Education in Neurodevelopmental Disabilities (LEND) network.

Methods Surveys were sent out nationally to current LEND trainees, practicing healthcare professionals, and family members of youth with NDD in November of 2020. Multiple choice and free response questions were completed and analyzed. A total of N=208 surveys were completed (88 LEND trainees, 94 practicing professionals, 23 family members).

Results Most survey respondents reported having positive experiences with telehealth. LEND trainees and current healthcare professionals cited increased access to care and engagement as the top benefit of telehealth. Most family members reported using telehealth services (78%) and felt it was superior to in-person visits in terms of location of visit, scheduling, and meeting transportation needs. Trainees and professionals agreed the top barriers to telehealth for families were lack of broadband access and complexity of implementation and use. LEND trainees agreed telehealth basics should be included in LEND curriculum.

Discussion Trainees, professionals, and family members all agreed that knowing the basics of telehealth is essential for effective telehealth service delivery. Emerging healthcare professionals need to understand how those they will be serving engage with technology, their levels of experience in this area, and effective strategies for engaging children and youth with NDD through telehealth. This will bridge the engagement gap many families of children with disabilities face when not meeting in person. Findings from this study contributed to the design of learning materials that currently support LEND trainees across the country in developing these skills.

Significance

What is already known? The COVID-19 pandemic forced the increased use of telehealth to deliver essential healthcare services. Families of children and adolescents with disabilities typically have an elevated need for services and little is known about their telehealth experiences.

What does this study add? The current study reports on the telehealth experiences of healthcare professionals and families of children and adolescents with disabilities to inform the training of future healthcare professionals.

Keywords Telehealth · Neurodevelopmental Disabilities · LEND

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Introduction

As the COVID-19 pandemic reached the U.S. in spring 2020, providers of healthcare and education services abruptly shifted from in-person to distance delivery models. Though the technology to virtually deliver care had existed for decades, most healthcare organizations and professionals had limited telehealth experience prior to the pandemic (Shaver, 2022; Weiner et al., 2021). There is a robust body of literature supporting the benefits of telehealth to deliver health-related services. Documented benefits include cost-savings, decreased wait times, and wider access to care (Gagnon et al., 2006; Gilbert et al., 2020; National Advisory Group, 2021; Wasch & Dicker, 2019; Zhou & Parmanto, 2019). However, there is limited research examining telehealth use by healthcare practitioners serving individuals with neurodevelopmental and related disabilities (NDD). Moreover, existing literature has not adequately included input from family members of children with NDD (Lerman et al., 2020; Pellegrino & DiGennaro Reed, 2020; Simacek et al., 2017; Tsami et al., 2019; Wainer & Ingersoll, 2014).

A lack of consistency in the inclusion of telehealth information within healthcare professional training has also been highlighted (Chike-Harris et al., 2020; Serwe et al., 2020). This gap highlights the need to include family perspectives in teaching healthcare professionals about the benefits and pitfalls of telehealth use in patient care (Hah & Goldin, 2019; Verma et al., 2019).

The Health Resources and Services Administration (HRSA) funded the American Academy of Pediatrics (AAP) to develop strategies for future providers to support families to use telehealth effectively. The AAP asked the Association of University Centers on Disability (AUCD) to create a telehealth learning module for the larger National Neurodevelopmental Disabilities (NDD) curriculum. The NDD curriculum is used by Leadership Education in Neurodevelopmental Disabilities (LEND) programs (interdisciplinary graduate level training) across the country to train future healthcare professionals. The purpose of this study was to identify telehealth benefits and barriers experienced by professionals and families of youth with NDD to inform the telehealth curriculum.

Methods

Participants

The primary goal of this work is to better understand the telehealth experiences of families of children with NDD to inform the design of national telehealth curriculum for

healthcare providers. Feedback was gathered from the following stakeholders:

- Family members of individuals with NDD ages 0–26 years.
- Current healthcare providers of services to pediatric patients.
- Trainees from LEND programs across the U.S.

Survey Design

Three surveys were developed by the project team to elicit feedback from each stakeholder group. Items were purposefully written to gather information relevant to the telehealth curriculum design process. Survey length ranged from 14 to 16 items. Most survey items were written in *multiple choice/select all that apply* format. Each survey also included 2–3 free-response questions. All groups were asked about the benefits and barriers to telehealth that families of youth with NDD have experienced.

Demographic information was requested but no personally identifiable information was collected. Prior to data collection, the study was approved for exemption by the University Institutional Review Board (IRB).

Survey Dissemination

Surveys were available over a four-week period in November 2020. Snowball sampling was used to recruit participants from across the country. Michigan LEND (MI-LEND) program faculty distributed survey links by email to colleagues and professional groups in their networks. Current and former LEND trainees were recruited through the national LEND trainee listserv. This listserv, maintained by AUCD, reaches hundreds of current and former LEND trainees.

Family members were recruited through the Michigan Developmental Disabilities Institute's (MI-DDI) eNewsletter subscriber list (approximately 1,100 recipients), social media platforms, website, and statewide disability partner organizations. Microsoft WORD and paper versions of surveys and assistance from project staff were made available. No accommodation requests were received.

Data Analysis

Descriptive data analyses were conducted (frequency distributions and means). Free response themes were independently coded by two members of the research team. Team members then met to resolve incongruencies and agree upon final themes that best represented responses.

Results

LEND Trainees

Eighty-eight (n=88) LEND trainees participated in the study. Participants came from 29 LEND programs across the U.S. and represented 25 disciplines. They were asked to indicate the types of services they've provided. Twenty-eight trainees (32%) indicated that they had not provided telehealth services. Likely reasons for this include being a family member/self-advocate who didn't provide health services or that they were still enrolled in their graduate programs. Trainees (n=60) who provided telehealth services completed the remaining survey items.

All trainees (100%) indicated that they were at least slightly familiar with telehealth and most (69%) were very or extremely familiar with it. Sixty-eight percent (68%) reported they had personally used telehealth to provide services to individuals with NDD. Most (58%) trainees indicated they used it in their practice most days with only 2% stating they rarely used telehealth.

When asked to select the types of telehealth services they had engaged in, trainees chose:

- Assessment/diagnoses (48%).
- Therapy (speech, OT, PT) (26%).
- Counseling (22%).
- Mental/behavioral health (17%).
- Medication management (10%).

When given a list of how they *most commonly used* telehealth, trainees selected:

- Direct services to clients (78%),
- Professional-to-professional consultation (70%).
- Patient follow-ups (63%).
- Education (57%).
- Intake, triage, and assessments (48%).

The most common benefits of using telehealth selected by LEND trainees included improved or increased:

- Access to care (for patients) (77%).
- Patient engagement (45%).
- Interdisciplinary collaboration (33%).
- On-demand options (28%).
- Healthcare/service delivery (27%).
- Clinical workflows/increased efficiency (25%).

Most trainees (63%) reported being satisfied/very satisfied with using telehealth to treat individuals with NDD and

67% said they were likely/very likely to use telehealth in their practice beyond the COVID-19 pandemic.

The most common telehealth barriers for patients selected were:

- Lack of access to broadband internet (57%).
- Complexity of implementation and use (55%).
- Patients lacking necessary technical skills (35%).
- Inadequate reimbursement (insurance) (23%).
- Reduced continuity of care (18%).

Trainees were asked “*What do you think every LEND Trainee needs to know about telehealth in order to improve the health and welfare of children and adolescents with ASD, NDD and other special healthcare needs?*” Representative comments for each emerging theme are listed below:

- “I think it is important for LEND trainees to understand the benefits and limitations of telehealth.” (*Telehealth Basics*).
- “Not all patients will have access to the resources, health literacy, or wi-fi to access telehealth without support. Additionally, you must use appropriate platforms for privacy, and know how to bill.” (*How to Adapt to Practice to Telehealth Setting*).
- “Communication via telehealth is not always the same as in-person.”; “Thinking creatively about how to engage children with NDD on telehealth is pertinent.” (*Communication/Engagement Strategies*).
- “Trainees will not only need to understand the impact of telehealth on disparities and health equity, but they will also need to be provided with clear examples of how telehealth appointments have and have not been successful.” (*Equity and Access*).
- “Telehealth has huge pro’s and con’s. For some families this is a much better fit and for others it’s a much worse fit.” (*Family/Patient Centered*).

Trainees were asked what they thought was missing from the current LEND NDD curriculum regarding telehealth. Sixty percent (60%) indicated that educating LEND trainees on the basics of telehealth use with families of youth with was most important. Providing trainees with concrete examples and strategies for effective telehealth implementation was key.

Healthcare Professionals

Ninety-four (n=94) practicing healthcare professionals participated in the study. All but one (99%) were from Michigan. Respondents reported using telehealth to provide mental/behavioral health services (81%), assessment/

diagnosis (77%), counseling (59%), medication management (59%), and therapy (speech, OT, PT) (44%). They indicated that they used telehealth for direct services to clients (89%), professional-to-professional consultation (62%), and patient intake, triage, and assessments (60%).

Most healthcare professionals (90%) reported having used telehealth to provide services for individuals with NDD. The majority (67%) used telehealth in their practice most days and were largely (77%) satisfied/very satisfied with using telehealth with individuals with NDD and their families.

When asked about the direct benefits of telehealth, 90% indicated being able to see patients without risking exposure to COVID-19 was important. Patient engagement (67%) and patient access to care (55%) were highlighted. Improvement in communication and engagement stands in opposition to 18% of LEND trainees reporting disruptions in continuity of care. This disparity in experiences may be due to LEND trainees being new to practice. Established healthcare professionals have more experience in patient tracking and follow-up which may explain this difference.

Barriers to telehealth identified by practicing professionals included:

- Lack of access to broadband internet (61%).
- Complexity of implementation (35%).
- Lack of skills to assess patients virtually (33%).

Despite these difficulties, most healthcare professionals (67%) reported that it was likely/very likely they would continue to use telehealth in their practice beyond the COVID-19 pandemic.

Practicing professionals were asked to select the topics they felt were most important to cover in future telehealth curricula. The impact of telehealth on disparities and health equity (30%) was the top choice. Telehealth privacy and security (16%) and choosing a telehealth delivery platform (12%) were also seen as important topics to consider.

Two free response questions were asked (“*What do you think healthcare professionals need to know to improve telehealth visits?*”; “*What do you think patients/families need to know about telehealth to make visits a better experience for them?*”). The top theme to emerge was being proactive in addressing the technological needs of patients. Acknowledging that many families do not have regular access to internet services is important. Professionals suggested offering direct coaching and support to families/patients to prepare them for telehealth appointments.

Families of Children with NDD Ages 0 to 26

Twenty-three (n=23) parents of children with NDD completed surveys. Most children were male (70%) and White (87%) with a mean age of 16.9 (± 5.4) years. The most common disability reported was Autism (61%). Intellectual (44%) and ‘other’ disabilities (30%) were also reported.

The majority (78%) of caregivers reported having had telehealth visits for their children. Sixteen (16) family members answered the question comparing their telehealth visits during the pandemic to in-person visits pre-pandemic. They identified three areas where telehealth improved their experiences:

- Location of the appointment (94%).
- Time involved (75%).
- Transportation (62%).

Other aspects of their appointments remained the same, such as costs (71%), quality of care (62%), and privacy (56%). Overall, 78% of parents reported being satisfied/very satisfied with using telehealth. Only one family reported being dissatisfied with their experience. Reported challenges included:

- Telehealth visits not being as personal (28%).
- Patients not having good internet/phone connection (22%).
- Not having the right equipment to connect (11%).

Those reporting internet or technology issues lived in urban areas of southeast Michigan, with no respondents from rural locations identifying internet access issues.

When asked how they prefer to meet with health professionals, all family respondents indicated meeting in-person was preferred. Despite this preference, meeting by video/telehealth was still rated highly. Most families (70%) said they would be likely/very likely to start or continue telehealth visits for their child if given the option.

Families were asked a free-response question regarding what their health professionals should know to make telehealth visits better for their child. Responses included:

- “*Doctor must talk in simple terms and be patient when waiting for an answer to a question.*”
- “*Our physician was on time and that was very important for the future.*”
- “*Doctor’s face should be on screen (at all times).*”
- “*Prior form to fill out regarding concerns or issues.*”

Discussion

This study was completed in November 2020, approximately six months after many in-person services for children with NDD were canceled due to the pandemic. Most survey respondents reported having had experiences with telehealth, with those experiences being largely positive. LEND trainees and healthcare professionals cited increased access to care and engagement as the top benefit of using telehealth to provide services to families of youth with NDD. These findings are consistent with current telehealth research, with improved access, participation, and monitoring of patients with NDD being highlighted (Aldharman et al., 2023; Hosley, 2022; Valentine et al., 2021).

Trainees and professionals agreed on the top barriers to telehealth for these families – lack of broadband access and complexity of implementation and use. These barriers echo other findings (Hosley, 2022; Keder et al., 2022; Valentine et al., 2021) that have cited implementation issues including failing technology, problems with audio and visual feeds, and difficulties in terms of eye contact.

Most family members reported having used telehealth services (78%) with the majority stating telehealth was better than in-person visits in terms of location of visit, time needed to prepare/attend, and transportation needs which is consistent with recently published studies (Hosley, 2022; Valentine et al., 2021).

Trainees, professionals, and family members all agreed that knowing the basics of telehealth (i.e., what it is, types, which healthcare services can be provided, how to book an appointment, how to connect) is essential for effective telehealth service delivery. This speaks to the need to include telehealth information in curricula aimed at training future healthcare professionals. Emerging healthcare professionals will need to understand how their future patients/families access and engage with technology and their levels of experience in this arena. A key to developing this skillset is the ability to take on the perspective of families. Overcoming technological barriers is only the start. Understanding health disparities and learning effective strategies for engaging children and youth with NDD through telehealth will bridge the engagement gap many families of children with disabilities face when not meeting with practitioners in-person. The findings from this study contributed to the design of learning materials that currently support LEND trainees across the country in developing these skills.

The study did have limitations. The use of snowball sampling to reach healthcare professionals and family members led to most respondents being in Michigan. This limits the generalizability of the findings. A broader, more nationally representative sample would provide a greater diversity of experiences and points of view. Another limitation

is that the average age of children/youth with NDD was 16.9 years, 87% were white, and most were diagnosed with autism (61%). This suggests that the findings may not be generalizable beyond the characteristics of our sample. The experiences of those with other neurodevelopmental disabilities and personal characteristics would provide a better view into the telehealth experiences of diverse families and youth.

Despite limitations, these findings add to our understanding of the telehealth experiences of current healthcare professionals and families of youth with NDD. Teaching the basics of telehealth and how to effectively engage families of youth with disabilities should be included in all curricula aimed at preparing future healthcare professionals. Systems of care have changed in response to COVID-19 and emerging leaders need to be prepared to work effectively in the digital world (Valentine et al., 2021).

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Data Availability Data and material can be requested of the lead author.

Code Availability Not applicable.

Declarations

Conflict of interest The authors report no conflicts of interest.

Ethics Approval Prior to data collection, the study was approved for Exemption by the Wayne State University Institutional Review Board (IRB).

Consent to Participate All participants consented to be part of the study.

Consent for Publication Not applicable.

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