



Topic Brief: Telehealth for Children with Neurodevelopmental Disabilities

Date: 1/05/2024

Nomination Number: 1005

Purpose: This document summarizes the information addressing a nomination submitted on June 3, 2022, ([link to nomination](#)) through the Effective Health Care Website. This information was used to inform the Evidence-based Practice Center (EPC) Program decisions about whether to produce an evidence report on the topic, and if so, what type of evidence report would be most suitable.

Issue: The nominators represent an advocacy group, the Child Neurology Foundation, which works to bring attention to and facilitate the removal of barriers to healthcare access for children with neurological conditions in the United States. The provision of healthcare through telehealth may increase access and provide beneficial services to children with neurodevelopmental disabilities and their caregivers, however, this mode of healthcare delivery may not be an effective method of treatment delivery for all patients. Consequently, the nominators are requesting an evidence review to help determine the effectiveness of telehealth for children with neurodevelopmental disabilities (NDDs) and their caregivers.

Findings: The scope of this topic met all EHC Program selection criteria and was considered for a technical brief. However, it was not selected.

Background

Neurodevelopmental disorders (NDD) are wide ranging and include cognitive disabilities, metabolic and genetic conditions, common nervous system disabilities, nerve and muscle disorders, prematurity effects, social deprivation, in utero exposure, and behavioral disorders.¹ While pediatric NDDs have rarely been assessed as a single entity, a recent systematic review of 17 articles reported the prevalence rates of NDDs to be 0.63% for intellectual disability, 5-11% for attention deficit/hyperactivity disorder (ADHD), 0.70-3% for autism spectrum disorder (ASD), 3-10% for specific learning disorder (SLD), and 1-3.42% for communication disorders.² In 2013, the costs of caring for individuals with autism spectrum disorder in the United States were estimated at \$137 billion, and the lifetime costs per individual ranged from \$1.4 million without co-occurring intellectual disability to \$2.4 million with co-occurring intellectual disability.³

Individuals with a NDD may require special needs from their health care services as they often face higher rates of psychiatric morbidity and have varying communication disabilities and preferences.⁴ Further, these disorders often require life-long management and multiple services.⁵ One study showed that adolescents and young adults with complex, childhood conditions use greater clinical resources, medical technology, and specialists compared to adult primary care

practices.⁶ There is also evidence that individuals with intellectual and developmental disabilities who are transitioning from pediatric to adult care have distinctly different needs for health care transition planning when compared to typically developing individuals.⁷ Another study that administered a questionnaire to general practitioners found that health care providers perceived greater burden from patients with learning disabilities.⁸ In providing care for the pediatric NDD population, parents may also require special training and support.⁹ Additionally, families with children who have a neurodevelopmental disorder may experience increased stress, financial insecurity, and other challenges.¹⁰⁻¹³ There has been a recent shift in the conceptualization of childhood disability, where the family context and impacts are of increasing interest in clinical care.¹⁴ Delivery of health care and treatment for NDDs thus need to be compatible with both the unique needs of the family and the child, presenting more nuanced care for this population.

Telehealth, or telemedicine, is the provision of healthcare to patients without an in-person office visit, such as by computer, smartphone, or telephone.¹⁵ While the wait time to see a neurologist for children with neurologic conditions averaged 9 weeks,¹⁶ the increased usage of telehealth during the COVID-19 pandemic dramatically reduced the wait time for patients. As indicated below, there is some evidence that telehealth may improve access to care and tele-interventions have demonstrated efficacy for improving symptoms of children with NDDs. However, given the special needs of this population, the effectiveness of the telehealth modality for children with neurologic conditions has yet to be fully established. The nominators are interested in an evidence review assessing the advantages and disadvantages of the telehealth modality for children with neurodevelopmental disorders to inform clinical practice with this population.

Scope

What are the (a) advantages and (b) disadvantages of telehealth interventions for children with neurodevelopmental disabilities?

Table 1. Question and PICO (population, intervention, comparator, and outcome)

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| Population | Children aged <21 years with an established neurodevelopmental disability and their caregivers. Subgroups: <ul style="list-style-type: none"> • Neurodevelopmental condition (examples below): <ul style="list-style-type: none"> ○ Severely physically limiting (cerebral palsy; spina bifida; acquired brain injury; degenerative or traumatic neurological disorders; genetic disorders such as Rett syndrome) ○ Mild-moderately physically limiting (vision, hearing, or speaking impairments; epilepsy; dyspraxia) ○ Cognitively limiting (intellectual and learning disabilities [mild, moderate, severe]; Down syndrome; Fetal Alcohol Syndrome) ○ Behavioral (ADHD, ASD) • Age of patient • SES • Gender/sex • Patient geographical location (e.g., urban vs. rural, state licensure issues) |
| Interventions | Telehealth using remote synchronous interventions (real-time visits such as video calls) with a health care provider for clinical management encounters (e.g., telehealth appointments) Exclude: diagnostic appointments |
| Comparators | In-person clinical encounter with a health care provider; no comparator or no care |
| Outcomes | Patient: clinical outcomes, patient compliance with telehealth treatment pathways, patient satisfaction, patient-reported telehealth uptake/continued use |

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| | <p>Caregiver: caregiver satisfaction, caregiver burden, caregiver self-efficacy, caregiver-reported telehealth updated/continued use</p> <p>Disadvantages: harms (any), training requirements (caregiver and provider), increased out-of-pocket costs (e.g., equipment for at-home physical therapy), insurance and provider-licensure barriers</p> |
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Abbreviations: ADHD=attention-deficit/hyperactivity disorder; ASD=autism spectrum disorder; SES=socioeconomic status.

Notes on inclusion and exclusion for this preliminary prioritization brief:

- The telehealth intervention should be restricted to remote synchronous interventions (video and telephone appointments) representing routine care from a health care provider for treatment or clinical management. Much of the published literature on pediatric telehealth for NDDs focuses on piloting novel, virtual interventions. These studies would not be eligible for evidence synthesis on the proposed topic as they do not represent routine care via the telehealth modality.
- Diagnostic appointments should be excluded to ensure that the target population is children and adolescents with a confirmed NDD.
 - This inclusion criteria may present a challenge in screening the literature as differentiating between diagnosis and assessment may require technical expert guidance and full text review. Routine treatment of some NDDs involves frequent assessment to ascertain treatment response and new directions.

Assessment Methods

See Appendix A.

Summary of Literature Findings

To address the advantages and disadvantages of the telehealth modality for children with neurodevelopmental disabilities, we searched 7 databases for systematic reviews, meta-analyses, primary literature, clinical trial registries, and systematic review protocols published between January 2018 and December 2023. We identified 22 systematic reviews, meta-analyses, and/or literature reviews and 11 review protocols that met the inclusion criteria described above in Table 1. Despite this, a new comprehensive review would not be duplicative, as the identified evidence syntheses report on the efficacy of pilot interventions using telehealth, only one NDD, or only one type of treatment or specific NDD. Further, most of the studies included in these systematic reviews were published more than five years ago, indicating that the available reviews may not report on the most updated evidence. While these reviews may be useful within the overall body of literature addressing the advantages and disadvantages of telehealth for children with NDDs, these reviews do not adequately report on the delivery of the telehealth modality for this population. Additionally, after review of 77 systematic review protocols, none will adequately address the main concerns of the nominator as they feature a population, intervention, and/or outcomes that are too narrow in scope. As such, a new systematic review on the advantages and disadvantages of routine care telehealth appointments for children with NDDs would shape virtual clinical care for a vulnerable population and be of great use to the Child Neurology Organization.

Across a five-year literature search for primary research and clinical trials (n=527), we identified 46 primary research studies and 11 clinical trial registries that met inclusion criteria. Many of these studies are retrospective analyses of data from telehealth appointments during the COVID-19 pandemic and show lessons learned that may be implemented into current care for children with NDDs. Other included studies assess the efficacy of routinely implemented treatment via

telehealth. It is also worth noting that a substantial number of these studies examine parent-facing or parent-mediated telehealth interventions for children with ASD (n=22). While these studies are informative, there may be an evidence gap in telehealth for parent-facing interventions for children with other NDDs.

If a systematic review on the advantages and disadvantages of the use of telehealth for families and children with NDDs were to be conducted, we estimate the review size would be large. Our literature search on this topic yielded many studies that focus on novel virtual, remote, or technology-based interventions, which were excluded as they do not represent routine care. Studies that evaluate the feasibility, acceptability, and efficacy of implementing the telehealth modality into routine care for this special population will be most relevant the nominators and other clinicians. A review of these studies has the potential to shape clinical and virtual care for children with NDDs.

Table 2. Systematic reviews, primary literature, and clinical trials, by key question.

| Question | Systematic Reviews (January 2020 – December 2023) | Primary Research (January 2018 – December 2023) |
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| KQ 1a: Advantages | <p>Completed Reviews</p> <ul style="list-style-type: none"> • Mild Physically Limiting Disorders: 4 ¹⁷⁻²⁰ • Severely Physically Limiting Disorders: 1 ¹⁷ • Cognitively Limiting Disorders: 1 ²¹ • Behavioral Disorders: 16 ²¹⁻³⁶ • Mixed Disorders: 11 ³⁷⁻⁴⁷ <p>Ongoing Reviews</p> <ul style="list-style-type: none"> • Mild Physically Limiting Disorders: 1 ⁴⁸ • Severely Physically Limiting Disorders: 0 • Cognitively Limiting Disorders: 0 • Behavioral Disorders: 1 ⁴⁹ • Mixed Disorders: 0 | <p>Completed Studies</p> <ul style="list-style-type: none"> • Mild Physically Limiting Disorders: <ul style="list-style-type: none"> ○ <i>Observational Studies</i>: 3 ⁵⁰⁻⁵² ○ <i>RCTs</i>: 6 ⁵³⁻⁵⁸ • Severely Physically Limiting Disorders: <ul style="list-style-type: none"> ○ <i>Observational Studies</i>: 0 ○ <i>RCTs</i>: 1 ⁵⁹ • Cognitively Limiting Disorders: <ul style="list-style-type: none"> ○ <i>Observational Studies</i>: 2 ^{60, 61} ○ <i>RCTs</i>: 1 ⁶² • Behavioral Disorders: <ul style="list-style-type: none"> ○ <i>Observational Studies</i>: 9 ⁶³⁻⁷¹ ○ <i>RCTs</i>: 11 ⁷²⁻⁸² • Mixed Disorders <ul style="list-style-type: none"> ○ <i>Observational Studies</i>: 11 ^{50, 83-92} ○ <i>RCTs</i>: 0 <p>Ongoing Clinical Trials</p> <ul style="list-style-type: none"> • Mild Physically Limiting Disorders: 0 • Severely Physically Limiting Disorders: 2 ^{93, 94} • Cognitively Limiting Disorders: 1 ⁹⁵ • Behavioral Disorders: 9 ⁹⁶⁻¹⁰⁴ • Mixed Disorders: 0 |
| KQ 1b: Disadvantages | <p>Completed Reviews</p> <ul style="list-style-type: none"> • Mild Physically Limiting Disorders: 1 ¹⁸ • Severely Physically Limiting Disorders: 0 • Cognitively Limiting Disorders: 1 ²¹ • Behavioral Disorders: 3 ^{23, 24, 27} | <p>Completed Studies</p> <ul style="list-style-type: none"> • Mild Physically Limiting Disorders: <ul style="list-style-type: none"> ○ <i>Observational Studies</i>: 1 ⁵² ○ <i>RCTs</i>: 2 ^{53, 58} • Severely Physically Limiting Disorders: <ul style="list-style-type: none"> ○ <i>Observational Studies</i>: 0 ○ <i>RCTs</i>: 1 ⁵⁹ |

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| | <ul style="list-style-type: none"> Mixed Disorders: 2 ^{39, 41} <p>Ongoing Reviews</p> <ul style="list-style-type: none"> Mild Physically Limiting Disorders: 0 Severely Physically Limiting Disorders: 0 Cognitively Limiting Disorders: 0 Behavioral Disorders: 0 Mixed Disorders: 0 | <ul style="list-style-type: none"> Cognitively Limiting Disorders: <ul style="list-style-type: none"> Observational Studies: 0 RCTs: 1 ⁶² Behavioral Disorders: <ul style="list-style-type: none"> Observational Studies: 3 ^{69, 70, 105} RCTs: 7 ^{72, 73, 78, 79, 81, 82, 106} Mixed Disorders <ul style="list-style-type: none"> Observational Studies: 7 ^{84, 85, 88-90, 92, 107} RCTs: 0 <p>Ongoing Clinical Trials</p> <ul style="list-style-type: none"> Mild Physically Limiting Disorders: 0 Severely Physically Limiting Disorders: 0 Cognitively Limiting Disorders: 1 ⁹⁵ Behavioral Disorders: 1 ¹⁰¹ Mixed Disorders: 0 |
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Abbreviations: RCT=randomized controlled trial

See Appendix B for detailed assessments of all EPC selection criteria.

Summary of Selection Criteria Assessment

The provision of healthcare through telehealth may increase access and provide beneficial services to children with neurodevelopmental disabilities and their caregivers, but this mode of healthcare delivery may not be an effective way of delivering treatment for all patients. Consequently, the nominators are requesting an evidence review to help determine for which groups of children with neurodevelopmental disabilities and their caregivers is telehealth effective.

Please see Appendix B for detailed assessments of individual EPC Program selection criteria.

References

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101. Tele-assisted behavioral intervention for families with children with autism spectrum disorders. Tele-assisted behavioral intervention for families with children with autism spectrum disorders: a randomized control trial. 2020.
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Appendix A: Methods

We assessed nomination for priority for a systematic review or other AHRQ Effective Health Care report with a hierarchical process using established selection criteria. Assessment of each criteria determined the need to evaluate the next one. See Appendix B for detailed description of the criteria.

Appropriateness and Importance

We assessed the nomination for appropriateness and importance.

Desirability of New Review/Absence of Duplication

We searched for high-quality, completed or in-process evidence reviews published in the last three years (January 2020 - December 2023) on the questions of the nomination from these sources:

- AHRQ: Evidence reports and technology assessments
 - AHRQ Evidence Reports <https://www.ahrq.gov/research/findings/evidence-based-reports/index.html>
 - EHC Program <https://effectivehealthcare.ahrq.gov/>
 - US Preventive Services Task Force <https://www.uspreventiveservicestaskforce.org/>
 - AHRQ Technology Assessment Program <https://www.ahrq.gov/research/findings/ta/index.html>
- US Department of Veterans Affairs Products publications
 - Evidence Synthesis Program <https://www.hsrp.research.va.gov/publications/esp/>
 - VA/Department of Defense Evidence-Based Clinical Practice Guideline Program <https://www.healthquality.va.gov/>
- Cochrane Systematic Reviews <https://www.cochranelibrary.com/>
- University of York Centre for Reviews and Dissemination database <https://www.crd.york.ac.uk/CRDWeb/>
- PROSPERO Database (international prospective register of systematic reviews and protocols) <http://www.crd.york.ac.uk/prospéro/>
- PubMed <https://www.ncbi.nlm.nih.gov/pubmed/>
- Joanna Briggs Institute <http://joannabriggs.org/>

Impact of a New Evidence Review

The impact of a new evidence review was qualitatively assessed by analyzing the current standard of care, the existence of potential knowledge gaps, and practice variation. We considered whether it was possible for this review to influence the current state of practice through various dissemination pathways (practice recommendation, clinical guidelines, etc.).

Feasibility of New Evidence Review

We conducted a limited literature search in the AHRQ database, Cochrane Central Register of Controlled Trials (CCRCT), the PCORI database, PROSPERO, PubMed, PsycINFO, and clinicaltrials.gov for the last five years (January 1, 2018 -December 6, 2023). We assessed 704 citations for relevancy to the key question to estimate the size and scope of potential evidence review. We identified 22 systematic reviews, 46 published studies, 12 ongoing clinical trials, and 11 ongoing systematic reviews that address the advantages and disadvantages of telehealth for children with neurodevelopmental disabilities.

Search strategy

Ovid MEDLINE ALL 1946 to December 06, 2023

Date searched: December 7, 2023

1 exp Brain Injuries/ or exp Neurodevelopmental Disorders/ or anxiety, separation/ or "attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/ or exp Cerebrovascular Disorders/ or conduct disorder/ or sluggish cognitive tempo/ or child behavior disorders/ or child development disorders, pervasive/ or autism spectrum disorder/ or asperger syndrome/ or autistic disorder/ or communication disorders/ or childhood-onset fluency disorder/ or social communication disorder/ or speech sound disorder/ or developmental disabilities/ or intellectual disability/ or learning disabilities/ or dyscalculia/ or dyslexia/ or dyslexia, acquired/ or specific learning disorder/ or motor skills disorders/ or mutism/ or reactive attachment disorder/ or schizophrenia, childhood/ or stereotypic movement disorder/ or tic disorders/ or tourette syndrome/ or Rett Syndrome/ or Cerebral Palsy/ or intellectual disability/ or cri-du-chat syndrome/ or de lange syndrome/ or down syndrome/ or exp mental retardation, x-linked/ or rett syndrome/ or prader-willi syndrome/ or rubinstein-taybi syndrome/ or trisomy 13 syndrome/ or wagr syndrome/ or williams syndrome/ (777745)

2 (ADHD or ASD or asperger* or (("attention deficit" or "conduct disorder" or "child behavior*" or "child behaviour*" or "child development*" or "childhood disintegrative" or communication or fluency or "motor skills" or neurodevelop* or neuro-develop* or pervasive or "reactive attachment" or "sluggish cognitive tempo" or "speech sound" or "stereotypic movement" or tic) adj2 disorder*) or autism or autistic or ((brain or neuro*) adj5 (disorder* or injur*)) or "cerebral palsy" or "childhood schizophreni\$2" or (("cri-du-chat" or "de Lange" or Down\$2 or neurodevelop* or neuro-develop* or Prader-Willi or Rett\$2 or Rubinstein-Taybi or Tourette\$2 or "Trisomy 13" or Wagr\$2 or Williams\$1) adj syndrome) or ((developmental or intellectual or learning or neurodevelop* or neuro-develop*) adj2 disabilit*) or dyscalculi\$2 or dyslexi\$2 or "mental retardation" or mutism or "separation anxiety").ti,ab,kf. (549664)

3 (autism or autistic or brain or development or neuro*).jw. (1720560)

4 or/1-3 (2487896)

5 Remote Consultation/ or Telemedicine/ or Telerehabilitation/ or Videoconferencing/ (45059)

6 (distance or erehab* or "e-rehab*" or portal\$1 or remote\$2 or tele* or video* or Webex or Zoom).ti,kf. or ((distance or erehab* or "e-rehab*" or portal\$1 or remote\$2 or tele* or video* or Webex or Zoom) adj3 (appointment\$1 or coaching or conference\$1 or consult\$1 or consultation\$1 or intervention\$1 or management or meeting\$1 or psyc* or session\$1 or therap* or treat* or training or visit\$1)).ti,ab,kf. (247600)

7 tele*.jw. (7736)

8 or/5-7 (266448)

9 and/4,8 (18403)

10 9 not ((exp Animals/ not Humans/) or (animal model* or bitch\$2 or bovine or canine or capra or cat or cats or cattle or cow\$1 or dog\$1 or equine or ewe\$1 or feline or goat\$1 or hamster\$1 or horse\$1 or invertebrate\$1 or macaque\$1 or mare\$1 or mice or monkey\$1 or mouse or murine or nonhuman or non-human or ovine or pig or pigs or porcine or primate\$1 or rabbit\$1 or rat\$1 or rattus or rhesus or rodent* or sheep or simian or sow\$1 or vertebrate\$1 or zebrafish).ti. or (addiction or alzheimer\$1 or class or classroom\$1 or dementia or game\$1 or gamification or gaming or hockey or instruction or learning or problematic or questionnaire or survey or videofluoroscop* or videogame\$1).ti. or geriatric*.jw.) (14146)

11 10 and (Transition to Adult Care/ or (adolescen* or baby or babies or boy\$1 or child* or family or families or father\$1 or girl\$1 or infant\$1 or juvenile\$1 or kids or menarche or mother\$1 or neonat* or newborn\$1 or parent\$1 or paediatric* or pediatric* or preadolescen* or prepubescen* or preschool* or pre-school* or preteen* or puberty or pubescen* or school* or

teen* or toddler\$1 or transition* or young* or youth\$1).ti. or (adolescen* or child* or paediatric* or pediatric* or youth).jw.) (2346)
 12 limit 11 to english language (2268)
 13 limit 12 to yr="2020 -Current" (965)
 14 13 and ((meta-analysis or systematic review).pt. or (meta-anal* or metaanal* or ((evidence or review or scoping or systematic or umbrella) adj3 (review or synthesis))).ti.) (71)
 15 limit 12 to yr="2018 -Current" (1223)
 16 15 and ((controlled clinical trial or randomized controlled trial).pt. or (random* or trial*).ti,kf.) (176)
 17 16 not 14 (171)
 18 15 and (Cohort Studies/ or Comparative Study/ or Cross-Sectional Studies/ or exp Evaluation Studies as Topic/ or Follow-Up Studies/ or Longitudinal Studies/ or Prospective Studies/ or (cohort\$1 or ((comparative or evaluation) adj3 study) or cross-sectional or follow-up or longitudinal\$2 or prospective\$2).ti.) (228)
 19 18 not (14 or 16) (175)

Ovid EBM Reviews-Cochrane Central Register of Controlled Trials November 2023

Date searched: December 7, 2023

1 Brain Injuries/ or Neurodevelopmental Disorders/ or anxiety, separation/ or "attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/ or Cerebrovascular Disorders/ or conduct disorder/ or sluggish cognitive tempo/ or child behavior disorders/ or child development disorders, pervasive/ or autism spectrum disorder/ or asperger syndrome/ or autistic disorder/ or communication disorders/ or childhood-onset fluency disorder/ or social communication disorder/ or speech sound disorder/ or developmental disabilities/ or intellectual disability/ or learning disabilities/ or dyscalculia/ or dyslexia/ or dyslexia, acquired/ or specific learning disorder/ or motor skills disorders/ or mutism/ or reactive attachment disorder/ or schizophrenia, childhood/ or stereotypic movement disorder/ or tic disorders/ or tourette syndrome/ or Rett Syndrome/ or Cerebral Palsy/ or intellectual disability/ or cri-du-chat syndrome/ or de lange syndrome/ or down syndrome/ or mental retardation, x-linked/ or prader-willi syndrome/ or rubinstein-taybi syndrome/ or trisomy 13 syndrome/ or wagr syndrome/ or williams syndrome/ (16708)

2 (ADHD or ASD or asperger* or ("attention deficit" or "conduct disorder" or "child behavior*" or "child behaviour*" or "child development*" or "childhood disintegrative" or communication or fluency or "motor skills" or neurodevelop* or neuro-develop* or pervasive or "reactive attachment" or "sluggish cognitive tempo" or "speech sound" or "stereotypic movement" or tic) adj2 disorder*) or autism or autistic or ((brain or neuro*) adj5 (disorder* or injur*)) or "cerebral palsy" or "childhood schizophreni\$2" or (("cri-du-chat" or "de Lange" or Down\$2 or neurodevelop* or neuro-develop* or Prader-Willi or Rett\$2 or Rubinstein-Taybi or Tourette\$2 or "Trisomy 13" or Wagr\$2 or Williams\$1) adj syndrome) or ((developmental or intellectual or learning or neurodevelop* or neuro-develop*) adj2 disabilit*) or dyscalculi\$2 or dyslexi\$2 or "mental retardation" or mutism or "separation anxiety").ti,ab. (37087)

3 or/1-2 (42193)

4 Remote Consultation/ or Telemedicine/ or Telerehabilitation/ or Videoconferencing/ (4415)

5 (distance or erehab* or "e-rehab*" or portal\$1 or remote\$2 or tele* or video* or Webex or Zoom).ti. (22642)

6 or/4-5 (24860)

7 and/3,6 (723)

8 7 not ((exp Animals/ not Humans/) or (animal model* or bitch\$2 or bovine or canine or capra or cat or cats or cattle or cow\$1 or dog\$1 or equine or ewe\$1 or feline or goat\$1 or hamster\$1 or horse\$1 or invertebrate\$1 or macaque\$1 or mare\$1 or mice or monkey\$1 or mouse or murine or

nonhuman or non-human or ovine or pig or pigs or porcine or primate\$1 or rabbit\$1 or rat\$1 or rattus or rhesus or rodent* or sheep or simian or sow\$1 or vertebrate\$1 or zebrafish).ti. or (addiction or alzheimer\$1 or class or classroom\$1 or dementia or game\$1 or gamification or gaming or hockey or instruction or learning or problematic or questionnaire or survey or videofluoroscop* or videogame\$1).ti. or geriatric*.jw.) (614)

9 8 and (Transition to Adult Care/ or (adolescen* or baby or babies or boy\$1 or child* or family or families or father\$1 or girl\$1 or infant\$1 or juvenile\$1 or kids or menarche or mother\$1 or neonat* or newborn\$1 or parent\$1 or paediatric* or pediatric* or preadolescen* or prepubescen* or preschool* or pre-school* or preteen* or puberty or pubescen* or school* or teen* or toddler\$1 or transition* or young* or youth\$1).ti. or (adolescen* or child* or paediatric* or pediatric* or youth).jw.) (261)

10 limit 9 to yr="2018 -Current" (166)

Ovid APA PsycInfo 1806 to November Week 4 2023

Date searched: December 7, 2023

1 exp autism spectrum disorders/ or brain injuries/ or exp developmental disabilities/ or exp disruptive behavior disorders/ or "emotional and behavioral disorders"/ or exp intellectual development disorder/ or exp learning disorders/ or neurodevelopmental disorders/ or exp traumatic brain injury/ or anencephaly/ or Cerebral Palsy/ or Crying Cat Syndrome/ or Down's Syndrome/ or Rett Syndrome/ or Tay Sachs disease/ (188787)

2 (ADHD or ASD or asperger* or (("attention deficit" or "conduct disorder" or "child behavior*" or "child behaviour*" or "child development*" or "childhood disintegrative" or communication or fluency or "motor skills" or neurodevelop* or neuro-develop* or pervasive or "reactive attachment" or "sluggish cognitive tempo" or "speech sound" or "stereotypic movement" or tic) adj2 disorder*) or autism or autistic or ((brain or neuro*) adj5 (disorder* or injur*)) or "cerebral palsy" or "childhood schizophreni\$2" or (("cri-du-chat" or "de Lange" or Down\$2 or neurodevelop* or neuro-develop* or Prader-Willi or Rett\$2 or Rubinstein-Taybi or Tourette\$2 or "Trisomy 13" or Wagr\$2 or Williams\$1) adj syndrome) or ((developmental or intellectual or learning or neurodevelop* or neuro-develop*) adj2 disabilit*) or dyscalculi\$2 or dyslexi\$2 or "mental retardation" or mutism or "separation anxiety").ti,ab. (276130)

3 (autism or autistic or ((development* or neurodevelopment* or neuro-development*) adj2 (disabilit* or disorder\$1 or syndrome\$1))).jw. (25791)

4 or/1-3 (324059)

5 online therapy/ or telemedicine/ or exp teleconferencing/ or teleconsultation/ or telepsychiatry/ or telepsychology/ or telerehabilitation/ (14103)

6 (distance or erehab* or "e-rehab*" or portal\$1 or remote\$2 or tele* or video* or Webex or Zoom).ti. (45096)

7 or/5-6 (52719)

8 and/4,7 (2634)

9 8 not ((exp Animals/ not Humans/) or (animal model* or bitch\$2 or bovine or canine or capra or cat or cats or cattle or cow\$1 or dog\$1 or equine or ewe\$1 or feline or goat\$1 or hamster\$1 or horse\$1 or invertebrate\$1 or macaque\$1 or mare\$1 or mice or monkey\$1 or mouse or murine or nonhuman or non-human or ovine or pig or pigs or porcine or primate\$1 or rabbit\$1 or rat\$1 or rattus or rhesus or rodent* or sheep or simian or sow\$1 or vertebrate\$1 or zebrafish).ti. or (addiction or alzheimer\$1 or class or classroom\$1 or dementia or game\$1 or gamification or gaming or hockey or instruction or learning or problematic or questionnaire or survey or videofluoroscop* or videogame\$1).ti. or geriatric*.jw.) (2147)

10 limit 9 to ((childhood <birth to 12 years> or adolescence <13 to 17 years>) and (100 childhood <birth to age 12 yrs> or 120 neonatal <birth to age 1 mo> or 140 infancy <2 to 23

mo> or 160 preschool age <age 2 to 5 yrs> or 180 school age <age 6 to 12 yrs> or 200 adolescence <age 13 to 17 yrs>)) (1082

11 9 and (Transition to Adult Care/ or (adolescen* or baby or babies or boy\$1 or child* or family or families or father\$1 or girl\$1 or infant\$1 or juvenile\$1 or kids or menarche or mother\$1 or neonat* or newborn\$1 or parent\$1 or paediatric* or pediatric* or preadolescen* or prepubescen* or preschool* or pre-school* or preteen* or puberty or pubescen* or school* or teen* or toddler\$1 or transition* or young* or youth\$1).ti. or (adolescen* or child* or paediatric* or pediatric* or youth).jw.) (1028)

12 or/10-11 (1327)

13 limit 12 to english language (1239)

14 limit 13 to yr="2020 -Current" (381)

15 14 and (meta-anal* or metaanal* or ((evidence or review or scoping or systematic or umbrella) adj3 (review or synthesis))).ti,ab. (34)

16 limit 13 to yr="2018 -Current" (520)

17 16 and (controlled or random* or trial*).ti,ab. (107)

18 17 not 15 (96)

19 16 and (((comparative or epidemiologic or evaluation) adj3 study) or cross-sectional or follow-up or (historic* adj4 control*) or "interrupted time" or longitudinal\$2 or prospective\$2 or retrospective\$2).ti,ab. (82)

20 19 not (15 or 18) (49)

PROSPERO Inception to December 6, 2023

Date searched: December 7, 2023

((adolescen* or baby or babies or boy* or child* or family or families or girl* or infant* or juvenile* or kids or menarche or neonat* or newborn* or parent* or paediatric* or pediatric* or preadolescen* or prepubescen* or preschool* or pre-school* or preteen* or puberty or pubescen* or school* or teen* or toddler* or transition* or young* or youth*) AND (distance OR erehab* OR e-rehab* OR portal OR portals OR remote OR remotely OR tele* OR videoconference OR Webex OR Zoom)):TI AND (Intervention OR Systematic Review OR Meta-Analysis OR Review of reviews):RT WHERE CD FROM 07/12/2020 TO 07/12/2023 (83)

ClinicalTrials.gov Inception to December 6, 2023

Date searched: December 7, 2023 [Expert Search Mode]

Recruiting, Not yet recruiting, Active, not recruiting, Enrolling by invitation Studies | ADHD OR ASD OR asperger OR (EXPAND[Concept] "attention deficit" OR EXPAND[Concept] "conduct disorder" OR behavior OR developmental OR disintegrative OR communication OR fluency OR EXPAND[Concept] "motor skills" OR pervasive OR speech OR sound OR stereotypic OR tic) AND disorder* OR autism OR autistic OR (brain OR neuro*) AND (disorder* OR injur*) OR cerebral palsy OR schizophrenia OR cri-du-chat OR de Lange OR Down syndrome OR neurodevelopmental OR neuro-developmental OR Prader-Willi OR Rett OR Rubinstein-Taybi OR Tourette OR Trisomy OR Wagr OR Williams OR (developmental OR intellectual OR learning) AND disabilit* OR dyscalculia OR dyslexia OR EXPAND[Concept] "mental retardation" OR mutism OR EXPAND[Concept] "separation anxiety" | distance OR erehabilitation OR e-rehabilitation OR portal OR remote OR remotely OR tele* OR videoconference OR Webex OR Zoom | Child | First posted from 12/07/2018 to 12/07/2023 (11)

Appendix B. Selection Criteria Assessment

| Selection Criteria | Assessment |
|---|---|
| 1. Appropriateness | |
| 1a. Does the nomination represent a health care drug, intervention, device, technology, or health care system/setting available (or soon to be available) in the United States? | Yes |
| 1b. Is the nomination a request for an evidence report? | Yes |
| 1c. Is the focus on effectiveness or comparative effectiveness? | Yes |
| 1d. Is the nomination focus supported by a logic model or biologic plausibility? Is it consistent or coherent with what is known about the topic? | Yes |
| 2. Importance | |
| 2a. Represents a significant disease burden; large proportion of the population | Yes. The prevalence rate of neurodevelopmental disabilities is 0.63% for intellectual disability, 5-11% for attention deficit/hyperactivity disorder (ADHD), 0.70-3% for autism spectrum disorder (ASD), 3-10% for specific learning disorder (SLD), and 1-3.42% for communication disorders. ² |
| 2b. Is of high public interest; affects health care decision making, outcomes, or costs for a large proportion of the United States population or for a vulnerable population | Yes. In 2013, the costs of caring for individuals with autism spectrum disorder in the United States were estimated at \$137 billion, and the lifetime costs per individual ranged from \$1.4 million (without co-occurring intellectual disability) to \$2.4 million (with co-occurring intellectual disability). ³ Several studies have found that individuals with NDDs have greater health care needs regarding utilization of services, accessibility, parent support, and specificity of care. ⁴⁻¹⁴ |
| 2c. Incorporates issues around both clinical benefits and potential clinical harms | Yes |
| 2d. Represents high costs due to common use, high unit costs, or high associated costs to consumers, to patients, to health care systems, or to payers | Yes. In 2013, the costs of caring for individuals with autism spectrum disorder in the United States were estimated at \$137 billion, and the lifetime costs per individual ranged from \$1.4 million (without co-occurring intellectual disability) to \$2.4 million (with co-occurring intellectual disability). ³ NDDs have greater health care needs regarding utilization of services, accessibility, parent support, and specificity of care. ⁴⁻¹⁴ |
| 3. Desirability of a New Evidence Review/Absence of Duplication | |
| 3. A recent high-quality systematic review or other evidence review is not available on this topic | Yes. We did not find any systematic reviews that adequately and comprehensively address this topic. |
| 4. Impact of a New Evidence Review | |
| 4a. Is the standard of care unclear (guidelines not available or guidelines inconsistent, indicating an information gap that may be addressed by a new evidence review)? | Yes, there are no guidelines addressing the issue. |
| 4b. Is there practice variation (guideline inconsistent with current practice, indicating a potential implementation gap and not best addressed by a new evidence review)? | Yes, there are no guidelines addressing the issue and there was an increase in the use of telehealth during the COVID-19 pandemic. |
| 5. Primary Research | |

| | |
|---|---|
| <p>5. Effectively utilizes existing research and knowledge by considering:</p> <ul style="list-style-type: none"> - Adequacy (type and volume) of research for conducting a systematic review - Newly available evidence (particularly for updates or new technologies) | <p>We found 22 systematic reviews, 46 published studies, 12 ongoing clinical trials, and 11 ongoing systematic reviews that address the proposed key questions for this topic.</p> |
| <p>6. Value</p> | |
| <p>6a. The proposed topic exists within a clinical, consumer, or policy-making context that is amenable to evidence-based change and supports a priority of AHRQ or Department of Health and Human Services</p> | <p>Yes. A review on this topic could be amended as telehealth utilization continues to increase and telehealth interventions continue to evolve.</p> |
| <p>6b. Identified partner who will use the systematic review to influence practice (such as a guideline or recommendation)</p> | <p>Yes, the Child Neurology Foundation is committed to work in digital health for children with neurodevelopment disabilities and would incorporate the results of an evidence report into clinical practice.</p> |

Appendix C. Topic Nomination

1005 Telehealth for Children with Neurodevelopmental Disabilities Topic Nomination

A topic nomination was submitted on the EHC website:

Submitted on Friday, June 3, 2022 - 13:37

Submit a Topic for a New Evidence Review

1. What is the decision or change (e.g. clinical topic, practice guideline, system design, delivery of care) you are facing or struggling with where a summary of the evidence would be helpful?

Telehealth usage and best practices for children with neurodevelopmental disabilities and their caregivers.

2. Why are you struggling with this issue?

1 in 5 children in the US live with a neurologic condition, which are wide-ranging with various causes, complications, and outcomes. Many conditions requiring life-long management of physical, cognitive, emotional, and/or behavioral symptoms. Despite the prevalence of neurologic conditions in the pediatric population, children and their families wait an average of 9 weeks in the United States to access a child neurologist. These families also experience social and economic challenges with nearly half reporting financial hardships, and a quarter of living in poverty.

In March 2020, these wait times changed almost overnight when telehealth became the primary way that Americans accessed healthcare. Our organization, the Child Neurology Foundation (CNF), which supports children with neurologic conditions and their families, wanted to better understand how the sudden change to telehealth affected our communities.

CNF first surveyed families in summer 2020 and then facilitated focus groups and interviews with caregivers and clinicians to dig deeper: Families told us that their wait times were dramatically reduced, with half receiving a neurology appointment the same week of their request. They also reported their children's behavior was often better during telehealth visits and that they were more able to focus during visits. However, 39% of parents told us that they would never again choose telehealth for their child. Despite the convenience of telehealth, they were concerned about the lack of connection between their child and providers. They missed small talk with clinicians, saying those chats are where much of the healing happens, especially for children with behavioral challenges or intellectual disabilities. Clinicians also reported somewhat contradictory feedback, reporting that while they valued improved continuity of care—with fewer patients falling through the cracks as check-in conversations became easier—they were frustrated by less effective physical exams, distracted parents and distracting home environments, and sometimes felt like they weren't being heard.

We have tried to address the issues within our capacity to do so. With our partners, we developed resources both for parents and clinicians to encourage best practices for a telehealth visit—both to prepare the child and caregiver for the telehealth appointment, but also to remind clinicians that patient engagement can look different through a screen.

To address some access issues our families experienced in the transition to a more digital world, CNF launched a Digital Access program in June 2021. We provide families with a child living with a neurologic condition with a Chromebook, an internet hotspot, and technology use training to access online resources, attend telehealth appointments, and connect with their communities online. We prioritized lower income families, with 64% of program participants having at least one adult in their household who is unemployed. Participating families represent over 30 neurologic conditions, with over half experiencing Autism Spectrum Disorder.

So far, this program is seeing positive results. Based on preliminary data: 36% of participating families use their device daily; 69% report improved telehealth visits once receiving their device and hotspot; 87% report increased ability to connect virtually with their support network and 67% can better access resources for their children's schooling. However, we are also learning that more than hardware and improved internet access is needed. Many families have said that because of their children's complex health needs, the technology itself needs to be more accessible: trackpads are unusable for some children with movement disorders or developmental disabilities, and a Chromebook's built-in speakers may be insufficient for children with auditory-processing disorders or who are hearing impaired. In addition, our participating families have reported continued needs in accessing telehealth and other digital services, stating that 16% lack reliable transportation to attend follow-up health appointments in-person; 27% are under-or uninsured and 29% still struggle to access the internet because they live somewhere a data hotspot does not work well enough to have reliable, fast internet access for video visits. Moreover, 20% of our participating families still have difficulty finding a child neurologist they like for their needs, and 58% say they still need information and education to fully understand their child's complex health needs.

While the Public Health Emergency that resulted in the policies creating an environment for telehealth to be as widely used will likely soon end, it is clear that there is enough good for families of children experiencing neurologic conditions to have this modality of care be something in a family's toolbox to provide the best care possible to a child with complex health needs. While we have tried to study and address the issues within our own community, an evidence review from AHRQ would help us, and other patient advocacy organizations that serve similar patient populations, navigate the peculiarities of pediatric telehealth, particularly among chronically ill and disabled populations.

3. What do you want to see changed? How will you know that your issue is improving or has been addressed?

Based on the work we have done over the past two years, we know there is much that can be done to create better, more inclusive telehealth for children with complex health needs. Those changes include improved education for clinicians and caregivers, empowering both stakeholder groups to feel more confident deciding when, and how, to use telehealth in the medical treatment of a young person with a neurologic condition. CNF and our partners have worked on this, and will continue to do so; this education will be even more effective with an adequate understanding of what the landscape of pediatric telehealth is at a national level.

The improvement of pediatric telehealth can be supported through systems-level interventions that remove barriers for all Americans to access quality healthcare. AHRQ's evidence report on telehealth usage for children with neurodevelopmental disabilities and their caregivers will only strengthen these advocacy efforts.

We will know there is improvement in this area based on the feedback we hear from the families we serve; both through the regular feedback we receive from working within our communities, and through the data gathering of our annual Needs Assessment where we have been tracking for the past two years how our families use telehealth, and our Digital Access program, which is launching its second year this summer.

5. What will you do with the evidence report?

CNF is committed to our work in digital health; we see this as an ongoing need within our community. While an evidence report soon would allow us to incorporate the latest findings into the work we are currently doing, we would be grateful for this report at any time—we do not see our work in this area slowing down.

Optional Information About You

What is your role or perspective?

Patient Advocacy Organization

If you are you making a suggestion on behalf of an organization, please state the name of the organization

Child Neurology Foundation

May we contact you if we have questions about your nomination?

Yes

Full Name

Jessica Nickrand

Title

Manager, Programs

Email Address

jnickrand@childneurologyfoundation.org

is_production

Yes

Form Type

Topic Nomination

The results of this submission may be viewed at:

[Telehealth for Children with Neurodevelopmental Disabilities | Effective Health Care \(EHC\) Program \(ahrq.gov\)](#)