Topic Brief: Telehealth for Autism Spectrum Disorder

Date: 8/9/2019
Nomination Number: 855

Purpose: This document summarizes the information addressing a nomination submitted on 5/6/2019 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: Diagnosing Autism Spectrum Disorder (ASD) diagnosis is resource-intensive and high demand, which results in long waiting times. The sooner a child receives treatment, the greater the chance for learning and progress. The mean age for diagnosis is 4 years old, but early intervention should occur at or before preschool age, as early as 2 years of age. This particularly an issue for people living in rural areas. Telehealth is proposed as a way to facilitate timely diagnosis and treatment for people with ASD but it is not clear whether diagnosis and treatment is effective.

Key findings

- Few studies examined telehealth for diagnosis and genetic counselling of ASD. Those that did covered a variety of technologies (including telephone, home videos, and videoconferencing). Some studies were very small, including less than 50 participants.
- We found three completed and in-process systematic reviews about delivering Applied Behavioral Analysis, a therapy to increase helpful behaviors that are helpful and decrease harmful behaviors, by telehealth.

Program Decision: The EPC Program will not develop a new systematic review because we did not find enough primary studies addressing the use of telehealth for diagnosis of ASD.

Background

- According to DSM-5[1], diagnostic criteria for Autism Spectrum Disorder (ASD) are
  - Persistent deficits in social communication and social interaction across multiple contexts
  - Restricted repetitive patterns of behavior interests or activities
  - Onset of symptoms in the early developmental period
  - Clinical impairment on social, occupation, or other important areas of functioning
  - Symptoms are not better explained by intellectual disability or global developmental delay
- CDC estimates that about 1 in 59 children has been identified with ASD (or 16.8 per 1,000 8-year-olds) in 2014.[2]

- Mean age of diagnosis is 4-5 years old.[3] However, early intervention for ASD occurs at or before preschool age, as early as 2 years of age. The sooner a child receives treatment, the greater the chance for learning and progress.[4]
- A review of practice guidelines for autism[5] found that
    - Guidelines advocated for diagnosis to take place within a multidisciplinary setting, with some suggesting this was ideal
    - The multidisciplinary team may include a physician, psychologist, speech language pathologist, and sometimes others (social worker, occupational therapist and genetic counselor).
    - Some suggested that an appropriately trained and experienced single professional was sufficient to diagnose in particular cases
    - There was a wide range of recommended assessment processes and diagnostic tools
- Diagnostic assessments for ASD are resource intensive, and high demand results in long waiting times.[6] Average wait time is 3.5 months but can be longer, up to a year.
- Other barriers to timely diagnosis include cost, lack of providers, and lack of comfort in diagnosing by primary care providers.[7]
- There is no standard treatment for ASD. Treatment aims to maximize function by reducing symptoms and supporting development and learning, such as Applied Behavior Analysis (ABA), sensory integration therapies, speech therapy, parent-mediated therapy, and medications.[8]
- Telehealth is the use of technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration. Technologies include videoconferencing, the internet, store-and-forward imaging, streaming media, and telecommunications.[9]
- Telehealth is proposed as a way to facilitate timely diagnosis and treatment for people with ASD.
- Washington Medicaid benefit allows ABA supervision to be provided through telehealth.

Nomination Summary

- We reached out to the nominator to clarify the scope. They confirmed their focus on autism spectrum disorders (ASD) with an interest in ASD diagnosis and delivery of ABA by telehealth. When few primary studies were identified related to diagnosis by telehealth, they requested a focus on the genetic counselling component of the assessment.
- They plan to use an evidence report to inform future investments in infrastructure for telehealth in their state.

Scope

Question 1: What is the effectiveness of telehealth for diagnosis of autism spectrum disorder (ASD)?
Question 2: What is the effectiveness of telehealth for genetic counselling in the assessment for ASD?
Question 3: What is the effectiveness of ABA delivered by telehealth for treatment of ASD?

To define the inclusion criteria for the key questions, we specify the population, interventions, comparators, outcomes, timing, and setting (PICOTS) of interest (Table 1).

Table 1. Questions and PICOTS (population, intervention, comparator, outcome, timing and setting)

Key Questions	Question 1: Assessment for ASD	Question 2: Genetic counselling for ASD	Question 3: ABA for ASD
Population	People with suspected ASD	People with suspected ASD	People with ASD
Interventions	Diagnostic assessment by telehealth	Genetic counselling by telehealth	ABA delivered by telehealth
Comparators	Diagnostic assessment face to face	Genetic counselling face to face	ABA delivered face-to-face
Outcomes	Diagnostic accuracy Need for follow-up assessment Cost Time to diagnosis Clinical outcomes	Need for follow-up assessment Cost Time to diagnosis Clinical outcomes	Clinical outcomes Time to complete treatment
Timing	All	All	All
Setting	Outpatient	Outpatient	Outpatient

Abbreviations: ASD=autism spectrum disorder; ABA=applied behavior analysis

Assessment Methods

See Appendix A.

Summary of Literature Findings

We found three systematic reviews addressing question 3 on the delivery of ABA by telehealth. We found no relevant reviews related to question 2. For key question 1 on diagnosis of autism, we found two systematic reviews. However we were not certain whether they were duplicative based on the abstract.

We found 9 primary studies related to ASD diagnosis. These studies covered a variety of technologies, including telephone, home videos, and videoconferencing. Number of study subjects ranged from 5 to 289. We found no studies relevant to question 2, on the use of telehealth for genetic counselling. See Table 2.

Table 2. Literature identified for each Question

Key Question	**Duplication (6/2016-6/2019)**	**Feasibility (6/2014-6/2019)**
KQ 1: Diagnosis, ASD	Total number of identified systematic reviews: 0	Size/scope of review Relevant Studies Identified: 9[10-18] Clinicaltrials.gov • Recruiting: 1 NCT03847337
KQ 2: genetic counselling	Total number of identified systematic reviews: 0	Size/scope of review Relevant Studies Identified: 0 Clinicaltrials.gov: 0
KQ 3: ABA for treatment of ASD	Total number of identified systematic reviews: 3 • Other group: 3[19-21]	Not done

Abbreviations: ABA=applied behavior analysis; ASD=autism spectrum disorder; KQ=key question

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

Summary of Selection Criteria Assessment

The use of telehealth for diagnosis and treatment of autism spectrum disorder is an important topic and a new systematic review could be highly impactful. We found reviews that address the delivery of ABA by telehealth, and too few primary studies were identified related to diagnosis and genetic counselling for suspected ASD. A new systematic review is not feasible.

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

Related Resources

In the course of the workup we identified resources that might be useful.

- Boisvert et al. Telepractice in the assessment and treatment of individuals with autism spectrum disorders: A systematic review.[22]
    - This is a relevant review but it was published in 2010.
- Goldstein et al. Bridging Care Gaps: Using tele-health to provide care for people with autism spectrum disorder. 2017.[23]
    - This literature review and commentary did not appear to be a systematic review, and was not considered duplicative.
- Parsons et al. Parent-mediated intervention training delivered remotely for children with autism spectrum disorder living outside of urban areas: a systematic review. 2017. [24]
    - This review included one study on parent training in behavioral interventions, including ABA.
    - Randall et al. Diagnostic tests for autism spectrum disorders in preschool children. 2018.[25]
    - This Cochrane systematic review assessed diagnostic tests for ASD, but did not look at their performance when delivered by telehealth.
- Tomlinson, S. R. L., Gore, N., & McGill, P. (2018). Training individuals to implement applied behavior analytic procedures via telehealth: A systematic review of the literature.[26]
    - This review focused on ABA training by telehealth, rather than delivery of ABA by telehealth.
- Wales et al. The efficacy of telehealth-delivered speech and language intervention for primary school-age children: a systematic review. 2017 [27]

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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 (June 2016-June 2019) 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.hsrd.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/prospero/
- PubMed https://www.ncbi.nlm.nih.gov/pubmed/
- PsycINFO http://www.apa.org/pubs/databases/psycinfo/index.aspx
- CADTH https://www.cadth.ca/
- Campbell Collaboration Systematic Review Library http://www.campbellcollaboration.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 PubMed from the last five years (June 2014-June 2019) on parts of the nomination scope not addressed by earlier identified systematic reviews. We reviewed all identified titles and abstracts for inclusion and classified identified studies by question and study design to estimate the size and scope of a potential evidence review.

Search strategy

Feasibility search for Genetic Counseling and ASD PubMed Searched on June 14th, 2019	
Key Question 2: Diagnosis of ASD	
Autism Spectrum Disorder	("Autism Spectrum Disorder"[Mesh]) OR (autism[Title])
AND	
Genetic Counseling	("Genetic Counseling"[Mesh]) OR "Genetic Counseling"[Title/Abstract]
	Filters activated: published in the last 5 years.
Total N=37	
Review* N=10 Systematic Review filter retrieved zero results, the less stringent Review filter was used instead	"review"[Filter]
RCT N=6	(((((((groups[tiab])) OR (trial[tiab])) OR (randomly[tiab])) OR (drug therapy[sh])) OR (placebo[tiab])) OR (randomized[tiab])) OR (controlled clinical trial[pt])) OR (randomized controlled trial[pt])
Other N=21	
ClinicalTrials.gov single trial identified: https://clinicaltrials.gov/ct2/show/NCT02769949?term=NCT02769949	

Feasibility search for ASD and Telemedicine PubMed Searched on June 5th, 2019 Note: results were small enough that no limits by date or language were used.	
Key Question 1: Diagnosis of ASD	
Autism Spectrum Disorder - diagnosis	("Autism Spectrum Disorder/diagnosis"[Mesh]) OR ((autism[Title]) AND diagnosis[Title])
AND	
Telehealth	(("Telemedicine"[Mesh])) OR ((telephone[Title/Abstract] OR telemedicine[Title/Abstract] OR telehealth[Title/Abstract]))
N=47	
Review* N=2 Systematic Review filter retrieved zero results, the less stringent Review filter was used instead	"review"[Filter]

Of special note: *Rural Trends in Diagnosis and Services for Autism Spectrum Disorder* - 2017 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5397491/pdf/fpsyg-08-00590.pdf	
RCT N=5	((((((((groups[tiab])) OR (trial[tiab])) OR (randomly[tiab])) OR (drug therapy[sh])) OR (placebo[tiab])) OR (randomized[tiab])) OR (controlled clinical trial[pt])) OR (randomized controlled trial[pt])
Other N=40	
Key Question 3: ABA delivered via telehealth	
Applied Behavior Analysis	"Applied Behavior Analysis"[Mesh] OR Applied Behavior Analysis[Title/Abstract]
AND	
Telehealth	"Telemedicine"[Mesh])) OR ((telephone[Title/Abstract] OR telemedicine[Title/Abstract] OR telehealth[Title/Abstract]
N=6	
SR=1	systematic[sb]
Telehealth as a Model for Providing Behaviour Analytic Interventions to Individuals with Autism Spectrum Disorder: A Systematic Review. - 2019 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6373531/pdf/10803_2018_Article_3724.pdf	
RCT=1	((((((((groups[tiab])) OR (trial[tiab])) OR (randomly[tiab])) OR (drug therapy[sh])) OR (placebo[tiab])) OR (randomized[tiab])) OR (controlled clinical trial[pt])) OR (randomized controlled trial[pt])
Telehealth and Autism: Treating Challenging Behavior at Lower Cost - 2016 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4727312/pdf/PEDS_20152851O.pdf	
Other=4	
11 Studies found for: **telemedicine | Recruiting, Not yet recruiting, Active, not recruiting, Completed, Enrolling by invitation Studies | Autism Spectrum Disorder** https://clinicaltrials.gov/ct2/results?cond=Autism+Spectrum+Disorder&term=telemedicine&type=&rslt=&recrs=b&recrs=a&recrs=f&recrs=d&recrs=e&age_v=&gndr=&intr=&titles=&outc=&spons=&lead=&id=&cntry=&state=&city=&dist=&locn=&strd_s=&strd_e=&prcd_s=&prcd_e=&sfpd_s=&sfpd_e=&lupd_s=&lupd_e=&sort=	

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 U.S.?	Yes
1b. Is the nomination a request for a systematic review?	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	CDC estimates that about 1 in 59 children has been identified with ASD (or 16.8 per 1,000 8-year-olds) in 2014.[2]
2b. Is of high public interest; affects health care decision making, outcomes, or costs for a large proportion of the US population or for a vulnerable population	Yes
2c. Represents important uncertainty for decision makers	Yes
2d. Incorporates issues around both clinical benefits and potential clinical harms	Yes
2e. 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. The total costs per year for children with ASD in the United States were estimated to be between $11.5 billion – $60.9 billion (in 2011 US dollars). This represents a variety of direct and in-direct costs, from medical care to special education to lost parental productivity.[28] In 2005, the average annual medical costs for Medicaid-enrolled children with ASD were $10,709 per child, six times higher than costs for children without ASD ($1,812). Intensive behavioral interventions for children with ASD cost $40,000 to $60,000 per child per year.[28]
3. Desirability of a New Evidence Review/Duplication	

Selection Criteria	Assessment
3. Would not be redundant (i.e., the proposed topic is not already covered by available or soon-to-be available high-quality systematic review by AHRQ or others)	Partly duplicative. We found 3 systematic reviews related to question 3 (delivery of ABA by telehealth); and no reviews related to questions 1 (ASD diagnosis) and 2 (genetic counselling in ASD diagnostic workup). Question 1 (autism diagnosis), we found two systematic reviews but were not certain whether they were duplicative based on the abstract. Both systematic reviews noted that there was potential effectiveness of telemedicine or telehealth to increase access to autism evaluations. • Knutsen et al. A systematic review of telemedicine in autism spectrum disorders.[29] • Sutherland et al. Telehealth and autism: A systematic search and review of the literature.[30] We found one completed and two in-process systematic review directly addressing question 3, on delivery of ABA by telehealth. • Ferguson et al. Telehealth as a model for providing behavior analytic interventions to individuals with autism spectrum disorder: a systematic review. 2018.[19] o This review looked only at telehealth technology that had two-way communication with a professional. It also focused on training, supervision or consultation by telehealth. o 28 studies were included. • Neely et al. Effects of telehealth mediated behavior analytic interventions and assessments on subject outcomes. PROSPERO 2019 CRD42019123500[20] • Khan et al. A systematic review and meta-analysis investigating the effectiveness of online therapeutic interventions delivered to children and young people with neurodevelopmental disorders. PROSPERO 2018 CRD42018108824[21]
4. Impact of a New Evidence Review	

Selection Criteria	Assessment
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)?	A review of practice guidelines for autism[5] found that • Guidelines advocated for diagnosis to take place within a multidisciplinary setting, with some suggesting this was ideal • The multidisciplinary team may include a physician, psychologist, speech language pathologist, and sometimes others (social worker, occupational therapist and genetic counselor). • Some suggested that an appropriately trained and experienced single professional was sufficient to diagnose in particular cases • There was a wide range of recommended assessment processes and diagnostic tools
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 is likely practice variation because of the diversity of recommended assessment processes and diagnostic tools.
5. Primary Research	

Selection Criteria	Assessment
5. Effectively utilizes existing research and knowledge by considering: - Adequacy (type and volume) of research for conducting a systematic review - Newly available evidence (particularly for updates or new technologies)	A new evidence review on questions 1 and 2 is not feasible. We found 10 studies. See Table 2, Feasibility column. Question 1: ASD diagnosis. These studies covered a variety of technologies, including telephone, home videos, and videoconferencing. • Bishop et al. The autism symptom interview, school-age: A brief telephone interview to identify autism spectrum disorders in 5-to-12-year-old children.[10] • Doyen et al. Telepsychiatry for Children and Adolescents: A Review of the PROMETTED Project.[11] • Juarez et al. Early Identification of ASD Through Telemedicine: Potential Value for Underserved Populations[12] • Nazneen et al. A Novel System for Supporting Autism Diagnosis Using Home Videos: Iterative Development and Evaluation of System Design.[13] • Smith et al. Investigating the accuracy of a novel telehealth diagnostic approach for autism spectrum disorder.[15] • Schutte et al. Usability and reliability of a remotely administered adult autism assessment, the autism diagnostic observation schedule (ADOS) module 4. [14] • Sohl et al. ECHO Autism: Using Technology and Mentorship to Bridge Gaps, Increase Access to Care, and Bring Best Practice Autism Care to Primary Care.[16] • Stainbrook et al. Measuring the service system impact of a novel telediagnostic service program for young children with autism spectrum disorder. [17] • Tariq et al. Mobile detection of autism through machine learning on home video: A development and prospective validation study.[18] • In-process clinical trial Can Novel Telemedicine Tools Reduce Disparities Related to Early Identification of Autism NCT03847337 o This study will compare two telemedicine assessment tools that could allow parents or providers in remote locations to complete an Autism Spectrum Disorder (ASD) risk assessment via telemedicine consultation with an expert psychologist. We identified no studies related to question 2 (genetic counselling).