

# Telemedicine for Children with Developmental Disabilities: A More Effective Clinical Process Than Office-Based Care

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## Abstract

**Background:** The literature on the use of telemedicine for children with developmental disabilities (DD) is limited and mostly describes telemedicine being used to link patients with distant subspecialty multidisciplinary care. Parents generally have reported satisfaction with such care and have perceived it to be equally effective as in-person care. Here we report on the use of school-based asynchronous telemedicine to connect children with DD with primary care providers. **Materials and Methods:** We developed Tele-Health-Kids, a school-based program using asynchronous telemedicine to connect children with DD with their primary care physician for the care of minor illnesses. We surveyed parents at enrollment and after the child's first telemedicine visit to assess satisfaction. We describe 4 cases that illustrate benefits, particularly for children with DD and challenging behaviors, suggesting that asynchronous telemedicine may actually be superior to traditional in-office visits in some circumstances. **Results:** Most parents expressed a high level of satisfaction with the program. Benefits identified include decreased stress to the child and the parents as well as increasing the likelihood of a successful medical examination due to greater cooperation by the child. Visits using asynchronous or "store and forward" telemedicine technology may be superior in some situations by allowing the visit to be performed at a pace that can be adjusted to the needs of the child with DD. **Conclusions:** More research in the use of asynchronous telemedicine for children and youth with DD, particularly for children with DD and challenging behaviors, is needed.

Key words: *pediatrics, telemedicine, behavioral health, telehealth*

## Introduction

Developmental disabilities (DD) affect over 13% of children younger than 18 years of age in the United States.<sup>1</sup> Many children with DD have other special healthcare needs, including chronic medical conditions and behavioral challenges. Children with DD often face unique logistical as well as psychological and behavioral barriers in accessing healthcare. These barriers may include the need for special transportation such as a vehicle with wheelchair capacity, special equipment, or attendants,

including multiple adult caretakers or a professional nurse. About 10–15% of children with DD have challenging behaviors, including aggression, destructive behavior, and self-injury. These behaviors tend to increase in adolescence, are more severe in individuals with limited communication skills, and may escalate in stressful situations.<sup>2</sup> Many children with DD find transitions to unfamiliar environments, such as traditional healthcare settings, to be particularly challenging, and these transitions may induce anxiety, fear, and disruptive behavior. For children with DD who live in rural areas, traveling a long distance to a healthcare facility compounds the other challenges they face in accessing care. Behavior problems may escalate during the long drive to a healthcare facility, and the child may become so uncooperative that the visit has limited value.

Telemedicine is used increasingly to improve access to care for children in rural areas. The few published reports describing the use of telemedicine for children with DD focus primarily on improving access to subspecialty care by reducing barriers of time and expense associated with travel to subspecialty care.<sup>3</sup> In a study using telemedicine for children with special healthcare needs in an underserved rural community, Marcin et al.<sup>4</sup> described three issues identified by parents that made telemedicine particularly attractive for use. These included needing to travel more than 1 h for subspecialty care, a parent missing work to attend the child's subspecialty appointment, and relying frequently on emergency department care or self-regulation of the child's medications.

Harper<sup>5</sup> examined the use of telemedicine for rural children with DD in Iowa to improve access to subspecialty care. This program connected children with special healthcare needs from three rural sites using real-time telemedicine to a university health center for multidisciplinary consultations. This application was studied with four groups of children, including one group of children with DD and severe behavioral disorders. Parents found the telemedicine consultations to be equally effective as in-person visits and reported high satisfaction levels. Other benefits of telemedicine reported by parents included reduced travel costs and reduced time necessary for a subspecialty visit. Harper<sup>5</sup> did not describe outcomes specific to children with DD and severe behavioral disorders.

A few studies describe the use of telepsychiatry with children and adolescents with DD. The Cedars-Sinai Telepsychiatry Clinic has treated challenging behaviors, mood disorders, and other psychiatric disorders in children and adolescents with DD in a collaborative care model with primary care providers using videoconferencing and demonstrated reduction in symptoms.<sup>6</sup> Pakyurek et al.<sup>7</sup> described children and adolescents with severe anxiety and autism as being more engaged during a telepsychiatry visit than they often are during

a traditional in-person psychiatry visit. Telemedicine also has been used among children with DD to improve the diagnosis and treatment of autism spectrum disorders.<sup>8</sup> Several programs use telemedicine to provide services to children with hearing impairment or speech and language disorders.<sup>9,10</sup>

Most of the telemedicine work to date in pediatric subspecialty care and telepsychiatry has been done using “real-time” or synchronous communication. Real-time telemedicine may be difficult with children with DD because it requires the child to cooperate at the same time as the healthcare provider is observing. Asynchronous or “store and forward” telemedicine may offer benefits for children with DD due to more flexibility in the timing of data collection for the visit. Some telemedicine programs have specifically excluded children with DD or challenging behaviors because it is simply too difficult or requires too much time to perform a (real-time) telemedicine visit with an uncooperative child.<sup>11</sup> Recently, Yellowlees et al.<sup>12</sup> described the feasibility and benefits of asynchronous telepsychiatry visits.

School-based telemedicine can serve as a tool to complement and expand access to children’s health services. It has been associated with a high degree of parent and provider satisfaction as well as reduced absenteeism from school. Pediatric subspecialty school-based telemedicine programs have been developed to care for children with conditions including asthma<sup>13</sup> and diabetes.<sup>14</sup> Although a few studies have reported on the use of telemedicine for the treatment of behavioral disorders in schools,<sup>15</sup> we are not aware of any school-based telemedicine programs that focus on the care of children with DD, particularly those with challenging behaviors. The purpose of this study was to describe the benefits of asynchronous school-based telemedicine for treatment of minor illnesses in the care of children with DD.

## Materials and Methods

We developed the Tele-Health-Kids (THK) program in two schools for children with DD in two rural counties in Northeast Ohio as a school-based telemedicine program that primarily uses store-and-forward technology to connect children with DD to their own primary care physician’s office for care of minor illnesses. Each of the school sites has an AMD-1500 integrated originating site telemedicine workstation (AMD Global Telemedicine, Chelmsford, MA) with a digital otoscope, telephonic stethoscope, digital camera, and video-conference camera. Each of the schools has a certified telehealth assistant trained in use of the equipment who has demonstrated a level of competence in using the equipment. We recruited four local primary care pediatric practices to participate in the project. The practices were chosen because they provide primary care for a large percentage of the students in these schools. For children who do not receive primary care in these four practices, we used the pediatric primary care practice at Akron Children’s Hospital as the default site for their telemedicine visits. Each primary care physician site has a provider site workstation including AMD/AFHCAN software, a receiving telephonic stethoscope, and videoconference camera. The project was approved by the Akron Children’s Hospital Institutional Review Board.

During school events such as an open house or parent-teacher conferences, we obtained consent from parents for their student to participate in THK. At enrollment, parents completed a survey about their knowledge of, expectations for, and concerns about telemedicine. About 1 week after a child’s first telemedicine visit, we contacted the parents by telephone to complete a brief survey about their satisfaction with their child’s first telemedicine visit. If the parents could not be reached by telephone, a survey and a stamped return envelope were mailed to them.

The survey at enrollment gathered demographic, healthcare, and insurance information and asked about the parents’ familiarity with telemedicine and their concerns about and expectations for the THK program. The post-visit survey used a 5-point Likert-type scale from “strongly agree” to “strongly disagree” to gather information about the parents’ experience with and satisfaction with their child’s first THK visit.

We conducted a conference call with school staff at the end of the first year of the program to determine their satisfaction and comfort with the program. We had a conference call with one member of each participating practice at the end of the first year of participation in THK to review their experience with the program.

## Results

The children enrolled in THK had a mean age of 9.2 years (range, 3–21 years). Most were white (96%), and 66% of parents had a high school education or less. Parents reported that annual family income was <\$30,000 for 38% of families, \$30,000–\$49,999 for 32%, and ≥\$50,000 for 28%. Of the children enrolled, 50% had Medicaid, and 45% had private health insurance. The children had many chronic conditions, and some children had multiple chronic conditions (*Table 1*). Most parents (96%) were “not at all” familiar with telemedicine.

**Table 1. Chronic Conditions of Children with Developmental Disabilities Enrolled in the Tele-Health-Kids Network (Based on Parent Report) (n=137)**

CHRONIC CONDITION	PERCENTAGE
Speech delay	28
Autism	24
Cerebral palsy	20
Seizure disorder	20
Attention deficit hyperactivity disorder	13
Down syndrome	12
Asthma	10
Heart defect	10
Severe visual impairment	9
Hearing impairment	4
Other	44

The survey at enrollment (*Table 2*) shows that parents expected less parental stress, more timely care for their child, and less need for travel. *Table 3* shows the results of the post-visit survey. Overall, parents were satisfied with the care their child received. In the early months, technical difficulties accounted for most of the cases where the parents did not express a high level of satisfaction. Most visits (94%) were completed by the physician within 60 min of receipt.

Five staff from the schools participated in a conference call to discuss their impressions of THK after the first year. They described benefits including that follow-up visits were more likely to take place and that medical care was performed in a timely manner. One nurse stated she felt empowered to be directly involved in the child's healthcare because she knew the physician's recommendations and could carry those out in school. The major challenge reported was equipment difficulties in the first few months of the program.

Four primary care physicians and one nurse participated in a conference call about their impressions of THK after 1 year of use. Their major difficulty was having to document both in their electronic medical record and in the THK software. All of the practices agreed to continue participating in the program.

We have performed nearly 200 cases using store-and-forward technology with children with DD. We chose 4 cases to illustrate specific benefits of asynchronous telemedicine for children with DD. Details have been altered to protect identity. We selected these cases to illustrate patient care situations where asynchronous telemedicine provided unforeseen benefits to the patient and where the asyn-

**Table 3. Post-visit Survey and Outcomes (n= 73)**

	PERCENTAGE
Parent responses (% who reported "agree/strongly agree")	
My child found it easier to have a telemedicine visit at school than to travel to the doctor's office.	84%
I am happy with the overall care my child received.	85%
The medical staff at school and at the doctor's office communicated well with telemedicine.	86%
The telemedicine visit, even if I had to pay for it, would still be economical for my family.	88%
I was satisfied with the first telemedicine visit.	95%
I will continue to use telemedicine for my child	100%
Child/parent outcomes as reported by parents	
Child remained in school	84%
Parent remained at work/school (only for parents who work or attend school)	85%
Prescription called/faxed in to pharmacy	15%

chronous telemedicine visit provided more effective and superior clinical care than a traditional in-office visit.

**CASE 1: CEREBRAL PALSY**

N.H. is a 14-year-old girl with spastic cerebral palsy who lives a traditional Amish lifestyle with her family in rural Ohio. When N.H. goes to a medical office, her family incurs considerable expense to hire a driver to transport them from their home. Her family does not have access to a specialized vehicle to accommodate her disability. During the trip, N.H.'s wheelchair is folded and stored while her mother holds N.H. on her lap. Using THK reduces the family's expense associated with transportation and risks of transporting N.H. without equipment designed to accommodate her disability.

N.H.'s parents are conservative about seeking medical care as they do not wish "to inconvenience the physician with unnecessary medical concerns." Because N.H. cannot clearly communicate her needs, her parents sometimes have difficulty determining when it is necessary to seek medical care. THK has provided a viable link among the family, the school, and the primary care office. These trusting relationships have enabled the family to learn which medical concerns require professional attention. THK provides a partnership between the school and the primary care pediatrician to help N.H. obtain quality care at the school for medical concerns before they escalate. The school and the primary care physician are looking after N.H.'s health in a coordinated manner and helping the family to become more knowledgeable and active participants in her care. N.H.'s parents ask the school to perform a telemedicine visit if they do not know whether N.H.'s symptoms are severe enough to require medical attention.

**Table 2. Percentage of Parents Who Responded "Agree" or "Strongly Agree" (n= 158) in the Parent Survey at Enrollment for Tele-Health-Kids (THK)**

	PERCENTAGE
Parents' expectations of THK	
Using THK will be more economical.	84%
THK visits will improve communication between the medical staff at school and my child's doctor.	95%
My child will receive medical care more quickly and more easily.	80%
Less need for travel	87%
I [parent] will be less stressed.	93%
My child will be less stressed.	75%
Parents' concerns about use of Tele-Health-Kids	
My child's doctor will still need to see my child in person after a THK visit.	38%
My child's doctor will not communicate with me as well as in-person.	13%
The school is too busy to help with my child's medical care.	15%

**CASE 2: MULTIPLE DISABILITIES**

S.K. is a 10-year-old girl with multiple chronic health conditions, including heart disease, blindness, and intellectual disability. She is nonambulatory and nonverbal. She requires frequent medical care but has been treated via THK for minor illnesses. S.K.'s parents are both employed outside the home and frequently must take time off from work to accompany S.K. to medical visits. S.K. becomes easily agitated and cries loudly when her daily routine is interrupted. Medical visits performed at school via THK have helped to maintain S.K.'s routine because she is examined by a familiar nurse at school and is diagnosed by her primary care pediatrician while her parents remain at work. S.K.'s parents appreciate that they miss work less often for healthcare visits by using THK and that S.K. receives quality medical care with her primary care pediatrician via THK without becoming excessively distressed.

**CASE 3: DOWN SYNDROME AND ANXIETY**

CJ is a large (82-kg) 16-year-old male with Down syndrome, multiple chronic health conditions, and challenging behavior. His family travels 35 miles to C.J.'s primary care physician's office. C.J. becomes anxious and apprehensive on the way to medical appointments. Because of several painful medical procedures, C.J. has become increasingly resistant to entering medical offices; both of his parents physically must assist C.J. to walk into the office. Because he is so resistant, C.J.'s parents are concerned that they may underestimate the severity of symptoms and not seek medical care when it is needed. C.J. is nonverbal and communicates only through sounds and gestures so his intent is not always clear.

C.J. trusts the nurse at school, who he knows does not draw blood or administer injections. THK has provided the means for C.J. to participate willingly in a medical examination at school leading to successful treatment of minor acute conditions using THK. C.J.'s parents are pleased with the acute care telemedicine visits and are advocating for THK to provide access to subspecialty care for C.J. at school so he can receive medical care without demonstrating oppositional behavior.

**CASE 4: AUTISM WITH DISRUPTIVE BEHAVIOR**

A.B. is a 14-year-old male with autism who becomes overstimulated by the bright lights, people, and environment he encounters when he goes to his primary care office. Because of his aggressive and resistive behaviors, his grandmother, who is his legal guardian, worries that she will no longer be able physically to take A.B. to his primary care office. A.B.'s behavior disturbs others in the office because he sometimes touches, pokes, or slaps other patients in the waiting room. To avoid this, the staff has arranged for A.B. to enter the office through a back door and immediately be escorted to an examination room. If he needs to wait for an extended time, he becomes more agitated, making the physical examination by his pediatrician more challenging, and sometimes impossible.

In contrast, a recent asynchronous telemedicine visit performed by a nurse at his school to examine a skin lesion proved to be a positive experience. A.B. is familiar with the nurse because she administers

medication to him daily. A.B. was cooperative and willingly participated in the examination. THK transmitted the relevant history and images to A.B.'s pediatrician, who diagnosed the skin lesion and called a prescription to the local pharmacy. A.B.'s grandmother refers to THK as "peace of mind," knowing that it provides a more positive experience for A.B. to receive medical care when it is needed.

**Discussion**

Our report demonstrates that families of rural children with DD experience many of the same benefits as other patients who use telemedicine, including reduced travel costs and reduced time lost from work. Parents report a high level of satisfaction with the use of asynchronous school-based telemedicine for their children. Moreover, the cases show that asynchronous telemedicine for rural children with DD may result in additional, more specific benefits for the child, parents, and healthcare providers. These include avoiding the need for special equipment or staff during travel, decreasing stress for the child and parents, and increasing the likelihood of a successful examination. Furthermore, Case 4 shows reduced risk to healthcare staff and other patients by avoiding situations that trigger disruptive behavior. Because many children with DD have limited communication skills, it is difficult for parents to determine whether their child's illness requires professional care. Because an asynchronous telemedicine visit was easier to perform, families often asked for telemedicine assessments of symptoms about which they were unsure. This helped parents to become more confident in their ability to determine how severely ill their child was and whether professional care was needed. Families have shown confidence and comfort with the use of technology for healthcare, similar to reports of e-visits where patients use telemedicine to determine whether care is needed for symptoms that may be considered routine.<sup>16</sup> These relatively unique benefits of asynchronous telemedicine for children with DD have not been described previously and indicate that, in some situations, asynchronous telemedicine may be superior to in-office care for children with DD.

Some studies of telepsychiatry have noted that children with developmental delays are difficult to assess adequately with telemedicine.<sup>11</sup> In contrast, Pakyurek et al.<sup>7</sup> suggested that for some children with attention deficit hyperactivity disorder or autism telemedicine may be superior to traditional in-person visits. Our cases suggest that many children with other types of DD tolerate the use of asynchronous telemedicine equipment well and that physical examination may be performed with less distress to the patient than is experienced in many in-person visits.

Our cases illustrate that many children with DD and challenging behaviors tolerate the use of asynchronous telemedicine equipment well. By receiving care in a familiar environment with less disruption to their routine, children with DD and challenging behaviors were likely to cooperate with the evaluation. Parents of children with DD often are under great stress and many times express dissatisfaction with some aspects of the care from their child's primary care physician. Liptak et al.<sup>17</sup> found that parents of children with DD ranked primary care providers very low on their understanding of stress on the family related to caring for the child with DD. Cases 3 and 4 illustrate how

asynchronous telemedicine reduced stress associated with seeking medical care for the families and for the children with DD.

Caring for children and adolescents with DD presents many complexities for primary care providers and their staff. Accessing care for these patients is often very stressful to the child, to the parents, and to other family members. When children are able to receive care in a less threatening environment and are less stressed by the visit, more positive outcomes for the child and family are likely. Reducing the likelihood of challenging behaviors also may result in a more successful and less stressful experience for healthcare providers and their staff.

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### Disclosure Statement

No competing financial interests exist.

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