Supporting the Needs of Children with Autism Spectrum Disorders in an Educational Setting using a Telemedicine Platform

Tyler Whitney Psy.D.[1], URLEND Trainee, Vauna Gross[2], URLEND Trainee, Audiology

[1]Intermountain Center for Autism and Child Development (ICACD), Meridian, Idaho

[2] Department of Audiology, Utah State University, Logan, Utah

Address correspondence and reprint requests to Tyler Whitney Psy.D., 2273 East Gala Street, Suite 120, Meridian, Idaho 83642; Tel: (208) 888-7104; Fax: (208) 321-4789; email: twhitney@icacd.org

Key Words: autism spectrum disorders, desired behavior, telehealth, video capture, personal electronic health record, individual education plan (IEP), Behavior Capture™ , Behavior Connect™

Abstract

Development of a new video capture and personal electronic health record platform has been created which will allow families with school age students who have autism spectrum disorders to document their child's developmental and academic progress and share this information confidentially with school personnel who can then assist the parents with creating an individual education plan (IEP) that will better serve each student with autism. The technology is easy to use and will provide parents and multidisciplinary school team members with a tool to disseminate pertinent developmental, emotional, and behavioral information about their child. The new platform meets the security, privacy, and control requirements associated with the multifaceted legal landscape of the USA. Current studies indicate that application of this type of platform in school settings as well as in the home environment are being received favorably by parents, educators, and healthcare providers alike. The new technology is being commercialized in the United States and internationally to the autism community under the trade names Behavior Capture™ and Behavior Connect™.

Supporting the Needs of Children with Autism Spectrum Disorders in an Educational Setting using a Telemedicine Platform

Autism has become one of the fastest-growing and most prevalent childhood developmental disorders in the United States. Autism is a neurological disorder that interferes with a child's normal development in language, intuitive thought, social interaction, and the ability to connect with surroundings (Reischl & Oberleitner, 2009). Researchers have not always distinguished between people with autism or high-functioning autism (Gutstein & Whitney, 2002). In fact, Kanner-type autism and Asperger's disorder are collectively often referred to as autism-spectrum disorders (ASDs), a designation that underscores the difficulty in separating Kanner-type autism from Asperger's disorder. Regardless of whether they are separate disorders or exist along a continuum, ASDs are quite heterogeneous and affect each individual differently in terms of learning ability, learning style, socialization, and communication (Greenspan & Weider, 1997; Gutstein, Burgess, & Montfort, 2007; Solomon, Necheles, Ferch, & Bruckman, 2007). Consequently, the need for highly specific individualized education plans exists for students with autism spectrum disorders in school settings.

Evaluation of a student's needs in a school setting has traditionally been done using standardized measures and functional behavioral assessment and analysis, which are reviewed by school based multidisciplinary treatment teams. These multidisciplinary school teams include parents, administrators, educators, special educators, and various other professionals depending on the students individual needs. These evaluations are routinely performed every 12 months and on a more in depth level every 36 months. Student performance in the school setting and behavior at school have become a key indicator for assessing a student's development and progress through life. A student's behavior also provides the basis for determining which behavioral, educational, or family supports may be effective in managing behavior that disrupts learning or is inappropriate in the school setting. Parents and educators must, therefore, be able to document a student's development over the course of their school career in order to establish and communicate a student's progress.

A convenient and universally applicable personal health record system and communication platform has not been available in the past that could address the needs of both parents and educators. The standard practice has been to record and communicate information about the child's behavior and health status using hand written "paper and pencil" reports which are then photo-copied and filed in notebooks and sent via fax or through the postal system. Sometimes off-the-shelf video conferencing hard-ware and software are used. Video and still images are e-mailed on insecure lines. These methods are not efficient and not readily available to all parties at every school site where a student may have attended or might currently be attending. Consequently, communication is not enhanced, but can be arduous and cumbersome. Storage and security can also be problematic.

Behavior Capture™ is an example of a novel Behavioral Imaging technology that also enables store-and-forward telehealth. This software-based video capture technology allows a

parent or caregiver as well as multidisciplinary school team members to save brief video clips of both pertinent special education information and behavioral incidents and the moments leading up to and resulting from these occurrences. Pertinent developmental and special education information is stored for later sharing with multidisciplinary school team professionals, either on a local PC or remotely through a secure consultation and records environment (such as Behavior Connect™).

A more active and effective partnership between parents and school multidisciplinary teams is necessary to address the challenges of supporting students with autism spectrum disorders. New telehealth technologies and electronic medical records storage and retrieval systems offer convenient and user friendly opportunities for parents and multidisciplinary school team members to communicate their current observations in an effective and regular fashion with security safeguards. By capturing, viewing, annotating, and sharing developmental growth in the academic setting with school based multidisciplinary team professionals, this enables all team members to better understand students with autism spectrum disorders and to provide the highest level of support in the school setting through the special education process. Multidisciplinary school team members can frequently receive pertinent information about the student with an autism spectrum disorder to get a solid idea of progress made over time. Progress can be archived by gathering short, relevant video captures over long periods of time and reviewing this data periodically to gain understanding of the student's development and current areas of concern.

Using a research method known as “backward mapping” (Walker & Koroloff, 2007), which begins at the “lowest” level of intervention, the multidisciplinary school team members, we can “identify the policies, resources, and supports that are needed from “higher” levels if the desired behavior is to occur” (Walker & Koroloff, 2007). The “desired behavior” in this project is defined as adequate learning by the child with an autism spectrum disorder in the academic setting.

“Students who interact with their peers during lessons are more motivated, more engaged with the material, and more capable at learning language, communications, and listening skills” (Harrison, 2010). However, students with autism spectrum disorders have long lived academic lives of various levels of isolation. Communication is difficult and social interaction is often much less than that of their typically developing peers (Gutstein & Whitney, 2002). Teaching students with autism spectrum disorders can be difficult in a school setting. Globally understanding the needs of a student with an autism spectrum disorder and their family is critical in supporting them in an academic setting.

Methods

Subjects

All three research design application subjects and their families came from a private, community-based clinic specializing in the treatment of ASDs in children, adolescents, and young adults. There was no need for a University Institutional Review Board to approve the research and its associated procedures as it is simply a research design application method at the current stage. To obtain subjects for this research design application,

Dr. Whitney identified and approached the parents or caregivers of potential subjects asking whether they would consider having their child or adolescent voluntarily participate in this research design application. In the cases where the participants themselves were capable of determining whether they would like to be involved in the research, Dr. Whitney also asked the potential subjects if they would like to participate in the research design application. Inclusion criteria for the study were: (1) a willingness to participate in the study, (2) current enrollment in the clinic, (3) age which would necessitate school attendance (5-18 years), and (4) a diagnosis of an ASD.

In all, three families provided informed consent for research design application participation. There were no families excluded because this was a research design application. All participants and their families are currently enrolled in treatment at the Intermountain Center for Autism and Child Development in Meridian, Idaho. All parents and caregivers gave informed consent to voluntarily participate in this research design application. Current care is under the direction of Tyler Whitney, Psy.D., Founder and Clinical Director of ICACD. Participation in no way influenced treatment of the participant and their family. The participants were of school age, one elementary school age, one middle school age, and one high school age. All participants currently carry a confirmed diagnosis on the autism spectrum.

Evaluation Tools

For the current research design application, a simple pre / post experience questionnaire was given. Each set of parents (3) were asked to complete pre and post standardized surveys regarding usability, functionality, and applicability of the technology to their multidisciplinary school teams. The research design application results indicate that all three users support the use of such a technology in school settings and believed that this technology would be widely accepted by the multidisciplinary school teams when improvements in student behavior are documented and then used to improve individual education plans and school support.

However, A twelve-month pilot study would need to be conducted to evaluate the benefits of the new behavior imaging technology in a field environment (Whitney, Oberleitner, & Reischl, 2011; in progress). The evaluation will focus on functionality and usability of the technology by parents and the multidisciplinary school team. Perceived usefulness in facilitating better communication, more effective individual education plans, and more effective school supports for students in grades kindergarten through 12 with autism spectrum disorders is currently being assessed.

Procedures

We utilized store and forward technologies, Behavior Capture™ and Behavior Connect™ allowing the parents or caregivers to create a map (electronic medical record) (Walker & Koroloff, 2007) of the student with an autism spectrum disorder and the family system. A general outline of a brief developmental history was constructed and given to each parent prior to taping the map. For

the purpose of this project, these maps have been and can be easily designed in a general sense by a clinical professional or multidisciplinary school team member (in this case, clinical psychologist) and are personalized with details provided by the student's parents. This map will be utilized by the multidisciplinary school team of the student with an autism spectrum disorder to create a fuller knowledge of the student with an autism spectrum disorder and their developmental history. Data analysis for the research design application was simply a review of each map and technical reformatting as needed.

Results & Discussion

Response by clinicians and families in this research design application were hopeful and positive, highlighting the promise of using a telehealth platform in allowing families to share important developmental background information with multidisciplinary school team members, both initially and in an ongoing manner. Recording and storing data for electronic medical records appears to be efficient, meaningful and safe. Use of technology allows more access for individuals and specialists both in and out of school systems. However, larger and more diverse populations need to be studied including broader populations in special education. Other healthcare providers outside the school system should also be considered for consultation on multidisciplinary school teams based on the needs of each student including, but not limited to, psychiatry, pediatrics, family medicine, audiology, and nutrition.

Results from larger telehealth studies including Solicitation Number: F1ATD49141A002-Air Force Medical Service, which the lead author participated in, as well as NIH SBIR Phase 2 grant -2R44HD052340-02, which included Georgia Institute of Technology (GIT), Boise State University (BSU), and Behavior Imaging, formerly Caring Technologies in Boise, Idaho, USA suggest that "Use of video-capture technology such as Behavior Capture™ in conjunction with personal electronic health record systems such as Behavior Connect™ will allow parents, schoolteachers, and caregivers to record a child's behavior at home and in the school for subsequent evaluation by specialists nationally as well as internationally" (Reischl & Oberleitner, 2009). Clearly, use of a telehealth platform to disseminate pertinent information to multidisciplinary school teams has the potential to provide more accurate information about the student, reducing costs to the education system and the parents, and allowing for more access to specialists and experts outside of the local, regional, and national area.

Ultimately, the goal of better information sharing at the direct service level is to improve support within the school setting for students with autism spectrum disorders who require special education. By providing a more efficient, user friendly, and secure method for sharing information amongst multidisciplinary school team members, it is the objective of this research design application to suggest a powerful method to better understand the specific needs of a student with an autism spectrum disorder.

References

1. Cox, K. F. (2005). Examining the Role of Social Network Intervention as an Integral Component of Community-Based, Family Focused Practice. Journal of Child and Family Studies (14:3); pp. 443-454.
2. DeAngelis, T. (2010). Placing the Patient Front and Center. American Psychological Association (41:11); pp. 42-45.
3. Greenspan, S. I., & Weider, S. (1997). Developmental Patterns and Outcomes in Infants and Children with Disorders in Relating and Communication: A Chart Review of 200 Cases of Children with Autistic Spectrum Disorders. *The Journal of Developmental and Learning Disorders. (1)*; pp. 87–141.
4. Gutstein, S. E., & Whitney, T. (2002). Asperger's syndrome and the development of social competence. *Focus on Autism and Other Developmental Disabilities. (17)*; pp. 161-171.
5. Gutstein, S. E., Burgess, A. F., & Montfort, K. (2007). Evaluation of the Relationship Development Intervention Program. *Autism. (11)*; pp. 397-411.
6. Harrison, D. (2010). Meeting the Needs of Special Needs Students Virtually. *The Journal.com*; 12/08/2010 pp. 1-4.
7. Oberleitner, R., & Laxminarayan, S. (2004). Information Technology and Behavioral Medicine: Impact on Autism Treatment & Research. Studies in Healthcare Technology and Informatics (103); pp. 215-222.
8. Reischl, U., & Oberleitner, R. (2009). Development of a Telemedicine Platform for the Management of Children with Autism. *German Journal for Young Researchers 1(1)*; pp.
9. Solomon, R., Necheles, J., Ferch, C., & Bruckman, D. (2007). Pilot study of a parent training program for young children with autism. *Autism. (11)*; pp. 205-224.
10. Walker, J.S., & Korloff, N. (2007). Grounded Theory and Backward Mapping: Exploring the Implementation Context for Wraparound. *Journal of Behavioral Health Services and Research (34:4);* pp. 443-458.

Acknowledgments

This project would not have been possible without the concerted efforts of our team members from different specialty backgrounds. In particular, we would like to thank our Faculty Mentor, Gwen Mitchell, Ed.S., for her belief in our abilities, advice, and encouragement; our participant families, Brad and Dana Peachy and their son, Ian, and Paul and Richelle Tierney, and their son, Nicholas, and Joseph and Diana Abramowski, and their son, Matthew. These families are tireless in their advocacy on behalf of their children and in parenting their children. We would also like to thank Behavior Imaging, specifically, Ron Oberleitner, CEO and Chairman of the Board, whose inspiration and belief in technology is changing the face of service delivery for autism spectrum disorders. In addition, we would like to thank our discipline coordinators, again, Gwen Mitchell, Ed.S., and Richard Harward, Au.D., CCC-A., the URLEND leadership project coordinator, Vicki Simonsmeier, M.S., CCC-SLP/Aud, and the URLEND co-directors, Judith Holt, Ph.D. and Sarah Winter, M.D. without whom this program and project would not have been possible.