Clinical Overview of the Need for Technologies for Around-the-Clock Monitoring of the Health Status of Severely Disabled Autistic Children

Gary Singleton, Steve Warren, *Member, IEEE*, and Wayne Piersel

***Abstract*—Despite the growing incidence and costs of autism, little has been done to apply technology advancements to the challenges faced by autistic individuals. The recent introduction of digital data collection to track the progress of treatment interventions has been an important contribution, but there are many other opportunities for technology to facilitate the development of autistic children and to assist the clinical staff who work with them. The realization of wearable devices to identify and track behaviors would significantly reduce the manual input of data into digital devices, and wireless physiological monitoring has the potential to provide predictors of unwanted behaviors. The development of such tools would change the intervention paradigms that currently exist.**

***Keywords*—autism, behavior tracking, disabled children, wearable devices, wireless sensor networks**

I. Introduction

Recent data from the Centers for Disease Control and Prevention estimate that the prevalence of autism spectrum disorder (ASD) is one in 88 children in the United States [1]. In 2007, Ganz estimated the annual cost of autism in this country at $35B [2]. Mandell and Knapp placed the annual cost closer to $137B [3]. Despite the growing incidence and cost of autism, little has been done to apply technology advancements to the challenges of individuals with autism beyond the use of augmentative communication devices [4], iPads and their associated applications [5], and socially assistive robots in therapeutic learning environments [6].

Autistic children often have difficulty with social interaction and communication, supplemented by a tendency towards repetitive behaviors. More severe cases may include an absence of verbal communication, poor self-help skills, and/or self-injurious or aggressive behaviors. These children are most often educated in specialized classrooms or occasionally in residential programs with highly trained intensive staffing. Intervention strategies are typically evidence-based practices that are primarily behavioral approaches, which require extensive data collection to assure that each approach is having the desired effect [7]. Traditionally, these data have been collected via paper and pencil, aggregated, entered into a spreadsheet, graphed, and returned to treatment teams for analysis and decision-making. Only recently has this process been streamlined with apps written for smart phones or iPods [8]. Past and current data collection processes are illustrated in Figure 1.

Manuscript received April 2, 2014 and accepted June 2, 2014. This work was supported in part by the National Science Foundation under grant CBET–1067740. Opinions, findings, conclusions, or recommendations expressed in this material are those of the author(s) and do not necessarily reflect the views of the NSF.

Dr. Gary Singleton and Dr. Wayne Piersel are with Heartspring, 8700 East 29th Street, Wichita, KS 67226 USA (gsingleton@heartspring.org; wpiersel@heartspring.org). Dr. Steve Warren is with the Department of Electrical & Computer Engineering, Kansas State University, Manhattan, KS 66506 USA (swarren@ksu.edu)

II. Opportunities

A. Wearable Devices for Behavior Identification

Though the digitization of the data collection process has been tremendously beneficial, more could be done to make the data gathering process seamless and less of a burden on staff who work with challenging students. The rapid evolution of body-worn sensors and devices can help to automate the identification of many behaviors that are being manually counted on digital devices. Figure 2 depicts this data collection and processing approach to aid children with severe disabilities and the staff that support their progress. For example, some children with autism will engage in self-injurious behaviors such as hitting their head. Sensors that can detect hand movement to the head and can differentiate between an unwanted behavior and a normal behavior, then upload the information to the database, would eliminate the need for human data entry into an iPod. Similarly, other behaviors such as hand or finger flapping, hand banging, rocking, dropping, jumping, climbing, tantrums, elopement, or loud vocal sounds may be better monitored by wearable sensors [9, 10]. Beyond relieving the staff of the data collection burden, the reliability of the data would be significantly enhanced. Table 1 offers a more comprehensive list of behaviors that are of interest.

B. Wireless Sensor Networks for Behavior Prediction

Wireless sensor networks have been used to monitor the activity levels and physiological well-being of patients in the hospital and in their homes [11]. A recent review of wearable sensors and systems discussed their application in the areas of medical and safety monitoring, home rehabilitation, evaluation of treatment efficacy, and early detection of disorders. Sensors are now available that monitor body temperature, position, heart rate, respiratory rate, blood oxygen saturation, electrocardiographic activity, and galvanic skin response [12]. Initial research with children with autism has measured heart rate, temperature, and galvanic skin response in an effort to detect changes in the autonomic nervous system that may predict subsequent behaviors [13]. The development of algorithms based on physiological data that would alert staff to the increased potential for maladaptive behaviors would significantly change the intervention strategy from responding to a behavior to avoiding the behavior altogether (see Figure 3).

978-1-4244-7929-0/14/$26.00 ©2014 IEEE

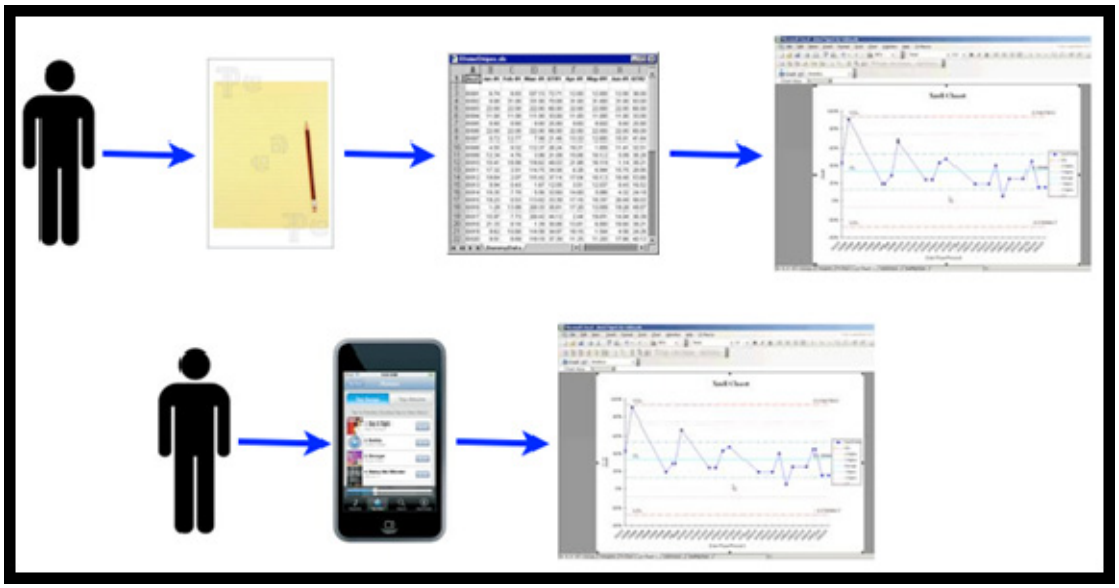

Figure 1. Past (upper) and current (lower) processes for collecting data related to children with autism.

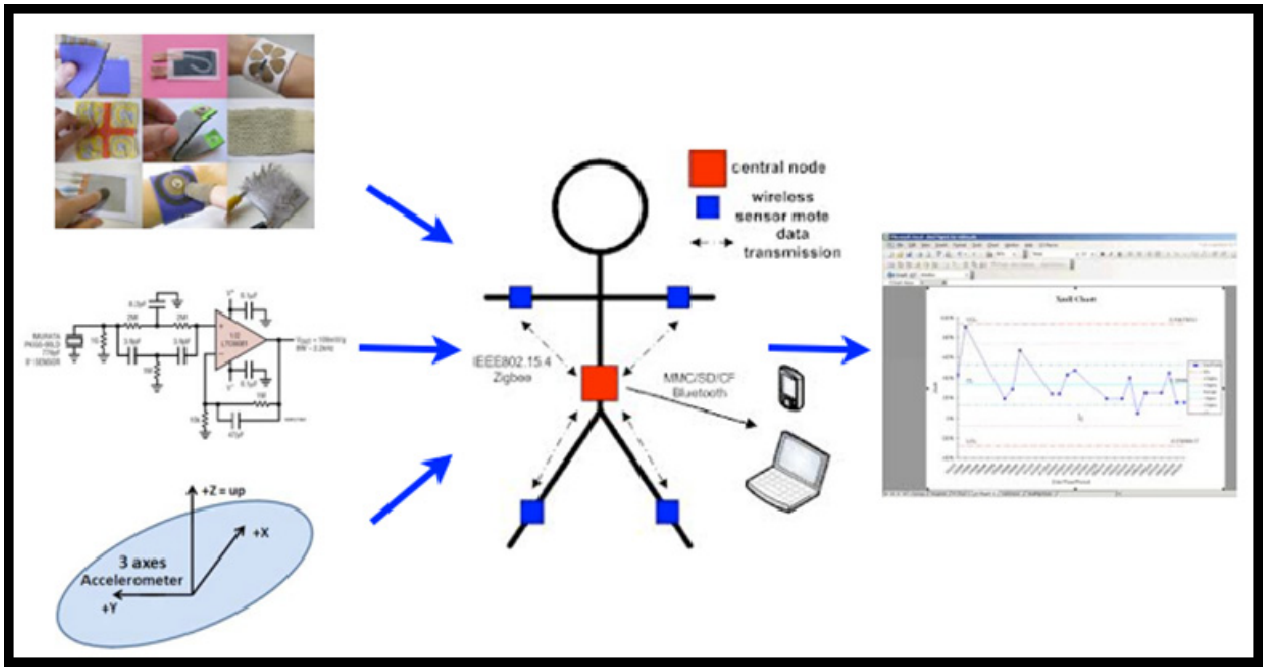

Figure 2. Potential future data collection process.

Table 1. Current behaviors tracked for the severely disabled children at Heartspring (most to least common).

1. Aggression	8. Food Stealing	15. Stripping/disrobing	22. Loud vocal sounds	29. Crying
2. Self-injurious behavior	9. PICA	16. BM accident	23. Stalling	30. Hand banging
3. Property destruction	10. Inappropriate Touch	17. UR accident	24. Motor movement tics	31. Picking
4. Tantrum	11. Inappropriate Talk	18. Smearing	25. Hands in pants	32. Public masturbation
5. Elopement	12. Restraint	19. Invading Personal Space	26. Lying	33. Hoarding
6. Dropping	13. Interfering with others	20. Time out room	27. Spitting	34. Self-stimulatory behavior
7. Perseveration	14. Intimidation	21. Non-cooperation / non-compliance	28. Rumination	35. Climbing

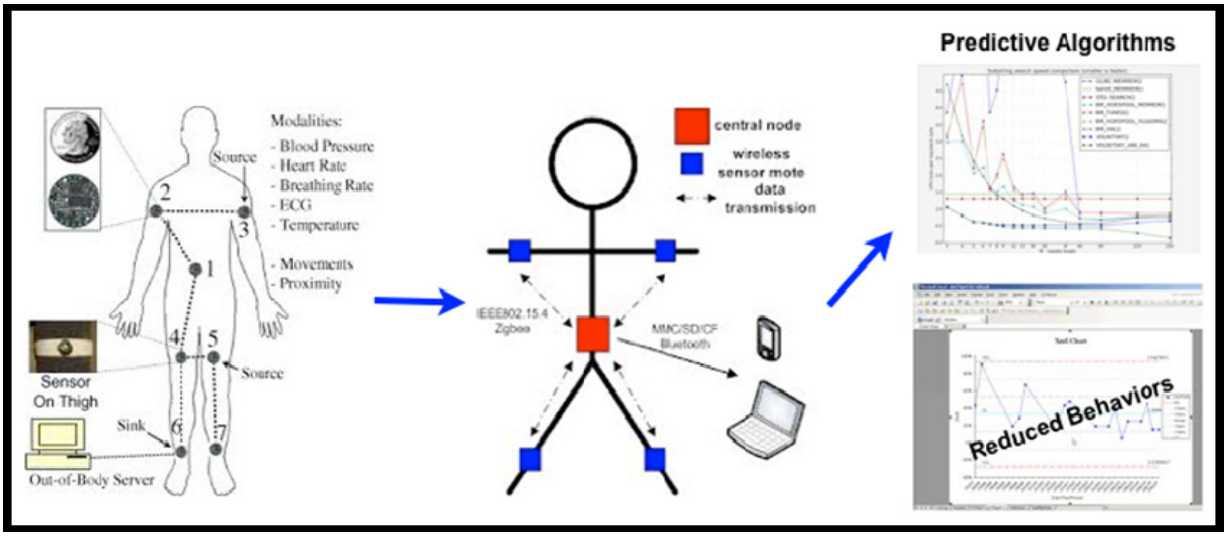

Figure 3: Wireless physiological monitoring toward the development of algorithms predictive of behaviors.

C. *Location Tracking Tools*

An additional area of opportunity is the development of resources that provide location tracking of students and staff with a resolution measured within inches. Since students with the most severe challenges of autism are intensively staffed one-to-one, tracking tools would help to archive student location versus time as well as identify nearby staff and other students, given that these and other factors can contribute to the onset of behaviors. Such a system would also facilitate the optimization of staff assignments, quantify student independence, and find wandering students.

III. Design Constraints

Applicable sensor-based devices need to be durable and unobtrusive. Children with autism may be sensitive to new stimuli that are introduced into their environment and particularly to devices that might be worn [14]. An increased probability of destructive behavior would exist should such devices prove to be irritating [15]. Simplicity in design and processing of information is important, as staff working with autistic children often have minimal technical proficiency.

IV. Conclusion

The applications discussed are straightforward in concept, but each offers implementation challenges in the areas of signal processing and hardware design, device robustness/comfort, acceptance by students/staff, and the analysis and interpretation of large quantities of data. However, successful implementation of any of these systems has the potential to make a real difference in the lives of children and in how services are provided for them.

References

[1] CDC. "Prevalence of Autism Spectrum Disorders-Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008," *MMWR*, Vol. 61, No. SS-03, 2012, pp. 1–19.

[2] Ganz, M. "The Lifetime Distribution of the Incremental Societal Costs of Autism," *Arch Pediatr Adolesc Med*, Vol. 161, No. 4, 2007, pp. 343–349.

[3] Mandell, D. and M. Knapp. "Estimating the Economic Costs of Autism," *Investing in Our Future: The Economic Costs of Autism*, Hong Kong, March 31, 2012.

[4] Baxter, S., P. Enderby, P. Evans, and S. Judge. "Barriers and Facilitators to the Use of High-Technology Augmentative and Alternative Communication Devices: A Systematic Review and Qualitative Synthesis," *Intl Journal of Language and Communication Disorders*, Vol. 47, No. 2, March–April 2012, pp. 115–129.

[5] Shane, H., E. Laubscher, R. Schlosser, S. Flynn, J. Scorce, and J. Abramson. "Applying Technology to Visually Support Language and Communication in Individuals with Autism Spectrum Disorders," *Journal of Autism and Developmental Disorders*, Vol. 42, No. 6, June 2012, pp. 1228–1235.

[6] Scassellati, B., H. Admoni,, and M. Mataric. "Robots for Use in Autism Research," *Annual Review of Biomedical Engineering*. Vol. 14, 2012, pp. 225–294.

[7] National Autism Center (NAC). *National Standards Report*, 2009, http://www.nationalautismcenter.org/nsp/reports.php.

[8] Marcu, G., K. Tassini, W. Carlson, J. Goodwyn, G. Rivkin, K. Schaefer, A. Dey, and S. Kiesler. "Why Do They Still Use Paper? Understanding Data Collection and Use in Autism Education," *CHI 2013: Changing Perspectives*, Paris, France, 2013, pp. 3177–3186.

[9] Fahd, A., M. Goodwin, S. Intille, and W. Velicer. "Automated Detection of Stereotypical Motor Movements," *Journal of Autism and Developmental Disorders*, Vol. 41, No. 6, pp. 770–782.

[10] Gonçalves, N., J. Rodrigues, S. Costa, and F Soares. "Automatic Detection of Stereotyped Hand Flapping Movements: Two Different Approaches," *2012 IEEE RO-MAN: The 21st IEEE International Symposium on Robot and Human Interactive Communication*, September 9–13, 2012, Paris, France.

[11] Ko, J., C. Lu, M. Srivastava,, J. Stankovic, A. Terzis, and M. Welsh. "Wireless Sensor Networks for Healthcare." *Proceedings of the IEEE*, Vol. 98, No. 11, November 2010, pp. 1947–1960.

[12] Patel, S., H. Park, P. Bonato, L. Chan, and M. Rodgers, "A Review of Wearable Sensors and Systems with Application in Rehabilitation." *Journal of Neuroengineering and Rehabiliation*, 2012, pp. 9–21.

[13] Goodwin, M. "Computational Behavioral Science: Developing Innovative Technology to Enhance Research and Practice in Individuals with Autism Spectrum Disorder," *Autism Spectrum Disorders: From Research to Practice Conference*, June 11–12, 2013, Galway, Ireland.

[14] American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th Ed.),* 2013.

[15] Matson, J. and M. Nebel-Schwalm. "Assessing Challenging Behaviors in Children with Autism Spectrum Disorders: A Review," *Research in Developmental Disabilities,* Vol. 28, Issue 6, 2007, pp. 567-579.