

# Data recording of seizures in children with autism spectrum disorder: description and social validation of computer-assisted measurement

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Some children with autism spectrum disorder (ASD) experience seizures and associated staring episodes, loss of consciousness, weakened muscle tone, and myoclonic jerking. Data recording of seizure frequency, duration, and co-occurring behavior is necessary to document the effects of anti-epileptic medications, identify contextual influences on seizure expression, and differentiate seizures from other movement disorders. We describe the design and operation of a computer-assisted system for recording seizures among children with ASD in a social validity study that revealed uniform approval and acceptance of the system from practitioners, clinicians, and nurse ( $N = 22$ ), parents ( $N = 11$ ), and neurologists ( $N = 7$ ). The objectives and benefits of targeting the social validity of technology-based seizure tracking are discussed.

**Keywords:** autism spectrum disorder; data recording; health monitoring; human services settings; seizures

## Introduction

Some children with autism spectrum disorder (ASD) experience seizures, with prevalence rates reported in a range of 2.7%–46% (Canitano, 2007, Strasser *et al.*, 2018, Thomas *et al.*, 2017, Tuchman and Rapin, 2002). The variability in prevalence estimates likely is due to different sampling methodologies, diagnostic criteria, and the ages plus cognitive levels of participants across studies (Spence and Schneider, 2009, Turk, 2009, Viscidi *et al.*, 2013). Multiple factors associated with seizures in ASD include intellectual disability, older age, poor communication skills, adaptive functioning deficits, and developmental regression (Bolton *et al.*, 2011, Viscidi *et al.*, 2013). The clinical effects from seizures are many, such as motor difficulties, high rates of stereotypy and problem behavior, delayed language acquisition, and more severe autism symptoms (Ko *et al.*, 2016, Tuchman and Cuccaro, 2011). Seizures are commonly diagnosed from electroencephalogram (EEG) recordings of abnormal electrical rhythms in the brain but sometimes, seizure activity on an EEG does not correspond with changes in overt behavior.

However, whole body shaking movements (generalized seizures), jerking of the head, torso, and extremities (myoclonic seizures), loss of muscle tone with falling to the ground (atonic-tonic seizures), and staring episodes (absence seizures) occur frequently.

Documenting the physical manifestation of seizures is necessary for several reasons. First, data on seizure frequency and duration can confirm EEG findings or support further assessment when observable behavior and electrical activity are dissimilar (Neill and Alvarez, 1986). Second, occurrence of seizures through direct observation and data recording provides outcome measures to evaluate the effects of anti-epileptic medications and other prescribed treatments for seizure control (Frye *et al.*, 2011). Thus, treatment decisions emerge from the analysis of seizure data. A third function of data recording is to determine whether seizures occur more frequently or not at all under certain environmental conditions. These data could suggest changes to variables such as ambient lighting, noise, and activities. Finally, data can assist with differentiation of seizures from tics, motor stereotypy, and other movement disorders often seen in children with ASD (Frye *et al.*, 2016).

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Braga-Kenyon *et al.* (2015) also proposed that practitioners, specifically behavior analysts, should be concerned with seizure tracking in the context of multidisciplinary teams serving children with ASD. They noted that ‘regarding seizures, there are data that the neurologist may not have access to and that the behavior analyst may want to share’ (p. 23). In illustration, Zlutnick *et al.* (1975) had care providers record behavior indicative of seizures in five children (4–17 years old) characterized by body rigidity, spasms, staring, myoclonic jerking, fist-clenching, arm-head flexion, and facial grimacing. These data served as outcomes measures in evaluating response interruption and differential reinforcement programmed to reduce seizures. Cataldo *et al.* (1979) also used observational data recording by hospital staff to measure myoclonic seizures in a 4-year-old child and assess intervention effectiveness from medication and contingency management.

Recently, digital platforms with web applications have been designed for persons to self-monitor and track seizures as well as communicate with health professionals (diary.epilepsy.com). Self-recording tools are useful with individuals who have the requisite operational skills but not among children and adults challenged by severe intellectual and developmental disabilities. Advances in computer technology and instrumentation have improved the quality, practicality, and portability of data recording by care providers (Kazemi and Ramirez, 2018, Whiting and Dixon, 2014, Yanagita *et al.*, 2016), suggesting utility with children who have ASD and seizures within their care environments. To maximize utilization, computer-assisted measurement should be relatively easy to implement. As well, the persons conducting data recording should approve the applicable methods and outcomes. Third, a principal reason for designing innovative methods of seizure tracking is to provide data that permit objective evaluation of treatment effectiveness and inform intervention choices by educational, therapy, and medical professionals concerned with seizure control.

The purpose of the present study was to socially validate a computer-assisted system for recording seizures in children with ASD at an education-treatment setting. Wolf (1978) described social validity from the perspective of consumer satisfaction, namely do the recipients of intervention and training judge the services they received as effective and acceptable? Service objectives, methods, and outcomes are targeted through social validity assessment (Kazdin, 1977, Foster and Mash, 1999) which usually consists of surveys and questionnaires distributed to direct (e.g. clients, practitioners, families) and indirect (e.g. administrators, community members) stakeholders (Schwartz and Baer, 1991). With regard to technology advances for data recording among persons with developmental disabilities, the results of social validity assessment can

confirm system utility, determine factors that contribute to consumer appeal, and suggest procedural changes. For care providers, in particular, positive social validity is desirable because it suggests that highly approved methods and procedures will be implemented and maintained with fidelity (Common and Lane, 2017, Luiselli, 2021).

Notably, the present study did not evaluate the reliability and accuracy of the computer-assisted system of seizure tracking, document the effects of training on care providers, or compare the system to other measurement methods. Rather, we describe the design and operation of the system, how care providers were trained to implement procedures, and the manner by which multiple stakeholders received seizure data as the context for social validity assessment. That is, the study focused exclusively on perceptions of the system as preliminary assessment to warrant further ‘user-inspired’ research (Erath *et al.*, 2021) directed at technology applications in service settings.

## Method

### Participants and setting

The study included three groups of participants who responded to a social validity questionnaire based on their knowledge of and experience with the seizure tracking system, described below. The first group was comprised of clinicians, program coordinators, classroom instructors, group home care providers, and nurses ( $N=25$ ) at a private residential school for 50 students (8–22 years old) with ASD and intellectual disability. These participants (hereafter, school staff) had a minimum of six months experience recording and reviewing data from the computer-assisted seizure tracking system with 11 identified students ( $M$  age = 17.5 years, three females, eight males) who had exhibited at least one seizure during the preceding 12 months. The second group of participants was parents ( $N=11$ ) of the identified students. These parents were provided seizure data each month and additional updates from the school at the time of neurology appointments. Finally, the neurologists ( $N=11$ ) who followed the students, also received seizure data, and conferred with parents formed the third group of participants. Thus, the participant sample represented individuals who could judge the system from three perspectives: (a) school staff implemented the system and analyzed seizure data, (b) parents received seizure data for progress monitoring and to reference during visits with their child’s neurologist, and (c) neurologists had access to the seizure data in confirming the therapeutic effectiveness of anti-epileptic medications.

Students at the residential school attended classrooms for approximately seven hours on weekdays and lived in six community group homes operated by the school. Classrooms were comprised of 5–6 students, a

**Table 1. Rank ordered social validity ratings by school staff (N = 22).**

Questionnaire statements	Average rating
The seizure tracking system produces data that informs decisions about the effectiveness of prescribed medications	4.6
The seizure tracking system is useful in recording frequency, duration, and specificity of seizures among the student population	4.5
The seizure tracking system enables care providers to record seizures reliably	4.5
The seizure tracking system is easy to implement and monitors seizures over an extended period of time	4.5
The seizure tracking system provides parents with useful data to review with their child's neurologist	4.5

Note: 1 = strongly disagree, 2 = disagree, 3 = neither disagree nor agree, 4 = agree, 5 = strongly agree.

primary teacher, and 3–4 teacher assistants. In the group homes, day and overnight care providers were present with the students seven days per week. The classroom instructors and group home care providers followed procedures outlined in student Individual Educational Programs (IEPs), implemented behavior support plans, managed daily living routines, and conducted environmental maintenance, among other responsibilities.

### Social validity assessment

The authors designed social validity questionnaires that contained five (school staff and parents) and three (neurologists) statements about the objectives, implementation, and application of the computer-assisted system. The questionnaire statements were derived from discussions we had about facets of the system best suited to the participant groups that would be informative and narrow enough in scope to promote a high return rate (Common and Lane, 2017, Luiselli, 2021, Schwartz and Baer, 1991). Specifically, the statements posed to participants concerned utility of system data recording, facility of measurement, usefulness of documenting seizure frequency-duration, and decision making about the effectiveness of prescribed medications (the actual questionnaire statements are detailed in Table 1 and Table 2 with the accompanying results). Participants endorsed one of five numerical ratings per statement according to a Likert-type scale (1: strongly disagree, 2: disagree, 3: neither disagree nor agree, 4: agree, 5: strongly agree).

The questionnaires were distributed to the participants via an online platform (SurveyMonkey®) which they were requested to complete anonymously and return on or before a specified deadline date. As depicted in Table 1 and Table 2, each questionnaire statement was a declarative sentence presented to the participants in an unbiased manner without implied responses. Data were quantified as the average numerical rating per questionnaire statement from the sum of item ratings divided by the number of participants responding to the statements.

### Seizure tracker system design and operation

The seizure tracker system selected for social validity assessment records, reports, and provides electronic notification of seizure events to nursing and administrative staff in a proprietary software created at the residential school. Specifically, school staff access the system whenever they observe students experiencing a seizure evident from observable behavior anywhere in the school environment (e.g. classrooms, group homes, outdoor campus). The behavior signifying a seizure is listed and defined for individual students. Steps for system operations are as follows:

1. Care providers select an application on iPad™ tablet devices using standard Windows authentication and password protocols.
2. Once logged in, care providers choose a 'seizure tracker' icon which opens the webpage shown in Figure 1.
3. Care providers enter the student (client) name, group home (placement), and type of seizure they observed from multiple categories available on the webpage.
4. There is additional space in which care providers record other information such as factors and behavior preceding the observed seizure and general comments.
5. Care providers click 'save' to enter, summarize, and store the seizure data and report within the system.

Residential school protocol requires that data entry be completed contiguous to detection of a seizure. Care providers deliver immediate care to students per physician orders and notify the nursing department if follow-up assessment is needed in classrooms and group homes. The seizure tracker system converts seizure frequency and duration data into student graphs illustrated in Figure 2. Nurses monitor these data and distribute reports to neurologists and other medical professionals involved with student care. Further, the seizure data are fully integrated within the student population database at the residential school and made readily available during regularly scheduled interdisciplinary review meetings. The seizure data and related information are also shared with families to keep them apprised of their child's progress and prepare for neurologist visits.

**Table 2. Rank ordered social validity ratings by parents (N = 11) and neurologists (N = 7).**

Questionnaire statements	Average rating
<b>PARENTS</b>	
The seizure tracking system provides useful data when I meet with my child's neurologist	4.6
The seizure tracking system is useful in recording frequency, duration, and specificity of my child's seizures	4.5
The seizure tracking system monitors seizures over an extended period of time	4.5
The seizure tracking system provides parents with useful data to assess the effectiveness of prescribed medications	4.5
The seizure tracking system provides data that informs treatment decisions by my child's neurologist	4.3
<b>NEUROLOGISTS</b>	
The seizure tracking system provides useful data when I meet with a child's parents	5.0
The seizure tracking system is useful in recording frequency, duration, and specificity of children's seizures	4.8
The seizure tracking system provides useful data that inform me about the effectiveness of prescribed medications	4.7

Note: 1 = strongly disagree, 2 = disagree, 3 = neither disagree nor agree, 4 = agree, 5 = strongly agree.

### System training

Classroom instructors and group home care providers were trained to implement seizure tracking during small group sessions arranged within a larger orientation schedule upon being hired at the private school. Within sessions, a lead trainer demonstrated operational steps while explaining the rationale for and objectives of data recording. Trainees then practiced using the system under simulated conditions and received performance feedback from the trainer consisting of praise and correction. Based on this model of behavioral skills training (BST) (Reid, 2017, Vladescu & Marano, 2021), classroom instructors and group home care providers were approved competent by the trainer when they demonstrated all of the steps required for system implementation correctly.

Following orientation training, the classroom instructors and group home care providers were responsible for seizure tracking during all activities with students. As described, they were required to record data within the computer-assisted system any time they observed a student experiencing a seizure. Classroom and group home supervisors monitored implementation of the system by checking with instructors and care providers on each recorded seizure. Points of review included the type of seizure observed, co-occurring environmental conditions, behavior sequelae, and compliance with post-ictal health protocols. Collaboration with school nurses also made it possible to review all seizure incidents and care considerations.

### Results


Table 1 shows the questionnaire statements and average numerical rating per statement endorsed by school staff (return rate = 88.0%) and Table 2 shows the questionnaire statements and average numerical rating per statement endorsed by parents (return rate = 100%) and neurologists (return rate = 63.6%). Overall, these results found average numerical ratings between 4 ('agree') and 5 ('strongly agree') for all statements contained in the questionnaires. Figure 3 presents these numerical ratings averaged for the full questionnaires among the three participant groups: school staff ( $M = 4.5$ ), parents ( $M = 4.5$ ), and neurologists ( $M = 4.8$ ).

### Discussion


We reported social validity assessment of a computer-assisted system for recording and reporting seizures displayed by children with ASD and intellectual disability at an educational-treatment setting. The system integrates multiple data recording operations (measurement, analysis, storage, distribution, communication), thereby increasing efficiency and portability of application (Saini and Roane, 2018, Yanagita *et al.*, 2016). Procedural advantages include integration of student academic, clinical, and health-related measures, ease-of-use, point-of-incident data entry, real time email notification, and robust reporting to persons involved with service delivery. School staff, parents, and neurologists approved system use, implementation, purpose, and effectiveness.

Of note, this social validity assessment was concerned with how different stakeholders 'used' the seizure tracking system, namely school staff responsible for data recording, parents interested in the day-to-day seizure status of their children, and neurologists who acquired objective information that informed decisions about medication administration. Schwartz and Baer (1991) advised that capturing the widest audience of direct and indirect consumers should be the prevailing objective when conducting social validity assessment. In this study, school staff would be considered direct consumers and parents and neurologists would constitute indirect consumers who were able to judge utility of the seizure tracking system from different but nonetheless valued perspectives. The approval from multiple stakeholders suggests that this method of seizure tracking would be acceptable in similar service settings for acquiring health related data to guide treatment planning for children with ASD, their families, and medical professionals.

As noted previously, the study did not evaluate procedural parameters of the seizure tracking system such as interobserver agreement (IOA), implementation integrity, or accuracy among data recorders. Therefore, the value of social validity assessment notwithstanding, several operations and implementation components of the system should be evaluated. Specifically, do care providers record seizure frequency and duration reliably and can they follow system requirements with fidelity? Of note, seizures

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All Placements  All Client

Date Of Seizure:   Time of Seizure: -- : -- : -- Seizure Duration (min:sec): -- : --

**During Seizure, Was the Client?**  
 Unconscious  Breathing Normally  Appear Flushed  Give out Epileptic Cry  
 Incontinent  Responding to Speech  Appear Cyanotic (Blue/Gray skin)

**During Seizure, Client's Body was:**  
 Limp  Rigid  Spastic

**During Seizure, Client's Eyes were:**  
 Up  Down  Left  Right  Staring Ahead

**During Seizure, Abnormal Movements of:**  
 Face  Only Left Side  Only Left Limb  Head  
 Entire Body  Only Right Side  Only Right Limb  Other

**Please Explain:**


**After Seizure, Client was:**  
 Asleep  Drowsy  Confused  Usual Self

**Does the client have a VNS (Vagal Nerve Stimulator)?**  
 Yes  No

**Number of times VNS was swiped?**  
 1 Time  2 Times  3 Times  4 Times  5 Times  N/A

**Seizure stopped after the:**  
 First Swipe  Second Swipe  Third Swipe  Fourth Swipe  Fifth Swipe

**Was Nursing Notified?**  
 Yes  No

**Nurse Name:**  **Nurse Notify Date:**   **Nurse Notify Time:** -- : -- : --

**Was Diastat Administered (If prescribed)?**  
 Yes  No  Not Applicable

**Was 911 activated?**  
 Yes  No

**Explain Precipitating Factors or Behaviors**

**Comments and Follow-up:**

Figure 1. web page view of form.

often occur with unmistakable physical markers (e.g. loss of consciousness, paroxysmal movements, dropping to the ground) but less demonstrable signs may be more difficult to detect unambiguously. Accordingly, measurement agreement between data recorders is essential. Concerning implementation integrity, any method of data recording is dependent on adherence to measurement guidelines and protocols

(DiGennaro Reed and Coddling, 2011). Hence, service provision within educational-treatment settings can be aided by ensuring that practitioners conduct computer-assisted data recording of seizures and other health measures consistently and accurately (Bird et al., 2022, Call et al., 2017, Shlesinger et al., 2020).

We emphasize that our computer-assisted system of seizure tracking was designed as proprietary software

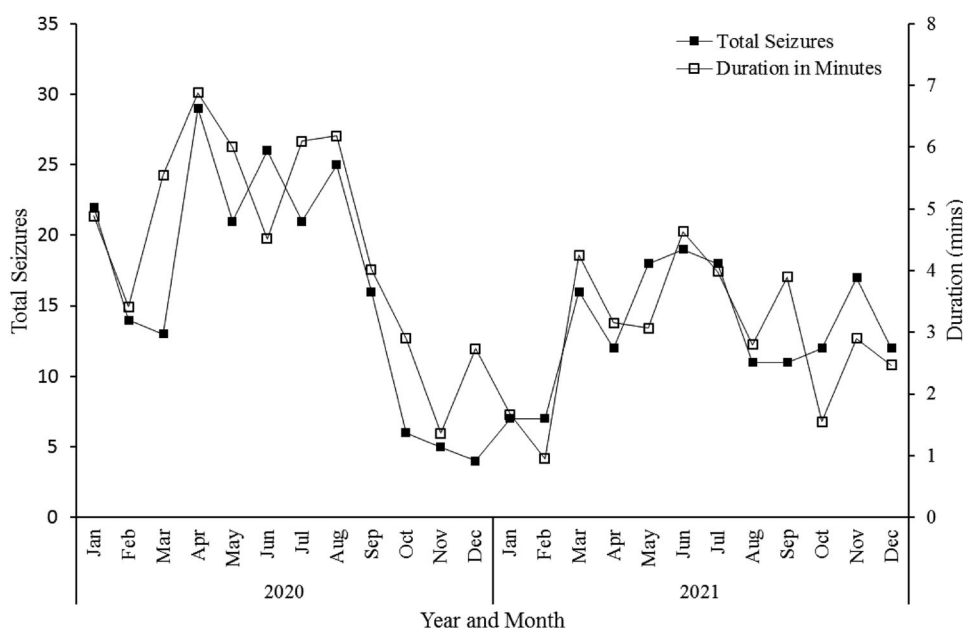


Figure 2. Total seizures and seizure duration.

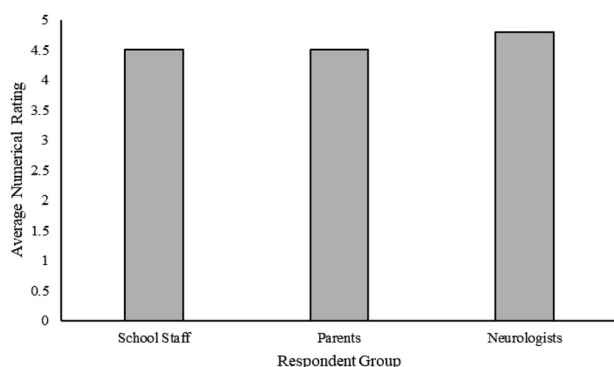


Figure 3. Average numerical rating per questionnaire among respondent groups.

Note: 1 = strongly disagree, 2 = disagree, 3 = neither disagree nor agree, 4 = agree, 5 = strongly disagree

by internal clinical computing specialists. It is possible that the unique functions of the system may not be replicable or sustainable in other settings unless similar resources are available, possibly leading to less-than-desirable social validity. There is evolving evidence that supports electronic data recording in behavior analysis practice and research (Bak et al., 2021, Kostewicz et al., 2016), but more exploration is needed. For example, how do practitioners customize common operating systems, are recorded data accurate representations of seizures, and what training approach is most effective with care providers? Apropos to our system of seizure tracking, we have not encountered procedural misapplication or implementation barriers but as acknowledged, further evaluation at the level of service provision is warranted. An instrument such as the Performance Diagnostic Checklist-Human Services (PDC-HS, Wilder et al., 2020) would be valuable in isolating conditions which may delimit computer-

assisted data recording and identifying solutions to overcome them.

Other considerations are that social validity assessment in this study was confined to a single educational-treatment setting and one method of seizure tracking. The participants included 40 total respondents, a reasonable sample of stakeholders, but further inquiry with potentially larger groups is indicated. One additional qualification concerns factors that may have contributed to the average high ratings (ceiling effect) on every questionnaire item among the three participant groups. Of course, these results may have accurately reflected the opinions of respondents while noting potential biases towards favorable ratings that could have been occasioned by either their relationships with the service setting or the inclusion of only positively worded items in the questionnaires (Swain et al., 2008). Finally, and as acknowledged previously, the three participant groups were exposed to the seizure tracking system in different ways and their judgments about utility should be interpreted accordingly.

In summary, monitoring and measuring the frequency, duration, and contextual variables associated with seizures in children with ASD is necessary for health monitoring. The computer-assisted system described in this report is based on currently available information technology and offers practitioners and their families a user-friendly methodology to benefit treatment planning. We found positive reactions to the system from multiple stakeholders and recommend more expansive study of applicability and operation that will promote use within diverse service settings.

### Ethical approval

All procedures performed with participants in the study were in accordance with the ethical standards of the

institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

### Disclosure statement

No potential conflict of interest was reported by the authors.

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### Data availability statement

Data availability is not applicable.

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