

# GeniAuti: Toward Data-Driven Interventions to Challenging Behaviors of Autistic Children through Caregivers' Tracking

EUNKYUNG JO, University of California, Irvine, USA

SEORA PARK, Seoul National University, Republic of Korea

HYEONSEOK BANG, Yonsei University, Republic of Korea

YOUNGEUN HONG, National Center for Mental Health, Republic of Korea

YENI KIM, Dongguk International Hospital, Republic of Korea

JUNGWON CHOI, National Center for Mental Health, Republic of Korea

BUNG NYUN KIM, Seoul National University Hospital, Republic of Korea

DANIEL A. EPSTEIN, University of California, Irvine, USA

HWAJUNG HONG, KAIST, Republic of Korea

Challenging behaviors significantly impact learning and socialization of autistic children and can stress and burden their caregivers. Documentation of challenging behaviors is fundamental for identifying what environmental factors influence them, such as how others respond to a child's such behaviors. Caregiver-tracked data on their child's challenging behaviors can help clinical experts make informed recommendations about how to manage such behaviors. To support caregivers in recording their children's challenging behaviors, we developed GeniAuti, a mobile-based data-collection tool built upon a clinical data collection form to document challenging behaviors and other clinically relevant contextual information such as place, duration, intensity, and what triggers such behaviors. Through an open-ended deployment with 19 parent-child pairs and three expert collaborators, caregivers found GeniAuti valuable for (1) becoming more attentive and reflective to behavioral contexts, including their own response strategies, (2) discovering positive aspects of their children's behaviors, and (3) promoting collaboration with clinical experts around the caregiver-tracked data to develop tailored intervention strategies for their children. However, participant experiences surface challenges of logging behaviors in social circumstances, conflicting views between caregivers and clinical experts around the structured recording process, and emotional struggles resulting from recording and reflecting on intensely negative experiences. Considering the complex nature of caregiver-based health tracking and caregiver-clinician collaboration, we suggest design opportunities for facilitating negotiations between caregivers and clinicians and accounting for caregivers' emotional needs.

CCS Concepts: • **Human-centered computing** → **Empirical studies in collaborative and social computing**; **Empirical studies in accessibility**.

Additional Key Words and Phrases: parent-clinician communication, personal informatics, children, autism, challenging behavior, behavior intervention, mobile application

Authors' addresses: Eunkyung Jo, University of California, Irvine, Irvine, USA, eunkyu@uci.edu; Seora Park, Seoul National University, Seoul, Republic of Korea, annieseora96@snu.ac.kr; Hyeonseok Bang, Yonsei University, Seoul, Republic of Korea, hsbang@yonsei.ac.kr; Youngeun Hong, National Center for Mental Health, Seoul, Republic of Korea, hye1503@naver.com; Yeni Kim, Dongguk International Hospital, Goyang, Republic of Korea, yeni1004@gmail.com; Jungwon Choi, National Center for Mental Health, Seoul, Republic of Korea, alzza55@gmail.com; Bung Nyun Kim, Seoul National University Hospital, Seoul, Republic of Korea, kbn1@snu.ac.kr; Daniel A. Epstein, University of California, Irvine, Irvine, USA, epstein@ics.uci.edu; Hwajung Hong, KAIST, Daejeon, Republic of Korea, hwajung@kaist.ac.kr.



This work is licensed under a Creative Commons Attribution International 4.0 License.

© 2022 Copyright held by the owner/author(s).

2573-0142/2022/4-ART92

<https://doi.org/10.1145/3512939>

### ACM Reference Format:

Eunkyung Jo, Seora Park, Hyeonseok Bang, Youngeun Hong, Yeni Kim, Jungwon Choi, Bung Nyun Kim, Daniel A. Epstein, and Hwajung Hong. 2022. GeniAuti: Toward Data-Driven Interventions to Challenging Behaviors of Autistic Children through Caregivers' Tracking. *Proc. ACM Hum.-Comput. Interact.* 6, CSCW1, Article 92 (April 2022), 27 pages. <https://doi.org/10.1145/3512939>

## 1 INTRODUCTION

Research suggests that 14-20% of young children engage in challenging behaviors that require intervention [65]. Both typically developing and autistic children engage in challenging behaviors such as self-injury and aggression [65], but autistic children show a higher prevalence [36, 63]. Such behaviors can hinder the children's learning and socialization [33, 60]. Caregivers of children who exhibit challenging behaviors also experience increased stress, burden of care, and risk of injury [2, 32, 46]. Therefore, mitigating challenging behaviors can improve both children and their family's quality of life.

Documentation of challenging behaviors is fundamental for identifying influencing environmental factors and developing individualized intervention plans [28]. Studies have shown the benefits of parent training for structured observation and documentation of challenging behaviors in allowing both caregivers and clinicians to better understand and identify patterns of the child's challenging behaviors leading to informed decisions for intervention planning [59, 70]. However, caregivers experience major challenges in behavioral tracking in daily settings. Even professionals, such as teachers, often find behavioral tracking burdensome given their other responsibilities [31, 39, 40], and so do caregivers of autistic children [53, 69], which might lead to lapses in data. In addition, caregiver-clinician collaboration around children's behavioral data might break down when the collected data is less clinically relevant or logged in a non-standard way [55, 85, 86].

To reduce caregiver burdens in behavioral tracking in daily settings and improve collaboration with clinical experts, we developed *GeniAuti*, a system that assists caregivers in systematically tracking their children's challenging behaviors and their response strategies for data-driven discussion with clinical experts. Inspired by prior research in patient-clinician collaboration around patient-generated data [15–17, 80, 86] and caregiver-based health tracking [38, 83, 88], *GeniAuti* assists caregivers with recording their children's challenging behaviors to promote collaboration around caregiver-tracked data. Based on the ABC model—a framework of analyzing behaviors to be addressed through Antecedent (A), Behavior (B), and Consequence (C) components [28], *GeniAuti* allows systematic documentation of challenging behaviors on the fly with the aid of various scaffolding features, such as a speech-to-text feature and a timer widget. With a data-sharing feature and visualizations showing challenging behavior trends, *GeniAuti* assists data-driven collaboration between caregivers and clinical experts.

We conducted an open-ended field deployment of *GeniAuti* with 19 parent-child pairs and three expert collaborators, including one psychiatrist and two behavioral therapists, for two to seven weeks. Our findings showed that participants found benefits to tracking with *GeniAuti* in becoming more attentive and reflective to behavioral contexts, including their own response strategies and discovering positive moments through tracking. In addition, using *GeniAuti* facilitated collaborative planning of intervention strategies through offering objective and structured logs that fit clinical experts' needs. However, the clinical recommendations imposed in the tracking structure of *GeniAuti* and the use of the ABC model occasionally conflicted with caregivers' viewpoints about how to best handle children's care. Although *GeniAuti* aimed to reduce the burden of logging challenging behaviors, participants still found the burden significant due to social circumstances and often found the process emotionally exhausting. In addition, data review through *GeniAuti* occasionally led caregivers and clinical experts to surface conflicting views around the causes

of children's challenging behaviors and disagreements around what advice to follow. Our work suggests opportunities and challenges in caregiver–clinician collaboration to support caregivers engaging in emotion-laden tracking by recognizing all stakeholders' needs in behavioral care, promoting negotiations between caregivers and clinicians to close the perspective gap, listening to caregivers' emotional needs, and helping recognize positive moments.

The key contributions of this work include:

- The design of GeniAuti, a system for caregivers to track and monitor the challenging behaviors of autistic children through scaffolded entry built on the ABC model [28] as well as other clinically relevant contextual information such as duration, place, intensity, and functions (i.e., cause) and data-sharing with clinical experts.
- Opportunities and challenges of caregivers' tracking of challenging behaviors through 19 participant experiences using GeniAuti for two to seven weeks. Despite the perceived value of data-driven collaboration with clinical experts based on systematically tracked data, participant experiences surface conflicting views between caregivers and clinical experts on how to interpret challenging behaviors and emotional distress resulting from recording and reflecting on repetitive, negative past experiences.
- Design recommendations for tracking tools designed for caregivers to manage a child's behavioral challenges, specifically ensuring all stakeholders' data needs are recognized in behavioral care, facilitating caregiver–clinician negotiations and discussions to learn about each other's perspective, listening to caregivers' emotional needs, and supporting celebration and learning from successful improvements.

## 2 BACKGROUND: CHALLENGING BEHAVIORS AND INTERVENTIONS

Challenging behaviors are those whose intensity, frequency, or duration is likely to threaten the quality of life or physical safety of an individual or others [23]. Research has suggested that both typically developing and autistic children engage in challenging behaviors such as self-injury and aggression [65], but autistic children show a higher prevalence [36, 63]. However, studies show large discrepancies in the prevalence rates due to the variations across studies in terms of definitions of challenging behavior, assessment measures used, and population [33, 63].

General categories of challenging behaviors include aggression, tantrums, noncompliance, self-injury, and property destruction [23]. Challenging behaviors can hinder children's learning and socialization, as children who exhibit challenging behaviors are vulnerable to exclusion from classrooms, local services, and peer groups [33, 60]. Caregivers of autistic children who exhibit challenging behaviors also experience increased stress, increased burden of care, and risk of injury [2, 32, 46]. Therefore, mitigating challenging behaviors in autistic children can improve both children and their family's quality of life.

To develop individualized intervention plans to address challenging behaviors, clinical experts first assess what factors cause such behaviors (function) [10, 18, 21]. Common functions (i.e., causes) for challenging behaviors include a desire for attention, access to preferred tangibles or activities, avoidance of demands to engage in non-preferred activities, and sensory stimulation [21, 58]. The initial step of identifying function is to observe and keep track of target behaviors in a systematic way. *The ABC model* is the most frequently used instrument in clinical settings for keeping track of behaviors, breaking down an event into antecedent (A), behavior (B), and consequence (C) [21, 28]. The Antecedent (A) refers to what happened right before the challenging behavior. Behavior (B) refers to the challenging behavior being targeted. Consequence (C) refers to what happened right after the challenging behavior as a result. Tracking this information allows clinical experts to develop a hypothesis, identify what triggers and maintains the behaviors

(antecedent or consequence), and devise intervention strategies by directly modifying antecedents and consequences that maintain the behaviors [22, 71].

Research has shown the effectiveness of actively involving caregivers in challenging behavior interventions in increasing the generalization of skills learned through intervention to daily settings [9, 59], and sustainability of the effects of interventions [9]. Therefore, most behavioral intervention programs include parent training to collaborate with caregivers as co-therapists [61, 79]. Training caregivers to observe and collect behavioral data is one of the core components of the parent training programs to address challenging behaviors. While collecting data through direct observation by trained experts is considered the gold standard for challenging behavior assessment and intervention [29], caregivers' behavioral data collection in everyday lives can allow for more frequent observation in more natural settings [64, 79]. Caregivers' behavioral data collection not only helps clinical experts make informed decisions about how to deal with challenging behaviors but also empowers caregivers to take an active role in the challenging behaviors interventions [59, 70].

### 3 RELATED WORK

In this section, we first review previous research in personal tracking and patient-clinician collaboration. Next, we discuss the benefits and challenges of caregiver-based tracking. Lastly, we examine prior studies for tracking autistic children's behaviors and identify a gap in supporting behavioral tracking practices of caregivers in daily settings.

#### 3.1 Personal Health Tracking and Patient-Clinician Collaboration

Personal informatics systems, which aim to help people understand their habits, such as their health, have primarily focused on individuals' tracking practices by helping them engage in self-reflection and gain self-knowledge [50, 51]. However, researchers in this area are increasingly supporting more collective and collaborative tracking practices by considering the roles of caregivers, such as family members and clinicians in self-tracking practices [24, 66, 75]. Self-tracking research has frequently pointed to different stages of use and goals for tracking technology, including when and how data is collected and reflected on [25, 50]. People have different preferred styles of engagement in personal tracking, including directive (aiming to achieve goals), documentary (aiming to collect a record), and diagnostic (aiming to find patterns) [78]. These styles then influence their use of tracking technology (e.g., frequency, depth of engagement) and desired features [25]. While numerous studies have demonstrated the benefits of personal tracking in achieving a health goal such as gaining self-knowledge, managing chronic conditions, or behavior change, recent studies described the emotional load that may be involved in personal tracking, particularly when individuals attempt to make sense of complex health conditions with great uncertainty or social stigma [3, 4, 19, 20].

As many self-trackers struggle to make sense of their health data, people increasingly seek help from their clinical experts [15–17, 42, 43, 80, 86, 89]. Involving and collaborating with clinicians in reviewing patient-tracked data can help both patients and clinicians better contextualize patients' symptoms, support diagnosis, personalize treatment plans, and increase patient adherence [15–17, 42, 43, 80]. However, clinicians often confront challenges when attempting to review patient-tracked data. Clinicians sometimes question the clinical relevance of the data or have concerns around the accuracy of the data [15, 86, 89]. In addition, they often lack time to review a large amount of data in time-constrained visits [15, 16, 42, 43, 80, 89]. In this sense, Chung et al. have characterized personal tracking data in patient-clinician collaboration as boundary negotiating artifacts [47] to mediate different spheres of expertise between patients and clinicians [16].

### 3.2 Caregiver-Based Health Tracking

HCI research has shown the benefits of caregivers' tracking in monitoring and assessing care recipients' health. Caregiver-tracked data can help enhance caregivers' understanding of their children's health and facilitate communication with clinicians [38, 83, 85] to develop personalized care plans. Most prior systems for caregivers have focused on care recipients' behaviors and health status while paying less attention to the impacts of caregiving activities on their family members' health. However, a few recent systems emphasized the role of caregiving activities on children's behaviors and health status. For example, Yamashita et al. [88] proposed a tracking system for caregivers taking care of a depressed family member, identifying that tracking caregivers' behaviors as well as care recipients' conditions can assist caregivers in developing better response strategies. Jo et al. [34] proposed a mealtime assistant application for monitoring parent-child mealtime conversation and food intake and demonstrated that caregivers' verbal responses and behaviors significantly impact children's eating behaviors.

Despite the benefits of caregiver-tracked data, there are unique challenges associated with collecting and utilizing such data. First of all, caregivers often find it challenging to continuously collect data related to their child's health due to their hectic lives [38, 83]. To lower caregivers' data-collection burden, several automatic tools have been proposed to collect physiological sensing data [14, 87] or capture videos of behavioral incidents at home [68, 69]. However, since complete automation of data collection might undermine individuals' self-awareness, researchers have argued the need for balancing manual and automatic tracking [12, 62].

In addition, caregivers might have insufficient knowledge to properly identify and document moments that experts would find it important to capture [7, 38]. Therefore, caregivers often need to collaborate with clinicians when tracking their child's health. Research has emphasized the importance of facilitating data-mediated communication between caregivers and clinicians [7, 81, 85]. Specifically, researchers have demonstrated that technological support such as data visualization could promote discussion between caregivers and clinicians by providing visual references and an overview of behavioral data [44, 45, 48].

### 3.3 Tracking Autistic Children's Behaviors

HCI researchers have long sought to better support tracking autistic children's behaviors to assist early diagnosis of developmental disorders [14, 87], better contextualize stereotypical behaviors [1, 67], or intervene around challenging behaviors [68, 76]. Prior work has emphasized a need to reduce the data-collection burden given other responsibilities of caregivers and experts. As part of an effort to minimize data collection burden, HCI researchers have aimed to automate the behavioral data-collection process using automated video capture [31, 39, 68, 69], physiological or motion sensors [76, 87], and the combination of both approaches [1, 67, 87]. These systems have been proposed for a variety of settings such as therapy settings [39, 40], school settings [31], and home settings [68, 69] to support behavioral tracking.

However, despite minimizing capture burden, previous studies on automatic behavioral data-collection methods pose several challenges to be used in daily settings, such as privacy concerns [30, 31, 67–69], obtrusiveness, especially for autistic individuals who have sensory difficulties [67, 76], inability to capture contextual information that is subjective and qualitative in nature [12, 54, 56], and inefficiency due to autistic individuals' highly variable behavioral patterns [1]. Therefore, manual capture is still widely used in autism behavioral health [55–57].

Research has also highlighted that behavioral tracking tools should consider collaboration among various stakeholders (e.g., multiple caregivers, teachers, therapists, and clinicians) taking care of neurodiverse children [44, 45, 48, 54–56, 77]. Past work has highlighted the importance of systematic

data collection to assist collaborative efforts among such diverse stakeholders since behavioral data collected through unstandardized methods is difficult to be reviewed and analyzed collaboratively [52, 56, 85, 86]. Specifically, to facilitate caregiver–clinician collaboration, studies have shown the value of translating structured clinical data collection forms into technology that provides better accessible ways to collect and reflect on data [38, 55, 83].

Having better access to data collection and reflection is also critical in collaborative behavioral tracking [31, 52, 54–56]. Marcu et al. [56] found that paper-based data collection methods, which are pervasively used in special education settings, often make it difficult for various types of practitioners to collaboratively collect and reflect on the behavioral data of students. Therefore, they highlighted a significant opportunity for technology to streamline the process from collecting to using behavioral data by making it more systematic and accessible to multiple stakeholders.

Relevant systems in supporting children’s behavioral data collection have primarily focused on minimizing data capture burden through automation [31, 68, 69] and improving the accuracy of data collection [31, 39]. Despite the potential benefits of manual tracking in capturing subjective, contextual information [12, 54] and increasing self-awareness of caregivers [88], there have been few studies examining caregivers’ perspectives on manually logging their children’s challenging behaviors. Based on the findings in collaborative reflection [54–56, 77], we see an opportunity for technology to support caregivers’ manual tracking with the support of structured data collection as well as providing easy access in daily settings. Therefore, in this work, we primarily leveraged structured manual tracking in GeniAuti for caregivers to improve self-awareness and gain self-insights through data collection in daily settings.

## 4 SYSTEM DESIGN

Based on an iterative design process to understand caregivers’ challenges and needs in tracking challenging behaviors, we present GeniAuti, a mobile application for structured data collection to support caregivers to systematically track challenging behaviors based on the ABC model. We describe the details of the features of GeniAuti, such as scaffolded data collection, data-assisted reflection with statistics and visualizations, and data sharing among different stakeholders.

### 4.1 Design Process

GeniAuti was designed through an iterative design process from 2018 to 2020. The design process consisted of two parts. We first conducted semi-structured interviews with three clinical experts, including two psychiatrists and a therapist, to identify challenges they often faced when consulting caregivers of children with developmental challenges. Interview questions surfaced the difficulties caregivers experience in the care process, types of information the experts needed to understand the context of behaviors, and what design opportunities should be considered. We found that a main obstacle caregivers faced in tracking was their multiple responsibilities. For instance, when a child exhibits challenging behavior, a caregiver has to balance intervening in the child’s behavior for safety with recording the incident. Therefore, while it is important to track of each incident at the moment, tracking at the moment might amplify a caregiving burden. The clinical experts noted that caregiver-tracked data on challenging behaviors should gather more information relative to their current practice, such as type, function (i.e., cause), and intensity. They also suggested the need for considering ways to quickly identify behavioral patterns from the caregiver-tracked data. Based on the findings of the study, we have proposed the concept of GeniAuti [13] with a low-fidelity prototype to help caregivers record challenging behaviors based on the ABC model.

To further understand the experiences of caregivers, we then interviewed six caregivers of autistic children and children with intellectual disabilities. Interview questions were similar to the interviews with clinical experts but focused on their first-hand experiences as primary caregivers

of their children's behavioral health. Caregivers reiterated the need for supporting data collection on the fly. In addition, they also wanted to collect a specific set of information in a structured manner. Since many of the caregivers were still in the process of figuring out why their children were showing certain challenging behaviors, they hoped to log as much information as they can, including descriptions of the behavior, duration, and frequency. They often used a simple memo app for tracking behavioral data. However, they found it difficult to get an overall trend of such free-form journal entries. Lastly, caregivers frequently mentioned that it was challenging to share behavioral data among multiple stakeholders. Oftentimes, a number of stakeholders such as co-caregivers, therapists, and special education staff were involved in children's behavioral health. However, the information sharing and care coordination responsibilities were centralized to a single primary caregiver on top of other caregiving responsibilities. Therefore, they found keeping track of behavioral data particularly important as it allowed them to share with multiple stakeholders based on records rather than verbally describing it each time.

Based on the findings of the formative study, we developed four main design principles for challenging behavior tracking tools for caregivers. First, behavioral data collection tools should facilitate structured data collection. Specifically, leveraging structured clinical data collection forms can help caregivers collect detailed behavioral data that aligns with clinical experts' needs in a systematic way. Second, challenging behavior tracking should be scaffolded to support in-situ data collection. Scaffolding features, such as a timer, preregistering options, and voice recognition, can offload the logging burden and make the recording process more efficient. Third, both caregivers and clinical experts need support for quickly examining behavioral patterns from the caregiver-tracked data. Data visualizations can provide an effective summary of behavioral data that can help caregivers and clinical experts collaboratively identify the patterns of behavioral data. Fourth, data sharing needs to be supported to facilitate collaboration among different stakeholders. Providing multiple stakeholders such as co-caregivers and clinical experts with access to caregiver-tracked data can offload caregivers' burden on sharing information and facilitate caregiver-clinician collaboration.

## 4.2 System Design

**4.2.1 System Overview.** In this section, we describe the features and implementation of GeniAuti. When a child shows challenging behavior, users (primary caregivers) record the details of the context associated with the behavior through the GeniAuti mobile application. Through a timer widget on the home screen (Figure 1b), users can immediately timestamp when their children show challenging behaviors and are sent to the logging screen in GeniAuti once they stop the timer to guide them to fill out the other information at their conveniences, such as place, ABC information, type, intensity, and perceived functions (a desire for attention, access to preferred tangibles or activities, avoidance of demands to engage in non-preferred activities, and sensory stimulation [21, 58]). For repetitive behavioral patterns, users can register them as 'frequent behavior' (Figure 1c) and create a new item with minimal effort afterward with the preregistered data. After users complete recording, GeniAuti generates a behavioral card for each behavior (Figure 3a). GeniAuti also provides descriptive statistics and charts (Figure 3c) summarizing daily, weekly, and monthly patterns of accumulated data. Users can access these cards, statistics, and charts through their smartphones. An invitation code (Figure 3d) allows them to share the behavioral data of children with other caregivers. The detailed design of the app is described below.

**4.2.2 Scaffolded Data Collection.** GeniAuti allows users to track children's behaviors based on the structure specifically designed to record challenging behaviors. Users can start logging a new item either by registering a new behavior or utilizing a 'frequent behavior,' explained below (Figure 1c). To register a new behavior, users first enter data in the following order: time (duration), location, and

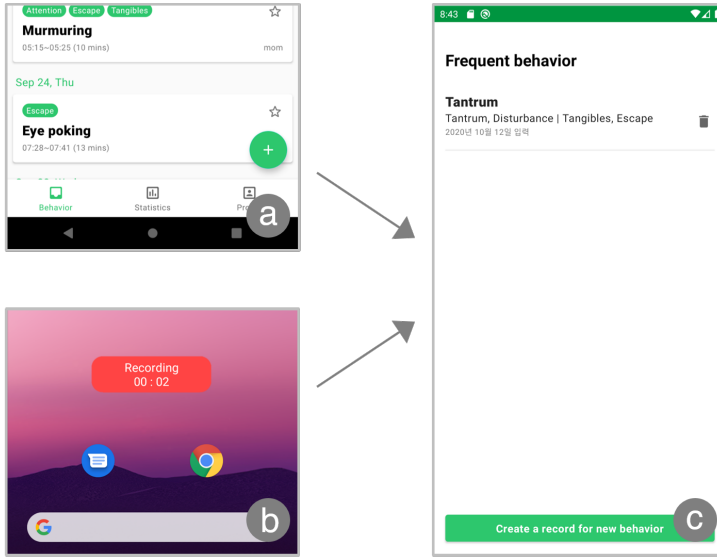


Fig. 1. Logging process: (a) Create a new data entry by clicking on the plus icon in the main screen, (b) Start and stop the timer widget, (c) Start logging data either by selecting one of the preregistered behaviors (i.e., frequent behaviors) or creating a record for a new behavior.

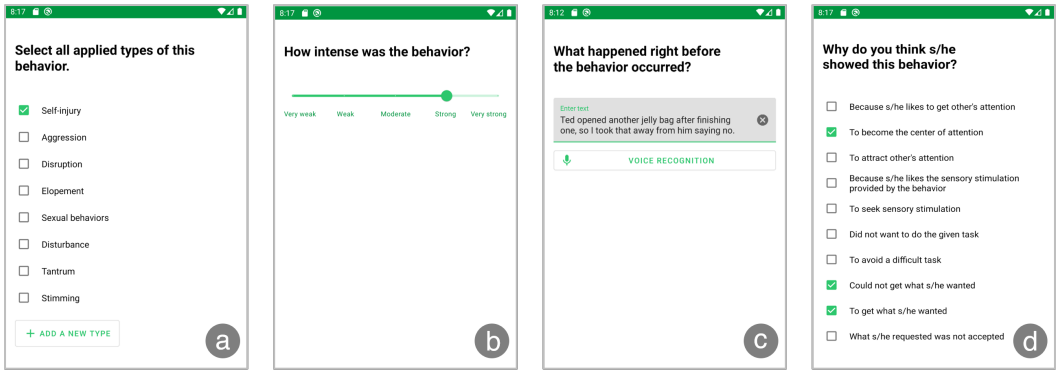


Fig. 2. (a) Specifying types, (b) Evaluating the intensity, (c) Describing an antecedent, and (d) Indicating functions of challenging behavior

title of the challenging behavior (see Figure 2). Then, they record the ABC information (Antecedent, Behavior, Consequence [28]) of the challenging behavior either by manually typing or through a voice-recognition feature (Figure 2c). After recording the ABC information, users select the type of behavior among eight categories (e.g., self-injury, aggression, destruction, etc.) [23] (Figure 2a) and rate the intensity based on a 5-point Likert scale (Figure 2b). Lastly, users specify what they think caused the behavior among common functions suggested by prior studies [21, 58] (Figure 2d). These predefined data fields allow caregivers to log all important information about the context of challenging behaviors. Upon completing the recording process, GeniAuti generates a new ‘behavior card’ (Figure 3a) for the users to review.



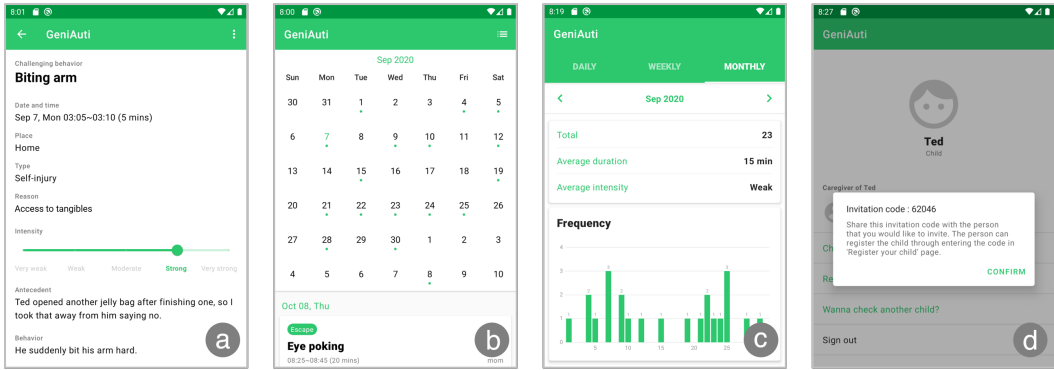


Fig. 3. (a) Behavioral card created after completing a data entry, (b) Calendar-based data browsing, (c) Descriptive statistics and charts, (d) Invitation code for data sharing

**4.2.3 Data Capture on the Fly.** To facilitate caregivers in tracking challenging behaviors on the fly in daily settings, we implement the following features. First, we developed a speech-to-text feature for recording the ABC information to enable recording even when caregivers' hands are busy. Users can verbally state the ABC information, and then the system converts it into text (Figure 2c). Second, we developed a timer widget that allows users to timestamp with a single tap when challenging behaviors occur (Figure 1b). When a child starts to hit others, for example, a caregiver can immediately start the timer on the home screen of their smartphone and stop it when the child calms down. Then, users are sent to the logging screen (Figure 2) to fill out the other information—such as place, ABC information, type, intensity, and perceived functions—at their convenience. Third, we developed a 'frequent behavior' feature (Figure 1c) to allow users to utilize preregistered data for recurring challenging behaviors. If a user saves an item as a 'frequent behavior,' they can create a new item with minimal effort afterward, as the tracker entries are automatically filled with preregistered data. When a user attempts to create a new entry, they can access the frequent behaviors that they have registered or register a new behavior in the app.

**4.2.4 Data-Assisted Reflection with Statistics and Visualizations.** Users can review their data through a calendar view (Figure 3b). GeniAuti presents a small dot under the date on which the behaviors were recorded, so users can explore specific dates of interest. Upon clicking on a specific date, users can access the behavioral card that provides all the details of the logged item. If users have specific episodes they would like to surface in an upcoming clinical consultation, they can mark the behavioral card with a star icon so that it is highlighted in the calendar (Figure 3b). In addition, GeniAuti provides statistics and visualizations to summarize the overall patterns of the behavioral data. The 'Charts' tab (Figure 3c) contains daily, weekly, and monthly charts on challenging behaviors for users to identify trends and patterns, and it provides descriptive statistics on the total number, average duration, and average intensity of challenging behaviors. Furthermore, histograms are presented to visualize the frequency, functions, types, and locations of challenging behaviors.

**4.2.5 Data Sharing among Different Stakeholders.** GeniAuti provides a data-sharing feature to facilitate data-mediated communication among caregivers and clinical experts. Users can share the child's data with other caregivers, teachers, therapists, or clinicians through an invitation code (Figure 3d). When others enter the invitation code (Figure 3d) when registering a new child in their app, they can access the accumulated data and record data about the child as well. Users can

register multiple children. For example, clinical experts or teachers can register multiple children and easily switch between them in the 'Profile' tab.

### 4.3 Implementation

GeniAuti was implemented on Android OS. To convert voice recordings to text, Google Speech-To-Text API was used. All tracking data was saved in a backend Google Firebase database, which also facilitated the sharing feature through shared invitation codes. For clinical experts, we provided an additional dashboard as an interactive Google spreadsheet, which they actively used for reviewing the caregiver-tracked data through GeniAuti.

## 5 STUDY DESIGN AND PROCEDURE

We conducted an open-ended field deployment with 19 parent-child pairs and three expert collaborators who have regularly seen the children at their clinical visits. The goal of the study was to identify the benefits and challenges of supporting caregivers' behavioral tracking through technology in daily settings and how GeniAuti supported or interfered with the process of addressing challenging behaviors. As every child shows different types of challenging behaviors and the ways in which caregivers deal with them differ, we did not instruct caregivers on how to use the app, including how long to engage with tracking, what behavior to track, and how frequently to record. Therefore, each caregiver and clinician was able to devise tailored intervention plans for each child's challenging behaviors.

### 5.1 Participants

We recruited primary caregivers of children who were exhibiting challenging behaviors from the Child & Adolescent Psychiatry and Behavior & Development Center at the National Center for Mental Health in Seoul, Korea (Hospital A) and the Psychiatry Department at the Dongguk University Ilsan Hospital in Goyang, Korea (Hospital B). The Behavior & Development Center at Hospital A is dedicated to providing interventions to assist children who have developmental challenges and experience difficulties in daily lives due to challenging behaviors such as self-injury or aggression based on applied behavior analysis (ABA) [6, 18, 59]. We closely worked with three clinical experts, including one psychiatrist (E1) and two behavioral therapists (E2-E3). E1 worked for the Child & Adolescent Psychiatry at Hospital A and moved to Hospital B in the middle of the study. E2 (a Board-Certified Behavior Analyst, BCBA) and E3 (a behavioral therapist) worked at Behavior & Development Center at Hospital A and practiced behavioral therapy based on ABA. E1-E3 assessed the eligibility of caregivers who they were working with based on the caregivers' bandwidth to participate and their children's challenging behaviors. Then, they asked caregivers who met the eligibility criteria if they would be interested in participating in this study. If caregivers indicated interest, the research team contacted them via call or had a short meeting when they visited for their children's consultations.

In the summer of 2019, eight participants (P1-P8) were enrolled through Hospital A. In addition, a year later, in the summer of 2020, after the COVID-19 pandemic outbreak, seven participants (P9-P10, P15-P19) were enrolled through Hospital A and four (P11-P14) through Hospital B. Ten children of participants (P9-P17, P19) were formally diagnosed with autism spectrum disorder (ASD). The rest of the children had not been formally diagnosed with ASD, but clinical experts suspected that they had ASD. The majority of the children had limited verbal communication abilities. All participants were mothers who self-identified as primary caregivers—who spend the most time with their children and plan for their intervention plans with providers—and self-reported that their children had exhibited at least one challenging behavior. The participants' ages ranged

Table 1. Participant demographics, clinical contexts, duration of app use, and number of entries created

Caregiver Demographics	Child Demographics	Hospital	Clinical Consultant	Days of App Use	Entries Created
P1 (F, 39)	M, 5	A	E1	19	31
P2 (F, 40)	M, 8	A	E1	19	7
P3 (F, 42)	F, 6	A	E1	35	11
P4 (F, 40)	M, 5	A	E1	24	12
P5 (F, 42)	M, 6	A	E1	12	57
P6 (F, 47)	M, 11	A	E1	10	9
P7 (F, 39)	M, 10	A	E1	15	11
P8 (F, 46)	F, 14	A	E1	14	41
P9 (F, 46)	M, 17	A	E2	37	23
P10 (F, 40)	M, 15	A	E3	67	33
P11 (F, 39)	M, 11	B	E1	46	37
P12 (F, 50)	M, 11	B	E1	56	16
P13 (F, 41)	F, 8	B	E1	29	26
P14 (F, 47)	M, 10	B	E1	21	31
P15 (F, 44)	M, 10	A	E3	35	148
P16 (F, 38)	M, 4	A	E3	30	32
P17 (F, 45)	F, 5	A	E2	13	3
P18 (F, 45)	M, 18	A	E2	7	4
P19 (F, 38)	M, 8	A	E2	12	2

from 38 to 50 years (mean age=42.5). Their children included 4 females and 15 males between the ages of 4 and 18 years (mean age=9.6).

As we did not instruct caregivers on how long to engage with tracking, the duration of study participation varied depending on each participant's willingness to use the system and/or the clinical experts' recommendations (Table 1). The average length of study participation was 26.4 days (SD=16.4). Over the course of the study period, each participant created 28.1 data entries on average (SD=32.7). The largest number of total data entries was 148 (P15), and the smallest was 2 (P19). P# denotes caregiver participants.

Previous experiences with collecting data on their children's challenging behaviors were varied by participants. Five participants reported that they had never documented their children's challenging behaviors. Twelve participants had used several paper-based methods, such as a diary and a desk calendar, an assignment book obtained from a child's school (P6), and the ABC form distributed by Hospital A (P9-P10). Only four participants had used computer-assisted methods, such as a note app (P7, P13), a journaling app (P16), and video recording (P3).

Four participants (P1-P3, P9) were relatively familiar with the ABC model, as they had completed a parental training program run by Hospital A when they started participating in the study. One participant (P8) was in the middle of taking the parental training at Hospital A, and five (P15-P19) started taking Hospital A's virtual parental training program when they started participating in the study. Eight participants (P4-P7, P10-P11, P13-P14) were relatively unfamiliar with the ABC model, as they had never taken relevant parental training.

Our participants were not given any monetary incentive for their participation; however, our expert collaborators offered complimentary sessions allowing in-depth discussion of the caregiver-tracked data as benefits for participants. This study was approved by the Institutional Review Boards of Hospital A and Hospital B, and informed consent was obtained from each participant.

## 5.2 Study Procedures

The study procedures consisted of interviews, observation of clinical sessions, and field deployment of GeniAuti. Before participants started to use GeniAuti, we introduced them to the concept and features of GeniAuti, asked about the kind of behaviors they would like to track, and had them fill out a short survey regarding their experiences in tracking challenging behaviors and parent-training programs. Then, participants used GeniAuti in their daily lives to track their child's challenging behaviors for 2–7 weeks, depending on each participant's willingness to use the system and/or the clinical experts' recommendations (Table 1). Since we hoped to explore the kind of behaviors that caregivers considered challenging, we asked them to record all types of behaviors that they considered challenging at first without providing specific guidelines. We then suggested that caregivers select one to two kinds of behaviors that had caused significant challenges to the daily lives of their children and the family. Then, clinical experts guided them to focus on tracking one or two behaviors that require behavioral intervention.

Twelve caregivers whose children were regular outpatients at Hospital A (P1–P8) and Hospital B (P11–P14) used GeniAuti for consulting with their psychiatrist during their in-person clinical visits. For these caregivers, E1 provided two to three in-person complimentary clinical sessions to debrief them on the data collected through GeniAuti. During the sessions, E1 briefly introduced the functions of challenging behaviors and the ABC model for those who had never taken any relevant parental training. The three authors alternately observed each clinical session and created observational field notes. On the other hand, the other seven caregivers (P9–P10, P15–P19) used GeniAuti to consult with their behavioral therapists (E2 and E3) while participating in the remote parent-training program. The parent-training program was developed and run by behavioral therapists at Hospital A in 2020 to help children with developmental disorders and their caregivers who had been impacted by the suspension of therapy programs after the COVID-19 outbreak. The impact of the remote parent-training program is outside the scope of this study. E2 and E3 were in charge of the parent-training program run by the Behavior & Development Center at Hospital A and provided four debriefing sessions on the caregiver-tracked data during the study. Due to the COVID-19 outbreak, the debriefing sessions were conducted remotely via phone or video calls.

Lastly, we conducted an hour-long exit interview with each participant to gain detailed information about the participants' tracking experiences with GeniAuti.

## 5.3 Data Analysis

We conducted a quantitative analysis by calculating descriptive statistics from GeniAuti usage logs to understand the overall patterns of system usage, the duration and intensity of challenging behaviors, and whether and with whom our participants shared data. For the qualitative analysis, interview sessions were audio-recorded and transcribed, and observational field notes for each clinical session were created to capture caregiver–clinician communication. The three researchers engaged in several rounds of open coding using a spreadsheet. Then, the team of authors conducted a thematic analysis [8] to identify and iteratively revise overarching patterns and themes through several rounds of peer-debriefing meetings. We also had several meetings with our expert collaborators to discuss the themes and to understand the benefits and challenges of GeniAuti from their perspectives.

## 5.4 Limitations and Future Work

- Not all autistic individuals experience behavioral challenges. Our work is focused on a specific population where participants had autistic children with limited verbal communication skills

and engaged in challenging behaviors. Thus, their experiences do not represent all autistic people's experiences, and our findings cannot be generalized to all autistic populations.

- Since our work is the first exploration into collaborative data-driven intervention for challenging behaviors in the CSCW community, we decided to focus on clinical experts and caregivers first. A question in this space is how to engage children who have limited verbal communication skills in the design process for their behavioral care. Engaging autistic children as care recipients would greatly help advance the understanding of the full picture of behavioral challenge care in the future. Previous studies have shown the value of developing ways to better engage autistic children and adolescents in their mental and behavioral health care [26, 41]. We see value in engaging autistic children in future work.

## 6 FINDINGS

In this section, we first examine the usage patterns of GeniAuti, including the number of data entries, kinds of challenging behaviors recorded, and duration and intensity of logged challenging behaviors. We also discuss how many participants used the data-sharing feature and with whom. Next, we present the qualitative findings of the study, paying particular attention to the benefits and challenges that caregivers experienced in each stage of tracking.

During the study period, our participants recorded various kinds of challenging behaviors through GeniAuti, including aggression (e.g., *biting others' arms, hitting others, throwing things, yelling and crying*), self-injury (e.g., *banging one's head against the wall/on the floor, hitting one's head*), and stereotypical behaviors (e.g., *repeating the same words, putting a finger in the anus*). As most therapy programs or schools have changed to online or were closed during the COVID-19 times, there were greater needs for caregivers to monitor and deal with their children's challenging behaviors at home. Many children started to show new challenging behaviors during the COVID-19 outbreak as their daily routines were interrupted. P12's child started to show head-butting behaviors, which P12 perceived were caused by the stress of not being able to go anywhere. Similarly, P9 also reported that her child's inappropriate urination was aggravated as he abruptly gained weight staying at home for extended periods. P13 noted that her child came to engage in more kinds of challenging behaviors compared to the pre-pandemic period, including *'throwing things,' 'inappropriate urination,' 'putting a finger in the anus,' and 'taking off shoes or clothes.'*

As for the duration of all logged items, the average length across participants was 14.7 minutes (SD=6.7). The shortest was 5.9 minutes (P5), and the longest was 31.7 minutes (P10). Our participants subjectively assessed the intensity of challenging behaviors exhibited by their child based on a 5-point Likert scale (from very weak to very strong) (mean=3.2). The most frequent rating was 4 (n=208), and the least frequent rating was 1 (n=11). When we asked participants about their criteria for rating the intensity during the interview, they mentioned the duration (P11, P12, P14, P15, P16, P19), the intensity of aggression (P11, P15), the volume of crying (P17, P19), the number of simultaneously exhibited behavioral patterns (P15, P18), the degree of potential harm to others (P10, P13), and whether caregivers felt that they could cope with the behavior (P12).

Eleven out of nineteen participants shared their child's behavioral data with others using the data-sharing feature. Two shared the data with family members, and seven shared it with the behavioral therapists who were active collaborators of our study (E2, E3) for the virtual parental training sessions. Two shared the data with a physical therapist or personal care attendants.

The qualitative analysis of interviews and observational notes revealed the lived experiences of caring for children exhibiting challenging behaviors. Overall, caregivers found using GeniAuti helped them become more attentive and reflective to behavioral contexts and discover positive moments through tracking. In addition, using GeniAuti facilitated collaborative intervention planning through clinically structured caregiver-tracked data. However, the use of GeniAuti also revealed

challenges of caregivers in collecting behavioral data in social circumstances and conflicting views of caregivers and clinical experts on interpreting challenging behaviors. We present our findings highlighting the benefits and challenges in each stage of caregivers' tracking experiences.

### 6.1 Becoming More Attentive and Reflective to Behavioral Contexts

In general, we found the characteristics of GeniAuti allowed caregivers to engage in data-driven reflective practices throughout the tracking process. Although the majority of the participants (N=14) indicated that they had previously documented their children's challenging behaviors using either paper-based methods (N=12) or general-purpose technology (N=4), all indicated that they had not been able to log data consistently nor organize data in a structured manner. The majority of the participants had used unstructured methods such as a pocket notepad or a simple memo app. Using GeniAuti, most of our participants frequently logged data (average number of logged items per day = 0.94) throughout the study period. Caregivers were able to integrate GeniAuti easily into their technology use routines throughout the day, which facilitated reflecting and understanding their children's challenging behaviors. For example, P17 liked that she was able to review her data at a time and place that worked best for her to reflect back on what kind of challenging behaviors her child showed that day, describing, *"I think it was convenient that GeniAuti was a mobile app. I could easily log data lying on my bed using my smartphone after my child fell asleep."* P5 also liked having access to descriptive statistics and visualizations of her tracking data for longer-term reflection whenever she wants.

In addition, building on a clinical data collection structure, the ABC model, GeniAuti provided participants a structure to log their children's challenging behaviors in a more systematic way. Six participants (P1, P3, P7, P8, P12, P15) said they benefited from the ABC model-based structure. P12 appreciated that GeniAuti enabled her to log data in a more detailed way relative to her previous practice: *"When writing in a notebook, I use to write down the behavior my son showed only without much detail. It was helpful to write down what happened before the behavior and how I responded step-by-step."* Similarly, P7 said, *"When I write them down on a blank page, it turns out pretty vague. By having a predefined list to fill out, I felt my recording became more systematic."* P1 also mentioned that it was a lot easier for her to understand the behavioral incidents later because of the structure.

Such constant and systematic tracking practices with GeniAuti enabled caregivers to become more reflective on the potential causes of their children's challenging behaviors. P17 came to observe her child's behaviors more carefully in her daily life. P2 and P6 said they came to organize their thoughts on what often caused their child's challenging behaviors while logging data. P9 and P18 noted they became more motivated to look for the causes of their children's challenging behaviors after using GeniAuti. P9 stated, *"Actually, I had almost given up figuring out why my child was showing such behaviors before the study. It was meaningful that I came to make constant efforts to look for the causes of my son's challenging behaviors while logging data."*

During the course of the study, eleven participants (P1, P2, P4, P5, P7, P8, P12, P18) were able to identify potential causes of their child's challenging behaviors through using GeniAuti. For example, P1 identified multiple causes of her children's challenging behaviors: *"I had thought the only reason that he showed the head-butting behavior was because he got anxious when a phone rang, but I discovered he often butted his head when he got upset when playing with his sister as well."* Similarly, P18 found GeniAuti helpful for discovering new potential causes of her child's challenging behaviors: *"I had thought my child lost his temper due to sensory stimulation from the zombie videos that he liked, but I realized that many times, he had angry outbursts when he wasn't able to get something."* Some participants mentioned specific features of GeniAuti that helped them gain new insights into the patterns of their children's challenging behaviors. Timestamping helped P12 figure out when her child was most likely to show challenging behaviors: *"I kept wondering if*

*my son's crying was just a tantrum or excessive arousal, and by logging data, I realized he mostly cried at around 4 to 5 PM when he got tired and sleepy.*" Similarly, through comparing records between days with the frequency graphs, P5 was able to identify that her son showed challenging behaviors, mostly during physical therapy sessions.

The caregivers became not only more aware of their child's challenging behaviors but also more reflective of their response strategies. Building on the ABC model, GeniAuti required caregivers to record how they responded to their child's challenging behaviors ('C'). Therefore, they naturally came to be more reflective about whether they appropriately respond to the child's behaviors. Three participants (P2, P3, P8) noted that these practices helped them discover which strategies worked for their children. P3 explained, *"If I didn't track, I couldn't really remember which worked and which didn't. Now that I have records, I can see when one didn't work and that I should try different ways next time."* This understanding enabled caregivers to speculate about how to improve their response strategies. Six participants (P3, P4, P8, P12, P13, P14) indicated that reviewing the data allowed them to consider how they could better respond to their children's challenging behaviors. Furthermore, being a collaborative tool for caregivers to share behavioral data with their clinical experts, GeniAuti implicitly nudged caregivers to respond to their children's challenging behaviors in the ways that the clinical experts recommended. For example, P3 said: *"When my daughter experiences meltdowns, she bursts into tears and screams very loudly in public. Her therapist has recommended not paying attention to it at all, but I used to try everything to calm her because it was very hard to ignore others' judgmental looks. [...] As I had to record and share data with my child's doctor when my daughter had meltdowns in public, I decided not to show any reaction, even when all the people passing by were staring at us."*

## 6.2 Challenges of Logging Behaviors in Social Circumstances

Some of our participants found it beneficial that GeniAuti made their recording process easier in everyday life. Five participants (P5, P8, P10, P15, P17) mentioned that they found it convenient to utilize preregistered options (i.e., frequent behaviors) when tracking. P15 said: *"After adding a few options that suited my child, I was able to complete recording in 2–3 minutes. That was so convenient!"* (P15) Similarly, P5 and P10 appreciated that they were able to log data conveniently with the frequent behavior feature without having to manually enter data.

Despite the perceived benefits of various scaffolding features, we observed several logistical challenges that the caregivers experienced during behavioral incidents. Participants mentioned they found it challenging to log data at the moment as they had to intervene in their children's challenging behaviors. P15 said, *"I do believe that the timer widget is a useful feature, but I couldn't use it at all. When my child exhibited aggressive behaviors, I sometimes didn't have my phone nearby or I barely had time to press the timer."* (P15) Therefore, 13 participants reported that they made data entries later on, rather than immediately after each behavioral incident, often after their child fell asleep. They mentioned that they often ended up forgetting to make a data entry or the details of the incidents when they did not record them right away.

Many participants also mentioned the distraction and noise during behavioral incidents hindered both modes of the data entries, manual typing and voice recognition. Three (P4, P5, P7) said it was difficult to organize their thoughts about the complex behavior incidents before typing data due to the distraction their children engaged in challenging behaviors. Two participants (P3, P8) mentioned that they could not use the voice recognition feature due to similar issues. Since screaming and/or crying behaviors were common among our participants' children, seven participants' logged those behaviors. P3 mentioned that her child often screamed and cried at the top of her lungs, so she could not use the voice recognition feature at all. Due to this challenge, our participants made minimal use of the voice recognition feature.

In addition, some caregivers could not use their smartphones in front of the children due to their excessive immersion in smartphone use. In many cases, children's challenging behaviors were related to the use of smartphones. For example, P12 and P13's children threw away things when their mothers told them to stop playing with a smartphone. P9's child urinated sitting in the chair when he was immersed in watching Youtube videos on a smartphone. Therefore, they tried to avoid using a smartphone in front of their children as much as they could and ended up logging data mostly at night after their child went to sleep.

Furthermore, oftentimes challenging behaviors occurred too frequently for caregivers to log every time. Five caregivers (P3, P5, P8, P9, P13) stated they were unable to track every challenging behavior as they occurred too often. P5 felt confused about specifying when her child exhibited challenging behaviors: *"He poked his eyes, so I started to record it right away, but he poked his eyes again in a minute even before I finished recording the previous one."*

In other cases, participants experienced emotional struggles that hindered in situ data collection. Participants mentioned that they were not ready for recording right after the episodes because of their emotional exhaustion. P9 described: *"I tried to collect myself before logging data when I became really upset because of my child's challenging behaviors."* (P9) The repetitive tracking of challenging behaviors provoked emotional exhaustion for some caregivers. Four caregivers (P5, P9, P16, P17) noted the negative feelings resulting from repetitively tracking challenging behaviors. P17 reported that *"As I recorded more, I felt more anxious about my child wondering if his status was that serious."* E2 noted that P9, who had used GeniAuti beyond the study period, ended up stopping tracking because she was too frustrated that her adolescent child kept showing inappropriate urination.

### 6.3 Emotional Benefits of Behavioral Tracking by Discovering Positive Moments

Although logging in GeniAuti was sometimes emotionally challenging for caregivers, many also experienced emotional benefits from tracking. P5 and P6 appreciated the times when their children's challenging behaviors improved through reviewing the frequency chart and severity trends. P3 valued that GeniAuti helped improve her husband's understanding of her daily struggles as their child's primary caregiver, as sharing data allowed him to review concrete examples of behavior incidents: *"Rather than me saying I had a rough day with my daughter, I felt it was more effective for him to see how many times and how hard she pushed me."*

Some participants used GeniAuti to highlight areas where their child's behaviors had improved even though its tracking structure did not specifically support such usage. P10 recorded when her child 'almost' exhibited challenging behaviors: *"My child has ups and downs. He sometimes shows several challenging behaviors in a row and then doesn't show any for a while. I often can't remember what he was like when not showing challenging behaviors. I wanted to keep those records, too."* (P10) Similarly, P12 pointed out that she wanted to track days when her child did not show any challenging behaviors: *"It's about recording challenging behaviors, so I didn't have to create logs when he didn't show any. But I felt it would be great to document cases where he was in a bad mood but didn't have an outburst. Our goal is to improve on challenging behaviors, so why don't we log the improvements?"* We found this need aligned with clinical experts' strategies of examining not only severe challenging behavior incidents, but also cases when they were successfully managed: *"We examine not only the worst days but also the best days, like what their schedule looked like, who they were with, etc., to continue them."* (E3)

### 6.4 Facilitating Collaborative Planning of Intervention Strategies through Clinically Structured Caregiver-Tracked Data

We found GeniAuti helped caregivers and clinical experts collaboratively plan data-driven intervention strategies tailored to each child. First, GeniAuti supported the clinical experts' practices



for integrating data to prepare for consultation sessions with caregivers. Using GeniAuti reduced clinical experts' integration burden by automatically creating tables and graphs. E2 mentioned, *"I used to type what caregivers wrote down on paper ABC forms, and then create tables and graphs using Excel and Powerpoint for review. It was nice that GeniAuti created them automatically."* In addition, participants described the benefits of sharing caregiver-tracked data with clinical experts in real-time. E2 and E3 used to collect the ABC forms that caregivers had filled out during the week in their weekly consultation sessions, analyze the data, and give comments to each caregiver in the following session, which meant there used to be at least a week-long gap between data collection and review with experts. After using GeniAuti, clinical experts valued that GeniAuti offered them real-time access to the caregiver-tracked data. E3 said, *"When I used paper forms, I could only get the data when I met parents in person for weekly sessions. And this hasn't been possible after the pandemic. Using GeniAuti, I was able to check how the children were doing whenever I was curious."* The real-time access to caregiver-tracked data helped clinical experts better prepare for the following consultations and provide caregivers more timely comments. E3 described: *"When I noticed that the frequency of challenging behaviors of the child increased abruptly or a new pattern of behavior [from the data], I was able to prepare for new interventions for the child before the next session."*

The use of GeniAuti also contributed to more efficient caregiver-clinician communication. All three clinical experts appreciated having caregiver-tracked data that they could refer to during their consultation sessions. There were benefits of having structured logs and visualizations through GeniAuti in reducing unnecessarily lengthy caregiver-clinician communication. For example, E1 said: *"When I ask parents how their child has been doing, they often talk about the first thing that comes to their mind or the most difficult time they had. Many times, they are confused about what happened before and after, and then it gets very lengthy. [...] It was much better for me to walk through the data through GeniAuti to find discussion points quickly."* Caregivers also appreciated that their conversations with clinical experts became more efficient and effective by allowing clinical experts to walk through their data. Five participants (P7, P11, P12, P14, P18) liked that they did not have to memorize and explain what they have gone through between the consultations to clinical experts.

In addition, using GeniAuti assisted clinical experts in looking into challenging behavior incidents more objectively by quantifying some aspects of the behaviors. E1 highlighted that reviewing GeniAuti data helped her understand each child's challenging behaviors in a more objective way: *"Parents' descriptions are sometimes very subjective, like, 'He drove me crazy last week.' Then it is very hard for me to understand how severe it was. With the structured logs and charts, I was able to see the patterns in a more objective way."*

Furthermore, caregivers felt that they received more detailed feedback from clinical experts during their consultation. Building on a commonly-used data collection method (ABC model) in clinical settings, caregivers were able to generate logs that fit clinical needs, which assisted clinical experts in providing more concrete, individualized feedback on how to mitigate challenging behaviors. After reviewing the data, E1 told P1 that she needed to continue ignoring her child's emotional crying, as paying attention could reinforce the behavior. P1 said: *"I used to explain what I thought was important, but I felt I got much more concrete feedback on which strategies were good or bad when having a discussion with my logs."*

## 6.5 Conflicting Views of Caregivers and Clinicians on Interpreting Challenging Behaviors

Engaging caregivers in clinically structured tracking practices with GeniAuti occasionally led to conflicts or tensions in interpreting children's behaviors. We found that clinical-based data collection structures could conflict with the caregivers' viewpoints on their children's behaviors.

Specifically, caregivers sometimes had difficulty specifying the cause of the behavior (function) among the four options GeniAuti provided. Four participants (P5, P7, P8, P11) noted that they could not identify causes of their children's challenging behaviors at all: *"I often felt that my son pinched me for no reason; I couldn't understand why at all."* (P11) Similarly, three participants (P1, P8, P10) were skeptical about documenting what happened right before the challenging behavior occurred (antecedents). P8 stated, *"What happened before she hit me? She was just in the car with me, looking outside peacefully. Then she hit me out of nowhere."* Furthermore, eight participants (P1, P2, P7, P8, P10, P12, P15, P19) reported that the four functions provided by GeniAuti did not match their perceived causes of their children's challenging behaviors, feeling that challenging behaviors were caused by their children's inner thoughts and feelings, which they could not observe and therefore track. For instance, P8 assumed her child's challenging behaviors were related to emotional stress experienced a few hours or even a few days before, rather than what happened right before them. Similarly, P10 guessed the reason her child hit his father as follows: *"He can't describe such complicated feelings, but I guess he was constantly reminded of the feelings he had when his father had gotten angry at him long before, even when his father did nothing to him at that time."*

The conflicting views often led to disagreement between the caregivers' and experts' interpretations of the children's challenging behaviors. We found sharing caregiver-tracked data through GeniAuti during the consultations made the tension visible and could even have promoted it. Clinical experts raised a concern that caregivers often interpreted their child's challenging behaviors in a subjective manner without evidence. However, some caregivers had strong enough opinions about the causes of the behaviors that they could not take experts' advice. For example, P9 strongly believed that her child's challenging behaviors became severe due to physical and psychological factors after her child gained weight. On the other hand, E2 thought his challenging behaviors had multiple functions resulting from environmental factors, such as seeking attention from his mother and avoidance of physical therapy sessions. Similarly, P15 felt frustrated that she was unable to find any particular function for her child's head-butting behaviors other than sleepiness, whereas E3 thought that P15 was missing something: *"[E3] says there must be a specific reason for such behaviors, but I can't find any even though I have tried for years. I think it is that he [E3's child] cannot handle himself when he becomes tired and sleepy. Theoretically, there should be a reason, but the real world doesn't always follow theories."* (P15) This tension led P15 to collect more data; she created 148 items during her study participation (35 days), which was higher than any other participant. Despite the intensive data collection practice, P15 still remained confused at the end of the study.

## 7 DISCUSSION

Through our deployment study, we found that caregivers perceived benefits in becoming more attentive and reflective to behavioral contexts and discovering positive moments using GeniAuti. Our findings also suggest the benefits of bringing clinical needs into caregiver-facing tools in collaboration with clinical experts. Clinical experts perceived that structured logs and visualizations of GeniAuti based on the ABC model and quantified aspects of challenging behaviors facilitated more efficient and effective communication with caregivers. However, our study also surfaced challenges in conflicting views between caregivers and clinical experts on interpreting challenging behaviors. Our findings shed light on the design of caregivers' tracking in emotion-laden domains in collaboration with clinicians by (1) ensuring all stakeholders data needs are recognized in behavioral care, (2) promoting negotiation between caregivers and clinicians to close the perspective gap, (3) listening to caregivers' emotional needs, and (4) enabling tracking non-events for recognizing positive moments.

## 7.1 Ensuring Caregivers, Clinicians, and Children's Data Needs are Recognized in Behavioral Care

Our findings indicated that the tracking structure of GeniAuti supported the goals of both caregivers and clinical experts for understanding the relationships between factors that influence challenging behaviors in daily settings. Through collecting clinically structured behavioral data using GeniAuti, caregivers and clinical experts both reported that they were able to gain useful data to identify factors that impact children's challenging behavior incidents. Having such data supported the experts in providing tailored recommendations for how the caregivers could change their response strategies and enabled more efficient caregiver-clinician communication in clinical consultations. This finding is consistent with prior work emphasizing the value of leveraging structured clinical data collection forms in promoting collaboration among different stakeholders [38, 55, 83, 86].

Despite such benefits, our findings during the study pointed to challenges in observation-based tracking by caregivers. GeniAuti's tracking structure is based on the ABC model, which has an underlying assumption that the cause of challenging behaviors can be best understood based on the observations and documentation of the environmental factors including others' behaviors (e.g., therapists, caregivers). However, some of our caregiver participants had a hard time determining the relationship between the environmental factors they could observe and their children's challenging behaviors. They often felt their children's challenging behaviors were unrelated to any environmental factors but rather related to other internal factors (e.g., fatigue, excessive arousal, anxiety, stress). However, our expert collaborators found it concerning that some caregivers discounted their potential influence on their children's behaviors and developed hypotheses without evidence and clinical support.

From the perspective of personal informatics, observation-based tracking is limited compared to tracking a person's own behaviors and thoughts, as it can only capture what is observable. Inner thoughts and feelings of the person being tracked are more challenging for another person to capture. Unlike previous behavioral tracking systems leveraging physiological sensing data [1, 67, 76], GeniAuti leveraged observation-based manual tracking which involves individuals' interpretation of the situations. Since caregivers are not professionally trained to conduct behavioral observation in most cases, there is a potential risk that they make flawed or inaccurate interpretations about whom they are observing [88], which introduces further challenges in integrating caregiver-tracked data into clinical settings. Physiological sensing can potentially supplement observation-based tracking by helping autistic children better communicate their emotional status with their caregivers and clinicians [67, 82]. However, leveraging these sensors requires careful consideration of privacy concerns of children whose behaviors are being observed [30, 31].

Engaging autistic children as care recipients in the co-design of technology support for behavioral challenge can further surface how different stakeholder needs align or are in tension with one another. Previous studies have shown the value of developing ways to better engage autistic children and adolescents in their mental and behavioral care [26, 41]. Supporting autistic children and adolescents to customize their own trackers with personalized goals can empower them to engage in active self-management and better communicate with their caregivers [41]. In the setting where GeniAuti was designed and deployed, the children had limited verbal communication skills. Developing methods for engaging these children in the design process is an important opportunity for future work.

## 7.2 Promoting Negotiations between Caregivers and Clinicians to Close the Perspective Gap

Challenging behavior interventions ultimately aim to modify behaviors of children, and how caregivers respond to their child's challenging behaviors greatly influences the behaviors. Therefore, similar to prior work where caregivers take on primary tracking roles [34, 74, 88], GeniAuti primarily aimed to change caregivers' verbal and behavioral response strategies as a precursor to modifying children's behaviors. In pursuit of this goal, GeniAuti required caregivers to observe and document their own behaviors alongside their children's behaviors. Unlike previous work in challenging behavior tracking, in which caregivers were mere consumers of the data collected by experts [31, 39] or passive recorders by marking what is perceived as challenging behaviors through video capture systems [69], caregivers were actively engaged in multiple roles in the tracking process using GeniAuti, such as observing their children and themselves, logging data, reflecting on the causes of the behaviors. Consistent with prior work in patient-provider collaboration around patient-tracked data [15, 16], this practice led caregivers to potentially change their own behaviors by learning about more and less effective strategies for caring for their children, speculating about how to improve their response strategies, and further sticking to expert recommendations.

However, we also observed significant tension when caregivers and clinical experts had different opinions about how to interpret the child's challenging behaviors, which might have hindered caregiver-clinician collaboration to better manage children's behavioral health. From clinical experts' perspective, such tension occurred when caregivers had rigid viewpoints about the causes of their children's challenging behaviors, leading them to be less receptive to the experts' recommendations. On the other hand, caregivers felt that clinical experts were not listening to their opinions on the causes of their child's challenging behaviors. Bringing clinical needs into caregivers' tracking tools surfaces the potential tension between caregivers and clinicians around how to interpret the data to develop behavior interventions for the children. This finding is consistent with prior work that showed conflicting interpretations between patients and clinicians around patient-tracked data [16, 37, 80]. In light of the framework of boundary negotiating artifacts [47], while GeniAuti seemed to work as an effective compilation artifact to facilitate sharing information and structuring artifact to guide caregiver's response strategies, it might have failed to serve as an inclusion artifact to facilitate negotiation and discussion between caregivers and clinical experts.

The tension between caregivers and clinicians might suggest an important learning opportunity for both stakeholders to better understand each other's goals and perspectives. Prior work has highlighted design opportunities for patient(caregiver)-provider collaboration to support identifying misalignment in perspectives [72] and adapting to where each other is in the learning process [77]. Aligning with this work, we suggest that future technology support for caregiver-clinician collaboration around childcare should provide explicit mechanisms for learning about and negotiating different perspectives. For example, providing specific conversational prompts about children's behaviors or annotation features could help ensure that they discuss critical information from each side [77] and gain situated understanding of each other's perspectives [16, 17, 72, 77]. Incorporating photo- or video-based artifacts as boundary negotiating artifacts into tracking technology for caregivers could also help resolve disagreements between caregivers and clinicians in behavioral care [16, 17, 83]. Collecting more data, however, could exacerbate the perspective gap between these stakeholders, leading them to become more defensive and emboldened by the data they have on their side. Addressing these tensions would benefit from further research on supporting caregivers and clinicians in collaboratively defining what data to capture and how to negotiate differing perspectives in reviewing the data for behavioral care.

### 7.3 Tracking as a Listening Tool for Caregivers

Through deploying GeniAuti, we learned about the lived experiences of caregivers taking care of children who engage in challenging behaviors, which included significant physical and emotional struggles. Documenting repetitive challenging behaviors was often physically and emotionally taxing for caregivers and a reminder of the daily struggles of caring for children who exhibit challenging behaviors. The findings on the difficulty of integrating clinically relevant metrics into tracking tools are consistent with prior Personal Informatics literature in emotion-laden domains [3, 4, 19, 20]. Figueiredo et al.'s work highlights that people engaging in fertility tracking experience frustration and distress due to uncertainty, specifically not being able to find an answer to a "why" question nor control many of the health indicators despite their tracking efforts [19, 20]. In addition, Ancker et al. suggest that personal health data might carry strong moral implications and patients often judge themselves based on the data [3]. Caregiver-based challenging behavior tracking shares many similar aspects, such as limited scientific knowledge about challenging behavior, the subjective and individualized nature, and low control on their children's behaviors. On top of that, in caregiver-based challenging behavior tracking, caregivers suffer from added frustration and distress due to not being able to get an answer from their child on "why" they engage in challenging behaviors when their children have limited verbal communication skills, the physical risk of aggressive or self-injurious behaviors, and unpredictability of when and where their children might show such behaviors. Furthermore, caregiver-tracked data might have stronger moral implications that introduce or exacerbate caregivers' self-guilt [11].

Being a clinically structured tracking tool, GeniAuti helped caregivers collect clinically relevant data. However, as a consequence of bringing solely clinical needs into tracking tools, caregivers sometimes felt that their tracking experiences with GeniAuti were cold or emotionless, as they did not consider their emotional burdens managing and documenting their children's challenging behaviors. Furthermore, when the data was relayed to other stakeholders such as clinical experts or co-caregivers who had less understanding and sympathy for the lived-in experience of caregiving, the frigidness of the interaction might have been exacerbated. While GeniAuti helped caregivers collect clinically relevant data and engage in efficient caregiver-clinician communication, it might have failed to serve as a tool that appeared to listen to caregivers or understand the struggles of tracking and the everyday experiences of their children's challenging behaviors. We see an opportunity for tracking technology to better serve as a listening tool for caregivers who engage in emotion-laden tracking. To assist caregivers in coping with their emotional challenges, caregiver-based tracking systems should leverage the benefits of self-tracking in supporting mindful journaling practices, and a room to vent about their emotional struggles [4, 5, 41, 49] beyond clinical metrics for children's health. Such systems could also incorporate ways to provide situated support for reducing parental stress [73]. Tracking systems can also support caregivers in sharing the data to allow family or friends to better understand their daily challenges. As prior work has suggested [35, 84], sharing data about caregiving activities and daily stress with co-caregivers can help them better empathize with and provide emotional support to primary caregivers engaging in emotion-laden tracking. We similarly see value in sharing similar data with clinicians because they often lack awareness or understanding of caregivers' daily challenges as well.

### 7.4 Tracking Non-Events for Recognizing Positive Aspects

Despite the emotional struggles of documenting their children's challenging behaviors in daily settings, some participants found emotional benefits in tracking when they discovered positive moments in their childcare. In contrast to tracking in some domains might have little room for individuals to find gradual progress or success other than achieving a single goal (e.g., fertility

tracking to get pregnant) [19, 20], challenging behavior tracking has a potential to motivate caregivers to find small achievements or improvements. When reviewing data, some of our participants recognized moments when their children's challenging behaviors improved in terms of frequency or severity, which made them feel relieved. Others tracked or wanted to track incidents when their children exhibited almost, but not quite, challenging behaviors to support reminiscence around successful moments. They mentioned that otherwise, they might not be able to remember if lapses in data were intended or due to successes or improvements when reflecting later.

These findings resonate with prior work in Personal Informatics [62, 66, 80] regarding the value of highlighting successes or improvements through self-tracking systems. Specifically, Matthew et al. [62] suggested the value of accounting for tracking and representing a "zero" day, meaning nothing prominent happened in self-tracking systems for individuals with bipolar disorder. Similarly, Marcu et al. [55] highlighted the need for encouraging awareness of desired behaviors as well as undesired behaviors when tracking children's behaviors for developing behavioral interventions. Extending the prior work's arguments, we suggest implications for designing tracking systems for caregivers to promote positive aspects of a journey to managing their children's behavioral challenges, aligning with more celebratory approaches to technology design [27]. Caregivers were not expected to log data in GeniAuti when their children did not exhibit challenging or erratic behaviors. However, caregivers found value in recording and reminiscing days when children did not show any challenging behaviors as they offered emotional benefits as well as insights to better intervene around the children's behaviors. This finding also resonates with previous studies that highlighted the sentimental value of children's health-related data for caregivers [38, 83]. Based on the findings, we suggest that there is an opportunity for tracking systems to actively scaffold tracking "non-events" in order to encourage users who engage in emotion-laden tracking to record and reflect on reminiscing and celebrating such positive experiences.

## 8 CONCLUSION

Our deployment of GeniAuti demonstrated that leveraging a clinical data collection form and providing scaffolding features for collecting, reflecting on, and sharing data in everyday life helped caregivers become more attentive and reflective to behavioral contexts, discover positive moments, and better collaborate with clinical experts to develop tailored intervention strategies. Caregivers' tracking of challenging behaviors offers opportunities and challenges for supporting tracking in emotion-laden domains in collaboration with clinicians, such as the need for recognizing all stakeholders' needs in behavioral care, promoting negotiations between caregivers and clinicians to close the perspective gap, listening to caregivers' emotional needs, and recognizing positive moments. We argue that further research in this area, particularly regarding how to incorporate and better utilize caregivers' computer-supported tracking practices into clinical contexts, can enhance caregivers' ability to deal with their children's challenging behaviors.

## ACKNOWLEDGMENTS

We thank Stephen Schueller and our anonymous reviewers for their feedback. We also thank our participants and clinical experts for their sincere participation. This work was generously supported by a grant of the Korea Health Technology R&D Project through the Korea Health Industry Development Institute (KHIDI) funded by the Ministry of Health & Welfare (HI18C1180) and the Basic Science Research Program through the National Research Foundation of Korea funded by the Ministry of Science and ICT (NRF-2020R1F1A1066408). This work was funded in part by the National Science Foundation under award IIS-1850389.

## REFERENCES

- [1] Fahd Albinali, Matthew S. Goodwin, and Stephen S. Intille. 2009. Recognizing stereotypical motor movements in the laboratory and classroom. (2009), 71. <https://doi.org/10.1145/1620545.1620555>
- [2] David Allen, Sarah Hawkins, and Viv Cooper. 2006. Parents Use of Physical Interventions in the Management of Their Childrens Severe Challenging Behaviour. *Journal of Applied Research in Intellectual Disabilities* 19, 4 (2006), 356–363. <https://doi.org/10.1111/j.1468-3148.2006.00292.x>
- [3] Jessica S. Ancker, Holly O. Witteman, Baria Hafeez, Thierry Provencher, Mary Van De Graaf, and Esther Wei. 2015. "You get reminded you're a sick person": Personal data tracking and patients with multiple chronic conditions. *Journal of Medical Internet Research* 17, 8 (2015), 1–19. <https://doi.org/10.2196/jmir.4209>
- [4] Amid Ayobi, Paul Marshall, Anna L. Cox, and Yunan Chen. 2017. Quantifying the Body and Caring for the Mind. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17* (2017), 6889–6901. <https://doi.org/10.1145/3025453.3025869>
- [5] Amid Ayobi, Tobias Sonne, Paul Marshall, Anna L Cox, and U C L Interaction Centre. 2018. Flexible and Mindful Self-Tracking : Design Implications from Paper Bullet Journals. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18* (2018), To appear. <https://doi.org/10.1145/3173574.3173602>
- [6] Donald M. Baer, Montrose M. Wolf, and Todd R. Risley. 1968. Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis* 1, 1 (1968), 1310980. <https://doi.org/10.1901/jaba.1968.1-91>
- [7] Ayelet Ben-Sasson, Eli Ben-Sasson, Kayla Jacobs, Elisheva Rotman Argaman, and Eden Saig. 2019. Evaluating Expert Curation in a Baby Milestone Tracking App. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland Uk) (CHI '19). Association for Computing Machinery, New York, NY, USA, 1–12. <https://doi.org/10.1145/3290605.3300783>
- [8] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (2006), 77–101.
- [9] Lauren Brookman-Frazee, Aubyn Stahmer, Mary J. Baker-Ericzén, and Katherine Tsai. 2006. Parenting interventions for children with autism spectrum and disruptive behavior disorders: Opportunities for cross-fertilization. *Clinical Child and Family Psychology Review* 9, 3-4 (2006), 181–200. <https://doi.org/10.1007/s10567-006-0010-4>
- [10] E G Carr and V M Durand. 1985. Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis* 18, 2 (1985), 111–126. <https://doi.org/10.1901/jaba.1985.18-111>
- [11] Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers: Designing for integrality. *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW* (2013), 91–102. <https://doi.org/10.1145/2441776.2441789>
- [12] Eun Kyoung Choe, Saeed Abdullah, Mashfiqui Rabbi, Edison Thomaz, Daniel A. Epstein, Felicia Cordeiro, Matthew Kay, Gregory D. Abowd, Tanzeem Choudhury, James Fogarty, Bongshin Lee, Mark Matthews, and Julie A. Kientz. 2017. Semi-Automated Tracking: A Balanced Approach for Self-Monitoring Applications. *IEEE Pervasive Computing* 16, 1 (2017), 74–84. <https://doi.org/10.1109/MPRV.2017.18>
- [13] Kiwon Choi, Dongho Jang, Dasol Lee, and Seoyoung Park. 2018. GeniAuti: Tracking challenging behaviors of children with autism for data-driven interventions. *ASSETS 2018 - Proceedings of the 20th International ACM SIGACCESS Conference on Computers and Accessibility* (2018), 480–482. <https://doi.org/10.1145/3234695.3240987>
- [14] Eunji Chong, Katha Chanda, Zhefan Ye, Audrey Southerland, Nataniel Ruiz, Rebecca M. Jones, Agata Rozga, and James M. Rehg. 2017. Detecting Gaze Towards Eyes in Natural Social Interactions and Its Use in Child Assessment. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies* 1, 3 (2017), 1–20. <https://doi.org/10.1145/3131902.arXiv:arXiv:1902.00607v1>
- [15] Chia Fang Chung, Jonathan Cook, Elizabeth Bales, Jasmine Zia, and Sean A. Munson. 2015. More than telemonitoring: Health provider use and nonuse of life-log data in irritable bowel syndrome and weight management. *Journal of Medical Internet Research* 17, 8 (2015), 1–16. <https://doi.org/10.2196/jmir.4364>
- [16] Chia Fang Chung, Kristin Dew, Allison Cole, Jasmine Zia, James Fogarty, Julie A. Kientz, and Sean A. Munson. 2016. Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW* 27 (2016), 770–786. <https://doi.org/10.1145/2818048.2819926>
- [17] Chia-Fang Chung, Qiaosi Wang, Jessica Schroeder, Allison Cole, Jasmine Zia, James Fogarty, and Sean Munson. 2019. Identifying and Planning for Individualized Change: Patient-Provider Collaboration Using Lightweight Food Diaries in Healthy Eating and Irritable Bowel Syndrome. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies* 3, 1 (2019), 1–27. <https://doi.org/10.1145/3314394>
- [18] J O Cooper, T E Heron, and W L Heward. 2007. *Applied Behavior Analysis*. Pearson/Merrill-Prentice Hall. <https://books.google.co.kr/books?id=6eRgQgAACAAJ>
- [19] Mayara Costa Figueiredo, Clara Caldeira, Elizabeth Victoria Eikey, Melissa Mazmanian, and Yunan Chen. 2018. Engaging with Health Data: The Interplay Between Self-Tracking Activities and Emotions in Fertility Struggles. *Proc.*

- ACM Hum.-Comput. Interact.* 2, CSCW, Article 40 (Nov. 2018), 20 pages. <https://doi.org/10.1145/3274309>
- [20] Mayara Costa Figueiredo, Clara Caldeira, Tera L. Reynolds, Sean Victory, Kai Zheng, and Yunan Chen. 2017. Self-Tracking for Fertility Care: Collaborative Support for a Highly Personalized Problem. *Proc. ACM Hum.-Comput. Interact.* 1, CSCW, Article 36 (Dec. 2017), 21 pages. <https://doi.org/10.1145/3134671>
  - [21] Karola Dillenburger, Mark F. O'Reilly, and Michael Keenan. 1997. *Advances in behaviour analysis*. University College Dublin Press.
  - [22] Kathleen Dyer. 2013. *Antecedent-Behavior-Consequence (A-B-C) Analysis*. Springer New York, New York, NY, 175–180. [https://doi.org/10.1007/978-1-4419-1698-3\\_1003](https://doi.org/10.1007/978-1-4419-1698-3_1003)
  - [23] E. Emerson and J. Bromley. 1995. The form and function of challenging behaviours. *Journal of Intellectual Disability Research* 39, 5 (1995), 388–398. <https://doi.org/10.1111/j.1365-2788.1995.tb00543.x>
  - [24] Daniel A. Epstein, Clara Caldeira, Mayara Costa Figueiredo, Xi Lu, Lucas M. Silva, Lucretia Williams, Jong Ho Lee, Qingyang Li, Simran Ahuja, Qiuer Chen, Payam Dowlatyari, Craig Hilby, Sazedha Sultana, Elizabeth V. Eikey, and Yunan Chen. 2020. Mapping and Taking Stock of the Personal Informatics Literature. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 4, 4, Article 126 (Dec. 2020), 38 pages. <https://doi.org/10.1145/3432231>
  - [25] Daniel A. Epstein, An Ping, James Fogarty, and Sean A. Munson. 2015. A lived informatics model of personal informatics. *UbiComp 2015 - Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing* (2015), 731–742. <https://doi.org/10.1145/2750858.2804250>
  - [26] Christopher Frauenberger, Judith Good, and Wendy Keay-Bright. 2011. Designing technology for children with special needs: Bridging perspectives through participatory design. *CoDesign* 7, 1 (2011), 1–28. <https://doi.org/10.1080/15710882.2011.587013>
  - [27] Andrea Grimes and Richard Harper. 2008. Celebratory technology: new directions for food research in HCI. In *Proceedings of the SIGCHI conference on human factors in computing systems*. 467–476.
  - [28] Gerald Groden. 1989. A guide for conducting a comprehensive behavioral analysis of a target behavior. *Journal of Behavior Therapy and Experimental Psychiatry* 20, 2 (jun 1989), 163–169. [https://doi.org/10.1016/0005-7916\(89\)90049-9](https://doi.org/10.1016/0005-7916(89)90049-9)
  - [29] Gregory P. Hanley, Brian A. Iwata, and Brandon E. McCord. 2003. Functional Analysis of Problem Behavior: a Review. *Journal of Applied Behavior Analysis* 36, 2 (2003), 147–185. <https://doi.org/10.1901/jaba.2003.36-147>
  - [30] Gillian R. Hayes and Gregory D. Abowd. 2006. Tensions in designing capture technologies for an evidence-based care community. *Conference on Human Factors in Computing Systems - Proceedings* 2 (2006), 937–946. <https://doi.org/10.1145/1124772.1124911>
  - [31] Gillian R. Hayes, Lamar M. Gardere, Gregory D. Abowd, and Khai N. Truong. 2008. CareLog: A selective archiving tool for behavior management in schools. *Conference on Human Factors in Computing Systems - Proceedings* (2008), 685–694. <https://doi.org/10.1145/1357054.1357164>
  - [32] S. Herring, Kylie M. Gray, J. Taffe, B. Tonge, D. Sweeney, and S. Einfeld. 2006. Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research* 50, 12 (2006), 874–882. <https://doi.org/10.1111/j.1365-2788.2006.00904.x>
  - [33] Robert H. Horner, Edward G. Carr, Phillip S. Strain, Anne W. Todd, and Holly K. Reed. 2002. Problem Behavior Interventions for Young Children with Autism: A Research Synthesis. *Journal of Autism and Developmental Disorders* 32, 5 (2002), 423–446. <https://doi.org/10.1023/A:1020593922901>
  - [34] Eunkyung Jo, Hyeonseok Bang, Myeonghan Ryu, Eun Jee Sung, Sungmook Leem, and Hwajung Hong. 2020. MAMAS: Supporting Parent - Child Mealtime Interactions Using Automated Tracking and Speech Recognition. *Proceedings of the ACM on Human-Computer Interaction* 4, CSCW1 (2020), 1–32. <https://doi.org/10.1145/3392876>
  - [35] Eunkyung Jo, Austin L. Toombs, Colin M. Gray, and Hwajung Hong. 2020. Understanding Parenting Stress through Co-designed Self-Trackers. *Conference on Human Factors in Computing Systems - Proceedings* (2020), 1–13. <https://doi.org/10.1145/3313831.3376359>
  - [36] Stephen M. Kanne and Micah O. Mazurek. 2011. Aggression in Children and Adolescents with ASD: Prevalence and Risk Factors. *Journal of Autism and Developmental Disorders* 41, 7 (2011), 926–937. <https://doi.org/10.1007/s10803-010-1118-4>
  - [37] Ravi Karkar, Jessica Schroeder, Daniel A. Epstein, Laura R. Pina, Jeffrey Scofield, James Fogarty, Julie A. Kientz, Sean A. Munson, Roger Vilardaga, and Jasmine Zia. 2017. TummyTrials: A feasibility study of using self-experimentation to detect individualized food triggers. *Conference on Human Factors in Computing Systems - Proceedings* 2017-May (2017), 6850–6863. <https://doi.org/10.1145/3025453.3025480>
  - [38] Julie Kientz, Rosa Arriaga, and Gregory Abowd. 2009. Baby steps: evaluation of a system to support record-keeping for parents of young children. In *Proceedings of the SIGCHI Conference on human factors in computing systems (CHI '09)*. ACM, 1713–1722.
  - [39] Julie A Kientz, Gregory D Abowd, and Gillian R Hayes. 2005. Abaris: Evaluating Automated Capture Applied to Structured Autism Interventions. *Lecture Notes in Computer Science*, Vol. 3660. Springer Berlin Heidelberg, Berlin, Heidelberg, 323–339.



- [40] Julie A. Kientz, Gillian R. Hayes, Gregory D. Abowd, and Rebecca E. Grinter. 2006. From the war room to the living room: Decision support for home-based therapy teams. *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW* (2006), 209–218. <https://doi.org/10.1145/1180875.1180909>
- [41] Sung In Kim, Eunkyung Jo, Myeonghan Ryu, Inha Cha, Young Ho Kim, Heejung Yoo, and Hwajung Hong. 2019. Toward becoming a better self: Understanding self-tracking experiences of adolescents with autism spectrum disorder using custom trackers. *ACM International Conference Proceeding Series* (2019), 169–178. <https://doi.org/10.1145/3329189.3329209>
- [42] Yoojung Kim, Eunyoung Heo, Hyunjeong Lee, Sookyoung Ji, Jueun Choi, Jeong-Whun Kim, Joongseek Lee, and Sooyoung Yoo. 2017. Prescribing 10,000 Steps Like Aspirin. (2017), 5787–5799. <https://doi.org/10.1145/3025453.3025570>
- [43] Yoojung Kim, Sookyoung Ji, Hyunjeong Lee, Jeong-Whun Kim, Sooyoung Yoo, and Joongseek Lee. 2016. "My Doctor is Keeping an Eye on Me!". (2016), 5620–5631. <https://doi.org/10.1145/2858036.2858145>
- [44] Ha-Kyung Kong. 2020. Addressing Cognitive and Emotional Barriers in Parent-Clinician Communication through Behavioral Visualization Webtools. *Chi* (2020), 1–12. <https://doi.org/10.1145/3313831.3376181>
- [45] Ha Kyung Kong, John Lee, and Karrie Karahalios. 2017. A comparative study of visualizations with different granularities of behavior for communicating about autism. *Proceedings of the ACM on Human-Computer Interaction 1, CSCW* (2017), 1–16. <https://doi.org/10.1145/3134694>
- [46] Luc Lecavalier, S. Leone, and J. Wiltz. 2006. The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research* 50, 3 (2006), 172–183. <https://doi.org/10.1111/j.1365-2788.2005.00732.x>
- [47] Charlotte P. Lee. 2007. Boundary negotiating artifacts: Unbinding the routine of boundary objects and embracing chaos in collaborative work. *Computer Supported Cooperative Work* 16, 3 (2007), 307–339. <https://doi.org/10.1007/s10606-007-9044-5>
- [48] John Lee, Ha Kyung Kong, Sanny Lin, and Karrie Karahalios. 2016. Plexlines: Tracking Socio-communicative Behaviors Using Timeline Visualizations. *AMIA ... Annual Symposium proceedings. AMIA Symposium 2016* (2016), 1890–1899.
- [49] Kwangyoung Lee and Hwajung Hong. 2018. MindNavigator : Exploring the Stress and Self-Interventions for Mental Wellness. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18* (2018), 1–14. <https://doi.org/10.1145/3173574.3174146>
- [50] Ian Li, Anind Dey, and Jodi Forlizzi. 2010. A stage-based model of personal informatics systems. *Proceedings of the 28th international conference on Human factors in computing systems CHI 10* (2010), 557. <https://doi.org/10.1145/1753326.1753409>
- [51] Ian Li, Anind K Dey, and Jodi Forlizzi. 2011. Understanding my data, myself. *Proceedings of the 13th international conference on Ubiquitous computing - UbiComp '11* (2011), 405. <https://doi.org/10.1145/2030112.2030166>
- [52] Gabriela Marcu, Hayden Demerson, and Chanamon Ratanalert. 2013. The Lilypad System: Designing for Collaborative Reflection. *WISH* (2013).
- [53] Gabriela Marcu, Anind K. Dey, and Sara Kiesler. 2012. Parent-driven use of wearable cameras for autism support. *Proceedings of the 2012 ACM Conference on Ubiquitous Computing - UbiComp '12* (2012), 401. <https://doi.org/10.1145/2370216.2370277>
- [54] Gabriela Marcu, Anind K. Dey, and Sara Kiesler. 2014. Designing for collaborative reflection. *Proceedings - PERVASIVEHEALTH 2014: 8th International Conference on Pervasive Computing Technologies for Healthcare* (2014), 9–16. <https://doi.org/10.4108/icst.pervasivehealth.2014.254987>
- [55] Gabriela Marcu, Allison Spiller, Jonathan Arevalo Garay, James E. Connell, and Laura R. Pina. 2019. Breakdowns in home-school collaboration for behavioral intervention. *Conference on Human Factors in Computing Systems - Proceedings* (2019), 1–12. <https://doi.org/10.1145/3290605.3300891>
- [56] Gabriela Marcu and Allison N Spiller. 2020. Collaborative Aspects of Collecting and Reflecting on Behavioral Data. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (2020), 1–13. <https://doi.org/10.1145/3313831.3376623>
- [57] Gabriela Marcu, Kevin Tassini, Quintin Carlson, Jillian Goodwyn, Gabrielle Rivkin, Kevin J. Schaefer, Anind K. Dey, and Sara Kiesler. 2013. Why do they still use paper? *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13* (2013), 3177. <https://doi.org/10.1145/2470654.2466436>
- [58] V Mark Durand and Daniel B Crimmins. 1988. Identifying the variables maintaining self-injurious behavior. *Journal of autism and developmental disorders* 18, 1 (1988), 99–117.
- [59] J.L. Matson. 2009. *Applied Behavior Analysis for Children with Autism Spectrum Disorders*. 1–270 pages. <https://doi.org/10.1007/978-1-4419-0088-3>
- [60] Johnny L. Matson. 2008. *Clinical assessment and intervention for autism spectrum disorders*. Academic Press.
- [61] Johnny L. Matson and Kimberly R.m. Smith. 2008. Current status of intensive behavioral interventions for young children with autism and PDD-NOS. *Research in Autism Spectrum Disorders* 2, 1 (2008), 60–74. <https://doi.org/10.1016/j.rasd.2007.03.003>

- [62] Mark Matthews, Elizabeth Murnane, and Jaime Snyder. 2017. Quantifying the Changeable Self: The role of self-tracking in coming to terms with and managing bipolar disorder. *Human-Computer Interaction* 32, 5-6 (2017), 413–446.
- [63] Micah O. Mazurek, Stephen M. Kanne, and Ericka L. Wodka. 2013. Physical aggression in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders* 7, 3 (2013), 455–465. <https://doi.org/10.1016/j.rasd.2012.11.004>
- [64] Helen Mcconachie and Tim Diggle. 2007. Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of Evaluation in Clinical Practice* 13, 1 (2007), 120–129. <https://doi.org/10.1111/j.1365-2753.2006.00674.x>
- [65] Andrea S McDougal, James; Hiralall. 1998. Bridging Research into Practice . to Intervene with Young Aggressive Students in the Public School Setting : Andrea S . Hiralall , Children ' s Seashore House Introduction .: (1998).
- [66] Elizabeth L. Murnane, Tara G. Walker, Beck Tench, Stephen Volda, and Jaime Snyder. 2018. Personal informatics in interpersonal contexts: Towards the design of technology that supports the social ecologies of long-term mental health management. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (2018). <https://doi.org/10.1145/3274396>
- [67] Nazneen, Fatima A. Boujarwah, Shone Sadler, Amha Mogus, Gregory D. Abowd, and Rosa I. Arriaga. 2010. Understanding the challenges and opportunities for richer descriptions of stereotypical behaviors of children with ASD: A concept exploration and validation. *ASSETS'10 - Proceedings of the 12th International ACM SIGACCESS Conference on Computers and Accessibility* (2010), 67–74. <https://doi.org/10.1145/1878803.1878817>
- [68] Nazneen Nazneen, Fatima Boujarwah, Agata Rozga, Ron Oberleitner, Suhas Pharkute, Gregory Abowd, and Rosa Arriaga. 2012. Towards in-home Collection of Behavior Specimens: Within the Cultural Context of autism in Pakistan. *Proceedings of the 6th International Conference on Pervasive Computing Technologies for Healthcare* February (2012), 9–16. <https://doi.org/10.4108/icst.pervasivehealth.2012.248701>
- [69] N. Nazneen, Agata Rozga, Mario Romero, Addie J. Findley, Nathan A. Call, Gregory D. Abowd, and Rosa I. Arriaga. 2012. Supporting parents for in-home capture of problem behaviors of children with developmental disabilities. *Personal and Ubiquitous Computing* 16, 2 (2012), 193–207. <https://doi.org/10.1007/s00779-011-0385-1>
- [70] Lisa A. Osborne, Louise Mchugh, Jo Saunders, and Phil Reed. 2008. The effect of parenting behaviors on subsequent child behavior problems in Autistic Spectrum Conditions. *Research in Autism Spectrum Disorders* 2, 2 (2008), 249–263. <https://doi.org/10.1016/j.rasd.2007.06.004>
- [71] Mark Palmieri. 2013. *Functional Analysis*. Springer New York, New York, NY, 1345–1351. [https://doi.org/10.1007/978-1-4419-1698-3\\_1034](https://doi.org/10.1007/978-1-4419-1698-3_1034)
- [72] Adrienne Pichon, Kayla Schiffer, Emma Horan, Bria Massey, Suzanne Bakken, Lena Mamykina, and Noemie Elhadad. 2021. Divided We Stand: The Collaborative Work of Patients and Providers in an Enigmatic Chronic Disease. *Proc. ACM Hum.-Comput. Interact.* 4, CSCW3 (2021). <https://doi.org/10.1145/3434170>
- [73] Laura Pina, Kael Rowan, Asta Roseway, Paul Johns, Gillian R Hayes, and Mary Czerwinski. 2014. In situ cues for ADHD parenting strategies using mobile technology. *Proceedings - PERVASIVEHEALTH 2014: 8th International Conference on Pervasive Computing Technologies for Healthcare* (2014), 17–24. <https://doi.org/10.4108/icst.pervasivehealth.2014.254958>
- [74] Laura Pina, Sang Wha Sien, Clarissa Song, Teresa M. Ward, James Fogarty, Sean A. Munson, and Julie A. Kientz. 2020. DreamCatcher: Exploring How Parents and School-Age Children can Track and Review Sleep Information Together. *Proceedings of the ACM on Human-Computer Interaction* 4, CSCW1 (2020), 1–25. <https://doi.org/10.1145/3392882>
- [75] Laura Pina, Sang-Wha Sien, Teresa Ward, Jason Yip, Sean Munson, James Fogarty, and Julie Kientz. 2017. From Personal Informatics to Family Informatics: Understanding Family Practices around Health Monitoring. In *Proceedings of the 2017 ACM Conference on computer supported cooperative work and social computing (CSCW '17)*. ACM, 2300–2315.
- [76] Thomas Plötz, Nils Y. Hammerla, Agata Rozga, Andrea Reavis, Nathan Call, and Gregory D. Abowd. 2012. Automatic assessment of problem behavior in individuals with developmental disabilities. *UbiComp'12 - Proceedings of the 2012 ACM Conference on Ubiquitous Computing* (2012), 391–400. <https://doi.org/10.1145/2370216.2370276>
- [77] Olivia K. Richards, Adrian Choi, and Gabriela Marcu. 2021. Shared Understanding in Care Coordination for Children's Behavioral Health. *Proceedings of the ACM on Human-Computer Interaction* 5, CSCW1 (2021). <https://doi.org/10.1145/3449095>
- [78] John Rooksby, Mattias Rost, Alistair Morrison, and Matthew Chalmers Chalmers. 2014. Personal tracking as lived informatics. *Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14* (2014), 1163–1172. <https://doi.org/10.1145/2556288.2557039>
- [79] Michael Rutter, Eric A. Taylor, and L. A. Hersov. 1994. *Child and adolescent psychiatry: modern approaches*. Blackwell Science.
- [80] Jessica Schroeder, Jane Hoffswell, Chia Fang Chung, James Fogarty, Sean Munson, and Jasmine Zia. 2017. Supporting patient-provider collaboration to identify individual triggers using food and symptom journals. *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW* (2017), 1726–1739. <https://doi.org/10.1145/2998181.2998276>
- [81] Donghoon Shin, Jaeyoon Song, Seokwoo Song, Jisoo Park, Joohnwan Lee, and Soojin Jun. 2020. TalkingBoogie : Collaborative Mobile AAC System for Non-verbal Children with Developmental Disabilities and Their Caregivers.

- Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (2020), 1–13.
- [82] Will Simm, Maria Angela Ferrario, Adrian Gradinar, and Jon Whittle. 2014. Prototyping 'clasp'. *Proceedings of the 2014 conference on Designing interactive systems - DIS '14* (2014), 345–354. <https://doi.org/10.1145/2598510.2600880>
  - [83] Seokwoo Song, Juho Kim, Bumsoo Kang, Wonjeong Park, and John Kim. 2018. BebeCODE: Collaborative Child Development Tracking System. In *Proceedings of the 2018 CHI Conference on human factors in computing systems (CHI '18, Vol. 2018-)*. ACM, 1–12.
  - [84] Seokwoo Song, Naomi Yamashita, and John Kim. 2020. Bodeum: Encouraging working parents to provide emotional support for stay-at-home parents in Korea. *ACM International Conference Proceeding Series* (2020), 38–49. <https://doi.org/10.1145/3421937.3421973>
  - [85] Janne Van Kollenburg, Sander Bogers, Heleen Rutjes, Eva Deckers, Joep Frens, and Caroline Hummels. 2018. Exploring the value of parent-tracked baby data in interactions with healthcare professionals: A data-enabled design exploration. *Conference on Human Factors in Computing Systems - Proceedings 2018-April* (2018), 1–12. <https://doi.org/10.1145/3173574.3173871>
  - [86] Peter West, Max Van Kleek, Richard Giordano, Mark J. Weal, and Nigel Shadbolt. 2018. Common barriers to the use of patient-generated data across clinical settings. *Conference on Human Factors in Computing Systems - Proceedings 2018-April* (2018), 1–13. <https://doi.org/10.1145/3173574.3174058>
  - [87] Tracy L Westeyn, Gregory D Abowd, Thad E Starner, Jeremy M Johnson, Peter W Presti, and Kimberly A Weaver. 2012. Monitoring children's developmental progress using augmented toys and activity recognition. *Personal and Ubiquitous Computing* 16, 2 (2012), 169–191. <https://doi.org/10.1007/s00779-011-0386-0>
  - [88] Naomi Yamashita, Hideaki Kuzuoka, Keiji Hirata, Takashi Kudo, Eiji Aramaki, and Kazuki Hattori. 2017. Changing moods: How manual tracking by family caregivers improves caring and family communication. *Conference on Human Factors in Computing Systems - Proceedings 2017-May* (2017), 158–169. <https://doi.org/10.1145/3025453.3025843>
  - [89] Haining Zhu, Joanna Colgan, Madhu Reddy, and Eun Kyoung Choe. 2016. Sharing Patient-Generated Data in Clinical Practices: An Interview Study. *AMIA ... Annual Symposium proceedings. AMIA Symposium 2016* (2016), 1303–1312.

Received January 2021; revised July 2021; accepted November 2021