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*Published in:*  
CHI EA '23

*DOI:*  
[10.1145/3544549.3585660](https://doi.org/10.1145/3544549.3585660)

*Publication date:*  
2023

*Document Version*  
Peer reviewed version

[Link to publication in Discovery Research Portal](#)

### *Citation for published version (APA):*

Scougal, E., Waller, A., Melinger, A., & Crabb, M. (2023). Perceived communication experiences of children and young people with Down syndrome: The impact of people, places, and AAC methods. In A. Schmidt, & K. Väänänen (Eds.), *CHI EA '23: Extended Abstracts of the 2023 CHI Conference on Human Factors in Computing Systems* (pp. 1-7). [226] Association for Computing Machinery. <https://doi.org/10.1145/3544549.3585660>

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# Perceived Communication Experiences of Children and Young People with Down Syndrome: The Impact of People, Places, and AAC Methods

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## ABSTRACT

People with Down syndrome can experience communication challenges, impacting daily interactions. Augmentative and Alternative Communication (AAC) can be beneficial, including signing and electronic communication aids. Research mostly focuses on intervention studies, limiting insight into real-world AAC experiences. An online survey was developed to investigate perceived challenges and opportunities related to AAC experienced by children and young people with Down syndrome and their families, completed by 264 caregivers. We report on AAC currently used, support received, and contextual influences. The results highlight that despite signing being the most used form of AAC for the group, its use presents barriers in wider social contexts due to required communication partner skill. Electronic AAC, however, appears under-used, and challenges related to support and the physical properties of communication aids are reported. Further research should extend understanding related to AAC use across social contexts and device onboarding to enhance societal participation and independence.

## CCS CONCEPTS

• **Human-centered computing** → **Accessibility technologies**.

## KEYWORDS

Down syndrome, Communication, Augmentative and Alternative Communication, AAC

## ACM Reference Format:

Elaine Scougal, Annalu Waller, Alissa Melinger, and Michael Crabb. 2023. Perceived Communication Experiences of Children and Young People with Down Syndrome: The Impact of People, Places, and AAC Methods. In *Extended Abstracts of the 2023 CHI Conference on Human Factors in Computing Systems (CHI EA '23)*, April 23–28, 2023, Hamburg, Germany. ACM, New York, NY, USA, 7 pages. <https://doi.org/10.1145/3544549.3585660>

*CHI EA '23, April 23–28, 2023, Hamburg, Germany*

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## 1 INTRODUCTION

Communication is a fundamental human right, recognised from childhood by the United Nations Convention on the Rights of the Child (UNCRC) [31]. People with Down syndrome have a high likelihood of verbal communication challenges across the life span, with over 95% of those with the condition perceived to encounter difficulty being understood [14]. This can create barriers to independence and social participation [5, 16]. Augmentative and Alternative Communication (AAC) methods such as manual signing or use of voice output communication aids (VOCAs) can facilitate and support communication where speech is absent, developing, or unclear [32]. Despite the widely reported communication challenges within this group, little work has explored the real-world impact of communication impairment and methods to support this. In the present study, we gain insight from caregivers of children and young people with Down syndrome relating to real-world use of AAC methods. In doing so, we aim to identify challenges and opportunities related to communication and AAC for children and young people with Down syndrome.

In this paper, we report on an online survey conducted with 264 caregivers of children and young people with Down syndrome. The questions reported within this paper form part of a larger survey (See Supplementary Materials). While signing was identified as the most commonly used form of AAC, challenges were identified relating to context and communication partner skill. Limited use of electronic AAC was also reported in addition to a reduction in satisfaction of support for children and young people using this approach. Participants also reported a belief that their child's current communication was limiting their ability to learn and interact with peers. The results suggest that there are opportunities to improve communication for children and young people with Down syndrome, increasing their potential and participation in society.

**Paper contributions:** This paper provides compelling support for multi-modal, as opposed to single-strategy, AAC use for children and young people with Down syndrome due to social and contextual limitations, particularly involving manual signing. If accessed and adequately supported, technology has the potential to play a leading role in enhancing the daily communication experiences and independence of those with Down syndrome. This paper has three contributions: Firstly, this paper presents insights

into the present use of AAC by children and young people with Down syndrome in the UK, highlighting widespread use of manual signing and infrequent use of VOCAs. Secondly, we highlight a perceived lack of support received by children and young people using VOCAs. Thirdly, we discuss the impact of people and place on the use of AAC strategies.

## 2 RELATED WORK

Down syndrome is a genetic condition, occurring in around 1 in every 800 live births [9]. There are three reported genetic origins, all involving an additional (or partial) copy of chromosome 21 in the cells of the body: Trisomy 21, Mosaicism, and Translocation [8]. While there are common traits and developmental patterns, the condition is heterogeneous and affects each person differently [1]. This includes characteristic craniofacial features, motor impairments, and intellectual disability [28]. Due to this, challenges related to communication are common from early years to adulthood, particularly in relation to verbal intelligibility [15].

### 2.1 Down syndrome and verbal communication

For children with Down syndrome, speech can be slow to emerge relative to typically developing (TD) peers [30]. The combination of words has also been described to occur at a slower rate, with reports of this skill developing between 3.5 to five years of age relative to approximately 18 months (TD) [23]. By this age, a child's social world has typically expanded from caregivers to include staff and peers at preschool, presenting a barrier to relationships and inclusion [24]. Beyond the formation and combination of words, factors including dysfluency, intonation, and articulation can present additional challenge [13].

Challenges related to the above can impact upon intelligibility across the lifespan, with over 95% of caregivers of children with Down syndrome perceiving their child to encounter difficulty being understood by others, particularly new communication partners or unfamiliar listeners [14]. It is, therefore, important to consider how communication beyond simple needs and wants can be enabled from early years and beyond within a range of communicative contexts and environments.

Speech and language therapy (SLT) is argued to be the most important intervention for people with Down syndrome from early years, facilitating the development of social and cognitive skills [7]. The nature of this intervention should be designed and conducted in partnership with familiar communicative stakeholders, including parents and teachers, in order to encourage and enable functional communication and interactions in daily life, including the classroom, community, and home environments [25, 26]. In the absence of speech, or when it is unclear, it is important to facilitate communication via augmentative or alternative methods, such as key word signing and the use of electronic communication aids. [32].

### 2.2 Unaided and aided Augmentative and Alternative Communication (AAC)

Unaided AAC refers to ways of supporting communication using the body, alongside speech where applicable. This includes body

language and gesture, in addition to signing systems such as Makaton (TM) which operate at a key word level [19]. Signing is reported to be the most commonly used form of AAC for individuals with intellectual disabilities [12] and can enhance the communication and cognitive skills of children with Down syndrome from early years, including vocabulary size [18]. Signing does, however, require fine motor dexterity, often a challenge for people with Down syndrome, and is dependent upon a shared communication partner skill set, potentially limiting the accuracy and scope of use [17, 21].

Aided AAC refers to strategies that enable or augment communication by offering representations of language components and concepts using pictures, symbols, words, or letters [4]. Such visual strategies complement visuospatial processing strengths reported in people with Down syndrome [20]. Implementation of these strategies can be 'low-tech', or paper-based, including the use of communication boards, symbols, or books. Alternatively, they can be delivered using 'high-tech', or electronic, methods, enabling digital voice output. The use of aided AAC has been reported to benefit object naming for children with Down syndrome in addition to supporting learning and narrative [10, 11]. Increased engagement within employment and volunteering contexts has also been reported for adults with Down syndrome when using aided AAC to reinforce training and support interactions [2]. Despite such reported benefits, it is felt that VOCAs may be under-used by this group relative to those with communication needs of another origin such as autism [3].

### 2.3 Real-world implications for communication

While the verbal challenges experienced by people with Down syndrome are widely reported, insights into real-world AAC use by this group are sparse. It is essential that we understand how people with Down syndrome are being enabled from childhood to be independent communicators using AAC where required. Given the reported differences in ease of being understood by familiar versus unfamiliar communication partners when using speech, it is also important to explore how effectively AAC can support communication within different social settings.

Based on the above, we ask **RQ: What are the challenges and opportunities associated with the types of communication used by children and young people with Down syndrome to communicate at home, school, and in the wider community?**

## 3 A SURVEY TO UNDERSTAND THE IMPACT OF CONTEXT AND AAC

A survey was conducted with caregivers to investigate the challenges and opportunities associated with the types of communication used by children and young people with Down syndrome at home, school, and in the wider community.

### 3.1 Materials & apparatus

An online survey was created and shared using JISC Online Survey software (<https://www.onlinesurveys.ac.uk>) following approval from the Research Ethics Committee. Automated branching was used within the survey, allowing response-specific navigation and question presentation throughout. Questions relating to AAC were presented to each participant three times to reflect different AAC

categories (signing, paper-based symbols or photographs, and voice output devices/apps), represented as '[AAC CATEGORY]'. Similarly, questions relating to context received triplicate presentation to explore AAC use in the home, at school, and in the wider community such as shops and restaurants, represented as '[SOCIAL CONTEXTS]'. The 45 questions presented within this paper span four sections and form part of a larger survey (See Supplementary Materials).

Section 1 explored demographic information across nine questions: Participant age and gender, child age and gender, UK home nation, participant education, and child education setting. Type of Down syndrome was also reported in addition to any additional diagnoses impacting communication.

Section 2 contained nine questions or statements relating to verbal communication abilities and the use of AAC: "Which best describes your child's typical use of spoken language?", "My child can understand more than they can express verbally", "Does your child currently use [AAC CATEGORY] to communicate with others?" and, if prior but not current AAC use indicated, "Please explain why your child no longer uses [AAC CATEGORY] to support communication". Optional open comments about communication and AAC were requested at the close of the survey.

Section 3 explored support related to communication and AAC, comprising seven questions or statements: "Does your child currently have a speech and language therapist?", "I am satisfied with the support my child is currently receiving/has received related to his/her use of [AAC CATEGORY]". "I am satisfied with the support I am currently receiving/has received related to my child's use of [AAC CATEGORY]".

Section 4 examined the impact of context on communication and AAC use. This comprised twenty questions or statements: "How often does your child use [AAC CATEGORY] when he/she communicates in [SOCIAL CONTEXTS]?", "People who know my child well have difficulty understanding his/her communication when he/she uses [AAC CATEGORY/ speech]", "People who first meet my child have difficulty understanding his/her communication when he/she uses [AAC CATEGORY/ speech]", "I feel my child's communication limits his/her ability to learn", "I feel my child's communication limits his/her ability to engage in social activities" and "I feel my child's communication limits his/her ability to form friendships with peers".

### 3.2 Participants

Participants were required to be a primary caregiver of a child with Down syndrome (aged 3 to 18 years). 264 caregivers completed the survey (female = 93.6%, male = 6.4%), ranging from 25 to over 65 years of age (18-24 years = 0%, 25-34 years = 5.3%, 35-44 = 36.0%, 45-54 = 50.0%, 55-64 = 8.3%, 65 and over = 0.4%). Participants' highest level of education achieved was reported: Doctoral = 3.4%, Postgraduate = 32.6%, Undergraduate = 28.4%, A level or equivalent = 18.2%, GCSE or equivalent = 9.1%, NVQ or equivalent = 6.4%, Other = 1.9%<sup>1</sup>. Participants lived across the UK (England = 62.1%,

Scotland = 29.9%, Northern Ireland = 5.3%, Wales = 2.7%), recruited via social media and Down syndrome organisations.

Participants reported on the gender of their child with Down syndrome (Male = 61%, Female = 39%), with ages ranging between 3 and 18 years of age (M = 9.94 years; SD = 4.31 years). Education setting was also indicated: Mainstream Primary or secondary = 57.2%, Specialist primary or secondary = 37.9%, Dual placement = 2.7%, Other = 2.3%, as was type of Down syndrome: Trisomy 21 = 95.8%, Mosaic = 1.9%, Translocation = 1.1% (unsure = 1.1%). Participants noted whether their child had an additional diagnosis that impacted upon their communication: Autism = 10.2%, Hearing loss = 25%, Dyspraxia / apraxia = 3.4%, Other = 12.5%.

## 4 RESULTS

Closed-questions were analysed in terms of frequency and proportion of responses. Seven-point Likert scale data were collapsed into disagree (comprising strongly, moderately and slightly disagree responses), neutral, and agree (comprising strongly, moderately and slightly agree) categories. Open, qualitative, data relating to AAC abandonment and additional comments were not formally analysed but used to add context to the quantitative data.

### 4.1 Communication methods past and present

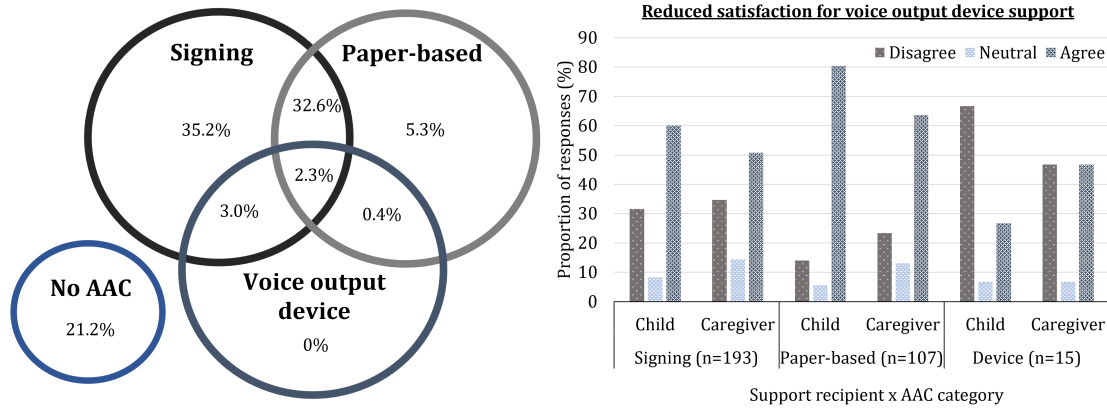
First, participants described their child's typical use of spoken language: No vocalisation = 4.5%, Pre-talking = 11.4%, Single words = 9.8%, 2-3 word phrases = 22.7%, Short sentences = 27.7% and Longer sentences = 23.9%. 82.2% agreed their child could understand more than they could express verbally (neutral = 2.7%, disagree = 15.2%).

Participants reported their child's current use of AAC to support communication: Signing = used by 73.1%, paper-based symbols or photographs = 40.6%, and communication devices = 5.7%. See Figure 1a for a breakdown of reported multi-modal uses of AAC, highlighting signing as being the most common approach, followed by use of both signing and paper-based methods. Open responses from those whose children no longer use particular AAC methods provided insight into factors contributing to abandonment of these methods. Reasons included the development of sufficient verbal communication skills, and limitations relating to AAC methods, including the physical properties of devices and paper-based resources. Participants described that it was *"too difficult to have [the device] charged, open and to hand. It is never in the right room. Signing is much easier"* [P25]. Training and communication partner skill was also highlighted as a reason for abandonment of signing, with P234 sharing, *"when he started school, no one understood his signs and the school didn't take steps to train staff"*.

### 4.2 AAC support

61% of participants reported their child to currently have a speech and language therapist (SLT). Participants also reported their satisfaction relating to the support they and their child have received relating to any currently used AAC methods (See Figure 1b). This highlighted discrepancies in the support received for paper-based methods between children and caregivers, and increased levels of dissatisfaction related to device support for children. P207 provided some context for this, stating, *"We were given a device during the COVID-19 period... but that was taken away after a few months as*

<sup>1</sup>UK educational qualifications. GCSE (General Certificate of Secondary Education) qualifications are gained between 15 - 16 years (approx). A Levels are typically gained between 16 to 18 years (approx). NVQs are National Vocational Qualifications.



**Figure 1: a. (left): Reported multi-modal uses of AAC (% (n=264)); Fig. 1b. (right): Proportion of Likert responses relating to the statements, "I am satisfied with the support my child/ I am currently receiving or have received relating to his/her use of [AAC CATEGORY]"**

*SLT felt he wasn't using it effectively and that the way forward was Makaton and Visuals".*

### 4.3 The impact of people and places

Participants reported variances in how frequently their child's current AAC methods were used when communicating in different social contexts (See Figure 2a). Notably, there was a reduction in the use of all three AAC categories within community settings relative to home and school, particularly for those using devices and paper-based methods. Open responses gave insight into the physical barriers potentially contributing to this, including P204 who shared, "We only have AAC on a laptop. If it was on say a phone he maybe more likely to use it in social situations". Participants also reported how frequently they perceived their children to encounter difficulty being understood by familiar and unfamiliar others when using AAC or speech (See Figure 2b). These results showed increased difficulty being understood by unfamiliar partners across all communication categories, but most notably within those using signing to communicate. This was frequently attributed to required communication partner skill, such as P235 who reported, "If people meet my child for the first time and know Makaton, they communicate well together, if they do not and rely on his speech alone they usually struggle to understand and rely on me interpreting".

Participant perceptions relating to the impact of their child's communication on aspects of their educational and social participation were also reported (n=256). 72.7% agreed that their child's current ways of communicating limited ability to learn (disagree = 20.7%, neutral = 6.6%) and 78.5% agreed that communication limited their child's ability to engage in social activities (disagree = 16.8%, neutral = 4.7%). 75.8% also agreed that their child's communication limited ability to form friendships with peers (disagree = 21.1%, neutral = 3.1%), such as P133 who described, "Children at nursery know him well and he does well socially but they do not know all of his signs. Family try with the signs but they do not know enough signs to fully understand him.". Similarly, P200 stated, "When my child has tuned in communicators supporting him, who sign and use pictures effectively with him, his development (in all ways) improves".

### 4.4 Summary of survey findings

While AAC is being used by the majority of children within the sample to support communication, barriers related to support and context were evident. This included dissatisfaction about the support given to children related to communication device use, and indications of restricted use within the community. Open responses highlighted the physical properties of aided AAC as contributing to this. The data also indicated increased difficulty communicating with unfamiliar communication partners when using signing, the most frequently used method of AAC. Coupled, the decreased use of AAC in the community, despite an increase in difficulty being understood by unfamiliar communication partners, raises a concern relating to the social participation of children and young people with Down syndrome.

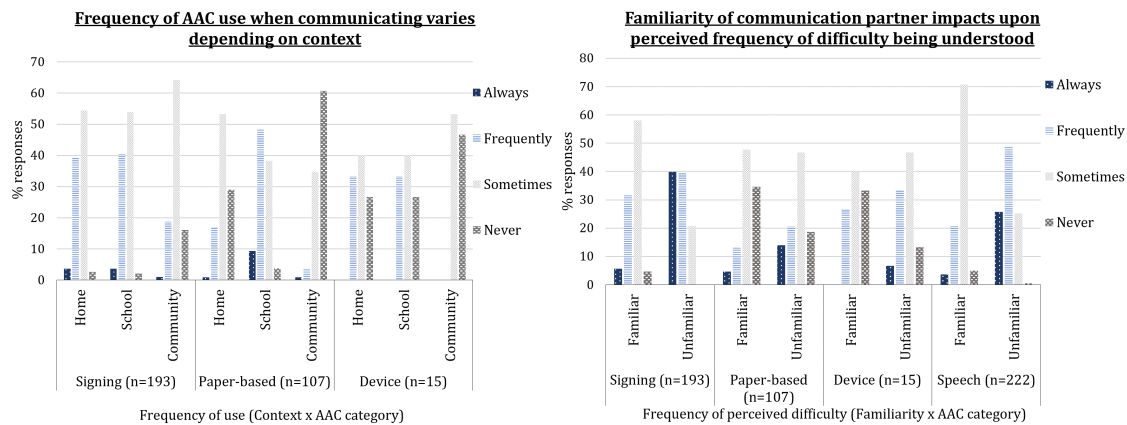
## 5 DISCUSSION

AAC methods can benefit those with communication needs. In this study, a survey was used to gain insight from 264 caregivers into the experiences of children and young people with Down syndrome regarding communication and the impact of context. While AAC methods are being used by the majority of this group, challenges were reported related to the effectiveness and practicality of such methods when communicating in different environments and with different people. In order to enable more effective communication experiences and support for this group, opportunities for practice will be proposed in addition to considerations for future research.

*RQ: What are the challenges and opportunities associated with the types of communication used by children and young people with Down syndrome to communicate at home, school, and in the wider community?*

#### **Challenge 1: The use of signing limits social interactions in wider contexts.**

Signing was reported as the most commonly used AAC method by this group, despite clear barriers to being effectively understood when communicating with familiar and unfamiliar communication



**Figure 2: a (left): Reported frequency of child’s use of signing, paper-based aids, and voice output devices when communicating at home, school, and in the community; Fig.2b (right): Perceived frequency of child’s difficulty being understood when communicating with familiar and unfamiliar others. Experiences of those using speech (single words or more) have also been included for analysis.**

partners. Although signing can be an invaluable communication method around trained partners, barriers related to factors such as skill and fine motor dexterity have been stated by researchers to potentially outweigh the benefits for people with Down syndrome given that alternative methods are now available in the form of aided AAC [27]. Aided AAC, particularly electronic, was used much less frequently, despite less perceived difficulty being understood by others relative to the use of signing. This is consistent with suggestions of an under-use of electronic AAC for this group within the literature [3]. **Researchers and SLTs must investigate the decision-making process currently resulting in the widespread adoption of unaided AAC over paper-based and electronic methods within this group.**

### **Challenge 2: Communication aid practicality and availability result in abandonment.**

Comments within the qualitative data suggested that practicalities related to the physical properties of aided AAC may be contributing to abandonment or reduced use of these methods, such as a device having to be moved between locations and charged. Paper-based books and cards also carry a physical burden [6]. This stands in contrast to signing which is, by nature, fully portable. Given the barrier to communication often encountered when using unaided AAC, those using signing must also have access to aided AAC methods to communicate with familiar or unfamiliar communication partners as and when required. **Consideration of the size and portability of devices and communication aids is therefore necessary when making decisions about AAC suitability to encourage use across contexts.**

A clear shift in the use of paper-based AAC across different contexts was observed, with greater frequency of use in school. While the reduction in community use may be attributed to the challenge outlined above, the discrepancy between home and school suggests that the resources may not be available, or deemed unnecessary, within the home context. It needs to be clarified, however, how

and how effectively, these children are communicating with others when not using this method. **Further research is required to understand the home/school discrepancy in paper-based AAC use to identify areas of need regarding AAC availability, cross-context practicality, and training.**

The identification of challenges gives rise to a number of opportunities to improve the communication experiences of children and young people with Down syndrome:

**Opportunity 1: Further work is required to understand the relationship between people, places, and techniques to facilitate communication by children and young people with Down syndrome.**

It is clear from the data that the frequency of use of AAC methods when communicating alters depending on the situational context, be it in the home, at school, or in the community. Further, the frequency of difficulty being understood by others when using methods of communication is also impacted by context with regard to whether a familiar or new communication partner is involved in an exchange. It is also clear that each AAC method has both strengths and limitations across contexts. However, approximately 40% of participants reported their child to be using only one AAC strategy to support communication. The efficacy of a sole AAC approach should, therefore, be called into question in favour of a multi-modal AAC approach to facilitate a means of communication irrespective of context [29]. We recommend that **SLTs should support people with Down syndrome, caregivers, and peers to use a range of AAC methods where required to facilitate communication, enabling more effective learning and social participation.**

**Opportunity 2: User and stakeholder involvement in onboarding increases the potential for AAC success**

The survey revealed instances of failings in support related to AAC. Caregivers of those using a device indicated reduced satisfaction with the support their child received. Open responses also

highlighted an instance where SLT removed a device as opposed to exploring and implementing relevant support strategies and techniques to enable use. Similarly, our participants described a need for more communication partner training related to unaided AAC for school staff, peers, and family members. To onboard and communicate effectively with AAC, stakeholders surrounding the communicator must be effectively trained to model, support, and promote the use of AAC across contexts [22]. **Further work is required to understand how children and young people with Down syndrome are being supported to onboard with AAC, identifying best practice.**

## 5.1 Limitations

While the online survey allowed for efficient distribution and enabled branching question presentations, the format may have limited the reach of the survey to those with digital literacy skills and access devices. Further, over 60% of participants were educated to degree level or above. It is possible that socioeconomic status and digital competency may have a positive impact on access to communication support and AAC technology, masking wider societal challenge. The perspectives gathered within the survey were also limited to that of the caregivers and not of individuals with Down syndrome directly. Due to this, follow-up face-to-face studies will be conducted with families and children and young people with Down syndrome to explore their personal experiences and insights related to communication. This will also allow the exploration of technical challenges and opportunities related to user interaction involving aided AAC.

## 6 CONCLUSION

While research has found AAC to be beneficial in supporting the communication experiences of children and young people with Down syndrome, research has focused on exploring and measuring the effects of AAC following intervention, overlooking lived experiences. A survey was conducted to gain insights from caregivers of this group into the AAC strategies being used within home, school, and community contexts. The results illustrated that challenges were being encountered related to context, AAC practicalities, and communication partner skill, limiting the scope and effectiveness of social interactions. Considerations were suggested relating to directions for future research regarding the AAC decision-making process, particularly involving exploration of the sparse use of devices, to identify best practice and barriers to supporting the social participation of children and young people with Down syndrome.

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