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Engaging children with developmental disabilities in online data collection procedures: Reflections and implications for future research

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Abstract

Purpose: This paper outlines reflections and recommendations about the processes involved in effectively engaging children with developmental disabilities in online data collection in special schools in England.

Design/Methodology/Approach: Data collection procedures were adapted and piloted for online delivery with children with developmental disabilities before data were collected online from 382 young children (aged 5-11 years) in 55 special schools in England as part of a randomised controlled trial (RCT) examining the efficacy of Headsprout Early Reading® on reading fluency.

Findings: The research team engaged with creative and adaptive methods throughout the process, from initial planning to delivery, to ensure successful and systematic data collection with children with developmental disabilities. It is possible to effectively engage children with developmental disabilities in online data collection procedures, and with appropriate planning and procedural considerations, this can be an enjoyable experience for children.

Research limitations/implications: Whilst there are geographical and logistical advantages to online data collection methods, there is also the potential for an increased administrative burden that should be appropriately planned and costed.

Practical implications: Purposely engaging online data collection methods can enable researchers to involve a greater number of children with developmental disabilities in research.

Originality: To the best of the authors' knowledge, this is the largest study using purposefully engaging online data collection methods with children with developmental disabilities in special schools. Furthermore, we provide detailed reflections and recommendations to support similar processes for future research.

Keywords: *developmental disabilities, special schools, data collection, online, reading interventions, reading skills*

Article classification: Research paper

Background

Over 1.6 million schoolchildren in England have special educational needs and/or disabilities (Department for Education [DfE], 2024), accounting for 18.6% of all English schoolchildren. Most schoolchildren with developmental disabilities attend mainstream schools with varying degrees of support, and over 160,000 children in England attend special schools (DfE, 2024).

Large-scale randomised controlled trials (RCTs) contribute to our understanding of educational intervention efficacy, supporting implementation of evidence-based practice for children, including children with developmental disabilities. Logistical challenges exist when collecting data from children with developmental disabilities, including relatively high incidences of pupil absences, staff absence and shortages, and events impacting pupil willingness or ability to engage. Further, some children with developmental disabilities, namely those who are autistic, may have co-occurring social anxiety (Spain et al., 2018), and could find face-to-face data collection methods aversive, opting out for this reason. These potential challenges, as well as the potential to include more children who are geographically and/or logistically “harder to reach” by researchers, are reasons to explore alternative methods of data collection in large-scale trials in this population. “Harder to reach”, in this context, is being used with the understanding that the responsibility of reaching these children is that of the researchers, and not of the children.

Children may also find quantitative data collection procedures, such as standardised assessments, to be long and boring (Brewer et al., 2013). Furthermore, it may be more difficult for children to participate in remote data collection, as the researcher is not present in the room to engage with them. Incorporating ‘gamification’ of research procedures may offer an engaging and motivating solution to potentially tedious, virtual data collection procedures (Brewer et al., 2013).

Study context and aims

This paper reports and reflects on the process of adapting and undertaking alternative methods of data collection with children with developmental disabilities to potentially overcome the aforementioned challenges. Our reporting of the process and our reflections are based on the data collection methods that were undertaken within a large-scale cluster RCT aiming to evaluate the effectiveness of an online reading intervention (Headsprout Early Reading® [HER®]) on the reading ability of children (5-11 years old) with developmental disabilities (including children with intellectual disabilities and autistic children) in special schools in England (Flynn et al., *under review*).

A total of 382 children from 55 schools were randomised to either receive HER® (n=181) or education as usual (n=201). All children who were recruited to the trial were between the ages of 5 and 11, did not have a reading ability beyond the level of HER® and could sit at a computer for up to ten minutes; understand and follow one- or two-step instructions; imitate spoken sounds/words; respond to feedback (praise or correction); and use some self-initiated speech (in English) (single words to short sentences).

Originally, in-person school data collection visits by Research Assistants (RAs) were planned, however this was not possible due to continued school visitor restrictions and the risk of viral infections (namely COVID-19) spreading between RAs and children, thus a pragmatic decision to move data collection online was made.

The aims of this paper are to (1) report on the processes we undertook to adapt, pilot, and use engaging data collection methods online with children with developmental disabilities in special schools, (2) reflect on the relative strengths, challenges, and limitations of these processes, and (3) to make recommendations for researchers and practitioners to use in future research and practice when collecting data from children with developmental disabilities.

Methods

The sample description, full methods, and findings of the RCT are reported elsewhere (Denne et al., 2023; Flynn et al., *under review*). This paper will focus on reporting and reflecting on our methods of adapting, piloting, and collecting data online with children with developmental disabilities based on our collective experience in the RCT. Both quantitative and qualitative data were collected online. Parental consent was obtained for all data collection, and child assent additionally obtained before data collection started. Quantitative measures (Dynamic Indicators of Basic Early Literacy Skills®

[DIBELS®; Good, Gruba and Kaminski, 2002] and a Reading Self-Concept Scale) were collected at baseline and follow-up (approximately 12 months post-randomisation) from all children in the intervention and control groups. Following quantitative follow-up data collection, a sub-sample of children from the intervention group were interviewed about their experiences of HER® using Talking Mats.

Understanding the needs and experiences of researchers and children is essential when planning data collection activities (Johnson, Hart and Colwell, 2014). Particular attention was paid to the needs of children with developmental disabilities throughout the adaptation and piloting process, including developing purposefully engaging break-out activities to motivate and engage children with developmental disabilities, adapting and piloting online data collection procedures, and training RAs to engage with children remotely. Ethical approval was received in December 2019 from the University of Warwick Humanities and Social Sciences Research Ethics Committee (HSSREC 37/19-20).

Online data collection methods

DIBELS®. The DIBELS® comprises five one-minute sub-tests, each assessing one core component of reading fluency: Letter Naming, Phonemic Segmentation, Nonsense Word, Word Reading, and Oral Reading, enabling measurement of change of fluency over time. The DIBELS® has been used with children with developmental disabilities (Grindle et al., 2021; Tyler et al., 2015a; 2015b). Three versions (beginning, middle, end) of each sub-test enable sub-tests to be repeated or restarted should interruptions occur without risking practice effects. It is traditionally delivered in-person and, as established through communication with the developers, online versions were not available at the time, so we adapted the mode of delivery (but not the assessment itself) to enable online data collection. PowerPoint presentations replicated each of the DIBELS® materials (all three versions of all five sub-tests), maintaining the order of letters and words, and the original font was matched as closely as possible to those available on PowerPoint.

Reading Self-Concept Scale. We adapted an existing 30-item measure of reading self-concept (Reading Self-concept Scale; Chapman and Tunmer, 1995) into a six-item measure, with input from adults with intellectual disabilities and carers, for use online with children with developmental disabilities. This scale measured perceptions of self-competence, attitudes about, and perceived difficulty with reading, each measured by two questions (one reverse scored). RAs would read statements to children, who would respond with either Yes or No (verbally or non-verbally, e.g., thumbs up/down); a further adaptation from the original five-point Likert scale measure. Practice questions were included, as per the original measure.

Talking Mats interviews. Interviews with children with developmental disabilities were conducted using the, already established and tested, online version of Talking Mats. Talking Mats have been used successfully with children with a range of communication support needs, including disabled children (Bradshaw et al., 2018). We began by showing children the Headsprout topic symbol and asked an open question: “How do you feel about Headsprout?”. We used a three-point top-scale (‘Like’, ‘Not sure’, ‘Don’t like’) for children to place the option symbols (which included ‘Being on the computer’, The teacher helping me’, ‘The characters’). To enable children to share their opinions about HER®, we screen shared and gave cursor control to children for them to edit their own Talking Mat, thus giving them ownership of their responses. As is typical practice with Talking Mats, we conducted a practice mat to familiarise children with the process and allow rapport building, and to assess whether any procedural adaptations were needed (e.g., two-point top scale [‘Like’, ‘Dislike’]).

Piloting data collection methods online

Smooth delivery was essential to maintain the attention of children online, and to ensure that the scores were an accurate reflection of reading fluency. Piloting individual components and the whole data collection procedure was essential to smooth and engaging delivery. Following initial research piloting between members of the research team, we piloted the whole procedure with four children from a special school that was not involved in the trial, finding that the language used during data collection needed to be further simplified, and so this was reflected in the RA data collection protocol.

Before Talking Mats interviews were conducted with children, we piloted the process with other researchers. During this piloting process, we found that Zoom offered more control to children, over Microsoft Teams, as they could more easily move the cursor using their own mouse as the interviewer shared their screen, and so this platform was used.

By undertaking a thorough piloting procedure, we built our collective capabilities (Johnson, Hart and Colwell, 2014), and identified and rectified potential problems with data collection, developing an in-depth understanding of the procedure and a detailed data collection protocol for RAs to support effective completion of engaging data collection activities. This process was critical in our understanding of where RAs could most effectively incorporate engaging activities into the data collection procedure, and would be an important component of future research adopting engaging online data collection methods with children with developmental disabilities. A step-by-step visual representation of how we successfully integrated the engagement activities and the online data collection methods, as refined during piloting, is presented in Figure 1.

****FIGURE 1 HERE****

Training and monitoring Research Assistants

We trained a team of RAs on Microsoft Teams in data collection procedures, including methods of engaging with and motivating children with developmental disabilities (as described below), and safeguarding. RA training was heavily practice-based and designed to build competence, confidence, and fluency in data collection methods.

Competency and fluency in engaging data collection methods was assessed by reviewing videos recorded by RAs with a partner. Feedback was provided on the accuracy of data scoring, “pupil” engagement activities, and delivery. RAs could begin data collection when they had demonstrated engaging, consistent, and accurate completion of the outcome measures to two members of the research team through recorded videos. RAs were supervised in peer groups throughout data collection. We recommend that practical training and ample practice, feedback, and reflection opportunities are offered during both training and data collection. Anecdotal feedback from RAs about the training highlighted the importance of taking this practical, and reflective, approach in building their confidence prior to data collection commencing.

Developing and adapting engagement activities

We had developed face-to-face methods of engaging children with developmental disabilities to establish rapport, and motivation to participate and continue and complete assessments within our previous work. Face-to-face engagement activities included blowing bubbles, drawing together with paper and pens, using puppets, and making toys, puzzles, and games available for children to play with between assessments. When planning online data collection methods for this RCT, we carefully considered how we could adapt and incorporate our existing, tried and tested, activities with additional, digital methods. This process was initially led by the core research team, and continued collaboratively with our recruited team of RAs during training sessions and weekly group supervision, where RAs were encouraged to share their experiences and examples of good practice (e.g., activities to successfully engage children). This was a process that RAs reported as being particularly helpful in building confidence and their development throughout data collection.

Our initial methods of engaging pupils were influenced by the work of Dr Jo Van Herwegen and colleagues (e.g., Tenenbaum and Van Herwegen, 2023) to “gamify” learning in young children. With this ethos in mind, we developed six illustrated interactive “activity boards” of a picture hidden behind objects on PowerPoint to engage and motivate children between assessments. Each activity board came with a starting narrative (e.g., cleaning mud off farm animals) for RAs to use with children and build on as they saw appropriate. RAs would click the mouse to remove a piece of the activity board, revealing a hidden piece of the picture. An example of an activity board, demonstrating the changes upon clicking, is included in Figure 2. Throughout data collection, some RAs reported in group supervision that they had adapted the activity boards to involve actions (e.g., blowing at the clouds on the screen, clapping to move rocks, stomping in imaginary muddy puddles next to the laptop, wiping the water off the screen) by children, who often wanted to touch and move the pictures on the activity boards. Involving actions in the activity boards was not something that we had considered during our initial development of them, further highlighting the importance of taking a collaborative approach between the core research team and the RAs completing data collection with children.

*****FIGURE 2 HERE*****

To complement the activity boards, in collaboration with the RAs, we developed a list of example activities for RAs to choose from in data collection sessions, including: resources (e.g., a sock puppet, stuffed toy, bubbles to blow at the camera, crayons and paper, musical instruments), physical activities (e.g., shaking and wiggling, dancing, follow the leader/copying actions activities), interacting (e.g., discussing interests, show and tell), singing songs, drawing or colouring using the computer or paper and pens, playing online games (e.g., noughts and crosses, picking which character would win a race, guessing the picture before it is complete), and watching a short video or song on YouTube. RAs were encouraged to be creative with activities and resources, and to share examples of activities that seemed to work particularly well for them in group supervision. We would recommend providing a non-prescriptive list of example activities for RAs during training to enable them to familiarise themselves with potential activities, and then supporting them to develop and/or source additional activities enabling a flexible and creative approach to engaging children in the data collection process. Further, group supervision provided opportunities for RAs to share their collective experiences in engaging children, allowing for continued peer learning, enhancing the overall quality of data collection processes.

To further support engagement activities, schools were also asked to provide a short list of likes and dislikes for each child. This information was shared with RAs ahead of sessions to enable them to prepare for sessions by identifying and personalising activities of interest for children based on their likes and dislikes. This process was also intended to build rapport and trust with children to ensure successful data collection (Johnson, Hart and Colwell, 2014). For example, a RA received information that a child liked ABBA so, with the permission of their teacher, the RA was able to motivate the child by playing ‘Mamma Mia’ at maximum volume at the end of the session. The RA reported that everyone sang along, and that the child thanked her, saying that she “had a lot of fun”. Other examples were where children were interested in a particular film or television show, so the RAs developed a suite of activities for between assessments, including watching a clip on YouTube, singing a song, the RA having a related soft toy to use as a puppet, and drawing pictures of a character/scene.

RAs were encouraged to change their Microsoft Teams background to a picture that aligned with the child's interests wherever possible to promote engagement with them on the screen and to support rapport and trust building (Johnson, Hart and Colwell, 2014). RAs reported that the activities used during the data collection procedure seemingly made the experience enjoyable for the children, encouraging children to engage with the brief data collection activities, and that they would end on a fun activity to ensure that children were leaving sessions after a preferred activity. It was not always possible to align activities with children's interests if sessions were booked at short notice, for example. In these cases, more general activities were used and RAs gauged children's interest in these activities and adapted future activities in line with their interest. The examples of personalisation highlight the importance of considering children's preferred activities was during data collection, and future work should prioritise personalising engagement activities to children's interest to maximise their engagement and motivation.

Finally, we allocated approximately 45-minutes per data collection session for each child. The DIBELS® is comprised of five one-minute sub-tests, and the Reading Self-Concept Scale took approximately 90 seconds to complete. We intentionally allocated longer than would be needed to complete all six assessments (c. 10-15 minutes, including reading instructions) to ensure that initial and continued engagement was prioritised throughout the data collection sessions, as well as allowing ample time for interruptions and distractions.

Implementing data collection procedures

Although parental consent was obtained, it was important that children started the data collection procedure feeling empowered to remove some of the implicit power held by RAs (Lambert and Glacken, 2011). Therefore, RAs obtained assent from children before beginning and continuing with assessments. To support this, RAs clearly explained what would be happening and asked if children were happy to begin or continue. To ensure that all children felt able to indicate their assent, they were able to indicate verbally or using thumbs up/down.

RAs collected data in individual Microsoft Teams meetings with children, who were each supported by a member of teaching staff at their school. As could be expected with any online procedure, there were some technical difficulties throughout. Where technical difficulties disrupted data collection, RAs followed the protocol and, where possible, restarted or rearranged the assessment for another time or day. Having a clear protocol, with a troubleshooting section, and procedure to follow was essential to ensuring that RAs could independently manage situations whilst not losing the attention and motivation of the children, thus further building their capabilities (Johnson, Hart and Colwell, 2014).

Initially, we had planned to undertake individual 45-minute appointments for each child, and RAs were trained with this procedure in mind, however some schools preferred to book longer group appointments, allowing flexibility to move children around in the order depending on other school activities, availability, and children’s emerging needs. Typically, data collection would last for around 30-minutes per child, including engagement activities. As data collection progressed, we consulted with schools to identify their preferred method (i.e., individual or group appointments). Breaks between data collection sessions in group appointments were short, so RAs prepared multiple activities and Microsoft Teams backgrounds ready to be used in concurrent sessions. This was an adapted way of working, and group supervision helped to support RAs to consider ways to maximise their preparation activities. In future work, we would recommend that researchers engage earlier with schools to identify their preferred data collection appointment method.

There were some reported instances whereby children were distracted by being in unfamiliar rooms. Based on our previous experience collecting data face-to-face with children with developmental disabilities, we anticipated that this would occur during online data collection as well, and prepared them accordingly to actively engage children in their distraction by suggesting that they explore the room and then return to the computer to report back to the RA. This activity enabled children to satisfy their curiosity about their surroundings and to then return to task. Being prepared for this eventuality ensured that RAs were able to effectively and appropriately respond, limiting the potential for disengagement from the children. In line with recommendations from Johnson, Hart and Colwell (2014) about building researcher capabilities, we would recommend that researchers develop an understanding of how children with developmental disabilities may interact with their environment during online data collection, and appropriately plan for potential distractions and disengagement.

Talking Mats. During Talking Mats interviews, there were some technical issues (e.g., lagging movements) with using Zoom to share control of the screen with children, meaning that some children faced difficulties in moving the option symbols themselves. Children were typically willing to try again, and were not seemingly frustrated by this issue. One child, however, was not able to use the controls and so the interviewer and the teacher supported the child by placing the symbols on their behalf. Where school resources allowed, some children were able to use a smartboard rather than the mouse attached to the computer. This method of completion worked well by providing a larger space for children to move symbols more easily using their palm, slowing the interview down, and giving children some movement around the room between the computer screen (to engage with the interviewer) and the smartboard (to place the symbol).

Teachers helped the interviewer to connect with the children, supported with technology, supported children to feel comfortable during the interviews, and provided additional context when confusion arose (e.g., one child was confused about the computer symbol because they had used an iPad to complete HER®). The interviewer was responsive to teacher feedback when additional context was provided and adjusted their approach, symbols, and/or language to best support children to engage in the interview. However, there were some instances where teachers interrupted the interview by offering their opinions on children's symbol placement which would have impacted the neutrality of the research process and may have influenced children to be more acquiescent or positive in their responses. In a face-to-face Talking Mat, the conversation is typically only between the interviewer and child sat side-by-side, with a support person either sitting away from the table or in another room. The issue of teachers interrupting the interview would, therefore, be less likely to occur, which could improve the children's engagement in the process. To negate this in future research, it would be helpful to provide teachers with some more direct information at the beginning of the interview about their role (i.e., to be a familiar person who could help with the practical aspects of the interview).

Reflections and recommendations

Adaptations to the data collection procedure were necessitated by the COVID-19 pandemic and related restrictions, however, the adaptations enabled us to reach a greater number of "harder to reach" children relatively easily and in a high volume. RAs successfully completed data collection with 382 children at baseline, and 294 children at the 12-month follow-up, and RAs and schools reported that children were not adversely affected by the online data collection procedures, and in many cases enjoyed the activities completed with RAs. This demonstrates that, with appropriate planning and preparation, it is possible to engage children with developmental disabilities effectively in online data collection procedures, collecting vast amounts of data, without adverse events for the children. Future research using online data collection methods should consider both the data collection and engagement activities as equally important in ensuring smooth and successful online data collection.

RAs were supported in their role by the practice-based training to proficiency and the detailed data collection protocol, which was an essential component ensuring that RAs were able to complete data collection independently, and effectively manage a number of possible scenarios. This also supported RAs to actively and effectively engage children with developmental disabilities in the online data collection procedures. Through working collaboratively with schools and RAs, researchers can support RAs to feel well-practiced, competent, confident, and prepared to effectively personalise engagement activities for children. Group RA supervision can also be a useful vehicle for sharing examples of good practice and for organically evolving methods of engagement.

Whilst there were logistical and geographical benefits to online data collection for RAs, the change in delivery method, from face-to-face to online, vastly increased the operational and administrative workload for data collection. Primarily, this was due to the need for a member of administrative staff to manage the availability of a team of RAs and 382 children in 55 schools, matching availability, setting up Microsoft Teams meetings, following up with schools about children’s interests to facilitate engagement activities, support RAs to contact teachers if they were late to pre-arranged appointments, and rearrange a large number of missed or disrupted appointments as RAs were not physically there to remind schools of appointments. This administrative support was essential in effectively supporting RAs to engage children in data collection activities, and should be factored into planning effective and engaging online data collection. We underestimated the scale of this core administrative and operational role during the baseline data collection, but were able to accurately estimate the amount of administration support needed to complete the 12-month follow-up, and arranged for dedicated administrative support to be provided enabling a more seamless process for schools and RAs. Researchers completing online data collection with children with developmental disabilities should not underestimate the planning needed to effectively complete data collection activities in this way.

Engagement activities should be planned in advance, but remain flexible enough to enable RAs to use them creatively with children to maximise their engagement and motivation throughout the data collection activities. Children’s interests should be incorporated into engagement activities wherever possible, including theming activities around interests and using Microsoft Teams backgrounds to generate interest in the RA on the screen. Researchers should not disregard their existing experience in face-to-face data collection with children with developmental disabilities, and can use this to adapt and generate online engagement methods. Importantly, researchers should continue to evolve and adapt their methods of engaging children with developmental disabilities in online data collection as technology and the need to complete data collection online develops.

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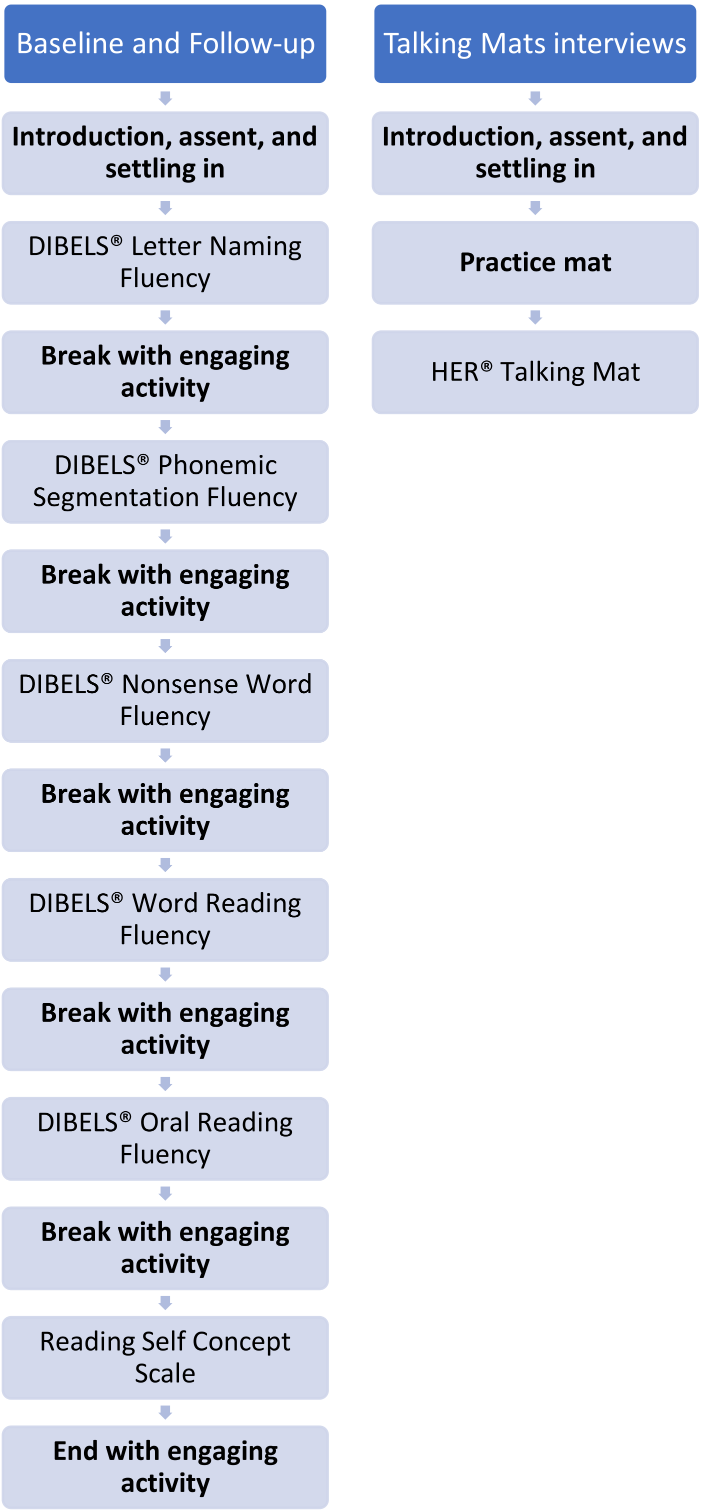

Figure 1. A visual representation of the data collection process at baseline, follow-up, and for the Talking Mats interviews (Note. **Bold type** indicates a data collection activity intended to engage or motivate children)

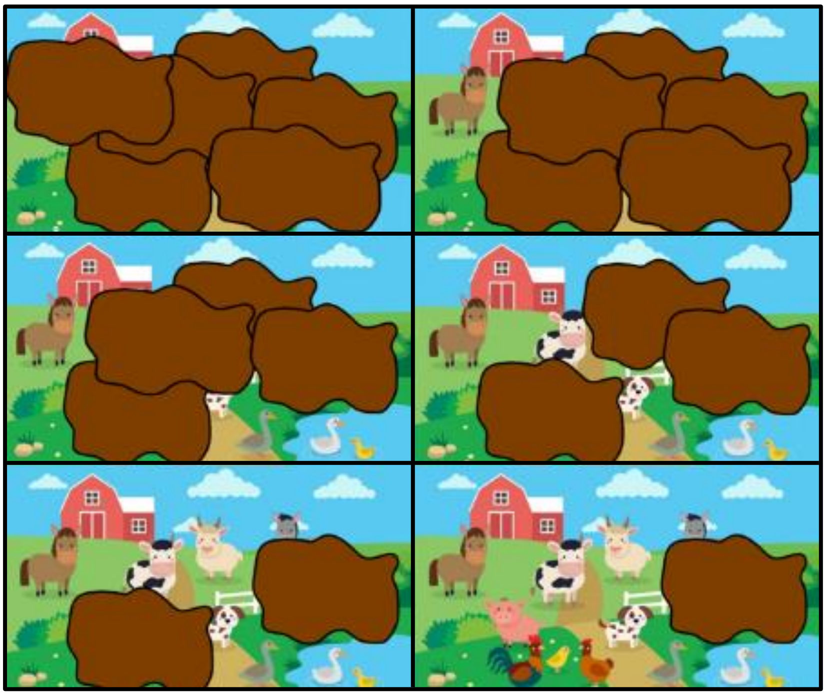

Figure 2. An example of an activity board, demonstrating the progression of the activity (the removal of one muddy puddle) upon clicking the cursor. The starting narrative was “The farmer’s tractor got stuck in the mud. The mud sprayed on all of the animals. We need to help them to get clean again.”