

‘Our Stories...’: Co-Constructing Digital Storytelling Methodologies for Supporting the Transitions of Autistic Children - Study Protocol

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Abstract

The voices of autistic children and their families are routinely underestimated and overlooked in research and practice. Research is challenged methodologically in accessing the views of autistic people who, by definition, are characterised by social and communication difficulties. Consequently, many voices remain unheard and experiences undocumented. This has important implications for the validity of research that is interested in improving the life experiences of marginalised groups since the representation of those experiences is partial and dominated by research perspectives that prioritise particular kinds of evidence. This situation matters because there remains a substantial gap between research and practice such that the longer-term outcomes for autistic people across social, educational and economic indices remain poor. We argue that research can only make an impact on practice if there is a genuine commitment to gathering and understanding these different sources of evidence in ways that connect research and practice from the start. This protocol describes a methodological project funded by the Economic and Social Research Council in the UK. The ‘Our Stories’ project applies and extends a participatory *Digital Stories* methodology to explore the research challenge of gathering a range of views from autistic children, families, and practice in authentic ways and at points of transition. *Digital Stories* is an accessible and inclusive methodology that supports the sharing of views and experiences in visual, video form. We describe the rationale for, and design, of the project across four pilot studies in different contexts as well as our approach to analysis and ethics. While our project focuses on autism, the knowledge we gain is applicable to research and practice much more widely and to any voices or groups who are marginalised from the traditional ways of doing research and to any contexts of practice.

Keywords

digital storytelling, voice, knowledge co-construction, close-to-practice research, participatory research, autism

Background

I think [the Digital Stories are] much better [than a written report] ‘cause you can get to see the child from their point of view, which is really good, and you can understand them better. From a piece of paper, it doesn’t matter what you write down ... you can’t explain Oliver on a piece of paper. No one ever, ever understands. So, seeing him like that on a screen, you kind of understand him a bit more ... - Lindsey, Oliver’s Mum (<https://autismtransitions.org/thoughts-on-digital-stories/>)

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Oliver is a 4-year-old autistic boy who was one of the participants in our Froebel Trust funded project that developed a strengths-based approach to supporting young children's transitions to their first school (<https://autismtransitions.org/>). Our approach was based on a Digital Storytelling methodology, developed from our earlier Economic and Social Research Council (ESRC) funded work in the UK, that explored teaching and learning methods and practices for technology-enhanced learning with autistic children and their teachers (Guldberg et al., 2017; Parsons et al., 2015). Digital storytelling is a way of expressing meaning and experiences through short videos, images and/or sounds that are curated and co-constructed *with* people whose voices are traditionally marginalised (Gubrium, 2009). It is a participatory and inclusive approach to documenting and sharing knowledge and experiences in ways that respect and value different forms of evidence compared to more traditional research methods (Parsons et al., 2021).

At the heart of this methodology is an understanding that many voices can be difficult to access or express in typical ways, and so become excluded from mainstream discourse and processes (Lambert, 2010; 2013). Digital Stories do not rely on formal spoken or written forms of communication and therefore give validation to different ways of 'knowing' about the world (Parsons et al., 2021). Oliver's story (which we called an 'I am...' Digital Story) was created using video cameras and Wearcams (<https://autismtransitions.org/i-am/>). In it, we can see the things that Oliver likes to do at nursery, what he is interested in, and the interactions he has with peers and staff; hear him trying to communicate with others; see him consistently wearing Batman and Spiderman clothes and how important these are to him; and observe where he needs support. Oliver would not have been able to verbally tell us about these things that make him the unique person that he is. Moreover, parents from the same project reported how difficult it was for them to communicate about their child within formal processes and how/why this methodology made a difference to them, for example:

'I think the Digital Stories are amazing, I loved them so much ... I think it would be amazing for schools and professionals to watch prior to the child's start ... There is too much pressure on the parents to have to try to explain what their child is like, because you can't explain in words a person, ... I don't like the pressure of explaining what my son is like myself, because I worry that I'm not portraying accurately enough ... – Anita, Oscar's Mum (<https://autismtransitions.org/thoughts-on-digital-stories/>)

Essential to the success of this research methodology was its co-construction with the children, families, and practitioners in early years practice (Parsons et al., 2021, 2022a, 2022b). Fundamental to this approach is an epistemological understanding that for research methods aimed at influencing practice, the generation of new knowledge must appropriately recognise, respect, and reflect the individual and local contexts

of inquiry (Thomas, 2012), as well as the expertise or craft knowledge of practitioners (Hammersley, 2005; Nind, 2006). Knowledge co-construction underpins action, participatory and inclusive approaches to research, which share a fundamental ethos of democratising research processes to accommodate different forms of knowledge and empower the voices of those who are traditionally silenced (Nind, 2017; Freire, 1970). In short, co-construction encompasses 'new knowledge creation (the *what*) through the shared endeavours of research and practice working together equally (the *how*)' on the questions that arise from practice (Parsons et al., 2022a, p.1065; emphasis in original).

The 'problem' of accessing the voices of autistic individuals and families is one that is shared between research and practice. In research, there is increasing recognition of the missing voices of autistic people to inform the evidence base about effective practices (e.g., Ridout, 2017), as well as the longstanding and problematic power imbalances between autistic people and research (e.g., Parsons et al., 2020). While research is beginning to report on the lived experiences of autistic individuals and challenge marginalisation (e.g., Fletcher-Watson et al., 2019; Chown et al., 2017), accounts remain limited and partial through mostly including methods designed to access the views of older and more articulate participants (DePape & Lindsay, 2016; Fayette & Bond, 2018; Tesfaye et al., 2019; Tyrrell & Woods, 2018).

Conceptually, knowledge (evidence) in the autism field is dominated by bio-medical research traditions with concomitant implications for research designs and methods (Guldberg, 2017). Within this context, the nature of knowledge production is questioned (Milton, 2014) and autistic children's voices are undermined and underestimated due to overly 'psychiatrised' discourses that fail to recognise neurodivergent individuals as competent 'knowers' in their own lives (Le Francois & Coppock, 2014; p.166). Methodologically, researchers have been challenged (and most have failed; Lewis-Dagnell, 2022) to find meaningful ways of authentically accessing and including the diverse voices of autistic children (Ellis, 2017), especially young children (Parsons et al., 2021) and those with more complex needs (Nind, 2008). Families also often feel excluded from discourses that prioritise scientific, rather than personal knowledge giving rise to calls for the need for more phenomenological approaches to understanding experiences (Lawlor & Solomon, 2017). In recognition of these wide-ranging challenges, Parsons et al., (2020, p.27) called for autism research to 'start from a different place' [i.e., a more democratic and participatory one] to address, understand, and meet a range of needs more effectively.

In practice, and despite policy mandates in England to the contrary (Department for Education & Department of Health, 2015), autistic children's voices are regularly overlooked and underestimated in formal processes intended to safeguard their interests (e.g., Palikara et al., 2018). Experiences of exclusion of autistic children and their families, especially within

education, are well documented (House of Commons Education and Skills Committee, 2006) and persistent (APPGA/National Autistic Society (NAS), 2017; NAS, 2021), with major concerns for long-term consequences and outcomes across social, economic, and educational indices (Ayres et al., 2018; Reaven, 2011; White et al., 2009). Overall, there is a very real need to find ways to challenge the traditional ‘ways of knowing’ in autism research (Guldborg et al., 2017) such that research can begin to be transformative for practice. *How* this can be achieved using novel and accessible digital methodologies, is the central objective for this project.

A Focus on Transitions as a Site for Research and Practice to Work Together on a Shared Problem

Transitions represent a powerful and important target for research and practice to work together to find a solution. Daily (horizontal) transitions as well as major life (vertical) transitions are aspects of life that are known to present particular challenges for autistic children and families (Nuske et al., 2019), and which contribute to feelings of exclusion and frustration reported (APPGA/NAS, 2017). Without appropriate planning and support, small changes within horizontal transitions such as to routines, food, or clothing, can create significant and distressing behavioural and emotional responses (Stoner et al., 2007). Similarly, major vertical transitions, such as between schools, are well-documented to create substantial challenges for children and families, with difficulties that may persist over time (Mandy et al., 2016). Additionally, with only 16% of autistic adults in full-time employment, transitions beyond school can be especially problematic for autistic young people, often because employers do not know what to expect or what support may be needed (NAS, 2017).

In a systematic review of the transition literature for autistic children and families, Nuske et al., (2019) identified that successful transition strategies included pre-transition visits to the home or school, and opportunities to visit and explore new classrooms and observe children’s responses. However, teachers reported finding these transition strategies hard to implement with school visits being ‘difficult or impossible in some school districts due to logistical issues such as late placements and limited teacher/parent time’ (p.317). Thus, providing context-specific information and individualised experiences for children and families was a major barrier to enabling effective transitions from the schools’ perspective. Additionally, and perhaps the most crucial barrier to supporting successful transitions, was the challenge of sharing information about the child between contexts which ‘parents and teachers reported...did not occur, despite the benefits for all involved’ (p.317). Thus, there was already a need to develop methods that more effectively support transition processes and this need became even more pressing with

lockdowns due to the Covid-19 pandemic. This provided the impetus for our project proposal, which we submitted to the UK’s ESRC project call for Research Methods Development Grants in May 2020. We heard in November 2020 that our proposal would be funded and commenced the project in February 2021 (Grant reference ES/V005286/1) to run until end September 2022.

Explanation and Justification of Method

We wanted to bring together a team of researchers and practitioners to address the methodological challenge of transitions for research and practice. We proposed methodological innovation in two main ways: (1) our Digital Storytelling methodology as previously developed focused on the *child* within the transition (*‘Who I am’*), but this project presents a unique opportunity to explore and include the *context* part of the transition (*‘Who/where we are & what we do’*); and (2) to extend the method through collaboration with new partners from the *What’s it Like?* Initiative (see below) using a range of immersive technologies, which enable contributions of vital perspectives from agents on both sides of the transition and provide a means of sharing these when physical visits and contact may not be possible or desirable.

Our research questions have been adjusted and expanded slightly during the project and are:

1. In what ways do autistic children, families, education and medical practitioners, and settings co-construct Digital Story methodologies to support horizontal and vertical transitions?
 - a. What processes facilitate or constrain the co-construction (e.g. mapping, planning, sharing) and who is involved in these processes?
 - b. What tools are used to create the Stories and what are the tools used for?
 - c. Whose and what knowledge is shared in the creation of the Stories?
 - d. What are the roles of the researchers in the co-construction of the Stories?
2. What are the affordances of Digital Story methodologies for enabling the contributions of different voices and creating transition tools for children, families, and settings?
3. How are these transition tools, and the process of their co-creation, evaluated by their creators and target users?
 - a. What do we learn about transitions and lived experiences of the children and families?
4. How can digital video technologies be applied to this methodology to make them scalable and accessible for research and practice?

Our project addresses the methodological challenge of supporting transitions in research and practice through knowledge co-construction. We work collaboratively across academic disciplines (Education and Psychology) and with non-academic partners in health, education, and inclusive technology design. Our collaboration includes existing relationships within our Autism Community Research Networks at Southampton (<https://acorns-soton.org.uk/>) and Sussex (<https://www.acorns-sussex.org.uk/>) [ACoRNS] and extends these to include Autek who are independent, inclusive developers of immersive technologies for and with neuro-divergent people (<http://www.autek.co.uk/>). Autek have used 360° photography and video, supported by Augmented and Virtual Reality to provide immersive experiential digital access to spaces that might cause anxiety for users (see <https://www.pals-society.com/whatsit-like>). Our project, therefore, sought to develop our understanding of the methodological challenge of supporting vertical and horizontal transitions for autistic children and families through four co-constructed pilot studies, which are described below.

There are *dimensions of difference* for extending our Digital Stories methodology around which the pilot projects vary, as well as *core methodological principles* that apply to all. Some dimensions describe the context and so are more fixed, others describe the digital tools at our disposal. The digital tools were applied flexibly and in co-construction with our project partners, based on their decisions about feasibility and appropriateness within each setting (see [Table 1](#) for a summary).

Description of the Four Pilot Projects

Pilot 1: Supporting School Transitions Through Sharing Student and Staff Knowledge of Self and Spaces. We worked with ACoRN@ Southampton partners Springwell School, Hill House School and New Forest School for this pilot. All are special schools that support children with complex needs including autism and had been included as named collaborators on the project proposal. At Springwell School all children in their final year of Primary school (aged 10–11 years) created individual ‘I am ...’ Digital Stories, 29 of which were granted permission to be shared with the research team, of which 7 can be shared publicly (the links to all publicly available videos are included in [Table 2](#)). These Stories were between 1.5–4 minutes long and used a combination of photographs, video clips and Webcam footage, with some children requiring more structure and support than others. They planned their Stories carefully using a booklet prepared by the school and their finalised Stories were shared with families and peers via a celebratory, online end of year assembly. Great Oaks School in Southampton is a secondary school for pupils with complex needs and is the main school to which children transition from Springwell. Great Oaks participated through creating a ‘We are’ virtual tour of the school ([Table 2](#)), informed in part by the wishes of students from Springwell who were not able to make

their usual familiarisation visits due to Covid-19 related restrictions.

Hill House School have already embedded the creation of ‘I am ...’ Digital Stories for some school leavers ([Burden & Marsden, 2020](#)) and so their focus was on creating a ‘We are’ tour to welcome new students and families to the school ([Table 2](#)). They worked with Autek and the research team over several months to produce a virtual tour that enabled 360° exploration of inside and outside spaces and included video clips of interactions between staff and students at selected ‘hot spots’ on the tour.

New Forest School wanted to support students transitioning into Key Stage 2 (KS2; for students aged 8–10 years) from their Outdoor Learning Centre and so focused on creating a ‘We are’ tour of the KS2 school site. This tour included 360° exploration of indoor and outdoor spaces, as well as short videos of key staff members introducing themselves and their role ([Table 2](#)). Three students were involved in developing a narrative voice-over for the tour, including commentary on what they really like about the school.

Pilot 2: Enabling Young People to Prepare for Transition from School to Adult Settings. This pilot worked closely with an 18-year-old female student, Lil, who was transitioning into post-compulsory education from New Forest School. Lil made an ‘I am ...’ Digital Story with help from her father to support her transition, which we have full permission to share ([Table 2](#)). Additionally, we worked with a community organisation called Friends of St James Park (FoSJP) in Southampton, UK to create a ‘We are’ tour with them ([Table 2](#)). This was targeted specifically at Lil and informed by some of her specific questions and requests. We were able to share Lil’s ‘I am ...’ Digital Story with FoSJP, and the FoSJP ‘We are’ tour with Lil to support her transition into work experience. Lil also tried out a Virtual Reality experience of the FoSJP tour, using a Google Cardboard headset.

Pilot 3: Facilitating Students to Understand and Communicate their Emotions to Support Everyday Transitions in School. *Just Right* is a traffic light system to support emotion and sensory self-regulation. It was developed within Brighton and Hove Inclusion Support Service for classroom and home use and is used in primary and secondary schools throughout the local authority. It is designed to help pupils identify and communicate their feelings by linking their experiences to different coloured ‘zones’, and to help pupils select strategies for self-regulation to return to or stay in the ‘green zone’, ready to learn. The programme was developed for autistic pupils but has been adopted as a school-wide approach in some settings. We used the Digital storytelling method with three autistic pupils (aged 13–16 years) who had experience using *Just Right* in a mainstream secondary school to co-produce ‘How I feel ...’ Stories. These Stories showed their experiences of the school environment and shifts in emotional and sensory states throughout the school day. We used several planning

Table 1. Core Dimensions of Difference and Methodological Principles for Each Pilot Project.

		Pilot Study			
		1 Supporting School Transitions	2 Enabling Post-school Transitions	3 Facilitating Understanding and Communication for Everyday Transitions	4. Smoothing Transitions for Interactions Between Families and Health Professionals
Dimensions of difference	Level of the transition The age/stage of the transition for children and young people	Macro (vertical) Primary and secondary	Macro (vertical) Post-secondary	Micro (horizontal) Secondary	Micro (horizontal) Family with boy (7 yrs) family with boy (11 yrs 11 months) Family with girl (12 yrs 10 months) Family homes
	Nature of the context to, or within, which the transition happens	School	School college employers/work experience	School	Family homes
	Digital technologies used to facilitate voices and create the stories	Digital cameras Wearcams 360° camera Tablets	Digital cameras Wearcams 360° camera Google cardboard smartphone	Filming: Wearcams 360° camera (360° lens and flat wide-angle lens) Editing: Laptops with iMovie flexclip online editing software	Filming: Smart phone digital camera Wearcams Editing: Laptops PC smartphone
Core methodological principles	Co-construction	The aim was for the creation of all digital stories to involve autistic children and young people, and key stakeholders (families, teachers, trainees etc) in their construction. This included making decisions about what is filmed, how it is filmed, and how/where/with whom the stories are shared			
	Accessibility and scalability	The technologies used and applied need to be within easy reach of most stakeholders so, for example, if we use virtual reality technology, we will explore how this can be done in the most useable and accessible way. Technologies used will be those that are easy to access 'off the shelf' and inexpensive			
	Evaluation	Focuses on bringing both sides of the transition together where feasible and appropriate, and sharing the range of perspectives involved (e.g., between adult and child, home and school). We are interested in: what has this process been like for the key stakeholders? What difference has it made/could it make to supporting transitions? What are the main features (key affordances) of the technologies used that have enabled useful and effective stories to be created?			

documents to help the pupils develop their ideas as a group. Students needed varying levels of support to capture their video, ranging from reminders to collect equipment to one-to-one support with covert filming. All pupils needed substantial support with editing but had clear and unique visions for their Stories' narrative. We have full permission for the videos to be shared (Table 2), and pupils discussed hoping their Stories might help other autistic pupils navigate their school environment and increase understanding about autistic pupils' experiences of school.

Pilot 4: Smoothing Transitions for Interactions Between Families and Health Professionals. The Time for Autism programme (TfA, not dated) is a mandatory course for fourth year medical students at the Brighton and Sussex Medical School in the UK, whereby pairs of medical students visit a family with an autistic child at home three times over the academic year. This pilot collaborated with TfA and supported three participating TfA families and two medical students to create Digital Stories that shared more information about themselves in advance of the visits.

We met with families to talk through how to create their 'Who we are ...' Stories, focusing on how to plan and choose what to include based on guidance materials provided. Families used photos, video and Wearcam footage, with

accompanying statements to create 3–4 minute videos that showed the things their autistic child was good at or enjoyed doing with family or by themselves (Table 2). One family independently created their Digital Story after the initial meeting and the other families needed further support to map and edit their Stories. Two medical students created 'I am ...' Digital Stories introducing themselves to their assigned family by showing how they like to spend their time when not studying. Stories lasted 1 minute and were created using Digital Story Guides.

Families shared their Digital Stories with their assigned medical students and the two medical students shared their Stories with their assigned family. All were viewed before the first meeting, two in-person and one on Zoom (due to Covid-19). Afterwards mothers and students were interviewed about creating, sharing, and viewing their Digital Stories before meeting for the first time.

Data Handling

A data protection impact assessment was created and agreed by the two academic institutions involved, together with a data flow description noting, for example, exact procedures for consent, agreed file naming conventions, web services used and file transfer protocols. All research materials, notes,

Table 2. URLs for Digital Stories and Virtual Tours that can be Shared Publicly.

Pilot Study	'I am'/'I Feel'/'We are' Digital Stories	'We are' Virtual Tours
1. School transitions	Springwell 'I am ...' digital Stories Aqtab- https://youtu.be/duTtFXY2rZE Bobby- https://youtu.be/lZmm2Ck6yCw Gisbert- https://youtu.be/suDj9clHx5s Jae- https://youtu.be/uHgVokxRYll Lewis- https://youtu.be/esjCb-9tB0Y Nathan- https://youtu.be/VwXyOWsy858 Noah- https://youtu.be/pHvMFA5A5s	Great oaks virtual tour https://vr.plusglobalmedia.com/tour/TTI7O99HEX Hill house virtual tour https://www.whatsitlike.co.uk/user/75 New forest school virtual tour https://www.whatsitlike.co.uk/user/78
2. Post-school transitions	Lil's 'I am ...' digital story https://youtu.be/rAgxO_l6ju8	Friends of St James' Park virtual tour https://vr.plusglobalmedia.com/tour/TTI7WVLFQW4
3. Everyday transitions	Celeste's 'how I feel' digital story https://youtu.be/L_dUSU0LgYs Tess' 'how I feel' digital story https://youtu.be/axMn3LWNXQ0 Aliyah 'how I feel' digital story https://youtu.be/qnPNtjUmYrc	
4. Healthcare transitions	Sydney's 'we are' family digital story https://youtu.be/C39lkBX42as Emily's 'we are' family digital story https://youtu.be/tt0gEdswc6w Family 3's 'we are' family digital story https://youtu.be/T7bDouEJ8cg Sasha's 'I am' digital story (medical student) https://youtu.be/r-uQ0oikrTU Tashi's 'I am digital story' (medical student) https://youtu.be/BIZyR_Bbfy0	

working documents and video data were stored on Box (<https://www.box.com/home>), a secure document-sharing system made available through the University of Sussex. This enabled the team to have secure storage and sharing compliant with relevant data protection legislation, with ready access to complete audit trails of document access and the ability to provide safe storage and viewing facilities for external users and stakeholders, with different permission levels.

Data Analysis

We are currently in the process of analysis which differs somewhat for each of the pilot projects. We are interested in the *content* of the Stories produced, the *processes* of their co-construction, and how they are *evaluated* by key stakeholders.

Content: For the ‘I am ...’ and ‘Who we are ...’ Digital Stories we are following the analysis method summarised in [Parsons et al., 2022b](#)) which involved creating a ‘transcript of action’ for each Story that describes what is *seen* as well as what is *said* and using our existing ‘I am ...’ Digital Story Framework ([Parsons et al., 2021](#)) to categorise this information. Once the videos are transcribed, it is possible to collate and represent the data in different ways; for example, [Parsons et al., \(2021\)](#) used word clouds to show the verbs that were used to describe children’s skills and activities.

For the ‘We are’ virtual tours, [Creswell’s \(2021\)](#) thematic analysis process is being followed. Although the steps are described sequentially, the analytic process is iterative and cyclical. Initial coding follows a descriptive approach in which sections of the data are summarised with short phrases. For example, children at the setting were described as ‘showing what’s important to them’, ‘really invested in the school’, and parents as seeing ‘their child belong’. Codes describing similar concepts are connected to form initial themes, for example, ‘a sense of belonging’.

Process: For reflecting on the process of story development, we will apply and adapt the [University of Cambridge’s Inclusive Design Framework](#) (not dated). We make some adaptations, for example dissolving the distinction between ‘experts’ and ‘users’, since we consider everyone to bring different and unique expertise to the project. This part of the analysis is ongoing but there are some important considerations so far. First, it was not possible to address the intersection between individuals and contexts in all projects in the way that we had initially planned, particularly in relation to post-secondary transitions into adult services or educational provision. Second, there was diversity in the ways that young people’s voices were enabled through the process of Story creation, with some being much more adult-led than others.

Evaluation: Feedback from all relevant stakeholders following the completion of some of the Stories was constrained by children moving to their new school/setting, but feedback was gained from a range of stakeholders mostly via semi-structured interviews to explore and document whether/how transition practices have been experienced differently through

using these new Digital Storytelling methods, and what may have been learned as a result. Based on the Inclusive Design Toolkit, we have included questions to establish the review criteria that matter to our project partners within each pilot so that successful outcomes are determined on whether the tools meet their needs and expectations, and potentially make a difference to practice.

In analysing the evaluation data, we draw primarily on [Braun and Clarke’s \(2021a, 2021b\)](#) reflexive thematic analysis which emphasises the importance of ‘... the researcher’s subjectivity as analytic *resource*, and their reflexive engagement with theory, data and interpretation (2021a, p.330; emphasis in original). This approach encourages flexibility, enables deductive as well as inductive orientations to the data, and eschews narrow interpretation. Given the important role that the research team played in the co-construction of the Digital Stories, their subjective lenses through the analysis process are important for making sense of what happened and what has been learned.

Rigour: Ensuring Quality in Qualitative Research Practice

[Braun and Clarke \(2021a, 2021b\)](#) are clear that concepts such as inter-rater reliability and consensus building have no place within a reflexive thematic approach, since these practices and ideas import assumptions from the positivist paradigm that are not aligned with the fundamental philosophical underpinnings of qualitative research. Thus, for them and for us, ‘rigour’ is demonstrated through epistemological clarity and coherence such that:

Analytic procedures, including those centred on ensuring and demonstrating quality, typically reflect underlying paradigmatic and epistemological assumptions about meaningful knowledge and knowledge production ([Braun & Clarke, 2021b](#), p.329).

Given our own emphasis on knowledge production as *co-constructed* through the creation of the Digital Stories and the importance of actively addressing the marginalisation of children’s and parents’ voices in research and practice, our work is positioned within a more pluralistic, experiential and, therefore, constructivist understanding of data and the meanings we derive from it ([Allison & Pomeroy, 2000](#); [Irving & Young, 2002](#)). Redistribution of power is also important within our processes of co-construction as well as our emancipatory intent; in other words, our research ‘... is not merely a study of convenience but one with significance and intentionality’ ([Shannon & Hambacher, 2014](#), p.2). We are oriented towards achieving changes in understanding, awareness, perspectives, attitudes, and practice through elevating otherwise marginalised voices, and so our work straddles both critical theory and constructivism ([Allison & Pomeroy, 2000](#)).

Therefore, we particularly focus on *authenticity* as the central pillar of quality in our research which, simply put, refers to ‘... the ability of the research to report a situation through the eyes of the participants’ (Cohen et al., 2011, p.184). More specifically, Shannon and Hambacher (2014) draw upon Lincoln and Guba’s (1985) dimensions of authenticity, of which *educative*, *catalytic* and *tactical* authenticity are of most relevance here. Space precludes detailed description, but these dimensions of authenticity focus, respectively, on whether (a) ‘participants experienced an increased awareness and respect for the viewpoints of others’ (Shannon & Hambacher, 2014, p.2); (b) stakeholders take action because of their participation in the process; and (c) there was a redistribution of power. These are key elements that have been woven into our evaluation tools and so are included in our ongoing analyses.

Ethics

The main ethical issues relate to the involvement of children and young people who may not be able to communicate in typical ways; potential ‘vulnerability’ of families due to the anxieties and challenges they experience; and ownership of the digital content produced within the project and whether/how that will be shared more widely.

Central to our approach are two main, interconnected features: (a) safe and trusting relationships and (b) clear communication. Relationships are critical to the successful ethical conduct of collaborative research since it is only within trusting relationships that risks can be taken in safe and informed ways. Conducting this research with our existing ACoRNS partners provided significant advantages since they already have established relationships with children and families and were the first points of contact for explaining the project and seeking their feedback, interest, and participation. We agreed all ethics protocols with our partners for how best to approach and explain the research to potential participants; the research team created drafts of the necessary information documents and consent materials which were then finalised with the settings involved. Ethics review was sought and granted from the University of Southampton’s Faculty of Social Sciences for pilot projects 1 and 2 (Ref # 62326.A5) and from the University of Sussex’s Sciences and Technology Cross-Schools Research Ethics Committee for pilot projects 3 and 4 (ER/DG241/12; ER/SH656).

Clarity of communication is essential within these relationships to ensure the voluntariness of participation and that trusting relationships are not exploited or taken for granted. We managed this in different ways depending on the preferences and needs of those taking part. We have the benefit that we already have examples of Digital Stories that are in the public domain and which can be shown to illustrate clearly what we mean (e.g., <https://autismtransitions.org/i-am/>). We

used Plain English versions of information sheets and consent forms with adult participants rather than relying on the jargon-laden and overly long University templates. We also used symbols and graphic illustrations as well as short videos to communicate project information to children.

The ownership of the digital artefacts produced lies primarily with our partners and the participants; it is their decision as to whether the Digital Stories will be shared beyond the project or made available publicly. Participants may feel that they want to show others what has been achieved, and settings may wish to share their Digital Stories with others as a way of promoting inclusive transitions for the future. Equally, they may prefer the materials to remain confidential within the project team. These possibilities were discussed at the start of the project and at the point of initial consent, and then revisited with participants once the Stories had been created so that they could decide whether and how the Stories could be shared more widely. This ‘two-step’ approach to consent was vital since we feel strongly that participants cannot consent to images being in the public domain until they have seen the final Stories and know how they feel about them. The fact that so many of the final Stories have been made available is an indication of how positively those participants felt about the Stories that were produced. Equally, the fact that not all of them are available illustrates the importance of our two-step approach since many parents were happy for their child to be included in the project but not for their Stories to be shared more widely.

Concluding Comments

Feedback from evaluations so far has been very positive about the benefits of the methodology for co-creating the Digital Stories, as well as the opportunities afforded for increased understanding, awareness, and dialogue that follow from sharing them with key stakeholders in these transition processes. We will report more formally on the outcomes of our evaluations in due course. In the meantime, we have secured further ESRC funding from the University of Southampton’s Impact Acceleration Account to create a series of short, animated video guides and accompanying written guidance materials, for promoting the methodology to researchers and practitioners. We finish with a quote from a foster carer who viewed the Stories from the pilot for smoothing transitions between families and healthcare professionals, to demonstrate why these materials may be useful:

I’ve loved watching [the Stories] this morning! I think they really demonstrate the strengths, skills and uniqueness of each child and their families. I’m so glad that you’re doing this project in this way. It’s such a simple idea, but one that I hope will have a huge impact ... You’ve managed to capture in just a few minutes, through music and visuals, what can’t easily be conveyed in words. I wish every family had the opportunity to do this for their child or young person!

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