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Using co-created video stories to support more equitable healthcare interactions for families of autistic children with learning disabilities

N Yuill

nicolay@sussex.ac.uk

University of Sussex School of Psychology https://orcid.org/0000-0002-2563-2704

Samantha Holt

University of Sussex https://orcid.org/0000-0003-1102-6188

Stephanie Daley

Brighton and Sussex Medical School https://orcid.org/0000-0002-5842-0492

Alison Smith

Brighton and Sussex Medical School https://orcid.org/0000-0002-7499-7136

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Abstract

BACKGROUND Autistic children with learning disabilities have poor health outcomes and increased mortality compared to other groups, with poorer healthcare experiences. Time for Autism (TfA) is an educational intervention supporting trainee doctors to better understand and empathise with this group. Digital Story-making is a method for families of autistic children with learning disability (LD) to create positive video narratives to support more neuroaffirmative ways of engaging with professionals.

OBJECTIVE We investigated the feasibility of Digital Stories to enhance the TfA intervention in supporting better understanding of the needs of this group.

METHODS Three families of autistic children with LD were supported to create short Digital Stories to share with medical students visiting them in the TfA intervention. Students also created Digital Stories. Three family members and two students were interviewed to gauge the potential effects of using such stories to facilitate engagement between the groups .

RESULTS Ten themes highlighted that the stories supported authentic representation of family perspectives, supported a more holistic view, powerfully supplemented written reports, presented implicit and contextual information to support better health provision, enabled parent reflection and neuroaffirmative approaches and increased reciprocity in medical interactions. Students appreciated advantages for learning and pre-visit familiarisation and suggested procedural changes for story creation by professionals.

CONCLUSIONS Co-creating digital stories is a feasible way for enhancing client voice in healthcare interactions and for professional learning. They can also provide powerful guidance, both general and tailored, for adapting medical environments to better support health needs of autistic children with LD.

Introduction

Health inequalities affect diverse groups of people. Research and practice are increasingly focused on ways to improve health and wellbeing in such groups. Families of autistic children with learning disabilities (LD) face particular challenges that are reflected in strikingly poor healthcare experiences and outcomes. A total population study in Scotland by (Dunn et al., 2020), using detailed data from the 2011 census on 0- to 75-year-olds, showed that autistic people with LD had a higher reported likelihood of mental illness, physical disability and sensory impairment than people who had just one of these conditions, with physical disability being especially increased in autistic children with LD. More recently the LEDER report (White et al., 2023) on notification of deaths suggests higher risks for autistic people with learning disability and a population study in Taiwan found increased mortality in autistic people with LD (Huang et al., 2024).

These two conditions therefore present a double disadvantage in health. There may be many reasons for the pattern of data, but there is evidence that poor healthcare delivery may contribute to this, and hence

that better understanding and adaptation by healthcare providers could improve the situation. A survey of adults (largely without LD) showed that autistic adults reported lower quality healthcare and more chronic health conditions than non-autistic adults (Weir et al., 2022). Barriers to healthcare for families with autistic children have been well-documented (Babalola et al., 2024); Boshoff et al., 2021). Doherty et al. (2022) reviewed factors in healthcare of adolescents and adults with intellectual disabilities and/or autism. They identified barriers in 6 areas: lack of specialist training, lack of knowledge and awareness (sometimes bringing negative attitudes and lack of reasonable adjustment), problems in communication (both in listening and in explaining to service users), fear and finally specific barriers in healthcare settings, such as the sensory challenges of clinical environments, lack of client involvement in decision-making and the need for extra time, e.g. in healthcare professionals getting to know the service user. These difficulties likely contribute to the poor health outcomes and reduced longevity found in autistic people.

Autism is viewed differently in a medical model compared to a social model of disability and can affect how services are provided. When parents have concerns about a child's development, conversations with healthcare professionals can understandably focus on developmental deficits and difficulties. The medical model of autism recognises differences from typical development and labelling this difference is essential for diagnosis. However, a diagnosis of autism continues to be described as a 'disorder' with 'persistent deficits' observed in behaviour (DSM-V: American Psychiatric Association, 2022); ICD-11; World Health Organization, 2021). This deficit-focused narrative is especially strong for autistic people with LD, particularly those who are minimally- or non-verbal (Haegele & Hodge, 2016). Autistic people with LD may not be portrayed as epistemic agents able to share knowledge about themselves (Chapman & Carel, 2022). This view can influence healthcare professionals' attitudes (Kapp, 2019), discouraging empathy and potentially contributing to health inequalities. A social model of disability focuses on how societal structures may produce disability by not providing appropriate supports for impairments. This model focuses on the environmental barriers, e.g. to healthcare, and how to surmount these to support more equitable access. This approach is rendered more powerful for autism by the 'double empathy' framework (Milton et al., 2022), which notes that the traditional focus on an autistic person having communication problems can be more constructively conceived as miscommunication, and lack of reciprocity, between autistic and neurotypical people.

The views of minimally or non-verbal autistic people with LD are under-represented in research and clinical practice (Russell et al., 2019), with an implicit assumption that their voices and experiences are too hard to reach (Parsons et al., 2021). Healthcare professionals may assume that such service users are unable to make choices (Peabody et al., 2024). However, minimally- or non-verbal autistic people routinely make decisions about the things they like and do not like: they are the knowers of the activities they enjoy, the things they are good at and that interest them. Despite this, such strengths-based attributes rarely feature in healthcare discussions. This paper focuses on finding ways for autistic people and their families to share this self-knowledge to alter the pervading deficit-focused narrative, showing the child and family perspective, to improve healthcare professionals' knowledge and attitudes and ultimately improve the quality of care provided.

The Digital Storytelling method was developed by Parsons et al. (2021) initially to support young autistic children to share their perspectives and experiences in transition from specialist nursery to primary school. The method involves co-creating a 3–5 minute video with clips and still images with first-person statements attributed to the child. Engaging stakeholders who know the child well and using techniques such as body-worn cameras in everyday settings help to capture the child's perspective as they engage in favoured activities, with the aim of having the audience see the world as the autistic child sees it. The story framework guides autistic people and their advocates through the process of co-creating a strengths-based story that enables the autistic person to show their favourite activities, interests, strengths and skills. Parsons et al. (2021, p.173) argue that they *"offer a very strong challenge to the notion that they [autistic children] cannot express their views and preferences"*.

Inadequate training in autism and LD within the healthcare workforce is cited as an important factor affecting health outcomes and levels of healthcare satisfaction for autistic adults and children with and without LD, and their parents and carers (Douglas et al., 2023). The recognised need for improved training about autism and LD for healthcare professionals, including medical students (Adirim et al.,2021); Azizatunnisa et al., 2024) is reflected in initiatives, notably the National Health Service England Oliver McGowan Mandatory Training in Learning Disability and Autism, (NHS England, 2025) addressing knowledge of and attitudes to autistic people with LD.

In response to the recognised difficulties, and in line with the Core Capabilities Framework (Department of Health & Social Care, 2019) which sets out essential capabilities for staff working with autistic people across their lifespan, [redacted] in the UK developed the Time for Autism (TfA) programme (Dhuga et al., 2022); (Gallaher et al., 2023). This is an innovative mandatory education programme whereby fourth-year medical students visit an autistic child and their family at home three times over the academic year. The premise is that spending time with an autistic child and their family in their home context will improve the medical students' knowledge and empathy, resulting in doctors being equipped to provide a better quality of care for autistic people in their future practice. This model of education has been found to be effective with healthcare in dementia, where poor healthcare attitudes are common (Banerjee et al., 2021); Daley et al., 2023). In the current study, we investigated the feasibility and potential benefits of adding a Digital Stories method within the TfA initiative, to enable the families of autistic children with LD to present a rounded picture of their children, to give medical students a fuller understanding of such children and to familiarise the families with the student visitors pre-visit. This involved three case studies where families in the TfA programme were supported to co-create Digital Stories to share in advance of the first visit from the pair of students allocated to them. In keeping with a double empathy viewpoint, we also asked the medical students to create short videos about themselves to share with the family in advance. We conducted post-visit interviews with parents and students, to inform a thematic analysis of their views on the potential for using Digital Stories in autism training.

Method

The study was approved by the university ethics committee (ref ER/SH656/3).

Participants: The study was advertised to all 110 families and 220 medical students taking part in the TfA programme in 2021-22. Three families with an autistic child and 2 medical students agreed to take part in the digital story project. All children had an autism diagnosis and attended special schools in southern England that required children to have an Education, Health and Care plan.

Procedure:

There were three steps: creating the stories, sharing the stories and interviewing the participants.

Story creation

Families: The researcher (Author1) visited parents at home to talk through the process of co-creating a Digital Story with particular emphasis on how to map the story using guides adapted from Parsons et al. (2021). The researcher gave an example for a family with an autistic young adult with LD. The mapping was designed to elicit 7 types of information:

Spaces; People and interactions at home; Independence and agency; Objects and Interests; Communication and Expression; Support; Skills and interests.

Parents were also given a body-worn camera and memory stick to use. All families were given the option of follow-up visits or email support following the initial meeting.

Students: The medical students were sent the Digital Story guides with brief text examples via email and offered email or in-person support if desired. The reduced list of 5 categories were: Spaces; People and interactions; Independence; Objects and interests; Skills and capabilities.

Story sharing

The stories were produced between 28th July and 6th September 2021. Completed stories were shared according to consent choices using a secure file sharing platform (Box) and secure links were sent to families and medical students in their allocated pairings to view before the first visit. The sharing permissions allowed viewing rights only, not editing or further sharing.

Interviewing

After stories had been shared and the first visit completed, the researcher separately interviewed the medical students and one member from each family (in each case, the mother) over videocall. The interview schedule (Appendix 1) covered the experience of creating the story, including motivation to participate and practicalities of production, feelings when creating, viewing, and sharing the story and experience and thoughts in using the story before the initial TfA meeting. Interviews were transcribed for thematic analysis using an intelligent verbatim method (McMullin, 2023). Author1 conducted initial reflexive thematic analyses for parents and for students, taking a critical realist stance on language and focusing on participants' lived experiences. After familiarisation with the data, Author1 generated initial themes and subthemes. The analysis underwent revisions in several rounds of discussion with Author 4,

ensuring themes were distinct and underpinned by data. The final version was produced after review and comment by all authors.

Consent

Parents and students were asked to give informed consent for participating, creating the stories and being interviewed. There was a further consent procedure for sharing final versions of stories once they had been created, with three different options: no sharing at all, sharing just with the research team and allocated students, or sharing universally. We also supported the parents in gaining assent from the children involved. Consent was also sought from any other person who might appear in the videos: this was primarily other family members.

The authors declare no competing interests.

We first report the characteristics and process for participants and describe the creation and sharing process. We then present a combined thematic analysis of parent and student interviews.

Results

Participant characteristics are shown in Table 1.

Table 1
Characteristics of participants and story creation

Participant	Characteristic of child/ student	# researcher visits	Time period of story-making	Final story length
Family 1	Son, 11 yrs	3	21 days	3.5 minutes
Family 2*	Daughter, 11 yrs	3	18 days	3.5 minutes
Family 3	Son, 7 yrs	1	28 days	3.5 minutes
Student 1	female	0: email guide only	“a few hours”	1:33 minutes
Student 2	female	1: phone call	not reported	1:12 minutes

* Meeting with students was by video, during COVID-19 restrictions.

Four other students were involved in the family visits but did not take part in story-making.

Creation and Sharing

All three families used smartphone images, film clips and wearcam footage. They included a wide variety of activities at home and elsewhere, with a range of people including family members and personal assistants. Each family also included subtitles and favourite music: where this was a commercial song, permission was in each case granted from the licence holder.

The students used their smartphones to make the video independently, using TikTok or other free software for editing. They covered hobbies and interests such as walking the dog and craft activities and used subtitles and voiceovers.

All three families wished to share their stories universally. They also shared the stories with others, notably the focal child, other family members such as grandparents, and in all cases, to staff at the child's school. The two students consented to share their videos with their allocated family and more widely. Two families (F1, F3) viewed a story from one of their two assigned medical students before the meeting. Students visiting F2 did not create a story, so only the family video was shared in this group. All 6 medical students making the visits viewed their allocated family's story before meeting them.

Interviews

The themes and subthemes, and their connections, are shown in Fig. 1. Five themes were specific to parents, three were common across parents and students, and two were specific to students. Quotes are identified as Family (F) or Student (S).

1. Authenticity

Parents felt that their stories had authenticity, both in representing their own lives and in capturing their child's essence.

1.1 "That is our life": conveying family lived experience

Stories illustrated central aspects of family life: *"it captured it to a T, that is our life"* and was an effective way of sharing experiences "*they [students] just got a good sense of our relationship with him"*. This sense of authenticity brought valuable practical consequences for interactions during the visit: "*you're a bit more honest or a bit more free flowing with what you're going to say"*; *"I had a different conversation with them [medical students] than I would have if they hadn't seen a film of him"*. Families valued having students hear their voices: *"it's all about your attitude towards the children and listening to the parents, about what they need"*.

1.2 Capturing what he is: the child's perspective

Families expressed the importance of the film representing their children: "*it's quite easy to capture the essence of [child]; to get a sense of the, uh, humanity in a person"* : *"it definitely captures him to us"*. Watching the stories would help "*to actually see the child behind the name"*. The drive for authenticity extended to the child: "[she] *enjoyed it just because she could be herself".* As one mother noted, the story gives *"a good gauge of his personality"*: this introduces the child as a personality beyond the medical label of a condition.

Making the films highlighted opportunities to show the child's perspective *"[she] told me which bits she wanted to keep… [I asked her] How do you want that to look?"*. This was a particular advantage for some:

"*it's particularly nice when you have a child who is non-verbal because, you know, it's nice how we would think he would like to be portrayed"*.

Parents were reflective and analytical about how they curated and represented their child's experience: *" I tried to do it from [child's] perspective"* - and recognised they might not always get it right: "*I try not to think I know what [child's] perspective is, because I feel like I don't most of the time*"; "*I don't think we're there [getting child perspective] yet"*. Capturing the child's view was vital: "*he just looks like he sort of sails through life….we were trying to get that across because that is a lot about him. So whether it's his perspective, but certainly captures what he is*".

On a more practical note, the small wearcams we provided could immersively illustrate a child's visual perspective but children could be reluctant to wear them: "*we tried to put the… little camera on him, but he wasn't having any of that"*. Parents sometimes filmed from behind the child, gaining the child's visual perspective.

2. A rounded view: Challenges in the context of strengths

Families particularly focused on the contrast between standard reports that highlight difficulties versus the strengths-based approach of the stories: *"if you're going to see a professional person, it's because you've noticed that there's something not right with your child so then that's what they focus on…[it is] nice for them to have a more rounded view."*. Being neuroaffirmative was important: *" [*in standard reports*] you're writing in, in black and white, all their negatives, all their failures, all the things they can't do"*.

Appointments with professional services were perceived to start very defensively, with a felt need to fight for services or to show challenges, whereas the videos were *"an appreciation*". Seeing the positive balanced the general media representation of autism: "*They don't notice you when … the kid's being normal. So therefore a lot of people's perspective of autism is the challenge … they wouldn't necessarily think that there's anything else to him*". Viewing the stories also eased the move to raising more challenging topics: *"when I was talking to them about some of the less positive stuff …, they already had… a feel of how he was, …rounded picture of how he actually is."* ; "*… you could go into the things that are extremely challenging, …because you knew that they already knew that he was a lovely boy "*. Having the positives first enabled parents to be more open about the challenges without fear of creating negative first impressions that might prove enduring. This balance contrasted with a felt need in standard settings to push the positive: *"I'm always really about portraying [him] in a really positive light because he can't talk for himself… so, … with the medical students, I felt [I could] go straight into what actually they could do that would make a massive impact."* .

However, parents also discussed the difficult issue of ensuring challenges were not made invisible: "*I think you would also need to see those breakdowns and those parts when she's not coping and what happens then to understand"; "you're looking at the positives, but you've got to also have the … realism in there as well*".

3. Seeing beyond the differences: Building relationships and differing audience perspectives

Parents were well aware of how a range of different people might view their child, influencing how they might behave around that child. This related both to understanding how different the child can be in an environment that supports them and how different audiences would perceive the story differently.

3.1 Building relationships with the child

Parents felt viewers could get a richer sense of their children as people, seeing beyond the overt differences and understanding how to relate to them better. This included extended family, friends and professionals:*"because of their] lack of understanding … they can't see beyond the differences"* ; "*I don't want people to just work … in order to keep him safe or happy, … I actually would like them to see the relationship that they can get with him*"; "*in the right setting with the right support, this is what they can do*". Because the stories showed everyday activities the children enjoyed, parents hoped this suggested ways of engagement: *"[he] loves people coming into the house, and he likes being around other kids … just likes to go on a trampoline, like their seven-year-old kids"; "you can see that [he] really likes eating out in restaurants… I think if people saw that [story], they would think … actually, you can do that with him"*.

3.2 Audience perspectives

Parents emphasised the varied reactions of different audiences (including themselves) and what different viewers might take from the stories. They spoke frankly about lack of understanding about autism in family and friends, that could make them feel misunderstood and isolated: *"[others] don't have a full understanding of autism and what it means… and, you know, going forward and the implications lifelong… … all they could say, was oh my God, it's so sad and, you try to explain*". The same behaviour, such as spreading food around while eating, could appear very differently in a video showing the full context rather than the bald fact of 'smearing food': "*it's something you hide away…but… a positive thing oh he's enjoying himself*", illustrated effectively by showing the child experiencing a very warm and humorous moment with the father when sharing food. Such moments could come over negatively to others: "*I've got friends when they sometimes have seen it and they are genuinely horrified and really worried about it*". Audience reaction may not always be positive: "*actually it's not [sad], it's really positive, it's quite poignant, it's quite emotional, but... they can't see beyond the differences*".

Sharing a Digital Story with different audiences was seen as helpful: "*I think that's really quite key [watching a story] because … these medical students go to such an extent to understand him … [other people] don't know what goes on at all really or what he enjoys*". Digital stories could also help interactions with wider family, such as a visit from relatives who had not seen the child for several years: "*they should have seen that (digital story) beforehand…cause they wouldn't have been nervous…they could have done with seeing it*". More broadly, the videos could provide "*more understanding around…autism and the problems it generates within the medical service*". Just being seen has a value for connecting: "*it's very isolating often, you know, you don't have everyone wanting to come into your house*". The specificity of a

story to a particular child was also important: contrary to one stereotype of autistic children not wanting close physical contact, one story showed "*he likes physical touch*".

All families shared the stories with school staff, one of whom noted: "*wouldn't that be amazing if we could do that for every child in school"*. This raised a question about what background knowledge might be needed to benefit from viewing: "*for those that don't know … too much about autism I don't know how it would benefit them other than them seeing what she liked, what she gets up to*".

The children themselves were also engaged audiences: one "*particularly liked to look out for himself in the video*." One elder sister, taking the role of the child's ambassador, found the video supporting her view that "*we don't need to fix him*". Another sibling "*like[d] watching it, he found it really interesting*").

4. The most important bit: A reflective and emotional space

Parents spoke articulately about the effects for themselves on co-creating the story: story creation was "*very much…a reflective space (F2);* "*this is probably the most important bit of it to be able to reflect"*. This reflection could have powerful effects: *"if you're in a really dark place, you don't see those positives, do you? And … you can say, well, actually … that child is amazing, we are doing a good job as a family."* Making the story enabled a parent *"to be able to actually notice and make myself notice (the positives)".* Seeing a digital story during the difficult time of diagnosis could have helped *"to get a sense of what can be achieved*", that *"a) … it was still going to be scary, but it would've been less scary, and b) I would have been a bit more hopeful back then and yes now I'm really hopeful"*.

The videos particularly reminded parents of positives: *"You just sometimes can get lost in the day-to-day trials and tribulations…[seeing the story] wow, that's amazing"*; "*when you've got a child with … special needs, you spend such an awful lot of time focusing on the things they can't do…to have something there to go, he can do this … it just sort of just puts a smile on your face*."

Making the stories also prompted thoughts about what is possible given suitable environments: "*you could…encourage something different and see what happens because something different can happen*". One mother noted that she could have created the video without the research support but that talking it over with the researcher and having her positive reaction to the clips "*really helped"*.

This reflection could also engender strong emotional reactions, with tears from one father and parents noting: *"I've got a bit of a lump in my throat because just watching it…it just sort of just puts a smile on your face"; "I watched it on my own first and sobbed… and other family members just said that how lovely it was and how special"*. Two families mentioned keeping and going back to the stories they had made, as a keepsake and perhaps also to look at changes over time.

5. A bridge between families and professionals

Parents emphasised the role of digital stories in building relationships across a range of professional services. A digital story "*brings the parents back into the conversation… you really do know your child best"* and helps start a new relationship: "*you would like to start things very positively with the school given that you're often having to fight for things"*.

One parent felt that showing stories in mainstream schools would enable the community "*to see [the child] as a human being"*. Stories could support recruitment and induction of personal assistants: "*I would like them to see what the relationship that they… can get with him"*, and as a pointer to future possibilities: "*it might not be like this when you meet him but … it might be where you get to*" .

This felt important for health settings. Seeing a story means "*[medical professionals] haven't got the stress of trying to get a sense of him….Give him a room where he can do this [using his interests]… then he'd be calmer… not as likely to want to go and pinch someone in the bed opposite"*. This could have much longer-term implications: "*[creating a digital story] could potentially be the difference between him being in the work force and not, or being in a college setting and not"*.

Stories could support mutual acceptance in relationships with professionals: *"they would be really helpful because we took over a year … to get [child] comfortable with the dentist. And so, it would probably be good that the dentist would be comfortable with [child]"*; *"I think some… professional educational [psychologists] can be quite defensive because they've had lots of run-ins … with parents … and I think actually this would help"*.

One parent reported a related bridging effect in watching the student videos, seeing them as individuals beyond their medical role: *"knowing that someone lives somewhere, they don't live in the hospital and they have pets"*.

The following three themes spanned both parents (marked P) and medical students (marked S).

6. A family behind him: Explicit and implicit information

Both parties insightfully saw that the videos provided more than the explicit strengths-based story: *"you can see like family dynamics […] and the things that aren't explicitly stated"* (S) and gave a glimpse into a home setting: "*the hospital … that's a very different setting to how someone is when they're at home and they're relaxed and … their whole family around them*" (S).

Watching closely and reflectively yielded a wealth of implicit information about children in their family context. For example, a clip taken from behind one child's head gives an immersive sense of his huge enjoyment in feeling the wind, but only implies the support needed for the shot to happen: *"it's a positive story, but actually the challenge is sort of there, you know, and him standing on the chairs…*"(P); *"we put strategies in place to try and minimize the effect of [struggles] … but it has to be like a military operation. there's never any spontaneity and it's hoping that shows through (P).* This suggests a need for acknowledgement and appreciation of how much families need to do to support their children.

The stories also illustrate relationships within the family: *"It gives a bit of a flavour of what the parents are like as well, which I think is nice"* (P). This could support professionals to interact more sensitively: *"if a health professional …could see …that dad clearly has a really good relationship with him, so I'll ask him how can I make [child] feel settled"* (P).

7. Looking in a different light: The power of video over text

This theme highlighted the multiple differences between information in video versus text. Both parents and students cited the special power of video to show the child in "*a different light" (P)*. Parents contrasted video with the usual experience of finding their child "*hard to explain in words*"(P) in a written report while students emphasised their preference of video for learning: *"with a video… you're actually kind of paying attention, I think the information… goes in a bit better…I think it's far more effective."* (S); *"I think you get a much better idea of someone…, who they are as an individual, from a video."* (S).

The density and immediacy of video compared to text was enhanced, as written reports could be skimmed: *"[video] definitely more useful, a written report …it tells you like about the bare bones, … you get so much more from seeing the video."* (S); *"we have so many things to read all the time, that we end up skim reading …whether we want to, or whether we don't"* (S).

Parents also understood the special impact of video: *"if the key things about a written report could be put into a video … maybe they'd look at it in a bit of a different light because they're reading lots of reports… it can become, not very personal"* (P), with the awareness that: "*a written report […] can be copied and pasted, frankly, from another child of another parent"*(P).

Seeing a memorable story during medical training could have lasting impact: *"how important it is that they do this now, because …they might … only think of [child] in 25 year's time and …they'll have more responsibility in the work that they're doing … and they might remember" (F).*

Video stories could also be archived to document change: *"if you were able to do, this is what she was like at 13 and this is what she's like at 18."* (P).

Parents felt video avoided the danger of misinterpretation in written reports in terms of both negative judgements: *"you see a little boy in it, more than like someone on paper that looks a bit scary"* (P) and in establishing the credibility of parents reporting challenges: *"professionals not just thinking the parents are exaggerating…making it out to be worse than it is, you know parent blaming"* (P).

Video could provide evidence more compellingly than words: *"parents' [spoken] judgment it could be a little bit blurred in that, 'Oh, he was really happy' and they [a professional] might say, Was he? Was he?" (P); "actually seeing him relax in the water, it's different seeing it…I think it's just a really good way of doing it"* (P).

The digital story method might also present information *“in a … much nicer way than writing it down in an email or a form [but] …everyone … would know that life's quite challenging”* (P).

Video might also engender greater empathy:*“[on paper] it's hard to really connect with it.”* (S); *“I think you get a much better idea of … who they are as an individual, from a video”* (S). For students in particular, this contrasted with their academic learning about autism: *“it's all been very academic, these things you’re looking for and here's the diagnostic criteria”* (S), especially being able to see people in context: *“we spend all our time learning about things in classrooms and then we're … in the hospital and that's a very different setting to how someone is when they're at home”* (S).

Video could also be more powerful to change views: *“I think when it's written, there's almost like that divide of …you can't really connect with the person…I think it really does change your ideas.”* (S).

8. An even playing field: Reciprocity and familiarity

Both families and students noted that the stories functioned to introduce each party before a visit that might otherwise cause some anxiety. This was seen as levelling potential inequalities in power between them.

8.1 Reciprocity: something in common

All three families provided stories for the students, who watched them. Two of the families saw only a single student story from the visiting pair, and one had no student story and a meeting via video call rather than in person. This provides a potential contrast between families. Both families and students mentioned the value of stories being mutually exchanged. The two families viewing a student story recognised reciprocity in sharing: “*we've got something in common … it puts you both on an even playing field” (P).* As one parent explained: *“it's like, I know a bit of something about you, you know a bit of something about me and it’s a conversation, but without necessarily being together.”* (P). A student also highlighted reciprocity of exchange: “*[the kids] have to meet a stranger too, and they’ve got to talk about all their experiences and the parents have to do it and they want to know who you are… you have like files … of notes and … this person’s medical history …it's a bit unfair*”(S). Sharing was important given that “*you're going to be quite personal about your life, particularly in the medical profession …you can sometimes feel a little bit intimidated…. you're not getting a complete stranger” (P).*

However, where sharing was not reciprocal, families found other ways to get to know students: one parent “*felt like I knew [student] really well because I'd seen her video” (P*), but noted the other (non-filmed) student was more vocal at the visit. Similarly, a student whose partner did not make a video reflected that: “*I don't really think it made a difference because … she's got a much bigger presence than I do in person*”(S). Student stories and meetings provided two different ways of getting to know the students, possibly suited to the students’ own preferred communication styles.

8.2 A sense of familiarity

Both parties valued gaining some familiarity before a visit:"[parents can] *feel like there's a really big gulf between them and professionals… [story sharing] can really help bridge that gap*" (P). Sharing could also benefit the child: "*[sharing] is a positive…you're telling your child who this person[student] is*"(P), although one parent felt that the initial meeting, via video call, made it harder for her child to engage with the students than being in person.

The students felt advance information about the family could support communication: *"the conversation … was facilitated by …familiarity, ….it wasn't this complete stranger who's then coming in asking all of these questions."* (S). Familiarity had consequences for reciprocity and honesty, providing "*a different conversation*"(P): "*you're a bit more honest or a bit more free flowing with what you're going to say if they don't feel so unfamiliar to you*" (P).

The final two themes arose from student interviews.

9. A starting point: Familiarity and structure

Students saw the family digital stories as providing a valuable grounding to a better understanding of the child at the visit itself: *"just turning up to a stranger's house when all you have is a piece of paper is a bit nerve-racking"* (S);*"he's quite a bit different …and I thought it was like a really good introductory video"* (S); *"it was just like, oh, I remember seeing this in the video"*.

This stories also helped structure the visit: *"one of the things that came up on video was about communication and so we were then able to ask… is there anything that we need to be aware of in terms of communication … before we, you know meet him"*;*" it helped us focus our questions… you don't want them [parents] to have to explain over and over again"*;*"it was a good starting point before … the meeting, to think about what … we wanted to get out of it."*.

Seeing family stories also helped provide basic background for the students: *"the person [student partner] … had kind of no experience of ever meeting anyone with autism and … seeing that video … helped shape a picture of … this is what this will look like, and this is what I need to be aware of, and how that must be for mum and thinking about questions, so I think it definitely does work"*.

10. Professional boundaries

A strongly-expressed aspect distinctive to the students' story creation was the challenge relating specifically to professional boundaries: "*there is some fear about how much you should share … a bit of nervousness around that… it's sort of tricky, (you) could be looked down upon… that's not part of your role and that could come from both sides [families and tutors]"; "there's like boundaries that you …don't want to cross …and there's a lot of professionalism issues. I think that would be a concern*".

In response to this challenge, both students suggested student videos could relate more to their professional role and the physical spaces that families might visit during an appointment: *“I don't think too many people would mind making a brief video ‘cause you don't have to include lots of personal things”*; *”it would probably be you know, here I am, here’s where I work, you know, this is what I look like, here’s where you’ll go”*.

Guidelines on creation and use could help: *“so there probably would have to be like guidelines and like what you can't say”*, though *“it's always up for a bit of a discussion because … social media presence …[has] increased at a more rapid pace than any guidelines could catch up with”*.

Nevertheless, making stories informal could retain the value of empathic connection: *“keeping it formal would be too much of a barrier. I don't know what the benefit then would be… because you're not really improving empathy or a connection or alleviating anxiety in doing that.”*.

Students also noted the obstacles of self-consciousness and time. One student expressed strong initial self-consciousness about making her own—“*Oh God I don't want to video myself! “* and some unfamiliarity or discomfort with social media and technology: “*there was a bit like nervous giggling throughout”*. However, this was overcome: *“I found the experience really wholesome, and it was really like fun to do”*, and could bring positive outcomes: “*I was quite proud of what it [Digital Story] was.”* .

Both students experienced time constraints in making their video, particularly during the summer. They felt students generally might think: *“I've got other things going on, I don't got time for that or you know, don't see the value in it”*. However, understanding the purpose of the videos could mitigate this constraint: “*I think if they don't understand what it's for then you probably wouldn't put much effort in and … you might kind of miss the point*.”

Discussion

Our study with 3 families of autistic children with learning disabilities and 2 medical students who visited them as part of a training programme showed that it is feasible and potentially powerful for families to use the Digital Stories method to co-create video narratives representing their children in a way that medical students found helpful. The story content has potential implications for the design and delivery of healthcare: families cited some important benefits of the creation process, and a range of audiences who might benefit from viewing them. Having medical students create stories also had value but posed challenges for professional boundaries. Our findings provide new suggestions for how and why such narratives might be developed and used in healthcare. We review first the lessons learned from the family stories, then from the student stories.

All themes in our analysis relate in some way to presenting an improved understanding of autistic children with LD. Families understood the real dilemma of authentically representing the perspective of children who do not communicate in words, even despite their own lived experience and understanding of their child. However, they perceived that videos could portray their lives more fully than a written

report. The affirmative, strengths-based stance of the stories were seen as very helpful. Importantly, this meant that families felt more able to discuss the challenges they experienced without feeling that they were only presenting a negative picture. However, there was a fine balance between showing positives while also appreciating the real challenges parents can face in supporting their child's health needs adequately.

Families noted that the videos could help viewers understand how their children are when in a supportive environment, suggesting ways to design their particular setting (e.g. hospital, school). There were clear examples of how the videos could provide more tailored healthcare, e.g. by bringing in a child's special interests and adapting to their communication patterns. This better understanding could engender potentially far-reaching changes, e.g. in planning the best physical accommodation for a child in hospital, and potentially across a much longer time frame: as one parent said, "*the difference between him being in the work force and not, or being in a college setting and not"*.

The power of video over text was a strong theme. Seeing a child in context gives more information and impact than can be conveyed in words, showing the child's wider network of relationships and community. Participants noted the immediacy and directness of video, which could support greater empathic understanding and provide clear evidence of children's essence and lived experience. As one mother said, *'it changed the conversation'*.

Students found videos a more engaging way to learn than text. Both students and parents noted how text in standard written reports could be skimmed over, or copied and pasted between reports, whereas the videos were individual and showed the family's own voice and perspectives. Students appreciated how the stories helped them understand more vividly how their interactions with this group could be made more supportive. Such videos, if shared, potentially provide a valuable archive that reflects the individuality of autistic people along with common issues for healthcare professionals to consider when constructing improved access to services.

The process of making and watching the stories was itself important. Co-creating video was, in one mother's words, "*the most important bit: a reflective space"*. This was particularly powerfully expressed given the "*day-to-day trials and tribulations*" and the sense of having to constantly fight for resources. The video narratives provided ways of standing back and recognising the child's strengths anew and seeing them from their own perspectives and agency: "*now I'm really hopeful*". One parent noted such stories could have been particularly powerful at the time of her child's diagnosis when she felt that "*everything had stopped*". This sense of narratives representing a moment in time was also raised when considering the stories as being a way to celebrate a child, a keepsake and an archive to document changes over time. Unsurprisingly, viewing the films could engender strong emotion.

Parents were thoughtful about whether they truly understood their child's perspective. There are complex issues about what constitutes true co-creation with the children involved, who used little spoken language. Families thought hard about how they might faithfully reflect their child's perspective, and story creation provided a powerful space for such reflection, enabling families to gather video of the

child freely engaging and interacting with people, things or activities as evidence of these preferences and responses.

Two themes emerged specifically for the students. Seeing the family stories in advance was greatly appreciated in preparing for and structuring the visit, as well as calming any anxiety. However, students encountered obstacles in creating their own videos, reflected in the fact we collected only two videos from a potential six. This was partly due to time restriction and lack of awareness of the potential value for the family, but the main issue related to the felt need for student doctors to maintain strong professional boundaries. Families expressed some interest in 'meeting' the students via the student story beforehand and felt the student stories bridged a gap or levelled the power in the relationship. However, a very brief video, perhaps just showing the student in their medical setting, might provide a sufficient introduction for the parents while providing enough professional distance for the students. Also, meetings being in the family home could add a greater sense of control and equity in the parents, so the asymmetry in sharing may be less important than if the meeting had been in a clinic. Having 'virtual tours' of clinics for families to view, termed 'We are…' stories for school settings (Parsons et al., 2023) could further support improved healthcare experiences.

Our study was a pilot to investigate the feasibility of the Digital Stories approach in healthcare and has limitations to be addressed by further research. The thematic analysis reflects the analysts' perspectives on parent and student responses. We had a small sample and participants were those who had time, resources and motivation to be involved, and to share their experience generously. Given the positive response to the Digital Stories approach, for family stories especially, their wider use has potential value but there is a challenge in supporting families to do this. For this project, a paid researcher supported the families as needed. There was wide variation in the support needed (see Table 1). Families often had existing video and photographic material documenting their lives and some had familiarity with editing techniques using their own technology (notably smartphones). However, many families will not have such time or resources. Providing this facility at large scale has many challenges. However, digital stories provided a space for an under-represented perspective to be made visible, showing a positive picture of strengths in preferred settings and warm interactions with the family in authentic contexts for people who can often experience very negative responses when out in public. The opportunity created for reflection and the positive emotions elicited were unanticipated effects that suggest such narratives could be a powerful means of seeing unrepresented perspectives, increasing client voice in health service design and finding new ways to make healthcare more accessible for autistic children with learning disabilities and their families. Such methods could be a powerful and engaging addition to planning documents such as health passports and a compelling educational resource for professionals.

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Figures

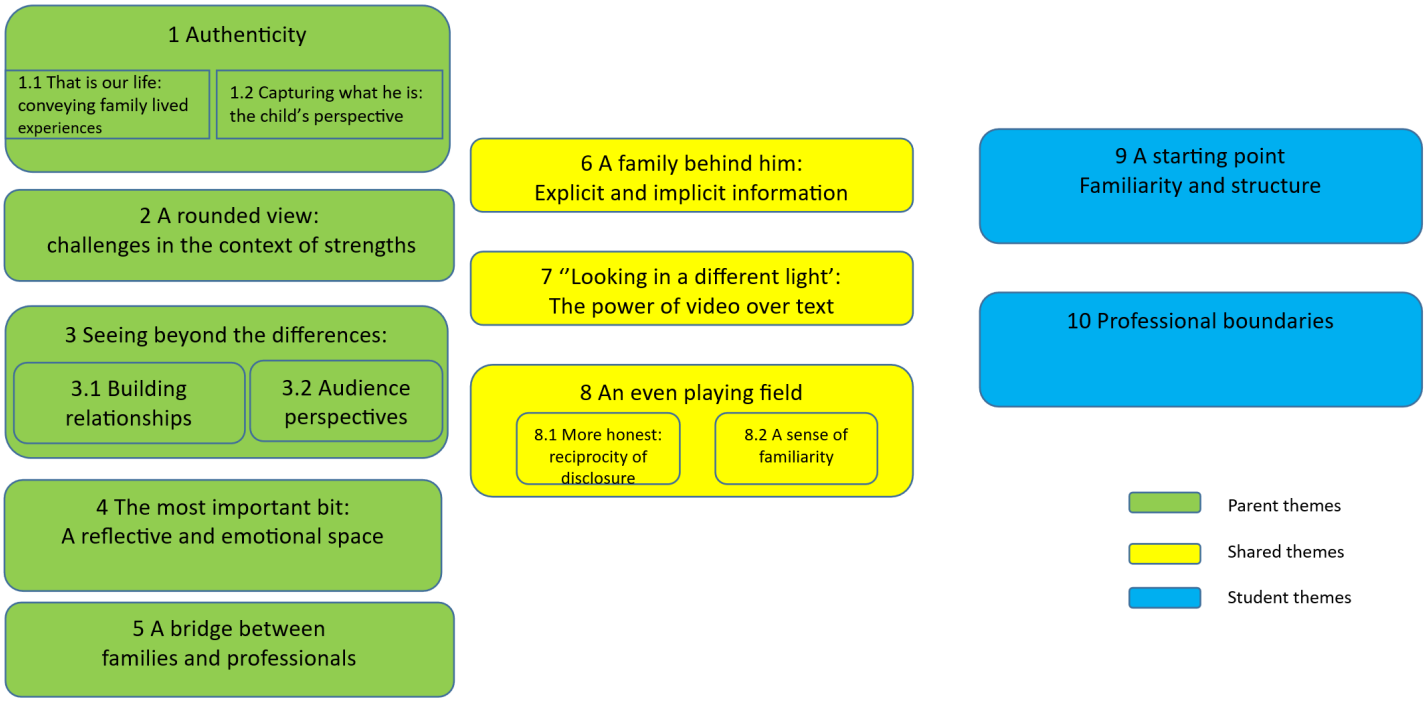


Figure 1

Diagram of themes from family and student interviews

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- Appendix1.docx