

DECEMBER 2021

MONASH HEALTHCARE INNOVATION SUMMER SCHOLARSHIPS

Project Aesop



Monash Partners
Academic Health Science Centre



**MONASH
YOUNG
MEDTECH
INNOVATORS**

Project Lead: Uni Han¹

Clinical Champion: Dinah Humphries²

1. Monash University

2. Monash Children's Hospital

Executive Summary

PICO: In paediatric patients with autism spectrum disorders and developmental disabilities, do digitally mediated social stories decrease periprocedural anxiety, maladaptive behaviours, and adverse clinical outcomes compared to traditional paper-based social stories?

Project Aesop's mission is to create an **accessible digital platform** to **deliver social stories for hospital and healthcare settings**.

We know it only takes **one negative experience** within the healthcare system for children to develop anticipatory or preprocedural distress.[1,2] The paediatric population, in particular paediatric patients with special needs, form an **especially vulnerable group** and are predisposed to developing posttraumatic stress disorders.[3] Importantly, it is also **not only short-term health outcomes**, but **long-term health outcomes** that may be impacted.[3] With the COVID-19 pandemic and the disruptions this has created in our health system and our daily lives, the ambient anxiety experienced by children has skyrocketed. Therefore, an **increasingly broader demographic of paediatric patients** may also benefit from the use of social stories.

Paper-based mediums do not allow for easily portability or accessibility. Existing digital platforms and applications possess both content and design issues. A social story is **more effective the more personalised** to the **individual** it is.[4, 5] A digital solution which allows for the **creative use of technology** and embodies thoughtful design decisions that allow for maximal user personalisation, while adhering to accessibility principles that **consider individual needs, preferences and abilities, developmental stage, and the various cognitive, sensory, and perceptual** challenges faced by children with autism and other developmental disabilities is needed.

We also know that the gap in outcomes for adults with disability and complex health needs begins to widen from childhood.[6] Most importantly, we need to continue to support the development of **safe, inclusive and positive interventions** for create more **equitable** healthcare systems for vulnerable populations.

Objectives

- ☐ To build a solution that increases **accessibility to social stories** and is useable for individuals on the autism spectrum or with intellectual or other developmental disabilities, as well as health professionals, support workers, families, carers, educators, and other stakeholders.
- ☐ To build a solution that equips all parties involved in the care of children with additional needs with a way to access and deliver a **comprehensive suite of high-quality social stories** out of the box.
- ☐ To build a solution that leverages the **advantages** of a **digital medium** to increase the **efficacy** of social stories.
- ☐ To build a solution with the potential to be **widely adopted** by **health networks and institutions**, in particular Monash Health.

Stakeholder Map

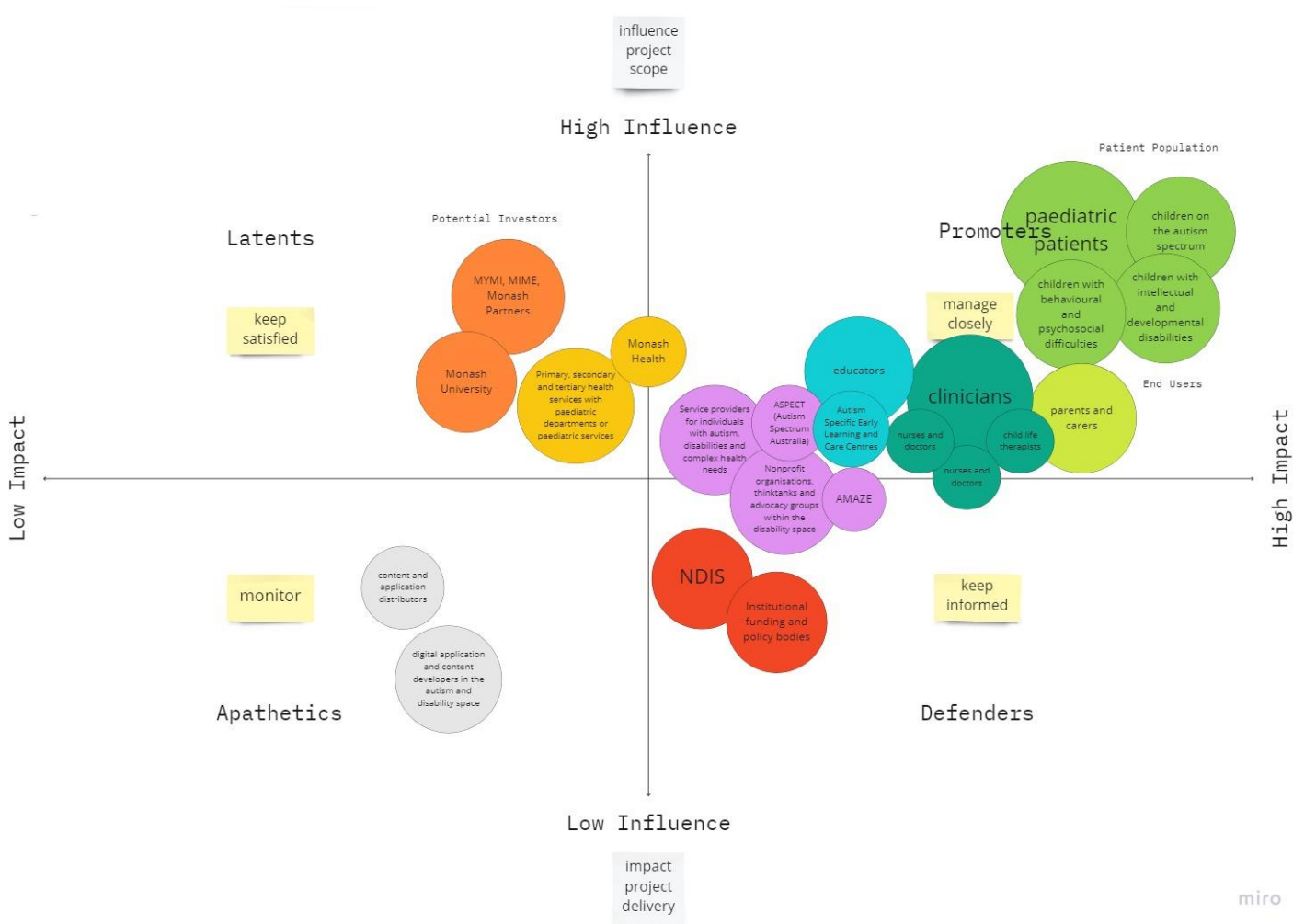


Figure 1. [Stakeholder map depicting key stakeholder groups and subgroups plotted by influence and impact.](#)

Gaps Analysis

Existing Solutions	Gaps in Solutions
Applied Behavioural Analysis (ABA) ABA is considered an evidence-based best practice treatment. It consists of an umbrella of behavioural therapies which utilise principles of operant and classical conditioning and aims to increase language and communication skills and decrease problem behaviours in children with ASD.	- Not accepted by many individuals with autism, and their families and carers. [7,8] - Not aligned with principles of acceptance and inclusion of neurodiversity and neurodiverse individuals in our society. - Attempts to fix, rather than understand behaviour.
Digital applications for preparing children for medical interventions and procedures Okee is a free mobile application designed by the Royal Children's hospital to prepare children for medical imaging. It contains a number of gamified and animated elements.	- Not built with the additional needs of individuals with developmental disability in mind; does not transmit information in a disability friendly way. - Scope of app is narrow and only focuses on medical imaging. - Focuses on exposure rather than education and step by step preparation.
Social Stories (paper-based medium) Social scripts or stories are arguably soft interventions in that they are not a targeted therapy for autism. Rather, they aim to prepare individuals for difficult situations or processes or to teach certain skills. As narratives and social learning tools, they aim to describe the literal concrete facts of a situation; the who, what, when, where and why questions for individuals with autism.	- Lack efficacy where they may be more effective at reducing maladaptive behaviours than in teaching skills or behaviours.[9] - Reduced efficacy where visual or textual content is not personalisable, a social story may not always be engaging or relatable for each child. - Lack of time, abilities or resources for clinicians and other stakeholders to create their own individualised social stories. - Decreased accessibility and portability.
Social Stories (digital mediums)	- Lack of leverage of potential advantages of multimedia and digital platform to enhance the efficacy of social stories and their ability to meet the needs of a heterogenous population. - Lack of accessible design, poor UIs - Lack of codesign; existing digital platforms built with little or no input from individuals with disability.

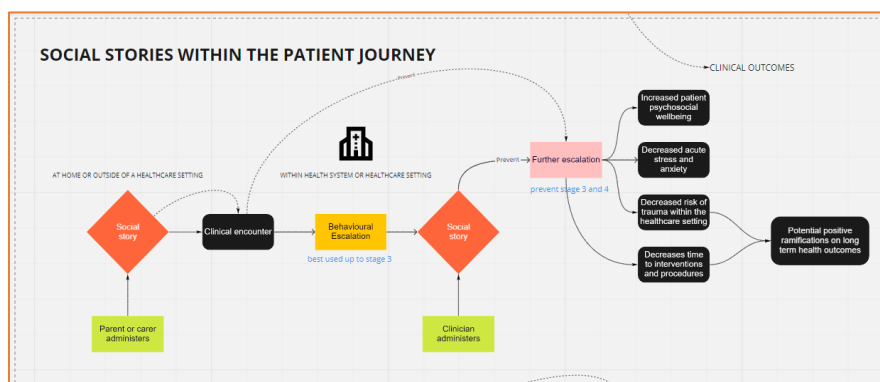


Figure 2. [Process diagram depicting the critical timepoints for administering social stories within the patient journey](#)

Quantitative Research

Background

Children and teenagers with autism spectrum disorders and other developmental disabilities have high rates of chronic comorbid conditions and are up to 10 times more likely to be admitted to hospital for medical illness.[10] While they have an increased average number of episodes of hospitalisation and increased average lengths of these episodes, they often do not receive the same quality of care.[11,12] Behaviour and communication difficulties are also significant barriers to children with ASD and developmental disabilities from accessing hospital care.[13, 14]

Clinical Gaps and Needs

Even minor medical procedures such as finger sticks and venepunctures can cause significant pain and fear in children.[15] However, research has shown that even for the general population of paediatric patients, interventions to reduce pain and distress are infrequently used.[16] In addition, children with ASD and developmental disabilities possess less resilience and fewer coping strategies. Innate sociocognitive features of developmental disabilities increase the susceptibility to various aspects of the medical environment. For example, children with ASD also often struggle with sensory sensitivity and altered sense perception in not only the five senses (sight, touch, hearing, smell and taste), but also internal senses such as proprioception (the sense of how one's body is oriented in relation to one's surroundings and moves through space) and introspection (the ability to sense and examine one's own mental and emotional processes.) Sensory and information overload are important considerations when it comes to preparing paediatric patients for procedures. Clinicians are often not equipped with the resources to adequately prepare a child with these needs. [13,14]

Health Outcomes

Reducing distress is crucial to avoiding an increase in anticipatory anxiety before subsequent procedures, which can amplify the perception of pain and contribute to an escalating cycle of fear and distress surrounding any future medical encounters.[1] Where there may be significant distress or communication difficulties, children with developmental disabilities are prone to aggressive or self-injurious behaviour.[15] Behavioural escalations may affect the delivery of healthcare in time sensitive situations. De-escalation may take a significant amount of clinician time and also hospital resources. In the setting of challenging behaviours, chemical sedation and even mechanical restraints may be used.[17] These are undesirable for individuals with disability, parents and carers and should be the last-line resort of clinicians. Preventing distress is also important for reducing rates of iatrogenic trauma and harm. Compliance, adherence and accessibility affect the ease at which an individual is able to access the health system, and more importantly receive quality care, all which are determinants of long-term physical and mental health outcomes and the psychosocial wellbeing of individuals with developmental disabilities and their carers and families.[18]

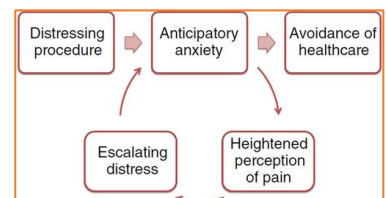


Figure 3. Long-term impact of distressing medical procedures on children [1]

Efficacy and Utility of Digitally Mediated Social Stories

All children should receive preparatory information prior to medical intervention or hospitalization.[19] Social stories are widely used and relied on by members within the autism and disability community.[20] Ease of access and dissemination of these stories would be better achieved through a digital platform. Today's children are digitally native, and this does not exclude children with developmental disabilities. In a survey of 80 parents and carers of children with ASD, 50% of parents indicated that their child understood new information or instructions best through communications tools such as picture exchange communication systems or an electronic device.[21] A number of studies have shown that digitally mediated social stories have the potential for increased efficacy in minimizing adverse behaviours and for decreasing acute anxiety.[22-25] Emerging research has also explored the advantages of using multimedia in social stories; from employing videos and audio to enhance social stories, to borrowing principles from music therapy and setting social stories to music.[26-29] A digital solution which may allow optionally access to multimedia that is able to deliver information in a way that is suitable for neurodiverse children may increase the comprehension abilities of children who are more advanced developmentally, while still catering towards the needs of children with less advanced comprehension abilities.

Qualitative Research

We were able to interview a number of clinicians; 3 clinicians (1 speech pathologist and 2 child life therapists with a background in early childhood education), 1 representative from ASPECT (Autism Spectrum Australia), the largest service provider for individuals with ASD and 1 community member with a background in volunteering with children with additional needs.

Why digitally mediated social stories?

Enhance a sense of agency for the child:

"they have their headphones... they have control over what they hear and see, it's their world"

Allows for better education and better preparation of the child:

Children may feel better prepared where they "hear things like sound, see an actual visual of bed moving, see a tourniquet being clicked on, actually visualise rather than rely on imagination"

May be able to adjust content better to individualise for developmental stage and comprehension abilities:

Some children may respond better to a "very basic picture and visuals", others might like to "interact or have videos", whatever might facilitate an appropriate level of "symbolic understanding"

Increased accessibility of preprocedural preparation for patients:

Useful "when a child is bedridden" and "when you can't physically take a kid to look at or experience the MRI"

With COVID, "more children are not attending preadmissions clinic", social stories are a good resource to provide to families prior to admission

Increased accessibility for clinicians:

"there's real limitations with hard copies of things"... it's "hard to get all the resources you need together"... "sometimes you have two minutes with a child before they are sent off to their procedure"

"the iPad is a big part of our existing workflow"

Facilitates communication between neurodiverse and neurotypical minds:

where communication difficulties may be a major stressor, it is important to get "down to their level" and to build a "bridge into their world"

Delivers information in a developmentally appropriate and disability friendly way:

Regarding Okee application:

"for kids who aren't necessarily neurotypical it's too much information" and "too confusing or abstract at times"

Delivers information effectively where there may be cognitive or sensory overload:

Social stories are "not always just useful for kids on the spectrum, sometimes they work just for an anxious child who needs the right words"

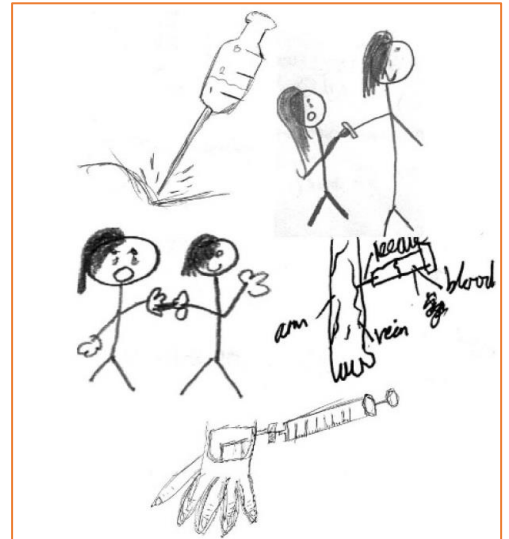
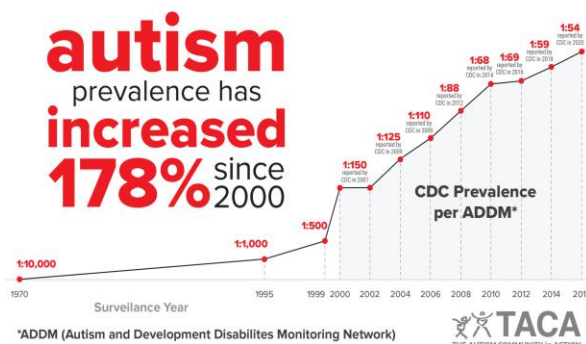


Figure 3. Children's drawings of venipuncture. Children emphasize the size of the needle and syringe, the emotional impact and the physical invasiveness of the procedure.[30]

Business Model and Market Analysis

ASD is currently the largest primary disability category for the NDIS.[31] The prevalence of ASD is increasing across all age groups, in particular in children aged 5-14, and it has now surpassed rates for children with well-known conditions such as cancer, Down syndrome, and spina bifida.[32] Approximately 7.4% (329,000) Australian children aged 0-14 have some level of disability, with the most common disability types being intellectual (4.3%) and sensory or speech (3.2%).[33] Approximately 80,000 children also have some degree of psychosocial disability.[33]

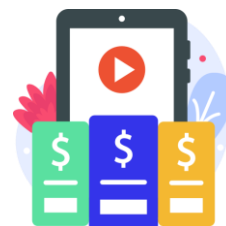


Monash Children's Hospital



The COVID-19 pandemic has revealed the cracks and gaps within our healthcare systems. The changes to the healthcare system as whole; the widespread implementation of PPE and masks, pre-emptive COVID testing and strained resources inherently increase the difficulty of delivering healthcare. Due to the pandemic, many paediatric patients may not attend preadmission clinics, where they usually receive information to help them prepare for medical interventions and procedures. In the acute care setting, it is also imperative to maintain high turnover and efficiency while providing patient-centered care. Therefore, this solution has the potential to be adopted by primary, secondary and tertiary health services involved in the care of paediatric patients. With a customisable digital platform developed, this may be attractive for health networks as they can create a centralized platform for social stories tailored specifically for their facilities.

Our solution possesses scalability due to the ease of adaptation and implementation of mobile applications into existing workflows. Mobile devices and tablets are commonly used by clinicians and allied health teams and are also ubiquitous amongst the general population of end users. No specialised training is required. There are minimal barriers for entry into the market, given the lack of competitors and high-quality solutions that exist. As this software solution does not meet the criteria defining a medical device, there are very minimal clinical or regulatory hurdles.[] Furthermore, it is not only children who may potentially derive benefit from this digital solution. With the content and digital platform developed, it does not take much to implement minor adaptations in order to deliver these resources to the adult population, for whom social or visual stories continue to be an important tool for assisting those adults in navigating the complexities of institutions and systems that are not built for their needs. With a digital solution, it may also be easier to address the needs of diverse populations. For example, for culturally and linguistically diverse populations, it may be easy to allow for a feature that changes the language of which the story is written in.



Where the fiscal burden for parents and carers is already high; cost barriers and maintaining accessibility for these stakeholders is a concern. The price charged to individual users would either be none or minimal and a one-off payment. In order to support the ongoing costs of application distribution, maintenance and development, it may be feasible to employ a subscription-based model for healthcare providers and other large for-profit institutions who may be interested in this digital solution. Other significant costs may include the costs of consultancy services in the co-design process, and any charges associated with the development of visual or textual content for digital social stories. It may also be possible to attract philanthropic funding to cover these additional operational costs. Indeed, existing solutions (Okee, free mobile application developed by RCH) allow for donations to be made from within their application.

Our Team



DINAH HUMPHRIES

Clinician Champion

Child Life Therapist
Early Childhood Advisor
and Consultant
Monash Children's Hospital

Dinah Humphries is a child life therapist at Monash Children's Hospital and has been working with children and families in various roles for over 20 years. She is also a registered music therapist and enjoys sharing her love of music with children. Dinah has a Bachelor of Music and Graduate Diploma of Education and is passionate about the importance of advocating for children in healthcare and education settings.

Dinah is committed to this project as it would provide a tool to assist professionals and families in advocating for and empowering children to be at the forefront of their own healthcare journey.



UNI HAN

Project Lead

DipLibArts (Philosophy),
BMedSci (Hons)
BMedSci/ MD Student
Monash University

Uni Han is a fifth-year medical student. She has a keen interest in child and adolescent mental health.

With this project, she hopes she can help deliver resource that equips clinicians to deliver better healthcare, and that facilitates for parents, carers, and individuals with developmental disability safer and more positive experiences within the healthcare system. She believes that in order to achieve more equitable health outcomes and create more equitable health systems, projects such as these provide a small, but important stepping stone for members of a vulnerable and marginalized community.

References

1. Carmichael N, Tsipis J, Windmueller G, Mandel L, Estrella E. "Is it Going to Hurt?": The Impact of the Diagnostic Odyssey on Children and Their Families. *J Genet Counsel*. 2015 Apr;24(2):325–35.
2. Hands C, Round J, Thomas J. Evaluating venepuncture practice on a general children's ward: Christopher Hands and colleagues investigated the level of distress for children undergoing venepuncture in hospital, and assessed whether there is scope to improve staff training and other aspects of managing the procedure. *Paediatric Care*. 2010 Mar 2;22(2):32–5.
3. Forgey M, Bursch B. Assessment and Management of Pediatric Iatrogenic Medical Trauma. *Curr Psychiatry Rep*. 2013 Feb;15(2):340.
4. Mintz J, Branch C, March C, Lerman S. Key factors mediating the use of a mobile technology tool designed to develop social and life skills in children with Autistic Spectrum Disorders. *Computers & Education*. 2012 Jan;58(1):53–62.
5. Alotaibi F, Dimitriadi Y, Kempe A. Perceptions of Teachers Using Social Stories for Children with Autism at Special Schools in Saudi Arabia. *Journal of Education and Practice*. 2016;7(11):87.
6. Krahn GL, Walker DK, Correa-De-Araujo R. Persons With Disabilities as an Unrecognized Health Disparity Population. *Am J Public Health*. 2015 Apr;105(S2):S198–206.
7. Kirkham P. 'The line between intervention and abuse' – autism and applied behaviour analysis. *History of the Human Sciences*. 2017 Apr;30(2):107–26.
8. Devita-Raeburn E. The controversy over autism's most common therapy [Internet]. *Spectrum | Autism Research News*. 2016 [cited 2021 Dec 9]. Available from: <https://www.spectrumnews.org/features/deep-dive/controversy-autisms-common-therapy/>
9. Johnson CE. The effectiveness of social stories on children with autism spectrum disorder: A literature review. James Madison University; 2015.
10. Bebbington A, Glasson E, Bourke J, de Klerk N, Leonard H. Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983–1999: a population-based cohort study. *BMJ Open*. 2013;3(2):e002356.
11. Lokhandwala T, Khanna R, West-Strum D. Hospitalization Burden Among Individuals with Autism. *J Autism Dev Disord*. 2012 Jan;42(1):95–104.
12. Bultas MW. The Health Care Experiences of the Preschool Child With Autism. *Journal of Pediatric Nursing*. 2012 Oct;27(5):460–70.
13. Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, et al. A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *J Autism Dev Disord*. 2019 Aug;49(8):3387–400.
14. Saqr Y, Braun E, Porter K, Barnette D, Hanks C. Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. *Autism*. 2018 Jan;22(1):51–61.
15. Duerden EG, Oatley HK, Mak-Fan KM, McGrath PA, Taylor MJ, Szatmari P, et al. Risk Factors Associated with Self-Injurious Behaviors in Children and Adolescents with Autism Spectrum Disorders. *J Autism Dev Disord*. 2012 Nov;42(11):2460–70.
16. Fein JA, Zempsky WT, Cravero JP, Shaw KN, Ackerman AD, et al. Relief of Pain and Anxiety in Pediatric Patients in Emergency Medical Systems. *Pediatrics*. 2012 Nov 1;130(5):e1391–405.
17. Menon K, Baburaj R, Bernard S. Use of restraint for the management of challenging behaviour in children with intellectual disabilities. *Adv Mental Hlth Intell Disabil*. 2012 Mar 2;6(2):62–75.
18. Vohra R, Madhavan S, Sambamoorthi U, St Peter C. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*. 2014 Oct;18(7):815–26.
19. 1. Emerson ND, Bursch B. Communicating with Youth about Pain: Developmental Considerations. *Children*. 2020 Oct 15;7(10):184.
20. Green VA, Pituch KA, Itchon J, Choi A, O'Reilly M, Sigafoos J. Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*. 2006 Jan;27(1):70–84.
21. Kopecky K, Broder-Fingert S, Iannuzzi D, Connors S. The Needs of Hospitalized Patients With Autism Spectrum Disorders: A Parent Survey. *Clin Pediatr (Phila)*. 2013 Jul;52(7):652–60.
22. Vandermeer J, Beamish W, Milford T, Lang W. iPad-presented social stories for young children with autism. *Developmental Neurorehabilitation*. 2015 Mar 4;18(2):75–81.
23. Ying KT, Sah SBM, Abdullah MHL. Personalised avatar on social stories and digital storytelling: Fostering positive behavioural skills for children with autism spectrum disorder. In: 2016 4th International Conference on User Science and Engineering (i-USEr) [Internet]. Melaka, Malaysia: IEEE; 2016 [cited 2021 Dec 15]. p. 253–8. Available from: <http://ieeexplore.ieee.org/document/7857970/>
24. Johnson N, Bree O, Lalley EE, Rettler K, Grande P, Gani MO, et al. Effect of a Social Script iPad Application for Children With Autism Going to Imaging. *Journal of Pediatric Nursing*. 2014 Nov;29(6):651–9.
25. Smith E, Toms P, Constantin A, Johnson H, Harding E, Brosnan M. Piloting a digitally-mediated social story intervention for autistic children led by teachers within naturalistic school settings. *Research in Autism Spectrum Disorders*. 2020 Jul;75:101533.
26. Doyle T, Arnedillo-Sánchez I. Using multimedia to reveal the hidden code of everyday behaviour to children with autistic spectrum disorders (ASDs). *Computers & Education*. 2011 Feb;56(2):357–69.
27. Sansosti FJ, Powell-Smith KA. Using Computer-Presented Social Stories and Video Models to Increase the Social Communication Skills of Children With High-Functioning Autism Spectrum Disorders. *Journal of Positive Behavior Interventions*. 2008 Jul;10(3):162–78.

References

28. Megan R. Partington. Social Stories as Songs: The Combination of Music Therapy and Social Stories for a Treatment Intervention for Children with Autism Spectrum Disorders. Ann Arbor: The Chicago School of Professional Psychology; 2010.
29. Xin JF, Sutman FX. Using the smart board in teaching social stories to students with autism. Teaching exceptional children. 2011 Mar;43(4):18-24.
30. Hands C, Round J, Thomas J. "When someone stabs you": children's perspectives of venepuncture. Archives of Disease in Childhood. 2009 Jun 1;94(6):466–466.
31. National Disability Insurance Agency. Outcomes for participants with Autism Spectrum Disorder (ASD). Geelong: NDIS; 2018 Jun p. 5.
32. Australian Institute of Health and Welfare. Autism in Australia [Internet]. Canberra: AIHW; 2020 Aug [cited 2021 Dec 9] p. 8. (Disability). Available from: <https://www.aihw.gov.au/getmedia/4f660e4b-d6cd-4a4e-9eea-13560f6a0d58/Autism-in-Australia.pdf.aspx?inline=true>
33. Australian Institute of Health and Welfare. Australia's Children [Internet]. Canberra: AIHW; 2020 Apr [cited 2021 Dec 9] p. 93–6. (Children & youth). Available from: <https://www.aihw.gov.au/getmedia/6af928d6-692e-4449-b915-cf2ca946982f/aihw-cws-69-print-report.pdf.aspx?inline=true>