

Citation for published version: Camilleri, LJ, Maras, K & Brosnan, M 2024, 'Self-Set Goals: Autistic Adults Facilitating Their Self-Determination Through Digitally Mediated Social Stories', Autism in Adulthood. https://doi.org/10.1089/aut.2023.0063

DOI:

10.1089/aut.2023.0063

Publication date: 2024

Document Version Peer reviewed version

Link to publication

Final publication is available from Mary Ann Liebert, Inc., publishers https://www.liebertpub.com/doi/10.1089/aut.2023.0063

University of Bath

Alternative formats

If you require this document in an alternative format, please contact: openaccess@bath.ac.uk

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Download date: 08. May. 2024

Authors: Louis John Camilleri, Katie Maras, and Mark Brosnan.

Title: Self-Set Goals: Autistic Adults Facilitating Their Self-

Determination Through Digitally Mediated Social Stories.

Journal: Autism in Adulthood.

Ahead of print: http://doi.org/10.1089/aut.2023.0063

Accepted for publication: December 8, 2023

Online Ahead of Print: January 19, 2024

Abstract

Background: Personalized and practical support can facilitate autistic adults' independence and agency and can enable enhanced self-determination whilst influencing quality of life. Notwithstanding, traditional supports or interventions for autistic adults typically seek to address perceived challenges associated with autism, rather than identify what the autistic person wants support with. In this research we explored the potential to empower autistic people by attaining their own self-set goals with the support of digitally mediated Social Stories.

Methods: We conducted a pre-post quasi-experimental design to investigate the usefulness and effectiveness of digitally mediated Social Stories for autistic adults to support the attainment of their self-set goals. Thirty-three autistic participants self-set goals and self-developed Social Stories using a digital application. We collected closeness-to-goal measures at baseline and after two weeks of reading their digitally mediated Social Stories themselves and we compared them to a control condition. We then evaluated the goals participants were interested in. The autistic adults also evaluated the usefulness of the intervention for them.

Results: Over two weeks, the use of self-set goals, combined with a digitally mediated Social Story, elicited a statistically significant increase in closeness-to-goal ratings with a large effect size. The majority of participants reported that digitally mediated Social Stories was an appropriate and effective form of self-support. Our analysis of the participants' goals indicated that autistic adults predominantly identified a need for support with increasing non-social behaviours.

Conclusion: Self-developed digitally mediated Social Stories can effectively support autistic adults in reaching their self-set goals. Digitally mediated Social Stories can support reflection on one's goals, increase commitment toward goals, break down tasks into meaningful parts, as well as create meaningful predictions for autistic adults. Thus, digitally mediated Social Stories have the potential to empower autistic adults to self-support reaching self-set goals.

Keywords: goal setting, SMART-goals, digitally-mediated social stories, self-determination, autism, adults

Community brief

Why is this an important issue?

Often when supporting autistic individuals, the focus is on perceived challenges associated with autism, without asking them what they really require. Yet, when we involve autistic individuals in identifying what support they need and what goals they would like to pursue, it can make their lives better.

What was the purpose of this study?

This study explored how a digitally mediated Social Story can support autistic adults achieve intervention goals they identified and wanted to accomplish on their own.

What did we do?

We asked 33 autistic adults to identify what goals they are interested in reaching. We then invited them to develop their own social stories, using a digital tool, which described how they could reach their goals. We also invited the participants to read their self-developed story for two weeks and measured the individuals' progress toward their specific self-set goals. Finally, we asked the autistic adults to share their thoughts about the support tool.

What were the results of the study?

The results suggest that self-set goals are useful and that self-developed social stories, which are developed using a digital tool and accessed on a digital device, can effectively support autistic adults in reaching their self-set goals. The goals which autistic adults self-identified focused mostly on increasing non-social behaviours such as gaining skills or completing tasks. Eighty percent of participants indicated that their experience with digitally mediated Social Stories within this study was positive. Autistic adults also reported how they felt more in control of their intervention.

What do these findings add to what was already known?

Previous studies have shown that Social Stories can be used to support children. This study shows that Social Stories can also be useful for adults. Adults can write their own Social Stories, and the process of using digital Social Stories can help autistic adults achieve the goals they set for themselves.

What are the potential weaknesses in the study?

Findings are limited to autistic people who have good reading, writing and comprehension skills. Further research is required to extend the findings to other groups.

How will these findings help autistic adults now or in the future?

This tool may serve to support the autistic community in making their own choices about what goals to work towards and how to reach those goals.

Self-set goals: Autistic adults facilitating their self-determination through digitallymediated Social Stories.

Research on supports for autistic adults lags behind those for autistic children.¹ The little research which is available indicates that autistic young adults prioritise personalized support which can enable them to remain as independent as possible² whilst autistic adults report a preference for practical supports which can enable enhanced participation in life.³ Agency and self-determination play a key role in the provision of such supports, and can contribute in shaping an individual's positive participation in various areas of life.⁴

Self-determination is defined as the act of making choices and decisions about one's own life without the undue influence of others.⁵ Self-determined behaviours are actions that enable an individual to act as a primary agent in one's life⁶ and self-determination skills are needed to promote quality of life of autistic adults. Self-set (autonomous) goals can contribute directly toward increased self-determination and independent functioning for members of the autistic community.8 Goals have been defined as the object or aim of an action that an individual is trying to accomplish, and goal setting and goal attainment are important components of self-determination.^{8,9} Self-set intervention goals specifically are an important component of self-determination, yet autistic people are rarely active participants in intervention goal setting, and many of the tools available to support autistic participation in this process are not necessarily effective. 10,11 In discussing the autistic community's involvement in autism research, Den Houting et al., 12 draw upon Arnstein's 13 seminal model of citizen participation to describe the varying degrees of power and control held by participants throughout a research process. They advocate for research methods and designs that actively involve and engage autistic participants by offering them high levels of power and decision-making. Facilitating the autistic community to set their own intervention goals fosters a high level of power and decision-making. Thus, the practice of autistic adults deciding for themselves on what goals to pursue, and on what outcomes to prioritise, can be seen as a research approach that actively engages participants to support self-determination.

Well-formulated goals are more effective than no goals or vague goals (e.g., 'to do my best'), as they provide direction and strategies to attain them. Such clear direction can make intended changes more likely, ¹⁴ which in turn can lead to improved quality of life. ¹⁵ The SMART-goal model, which assesses the Specific, Measurable, Achievable, Realistic, and Timed aspects of goals, is a widely employed framework for goal setting in both research and clinical settings. ^{16,17} SMART criteria enable effective measurement and evaluation of goal attainment. ^{18,19,20} Idiographic measurement, which focuses on individually selected functional relations, is valuable for assessing goals that individuals themselves wish to achieve, as it offers sensitivity and relevance to their unique needs and aspirations. ^{21,19,22} Lee et al. ¹⁸ employed Goal Attainment Scaling to assess individualized outcomes among autistic participants with diverse goals and characteristics, while Banwell et al. ²³ utilized idiographic goal-based measures for progress monitoring in digital therapy with non-autistic adults. These approaches serve as valid, standardized measures for group design studies, ensuring equivalence across personalized goals. ^{22,24,25}

It is becoming increasingly evident from literature that a wide variety of interventions can benefit from incorporating a goal-setting element or component within that intervention⁸. One intervention developed for the autistic community which involves a strong goal-setting element is Social Stories. Social Stories are narratives that conform to 10 specific criteria developed by Gray and Garand, ²⁶ the first of which is to set an appropriate goal for the Social Story. 26-28. The remaining criteria define how the story can be structured and implemented to attain the goal. Social Stories are widely used and perceived to be highly acceptable by both parents of autistic children and professionals supporting autistic children - such as teachers, therapists, clinicians, and researchers. ²⁹⁻³² Contrary to research on the use of Social Stories with children, the research on the use of Social Stories with adults is very limited. However, the little research available (e.g., Bross et al. 33) reports that the Social Stories intervention (also known as social narratives when used by adults ³⁴) can be useful for autistic adults. Furthermore, the few studies with autistic adults indicate that the Social Stories intervention can have a positive, albeit "short-lived" effect on improving social interaction in autistic adults³⁵ and can also inform behaviour change (such as improve age-appropriate greeting and nose-wiping behaviour).³⁶ Bross et al's.,³³ study utilised Social Stories to support an autistic 20-year-old male to enhance his job-skills as a grocery store courtesy clerk. The case study involved a package intervention which included video models, on the job bagging training with prompts, and Social Stories. The Social Stories were utilised in view of their ease of use and accessibility for co-workers to read with the participant.

Outcomes of the study were positive with reported improvement in on-task performance.

Nevertheless, it is difficult to conclude which element of the intervention (Social Stories, training with prompts, or video module) was more effective in this single case study.

A meta-analysis of the effectiveness of Social Stories by Kokina and Kern ³⁷ highlighted that the goals of Social Stories were predominantly to increase appropriate behaviours or to reduce inappropriate behaviours (with some Social Stories focused on reducing anxiety³⁷). For both goals, the gauging of what is appropriate or inappropriate was usually determined by the author of the story, who was frequently a non-autistic adult.³⁸ Kokina and Kern³⁷ also reported that the overall effectiveness of Social Stories was 'questionable', but more effective when addressing inappropriate behaviours. Leaf et al.,³⁹ similarly reported discrepancies in literature pertaining to the utilization and efficacy of the intervention. Seventeen reviews of Social Stories literature were synthesised by Camilleri et al.⁴⁰ who found that the variability in effectiveness of Social Stories was consistent across the literature reviews and may relate to variability in the application of Gray's criteria.

Recently, digital technology has supported the development and delivery of Social Stories in a manner consistent with Gray's criteria. ^{29,41} The Stories Online For Autism app (sofa-app.org) was co-developed with the autistic community, following a framework for participatory autism research (Interface Design Experience for the Autistic Spectrum, IDEAS ^{42,43}) when co-creating digital technologies with the autistic community. ^{44,45} In addition to goal setting and developing a Social Story to attain the goal, the SOFA-app also uses idiographic measurement in the form of Goal Based Outcomes – 'how close are you to achieving this goal?' on a scale from 0 (not at all) to 10 (completely). ⁴⁶ Professionals have used the SOFA-app to effectively support autistic children to attain goals of improving appropriate behaviours and reducing anxiety. ⁴⁷⁻⁴⁹ Additionally, digital technology-based support has been particularly useful during disruptions to in-person support caused by the COVID-19 pandemic. ^{50,51}

To date, Goal Based Outcomes generally (with some exceptions e.g., Banwell et al.,²³) and Social Stories specifically have focussed on supporting children. In the case of Social Stories, parents or professionals are usually tasked with setting the goals. Ideally, the autistic person would be the main informant in the goal-setting and attainment-monitoring process.⁵² The SOFA-app has the potential to support self-setting goals and subsequently

support self-determination in the autistic person. 41 Self-setting goals could be particularly relevant for autistic adults given the substantial heterogeneity of autism and variation in outcomes in this group. 18 Furthermore, through the use of Social Stories and Goal Based Outcomes, the SOFA-app can also support autistic adults with organization and planning. The identification of goals, as well as the self-monitoring aspect of the intervention, may also encourage increased insight (i.e., awareness and understanding of one's behaviour). Such higher-order cognitive abilities (i.e., organization, planning and insight) are important components of executive function as defines by the International Classification of Functioning. 53 Executive function is defined as a number of cognitive abilities - which include abstraction, organization and planning, time management, cognitive flexibility, insight, judgment, and problem-solving – involved in the act of behavioural regulation. 54 Many autistic individuals struggle with executive functioning skills. 55,56 Digital technology has been shown to benefit autistic individuals by supporting various aspects of executive function, with insight (i.e., self-monitoring), in particular, being an element which may be especially impacted. 57

In this study, therefore, we used the SOFA-app to investigate the practice of autistic adults identifying self-set goals, self-developing Social Stories to attain these goals, and self-monitoring attainment of these goals. We also aimed to investigate the type of goals autistic adults were interested in, and to explore if digital supports can support autistic adults in reaching their own goals, and thus contributing towards supporting their self-determination. Thus, through this study we aimed to specifically answer the following research questions:

- Can a two-week digitally mediated Social Stories intervention support autistic adults in reaching their self-identified goals?
- 2. What goals are autistic adults interested in achieving using a digitally-mediated Social Stories intervention?
- 3. Do autistic adults approve of a digitally-mediated Social Stories intervention?
- 4. What experiences of the intervention do autistic adults report?

Method

Participants

We recruited participants in the UK via online methods through (1) advertising via the Autistica Network, (2) advertising via the University of Bath Research Database, and (3) advertising via the National Autistic Society Database. An a-priori power analysis using G*Power version 3.1.9.7⁵⁸ indicated that for this study to detect a medium effect size of 0.5, a minimum sample size of 27 was necessary to achieve Cohen's⁵⁹ recommended power of .80. Finally, we recruited 33 individuals to participate in the study.

Participants were required to have a formal diagnosis of Autism Spectrum Disorder from a clinician (or Asperger Syndrome, etc. see Table 1) aged 18 or over, have the ability to read and comprehend the information sheet and give informed consent, as well as to be able to read and respond to the questionnaire measures. Participants were also required to own an internet-enabled digital device (i.e., a smartphone or tablet). Table 1 provides a summary of the participants' demographic data.

Research design

Upon registering an interest in the study, participants viewed a YouTube video explaining the nature of the study [The video is available here: https://youtu.be/6Vg4ihg07qY]. The video explained that the study would be using the SOFA-app to support participants in developing Social Stories to address a goal that they wanted to target. A subsequent video then detailed how to set SMART goals (see Measures for details) [The video can be found here: https://youtu.be/6hKzXFDfPGY].

We used a pre-post quasi-experimental design. Autistic adults identified a goal that they wanted to target by using a Social Story, which they also developed and delivered themselves (Experimental Goal). Participants also identified a second goal that they wanted to target but that was not addressed in the present study (Control Goal). The difference between the Experimental Goal and the Control Goal was that a Social Story was developed and delivered (i.e., read) for the Experimental Goal but not for the Control Goal. Participants read the Social Story targeting the Experimental Goal themselves using a digital application (SOFA-app) every day for two weeks. Participants rated their closeness-to-goal (for both Experimental and Control Goals) at the beginning of the two weeks, after one week, and at the end of the two weeks. After two weeks, participants took part in an online evaluation of

the study. This could be undertaken via an online survey or via an online interview, whichever the participant preferred.

Table 1 - Participants' demographic data

	All par	ticipants	Comple ipants experimen g	
	Frequency (n)	Percentage (%)	Frequency (n)	Percentage (%)
Total number of participants	33	100	20	100
Gender				
Female	20	60	11	55
Male	10	30	8	40
Non-binary	2	7	1	5
Transgender	1	3	-	-
Nationality				
Austrian	1	3	1	5
British	23	70	11	55
Dutch	1	3	1	5
German	2	6	2	10
Italian	1	3	1	5
Maltese	4	12	4	20
United States	1	3	-	-
Race/Ethnicity				
British Asian	2	6	2	10
Mixed ethnicity	2	6	1	5
White	28	85	16	8
Rather not say	1	3	1	5
Diagnosis				
Autism Spectrum Condition (ASC)	4	12	1	5
Autism Spectrum Disorder (ASD)	16	48	8	40
Aspergers	7	21	7	35
Autism	5	15	3	15
High Functioning Autism (HFA)	1	3	1	5
Other diagnosis				
Attention Deficit, Hyperactivity Disorder	7	21	6	30
(ADHD)	_			
Mood Disorders	8	24	3	15
Specific Learning Disorder (SLD)	1	3	-	-
None	17	52	11	55
	Mean (SD)	Range	Mean (SD)	Range
Age	37.73 (13.06)	20 to 66	38.05 (12.12)	20 to 64
English Language skills	(23.00)		\· <i></i> /	
	8.61	_	8.35	6 to 10
Writing - M (SD)	(1.35)	6 to 10	(1.46)	
D 11 (2/22)	8.97	6 - 6 -	8.80	6 to 10
Reading - M (SD)	(1.10)	6 to 10	(1.11)	
0 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	8.70	.	8.70	6 to 10
Comprehension - M(SD)	(1.13)	6 to 10	(1.03)	
	85.45		87.65	76 : : -
Autism Quotient (Short)	(8.54)	70 to 101	(9.05)	70 to 101

SD = Standard Deviation

Measures

Initially participants provided the demographic information which appears in Table 1.

English language skills

Participants self-reported their perceived levels of competence in reading, writing, and comprehension skills on an 11-point scale from 0 (poor) to 10 (high). This measure was taken from Smith et al. 48,49

Autism Quotient (AQ-short)

The AQ-Short⁶⁰ is a 28-item version of the longer (50-item) Autism-Spectrum Quotient (AQ).^{61,62} The AQ-Short has a reported acceptable to good internal consistency (α = .77). Participants are asked to rate how strongly they agree or disagree with the statements using a 4-point Likert-type scale from strongly agree to strongly disagree. Items were scored 1 to 4, with a higher score indicating more autistic-like traits (some items are reverse scored). A cut-off of 70 was used. A cut-off of 70 has sensitivity and specificity of .94 and .91, respectively.

Self-set SMART-Goal rating

We adapted the SMART-Goal rating from Bowman et al.'s¹⁷ SMART-Goal Evaluation Method (SMART-GEM). Participants were asked to rate the goal they identified in terms of five criteria: Specific, Measurable, Achievable, Realistic, and Timely. They were asked the following questions: (1) Does the goal specify what behaviour is being targeted? (2) Can closeness-to-goal be measured on a scale from 0 (not at all) to 10 (totally)? (3) Does the goal present a sensible and practical idea of what can be achieved or expected? (4) Is the goal realistic? i.e., does it represent a behaviour that can be achieved? (5) Can this goal be achieved in the expected time frame? Each affirmative answer would correspond to one point. A total of five points indicate that all five SMART goal criteria were met. SMART-Goal ratings were given by the participants for their goals. At the end of the study, each goal was blind-rated independently by the first author in order to investigate objectively the quality of each goal in terms of the SMART-Goal framework (see Supplementary Figure A).

Social Story self-development and self-delivery

We shared guidelines on how to develop a Social Story with each participant. The guidelines consisted of the following recommendations: Stories should (1) be written in the first person, (2) consist of 8 to 18 sentences, with one or two sentences on a separate page, (3) consist of a description of the goal, and (4) include a description of how the goal can be reached.

Each participant developed their own Social Story digitally on the SOFA-app. Supplementary Figure B presents an example of a story which was created by one of the participants. The story was stored and accessed (i.e., read) via the SOFA-app. An example of a story, as viewed (i.e., read) on the SOFA application, can be found at this link https://youtu.be/Jw-MREUcdy8. We also gathered quantitative data on the number of times (i.e., frequency) the story was read during the two-week study. The story was read by participants from once every day, to multiple times a day. We analysed each story using Smith et al.'s 48 Carol Gray Assessment Framework (CGAF, see Supplementary Figure C) for the evaluation of the Social Stories' adherence to Gray's criteria.

Goal Based Outcomes

For both goals (Experimental and Control), we used an 11-point scale to allow for more flexibility and personalisation of the scaling process. 46-49 We used the Goal Based Outcomes measure to evaluate the rates of meaningful improvement in the self-set goals whilst also allowing for adequate evaluation of closeness-to-goal evaluation across participants' ratings. 63,64 Participants rated how close they were to achieving their goals at baseline (when the goal was set, before writing the Social Story), at the end of week 1 and the end of week 2. The baseline, first week, and second week closeness-to-goal measures were completed by the participants electronically through Qualtrics (https://www.qualtrics.com). An automatic reminder with the apposite link was sent for the participants to access the closeness-to-goal rating tasks. On each occasion, closeness-to-goal was rated on an 11-point scale, with 0 indicating that the goal was not at all reached, 5 indicating that the goal was midway towards being reached, and 10 indicating that the goal was totally reached.

Evaluation

Participants responded to 12 evaluation questions, based on Proctor et al.'s⁶⁵ intervention appropriateness measures and Weiner et al.'s⁶⁶ feasibility of intervention measure. We administered these questions (detailed in Table 5) through an online questionnaire at the end of the study. The questions aimed to determine the extent to which participants believed the digitally-mediated Social Stories support tool was acceptable, appropriate, and feasible for autistic adults. Participants replied by stating their degree of agreement on a 5-point Likert scale. The possible replies were: (1) Completely disagree, (2) Disagree, (3) Neither agree nor disagree, (4) Agree, and (5) Completely Agree. The evaluation questions had a high level of internal consistency, as determined by a Cronbach's Alpha of 0.93. Further open-ended questions were asked (see Supplementary Figure D) and participants were given the option to respond through an online survey or through an online interview on Zoom (which was audio-recorded for subsequent transcription). The choice was made by each individual participant who answered a question included in the second-week measure in which they indicated their specific preference. Eleven of the participants opted for a meeting on Zoom, whilst 22 completed an online survey. There were no noticeable differences between the replies that were obtained through the two formats.

Procedure

We invited participants to read information letters and view a video presentation that explained the research procedure. Subsequently, we invited the participants to follow a sequence of instructions consisting of eight steps: (1) Complete an online questionnaire consisting of demographic information as well as the Autism Quotient (AQ-short); (2) View videos about how to download the application; (3) Identify a personal SMART goal and develop one's own Social Story aimed towards reaching that goal (and identify a control goal); (4) Complete an online baseline questionnaire; (5) Read the Social Story daily for two weeks using the SOFA-app; (6) Complete an online progress checklist after the first week of reading the Social Story; (7) Complete an online progress checklist after the second week of reading the Social Story; and (8) Participate in a final evaluation.

Community involvement

The community was involved at various stages in this study. First at the development stage of the SOFA-app.^{29,41,44} Furthermore, the rationale for the study was identified by autistic adults who inquired about how the SOFA-app can be useful for them. We also consulted with three autistic adults about the research design. A number of changes and additions were made in view of the recommendations arising from the consultations. These included: structuring the instructions in a clearer and more specific manner (over 16 instead of 8 steps, the creation of video presentations on how to identify a SMART goal and how best to develop a story using the SOFA-app, and an option for an online evaluation survey instead of an online interview, which could have been taxing for some participants.⁶⁷

The whole research process was carried out with very little researcher involvement. The SMART goals were identified by the participants whilst the Social Stories were all developed by the participants. Furthermore, participants' level of control can be considered high¹² in terms of (1) which goal was self-set, and (2) the Social Story that was developed and self-delivered to reach that goal. To recognise the personal expertise required for the participants' role, and the associated level of responsibility in relation to project aims⁶⁸ participants were provided the choices of a monetary contribution or an Amazon Gift Card by way of honorarium.

Data Analysis

Quantitative data were inputted into SPSS (version 28). We used the Shapiro—Wilk normality test to identify departures from normality and paired-samples t-tests to determine whether the mean difference for change in closeness-to-goal rating (from baseline to the first week, first week to the second week and baseline to the second week) was statistically significant. In cases where the normality assumption was violated, we used a bootstrapped t-test. We analysed the type of goals that were identified by the participants to investigate what the participant's focus and interests were. Using an Intra Class Correlation Coefficient (ICC), we investigated the agreement between the participants' and the first author's SMART rating of the experimental goals. We used Cohen's k to determine the agreement between authors' judgements about the type and classification of goals identified by the participants. We ran a regression analysis to investigate the relationship between the researcher's SMART-goal rating and change in closeness-to-goal.

The qualitative data from the online evaluation survey and interviews was transcribed and inputted into NVivo. We analysed the data inductively (i.e., through the identification of codes directly from the raw data, and without being constrained by pre-existing theories⁶⁹) by the first author, to discover patterns and themes related to participants' experience of the study. This was carried out by utilising a conventional approach to content analysis^{70,71}. Through this approach we identified primary codes, denoting entities that encapsulated at least one specific observation. We grouped these codes into categories, which we further reviewed and refined to create overarching themes. These overarching themes (i.e., conceptual constructs that encompass multiple observations or facets) emerged as a result of this iterative process.⁷²

Ethics

This study received ethical approval from the University of Bath Psychology Research Ethics Committee (PREC, Project ID 19-309). Informed consent was obtained from all participants.

Results

Quantitative findings

All participants' AQ scores were above the cut-off of 70 and all had good levels of English language skills (see Table 1). All participants completed the protocol for the experimental goal and 20 participants identified a second control goal. The means for the closeness to goal ratings are reported in Table 2.

Table 2 - Descriptive statistics of closeness-to-goal measures.

Experimental Goal [All participants]		(n=33)	
_	Mean	SD	Range
Baseline closeness-to-goal	2.73	2.43	0 to 8
First-week closeness-to-goal ratings	5.58	2.46	1 to10
Change in closeness-to-goal after the first week	2.85	2.12	0 to 9
Second-week closeness-to-goal ratings	6.94	2.62	0 to10
Change in closeness-to-goal from the first to the second week	1.36	1.78	-3 to5
Total change in closeness-to-goal (Baseline to the second week)	4.21	2.57	-3 to 8
Experimental Goal [subgroup who completed experimental and con goal]	trol	(n=20)	
Baseline closeness-to-goal	3.35	2.60	0 to 8
First-week closeness-to-goal ratings	6.45	2.31	1 to 10
Change in closeness-to-goal after the first week	3.10	2.25	0 to 9
Second-week closeness-to-goal ratings	7.65	2.10	3 to 10
Change in closeness-to-goal from the first to the second week	1.20	1.69	-3 to 4

Total change in closeness-to-goal (Baseline to the second week)	4.30	2.18	0 to 8
Control Goal	(n=20)		
Baseline closeness-to-goal	1.80	1.77	0 to 5
Second-week closeness-to-goal	3.30	1.69	0 to 7
Change in closeness-to-goal after two weeks	1.50	1.00	0 to 3

SD = Standard Deviation

First-week outcomes

Thirty-three (N=33) participants identified a SMART goal and developed a Social Story for that goal. Each participant subsequently completed baseline closeness-to-goal measures (M=2.73, SD=2.43). After reading/accessing the story daily using the SOFA-app for one week, outcome closeness-to-goal measures were completed (M=5.58, SD=2.46). Of the 33 participants, the story produced an improvement (i.e., an increase) in closeness-to-goal ratings in 31 (94%) of the participants, whereas two participants saw no improvement. There was a statistically significant improvement in closeness-to-goal after one week of accessing a digitally mediated Social Stories (M=2.85, SD=2.12), BCa 95% CI [2.18, 3.58], t(32)=7.71, p<.001. A Cohen's d of 1.16 is indicative of a large effect size.

First-week to second-week outcomes

At the end of the second week, participants again completed closeness-to-goal ratings (M = 6.94, SD = 2.62). Twenty-five (76%) participants reported an improvement in closeness-to-goal ratings, four (12%) participants reported a regression (i.e., a decrease in closeness-to-goal ratings) whilst the remaining four (12%) participants reported unchanged ratings. There was a statistically significant increase in closeness-to-goal ratings from the first to the second week (M = 1.36, SD = 1.78, 95% BCA [0.73, 1.99), t(32) = 4.40, p < .001, Cohen's d = 0.54 (indicative of a medium effect size).

Baseline to second-week outcomes

Over the two weeks combined, the use of a digitally mediated Social Story elicited a mean increase of 4.21 (SD = 2.57), 95% CI [3.30, 5.12] in closeness-to-goal ratings. This difference is a statistically significant increase in closeness-to-goal rating, 95% CA [3.30, 9.41], t(32) = 9.41, p < .001, Cohen's d = 1.67 (indicative of a large effect size).

Control Goal outcomes

Twenty participants also self-set a Control Goal that was not supported by a Social Story. The closeness to this Control Goal was also rated at baseline and at the end of week

two. There was a statistically significant increase in closeness-to-goal ratings for the Control Goal from baseline ratings (M = 1.80, SD = 1.77) to outcome ratings after two weeks (M = 3.30, SD = 1.69) of 1.50 (SD = 1.00), 95% CI [1.03, 1.97,], t(19) = 6.71, p < .001, d = 0.87.

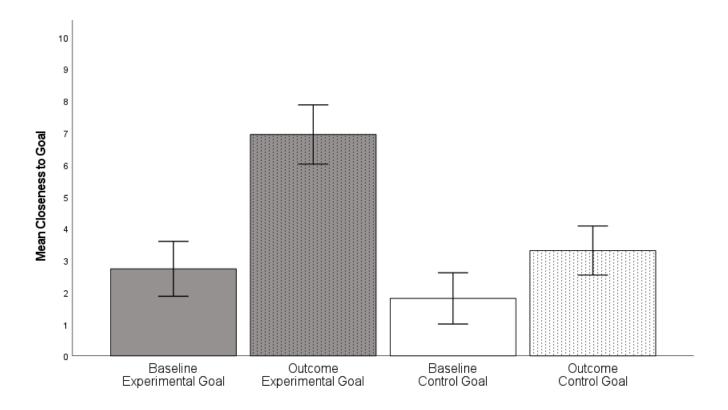
The mean change in closeness-to-goal for the control goal (M=1.50, SD=1.00) was lower than the change in closeness-to-goal for the goal for which a digitally mediated story was written (M=4.30, SD=2.18) (Figure 1). There was a statistically significant difference in mean change in closeness-to-goal ratings of 2.80, 95% CI [1.66, 3.94], t(19)=5.13, p<.001, d=1.65. Thus, the effect size was larger for the Experimental Goal than the Control Goal.

As not all participants monitored a Control Goal, we compared the closeness-to-goal ratings for the Experimental Goal between those who did (n = 20, M = 4.30, SD = 2.18) and those who did not (n = 13, M = 4.08, SD = 3.17) monitor a Control Goal. We found no discernible difference between these two groups, M = 0.22, 95% CA [-0.223, 0.930], t(31) = 0.240, p = .812, d = 0.08

Change in Experimental & Change in Control Goal outcomes (n=20)

We carried out a paired-sample \underline{t} -test to investigate the difference between the change in experimental closeness-to-goal ratings of participants who completed both experimental and control conditions (n = 20) and the change in their control closeness-to-goal ratings. Thirty percent of these participants also reported having Attention Deficit Hyperactivity Disorder (ADHD). Participants' change in closeness-to-goal ratings in the experimental condition (n = 20, M = 4.30, SD = 2.18) was higher when compared to change in closeness-to-goal ratings in the control condition (M = 1.50, SD = 1.00). This difference (M = 2.80, M = 2.44) was statistically significant, 95% CI [1.658, 3.942], H = 5.130, H < .001, H = 1.15.

Figure 1 - Mean closeness to goal for experimental and control goals



Classification of Goals

We inductively analysed the goals which were identified by the participants. This enhanced comprehension of participants' preferred goal types and facilitated comparison to be made with existing literature. This analysis resulted in five categories of goals: (1) to decrease non-social behaviours, (2) to increase non-social behaviours, (3) to decrease social behaviour, (4) to increase social behaviour, and (5) to decrease anxiety. Two of the researchers (first and third authors) then independently categorised the 33 experimental goals. The interrater agreement obtained was 97%. Cohen's κ confirmed a very strong agreement between authors' judgements, κ = .944, p < .001. Disagreements were resolved by the second author. There were no statistically significant differences between the type of goal and change in closeness-to-goal ratings, F(1, 31) = 0.01, p = .99, see Table 3. The control goals that were identified, for which no stories were developed, were similar to the experimental goals, see Table 4.

SMART goal analysis

To determine if there was agreement between the SMART goal ratings which were given to each Experimental Goal by the participants and by the first author, we carried out an Intra Class Correlation Coefficient (ICC). The ICC was based on an absolute agreement and a two-way mixed-effects model. The SMART rating consisted of a five-point scale. For each criterion that is reached (i.e., Specificity, Measurability, Achievability, Realistic, and Timely) one point is given. A total of five points indicate that all of the criteria were met. There was a statistically significant difference between the two sets of ratings (i.e., from the participants and the researcher). Participants gave higher SMART ratings to their goals (M = 4.97, SD = 0.17, Range = 1, Minimum = 4, Maximum = 5) compared to the researcher's ratings (M = 3.76, SD = 1.17, Range = 4, Minimum = 1, Maximum = 5). The average measure ICC was .033, which indicates poor reliability, with a 95% confidence interval from -0.296 to 0.361, F(32,32) = 1.07, p = .425. However, there was no statistically significant relationship between total SMART-goal rating and change in closeness-to-goal, F(1,31) = 0.15, p = .70. We conducted this analysis with the researcher's SMART rating as there was a ceiling effect for participants' SMART goal rating.

The first author analysed the control goals in terms of SMART criteria. The Control goals obtained a mean SMART goal rating of 3.20 (SD = 0.83) whilst the Experimental goals obtained a mean SMART rating of 3.76 (SD = 1.17). There was no statistically significant difference between experimental and control goal SMART ratings, M = 0.56, 95% CI [-0.05, 1.16], t(51) = 1.857, p = .069.

Analysis of social stories

Each of the Social Stories (N=33) consisted of 5 to 18 sentences (M = 10.97, SD = 4.10). Twenty-four percent of participants included pictures in their Social Stories, whilst 76% did not. Twenty of the Social Stories (60%) met all of Gray's criteria, whilst 13 (40%) did not (see Table 5). From the latter thirteen (40%) Social Stories did not have the correct ratio of descriptive (i.e., a sentence that provides specific, factual information about a situation) to coaching (a sentence that provides guidance on how an individual should behave in a specific situation) sentences (thus not meeting criterion no. 8), whilst three of the Social Stories (9%) consisted of coaching sentences alone (thus not meeting criterion no.7).

We ran an independent samples t-test to investigate the difference in change in closeness-to-goal ratings between Social Stories that met all of Gray's criteria and those which did not. The change in closeness-to-goal ratings in Social Stories which followed Gray's criteria (M = 4.30, SD = 2.49) was not significantly higher than the change in Social Stories which did not (M = 4.08, SD = 2.78), t(31) = 0.240, p = .812.

Table 3Classification of Experimental Goals

Type of goal	Frequenc	Percentage	Change in c to-goal		o g. of gools
Type of goal	y n	%	Mean (SD)	Range	e.g., of goals
Decrease non-social behaviour (e.g., reducing repetitive actions or thoughts)	2	6.1	3.00 (4.24)	0 to 6	Stop chewing fabric
Increase non-social behaviour (e.g., supporting gaining skills or completing tasks)	22	66.7	4.18 (2.77)	-3 to 8	Be more healthy and fit
Decrease social behaviour (reducing negative emotions or antisocial behaviour)	2	6.1	6.00 (2.83)	4 to 8	Reducing fear of failure
Increase social behaviour (e.g., supporting communicating or interacting with others)	3	9.1	3.33 (1.16)	2 to 4	In one day, I have to make time for up to 3 people.
Decreasing anxiety (e.g., supporting change or transition)	4	12.1	4.75 1.71)	3 to 7	Taking myself outside my comfort zone (home) with a little less worry and trying to be less anxious

SD = Standard Deviation

Summary of Evaluation

All participants completed the summary evaluation. Responses obtained by the participants indicated that the majority (>80%) agreed (i.e., gave a rating of 'somewhat agree' or 'strongly agree') that digitally mediated Social Stories meet their approval and were appealing. The majority (>87%) also agreed that digitally mediated Social Stories were suitable, applicable, and fitting for autistic adults and >80% reported that digitally mediated Social Stories was an appropriate tool for support (see Table 6). One-sample t-tests confirmed that all the evaluation means were above the midpoint of the scale (all ps < .001).

 Table 4 - Classification of Control Goals

Type of goal	Frequenc	Percentage	Change in to-goal		a a of sools
Type of goal	y n	%	Mean (SD)	Range	e.g., of goals
Decrease non-social behaviour (e.g., reducing repetitive actions or thoughts)	-	-	-	-	-
Increase non-social behaviour (e.g., supporting gaining skills or completing tasks)	16	47.1	1.38 (1.03)	0 to 3	e.g., Make a start on the house decorating.
Decrease social behaviour (reducing negative emotions or antisocial behaviour)	-	-	-	-	-
Increase social behaviour (e.g., supporting communicating or interacting with others)	3	8.8	2.33 (0.58)	2 to 3	e.g., Engage more frequently with colleagues from work.
Decreasing anxiety (e.g., supporting change or transition)	1	2.9	1.00 (-)	1 to 1	e.g., To cope better when things are not perfect first time.

SD = Standard Deviation

 Table 5 - Summary of Social Story analysis

Used Pictures in Stories	Frequency	Percentage
Yes	8	24
No	25	76
Conform to Gray's criteria		
Criteria 1: The SS goal	33/33	100
Criteria 2: Two step discovery*	33/33	100
Criteria 3: Three parts and a title	33/33	100
Criteria 4: 'FOURmat'*	33/33	100
Criteria 5: Five factors define voice &	33/33	100
vocabulary		
Criteria 6: Six questions that guide story	33/33	100
development		
Criteria 7: Seven types of sentences	30/33	91
Criteria 8: A GR-EIGHT formula (sentence	20/33	60
ratio)		
Criteria 9: Nine makes it mine*	33/33	100
Criteria 10: Ten guides to editing &	33/33	100
implementation Edit		

^{*}Criteria automatically met by self-developing SS

Table 6 - Summary of appropriateness measure outcomes

Evaluation questions	Mean	SD	Range
Digitally-mediated social stories meet my approval.	4.15	0.90	2 to 5
Digitally-mediated social stories are appealing to me.	4.00	1.12	1 to 5
I like digitally-mediated social stories.	4.18	0.92	2 to 5
I welcome digitally-mediated social story support.	4.36	0.78	2 to 5
Digitally-mediated social stories seem fitting for autistic adults.	4.15	0.76	2 to 5
Digitally-mediated social stories seem suitable for autistic adults.	4.21	0.89	1 to 5
Digitally-mediated social stories seem applicable for autistic adults.	4.30	0.77	2 to 5
Digitally-mediated social stories seem like a good match for autistic adults.	4.12	0.78	4 to 5
Digitally-mediated social stories seem implementable.	4.58	0.50	4 to 5
Digitally-mediated social stories seem possible.	4.70	0.47	3 to 5
Digitally-mediated social stories seem doable.	4.67	0.54	2 to 5

SD = Standard Deviation

Qualitative Findings

Table 7 presents the themes and categories the emerged from the content analysis. We identified two themes, and a number of associated categories, from the interview data as well as the open-ended questions from the final evaluation survey. Table 7 also includes a representative quote for each category, along with the age and gender of the quoted participants.

Table 7 - Summary of themes and categories

Themes	The experience of a digital tool	The experience of a digitally mediated social stories
Categories	Control e.g., "doing things at my own pace whilst feeling less patronised" — 28-year-old female	Reflecting on behaviour e.g., "It helps me understand why I am struggling with certain goals" – 46-year-old, female.
	Autonomy e.g., being able to do things on my own and in my own space" – 56-year-old male	Motivating e.g., "I did find that it helped to keep me motivated to achieve my goal" – 21-year-old transgender.
	Discrete e.g., Other people wouldn't know what I was looking at on my phone so it made using the social story discreet" – 34-year-old female.	Break down tasks into meaningful parts. e.g., "I would use this app to help me break down tasks, and know what was coming re tasks, which were causing me anxiety." – 44-year-old, non-binary.
	Accessible e.g., "Having a digital intervention on my phone made it easy to access. It also meant I had it everywhere I was so I could look at it when I remembered." — 39-year-old female.	Making predictions e.g., "I would use this app to help me break down tasks, and know what was coming re tasks, which were causing me anxiety." – 44- year-old, non-binary."
		Creating rules

Themes	The experience of a digital tool	The experience of a digitally mediated social stories
		e.g., "I would write a story that made the rules which I had to follow clear" – 56-year- old, male.

Discussion

This study examined the extent to which autistic adults utilise self-set goals they would like to achieve, and the utility of self-developed and self-delivered Social Stories to address these goals whilst self-monitoring goal attainment. Providing support to formulate SMART goals and to develop Social Stories (with Goal Based Outcomes) resulted in autistic adults independently establishing objectives and determining the necessary support to attain them. This self-mediated support had a large positive effect upon participants getting closer to their self-set goals. This study demonstrates that autistic adults can effectively use digitally mediated Social Stories to address behaviours that autistic adults themselves would like to change. Whilst there was a range of self-set goals, the majority of participants were seeking support with increasing non-social behaviours (such as "Organising a writing Archive", or "Work every day for three hours on my business"). The majority of participants reported that digitally mediated Social Stories was an appropriate and effective form of support. The digital aspect of the support facilitated a sense of control and autonomy as well as being discrete and accessible.

This study's strength lies in involving the adult autistic population in every stage, from recognizing the study's need to contributing to the research design. Participants independently explored goal identification, Social Story development, and outcome monitoring. Participants acted as the primary causal agents, and were autonomous in terms of identification of goals, and in the pursuit of reaching those goals, and in so doing fostered self-determination.⁷³ Qualitative findings underscored participants' emphasis on autonomy and self-paced actions, aligning with research emphasizing the link between self-determination and quality of life.^{7,74,75}

Many of the participants made significant progress towards their goals, though few achieved a closeness-to-goal rating of 10. This raises questions regarding the adequacy of the two-week timeframe and the attainability of chosen goals. Analysing goals using the SMART-Goal rating system, it is notable that participants' and the first author's ratings differed, suggesting varying emphasis on SMART-goal considerations. However, the first

author's SMART ratings didn't predict closeness-to-goal changes, indicating the beneficial impact of engaging in the SMART goal process, even if all criteria aren't fully met.

It is also important to note that three things were introduced in this study: SMART goals, Goal Based Outcomes and Social Stories, and it is not possible to identify the distinct contributions of each. However, closeness-to-goal improved more with a Social Story than without. The Control Goal's improvement may be attributed to Goal Based Outcomes and SMART goal conceptualization, while the Experimental Goal benefited additionally from the Social Story aspect. This aligns with literature highlighting the advantages of self-set goals for autistic participants⁸. The additional benefit of the Social Stories when appropriately structured (via the SOFA-app) also aligns with existing research, 40 and participants' stories in this study met 60% of Gray's criteria, exhibiting a high degree of fidelity.

Despite the effectiveness of appropriately structured Social Stories, there is little understanding of the mechanisms by which Social Stories impact behaviour. 76 The qualitative findings potentially shed light on the mechanisms that could be underpinning the Social Story process, that is: increase of reflection on the target behaviour, breaking down a task into meaningful parts, creating rules, and making predictions. These elements are suggestive of mechanisms which could be supporting executive functioning skills. Reference to increased reflection, as a benefit of the intervention, points towards an important element of executive functioning, namely "insight". Digital supports are reported to support this particular area of executive functioning,⁵⁷ and the metacognitive insight and awareness in the form of reflection seems to have played an important part in the intervention. Other identified mechanisms, such as creating rules, and making predictions, could also be suggestive of elements of executive functioning.⁵⁴ Thus, the intervention could be supporting autistic adults with working memory and planning, which are skills required to create rules and make predictions. However, such elements could also be indicative of other mechanisms involving analysing systems in terms of rules (also known as systemizing⁷⁷). A rule-based account of the Social Stories intervention has been proposed,³⁸ which utilises a strengths-based approach rather than a deficit approach. Through this strengths-based "lens", the Social Stories can be seen as a tool which harnesses relative autistic strengths in rule-based thinking.

The goals identified by participants in the present study offer valuable insights into the interests of autistic adults and the specific areas where they perceive a need for support. Interestingly, these goals don't neatly align with Kokina and Kern's³⁷ classification. Most of the participants' goals targeted non-social behaviours (e.g., supporting gaining skills or completing tasks), indicating a perceived achievability or importance in using the support tool for such objectives. Examples included: to recommence physical exercise by going for a walk in and around my village, twice a week, of 10 minutes for each walk; and to put children to bed by 9 pm every day. Traditionally the goals set for Social Stories have been set by others (such as parents or professionals) for autistic children. The evaluation in the present study indicates that Social Stories are also acceptable for autistic adults. The few studies that have used Social Stories for adults have focussed on social goals, ^{35,78} possibly reflecting a misalignment in perceived support needs between non-autistic and autistic adults.

Limitations

In this study we included Social Stories, SMART goals, and Goal Based Outcomes in the intervention. While the focus was on digitally-mediated Social Stories, attributing outcomes solely to it is challenging. We included a control condition to emphasize Social Stories' impact on closeness-to-goal ratings. Nevertheless, positive outcomes in both conditions hinder identifying the primary contributor. This challenge raises the possibility that the intervention is a "package" support tool for executive functioning skills rather than solely a Social Stories intervention. However, this doesn't preclude that the Social Stories intervention supported executive functioning through reflection and by highlighting patterns and rules. Hence, investigating whether executive function or other rule-based mechanisms underpin or inform the Social Stories intervention could be a focus of future research.³⁸

Crucially, all data is self-reported from autistic adults, introducing potential biases like social desirability effects. We decided not to use an independent rater to preserve autonomy and control factors which were also highlighted in qualitative findings. In this study the focus remained on the perception of autistic participants, revealing a positive outcome tied to increased self-determination through independently set goals and self-developed stories.

A potential study limitation is the lack of formal reporting of autism diagnosis. Due to the study's nature, re-administering formal autism assessments wasn't viable. Using the AQ- Short, all 33 participants scored above the 70 cutoff, which is consistent with an autism diagnosis. However, the sample's generalizability to the broader autistic population is uncertain. Participants had good reading, writing and comprehension skills, making co-occurring intellectual disability unlikely, though successful self-maintained interventions for those with intellectual disability suggest potential applicability to this group. 8,52,79

The first author's lack of familiarity with the participants made it difficult to ascertain the physical attainability of their goal. This hindered assessing goal attainability, posing a study limitation. Achievability was evaluated based on goal syntax, specifically, by considering language use for articulation (e.g., becoming rich is probably not achievable within the study's two-week timeframe).

Finally, some participants didn't complete the Control Goal aspect, potentially biasing effect size interpretation. However, changes in Experimental Goals were consistent regardless of Control Goal monitoring, suggesting a possible effect of goal setting or a social desirability impact from research involvement.

Implications

An aspect which differentiates this study from other Social Stories studies is the identification of participants' own goals. Previous Social Stories research investigated how the intervention can teach pro-social behaviour or decrease "aberrant behaviour". 80(p.127) In both cases, what behaviour needs to be taught, and what is considered "aberrant", or inappropriate, is determined by non-autistic individuals. This study challenges this deficit approach and emphasises how agency can positively impact intervention outcomes. Thus, including participants in the setting of their own intervention goals may enhance the intervention's relevance and impact. Qualitative insights from the study underscore the autonomy and control experienced by autistic participants. Their active engagement reflects a prioritization of autonomy and control, demonstrating the positive outcomes that can arise from such considerations. It is therefore essential for future research endeavours to concentrate on greater involvement of the autistic community in determining intervention and support goals. By incorporating the autistic community's perspectives and insights, research can yield interventions that are not only effective but also truly reflective of the needs and desires of the community.

Conclusion

Digitally mediated Social Stories supported autistic adults to move significantly closer to their self-set goals. Autistic adults successfully self-set goals, self-developed and self-delivered Social Stories and self-monitored their goal outcomes. This approach, which includes high levels of participant control, may serve to support self-determination for the autistic community. As Lee et al. state: 'Everyone has unique dreams and goals for their lives: To judge whether an intervention is maximally beneficial, researchers should—along with objective measures—seek to assess personalized outcomes that are important to autistic individuals' (p. 8). The approach of the present study allows for group-based analyses of individual self-set goals to facilitate participants' active engagement in research. This study can also shed light on a possible avenue for exploration of the utility of digital technology to support further autistic adults' self-determination.

Declarations:

Compliance with Ethical Standards: All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee (University of Bath Psychology Research Ethics Committee - PREC).

Conflict of interest: All authors declare no conflict of interest regarding this study. MB was part of the team that developed the SOFA-app, but this app is free of charge – there are no financial conflicts of interest.

Funding: This study was funded by the John and Lorna Wing Foundation (https://www.johnandlornawingfoundation.org/)

Authorship Confirmation Statement: LJC, KM and MB conceived the study. LJC secured funding. LJC designed the study, collected, analysed the data and wrote the original draft of the article. KM and MB supervised the study. All authors contributed to reviewing the analysis and editing the article before submission.

References

- 1. Howlin P. Adults with Autism: Changes in Understanding Since DSM-111. *Journal of Autism and Developmental Disorders*. 2021;51(12):4291-4308.
- 2. Griffith GM, Totsika V, Nash S, Hastings RP. 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism.* 2012;16(5):532-546.
- 3. Finch TL, Mackintosh J, Petrou A, et al. "We couldn't think in the box if we tried. We can't even find the damn box": A qualitative study of the lived experiences of autistic adults and relatives of autistic adults. *PLOS ONE*. 2022;17(3):e0264932.
- 4. Clouder L, Karakus M, Cinotti A, Ferreyra MV, Fierros GA, Rojo P. Neurodiversity in higher education: A narrative synthesis. *Higher Education*. 2020;80(4):757-778.
- 5. Wehmeyer ML. A functional model of self-determination: Describing development and implementing instruction. *Focus on autism and other developmental disabilities*. 1999;14(1):53-61.
- 6. Wehmeyer ML. Self-Determination and Individuals with Severe Disabilities: Re-Examining Meanings and Misinterpretations. *Research and Practice for Persons with Severe Disabilities*. 2005;30(3):113-120.
- 7. Kim SY. The experiences of adults with autism spectrum disorder: Self-determination and quality of life. *Research in Autism Spectrum Disorders*. 2019;60:1-15.
- 8. Carr ME, Moore DW, Anderson A. Goal Setting Interventions: Implications for Participants on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders*. 2014;1(3):225-241.
- 9. Locke EA, Shaw KN, Saari LM, Latham GP. Goal setting and task performance: 1969–1980. *Psychological bulletin*. 1981;90(1):125.
- 10. Hodgetts S, Park E. Preparing for the future: a review of tools and strategies to support autonomous goal setting for children and youth with autism spectrum disorders. *Disability and Rehabilitation*. 2017;39(6):535-543.
- 11. Hodgetts S, Richards K, Park E. Preparing for the future: multi-stakeholder perspectives on autonomous goal setting for adolescents with autism spectrum disorders. *Disability and rehabilitation*. 2018;40(20):2372-2379.
- 12. Den Houting J, Higgins J, Isaacs K, Mahony J, Pellicano E. 'I'm not just a guinea pig': Academic and community perceptions of participatory autism research. *Autism*. 2021;25(1):148-163.
- 13. Arnstein SR. A ladder of citizen participation. *Journal of the American Institute of planners*. 1969;35(4):216-224.
- 14. Erez M. Goal Setting. In: Wiley Encyclopedia of Management. 2015:1-4.
- 15. Ogbeiwi O. Why written objectives need to be really SMART. *British Journal of Healthcare Management*. 2017;23:324-336.
- 16. Bovend'Eerdt TJ, Botell RE, Wade DT. Writing SMART rehabilitation goals and achieving goal attainment scaling: a practical guide. *Clinical Rehabilitation*. 2009;23(4):352-361.
- 17. Bowman J, Mogensen L, Marsland E, Lannin N. The development, content validity and inter-rater reliability of the SMART-Goal Evaluation Method: A standardised method for evaluating clinical goals. *Australian Occupational Therapy Journal*. 2015;62(6):420-427.
- 18. Lee CE, Shogren K, Segal J, Pezzimenti F, Aleman-Tovar J, Taylor J. Goal attainment scaling-community- based: A method to incorporate personalized outcomes into

- intervention research with youth and adults on the autism spectrum. *Autism.* 2021;26.
- 19. Jacob J, Edbrooke-Childs J, Costa Da Silva L, Law D. Notes from the youth mental health field: Using movement towards goals as a potential indicator of service change and quality improvement. *Journal of Clinical Psychology.* 2023;79(3):697-710.
- 20. Law D, Jacob J. Goals and goals based outcomes (GBOs): Some useful. information Third Edition CAMHS Press. 2015.
- 21. Haynes SN, Mumma GH, Pinson C. Idiographic assessment: Conceptual and psychometric foundations of individualized behavioral assessment. *Clinical Psychology Review*. 2009;29(2):179-191.
- 22. Duncan C, Cooper M, Saxon D. Test–retest stability, convergent validity, and sensitivity to change for the Goal-Based Outcome tool for adolescents: Analysis of data from a randomized controlled trial. *Journal of Clinical Psychology*. 2023;79(3):683-696.
- 23. Banwell E, Salhi L, Hanley T, Facey-Campbell N. The use of goal-based outcome measures in digital therapy with adults: What goals are set, and are they achieved? *Counselling and Psychotherapy Research.* 2022.
- 24. Ruble L, McGrew JH, Toland MD. Goal Attainment Scaling as an Outcome Measure in Randomized Controlled Trials of Psychosocial Interventions in Autism. *Journal of Autism and Developmental Disorders*. 2012;42(9):1974-1983.
- 25. Logan B, Jegatheesan D, Viecelli A, Pascoe E, Hubbard R. *Goal Attainment Scaling as an Outcome Measure for Randomised Controlled Trials: A Systematic Scoping Review.* 2021.
- 26. Gray CA, Garand JD. Social Stories: Improving Responses of Students with Autism with Accurate Social Information. *Focus on Autistic Behavior*. 1993;8(1):1-10.
- 27. Gray C. *The new social story book.* Future Horizons; 2000.
- 28. Gray C. Comparison of Social Stories™ 10.0 10.2 Criteria.

 https://carolgraysocialstories.com/wp-content/uploads/2015/09/Social-Stories-10.0-10.2-Comparison-Chart.pdf. Published 2015. Accessed 2022.
- 29. Camilleri LJ, Maras K, Brosnan M. Mothers' and practitioners' insights on the use of digitally-mediated social stories with children on the autism spectrum: A convergent mixed-methods study. *Res Dev Disabil.* 2021;119:104104.
- 30. 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;27:70-84.
- 31. Hess KL, Morrier MJ, Heflin LJ, Ivey ML. Autism Treatment Survey: Services Received by Children with Autism Spectrum Disorders in Public School Classrooms. *Journal of Autism and Developmental Disorders*. 2008;38(5):961-971.
- 32. Moore D, Wright B, Williams C, Moore K, Dempster PG. The experiences of parents and teachers who use social stories for children with autism spectrum disorders. *Clinical Psychology Forum.* 2014;1:10-13.
- 33. Bross LA, Travers JC, Munandar VD, Morningstar M. A packaged intervention to improve job performance of a competitively employed young adult with autism spectrum disorder. *Journal of vocational rehabilitation*. 2020;53(2):249-256.
- 34. Gray C. What is a Social Story? https://carolgraysocialstories.com/socialstories/what-is-it/. Published 2023. Accessed 08/2023.
- 35. Samuels R, Stansfield J. The effectiveness of social stories[™] to develop social interactions with adults with characteristics of autism spectrum disorder. *British Journal of Learning Disabilities*. 2012;40(4):272-285.

- 36. Karayazi S, Evans PK, Filer J. The effects of a social story[™] intervention on the prosocial behaviors of a young adult with autism spectrum disorder. *International journal of special education*. 2014;29(3):1-8.
- 37. Kokina A, Kern L. Social Story™ Interventions for Students with Autism Spectrum Disorders: A Meta-Analysis. *Journal of Autism and Developmental Disorders*. 2010;40(7):812-826.
- 38. Camilleri LJ, Maras K, Brosnan M. A rule-based theoretical account of social stories to address the double empathy problem. *Frontiers in Psychology.* 2023;14.
- 39. Leaf JB, Ferguson JL, Cihon JH, Milne CM, Leaf R, McEachin J. A Critical Review of Social Narratives. *Journal of Developmental and Physical Disabilities*. 2020;32(2):241-256.
- 40. Camilleri LJ, Maras K, Brosnan M. Autism Spectrum Disorder and Social Story Research: a Scoping Study of Published, Peer-Reviewed Literature Reviews. *Review Journal of Autism and Developmental Disorders*. 2022;9(1):21-38.
- 41. Camilleri LJ, Maras K, Brosnan M. The impact of using digitally-mediated social stories on the perceived competence and attitudes of parents and practitioners supporting children with autism. *PLOS ONE*. 2022;17(1):e0262598.
- 42. Benton L, Johnson H, Ashwin E, Brosnan M, Grawemeyer B. Developing IDEAS. 2012, 2012.
- 43. Benton L, Johnson H, Brosnan M, Ashwin E, Grawemeyer B. *IDEAS: An interface design experience for the autistic spectrum.* 2011.
- 44. Constantin A, Johnson H, Smith E, Lengyel D, Brosnan M. Designing computer-based rewards with and for children with Autism Spectrum Disorder and/or Intellectual Disability. *Computers in Human Behavior*. 2017;75:404-414.
- 45. Parsons S, Yuill N, Good J, Brosnan M. 'Whose agenda? Who knows best? Whose voice?' Co-creating a technology research roadmap with autism stakeholders. *Disability & Society.* 2020;35(2):201-234.
- 46. Marshall D, Wright B, Allgar V, et al. Social Stories in mainstream schools for children with autism spectrum disorder: a feasibility randomised controlled trial. *BMJ Open*. 2016;6(8):e011748.
- 47. Hanrahan R, Smith E, Johnson H, Constantin A, Brosnan M. A Pilot Randomised Control Trial of Digitally-Mediated Social Stories for Children on the Autism Spectrum. *Journal of Autism and Developmental Disorders*. 2020;50(12):4243-4257.
- 48. 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;75:101533.
- 49. Smith E, Constantin A, Johnson H, Brosnan M. Digitally-Mediated Social Stories Support Children on the Autism Spectrum Adapting to a Change in a 'Real-World' Context. *Journal of Autism and Developmental Disorders*. 2021;51(2):514-526.
- 50. Kumm AJ, Viljoen M, De Vries PJ. The Digital Divide in Technologies for Autism: Feasibility Considerations for Low- and Middle-Income Countries. *Journal of Autism and Developmental Disorders*. 2022;52(5):2300-2313.
- 51. Manning J, Billian J, Matson J, Allen C, Soares N. Perceptions of Families of Individuals with Autism Spectrum Disorder during the COVID-19 Crisis. *Journal of Autism and Developmental Disorders*. 2021;51(8):2920-2928.
- 52. Shogren KA, Bonardi A, Cobranchi C, et al. State of the Field: The Need for Self-Report Measures of Health and Quality of Life for People With Intellectual and Developmental Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*. 2021;18(4):286-295.

- 53. World Health O. International classification of functioning, disability and health: ICF. In. Geneva: World Health Organization; 2001.
- 54. Wallace GL, Kenworthy L, Pugliese CE, et al. Real-World Executive Functions in Adults with Autism Spectrum Disorder: Profiles of Impairment and Associations with Adaptive Functioning and Co-morbid Anxiety and Depression. *Journal of Autism and Developmental Disorders*. 2016;46(3):1071-1083.
- 55. Johnston K, Murray K, Spain D, Walker I, Russell A. Executive Function: Cognition and Behaviour in Adults with Autism Spectrum Disorders (ASD). *Journal of Autism and Developmental Disorders*. 2019;49(10):4181-4192.
- 56. St. John T, Woods S, Bode T, Ritter C, Estes A. A review of executive functioning challenges and strengths in autistic adults. *The Clinical Neuropsychologist*. 2022;36(5):1116-1147.
- 57. Desideri L, Santantonio A, Varrucciu N, Bonsi I, Sarro R. Assistive Technology for Cognition to Support Executive Functions in Autism: A Scoping Review. 2020.
- 58. Faul F, Erdfelder E, Lang A-G, Buchner A. G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*. 2007;39(2):175-191.
- 59. Cohen J. A power primer. *Psychol Bull.* 1992;112(1):155-159.
- 60. Hoekstra RA, Vinkhuyzen AAE, Wheelwright S, et al. The Construction and Validation of an Abridged Version of the Autism-Spectrum Quotient (AQ-Short). *Journal of Autism and Developmental Disorders*. 2011;41(5):589-596.
- 61. Hoekstra RA, Bartels M, Cath DC, Boomsma DI. Factor Structure, Reliability and Criterion Validity of the Autism-Spectrum Quotient (AQ): A Study in Dutch Population and Patient Groups. *Journal of Autism and Developmental Disorders*. 2008;38(8):1555-1566.
- 62. Wakabayashi A, Baron-Cohen S, Wheelwright S, Tojo Y. The Autism-Spectrum Quotient (AQ) in Japan: A Cross-Cultural Comparison. *Journal of Autism and Developmental Disorders*. 2006;36(2):263-270.
- 63. Krause KR, Edbrooke-Childs J, Singleton R, Wolpert M. Are We Comparing Apples with Oranges? Assessing Improvement Across Symptoms, Functioning, and Goal Progress for Adolescent Anxiety and Depression. *Child Psychiatry & Child Psychiatry*
- 64. O'Reilly A, McKenna N, Fitzgerald A. Measuring goal progress using the goal-based outcome measure in Jigsaw A primary care youth mental health service. *Child and Adolescent Mental Health*. 2022;27(3):238-245.
- 65. Proctor E, Silmere H, Raghavan R, et al. Outcomes for Implementation Research: Conceptual Distinctions, Measurement Challenges, and Research Agenda.

 Administration and Policy in Mental Health and Mental Health Services Research. 2011;38(2):65-76.
- 66. Weiner BJ, Lewis CC, Stanick C, et al. Psychometric assessment of three newly developed implementation outcome measures. *Implementation Science*. 2017;12(1).
- 67. Kaplan-Kahn EA, Caplan R. Combating stigma in autism research through centering autistic voices: a co-interview guide for qualitative research. *Frontiers in Psychiatry*. 2023:14.
- 68. Fletcher-Watson S, Adams J, Brook K, et al. Making the future together: Shaping autism research through meaningful participation. *Autism.* 2019;23(4):943-953.
- 69. Kondracki NL, Wellman NS, Amundson DR. Content analysis: review of methods and their applications in nutrition education. *J Nutr Educ Behav.* 2002;34(4):224-230.

- 70. Hsieh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. *Qualitative Health Research.* 2005;15(9):1277-1288.
- 71. Bengtsson M. How to plan and perform a qualitative study using content analysis. *NursingPlus Open.* 2016;2:8-14.
- 72. Lindkvist K. Approaches to textual analysis. *Advances in content analysis*. 1981;9(1):23-42.
- 73. Wehmeyer ML, Abery BH, Mithaug DE, Stancliffe RJ. *Theory in self-determination:* Foundations for educational practice. Charles C Thomas Publisher; 2003.
- 74. White K, Flanagan T, Nadig A. Examining the Relationship Between Self-Determination and Quality of Life in Young Adults with Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities*. 2018;30:1-20.
- 75. Webster AA, Garvis S. What does success mean for autistic men? A narrative exploration of self-determination. *Autism & Developmental Language Impairments*. 2020;5:239694152094552.
- 76. Reynhout G, Carter M. Social Stories™: a possible theoretical rationale. 2011;26(3):367-378.
- 77. Baron-Cohen S, Lombardo M. Autism and talent: The cognitive and neural basis of systemizing. *Dialogues in Clinical Neuroscience*. 2017;19:345-353.
- 78. Kagohara D, Achmadi D, van der Meer L, et al. Teaching Two Students with Asperger Syndrome to Greet Adults Using Social Stories((TM)) and Video Modeling. *Journal of Developmental and Physical Disabilities*. 2013;25:241-251.
- 79. Shogren KA, Dean EE, Burke KM, Raley SK, Taylor JL. Goal Attainment Scaling: A Framework for Research and Practice in the Intellectual and Developmental Disabilities Field. *Intellect Dev Disabil*. 2021;59(1):7-21.
- 80. Leaf J, Oppenheim-Leaf M, Leaf R, et al. What is the Proof? A Methodological Review of Studies That Have Utilized Social Stories. *Education and Training in Autism and Developmental Disabilitites*. 2015;50:127-141.

Supplementary Figure A

The SMART-Goal rating framework is designed to help you evaluate the quality of your story goals.

- ✓ Specific detailed and focused; describe exactly what is to be accomplished
- ✓ <u>Measurable</u> possible to determine whether you have achieved the goal
- ✓ <u>A</u>chievable can you, do it? Is it possible?
- ✓ <u>Realistic</u> feasibility; can you incorporate the goal into your schedule?
- ✓ <u>Time-frame</u> include a specified time frame

Instructions:

For each goal that you have, answer question 1 to 4 and circle your reply (Y= yes, N = No).

E.g., If your goal specified what is being targeted, then your reply to question no.1 is "Y".

In the adjacent box, score 1 (one) for a "Yes" and 0 (Zero) for a "No".

Each question represents one of the four criteria used to evaluate the quality of your goals.

Subsequently, compile the total of criteria obtained. Based on the number of criteria addressed.

Specific	1. Does the goal specify what behavior is being targeted?	Y / N	
Measurable	Can closeness to goal be measured on a scale from 0 (not at all) to 10 (totally)?	Y / N	
Achievable	3. Does the goal present a sensible and practical idea of what can be achieved or expected?	Y / N	
Realistic	4. Is the goal realistic? i.e., does it represent a behaviour that can be achieved?	Y / N	
Time-frame	5. Can this goal be achieved in the expected time-frame?	Y / N	
		TOTAL	

Supplementary Figure B

Example of story developed by a participant (50- year-old female)

Goal: To make my home more homely in the coming weeks.

Since moving into my new house I have struggled to make the house homely.

I tend to spend as much time as possible away from where I live.

I go for walks and to the library to use the WIFI to do my work.

I want to make where I live homely.

I need to make it tidier and warmer.

Buying new furniture can make the place look nicer and feel warmer.

More furniture can also help me with keeping the place organised.

Making my house more organised, warmer and nicer will make it feel more homely.

I find it hard to spend time on my home.

So I now need to schedule time to work on making my house homely.

Making my house homely is important for me.

I will start making changes by looking for furniture online.

I will then look for shops in the neighbourhood which purchase furniture.

Supplementary Figure C

The Carol Gray Assessment Framework, CGAF

Criterion	Question(s)	Yes/No	1/0*
1: The Social Story Goal	Does the story share accurate information in a safe and meaningful way?		
2: Two step	Have you tried to gather information to help		
discovery	understand the situation from the perspective of the individual?		
	Is there one clear focus, topic or goal for the social story?		
3: Three parts	Does the SS have a title, introduction (identifies and		
and a title	introduces the topic), body (adds detail) & conclusion (reinforces and summarises the information)?		
4: 'FOURmat'	Is the social story appropriate for the individual's ability (understanding, attention span, language)?		
5: "Five	Does the story adhere to the following:		
Factors Define	 Written using first or third person 		
Voice &	perspective		
Vocabulary"	 Past, Present, and/or Future Tense; 		
	 Positive and Patient Tone 		
	Literal Accuracy;		
	Accurate Meaning.		
6: Six	Does the social story answer questions relevant to the		
Questions that	specific topic (who, what, when, why, where, how)?		
guide Story development			
7: Seven Types	Does the social story have at least one descriptive		
of Sentences	sentence?		
8: 'A GR-EIGHT	Does the social story have fewer coaching sentences		
Formula'	than descriptive sentence? (number of Descriptive		
	sentences divided by number of Coaching sentences ≥ 2)		
9: Nine Makes it Mine	Is the social story tailored to the individual's interests?		
10: Ten Guides	• Edit		
to Editing &	Plan for Comprehension;		
Implementatio	Plan Story Support;		
n	Plan Story Review;		
	 Plan a Positive Introduction; 		
	Monitor		

^{*}Meets criteria = 1, Does not meet criteria = 0

Supplementary Figure D

Interview questions that were administered during the online survey and online interview:

Q1: Please describe your experience as a participant in this study.

Q2: How was your experience with using the digital application to develop and deliver your own stories?

Q3: Did you reach your goal at the end of the two weeks?

Q4: How was your experience of identifying your own goal?

Q5: What is your opinion of the usefulness of digital technologies, such as SOFA, for autistic adults?

Q6: Was the digital aspect of the story development and self-delivery something you enjoyed? Can you explain?

Q7: What do you think are the benefits of digital technology for the autistic community?