

Support Preferences and Clinical Decision Support Systems (CDSS) in the Clinical Care of Autistic Children: Stakeholder Perspectives

Author

Sulek, Rhylee, Robertson, Julia, Goodall, Emma, Liew, Alan Wee-Cheung, Pillar, Sarah, Upson, Gemma, Whitehouse, Andrew JO, Wicks, Rachelle, Trembath, David

Published

2024

Journal Title

Advances in Neurodevelopmental Disorders

Version

Version of Record (VoR)

DOI

[10.1007/s41252-024-00410-4](https://doi.org/10.1007/s41252-024-00410-4)

Rights statement

© The Author(s) 2024. This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>.

Downloaded from

<https://hdl.handle.net/10072/431711>

Griffith Research Online

<https://research-repository.griffith.edu.au>



Support Preferences and Clinical Decision Support Systems (CDSS) in the Clinical Care of Autistic Children: Stakeholder Perspectives

Rhylee Sulek^{1,2} · Julia Robertson³ · Emma Goodall¹ · Alan Wee-Cheung Liew⁴ · Sarah Pillar² · Gemma Upson² · Andrew J. O. Whitehouse² · Rachelle Wicks⁵ · David Trembath^{1,2,5}

Accepted: 21 June 2024
© The Author(s) 2024

Abstract

Objectives Clinical decision support systems (CDSS) are increasingly utilised within healthcare settings to enhance decision making. However, few studies have investigated their application in the context of clinical services for autistic people, with no research to date exploring the perspectives of the key stakeholders who are, or in the future may be, impacted by their use. Given the importance of stakeholder perspectives in ensuring that CDSSs are relevant, feasible, and acceptable to those who use them, the aim of this study was to examine the views of key stakeholders in relation to support preferences and a proposed CDSS intended to aide in the selection of the most appropriate supports for autistic children.

Method Using a co-designed, mixed-methods approach, 20 participants comprising autistic adults, parents of autistic children, and practitioners providing services to autistic children were invited to participate in focus groups, or an open-ended online survey, to explore views regarding support provision and any opportunities, barriers, recommendations, and support for the use of CDSSs in clinical practice.

Results Participants highlighted potential benefits of using a CDSS in clinical practice, such as creating efficiencies and consistency in decision making when selecting therapies and supports, provided it was part of a holistic approach to working with autistic children. Potential barriers largely centred on concerns about the safety of data to be utilised within the system.

Conclusions The findings indicate that CDSS have the potential to play a valuable role in selecting supports for autistic children, providing appropriate safeguarding occurs.

Keywords Autism · Clinical decision support system · Therapy · Intervention · Evidence-based practice · Experiences

Clinical supports during the early years can help provide a positive foundation for independence and later learning and participation for many children with a diagnosis of autism and/or other neurodevelopmental conditions (Cioni et al., 2016). The substantial variation in individual profiles

of needs and strengths across children with a diagnosis of autism necessitates individualised supports. Decision-making regarding the selection and implementation of the most appropriate supports should occur within an evidence-based practice (EBP) framework, whereby practitioners integrate the best available empirical evidence, an understanding of the individual (i.e., the child and their family), availability of supports, and their own professional judgement (Sackett et al., 2000). Ensuring the most appropriate supports are recommended is critical to maximise clinical outcomes and minimise risks for children and families, who may otherwise be exposed to ineffective and potentially harmful practices. In the absence of clear and consistent research evidence to inform the selection of therapies and supports, allied health practitioners may need to rely heavily on evidence generated in clinical practice when making recommendations for individual children and families to improve outcomes. Computerised Clinical Decision Support Systems (CDSS) may

✉ Rhylee Sulek
r.sulek@griffith.edu.au

¹ Menzies Health Institute Queensland, Griffith University, Griffith University Parklands Dr, Southport, QLD 4222, Australia

² Clinicids, Telethon Kids Institute, Perth, Australia

³ School of Medicine and Dentistry, Griffith University, Southport, Australia

⁴ School of Information and Communication Technology, Griffith University, Southport, Australia

⁵ School of Health Sciences and Social Work, Griffith University, Southport, Australia

offer a novel solution to improving the timeliness, accuracy, and appropriateness of clinical decisions within the context of child neurodevelopmental conditions, such as autism.

CDSS are intended to enhance clinical decision making, and ultimately service delivery (Sutton et al., 2020). They work to match an individual's data (i.e., the person accessing clinical services) with a broader knowledge base—drawn from the literature, practice information, or aggregated data of individuals who have received supports—to generate personalised recommendations (Lysaght et al., 2019; Sutton et al., 2020). While CDSS are intended to augment, rather than replace, traditional decision-making processes and practices (Sutton et al., 2020), advances in technology (e.g., machine learning and artificial intelligence [AI]) have enabled these systems to leverage complex data sets in providing recommendations and clinical insight, with inbuilt logic able to analyse and connect seemingly disparate information to inform decision making (Lysaght et al., 2019; Sutton et al., 2020). CDSS have been developed and implemented to support a range of processes within healthcare settings, including (but not limited to) diagnostic support (Honaker & Downs, 2018; John et al., 2007), client safety, in particular pharmaceutical management (Zorina et al., 2013), and documentation of clinical processes (Haberman et al., 2009). The application of CDSS in generating evidence informed recommendations for treatment selection in psychotherapy practice, based on client characteristics, has also been investigated (see Lutz et al., 2021). However, despite the widespread potential for CDSS to support practitioners working with children diagnosed with neurodevelopmental conditions such as autism, their application has yet to be explored.

In a recent scoping review, the authors (Sulek et al., 2022) examined the available literature relating to the use of CDSS in the delivery of clinical services to children with neurodevelopmental conditions. Of six studies that met inclusion criteria, all studies described a CDSS that aimed to support the screening and/or diagnosis of children for neurodevelopmental conditions (including autism, attention-deficit/hyperactivity disorder, language disorder, broad developmental conditions), and five of these reported on one CDSS, the Child Health Improvement through Computer Automation system (CHICA). While outcomes of CDSS implemented in these studies were broadly positive, leading to higher screening compared to baseline levels or a control group, there was little consideration of potential barriers and enablers to CDSS. Additionally, there were no attempts made to capture feedback from a diverse group of end users of these systems following their implementation, and little evidence to suggest the involvement of end users in their development (Sulek et al., 2022). Further, despite the potential application of CDSS to aid clinical decision making regarding the appropriateness of available therapies and supports in

neurodevelopmentally diverse children, this has yet to be explored in the extant literature.

The lack of evidence regarding end user and other stakeholder views towards CDSS is salient given possible risks of CDSS that have been raised. As noted by Sutton et al. (2020) concerns have ranged from the risks of alert fatigue (whereby users ignore system alerts if these are too frequent or perceived as not helpful), the requirement of ongoing system maintenance, and the operational impact of an incomplete or not regularly updated knowledge base. Criticisms of CDSS have also included a lack of studies examining the outcomes of individuals, in addition to practitioner outcomes after the implementation of CDSS (Trevana et al., 2014). However, a more recent review has found that the majority of papers included (69%) reported on medical outcomes of individuals, with positive outcomes (e.g. improvements in patient symptoms and treatment adherence) frequently cited (see Kruse & Ehrbar, 2020).

With advances in research, information and communication technology, AI, and machine learning, the authors suggest that CDSS may provide a novel tool to assist allied health practitioners in making tailored decisions to support neurodevelopmentally diverse children. For example, for a family whose child has just received an autism diagnosis, a CDSS may be implemented at the point of contact with an allied health service to capture key information about the child and family, which is then combined with evidence from the best available research and clinical practice to make recommendations regarding the available supports which are likely to best match their needs and desired outcomes. However, before such a system is developed, there is a clear need to first understand how utilisation of a CDSS might be perceived by end users. Therefore, this study aimed to first examine the views of key stakeholders concerning the provision of therapies and supports and clinical decision making, and second, gather their views on a proposed CDSS, intended to aide in the selection of the most appropriate supports for autistic children.

Method

Design

A co-designed approach was employed in the present study, whereby researchers and individuals with lived experience as autistic adults, parents and caregivers of autistic children, and practitioners providing services to autistic children were engaged across multiple stages of the research process. A mixed-method qualitative design was then employed, utilising a series of focus groups and open-ended surveys conducted with key stakeholder groups to investigate consumers' views regarding opportunities, barriers,

recommendations, and support for the use of CDSSs in clinical practice.

Participants and Procedure

Ethics approval was obtained from the first author's research institute (HREC 2021/698).

Advisory Group

Potential advisory group members were identified through the research teams' professional networks and were approached and invited via email to contribute to the project. All invited individuals ($n=6$) agreed to take on a role within the advisory group, with members who participated in advisory group activities outside of their regular work duties ($n=4$) offered an honorarium to acknowledge their contributions. Members of the advisory group met on multiple occasions, with meetings facilitated by the first and last authors, and assisted in development of the frame of the research. Key responsibilities of the advisory group included (a) determining the language to be used when referring to individuals with a diagnosis of autism; (b) providing perspectives and feedback on the semi-structured focus group/survey guide; (c) providing feedback on the slide deck to be used during focus groups to ensure the content was appropriate, accessible, and suitable for each participant group; (d) assisting with interpretation of data collected; and (e) contributing to preparation of the manuscript.

Focus Groups

Participants were snowball recruited via social media posts and the professional networks of the study authors. Potential participants were invited to register via an online form, which included detailed study information and asked participants to indicate their consent to participate. Participants were also asked to indicate their preferred date to attend an online focus group. Those who registered were sent links to access the online focus group, including information about the accessibility features of Microsoft Teams software that would be used to facilitate focus groups, and a sample of the focus group questions ahead of time. Participants were asked to first reflect on their experiences of accessing (autistic individuals and parents/caregivers) or providing therapies and supports (practitioners), including the consideration of how decisions are made. Participants were then asked to provide feedback on a proposed CDSS that might be used in practice to assist practitioners in their selection of therapies and supports for autistic children. See the Appendix for the semi-structured interview guide. A series of PowerPoint slides were used to facilitate the focus groups and included information about the broader study goals and the research

team, and an overview of the questions to be addressed during the session. Those attending were invited to have their camera on or off for the duration of the focus groups and were able to provide responses via the chat function if preferred. Where participants had registered and were subsequently unable to attend their scheduled focus group, they were invited to complete a short survey addressing the same questions. The online survey included embedded videos to help contextualise the questions and ensure participants had the same information to respond to as the other focus group members.

Of 38 individuals who registered their interest in participating in the research, a total of 14 participants attended a focus group ($n=9$ autistic adults, $n=2$ parents, $n=3$ practitioners). A further six participants completed the online survey ($n=1$ autistic adult, $n=4$ parents, $n=1$ practitioner). Across groups, participants predominantly identified as female (60%) were aged between 18 and 49 years, with the majority indicating a bachelor's degree as their highest educational qualification (55%). For autistic adults ($n=10$), the majority (80%) of this cohort indicated that they had previously accessed therapies and supports, including psychology services, occupational therapy, speech and language therapy, and psychiatry. All parents ($n=6$) indicated they had previously accessed therapies and supports for their autistic child, including psychology services, occupational therapy, speech and language therapy, behaviour therapy, paediatricians, and dieticians. Participating practitioners ($n=4$) included a behaviour therapist, early education teacher, occupational therapist, and psychologist. The majority of practitioners (75%) provided services to children aged 0–5 years and worked in a single discipline private practice. See Table 1 for further details.

Analysis

The framework method of analysis, as outlined by Gale et al. (2013), was selected to qualitatively analyse participant data. This method was well suited to the study aims, given its capacity to make comparisons and identify relationships across groups of participants. Further, it allowed for the application of pre-defined concepts to the data while also giving space for new ideas to be generated during analysis.

As per Gale et al. (2013), focus groups transcripts and survey responses were analysed using the seven stages of the framework method of analysis. Following transcription of focus groups (stage one), all responses were read, and re-read, in full by the first and second authors (stage two). Any notes collected during focus groups were also reviewed during this stage. Line by line, open coding was then conducted independently by the first and second authors on two transcripts (stage three). Following independent coding, the first and second authors met to discuss the coding schemes

Table 1 Participant demographics

Demographics	<i>N</i>	%
Age		
18–29	9	45
30–39	7	35
40–49	4	20
Gender		
Female	12	60
Male	5	25
Non-binary	3	15
Education		
Secondary (high) school	3	15
Trade/technical/vocational training	4	20
Bachelor's degree	11	55
Postgraduate degree (master's or PhD)	2	10
Autistic adults*		
Previous accessed therapies and supports		
Yes	8	80.00
No	2	20.00
Types of professionals previously accessed (all that apply)		
Occupational therapist	3	30.00
Psychologist	8	80.00
Speech language pathologist	2	20.00
None	2	20.00
Other	3	30.00
Parents or carers of autistic children*		
Previous support accessed		
Yes	6	100.00
No	0	0
Types of clinicians accessed (all that apply)		
Behavioural therapist	2	33.33
Occupational therapist	5	83.33
Psychologist	4	66.67
Speech language pathologist	4	66.67
Other		
Practitioners*		
Profession		
Behaviour therapist	1	25.00
Occupational therapist	1	25.00
Psychologist	1	25.00
Early education teacher	1	25.00
Age range of clients		
0–5 years	3	75.00
6–12 years	3	75.00
12–18 years	2	50.00
Setting		
Single discipline private clinic (e.g., speech pathology only)	3	75.00
School	1	25.00
Capacity		
Individual practice/sole practitioner	4	100

Note. *N* = 20 (*n* = 10 autistic adults, *n* = 6 parents/carers, *n* = 4 practitioners)

used. Any differences in coding, differences in interpretations of the data, or overlap between codes were discussed until the authors reached a consensus. Similar codes were then grouped into categories, with the first and second authors creating brief descriptions of each code, which formed the analytical framework (stage four). The analytical framework was then taken to the advisory group who were invited to provide feedback. No changes were made at this stage. The first and second authors then applied the analytical framework to the remaining transcripts, creating new codes where necessary (stage five). NVivo software was used to code all transcripts, with participant data charted into a matrix (stage six). The matrix can be accessed via request to the first author. After reviewing the matrix, the first and second authors met again to generate themes, making connections across participants and categories (stage seven). This process was guided by the research aim, with themes and associated subthemes reflective of the use of a CDSS in the context of broader issues surrounding support provision. The development of themes aimed to provide abstract explanations of the data collected. In reporting the results, participant identifiers have been used where an ID beginning with an 'A' indicates an autistic adult, 'Pa' indicates a parent, and 'Pr' indicates a practitioner.

Credibility

Several measures were taken to ensure the quality of this study. Participants were sent a summary of the results to ensure that the findings were an accurate representation of experiences and provided an opportunity to provide any further feedback or clarification at this stage. No further feedback was received from participants; however, it is possible that this is indicative of participants lacking time to respond to this request rather than their agreement with the interpretation of the data collected. The advisory group was also provided with a summary of the coding framework and associated quotes and were given the opportunity to review and contribute to the preparation of the manuscript. Furthermore, quotes and phrases used by the participants have been used in reporting the findings of this study, to ensure that the findings reflect the voice of the participants.

It is also important to note the perspectives that the research team brought to the study (Patton, 2015). The first author is a research fellow who believes in the importance of utilising evidence-based practice frameworks in supporting autistic children and their families. The second author is a research assistant with lived experience of disability with experience in co-design. The remaining authors represent multiple perspectives including autistic individuals, parents of autistic young children, practitioners, and those working in research fields related to autism and disability more broadly.

Results

The analysis resulted in the identification of two themes, each with associated subthemes, see Table 2. The first theme, '*Shift in support provision*,' encompassed the experiences of participants in accessing and providing supports, highlighting important learning opportunities for the implementation of CDSS. Theme two, '*Benefits and barriers of a CDSS*,' explicitly identifies participant perspectives regarding the potential benefits and possible barriers of integrating a CDSS in the clinical decision-making process. These themes, along with illustrative quotes, are presented below.

Theme One: Shift in Support Provision

"Consider Us as Whole People"

All participants described the need to consider the complexity of the children and their family's accessing therapies and supports, including factors both inherent to the child and family and their immediate context. For one autistic adult, they expressed a desire for practitioners to consider the ways in which their autism diagnosis may impact their access to other supports, "If I'm going to a psychologist, for example for a non-autistic reason, whether that be my anxiety, through the roof or whatever. I still think they need to make sure that that service is appropriate for autistic people if that makes any sense" (ID A1). However, for another autistic individual, their autism diagnosis could overshadow other support requirements, leading to unmet needs "it was that assumption that autism is this overarching umbrella of my life than looking at all the different areas on how my on how my brain works" (ID A2). Evolving understandings of how females present with autism is also required, "... so in young girls they will go you are depressed, and you are anxious. Not that you are facing, you know like huge challenges. They will go for the easiest option." (ID A5). One parent similarly shared that support for autistic young girls looks different, "so going somewhere that really understood girls. I didn't know, you know, we all know the stereotypes about ASD. I didn't realise how it presents with in girls" (ID Pa2).

It was also noted that factors external to the individual should be considered when recommending supports and services, as one autistic adult stated "because I'm relatively rural. Like I don't live in the city. It's like that kind of limits options, I guess" (ID A1). One practitioner also highlighted the need to reflect on family circumstances when planning for supports, "logistics and timing and energy and parent mental health? What else is going on

Table 2 Themes, subthemes, and associated quotes

Themes and subthemes	Associated quotes
Theme 1: Shift in support provision	
<i>Consider us as whole people</i>	<p>“Yeah, she definitely failed to take into account like a lot of like, I also have OCD ... She was kind of ignoring that as a factor which kind of halted a lot of different treatment opportunities.” (Autistic adult)</p> <p>“I think they need to have a really good understanding first and foremost about what your family dynamic is because if you don’t know what that looks like and have an understanding of the practical side of home slash work slash schooling slash, what you know whatever happens in that person’s life without having that really good depth, it’s very, I think that it’s not as beneficial.” (Parent)</p>
<i>What the autistic person wants themselves</i>	<p>“It must always be in the best interests of the autistic person themselves or the person who is suspected to be potentially autistic and is going through this decision-making process.” (Autistic adult)</p> <p>“Each autistic child has different needs and support. They (practitioners) need to make sure to clearly understand about child conditions before recommending any therapy. Not just use same therapy method for similar cases.” (Parent)</p> <p>“Listen to autistic adults speaking about their experience... I really try and listen to people’s lived experience as well and that influences what I do also. Especially around autistic identity and having a strengths-based practice.” (Practitioner)</p>
Theme 2: Benefits and barriers of a CDSS	
<i>This could be very useful</i>	<p>“When it comes to disability support, and I think in some circumstances that could be beneficial for devising up an individual learning plan or education plan.” (Autistic adult)</p> <p>“I think overall it certainly helps develop the opportunities to give parents the best advice based on the evidence. But that doesn’t always fit.” (Parent)</p> <p>“Some of them (parents) are really quick to say, ‘I just want my child in a mainstream setting’, whereas we know clinically that’s not the best for them. But this might help back up some of that because, you know, it has been a process and it’s. It’s all been, you know, vetted.” (Practitioner)</p>
<i>A little wary</i>	<p>“...because that sort of thing is something that is principally like, it’s not up to a computer to decide yes, you are autistic, or yes, you have depression or something like that, like that’s, it’s a really problematic approach there.” (Autistic adult)</p> <p>“I definitely see a lot of value in that, but I would be hesitant to utilise it if there was no flexibility in pulling some parts out, but no one knows their child like a parent does. (Parent)</p> <p>“But I have a slight hesitation because I guess information is power and I would want to know how in detail how that how that system worked to be confident that I was contributing to a system that I felt was really clinically sound and really ethical and not that couldn’t be like misused or something.” (Practitioner)</p>

in the family? Sometimes we have siblings, and we might have multiple clinicians working with other family members. So, thinking about the family functioning generally” (ID Pr2). This was further supported by another practitioner who said “What’s a reasonable amount of therapy that you can incorporate into your daily life? Because it’s not just me. There’re other therapists as well. So yeah, trying to help provide adequate and yet not overwhelming supports for a family...” (Pr3). Understanding the context of the whole family was also important to parents who participated, as one mother stated,

I have a child, he’s predominantly in a wheelchair, my other child, so some of the recommendations for us really can’t fit, uh, because they’re not practical for me to be able to manage individual care specifically in a situation where there’s not. It’s not set up for other abilities as well. (ID Pa1)

Finally, there was a shared desire across participant groups for each person accessing supports to be considered unique individuals. As one autistic adult highlighted, a diagnosis of autism may look different from person to person, “There’s no, you know, just stereotypes that become like kind of arbitrary as if this person must be like them because he’s under this certain diagnosis. It’s more understanding that it’s individuals” (ID A7). The need to consider the unique presentation of individuals was viewed as particularly salient in the selection of the most appropriate support for that person, as described by an autistic individual, “No two of us are exactly alike, so just because something worked for one person doesn’t necessarily mean it’s going to for everyone else” (ID A6). While practitioners may draw on their experiences with other children with an autism diagnosis when working to support a particular child and family, it was noted that this may be a concern “... I suppose families could feel

you're, as a clinician, kind of putting my child in the same box as every other child that's has a [sic] has similar support needs" (ID Pr3). This was further corroborated by a parent who stated "each autistic child has different needs and support. They need to make sure to clearly understand about child conditions before recommending any therapy. Not just use same therapy method for similar cases" (ID Pa5).

"What the Autistic Person Wants Themselves"

Central to proposed shifts in the provision of support to autistic individuals were issues around agency and consent provided by those receiving supports. Reflecting on their own experience in receiving supports as a child, one autistic individual highlighted a lack of agency given to young people engaging with support providers, "just as an example for a lot of parents they want their kids enrolled in things like [specific therapy]. Regardless of the autistic persons feelings about that and that their autonomy and like communication is often ignored and dismissed" (ID A2). Placing the child or young person receiving supports at the centre of decision-making processes was non-negotiable, "It needs to remain current and relevant and practical and at the number one priority should be the autistic person and ensuring that they are happy and healthy and benefit from this the most" (ID A6). A sentiment that was further emphasised by a parent who commented, "I would like to have clinicians who consider the conditions of the child to support the child best" (ID Pa5).

Participating practitioners, when reflecting on their own practice, also highlighted the importance of working in the interests of the child and involving them in aspects of decision making, "They're sort of ongoing conversations that we have with families and encouraging with family to bring it back to some of the child's goals as well and keeping the child centre" (ID Pr2). This practitioner further specified what this looked like involving the child in the early stages of goal setting, "we really try to be collaborative with their child, so identifying goals that the child has about areas that they're finding difficult and coming up with ideas for need based on that" (ID Pr2). Having a thorough understanding of the child, the family, and their context also supported another practitioner in their decision making,

... Something strategic and manualised can then become very flexible and individualised based on [family functioning] like whether you know even [their] access to materials at home. And making a set of objectives really pragmatic for that child and for their family as well. (ID Pr1)

Theme 2: Benefits and Barriers of a CDSS

"This Could Be Very Useful"

Some potential advantages to the integration of a CDSS in decision making included streamlining service delivery. For some, it was suggested that this might look like efficiency in connecting children and families with the most appropriate therapies and supports,

I think if like the proper treatment, can be the first thing that is tried as an option instead of like the fourth or fifth. Yeah, it would just save a lot of time and money in terms of helping people out with that kind of thing. (ID A2)

Creating consistency in decision making processes was also seen as a potential advantage, including in the ways in which decisions are communicated with children and families, as one practitioner noted, "if there were some way to take the way we do things and sort of format it in a readable format ... if everyone was on the same page, then that would be pretty cool" (ID Pr1). In addition to creating efficiencies in communicating decisions, one autistic adult suggested a CDSS may encourage practitioners to gather information which aligns with the holistic approach described earlier, "it would be a good idea for clinicians to have prompts about, you know, including a more complex and comprehensive picture for their patients and their clients" (ID A6).

That a CDSS might help build capacity in practitioners providing services to children and families was raised across groups. As one parent noted, this might be particularly salient where practitioners are less experienced, "I feel that depending on the clinician this could be very useful as they often have limited experience dealing with severe autism" (ID Pa4). Similarly, another practitioner highlighted that the tool may serve different functions for different users, depending on their experience, "I think it's for someone who you know has some experience, it's going to be a well, number one, probably both reassuring that they're on the right track and give them some additional ideas that they might not have thought of. And I think for younger graduates it's going to probably reduce a lot of their stress" (ID Pr3). The idea that a CDSS might highlight previously under-utilised or unknown supports was also highlighted, as one autistic adult stated, "best case scenario, clinicians are authentically using this tool to help them make better, you know a better outcome for their client in, or there's this modality that we haven't thought about before" (ID A5). This was further highlighted by a practitioner who recognised that in practice there may be over reliance on familiar strategies, with a CDSS possibly helping to overcome this,

I mean that there is that clinical bias of you know, these are my three go to things that I think of or recommend and so making sure that clinicians are thinking really broadly about and that and holistically about the whole the whole picture and thinking of and so I think it will be really helpful in that way. (ID Pr2)

Despite the possible benefits of CDSS in building capacity, as one autistic adult stated, ongoing practitioner training in working with autistic individuals should remain a priority,

We need to kind of retrain the [sic] clinician... to understand autistic thinking. All that kind of stuff before we bring in systems like that in order to provide the best ethically and autistic centred therapy or support or whatever. (ID A1).

“A Little Wary”

Despite generally supportive views around utilising a CDSS to support decision making, participants raised concerns. Among these were issues of data access and confidentiality, as one practitioner queried, “I’m kind of curious about who owns the information and who has access to it?” (ID Pr2). Safeguarding participant data through clear planning and ethical processes was suggested by another autistic adult to avoid possible misuse of sensitive information, “What are the ethics and what’s the worst possible scenario...that this data could end up leading to?” (ID A5). A sentiment further supported by a parent who enquired, “I’m guessing when you do any of these things you do the detailed risk analysis?” (ID Pa2).

Participants also recognised the potential limitations of a computer-based system in its ability to provide individualised supports to children and families, as highlighted by one autistic adult “you don’t get that personalised support with an AI bot, no matter how well you train it up, it’s just never going to happen” (ID A1). The need for a CDSS to be complementary to a practitioner’s interactions with children was further raised by a parent who said, “It might be helpful for autistic children, as long as the time clinicians spend on each child need to be more than on computer tool system” (ID Pa5). Participating practitioners further raised concerns about a CDSS reducing individualised approaches to supports, “That, you know, you’ve got a child and family like this, so do this. And that may feel uncomfortable to therapists who are used to really customising in and individualising supports” (ID Pr3). A concern also expressed by some parents, “I think overall it [could] certainly help develop the opportunities to give parents the best advice based on the evidence. But that doesn’t always fit” (ID Pa1).

Discussion

Connecting autistic children and their families with appropriate therapies and supports that meet their individual goals, in a timely manner, is a known priority of practitioners working with children with neurodevelopmental conditions such as autism. The implementation of a CDSS in this field may contribute to meeting this need; however, little is known about their acceptance by key stakeholders in this field. The purpose of this study was, therefore, to understand experiences of key stakeholders relating to the delivery of therapies and supports, and to further explore their views about the implementation of a proposed CDSS intended to aide in the selection of the most appropriate therapies and supports for autistic children.

In sharing their experiences accessing or providing therapies and supports, the first theme captured desires expressed by stakeholders regarding overarching shifts in supporting autistic individuals and their families. The need for more holistic approaches to support provision is consistent with the neurodiversity movement, which encourages a move away from deficit focused conceptualisations of autism and towards embracing individual strengths and placing value in individual differences (Botha et al., 2022; den Houting, 2019). By recognising and respecting individual differences and placing the person with autism at the centre of decision-making processes, therapies and supports provided are much more likely to meet the needs of the individual and their family. Stakeholders in the current study further highlighted the need for holistic therapies and supports to also capture the broader familial and environmental contexts of individuals. Possible frameworks for achieving this have previously been suggested relating to determining the optimal amount of intervention (see Trembath et al., 2021). This framework encourages practitioner to be cognisant of key factors when making decisions and include recommendations to consider the practicality of the fit between suggested therapies and supports and an individual and family’s circumstances, the desirability of the amount of support to both the child and family, and both the possible benefits and costs to the child and their family (Trembath et al., 2021).

Clearly, for a CDSS to be appropriate, it will need to align with and support the positive shift in practice participants describe. For example, although a CDSS has the potential to assist clinicians in identifying and making sense of vast amounts of information to support personalised decision making, a poorly designed system could result in the adoption of simplistic impairment-focused algorithms that would undermine the gains made towards neurodiversity-affirming, holistic practice. The views shared by participants in the current study highlight the

importance of human interaction in clinical support provision, emphasising that while a CDSS may contribute to the decision-making process, it cannot, and should not, replace or minimise the importance of highly skilled practitioners who are trained and experienced in the provision of neurodiversity affirming therapies and supports.

The second theme outlined the possible benefits and barriers regarding the implementation of a CDSS as proposed. The various stakeholders identified the potential to support efficiencies in the delivery of services to autistic children, which may in turn help address chronic challenges children and families face in accessing services (Commonwealth of Australia, Department of the Prime Minister and Cabinet, 2023). Indeed, with the increasing role of technology in medicine and the shift towards electronic medical records and databases, we expect that tools such as CDSS will gain increased importance and become more common in clinical settings (Chen et al., 2023). When coupled with advancements in AI, these systems will likely continue to self-improve in their capacity to analyse the vast oceans of data to provide decision support, a prospect which is likely attractive to practitioners. However, despite the great potential of AI-based CDSS in healthcare, there has not been widespread adoption of this technology in clinical practice given many challenges that are yet to be overcome, of which a major one is concerning the explainability of the AI prediction (Amann et al., 2020; Chen et al., 2023; Shortliffe & Sepúlveda, 2018).

Explainability, also referred to as transparency or interpretability, enables user understanding and interpretability of predictions generated by AI-enhanced CDSS (Amann et al., 2020). From both a practitioner and client perspective, increased explainability may help generate trust in users of AI technology and overcome the concerns raised within the present study. This seems particularly salient when considering the application of CDSS in decision making regarding the appropriateness of therapies and supports for children with neurodevelopmental conditions and their families. In person-centred care, those receiving supports are considered active partners in the care process and should share in decision making, with explainability necessary to facilitate a shared decision-making process (Amann et al., 2020). The legal and ethical difficulties arising from lack of explainability, and trust, may prevent AI-based CDSS from fulfilling their potential to improve individual outcomes (Amann et al., 2020; Chen et al., 2023; Shortliffe & Sepúlveda, 2018).

Limitations

The findings of the present study explore broader concerns regarding the provision of therapies and supports for autistic children and provide a preliminary glimpse into issues

surrounding potential implementation of CDSS. The methodological strength of this study lay in its codesign and the ability to ensure that key stakeholder perspectives were gathered when seeking feedback on CDSS. A core limitation of the current study was its small sample size. Despite meeting recruitment targets prior to conducting focus groups, less than half of the registered participants attended their scheduled focus group. While focus groups were supplemented with the invitation to provide written feedback via an online survey it is important to note that this approach lacks the depth and richness of information gathered in group settings. Further, we did not capture information on participants' race, ethnicity, cultural backgrounds, or socio-economic status. As these factors may impact the experiences of individuals in accessing or providing therapies and supports, future research should endeavour to capture a broader range of perspectives.

Conclusion

CDSS have the potential to support clinical decision-making and work towards eliminating inefficiencies in the provision of therapies and supports to autistic children and their families. With few attempts to utilise CDSS in the field of autism, and those attempts largely concerned with diagnostic processes (Sulek et al., 2022), it is suggested that any future attempts to support implementation are informed by findings from broader fields of study and developed in collaboration with key stakeholder groups. This will ensure that systems are designed and implemented in ways that create confidence, build trust, and complement existing best practice frameworks in support provision for autistic children and their families.

Appendix

Sample Focus Group Questions—Autistic Adults

We would like to hear about your experiences of working with clinicians to make decisions about the supports provided to you. This could include working with a speech pathologist, psychologist, occupational therapist, or other allied health worker.

- Reflecting on these experiences, how do you think these clinicians' made decisions about the supports they recommended?
- What types of information do you think they (the clinician) considered when making their recommendations?
- What types of information would you like them to consider when making decisions?

What about information clinicians have gathered from working with other autistic persons who have accessed the service previously? For example, if they had information to suggest that some people with a particular profile of skills and needs seem to benefit most from approach A, whereas others who have a different profile of skills and needs seem to benefit most from approach B, would you like them to consider this when making recommendations for you?

- Why? Why not?
- How would you feel about your own information being used in a similar way – completely de-identified of course – in attempt to make the best possible recommendations for other autistic persons in the future?

As you may be aware, in most healthcare settings electronic medical records are now the norm. This can include the results of assessments you have completed, or other therapy data (depending on the setting) being stored electronically. This has opened up the possibility of using artificial intelligence and machine learning to look for patterns in the data that clinicians are collecting, to try to answer questions such as which approach seems to be most effective for autistic children or adults, and under what circumstances. If done appropriately, this information could be used to inform – not replace – the recommendations clinicians make.

- How do you feel about this?
- What are the potential benefits?
- What about the risks?
- What safeguards would you like to put in place?

Acknowledgements We thank the autistic individuals, parents, and clinicians who contributed to this project, including members of the advisory group Kim Delroy, Karen Fleischer, and Katia Haines.

Funding Open Access funding enabled and organized by CAUL and its Member Institutions. This research was supported by a Griffith University Health Group Seed Grant.

Data availability Deidentified data can be requested from the corresponding author.

Declarations

Conflict of Interest The authors declare no competing interests.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will

need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>.

References

- Amann, J., Blasimme, A., Vayena, E., Frey, D., & Madai, V. I. (2020). Explainability for artificial intelligence in healthcare: A multidisciplinary perspective. *BMC Medical Informatics and Decision Making*, 20(1), 310. <https://doi.org/10.1186/s12911-020-01332-6>
- Botha, M., Dibb, B., & Frost, D. M. (2022). "Autism is me": An investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, 37(3), 427–453. <https://doi.org/10.1080/09687599.2020.1822782>
- Chen, Z., Liang, N., Zhang, H., Li, H., Yang, Y., Zong, X., Chen, Y., Wang, Y., & Shi, N. (2023). Harnessing the power of clinical decision support systems: Challenges and opportunities. *Open Heart*, 10(2), e002432. <https://doi.org/10.1136/openhrt-2023-002432>
- Cioni, G., Inguaggiato, E., & Sgandurra, G. (2016). Early intervention in neurodevelopmental disorders: Underlying neural mechanisms. *Developmental Medicine & Child Neurology*, 58(Suppl 4), 61–66. <https://doi.org/10.1111/dmcn.13050>
- Commonwealth of Australia, Department of the Prime Minister and Cabinet. (2023). *Working together to deliver the NDIS – Independent review into the National Disability Insurance Scheme: Final report*.
- den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, 23(2), 271–273. <https://doi.org/10.1177/1362361318820762>
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1), 117–124. <https://doi.org/10.1186/1471-2288-13-117>
- Haberman, S., Feldman, J., Merhi, Z. O., Markenson, G., Cohen, W., & Minkoff, H. (2009). Effect of clinical-decision support on documentation compliance in an electronic medical record. *Obstetrics & Gynecology*, 114, 311–317. <https://doi.org/10.1097/AOG.0b013e3181af2cb0>
- Honaker, S. M., & Downs, S. M. (2018). Automated universal OSA screening in pediatric primary care. *Sleep*, 41, A277. <https://www.embase.com/search/results?subaction=viewrecord&id=L622361372&from=export>
- John, R., Buschman, P., Chaszar, M., Honig, J., Mendonca, E., & Bakken, S. (2007). Development and evaluation of a PDA-based decision support system for pediatric depression screening [Article]. *Medinfo*, 12(Pt 2), 1382–1386. <https://www.embase.com/search/results?subaction=viewrecord&id=L350039388&from=export>
- Kruse, C. S., & Ehrbar, N. (2020). Effects of computerized decision support systems on practitioner performance and patient outcomes: Systematic review. *JMIR Medical Informatics*, 8(8), e17283–e17283. <https://doi.org/10.2196/17283>
- Lutz, W., Deisenhofer, A.-K., Rubel, J., Bennemann, B., Giesemann, J., Poster, K., & Schwartz, B. (2021). Prospective evaluation of a clinical decision support system in psychological therapy. *Journal of Consulting and Clinical Psychology*. <https://doi.org/10.1037/ccp0000642>
- Lysaght, T., Lim, H. Y., Xafis, V., & Ngiam, K. Y. (2019). AI-assisted decision-making in healthcare. *Asian Bioethics Review*, 11(3), 299–314. <https://doi.org/10.1007/s41649-019-00096-0>
- Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (4th ed.). SAGE Publications, Inc.
- Sackett, D. L., Richardson, W. S., Straus, S. E., Rosenberg, W., & Haynes, R. B. (2000). *Evidence-based medicine: How to practice*

- and teach EBM (Vol. 2). Churchill Livingstone. <https://books.google.com.au/books?id=oIjrAAAAMAAJ>
- Shortliffe, E. H., & Sepúlveda, M. J. (2018). Clinical decision support in the era of artificial intelligence. *Journal of the American Medical Association*, 320(21), 2199–2200. <https://doi.org/10.1001/jama.2018.17163>
- Sulek, R., Robertson, J., Baque, E., Liew, A. W. C., Shirota, C., Upson, G., Whitehouse, A. J. O., & Trembath, D. (2022). The use of Clinical Decision Support Systems (CDSS) in the delivery of services to children with neurodevelopmental conditions: a scoping review. OSF. osf.io/m7p2x
- Sutton, R. T., Pincock, D., Baumgart, D. C., Sadowski, D. C., Fedorak, R. N., & Kroeker, K. I. (2020). An overview of clinical decision support systems: Benefits, risks, and strategies for success. *npj Digital Medicine*, 3(1), 17. <https://doi.org/10.1038/s41746-020-0221-y>
- Trembath, D., Waddington, H., Sulek, R., Varcin, K., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Silove, N., & Whitehouse, A. (2021). An evidence-based framework for determining the optimal amount of intervention for autistic children. *The Lancet Child & Adolescent Health*, 5(12), 896–904. [https://doi.org/10.1016/S2352-4642\(21\)00285-6](https://doi.org/10.1016/S2352-4642(21)00285-6)
- Trevana, L., McCaffery, K., Salkeld, G., Glasziou, P., Del Mar, C., Doust, J., & Hoffman, T. (2014). *Clinical decision-making tools: How effective are they in improving the quality of health care?* Australian Healthcare & Hospitals Association. https://ahha.asn.au/system/files/docs/publications/deeble_issues_brief_nlcg-2-clinical_decision-making_tools.pdf
- Zorina, O. I., Haueis, P., Greil, W., Grohmann, R., Kullak-Ublick, G. A., & Russmann, S. (2013). Comparative performance of two drug interaction screening programmes analysing a cross-sectional prescription dataset of 84,625 psychiatric inpatients. *Drug Safety*, 36(4), 247–258. <https://doi.org/10.1007/s40264-013-0027-9>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.