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Teams, tools, and time: a mixed methods study of workforce practices to identify mental health concerns in young people with complex communication needs

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ABSTRACT

Purpose: To understand the current practices and future needs of practitioners involved in identifying low wellbeing and/or mental health problems in 10–24-year-olds with complex communication needs.

Methods: This mixed methods study (cross-sectional survey and follow-up focus groups) included participants who may be involved in identifying mental health concerns in young people with complex communication needs. Analyses included descriptive statistics (quantitative data) and interpretive description methods (qualitative data). These data were then synthesised before interpretation.

Results: Survey participants (n = 112 from 17 occupational backgrounds) mostly used "interaction with the person" to identify both low wellbeing and mental health problems. The least used method was "formal tool". An interpreted description of focus group data (n = 19 participants) produced a six-part Practitioners' Story. The Story described practitioners' current practice (facilitating and inhibiting), feelings towards the present situation, and ideas for improving identification of mental health concerns in this population.

Conclusions: There was little consistency in how mental health concerns were evaluated in young people with complex communication needs, but informal methods were most common. Workforce education, access to relevant resources, and service settings which promote a collaborative approach to assessment should be prioritised to better address the mental health needs of this currently underserved population.

IMPLICATIONS FOR REHABILITATION

- Practitioners from a range of occupational backgrounds are involved in identifying mental health concerns in young people with complex communication needs.
- Practitioners need to understand wellbeing *and* mental health problems as separate but related constructs, and that one or both may need addressing.
- Practitioners should not avoid, and be willing to, ask augmentative and alternative communication (AAC)-users about their mental health, even if it is out of their comfort zone.
- Identification of mental health concerns in this cohort requires collaborative practice, access to and skills in using relevant tools, and sufficient time.

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Mental health; wellbeing; workforce; communication; AAC; augmentative and alternative communication; mixed methods

Introduction

Complex communication needs is a broad term encompassing speech, language, and other communication impairments, and is used to describe people who are unable to use natural speech to meet their daily communication requirements [1]. People with complex communication needs often use augmentative and alternative communication (AAC) which can supplement or replace speech, and/or support

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receptive language [2]. With limited literature on the mental health of AAC-users [3], data from populations in which complex communication needs are common can be reviewed. For example, elevated risk of mental health problems exists in people with speech, language and communication needs [4], cerebral palsy [5], intellectual disability [6], and other neurodevelopmental disorders [7]. Additionally, risk factors associated with low mental health (e.g., loneliness) are also associated with disability [8]. Despite this, young people with complex communication needs face barriers accessing services to address low wellbeing and/or mental health problems, in part, due to workforce and system inadequacies and barriers [9–11].

Mental health and mental health problems are considered two separate constructs as part of the dual continua model [12]. Mental health is "a state of wellbeing" as per World Health Organisation [13] – the presence of a condition, rather than merely the absence of mental health problems. Mental health, or wellbeing as it will be referred to in this paper, is measured on a continuum ranging from flourishing to languishing [14]. Flourishing describes positive emotion and functioning well. Languishing describes feelings of stagnation and emptiness. In contrast, mental health problems range from mild symptoms of mental strain to severe symptoms that fulfil diagnostic criteria for mental disorder, such as anxiety and depression [15]. According to the model, states of flourishing can co-occur with mental health problems, meanwhile states of languishing can occur in people who do not experience mental health problems. Some studies have suggested a possible protective role of good wellbeing on mental health problems [16] and that assessment of both constructs enables good understanding of an individual's experience [17,18].

The National Mental Health Commission (NMHC) in Australia states that "the current mental health workforce does not have the capacity to deliver quality mental health services to diverse communities" [19]. Amongst these diverse communities are people with complex communication needs. A modified Delphi study [20] determined 102 core workforce attributes for delivering mental health services to people with intellectual disability. Attributes within this study's *Communication* domain highlight the importance of mental health professionals determining a person's preferred method of communication, adapting their own communication to meet individual preferences, using AAC if required, and seeking support from a communication specialist if needed. The NMHC also states that a "coordinated approach will need to prioritise creating pathways to care and integrating services across various sectors" [19]. Coordination is particularly relevant for young people with disabilities as they often engage with many services including schools, the National Disability Insurance Scheme (NDIS), and primary and tertiary health care. This means several practitioners are involved in their care who may be involved in identifying low wellbeing and/or mental health problems. In Australia, specialist mental health services for people with disability are scarce and generalist mental health clinicians may be, or feel, inadequately skilled to meet the needs of people with communication disability [21]. A scoping review [22] described barriers to accessing mental health services for people with intellectual disability, including the siloing of service sectors, competing service models, unclear referral pathways, and failure of interagency communication. These findings highlight a need for research into services supporting the mental health of people with disability. If the mental health workforce currently lacks the required attributes and connectedness to identify low wellbeing and/or mental health problems in young people with complex communication needs, then who is doing it? Which workforce members are, or should be, equipped with the knowledge and skills required, and which systems are, or should be, implicated?

Along with lack of clarity about who is involved, it is also unclear what strategies and methods are used to assess mental health in young people with complex communication needs given intricacies arising from communication disability. There may be an over-reliance on interpreting physical changes and observable behaviours as a measurement of mental health for people with complex communication needs [23], or indeed the opposite whereby low wellbeing and/or mental health problems go undetected as their manifestations are incorrectly attributed to the person's disability [24]. Effective communication is needed for self-report of low wellbeing and/or mental health problems because assessment usually involves asking questions about internal states. However, in the case of young people with complex communication needs, there can be a mismatch between their form of expressive communication and what practitioners understand [25]. These mismatches are likely exacerbated for clinicians who do not frequently work with people with disability and for people who have very early communication skills (e.g., low literacy, pre-symbolic). There are also time-related barriers to self-report [2], as well as a paucity of appropriate instruments measuring mental health for people with complex communication needs [26]. A recent chart review by Tremblay et al. found that 15–24-year-olds with physical disability attending rehabilitation settings had a range of mental health problems but no mental health assessment instruments were documented in their charts [27].

Much of the existing research has explored access to mental health support for people with disability, but not necessarily for people with complex communication needs. We acknowledge that access to mental health support for all young people is currently fraught [28,29]. However, for those with complex communication needs, communication-specific factors add complexity and demand specific attention. A recent qualitative pilot study by Watson et al. [11] described the experiences of three adult AAC-users when accessing mental health support. However, there is a notable gap in understanding the workforce perspective on this topic, their insights into current practice and what would benefit their work in this area. The current study aimed to address this gap as its findings may identify next steps and guide development of resources as needed.

Study aims and objectives

This study aimed to understand the current practice and future needs of the workforce involved in identifying low wellbeing and/or mental health problems in 10–24-year-olds with complex communication needs. By "involved in identifying", we refer to a process which might include noticing and responding to signs and symptoms, screening, referral, and differential diagnosis – meaning that a range of people in the workforce are involved. The objectives were (1) to characterise the workforce involved; (2) to describe *how* they identify, including the tools and strategies used; and (3) to identify what the practitioners require to be able to do so more effectively.

Methods

The study used a sequential explanatory mixed methods design with two phases [30]. A cross-sectional survey was used to collect quantitative and qualitative data and follow-up focus groups with a subset of survey participants were used to collect in-depth qualitative data. This method was chosen because the survey would capture the experiences of a larger number of individuals, whilst the focus groups – which are well-suited to investigating contextual and relational perspectives [31] – would enrich the survey results. Ethical approval was obtained from the University of Melbourne Human Research Ethics Committee (ID: 25734).

Participants

People in workforce who may be involved in identifying low wellbeing and/or mental health problems in people with complex communication needs aged 10–24 years were eligible for this study. This included educators (e.g., teachers, education support staff), disability workers (e.g., paid support worker, allied health), and health professionals (e.g., GPs, paediatricians, psychologists, allied health). People were excluded if they were not living in Australia and/or if they were under 18 years old at enrolment.

The study selection criteria were determined by the authors all of whom have relevant clinical or lived experience (see *Researcher Position Statements*). The rationale was to understand the perspectives of any person in the workforce who might be in a position to support wellbeing and/or mental health problems by identifying when concerns may be present. We did not restrict the eligibility by profession or scope of practice for two reasons:

1. Young people with disability have high health service utilisation [32] and additionally engage with many people across education, health, and disability services. There are, therefore, several people who could notice signs of mental health problems and support next steps to accessing care.
2. Supporting wellbeing, i.e., the presence of good mental health, lies within anyone's scope of practice.

Methods – survey

Recruitment

Participants were recruited to the survey via convenience and snowball sampling; the study was advertised on research groups' social media, across disability organisations, and amongst the authors' known networks. The anticipated sample size for the survey was up to 200 participants. Survey participants provided implied consent via their voluntary participation in the questionnaire.

Data collection

Survey data were collected and managed using REDCap [33] hosted at The University of Melbourne. Survey design followed a mixed funnel format [31] (i.e., questions' content moved from broad to specific) and was designed to take no longer than 20 min as response rates decline with increased survey length [31]. The survey collected data on demographics, occupational characteristics (service setting, primary caseload), professional characteristics (years' experience, experience and training regarding complex communication needs and/or mental health problems), assessment of mental health problems and wellbeing in people with complex communication needs. Definitions of wellbeing and mental health problems were provided in the survey so that participants could respond to items appropriately. These definitions, and other information about survey design and items, are provided in Tables S1 and S2.

Data analysis

Quantitative survey data were analysed descriptively in SPSS software (SPSS Inc., Chicago, IL) [34]. Given the survey's exploratory focus, we reported responses from all respondents, including partial responders. Free-text responses were reviewed qualitatively and contributed to tailoring the focus group discussions, a form of mixed methods integration where "one database informs the data collection of the other" [35]. For example, a focus group prompt arising from free-text responses was "In the survey, some people said that they adapt tools for people with complex communication needs, *if appropriate*. Talk me through how someone might decide if it is appropriate to adapt a measure?"

Methods – focus groups

Recruitment

Participants were recruited to the focus groups using a participant-selection method, allowing researchers to purposefully select participants from those who expressed interest in taking part in a follow-up focus groups by leaving their contact details in the final part of the survey. There was no anticipated sample size for the focus groups as the number of participants needed to gain a rich understanding of the research question would depend on the quality of the interviews and the breadth and depth of participants' knowledge and experience. Focus group participants provided written consent by signing and returning the Participant Information and Consent Form.

Data collection

Focus groups were conducted virtually on Zoom and followed an interview schedule. Topics included barriers and facilitators to identifying low wellbeing and/or mental health problems in young people with complex communication needs; comparisons between mental health problems and wellbeing; the role of AAC in mental health assessment; what is needed to make this task easier. JP facilitated the discussion with a second person present to provide technical support. Both researchers wrote field notes to collect reflections following each group. The focus groups took between 60 and 90 min each and were recorded and transcribed verbatim.

Data analysis

Qualitative focus group data were analysed using interpretive description methods [36,37]. Majority of analysis was completed by JP, but all authors were involved to varying degrees. Analysis was an iterative process including data immersion by reading and rereading transcripts, summarising first impressions, inductively coding meaning units from each transcript, reviewing these tentative codes to find patterns, reviewing the transcripts again where clarification was indicated, and restructuring or renaming codes to more accurately reflect their content/meaning. NVivo software [38] was used to manage initial coding and then standard word processing software was used. Records of analysis were stored as part of an audit trail.

Data synthesis

Survey and focus group findings were mixed at the synthesis and interpretation stages. Results were integrated by concurrently reviewing the two datasets to identify convergent, divergent, complementary, or expansive links [39]. Results of the integration were presented in a table and then used to produce a discussion following a narrative weaving approach [35]. Quotes were not attributed to individual participants in the "Results" section, but context was provided by way of labelling the work sector of the participant who had given the quote. This was to maintain participant confidentiality and because the perspectives of all focus group participants informed the findings, and the quotes were used to exemplify those findings.

Rigour and quality assurance

The survey was pilot tested by colleagues to check for clarity of items and time to complete. REDCap validation rules and branching or piping functions were used to ensure data consistency across fields. Participants selecting "yes" to the initial question *Have you completed and submitted this survey already?* were prevented from completing it again, limiting repeated participation. Finally, data cleaning methods were applied to identify missing values and nonsensical responses.

Member checking and reflexivity contributed to the credibility of focus groups. This involved sending a high-level summary of findings to participants for validation or alternative interpretations, whilst reflexivity involved investigators considering how their expertise influenced data interpretation.

Researcher position statements

The first author, JP, is a speech pathologist conducting disability research and working clinically with children and young people with communication disability. Authors CI, MG, and DC are researchers with clinical backgrounds in occupational therapy, psychology, and psychiatry, respectively; DC also currently practices clinically. Authors SW and GB are young people with communication disability, and author CP is a parent of a child with communication disability. Overall, consumer involvement kept the work focused on what would be meaningful to those at the heart of the research and likely resulted in more a meaningful interpretation of study results. The GRIPP2 short form [40], completed jointly by JP, SW, GB, and CP describes consumer involvement in this study in further detail (S3).

Results

Demographic data

Survey participants (n = 112) ranged in age 20–67 years (median = 39; IQR = 30–51). They represented 17 occupational backgrounds with years of experience in their occupation ranging 1–40 (median = 10; IQR = 4.25–23). Survey participants worked mostly in education (45.5%) or disability (32.1%) service settings. Focus group participants (n = 19) represented 10 occupations with years of experience in their occupation ranging 1–40 (median = 23; IQR = 8-30). Additional participant characteristics are displayed in Table 1.

Table 1. Participant characteristics.

Characteristic		Survey (*n* = 112)		Focus groups (*n* = 19)	
		n	%	*n*	%
Sex	Female	89	79.5	14	73.7
	Male	21	18.8	5	26.3
	Another term	1	0.9	0	0.0
	Prefer not to say	1	0.9	0	0.0
State/territory	ACT	1	0.9	0	0.0
	NSW	13	11.6	0	0.0
	NT	1	0.9	0	0.0
	QLD	9	8.0	1	5.3
	SA	2	1.8	0	0.0
	TAS	0	0.0	0	0.0
	VIC	84	75	18	94.7
	WA	2	1.8	0	0.0
Geographical setting	Major city	78	69.6	17	89.5
	Inner regional	19	17	2	10.5
	Outer regional	15	13.4	0	0.0
	Remote	0	0.0	0	0.0
Occupation	Disability support worker	3	2.7	0	0.0
	Nurse	4	3.6	2	10.5
	Occupational therapist	9	8.0	1	5.3
	Paediatrician	4	3.6	2	10.5
	Physiotherapist	6	5.4	2	10.5
	Psychiatrist	3	2.7	0	0.0
	Psychologist	7	6.3	2	10.5
	Registered music therapist	3	2.7	1	5.3
	Social worker	4	3.6	2	10.5
	Speech pathologist	24	21.4	5	26.3
	Teacher (incl. principal)	26	23.2	1	5.3
	Teacher aide	7	6.3	0	0.0
	Other, e.g., counsellor	12	10.7	1	5.3
Service settings (mostly) working in	Education	51	45.5	5	26.3
	Physical health	14	12.5	7	36.8
	Mental health	8	7.1	2	10.5
	Disability	36	32.1	5	26.3
	Other not specified	3	2.7	0	0.0

Results – survey

Participants' experiences working with young people with complex communication needs and young people with mental health problems

Participants had a median of 10 years' experience working with young people with complex communication needs (IQR = 3.5–20.0) and a median of 10 years' experience working with young people with mental health problems (IQR = 5.0–20.0). They rated frequency of their interactions on a visual slider scale with "a couple of times a year" and "almost every day" as endpoints. Placement of their response on the slider was assigned a numerical value between 0 and 100. The median score for interactions with young people with complex communication needs was 95 (IQR = 68.0–99.5) and for interactions with young people with mental health problems was 82 (IQR = 69.0–97.5). These data are represented in Table S4.

Identifying mental health problems in people with complex communication needs

Most participants (58.8%) reported they have identified mental health problems in a young person with complex communication needs, of which 48.3% reported it is part of their role to do so. Of the remaining 41.2% of participants who reported they have not identified mental health problems in a young person with complex communication needs, 52.4% reported it is not required of them (Table S5). 96.1% of participants reported that identifying mental health problems in this cohort is "important" or "very important" (Table S6).

Methods for identifying mental health problems in people with complex communication needs

Participants mostly used "interaction with the person" to identify mental health problems in young people with complex communication needs, and "formal tool" was the method used least (Table 2). Tables

Table 2. Methods used by participants to identify mental health problems in young people with complex communication needs.

Method	% of participants who used this method
Interaction with the person	64.7
Clinical judgement based on observation of the person	47.1
A "gut" feeling[a]	16.7
Formal tool (e.g., screener, diagnostic interview)	14.7
Other[b]	12.7
"I don't"	20.6

Participants could select more than one response, except when selecting "I don't".

[a] A colloquialism similar in meaning to 'intuition' or 'the use of unconscious information'.

[b] Examples of Other: "discussion with family", "review of file information", and "collaboration with team".

S7, S8, and S9 demonstrate participants' use of different methods for identifying mental health problems against variables including experience, training, and occupation.

Between 47% and 80% of participants were unfamiliar with each of the 12 listed instruments for measuring mental health problems (Figure S1). The Strengths and Difficulties Questionnaire (SDQ) was the instrument that was used by most respondents – 11% had used it for people with complex communication needs and an additional 14% had used it for people without complex communication needs. For all other instruments, no more than 7% of participants had used each for people with complex communication needs.

Of the 13 participants who were given the survey item about adaptations, 76.9% "always or often" used examples to clarify the meaning of a question, and the remainder use this adaptation "sometimes" – this was the most used adaptation. All participants also used facial expression, body posture, gesture, or pictures as AAC, although to a lesser extent than they used examples. The least used adaptations were pre-teaching and changing the layout or presentation of a tool. Figure S2 illustrates participants' frequency of use of 10 adaptations.

Formal training on mental health problems and/or complex communication needs

A total of 107 participants completed both survey items on formal training (Table S10). Most participants had received formal training in complex communication needs (68.2%) and/or mental health problems (61.7%) during tertiary education or as professional development. Notably, just 5.6% of participants received formal training in both complex communication needs and mental health problems within their tertiary education and 15.0% of participants had received no formal training at all in either complex communication needs or mental health problems.

Confidence across complex communication needs and identifying mental health problems

Participants rated their confidence communicating with people with complex communication needs (median = 72; IQR = 50.0–88.75) and identifying mental health problems in young people generally (median = 50; IQR = 35.5–77.5). Median participant confidence in identifying mental health problems in young people with complex communication needs was 37 (IQR = 21.0–56.5). Figure 1 illustrates participant confidence identifying mental health problems in young people with complex communication needs according to their training.

Identifying low wellbeing in people with complex communication needs

Most participants (70.8%) reported they have identified low wellbeing in a young person with complex communication needs, of which 47.0% reported it is part of their role to do so (Table S11). 95.8% of participants reported that identifying low wellbeing in this cohort is "important" or "very important" (Table S6). The most commonly used methods to identify low wellbeing were interaction with the person (62.5%) and clinical judgement based on observation (53.1%) (Table S12).

Results – focus groups

Six focus groups were completed. Each group had between two and seven participants and was heterogenous in terms of occupation. Whilst we planned for purposeful allocation of participants to focus

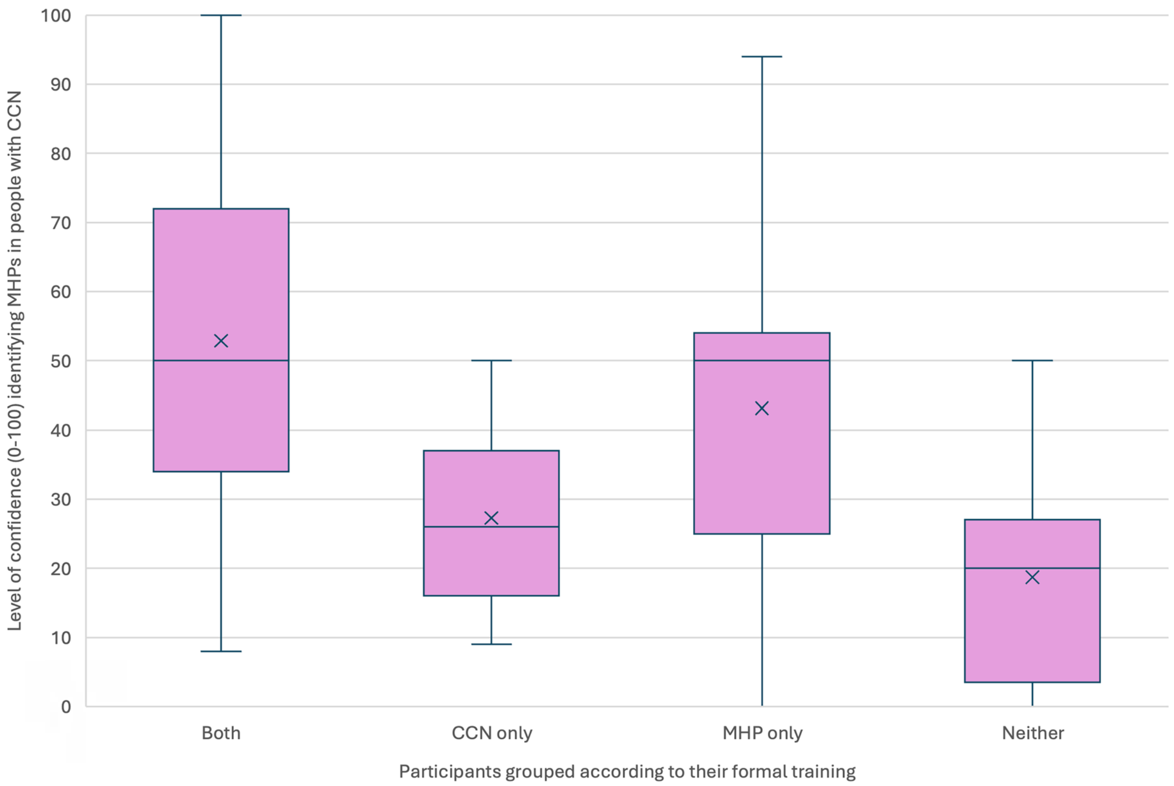
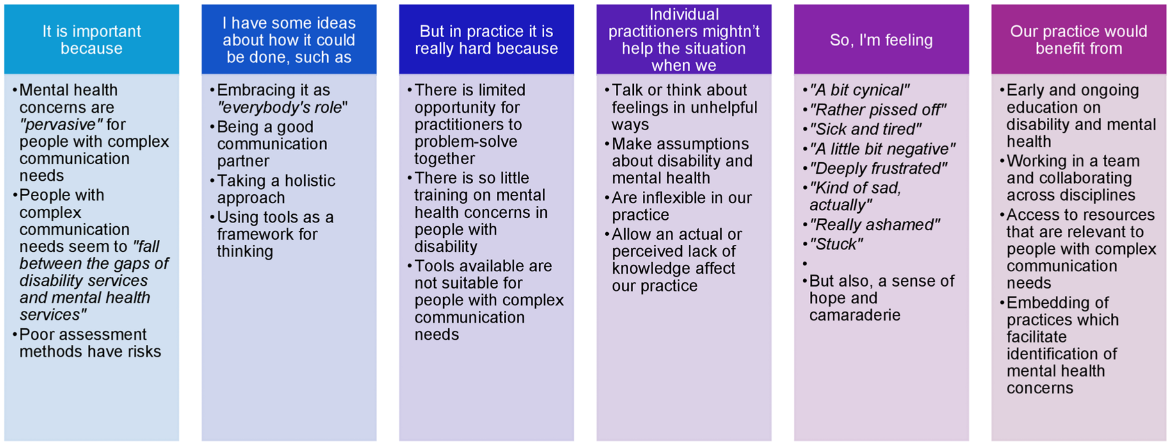


Figure 1. Confidence identifying mental health problems in people with complex communication needs according to their formal training. Both: formal training in both complex communication needs and mental health problems; CCN only: formal training in complex communication needs but not mental health problems; MHP only: formal training in mental health problems but not complex communication needs; neither: no formal training in complex communication needs and no training in mental health problems.



It is important because

- Mental health concerns are *"pervasive"* for people with complex communication needs
- People with complex communication needs seem to *"fall between the gaps of disability services and mental health services"*
- Poor assessment methods have risks

I have some ideas about how it could be done, such as

- Embracing it as *"everybody's role"*
- Being a good communication partner
- Taking a holistic approach
- Using tools as a framework for thinking

But in practice it is really hard because

- There is limited opportunity for practitioners to problem-solve together
- There is so little training on mental health concerns in people with disability
- Tools available are not suitable for people with complex communication needs

Individual practitioners mightn't help the situation when we

- Talk or think about feelings in unhelpful ways
- Make assumptions about disability and mental health
- Are inflexible in our practice
- Allow an actual or perceived lack of knowledge affect our practice

So, I'm feeling

- *"A bit cynical"*
- *"Rather pissed off"*
- *"Sick and tired"*
- *"A little bit negative"*
- *"Deeply frustrated"*
- *"Kind of sad, actually"*
- *"Really ashamed"*
- *"Stuck"*
-
- But also, a sense of hope and camaraderie

Our practice would benefit from

- Early and ongoing education on disability and mental health
- Working in a team and collaborating across disciplines
- Access to resources that are relevant to people with complex communication needs
- Embedding of practices which facilitate identification of mental health concerns

Figure 2. The Practitioners' Story: experiences of identifying mental health concerns in people with complex communication needs.

groups, due to challenges with scheduling conflicts, focus group composition was based on participant availability. Two participants provided feedback on the high-level summary that was emailed, confirming that the summary reflected their views.

As analysis progressed, themes were inductively found to have an underlying sequence that was akin to a narrative. This led to using the notion of a "story" to present the qualitative data. Thus, the final analysis of focus group data produced an interpreted description in the form of a "Practitioner's Story" (Figure 2). The story is explained in detail below. Additionally, we identified four characteristics of having

Table 3. Characteristics of having complex communication needs that contribute to the Practitioners' Story.

Characteristic	Description	Example quote(s)
Significant need for time	More time than usual is needed within a single interaction because communicating using AAC takes longer than using speech. Development of rapport over time enables practitioners to become trusted communication partners and to observe change over time.	"Time!! Because if you are genuine in your intention and desire to talk to a young person who has complex communication needs, you just need time. You need time and patience."
Heterogeneity of communication methods	People with complex communication needs are a heterogenous group. They may or may not be intentional communicators, symbolic communicators, or literate. There is a wide variety of communication aides used by this cohort.	"Their ways of communicating are highly idiosyncratic and individualised."
Differing presentation of mental health concerns	Mental health concerns may present differently in people with complex communication needs than people without disability. Social and emotional difficulties can present as behavioural concerns.	"I haven't noted really early communicators to [present] like what you would typically think of a child who has depression… [They] have behavioural difficulties, which is maybe how they express that."
Other health and social demands	Some young people have health needs (e.g., deaf-blindness, learning disability, complex medical needs) or are experiencing multiple disadvantages which add complexity and competing demands.	"Often, they have more complex bodies. Or they may be in more pain, potentially, and positioning becomes an issue. Or, you know, it might be vision."

complex communication needs that contributed to the Practitioner's Story by explaining aspects or adding complexity (Table 3).

Although the aim of this study was to explore both wellbeing *and* mental health problems as separate constructs, they were not typically distinguished throughout the focus groups. This is because there did not seem to be major differences between participants' experiences addressing low wellbeing compared to mental health problems. Therefore, to remain authentic to the participants' views, the term "mental health concerns" is used in the "Results and Discussion" sections of this paper to encompass both low wellbeing and mental health problems. Where participants did distinguish their experiences, this is demonstrated in the "Results and Discussion" section through the use of the specific relevant term "wellbeing" or "mental health problems".

Identifying mental health concerns is important because…

Identifying mental health concerns in people with complex communication needs is important for reasons beyond those applicable to people without disability. Participants described mental health concerns as "pervasive" for people with complex communication needs. Participants had the impression that this cohort are "more at risk of mental health and wellbeing challenges", symptoms of anxiety and depression would be "very much compounded for people with disabilities", and that, for some, their "pain, discomfort, and perhaps isolation" would contribute to the elevated risk. Despite this, there was a belief that young people with complex communication needs "fall between the gaps of disability services and mental health services", particularly people with more severe impairments. Participants also described a need for *good* assessment methods – that without them, an "emphasis on behaviour problems" could obscure mental health, and an over-reliance on informant reports is insufficient or inaccurate.

> We don't always use the language of mental health, even though that's what we're talking about when we talk about behaviour and emotional problems. – Participant working in health sector

Practitioners have ideas about how it could be done…

There are approaches which might facilitate identification of mental health concerns in people with complex communication needs. Participants overwhelmingly felt that identifying mental health concerns in young people with complex communication needs was everybody's role and that they "all need be equipped" to do so, regardless of occupation or discipline. Meaningful engagement with a young person with complex communication needs and a "listening attitude" were identified as important ways to assess mental health. Participants said, that to have conversations successfully, practitioners need to be trusted communication partners, maintain an attitude of curiosity, and be willing to "give it a shot".

> A lot of people say, 'I can't do it because I'm not expert on PODD (Pragmatic Organisation Dynamic Display) book…' and actually you don't have to be. – Participant working in health sector

> As soon as he knew that his answers were going to be confidential, he was much more willing to share. And we had a much bigger conversation around the feelings that he was having. – Participant working in disability sector

The use of formal tools was a contentious topic; however, the overall sense was that tools are best applied as a "framework" to guide thinking (particularly for clinicians who "don't have as much experience in the field") or to "pinpoint more particular symptoms" when used at the right time in an assessment process. Participants said that ideal assessment is holistic and characterised by gathering information from multiple sources (e.g., the individual, their family, clinical observation), "integrating of all these different knowledges", "looking at the setting in which they're living in day to day", and considering the "broad, big picture" of their life.

But in practice it is really hard because…

Training and work environments do not facilitate identification of mental health concerns in people with complex communication needs. Siloed systems were described as a flaw in current practice which hinders opportunity for practitioners to problem-solve together. Participants identified that fewer multidisciplinary settings and more single-practitioner clinics meant their focus has "become narrowed" and that clinicians with certain skillsets (e.g., speech pathologists for communication) are missing from mental health services.

> To get a multidisciplinary, thorough assessment of neurodevelopment and mental health is next to impossible in our service systems. It's all siloed. And so, we expect children's issues to be siloed as well. – Participant working in health sector

Participants noted that there is little training at the intersection of mental health and disability. They were dissatisfied with poor coverage of mental health in disability-related degrees, and disability coverage in mental health-related degrees.

> When I was in uni, this wasn't even a thing. This wasn't a thing that was discussed, or even mentioned, in my course. – Participant working in disability sector

Some participants described challenges accessing what training and education *is* available, including limitations on what topics are eligible as continuing professional development for certain professions. One participant, a psychologist, felt they should not undertake Keyword sign training as it would not contribute to their continuing professional development credits.

A dearth of appropriate tools to assess mental health concerns in young people with complex communication needs was discussed by participants. They felt that tools had not been developed with this cohort in mind and often excluded use of alternative forms of communication.

> So, we might not be capturing the nuances of what anxiety or depression look like in this group of people. – Participant working in education sector

> I just think it's not right that we should do a particular assessment and it says children can't use AAC?! Well, if that's their way of communicating, why should they be penalised? – Participant working in health sector

Practitioners mightn't help the situation when they…

Individual practitioners may act or think in ways that do not facilitate identification of mental health concerns in people with complex communication needs. Unhelpful assumptions about disability and mental health were discussed by participants. They explained that individual practitioners might hold beliefs which "interrupt" their inclination to assess mental health concerns in people with disability.

> People may wrongly assume that if someone's not communicating that they're sad or low or worried or stressed, then they mustn't be feeling it. – Participant working in education sector

> Many people assume that somebody with a learning disability doesn't have the capacity for a mental health problem. – Participant working in health sector

Participants also described inflexibility of practitioners as a barrier to assessment of mental health concerns for people with complex communication needs. Examples given included: appointments being "driven by what the doctor wants", a lack of nuance in approaches to assessment, being overly prescriptive in the use of formal tools, and a tendency to narrow down and get stuck on disability thereby hindering exploration of mental health concerns.

Fear and discomfort were considered reasons individual practitioners might "shy away" from hard conversations about mental health concerns. Their tendencies to pathologise normal negative emotions, to attempt to fix those emotions rather than give them space, and to force feelings into dichotomies were also seen as barriers.

> There's a really pervasive culture in disability that persists… That for people with disability [you ask] 'Is this good day, did you have a good day, is everything good?!'… And if people are frustrated or grumpy, they're redirected. That negativity and the frustration is not received and held; there's not a space for that. – Participant working in disability sector

Participants reported that some practitioners might allow an actual or perceived lack of knowledge be a reason they do not provide care. This was mostly characterised by a lack of confidence in AAC and a subsequent hesitation by practitioners to venture beyond their usual areas of practice. At other times, it was characterised as a reluctance to take on complex cases.

> And yet that same child will be completely dismissed by the doctor, because they see that [communication book] and say 'Oh, not for me. Can't communicate.' – Participant working in health sector

So, practitioners are feeling…

Practitioners generally held negative views about the current situation. There was a sense of exasperation, shame, sadness, and cynicism throughout the discussions, as evidenced by quotes in Box 5 of Figure 2. Some participants felt ashamed that they were not doing better in their practice. Others felt exasperated about system barriers and said that, when people try to address those barriers, "things get stuck" and "it's not got that far". Several participants demonstrated doubt: one participant believed that their ideal world was "unachievable", and another said their ideal world "will take 30 years of political and philosophic change".

Whilst the tone of these focus groups was generally negative, there was also a sense of hope and camaraderie from some participants:

> It's very, very exciting that [there are] more discussions and more papers and people are talking about it more. – Participant working in education sector

> It is also sort of nice to know that everyone's working together on this. – Participant working in disability sector

Their practice would benefit from…

Enhancing practice in this area will require access to relevant knowledge and resources. When asked what they needed to be able to better assess mental health concerns in people with complex communication needs, participants agreed that their most pressing need was a "cohesive team approach" in which a practitioner could feel "most potent as a professional". They indicated that teams are crucial and that an ideal team would include "people who can integrate the complexities".

> To do this effectively, you need different skill sets in the room, and you do need a more wraparound multidisciplinary [approach]. – Participant working in disability sector

> The power is not in my individual capability, but in what we bring together to the table. – Participant working in education sector

To address the identified knowledge gap, participants felt that at least foundational instruction on the intersection of disability and mental health at university is essential – this being the case across several qualifications (those mentioned included psychiatry, psychology, speech pathology, and counselling). In addition, practitioners would benefit from access to transdisciplinary ongoing professional development opportunities of varying formats. Examples given were "accidental counsellor" courses and "communication-partner" training.

Whilst the need for tools was debated amongst some participants ("it's the conversation that matters!"), a common view was that tools which can be used flexibly to support conversations about mental health would be useful for practitioners. It was also noted that, because systems are hard to change, the development or adaptation of instruments for use with young people with complex communication needs might be a more workable next step.

> Something like [a screening tool] to guide questioning. Whether it gets filled out properly or not [doesn't matter]. – Participant working in health sector

> A guided conversation that has the flexibility to respond to what's actually happening in front of you. – Participant working in health sector

Participants described the "incredible value" of embedded practice for providing opportunity for interactions about mental health, and for addressing practitioner accountability. Examples included routine mental health check-ins built into Electronic Medical Records and appointment reminder texts reminding patients to bring their AAC and come prepared with topics for discussion, including mental health.

> In practice, I think having it front and centre as part of core medical review is a good place to start. – Participant working in health sector

Data synthesis

Quantitative and qualitative results were mixed and synthesised by identifying links between the datasets (Table 4). Qualitative results primarily expanded upon or explained quantitative findings; however, there were some divergent links. This synthesis underpins the following discussion.

Discussion

The objectives of the study were (1) to characterise the workforce involved in identifying low wellbeing and/or mental health problems in 10–24-year-olds with complex communication needs; (2) to describe *how* they do so, including the tools and strategies used; and (3) to identify what the practitioners require to be able to do so more effectively. The main findings of this study are that there was little consistency in how mental health concerns are evaluated in young people with complex communication needs – possibly a function of the wide range of practitioners involved – but informal methods seem to be most common, and that workforce education, access to relevant resources, and service settings which promote a collaborative approach to assessment should be prioritised to improve practice in this area.

Who does it and how?

The involvement in this study of practitioners from different occupations supports the qualitative finding that it is "everyone's role" to be involved in identifying mental health concerns in young people with complex communication needs. Our survey showed a greater proportion of participants perceived identifying low wellbeing as part of their role, compared to identifying mental health problems. This aligns with standard practice in which diagnosis of mental disorder (which lies within the category of mental health problem) is the responsibility of a mental health professional (e.g., psychiatrist), whereas recognising low wellbeing is generally within the remit of a range of people. However, the diagnostician is not the only person involved in identification of a health condition such as mental disorder. Balogh et al. [41] state that people involved in identifying a health condition also includes "peripheral professionals". Given that over half of the survey respondents claimed to have identified mental health problems in young people with complex communication needs, it would be important to clarify whether they recognised signs and symptoms of a mental health problem, or, whether they perceived themselves as diagnosing

Table 4. Synthesis of quantitative and qualitative data.

Quantitative data	Qualitative data	Synthesis
Participants were from >10 professional backgrounds (Table 1).	Identifying mental health concerns in young people with CCN is "everybody's role" (Figure 2, Box 3).	The qualitative finding explains why participants came from several occupational backgrounds, increasing credibility of the study with such a heterogeneous sample. (*Complementarity*)
23.5% reported that identifying MHP in young people with CCN is *not* part of their role but they do it anyway; 21.6% reported they don't identify MHP in young people with CCN because it's not required of them (Table S2).	Identifying mental health concerns in young people with CCN is "everybody's role" (Figure 2, Box 3).	Even though it is not the role of almost half of the survey participants, half of those do it anyway. Does this imply they think it should be their role, or maybe they feel they should take some responsibility in this area anyway? (*Divergent*)
91% think identifying MHP in young people with CCN is very important (Table S9).	Identifying mental health concerns in young people with CCN is important for reasons beyond those applicable to people without disability (Figure 2, Box 1).	Identifying mental health concerns in people is important for anyone with or without disability. The qualitative data *expands* on this with reasons for this importance beyond those relevant for a general population.
15% use formal tools to identify MHP in young people with CCN (Table 2).	Available tools are not suitable for people with CCN (Figure 2, Box 3). However, tools could be used as a framework for thinking (Figure 2, Box 2).	The qualitative data *complements* the quantitative data by explaining a potential reason for tools being used less so than other methods (their unsuitability for people with CCN) and it *expands* on this by suggesting how tools are used in the instances where they are employed.
65% use interaction to identify MHP in young people with CCN (Table 2).	Taking a holistic approach to assessment is one way it should be done (Figure 2, Box 2).	The qualitative finding may explain why interaction was a commonly used method (it may be more holistic than other methods). (*Complementarity*)
Participants' use of instruments for MHP is low – 11% have used SDQ for people with CCN, ≤7% for all other listed instruments (Figure S1).	Tools available are not suitable for people with CCN (Figure 2, Box 3).	The qualitative and quantitative data *complement* each other, with the qualitative data explaining a potential reason for instruments being used infrequently.
Adaptations to instruments that require more time are done less frequently than adaptations that can be done spontaneously (Figure S2).	A significant need for time is a characteristic of having CCN (Table 3).	Both data *converge* on this point; the quantitative finding demonstrates the role of time by offering an example that highlights its significance.
5.6% received training on both CCN and MHP within their tertiary education (Table S6).	There is so little training on mental health concerns in people with disability (Figure 2, Box 3).	Both data *converge* on this point; the qualitative and quantitative findings confirm each other – increasing credibility.
15% had received no formal training at all in either CCN or MHP (Table S6).	Practitioners might allow an actual or perceived lack of knowledge affect their practice (Figure 2, Box 4).	The qualitative finding *expands* on the quantitative finding by providing a possible consequence of low levels of training in this area.
Participants with formal training in both CCN and MHP reported confidence levels higher than the sample median, and those without formal training in either reported confidence levels lower than the sample median (Figure 1).	Practitioners might allow an actual or perceived lack of knowledge affect their practice (Figure 2, Box 4).	The quantitative data suggest that training might influence practitioners' confidence, and the qualitative data *expand* on this by suggesting this in turn might influence their practice.

CCN: complex communication needs; MHP: mental health problems; SDQ: Strengths and Difficulties Questionnaire.

a condition. The latter might pose scope of practice concerns given the potential for, and possible ethical and clinical implications of, misidentification of mental health problems in people with disability.

Our survey findings indicate that the initial identification of both low wellbeing and possible mental health problems in young people with complex communication needs typically occurs via interaction. We hypothesise this is because it is an approachable method for practitioners who are otherwise untrained or inexperienced in identifying mental health concerns. Our findings suggest that practitioners with frequent or long-term contact with the individual (e.g., teachers, speech pathologists, and paediatricians) are well-placed to recognise mental health concerns via this method – a likely result of time spent developing rapport, building trust, and understanding individual communication modalities. A qualitative study by Watson et al. [11] described similar themes: a "long-lasting therapeutic alliance" and "mutual trust" being two practices identified by their participants (adult AAC-users) as facilitators of interactions about mental health. Similarly, Nijhof et al.'s qualitative study [42] described support workers and people with intellectual disability "knowing each other well", which contributed to support workers' capacity for identifying and following up the health needs of their clients, including those who were minimally verbal.

Tools were used infrequently to identify mental health concerns with two reasons suggested for this: (1) the scarcity of suitable diagnostic instruments tailored for people with complex communication needs and (2) a preference for using more "*ad hoc*" but holistic methods. We could not determine associations between instrument use and other participant characteristics due to sample size limitations; however, a 2010 study [43] surveyed a multidisciplinary sample of 1442 mental health professionals about their attitudes towards standardised mental health assessment tools. They found that professional discipline was predictive of attitudes towards tools, and that perception of a tool's practicality predicted participants' likelihood of using it.

The present study also highlighted a difference of opinion on how tools should be used – some practitioners believed that they should be tailored precisely to the population of interest whereas others felt that using tools flexibly is justified for people with disability. This divergence may reflect differences in professional models of care or service funding structures.

It should be noted that the qualitative finding of "everybody's role" diverged from the quantitative data, indicating that not all practitioners think this is so. We pose whether this might introduce risks to accountability – if it is everybody's role, does it become no-one's responsibility? Further inquiry on this is warranted. Along a similar vein, our study identified an alarming aspect of current practice: practitioners who identify a potential concern become "stuck" on who the next person is to facilitate further investigation or intervention. In this next stage of mental health assessment, it does not appear to be "everybody's role", and there is no clarity about whose role it is.

What do practitioners need to be able to do it better?

Our findings suggest that there are two layers of barriers and, subsequently, two layers of needs which reveal clear implications for practice. The first layer stems from practitioners' unhelpful beliefs and attitudes which "interrupt the potential" for interactions about mental health with AAC-users. The second layer centres on inadequate workforce capacity: a lack of collaborative practice, training, and appropriate tools, which pose challenges for assessing mental health in young people with complex communication needs – even amongst practitioners with supportive beliefs and attitudes.

Layer 1: beliefs and attitudes

Unhelpful attitudes and beliefs are the first barrier to identification of mental health concerns in young people with complex communication needs. These attitudes interfere with mental health assessment before it even begins or block mental health assessment from progressing through a challenging point. Unhelpful beliefs, feelings, and attitudes identified in our study are reflected elsewhere in the literature [11,20, 44–48]. Practitioners must understand and believe that people with complex communication needs can and do experience mental health concerns, and that they are entitled to have those concerns heard and addressed. Practitioners with a sense of responsibility, who do not let their apprehension hold them back, and who are willing to ask an AAC-user about their mental health even if it's out of their comfort zone are essential. A point of interest from this study is the differing opinions about whether practitioners require knowledge on AAC to be able to communicate with an AAC-user – some AAC systems (e.g., alternative access, non-electronic) are daunting to the untrained eye, however, yielding to unease could lead to ignorance of the problem. Consistent with findings from a qualitative study in which AAC-users were interviewed about their mental health experiences [11], our study suggests it is essential for practitioners to adopt a "give it a go" attitude, independent of their AAC experience and skill. However, even when practitioners do have the desired, helpful attitudes, they then face a second layer of barriers.

Layer 2: workforce capacity

The need for collaboration, training, and tools for quality mental health care is not a novel finding [19,20]; however, our study highlighted the intensified necessity of these for people with complex communication needs.

Collaborative practice. This study suggests that collaboration between practitioners and across disciplines facilitates identification of mental health concerns in young people with complex communication needs.

A wrap-around approach was the favoured form of collaboration – characterised as practitioners from several disciplines and parts of a young person's life coming together as a team. The team may consist of teachers, paediatrician and/or general practitioner, community allied health team, and importantly, the young person's family. This wrap-around approach was deemed particularly vital for early communicators who do not use intentional symbolic language to express internal states, as input from and discussion amongst several sources is needed to paint a picture of their experience from which an assessment of mental health can be made.

For some people with complex communication needs, a wrap-around interdisciplinary team may not be required for mental health assessment. For AAC-users who consistently communicate effectively with familiar partners, collaborative practice may look like a speech pathologist working alongside a mental health practitioner. For example, several participants in our study described speech pathologists as potential "AAC-interpreters". The same finding was also seen in a study of adult AAC-users' perspectives [9]; communication assistants were seen as a potential member of the microsystem in which AAC-users and mental health practitioners interact.

Collaborative practice is not without its pitfalls – one being the compromise of the AAC-user's privacy when sharing information in teams or when including a communication assistant in a mental health interaction. If implementing collaborative practice, our recommendation is to obtain consent from the AAC-user before sharing sensitive information with other practitioners.

Training and education. A finding of this study is that practitioners' tertiary education does not usually cover both communication disability and mental health, despite participants emphatically feeling that it would support their practice. Given the diverse occupational backgrounds of participants and the element of a shared responsibility, ideally, any practitioner who works with young people with disability should have the training to identify whether they are experiencing mental health concerns. Including content on communication disability and mental health in pre-service education of different disciplines may be necessary. An inspection of course content across disciplines, similar to Trollor et al.'s audits [49,50], would support prioritisation around this. Since different practitioners may assume different roles within the process of identifying a mental health concern, it might be most impactful to deliver targeted training. For example, upskilling those who frequently interact with young people with complex communication needs (e.g., school staff) on screening, or training mental health practitioners on using AAC for further investigation of mental health concerns.

Another avenue for training and education is around the mental health-related vocabulary available to AAC-users. A lack of appropriate vocabulary can have considerable impacts on conversations about wellbeing [51]. We propose that when practitioners have a strong understanding of the potential limitations of AAC systems, they are better equipped to more comprehensively support the AAC-users they work with.

Crucially, the training should recognise wellbeing as separate from mental health problems and encourage the promotion of positive wellbeing *and* the prevention or management of mental health problems. This is of particular importance as focus group participants often did not distinguish wellbeing and mental health problems; when they did, it was mostly to express that they "hadn't thought about the wellbeing side of things". Training which addresses the two as separate constructs might increase knowledge about both and encourage practitioners to more readily ask people with complex communication needs about their wellbeing. Our results also suggest that training must include "translation to supports". Practitioners need knowledge not just about screening and identification of mental health concerns, but also on *next steps*. Participants expressed unease screening for mental health concerns if they had no next step. Therefore, training must bolster knowledge on service pathways (e.g., appropriate referral and handover processes, programs offered by other sectors) and advocacy (e.g., using the *Mental Health and Wellbeing Act 2022* (Vic) [52] to assert *any* young person's right to mental health support, including those with disability).

Another worthy suggestion that emerged from this study is for professional regulatory bodies to review what is eligible as continuing professional development – transdisciplinary knowledge gained from professional development outside of one's specific discipline is crucial to having a robust workforce and should be permitted, encouraged, and funded. This aligns with recommendations made in intellectual disability literature – Weise et al. suggest we "develop mechanisms for training in this area to contribute towards professional development points" [20] and Wark et al. suggest we "provide training in the area of being an ‘accidental counsellor’ and mental health first aid” to disability workers [53]. These two courses mentioned were also identified in our study, as well as communication-partner training which is of particular relevance to AAC-users.

Tools. The third identified resource was tools that are needed to improve identification of mental health concerns for young people with complex communication needs. Synthesis of our quantitative and qualitative results suggest that tools are used less frequently than other methods of identifying mental health concerns because they are not suitable for people with complex communication needs – they are too prescriptive and not holistic. This aligns with existing literature: measures of some mental disorders exist for adjacent populations (e.g., intellectual disability [54]), but a recent systematic review found no measures of wellbeing for people with complex communication needs [26]. However, if practitioners have limited knowledge in this area, relying on clinical judgement alone is unlikely to be the most sensible solution. Whilst there was tension between holistic assessment and formal assessment in our study, the two are not mutually exclusive – and perhaps we should strive to formalise a holistic method for identifying mental health concerns in this cohort. Therefore, we propose that a holistic formal assessment that explicitly allows flexibility is required. Reasoning for these features is below:

- A formal tool provides structure for practitioners to follow, empowering those with limited knowledge on the topic to have a go. Formalising a tool might facilitate its acceptance and use across different organisations and sectors. It may promote effective handovers and support applications to programs and funding.
- A methodical but flexible approach addresses the characteristic of *heterogeneity of communication methods*. The explicit permission and encouragement of flexible use of a tool might alleviate practitioners’ concerns about deviating from administration guidelines when adapting tools for people with complex communication needs.
- A holistic tool is one which considers several aspects of the person, not mental health in isolation. In particular, this addresses the characteristic of *other health and social demands*. A tool which considers a person’s mental health in the context of their daily life may also generate meaningful *translation to supports*.

Future work

Amongst several directions for future work outlined in the “Discussion” section, a promising avenue is the development of a guided conversation tool. This tool would include ways to have conversations about mental health with people who use various communication modes and systems, enabling collection of direct report of their experiences. It may draw upon existing resources, but its codesign with young people with complex communication needs is imperative. Ideally, the tool would simultaneously act as a teaching resource so that practitioners could learn about mental health and communication by using it and it would be embedded into practice to promote uptake. We acknowledge that the issues in focus cannot be addressed by simply identifying a need; the need itself must also be addressed. Currently, so many young people with complex needs “fall through the cracks”, and so a major uplift of universal mental health services and ease of its navigation is needed.

Strengths and limitations

The heterogeneity of participants can be seen as both a study strength and limitation: we were not able to distinguish between perspectives of participants from different occupational backgrounds or service settings, but by not restricting inclusion to certain professions, we gathered insights from a broad range of practitioners who might have been otherwise overlooked (e.g., registered music therapist, behaviour support practitioner). In doing so, we can reflect on underutilised capability and consider new avenues for collaboration. One other limitation of this study is the concentration of participants primarily from one Australian state (Victoria) and major cities, rather than from a broader range of geographical regions. This means that practice and experiences of practitioners in rural or remote areas may not be sufficiently captured.

Conclusions

The current study has described the workforce of practitioners involved in identifying mental health concerns in young people with complex communication needs and described the methods by which they do so. A Practitioner's Story was generated which described the experiences of the participants. Importantly, this Story highlighted several future needs which may be actioned to improve practice in this area. These include promoting enabling attitudes and beliefs; collaboration between practitioners and across sectors; training and education at the intersection of mental health and disability; and the development and implementation of a holistic formal assessment of mental health that allows flexibility. Next steps must involve young people with complex communication needs directly, particularly through their active participation in codesigning an appropriate mental health assessment.

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Data availability statement

The authors confirm that the data supporting the findings of this study are available within the article and its supplementary materials.

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