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Assessing mental health of people with complex communication needs: A systematic review.

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ABSTRACT

Mental health is "a state of wellbeing" as per the World Health Organisation. People with disabilities generally experience poorer wellbeing than those without disabilities. Instruments which assess wellbeing or its three core components (emotional, psychological, social) may be less accessible or appropriate for people with complex communication needs (CCN). This study aimed to identify and describe instruments used to measure wellbeing in people with CCN. A systematic review following PRISMA guidelines was conducted. Six databases were searched to identify studies where wellbeing was measured in people with CCN. Two reviewers extracted data to describe the studies, participants, instrument(s) used, and adaptations applied. Instrument items were then mapped to indicators of mental health. Twenty-six studies were included. Participants' receptive language ranged normal to profoundly impaired and they used a variety of expressive communication methods. Twenty-two different instruments were identified; ten of which were quality-of-life measures. Adaptations were made to instruments in eight studies, mostly to administration procedures. Item mapping revealed that while some wellbeing indicators were represented within the included instruments, coverage was insufficient to consider any instrument a "measure of wellbeing" for this population. Some instruments had features which made them more appropriate for people with CCN: ensuring communication access; recognising the relative importance of wellbeing indicators to an individual; collecting information from multiple sources when using proxy-report; and acknowledging environmental factors. Research is required to develop or adapt an instrument for valid and reliable measurement of wellbeing in people with CCN, ensuring the instrument addresses their communication access needs.

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1. Introduction

Complex communication needs (CCN) is a broad term encompassing speech, language, and other communication impairments. A person has CCN if they are unable to use speech to meet their daily communication requirements (Porter & Kirkland, 1995). People with CCN may use alternative and augmentative communication (AAC). Alternative refers to methods which replace speech, whereas augmentative refers to methods which supplement speech. It is estimated that 1 in 500 Australians have CCN (Perry et al., 2004). This heterogeneous group often have limited opportunities for interaction with others and experience challenges having their needs met (Beukelman & Light, 2020). These restrictions may impact upon the mental health of a person with CCN and compound any usual impacts upon mental health that an individual can experience.

1.1. Conceptualising the construct of good mental health

There are several ways to conceptualise and describe mental health and wellbeing (e.g., Deci & Ryan, 2000; Seligman, 2011), however consensus is that good mental health is a positive phenomenon, not merely the absence of mental health problems. Westerhof and Keyes (2010) characterise this as a dual continua model in which mental health and mental health problems are separate, but related, constructs. Keyes' model of mental health (2002, 2005, 2007), which builds upon earlier work by Jahoda (1958) and Ryff (1989), contends that good mental health consists of three core components: emotional wellbeing, psychological wellbeing, and social wellbeing. Mental health as a positive phenomenon, and the presence of these components of wellbeing, is reflected in the World Health Organization (WHO) definition of mental health (2004): "a state of wellbeing in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community". This suggests that the terms positive mental health and wellbeing may be used interchangeably; in this paper, we will use the term *wellbeing*. Strengths of Keyes' model of mental health include 1) the inclusion of social wellbeing as a distinct component which includes acknowledgement of community engagement, not just personal relationships, and 2) the consideration of both ends of a mental health spectrum, from flourishing to languishing, and maintaining that both of these states are distinct from mental health problems and mental illness.

We must also consider the construct of Quality of Life (QOL) as it relates to wellbeing. QOL encapsulates a wider range of factors other than wellbeing—of the eight widely acknowledged QOL domains (Schalock & Verdugo, 2002), five are conceptually aligned to wellbeing. The QOL domains that do not relate to wellbeing as defined by Keyes are physical wellbeing, material wellbeing, and rights. Although the constructs are different, the terms QOL and wellbeing are sometimes used interchangeably in the literature (e.g., Cooke et al., 2016) and so it is worth noting their properties.

Emotional wellbeing, psychological wellbeing, and social wellbeing are measured using thirteen indicators (Keyes, 2002, 2005), as outlined in Table 1.

Table 1
Core components and indicators of wellbeing (Keyes, 2002, 2005).

Core component of wellbeing	Component description	Indicator	Indicator definition
Emotional wellbeing	Feelings of happiness and satisfaction with life.	Positive affect	Regularly cheerful, in good spirits, happy, calm and peaceful, satisfied, and full of life
		Avowed happiness or avowed life satisfaction	Feels happy or satisfied with life overall or domains of life
Psychological wellbeing	Positive individual functioning in terms of self-realization; thriving in private, personal life.	Self-acceptance	Holds positive attitudes toward oneself and past life and concedes and accepts varied aspects of self
		Personal growth	Shows insight into own potential, sense of development, and open to new and challenging experiences
		Purpose in life	Holds goals and beliefs that affirm sense of direction in life and feels that life has a purpose and meaning
		Environmental mastery	Exhibits capability to manage complex environment, and can choose or manage and mould environments to suit needs
		Autonomy	Exhibits self-direction that is often guided by his or her own socially accepted and conventional internal standards and resists unsavoury social pressures
		Positive relations with others	Has warm, satisfying, trusting personal relationships and is capable of empathy and intimacy
Social wellbeing	Positive societal functioning in terms of being of social value; functioning optimally in society.	Social acceptance	Has positive attitude toward others while acknowledging and accepting people's differences and complexity
		Social actualisation	Believes that people, social groups, and society have potential and can evolve or grow positively
		Social contribution	Feels that one's life is useful to society and the output of his or her own activities are valued by or valuable to others
		Social coherence	Interested in society or social life; feels society and culture are intelligible, somewhat logical, predictable, and meaningful
		Social integration	Has a sense of belonging to a community and derives comfort and support from community

People with disabilities generally experience poorer wellbeing and more mental health problems than those without disabilities (Australian Institute of Health and Welfare (AIHW), 2016; Downs et al., 2018; Eres et al., 2022; Whitney et al., 2019; Whitney, Warschausky & Peterson, 2019; Wolman et al., 1994). Data on the mental health specifically of people with CCN is scant. However, we can assume it is a significant issue; people with CCN may be considered vulnerable to wellbeing concerns as some risk factors, such as loneliness and abuse, are more common in people with disability (Balandin et al., 2006; Cooper et al., 2009; Robinson & Chenoweth, 2011). Therefore, to better understand, describe and support the wellbeing of people with CCN, we require valid and reliable measures of the construct.

1.2. *Available literature is often about related, but different, constructs and populations*

A systematic review of instruments measuring mental health and mental health problems in individuals with severe to profound intellectual disability (Flynn et al., 2017), and a similar review for adults with mild to moderate intellectual disability (Patel et al., 2023), contribute valuable insights. Whilst some comparisons may be drawn between the intellectual disability and CCN populations, they are different groups with unique characteristics and needs. Likewise, reviews focusing on conditions such as stroke, amyotrophic lateral sclerosis, and dementia may provide some insight into existing instruments, but these conditions are also not synonymous with CCN.

This lack of distinction between populations reflects much of the existing literature—people with CCN are often not the population of interest in research studies. An exception to this is a systematic review by Wolters-Leermakers and colleagues (2022) which focused on people with complex and multiple communicative disabilities, a subgroup of people with CCN who have additional impairments. That review, however, sought quality of life (QOL) measures—a related, but distinct construct to wellbeing. They found that one study used self-report alone, one used self- and proxy-report, and 14 used proxy-report alone to collect information about QOL for this cohort (Wolters-Leermakers et al., 2022).

1.3. *Efforts to address measurement barriers remain insufficient for people with complex communication needs*

A commonly used method to circumvent barriers attaining self-report from people with cognitive and communication impairment is to use proxy-report. This involves proxies—typically family members, close friends, or caregivers (paid or unpaid)—responding on behalf of another individual. However, proxy-report alone is not preferred for various reasons. As discussed in several papers, it may be less accurate for non-observable, subjective, and sensitive topics; evidence suggests that proxies under-report symptoms related to internal states such as depressive symptoms for people with intellectual disability (Mileviciute & Hartley, 2015; Scott & Havercamp, 2018) and that they report lower QOL for people with intellectual disability than what individuals self-report (Balboni et al., 2013; Schmidt et al., 2010). There are also ethical reasons proxy-report alone is not preferred. The United Nations Convention on the Rights of People with Disabilities (2006) explicitly states that people with disabilities should be able to express their views through the use of AAC and other “accessible means, modes and formats of communication of their choice”. This highlights that having CCN is not sufficient to justify proxy-report over self-report and people with CCN should be provided with access supports to communicate autonomously.

Design features of, and adaptations to, instruments may increase their accessibility and facilitate self-report. However, work on instrument design once again does not include or fully represent people with CCN. Kooijmans and colleagues (2022) conducted a systematic review of adaptations made to self-report measures for people with intellectual disability and found that most studies excluded people of “limited verbal ability”. Kramer and Schwartz (2017) and Walton and colleagues (2022) used content, layout, and administration design features to increase cognitive accessibility of patient-reported outcome measures—but the participant groups in these studies included only individuals who “had adequate language and cognitive abilities” or used spoken words supported by a communication partner or alphabet based AAC strategies.

1.4. *Study aims and objectives*

Access to valid and reliable tools for measuring wellbeing is crucial for understanding the experiences of people with CCN. To date, no systematic literature review has explored measures of wellbeing for people with CCN, and so it is unclear whether such instruments exist for this population. This undermines the rights of people with CCN by not facilitating equitable access to healthcare (United Nations, 2006). The current systematic review therefore aimed to identify, describe, and evaluate the psychometric properties of instruments used to measure wellbeing in people with CCN. The objectives were (1) to identify which instruments have been used to measure wellbeing in people with CCN, and with what adaptations; (2) to describe the identified instruments by mapping them to components of wellbeing; (3) to evaluate the validity, reliability, and responsiveness of the instruments measuring wellbeing in people with CCN.

2. Methods

2.1. *Study design*

This systematic review was conducted according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021). The protocol for this review was prospectively registered on PROSPERO, an international prospective register of systematic reviews [CRD42022354051].

2.2. Search strategy

Searches were conducted in August 2022, and updated in July 2023, in six electronic databases: Medline, Embase, Web of Science, CINAHL, PsycINFO, and PubMed. Grey literature was not searched to maintain the review's feasibility within given resource constraints. Search terms included terms that define the population (people with CCN and/or AAC-users), measurement instruments, and the construct of interest (wellbeing). Full search strings are available in Table S1 in supplementary material. No restrictions on language were placed. A research librarian assisted with the development and the execution of the searches. Results from the searches were imported to Endnote (2013) and duplicates were removed. They were then imported to Covidence Systematic Review Software (Veritas Health Innovation, 2025) and any remaining duplicates removed.

2.3. Selection criteria and screening

Studies were included if (1) the article included an instrument which the authors reported measured component(s) of wellbeing and (2) the identified instrument was used to measure the component(s) in people with CCN and/or AAC-users. For studies with mixed samples, at least five participants must have CCN or be AAC-users. Studies were excluded if (1) the instrument was not named; (2) the article was published before 1980; (3) full text was not available; (4) the article was a conference abstract, thesis, book chapter, letter to editor, or review paper. References of included studies in potentially relevant reviews were checked against eligibility criteria. No restriction was placed on age of participants. Title and abstracts were screened by two reviewers independently according to eligibility criteria. Disagreements were resolved by a third reviewer. Articles included at the title and abstract level then underwent full-text review by two reviewers independently. Disagreements were resolved by discussion.

During screening, QOL measures were only included if they were specifically reported as being used to measure wellbeing or components/indicators of wellbeing. Health-related QOL instruments (e.g., Stroke and Aphasia Quality of Life Scale-39; Hilari et al., 2003) and instruments about the impact of a factor on wellbeing (e.g., Psychosocial Impact of Assistive Devices Scale; Jutai & Day, 2002) were excluded.

2.4. Data extraction

A customised Excel spreadsheet was designed to meet study aims and used as a data extraction tool to achieve consistent data recording. The spreadsheet was piloted on three randomly selected included papers. Data were collected on publication characteristics (author, year, study design, aim of study), sample characteristics and condition (age, sex, primary and secondary conditions), and participants' communication (methods of expressive communication, receptive language and/or cognition, any other data available about communication status). The instrument(s) reported to measure wellbeing, or components of wellbeing, were identified and data were extracted on respondent, construct measured according to article, context/setting, and adaptations. Adaptations were classified as content, layout, or administration procedure adaptations, which are instrument design features that increase cognitive accessibility of patient-reported outcome measures (Kramer & Schwartz, 2017). Extraction of these data was completed by one researcher and checked by another with no discrepancies reported.

Data were also extracted about each instrument (e.g., target population, recall timeframe, scales, response options) using an Excel spreadsheet adapted from a COSMIN example table (Mokkink et al., 2018). These additional data elements were extracted by one researcher from copies of the instruments, their manuals, and relevant literature (e.g., primary introductory paper) which were located via a subsequent instrument-specific search or author query.

2.5. Construct mapping

Instruments were independently mapped to Keyes' thirteen indicators of wellbeing (2002, 2005; Table 1) by at least two researchers and consensus reached through discussion and mutual agreement. Members of the research team with clinical and research expertise in mental health were involved in the data analysis, as per mapping recommendations (Cieza et al., 2005) which state that one should have good knowledge of the conceptual and taxonomical fundaments of a model before linking meaningful concepts. The indicators of positive mental health were continually referenced whilst reviewing instruments and related materials. When mapping

Table 2
Examples of fully-mapped, partially-mapped, and non-fitting items using items from WHOQOL-BREF (World Health Organization, 2012).

	Example	Reason
Fully mapped	“To what extent do you feel your life to be meaningful?” (WHOQOL-BREF)	This links to the definition of Purpose in Life “…feels that life has a purpose and meaning”.
Partially mapped	“How often do you have negative feelings such as blue mood, despair, anxiety or depression?” (WHOQOL-BREF)	*Part* of this item (“…negative feelings such as blue mood…”) links to the definition for Positive Affect. However, the item also includes terms “anxiety” and “depression”, therefore addressing mental health problems, not wellbeing alone.
Non-fitting item	"How satisfied are you with the conditions of your living place?" (WHOQOL-BREF)	Living conditions do not link to any indicator of wellbeing.

items to instruments, the following elements, adapted from Adair et al. (2018) and Darzins et al. (2017), were considered: (1) definitions provided by the instrument's authors; (2) purpose of the instrument (i.e., screening, diagnostic, or outcome measure); (3) items in the instrument and their phrasing; (4) scales, response categories, and scoring of the instrument; and (5) the construct quantified by the output. Each item in an instrument was identified as mapping 'fully' or 'partially' to its most relevant indicator of wellbeing, or as 'non-fitting' to any category (Table 2). Findings from this phase were synthesised to demonstrate the number of items from each instrument that mapped to the indicators of wellbeing.

2.6. *Evaluation of measurement properties*

As described in the registered protocol, the Consensus-based Standards for the selection of health Measurement INstruments (COSMIN; Prinsen et al., 2018) was the approach chosen to evaluate measurement properties of instruments that measure wellbeing. To be included in this phase of the review, instruments needed to be both relevant and comprehensive as determined by the construct mapping process described in 2.5. COSMIN defines relevance as 'all items should be relevant for the construct of interest' and comprehensiveness as 'no key aspects of a construct should be missing.' (Prinsen et al., 2018).

3. Results

Searches retrieved 11,729 records with 8539 studies eligible for title and abstract screening after deduplication. Subsequently, 547 articles were screened at the full-text level, with a final 26 articles meeting criteria for data extraction (Fig. 1).

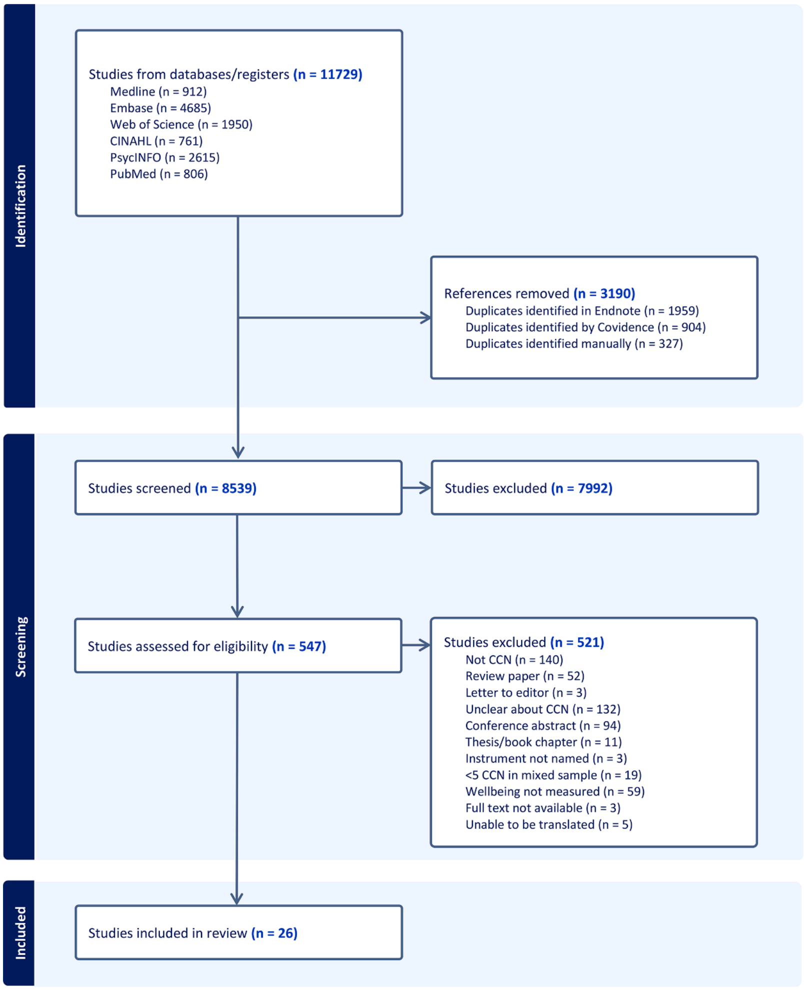


Fig. 1. Prisma flowchart. CCN: Complex communication needs.

3.1. Characteristics of the included studies

Each article reported on a unique study. Study designs included intervention (n = 13), cross-sectional (n = 6), instrument development or validation (n = 3), descriptive (n = 3), and case report (n = 1). Thirteen studies included participants with a developmental or child-onset condition and 13 included participants with an acquired or adult-onset condition. Participants ranged in age from 3 to 88 years, and sample sizes of participants with CCN ranged 1 to 512 (total n = 946). Some participants had secondary conditions in addition to their primary diagnosis (e.g., hearing/vision impairment, behavioural problems). There were mixed samples (i.e., where not all participants had CCN) in eight studies. Participants used a range of symbolic and non-symbolic expressive communication methods. Participants' receptive language was not clearly reported in many studies, rather receptive language skills could be inferred from the text and ranged from normal to severely impacted. Additional study characteristics are in Table 3.

3.2. Adaptations made to instruments

Adaptations were made to instruments in eight studies (Table 4). Thirteen adaptations across seven studies were made to administration procedures, most of which enabled participants to use AAC to respond to instrument items. Eight adaptations across five studies were made to content, which included visual supports (e.g., pictures or videos) and changing the response method in a way that could have altered meaning of the item (e.g., using forced choice or a single-item-scale). Two adaptations were made in one study to layout, and involved items being shown one at a time on an eye-gaze device.

3.3. Characteristics of the instruments

Twenty-two different instruments were used to measure wellbeing, or its core components, across the 26 studies (Table 5). These instruments were identified as intending to measure wellbeing, or its components, in the studies in which they were used, however they may not have been designed to measure wellbeing by their original developers. Upon review of the instruments and their manuals, the constructs designed to be measured by these instruments are QOL, self-determination, state of depression and anxiety, happiness, general wellbeing, social support networks, emotional and behavioural difficulties, health status, health-related QOL, mood state, self-esteem, and subjective wellbeing.

Some instruments were developed for a general population, and some were developed for a clinical population, e.g., Arc's Self-Determination Scale for people with cognitive/developmental disabilities, Cerebral Palsy Quality of Life Questionnaire (CP QOL) for people with cerebral palsy, McGill Quality of Life Questionnaire-Revised (MQOL-R) for people with life-limiting illnesses, and Visual Analog Mood Scales (VAMS) and Visual Analogue Self-Esteem Scale (VASES) for people with aphasia. Most instruments were questionnaires, with a mixture of self-report and proxy-report. One instrument used observation alone and one used observation alongside self- and proxy-report.

3.4. Wellbeing construct mapping

Due to the existence of different versions of the 22 instruments, 36 tools in total were to be mapped to Keyes' indicators of wellbeing. One instrument (Engell et al., 2003) could not be retrieved even after attempting to contact authors and relevant research groups, resulting in 35 instances of mapping. Table 6 shows mapping of the instruments to the thirteen indicators of wellbeing. Eight of the 22 instruments mapped only to emotional wellbeing. Out of the 22 instruments, 16 had items that fully or partially mapped to emotional wellbeing, 10 to psychological wellbeing, and six to social wellbeing. Only the CP QOL had one or more items that fully mapped to each of the three core components of wellbeing.

Non-fitting items linked to topics such as physical health (e.g., *"Over the past two days, my physical symptoms (such as pain, nausea, tiredness and others) were…"*[Cohen et al., 2017]); living conditions (e.g., *"Have you enough money to meet your needs?"* [Schmidt et al., 2006]); anxiety or depression (e.g., *"I get a sort of frightened feeling as if something awful is about to happen."* [Zigmond & Snaith, 1983]); environmental supports (e.g., *"How do you feel about the special equipment that is available in the community (ramps, escalators, wheelchair access)?"* [Davis et al., 2013; Waters et al., 2013]); or behavioural tendencies (e.g., *"Generally well-behaved, usually does what adults request."* [Goodman, 1997]).

Detailed mapping results are available in Table S2 in supplementary material.

3.5. Psychometric evaluation of wellbeing instruments

No instrument was identified as relevant and comprehensive, as each had several items that could not be mapped to the wellbeing construct (not relevant) and/or did not cover all three core components of wellbeing (not comprehensive). As such, no instrument met our criterion for evaluation, and none were assessed using COSMIN.

4. Discussion

This systematic review aimed to identify, describe, and evaluate instruments used to measure wellbeing in people with CCN. Twenty-six studies included 22 instruments, in which emotional wellbeing was most represented. There was no measure of wellbeing used with people with CCN that could be evaluated for psychometric properties. The population for this systematic review was people

Table 3
Study and participant characteristics.

First author (year)	Study design	Total participants (participants with CCN)	Age range in years	Primary condition [secondary conditions]	Expressive communication characteristics of participants with CCN	Receptive language and/or cognition of participants with CCN	Wellbeing instrument(s) used
Aithal (2021)	Intervention: pilot crossover trial	26 (10)	8–13	Autism	Spoken single words/ phrases; Manual sign	Mild to severe difficulties across social, emotional, communication, and cognitive.	SDQ
Corallo (2017)	Intervention: pre-post design	15 (15)	NS (Mean = 48.65)	LIS	NS	Preserved consciousness and intellectual function; those with receptive aphasia were excluded.	SF-36
Cunningham (2003)	Intervention: ABA design	4 (4)	47–75	Post-stroke	Vocalisations; Gestures; Spoken single words/phrases; Writing; Drawing	Moderate or severe comprehension difficulty, but able to follow simple conversation when supported; no major cognitive problems.	VASES
Dahl (2022)	Cross-sectional	35 (18)	59–88	Total laryngectomy	Tracheoesophageal prosthesis; electrolarynx; oesophageal speech; Mouthing; Gesture; Communication boards or books; High tech devices; Writing; Manual sign	NS; presumably normal given primary condition.	LSNS-R; 100 mm VAS
Darling (2015)	Intervention: multiple baseline design	3 (3)	30–57	ID; PMD [CP; physical disability NOS; seizures/ epilepsy; hearing and/or vision problems]	Eye contact; Gesture	NS; affected given primary condition and as per article, "participants [were] adjudicated incompetent to consent".	Indices of Happiness
Engell (2003)	Instrument adaptation and validation	26 *(8)*	26–69	Post-stroke	NS	Global aphasia which indicates receptive language is impaired.	ALQI
Fellinger (2021)	Instrument adaptation and validation	61 (61)	NS (Mean = 45.67)	ID; hearing and/ or vision problems	Manual sign	Cognitive levels of the sample varied. N = 12 could not participate due to a lack of basic understanding.	EUROHIS-QOL; Stark QOL; Light response
García (2020)	Cross-sectional	281 (182)	24–62	ID [CP; physical disability NOS; behavioural problems; hearing and/or vision problems]	Gesture; Communication boards or books; High tech devices; Spoken single words/phrases; Writing; Drawing; Manual signs; Pictographs	Some cognitive impairment implied.	San Martin Scale
Hamm (2006)	Descriptive	8 (8)	19;9–24;9	Autism; CP; ID; Rett's [Hearing and/or vision problems]	Vocalisations; Eye-pointing; Eye codes/ blinks; Yes/no; Gestures; Communication boards or books; Alphabet boards; High tech devices; Spoken single words/phrases; Manual signs	Receptive language deficits implied.	QOLP-PD

(*continued on next page*)

Table 3 (*continued*)

First author (year)	Study design	Total participants (participants with CCN)	Age range in years	Primary condition [secondary conditions]	Expressive communication characteristics of participants with CCN	Receptive language and/or cognition of participants with CCN	Wellbeing instrument(s) used
Karlsson (2019)	Intervention: pre-post design	5 (5)	3–5	CP [Hearing and/or vision problems]	Yes/no	Markedly better ability to understand language than to express themselves, as reported by their parents.	CP QOL
Korner (2013)	Cross-sectional	38 (16)	NS (Mean = 63.7)	ALS	High tech devices	NS	SF-36
Lancioni (2007)	Intervention: ABAB design	9 (9)	3.9–18.8	PMD [ID; physical disability NOS; seizures/epilepsy; hearing and/or vision problems]	Vocalisations; Head or facial movements/ expressions	Authors estimated severe to profound ID, indicating receptive language and cognitive impairments.	Indices of Happiness
Linse (2018)	Cross-sectional	11 (11)	NS (Mean = 54.7)	ALS	High tech devices	Preserved consciousness and cognitive function.	WHO-5; SeiQoL-DW
Londral (2015)	Cross-sectional	27 (27)	39–83	ALS	NS	NS; presumably normal given "patients with other medical conditions" excluded.	WHOQoL-BREF; MQOL
Lund (2006)	Descriptive	7 (7)	19–23	CP [Hearing and/or vision problems]	Vocalisations; Eye-pointing; Eye codes or blinks; Yes/no; Gestures; Communication boards or books; Alphabet boards; High tech devices; Pictographs	Range of receptive language deficits.	Arc's Self-Determination Scale; QOLP-PD
Magee (2006)	Intervention: pre-post design	1 (1)	70	Post-stroke	Spoken single words or phrases	NS, but implied normal.	VASES; VAMS; HADS
Mjorud (2014)	Instrument validation: principal component analysis	661 (512)	NS (Mean=85.34)	Dementia	Vocalisations; head or facial movements/ expressions	Cognitive decline associated with dementia in domains including orientation, memory, judgement, personal care.	QUALID
Rousseau (2013)	Cross-sectional	19 (19)	24–65	LIS	Eye codes or blinks	"Preserved intellectual function", assuming normal receptive language	MQOL; SF-36
Snoeys (2013)	Descriptive	8 (8)	19;11–61;7	LIS [Post-stroke]	Eye codes or blinks; Head or facial movements/ expressions; Gesture; Alphabet boards; High tech devices; Spoken single words/phrases	NS	SF-36
Stasolla (2013)	Intervention: ABAB design	3 (3)	6–9	CP [ID]	Yes/no; Head or facial movements/ expressions	Moderate range of ID; participants able to match an object with its picture and an object within its semantically appropriate category.	Indices of Happiness

(*continued on next page*)

Table 3 (*continued*)

First author (year)	Study design	Total participants (participants with CCN)	Age range in years	Primary condition [secondary conditions]	Expressive communication characteristics of participants with CCN	Receptive language and/or cognition of participants with CCN	Wellbeing instrument(s) used
Stasolla, de Pace (2014)	Intervention: pre-post design	3 (3)	8.4–10.5	Rett's syndrome [ID; physical disability NOS; seizures/epilepsy; behavioural problems]	Vocalisations	Authors estimated severe to profound ID, indicating receptive language and cognitive impairments.	Indices of Happiness
Stasolla, Damiani (2014)	Intervention: multiple baseline design	2 (2)	8.7–9.7	X-fragile [ID; physical disability NS; behavioural problems; PMD]	NS	Same as Stasolla, de Pace (2014)	Indices of Happiness
Stasolla, Perilli (2017)	Intervention: ABAB design	3 (3)	8.8–10.5	X-fragile [ID; behavioural problems]	Vocalisations; Spoken single words/phrases	Same as Stasolla, de Pace (2014)	Indices of Happiness
Stasolla, Caffo (2017)	Intervention: multiple baseline design	2 (2)	5–6	Congenital encephalopathy [ID; physical disability NOS]	Vocalisations	Same as Stasolla, de Pace (2014)	Indices of Happiness
Van der Gaag (2005)	Intervention: pre-post design	38 *(8)*	31–81	Head injury; post-stroke	Head or facial movements/ expressions; Gesture; Drawing	No significant cognitive difficulty	EQ-5D
Wilson (2011)	Case report	1 (1)	29 or 30	LIS	Eye-pointing; Yes/no; Alphabet boards	Cognitive function 'for the most part good'.	SF-36; HADS

(Aithal et al., 2021; Corallo et al., 2017; Cunningham & Ward, 2003; Dahl et al., 2022; Darling & Circo, 2015; Engell et al., 2003; Fellinger et al., 2021; García et al., 2020; Hamm & Mirenda, 2006; Karlsson et al., 2019; Körner et al., 2013; Lancioni et al., 2007; Linse et al., 2018; Londral et al., 2015; Lund & Light, 2006; Magee et al., 2006; Mjørud et al., 2014; Rousseau et al., 2013; Snoeys et al., 2013; Stasolla, Caffò, et al., 2017; Stasolla, Damiani, et al., 2014; Stasolla, De Pace, et al., 2014; Stasolla, et al., 2013; Stasolla, Perilli, et al., 2017; van der Gaag et al., 2005; Wilson et al., 2011).

LIS: locked-in syndrome; CP: cerebral palsy; PMD: profound multiple disabilities; ID: intellectual disability; ALS: amyotrophic lateral sclerosis; NOS: not otherwise specified; NS: not stated.

SDQ: Strengths and Difficulties Questionnaire; SF-36: Short Form Health Survey; VASES: Visual Analogue Self-Esteem Scale; LSNS-R: Lubben Social Network Scale-Revised; 100 mm VAS: 100 mm visual analogue scale; ALQI: Aachen Quality of Life Inventory; QOLP-PD: Quality of Life Profile for Adults with Physical Disabilities; CP QOL: Cerebral Palsy Quality of Life Questionnaire; SeiQOL-DW: Schedule for the Evaluation of Individual Quality of Life-Direct Weighting; MQOL: McGill Quality of Life Questionnaire; VAMS: Visual Analog Mood Scales; HADS: Hospital Anxiety and Depression Scale; QUALID: Quality of Life in Late Stage Dementia.

with CCN, which is a heterogeneous cohort. Consistent with this, the samples in the included studies involved people across a range of ages, diagnoses, expressive and receptive communication profiles, and cognitive statuses.

4.1. *Construct measured*

Although the focus of this review was wellbeing, we found that study authors tended to select instruments measuring QOL. These papers were included in the review because they reported on components of wellbeing as part of QOL or because authors used the terms "wellbeing" and "quality of life" interchangeably or together. A similar trend was observed in a meta-review by Black and colleagues (2022) in which "theoretical domains [of mental health] were inconsistently defined" and instruments were "frequently described as measuring different domains in different reviews." Whilst there is conceptual overlap between QOL and wellbeing, it is crucial they remain separate because there are known problems with QOL measures related to the different models of QOL, its overlap with other constructs, and there being several applications for QOL measures including for economic or health utility purposes. Although we did not identify any measures of wellbeing for this cohort, the mapping process demonstrated that many measures have *items* that map to wellbeing indicators. In particular, emotional wellbeing was most frequently represented in the instruments. This is consistent with findings from Black et al. (2022), and may reflect the fact that emotional wellbeing relates to mood and affect which are measured in depression screening instruments (e.g., Hospital Anxiety and Depression Scale [HADS]). These findings suggest that, in the absence of wellbeing instruments for this cohort, some of the identified instruments may be used to give a sense of emotional wellbeing. However, the results would not be validated as conceptual clarity is an essential element of valid measurement. If using these instruments, it would be important to acknowledge that the instruments are in fact measures of other constructs (e.g., QOL, mood state, self-esteem), and report on them as such.

4.2. *Adaptations*

Adaptations were made to instruments in eight studies. These adaptations covered all three categories of design features, proposed

Table 4
Adaptations made to instruments.

Study	Instrument	Adaptations to Content [C], Layout [L], or Administration procedure [A]$^{\#}$	People involved in the adaptation
Corallo 2017	SF-36	A computerized version of the questionnaire was given. [A] The assessment was split into different sessions to prevent fatigue. [A]	Investigator planned.
Engell 2003	ALQI	An adapted pictorial version was used. Pictograms used for both question content and response options. [C] Forced-choice response format. [C] Multimodal input (e.g., headings read aloud to participant by administrator). [A]	Investigator planned.
Fellinger 2021	EUROHIS-QOL	Translated into an Easy-to-Understand Sign Language version to meet the needs of individuals with ID and limited sign language skills. Items were presented as videos of a signed question. [C] Responses were given on a visual scale with smileys. [C] Administrator explained the scale. [A] Training questions were given immediately before the questions. [A] Optional scripted examples could be given to support comprehension. [C] It was administered as a standardised face-to-face interview (instead of self-administered computer-based). [A]	Designed and planned by the following people: deaf professional working in education and care; sign competent neuropsychiatrist; linguist; psychologist; care professionals; native signer; professional sign language interpreter.
Hamm 2006	QOLP-PD	Helper gave assistance. The amount of assistance received was indicated from a list of alternatives, e.g., "My helper answered all of the questions for me by thinking about what I would say if I could answer them myself". [C]	Investigator planned for the adaptation; participant and helper chose whether to use it.
Linse 2018	WHO-5	Eye-Tracking Computer System (ECTS)-based version: To select an answer, participants fixated on the corresponding gaze-aware button. [A] Each question was displayed on a separate screen. [L]	Investigator planned.
	SeiQoL-DW	ETCS-based version: To select an answer, participants fixated on the corresponding gaze-aware button. [A] Each question was displayed on a separate screen. [L]	Investigator planned.
Lund 2006	Arc's Self-Determination Scale	Participants responded to multiple choice questions via PAS. [A] Participants used their AAC systems to answer open-ended questions. [A]	NS
Rousseau 2013	MQOL	Only the Single-Item-Scale was given. [C] Participants responded using an eye opening/closing code. [A]	NS
	SF-36	Participants responded using an eye opening/closing code. [A]	NS
Snoeys 2013	SF-36	Addition of a set of more specific questions for the condition. [C] Adherence to a multiple-choice format as much as possible, so that participants were only required to provide a yes or no response. [A]	Investigator planned.

#Content: The meaning conveyed in each item; Layout: The arrangement of words, images, and response options; Administration Procedures: The processes followed by the respondent and the administrator to complete the self-report (Kramer & Schwartz, 2017).
SF-36: Short Form Health Survey; ALQI: Aachen Quality of Life Inventory; QOLP-PD: Quality of Life Profile for Adults with Physical Disabilities; SeiQOL-DW: Schedule for the Evaluation of Individual Quality of Life-Direct Weighting; MQOL: McGill Quality of Life Questionnaire.

by Kramer and Schwartz (2017), that can be optimised to increase cognitive accessibility of self-report instruments. Whilst most adaptations related to administration procedures, no patterns were identified in the participant characteristics of these studies. It might be expected that studies with participants who had more significant impairments would have made more adaptations to their chosen instrument(s) but this was not necessarily the case in the current review. There are two possible reasons for this. One, instruments selected for use with those participants may have been designed in a way that already made them accessible to people with CCN. Two, they may have used proxy-report or been observational instruments, meaning adaptations were not required as the person with CCN was not the respondent. It is worth noting that all adaptations reported in the studies were planned; spontaneous adaptations (e.g., taking a break, repeating a question, using manual sign, facial expression, or gesture to aid comprehension) were not reported, but may have been used.

Table 5
Instruments used to measure wellbeing.

Instrument (n = 22) and versions	Target population	Construct measured as per manual	Measure type	Respondent	Description
100 mm VAS	NS	QOL	Scale (continuous)	Self-report	This measure was based on a VAS for pain, but instead the item read “how satisfied are you with your quality of life?” Participants indicate the location on a VAS that best represent their QOL.
ALQI	Neurosurgical patients with brain damage of mixed aetiology.	QOL	Questionnaire	Self-report and parallel proxy-report versions	117 items across 11 domains: activation; mobility; housework; social contact; family relations; ambulation; work; free-time activities; autonomy; communication; cognitive capacity. Response method: binary choice (true/false) and 3-point scale for degree of burden.
Arc’s self-determination scale Adult version Adolescent version	Adults and adolescents with cognitive and developmental disabilities	Self-determination	Questionnaire	Self-report	72 items across 4 domains: autonomy; self-regulation; psychological empowerment; self-realisation. Response method: Autonomy items with a 4-point scale; Self-regulation items with written/verbal responses; Psychological empowerment and Self-realisation items with binary choice.
CP QOL Child self-report Child primary caregiver Teen self-report Teen primary caregiver	Children with CP 4–18yo	QOL	Questionnaire / interview	Primary caregiver and/or self-report. (The CP QOL Child self-report version is not intended for use with 4–9-year-olds.)	CP QOL Child primary caregiver version has 65 items across 7 sections: social wellbeing and acceptance; participation and physical health; feelings about functioning; emotional wellbeing and self-esteem; pain and impact of disability; access to services; family health. CP QOL Child self-report version has 53 items across 5 sections. Access to services and Family health are not included in Child self-report version. CP QOL Teen primary caregiver version has 88 items across 7 sections: general wellbeing and participation; communication and physical health; school wellbeing; social wellbeing; access to services; family health; feelings about functioning. CP QOL Teen self-report version has 72 items across 5 sections. Access to services and Family health not included in Adolescent self-report version. Response method: 9-point scale.
EUROHIS-QOL	Adults	QOL	Questionnaire	Self-report	8 items (taken from WHOQoL-BREF), with 2 questions each on psychological, physical, social and environmental domains. Response method: 5-point scale.
EQ-5D EQ-5D-5L EQ-5D-3L EQ-5D-Y	Adults. The youth version is for 4–15yo.	Health status	Questionnaire and a VAS	Self-report, proxy-report, and interview versions.	5 items that cover: mobility; self-care; usual activities; pain/discomfort; anxiety/depression. Response method: 3-point scale (3-level version) or 5-point scale (5-level version). The VAS component is a vertical scale where endpoints are labelled ’Best imaginable health state’ and ‘Worst imaginable health state’.
HADS	General medical outpatients. Originally developed for people 16–65yo.	States of depression and anxiety	Questionnaire	Self-report	14 items across 2 scales: depression and anxiety. Response method: 4-point scale.
Indices of Happiness	People with profound multiple disabilities	Happiness	Observational	NA	Total observation is 10 min of alternating 10 s observation intervals and 5 s recording intervals. Observers only record Indices if they are sure they occurred. Indices of Happiness: any facial expression or vocalisation typically considered to be an indicator of happiness among people without

(*continued on next page*)

Table 5 (*continued*)

Instrument (n = 22) and versions	Target population	Construct measured as per manual	Measure type	Respondent	Description
					disabilities including smiling, laughing, and yelling while smiling. Indices of Unhappiness: any facial expression or vocalisation typically considered to be an indicator of unhappiness among people without disabilities including frowning, grimacing, crying, and yelling without smiling.
Light response	Deaf people with ID	General wellbeing	Scale (discrete)	Self-report	Participant adjusts the brightness of a light bulb with the help of a five-level controller to express their perception of their QOL, where complete darkness (level 1) corresponds to the lowest QOL and the brightest level (level 5) corresponds to the best QOL.
LSNS LSNS-R LSNS-18 LSNS-6	Older adults	Social support networks	Questionnaire	Self-report	12 items across 2 domains: family and friends. Response method: 6-point scale. (LSNS-6 has 6 items, LSNS-18 has 18 items)
MQOL MQOL-R MQOL-E	People with life-limiting illness/ end-of-life populations	QOL	Questionnaire	Self-report	14 items across 4 subscales: Physical; Psychological; Existential; Social. Plus, a Single Item Scale. Response method: 11-point scale with verbal anchors at each end. (MQOL-E has 20 items across 8 subscales)
QOLP-PD	Adults with intellectual/ developmental disability	QOL	Mostly questionnaire administered by interview. Part of the assessment is based on observation.	3 sections to be used together: Participant Interview (self-report), Other Person Questionnaire (proxy-report), and Assessor Questionnaire.	The Participant Interview and Other Person Questionnaire each have 54 items (some items have Part A and B for importance and satisfaction) across 9 subscales: BEING (Physical, Psychological, Spiritual); BELONGING (Physical, Social, Community); BECOMING (Practical, Leisure, Growth). There are an additional 6 items which assess Decision-making and Opportunity. The Assessor Questionnaire has 27 items across the same 9 subscales as above. Response method: 3- or 5-point scale, depending on item. A 2-point scale may be used if this is deemed more appropriate for the participant. There are also visual representations of the scales that can be used as aids. The Assessor Questionnaire also has some open answer items.
QUALID	People with late-stage dementia	QOL	Questionnaire administered by interview	Proxy-report	11 items. Response method: 5-point scale. In addition, there are 2 items with a 3-point scale for the interviewer to answer about the a) quality of interview and b) knowledge/ familiarity of the caregiver informant with the subject.
San Martin Scale	People with significant disabilities aged 18+ years	QOL	Questionnaire	Proxy-report	95 items across 8 subscales: Self-determination; Emotional wellbeing; Physical wellbeing; Material wellbeing; Rights; Personal development; Social inclusion; Interpersonal relations. Response method: 4-point scale
SDQ 2–4yo 4–10yo 11–17yo 11–17yo self-rated	Children 2–17yo	Emotional and behavioural difficulties	Questionnaire	Proxy-report only for 2–11-year-olds. Self-report and/or proxy-report for 11–17-year-olds.	25 items across 5 subscales: Emotional symptoms; Conduct problems; Hyperactivity/inattention; Peer relationship problems; Prosocial behaviour. Response method: 3-point scale
SeiQOL-DW	Adults in a “variety of patient groups”	QOL	Analog scale and interview	Self-report	A three step process whereby A) participants name 5 areas of life that are important to their QOL; B) participants determine their current status on those 5 areas by drawing a

(*continued on next page*)

Table 5 (*continued*)

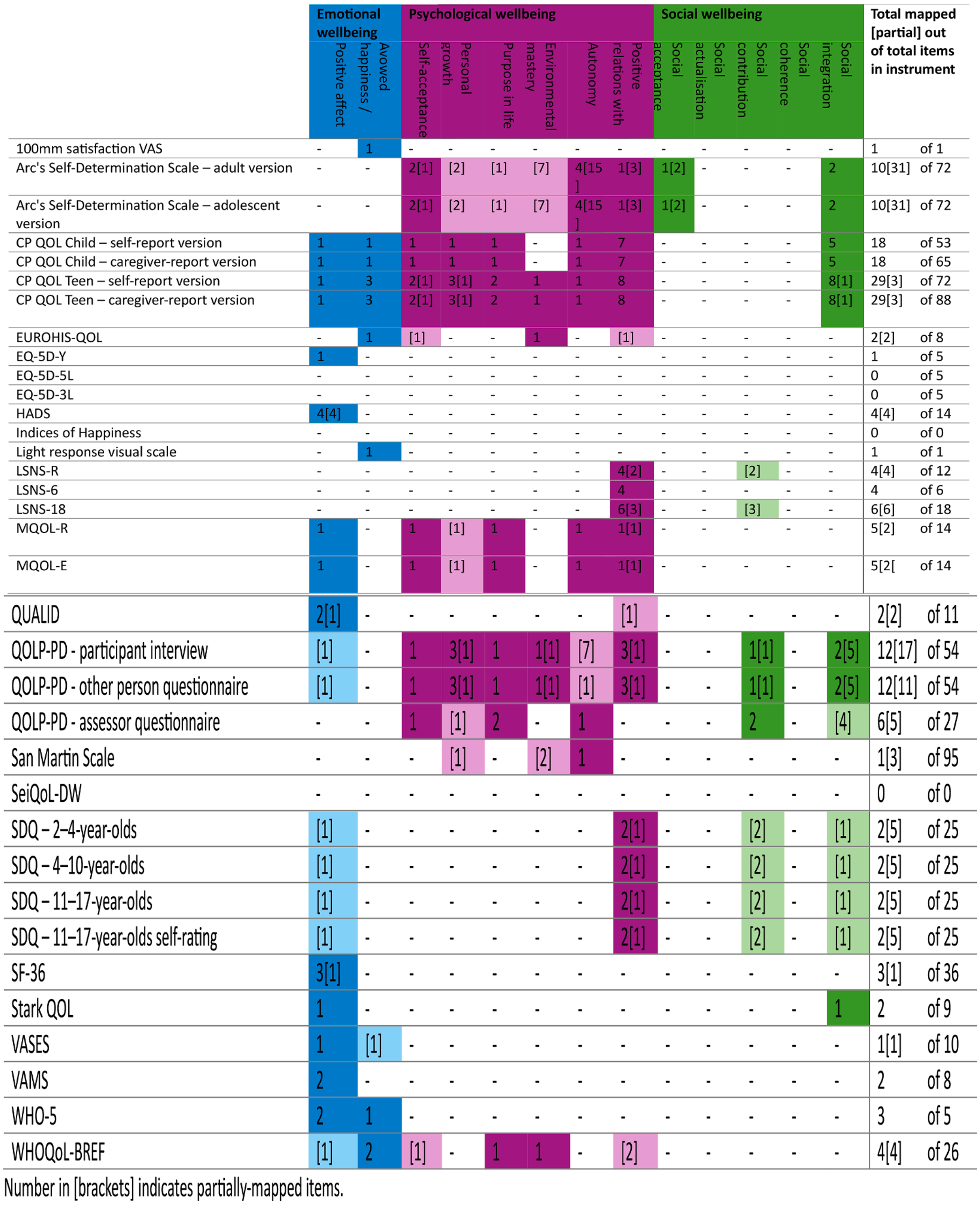
Instrument (n = 22) and versions	Target population	Construct measured as per manual	Measure type	Respondent	Description
					bar graph and then complete a VAS of their overall QOL; and C) participants use a "weighting" instrument (five interlocking, coloured laminated circular disks that are rotated around a central point to form a pie chart) to demonstrate the relative importance of these areas to each other.
SF-36	NS	Health status	Questionnaire	Self-report	36 items across 9 areas: physical functioning; bodily pain; physical role functioning; emotional role functioning; mental health/emotional wellbeing; social role functioning; energy/fatigue; general health perception; perceived change in health. Response method: depends on question. Items may have 3-, 5-, or 6-point scale, or be binary choice.
StarkQOL	Intended to be translated into other languages and used by people who cannot read	Health-related QOL	Questionnaire	Self-report	9 items across 2 subscales: Mental QOL and Physical QOL. Response method: 2-, 3-, or 5-point scales (with pictures)
VAMS	Aphasic patients and other neurologically impaired individuals	Mood state	Analog scale	Self-report	8 items. Response method: Respondents indicate (with pencil) the point along a vertical line that best describes their current state for that item
VASES	People with aphasia	Self-esteem	Questionnaire	Self-report	10 items. Response method: 5-point scale
WHO-5 questionnaire	General populations aged 9+yo	Subjective wellbeing	Questionnaire	Self-report	5 items. Response method: 6-point scale
WHOQoL-BREF	General populations	QOL	Questionnaire	Self-report	26 items across 4 subscales: Physical health; Psychological; Social relationships; Environment. Response method: 5-point scale

(Brumfitt & Sheeran, 1999; Carlsson, 1983; Cohen et al., 2017, 2019; Davis et al., 2013; EuroQol Research Foundation., 2018; EuroQol Research Foundation, 2019, 2020; Fellinger et al., 2021; Goodman, 1997; Green & Reid, 1996; Hardt, 2015; Hütter & Gilsbach, 2002; Lubben, 2025; Lubben, 1988; O'Boyle et al., 1995; Renwick & Myerscough, 2012; Schmidt et al., 2006; Staehr, 1998; Stern et al., 1997; Verdugo et al., 2014; Ware & Sherbourne, 1992; Waters et al., 2013; Wehmeyer & Kelchner, 1995; Weiner et al., 2000; World Health Organization, 2012; Zigmond & Snaith, 1983).

QOL: quality of life; CP: cerebral palsy; VAS: visual analogue scale; ID: intellectual disability; NA: not applicable.

100 mm VAS: 100 mm visual analogue scale; ALQI: Aachen Quality of Life Inventory; CP QOL: Cerebral Palsy Quality of Life Questionnaire; HADS: Hospital Anxiety and Depression Scale; LSNS-R: Lubben Social Network Scale-Revised; MQOL: McGill Quality of Life Questionnaire; QOLP-PD: Quality of Life Profile for Adults with Physical Disabilities; QUALID: Quality of Life in Late Stage Dementia; SeiQOL-DW: Schedule for the Evaluation of Individual Quality of Life-Direct Weighting; SDQ: Strengths and Difficulties Questionnaire; SF-36: Short Form Health Survey; VAMS: Visual Analog Mood Scales; VASES: Visual Analogue Self-Esteem Scale.

Table 6
Mapping of instruments to indicators of wellbeing.



	Emotional wellbeing		Psychological wellbeing						Social wellbeing					Total mapped [partial] out of total items in instrument	
	Positive affect	Avowed happiness /	Self-acceptance	Personal growth	Purpose in life	Environmental mastery	Autonomy	Positive relations with	Social acceptance	Social actualisation	Social contribution	Social coherence	Social integration		
100mm satisfaction VAS	-	1	-	-	-	-	-	-	-	-	-	-	-	1	of 1
Arc's Self-Determination Scale – adult version	-	-	2[1]	[2]	[1]	[7]	4[15]	1[3]	1[2]	-	-	-	2	10[31]	of 72
Arc's Self-Determination Scale – adolescent version	-	-	2[1]	[2]	[1]	[7]	4[15]	1[3]	1[2]	-	-	-	2	10[31]	of 72
CP QOL Child – self-report version	1	1	1	1	1	-	1	7	-	-	-	-	5	18	of 53
CP QOL Child – caregiver-report version	1	1	1	1	1	-	1	7	-	-	-	-	5	18	of 65
CP QOL Teen – self-report version	1	3	2[1]	3[1]	2	1	1	8	-	-	-	-	8[1]	29[3]	of 72
CP QOL Teen – caregiver-report version	1	3	2[1]	3[1]	2	1	1	8	-	-	-	-	8[1]	29[3]	of 88
EUROHIS-QOL	-	1	[1]	-	-	1	-	[1]	-	-	-	-	-	2[2]	of 8
EQ-5D-Y	1	-	-	-	-	-	-	-	-	-	-	-	-	1	of 5
EQ-5D-5L	-	-	-	-	-	-	-	-	-	-	-	-	-	0	of 5
EQ-5D-3L	-	-	-	-	-	-	-	-	-	-	-	-	-	0	of 5
HADS	4[4]	-	-	-	-	-	-	-	-	-	-	-	-	4[4]	of 14
Indices of Happiness	-	-	-	-	-	-	-	-	-	-	-	-	-	0	of 0
Light response visual scale	-	1	-	-	-	-	-	-	-	-	-	-	-	1	of 1
LSNS-R	-	-	-	-	-	-	-	4[2]	-	-	[2]	-	-	4[4]	of 12
LSNS-6	-	-	-	-	-	-	-	4	-	-	-	-	-	4	of 6
LSNS-18	-	-	-	-	-	-	-	6[3]	-	-	[3]	-	-	6[6]	of 18
MQOL-R	1	-	1	[1]	1	-	1	1[1]	-	-	-	-	-	5[2]	of 14
MQOL-E	1	-	1	[1]	1	-	1	1[1]	-	-	-	-	-	5[2[	of 14
QUALID	2[1]	-	-	-	-	-	-	[1]	-	-	-	-	-	2[2]	of 11
QOLP-PD - participant interview	[1]	-	1	3[1]	1	1[1]	[7]	3[1]	-	-	1[1]	-	2[5]	12[17]	of 54
QOLP-PD - other person questionnaire	[1]	-	1	3[1]	1	1[1]	[1]	3[1]	-	-	1[1]	-	2[5]	12[11]	of 54
QOLP-PD - assessor questionnaire	-	-	1	[1]	2	-	1	-	-	-	2	-	[4]	6[5]	of 27
San Martin Scale	-	-	-	[1]	-	[2]	1	-	-	-	-	-	-	1[3]	of 95
SeiQoL-DW	-	-	-	-	-	-	-	-	-	-	-	-	-	0	of 0
SDQ – 2–4-year-olds	[1]	-	-	-	-	-	-	2[1]	-	-	[2]	-	[1]	2[5]	of 25
SDQ – 4–10-year-olds	[1]	-	-	-	-	-	-	2[1]	-	-	[2]	-	[1]	2[5]	of 25
SDQ – 11–17-year-olds	[1]	-	-	-	-	-	-	2[1]	-	-	[2]	-	[1]	2[5]	of 25
SDQ – 11–17-year-olds self-rating	[1]	-	-	-	-	-	-	2[1]	-	-	[2]	-	[1]	2[5]	of 25
SF-36	3[1]	-	-	-	-	-	-	-	-	-	-	-	-	3[1]	of 36
Stark QOL	1	-	-	-	-	-	-	-	-	-	-	-	1	2	of 9
VASES	1	[1]	-	-	-	-	-	-	-	-	-	-	-	1[1]	of 10
VAMS	2	-	-	-	-	-	-	-	-	-	-	-	-	2	of 8
WHO-5	2	1	-	-	-	-	-	-	-	-	-	-	-	3	of 5
WHOQoL-BREF	[1]	2	[1]	-	1	1	-	[2]	-	-	-	-	-	4[4]	of 26

Number in [brackets] indicates partially-mapped items.

Number in [brackets] indicates partially-mapped items.

4.3. *Considerations for assessing wellbeing in people with CCN*

In the absence of wellbeing measures for people with CCN, we might then consider how existing wellbeing measures, such as the Mental Health Continuum-Short form (MHC-SF; Keyes et al., 2008; Yeo & Suárez, 2022), could be adapted or used in such a way that makes them more accessible to people with CCN. Four considerations are proposed below; however, their applicability should be considered in relation to the specific purpose for which the instrument is designed or used.

Ensure individual cognitive and communication access needs are met.

Supports should be provided so that having CCN does not be preclude a person from completing self-report instruments. Some instruments described alternatives to their typical administration for people who had specific communication access needs, e.g., the EQ-5D and WHOQOL-BREF can be interviewer-administered if a respondent does not have sufficient reading ability to self-complete. Other instruments permit the use of alternative communication methods, e.g., the Quality of Life Profile for Adults with Physical Disabilities (QOLP-PD) manual acknowledges communication access needs and states that “all efforts should be made to assist individuals to answer the questions for themselves” and that “participants may use non-verbal methods of communicating to respond to the questions”. Importantly, these alternatives and permissions are specified in the instruments’ user manuals, which means that interviewers would be aware that they can apply the adaptations, if necessary, and that subsequent results are recognised.

There are some considerations to be made when employing access strategies. Instrument administrators should know how to determine whether an individual requires communication access supports. For example, in the QOLP-PD, interviewers are instructed to use the included Screening Tool for Cognitive and Communicative Ability to ascertain whether a person is able to comprehend the questions, make evaluative distinctions using rating scales, and communicate a response. Only those respondents who do not meet these criteria, even using non-verbal communication modes, would be precluded from using the self-report component of the QOLP-PD. A further consideration is the validity and reliability of instruments and score equivalency between typical and communication accessible methods. People administering these instruments should review the validity, reliability, and score equivalency of the instrument when administering it in a non-typical manner—not to discourage them from doing so, but to ensure accurate, authentic reporting of results.

Recognise the relative importance and relevance of wellbeing indicators to an individual.

Components and indicators of wellbeing may have varying levels of importance or relevance for individuals, so weighting systems can be used to provide a deeper understanding of their experience. For example, a person might indicate that Personal Growth is very important to them and Social Contribution less so, providing insight into where efforts should be focused to have the greatest impact on their wellbeing. This is consistent with findings from an exploratory qualitative study in which authors described variation in relative value of QOL domains for people with intellectual disabilities (Morisse et al., 2013). The Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SeiQOL-DW) has a weighting system whereby participants use a pie-chart to demonstrate the relative importance of different aspects of their life. The physical pie-chart may be particularly accessible to people with cognitive impairments for whom seeing or touching an object supports their comprehension. The concept, however, can also be translated to a digital version whereby people using technology (e.g., eye-gaze) could independently manipulate a pie-chart. The weighting system could take other forms: ranking indicators in order of importance (which can be done using different access methods: digitally, pointing, or physically manipulating printouts of words or pictures); picking the 3–5 most important/relevant indicators without ordering them; or, as done in the QOLP-PD, scoring indicators for both satisfaction and importance.

Collect information from multiple sources when using proxy-report.

Even though obtaining information from a person with CCN about their wellbeing via self-report is preferred for accuracy and ethical reasons (Balboni et al., 2013; Mileviciute & Hartley, 2015; Schmidt et al., 2010; Scott & Havercamp, 2018; United Nations, 2006), it can pose challenges in some cases. To address this, information can be collected from multiple sources. The QOLP-PD, for example, consists of a Participant Questionnaire, Other Person Questionnaire, and Assessor Questionnaire; the CP QOL has a parent-proxy version and a self-report child version. Importantly, the manuals of these two instruments specify that *all versions* should be completed—this is in contrast to other instruments (e.g., EQ-5D, Strengths and Difficulties Questionnaire SDQ) in which self- and proxy-report versions exist but there is no explicit expectation that both should be completed. Some instrument administrators might choose to use multiple versions; however, when working with people with CCN, this should be specified in user manuals to ensure its intentional and consistent implementation. For example, the manual instructions for the CP QOL state: “Parents and children may report different levels of QOL. Consequently, it is recommended that both versions are used, if possible. Statistical analyses should be conducted on both parent proxy and child self-report scores and both should be reported and interpreted” (Waters et al., 2013, p. 11).

In the QOLP-PD, if an individual cannot complete the Participant Questionnaire, the instrument manual states that the Other Person Questionnaire should be independently completed by *two* people. This reflects the recommendation by Scott and Havercamp (2018) that, if proxy-report is required, triangulation of reports from multiple people may be more accurate than a report from a single proxy. When collecting proxy-report, it is also important to remain aware of who the proxy is, the nature of their relationship to the person with a disability, and their knowledge of that person in relation to the construct being measured. In the current review, we identified some instruments which specified who would be a suitable a proxy, e.g., a professional who has known the person for at least three months or a family member who knows the person well (Renwick & Myerscough, 2012; Verdugo et al., 2014).

Set the scene for wellbeing by acknowledging environmental factors.

Consideration of environmental factors can contextualise wellbeing, particularly for those with complex needs who may have limited control over their environments. The San Martin Scale, which was developed for people with “significant disabilities”, includes many items about environmental factors such as “*Persons providing him/her supports take into account his/her preferences and choices*” and “*In the service he/she attends, activities or supports that enable him/her to maintain social interactions are planned*”. The actions of support people and the settings in which people with disability live, work, learn, and play are important aspects of their lives and may contribute to their wellbeing. As such, understanding environmental factors provides necessary contextual information to paint a clearer picture of the wellbeing of people with complex disability. A Delphi study (Gómez et al., 2015), aiming to operationalise QOL for people with profound intellectual and multiple disabilities, achieved consensus on indicators of QOL for this cohort. Many of the indicators were environmental, e.g., what others do to/for the person with disability and what supports are in place. Even though the environment itself is not wellbeing, including supplementary items on environmental factors in wellbeing instruments may inform the modification or optimisation of environments to best support a person with a disability to experience good wellbeing.

4.4. Strengths and limitations

A strength of this review is its focus on people with CCN, a group often excluded from research (Taylor & Balandin, 2020). Since CCN is not a diagnosis, but a functional description, it is not reported in the literature in a consistent way. Therefore, another strength of this review is the comprehensive literature search which included several synonyms of and alternate terms for CCN, optimising chances of capturing all papers with participants who had CCN. Another strength of this review is that no restrictions were placed on age nor on the cause/onset of CCN. This was done purposefully as instruments identified for certain clinical populations might be considered or adapted for others. Finally, this review provides four features of instruments that can be considered when administering, adapting, or developing wellbeing instruments for people with CCN: ensuring cognitive and communication access; collecting information from multiple sources; recognising the relative importance and relevance of wellbeing indicators to an individual; and setting the scene for wellbeing by acknowledging environmental factors.

There were some limitations of this systematic review. Wellbeing, or its components, may be measured in instruments that were not identified in this review. For example, SEAS-PCS (Batorowicz et al., 2017) is used to measure participation experiences in young people with CCN. The instrument contains some scales that may be relevant to wellbeing (e.g., social belonging) but was not described in any papers as measuring wellbeing or its components, hence was not included. Another limitation is that this review may not reflect the clinical practice of clinicians working with people who have CCN, nor does it reflect situations in which wellbeing is assessed without a named instrument. Future research may explore clinical practice and/or other methods for assessing wellbeing in this cohort. Lastly, we acknowledge that this review was undertaken using the dual continua model as a guiding theoretical perspective, and that using another theoretical perspective may have yielded different results.

5. Conclusion

Using robust systematic review methods, no instruments measuring wellbeing in people with CCN were identified. The term ‘wellbeing’ was used inconsistently in the included articles and many of the identified instruments were measures of QOL. Several instruments contained items that mapped to wellbeing indicators, particularly emotional wellbeing, however only the CP QOL had at least one item that fully mapped to each of the three core components of wellbeing. Importantly, this systematic review identified and describes four features of instruments which may increase their accessibility and utility to people with CCN and links these features to examples from identified instruments. Readers should consider these features when administering, adapting, or developing wellbeing instruments for people with CCN. Future research should prioritise identifying an appropriate wellbeing measure for adaptation for use with people with CCN.

Data availability declaration

Data available as supplementary material.

CRediT authorship contribution statement

Jacinta Molini Pennacchia: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. **Jørn Østvik:** Investigation, Writing – review & editing. **Iain Dutia:** Investigation, Writing – review & editing. **Megan Walsh:** Investigation, Writing – review & editing. **Dave Coghill:** Methodology, Formal analysis, Writing – review & editing, Supervision. **Mats Granlund:** Methodology, Formal analysis, Writing – review & editing, Supervision. **Christine Imms:** Methodology, Formal analysis, Writing – review & editing, Supervision.

Declaration of competing interest

None.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jcomdis.2025.106494.

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