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Mental health and mental health problems among users of AAC: a scoping review

Jørn Østvik^a , Mats Granlund^{a,b}  and Astrid Røsland Seim^a 

^aDepartment of Mental Health, Norwegian University of Science and Technology (NTNU), Trondheim, Norway; ^bCHILD, Department of Social work, School of Health and Welfare, Jönköping University, Jönköping, Sweden

ABSTRACT

Functional communication is crucial for mental health and for coping with mental health problems. People with disabilities are at increased risk of mental health problems, and people who use augmentative and alternative communication (AAC) are reported to be at greater risk of depression and anxiety than people without impairments. This scoping review summarizes existing knowledge about the mental health and mental health problems of people who use AAC. The review includes nine publications, published between 2001 and 2022. These mainly report on adults and elderly people who use AAC. Four of the nine publications included people who use AAC due to acquired impairments. None of the studies reported the prevalence of mental health problems and only a few addressed factors of positive mental health. The results indicate a shortage of theoretical accounts for most of the publications included, and the publications are not built on each other. The scarcity of knowledge is discussed in relation to the idea that the need for communicative support is a need based on communicative functioning rather than any diagnostic category and thus not visible in much of the health literature based on diagnostic categories. Several implications for practice and research are suggested.

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KEYWORDS

Mental health; well-being; mental health problems; augmentative and alternative communication; scoping review

Augmentative and alternative communication (AAC) includes various means of communication other than spoken language or sign language and “refers to the methods, tools, and theories of nonstandard linguistic and nonlinguistic forms of communication by and with individuals without or with limited functional speech” (Loncke, 2019, p. 1). The prevalence of individuals having a need for communicative support strong enough to require AAC for functional communication is not well known. This gap in knowledge might be related to that AAC is a functional difficulty rather than a diagnostic criterion. Much of health research is based on investigating diagnostic groups. Since the establishment of AAC as a professional field in the 1950s, mental illness has been identified as a primary global health challenge (Vigo et al., 2016), accounting for up to 20 years’ reduction in lifespan and profound individual and societal costs (Wykes et al., 2015). The significance of communication for mental health and well-being in both general and clinical populations is now well-established (Segrin, 2014), and a recent review entrenched the association between a lack of social communication skills (excluding autism spectrum disorder) and mental health problems from childhood to adulthood (Dall et al., 2022). Access to mental health services for users of AAC has been found to depend on many factors, including the communication between the patient and therapist, the language skills of the AAC user, the use of a communication assistant, the skills of the therapist, the billing system for mental health

services, and the system and policy factors that influence such services (Noyes & Wilkinson, 2022, 2024). There is limited knowledge about the well-being, mental health, and mental health problems of individuals who use AAC. Although the use of AAC may facilitate social interaction and mitigate barriers (Cleary et al., 2018; Güroğlu, 2022; King et al., 2016), intervention research of AAC focuses mostly on communicative aspects of AAC (Prinsloo et al., 2024), and less on participation and related health outcomes (Light et al., 2019; Light & McNaughton, 2015; McNaughton & Light, 2015). To provide adequate services and care for individuals who need AAC, knowledge is needed about the prevalence and predictors of mental health and mental health problems in this population. The current scoping review attends to this need by summarizing what is currently known about the mental health and mental health problems among users of AAC.

The point at which mental health problems are severe enough to be diagnosed as a mental illness is arbitrary (Dalman et al., 2015). Most mental health problems have a shorter duration and less severity than a mental illness. However, mental health problems may cause substantial functional impairment despite the unfulfillment of diagnostic criteria for psychiatric disorders and classification as a mental illness. In this paper, mental illness is seen as a severe and intensive type of mental health problem, situated within a continuum from severe to no mental health problems (Granlund et al., 2021).

CONTACT Jørn Østvik  jorn.ostvik@ntnu.no  Department of Mental Health, Norwegian University of Science and Technology (NTNU), 7491 Trondheim, Norway.

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Because mental health involves more than the mere absence of mental health problems (Keyes, 2005; WHO, 2005), we investigate mental health as a concept in itself, separate from the concept of mental health problems. People can simultaneously perceive mental health problems and mental health where mental health may protect from the consequences of mental health problems (Westerhof & Keyes, 2010). Mental health may be conceptualized as a continuum of subjective and psychological well-being (Dalman et al., 2015; Granlund et al., 2021), ranging from flourishing (i.e., being filled with positive emotion and functioning well psychologically and socially) to languishing (i.e., emptiness and stagnation, constituting a life of quiet despair) (Granlund et al., 2021; Keyes, 2006; Keyes et al., 2002). Psychological well-being is also reported to be related to functional communication (Wolters-Leermakers et al., 2022). Communication is vital for the establishment of social relationships and close friendships, which are important for the mental health of people in general (Diaconu-Gherasim et al., 2023; Stancliffe et al., 2010), including those with physical (Tough et al., 2017) or intellectual (Cummins, 2020) impairments. However, for users of AAC, there is a lack of knowledge about social relations and friendships and how they are related to mental health (Blackstone et al., 2007; O'Keefe et al., 2007). The limited body of research on AAC and social relations indicates that children and adolescents who use AAC are at risk of few and/or superficial friendships (Chung et al., 2012; Midtlin et al., 2015; Østvik et al., 2018; Therrien et al., 2016), with potential negative effects on mental health. Loneliness is associated with mental health problems (Beutel et al., 2017; Hards et al., 2022), and feelings of loneliness are apparent among children (Raghavendra et al., 2013), young adults (Cooper et al., 2009), adults (Stancliffe et al., 2010), and elderly people (Balandin et al., 2006; Ballin & Balandin, 2007) who use AAC. To better meet the needs of AAC users, health and social workers need knowledge about the current mental health and interventions or factors associated with improved mental health such as supporting social relationships in this population.

Users of AAC are a heterogeneous group. The use of AAC is not tied to any specific diagnosis, but rather reflects functional problems that may occur within different diagnostic categories, or even in people without a known diagnosis. Some people have congenital functional impairments that necessitate the use of AAC from early childhood and throughout life (e.g., for some with autism spectrum disorder (ASD), cerebral palsy (CP), or Down syndrome). Other people start using AAC at an older age (e.g., following the acquired motor impairment of amyotrophic lateral sclerosis (ALS)). It may be the case that the mental health and mental health problems of people with congenital needs for AAC differ from those of people who develop a need for AAC later in life. To provide adequate services, knowledge of the mental health and mental health problems of both groups is warranted, and both groups are therefore included in the current review.

Individuals with disabilities of all ages are at greater risk of mental health problems in terms of anxiety and depressive symptoms than typically developing peers (Augustine et al., 2022; Oeseburg et al., 2010; 2011; Smith et al., 2019; van Steensel et al., 2011). Among Australian adolescents and

adults with profound disabilities affecting their functional communication, 50.2% self-report mental health problems (Australian Institute of Health & Welfare, 2016). However, the mental health problems are not necessarily caused by the disabilities themselves. For deaf people using sign language, the increased risk of mental health problems (de Graaf & Bijl, 2002; Fellingner et al., 2012; Kvam et al., 2007; Øhre, 2017) is arguably not caused by the deafness, but rather mediated by factors such as physical health problems, adverse living conditions, and communication problems (van Gent et al., 2007). A systematic review recently found that the trajectories of mental health problems in children with disabilities are predicted by the same factors as in children without disabilities (e.g., family circumstances and socioeconomic status) (Danielsson et al., 2024). Most of the studies in the review were based on proxy ratings, rather than self-reports, and persons in different diagnostic categories were compared. Users of AAC, however, were not a specified subcategory, and the predictors and trajectories of mental health problems in children who need AAC cannot be deduced from the data. A proxy "... is a person who reports an outcome on behalf of" another person (Roydhouse et al., 2022, p. 318), and is often represented by family members or staff (Bersani Jr, 1999). However, proxy reports are considered to have limited reliability (Brewster, 2007; Eiser & Morse, 2001; Østvik et al., 2018), for example due to emotional involvement, information interpreted as substitutional, and lack of insights into other people's lives.

Although research is scarce (Di Marco & Iacono, 2007; Enderby, 2014; Hourcade et al., 2004; McNaughton & Light, 2015), users of AAC may be at greater risk of mental health problems (Smith, 2005) than people without disabilities due to for example depression related to having a communication disability (Crawford, 1987), exposure to trauma and abuse (Collier et al., 2006; Ottmann et al., 2017), and a lack of reliable and competent communication partners in situations of grief and loss (Dark et al., 2011). Indeed, users of AAC are reported to be at greater risk of depression and anxiety than people without impairments (Di Marco & Iacono, 2007; Stransky et al., 2020) but comparisons of people with disability with and without a need for AAC are rare. Overall, the prevalence of mental health problems among people who use AAC are uncertain (Di Marco & Iacono, 2007).

Researchers have reported an increased need for mental health services among users of AAC (Collier et al., 2006; Di Marco & Iacono, 2007; Iacono et al., 2008). However, the uncertain prevalence rates of mental health issues (Hagiliassis et al., 2005) and challenges in identifying these issues are recognized barriers to providing adequate mental healthcare for this population. These challenges include vocabulary limitations, extended conversation times with AAC, communication breakdowns, and reduced ability to express emotions due to the lack of prosodic and acoustic cues in speech-generating devices (Noyes & Wilkinson, 2022). Importantly, there is limited research about the provision of mental health care to people who use AAC, and how this population perceive the provision of such support (Noyes & Wilkinson, 2024). Other factors hindering adequate healthcare include underreporting of mental health needs when using speech substitutes (Di Marco & Iacono, 2007) and the lack of tools to assess mental health in

AAC users (Di Marco & Iacono, 2007; Hagiliassis et al., 2005). Lack of access to the vocabulary necessary to self-report on mental health and well-being (Collier et al., 2006) might affect how people who use AAC can manage their mental health problems, and staff may lack the necessary skills to assess and intervene concerning mental health problems for people using AAC as their primary mode of communication. AAC has an important function not only for expressive language to communicate wants and needs, exchange information, develop social closeness, and participate in various contexts (Light, 1988), but is also vital for comprehension of verbal language (Drager et al., 2010). This has implications for the beneficial potential of health services provided to users of AAC. To adequately tailor health care services to meet the needs of users of AAC, stakeholders need knowledge not only about the levels and characteristics of mental health and mental health problems in this population, but also about what facilitates or hinders improvements in mental health and reductions in mental health problems for this group within the current service system.

The current study therefore aims to review existing knowledge about mental health, mental health problems, and predictors thereof, for people who use AAC. We aim to do so by addressing the following research questions: Among people who use symbolic or non-symbolic forms of AAC: 1) what characterizes mental health as reported by users of AAC; 2) what characterizes mental health problems as reported by users of AAC; 3) which factors are reported to impact mental health; and 4) which factors are reported to impact mental health problems?

Method

Although this review followed the criteria for systematic reviews as described by Schlosser et al. (2007) and the protocol was developed and registered in Prospero (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=368390), this study is characterized as a scoping review, due to the relatively broad aim and research questions. A scoping review differs from a systematic review in that it aims to determine what range of evidence is available on a specific topic, and to provide an overview of existing evidence regardless of quality (Munn et al., 2018). The approach taken by Arksey and O'Malley (2005) and extended by Levac et al. (2010) was used.

Scope and selection principles

One inclusion criterion was the use of any type of unaided or aided communication, including sign systems (e.g., signed Norwegian, signed English and equivalent which is different from sign language), among people with AAC as their main communication form. The inclusion criterion for document language was literature in English, Norwegian, Swedish, or Danish. The publication types included peer reviewed articles, doctoral dissertations, and master's theses. The type of study was restricted to recent empirical studies, and for pragmatic reasons limited to those published in year 2000 or later. To the

extent that older, relevant literature exists, it was expected to be referred to in included publications. There were no delimitations for age or geographic region, and publications based on self-reporting and/or proxy-reporting were included.

The exclusion criteria encompassed AAC not used as the main communication form, AAC used in a short time-perspective (e.g., when in intensive care), sign language, facilitated communication, and the lack of mental health or mental health problems as a topic. Publications in languages other than English, Norwegian, Swedish, and Danish were excluded. We also excluded publication types such as non-peer reviewed publications, books, book chapters, reports, government documents, bachelor's theses, unpublished material, conference papers, publications not reporting new empirical data, other publication types not described in the inclusion criteria, as well as reviews and other study designs not resulting in empirical data, and publications without full text available. However, some excluded publications were referred to in the introduction of this review.

Search strategy

The literature search was conducted by the first author in the period August to October, 2022. The search terms and Boolean operators were constructed in collaboration between the authors and a librarian at the [name of the university] and are presented in Table 1.

The search in English was conducted in 13 databases: AMED, EBSCO Psychology & Behavioral Sciences Collection, EMBASE, ERIC, Medline, PsycARTICLES, PsycINFO, PubMed, ScienceDirect, Scopus, Social Services Abstracts, Sociological Abstracts, and Web of Science. In addition, PROSPERO was also searched. Equivalent search terms were developed in Norwegian, Swedish, and Danish, and searches in the Scandinavian languages were carried out in seven databases, respectively: Bibliotek (dk), Bora (no), Diva (swe), Duo (no), Idunn (no), NTNU Open (no), and SweMed+ (swe). Citation searches (i.e., searches for citations to locate additional relevant literature) were conducted in Google Scholar alerts during the search period once a set of articles that fully met inclusion criteria was achieved.

Procedure

The literature search resulted in 4,798 publications. One publication identified through citation searching was manually

Table 1. Search terms.

Search Terms and Boolean Operators
("mental health" OR "mental disorder*" OR "mental health problems" OR "mental illness" OR "psychological health" OR "psychological illness" OR wellbeing OR "well being" OR depression OR anxiety) AND ("augmentative and alternative communication" OR AAC OR "augmentative communication" OR "Alternative communication" OR "complex communication needs" OR CCN)

Note. The search terms and the boolean operators were used in the literature search in all databases. Because of the conceptual overlap between mental health problems and Neurodevelopmental disorders (NDD) search terms directly related to NDD (e.g., ADHD, ASD) were left out when specifying search words for mental health problems.

added in Covidence. Covidence is a web-based collaboration software platform that streamlines the production of systematic and other literature reviews. Bibliographical data, including abstracts for the publications, were imported to Endnote. After removing duplicates ($n=1,317$) and publications published prior to year 2000 ($n=641$), full-text copies were searched for in Endnote. In total, 2,840 references, abstracts, and full text copies were exported from Endnote to Covidence. First, publications were automatically checked for duplicates that might have been missed in Endnote ($n=251$). Second, the first author screened titles and abstracts for 2,573 publications. Of these, the second author screened 180 publications and the third author screened 175 publications. In this phase, 17 duplicates were identified manually, and 2,476 publications were excluded in accordance with the exclusion criteria. Third, all authors assessed full text publications ($n=97$) for eligibility. Nine publications were included in the review. After inclusion, the reference lists of the nine included publications were reviewed to identify any additional publications relevant for inclusion in the study. However, none were identified. The review process is illustrated in Figure 1.

Next, the authors completed the data extraction form for each of the publications included (details below).

Data extraction and data analysis

A data extraction protocol was developed by the first and second author, which included publication characteristics (study ID in Covidence, author(s), publication year, title), study characteristics (study design, aim of study, research questions, hypotheses, methods (data collection methods,

instruments/materials that include questions about mental health and mental health disorders), country, setting/context where the data collection took place, data analysis, data reporting (self-reporting or proxy-reporting)), sample characteristics (age, diagnosis/impairment, severity of diagnosis/impairment, reported issues related to mental health and mental health problems, number of participants, recruitment, AAC system (representations of symbolic communication, selection techniques, other relevant information)), results from the study (main results, the authors' conclusion of main results, aspects of mental health and mental health problem in the results, factors impacting on mental health and mental health problems), interventions (aim, type, frequency, duration, content, measure of outcome, outcomes), theoretical perspectives represented in the publications (definitions of mental health and mental health problems, theory of mental health and mental health problems, contextual factors, social aspects (i.e., social relationships, friendships, loneliness) related to the results, dimensions of well-being)), adaptations for communication about mental health among AAC users (e.g., organizing a pre-interview meeting to introduce content of in-depth interview and enable participants to prepare responses in their AAC system, provision of access to graphic symbols representing vocabulary related to feelings, speech directed to parent who mediated communication with the interview), and suggestions for future research. A data extraction template was developed in Covidence (Version 2), and the data extraction was conducted by all authors independently. Discrepancies were identified and resolved through discussion by the authors. The extracted data were exported to Microsoft Excel for further analysis. The data from each study that related to this study's research

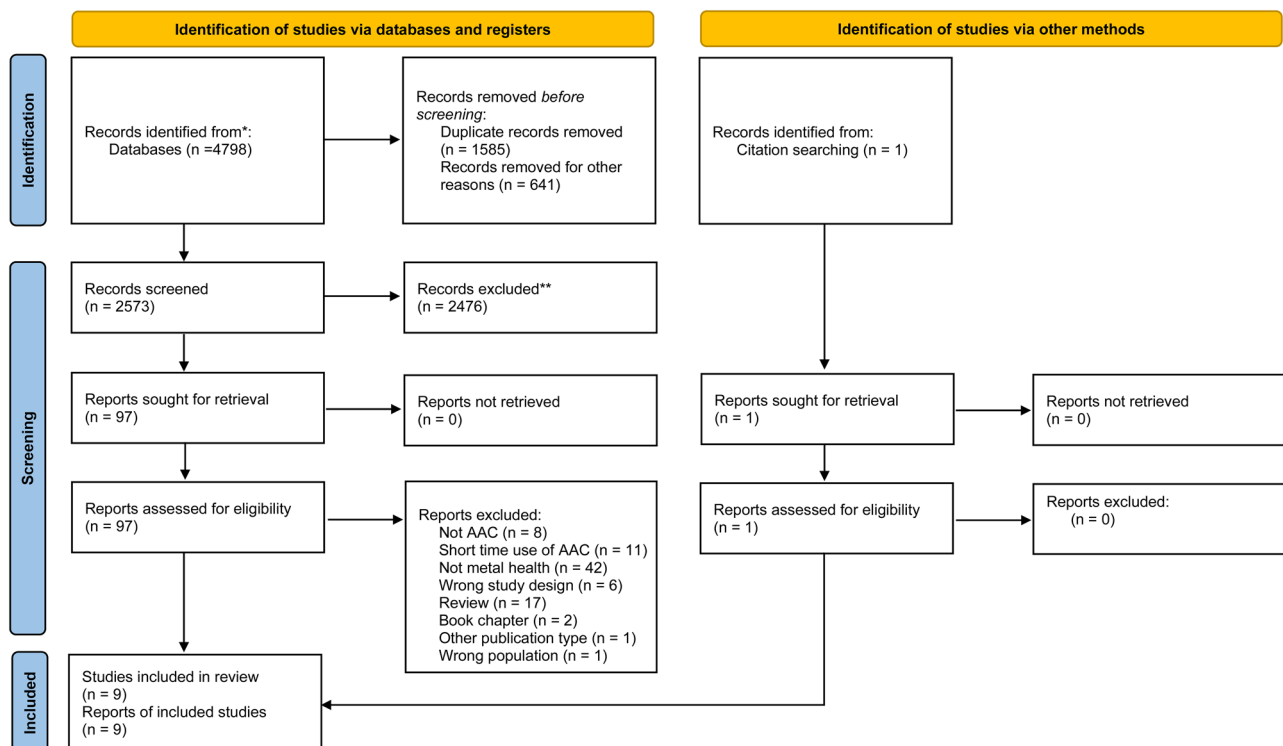


Figure 1. The review process.

questions were analyzed using thematic analysis which is adequate for literature reviews (Purssell & Gould, 2021), and descriptive analysis (Lee, 2020). Due to the few included studies and the few relevant results in the included studies, thorough analyses as described by Aveyard (2019) could not be conducted as planned, and we instead used a simpler content analysis methodology to identify relevant themes. All relevant findings in the extracted data were identified and the reported results in the publications included in this review were categorized in four main themes; Mental health aspects, Research focus, Reports of mental health and mental health problems, and Barriers and facilitators in accessing mental healthcare. The content of the main themes was checked for internal and external consistency. Demographic data were then identified and categorized.

Results

Nine publications fulfilled the inclusion criteria and were included in the review. The publications were issued between 2001 and 2022, all in the English language, and reported results from studies conducted in eight countries (Australia, Canada, Germany, Italy, Portugal, Sweden, Taiwan, and the USA). Three studies were based on qualitative data, whereas six studies made use of quantitative data. All data were based on self-reports by participants who use AAC.

Participants

The age of the participants across the studies spanned 5 to 65+ years, with 5-12 years (one study), 13-18 years (one study), 19-65 years (eight studies), and 65+ years (four studies). The number of participants varied between 3 and 78. All studies included participants with motor impairments, while auditory impairments and intellectual impairments were each represented by one publication. The studies represented a range of symbolic AAC systems, including speech generating device ($n=7$), communication board ($n=3$), graphic symbols ($n=2$), sign systems ($n=2$), pictures ($n=1$), communication book ($n=1$), and orthography ($n=1$). In three studies, participants made use of an interpreter (i.e., a communication assistant) (Balandin & Morgan, 2001; Fäldt et al., 2022; Watson et al., 2021), and three studies made use of other communication modes (i.e., speech, speech directed to parent who mediated communication, laptop with software for communication, and other systems not specified) (Balandin & Morgan, 2001; Dattilo et al., 2008; Fäldt et al., 2022).

Mental health aspects

Positive mental health (well-being) was the subject of seven publications (all publications except for Balandin & Morgan, 2001, and Fäldt et al., 2022), while eight publications encompassed mental health problems (all publications except for Londral et al., 2015). A distinction between mental health and mental health problems in the reporting of results was made in five studies (Corallo et al., 2017; Hwang et al., 2014; Körner et al., 2013; Maresca et al., 2019; Watson et al., 2021).

Only one publication defined mental health explicitly (Watson et al., 2021, p. 102), referring to WHO's (2016) conceptualization: "Mental health is foundational to our capacity to cope with stressors, contribute to our communities, and manage our emotional and physical wellbeing". Other publications related mental health implicitly to positive attitudes (Dattilo et al., 2008), positive mental health (Körner et al., 2013; Maresca et al., 2019), and quality of life (Hwang et al., Londral et al., 2015).

Research focus

Five studies made adaptations for communication about mental health/mental health problems for participants using AAC. Such adaptations related to: 1) Clinical practice, such as bringing a trusted person to the doctor's consultation for communicative support (Balandin & Morgan, 2001). 2) Research practice, such as arranging a pre-interview meeting introducing the content of a later in-depth interview providing the possibility to prepare for the interview by generating prepared responses in the AAC system (Watson et al., 2021), using a customized table with series of symbols representing specific categories within a conceptual pyramid of human need (Maresca et al., 2019), using an interview guide with pictorial support by using symbols from bildstod.se (Fäldt et al., 2022), using speech directed to parent who mediated communication with the interviewer (Fäldt et al., 2022), using hand signs based on Swedish sign language (Fäldt et al., 2022), and using graphic symbols for communicating about mental health and mental health problems (Corallo et al., 2017; Fäldt et al., 2022). No publications defined mental health problems. However, two publications gave an implicit account of the concept by referring to the instruments used. Five of the nine studies included interventions aimed at improving communication by using AAC (Corallo et al., 2017; Hwang et al., 2014; Körner et al., 2013; Londral et al., 2015; Maresca et al., 2019). Only two publications explicitly stated that the aim was to investigate how the use of AAC impacted mental health and/or mental health problems (Corallo et al., 2017; Watson et al., 2021), while four publications stated that the aim was to study how the use of AAC affected quality of life (Hwang et al., 2014; Körner et al., 2013; Londral et al., 2015; Maresca et al., 2019). Table 2 provides an overview of the publications included.

Reports of mental health and mental health problems

No publications reported on the characteristics of mental health or mental health problems among users of AAC, such as prevalence or types of mental health problems. Concerning factors with an impact on mental health, early intervention implementing the use of communication devices was reported to promote higher well-being rates among patients with ALS than for a control group (Londral et al., 2015). The authors concluded that the introduction of a communication device in the early stage of bulbar-onset ALS might improve the patients' skills in using communication devices in later stages of the disease, as more complex strategies for access to such

Table 2. Overview of included publications.

Author	Year	Country	Objective/aim	Participants			Summary of results
				Age	Type of impairment	Diagnosis	
Balandin & Morgan	2001	Australia	Gain a profile of individuals with cerebral palsy who are aging, explore health and health care issues pertinent to this group, and explore issues of access to information.	30-69	Motor impairment	Cerebral palsy	Participations reported anxiety (19 %) and depression (15 %).
Corallo, Bonanno, Lo Buono, De Salvo, Rifici, Pollicino, Allone, Palmeri, Todaro, Alagna, Bramanti, Bramanti, & Marino	2017	Italy	Evaluate the impact of the AAC on anxiety and depression performances and the quality of life of patients who have the locked-in syndrome (LIS) and that of their caregivers.	48.65 ± 10.73 (mean ± standard deviation)	Motor impairment Other	Locked-in syndrome	A reduction of symptoms of depression and anxiety was reported after AAC training among patients with LIS. A significant positive correlation between symptoms of anxiety and bodily pain was observed.
Dattilo, Estrella, Estrella, Light, McNaughton, & Seabury	2008	US Canada	Investigate perceptions of adults with cerebral palsy who use AAC systems about their homes and community recreation activities and leisure experiences.	27-44	Motor impairment	Cerebral palsy	Mental health (wellbeing) was related to recreation among adults with cerebral palsy.
Fäldt, Klink, Warner, & Sarkadi	2022	Sweden	Determine how children with disabilities have experienced the COVID-19 pandemic and its impact on their lives.	5-13	Motor impairment Intellectual impairment Auditive impairment Other	Autism spectrum disorder, ADHD	Levels of anxiety and fear increased due to knowledge of the COVID-19 pandemic among children who used AAC.
Hwang, Weng, Wang, Tsai, & Chang	2014	Taiwan	Investigate whether an eye-tracking assistive device improves the quality of life for ALS patients, and whether this device affects the burden experienced by caregivers.	40-85	Motor impairment	ALS	Most patients with ALS who did not use the eye-tracking assistive device were more depressed. The burden of care was reduced for the caregiver when the patients used an eye-tracking assistive device.
Körner, Siniawski, Kollwe, Rath, Krampf, Zapf, Dengler, & Petri	2013	Germany	Investigate and compare the impact of speech therapy and communication devices on quality of life and mood in ALS patients, and to understand whether communication devices can improve/maintain quality of life in severely dysarthric patients.	63.7 (mean)	Motor impairment	ALS	ALS patients who use a communication device were less depressed and had a better mental health due to the positive effects on communication.
Londral, Pinto, Pinto, Azevedo, & De Carvalho	2015	Portugal	Explore the impact of early support with communication devices on quality of life of ALS patients. Evaluate the efficiency of communication devices in supporting speech dysfunction.	39-83	Motor impairment	ALS	Early intervention with use of a communication device resulted in higher scores in wellbeing among patients with ALS during the first periods of the intervention.
Maresca, Pranio, Naro, De Luca, Maggion, Scarcella, De Domenico, Bramanti, Nibali, Portaro, & Calabro	2019	Italy	Evaluate the efficacy of low-tech AAC aids in improving quality of life and mood disorders, as well as the psychosocial impact of assistive devices among patients with ALS. Evaluate the efficacy of low-tech AAC aids in improving quality of life and mood disorders. Assess the psychosocial impact of assistive devices on patients and the influence of these tools on the caregiver burden.	58-87	Motor impairment	ALS	Use of AAC aids demonstrated positive effects on the patients' wellbeing and levels of anxiety and depression among patients with ALS.
Watson, Raghavendra, & Crocker	2021	Australia	Explore the views and perceptions of individuals who use AAC regarding mental health and wellbeing.	39-59	Motor impairment	Cerebral palsy Mitochondrial myopathy Leigh's syndrome	Participants experiences several barriers in receiving mental health support, such as policy, and the practice, knowledge, skills, and attitudes among communication partners.

devices become necessary. Similarly, Maresca et al. (2019) reported improvements in well-being due to use of low-tech AAC aids among ALS patients.

Several studies reported a reduction in symptoms of depression and anxiety after introducing AAC to people with acquired needs. Patients with ALS reported a reduction in symptoms of depression after an intervention using AAC by a speech generating device with a keyboard or scanner to detect head/eye movement (Körner et al., 2013), an eye-tracking assistive device (Hwang et al., 2014), or a low-tech AAC device (Maresca et al., 2019). Other researchers reported a reduction in symptoms of anxiety after AAC training among patients with locked-in syndrome (Corallo et al., 2017) and ALS patients using a low-tech AAC device (Maresca et al., 2019). The focus on acquired impairments in the studies can be explained by the change in functioning in these persons (from verbal to nonverbal) as well as the fact that the persons had a life-threatening condition, ALS. It is reasonable to assume that for people born with impairments drastic changes in functioning are more difficult to detect because of the communicative impairments. No studies explicitly linked the use of AAC to mental health or mental health problems for persons born with impairments.

Barriers and facilitators in accessing mental healthcare

One study (Watson et al., 2021) described barriers and facilitators of access to effective support to enhance mental health and well-being for adults using AAC. The following factors were reported: 1) Policy: Access barriers related to appointment time restrictions, a limited number of appointments available, and lack of training of staff to meet the needs among people who use AAC during consultations. 2) Communication partners' practice: Barriers related to limitations of choice and control among AAC users, which resulted in lasting negative effects on their mental health and well-being, experience of ignorance, and expression of feelings and requests not taken seriously, and overreliance on proxy reports among professionals. Reported facilitators in practice were everyday communication partners who provided the time required to express their thoughts adequately through additional appointment time, or by setting aside for meaningful conversations on a regular basis, and the communications partners' ability to support AAC users in seeking help. 3) Communication partners' knowledge: The reported barriers were lack of knowledge of AAC (e.g., reluctance to accept AAC), and lack of knowledge of mental health support (e.g., not being offered emotional support or support to manage responses to stressful situations, or support to locate mental health support), indicating a shortage of mental health literacy among professionals and caregivers. Communication partners rarely had knowledge of both AAC and mental health support. 4) Communication partners' skills: The reported skills that presented barriers were communication partners directing communication, dismissal of communication, and rushing communication. On the contrary, the reported skills that facilitated effective support related to a willingness to use AAC, AAC-specific skills, general

communication skills, and support skills. 5) Communication partners' attitudes: Barriers related to devaluing attitudes (e.g., being met with the expectation of having little meaningful to say) and insufficient access to vocabulary to communicate about abuse and neglect, limited self-determination and a sense of competence among users of AAC. Reported facilitators were communication partners that had a person-centered attitude, and who provided options and respected the AAC users' choices.

Discussion

The purpose of this study was to review existing knowledge about mental health and mental health problems for users of AAC, and the factors reported to impact these. Despite thorough search strategies and the use of extensive search terms, results included few and thematically fragmented studies, indicating a general lack of research of mental health and mental health problems among people who use AAC. In addition, except for one publication (Watson et al., 2021) that defined mental health explicitly, the lack of a theoretical account of mental health and/or mental health problems among persons using AAC was apparent in the reported research. The included publications did not build on each other, indicating an absence of systematic development of knowledge within this field. The review process gained no data to answer the question about what characterizes mental health or mental health problems among people who use AAC, leaving research questions #1 and #2 unanswered. Research questions #3 and #4 could only be partly or weakly answered, due to a shortage of relevant data. Nonetheless, results indicate that the use of AAC technology in terms of speech-generating devices and low-tech AAC devices may improve mental health (well-being) among patients with ALS (Londral et al., 2015; Maresca et al., 2019). AAC technology was also part of the interventions to reduce symptoms of depression among patients with ALS (Hwang et al., 2014; Körner et al., 2013; Maresca et al., 2019) and of anxiety among patients with ALS and locked-in syndrome (Corallo et al., 2017; Maresca et al., 2019). These beneficial effects of AAC technology are likely to be explained by the facilitation of functional communication, which is known to be associated with positive mental health (psychological well-being) (Wolters-Leermakers et al., 2022). The use of technology to facilitate functional communication may promote a person's ability to live a happy or pleasant life (hedonic well-being) and a meaningful and goal-directed life (eudaimonic well-being) (Granlund et al., 2021; Westerhof & Keyes, 2010). Since AAC is important for both expressive and receptive language (Drager et al., 2010), the use of AAC may be crucial to the understanding of an individual's mental health and mental health problems.

As for other populations, mental health would be expected to vary from low well-being (languishing) to high well-being (flourishing) (Granlund et al., 2021; Keyes, 2006; Keyes et al., 2002) in persons who use AAC for everyday communicative interaction. One study (Di Marco & Iacono, 2007) that have investigated mental health and mental health problems in

people who use AAC reported that users of AAC have higher prevalence rates for mental health problems compared with people without disabilities. This corresponds with the reported higher rates of mental health problems among people with communication disorders in general (Stransky et al., 2020). Well-being or positive mental health is less investigated. Thus, to gain knowledge about what characterizes mental health and what factors impact on mental health among people who use AAC, we need to understand the depths of what contributes to the perception of meaning in the lives of people in this population.

The participants in the studies identified in this review included mainly people who used AAC due to acquired needs, with ALS as the most dominant diagnostic group. Little attention was given to people who had used AAC throughout their lives. It is noteworthy that people with intellectual impairments were represented in one of the publications only, although they represent a large group using AAC. Although this review cannot decipher why individuals with intellectual impairments seem to be under-represented in existing research, it clearly points to the need for increased knowledge about the mental health and mental health problems of AAC users with, as well as without, intellectual impairments. As persons using AAC are a heterogeneous group with great variations in the communication systems used, and the reasons for and duration of the need for AAC, it is important to gain knowledge about mental health and mental health problems across a wide range of diagnostic categories. Furthermore, to identify individual needs and provide relevant mental health support to individuals who use AAC, knowledge is needed about the characteristics and predictors of mental health and mental health problems among both people who use AAC for developmental reasons, and those who need AAC due to acquired injuries. A special problem is the lack of longitudinal studies delineating trajectories of mental health and mental health problems in users of AAC.

Also worth noting was the skewed age distribution in the studies that were included. Children and adolescents were represented in only one study (Fäldt et al., 2022), while the rest of the studies encompassed participants between 19 and 65+ years of age. Children and adolescents with disabilities are at greater risk of mental health problems than typically developing peers (Augustine et al., 2022; Oeseburg et al., 2010; 2011; van Steensel et al., 2011). It is thus important to gain knowledge about the mental health and mental health problems of children and adolescents who use AAC. Such knowledge is a prerequisite for preventive efforts and early interventions to support positive mental health and reduce mental health problems.

This review highlights the scarcity of published studies reporting on the prevalence of mental health problems and mental health for people who use AAC to communicate, and that research on mental health and mental health problems among people who use AAC in general is very limited. The results confirm earlier reports of the lack of data considering the size of and variations in the populations of people who need AAC to communicate (CommunicationFIRST, 2023). In the following, we discuss possible reasons for the lack of

research of mental health and mental health problems among people who use AAC, and how to move the field forward.

First, the communicative aspects (e.g., interventions for supporting communication by use of AAC, use of speech-generating devices, selection techniques for using AAC, vocabulary selection) have dominated the research on AAC (Light et al., 2019; Light & McNaughton, 2015; McNaughton & Light, 2015; Prinsloo et al., 2024). Possibly, because communicative aspects are a prerequisite for developing functional communication, the perceived importance of studying communicative aspects may have overshadowed the perceived importance of research on mental health aspects. Future research may take advantage of existing knowledge about the communicative aspects of AAC, for example, to enable self-report of mental health and mental health problems among people who use AAC.

Second, people with AAC may not be identified in the research of mental health among people with disabilities. People who use AAC are represented within many diagnostic groups (e.g., cerebral palsy, intellectual disability, autism spectrum disorder) while constituting only a small proportion within each group. Hence, they may not be presented or analyzed as a specific subgroup (Danielsson et al., 2024), and therefore remain unidentifiable. To be identified, the group needs to be defined based on functioning rather than diagnosis. This functional approach is very much in line with the contemporary trend in health research to add the perspective of functioning to traditional indicators of health as expressed by WHO, i.e., mortality and morbidity (Bickenbach et al., 2023). In the last 50 years there has been an increasing discussion about WHO's definition of health (WHO, 1948) "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". Since 1948 the demography of populations and the nature of disease in general have changed a lot. From primarily acute diseases and long-term diseases that led to early death to a large proportion of the population living for many years with long term illness. Thus, many people do not have complete health in terms of physical, mental, and social health but still live a "healthy life". Therefore, Huber et al. (2011, p. 2) suggest that health could be defined as "the ability to adapt and to self-manage". In other words, focus for health research should be on functioning in everyday life as a supplement to mortality and morbidity. A focus on functioning implies that people who function well can be considered healthy despite having long term health conditions. It also means that health systems need to focus on functioning, not only on mortality and morbidity when evaluating the effectiveness of health care interventions. Bickenbach et al. (2023) discuss the human functioning revolution and its implications for health systems and sciences suggesting that functioning should be a third indicator of health as a supplement to morbidity and mortality: "Functioning includes the functions and structure of the body that constitute the intrinsic health capacity as well as the performance of simple and complex activities in interaction with the person's physical human built environment and social environment" (Bickenbach et al., 2023, p. 2). One

of the conclusions is the need to prepare health care systems to focus on optimizing functioning (Bickenbach et al., 2023). A focus on optimizing functioning requires that the system is flexible enough to adapt to different difficulties of functioning regarding both functioning as an outcome and functioning as a means (tool) in collaborating with clients/patients in planning and implementing intervention. People who need to use AAC to communicate may have problems with communicative functions necessary for interacting with other people about mental health and mental health problems (communication as a tool/means). This can lead both to an increased risk for mental health problems as well as difficulties with obtaining support for building mental health and decreasing mental health problems as reported by Watson et al. (2021). People who use AAC may therefore be seen as a group of people that have difficulties with reaching good functioning in terms of positive mental health and few mental health problems because of difficulties with interacting with professionals within health care systems. In our view, including functioning in the interpretation of health will be important in further research among people who use AAC. Thus, the field will benefit from interventions that provide relevant knowledge to strengthen the accessibility to mental health care services for this population.

Third, the difficulties using spoken language make it more difficult to involve people who use AAC as respondents in prevalence studies or as interviewees in qualitative studies or partners in planning intervention. Research is needed not only about how measures of mental health and mental health problems can be adapted to persons that use AAC, but also about how procedures for communicating with persons who use AAC about their mental health can be implemented by habilitation and mental health services.

Limitations

A limitation of this review is the small number of publications included. An extension of the publication period prior to the year 2000 might have increased the number of relevant studies. However, it is reasonable to argue that most relevant publications issued before the year 2000 would most likely have been referred to in the included publications, and the lack thereof lends support to the credibility of our results. However, the inclusion of publications reporting on short-term use of AAC (e.g., use of AAC in intensive care), which were excluded from this review ($n=12$), might have broadened the findings of mental health and mental health problems among users of AAC. An extension of the search terms to capture relevant literature using alternative academic terms to those chosen might have increased the number of publications included (e.g., the inclusion of terms for communicative support among people with developmental disabilities or aphasia not described as use of AAC). Nevertheless, we argue that the most relevant terms were included, and that the results can be deemed trustworthy. One explanation for the scarcity of studies is that many studies are based on diagnostic groups with some individuals who use AAC to communicate,

while others do not. Studies of identified users of AAC, independent of diagnostic groups, are needed. In the initial screening process, publications were evaluated by one of the authors and excluded based on the exclusion criteria. The lack of involving multiple evaluators at this stage introduces a potential limitation to the study and deters any assessment of the reliability of these initial exclusion decisions. However, because the exclusion criteria were very specific and unequivocal, we consider the risk of misjudged initial exclusions to be low. Later in the process, when the inclusion criteria were applied together with the exclusion criteria, evaluations were conducted by multiple authors as described, strengthening the reliability of the final inclusion/exclusion decisions.

Although all the publications included in this review reported on self-reports, the use of proxy reports is extensive in AAC research (Curtis et al., 2022). Proxy reports may have questionable reliability when assessing phenomena that are highly dependent on personal experience and perceptions, such as mental health problems and mental health. We therefore view the use of self-report in the included publications as a strength and argue that future research should seek to include self-reports in addition to proxy reports when assessing the mental health and mental health problems of people who use AAC.

The lack of theoretical linkages concerning mental health and mental health problems in the publications that were included made it difficult to have an in-depth discussion about the results. Future research needs to investigate the relationship between the two continua mental health problems and mental health. It might be the case that functional use of AAC has a direct impact on well-being that, in the long run, might mitigate the development of mental health problems.

Given that the ability to communicate efficiently is of vital importance to our mental health, the degree to which available AAC methodology improves a person's ability to communicate is likely to be an important factor in the prediction of mental health and mental health problems within this population. Therefore, results are limited by the lack of evaluations of the effectiveness or success of the AAC systems applied on well-being, which was considered beyond the scope of this study.

Implications and future directions

The findings from this study have several clinical implications. First, increased efforts to provide users of AAC with the necessary vocabulary to self-report on mental health and mental health problems (Collier et al., 2006; Watson et al., 2021) may promote their ability to exert autonomy and notify their mental health support needs when necessary. Second, strengthening competency among communication partners may promote communicative practices that acknowledge the expressions of feelings, requests, choices, and controls of users of AAC regarding their mental health and well-being (Watson et al., 2021). Additionally, it is vital to provide everyday communication partners with the skills necessary to communicate with users of AAC, as well as basic knowledge about mental health and

mental health support, to identify the need for, and facilitate access to, mental health support. Third, it is important to strengthen awareness of mental health problems and provide equal access to mental health services for those using AAC (Watson et al., 2021). There is a need to develop competence among rehabilitation and mental health professionals in providing mental health support using AAC, both in to screening for mental health problems among users of AAC, and with respect to skills and knowledge about how to provide psychotherapy using AAC. In addition, country specific system barriers to providing mental health support, such as the billing health insurance in the US (Noyes & Wilkinson, 2022), need to be considered. Finally, education and resources in mental health that emphasize e-mental health and peer support need to be developed (Watson et al., 2021).

Based on the current review, implications for future research include the following: First, prevalence studies acquiring knowledge about the status of mental health and mental health problems among people who use AAC are warranted. This review and other related research (CommunicationFIRST, 2023) underpin this need. Second, to acquire knowledge about mental health support for people using AAC, it is important to develop strategies that support awareness to mental health support based on collaboration between researchers and people who use AAC and their communication partners. Third, there is a need to identify and explore predictors of mental health and mental health problems among users of AAC. Fourth, it is essential to engage in research that considers the diversity among people who use AAC as a means of obtaining relevant knowledge about mental health and mental health problems for this heterogeneous group. Fifth, additional reviews on this topic are warranted; particularly ones that explore literature where mental health is the focus of interest and include studies that describe users of AAC in other terms than the inclusion criteria and the search terms in this review. Sixth, there is a need to investigate how the therapeutic work related to mental health is conducted among users of AAC; how people who use AAC can be supported to communicate about mental health and mental health problems; and the consequences of not providing sufficient access to conversations about mental health for persons using AAC in families, among friends, and in mental health care (cf. Noyes & Wilkinson, 2022, 2024). Seventh, we know little about the extent of loneliness among people who use AAC, and how loneliness affects mental health/well-being and mental health problems for this group. Additionally, a comparison of feelings of loneliness among people who communicate with speech and people who use AAC has not yet been conducted (Smith, 2015). Eighth, the reported causal relationship between the use of a communication device by persons with ALS and the improvement of mental health should be investigated using prospective and longitudinal analyses (Körner et al., 2013). These first eight research efforts should include people in all age groups and people with respectively congenital and acquired communicative impairments. Finally, it would be beneficial to conduct longitudinal studies delineating trajectories of mental health and mental health problems among users of AAC in general.

Conclusion

The results from this review demonstrate that knowledge about the mental health and mental health problems of people who use AAC is very scarce. There is a need for substantial research efforts in all age groups. In particular, the need for knowledge about mental health and mental health problems in children and adolescents who use AAC, as well as in adults who use AAC due to congenital impairments, is paramount.

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ORCID

Jørn Østvik  <http://orcid.org/0000-0001-7427-1506>

Mats Granlund  <http://orcid.org/0000-0001-9597-039X>

Astrid Røslund Seim  <http://orcid.org/0000-0002-8505-554X>

References

- * Studies included in this review.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Augustine, L., Lyngnegård, F., & Granlund, M. (2022). Trajectories of participation, mental health, and mental health problems in adolescents with self-reported neurodevelopmental disorders. *Disability and Rehabilitation*, 44(9), 1595–1608. <https://doi.org/10.1080/09638288.2021.1955304>
- Australian Institute of Health and Welfare. (2016). *Health status and risk factors of Australians with disability 2007-2008 and 2011-2012*. AIHW.
- Aveyard, H. (2019). *Doing a literature review in health and social care: A practical guide* (4th ed.). Open University Press/McGraw-Hill Education.
- Balandin, S., Berg, N., & Waller, A. (2006). Assessing the loneliness of older people with cerebral palsy. *Disability and Rehabilitation*, 28(8), 469–479. <https://doi.org/10.1080/09638280500211759>
- *Balandin, S., & Morgan, J. (2001). Preparing for the future: Aging and alternative and augmentative communication. *Augmentative and Alternative Communication*, 17(2), 99–108. <https://doi.org/10.1080/aac.17.2.99.108>
- Ballin, L., & Balandin, S. (2007). An exploration of loneliness: Communication and the social networks of older people with cerebral palsy. *Journal of Intellectual & Developmental Disability*, 32(4), 315–326. <https://doi.org/10.1080/13668250701689256>
- Bersani, H.Jr, (1999). Nothing about me without me: A proposal for participatory action research in AAC. In *Augmentative and alternative communication: New directions in research and practice* (pp. 278–289).
- Beutel, M. E., Klein, E. M., Brähler, E., Reiner, I., Jünger, C., Michal, M., Wiltink, J., Wild, P. S., Münzel, T., Lackner, K. J., & Tibubos, A. N. (2017). Loneliness in the general population: Prevalence, determinants and relations to mental health. *BMC Psychiatry*, 17(1), 97. <https://doi.org/10.1186/s12888-017-1262-x>
- Bickenbach, J., Rubinelli, S., Baffone, C., & Stucki, G. (2023). The human functioning revolution: Implications for health systems and sciences. *Frontiers in Science*, 1. <https://doi.org/10.3389/fsci.2023.1118512>
- Blackstone, S., Williams, M. B., & Wilkins, D. P. (2007). Key principles underlying research and practice in AAC. *Augmentative and Alternative Communication* (Baltimore, Md.: 1985), 23(3), 191–203. <https://doi.org/10.1080/07434610701553684>
- Brewster, S. J. (2007). *Asymmetries of power and competence and implications for AAC: Interaction between adults with severe learning disabilities and their care staff*. University of Birmingham.]

- Chung, Y.-C., Carter, E. W., & Sisco, L. G. (2012). Social interactions of students with disabilities who use augmentative and alternative communication in inclusive classrooms. *American Journal on Intellectual and Developmental Disabilities, 117*(5), 349–367. <https://doi.org/10.1352/1944-7558-117.5.349>
- Cleary, M., Lees, D., & Sayers, J. (2018). Friendship and mental health. *Issues in Mental Health Nursing, 39*(3), 279–281. <https://doi.org/10.1080/01612840.2018.1431444>
- Collier, B., McGhie-Richmond, D., Odette, F., & Pyne, J. (2006). Reducing the risk of sexual abuse for people who use augmentative and alternative communication. *Augmentative and Alternative Communication (Baltimore, Md.: 1985), 22*(1), 62–75. <https://doi.org/10.1080/07434610500387490>
- CommunicationFIRST (2023). AAC counts I: The urgent need for better data about people with significant speech disabilities. <https://communication-first.org/aac-counts/>
- Cooper, L., Balandin, S., & Trembath, D. (2009). The loneliness experiences of young adults with cerebral palsy who use alternative and augmentative communication. *Augmentative and Alternative Communication (Baltimore, Md.: 1985), 25*(3), 154–164. <https://doi.org/10.1080/07434610903036785>
- *Corallo, F., Bonanno, L., Lo Buono, V., De Salvo, S., Rifici, C., Pollicino, P., Allone, C., Palmeri, R., Todaro, A., Alagna, A., Bramanti, A., Bramanti, P., & Marino, S. (2017). Augmentative and alternative communication effects on quality of life in patients with locked-in syndrome and their caregivers. *Journal of Stroke and Cerebrovascular Diseases: The Official Journal of National Stroke Association, 26*(9), 1929–1933. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2017.06.026>
- Crawford, J. D. (1987). Individual psychotherapy with the nonvocal patient: A unique application of communication devices. *Rehabilitation Psychology, 32*(2), 93–98. <https://doi.org/10.1037/h0091566>
- Cummins, R. A. (2020). Quality of life of adults with an intellectual disability. *Current Developmental Disorders Reports, 7*(3), 182–187. <https://doi.org/10.1007/s40474-020-00205-x>
- Curtis, H., Neate, T., & Gonzalez, C. V. (2022). State of the art in AAC: A systematic review and taxonomy [Paper presentation]. Proceedings of the 24th International ACM SIGACCESS Conference on Computers and Accessibility, 249–22. <https://doi.org/10.1145/3517428.3544810>
- Dall, M., Fellingner, J., & Holzinger, D. (2022). The link between social communication and mental health from childhood to young adulthood: A systematic review. *Frontiers in Psychiatry, 13*, 944815. <https://doi.org/10.3389/fpsy.2022.944815>
- Dalman, C., Bremberg, S., Åhlén, J., Ohlis, A., Agardh, E., Wicks, S., Lundin, A. (2015). *Psykiskt välbefinnande, psykiska besvär och psykiatriska tillstånd hos barn och unga - begrepp, mätmetoder och förekomst*. En kunnskapsöversikt. Forte-Forskningsrådet för hälsa, arbetsliv och välfärd. Retrieved February 3, 2021, from <https://forte.se/publikation/begrepp-matmetoder/>
- Danielsson, H., Imms, C., Ivarsson, M., Almqvist, L., Lundqvist, L.-O., King, G., Adams Lyngbäck, L., Andersson, A. K., Arnell, S., Arvidsson, P., Augustine, L., Brooks, R., Eldh, M., Engde, L., Engkvist, H., Gimbler Berglund, I., Green, D., Huus, K., Karlsson, C., ... Granlund, M. (2024). A systematic review of longitudinal trajectories of mental health problems in children with neurodevelopmental disabilities. *Journal of Developmental and Physical Disabilities, 36*(2), 203–242. <https://doi.org/10.1007/s10882-023-09914-8>
- Dark, L., Balandin, S., & Clemson, L. (2011). Communicating about loss: Experiences of older Australian adults with cerebral palsy and complex communication needs. *Communication Disorders Quarterly, 32*(3), 176–189. <https://doi.org/10.1177/1525740109353936>
- *Dattilo, J., Estrella, G., Estrella, L. J., Light, J., McNaughton, D., & Seabury, M. (2008). "I have chosen to live life abundantly": Perceptions of leisure by adults who use augmentative and alternative communication. *Augmentative and Alternative Communication (Baltimore, Md.: 1985), 24*(1), 16–28. <http://www.ncbi.nlm.nih.gov/pubmed/18938755> <https://doi.org/10.1080/07434610701390558>
- de Graaf, R., & Bijl, R. V. (2002). Determinants of mental distress in adults with a severe auditory impairment: Differences between prelingual and postlingual deafness. *Psychosomatic Medicine, 64*(1), 61–70. <https://doi.org/10.1097/00006842-200201000-00009>
- Di Marco, M., & Iacono, T. (2007). Mental health assessment and intervention for people with complex communication needs associated with developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*(1), 40–59. <https://doi.org/10.1111/j.1741-1130.2006.00096.x>
- Diaconu-Gherasim, L. R., Nicuță, E. G., Crumpei-Tanasă, I., & Opariuc-Dan, C. (2023). Perception of friendship quality and mental health: School goal structures as moderators. *School Mental Health, 15*(3), 1003–1016. <https://doi.org/10.1007/s12310-023-09601-1>
- Drager, K., Light, J., & McNaughton, D. (2010). Effects of AAC interventions on communication and language for young children with complex communication needs. *Journal of Pediatric Rehabilitation Medicine, 3*(4), 303–310. <https://doi.org/10.3233/PRM-2010-0141>
- Eiser, C., & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 10*(4), 347–357. <https://doi.org/10.1023/a:1012253723272>
- Enderby, P. (2014). Introducing the therapy outcome measure for AAC services in the context of a review of other measures. *Disability and Rehabilitation. Assistive Technology, 9*(1), 33–40. <https://doi.org/10.3109/17483107.2013.823576>
- *Fäldt, A. E., Klint, F., Warner, G., & Sarkadi, A. (2022). Experiences of children with disabilities during the COVID-19 pandemic in Sweden: A qualitative interview study. *BMJ Paediatrics Open, 6*(1), e001398. <https://doi.org/10.1136/bmjpo-2021-001398>
- Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *Lancet (London, England), 379*(9820), 1037–1044. [https://doi.org/10.1016/s0140-6736\(11\)61143-4](https://doi.org/10.1016/s0140-6736(11)61143-4)
- Granlund, M., Imms, C., King, G., Andersson, A. K., Augustine, L., Brooks, R., Danielsson, H., Gothilander, J., Ivarsson, M., Lundqvist, L.-O., Lyngegård, F., & Almqvist, L. (2021). Definitions and operationalization of mental health problems, wellbeing and participation constructs in children with nnd: Distinctions and clarifications. *International Journal of Environmental Research and Public Health, 18*(4), 1656. <https://doi.org/10.3390/ijerph18041656>
- Güroğlu, B. (2022). The power of friendship: The developmental significance of friendships from a neuroscience perspective. *Child Development Perspectives, 16*(2), 110–117. <https://doi.org/10.1111/cdep.12450>
- Hagiliassis, N., DiMarco, M., Gulbenkoglou, H., Iacono, T., Larkin, H., & Watson, J. (2005). The Bridging Project: Physical disability and mental health. *In-Psych: The Bulletin of the Australian Psychological Society, 27*(4), 22–24.
- Hards, E., Loades, M. E., Higson-Sweeney, N., Shafran, R., Serafimova, T., Brigden, A., Reynolds, S., Crawley, E., Chatburn, E., Linney, C., McManus, M., & Borwick, C. (2022). Loneliness and mental health in children and adolescents with pre-existing mental health problems: A rapid systematic review. *The British Journal of Clinical Psychology, 61*(2), 313–334. <https://doi.org/10.1111/bjc.12331>
- Hourcade, J., Pilotte, T. E., West, E., & Parette, P. (2004). A History of Augmentative and Alternative Communication for Individuals with Severe and Profound Disabilities. *Focus on Autism and Other Developmental Disabilities, 19*(4), 235–244. <https://doi.org/10.1177/10883576040190040501>
- Huber, M., Knottnerus, J. A., Green, L., Horst, H. v d., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M. I., Meer, J. W. M. v d., Schnabel, P., Smith, R., Weel, C. v., & Smid, H. (2011). How should we define health? *BMJ (Clinical Research ed.), 343*(jul26 2), d4163–d4163. <https://doi.org/10.1136/bmj.d4163>
- *Hwang, C.-S., Weng, H.-H., Wang, L.-F., Tsai, C.-H., & Chang, H.-T. (2014). An eye-tracking assistive device improves the quality of life for ALS patients and reduces the caregivers' burden. *Journal of Motor Behavior, 46*(4), 233–238. <https://doi.org/10.1080/00222895.2014.891970>
- Iacono, T., Hagiliassis, N., Gulbenkoglou, H., Di Marco, M., Watson, J. (2008). *Because mental health matters: Submission to the Victorian Department of Human Services, in response to the consultation paper, May 2008*. Scope. http://www.scopevic.org.au/wp-content/uploads/2015/01/Because_mental_health_matters.pdf

- Keyes, C. L. (2005). Mental illness and/or mental health? Investigating axioms of the complete state model of health. *Journal of Consulting and Clinical Psychology*, 73(3), 539–548. <https://doi.org/10.1037/0022-006x.73.3.539>
- Keyes, C. L. (2006). Mental health in adolescence: Is America's youth flourishing? *The American Journal of Orthopsychiatry*, 76(3), 395–402. <https://doi.org/10.1037/0002-9432.76.3.395>
- Keyes, C. L. M., Shmotkin, D., & Ryff, C. D. (2002). Optimizing well-being: The empirical encounter of two traditions. *Journal of Personality and Social Psychology*, 82(6), 1007–1022. <https://doi.org/10.1037/0022-3514.82.6.1007>
- King, A. R., Russell, T. D., & Veith, A. C. (2016). Friendship and mental health functioning. In M. Hojjat & A. Moyer (Eds.), *The Psychology of Friendship* (pp. 249–266). Oxford University Press.
- *Körner, S., Sieniawski, M., Kollwe, K., Rath, K. J., Krampfl, K., Zapf, A., Dengler, R., & Petri, S. (2013). Speech therapy and communication device: Impact on quality of life and mood in patients with amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, 14(1), 20–25. <https://doi.org/10.3109/17482968.2012.692382>
- Kvam, M. H., Loeb, M., & Tambs, K. (2007). Mental health in deaf adults: Symptoms of anxiety and depression among hearing and deaf individuals. *Journal of Deaf Studies and Deaf Education*, 12(1), 1–7. <https://doi.org/10.1093/deafed/enl015>
- Lee, J. (2020). Statistics, descriptive. In *International encyclopedia of human geography* (2nd ed., pp. 13–20). Elsevier. <https://doi.org/10.1016/B978-0-08-102295-5.10428-7>
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5(1), 69. <https://doi.org/10.1186/1748-5908-5-69>
- Light, J. (1988). Interaction involving individuals using augmentative and alternative communication systems: State of the art and future directions. *Augmentative and Alternative Communication*, 4(2), 66–82. <https://doi.org/10.1080/07434618812331274657>
- Light, J., & McNaughton, D. (2015). Designing AAC research and intervention to improve outcomes for individuals with complex communication needs. *Augmentative and Alternative Communication* (Baltimore, Md.: 1985), 31(2), 85–96. <https://doi.org/10.3109/07434618.2015.1036458>
- Light, J., McNaughton, D., Beukelman, D., Fager, S. K., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019). Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication* (Baltimore, Md.: 1985), 35(1), 1–12. <https://doi.org/10.1080/07434618.2018.1556732>
- Loncke, F. (2019). *Augmentative and alternative communication: Models and applications*. Plural Publishing, Incorporated.
- *Londral, A., Pinto, A., Pinto, S., Azevedo, L., & De Carvalho, M. (2015). Quality of life in amyotrophic lateral sclerosis patients and caregivers: Impact of assistive communication from early stages. *Muscle & Nerve*, 52(6), 933–941. <https://doi.org/10.1002/mus.24659>
- *Maresca, G., Pranio, F., Naro, A., De Luca, R., Maggio, M. G., Scarcella, I., De Domenico, C., Bramanti, P., Conti Nibali, V., Portaro, S., & Calabrò, R. S. (2019). Augmentative and alternative communication improves quality of life in the early stages of amyotrophic lateral sclerosis. *Functional Neurology*, 34(1), 35–43.
- McNaughton, D., & Light, J. (2015). What we write about when we write about AAC: The past 30 years of research and future directions. *Augmentative and Alternative Communication* (Baltimore, Md.: 1985), 31(4), 261–270. <https://doi.org/10.3109/07434618.2015.1099736>
- Midtlin, H. S., Næss, K.-A. B., Taxt, T., & Karlsen, A. V. (2015). What communication strategies do AAC users want their communication partners to use? A preliminary study. *Disability and Rehabilitation*, 37(14), 1260–1267. <https://doi.org/10.3109/09638288.2014.961659>
- Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, 18(1), 143. <https://doi.org/10.1186/s12874-018-0611-x>
- Noyes, A. M., & Wilkinson, K. M. (2022). Supporting access to mental health services for patients who use augmentative and alternative communication: A proposed framework and suggestions for future directions. *American Journal of Speech-Language Pathology*, 31(5), 2268–2282. https://doi.org/10.1044/2022_AJSLP-22-00089
- Noyes, A., & Wilkinson, K. M. (2024). A pilot qualitative study of adult AAC users' experiences related to accessing and receiving mental health services. *Augmentative and Alternative Communication*, 40(3), 238–252. <https://doi.org/10.1080/07434618.2023.2294734>
- O'Keefe, B. M., Kozak, N. B., O'Keefe, B. M., Kozak, N. B., Schuller, R., O'Keefe, B. M., Kozak, N. B., & Schuller, R. (2007). Research priorities in augmentative and alternative communication as identified by people who use AAC and their facilitators. *Augmentative and Alternative Communication* (Baltimore, Md.: 1985), 23(1), 89–96. <https://doi.org/10.1080/07434610601116517>
- Oeseburg, B., Dijkstra, G. J., Groothoff, J. W., Reijneveld, S. A., & Jansen, D. E. M. C. (2011). Prevalence of chronic health conditions in children with intellectual disability: A systematic literature review. *Intellectual and Developmental Disabilities*, 49(2), 59–85. <https://doi.org/10.1352/1934-9556-49.2.59>
- Oeseburg, B., Jansen, D. E. M. C., Groothoff, J. W., Dijkstra, G. J., & Reijneveld, S. A. (2010). Emotional and behavioural problems in adolescents with intellectual disability with and without chronic diseases. *Journal of Intellectual Disability Research: JIDR*, 54(1), 81–89. <https://doi.org/10.1111/j.1365-2788.2009.01231.x>
- Øhre, B. (2017). *Mental Disorders and traumatic experiences in deaf and hard of hearing adult psychiatric outpatients*. University of Oslo.
- Østvik, J., Ytterhus, B., & Balandin, S. (2018). 'So, how does one define a friendship?': Identifying friendship among students using AAC in inclusive education settings. *European Journal of Special Needs Education*, 33(3), 334–348. <https://doi.org/10.1080/08856257.2017.1312799>
- Ottmann, G., McVilly, K., Anderson, J., Chapman, J., Karlyawasam, I., Roy, A., Satari, N., & Stefano, A. (2017). Barriers and enablers to safeguarding children and adults within a disability services context: Insights from an Australian Delphi Study. *Social Policy & Administration*, 51(3), 488–510. <https://doi.org/10.1111/spol.12189>
- Prinsloo, P., Dada, S., Bastable, K., Raghavendra, P., & Granlund, M. (2024). The application of the family of participation-related constructs (fPRC) framework to AAC intervention outcomes in children with complex communication needs: A scoping review. *Augmentative and Alternative Communication* (Baltimore, Md.: 1985), 40(3), 182–195. <https://doi.org/10.1080/07434618.2023.2276701>
- Pursell, E., & Gould, D. (2021). Undertaking qualitative reviews in nursing and education - A method of thematic analysis for students and clinicians. *International Journal of Nursing Studies Advances*, 3, 100036. <https://doi.org/10.1016/j.ijnsa.2021.100036>
- Raghavendra, P., Grace, E., Newman, L., Wood, D., & Connell, T. (2013). 'They think I'm really cool and nice': The impact of Internet support on the social networks and loneliness of young people with disabilities. *Telecommunications and the Digital Economy*, 63(2), 1–22. <https://doi.org/10.7790/tja.v63i2.414>
- Roydhouse, J. K., Cohen, M. L., Eshoj, H. R., Corsini, N., Yucel, E., Rutherford, C., Wac, K., Berrocal, A., Lanzi, A., Nowinski, C., Roberts, N., Kassianos, A. P., Sebille, V., King, M. T., & Mercieca-Bebber, R. (2022). The use of proxies and proxy-reported measures: A report of the international society for quality of life research (ISOQOL) proxy task force. *Quality of Life Research*, 31(2), 317–327. <https://doi.org/10.1007/s11136-021-02937-8>
- Schlosser, R. W., Wendt, O., & Sigafoos, J. (2007). Not all systematic reviews are created equal: Considerations for appraisal. *Evidence-Based Communication Assessment and Intervention*, 1(3), 138–150. <https://doi.org/10.1080/17489530701560831>
- Segrin, C. (2014). Communication and personal well-being. In A. C. Michalos (Ed.), *Encyclopedia of quality of life and well-being research*

- (pp. 1013–1017). Springer Netherlands. https://doi.org/10.1007/978-94-007-0753-5_446
- Smith, M. M. (2005). The dual challenges of aided communication and adolescence. *Augmentative and Alternative Communication*, 21(1), 67–79. <https://doi.org/10.1080/10428190400006625>
- Smith, M. M. (2015). Adolescence and AAC: Intervention challenges and possible solutions. *Communication Disorders Quarterly*, 36(2), 112–118. <https://doi.org/10.1177/1525740114539001>
- Smith, K. J., Peterson, M. D., O'Connell, N. E., Victor, C., Liverani, S., Anokye, N., & Ryan, J. M. (2019). Risk of depression and anxiety in adults with cerebral palsy. *JAMA Neurology*, 76(3), 294–300. <https://doi.org/10.1001/jamaneurol.2018.4147>
- Stancliffe, R. J., Larson, S., Auerbach, K., Engler, J., Taub, S., & Lakin, K. C. (2010). Individuals with Intellectual disabilities and augmentative and alternative communication: Analysis of survey data on uptake of aided AAC, and loneliness experiences. *Augmentative and Alternative Communication*, 26(2), 87–96. <https://doi.org/10.3109/07434618.2010.481564>
- Stransky, M. L., Oshita, J. Y., & Morris, M. A. (2020). Prevalence of behavioral health problems among adults with and without communication disabilities. *Journal of the American Board of Family Medicine: JABFM*, 33(6), 932–941. <https://doi.org/10.3122/jabfm.2020.06.200216>
- Therrien, M. C. S., Light, J., & Pope, L. (2016). Systematic review of the effects of interventions to promote peer interactions for children who use aided AAC. *Augmentative and Alternative Communication (Baltimore, Md.: 1985)*, 32(2), 81–93. <https://doi.org/10.3109/07434618.2016.1146331>
- Tough, H., Siegrist, J., & Fekete, C. (2017). Social relationships, mental health and wellbeing in physical disability: A systematic review. *BMC Public Health*, 17(1), 414. <https://doi.org/10.1186/s12889-017-4308-6>
- van Gent, T., Goedhart, A. W., Hindley, P. A., & Treffers, P. D. (2007). Prevalence and correlates of psychopathology in a sample of deaf adolescents. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 48(9), 950–958. <https://doi.org/10.1111/j.1469-7610.2007.01775.x>
- van Steensel, F. J. A., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review*, 14(3), 302–317. <https://doi.org/10.1007/s10567-011-0097-0>
- Vigo, D., Thornicroft, G., & Atun, R. (2016). Estimating the true global burden of mental illness. *The Lancet. Psychiatry*, 3(2), 171–178. [https://doi.org/10.1016/s2215-0366\(15\)00505-2](https://doi.org/10.1016/s2215-0366(15)00505-2)
- *Watson, E., Raghavendra, P., & Crocker, R. (2021). Mental health matters: A pilot study exploring the experiences and perspectives of individuals with complex communication needs. *Augmentative and Alternative Communication (Baltimore, Md.: 1985)*, 37(2), 102–112. <https://doi.org/10.1080/07434618.2021.1921845>
- Westerhof, G. J., & Keyes, C. L. M. (2010). Mental illness and mental health: The two continua model across the lifespan. *Journal of Adult Development*, 17(2), 110–119. <https://doi.org/10.1007/s10804-009-9082-y>
- Wolters-Leermakers, N., Van den Bogaard, K. J. H. M., & Prins, M. (2022). Understanding quality of life in people with complex and multiple communicative disabilities: A narrative overview of the empirical research literature. *Journal of Intellectual Disabilities: JOID*, 0(0), 17446295221146849. <https://doi.org/10.1177/17446295221146849>
- World Health Organization (1948). Constitution of the World Health Organization. <https://www.who.int/about/governance/constitution>
- World Health Organization (2005). *Promoting mental health: Concepts, emerging evidence, practice: A report of the World Health Organization*, Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne.
- World Health Organization (WHO) (2016). *Mental health: Strengthening our response*. Retrieved from <http://www.who.int/mediacentre/factsheets/fs220/en/>
- Wykes, T., Haro, J. M., Belli, S. R., Obradors-Tarragó, C., Arango, C., Ayuso-Mateos, J. L., Bitter, I., Brunn, M., Chevreur, K., Demotes-Mainard, J., Elfeddali, I., Evans-Lacko, S., Fiorillo, A., Forsman, A. K., Hazo, J.-B., Kuepper, R., Knappe, S., Leboyer, M., Lewis, S. W., ... Wittchen, H.-U. (2015). Mental health research priorities for Europe. *The Lancet. Psychiatry*, 2(11), 1036–1042. [https://doi.org/10.1016/S2215-0366\(15\)00332-6](https://doi.org/10.1016/S2215-0366(15)00332-6)