Contextual support and quality of life of individuals with intellectual disability and severe and persistent challenging behaviour

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CHAPTER 5

Augmentative and alternative communication, intellectual disability and challenging behaviour: Effects on adult quality of life

Status: Under review

ABSTRACT

Difficulties in communication for individuals with intellectual disability (ID) often hamper the expression of their needs, which may lead to challenging behaviour (CB). The use of Augmentative and Alternative Communication (AAC) may result in an increase in adaptive communication facilitating the expression of needs, which ultimately is expected to improve Quality of Life. In case AAC goals were present in the Individual Support Plans of persons with ID who receive 24/7 intensive support due to severe CB, we determined whether those goals were actually implemented, and whether quality of life improved after one year, compared to the development of individuals with ID and CB without AAC implementation. The effect of AAC was associated with the quality of its implementation: when implemented as intended, CB remained stable over time and quality of life tended to improve, whereas CB deteriorated and quality of life remained stable over time when implementation was poor.

Augmentative and Alternative Communication, Intellectual Disability and Challenging Behaviour: Effects on Adult Quality of Life

Challenging behaviour (CB) in individuals with intellectual disability (ID) is defined as culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, and as behaviour which is 'likely to seriously limit use of ordinary community facilities or results in the person being denied access to those facilities (Emerson & Einfeld, 2011, p. 4). A mismatch between a person's competencies and (contextual) support can result in challenging behaviour (Schalock et al., 2021). This behaviour can add up to multiple negative outcomes, such as lower quality of life, risk of self-harm, seclusion/separation, or may result in risk of harm and distress for the support team. People with ID and CB more often live in specialized care settings, in which a higher prevalence of challenging behaviour, i.e. of 50-80% vs. the estimated 10-18% in people with ID in general (Bowring et al., 2019; Totsika & Hastings, 2009).

Individuals with intellectual disability have more difficulty communicating (Oliver et al., 2022; Schalock et al., 2021), and severity of communication difficulties is associated with higher levels of challenging behaviour (Bowring et al., 2019; Oliver et al., 2022). We therefore argue that individuals with severe challenging behaviour in an intensive support needs setting also have complex communicational needs. Deckers et al. (2024) describe individuals with communication support needs as "people who cannot rely on speech alone to be heard and understood, and to understand their communication partners".

Challenging behaviour or 'behavioural problems' may serve different functions which are believed to be interrelated. The 'unmet needs' framework (Cohen-Mansfield, 2013) states that this behaviour may be a behavioural expression of an attempt to communicate 'a need' or a distressed emotion as a last resort when the individual cannot communicate it in any other way (National Collaborating Centre for Mental Health, 2015). Difficulties in communication therefore can be seen as an important focus of intervention (Oliver et al., 2022).

Communication is an essential part of adaptive functioning and being able to express oneself and having the ability to engage in interactions is considered to be of pivotal importance (Sparrow et al., 1984). Communicative competence is defined by Light (1989, p. 137) as "a relative and dynamic, interpersonal construct based on functionality of communication, adequacy

of communication, and sufficiency of knowledge, judgement, and skill in four interrelated areas: linguistic competence, operational competence, social competence, and strategic competence", which can be influenced by psychosocial factors but also environmental barriers and environmental support (Light & McNaughton, 2014). Therefore, not only the individual but also the professional caretakers are an important target for intervention to facilitate effective, adaptive communication for individuals with intellectual disability and challenging behaviour and to reduce barriers (Light & McNaughton, 2014). Communication in individuals with ID and challenging behaviour and therefore communication support needs can be facilitated by the use of augmentative and alternative communication (AAC) strategies.

AAC refers to interventions for people with communication support needs that support communication through non-verbal communication modes (gestures, objects, symbols) or, for example, through assistive technology such as speech output technologies (Beukelman & Light, 2020; Schlosser, 2003). AAC needs to be implemented in the individual's daily life. The implementation of AAC in daily life has indeed been reported to result in better communicative functioning. For example, Benson-Goldberg et al. (2023) showed that children with intensive support needs improve in communication over time when teachers were systematically provided with the skills, knowledge and resources required to provide individualized AAC.

Since communicative competence is believed to be positively related to quality of life (Garcia et al., 2020; Wolters-Leermakers et al., 2022), communication support using AAC should be prioritized within the systems of support for adults with intellectual disability and communicational problems. Support staff indeed report an improvement in quality of life when communication support is prioritized, when it is carefully adjusted to one's needs and competencies (Dalton & Sweeney, 2013). In general, various meta-analyses report positive effects of AAC on communication skills and/or challenging behaviour in children and adolescents with ID (Ganz et al., 2017; Ganz et al., 2023)

Aforementioned studies into effects of AAC were focused on (young) children with ID. Studies on communication interventions with *adults* with intellectual disability and challenging behaviour, however, are scarce and more research is needed, (Ganz et al., 2017; Heath et al., 2015; Walker & Snell, 2013). Reichle et al. (2019), and Light and Mcnaughton (2015) emphasize the importance of tailored AAC strategies, highlighting the necessity to align communication modes with individual skills and contextual demands, stressing the need for further research, including follow-up of the effects of AAC over time.

The present study focusses on AAC and its effectiveness on quality of life and behavioural problems for adults with ID and challenging behaviour residing in an intensive support need setting with 24/7 care. It is the first study to explore the effectiveness of AAC over a one-year period in adults with such intensive support needs.

Essentially, the elements in an Individual Support Plan (ISP) are based on the individual's unique profile of competencies and assessment of contextual factors that can enhance a person's functioning (Buntinx & Schalock, 2010; Shogren et al., 2018; Verdugo et al., 2024). There is a limited amount of research into the value of ISP's, although setting specific goals is thought to sharpen focus of support and facilitate monitoring of implementation (Kamstra et al., 2017).

We argue that the inclusion of goals implying the use of AAC in the ISP helps to improve adaptive communication skills, in particular when these goals are regularly followed up by the multidisciplinary support team that developed those goals, so they can be adjusted constantly to the persons' needs and growth in a given period in time. Therefore, we expect the group with AAC goals included in the ISP will improve in adaptive communication which is further hypothesized to at least stabilize or improve functioning over time as expressed in Quality of Life and challenging behaviour. It is further explored whether the planned AAC goaled interventions, as described in the ISP goals, were implemented as intended (appropriate use of AAC) or were not (no or inappropriate use of AAC), and whether this adds positively to the effect of the interventions over time in individuals with appropriate use of AAC.

METHOD

Procedure

Data used in this study were collected during a large longitudinal study [*SCORE*]. The SCORE study evaluating the effects of regular care of persons living in group homes, with intellectual disability and intensive support needs due to persistent challenging behaviour. Four service organizations for people with intellectual disability participated in this study. Participants all reside in group homes in residential care facilities, where they receive 24 hour care for support in all areas of life, provided by a specialized support team. Typically, in intensive support the client-direct caretaker ratio is 4/3:1.

The design of the present study is longitudinal, collecting survey data in two time waves, starting in 2017, with one-year follow-up starting in 2018. Ethical approval for the study was granted by the ethics committee of the Faculty of Social and Behavioural Sciences, Department of Clinical Neurodevelopmental Sciences, University of Leiden, The Netherlands (ECPW-2015/094), and the ethical committee of the largest participating service organization (Ipse de Bruggen).

Participants

Persons and their support teams were eligible for inclusion when individuals met the following criteria: Adults with intellectual disability, living in residential care facilities in group homes, with a very intensive support need due to severe challenging behaviour, i.e. persistency of challenging behaviour over at least two years.

Candidates eligible for inclusion (*N*=543) and their legal representatives were invited to participate in the study. Legal representatives (and where applicable, the persons with ID themselves) were informed about the study by written and online information and asked for informed consent. Seventy percent of the candidates of the four service organizations responded to the invitation (*N*=381) of which *N*=92 (24.4%) declined participation and *N*=289 agreed to participate.

N=56 participants dropped out during the course of the study, due to e.g. moving to another service organization, illness or death, logistic problems within the support team, or withdrawal of consent. Further, participants were only included in this study when, ISP data and at least one of the questionnaires were available. This resulted in a further loss of *N*=37 participants, due to not returned questionnaires or interview planning difficulties resulting in a total of *N*=196 participants (66% male), mean age 41.21 years (*SD*=14.59).

In the longitudinal outcome analyses, we lost participants at the follow-up (after one year) because of missing values (on measures DBC-A *N*=11, Vineland Screener *N*=28, SMS *N*=32). Missing value analyses demonstrated that these participants did not differ from the participants remaining in the study on measures of challenging behaviour, adaptive communication, gender distribution or age (336.>*p*.799). Participants were only included in the analyses if they had measures on both T1 and T2, per variable of interest.

All participants had a multidisciplinary support team that developed their ISP. This support team is typically composed of direct caretakers, relatives and/or representatives, location management, and other care professionals (such as at least a physician, a psychologist or a pedagogue or specialists regarding specific interventions, such as a speech/language therapist, occupational therapist, psychomotor therapist, physiotherapist). If possible, the support team involves the individual with ID during the design of the ISP.

Measures

Challenging Behaviour, Developmental Behaviour Checklist – for Adult (DBC-A)

The DBC-A is a carer-completed 107-item questionnaire that assesses a comprehensive range of emotional, behavioural and mental health problems in adults with ID (Mohr et al., 2005; Mohr et al., 2011; Mohr et al., 2012). Professional primary caretakers were asked to fill out the questionnaire. Questions can be answered by assigning 0, 1, or 2, a higher number reflecting higher frequency of the particular challenging behaviour. Next to a Total composite score, six problem domains scores are computed, i.e. for Disruptive behaviour, Communication Disturbances and Anxiety, Antisocial behaviour, Self-absorbed behaviour, Depressive symptoms, and Problems Relating to Social interaction. Mean item scores (MIS) were computed for the total composite score. A higher score denotes more challenging behaviour.

Equivalent mean scores can either be derived by a large number checked '1' or a low range of items checked '2'. To gain a better understanding of the experienced range and intensity of behaviour, the Proportion of Items positively Checked (PIC) and the Intensity Index (DBC I.I.), i.e. the proportion of positively checked items which are scored '2', were calculated, as suggested by Taffe et al. (2008). First, Proportion of Items Checked for the total problem behaviour score was calculated (PIC, proportion of number of checked items/total items of subdomain), representing a measure of the range in severity of displayed challenging behaviour. The sum of items checked 2 per domain was then divided by the PIC, resulting in a DBC-I.I. score per subdomain, representing a measure of intensity of CB. The DBC-A is a reliable and internally consistent instrument with Cronbach's alpha for the total score of α = .95 and for the subscales α = .71 - .91 (Mohr et al., 2011).

Quality Of Life: San Martin Scale

The San Martin Scale (SMS) (Verdugo et al., 2014) was used to measure quality of life (QoL). The SMS contains 95 items, resulting in eight domains (11-12 items per domain), based on the Quality of Life framework by Schalock et al. (2002). The San Martin Scale has a good reliability and validity (construct, convergent and divergent) for persons with intensive support needs and different levels of intellectual abilities (Verdugo et al., 2014), including relatively higher ID-levels which allows comparisons to be made across different levels of ID (Navas et al., 2024; Traina et al., 2022; Verdugo et al., 2014). Cronbach's alpha ranges from .82 to.93 (domains) and .97 (total score) (Verdugo et al., 2014). Domains included are Self-Determination, Emotional Well-being, Physical Well-being, Material Well-being, Rights, Personal Development, Social Inclusion, and Interpersonal Relations. The SMS is completed by a caretaker who knows the participant best. Items are statements about the participant's life scored on a 4-point Likert scale, ranging from 'never (1)' to 'always (4)'. Item scores result in a Total QoL Score, converted to Mean Item Scores (SMS MIS) for total QoL.

Example items are "He/she has the opportunity to deny doing certain activities that are irrelevant to his health (e.g., partake in leisure activities, go to sleep at a certain time, wear the clothes that other choose)" (Self-Determination), "The person is previously informed about changes in the person that provides support (e.g., due to shifts, leaves, vacations, familial situations, etc.)" (Emotional Well-being), "Has adequate hygiene (e.g., teeth, hair, nails, body) and self-presentation (e.g., clothes that are adequate for his age, for the occasion etc.)" (Physical Well-being), "He/she has his own material possessions to entertain himself (e.g., games, magazines, music, television, etc.)" (Material Well-being), "His/her rights are defended and respected (e.g. confidentiality, information about his/her rights as users, etc.)" (Rights), "He/she is provided with new instructions and models to learn new things" (Self Development), "Participates in inclusive activities that interest him/her" (Social Inclusion), "He/she has the opportunity to meet people outside from the support group" (Interpersonal Relationships).

Adaptive Communication: Vineland Adaptive Behavior Scales (Vineland II) And Vineland Screener

The Vineland II (Sparrow et al., 2005), administered at the first time wave, is a commonly accepted measure of adaptive skills and has been used extensively

in research in subjects with intellectual disability. Data were collected through semi-structured interviews with the professional primary caretaker by certified master students and research assistants who completed training and supervision in Vineland II interviewing.

The Communication domain of the Dutch translation of the Vineland screener 0-12 (Sparrow et al., 1993; van Duijn et al., 2009), a shortened version of the Vineland-II (Sparrow et al., 2005), was used to assess adaptive communication. The Vineland Screener (VS) is a commonly accepted measure of adaptive behaviour and consists of a questionnaire of 90 items, each rated from 0-2. It was administered at the second time wave and is a short form of the expanded interview, which covers the same four domains on Communication, Daily living skills, Socialization and Motor skills. A composite score of the four domains, as well as the four domain scores individually showed good internal consistency and reliability: Cronbach's α >.95, (van Duijn et al., 2009). Since the expanded interview was only administered in the first wave, items corresponding with the screener items were selected from the expanded interview to create comparable total and domain scores of adaptive behaviour over time, expressed as mean item scores. For the present study, the domain Communication was used as a measure of adaptive communication (VS Com MIS at T1 and T2). A higher score means higher adaptive communication skills.

For the descriptive variable regarding speech, we used Norrelgen et al. (2015) classification of verbal, minimally verbal and speech, for which we used with two items from the Vineland-II Expressive Subdomain: "Names at least three common objects (bottle, dog, favorite toy, etc.)" and "Uses phrases containing a noun and a verb". This resulted in three subgroup as follows: (1) *nonverbal*: does not speak three words, (2) *minimally verbal*: does speak three words, but does not use sentences with a noun and a verb, and (3) *verbal*: uses >3 words and speaks in sentences using a noun and verb.

AAC Intervention Goals In The Individual Support Plan (ISP)

Intervention goals in the ISP referring in any sense, i.e. ignoring quality of formulated goals, to the use of AAC were counted. Intervention goals (IG) were coded as 'AAC-intervention goal' when AAC was mentioned in the intervention goals, i.e. referring to the use of objects, gestures, pictograms, and photos in the IG. Participants were divided into two groups, with or without planned intervention goals relating to AAC (AAC vs. No-AAC).

Actual Implementation Of AAC

In practice there may be a discrepancy between planned and actually implemented interventions. To address this issue, an expert delegation of each involved multidisciplinary support team, i.e. a member of the direct staff, the primary involved psychologist/orthopedagogue and a family member/ representative, were interviewed about the quality and quantity of contextual care for each specific individual. They were asked to find consensus about their opinion about the following statement "The daily support team makes appropriate use of AAC for this individual". Appropriate meant as intended and consistently. Examples of AAC were furthermore given verbally, like working with gestures, pictures, sensations, objects, pictograms, and were discussed when needed. The question whether daily AAC support was present and appropriately used was assigned a score of 1 (totally disagree or 'not applicable', i.e. AAC was not present at all) to 5 (totally agree). In the end, for the final answer, the three respondents had to reach consensus. Higher scores signify higher appraisal of the use of AAC, lower scores refer to less or no use of AAC. These scores were dichotomized into a Group variable AACuse. No-AACuse representing scores 1-3 (no or insufficient daily use of AAC) an AACuse representing scores 4 – 5 (appropriate daily use of AAC).

Statistical Analyses

As the groups differed sharply in sample size, Levene's test for equality of variances of the variables of interest were used. All analyses met the necessary assumptions, except for DBC PIC and VS Com MIS. After applying square root transformation, assumptions were met for VS Com MIS (Levene's n.s.). For DBC PIC, the removal of five outliers (one in AAC group, four in No AAC group) was sufficient to meet the assumptions.

Five RM ANOVAs were planned to explore whether quality of life, challenging behaviour, and adaptive communication differed between individuals with and without AAC goals in their ISP, whether outcome on these variables of interest changed over time, and whether eventual changes were different between groups. The analyses were performed with Group (AAC goals vs. No-AAC goals) as between subjects (BS) factor, Time (T1 vs. T2) as within-subject (WS) factor, and DBC measures (DBC MIS, DBC PIC, DBC I.I.), Vineland (VS Com MIS) and SMS (SMS MIS) as dependent variables, respectively. When interpreting Group and Time effects, possible interaction effects are taken into account.

Only for the group *with* AAC goals in their ISP, it is further explored whether (quality of the) actual use of AAC had an impact on the effect of the AAC intervention over time. The inquiry into actual daily use of AAC resulted in the formation of two groups: AACuse and No-AACuse. Another series of five similar RM ANOVAs were conducted, but this time with (AACuse vs. No-AACuse) as BS factor.

Data were analysed using SPSS statistics version 29 (IBM, 2023). Significance level was set at $p<0.05$.

RESULTS

Description

For a total of *N*=196 participants on T1, in the support plans of only 24.5% (*N*=48) participants, intervention goals were found in which AAC was mentioned in their goals as tool. In 75.5% (*N*=148) of the cases participants did not have AAC mentioned in their goals

Among participants with data available for measures on T1 and T2, gender was equally distributed (65% vs. 64% male respectively, *p*=.621) among groups with and without AAC related goals. Individuals without AAC related goals had a higher calendar age in years (*M*=43.01, *SD*=15.09) than those with AAC goals (*M*=37.81, *SD*=12.42), [*t*(170)=2.048, *p*=0.42]. Verbality was not equally distributed across both groups [$\chi^2(2, N = 166) = 6.792$, $p < 0.034$]. Of those with AAC-goals 36.4% were non-verbal, 4.5% minimally verbal and 59.1% verbal. Of individuals without AAC-goals 19% were non-verbal,, 10.7% minimally verbal and 71.3% verbal.

AAC Goals Vs. No AAC Goals In The ISP

For Quality of Life (SMS MIS), the RM ANOVA resulted in a significant main effect of time [$F(1,152)=13.480$, $p<.001$, $\eta_p^2=.081$], indicating an overall improvement over time in Quality of Life. The main effect of Group (AAC goals vs. No-AAC goals) and the Time*Group interaction were non-significant ($p=.280$ and $p=.517$, respectively), indicating no differences between groups on T1 and T2.

For challenging behaviour the analyses with total DBC-A MIS, PIC, and I.I. as dependent variables, respectively, yielded only non-significant results for the main effect of Time and the interaction Time*Group ($.147<p<.758$), suggesting that, independent of group, changes over time were not significant. Main

effects of Group were significant for total DBC-A MIS [F(1,170)=8.988, *p*=.003, η_p^2=.05], and DBC PIC [F(1,170)=8.190, *p*=.005, η_p^2=.046, indicating more severe behaviour for the AAC group (Table 1).

Table 1

*Characteristics (M, SD) for individuals with severe CB in intensive 24/7 support settings, divided in groups with (N1)/without (N2) AAC related goals mentioned in their Individual Support Plan (ISP), i.e. only for those included with scores on T1 and T2 on challenging behaviour [DBC total Mean Item Score (DBC-MIS), Proportion of Items Positively Checked (DBC-PIC), and Intensity Index (DBC-II)], adaptive communication (VS Com MIS), and quality of life (SMS MIS). ** significant differences between Groups at p<.05.*

		AAC goals		No AAC goals	
	N1/N2	**T1**	**T2**	**T1**	**T2**
Adaptive Communication VS Com MIS**	39/120	.54 (.38)	.53 (.45)	.93 (.58)	.93 (.60)
Challenging Behaviour					
DBC MIS**	44/128	.60 (.19)	.63 (.20)	.51 (.21)	.51(.23)
DBC PIC**		.43 (.11)	.45 (.11)	.38 (.13)	.37 (.14)
DBC-I.I.		.40 (.17)	.39 (.20)	.34 (.18)	.33 (.20)
Quality of Life SMS MIS	38/116	2.84 (.33)	2.93 (.29)	2.88 (.29)	3.00 (.33)

For adaptive communication (VS Com MIS), a significant Group effect [F(1,156)=13.13, *p*<.001, η_p^2=.0278, and a non-significant main effect of Time (*p*=.241) were found. Combined with a nonsignificant Time*Group interaction (*p*=.721), this indicates that groups differ on adaptive communication, with the group with AAC goals scoring lower, and that group differences remained stable over time.

Actual (Daily) Use Of AAC Goals When Included In ISP

For those with goals in their ISP relating to AAC, for *N*=22 (45.8%) direct support staff actually used AAC in daily life of this individual (AACuse), and for N=26 (54.2%) AAC goals were not fully, insufficiently or not at all implemented (No-AACuse). We examined how the appropriateness of the use of AAC (carried out as intended vs. not fully, insufficiently or not at all) affected the outcome on the variables of interest.

For QoL (SMS MIS), the RM ANOVA showed a non-significant effect of Time (*p*=.126) and Group (*p*=.605), but a trend significant effect of Time*Group, accompanied by a moderate effect size [F(1,36)=5,973, *p*=.074, η_p^2=.086], suggesting that those with AAC use showed an improvement in QoL over

time whereas those without AAC use did not. Post hoc analysis confirmed a significant change (improvement) only for this group [$t(20)$=-2,603, p=.017]

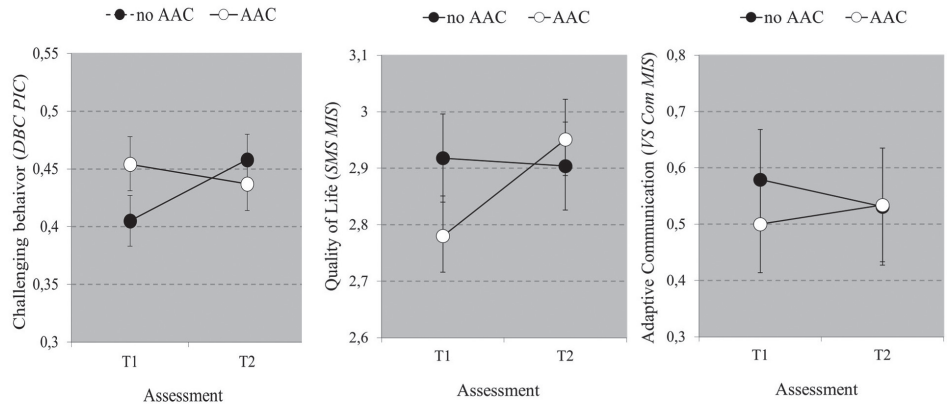
RM ANOVAs for Adaptive Communication (VS Com MIS) yielded a non-significant main effect of Time (p=.862) and Group (p=.770), accompanied by a nonsignificant Time*Group interaction, indicating no differences in outcomes on adaptive communication for those with and without AAC-use.

As regards Challenging Behaviour, only for DBC PIC, a significant Time*Group interaction was found, accompanied by a large effect size [$F(1,43)$=6.898, p=.012, η_p^2=.138, Figure 1, left panel]. reflecting a deterioration in challenging behaviour, for those individuals for whom AAC was not implemented in clinical practice although it was mentioned in their support plan. Post hoc analysis confirmed a significant change (deterioration) only for this group [$t(23)$=-2,781, p=.011]. Time-effect (p=.178) and Group-effect (p=.625) were non-significant for DBC PIC.

We have rerun the analyses with Vineland domain Communication as covariate, with no differences in results.

Figure 1

*Left panel: Challenging Behaviour (DBC PIC) over time for individuals with ISP goals, as a function of Group: AAC use in daily practice (yes vs. no), with a higher value meaning higher CB (± SEM) showing a significant Time*Group interaction. Centre panel: Quality of Life (SMS MIS) over time for individuals with ISP goals, as a function of Group: AAC use in daily practice (yes vs. no), with a higher value meaning higher QoL (± SEM). Adaptive Communication (VS Com MIS) over time for individuals with ISP goals, as a function of Group: AAC use in daily practice (yes vs. no), with a higher value meaning higher level of adaptive communication (± SEM)*



DISCUSSION

The present study focused on individuals with intellectual disability (ID), who, due to severe challenging behaviour (CB), need intensive 24/7 support on all domains of daily functioning. Challenging behaviour in these individuals is known to be partly associated with difficulties in expressing their needs, resulting in frustration which may manifest itself in increased challenging behaviour. This follow-up study examined to what extent the use of Augmentative and Alternative Communication (AAC), as expressed in AACrelated goals in individual support plans (ISP), has a favorable effect on adaptive communication, on challenging behaviour, and consequently on quality of life. Furthermore, if AAC-related goals were present in individual support plans, we were interested whether the quality of AAC use (i.e. whether AAC was implemented as intended versus insufficiently or not at all) in daily life, influenced outcomes over time.

First of all, it was found that for only twenty-four percent of the 196 participants AAC was part of their ISP goals, which was unexpectedly low, given the nature of the intensive support they require, especially with respect to communication. This percentage may suggest that the need for individual AAC goals in care for persons with communication problems, severe behavioural problems and intellectual disability, is not fully recognized, or may reflect challenges in implementing AAC or a lack of expertise among the staff with regard to AAC implementation in care for adults with ID and CB, in line with earlier findings regarding staff's knowledge about AAC systems (Dalton & Sweeney, 2013; Sutherland et al., 2014). Andzik and Chung (2022) argue that it is crucial that service providers acknowledge that communication needs of adults may shift as they grow older and that attention for and re-assessment of AAC needs may be necessary, especially in an intensive support setting, where staff not only serve as daily caregivers but also as primary communication partners.

We found that individuals without AAC goals exhibited less challenging behaviour and showed better adaptive communication than individuals with AAC goals in their ISP. Individuals without AAC goals were more often able to verbally communicate, suggesting that support teams assign AAC supported treatment more often to individuals with more challenging behaviour and low levels of adaptive communication. While this may seem to be adequate, this may actually reflect what Deckers et al. (2024) describe as the tendency

in clinical practice of AAC often being indicated on the basis of observable communication features (output level), which in our population may have been the inability to produce spoken words. Persons with communication problems despite higher verbal skills therefore could have been overlooked as candidates for support by AAC. One might even argue that challenging behaviour in itself should be indicative for need of AAC.

It was found that, if AAC-goals were implemented in individual support plans, and when AAC goals were implemented as intended, i.e. quality and quantity of AAC was appropriate (vs. improper or not al at all), challenging behaviour remained stable over time and quality of life tended to improve. When AAC related intervention goals were present in the support plan but AAC was not actually used in daily practice or judged as insufficient, indicating failed implementation, challenging behaviour increased over time and quality of life remained the same. Our results seem to be partly in line with the outcome of reviews into single case AAC interventions in children and adults by Walker and Snell (2013) and Heath et al. (2015). They found that these interventions were effective in reducing challenging behaviour in children, but less effective in adults with challenging behaviour, possibly due to their long established patterns of communication through challenging behaviour. The present study demonstrated that challenging behaviour deteriorated over time when implementation of AAC-related goals failed and underscores that AAC has a potentially beneficial effect on Quality of life and challenging behaviour, when utilized expertly.

For individuals with severe challenging behaviour, guidelines for disentangling different aspects of challenging behaviour highlight that a multidisciplinary support team should utilize the outcome of repeated evaluation of implementation of interventions focusing on communication problems (Embregts et al., 2019) (National Collaborating Centre for Mental Health, 2015). The potential benefits of AAC when properly implemented, underline that support teams should use expertise to properly implement AAC interventions and avoid or correct shortcomings by evaluation of implementation. It is therefore suggested that implementation of AAC should be set up, guided and monitored by a multidisciplinary team, as laid out in a clear and comprehensive plan that focuses on environmental changes and improvement in quality of life, as recommended by Denne (2020).

A limitation of our study is the lack of information regarding the specific type of AAC interventions, which precludes to draw more specific conclusions

about the efficacy of specific types of AAC, although this would require a larger number of participants than were available. Moreover, future studies should examine not only whether AAC is available and used in daily practice in long-term care for adults with ID and CB, but also whether and how individuals themselves take the initiative to use AAC in their daily environment. This would add to the further understanding of the mechanisms by which AAC can contribute to communicative competence, to challenging behaviour and quality of life. Furthermore, based on the finding that AAC goals were given to persons with severe verbal communication difficulties, future research could focus on the added value of AAC interventions for individuals with a broader profile of communication difficulties instead of verbal communication problems alone. An assessment framework for AAC could aid in the decision-making process for initiating AAC, by evaluating a broader range of (dys) functions (Deckers et al., 2024; Jansen et al., 2020; Van Balkom et al., 2017).

In conclusion, this study highlights that a focus on AAC potentially can have a positive impact on quality of life and managing challenging behaviour. Therefore, we advocate for a focus on AAC, especially when challenging behaviour is present. Clinically, the findings implicate the need for multidisciplinary efforts to ensure that AAC goals are effectively implemented.

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