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# "Finding Common Ground" – Impact of a Complex Intervention on Collaboration in Augmentative and Alternative Communication Care of People without Natural Speech

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**Purpose:** Many care settings are characterized by collaboration between a variety of stakeholders. People without natural speech who rely on augmentative and alternative communication (AAC) are often strongly dependent on the involved stakeholders and collaboration among them. Since collaboration can be challenged by many barriers, this study examines the impact of a complex intervention on collaboration in AAC care. **Methods:** In a quasi-experimental mixed methods intervention study which include AAC training, AAC therapy and case management, caregivers of AAC users were surveyed at 3 time points to assess collaboration and case management in the intervention versus comparison group. In addition, semi-structured focus group interviews were conducted with caregivers in the intervention group. Quantitative data were analyzed descriptively and by comparison of means. Qualitative data were analyzed using qualitative content analysis.

**Results:** The Mann–Whitney *U*-test showed significantly better collaboration in the intervention group with stakeholders that are more actively involved in AAC care, such as schools (p=0.026) and residential or social facilities (p=0.010), but not with passive stakeholders such as health insurance companies. Most aspects of case management were rated significantly better in the intervention group (p<0.001). The focus group results show mainly positive changes in collaboration with the active stakeholders, such as more commitment and openness toward AAC.

**Conclusion:** The results show a positive impact of the intervention on the collaboration between stakeholders involved in AAC care – especially with active stakeholders. In particular, the organization of care and the accompanying case management by the AAC consultation centers seem to positively affect collaboration.

Keywords: stakeholders, teamwork, mixed methods, focus groups, complex care

## Introduction

People with complex and chronic medical conditions require holistic healthcare with a collaborative approach. This includes, for example, the care of children with complex rare diseases, eldercare, or the care of people with disabilities.<sup>1–3</sup> However, healthcare is often organized in a fragmented way, and collaboration between stakeholders involved in the care of an individual patient is often insufficient.<sup>4</sup> In this paper, collaboration is defined according to Reeves et al<sup>5</sup> as a

[...] partnership, often between people from diverse backgrounds, who work together to solve problems or provide services.

Schoen et al<sup>4</sup> found in their survey of 11 selected countries (including Germany, USA, and Sweden) that the care of people with complex healthcare needs is often insufficiently coordinated, that providers collaborate too little in teams, and that adequate communication is often lacking. This can cause manyfold problems such as inconsistent care, stakeholder dissatisfaction, unmet care needs, treatment errors, and poorer health outcomes.<sup>1,3,4,6</sup>

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#### Collaboration in Augmentative and Alternative Communication (AAC) Care

As one exemplary area of care for persons with complex health needs, AAC requires the integration of a variety of heterogeneous stakeholders to be able to meet the complex care needs of many people who rely on AAC.<sup>7–9</sup>

People who – due to either congenital conditions, such as Down syndrome and autism spectrum disorder, or acquired disabilities, such as stroke and traumatic brain injury – have complex care and communication needs often rely on AAC.<sup>10–12</sup> A variety of AAC systems exist and can be broadly divided into unaided AAC systems (eg, gestures) and aided AAC systems (eg, electronic devices with voice output).<sup>13–15</sup> Since the group of people with complex communication needs is very heterogeneous in terms of age and disabilities, individual needs and abilities need to be taken into account in care with AAC.<sup>10,11,16,17</sup>

Considering this heterogeneity, many different stakeholders are involved in AAC care (eg, kindergartens, schools, or sheltered workshops). Many AAC users cannot operate the AAC system without support and are dependent on their caregivers. The types of stakeholders involved in AAC care and their collaboration differ between countries, mainly due to different regulations and the resulting differing stakeholder responsibilities.<sup>18–20</sup> Since in almost all countries speech and language pathologists, educators as well as informal caregivers (eg, parents) are involved, the AAC networks can nevertheless be compared across countries.<sup>16,21</sup>

Previous research has shown that in Germany, stakeholders involved in AAC care can be roughly divided into active and passive stakeholders (Figure 1).<sup>22</sup> Active stakeholders such as educators and institutional employees (eg, teachers, employees of kindergartens), therapists (eg, speech and language pathologists, physiotherapists), informal caregivers (eg, parents, spouses), and AAC consultants are directly involved in the implementation of AAC and use the AAC system together with the AAC user. In Germany, there are only a few independent AAC consultation centers that provide support in the assessment and implementation of AAC systems. Passive stakeholders, such as medical care providers (physicians), health insurance companies, and medical equipment suppliers, are responsible for the procurement of AAC systems and are not directly involved in AAC implementation.<sup>22</sup>

Often, there is insufficient collaboration between the stakeholders involved in AAC care, so it is common that stakeholders use the AAC system differently and, consequently, inconsistently.<sup>17,23</sup> Results of our previous qualitative focus group study with informal caregivers (eg, parents) and formal caregivers (eg, teachers, therapists) of AAC users highlighted the relevance of good collaboration in AAC care for adequate implementation of AAC. Four factors were identified as key barriers to and facilitators of collaboration: openness toward AAC, knowledge about AAC, implementation of AAC, and communication between stakeholders. Overall, due to problems with AAC system procurement in the form of delays or rejections, collaboration with passive stakeholders was experienced as more problematic than with active stakeholders. Barriers in collaboration with active



Figure 1 Intervention elements and involved active and passive stakeholders; METACOM Symbol © Annette Kitzinger.

stakeholders were mainly caused by stakeholders' working conditions and poor commitment to AAC.<sup>22</sup> Results from other studies confirm the relevance of collaboration in AAC care.<sup>9,21,24–28</sup>

## Collaboration in the Intervention

The previously listed potential barriers to collaboration in AAC care, among other aspects, were addressed in the research project "New Service Delivery Model for Augmentative and Alternative Communication (AAC) Devices and Intervention". Within the project a complex intervention was tested in three German AAC consultation centers. This new service delivery model (nSD) includes an independent initial AAC assessment and consultation (AAC system selection), four sessions of AAC training and twenty sessions of AAC therapy for the AAC users and the involved stakeholders. In addition, accompanying case management is offered, which coordinates care and fosters collaboration between stakeholders. All elements of the intervention were carried out by the AAC consultation centers. The main goals of the project were to improve pragmatic communication skills, quality of life and participation of AAC users, and satisfaction of informal and formal caregivers with the AAC system. In addition, the intervention aimed to standardize AAC care and to improve the implementation of AAC among all stakeholders.<sup>29</sup> The structure of the intervention and the involved active and passive stakeholders are presented in Figure 1.

# Aim and Research Questions

This study aims to determine the extent to which the intervention strengthens collaboration in AAC care. As a result, the following research questions have been identified: How does the intervention impact collaboration with the active and passive stakeholders in AAC care? Which elements of the intervention have a concrete impact on collaboration, and what is the role of case management in particular?

# Materials and Methods

## Study Design

The evaluation study uses a quasi-experimental mixed methods design. Whereas the intervention group received different intervention elements as described above, the comparison group received only the initial AAC assessment and consultation. All components of the intervention and comparison groups were managed by the three AAC consultation centers participating in the project.<sup>29</sup> The formal caregivers (eg, teachers or speech and language pathologists) and informal caregivers (eg, parents or relatives) of the AAC users in the intervention group and in the comparison group were surveyed at three timepoints (T0=after initial AAC assessment and consultation; T1=4 weeks after AAC system receipt [after AAC training]; and T2=3 months after AAC system receipt [after AAC therapy]). Additionally, focus group interviews were conducted with informal and formal caregivers and AAC consultants of the intervention group. Since the status quo was already qualitatively surveyed in a previous study by means of focus group interviews,<sup>22</sup> the qualitative survey in this study focused exclusively on the intervention group as part of the process evaluation. The mixed methods study uses a convergent design. Qualitative and quantitative data were collected concurrently, answering the same research questions, and therefore carry equal weight. The results of both methods are merged in the results section and are considered together in the discussion.<sup>30,31</sup> The data were collected in the period between June 2018 and April 2021.

## **Ethical Considerations**

The study received consultation from the Ethics Committee of the Faculty of Medicine and Health Sciences of the Carl von Ossietzky University of Oldenburg, which issued a positive vote (2017–137) and complies with the Declaration of Helsinki.

## Inclusion Criteria and Recruitment

Inclusion criteria for AAC users' participation in the study were the existence of a congenital or acquired severe disability associated with loss of natural speech. All age groups (age range of participating AAC users: 1–80 years) and diseases were included in the study. The wide age range of the participating AAC users allowed us to assess and analyze the different AAC networks and forms of collaboration among the involved stakeholders. Allocation to the intervention or comparison group was determined by the health insurance affiliation of the AAC users. Recruitment of participants into the intervention and comparison

groups took place during the initial AAC assessment and consultation, during which they received all information about the study in written form at the three participating AAC consultation centers. If participating, it was necessary to nominate at least one, or ideally two, caregivers (formal and informal) to include into the study. All included caregivers who submitted informed consent were invited to take the quantitative survey.

Homogeneous focus group interviews were conducted with consultants of the AAC consultation centers who implement the intervention and at the same time act as case managers. Additionally, heterogeneous focus group interviews were conducted with informal and formal caregivers. Participants of the heterogenous focus groups were recruited by purposeful sampling<sup>32</sup> to ensure a diverse sample. Sampling criteria for formal caregivers covered the occupational groups and, for informal caregivers, the relationship to the AAC user. Another inclusion criterion for informal and formal caregivers was for AAC therapy to have been started already so that they had experience with all elements of the intervention. To prevent selection bias, recruitment of focus group participants was carried out by the evaluators without the help of the AAC consultation centers. All participants in the qualitative and quantitative surveys agreed to the publication of anonymized results within the consent form.

# Data Collection

#### Qualitative Data

The focus group interviews were carried out by three researchers – two moderators (SAKU and AZ) and one person for documentation (HS or AL) – and were conducted at the three AAC consultation centers involved in the project. All interviews were audio recorded, and prior to the interviews, participants were informed both verbally and in written form about the interview's aims and data protection measures. At the beginning of the interviews, participants were asked to give their written informed consent. A semi-structured interview guideline<sup>33–35</sup> with the following main guiding questions was used:

- How was the intervention practiced?
- What are your experiences with the intervention?
- How would you rate the effects of the intervention?
- Is there any need to modify the intervention?

Moreover, participants were shown an illustration in the form of a stimulus that presented the potential active and passive stakeholders of the AAC network. Using red and green stickers, participants were asked to visualize whether within the intervention, collaboration with these stakeholders has improved, deteriorated, or remained unchanged. Afterwards, participants were asked to report in detail on their experiences with these stakeholders.

## Quantitative Data

The formal and informal caregivers from the intervention and comparison groups were surveyed at three time points. To survey collaboration with passive stakeholders (T1) and active stakeholders (T1 and T2), self-developed items were used with response categories on a 5-point Likert scale ranging from "0=very poor" to "4=very good". Case management was assessed using two instruments with self-developed items (T1 and T2), one using a 5-point Likert scale ranging from "0=none" to "4=very much" and the other using binary response categories ("Yes" or "No"). In addition, the T0 questionnaire asked for socio-demographic information (eg, Tables 1 and 2). All questionnaires were designed with the help of cognitive pretests<sup>36</sup> (n=16 pretest interviews with informal and formal caregivers of AAC users). To increase response rates, a first reminder was sent after 2 weeks and a second one after 2 more weeks.<sup>37</sup>

## Data Analysis

#### Analysis of Qualitative Data

The focus group interviews were audio-recorded and subsequently transcribed and pseudonymized. Transcripts were analyzed using structured qualitative content analysis according to Kuckartz.<sup>38</sup> Initially, for all focus group interviews, a priori main categories were determined deductively on basis of the guiding questions. Subsequently, inductive subcategories were developed during the coding process. Two evaluators independently coded all interviews and compared the results in a subsequent consensus agreement. For the coding process, MAXQDA Analytics Pro 2020 (version 20.4.0) software was used.

Table I Sample Description of Focus Group Participants						
Focus Group Participant Characteristics (Intervention Group)	n (%)					
Total number of participants	31 (100)					
Homogeneous focus groups (n=3)						
Consultants at AAC consultation centers	11 (35.5)					
Heterogeneous focus groups (n=4)						
Informal caregivers (parents)	8 (25.8)					
Therapists	2 (6.5)					
Educators and institutional employees						
Teachers	3 (9.7)					
Employees of homes for persons with disabilities	2 (6.5)					
Employees of sheltered workshops	I (3.2)					
Educators	3 (9.7)					
Remedial teachers	I (3.2)					

25 (80.7) 6 (19.4)

I (3.2)

6 (19.4)

11 (35.5)

11 (35.5)

2 (6.5)

Note: Due to rounding, percentages might not add up to exactly 100%.

#### Table 2 Sample Description of Survey Participants

Sex Female

Male Age groups 18–25 years

26–35 years

36-45 years

46-55 years

56-65 years

Survey Participant Characteristics (T0+T1+T2 Completed)	Intervention Group n (%)	Comparison Group n (%)
Total number of caregivers	184 (100)	97 (100)
Formal caregivers	83 (100)	40 (100)
Educators and institutional employees		
Teachers	21 (25.3)	15 (37.5)
Educators	18 (21.7)	3 (7.5)
Employees of residential or social facilities (eg, homes for persons with disabilities,	17 (20.5)	5 (12.5)
sheltered workshops)		
Therapists	24 (28.9)	14 (35)
Other formal caregivers (eg, remedial teacher)	3 (3.6)	3 (7.5)
Informal caregivers	101 (100)	57 (100)
Spouse/Partner	2 (2)	I (I.8)
Mother/Father	80 (79.2)	56 (98.2)
Other informal caregivers (eg, relatives)	19 (18.8)	0 (0)
Sex		
Female	149 (81)	81 (83.5)
Male	35 (19)	16 (16.5)
Age groups		
0–29 years	31 (16.8)	9 (9.3)
30–39 years	66 (35.9)	23 (23.7)
40–49 years	57 (31)	36 (37.1)
50–59 years	23 (12.5)	26 (26.8)
60–69 years	7 (3.8)	3 (3.1)

#### Analysis of Quantitative Data

The paper questionnaires were scanned using the Electric Paper TeleForm software, tested for plausibility and exported to IBM SPSS V.27 software.

All informal and formal caregivers from whom all questionnaires (T0, T1 and T2) had been returned were included in the analysis. No imputation of missing values was performed. Quantitative results were analyzed descriptively, and nonparametric mean comparisons were calculated with Mann–Whitney *U*-tests using SPSS. Effect sizes were calculated using the Pearson correlation coefficient r. Moreover, Pearson's chi-square test was conducted for the nominally scaled items. Prior to conducting statistical tests, the statistical assumptions were tested (results not reported here).

## Results

## Sample Description

Figure 2 illustrates the flow charts of the two comparison groups. Accordingly, the sample of valid cases is n=184 caregivers (response rate of 68.9%) in the intervention group and n=97 caregivers (response rate of 63.4%) in the comparison group.

A total of seven focus group interviews were conducted – three of them homogeneous and four heterogeneous – with a total of 31 participants. The interviews lasted on average 82 minutes. All demographic characteristics of study participants in the quantitative and qualitative data collection are listed in Tables 1 and 2.

## Visualization of Changes in the Collaboration

Table 3 presents the focus group results from the visualization of changes in the collaboration with various stakeholders as a result of the intervention. Accordingly, collaboration with active stakeholders, such as therapists, was reported to be



Figure 2 Flow charts of the intervention group and comparison group.

Collaboration with Stakeholders	No Improvements in Collaboration	Improvements in Collaboration	Total Number of Stickers		
Active stakeholders					
Informal caregivers	3	21	24		
AAC consultants	0	12	12		
Educators and institutional employees	2	22	24		
Therapists	4	21	25		
Passive stakeholders					
Medical care providers	7	2	9		
Medical equipment suppliers	7	3	10		
Health insurance companies	13	3	16		
Total number of stickers	36	84	120		

**Table 3** Visualization of Perceived Improvements in the Collaboration with Stakeholders Within the Focus Group Interviews

**Notes**: Within the focus group interviews, all participants received red and green stickers to visualize whether collaboration has improved, deteriorated or remained unchanged within the intervention.

considerably improved. In contrast, there were few reports of improvements in the collaboration with passive stakeholders, such as health insurance companies.

## Organization of Collaboration in the Intervention

From the focus group participants' narratives on their experiences visualized in Table 3, a category system was developed with the following three main categories (Figure 1): organization of collaboration in the intervention, impact of the intervention on collaboration with active stakeholders, and impact of the intervention on collaboration with passive stakeholders. Quantitative and qualitative results are presented below for each main category, starting with organization of collaboration in the intervention.

Focus group participants reported that within the initial AAC assessment and consultation, the AAC consultation centers determined which stakeholders are the closest caregivers of the AAC user. All relevant stakeholders were gathered around one table and jointly determined the most appropriate AAC system (joint round tables).

According to the focus groups, the subsequent AAC training was used to identify the stakeholders' and AAC users' concrete experiences with AAC and indicated at which points they need support. In the subsequent AAC therapy focus group participants reported that the stakeholders and the AAC consultants worked together to achieve the previously defined goals. The importance of the joint meetings is emphasized by the following quote from a teacher:

I found everything the father said important, too, that you just, from time to time, [have] something like a round table or that. the practice actually does do that, but that you just often sat together with a lot of people, thought about things, and that, in the beginning, you also had an open-ended discussion [...] So, there was just a lot of support, and I found that to be very, very positive. (B4AT1B#2, 35)

#### Case Management

Both comparison groups received holistic support from the AAC consultation centers during initial AAC assessment and consultation. The intervention group additionally received support from the AAC consultation center in the form of case management throughout AAC care. Descriptive results from the evaluation of case management as measured by the assessment of received support and support needs are presented below (Table 4).

For items 2, 3, and 4, the Mann–Whitney *U*-test revealed that caregivers in the intervention group (median=3.00 for items 2–4) reported significantly better support than those in the comparison group (median=2.00 for items 2 and 4, and median=1.00 for item 3), with p<0.001 for item 2; p<0.001 for item 3; and p<0.001 for item 4. Cohen's<sup>39</sup> effect size for these three items shows a low to medium effect (r=0.286, r=0.448, and r=0.426, respectively).

Furthermore, (un)met support needs that were assumed to be influenced by case management are presented in Figure 3 as a group comparison.

Time Point	Items	Intervention Comparison Group Group							
		n	n Mdn n Mdn		Mann-Whitney U-Test			Effect	
						U	z	р	size r
	How much support did you receive from the AAC consultation center during AAC care								
тι	I in applying for the new AAC system?	141	3.00	70	3.00	4314.00	-1.590	0.112	
	2in defining a common goal of AAC care?	165	3.00	74	2.00	4016.50	-4.417	<0.001*	0.286
Т2	3in involving the AAC user's environment (eg, family, kindergarten, sheltered workshop) in the use of the new AAC system?	159	3.00	69	1.00	2500.50	-6.758	<0.001*	0.448
	4 in achieving the defined common goal of AAC care?	160	3.00	65	2.00	2471.00	-6.384	<0.001*	0.426

#### Table 4 Assessment of Case Management

Notes: Significant results are marked with \*p=significance level: \*Statistically significant at 5% level. Abbreviations: Mdn, median.

For all items, caregivers in the intervention group reported lower unmet support needs than did those in the comparison group. The results of the Pearson's chi-square test indicate that for the items goal definition, networking, ongoing content adaption, and AAC utilization, this group difference in support needs is significant.

The focus group results illustrate that case management involved a network analysis as a tool to identify all relevant stakeholders. In addition, case management especially supported formal and informal caregivers in need of support. Case management was described to mediate between the stakeholders and to promote information exchange. Participants reported that case management intervened and took over communication with the health insurance company in the event of problems with the application for AAC systems. Another reported task of case management was to organize a good



Figure 3 Case management assessment: Unmet support needs in AAC care the intervention versus comparison group. Note: Chi-square test: significant results are marked with \* (p<0.001; p<0.001; p<0.001; p<0.001; p<0.001).

conclusion of the care so that all stakeholders knew how to proceed after the intervention ended. The relevance of case management for collaboration is underlined by the following quotation:

But for that, in particular, I find [..] this case management, this passing on of information, so important, right? That if a highlight situation occurred somewhere, that all other caregivers know about this highlight. (B2BT1M#1, 157, AAC consultant)

## Impact of the Intervention on Collaboration with Active Stakeholders

The following Table 5 compares how caregivers rated collaboration with the respective active stakeholders in the two comparison groups at T2. The Mann–Whitney *U*-test indicates significantly better collaboration with the school and the residential or social facilities in the intervention group (school median=3.00; residential or social facilities median=3.00) than in the comparison group (school median=3.00; residential or social facilities median=2.00), school p=0.026; residential or social facilities p=0.010. With an effect size of r=0.218 for collaboration with the school and r=0.321 for collaboration with residential or social facilities, this is a low to medium effect according to Cohen.<sup>39</sup> With regard to kindergartens and therapists, there were no significant group differences.

The impact of the intervention on collaboration with active stakeholders is described in more detail below using the focus group results.

#### Educators and Institutional Employees

The intervention was perceived to lead to more intensive communication and better collaboration in the implementation of AAC with educators and institutional employees. Furthermore, these stakeholders are described as being more open towards AAC:

My contact simply became even closer that way. Also, that we now talk about which \*AAC system\* (quietly laughing) we should take, and so on. Right? That we coordinate everything with each other, so that you can really collaborate well. (B3AT1B#1, 322, remedial teacher)

Negative experiences were also reported. Some stakeholders seemed to feel disturbed when AAC consultants visited their institution to provide AAC therapy and were unwilling to participate in the implementation of the intervention – as the following quote of an AAC consultant illustrates:

Time Point	Items	Intervention Group		Comparison Group					
		n	n Mdn n Mdn		Mdn	Mann-Whitney U-Test			Effect
						U	z	р	size r
	Use of the new AAC system eg, talker, communication board, gestures: How do you rate collaboration in the last 4 weeks with								
Т2	the crèche/the day center/the kindergarten?	67	3.00	34	3.00	892.50	-1.859	0.063	
	the school?	66	3.00	38	3.00	946.50	-2.225	0.026*	0.218
	the residential or social facilities (eg, assisted living, sheltered workshop)?	50	3.00	15	2.00	216.00	-2.585	0.010*	0.321
	with therapists (eg, speech and language pathologists, physiotherapists)?	117	3.00	51	3.00	2621.00	-1.334	0.182	

Table 5 Evaluation of Collaboration with the Respective Active Stakeholders in the Intervention versus Comparison Group

Notes: Significant results are marked with \*p=significance level: \*Statistically significant at 5% level. Abbreviations: Mdn, median.

And one kindergarten really views it critically, too. They also, I think, feel a little bothered by my presence; I experience the same at sheltered workshops, too, now. They, well, they feel that it's an additional burden since I want to schedule appointments with them. (B2BT1M#1, 143)

#### Homes for Persons with Disabilities

In collaboration with homes for persons with disabilities, participants reported that the intervention had primarily improved communication and the commitment to participate in the implementation of AAC. This is shown by the following quote from an AAC consultant:

I'm in contact with three homes for persons with disabilities, and really [...] three very positive contacts. [...] where the information exchange works great, where the attitudes are right. Where, well, collaboration, right? You delegate tasks, they are completed and taken on, where that works really well. Yes. That's nice. And kind of new to me. (B2BT1M#1, 333-335)

#### Therapists

Collaboration with therapists was reported to be positively influenced by the intervention. In particular, contact and communication with speech and language pathologists was experienced to have improved. Therapists were described as more committed and open to implement AAC under common goals. In some cases, the intervention led to new collaborations with occupational and physical therapists:

Well, I just think that due to this study and these round tables that were held, speech and language pathologists, occupational therapists, physiotherapists just got on the same page, that they all truly work with the same medium. And that things are consistent for the child. (B1AT1B#2, 248, motor activity therapist)

#### Informal Caregivers

Participants reported that the intervention has mainly led to better contact with informal caregivers since they were more involved in the care process. In addition, the interviews revealed better collaboration in the implementation of AAC, which could be explained by greater commitment and openness by the informal caregivers. The involvement of further family members had also improved – as the following quote from an educator illustrates:

Well, collaboration with parents is just really good. That's not always the case, unfortunately. And also, the siblings or grandma and grandpa, who didn't have any idea at all about how to somehow communicate with the child before, they show up to our kindergarten now and say, I need your help again. (B4AT1B#1, 307)

However, it was also reported that collaboration with some informal caregivers was difficult because they showed no interest in AAC and did not have an adequate understanding of AAC, which was partly explained by language barriers.

## Impact of the Intervention on Collaboration with Passive Stakeholders

Since there is no collaboration with the passive stakeholders beyond procuring AAC, the caregivers from the two comparison groups were asked to rate collaboration only through the T1 questionnaire. The descriptive results in Table 6 show that the ratings of collaboration with passive stakeholders do not differ significantly between the two groups.

To clarify the quantitative results the following section deals with the impact of the intervention on the individual passive stakeholders derived from the focus group interviews.

#### Medical Care Providers

Collaboration with medical care providers was reported to have remained unchanged. Overall, interviewees made few statements about physicians since little collaboration took place. The main criticism was that physicians' knowledge of AAC was too limited, and they would therefore not provide any information on this topic. Participants reported that some physicians felt patronized when caregivers or therapists had to inform them about AAC, which led to a professional dispute. The passivity of physicians in the care process is illustrated by the following quote from a mother:

Time Point	Items	Intervention Group		Compar	ison Group					
		n Mdn		n	Mdn	Mann-Whitney U-Test				
						U	z	р		
	The path to the new ACC system: your experiences How do you rate the collaboration with									
Т2	the medical equipment supplier?	100	3.00	60	3.00	2972.50	-0.108	0.914		
	the health insurance company?	95	3.00	53	3.00	2360.50	-0.673	0.501		
	the physician?	86	3.00	44	3.00	1777.50	-0.620	0.535		

Table 6 Assessment of Collaboration with the Respective Passive Stakeholders by the Intervention and Comparison Group

Abbreviation: Mdn, median.

[...] where's the physician? Now, at this moment, what does he even control? The physician prescribes a service, after all. Because it's medically necessary for this to be done. But he he's not at all on our side. (B6AT1B#2, 219)

#### Health Insurance Companies

Only insured persons of one specific health insurance company were able to participate in the intervention. Although this health insurance company was a partner in the project, several collaboration problems were described. In many cases, participants found their applications for AAC systems to be rejected in whole or in part, apparently arbitrarily; as a result, statements and objections had to be written with great effort to finally receive approval. The following quotations illustrates these aspects:

Right, that the care doesn't go smoothly, from the health insurer's side, we actually experience that a lot currently, right? That parts are not approved, that different medical equipment suppliers are involved, rather than the ones (clears throat) we would like. [...] Also stuff like, like trials. trials first being approved, and then, after the trial, despite another evaluation, things not being provided for permanent use. (B2BT1M#1, 98, AAC consultant);

The health insurance company had quite a lot of excuses why we can't get it yet. [...] Then my speech and language pathologist had to confirm again that it's the right one, and it just took four, five months until we got it. (B2AT1B#1, 5, father)

#### Medical Equipment Suppliers

The AAC consultants reported several problems in their collaboration with medical equipment suppliers. These difficulties were mainly caused by a law that requires the suppliers to conduct an AAC consultation. In the context of this obligation to provide AAC consultation, the AAC consultation centers' recommendations had been questioned:

[...] I also had this issue with medical equipment suppliers before, that they [...] were unhappy about our choice and actually insisted on their right to present something else again, and they said, well, what do you even presume to be capable of, as a company-independent therapist? So, these discussions definitely very strongly attacked my expertise and professional knowledge [...]. (B3AT1M#1, 353, AAC consultant)

Nevertheless, collaboration with some suppliers was reported as having improved due to closer contact and the establishment of a trustful relationship, and some informal caregivers reported that medical equipment suppliers supported them in technical problems with the AAC system.

## Discussion

In this study, we examine the extent to which a complex intervention in AAC care affects collaboration among stakeholders involved in care. Overall, the results of the quantitative and qualitative surveys show a positive impact of the intervention on collaboration in AAC care in many, but not all regards.

Specifically, the results indicate a positive impact of the intervention on collaboration with active stakeholders. The quantitative results show a significant improvement in collaboration with the school as well as with the residential or social facilities. The qualitative results match these results and explain that, among other things, communication with the homes for persons with disabilities and their commitment to implement AAC has improved. Nevertheless, the implementation of the intervention has also revealed new barriers in collaboration with active stakeholders. Since standard AAC care does not involve as many on-site therapy sessions, this additional effort of AAC implementation and progress monitoring was overstraining for some stakeholders, such as kindergartens and sheltered workshops. It is safe to assume that this overload is mainly due to working conditions such as lack of staff and time.<sup>22</sup> Previous studies show how important it is to the success of AAC care that informal caregivers (eg, parents) have a positive attitude towards AAC care, that they receive sufficient support from other stakeholders to implement AAC, and that they are involved in the decision-making process.<sup>22,40,41</sup> Consequently, interventions should not only consider the needs of the AAC users, but also those of the informal caregivers.<sup>42</sup> In this regard, our study results indicate that the intervention positively influenced participation in AAC care as well as informal caregivers' openness towards AAC by involving them in all elements of the intervention and keeping them informed about the AAC user's development.

Collaboration with passive stakeholders, on the other hand, does not appear to have changed significantly as a result of the intervention. Regarding to AAC system procurement, which requires collaboration with physicians and health insurance companies, this result was partly to be expected since both groups received the same care up to the point of receiving the AAC system. The fact that n=22 cases (see Figure 2) in the comparison group were unable to participate because the health insurance companies did not approve their application shows persistent problems. Based on the intervention group's partially negative ratings of collaboration with passive stakeholders voiced in the focus groups, we would have expected lower ratings in the survey (Table 6). This could depend on the method since the atmosphere and nature of the questions in the focus group interviews may have led to more reflection and discussion. Another explanation could be that the focus group interviews included not only informal and formal caregivers of AAC users, but also AAC consultants who might view the collaboration with passive stakeholders more critically due to their key function in the collaboration with those stakeholders. Through their role as case managers, AAC consultants must take care of problems in AAC system procurement and thus often directly face collaboration problems. Although the health insurance company of the intervention participants is an official project partner, problems such as late delivery and rejections have been reported. As there is no continuous contact person, AAC system procurement seems to depend on the assigned contact persons and their knowledge.

The results show that especially the intervention elements such the joint round tables<sup>43</sup> with joint definition and pursuit of goals during AAC training and therapy as well as case management make an important contribution to the promotion of collaboration. Since in initial AAC assessment and consultation, a stakeholder analysis of the AAC network is being done and subsequently, relevant stakeholders are involved in the decision-making process regarding the AAC system selection, collaboration with stakeholders is directly initiated. Especially through case management, collaboration in the network can be established and strengthened sustainably. This enables collaboration and AAC care to continue successfully after the end of the intervention.

The intervention can be characterized according to the conceptual framework for interprofessional teamwork of Reeves et al.<sup>5</sup> This framework includes four domains: Relational, Processual, Organizational and Contextual. The classification clarifies the effect modes of the intervention, presents them in a structured way, and enables a better comparability to other interventions. Since the intervention involves the organization of joint round tables with all relevant stakeholders to reach joint agreements, it can be characterized as a communication intervention within the "Relational" domain. Furthermore, the intervention includes case management for the coordination of care and the organization of collaboration and thus fits the domain "Processual". Finally, the intervention represents a re-organization of AAC care because this was the first time for such form of AAC care to be financed by a health insurance company; it therefore fits in the domain "Organizational". Accordingly, the intervention cannot be assigned to only one domain, but is a multifaceted intervention. Thus, it becomes clear that the intervention has an impact on various aspects of collaboration.

Compared to our previous study by Uthoff et al<sup>22</sup> in which four main barriers and facilitators for collaboration in AAC care (openness toward AAC, knowledge about AAC, implementation of AAC, and communication between stakeholders) could be analyzed, the results show that especially the factors of openness toward AAC, implementation of AAC, and communication between stakeholders were positively influenced by the intervention, in particular with regard to collaboration with active stakeholders.

## Limitations and Strengths

The relatively low case numbers in the survey can be seen as a limitation. However, since the target group is rather difficult to reach and similar studies usually are conducted with smaller sample sizes, the sample size can be considered comparatively large. Although the sample of AAC users and thus also of stakeholders was very heterogeneous and implies certain methodological difficulties, this heterogeneity made it possible to achieve an overview of a variety of AAC networks and to answer the research questions. Thus, it also became clear that different aspects of collaboration are relevant depending on the stakeholders involved. Since the healthcare structures in other countries are different, the intervention and the study results might not be entirely transferable. In particular, the COVID-19 pandemic, which occurred during the survey period, negatively influenced study conduct, as it temporarily prevented any in-person collaboration between stakeholders. This was partially compensated by online therapies, but the original level of collaboration could not be achieved. AAC users were not involved in the data collection for methodological and pragmatic reasons, as they would have required a higher level of support to participate, for example in focus group interviews. As these resources were not included in the project plan and the investigation of the research question was primarily about collaboration among the stakeholders, we decided against the participation of the AAC users. While, interviews with AAC users were conducted as part of the project, they did not cover the topic of collaboration and therefore were not used as a data source in this paper. Overall, this study can be considered a comparatively large mixed methods study in the field of AAC research. The mixed methods design enabled a more comprehensive understanding of the complex context in which this study took place and thus contributed to more profound knowledge on the intervention and the topic of collaboration.

# Conclusion

This paper presents new insights in intervention research to promote collaboration in AAC care and identifies measures with the potential to improve collaboration. These measures can be further developed and might be applicable to other complex care settings involving multiple stakeholders, such as mental healthcare, geriatric care, and care for people with rare diseases.

The study illustrates that the networks in AAC care are heterogeneous and that collaboration is highly dependent on individual persons. If a stakeholder is not committed to implement AAC and does not communicate with the other stakeholders, successful collaboration and therefore successful AAC care is hardly possible. The intervention shows that case management can provide support in this case by coordinating the collaboration. Many stakeholders, like parents, teachers, or therapists, usually do not have the capacity to fulfill such a role. Therefore, the care provided by the AAC consultation center and case management is an important resource for relieving the other stakeholders and taking over tasks such as communication with the health insurance company in case of a rejection, passing on information, or organizing joint meetings.

The results show that the intervention did not substantially improve collaboration with passive stakeholders. While case management provided support, many of the problems are due to legal regulations, which were hard to resolve within this project and this complex intervention without the possibility of changing the health policy context. Standardization of AAC care with clearly defined responsibilities would help solve some problems. In our view, the next step should be to develop the intervention further with the help of a large-scale study. One idea could be to integrate a common communication channel in the form of an app, based on the study of Shin et al,<sup>44</sup> in which stakeholders can share their experiences with AAC use at any time. After the experience of the COVID-19 pandemic, it seems to make sense to complement the intervention with digital communication channels. Furthermore, it might be useful to integrate models of interprofessional education (IPE) and interprofessional collaborative practice (IPCP) into future interventions, as also

recommended in the publication by Lou et al.<sup>9</sup> Since this study focuses on intermediate outcomes, namely the impact of the intervention on collaboration, future studies should expand on the impact of the intervention and hence improved collaboration on patient outcomes such as pragmatic communication skills, quality of life, and participation.

# **Abbreviations**

nSD, new service delivery model; AAC, augmentative and alternative communication; Mdn, median; IPE, interprofessional education; IPCP, interprofessional collaborative practice.

## Acknowledgments

The authors thank Ann-Kathrin Löhr (AL) and Helge Schnack (HS) for their excellent support within the research project. Furthermore, we thank all participants for their study participation and the three AAC consultation centers for the good collaboration.

# **Author Contributions**

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

# Funding

The project on which this paper is based is funded by the Innovation Fund of Germany's Federal Joint Committee (Grant No 01NVF17019).

## Disclosure

The authors report no conflicts of interest in this work. The authors alone are responsible for the content and writing of this article.

# References

- 1. Currie G, Szabo J. "It is like a jungle gym, and everything is under construction": the parent's perspective of caring for a child with a rare disease. *Child Care Health Dev.* 2019;45(1):96–103. doi:10.1111/cch.12628
- Jirau-Rosaly W, Brown SP, Wood EA, Rockich-Winston N. Integrating an interprofessional geriatric active learning workshop into undergraduate medical curriculum. J Med Educ Curric Dev. 2020;7:1–6. doi:10.1177/2382120520923680
- 3. Tsakitzidis G, Timmermans O, Callewaert N, et al. Outcome indicators on interprofessional collaboration interventions for elderly. *Int J Integr* Care. 2016;16(2):1–17. doi:10.5334/ijic.2017
- 4. Schoen C, Osborn R, Squires D, Doty M, Pierson R, Applebaum S. New 2011 survey of patients with complex care needs in eleven countries finds that care is often poorly coordinated. *Health Aff*. 2011;30(12):2437–2448. doi:10.1377/hlthaff.2011.0923
- 5. Reeves S, Lewin S, Espin S, Zwarenstein M. Interprofessional Teamwork for Health and Social Care. Oxford, UK: Wiley-Blackwell; 2010.
- Hwang K, Johnston M, Tulsky D, Wood K, Dyson-Hudson T, Komaroff E. Access and coordination of health care service for people with disabilities. J Disabil Policy Stud. 2009;20(1):28–34. doi:10.1177/1044207308315564
- 7. Beukelman DR, Fager S, Ball L, Dietz A. AAC for adults with acquired neurological conditions: a review. *Augment Altern Commun.* 2007;23 (3):230–242. doi:10.1080/07434610701553668
- Light J, McNaughton D. The changing face of augmentative and alternative communication: past, present, and future challenges. *Augment Altern Commun.* 2012;28(4):197–204. doi:10.1177/1044207308315564
- Luo F, Blackstone SW, Canchola J, Roman-Lantzy C. Working with children with cortical visual impairment who use augmentative and alternative communication: implications for improving current practice. *Augment Altern Commun.* 2022;1–15. doi:10.1080/07434618.2022.2085622
- 10. Beukelman DR, Mirenda P. Augmentative & Alternative Communication: Supporting Children and Adults with Complex Communication Needs. 4th ed. Baltimore, Md.: Paul H. Brookes; 2013.
- 11. Creer S, Enderby P, Judge S, John A. Prevalence of people who could benefit from augmentative and alternative communication (AAC) in the UK: determining the need. *Int J Lang Commun Disord*. 2016;51(6):639–653. doi:10.1111/1460-6984.12235
- 12. Harding C, Lindsay G, O'Brien A, Dipper L, Wright J. Implementing AAC with children with profound and multiple learning disabilities: a study in rationale underpinning intervention. J Res Spec Educ Needs. 2011;11(2):120–129. doi:10.1111/j.1471-3802.2010.01184.x
- 13. Baxter S, Enderby P, Evans P, Judge S. Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis. *Int J Lang Commun Disord*. 2012;47(2):115–129. doi:10.1111/j.1460-6984.2011.00090.x
- 14. Sigafoos J, Drasgow E. Conditional use of aided and unaided AAC. Focus Autism Other Dev Disabl. 2001;16(3):152-161. doi:10.1177/ 108835760101600303

- 15. Wilkinson KM, Madel M. Eye tracking measures reveal how changes in the design of displays for augmentative and alternative communication influence visual search in individuals with down syndrome or autism spectrum disorder. Am J Speech Lang Pathol. 2019;28(4):1649–1658. doi:10.1044/2019\_AJSLP-19-0006
- Dietz A, Quach W, Lund SK, McKelvey M. AAC assessment and clinical-decision making: the impact of experience. *Augment Altern Commun.* 2012;28:3. doi:10.3109/07434618.2012.704521
- McNaughton D, Light J, Beukelman DR, Klein C, Nieder D, Nazareth G. Building capacity in AAC: a person-centred approach to supporting participation by people with complex communication needs. *Augment Altern Commun.* 2019;35(1):56–68. doi:10.1080/07434618.2018.1556731
- Binger C, Ball L, Dietz A, et al. Personnel roles in the AAC assessment process. Augment Altern Commun. 2012;28(4):278–288. doi:10.3109/ 07434618.2012.716079
- 19. Subihi AS. Saudi special education student teachers' knowledge of augmentative and alternative communication (AAC). *Int J Spec Educ*. 2013;28 (3):93–103.
- 20. Waller A. Public policy issues in augmentative and alternative communication technologies a comparison of the U.K. and the U.S. *Interactions*. 2013;20(3):68. doi:10.1145/2451856.2451872
- 21. Hunt P, Soto G, Maier J, Müller E, Goetz L. Collaborative teaming to support students with augmentative and alternative communication needs in general education classrooms. *Augment Altern Commun.* 2002;18(1):20–35. doi:10.1080/714868359
- 22. Uthoff SAK, Zinkevich A, Boenisch J, Sachse SK, Bernasconi T, Ansmann L. Collaboration between stakeholders involved in augmentative and alternative communication (AAC) care of people without natural speech. J Interprof Care. 2021;35(6):821–831. doi:10.1080/ 13561820.2020.1860918
- Johnston SS, Blue CW, Stegenga SM. AAC barriers and facilitators for children with Koolen de Vries syndrome and childhood apraxia of speech: parent perceptions. Augment Altern Commun. 2022;1–13. doi:10.1080/07434618.2022.2085626
- 24. Chung Y-C, Stoner JB. A meta-synthesis of team members' voices: what we need and what we do to support students who use AAC. *Augment Altern Commun.* 2016;32(3):175–186. doi:10.1080/07434618.2016.1213766
- Murray J, Lynch Y, Meredith S, et al. Professionals' decision-making in recommending communication aids in the UK: competing considerations. Augment Altern Commun. 2019;35(3):167–179. doi:10.1080/07434618.2019.1597384
- 26. Stoner JB, Angell ME, Bailey RL. Implementing augmentative and alternative communication in inclusive educational settings: a case study. *Augment Altern Commun.* 2010;26(2):122–135. doi:10.3109/07434618.2010.481092
- 27. Alant E, Champion A, Peabody EC. Exploring interagency collaboration in AAC intervention. Commun Disord Q. 2013;34(3):172-183. doi:10.1177/1525740112455432
- Snodgrass MR, Meadan H. A boy and his AAC team: building instructional competence across team members. *Augment Altern Commun.* 2018;34 (3):167–179. doi:10.1080/07434618.2018.1491059
- Zinkevich A, Uthoff SAK, Boenisch J, Sachse SK, Bernasconi T, Ansmann L. Complex intervention in augmentative and alternative communication (AAC) care in Germany: a study protocol of an evaluation study with a controlled mixed-methods design. *BMJ Open.* 2019;9(8):e029469. doi:10.1136/bmjopen-2019-029469
- 30. Creswell JW, Plano Clark VL. Designing and Conducting Mixed Methods Research. 3rd ed. Thousand Oaks: SAGE; 2018.
- 31. Creswell JW, Plano Clark VL. Designing and Conducting Mixed Methods Research. Thousand Oaks, Calif.: SAGE; 2011.
- 32. Patton MQ. Qualitative Research and Evaluation Methods. 3rd ed. Thousand Oaks: SAGE; 2002.
- 33. Goodman E, Kuniavsky M, Moed A. Observing the User Experience: A Practitioner's Guide to User Research. 2nd ed. Amsterdam: Morgan Kaufmann Elsevier; 2012.
- 34. Greenbaum TL. The Handbook for Focus Group Research. 2nd ed. Thousand Oaks: SAGE; 1997.
- 35. Morgan D. Focus Groups as Qualitative Research. Thousand Oaks: SAGE; 1997.
- 36. Collins D. Pretesting survey instruments: an overview of cognitive methods. Qual Life Res. 2003;12(3):229-238. doi:10.1023/A:1023254226592
- 37. Dillman DA. Mail and Telephone Surveys: The Total Design Method.: A Wiley-Interscience Publication. New York: Wiley; 1978.
- Kuckartz U. Qualitative Inhaltsanalyse: Methoden, Praxis, Computerunterstützung [Qualitative Content Analysis: Methods, Practice, Software Support]. 3rd ed. Weinheim/Basel: Beltz Juventa; 2016.
- 39. Cohen J. Statistical Power Analysis for the Behavioral Sciences. 2nd ed. Hillsdale, N.J.: L. Erlbaum Associates; 1988.
- 40. Moorcroft A, Scarinci N, Meyer C. 'We were just kind of handed it and then it was smoke bombed by everyone': how do external stakeholders contribute to parent rejection and the abandonment of AAC systems? *Int J Lang Commun Disord.* 2020;55(1):59–69. doi:10.1111/1460-6984.12502
- 41. Moorcroft A, Scarinci N, Meyer C. Speech pathologist perspectives on the acceptance versus rejection or abandonment of AAC systems for children with complex communication needs. *Augment Altern Commun.* 2019;35(3):3. doi:10.1080/07434618.2019.1609577
- 42. Zinkevich A, Lubasch JS, Uthoff SAK, et al. Caregiver burden and proxy-reported outcomes of people without natural speech: a cross-sectional survey study. *BMJ Open*. 2021;11(8):e048789. doi:10.1136/bmjopen-2021-048789
- 43. Giel B, Liehs A. "Moderierte Runde Tische" (MoRTi) in der Inklusion ["Moderated round tables" (MoRTi) in inclusive education]. *Sprachtherapie aktuell*. 2016;3(1):Articlee2016–04. doi:10.14620/stadbs160904
- 44. Shin D, Song J, Song S, Park J, Lee J, Jun S. TalkingBoogie: collaborative mobile AAC system for non-verbal children with developmental disabilities and their caregivers. Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems; 2020 Apr 25–30; Honolulu, HI, USA: Association for Computing Machinery; 2020: 1–13. DOI:10.1145/3313831.3376154.

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