University of Groningen

Effects of changes in life circumstances on interaction and communication in adults with congenital deafblindness and an intellectual disability

Bloeming-Wolbrink, Kitty A.; Janssen, Marleen J.; Ruijsenaars, Wied A. J. J. M.; Menke, Roelof; Riksen-Walraven, J. Marianne

Published in:
British Journal of Visual Impairment

DOI:
[10.1177/0264619614558429](https://doi.org/10.1177/0264619614558429)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2015

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Bloeming-Wolbrink, K. A., Janssen, M. J., Ruijsenaars, W. A. J. J. M., Menke, R., & Riksen-Walraven, J. M. (2015). Effects of changes in life circumstances on interaction and communication in adults with congenital deafblindness and an intellectual disability. *British Journal of Visual Impairment*, 33(1), 31-44. <https://doi.org/10.1177/0264619614558429>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

Effects of changes in life circumstances on interaction and communication in adults with congenital deafblindness and an intellectual disability

British Journal of Visual Impairment

2015, Vol. 33(1) 31–44

© The Author(s) 2014

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/0264619614558429

jvi.sagepub.com **Kitty A Bloeming-Wolbrink**

Royal Dutch Visio, The Netherlands; University of Groningen, The Netherlands

Marleen J Janssen

University of Groningen, The Netherlands; Royal Dutch Kentalis, The Netherlands

Wied AJJM Ruijsenaars

University of Groningen, The Netherlands

Roelof Menke

Royal Dutch Visio, The Netherlands

J Marianne Riksen-Walraven

Radboud University Nijmegen, The Netherlands

Abstract

This study examined the effects of the first 2 years of the ongoing Project CHANGE, aimed at improving interaction and communication in adults with congenital deafblindness (CDB) and an intellectual disability (ID). Six adults with no history of deafblind education participated in this study. These first 2 years of CHANGE involved an improvement in living conditions, including a transition to a new group home and interactions with specialized caregivers. Video recordings and file information were used to measure interaction and communication during baseline (T0) and two subsequent periods (T1 and T2). The results show an improvement in interaction: attention by the caregiver, confirmation by the caregiver, and affective involvement all improved. An improvement was also shown in the participants' level of expressive communication and in the

Corresponding author:

Kitty A Bloeming-Wolbrink, Royal Dutch Visio, Rijksstraatweg 61, 9752 AC Haren, The Netherlands.

Email: KittyBloeming@visio.org

variety of their communicative behaviors. The improvements over time emphasize the need for a specific approach for persons with CDB and an ID.

Keywords

Adults, communication, congenital deafblindness, intellectual disability, interaction

Introduction

Frequent and affectively pleasant interaction with others is essential for satisfying the fundamental and pervasive human need to belong (Baumeister & Leary, 1995), for quality of life (Prain, McVilly, & Ramcharan, 2012b), and for development (Dammeyer, 2010). Empirical research has shown that such interaction fosters well-being and improves the functioning of persons of all ages (Diamond & Aspinwall, 2003; Sroufe, 1995; Trevarthen & Aitken, 2001). However, establishing harmonious social interactions and subsequent communication is challenging for persons with congenital deafblindness (CDB) and their communication partners (Bruce, 2005; Dalby et al., 2009; Damen, Janssen, Huisman, Ruijsenaars, & Schuengel, 2014; Dammeyer, 2010; Hart, 2010; Martens, Janssen, Ruijsenaars, & Riksen-Walraven, 2014). Both the persons with CDB and the communication partners lack skills for establishing interpersonal contact and for exchanging thoughts and emotions (Martens et al., 2014). The interactive and communicative signals given by persons with deafblindness are often hard to interpret and unfold at a slow pace (Janssen, Riksen-Walraven, & Van Dijk, 2003a). Communication is complicated further if someone has both a sensory and an intellectual disability (ID) (Evenhuis, Sjoukes, Koot, & Kooijman, 2009).

Here, interaction is defined as the process in which two individuals mutually influence each other's behavior (Bjerkman, 1996; Janssen, Riksen-Walraven, & Van Dijk, 2003b). Communication is defined as a more complex form of interaction, with meaning being transmitted by expressions that are perceived and interpreted by the communication partner (Janssen et al., 2003b). Information is conveyed to others, and information from others is received and interpreted (Rowland, 2009). For persons with CDB and an ID, specialized knowledge and training of communication partners is needed to realize harmonious interactions and communication.

In the Netherlands, many adults with CDB live in group homes for persons with an ID. Adults with CDB living in settings for persons with an ID often have little experience with harmonious interactions. Often, staff has no special knowledge of sensory impairments.

Persons with deafblindness need highly specialized care and rehabilitation to stimulate communication and development. A clearly structured environment, individual programs to enhance communication, and predictability of activities of daily life are some recommendations from the literature (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Fellingner, Holzinger, Dirmhirn, & Goldberg, 2009). In a world that emphasizes sight and hearing, persons with CDB miss out on incidental learning opportunities (Bruce, 2002; Bruce, Godbold, & Naponelli-Gold, 2004; McInnes, 1999). When no special attention is given to the deafblindness, this may result in, for example, a limited development and deviant behavior. Several authors even mention the risk of an incorrect ID diagnosis in the case of deafblindness (McInnes, 1999; Narayan & Bruce, 2006).

As earlier studies have shown, interaction with children with deafblindness or adults with intellectual and visual disabilities can be improved by training their communication partners (e.g. Damen, Kef, Worm, Janssen, & Schuengel, 2011; Janssen et al., 2003a). The aim of this study was to examine whether an improvement in living conditions, including interactions with specialized

and trained communication partners, can improve interaction and communication in adults with CDB and an ID who have never received deafblind education.

The participants in this study underwent a pervasive change in living conditions and social experiences, which we labeled “Project CHANGE.” Here, the effects of the first 2 years of the project were examined. The 2-year period started with the participants moving from group homes for persons with a visual disability and an ID to a group home for persons with CDB and an ID, in which communication partners (caregivers) were specially trained. The relevant changes are described in more detail in section “Methods”. The expectation was that the changes would lead to increased opportunities for experiencing harmonious interactions and that this would bring about an improvement in the interaction and communication between the participants and their communication partners.

This study is the first to examine the effects of a pervasive change in both living conditions and social experiences in adults with CDB and an ID on interaction and communication.

Methods

Participants and setting

The study was conducted at a setting for persons with intellectual and sensory disabilities in the Netherlands. Six adults with CDB and an ID participated in the study: four males and two females. Their average starting age was 42 years, ranging from 37 to 48 years of age. The degree of intellectual and sensory disability, and the interaction and communication strategies used, varied. Table 1 provides an overview of relevant participant characteristics. None of the participants received deafblind education before or was educated with a consistent approach geared at persons with CDB.

The study was approved by the board of the residential setting. Informed consent was obtained from the participants’ legal representatives. To protect the participants’ identities, fictitious names are used in this article.

Project CHANGE

Project CHANGE began with the transition of the participants from a group home with four to seven residents with a visual disability and an ID to a twin house with eight residents with CDB and an ID, divided into two groups of four residents. During most of the day, the staff–client ratio was 1:2. At the start of the project, the staff comprised 15 caregivers, two educational psychologists, and a coordinator. One participant (Harold) knew none of the caregivers at the new setting. Four participants (Richard, George, Tina, and Romy) were acquainted with one of the caregivers. The sixth participant (Charles) knew two of the caregivers. Both the caregivers and the coordinator interacted directly with the participants. The daily care and activities were offered by the same caregivers. The caregivers, both before and after the transition of the participants, differed with regard to their age, educational background, and the years of working experience. All of them were qualified for working in care settings and had some experience in working with persons with an ID and a visual disability.

Prior to the participants’ move to the new group home, all staff were trained to adjust their approach to the specific needs of the participants. They followed a 4-day training course on interaction and communication, consisting of, among others, a brief introduction on the basic principles of interaction with persons with CDB, information on normal language development and language development in persons with CDB, individual communication plans, and on bodily contact. This training was provided by two specialists from a center of expertise on deafblindness, one of them

Table 1. Participant characteristics at the start of the study.

Participant	Age (years)	SRZ score ^a	Interaction and communication ^b	Visual disability ^c	Hearing disability ^d
Richard	39	4	Interaction categories attention, confirmation, affective involvement; objects of reference; tactile signs (after 9-month extension of number of tactile signs)	Blind	Profound hearing loss
George	48	4	Interaction categories attention, confirmation, affective involvement; objects of reference; tactile signs (after 9-month extension of number of tactile signs)	Blind	Profound hearing loss
Tina	37	4	Interaction categories attention, confirmation, affective involvement; objects of reference	Totally blind	Moderate/severe hearing loss
Harold	37	4	Interaction categories attention, confirmation, affective involvement; objects of reference; tactile signs (after 9-month extension of number of tactile signs)	Totally blind	Hearing loss; unclear whether there is residual hearing
Romy	48	4	Interaction categories attention, confirmation, affective involvement	Blind	Severe hearing loss
Charles	40	3	Interaction categories attention, confirmation, affective involvement; objects of reference (after a year)	Blind	Profound hearing loss

^aA social competence SRZ score of 3 or 4 is appropriate in case of a profound intellectual disability (Kraijer, Kema, & De Bildt, 2004).

^bInteraction and communication from the moment of the transition to the new group home.

^cTotally blind: no light perception; blind: blind with light perception.

^dModerate hearing loss: 41–60 dB; severe hearing loss: 61–80 dB; profound hearing loss: ≥81 dB.

being the second author. Information about the exact content of the training is available from the first author. In addition, the educational psychologists and the coordinator followed a 2-day training in video analysis, preparing them for on-the-job coaching of the caregivers. Ten months after the start of the project, they had a follow-up training. Nine months after the move, all staff received a half-day of instruction on tactile sign language.

Starting after the transition and continuing for 2.2 years, caregivers were coached on-the-job individually by the coordinator, and caregivers and the coordinator were coached individually using video analysis by the educational psychologists. Both forms of individual coaching were offered multiple times a week. The number of individual coaching sessions caregivers had per month was dependent on their working schedule. Once a month, video analysis was done with the whole team. A video was reviewed by the team, reflections were made, and new ways of doing things were suggested. The main focus in all coaching was on developing the interaction skills of the caregivers and on recognizing the expressions of the participants.

General procedure

Interaction and communication were measured using video recordings and file information during three periods: T0 was the 13-month baseline period before the transition. T1 and T2 were 6-month periods starting 3 and 20 months after the move, respectively. Figure 1 gives a timeline of the different events.

Figure 1. Timeline.

Measures

Interaction

Video recordings. Video recordings were regularly made to gain insight into the daily life of the participants. The number and duration of the recordings were among others dependent on the variety of activities, also including interactive and communicative situations. To examine the effects of Project CHANGE on interaction, 5-min video fragments were selected for T0, T1, and T2. For the sake of comparability within and between participants, we selected video fragments recorded in the same situation, that is, meals. Meals were chosen because they were fixed moments in the daily schedule for all participants, during which there had to be contact between participant and caregiver. Before and shortly after the transition of the participants, contacts between participants and caregivers were often rare in other situations, due to, for example, lack of time and many practical tasks for the caregivers during this period.

Because of this choice for the meal situation, at T2 a fragment could be selected for only three out of six participants. For Harold, we had to use a fragment for T1 that fell shortly outside the T1 period. Because no major interventions have been done since T1, the expectation is that this will not influence the outcomes. It should also be noted that it was not per definition with the same caregiver with whom the participants were observed during the meals at T0, T1, and T2. For that reason, we could not examine the role of individual caregiver characteristics in the change of participant–caregiver interaction over time.

Interaction categories. The following four categories of interactive behavior (adopted from Jansen et al., 2003b) were used to measure the quality of interactions:

- 1a. Attention by the caregiver: focus on the interaction partner, content of the interaction, people, or objects within the interaction context, for example, looking in the direction of the participant.
- 1b. Attention by the participant: see definition 1a, for example, establishing physical contact with the caregiver.
2. Confirmation by the caregiver: clear acknowledgment that an initiative has been noticed and recognized, for example, by repeating the initiative of the participant in a way the participant can perceive.
3. Affective involvement: mutual sharing of emotions between caregiver and participant, for example, laughing together, in a way the participant can perceive.

Observation procedure and scoring. Each video was coded independently by two observers on a specially designed observation form. Samples of 10-sec intervals were used. Per interval, attention by the participant, confirmation by the caregiver, and affective involvement were coded 1 if observed at least once and coded 0 if not observed. Attention by the caregiver was coded 1 if observed during the main part of the interval and otherwise coded 0. For each category, an interval was excluded from coding if the information needed was lacking (e.g. if the caregiver was not visible, attention could not be observed). An overall score, reflecting the occurrence of a certain behavior in the 5-min episode, was calculated as the percentage of coded 10-sec intervals during which that behavior was observed.

Three trained observers, bachelor's students in special needs education, coded the videos. To control for observer drift, the videos were presented at random to the observers. Definitions of the categories were read prior to each observation session.

Table 2. Protocol for completing the Communication Matrix retrospectively (Bloeming-Wolbrink, Van den Bovenkamp, & Janssen, 2010).

Step	Description
1	Get familiar with the Communication Matrix. This includes the definitions of the four communicative functions, the seven levels of communication, and the communication skills.
2	Gather all files and video recordings for a specific research period.
3	Examine all files kept by the setting for information on communication skills. If a communication skill is identified, allocate it to a function (refuse, obtain, social interactions, or provide or seek information) and a level. Fill in the Communication Matrix, and note from which part of the files the information was extracted.
4	Examine the video recordings and identify communication skills of the participant. If a communication skill is identified, allocate it to a function (refuse, obtain, social interactions, or provide or seek information) and a level. Fill in the Communication Matrix. Note all necessary characteristics to locate the specific fragment in which the communication skill was displayed.
5	Repeat steps 2, 3, and 4 for each research period so that matrices for all research periods are completed.

Inter-rater reliability. Prior to the formal data collection, the observers were trained with the intention of reaching 80% inter-rater reliability for the occurrence of the interactive behaviors for three training videos per participant. The training videos were not used for the actual coding.

Following Prain, McVilly, and Ramcharan (2012a), inter-rater reliability for the actual research recordings was calculated in two ways. The percentage agreement across measurements and participants was calculated by dividing the number of agreements on occurrences and non-occurrences by the total number of agreements and disagreements, and multiplying the resultant number by 100. The results were good: 99.1% for confirmation by caregiver and affective involvement, 94.7% for attention by caregiver, and 91.0% for attention by participant. The Kappa inter-rater reliability coefficient was also good: .85 for affective involvement, .85 for attention by caregiver, .83 for confirmation by caregiver, and .81 for attention by participant.

Communication

Communication Matrix. To assess the expressive communication skills of the participants, an adapted version of the Communication Matrix of Rowland (2004) was used. Table 2 presents the protocol for this adapted version.

The Communication Matrix is suitable for assessing adults, even if they are deafblind, and can be completed using observation (Rowland, 2009). The Communication Matrix distinguishes four communicative functions (*refuse, obtain, social interactions, and provide or seek information*) and seven levels of communication for each of the functions, ranging from *pre-intentional behavior* (0–3 months in the normal population) to *language* (24+ months) (Rowland, 2011; Rowland & Fried-Oken, 2010). Each separate function can be expressed by someone on more than one level of communication. The method yields a differentiated profile of the person assessed, representing both the level and the variety of expressive communication skills for all four communicative functions.

In addition to the level and function of the various communication skills, the matrix differentiates between emerging and mastered communicative skills, as testified by, among others, the variety of contexts in which a skill is witnessed (Rowland & Fried-Oken, 2010). This differentiation was not included in the adapted version used here.

Table 3. Occurrence (%) of the interaction categories at T0, T1, and T2 for the six participants.

Participant	Attention by caregiver			Attention by participant			Confirmation by caregiver			Affective involvement		
	T0	T1	T2	T0	T1	T2	T0	T1	T2	T0	T1	T2
Richard	0	67.9	67.9	53.3	63.3	78.6	0	0	0	0	0	0
George	46.7	100	90	93.1	60	53.3	0	10	16.7	0	16.7	23.3
Tina	95.2	60	100	78.6	56.7	66.7	0	0	0	0	0	0
Harold	51.7	75.9	— ^a	33.3	63.3	—	0	3.3	—	0	0	—
Romy	92.3	96.2	—	40	46.7	—	0	0	—	0	0	—
Charles	79.2	100	—	83.3	66.7	—	0	10	—	0	10	—

^aNo relevant data available in this research period.

Observation procedure and scoring. The Communication Matrix was completed retrospectively following the protocol presented in Table 2. It was completed separately for T0, T1, and T2, on the basis of videos and file information on communication. The videos contained a variety of situations which included communication, like meals and day activities. File information consisted of (1) a profile of communication, containing information about the participants’ communication toward the caregivers, as well as the caregivers’ communication toward the participants; (2) an Individual Support Plan with relevant information about the participant, like vision, hearing, ID, additional disabilities such as epilepsy, and aims for support; (3) a multidisciplinary report, containing the most important information from the previous year; and (4) information from observation scales, like the Social Competence Scale (SRZ) (Kraijer et al., 2004) (included in Table 1). The communication skills observed at T0 and T1 were included in the scores for subsequent periods, on the assumption (from clinical experience) that expressive communication skills are stable over time.

For each participant, both the level and variety of expressive communication skills were assessed. The highest level of communication was represented in scores for T0, T1, and T2 and for the increase from T0 to T2. One score was assigned for each separate communicative function (*refuse, obtain, social interactions, and provide or seek information*).

The Communication Matrix distinguishes 80 communication skills across levels and functions. The variety of communication skills was calculated by assigning 1 point per communication skill, with a maximum of 80 points. The percent equivalent was calculated by dividing the total number of points by the maximum number of points (80), and multiplying the resultant number by 100. Improvement in variety of communication from T0 to T2 was expressed as a percentage gain score, which was calculated by dividing T2 – T0 by the T0 score, multiplied by 100 (Rowland & Schweigert, 2005).

Inter-rater reliability. A master’s student in special needs education completed the Communication Matrices after receiving instructions from the first author, who also corrected the matrices.

Results

Interaction

Table 3 summarizes the occurrence of the interaction categories at T0, T1, and T2 for all six participants.

Table 4. Level of communication for the functions refuse, obtain, and social interactions at T0, T1, and T2 for the six participants.

		T0	T1	T2	Gain T0–T2 ^a
Richard	Refuse	IV	IV	IV	0
	Obtain	IV	VI	VI	2
	Social	III	III	III	0
George	Refuse	III	III	III	0
	Obtain	I	III	III	2
	Social	II	II	III	I
Tina	Refuse	III	III	III	0
	Obtain	II	III	III	I
	Social	III	III	III	0
Harold	Refuse	II	II	II	0
	Obtain	IV	VI	VI	2
	Social	III	III	III	0
Romy	Refuse	III	IV	IV	I
	Obtain	III	III	III	0
	Social	III	III	III	0
Charles	Refuse	II	III	III	I
	Obtain	II	II	II	0
	Social	II	II	II	0

^aGain score represents the increase in levels from T0 to T2.

Attention by caregiver. The occurrence of attention by the caregiver had improved at T1 as compared to T0 for five participants; for Tina it decreased. At T2, the occurrence of attention by caregiver was higher as compared to T0 for Richard, George, and Tina.

Attention by participant. Comparison of the occurrence of attention by the participant at T1 versus T0 yields an inconsistent picture: an improvement for Richard, Harold, and Romy, but a decrease for the others. The results at T2 are inconsistent as well: an improvement for Richard and a decrease for Tina and George when compared to T0.

Confirmation by caregiver. Confirmation by the caregiver did not occur for any of the participants at T0. At T1, confirmation occurred for George, Harold, and Charles. At T2, confirmation further improved only for George. No confirmation was observed for Richard and Tina at T2.

Affective involvement. Affective involvement did not occur at T0 for any of the participants, but at T1 it occurred for George and Charles. At T2, affective involvement was still higher as compared to T0 for George. No affective involvement occurred at T2 for Richard or Tina.

Communication

Table 4 presents the highest level of communication by the six participants for the functions *refuse*, *obtain*, and *social interactions* at T0, T1, and T2, as well as the increase in levels from T0 to T2. The communicative function *provide or seek information* did not occur.

Two participants, Romy and Charles, showed a higher level of communication at T2 compared to T0 for the function *refuse*. The other four participants obtained a higher level of communication

Table 5. Variety in communication skills (%)^a at T0, T1, and T2 for the six participants.

Participant	T0	T1	T2	% Gain T0–T2 ^b
Richard	18.8	21.3	23.8	26.7
George	7.5	11.3	13.8	83.3
Tina	11.3	12.5	13.8	22.2
Harold	15	16.3	17.5	16.7
Romy	10	11.3	11.3	12.5
Charles	8.8	10	10	14.3

^aComputed as the total number of points (1 point for each communication skill possessed) divided by the maximum number of points (80), and multiplying the resultant number by 100.

^bComputed as T2 – T0 divided by T0, multiplied by 100.

at T2 for the function *obtain*. For George, the level of communication at T2 was higher than at T0 for the function *social interactions*. The level of communication increased for all participants in at least one communicative function.

Table 5 presents the variety of communication skills assessed at T0, T1, and T2 for all participants and the percentage gain from T0 to T2.

The variety of communication skills (a percentage score) improved for all participants. The gain ranged from 12.5% to 83.3%. This means that the number of communication skills the participants possess increased, regardless of the level and function of communication. Tina, for instance, possessed no communication skills for the function *obtain* at level 3 at T0, one (requests more object) at T1, and another one (requests new object) at T2. At T1, she asked for the next piece of bread by holding up her hand. At T2, she asked for a drink by holding her hand in the position for drinking, while eating porridge. George possessed the communication skills belonging to levels 1 and 2 of the Communication Matrix for the function *social interactions* at T0 and T1. At T2, he had acquired a communication skill at level 3 for this function, “shows affection.” This meant that George “expressed interest in other people” at T0, for example, by touching the caregiver during shaving. At T2, he “showed affection,” for example, by sitting next to the caregiver while smiling.

Discussion

This study examined the effects of the first 2 years of participation in Project CHANGE on the interaction between participants with CDB and an ID and their caregivers and on the participants’ expressive communication skills. In the first 2 years of project CHANGE, the participants underwent a pervasive change in living conditions and social experiences, starting with a transition to a new group home. Here, they came to live with other persons with deafblindness. Staff was trained and coached in offering the specialized care needed to the participants. The environment was clearly structured, individual programs to enhance communication were followed, and activities of daily life were made predictable, following recommendations from the literature (Evenhuis et al., 2001; Fellingner et al., 2009). Overall, the conclusion is that the changes have resulted in an improvement in interaction and communication. Positive results are found in the occurrence of attention by caregiver, confirmation by caregiver, and affective involvement, as well as in the level of expressive communication on three functions of communication and in the variety of communication skills across levels and functions possessed by the participant. The results for attention by participant, however, are not clear.

Attention by the caregiver is part of, but also a prerequisite for, harmonious interactions with persons with CDB and an ID. The improvement in attention has probably laid the foundation for

further harmonious interactions. Confirmation by the caregiver is also an important ingredient of harmonious interactions. The confirmation that an initiative has been noticed and recognized does not come naturally in interaction with persons with CDB and an ID. The highly insufficient confirmation by the caregiver at T0 emphasizes the need for special training or coaching. Such training and coaching can indeed be effective, as demonstrated by the occurrence of confirmation by the caregiver for George, Harold, and Charles at T1 and for George at T2. The same can be said for affective involvement or the mutual sharing of emotions. Affective involvement was lacking entirely at T0, which stresses the need for special training aimed at fostering this important aspect and outcome of harmonious interaction. Again, after training and coaching (T1), affective involvement did occur for George and Charles. At T2, affective involvement occurred for George.

The varying results for attention given by the participant are puzzling, possibly because the improved attention by the caregiver resulted in their being more observant of the participants' signals. If a caregiver observes the person with CDB and an ID regulating intensity, and respects this, the attention paid by the participant might wane. In this study, regulation of intensity was not included as a variable. Because we found no prior studies that report on this relationship, we cannot draw any conclusions about this here. Research on the relationship between the attention by the caregiver and regulation of intensity by the person with CDB and an ID is much needed.

Expressive communication skills of the participants also improved, both in the level of communication for the functions *refuse*, *obtain*, and *social interactions*, and in the variety of communicative behaviors. It implies that the participants learned to express themselves better, having a broader range of communicative behaviors at their command, and achieving a higher level of communication. The communicative function *provide* or *seek information* did not occur in this study. It might be that more attention for this function is needed in training and coaching for developing this function (Damen et al., 2014), but in this study this was not the aim.

As stated in "Introduction" section, harmonious interaction is important for the well-being and functioning of persons of all ages (Diamond & Aspinwall, 2003; Sroufe, 1995; Trevarthen & Aitken, 2001) and is essential for satisfying the human need to belong (Baumeister & Leary, 1995), quality of life (Prain et al., 2012b), and development (Dammeyer, 2010). Our study shows improved interaction and communication with persons with CDB and an ID in adulthood, even when no special attention was given to the deafblindness in their youth, which is a promising result for all persons with CDB and an ID living in similar settings. It is recommended to teach professionals on deafblindness and its consequences for daily life. A second recommendation is to make regular use of video analysis to improve the interaction skills of caregivers and to recognize and interpret interactive and communicative expressions of the persons with CDB and an ID.

Limitations and directions for future research

The first 2 years of Project CHANGE included many changes for the participants (new home, smaller living group, new approach). Our results suggest that these changes have led to an improvement in the interaction and communication (which we used as outcome measures). It may be assumed that the interaction training for the caregivers has contributed most to this effect, but it cannot be excluded that other changes in living conditions have also contributed, for example, by improving the mood of the participants, which, in turn, may have made it more easy to establish interaction and communication. Given that we focused specifically on the effects of CHANGE on interaction and communication and did not include other outcome measures, we cannot draw any valid conclusions regarding the possible effect of other changes in living conditions beyond the interaction training.

The video recordings used to observe interaction were selected to include comparable situations at the different time periods for each participant. However, different caregivers were included in the videos, which may have influenced the results, as interaction and communication skills, age, level of education, and years of experience will vary between caregivers. Since different caregivers were observed while interacting with the participants at T0, T1, and T2, it was not possible to control for caregiver characteristics in this study; only the effects across caregivers could be examined. For future studies examining participant–caregiver interactions over time, however, we recommend to examine the role of caregiver characteristics. It would be interesting, for example, to examine the role of the length of the relationship between participant and caregiver in interventions to improve interaction and communication.

An evaluation of the caregiver's perception and professional development is lacking in this study. Since this could have added important information, our recommendation for future studies is to include a systematic evaluation by the caregivers.

Measuring communication retrospectively has its limitations. The results are confined to communicative behaviors recorded on videos or in files: greater variety of communicative behaviors or a higher level of communication might well be witnessed in everyday life. Besides that, the participants' files contained mainly general information. This made it difficult to allocate the information to the specific communicative behaviors in the Communication Matrix.

As this study underlines, adults with CDB and an ID do require a special approach when it comes to interaction and communication. The average age of the participants was 42 years, and they had never been offered an approach designed to meet their specific combination of disabilities. Far into adulthood, they entered the Project CHANGE, specially designed to improve their interaction and communication. The results show that a tailored approach can be fruitful, regardless of their age. It is remarkable that the observed improvements already took place during the first 2 years, with minimal training and on-the-job coaching of the involved staff.

After the first 2 years, Project CHANGE has continued, with more specific training and on-the-job coaching being provided to caregivers. Future research will show whether this has led to further improvements in interaction and communication in persons with CDB and an ID.

Acknowledgements

We would like to acknowledge the contributions of Lisanne van den Bovenkamp, Bianca Wiegers, and staff and clients of Royal Dutch Visio, The Netherlands. We would also like to acknowledge the contributions of Yvonne Okken, Fardau Jansma, Christianne Wester, and Selma Sjuts of the University of Groningen, Department of Special Needs Education and Youth Care, The Netherlands.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This research was funded by Royal Dutch Visio, and by the University of Groningen, Department of Special Needs Education and Youth Care.

References

- Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117, 497–529.
- Bjerkman, B. (1996). When do congenital deafblinds communicate? On the distinction between communication and other types of social contact. In M. Laurent (Ed.), *Communication and congenital deafblindness*:

- The development of communication. What is new?* (pp. 179–194). Suresnes, France: Centre national de Suresnes.
- Bloeming-Wolbrink, K. A., Van den Bovenkamp, L., & Janssen, M. J. (2010). *Protocol for completion of the Communication Matrix in retrospect*. Vries, The Netherlands: Royal Dutch Visio.
- Bruce, S. M. (2002). Impact of a communication intervention model on teachers' practice with children who are congenitally deafblind. *Journal of Visual Impairment & Blindness*, 96, 154–168.
- Bruce, S. M. (2005). The impact of congenital deafblindness on the struggle to symbolism. *International Journal of Disability, Development and Education*, 52, 233–251.
- Bruce, S. M., Godbold, E., & Naponelli-Gold, S. (2004). An analysis of communicative functions of teachers and their students who are congenitally deafblind. *RE:view*, 36, 81–90.
- Dalby, D. M., Hirdes, J. P., Stolee, P., Strong, J., Poss, J., Tjam, E. Y., & Ashworth, M. (2009). Characteristics of individuals with congenital and acquired deaf-blindness. *Journal of Visual Impairment & Blindness*, 103, 93–102.
- Damen, S., Janssen, M. J., Huisman, M., Ruijsenaars, W. A. J. J. M., & Schuengel, C. (2014). Stimulating intersubjective communication in an adult with deafblindness: A single-case experiment. *Journal of Deaf Studies and Deaf Education*, 19, 366–384. DOI:10.1093/deafed/enu006.
- Damen, S., Kef, S., Worm, M., Janssen, M. J., & Schuengel, C. (2011). Effects of video-feedback interaction training for professional caregivers of children and adults with visual and intellectual disabilities. *Journal of Intellectual Disability Research*, 55, 581–595.
- Dammeyer, J. (2010). Interaction of dual sensory loss, cognitive function, and communication in people who are congenitally deaf-blind. *Journal of Visual Impairment & Blindness*, 104, 719–725.
- Diamond, L. M., & Aspinwall, L. G. (2003). Emotion regulation across the life span: An integrative perspective emphasizing self-regulation, positive affect, and dyadic processes. *Motivation and Emotion*, 27, 125–157.
- Evenhuis, H. M., Sjoukes, L., Koot, H. M., & Kooijman, A. C. (2009). Does visual impairment lead to additional disability in adults with intellectual disabilities? *Journal of Intellectual Disability Research*, 53, 19–28.
- Evenhuis, H. M., Theunissen, M., Denkers, I., Verschuure, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, 45, 457–464.
- Fellinger, J., Holzinger, D., Dirmhirn, J., & Goldberg, D. (2009). Failure to detect deafblindness in a population of people with intellectual disability. *Journal of Intellectual Disability Research*, 53, 874–881.
- Hart, P. (2010). *Moving beyond the common touchpoint: Discovering language with congenitally deafblind people* (Unpublished doctoral dissertation). University of Dundee, Scotland.
- Janssen, M. J., Riksen-Walraven, J. M., & Van Dijk, J. P. M. (2003a). Contact: Effects of an intervention program to foster harmonious interactions between deafblind children and their educators. *Journal of Visual Impairment & Blindness*, 97, 215–229.
- Janssen, M. J., Riksen-Walraven, J. M., & Van Dijk, J. P. M. (2003b). Toward a diagnostic intervention model for fostering harmonious interactions between deafblind children and their educators. *Journal of Visual Impairment & Blindness*, 97, 197–214.
- Kraijer, D. W., Kema, G. N., & De Bildt, A. A. (2004). SRZ, SRZ-i. *Sociale Redzaamheidsschalen*. Handleiding [Social Competency Scale. Manual]. Lisse, The Netherlands: Swets & Zeitlinger.
- Martens, M. A. W., Janssen, M. J., Ruijsenaars, W. A. J. J. M., & Riksen-Walraven, J. M. (2014). Introducing an intervention model for fostering affective involvement with persons who are congenitally deafblind. *Journal of Visual Impairment & Blindness*, 108, 29–41.
- McInnes, J. M. (1999). Deafblindness: A unique disability. In J. M. McInnes (Ed.), *A guide to planning and support for individuals who are deafblind* (pp. 3–33). Toronto, Ontario, Canada: University of Toronto Press.
- Narayan, J., & Bruce, S. M. (2006). Perceptions of teachers and parents on the cognitive functioning of children with severe mental disability and children with congenital deafblindness. *International Journal of Rehabilitation Research*, 29, 9–16.
- Prairie, M. I., McVilly, K. R., & Ramcharan, P. (2012a). Being reliable: Issues in determining the reliability and making sense of observations of adults with congenital deafblindness? *Journal of Intellectual Disability Research*, 56, 632–641.

- Prain, M. I., McVilly, K. R., & Ramcharan, P. (2012b). Interacting with adults with congenital deafblindness: The experience of disability support workers. *Journal of Intellectual & Developmental Disability*, 37, 27–34.
- Rowland, C. (2004). *Communication Matrix: A communication skill assessment*. Portland, OR: Oregon Institute on Disability & Development, Oregon Health & Science University.
- Rowland C. (Ed.). (2009). *Assessing communication and learning in young children who are deafblind or who have multiple disabilities* (Design to Learn Projects). Portland, OR: Oregon Health & Science University.
- Rowland, C. (2011). Using the Communication Matrix to assess expressive skills in early communicators. *Communication Disorders Quarterly*, 32, 190–201.
- Rowland, C., & Fried-Oken, M. (2010). Communication Matrix: A clinical and research assessment tool targeting children with severe communication disorders. *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach*, 3, 319–329.
- Rowland, C., & Schweigert, P. (2005). *Learning to learn: A systematic child-centered model skill development in young children who are deafblind* (Final report). Portland, OR: Oregon Institute on Disability & Development, Oregon Health: Science University.
- Sroufe, L. A. (1995). *Emotional development: The organization of emotional life in the early years*. Cambridge, UK: Cambridge University Press.
- Trevarthen, C., & Aitken, K. (2001). Infant intersubjectivity: Research, theory, and clinical applications. *Journal of Child Psychology and Psychiatry*, 42, 3–48.