IDENTIFYING EXPRESSIONS OF PLEASURE AND DISPLEASURE BY PERSONS WITH PROFOUND MULTIPLE DISABILITIES[1]

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Abstract

Background: The aim of this study was to explore a procedure for drafting individualised profiles of how people with profound multiple disabilities express pleasure and displeasure.
Method: There were six participants with profound multiple disabilities. The procedure involved an observational analysis of videotaped critical incidents by a researcher and a questionnaire for parents and support workers.
Results: The procedure is useful to make an individualised profile of the ways a person with profound multiple disabilities expresses his/her pleasure and displeasure. Despite the significant correlation between the parents, the support workers and the researcher, they still have complementing contributions to identify affective expressions. People with profound multiple disabilities especially use sounds and facial expressions to express pleasant and unpleasant emotions and positive or negative moods.
Conclusions: The procedure may be useful in services or schools to learn more about the affective communication of these people, to determine their specific interests and to evaluate the effects of living and support characteristics on their well-being.

Introduction

Quality of life is experienced when a person's needs and wants are met and when one has the opportunity to pursue life enrichment in major life settings (Schalock et al., 2002). A key facet of quality of life is subjective well-being that, according to Schalock and Felce (2004), includes two aspects: 'satisfaction' representing the global judgements about one's life and

'happiness' reflecting positive and negative affects of positive or negative emotions and moods. During the past decade several methods have been developed to evaluate life satisfaction and happiness. Since the person with a disability is considered to be the most important source of information concerning his own well-being, these methods typically involve self-reports (Cummins, 1997; Schalock et al., 2002). It is much more difficult however to determine the degree of happiness or satisfaction persons with profound multiple disabilities experience. Their profound intellectual disability, severe motor limitations and sensory impairments interfere with their cognitive and communicative abilities. Their communicative abilities are mostly situated at a pre- or proto-symbolic level, characterised by bodily and idiosyncratic expressions (Grove, Bunning, Porter & Olsson, 1999).

There is an ongoing search for methods that are suitable to study subjective well-being in people with profound multiple disabilities. Most frequently used are questionnaires or interviews of people that know the person well (Cummins, 1997; Schalock, 1996). Research however showed a lack of agreement between respondents when interpreting the affective communication of people with profound multiple disabilities (Hogg, Reeves, Roberts & Mudford, 2001). Other studies yield conflicting results when comparing proxy responses with self-reports from people with an intellectual disability. Some authors have reported little agreement between persons with an intellectual disability and proxies on questions regarding the quality of their life or support (Heal & Sigelman, 1996; Stancliffe, 2000); others have noted a greater concordance (McVilly, Burton-Smith & Davidson, 2000). The concurrence between subject and proxy ratings seems to be more of a problem in evaluations of emotional experiences and personal preferences, than for more objective issues (Perry & Felce, 2002).

In some recent studies intensive participatory observation of the person with profound multiple disabilities has been used in natural occuring situations (Lyons, 2003). Although it is very time-consuming, it seems to be a useful and valid method to discern the life satisfaction

of these persons. Other systematic observation procedures focusing on behavior states may also contribute to an improved understanding of the life experiences of individuals with complex needs (Arthur, 2004; Guess, Roberts & Rues, 2002). In the context of preference assessment, observations are made of elicited affective responses to different items or situations (Hagopian, Long & Rush, 2004; Hatton, 2004; Lancioni, O'Reilly & Emerson, 1996; Logan & Gast, 2001). Reid and Green (2002) found that ratings of preferences of people with profound multiple disabilities by proxies differed from the preferences that were identified by observation of indices of happiness/unhappiness in reaction to different stimuli.

As a result of methodological difficulties there is a lack of explicit knowledge about the way an individual with profound multiple disabilities expresses his feelings and preferences (Daelman, 2003; Roemer & Van Dam, 2004; Zijlstra, 2003). Caregivers gradually build up practical knowledge in recognizing and interpreting subtle behavioural signals. This knowledge however remains predominantly intuitive, fragmented and unused and ends up being lost when significant persons passes out of the client's life. The latter is often the case for professionals given the high staff turnover rates in services for this target group (Bradley, Taylor, Mulkern & Leff, 1997; Zijlstra, Vlaskamp & Buntinx, 2000). Consequently, the feelings and preferences of people with profound multiple disabilities often remain insufficiently known.

Another important issue is the question whether the expressions of pleasure and displeasure are affective rather than intentional communication. Criteria to define intentional communicative behaviour usually imply dyadic interaction (bodily proximity of the communication partners), purposiveness (expecting behavioural changes in the partner and expressing appreciation in attaining the goal) and directionality (directing behaviour to another person) (Warren, Yoder, Gazdag, Kyoungran & Jones, 1993). In her study of the communicative behaviour of four children with multiple disabilities Daelman (2003) found

that of the 819 instances of communicative behaviour that were noticed by the respondents, 51.5% could be classified as intentional based on the above mentioned criteria, 39.2% as not-intentional and 9.3% as doubtful intentional. The presupposition that persons with profound multiple disabilities are potentially able to make known their inner states of emotions and feelings, albeit unconventionally, is supported by several researchers (Green & Reid, 1996; Lyons, 2003). It is a continuous challenge for those working with these people to interprete the meaning of their affective expressions, including happiness and preferences, in an adequate and consistent way. The transition to intentional communication may be supported by consistently overinterpreting the client's behaviour as if it were intentional, by negotiating and taking turns on spontaneous gestures that arise in predictable daily routines and by referring to a certain blended (bodily, emotional, cognitive) impression that the person had earlier (Daelman, 2003; Nafstad & Rødbroe, 1999; Rødbroe & Souriau, 1999). This process requires intensive dyadic interactions including active participation and emotional involvement of the person with profound multiple disabilities (Arthur, Butterfield & Sigafoos, 1995; Nind & Hewett, 2001).

In this study we wanted to explore a procedure to develop an individualised profile of the ways a person with profound multiple disabilities expresses pleasure and displeasure. The procedure involves different methods and different sources of information. Two research questions relate to the value and the usefulness of the procedure, the third refers to the content of the individualised profiles:

1. Does the procedure yield meaningful, useful and sufficiently differentiated information?
2. To what degree do different respondents agree on the expressions of pleasure and displeasure?
3. How do people with profound multiple disabilities express their pleasure and displeasure?

Method

Participants

For the selection of our participants, we started from a professional expert group. In this group 20 staff members, that are working in day care centres, community based services and residential institutions for persons with profound multiple disabilities, are meeting regularly to discuss different topics concerning quality of life and quality of support of the target group. Six of them agreed to cooperate. They selected at random one participant in the service where they are working. The only criterium was that the participant did not use words or conventional sign codes to express his/her feelings or preferences. The total number of potential participants in these services ranged from 8 till 72. Each service followed the rules regarding the protection of the privacy of the clients during the selection and research process. Consent for participating in the research process and the video-registration was asked from the legal guardian of the person with profound multiple disabilities. Formal ethics approval was not requested as it was not enforced by national law at the moment we conducted the study.

The table gives an overview of characteristics of the participants.

Insert table 1

All participants have a profound intellectual disability as well as severe motor and/or sensory limitations. These are associated with several medical problems. They are all non-ambulatory, mostly because of a spastic quadri- or tetraplegia. They are functioning on a pre- or protosymbolic communicative level. The level of communicative functioning was established on the basis of an assessment by a speech therapist working at the residential service or the

day care centre that the participants attend. They are dependent on support workers for all basic needs. Ages ranged from 8 years to 29 years. Parents are in all cases still very much involved with their child. Three participants are taken care of in a residential service during the week, three others are living at home and attend a day care centre. In Flanders children with profound multiple disabilities may be exempted from schooling. In this case they are offered adapted activities in a day care centre. If children with profound multiple disabilities in Flanders attend a school, then it concerns nearly always a school for special education.

Procedure and data-gathering

For each participant we have collected two sorts of data. First of all we asked for video-samples of four critical incidents where the person expresses pleasure and four critical incidents where the person expresses displeasure. We defined a critical incident as 'a situation that is typical for the person and that clearly shows that the person experiences pleasant emotions and positive moods or unpleasant emotions and negative moods' (after Diener, 2000, p.34). The video-samples were selected by a member of the staff. They lasted two minutes and were taken from situations that were as diverse as possible (e.g. bathing, eating and doing activities).

Next, a short questionnaire was composed asking parents and direct support workers separately to indicate from a list of 14 behavioural categories (see table 2) five categories the person uses most frequently to make clear that he/she experiences pleasant emotions and positive moods and five categories the person uses most frequently to make clear that he/she experiences unpleasant emotions and negative moods. These selected behavioural categories had to be arranged in order of frequency for that particular individual.

Analysis

In the questionnaires, as well as in coding the critical incidents, we used a taxonomy of 14 behavioural categories. We started from the taxonomy of Van der Maat (1992) which is based on an extensive analysis of the communication of people with profound intellectual disabilities with their usual caregivers. This taxonomy included ten main categories of behavioural form: (1) gaze direction, (2) facial expression, (3) sounds, (4) head posture, (5) head movement, (6) body posture, (7) movement of lower limbs, (8) movement of upper limbs, (9) mouth movements and (10) physiological reactions. The agreement between respondents in using the taxonomy was 96% (Van der Maat, 1992). In the study of Daelman (2003) that used a sligthly modified version of this taxonomy a high interrater agreement was found with a kappa coefficient of .90. We made some small adjustments to this taxonomy. First of all we differentiated the broad category of movements of the upper limbs: towards the person himself (8a), an object (8b) or a person (8c). Two behavioural categories were added because recent research (Daelman, 2003) has demonstrated that they may be useful for persons with multiple disabilities: (11) aggression and (12) conventional gestures. The operational description with some behavioural operationalizations of each category is given in table 2.

Insert table 2

The video-samples of the critical incidents were arranged in time-intervals of 30 seconds, resulting in each case in 16 intervals for pleasure and 16 intervals for displeasure. Each time interval contained exclusively an instance with signals indicating pleasure or an instance with signals indicating displeasure. Per time interval the researcher coded all behavioural signals indicating to him pleasure or displeasure of the person. In the context of

our study 25% of the raw material which was randomly selected, was double (blind) coded. Per time interval the behavioural signals that were coded by each rater were compared. The interrater agreement was relatively high, with a weighted kappa-coëfficient of .70.

For each participant we have listed the top five of behavioural categories by which he/she most frequently expresses pleasure and displeasure according to each respondent (parent – support worker – researcher). The top five of behavioural categories as given by the parent and the support worker were taken from the questionnaires. To calculate the top five according to the researcher, we performed a frequency count of the coded behavioural signals for a participant across all time intervals. The behavioural category that occured most frequently, got the ranking of five, the second most frequently four and so on. Finally, we have calculated the Spearman ranking correlations between pairs of respondents.

Results

Research question 1

First we have drafted an individual profile of the ways each participant expresses his/her pleasure and displeasure. In the following graphs this is illustrated for two of the participants, one child and one adult.

Insert figure 1 – 4

The height of the bar is defined by the sum of the ranking numbers given by each of the three respondents for that particular behavioural expression (5 = most frequent). From such a profile one can deduce the behavioural expressions the participant frequently presents, according to one, two or three respondents and the behavioural expressions this participant

does not present according to the different respondents. One can also see whether the person exhibits a limited number of behavioural expressions in a high frequency or a lot of behavioural expressions in a moderate or low frequency.

For *participant two* for example it becomes clear that she expresses pleasure as well as displeasure especially by sounds and facial expressions. Body posture and head movements are mentioned by two or three respondents as indices of pleasure and displeasure. Movement of the lower limbs is only seen as an expression of pleasure, agressive reactions only as an expression of displeasure. Some behavioural expressions are indicated by only one respondent: mouth movements and movements of the lower limbs as indices of pleasure and gaze direction and movement of the upper limbs to herself as indices of displeasure.

The individual profile of *participant three* is quite different. Most frequently used expressions of pleasure are facial expressions, followed by four almost equivalent categories, namely sounds, head movements, movements of the upper limbs towards herself and mouth movements. Body posture and physiological reactions are mentioned by just one respondent as an expression of positive affect. Displeasure is expressed most frequently by physiological reactions and facial expressions and also by sounds, body posture and mouth movements. These behavioural expressions are all mentioned by at least two respondents.

When comparing the individual profiles of the six participants, we see similarities as well as differences. Across the participants six to eight behavioural categories are mentioned in the top five per participant, for pleasure as well as for displeasure. Only three of these categories are present in the top five of all participants: facial expressions, sounds and head movements. The category of conventional gestes has never been used in the ranking. All other behavioural categories are mentioned one to five times in the top five.

For four of the six participants facial expressions and sounds are most frequently used to express their pleasure and displeasure. Two participants however have a totally different

profile. Participant three uses, next to facial expressions, especially head and mouth movements to express pleasure and physiological reactions to express displeasure. Participant six does not frequently use facial expressions. Her pleasure is mainly deduced from sounds and movements of the upper limbs and her displeasure from sounds and mouth movements.

We observed that for several participants the same categories of behaviour are used as indices of pleasure as well as of displeasure. Table 3 shows that this is on average the case for 60% of the behavioural categories that have been indicated.

Insert table 3

A closer analysis of the video-samples of the critical incidents of pleasure and displeasure that have been coded by means of the same behavioural categories, shows that the behavioural expressions may be very different. An incident for instance in which the person makes grimaces and whining noises when he is in pain has been coded by means of the categories facial expressions and sounds. Those same categories are used to code an incident in which the same person smiles and makes humming noises when listening to music.

Research question 2

Insert table 4

For five of the six participants there was a significant correlation regarding expressions of pleasure between at least two pairs of respondents. With regard to expressions of displeasure this applies to four of the six participants. For participant five there is very little agreement between the pairs of respondents with regard to expressions of pleasure as well as of

displeasure. For participant one the lack of agreement specifically concerns the expression of displeasure. The average correlation is almost equal for pleasure (0.63) as for displeasure (0.61). It is on average the highest between parents and direct support worker (0.71) and lowest between parents and researcher (0.55).

Research question 3

Insert Figure 5

With the exception of conventional gestures all behavioral categories are used to categorize the expressions of pleasure and displeasure. For all the participants and all the respondents the behavioural categories most frequently mentioned as *indices of pleasure* are: sounds (25.6%) and facial expressions (23.8%) followed by head movements (11.5%), body posture (9.3%), movement of the upper limbs towards objects (8.2%) and mouth movements (7.1%).

Feelings of displeasure are also exhibited most frequently by sounds (25.9%) and facial expressions (20.7%). Next are body posture (11.6%), mouth movements (11,3%) and head movements (7.9%). Aggressive (6.8%) and physiological reactions (4.1%) also seem to be indices of displeasure that one should pay attention to.

Discussion

The aim of this study was to explore the usefulness and the value of a procedure to draft an individualised profile of the ways a person with profound multiple disabilities expresses pleasure and displeasure. The procedure involves a rating scale for parents and support

workers and an observational analysis of videotaped critical incidents by an external researcher.

As to the *first research question*, the results show that it is possible and meaningful to draft an individual profile of the affective expressions of a person with profound multiple disabilities, using a combination of methods and perspectives. This fits in with the idea of 'methodological pluralism', advocated by Reid and Green (2002) and Schalock, Bonham and Marchand (2000). Multiple strategies seem most appropriate to examine subjective events of individuals with limited communicative abilities. Lyons (2003) combined participatory observation with semi-structured interviews of proxies. In order to reduce the time-investment that is needed for participatory observations, one can make use of critical incidents. However, this study demonstrates that these critical incidents must be selected carefully. The situations should be differentiated enough. The quality of the video-samples must be checked, e.g. that the person is shown entirely, that it is clear whether the person in question or others in the group are making noises, etc.

The *second research question* was to what degree different respondents agree on the expressions of pleasure and displeasure and have a complementary contribution. We included parents, direct support workers and an external researcher. In most cases, we found that the ranking order of expressions of pleasure and displeasure significantly correlated between at least two pairs of respondents. Working with relative judgements may probably be more reliable to identify indices of happiness than absolute ratings. This fits with the observation of Hogg et al. (2001). They found a higher level of agreement between support staff with regard to the interpretation of affective communication of people with profound multiple disabilities in the relative order of the samples than for the absolute rating values. Despite the relatively high concurrence between respondents, the results of this study also demonstrate that different respondents mention partly the same, but also partly other expressions of pleasure and

displeasure. Since there is no absolute standard to judge by whether all these identifications are correct, we believe it is better to consider them as complementing contributions to the profile of expressions of positive and negative affect.

The contribution of an independent observer is rather special. He may approach the person with profound multiple disabilities and his/her expressions of pleasure and displeasure with an open mind. In this way he may be an unprejudiced and complementary source of information, next to the proxies. The proxies on the other hand have the advantage of knowing the person and/or the context, which plays an important role in adequately interpreting presymbolic communication. We agree with Lyons (2003) that interpretations of feelings and emotions of persons with profound multiple disabilities may be validated by triangulating data on an individual's communicative behaviour profile obtained from two familiar observers and a third unfamiliar observer. Daelman (2003) also found that groups of respondents, with varying levels of knowledge of and experience with the child and/or the context, made significantly different interpretations of the same video-taped interactions between a child with multiple disabilities and a caregiver. Respondents that were not familiar with the child nor with the context saw much communicative signals, which points out their open-mindedness. They noticed especially social interactive behaviour with which the child sought contact with the caregiver. On the other hand, the respondents that were familiar with the child and the context, approached the range of behavioural signals more selectively. They noticed significantly more intentional behaviour and idiosyncratic expressions with referential characteristics then the outsider.

According to the *third research question*, we may conclude that persons with profound multiple disabilities express their happiness through consistent behavioural repertoires. Their feelings of pleasure and displeasure are mainly deduced from sounds and facial expressions, whether or not in combination with body postures and movements of parts of the body. It is

possible that behaviours conventionally viewed as indicative of affect in the wider population are typically attributed with the same significance when exhibited in people with profound multiple disabilities. The question remains unanswered whether parents, support workers and independent observers sufficiently take into account idiosyncratic behaviours or indiosyncratic use of general behavioural expressions, not typical of the wider population's expression of affect, but still indicative of positive or negative responses of people with profound multiple disabilities.

This study has several limitations. Due to the small sample size the results of this study may not be generalized. Although the multi-method and multi-perspective procedure seems promising, future research with a larger number of participants with profound multiple disabilities is needed to underpin the usefulness and the validity of the proposed strategy. Findings may also be limited by the predetermination of categories of communicative behaviour and by the lack of differentiation in subcategories. The overlap in behavioural indices of pleasure and displeasure for example demonstrates the necessity of describing which specific characteristics and/or combinations of the general behavioural categories actually signal pleasure or displeasure. Finally the individual profiles of affective communication that were drafted in this study, are only momentary. It would be interesting to know whether a repetitive identification of a person's subjective experience may yield different results. One might expect that new behaviours may acquire significance as entailing affective communication through experience of the individual in a wide range of contexts over a period of time (Grove et al., 1999).

Drafting an individual profile of the ways a person with profound multiple disabilities expresses pleasure and displeasure may be an important aspect of the quality of support for

this group, considering that the affective communication that is typical of a given person is often not known or not made explicit by support workers (Daelman, 2003; Roemer & Van Dam, 2004; Zijlstra, 2003). It could support the exchange of information and understanding of affective expressions of subjective well being between professionals and/or parents (Lyons, 2003). Information about the individual indices of (dis)pleasure should therefore be part of the support plan of each person with profound multiple disabilities. Recently several training programs have been developed for caregivers to observe and interprete the communicative behaviour of persons with profound multiple disabilities more accurately and to respond to it more adequately in their daily work (Bloomberg, West & Iacono, 21003; Dobson, Upadhyaya & Stanley, 2002; Roemer & Van Dam, 2004; Wakefield & Ogletree, 1995). It improves the support workers' sensitivity and responsitivity. A sensitive responsive approach in turn leads to a growing feeling of basic trust and competency of the person with profound multiple disabilities.

The profile may assist parents or other support workers to learn more quickly and/or thoroughly about the wants, likes and preferences of the person with profound multiple disabilities. When presenting the individual with certain stimuli, activities or persons, one can carefully record how the individual responds by observing the previously determined indices of pleasure or displeasure (Reid & Green, 2002).

Several internal or personal and external or environmental factors are highly related to the expressions of pleasure or displeasure. One can hypothesise for example that physical (Zijlstra & Vlaskamp, 2004) or mental discomfort (Oliver, 2004) leads to expressions of displeasure. But also environmental features such as the frequency and the nature of activities in which the person with profound multiple disabilities can actively participate (Vlaskamp & Zijlstra, 2004) and the nature and the frequency of positive interactions with support staff (Felce, Jones & Lowe, 2002) may be related to expressions of pleasure and displeasure.

Therefore, a profile of individualised expressions of positive or negative affect may be useful to determine the individual's evaluative reactions to environmental or support characteristics or changes.

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Table 1: Characteristics of the six participants

Participant	Age	Sexe	Nature of disabilities	Support setting
P1	9	F	Profound intellectual disability, spastic quadriplegia, blindness, epilepsy, pulmonary affection, digestive upsets, otitis, cystitis	Day care centre
P2	8	F	Profound intellectual disability, spastic quadriplegia, blindness	Day care centre
P3	29	M	Profound intellectual disability, spastic quadriplegia, blindness, epilepsy, feeding problems	Residential service
P4	16	M	Profound intellectual disability, spastic quadriplegia, epilepsy, central visual impairment, chorioretinitis	Residential service
P5	26	F	Profound intellectual disability, Rett syndrome, partial sightedness, motor impairments	Day care centre
P6	18	F	Profound intellectual disability, epilepsy, motor impairments, autism	Residential service

M= male, F=female

Table 2: Operational definition of the taxonomy

Category	Operational definition
Gaze direction	Regards the direction in which the person looks. (E.g. look at, look away)
Facial expression	Regards expressions at face heigth. (E.g. smile, make grimaces, make a lip)
Sounds	Regards the voice of the person. (E.g. moan, shout, yell, laugh, cry, jabber, scream, whine)
Head posture	Regards the position of the head whether or not in proportion to other parts of the body. (E.g. hang one's head, slope one's head)
Head movement	Regards a separate movement of the head. (E.g. move one's head in the direction of a person, sound or object, turn, nod, shake one's head)
Body posture	Regards the posture of the body at large. (E.g. sitting, standing or lying position, tensed posture)
Movement of lower limbs	Regards a separate movement of feet or leggs, not in order to move forward and that is not aggressive or self-injurious. (E.g. kick with one's feet, stamp one's foot, move one's feet)
Movement of upper limbs towards the person himself	Regards a separate movement of hands or arms towards the person himself that is not aggressive or self-injurious. (E.g. caress, stroke, rub oneself)
Movement of upper limbs towards an object	Regards a separate movement of hands or arms towards an object that is not aggressive. (E.g. reach, touch, push, grab an object)
Movement of upper limbs towards a person	Regards a separate movement of hands or arms towards a person that is not aggressive. (E.g. reach, touch, push, grab a person)
Mouth movements	Regards a movement of the mouth, not in order to produce a sound. (E.g. suck one's fingers or hands, gnash one's teeth)
Physiological reactions	Regards a physiological reaction of the body. (E.g. blush, sweat)
Aggression	Regards aggressive behaviour directed at oneself, another person or an object. (E.g. bang one's head, hit, scratch)
Conventional gestures	Regards gestures that are conventional for communication in a particular culture. (E.g. wave, nod yes, nod no, point, clap one's hands)

Figure 1: individual profile participant 2 – expressions of pleasure

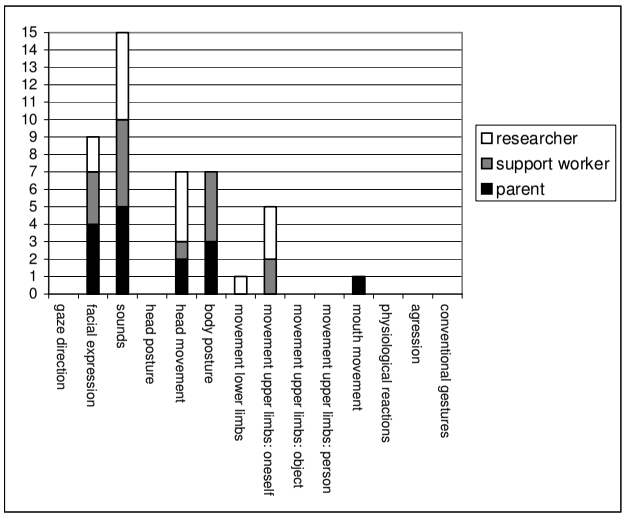

Figure 2: individual profile participant 2 – expressions of displeasure

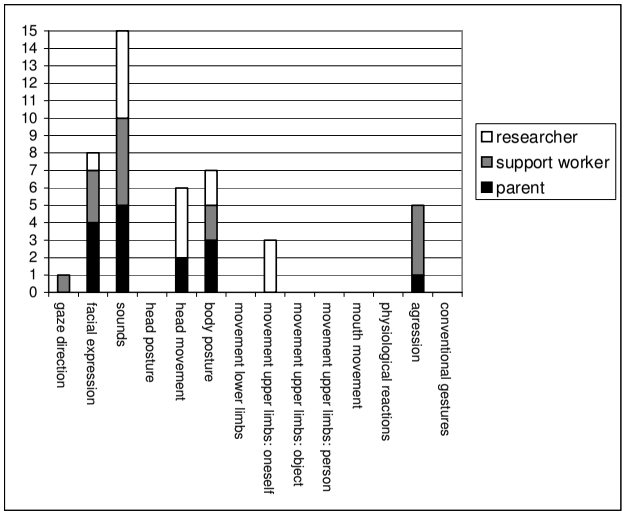

Figure 3: individual profile participant 3 – expressions of pleasure

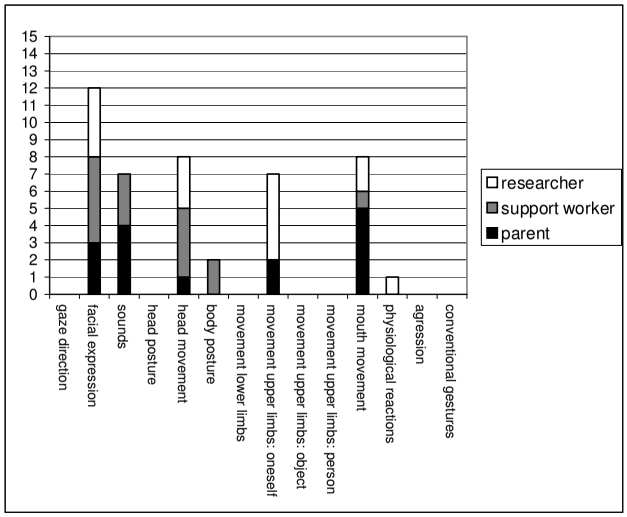

Figure 4: individual profile participant 3 – expressions of displeasure

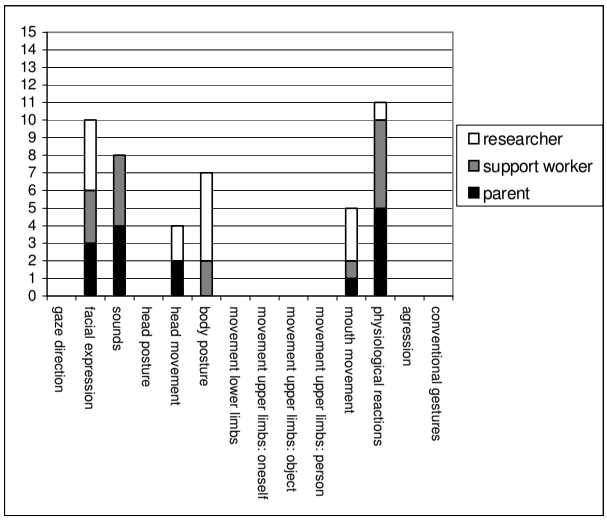

Table 3: Overlap in behavioural categories for pleasure and displeasure

Participant	% overlap
P1	6/9 (66.6%)
P2	5/9 (55.5%)
P3	6/7 (85.7%)
P4	7/8 (87.5%)
P5	5/10 (50.0%)
P6	3/10 (30.0%)
Total	32/53 (60.4%)

Table 4: Correspondence between respondents in identifying expressions of pleasure and displeasure

Pleasure						
Participant	Parent – Support worker		Parent - Researcher		Support worker - researcher	
	r_s	p	r_s	p	r_s	p
P1	0.62	p<0.01	0.48	n.s.	0.64	p<0.01
P2	0.81	p<0.001	0.56	p<0.01	0.73	p<0.001
P3	0.74	p<0.001	0.71	p<0.001	0.47	n.s.
P4	0.98	p<0.001	0.56	p<0.01	0.48	n.s.
P5	0.44	n.s.	0.45	n.s.	0.77	p<0.001
P6	0.71	p<0.001	0.47	n.s.	0.77	p<0.001
Mean	0.72		0.54		0.64	
Displeasure						
Participant	Parent – Support worker		Parent - Researcher		Support worker - researcher	
	r_s	p	r_s	p	r_s	p
P1	0.43	n.s.	0.33	n.s.	0.30	n.s.
P2	0.79	p<0.001	0.76	p<0.001	0.45	n.s.
P3	0.79	p<0.001	0.60	p<0.01	0.68	p<0.01
P4	0.78	p<0.001	0.36	n.s.	0.57	p<0.01
P5	0.44	n.s.	0.52	n.s.	0.75	p<0.001
P6	0.99	p<0.001	0.72	p<0.001	0.78	p<0.001
Mean	0.70		0.55		0.59	

Figure 5: Expressions of pleasure and displeasure across participants and respondents