

Challenging behaviour in an adult male with congenital deaf-blindness: analysis and intervention

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People with severe congenital disabilities have been assessed on negatives, on what they do not have. Skill training and education of these missing abilities have been the major focus for the habilitation since emergence of the normalization ideology in the 1960s. Developmental theories and movements like quality of life and positive psychology have changed focus from training and education to well-being and other internal states in people with disabilities. This article describes how challenging behaviour vanished in a deaf-blind man when developmental theory was applied as the framework for his habilitation. Emotional processing and initiatives increased and the man became easier to understand for the staff. The special case of a deaf-blind man illustrates how simple a focus on internal states may slip and be exchanged for intervention dominated by demands and training. The article discusses whether the framework employed in the present intervention should be present in all kind of habilitation.

Keywords: challenging behaviour; deaf-blindness; emotions; individual variations; internal states

Introduction

For several decades normalization has been the theoretical foundation and aim of the habilitation of individuals with severe congenital disabilities, both in Norway and in most other Western countries (Dykens 2006; Holm, Holst, and Perlt 1994; Solum 1993; Wolfensberger 1972). The normalization movement had its roots in beliefs in remediation training programmes and looked upon people with mental retardation as a homogenous group who needed training to improve their adaptive skills. Little or no focus was on the individual variation (Wolfensberger 1972). This minimal focus on each individual's level of development and skills still seems to be the case today for many theoretical frameworks and movements involved in treatment of people with mental retardation (Dykens 2006; Solum 1993). The emergence of the normalization ideology in the 1960s represented a big step forward compared with the aimless care of residents in large institutions in previous times. Before the establishment of normalization as the guiding principle, the physical means for survival were supplied, but too often in a context of social isolation and no organized work for positive development. Normalization implied that efforts in skill training,

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education and inclusion in local communities were made (Dykens 2006; Holm, Holst, and Perlt 1994). However, normalization also meant that there was little focus on the subjective well-being and other feelings of the residents. The principal focus was on behaviour and skills, and the shaping of residents as inconspicuous as possible. Dykens (2006) states that caregivers and researchers in the mental retardation field for decades now have stressed physical life conditions and adaptive behaviour in this population, and that we know next to nothing about their positive internal states. This focus has led to diagnosis based on negatives, on what people do not have (Dykens 2006).

Theories

Theoretical approaches that may be considered to have their focus on what people do not have are psychoanalysis, behaviourism and the communication hypothesis. Psychoanalysis explains challenging behaviour as a result of unconscious conflicts caused by immature developed inner psychological structures. Self-injurious behaviour is a way to reduce anxiety that occurs as a result of these unconscious conflicts (Romanczyk, Lockshin, and O'Connor 1992; Tyson and Tyson 1990). The behaviouristic approach explains challenging behaviour as a result of the consequences the behaviour is met with, and consequences must be changed to train their behaviour in adaptive direction (Hastings, Remington, and Hopper 1995; Lovaas and Smith 1994). The communication hypothesis is grounded on Skinner's (1957) behaviouristic approach to communication, and describes how training should be performed to improve their communication as an adaptive skill.

In contrast, the developmental approach focuses on the reciprocal influence between the individual and the surroundings over a period of time, referred to as transactional development (Sameroff and Chandler 1975; Sameroff and Fise 2000; von Tetzchner 2003). This reciprocity in interaction presupposes several specific conditions: (1) that the communication partner always observes emotional utterances and behaviour that indicate internal states (Sroufe 1996); (2) that the communication partner is aware of emotional maturity in the individual (Sameroff and Fise 2000); (3) that emotional maturity is operationalized as capability to identify and regulate own emotions (Campos, Frankel, and Cameras 2004; Cole, Martin, and Dennis 2004; Eisenberg and Spirad 2004); and (4) that the communication partner adjusts the situation to increase the possibility that the individual him/herself exposes his/her wishes and needs through initiatives. The probability of observing the true internal emotional states increases dramatically when a communication partner reads them from the other person's initiatives rather than from responses (Sameroff and Chandler 1975). The developmental approach has as the goal in treatment of challenging behaviour to change interaction from dysfunctional to functional, which presupposes initiatives, understanding of internal states and understanding of the person's capability of regulating her/himself.

Movements

Movements concerned with habilitation more-or-less incorporate internal states and probability to regulate emotions in their research and treatment. The dual-diagnosis movement reflects the fact that people in need of habilitation are at higher risk of developing psychopathology. It thereby often possesses a dual diagnosis – a diagnosis

that places the person in need for habilitation and a psychiatric diagnosis (Einfield and Tonge 1996). Research in this tradition has focused on negative behaviours and symptoms. Dykens (2006) found 1825 articles in Medline on such double diagnoses. Only 19 of these examined happiness in people with dual-diagnoses. The rest focused on different psychiatric diagnoses. The personality-motivation movement has recently examined the desire of children to master tasks (Nichols, Atkinson, and Pepler 2003). The movement has accomplished important work, but has only taken a limited part of inner states into consideration, and has failed to take their work out of the classroom and into the outside world (Dykens 2006). Positive psychology declares explicitly that positive internal states are the focus for treatment. Positive psychology has similarities to the developmental approach in focusing on internal positive states, but differs in the way that reciprocity, emotional maturity, the importance of initiatives, and the long-term effect of transaction on the relation are not included explicitly (von Tetzchner 2003).

The quality of life movement with its focus on subjective quality of life has emerged as an alternative to the normalization ideology for persons with severe or profound disability (Holm, Holst, and Perlt 1994; Solum 1993). In particular, it is now widely recognized that the subjects' own feeling of happiness or well-being is an important focus in all habilitation, not just for ethical reasons, but also because it is an important motivating force for positive social development and optimal functioning in daily life, and because it is connected to better physical and mental health (Lyubomirsky, Sheldon, and Schkade 2005).

Most people with congenital disability are cognitively capable, but some also have an intellectual disability. When the subjective quality of life concept is used in relation to persons with severe congenital and intellectual or communication disabilities, we need to consider how the well-being of an individual who cannot report his/her feelings in a conventional language is to be observed, reported and measured. This question pertains to the issue of self-reports (e.g., in the form of questionnaires or interviews) versus third-person observations. As pointed out by Goode (1997), both types of data are indirect indices of feelings or states and neither of them is more objective or truer than the other one per se. Because self-reports of well-being and happiness may easily be distorted by random factors that often cannot be controlled (see Kahnemann 1999), third-person observations may give the most reliable data, even in cases where subjects are capable of self-reports. Emotions normally have a public aspect, and Larsen and Fredrickson (1999) argue that most self-reported measures also can be obtained from a third-person perspective. They cite evidence that simultaneous reports of feelings from self and others show highly convergent results. The quality of life movement is also concerned with the stability of well-being in people with severe or profound disabilities (Diener and Lucas 1999; Kahnemann 1999).

The principal hypothesis in the quality of life movement is that the quality and quantity of adequate social contact and communication have great impact on an individual's well-being, and that increased well-being leads to a decreased probability of challenging behaviour.

Deaf-blindness

Deaf-blindness is a condition where social contact and communication may be dramatically reduced because people with deaf-blindness have fewer initiatives and

emotional expressions differ from those of seeing and hearing people. Utterances may be delayed and also have different forms (Burlingham 1964; Fraiberg 1977; Goodenough 1932; Jacobsen 1995; Warren 1994). Development of internal states and the capability to self-regulate are at risk, and the probability of emergence of challenging behaviour increases (op.cit.). The use of a deaf-blind man as a case study may therefore be a key example to illustrate how easily the focus on inner state and self-regulation may slip, and be exchanged for a focus on external life conditions. Nevertheless, self-regulation and internal emotional states in deaf-blind people have not been the subject of scientific studies. Of all articles on deaf-blindness in psychological scientific databases only one article addressed emotions (Goodenough in 1932). Most articles were about deaf-blindness and communication. One could assume that emotionality was implicit or implied in many articles, but they were mostly cognitively directed (Bruce 2005; Hart 2006).

Disturbance in central nervous activation and attention in people with deaf-blindness may also place self-regulation, social contact and communication with people with deaf-blindness at risk. For instance, brightness in the eyes is a main observational cue to identify which behavioural state a baby possesses (Wolff 1987), which in turn gives us indications of how to approach the baby. Central nervous system activation may for this reason be hard to identify in infants with deaf-blindness (Jacobsen, Grøttland, and Flaten 2001). To identify what inner state a baby possesses is the start on the developmental pathway from external regulation by the caregivers to self-regulation (Sameroff and Fise 2000; Sroufe 1996; Wolff 1987). Also other spontaneous behaviour depends heavily on visual perception (Burlingham 1964; Fraiberg 1977).

Kopp (2002) and Ruff and Rothbart (1996) discuss the co-development of visual attention and emotion-regulation. Early attention is reactive and has a reflexive character. Eye tracing and eye contact with social implications replace the reactive attention. Acuity increases and the ability to inhibit saccadic responses develops, which are prerequisites for sustained visual attention (op.cit.). The inhibition of saccadic responses seems to be so rigid in the first two years of life that it restricts free visual scanning in many contexts (Jacobsen, Magnussen, and Sundet 1995). This developmental limitation may be considered as functional for emotional and cognitive organization of sensory/perceptual input (Jacobsen, Magnussen, and Sundet 1995; Turkewitz and Kenny 1985).

Vision differs from the auditory sense and tactile sense in important ways considering development of emotion-regulation. The most obvious way these senses differ in this respect is that visual stimuli are evident (when we see a well-known face we recognize it immediately), which opens for a spontaneous response (Burlingham 1964; Fraiberg 1977). Auditory and tactile stimuli are seldom evident. When we hear a voice without seeing the person who is talking, we tend to enter a more time-consuming cognitive process (op.cit.). We stop our own activities, listen carefully and then produce a response like 'Karla, is that you?'. Parallel with this spontaneous or delayed response are constellations of physiological arousal. Visual stimuli excite the central nervous system, arousal is increased, and there is a tendency to spontaneous responses. Auditory and tactile stimuli (when isolated from visual stimuli) decrease the activation in the central nervous system, arousal decreases, and there is a tendency to passivity (Aslin 1985; Jacobsen 1995). Arousal and visual attention are intimately linked and appear to be mediated by a modular cortical-limbic-reticular network (Heilman 1979; Mesulam 1981; Watson, Valenstein, and Heilman 1981).

To avoid stereotype patterns in interaction with deaf-blind people like that we direct them and they are directed, we need intervention systems that reflect the difficulties in social life with dual sense impairment. But the theoretical framework must also reflect emotions, emotion-regulation and the human need to regulate the social environment (Campos et al. 1994; Damasio 1996; Thomson and Calkins 1996).

Panic attacks

Two similar models for panic disorders have been developed, one by Clark (1986) and one by Wolpe and Ravan (1989). These models consist of cognitive, emotional and classical conditioning elements. LeDoux (1996) outlined how these models may be understood from the perspective of neurophysiology. This author showed that strong bodily sensations (like unregulated emotions), with low information value, direct the individual's attention towards the sensation as physiologically threatening. Sensations are misinterpreted as signs of an immediate impending disaster such as having a heart attack, suffocating or collapsing. The sensations most often misinterpreted are those associated with anxiety, although other sensations, for example, those associated with normal deviations or low blood sugar, may also be misinterpreted (Clark 1986; Wolpe and Ravan 1989). Clark's and Wolpe's and Ravan's models suggest that persons with immature regulation of emotions may be at risk of panic attacks.

David

The current study presents a 28-year-old deaf-blind man, 'David', who lived in a small housing unit together with three other people diagnosed with deaf-blindness. Presentation of David will be given in the method section under the heading 'Subject'.

The intervention, result of treatment and discussion from this case study illustrate a framework from developmental psychology with elements from the quality of life movement and positive psychology for the treatment of an adult male with congenital deaf-blindness. Details of the intervention, results and discussion will be presented.

Method

The present description of 'David' is based on pre- and post-treatment videotapes, a general description of the situation when videos were recorded, written reports, and his medical records. Permission was obtained from David's mother to release the videotapes, daily journals and medical records to the present authors. Videotapes were recorded from pre-treatment and post-treatment. One videotape of pre-treatment and one videotape of post-treatment were randomly chosen (the duration of the tapes were approximately 40 minutes each). Two additional videotapes from pre- and post-treatment were randomly chosen to confirm that the tapes chosen for the main analysis were representative of situations and of the time period. These additional videos were taped for the first five minutes of every half-hour during one day to avoid bias in any direction. This form of data selection was chosen to facilitate elaborate description of the situations in which the analyzed behaviour occurred. A pragmatic description in addition to objective data (like scoring of videotapes after

predetermined categories with two scorers and measurement of inter scorer reliability) increased both the scientific and clinical understanding of the processes which accompany changes. Two persons scored the pre- and post-treatment videotapes independently. The inter reliability between the two scorers was 0.96.

The following behaviour categories were included in the data analyses:

1. Who initiated the interaction?
2. Type of initiative
 - directed towards activities
 - establishing of contact
 - other content (like orientation about time, other persons present or plans for the evening)
3. Was the initiative responded to with resistance or no resistance/interest from David?

Initiatives are defined as approaching another person with a message formulated in a formal language like sign language or a message in informal signals, holding around a person or attending a person and pushing the person away. Initiatives may be directed towards activities, towards establishment of contact or other content, like an orientation about time or other persons present.

A general observation of the occurrence of positive and negative emotional expression was carried out and written down in daily reports.

Subject

David was a 28-year-old congenitally deaf-blind man. He was totally blind; the retina was destroyed in both eyes. He may also be considered as totally hearing impaired in the sense that he could not detect a distinct sound, but he could detect resonance and vibrations through the hearing system. In daily life he showed high cognitive capability through interest for learning, recognition of persons and objects and from a remarkable memory. He also enjoyed sharing previous experiences with new people and could be persistent in his procurement until the person present understood him. He used some sign language and informal signs. Emotionally he could be eager, but seldom displayed emotional expressions of happiness and joy. He showed few expressions of sadness, but he could be outraged. A peculiar phenomenon concerning his rages was the relatively long periods between when they appeared (there could be a month between), but when they appeared they were extremely strong and lasted for days. This was a special behavioural pattern in this deaf-blind man's life. He showed resistance and mild forms of rage for longer periods of time, and then expressed extreme rage. He would then hit, throw, bite, smash furniture and glasses and he could also lose his normal ability to sleep for several nights. These periods were relieved with resistance and milder forms of rage again. This characteristic pattern of emotions is the focus for this study, both to understand the pattern and to treat it. David was diagnosed as having panic anxiety by the first and the second authors.

Procedure

An initial analysis of the interaction between David and the members of the staff showed a dominating pattern (even though there was a little variation among the staff members): Interaction was almost exclusively initiated by the staff.

Characteristically, interaction was initiated by staff members with some kind of demand that David should participate in one or another activity. The demand was most often responded to with resistance from David. This was followed by repetition of the demand from staff member and met with increased resistance from David. As therapeutic intervention to this rigid, dead-locked pattern the staff-members' focus was directed away from a demanding and training oriented programme towards an intervention where understanding of David's behaviour was the principal concern and the foundation for communication. The best way to understand him was to wait for his initiatives and respond to them. Staff members were also instructed to observe if David displayed positive emotions like eagerness when he expressed need for something, or happiness when the staff understood what he wanted. Staff members were also instructed to see whether he displayed negative emotions, like irritation when he had to wait or rage when he was misunderstood. They were also instructed to respond actively to whatever emotion he displayed. The staff members were supervised regularly once a week by David's special teacher, who also gave supervision via video once a month. They were given lectures every three months, in subjects like how to understand another person's emotions, how to respond to the other person's emotions, social interaction including communication, self defence and how invasion from another person affects us. In addition, they attended a group where they could outline their own emotions regarding David's invasions of them, and how they reacted to his extremely strong tantrums. The supervision-programme suggests that a focus change from controlling and demanding to see and understand a person is neither easy nor quick. It is a time-consuming and complicated process where the staff members' attention is directed from running a rigid programme to being observant, relativistic (to see events in context), creative, autonomous, and flexible. Such a complicated process is continuous, it is a frame of understanding of treatment, social interaction and human needs.

Results

Both pre- and post-treatment descriptions are taken from the videotapes according to the categories given in the Method section. Some general descriptions of a more anecdotal character are also given for illustrations.

Pre-treatment

Staff members took 59 initiatives to interact with David, while David took 7 initiatives to interact with staff members. Eighty-nine per cent of the initiatives were from the staff, while only 11% were introduced by David. Analysis of the additional tape confirmed the difference in initiation of interaction: 37 (92.5%) of the initiatives to interact were initiated by the staff, while 3 (7.5%) were initiated by David.

Of the 57 initiatives from the staff, 41 (72%) were directed towards activities, 5 (9%) were directed towards contact, while 11 (19%) had other content like orientation about time or persons present. The additional tape confirmed the results from the main tape: 30 (81%) of the initiatives from the staff members were towards activity, 4 (11%) were to establish contact and 3 (8%) of the initiatives had other content.

David showed resistance to 32 (56%) of the staff's initiatives and no resistance or interest to 25 (44%) the rest of the initiatives. Analysis of the additional tape confirmed this tendency from the main tape. David responded with resistance to

27 (73%) of the staff's initiatives, while he responded with no resistance or interest to 10 (27%) of the staff's initiatives.

Before treatment David had extremely strong tantrums involving throwing, biting, hitting, pulling by the hair. During these tantrums he also smashed furniture and windows and lost his ability to sleep for several nights.

His emotional expressions were dominated by negative expressions related to the staff members' proposals of new training and activities.

Post-treatment

Analysis of the main video after treatment showed that 32 (64%) of the initiatives were taken by David, while staff members initiated interaction 18 (36%) times. This change in communication pattern from before treatment was confirmed by the analysis of the additional video, which showed that David initiated communication 25 (58%) times and the staff members took 18 (42%) initiatives to communication.

One (6%) of the initiatives from the staff in the main video was towards activities, 9 (50%) were towards contact, and 8 (44%) had other content. Even if it was not as evident as in the main tape, the same tendency of change from initiatives directed towards activity to initiating contact was confirmed in the additional tape: five (28%) of initiatives from staff were directed towards activities, seven (39%) initiated contact and six (33%) initiatives had other content.

After treatment David showed resistance to 2 (11%) to the staff's initiatives, while he showed no resistance or interest to 16 (89%) of the staff members' initiatives. Analysis of the additional tape confirmed the same change from pre- to post-treatment. In this tape David showed resistance to 4 (22%) of the staff members' initiatives, while he showed no resistance or interest to 14 (78%) of the staff's initiatives to communication.

The extremely strong tantrums had disappeared. Written journals showed that he displayed more frequently both positive and negative emotions compared with before treatment. Emotions were more connected to events and thereby more accessible to understand and act upon according to meaning.

One general description from an incident of a more anecdotal character is also given from the main post-treatment tape for illustration: David and a male staff member are standing on the floor, located closely to each other. David approaches the staff member and invites him to follow him. The staff member follows him willingly. David leads him to the toilet and asks the staff member eagerly to do a toilet visit. The staff member attains the toilet. David looks pleased. After a short period of time the staff member returns from the toilet. David asks by sign language for chewing tobacco, but does not get any answer. David looks a bit confused. He sends the staff member once more to the toilet. David does not look pleased when the staff member returns a second time from the toilet. He then takes the staff member for a cup of coffee.

After the video was filmed, the staff member was asked if he understood what David's confusion connected to the toilet visits was all about, and if he understood what David wanted. The staff member admitted that they often offered David some kind of chewing tobacco after David had visited the toilet. He supposed that David arranged the situation to get some chewing tobacco. He himself was not sure of the legality of handing out tobacco to David, so he did not offer him some when he was filmed.

Discussion

Behaviour changes in the deaf-blind man and in staff members from pre- to post-treatment were:

- (1) Initiatives to interaction from David increased dramatically, whereas initiatives containing demands from staff decreased dramatically.
- (2) Behaviour related both to positive and negative emotions occurred more frequently after treatment, and was more related to events.
- (3) The monthly strong tantrums (panic attacks) with durations of days had disappeared.
- (4) David's response to staffs' initiatives changed from resistance to interest or no resistance.
- (5) The content of the staff's initiatives changed from activity to contact.

The results represent a marked change in communication pattern between the deaf-blind man and his staff members. The five previous points sum up the data and show that the overall change is substantial. David's initiatives are now dominating the communication, offering quite another way to understand David's internal emotional states, compared with before intervention when staff members directed him and he resisted. Staff member's initiatives also changed from being demanding to be directed towards establishing contact.

These shifts include a reciprocal influence between communication partners, observation of emotional utterances that indicate emotional states and emotional maturity, adjustments to increase the probability for initiatives from David and the wish to develop a functional interaction together with David. However, probably the most important element in the staff's development was the time-dependent changes. This were the changes that occurred through new experiences with David, and constant discussions of these experiences. When they allowed him time he initiated communication in a way that meant they could understand his intentions, emotional states and needs. They simply started to look upon him in a different way. Their new way of thinking and feeling about David came from positive transactional effects. The same positive transactional effects also affected David. He could now trust people. If he needed time, no one pushed him any more. If he needed to stand and hold around people to consolidate the situation, the staff members gave him the opportunity to do so. If he showed resistance, he was met with a real wish to understand the meaning behind the resistance. His growing interest for contact, communication and participation was also met. His challenging behaviour simply disappeared. His panic attacks vanished when he was not pushed around all the time.

The main goal of treatment was not reduction of symptoms (challenging behaviour), but emergence of David's emotions and needs, and to meet him in a way that enables him to regulate his own behaviour (Watson and Bedard 2006). We saw the disappearance of the challenging behaviour as a result of the focus on David's initiatives, emotions and needs. From the viewpoint of developmental psychological theory the effect of treatment should be measured in terms of emergence of emotionality. More distinct emotional expressions increase the probability of positive transactional effects, whereas reduction of symptoms most probably only reduces negative transactional effects and increases the risk of development of passivity. More distinct emotional expression also offers a possibility for communication partners to see and understand the person and activate autonomy both in the person

in question (as demonstrated by David) and in his interaction with others. It was also the case with David, that the increase in emotional processing and responding surroundings made neurological activation understandable as the physiological part of the emotion. Threatening neurological activation with little informational value may on the other hand lead to panic attacks. With the emergence of emotionality for David, there was no need for direct treatment of the challenging behaviour.

The present intervention is within a framework of developmental theory outlined in the introduction. This framework is not focused on cause-effect in treatment, but on how positive transactions initiate developmental processes. The discussion shows how the relations with David were directed towards understanding of his inner states, his ability to regulate himself, his needs and the cognitive content in his initiatives and communication. But most important are the changes from negative to positive transactions. Through the discussion and the new way the staff member approached David and interacted with him, they started to look upon him differently. They understood when he needed time or room. Resistance was no longer a negative response, but a response that needed to be understood. The strength of developmental theory is its explicit inclusion of time-dependent dynamical elements. Movements like quality of life and positive psychology include many of the elements of developmental theory, but not explicitly the time-dependent transactional effects. Nevertheless, development of positive transaction may come as a side effect of interventions from these two movements.

David as a deaf-blind man illustrates a high risk for poor development of self-regulation, central nervous over-activation, and development of panic attacks or other forms of anxiety. If this is the case for many people with deaf-blindness, we therefore need even more considerations and adjustments of how deaf-blind people should be approached and interacted with in most other cases. Also people with intellectual disabilities are at high risk of poor development of self-regulation, central nervous over-activation and development of anxiety. Thus, the understanding of human needs reflected in developmental theories, the quality of life movement and the positive psychology movement should be implemented in any kind of therapy, intervention or daily life interaction with people with many different kind of disabilities.

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