

Supported Autonomy

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Mr. Klundert was a big, strong man of 60 years of age. In 1990 he had a cerebral haemorrhage. Five years later he was treated in a psychiatric clinic because of complications. He was treated for impulsive aggression. After this treatment he was placed in his own apartment in an dwelling for clients with brain injury. During the day he would go to an activity centre, where he “works” as he put it himself. At first this was very much an uphill struggle. It was almost impossible for him to be in the same room with the other inhabitants for a long period of time. He found it difficult to cope with lively situations. He released his tension by walking away, swearing and throwing stuff around. This caused co-visitors and employees to feel unsafe. Often Mr. Kundert could be calmed down by distracting him.

This article is about the autonomy of people with impairments in their executive functions and about how professionals can support these people better. During recent years, clients receiving mental health care, disabled care and nursing care are more and more supported and treated at home. The main object is that clients can continue with their lives and their corresponding roles in society. This life at home appeals to the autonomy of the clients, however, this is difficult for people with impairments in their

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executive functions, for, as a result of their disorder, these people often have problems with their self-regulating capacity.

Support must be directed to the context in which the client lives. That which a client learns in an institution or clinic can hardly transfer to a different environment. The structure the institution provides, which overcomes a number of limitations and apparently provides a footing, is not present when a client returns home or to work. In the living environment, however, self-regulation is imperative. The acquisition of abilities in the institution does not lead to application of these abilities in the home situation.

In this article we will discuss the following subjects:

- a historic perspective
- supportive autonomy
- self-regulation
- executive functions
- social emotional development
- support of autonomy including: cognitive coaching and self-regulation; safety; meaningful environment; being important to another person, sense of meaning and daily programme.
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Anecdotal illustrations from Mr.Klundert’s case will be provided.

A HISTORIC PERSPECTIVE

Until the seventies of the previous century the care for people with a limitation was dominated by the defect model based on medical practice. This was mainly the case for people with a mental or physical handicap and for people with a psychiatric disorder. The shortcomings of the person in question were the central point and all attention was focussed on curing or diminishing these shortcomings. Because recovery was in many cases impossible, people with a limitation in social functioning were put in large institutions far away from society. Those facilities applied a totally autonomous system of conventions and values. All activities took place in the same environment and with the same people.

From the sixties of the former century the realisation grew that life in these institutions led to detachment from the living world and paralysation in fixed patterns (i.e. total institutionalisation, hospitalisation)(Goffman 1961). In psychiatry and other fields of care for the mentally handicapped, movements arose which argued for a development-oriented approach for people with a limitation in social functioning (i.e. anti-psychiatry, normalisation). The philosophy then was that people should not be put away, but should, with the help of professional support, take part in society as full-fledged citizens. This view also worked the other way round so that people from outside the institution were brought in to work and interact with the clients within the institution. Within the care for the mentally handicapped, the medical model was replaced by the development model.

In the eighties and nineties, the development model evolved into the support model, in which the offering of support and the promotion of taking part in society were the central points of attention. This movement could also be noticed in psychiatry where the rehabilitation approach evolved. Both models focussed on negotiation instead of patronizing and taking over responsibilities. More recently the competence model has evolved in which the competences of the client are the focus of attention. Here a balance is sought for between the development tasks and the abilities of the client, and

the factors that have a positive or negative influence on the abilities.

SUPPORTED AUTONOMY

Supported autonomy means that there is no longer a patient but an autonomous person who is being supported in functioning within society. The term supported autonomy is a dialectic term because it expresses someone's dependence as well as his or her independence. In supported autonomy a client is supported in such a way that he or she can function as autonomously as possible. A clear and safe framework is necessary for one to be able to develop autonomy. This may mean that support is particularly necessary to be able to stimulate autonomy. Autonomy implicates direction over the living environment and a grip on choices. For this, self-regulation is needed. The balance between self-regulation (autonomy) and support (safety) is, among other things, shaped by offering proactive boundaries.

Supported autonomy is a central term in all sorts of care and assistance. A client is supported in his or her personal development, which he or she shapes themselves. Making a dependent person independent seems a paradox, but for all persons who are being supported in social functioning, up to and including detainees, being able to give direction to their own lives is a determining factor for their development. Also, for seriously limited people, it is of the utmost importance to have a grip on their living environment within their possibilities.

The role of the care provider or social worker changes with supported autonomy into that of supporter. This changing role may require a shift in orientation and method from the provider. Routines and professional identity of the care provider or social worker were, after all, based on taking over the responsibilities of the client. Respecting the autonomy implies that social workers support the client in taking responsibility for one's own behaviour and directing one's own life. On the one hand the social worker will have to be reserved in this process, on the other hand he or she has to offer frameworks in which the client can function

optimally. To what extent the client is capable of self-regulation is an important factor in being able to function more or less autonomously. The support has to be in line with this.

EXECUTIVE FUNCTIONS

In the brain the frontal lobe manages the self-regulation of cognitive and social behaviour. The executive functions are also localized there including:

- self-awareness of weaknesses/strengths and understanding of the level of difficulty of certain tasks;
- the capability to set realistic goals;
- to be able to plan and to organise behaviour to reach these goals;
- to initiate behaviour directed towards reaching the goals and to avoid ineffective behaviour;
- to monitor the execution and to evaluate with regard to the goals;
- to flexibly revise plans and strategically solve problems (act upon feedback).

The executive functions develop from childhood into early maturity. Brain damage and psychiatric disorders can slow down and interrupt this development process. After the injury the executive functions, however, will further develop again and this can require support (Ylvisaker & DeBonis, 2000). Problems with the executive functions often lead to a decline of verbal fluency, problems with flexible, abstract and logical reasoning, a poor problem solving ability and problems with planning. Reduced executive functioning can also lead to limitations in self-awareness and self-regulation (Ownsworth, 2002).

Executive functions influence the ability to learn and also one's behavior. To be able to learn it is required to adjust behaviour on the basis of feedback. Training, generally speaking, leads to generalisation. The executive functions help with the transfer of knowledge and skills in different situations. People with executive problems can only associate training with the context in which the training takes place. An

example is the acquisition of domestic skills in the day activities centre but then not being able to carry them out at home. People with disorders in the frontal lobe often have problems with consciously having control over their behaviour while automatic behaviour stays intact relatively well. Interventions which are directed to conscious self-regulation will most probably have little result (Ylvisaker & DeBonis, 2000). With clients who show behavioural changes, like impulsiveness and chaotic behaviour or, just to the contrary, apathy, it may also be a question of problems in the executive functions (Tate, 1999). After all, the self-regulation of behaviour is damaged.

After his cerebral haemorrhage Mr. Klundert had difficulty with too many stimuli. His executive functions had been damaged. With a lot of activity and many stimuli he would lose track, leaving him unable to make choices. He would, therefore, strand in his acting. Stimuli also gave him more stress. He could regulate this stress less well because the feedback mechanism did not function very well anymore. This caused him, in cases of stress, to have more impulsive aggression during which he released his tension by walking away, swearing and throwing stuff around.

SELF-REGULATION

In self-regulation, feedback mechanisms are determining factors for our behavior. These feedback mechanisms are part of our executive functions. When feedback mechanisms function less well, old reflexes can be activated, through which someone is more able to maintain himself. If the ability to learn is missing, ingrained working methods can be applied in a similar context (i.e. in behavioural modification). Behavioural modification (Beeckmans & Michiels, 2000; Guecio & McMorrorrow, 2002; Ylvisaker e.a., 2003) is a form of support, directed towards increasing desirable behaviour and diminishing undesirable behaviour, by:

- adapting the environment
- making use of cues in the environment and avoiding triggers

- rewarding desirable behaviour
- social skill training
- psychopharmacologies
- relaxation therapy

Cues and triggers are stimuli which set something off. A cue will lead to desirable behaviour and a trigger to undesirable behaviour. The autonomy and quality of life of people increases when they can live and work in their own environment, a meaningful environment, in which someone shapes his or her life and can be important to another person. Autonomy implicates self-control. In particular, for those with a limitation, who live and work more and more in their own environment, self control issues are less explicitly present. Our hypothesis is that if this self-regulation is supported, the autonomy of the client is being enforced.

SOCIAL-EMOTIONAL DEVELOPMENT

Besides someone's cognitive ability with regard to self-regulation, it should also be taken into account what someone is able to handle socially and emotionally. Attention to social-emotional problems, such as making and maintaining contacts and preventing social isolation is of importance. A useful way of spending the day plays an important part in this.

Interactions have social and emotional consequences. It can be an uphill battle because of cognitive problems. Through executive problems someone becomes more impulsive in his or her emotions and is less sensitive towards others. Impotence can lead to aggression. If someone was pre-morbidly easily angered or overcharged, this is reinforced by injury. At the same time emotions must be regulated in order to be able to influence interactions in a safe manner. Safety is a basic condition in support. In case of supported autonomy safety is related to the predictability of the environment for the client. In the case of Mr. Klundert, impulsive aggression is a result of not being able to properly regulate emotions. In social situations it is clearly visible that emotionally he is more stable.

Impulsive aggression by Mr. Klundert created insecurity for his environment. Furthermore these incidents led to social exclusion. Transitions from work to home are more difficult when incidents have occurred. Returning to and closure of incidents are important to all those involved. When Mr. Klundert had calmed down, he recounted together with his supporter that the incident was unpleasant and not meant that way. This was to promote social skills and to prevent exclusion of Mr. Klundert. Incidents were reported to the housing counsellors, in order for them to be able to assess the frame of mind of Mr. Klundert. To make the environment for Mr. Klundert as predictable as possible, he made a fixed programme for himself together with his supporters. The programme held distinct agreements about what to do in case of tension or in the unlikely event that impulsive aggression should occur anyway. For example he generally ate in his room together with a fellow participant. If he felt relaxed he sometimes opted for having lunch in a group. If he was not relaxed, the supporter would see to it that he was distracted and would lead him to a more quiet environment. Mr. Klundert could step outside. The activity centre was fenced in so that he could not get lost. This gave him autonomy when he wanted to go for a walk in order to escape the tension.

SUPPORT OF AUTONOMY

Ingrained behavioural patterns in themselves are not sufficient to cause someone to be activated. With executive problems it is within reason to be able to lay a claim on learning methods that make less use of self perception, understanding of situations, spatial aptitude, recognizing connections and relations, flexibility, frustration tolerance and the distinction between essentials and side-issues. Such a structured learning method (Palm 1997) is provided by:

- step by step method;
- concrete clear language;
- short sentences;
- one communicative message at a time;

- verbal and non-verbal congruity (facial expression, gestures, intonation);
- being directive;
- giving feedback;
- handing alternatives;
- fixed routines;
- training within context;
- unequivocal, short term goals;
- not entering into discussions but going along and adjusting.

It is important that interventions are contextual and that they are based on daily routine (Ylvisaker & DeBonis, 2000). In five steps these authors define the structure of the interventions: (1) identify what does and what does not work for the individual in his daily routine; it is important with this to distinguish between cues and triggers. (2) Identify which changes (in the environment as well as in the behaviour of others or one's own behaviour) have the potential to convert negative, unsuccessful routines into positive behaviour. (3) Identify how these changes in daily routines can be motivating to the individual and the people directly around him. (4) Implement the necessary aspects which support the intensive practice with positive routines in a 'real-world' context. (5) Gradually and systematically withdraw support and systematically extend the context as soon as this becomes possible.

Mr. Klundert had always been a very creative, quiet man. He was a graphic designer and did a lot of photographing. Privately he loved to go for walks. His work used to give him a lot of satisfaction and acknowledgement. Graphic work, like colouring mandalas, tessellating in paintings, lamps, on wood and with fabrics, gave him a lot of recognition. He could fall back on routines that he already enjoyed in the old days. Sometimes he could not manage to come into action. In that case he needed a first step in a series of actions (a cue) from the supporter, after which he would follow ingrained patterns by himself (step 1). Impulsive aggression in case of tension is an unwanted routine. A trigger for Mr. Klundert was when several people asked him a question at the same

time. This made him lose all track of the situation and that caused tension. Impulsive aggression rendered him insecurity and the risk of social exclusion. Overview, peace and a fixed pattern could release the tension without causing damage. Mr. Klundert could choose from a number of different possibilities. He could move to a quiet room, he could regularly go to the toilet to avoid stimuli, he could go for a walk outside and with support he could get back to incidents (step 2). By linking the alternatives up with that which he already enjoyed and was used to, he was motivated to change. Besides he got support in entering into a conversation which had become difficult since he suffered brain damage because he had less insight in his behavioural regulation. The supporter encouraged him by opening the conversation (cue), but did not take over. This also gave Mr. Klundert a pleasant feeling (step 3). The alternatives to act were included in a programme. Mr. Klundert carried this with him and this was also pointed out to him by the supporter. This was done by the housing counsellors as well as by the supporters in the day activities centre. In this way he learned to use it in his everyday living environment as well as in his working environment (step 4). Increase of activities or change of complexity would not come up for discussion until the pattern had become ingrained with Mr. Klundert and support was withdrawn. For example he could also enjoy the lunch he normally had with a fellow participant in his office, in the kitchen of the day centre. This meant the same activities but a new context (step 5).

The above-mentioned approach fits in with the executive functions and the corresponding routine. It is important to make a habit of these (intellectual) processes. This way self-regulation becomes a routine within a fixed context with recognizable interactions. Taking over direction often has a contrary effect and causes oppositional behaviour. Respectful treatment and clear communication are therefore important aspects to help people with acquiring new behaviour (Benson et al., 2000; Willis & LaVigna, 2003).

In order to be able to be respectful and directive towards Mr. Klundert it was essential to make contact with him. Communication and attitude aspects that play an important role for him were:

- *sincerity, being truly happy to see him;*
- *tuning in to a slower rhythm;*
- *no saddling with responsibilities, decisions and choices;*
- *leaving choice from alternatives (that do not overcharge or cannot lead to failure);*
- *handing recognizable incentive to act;*
- *coaching and letting decisions link up as much as possible with wishes;*
- *giving tasks in the field that he is good at;*
- *discreetly taking over that which he is not good at;*
- *ask him to help you, invite, no force, space;*
- *paying compliments, humour.*

Supporters concentrate on support of executive functions by giving examples, doing things together and the final coaching of someone else (master-pupil). Communication is an important means in this. Tone, choice of words and phrasing questions turn out to be important aids (Ylvisaker & DeBonis, 2000). In the acquisition of behavioural patterns it is essential that the client learns to apply these in his or her own living environment. This is especially complex because the behavioural patterns can best be build around cues or triggers. By using cues and avoiding triggers the behavioural pattern is more based on reflexes than on conscious transfers which enlarges the chance of success. The trick is to recognize the right cues and triggers.

In the case of Mr. Klundert an analysis was made and a training plan had been drawn up based on the steps of Ylvisaker en DeBonis (2000). In this regard the possibilities and wishes of the individual had been looked at, taking into account the executive functioning. By way of engraining new patterns and falling back on routines, behavioural modification stimulates autonomy and self-regulation of people with impairments in the executive functions. It is important that this takes place contextually.

Mr. Klundert and his environment are contented. He experiences a lot of satisfaction in his work and he looks forward to it. The escalations visibly diminished. Mr. Klundert is more and more capable of staying in the group for longer periods of time. Because of the clarity and the unequivocality in approach it is very surveyable and predictable for him. He reacts well to triggers by walking away from them and has included the positive clues in his daily rhythm.

References

- Beeckmans, K. & Michiels, K. *Kopzorgen na een hersentrauma: de psychologische gevolgen van een traumatisch hersenletsel; een boek voor patiënt, familie en hulpverlener*. Garant, Leuven/ Apeldoorn, 2000
- Benson Yody, B., Schaub, C., Conway, J., Peters, S., Strauss, D. & Helsinger, S. Applied behavior management and acquired brain injury: approaches and assessment. *Journal of Head Trauma Rehabilitation*, 15, 1041-1060, 2000
- Goffman, E. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York, Doubleday, 1961.
- Guercio, J.M. & McMorrow, M.J. Proactive protocols for severe unwanted behavior after acquired brain injury. *Case Manager*, 13, 55-58, 2002
- Owensworth, T.L., McFarland, K., & Young, R. McD. The investigation of factors underlying deficits in self-awareness and self-regulation. *Brain Injury*, 16, 291-309, 2002
- Palm, J.H.W. *Veranderd leven: begeleiding na hersenletsel*. (Changed life: support after brain injury). Van Gorcum, Assen, 1997
- Tate, R.L. Executive dysfunction and characterological changes after traumatic brain

injury: two sides of the same coin? *Cortex*, 35, 39-55, 1999

Willis, T.J. & LaVigna, G.W. The safe management of physical aggression using multi-element positive practices in community settings. *Journal of Head Trauma Rehabilitation*, 18, 75-87, 2003

Ylvisaker, M. & DeBonis, D. Executive function impairment in adolescence: TBI and ADHD. *Topics in Language Disorders*, 20, 29-57, 2000

Ylvisaker, M., Jacobs, H.E. & Feeney, T. Positive supports for people who experience behavioural and cognitive disability after brain injury (a review). *Journal of Head Trauma Rehabilitation*, 18, 7-32, 2003