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PO Box 117
221 00 Lund
+46 46-222 00 00

Driving to Learn

*The Process of Growing Consciousness of Tool Use
– A Grounded Theory of De-plateauing*

Lisbeth Nilsson

Department of Health Sciences
Division of Occupational Therapy
and Gerontology



DRIVING TO LEARN

The Process of Growing Consciousness of Tool Use – A Grounded Theory of De-plateauing

Lisbeth Nilsson

Akademisk avhandling

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Title and subtitle DRIVING TO LEARN The Process of Growing Consciousness of Tool Use – A Grounded Theory of De-plateauing.			
Abstract <p>The Driving to Learn project explored possible achievements of training people with cognitive disabilities in a joystick-operated powered wheelchair utilizing the grounded theory approach. Theoretical sampling led the concomitant collection and analysis of data. During a period of 12 years, 45 participants with profound cognitive disabilities, aged 12 months to 52 years, were engaged in the project. Typically developed infants and participants with less degree of cognitive disabilities formed two reference groups. Data sources were video-recordings, field notes, interviews and information from medical records. Constant comparative analyses led the emergence of an eight-phase process of growing consciousness of tool-use, training strategies, a tool for assessment of joystick-use and identification of factors influencing the outcome of the training. The tool was tested for inter-rater reliability and used to evaluate the outcome of the 45 participants.</p> <p>Growing consciousness was by amplification conceptualised to a grounded theory of de-plateauing. Attainment of de-plateauing was reliant on the interdependent properties motivation, endurance, responsiveness, adaptability and access to resources with high predictability and usability. De-plateauing was defined as a positional change exceeding preconceived expectations. I argue that the grounded theory of de-plateauing might be useful in many more fields, where the phenomenon of plateauing attitudes is present either explicitly or implicitly.</p>			
Key words: activity, occupation, facilitate, growth, self-awareness, control, well-being, powered wheelchair, joystick, profound cognitive disabilities, assessment, outcome			
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 Lisbeth Nilsson, Division of Occupational Therapy and Gerontology, Department of Health Sciences,
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Om att hjälpa...

Om jag vill föra en människa
mot ett bestämt mål
måste jag först finna honom
där han är
och börja just där.

Den som inte kan det
lurar sig själv
när hon tror
att hon kan hjälpa andra.

För att hjälpa någon
måste jag visserligen förstå
mer än vad han gör,
men först och främst
förstå det han förstår.

Om jag inte kan det,
så hjälper det inte
att jag kan och vet mycket mer.

Vill jag ändå visa
hur mycket jag kan,
så beror det på att jag är fåfång och högmodig
och egentligen vill bli beundrad av den andre
istället för att hjälpa honom.

Sören Kirkegaard 1813–1855

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This thesis is based on the following publications referred to by their Roman numerals:^a

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- III. Nilsson, L. & Eklund, M. (2006). Driving to learn. Training in powered wheelchair with those with cognitive disabilities. *International Journal of Therapy and Rehabilitation*, 13, 11, 517–527.
- IV. Nilsson, L., Eklund, M., & Nyberg, P. (2006). Driving to Learn in a powered wheelchair: Inter-rater reliability of a tool for assessment of consciousness of joystick-use. Manuscript submitted for publication.
- V. Nilsson, L., Nyberg, P., & Eklund, M. Training characteristics important for growing consciousness of joystick-use in people with profound cognitive disabilities. The Driving to Learn project. Manuscript submitted for publication.

^aAdditional results, not previously published, are included in the thesis.
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Driving to Learn

The Process of Growing Consciousness of Tool Use – A Grounded Theory of De-plateauing

Lisbeth Nilsson

Introduction

Why did I think that people with profound cognitive and multivariate additional disabilities might benefit from powered wheelchair intervention? When I worked as an occupational therapist in a rehabilitation team for children and adults with disabilities, I realized that it was challenging to work with this population. It was hard to find the right conduct to relate to and to interact with each of the individuals. Their appearances were different, but at the same time, alike. The team members took measures to provide the parents and their children with assistance and technical aids to enable good care, but they had difficulty finding suitable training methods other than physical therapy. However, 20 years ago a local manufacturer gave the rehabilitation team access to a new powered wheelchair prototype for children. We introduced the prototype at a special school where we engaged

three young schoolboys with profound mental retardation and multivariate additional disabilities in powered wheelchair training. One of the boys developed the ability to steer goal-directed even though it had taken him six years to reach his current level of joystick-use. This extraordinary experience strengthened my belief that all people are capable of reaching unexpected levels of ability, but also left me with the question – how could this achievement be possible?

In November 1992, I went to Lund University to attend a distance course called ‘Steg 2’, equivalent to a candidate exam in occupational therapy. I still remember the feeling of being an outsider, due to my feeling of knowing too little to belong to the group. The first study week we were asked to present an idea that could form a project plan. When one day was left of the first week, my head was overwhelmed with new information and new impressions. In the middle of the night I sud-

denly woke up with an idea of what to do. I wrote down the idea and relieved, fell asleep again. The next day I had the opportunity to present my nightly idea to the course leaders Ulla Kroksmark and Åke Isacson. Caught in our discussion of how to proceed with a project plan of a study of powered wheelchair training, I missed the buss to the airport. Åke drove me to the airport in his car, while continuing the discussion. He said one thing that I always will remember: 'This is what you dream about, to instantly wake up with an idea about what to focus your research on. Stick to your idea!' and I have done so for an elongated time.

The idea was to focus my research on exploring what could be achieved from training people with profound cognitive disabilities in a joystick-operated powered wheelchair. The research project engaged the first participants in January 1993 and slowly expanded to an expedition exploring different tracks and leads emerging in the concomitant data collection and analysis. The project is not finished, there are still more tracks to explore and parts to be presented. However, the point has now been reached when it is time to summarize and synthesise the five parts that form this thesis.

I will start with a presentation of the focused population and predictions and attitudes concerning their capacity. I will then relate their limited possibilities to participate in developing activities to the fields of knowledge that I have found as most relevant to compare with.

People with profound cognitive disabilities

People with profound cognitive disabilities are a wide-ranging population with complex manifestations (Arthanat, Nochajski, & Stone, 2004). These people have pervasive activity limitations due to their profound cognitive disabilities. They have in common

that their disabilities are caused by disorders of brain formation and function or damage to the brain (Arthanat *et al.*, 2004; Battaglia & Carey, 2003). The cognitive disabilities can be of different aetiology, such as developmental and neurodevelopmental disabilities, mental retardation, trauma or aging (Lewis, 2006). The exact cognitive function of people with profound cognitive disabilities can be difficult to assess reliably due to multivariate additional disabilities, reducing physical and communicative capacity (Arthanat *et al.*, 2004; Gordon, Schanzenbacher, Case-Smith, & Carraso, 1996; Neistadt & Crepeau, 1998). These people need extensive or pervasive support in their daily activities (Ross & Bachner, 1998) and they show limited reactions and give unfamiliar responses to others' invitations to interact (Brodin, 1991; Granlund, Björk-Åkesson, Brodin, & Olsson, 1995; Granlund & Olsson, 1993).

Veiled potential for development

People with profound cognitive disabilities are extremely difficult to engage in any activity and often live in a state of passivity and dependency – being totally reliant on their caregivers (Weisz, 1979). Although their state and outward appearance may hide undeveloped potential (Kielhofner, 1992), clinicians often question the utility of teaching these people due to their apparent poor prognosis for learning meaningful and durable skills (Saunders, M., Timler, Cullinan, Pilkey, Qvestad & Saunders, R., 2003).

International Classification of Diseases – ICD-10

As the concept cognitive disabilities contains different aetiologies a description cannot be found in the ICD, tenth edition. The following description is, with reservation for too high a stipulated mental age, regarded as compatible to the population of profound cogni-

tive disabilities: 'IQ under 20 (in adults, mental age below three years). Results in severe limitation in self-care, continence, communication and mobility.' (WHO, 2006a, chapter V mental and behavioural disorders, F73).

International Classification of Functioning, Disability and Health (ICF)

The ICF complements the ICD-10 by looking beyond mortality and disease. It provides descriptions of body functions and structures, activities and participation (WHO, 2006b).

People with profound cognitive disabilities experience major activity restrictions and participation limitations. The body domains related to these problems are the mental functions and the structure of the nervous system. These people have profound impairments regarding learning and applying knowledge, communication, mobility and interpersonal interactions and relationships. Also environmental factors, such as products and technology and the attitudes of others, can serve to limit this population's activity and participation. (Arthanat *et al.*, 2004).

Research on enhancing constructive performance in people with profound disabilities

Assistive technologies are often too complex for people with cognitive disabilities and this population needs a lot of training to learn how to utilize devices (Scherer & Bodine, 2006). However, numerous research reports on different methods intended to enhance constructive performance in people with profound disabilities have been published during the past decade (e.g. Ivancic & Bailey, 1996; Lancioni, O'Reilly & Emerson, 1996; Lancioni, O'Reilly, Campodonico & Manti, 1998; Lancioni, O'Reilly & Basili, 2001a; Lancioni, O'Reilly, Singh, Oliva & Groenweg, 2002; Saunders, Smagner & Saunders,

2003; Dixon, Rehfeldt & Randich, 2003; Shull, Deitz, Billingsley, Wendel & Kartin, 2004; Cannella, O'Reilly & Lancioni, 2005; Saunders, M., Saunders, R., Mulugeta, Henderson, Kedzior, Hekker *et al.*, 2005; Lancioni, O'Reilly, Singh, Oliva, Scalini, Vigo *et al.*, 2005; Lancioni, O'Reilly, Singh, Sigafoss, Tota, Antonucci *et al.*, 2006). Different types of micro switches are the most frequently used technical devices in this research. The participants/switch-users are stimulated to activate a switch by use of different reinforcing objects or events. An often-considered issue in the research is the failure to observe consistent changes in the switch-user's behaviour (Saunders, Timler *et al.*, 2003). Reasons suggested for this failure include the problems: to identify an object or event that stimulate response; to properly choose and position the switch; and the participants level of cognitive functioning (Lancioni, O'Reilly & Basili, 2001b). However, typically the research in this field is experimental, shifting between trials where switch-use gives an effect and trials where switch-use does not give an effect. The numbers of trials in the experiments are relatively few and the sessions seldom last more than 15 minutes (Saunders, Timler *et al.*, 2003). The population with profound cognitive disabilities is vulnerable due to their invasive disabilities and their need of long periods of training to show signs of consistent changes in behaviour (Saunders, Timler *et al.*, 2003). Thus, it may possibly be the experimental design with periods of non-effective trials that interrupts an initial understanding of relations between own actions and the resulting effects. People with disabilities may lose interest in a world they do not understand or expect to control (Brinker & Lewis, 1982). People with profound cognitive disabilities frequently experience uncontrollable events that may evoke learned helplessness (Seligman, 1975; Swin, Anson & Deitz, 1993; Weisz, 1979). Thus, their experience of unpredictable effect – not effect in the experimental situation, may be

a factor negatively influencing their ability to learn cause-effect relationships.

Confining attitude

A question quoted in Ross and Bachner (1998, p. 94) is a typical example of a confining attitude, "Why serve those who show a minimal level of independent purposeful function?" Altogether, this group of people is often considered as not having the potential for development. It is often claimed that people with profound cognitive disabilities have reached their ceiling or plateau of cognitive development (Chadwick, Cuddy, Kusel & Taylor, 2005; Greenspan, 1999). Thus, the profound cognitive and additional multivariate disabilities work as a barrier for these peoples' development of potential capacity to be active, conscious and occupied.

Activity and consciousness

Human activity requires consciousness and consciousness develops through activity, interaction and communication. (Engeström, Miettinen & Punamäki, 1999; Leontjev, 1977; Luria, 1976; Vygotsky, 1978). The question is: How can we assist people to experience activity and develop consciousness?

People with profound cognitive disabilities, as mentioned above, experience major restrictions and limitations related to activity and participation. These hindrances together with negative attitudes influence the unveiling of these people's hidden potential to take part in developing activities.

Activity – causes changes in positions

Human activity could be considered as varying combinations of movement, motion or mobility. The motion takes on many different forms, such as performance of concrete activities, interaction with objects, social interaction

with others, experience of feelings, communication and thinking. Activity involves a wide range of possible causes of changes in position between different entities. Body-parts change position during performance and the actor is changing the positions of objects or tools used during activity. Motion in-between different actors' change their inter- and intra-position. Emotions and feelings move and change people. Communication and thinking are motions that may change one's own or other's positions. People are moved to do things, motivated to make a change. Being able to move, to set in motion and to use mobility gives opportunities to change position in a micro- as well as a macro perspective, in a material or an abstract, an intellectual, psychological, emotional and /or a physical dimension.

We live and are active through our bodies and the way we live our bodies determine our personal experience of the world. The body can be considered a viewpoint from which we experience and act upon the world, the centre from which we exist, attend and behave to the world (Kielhofner, 1995). Seeing ones body this way elucidates the importance of access to activities that can create meaning and motivation for doing things that might make a change in our lives. Disabilities not only delimit the viewpoint from which to develop consciousness of the world they also delimit the variety of activities possible to participate in.

People with profound cognitive disabilities experience devastating consequences of their impairments resulting in limited capacity of living their bodies and limited abilities to make changes in their position in life.

Consciousness and attention

The brain is the target for an endless stream of sensory impressions. A very small amount of the sensory information is consciously perceived (Feinstein, Stein, Castillo & Paulus, 2004; Nørretranders, 1996). Attention is

complex as it incorporates different mechanisms helping humans in handling incoming information, external as well as internal. One proposal of how to distinguish the attention mechanisms is: scanning of sensory flow, attention attraction to unexpected changes and deliberate attention-focusing (Brinck, 2000). Conscious perception means to be aware – to have knowledge of – sensory stimulus. The abilities to attend to stimulus and remember previous events are essential components of conscious perception (Feinstein *et al.*, 2004).

People with profound cognitive disabilities often have a low basic state of arousal due to being exposed to a relatively low flow of sensory information (Arthur, 2004). If their attention is focused it may be as a direct consequence of attention attraction (Brinck, 2000), which means that their attention is attracted by unexpected events such as change or a novelty in the environment.

Behaviour

Bodily movements are simple physical events that are goal-directed, meaning they are directed towards a set of satisfactory conditions. The behaviour is not necessarily linked to an explicit and conscious representation of a specific condition, and it does not contain a consciously experienced reward-producing component. Much behaviour can take place in a semi-automatic manner. (Metzinger & Gallese, 2003).

A person with profound cognitive disabilities can be observed scratching a body part, rubbing an eye, picking a nostril or engaging in stereotype behaviour with fine precision. However, such precise movements might not be used for performance of other activities.

Body and hand-use

Infants develop whole hand voluntary grasping at 3–4 months, however at that age the

infant lacks the capability to couple a grasp with a reaching movement (Eliasson, 1994; Savelsbergh, von Hofsten & Jonsson, 1997). The stabilization of trunk, shoulders and elbows are a prerequisite for adequate grasping and manipulation. Anticipatory control of grip develops rapidly after the first successful voluntary grasp (von Hofsten, 1997; von Hofsten, Vishton, Spelke, Feng & Rosander, 1998). At the age of five months a preparatory grasping mechanism has developed together with the capacity to do adjustments in hand orientation by wrist movements. At the age of six months, the child's previous experiences have established a representation of a manual action scheme for grasping and transferring an object to a new location (Eliasson, 1994; Király, Jovanovic, Prinz, Aschersleben & Gergeley, 2003).

Generation and modulation of force and speed are prerequisites for effective and smooth use of body and hands in specific activities (Carr & Shepherd, 1998; Gazzaniga, Ivry & Mangun, 2002). Periods of high variability in performance of a task often foregoes the development of a more stable pattern of effective execution of the task, also called attractor pattern (Carr & Shepherd, 1998; Haugen & Mathiowetz, 1995).

People with profound cognitive disabilities have, due to their impairments, limited opportunities to take part in activities that may develop their understanding and use of body and hands. Thereby their achievements of patterns for effective manipulation and body-use are dependent on others assistance and guidance in different activities.

Self-produced movement

Self-initiated mobility is considered very important for psychological changes during infancy (Anderson, Campos, Anderson, Thomas, Witherington, Uchiyama *et al.*, 2001). Self-produced movement with concurrent visual feed-back is necessary for the develop-

ment of visually guided behaviour (Held & Hein, 1963). The human age of 7–9 months is pointed out as a period of rapid developmental reorganisation. The relationship between infants self-produced locomotion and their development in other areas in this period is well documented (Bertenthal, Campos & Barrett, 1984). Acquisition of motor skills produces experiences that enable a number of new developmental changes in the same and different areas. The emerging ability to move around creates a new level of interaction between the infant and the environment (Anderson *et al.*, 2001; Bertenthal *et al.*, 1984).

The majority of people with profound cognitive disabilities do not develop the ability to be independently mobile. Therefore the opportunities to explore and move around in their immediate vicinity are severely restricted.

Self-awareness and agency

Newborn babies consciously experience their actual sensory states such as hunger and pain. Newen and his co-workers (2003) call this basic form of consciousness phenomenal self-acquaintance. Development of self-awareness is dependent on the experiences from active voluntary movement. At around two months of age infants have a sense of how the body is situated in relation to other entities in their vicinity. Active explorations provide experiences of consistency between seen and felt bodily movements (Rochat, 2003). This coherence of visual, tactile and proprioceptive perceptions constitute the sources of bodily awareness, which is necessary for the ability to consciously use arms and hands for reaching and grasping (Tsakiris, Prabhu & Haggard, 2005). When a baby starts to produce joint attention concerning an object, conceptual self-consciousness has developed (Newen & Vogeley, 2003). Self-consciousness is defined as the ability to become aware of one's own states as one's own.

The experience of ownership of perceptions provided by active movement is distinguished from the sense of agency provided by the recognition of the own ability to intentionally cause an action or cause an effect by an action (Farrer, Franck, Paillard & Jeannerod, 2003). It is possible to feel an ownership of moving or being moved without feeling an agency of causing or controlling that movement (de Vignemont & Fournier, 2004; Newen & Vogeley, 2003). The experience of personal agency may be stronger when performing actions that require effort and concentration compared to skilled actions that are performed more effortlessly (Nahmias, 2005).

Due to the limited ability to actively move and explore the representations of their own body and other entities, people with profound cognitive disabilities are dependent on others to create the experiences that build up body-awareness, self-recognition and sense of agency of causing or controlling effects.

Goal-directed action

Infants can represent and interpret actions as goal-directed by the age of 6–9 months (Király *et al.*, 2003). Infant motor development has an impact on a range of perceptual, cognitive and emotional changes (Anderson *et al.*, 2001). Infants' active exploration and production of consequences enable them to develop contingency awareness (Brinker & Lewis, 1982). At first the interaction with an object is strongly linked to the physical action, but then a different way of interacting develops that is directed towards achievement of a certain effect or outcome (Becker, 2006). Via the experience of repeated contingency the infants establish a generalized expectancy that the world is controllable (Brinker & Lewis, 1982). The formation of action goals is related to the anticipation of action effects and anticipation of effects plays an important role both in action acquisition and control (Király *et al.*,

2003). The ability to perceive others actions as goal-directed is to attribute goals to their actions (Csibra, 2003). Goal attribution can be demonstrated in early infancy, which suggests that goal-directedness develops due to a more general representational understanding of the concept of goal, and not as a function of piecemeal learning about particular actions (Király *et al.*, 2003).

Goal-directed actions are subjective phenomena that involve conscious self-representation, a representational perspective on the world and composition of subsets of goal-directed movements (Metzinger & Gallese, 2003). An action is goal directed if it is performed to achieve an end (Csibra, 2003). Mental actions, such as concentrating, reflecting, recalling, taking consequences under consideration and planning are involved in the formation of goal-directed activity (Nahmias, 2005). Many different moves or movements can constitute the same goal-directed action. Actions do not necessarily involve reflexive self-consciousness, understanding of concepts or mastering of language. For an action to be goal-directed it is enough that the actor attends to the action goal or selects a specific motor pattern for execution. (Metzinger & Gallese, 2003). This suggests that people with profound cognitive disabilities do and might further develop the ability to undertake goal-directed actions.

Nevertheless, limited abilities to actively partake in different activities cause a vicious circle for people with profound cognitive disabilities and limit their possibilities to develop understanding of contingencies, perceive others goals, form own goals and perform goal-directed activity.

Tool-use and skill acquisition

Infants and young children acquire tool-use skills somewhere between 9 and 18 months of age, long after their development of sensory-motor control for reaching and grasp-

ing (Johnson-Frey, 2004). The process of acquiring skills needed for perception of a tools representation and for planning how to use it, is a form of perception-action coupling that needs to be learned and adapted through continued exposure. The adaptation of particular patterns of action is based on the accumulation of previous responses and expectations (Baber, 2006; Lockman, 2000). Action development involves manipulation, trial and error, explorative and experimental handling to detect and interpret the affordances offered by a tool (Lockman, 2000).

Baber (2006) claims that research on physical aspects of human activity has little room for consideration of cognition, and research on cognitive aspects seldom mentions the physical aspect of performance. Development of understanding of the physical principles and the causal regularities that underlie the use of a tool is necessary for flexible usage of the tool in different contexts. If learning is based on association and conditioning the usage of the tool will be dependent on specific stimuli used during training (Chapell, 2006). The process of learning tool-use is proposed to involve perception-action coupling, psychomotor abilities, manipulation and controlled handling, reflection on and anticipation of effects, tool use-outcome coupling and ability to learn skills from others (Baber, 2006).

Tools are cultural and can be more or less complex to use. Tools can be material, such as hammers, pencils; semantic, such as alphabet and sign language; or constitute combinations of material-semantic-abstract characteristics such as computers (Macdonald, 2006; Vygotsky, 1986/1994). Understanding of the representations necessary for using a tool is separable from the semantic knowledge of characteristics, functions and appropriate sequencing of actions associated with of the tool-use (Johnson-Frey, 2004). Based on neuroimaging it is proposed that acting on objects (reaching, grasping and manipulation) is supported by schemata resulting from sensory

motor transformations, whereas acting with objects (tool use) is supported by schemata arising from the distributed practice of skilled action (Johnson-Frey & Grafton, 2003). The representations of a tool can be manipulated, handled or used either internally or externally e.g. head counting or calculating using pen and paper or calculator. If the representations of a tool are not recognised, the tool is merely an object and cannot be used to direct force onto the world, to cause effects and control events (Baber, 2006).

People with profound cognitive disabilities rarely develop the sensory-motor and cognitive abilities needed for acquisition of tool-use. This may be dependent on their limited experiences and frames of references concerning use of tools. Their limitations may also be influenced by which perspective others adopt on the subject of caring contrasted with rehabilitation. The perspective adopted directs the interventions legitimated and applied with this population.

Interaction and communication

Interaction and communication take place in the dimensions of time and space, and teaching and learning are specialized forms of human interaction (Hall, 1990). Learning of novel motor and cognitive skills requires conscious efforts (Seth, Baars & Edelman, 2005). Sequential interaction that involves an object, requires a more complex interaction and a better understanding of the order and timing of the events compared to interactions without objects (Granlund & Olsson, 1993).

Body and hands are consciously or unconsciously used for communicative behaviours. Gestures can transmit communication and reflect knowledge that a person possesses but does not verbalize. Gestures are pervasive, overt and interpretable. Thereby, gestures could give information about unspoken knowledge. There is growing evidence that gestures not only reflect understanding but

also shapes it. The use of gestures may facilitate learning and contribute to cognitive growth (Goldin-Meadow, 2000).

People learn to seek patterns in interaction and scale perceptions up or down depending on the type of interaction. As an example, interactions or communications with infants are scaled differently from those with adults. This leads to a comprehensible occupational blindness that makes it almost impossible to pay close attention to interaction or communication of other types on other wavebands. (Hall, 1990). This may intrude on interaction with people who use other ways to communicate whether their mother tongue, an alternative way to communicate or a technical terminology. Thus, this blindness may account for the difficulties often experienced in interpreting and responding to the unfamiliar communicative behaviours of people with profound cognitive disabilities (Brodin, 1991; Granlund *et al.*, 1995).

People with profound cognitive disabilities have limited repertoires of interaction and communication and difficulties in understanding order and temporality. Thus, a general understanding of how these peoples' actions and interactions are sequenced and a specific enhancement of efforts to interpret their behaviours are needed to be able to appropriately respond to and teach this population.

Teaching and learning

Interaction involving people and cultural tools plays an important role in teaching, learning and the development of body and mind (Hatano & Wertsch, 2001). The tools mediate behaviour, transform knowledge and enhance thinking (Gauvain, 2001). The idea of mediation is central to the theory of socio-cultural psychology as originated by Vygotsky (1978). In a learning situation the teachers can be seen as agents using mediational means. Their means are cultural tools

that can be either material or semiotic. They use the tools to mediate or transfer knowledge to the trainees. The trainee's capacity, access to and use of appropriate tools, together with the construction of the learning context and the expectations on behalf of all persons involved limit what the teachers can achieve with their trainees (Macdonald, 2006). In a successful teaching – learning situation the teacher can use purposeful activity to create meaning, motivation and mastery.

Becoming an occupational being

Infants become aware of purposeful actions through interaction, exploration and play. Occupational engagement serves as a change mechanism, a medium for development of occupational behaviour (Humphry, 2002).

Occupation can be viewed as a synthesis of 'doing', 'being' and 'becoming' (Wilcock, 1998a). 'Doing' is often used synonymous with occupation. 'Doing' what you want to do and what you enjoy doing, brings about satisfaction and happiness. 'Doing' activities or occupations exercises, maintains and develops physical and intellectual capacities and provides the means for social interaction and mutual growth. People's tools, symbols and values influence their interaction and support of each other (Gauvain, 2001). 'Being' can be regarded as a state of existing, being-within-self, which means to have time to discover self, to think and reflect. 'Becoming' an 'I', a competent and social being, is dependent on 'doing' related to individual, historical and cultural development. 'Becoming' holds a belief in humans' potential capacity and ability to grow (Wilcock, 1998a).

Occupation must evidence purposiveness and intentionality in organizing behaviour according to some objective or goal. However, the recognition of occupational behaviour is especially difficult when access to people's subjective experiences is denied. Motor ex-

pressions afford an impartial view of purpose and intention but are indispensable for recognition of emerging expressions of occupational behaviour. When indicators of intentional behaviours are identified, further development of purposiveness can be supported in aware and meaning creating actions (Wood, Towers & Malchow, 2000).

Purposeful activity creates meaning and motive for doing (Bruner, 1990; Macdonald, 2006). To be motivated means to be moved to do a certain activity (Ryan & Deci, 2000). Goal-directed activities such as hand-use, self-produced mobility and use of concrete, abstract or semantic tools may be considered main organizers of human consciousness (Bertenthal *et al.*, 1984; Király *et al.*, 2003; Toates, 2006).

People with profound cognitive disabilities have limited capacity and are given few opportunities to take part in activities that are creating meaning and motivation. To become doers they are totally reliant on other's belief in their veiled potential to be active and develop consciousness.

Powered mobility intervention

Access to powered mobility intervention requires certain cognitive abilities (Verburg, 1987). It is proposed to use a single switch controlled device to assess a person's ability to understand simple cause effect relationships before the onset of training in powered mobility (Cook & Hussey, 1995). Researchers have identified cognitive requirements for training in a powered wheelchair and developed cognitive assessment batteries that provide therapists with guidelines for intervention and prescription of powered mobility (Guerette, Tefft, Furumasu & Moy, 1999; Tefft, Guerette & Furumasu, 1999; Furumasu, Guerette & Tefft, 2004). However, persons with profound cognitive disabilities are not thought of as candidates for use of

single switch controls or training in a powered wheelchair due to their limited cognitive function (Ross & Bachner, 1998).

Independent powered mobility

Previous studies have demonstrated the importance of giving children with physical disabilities and minor or moderate cognitive disabilities, access to independent powered mobility in early childhood (Bottos, Bolcati, Sciuto, Ruggeri & Feliciangeli, 2001; Butler, 1986; Dietz, Swinth & White, 2002; Furumasu, Guerette & Tefft, 1996; Iles & Shouksmith, 1987). The experiences of being independently mobile influence positively on the development of psychosocial and intellectual abilities (Butler, 1986; Hardy, 2004; Paulsson & Christoffersson, 1984; Wiart & Darrah, 2002). Whether this is also true for people with profound cognitive disabilities is not known as, to the best of my knowledge, studies of training this population in joystick-operated powered wheelchair do not seem to exist.

The Driving to Learn project

At the time of the onset of this research project the Swedish Handicap Institute recommended powered wheelchair training with a line follower system for the population with severe and profound cognitive disabilities (Birath, 1985 and 1987).

The line follower system was developed to give people with severe and profound cognitive abilities access to independent mobility (Call Centre, 1988; Nisbet, 2002; Odor & Watson, 1994; Sanders & Stott, 1999). A powered wheelchair or platform with that system can, by use of a sensor, follow a line of black or white tape attached to the floor or ground. A single switch contact is used to activate power. Speed is set low to keep the chair/platform on track and the user cannot regulate the speed. On the line the chair can

only go forward, as reversing or turning round is not possible. Reports from testing line follower systems are both encouraging and disappointing. Participants with severe or profound cognitive disabilities have shown ability to succeed by reaching a limited version of independent mobility, but only very few accomplished a transition to a joystick-operated powered wheelchair (Birath, 1989; Christiansson & Hjortsby, 1991).

People with profound cognitive disabilities rarely get access to the powered mobility technique with line follower system. They are not considered able to learn how to use an operating tool (Ross & Bachner, 1998) and the availability of the technique is still scarce in clinical practice. The limited access in clinical practice may be due to the health professional's lack of knowledge of existing research and development but also to the difficulty in obtaining expensive equipment when health care economic resources are cut down (Copley & Ziviani, 2004).

The initially mentioned extraordinary clinical experience made it natural to question the recommendations to use the line follower system and instead explore the possible benefits of training free driving in a joystick-operated powered wheelchair.

The initial problem was to get an idea of how to develop an appropriate training approach. The participants did not respond to verbal instructions and showed aversion to being touched on their hands. The first trials indicated that free driving might be excited by use of gentle verbal encouragement and manual guidance of acts on the joystick. Florence Clark said, after viewing one of the first video-recordings from a session where a trainee kept on driving in narrow circles after release of manual guidance: 'he is giving himself sensory integration' (Personal communication, Lund University, 1995-10-05). Clark, on the same occasion, claimed that it would be favourable to choose the activity perspective for the project as that was broad-

er compared with the more narrow cognitive perspective. In sensory integration (SI) theory active movements are seen as founders of the development of neural models or memories of how it feels to move (Fisher, Murray & Bundy, 1992; Miller, 1988). Important intervention ideas in the SI-theory are that the child should be able to direct and influence the utilized activity, the activity should be meaningful for the child and the activity should be developing and demand adaptive responses (Ayres, 1987; Fisher *et al.*, 1992). Those ideas worked as guidelines for the development of the training approach.

New ways to use well-known tools

The idea to use powered wheelchair intervention as a resource for teaching people with profound cognitive disabilities simple cause-effect relationships, constitutes a new way to use a well-known tool. At the commencement of the project other professionals questioned the idea. In rehabilitation and in special education the common intervention for stimulation of causality awareness was the use of single switches to control toys or apparatuses. To use such an expensive tool to train people who were not expected to reach the traditional goal – learning to drive safe and functional (Furumasu *et al.*, 2004), seemed to others as a waste of resources.

New ideas are often met with resistance, as they extend beyond the well-known boundaries of existing knowledge and experience within the involved division of practice. The perceptions of the framework in existing practice, regarding how things should be done, often preclude development of new approaches and attitudes (Glaser, 1998).

Successful constructions of new models of action need to be based on careful historical and empirical analyses of the field in question. In doing so, the researchers involved need to be engaged in forming societally new arte-

facts and forms of practice jointly with their subjects. The resulting theoretical concepts and methods may provide a two-way bridge between general theory and specific practice, thereby serving as intellectual tools for reflective mastery of practice (Engeström, 1999).

Aim

The overarching aim of the project was to explore what could be achieved from training people with profound cognitive disabilities in a joystick-operated powered wheelchair.

The specific aims were as follows:

- To explore which acts and behaviours could be interpreted as achievements and trace trajectories or patterns in the attainments.
- To explore if there were training strategies that could facilitate learning of joystick-use.
- To explore the training context with a focus on physical, psychological and social factors facilitating or hindering achievements.
- To evaluate a tool for assessment of achievements of joystick-use developed during the project.

Materials and methods

This thesis is based on the project Driving to Learn. The project explored the possibilities to develop potential capacity of activity and consciousness in people with profound cognitive disabilities by training in joystick-use. In addition a grounded theory of de-plateauing emerged.

General methodological approach

The project adopted the classical Grounded Theory (GT) methodology (Glaser &

Strauss, 1967; Glaser, 1978 and 1998). Out of the five papers that composed this thesis, three parts are entirely based on this methodology (Papers I – III). The other two parts employed the qualitative data and results for testing the inter-rater reliability of the developed assessment tool (Paper IV) and for analysing influences on the trainees' outcome regarding joystick-use (Paper V).

The classical Grounded Theory methodology

Glaser and Strauss (1967) presented the idea of GT in 'The discovery of grounded theory'. Glaser alone wrote a second book on the methodology 'Theoretical sensitivity' (1978). Strauss took the GT methodology in a direction different from that outlined in 1967, while Glaser held on to the clarification and amplification of the original classical GT method. He has written numerous books, in order to support 'the minus mentored' (1998), assignable to those who rely on the books to make an adequate application of the methodology (Glaser, 2001, 2003 and 2005; Glaser & Holton, 2004).

GT research starts with a general question concerning a special area of interest (Glaser & Strauss, 1967; Glaser, 1978 and 1998). The *Driving to Learn* project started with an open question induced from clinical work: what can be achieved if people with profound cognitive disabilities get access to training in a joystick-operated powered wheelchair?

In GT the intentions are to understand the action in the area from the point of view of the actors involved, to find the answers to 'what is going on, what is the actor's main concern and what is the prime mover of the action and interaction' (Glaser, 1992; Glaser, 1998 and 2001). All is data, meaning that

the briefest of comment to the lengthiest interview, written words in magazines, books and newspapers, documents, observations, biases

of self and others, spurious variables, or whatever else may come the researchers way in his substantive area of research is data for grounded theory (Glaser, 1998, p 8).

All kinds of data, qualitative as well as quantitative, can be used with the methodology. GT is concerned with comparing data irrespective of the cases' equivalence on similar properties and similar outcomes (Glaser, 2003).

The project was an exploration of a relatively unknown field, Although the actors with profound cognitive disabilities could not be interviewed we could observe their reactions, behaviours and activity. These observations formed the basis for understanding of the actors main concern and prime mover of their action and interaction.

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges (Glaser, 1978, p 36).

Systematic open coding of raw data and emerging substantive codes directs the constant comparative analytic process of selective coding, pattern seeking, writing memos and sorting (Glaser & Strauss, 1967; Glaser, 1978, 1998 and 2003). The selective coding generates ideas on relationships and connections between codes, categories and indicators and these ideas have to be memoed and written down immediately, otherwise they are forgotten (Glaser, 1978). Theoretical codes on relationships between the substantive codes emerge from sorting and resorting memos and may raise the findings from a descriptive to a conceptual level (Glaser, 2001 and 2005). It is important to try to stay open while in the field (Glaser, 2005). To stay open includes both looking for more data to compare with, coding for new categories and modification of the emerging theory. This process of theoretical sampling can lead to saturation, meaning the point where new

data does not add to or change the emerged categories (Glaser, 1978).

GT is a rigorous process that may lead to the generation of conceptualised, integrated patterns, as indicated by categories and their properties (Glaser, 2001). In a GT all categories and their properties stand in some relation to the others. The theory is not a truth but a hypothesis that may be verified or modified by the originator or others (Glaser, 1998). A grounded theory should 'fit, work and be relevant' in the area of interest and it should be 'modifiable' (Glaser, 1978 and 1998). 'Fit' means that the categories of the theory must be grounded in data. Data should not be forced to fit pre-existing categories or discarded in favour of keeping an extant theory intact. If a theory 'works' it can explain what happened, interpret what is happening and predict what will happen in the field of interest. A theory is 'relevant' if the actors in the field of interest attain it. Generation of theory is an ever-modifying process and variation and relevance is ever changing in the world. A theory is not sacred and can always be 'modified' to keep up with changes. (Glaser, 1978).

The trainees in the Driving to Learn project developed extremely slowly, thus it took many years of analysis to discover the basic social-psychological process and to conceptualise a theory resolving the problems in the area of interest.

Participants

The participants, also called trainees, were sampled among children, adolescents and adults listed in the Paediatric Rehabilitation Teams, Community Day Centres and Health Care Centres in the geographic area of Norrbotten County Council.

The criterion for engagement in the project was profound cognitive disabilities, or being at a very high risk of developing this condition. During a period of more than 12 years,

45 participants were engaged in the project according to the theoretical sampling, 20 were female and 25 male. At commencement of the training they were aged 12 months to 52 years, and had a median age of 11 years. Forty participants were assessed to have profound cognitive disabilities. The other five were younger than two years, but assessed to be at very high risk of developing profound cognitive disabilities.

Except for their cognitive disabilities, all the participants had multivariate additional disabilities including no speech or ability to use augmented or alternative communication. The additional disabilities were severe or profound physical disabilities, visual and hearing impairments, autistic or challenging behaviours and seizures. All had a pervasive need of assistance with the most basic activities of daily life, such as feeding and toileting.

Six participants, two school children, two teenagers and two adults, were able to walk with or without technical devices despite their profound cognitive disabilities.

Reference groups

From the fifth year on, other participants also were sampled for the project. They cumulatively formed two different reference groups.

Reference Group I included 17 typically developed infants, aged 3 to 12 months, without any known disabilities. The 17 infants made 40 trials in a powered wheelchair, one to six each with one-month in-between trials. The sampling of Reference Group I was made to compare the performance of the 45 participants with profound cognitive disabilities to the performance of infants in order to explore similarities in observed signs of development of joystick-use.

Reference Group II incorporated 64 participants, aged 16 months to 86 years, with less degree of cognitive disabilities. The par-

ticipants in this group were recruited from the same institutions and geographical area as the primary group and were also engaged in the project according to theoretical sampling. The sampling of Reference Group II was made to compare similarities in the trajectory of possible achievements regardless of age or degree of cognitive disabilities.

Representation in the papers

Two pre-school children, aged four and five years, were the first to be engaged in the powered wheelchair training (Paper I). The total of 45 trainees with profound cognitive disabilities and the two reference groups were engaged in the training to identify signs of achievements (Paper II). The 45 trainees' powered wheelchair interaction was focused to identify factors hindering or facilitating achievements (Paper III). Twenty-four video-clips were extracted from video-recordings of the 45 trainees and the two reference groups to test the inter-rater reliability of a tool developed for assessment of the trainee's achievements (Paper IV). The 45 trainee's achievements were statistically analysed to identify factors influencing the outcome of the training (Paper V).

Training procedures

The Driving to Learn project was conducted in a rural area in the northern part of Sweden. This circumstance, together with a small number of eligible participants, contributed to the geographical distribution of trainees and involvement of other trainers in the conduction of the project.

Trainers

From the beginning I was the sole trainer, but quite soon, as a necessity of the rural context and the small number of people with profound cognitive disabilities, others also took

on the role of trainer. These other trainers were parents, personal assistants, occupational therapists, physical therapists, teachers, teacher's assistants and other staff members in the locations where the training took place. I continuously, and to the limit of my actual knowledge, tutored and supervised the other trainers at repeated follow-up visits or through dialogues over the telephone.

Training locations

The first participants came to the paediatric clinic for training. However, later training also took place at home, at training schools, at day centres, at health care centres and other paediatric clinics in the area of Norrbotten County Council.

Powered wheelchairs

An old-fashioned model of powered wheelchair for children, designed during the eighties, was used for the training with the pre-school children and the tests with the infants. A simple working proportional joystick was used to operate these powered wheelchairs. When older children, teenagers and adults were engaged in the training other models of standard powered wheelchairs and three prototypes of a training powered wheelchair were used for the training. Typically, the powered wheelchairs were equipped with a transparent tray with a recess for the upper body. The tray was mounted on the armrests and the joystick was placed in the midline of the tray about six centimetres from the recess.

Training procedure

At the start of the project no reports of training joystick-use with this population could be found. Thus, the training procedure developed with time, guided by increased experience from the trainees' activity and reading of literature from different fields, such as occu-

pational therapy theory, paediatric and adult rehabilitation, developmental psychology, neuropsychology and pedagogy. The trainees were stimulated to explore joystick-use by free style trial-and-error driving. Periods of stimulation to explore were alternated with periods of manual guidance of the trainees' hand or hands on the joystick. Verbal encouragement was used now and then to stimulate the trainee to persist with exploration or to couple a word or a short sentence to an act. The goal with the training procedure was to make the trainees initiate exploration themselves and to make them understand short requests from a distance.

The typically developed infants were stimulated to joystick-use in a similar way, in co-operation with an accompanying parent. Trainees with less degree of cognitive disabilities were also encouraged to explore and experiment with free driving. However, they were generally more able to learn by repeated verbal instructions than the trainees with profound cognitive disabilities.

Data sources

From 1993 to 2006 video-recordings, field notes and open interviews were used to collect data related to the physical, psychological and social context of the training sessions (Papers I–III).

Short clips extracted from the video-recordings together with two sets of evaluation questionnaires were used to test the inter-rater reliability of a tool for assessment of joystick-use, developed during the project (Paper IV).

Trainee and training characteristics were available from medical records and earlier collected data. This data was used to analyse factors influencing the outcome of the 45 trainees with profound cognitive disabilities. (Paper V).

Data collection and analysis

Concomitant data collection and analysis of Papers I–III

After a training session, field notes were written down and the video recording on a small camera-tape was transferred to VHS-tape, providing the first inspection of the recording. The field notes, spotlighting important incidents during the training, guided the first inspection of the recording, but focus was also on all changes in the trainee's behaviours, acts and activity. During the initial years of the project, each recording was viewed many times in order to recognize minor changes. Moreover, about 20 hours from the training sessions with the two first engaged pre-school children, were transcribed in a very detailed manner. This approach to the data developed the observer's sensitivity for subtle changes and unfamiliar communicative behaviour in the viewed scenes. This sensitising process enhanced the recognition of novelties in the trainees' behaviours and acts and the identification of what could be interpreted as developmental changes. After accomplished sensitising a thorough detailed inspection of the video-recordings in their whole length was found unnecessary.

The open interviews with other trainers and persons acquainted with the trainee focused on recognized changes in and interpretations of the trainee's behaviours or acts during the training sessions.

The constant comparative analysis of data has been performed from different perspectives, focusing on the trainee's achievements gained from training in joystick-use in a powered wheelchair and on facilitating or hindering properties in the physical, psychological and social context of the training. The video documentation was used for recurrent analyses from different perspectives on interaction. Moreover, perspectives of the training context not considered in the beginning of the

project were captured on the tape and open for new analyses. For the whole period, collected and analysed data has been compared to relevant literature in different fields to improve the analyses.

Data collection and statistical analysis of Paper IV

In Paper II an eight-phase process of growing consciousness of joystick-use emerged and a tool for assessing phase was revealed. In Paper IV three independent raters tested the inter-rater reliability of the assessment tool by assessing 24 video-clips. The raters were occupational therapists and two of them had experience from the field of interest and one was inexperienced. I was the criterion rater who selected the clips from the accumulated data-base of video-recordings. Each phase in the process was represented by three video-clips, and the length of each clip was between two to five minutes. Descriptive statistics and weighted kappa were calculated.

Data collection and statistical analysis of Paper V

To evaluate the 45 trainee's results from the training, an outcome variable, 'reaching control of steering', was defined. The outcome was evaluated by using the tool for assessment of phase of joystick-use, developed in Paper II and tested in Paper IV. Control of steering was defined as having reached phases six to eight at the final evaluation. Information from medical records and earlier collected data were utilized for analysis of factors related to the outcome. This information comprised characteristics of the training situation (number of training sessions, number of training spots, length of training period), of the trainers (professional or not) and of the trainees (degree of physical disability, visual impairment, autistic behaviour and walking

ability). The chi-square test and, when applicable, Fisher's exact test were used for the statistical analysis. Due to the lack of power, no multivariate analyses were performed.

Repeated analyses of data

Repeated comparative analyses were aimed at elevating the project findings to a higher conceptual level. A lift to a higher conceptual level may make the findings more general and attainable also in other substantive fields. The repeated comparative analyses utilised data concomitantly collected and analysed from the start of the training in 1993 up to May 2006. The analyses involved comparisons of video-recordings, field notes, notes from interviews and memos concerning inter-relationships in the training situation. The analyses took different perspectives on the training situation to explore physical, psychological, social and cultural aspects influencing the outcome of the training on behalf of the different partakers. Besides, comparisons were made with appropriate literature in relevant fields.

Ethics

As the participants were not able to give informed consent to engagement in the training it was especially important to ensure that the ethical committee authorized the project. The research ethics committee at Umeå University approved the project on three different occasions. Approval was decided for children with multiple disabilities Um §311/94, dnr 94-229, for infants Um §144/97, dnr 97-101, and for people with profound cognitive disabilities Um §422/98, dnr 98-335. The participant's parents or other related persons gave informed consent to participation along with written agreement to video recording of training sessions. These related persons were able to withdraw the participants from training at any time.

Results

The presentation of the results from the Driving to Learn project is divided into two sections. The first section deals with growing consciousness of tool-use in the field of training joystick-use with people with profound cognitive disabilities. The second section deals with the emergence of the grounded theory of de-plateauing.

Driving to Learn. Growing consciousness of tool-use

Knowledge of what might happen if people with profound cognitive disabilities get access to training of joystick-use was lacking at the commencement of the project. Thus, the knowledge emerged with my own and the other trainers growing consciousness of what could be regarded as achievements, how to stimulate the attainments and what hindered or facilitated the trainees' growing consciousness of joystick-use. A structure of a process of growing consciousness emerged together with tools for implementation of Driving to Learn and assessment of joystick-use training.

Possible achievements from Driving to Learn (Paper I)

The results of two pre-school children, who were the first to be engaged in the project, indicated that training in a joystick-operated powered wheelchair could lead to constructive achievements for the trainees. The changes observed appeared to be related to the trainee's level of alertness, use of hands and interaction with the physical and social environment. These encouraging experiences led to the engagement of new trainees.

The process of growing consciousness of joystick-use (Paper II)

New indicators of changes in the trainees' alertness and activity accumulatively confirmed the earlier observations of achievements. Some indicators verified old categories of achievements and some indicated new categories. Reactions, behaviours, acts and actions were categorised, and the categories were inter-related and related to their indicators. Comparisons to trainees with less degree of cognitive disabilities, and infants, supported the emergence of what was called the process of growing consciousness of joystick-use. Over the years it slowly emerged that this basic social-psychological process consisted of several distinct phases. At this point eight stringently separate phases of the process have been distinguished. Each phase was indicated by eight categories: activity form, behaviour—activity, hand and arm movement, consciousness of joystick-use, alertness, motive, driving-style and expression. Below follows a short characterisation of the eight phases.

- Phase 1. A new activity. Trainee not aware of possible effects.
- Phase 2. The beginning of understanding of the possible effects.
- Phase 3. Control of basic effect – onset of movement.
- Phase 4. Exploration of effects, direction and speed.
- Phase 5. Experimentation to find a pattern for steering.
- Phase 6. Control of steering, but coarse and unsafe.
- Phase 7. Smooth control of direction and speed. Safe.
- Phase 8. Navigate in different milieus to do other things.

The basic social-psychological process of growing consciousness was, when identified,

the basis for assessing the trainees outcome of training in a joystick-operated powered wheelchair.

Training strategies (Paper II)

In parallel with the emergence of the process, comparisons were made to find out which training strategies facilitated or hindered the trainee's progress in the process. This way, strategies for each phase in the process were identified. The revealed strategies were implemented in the training in joystick-use to facilitate the trainee's eventual accomplishment of transition from actual phase of consciousness to next phase in the growth process.

A tool for assessment of phase of consciousness of joystick-use (Paper II)

The descriptions of the identified eight-phase process of growing consciousness, with its critical transitions and fickleness in growth, together with the facilitating training strategies were considered as tools for implementation of the training method. Furthermore, the simplified scheme over the phases and the description of the process were considered as tools for assessment of a trainee's actual ability of joystick-use. Thereby the tools were used as guidelines for intervention, assessment of a trainee's immediate capacity and choice of appropriate training strategies.

The trainer's growing consciousness of method-use (Paper II)

When analysing data from the perspective of hindrances and facilitators in the training context, the trainee's interaction with the trainer also came into focus. An increasing amount of data pointed at the mutuality in their processes of growth. The trainee's achievements of joystick-use were dependent on the train-

er's growing consciousness of method-use and the trainer's achievements of method-use were dependent on his or her recognition of the trainee's growing consciousness of joystick-use. Furthermore, when comparing the elements in the trainees' eight-phase process of growing consciousness of joystick-use with the process of the trainer's growth regarding method-use, the same categories were found, but at a higher level of complexity in the activity and the cognitive operations.

Characteristics of powered wheelchair-use (Paper III)

When entering the field of interest, the focus for observation was directed towards the trainees' reactions and activity when positioned in the powered wheelchair. However, collection and analysis of an increasing amount of data indicated that other factors related to trainee – powered wheelchair interaction influenced the trainee's possible achievements. Due to the recognition of hindering aspects connected to the function, the use of standard powered wheelchairs for training was halted. In the search for a powered wheelchair with characteristics facilitating growing consciousness of joystick-use in people with profound cognitive disabilities, a contact with a powered wheelchair manufacturer was established. Three different prototypes were constructed. The accumulating recognition of facilitating or hindering characteristics connected to powered wheelchair-use was the foundation of the construction of each of the prototypes. It emerged that a proportional joystick with functions such as direct reaction at activation, same speed in all directions and same effect at any occasion were characteristics facilitating achievements. Many years of analysing the trainees' interaction with the prototypes forewent the conceptualisation of predictability and usability of the powered wheelchair functions as most important for the trainees' growing consciousness of joystick-use.

Inter-rater reliability of the assessment tool (Paper IV)

To do the analysis of the inter-rater reliability of the tool for assessment of phase of joystick-use, a triplicate set of my criterion assessment of the 24 video-clips (thus resulting in 72 cases) was compared with the other three raters sets of assessment. This statistical calculation gave a weighted kappa value of 0.85. Despite the fact that one of the three raters was inexperienced of the population and the intervention, the weighted kappa value for their assessments were very similar when compared separately to the criterion rating. All three raters judged the tool as having a high degree of usability for assessing phase of consciousness.

Training characteristics important for the outcome (Paper V)

Out of the 45 trainees with profound cognitive disabilities, eight had reached control of steering at evaluation of the outcome of the training. These achievements surpassed by far the expectations of parents, medical professionals, trainers and others acquainted with the trainees. Out of the eight trainees who reached steering control, five were engaged in the training at an age between 1 and 6 years, two between 7 and 20 years of age and one at an older age. Factors significantly associated with reaching control of steering were: taking part in more than 30 training sessions ($p=.004$), training at two or more training spots ($p=.007$), a training period longer than two years ($p=.016$) and a high degree of training with a professional trainer ($p=.045$). No trainee characteristics were significantly related to the outcome.

Parallel processes of growth

In Paper II the mutual dependency between trainee and trainer was described, but reiter-

ated analyses of data elucidated that the pattern of inter-dependency concerning the involved persons' processes of growth was more complicated. Notes from the training sessions and the interviews together with the video-recordings were reviewed to explore the differences and similarities in the perspectives of the trainees, the trainers and the supervisor. The new analysis modified the understanding of the interconnectedness between the partakers' processes of growing consciousness.

- Trainees were exploring or learning how to use a joystick to operate a powered wheelchair taught by trainers.
- Trainees were exploring or learning joystick-use taught by trainers who were exploring, learning or developing method-use.
- Trainees were exploring or learning joystick-use taught by trainers who were exploring or learning method-use taught by a supervisor who was exploring, learning, developing and trying to teach method-use.

Each partakers growth was influenced by the others manners of exploring, learning, method developing or trying to teach tool-use. The trainees growth of joystick-use was dependent on the trainers' and the supervisor's growth of method-use. The trainers growth was dependent on the trainees growth of joystick-use but also on the supervisor's growth of method-use. The supervisor's growth was dependent on the trainee's and the trainer's growth but also on a variety of external support. The achievements on behalf of each partaker (trainee, trainer, supervisor) were dependent on the dynamic and negotiation in each of these constellations of social-psychological interaction.

Growing consciousness – a theory of de-plateauing

The experiences from the Driving to Learn project were evidence that people with profound cognitive disabilities, with the assis-

tance of others, were capable of developing unexpected levels of tool-use. The unveiling of the trainees' unpredicted ability to grow was considered a breakdown of traditional mindsets of developmental plateaus. The involvement in learning tool-use increased the trainees' level of constructive performance. While they grew more self-aware or became in control of new effects they displayed signs of well-being, such as smiles, laughter and decrease of challenging behaviours.

To be occupied with caring for people with profound cognitive disabilities is not considered a high status work and the trainers initially had no or low expectations of their own abilities to assist growth in this population. Thus, the trainers had what could be characterised as a plateauing attitude regarding their own capacity to promote growth in their caretakers. Their growing consciousness of method-use caused a breakdown of their self-plateauing attitude and effected an increased self-confidence and belief in the own capacity to make a change by using the training method. Their breakdown typically was associated with the recognition of a particularly apparent change in their trainee's behaviour.

The emergence of the theory

The knowledge gained in the project was for a long time a pure description of relationships between observed categories and indicators in the field of powered wheelchair training. In the analysis, the problem was to raise the descriptions to a more conceptual level. It was challenging to change perspective from relationships between categories and indicators to a whole integrated perspective with more general applicability to training with people with profound cognitive disabilities. The attendance at four GT-seminars conducted by Glaser assisted my growing consciousness of grounded theory-use, a growth that otherwise had stopped at a descriptive level. A higher conceptualisation of the findings was ini-

tiated by going back to existing data (notes from training sessions and interviews, video-recordings and memos) to extract a general core category by repeated comparative analysis. The core category that emerged was growing consciousness, which by amplification was elevated to a higher conceptual level – de-plateauing – meaning to elevate above expected plateaus or predetermined ceilings for development.

Further analyses and sorting of memos supported the fact that the properties found to be the most important for achievement of growing consciousness were also the most important for attainment of de-plateauing. These analyses indicated that the attainment of growth or de-plateauing required motivation, endurance, responsiveness, adaptability and resources with high predictability and usability. The necessity of these properties for growing consciousness were briefly outlined in Paper II, but are further expanded here to a grounded theory of de-plateauing.

Motivation/drive

To have or to develop drive or motivation was a necessity for engagement in a new or unfamiliar activity, interaction, teaching, learning or communication. Without drive or motivation the person never engaged in, or persisted with, the new occupation or unfamiliar event. Motivation provided joyfulness, belief in possibilities, positive expectations and eagerness to act and respond. Motivation was a requirement for acting or doing the activities that generally was not expected to give foreseeable effects or results.

The drive may be encouraged by intrinsic or extrinsic movers or rewards or faded out by negative attitudes or experiences (Fortmeier, 1985; Olsson, 2004; Ryan & Deci, 2000). The encouraging or diminishing of motivation might be a result of an intra-personal as well as an interpersonal event (Mead, 1967). The resulting self-determination might be

caused by an inner deliberation between I and me or of an external stimulation or encouragement (Poulsen, Rodger & Ziviani, 2006; Ryan & Deci, 2000).

Endurance

In order to evolve and keep up endurance, the person had to attribute a certain goal to his or her action or occupation. Without a goal for the tool-use, and hope for success, it was hard to persist with the 'doing'. The person needed endurance to persist with exploring, exercising, training or practising the tool-use and resisting impulses to change activity before the actual doing was finished. Endurance was a requirement for standing the boredom of necessary reiteration while awaiting results to appear.

People strive for stimulation. Thus it is hard to stand boredom and repetition of indifferent activities. Reiteration can give an impression of saturation and cause a need for change (Asplund, 1967). The predictability of the outcome is a factor that maintains endurance to stay present in an activity or occupation and to concentrate the attention on relevant stimuli and responses (Reid, 2005).

Responsiveness

Responsiveness involved the striving for an empathetic, dialogic approach in building relationships with others and staying open for reception of odd or unfamiliar ways to interact and communicate. The responsiveness was influenced by the person's alertness, attentiveness and ability to recognise communication, undertake flexible interpretations of others reactions, activity and interaction, as well as make efforts to respond in as appropriate a manner as possible. Responsiveness was a requirement for developing a positive mutuality in interaction and communication.

An act or communication that is not recognised may just as well not have happened,

as it cannot be responded to (Asplund, 1987). Taking on the other's attitude or perspective is part of understanding or interpreting intentions and responding adequately (Mead, 1967). An empathetic reciprocity is needed to establish mutual relationships, understanding and resonance between people (Adenzato & Garbarini, 2006). Awareness of communicative intentions and mutual recognition are necessary for development of self-awareness, representation and meta-representation, also known as theory of mind (Parker, Mitchell & Boccia, 1994).

Adaptability

Adaptability involved adjusting the activity to the personal pace, the generation and the organisation of acts. This meant to take the time needed to wait for acts causing effects, stimulate the process of developing efficient orders for doing and avoid forcing a product not based on the integration of doing and cognition. Adaptability was a requirement for fitting use of, for example, approaches, methods, tools or other artefacts, or the physical and social environment to the self or the people involved in an actual situation.

The adaptability concerns the actor, the object(s), the co actor(s) and the environment. Adaptability applies to adjusting and modifying circumstances to best fit personal characteristics, the activity to be performed and the social and cultural context (Dunn, Brown & McGuigan, 1994; Peloquin, 1990). The degree of adaptability influences a person's performance of an activity or occupation in a certain context (Dunn *et al.*, 1994).

Resources with high predictability and usability

Resources included material, physical, psychological, social or environmental aspects, such as money, time, locations, equipment, tools, capacity, staying power, support from

other people or general access to societal facilities. Resources with high predictability and usability were a requirement for initiating and realising the setting of the de-plateauing context.

Interdependency between properties

It was observed that the five described properties had to be at hand to achieve de-plateauing. There was a strong interdependency between the requirements, implying that if any of the five were missing the remaining four could not bring about the achievement. The trainees and the trainers motivation or drive was needed to keep up endurance to persist with the goal-directed tool-use. Successful mutual responsiveness and adaptability nurtured their motivation and endurance which were necessary to support the unveiling of capacity and to gain access to the resources needed for realising a de-plateauing context for the powered wheelchair training.

The theory of de-plateauing is grounded in repeated comparative analyses of the project data and can be defined as a positional change exceeding preconceived expectations. Attainment of de-plateauing may be possible if the described interdependent circumstances are at hand. The repeated analyses of data exposed that if the physical and social-psychological factors of the training context had been facilitating to a higher degree, more trainees with profound cognitive disabilities could have de-plateaued to higher levels of joystick-use.

Discussion

The overarching aim of the Driving to Learn project was to explore possible achievements from training people with profound cognitive disabilities in a joystick-operated powered wheelchair. The specific aims included

exploration of facilitating or hindering influences connected to the trainee and to the physical, psychological and social aspects of the training context. The identification of the basic social-psychological process of growing consciousness of tool-use shows how physical, social and cognitive aspects of human performance are linked. The discovery of the process, the facilitating training strategies, the tool for assessment of actual tool-use and the mutuality in the growth process provides important knowledge for the development of rehabilitation strategies for people with profound cognitive disabilities. The discovered knowledge may also be useful in other fields where activities or occupations that include teaching and/or learning are performed. Furthermore, the grounded theory of de-plateauing may have implications in many fields where people have veiled potential capacity but are arrested by their own or other's plateauing attitudes.

Methodological considerations and the grounded theory approach

It might be an advantage that the project had a non-experimental design with many trainees being engaged in continuous long-term training. Contemporary studies using experimental design with people with profound cognitive disabilities have reported difficulties in establishing consistent changes in their behaviour (Lancioni *et al.*, 2001b; Saunders, Timler *et al.*, 2003). A reason for this difficulty, not considered in any of these research reports, might be that the inconsistent experiences provided by the experimental situations hampered the participants' development of contingency awareness.

Valsiner (2006) claims that it is favourable if the researcher sets up hypotheses based on careful considerations of the phenomena of interest. Scientific knowledge starts to grow on the basis of the first induction, which in-

volves the personal intuitive understanding of a certain phenomenon. The subjects and the researcher are co-constructors of knowledge based on synthesis of extrospective experiences. It is the activity in the field of interest that constructs the meaning of data, which the scientist uses for the emergence of new knowledge. Boroditsky (2007) found that comparison on perceptions of differences and similarities in the development of knowledge can alter the way objects or events are perceived. Comparisons guide the discovery of new similarities and differences and sharpen the boundaries between phenomena, and these biases may be beneficial for separating bits of experiences into categories, clearly define concepts and helping to create new structures of knowledge.

The grounded theory methodology should be used to resolve the main concern that people experience in a substantive field. However, it was most difficult to interpret the interests of the people with profound cognitive disabilities, as they were not able to verbally or by other means declare their experiences and concerns. Naturally the relatives, caregivers, therapists, and all others living in the contiguity of those people, are the ones that develop, possess and communicate the attitudes that are judged to be in the interests of this population (Elliott & Elliott, 1991). We, the others, base our attitudes on interpretation of their acts, interactions, non-verbal cues (facial expressions, eye contact, hand gestures, body movement and sounds) (Goldin-Meadow, 2000), and our eventual perception of patterns in their response to different events. Thus, what induced the Driving to Learn project was actually my own interpretation of the main concern of people with profound cognitive disabilities. My interpretation of their main interest was based on the earlier clinical extraordinary experiences. The clinical experiences indicated that these people had hidden potential capacity, and my judgement was that their concern might be unveil-

ing potential capacity and reaching achievements. I wanted to support their growth of ability by training joystick-use in a powered wheelchair and find out if growth in this area could enhance their general ability to understand and interact with their environment. The findings from the project might be regarded as indicators justifying my initial interpretation of these people's concerns. Others' research has shown that support of constructive performance provides these people with opportunities to enhance life experiences and sense of well-being (Lancioni *et al.*, 2001a; Lindsay, Pitcaithly, Geelen, Buntin, Broxholme & Ashby, 1997).

The most valuable data source in the project was the video-recordings, as they always were available for repeated observations or new inspections from different perspectives. In classical grounded theory Glaser pleads for one not to use tape recordings and not to make transcriptions when collecting and analysing data (Glaser, 1998). However, Glaser said at our first personal communication (Grounded Theory Seminar, Malmö, September, 2003), 'in your study of this population video-recordings are a necessary data source'.

The discovered process of growing consciousness and the theory of de-plateauing are not truths but hypotheses that are modifiable. The generation of them was an ever-modifying process as changes in the field occurred over the project time. How the process and the theory emerged was directed by the constant comparison of observed changes in the trainees, trainers and training context and by switches in whose perspective was focused on. The emergence was also influenced by my own growing consciousness of how to use the GT-methodology. The minus mentored who is teaching himself by studying books on the GT-method has a learning curve with delayed action (Glaser, 1998). The minus mentored state is usually not tolerated for long as feedback and discussions are necessary. Thus, par-

ticipating in GT-seminars and networking with other classical GT-users enhanced my learning of the method.

As the emergence of a core category is in the eye of the researcher, more than one grounded theory could emerge in a field of interest. In my view the core category was growing consciousness and by amplification the core was transubstantiated into de-plateauing. Other researchers might have seen other core categories. This does not mean that one grounded theory is trust-worthier than another. How good a theory is depends on its fit, how it works, its relevance for the field and its modifiability.

Findings from the constant comparative analysis and previously collected data in the project were used for testing the assessment tool and analysis of factors influencing the outcome of training joystick-use. The testing of reliability and the outcome analysis were other ways to compare data. Thus the results in Paper IV and V were dependent on the accuracy of previous analyses in the project. A strength was that the quantitative analyses supported the results of the qualitative analyses.

A scientific challenge was the balancing between the roles of being trainer, method developer, supervisor and researcher. The long project time, the involvement of other trainers, the co-operative process of development of the method and the test of the developed tool for assessment of phase of growing consciousness may have contributed to reduction of this role problem. An advantageous effect from the shifts between perspectives and roles may be the realisation of the complicated inter-relationships between the trainee's, trainer's and supervisor's processes of growing consciousness of tool-use. Progress in their respective processes showed to be dependent on the dynamic and negotiation of their interaction at each training occasion. Thus, it was not only the capacity and activity of the trainee that influenced on the outcome

of the training but also the capacity and activity of all partakers involved in a training session. The dynamic of these inter-relationships was decisive for successful implementation of the new training method. Awareness of the partakers' growth processes was a prerequisite for trustworthy analyses as the differences in their progress or non-progress influenced the project result either positively or negatively.

Growing consciousness of tool-use

People with profound cognitive disabilities have profound limitations in the development of self-identity and in the ability to react, act and interact in relation to their environment. To find a stimulating and age appropriate activity that can unveil their potential capacity represents a great challenge to persons living close to these people. It is not easy to find a stimulating activity, as people with profound cognitive disabilities are often highly introverted and pay little regard to external stimuli or invitations to interact. The powered wheelchair training was primarily used for moving – motivating by movement – and 'driving to learn' not for learning to drive. The approach for the training was to teach the trainees that they were separate beings with arms and hands that could be used for handling objects (joystick) and causing effects (movement).

The guiding of the trainees' acts on the joystick assisted the cause of the effect of 'movement of the powered wheelchair'. This effect was powerful as it seemingly stimulated and encouraged the trainees to take their own initiatives to explore how to cause a new onset of motion. The trainee's growing consciousness of joystick-representation was accompanied by a growing consciousness of 'self' with the ability to cause the change of position in the room. As the process of growing consciousness emerged it became more obvi-

ous that the ability to cause the movement of the chair was not the only factor stimulating growth. It was the combination of the ability to cause the effect of movement together with the ability to use the tool to control the direction and the speed of the chair that was so powerful for the trainee's development of self-consciousness and a sense of agency and mastery.

The facilitating characteristics of powered wheelchair-use were related to functions that influenced predictability and usability. Predictable effects and usability were essential prerequisites for developing contingency awareness and learning about cause-effect relationships. The development of a 'one-for-all' training powered wheelchair was a necessary step to facilitate the outcome of the training and to increase accessibility to training by using one powered wheelchair for many trainees.

Another scientific challenge in this research was to find a pattern among the trainee's achievements and to grow conscious of which training strategies to use to facilitate the trainee's growth. The identification of the basic social-psychological process and the development of the training strategies followed hand in hand. When the eight-phase process of growing consciousness of joystick-use was identified it also worked as a tool for assessment of the trainee's actual position in the process. The trainee's process of growth could float between two or more phases during a session depending on actual health state, factors related to the training context or closeness to a transition to a new phase in the process. Due to the floating, it was of great importance for the trainer to be able to predict the trainee's immediate ability of joystick-use to in turn predict which training strategies to utilize at each point of a training session.

The inter-rater reliability of the tool for assessment of joystick-use was tested with a very good result, but still there are refinements to do to further clarify the distinctions between

the phases. Also of special interest was that the inexperienced rater had a similar degree of agreement with the criterion rating as the two experienced raters. This indicates that the tool may work reliably and be useful in clinical practice. In particular regarding the population with profound cognitive disabilities, it is critical to be able to do a reliable assessment to put the 'just right challenge' facilitating their growth.

The analysis of the outcome of the 45 trainees showed that training characteristics, such as many training sessions during a long training period, were significantly associated with their reaching of steering control. Beforehand it was tempting to assume that the trainee characteristics were the most decisive factor for their growing consciousness of joystick-use, but this did not turn out to be the case. This was an important finding as the plateauing attitude regarding these people's possible achievements is most often associated with their combinations of disabilities and not with their slow development and long learning curve.

A grounded theory of de-plateauing

The result of the outcome analysis underlines that the theory of de-plateauing is relevant for people with profound cognitive disabilities, as in order to be able to grow consciousness they are dependent not only on their own but also on others' motivation, endurance, responsiveness, adaptability and access to resources with high predictability and usability.

The data source most important for the repeated comparative analyses was the video recordings from the training sessions, which had caught the perspective of all actors on the scene. Trainee, trainer and supervisor seemingly needed the same inter-dependent properties to achieve de-plateauing by growing more conscious of their respective tool-use. Attainment of growing consciousness

was characterised by increased sense of self, ability to perform goal-directed activity and being in control of tool-use. Goal-directedness and control involved the ability to handle generation, grading, timing and planning of direction and speed (pacing) related to their specific tool-use activity or occupation.

Differences between the tool-use activities or the occupations performed by the trainee, trainer and supervisor were found in: the degree of cognitive demand from low to high; level of sophistication from simple to complex; level of abstraction from material to abstract; and pace of performance from slow to rapid. Regardless of these differences their process of de-plateauing followed similar trajectories and involved similar categories.

The shared process of growing consciousness of tool-use will be further explored to increase stringency and to identify more general conceptualisations of categories and indicators of the eight phases in the process. Additional investigation of the theory of de-plateauing will be done to ensure its relevance as a formal theory attainable in other fields.

Occupational therapy and de-plateauing by growing consciousness

In occupational therapy the core purposes are enabling, enhancing and empowering (Hagedorn, 1995, p 32). A central value is the belief in people's worth and potential capacity irrespective of disabilities and the occupational therapist's obligation to by empathetic support tease out that capacity (Kielhofner, 1992). Occupational engagement is related to individual biological characteristics but also to the physical, social-psychological and cultural environment a person lives in (Wilcock, 1998b). Adapting to new circumstances and learning new skills requires that a person's capacity is challenged in an appropriate way (Yerxa, 1998). Consciousness is shaped by

activity and orients humans in adapting to and restructuring conditions in their environment (Luria, 1976). A more knowledgeable person may assist other persons to do more than they can by themselves – however within the limits set by the persons' actual state of development and capacity (Vygotsky, 1986/1994). When focusing on the problems of educating children with mental retardation, the Russian psychologist Vygotsky concentrated his attention on their abilities and strengths. He searched for potential capacities that could be developed and in the search he relied on qualitative descriptions of the special organisation of their behaviour (Luria, 1979). In education it is important to concentrate on the process by which a person's understanding of a situation is established. If the result of teaching or training is a product that is dependent on a certain stimulus in the environment, the experience or knowledge has not been processed and cannot occur without that stimulus (Chapell, 2006). First-hand effects or results of acts, actions and activities are important experiences underlying the integration of understanding of what can be achieved by using different kinds of tools (Ross & Bachner, 1998).

The processes identified in the project indicates that we, the practitioners working with people with profound cognitive disabilities, may be able to grow conscious of our potential to assist growing consciousness in this population. It might be very difficult and take a long time but it can also be very satisfying and beneficial to the people involved in the training. Practitioners and staff may be empowered and experience a rise in quality in life by the feeling of being able to stimulate gain of awareness in the ones they serve (Baum, 2005). By increasing our own consciousness of capability to grow or assist others growing consciousness, we may all de-plateau to a certain degree. By so doing we might come a little bit closer to becoming the ones we have capacity to be (Wilcock, 1998a).

Conclusions

The Driving to Learn project used powered wheelchair intervention to assist learning of tool-use via the moving experience of driving. The result showed that it was possible to stimulate growing consciousness of joystick-use in people with profound cognitive disabilities. In the project a method for training and a tool for assessment of the trainee's outcome were developed. The assessment tool could reliably measure the trainee's actual phase in the process. The measure provided a prediction of which training strategies to use to facilitate the trainee's progress. With de-plateauing properties at hand the trainees could grow more conscious of tool-use and develop a sense of self and well-being.

When exploring which physical, psychological and social factors hindered or facilitated the trainee's outcome of the training the

focus switched between all the partakers' perspectives and roles in the growth process. The patterns of activity forming the intertwined growth processes showed that de-plateauing was dependent on evolving of mutual interaction with respect to the actors involved in the occupation. The different actors de-plateauing and growth in the activities and interactions were dependent on their motivation, endurance, responsiveness, adaptability and access to resources with high predictability and usability.

De-plateauing, identified as the core category in repeated comparative analyses of the data, can be defined as a positional change exceeding preconceived expectations. De-plateauing may be possible to attain if the just mentioned interdependent circumstances are at hand. I argue that the grounded theory of de-plateauing might be useful in many more fields, not only those where the phenomenon of plateauing attitudes is obviously present.

Svensk sammanfattning/ Summary in Swedish

Denna avhandling presenterar en teori om hur utforskande och hantering av verktyg kan få människor att överskrida förutfattade uppfattningar om begränsningar.

Personer med grava kognitiva funktionshinder har mycket svåra begränsningar i sina förutsättningar att delta i aktiviteter som kan skapa mål och mening och bidra till förändringar i deras liv. De har svårartade inskränkningar när det gäller att förstå och använda sin egen kropp och sina sinnen. Denna utsatthet gör att de är helt beroende av andra för att få stöd och tillgång till möjligheter att utforska och förstå omvärlden.

Vanligtvis brukar personer med grava kognitiva funktionshinder inte erbjudas träning i elrullstol manövrerad med styrspak, eftersom de inte förväntas ha de förutsättningar som krävs för att lära sig verktygsanvändning. Jag började ifrågasätta detta synsätt efter en synnerligen speciell upplevelse i mitt kliniska arbete. En skolpojke med grava kognitiva funktionshinder och svår synnedsättning klarade av att lära sig att köra elrullstol på ett målinriktat sätt. Det krävde sex års träning, men han lyckades. Denna upplevelse stärkte min undermedvetna känsla att personer med grava kognitiva funktionshinder kan utvecklas mer än man tror bara de får tillgång till ett verktyg och ges tillräckligt lång träningstid. Med denna utgångspunkt startade jag min forskarutbildning, skaffade mer kunskap om vilken betydelse självständig förflyttning har för utvecklingen och inledde mina studier av träning i elrullstol. Projektet fick så småningom benämningen Köra för att Lära. Namnet markerade att tanken med träningen var att personerna skulle köra elrullstol för att öka sitt medvetande, inte för att lära sig köra säkert och funktionellt.

Avhandlingen bygger på resultat från

projektet Köra för att Lära som pågått sedan 1993. Syftet med projektet var att utforska vad som kan uppnås genom att ge personer med grava kognitiva funktionshinder tillgång till träning i elrullstol. Projektet har både underförstått och uttryckligt använt forskningsmetoden grundad teori. Metoden präglas framför allt av att data samlas in och analyseras parallellt. Förklaringsförsök och antaganden som framträder som resultat av de ständiga jämförelserna mellan nya och gamla data avgör inriktningen på det fortsatta arbetet. Från början engagerades personer med grava kognitiva funktionshinder (totalt 45) i träningen, senare engagerades även personer med lindrigare kognitiva funktionshinder (totalt 64) och normalutvecklade spädbarn (totalt 17) i projektet. När projektet inleddes gick det inte att hitta råd för träning i styrspaksmanövrerad elrullstol med denna målgrupp. Därför blev fortlöpande analyser av data vägledande för förståelsen av vilka faktorer som hindrade eller främjade deltagarnas utveckling av förståelse för styrspakens funktioner. Träningen genomfördes inom Norrbottens län, på rehabiliteringar, träningsskolor, dagcenter för vuxna med utvecklingsstörning samt en vårdcentral. Först var jag ensam tränare men ganska snart började den rollen delas av föräldrar, andra arbetsterapeuter, lärare, sjukgymnaster, assistenter och omsorgspersonal. Videoinspelningar, oftast av hela träningssessioner, tillsammans med anteckningar från observationer och intervjuer var de viktigaste datakällorna. Den konstanta jämförelsen av deltagarnas reaktioner och aktivitet ökade gradvis förståelsen för hur olika förändringar i deras aktivitet kunde tolkas som tillväxt av deras medvetande och vad som stimulerade denna tillväxt. Olika elrullstolar provades för träningen och det visade sig tidigt att vissa egenskaper hos standardmodeller av elrullstolar hindrade tillväxten av medvetande. Med stöd av den kunskap som utvecklades under projektet konstruerades olika prototyper av en speciell elrullstol för träning. Dessa prototy-

per användes av flertalet deltagare efter 1997. De fem delarbeten som ingår i avhandlingen utforskade om och hur träningen i elrullstol kunde öka deltagarnas medvetande om verktygets - styrspakens - funktioner och användning, samt hur deras eventuella tillväxt kunde utvärderas på ett tillförlitligt sätt.

Första delarbetet beskrev de effekter träningen hade för de två förskolebarn med grava kognitiva funktionshinder som först engagerades i träningen. Barnen som var fyra och fem år fick en högre vakenhetsgrad, började upptäcka sina händer, visade tecken på att uppfatta samband mellan sina egna handlingar och dess effekter och visade större intresse för sin närmaste omgivning. Deras framsteg var uppmuntrande och ledde till att fler deltagare engagerades i projektet.

I delarbete två presenterades strukturen hos en basal social-psykologisk process som kallades 'tillväxt av medvetande' om verktygsanvändning (användning av styrspak). Arbetet baserades på 45 deltagare med grava kognitiva funktionshinder och två referensgrupper. Den identifierade processen tillsammans med de träningsstrategier som främjade tillväxten utgör en modell för träningsmetoden Köra för att Lära. Genom en schematisering av tillväxten av medvetande och en beskrivning av processens åtta faser skapades ett bedömningsverktyg för evaluering av deltagarnas aktuella fas i processen. Det ömsesidiga beroendet mellan tillväxt hos styrspaksanvändare och metodanvändare (tränare) belystes också i detta arbete.

I delarbete tre presenterades de hindrande och främjande egenskaper som rörde deltagarnas användning av elrullstolen. Arbetet baserades på de 45 deltagarna med svårast funktionshinder. Elrullstolsfunktioner som gav hög användbarhet och förutsägbarhet av effekter främjade förståelsen av orsakssambanden mellan egen akt på styrspaken och elrullstolens rörelser. Direkt effekt vid utslag med spaken, samma effekt i alla riktningar och ett klart plexibord med mittpla-

cerad, nedsänkt styrspak är exempel på sådana egenskaper.

I det fjärde delarbetet prövades tillförlitligheten hos det bedömningsverktyg som skapades i arbete två. Tre oberoende bedömare/ arbetsterapeuter skattade aktuell fas hos deltagare på 24 videoklipp (längd 2-5 minuter). Klippen valdes ur det samlade videomaterialet från alla deltagare (totalt 126). Bedömarernas skattning jämfördes med min egen bedömning som utgjorde facit. Resultatet visade att verktyget hade hög tillförlitlighet och var lämpligt för användning i kliniskt arbete.

Det femte delarbetet utforskade vilka faktorer som inverkar på de 45 deltagarnas resultat av träningen i elrullstol. Egenskaper hos deltagarna och träningssituationen ställdes mot uppnådd förmåga att styra stolen med spaken. De viktigaste främjande faktorerna för inläring av styrning rörde träningens längd, mer än 30 träningsstillfällen och träning mer än två år, men även vem som skötte träningen i högst utsträckning och om den utfördes på mer än ett ställe. Inga egenskaper hos deltagarna hade en signifikant hindrande effekt på deras resultat.

I sammanfattningen av de fem delarbetena presenteras även den begreppsliga överföringen från 'tillväxt av medvetande' till 'lyft över plåtår'. Genom att få medvetandet att växa kan man lyfta över förväntade plåtår eller bryta genom tak som satts för möjlig utveckling. De förutsättningar som krävs för att möjliggöra 'lyft över plåtår' är en samtidig närvaro av motivation, uthållighet, ömsesidigt positivt samspel, anpassningsbarhet och tillgång till resurser med hög förutsägbarhet och användbarhet. Närvaron av egenskaperna krävs både hos den som ska lära ut och den som ska lära in. 'Lyft över plåtår' kan definieras som en positionsförändring som överskrider förutfattade förväntningar.

Avhandlingen visar att det är fullt möjligt att stödja 'tillväxt av medvetande' eller 'lyft över plåtår' till oförutsedda nivåer, men att tillväxten eller lyftet är beroende av många

samverkande förutsättningar. Denna kunskap har giltighet oavsett om man är 'normalhindrad' eller har ett kognitivt funktions-

hinder och är därför användbar inom många olika områden där begränsande attityder hindrar människors utveckling.

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