During recent decades great progress has been made in the development of assistive technologies for people with disabilities. These advances have undoubtedly improved the life of many individuals with severe or profound disabilities. A small group of individuals with profound cognitive disabilities is generally not thought capable of using these new technologies. Individuals with profound cognitive disabilities function at a very early developmental level, experiencing difficulty sensing, integrating, interpreting, and responding to environmental stimuli.

Technical aids to facilitate daily care are often prescribed for individuals with profound cognitive disabilities, but high-technology aids such as powered wheelchairs are not. Professional guidelines regarding the prescription of powered wheelchairs (Cook & Hussey, 1995; Neistadt & Crepeau, 1998) recommend that individuals who lack the skills required to control the powered wheelchair should be excluded from prescription, as it is considered that inadequate skills may risk the safety of both the user and others. Thus, these typical recommendations exclude individuals with profound cognitive disabilities from access to training in powered wheelchairs.

Individuals with profound cognitive disabilities are extremely difficult to engage in any activity. Their inability to respond to stimulation and new activities inhibits their development of curiosity and self-initiated behavior. In addition, they have very little understanding of how to interact intentionally or behave in a way that influences their environment. This limited understanding results in a rudimentary repertoire of responses to external stimuli. Their responses, if any, may go unrecognized, or fail to be interpreted as interactive behavior. Others in their environment may, due to the infrequency of responses, grow less receptive to their behavior and less inclined to provide reinforcement through interactive responses (Brodin, 1991).

An individual with profound cognitive disabilities who has additional disabilities in the form of visual and motor impairments experiences further limited access to visual and sensory motor stimulation. Development of the understanding of the use of the hands for reaching, grasping, and manipu-

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CASE REPORT

Driving to Learn: A New Concept for Training Children With Profound Cognitive Disabilities in a Powered Wheelchair

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KEY WORDS
- assistive technology
- profound mental retardation
- severe visual impairment

Analysis of the case studies of two preschool children with profound cognitive disabilities indicates that training in a powered wheelchair can increase wakefulness and alertness, stimulate a limited use of the arms and hands, and promote the understanding of very simple cause-and-effect relationships. The enhanced activity level had a positive influence on the children’s ability to react to external stimuli and invitations to interact. These effects in turn promoted the development of initiative and exploratory behavior. Because of their profound cognitive disabilities, neither of the children was able to reach the normative training goal—to be able to drive purposefully and safely. In this paper the target group is defined according to criteria for the prescription of powered wheelchairs and the resulting new concept of "driving to learn" is described and discussed from different aspects.

lating is highly dependent on the individual’s ability to recognize, organize, and interpret visual and sensory motor impressions (Brodin, 1991; Sonksen, Levitt, & Kitzinger, 1984).

During the last 20 years, studies have demonstrated the impact that independent powered mobility has on individuals with disability (Birath, 1989; Butler, 1986; Odor & Watson, 1994). However, studies with individuals who have profound cognitive, motor, and visual impairment using a joystick-operated powered wheelchair for training, could not be found. Earlier experience gained by the first author (LN) has shown that using powered wheelchairs for training can be worthwhile. One 13-year-old boy with profound mental retardation, after 6 years of training, developed the ability to drive purposefully in the demarcated and familiar classrooms of his special school. This serendipitous discovery stimulated an interest in exploring what benefits individuals with profound cognitive disabilities might gain from training in a powered wheelchair.

This paper describes the performance and effects observed in two preschool children with profound cognitive disabilities and additional visual and motor impairments, who received training using a joystick-operated powered wheelchair. These children’s clinical conditions, and the method, intervention, and results of the training have previously been more thoroughly described in a master’s thesis that is available at http://www.lisbeth-nilsson.b.se/magister/eng__uppsats.pdf (Nilsson, 1996). Our intention now is to highlight and discuss the effects, other than purposeful driving, that this method of training in a powered wheelchair produced in these two children.

Method
The approach of this study is that of the case study tradition (Yin, 1988). The purpose of the case studies was to analyze and compare changes in individual behavior and development during training using a joystick-operated powered wheelchair.

Participants
Six preschool children with profound cognitive disabilities were found in a habilitation register covering the population of 65,000 inhabitants living in a rural area in northern Sweden where the study was conducted. The children had additional disabilities in the form of profound motor and visual impairment. Only two of the six children were able to participate in the study, as the other four lived 100 to 125 km away and were therefore unable to take part in an intensive training program at a clinic for child habilitation.

The two participants were one girl, Anna, aged five and one boy, John, aged four (names are pseudonyms). Both Anna and John were nonverbal, showed very limited body movement, did not reach, grasp, or manipulate objects, and showed little or no visual tracking or eye contact. Both were incontinent of bowel and bladder. Their profound disabilities prevented them from using assistive technology such as single switch controls. Therefore, neither of the children had been offered the possibility of powered mobility as they were not thought to have the necessary capability.

Design and Procedure
The powered wheelchair used for the training was designed for small children. The joystick was mounted in the middle of a transparent tray 6 cm from a recess for the upper body. The design of the chassis and the electronics of the wheelchair were very typical and standard. Anna did have a special seating insert that fitted into the chassis without other special adaptations.

LN carried out the intensive training with the powered wheelchair, one to three times a week for 4 months in a special playroom at the clinic. Parents or assistants accompanied the children during the training sessions. Each session lasted between 30 and 90 min, depending on the child’s level of alertness and health at the time. If the child showed reactions that could be interpreted as negative (e.g., stiffening the body or crying) the session was discontinued before the set upper limit of 90 min. Manual guidance and hand-over-hand assistance were used to help the children initiate activation of the joystick. During the entire training program, verbal feedback and natural consequences were used to teach each child that movement and behaviors could have an impact on objects and events in the close vicinity. Manually guided actions were accompanied by verbal descriptions of the activity, for example, guiding the child’s hand to the joystick while giving verbal descriptions such as “this is your hand, the stick is in your hand, try to hold on to it.” The guiding and describing were performed slowly and adjusted according to the child’s reactions or responses. The wheelchair was only set in motion when the child had his or her hand on the joystick to promote the development of understanding the connection between activity on the joystick and motion of the wheelchair.

After about 4 months, the training was transferred to the children’s homes where the parents and assistants carried out the training under the supervision of LN, who visited or telephoned periodically. Two special visits by LN were made to the children’s homes, one to deliver the wheelchair and give instructions on how to continue the training and one for follow-up about 12 months after the first training session.

Data Collection
A data triangulation approach was used to make comparisons and draw conclusions about the children’s behaviors during the training. The target behaviors were reactions to the training, unintentional behaviors, and intentional activity in the wheelchair. The three methods used for data collection were video-recordings, field notes, and in-depth interviews.

Every training session at the clinic was video-recorded. Two sessions of the children’s training at home were video-recorded, one at the time of instruction and one at the 12-month follow-up visit. The recordings were of the same length as the training sessions (i.e., 30–90 min). We documented a total of 42 sessions, 20 with Anna and 22 with John, making about 30 hours of recordings. One or two observers, habilitation staff who were acquainted with the participants, were present at every session at the clinic, and they wrote field notes from their observations. The field notes focused on descriptions of new or special reactions or behaviors during the session. In connection with the training sessions at the clinic and the supervision of the training at home,
LN did in-depth interviews with parents and assistants. The interviews focused on how parents and assistants experienced the training and the children's changing behaviors over time.

**Data Analysis**

The analysis process was influenced by the constant comparative method described by Glaser and Strauss (1967). As the participants could not express themselves using speech, the analysis of data was an ongoing process using the three data sources for observation, interpretation, and reflection both during the study and afterwards.

Each video-recording was examined several times, both in close connection to the recorded session and later for comparison with new data. The field notes served as starting points for the first examination of a recorded session. Every examination aimed to observe the variability in each child's behavior during the activity in the powered wheelchair and to recognize small details that signaled change, difference, or novelty in behavior. Focused behaviors were facial expressions, body movements, vocalizations, and reactions to interaction. After several video examinations LN wrote very detailed transcriptions from the video-recordings. Behaviors or changes observed on inspection of the recordings were compared with field notes and interviews. Parents, assistants, and two occupational therapists, not otherwise involved in the study, also inspected sections of video-recordings containing changes in behaviors to give their independent interpretations of the special behaviors. During the process of analysis a number of revisions were performed with regard to the interpretation of observed changes in behavior during the progressing training.

**Results**

The results are presented as descriptions of the changes of the children's behaviors in the powered wheelchair and the effects observed during the training period. The children's behaviors in the wheelchair are described in terms of their reactions, actions, and interactions, with the major intent to display how they developed some consciousness and awareness of the relationships between their actions on the joystick and the motion of the chair.

**Performance in the Powered Wheelchair**

Each child showed an individual pattern of performance when seated and guided to drive the powered wheelchair. The differences between the patterns were thought to depend on diagnosis, previous experience, and innate potential to use the hands for manipulation. However, in these two children the experience of motion in the chair, even if they did not understand how it was produced, obviously reduced their anxiety and excited their curiosity. John and Anna seemed calm, relaxed, and held their eyes open while in the wheelchair, although they usually cried and made their bodies stiff in other unfamiliar situations.

Performance on the 1st Session. John had a great aversion to touching, being touched, and being seated in unfamiliar situations. However, when first seated in the powered wheelchair and experiencing its movement, John became calm and silent. He did not take any initiative to touch anything but accepted hand-over-hand guidance on the joystick. The first training session lasted for more than half an hour but John did not progress beyond the stage of guided driving. When guidance was withdrawn John withdrew his hand and held it close to his chest, sitting still with his head in an upright position as if waiting for the motion to continue. He did not show any signs of understanding that he could initiate movement himself by activating the joystick. His understanding of the use of the hands appeared to be very limited. John could use his left hand only for stereotyped behavior—holding one favorite toy and his special feeding bottle. Initiative for reaching and grasping had not developed.

Anna almost always needed guidance of her hand to the joystick due to her severe spasticity and visual impairment. On some occasions, after a great effort and with obvious intention, she was able to carry out self-initiated driving (e.g., first abducting the shoulder, flexing the elbow, and then rapidly extending the arm towards the joystick and gripping it). Her movements lacked precision so sometimes she made one or two unsuccessful attempts and then appeared to give up. Some days Anna could maintain her grip on the joystick for as long as 15 minutes, other days she lost her grip almost immediately. This inconsistent capacity was considered to be related to both her physical condition and alertness at
the time. She fluctuated between maintaining the driving position after release of guidance and driving by self-initiating intentional pushes or pulls with the joystick from the neutral position. Rarely, on better days, she could activate the joystick with very slow fine movements in an experimental way, but she seemed to have the required strength and concentration for only short periods of such experimental manipulation.

Observed effects judged to be the result of the training included increased wakefulness and alertness, a beginning of very limited use of the hands and arms and a promotion of understanding of the very simple relationship between action on the joystick and motion of the chair. John sometimes arrived at the training sessions asleep or acting very tired, but as he was being positioned in the powered wheelchair, he would straighten up and look around. When seated in the powered wheelchair, Anna almost always tried to hold her head up and look around; when not in the wheelchair, Anna often sat with her head slumped forward, looking down at her lap.

From the start, John showed severe aversion to holding and touching things, and held his forearms and hands close to his chest. After 6 weeks of training, John started to tentatively touch the table or the arm support of the chair with the fingertips of his left hand. His carers reported that he had begun similar tentative touching in other situations such as when he was being fed, touching the surface of the table, or the arm or hair of the person feeding him. When driving in circles, Anna first showed an interest in looking up at the rows of fluorescent lamps hanging from the ceiling. After a few sessions she started to look intensely at her hand when it was placed on the joystick. Both children seemed to react more to external stimuli and to show more interest in persons and objects in their vicinity.

The effects were concluded to be a result of the training as no other changes in their families, personal contacts, or interventions were made during the training period. According to parents and assistants, no other activity had made the same impact on the children’s behaviors over such a short time span.

Discussion

The results of this study form the basis of a new concept of training in powered wheelchairs. The aim of this method is to use the experience of powered mobility to enhance alertness in individuals with profound cognitive disabilities and thereby stimulate the development of intentional behaviors and actions. This method of training in powered wheelchairs is called “driving to learn.”

The target group for this training is composed of individuals who have profound limitations in the development of self-identity and in the ability to act, react, and interact in relation to their environment. Finding a stimulating and age appropriate activity that can benefit these individuals and support their optimal development represents a great challenge for all relatives, therapists, teachers, and other staff. This is not easy, as individuals with profound cognitive disabilities and visual limitations are very often highly introverted and pay little regard to external stimuli or invitations to interact from others.

Cook and Hussey (1995) and Neistadt and Crepeau (1998) argue that any evaluation of the benefit of using certain assistive technology aids must be made in relation both to the benefits that can be gained by use of other aids and to the costs for society. Why then use an expensive powered wheelchair with an individual who is not expected to become a driver? Because even unintentionally activated mobility stimulates most sensory channels and changes body position in space, and these bodily experiences in turn raise the individual’s alertness. As the children participating in the study became more alert and attentive, they became more receptive to external stimulation and interaction. Their heightened alertness in combination with having the joystick positioned in the midline gave them opportunities to accidentally activate the joystick and thereby experience motion. This experience when repeated numerous times led to a beginning of intentional activation of the joystick. As the children developed a use of their arms and hands, even if only in a very limited range, they enhanced their prospects of developing an understanding of very simple causal relationships.

For individuals with profound cognitive disabilities, the gained benefits are small but very important steps on the way to realizing their embryonic potential to influence their close vicinity. Moreover, if one powered wheelchair could be used for training many individuals, the balance between benefits to the individuals and costs to society may be viewed in a more favorable light.

There is a further aspect. Sometimes an individual’s ability and potential are difficult to assess because of his or her profound disabilities. In such cases “driving to learn” may help to make the underlying potential more apparent. The training may reveal previously unrecognized abilities and determine an individual’s full potential. In these case studies, John was, in the beginning, assessed as having a better potential for driving than Anna. The results, however, clearly showed us how wrong this assessment had been. It was Anna who had the greater potential, but that potential was masked by her restricted ability to move her arms and hands.

This method of training is based on the concept of using driving for learning, as opposed to learning how to drive. The aim is to teach the individual that he or she is a separate being with arms and hands that can be used for handling objects. If an individual can learn that it is possible to influence his or her position in space by activating the joystick, he or she may be more inclined to learn how to use single switches to control other equipment such as toys, tape-recorders, or simple assistive communication technology (Nilsson & Nyberg, 1999).

Further studies with more individuals of different ages are needed to see if the effects observed in the development of these two preschool children can be reproduced when training other individuals with similar disabilities.

Kielhofner (1992) suggested some guiding principles for those who work with individuals with profound developmental disabilities. “A deep ingrained value of occupational therapy is the belief in capacity and the therapist’s obligation to tease out that capacity. No capacity or potential is too small or insignificant to warrant support. Moreover, there is a tough-minded conviction in the potential of persons, even when
that potential is not readily apparent” (p. 73). These principles will also serve as guidance in further studies.

**References**


