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Masters Thesis:

What can be achieved by training in a powered wheelchair?

A study of two multihandicapped preschool children.

Key Words: self-directed mobility · mental retardation · visual impairment

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Abstract

Conservative prescription criteria for powered wheelchairs has often ruled out children with multihandicaps as candidates for independent mobility. Their outward appearance and multiple dysfunctions conceal their potential for development and success. Results of an initial pilot study with two preschool children with severe handicaps revealed that a carefully prescribed program of self-directed wheelchair locomotion for these children include increased alertness, mastery and developing the understanding of simple cause-and-effect relationships. This in turn increases the ability for exploratory behavior and sensory intake and integration.

Compared to many other countries, Swedish authorities have canalized resources to habilitation and not only for caring of severely handicapped children. This paper describes two case studies depicting the outcome of powered wheelchair training for two preschool children.

Background

The increasing numbers of children with severe disabilities

Due to continuous improvements in pre- and neonatal care over the last several decades the number of living, severely handicapped children has increased substantially. Several studies have shown a steady or even accelerating increase in the percentages of impairments as well as a greater severity of impairment patterns, especially among extremely preterm survivors (Hagberg et al., 1989 a ; Hagberg et al., 1989 b; and Hagberg et al., 1993). The prevalence of cerebral palsy is about 2/1000 in most populations studied, and up to 35% of those are also severely mentally retarded (Nicholson & Alberman, 1992). The very satisfactory increase in neonatal and postnatal survival rates has however a reverse: the accumulating cohort of impaired children. Studies from the western part of Sweden show that the proportion of children with infantile hydrocephalus surviving with major additional neurological impairments, to 2 years of age, increased significantly from 39% in 1973-78 to 58% in 1987-90. (Fernell et al 1994). Most studies on the field focus on outcome for preterm survivors or for specific diagnoses such as cerebral palsy or infantile hydrocephalus, whereby a comprehensive judgement concerning children with severe impairment as a whole is not possible to achieve. It is clear, however, that the total group of children with severe impairment increases in numbers (Bengt Hagberg personal communication, 1995). These observations indicate a growing demand for habilitation efforts on behalf of the different care givers concerned.

Habilitation and technical development

In Sweden the current habilitation program for children with severe motor and cognitive disabilities is focused on technical aids and motor function, with little emphasis on training of cognitive and perceptual skills. Often the therapeutic habilitation program is intensive during the pre-school years, with diminishing service after the age of seven. At that point special training schools address for most of the child’s further habilitation needs.

Traditionally powered wheelchairs are used in habilitation for transportation. At the forefront of powered mobility today is the development of technological adaptation systems allowing for autonomous transportation even for individuals with limited or no driving control. Piloting or steering can be controlled for example with special interfaces (one to five simple switches) or a standard proportional joystick. The use of wheelchair controller systems such as a line follower, collision sensors or advanced electronics to regulate speed and turn angles is spreading. These facilities makes powered mobility achievable for people with severe functional disabilities and mental retardation. (Handikappinstitutet, 1985, and 1987; Birath, 1989; Paulsson & Winnberg, 1991; Odor & Watson, 1994). The recent advancement of mobility technology appears to be successful in some aspects, allowing mobility on a restricted path, and developing basic cause-and-effect understanding for persons with severe disability. However this technology does not seem to augment the development of more complex cognitive and/or perceptive abilities such as understanding how to drive in different directions and how to vary speed. The child may not learn how to adjust his or her position in space in order to look in the direction of interesting events or how to navigate through environmental obstacles such as piloting the wheelchair in a room and through doorways without bumping into or colliding with things. This is especially true for individuals who have trained in powered wheelchairs with line follower who have shown great difficulties developing the talent for free driving without adaptations (Birath, 1989; Christiansson & Hjortsby, 1991).

A serendipitous discovery

During the late eighties three children with severe multiple handicaps who attended a special school in the catchment area of Gallivare Child Habilitation Clinic were trained for self-directed mobility using an old standard electric wheelchair. Expectations for successful outcomes were low but it was thought that there may be some potential for limited motorized independence. No organized training program was provided to the school-staff. The children's mobility training was conducted by assistants to the teacher. One child died, second moved to another area. The third child, however, after a period of six years was finally able to perform goal-directed mobility using an electric wheelchair without line follower in the well known school environment. This serendipitous discovery led us to contemplate a new habilitation program based on conventional developmental psychological theories (mainly Piaget's and Vygotsky's) with the utilization of ordinary powered wheelchairs, directed by the handicapped child.

Purpose

This paper describes two young multihandicapped children's training in self-directed locomotion. Our intention is to elucidate what can be achieved by experiencing independent mobility. Successes and failures during the training process are analyzed to illuminate how others can avoid similar pit-falls. Existing hindrances and possibilities for development in the child's physical and social environment are described.

Method

The approach in this study falls within the case study tradition (Yin, 1989). For obvious reasons there is no possibility to perform case-control studies on such a heterogeneous group of children. In a catchment area of normal population, children with the same combination and degree of severe multiple disability may not be found, due to the heterogeneity in diagnoses, and to the low number of children with severe multihandicap. Furthermore, established instruments for measuring development of motor skills and cognition are not useful for detecting the very subtle developmental changes that these children may show. The focus of the presented case studies is to analyze how the children's ability for independent mobility in the powered wheelchair developed over time. A detailed analysis of the training process may be a foundation for extending a theoretical framework on how to facilitate the developmental process for children with severe disabilities.

In the catchment area of Gallivare Child Habilitation Clinic lived six preschool children with multiple severe disabilities. Within this area lives about 65 000 inhabitants. The selection of the two children presented, was directed by their geographical distribution in the area. Four of the children lived at a distance of 75 to 100 miles from the Habilitation Clinic and could therefore not be included in the initial intensive training program. The unexpected good results of the two children's intensive training made it later appear worth while to expand the study to include the total group.

The two participating children (one girl aged five and one boy aged four) both had multiple severe functional disabilities including mental retardation, physical disability, vision- and hearing impairment, disturbances in perceptual abilities and no speech. Neither of them had previous experience of using self-directed locomotion in a powered wheelchair. Both children lived with their families and had a personal assistant, paid by the community council, who cared for them in daytime.

Training in the powered wheelchair begun in the habilitation clinic in a special playroom. No special adjustments were made to the wheelchair with the exception of using an adapted seating insert for the girl due to her spasticity. A joystick placed in the middle of a transparent plate was used as steering-gear. Manual guidance, hand over hand assistance, was used to help both children understand how to activate the joystick moving the wheelchair. During the entire training program verbal feedback and natural consequence were used to deliberately communicate the impact of the children's movements and actions on things and events in their environment

(Berg et al., 1982). Parents or assistants accompanied their children during the training sessions. Each session lasted between a half and one and a half hours. After a period of two to three months the families got access to a wheelchair for training the children at home too. One month later, the training was continued only in the child's home by parents or and assistants. During this phase the therapist supervised the training at periodic visits to the children's homes or by telephone calls.

To make comparisons and draw conclusions on the development of independent mobility skills in a powered wheelchair during the training, video-recordings were made of every training session in the habilitation clinic. Two recordings were made at home for each child, one when the wheelchair was introduced in the child's home and one at the end of the pilot study. The length of the recordings varied from about ½ hour to 1½ hours, depending on the child's actual status at the training session. A total of 42 sessions were documented, 20 of the girl and 22 of the boy, comprising about 30 hours of recordings. Every session in the habilitation clinic was recorded in its full extent. The video camera was equipped with wide-angle lens and placed on a tripod. When needed the camera was adjusted to catch the events in the room. One or two observers were present at every session and written field notes from the observations were been recorded. Qualitative interviews with parents and assistants were made with focus on how they experienced the training and the children's development over time. Daily notes from training sessions and interviews were written down in a semi authentic manner.

The analysis of the empirical sources took on some different directions. The video-recordings were analyzed by repeated inspection, notes on significant events, and signs of development were made at each occasion (Gordon & Gallup, 1994). What constituted a significant event developed over time as an outcome of a growing ability to interpret the possible meaning of the children's signs and behaviors observed on the recordings. The written field notes took the form of both descriptions of what actually happened during the session, who were attendants, time of the day; and preliminary interpretations of significant observations made. The latter were an important part of the interpretative process, at every stage they formed a platform for the following extension of the analysis. Interpretations of significant events on the video-recordings made by parents, assistants, and other observers were another part of this. Thus a number of revisions were made during the analyzing process with regard to the meaning of different signs and events observed during the training sessions. In the end a conclusion was reached which we judged as saturated in the sense that no major revision seemed possible.

Result

Starting-point: function and potential

The five-year-old girl, hereafter called Anna, had a tetraplegic cerebral palsy with severe limitations of motor function, mental retardation, severe visual impairment, perceptual dysfunction and no other communication than natural reactions and sounds. Her sensory-motor function was highly restricted, her arms and legs were most often held straight forward and crossed over if she was not positioned in a special way. Voluntary movements could be executed only with great effort. When holding things placed into her hand she appeared to utilize spasticity and she often did not seem to have control when to release and let go. Findings from the initial assessment suggested that she had a low potential to develop capacity to self-directed mobility. It was assumed that she would have great difficulties developing voluntary control of her movements to direct the joystick and to understand and master steering.

The four-year-old boy, hereafter called John, had a diagnosis of Sturge-Weber, a condition which in his case included severe mental retardation, visual and hearing impairment, severe perceptual dysfunction and no other communication than natural reactions and sounds. His sensory-motor skills were severely developmentally delayed: he could walk a few steps with support, he would not hold anything but his feeding bottle and a special favorite toy in his left hand, and he did not use his right hand for grasping at all. Findings from the initial assessment determined that he had the potential to develop the capacity to understand simple cause-effect relationships, e.g. understanding that pushing or pulling the joystick made the wheelchair move.

Initiation phase

During the first session observations of Anna gave the impression that she understood there was a relationship between the occurrence of movement of the wheelchair and her hand's movements on the joystick. She was not able to position her hand by herself on the control. Prior to training, actions to reduce spasticity in her arm and guidance of her hand to the joystick were necessary to facilitate hand placement in the driving-position. While in position Anna could start and stop the wheelchair by herself. After doing so the first time she looked astonished and a bit afraid. Then her expression turned into one of curiosity and a happy face. In the beginning she drove in forward circles. On one occasion, however, Anna went straight ahead and collided with a small table. The loud sounds and the rush of adults around her apparently frightened her; when we tried to position her hand again, she started to cry and repeatedly withdraw her hand from the joystick. We asked her if she had been frightened and told her that it was all right to collide with things. Her expression suggested that she appeared to understand and even if she took up a cautious attitude the training could go on after adults encouragement. Although her sight was reportedly very impaired, while driving in circles she started to look intensely at her hand as if she wanted to discover what was really happening with her hand in action on the joystick. A couple of times she stopped and started all the while still intensely observing her hand. She then looked up and then around and laughed. It seemed as if she liked the experience of exploring the mystery of self-directed mobility. To our knowledge this was the first time she had an opportunity to do anything without aid from someone else. It appeared to be a very stimulating and motivating event for her.

John was said to have a profound aversion against being placed in technical aids not familiar to him. Now, however, he sat without crying and without extending his whole body to get out of the wheelchair, which was his usual reaction. Even though he did not appear to like the transparent plate being placed in front of him, he accepted it when his assistant showed him that the chair could move. It was obvious that the situation was novel and a bit scary to John, but at the same time it interested him and made him curious. When feeling insecure or not being activated he typically sat slowly clapping his fingers while looking down. This behavior also occurred when he was introduced to the wheelchair. He disliked having his hands touched and did not like holding things. John never reached out to take an object or manipulate anything. During the wheelchair training he was manually guided, by mild force, to hold his hands on the joystick. He accepted this provocation only because of the movement that occurred simultaneously. In this manner he was continuously ”forced” to start and keep the wheelchair going. After a while he was given some time to reflect on the situation. He sat still in anticipation as if he was waiting for the chair to move again. When nothing happened he looked up and around slowly clapping with his hands close to the body. Then he started to rock forward in the chair. We were informed that John often rocked if he was seated in his sulky or in the car as if he knew these were things that could move. The rocking was therefore taken as his sign for ”make it go again”. It was apparent that he did not understand his role in directing the wheelchair. Nevertheless he was interested in getting the chair in motion even if he did not realize that there was a relationship between the joystick and the movement of the wheelchair.

What makes one continue when the benefit is not obvious?

Naturally those involved in the training of the children were recurrently stricken with doubts. These doubts mainly concerned the possibility for success. At times there appeared to be no prospects for independent self-directed mobility, the child could not or refused to reach out for the joystick. Neither seem to understand the simple cause-and-effect relationships of the joystick and the chair’s movement. When these doubts occurred, previous successful experience of one boy made it worthwhile to go on. Driven by curiosity about potential outcomes and recognition of the necessary repetition of the skill in order for these children to learn to drive were impetus for continuing the project.

Special processes of development - Anna

From the first occasion Anna seemed to realize how to get the chair in motion, even if she did not manage to direct it consciously. Manual guiding her arm was necessary to place her hand in position on the joystick. Whenever the wheelchair moved in an unexpected way she however appeared worried and tense. With her hand on the joystick she could often master starting and stopping if she was left to initiate this on her own. When she needed to stop to avoid a collision or when she was asked to stop, she did not always manage to voluntary bring the joystick in neutral position in the accurate moment. Often she collided with objects in the environment or was incapable of following the instruction. After a while, however, she found her own solution to the problem, she withdrew her hand off the joystick in order to stop. Her reaction time when performing voluntary movements with her hand was delayed and she had limited capacity to simultaneous control her body position, explore driving and interact on the environment. The necessary concentration and the strenuous work she had to execute to master voluntary movements was intense and tiring. Recurrently she needed breaks, to have a drink of water or to be seated for a while in an extremely flexed position to relax. When instructed, she managed to maintain her grasp on the joystick while she was given guidance at her wrist to get the idea of how to direct the chair. Occasionally she managed to perform turns both to the left and to the right driving with her left hand. During the training sessions she was alert and concentrated and she gave clear signals when she was tired or wanted to finish. After five weeks of training, for the first time she managed to grasp the joystick and drive away on her own without guidance.

Often progress appeared to occur by chance. For example, on one occasion when her mother tried to guide her hand Anna would not cooperate. Her spasticity seemed to increase. After having her arm extended and manipulated to decrease tense Anna started again. With her left arm flexed and her body extended she stretched out her left arm in extension and happened to grasp the joystick with her head still in a backward position. A spontaneous excited comment from the adults around her made her lose the grip. Although she tried she could not repeat this success. Later on she managed to grasp the joystick on her own now and then mainly on days when she was feeling well, and relaxed. After two months of training, she started to move the wheelchair backwards in circles. She now managed to drive both in a forward and a backward direction. It was obvious that she enjoyed the mastery of a new direction especially when it was recognized with rewarding words from the adults. In the next four weeks her capacity to control her grasp function grew, even when there were loud unexpected sounds and people crowded around her. We interpreted this as an increased voluntary motor skill and a increased simultaneous capacity. Her will to interact with people around her had grown, and her joy in the motivating activity was obvious.

Special process of development - the boy

The boy showed a growing interest in the possibility of getting the wheelchair in motion even though he did not understand how. He seemed somehow to develop an awareness and expectation when he entered the training room. When he arrived for a training session he sometimes was very tired and almost sleeping but as soon as he was seated in the wheelchair his alertness rose and he took on an interested and perceiving attitude. The first two months of training his development in the wheelchair had a peculiar progress. About two weeks passed until he managed to maintain the force necessary on the joystick to drive a couple of meters on his own. Several weeks later he could maintain the movement on his own more consistently. Mainly he drove in circles, often gazing downwards. This period was followed by a period of two weeks when he almost always refused to allow hand over hand guidance. When he couldn’t get the wheelchair moving he expressed discontent with gestures and sounds. However, when guiding was instituted without his consent resulting in the chair moving again, he sat silent, still looking up and forward. During this period he showed an awakening interest in the environment that we had not observed earlier. We hypothesized that he could not manage to look around and maintain the motion simultaneously. This was supported by observations where he started to alternate between ‘driving-sessions’ and ‘looking-sessions’. Successively he began to master both driving and looking around at the same time. He expressed joy when feeling the motion by smiling and silently laughing while driving fast in circles. He also showed more obvious reactions to visual environmental stimuli. In this phase, after six weeks of training, for the first time he grasped the joystick and drove about a meter on his own. Seemingly at random he grasped the control again but did not push so nothing happened. On the same occasion he begun for the first time to follow instructions to push harder when he had his hand on the joystick. After two months of training he could sometimes manage to initiate driving and simultaneously look around when driving The consequent verbal instructions combined with guidance had at last given some results.

It was during this period that we for the first time observed John making a special sound as if he was imitating a car. He combined it with a peculiar grimace with his mouth and started to rock forwards in the chair. We did not observe the grimace until he combined it with this special sound. Inspection of earlier video recordings made it clear that the grimace had shown up at the first session but then only once and had gone unnoticed. Video data were the only way to observe, register and analyze these subtle but important details.

From initiation to progress

At the beginning Anna had almost no capacity to manipulate and explore the wheelchair control due to her spasticity and limited manipulation skills. She gave the impression she understood the relationship between joystick and wheelchair movement already during the first training session. At this point we could not imagine her independently initiating and performing the movement of the hand to the joystick. Surprisingly she performed this skill for the first time after only five weeks of training. It required great effort and was not easy for her to replicate but she appeared to intentionally perform this skill. Clearly the engagement in such a motivating activity had enhanced her capability to control voluntary arm movements. It was obvious that she also used her remaining vision more effectively during this period. Driving in circles she controlled her position in space by starting and stopping to look around from different angles. She enjoyed this mastery experience and was often laughing and smiling during the activity.

John had great difficulties in understanding how to initiate driving although he gave the impression that he knew the wheelchair could move. After a couple of months, patient interaction with manual guiding and naming resulted in occasional independent attempts to grasp the joystick and success in drive on his own. Often he drove in circles or at random in different directions. John like Anna used his remaining vision in a more obvious manner than before. He held his head up and looked at the environment when driving, stopping and starting. He seemed to recognize contrasting colors and black and white at a distance of about two meters. He enjoyed the training which was, except from holding his feeding bottle when drinking, the only object related activity he could sustain on his own,.

Discussion

Obviously it is not possible to draw comprehensive conclusions from a study of the training of two children. However, the careful analysis of videotapes from these sessions, in combination with personal communication with parents and other persons involved, allow us to point to certain characteristic features that appear to be of importance in understanding the necessary prerequisites for the results obtained. We also point to clues in designing a more extensive training program: the interpretation of signs of progress during the training, the design of interaction strategies, and the structuring of the environment.

Assessment, motivation and an enjoyable activity

The two children showed quite different abilities already from the first day of training. It was recognized that the possibility to act in a meaningful and enjoyable activity gave an intrinsic motivation to develop abilities not clearly perceptible at the first glance. Though not obvious, these children had more potential capacity to interact with objects than was expected. Their outward appearance belied their eventual motor and cognitive performance. Anna's restrictions of motor function due to spasticity limited her potential for driving in our early judgment. In spite of her spasticity, she had more cognitive ability than we anticipated from her limited movement pattern and restricted non-verbal communication. John we erroneously judged to have a higher potential for development since he had no neuromuscular limitations such as spasticity. His limited motor skills were due to severe mental retardation and thereby less obvious from his passive appearance. It is too easy to be misled by the child's outward advantages or disadvantages instead of seeking the undeveloped potential. Intellectual capacity is often wrongly associated with motor skill and verbal expression. To give the children opportunity to engage in meaningful activity in a real setting, demonstrated how context is a powerful method to assess functional capacity. The access to of independent self-directed mobility in a powered wheelchair was a meaningful and highly motivating activity. Intrinsic motivation in this enjoyable activity in combination with interaction with the environment made the children endeavor to master the situation.

In our interaction with the children we need to demonstrate belief in their potential to develop, understand and master the activity. It is extremely important to look at the child with disability as a learner. Such conviction on the part of the parents and all other people surrounding the child can lead to a self-fulfilling prophecy. Being carefully attuned to the child's subtle cues can uncover the developmental changes in this unfolding process (Brinker & Lewis, 1982).

How to foster the child's growth in the activity

From the start these children had little or no ability or motivation to reach out for and manipulate objects or to touch persons close to them. This lack of sensory experience and the resultant limited understanding of the environment can make the child aversive to new unknown situations. To develop the child's interest in the outcome of manipulating the joystick manual guiding is needed to encourage exploration. Especially in the beginning but also in later periods there may be a need for mild force or provocation to facilitate interest and motor skill. The child may feel insecure, aversion to being touched, fright or frustration when not mastering the situation, or an eagerness to try on his or her own. In all of these cases the child may refuse guidance. It is of utter importance to give a continued encouragement and guidance to help the child overcome these obstacles, otherwise the child may not be able to get past these obstacles on his or her own. In order to support the child's mental and cognitive development in understanding the environment, there is a need to accompany these environmental explorations with words or signs for things related to performance and activity. Even if it is not clear whether or not the child is initially able to interpret the words or signs, continued and repetitious instruction must be given so that the child may learn concepts for certain parts of the body, things and actions. When the concept is presented in the appropriate context with a sufficient number of repetitions the child can learn, interpret and integrate the understanding of the word, sign or direction. This is a necessary prerequisite for verbal or signed interactions, further on. To be able to develop the ability to understand simple explanations and to follow a request, the child needs an idea of the results of his or her actions and the names associated with the things he or she interacts with.

Conditions during the training

It is necessary to try to interpret and understand the single child's special needs for sensory stimulation and grading of sensory input during the training sessions. The child's sensory needs can change from day to day, depending upon the child's state of health. Some days the child may need to be trained in a stable and unchanging environment. Silence and a well known environment are particularly needed when the child is asked to assimilate information and learn new skills. This is especially important in the beginning of the training before the child's understanding of simple cause-and effect relations has been established. Other days when the child is more alert and can concentrate on multiple stimuli tolerance for more stimuli and greater complexity is noted. It is important to be observant and use these occasions to assist the child to develop a higher capacity for managing simultaneous sensory input by learning to maintain his or her performance without being disturbed by background noise and conversation. We also noted that it was more stimulating for the children to train in the playroom with all of its furniture and shelves filled with toys than in a bigger room with less interesting things or in an big gymnasium.

Signs and key-events to be interpreted

It is not the child's appearance we should assess but his or her actions and performance in the powered wheelchair. How does the child react when he or she unintentionally sets the wheelchair in motion? Are there any observable signs of emotional reactions, expressions of interest in the new situation, of curiosity or a will to explore? These special key-events may be for example when the child tries to sign or communicate their interest to get the locomotion started again or when the child for the first time independently grasps the joystick. In the early stages success can be judged as the child independently maintaining a pull or push on the joystick. These kinds of actions may stimulate the child to reflect on what is happening and how it is happening. Usually the children directed the wheelchair in circular motions, often repeatedly, because of the child's lack of understanding of the joysticks steering function. By driving in circles the child receives multi-sensory stimulation that enables an increased alertness and better integration and use of sensory stimuli and more skilled interaction with the environment (Ayres, 1987; Fisher et al., 1992). Rotating impacts the vestibular system bringing an enjoyable feeling of motion to the body. It is important though to observe for signs of nausea especially because multihandicapped children may tolerate a greater amount of circular movement than other children and their verbal communication skills are severely limited. Driving in circles also gives the child an opportunity to create their own special view of things in the surrounding environment. When managing to start and stop on their own the child may be observed to demonstrate improved use of vision evident in head movements and eye gaze.

Video recordings made during the sessions can catch small, but important events of short duration. Alternative interpretations of the child's special behavior is necessary to be able to understand the child's experiences and what these expressions mean. Comparing behavior on similar occasions and through discussions with caregivers, conclusions can be drawn about which alternative interpretations are the most appropriate and enlighten participants to what the child is communicating.

Self-produced locomotion and development

The relationship between self-produced locomotion and development in other areas during infancy is well documented . Bertenthal and colleagues (1984) points out that the 7 - 9 month period for infants is one of rapid developmental reorganization. Moving around creates a new level of interaction between the baby and the environment. Studies on infants with locomotor restrictions point out the impact that independent mobility has on self-initiative and achievement motivation (Butler, 1983; Butler, 1986). The lack of opportunity to explore and interact with the physical environment has been shown to be a barrier to both cognitive development and general adjustment in children with cerebral palsy (Iles & Shouksmith, 1987). Granlund and others (1991) have studied persons with severe multiple dysfunctions including profound mental retardation and found a high correlation between independent mobility and communication. Individuals with mental retardation who have got the opportunity for independent mobility in powered wheelchairs showed more active communication skills after acquiring locomotor skills. Use of powered wheelchairs for independent mobility can positively affect social interaction, initiation and frequency of communication (Butler, 1986; Birath, 1989; Granlund et al., 1991).

Visual disability and motor development

Vision has long been considered an essential perceptual channel for typical development. In babies with severe visual disability motor development is commonly delayed. The drive to explore , to interact and to master skills is often diminished when visual stimulation and feedback are limited. Development of the understanding of the hands potential to reach and grasp things must be aided by other senses when vision can not mediate necessary interactions. Lack of tactile experience can lead to tactile defensiveness and avoidance of contact. Curiosity, manipulative and exploratory behavior needed for normal development may be restrained for these children. (Sonksen et al., 1984).

Learned helplessness versus mastery and control

Subject to repeated failure, a person can develop learned helplessness when attempting to control the outcomes of interaction with the environment especially when feedback suggests that these failures result from stable, uncontrollable factors, such as insufficient ability. Individuals with mental retardation are a group at risk for learned helplessness. The exposure to successive failures that the mentally retarded can experience resemble the techniques used to induce helplessness experimentally (Weisz, 1979). Seligmans (1975) experiments on learned helplessness describes how the loss of effective actions within the environment and the feeling of not being able to control the situation makes decreases an individuals' attempts to interact with others. This highlights how children with multiple handicaps often are experiencing circumstances that may well induce learned helplessness. When their efforts at communication go unrecognized, or are not so obvious to their characters there is a high risk they may be misunderstood or get a wrong response, and eventually fail to communicate at all. This leads to less motivation in the disabled to communicate and less reinforcing communicative responses from persons interacting with them in their environment (Brodin 1991).

Curiosity and initiative to investigate the environment, and to assimilate and adapt to new things or events lay the foundation of development. Opportunity to engage in successful mastery experiences build the feelings of competence and control. Limited motor performance and the absence of independent mobility is a hindrance to exploratory behavior. Dependence on the caregiver makes the child vulnerable, passive and reliant. This can inhibit curiosity and self-initiative behavior. Training in a powered wheelchair gives the child with multiple handicaps a chance to experience independence and control. Moreover it gives rise to motivation, extending exploration to new situations and may start the process of evolving self-awareness. (Butler, 1986; Paulsson & Winnberg, 1991)

Direct and indirect goals

Prescription and assessment policies for powered mobility equipment are still rather conservative and governed by available economic resources. A utility principal is used to canalize resources to areas where maximum benefit may be obtained. With a multihandicapped person it is anticipated success in achieving high set goals may be guarded. Due to low expectations for children with multiple disabilities and a blurred idea of the potential benefit for these children authorities have little interest in investing in equipment or services aimed at reaching an uncertain goal. To be able to provide the opportunity for self-directed mobility to children with multiple dysfunctions, we ought to shift this perspective when determining future goals. The direct or primary goals has to be to reinforce the child to experience and sustain the enjoyable and motivating movement of the powered wheelchair and to facilitate the child's environmental exploration during self-directed mobility. These goals also includes the acquisition of motor skills and development of cause-effect learning to use technology to move the chair, and facilitation of sensory experiences that increase alertness and motivation. The indirect or secondary goal is the development of goal-directed independent mobility in the powered wheelchair. This goal may be in the distant future and may not ever be reached, however the benefit of the primary goal is not to be underestimated, new doors to development are opened when the child understands simple cause-and-effect relations, and explores the use of the hand as a tool in activity. Operating toys with simple switches, use of simple communication aids and easy data programs can be the extension of this training program.

Conclusions

The two multihandicapped children described above made clear steps forward in their development of self-directed mobility in powered wheelchairs. Their common improvements included an enhanced alertness and concentration during the experience of self-directed mobility. This in turn widened their attention to environmental sensory input, and the use of this input to guide action enhancing sensory integration. Both children have shown an improved capacity to interpret and use information from simultaneously occurring sensory channels. From their initial starting position, they have developed a better understanding of their hands as tools for activity and started to coordinate eye and hand-movement. Their understanding of simple cause-and-effect relationships has evolved while driving the wheelchair and they have experienced autonomy in controlling their own mobility and aspects of their environment. It seems that some of these effects are maintained and even transferred to other activities. Foe example increased exploratory behavior and increased ability to use and integrate sensory information in other activities. It can not yet be estimated how far they can reach on the road to goal-directed mobility, only the ongoing training will determine this. With limited cognitive skills and frequent episodes of ill health, these children need extended practice sessions over years in order to assimilate and adapt to new events.

For the child who is severely disabled and retarded to develop more complex behavior it is essential to allow opportunities for growth in the selected activity. Altering any modality in the activity ever so slightly often present a new challenge to the child who then needs to modify and adapt his or her behavior to master these new circumstances. If severely retarded, the child may experience these slight changes in the activity as new requiring the adaptation process to start over from the beginning.

Hindrances to this process, besides the child's combination of disabilities, are the caregiver's and the habilitation staff's lack of experience in interacting with, and interpreting the child's behavior and signals. Uncovering the child's attempts at communication point to the possibilities of undiscovered or undeveloped capacity in the child.

This is why it is so important to see the multihandicapped child as an individual with potential for development. By sharpening our own senses to watch for subtle changes in the child's behavior, we develop the means for giving more adequate reinforcement and feedback which stimulates the child's development. The possibility to develop independent mobility in a powered wheelchair opens new doors of development for the multihandicapped child. The potential developmental gains for the child can not be overestimated; with multiple disabilities every step to foster and utilize the child's existing capacity is a worth while effort. These observations have enhanced our belief in the potential of the child with multihandicaps to exceed current limited expectations and has turned our attention to shortcomings in the social environment.

To look for undeveloped potential

A quotation from Kielhofner suggests central values for practice that need to lead practitioners who work with children who are multiply handicapped to believe in the children's potential. ”A deep ingrained value of occupational therapy is the belief in capacity and the therapists 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.”(Kielhofner, 1992, p 73).

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