

POWERED MOBILITY FOR THE UNDER-TWOS
RUTH EVERARD

Introduction

In 1981, Dan and Louise Everard put their 22-month-old daughter, Ruth, in a specially designed powerchair which provided three-dimensional mobility and direct access to her environment. [1] This was in an effort to enable her to achieve her normal developmental milestones, despite immobility caused by type II spinal muscular atrophy. The importance of a child's need for independent locomotion to prevent developmental delay has since been documented.[2] Ruth is thought to be the oldest example of a disabled person who has, by virtue of artificial locomotion, been able to follow a developmental process equivalent to the accepted norms for a young child.

Since Ruth's first mobility, the family have worked providing other children with mobility which aims to replicate age-appropriate opportunities for normal child development and to accelerate development which has been delayed by mobility impairment.[3] It is now understood that milestones occur in order, even between different areas of development. If mobility has to be introduced at a stage later than the ideal, it can to some extent still trigger late attainment of milestones which have been delayed to date.

This paper explores the developmental stages observed for artificially mobile children compared with able-bodied children and is based upon the anecdotal experience of Dan, Louise and (latterly) Ruth Everard of approximately 800 children in need of powered mobility over a period of twenty-five years. The ages at which the children first became mobile range from eleven months to ten years or more. The diagnoses include, but are not limited to: neuromuscular conditions including spinal muscular atrophy (SMA) types I, II and III, Duchenne muscular dystrophy and other congenital forms of muscular dystrophy; spastic, athetoid and ataxic cerebral palsy; spinal injury; spina bifida; osteogenesis imperfecta; morquio syndrome; post polio; arthrogryposis; dystonia; and congenital and acquired limb deficiency. Some cases involved the combination of more than one of these diagnoses and many were combined with concomitant disabilities which have included: juvenile arthritis; speech, vision and hearing disorders; hydrocephalus; microcephaly; epilepsy; learning disabilities; and respiratory complications requiring ventilation by tracheostomy.

The Everard family's continuing work in this field has run concurrently with changes in approach, both within child development practices and within the rehabilitation field. Child development theorists have shifted in the last twenty years from focusing on diagnosis and treatment of developmental delay to intervention and prevention. Similarly, while the post-war era saw rehabilitation practices favour "normalisation" of function and locomotion, there has been a change beginning in the mid-1970s to the facilitation of full participation in society by alternative means.

The Purpose of Mobility

The over-arching objective for expedient mobility provision is to artificially achieve as much independent access to the environment as would be available to the child in the absence of the mobility impairment. In this way a mobility disability is not allowed to become a developmental disability, because the ability to explore the environment is not impaired.

Fears in the early 1980s that providing artificial locomotion would decrease the child's motivation to walk by themselves have proven to be unfounded. No study has given any suggestion that this may be the case and, in fact, the opposite has been observed: that a child who is artificially mobile better understands what his therapists are trying to achieve and is motivated to improve his own body's mobility.

The Practicalities Which Cause Delay in Intervention

Many factors affect the time-scale upon which intervention is possible to achieve artificial mobility. It is likely in many cases that diagnosis of a child's condition will only take place in response to his failure to achieve a particular milestone and that therefore, by definition, the delay has already begun. Before appropriate intervention can take place (ie provision of mobility by an alternative means such as a powerchair) it is necessary to deal with the immediate medical considerations which present themselves. Then appropriate equipment must be identified and funding must be put in place, by whatever means, to purchase the equipment necessary. In addition, it may be that other problems present themselves, such as the fact that the family do not live in a house which can accommodate a powerchair and a move is necessary.

It is also vital that the child's parents and any other members of the family who have a significant role to play in the child's daily life come to terms with the diagnosis and are allowed to grieve. Consideration should be given to supporting the marriage and/or other family relationships which are at risk at this time of intense stress and emotion. The child may also have an immediate grief reaction if the condition has a sudden onset, but it is likely that provision of mobility will help a child to come to terms with his disability, whereas the adults around him are more likely to see any intervention as an admission, or at least a reminder, of the diagnosis.

Nevertheless, the ideal for introduction of powered mobility is the point at which a delay would otherwise have occurred. In the face of the medical, practical and social realities, it is estimated that a child may be able recover from delays to development up to around the age of two years without the phenomenon of "learned helplessness" – the irreversible underlying psychological effect of being unable to carry out tasks for oneself which leaves a person with a permanent passive attitude and inability to fully develop independence into adolescence and adulthood.[ref] After the age of two years, development can be accelerated by the introduction of mobility but it is likely that prolonged effects of immobility will remain and developmental disability may be observed.

Considerations According to Circumstance and Diagnosis

The considerations for provision and design of equipment and fulfillment of developmental needs vary according to the child's history, diagnosis and prognosis, in addition to the severity of disability.

In conditions in which deterioration will take place, such as Duchenne muscular dystrophy, it is likely that the child's development has begun normally (or close to normally) and the impairment is slowing developmental progress as the condition becomes more apparent. It is likely that diagnosis will come after some delays have already occurred, although any further loss of function will be predictable into the future to some extent. In these circumstances the equipment should be designed to provide more and more assistance as the condition progresses and should be made available at an early stage to accelerate delayed development and prevent further delays. From a socio-psychological perspective, there is a larger window for introducing equipment before it is wholly and undeniably necessary and in this way it can already be in place at the appropriate time and may be more easily acceptable to the child and family. By helping a family to choose to include the equipment earlier to augment the child's development, it can ease the adjustment for all concerned as the condition progresses and, hence, the introduction of mobility equipment seems less of an admission of defeat.

For conditions such as cerebral palsy, where control of the body is impaired but strength is largely unaffected and further deformity may be avoided through good

posture and therapy, equipment should be designed to allow for as much of the child's natural functionality. The issues to be addressed centre on allowing the child to move in his environment at an age-appropriate speed and range and on facilitating use of the body to its maximum without over-burdening the child. Because of the opportunity for functional improvement by motor training, mobility provision is often put off. However, the introduction of age-appropriate locomotion can trigger motor, social, language, intellectual and psychological development and can therefore improve the results achieved by therapy. It is likely that diagnosis will have taken place before mobility milestones are delayed and therefore, from a practical point of view, the opportunity exists to introduce equipment which can facilitate mobility development without delay. It has recently been shown, in cases subjected as children to post-war practices of normalisation, that stretching a child's physical performance to the maximum the body can possibly achieve in daily life will result in "burn out" in adolescence or shortly thereafter and in this case early child development will have been adversely affected to no advantage in adulthood.

Where a condition has been caused by a catastrophic event either by injury (ie spinal injury or limb amputation) or illness (ie Guillain-Barré syndrome, meningitis or polio), the child has begun the progression through development milestones on the normal path. It is almost certain in these circumstances that opportunities for development will be halted by hospitalisation and the child will need time not only to regain health but to adjust (with the family) to the alternative approach to continuing developmental progress. Nevertheless, depending on the age at which the event occurred, the child will have achieved certain milestones which will stand him in good stead for mobility by another means. It may be that skills previously gained are lost, but regaining them or finding an alternative should not be confused with acquisition of new skills. Here the objective is to keep developmental delay to a minimum and facilitate acceleration back to the age-appropriate stages with alternative locomotion.

For conditions such as spinal muscular atrophy and arthrogryposis, in which there are limitations to movement and strength but little change over time and/or opportunity to limit further loss of function, a primary objective is to counter limitations on reach, upper body strength and balance as well as simple mobility. This will allow access and physical interaction to facilitate the exploration processes in normal child development. In some cases (SMA type II, for instance) diagnosis will be in response to a failure to reach a particular milestone and therefore provision of mobility must be focused on accelerating development back to its proper course after the inevitable delay. Less severe conditions (ie SMA type III) may not prevent locomotion entirely but may present limitations later which affect opportunities available in comparison to the child's peers. In that case equipment may be designed to compliment walking and crawling, which may be more acceptable and convenient for some of the time. Where some locomotion takes place naturally the urgency for provision may be less, but earlier introduction of equipment prevents delay and eases acceptance.

For the most severely disabled of children and for those with life-limiting conditions, particularly those in which the prognosis is of significant and catastrophic deterioration, it can be easy to provide intervention which cocoons and cares for the child with little stimulation for achievement of the few possible milestones and experiences. Bottos[5] proposed a four-way categorisation of capability for independence. Associated with the category of the most severe physical and mental disabilities, where it may be expected that independent locomotion would be impossible, are the risks of the relationship between the child and caregiver becoming symbiotic and unhealthy and of deformities developing, each risk indicating increased difficulties for care later. Deformities should be prevented by good postural support and physiotherapy, but while it may be true that the child is indeed incapable of independent movement it should be born in mind that technology exists which may be able to allow an apparently totally dependent child to exercise something of independence. Family relationships are strengthened and the child's quality of life may be massively improved

by experimentation with an optimistic and challenging course of intervention.

Mapping Accepted Age-Appropriate Child Development to an Alternative Path for the Artificially Mobile Child [6]

The primary source of learning until the age of six months is through observation rather than exploration and no baby of this age is independently mobile. In the event that a child has had sensory impairment during this time it should be considered that later, when mobility becomes appropriate, prompt intervention may enable the child to counter some of those detrimental effects by physical interaction in the same way as children without any mobility impairment do (such as exploring by touch for the visually impaired or feeling vibrations caused by sound through objects for the hearing impaired).

The earliest a child without impairment is likely to become mobile naturally is around the age of six months by rolling and, in a few cases, shuffling or crawling. Play and development at this stage begins to be based on the child's own instigation of interaction with the environment. Typically, at around six months of age a child will be competently manipulating his environment in ways such as controlling a bottle and shaking a rattle with interest. The child is able to grab an object with both hands and has the beginnings of understanding of cause and effect on which to build from experience through movement.

A six-month-old can begin to learn to move independently by artificial means, provided that the machine has been designed with a child so young in mind and that it is programmed to allow for the developmental processes safely. In the case of a child with a known prognosis at birth or a family who have undergone pre-natal genetic diagnosis it may be possible to have the powerchair ready for the disabled child at the age of six months, but this is incredibly unlikely and the disadvantages might be considered to outweigh the benefits. The Everards have experimented with a non-disabled child at six months of age and shown that children this young have hand-eye coordination and cognition so that it is theoretically possible for them to use a powerchair. It should be noted that this potentially ambulant child with whom brief trials were carried out was not herself mobile yet. This raises the question of whether there is a minor risk at this age of prolonging the total period of time during which the child has an "abnormal mobility experience" by going too far the other way, forcing greater mobility than is normal for the stage of development and therefore unnecessarily altering the experiences of very early childhood. The effects of a child being too mobile for his age have never been explored and are unlikely ever to be, given the realities of provision. It is more probable, however, that the introduction of a powerchair at too early an age will simply encourage familiarity and the child's instincts for mobility will emerge at the appropriate time. The obvious advantage of this is that no developmental delay whatsoever can take place. Any adverse effects are more likely to be with the parents and family who are either not emotionally ready to accept the change in their circumstances or unrealistically expect to see proficient locomotion as an immediate result of the intervention.

At around nine months mobility is normally achieved by rolling, crawling and shuffling. Typically, children become proficient and can move quickly and determinedly. A child is unaware of dangers but is beginning to learn from experience. A child who is able will start to pull himself up on furniture, varying height, position and view. This is the beginning of active exploration of the environment and the ability to reach, grab and manipulate objects is crucial to the learning process. A child shows awareness of items within immediate reach and demonstrates decision-making by consideration of unfamiliar objects before grabbing them. He can also focus on items and people up to three or four metres away and shows an interest which motivates independent movement towards them. A child whose physical condition prevents this independent locomotion has yet to learn that it is impossible. Instinctively he still

believes that it will become possible and by intervention at this stage any risk of “learned helplessness” can be avoided.

The nine-month-old child is starting to understand the word “no”. This is learned through independent action and a level of discipline which is unnecessary if the child does not have choice over his position or actions. To begin with, the word “no” is used by the adults around him alongside physical gestures and restraint and so understanding of the vocabulary will be delayed if the child cannot initiate physical actions. This language milestone will quickly follow the provision of artificial mobility and if the provision is later than nine months it may be slowed or less pronounced until locomotion, although it is unlikely to be totally absent as it can also develop through observation and static interaction. More generally, babbling and attempts to form speech begin at this stage alongside first mobility. While speech is not prevented altogether by immobility, it is often slowed, particularly for children who do not have above-average intellect. One hypothesis for this is that the immobile child has limited need for vocabulary – it is likely that the parents and carers are proficient at understanding different cries and the normal daily routine of needs. One particular child with athetoid cerebral palsy who became mobile artificially with the help of the Everards at age twelve had a vocabulary of less than 50 words at the time she became mobile. Within three months of locomotion her vocabulary was noticeably rising and within the year it was over 200 words, the theory being that her increased experiences motivated her to express her thoughts and recount those experiences rather than simply demanding basic needs: “drink”, “biscuit”, “toilet” etc.

Communication does not always increase, but tends to move towards the modal rate for the age group. Butler's study, in 1986, of six children between 23 months and 38 months of age who were given powered mobility showed that self-initiated communication in two of the subjects decreased upon the introduction of locomotion. [7] The observation was made that these two children had previously been very demanding and upon being independently mobile their demands on those around them reduced.

It is not outside the normal range for a child to begin to walk between the ages of nine and twelve months. It is understood that children who “bottom shuffle” will tend to be delayed in walking. Some walk without previously moving independently at all and the question remains whether this fact demonstrates that no child needs to be mobile before mobility in a standing position or alternatively whether missing the crawling milestone is indicative of other developmental factors in some children which mean that these particular individuals have no need of it. Caution should therefore be exercised in any justification of delaying locomotion in the non-ambulant child as it is impossible to know if, without mobility impairment, the child would naturally have been mobile before walking (and hence have been mobile before twelve months).

It should be expected that a child in artificial powered mobility will follow a similar timescale for becoming proficient as the ambulant child from first steps to being steady on his feet. There will, therefore, be a period of around six weeks when the child does not have complete control of his powerchair. It should be expected, as with the ambulant child, that many mistakes will be made and bumping into furniture will be common initially. In the normal way the environment should be made safe for the child but, given the force and size of a powerchair and how much more protected the child is than his ambulant peer, more consideration should be given to preventing damage to precious items in the environment. The child will quickly incorporate the machine into his own body image and by the time he is proficient he will have an acute awareness of the size and shape of the machine he uses. Depending on the type of machine, he may be sensitive to physical feedback about the environment from the machine. A five year old who is familiar with his powerchair may be able to feel change of floor surface or a door closing against the machine or even be aware of running over a piece of paper without being able to see it. In the event that a child takes significantly longer to

develop skills than equivalent ambulant peers (taking into account concomitant learning disabilities) it should be considered whether the configuration of the equipment, seating or controls may be altered for optimum control. For a child with either strength (ie neuromuscular) or control (ie cerebral palsy) difficulties a matter of two inches difference in positioning a switch or joystick may be the difference between success and failure.

Motivation to initiate independent movement will vary according to the character of the child. Like the ambulant child, many will remain passive for some time, developing the skills necessary to move but only performing them upon instruction by adults. The goal is independence and it is important to identify items, such as food or a favourite toy, which will tempt the child to make the mental connection between his ability to move and the possible purposes for doing so. If possible, it is better to do this by positioning such an item and leaving the child for a few minutes at a time in order that the child does not experience an adult's refusal to assist him. Such refusal can engender resentment which may be detrimental long-term for a person who, realistically, will be dependent on others more than most during his life-time.

Before articulate language is mastered, physical forms of expression are normally used by children. Frustration is expressed physically by hitting, grabbing and pushing. The immobile child is, to some extent, prevented from doing this. The artificially mobile child will use a powerchair as an extension of his own physicality for these purposes and it should be expected that after the period of learning, temper tantrums will be effected using the powerchair purposefully. Discipline must be employed in these circumstances in the same way as with an ambulant child and decisions in supervision must take into account the size and force of the powerchair. Normal developmental progress will be effected by such discipline, to the long-term benefit of the child, and the temptation to prevent use of the powerchair under these circumstances should be weighed against the likely long-term developmental detriment by removing it.

When tired, just as an ambulant child will become clumsy, a child who is normally proficient in his powerchair will make mistakes and parents and carers will learn to recognise these signs. Over-excitement and distraction, too, will cause errors equivalent to the non-disabled child.

At twelve months a child can understand simple instructions such as "come to Mummy" when associated with a gesture, making the teaching process for a powerchair increasingly easy. Objects will be identified at this age with "definition-by-use" so the child is clearly capable of understanding the purpose of items, including a powerchair. This is the age at which children typically begin to involve themselves in assisting others, sometimes showing a wish to give items to those around them, and the immobile child can develop frustration at feeling futile because inclusion in daily life is limited. The opportunities to praise a child for giving an object to an adult or helping in getting ready are limited without independent mobility. A study has shown that children who are ambulant at twelve months will begin to feed themselves, while those who are not will need to be fed. [8] At this age, a child also demonstrates affection to familiar people and this, too, can be practically impaired by immobility, as such affection tends to include moving towards or following the person in question.

In the ideal situation, by fifteen months a non-ambulant child should be artificially mobile. Milestones which he is now expected to achieve include going to the window to watch what is going on through it, following instructions such as "come for dinner" and "don't touch", exploring the possibilities for play with toys and household items, hiding and finding toys, carrying items, and a heightened general level of curiosity. Any immobility will delay these achievements and consequently have a detrimental effect. At this stage constant supervision is necessary as there is little or no sense of danger. In the months after a child's first birthday he will begin to spontaneously use a few recognisable words correctly and will mimic adults. Words such as "hot" and "oh dear"

come into use with new experiences.

At eighteen months a child walks steadily and proficiently and can run, but has difficulty avoiding obstacles when running. Transposed to the artificially mobile child, this tendency to bump into things is often taken to be an indication that the child is not ready for powered mobility, but it is simply a natural part of the normal developmental process. Professional advisors and families of disabled children must recognise that the child should not be judged as the driver of a vehicle, but as a young child experimenting with movement.

Between the ages of two and four, the questions “why?”, “who?” and “what?” start to be asked continually. This milestone is noticeably lacking in the immobile child and will accelerate suddenly upon provision of locomotion. The pre-school child is also restless and when mobile will be constantly active.

The achievement of artificial mobility can enable a child to follow the majority of milestones with his peers. These may include: physical outdoor play, throwing and catching, depth and distance perception, feeding, dressing, make-believe, assertion of will, social interaction and the development of self. In the event that locomotion has been delayed, all milestones which follow mobility should be expected to be absent, limited, impaired or delayed.

Conclusion

There is often an argument that a “bright” child should be given powered mobility at an early age because he already demonstrates the skills to be able to master it. Rather, while he is undeniably in need of such mobility and should not be denied it, he is demonstrating the capacity to partially overcome a mobility impairment without intervention. Conversely, a child who has yet to show coordination skills and spatial awareness appropriate for proficient use of a powerchair demonstrates the need for adequate intervention to prevent the mobility impairment causing developmental delay. Here, the need for mobility is all the greater. The powerchair might be under-utilised for a short time and the child may learn by making mistakes, but ultimately the powerchair will be taken on as a tool and milestones can be reached earlier than otherwise possible.

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