

Freedom to move

*How can we ensure that mobility solutions promote independence, rather than hindering a child's development? **Julianna Arva** explains all*

There are many ways in which well-meaning people hold back a child's mobility unnecessarily. With all good intentions, professionals and parents often make the mistake of providing a child who is not capable of moving by him/herself with mobility equipment that will actually adversely affect his/her development.

This phenomena is global; it comes from common logic, and a misguided sense of trying to achieve an "as close to typical as possible" status for children with mobility issues. It starts in infancy and tends to last until the child becomes capable of standing up for what s/he wants. In essence, the phenomenon is this: the visually least invasive equipment appears to be the obvious first choice when selecting a mobility device for a child.

However, if we dig a little deeper, we find that often the opposite is true. A good indication of this is that many youngsters, when they get old enough to choose for themselves, make choices which differ from those of their parents and caregivers. They tend to pick a mobility solution that should have been issued for them a long time before.

What children want

So what exactly is the divide between the two perspectives, between appearance and function? Parents often prefer their children to look as close to "normal" as possible. It is understandable; as we grow up and learn to navigate society, we discover all the attitudes towards people who are different. We would like to protect our child from this attitude, so we select the least "disabled-looking" equipment which will get him/her around.

Children, on the other hand, have not yet experienced these attitudes – they don't care about looking normal; what they care about is acting normal. What good does a mainstream looking stroller do for a child, if s/he cannot run around in it with his/her peers? Sitting in a corner in a pretty piece of equipment is nowhere near as much fun as running around with the others in a bulkier one. Small children have not yet developed understanding of the norms – they don't know that their disability makes them different, or if they know, they often don't care – just as long as they don't stay out of the activity because of it.

Their self image develops step by step, and we need to ensure that this image will be of a confident, self-assured, independent person. The frequently-seen learned helplessness in children with disabilities can be avoided if they are taught to be independent from the start. Such overreliance on caregivers, and the lack of independence, develops by age four, according to studies, so we need to show children ways that they can cope for themselves well before they reach that age.

Helping parents move forward

Another psychological factor at play is that parents also often struggle with the acceptance of their child's diagnosis, and all its consequences. Allowing your child to move from a stroller into a wheelchair is a very big step towards this acceptance.

Many parents break into tears the first time a wheelchair is mentioned to them; this equipment and what it symbolises somehow announces, finalises and officially declares the existence of the disability. This really can be a hard pill to swallow, and all professionals around the family should do their best to ease them into the transition. It is our role, as teachers, caregivers, therapists or doctors to show them positive examples, to help them understand that a better future awaits their children if they become independently mobile early on. At this stage, parents usually cannot see that far into the future and do not have an understanding of the benefits of independent function versus minimally disabled appearance. Those of us with years of experience behind us, who have seen many children turning into adults – some autonomous and others remaining dependent – can help parents to see that difference.

Professional focus

Sometimes, professionals also make a well-intended but misguided choice of mobility device. The mobility industry is actually very young, and our understanding of the effects of our choices is continually developing. What research institutions reveal does not get into mainstream thinking for many years; until then, we base our work on common sense and what we learn from cases encountered.

A typical example of misguided thinking is the case of overweight children in wheelchairs. Many practitioners think that these children should push a manual chair to exercise and keep their weight under control. While it makes logical sense, we forget that those of us walking are not using our general mobility as a tool of exercise. We will not wake up one hour earlier just to jog to work instead of taking the bus. We dress up nice and would like to keep clean and tidy until the end of the day. Youngsters in wheelchairs have the same desire – to keep neat and tidy throughout the day, not to tire themselves out by trying to get somewhere. Fitness is necessary for all people, especially those who are obese; however, we cannot and do not sacrifice our own mobility to get training – nor should we expect that from any child in a wheelchair. Most people have a bucketful of energy when they start the day – this energy can be spent on meaningful activities, or on trying to get to them.

It has also been shown that children who are capable but not efficient at pushing a manual wheelchair extend their level of activity once provided with a powered wheelchair. They start doing more, as they see more possibilities; when mobility is tiresome, people are more likely to stagnate and become unmotivated.

As professionals, especially in the school setting, we are also concerned about safety – and rightly so. We must ensure that any child in a wheelchair, as well as all other children, will be safe. Therefore, children who misbehave are often separated from their powered mobility device, as a first means of reprimand. Again, in such cases, we must be cognisant of the effect this has on the child – we wouldn't tie a walking child's legs together if s/he misbehaved. We should attempt to utilise similar sanctions with wheelchair-using children as we do with those who ambulate. Many children with disabilities, especially if not verbal, use their mobility as a means of self-expression. When they misbehave with it, the underlying cause should be investigated and addressed, instead of their mobility being limited.

Finding the right equipment

There are many types of mobility devices, and the options are constantly expanding. In addition to new and interesting technologies becoming available, many hybrids of existing types also surface routinely. National and local trade shows usually provide the best opportunity to keep up to date with the options. However, a critical approach to the selection of equipment is vital; not even the most exciting or best device will work for the child if it is not selected and adjusted appropriately. It is easy for all concerned to get excited about new products at times, but careful consideration of the child's abilities, as well as the family's possibilities and limitations (such as transport) must be given.

The main focus of the selection must be function. The mobility device needs to be able to get the child around effortlessly, as much as possible. There are, though, many other factors to consider, and our selection may be completely off (or end up in the closet) if any of these issues are ignored; accessibility in the home, transport in all necessary vehicles, the family and child's aesthetic preferences, ease of use, the possibility to grow and adapt with the child, durability, maintenance requirements, ease of cleaning and safety are all important considerations.

Gait trainers and mobile standers are training devices and, as such, are not to be confused with means of mobility. It is delightful to be able to move about during standing, however, for non-ambulatory children, standing is often a demanding task which should have its limits.

Supportive strollers are often beneficial to have around as secondary devices; they can fit into even the smallest cars and are easy to take on the plane or train for holidays. They are not designed to be a primary means of mobility, simply because their support surfaces are not typically firm and sufficiently fitted for proper postural support. The long-term lack of appropriate support for the body may result in many negative physiological and functional effects. Such strollers are often preferred by families due to

their unobtrusive looks, but parents should be enlightened about the possibilities and limitations of these devices.

Positioning strollers should be utilised for children who need postural support already at a few months of age – as soon as normally developing children start to sit up. As the child grows and develops, however, frequent re-assessment is needed to evaluate whether the child has progressed to a level of independent mobility. Often, children are left in such devices for too long. If the child is not a candidate for independent mobility, sooner or later a tilt wheelchair should be measured for, as these can provide better postural support.

Manual, tilt-in-space, dependent wheelchairs are the choice for children who are not capable of pushing a manual chair on their own, or driving a powered wheelchair independently. Again, caution should be exercised to give every opportunity to children to be independent; many will do well in a powered chair even if they have severe motor and some cognitive dysfunction. If the child is able even to play with mobility and wheel just a few feet, a supportive tilting wheelchair with large rear wheels is a possibility.

Manual, self-propelled wheelchairs also come in many shapes and sizes. They are designed for kids with many levels of mobility – some for the very active, who are only limited in the lower extremities, and some for children who also have issues in their upper bodies. Many seating and accessory options are available to help optimise the child's pushing abilities – proper configuration ensuring good access to the wheels is therefore vital. In general, if the child is able to get around outdoors with the manual wheelchair, it is probably the right choice for him/her.

Powered wheelchairs are the largest and most expensive piece of equipment and, as a result, they are, often thought of as the last resort. This is a great shame. When non-mobile children can get around in a powered chair, their world simply lights up. Many parents who were initially resistant to the thought of a powered chair are amazed to see a different character blossoming before their eyes due to independent mobility; a child's curiosity, intelligence and sense of humour can really come to the fore. What's more, a powered chair is not only for those without cognitive difficulties; as mobility is a very basic instinct in humans, many children who function cognitively at a relatively low level can learn to drive a powered chair. None of the technology needs to be understood, just the cause and effect relationship of pressing a certain switch and moving in a particular direction.

Hybrids of many different types are also available in the market, such as manual chairs which can turn into powered chairs (or the opposite), motorised standers and power-assisted manual chairs. These are often used when the child is right on the borderline between two devices, or as a result of a more complex background, such as living in two homes, one of which is not accessible.

The most important thing, whatever type of equipment we are looking at, is that we keep our focus firmly on the child's mobility throughout his/her development. As children grow and develop, their abilities also change; we must frequently revisit the possibility of independent, functional mobility, to catch the right and first moment that this is possible. As cognitive improvement leads to better mobility, so mobility can also augment children's development and help them grow into independent and self-sufficient adults.

Further information

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