Comprehensive Guide to Powered Mobility

For Families of SMA

When selecting the first mobility device the choices can be overwhelming. This document aims to guide you through the selection process as well as offer help to obtain funding. Strollers, manual wheelchairs and power wheelchairs are all possible alternatives. Efficiency, durability, comfort, ease of use, and other features will define your selection.

There are several major areas you need to consider when selecting the appropriate powered mobility device: bases, seat functions, seating systems, and access/control methods. Today's technology allows you to mix and match a variety of features. This mobility equipment will be used for many years to come so careful selection and consideration is of utmost importance. We hope that you will find this guide helpful in your decision making process.

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A wheelchair consists of many variables, which all need to be configured to a specific individual. No two wheelchairs are alike when done properly. In addition, it needs to fit like a pair of shoes, since it will not only act as a mobility device, but also the user's seat and primary interface for many hours every day, for years to come. A wheelchair can be a gateway to independence and a very active lifestyle – or it can be the cause of a lot of headaches and frustrations, when not selected properly.

It is difficult to get reimbursement for good quality and highly capable wheelchairs, therefore proper selection first time around is crucial. While other medical issues might now be overwhelming, it is worth spending time and "doing your homework" regarding the wheelchair selection. Please see List of Resources at the end of this guide for specifics.

So, where do you start?

Before your appointment:

- Read this and other guides to get a better understanding of what variables to look for, and what features to consider. Learn what questions to ask and why. (i.e. seat to floor height, control options, attendant controls, transportation, etc.)
- Talk to other users and their families, hear their experiences
- Browse some user groups for feedback
- Browse manufacturer's sites to get a better understanding of the available products
- Visit local trade shows to see and try a variety of products
- Get recommendations for a good supplier and a knowledgeable therapist from other FSMA members in your area
- Don't be shy to contact your manufacturer's representatives. Most large companies have territory managers who will be glad to answer questions and point you to respectable hospitals and clinicians.

Your appointment:

- It is important to work with a knowledgeable therapist and a reputable dealer. If your child's needs are involved, make sure you see a therapist who is specialized in Assistive Technology and does wheelchair assessments on a regular basis. There are only a handful of therapists who are very savvy in technology – you can usually find them in larger hospitals and clinics in the larger cities.
- A reputable and knowledgeable supplier will also be needed to ensure careful follow-up, continued support and proper integration of technology.
- RESNA (The Rehabilitation Engineering Society of North America) provides the only certification currently available to prove proficiency in Assistive Technology. Their website provides a list of ATPs (Assistive

Technology Practitioners – certified clinicians), and ATSs (Assistive Technology Suppliers – certified dealers). Not all good practitioners are certified, and not all certified people are savvy in wheelchairs. This is a voluntary certification for people working with all assistive devices. However, if no other recommendations exist, this might be a good resource to find qualified practitioners.

- Depending on the needs, the assessment might be a single occasion or a series of occasions to look at different options and/or provide training.
- Ask questions. Try a variety of equipment. Try the wheelchair in your vehicle, home, etc. to ensure everything will fit with your surroundings.
- Be sure to discuss and agree to all details of the equipment.

After the appointment:
Your therapist, doctor and supplier will assemble the paperwork and submit it to your insurance. It usually takes minimum 3 months from assessment (evaluation) to delivery of the equipment. Keep in touch with the professionals and help advocating to your insurance if possible. The more you are involved the higher the chances to get the equipment faster. If the equipment is denied, appeal.

After delivery:
Be sure to have asked all your questions – you will have to deal with training and maintenance. Often you will also have to educate other caregivers, such as school staff etc. on the proper use of the equipment.

Chapter II:
FAQ on early provision of independent mobility

Why is efficient mobility a priority?
Children learn through exploring their environments. Without efficient and independent mobility, you child is more likely to develop dependency on others. Think about how a child learns: approaching objects that tweak their curiosity, touching them, playing with them, exploring their environment. Making mistakes, learning from them. Children want to move constantly! Playing with and competing against each other. Now think of a child in a stationary position – she can look around and see others do things, but all she can play with is what was handed to her. She can not approach things on her own; she can not do random exploration. She does not develop the ability to make decisions on her own. In addition, she might develop negative personality traits as a consequence of just having to point at things and wait for someone to bring them to her. With mobility comes opportunity as well as responsibility – both prerequisites of independence, confidence and a positive social attitude.

What is "efficient" mobility?
Your child needs to be able to get around effortlessly throughout the day, accessing the same environments as all other children. That means she has to be able to move across rooms, around the playground, in the yard, down the street, at church, in the mall, between classrooms. Having just enough strength to turn a manual wheelchair around and move a few feet does not qualify for efficient mobility. Always opt for a lesser alternative that provides efficiency – however, most children with SMA will not have sufficient strength to be efficient with a manual wheelchair. In addition, most pediatric manual wheelchairs are equal to or heavier in weight than the child occupying it, and due to growth concerns their access to the drive wheel is often not set up properly.

Many children may benefit from utilizing a manual wheelchair to help maintain upper extremity strength and range – therefore some families opt for both solutions, a powered wheelchair for distances and a manual wheelchair for closed, indoors environments. Obviously both devices may be difficult to obtain through your insurance.

Isn't my child going to lose her strength due to using a power wheelchair?
Exercising is important for everyone – however, mobility and exercise are not the same. Think of your own routine – adults *drive* to the gym to get on the treadmill. They *drive* to the park to ride their bicycle, etc. We drive around for a long time just to find the nearest parking spot to the mall entrance. Mobility needs to be effortless and should not be tiring – there are other ways to maintain strength and endurance.
When your child wakes up in the morning she has a finite supply of energy. That energy can be spent on trying to get somewhere, or she can get there easily then use her energy to actually do something. In addition, research has found that children typically do not lose gross motor function due to power wheelchair utilization, since they still utilize those functions for other tasks.

Some people opt for a hybrid solution, a power assisted device. This is essentially a manual wheelchair equipped with motors in the wheel hubs. When the user pushes the handrim, it activates the motors which help the chair to roll faster and longer. These devices are easier to push than manual wheelchairs, and easier to transport than power wheelchairs. However, the user still needs to have appropriate strength and range of motion in the upper extremities, and the device weighs quite a bit even when taken into pieces. Also, power assisted wheelchairs can not be equipped with seat functions, so your child needs to have enough upper body strength to sit upright all day.

What is a good age to get started with powered mobility?

In short, as young as possible. Many children, particularly with SMA get started driving as early as 18 months of age, and some are starting even younger. Consider normally developing children – they crawl at 5 month of age, stand up around 8-9 months and walk around at 12 months. Obviously, children have the perception of mobility and the concept of directionality before they turn one year old. Mobility consists of developing motor function and perceptual skills. Most children with SMA are very intelligent and are cognitively ready for mobility at a very young age. Learning an upper extremity motor function is all it takes to be mobile – moving a hand switch, a joystick, etc.
The younger you start, the more the power chair aids personality and cognitive development, and it also becomes a natural part of your child's self image. By the time children get to school, they should be able to focus on academic development as opposed to working on mobility.

Is it safe for a small child to drive a power wheelchair?

Is it ever safe for a small child to be left alone? The answer is obviously no; any small child requires constant supervision and that is no different with a child driving a motorized wheelchair. Supervision however is not to be confused with the lack of independence – we will always watch over small children but allow and encourage them to do as much as possible on their own, so eventually they can do all those things unaided and unsupervised. There are many ways to enhance safety for a beginner driver – you can place bumpers around the chair, make programming changes (i.e. turn speed and torque/power down, etc), have an emergency stop switch handy. Keep in mind though that we all learn through making mistakes; most of us never learned that fire hurts until we put our fingers across a candle. Children fall many times before they eventually learn to stand and walk. Mistakes and failure are a natural part of the learning curve – bumping into the walls with a power chair is also an essential step to becoming a proficient driver.

Is there anything I need to know about teaching my child to drive?

In brief, learning to drive a power chair is no different from learning to walk, and you should treat it accordingly. Encourage your child but do not provide too much direction. Let her develop the will to move, the understanding that the controls make the chair move, and the perception of directionality. Understand that some days just sitting in the chair and getting used to the thought may be enough. Do not use language she may not yet understand (such as left, right, stop, slow down, etc.) Rather, substitute with simpler words and expressions that she is used to (Come here, follow me, take your hand off the stick, push your hand towards me, etc.) Do not reach for the controls and try doing it

instead of your child. Most of all, be patient – hard as it might be, your child will develop an understanding quickly if the right support is provided.
Provide a safe environment while your child learns to drive – level surfaces, few obstacles, and possibly a harder surface (it requires more torque to move on carpet.) It is advisable to use low speed and torque settings for a beginner driver. Keep your child motivated through use of their favorite toys, etc, so they develop an understanding that movement will be purposeful.

Chapter III:
Power wheelchair bases

When selecting your first power chair, chances are that you will be overwhelmed with the selection and the features. You may feel like making a quick selection since you have so many other medical issues to worry about. The decision, however, is very important since this chair will be your child's vehicle and mobility for many hours every day for several years. There is NO perfect power wheelchair. Every type will have its tradeoffs – you need to match the technology to your lifestyle and preferences as well as your child's medical needs. Here are certain features to consider and compare:

Drive configuration – location of the larger drive wheels on the base of the wheelchair

- *Front wheel drive*

Large front drive wheels pull the weight instead of pushing it. This allows for improved curb and obstacle climbing capabilities, better handling in soft terrain such as grass and gravel. It also provides very intuitive and tight maneuvering (i.e. turning into a doorway from the hall). Since there are no front casters spinning, you can pull in the footplates closer to the body, while still maintaining a lower seat to floor height.
Disadvantage of the front wheel drive system is the potential for fishtailing – If you go higher speeds the rear of the chair may "wiggle" around. This issue has been resolved on some models but not all. The client also needs to get used to having a lot of the wheelchair behind her, so she needs to be cautious when turning in tight spaces.

- *Mid wheel drive*

Mid wheel drive wheelchairs have the tightest turning radius. While turning radius does not always equal maneuverability, it is a very beneficial feature for indoor use. It is also intuitive to drive since the drive wheels tend to be right underneath the user.
Major disadvantage is a tendency to "highcenter" – this means that with 6 wheels on the ground, the drive wheels can get stuck in the air when initiating a ramp or other obstacle. More and more mid wheel drive configurations offer different tracking and curb assist capabilities – while it is still not the best configuration for outdoors use, the performance constantly improves.

- *Rear wheel drive*

Rear wheel drive wheelchairs used to offer the best tracking – that is, they were able to go straight without a tendency to veer off to the side. With new gyroscopic and alike technologies, both mid and front wheel drive configurations are getting better tracking now. Due to the inherent tracking

characteristics of rear wheel drives, they may be a good choice for heavy outdoors use and/or if you want high speed.
On the downside, much of the user weight is placed above the drive wheels limiting curb climbing ability. Also revolving casters limit footrest placement options.

Ability to accept a ventilator

If you child is likely to need a ventilator in a few years, you will need a wheelchair that can support it. It may mean that you need to opt for a bigger, more rugged base than you would otherwise. Keep in mind the size and weight of the ventilator as well as all other accessories you may need to carry (i.e. suction machine). Also choose a configuration where you can still use the seat functions if a ventilator is added.

Seat to floor height

Seat to floor height of the wheelchair is very important. Small children benefit from sitting low to the ground, being on peer level for most activities. A generic preschool table is 19" at the bottom from the floor. With the child's thigh and the wheelchair cushion, it places the necessary seat to floor height low if she is to be able to participate in table activities in a typical/mainstream preschool.
However, it is ideal if they can also have access to family dining room, bookshelves, kitchen counters, etc. This need can be met with elevating seats and/or seats that move to the floor; however, there may be funding difficulties. During the evaluation carefully assess how high the seat is from the ground, and what your child needs during her typical daily activities.

Transportability

Some wheelchairs come standard with tie town attachment points, while some offer it as an option. It is likely that you child will need those when taking the school bus. As for private transportation, most manufacturers recommend that the child be transported outside the wheelchair in a regular, or specially adapted booster seat. Do not let the large size and the weight of a power chair intimidate you – while it does not fit a regular family sedan, there are alternative and economical transportation options for minivans and SUVs, especially if the child is not seated in the wheelchair. Should you be looking for a crash tested wheelchair? In reality few power wheelchairs are crash tested and crash testing standards are only voluntary. While it might be a consideration, keep in mind that it would significantly limit your choices.

Transportable or folding power chairs

A folding power chair may sound like a good idea, but in reality, with today's technology, it may be a bit of an oxymoron. A folding, transportable power chair needs to be very light weight by nature, therefore it is likely to compromise drive performance. It may be a good idea as a secondary chair or for lighter use, but consider all variables before you opt for one as a primary mobility device for significantly involved children.

Drive performance (Speed, range, incline, curb climbing)
Performance variables may show a difference between ruggedness and durability of the different bases. Do not let these variables rule your decision, but it is recommended to have a look at them.

- What is the maximum *speed* of the chair? Keep in mind that most chairs are programmable, so you can start slower than speed up as your child becomes proficient. Also remember that even the "slower" power chairs typically offer a top speed (4-5 m/h) that is already higher than a typical walking speed.
- *Range*: how many miles can the chair run between charges?
- *Incline*: What degree of ramp/other incline can the chair mount?
- How many inches of *obstacle* can it climb?
- Also keep in mind that some companies specify their tested, recommended, safe results, others might market their maximum abilities. It is always a good idea to try the chair in different settings to assess it for yourself (on ramps, through door thresholds, in grass, etc.)

Suspension
Suspension is not available in all chairs, nor is it always needed, however, it has many benefits, especially at higher speeds. It enables a smoother ride, which improves comfort and helps maintain position, which can be important for users with limited trunk control and strength. A smooth ride can help maintain head position for users with weak neck musculature, and can also reduce the risk of developing pressure sores. A suspension may be important especially for larger children, and with heavier outdoors use.

Growth
Due to insurance reimbursement, any wheelchair will typically have to last about 5 years, so make sure the system offers enough growth to last that time frame.

Programming/electronics
Can the wheelchair accept alternative controls? What can be programmed (speed, torque/power, joystick throw, etc.) If you are savvy with electronics, you could consider getting a programmer so you can make changes at home as your child progresses in driving.

Warranty/reputation
What is warranteed, and for how many years? Check out some online chatgroups and associations to receive information from others on different manufacturers and models.

Ability to accept seat functions

With limited strength and endurance, chances are that your child would benefit from certain functions to be able to stay in the chair for longer periods of time. Tilt, recline, seat elevation, elevating legrests, etc. are all different options. Some chairs can be fitted and/or retrofitted with functions while others cannot. Also check what it takes to add seat functions at a later point in time if it becomes necessary.

Maintenance:

Keep in mind that the wheelchair is a highly involved electro-mechanical device, and as such, requires regular maintenance. Obviously there will be fewer maintenance issues on a manual wheelchair, which mostly just requires cleaning and tightening of nuts and bolts, and maybe some upholstery change. Power wheelchairs require some of the following maintenance:

- Regular charging of battery (depending on use, daily or a few times a week)
- Replacement of battery (typically they last 1-2 years)
- Maintaining tire pressure
- Replacing tires
- Occasional “check-up” – ensure connections are good, etc.

As with any electro-mechanical device, there will be some failures so you need to find a supplier that has a good reputation for service, the same way you probably work with a good car mechanic. It is advisable to have a professional work on the wheelchair instead of yourself to avoid warranty problems.

Aesthetics

The wheelchair will become part of who your child is and will help formulate her self image. Therefore an aesthetic package that places the child in the focus instead of the mechanics and electronics is preferable.

Chapter IV:
Seat functions

Seat functions may seem intimidating or an "overkill" sometimes. They do, however, serve many functions in the areas of prevention, enhanced function and comfort. Try to simulate some of those functions so you can experience for yourself what they mean – imagine a Lazy boy's recline or elevating leg feature, or how you change positions in your car seat. Sitting in one position without any movement throughout the day is very tiring. Seat functions can help ease this by replacing/supporting the body's movements. They also help utilize gravity to ensure better posture in the seat. Better posture usually leads to better function in respiration, digestion, or the upper extremities, and it also helps delay some secondary complications.

Also, think ahead. Your child may be only 2 years old now, very light weight and spending only a few hours a day in the wheelchair. In a few years, however, she may use the wheelchair all day, for all activities, and will also be heavier to transfer in and out of the wheelchair. Seat functions such as tilt may be more important down the road than you might currently think.

Manual or power?

Some functions are available both in manual and powered version (such as tilt and recline). A manual seat function is usually operated by an attendant, while the powered seat function is operated by the user of the wheelchair. Whenever possible, allow the occupant to operate these functions – they know their bodies best, and it is often intimidating to constantly ask for assistance. This may leave children in pain because they will rather not ask to be repositioned. On the other hand, they do not need to understand the biomechanical principles in order to use these functions – children can learn at a very young age, that they can become more comfortable simply by pressing a certain button, so this can become second nature.

The following are the most frequently used seat functions:

Tilt

When tilting back in space, the whole seating system tilts therefore the seated angles are maintained. This option helps maintain the position better, but does not provide any passive stretching or position change; rather, it utilizes gravity to affect the body differently for pressure relief and chest extension.

Benefits:

- Allows independent orientation change
- Reduce pressure from Ishial Tuberosities (sit bones) without compromising seated posture – helps prevent pressure sores

- Compensate for limited trunk stability – even a slight tilt may utilize gravity to help extend the trunk and maintain a more extended position
- Reduce shear as much as possible, as compared to recline
- Maintain proper position related to AAC (Alternative and Augmentative Communication) devices, computer, even when tilted
- Safer negotiation of inclines – can increase ground clearance by slight tilt
- Improved respiration and digestion through more trunk extension
- Utilize gravity for postural control, prevention of typical secondary complications such as posterior pelvic tilt, kyphosis, scoliosis, pressure on the internal organs and compromised vital organ capacity
- Some control of edema, if combined with elevating legs

However, tilted is not a very functional position (line of sight is upwards) so if tilt-in-space is used on the wheelchair, there needs to be dynamic variation between upright and tilted positions. Since the seated angles are maintained, other means are to be utilized to help prevent contractures.

Recline

Recline refers to opening (or closing) the backrest angle relative to the seat. Various angles provide different benefits, and they may be available with shear reduction. Shearing is an unfavorable force that develops due to the body and the seat moving relative to each other and friction arising between the two. Some shearing is good to maintain position and prevent sliding, but extensive shearing may lead to compromised skin or pressure sores. Shear reduction means that the mechanical component of the backrest and the actual user interface of the backrest moves relative to each other while reclining, thus reducing shearing on the user's back.

Benefits:

- Provides passive range of motion – helps prevent contractures at the hip
- Distributes pressure over largest surface of body
- Increases tolerance to staying in wheelchair
- Allows multiple functional positions
- Improves trunk stability, postural stability
- Allows supine transfers
- Allows better trunk position to accommodate kyphosis
- Can decrease fatigue
- Can facilitate bladder emptying, better catheter or urinal use
- Allows positioning for diapering without transfer

- Increases respiratory capacity
- Allows change of hip position for pain relief
- May allow reduction of attendant/caregiver hours

Elevating legrests

Elevating legrests change the angle of the legrest relative to the seat. It may be available with articulation, which means that the footplates move down on the legrests while elevating. This allows for better knee extension, especially for taller users.

Benefits:

- Improves LE (lower extremity) circulation
- Helps maintain stretch and range of motion for at the knees
- Accommodates LE range of motion deficits
- May be needed to support cast, splint, or prosthetics
- Change of position due to pain or neuropathy in LEs
- Allows better bowel/bladder management
- Allows clearance to navigate thresholds, ramps, etc., while the legs can be pulled in closer to the wheelchair for better maneuverability indoors.
- Helps reduce edema, BUT only if the legs are above heart (i.e. with a combination of elevating legs plus tilt or tilt/recline).

Seat elevator

A seat elevator will raise and lower the user in their seated position through the use of an electro-mechanical lift system, without changing the seated angles or the seat's angle relative to the ground, in order to provide varying amounts of added vertical access.

Benefits:

- Allows access 6-10" higher
- Increases reach and gives more independence
- Facilitates lateral transfers
- Facilitates forward transfer by allowing legs, hips to be more extended
- Allows adult users to reach items which should be kept out of the reach of small children (for example, medications)
- Driving while elevated allows better eye contact, allows better positioning for reaching

- May reduce repetitive injury of the neck, by allowing eye to eye conversations
- Allows access to ADLs (Activities of Daily Living) – cooking, microwave, sinks, water faucet, etc.

Seat to floor function

The seat lifts off from the base and moves forward than lowers the occupant to the floor.

Benefits:

- Peer interaction for children – can participate in circle time, etc
- Access surfaces lower – therapy mats, shelves, etc.
- Some children may be able to transfer independently when being low to the ground.

Standing

Some wheelchairs (manual and power) offer integrated standing. This helps making standing a more frequent, integrated, mobile exercise, and allows it to become a functional part of the day. Some tradeoffs exist with standers, such as increased seat to floor height, heavier wheelchair, possibly slightly compromised sitting position.

Benefits:

- Significantly increased environmental access (basically increased vertical access equals the user's thigh length: 10"-20")
- Reach to shelves, cooking, sinks, fire alarm, light switches, payphone, vending machines, water faucets, grocery shelves, etc.
- More independence due to better access to surfaces
- Improved Bone Mineral Density (recent studies indicate that dynamic loading of the bone is superior in maintenance of BMD as compared to static loading, which is provided by stationary standers)
- Reduction in pressure sores (when standing, there is no pressure at all on the sit bones)
- Reduction/delay of secondary skeletal deformities (standing helps extend the upper trunk, delaying kyphosis and scoliosis)
- Reduced occurrence of urinary tract infections
- Reduced muscle atrophy and delayed contractures
- Improved respiratory capacity, better speech, breathing and less coughing

- Less gastro-intestinal complications, because there is less pressure on the internal GI organs
- May allow use of a public urinal for male users
- Increases self confidence by allowing to assume an “equal”, standing position and eye to eye conversations

Chapter V:
Seating systems

Proper selection and professional guidance in the seating system is of utmost importance, since it is the ultimate interface between the user and the wheelchair. This is the seating system surrounding the client all day, and can make all the difference in comfort, sitting tolerance, and prevention of secondary complications.

While comfort in a wheelchair is often quite neglected, it is very important especially with SMA. When seating children in wheelchairs we have a tendency to focus on prevention rather than comfort, though both are of equal importance. Comfort translates into decreased pain and improved sitting tolerance, and better function.

There is no gold standard in seating, since every person is so different; all components of the system have to be matched to the specific user. It is highly recommended to work with a qualified therapist to determine the specifics of the seating system.

One important aspect of seating is that the systems are meant to *accommodate* rather than *correct*. That means that if your child has fixed contractures of the hip, knee, or ankles, or a spinal deformity, do not expect the seating system to "straighten her up." It is very uncomfortable to sit in a way that forces the body into a certain position against its tendencies. Forced postures usually show up in new deformities that the body develops to balance those forces. If your child requires posture correction, a body jacket or other orthosis may be more effective and/or more comfortable. If your child uses a body jacket, make sure the seating system works well with it.

Seating systems are modular and vary from a simple seat and back to a system supplied with many parts and accessories. It is beyond the scope of this guide to describe details of seating systems. Below some considerations and possible accessories:

Seats and cushions:
There are hundreds of off the shelf cushions on the market, plus many clients will end up with a custom made product. Cushions are typically categorized by material: foam, gel, air, honeycomb, etc., and many hybrid versions. The materials, covers, and the shape of the cushion will effect pressure distribution, scope of positioning, moisture/sweat issues, ease of maintenance, and other features. For example, with very low tone practitioners may opt for a cushion that is contoured more aggressively, and if there is a lot of sweating and problems with heat build up, you may consider fabric instead of a cover that is easy to wipe off. A proper cushion is vital to help maintain the pelvis's position in the wheelchair, which is the basis for the rest of the body's alignment.

Backrest:
While backrests are often treated secondary to cushions, fact is that they are just as important for comfort and posture. A planar type backrest (often utilized for children) allows for growth, so it is quick to modify and your child will not need a new one for

maybe years. A contoured back, on the other hand, provides more contact surface therefore more comfort.
In general, the more contour, the less freedom of movement – which may make contoured backs somewhat more appropriate for children with low trunk control, as they provide more support. Children with SMA also tend to prefer softer materials on both the seat and the back - to get a "hugging feeling" – which makes for a more pleasant sensory experience. As with cushions, the selection of backrests is very wide, and many companies offer custom fabricated backrests. Typically most wheelchair frames interface with most seating systems.

Footrests:
Footrests can flip up or swing out of the way to ease transfers. They may be height and angle adjustable to accommodate contractures of the foot.

Headrest:
For a user with poor head control proper support is needed. Head supports vary widely from thin well targeted pads to softer larger surfaces. If you are going to use recline and a very supportive headrest, a shear reducing backrest is definitely recommended to keep the headrest in position relative to the head.
At least a simple headrest is typically prescribed, as it tends to be a requirement on school buses for transportation.

Lateral supports and hipguides:
These accessories are often utilized to help the hips and the trunk to maintain midline, or whatever the user's comfort position is. Some are available with summer/winter hardware, which means you can easily vary the width depending on how thick clothing your child wears. They also come in swing-away or removable hardware, to ease transfers.

Belts and harnesses:
Seat belts, chest belts, footstraps and anterior chest harnesses (butterfly harnesses) are available in a variety of materials and sizes. These accessories help some children maintain position in their wheelchairs as well as ensure safety. For example, a power wheelchair user with low tone in the trunk may easily pitch forward at a sudden stop, so a chest strap may be needed to help maintain trunk position. A seat belt (pelvic belt, lap belt) is typically prescribed with any wheelchair to ensure safety. Footstraps are often prescribed to help maintain foot positioning and prevent contractures.
These devices may be preventive and safe, but their over-utilization can be counter effective. They restrict movement and are not aesthetically pleasing. In addition all caregivers need to be instructed of their proper use. If the straps will be worn throughout the day tightly, it is recommended to look at padded, stretchy options to improve comfort. It is important to realize that the major negative factor in seating is gravity, which can not be counter-effected easily. Sometimes tilt and other seat functions are much more effective than straps in maintaining posture.
Shoulder harnesses are also often required by school transportation, even though they are not approved transportation safety devices.

Armrests and laptrays:
Armrests should be as close to the body as possible to provide support, and preferably built with a softer material. The more weight bearing assumed through the arms, the less pressure on the buttocks. Laptrays are often used to provide a surface for activities, if the child has difficulties pulling up to a table, or to provide more upper extremity support. They are usually easily removable, and can be clear (more aesthetic), or solid color (in case somebody has a visual deficit).

Custom molded seating:
Custom molds can be created as a cushion, a backrest or both. They are usually very restrictive for movement; however, they can accommodate significant postural deformities better than off the shelf seating systems. Custom molds are rarely prescribed for children, because they can not be grown, and for the most part children do not have severe deformities to warrant a custom mold.

Chapter VI:
Controls / Electronic interfaces / Access methods

The advancement of power wheelchair electronics in the past couple of decades has been quite amazing. There is a variety of access methods available to control the movement of a power wheelchair as well as the seat functions. In fact, even if only one part of your body can move with very little strength and excursion, even if only in one direction, you can make a wheelchair move in all directions, tilt, recline, and do everything else.

Access methods are usually categorized by "proportional" or "digital" controls. Many users with SMA will be candidates for proportional controls, whether a standard joystick unit or an adapted version.

With a progressive condition it is wise to consider future electronics possibilities. Some wheelchairs have "expandable controllers", which means that alternative access methods can be added later even if the client starts with a standard joystick.

Many variables on a power wheelchair can be programmed to ensure adequate response to the user's input. Such variables include but are not limited to: speed, power/torque, acceleration, deceleration, joystick throw, etc. Most manufacturer offer programmers on their order forms, but they are typically not ordered with the wheelchair. There are also non-programmable wheelchairs on the market but these are rarely appropriate for users with SMA. Programming capabilities vary by make and model.

Proportional control

Proportional means that the speed of the chair is proportional to the displacement of the control unit – for example, as the user moves the joystick further forward the chair will go faster and faster. In addition proportional control allows moving in any direction within the 360° radius – for example, the wheelchair moves the same direction as the joystick is pointing.

- *Standard joystick.*

Usually located on the side of the wheelchair, attached to the armrest, but alternative placements are possible (such as mid line mounting, often preferred for very small children). The programming variables allow many people to access driving using a regular joystick. For example, reducing "joystick throw" to 50% means that the wheelchair will respond fully when the joystick is pushed only half way.
Alternative handles can also be used; carrot, T handle, large and small balls, etc. to ease grasp on the joystick.

- *Mini joystick*

This is pretty widely used among wheelchair users with SMA. If there is not enough strength or range present to use a standard joystick, the Mini may be a very appropriate alternative. It provides full proportional control (which is typically better, a more natural way to drive), and also allows access to all seat functions. Typically there is a need for a switch of some kind placed somewhere the user has consistent motion, which acts as a "mode" switch to change between driving, speed change and power positioning/seat functions. Then, moving the joystick left and right, up or down will activate those functions and/or change the speed.

The user needs very little force and very little range to activate this joystick – in less than ¼" displacement you can achieve full speed and get acceleration and other variables for very accurate and refined driving. However, the user needs to be able to move in all 4 quadrants.

This joystick minimizes fatigue and enables many users with SMA to drive throughout the day. It is, however, quite fragile, so special care needs to be taken when transferring in and out of the chair, etc.

It can be placed anywhere around the body, and is often used with a mid line mount and good arm support.

- *Other proportional controls*

There are other alternatives, such as touch pads (which looks and works like a mouse pad on a laptop), and the Magitech (which is a small tilt sensor making the chair move towards the direction of tilt). With the appearance and popularity of the Mini, especially among people with SMA, their application has been reduced.

Digital control

Digital control is also referred to as switch control. The opportunities are endless – multiple switches and single switches of any size and shape. Switch control offers movement in 4 distinctive directions, 90° apart (forward, reverse, left, right). It is a good alternative if proportional driving is not possible – another alternative to achieve independence in mobility and potentially computer applications. Some therapists prefer digital controls as a training tool for first time drivers, assuming that it is easier to understand directionality through their use. Keep in mind, however, that proportional control provides a more natural (and usually faster) way of moving about.

- *Multiple switches*

The most frequently used multiple switch control is a head array. This device incorporates all switches into the headrest, and it is the movement of the head that controls the movement of the wheelchair. Most children with SMA may find this option fatiguing. Other switch controls available can be placed near the

hand, elbows, feet, or just about anywhere where consistent movement is detected. Many users with SMA may opt for fiber optic switches, which can detect very slight motion in any direction and can be placed anywhere around the body.

- *Single switch scanning*

If all else fails but the user has consistent reliable movement in one direction at one body part and a reasonably good reflex time, single switch scanning is a possibility. In this option only a single switch is used, the activation of which stops the scanning sequence on the display. For example, it might be scanning through: "Drive, seat function, speed change", then after the user presses the switch at "drive", it might start scanning the directions; "forward, reverse, left right".
Scanning interval can be pre-programmed. Some users develop very high proficiency with this method. Single switches are available in all shapes and sizes; small & light touch (Microlite), large, plush, with or without audio feedback, or a fiber optic beam. Clients have accessed single switches through their tongues, toes, etc.

Attendant controls:

An attendant control is a secondary joystick usually placed on the back of the chair. It allows a caregiver to walk behind the chair and drive it with a joystick, in case the occupant is fatigued. Power wheelchairs are very heavy, often in the 200-300lb range, so pushing them via push handles is overly demanding for long distances.
Attendant controls can be useful for example when you have a very young child who is just beginning to drive, and you want to help her navigate through busy areas in the mall or a restaurant. Specifically for SMA, children have a tendency to get tired before the day is over, so an attendant control would allow the caregivers to drive the chair when fatigue occurs. Unfortunately attendant controls are often not covered by insurance.

Integration of technology:

Computer access modules, communication devices, environmental controls can all be integrated with the drive controls of the wheelchair. The advantage of integrating technologies is that everything will be controlled by the same body part, so if there is a preferred site on the body or there is only one reliable access site, this is a good solution. However, there are disadvantages of integration. It takes time (and cognitive readiness) to scan through options and switch from one device to another. If the wheelchair control has a failure, everything else becomes impossible to control.
With constant advancement of technology, integrated controls are gaining popularity among children with SMA – often integrating computer access with their wheelchair joystick/mini joystick control.

Chapter VII:
Funding

The key to obtaining funding is good documentation. You should work with professionals who have expertise and credibility to supply such documentation.

It is always recommended to have a physical or occupational therapist involved with the process in addition to the physician and the supplier. In general, the physician signs off on the prescription, but they usually refer the details to other professionals. The therapist has thorough knowledge of physiology as well as the specific client, while the suppliers have a good grasp on the available technology. Of course there is a lot of overlap, but a good team can make all the difference.

Every funding source has their own criteria and requirements – the following guidelines are general, so please check your insurance's specific requirements and coverage criteria.

- Usually the reviewer does not know your child. A detailed description of the person, the problem and the benefits of the proposed solution can help justify the equipment.
- The LMN (Letter of Medical Necessity) needs to be concise but thorough. Reviewers do not have time to read details that aren't applicable to the device. Most well-written letters for mobility devices tend to be around three to four pages. However, an LMN can certainly be longer or shorter, depending on the specific situation.
- Photographs are an asset. They speak volumes and are quick to review. They're more descriptive than words can ever be, and they help turn a claim number into a face for the reviewer.
- Videos can also help justify medical necessity. In general, it is a good idea to film any difficult or controversial request (i.e. integrated standers, seat to floor function, very young driver, etc.), and it is a good tool to use in appeals if needed.

The LMN is likely to be written by your therapist and signed by the physician. The following information should be included:

- Basic client data
- Diagnosis, symptoms, past progression
- Expected progression
- Goals and life roles
- Current system.

  Just because her system is five years old, your child is not automatically eligible for a new one. You need to explain why her current system does not work. Is it beyond repair? Does it lack certain necessary features? Has your child outgrown it? Has her disability progressed requiring additional features?
- Physical/cognitive abilities and limitations
- Seating and mobility needs.

Description of the need and requirements should always precede description of the final product.

- Assessment methods and clinical trials.

The reviewer needs to be able to follow your team's thought process. How did they come to the conclusion that this is the appropriate device? A brief description of the assessment methods will help them understand the proposed equipment: client interview, mat assessment, driver training, pressure mapping, trial in the home, trial in family vehicle, etc. When the reviewer sees that a thorough assessment has been done, she is also more likely to approve the recommendations.

- Equipment chosen, justified item by item.

Everything on the wheelchair that has a charge needs to be separately justified. For example, batteries – the wheelchair will not run without them (may be obvious yet needs to be stated).

- Utility of the device in the home.

Most funding sources require that any feature of the wheelchair has beneficial effects in the client's home setting. For example an elevating seat may help access shelves and tables at school, but instead it should be justified by access to family dining table, kitchen counters, bathroom sink, etc.

- Why is it the best alternative?

Describe more economical alternatives that were considered, and why they were not adequate. Denials like "choose a less costly alternative" are not acceptable, as long as you can prove that there is no cost competitive alternative with *the same or comparable features*.

- How the device will benefit the user (refer back to the needs section)
- What would happen to the user without this equipment?

Describe all the negative consequences of not having the equipment approved. Depending on the equipment and client, this may include risk of falls and fractures, development of secondary complications, learned helplessness, etc.

- Focus on medical necessity.

A variety of definitions exist for medical necessity. If the equipment gets denied stating "it is not medically necessary", be sure to ask your insurance for their specific definition. Focus your letter on medical features instead of social or psychological. For example, a stander may allow for eye to eye conversations and feeling of equality, but the LMN should rather focus on prevention of osteoporosis, etc.

<u>Denials:</u>

In today's funding environment getting equipment covered is ever increasingly difficult. This may cause a lot of frustration and wasted time. Unfortunately, denials do occur even with the best justification. Therefore you should always start the equipment process early. A knowledgeable professional will be able to address many of the potential denial reasons already in their original documentation.

Do appeal. A large percent of equipment gets denied, and a large percent of those appealed get approved. Also keep in mind that every time you do not appeal, you damage your chances of getting equipment approved in the future, as well as that of others. Every single equipment which was fought for until it is approved, helps improve the system and the future of technology availability for people with disabilities.

Last but not least, keep in mind that reviewers never hear about the success stories. They only see claims and complaints. Let us help them understand the benefits of these devices by describing how they make a difference. After approval, write them a letter and describe how this equipment changed your child's and your family's life. It will help your next claim as well as other people's claims, and may eventually help loosen the funding squeeze.

If you have any comments/questions regarding this guide, please contact:

Julianna Arva
Pediatric Product Specialist
Permobil Inc.
Ph: 800-285-3114 x 285
Email: Julianna.a@permobilus.com

List of Resources:

These links are provided for convenience only. FSMA possesses no control over such links, and makes no express or implied warranties, representations or endorsements of any kind regarding any linked site, and assumes no liability of any kind for any information contained in any linked site.

Conferences/Trade shows:

- Abilities Expos www.abilitiesexpo.com

User oriented expos in several cities across the country.

- Medtrade www.medtrade.com

Professional oriented trade show, the largest in the country. Open attendance to anyone.

- Resna www.resna.org

Professional organization and annual conference at varying locations. The conference offers open attendance to the expo one day.

- International Seating Symposium http://www.iss.pitt.edu

Annual conference varies between Vancouver and Orlando. The conference offers open attendance to the expo one day.

- In addition, there are many local expos organized by suppliers and/or schools. Ask your therapist and suppliers for upcoming events.
- FSMA offers an annual conference as well. www.fsma.org

Professional organizations:

- Resna www.resna.org

Organization for all Assistive Technology providers, clinicians, researchers and suppliers. Provides info on annual conference/expo as well as a list of certified professionals.

- NRRTS www.nrrts.org

National Registry of Rehabilitation Technology Suppliers. Professional and voluntary organization of suppliers/dealers. You can find registrants in your area through their website as well as professional code of ethics.

User websites, chatrooms:

- FSMA website www.fsma.org
- Wheelchair junkie www.wheelchairjunkie.com

A very active chat forum for wheelchair users, mostly highly active adults.

- Able data www.abledata.com

Comprehensive information on various aspects of technology, link to manufacturers, etc.

- Wheelchairnet www.wheelchairnet.org

Comprehensive information on various aspects of technology, training, latest research, etc.

Magazines:

- New Mobility www.newmobility.com

User oriented magazine. New publication "Kids on Wheels" is a very comprehensive guide to pediatric mobility issues.

- Mobility Management www.mobilitymgmt.com

Interesting articles, product information, mostly targeting professionals.

- Exceptional Parent www.eparent.com

Magazine focusing on parenting a child with disability. Also offers educational sections via teleconferencing.

Manufacturers:

There are innumerable products available related to wheelchairs. Hundreds of cushions, seating accessories, switches, etc. This list is not intended to be comprehensive, rather provide references for some of the largest and most widely used manufacturers with products related to powered mobility:

- Permobil www.permobil.com

Manufacturer of powered wheelchairs, functions and seating ranging from pediatric to adult.

- Pride Mobility Products www.pridemobility.com

Manufacturer of powered mobility products and related items ranging from pediatric to geriatric.

- Invacare www.invacare.com

Manufacturer of power and manual mobility, hospital beds, accessories, etc.

- Sunrise Medical www.sunrisemedical.com

Manufacturer of power and manual mobility, hospital beds, accessories, etc.

- ASL www.asl-inc.com

Manufacturer of switched solutions/adaptive controls for individuals requiring more comprehensive access than a joystick.

- Switch It www.switchit-inc.com

Manufacturer of switched solutions/adaptive controls for individuals requiring more comprehensive access than a joystick.

- Enabling Devices www.enablingdevices.com

Affordable adapted toys, switches, etc.