



SEATING AND MOBILITY PROVISION WITH TEENS:

A TIME OF TRANSITION

Growing pains in adolescence encompass the entire spectrum. Physical changes often capture the spotlight but are closely intertwined with character development. This is a time when boundaries are questioned, pushed and often broken and moments can begin to define individuals. More often than not, these defining times emerge out of engagement in family, social and academic life. Physical barriers to participation are often a hallmark component of disability. Technology, equipment and education when well implemented can often minimize these participation barriers. When this technology and equipment is not well prescribed or when education is lacking, barriers can be magnified rather than eliminated. Pathways to independence are rarely downhill and coordinating a team approach to equipment provision that facilitates the emergence of a successful individual somewhere along the way has its ability to challenge the strongest leadership.

Frequently adolescents are caught in between pediatric- and adult-based services, which can create a gap in professional skill sets to optimize equipment for this age group. Diagnoses such as cerebral palsy and myelomeningocele can often conjure up images of children of elementary school age or younger. These diagnoses are considered non-progressive, meaning the disease or injury process does not worsen with time. However, many secondary changes occur as a result of the primary impairment that can have a detrimental effect on function as that child moves toward adulthood.

Families, the individual and sometimes the professionals can be easily trapped in a pediatric mindset where concepts such as pressure ulcers, pain and spinal surgery fall under the misperception that these concerns are down the road. As a result, these adolescents and caregivers often find themselves in new territory when contractures, scoliosis, and fatigue seem to suddenly appear. A need may be created to consider equipment use or replace current equipment. Many of these complications can surface during a mobility evaluation, creating opportunities for education as well as entry points for referrals for supplementary medical assessment and intervention. All too frequently, adolescents with long-term diagnoses have exhausted their interest and participation in regular therapy and there is a void in service provision to smooth this multifaceted transition to adulthood.

Physically, adolescent growth spurts often coincide with worsening joint contractures as well as an increase in progression of neuromuscular scoliosis and pelvic asymmetries. Muscles under the influence of spasticity often lose the extensibility of fibers that are found in typical muscle composition. This decrease in inherent flexibility becomes problematic during a growth spurt when bone growth requires a corresponding increase in muscle length. From a seating perspective, changes in lower extremity range of motion, particularly hamstring muscle length

and hip flexibility can directly impact posture and mandate changes in wheelchair configuration. In addition to the seating itself, the orientation of the system through both tilt and recline can help functionally compensate for muscle length and tone changes. For example, if extensor muscle recruitment creates anterior progression on the seat surface, a combination of tilt and recline may allow for the individual to independently reposition themselves, decreasing reliance on a caregiver. Unique combinations of lateral tilt, anterior tilt and pre-cline to the typical posterior orientation changes should also be considered to increase variety in positions for task performance as well as to compensate for a loss of flexibility in cervical musculature which may limit visual field through poor head orientation. In many instances, creative opportunities for supplemental positioning including nighttime positioners and stretching through weight bearing in supported standing can assist with overall joint maintenance.

WHEN THIS TECHNOLOGY AND EQUIPMENT IS NOT WELL PRESCRIBED OR WHEN EDUCATION IS LACKING, BARRIERS CAN BE MAGNIFIED RATHER THAN ELIMINATED.

For many young people, a marked increase in the progression of neuromuscular scoliosis occurs during adolescence. In cerebral palsy there is a 30 percent incidence of scoliosis and for those in the more impaired range, there is a 50 percent risk of moderate or severe scoliosis by age 18. Duchene muscular dystrophy has a rate of scoliosis of 48 percent to 93 percent while spinal muscular atrophy rates vary from 58 percent to 95 percent with fluctuations based on classification and severity.¹ Many of these moderate-to-severe curves will warrant surgical intervention. From an equipment perspective, collaboration with physicians and surgeons is imperative to the timing of modifications to existing wheelchairs or prescription of new ones. If surgery is looming, discussion with the surgeon either directly through the seating clinic team or indirectly through an educated family member or wheelchair user can coordinate timing of post-op reassessment to minimize wait times for often already overdue equipment.

Skin integrity and pressure management are new considerations that are frequently not an issue with young children with neuromuscular impairments. Part of the aging process toward adulthood creates integumentary changes that affect both tissue resiliency and wound healing. In the young child during healing, collagen, elastin and granulation tissue form rapidly. As the child ages, these processes slow, which requires increased time for healing.² In addition to changes in skin composition, worsening pelvic asymmetries, hip dislocation or subluxation and spinal scoliosis can create asymmetrical sitting postures. All of this combined with the high probability of increased time in equipment as well as decreased opportunities for weight shifting can be problematic. For some, pressure management is not a new concept. However many teens or caregivers of teens have missed this component of their therapeutic routine and all too frequently, the introduction to weight shifting techniques and pressure management comes following the development of their first pressure ulcer. Further complications may arise as individuals may experience significant changes in voiding patterns or volume. In the presence of incontinence, the incidence of large volume voids can directly affect skin integrity from increased moisture. Explorations of alternative methods to manage incontinence are often overlooked if the problem has been longstanding. Identification and referral may need to be initiated by the seating clinic team as they may be the first specialty to identify this as a risk factor for optimal skin health.

Emerging independence can be facilitated by incorporating the adolescent as a primary team member in equipment decisions. Family dynamics and historical practices can influence the adolescent's initiation to participate. This shift in decision making from parent to young adult can be simplified by directing the evaluation towards the wheelchair user rather than the parent and/or caregiver. There can be a tendency to use the current equipment as a framework for decision making. Though it is good practice to determine pros and cons of current equipment, present ingenuity and future insight can minimize the risk of duplicating a set of wheels that might have been perfect for a child but cannot well support the emergence and expression of a young adult self. Discussing the environments and activities where the chair will need to function over the next five years in addition to the current environment is necessary to anticipate equipment goals. Though this consideration is important with any age group, the adolescent has the potential to transition between multiple school environments as well as the mobility constraints created by college campuses. It is often difficult for the user to anticipate the

physical demand of negotiating the urban or rural campus. Assessment of community based function and/or encouraging local campus visits in either current or trial equipment can provide a framework for decision making.

THIS SHIFT IN DECISION MAKING FROM PARENT TO YOUNG ADULT CAN BE SIMPLIFIED BY DIRECTING THE EVALUATION TOWARD THE WHEELCHAIR USER RATHER THAN THE PARENT AND/OR CAREGIVER.

The transition to community based aides on a college campus from family based supports in the home can create new dilemmas for sitting tolerance, environmental access, and self care. These aides may run late or not show up at all, requiring the individual to spend several additional hours in their wheelchair. Power seat functions, which may seem unnecessary to caregivers and adolescents with the sometimes unrecognized supports of their home environment, become critical to manage unanticipated extended periods of time in their chair. The addition of power recline and elevating leg rests to a system where tilt was previously sufficient can bridge the gap between the family home and independent living scenarios. Furthermore, the addition of anterior tilt may increase the opportunity to access lower table heights as environments increase in variety and decrease in predictability. College dorms often have significant space limitations. Consideration of combining equipment such as a power standing feature to replace a stationary stander that cannot travel to school, allows for the medical and functional benefits of standing to be continued rather than abandoned. These scenarios may be difficult to predict by families and therefore professional insight

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into potential future challenges will create an opportunity for discussion and thoughtful equipment decisions.

While functioning crystal balls are hard to come by, there are some trends in adolescent development in the presence of disability that need to be on the table for discussion and problem solving. While addressing all these issues in the seating and mobility evaluation can be a lengthy process, utilizing appropriate referrals to medical specialties can be an efficient way to manage complexities and identify solutions for seating related challenges. Re-engagement in short term physical or occupational therapy may be indicated to target goals of pressure management, weight shift techniques, fine tune transfer skills for sheer reduction, and train or re-train community based wheelchair skills. Above all, the education of the family and the adolescent, combined with the identification and consideration of this multitude of factors during the evaluation process, will optimize equipment choices for a more effective launch to adult independence.

Optimizing equipment prescription during transitional times should include:

- Medical referrals to specialists such as urology and orthopedics
- Therapy referrals
- Community based mobility assessment and equipment trial
- Consolidation of equipment to minimize transfers or space constraints
- Education regarding skin, sitting tolerance, and postural management
- Discussion about future plans and considerations to maximize independence

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²BAHARESTANI, M. AN OVERVIEW OF NEONATAL AND PEDIATRIC WOUND CARE KNOWLEDGE AND CONSIDERATIONS. *OSTOMY WOUND MANAGEMENT.* 2007;53(6):34-55.