

Recommendations for wheelchair fitting for children/adults with SA/CRS

Because SA/CRS impacts each person differently, there is no single set of recommendations that is suitable for everyone. However, there are a variety of characteristics that are unique to the SA/CRS population.

Type of chair:

Usually, for the individual with SA/CRS who is a wheelchair user either full or part time, the overall rule of thumb for fitting a wheelchair is “less is more”-less weight, less “extras”, less width usually results in achieving the goal of maximizing the efficiency of the push and maneuverability of the chair. A person with SA/CRS is usually a good candidate for a rigid, ultra-light custom manual wheelchair and can usually be expected to maximize **wheelchair development skills**. For information comparing power/motorized wheelchairs and manual wheelchairs, see this page.

Characteristics to be considered for wheelchair seating	Recommendations
webbed, fused bent legs in a Buddha or “frog leg” position with widest measurement knee to knee.	<p>The narrower the chair, the more efficient the push and more responsive the chair is. If the child has webbed legs, this narrow chair fitting is often a challenge to achieve and a wide chair to accommodate knee length leaves the child unstable, the shoulders at risk from strain from a wide pushing angle, and poor maneuverability in the chair, which only increases with age as the knee width increases from growth.</p> <p>While surgery is the most effective way to address this issue (see at-knee disarticulation), that option is not always chosen for the child. With at-knee disarticulation, the upper legs can be brought forward for proper fitting at hips and a narrow chair width. Without disarticulation, the PT may be able work to bring the legs into a crossover position with less wide splay of the hips allowing for a narrower seat. Some seat inserts and some side guards may effectively bring widely splayed abducted hips to the center alignment.</p> <p>A molded seat cushion that is raised on each side with child seated in the center of the “V” may raise knees upward if they cannot be brought forward. The angle allows for a slightly narrower seat between the wheels.</p>
straight fused legs that do not bend	There are a few chair designs that make a slanted frame in front that accommodates the legs, and sometimes a front platform is added to the chair. These additions decrease

	<p>the maneuverability of the chair. When the child is young, sometimes the chair seat length is elongated to accommodate support under the legs. This addition is a challenge for center of gravity in the chair so it also decreases the chair maneuverability and eventually will not be an option as the child's legs grow longer.</p> <p>Some individuals opt for at knee disarticulation to address the issue of legs that will not bend for seating in a wheelchair (as well as seating anywhere else such as public transportation, airplanes, buses and so on). Some opt for removal of growth plates to keep the legs from getting so long that they significantly impede seating options. The second option often allows the child to walk or stand at least through childhood and sometimes into adulthood as the child with fused straight legs may use the legs for standing or walking.</p>
<p>Short torso, often with lack of connection between pelvis and spine. That means the individual often sits in a position that leans forward over the thighs. The torso may appear unstable, but potential for development in balance is high.</p>	<p>A common error in wheelchair seating for the SA/CRS population is seating the child too low in the chair, requiring the child to raise the shoulder high in order to make the push stroke. A thick seat cushion addresses this issue. Some individuals prefer a seat cushion that is 3.5 to 4 inches thick. By raising the seat position, the individual has a more efficient and ergonomical push stroke , preserving shoulder health.</p> <p>Also, due to the short torso, when seating depth is too low, side guards are often made too high, interfering with pushing, and arm rests in particular interfere with pushing, but the thick seat cushion will resolve this issue at least for the side guards.</p> <p>Because of the short torso, arm rests are usually in the way and force an inefficient push with shoulder strain. Individuals seated too low in the chair with arm rests find that the arm rests are centimeters from the child's arm pit. Although there is sometimes issue with trunk control initially, arm rests are not recommended. These are usually the first things that need to be stripped off of the chair to make it effective for the user with SA/CRS.</p> <p>Due to the short torso, a seat 'dump' is not recommended.</p> <p>Because the child with SA/CRS, particularly when there is a short torso, may initially lack some trunk control, anti-tip</p>

	<p>bars are important for the young child. Many youth wheelchair users remove anti tip bars as soon as they can balance a wheelie, sometimes by age 4-6, but a balanced wheelie skill may not come until age 10 for some with SA/CRS because of lack of trunk control (since there is sometimes no connection between the end of the lower spine and pelvis.)</p> <p>The issue with torso control does not mean that the trunk is unstable for pushing balance. Proper seating at hips usually allows for good balance. Chest straps are usually not recommended. The potential for development of increased trunk control and balance is usually excellent.</p> <p>Due to the child's short torso, sometimes a 3 inch seatbelt for the smallest child is more than sufficient to anchor the entire trunk. By teen and adult age, usually the seatbelt is not used at all.</p>
<p>Small size overall (some adults 2-3 feet in height 50-70 lbs)</p>	<p>The child's first wheelchair at around 18 months to 2.5 years of age may need to accommodate a child who weighs less than 20 lbs, even less than 15 lbs. and who may have less than 4 inches of torso height from hip to neck. The zip zac type chair http://zipzac.com/ The homemade version (the bumbo wheelchair) http://www.instructables.com/id/DIY-Bumbo-Wheelchair-for-Kids/ may be suitable but the use of a bumbo seat may not always accommodate the webbed/fused bent legs. It may be necessary to do cut outs to modify the design.</p> <p>There are not many very small pediatric wheelchairs on the market. See Wheelchair equipment listing.</p> <p>The small size indicates the need for lightweight, typically ultra lightweight custom manual wheelchairs from early childhood through adulthood.</p> <p>Based on the patterns of the child's growth, which may be very slow, a wheelchair fit at 2 may still be well fitting by age 5 in terms of seat size, but will probably need to be higher off of the floor to allow for school desk seating. "Growing" wheelchairs are heavy and bulky and usually not recommended because the child with SA/CRS is typically small and not growing significantly over time.</p>
<p>Small size of legs</p>	<p>Center of gravity/center of balance is an essential</p>

<p>which are not webbed and not splayed outward but which are bent/fused more than 90degrees with very limited depth for sitting.</p>	<p>measurement for the individual with SA/CRS in wheelchair fitting. If that measurement is wrong, front wheels of the chair will spin (shopping cart syndrome) because there is not enough weight on the front of the chair (lack of leg weight). The efficiency of the push and chair maneuverability will be impacted when the center is set too far forward or backward.</p> <p>When there is not much seat depth, (sometimes only a few inches,) use of a thick back insert has been seen to keep the child forward enough in a chair where the seat is too deep. Ideally seat depth in this case is reduced as much as possible and the back insert is lightweight. Chair measurement for center of balance must take into account the short seating depth. The brand of chair may need to be chosen with the need to narrow the seat depth.</p>
<p>Sensitive points along the spine, sometimes at end of spine</p>	<p>Hard, heavy, molded seating systems may not be ideal. Cloth/fabric back seating may accommodate the back better. The spine of the individual with SA/CRS is typically fairly rigid and not prone to change so seating systems designed to support the spine may not be necessary. Due to the lack of connection between spine and pelvis, the child may sit forward, making the seating system ineffective anyway.</p> <p>As there may not be connection between the lower spine and the pelvis attempting to “push” against the spine to correct spine curve/posture by use of molded seating systems may be ineffective and serve only to make the chair heavy and add extra expense.</p> <p>Sometimes foam build up support on the side of the chair inside/over the side guard to support an individual who tends to lean to the right or left (scoliosis) may be more effective than a back molded seat insert.</p>
<p>Adult (Sometimes child) obesity</p>	<p>Obesity is a challenge for some individuals with SA/CRS. For that reason, among many others, a manual chair is usually recommended over a motorized chair. With proper alignment of shoulders, the concern about “preserving shoulders” in favor of a motorized chair seems unwarranted when the risk of obesity will severely strain the shoulders much more than a properly aligned wheelchair push. Many teen and adults wheelchair users alternate between hand walking and wheelchair pushing and if at some point when they age they experience some shoulder issues, the devices such as push assist or rowing</p>

	<p>wheelchairs may be good options.</p> <p>A motorized wheelchair presents a number of issues because of the high cost of transporting the chair. While it is sometimes thought to help a child “keep up with peers”, there are many devices with hand controls such as the “wild thing”, and handcycles that will accomplish this goal.</p> <p>A motorized chair requires a specialized van with a wheelchair lift. As most families can’t afford these vehicles and insurance does not pay for them, and grant and loan programs address only a small part of the overall cost. Without being able to go anywhere except home and school in a motorized chair, an individual with a motorized wheelchair is socially restricted.</p> <p>The gradual increase of arm/shoulder strength accomplished by daily pushing a manual chair is not accomplished, resulting in an older child/adult who is not able to perform activities of daily living that depend on being able to lift the body with arms and shoulders.</p> <p>A rigid ultra light wheelchair can be easily tossed into a trunk or back seat of just about any car. It affords the individuals an opportunity to participate in society without the extra burden of cost for a wheelchair van and lift. It allows for continuous exercise to decrease the risk of obesity and increase independence.</p> <p>Some individuals who have additional conditions or who are already obese may have no other alternative but to use a motorized/power wheelchair. Some individuals who have significant distances, such as on a college campus, may want to consider partial use of a motorized wheelchair if insurance does not prohibit having both as an option.</p> <p>Ordering a motorized chair because of challenges with seating is not recommended as there are reasonable options for obtaining a good seating fit without moving to the choice of a motorized chair. There are also now wheelchair push assist devices that are much more manageable options than a motorized chair.</p>
Narrow hips	Fitting a chair narrow to the hips is ideal for maneuverability and shoulder angle for push, but for some with SA/CRS there is a significant change in width between

	<p>hip and rib cage, with the rib cage much wider than the hip. Because the torso may be short, the side guards fit for the narrow wheelchair press into the rib cage. The thick seat cushion accommodates this issue for some.</p> <p>For others, seat cushion inserts at sides, inside side guards may need to be customized to provide a tight fit at the hips and space for the rib cage may be necessary. Side guards may need to be customized for their angle of taper at the front as well. Side guards are effective for keeping abducted/splayed legs more forward, particularly for those with at-knee disarticulations if there is less taper toward the front.</p>
<p>Concerns about wheelchair pushing strength/preservation of the shoulders. Because the condition may be a part of VACTERLS association, some individuals may lack strength in wrist or thumb or may have anomalies of the hand or arm that impact pushing the wheelchair. Most do not lack strength in hands, arms, neck, shoulders or upper torso. For reasons discussed in other sections here, a manual wheelchair is recommended.</p>	<p>It is recommended that the manual chair be the primary option, even if a push assist device is needed. The smart drive power assist combines the efficiency and ease of use of a manual wheelchair with an assistive device that is detachable.</p> <p>https://www.youtube.com/watch?v=GWKcaf6ffRE http://www.max-mobility.com/smartdrive/#mx2pluspushtracker</p> <p>Additionally, wheelchair pushing ergonomics have been addressed by the rowchair http://www.rowheels.com/</p>
<p>Most do not lack strength in hands, arms, neck, shoulders or upper torso. If not currently present, usually there is high potential for it to be developed. Some individuals may have</p>	<p>Most individuals with SA/CRS do not lack head control and are not served by high backed wheelchairs nor by head rests. With short torso and small, narrow hips, the individual with SA/CRS has a lot of balance and movement control through head and shoulder position. When head position/shoulder is reduced and restricted by high back and or head rests, mobility efficiency and range s reduced as well. High backs are a frequently seen error in wheelchair fitting in this population. Back height for the</p>

<p>additional conditions which impact upper body strength.</p>	<p>youngest child should not be above the shoulders, and as the child grows older a back height below the shoulder blades allows for maximum control of the chair.</p> <p>Some school districts require a headrest for bus transport. If that is the case, an easily removable headrest may be required for bus transportation only. Another option is for the child to transfer to a regular bus seat.</p>
<p>The option of push handles</p>	<p>Push handles may be an option of personal preference. Many teen and adult users prefer not to have push handles on the chair at all because they encourage people to grab and push, and the handles get caught on things. The individual is usually fully capable of pushing their own chair, and if need be, the back of the chair provides sufficient push surface even if it low. Other users prefer to have push handles, or those that can be folded down, so that there is an option for pushing when needed.</p>
<p>Individuals with SA/CRS typically do not have cognitive delays. Some may due to factors not associated with SA/CRS</p>	<p>Without cognitive delays the prediction can be made that the child is capable of developing and maximizing manual wheelchair skills.</p> <p>When there are cognitive delays present, those may impact wheelchair fitting options and goals on a case by case basis.</p>
<p>Individuals with SA/CRS who have high level absence of the lumbar (part of thoracic perhaps) spine are often “hand walkers”. They can usually pull themselves up into and out of a chair easily-and this ability increases as they mature in age.</p>	<p>While the individual may not need a foot plate, some use the foot plate as a step up when climbing into the chair. Others use it for creative ways of carrying items. A fold up footrest is ideal so that it can be tucked out of the way until needed. For those with fused bent or straight legs, the foot rest is seldom providing actual support. For those with very small legs that approximate a 90 degree sitting angle, the footrest might be brought up very high for support smaller legs. This will not be possible for many chair designs.</p>

Photos examples below.

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small child's chair. Arm rests restrict pushing. Seat accommodates Buddha position, widely splayed legs, wide knees.



arm rests removed. Thickness of seat belt doubles to support torso. Custom seating brings needs up at an angle to allow for narrower chair. Wide splay of knees shown, legs do not cross over each other.



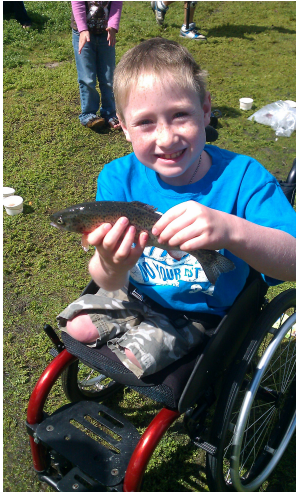
one child, narrow seat depth with legs in front of chair. Second child, legs straight, with front platform



cross leg seating, seated low in chair, side guards front contact upper thigh. Shoulder raise for push. Thicker seat cushion would address this issue and lower back.



Back height below shoulder blades. High seat cushion, no push handles. Footplate set high as “step”. Side guards maintain forward position of legs (disarticulated)



Side guards keep legs (disarticulated) forward in position. Foot plate set high and used as “step” to transfer from floor to chair.



Chair fit narrow to hips with 9 inch width, 3.5 inch seat cushion, low back.



custom side guards not tapered in front, low back, fabric