



COMPLEX



## THE PRESIDENT OF NRRTS

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In preparing this forward for the re-release of **COMPLEX**, I read the book again. It is always within easy reach in my home office. Nine years after its initial publication, I am still struck by Mark's graceful portrayal of extraordinary people doing ordinary things. Mark's compassion and humanity is reflected in every photograph and in every word of the book. He perfectly depicts the promise of Complex Rehab Technology (CRT) and its impact on the people that use it. **COMPLEX**, will also remind its readers how little has changed. We still fight every day for the proper interventions. Paperwork, denials, resubmissions and frustration still fill our days. Our fellow human beings in other countries still struggle every day for the basics of life let alone the promise of CRT. Enjoy this wonderful book and let it be your motivation to stay involved and change what needs to be changed.

*Gerry Dickerson, ATP, CRTS®, NRRTS Simon Margolis Fellow and RESNA Fellow*



## THE EXECUTIVE DIRECTOR AT NCART

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Protecting access to Complex Rehab Technology (CRT) starts with educating policy makers. **COMPLEX**, communicates important messages in photos and words highlighting how CRT contributes to the health and independence of people with disabilities. It is a great resource to illustrate the application and real benefits that come from proper #Access2CRT.

*Donald E. Clayback*



## AN OCCUPATIONAL THERAPIST

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I have worked with people who are Complex for over 30 years. What drew me to Complex Rehabilitation Technology all those years ago was not the bells and whistles, it was the life changing impact for the end-user. People with complex needs could now communicate, be mobile, be more functional, participate, and view themselves as a capable person. Mark Sullivan has done an amazing job in presenting people with Complex needs as just that – people. People and families who are valuable members of our community. I highly recommend this book for all team members!

*Michelle L. Lange, OTR/L, ABDA, ATP/SMS*



## A CRT CONSUMER ADVOCATE

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I am an incomplete C4/C5 quadriplegic. I was paralyzed when I was nine months old from a rare virus, Transverse Myelitis. I'm now 37 and a sports producer in Denver, Colorado. I live a very independent life but would not be able to do so without Complex Rehab Technology. I utilize an electric wheelchair with a tilt system for my daily mobility. I work long days and the tilt system allows me to relieve pressure so that I don't develop skin sores. I also have a custom seating system that is molded to my body. I'm very petite so my cushion helps protect the skin around my boney prominences such as my hips and tailbone. Without these essential pieces of Complex Rehab Technology; I would not be able to work, be a taxpayer or even leave my home.

*Jenny Siegle*



# COMPLEX

MARK C. SULLIVAN



**NRRTS**

National Registry  
Of Rehabilitation  
Technology Suppliers

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*NRRTS is a professional association supporting individuals who provide Complex Rehab Technology (CRT), including wheelchairs and seated positioning systems for people of all ages and diagnoses who have postural or mobility deficits. Our professionals offer quality care and service using specialized knowledge, training, experience and skills to match the consumers' needs to appropriate equipment.*

# DEDICATION

COMPLEX is dedicated to the men and women of the Complex Rehab industry who are working hard every day to develop products that bring mobility, comfort, safety and, most of all, independence to thousands of individuals. It is also dedicated to those with disabilities who utilize these products to enrich their lives and the lives of those around them, and who contribute to the economic productivity of countries around the world.

COMPLEX is also a testament to those individuals who work in emerging and developing nations to provide the products and systems we are fortunate to have here in the United States.

*I want to extend my sincere thanks to all of those individuals who fight to maintain our high-value, high-quality Complex Rehab industry in the United States and those individuals who work and struggle in other countries to improve the independence and strengthen the rights of those with disabilities.*

— Mark Sullivan



A friend recently shared with me that we often do a disservice to our industry by always showing the most active and photogenic consumers in our literature.

She is correct.

As important as it is to demonstrate that people with disabilities can be happy, active and productive people, we need to bring attention to the multitudes who are the most vulnerable and those who have not been afforded access to Complex Rehab in their early developmental stages.

Many of these children cannot speak for themselves, so we must speak for them. The images in this book illustrate the urgent need to properly and comprehensively address these issues.

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“Complex” as defined by Webster is: *a whole made up of complicated or interrelated parts.*

This is a most appropriate term for the field of seating and mobility provision. It well describes the process of taking the interrelated pieces of human intelligence; available and functional body locations (be that a finger, a toe, head or mouth); clinical, safety, comfort and communication goals; and the art and science of seating, to create a whole being capable of moving in space.

The pages of **COMPLEX** will walk through the complicated process of Complex Rehab through words and photographs depicting the art, science and emotion of what the individual contributes and desires.

Two of the people shown in the book, Emily and Sean, write for themselves, while I will have to speak for Mathew, Pearce, Jordan and Amy. Each is a unique individual who contributes immensely to the world we live in and, more importantly, to the families and friends who love them.

The centerpiece of the book is a written and visual case study of the complete provision process of a new system for Mathew from evaluation through delivery. The photographs will demonstrate the complexity of the process along with the necessary contributions and individual skill sets of each team member involved, including client, mother, caregiver, therapist, technician, manufacturer and the person who pulls it all together: the rehab technology supplier.

For people with disabilities, life is all about respect.

Respect for the individual. Respect for the contributions they make. Respect for the lives they enrich. Respect for their right to be part of the social fabric. Respect for their right to be mobile.

Most of these people do not need me to speak on their behalf, but many do need a voice who can speak a little louder and be a little more demanding. In my first book, *DENIED*, I tried to bring attention to the difficulties and challenges those with disabilities face in becoming productive citizens, noting it all starts with the ability to be comfortable, mobile, safe and able to optimize function to allow for maximum independence, which leads to maximum contribution.

This book attempts to put a face on the challenges encountered by people with complex disabilities who, despite being severely limited physically, have the ability to positively impact and benefit those around them, rather than be seen as an economic cost.

With global health care systems under tremendous pressure, each area of the system must be able to show how it can lower costs, add value and contribute to a sustainable economic model. The people in this book demonstrate how that can be achieved. Given the proper tools, the unique (but representative) people profiled in these pages are able to lower costs, reduce family strain,

be stewards of reasonable spending and contribute to economic stability.

The respect our industry and our consumers desire comes from passion driven by the human need to be creative, productive, accepted and free to express the spirit that exists within us all. No matter what the body lacks, the mind can imagine and fulfill a life of contribution, wonderment and inclusion.

Who are we to determine for those who cannot speak well, or at all, that they do not have the same visions of soaring high above the rim or feeling the rush of warmth that comes from being touched by someone who loves them?

And what of those with or without disability who don't dream of curing cancer, but simply dream of belonging

and participating in what some call the ordinary, yet to others is extraordinary?

Dreaming big is relative to the starting point of one's abilities and opportunities. What is not relative is the presence of the human spirit inside us all, which is in evidence throughout the world. Some simply need a helping hand for that spirit to be released.

Respecting the human spirit, which exists in people with disabilities as well as those without, is our job as members of a democratic society, and it is our responsibility to set the minimum standard for enabling each to have the tools to pursue opportunity.

It isn't our job to guarantee success, only to allow access to opportunity and contribution.



**COMPLEX:** *These introductory photos represent children from other countries who were once neglected by their families but are now safe and receiving proper nutrition in a caring facility.*



## COMPLEX (n)

com·plex | \ käm-pleks

1. a whole made up of complicated or interrelated parts
2. the process of taking the interrelated pieces of human intelligence; available and functional body locations (be that a finger, a toe, head or mouth); clinical, safety, comfort and communication goals; and the art and science of seating, to create a whole being capable of moving in space



Ever since I was a young girl, my parents told me I could be anything I wanted to be and do anything I wanted to do. The fact I had muscular dystrophy and was dependent on a wheelchair did not place any boundaries on their expectations for my future.

I took their words to heart, believing with the combination of determination and progressive technology, I could have a productive and relatively independent life.

The adventure began by entering into the same public schools my able-bodied older brother was attending. Of course, children pay no mind to differences and barely seemed to notice I was not up on my feet chasing them but was instead pushing my chair as hard as I could to keep up. Things were easiest at that time, physically speaking, but as I grew so did the challenges.

By the time I was 10 years old, my disability, paired with the effects of gravity, began to take its toll on my body. I went from a manual chair to a scooter, and soon after that to a motorized chair. I also lost the ability to sit up straight on my own and required a custom molded seat for support and a headrest to keep my head upright.

At first it was a hard adjustment for me to go from being able to sit on my own in any chair to being so dependent on my custom-made seat, but with time and maturity I have grown to be extremely grateful such things are available. My chair and my seating system are, in essence, an extension of my body. They are specific to my needs and are what allow me the freedom I have to work in an office building rather than at home, to have an active social life with friends, and to go and enjoy a night out. To put it succinctly, my wheelchair is what allows me to live the life I dreamed of as a child!

One of my life's goals has been to be seen as an active and independent individual in today's society by having a job. I sought to reach this goal by joining

my peers in going away to college and earning a BA in Communication Studies. I now have a job in marketing and believe my success in achieving this goal has much to do with the outstanding technological resources available to me.

For instance, the elevating option on my wheelchair is not only helpful for reaching things above table level, such as most light switches or elevator buttons, but also helps me to see eye-to-eye with someone who is standing. This is extremely valuable to me as it eliminates a lot of awkward situations where people are not sure if they should take a knee or just talk to the top of my head. Being able to come to a more natural height allows the people I am speaking with to speak directly to me and quickly look past my disability.

Reclining ability is also an imperative function of my wheelchair. Because I spend up to 12 hours a day sitting in my chair, skin breakdown is a likely possibility for me. By shifting my weight and position when tilting my chair back, I greatly cut down my chances of skin sores and ulcers. I know from my able-bodied friends that sitting in a chair for more than just an hour or two can be taxing, so I am very thankful to have the opportunity to change my seating position at will.

Another key element to maintaining my active lifestyle is my ramp van. With the help of the Bureau of Vocational Rehabilitation, I was able to purchase and renovate a minivan. Without having personal transportation, getting to work each week would be a much more daunting task. Not only does my van enable me to get to the necessary doctor and physical therapy appointments so I can maintain my health, it also allows me to go out with friends and family for fun social events. I cannot imagine life without an accessible vehicle of my own.

I am now 28 years old, and I can safely say my parents were right in encouraging me the way they did when I was young. My dependency on my wheelchair has not been a hindrance to my life. In fact, it has played a key role in making it as active, exciting and eventful as it is!



**INDEPENDENCE:** *Emily at home*



**HOME:** This home setup is almost as well-equipped as a hospital room. Home is patient-preferred and cost effective and should have better outcomes although the clinical data is not yet there. But ask any person with a disability, and he/she will most likely agree.



**GOALS:** *The desire to be at home and the easing of the caregiver's physical stress is a recurring theme throughout this book.*



**BREATHE:** Life's activities start with breathing. Having access to portable oxygen attached to the mobility device is the first step in having access to the outside world. Here, the combination of an oxygen device, a mobility device, a molded seating system and a head support are all necessary to permit access to a computer. Without portable oxygen, Emily would be in bed and unconnected.



**CONNECTION:** A 360° headrest support provides the necessary visual position to allow Emily to read for education, work and pleasure. Without it, she would not have the strength to accomplish the most basic of tasks.



**UNSUPPORTED vs. SUPPORTED, Example One:** (left) This picture is an accurate depiction of what happens to a person with a weak muscle structure when the support provided by Complex Rehab equipment is taken away. It represents a total loss of functional ability and access. (right) The support of the proper equipment and fitting makes all of the difference to vision, comfort, safety and access, as the picture on the right illustrates.



**BEAUTY:** People with disabilities have the same vanity and fears of inadequacy we all have. Looking our best each day allows us to perform better as we feel more confident in the way we look. We are all the same in this way.

# MEET SEAN

I work with Advocacy Inc., a nonprofit organization that protects the civil and human rights of Texans with disabilities through a fellowship sponsored by Equal Justice Works. I assist people with disabilities in obtaining equal access to education, employment and community services, complementing Advocacy's services not only by providing legal assistance to these individuals but also teaching them self-advocacy skills.

Because I have cerebral palsy and quadriplegia, I operate my motorized wheelchair by the use of head movements and rely on an interpreter or a specialized computer to do my work. I became motivated to take a lead role in expanding the awareness and protection of disability rights in the community and encountered numerous barriers throughout my undergraduate and law school careers. Using my experiences and knowledge from overcoming these obstacles, I now assist people with disabilities in breaking down the barriers of discrimination that prevent them from becoming productive citizens. I work in the legal arena to continue achieving this goal by educating people with disabilities on their employment and educational rights.

To that end, I created a manual to assist both the employer and employee to build a constructive working relationship. This manual is a part of my Equal Justice Works project to educate people with disabilities on their rights in the workplace and how they can self-advocate to protect their rights in the community. This project will also break new ground in that each stage will focus on educating students in those skills, while focusing on ensuring the proper implementation of the Individuals with Disabilities Education Act (IDEA) and assisting students with disabilities in taking advantage of the full benefits of this federal law during their secondary education. I will also show people with disabilities how to employ the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 to ensure their own access to an equal opportunity for higher education. Like this FIP manual, I will also be creating an education manual for students with disabilities.



**ASYMMETRY:** *Complex Rehab industry professionals would have a great time debating the positives and negatives of the way Sean sits. However, there is never one right answer, which is what makes the evaluation process so complicated and critical. For Sean, this is his preferred and most functional setup.*

# SEAN



**EDUCATION:** Sean has a law degree from the University of Texas and is an advocate for people with disabilities. He has the ability to accomplish much by accessing his work via computer with the help of head switches and infrared technology, enabling him to type and use the computer, as well as an integrated speech program.



**ACCOMPLISHED:** Sean's arms and legs are essentially uncontrollable and not functional for typing or driving his chair. Because of his intelligence and determination, he has developed the functional ability to be productive and help others through the use of his head and switches that access his computer and environmental controls.

# MEET AMY

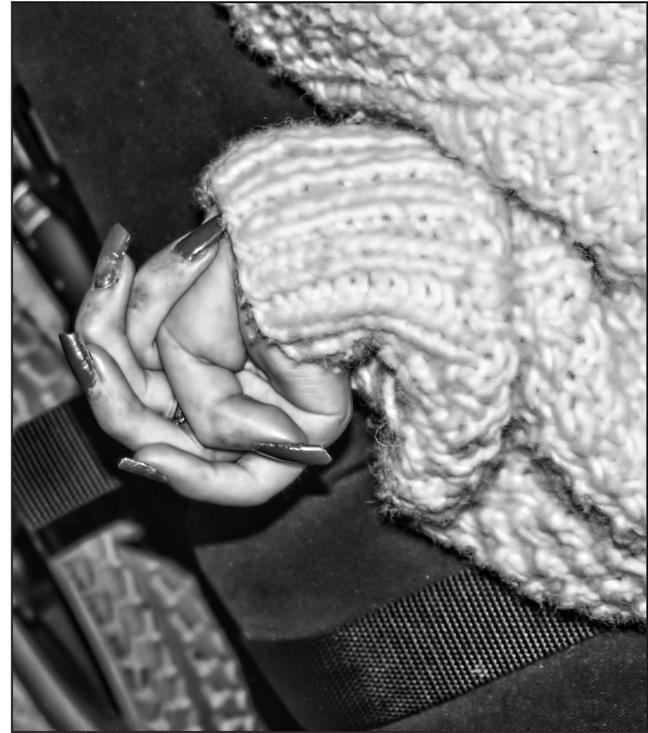
How, you wonder, can Amy contribute to economic stability with the seriousness of her disability, caused by more than 30 years of cerebral palsy leading to significant deformity? Assuming you do not advocate institutionalizing people like Amy or leaving them unattended all day, looking inside her as a person can lead you to the answer.

Fortunately for Amy, she comes from a very loving family including two parents, brothers and sisters, nieces and nephews, who care for her and respect her as full member of the family. Her parents have cared for her since birth in their home, avoiding the costs of pressure sores or other costly medical complications that are often associated with people in the care of institutions with inadequate staff.

As Amy's parents have aged, the process of dressing, feeding, bathing and attending to her has become more and more difficult. Without the assistance of a ceiling lift, bath positioning equipment, a molded seating system and a tilt-in-space manual chair, the chances of one of them becoming injured and/or disabled would increase significantly.

At the point one or both of Amy's parents become unable to care for her, the costs to the health care system will increase exponentially. It is to the benefit of the system to keep the parents as caregivers, helping them stay as healthy – and free from injury – as possible. Yet so often the reimbursement systems will not acknowledge or pay for a product or feature that benefits the caregiver.

How can that be?





**VOICELESS:** Some people can speak well or access computers and speech devices, but not Amy. Who will speak for her?



**CAREGIVING:** For 33 years, Amy's parents have cared for her and lifted her. Without the equipment she has at home including this tilt-in-space chair, molded seating systems, a ceiling lift and bathing equipment, her parents' aging bodies would have given out long ago, and Amy would be in an institution or residential home. When her parents are gone, who will speak and care for Amy?



**WORK & SCHOOL:** Amy attends a workshop every day where she is surrounded by others and even has a small job for which she receives a paycheck. By being in a molded system and mostly supine to accommodate her contractures, Amy can tolerate being at the workshop each day. Without it, she would be in bed 24 hours a day.

# MEET JORDAN

Jordan has Osteogenesis Imperfecta (OI) which is a genetic condition affecting bone formation, bone strength, and structure of other tissues. As a result, his bones are quite fragile, which makes him highly susceptible to fractures. OI ranges greatly in severity and impacts function, including mobility. These photos were taken in 2011 when we first met Jordan.

Jordan is now a 23 year-old college student majoring in Sociology at Edinboro University, a Pennsylvania state school. His second and last Arrow series power chair—with a full complement of power seating functions with elevation—has enabled him to move freely about all areas of his ADA-accessible campus year-round. (Pennsylvania's harsh "snow belt" winters couldn't even slow him down!)

His powered-seating afforded Jordan the possibility to shift and change positioning when he experienced pain in the middle of a class, lab, or extracurricular campus ministry activity. (Unfortunately, he still experienced fractures related to his Type III OI.)

Two accessories made a world of difference for Jordan in his successful integration into regular campus activities:

1. Armrest storage box - this unique and amazingly helpful accessory by Motion Designs is available as an add-on to most custom seating systems. This storage option allowed Jordan to effortlessly manage items that his peers would put into pockets or purses.
2. A lighting system - Pennsylvania winters are cold and dark. Jordan's lighting system gave him visibility in high-traffic environments, enabled him to stay out after dark, and safely lit his pathways on his way to class, which often helped him avoid patches of ice.

Jordan's success was dependent on not only durable medical equipment, but also the literal hundreds of medical personnel, equipment designers and industry professionals working together to make Jordie's life his own. One can never say "thank you" enough to legends who made Jordan's independent mobility possible.

When he receives his degree, Jordan plans on pursuing a career in medical administration.



**NECESSITY:** Most funding agencies don't consider elevating seats medically necessary. Don't tell that to Jordan or his parents. Without an elevating seat, Jordan would be staring at the base of the counter instead of the family album. Jordan's elevating seat gives him not only better access to the kitchen appliances and sink but also brings him closer to his father's gaze for normal, playful interaction. Who decided that "medically necessary" was only about physical necessity? What about emotional, psychological, developmental and functional necessity?



**RESPONSIBILITY:** *It is very important for young children with disabilities to learn responsibility and independence early on, just as it is important for all children. Once again, the elevating seat allows Jordan to complete some of his chores and independently access his bedroom furniture. Not medically necessary? Some would say. But none would deny that it is certainly functionally necessary.*

# MEET PEARCE

These photos were taken when we first met Pearce in 2011, the first year this *COMPLEX* book was published. He was diagnosed with cerebral palsy.

Pearce is starting high school this year and is enrolled in all regular education classes. Thanks to devices that provide ways for him to talk with a communication device and be independently mobile with a power wheelchair, he is able to participate in the activities other teenagers enjoy: ice hockey, watching YouTube videos and hanging out with friends!

Devices that allow social interactions without attendants or adults and provide independent mobility are invaluable to the growth and development of any child. Fortunately for Pearce, he has been well-equipped with these aids.





**HEALTHY FUN:** (left) This is Olympic bodybuilding for Pearce, under the watchful eye of the family dog and the help of a standing frame. Pearce is building bone density, preventing (or at least delaying) deformity, improving function and allowing him to have some plain old fun. (right) Pearce may never get to drive one of these for real, but it is important to realize he has dreams just like the rest of us. It is too early to tell which of Pearce's dreams he will be capable of making come true.

# CASE STUDY: MATHEW (9)

At the time of this case report, Mathew was a 9 year, 4 month-old adolescent attending a life skills support classroom at a local elementary school. Medical records indicate his mother had a typical pregnancy and delivery, but in early infancy Mathew demonstrated feeding difficulties and increased muscle tone. Upon further testing it was found he exhibited microcephaly, mildly enlarged ventricles with enlarged subarachnoid spaces, myelination abnormalities of cranial nerves, abnormal formation of convolutions of the brain, as well as cerebral palsy. Specific tests were done to discern a mitochondrial disorder; however, they were found inconclusive.

Mathew's records also show he suffers from high lactic acid levels, gastroesophageal reflux, as well as impaired swallowing with the risk for aspiration. He underwent surgery for G-tube placement in September 2007. He has also been diagnosed as experiencing epileptic seizures that are now controlled through medication administered via G-tube.

Over the years, Mathew has participated in Botox therapy to manage his spasticity, including bilateral hip adductors in 2003 and again in 2005, as well as bilateral hamstrings and gastrocnemius in 2004. He had an implanted Baclofen pump (June 2005) and has undergone several orthopedic procedures to reduce contractures in bilateral lower extremities. From 2005 to 2009, Mathew participated in tendon lengthening of bilateral hip adductors (performed three times during the years indicated), left iliopsoas, bilateral medial hamstrings, and bilateral gastrocnemius. He has also had bilateral hip osteotomy, bilateral percutaneous subtalar stabilization, bilateral peroneal lengthenings, and bilateral medial, distal and tibial epiphysiodesis. He also underwent a procedure to remove the hardware utilized in his hip osteotomy.

Mathew requires moderate to extensive adaptations to access his home, school and community environment

safely. He utilizes a power wheelchair as his primary means of mobility. He also has an adapted stroller, gait training device, adapted bicycle, a sit-to-stand stander, and his home is modified with an adapted toilet seat and adapted bath seat. Mathew also utilizes therapy balls, feeder seat, peanut ball, bolster, mat table, adapted crayons, name stamp, wheelchair accessible desk, feeding pump, IV pole, suction machine, specialized bed and a van with wheelchair ramp. He has daily accompaniment by a nurse.

Motorically, he demonstrates the ability to roll bilaterally and propel himself on a scooter board for 7 feet while on his belly, with a strap to promote stability and to keep him from slipping off of the board. He is able to army crawl for 5 feet to interact in a game or gather manipulatives and place them in a container. When performing sit-to-stand transfers, Mathew will perform 50% with only contact guard, and the other 50% with maximal assistance. He displays the ability to isolate his legs during this activity and effectively uses his upper extremities to interact in a game or activity. He demonstrates the ability to fling a ball for 1 to 2 feet with support at the trunk. Mathew consistently ambulates 20 feet in his gait training equipment and participates in a daily standing program.

Mathew relies on his power chair for social interaction and independent mobility, and has utilized power mobility since the age of 4. With his current seating and mobility system, Mathew is able to turn and maneuver using a left hand mounted joystick with 75% cueing, sometimes requiring hand-over-hand control in complicated situations or when he becomes distracted. He utilizes his power wheelchair throughout his home, school and community environments. He displays the ability to drive 200 feet in 15 minutes with cues for attention to task,



**MORNINGS:** Just as with Emily, life starts with the basics of breathing. The day begins with the clearing of Mathew's lungs.

# CASE STUDY: MATHEW (9)

as he is highly distractible, and presents with a flexed posture with his resting eye gaze at his knees or the floor. Mathew is a very social child and is often encouraged by family, teachers and peers as he travels. Within his school day, Mathew has the opportunity to be included with same age peers for non-academic subjects, group learning experiences, and social interaction. In the community he participates in adapted sports, Boy Scouts, family outings and school trips.

Mathew's current mobility system does not work well for him in tight spaces such as aisles, between desks in classrooms, tables in the lunchroom, public restrooms or within his own home. Turning and interacting with peers and loved ones, or backing up to gain access to an activity, causes him to knock over furniture and experience near misses of the people around him due to an increased turning radius and less responsive drive equipment.

When reviewing his Re-Evaluation Reports (RR) and Individualized Education Plan (IEP), it was noted Mathew is functioning at a low cognitive range in comparison to his same-aged peers who are developing typically (test performed was the Comprehension Test of Non-Verbal Intelligence). He is highly distractible and requires cues to redirect his attention. It was noted, however, it is difficult to fully evaluate his exact cognitive potential. According to his speech therapist, he demonstrates behavioral concerns and frustration secondary to his inability to communicate his needs effectively. He utilizes moans, squeals, and limited body language (i.e. pointing, eye gaze) to convey his wants and needs. Mathew continues to display improvement in his receptive language even though his expressive communication remains limited by unintelligible speech. His school-based speech and language pathologist, and an assistive technology professional, have recently submitted for an augmentative and alternate communication or speech generating device to develop these skills.

He demonstrates competency with the use of the joystick on his wheelchair along with a jelly bean switch for selection of a given icon, although he still demonstrates a preference for single point selection.

A clinical seating assessment with mat evaluation was performed. Mathew was able to sit independently in a "slump" sitting posture but does not have adequate protective reaction responses to remain sitting. His pelvis is oriented posteriorly and moderately flexible toward a neutral position, with a left pelvic obliquity and right pelvic rotation, both of which can be reduced toward a more neutral orientation of the pelvis without full correction.

Mathew has good head control when his trunk is properly supported and, when he desires, can maintain a neutral head and neck alignment. Mathew has sufficient hip range of motion to accomplish sitting in an upright position. Mathew lacks 30 degrees of knee extension while seated, and his ankles are able to achieve a neutral orientation after being stretched and in AFOs.

Mathew has limited active range of motion in both upper extremities and has difficulty maintaining grasp and manipulating objects with his hands. He can, when supported proximally, elevate his arms. He can move objects on a tabletop surface, direct select switches and activate zones on the screen of his speech device independently. When using a joystick, he employs different methods to activate the drive control. Sometimes he uses a thumb in palm posture but predominantly he uses the palm of his hand or modified grasp.

Mathew's existing power wheelchair is fitted with a custom contoured wood and foam seating system with multiple postural prompts, which is now too small and does not provide adequate support to help him keep himself in an upright "active" posture. The wheelchair



**GROWTH:** Time is running out as Mathew grows taller and his mother grows older. Our reimbursement community almost always refuses to pay for features to help the caregiver, which are not considered "medically necessary," even though they help save tens of thousands of dollars over time by keeping people in the home and preventing injuries to those caregivers.

# CASE STUDY: MATHEW (9)

has a power tilt feature that is activated through the driver control.

During this assessment, five goals were established that fall under the following overall objective:

The application of a TDX mid-wheel drive power wheelchair with power tilt, custom seating and driver interfaces will enhance Mathew's inclusion and independent participation throughout his home, school and community.



## FIVE GOALS

1. While using the new powered seating and mobility system, he will experience an improved ability to independently navigate throughout his environment without hindrance. Mathew will have more precise drive capabilities, improving his maneuverability and safe independent access of the lift on his school bus, tight spaces in his home, classroom and community. While in his home, he will be able to maneuver close enough to independently activate wall mounted light switches. He will experience a significant decrease in collisions with objects such as furniture and store fixtures as well as improved access to public restrooms at the mall, sporting events, parks and beaches (desired family goals).
2. Utilizing the integrated infrared and mouse emulation system, Mathew will be able to independently change the television channel from across the room, and access any computer within his school environment in the same manner a typical developing child would (i.e. computer labs, individual learning opportunities within classroom settings).
3. Mathew will demonstrate increased attention to task and safety with provision of the new powered mobility system with custom adapted seating. The correct application of these systems will allow for a reduced incidence of errors, and an increase in speed over distances to change classes in school, allowing him to keep up with family and peers during family activities within the home environment and out in the community.
4. Mathew will improve his ability to interact with his family and peers by reducing the barriers to access his AAC or SGD so that he may engage in spontaneous conversation.
5. Mathew will sit in a stable supported posture with a resting eye gaze at or near horizon in an active/ready state.



**PROCESS:** To provide independent mobility, the Complex Rehab process involves all of the following: evaluation, determination, measuring, fitting, assembly, fabrication, modification, trial, testing and finally, delivery.

## OUTCOMES

Outcomes of this case report were based on direct observations within his home and school environments, as well as from interviews with family and support personnel. These were noted throughout the course of the year following receipt of Mathew's new power mobility system with adapted seating.

A significant change was noted in his postural orientation in response to being properly seated. Six to 8 weeks after being seated 6 or more hours in his new adapted seating system, Mathew was able to tolerate an upright active sitting posture with a neutral pelvis and reduced kyphosis, resulting in an eye gaze that was at or near horizon. This improved head and neck orientation is directly related to his ability to consistently focus on the activities at hand. Mathew still requires a firmly cinched four point padded seat belt to maintain consistent pelvic weight bearing and keep his pelvis correctly oriented in his custom molded seat cushion. A backpack style shoulder harness is required to maintain his shoulders in a more retracted orientation. Removing the shoulder harness is an ongoing goal, but at this time we are satisfied with his ability to sit with a reduced flexible kyphosis.

After learning to maneuver the Invacare TDX mid-wheel drive power wheelchair, Mathew demonstrated significantly improved maneuvering skills in tight environments. He has experienced an 85% reduction in striking objects with his power wheelchair with only 25% cues from his caregivers. This dramatic improvement was achieved despite the fact that the new power mobility base was 1.5 inches wider and 2 inches longer overall.

His improved sitting posture and head and neck orientation dramatically contributed to his precision while driving his wheelchair. The new power wheelchair also had the ability to have multiple driving parameters modulated to accommodate Mathew's specific needs.

Close supervision is still required when embarking and disembarking from the bus via a lift due to preference of support staff; however, he is able to assist in the process to a much greater degree since receiving his new powered mobility system. Within two months of receiving his new equipment, Mathew was able to access light switches throughout his home.

Mathew has benefited greatly from using the infrared and mouse emulation devices. He is able to turn the television on and change the channel once he has received assistance to access that menu in the integrated power wheelchair electronics. It has not been determined at this time why he requires assistance to access the menus; however, we feel it may be related to his maturity. Having the mouse emulation capacity has opened up opportunities for Mathew to express himself within his school environment. In addition to being able to access the same computers as his typically developing peers, he was able to connect with his teacher's laptop computer so that he could project over an LCD projector and participate in the classroom activity in front of his peers. This is the equivalent of him being able to raise his hand and answer a question.

Mathew also experienced a great increase with speed over distances. Initially, he required 15 minutes to travel 200 feet between classrooms. After navigating his school environment with his new powered mobility system, Mathew is able to complete this task in an average time of 5 minutes (a reduction of 66 percent); however, he has completed the task as quickly as 2 minutes and 16 seconds (a reduction of 85 percent). As an example of his improved ability to navigate independently without being distracted or striking objects, Mathew was able to participate in the local zoo parade with indirect supervision without incident along the entire parade route. Mathew still requires verbal cueing periodically, which is typical for a child of his developmental age.



*PLAY: Sometimes children need to rid themselves of the pressure of gravity and just play.*

Mathew's goal to improve his ability to interact with his family and peers with his speech generating device had mixed results. Mathew is able to independently access his AAC/SGD; however, he generally prefers direct selection with his finger (a slower communication rate, but more efficient for Mathew). The joystick input method requires speed and accuracy that exceed Mathew's ability to use the integrated solution accurately at this time.

In the electronics package offered on the power wheelchair, the cursor speed initially appeared to be directly related to the overall driving speed of the wheelchair. Slowing the cursor speed to a point where Mathew could actually manage it resulted in unacceptable driving performance. (This issue was resolved through programming after consultation with the manufacturer.)

We predict that once Mathew realizes that utilizing his AAC/SGD is a social, age appropriate, efficient mode of communication, his interest and, therefore, his success will increase. That being said, due to the overall benefit derived from the properly-fitting wheelchair and integrated electronic augmentative solutions, Mathew is able to interact with peers, family and school staff with only a few adaptations.

## CONCLUSION

The application of the seating mobility device, appropriate custom seating and electronic assistive technology, when combined with a therapeutic and training regimen within the home and school settings, resulted in a significant improvement in Mathew's ability to be independent within his home and school environment. Clear, measurable gains were made in his ability to direct his own behavior with increased velocity, accuracy and safety. This overall effect will have significant benefits to Mathew as he matures and persists in his efforts to develop and live as independently as possible.

## NOTE FROM THE CASE STUDY AUTHORS

Mathew is a 9 year-old boy who lives with his family and attends school in Millcreek, Pennsylvania. He is a great kid with typical boy interests. His case reveals a complicated medical history and need for support. This support comes from his family, first and foremost. His medical needs are varied and complex. He and his family, during the last nine years, have had to bravely face and overcome many obstacles. Painful surgeries with uncertain outcomes, daily medicines and nursing care, countless hours traveling to and consulting with dozens of clinicians and physicians, as well as many sleepless nights, are woven into Mathew's life experience.

The case study presented has a specific focus but is more broadly a view of years of work and successful effort from Mathew, his family and a large group of dedicated professionals. Mathew is unique, and he is one of more than 500 children we see each year in our separate practices with similar needs. The number of individuals and families facing these issues is immense.

The equipment and care we recommend for Mathew, and people like him, are required for him to be independent and to reach his potential, especially when viewed as part of a monumental effort by so many people. If this type of support and equipment is denied for short term financial reasons, the recipients are significantly impacted for years, if not permanently.

Thank you for taking time to connect with Mathew and all of the individuals and families featured in this book. We are happy and proud to be a part of bringing to light this essential work.

*Elizabeth S. Beckman, DPT and Jim Noland SMS*

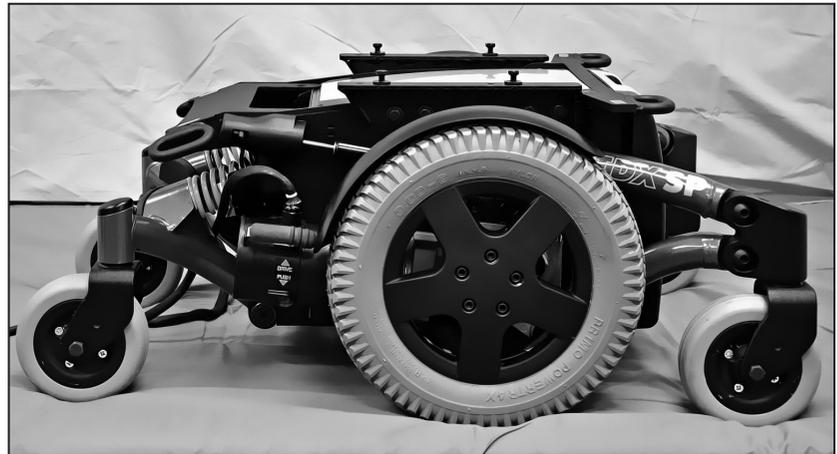


# COMPLEX: EQUIPMENT FOUNDATION

When it comes time to assemble and set all of the components the technician is an integral part of the Complex Rehab team. The process often requires combining products from multiple manufacturers into a finished system designed for a specific individual.

Cutting, drilling, adjusting and assembling can take hours and requires an experienced hand. Once the consumer is put into the mobility device, more fine tuning and adjusting often needs to be done. The fit is no less important than the fit of a prosthetic leg.





**USEFUL & NECESSARY DEVICES:** Wheelchairs appear to be one device, but they are really many intricate and useful devices put together to accomplish a specific purpose. The mobility base is the foundation of the total system and provides the technology for movement, but by itself is useless for many people.

# COMPLEX: POSITIONING



**ATTACHMENT POINTS** (left): Even little things, like the location of the chest harness, matter. **TRUNK** (right): Proper trunk positioning improves range of motion, movement and stability, providing an appropriate range of function.



**HEAD** (top left): The headrest fulfills the dual purpose of support for function and rest when needed.  
**LATERALS** (bottom left): Proximal support equals distal function.  
**BIANGULAR** (right): Nuances such as back angle make a difference.

# COMPLEX: POSITIONING



**STABILITY AND SECURITY:** Unintended movement can potentially cause loss of function. Cushion, positioning strap and adductor create a stable base. Pelvic stability is important for extremity support.



**SYMMETRY:** *Tilt in Space* is used not only for the obvious purpose of pressure relief but can also be used for self-positioning and to increase stability for some functional tasks. Tilt is used many times throughout the day for multiple tasks.

# COMPLEX: ADAPTATIONS

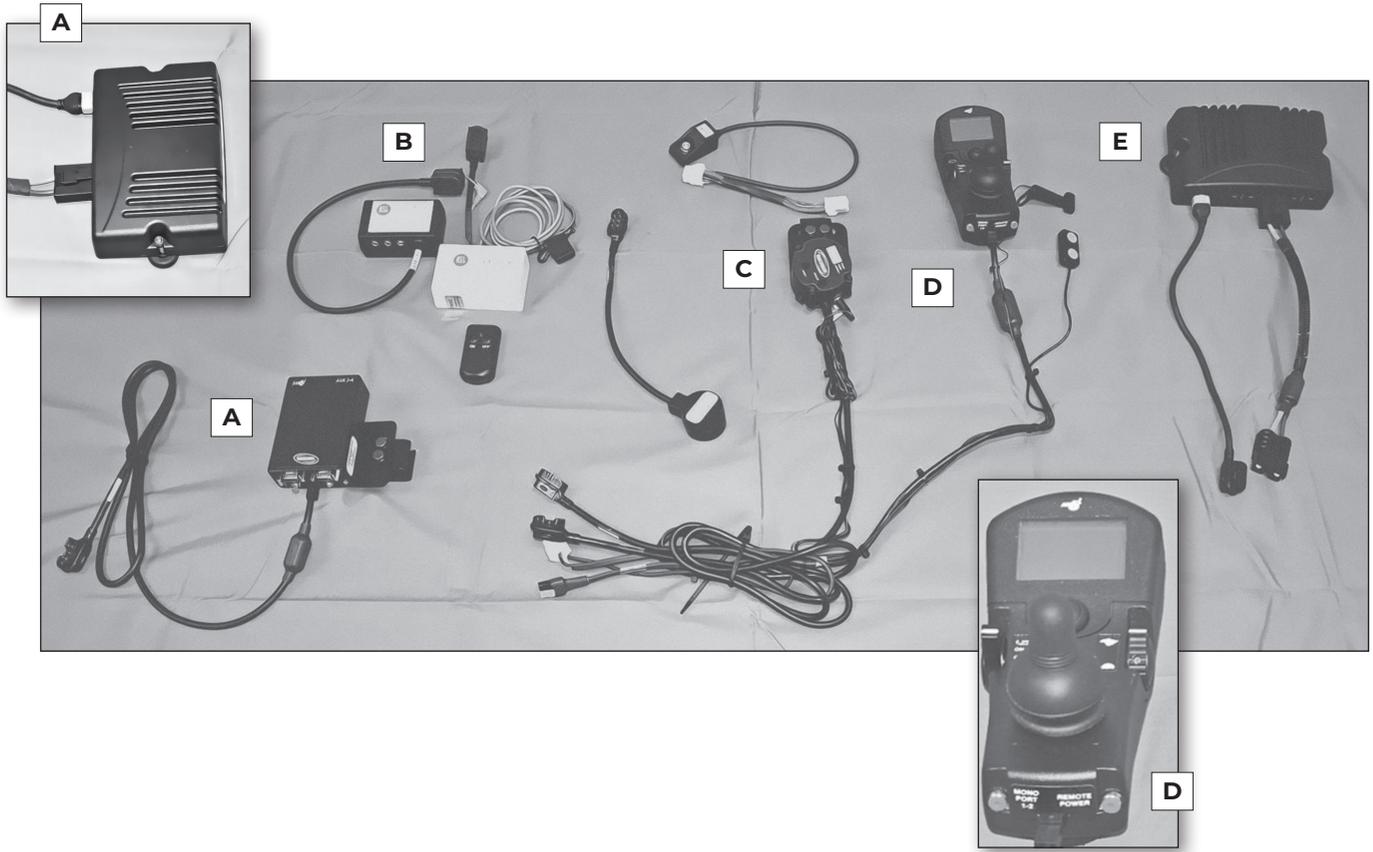


**CUSHION SHAPE** (top left): Shape and material equal stability and comfort.

**PELVIS CONTROL** (bottom left): The pelvis must be stable and correctly positioned for a person to be independent.

**GROWTH** (top right): Children quickly grow out of their systems.

**TRANSPORTATION** (top right): Tie down brackets are not used in the home, but they are used to leave the home.



**A. CONTROL BOX**  
to connect the user  
and wheelchair to  
electronic devices

**B. REMOTE  
STOP SWITCH**  
for careful parents.

**C. INFRARED  
CONTROLLER**  
for computer  
access and  
control of home  
environment

**D. JOYSTICK**  
with different  
drive programs

**E. CONTROLLER**  
The brain of  
the wheelchair

# COMPLEX: PROGRAMMING



**INDIVIDUALS:** Like snowflakes, every person is unique. Programming allows a Rehabilitation Technology Supplier (RTS) to customize a solution that allows the consumer to control his environment.



**MAXIMIZING SOLUTIONS:** *Having access to communication is a basic human need. The total system is designed to use what abilities the RTS consumer has. Even with one functional hand, a consumer can control movement, speech and environment, thus ever-increasing independence!*

# COMPLEX: OBJECTIVES



**POOR POSTURE** (left): Creates poor function  
**IMPROVEMENTS** (right): The new system creates better form due to improved stability



**RESULTS:** *Mobility, comfort, function, communication, control, independence, self-image, and joy!*

# COMPLEX: TEAM SUCCESS

The delivery and final fitting are the fun part of the process. Often the entire team will attend to make the final adjustments, make sure all of the clinical and functional goals have been met and the consumer and family are satisfied with the final product. This is the culmination of months of evaluating, writing medical justification, gathering documentation from therapists

and physicians, submitting for prior approval, ordering the product, receiving the product, assembling the product, delivery, final fitting and ultimately billing. This entire process can take 3-6 months in many cases and the consumer often is frustrated and has little understanding of the process required. But when it all comes together it is usually a very happy event.





As the Complex Rehab industry struggles to maintain its level of care and service in the face of existing health care costs and reimbursement cuts in the United States of America, other parts of the world aspire only to the most basic levels of care. Wars have ravaged many infrastructures over the last several decades in Latin American countries such as Colombia, Nicaragua and El Salvador; African countries such as the Congo, Sudan and Rwanda; and even in parts of Europe during the Balkan Wars and the breakup of Soviet states.

Those with complex disabilities are often hidden or forgotten in the best of times, but as countries come under siege, the search for the basic necessities of safety, food and health care for the able-bodied puts the needs of the disabled at the bottom of the hierarchy. Those victims of war and the land mines left behind become more visible after the conflict ends, and receive needed awareness (though oftentimes no help). But for those born with disabilities such as cerebral palsy, developmental disabilities with associated physical disabilities result in them being tucked away in thousands of homes in rural villages and large cities. Those even less fortunate are in institutions with inadequate care, left to grow old in a vacuum as the world around them moves on.

The United States must do two things simultaneously: fight those who seek to set the rights and needs of the disabled in the United States backward through draconian cuts, while exporting our knowledge to advocates in other countries willing to fight for, and care for, the hidden victims of war, poverty and ignorance. Several government agencies such as the U.S. Aid for

International Development and the U.S. Department of State have sponsored projects and organizations that actively campaign – and develop equipment and tools – for those with disabilities. For that I personally thank them, and assure taxpayers their tax dollars directed to those projects are well spent. If our own consumer agencies were as close to the fighting and service delivery in the United States as these agencies are to Complex Rehab consumers in developing nations, I believe the conversations and programs would be much stronger and healthier.

What follows are images of what happens to people with disabilities and their families when a proper health care system and advocacy programs are not in place, or are disrupted due to war or poverty. If ever there was a way to see what would happen should America's Complex Rehab system and equipment be taken away or reduced, look no further than countries that lack access. So often in the United States, the industry is asked for clinical documentation regarding the outcomes and validity of what we do. How do you do that? Let a few children go without equipment and document the results? That is unimaginable here, yet unfortunately it is exactly what happens in other countries.

Presented in this section will be examples of “reverse case studies.” The featured photographs will provide visual illustrations testifying to the significance of appropriate Complex Rehab provision, by showing what happens when it is not available or accessible.

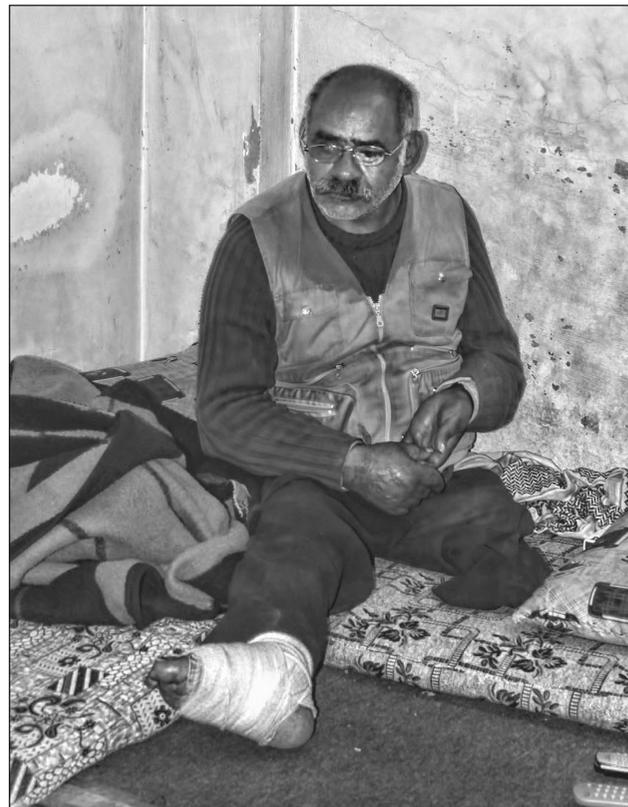
We begin with a child only slightly older than Mathew who has a similar diagnosis. Just like Mathew, he is non-verbal but very bright and understands most everything his parents and brother communicate to him. But unlike Mathew—because of his economic situation and lack of health care—he does not attend school, does not sit up, and remains on the floor nearly 24 hours a day. Complex Rehab intervention has not occurred. The teen's only assistance has been the donation of a wheelchair that has not been modified to fit his specific health needs. I would argue this is the same as having no equipment at all...



**DAILY LIFE:** This teen with cerebral palsy spends most of his days on the floor. Having no access to sitting and lying positioning equipment has led to more aggressive deformity.

**NECESSITY OF CUSTOMIZATION:** Though the teen has a donated wheelchair, he is unable to sit in for more than 2 minutes at a time. With no support in the chair, the teen's body falls to its default position in less than a minute. He will be provided with proper equipment because of the visit to his home, but thousands remain behind unseen.

# COMPLEX: IN DEVELOPING COUNTRIES



**FAMILY** (left): Twin brothers, age 16, one with cerebral palsy; (right) The teen's father lost a limb and was paralyzed in a land mine accident. Because he has not had access to a pressure relieving cushion, he has been hospitalized several times for his pressure sores.



**UNSUPPORTED vs. SUPPORTED, Example Two:** (left) This South American child was given a new wheelchair through a U.S. Department of State project, but his head was unable to be positioned with the provided seating system. As a result, his vision was directed at the ceiling. (right) Some foam was used to teach the technicians and simulate neck support to improve the child's line of vision. The technicians were later able to craft a better version to bring his vision in line with the room's surroundings, and his eyes and head movements immediately began to follow the voices and actions around him. Crude, but effective.

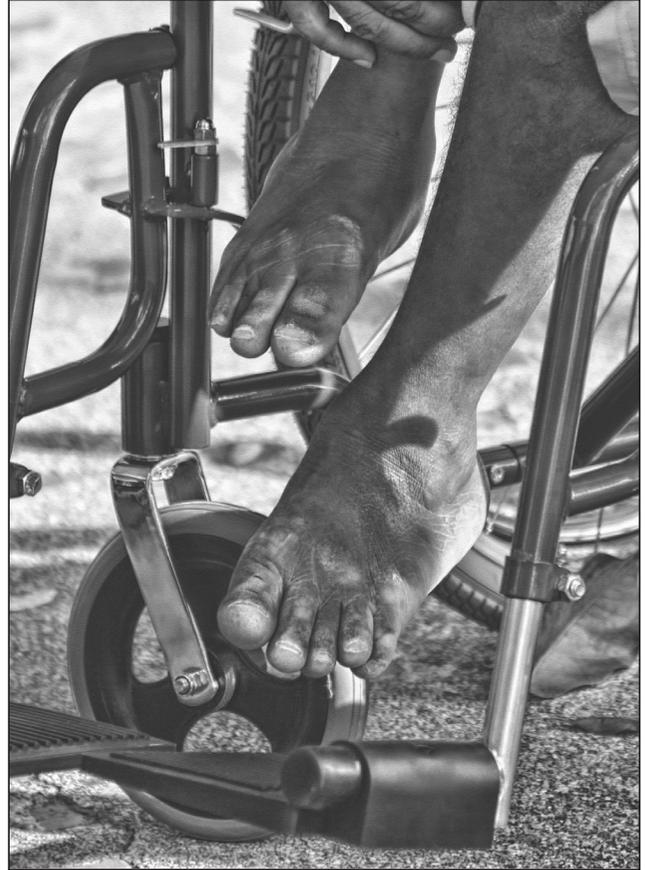
# COMPLEX: IN DEVELOPING COUNTRIES



**ANTICIPATION & HOPE:** During this wheelchair ceremony, dozens of parents carried their small children and teenagers for several miles to receive the first wheelchair they would ever own. They sat for hours without complaint to get the most basic of mobility.



# COMPLEX: IN DEVELOPING COUNTRIES



**LIMITATIONS:** In the United States of America, talented Rehab Technology Suppliers and clinicians would spend hours assessing and addressing the legs of this child to delay further deformity, prevent sores and improve comfort. In other countries, however, such resources aren't so readily available. This will have to do for now.



**HIDDEN DANGERS:** Despite a decade of work by the Colombian military and the support of the U.S. Department of State, thousands of land mines remain in Columbia. Every day, two or three people fall victim to those mines. Victims in rural areas must sometimes wait years for the most basic of prostheses.

# COMPLEX: IN DEVELOPING COUNTRIES

At right, a young single mother with a lifetime of care ahead of her waits with her child to receive a wheelchair wholly inadequate for her needs. This family's needs were particularly heartbreaking, and a tilt in space chair was sent to her from the United States several months later – a bad habit to start because the needs in these countries are a bottomless pit. Better we transfer knowledge to those willing to build an infrastructure from within, including the ability to evaluate, build, deliver and service.

How a country treats its disabled is an overall indicator of its civility. In the United States, we would be embarrassed to have a child seated this poorly (below) and strapped this inadequately, but it is a vast improvement over the tired arms of his mother!





**OVERCOMING OBSTICALS:** *As conflict subsides and the guerrillas and drug lords are pushed further into the valleys, families emerge to seek help from dedicated organizations seeking to offer them a better life.*

# COMPLEX: IN DEVELOPING COUNTRIES



**NEED VS. WANT:** A wheelchair is not a wheelchair...it is an absolutely necessity. It functions as a part of the body. Its use leads to increased independence, function, and sense of worth.



Special thanks to Emily, Sean, Jordan, Pearce, Mathew, Amy and their families for being willing to take part in this exciting project. Most of us will never know the amount of work and effort that is involved for these individuals and families to get ready each and every day. I had the unique opportunity to witness some of that by arriving at homes very early in the morning to watch the process unfold, and I salute all of you for the hard work you put in every day without complaint.

I wish to give special thanks to Jim Noland, father of Jordan, for his willingness to let me document the entire lengthy process of providing Mathew with his new Seating and Mobility equipment. Thanks to Mathew's therapist, Elizabeth Beckman, DPT, who provided the clinical guidance necessary to determine the proper set of goals and outcomes. Thanks to both for their outstanding case study review of Mathew.

I would also like to thank Invacare, who was kind enough to donate the power wheelchair used for the case study.

Thanks to Brennan Arbogast, ATP, CRTS® from National Seating and Mobility for his dedication and great work on the mobility base and seating for Amy, as well as the great team at Adaptive Switch Labs for its singular focus on bringing powered mobility to thousands through the creative use of alternative driver controls.

Thank you to the U.S. Department of State Program for Weapons Removal and Abatement for sponsoring so many great Victims Assistance programs around the world, including those in Colombia and the Middle East shown in this book. A very warm thank you to CIREC of Colombia which has devoted the last 35 years, through the roughest of times, to providing physical, social, vocational and mobility support to those who were displaced, injured and forgotten. I have learned much from them during my many trips to Colombia. They walk the walk when it comes to not only providing, but more

importantly, teaching people how to move forward on their own. Additional thanks to the Polus Center for Economic and Social Development in the United States, Nicaragua, Peru and the Middle East. Just as with CIREC, I have learned much from my travels with them, visiting war victims and the forgotten, from their philosophy of total integration and from their self-sustaining programs.

My final, and most sincere, thank you goes to all of the great rehab technology suppliers, ATPs, clinicians and manufacturers who focus every day on bringing independence and comfort to those with Complex Rehab needs. I know you do it out of love for what you do and because it needs to be done.

# FROM THE AUTHOR



## MARK C. SULLIVAN

Mark C. Sullivan began his career as a Recreational Therapist in 1975, working with people with disabilities in both psychiatric and physical medicine rehabilitation hospitals. For the past 35 years, he has worked in complex rehab product development and marketing for Invacare, Ride Designs and Convaid. He is an advisory board member of the International Society of Wheelchair Professionals (ISWP), former chair of the ISWP Standards Working Group, the 2012 recipient of the United Cerebral Palsy/ Wheels for Humanity Ambassador of Mobility Award, a former Board Member of the American Occupational Therapy Foundation, a former Board Member of NCART and a NRRTS Honorary Lifetime Member.

Mark has volunteered for the Polus Center for Social and Economic Development as well as the U.S. State Department teaching complex rehab in less resourced countries around the world. He authored DENIED about the complex rehab sector and was lead author on the ISWP Wheelchair Design Guidelines.

Mark is currently the President of Sullivan Consulting and does independent contract work for the Convaid and R82 brands of ETAC.

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**NRRTS**

National Registry  
Of Rehabilitation  
Technology Suppliers

NRRTS is a professional association supporting individuals who provide Complex Rehab Technology (CRT), including wheelchairs and seated positioning systems for people of all ages and diagnoses who have postural or mobility deficits. Our professionals offer quality care and service using specialized knowledge, training, experience and skills to match the consumers' needs to appropriate equipment.

*Copies of this book are available for purchase at [www.nrrts.org](http://www.nrrts.org).*

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