



Building Local/Global **Spina Bifida** **Communities with Adaptive Design**

Construyendo Comunidades Locales/Globales de
Espina Bifida con Diseño Adaptado



This Idea Book summarizes six weeks of creativity, information sharing, and community building among children with spina bifida and their families in Syracuse, New York, USA and Ibarra, Ecuador. Serendipity (and cardboard!) brought us together!

During July and August 2018 our two communities were in regular contact via video-conference, email, Instagram and Facebook. The goal was to share design ideas for low cost equipment for kids with spina bifida. This is where the cardboard comes in.

Triple-ply cardboard is an eco-friendly material that is available all over the world. It is durable and strong. It can be readily cut, bent, glued, and painted. It is the perfect material for making custom designs. Why is this important? Each child with spina bifida has unique positioning and mobility challenges. Plus, as is true for all children, children with spina bifida are always growing and changing. Manufactured equipment can be very expensive and may not be immediately or readily available. Designs that are made locally with cardboard can be used right away and are easily modified. They are co-created with families, clinicians, friends and neighbors to meet the specific needs of a specific child. This hands-on experience is tremendously satisfying! And it is not just about the end product! Creating solutions, working together, and building community brings much joy!

SERENDIPITY

Our 6-week Summer project began over a slice of pizza. Kit Frank was driving through Syracuse and stopped by for lunch. Our adaptive design group in Syracuse, Arise Adaptive Design, was eager to learn about Kit's many years experience building adaptive designs in Ecuador as an occupational therapist at Prótesis Imbabura.

Our pizza get-together can be traced to a mutual friend, Alex Truesdell, founder of the Adaptive Design Association in New York City. Alex has inspired many of us with her credo: **Build for One. Engage Everyone. Change Everything.**

Before we knew it, the ideas discussed over pizza became a reality! The Hispanic communities of Syracuse University and Central New York gave us workshop space at La Casita Cultural Center on Syracuse's near west side. We invited teens and young adults from our Spina Bifida Center in Syracuse to help run and participate in a "Local/Global Adaptive Design Camp" at La Casita. Over six weeks we learned together how to build adaptive designs in cardboard, PVC, and other low cost materials. The designs were made with and for the children who were seen at our weekly Spina Bifida Clinic at Golisano Children's Hospital in Syracuse. Meanwhile in Ibarra, Kit invited children with spina bifida and their families to weekly gatherings during which we shared adaptive design ideas via video conference. We also shared ideas via Facebook and Instagram. At the end of the six weeks we all gathered at La Casita (in person and by video conference) to celebrate our Local/Global Community.

This Idea Book documents our six-week long collaboration to build adaptive designs and to bring together families in Syracuse and Ibarra. This Idea Book was created to spark interest in adaptive design among spina bifida communities worldwide. Enjoy!

Maddy Locastro, Kit Frank, and Nienke Dosa

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Front cover and left

Maddox enjoys driving his school bus. A big thank you to East Syracuse Home Depot and manager Mike Stermer for hosting several adaptive design builds!

LOCAL/GLOBAL PARTICIPANTS

Ann Marie Abt	Lisa Neville
Rebecca Alexander	Wade O'Brien
Ethan Baker	Monica Pacone-Weber
Jill Boyer	Kathryn Palomino
Don Carr	Tere Paniagua
Richelle Castellon	Patchett Family
Yanina Colberg	Pominville Family
Juan Cruz	Stephanie Santiago
Tim Davis	Schmidt Family
Carole Dennis	Peyton Sefick
Martine Dosa	Maggie Sexton-Dwyer
Jolene Dosa	Gary Slutzky
Elliot Family	Teri Smith
Jesse Evensky	Precious Sneed
James Fathers	Sharon Stansfield
Alicia Flinn	Sarah Steele
Ford Family	Cindy Steele
Frickey Family	Mike Stermer
Forough Jafari	Zulma Tovar-Spinoza
Christina Kim	Luma Trilla
Leonard Family	Tracy Walker
Barbara Lindenmayer	Erin Wentz
Lindsley Family	Angela Wilde
Sophie Nash	Christine Whitney
Connor McGough	Wurst Family
Moore Family	
Potter Family	

Kit Frank, Paty Reascos, Alicia Rivadeneira, Kyla Greenhut and Beth Parrott, employees and volunteers of Prótesis Imbabura

11 Physical therapy students from Universidad Técnica del Norte, Ibarra, under the supervision of Majister Katty Esparza, Licenciada Veronica Potosi, y Majister Cristian Torres, Coordinadores de prácticas en la comunidad

7 rehabilitation professionals from the Municipio of Tabacundo, Canton Pedro Moncayo

13 occupational therapy students and professionals from various universities in the US and Australia, through Crecer (Centro de Rehabilitación, Educación, Capacitación, Estudios y Recursos), Ibarra, supervised by Elaine Keane, OTR

Families living with spina bifida in the province of Imbabura, facilitated by Narcisa Oviedo and Margarita Cevallos

Booklet Design by Holly Boice Scherzi





Welcome To Syracuse

43.0481° N, 76.1474° W



The Spina Bifida Center of Central New York thanks
La Casita Cultural Center and Arise Adaptive Design.
We built a great community together this Summer!

100 Families

The Spina Bifida Center of Central New York provides medical care to approximately 100 children and their families. We are located at Golisano Children's Hospital at Upstate Medical University in Syracuse, New York. Our patients come from a 24-county region that includes several small cities, a military base, and beautiful rural areas in Central New York. Our medical team includes doctors who specialize in neurosurgery, urologic surgery, orthopedic surgery, and developmental pediatrics. Our team also includes nurses, a social worker, a nutritionist, and a physical therapist.

Many families travel a long

distance to Syracuse for their annual comprehensive care visit. We do our best to coordinate multiple appointments on the same day.

At our Center we also offer "Group Visits". Group visits combine a brief medical visit with a wellness program for children and an educational session for parents. Group Visits take place in the evening, include supper and bring 6-8 families together to learn about topics such as adaptive sports and educational advocacy. Families also stay connected via Facebook and a quarterly newsletter.

This guidebook describes a project that evolved from our Group Visits program.



100 FAMILIAS

El Centro de Espina Bífida de Central New York brinda atención médica a aproximadamente 100 niños y sus familias. Estamos ubicados en Golisano Children's Hospital en Upstate Medical University en Syracuse, New York. Nuestros pacientes vienen de 24 condados diferentes que incluye varias ciudades pequeñas, una base militar y bellas áreas rurales de

el centro del estado de New York. Nuestro equipo incluye médicos que se especializan en neurocirugía, cirugía urológica, cirugía ortopédica, y pediatría de desarrollo. Nuestro equipo también incluye enfermeras, una trabajadora social, una nutricionista, y una fisioterapeuta.

Muchas familias viajan una larga distancia hasta Syracuse

para su visita anual de atención integral. Hacemos todo lo posible para coordinar citas múltiples en el mismo día.

En nuestro Centro también ofrecemos "Visitas Grupales." Las Visitas Grupales combinan una visita médica breve con un programa de bienestar para niños y una sesión educativa para los padres. Estas tienen lugar por la tarde e incluyen cena.

Reunimos 6-8 familias para aprender sobre temas como los deportes adaptados y defensa educativa. Las familias también permanecen conectadas a través de Facebook y un boletín trimestral.

Esta guía describe un proyecto que se desarrolló a partir de nuestro programa de Visitas Grupales.

ARISE Adaptive Design

www.arisead.org
cmcgough@ariseinc.org
315-671-5104
ARISE Inc.
635 James Street
Syracuse, NY 13023

ARISE Adaptive Design is a volunteer collective of people with all types of abilities, their families and friends, clinicians, designers and makers. People with disabilities and their families are equal members of their design teams. Together we identify solutions to provide access and full participation in a wide range of activities and settings. Families have long been the greatest innovators in creating design solutions. Family-centered co-design takes families' ingenuity one step further. We bring together design teams that include people with a variety of personal and professional

skills and perspectives. This approach builds on families' skill sets and enables larger community sharing by exposing clinicians, designers, and makers to collaboration. Learn more at ARISEAD.org



DISEÑO ADAPTADO DE ARISE

Diseño Adaptado de ARISE es un colectivo voluntario de personas con todo tipo de habilidades, sus familias y amigos, médicos, diseñadores y fabricantes. Las personas con discapacidades y sus familias son miembros iguales de sus equipos de diseño. Juntos identificamos soluciones para proporcionar acceso y participación completa en una amplia gama de actividades y entornos. Las familias han sido durante mucho tiempo las mejores innovadores en la creación de soluciones de diseño. El co-diseño centrado en la familia lleva el ingenio de las familias un paso más allá. Reunimos equipos de diseño que incluyen personas con una variedad de habilidades y perspectivas personales y profesionales. Este enfoque se basa en las habilidades de las familias y permite un mayor intercambio de la comunidad al exponer a médicos, diseñadores y fabricantes a la colaboración. Aprender más en ARISEAD.org.

Medical Considerations

This table gives a general overview of the orthopedic, bracing, and equipment needs that someone with spina bifida might have. It is organized into categories based on “functional motor level”. Each person with spina bifida is unique, and some may have more muscle weakness than others. Most people with spina bifida also have numbness in their legs and neurologic changes that affect bowel and bladder function. Seating, mobility and bracing for a child with spina

bifida are typically addressed with input from the medical team, which may include orthopedic surgeons, physiatrists, developmental pediatricians, occupational therapists, physical therapists and orthotists. The adaptive designs in this Idea Book complement the orthotics, seating and mobility equipment recommendations that are summarized on this table.

Spine Level	Possible Muscle Function	Possible Orthopedic Concerns	Possible Orthotics Needed	Possible Equipment for Functional Mobility
T6-9 T9-12 L1	Upper trunk (abdominals) No LE function Abdominals + paraspinals = some pelvic control Complete trunk function Lower trunk (abdominals) Hip flexors (weak) 2/5	Kyphoscoliosis Lumbar hyperlordosis Coxa valga-hip dislocation Decreased bone density Fractures Contractures: Hip: abduction, flexion, external rotation Knee: flexion, extension Foot: heelcord, clubfoot	TLSO Night splints: body, hip abduction, KAF, AF Early: Parapodium, (10 months of age and up to 2 years) Later: Stander, RGO, HKAFO, KAFO Caution: Preserve UE function with level transfers, stable seated posture. Maintain strength + flexibility of shoulders/arms.	Community: Wheelchair/ wheelchair cushion, transfer board Home: • Walker/Crutches (for household or exercise walking) • Raised, padded commode seat • Bath bench • Mirror for skin checks • Stander: 1 hour/day minimum starting at 10-12 months of age. • Driving with hand controls • Learn public transportation
L2 L3	Hip flexors 3/5 Hip abductors 3/5 Knee extensors 3/5	Scoliosis, Overuse of UE's Lumbar hyperlordosis Hip subluxation Coxa valga-hip dislocation Decreased bone density Fractures Contractures: Hip: flexion Knee: flexion, extension Foot: heelcord, clubfoot	Night hip abduction splint Early: Parapodium (10 months of age up to 2 years) Later: Stander, RGO, HKAFO, KAFO (if quads are less than 3/5 strength) L3-5 May be temporarily addressed by twister cables or derotations straps	Community: Wheel chair + cushion Home: Stander: 1 hour/day minimum Early: May use walker or crutches Later: Wheelchair in home
L4 L5	Medial knee flexors 3/5 Ankle dorsiflexor 3/5 Hip abductors (weak) 2/5 Lateral knee flexors 3/5 Ankle invertors 3/5 Long toe extensors Long Toe extensors (palpate at ankle)	Lumbar hyperlordosis Coxa valga Contractures: Hip: flexion Knee: flexion (avoid crouch gait) Foot: • Progressive calcaneus (tight heelcord) • Calcaneovalgus • Equinovarus-Clubfoot • Paralytic Vertical Talus	Night hip abduction splint Early: Parapodium Later: RGO, HKAFO, KAFO, AFO, (L3-L4 CCAFO) L4-5 Toeing in gait and weak gluteals may be temporarily addressed by twister cables and/or rotation straps Consider shunt malfunction and/or tethered cord	Community: Wheelchair, walker, crutches, cane. Strong medial hamstring needed for community gait Home: Early: on: may need no support Later: May require UE support
S1 S2	Hip abductors 3/5 Hip extensors (weak) 2/5 Plantar flexors (weak) 2/5 Hip extensors 4/5 Plantar flexors 3/5 Toe flexors 3/5	Monitor hips closely Contractures: Foot: • Calcaneus (tight heelcord) • Calcaneovalgus • Pes Cavus • Clubfoot • Toe clawing (flexion) • Heel/foot ulcers	AFO, SMO (supra malleolar orthotics), shoe inserts or no orthotics S1-2 Toeing out gait Use of crutches may decrease the valgus forces at the knee and also improve endurance	Community: Walking with walker, crutches, or cane. Gluteus lurch/Trendelenburg gait aided by cane or crutches. Long distance alternative: lite weight wheelchair, bike, scooter Home: May need no support.
S3-5	All muscle activity + bowel/bladder function may be normal	None	None or shoe inserts	None
<p>Muscle grades: 5 = normal 4 = good 3 = fair 2 = poor 1 = trace</p> <p>Flexion = bend Extension = straighten Adduction = bring toward Abduction = take away</p> <p>Invert = move in Evert = move out Medial = inner Lateral = outer</p> <p>T = thoracic L = lumbar S = sacral O = orthosis RGO = reciprocating gait orthosis H = hip K = knee A = ankle F = foot CC = crouch control Gait = walking style Coxa = hip Calcaneus = heel bone Talus = ankle bone</p> <p>UE = upper extremities/arms LE = lower extremities/leg</p>				

This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.

Contributing Editors
Tim Brei, MD and Liz Kelly, PT

Acknowledgement:

This table was adapted with permission from an educational handout that is entitled “Level of SB Function” authored by Timothy Brei, MD and Liz Kelly, PT. “Level of SB Function” is available on the website of the Spina Bifida Association at: <https://spinabifidaassociation.org/wp-content/uploads/2015/07/HOW-SB-LESIONS-IMPACT-DAILY-FUNCTION1.pdf>

Adaptive Design Solutions



Cole

Cole's physical therapist designed a wedge that is balanced on a pool noodle. This way Cole can experience side-to-side motion during tummy time. Cole's "wedge with wings" improves head control and encourages Cole to shift visual attention, which may help with learning later on . . .

El fisioterapeuta de Cole diseñó una cuña equilibrada en una pieza de esponja. De esta forma, Cole puede experimentar un movimiento de lado a lado durante el tiempo boca abajo. La "cuña con alas" de Cole mejora el control de la cabeza y anima a Cole a cambiar la atención visual, lo que puede ayudar a aprender más adelante . . .



... when Cole is older a Ball Maze Tray will be a fun way to develop hand eye coordination!

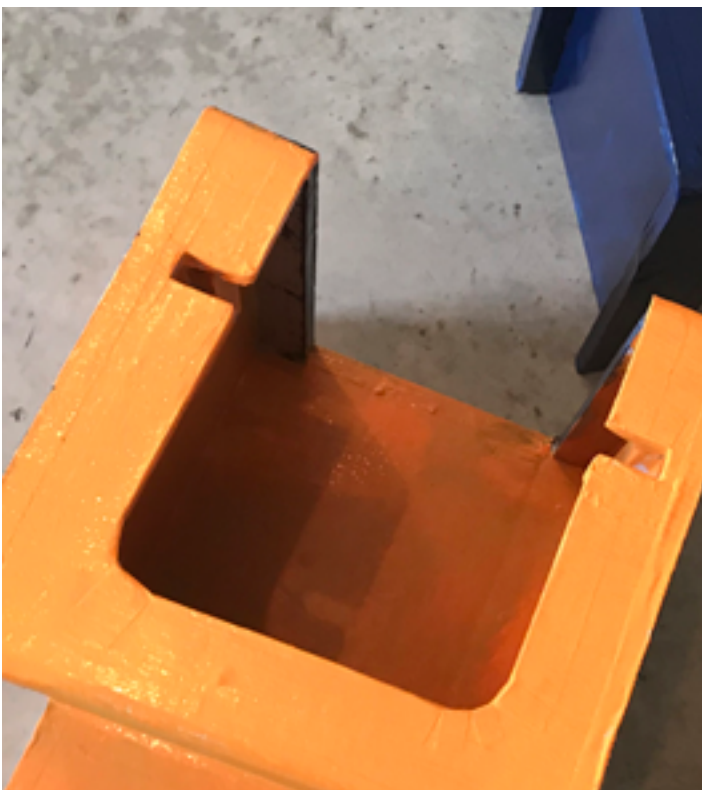
... cuando Cole sea mayor una mesita de laberinto con bolas será una forma divertida de desarrollar la coordinación ojo-mano!



Maddox

This stander is just the right size for Maddox.

Este stander es el tamaño correcto para Maddox.



Landon

We made a custom chair with a fold out soccer table for Landon. Landon's mom added a slight tilt to the table so that the ball would roll back to Landon's right side. This helps to make his right arm stronger. Plus...it's fun!

Hicimos una silla personalizada con una mesa plegable de fútbol para Landon. La madre de Landon agregó una inclinación leve a la mesa para que la bola rodará hacia el lado derecho de Landon. Esto ayuda a fortalecer su brazo derecho. Además ... ¡es divertido!



Faith

Faith has a gastrostomy tube because she is unable to safely swallow food by mouth. The feeding pump came with a hospital IV pole that kept her tethered in the kitchen area. Faith wanted to keep playing with her brothers and sisters in the living room. A back pack was too heavy. We used PVC to make a lightweight feeding pump carrier on wheels that Faith could easily move from place to place. Faith and her siblings decided to decorate it with purple tape!

Faith tiene un tubo de gastrostomía porque no puede tragar la comida de manera segura por la boca. La bomba de alimentación está conectada a un poste intravenoso (IV) que no le permitía salir de la cocina. Faith quería seguir jugando con sus hermanos y hermanas en la sala. Una mochila era demasiado pesado. Usamos PVC para fabricar un transportador liviano con ruedas para la bomba de alimentación que Faith podía mover fácilmente de un lugar a otro. ¡Faith y sus hermanos decidieron decorarlo con cinta adhesiva morada!



J.M.

J.M. uses transfer steps to get in and out of bed. This helps her to be even more independent than she already is!

J.M. usa escaleras de transferencia para entrar y salir de la cama. ¡Esto la ayuda a ser aún más independiente de lo que ya es!



James

When James gets home he takes his braces off and just tosses them on the floor. They are often in the way. The solution? A brace holder that keeps the braces safe and the house tidy!

Quando James llega a la casa, se quita los aparato ortopédico y los arroja al piso. A menudo están en el camino. ¿La solución? ¡Un soporte para los aparatos ortopédicos que mantiene los aparato ortopédico y la casa ordenada!



Deanna

Deanna is a mom who came up with this idea: A self-care kit for bathroom routines. The kit keeps everything in one place. It includes a visual schedule that helps with sequencing of tasks such as brushing teeth, taking medications, cathing on schedule, and performing daily skin checks.

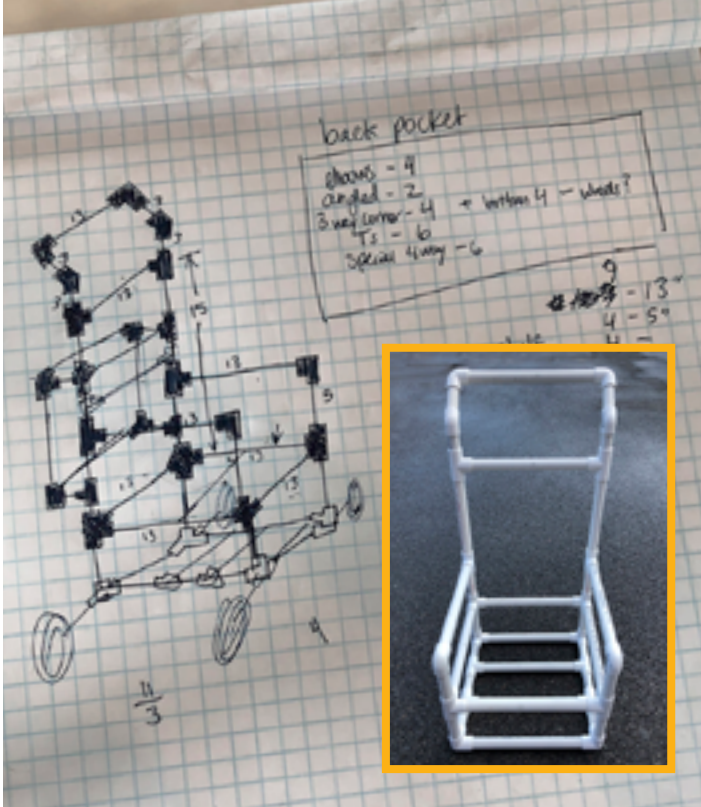
Deanna es una madre que pensó en esta idea: Un kit de autocuidado para rutinas de baño. El kit mantiene todo en un solo lugar. Incluye un programa visual que ayuda con la secuenciación de tareas como cepillarse los dientes, tomar medicamentos, cateterizar según el horario y realizar chequeos diarios de la piel.



Liz, Christina, Stephanie, Caleb, and Peyton

Everyone likes the beach. Not all beaches are accessible.
Wouldn't it be great to have a portable beach chair?

A todos les gusta la playa! No todas las playas son accesibles.
¿No sería genial tener una silla de ruedas de playa portátil?




Creating Solutions Sharing Information Building Community

Creando soluciones Compartiendo información Construyendo comunidad



1  Adaptive Design Association NYC
Asociación de diseño adaptativo NYC
AdaptiveDesign.org/learning-library

2  Facebook Local/Global Adaptive Design Forum
<https://www.facebook.com/Adaptivedesignforum/>


3  Instagram - Building Local/Global Spina Bifida Communities
<https://www.instagram.com/localglobalspinabifida/>


4  Arise Adaptive Design
<http://www.arisad.org>

5  Spina Bifida Association
<http://spinabifidaassociation.org>

6  International Federation for Spina Bifida and Hydrocephalus (IFSBH)
<https://www.ifglobal.org/en/>

7  Association for Spina Bifida and Hydrocephalus (APEBI) - Argentina
<http://www.apebi.org.ar/>

8  Building Local/Global Spina Bifida Communities Map
<https://www.zeemaps.com/>

9  Prótesis Imbabura
<http://protesisimbabura.com/>

10  Zoom Video Conferencing
<https://zoom.us/>

11  GATE - World Health Organization
<http://www.who.int/>