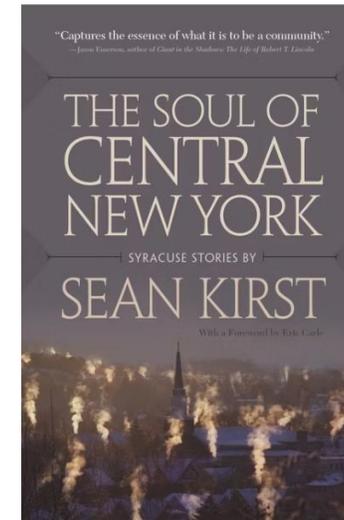


# Community-Centered Spina Bifida Care

Nienke P. Dosa MD MPH [dosan@upstate.edu](mailto:dosan@upstate.edu)



## *Spina Bifida Center of Central New York - Golisano Children's Hospital*



# Spina Bifida Center of Central New York - Golisano Children's Hospital

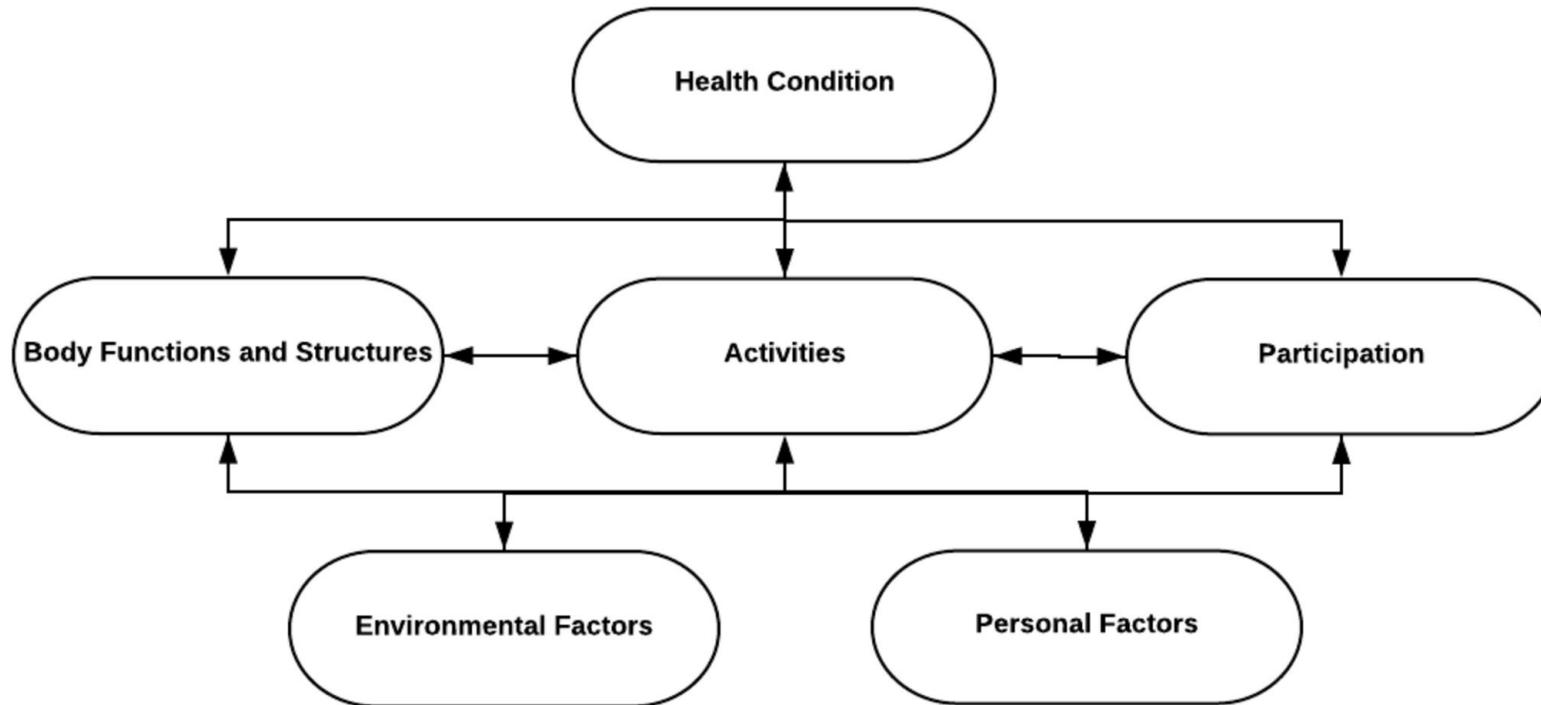


## Serving the Community

Spina Bifida Association of New York State (SBANYS) is dedicated to serving and supporting every person and family impacted by Spina Bifida. We do this by offering programs, resources, education, services, and support; while advocating for the community on the local and federal level. Annually, the Association typically hosts over 30 in-person and virtual programs and responds to over 2,000 consumer and provider requests for assistance. Many of our programs are in collaboration with our Spina Bifida Chapters across the United States, linking the community as a whole. We look forward to pursuing our mission and enhancing our support for all those impacted by Spina Bifida with your help!!

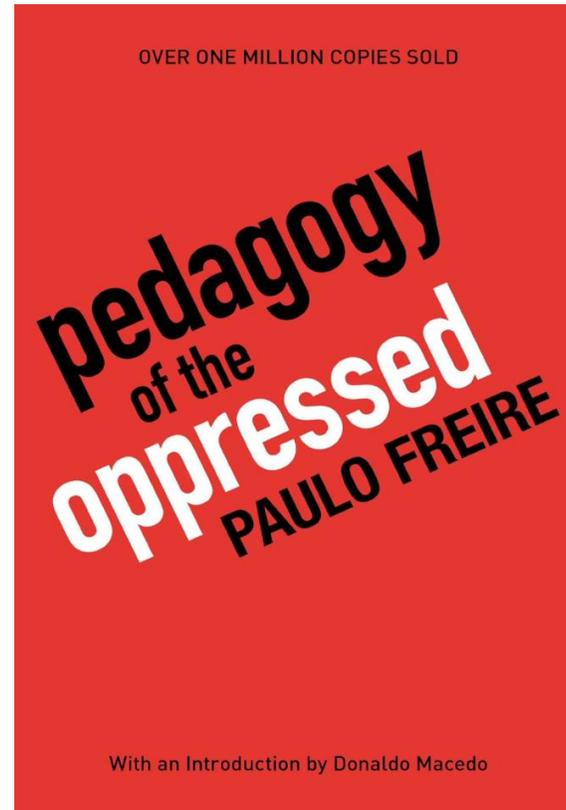


# International Classification of Functioning, Disability and Health (ICF)



# Paolo Freire

**Praxis:** Lived experience that leads us to act together in ways that make for justice and human flourishing.



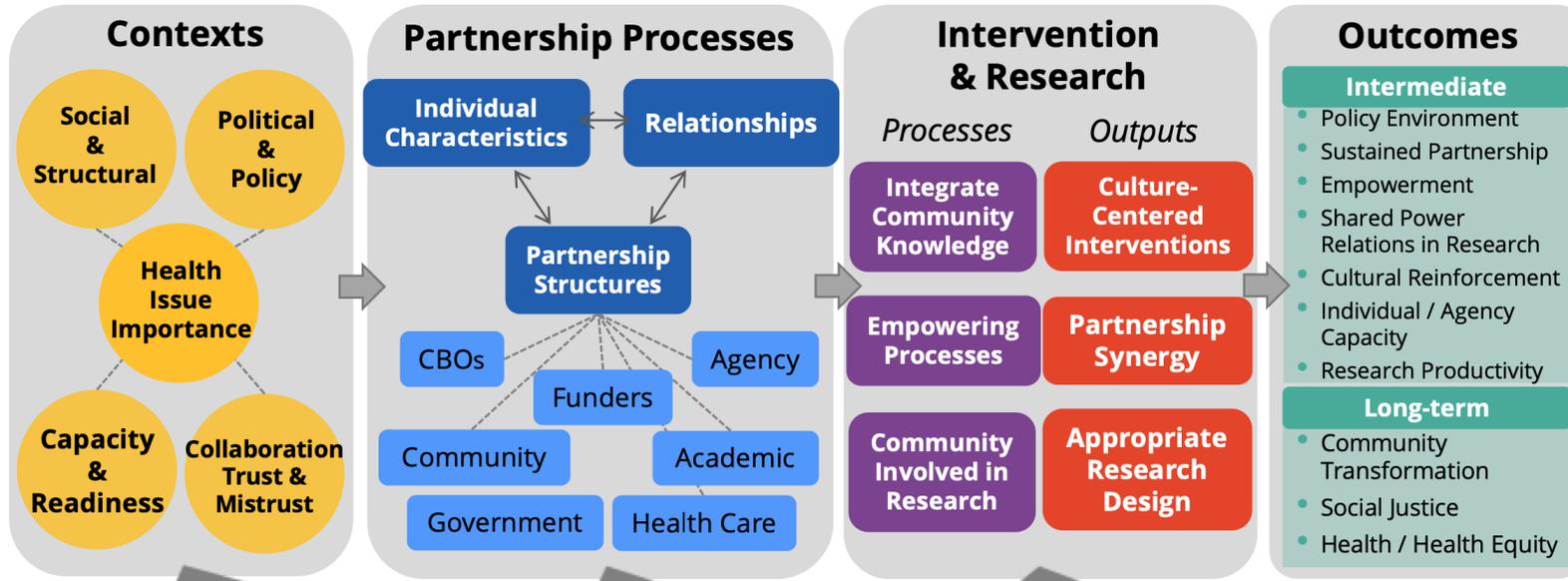
# Community-Based Participatory Research

A collaborative research method that equitably involves all partners, starts with research topics important to the community, combines knowledge with action, and aims for social change to improve health outcomes and eliminate health disparities.

- ▶ W.K.K. Kellogg

# CBPR Conceptual Model

Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010, <https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html>



Visual from amoshealth.org 2017



<https://engageforequity.org>

# Basic Tenets of CBPR

- ▶ Recognizes community as a unit of identity
- ▶ Builds on strengths and resources
- ▶ Focuses on community driven issues
- ▶ Collaborative, equitable partnerships
- ▶ Co-learning and empowerment
- ▶ Mutually beneficial Integration of knowledge and action
- ▶ Cyclical and iterative process (action->reflection->action)
- ▶ Share what is learned with all partners, showcase in the community
- ▶ Long term commitment and sustainability

# CBPR References

Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Public Health*. 2010 Apr 1;100 Suppl 1(Suppl 1):S40-6. doi: 10.2105/AJPH.2009.184036. Epub 2010 Feb 10. PMID: 20147663; PMCID: PMC2837458.

Wallerstein N, Oetzel JG, Sanchez-Youngman S, et al. Engage for equity: a long-term study of community-based participatory research and community-engaged research practices and outcomes. *Health Educ Behav*. 2020;47(3):380-390. doi: 10.1177/1090198119897075

Wilkins CH, Alberti PM. Shifting Academic Health Centers From a Culture of Community Service to Community Engagement and Integration. *Acad Med*. 2019 Jun;94(6):763-767. doi: 10.1097/ACM.0000000000002711. PMID: 30893063; PMCID: PMC6538435.

Park A, van Draanen J. Community-Partnered Research appraisal tool for conducting, reporting and assessing community-based research. *BMJ Open*. 2024 Apr 25;14(4):e081625. doi: 10.1136/bmjopen-2023-081625. PMID: 38670613; PMCID: PMC11057323.

Eisenberg Y, Rimmer JH, Mehta T, Fox MH. Development of a community health inclusion index: an evaluation tool for improving inclusion of people with disabilities in community health initiatives. *BMC Public Health*. 2015 Oct 13;15:1050. doi: 10.1186/s12889-015-2381-2. PMID: 26462917; PMCID: PMC4603756.

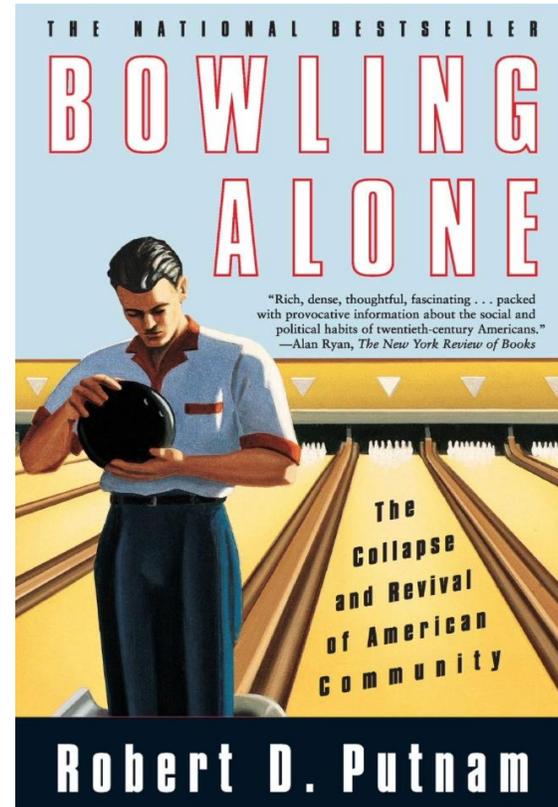
Yejong Yoo P, Majnemer A, Wilton R, Ahmed S, Shikako K. Application of the child community health inclusion index for measuring health inclusion of children with disabilities in the community: a feasibility study. *BMC Pediatr*. 2023 Feb 20;23(1):86. doi: 10.1186/s12887-023-03884-8. PMID: 36803575; PMCID: PMC9939852.

# Robert Putnam

## Social capital

Is defined as the value that is derived from social networks and norms of reciprocity. Social capital is essential for a healthy society and strong democracy.

- ▶ Bonding social capital
- ▶ Bridging social capital



Netflix: <https://joinordiefilm.com>

# Community-Centered Care in Syracuse

1. Group Visits 2010-2018
2. Fitness Inclusion Network 2012 ->
3. Adaptive Design Association 2016 ->
4. AT Village Advocacy 2021 ->

# Community-Centered Care in Syracuse

1. **Group Visits** 2010-2018
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# 2010-2018 Fit Families Group Visits



Goal: promote physical activity



# What are group visits?

*Group Visits combine:*

Medical care

Psychosocial support

Information about resources

*Building community...*



# Historical context

- ▶ 100 years ago: Joseph H. Pratt MD, TB patients at MGH
- ▶ 1970s: Cleveland Clinic, Kaiser Permanente: well child visits
- ▶ 1990s:
  - ▶ Early: John Scott MD: Cooperative Health Care Clinics (CHCC) for adult chronic disease
  - ▶ Mid: Drop-In Group Medical Appointments (DIGMA)
  - ▶ Late: Empowerment Model designed to treat loneliness
- ▶ 2010's: 10% Family Physicians offer group visits
- ▶ 2020's: Telehealth group visits



# Cooperative Health Care Clinics

- ▶ CHCC High Risk Cohort Clinics (Diabetes)
  - ▶ All ages
  - ▶ Patient Education Curriculum
  - ▶ 2-2.5 hours
  - ▶ 20 patients
  - ▶ Interactive discussions
  - ▶ Self management
  - ▶ Behavior action plans

# Drop-In Group Medical Appointments

- ▶ (DIGMAs) are composed of different patients from meeting to meeting
- ▶ Patients with chronic conditions “drop in” for specific medical topics
- ▶ 90 minutes, 10 to 15 patients
- ▶ Behavior specialists
- ▶ Group discussions

# Our Group Visit Program

## Diabetes care

- ▶ Diabetes educator
- ▶ Lifestyle changes
- ▶ Monitor A1C

## Spina bifida care

- ▶ Adapted physical educators
- ▶ Promote physical activity
- ▶ Monitor weight, skin integrity, continence, etc.

# Goals

- ▶ Increase physical activity (lifestyle change)
- ▶ Promote participation

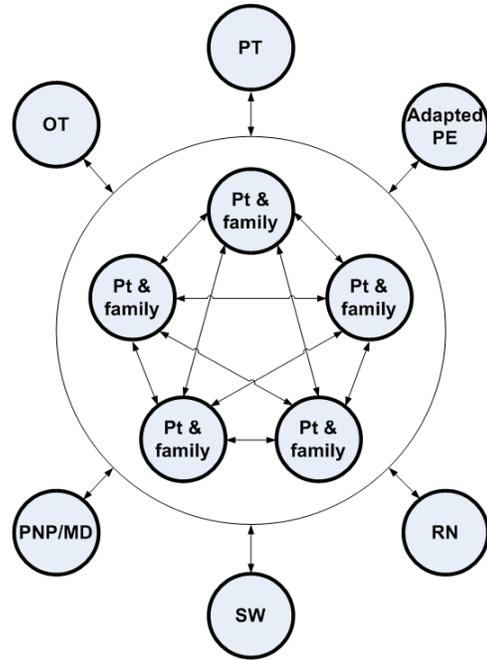
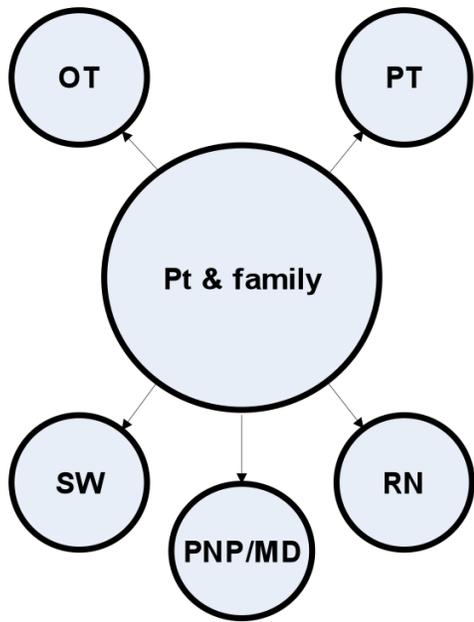


# Group Visit Format

Time:	5:30-6:00	6:00-6:30	6:30-7:00	7:00-7:30	7:30-8:00
Activity:	Registration & Nursing Assessment	Light meal & Announcements	Kids: Gym Parents: Guest speaker	1:1 consults with MD, RN, PT, APE	Debriefing
Personnel:	RN, SW, MD register patients and do assessments.  Adapted Physical Education staff and service learning students set up in the gym	Everyone sits down together for a light meal.  Service learning students typically sit with kids.  Towards the end of the meal, new families are introduced and announcements are shared. Everyone contributes to the announcements, including kids.	Service learning students and APE staff bring kids to the gym.  Parents have the option of staying with their child or joining other parents for an information session with a guest speaker.  Social Worker introduces the guest speaker and leads the group session with parents.  Medical team floats between the two locations.	Parents join kids in the gym.  Medical team and APE team is available for 1:1 discussion.	Medical faculty and adapted physical education faculty meet with service learning students to discuss patients and answer questions.

# Group Visit vs. Comprehensive Care

*promotes informal networking*



# Group Visit vs. Comprehensive Care *provides access to expertise*



# Group Visit vs. Comprehensive Care

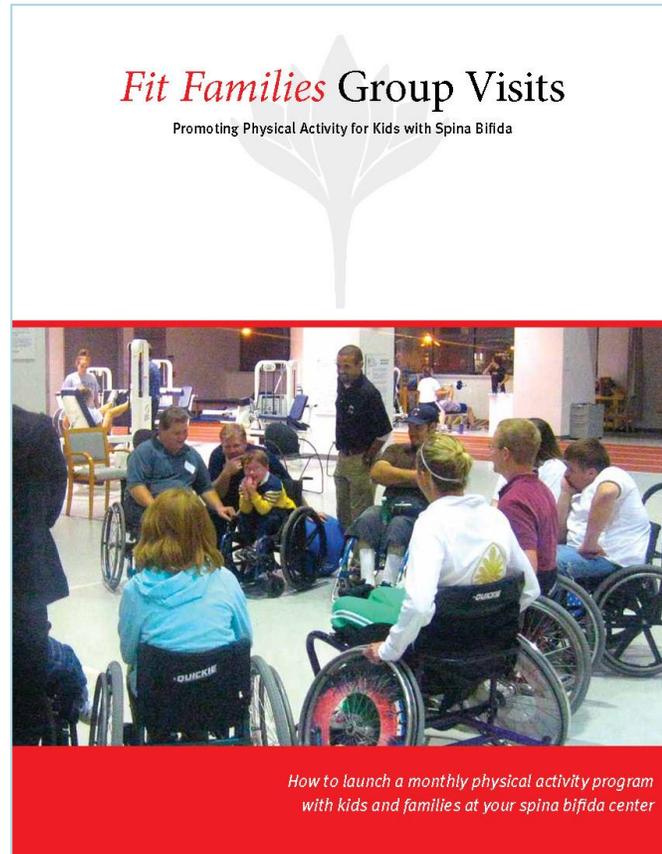
*efficient way to provide team-based care*

**8 Hours**



**2.5 Hours**

# Group Visit Manual



[https://www.upstate.edu/specialneeds/pdf/inclusive/2012\\_fit-families-group-visits-promoting-physical-activity-for-kids-with-spina-bifida.pdf](https://www.upstate.edu/specialneeds/pdf/inclusive/2012_fit-families-group-visits-promoting-physical-activity-for-kids-with-spina-bifida.pdf)

# \$tart up costs

- ▶ Spina Bifida Fund
- ▶ CNY Community Foundation
- ▶ Children's Miracle Network
- ▶ Upstate Advocates
- ▶ American Legion Auxiliary
- ▶ Christopher Reeve Foundation
- ▶ Mike Casale's birthday party



# Time Line: 2 months prior

- ▶ Meet with leadership
- ▶ Determine goals
- ▶ Inventory / Resources
  - ▶ Staff
  - ▶ Space
  - ▶ Funding
  - ▶ Participant list
  - ▶ Invite speakers



# Time Line: 1 month prior

- ▶ Send out invitations
- ▶ Call all patients and families who received invitations
- ▶ Review schedule for group



# Time Line: One week ahead

- ▶ Create roster and sign in procedure
- ▶ Call patients and families to remind them of group
- ▶ Consider barriers, e.g., transportation



# Time Line: Day of Group

- ▶ Set up room
- ▶ Staff stations (registration, nursing assessment, etc)
- ▶ Manage flow of traffic
- ▶ Debrief



# Group Visits: What we learned

- ▶ High Satisfaction with Care (families and providers)
- ▶ Excellent interdisciplinary service-learning opportunity
  - ▶ MD, PT, OT, Adapted Physical Education students
- ▶ Group Visits are Feasible
  - ▶ Space-Personnel-Billing (these are inter-related!)
  - ▶ Privacy/HIPAA is not a barrier (sign confidentiality agreement)
  - ▶ Efficient way to access expertise and provide team-based care
  - ▶ Age range among patients is a plus
  - ▶ Families will travel to participate

# Community-Centered Care in Syracuse

1. Group Visits 2010-2018
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# Fitness Inclusion Network

## Who we are:

- ▶ Athletes/Families; Disability Advocates; Health Care Providers; Professionals in Adapted Physical Education; Academics/Students; City Parks and Recreation, County Health Department, Non-Profits.

## Our mission:

- ▶ To develop innovative ways to promote and support inclusive fitness for children, adolescents and adults with disabilities in Central New York.



# Fitness Inclusion Network

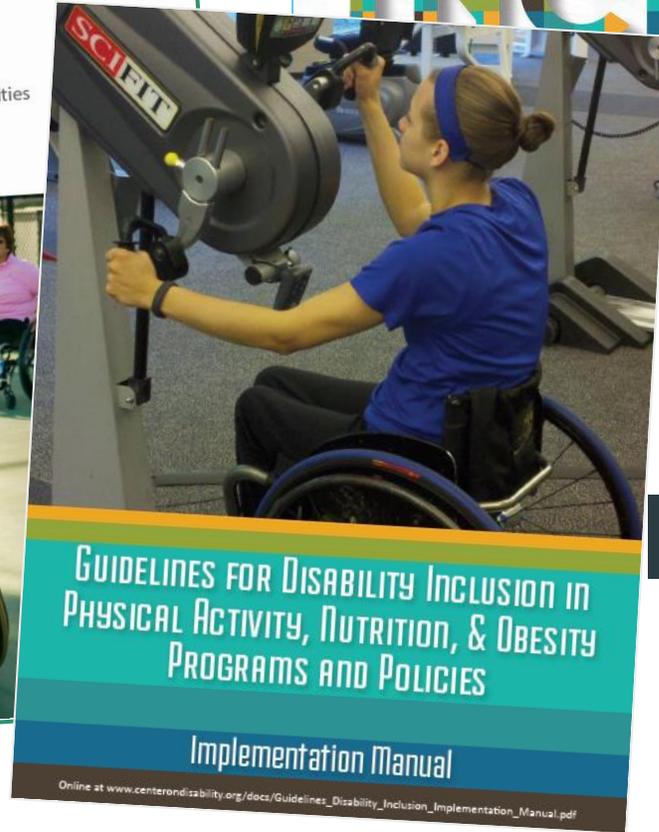
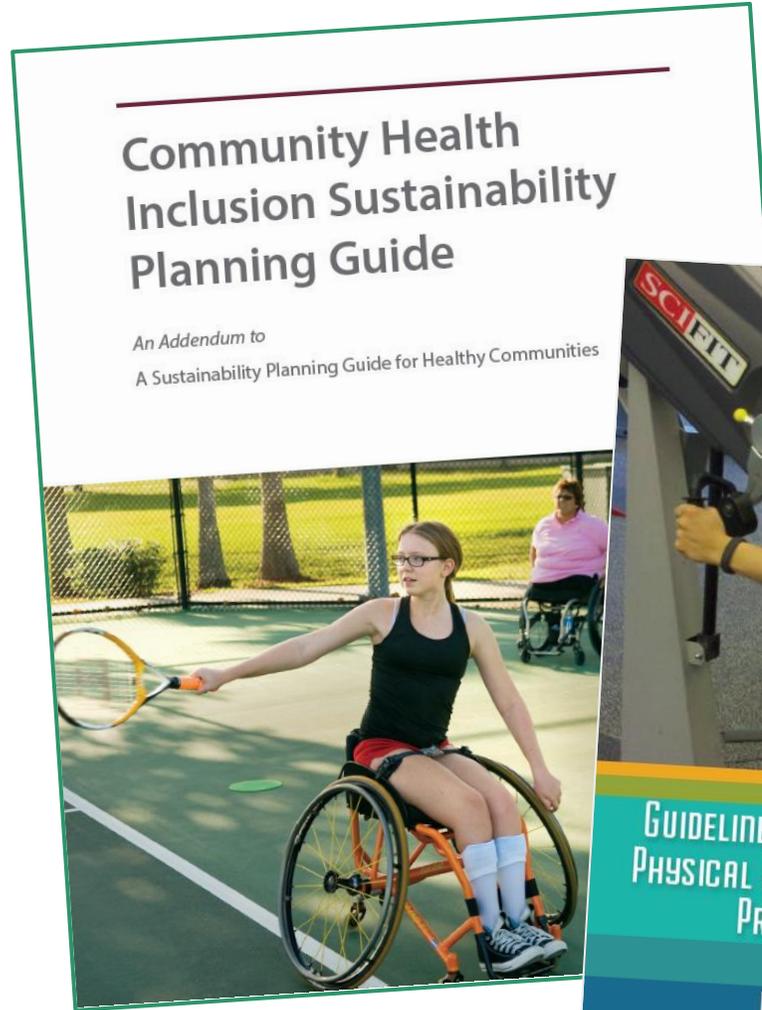
What we do:

- ▶ Annual conference (venue and format different each year)
- ▶ Inclusive programs in area schools and parks
- ▶ How-to guides for high school students



Fit-IN First Annual Conference & Power Mobility Workshop Participants

# National Context

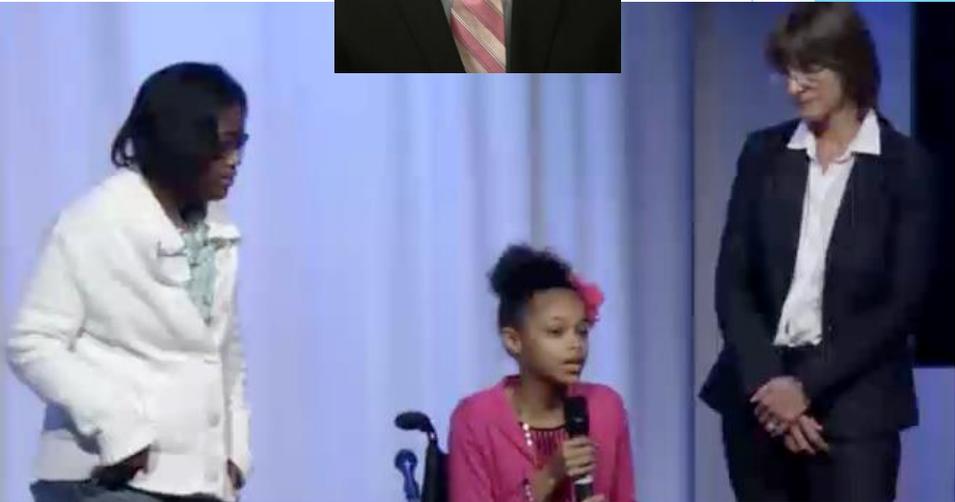


Inclusive Community Health

# Fit-In 1: New Paradigms for Power Mobility



# Fit-In 2: Activating Communities



# Fit-In 5: Walks & Talks along the Inner Harbor



# Fowler High School: Mapping Inclusion



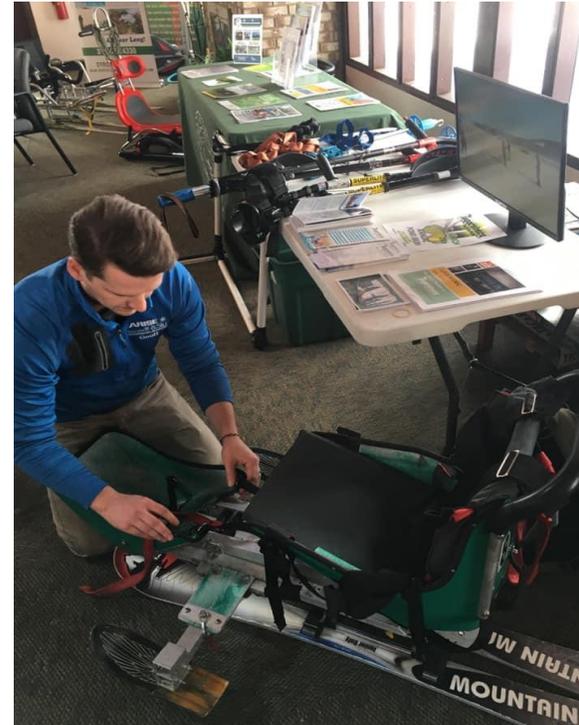
# Nottingham High School: Ballet for All



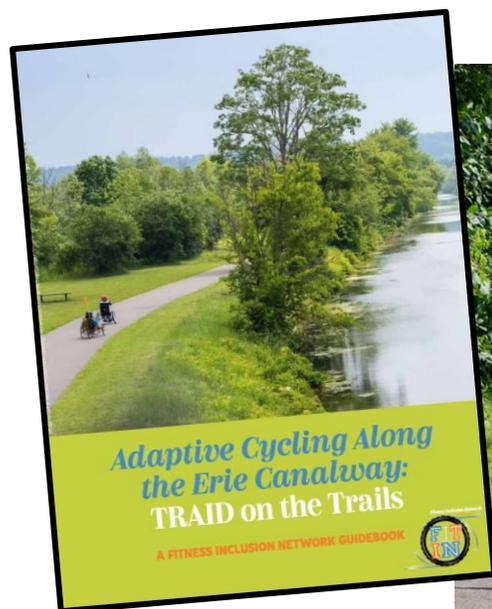
# Nottingham Unified Wheelchair Basketball



# Adapted Winter Sports Day: Syracuse Parks and Recreation

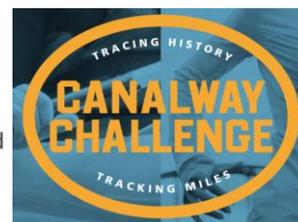


# On the Trails: NYS Erie Canalway Tourism Collaboration



## Start rolling with your Virtual 1st Mile!

Choose from Peloton-style videos filmed in Central New York and the Greater Rochester area. Complete your 1st Mile and keep going!



# Syracuse Parks and Recreation

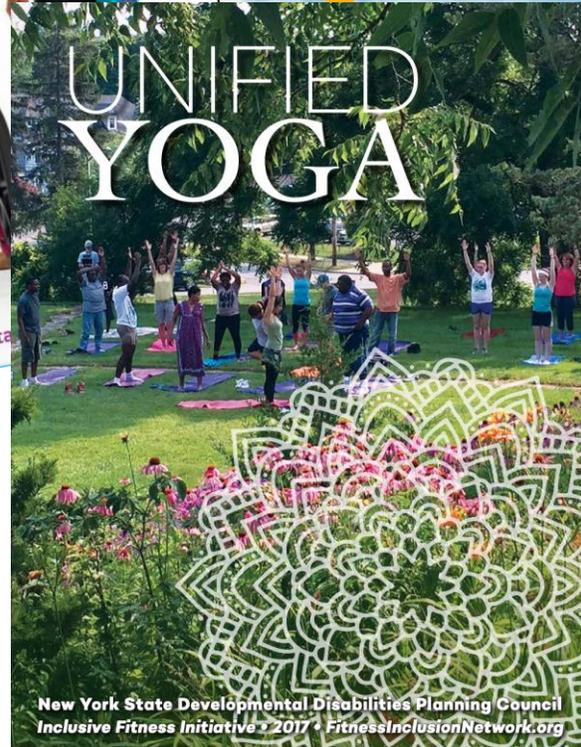
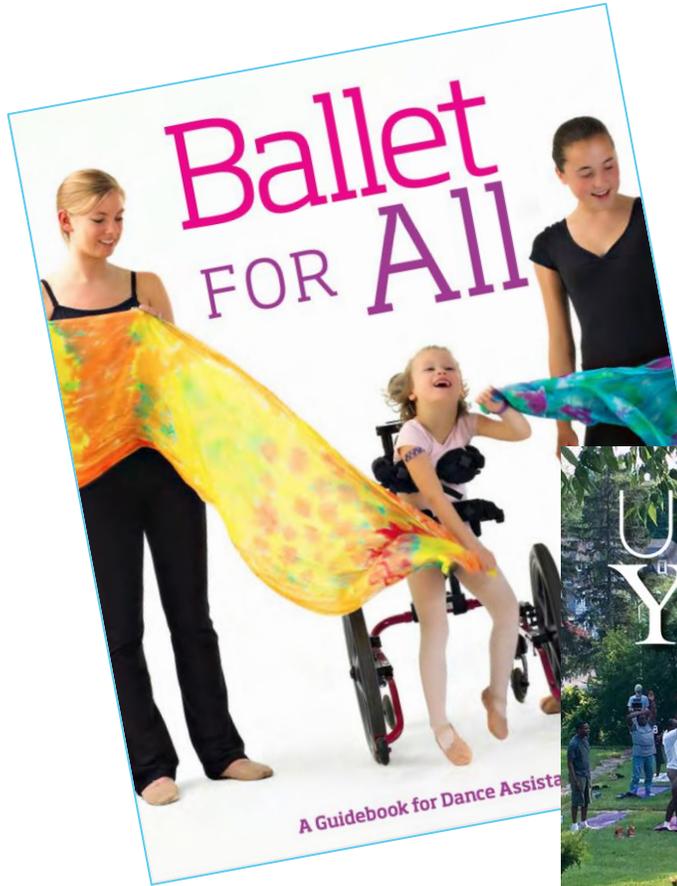
Power wheelchair charging stations

Accessible kayak launch sites

Adaptive cycle loan closet

Transportation summit: accessible public transport to parks





# What we learned

- ▶ High school students are change agents
- ▶ Excellent service-learning opportunity and career pathway
- ▶ Flexible funding allowed us to boost grassroots initiatives
  - ▶ Networks are nimble! “Institutes” and “Centers”, less so...
- ▶ It is easy to get grants for small projects
- ▶ Persistence pays off: City now funds several of our programs (sustainability)

# Community-Centered Care in Syracuse

1. Group Visits 2010-2018
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# ADA Weekend Workshop Syracuse, June 2016



**Adaptive Design**  
association, inc.

ABOUT FABRICATION EDUCATION REPLICATION HOW YOU CAN HELP

- Overview
- Courses
- Learning Library
- Internships
- Presentations and Lectures
- In The Classroom



03.3 - Cutting Basics - Cutting with a jigsaw



03.4 - Cutting Basics - Cutting with a bandsaw



**BENDING**

04.1 - Bending - Bending single-wall cardboard



04.2 - Bending - Bending triple-wall cardboard



# Adaptive Design Association



**Adaptive Design**  
association, inc.

Founded in 1981 by Alex Truesdell, who was recently honored with a MacArthur genius Award. This non-profit, based in NYC, has for 35 years focused on producing customized adaptive designs in a range of affordable and readily available materials.

# Paradigm shift



*“Our purpose is to investigate a revolutionary shift, one where we reject barriers and segregation and choose instead to imagine and build custom adaptations: where we share designs and stories; and where we respond to difference and disability, not with fear or neglect but with solidarity and love”*

# Materials

- ▶ Triple-ply cardboard
- ▶ Exacto knife, jig-saw
- ▶ Paper and glue for edging
- ▶ Water based paint and polyurethane varnish



# Six Principles of Fabrication

1. Safe
2. Needed
3. Wanted by the user and the team
4. Attractive
5. Durable
6. Low cost materials that are eco-responsible



*“Creating custom adaptations is a great joy. It is also a great responsibility”*

**Co-creation: ownership, trust, responsibility**

# Responsibility vs. Liability

Consider liability of current DME model: Toddler does not have timely access to custom equipment for motor learning, social participation, and play. What are the consequence of this on brain development?

*“Difficulties in movement, timing, and attention control are common in children with spina bifida. Encouraging the child to initiate and respond to environmental contingencies that require action may facilitate the development of assembled processing among children with spina bifida.”*

Fletcher, 2008

# Parapodium



# Custom Seating



# Activity table to promote bimanual play



# Early access to power mobility (up-cycle)



# Lightweight portable steps to access kitchen sink



# Why adaptive design?

Durable Medical Equipment

vs.

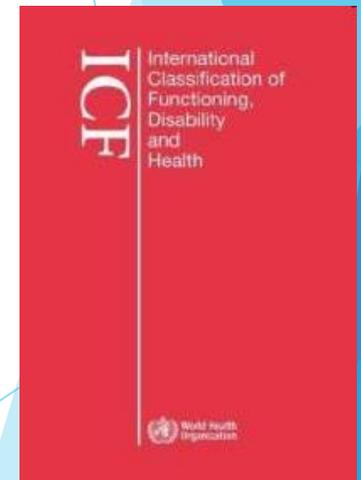
*Adaptive Design!*

Q: *Is it medically necessary?*

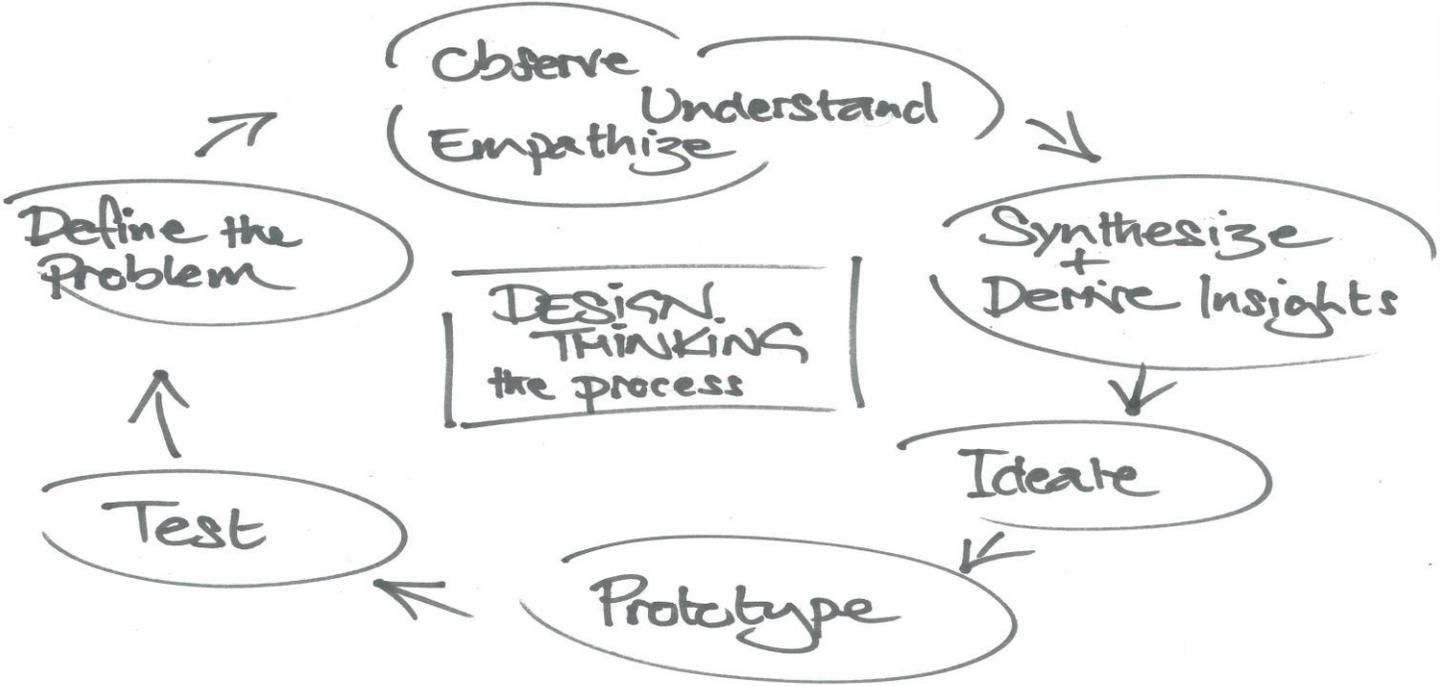
Q: *What do you envision for child?*

- ▶ Paperwork demoralizing
- ▶ Process is time consuming  
*Children rapidly outgrow!*
- ▶ Expensive
- ▶ Hard to modify

- ▶ Custom-made
- ▶ Low-cost materials
- ▶ Made on the spot
- ▶ Empowers families
- ▶ Builds community



# Design Thinking



## Adapted Design: modify things to improve their use



# Adaptive Design: co-creation, customized solutions



# Co-creation



Home made equipment solutions that promote physical activity and social participation!

*Design innovation informed by lived experience*

# Co-creation

bacteria. The recognition that sterility of the catheter was unimportant was provided by the patient herself: (Nurse Betty Lowe relates to Bloom that,) while traveling in Europe she dropped her sterile catheter on the floor of a public restroom and, unable to re-sterilize it, she simply proceeded with her catheterization with no ill effects." --



Lapides and Lowe (1971): clean intermittent catheterization

***Design innovation informed by lived experience***

# Arise Adaptive Design Maker Space at Regional Independent Living Center



# Prone stander and affordable power mobility for toddlers



# Adaptive Design and Community Centered Spina Bifida Care

## Equipment coordinator

1. Liason to PT/OTs in region
  - ▶ *Info on DME, alternative funding options, loan closets*
2. Tracks DME orders
  - ▶ *Community based quality improvement initiative*
3. Organizes design workshops
  - ▶ *Group Visit model*
4. Builder extraordinaire



The newest member of our multidisciplinary spina bifida team

# Beyond DME: Our equipment coordinator helps families to access community-based equipment solutions...

Charity

## Adaptive Design Association!

Loan Closet

Craig's List

504/IDEA (Schools)

Paying it Forward

Early Intervention

Academia

ADA

GoFundMe

Section 8 Housing



Spine Level	Possible Muscle Function	Possible Orthopaedic Concerns	Possible Orthotics Needed	Possible Equipment for Functional Mobility	Possible Cognition, Executive Function
T9-g	Upper trunk (abdominal) No UE function	Erythrocytosis Lumbar hyperlordosis Cervical/hip dysfunction Decreased bone density Pressure	11SD Night splints/body, hip adapters, SAE, AF	Community wheelchair wheelchair cushion, transfer board	Executive function impairments can impact education, social and self-care skills
T9-g	Abdominals + paraspinals = some pelvic control		Early P-axillary, (to months of age up to a year)	Home Walker/Couch (for household or exercise walking, Rained, padded seats) Bath bench Mats for chair-chairs Stander: 1 hour/day minimum starting at 10- months of age	Cognitive function can vary with the degree of hydrocephalus, and the involvement of the mesencephalic system. Function may not be related to level of lesion or ability to walk. Support early assessment of attention difficulties, sensory/motor integration, visual perception, visual motor ability, psychosocial development in addition to language and communication ability
L1	Complete trunk function Lower trunk (abdominal) Hip flexion (weak) L5	Contractures Hip abduction, flexion, external rotation Knee flexion, extension Foot: heelcord, clubfoot	Caution: Preserve UE function with foot transfer, stable seated posture Monitor energy + flexibility of shoulder/arms	Community wheelchair + cushion Home Stander: 1 hour/day minimum Early may use walker or couches Later wheelchair in home	Independent living: Occupational Therapy Goals: Basic activities of daily living (BADL) or bathing, dressing, grooming, bowel/ bladder program, etc. or home equipment: mechanical assistive of daily living (MADL) Shopping, meal preparation, use of home appliances, early learning/operation of all ADA is total
L4	Medial knee flexion L5 Ankle dorsiflexion L5 Hip abduction (weak) L5 Lateral knee flexion L5 Ankle inversion L5 Lung lift extensors (pape or arid)	Lumbar hyperlordosis Cervical rigidity Contractures Hip flexion Knee flexion (severe) avoid gait Foot: Progressive calcaneus (right handed) Calcaneus/heel Equinovarus-Clubfoot Perilytic Vertical Talus	Right hip abduction splint Early: Reposition (to months of age up to a year) Later: Stander, RCO, HKAFO, HKAFO (knee are less than L5 strength) L5 May be temporarily addressed by heeler cables or distraction straps	Community wheelchair: walker, cushions, cane Later: RCO, HKAFO, KATO, HFO (L5 + C/CAP) Home early on may need no support Later may require UE support	Physical Occupational Therapy Goals: Basic Goals 1. Achievement: Full ROM 2. Achievement: Full strength in most muscles for ADL's and mobility 3. Location: activities including ambulation skills: sitting, shower, getting up, walk on various surfaces, transfer to various surfaces (chair, car, bed), 4. Achieve maximal sitting tolerance with skin track 5. Achieve cardiovascular endurance 6. Ability to perform or direct care involving care + maintenance of vehicle + equipment 7. Obtain recommendations re: home modifications
L5	Medial knee flexion L5 Ankle dorsiflexion L5 Hip abduction (weak) L5 Lateral knee flexion L5 Ankle inversion L5 Lung lift extensors (pape or arid)	Lumbar hyperlordosis Cervical rigidity Contractures Hip flexion Knee flexion (severe) avoid gait Foot: Progressive calcaneus (right handed) Calcaneus/heel Equinovarus-Clubfoot Perilytic Vertical Talus	Right hip abduction splint Early: Reposition (to months of age up to a year) Later: Stander, RCO, HKAFO, HKAFO (knee are less than L5 strength) L5 May be temporarily addressed by heeler cables or distraction straps	Community wheelchair: walker, cushions, cane Later: RCO, HKAFO, KATO, HFO (L5 + C/CAP) Home early on may need no support Later may require UE support	Physical Occupational Therapy Goals: Basic Goals 1. Achievement: Full ROM 2. Achievement: Full strength in most muscles for ADL's and mobility 3. Location: activities including ambulation skills: sitting, shower, getting up, walk on various surfaces, transfer to various surfaces (chair, car, bed), 4. Achieve maximal sitting tolerance with skin track 5. Achieve cardiovascular endurance 6. Ability to perform or direct care involving care + maintenance of vehicle + equipment 7. Obtain recommendations re: home modifications
S1	Hip abduction L5 Hip extension (weak) L5 Pector flexion (weak) L5 Hip extension L5 Pector flexion L5 Toe flexion L5	Monitor hips closely Contractures Foot: Calcaneus (right handed) Calcaneus/heel Equinovarus-Clubfoot Perilytic Vertical Talus	HFO, SMO (bipartite) malleolar orthotics, shoe inserts or no restriction Toe: Tearing out gait Use of crutches may	Community walking with walker, cushions, cane Cane/Land Transfer/rolling gait aided by cane or crutches Long distance alternative	

Spine Level	Possible Muscle Function	Possible Orthopaedic Concerns	Possible Orthotics Needed	Possible Equipment for Functional Mobility
<p>88 and above: No aware of signs and symptoms of acute malnutrition and reduced bone mass</p> <p>Contributing Editors: Tim Bink, MD and Liz Kelly, PT</p> <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.</p> <p>www.spinabifidaassociation.org • 4150 MacArthur Boulevard NW, Suite 250, Washington, DC 20007 • 800-621-3141</p> <p>www.spinabifidaassociation.org • 4150 MacArthur Boulevard NW, Suite 250, Washington, DC 20007 • 800-621-3141</p>				

Set standards to facilitate access to DME (SBA Guide for Physical Therapists)

# The Triple Aim

## and Community Centered Spina Bifida Care



Decrease  
Healthcare  
Costs



Improve  
Population  
Health



Enhance  
Care for the  
Individual

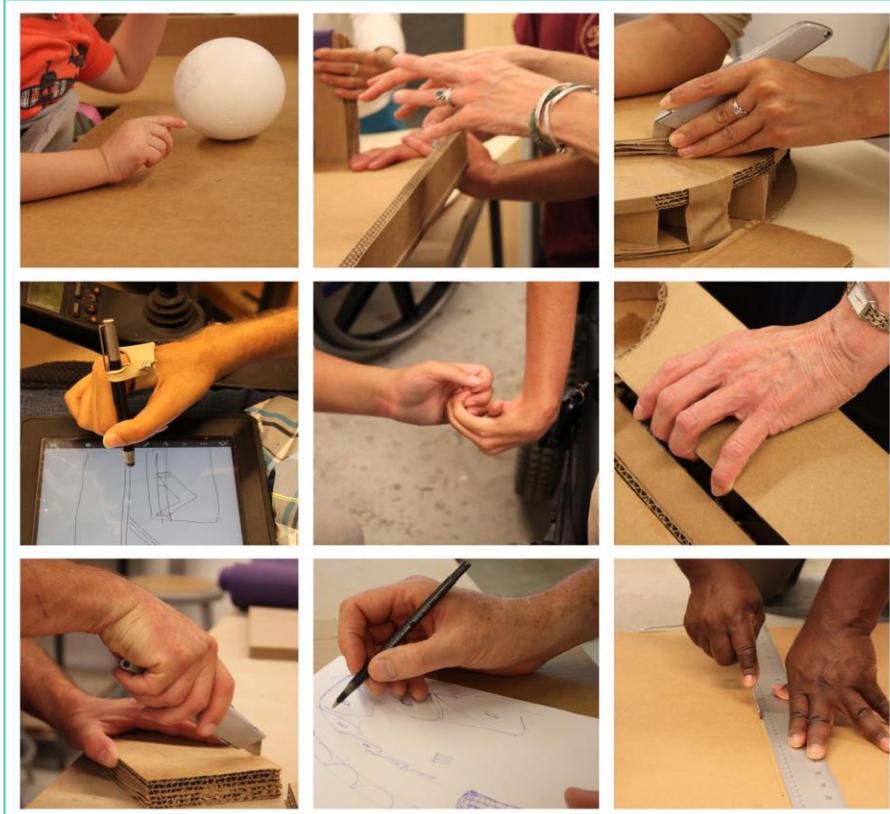
## *Think local!*

ADAPTIVE DESIGN ASSOCIATION:

- Decreases healthcare costs
- Improves health of SB population
- Enhances care for the individual

# The Quadruple Aim





# Community building



# Community building



# Community Awareness



# Reflection



# Reflection



[https://www.upstate.edu/specialneeds/pdf/buildingmobilityinsyracuseandbeyond\\_lowresversion.pdf](https://www.upstate.edu/specialneeds/pdf/buildingmobilityinsyracuseandbeyond_lowresversion.pdf)

# Historical context



**19<sup>th</sup> century:**  
local, handmade, affordable



**20<sup>th</sup> century**  
manufactured, expensive



**21<sup>st</sup> century**  
local, handmade, affordable

# Global context



**19<sup>th</sup> century:**  
local, handmade, affordable



**20<sup>th</sup> century**  
local, handmade, affordable

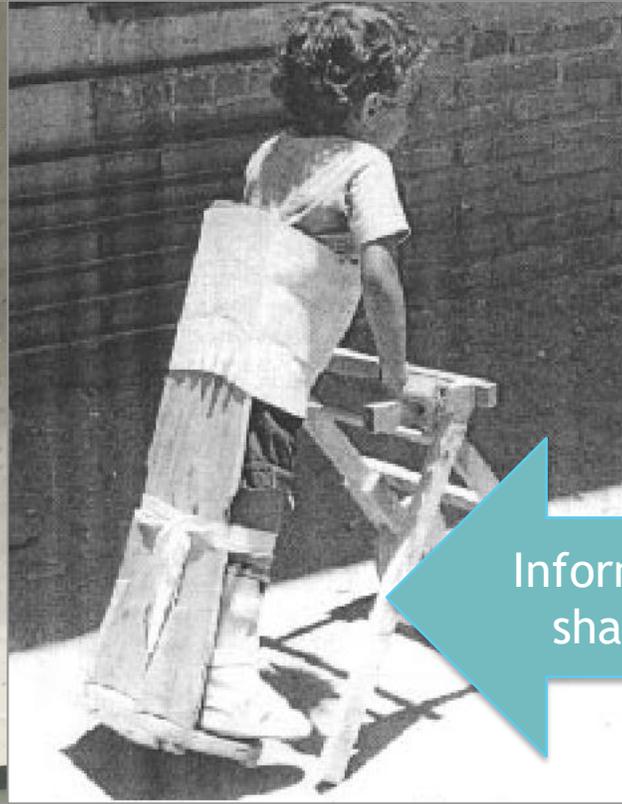


**21<sup>st</sup> century**  
local, handmade, affordable

# Global context



**19<sup>th</sup> century:**  
local, handmade, affordable



**20<sup>th</sup> century**  
local, handmade, affordable



**21<sup>st</sup> century**  
local, handmade, affordable

Information  
sharing!

# Local/Global Information Sharing



# Crowd source design thinking...



# ...for community centered solutions

 **motivation**  
FREEDOM THROUGH MOBILITY

[Who we are](#) | [Our wheelchairs](#) | [Our work](#) | [Do something](#) | [Latest](#)

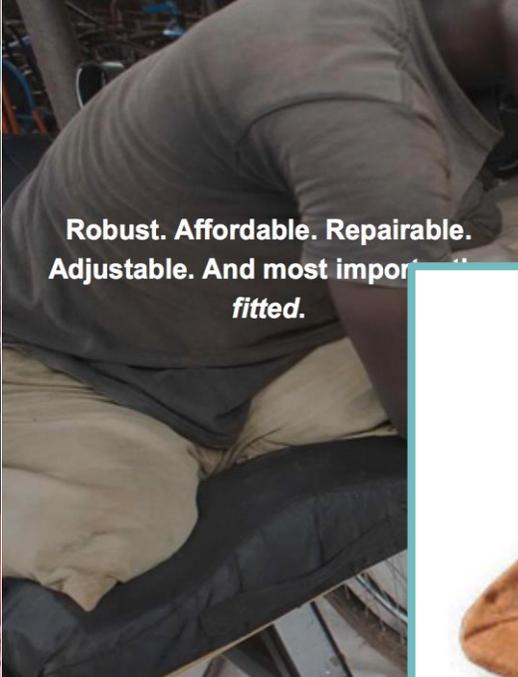
## A Tanzanian Journey

Meet the mothers who are overcoming community discrimination...



 **motivation**  
FREEDOM THROUGH MOBILITY

Robust. Affordable. Repairable.  
Adjustable. And most importantly,  
*fitted.*



seat cushions made of local materials  
coconut fiber and natural rubber latex



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

Construyendo Comunidades Locales/Globales de  
Espina Bifida con Diseño Adaptado



## **Construyendo Comunidades** **Locales/Globales de Espina Bifida** **con Diseño Adaptado**

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





Families gather at Prótesis Imbabura to talk about medical care for their children and adaptive design solutions for seating, mobility, play and learning.



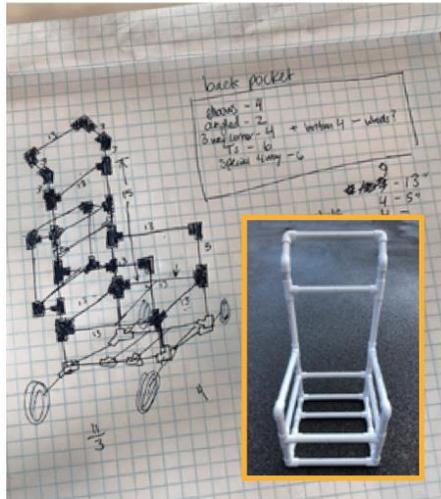
Participants shared a meal and celebrated the Local/Global Community at La Casita Cultural Center in Syracuse, New York.

<p><b>1.</b> <i>Local/global communities are driven by youth leaders such as Caleb and Stephanie.</i></p>		<p><b>2.</b> <i>The community based design team is formed around the family. The Spina Bifida Center inspires interest in design solutions.</i></p>		<p><b>3.</b> <i>Locally available low cost materials such as cardboard are used to create custom designs.</i></p>
	<p><b>4.</b> <i>Weekly skype calls allow design teams in Ibarra and Syracuse to share ideas and demonstrate building techniques.</i></p>		<p><b>5.</b> <i>Home visits enable design teams to observe a family's challenges, to record ideas, and to take measurements.</i></p>	
<p><b>6.</b> <i>Builds take place in the community and include pot luck meals to encourage bonding.</i></p>		<p><b>7.</b> <i>Families analyze and record use of the design at home for additional modifications.</i></p>		<p><b>8.</b> <i>Design solutions are shared both locally and globally via social media and the Spina Bifida clinical care network.</i></p>

# Liz, Christina, Stephanie, Caleb, and Peyton

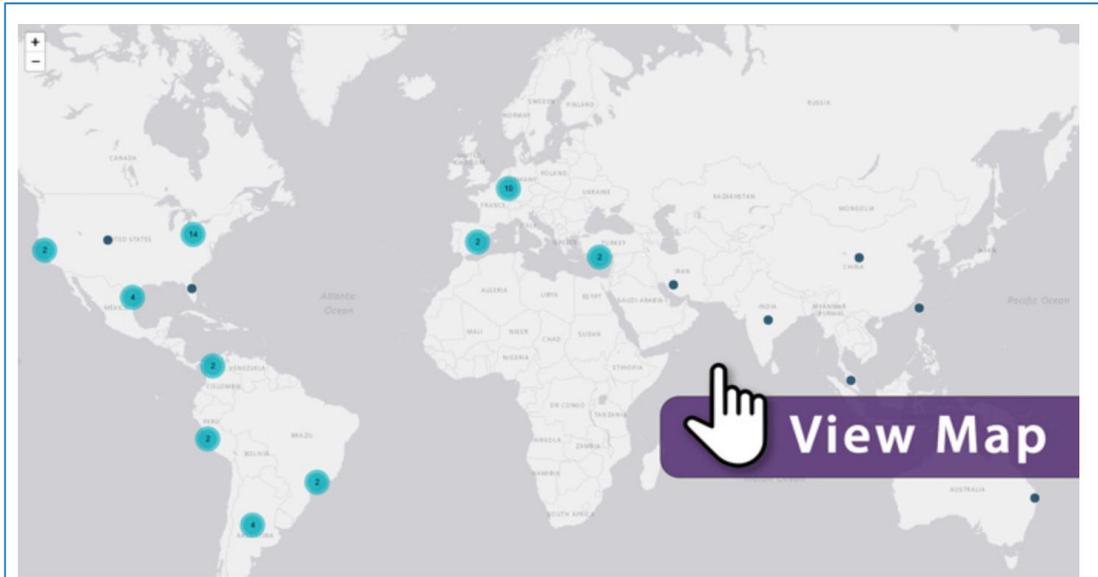
Everyone likes the beach. Not all beaches are accessible. Wouldn't it be great to have a portable beach chair?

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



# Spina Bifida Care: Local/Global challenge

Link highly technical and specialized surgical care with community-centered spina bifida care



## Fetal Surgery for Spina Bifida

Dosa NP, Ahmed YS, Alriksson-Schmidt A, Castillo H, Contepomi S, Locastro MM, Koning J, Koutsouras G, Kutwa E, Mahorta A, MacFarland S, Öhrvall AM, O'Neill P, Overvelde A, Peny-Dahlstrand M, Shaw A, Stockman J, Tovar-Spinoza Z, Castillo J. *Spina Bifida Global Learning Collaborative: Educating the next generation of clinicians, researchers, and advocates*. *J Pediatr Rehabil Med*. 2023;16(4):657-663. doi: 10.3233/PRM-230037. PMID: 38143399; PMCID: PMC10789363.

# What we learned

- ▶ Working together with families builds community
  - ▶ Our Adaptive Design program supports both “bridging” and “bonding” social capital
- ▶ Adaptive Design is “in the air” and can be readily linked to STEAM initiatives
- ▶ Art/Engineering perspective is refreshing for clinicians: Solution oriented!
  - ▶ Not DME paperwork!
- ▶ Great potential for local-global innovation via information sharing

# Community-Centered Care in Syracuse

1. Group Visits 2010-2018
2. Fitness Inclusion Network 2012 ->
3. Adaptive Design Association 2016 ->
4. AT Village Advocacy 2021 ->

# AT Village



#1 Gripe about accessing  
equipment -

The amount of time it takes  
to get equipment - Need is immediate  
but approval takes months.

# Durable Medical Equipment:

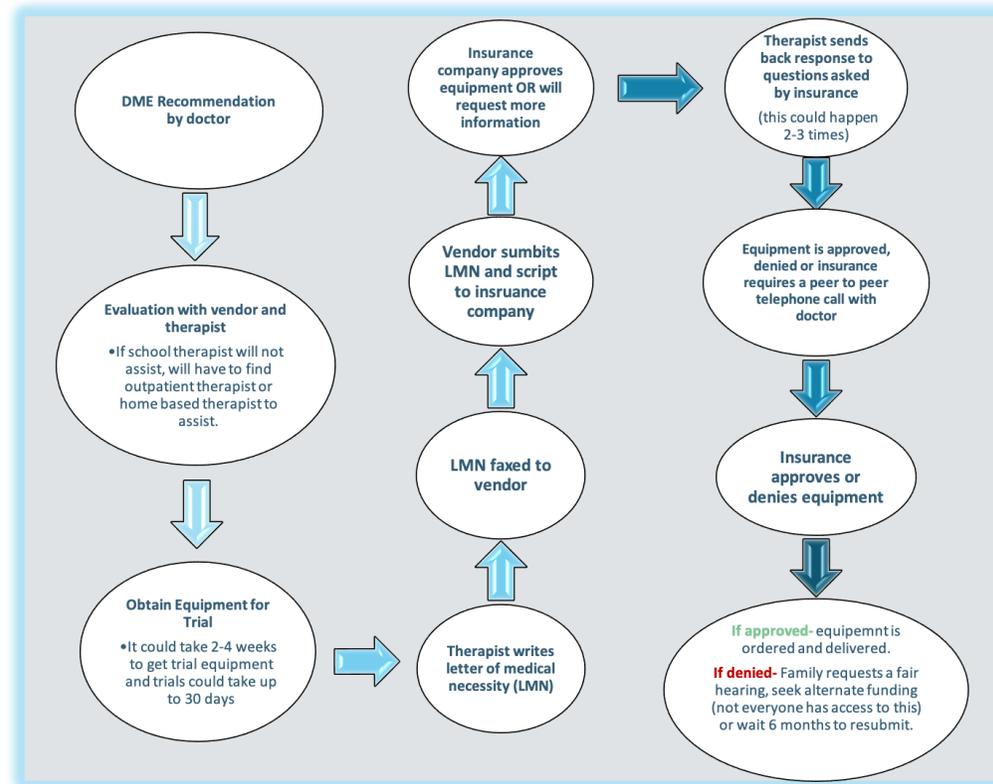
Process for obtaining DME is complex, confusing, negative

Lots of steps

Lots of people

- ▶ Family
- ▶ Physician
- ▶ Therapist
- ▶ Care manager
- ▶ Vendor Administrative staff
- ▶ Assistive Technology Professional
- ▶ Insurance Reviewer

Lots of paperwork

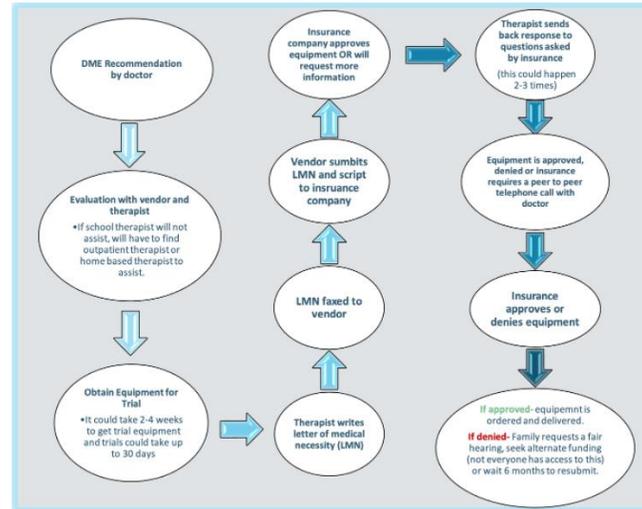


# Medical Model

Rx →



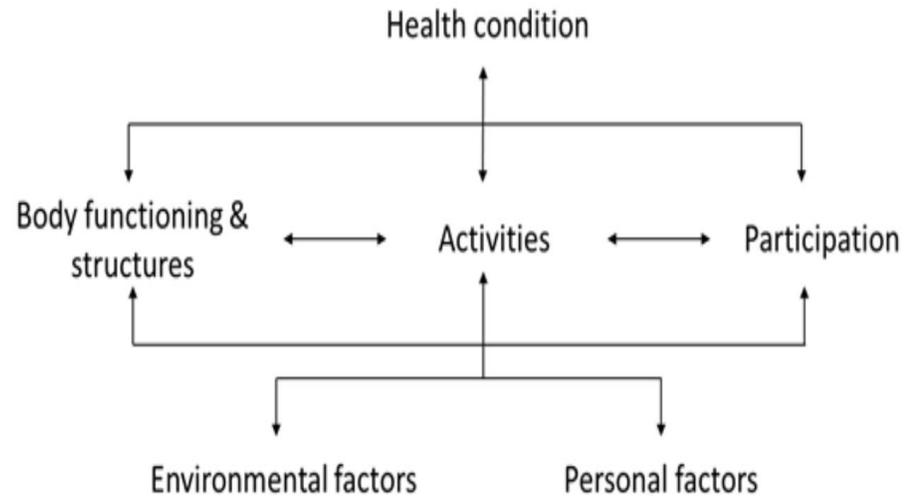
Rx →



DME is not a pill!



# Social Model



International Classification of Functioning, Disability, and Health : ICF. Geneva:World Health Organization, 2001.

# Health consequences when DME delayed

Pressure sores in adult with spina bifida

ED visits for autistic teen with escalating behaviors

Osteoporosis in child with cerebral palsy

Missed school days/social isolation

# Health Care Costs and Utilization

Health Service	% Utilizing	% of total spend
Medical equipment	17	0.8
Home health care	3	1.6
Testing	55	1.8
Primary care	60	2.2
Emergency care	32	3.1
Outpatient therapy	22	4.7
Medications	90	13.4
Specialty care	66	25.1
Hospital care	13	47.2

Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood)*. 2014;33(12):2199-2206.

Solution: Social Networking

# Paradigm Shift



# Assistive Technology is Rx for Participation



# All technology is assistive technology



“...when we make adaptations a matter not only for individuals but also for societies, we can choose to let tools for assistance be unifying, giving all of us the power to envision abilities and inclusion...”

# Jason



Locastro M, Robinson J, Robinson E, Dosa NP.  
*It Takes a Village: Building Community With  
Assistive Technology.* Pediatrics. 2022 Aug 1;  
150(2):e2021053623.

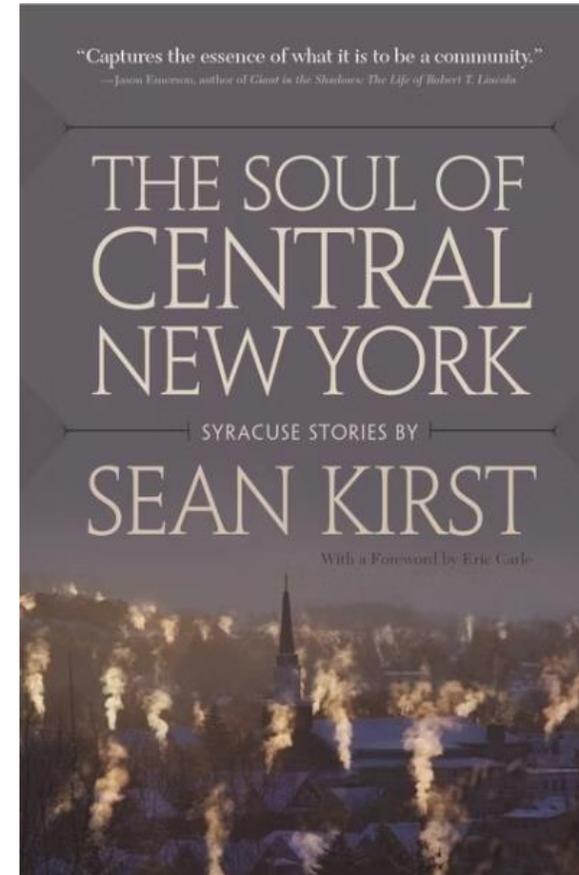
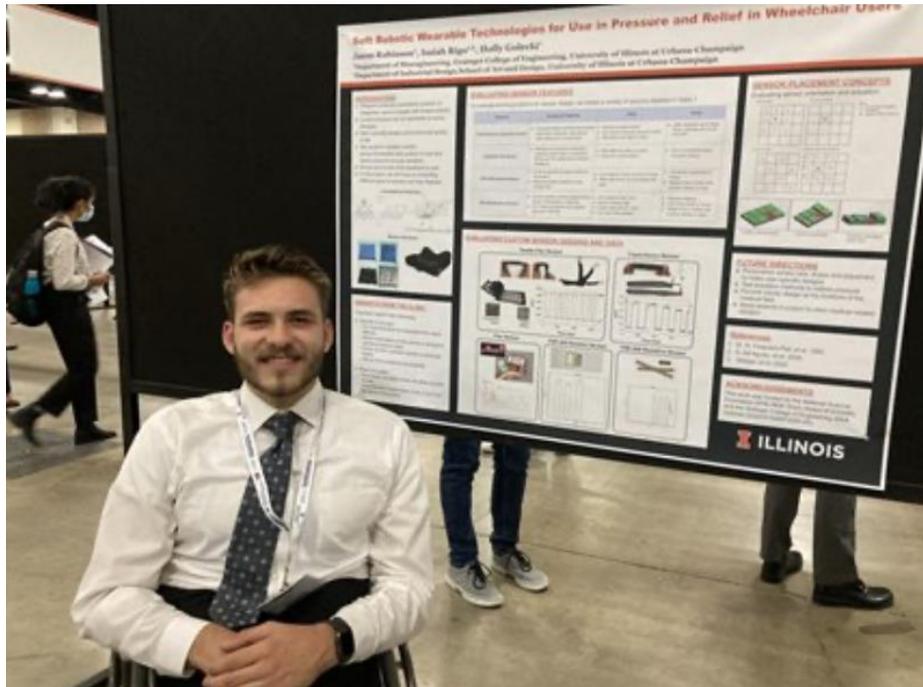
# AT Village Paradigm

	Maker Spaces	Loan Closets	Sports & Recreation	DME Advocacy
<b>Examples</b>	Arise Adaptive Design Makers Making Change Go Baby Go! E-nable	JRob Foundation TRAID Program Facebook equipment share	On the Trails Cycle Fair Erie Canal Tourism NYS CNY Adaptive Sports Unified WC Basketball Ballet for All	Establish community standards for timely delivery
<b>Partners</b>	School STEAM Programs Designers and Engineers	Libraries Schools Parks DME Vendors	Libraries Schools Parks Sports Community Independent Living Ctrs Hospital Systems DME Vendors	Independent Living Ctrs Disability Rights New York DME Vendors
<b>Roadblocks</b>	Liability	Liability	Liability	Prior approval repairs Vendor monopoly Disincentives to refurbish
<b>Facilitators</b>	IDEA Section 504 ADA	IDEA Section 504 ADA	IDEA Section 504 ADA  Professional certification	Right to Repair Killian's Law Gold Pass

**Policy**

# What we learned

- ▶ Effective advocacy = sharing our stories



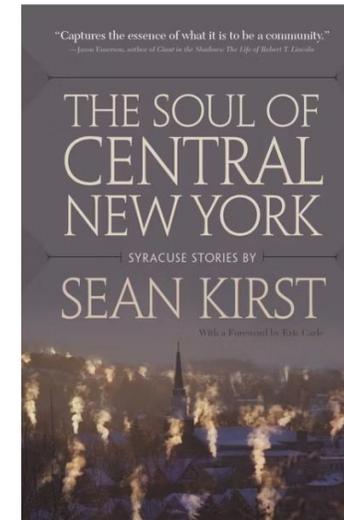
Policy

# “It takes a village”



# Community-Centered Spina Bifida Care

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<https://www.upstate.edu/specialneeds/departments/inclusive-fitness-adaptive-design.php>