What are you doing in your practice to connect CYSHCN and their families to community resources?
Case Example

- Referred to Early Intervention @ 18 month WCC
- Started with SLP, PT, and OT within 2 months of visit
  - 33%+ delays in adaptive, cognitive, language, social-emotional, and fine motor domains
- Formally diagnosed with Autism Spectrum Disorder per DBP evaluation within 4 months of visit
  - Lab, MRI, and EEG evaluation obtained and negative

- Now what???
So many of our friends’ kids are receiving occupational therapy or physical therapy. My son is very coordinated, but could there be any reason he needs it?
AAP Policy

- Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs
- Council on Children With Disabilities
- Pediatrics 2005;116:1238-1244
Community Resources
Philadelphia Roots

- The Children’s Advocacy Project of Philadelphia (Cap4Kids)
- Developed in 2004
- Pediatrician and 2 pediatric residents
- Purpose: to help busy practitioners learn more about social service agencies, advocacy programs, and laws in their geographic area.
## The Research - The Users


<table>
<thead>
<tr>
<th>Role</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatrician</td>
<td>41</td>
<td>(12.5%)</td>
</tr>
<tr>
<td>Pediatric Resident</td>
<td>63</td>
<td>(19%)</td>
</tr>
<tr>
<td>Pediatric Specialist</td>
<td>6</td>
<td>(2%)</td>
</tr>
<tr>
<td>Family Practitioner</td>
<td>2</td>
<td>(0.5%)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>82</td>
<td>(25%)</td>
</tr>
<tr>
<td>CBO Staff</td>
<td>43</td>
<td>(13%)</td>
</tr>
<tr>
<td>(Community based organization)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>38</td>
<td>(12%)</td>
</tr>
<tr>
<td>Teacher</td>
<td>33</td>
<td>(10%)</td>
</tr>
<tr>
<td>Question skipped</td>
<td>19</td>
<td>(6%)</td>
</tr>
</tbody>
</table>
The Research

Pre-CAP4Kids Knowledge

- Very knowledgeable 29 (9%)
- Knowledgeable 70 (23%)
- Average knowledge 92 (30%)
- Familiar with a few CBOs 67 (22%)
- Not at all knowledgeable 49 (16%)
The Research
Post-CAP4Kids Knowledge

- Much more knowledgeable 50 (17.5%)
- More knowledgeable 156 (54.5%)
- Know a few more CBOs than prior 66 (23%)
- No more knowledgeable 15 (5%)
Philadelphia Study 2006
Educational Tool

- Excellent: 127 (43%)
- Above average: 116 (39%)
- Average: 29 (10%)
- Poor: 0
- Unsure: 25 (8%)
User Feedback

“I am often finding out more things every time I visit the Cap4Kids site. I often use it as a starting point because it is rare that after I visit the site that I would need to search elsewhere.”

“I am glad that there is a doctor that recognizes the need to be involved with other community based organizations and who has a grassroots approach. Thank you for your advocacy. I hope other doctors follow in this philosophy.”
“A wonderful site!! Has truly helped my patients tremendously. Has made me a much more effective and complete pediatrician.”

“This is a resource that should exist in every city in America, regardless of size. Every parent in the Delaware Valley should be told about it.”
The Spread of CAP4Kids

CAP4Kids has since spread to many locations across the nation including Baltimore, Columbus, Hawaii, Kansas City, Miami, New York City, Penn State, Pittsburgh, St. Louis, Utah, … and now ROCKFORD!
Winnebago and Boone Counties have...

>250 Child-Related Service Agencies

And now 1 Website coordinates them all

with 22 Categories

http://cap4kids.org/rockford
Mission Statement

To bridge the gap between the many quality social service agencies in Winnebago & Boone Counties and the families and children that need their help the most.
Secondary Goals

➢ To educate healthcare and social service providers, as well as parents and other community members, regarding the multitude of service agencies dedicated to serving children in our area.

➢ To identify areas of need in our community that can potentially be addressed with new, innovative, & evidence-based programs.
CAP4Kids Rockford equation

Dr. Schulz’s interest

+ Judge Holmgren’s Prenatal-6 task force

+ Crusader’s support

+ Many community organizations’ efforts

A true community project!
Timeline

August 2010
- Started at Crusader

Fall 2010
- Met with Judge Holmgren and Prenatal to 6 task force members
- Enlisted help of two 2nd year UICOM-Rockford medical students (required community project)
- Enlisted help of community members and organizations to research, review, and refine website resources (via task force connections)

April 2011
- Site completed
- Press conference kick-off

July 2012
- Formatting change
Sponsors

-Crusader Community Health, Winnebago County Health Department, The Prenatal to Six Committee of the 17th Circuit Court, University of Illinois College of Medicine at Rockford, Rockford Health Council, University of Illinois Division of Specialized Care for Children, Easter Seals, Youth Services Network, United Way of the Rock River Valley, United Way of Boone County, Early Learning Council, Rockford College Early Childhood Program, Actual! Authentic Solutions, Come Together Rockford, Rockford Mental Health Association, City of Rockford Health and Human Services Department, The Workforce Connection, Rockford Public Schools District #205, Hoffman Law Office, Ltd., Winnebago County Juvenile Probation, Rockford Public Library, Roosevelt University

Thank you all for your efforts!!
Getting the word out!

- Press Release
- Website newsletter article
- Website PowerPoint
- Facebook Page
- Email: CAP4KidsRockford@gmail.com
- Mailing list
- Word of mouth
- Presentation circuit
- Panel card/magnet promotion (Nov 2011)
  - All public Winnebago & Boone County schools
  - Crusader/WCHD
  - Also available on the website!
Successes

- Great community buzz and support
- Currently averaging ~1,000 hits/month
- Helped secure an Illinois Maternal, Infant and Early Childhood Home Visiting (MIECHV) grant for Winnebago County
- Resource/tool for development of 211, an on-going community mapping project, Early Learning Council’s pediatric system of care, and other community projects
- Many individual child and family successes!
Resources for Implementation

- [http://cap4kids.org](http://cap4kids.org)
- [http://www.211.org](http://www.211.org) (United Way)
- Already existing agencies & lists:
  - Hospitals
  - Health Departments
  - Pediatric Residency Programs
  - Local Community Based Organizations