



Cerebral Palsy Collaborative of Western New England

Symposium of Clinicians, Researchers, and Community Agencies June 23, 2017

Executive Summary

On June 23, 2017 clinicians, researchers, and community agencies from Western New England gathered at the Shriners Hospitals for Children for the first annual symposium. This symposium brought together representatives from families, academic institutions, healthcare organizations, and local agencies in the area to:

- Discuss how we currently meet the needs of individuals with cerebral palsy
- Identify needs for clinical care, research, and education
- Improve how we are working together

There were approximately 30 participants representing more than 10 institutions or agencies in the greater Hartford, Springfield, and Berkshire regions. The morning consisted of 15 presentations about the challenges, successes, future visions, and needs for services, research, and education.

The afternoon consisted of Word Café roundtable discussions of the strengths, weaknesses, opportunities, and threats to improving services, research, and education for empowerment of providers, individuals, and families.

In the paragraphs below, we summarize the themes, topics, and ideas generated by the brainstorming sessions.

Strengths

Perceived strengths included the themes of individual and organizational desire to collaborate; being within an environment and region that supports collaboration to build better services using a systems approach; availability of technology that facilitates collaboration and success; available clinical, research, and education capacity; and a regional culture that supports collaboration and recognition of disability as an important social context. Individual desire to collaborate was expressed by all participants; passion for this issue crossed the backgrounds represented at the symposium, which was described as a collegial environment. Organizational desire was expressed through a recognized overlap in the mission of medical and community programs. The presence of organizational leaders committed to driving change was recognized, as was institutional support for community health needs assessment and program development in collaboration with community partners. The symposium was identified as the start of a multidisciplinary, multigenerational conversation with the ability to break down silos and make a significant contribution to improving the excellence of regional care for people with cerebral palsy. This was supported by the existence of family advocacy for change and development of new programs.

A second strength identified was that the environment supports collaboration efforts to build better medical and community services. There is a recognized need within the region that care for people with cerebral palsy is underserved. The region has a high population density in many areas, with close geographic proximity, making transportation easier in all but the outlying areas, which are quite remote. The health care facilities, CCMC and SHC, both have strong brand names with a lot of regional recognition, strength, and quality. Medical services lines are cognizant of, but not well integrated with community services. Both Connecticut and Massachusetts have high rates of insured children and good support

within the Medicaid system in both states. Care coordination within the states is improving, but not strong. The built environment is mixed, with aging housing stock and neighborhoods in Hartford and Springfield; however, the institutional built environment is strong with good capacity for health care services and meeting spaces.

Availability of technology was identified as a strength in the region, which boasts two state of the art motion analysis centers, providing good opportunity for quantitative comparative effectiveness research. Other technology, such as communication via web, teleconferencing, and skype are available, however institutional policies limit use for patient care conversations. Accessible technology is available from multiple community partners including United Cerebral Palsy, who have a formal program to distribute accessible technology within the region.

The region has clinical, research, and educational capacity that is backed by strong community support. Intellectual capacity is demonstrated through the many educational institutions in the region that participate in care of youth and adults with cerebral palsy. Research expertise is present at the University of Hartford, CCMC and SHC, with a dedicated grant program available through SHC for single and multisite studies. Medical expertise in developmental pediatrics, pediatrics, orthopaedic surgery, physical medicine and rehabilitation, physical and occupational therapy, and other specialties are available within the region and represented at the symposium. Among the group of researchers, educators and clinicians, the perception is that there are creative thinkers who want to collaborate. Additionally, the regional educational institutions are interested in preparing their students for early exposure to clinical programs and clients through integrated clinical experiences (ICE).

The final strength identified was a regional culture that supports collaboration. The culture of the Northeast is perceived as progressive and inclusive, and values helping people in need. Because of these values, it is perceived there is less stigma associated with disability that leads to improved communication. This is operationalized in increased ability to fundraise for efforts related to disability, increasing the philanthropic capability of the region, as well as availability of volunteers.

Weaknesses

The following issues were reported by the group:

1. Health care system

- a. Medical providers not focusing on the home environment
- b. Institutional focus on productivity
- c. Isolations: medical/clinical/academic/recreation – do we talk to each other?

2. Navigation of the system from the time of diagnosis

- a. How do families know what is available?

For example, the Center for Human Development, Jewish Community Center, Shriners Hospitals for Children, and Connecticut Children's Medical Center.

3. Research

- a. Funding: There are smaller grants – we need them to be BIGGER
- b. Time: we are focused on productivity and this does not bring in money (tone management meets during everyone's lunch hour)

4. Housing restrictions/access

5. Medical Providers

- a. Doing only a moderate job with future expectations

6. Geographic Mindset

- a. How do patients take advantage of local opportunities and beyond?
- b. "Touting" our program as "the only one", "the best kept secret" may be doing the system a disservice

7. Language barriers

- c. Spoken language, non-verbal

8. Access

- a. Based on GMFCS levels – more involved = less access, but more involved = more services
- b. Socioeconomic status challenges – more affluent = greater resources

9. Parent education variability

- a. Degree related: higher degree = better system navigation
- b. Regarding child specific disability – related to information shared

10. Parent Resources

- a. Do they have extended family to help/respice?
- b. Facilitated family discussions/sharing of health information
- c. Do they have social supports for help/respice?

11. Caregiver health throughout the lifespan

12. Transportation

- State by state variables
- Modifications to personal vehicles
- Public transportation

13. Stigma

- Ortho is cool, neuro, mental health is not
- “Labelled”
- “Fear of”, “feeling of intimidation”

14. Insurance

- Variability among insurance providers

Opportunities

We recognize tremendous possibility and many opportunities to positively impact the lives of children, adults, and families by extending the reach and impact of our individual services through coordination and collaboration. Our conversations about opportunities revealed our own understanding of the greatest needs of this population as well as a strong interest in partnering with children, youth, adults, and families to learn more fully about their experiences and needs. We want to hear their stories and present-day experiences with living with cerebral palsy. We are interested in learning more about their personal successes, challenges and needs in daily life in order to develop programs and supports that support improved participation and quality of life.

What is the ideal?

We want to get the word out and highlight the successes of our programs to eliminate the “best kept secret” effect. We propose that this may be most effective through events which feature “whole life” activities and experiences rather than more traditional booth-oriented informational events.

We want to see a more integrated continuum of care that incorporates social skills training, a focus on the development of a positive self-image, and community based fitness and participation programs in all healthcare and educational services. We identified four key factors necessary to accomplish this:

1. Easy and clear access and navigation for healthcare services at all ages and particularly around the transition to adulthood.
2. Easy and clear pathway to access and navigate community programs for children, adults with CP and their families. This includes better access to practical knowledge and opportunities for knowledge sharing for families.
3. Easy and clear process for providers to integrate community program referral or recommendations to “extend the plan of care” in their clinical practice.
 - Focus on integrating fitness in the plan of care from the beginning with referral or recommendation at discharge
 - Include focus on support for developing social skills and a positive self-image
 - Better access to practical knowledge and opportunities for knowledge sharing for providers.

4. Engaged educational organizations (schools, after school programs, etc) willing to partner with community programs to incorporate fitness, social skills, and other community program services where children are during most of their day.

A variety of strategies, events, projects, and programs were proposed to address these priorities. Three categories of opportunities emerged in the discussion: 1) questions we are asking, 2) actionable ideas for the collaborative, and 3) actionable ideas for individual organizations.

Questions we are asking:

- How do we support children and families in making that first phone call to follow through on recommendations of healthcare provider to transition to community programs?
- How can we build capacity for peer to peer support (child to child, adult to adult, caregiver to caregivers) in multiple formats and for access on multiple devices?
- How can we support organizations in providing structured time for parents to connect at child-focused programming?
- How can we support parent/caregiver advocacy capacity and efforts?
- How can we support child/youth advocacy capacity and efforts?
- Are there opportunities to solidify a bigger network for fundraising through the Cerebral Palsy Collaborative of Western New England?
- When and how should we connect with policy makers such as our local and state board of education, insurance companies, accountable care organizations (ACO), state representatives and senators, local government and government agencies?

Actionable ideas for the Cerebral Palsy Collaborative of Western New England:

- Establish and support more systematic sharing of information among providers and parents/children in web-based, live, social media formats
- Develop visual materials for social media, regular media to promote positive self-image among youth and adults with cerebral palsy.
- Develop tailored materials to educate children, youth, caregivers, medical community about transition to adulthood. (AAP has developed this for pediatricians and may be a good resource here)
- Support multi-disciplinary research collaborations among sub-specialty medical providers
- Support multi-site research incorporating community programs to investigate the process of moving from medical to community services
- Establish a CP Collaborative brand and marketing tools to increase the impact of this group.
- Develop and maintain a database listing details of each organization, opportunities for participation, contact information, developing programs.

Actionable ideas for individual organizations:

- Display looped videos highlighting community programs in waiting rooms of medical organizations
- Provide links to community program webpages on medical organization's website
- Developed tailored social media materials and distribute to parent/caregiver/patient social media sites.
- Host community organization table displays at Walk-a-thons, other large events
- Develop and host a "kids as self-advocates" group with a synchronous time for parents to socialize and support each other. Parent component would likely need a facilitator.
- Establish partnerships and programs that link families with family support centers.
- Allow community programs to add the medical organization's logo to promotional materials

An over-arching theme of these discussions was the opportunity to including families and individuals with cerebral palsy in meaningful ways at every step of the process going forward.

Threats

Threats identified included social, physical, individual, and institutional barriers to providing the optimum quality of care to meet the needs of individuals across the lifespan.

Social barriers identified are as follows. Participants identified families may have a lack of understanding about the unmet needs of their family member with cerebral palsy as to the health, social, and emotional needs. Families are not accessing information, either because it is not available or there may be a language barrier. Families' priorities may be different than that of the providers, and may not include physical activity programming. Breakdown of the family unit and lack of social support for families of individuals with cerebral palsy also contribute to the ability of families to participate in additional programming. Additionally, families of low socioeconomic status and families who are working (life balance) may have difficulty with transportation or making appointment times for additional programing.

Other social barriers include the larger national political climate of budget cuts, public insurance changes, and the potential of major cuts to the educational and social services available to individuals with disabilities. There is a lack of a strong advocacy base in DC for individuals with CP; there is inadequate funding for CP specific research and no CP specific public policy.

Institutional barriers identified are as follows. Institutions do not provide a value or resources for providing the highest quality of care for individuals with CP. Providers do not have the time to develop and sustain high quality programs. Oftentimes there is a lack of depth of providers in providing high quality care, when a specific provider leaves, the program stops. Institutions also do not have a lifespan framework for the care of individuals with CP, but use an episodic care approach. Health care reimbursement for the management of children with CP does not support multidisciplinary clinics, and oftentimes the payment of services results in a loss to the providers. Care is fragmented, and there is inadequate sharing of information among providers who care for individuals with cerebral palsy at various institutions. There is no centralized medical record or ability to share medical information across institutions easily. Institutions do not have the space needed for clinics, programming, labs, and other services to provide state of the science of care. Excellent programming may also have a low turn out due to all the barriers to participation, and despite the high need are terminated due to the low participation.

Individual person barriers to receiving high quality care that includes the physical activity for the promotion of health and wellbeing include the following. The individual's health may be so fragile, that participating in additional activities outside the home or routine daily care may not be feasible. The individual may have significant pain that interferes with movement, transfers, or participation in various activities. The individual's severity of gross motor involvement may make vigorous exercise challenging to achieve.

Action Plan

Below we summarize the action plan as agreed upon by the participants.

What's Next?

- Develop a website or webpage
 - Build collaboration and connect
 - Develop branding/charter/organizational structure
 - Develop mission/goals/vision

- Leaders develop an executive summary
 - Send to group to validate
 - Add to webpage
- Consider expanding family/parent voice through a future forum focused on that population
 - Perform a SWOT analysis or similarly activity
- Add insurers, early intervention and other stakeholders
- Sponsor another event like the CP collaborative
- Complete and distribute the BFit Program Manual
- Bring community videos into the outpatient clinical environment
- Increase collaboration locally and regionally
 - Organization – agency – education
 - Care/education/research/recruitment
- Define and implement best practices
- Develop a database for resources/programs/expertise/research projects
 - Google map based app?
- Develop systematic research/program efforts
- Develop global goals and prioritize
- Broaden stakeholder involvement
 - Early intervention
 - Insurers
 - Education
 - Family
 - Send ideas to Mary
- Provide educational workshops after better understanding the needs of different stakeholders

Feedback on the Day

The group performed an alpha delta activity- we identified what went well for the day, and what we would change in the future.

The positive aspects of the day included that the group was multidisciplinary, the energy created by the brainstorming and sharing of perspectives, the organization of the roundtables especially the timing, the location of the activity at Shriners Hospitals (others could see the hospital), the delicious food, the space which was conducive to such a meeting format, the day of the week (Friday), the leadership team, and the discussion generated.

The aspects of the day that could be changed include broadening the group of stakeholders to include more family voices, insurance agencies, and other relevant stakeholders. Changing the timing of the symposium- this late in June was difficult as many were on vacation. A March meeting was suggested as March is Cerebral Palsy month. Possible agenda change to include some discussion in the morning to break up the day. Another suggestion was to change the location to another agency so that we can all get to view the various facilities in the region. Also a suggestion was to consider smaller, more focused and frequent meetings.

Goals for the Next 6-12 Months

1. Dissemination
 - a. Produce and distribute an executive summary
 - i. Leaders to Mary within 2 weeks
 - ii. Mary to group by 7/30
 - b. Produce and distribute a draft web page
 - i. by 9/1 (Mary)
2. Draft plans for a family forum/survey
 - a. Draft from Katie, Danni, Mary, Maria by 7/30
 - b. Pixie to summarize currently planned regional forums
3. Begin to compile and develop a database of regional resources
 - a. George, Paul, Sylvia – demo by 9/1
4. Host another CP Collaborative Meeting with expanded stakeholder representation
 - a. Mary, George
 - b. Host in March = CP Awareness Month

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