Parents Speak Out-3

Action Steps from Family Leaders to Advocate for Care Coordination

How we gathered the information

Several Beach Center staff spoke with family leaders from across the country about the care coordination practices in their respective states. It was clear from these conversations that the implementation of care coordination within a medical home model or outside of that model varies significantly across states. We compiled action steps from the family leaders that might be helpful for families in advocating for care coordination.

Beach Center on Disability
Making a Sustainable Difference in Quality of Life

10 Action Steps from Family Leaders

1. Become educated about care coordination.

A common theme across the conversations we had with the family leaders is that families are the ultimate care coordinator for their child. Families know their child best and are with their child 24 hours a day and throughout the lifespan. Becoming educated about care coordination will help you navigate the system and organize the different services to meet your child's and family's needs.

Below are a few resources to assist with this process:

- Medicalhomeinfo.org (http://medicalhomeinfo.org/)
- Medicalhomeplus.org (www.medicalhomeplus.org)
- Bright Futures (www.brightfutures.org)
- The Center for Children with Special Health Care Needs (http://www.cshcn.org/index.cfm) has care coordination tools available on-line: http://www.cshcn.org/resources/carecoordination.cfm. Some of the documents are available in Russian, Spanish, and Vietnamese.

2. Communicate effectively with service providers.

Communication is at the heart of care coordination. If you do not have access to a care coordinator, you will find navigating the system easier if you have open and effective communication with service providers.

- Think about questions you may have before going to the doctor. Write these questions down and take them with you to the appointment.
- If you forget to ask a question during the appointment time, follow up after the visit with a phone call.
- Contact your local family advocacy organization (e.g., Family Voices, Federation for Families, Parent to Parent, the Arc, Parent Training and Information Centers) to locate training on parent-professional partnerships.
- Bright Futures (http://brightfutures.aap.org/web/) created a pocket guide for families that provides information about parent-professional partnerships.

3. Explore your vision.

Every family struggles with the day-to-day stresses of work, relationships, and family dynamics. It can be overwhelming at times, making it difficult to think about the big picture. Taking a moment to plan for future goals and visions for your child and your family will help you articulate the services and supports needed to reach those goals.

- One tool to help articulate your vision for your child over the long term is the Group Action Planning (GAP) tool. Many vision tools, similar to this one, are available in the literature; we provide a link to a manual to learn how to conduct a GAP meeting. http://www.beachcenter.org/resource_library/beach_resource_detail_page.aspx?intResourceID=743&Type=Manual

4. Be willing to challenge the status quo.

- If care coordination is not offered in your child's physician's office, share why it would be helpful for your child and family.
- Provide specific examples of care coordination services in which you would like assistance (e.g., referrals to specialty doctors, finding medical equipment for your child, insurance denials).

5. Find out about existing practices that have adopted the medical home philosophy.

Most likely, not every practice in your area has adopted a medical home philosophy. Find out if there is a practice in your area that supports these principles for children with special health care needs.

- Talk with other parents who have excellent care coordination for their child or whose doctor implements the medical home philosophy.
- Interview the staff about strategies they used to implement the medical home philosophy and share these strategies with your doctor.
- Look for successful medical home practices or programs in other states; share those programs with your state Title V office and discuss what is possible to implement in your state. A promising model, Care Connection for Children, is being implemented in Virginia (http://www.careconnections.vcu.edu/).

6. Develop a care notebook or care plan.

A care notebook can be helpful in organizing all of the information about your child's medical and service needs. It is useful to share this notebook with your child's doctor, specialist, nurses, teachers, and other service providers who work with your child. Be mindful that this is a living document and will change as the needs of your child and family change.

- In some states, Title V programs have developed model templates for care notebooks. Check out the resources available within your state's Title V program by visiting your state Department of Health website.
- You could also use person-centered planning strategies to identify your child's and family's strengths and support needs.

7. Learn about roles of different case managers.

Each agency or system (e.g., developmental disability council, Medicaid waivers) are the gate-keepers to their programming and funding; each system will have a case manager.

- Learn about the roles and expectations of the different case managers with which you work related to the services they can provide.
- Spend time thinking about your own role in coordinating care for your child.

8. Advocate for coordinated care if you live in a rural community.

- Some states send specialty care to families in rural communities. Contact your local family advocacy organization to see if this might be available in your state.
- Some states and/or medical practices are using telemedicine to reach families that live in rural communities. Find out more about telemedicine (http://www.telemedicine.com/whatis.html); if this is something your family needs, work with your local family advocacy agency and provider to implement this process.

9. Understand and share reimbursement strategies with your child's medical providers.

Reimbursement of care coordination can be the biggest facilitator or barrier to medical practices offering care coordination services.

- Inform your general practitioner, internist, or pediatrician about how to get reimbursed for this service. To obtain information about CPT codes, follow this link: http://www.medicalhomeinfo.org/tools/Coding/Care%20Coordination%20Toolkit%2006.pdf
- Find out about grants or state funding initiatives that may be available to support care coordination within a medical home model in your child's doctor's office by contacting your local family advocacy organization.

10. Become active at the state level.

Across states, different types of stakeholders (e.g., doctors, family advocacy organizations, parents) take the lead in advocating for care coordination practices in their state.

- Link with different stakeholders to advocate for comprehensive and effective care coordination in your state. You may contact your state's family advocacy organization that focuses on health care issues. Visit the National Family Voices (http://www.familyvocies.org) and Parent to Parent (http://www.p2pusa.org) websites to find a local chapter in your area to learn about the care coordination efforts in your state.

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