

PARENTS SPEAK OUT-2

Family Strategies and Resources to Advocate for Care Coordination

On our [Community of Practice](#) website parents shared their perspectives in advocating for care coordination. Below are some comments from families you may find useful when investigating how to obtain care coordination for your child.

How can families best advocate for care coordination?

“...as advocates families need to call different clinics and check to see if there is a care coordinator before choosing a physician.”

“I found my doctor’s office through my national network when we were moving, and now that I am active with my local Special Education parents, fully 90% of the families use this practice – and those that don’t take the practices to their pediatricians.”

“I think that as parents network, they can find out by word of mouth which agency they would like to try.”

“...if we can get clinics that successfully implement care coordination to share how they do it with other clinics, we will be more likely to see good models of care coordination pop up.”

Beach Center on Disability
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“More agencies are being sensitive to consumer/family driven initiatives ...in the area of Maternal and Child Health with the Children with Special Health Care Needs program, Parent Advisory Groups and Parent Input is mandated by our grants.”

“Parents are speaking up and demanding better service. Each state has a parent advocacy group that provides regular trainings for families on how to advocate for their needs.”

“From my experience, the insurance company only makes the care coordination available after the parent asks for the service.”

“...there are some parents, providers, and concerned parties that are good at becoming involved in policy and politics. There are individuals that can see the problem, write a letter, and send it to the person in authority that can work towards the change they desire for their children and other children to follow. It has been a concern – disjointed services for children/adults with special needs. ...it has improved a little, slowly, with lots of voices...I have seen private pockets of people who work very diligently to meet needs. Even a little change can affect a system, so go ahead and tactfully advocate...for what is needed for your child/family.”

Action Steps

- Shop for providers who offer care coordination.
- Ask for care coordination, it may only be available to those who ask.
- Attend a training on how to advocate for your needs.
- Promote systems change by writing a letter or tactfully making suggestions.

What can families do to obtain quality care if professional care coordination is not available?

“I have a general consent form that states that I give permission for ‘XYZ’ to speak to ‘ABC’ regarding my child and sign it and create one for all who are involved. When a plan is updated or new service determined, I pass along a consent form.”

“...my first thought was for the parent to start organizing a notebook with information on her child....to help families organize medical information, reports, apts., etc.”

“It is good to copy reports and make sure that your doctor who is providing a medical home for your child has a record of all the different providers’ information. When you go in for regular medical visits take along your notebook and let them update their files.”

“There is a good little book for health history on www.lilangelgifts.com . I have one of these small books for each child to keep all the dates of hospitalizations, and current and past meds handy.”

“At the end of each year, I request a copy of my child’s record for that year. So I get a copy of all the visit notes from each specialist and discharge summaries. They are then filed under each specialty (GI, Neuro, Ortho, etc.) This way I can get a quick medical update of one area at anytime.”

Action Steps

- Organize information: create an information notebook and copy all reports.
- Build partnerships with medical professionals.
- Stay informed by visiting websites sponsored by groups that support care coordination.

“The Massachusetts Consortium for Children with Special Health Care Needs at New England Serve www.NEserve.org is doing some great focus groups, and studies on care coordination and how to make the medical home model and ‘one stop shop’ a reality.”

“Kansas provides a Make a Difference hotline at 1.800.332.6262 for resource information state wide.”

“Get a care coordination toolkit at: <http://www.medicalhomeinfo.org/tools/Toolkits.html>”

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Beach Center on Disability

The University of Kansas

1200 Sunnyside Avenue, 3111 Haworth Hall • Lawrence, Kansas 66045

Telephone: 785.864.7600 • TTY: 785.864.3434

www.beachcenter.org

