



Champions for Inclusive Communities

Star Community

Cleveland, OH

Seven years ago, as the Ronald McDonald House® of Cleveland, Inc. (RMH) was preparing to celebrate its 25th anniversary, a retired physician on the planning committee decided they needed to do something special for families as part of the celebration. The other committee members agreed and a focus group of eight organizations was formed to discuss the current needs of families. It was discovered that, while families stayed at RMH, they felt secure and supported by the network of professionals available at the medical facility. But once it came time for them to leave this supportive setting and return to their home and community, these families often felt isolated and lost when it came to finding services for their child with special health care needs (CSHCN) on their own.

This is how Tools for Today and Tomorrow (Tools) was born. Two conferences were held, both in 2004 and in 2005, for families of CSHCN to network and learn more about key non-medical advocacy, family, financial, and legal issues. At the end of the second conference, it was apparent to the growing group of partner organizations—today known as the Tools Consortium—that this resource was significantly valued by families in the community.

From there, the program only expanded.

In 2006, Linda Kresnye – Program Manager of Tools for Today and Tomorrow – was hired to oversee the creation and maintenance of a family-friendly, informative website. The site is essentially meant as a “one-stop shop” for families to find categorized information. Craig Wilson, Executive Director of RMH says of Linda, “she has done a fantastic job at identifying resources and forming partnerships.” Cindy Norwood, Executive Director of The Arc of Greater Cleveland and the parent of a child with special needs, also praises Linda’s work on the website’s community calendar where organizations can post informational/educational events for free.

In 2006, Tools became an official program of RMH. RMH was chosen because it is “neutral” among participating members, some of which are competitors. Today, the Tools Consortium consists of 24 organizations in greater Cleveland, including three major hospital systems (Cleveland Clinic, MetroHealth, and University Hospitals Rainbow Babies and Children’s Hospital), as well as boards, schools, and disability organizations. They willingly and successfully pool their time, talents, resources, and community connections in support of the program. This unique collaboration has helped raise awareness and understanding among families and professionals about the lifespan needs of children with chronic illnesses and/or disabilities. It has also helped put them in contact with community resources and support to help meet their individual needs, regardless of diagnosis. The continued growth of the program is the result of ongoing collaboration among these organizations and families.

Measuring Progress

The Tools program is fairly confident they have had a positive effect on the Cleveland community. One of the reasons for their confidence is the ongoing effort to measure and track families’ feedback to many different aspects of their program. They track website traffic and survey families about the website, asking useful questions such as, “Did you find the information you were looking for and was it easy to use?” and “Did you find new information and ideas?”

Linda has also created a survey tool to be used following the workshops for families that measures the workshop’s impact. Questions assess whether the family member feels more confident and informed about the issue(s) they are facing and whether there were further issues the family member would like to have addressed.

The results from these surveys are not filed away, either. The Tools for Today and Tomorrow’s steering committee has a subcommittee focused on Education and Outreach. They use these surveys to glean new ideas and carefully consider evaluation reports for new workshop topics.

MetroHealth: Providing Medical Homes for a Lifetime

Much of the medical home effort in the Cleveland area is being addressed through the Comprehensive Care Program at MetroHealth. The Comprehensive Care Program serves children, youth, and adults with medical disabilities and special needs. They strongly believe in keeping clients, if possible, throughout the life span. “Double-boarded” doctors who are able to provide care to both children and adults help their clients make a seamless transition from pediatric to adult-centered health care and maintain relationships that have developed over time.

Another strong component of the Comprehensive Care Program is care coordinators who can support the family and address their questions and concerns. Dr. Irene Dietz, MD, and Medical Director of the Comprehensive Care Program, says, “I think [care coordinators] are very comforting to the family - they get to know that person on a first name basis. And if [the coordinator] doesn’t know the answer, it’s a nice triage – they can at least either get the answer for the family or provide resources.” Care coordination for families is usually localized to the program’s own staff members. In most cases, either a nurse practitioner or an RN will coordinate services for the families they are already seeing.

Ann Forster, Certified Nurse Practitioner, adds that the key to a successful medical home is making sure each family knows the first number to call that will reach a knowledgeable care coordinator, and making sure families can identify a primary care provider. It’s also important that the family trusts that these care providers won’t just view them as another patient in the lineup. Instead, the

What makes a Star Community?

Star Communities show excellence in 6 Performance Measures:

- Families are partners
- A "Medical Home" provides coordinated care
- Children receive early and continuous screening
- Families have adequate funding/insurance to pay for services
- Services are organized so families can use them easily and are satisfied
- Youth receive necessary services to make the transition to adult life

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family should rest assured that the providers know their family personally and will openly converse with them about their child's needs. Ann mentions a trend in medicine right now that decentralizes all communication: all calls go through a central line and are triaged from there. The Comprehensive Care Program tries to avoid this as much as possible by employing a secretary who makes all the appointments and subsequently gets to know the family, just like the providers. As a result families learn that if they leave a message, it will be returned quickly; when they call about a problem their child is having, they will be directed straight to the appropriate person in the office – all because the person taking their call knows them, and knows their background.

The Comprehensive Care Program has a sound grasp on medical homes for families, and is trying to spread the word about its effectiveness to other providers in the community. They communicate regularly with specialty clinics and have found that many doctors are more than willing to communicate about the status of the child's health. They also make sure to send a detailed report with health updates and recommendations when a family visits another clinic.

Family Empowerment

“Family empowerment and involvement is highly valued within each of the Tools Consortium organizations and within the Tools program. Families become empowered when they are informed, supported, and involved. It's key to building effective relationships, improving services, and helping children achieve their potential, and why Tools exists,” explains Craig Wilson.

Years ago, when the Comprehensive Care Program decided to really push for medical homes, they formed a parent advisory group. This is a group of parents of children with all different kinds of special health care needs that meets monthly to offer advice and support to each other. Dr. Dietz has found as she has sat in on the meetings that parents become very willing to share their stories about what has worked for them in the system and what has not. She states that it's great to watch how this advice can help other families in similar situations. Ann Forster also points out that it gives the parents a great deal of confidence to be a member of the parent advisory group. Many of them at first say they don't have anything to contribute, but as they become more involved, they realize that they can make a difference in the lives of other families.

Providing a Safety Net for Families

The MetroHealth System is one of the three major health care systems in Cleveland, Ohio along with the Cleveland Clinic and University Hospitals of Cleveland. MetroHealth is the safety net hospital for the residents of the city of Cleveland and Cuyahoga County. This means they are committed to serving anyone who goes to them for services – even families without insurance.

Providers also try to make sure families know about the wealth of state resources that are available to them, such as Medicaid, SSI, and County Board services. Learning to navigate the financial maze is daunting. Professionals often refer families to www.toolsfortoday.org where they can learn more about these resources, and also find out about and register for Tools and other community-sponsored workshops that target these topics.

Ann has also found that, as far as complicated applications for insurance goes, “electronic medical records are a big help.” These cut down on repeated questions and make it simple to ask pertinent questions at follow up. This is especially useful for patients who see many different providers and specialists. Instead of being asked the same questions over and over, the providers can search for and find the patient's up-to-date electronic record and be prepared with all the relevant information they need.

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The Tools Consortium also does their part in helping families out financially by supporting Tools workshops, and providing scholarships to attend Tools conferences.

Community Screening

Much of the developmental screening in the community takes place through Help Me Grow. Help Me Grow serves children ages birth to three through home visits, links to resources, positive parenting classes, and, of course, developmental screening. Since the program serves about 1,900 Part C children and 4,000 at-risk children in Cuyahoga County, they reach many of the children with special health care needs and their families in the community. Melissa Manos, Project Director of Help Me Grow for Cuyahoga County, says, “We really appreciate entities like Tools for Today and Tomorrow that educate families about community resources like Help Me Grow.”

Transition to Adulthood and Across the Lifetime

Transition from school to work, home to community, and pediatric to adult-centered health care is at the forefront of many of the community efforts in the Cleveland area. Bob Clampitt, the Director of Special Pupil Services of Mayfield City Schools and Tools Consortium member, works with 16 surrounding school districts to provide effective vocational programs for youth with special health care needs. Bob manages special education procedures, works closely with the students' health care providers to ensure consistency in services, oversees inclusion in classrooms, and works with Help Me Grow to ensure a seamless transition from the 0-3 program to the education system.

Bob also works with the schools to initiate a transition plan starting when the youth turns 14. At that time, they make a transition statement. Two years later, the schools draft a plan for the youth to transition into the community. This includes making sure the youth have the skills they want and/or need as well as making sure they know what to expect when they graduate and transition into adult life.

Cindy Norwood, Executive Director of The Arc of Greater Cleveland, can testify to the excellent work the community does in transitioning youth through a lifetime. Cindy's daughter was born prematurely and spent her first year and a half in the hospital. She subsequently had many chronic health issues and some developmental disabilities. Many of the doctors who treated her did not expect her to live past infancy. However, with the help of many organizations in the community and a parent's steadfast love and determination, today her daughter—age 26—is thriving on her own independently. Cindy says, “Tools for Tomorrow is a great example of how you never know how you're going to influence a family. It's so critical to find them early so they know where to go. It makes the journey a little easier.”

A Community Coming Together for Families

The network of organizations that partner with Tools for Today and Tomorrow is extensive and far-reaching. No one in the community could have predicted the impact the organization would have on families when it began seven years ago. But today, the Tools program brings together professionals and organizations from across the community to provide a “one-stop shop” of services for families who are faced with uncertain situations involving their child's health care needs. And the program is expanding. Already Tools for Today and Tomorrow has signed an agreement with neighboring Lorain County to replicate the program there as well.

Melissa Manos of Help Me Grow describes the community's mission well: “We want to support families to become their children's best advocate. And how do you do that? You build relationships.”