

Medical Home in Minnesota — A Year of Progress

The ideal that “every child should have a medical home” has been taking hold in Minnesota over the past 18 months. In March of 2004, eleven medical home teams came together as a learning community to begin to take the many small steps that would move them towards an ever higher level of “medical homeness.” Almost without exception, the teams — each comprised of a physician, parents of children with special health needs, and a practice based nurse — bonded as a strong unit of change agents. At the kick-off of the second year’s learning collaborative, parents who had been involved since the beginning all agreed that they felt like valued members of a team that was making a difference in the health care and lives of children with special health care needs. Physician team leaders and the practice care consultants all said that without parent partners few if any of their successes would have been realized.

At the publication of this issue of *Special Connections*, the work and the word have spread. Of the eleven

original teams, all are continuing in one form or another. An additional five teams started in September of this year and are working alongside the veteran teams. More teams are joining in January 2006.

In addition to spread to new teams, some of the original practice teams have implemented “spread” throughout their organizations. In CentraCare Women’s and Children Clinic in St. Cloud, the care coordinator who began early in the team’s process at 3 hours per week working with the physician team leader champion, is now more than 20 hours per week and is working with all the pediatricians in the clinic developing care plans for CYSHCN. At most of the clinics, the spread of the concept has gone beyond the original physician champion. Some of the spread of medical home is highlighted in this issue’s articles.

At the state level, exciting things are happening as well. With a new federal grant from the Maternal and Child Health Bureau (part of the Health Resources Services Administration

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of the U.S. Department of Human Services), the Minnesota Children with Special Health Needs program (MCSHN) of the Minnesota Department of Health will be continuing and expanding its work. The partnership between MCSHN, Minnesota Academy of Pediatrics and PACER Center will be expanded to include the Minnesota Department of Human Services and Wilder Research Center. The partners are working on spreading the word on the benefits of Medical Home as well as studying the cost impact of Medical Home.

This issue of *Special Connections* brings together various articles and data published about the first year of work of the medical home learning collaborative. It has been an exciting time for Medical Home in Minnesota.

“When families and their doctors work together to make comprehensive care in the community a reality, this partnership is called a Medical Home.”



Clinic Works to Improve Treatment of Special Needs

Patients’ plans detail all aspects of their health, help them get specialized care

*By Benjamin Malakoff
Staff
St. Cloud Times Metro
bmalakoff@stcloudtimes.com
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Lynette Hurre used to prepare a list of questions for the physician at appointments for her son Jordon, 14, who was born with a congenital defect that caused problems with his diaphragm.

She and the doctor could only cover a few of those topics each time — she’d have to wait until next time to cover others.

Now, CentraCare Clinic is also in a national program’s effort to improve care for children with special needs.

The Medical Home Project provides a care plan for each child — a comprehensive document concerning his or her health care as a way to improve it.

The plan will feature a short history, list of medications, physician contact information, areas of concern and other information.

It can be used to help doctors and others become more familiar with a child’s needs.

Extra attention

The care plans will let care providers know that some children, such as Jordon, need longer appointments so all concerns can be addressed.



Ashley Peterson and daughter Camerynn. Ashley is also a parent member of the CentraCare team.

“A lot of times, you’re on your own,” Hurre said. “Different doctors don’t know us. If you don’t have a care plan, you don’t know. We found that the care plan kind of backs you up.”

Hurre said her husband wished the care plan was around when Jordon was born.

“When a child goes to the ER or has an emergency, it allows providers to deal with the child in each place,” said Emily Stevens, director of nursing for CentraCare Clinic. “It forces the clinic to look at the true needs.”

Family-centered

The term “special needs” has a wide-ranging definition that can be applied to children with asthma, diabetes, autism, mental-health issues, physical limitations, emotional problems or other conditions.

The Medical Home Project began in Minnesota in 2004 with funding from several organizations,

including the Department of Health. The program went national this year.

The goal is an improvement in overall care and health, as evidenced by things such as a reduction in emergency visits, missed school days and unplanned medical visits, project facilitator Sandy Engdahl said.

“An important part of this project is to involve parents of special-needs children,” said Marilyn Peitso, a doctor helping to organize the program.

Historically, care providers told patients what they need.

“Now (they) work with them,” Stevens said. In April, the group had a dinner with eight families of special-needs children to generate ideas to improve the project.

New approach

Peitso said medical care generally is structured to care for healthy people while the project is attempting to make it more natural to care for unhealthy ones. The challenge of the Medical Home Project will be implementing it and integrating it into medical care without interruption.

“These changes are like changing a bicycle tire while still riding a bicycle,” Peitso said.

CentraCare Clinic has about 17,300 active patients, almost 2,300 of whom — 13 percent — can be considered people with special needs, Peitso said.

So far, 49 care plans have been written for special-needs children at CentraCare Clinic.

There are 18 pediatric health providers at CentraCare Clinic, 17 of whom are pediatricians.

Parents are given copies of their child’s care plan so they can show it to care providers in case of an emergency. The care plans are also provided to children’s schools.

Specialists who treat children with care plans are asked to fax forms back to the clinic so the treatment can be recorded on the care plan.

“This is a project that will never be completed,” Engdahl said. She called it “completely fluid.”

Ashley Peterson, whose daughter Camerynn, 4, has special needs and a care plan through CentraCare Clinic, is helping shape the Medical Home Project from a parent’s point of view.

“This has helped us a lot,” Peterson said. “I have the power to make changes.”



The Medical Home Index — A Measure of Improvements

Reprinted with permission from Minnesota Pediatrician, Spring 2005

Written by Ann Ricketts

It has been a year since the Minnesota Chapter of the AAP, PACER Center and the Minnesota Children with Special Health Needs Section of the Minnesota Department of Health came together to work on the Minnesota Medical Home Learning Collaborative. In mid-March of 2004, eleven teams — each comprised of a physician, two parents and a care coordinator/nurse — first met in a two-day learning session to kick off a year long learning process to realize “medical home improvements.” These eleven teams have met twice since then in two-day learning sessions, linked by action periods in between.

The American Academy of Pediatrics has established access to high quality health care through a medical home with appropriate reimbursement to the pediatrician as its top priority. According to E. Stephen Edwards, M.D., FAAP, Immediate Past President of American Academy of Pediatrics, “We need not only the vision

of the medical home but also the demonstration of practical tools and methods that have proved successful in overcoming recognized barriers to providing care that is accessible, family centered, comprehensive, continuous, coordinated, compassionate, and culturally effective.” (*Pediatrics, May 2004 Supplement*).

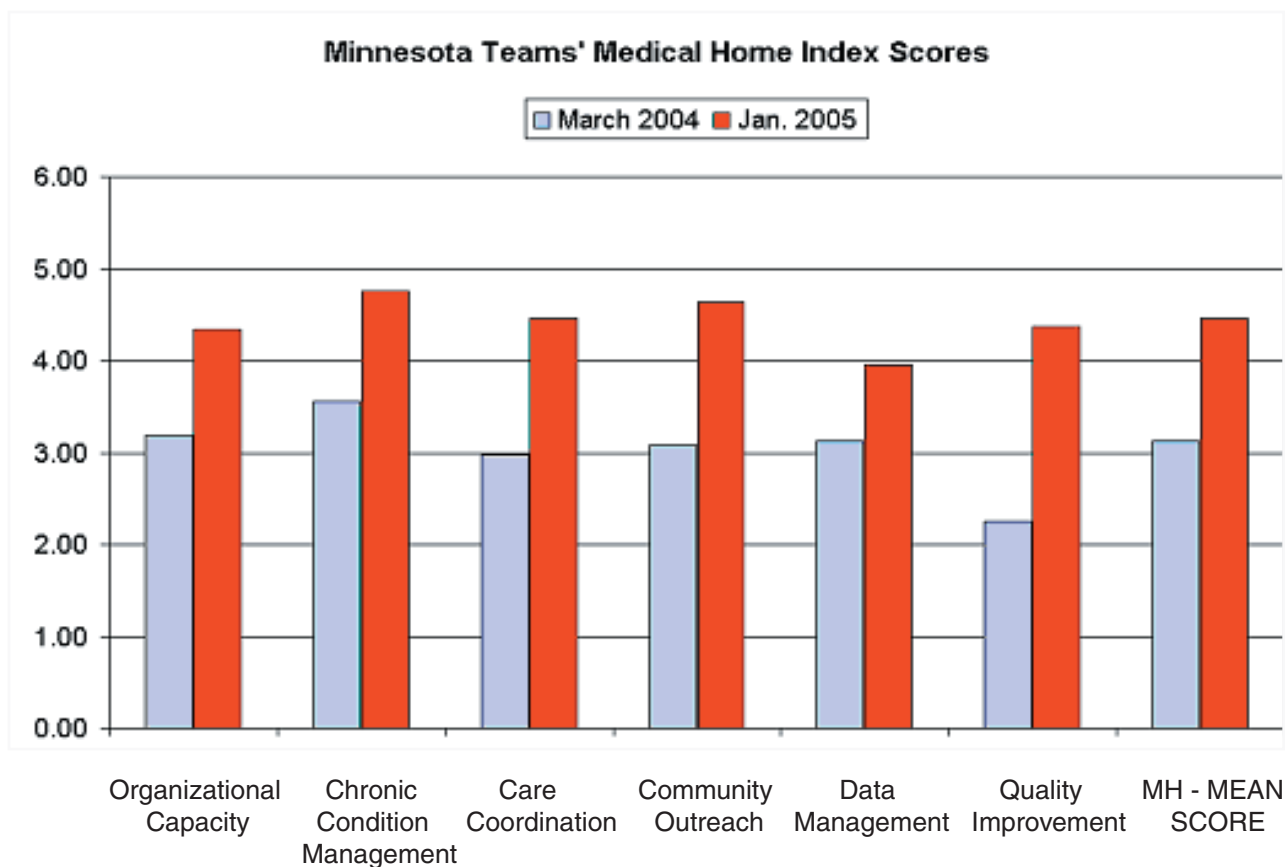
One of the practical tools used here in Minnesota was the Medical Home Index. Carl Cooley, M.D., FAAP, and his co-director, Jeanne Mcallister, M.S., M.H.A., of the Center for Medical Home Improvement (CMHI) developed and validated a tool or index to measure the “medical homeness” of practices providing care to children with special health care needs — the Medical Home Index (MHI) — which provides a *point-in-time assessment* of the implementation of medical home elements.

The Medical Home Index is a tool which very concretely, descriptively, and explicitly gives a practice a sense of its degree of “medical homeness.” For example, under the Chronic Condition Management domain’s theme of “Identification of Children,” a practice would decide whether it had achieved “partial” or “complete” success in one of four levels.

Domain 2: Chronic Condition Management (CCM): For CSHCN and Their Families				
THEME:	Level 1	Level 2	Level 3	Level 4
#2.1 Identification of Children in the Practice with Special Health Care Needs	Children with special health care needs (CSHCN) can be counted informally (e.g. by memory or from recent acute encounter); comprehensive identification can be done through individual chart review only. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE	Lists of children with special health care needs are extracted electronically by diagnostic code. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE	A CSHCN list is generated by applying a definition, the list is used to enhance care +/- or define <i>practice</i> activities (e.g. to flag charts and computer databases for special attention or identify the population and its subgroup). <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE	In addition to Level 3, diagnostic codes for CSHCN are documented, problem lists are current, and complexity levels are assigned to each child; this information creates an accessible <i>practice</i> database. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE

The overall mean score of the eleven teams in March of 2004 was 3.13 out of a total possible score of 8.00. Many of the physicians noted that completing the Medical Home Index the first time was “depressing.” One of the physicians noted that it was so disheartening to complete the MHI the first time that she thought there should be a “warning” up front. Reaching a score of eight seems almost a stratospheric goal.

But in January of 2005 when all the teams again completed the MHI, the picture was brighter. The improvements were significant — a 42 percent increase in the mean score overall for all the teams combined. The chart below shows the changes between March of 2004 and January of 2005 in each of the six domains. By percent improvement, the changes for each domain were: 36 percent for Organizational Capacity, 34 percent for Chronic Condition Management, 50 percent for Care Coordination, 50 percent for Community Outreach, 27 percent for Data Management, and 94 percent for Quality Improvement.



There were some themes where the improvement was greater than 60 percent, and in one the increase was 126 percent. This latter improvement was in the theme “Identification of children in the Practice with Special Health Care Needs.” This was one of the lower scores at the onset of March 2004. By January 2005, the new score was 5.09 — one of the highest.

One theme actually decreased between learning sessions — “Supporting the Transition of Adult Health Care Services.” This is an area that the teams are only now developing action plans to address.

Other areas were emphasized in the action periods between the learning sessions — family partnerships, care plan development and care coordination, communications with specialists and coordination and communications with community organizations.

The scores on the Care Coordination domain increased in many of the specific themes; scores on the “Family Involvement” and “Care Coordination/Role Definition” were each at 5.27 with greater than 50 percent improvements in both. There was a 68 percent improvement in the score for “Assessment of Needs/Plans of Care” with a 2005 score of 5.18. The score on “Resource Information and Referrals” improved significantly, but started very low — it went from 2.25 to 3.82.

The highest score on any item was a 5.45 for the theme, “Cooperative Management Between Primary Care Provider and Specialist.”

Finally, one of the greatest increases in scores between March of 2004 and January of 2005 was for both the two themes in the Quality Improvement Domain. There was a 99 percent increase in the “Quality Activities (processes)” theme — from 2.33 to 4.64. The teams moved from barely into Level 2 to solidly in Level 3. The whole Medical Home Learning Collaborative process was clearly a quality improvement process.

Domain 6: Quality Improvement/Change: For CSHCN and Their Families

THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<p>#6.2 Quality Activities (processes)</p>	<p><i>Primary care providers (PCPs)</i> have completed courses or have had an adequate orientation to continuous quality improvement methods.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Corporate owners, administrators or payers identify <i>practice</i> deficits and set goals for improvements; <i>practice</i> providers and staff are identified to fix problems with limited participation in the process.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Periodic, formal, and informal quality improvement activities gather staff input about <i>practice</i> improvement ideas and opportunities or <i>CSHCN</i>; efforts are made toward related changes and improvements for this population.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, the <i>practice</i> systematically learns about <i>CSHCN</i> & draws upon family input; together the <i>practice</i> and families design and implement office changes that address needs and gaps; they then study their outcomes and set accordingly.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>

For the eleven teams who are participating in the Minnesota Medical Home Learning Collaborative, the MHI will continue to be a helpful tool for improvements. The 25 themes within the six domains will provide a framework for improvement over more than a few years.

The Medical Home Index is available for any practice that would like to assess itself, as is the companion index for families — the Family Medical Home Index. The tools are available to be downloaded from the website for the Center for Medical Home Improvement — www.medicalhomeimprovement.org.



More Measures — The Family Medical Home Index — A Companion to the Medical Home Index

Written by Ann Ricketts

The Family Medical Home Index (FMHI), which measures the organization and delivery of primary care for children with special health needs from parent points of view, was given to parents both before the first medical home collaborative meeting and then at the end of the third session ten months later. The FMHI is a companion tool alongside the Medical Home Index.

There were 15 respondents to the first mailing of the FMHI and ten to the second mailing in early January of 2005.

In both surveys, questions about the quality, concern and care shown by the primary care provider were ranked very high. All the respondents on both surveys said “yes” to the statement: “From my experience, I believe that my PCP (primary care provider) and the staff and his/her office have a commitment to provide the quality care and family supports that we need.”

There were many questions where the average of all the answers increased on the second set of questionnaires by more than 15%. Specifically, the questions which had the greatest percentage increases in the average of the scores between 1 (Never) and 4 (Always) increased were as follows:

“My primary care provider (PCP) uses helpful ways to communicate . . . with my child.” 27% increase from 3.0 to 3.8

“My PCP asks me to share with him/her my knowledge and expertise as the parent or caregiver of a child with special health care needs (CSHCN).” 16% increase from 3.1 to 3.6.

“I am asked by our PCP how my child’s condition affects our family (e.g., the impact on siblings, the time my child’s care takes, lost sleep, extra expenses, etc.).” 20% increase from 2.1 to 2.4.

“Planning of care for my child includes the writing down of key information (e.g., recommendations, treatments, phone#).” 17% increase from 3.0 to 3.5.

“Planning of care for my child includes setting short term goals (e.g., for the next three months).” 23% increase from 2.6 to 3.2.

It was the statement —“My primary care provider and staff work with our family to create a written care plan for my child” — that had the greatest percent increase — from 1.7 to 2.7. More significantly, only four of the 15 respondents to the first survey responded that they that they received a copy of their child’s plan at all, while all of the ten respondents in January of 2005 said they had received a copy. Two of the first time responders who said they had a written plan were parents with North Point Clinic and they were not represented on the second survey.

This was very exciting news. The care plan definitely has been taking hold with the practices.

There were some areas where scores actually went down. The statement — “My PCP has a staff person or a “care coordinator” who will help each person involved in my child’s care to communicate with each other” — went from a 4 to a 3. This result may well reflect a change in expectations between knowing nothing about medical home, and spending almost a year involved in making changes to a system. That statement was actually a several-part question. There was a 24 percent *increase* (from 2.5 to 3.1) in the statements about the care coordinator who will “help to find needed services (e.g., transportation, durable equipment and home care) and “make sure that the planning care meets my child and my families’ needs.”)

The ability of a care coordinator or other staff person to “help each person involved in my child’s care to communicate with each other” is a work in progress and very much part of the current year’s work.

The only other area where there were drops in scores was on the yes or no statement, “Office staff help me to connect with family support organizations and informational resources in our community and state.” This is an area that the teams have already identified as an area in need of attention. At the Learning Session in January of 2006, a time will be devoted to helping practices and families work together to identify family to family support systems.



Rooting for the (Medical) Home Team

Early Childhood Connection, A Newsletter for Minnesota Families of Young Children with Disabilities, Winter 2005

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The “medical home” team is a new approach that provides high-quality, family-centered health care services to children with chronic health needs.

When Alaina Butcher, now 4 years old, was born prematurely and with complex health needs, her parents faced challenges from the health care system they thought would help them. As Jenny and Kevin Butcher of Watertown, Minn., learned how to provide complicated care for their new baby, they found they also needed to understand medical jargon, juggle appointments with specialists, and navigate roadblocks to Alaina’s care. Chief among those roadblocks were a lack of coordination among the baby’s physicians and the failure of some in the medical community to recognize the family as partners in their daughter’s care.

Therese and Ted Salonek of Montrose, Minn., had similar difficulties when their daughter, Hope, now 8, was born with Down syndrome and medical needs. Though many of Hope’s health care issues are now resolved, Therese remembers how difficult their experiences were. Serving children with chronic health needs in traditional clinic settings is like “fitting square pegs in round holes,” she said.

The Butchers and the Saloneks both wished they could do something to help improve the system and make life easier for other families who have children with chronic health needs. Then, their pediatrician asked them to participate in something called the Minnesota Medical Home Project. The year-old effort is part of a medical home grant through the Minnesota Children with Special Health Needs program at the Minnesota Department of Health.

The grant, provided by the federal Maternal and Child Health Bureau, helps 11 medical-home teams based in clinics across the state. Its purpose is two-fold: 1) to improve the quality of care provided to children with special health care needs and disabilities at local clinics; and 2) to discover how the medical home concept can bring comprehensive and competent care to all children.

The two families began to learn more about the project. A “medical home,” they discovered, is a way to provide high-quality, family-centered health care services. It is an approach where the primary care doctor, a clinic care coordinator, and the family have a trusting relationship. They work together to coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family.

The project was just the kind of opportunity the two families sought. Their pediatrician, Dr. Kathy Sweetman at Lakeview Clinic in Watertown, leads one of the 11 medical home teams. Jenny Butcher and Therese Salonek were happy to join.

Sweetman’s team began with three goals:

1. To help families feel supported in the medical arena, especially families that need to see their doctor often because of their child’s chronic illness;
2. To improve collaboration among the child’s medical professionals, school, and community; and
3. To connect families to resources within their communities.

Soon, the team invited Kate Fasching, an early childhood special education teacher in the Waconia school district, to join them. Fasching had just finished a paper on medical home and family-centered care issues for her master’s degree. Team members liked the idea of connecting the medical team and the school. It provides better care and services to the child, Fasching explained.

“I feel that often we are not catching developmental delays in children early enough,” she added. “Sometimes, their delays are not discovered until their preschool or kindergarten screening. The medical home is not about saying that someone isn’t doing their job, it’s about what is best for the child and the child’s family, and how we can diagnose disabilities at an earlier age.”

Through the broad expertise of its members, Sweetman’s team is achieving impressive results. They have created everything from comprehensive records, to conferences, to support groups. Among their achievements:

- **Shared records.** The team developed a system to include all of the child’s records — from the doctor’s office to the school and beyond. The combined record can be copied for all the child’s service and medical providers. It includes information on specialists, their phone numbers, and diagnoses made. This information is especially important when a child’s medication changes frequently, said Sweetman. Eventually, the paper record will be transferred to a computer system, so it can be easily updated and sent electronically to all service providers upon the parent’s request.
- **User-friendly clinics.** The team worked to make the Lakeview Clinic more user-friendly. Parents of children with chronic needs used to call the clinic, then wait for staff to pull the child’s record before they received a response from the doctor. Now, clinic staff immediately transfers them to their child’s doctor or nurse to see if the concern can be addressed over the telephone. “This was suggested by the parents on the team and has proved to be a very patient friendly move,” Sweetman said.
- **Family-centered care approach.** The team also worked to improve the family-centered care approach of clinic staff on the telephones. Training included teaching them what kinds of questions to ask the parents when they call.
- **Conference for physicians and the community.** To help physicians better identify developmental delays in some children, the team will conduct a conference for physicians and the community this spring. It will include speakers on early intervention, screening tools, problem-solving techniques, and discussion about compensation — who is going to pay for the medical home and services.

In the months ahead, the team also plans to reach out in other ways. They expect to develop printed handouts and brochures on the medical home approach, what it means to the community, and how physicians can practice it. They also want to find ways to connect children with special health needs to community resources, including county and other professionals who can provide needed services to families and children. Other plans include creating support groups for families of children with disabilities and developing better collaboration between the doctor’s office and the school.

Team members are pleased with their efforts. Jenny Butcher sees having a computerized care plan for Alaina as a major benefit. Having her daughter's comprehensive records—from information about the family's insurance, to Alaina's allergies, to procedures to avoid — will take much anxiety out of emergency trips to the clinic or hospital, she said. Both mothers said direct access to the physician or nurse will improve care to children.

“We do not have our care plans working perfectly,” Sweetman noted. “They require many hours and continuous correction, but we have made significant progress.”

“I so appreciate the parents' perspective,” Sweetman added. “It has not been an easy thing to do. Change never is, but it has been a very rewarding experience and one that will greatly improve the quality and continuum of care that a child receives in the future.”



A Medical Home Away From Home

Written with permission from THE JOURNAL, New Ulm, June 27, 2005 (Health Section)

A New Ulm team's commitment to a national program aimed at streamlining and coordinating care for medically needy children has won national recognition.

New Ulm resident Marion Aiken didn't ask for her beloved daughter Amanda to be born with special health care needs.

But 12 years ago when Amanda was born at only 31 weeks gestation due to a fetal maternal hemorrhage — the infant had lost almost all of her blood through her umbilical cord, which had failed to attach securely to the placenta — she had a myriad of health concerns.

All of her major organs had shut down and her lungs were beginning to crystallize. She had an actual birth weight of 2 pounds, 5 ounces and was immediately put on a respirator.

“You feel so helpless,” Marion said. “You hope and pray that they are healthy and have 10 fingers and 10 toes and it doesn't happen and you say, ‘Oh boy, what are we going to do?’”

Thanks to top-notch health care from doctors at Abbott Northwestern and Children's hospitals in the Twin Cities, Amanda survived. With ongoing care at Gillette Children's Hospital and New Ulm Medical Center for cerebral palsy, pervasive developmental disorders, cognitive delays, asthma and other problems, she is thriving today.

But the years have been a roller coaster ride for Marion and her husband, John.

Many times, those bumps came in the form of frustrations caused by a lack of communication between multiple health care providers in different communities, difficulties coordinating care for her daughter and spending time explaining Amanda's condition over and over again to each new physician.



Marion Aiken and daughter Amanda. Marion is part of the New Ulm Medical Center Medical Home Initiative.

Lately, however, the Aikens' ride has smoothed out significantly.

A program, undertaken by New Ulm Medical Center pediatrician Dr. Clifford Wu, is helping hundreds of parents whose children have special health care needs experience continuity in their health care that has been lacking.

The Medical Home Initiative, sponsored by the Minnesota Department of Health and the Minnesota Chapter of the American Academy of Pediatrics, aims to bring together ideas from a contingent of 11 medical facilities state-wide in a collaborative effort to provide patients with a medical "home" no matter where they receive health care.

"It's the idea that every child deserves a medical home," Wu said. "It's a conceptual place where a child can receive comprehensive, coordinated and compassionate care. But it's not just the child; it's the child's family that is impacted. The emphasis of the program is on children with special health care needs those with genetic defects, chronic illnesses, heart problems, diabetes, arthritis and even asthma."

Some of the aspects of the multi-faceted initiative include the creation of emergency care plans for the approximately 200 children with special health care needs seen at the medical center; development of a communication system that gives out-of-town specialists a device to immediately communicate changes in a child's care to Dr. Wu; assistance for parents to coordinate appointments, both locally and far away; and priority access to Dr. Wu at set times throughout the day.

"What the medical home means for us as a family, is a coordination of care," said Aiken, who belongs

to the medical center's medical home initiative committee along with Wu, fellow parent Clair Gieske and Cindy Wellner, clinic LPN.

"It is giving my daughter and our family support in the medical arena where there has always been a gap. Dr. Wu has given us the opportunity to do more at home in New Ulm and we have the continuity now."

The continuity is epitomized by and experience Amanda had in May. She was being seen by one of her many doctors at Gillette Children's Hospital in St. Paul for a problem in the area of her spinal column. That doctor asked the Aikens if Amanda had ever had a CT scan. Aiken said she had one performed recently and, in fact had a copy of the report and images on a CD-Rom, which was created by medical center staff expressly for the Aikens and filled with fundamental information from Amanda's medical record.

"That doctor was able to sit and look at the image and said it was just awesome; he was blown away." Marion said. "He knew the results then and there, didn't have to order another CT scan for Amanda and we knew the next course of action without it taking days."

"Not only did she avoid duplicate procedures and tests, but we got our answers immediately. It's the worst feeling, waiting for days for doctors to look at the test results and tell us what we need to do, because you don't know how your life will have changed by then. I can't even put into words how excited I am about this, how well it's working out. It's like Christmas, you keep discovering new things to get excited about."




The Minnesota Medical Home Project
(Minnesota Medical Home Collaborative)
is a partnership between The Minnesota
Department of Health, the Minnesota
Academy of Pediatrics Foundation and
PACER Center/Family Voices of Minnesota.

The Minnesota Medical Home Learning
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*The staff person for the Minnesota Medical Home
Learning Collaborative is:*

Carolyn Allshouse
MDH-MCSHN
P.O. Box 64882
St. Paul, MN 55164-0882
651-281-9970
carolyn.allshouse@health.state.mn.us

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85 East Seventh Place, Suite 500
P.O. 64882
St. Paul, MN 55164-0882