

FAMILY VOICES OF WISCONSIN

DID YOU KNOW? NOW YOU KNOW!

An Introduction to Health Care Coverage and Community Supports for Children and Youth with Disabilities and/or Special Health Care Needs

Statewide Respite Conference
October 4, 2006 – Janesville, WI



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Welcome and Introductions

- ♥ About this training
- ♥ About Family Voices of Wisconsin
- ♥ About the Regional CSHN Centers
- ♥ Meet each other



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Structure of Training

- ♥ Case based method of instruction
- ♥ Meet the Goodpeople Family



Preview Activity

What Do I Have
At My Fingertips?



Part A

The Journey of Parenting a Child with Special Needs



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The Story, Part A

Consider Fred and Sue Goodpeople and their two children, Katy, age 3 and her newborn sister Emma. Emma had a traumatic birth and was deprived of oxygen during her delivery. As a result, Emma has a preliminary diagnosis of cerebral palsy and it is anticipated that developmental delays will arise as she grows up. The family lives in Parkopia, which has a wonderful children's hospital and teaching institution. Shortly after Emma was born, she was transported to the children's hospital and spent five weeks in its Newborn Intensive Care Unit (NICU).



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The Story, Part A, continued

While they were in the NICU, the hospital's fabulous social worker, Louise Imahelp, got to know the family and gave them many resources that could be helpful to them. Fred and Sue were overwhelmed, and couldn't take in all the information that was given to them by Louise and many other well meaning individuals.



Questions and Considerations

- ♥ What is different about having a child with a disability or a special health care need?
- ♥ What has been most helpful to you as you learn about health care and community resources?
- ♥ What has been most difficult for you as you learn about these resources?



The Learning Journey

Throughout this training and in your journey, remember the following:

- ♥ Various professionals will be well meaning and attempt to provide information to you whether you are ready or not – You can and should ask for information in a format you are comfortable with.
- ♥ You are on a journey of life long learning and cannot know everything there is to know.
- ♥ Regardless of where you are on the journey, you know your child best and must always bring that expert perspective to any conversation.



You Are Your Child's First and Best Advocate

- ♥ You are the most important person in your child's life. You have expertise about your child no one else has.
- ♥ When you have a child with special needs, you may need to develop relationships with people you have not expected.
- ♥ You often might have to be more assertive in voicing your opinions than you are comfortable with.



How to be an Effective Advocate

- ♥ You can disagree without being disagreeable – be well informed, calm, prepared and persistent
- ♥ Remember your goals – take one issue at a time
- ♥ Set reasonable goals – set one goal and try to be assertive
- ♥ Think about where you might be willing to compromise. Agreeing on part of an issue is often a start in the right direction.
- ♥ Express your feelings without blaming messages – “I” messages rather than “You” messages. Avoid the word “should.”
- ♥ Stay informed – read newsletters, check out websites, attend workshops, talk with other parents, participate on advisory committees. How can a person be “in the know” – where can resources be found?



Part A – Handouts

The Parenting Journey

- ♥ Family Voices Advocate Tip Sheet
- ♥ Advocacy Roles Parents Can Play



PART B

Public Support Systems Available to Assist You and Your Child



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The Story, Part B

When Emma was several months old and was medically stable, Fred and Sue realized that they needed a break from the intensive care they were providing to both their daughters. They mentioned this to Jody, their county service coordinator, who immediately realized that she should have already made a referral to the county's Family Support Program. Jody began a conversation with Fred and Sue about different services that Emma could be eligible to receive. Fred and Sue were very confused about how all of these services worked together, so Jody illustrated ways in which the federal, state and local systems of support were coordinated.



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Questions and Considerations

- ♥ What are some of the programs and supports that you and your family are already involved with on your journey?



The Relationship Between Federal, State and Local Programs

Federal Government provides Funding and Requirements to

State Governments who provide Funding and Requirements to

Local Systems of Services, including Counties



Wisconsin Services for Children with Disabilities

- ♥ In Wisconsin, the delivery of some services are the same for all children (statewide programs) and some services differ in delivery, availability and waiting lists from county to county (county based programs)



County Delivery of Services

- ♥ In Wisconsin, the county governments have a lot to do with how, and to what extent, services are delivered to both children and adults with disabilities
- ♥ There is great variability in the delivery and quality of services among all 72 of Wisconsin's counties
- ♥ Important to continually keep county supervisor's aware of issues that affect your child and your family



County Based Programs

- ♥ Family Support Program (FSP)
- ♥ Medicaid waiver programs, including CIP, COP, Children's Home and Community Based Waivers
- ♥ County services, e.g. Respite Program
- ♥ Community Support Program (wraparound)



Statewide Programs

- ♥ These programs include:
 - ▶ Birth to 3 Program
 - ▶ Medicaid card health services
 - ▶ Regional CYSHCN Centers
 - ▶ Early Childhood through the public schools with IEP
 - ▶ K-12 education through the public schools with IEP
 - ▶ Transition services (14 – 21) through the public school with IEP (although services vary greatly between school districts)
 - ▶ Social Security Programs (including Supplementary Security Income (SSI))



Federal Programs

- ♥ Some federal programs that affect CYSHCN include:
 - ▶ Centers for Medicaid and Medicare Services (CMS)
 - ♥ Provides funding for Family to Family Health Information Centers
 - ♥ Medicaid services
 - ▶ Maternal and Child Health Bureau (MCHB)
 - ♥ Provides funding for Wisconsin's Title V program and its Regional CYSHCN Centers
 - ▶ Office of Special Education Programs (OSEP) from the US Department of Education
 - ♥ Birth to Three Programs
 - ♥ School based special education
 - ▶ Social Security Administration (SSA)



Part B – Handouts

Public Support Systems

- ♥ Wisconsin Services for Children with Disabilities
- ♥ State Level Councils, Boards, Committees and Organizations



PART C

PRIVATE HEALTH INSURANCE



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The Story – Part C

Two parents, Fred and Sue, are both employed. Health insurance is offered through Sue's employer, for which she spends \$200/month to cover her family. They have three children, one of whom has special needs. Their children, Katy age 16; Emma, age 13, who has cerebral palsy and developmental delays; and Ali, age 10, live at home with their parents in Wisconsin. They recently moved within their state to Wisconsin from Parkopia where they were getting wonderful services for Emma. Their move was precipitated by a job change for Sue. They anticipated that the services for Emma in Wisconsin would be the same as they were in Parkopia.

On the first day of Sue's job, she met with her human resources director who gave her information on her family's health insurance plan. The plan seemed fairly comprehensive to Sue and she was pleased with that. However, when Sue asked about a particular hospital, she was informed that it wasn't a part of the plan.



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Lost in Stuckville

- ♥ What is most important for you when you think about your child's health care coverage?
 - ▶ Choice of specialists
 - ▶ Location of doctors
 - ▶ Primary care doctor
 - ▶ Services/durable medical equipment



The First Question to Ask: Type of Plan

- ♥ Am I in a managed care plan or do I have fee for service coverage?
- ♥ Managed Care Plans are also known as Health Maintenance Organizations (HMOs), Preferred Provider Organizations (PPOs), or Care Management Organizations (CMOs)
- ♥ Do you know the difference between the two coverage plans?



Fee for Service Plans

- ♥ You can typically use any doctor you want, as long as they accept your health insurance.
- ♥ Need to know what your deductibles and co-pays are. Also need to know maximums that you will need to pay and limits (ceilings) of what your insurer will pay.
- ♥ Insurers often will pay “reasonable and customary” costs – you might be responsible for expenses over what the insurer defines as such.



Managed Care Organizations

- ♥ Most common form of coverage and usually more affordable than fee for service coverage.
- ♥ If I am in managed care, I need to know who providers are and if you can ever go “out of network.”
- ♥ Need to know the rules and policies; when Prior Authorizations are needed; whether or not there are any exceptions that would allow you to go out of the network. May have additional costs if you go out of network.



The Benefits Plan

- ♥ Insurance covers only what is written into the Benefits Plan
- ♥ This Benefits Plan is not the marketing brochure you might get – it is the legal binding contract between you and your insurance company. It defines what is and is not covered. And, it can sometimes be ambiguous.
- ♥ You can get a copy of your benefits plan from your employer's human resources office
- ♥ Reality Check – How often do you get to read a plan or policy before accepting a job?



What is in Your Benefits Plan?

- ♥ Benefits – what is covered ? What about caps on services (especially therapies?)
- ♥ Exclusions – what is not covered ?
- ♥ List of providers – who can we see ?
- ♥ Who makes medical decisions in your plan?
- ♥ What about pre-existing clauses? Is this a concern?
- ♥ What is your appeal process?
- ♥ Can your policy be renewed automatically? Can it be cancelled? If so, with what notice?
- ♥ Where can I seek help if this is “Greek to me?” Is there a customer service representative who can REALLY help me?



How Can You Protect Yourself?

- ♥ Read your benefits plan
- ♥ Understand what it says
- ♥ Get help from your employer or the insurance company or an advocate if you don't understand something
- ♥ Work in collaboration with the insurer
- ♥ Never take no as the final answer – if you receive a denial for services, find someone to help you. Sometimes an advocate can assist in getting the answer changed.



Part C – Handouts

Private Health Insurance

- ♥ Family Voices Handout: Private Insurance Issues
- ♥ Family Voices Handout: Private Insurance Checklist



Part D

Selecting a Primary Physician



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The Story – Part D

Sue noticed that some pediatricians that were recommended to her by neighbors were included in the plan. Sue realized that she and Fred needed to choose one doctor for their children's primary doctor, but they didn't have time to interview the prospective doctors. So, Sue and Fred chose the pediatrician that was closest to their home.

Sue, being a proactive parent, set up an appointment for each of girls to meet Dr. Smith before an illness occurred. At the visit, Dr. Smith was cordial, but seemed put off by Emma's challenges. There wasn't an examination room big enough for Emma's wheelchair, her mother, and her sisters (who help advocate for Emma) and Dr. Smith didn't seem comfortable with Emma and didn't understand why her sisters were at the



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The Story, Part D, continued

appointment with her. He did not address her directly, like he did with Katy and Ali. He also referred to her as wheelchair bound and mentally retarded. His mannerisms and use of out of date language indicated that he was out of the loop of working with youth with disabilities.

This first appointment left Sue and her daughters feeling very uncomfortable and disappointed that the doctor they chose was not compassionate and family centered as their former pediatrician, Dr. Swell.

The next day, Sue was still dismayed at the negative doctor's appointment. She decided that she and Fred needed to make time to interview other potential doctors. She referred back to her list of primary care doctors who are participating in her health plan and decided that it would be a good idea to talk with them to determine a better suited physician for her daughters.



Lost in Stuckville

- ♥ What are the things you value most in a primary care doctor?
 - ▶ Location
 - ▶ Office staff
 - ▶ Knowing about child's disability or willingness to learn
 - ▶ Communication style/skills



Five Steps for Choosing a Primary Physician

- ♥ Step 1: Identify your health care goals for your child and family.
- ♥ Step 2: Identify those doctors that you want to further investigate.
- ♥ Step 3: Interview those physicians.
- ♥ Step 4: Reflect on your interviews.
- ♥ Step 5: Select the doctor and provide information about your child to this person and their staff.



Part D: Handouts

Selecting a Primary Physician

- ♥ Interview Questions to Assist in Choosing a Physician
- ♥ Interview Questions to Assess How a Clinic Operates



Part E

Partnership with Your Child's Health Care Provider



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The Story – Part E

After interviewing three doctors and selecting a wonderful pediatrician, Dr. Superb, Sue set up another first doctor's visit for the girls. They were all thrilled with Dr. Superb and her great compassion and respectful interactions with Katy and Ali. She asked a lot of questions about Emma and seemed to have a general knowledge of cerebral palsy. Sue and Dr. Superb talked about specialists that Emma might need. In reflecting on the meeting, however, Sue was concerned that Dr. Superb never spoke directly to Emma or addressed questions to her. Sue was hoping that she had located a doctor that could be with Emma as she grew into adulthood. But, Sue wondered, how could a trusting relationship develop between Emma and Dr. Superb if there were communication issues? Sue decided that she would need to talk with Dr. Superb about this concern before the next appointment.



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Lost in Stuckville

- ♥ What kind of relationship do you want to have, and your child to have, with your child's primary physician?
 - ▶ If I want to be a partner in decision making with my child's doctor, how do I communicate that?
 - ▶ If I have a concern about the doctor's communication style, what do I do about that?



Four Things to Keep in Mind

- ♥ Remain realistic about what you can expect of your child's physician
- ♥ You are part of the health care team. This means that you have responsibilities for communicating effectively with your child's physician, keeping records, and following up. Good reciprocal communication is key to almost everything.
- ♥ Doctors are human and, like you, may occasionally be frustrated by your child's condition or the lack of answers to questions.
- ♥ Don't give up – be persistent!



What You Should Expect from Your Doctor's Office: The Medical Home

- ♥ A medical home is not a home with a lot of medical equipment. It is not a place at all.
- ♥ A medical home meets not only the medical needs, but also the educational, developmental and emotional needs of the child.
- ♥ Ideally one team of health care providers will care for a child's acute as well as preventative and primary care needs.



What You Should Expect from Your Doctor's Office: The Medical Home, continued

- ♥ A medical home must be built on a foundation of trust and respect, which requires time, commitment, problem solving and a lot of dialogue.
- ♥ A medical home provides coordinated and comprehensive care because it has been built with communication and collaboration.
- ♥ A medical home supports care in the home, within the community, whenever this is possible. It seeks to maximize function for not only the child, but also for the family and the community.



Part E: Handouts

Partnership with Your Child's Health Care Provider

- ♥ The Medical Home Family Index
- ♥ Family Voices: Before, During and After the Appointment



Part F

Medicaid



The Story – Part F

During an early appointment, Sue expressed concern about the ongoing expenses of diapers and over the counter medications for Emma's allergies and digestive issues. Dr. Superb's nurse, Sheila, asked Sue about her health insurance coverage for Emma. When Sheila mentioned public health insurance (Medicaid) to Sue, Sue commented that she assumed that Emma was not eligible because the family wasn't poor.



The Story, Part F, continued

Sheila explained that children with significant disabilities could be eligible for Medicaid regardless of family income and that Medicaid could be helpful to the family as a second source of health care payment. Sheila said that Medicaid would pay for Emma's diapers and her expensive over the counter (non-prescription) antacids and allergy meds. Sheila gave Sue the contact information for Wisconsin's Katie Beckett consultant and suggested that she begin the application process.



Lost in Stuckville

♥ What do I need to know about Medicaid?



What is Medicaid and Why Should I Care About It?

- ♥ Medicaid is sometimes referred to as Title 19, Medical Assistance or MA.
- ♥ Federal program managed and partially funded by states – each state is different
- ♥ Administered by the Wisconsin Department of Health and Family Services (DHFS)
- ♥ Wisconsin has a generous state plan



What are the Doorways into Medicaid?

- ♥ Two common ways define eligibility: by disability and by income
- ♥ Disability eligibility: Katie Beckett; SSI
- ♥ Income eligibility: SSI, BadgerCare, W2, Healthy Start



Medicaid is Medicaid

- ♥ Regardless of the doorway into Medicaid, Medicaid card benefits are the same. However, differences may exist in access to providers and co-pays, depending on doorway entered.
- ♥ Card benefits refer to services that are covered by showing your blue Forward card. Providers often will run this card through a scanner to see if you or your child are still covered.



What is the Katie Beckett Program?

- ♥ In Wisconsin, children and youth (up to their 19th birthday) who have a disability and requires an institutional level of care may qualify for Medicaid through the Katie Beckett program. Only the child or youth's income and assets are considered, not the family's income and assets.
- ♥ Eligibility is reassessed annually – children who receive Medicaid through the Katie Beckett program must continue to meet the level of care requirements. As of July 2006, proof of citizenship is required.



Can My Child Have Both Private and Public Health Insurance?

- ♥ Yes!
- ♥ Medicaid is the payer of last resort – all other insurances pay first.
- ♥ Medicaid can cover private insurance co-pays
- ♥ Medicaid can cover additional therapies and services for your child above those covered by your private health insurance.



What Kinds of Things Can the Medicaid Card Pay For?

- ♥ Services needed due to “medical necessity”, including diapers for children over age 4, medical transportation, personal care services, and mental health services
- ♥ Health Check (Early and Periodic Screening, Diagnosis and Treatment – EPSDT) and Health Check Other Services
- ♥ Home and community based services authorized under a waiver
- ♥ Complete listing can be found at:
<http://www.emhandbooks.wi.gov/meh/>



What are Medicaid Waiver Programs?

- ♥ Waivers are a way to use Medicaid funding in a flexible way
- ♥ Wisconsin has several waivers. Some are for particular age groups and others are for particular disability groups.
- ♥ Waivers used in Wisconsin that can be used for children include the Community Options Program (COP), the Community Integration Program (CIP), the Brain Injury Waiver, and the Children’s Long Term Support Waivers.



What are Waiver Programs, continued

- ♥ The Children's Long Term Support Waivers (CLTS) serve kids living with their families who meet the level of care in one of three areas of disability: physical disabilities, developmental disabilities, and severe emotional disturbance. The level of care required is an "institutional" level of care, the same level of care that is needed to access Medicaid through the Katie Beckett program.
- ♥ A parental cost share was implemented on a sliding fee scale, effective during the summer of 2005.



Tell Me More About HealthCheck and HealthCheck Other Services

- ♥ A Health Check exam provides comprehensive health checkups
- ♥ Health Check Other Services covers medically necessary goods and services not typically covered by Medicaid. Needs to be prescribed as an outcome of a Health Check coded exam. (Also known as a comprehensive inter-periodic exam.)



What is the Process for Getting Services through Health Check Other Services?

- ♥ After the Health Check exam, get a prescription for the service/equipment from your child's doctor. The prescription must have the date of the health check exam and the name of the provider who conducted it.
- ♥ Take the prescription to the Medicaid certified provider
- ♥ The provider may need to do a prior authorization request – important to write “Health Check Other Services” in big letters across the top of the PA request
- ♥ The provider needs to write “Health Check Other Services” when billing Medicaid for the approved services



Best Kept Secrets of Medicaid

- ♥ It bears repeating that Medicaid pays for:
 - ▶ Personal care
 - ▶ Diapers
 - ▶ Therapy equipment
 - ▶ Over the counter medications
 - ▶ Additional therapies and services



Part F: Handouts

Medicaid

- ♥ Medicaid 101
- ♥ Wisconsin Medicaid Programs 2005 – 2006
- ♥ Description of Services Under the Waiver
- ♥ Step by Step Guide to Health Check Other Services



Part G

Prior Authorizations and Getting Services and Supplies



The Story – Part G

When meeting with Emma, Dr. Superb determined that she needed to have physical therapy at the community clinic that specializes in treating children with cerebral palsy. Dr. Superb also thought that Emma would benefit from a communication device, so an appointment was set up with a community specialist to do an augmentative communication evaluation. Sue was thrilled that she finally found a pediatrician who could relate well to each of her children and was supportive of her and Fred as well.



The Story, Part G, continued

Sue located a community based therapist who could provide physical therapy. At the end of the initial evaluation, the PT identified a number of areas on which she wanted to work with Emma. The PT requested a copy of Emma's IEP, explaining that she needed to work on things that the school wasn't addressing. A few weeks later, the therapist found out that the PA was denied. Sue was distraught, as the doctor prescribed therapy as a way to avoid surgery. Sue called Sheila, her very helpful nurse in Dr. Superb's office, who said that she would talk with the PT to see what might be done to appeal the decision. Sheila also suggested that Sue call her Regional CYSHCN Center for assistance in seeing what can be done about the denied prior authorization request.



Lost in Stuckville

Are there things my child needs that I've been told my insurance doesn't cover?



Medical Necessity

- ♥ Medical necessity is the standard used to evaluate all requests for services
- ♥ DHFS definition: "Wisconsin Medicaid reimburses only for services that are medically necessary as defined under DHFS medically necessary service is defined as a covered service that:
 - ▶ Is required to prevent, identify, or treat a recipient's illness, injury, or disability.
 - ▶ And meets the following standards:



Standards of Medical Necessity

- ▶ Is consistent with the recipient's symptoms or with prevention, diagnosis or treatment of the recipient's illness, injury, or disability;
- ▶ Is provided consistent with standards of acceptable quality of care applicable to the type of service, the type of provider and the setting in which the service is provided;
- ▶ Is appropriate with regard to generally accepted standards of medical practice;
- ▶ Is not medically contraindicated with regard to the recipient's diagnoses, the recipient's symptoms or other medically necessary services being provided to the recipient;
- ▶ Is of proven medical value or usefulness and, consistent with s. [HFS 107.035](#), Wis. Admin. Code, is not experimental in nature;



Standards of Medical Necessity, continued

- ▶ Is not duplicative with respect to other services being provided to the recipient;
- ▶ Is not solely for the convenience of the recipient, the recipient's family or a provider;
- ▶ With respect to prior authorization of a service and to other prospective coverage determinations made by the Department of Health and Family Services (DHFS), is cost-effective compared to an alternative medically necessary service that is reasonably accessible to the recipient; and
- ▶ Is the most appropriate supply or level of service that can be safely and effectively provided to the recipient.

This definition applies to all Medicaid services.



Prior Authorizations

- ♥ Why are they so important?
- ♥ Why are they so complicated?
- ♥ Who makes the decisions to approve or deny the request?
- ♥ Families must be proactively involved in the development of prior auth requests.
- ♥ Who's job is it to get the PA? How do I know when one is needed? How do I know if/when it needs to be renewed?



Considerations When Approving a Prior Authorization

- ♥ Whether the service is medically necessary and appropriate
- ♥ How much it will cost
- ♥ Whether it is likely to be effective, of high quality and at the right time
- ♥ Whether there is a less expensive or more appropriate alternative
- ♥ Whether the provider or recipient has overused or misused services



Steps for Getting Services and Supplies or Equipment

- ♥ Identify needs, including in-home supports
- ♥ Doctor writes prescription
- ♥ Family and/or doctor identifies provider
- ♥ Family works with provider to submit PA
- ♥ Submit PA to private insurance and Medicaid simultaneously
- ♥ PA's are approved for time and intensity; be aware of submission rules
- ♥ If approved, services are provided
- ♥ If denied, work with the provider to file an appeal



Common Misconceptions

- ♥ Providers will say that something is not covered if they don't want to do a PA or if a PA was denied
- ♥ Providers sometimes forget to stress medical necessity in the PA – services must be medically necessary!



Avoiding Duplication of Services

- ♥ Educational necessity vs. medical necessity
- ♥ Avoiding duplication of services
- ♥ Identifying an ally to work with you
- ♥ Importance of the IEP to include service delivery



Denials Happen...What to Do

- ♥ Accept every opportunity to appeal and don't miss deadlines – an appeal request must be filed 45 days after the denial. **IMPORTANT** – if you are already receiving Medicaid, and the request is filed within 10 days, Medicaid must continue providing benefits until the decision from the hearing officer is received
- ♥ Develop a paper trail: documents, letters, phone calls
- ♥ Get as much detail of the denial as possible – keep your appeal specifically focused on the reason of the denial
- ♥ Present information in an objective manner, but don't hesitate to present the human side of the needs of your child and family
- ♥ If possible, bring your child to the hearing. Also consider an advocate, friend, therapist or family member.



Part G: Handouts

Prior Authorizations and Getting Services and Supplies

- ♥ School and Community Based Services Brochure
- ♥ Follow Up to a Prior Authorization denial



Conclusion

Wrap Up and Evaluation



Regional CYSHCN Centers

- ♥ Contact the Center that serves your county if you have specific questions about health care coverage or access and community resources. They are an invaluable source of information for the entire state, and for your particular county and community.



Family Voices of Wisconsin

- ♥ Developing a network of parents who are learning about, thinking about, and working on improving a system of health and community resources
- ♥ Newsletter
- ♥ Email notices of opportunities
- ♥ Parent trainers network



Wrap Up

- ♥ Remember your supports and call on them for help – your insurance plan/provider; case managers; school team, friends, family. There are many advocates and resources to help you with your journey. Good luck!

- ♥ Evaluation



Contact Us!

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