

INTRODUCTION TO TEAMS

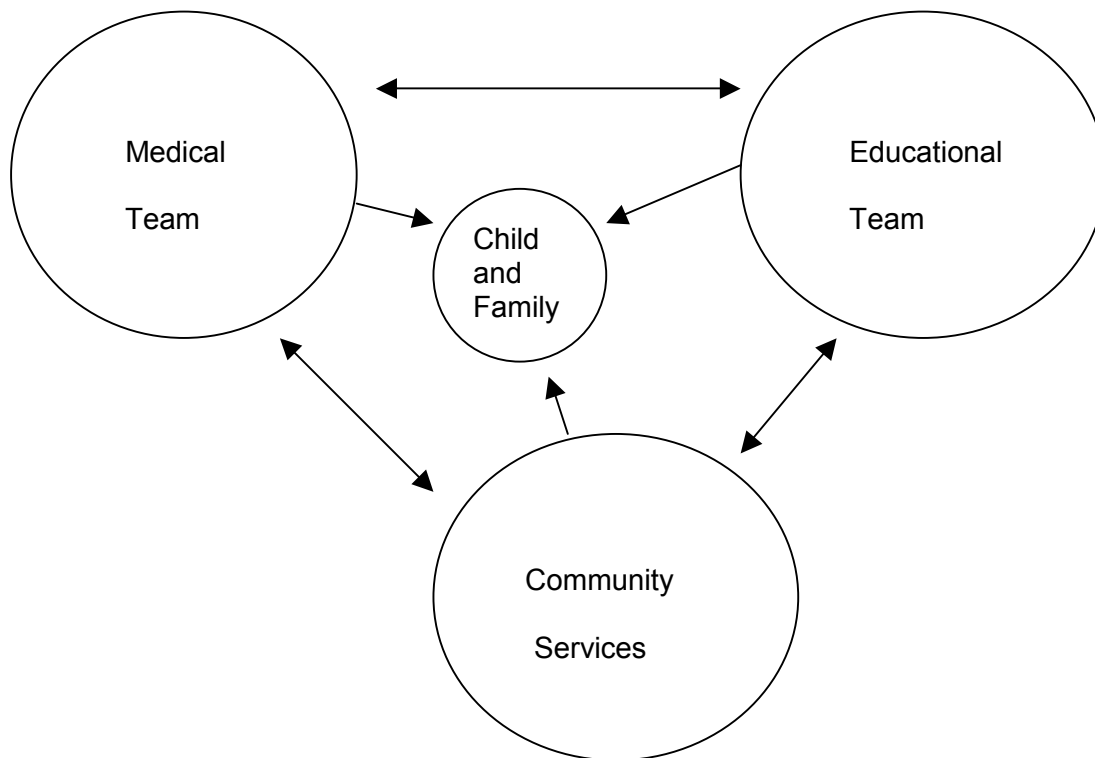
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All children with CHARGE are unique and often absolutely delightful. Underneath all the possible medical and educational challenges is a terrific human being who wants to be a part of the family and community just like every other child. Regardless of the number of medical and sensory issues, every single one of these children has the potential to learn, to communicate and to lead a satisfying life.

This is not to say that no challenges exist. They do, to a greater or lesser extent. It would be wise to keep in mind, however, that the way the children deal with their own challenges may reflect the attitudes of the people around them. As in all relationships, the more positive we are, the more positive they are.

Because each of the many possible medical findings in CHARGE can vary from being absent to profoundly affected, no two children have exactly the same findings. As a result, a variety of specialists enter the lives of families to deal with the different individual issues. The parents themselves are the only ones that stay constant in the life of the child as professionals come and go. They may need to interact with a variety of specialists, many of who have never heard of CHARGE. By default, the parents become the tireless teachers, team leaders and case managers.

Families will interact with three major systems: medical, educational and community services as shown in Figure 1:



Coordination of services and communication between systems (teams)

When many different specialists are needed in any of the systems, it is usually necessary to have a **coordinator** within each system. If one coordinator is not automatically assigned, the family would be wise to ask for one. In reality, the parents (most often the mother) are the ultimate coordinators.

Somehow information needs to flow within and between the systems, each of which has its own way of doing things. The ideal would be for the coordinators from each system to talk to each other, but this may be difficult. It is often difficult to get member of the *same* system to communicate with one another.

Typically, *medical* people deal with other medical people in writing, both because of the legal requirements and because they may not be able to talk to each other because of time or distance. They will write a summary letter when requested to do so. You can request copies of these letters as well as other medical records. You can request copies for yourself and/or copies to be sent to others.

Typically, *educational* people talk to the classroom teacher (not always to the parent) and put their findings in writing only when requested. Again, you can request written summaries be done and have copies made for you and others. Certain summaries that deal directly with the assessment of medical issues (e.g. Functional Vision Evaluations and Audiograms) should also be sent to the medical coordinator.

Each of the *community agencies* has a different way of dealing with issues, so some keep written records and many do not. This means it may be hard for the family to keep track of what is going on. You should ask for written reports at every opportunity. These records will come in handy whenever the child has to move from one system to the other but especially going from one town to another.

TEAMS AND RESOURCES

Jeanne McMullen, mom to Caitlyn (age 6) CHARGE
Pittsburgh, PA

Effective management of the child with CHARGE Syndrome has always been a work in progress for us. The key is to develop a good team of professionals around you. Consider yourself the team captain and your service providers the players. Continually evaluate which team members are playing their positions optimally and which ones are not, for if one position is slacking, it affects the child's ability to function as a whole. Often our mistake has been to stay too long with a doctor or program, yet if someone is not pulling his weight now, he never will. Remember, "Keep the best; replace the rest."

The Medical Team

When attending appointments whether at school or the **doctors**, go prepared to do business. Dress professionally, and come prepared with any documentation to back up your concerns. This may include physician reports (remind each physician to "cc" every report to you and request a copy of all evaluation and lab results for coordination of care), diary of ongoing symptoms as they occur, or communication book from school. Write down your concerns ahead of time (use the Medical pad that comes with the Manual). Remember to prioritize your concerns. Seeing a physician with more than three concerns in one appointment may confuse the doctor and allow you both to be sidetracked. Marathon IEP meetings leave you not thinking clearly, and end unresolved. Remember you can always schedule follow up appointments.

Upon return home, jot down a detailed minutes of the appointment including what concerns discussed were left unresolved. Using a spiral bound notebook for each (medical, educational, and community), will give you something admissible in court should the need arise. Spiral bound, not loose leaf, cannot be added to at a later date and carry more weight with a judge.

Personality conflicts and differences of opinion will be inevitable, but if you keep your cool, your opinion will be respected and heard. Many professionals have experience dealing with irate parents and will often just respond by ignoring them. Keeping the lines of communication professional and amicable will alleviate stress and in the long run work in your favor. Being pleasant doesn't have to mean being a pushover. Be firm.

My medical team is constantly changing. A good doctor must be a good listener and must address concerns adequately. I have learned that the "best in the city" is often not the best for us. Doctors with overblown reputations are often overscheduled and have students or new technicians doing much of the examining. They allow little time for parent concerns, and mistakes can be made in their rush. Include **nurses** in your team. They are easier to reach, are often better listeners, and can handle many problems themselves.

Learn the system at the hospital. Most hospitals have a **patient advocate** who you should get to know before a problem arises. Ours has been instrumental in cutting through "red tape" when scheduling dual procedures, searching for lost records and handling complaints. During long recoveries following surgeries, having her assistance meant we could grab a bite to eat or

use the facilities--something necessary to get us through the day. Take advantage of their **home health care coordinator** when faced with problems regarding your home care providers.

The Community Team

Advocating for services in your community takes time and will never end. Start with your **blue pages** in the phone book. Many large cities maintain help lines that parents can call like “The Special Kids Network” in Pennsylvania. **Parent-to-Parent** is a good way to start too, for most parents know far more about the system than any single professional can. Most states have programs under “**Family Support Services**” which provide services and funding for therapeutic programs not covered by insurance such as therapeutic horseback riding or assertive technology. Eligibility requirements and services vary from state to state. In Pa., like many other states across the U.S., the transition from institutionalized care to family centered care has become a priority. Here, eligible children are granted intensive therapeutic services to teach them more independent and appropriate behavior at home and in the community. These services, which can alleviate some of the burden and stress at home, are often only available to those families that hear about them from other families and then advocate effectively for them.

Your local schools serving deaf and blind children often have catalogues for recommended toys and other resourceful information that can help even when your child is still too young to attend. The **library** often can do funding searches for you when looking for grants. Organizations such as **Easter Seals** often have loaner assistive technology you can try before making a major purchase.

Only by chance have we learned about programs in our state which not only allow my child **Medical Assistance** but also pay her monthly premiums to keep her on private insurance as well. Through trial and error, we learned how to effectively advocate for reimbursement for traditionally noncovered services such as transportation expenses (MA transportation program), nutritional supplements (**WIC**), and even adapting her tricycle (investigating the MA system and appealing). We have been fortunate to have a **toy-lending library** in our city whose primary goal is to provide an accessible and inclusive play-space for children of ALL abilities to play together. They have been instrumental in helping families like me secure state funding to hold workshops, camps, and build more programs that serve our needs.

The Educational Team

Every state in the U.S. must maintain a help line for concerns regarding educational rights like the “**Parent Education Network**” in our state. They can answer questions over the phone as well as offer workshops on educational advocacy. Ironically, good advocacy skills may be necessary to find a good educational advocate to help you, as the system is overworked and underfunded. Most **educational advocates** will often only support you in your role as advocate, as opposed to advocating for you. We have been fortunate to find one at our county. His role has been carefully defined as to not “get parents what they want” but to insure legal compliancy within the school district, which is basically all you really want or need in an advocate. As you build your support team in the community, friends, social workers, etc., remember many of them can be utilized at IEP meetings to avoid being outnumbered. Having support at these meetings can alleviate stress as well as having witnesses for possible due process.

They say it “Takes a Village.....”. It cannot be more true when you have a special needs child. When my daughter was an infant, her medical needs were far too intense, and we as parents far too naive that we were unable to handle anything more than our grief. *Yet, a few well-placed phone calls in the beginning would have saved us thousands of dollars, would have made a difference in our daughter’s access to care and services, and resulted in a better quality of life then and now.* Now, I have become a parent many turn to for information. As I help them, they help me, for there’s always something they’ve learned that I haven’t (like using adult socks to teach my daughter initial dressing skills). Learn the system. Develop relationships. And NETWORK, NETWORK, NETWORK!

EDUCATIONAL TEAMS

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The educational team is a group of people who join together to collaboratively design and carry out plans for a student in special education. The team approach allows many people with different perspectives to come together and work to enhance the education of the student. Each team member may have specific knowledge about certain areas of a child's education (for example, a physical therapist has knowledge of a child's gross motor abilities). However, when all members come together and share knowledge, everyone's expertise on the child is enhanced. The team may address discipline-specific issues or general issues. For example, an issue of communication and behavior may lead to ideas from the speech and language pathologist. However, all team members working with the student may contribute to this discussion by talking about how the child communicates and behaves with each of them. In that way, a bigger picture is seen, and solutions come more easily. When members share their knowledge, it can lead to sharing roles. Each member becomes aware of all aspects of the student's learning. Here is a list of common team members and their typical roles with students:

Team Member	Knowledge Area
Parent	General
General Education Teacher	General Curriculum
Special Education Teacher	Social/Self-Help/Cognitive/Curricular Adaptations
Instructional Aide	Carry out instructional plans with student
Speech and Language Pathologist	Communication/Language/Speech
Occupational Therapist	Fine Motor, Oral-Motor, Sensory, Functional Adaptations
Physical Therapist	Gross Motor, Sensory, Posture, Endurance, Mobility
Audiologist/Hearing Specialist	Hearing Aids, Hearing Ability, Auditory Training
Vision Teacher	Vision Ability/Visual Adaptations
Orientation and Mobility Instructor	Cane Skills, Routes, Mobility
School Psychologist	Assessment, Behavior, Educational Recommendations
School Social Worker	Counseling, Social Skills, Community Connections and Resources
School Counselor	Counseling/Therapy/Social Skills
Building Principal	Resources/Schedules
Special Education Administrator	Resources/Special Education Rules

Teams **evolve**. Not everyone comes to the table with an idea about what will happen. Rainforth & York-Barr (1997) explain:

The primary function of collaborative educational teams is to support students with disabilities during their public school years to acquire the knowledge, skills, and dispositions to lead meaningful, contributive lives. This work is given specific focus through each student's IEP. . . Not all team members come to a team with clarity of purpose regarding educational process and outcomes or their respective roles and contributions; certainly, not all team members come with *shared* clarity of purpose. As members work together, clarity emerges (p. 250).

Team Leadership. A team will need a leader. This is often the case manager, or special education teacher, although anyone else on the team, including the parent, could take on this role. This person will need to organize agendas, check schedules, send out notices and minutes, and facilitate the meetings. The team may choose another member to record the minutes. The team facilitator's role is one of cheerleader. This person must support and encourage other members of the team.

The parent's role. Parents should be welcomed as equals in any team that forms around their child. A parent's role on the team is to provide information about the child, make suggestions about strategies that may work with the child, and advocate for the needs of their children, among other things. Although advocacy means speaking up for what you believe is best for your child, it is best to do this in an assertive, but not aggressive way. The team process may seem as if is stalling at times, but it does take time for everyone to come around to one person's way of thinking. If you can, find a way to advocate without being adversarial. And always remember that you are the expert when it comes to your child. You know your child better than anyone!

TWO SCULPTORS

*I dreamed I stood in a studio
And watched two sculptors there,
The clay they used was a young child's mind
And they fashioned it with care.
One was a teacher; the tools she used
Were books, music and art.
One, a parent who worked with a guiding hand,
And a gentle, loving heart.
Day after day the teacher toiled
With touch that was deft and sure,*

*While the parent labored by her side
And polished and smoothed it o'er.
And when at last their task was done,
They were proud of what they had wrought;
For the things they had molded into the child
Could neither be sold nor bought.
And each agreed he would have failed
If he had worked alone,
The parent and the school,
The teacher and the home.*

Author Unknown

For more information about educational teams, the following resource, quoted in this document, is very helpful:

Rainforth, B. & York-Barr, J. (1997). Collaborative Teams for Students with Severe Disabilities: Integrating Therapy and Educational Services, Second Edition. Baltimore, MD: Paul Brookes Publishing.

ROLES OF PEOPLE ON YOUR EDUCATIONAL TEAM

EDUCATOR	ROLE
Teacher – Classroom	
Teacher – Special Ed	
Teacher – MSMI	
Teacher – DHH	
Teacher – Vision	
Teacher – O&M	
Teacher – DB Specialist	
Teacher – DAPE	
Teacher –	
Intervener	
Paraprofessional	
Interpreter	
OT	
PT	
Speech	
Audiologist	
Psychologist	
Principal	
Guidance counselor	
Director of Special Ed	
RLIF	
Vocational specialist	
Parent advocate	
SSB counselor	

A CIRCLE OF FRIENDS

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A Circle of Friends is a circle of support, which forms around a person with a disability. It is meant to be a support to the person's inclusion into the school, community, and workplace, and thus, is considered an "inclusion tool". The person with the disability invites who he or she wishes to be involved in the circle, based upon who they feel supports them in their lives. For a person with limited communication skills, those closest to the person (parents, for example) would decide who would be invited.

Circles of Friends often start by using a person-centered-planning process: Making Action PlanS (**MAPS**), Personal Futures Planning, or Planning Alternative Tomorrows With Hope (**PATH**). Then the action plan is carried out by the members of the circle. Here are my experiences with it:

I am a member of a circle for a 35-year-old woman who has significant disabilities. After carrying out MAPS and action plans, we successfully assisted her in finding the needed supports to move from a sheltered workshop where she was doing meaningless piecework and hating her life, to a job in the community. The people involved in her circle were able to advocate with the agencies serving her to free up the money used for the segregated program to be used for the integrated program. She now has an in-home assistant who facilitates her inclusion into the community. Our next step as a circle will be to attempt to help her move from her parents' home to a home of her own, with the needed support. She is so much happier.

Circles of friends may or may not involve professionals, depending upon whether the person feels these folks are part of her/his support network. This person included her Developmental Disabilities (**DD**) caseworkers in her circle. Community Mental Health, the agency responsible for services to the DD population in Michigan, also supplied the circle facilitators.

The MAPS process is facilitated by two people: a verbal facilitator and a graphic facilitator (who records the ideas of the others through the use of words and imaginative graphics depicting the ideas so that everyone can access them).

My son Jacob's circle of friends includes his school friends, for the most part, although the deaf-blind consultant attends and helps facilitate. She has provided deaf-blind simulations, helped the kids come up with name signs for themselves to use with Jacob, and answered questions for the group. This year the general education teacher has been attending. This has never happened before, and really helps her to understand what the circle can provide to the school in terms of ideas for supporting Jacob. As much as we would like for the school personnel to attend, it happens seldom. We meet after school once a month, and the teachers just can't or don't want to stay that long, for something they don't understand. What is difficult is that I attend team meetings and circle meetings, and it is very clear to me that these two groups should be consulting with one another to facilitate Jacob's inclusion, but they just don't.

Jacob's circle has about 18 student members, about half boys/half girls. They have identified themselves over the years as the kids who really seem to connect with and care about Jacob in his inclusive setting (he is in sixth grade, this year). Although Jacob doesn't give these kids

much social feedback, they really care about him, and have hung in there with him. Most of them are charter members, since 1st grade. During each meeting we spend some time planning, snacking, interacting, and having fun. Until now, the circle has mostly focused on social interaction with Jacob. This year we are focusing more on transition to the middle school (there is only one middle school in town.) The kids have decided to go to all of the sixth grades in the city (six schools) to speak about Jacob and his circle of friends. Then when Jacob starts middle school inclusion, there will be (hopefully) much less "pointing at the freak" than there would otherwise be, because of understanding having been facilitated. Activities we have undertaken in the past couple of years have included the following:

Halloween party: the kids each bring a snack, decoration, and game that Jacob can access (usually they make something really neat), and something for the haunted house. (I don't have to bring anything!) They come in costume and have a great time. This year, after the db simulation, they decided to do the haunted house in the dark, to see what it would be like for a person who is blind.

Birthday Party: each year they decide to hold this in the same place, the local pool. They tried the gymnastic center one year, but Jacob hated it, and they learned that because swimming is his favorite activity, and because it is his birthday, the pool is a better place. One year in thinking about a party they were talking about what they would enjoy, and began to talk about going to a movie. One of the members spoke up suddenly and said, "We'd like that, but what would Jacob like?" The party was held at the pool.

Last year for his birthday they made him a quilt with photos of themselves scanned onto it. They decorated it with tactile paint, etc. We keep it on his bed, so he can see all of them. It is really beautiful. I will be bringing it to Indianapolis for my presentation on Circles, so all can see it.

Canoeing last summer: Jacob loved this. He sat in the middle at the bottom with another student sitting behind him, and trailed his fingers in the water. I didn't even have to be in his canoe, which made it much more fun for me!

School talent show: One year the circle did a "men in black" "Men in Black" number, really cute, all dressed up in ties and sunglasses, and Jacob was "the alien", because he was still using a wheelchair. They made (Jacob helped) a paper mache alien head to fit over his wheelchair, and we rigged up a jellybean switch for him to operate the lights in the eyes. It was a cool dance. You will see the video of that at the conference, too. Last year they did a number from Tarzan, Trashing the Camp. They dressed up as gorillas, and danced. Jacob and a few others stood in the back and were percussion, hitting pie plates with wooden spoons during the number.

One girl was running for student council president, and on her poster, she wrote:

"Activities I am Involved In:

Jacob's Circle of Friends

Junior Choir

Girl Scouts"

. . . . in that order!!! I was thrilled by this!

A volunteer special education student facilitates the circle each year from our university. This has worked out great, as I still have input, but much less work. She brings the snacks, supplies, etc.; I just reimburse her. Ideally, the circle would be facilitated during school by a teacher, and could include the whole class that Jacob is in. This is a different model, but would lend itself to more ideas being generated for inclusion in school lessons. This might be a good model for

Junior High.

Membership in the circle evolves, and will continue to. Some drop out, some join, but most stay the same. As they move away to college, etc., we hope people will continue to identify themselves as they get to know Jacob. We hope the circle continues throughout his life span, although this is difficult, as kids get busier with sports, adults get busy with studies, jobs, families. It will change, but hopefully, will always be there to fall back on in a time of crisis, even if through an email listserv!! Our ultimate goal is that Jacob will have a circle of support in place to take over decision making for him in case something happens to his father and me. He would have a guardian, of course, but also a "steering committee", with his best interests, dreams, and wishes at heart!

Another focus for us this year is fundraising. The kids (hopefully about 8 of them) are going to try to raise enough money to support their attending the CHARGE conference in Indy. I have invited them to help me present on Circles of Friends. I have had them do this in several forums before, and they do a GREAT job! I hope they can raise enough funds, because I really want all of you to meet these great kids. And their parents always extol the virtues of the circle, how valuable it has been to their character building, sensitivities to differences, compassion, and ability to think and plan for things. It also becomes a general circle of social support to all of them, not just for Jacob, but more and more for the group as a whole--they ALL support each other!

In a recent video interview, one charter circle member was asked why she thought the circle was important. I kind of held my breath, wondering what she would say. She blew me away. She said, "the circle is important because we help make sure that Jacob participates and is included in everything. That's important, because if he wasn't included in everything, he'd just be with teachers all day, and who would want to just be with teachers all day? That's no fun!" I loved that response, because it shows that she sees Jacob as a KID, first!

Lastly, these kids are the kids who will grow up to be leaders, workers, legislators, educators, etc. in our and other communities. They will use this experience to further the lives of people with disabilities in whatever career they pursue. They will grow up to be Jacob's employers, support persons, and friends, and employers, support persons and friends to others with disabilities. Jacob will have a group of people committed to ensuring he has a rich, life. Not just an integrated life, not just a life free of pain, abuse, neglect, segregation. An "enviable" life.

For more information on MAPs, PATH, PFP, or Circles of Friends, consult the following references:

Falvey, M.A. (1998). Inclusive and heterogeneous schooling: Assessment, curriculum, and instruction. Baltimore, MD: Paul Brookes.

Koegel, L.K., Koegel, R.L., & Dunlap, G. (1996). Positive behavioral support. Baltimore, MD: Paul Brookes

Pearpoint, J., Forest, M., & O'Brien, J. MAPs, Circles of Friends, and PATH: Powerful tools to help build caring communities. In Stainback, S., and Stainback, W. (Eds.), Inclusion: A Guide for Educators. Baltimore, MD: Paul Brookes

PERSON-CENTERED PLANNING

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Person-Centered Planning is a process that facilitates inclusion of individuals with disabilities into natural environments, including general education classrooms in neighborhood schools, work environments, and other aspects of their natural communities. These techniques employ the use of large group graphics (large paper and colored markers which “graphically” illustrate the points being expressed), and facilitation techniques that enable groups of people to learn more about and plan a more positive future for a person with a disability and their family (Koegel, Koegel, & Dunlap, 1996).

The outcomes gained through Person-Centered Planning techniques include:

- Being present and participating in community life;
- Gaining and maintaining satisfying relationships;
- Expressing preferences and making choices in everyday life;
- Having opportunities to fulfill respected roles and to live with dignity; and
- Continuing to develop personal competencies (Koegel, Koegel, & Dunlap, 1996).

All person-centered planning approaches begin with a focus on the wants and needs of an individual and recognize the importance of both formal and informal supports in assisting the person to achieve his or her dreams (Mount, 1994).

MAPs: Making Action Plans:

MAPs is a person-centered planning tool used with people with of all ages, and is frequently carried out by the person and their Circle of Support. A MAP has two facilitators. One who records what happens on large paper with colored markers, and the other facilitates the process. A personal and informal atmosphere is used (snacks, beverages, etc.) Everyone who is important in the child’s life is present and participates. The focus during the process is on what the person and/or the family want. There is commitment to a plan of action (what can be done right away) and a date is set to meet again (Pearpoint, Forest, & O’Brien, 1996).

The following questions are asked of the person and the Circle:

- What is this person’s history? What is your history with this person?
- What are your dreams for this person? What are this person’s dreams?
- What are your nightmares for this person? What are this person’s nightmares?
- Who is this person? (One or two word phrases)
- What are this person’s strengths?
- What are this person’s needs?
- What would a perfect school day look like for this person?/Action plan

From this person-centered approach, planning activities can then be carried out. These may include IEPs, team meetings, Circle of Friends activities, or anything else.

Pearpoint, Forest, and O'Brien (1996) write:

A MAP is not an academic exercise. A MAP is a genuine personal approach to problem solving. A MAP is for people who are vulnerable, and the outcome decisions of a MAP session have life and death implications for how the person will live his or her life. It is not a professionally controlled, expert-model, top-down management tool. A MAP is a group, problem-solving, cooperative, collaborative team approach to planning (p.74).

Circles of Friends: (or Circles of Support)

A Circle of Support is a group of students who come together regularly to share and problem solve with and around the life of a person with a disability. These can be formal (i.e., with a facilitator and scheduled meetings), or informal (i.e., a group of friends that meets at lunchtime at school). Formal Circles of Friends may start with a MAPs process, and move on from there to help the person with a disability realize his or her dreams.

For students, a Circle is typically facilitated by school personnel, such as the classroom teacher, with either a group of children or the whole class, on a regular basis, to assist with person-centered planning for the child who has a disability in an inclusive setting. However, a Circle may be facilitated by a family or community member, outside of the school setting. For adults, these may be facilitated by case workers, or friends. The goal is to eventually withdraw the formal facilitator and let the naturally occurring peer relationships take over. The circle may evolve into a support circle for each member, and not just for the person with a disability.

Pearpoint, Forest, and O'Brien (1996) write:

A circle of friends is not a trick or a gimmick; it is a powerful tool. Like a chisel, it can pry open one's heart, soul, and thoughts or create a work of art. A work of art does not happen overnight; neither does building circles or communities. Circles and community building are commitments. Circles and community building are as important as math, physics, or history and are part of a curriculum of caring (p. 77).

Personal Futures Planning (PFP) and Planning Alternative Tomorrows with Hope (PATH)

Personal Futures Planning and Planning Alternative Tomorrows with Hope are other person-centered planning tools, which expand on the MAPs process. All of these tools expand and alter the typical "system-centered" planning done for these individuals, and take into account the preferences, strengths, and individuality of an individual with a disability.

To implement a person-centered-plan or start a Circle of Friends for your child, contact your local agency serving people with developmental disabilities (i.e., in Michigan, Community Mental Health serves that purpose), or your child's school and ask them to research and carry out this process with your child.