

Parent to Parent Training:

Section I

Learning the Skills

Section II

Designing the System

A resource manual produced by:

Minnesota Technical Assistance for Family Support

Strengthening and broadening family involvement efforts



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Parent to Parent

Section I

Learning the Skills



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Quality Indicators of Effective Parent to Parent Support

Respectful

- Remembering who is in charge of the problems and solutions
- Behaving in a way that affirms a person's basic worth, regardless of their beliefs or actions

Objective

- Accepting a parent "as is" in their emotional adjustment, without prodding them to where they "should" be
- Withholding judgments to acknowledge varying points of view
- Sharing unbiased information

Warm

- Accepting
- Caring
- Understanding

Genuine

- Real -- no phoniness, pretense, or patronization

Empathetic

- Seeing the situation through the eyes of the parent
- Believing that everyone's actions and beliefs make sense from their perspective

Competent

- Completing and carrying out personal responsibilities
- Communicating personal thoughts and ideas clearly

Timely

- Making first contact within 48 hours of the referral
- Returning calls and following up promptly

Flexible

- Connecting, as appropriate, in a variety of ways (initial phone contact, visiting at family's home, meeting community site – coffee shop, fast food spot, etc. email)
- Responding to family structure, traditions, patterns, practices- culturally competent
- Meeting at times that work for the family

Easily available

- Easy to find – Reflecting widespread community awareness and ability to make matches quickly
- Easy to access – Streamlined referral process that reflects coordination between referral source and Mentor Parent



Effective Parent to Parent Support

“Mentor parents understand that the event that has altered their lives is painful. Parents do not have the power to change the event but they can change the way they think about it...New parents may not know this. Mentor parents are not saying it is easy, but they can teach this. They can plant the seed.”

Janice Wright, Parent to Parent of Vermont

Effective Parent to Parent Support can:

- **Ease** the pain. . . but not remove it
- **Affirm** or validate feelings or emotions . . . but not change, or control them
- **Offer** information and resources . . . but not provide a diagnosis, give advice or make decisions
- **Explore** options and ideas . . . but not solve every problem
- **Provide** a partner on the journey . . . but not fix the situation
- **Reduce** isolation . . . but not provide a social life or offer lifelong friendship
- **Encourage** with hope . . . but not predict the future
- **Foster** adjustment . . . but not force acceptance

In responding to the reality of life’s circumstances a parent has an opportunity to become someone new and different, to grow and learn, and become more than he/she is. Respectful Parent to Parent programs make a point not to undercut that growing process by making parents dependent on their help or advice, but rather to foster self reliance. Parent to Parent Support should not resemble a service that is done **to** families or **for** them. With effective support, families will find their own ways to survive and cope. They will create their own new reality and assume responsibility for their own lives.



Self-Assessment for Parent Mentors

Answer these questions.	Yes	No	Sometimes
1. Am I a good listener?	_____	_____	_____
2. Do I generally possess a positive outlook?	_____	_____	_____
3. Am I realistic, yet hopeful?	_____	_____	_____
4. Do I have a comfort with and an understanding of my own grief?	_____	_____	_____
5. Am I a creative and proactive problem solver?	_____	_____	_____
5. Am I open and comfortable offering support and emotional encouragement on a personal level?	_____	_____	_____
6. Do I believe that every child is valuable?	_____	_____	_____
7. Can I be honest, yet temper it with kindness?	_____	_____	_____
8. Am I flexible when changes occur or things don't go as planned?	_____	_____	_____
9. Do I have the time and energy to be a parent mentor?	_____	_____	_____
10. Can I support the individual decisions of parents even if I don't agree with them?	_____	_____	_____
11. Do I believe each culture has a right to its own beliefs and values?	_____	_____	_____
12. Am I ready for the emotional impact of connecting with another family?	_____	_____	_____
13. Have I successfully integrated a child into our family and community?	_____	_____	_____
14. Am I competent and able to carry out my commitments and responsibilities?	_____	_____	_____

Supporting other families requires commitment and effort. As parents of children with disabilities there are times when supporting other families is not what is best for me, my family or other families. I need to be aware of my situation and personal well being, and if being a parent mentor and supporting other families is not right for me at a certain point in time, I need to step out of the parent mentor role.



Grief and Lost Dreams

Grieving touches the lives of parents and other loved ones of children with disabilities. People experience grief in their own unique way. Each may follow very different paths as they deal with their own grief. For a husband and wife, or long-time partners, the paths can vary greatly and create their own unique set of challenges.

Siblings are also impacted by grief. Children often do not demonstrate their grief the same way adults do. A child or young adult's attention span is not as long as an adult's and just because they may go out and play does not mean they are not grieving. Remember, 'children love, therefore they grieve'.

A new reality often comes quickly and abruptly to parents of children with a disability. Although it is natural if at first the mind can't shift immediately, it is important at some point to move forward to acceptance and understanding. Parents who don't move ahead often become stuck in anger, denial, despair or high anxiety levels.

There are no set 'stages' of grief, specific 'cycles' to follow and no right or wrong way. Being the parent of a child with a disability can be an emotional roller coaster. There are some typical emotions and feelings associated with grief. A parent may or may not go through these and may feel them at any time. Some parents skip these emotions, some feel more than one at a time. Some typical emotions are:

Denial—Basic disbelief about a situation that exists

Accompanying feelings or actions may be:

- *'Someone has made a mistake'*
- *'This can't be happening to us'*
- *'At some point I will wake up and this will all be over'*
- *'If I acknowledge it or say it out loud that means it's real'*

Denial has some benefits: It can keep parents from feeling overwhelmed or protect a person until they can tap their own emotions, strengths and other support systems. It is also a sign of the beginning of acceptance of a situation. If there was not a situation to deny a parent wouldn't be in denial.



Despair—Being without any hope

Accompanying feelings or actions may be:

- Mourning as if there's been a death
- The aching sorrow or sadness that comes with loss
- Disappointment that things are not turning out as hoped or dreamed
- Self-pity—'Why me? Why my child?'
- Fear or anger turned inward
- Not participating or responding to what's going on
- Building a cocoon around myself

Every one who is dealing with despair is dealing with depression at some level. It is a part of grieving. When despair becomes all-consuming and paralyzing, it is appropriate and necessary to seek professional help.

Guilt—Feeling of having done something wrong that caused the situation

Accompany feelings and actions may be:

- Admonishing myself over what I may have done
- Questioning if there is something I could have done differently to avoid this
- Feeling deserving of blame for the situation
- Believing it is punishment for some act

Feelings of guilt and self doubt are normal for parents of children with disabilities. A challenge exists, however, if guilt becomes the only focus and self-blame becomes overwhelming.

Blame—To put the responsibility on someone or something else for causing the situation

Accompanying feelings and actions may be:

- 'This is not my fault'
- 'It must be from their side of the family'
- Blaming the messenger - doctor, therapist, family member or friend
- Intense desire to find out who or what caused this situation



Anger—A hostile or inflamed feeling

Accompanying feelings and actions may be:

- Strong feelings of resentment toward others who don't have to experience what I do
- Demonstrating aggression through verbal and non-verbal expressions
- Sense of frustration over such things as lack of action, other's lack of understanding
- Wanting to lash out and hurt others, so they feel the pain and loss
- Outbursts over what I perceive as injustices
- The word 'fair' is no longer in my dictionary

Anxiety and Fear—Being uneasy or worried

Accompanying feelings and actions:

- Uncertainty and concern about what the future may hold for my child
- Uncertainty and concern about how this child with a disability will change our life and family
- Tension in my mind and body
- Frenetic thoughts about what this may mean
- Constant movement to keep the worry at bay
- Kicking into 'high gear' and becoming super efficient

Acceptance and Adjustment are a part of grief. **Acceptance** is the realization and willingness to believe that something is true or a fact, and results in coming to terms with it. Acceptance can cause mixed emotions such as: resolution, sadness or relief. **Adjustment** means adapting to new circumstances, environments or conditions and often follows acceptance. Adjustment typically represents moving forward, getting on with what needs to be done.

Grief is a healing process, which never completely ends for parents of a child with a disability. Grief is normal and healthy and not to be avoided. It is important not to run from, deny or intellectualize the feelings. One thing is certain—we need an outlet for our emotions. The goal is to **cope** with the disability.



Lost Dreams

Lost dreams and the building and creating of new dreams are an integral part of grief. When a child has a disability many of the dreams for the child and family are lost. Dreams may change; personal and family activities may be different, expectations for education may change, as well as many expectations for the future.

It is difficult to have hopes and dreams lost and it is the reason we grieve. We grieve for the child we thought we were going to have, we grieve for the opportunities that will never happen, we grieve because the path for our child will not be as smooth as we had hoped.

The challenge is to see hope, promise and value in the child, find acceptance and make meaning of a new life, find a new normal for a family and open the door for new hopes and dreams to emerge. It will take time, but the joys over the accomplishments of a child with a disability can be rich and fulfilling. There will still be dreams, just different ones.



Supporting Those Who Are Grieving

Grieving is a process that takes time and cannot be denied. People approach grief very differently. Some may face it head on and take very specific steps to deal with their grief. Others may let the pain and feelings come at will and work through them in a less intense, direct or obvious way. How a person will grieve is best left to each individual. The support being provided to someone who is grieving should complement that person's style and approach. Some options for supporting people who are grieving:

- Asking people what they need.
- Giving permission to grieve.
- Validating feelings and emotions.
- Listening to someone who wants to talk quietly about what has happened.
- Listening to someone who is angry and needs to vent about what has happened.
- Being a silent partner for someone who wants company, but silence.
- Providing books, videos, poems or newsletters on grief, feelings or other parent's stories about their grief if requested.
- Connecting them to an appropriate support group or a grief support group if requested.
- Suggesting appropriate speakers or workshops if requested.
- Sharing appropriate ideas and suggestions about how other parents have approached grief if requested.
 - Express their feelings through writing, drawing, painting or other creative outlets
 - Organize keepsakes
 - Work through grief very pointedly and with intent
- Suggesting and searching out spiritual support for people if requested.
 - Pastor, clergy or other spiritual leader
 - Appropriate materials that will provide spiritual support
 - A parent from the person's spiritual circle who might be a match
 - Meditation
 - Spiritual readings
- Suggesting and seeking out professional counseling if requested.
- Being patient and kind to those who are grieving.
- Checking in periodically by phone or visits. Support for those who are grieving doesn't end with one visit.



What was Helpful in Finding Hope?

As a parent mentor it may be helpful to expand your ideas for finding hope beyond your own experience, to better support other parents.

Discussion Notes:



Important Communication Skills

There is no gimmick, trick or strategy that will immediately make anyone a flawless communicator. Sharing important concepts, practicing helpful techniques, and increasing personal awareness of how messages are perceived will be useful as communication skills are increased.

Communication experts estimate that only 10 percent of our communication is represented by the words we say. Another 30 percent is represented by how we say things and 60 percent is our body language.

Specific skills necessary to communicating effectively include:

1. Listening

Listening is the most basic communication skill. To begin, **STOP TALKING**. People cannot listen while talking. Give parents time to tell their story. Don't give up too soon. Do not interrupt.

Concentrate on **what** is being said, actively focusing attention on words, ideas and feelings. Listen for what is **not** said. As much can be learned by determining what the other person leaves out or avoids talking about as by listening to what is said. Also, listen to **how** something is said. Attitudes and emotional reactions may be more important than actual words.

To be a **good** listener:

- Pay close attention to what is being said.
- Strive to understand the speaker's message.
- Demonstrate an open attitude.

To be an **active** listener:

- Key into specific words used and avoided (*spells instead of seizures, busy and not hyperactive, slow and not delayed*)
- Use verbal prompts (*I see, Oh?, Uh-huh*) and gestures (*smile, nod*) to indicate understanding
- Offer feedback, summarize and rephrase things. (*So after the visit to the clinic, you felt relieved, it sounds like that meeting really clarified your questions, that behavior seems to be happening more often*)



To be an **empathetic** listener:

- Try to see the situation through the speaker's eyes.
- Set aside personal opinions, feelings and issues. Focus on the parent's issues.
- Accept the speaker's feelings without making judgments.
- Remember the pain. Be sensitive to the rawness of a new parent's pain.

2. Attending

- **Concentrate.** Focus on the feelings a family may be having. Are there feelings of apprehension, dread, confusion, excitement?
- **Eye contact.** Most people are comfortable with a reasonable amount of 'natural' eye contact. Be aware that the level of acceptable eye contact may vary across cultures, gender and socioeconomic status.
- **Touch.** The appropriateness of touch depends on many factors. This includes depth of relationship, cultural boundaries, gender boundaries, and individual comfort levels. Do what is comfortable and be sensitive to others, but remember that personal touch is powerful and the connection made by a hand on a shoulder, or a warm handshake is enormous.
- **Posture.** Leaning toward or away from others may influence personal impressions. Posture can be interpreted as indicative of the listener's attitude. Avoid being stiff or sloppy.
- **Space.** . Sitting at right angles to the person you are talking with offers the best approach—avoid sitting across from each other at a table. In America people usually stand 2-3 feet from each other to communicate. However, in the Middle East, they generally stand 6-12 inches from each other, and in England they stand 5 feet apart. Watch for comfort cues.
- **Vocal cues.** Tone of voice, rate of speech, sighs, and coughs convey a lot of information about the speaker.
- **Body movement.** Be aware of personal small repetitive movements (tapping a pencil, wiggling a foot, swaying, etc.) that might be annoying or distracting. Also be alert to the speaker's current status. While speaking with someone who is distraught and very troubled, it is best to try to stay calm, speak in a quiet voice, use fewer words, and attempt to establish a quieter encounter.



3. Asking questions

Questions, when used effectively, can accomplish many **purposes**. They can be used to:

- **clarify or focus** -- repeat a portion of the person's remarks in the form of a question, urging the speaker to be more specific. (Parent: *He is irritable, clingy, has no appetite, and is not sleeping well.* Parent mentor: *Cranky and more dependent?*)
- **motivate communication** -- stimulate the exchange of information by asking questions that cannot be answered in just a few words. (*How did the doctor give you this information?*, *What strategies have you tried to get him to sleep in his bed?*)
- **refocus a speaker** -- ask the speaker to simplify or come to a conclusion. (*are you saying that...*”, or *do you mean that...*’).

Sometimes it is helpful to ask questions in a certain order.

1. Start with **present behaviors, activities or experiences**. This helps establish the context for other questions. (*How are things going with feeding?* *What resources are helpful now?*).
2. Then go on to ask questions about the **past**.
3. Then questions related to the **future**.
4. **Opinion or feeling questions** should follow. (*So how did you feel about that doctor's recommendations?* *What did you think of the meeting?*).
5. **Keep demographic questions to a minimum**--specific information related to age, occupation, religious affiliation, employment, etc.

How questions are worded makes a difference.

- Phrase some questions in statement form. (*Tell me what you think...say a bit more about...*)
- Be careful to ask one question at a time. It is uncomfortable and confusing to have multiple questions to address.
- Clearly state questions. Ask directly, without having to reword or explain.

Avoid these types of questions:

- Questions that have an obvious answer – can be demeaning
- Questions that test knowledge – can be threatening
- Questions that violate privacy – can be intrusive
- Questions that ask ‘why’? -- can be interfering



4. Sharing Selectively

- Recognize personal biases. Know what triggers personal anger and judgments. Identify personal ‘hot buttons’.
- Share BRIEFLY similar experiences and feelings with the parent, as appropriate. Do not attempt to match every situation.
- Consider carefully the impact of sharing photos. Sometimes the visual impact of seeing the reality of a disability is difficult for new parents.
- Qualify everything. (*‘Every child and situation is different’, ‘Some parents find it helpful to...’*).
- Make no promise you cannot keep; offer no false assurances.
- Trust personal instinct. Are parents really asking questions that they want answers to?
- Start again. Everyone makes mistakes, says things out of line. It is ok to make a correction, apologize, back up and start again.
- Use ‘I messages’ to take responsibility for personal feelings. (*I hear you talk about your child’s problems, but I haven’t heard much about his skills and strengths. I was afraid the first time I went to a neurologist with my daughter.*)

5. Avoiding these communication stoppers

- **Threaten** the other person or their actions. (*You’ll be sorry if you don’t address that discipline issue now. If you know what’s good for your child, you will change schools right now.*)
- **Criticize** the other person or their actions. (*I really don’t think you talk to your child enough. I can’t believe you are satisfied with that clinic.*)
- **Preach** or give moral lessons or utter platitudes. (*Things could be worse. I could never do what you do. I know just how you feel.*)
- **Order** the other person. (*You have to sign up for respite care. Just change therapists.*)
- **Divert** the other person. (*Let’s talk about something happier now.*)



Communication Scenarios

1. I don't know what I would do if I couldn't visit with you. I am all on my own and it is so hard. You are the only one who seems to care.
2. My child is a brat. I don't want to take him anywhere. Everyone looks at us and I know they are thinking that I am an awful mother.
3. Our family never does anything together except fight. The kids are always fighting and my husband and I are either working, arguing or sleeping.
4. Our son is disabled, and having him made our family disabled.
5. I am so tired of my IFSP team. Decisions keep being made without me.
6. There is something wrong with my child. I've been to the doctor, and he tells me to just keep an eye on him and come back in six months.
7. I am so sick of people coming to our house all the time.
8. My mother-in-law is putting novenas in the paper, praying that my son's Down Syndrome will go away.
9. My husband goes fishing every weekend and always leaves me alone with the kids.
10. I would really like to go back to work. I am going crazy being at home all the time, but there is no one willing to take care of my son.
11. I have NO time to spend with my other kids.
12. I am just so tired. I really don't care about anything anymore.
13. My mother thinks it's my fault that my son has autism.
14. My husband just doesn't get it-he refuses to even talk about what is going on.



People in High Stress or Traumatic Situations...

- May not hear or retain all of the information
- May inadvertently reveal more about themselves than they are comfortable having others know
- May feel that they have lost control of their life
- May find it difficult or even impossible to make decisions
- May expect a parent mentor to make decisions for them or give them direct advice
- May need to vent and express feelings, such as anger
- May have their own needs for a meeting, and may not hear accurately what a parent mentor says
- May view the experienced parent as some kind of expert with all the right answers
- May feel vulnerable, lost and alone
- May ask questions without being prepared for the answers
- May resent a parent mentor's ability to survive

Thinking back about a period of high stress in my life.

- What do I remember about the feelings I had?
- What do I remember about information I received during this time?
- How did I react or behave?



Honoring Cultural Diversity

Developing cultural competency is an ongoing process of self growth and not an accumulation of knowledge. These five steps may provide a useful framework to begin the process.

1. Consider the levels of culture

- Surface. This most superficial level of culture refers to what we can see or information we learn, (i.e. ethnic food, a different language, music or architecture of a certain culture). Mistaken assumptions about these things are not taken very seriously.
- Unspoken rules. We learn these through our experiences, (i.e. rules of courtesy; use of time and punctuality, rules of conduct for restaurants and social occasions, shopping, etc.) by trial and error. When we break these rules, others are offended and respond negatively.
- Unconscious rules. These invisible rules are learned through imitation, especially early childhood, (i.e. use of nonverbal communication, touching, “comfort zone” spacing, eye contact, body language, tone of voice). Lack of awareness of these rules across cultures or breaking them can result in strong negative feelings, discomfort and possible hostility.

2. Enhance self awareness. This includes identifying our own characteristics, race, religion, family values, biases or prejudices etc. By learning more about ourselves, we see how our views influence our thoughts about others. Learning to articulate our own family story also serves to enlighten us further.

3. Learn about other cultures. Within our communities, there are vast numbers of racial and ethnic groups – representing many geographic areas, religions, languages, beliefs and customs. No one can know it all so aim to become generally familiar with general traditions, customs, and values. Remember, though, that overgeneralization leads to stereotyping. Remember each family’s culture is unique and is defined by factors such as events, history, traditions and viewpoints that are as complex and varied as our own family story.

4. Learn how different cultures view the concept of disabilities. A family’s view of disability influences their expectations, achievement, medical interventions they choose (or do not choose), etc. For instance, one family may view disability as a blessing. Others may view disability as a curse or as retribution for previous sins and therefore an embarrassment to the family.

5. Respect and partner with the family. Families will be able to determine when there is a sincere interest in understanding and supporting them. Don’t assume anything. For example, a family nodding their heads “yes” might only be indicating that they heard the information; it may not indicate their agreement or understanding. Pay attention and watch for cues from families. Don’t be afraid to ask questions.



Boundaries

Boundaries are limits. They are lines that tell us where we end and others begin. If we have clear boundaries, we know what we feel and we don't absorb or take responsibility for others' feelings just because we are close to them or we love them. With clear boundaries we can determine what is our responsibility and what is the responsibility of others.

Without boundaries, we take on others' feelings, let people use us and do not recognize that we have any rights at all. We may lose the sense of being a separate person and have a tough time keeping our own personality intact around other people.

Consider these guidelines in order to set and maintain healthy boundaries as a parent mentor.

1. Work as part of a team. Know team members and recognize resources. Use the help and guidance of others as you discuss questions about boundaries with them.
2. Be aware of behaviors that indicate that boundaries are not in place in the mentorship relationship, such as telling too much, calling too often, expecting favors, depleting personal energy.
3. Learn to recognize those situations that call for more skilled intervention, such as mental illness, addiction, depression and abuse

Ways We Violate Others' Boundaries

- Disregarding confidentiality – telling people's private matters to others
- Controlling, manipulating, or making decisions for others
- Speaking for others
- Using others' possessions without permission or not returning borrowed items
- Ignoring requests for emotional or physical space
- Relentless questioning, badgering, and criticizing
- Reading others' private papers, letters, journals and prying into others' drawers, purses, and briefcases
- Touching people without asking
- Giving unwanted advice, rescuing, enabling, and taking over others' lives
- Talking about people in front of them
- Abusing others - physically, sexually, emotionally or verbally
- Needling nosiness, pointed or unnecessary questioning



Situational Boundary Violations

Are these situations generally, never or sometimes OK?

1. Stopping in at a family home for an unexpected visit to ‘see how things are going’.
2. Giving a parent a ride to the grocery store because she has no transportation.
3. Hugging a parent as you leave.
4. Sharing the details of your recent divorce.
5. Asking colleagues to bring a grocery item for a family who is struggling financially.
6. Scheduling additional homevisits because of concern about a parent’s safety.
7. Using terms of endearment (‘honey’, ‘dear’) with parents.
8. Correcting a parent when he/she calls another a racist name.
9. Questioning the use of profanity to their children.
10. Lending money to a parent.
11. Having a parent call my home.
12. Offering to care for children during an important legal appointment.
13. Asking detailed questions about family matters.
14. Bringing a small gift during a visit.
15. Complaining or arguing with a family about how professionals are working with the family.
16. Getting in the middle of relationships (parent/child/professionals).



Personal Boundary Violations

(Self-Reflection Exercise)

Be aware if:

1. I always listen to and support others, but I seldom ask anyone for support for myself.
2. If someone helps me, I usually do as much or more in return.
3. If I don't respond to someone else's needs, I feel selfish or guilty.
4. I say yes too often.
5. Once I say yes or commit to something, I will do anything to accomplish it.
6. I avoid conflict at all costs.
7. I only feel appreciated and worthwhile through my work.
8. I will do absolutely anything for the families I work with.
9. I disclose more information to families than I probably need to.
10. I feel like nobody cares about this family like I do.
11. I think I am the only one who can really help this family.
12. I enjoy knowing that someone needs me.
13. I feel anxious about the families I am connected with because they aren't following my advice.
14. I find myself very frustrated with others involved with this family, because they just don't 'get it'.
15. I believe I do know what is best for the families I work with.
16. I think of them and refer to them as 'my families'.



Helping or Hindering

If you have come here to help me, you are wasting your time. . . But if you have come because your liberation is bound up with mine, then let us work together.

Anonymous, Australian Aboriginal woman

Most likely a parent mentor will have a limited role with the families. It is critical for potential parent mentors to give deliberate thought to what personal need is motivating them to serve. By focusing too strongly on our own need to help, we can easily lose sight of the family's need to grow and learn from their own journey. If we see ourselves as a fixer or therapist, then we will treat families as though they need to be fixed. The nature or tone of what occurs between a parent mentor and a family is very important and will color future interactions and relationships.

Help giving will cause further problems if it:

1. Undermines a parent's sense of competence and control.
2. Fosters dependency or seems like the mentor has control of parents' decisions.
3. Implies an obligation and makes parents feel as though they owe someone or need to repay.
4. Is uninvited or comes from someone the parent doesn't trust or value.
5. Is different than what the parent requested or expected.
6. Dominates and controls so that refusal of help is seen as ungrateful by the mentor.
7. Is seen as necessary by the mentor but parent doesn't see the problem or need.

All parents need to learn new skills or competencies to be effective in their role. Good parent mentoring does not get in the way of that process by doing for others, but rather teaches others to do for themselves.



What Parent Mentors Are and Are Not

They are not:

- ... a counselor
- ... a social worker
- ... a physician or diagnostician
- ... a decision maker or advice giver
- ... a moral or ethical judge

They are:

- ... one to one support
- ... a resource
- ... an active listener
- ... a person who has “been there”

Parent mentors offer emotional support and share information regarding resources and services.



Visiting with Families

Making meetings with families successful can be accomplished with a few key pieces of information and a little planning. Tips to help in planning visits with families are:

1. Initial phone call tips:

- Make a personal introduction
- Share where the referral came from
- Offer a brief description of the parent mentor role
- Offer a chance to meet (their home, a park, a restaurant)
- Clarify expectations for the meeting (length of time, children welcome, nothing to bring)
- Get good directions
- Offer an invitation to both parents

2. On the initial visit, remember:

- Be on time
- Ask where the parent would like to visit (living room, kitchen, etc.)
- Start with positive statements. (the garden is lovely, the child has beautiful eyes, such pretty curls in their hair, etc.)
- Offer contact with everyone in the room (adults, children, guests, etc.)
- Watch personal dress. (avoid over dressing and in some cases under dressing)
- Accept hospitality (even if it's not a personal preference)
- *Do more listening than talking*

3. Clarify the expectations the family has for a parent mentor:

- Be willing to accept 'no thank you' to offers made
- Identify the concerns of the family



- Define a plan that is empowering to the family (*I'll do...you'll do...*)
- Leave with a link established. (“Would it be OK if I called in a couple weeks, when I have this information gathered maybe we can get together again, you have my number if something comes up between now and our next visit, etc.”)

4. Safety considerations:

When visiting families it is rare for situations to arise that create concerns or are unsafe. For personal safety it is better to have strategies ready to use in that rare situation.

- Trust personal intuition.
- Carry a cell phone if possible.
- Tell someone where the meeting will take place and the anticipated length of the meeting.
- Keep the door in sight.
- Pay attention to the neighborhood and the surroundings.
- Take a partner if necessary.
- Have a friend or colleague call shortly after arrival if in doubt or concerned about a situation. The friend can make sure everything is OK or provide an excuse to leave.
- Make up an excuse, apologize and leave, if a situation seems unsafe.



Child Abuse and Maltreatment Issues

What we know:

Children with disabilities are particularly vulnerable to abuse and neglect. National data indicates that compared to other children, children with disabilities are:

- 1.6 times more likely to be physically abused
- 2.2 times more likely to be sexually abused
- Much more likely to be maltreated by a family member or someone they know
- More likely to be abused if they have multiple disabilities versus one disability

SOURCE: Strategies for Public Health, Vol.2 Violence: Child Maltreatment Including Children with Special Health Needs. Pages25-27. (2002)

Terms relating to child abuse and neglect:

Mandated Reporter: a person, who, by his/her professional relationship, knows or has reason to believe a child is being neglected, sexually or physically abused as defined by law, or has been abused within the preceding three years, is required to report this knowledge to the appropriate local welfare or law enforcement agency.

Maltreatment of Minors: jeopardizing of children's health or welfare through physical or sexual abuse, mental injury, threatened injury, or neglect; maltreatment is commonly referred to as abuse.

Sexual Abuse: forced sexual contact. This contact may be physical as in the case of sexual touching or penetration. Non-physical contact considered as sexual abuse includes: exhibitionism, suggestive comments, or the use of children in pornography.



Neglect: failure by a person responsible for a child's care to supply a child with necessary food, clothing, shelter, education, and/or medical care when reasonably able to do so, or failure to protect a child from conditions or actions which imminently and seriously endanger the child's physical or mental health when reasonably able to do so.

Physical Abuse: any physical or mental injury, or threatened injury, inflicted by a person responsible for the child's care on a child other than by accidental means, including any physical or mental injury that cannot be explained by the child's history or injuries.

Local Decisions and Arrangements:

Across the state of Minnesota there is variability in defining who is a mandated reporter and how reports of child abuse or neglect are handled.

Issue affecting the reporting of child abuse and neglect:

- Volunteer or paid parent mentors
- Agencies employing parent mentors
- Directions given by attorneys from local agencies
- Traditions and existing practices
- Licensure a person has

The questions and concerns are issues that need to be addressed and a protocol developed for how parent mentor should handle concerns. It is also important for parent mentors to know that the chance of being connected to a family and being in a situation where child abuse and neglect are present is highly unlikely.

Each area will need to review existing child abuse and neglect reporting requirements. This can be done by reviewing written policies and procedures, speaking to attorneys for the agency, and accessing local child protection workers.



Taking Care of Ourselves

Resiliency is the power of recovery - Garmezy, 1992, Parent to Parent of Vermont

When working with families who are in pain, it is very important to make self care a priority. If we give away all our energy to others and their problems, we deplete the personal energy needed to work and care for ourselves and our families.

- 1. Carve out some personal time and space, and use it.**
 - Claim time alone-- running, reading, a night out or time with a friend, etc.
- 2. Explore and define self knowledge and understanding.**
 - Identify personal biases and stress triggers. Learn to recognize them when they show up.
 - Set clear boundaries with families.
 - Get personal needs met in places other than work.
- 3. Be willing to ask for help.**
 - Know when to refer.
 - Ask for help as a way to grow stronger.
 - Request and expect ongoing support and supervision as critical to growth and learning.
 - Grow. Go to trainings.
 - Find peer support outside of work.
- 4. Develop and guard self respect.**
 - Do not become more invested in families than they are in themselves.
 - Keep relationships balanced.
 - Meet the expectations of the role, but keep them reasonable.
 - Let actions reflect beliefs.
 - Be selective about issues for increased involvement.
- 5. Enjoy life.**
 - Laugh a lot.
 - Acknowledge and rejoice in accomplishments, big and small.
 - Maintain physical health through sleep, exercise, good nutrition.
 - Seek emotional health through loving, supportive relationships and obtaining counsel when needed.
 - Employ a spiritual practice such as prayer, meditation or reflection to make life meaningful.



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Parent to Parent

Section II

Designing the System



Minnesota Technical Assistance for Family Support

Strengthening and broadening family involvement efforts

Parent to Parent-Designing the System Planning Overview

These steps offer a supporting framework for community teams of parents and professionals to establish, maintain and enhance locally based parent to parent initiatives.

1. **Develop Key Alliances**
2. **Design a Model**
3. **Design a Marketing and Outreach Campaign**
4. **Determine Governance and Funding Sources**
5. **Train and Support Parent Mentors**
6. **Evaluate the Program**

Start small, start now and grow as you are able.



Minnesota Technical Assistance for Family Support
Strengthening and broadening family involvement efforts

Parent to Parent Planning Worksheet

Step 1. Develop Key Alliances	Who will take the lead	Timeframe
<p>A. Identify key people whose support is essential to make this work. For example, Director of Special Education, Coordinators, Supervisors of programs and Service Providers from Social Services, Public Health and Education.</p>		
<p>B. What can key people bring to the table that will be important to this effort?</p>		
<p>C. How will we introduce key people to this initiative?</p>		
<p>D. How will we communicate with them in an ongoing way?</p>		
<p>E. What concerns might key people have about this effort?</p>		



Parent to Parent Planning Worksheet

Step 2. Design a model	Who will take the lead	Timeframe
<p>A. Determine a geographical area. Will the geographical area be defined by school district lines, Interagency Early Intervention Committee or county boundaries? (If the geographical area includes an area which did not have representation on the original team, invite the necessary community members.)</p>		
<p>B. Identify a target audience.</p> <ul style="list-style-type: none"> • Will it be parents of children with an IEP/IFSP/IIP? • What ages? • Specific disabilities? • Specific groups of parents? 		
<p>C. Will parent mentors be paid or volunteer?</p>		
<p>D. Will a coordinator be identified to oversee the development and operation of this effort?</p>		



Parent to Parent Planning Worksheet

Step 2. Design a model (continued)	Who will take the lead	Timeframe
E. Will we match parent mentors with other parents of children with similar needs or have one parent available a resource to all parents?		
F. Develop a job description for parent mentors and project coordinator. (See Attachment A for sample job description)		
G. Develop procedures for a ‘chain of authority’, supervision and performance evaluation.		
H. Recruit parent mentors (See Attachments B on finding and recruiting) <ul style="list-style-type: none"> • Will parent mentors be invited to join or required to apply to become parent mentors? (See Attachment C on screening criteria) • Develop processes and items such as: interview format/questions and rating scale. • Recruit small team to interview 		



Parent to Parent Planning Worksheet

Step 2. Design a Model (continued)	Who will take the lead	Timeframe
<p>I. Determine a referral process.</p> <ul style="list-style-type: none"> • What is an appropriate referral • Will a referral come through a central contact or directly to a parent mentor? • How will a parent mentor contact newly referred parents? • What is the timeframe for contacting the newly referred parent (Research recommends contact within 48 hours of referral) • What procedures and forms are needed to track referrals, contacts made and other data? (See Attachment D for sample contact log) 		
<p>J. Develop a feedback/reporting mechanism for board, funders and other key People (i.e., written updates and periodic personal visits.)</p>		



Parent to Parent Planning Worksheet

Step 3. Design a Marketing and Outreach Campaign	Who will take the lead	Timeframe
<p>A. Identify techniques/approaches to be used to reach the public and generate referrals. (See Attachment E on Marketing and Outreach)</p> <p style="padding-left: 40px;">For example: a brochure, articles in newspapers and in newsletters and public service announcements for use on TV and radio.</p>		



Parent to Parent Planning Worksheet

Step 4. Determine a governance structure and funding sources	Who will take the lead	Timeframe
<p>A. Will we stand alone as a 501c3 non profit organization or seek an established community organization to be a fiscal host?</p> <ul style="list-style-type: none"> • If we join an established fiscal host: <ul style="list-style-type: none"> ○ How independent can we be within this organization? (relating to grant activities, spending funds, issuing contracts, etc.) ○ Will we have our own advisory board? ○ Is some degree of support available? (Office space, supplies, etc.) • If we become a 501c3: <ul style="list-style-type: none"> ○ What are the requirements? (Filing tax forms, establishing a board of directors, employing staff, etc.) ○ Who will file the paperwork to become a 501c3? ○ Will we seek legal advice? 		
<p>B. What budget do we anticipate we will need?</p>		
<p>C. What are potential sources of funding? (Grants, donations, fund raising, etc.)</p>		
<p>D. What will the fiscal reporting system consist of? (timely reimbursement, audit trail, budget updates, etc.)</p>		



Parent to Parent Planning Worksheet

Step 5. Train and Support Parent Mentors	Who will take the lead	Timeframe
<p>A. Will we adopt an existing curriculum for INITIAL parent mentor training or will we create our own? If we create our own, what specific components will be included?</p>		
<p>B. Will we train parent mentors or use outside trainers?</p>		
<p>C. How will we offer ONGOING support to parent mentors? (See Attachment F on supporting parent mentors) What topics will be addressed in ongoing support and training?</p>		



Parent to Parent Planning Worksheet

Step 6. Evaluate the Program	Who will take the lead	Timeframe
<p>A. Establish a system of data collection</p> <p>What information will be collected and how?</p> <ul style="list-style-type: none"> • Parents capacity to meet the needs of children with disabilities • Referral data (number of referrals, sources of referrals, number of matches, etc.) • Demographic information (age of child, disability, geographic location, etc.) • Identified parental issues and needs • Referred families satisfaction with process • Secondary effects/outcomes of parent mentor program 		
<p>B. How will we report data to key stakeholders? (funders, administration, mentors, staff, etc.)</p>		
<p>C. What are the projected future needs base on the data?</p>		
<p>D. How will we acknowledge our successes and celebrate them?</p>		



Parent Mentor Job Description

Overview: Provide support to families of children with disabilities in a manner that empowers and fosters independence.

- Job Duties:**
- 1. Family support**
 - Provide emotional support
 - Share information and resources
 - 2. Track information**
 - Record contact with families
 - Keep notes on pertinent information and follow-up plan
 - Track issues that impact families
 - 3. Confidentiality**
 - Maintain a practice of confidentiality
 - Respect families' privacy

- Qualifications:**
- Be the parent or caregiver of a child with special needs
 - Have some flexibility in scheduling
 - Demonstrate ability to effectively communicate
 - Possess the desire to support other families

Reports to: Project Coordinator



Finding and Recruiting Parent Mentors

Not one Way, Not One Time, Not One Person

There are many factors to consider when developing a pool of parent mentors, some more obvious than others. Use these key concepts when finding and recruiting parent mentors.

1. Use personal and general approaches to recruit parent mentors
 - **Personal** – contacting potential candidates directly
 - Referrals from others – seek input and use the advice of staff who already have a relationship with parents
 - Phone calls of invitation
 - Letters with a follow up call
 - **General** – through media, ads, or mailings
 - Presentations to groups
 - Advertise in newspapers and newsletters
 - Mailings to parents in data base
2. Make the **message** clear, understandable and accessible
 - Write simply
 - Oral as well as written
 - Translated as appropriate for diverse cultures
3. Seek mentor parents in an **ongoing** way throughout the year
Families' personal energy and priorities can change quickly, so consider:
 - **Timing** – Repeat the invitation periodically to parents who would appear to have strong skills for this
 - **Awareness and Discretion** – Times of crisis are intense for parents. Crises can come and go, and a parent may welcome this opportunity when life becomes less demanding.
4. Recruit parents who **represent the community**
 - Culturally
 - All income levels, all neighborhoods
 - More than one token parent
 - The right people-- Refer to *Screening Criteria for Parent Mentors*
 - Are they connected to their own group?
 - Are they proactive problem solvers?
 - Do they follow through?
5. **Review** the process periodically for effectiveness.



Screening Criteria for Parent Mentors

Consider selecting parent mentors who:

- ARE GOOD LISTENERS...Able to listen without passing judgment on others
- Are the parent of a child with a disability
- Have a child that is the same or close to the ages of the target audience
- Have the time and energy in their life to commit to the role of parent mentor
- Are personally well adjusted with a positive outlook, realistic, yet hopeful
- Live within reasonable geographic proximity (this may not always be possible depending on population density and low incidence disabilities)
- Have successfully integrated a child into their family and community. This will mean different things to different people.
- Have a comfort with and an understanding of their own grief
- Are proactive and creative problem solvers
- Share the belief that every child is valuable
- Are sensitive to ethnic and cultural differences
- Are open and comfortable offering emotional support and encouragement on a personal level
- Are able to adapt to referred families' environments
- Are prepared to get emotionally and personally involved with another family
- Are competent and able to follow through on their commitments and responsibilities
- Are mature:
 - Able to accept rejection without being personally offended
 - Able to work without a lot of praise or affirmation
 - Able to give to others without expectations



Parent Mentor Contact Log

Parent's/Caregiver's name: _____ Child's name: _____
Disability: _____ Child's age: _____
Address: _____ Phone number: _____
_____ E-mail: _____

Date of contact: _____ Amount of contact time: _____
Method of contact: _____
Notes/Issues:

Follow up:

Date of contact: _____ Amount of contact time: _____
Method of contact: _____
Notes/Issues:

Follow up:

Date of contact: _____ Amount of contact time: _____
Method of contact: _____
Notes/ Issues:

Follow up:



Marketing a Parent to Parent Program

We planned, designed and worked to get our parent to parent efforts up and running. We have parent mentors trained and ready...and no calls or requests are coming in....

Avoid frustration and disillusionment by paying attention to marketing the parent to parent initiative right at the beginning. Start early and keep efforts ongoing to engage key people and get the word out. If people don't know what the program is or how to get in touch with parent mentors, it won't be seen as useful or valuable.

Remember these helpful hints:

- **Develop a promotional packet.** Design a variety of materials that highlight the intent of the program, the role of parent mentors, how and to whom referrals should be made, the geographical boundaries of the initiative (and designated population), and the sponsors. Materials could include:
 - Flyer or brochure
 - Informational bookmark
 - Public Service Announcements
 - Outline for presentations to groups
 - Post Cards
- **Make personal contact.** It is the best approach to reach people. It is always easier to remember an initiative that has a face and name attached to it. Meet face-to-face with people in key positions and with those who are connected to a naturally occurring positive social network:
 - Teachers and principals
 - Nurses and personal care attendants
 - Social workers
 - Doctors and clinic administrators
 - Directors of agencies and programs
 - Community movers and shakers
- **Develop an ongoing cycle of outreach.** Keep talking to people. Never assume that once a brochure has been sent, a presentation made or information shared that the outreach is complete. Staff changes, people forget, lives are busy and connections need to be continually reinforced.
- **Highlight the need.** Share the impact of a parent to parent connection from the perspective of parents as well as professionals in the service system.
 - Write articles in newsletters and newspapers.
 - Highlight the effort on radio stations.
 - Speak at local parent/school gatherings.
 - Offer presentations to county commissioners, service clubs, boards, etc.
- **Keep recruiting potential parent mentors.** As efforts grow, the need for more parent mentors will emerge. Be ready to offer ongoing training, support and connections.



Ongoing Support for Parent Mentors

Being a Parent Mentor and providing support to parents of children with disabilities can be a rewarding experience. It can also be challenging and emotionally draining. A Parent Mentor is also the parent of a child with a disability and may need support because of their own situation. Strategies to support Parent Mentors are:

1. Share at parent mentor meetings

This can be done as a part of scheduled gatherings. It is important to allow time at each meeting for personal sharing and discussion between parent mentors. It need not be a long time, 20-30 minutes is usually adequate.

2. Seek a professional partner who is committed and invested in parent to parent efforts

A professional partner for parent mentors to connect with provides another source of support and information. There may be times when it is not appropriate or comfortable sharing certain information with or asking questions of other parent mentors. Advice or input from a professional should be available when needed.

3. Allow parent mentors to temporarily step out of their role

Life is full of ups and downs and surprises for ANY parent of a child with a disability. It is important that parent mentors are able to step out of their role as a parent mentor when their own life requires it. This is an option/policy that parent mentors need to be made aware of when being recruited and reminded of periodically. There should be no guilt or burden when a parent mentor needs to do this.

4. Encourage relationships to develop between parent mentors

One of the greatest sources of support to a parent of a child with a disability is a connection with another parent of a child with disabilities. This is also true for parent mentors. Parent mentors can be an important source of support and information to each other. The development of one to one relationships between parent mentors may be more appropriate for some than sharing in a group setting.

Supporting parent mentors is a basic concept, yet crucial to the success of a parent to parent project. It is important that supporting parent mentors not be over looked and that it becomes an ongoing part of a parent to parent project.

