

Parent Support Group

Technical Manual

Joe DeBonis, MA, LPCC
Project Jericho



Specialized Family Services



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New Mexico Developmental Disabilities Planning Council**



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Introduction

Parents of young children who have disabilities face many challenges and can benefit from outside assistance. In most cases, this assistance takes the form of various types of services that address their child's developmental and/or medical needs. However, it is important to recognize that parents of children who have disabilities or special needs are often dealing with a myriad of concerns and stressful situations and could also benefit from direct support for themselves to help address their needs.

The Parent Support Project, funded by the Developmental Disabilities Planning Council, provides support for parents through the implementation of parent education and topic/discussion groups in Albuquerque, Taos and Silver City, New Mexico. Through the Training and Technical Assistance Programs in the northern and southern parts of the state (UNM Taos Family Resource Center and La Familia Resource Center) and Alta Mira Specialized Family Services in the Central New Mexico, the Parent Support Project provides direct support to parents through shared group experiences. Two group sessions are offered each month, the first utilizes trainers within each community to provide training on topics related to disabilities while the second session focuses on facilitating a discussion group where parents discuss topics related to having a child with a disability or special needs. These sessions are coordinated by a group facilitator.

Through these efforts, parents of children with special needs become less isolated and obtain relevant information to help them deal with the challenges related to having a child with special needs. These sessions also provide parents with an opportunity to connect with other parents who have had similar experiences.

The purpose of this manual is to assist other communities that wish to develop a parent support program using the model developed for the Parent Support Project, as well as offering other useful information relating to parent support.



Considerations

In writing this manual I will share my insights as a counselor and group facilitator with 18 years of experience working with families who have young children with special needs. Having mentioned this, I begin with the caveat that I do not assume to know what the parent of a child with a disability feels. If I have learned one thing in my years of working with this population, it is that parents of children with special needs want others to understand that their feelings, thoughts and experiences are unique. To try to compare their experiences with other life experiences that I may consider to be similar would be insensitive and may alienate parents. I am aware of the range of feelings that these parents have experienced only through what they have told me in counseling sessions or in the parent groups which I have facilitated.

I make this important point for a number of reasons: First, in order to attract people to a group in which they are identifying themselves by way of a potentially sensitive issue, they will need to feel respected and safe from the start. Parents will be assessing your ability to be respectful and provide a comfortable and safe environment, beginning with your first interaction with them. A group facilitator must be willing to learn about each individual parent participant by being a good listener and avoid making any assumptions about their feelings.

Another reason to proceed cautiously with parents is because many of them have been treated insensitively by others. From extended family members to friends and medical professionals, many parents have endured comments from individuals which may have been well intentioned, but were hurtful nonetheless. In addition, confronting these individuals about their comments can be very difficult for parents. As a result, parents remain silent for the most part for fear of further negative repercussions. These accumulated injuries can also lead to apprehension about joining a parent group. It is important to remember in your attempts to attract parents to a group setting, anything you do or say that rings of insensitivity may send them running in the opposite direction.

Another thing to keep in mind is that parents who have children with special needs are “parents” first and foremost. And like all parents, they have hopes and dreams for their children. Hope is like an open window through which a soft, summer breeze brings visions of a future filled with good things. In

working with parents it is important to keep this in mind so you do not unintentionally close that window. This can happen to parents when others predict a bleak picture of their child's future. I have met dozens of parents over the years that were told that their child would never walk, talk, see, or even make it to their first birthday. And each one of these parents was triumphant in telling their story when the crystal ball gazers were proven wrong!

Sometimes that window of hope can only be kept open a crack by a parent. In these situations, others may mistakenly diagnose this hope as "denial". It's a strange thing, but I've watched professionals with a crusader-like effort beat the hope out of parents by pounding them with the "facts" that they feared the parents didn't quite understand, all believing the parents were in "denial". I don't believe these professionals were intentionally being malicious or hurtful; they probably overlooked or failed to understand the psychological needs of these parents. The parents understood the facts, but to live in those facts every waking hour would make it impossible to get through the day. Parents instead choose to shift their focus to dream of possibilities, even though the odds may be against those possibilities. Validating their hopes and dreams is like tossing them a life-line. All parents build dreams for their children and we must recognize and honor them if we wish to be supportive.

Another major consideration is how to select a support group facilitator for parents who have children with special needs or disabilities. When I first started facilitating parent support groups in my late twenties I was equipped with my masters degree in counseling and not much else. I did not have a child with a disability. I wasn't even a parent. I lacked real life experience in these areas and often put my foot in my mouth with comments I made. Not having had the shared experience of having a child with special needs, I often felt like an outsider. As soon as I learned to get out of the way and let the participants lead, things went much better. I learned to limit my

involvement to facilitating discussion, reflecting feelings and being a good listener instead.

One could argue that the best facilitator for a parent group would be a parent who has a child with special needs. In our current project we have found that there are many benefits to this. Vicki Galindo, who is a parent of a child with special needs, is facilitating the parent group in Silver City which has had a consistently high turn out. A parent who has a child with special needs does not start off as an "outsider"; they begin as one of the group. Having been through the same or similar circumstances the parent-facilitator is able to discuss sensitive issues with more confidence. However, it is also important for the parent-facilitator to have some experience or training in group facilitation and active listening. One must balance sharing personal experiences with encouraging others in the group to share their experiences. A facilitator's main function is to keep everyone involved by guiding the smooth flow of discussion.

A non-parent can also be an effective facilitator. A background in counseling, social work or group facilitation would be useful for this person to have in order to understand group dynamics and interpersonal communication. In addition, a background in mental health will also enable the facilitator to assess if any individual participants need to be referred to a mental health professional. But at no point do we want to "pathologize" parents. Having a child with a disability presents a certain set of challenges to parents, but it does not necessarily cause them to develop a psychological disorder. This is an important point because participants will sense if they are being scrutinized in this manner, and this makes it difficult for the facilitator to earn their trust.

Valid arguments can be made for choosing a parent facilitator or for choosing a professional with a mental health background as a parent group facilitator. The combination of the personal experience of being a parent and having formal training in the areas of social work or counseling would be a perfect balance.

Getting Started

In order to succeed in developing a parent support program, it is important to begin by soliciting input from potential group members. This could be done through a survey (see Appendix A) which can be given to parents through an early intervention provider, private therapists or a public school program. Providing parents with a survey listing possible training and discussion topics will help determine their interests as well as encourage them to suggest other topics relevant to them. The survey should have a space where parents can write down these other topics of interest. Polling perspective participants about the best time and day of the week to meet will help in scheduling the group in order to maximize attendance.

After the surveys are returned and the data is analyzed, a plan and schedule for group meetings can be worked on. In our project we chose to provide two meetings a month. For the first of the two meetings, the “training group”, there is a presentation on one of the topics which parents had identified as being of interest. In addition, a group facilitator attends the training to facilitate discussion after the presentation and sometimes during the presentation. The second meeting of the month is a “topic/discussion group” meeting. During this session, the same facilitator leads a discussion around a topic which was identified by parents as being of interest. This topic could be a spin-off of the training group presentation offered earlier in the month. For instance, a training group on “How to Effectively Work with Professionals” could be followed up with a topic/discussion group on “The Challenges in Working with Professionals”. During the topic/discussion group, participants may share personal experiences that were challenging for them that involved partnering with professionals. This example demonstrates the importance of having the group facilitator participate in both monthly meetings. Having the facilitator at both meetings adds continuity in that they can refer back to information provided in the training groups during the topic/discussion meetings. Or, if a participant refers to something presented in the training, the facilitator will be familiar with that information as well.

In order to insure a good turn-out for these group meetings, it is important to get the word out to the community about the groups. For our group in Albuquerque, we started by compiling a mailing list comprised of parents who filled out the initial

survey we distributed and who asked to be on our mailing list. We then added agencies, organizations and practitioners in the community who are in contact with parents of young children with special needs. To complete the list we included all the families enrolled in the Alta Mira Early Intervention Program.

At the beginning of each month we put together a flyer with information about the groups for that month including titles of the training and topic/discussion groups, dates, location and times (see sample in Appendix B). In addition we also listed the same for the following month on the same flyer. In order to be able to include the information for the following month, we needed to plan the groups two months ahead of time. Also included on each flyer is a notification of the availability of child care. Child care is crucial for parents to attend group meetings.

It is important to follow-up with key figures in agencies and organizations after flyers have been sent out. Taking the time to discuss the

group with these individuals, either by phone or in person, will increase the likelihood of them spreading the word and passing on the information to families and other providers. Enlisting these individuals early on and informing them of this new resource in the community is important to the success of the groups.

In our project we are finding varying degrees of success in getting people to participate in our groups. At La Familia in Silver City they have had high attendance from the start which helped participants form a core group with regular attendance. A core group can be defined as a subset of the larger group that attends each meeting and develops a bond between members. Having a core group helps assure good ongoing attendance. When individuals connect with each other in this type of setting, relationships develop that help bring parents back to the meetings. Remember that being diligent about advertising the group will play a big role in attracting enough attendees to form a core group.

Up and Running

There are many factors that will influence the ongoing success of a parent support program. The skills of the group facilitator, whether that individual is a parent or not, will play an important role in whether participants return. The facilitator must be able to draw people out, keep conversation moving and not dominate the group with personal sharing. In addition, the facilitator must help individuals feel valued, respected and safe. This is accomplished by treating parents with respect, refraining from judgmental statements, and by keeping others from being disrespectful or judgmental towards other participants as well.

A good facilitator will make sure that the less assertive participants in the group are given the opportunity to speak. Drawing out the parent who may not jump right into a conversation helps them feel like what they are thinking and feeling is important. The facilitator acts as a traffic cop for the group to prevent one or two individuals from dominating the discussion, while ensuring that everyone gets a chance to be heard. At the same time, the facilitator must also be able to intuit and respect a participant's wish to just listen.

The facilitator must protect participants by stepping in if someone is being critical or judgmental of another member of the group. Well intentioned, but nonetheless heavy handed advice from another member of the group needs to be tactfully discouraged by the group facilitator. There are times when parents will seek advice and input from other group members. At other times, all they really want is an opportunity to talk about their experiences and their feelings. Attention to these issues will help the development of trust in the group and increase the chances of establishing a core group.

Another consideration is to discuss confidentiality with the group. The facilitator should ask participants to keep everything that is said during the group meetings in confidence in order to lay a foundation of trust among its members. Generally speaking, parents want to feel that if they share something personal in a group meeting that they are not going to hear it repeated at the next table while having dinner at the local cafe. Asking people to practice confidentiality can be reassuring and will increase the chance of participants feeling comfortable enough to talk about sensitive subjects. At the same time, the facilitator should state that he/she cannot guarantee confidentiality from the participants since they are not bound to

a code of ethics, like a counselor or social worker would be.

It is important to give participants time to introduce themselves and share a bit about themselves at the first meeting and to continue this practice for each meeting. The goal is to help parents get to know each other and discover things they have in common which often will lead to the development of bonds among them.

Consistency is a crucial component to the success of an ongoing parent group. The time, date and location should remain the same. Once parents have incorporated these into their schedule it becomes more difficult to make changes. Also, there may be prospective participants out there who intend to join a group meeting and work to rearrange their schedules so they can attend. If the time or date changes you may have effectively eliminated them from participating. Parents often have complicated schedules and must fit in regular therapy appointments, medical appointments and service plan reviews into their week, so they need consistency if they are to commit to other activities like parent groups.

The group facilitator must attend the group regularly. Even if group membership shifts, parents need to be assured that they will at least

know one person when they show up, that being the facilitator. The facilitator should make every effort to be at every group session. Canceling sessions or utilizing a substitute will negatively impact attendance and may also send a message to parents that the group is not a high priority for the facilitator.

The benefits of participating in a parent support group are many. One of the long ranging benefits is the networking amongst parents that develops within the groups. In my experience, I have witnessed friendships that have been forged in a parent group that have gone on for many years long after the actual group participation had ended. Another reward of participating in a support group is meeting others who share the same challenges. Through these connections people feel less isolated and alone. Many of the parents I have met over the years who have children with disabilities report that parents of typically developing children are sometimes unable to understand how they feel. Connecting with another parent who has a child with special needs is often like entering a new world where people speak your language. Sustaining this type of connection beyond the parent group is a priceless gift with ongoing benefits that each parent gives to the other.

Summary

Support groups have been around since the 1960's and participation in them has benefited many people over the last four decades. Parents of children with special needs participating in a support group come to that group with a shared experience. As a group facilitator it is important to try to get to know these parents as unique individuals and not assume they are all the same just because they have a common experience. By so doing the facilitator conveys respect and sensitivity to the parents.

Establishing trust within a group comes from treating people with respect, being non-judgmental, and taking steps to keep participants feeling safe. Offering the group at a consistent location, time and day as well as regular attendance by the group facilitator, is another way of helping to establish trust within the group. All of these will play a part in the development of a core group that will consistently attend meetings and add to the success of the program.

A long lasting benefit from any support group experience involves the relationships that develop during those sessions. These friendships can outlast the group participation and continue to provide support for parents for years to come.

Facilitating Parent Support Groups:

A Parent's Perspective

Vicki Galindo facilitated the parent support groups at La Familia in Silver City for the project. In order to include her thoughts about facilitating a parent group she agreed to answer a set of questions:

1. What advantages to facilitating a parent support group are there in being a parent of a child with special needs?

The first thing is trust, if parent's know you are a parent of a child with special needs, they feel more comfortable with you, simply because you have most likely been in their shoes. Secondly, I feel when parents are supported by other parents they learn the differences about each other's situation and different disabilities. It gives them new ideas about ways to help their child.

Another advantage is being able to share success stories. Also, being a parent-facilitator makes families feel they are not alone, that having a child with special needs happens to other families. It gives them hope and helps them to express their thoughts, the cycles of grief, and feel acknowledged.

2. What are some of the things parents struggle with?

Every parent asks himself or herself, "Am I doing all that I possibly can to help my child?" Sometimes parents get so involved with work, hobbies, other interests, they don't realize they are spending more time on these other things. They feel guilty because they would like some time for themselves but they also want to do all they can for their child.

Parents of children with disabilities have more stress. They have a harder time maintaining and keeping jobs. Their relationships with their spouses are strained, therefore they have higher divorce rates. I personally feel that having a child with a disability either makes your relationship stronger or it tears it apart. One thing is for certain, you develop your coping skills. Having a child with special needs puts a twist in the entire family structure, including siblings and extended family.

3. What are some specific instances that stand out for you where being the parent of a child with special needs helped you offer something during a meeting that a "non-parent" facilitator may not have been able to offer?

Trust comes to mind, if they know you have been through a similar journey, they trust you more. I like to have parents introduce themselves; I ask them to give a brief little story about their child with special needs and their other children, what they are looking for in a support group and what they are working on presently. Some times it can get very emotional and it's important to let them know it is OK to cry. I usually explain that crying releases endorphins in the brain, then I try to lighten the situation by telling them that after a good cry I usually feel great! Being able to acknowledge their feelings is something only another parent actually understands.

As a parent I am able to offer true-life stories. This is a great way to start a conversation. My interactions with the group, asking them what they think makes them feel included and a key part of the group. Not all parents want to share in a group, but prefer a one-on-one type of support. Some parents fear having to talk in a group setting.

4. What are some of the things that parents are looking to get out of these groups?

They look for ways to get through difficult times. They look for learning opportunities. They look for re-assurance that they are doing everything they possibly can for their child. They look for understanding. When a parent is supported, they in turn want to support other parents. They remember the help they received, it might be something very simple, but simply listening to a new parent is a valuable tool. They also look for friendship and camaraderie with other parents. There is an unspoken understanding that is present when parents get together.

5. Were there times when you were able to help others share their feelings by sharing your own? Tell about those instances.

When I talk about the lost dream or the vision of what my child was supposed to be like,

it sparks interest in other families. Talking about how other people reacted when I told them about the news of having a child with a disability is often helpful to other parents. I also tell stories of who in my life helped and supported my family. Having a child with a disability does affect the entire family. For example, my grandmother who was a nurse for 31 years, and incidentally took care of me when I was born, told me "Vicki you're just going to have to work with her a little more than the other kids." To me that was early intervention; don't put limits on her, treat her like she did not have a disability. It's important to remember that they are more like other children than they are not.

Another story I like to share with families has to do with when a mom asked me, "Do people ever stop staring at you and your child?" I told her, "No, but for every rude stare, I get twenty or more warm and understanding smiles." Then I explain as a parent you should take that as an opportunity to educate others and be an ambassador for your child.

6. Did you find it easy developing rapport with the participants? Did they feel comfortable with you early on?

I felt very at ease; that is the advantage of being a parent. You can see it on their faces when you say something that they can really relate to. When parents tell their story, it helps them heal. Each time they tell their story it is a little easier. Developing that rapport early on is a key element. And a big part of that is just being a good listener.

7. What insights were you able to share with participants?

A very common question I get is, "How many skills is my child going to learn?" I explain that I don't give advice. Parents have all the answers; I assure them they will "know" when something is working or when it is not. I encourage them to not put limits on their child. Let them explore whatever holds their

interests. I try to point out that parents are the first teachers and the experts about their child. Parents can eloquently tell you what makes their child extremely happy and how they learn. I also encourage them to look down the road a few years later towards the future.

8. What insights would you like to share about facilitating a parent group?

Make the other parents feel their story is important. I always thank them for their input. Offer dinner or lunch so they won't have to do one more thing (this could make the difference between going or not going to the group). Give them topics that hold their interest. Let the parents take the lead. They will form relationships with each other and then when one parent needs support they will call upon each other. For example, in the grocery store they talk about things they are hoping their child will achieve, or little milestones they can brag about. They may seem little to other people but to parents they are monumental. One very small thing I like to do is invite a mom or a mom and

dad to lunch. Sometimes they really get a thrill out of something like that. I think it is because it is a social thing, and an icebreaker.

9. Is there anything else you would like to add?

Support groups are beneficial; they encourage families to get involved with their community and a support system. It makes them check and see if they are doing everything that they possibly can for their child. It gives them hope and validates their feelings. I feel the person who facilitates the support groups needs to know their community and 'work behind the scenes' for those parents who do not want support in a group setting. Some prefer a more one-on-one type of information sharing experience. To me, "working behind the scenes" means calling parents, sending them information that relates to their child's disability, connecting them to other experienced parents, or simply offering to help.

Being upfront is the most appropriate way to deliver your stories, even admitting when you have made mistakes. Parents and families have all the answers, they just don't always know it



Appendix A





Alta Mira Specialized Family Services

Parent Training & Topic Group Survey

Through a grant from the Developmental Disabilities Planning Council (DDPC) we will be offering parent training and parent support groups. Please take a moment and answer the questions below to help us plan for this project.

Please check the box next to the training topics listed below that you are interested in:

- Understanding how children typically grow and develop
- How can I help my child meet developmental goals during our daily routines?
- Suggestions for dealing with challenging behaviors
- Handling the holidays
- Effective communication with adults and children
- Setting limits and boundaries with others
- How can I help my child with their speech development?
- Understanding sensory issues in young children
- How to find time for myself and why it's important
- Dealing with stress
- Understanding Early Intervention Services

Others: _____

Please check the box next to the topics you would be interested in discussing with other parents who have children with special needs:

- It's difficult to talk to certain people about my child's special needs
- When parents compare their children's skills
- Dealing with all the professionals: The ups and downs
- The challenges of having a child with special needs
- The challenges of finding child care
- Parents of typically developing children don't understand our challenges
- My family does not understand my child's needs

(over)

Other: _____

When would be the best time for you to attend a training or topic group meeting?

- Mornings, weekdays
- Mornings, Saturdays
- Afternoons, weekdays
- Afternoons, Saturdays
- Evenings, weekdays

There will be one training/educational meeting a month where participants will hear from a presenter. The second meeting during the month will be a topic group in which parents of children with special needs will get together with a facilitator to discuss a topic.

If you would like to be contacted directly about these trainings and parent topic groups, please fill out the following:

Name: _____

Address: _____

_____ zip _____

Phone number(s): _____

E-mail address: _____



Appendix B



Parent Group

Parents of young children with special needs meet every second and fourth Wednesday of the month from 10:00-11:30 a.m. at Alta Mira, 1605 Carlisle NE (on the west side of Carlisle between Indian School and Constitution). These meetings consist of a training session (conducted by Nicole Berezin) on the second Wednesday and a topic/discussion group (facilitated by Kim Grey) on the fourth Wednesday. Child care is provided. For more information or to be placed on our mailing list, please contact Kim Grey, 366-2161, or Joe DeBonis at 366-2157; email jdebonis@altamiranm.org.



**Funding Provided by the Developmental
Disabilities Planning Council**

Training

“How to Strengthen Your Relationships”

Topic/Discussion

“The People Who Support Us”

Training

Family Member Panel Discussion:

“Challenges and Triumphs Through the Years”

Topic/Discussion

“Challenges and Triumphs Through the Years”

Alta Mira Specialized Family Services, Inc., 1605 Carlisle Blvd. NE, Albuquerque NM 87110



Appendix C





Sample Training Outlines

Nicole Berezin

Challenges and Triumphs Through the Years

Parent Panel

Introductions- Have each participant on the panel introduce themselves.

Have participants introduce themselves and give them an opportunity to ask questions.

- Describe a challenge and a triumph that you faced and met in the first 5 years.
- Describe the challenges and triumphs that you faced during the school years.
- Describe the strategies that you used to face and thrive during times of transition.

Encourage sharing and exchange.

How to Develop and Maintain Strong Relationships

- **Discussion-** Ask participants to list the characteristics of individuals that they have maintained long-term, supportive relationships with. (Suggest trust, active listening, respect, understanding...)
- Ask participants to list characteristics of these relationships. (Suggest making time, taking time, respect, relationships are a priority.)
- Ask participants if any of these characteristics carry over to professional relationships that they have.
- Ask participants to work as a team to develop strategies and techniques to build these relationships.

How to Partner with Professionals

Purpose: Create strategies with parents that they can use while working with professionals in order to achieve outcomes for their children.

Objectives:

1. Determine and define top three to five situations in which parents need to utilize partnering strategies.
2. Discuss ways in which to turn challenges into successes
3. Define the role and rights of parents while partnering with professionals.

Agenda:

Introductions and Opener: 15-20 minutes

- Each participant introduces themselves (remind folks to use first names for HIPAA purposes) and describes a situation in which they have to partner with professionals (examples- Dr's appts., IFISP's, meetings with Developmental Specialists, Social Workers, Psychologists, Psychiatrists, Teachers.....).
- Facilitator-probe for details about what makes these situations challenging such as their perceptions about attitudes, feelings of being overwhelmed, intimidated....Discuss and support participants in their feelings and discuss that it is possible work with professionals even with these feelings and develop outcomes together.....

What works?: 15-20minutes

- Facilitator- divide participants into pairs and give each pair flip charts and markers. Ask participants to list what has worked for them in dealing with professionals...probe for preparing a list of questions, expectations, knowing what their rights were, advocacy skills, knowledge of a grievance procedure.....
- Discuss strategies

Developing Action Plans: 15-30 minutes

- Facilitator- Assign each group a situation and provide pens, paper. Direct them to develop an action plan containing strategies and techniques that were discussed. Share handouts reflecting these strategies.

Debrief and Summarize: 15-20 minutes

How to Partner with Professionals

Action Plan

1. What situation is this action plan for?
 - IFSP
 - Dr.'s Appointment
 - Therapy Appointment
 - Benefits Appointment
2. Who will be attending?
3. What is the reason for the appointment/meeting?
4. What do I want to get done at this appointment/meeting?
5. What questions do I have.



