

# Families as Faculty

## Occupational Therapist

### Student Handbook

University of New Mexico

UNM-Farmington

Western New Mexico University

WNMU-Graduate Studies Center Gallup

New Mexico State University

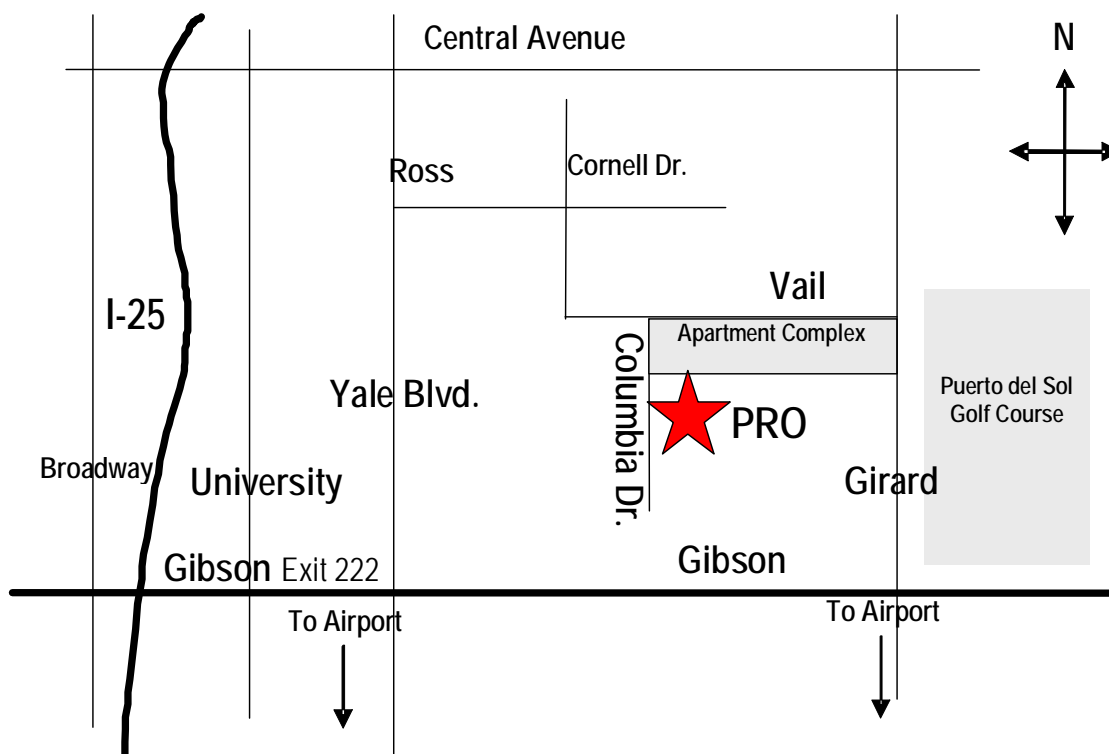
Eastern New Mexico University

Central New Mexico Community College



**Parents Reaching Out**  
*Your One Stop Resource for a Stronger Family*

# How to Find Us



From I-25—take the Gibson Blvd Exit (222) and go East on Gibson. Turn left at the third stop light (Girard). Turn left on the first street—Vail. Go one block to Columbia. Turn left on Columbia. Go about a half of a block (past brown apartments). Parents Reaching Out is the concrete building on the left. Welcome!

## Parents Reaching Out

1920 B Columbia Drive, SE  
Albuquerque, NM 87106  
1-505-247-0192 ♦ Fax: 505-247-1345  
1-800-524-5176  
[www.parentsreachingout.org](http://www.parentsreachingout.org)

## **Welcome to Families as Faculty!**

The materials in this handbook will provide you with information about the Families as Faculty experience and Parents Reaching Out, the hosting organization. You will also find information and resources for families and professionals about family-professional communication, family-centered care, special education, as well as essays and poems by families who have children with special needs. We hope that each in their own way will help support you in your class work and help you prepare for your family visit.

We are pleased to have so many supportive and enthusiastic colleagues around the state who have helped Families as Faculty to grow and continually evolve and deepen. We also want to say “*thank you*” many times over to the more than 150 host families in communities throughout New Mexico who are critical in making this experience a memorable and often transformational learning experience for students.

Families as Faculty has four parts: 1) an orientation session in which you will learn the guidelines for your family visit and hear an adjunct family faculty member’s experiences having a child with special needs and receiving occupational therapy, 2) a family visit with a partner, 3) writing a reflection paper and, 4) a wrap up session during which we will discuss your experience and reflect upon the challenges and rewards of partnering with families and its implications for your professional practice.

We look forward to meeting with you and arranging a successful family visit.

*Families as Faculty Staff*

Let us put our minds together  
and see what  
life we can make  
for our children.

*Chief Sitting Bull*



# Families as Faculty OT Student Handbook 2008-2009

## ***Welcome***

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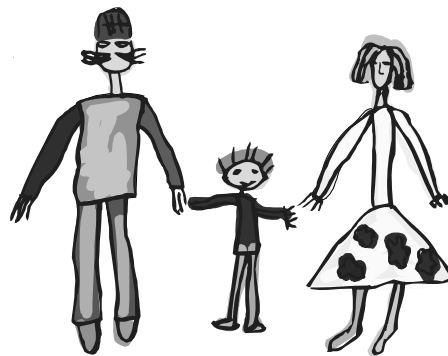
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Parents Reaching Out is funded through grants from the U.S. Department of Education, Office of Special Education Programs as the Parent Training and Information Center for New Mexico in addition to the federal Maternal and Child Health Bureau as the New Mexico Family to Family Health Information Center. The contents of this handbook were developed under the grant. However, the contents do not necessarily represent the policy of the US Department of Education, and you should not assume endorsement by the Federal Government.

In addition, Families as Faculty appreciates the funding support from the New Mexico Public Education Department, New Mexico Department of Health, Family Infant and Toddler program (FIT) and the University of New Mexico School of Medicine-Continuum of Care.

"The way schools care about children is reflected in the way schools care about the children's families. If educators view children simply as students, they are likely to see the family as separate from the school. That is, the family is expected to do its job and leave the education of children to the schools. If educators view students as children, they are likely to see both the family and the community as partners with the school in children's education and development. Partners recognize their shared interest in and responsibilities for children, and they work together to create better programs and opportunities for students."

Dr. Joyce Epstein, "Caring for the Children We Share"



# Overview

Families as Faculty (FAF) is often called a transformational experience by students who participate in this program. This innovative component of undergraduate and graduate education course work is a collaborative program between Parents Reaching Out (PRO), New Mexico's Parent Training and Information Center and six New Mexico universities. At its center, is a student visit with a family who has a child with special needs. Students learn first hand from host families about their experiences, both positive and negative, with health care service systems. Families as Faculty provides students with a hands-on, real life experience at a crucial time in their professional preparation program.

As a result of this personal and often intimate visit, students leave with an appreciation and better understanding of the joys and challenges of having a child who has special needs. They also frequently reflect on their own attitudes about children with special needs and their families, questions about how to effectively collaborate with families, and their capacity to effect positive change on systems to better serve children.

Families as Faculty is an adaptation of a family-centered care curriculum for health care students and is based on the following principles: *collaboration, information, respect, support, flexibility, strengths, empowerment and choice*. Families as Faculty has also been adapted for educators using the precepts of the Individuals with Disabilities Education Act (IDEA). Today, this program reaches nearly 300 students a year on campuses across the state: University of New Mexico, University of New Mexico-Farmington, Western New Mexico University, Western New Mexico University-Graduate Studies Center, Gallup, New Mexico State University and Eastern New Mexico University and Central New Mexico Community College.

## Goals

It is our expectation that students will come away from their visit with 1) a better understanding of the family-professional relationship; 2) a view of families as resources from whom they can learn; 3) an understanding that all children and families are different, each with unique strengths, values, beliefs and challenges and, 4) a consideration of their own personal beliefs, values and attitudes about children, families, the health care services system and their capacity to effect positive change in it.

Families describe this program as empowering for them and their children and as an opportunity to make a difference in the health care services system. They also have a chance to teach students about a particular disability in real life and strategies that could be helpful in OT therapy. Students often describe this experience as one of the most important in their coursework. "This experience was extremely eye-opening for providing some realization of how difficult it is to care for children with disabilities," said one student. "I was aware at a cerebral level, and this gave that awareness a human element."

## **Connecting Students with Families**

Host families are recruited and trained by Parents Reaching Out. They are required to participate in an orientation, Host Family 101. During this hands-on session, families become familiar with program goals, practice how to frame their family story around one or more of the goal areas, and are offered ideas to help ensure a successful visit.

An Adjunct Family Faculty and a FAF staff member conduct an orientation session for students. This family faculty is an experienced host and has completed a training and mentoring program with the FAF staff. During the session, program goals are discussed, a family story is shared highlighting each program goal, tips for a good visit are offered, and assignments are made.

The assignment is in the form of an invitation from the family. It contains contact information, favorite family activities, suggestions on how make a good contact call, and the names and ages of the children in the family. No disability or diagnosis is provided. It is our goal that students visit the family with an open mind and a willingness to ask questions. Although students are asked to prepare for the visit and have questions in hand when they go, they are instructed that this is *not an interview*, but a rather, an informal meeting.

Visits are planned for two hours and generally take place at the home of the host family. Families determine when and where they will meet with students, and who among family members will be present. It is important that the visits are held at a place of the family's choosing. Being in a familiar setting helps them to manage the meeting and the environment, creating a shift in perspective for students.

## **Impact of Families as Faculty**

Listening to family stories helps students understand the impact a therapist and the health care services system can have on child and his or her family. In addition, they also come to see the child a member of a family, as someone who is loved, has interests, conflicts and needs, just as any other child might. Students have an experience with a family to talk about more than a diagnosis and therapy.

A follow-up discussion is held with students when the visits are completed. An Adjunct Family Faculty and FAF staff member facilitate this session. Each student has the opportunity to talk about the visit—what they learned from the family, the child, about the disability, the health care service system and its implications for their future practice.

# Families as Faculty Goals

*Participation in Families as Faculty has opened my eyes in ways that no amount of classroom lecture or library research ever could. I was allowed to experience, rather than discuss, real life issues with a family from my own community.* Student

## Goal One

To give students an opportunity to see a child beyond his or her illness or diagnosis and as a member of a family and community

*It is wonderful to see them first and foremost as a family, instead of as patients. I will always remember that my patients are more than their disease, they are individual people.* Student

## Goal Two

To help students recognize and acknowledge their own values, attitudes and personal beliefs while still respecting the perspective of the family

*I have come to understand that the way we respond to people who are different in any way, clearly reflects our own willingness to either expand our horizons, or to shrink back in fear. The manner in which we interface with people with apparent disabilities is far more reflective of our own personal capacities than those of the person we interface with.* Student

## Goal Three

To provide students an opportunity to view families as knowledgeable partners from whom they can learn

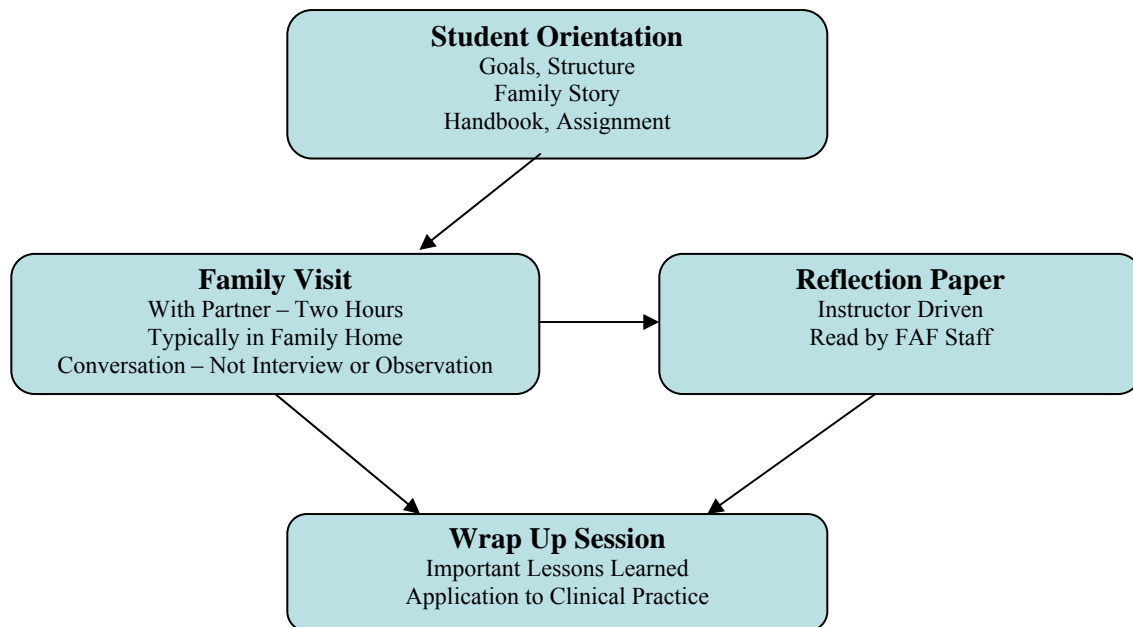
*We need to move past the politics and realize that it is very important to not only pay close attention to all children, but also to the parents because they know the child better than we will every get to know him or her in the one year we may spend with that child.* Student

## Goal Four

To provide students an opportunity to explore the complex needs and strengths of families coping with a chronic condition or disability

*I was humbled by their positive approach. I have heard people wonder if they would have the strength to raise a disabled child. After spending time with (Connie's) family, I am more convinced than ever that we all have the strength, what we may be lacking is an open mind.* Student

## Families as Faculty – At a Glance



## Families as Faculty Continues to Grow

<b>Year</b>	<b>Sites</b>	<b>Classes</b>	<b>Students</b>	<b>Host Families</b>
<b>2001-02</b>	<b>2</b>	<b>6</b>	<b>139</b>	<b>40</b>
<b>2002-03</b>	<b>5</b>	<b>12</b>	<b>284</b>	<b>80</b>
<b>2003-04</b>	<b>5</b>	<b>15</b>	<b>395</b>	<b>92</b>
<b>2004-05</b>	<b>5</b>	<b>14</b>	<b>300</b>	<b>120</b>
<b>2005-06</b>	<b>6</b>	<b>15</b>	<b>320</b>	<b>135</b>
<b>2006-07</b>	<b>5</b>	<b>16</b>	<b>260</b>	<b>150</b>
<b>TOTAL</b>	<b>5</b>	<b>78</b>	<b>1698</b>	<b>150</b>

*Students come into our home. They meet real kids with challenges.  
They hear real stories of experiences, some good, some bad.*

Family Faculty

## **A possible starting point for our conversations**

*For conversations to take us to a deeper realm, I believe we have to practice several behaviors. Here are the principles I've learned to emphasize before we begin a formal conversation process.*

We acknowledge one another as equals.

We try to stay curious about each other.

We recognize that we need each other's help to become better listeners.

We slow down so we have time to think and reflect.

We remember that conversation is the natural way humans think together.

We expect it to be messy at times.

By Margaret Wheatley  
from *Turning to One Another*  
Berrett-Kohler Publishers, Inc. 2002

# The Power of Story Telling

*Their story, yours, mine – it's what we all carry with us on this trip we take, and we owe it to each other to respect our stories and learn from them.*

Everyone has a story to tell. Our stories reveal how we think about ourselves, how we define and give meaning to our experiences and how information is selectively passed on from one generation to the next. Our stories are shaped by what we pay attention to. And what we pay attention to is influenced by gender, age, culture, family history, values and expectations for the future.

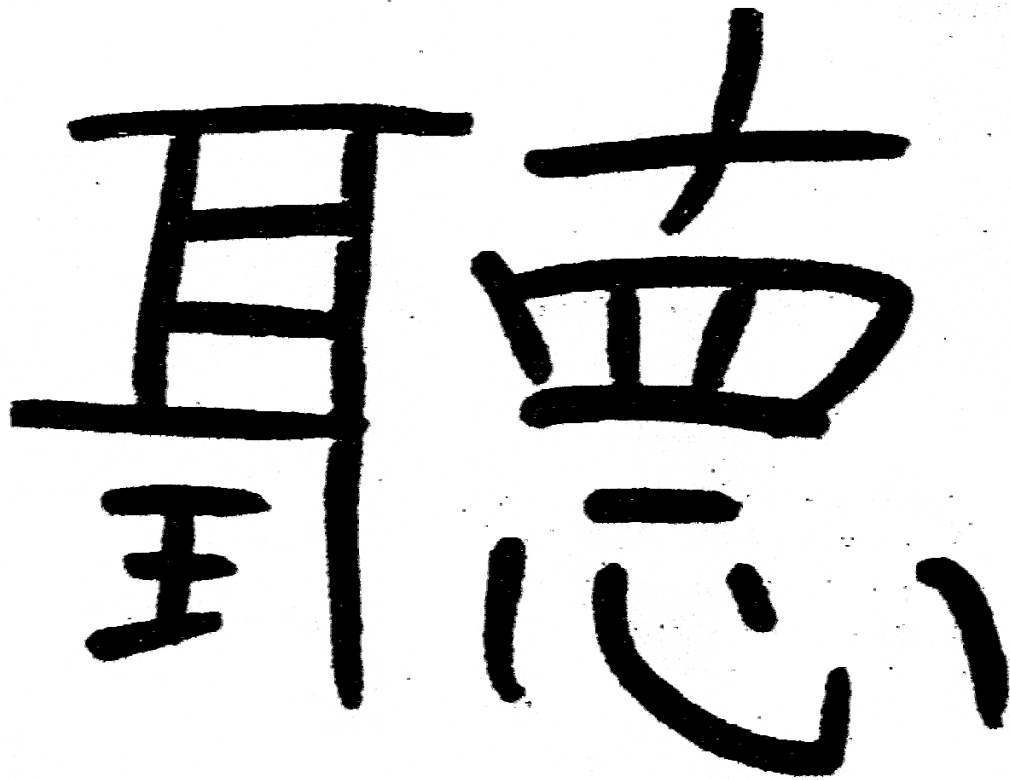
The Families as Faculty experience is based on the central principle of story telling, a language common to families everywhere.

Professionals too, are familiar with story telling. Many family-professional interactions begin with a description of the child's experience: the "story" of the problem. Before strategies can be developed and put into place, it is our belief that professionals must first understand the meaning of the child's behavior in the larger context of his or her life.

By inviting students into their homes and communities, families have the opportunity to teach the kinds of lessons that can't be learned in school or at a therapy session. There, the emphasis is on the diagnosis or problem. In the home and community, the emphasis is on living life to the fullest.



## The Chinese character "to listen"



**includes the symbols for  
the ear, heart, and with effort.**

# Reminders for Your Visit

## Before You Call

- ✓ Have three dates and times that you and your partner have agreed on before you call your host family. Allow them to take the lead on what date and time will be the most convenient for their schedule.
- ✓ Review the phone tips on your invitation before calling your host family.
- ✓ Call your host family within ONE WEEK of the orientation.

## The Call

- ✓ Be sure to leave your name and telephone number with your host family.
- ✓ Tell your host family that your partner (his/her name) will be calling to confirm the visit.
- ✓ Call your host family to confirm your appointment at least TWO days before your visit.

## The Visit

- ✓ Go with an open mind.
- ✓ **Keep family information confidential.**

### Tips for a Successful Visit

Follow-up is very important. If you can not reach your host family within ONE WEEK, contact Parents Reaching Out so that we can help you arrange a visit. (See your invitation for contact information.)

Be flexible about the day and time to meet with your partner and host family.

*ONLY Families as Faculty staff can change your host family assignment. You are expected to go with your partner(s) to the family to whom you are assigned.*

Be understanding of the busy schedules and the demands of everyday family life. You may not be able to meet the child(ren) or the entire family during your visit.

The focus of the visit is the family's experience, NOT the child's disability.

Your assignment is to listen and observe and not to make assumptions or judgments about what you hear or see.

Be thoughtful about the questions you ask about family life or the child's disability.

Be sensitive in your responses to what the family says or does. Take care in making comments about family life or the child's disability. Be thoughtful in your remarks and choice of words.

Remember, this is **NOT** an interview. It is a time for your host family to share their experiences. **BE AN ACTIVE LISTENER!**

Note: This evaluation form is sent to your host family. They complete and return it after your visit with them. A copy is shared with your instructor and the original is kept at Parents Reaching Out for evaluation purposes.



Families as Faculty  
**NURSING**  
 Student Evaluation

Please return by \_\_\_\_\_

*Please be as forthcoming as possible. Your responses are also shared with the university faculty to provide feedback to them and to help us improve Families as Faculty. Thank you!*

Name \_\_\_\_\_ Visit Date \_\_\_\_\_ Number Family Members Present \_\_\_\_\_

Student A \_\_\_\_\_ Student B \_\_\_\_\_

Would you like to be contacted about this visit? \_\_\_ Yes Best time to call: \_\_\_\_\_

Please answer the questions below for each student using a scale of 1 to 4. Place an x in the appropriate box to indicate your answer.		Student A			Student B			
		2	3	4	1	2	3	4
1. Did the student show an awareness of the purpose of the visit?	1 No, not at all 2 Somewhat 3 Mostly 4 Yes, very much							
2. Did the student have an open attitude to listen and learn from you and your family?								
3. Did the student contact you in a timely and courteous way to arrange or confirm the visit?								
4. Based on this visit, does the student have the potential to be a therapist with whom you would feel comfortable? Please feel free to comment in the space at the bottom of the page.								
5. Do you think the student gained an understanding of the goals of the program as a result of this visit?								
6. A. Was your child present for any or all of the visit? <input type="checkbox"/> YES <input type="checkbox"/> NO If your child was present, please answer B. B. Briefly describe how each student interacted with your child during the visit.								
7. Where did you and the students meet?								

8. Please check one or more of the principles of family-centered care that you talked about with the students.

- respect       strengths       information       choice  
 support       flexibility       collaboration       empowerment

Other comments.

## Notes

# Expanding What We Know





# Family-Centered Care

## Questions and Answers<sup>1</sup>

### **What is family-centered health care?**

Family-centered care is an approach to the planning, delivery, and evaluation of health care that is governed by mutual beneficial partnerships between health care providers, patients, and families. Family-centered applies to patients of all ages, and it may be practiced in any health care setting.

**What are the principals of family-centered care?** Family-centered care is characterized by four principals:

1. People are treated with dignity and respect.
2. Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.
3. Patients and family members build on their strengths by participating in experiences that enhance control and independence.
4. Collaboration among patients, family members, and providers occurs in policy and program development and professional education, as well as in the delivery of care.

### **What is meant by the word “family”?**

The word “family” refers to two or more persons who are related in any way—biologically, emotionally, or legally.

### **How is “family” defined for an individual patient?**

The definition of family, as well as the degree of family involvement in health care, is controlled by the patient, provided he or she is developmentally mature and competent to do so. In pediatrics, families define for themselves who their family members are. The term “family-centered” is in no way intended to remove control from adults who are competent to make decisions concerning their own health care. The term “patient-and family-centered” may be used outside of the pediatric setting in order to make this explicit.

### **Is there a difference between family-centered care and family-focused care?**

Both approaches acknowledge involvement with the family as a fundamental element of care. In family-focused care, professionals may provide care from the position of an “expert”; they tell the family what to do. They do things to and for the patient and family and consider the family the “unit of intervention.”

Family-centered care, by contrast, is characterized by a collaborative approach to caregivers and decision-making. Each party respects the knowledge, skills, and experience the other brings to the health care encounter.

### **Does family-centered care have anything to do with family practice?**

Family practice is a medical specialty. Although the principles of family-centered care are particularly suited to the practice of family medicine, they transcend medical specialty.

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<sup>1</sup> Family Centered Care: Questions and Answers The Institute for Family-Centered Care 7900 Wisconsin Avenue, Suite 405, Bethesda, Maryland 20814 Phone: 301-652-0281 • Fax: 301-652-0186 www.familycenteredcare.org

### **Family**

Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. A family is culture unto itself, with different values and unique ways of realizing its dreams; together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states and nations.

New Mexico Young Children's Continuum, 1990  
Edited by Polly Arango

Family-centered services are based on a set of deeply held values and beliefs about relationships: between children and their families; between professionals and parents; and the role of community services as a whole. Family-centered services ensure the well-being of all children including those with developmental delays and disabilities and their families.

*Family-centered care* is based on developing mutual partnerships between professionals and the families to insure that services are planned and delivered to meet the unique needs of the family as a whole. Family-centered care is based on these core concepts:

**Dignity and Respect:** Listening to and honoring the family perspective and choices.

**Information Sharing:** Building family capacity by providing unbiased information in ways that are affirming and useful. Sharing timely, complete and accurate information to provide choice and empower informed decision-making.

**Participation:** Encouraging and supporting families to participate and make decisions that affect the outcomes for their family member

**Collaboration:** Using processes to promote family involvement in developing policies, implementing programs and evaluating results. Practices insure that family knowledge, values, beliefs and cultural backgrounds are included in planning and delivering services and care.

Source: Institute for Family Centered Care <http://www.familycenteredcare.org>

### **What does a family-centered approach mean for families?**

The ultimate outcome of a family-centered approach is to enhance the well-being of the family as a whole. It is designed to minimize stress, maintain or enhance relationships within the family, and makes it possible for the family to (as closely as possible) follow the lifestyle they choose for themselves. The definition of success looks different for each family.

### **What is the purpose of family-centered services?**

Family-centered care is about *family empowerment*. Families share expertise on their child and gain the sense of confidence that comes from making informed decisions that are right for their family. The outcomes benefit the well-being and development of the child and family as a whole. Family-centered care is the continual pursuit of being responsive to the priorities and choices of families.

### **Family-Centered Professionals:**

- View the family as a whole for service delivery and recognize that the well-being of each family member has an impact on every other member of the family.
- Recognize child and family strengths and views them as capable and competent. Providers help parents recognize their own personal and family strengths. They encourage families to build upon existing knowledge and skills. They show families genuine respect and sincere appreciation of even their smallest successes.
- Respond to family priorities to help families accomplish *their* DREAMS, not what the professional thinks should be important to them and share expertise without judgment.
- Individualize service delivery through plans tailored to family priorities. Services are not “one size fits all”. It is the family that determines the “best fit” for their family.
- Respond to changes in family priorities through trusting relationships formed during continuous communication that goes beyond an annual meeting or set of scheduled visits.
- Support family lifestyles and recognize that families go about their daily lives in different ways. Families change as they cope with events in their life (child birth, caring for a child with special needs, illness, employment, changes in relationships or cultural traditions).

# NM Family to Family Health Information Center

Parents Reaching Out is the New Mexico Family to Family Health Information Center (F2FHIC) through a grant from the federal Maternal and Child Health Bureau. Previous grants from The Centers for Medicare and Medicaid Services (CMS) helped us build a strong foundation to improve families' ability to access to health care in our state. We offer tools and resources to help them better understand the health care system and make informed choices to access quality services that meet their needs. It is our goal to help families understand their rights and become informed about:

- Health care insurance
- Managed care providers
- Medicaid
- Supplemental Security Income (SSI)
- Home and Community Based Waiver options
- Developmental Disabilities Waiver (DD)
- Medically Fragile Waiver
- Disabled & Elderly Waiver (D&E)
- Mi Via

We also provide training and consultation for health care professionals to promote family involvement and informed decision making on health care issues. The Family to Family Health Information Center brings the family perspective to policy discussions and decisions through our work with local, state and national advisory boards of agencies and services providers.

## Learning Opportunities

As the F2FHIC, Parents Reaching Out offers workshops designed for families, professionals and community members and include;

- **Coping with Stress and Navigating the Health Care Systems** Families are offered a range of tips to help reduce the stress of daily challenges in caring for their children who have special health needs. Tools are also provided to help families navigate the health care system. Information about Medicaid, SSI, and home-community waiver programs is also disseminated and discussed.
- **Medicaid 101** Families and professionals learn about the difference between Medicare and Medicaid, the services offered, the application/eligibility/appeal processes and the latest state and national changes in Medicaid regulations.
- **Developmental Disabilities Waiver (DD Waiver) Application Process** Families learn important tips on how to apply for the Development Disabilities Waiver and the documentation required by the Developmental Disabilities Support Division. Other waiver programs are also discussed.
- **How to Apply for Home and Community Based Waiver Services** Families learn about eligibility and how to apply for the New Mexico Home and Community Based Service Waiver programs: the DD Waiver, Medically Fragile Waiver, and the Disabled & Elderly Waiver.

# Family Health Care Information

Parents Reaching Out has developed a variety of Health Care Access publications and Family Health Care Tip Sheets that cover topics those listed below and many more. Many of our publications are available in English and Spanish. These publications are available in hard copy and on CD, or may be downloaded from our website: [www.parentsreachingout.org](http://www.parentsreachingout.org)

## **Family Health Care Tips (Fact Sheets)**

1. Advocacy and Health Care
2. Teen Scene: Communicating with Doctors
3. Prepare Your Child for Doctor Visits
4. DD Waiver
5. Medicaid
6. SSI (Social Security Supplemental Income)
7. Preventing Medical Errors
8. Transition Health Care
9. HIPPA—What Does It Mean?
10. Parents-Questions to Ask Your Child’s Doctor
11. Handling Medical Appointments
12. Mi Via
13. What is EPSDT?

*Health Care Access publications include:*

**DD Waiver Application Handbook and DD Waiver Allocation Handbook:** These handbooks offer information and advice from families, advocates, case managers and agencies and provide a “road map” for families and individuals.

The DD Waiver *Application* Handbook provides a step-by-step explanation of the application process.

The DD Waiver *Allocation* Handbook describes how to access DD Waiver services after receiving notification of acceptance to the DD Waiver.

**Know Your Options: Home and Community Based Waivers in NM:** Provides eligibility criteria and descriptions of services for Mi Via, the DD Waiver, D&E Waiver and Medically Fragile Waiver.

**A Guidebook to Supplemental Security Income (or SSI to those in the know):** We know from experience that the Supplemental Security Income (SSI) system is not an easy one to get around. This guidebook answers important questions such as: Who is eligible? How do you apply? Is the application process complicated? Where do you get help? and Is there an appeal process?

As an occupational therapist, you may be working in a school setting with children who have special educational needs. Special education is a service brought to children through the Individual Education Program (IEP), of which OT services may be a part.

The Individuals with Disabilities Education Act (IDEA) is a federal law which outlines the rights and responsibilities of families and those who provide services for children with special needs. Following is an overview of the spirit and principles upon which the law is based.

## **Individuals with Disabilities Education Act (IDEA)**

### ***IDEA as a Cultural Statement***

IDEA encompasses six principles of law:

1. Zero reject or the right of every child to education
2. Nondiscriminatory assessment, or the right to a fair evaluation to determine appropriate educational placement
3. Individualized and appropriate education to ensure that education is meaningful
4. Least restrictive environment to ensure that children with disabilities can associate with typical peers to the maximum extent appropriate to their needs
5. Due process to ensure the child's right to challenge any aspect of education
6. Parent participation, which allows parents to participate in the education decision-making process

By Maya Kalyanpur and Beth Harry  
*Culture in Special Education*  
Paul H. Brooks Publishing Co. Baltimore, 2004

# Additional Publications of Parents Reaching Out

*The follow publications are available in hard copy and on CD. If you would like a copy of our materials, please feel free to visit our office, download from our web site or call the Resource Coordinator at 505-247-0192 or 1-800-524-5176 to place a request.*

\* Indicates Spanish version is available

## **Acronyms, Abbreviations and Definitions**

**A Bridge to the Future** \* (Ability Pathway to Diploma)

**Book of Ideas** \* (Learning Styles, Instructional Strategies and more)

**Did You Know Fact Sheets** \* (NCLB, Literacy, Parent Involvement, Early Childhood)

**Early Intervention and Natural Environments** \* (Birth to three)

**Extended School Year** \* (Special Education Related Service)

**Family Health Care Tips**\* (Fact Sheets on Health Care Access)

**Family Connections Series**\* (6 books based on the Epstein Model for Quality Schools)

**Family Involvement: Building Community Partnerships**\* (Schools & Systems Change)

**First Steps Fact Sheets**\* (Early Intervention)

**How Can I Help This Child?** (Sensory Integration)

**Let's Begin the Journey** \* (Overview of Special Education)

**Mission Transition** \* (Head Start to Elementary)

**Next Steps to Success** \* (Early Intervention to Early Childhood)

**Open Line and More** \* (Communication Skills)

**Positive Directions for Student Behavior** (Intervention Strategies & Tools)

**Practical Inclusive Education in New Mexico** \* (Differentiated learning at its best)

**Telling Your Story** \* (Communication Skills—Sharing Your Perspective)

**The Journey Continues**\* (Standard and Career Readiness Paths to Diploma)

**The Handbook: Parental Rights and Special Education Procedures** \* (IEP Process)

*We also distribute New Mexico Public Education Department-Technical Assistance Documents: Pathways to the Diploma; SAT- Student Assistance Team and the Three-Tiered Model of Student Intervention; and Gifted Education and publications from other agencies.*

# New Mexico Resources for Professionals and Families

## U.S. Congress – New Mexico Delegation

Parents Reaching Out recommends that you first contact the New Mexico office(s) of our Congressional Representatives. Their staff can assist you and insure that your information gets to your Senator or Representative in a timely manner. This is especially true if you are writing letters.

### Representative Steve Pearce

1408 Longworth House Office Building  
Washington, DC 20515  
202-225-2365 <http://pearce.house.gov/>

#### *New Mexico Offices*

1923 North Dal Paso Hobbs, NM 88240  
505-392-8325 phone 505-433-8325 fax

400 North Telshor, Suite E Las Cruces, NM 88011  
505-522-2219 phone 505-522-3099 fax

1717 West 2nd Street, Suite 100 Roswell, NM 88201  
505-622-0055 phone 505-625-9608 fax

111 School of Mines Road Socorro, NM 87801  
505-838-7516 phone 505-838-4027 fax

### Representative Tom Udall

1414 Longworth House Office Building  
Washington, DC 20515  
202-225-6190 <http://www.tomudall.house.gov/>

#### *New Mexico Offices*

811 St. Michael's Drive Suite 104  
Santa Fe, NM 87505  
505-984-8950 tel 505-986-5047 fax

Rio Rancho City Hall  
3900 Southern Blvd. SE Rio Rancho, NM 87124  
505-994-0499 phone 505-994-0550 fax

Clovis-Carver Public Library  
P.O. Box 868 Clovis, NM 88102  
505-763-7616 phone 505-763-7642 fax

110 W. Aztec Gallup, NM 87301  
505-863-0582 phone 505-863-0678 fax

P.O. Box 926 Las Vegas, NM 87701  
505-454-4080 phone 505-454-4078

Farmington City Hall  
800 Municipal Drive Farmington, NM 87401  
505-324-1005 phone 505-324-1026

### Representative Heather Wilson

318 Cannon House Office Building  
Washington, DC 20515  
202-225-6316 <http://wilson.house.gov/>

#### *New Mexico Office*

20 First Plaza NW Suite 603  
Albuquerque, NM 87102  
505-346-6781 phone 505-346-6723 fax

### Senator Jeff Bingaman

703 Hart Senate Office Building  
Washington, DC 20510  
202-224-5521  
<http://bingaman.senate.gov/>

#### *New Mexico Offices*

625 Silver Avenue, SW Suite 130  
Albuquerque, NM 87102  
(505) 346-6601

148 Loretto Towne Centre  
505 South Main Las Cruces, NM 88001  
(505) 523-6561

118 Bridge Street, Suite 3  
P.O. Box 1977 Las Vegas, NM 87701  
(505) 454-8824

Suite 409  
105 West Third Roswell, NM 88201  
(505) 622-7113

Suite 101  
119 East Marcy Santa Fe, NM 87501  
(505) 988-6647

### Senator Pete Domenici

328 Hart Senate Office Building  
Washington, DC 20510  
202-224-6621 <http://domenici.senate.gov/>

#### *New Mexico Offices*

Albuquerque Plaza  
201 3rd Street, NW Suite 710  
Albuquerque, NM 87102  
5505-346-6791 phone 505-346-6720 Fax

120 South Federal Place Suite 302  
Santa Fe, NM 87501  
505-988-6511 phone 505-988-6514 Fax

505 South Main, Suite 118  
Loretto Town Center  
Las Cruces, NM 88001  
505-526-5475 phone 505-523-6589 Fax

Federal Building  
500 North Richardson Suite 227 Roswell, NM 88201  
505-623-6170 phone 505-625-2547 Fax

## ***New Mexico Agencies and Organizations***

### **Governor**

Honorable Bill Richardson  
Office of the Governor  
State Capitol, Room 400, Santa Fe, NM 87501  
(505) 476-2200 Web: [www.governor.state.nm.us/](http://www.governor.state.nm.us/)

### **Governor's Commission on Disabilities**

Lamy Building, Room 117  
491 Old Santa Fe Trail, Santa Fe, NM 87501  
(505) 476-0412; (877) 696-1470 (in NM)  
(505) 476-0413 (TTY) Web: [www.nmgcd.org](http://www.nmgcd.org)

### **New Mexico Aging and Long-Term Services - Elderly and Disability Services Division**

1190 St. Francis Drive, Room N-3050  
P.O. Box 26110, Santa Fe, NM 87502  
(505) 827-2574 Web: [www.nmaging.state.nm.us/Elderly\\_Disability\\_Services\\_Division.html](http://www.nmaging.state.nm.us/Elderly_Disability_Services_Division.html)

### **New Mexico Career Technical Work Force Education Bureau**

Public Education Department - Education Building  
300 Don Gaspar Avenue, Santa Fe, NM 87501  
(505) 827-6512 Web: [www.ped.state.nm.us](http://www.ped.state.nm.us)

### **New Mexico Children, Youth and Families Department**

P.O. Drawer 5160  
Santa Fe, NM 87502  
(505) 827-9988 Web: [www.state.nm.us/cyfd](http://www.state.nm.us/cyfd)

### **New Mexico Commission for the Blind**

2905 Rodeo Park Dr. East Building 4 Suite 100  
Santa Fe, NM 87505  
(505) 446-4479; (888) 513-7968 Web: [www.state.nm.us/cftb](http://www.state.nm.us/cftb)

### **New Mexico Commission for Deaf and Hard of Hearing Persons**

2500 Menaul NE, Albuquerque, NM 87110  
(505) 881-8824; (800) 489-8536 (V/TTY, in NM only)  
Web: [www.nmcdhh.org](http://www.nmcdhh.org)

### **New Mexico Developmental Disabilities Planning Council**

810 West San Mateo Rd. Suite C  
Santa Fe, NM 87505  
(505) 476-7321 Web: [www.nmddpc.com](http://www.nmddpc.com)

### **New Mexico Division of Vocational Rehabilitation / Public Education Department**

435 St. Michaels Drive Building D  
Santa Fe, NM 87505  
(505) 954-8511 / 1 (800) 224-7005 Web: [www.dvrgetsjobs.com](http://www.dvrgetsjobs.com)

**New Mexico Department of Health**

Family Health Bureau/ Children's Medical Services  
2040 S. Pacheco, Santa Fe, NM 87505  
(505) 476-8905 Web: [www.health.state.nm.us/](http://www.health.state.nm.us/)

**New Mexico Family, Infant Toddler Program** Ages Birth Through 2

New Mexico Department of Health/Long Term Services  
1190 St. Francis Drive, Santa Fe, NM 87502  
(877) 696-1472 Web: [www.health.state.nm.us](http://www.health.state.nm.us)

**New Mexico Public Education Department**

Curriculum & Instruction, No Child Left Behind, Charter Schools  
300 Don Gaspar  
Santa Fe, NM 87501-2786  
Phone: (505) 827-5800 Web Address: <http://www.ped.state.nm.us/index.htm>

**New Mexico Public Education Department: Special Education Bureau**

Transition, Early Childhood Special Education, Rural Education, Mediation Services  
120 S. Federal Place Room #206  
Santa Fe, NM 87501  
(505) 827-1457 Web: [www.ped.state.nm.us/seo](http://www.ped.state.nm.us/seo)

**New Mexico Technology Assistance Program**

435 St. Michael's Drive, Building D  
Santa Fe, NM 87505  
(800) 866-2253 (V); (800) 659-8331 (TTY) Web: [www.nmtap.com](http://www.nmtap.com)

**Center for Developmental and Disabilities (CDD)** University of New Mexico

2300 Menaul Boulevard  
Albuquerque, NM 87107  
(505) 272-3000 Web: <http://cdd.unm.edu/>

**Disability Law Resource Project** (Regional ADA / IT Technical Agency)

2323 S. Shepard Boulevard, Suite 1000, Houston, TX 77019  
(713) 520-0232 (V/TTY); (800) 949-4232 (V/TTY)  
Web: [www.dlrp.org](http://www.dlrp.org)

**Native American Disability Law Center**

3535 East 30<sup>th</sup> St. Suite 201  
Farmington, NM 87402  
(505) 566-5880; (800) 862-7271 (in NM)

**Protection and Advocacy System**

1720 Louisiana Boulevard, Suite 204  
Albuquerque, NM 87110  
(505) 256-3100; (800) 432-4682 (in NM)  
Web: [www.nmpanda.org](http://www.nmpanda.org)

## ***Disability-Specific Organizations***

### **Attention Deficit Disorder**

#### **Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)**

8181 Professional Place, Suite 150  
Landover, MD 20785  
(310) 306-7070 Web: [www.chadd.org](http://www.chadd.org)

#### **National Attention Deficit Disorder Association (ADDA)**

P.O. Box 543 Pottstown, PA 19464  
(484) 945-2101 Web: [www.add.org](http://www.add.org)

#### **Attention Deficit Disorder Association– Southern Region (ADDA)**

12345 Jones Road, Suite 287, Houston, TX 77070  
(281) 897-0982 Web: [www.adda-sr.org](http://www.adda-sr.org)

### **Autism**

#### **New Mexico Autism Society**

P.O. Box 30955 Albuquerque, NM 87190  
(505) 332-0306 E-mail: [nmautism@nmautismsociety.org](mailto:nmautism@nmautismsociety.org) Web: [www.nmautismsociety.org](http://www.nmautismsociety.org)

### **Brain Injury**

#### **Brain Injury Association of New Mexico**

121 Cardenas, N.E., Albuquerque, NM 87108  
(505) 292-7414; (888) 292-7415 (in NM)  
E-mail: [info@braininjurynm.org](mailto:info@braininjurynm.org) Web: [www.braininjurynm.org](http://www.braininjurynm.org)

### **Learning Disabilities**

#### **New Mexico Learning Disabilities Association**

P.O. Box 556 Albuquerque, NM 87110  
(505) 821-2545 Web: [www.vivanewmexico.com/nmlda](http://www.vivanewmexico.com/nmlda)

### **Mental Health**

#### **NAMI-New Mexico**

P.O. Box 3086 Albuquerque, NM 87190-3086  
(505) 260-0154; (800) 953-6745  
E-mail: [naminm@aol.com](mailto:naminm@aol.com) Web: <http://nm.nami.org>

### **Mental Retardation and Related Developmental Disabilities**

#### **The Arc of New Mexico**

3655 Carlisle, N.E., Albuquerque, NM 87110  
(505) 883-4630; (800) 358-6493 (in NM)  
E-mail: [arcnm@arcnm.org](mailto:arcnm@arcnm.org) Web: [www.arcnm.com](http://www.arcnm.com)

### **Speech and Hearing**

#### **New Mexico Speech-Language-Hearing Association**

P.O. Box 66085 Albuquerque, NM 87193-6085  
(505) 899-6674; (800) 292-8465  
E-mail: [nmsaha@qwest.net](mailto:nmsaha@qwest.net) Web: [www.nmsaha.net](http://www.nmsaha.net)

## ***Organizations Especially for Parents***

### **Abrazos Family Support Services**

Education for Parents of Indian Children with Special Needs (EPICS) Project

P.O. Box 788, Bernalillo, NM 87004

(505) 867-3396 (V/TTY) E-mail: [info@abrazosnm.org](mailto:info@abrazosnm.org) Web: [www.abrazosnm.org](http://www.abrazosnm.org)

### **American Foundation for the Blind (Southwest)**

11030 Ables Lane

Dallas, TX 75229

(214) 352-7222 Web: [www.afb.org](http://www.afb.org)

### **Family Voices**

2340 Alamo SE, Suite 102

Albuquerque, NM 87106

Voice: 505-872-4774 or 888-835-5669

Fax: (505) 872-4780 Web: [www.familyvoices.org](http://www.familyvoices.org)

### **National Fragile X Foundation**

P.O. Box 190488

San Francisco, CA 94119

(800) 688-8765 Web: [www.fragilex.org](http://www.fragilex.org)

### **Parents for Behaviorally Different Children**

1101 Cardenas, N.E., Suite 202

Albuquerque, NM 87110

(505) 265-0430; (800) 273-7232

Web: [www.pbdc.org](http://www.pbdc.org)

### **Parents Reaching Out (Parent Training and Information Center (PTI) / Parent to Parent)**

1920 B Columbia Dr. SE

Albuquerque, NM 87106

(505) 247-0192; (800) 524-5176

Web: [www.parentsreachingout.org](http://www.parentsreachingout.org)

### **STEP\*HI Parent/ Infant Program (Early Childhood Programs)**

New Mexico School for the Deaf

1060 Cerrillos Road

Santa Fe, NM 87503

(505) 476-6300 Web: [www.nmsd.K12.nm.us](http://www.nmsd.K12.nm.us)

*“It’s Not That Easy Bein’ Green.”*





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THE MOST APPROPRIATE LABEL IS  
USUALLY THE ONE PEOPLE'S PARENTS  
HAVE GIVEN THEM.

# Stigma

*It's not that easy bein' green.*

-Kermit the Frog

It's not easy being green, even by association. As parents of children with disabilities, we are what the sociologist Erving Goffman call "wise ones," meaning "in the know." Because of our relationship to someone who has a disability, we have special knowledge and experience of disability, even though we are not disabled ourselves. And we react to our greenness in different ways. Some of us want to hang out almost exclusively with green folk. Some of us don't want anything to do with other green people. When we are away from our child, many of us choose to "pass," not revealing that we're really green, while others readily talk about their greenness. Whether we mostly tend to "pass" or mostly tend to "tell," there is always a choice to be made, which in itself can be wearing.

We struggle with our greenness, but our greater pain is knowing that our child has this struggle. It can be difficult for us to separate from our child, remembering that he, not we has the disability, and that his experience of it is different from ours. As our children grow older, they will find their own ways to think about and deal with their disabilities. They may reject and criticize the ways we have characterized their disabilities and the decisions we have made for them. They may accuse us of insensitivity, failure to understand and accept, or, worse, misguided or unfair treatment. They will undoubtedly be right on some points. After all, we're not really green.

It's not easy being green. Being wise isn't easy, either.

By Barbara Gill

from *Changed by a Child*

Bantam Doubleday Dell Publishing Group, NY 1997

# Welcome to Holland

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. Michelangelo's David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place.

It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills. Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy going to and from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never ever, ever go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

By Emily Perl Kingsley  
Copyright © 1987 Emily Perl Kingsley

Emily Perl Kingsley has been writing scripts for Sesame Street for thirty years. Much of her work on the show has focused on enhancing the understanding and acceptance of people with disabilities. Emily is mother of Jason Kingsley (1974) and served as the dictation typist for Jason's and Mitchell Levitz's book *Count Us In: Growing Up with Down Syndrome*.



## Celebrating Holland



I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned. I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger, the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay.

Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time. I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring.

Holland wasn't so bad. I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land.

Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do ) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts.

I have come to love Holland and call it Home. I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

By Cathy Anthony, 2001

Cathy Anthony is a parent, advocate and the Executive Director of the Family Support Institute in Vancouver, British Columbia ([www.vcn.ca/bcacl/fsi.htm](http://www.vcn.ca/bcacl/fsi.htm))

## **Recommended Reading: The Family Perspective**

*The following books can be found at the Parents Reaching Out (PRO) Resource Center.*

Berube, M. (1996). *Life as we know it: A father, a family and an exceptional child*. New York: Pantheon Books

Fadiman, Anne (1998). *The Spirit Catches You & You Fall Down*. Farrar, Strauss & Giroux, NY

Fialka, Janice, (1999). *Do you hear what I hear?* Ann Arbor: Proctor Publications

Fialka, Janice (1997). *It matters, lessons from my son*. Ann Arbor: Proctor Publications

Fialka, Janice (2005). *Whose life is it anyway?* Madison: University of Wisconsin

Kaufman, S.Z. (1998). *Retarded isn't stupid, Mom!* Baltimore: Paul H. Brookes Publishing Co.

Marsh, J.D. (1995). *From the heart: On being the mother of a child with special needs*. Bethesda: Woodbine House

Meyer, D.J. (1995). *Uncommon Fathers: Reflections on raising a child with a disability*. Bethesda: Woodbine House

Schulze, C. (1993). *When snow turns to rain: One family's struggle to solve the riddle of autism*. Bethesda: Woodbine House

Simons, R. (1985). *After the tears: Parents talk about raising a child with a disability*. San Diego: Harcourt, Brace and Co.

Spiegle, J. A. & R. A. van den Pol (Eds.) (1993). *Making changes: Family voices on living with disability*. Cambridge, MA: Brookline Books

Sullivan, T. (1995). *Special parent, special child: Parents of children with disabilities share their trials, triumphs and hard-won wisdom*. New York: G.P. Putnam's Sons

# **Stress and the Family of a Child with a Disability**

Stress is not unique to families. However, families who have children with disabilities may have additional stressors that are unique. Some of these stressors include:

- Stares and rudeness from strangers.
- Rejection or lack of help from relatives.
- Clashes in priorities among family members.
- Siblings feeling guilty, jealousy, embarrassment, confusion.
- Failure of one or more family members to be involved with the child with a disability.
- Perceived judgmental attitudes from professionals.
- Time demands.
- Problems with transportation.
- Inaccessible home.
- Financial burdens.
- Physical care of a disabled child.
- Lack of respite care.
- Lack of leisure activities for the child with disabilities.
- Sadness over limitations of child with disabilities.
- Private life open to many professionals.
- Child's behavior out of control.
- Lack of information about the disability.
- Lack of services.
- Feeling limited in recreational opportunities.
- Making decisions about placements.
- Attending Individualized Education Program (IEP) meetings.
- Dealing with sexuality of disabled adolescent.
- Dealing with demands for more independence from disabled child.
- Fear of the future for the child with disabilities.
- Disruption in routine.
- Wishing the child could die, or thinking other bad thoughts about a child with disability, then feeling guilty.
- Fear the child might die.

- Feeling professionals not being honest with you.
- Feeling isolated.
- Child having no friends.
- Not understanding systems that the parent must work with.
- Child being uninsurable.
- Having to impoverish the family to be eligible for services.
- Some people thinking the disability is the parent's fault.
- People implying the parent isn't doing enough to help the child.
- Too much advice from well-meaning people.
- Lack of knowledge about where to get equipment or other special services for the child.
- As the child gets older, society doesn't perceive him or her as cute anymore.
- Unrealistic portraits of miracle cures by media and other people suggesting to parents they could cure their child.
- Inaccessibility of public and private facilities.
- Red tape to obtain services.
- People telling the parent he/she is special because of having a child with disability.
- Fear of asking questions of professionals.
- Worry that the child will out-live the parent or who will take care of the child after the parent dies.
- Fear that others will take advantage of a child with a disability.
- Difficulty in communicating the child's needs to teachers.
- Fear of separation from the child.
- Transitioning from one program to another.
- Everyone thinking the child is "normal" and being intolerant of his or her differences.
- Not wanting to cry or become emotional in front of others.

This is long list of stressors and most families of children with disabilities can feel several of them at any given time. Learning and understanding the stressors that they face will enable professionals to be more sensitive and effective in working with them.

## Where are the Parents?



*Advocacy, Inc. of Austin, TX printed this article from a parent website. The author had been asked one too many times why more parents of children with special needs were not more involved in PTA and other similar school activities. Below is her response.*

**Where are the parents?** They are on the phone to doctors and hospitals, fighting with insurance companies, wading through red tape in order that their child's medical needs can be properly addressed.

They are buried under a mountain of paperwork and medical bills trying to make sense of system that seems to be designed to confuse and intimidate all but the very savvy.

**Where are the parents?** They are at home diapering their 15-year old son, or trying to lift their 100-pound daughter onto the toilet.

They are spending an hour at each meal trying to feed a child that cannot chew, or laboriously and carefully feeding their child through a G-tube.

**Where are the parents?** They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for test results to come back and wondering: Is this the time that my child doesn't pull through?

They are sitting in hospital rooms as their child recovers from yet another surgery.

They are waiting in long lines in clinics because no insurance company will touch their child.

***Where are the parents?*** *They are busy trying to survive.*

**Where are the parents?** They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night and must be constantly watched, lest he or she do him/herself or another member of the family harm.

They are sitting at home with their child because family and friends are too intimidated or unwilling to help with childcare, and agencies that are designed to help are suffering cutbacks.

**Where are the parents?** They are trying to spend time with their non-disabled children as they try to make up for the extra time and effort that is critical to keeping their disabled child alive.

They are struggling to keep a marriage together, because adversity does not always bring you closer.

They are working two, sometimes three jobs in order to keep up with the extra expenses.

And sometimes, they are a single parent, struggling to do it all by themselves.

**Where are the parents?** They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything.

They are trying to patch their broken dreams so that they might have some sort of normal life for their children.

# You Can Make a Difference in Our Lives

[Thoughts to professionals from a parent]

You have the opportunity not to be frightened by our anger ... to embrace it, to welcome it, and even to invite it on a good day. Obviously, you cannot do it every day.

You have the opportunity not to be intimidated when we blow off steam. You have the opportunity not to personalize these angry, negative feelings.

The great challenge for you is to give us the opportunity to fall apart once in a while. You may be surprised by how quickly we recover when we are given the opportunity to feel our feelings in the company of experienced and caring professionals.

I have a tender spot in my heart for a particular physician who provided care for my son. Several years ago, my son was hospitalized with complications from a very serious seizure. My husband and I were scared and overwhelmed by all that we did not know or understand.

We were resting in the hallway of the hospital to get a break from the intensity of being with our child who was hooked up to numerous tubes. A group of physicians walked by, stopped at our son's doorway, and began to "conference the case." To my surprise I leaped from my chair and in a very loud voice lectured them on how this "patient" was MY son and a REAL human being.

The physician in charge was very kind and tolerant. He maintained eye contact with me, listened, acknowledged my fear, and then he asked if he could accompany me to examine my son. I watched the other physicians in the group maintain their distance from me. However, this particular doctor remained engaged, responsive and accepting. Eventually, I used humor to discuss the particular event. His acceptance of my anger was almost as great a gift as his expert clinical care of my son. He had the great wisdom not to personalize the strong feelings. He understood their origin.

by Janice Fialka from  
*It Matters, Lessons From My Son*  
Huntington Woods, MI, 1997

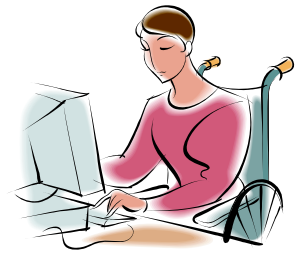
# Lessons of Segregation

## Revolutionary Common Sense

By Kathie Snow

*Kathie Snow is a zealous promoter of new ways of thinking about disability. Her website, as well as her newsletters, articles, workshops and presentations offer a new perspective about disability. Lessons of Segregation: Revolutionary Common Sense appeared in the November 2006 issue of the Disability is Natural newsletter. Unedited excerpts from this article are included below. If you would like a PDF version of this article to share with others for non-commercial purposes, please visit: [www.disabilityisnatural.com](http://www.disabilityisnatural.com)*

Gina has a Master's degree, lives in her own home, and has enjoyed moving up the corporate ladder in a variety of professional positions. When she was a young child, her parents followed conventional wisdom and placed Gina in a residential "crippled children's" school. She only saw her family once a month, and she grew up surrounded by children with orthopedic disabilities, along with therapists, special educators, and other professionals. She ultimately became accustomed to this "placement"—to the point that this sheltered, artificial setting seemed the norm, and life in the real world seemed strange. This particular school had high expectations for its students, so Gina received an academic education which enabled her to move on to college.



Outwardly successful, 42-year-old Gina struggles daily with the demons of segregation. Spending her formative years (ages 5-18) in a special, segregated environment caused deep wounds that have never healed, and they're reopened regularly. When faced with any difficulties at work or with family, Gina automatically believes she's at fault, incompetent, and unworthy; and she feels she doesn't belong. Being "sent away" by her parents taught her that she didn't belong because of her disability; she wasn't "good enough." As an adult, this deeply-rooted emotional pain is almost too much to bear, and has created more difficulties for Gina than her disability. She's currently in counseling, hoping to exorcise the demons that haunt her daily.



Brad's life has been different, and he's learned other lessons from segregation. He grew up at home with his family, but he never attended the same schools as his brother and sister. At the age of three, he was put on the Special Ed bus for the 45-minute ride to the Special Ed Preschool. During public school years, he never knew what grade he was in, a common occurrence when children with disabilities of various ages are grouped in the same special ed ungraded classroom. Unlike children without disabilities who are exposed to greater learning opportunities and responsibilities as they move up the "grade ladder," Brad's educational and social growth were almost static. Little was expected of him throughout his childhood by his parents or the special ed teachers. No one ever talked to him about his future and his potential. At age 22, he aged out of special ed services and left the school system with a "certificate of attendance" instead of a diploma. While his brother and sister moved on to college and jobs, Brad went from the segregation in public school to segregation in a group home, day programs, and sheltered workshops.

Brad's service coordinator has tried to "place" Brad in a real job in the community, but all attempts have failed. Like Gina, Brad learned some powerful lessons from segregation. He, too, learned that he didn't belong in the real world. But in his case, this lesson is manifested in Brad's belief that he doesn't have to work or assume any responsibilities for himself. He's learned to be helpless. If little or nothing has been expected from him his entire life, why should things change now?

Delia, a special ed teacher, has recognized the benefits of inclusive education and is working to move her sixth grade students out of her segregated classroom and into general ed classrooms. But the general ed teachers complain that these students "don't know how to behave". They don't know how to take turns, raise their hands and wait to be called on, use their "indoor" voices, and other ordinary student behaviors most children learn in kindergarten. The general ed teachers feel this situation is the result of the students' disabilities.

Delia recognizes that the place to learn these real-life skills is the real-life environment of a general ed classroom. But she expresses valid concerns that the general ed teachers (even with Delia's assistance) won't take the time or make the effort to help these students learn how to succeed in the real world. If this occurs, back into a segregated setting they'll go. So when will they learn? Who will take the time and make the effort? If no one does, these young people will be shipped back to segregated special ed classrooms, where the lessons of segregation will be reinforced. As adults, they will not be prepared for life in the real world, but only for a life of segregation in congregate living quarters and sheltered work/activity programs.

Some educators, and some parents, have looked into their mythical crystal balls and prophesied that students with disabilities will never be able to work, so why bother with an academic education? Their "educated" minds have missed the more important prophecy—the self-fulfilling prophecy that if students are not educated, they won't be in a position to achieve gainful employment. Duh—this isn't rocket science!

But there are schools where educators include all students in general ed classrooms, where general and special ed teachers work side-by-side, ensuring that all students learn and belong. These educators have recognized the dangers of segregation and the benefits of inclusion, and they do what it takes to make it work.

If we support the segregation of people with disabilities, we must also bear the responsibility for the consequences of our actions: children and adults whose hearts and minds are scarred by feelings of inferiority and who are ill-prepared for life as successful citizens in our society. If we do not support segregation, when will we turn our righteous indignation into action?



# I'm Special



I'm special. In all the world, there's nobody like me.

*Since the beginning of time, there has never been another person like me. Nobody has my smile. Nobody has my eyes, my nose, my hair, my hands, my voice. I'm special.*

*No one can be found who has my handwriting. Nobody anywhere has my taste—for food, or music or art. No one sees things just as I do.*

*In all of time, there's been no one who laughs like me, no one who cries like me. And what makes me laugh and cry will never provoke identical laughter and tears from anybody else, ever. No one reacts to any situation just as I would react. I'm special.*

I'm the only one in all of creation who has my set of abilities.

*Oh, there will always be somebody who is better at one of the things I'm good at, but no one in the universe can reach the quality of my combination of talents, ideas, abilities and feelings.*



*Like a room full of musical instruments, some may excel alone, but none can match the symphony sound when all played together. I'm a symphony.*

*Through all of eternity no one will ever look, talk, walk, think, or do like me. I'm special. I'm rare. And in all rarity there is great value. Because of my great rare value, I need not attempt to imitate others. I will accept—yes, celebrate—my differences.*

*I'm special. And I'm beginning to realize it's no accident that I'm special. I'm beginning to see that God made me special for a very special purpose. He must have a job for me to do that no one else can do as well as I. Out of all the billions of applicants, only one is qualified, only one has the right combination of what it takes.*

That one is me. Because...I'm special.



*Anonymous*

# Amazing Teen Left Enduring Legacy

By Lloyd Jojola, *Journal Staff Writer* (Albuquerque Journal, April 28, 2007)

It was a particularly tough year — fourth grade — for Zak Hollis.

He was teased and bullied on the playground — branded with names like "tic boy" and "retard," said his mother, Sandra Hollis.

There was the time he vomited on the classroom floor, he had been throwing up a lot at school due to the stress, and came home crying. He told his mom what happened, including that the teacher ordered him to write a letter of apology to the school janitor.

"It took like 45 minutes for him to write it," Sandra Hollis said. "And he said, 'Dear Mr. Janitor, I'm so sorry I vomited on your floor. I'm so sad at school. Sincerely, Zak Hollis.'"

It was after such hard days that Sandra hugged her son, who early in his life was diagnosed with Tourette's syndrome and obsessive-compulsive disorder.

"I'd look him in the eyes and I'd say, 'Hold your head with grace and get out there.'

"And he would go. Every day, he'd go."

Zachary Hollis, a La Cueva High School sophomore who died April 19 in a one-car accident, was instrumental in raising awareness about Tourette's syndrome.

He spoke at local schools and to other afflicted children who needed or sought support, and appeared in a number of news articles.

Hollis, 16, was active in the National Tourette Syndrome Association, writing articles and serving as an editor for the organization's children's newsletter. He traveled to Washington, D.C., yearly to meet

with congressional members to enlighten them about Tourette's syndrome and lobbied for health care improvements.

"He testified in front of the Department of Education in the summer of 2005, advocating for the inclusion of Tourette's syndrome in the IDEA, the Individuals with Disabilities Education Act, that actually happened," said Judit Ungar, president of the New York-based National Tourette Syndrome Association.

"He made an impression on people when they met him, those folks on The Hill here," she said from the nation's capital this week.

"He was an amazing kid who touched people, was not afraid to talk about his disabilities."

Hollis was diagnosed with Tourette's syndrome and obsessive-compulsive disorder when he was 8.

"The tics were really bad and he lost the ability to read and write for eight-and-a-half years," Sandra Hollis said.

Tourette's syndrome, by general definition, is a neurological disorder characterized by recurrent, involuntary body movements and vocal tics and it often has associated conditions, such as obsessive-compulsive disorder.

For Hollis, the tics could be severe. His mother remembered third through eighth grades as being an especially difficult period.

After a negative experience at one school, he received help through assistive technology and the support of some "wonderful" educators and staff at Chelwood elementary, Eisenhower middle and La Cueva high, Sandra Hollis said.

Hollis himself "worked with great perseverance and success to overcome its effects."

It didn't hurt that he had a great sense of humor.

Sandra Hollis recalled how, while he was in the second grade, a new student was brought into his class.

The student was unfamiliar with Zak's disorder.

"This little boy began inching his desk farther and farther away from my son," she said. "And, Zachary, he sensed this little boy's unease. He leaned over to him and he said, 'I have tics, but I don't have fleas.' "

The quip became the logo for the New Mexico Tourette Syndrome Association.

Earlier this week, during a conference in Washington, D.C., Ungar spoke to a group of people with Tourette's syndrome and asked for a moment of silence for Zak.

"And then I started to laugh," she said, "because, if Zachary was here, he would say to me, 'Judith, how can you ask a group of people with Tourette syndrome to be silent?'"

"And that's the way he would make you laugh all the time."

Lynda Hahn, Zak's teacher for three years at Eisenhower, called him "one of those people who brightened a room... "

"He was a gifted student who was passionate about learning," she wrote in an e-mail to the Journal. "... He was a special young man who forever changed the way I taught students. He enriched my life and made me a passionate advocate for the learning needs of students with special needs."

Hollis was a National Junior Honor Society member by middle school who continued to excel academically.

"He really came a long way," Sandra Hollis said. "For years, he was taught one on one and he really progressed this year to being able to go into a regular history class and a regular English class."

He "just was feeling very good about things," she said.

"He still couldn't function a whole day because, neurologically, he wore out quicker than other kids. But he was college prep, and he was doing it."

He was involved in the Boy Scouts for years and was awarded the rank of Eagle Scout posthumously.

City police reported that at close to 2 a.m. on April 19 Hollis was driving a Toyota Corolla west on Montgomery at a "high rate of speed" and was trying to turn south onto Wyoming. He lost control of the car and crashed.

Sandra Hollis said Zak "had several months of the best health he had had in nine years due to the anti-seizure meds they discovered to help him."

"My son began reading and writing again for the first time in over eight years," she said.

But he also had trouble sleeping.

Those factors, Sandra Hollis believes, ultimately resulted in his death.

She suspects he got up during the night, as he couldn't sleep and didn't want to wake her, and tried to practice driving. He had taken driver's education and passed.

"He was a very strong-willed, extremely persistent young man, which is what got him through so much," she said.

Some time ago, Zak decided to donate his brain to Harvard University for Tourette's syndrome research.

That wish was carried out.

**Notes and Reflections**

# Clinical Practice



*“Una mano lava a la otra  
Y las dos lavan la cara.”*

*One hand washes the other,  
And both wash the face.”  
(collaboration is key)*

-Spanish Dicho

# Do You Hear What I Hear?

## *Introduction*

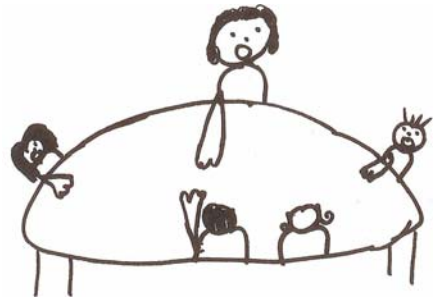
The following excerpt is taken from an extraordinary book; *Do You Hear What I Hear? Parents and Professionals Working Together for Children with Special Needs* by Janice Fialka, MSW, ASCW and Karen C. Milkus, PhD (Proctor Publications, Ann Arbor, MI, 1999). It has been reprinted here with their permission.\*

We felt this chapter offered a unique perspective on the experience families who have children with special needs encounter as they first meet with and engage professionals who will serve their child. Scenes one through six describe with great insight and clarity, the first tentative steps in their journey toward partnership.

### *Families as Faculty Staff*

The dance of the partnership is an adventure with an array of emotions and reactions that parents and professionals experience along the way. Partners' feelings and thoughts are unique to the people involved, but their existence is a reality. All too often, however, these feelings, concerns, and hopes remain unarticulated and unaddressed—hidden voices. The power of unspoken worries and reactions should not be underestimated as they shape relationships and determine outcomes for the children involved.

Therefore, if partners can become more aware of and sensitive to these needs and emotions, some of the stress and misunderstanding generated in partnerships might be reduced. Collaboration on behalf of children could then be that much more effective and enduring.

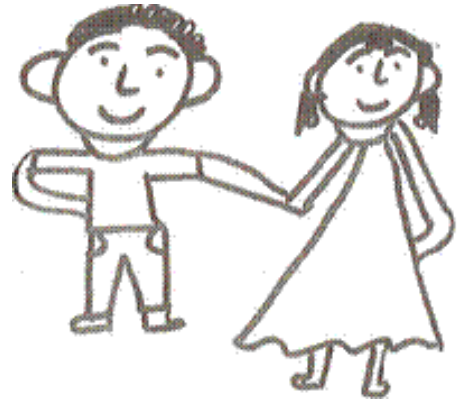


It is in this spirit that we offer the following descriptions of some of the internal experiences for each partner during a child's assessment. The wondering, doubts, and responses shared by Mrs. Lewis, the mother, and Dr. Gordon, the professional, may be experienced by caring, competent and (even) seasoned parents and professionals everyday at all levels of partnership.

Janice Fialka and Karen C. Milkus, 1999

## **The Situation**

John and Susan Lewis have one child, Sam, who is four years old. Over the years, Sam has become an engaging and active child who also has developed differently and more slowly than many of his peers. Some of Sam's delays are worrisome to his parents. John and Susan have taken Sam to several physicians and other professionals who have conducted numerous assessments of Sam's strengths and needs. Most recently, Sam has been referred to the school psychologist, Dr. Rhonda Gordon, for a complete assessment in preparation for a kindergarten placement.



## **Our Story's Design**

These six scenes describe six moments in the lives of John and Susan Lewis, their child, Sam and Dr. Gordon. The scenes take place before, during, and after the initial assessment of Sam by the school psychologist.

Each of the six scenes is presented from two perspectives: the mother's thoughts and feelings are described followed by the professional's. After each scene, two lists of practical suggestions and considerations are offered: one list contains suggestions for professionals to consider from the parent perspective and the second list contains suggestions for the parents to consider from the professional perspective.

## SCENE 1

### THE PARENT'S VOICE

John, Sam, and I have been ushered into your office. I had no idea there was an additional wing to our neighborhood school. But I never thought my child might need special education services, either. Sam is clutching his pride and joy, his new blue train engine. He sings out "Choo-choo" as you greet us.

Since before his birth, we've had wonderful dreams for our son. We bring you our dreams, our doubts, and our fears. Why is he different? What should we be doing?



We've been through so much in the last two years. First our pediatrician said, "Everything is going to be fine. Sam's just a bit slower. He'll catch up." We tried to believe him, but after a few months and not much "catch up," I took him to another pediatrician. She wasn't as confident that his delays were typical. She led us to a neurologist, a geneticist, an audiologist, a speech therapist, more and more tests, and now to you, the school psychologist. It was hard to pick up the phone to make this appointment. You have no idea how hard. Just filling out your paperwork took more strength than I ever thought I had. Stepping over your threshold was an act of pure will. For us, everything we've wanted and hoped for is on the line. I wonder if you know that.

Our feelings are mixed. I find myself chanting: "Do well. . . don't do well. . . do well. . . don't do well. . . ." Part of me hopes my son will let you see all his difficulties and delays so you can get him more help. Part of me hopes just as hard that you will see all his strengths and abilities so we won't need any more tests, any more specialists.

Please know this. I'm not sure I can handle one more person telling me my child isn't "normal". I'm scared. At times, my husband and I feel lost, alone. I wish that all this worry would go away so I could go on being Sam's mom, being me.

## THE PROFESSIONAL'S VOICE

*As you enter my office, I am struck by your faces: your child beaming with pride as he shows me his toy train, and you, Mr. and Mrs. Lewis, your faces stamped with hope, fear, and grief. Week after week, families like yours come to me with their expectations and dreams.*

*You may not believe this, but this is difficult for me. You want me to fix it. Probably I cannot.*

*Your questions are complicated. You need answers, and deservedly so. "Exactly what's going on with my child?" you will ask. "Why did this happen?" "What causes this?" "Will he be able to go to regular kindergarten or high school or college?" "Could he get married?" "What kind of job could he have?" "Which treatment is best?"*

*I long to give you answers, but often I just don't have all the answers.*

*Some parents are angry. Some appear withdrawn. Some are easy to talk with, others are more reticent. Some question my expertise what makes me think I know what is best for their child? I'm wondering which way will you react?*

*I must ask you questions about your child that may evoke strong feelings in you. Some questions you have already answered to many other specialists. You must be tired of telling your story over and over. I will try to be sensitive to your feelings.*

*Are you desperate to hear the words "typical," "age-appropriate," and "everything will be fine?" What if I cannot say those words to you? What if the words I say are devastating?*



*I want to give you answers, but I worry they won't be the ones you want. I want to be helpful, to offer my knowledge, skills, and experiences, but I worry that, at least for now, it won't seem like help.*

*Some days, I feel very alone in this work.*

## IDEAS TO CONSIDER FOR SCENE ONE

### PARENT TALKS WITH THE PROFESSIONAL:



- I want your help, really I do, but I'd rather not NEED your help. I didn't choose my child's problems. Most days I wish the problems, the meetings, the tests, the worries would just go away. I just want to be Mom.
- I'm not mad at you. I'm tired and I'm scared.
- I need your kindness.
- Help me know what other parents feel and think when they go through this.
- Please show me that you know this is tough.

### PROFESSIONAL TALKS WITH THE PARENT:



- *Coming in to have your child tested must be very hard to do. Each parent comes with unique worries, questions, and knowledge. It helps me to know what would be helpful to you. I want to know your concerns and questions so I can be more sensitive and responsive. If there are important things you want me to know, please tell me. I will respect your thoughts and be careful with them.*
- *Provide me with complete information about your child, including previous evaluations and interventions. Let me know if you agreed or disagreed with the findings.*
- *Let me know the conditions under which you are coming in for this evaluation. Did you choose to get this assessment, or are you feeling pressured by another professional, by the school system or a family member?*



## SCENE 2

### THE PARENT'S VOICE

We sit down on your gray padded chairs. The sunlight behind you blinds my vision of you and your desk, so I push back my chair.

Sam, my Sam, wanders over to your bookshelf. I know he's looking for books about trains and trucks. Should I tell him to sit down? Or is it okay for him to roam? Which looks better in your eyes?

I'm anxious these days. Is this the sixth or seventh test? I've lost count, but I know there have been too many. Testing days make me even more anxious. I'm less sure of myself. I doubt myself more. How much of Sam's problem is my fault? My husband's? These days we argue more. Is that the reason for Sam's differences?

You seem to approve of Sam's roving. Smiling, you ask, "What do you like to read about, Sam?" My shoulders loosen. I relax a bit in my chair.

Now you explain about the tests you'll administer. I get stuck on the word "administer" and only hear bits of the next few sentences. Sam doesn't want to be "administered to". He just wants to play with his train.

"Any questions?" you ask. I wish I were armed with smart, impressive questions, but I just say, "Not yet." We reluctantly rise from our chairs and you point John and me toward the waiting room. I want, desperately to tell you: Sam often needs to have questions repeated several times. Sam likes to play hide-and-seek. Sam hates hard chairs. Sam—

There's so much I want to say. John looks stiff, but he thanks you and asks you how long the testing will take. I glue on my smile and say brightly, "Bye, Sam. See you later!" Sam smiles, waves good-bye, and then goes on playing.

I wonder if you have the answers.

## THE PROFESSIONAL'S VOICE

*Your child has found my bookshelf and is flipping through the children's books I have collected over the years. I am drawn to him and want to join him in his search for train books, but I see your faces, Mr. and Mrs. Lewis, and instead I decide to address your uncertainties and questions.*

*I explain the tests I will use, the McCarthy or maybe the preschool version of the Wechsler. Your shoulders stiffen, Mr. Lewis. You, Mrs. Lewis, rise from your chair and walk over to your child. You wrap him in your arms, pulling him ever-so-slightly away from me, as if you are shielding him.*

*Do I look so terrifying? Do my words, meant to comfort, do the opposite? I recall the first time I met with a family during my graduate internship. I was unprepared for the mother's flood of tears as I relayed the test results about her four-year-old son who was diagnosed with autism. She taught me what no textbook could: how painful and frightening this process can be for parents. I have not forgotten that lesson.*



*I want you to know that I will look at your child's problems, but I will still see the wonder of him. I know he is special. You help me know just how special when you tell me about his favorite games, what makes him laugh and cry, what you love to do with him as well as what challenges him and your family. I want to know what you see, what only a mom or dad can know.*

*It is in your faces. You are afraid. You think your dreams for him are not safe with me. I feel some anxiety too. What am I going to see? What am I going to learn about your child that you know and wish were not so?*

## IDEAS TO CONSIDER FOR SCENE TWO

### PARENT TALKS WITH THE PROFESSIONAL:



- I'm a good parent. I want you to know that. Please ask what I think. I know so much about my child, more than anyone else in the world. I may not be able to describe him in the same words you use. Let me know that my words are just fine.
- Some days, evaluations and assessments feel like judgments of me as a parent.
- This is all new to me. Please tell me what to expect from your words, reports, and tests. Sometimes I don't know what the "next steps" will be. I can't always remember all the names of the professionals and tests. You can help by giving me written lists of the professionals' names, roles, and brief descriptions of the tests.
- If you tell me about the strengths of my child as well as his challenges, I'll know you're seeing my whole child.
- Give me a chance to ask questions now and later. I may also need to ask the same questions over and over.

### PROFESSIONAL TALKS WITH THE PARENT:



- *Tell me what you hope I'll see about your child.*
- *Feel free to ask questions, now and later. I know this experience might be new for you. Sometimes parents do not feel clear about questions, especially in the beginning. I hope you'll be comfortable enough to share your uncertainties with me at any point in time.*
- *I try to be careful and sensitive about the words I use. Forgive me if I use some that might offend you or that might not feel quite right. Let me know that, too. I am learning what is comfortable and acceptable for you and your family.*
- *One of the tough parts of my work is that I often have tight deadlines and a heavy work load. I will give your child every possible attention.*
- *Please know that I do this work because I want the best for your child.*



## SCENE 3

### THE PARENT'S VOICE

Two hours have passed. Finally, you bring our Sam back. He proudly pushes his train stickers too close to my eyes so I won't miss your gift. I look in your eyes, afraid I might read your mind. I'm relieved you can't read mine. My desperation scares me. You look in control. Why can't I?

You say you enjoyed meeting the three of us. "Sam worked hard," you say. You crouch down to Sam's level and smile. "Thanks, Sam," you say, then add something about meeting us in two weeks to give us the complete report.



Sam's arms and energy pull us into our car. John's jaw is tight. He mutters, "Two weeks. . . "

Sam bounces in the back seat, kicks the upholstery, and wiggles the door lock switch. He is jabbering incessantly. I try to decipher his words but the sounds are all jumbled up with my thoughts: What did she learn about Sam? Will he catch up? Can we handle this? Is this forever?

Sam screeches his high-pitched squeal, the one that means "You're not listening to me." He's right. He's demanding our attention. Could he get a few extra points on his IQ test for being assertive with us? Isn't this an important sign of intelligence?

That evening nothing goes right. Dinner burns to a smelly crisp, and every credit card company picks that moment to call—I feel so alone. I must visit the funeral home. My friend Linda's mother has died. As I stand in line to express my regrets, I feel Linda's sorrow and loss, but I feel my grief, too. My dreams for Sam are being challenged, some may die. Who will stand in line to console me? Who will even know?

I'm too tired to sleep. I sit up most of the night worrying. Dr. Gordon, what did you find? Two weeks? TWO WEEKS until we know what you think about our Sam?

## THE PROFESSIONAL'S VOICE:

*I am glad we've reached the end of this session. Your child is tired and more than a little cranky. His eyes and tiny body are darting from corner to corner. He resists all my coaxing to get him to play with the blocks. It is time to stop.*

*He worked hard. I feel my fatigue, too. I offer him stickers, and he pushes through the pile, searching for the right one. Finally, he uncovers a train, of course! He seems delighted with his selection. I am glad. I lightly rub the back of my neck and am reminded how absorbed I become when I test a child. Sam tries to speed down the hall but I slow him down by reaching for his tiny wiggling hand. When we arrive in the waiting room, he rushes to you to show you his stickers.*

*I smile, but my heart is aching for you. Your child has just demonstrated significant delays in a number of areas, not just in language, not just in problem-solving, but also in motor development and some of the everyday living skills he should have acquired by now. Memory tasks were hard from him, and he could not manage some of the early conceptual reasoning items.*



*I am glad you brought Sam in for this assessment. I think my findings and your knowledge of your child will help identify some of the next steps and supports so he can reach his potential. But I am well aware that these next steps will feel to you as his parents like climbing a steep mountain in the bitter cold.*

*I see you greet your child, Mr. and Mrs. Lewis. I know you want me to tell you something, or maybe everything-right now, right this very second. I can't. I need time to think about what I've learned and to prepare a report in a careful and useful manner.*

*I wonder how much you already realize. I worry that my findings will send arrows through your hearts.*

## IDEAS TO CONSIDER FOR SCENE THREE

### PARENT TALKS WITH THE PROFESSIONAL:



- Waiting for test results is the pits!
- Please prepare me for the challenge of waiting. Tell me some parents feel nervous, irritable, lonely, scared, or sad, that some withdraw for a while, that others feel a burst of energy and attempt to complete every task on their “to do” list. Suggest things I might do to help us through this waiting time.
- I know you need to consider carefully before you can give us results. For now, can you give us an inkling of hope-or some feedback?
- It may be helpful if I'm reminded that I did the right thing by bringing my child in today.
- Tell me you will help me through the next few steps—that you'll make sure we get connected to some helpful resources, other parents, agencies, reading materials. Don't underestimate the importance of these sources.

### PROFESSIONAL TALKS WITH THE PARENT:



- *I know waiting is hard. I need time to review the test results and my observations of your child. I don't want to make quick judgments.*
- *If I am forced to delay this process, I will keep you informed and will do my best to complete the report in a timely fashion. I appreciate your understanding.*
- *It may help you to know that I see many families, each with unique needs and desires. Some parents want lots of details; others want the main points and details later, over time. Some parents want to hear every score; others want information about their child with less attention on the scores. There is no one procedure that is right for all. If you know what is most comfortable for you, please let me know. I'll try to be sensitive to your wishes.*
- *I don't want children to be reduced to test scores. Know that I work to see the strengths and wonder of each child.*



## SCENE 4

### THE PARENT'S VOICE

How did your two weeks turn into three? I tried to be pleasant when the school called to say you had to reschedule due to a family illness, they said. But I didn't feel pleasant, just upset. This is our verdict. We need to know NOW!

Sam has stayed home with his grandma. As you lead John and me down the long hall to your office, you apologize for the delay and say it must have been hard to wait the extra week. That helps. I want to thank you for understanding, but I don't. It's too hard to juggle all my feelings.

I'm determined to listen, but my eyes fly-away from your face to your floor, your walls, your diplomas, your bookcases where Sam gleefully found your books about trains and trucks. You lean towards us, and you start speaking without notes. I force myself to look at you and not the report on your desk. Your voice is direct. You look right into our eyes.

You describe Sam's "charming qualities" and you smile. I like your word "charming". I remember the first time Sam watched "Thomas the Train" on TV. He was munching on his favorite food, homemade French fries with loads of ketchup. He charged right up to the screen to hear the talking train that ROLLED its big eyes. He was so excited he splattered ketchup all over his face and shirt. I almost tell you about the ketchup, but then decide not to.

You fold your hands and consult your report. A torrent of words rushes at John and me, sweeping away my Sam and his ketchup stains. Too many words, they all run together: Cognitiveimpairmentmotordelayreducedvisualmotorintegratedyspraxia.

I think, "If I were a good mom I'd hear every word." I must be experiencing a motherhood malfunction. Scored-in-the-fifth-percentile-on-scored-in-the-tenth-percentile-on-fourth-percentile-seventh—

The words fly at jet speed right out of my head. I'm drawn back to your office when splashes hit my clenched fist. I don't want to cry. Not here. NOT NOW!

"You don't have to hear everything today" you say. "It's a lot to handle. We can talk again." Your words stay with me. I'll replay them later. For the present, John and I search for each other's hands. Silently we ask, "What do we do now?"

## THE PROFESSIONAL'S VOICE

*I've been worrying about this meeting.*

*I chose this work because I wanted to make things better for children and their families, not worse. It is heart wrenching to bring "bad news."*

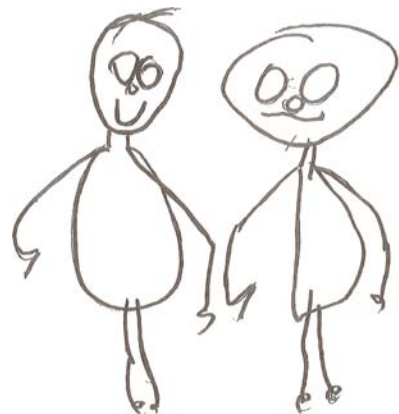
*I've thought a lot about my report. How to be accurate and clear, gentle and helpful? How to capture on paper your engaging child with his strengths and his difficulties? How to write an insightful, professional report without breaking your hearts?*

*You both sit so bravely, so straight in your chairs. I begin by telling you that I was delighted to work with your child. "He has wonderful energy and a strong ability to connect with people. I chuckled each time he gleefully shouted, 'Sure!'" Our eyes connect when I describe your child.*

*Then I move into the more formal findings. My words do not come easily. All the choices seem harsh: Challenged. Compromised. Diminished. Reduced for his age.*

*The paradox is that to help I must hurt. In order to establish his eligibility for services, I must document his deficits. I worry. Will his strong points, his expressiveness and his persistence, get buried under an avalanche of test scores and terminology?*

*You both nod, but your eyes look at something far away. I can't tell where you are or what you are hearing. Tears appear in your eyes, Mrs. Lewis, and drop on your blouse and your hand. I hesitate. Do I speak out loud to your tears? I want to reach out and touch you, but I don't know if that would be comfortable for you. What do you want right now? How can I be helpful?*



## IDEAS TO CONSIDER FOR SCENE FOUR

### PARENT TALKS WITH THE PROFESSIONAL

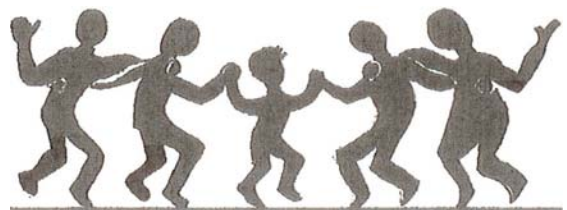


- When you give us initial diagnosis or assessment results, choose a time to talk when all the significant people are available. Let's talk about who I'd like to have present at this meeting.
- Please meet us when and where we can have privacy and no interruptions.
- Refer to my child by name. Tell me what you liked about him. When I sense your regard for him, I can hear your words better.
- Be honest with us. Don't hide what you know.
- Refrain from overwhelming us with volumes of details. Try not to project too far into the future, at least for now.
- Give us examples which keep our hope afloat. We are gradually beginning to form new dreams and expectations.
- Give us as many resources as you can. It's best if you hand us written lists, brochures, and pamphlets to take with us. This may give us direction and hope.
- Be comfortable with our tears, our silence, our frustration, and our fears.
- Don't tell us, "It could be worse." (As one parent said, "It could be better, too.")
- Know that your sensitivity is a great comfort for us. You can't take away our strong feelings, but you can offer support and understanding. Never underestimate the power of listening and caring.



## PROFESSIONAL TALKS WITH THE PARENT:

- ♦ *I want you to know that I would never intentionally cause you pain or hurt.*
- ♦ *Please know that it's normal for you to want all the answers, to know what the future will bring. After all, you are the child's parents. Unfortunately, I do not have all the answers, and the future is impossible to predict accurately. I will be honest with you, even though it may be hard to listen to the uncertainty. I encourage you to ask questions as frequently as you need to.*
- ♦ *If you feel unclear about a recommendation, or if you disagree with aspects of the report, let's talk about it. You know your child in hundreds of ways that no one else does: playing choo-choo train on the kitchen floor, dancing at Grandma Rose's party, swinging in your yard, eating his morning oatmeal, squealing in the back seat of the car. Your input is so very important. It helps me create a full and accurate picture of him.*
- ♦ *Know that in the real world of qualifying for services, the written report may need to emphasize his difficulties. I will remind you of this harsh reality and will do my best to include his strengths as well.*
- ♦ *If you feel I am rushing you through your feelings, please let me know. If I am going too slow, let's talk it over. Our partnership works best when we guide each other.*
- ♦ *When you can, give me honest, constructive feedback about this process and my role in it.*
- ♦ *Understand that I want to help your child and support you in your efforts in every possible way.*



## SCENE 5

### THE PARENT'S VOICE

It's been twenty-four hours since we sat in your school office, and it feels like a century, a century waiting for news no one wants.

I glance up from my soggy cereal and cold cup of coffee. The calendar on the side of the refrigerator reminds me: it's John's mother's birthday. My stomach knots. It will be the celebration of the decade. How can I possibly drag my body to Rose's party? How can I possibly face red balloons, colored streamers, smiling faces, kids chasing kids? NORMAL kids chasing NORMAL kids? How can John and I walk into that room pretending that we are just fine thank you. That Sam is just fine, thank you. That our future will be just fine, thank you.

I can picture it now, the voices of my sisters-in-law: "Jennifer is so bright. We're sending her to the Montessori school." "Josh was reading when he was three!" "Courtney's music teacher tells us she has unusual talent—

No one ever asks about Sam. They know something's not quite right, and it makes them awkward. Tonight we will stand in that room full of kind, well-meaning people, and no one will know what to say.



Dr. Gordon, it was hard to hear what you told us, but it was also a great relief to be able to talk with you. You don't know how lonely it's been, how worried I've been about Sam's delays, how alarmed I've been by his halting speech, how crushed I've been to see his sweet legs fail at running as fast as the other kids.

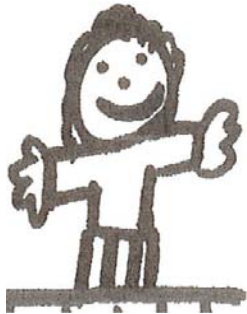
You had words and explanations for things I noticed in Sam a long time ago. Some of your words felt like new keys to locked doors. I stuck the papers you gave us the "additional resources for families" in the piles on my bedside stand. I can't read them yet. Maybe not even next week.

But I will. . . when I'm ready.

## THE PROFESSIONAL'S VOICE

*When I left my office yesterday evening, I was weighed down with loss and sadness. Those feelings lurk just around the corner today and, appear unexpectedly while I am at the grocery store.*

*Two young mothers who obviously know each other are standing in the produce section. Their sons about Sam's age are chattering away. I move closer. One of the boys tells a terrible joke, one of those jokes only funny to five-year-olds, and the boys laugh raucously. Your child, I realize with sadness, would probably not understand such a joke.*



*The mothers' words float across the grapes and broccoli: "Mrs. Miller is a WONDERFUL kindergarten teacher. . . most of her kids are reading by the end of the year. . . and she really challenges kids in science and math, too! When Amanda had her, Mrs. Miller had them all building volcanoes!"*

*Could your child hold his own in such a class? Would such a setting welcome him? Could Mrs. Miller meet your child's needs, too? Sighing, I push my cart towards the deli section.*

*Mr. and Mrs. Lewis, you are at the beginning of a long journey. Yours is a trip with no road map and no end in sight. Will you be able to be realistic about your child, about his abilities and his difficulties? You see a child who has more capabilities than I saw but, of course, you know him better than I do. Or, as the jargon goes, are you in denial? Is being in denial such a bad thing? Could it be necessary? Might it even be helpful? Maybe "denial" means you have the 'pause button' pushed so you can slow down this process and absorb it bit by bit, frame by frame.*

*I wonder how you are feeling today. Are you prepared for heart-breaking reminders of your son's difficulties even in the produce department? Will you still be able to see Sam's many gifts?*

## IDEAS TO CONSIDER FOR SCENE FIVE

### PARENT TALKS WITH THE PROFESSIONAL



- Please know there is more to my life than having a child with special needs, but right now I'm having a hard time thinking about anything else. I feel consumed by this. Life feels fragile.
- I might not be able to follow up immediately on your suggestions. It's not because I don't care or I'm "in denial." I need time and support to absorb all of this to rearrange my dreams.
- Let me know if you learn about other resources, parent groups, or information that might be relevant to my search for understanding my child and what he needs.
- If you can phone me to see how I'm doing, it may help me feel less alone. I'm learning that many family members and friends may not know how to reach out to me during this challenging time. They worry that they may be intrusive. You, more than most people, have a sense of what I'm dealing with.

### PROFESSIONAL TALKS WITH THE PARENT



- *I really care about the children I meet. I want to be helpful to them and their families.*
- *If there is something that I've done that was useful, feel free to let me know about it. I can learn from your ideas and feedback.*
- *If something does not work, I want to know that, too. If any of the resources or referrals weren't useful or no longer existed, please consider passing on that information to me.*
- *My thoughts of your child and you, too, do not end when the test report is locked in my office. I like hearing how your child is doing.*



## SCENE 6

### **THE PARENT'S VOICE**     **Six months later**

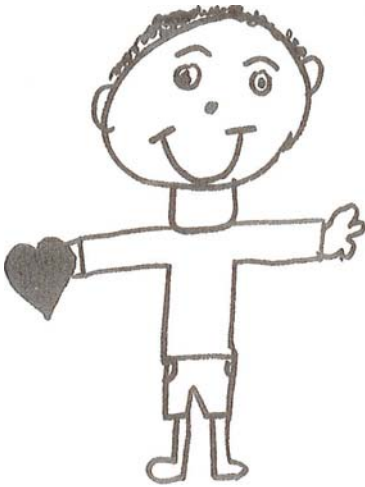
I linger outside the door to Sam's kindergarten classroom. It's my monthly afternoon to be a parent volunteer in his class. Before entering the room, I pause and sneak a glance at Sam through the tiny window in the closed door. I want to see how—or if—he interacts with the other kids. I want to know how he's doing in this "regular kindergarten with special supports for Sam." As I lean closer to the window glass, I'm surprised to see you, Dr. Gordon. You and Sam are digging in the sand table near the corner of the room. I can't make out your words, but I can tell you are trying to make Sam laugh. He does! It's been months since you tested Sam. Queasiness in my stomach returns, reminding me of those earlier days in your office when John and I sat on those gray chairs near the bookshelf. We were hoping you would tell us, IN NO UNCERTAIN TERMS, that Sam would be just fine. That didn't happen.

My whole world turned upside down that day, but I am still standing. In many ways, I feel different from that mother who sat in your office listening to you use unfamiliar words that scarred my soul. I have learned so much about Sam and the world of special needs. I know about resources, and I am involved in getting the best services for Sam and our family. I've talked with two other moms who have children with special needs. These moms helped me to feel less alone and unsure of myself. They've introduced me to so many resources. I still have many worries about Sam. Some nights I wake up in a cold sweat. Sometimes, when I'm swinging Sam in the park, tears unexpectedly slide down my cheeks. But I also feel a renewed sense of myself. I feel a bit more confident and more determined. New dreams for Sam and our family are beginning to take shape.

Those first meetings with you were so hard. I didn't want to hear your words, yet I knew I had to listen. I remember that you called a week or two after giving us the results of his assessment. Your call and concern meant so much to us. You couldn't make Sam "catch up," but you did help ease some of the worry and sadness. You took your time in answering my questions. You even helped us know what questions to ask. You led us to some helpful resources and other parent groups. The school bell rings, and I jump. It's time to go in. I open the door, greet Sam's teacher, and walk across the room. I decide to join you and Sam at the sand box. Sam screeches with delight when he sees me. We embrace and then shove our hands into the cold, wet sand. I touch Sam's pudgy, low-muscle tone fingers and wonder what we will build.

## THE PROFESSIONAL'S VOICE Six Months Later

*Whenever I have a minute, I like to slip into the classroom and visit one of the children I've tested. Today, I am spending time with your child when you appear in his classroom. It is good to see you both.*



*Sam sparkles with his special exuberance for people. He is very sensitive to others. Today, Shauna was longingly watching the other children at the sand table. They didn't pay attention to her, but your Sam called out cheerfully, "Shauna, Shauna, here!" and he handed her a shovel. It was just the invitation she needed.*

*Sam seems to be doing well in this class. Mrs. Katz has carefully adapted the kindergarten curriculum for your child so that he is both challenged and supported. I cannot help but wonder if next year's teacher will be as skilled in including him and the next year's teacher and the one after that? What lies ahead for him and you?*

*Mrs. Lewis, what is it like for you to work in this classroom where you see how much some of the children Sam's age can do? You look more "settled" today than the last time we met. But I would guess that pain and loss can be easily triggered for you, probably when you least expect them.*

*I want to stay longer, but I have more than a handful of children waiting to be evaluated. In my heart, I know there will be other wonderful children with loving parents with whom I must share difficult news.*

To learn more about Janice's training on parent professional partnerships or to order her other books and writings, please visit her web site: [www.danceofpartnership.com](http://www.danceofpartnership.com). The site includes the writings of and about her son, Micah as well as those of her daughter, Emma. You can also read a description of her training entitled, "The Dance of Partnership: Why do my feet hurt?"\*\*

## The Starfish Story



A man was walking along the beach. Far in the distance, he could see a stretch of beach where hundreds of starfish had washed up on the shore. As he got closer, he could see a young boy picking up the starfish, one by one, and throwing them back into the ocean. The man stood and watched. He felt the futility of the boy's actions; there were so many starfish and only one boy trying to save them. He shook his head with frustration and walked closer to the boy and the hundreds of starfish.

He watched again and finally he could watch no longer. He walked over to the boy and said, "Why are you doing that? There are hundreds of starfish and only one of you. What you are doing is impossible! You will never save them all, and besides what difference does it really make?"

The boy looked at the man as he picked up one more starfish and threw it back into the sea, and then replied, "It made a difference to that one!" After a moment the man, too, bent to pick up a starfish and threw it into the water and the safety beyond the breaking waves.

Like the boy and the man in the story, we can make a difference, one by one.

## Notes



# Parents Reaching Out

*Your One Stop Resource for a Stronger Family*

As a statewide non-profit organization, we connect with parents, caregivers, educators and other professionals to promote healthy, positive and caring experiences for New Mexico families and children. We have served New Mexico families for over twenty five years. Our staff and Family Leadership Action Network reflect the unique diversity of the communities throughout our state.

Children do not come with instructions on how to deal with the difficult circumstances that many families experience. Parents Reaching Out believes that families' needs go beyond the bounds of formal services. *What we can offer to each other is uniquely ours. We have all been there.*

## Our Mission

The mission of Parents Reaching Out is to enhance positive outcomes for families and children in New Mexico through informed decision making, advocacy, education, and resources. Parents Reaching Out provides the networking opportunities for families to connect with and support each other. This mission supports *all families* including those who have children with disabilities, and others who are disenfranchised. Parents Reaching Out achieves this by:

- ♦ Developing family leadership
- ♦ Connecting families to each other
- ♦ Building collaborative partnerships
- ♦ Providing families knowledge and tools to enhance their power

## Our Beliefs

- ♦ Families need support where ever they are in their journey.
- ♦ All families care deeply about their children.
- ♦ Families may need tools and support to accomplish their dreams.
- ♦ All families are capable of making informed decisions that are right for their family.
- ♦ Families in the state benefit from our organization having the staff and materials that meet their diversity.
- ♦ Systems that listen carefully to the family perspective improve outcomes for our children.

We invite all families and those serving families and children in New Mexico to make *Parents Reaching Out your one stop resource for a stronger family*. Our publications, workshops, and Resource Center offer tools for informed decision-making and building partnerships in communities. Our trained staff and network of volunteers are here to serve you.

*Parents Reaching Out is the home of:*

NM Parent Information and Resource Center (NMPIRC)  
NM Parent Training and Information Center (NMPTIC)  
NM Family to Family Health Information Center (NMFFHIC)

## Parents Reaching Out

1920 B Columbia Drive, SE  
Albuquerque, NM 87106  
1-505-247-0192 ♦ 1-800-524-5176  
[www.parentsreachingout.org](http://www.parentsreachingout.org)

From I-25—take the Gibson Blvd Exit 222 and go East on Gibson. Turn left at the third stop light (Girard). Turn left on Vail. Go one block to Columbia. Turn left on Columbia. Parents Reaching Out is on the east side of the street. Welcome!

