

Supported Families

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Center for Learning and Leadership/UCEDD
Oklahoma Family Support Partnership Project





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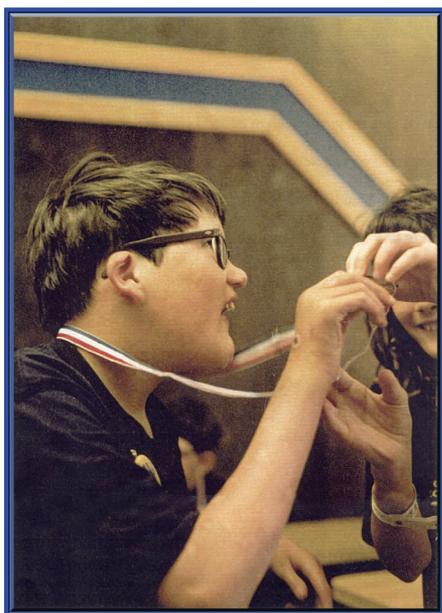
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d edication

A few days after I completed work on this booklet, my son, Doug, became seriously ill; a few days after that he died. I want to dedicate *Supported Families* to Doug in the hope that his bravery, his sweet personality and his zest for life will inspire people with disabilities, their families and their communities to strive for success and to help each other along the way. — *Judy O. Berry*



Doug Berry shows off his medal from Special Olympics.



acknowledgements

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about the author

Judy O. Berry, Ed.D., is a professor of psychology at the University of Tulsa specializing in developmental and family psychology. She is the author (with Michael Hardman) of *Lifespan Perspectives on the Family and Disability*. Her research centers on parental stress in dual-earner families and in families that include a child with disabilities or chronic illness, and she developed (with Warren Jones) the *Parental Stress Scale*. She has received a number of advocacy awards for her work in the field of disabilities, including the Tarbel Achievement Award and the Medicine Wheel Award.



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introduction

Three decades ago, a small group of parents in Pennsylvania joined a group of professional advocates to ask the state to allow their children with disabilities to go to school. It may seem incredible now that it took the court system to grant this very basic right to some of America's children. In fact, these were the children who needed most of all to be in school, both for an education and to be a part of the community. Other court cases and federal legislation followed and today it is a given that all children are a part of our schools.

Being a part of the community is more complicated. The community is where we live and the people who surround us. For children, it is, of course, their parents, siblings, babysitters, teachers and friends. Community also means children's doctors, little league coaches, camp counselor and people who sell shoes and cut hair. Legislation that brought school services for children with disabilities also brought training for teachers and others providing direct services for children, but gaps remain. Some service providers are skilled with children and the families in which they reside; some are less so. Some people in the community, not likely to have received training, seem intuitively attuned to the needs and feelings of children and families; some do not. And yet, families with children with disabilities need; in fact crave, the embrace of the whole community for their sons and daughters. It is our last frontier. When I use the word "our", I am speaking for all Oklahoma families that include a member with a disability. My family includes my son, Doug, now a young adult who was born with multiple developmental disabilities. I also am a

psychology professor specializing in developmental and family psychology. In this role, I have worked for several years as a consultant to an amazing group of professionals at the Center for Learning and Leadership, a part of the University of Oklahoma Health Sciences Center. One project of the Center is the Oklahoma Family Support Partnership.

The Oklahoma Family Support Partnership grew out of the need to enhance the system of family support for families of children, youth and adults with disabilities by making positive changes in both policy and practice related to family support. An integral part of the project has been the development of the Oklahoma Individual and Family Support Principles and endorsement of these principles by programs and agencies serving families. In addition, this project provides training and technical assistance to service providers and families in the use of these principles as the scaffolding on which services are built.

The purpose of this booklet is to present the Oklahoma Individual and Family Support Principles, illustrated by success stories. As a bonus, the reader will get to meet several Oklahomans who are doing a good job in their everyday lives. The people featured here responded to the needs that they encountered, not because Oklahomans with disabilities have legal rights, but because it was the right thing to do.

Oklahoma Individual and

- ... are guiding truths that shape the way individuals, families and service providers interact.
- ... establish common ground upon which individuals, families, advocates and service providers operate.
- ... form the basis for program policy and practice.

WHEN WE ENGAGE WITH INDIVIDUALS AND FAMILIES WE WILL ...

HONOR THEIR EXPERTISE and right to make choices that they know to be in their own best interest.

RESPECT AND ACCEPT THEIR VALUES that are based in personal preferences, cultural beliefs and life-ways.

SUPPORT INDIVIDUAL AND FAMILY RELATIONSHIPS that are safe, stable and long lasting.

FOCUS ON THE ENTIRE FAMILY as it is defined by the family.

PROMOTE FLEXIBLE SERVICE AND FUNDING supporting individual and family control over who, what, when, where and how supports are provided.

Family Support Principles

AFFIRM LIFESPAN PLANNING AND SELF-DETERMINATION

that encourages decision-making and planning for independence beginning within the family when children are young, following the individual throughout his or her life and including aging issues.

ASSURE PARTNERSHIPS THAT ACTIVELY INCLUDE INDIVIDUALS AND FAMILIES

in planning, development, implementation and evaluation of policies, practices and personal programs.

PRACTICE OPEN COMMUNICATION

promoting a clear understanding of all aspects of systems policy, procedure, practice and all other information regarding them.

RECOGNIZE THE IMPORTANCE OF THE COMMUNITY,

where individuals and their families belong and realize their full potential.

All people need enduring, stable family and community relationships. All families need support at times in their lives to maintain these lasting relationships. Individual and family support must assist across the lifespan, supporting the child within the family and the individual reaching independence. This assistance builds on natural sources of support, including extended families, friends, neighbors and community associations. The way support is provided is a reflection of what we believe about individuals and families, a way of thinking about individuals and families, and a way of engaging with individuals and families.

honor their expertise

When professional experience joins the expertise of parents, the ones who know the child the best, results can be awesome.

Nathan, my only child, was born with Down syndrome. He received early intervention services from the time of his birth, and the therapists were great with him. When Nathan was 9 months old, I decided that I would try weaning him from his bottle. So, one week when his therapist came I asked her how you teach a child to drink from a straw. I had no idea how this occurred or even when it should occur. She described the procedures to me and the next week when she came, I was proud to show off Nathan's new skill – he was drinking from a straw.

The therapist was shocked. She told me that she had almost *not* told me how to teach Nathan since this was an early age even for a typically developing child. Lucky for us, she assumed Nathan could do it and didn't assume he couldn't do it. Furthermore, she respected my ability to teach him.

Nathan has many strengths and surprises many people (including me!) with what he does and what he knows. Even now, five years later, when I see him drink with a straw it brings a grin to my face.



Respect and accept their values

This family valued inclusion, being a part of the school and the community. It was not easy to achieve, but worth all efforts.

My brother was diagnosed with mental retardation 47 years ago. But I always thought my brother was smart! Different, yes, but smart, very smart! When he was 15 and I was 18, I took it upon myself to get him into regular high school classes. I pitched most of the school districts in the large urban area where we resided, trying to sell them on the idea of having my brother included in typical high school classes. Each of these attempts met with instantaneous failure! Worse yet, though reluctant at first, my brother had decided he wanted to be in regular classes too.

Discouraged, I convinced myself to try once more, in what I thought was the worst school district in the area. Just like the other times, I made an appointment with the principal and told my brother's story. I was passionate that my brother was capable of learning in typical classes even though he did not know the alphabet and could not read. I promised to tutor him with all my might. I even offered to move and drop out of college to push my dream into reality.

I got the shock of my life! She agreed to try it! In the most unexpected place, I found a principal with the grit to leap beyond my brother's label. She changed the course of my brother's life forever. This memorable woman respected our

values, dreamed a dream with me, and had the vision and authority to shift my brother's educational prospects to a richer and more promising future. She allowed him to discard his label – designed to limit – and transcend it for a life of self-determination and hope.

My brother learned to read and write. He blossomed in math and science. He graduated from high school with As, Bs and a few Cs. After high school and still determined, he took flying lessons and received the highest score on both the written and flight portions of the pilot's exam in the history of the flight school. Because that principal believed in my brother and the values of our family, my brother continues to soar.



Support individual and family relationships

A sister can be a little girl's best friend during tough times. A caring teacher helped these girls stay connected for their mutual benefit and enriched their friendship network.

Nicole was always in tow at her sister's multiple doctors' appointments and hospital stays. You see, her little sister, Katie, had a very rare, undiagnosed mitochondrial disorder with an underlying genetic syndrome.

Katie's gastrointestinal tube needed to be replaced because multiple seizures made normal feeding impossible. Nicole had started kindergarten so this would be the first time she would not be near Katie while she was in the hospital. I wasn't sure how Nicole would react, or if she would be able to function in school that day. I was very open with Nicole's teacher and told her what she might expect and to call me if Nicole became too upset. I did not receive a call. Nicole had a good day because her teacher used this as an opportunity to teach the children about nutrition and various ways that people can eat.

When Katie was well enough to visit the school, I took her and "fed" her in front of all the children and let them ask as many questions as they could think of. This class of 20 kindergarteners became Katie's new best friends. They loved Katie, like Nicole did.



ocus on the entire family

Being a sibling, in any family, involves both joy and woe. But having a brother or sister with a disability can be particularly challenging and particularly rewarding. A sensitive teacher supported my family and guided the entire first grade in a positive direction.

My son, Ryan, became an advocate for his big brother, Doug, at an early age, in a way that helped Ryan directly while increasing positive attitudes toward people with disabilities in a broader sense. As a first grader, Ryan came to me dismayed. Classmates on the playground were calling each other "retard." We had previously discussed diagnostic labels, and he knew that mental retardation was part of his brother's diagnosis. He knew as well that "retard" was an unacceptable and hurtful term. He did not know why his friends were saying it or what he should say to them. I explained to him that his classmates probably had not had the chance to get to know someone with disabilities as a person and as a friend. I asked him if he would like to tell his classmates about Doug. He said that he would. The next step was to talk with his teacher. She was concerned by the report of the playground conversation and said that she would address that directly. She agreed, however, that a personal touch would probably do much more to solve the problem.

Special Olympics gave us the perfect opportunity. Doug had gone to the state games in Stillwater and returned with a

gold medal. Ryan thought it was awesome, saying with wonder, "Doug got the gold." He decided to take the medal to show the first graders when he told them about Doug. I asked him what he planned to say. He said he would show the medal and tell how Doug won it. Then he was going to tell them not to say words like "retard" because ... He stopped then and asked, "Can you go to jail for that?" I told him that you could not (although maybe it's not such a bad idea), but that words like that hurt people with disabilities and their families. He said, "Then that's what I'll say." And he did. His teacher said he was wonderful, and his classmates dropped that word from their vocabularies.

P

romote flexible service and funding

Helping a child get needed services is only half the battle for families; getting the services funded is the other half. Families win when informed and determined professionals join their ranks.

When my daughter, Bridget, was 3 years old, she hit a "stuck point" in her progress with occupational therapy. Among her multiple disabilities was cerebral palsy, and she had so much spasticity in her right leg that it prevented her from walking. However, the orthopedist and physical therapist who evaluated her did not think she could benefit from either tendon release surgery or physical therapy due to her multiple disabilities, and I was unable to change their minds.

Bridget's occupational therapist gathered information about the benefits of both the surgery and the physical therapy, documented Bridget's remarkable successes with occupational therapy and was able to persuade the physician and therapist to be flexible and approach their interventions with Bridget in a way that would succeed. Also, the occupational therapist researched available funding for both services and was able to assure that the cost would be covered.

Following the surgery, Bridget walked independently before the cast was removed from her leg! After a few

physical therapy sessions, her strength and agility greatly improved and walking became her preferred way of getting around. Bridget is now 32 years old and the ability to walk independently has made all the difference in her quality of life. Since Bridget has a severe vision loss and is deaf, the ability to experience the world and interact with people from an upright position has been a key to her relationships with people and her pleasure in life.

affirm lifespan planning
and self-determination

Families particularly value professionals who look at the big picture and take into account lifelong needs. Jennifer's family found such a person.

Gulp! Gag! Spew! Taking oral medication has always been so difficult for Jennifer. This has posed as many problems as any illness. Jennifer has no suck, blow or swallow response. Mild upper respiratory irritations have always been a health issue for her. A cold could prove to be a major illness, complicated always by aspiration of medications and fluids. We tried everything. We tried different positions (glad we don't have photos); we tried different consistencies; we tried droppers and even a squirt gun. We looked at the time of day; we looked at the size of dosage. Nothing helped.

Jennifer dreaded the efforts to self-medicate and dreaded all attempts to assist. Being assisted meant that someone would have to schedule visits to Jennifer at medication times, no matter what, determine if she was getting enough medicine to be therapeutic, adjust dosage and call a physician if all positions, mixtures, drops and squirts failed. Medications have truly been a lifespan issue for Jennifer, her family and staff.

On one of those torturous occasions, Jennifer's regular physician was unavailable, and she was referred to a new

doctor. He read Jennifer's file and asked what had been successful in the past. Naturally, as the record-keeping mom, I related our best efforts, positions and squirts. "Not good enough," he declared. I was so flabbergasted I sputtered. He went on to explain, "I mean Jennifer could benefit from a long-acting antibiotic injection and save you and her from a complicated medication regimen. We'll know she got the exact amount prescribed and eliminate those complications. How's that sound?"

I was so stunned that there was an alternative to our years of strangling efforts, I could hardly speak. Jennifer got well easily, and I am eternally grateful.

assure partnerships that actively include individuals and families

Partnering with one another and with a professional leader gives families needed support and empowers them.

When my son was 18 months old, he was being diagnosed in many different ways to try to label his various idiosyncrasies. Nothing felt quite right and my son didn't fit the rigid molds of these "labels." I was going out of my mind. I went through many emotions. First, I thought, "What have I done to cause this?" Then I immediately went into my I-can-fix-this mode. I searched the Internet. I read books. Finally, I was referred to the coordinator of a support group for mothers of children with special needs. I didn't realize it at the time, but this unsuspecting group of mothers would literally change the way I perceived my life, and more importantly, children with disabilities, including my son.

Nervous and extremely self-conscious, I attended my first meeting. When the mothers introduced themselves and the diagnoses of their children, I was convinced I had taken a wrong turn. Autism? Cerebral palsy? Down syndrome? Other names were so long and obscure even the acronyms sounded like I fell head first into my alphabet soup. Mental retardation? My child is NOT retarded! He's smart, very smart, gifted in fact! I was NOT like these other women, and they couldn't possibly help me. At least that is what I thought.

After the first hour, I put away my pride and began to actually listen. I was like these women and they were like me. They were scared, concerned, caring and often funny. Their children may have problems different from my child, but the process, the parent-child dynamic, the advocating for the best interest of the child, all that was the same. The more I listened, the more I realized their children shared common symptoms with my child. I wasn't alone in the world where a child never sleeps or cannot stand to have certain foods and textures touch him. Instead of trying to declare myself as different, I looked for things we had in common and I asked questions and searched for answers.

I was so lucky to have a room full of wise and experienced mothers to help me. If one didn't know the answer, surely the next mother would. I don't believe I have ever gone to a meeting and left without learning something that could help my child. It may be advice on how to help with education. It may be a solution to our sleep issues. It may be new and different drugs and treatments others have success with. If nothing else, it might be a hug or a simple word of support.

Soon, other new members were joining the group. I could see the anxiety and concern on their faces and I remembered how I felt. Now I am one of those women who are sought out for advice and wisdom. I could never have endured my "trial by fire" without the support of the mother's group. We are all teachers/learners and we are all there for each other. Most importantly, we are not crazy!

P

ractice open communication

This school system had doubts about its ability to meet the needs of this new student, but its administrators successfully communicated how hard they would try and how much they wanted it to work. And it did!

As Jenny entered middle school in a new, much smaller community, we were anxious about the change to middle school with new teachers, classes and friends. Our anxiety was compounded by Jenny's need for significant special education support across all areas of learning and life. As it turned out, the school's staff was more anxious than we were because they had heard of us. My wife was a health systems administrator in services for children with disabilities and I was a state-level administrator for the early intervention program.

We also were active in disability advocacy groups. We must have looked like formidable parents to that little school district. The special education administrator, in an apologetic tone, told us that they had never had any experience with a student having the extensive needs that Jenny appeared to have. However, she said that everyone would work on figuring out the best way for Jenny to be a part of their school and that they had never had a student that they couldn't serve.

She was right. This little district used what it had to provide what Jenny needed. It wasn't elaborate or expensive. It was an honest commitment to providing all its students a good education. Jenny was one of its students.

More than that, she was a student who had an opportunity to participate in extracurricular activities for the first time in her life. Jenny's teacher aide had an obligation to be at cheerleading practice after school, but it conflicted with her supervision of Jenny waiting to get on the bus. She asked if Jenny could accompany her to cheerleading practice. The cheerleading team took it from there. They wanted Jenny to be a part of the team and wrote a cheer just for her. Jenny always threw everything that was placed in her hands, usually within seconds. Jenny's team members saw that as an asset instead of a deficit. They wrote a cheer that passed the pompoms to Jenny just seconds before it was time to throw them. Jenny cooperated, and the cheer was a success. We spent lots of money on special red and white sneakers, sweaters, skirts and tights – an opportunity that we would never have had anywhere else and an opportunity that Jenny would never have had anywhere else.



Recognize the importance of the community

I am concluding with a story from my personal past that demonstrates, from a broad perspective, both the stress that often punctuates the lives of families that include a child with a disability and the kindness of strangers.

I lived in Oklahoma City and was driving with Doug (age 2) in the car seat beside me on one of the highways that cut across and connect various parts of the city. I was startled to hear a loud voice coming from somewhere outside the car, command: **PULL OVER TO THE SIDE AND STOP!**

I drove on, convinced that whatever that voice was, it had nothing to do with me. Two more repetitions of **PULL OVER TO THE SIDE AND STOP!**, and the sighting of a highway patrol car in my rear view mirror made me realize that the message was, indeed, for me. I pulled over and stopped and fumbled for my driver's license. The officer appeared at my window and asked me if I knew what I had done wrong. I said I had no idea. I think he told me, but to this day, I don't know what it was. I knew, however, that I was distracted and that he was probably right and I was probably wrong. I apologized and promised to never do it again. He said, "Fine," but he had to give me a ticket. As he started to write the ticket I started to cry. Doug, sensitive to my moods, joined in.

Those first tears opened the floodgates of my piled-up stress, and soon I was sobbing. Again, Doug joined right in.

The officer was astonished and very concerned. He said, "I don't think you are in a condition to continue driving. Where are you going?" I answered, "I'm taking my son to a therapy program for deaf-blind and multihandicapped babies at the medical center," and continued to sob. He said, "Can I call someone? Where is your husband?" I answered, "He is in the hospital." He stood there stunned for a moment and then ripped the ticket into little pieces.

I told him that he didn't need to do that, that I was sure I deserved the ticket and was, in fact, grateful to have a long over-due cry.

He stayed with us until Doug and I both calmed down. Then I carefully drove on to the medical center for Doug's therapy program.

To order copies of
Supported Families
or the
**Oklahoma Individual and Family Support
Principles**

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Endorse the Oklahoma Individual and Family Support Principles

The Center for Learning and Leadership invites you to endorse the Oklahoma Individual and Family Support Principles. If you agree with the principles and want to join others in distributing or sharing them, complete and sign the form on the next page. If you are signing on behalf of an agency or organization, please provide a letter of endorsement on letterhead. Send or fax the form and/or letter to the attention of Vyonda G. Martin at the above address. We will add yours to the list of endorsements and send you copies of the principles to share with other individuals, families, faculty and representatives of agencies and organizations.

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I/we endorse the Oklahoma Individual and Family Support Principles. I/we agree with the principles and want to share information about the principles with others. Please count on me/us to:

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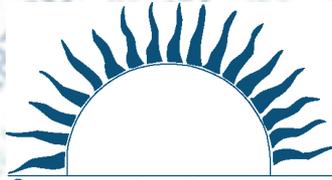
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