Wisconsin Council on Developmental Disabilities

Cultivating Competence

2nd Edition

Directory and Resource Guide on Supported Parenting

Edited by Dolores Ullmer Liamba

With contributions from Howard Mandeville,

Polly Snodgrass & Mark Sweet

SUPPORTED
PARENTING
SERIES

WISCONSIN COUNCIL ON DEVELOPMENTAL DISABILITIES
WCDD
Promoting Independence and Equality

Cultivating Competence

2nd Edition

Directory and Resource Guide on Supported Parenting

October, 2000

Edited by Dolores Ullmer Liamba

With contributions from Howard Mandeville, Polly Snodgrass & Mark Sweet

This publication was funded, in part, by the Wisconsin Council on Developmental Disabilities using federal funds provided under P.L. 104-183 through a grant authorized by the Administration on Developmental Disabilities and the U.S. Department of Health and Human Services. Grantees undertaking projects with Council sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not,therefore, necessarily represent the official position or policy of the Wisconsin Council on Developmental Disabilities. The information reported herein was compiled pursuant to the State Plan on Developmental Disabilities.

SUPPORTED
PARENTING
SERIES

Wisconsin Council on Developmental Disabilities
600 Williamson Street • PO Box 7851 • Madison, Wisconsin 53707-7851
Voice 608/266-7826 • FAX 608/267-3906 • TTY/TDD 608/266-6660
Email: wiswcdd@dhfs.state.wi.us • Internet: http://www.wcdd.org

Introduction

In the 10 years since the first edition of Cultivating Competence was published, families headed by parents with cognitive disabilities have become more visible in our communities and are becoming increasingly noticed within several service systems. Agencies providing child protective services, family violence intervention, public health services, and disability-related services generally recognize that parents with disabilities and their children are both under-served and inadequately served in these systems.

WCDD offers this second edition of Cultivating Competence in the hope that readers will use it as a springboard to generate their own local supported parenting programs and that they will connect with their colleagues across the country to share ideas, inspiration, and support.

Gradually, over the past decade, a number of communities across America have begun to develop some capacity to support parents with disabilities and their families. In most states the leadership for developing or adapting models of supported parenting has emerged at the local level, usually due to the commitment and vision of local leaders and advocates. Supported parenting has had virtually no systemic support or targeted funding from state or federal governments.

Many of the pioneer agencies represented in the first edition continue their mission in supported parenting and are again described in this second addition. Other programs have started in that time and 40 are described in this updated version.

The programs presented here represent a diverse array of approaches and perspectives. They share a similar philosophy grounded in the belief that children, families and communities benefit from support tailored to the needs and preference of parents with disabilities. Cultivating Competence is intended to be a sampler of available models rather than an exhaustive directory of all supported parenting agencies. Inclusion in this document is not necessarily an endorsement of any of the programs described.

Howard Mandeville

Supported Parenting Series Editor

Wisconsin Council on Developmental Disabilities

This book is dedicated to the families receiving services from the programs in this directory. They continue to teach us much of what we know about supported parenting. The parents struggle to raise their children and move out of poverty. They refuse to give up on the love they hold for their children. Their strength and perseverance are greatly admired. A parent who attended a national conference on supported parenting in Madison stated what is really needed when she said,

"We are all in this together so share with me."

Contents

I. INTRODUCTION 3

II. PROGRAM DESCRIPTIONS:

California

Family Support Services (FSS) 8
Through The Looking Glass 9
UCLA Parent/Infant Health & Wellness Project and Parenting Program 10
Training Toward Self-Reliance, Inc. (TTSR) . 11

Colorado

Parents and Children Together Club (PACT) 12

Georgia

Georgia Family Support 13

Hawaii

Project Kako'o Supported Parenting 14

Indiana

Project ASPIRE 15

Maryland

Parents In Action (PIA) 16

Massachusetts

Home for Little Wanderers 17
Positive Parenting Resource Center 18

Michigan

Infant Mental Health Services of Arbor Circle 19
Parent/Infant Program 20

Minnesota

Hennepin County Parent Support Project . . 21
Reuben Lindh Learning Center Parenting Program 22
Parenting PLUS Program 23
Nekton In-Home Family Program (IHFP) . . 24

Missouri

Parents Learning Together 25

New Jersey

Parent Enrichment Project (PEP) 26
Parents and Children Together (PACT) 27
Alternatives, Inc. 28

New York

Family Support Program 29
Parent and Child Training Club (PACT) . . . 30

North Carolina

Families on the Grow 31

Oregon

Families with Special Needs Program 32

Pennsylvania

ESPRIT 33

Washington

Gateway Family Support 34

Wisconsin

Developmental Disability Counseling 35
Neighbors Network 36
Supported Parenting/Healthy Families Program 37
Positive Parenting Project 38
Parents and Children Together Program . . . 39
Family Education and Resource Center 40
Community Living Program 41
Catholic Charities Supported Parenting Project 42

III. FOOD FOR THOUGHT

Issues, Ideas, and Strategies

Guiding Principles for Supporting Families Headed by Parents With Cognitive Limitations 45
Discovering the Parent's Language of Learning 49
A Conversation with Polly. 57
Moms' Day Out 69
Dreams for Our Children 78
APPENDIX A: Suggested Readings. 80

Program Descriptions

Cultivating Competence - 2nd Edition

Directory and Resource Guide on Supported Parenting

CALIFORNIA

Family Support Services (FSS)

David Becker or Robyn Edwards
Family Support Services
Greater Southeastern Apartment Training (GSAT)
P.O. Box 1458, Bellflower, CA 90707
(888) 867-3612 or (562) 804-7660
Fax: (562) 804-7471

Family Support Services (FSS): This program of the Greater Southeastern Apartment Training (GSAT) offers Family Support Services to persons with developmental disabilities who are either pregnant or raising children to specifically address parenting and child rearing issues as well as Supported Living Services. Many of the parents in the program have a secondary diagnosis of mental illness. GSAT was founded in 1981 to provide services to people with developmental disabilities. GSAT provides Independent Living Services (ILS), Supported Living Services (SLS), and Family Support Services (FSS) in Southeast Los Angeles, San Fernando Valley, San Gabriel Valley and Imperial County.

Parenting Program:

This program provides support necessary to keep the family unit intact. The consumer and her/his circle of support determine the goals. Services are provided on a one-to-one basis, in natural environments. Meetings are scheduled at mutually agreed upon times, for 1-2 hours, 4-6 days a week. GSAT staff and the consumer work to achieve desired outcomes. Areas of need are parent education and parent/child relationships; menu planning; grocery shopping; meal preparation; budgeting and money management; child development and discipline; organization of living environment; first aid, health, medical, and dental care; counseling; socialization and play skills; personal skills and mobility; and emergency intervention with the family, as needed. Advocacy with the Department of Children and Family Services and Children's Dependency Court is also available.

Staff:

Professionals

Funding:

Regional Center system through California Department of Developmental Services

CALIFORNIA

Through the Looking Glass

Sherrie Hansen
Through The Looking Glass
2198 Sixth Street, #100
Berkeley, CA 94710-2204
(800) 644-2666 Fax: (510) 848-4445
E-mail:TLG@lookingglass.org
Web-site: www.lookingglass.org

Through the Looking Glass (TLG): This program serves a diverse population of individuals with developmental disabilities who are pregnant, parents and their babies (birth to three), or children. Parents with other disabilities and their babies, as well as parents and their babies with disabilities also receive services. The program has expertise working with parents who have a physical or sensory component to their disability or who have a dual diagnosis. Operating since 1982, the agency has used a non-pathological blend of infant mental health, family therapy, developmental, and educational approaches. There is a strong "peer" element, integrating professional staff who are parents of children who have disabilities, or are family members and professional staff who have disabilities. TLG is a National Resource Center for Parents with Disabilities which includes publications (such as the newsletter, "Parenting with a Disability"), clearinghouse, parent-to-parent network, technical assistance and training for professionals – all national in scope. Custody, pregnancy, birthing, and intervention are included as emphases of the Center.

Parenting Program:

Home, residence, or foster home visits are provided to meet the needs of each family (frequency averages twice a week). Services, tailored to each family situation, address the infant/parent or infant/child relationship, parenting skills, development of the baby, the couple/family relationship as it impacts parenting, preparatory work for these during pregnancy (as well as pregnancy and birthing focused work). The program also offers case management, evaluation, advocacy, information and referral, resources (e.g., adaptive parenting equipment and strategies). Groups for parents with cognitive disabilities and their adolescent children are offered.

Staff:

Mental health and developmental specialists, primarily with personal disability experience (MA or PhD level).

Funding:

Regional Center of the East Bay, Part C funding; County Department of Social Services (Child Protective Services) contracting; NIDRR, U.S. Department of Education grant for groups and National Resource Center.

CALIFORNIA

UCLA Parent/Infant Health & Wellness Project & Parenting Program

Alexander J. Tymchuk, Professor, Department of Psychiatry
School of Medicine, UCLA
760 Westwood Plaza
Los Angeles, CA 90024-1759
(310) 825-0026 Fax: (310) 206-4446 E-mail: ATymchuk@mednet.ucla.edu

---

UCLA Parent/Infant Health & Wellness Project & Parenting Program: Started for research and direct service, this program lacked a coordinated national or state interest so changes were made. After 2 decades of operation, welfare policy changes showed a need to integrate services for families where one or both parents has a history of cognitive impairment. Now the program has three major components. One focuses on competency determination for parents who are cognitively impaired. For two years the program has been involved in a large class action suit for people involuntarily sterilized on the basis that they would be incapable parents. Another part of the program is training, done through the University and other services like child protection, public health, American Indian, etc. The Nurturing Program for Parents with Special Needs has been developed and published through Family Development Resources, Park City, Utah. The Curriculum for Parents with Special Needs is available from the Red Cross, Los Angeles Chapter. Various healthcare and injury prevention booklets and curricula are available in English and Spanish.

Parenting Program:

The parenting program is directed at establishing a model for the provision of self and young child health, safety, and well-being preparatory and preventive education for parents with individual learning needs associated with a disability and to demonstrate the applicability across sites and agencies. The program just completed a community-based cross-sector random clinical trial comparing two approaches. After pilot testing in Sacramento and Los Angeles, the effort ran for 4 years in Los Angeles and Ventura Counties with 212 mothers receiving home instruction and 61 receiving materials only. The results demonstrated clearly the validity of the materials and the processes. Now, ways to disseminate as well as to study other longstanding issues in the field are being addressed.

Staff:

Professionals and students.

Funding

Primarily University and grant supported (e.g. The California Wellness Foundation, SHARE, The Entertainment Industry Foundation).

CALIFORNIA

Training Toward Self-Reliance (TTSR)

Paula Valdez
Training Toward Self-Reliance, Inc. (TTSR)
1491 River Park Drive, Suite 200
Sacramento, CA 95815
(916) 920-8877, Ext. 103
Fax: (916) 920-8977
E-mail: ttsr@jps.net

Training Toward Self Reliance, Inc.: (TTSR) provides services to people with developmental disabilities in order to assist them to become participating members in the community. The agency began offering community-based independent living skills and functional-living skills services in 1982. In 1986, TTSR expanded its services to include instruction and support in parenting skills. The parenting program is for parents with children who are at risk for developmental delays and/or abuse and neglect. Agency staff provide consultation to independent living and parenting programs nationwide.

Parenting Program:

The program uses a holistic approach that consists of three components: one-to-one in-home instruction, parent group support/instruction, and assistance in accessing community resources. The in-home instruction is individualized and the parents and staff work together to determine goals and content of instruction, success criteria, and length of service. The parent group meets biweekly for two hours to discuss parenting issues and to offer support and socialization opportunities. The group also participates in community outings. Community resource assistance includes informing parents of what is available, assisting them with understanding the policies and procedures of a program or service, and acting as an advocate when necessary. The program is currently serving 75 families.

Staff:

Professionals.

Funding:

Alta California Regional Center

COLORADO

Parents and Children Together (PACT)

Annette Moffatt
PACT Director
ARC of Adams County
8805 Fox Drive, # 100
Thornton, CO 80221
(303) 428-0310
Fax: (303) 650-9070

Parents and Children Together (PACT): PACT began in 1984 as a parenting support group for parents with developmental disabilities. Today it serves over sixty families every month in the Denver area. PACT offers parenting skills training and support, crisis intervention, assistance with accessing community resources, social events and a variety of supplemental services including car seat loans, home safety equipment, baby furniture, and emergency assistance.

Parenting Program:

Parent educators make weekly home visits to provide individualized parent skills training. The home visits include planned curriculum, discussion, demonstration, outings and role modeling. The topics are individualized for each family and include child development, discipline, home safety, nutrition, social skills, money management, etc. There are several social events for PACT participants as well, and transportation or mileage reimbursement is provided. The events include a family fun night, a PACT fair, a holiday party and gifts for all family members in December, and the annual parents' night out and award ceremony. Parent Educators work with no more than seven families at a time in order to provide comprehensive and high quality services.

Staff:

Professionals and paraprofessionals.

Funding:

Arc of Adams County; Mile High United Way; County Departments of Human Services for Adams, Arapahoe, Denver and Jefferson Counties; and individual donations.

GEORGIA

Georgia Family Support

Mary Yoder
Georgia Family Support
Atlanta Alliance on Developmental Disabilities
828 W. Peachtree, NW, Suite 304
Atlanta, GA 30308
(404) 881-9777, Ext. 211
Fax: (404) 881-0094

Georgia Family Support: Formerly Project: RESCUE, this program began in 1969. It is a community-based program that provides support to eligible children and adults with cognitive disabilities who live in Fulton County. Today the program provides services and support for approximately 125 families, thirty-seven percent of the families are headed by mothers with mental retardation. Frequently addressed issues relate to the family's poverty level, experiences of living in public housing facilities in a large metropolitan area, negotiating with other agencies and organizations in the community, and also parent training.

Parenting Program:

The program provides home-based management and crisis intervention services as well as one-on-one intensive training. The training is individualized to meet the needs of each parent. Services continue as long as needed, in fact, several of the mothers have been with the program since 1969. The program also recruits and pays neighbors to provide support to the parents. The neighbor may visit several times during the day to assist the parent during busy periods to help ease some of the stress that might occur as children are getting ready for school or when they come home in the afternoon.

Staff:

Professionals, paraprofessionals, and volunteers.

Funding:

Mental Health, Mental Retardation, and Substance Abuse Regional Boards; United Way; and private contributions.

HAWAII

Project: Kako’o Supportive Parenting

Stacy M. Kong
Supportive Parenting Project
Department of Public Health, Family Health Services Division
1600 Kapiolani Blvd, Suite 1401
Honolulu, HI 96814
(808) 942-8252
Fax: (808) 946-5222

Project: Kako’o Supportive Parenting:

In 1995, The Zero-to-Three Hawaii Project of the Department of Public Health began a five-year model demonstration project to support families headed by a parent with a cognitive disability who are raising children under the age of three. Project Kako’o uses a collaborative team approach that includes the entire family in the support process. The project also provides community education and training to agencies in the community that are serving the families. More than 30 families have received services and support since the project began.

Parenting Program:

The project uses staff and volunteers to support the family with raising their children and also to help identify resources in the community that can provide additional services. The project can also assist with identifying and developing adaptive materials to support the parents with disabilities. Volunteers support and assist the families in many ways such as teaching and reinforcing home management skills, providing transportation, going along with the family on activities and outings, and providing peer support.

Staff:

Professionals and volunteers.

Funding:

Early Education Program for Children with Disabilities (EEPCD) of the Office of Special Education (OSEP), U.S. Department of Education.

INDIANA

Project ASPIRE

Kathy Ballard
Noble of Indiana
Pan Am Plaza
201 S. Capital, Suite 800
Indianapolis, IN 46225
(800) 929-3002 or (317) 264-1422
Fax: (317) 264-5300

Project ASPIRE: Project ASPIRE is a program through Noble of Indiana, designed to assist parents with cognitive delays. Noble of Indiana (formerly Noble Centers) provides services to over 2,000 children and adults with developmental disabilities in Indiana through nine locations. Noble's Children Services provides community-based early intervention services and therapies to babies and toddlers with disabilities or at risk for delays. The School-To-Work program partners with 16 high schools to help young adults with disabilities make the transition from high school to the work force by obtaining valuable work experience in the community. The Supported Employment Service assists hundreds of adults in obtaining jobs in the community, enabling them to live more independently. Assistance is also given to employers to help them with hiring individuals with disabilities, enabling them to diversify their workforce.

Parenting Program:

Project ASPIRE is a three-step approach that provides home-based visits where parenting issues are addressed one-on-one in the natural environment; parent education classes based in the community; and social/recreational events designed to help parents identify community activities for the entire family. Staff also act as the school liaison if the children are in school. The goal of the project is to empower parents to increase their confidence and competence in their parenting abilities; nurture a stable and supportive family environment; and enhance their children's development by addressing their basic life needs, establishing positive relationships with their children's schools and making meaningful community connections.

Staff:

Professionals.

Funding:

United Way, government, sheltered work income, fees, grants, and private donations.

MARYLAND

Parents In Action (PIA)

Bernadette Irwin
PIA, PACT: Helping Children with Special Needs/
An Affiliate of Kennedy Krieger Institute
5512 Baltimore National Pike
Baltimore, MD 21228
(410) 455-0404 Fax: (410) 747-3617
E-mail: Irwin@Kennedykrieger.org Web-site: www.kennedykrieger.org

---

Parents in Action (PIA): PIA provides home and center-based services to parents with cognitive limitations and whose children are birth through five years of age. The goals of the program are: (1) to keep families headed by parents with cognitive limitations safely intact by teaching the mothers and fathers effective parenting and independent living skills, (2) to help the children in these families stay developmentally on target by role-modeling activities designed to stimulate the children's developmental growth and to access early intervention services, as needed, and (3) to provide family-centered planning coordination to assist parents in identifying and access resources within their own communities. PIA also serves as a training site by providing opportunities to those in or entering the human services arena to learn how to work more effectively with this population. Parents participate voluntarily in this program.

Parenting Program:

PIA offers many activities to engage the parents and children in learning opportunities. The center-based group approach teaches parenting and independent living skills, provides for socialization for parents, and age-appropriate activities for children. The program assesses the children's development and if a delay is noted, they are provided with therapies and referred to appropriate programs. The home-based services allow staff and students to provide parents with the individualized attention they need to adapt classroom learned skills to their home and communities. Planning coordinators assist in identifying services and resource needs, assure that the family receives appropriately delivered services, identify funding sources or assist with funding if emergency services are required, and assist the family to plan for future self-advocacy and coordination.

Staff:

Professionals, interns and students.

Funding:

State of Maryland Department of Health & Mental Hygiene; United Way; private foundations.

MASSACHUSETTS

Home For Little Wanderers

Nancy Tavares
Home for Little Wanderers
271 Huntington Avenue
Boston, MA 02115
(617) 267-3700 Ext. 636
Fax: (617) 267-7334

Home for Little Wanderers: The Boston Children's Service Association has a Family Support Program for parents with cognitive limitations and developmental delays who have a child living with them. To be eligible for the program parents must be eligible for services from the Department of Mental Retardation, have an IQ of 70 or below, and live in the DMR Region VI-, Boston. In addition to the Family Support Program there is a specialized or therapeutic foster care program for adults and children. Three families are currently in foster care.

Parenting Program:

The Family Support Program offers a variety of services that include in-home parent skills training, a parent aide program, linkage with community resources, behavior management training, and individual and family counseling. The in-home parent training offers parents two to five hours per week of training from a family support worker. The parent aide program uses parent aides to provide parent skills training, peer counseling, and assistance with accessing community resources. The parent aide visits the parent weekly and agrees to be involved with the parent for at least 7-9 months.

Staff:

Professionals and paraprofessionals.

Funding:

Department of Mental Retardation, Department of Social Services, and Department of Public Health.

MASSACHUSETTS

Positive Parenting Resource Center

Susan Jones
Positive Parenting Resource Center
The ARC of Franklin County
111 Summer Street
Greenfield, MA 01301
(413) 774-2105 Fax: (413) 774-2585
E-mail: arc@crocker.com Web-site: www.arcfcty.org

Positive Parenting Resource Center: This program is part of the Arc of Franklin County which has provided support, services, and advocacy to individuals with developmental disabilities and their families since 1951. The Arc has a Family Support Program that serves more than 120 families in the Franklin and Hampshire region. Services include respite staffing, educational advocacy, information and referral to community resources, various parenting groups, and flexible Family Support funding. In addition staff provide consultation and training to other agencies working with individuals with developmental disabilities. The agency has recently formed the Statewide Coalition for Supporting Parents with Cognitive Challenges for professionals, parents, and support people. The mission of the coalition is to support parents through training, collaboration, community partnerships, and positive communication.

Parenting Program:

The program offers case management services, parent education, and support groups to parents with cognitive disabilities who have children of all ages. In the North Quabbin area, a moms group meets weekly and a couples group meets monthly. In the Greenfield area the moms' group meets biweekly and the couples group meets monthly. Topics for the group meetings include child development, positive discipline and limit setting, health and safety, parenting skills development, and understanding abuse and neglect. The program is currently serving 37 families with six of the families receiving in-home support.

Staff:

Professionals, paraprofessionals, and volunteers.

Funding:

Massachusetts Department of Mental Retardation and grants from Children's Trust Fund, Even Start, North Quabbin Family Network, and United Way.

MICHIGAN

Infant Mental Health Services of Arbor Circle

Cathy Nietupski
Arbor Circle Infant/Toddler Development Services
1115 Ball Avenue N.E.
Grand Rapids, MI 49505
(616) 456-6571
Fax: (616) 458-0095
E-mail: cnietupski@arborcircle.org

Infant Mental Health Services of Arbor Circle: The Arbor Circle Corporation (five organizations that merged in 1996), has an Infant Mental Health program for residents of Kent County. The programs, including the Volunteer Early Intervention Project, combined into the Infant-Toddler Development Services. The programs have been in existence since 1984 with a focus on parents with developmental disabilities since 1985. About 400 families a year are served and about 2000 families in the past six years have been served. Infants age birth to three or parent in third trimester of pregnancy are eligible. Other criteria include disruption of infant/parent relationship as a result of parent with mental retardation, mental illness or low functioning; parent with mental illness, parent with physical challenges; grief, loss or other concerns; separation or transition from primary caregiver(s); infant with special needs that impact positive attachment with parent/caregiver; or infant who has experienced a traumatic event. Services include infant mental health interventions, evaluations of infants in relationship to caregivers, mentor, infant development assessments, sensory integration, parent/infant support and play groups, advocacy for families, collaboration with service providers, telephone "warm line", and consultation and training.

Parenting Program:

Intervention strategies include in-home infant mental health Intervention, reduction of social isolation, and parenting skills/role modeling with a paid mentor, and collaboration with community services as needed. An Infant Mental Health therapist develops an intervention plan with the family that includes in-home visits from one to twelve times a month, and developmental assessments of infant or toddler using Ages and Stages or the Infant Developmental Assessment (IDA). The intervention plan may also include a sensory integration assessment and intervention, participation in an infant/parent play group, or psycho-educational parent/infant support.

Staff:

Professionals and mentors.

Funding:

Community Mental Health, United Way, and Community Collaborative Grants.

MICHIGAN

Parent/Infant Program

Patricia J. Rea
Parent/Infant Program
Livingston County Community Mental Health
3760 Cleary College Drive
Howell, MI 48843
(517) 548-0081 Fax: (517) 548-0498
E-mail: blazes203@aol.com

Parent-Infant Program: Livingston County Community Mental Health provides a variety of services to the citizens of Livingston County including the Parent-Infant Program, a specialized service for parents with children 0-3 years of age. The agency offers other programs for families including Prevention Services, Family Support, and Parents with Special Needs Project.

Parenting Program:

The Parents with Special Needs Project began in 1999. The project is a voluntary program for parents with cognitive limitations who have young children 0-5 years of age. Families and community team together in a strength-based wrap-around process aimed at helping the parents function more independently and effectively. This process focuses on all aspects of an individual's and family's life such as parenting, childcare, basic needs, safety and emotional issues.

Staff:

Professionals, parents, volunteers.

Funding:

Strong Family Safe Children grant through Livingston County Human Services Collaborative Body.

MINNESOTA

Hennepin County Parent Support Project

Bruce Kerber or Debbie Silverstein
Hennepin County Parent Support Project
15-A Hennepin County Government Center
300 S. 6th Street
Minneapolis, MN 55487-0150
(612) 348-6417 or 348-3469
Fax: (612) 348-2856

Parent Support Project (PSP): It began in 1989 as a joint service delivery model between the Child Protection Division and the Developmental Disabilities Division within the Adult Services Department. It was created to better serve the population of parents with cognitive limitations (IQ of 80 or below) who were at significant risk of neglecting their children's needs or where neglect had been substantiated by CPS. The PSP has since evolved to accept referrals from any social service program area within the Children's and Family Department of Adult Services Department where there is abuse and/or neglect present (or risk of) due to the cognitive limitations of the primary caretaker(s). The goal of the PSP is to work in collaboration with the various County Programs and Divisions to reduce the likelihood of further child abuse and/or neglect by helping the parent(s) to recognize their children's needs and then respond appropriately. The average length of involvement by PSP is approximately one year.

Parenting Program:

PSP provides an intensive home-based approach, working with parents to enhance parenting skills. Services provided by Social Workers include assistance with reunification (if a child is in out-of-home placement and a return to the family is being considered), child focused services, assistance with housing, homemaking instruction, daily living and social skills acquisition, health and hygiene instruction, crisis intervention, advocacy, and case management. When a case is assigned to a PSP Social Worker, a thorough assessment will occur. Once the assessment is completed, a comprehensive service plan will be developed. Progress reviews will occur on a quarterly basis or as needed to provide information to all interested parties.

Staff:

Professionals.

Funding:

Hennepin County Community Services Department.

MINNESOTA

Reuben Lindh Learning Center Parenting Program

Audrey Kvist
Reuben Lindh Family Services
3616 12th Avenue South
Minneapolis, MN 55407
(612) 721-5111 Fax: (612) 728-0587

Reuben Lindh Learning Center Parenting Program: The program began in 1970 and offered educational services to children with developmental disabilities. In 1977 the Center initiated services to parents with developmental disabilities in the Minneapolis metropolitan area. More than 600 families have been supported through the efforts of the Center. The Center's community based services are used by families who have multi-generational problems, are with young children who are at risk of abuse and neglect, are reuniting after a foster care experience, are recovering from alcohol or chemical addiction, or are completing their conditions of probation. Programs include Family Partnership, Family Therapy, Housing Resource Center, Little Earth of United Tribes Preschool and Family Support Services, Multi-cultural Therapeutic Preschool and Family Support Services, Parenting Program, RAP (Rebuilding Appropriate Parenting), Infant REACH (Resources Entering A Child's Home), Rebound, Southeast Asian Preschool and Family Support Services, Unified Therapies, and Visitation Center.

Parenting Program:

The parenting program at the Center offers intensive and long-term support to parents with children between birth and five years of age. Twenty-four families are currently receiving support. The families receive hands-on parent training with their children in half-day sessions, four days per week at the Center. The classes focus on a variety of topics including parenting, self-esteem, relationships, cooking, nutrition, health, sexuality, family planning, remedial reading, math, money, and time management. The Center provides transportation services for each family to the training classes. Additional time is spent with each family in the home on a one-to-one basis. The Center also offers support groups for fathers, siblings, and an intake group for new families to learn about the services of the Center and to discuss topics of interest. In addition, each family receives advocacy and support serves, if needed.

Staff:

Professionals.

Funding:

County Department of Early Childhood, United Way, and private donations.

MINNESOTA

Parenting PLUS Program

Peggy O'Toole-Martin
Parenting PLUS Program
126 Woodlake Drive Southeast
Rochester, MN 55904
(507) 285-8033
Fax: (507) 529-4625
E-mail: po'toole-martin@esc.rochester.k12.mn.us

Parenting PLUS Program: The program is a collaborative effort between Parents Are Important In Rochester (PAIIR), Arc of Southeastern Minnesota and Olmsted County Community Services. PAIIR is the Rochester Public School's Early Childhood Family Education Program (ECFE). Minnesota's ECFE Program is the oldest statewide support and education program for families with children from birth to kindergarten enrollment. PAIIR has been providing support and information through a variety of classes since 1974. PAIIR's mission is to strengthen families through the education and support of all parents, helping them to provide the best possible environment for the healthy growth and development of their children.

Parenting Program:

The Parenting Plus program supports and strengthens the skills of parents with cognitive disabilities and enhances the competence of their young children. Parenting Plus provides parent education and support, early childhood education, parent/child interaction time, home visitation and mentoring, and resource development. Parenting Plus enrollment requires that parents must be currently pregnant or have children up to kindergarten enrollment, and resides in Olmsted County.

Staff:

Professionals.

Funding:

Local Collaborative Time Study grant and PAIIR.

MINNESOTA

Nekton In-Home Family Program (IHFP)

Deborah Muenzer-Doy
Nekton In-Home Family Program (IHFP)
276 North Snelling Avenue
St. Paul, MN 55104
(612) 644-7680

Nekton In-Home Family Program: In 1981 Nekton began offering support services to families in which one or both parents have mental retardation and to low functioning families receiving Child Protection Services. Currently the In-Home Family Program (IHFP) is in Hennepin, Ramsey, Dakota, and Anoka Counties. The Nekton Organization offers services to individuals with developmental disabilities. The organization began in 1973 with a group home and foster home program.

Parenting Program:

The IHFP provides in-home as well as group training sessions to teach parenting skills. The group training sessions are held for six-week periods and cover a wide range of topics (e.g., self-esteem, nutrition, behavior management, sexuality, personal care, neglect and abuse, and safety). Families are provided with long-term support by family service workers who coordinate services and provide assistance with parent training. The family service workers each support from six to eight individuals and average five hours of service weekly to each family. The workers are available when the family needs support. IHFP uses flexible staffing schedules to meet the medical, child care, housing, and personal care needs of each family.

Staff:

Professionals and paraprofessionals who are parents.

Funding:

Contracts with County Community Services Departments.

MISSOURI

Parents Learning Together

Cathy Hayes
Parents Learning Together
3840 Lindell Boulevard
St. Louis, MO 63108
(314) 533-1214
Fax: (314) 531-5874

Parents Learning Together: The St. Louis ARC expanded its services in 1986 to include a parenting program called Parents Learning Together. This program offers families headed by a parent with cognitive disabilities the services and support to improve their parenting skills and to learn new techniques that will assist them in taking the best possible care of their children. The St. Louis ARC provides advocacy, support, and services to more than 4,900 St. Louis individuals with developmental disabilities (primarily cognitive disabilities) and to their families to achieve their goals in the home, workplace, and community. Programs and services include residential, early intervention, adult day and employment, family support, leisure, respite, support groups and parenting services.

Parenting Program:

Parents with children aged birth through 12 years of age enter the program by self-referral or referrals from other agencies. Parents participate in one center-based program day each week. Education programs include nutrition, health care, safety, behavior management, child development, family relations, and household management. Each family also receives one to three hours of home based services weekly. Intensity of service varies according to parent preference and need. The home visits provide an opportunity to assess how parents are applying the skills and information they learned at the center. Parents also receive other services, such as case management, advocacy, information and referral, child assessment, and transportation to the center. The program is currently serving 25-30 parents.

Staff:

Professionals.

Funding:

Grant from the St. Louis Office for Mental Retardation/Developmental Disability Resources, United Way, and fund raising.

NEW JERSEY

Parent Enrichment Project (PEP)

Sheila Flamm
Parent Enrichment Project (PEP)
Community Access Unlimited
60 Prince Street
Elizabeth, NJ 07208
(908) 354-3040 Fax: (908) 354-2665
E-mail: sidcau@prodigy.net

Parent Enrichment Project (PEP):

A program through Community Access Unlimited, the Parent Enrichment Project is celebrating its ninth year providing parenting education and support services to families at risk of abuse and neglect in Union County. In 1998, PEP sponsored a conference on parents with disabilities that resulted in PEP taking a leadership role in forming a statewide network of parenting education and support providers. Community Access Unlimited has served people with disabilities, youths, elderly, and families at risk of abuse and neglect since 1979. The agency offers a wide array of support services that include supervised and supportive living apartment program, education and recreational programs, money management training, parenting skills, independent living skills, employment training, and advocacy.

Parenting Program:

The three main components of the program are parenting education classes, accessing community resources, and home visitation to work on consumer-driven parenting goals. The curriculum topics include child development, family planning and pre-natal care, nutrition, health and fitness, positive discipline techniques, and home and community safety. Transportation and child care are available. In addition to home visitation and professional staffing support to access community resources, families also benefit from PEP's large volunteer base that connects families at risk to individuals in the community that can offer them long-term companionship and support.

Staff:

Professionals and volunteers.

Funding:

Children's Trust Fund Grant.

NEW JERSEY

Parent and Children Together (PACT)

Jeanne Guarnieri
Parents and Children Together (PACT)
The ARC of Somerset
141 S. Main Street
Manville, NJ 08835
(908) 725-8544
Fax: (908) 725-0729

Parents and Children Together (PACT): The ARC of Somerset County offers the Parents and Children Together (PACT) program, which is a community-based parenting education program for families headed by parents with developmental disabilities. On average, 20 families with a child age range birth through adolescence, receive services. The ARC of Somerset County is a non-profit agency serving the needs of people of all ages with developmental disabilities.

Parenting Program:

Program services address child growth and development, responsibility and discipline, health education and nutrition, creating safe/responsive environments for children, fostering positive family partnerships with school personnel, service coordination for individuals with substance abuse problems, and help with securing entitlements. Program components include home visiting, parent support groups, individual counseling, parenting education workshops, service coordination, "warm line" telephone support service and developmental day care. Each family receives an average of two hours per week of in-home parenting education and family support services.

Staff:

Professionals.

Funding:

New Jersey Division of Developmental Disabilities, County Department of Human Services, United Way, and fund raising.

NEW JERSEY

Alternatives, Inc.

Mary Quesada
Alternatives, Inc.
600 First Street
Raritan, NJ 08869
(908) 685-1444
Fax: (908) 685-2660

Alternatives, Inc.: Alternatives, Inc. is a community-based social service agency that has been providing comprehensive services to individuals with a variety of special needs in five New Jersey counties since 1979. For the last eight years services have been provided to parents with developmental disabilities and now eight families are served through two different programs. The Residential Parenting Program (RPP) provides skill training and offers 24 hour staff supervision to parents who need intensive support to raise a family on their own. The Supported Living Program (SLP) offers support in a semi-supervised setting where parents live in their own apartments in the community.

Parenting Program:

The Residential Parenting Program is a transitional program that assists parents in developing the skills necessary to live in the community. The Supported Living Program provides 6-12 hours of staff contact each week with 24-hour emergency contact by phone if needed. Some parents completing the RPP program continue to receive support in a semi-supervised setting. In both programs, parents receive support and training in the areas of parenting, child development, money management, health and safety, community and daily living, home maintenance, recreation, education and vocational skills.

Staff:

Professionals.

Funding:

State of New Jersey Division of Developmental Disabilities.

NEW YORK

Family Support Program

Susan Streeter or Patricia DeNigro
Family Support Program
Herkimer Area Resource Center
P.O. Box 271
Herkimer, NY 13350
(315) 866-7100, Ext. 242
Fax: (315) 866-3996

Family Support Program: The Family Support Program of the Herkimer Association for Retarded Citizens (HARC) offers a wide range of services to individuals with developmental disabilities who live in Herkimer County. Services that are provided include advocacy, independent living, homemaking skills, medical management services, case management, recreation, respite services, and professional counseling. HARC was established in 1960 and began offering programming in 1972. Today, HARC serves over 600 people a year and offers services in four main program areas: Herkimer Industries Sheltered Workshop Program, Day Services Program which includes Family Support Program, and Residential Services Program and Vocational Training Employment Services.

Parenting Program:

Parents receive most services through the Family Support Program. In addition, there are case managers who provide one-to-one individualized parent skills training in the family home. The program currently serves 85 families. Caseworkers and Habilitation Aides establish a trusting and nurturing relationship with the parents to assist them with raising their children, to support them with resolving family problems, and to help them obtain community resources. Parent aides spend at least four hours per week with each family and maintain telephone contact as needed. Two curricula have been developed for use with the families; one dealing with infant care and stimulation and another on grooming.

Staff:

Professionals and paraprofessionals.

Funding:

New York State Office of Mental Retardation and Developmental Disabilities under a Family Support Services contract.

NEW YORK

Parent and Child Training (PACT)

Ruth Autore
Parent and Child Training (PACT)
University of Rochester Medical Center Social Work Division
601 Elmwood Avenue, Box 650
Rochester, NY 14642
(716) 275-2400 Fax: (716) 461-5275

Parent and Child Training (PACT): PACT is a program that offers comprehensive services to meet the physical and psychosocial needs of families at risk of child abuse and neglect. About 40% of the families served by the program are headed by parents with developmental disabilities. PACT provides individualized services during pregnancy and the first two years of the child's life. To be eligible for the program parents must be residents of Monroe County, be pregnant at the time of referral, and be willing to receive obstetrical and pediatric care at Strong Memorial Hospital. PACT is administered by the Social Work Division of Strong Memorial Hospital and collaborates with the Monroe County Department of Social Services. The program serves 50-60 families each year.

Parenting Program:

Paraprofessional counselors provide in-home support and training in a variety of areas, such as parenting and childcare skills, use of community resources, household management, building self-esteem, nutrition, safety, and parent/child relationships. The program offers other services that include social work intervention, case management, prenatal and pediatric care, crisis intervention, parent support groups, advocacy, social activities, and transportation. Caseloads remain small (12 cases per full-time counselor) in order to meet the needs of each family.

Staff:

Professionals and paraprofessionals.

Funding:

Grant from the Monroe County Department of Social Services.

NORTH CAROLINA

Families On The Grow

Helen Leblond
Families On The Grow, Exchange CAP Center
508 Sasser Street
Raleigh, NC 27604
(919) 834-8687
Fax: (919) 831-0583
E-mail: capctr@ibm.net

Families On The Grow: Families on the Grow is program of the Exchange CAP Center which provides services and programs to residents in Wake County to prevent child abuse and neglect and enhance parent/child relationships. The agency has served over 1,200 clients since it was established in 1988. The Center is an affiliate of the National Exchange Club Foundation for the Prevention of Child Abuse. Services to families include early intervention, parent aide, adolescent parenting, and supported parenting project for parents with cognitive limitations who have children between the ages of birth to five.

Parenting Program:

Families On The Grow is an interagency collaborative effort to provide support and services to families in the community. The program provides in-home parent visitors who provide support and education to help the parents with raising their children. The support worker also provides assistance to families to learn about and receive other services that are available in the community such as public health, human services, education, etc. Wake Technical Community College offers parenting and practical life skills classes to the parents. The Arc of Wake County provides a weekly playgroup for families and Wake County Human Services provides case management and evaluation. The program is currently serving 90 families.

Staff:

Professionals.

Funding:

Wake County Smart Start and a grant from the North Carolina Council on Developmental Disabilities.

OREGON

Families with Special Needs Program

Jan Aho
Families with Special Needs Program
Pearl Buck Center, Incorporated
5100 W. Amazon Drive
Eugene, OR 97405
(541) 345-8506 Fax: (541) 345-0327
Website: www.pearlbuckcenter.com

Families with Special Needs Program (FWSN): FWSN provides: 1.) a tuition-free a NAEYC-accredited preschool for children aged 2-6 years born with average or above average intelligence to parents with developmental disabilities; and 2.) case management services to provide advocacy, referral, and emotional support to individuals and families. The Pearl Buck Center, Inc. is a non-profit organization serving people with developmental disabilities living in Lane County since 1953.

Parenting Program:

The Families With Special Needs preschool provides critical stimulation necessary for children to reach their potential and assists parents to meet their children's needs. The year-round preschool program provides transportation to and from school; breakfast, lunch, and snack; and regular home visits. Case management services help parents secure and maintain adequate housing, nutrition, safety, and prevents abuse and neglect. The Pearl Buck Center collaborates with many external agencies to ensure the children's healthy development, and to educate parents. The program currently serves up to 30 children.

Staff:

Professionals.

Funding:

United Way, local government, endowment interest, and private donations.

PENNSYLVANIA

ESPRIT, ARC-Allegheny

Mary Judge
ESPRIT, ARC-Allegheny
711 Bingham Street
Pittsburg, PA 15203
(412) 995-5000, Ext 421 Fax: (412) 995-5001
E-mail: arcallegheny.org
Website: www.arcallegheny

ESPRIT, ARC-Allegheny: ESPRIT (Educational System for Parents who are Retarded with Infants and Toddlers) of the The Association for Retarded Citizens (ARC)-Allegheny, has been providing services to families since 1979. To be eligible for the parenting program parents must live in Allegheny County, be registered with the county-based service unit, and accept both in-home and center-based services. The Association for Retarded Citizens (ARC)-Allegheny has been serving people with developmental disabilities for more than 35 years. The organization offers a variety of programs and services including vocational training, respite care, independent living skills training, recreation and leisure activities, an early intervention program, a toy lending library, a college credit homemaking course, and a parenting program.

Parenting Program:

Currently ESPRIT serves 35 families headed by parents with mental retardation who have a child between birth and three years of age. A family and community specialist provides in-home parent training and support to each family. The visits average twice a week for 90 minutes each. At the agency, parents receive education and training from a developmental coordinator. Families with children under two years of age come to the agency once a week and families with children two years of age and older come to the agency twice a week. Each session lasts approximately four hours. Children with developmental disabilities receive additional services from a developmental therapist. ESPRIT collaborates with other agencies in the community that also provide services to these families (e.g., child protective agency, hospitals, and clinics).

Staff:

Professionals and volunteers.

Funding:

County funding and Title 1 for Early Intervention.

WASHINGTON

Gateway Family Support

Jan Hots
Gateway Family Support
Deaconess Children's Services
4708 Dogwood Drive
Everett, WA 98203
(425) 259-0146
Fax: (425) 252-7612

Gateway Family Support: Gateway Family Support is a program which started in 1992 through Deaconess Children's Services. Deaconess is 101 years old and has grown from humble beginnings as a county orphanage in the last century to a position of respect as a friend and advocate for the children and families without other resources to overcome barriers (social, physical, emotional, or cognitive) that hinder development of their fullest potential. Assistance is provided through different programs with a common goal of prevention and early intervention of abuse; support services to special needs families; parent education and education to the community regarding these and other social issues.

Parenting Program:

Gateway Family Support Program provides intensive family support services to parents with developmental disabilities who are parenting children 0-18 years old. The program uses an outreach model and believes strongly in family support principles. The main focus is parenting and family support, including meal preparation, proper nutrition, safety, budgeting, legal advocacy and community resources utilization. At the parents' request, the agency expanded the optional parenting support group to three times a month due to excellent participation. Transportation and childcare are available. The program is currently serving 25 families.

Staff:

Professionals, paraprofessionals, and volunteers.

Funding:

United Way and Department of Developmental Disabilities.

WISCONSIN

Developmental Disability Counseling

Nereida Diaz
Supportive Parenting Program
Developmental Disability Counseling
3311 Prairie Avenue
Beloit, WI 53511
(608) 365-8787
Fax: (608) 365-1279

Developmental Disability Counseling: This program serves individuals of all ages with developmental disabilities who live in Rock County. Programs provided by the agency include Family Support Program, Traumatic Brain Injury Support Services, Case Management, Community Connections Day Support, and Supportive Parenting. The agency is committed to provide case management, therapeutic intervention and support to individuals and their families.

Parenting Program:

The Supportive Parenting Program has been providing services and in-home support to families for the last ten years. Staff work with parents to develop a service plan. The program links families to community services and provides support in any area that is needed including nutrition, safety, discipline, age appropriate play and expectations, budgeting and home management, self esteem and stress relief, etc. The program also offers a monthly support group meeting for mothers called "Mom's Day Out." In order to participate in the program, parents must voluntarily agree to services and be eligible for Medicaid. The program currently serves 15 families.

Staff:

Professionals.

Funding:

Catholic Charities, Rock County Developmental Disability Board, Medical Assistance, and grants.

WISCONSIN

Neighbors Network

Sue Schwab
Neighbors Network
Jackson County Department of Health and Human Services
PO Box 457, 420 Hwy 54 West
Black River Falls, WI 54615
(715) 284-4301 Fax: (715) 284-7713
E-mail: sschwab@cuttingedge.net

Neighbors Network: This program is part of the Jackson County Department of Health and Human Services. In operation since 1982, the program is designed to support families (some families are headed by a parent with mental retardation) on a short-term basis through the assistance of paid neighbors. Families generally enlist the support of the Neighbors Network for approximately six months with a three-month extension when additional services are required. Services may be extended into a long-term supported caretaker model. Parents also have a county social worker who serves as a resource for the neighbor and handles case management and the administrative details of the program. This role is kept separate from the neighbor's role. The neighbors emphasize their role as a friend and de-emphasize their role as a representative of the county.

Parenting Program:

The Neighbors Network uses a parent-to-parent approach to establish relationships between families and neighbors. The neighbors are parents who can relate parenting experiences to families who need support to manage their family activities. The parent defines what is or isn't working by talking with the neighbor who is available at various times of the day when the family may need assistance. A neighbor may work for a few hours in the morning to help a parent get the children ready for school and then return when the children come home from school in the afternoon. The neighbor may assist in preparing dinner or modeling routines and skills with the family.

Staff:

Professionals and paid volunteers.

Funding:

County Human Services Department/Family Preservation.

WISCONSIN

Supported Parenting/Healthy Families Program

Polly Snodgrass or Gina Haberly
Supported Parenting/Healthy Families Program
Family Services
131 S. Madison Street
Green Bay, WI 54301
(920) 436-4374 or 743-3435
E-mail: pollys@netnet.net

Supported Parenting/Healthy Families Program: The Supported Parenting Program serves parents with developmental disabilities through the Healthy Families Program in Door County. Since 1899, Family Services has provided a variety of services for individuals, couples, families, youth, elderly, and disabled. Some of the programs include Alcohol and Other Drug Abuse Treatment, Crisis Center, In-Home Counseling Services, Healthy Families, Families and Schools Together (FAST), Treatment Foster Care, Adolescent Day Treatment, Sexual Assault Center, Visiting Nurses, Learnfaire Case Management, etc.

Parenting Program:

The Supported Parenting Program provides in-home support to families with children between birth and five years of age. Supportive services are individualized to meet the needs of the family and include case management, advocacy, transportation, and parent education in the areas of nutrition, home management, parent/child relationships, recreation and social activities, and health and safety. The program also offers a support group to parents which meets monthly for social events and an educational topic. Topics vary and focus on issues around parenting, nutrition, first aid, health care, etc. Staff collaborate with other agencies in the community to assure that families receive the support they need. The program director also provides consultation and training to agencies and service providers throughout Wisconsin and the United States.

Staff:

Professionals.

Funding:

Medicaid, United Way, Department of Health and Family Services grant, Door County Social Services, and donations.

WISCONSIN

Positive Parenting Project

Jackie Manlick
Positive Parenting Project, Brown County ARC
1673 Dousmnan Street, P.O. Box 12770
Green Bay, WI 54307-2770
(920) 498-2599
Fax: (920) 498-2652

Positive Parenting Project: The Positive Parenting Project is a program of the Brown County ARC (BCARC), a private non-profit agency that has served individuals of all ages with developmental disabilities since 1957. The agency provides a wide array of services including supported employment and employment training, respite care, family support, an early intervention program, citizen advocacy, a parenting program, and ancillary services. The Positive Parenting Project serves families in Brown County in which one or both parents have a developmental disability. The parenting program has been providing services since 1986.

Parenting Program:

The Positive Parenting Project provides in-home, individualized, and intensive services to families with children. Services include case management, advocacy, evaluation, transportation, and parent education in the areas of nutrition, home management, behavior management, recreation and social activities, health and safety, physical care and parenting skills. The project uses a preventative and positive support approach with the parents to build on the family's strengths. Program staff actively collaborate with other agencies and programs in the community to assure that all the needs of the families are met. The program is currently serving 37 families.

Staff:

Professionals.

Funding:

Brown County Community Services Board and United Way.

WISCONSIN

Parents and Children Together Program

Donna Chesley
Parents and Children Together Program
Exchange Center for the Prevention of Child Abuse
2120 Fordem Avenue
Madison, WI 53704
(608) 241-3434 Fax: (608) 241-2224
E-mail: exchange@chorus.net

Parents and Children Together Program:

The Exchange Center for the Prevention of Child Abuse established in 1984, is a non-profit, parent support agency serving families throughout Dane County. They began offering services to parents who have special needs in 1989. There are three parenting support programs: Parenting Partnerships, Parents and Children Together, and Welcome Baby. Each program provides families with intensive, home-based support, parent information, and advocacy. One or both parents need to have cognitive limitations to be involved in the Parents and Children Together Program.

Parenting Program:

The Parents and Children Together Program was designed to meet the unique learning needs and learning styles of families headed by parents with cognitive limitations. Parents decide the type and level of service to be provided. Services include finding, advocating, and coordinating resources, providing intensive emotional support, facilitating the development of social relationships, providing parent training and education, intervening in crisis situations, and matching a parent with a parenting partner volunteer as requested for additional support.

Staff:

Professionals and trained volunteers.

Funding:

Dane County Human Services Adult Community Services, United Way, grants and private donations.

WISCONSIN

Family Education and Resource Center

Ruth Hahnke
Family Education and Resource Center
Lakeshore CAP
540 North 8th Street
Manitowoc, WI 54220
(920) 682-1742
Fax: (920) 686-8700

Family Education and Resource Center:

This program serves families in Manitowoc County who have children ages birth to six years of age. The goal of the agency is to promote positive parenting and enhance family living. The Center provides several programs and services that include parenting classes, monthly parenting presentations, play groups, support groups, teen parent education, individual parent support, in-home parent education, and a resource lending library. The Center is also able to provide transportation and childcare to families when needed.

Parenting Program:

The Supported Parenting Program helps parents with developmental disabilities to increase their parenting skills with intensive, in-home support and instruction to meet the families needs in the areas of health and safety, growth and development, nutrition, parent/child interaction, child stimulation, and personal development. Staff also assist the family with understanding and using resources and services in the community. The program is currently serving ten families.

Staff:

Professionals and paraprofessionals.

Funding:

Children's Trust Fund, grants, and donations.

WISCONSIN

Community Living Program

Pam Smith
Community Living Program
Milwaukee Center for Independence
1339 N. Milwaukee Street
Milwaukee, WI 53202
(414) 272-9277 Fax: (414) 272-9205
E-mail: psmith@mail.mcfi.net

Community Living Program: This program of the Milwaukee Center For Independence helps adults with cognitive limitations reach the fullest extent of independent living capabilities by providing training and case management. Services are provided in the following areas: housekeeping and maintenance; mobility and mass transit skills; interpersonal skills; health and safety practices; financial management; parenting skills; utilization of community resources; and problem solving, crisis management and natural support building. Participants must be Milwaukee County residents over the age of 21 who are eligible for CIP, COP, or have the ability to pay. The program also offers training and technical assistance to other agencies in the community to improve service delivery to adults with disabilities. The Milwaukee Center For Independence serves individuals with developmental disabilities of all ages.

Parenting Program:

To be eligible for the parenting program at least one parent from the family must meet the county criteria for mental retardation. Intensive support is provided to parents who have children of all ages. Program support includes in-home parenting instruction, weekly parent education classes, assistance with use of community resources, individual counseling, recreation and social activities, and self-advocacy. The program has been serving parents since 1974. Currently 30 families are receiving services.

Staff:

Professionals, paraprofessionals, and volunteers.

Funding:

Adult Developmental Disability Services, Milwaukee County, State of Wisconsin Child Welfare, and grants.

WISCONSIN

Supported Parenting Project

Wendy Rhodes
Catholic Charities Waukesha
741 N. Grand Avenue, Suite 210
Waukesha, WI 53186-4820
(414) 547-2463
Fax: (414)547-8002

Supported Parenting Project: This program is a part of Catholic Charities Waukesha. Catholic Charities provides counseling services to families in Waukesha County who are facing difficulties and crisis such as marital conflict, parent/child tensions, alcohol and drug issues, family violence, depression, etc. Other programs are homemaker services for the elderly, outreach to the Hispanic community, supported parenting, and child abuse prevention programs.

Parenting Program:

This program began serving families in 1989 and today is serving 16 families. Parents with a child between the ages of 0-5 are eligible to receive services. The program provides intensive in-home instruction in the areas of health and safety, growth and development, nutrition, parent-child interaction, child stimulation, use of community resources, and personal development of the parent. Group parenting classes are also available. Services and support are available to meet the unique needs of each family.

Staff:

Professionals.

Funding:

Milwaukee Catholic Archdiocese, United Way, Children's Trust Fund, Waukesha County, and grants.

Food for Thought

Cultivating Competence - 2nd Edition

Directory and Resource Guide on Supported Parenting

Guiding Principles

Supporting Families Headed by Parents with Cognitive Limitations

The issues of families headed by parents with cognitive limitations are notable for their ambiguity. They do not present the open and shut, black and white circumstances that lend themselves to clear-cut laws, policies, and agency procedures. Much is left to the judgment of the person the family turns to for support.

To assist support agencies in sorting out the ethical dilemmas encountered in helping parents who have cognitive disabilities and their children, the Supported Parenting Project offers the following guiding principles.

All people have fundamental rights, regardless of disability. The rights of any citizen to pursue life, liberty, and happiness are not conditional on a citizen's disability or need for support. The right to take on family roles and live in the community cannot be abrogated merely because a person has a disability.

> *Parents known for their disabilities also have some abilities -- they have skills that our support services can help them enhance.*

Parents must be partners in support services. Parents, regardless of the characteristics that challenge their ability to parent, have a special bond of kinship and commitment with their children. They are best served when they are encouraged and supported to be a part of the service planning and decision-making process and empowered to be partners in the services developed for their children. When support is organized from a family-centered perspective -- "what can we do to support the survival of this family?" -- interventions are more likely to be mutually agreed upon and involvement with outside support is seen as less threatening by the family.

Build on family strengths. Children's greatest resource is their family. Often, an agency's involvement with a family is on the child's behalf and intervention is framed solely by parent deficits. The parent is seen as a problem, not as a "developing resource" so the worker develops a skeptical and punitive posture. The parent's perceived shortcomings become such a prominent focus that contributing factors such as poverty, powerlessness, lack of community resources, and the stigma associated with disability recede from conscious attention. Seeing the family only in terms of its deficits diminishes both the family and the support system's ability to be helpful. Parents known for their disabilities also have some abilities -- they have skills that our support services can help them enhance. Family bonds cannot be replaced painlessly by any array of services or alternate care arrangements. The way to support parents is to strengthen their capacities and internal resources.

Do no harm. The weight of a support system on a family seen as needing help can be burdensome. There is a tendency of the service system to take control and erode personal autonomy. The social costs of the harm caused by well-intentioned interventions may outweigh both the benefits of intervention and the risks of not intervening. This is not to say that there is no role for formal support services. It only means that we need to be careful to insure that the "act of helping" does not overwhelm a family and/or transform it beyond recognition. Agents of the service system need to resist the temptation of taking control away from parents.

Support community and family membership. Parents with impaired functional skills and their families have always been in our communities but not always recognized as such. Often, families did not emerge to be noticed by the formal support system because they were absorbed and assisted by their extended family members. Our services should not displace the roles of extended family members, friends, neighbors, or other community resources. Families are best supported in the context of their extended families and their communities. Successful support services value the integrity of the family and help to provide links to traditional family and community resources. When families seem to be cut off from extended family and community, what can be done to bring them back into roles that are mutually acceptable? When friends or extended families seem to be contributing to the instability of the family, how can their interest in the family be saved while their seemingly harmful input redirected? Given an individual family's interests and preferences, what are the community resources such as churches, neighborhood organizations, parent-teacher organizations, that can be called on to increase their accessibility to these families?

Rethink the goal of total independence for families. One obstacle encountered in supporting parents who have disabilities is the assumption that our purpose is always to help a family achieve totally independent functioning. Many families will need help over the long term. Some will need a substantial degree of support as long as the children are still at home. Some interventions will have the focus of training for independence. Other help may be instrumental, for example, child-proofing the home, giving a ride to the store or balancing a checkbook. Independence may take a back seat to the overriding goal of the health and well-being of the family. Sometimes we may need to rethink an attitude that families don't "deserve" the resources they use. Rather than voicing concern about a family becoming "dependent" on services, it may be helpful to put that dependence in perspective and realize that no one is totally dependent nor wants to be. Our interdependence is what helps us feel socially connected.

Use care in judging the survivability of a family. One of the most challenging aspects in supporting families headed by parents with disabilities is encountering that grey line that separates parental care that may be less than optimal from a situation which is detrimental to the interests of the child. It is not unusual for support providers to be called on to make judgments about a family's prospects that will influence whether or not the family stays intact. Laws of the land frame a policy of promoting the permanence of families: only compelling evidence of harm should trigger the termination of parental rights. Permanency planning policy is premised on the idea that direct, time-limited interventions will lead to prompt answers regarding whether a family stays intact or a child is freed for another permanent option such as adoption. This approach can conflict with what we know about the complex, continuing issues facing a parent whose disability is permanent. The rights of a child may be compromised by delaying court intervention; the rights of a parent may be compromised by actions that lead to a swift termination of parental rights. The immediate risk to a child may be alleviated by out of home placement, but the long-term harm of losing the identifying connection to the birth parent can be devastating.

Innovative methods of keeping families together need to be discovered, such as extending the availability of parent aids, combining child and adult foster care, open adoption, shared parenting arrangements, and recruiting volunteer parent mentors.

Service systems and courts need to be more resourceful in their efforts to avoid permanently severing family ties. Innovative methods of keeping families together need to be discovered, such as extending the availability of parent aids, combining child and adult foster care, open adoption, shared parenting arrangements, and recruiting volunteer parent mentors.

Families need comprehensive, coordinated and flexible support. Families headed by parents with disabilities are best served by comprehensive and flexible support services. Usually, no single agency is able to provide all needed services to these families. Coordination of services, cooperation and shared responsibility are necessary components of a service system that meets the varied needs of parents and their children. Families and all individual family members grow and develop. As their capacities, needs, and preferences change, so, too, should their support services.

Long term support is fundamental to Supported Parenting. When a family's need for assistance is due to the permanent disability of the parent, support for the family needs to be available on a continuing basis. Crisis-driven, short-term services often result in frustration, burnout and blame on the part of the worker and mistrust, despair, and cyclical crisis episodes for families. Long-established and continuing working relationships with families can result in greater mutual trust and respect, a maturation in the ways families use support, more opportunities for prevention and early intervention, and opportunities for workers to develop a more holistic approach (in contrast to a sole emphasis on one "presenting problem").

Howard Mandeville directs projects in the areas of supported parenting, personal safety, self-determination, self-advocacy, supported housing, and health for the Wisconsin Council on Developmental Disabilities.

(608) 266-9538 Fax: (608) 267-3906
E-mail: mandehj@dhfs.state.wi.us

Discovering the Parent's Language of Learning

An Educational Approach to Supporting Parents with Cognitive Disabilities

Mark Sweet, Ph.D.
Trainer and Consultant
Wisconsin Coalition for Advocacy

Parents with cognitive disabilities face many challenges. Some arise directly from the learning problems that can make it harder to acquire and apply all of the new skills and information needed to be a good parent. Some of the challenges are the result of assumptions that are made about "people like that." Other challenges are attributable to the mismatch between the methods that are used to help and the learning strengths of those who are supposed to benefit from them.

Effective support for families headed by parents with cognitive disabilities requires an individualized approach. You cannot offer assistance in French to someone who understands English and call it support. We vary as learners. Noticing the variation is not as clear as the distinction between English and French, but it is not so complicated that we cannot all do better by learning a little more about it.

The Goal: To match our methods of support to the individual learning needs of the persons receiving it.

Introduction

Many of the people who provide instructional and emotional support to parents with cognitive disabilities have training as nurses, social workers, and early childhood specialists. The intent with this section is not to replace the skills and knowledge gained from these other areas, but to supplement them by adding an adult learning perspective. In addition to professional training, there is the issue of social interaction. Some people experience discomfort or feelings of awkwardness when interacting with a person described as having a cognitive disability. What assumptions can be made, if any?

We often assume that others share our perspectives and our values. Then, it does not seem like a big leap to assume that if our intentions are honorable, our actions will be welcomed and helpful. When people seem not to welcome or be helped by these actions, we might judge them uncooperative, uncaring, or not smart enough to do better. And then, we might generalize our assumption and judgment to others who have a similar diagnostic label. Such assumptions and subsequent judgments are not reasonable. There is always more to the story when we become better acquainted with someone; when we consider a person's actions in a larger context.

Consider these points of view:

- I smile and nod when you talk to me. I'm polite. I say "yes" and "thank you" a lot because yes and thank you seem to be what people most often want me to say. I can do what you want. I'm a good parent.
- I don't know where to look. I see you talking. I see my daughter is on the floor. The TV is on. The magazines are right here and my neighbor just drove by. I don't know what you want from me. You make me nervous.
- You just ask questions all the time. I want to do something. Sitting and talking makes me feel like I'll explode.

- You just show up, but you're not my family or my friend. You're not my doctor. I've had other workers like you. They're all gone now.
- These problems are not my fault. I didn't do anything wrong.

Can you remember or imagine yourselves ever having similar thoughts? These are not necessarily the perspectives of uncooperative, uncaring, or incapable people. They are feelings that any one of us might have under certain conditions. They might also be the perspectives of people who have had a difficult time learning throughout their lives.

The attempt to provide support is not the same as actually providing it. . . It is not enough to have a sincere intention. We also have to offer support in a way that a particular person can understand.

We cope with all of life's complexity by what we do. Some of our actions can be called skillful coping and some of it is not so skillful. Especially when your intention is to offer help, rather than naming "bad" behavior, it might be more helpful to notice how a person is coping with difficult conditions. How we cope has a great deal to do with how we learn.

Learning and Learners

The Pattern of Learning

Learning follows a pattern. First we perceive. Perception refers to what first catches our attention. Then we discriminate. We have to sort what is most relevant from what is less relevant in order to accomplish a goal. Finally, we tie together what we have perceived and discriminated. This tying together enables us to apply what we have perceived and discriminated. This is when learning has occurred.

We see, we hear (especially language), and we physically experience (or feel) in a pattern. People do not all follow the same pattern in order to learn. The better you recognize someone else's natural pattern of learning, the easier it can be to provide usable support.

The attempt to provide support is not the same as actually providing it. If I had written this in Spanish and you only read English, my attempt might be sincere, but my method would be wrong for you. It is not enough to have a sincere intention. We also have to offer support in a way that a particular person can understand.

Part 1: Perception

There is a way that is most natural for each of us to connect with what is going on around us. Some people perceive the world around them by how things feel -- this is **kinesthetic perception**. They might want to touch everything or be in motion. They might notice comfort and discomfort immediately -- too hot, too cold, too soft, too hard, etc. Others initially perceive the world through sound, especially language -- this is **auditory perception**. Still others most easily perceive the world by what they see. This is **visual perception.**

We reveal something about our natural perceptual style each time we encounter a new situation. Some people try to physically participate immediately or they notice "the feel" of a place. Some enter talking or busy in thought. Their attention might naturally be attracted toward existing sound. These people might try to join any ongoing conversation. Others actually slow themselves down both physically and mentally when entering a new setting in order to look around and notice their surroundings visually. They most naturally try to make themselves comfortable by noticing how things look.

When left on our own, there are ways that each of us tries to become familiar and comfortable with our surroundings and our situation - through our bodies, our ears, or our eyes.

Part 2: Discrimination

Perception is essential, but will get us only so far. When we try to accomplish a new goal, or just find comfort in a new situation, we will most likely become confused. We perceive more than is necessary, whatever our method. When that happens, either on our own or with assistance, we have to discriminate what is most relevant from all that we initially perceived. From perception to discrimination there is a sensory shift.

Discriminating is about sorting through all of the clutter to clarify or refine what has been perceived. It is a highlighting step that calls special attention to what we have already seen, heard, or felt. In order to discriminate, we shift from one sensory method to another. For example, if I perceive visually, I am looking around but not "seeing" what is most relevant, I will have to either hear about it, or physically experience it.

Part 3: Tying It All Together = Learning

The third step in the process of learning is to tie together what has been perceived and discriminated in order to make our understanding whole. For this, another shift is needed. Learning includes all three methods (kinesthetic, auditory, and visual) in some combination that creates a pattern of learning. If I am initially drawn to what I see, and then make sense of what I am seeing by hearing about it, I will tie it all together by shifting to direct physical experience.

Each of us has a pattern in which learning is most natural and easiest. There is an order in which learning makes the most sense. A lack of progress does not mean that someone is not capable of learning. A person might not understand what it means to "put four ounces in the bottle" but might understand, "fill it to here" when “here” has a textural difference that can be **felt** on the bottle or a piece of red tape that can be **seen**.

To become familiar with others’ learning pattern, notice how they approach places and activities when left on their own. Which sense seems to be most alert at the beginning? Do you notice more physical attention, auditory or language attention, or visual attention? When you offer support, notice which sense you are addressing and whether it seems helpful. Your attempt can be honest, but if the person you are trying to support is not helped, it is as though you are using one language with a person who understands another.

If what you are doing is not helpful, try something else. You will only remember to try a different way if you remind yourself that learning happens through the senses, and you take notice of what you are doing. Most commonly, we want to tell people what they need to know, and explain to them why they need to know it. It seems like the fastest way to teach. In reality, it is a method that sabotages many support relationships because talking is not helpful teaching for everyone. Do not give up. Try something different.

Remembering

Many of us use reminders throughout our lives without thinking about them as accommodations. Maybe you use a daily calendar to remind yourself what has to be done or where you have to go. Maybe you associate starting dinner with hearing the theme song of a particular television program. Or you might look at coupons that remind you what to buy. Knowing how to do something and remembering to do it are actually different skills.

The implication, when someone has trouble remembering, is that some kind of accommodation might be needed in order to help the person remember to do it.

Integrating What Is Learned

A bit different than remembering what to do is integrating it. Some of us find it easy to integrate new learning into everyday routines. One person might learn to write checks and be able to pay bills. For another, writing a check would not automatically be integrated into the more complex activity that includes taking in the daily mail, recognizing the bills, identifying the amount due, writing the check, ensuring sufficient funds, putting the check and billing stub in the correct envelope, addressing and stamping the envelope, and getting the envelope mailed. Skills are used in the context of bigger activities. The implication, for a person who has difficulty integrating what is learned into the general activities of the day or week, is to teach the skills within the context of the whole activity.

In other words, teach the whole activity, or a routine of several activities, as compared to teaching an isolated skill.

Motivation and Encouragement

People talk of motivation and "readiness" to learn. When these comments are used in relation to a person with a cognitive disability, the implication is that a person's lack of progress is a function of the disability. What seems more accurate is that a person can learn if she or he:

- is taught the things that she/he has interest in learning;
- is taught in small manageable steps;
- is taught in a way that matches her/his learning pattern;
- is taught in a way that is enjoyable and light (rather than directive); and
- is taught in a way that helps her/him to feel proud of participating.

Another aspect of motivation is encouragement. It's fast and easy to say "good job." It is less easy to repeat a good job when you do not know what you did. I have to know what I did well before I can do it again.

Be as specific as possible when complimenting someone's efforts.

Temperament

It is said that we are born with our temperament. Temperament has been described on a scale between timid and bold. Some people approach everything with great optimism and energy, while others use more caution and take more time. It is not wise to approach people with the idea that you will change their basic temperament. What we can do for those we support is to recognize basic factors of temperament and accept them. Bold people can learn that in certain situations it might help to hold back a little and timid people can learn that in certain situations it might help to practice being a bit more assertive. However, it is not reasonable to expect bold people to be timid, or timid people to be bold.

The implication is to keep these personal qualities in mind when deciding how to offer your support, and to help people learn to cope with their own temperament.

Acknowledging Emotion

People who "help" might lose sight of the fact that their very presence in someone else's life can be the reminder that the person being helped is not doing well enough. After what has possibly been a long history of difficulty with learning, you are another in a succession of people who have showed up to help. Some of those who preceded you might have been helpful and others not; some were probably respectful and others not. It is not reasonable for any helper to assume that a person should be trusting and grateful without allowing her/him time to check you out; to assess you.

Personal emotions play an important role in learning. You might talk to a mother about creating a safe and stimulating play area for her child. She tells you how hard she is trying and how many other things there are to do. She shifts in her chair and tightens her face. Recognize her discomfort. These might be signals for you to slow down. This might not be the time to move forward, but a good time to acknowledge her feelings, and strengthen your relationship in the process.

You might support this parent well by acknowledging her message. This is not the same as encouraging her behavior. You might say something like, "You're right. There's so much to do when you have a child. Sometimes it feels overwhelming to be a parent." Basic acknowledgment that you heard what she said can make an enormous impression, rather than new directions, more questions , or a pep talk. Pause and notice the effect your words have. Then you might ask, "If there was a way I could help make this easier for you, would that be of interest to you?" If you continue to move forward on your agenda (about clearing a play space), without first acknowledging her present situation, or finding out if she wants your help, it is doubtful that she will be able to hear you.

The discussion of emotion and motivation raises the issue of pace. . . When people are asked to do too much, too soon, their effort can result in failure that might look like a lack of cooperation, caring, or capability.

How Much, How Soon

The discussion of emotion and motivation raises the issue of pace. How much? How soon? When supporting a parent who is having difficulty, you are always aware of the child. It is natural to want all improvements to happen quickly for the child's benefit. There is also the reality that learning takes practice and practice takes time. Things seem easy only when you know how to do them. What seems easy to you might not seem easy to someone else for a variety of reasons. Learning is not an all-or-nothing, or an all-at-once, venture. You have probably heard the adage, "success breeds success." When people are asked to do too much, too soon, their effort can result in failure that might look like a lack of cooperation, caring, or capability.

Any skill or activity can be taught and learned as smaller more manageable steps. It is hard to build success on a feeling of being overwhelmed. It is much easier to build on the experience of participation, accomplishment, and enjoyment.

Providing Instructional and Emotional Support

Having a plan for support takes some thought. The support offered has to match the learner's ability to receive it. The desire to rush to a solution as soon as possible is understandable; sometimes even court ordered. Unless there is an immediate safety crisis, take a more thoughtful approach. Ask some questions.

> *Any skill or activity can be taught and learned as smaller more manageable steps. It is hard to build success on a feeling of being overwhelmed. It is much easier to build on the experience of participation, accomplishment, and enjoyment.*

- **What Is the Whole Picture?** Develop a portrait of this person's life, not just the perceived problem. In haste, it is easy to take notice of what is not happening. Take the time to notice what is happening, and a broad enough view to notice what is working well.

- **How Does She/He Learn?** Develop the habit of asking the question, "What helps?" What helps her engage most easily? What helps him to express himself? What kinds of activities attract her attention? What does he do to make himself comfortable in a new or busy situation? There is more to be gained by being curious than by noting what the person does not do.

- **What Is the Nature of the Difficulty?** What might be contributing to the difficulties? We struggle for a variety of reasons including: physical factors; organizational and time factors; lack of helpful instructional support; memory problems; fear of embarrassment; lack of confidence; etc. It is important to make a guess based on some evidence. Ask what might be interfering with someone achieving a personal goal before deciding how you will offer to help.

- **What, How Much, and How Soon?** I cannot teach you to do something that you really do not want to do. I might, however, be able to engage you in small ways to do a little bit more than you used to do, and to build on that if I engage you with good humor, respect, and careful attention not to overwhelm you.

A Helper's Challenge

It would probably be easy to generate a list of things that another person does that drive you a little crazy. (Others could probably generate a list about you, too.) It might be interesting to generate and review such a list with the perspective that people do things because doing them seems to "work." This is not to suggest that all actions are valued or skillful, only that they are repeated because at a given point in time they are the most familiar responses.

If I want to support someone well, I have to be at least as aware of myself as the other person. When that person does the things on the list that I have already acknowledged are frustrating, what happens to me? What do I think - what do I say to myself? How does my body feel - where does it hurt? What do I see, beyond the "bad" behavior?

Now is the time to remember the flight attendant's message: "Take care of yourself before you try to help someone else." The personal challenge that is experienced after another person does or does not do something, does not have to result in a mindless reaction. With awareness, we can prepare for that event. I can notice whether my thinking is helpful or not. I can restore natural breathing and let the body tensions I am feeling relax, and I can see that this is a whole person in front of me who is trying to live a life. I can call on compassion rather than judgment. If I recognize my own signals of feeling challenged, I can make better choices about helping someone else. By taking care of myself, I can be more empathetic (and wonder what it's like to be this other person). I can acknowledge someone else's experience (and in doing so, build trust). I can offer helpful instruction (by drawing out the competence that already exists).

Rather than reacting, I can choose the response that might be most helpful.

Mark Sweet is a consultant at the Wisconsin Coalition for Advocacy, specializing in adapting instructional support for children and adults with developmental disabilities.

A Conversation with Polly

An interview by Dolores Ullmer Liamba

Polly Snodgrass has been involved in supported parenting since 1985. At that time she formed the first supported parenting program in Green Bay, Wisconsin. During the eleven years that she was there she both directed the program and provided a great deal of direct service. She is now one of the people who provides technical assistance, consultation, and training to others who would like to start supported parenting or who would like to improve the level of services they offer to parents with cognitive limitations.

Recently Polly and Dolores got together to discuss important issues about supported parenting in Wisconsin. Polly explains her views about supported parenting as well as her experiences with working with families.

The Philosophy of Supported Parenting

Dolores: *Let's talk about supported parenting in Wisconsin and what our philosophy is about providing support to families.*

Polly: One of the difficult points to get across to people about supported parenting is that there is not one model of services that is appropriate for all parents with cognitive disabilities or all agencies or persons providing those kinds of services. From my perspective supported parenting is a philosophy not a curriculum. I think it is a philosophy that basically says a lot about what our values are about families and about members of our community. Supported parenting is a commitment to those in our community who are the most vulnerable, people with disabilities, women, and young children.

Dolores: *This also includes people living in poverty. Don't you think that also brings in vulnerability?*

Polly: Absolutely. I think poverty is probably the greatest hardship for individuals that I've worked with over the last 15 years in supported parenting. It's not the learning difficulty that's really the biggest obstacle to their raising children, it's their lack of resources.

Dolores: *How are parents involved in the decision-making and planning for the services that a family might receive?*

Polly: It always strikes me as odd when people ask how we make a service plan with parents who have cognitive disabilities. Many professionals and others in the community think that parents don't have the skills or the knowledge to tell us what it is they need. But what I found is that the best way is just to ask and most parents are amazingly good at telling you what they need depending on how you ask the question. We will sometimes ask questions in a way that removes the barrier of fear or mistrust by simply saying not what do you need or I notice your life's a mess and would this help you get out of it. We may say things like, "some of the families that we work with that are in your situation tell us that this might be helpful," and then we list some of the services and ask, "would any of these be helpful to you?" or we'll ask questions that get at what exactly they may want or need.

The parents are amazingly good at telling us exactly what it is they need in order to care for themselves and their children. Sometimes we will frame or ask questions in a way that gives them an opportunity to reach and stretch and dream a little. We'll say things to them like "if you never had children, what do you think you would be doing today? or, when you were growing up, what did you think life would be like for you when you were a grown up? or, if I gave you a day to spend in any way you wanted what would you do with it? or, if you weren't responsible for anyone else but yourself today, what do you think you would be doing right now?" And it's amazing how good they are at getting at the same kinds of things that you and I have which are hopes and dreams for our present and for our future and for our children.

Strengths Perspective

Dolores: *Related to that, I think it is important to consider that when we look at families we can look at them in two different ways. You can look at the difficulties they are facing, their weaknesses, their problems or do what we try to do in supported parenting and look at the strengths of the parents and the family and try to build from there. Then piece by piece to support the family and the parents to become stronger to do the things they need to do day-to-day to raise their children.*

Polly: Yes, I'm amazed at how much time, money, and energy is spent on assessing families, which is basically another way of saying let's find out what's wrong with them. Sadly, the parents usually know very well what's wrong with them. Part of their problem is they've been told what's wrong with them from a very early age. Most of them have had fairly negative experiences in the school system. Some grew up and were educated, or not, at a time when special education was not mandated. They were always the student in the classroom who didn't know the answer, who felt they were different from everybody else and they were treated differently. And some are very articulate about what that experience did for them.

I think that those of us who provide services now have the responsibility to help families find what is going well. I've never met a family that did not have a number of strengths. But I've met many families that - if you ask them the question, "what do you think is the best thing about your family, or what is going well, or what are your personal strengths?" - most of them can't answer that question.

Dolores: *I guess I would say the same thing, too, with my involvement with families and what I've seen over the years. Frequently they have not been treated well by the people around them in our society. If a parent is not very articulate in asking for what she needs, or is afraid to come forward to request services, she may be pushed aside or treated in such a way that she learns to be quiet and not make any demands. I know many stories about how some professionals treated families in a very demeaning way when they made mistakes. For example, an intake worker yelled at and humiliated a mother in the public waiting room of the agency because the mother put her name on the wrong line of the intake form. The mother was devastated. Luckily, the support worker was there to intervene and advocate.*

Polly: I see that too and I think unfortunately some parents do as you said; they just learn to be quiet and not ask the questions and not make waves. There is another group, who instead are angry. And neither of them then are able to use skills to get what it is that they need and want. If they don't ask or if they ask in a way that's not polite, you often don't get what you want.

I think that part of the problem with professionals is a lack of understanding. I think we are very quick to jump to the conclusion that if people don't do something we use that terrible word we use in human services, "non-compliant". We make the assumption they don't want to do it rather than they are unable to do it, or don't understand what it is you want them to do. But I think some of that also comes from our own ineptness and our own discomfort. I think when professionals don't know what to do, we are very rarely willing to turn the blame on ourselves. So we are much more likely to say it's the person we are trying to help.

Dolores: *…it's your problem, it's not me.*

Polly: Exactly, and I've found that one of the best things about the supported parenting movement in Wisconsin is that we have been able to sensitize, I think, a fairly significant group of professionals to what these parents are about, what they need, why they do or don't do what it is that we need from them. I think once people understand, it's a rare individual who is not willing to at least give it a try. There are some people who we are not going to be able to educate, or to teach them how to be sensitive to other people's needs. But there's a large group of people that I think would do better if they only knew how. That's why many of us in Wisconsin spend a significant amount of time trying to teach people how to work better with families.

I think when professionals don't know what to do, we are very rarely willing to turn the blame on ourselves. So we are much more likely to say it's the person we are trying to help.

Dolores: *That is what I have found as coordinator of the Supported Parenting Project. People are constantly calling me because they are working with a family headed by a parent with cognitive disabilities that they think needs additional assistance. Sometimes the professional or support worker isn't sure what to do and they want to help the family in the best way possible.*

Polly: Yes, I agree.

Learning Style

Dolores: *I have found that many of the parents have difficulty reading, telling time, keeping appointments, filling out forms and other things most parents must do all the time in our daily lives. Let's talk a little bit about the parents' special learning needs.*

Polly: Yes, I think that if we're going to be able to design services that will address those needs, then we do have to spend some time thinking about what those need are and what kind of barriers those needs create. When parents are trying to get services for themselves and for their children and trying to get through a day of normal daily living it's difficult. Try to get through one day without reading anything. Try to assemble something that comes with one part missing and see how frustrated you are and how long it takes you to do it. What I try to remind myself when I find myself in one of those positions where I'm very frustrated trying to complete a task. I try to think to myself, this is what it's like for them everyday, everything that they do. So I think we have to look at ways that can address these needs.

There's a person in the supported parenting movement named Mark Sweet who has done a lot of work around how people learn, not just parents with disabilities, but how everyone learns. One of the best pieces of advice that I've picked up from Mark is to ask people what helps. When you need to learn something what would help you. And I think the other side of that coin is to say to people when they are not doing what it is they need to do is ask them why, and to ask the questions that will get at the why. So that if they're not making it to doctor's appointments to find out why. Is it because, you can't remember the appointment, you don't have a calendar, you can't use the phone, you don't know what they wrote on the card the last time, or you can't read it. Then figure out what it is that we need to do in order to eliminate that barrier.

I think some of the services we offer to parents are services that all of us need and want. The difference is we have people in our lives who will step in and fill that need and many of the families that we see don't.

It is difficult to teach about supported parenting because there is not just a set of rules that you abide by. You need to individualize the service to each parent, to their own situation, and to their own learning style. But I think, in general, we have to recognize there are certain cognitive processes that if you have a learning disability are going to be a challenge and we need to just routinely address some of those. First of all, you don't give instructions in writing if someone can't read.

Dolores: *Yet written instructions are given all the time when you go to the doctor or any agency. For example, I know if I take my sick child in to the clinic the nurse or doctor will give me a lot of information. I also know I need to write some of things down so I will not forget anything later when I'm at home. Sometimes I'm also given written instructions that can be confusing or does not answer all of my questions. Then I think of someone who is in there with her child and cannot write down all of those important things being said or is given the written instructions and then goes home and may be told "when these things happen call us."*

Polly: What we find works very well is to suggest to the parents to take someone with them. It can be a professional who's working with you but it doesn't have to be someone who's paid to be there. But take someone with you. I have a friend who has cancer and every time she goes to the doctor she hears news that she doesn't want to hear sometimes and is so emotionally involved in what he's saying that intellectually she isn't always able to soak it all in. She has a friend who goes with her to every appointment. Her friend's job is to write down what he says and to help her remember what it was that she wanted to ask. And then to help her to remember afterwards what it was that the doctor wanted her to do.

I think some of the services we offer to parents are services that all of us need and want. The difference is we have people in our lives who will step in and fill that need and many of the families that we see don't. So unless there is someone who is either paid to be there or someone paid to be there has helped them to identify an unpaid person to be there then they are not going to be able to function to their full capacity without those kinds of supports. I'm not so sure that those supports are always so different from what many other people in our community need who don't have disabilities. The difference is if you have a disability you're much less likely to be able to get it for yourself.

I think that appointment keeping is really important because it's one of the things that gets parents in trouble. If you don't show up for your appointment with Human Services, you could lose your children. If you don't show up for your appointment with the person who is giving you your food stamps, you'll lose your benefits. If you don't show up for a couple of doctor appointments in a row that clinic will no longer see you. So they lose very basic, significant, necessary kinds of things. This is all due to their difficulty with this one skill. It's rare to find anyone in the general public who if a patient doesn't show up for an appointment will say to themselves, "I wonder if she knew when it was? I wonder if she knew how to get here? I wonder if she understood what it was when she left the office last time that we were expecting?" You don't find someone in the food stamp office who will call a recipient and say, "Did you realize you had an appointment at 2:00 today?" But sometimes that's all it takes or to call the day before and say you have an appointment tomorrow at 2:00. We found if you do those very small things for parents often their functioning improves immeasurably by something as simple as a phone call to remind them.

Lack of Phone and Transportation

Dolores: *Yes, phone calls to remind parents can be very helpful. But for many of the families living in poverty there are added difficulties because they may not have a telephone or transportation. So, because of that, they may have to go out and wait for a bus and will probably have to transfer because that appointment is across town in a different neighborhood. I know if I have a doctor's appointment they usually call me a day or two ahead to remind me. But, if I don't have a telephone how can I be reminded of that appointment and how can I call to say I'm going to be late if a bus doesn't come or there is a snow storm?*

Polly: I think you have identified the real barriers to families getting services. I'm always amazed with the transportation. People will say to me, "Can't you just tell them to get the bus." And I think when you tell someone to get the bus to an appointment you're making many assumptions that we probably have no right to be making. We are assuming that they know how to read a bus schedule. We are assuming that they know how to plan activities and time so that they know if I'm taking both my children to the doctor and the bus is coming at five after two, what time do I have to get my children up from their nap and get them dressed and how long will it take me to get from my front door to the bus stop. It also assumes you can figure out if the fare is 75 cents each way for me and 50 cents for my children, how much money will I need for both ways. Because most of the time on the bus now you need to have exact change. It assumes you know how to make a transfer and you'll know which stop to get off in order to go to the doctor. And then it assumes that you can turn around and do all of that backwards to get back home. And I think that's an enormous number of assumptions that we make.

We work on things like taking the bus route with people. But frankly, if you live in Wisconsin where we live and it's the middle of winter and you have sick children, you don't see very many people waiting for the bus to go to the pediatrician. If my car breaks down and I don't have a way to get to the doctor, I have at least a half dozen people I can call who will give me a ride or I have the financial means to call a cab. I do have a phone and I would have enough money to pay for a cab in an emergency.

I think we have to recognize how often the difference between whether or not children get health care is whether or not their parent has a ride. If our goal is really to make sure children have appropriate care then we have to make the commitment to making sure their parents have a way to get them there. The difference in whether or not people get a service is very often whether or not they have a ride. We solved that by simply taking them. I've had a number of people say to me, "Don't you worry about liability having these people in your car." But frankly, you're much more likely to sue me if I have an accident with you in my car than they would. I look upon it in the same way. If we leave today and you are out in the parking lot and you have a flat tire, I'm not going to say to you, nor would anyone expect me to say to you, "I'm sorry Dolores I can't give you a ride to the garage because you might sue me if I get in an accident along the way."

I think we don't extend those everyday normal courtesies and kindness to these families that we would to each other and they are in far greater need of it than you are. You would find a ride if I didn't get you one there, but they're unlikely to. I think that spills over into a number of things.

Managing Money

Dolores: *Let's talk about budgeting and managing money.*

Polly: I think one of the things that sometimes gets parents in a lot of trouble with people who are paid to work with them is how poorly they manage money. The first thing we have to recognize is they don't have very much money to manage.

Dolores: *Exactly. The average person manages money poorly, but many have enough that they can play with their budget a little if they are short a little one month and can make it up in another. But when you only have the very basics, very minimum finances to work with, it is hard, if not impossible, to make it up in another month.*

Polly: When I first started working with these families we sat down and started working out budgets and after the first two or three I found myself saying well, you just don't have enough. These are your basic expenses and this is your basic income and there is this huge discrepancy between the two of them. So it was discouraging for me to try to figure out how we were going to get them out of this financial hole. I can't imagine what it would be like for them to sit down and see that. And actually they really don't even see it in black and white. What they understand is that three weeks into the month, they have no money left and there's another week before they are going to get any money. Or what they may not understand is that they have not had enough to eat or they have not had what they needed for two weeks and now they got a check today. Why shouldn't they just go out and buy all the food they need for this week? Why should they have to plan to deprive themselves again later in the month?

I think as a society we need to decide if we're going to commit to making sure that every child has the basics. That every child has a roof over her/his head and has three meals a day and has appropriate clothing to wear, and that the families are going to have the resources to be able to provide that. I do think they don't always budget well, but frankly there's no one in my house that does either and people still like us even though we don't always manage our money well. But I think it's one of those things that cause people to really have some very negative feelings about them.

For some reason we don't want to allow people who are poor or people who have disabilities to make those same kind of choices that we make.

When you see some of the choices the parents make, it's hard for people to understand. If you don't have enough food why do you have a VCR? What people fail to recognize is that these families don't read books, they don't take vacations, they don't go to the movies, they have no disposable income for recreation. So the VCR is it. That's pretty much their escape. That's the only means of entertainment or amusement that either they or their children have. And then I look at my own life as well, I can't tell you how many times I've bought a dress because it made me look 10 pounds thinner even though I couldn't afford it. I think we all make these kinds of choices.

Dolores: *I think of how often we go to the store and see a piece of chocolate or cheesecake and just buy it.*

Polly: Exactly, if I'm having a bad day and I have to make a choice between an apple and a chocolate candy bar, three guesses which one I am going to pick. For some reason we don't want to allow people who are poor or people who have disabilities to make those same kind of choices that we make. And frankly living the lives they lead, they need that piece of chocolate far more than either you or I. And they need whatever that is that made them feel a little better about themselves that day, much more than you or I do.

Living in Poverty

Dolores: *Can we talk a little bit more about how most of the families are living in poverty?*

Polly: Well, I'm always amazed when we say to people you need to pull yourself up by your bootstraps. If you don't have any boots and you don't know how to pull yourself up by the straps if you did have them, then what we're asking is totally unrealistic. Most of the families I work with, I am finding, have similar needs. Incidentally, the families I am working with in my current position don't have disabilities but also live in poverty. They have not had lives that prepare them to work, to manage their daily lives, or to manage those two things together. It's also difficult to understand how to manage a home and a family and also to manage a job and all the responsibilities that come with that.

The kinds of jobs the parents usually get are jobs that are difficult to fill by other people, for example, working in fast food. And if you have even a basic knowledge about persons with cognitive disabilities, you recognize that just the word "fast" is a problem right there. They do best when they can do work that is a little more methodical. That's more predictable. That has more repetition. And they certainly don't do it in a hurry and often become less competent in a situation where they are pressured to work quickly.

We put them in situations where they are least likely to succeed, and then we expect them to stick with that whether or not it's going well. I think we don't often recognize how much the right job can do for a person's self-esteem. For not just the financial rewards that come from having a job, but the sense of accomplishment and normalcy that comes from being able to go into the workplace every day and do something that is meaningful and to be compensated for it. We don't tend to put them in those kinds of situations. We tend to offer them the jobs that the rest of us don't want. And then to be angry when they don't like it or don't succeed.

I think we also often don't recognize how close to the edge they live. If they do have a car and their car breaks down, they don't get to work that day. And that most of the kinds of jobs they're in, if they don't get to work that day, there is no job waiting for them the next day. If I have car trouble and I call my boss and say I'm going to be a little bit late today, my car broke down, she would be very unlikely to say to me, "if you can't get here on time then don't bother to come ever again." But the parents hear that frequently. The assumption is always made that if they are absent or they are late that it was intentional. That it was irresponsibility. Many families live so close to the edge that a variety of factors mean they can't get to work. These include situations like a radiator hose blowing on the way home, not having the money for your bus fare that morning, not having an alarm clock to wake you up, not having any backup what-so-ever if you wake up and you have a sick child, or your babysitter calls and says I'm not making it. It's often again not their disability that's the primary barrier to them working, but it's their life circumstances and their lack of experience and anything similar to having to be in the kind of routine that it takes to get to work every day.

Many families live so close to the edge that a variety of factors mean they can't get to work. These include situations like a radiator hose blowing on the way home, not having the money for your bus fare that morning, not having an alarm clock to wake you up, not having any backup what-so-ever if you wake up and you have a sick child, or your babysitter calls and says I'm not making it.

Dolores: *I think that's one of the values I see with supported parenting. What I've seen over the years is that we've been able to work with those families on the edge to help them to get to a point where they can manage many of the things that they couldn't manage in the past. Would you agree?*

Polly: Absolutely, and I think the difference is saying to them, "what would you like to do?" We've had experience with a mother who for years had been working in a sheltered workshop and when she got pregnant she was referred to me because of her pregnancy. One of the things that her case manager said to me was, "Her work history is terrible. She is not at all responsible about getting to work so we are very worried about what kind of parent she is going to be."

As it turned out, when I got the woman's occupational evaluations and a psychological evaluations from when she was in high school, I found that she had repeatedly said that what she really wanted to do was work with children. But instead she was making hammocks. We found her a job working in a day care and she was so successful there that we had a difficult time convincing the day care teacher that she did indeed have a cognitive disability and couldn't read, so please don't give her these things in writing.

The teacher kept insisting that there was nothing wrong with the way she learns and she did as well as anybody else in her classroom. And it was true. When she was put in a job that utilized her skills, her natural inclinations and what she most desired to do, she performed beautifully and her attendance was great. Of course, those same skills were what made her a wonderful parent. She is very successfully raising a child who is now eight years old. She is also working in the community in a regular work setting. I don't think there is anyone around her who suspects that she has any kind of learning difficulties.

Dolores: *Which I think goes back to the key with working with families, too, is that we're looking at the strengths and trying to build on them, rather than looking at a weakness and saying, "this can't be, this can't work, it won't happen." It all goes back to our philosophy on how we see things. Whether we believe it can happen or it can't. And what we are willing to put in to make sure that we look at the strengths and continue to look and build on those strengths for families.*

Polly: Absolutely. I was always struck by the fact that no one had said to her, "Why don't you get to work? Why are you absent so much, why are you late so many times? Do you like this job? Is there a problem why you are not getting here?" Instead the response was, "You realize you've missed three days this month and if you miss one more you'll be sanctioned." I love that word too. It basically means you'll be punished.

Consistency and Reliability

Dolores: *Again, another punishment. I'd like to talk now about how supported parenting services have helped families. Can we talk about some of the changes we've seen in children and parents?*

Polly: I think the biggest thing that has helped the families that I have worked with over the years is having someone who's consistent and reliable. It's also important to have someone who believes in them and can help them to believe in themselves. I think when families have that then you will see many changes happening in them. The biggest is in self-esteem. I honestly feel if you could raise self-esteem of both the parents and children, 90% of our work would be done. Because I think it's that lack of confidence and belief in themselves and in their own capabilities and belief in their own future that is often what hinders them from making progress.

Specifically what we see in parents is a change in affect. What you often hear when these mothers in particular are referred to us is, "it's like there's no one in there. They don't smile, they look the same all the time. There's this flat look about them." This is true even about things as practical as what they're wearing.

We take a lot of photographs of the families and we've noticed as time goes on there are changes in their appearance. In the initial photographs they are wearing very dark, dull, bland kinds of colors and their hair isn't done. It happens so gradually, you are not even aware of it until you look at pictures over a period of time. Then you begin to notice they're wearing colors, that there's variety, they smile more, and sometimes they'll have a new haircut. We see a huge difference in the health of their children. We find when you remove those barriers it's a rare parent who is not willing to get well-child care as well as prompt care for sick children. The children are immunized.

Developmentally, we see huge gains in the children when we provide their parents with the tools and skills and activities to stimulate appropriate growth and development. We also find the public deals differently with these families after we've worked with them for awhile. I think it comes from the parents learning how to handle themselves more appropriately in public, how to work the system, and how to get what they need. It also comes from the community seeing these families in a different light. Believing in them often causes other people to believe in them.

Having someone to explain the reasons why things don't always get done or why things don't get done in the way the world expects, causes some change in sensitivity. When you treat people better, you get more from them. The more other people treat them better, the better they function. We give people the tools. You know you would never say to a carpenter go build a house and leave your toolbox in the truck. That is often what we do with families. We say make yourselves strong and whole and capable, but do it without any of the tools that you need to do it with.

Dolores: *Yes, so often many people are not willing to give them the tools or to take the time to show them how to use them.*

Polly: Giving them the toolbox won't help unless you help them learn what to do with what's in there. When you give them a better life they often become better parents. If you're worried about whether you're going to be able to pay the rent or you're going to get beaten up today, or if you're worried about just getting through the day, then it's unlikely you're going to be a capable, nurturing parent.

Times Have Changed

Dolores: *You've been working with families in supported parenting for quite a few years. Do you think things have changed for families?*

Polly: I think they've changed several times during the time I have been doing this. I think it's harder for all families to raise children these days. What I found when I first started doing this work was benign neglect of parents with disabilities. No one was doing very much for them. People had very little understanding of who they were even though they had always been there. They've not always been labeled. They've not always been understood. People just sort of let them be.

I think as a result of things like the supported parenting movement in Wisconsin and in other places, people did become more aware. There were good, kind, well-meaning, intelligent people who said, "oh, this is who you are talking about. I know those families, I didn't recognize that was why they weren't functioning well." And I think some of those people made enormous changes in their own thinking and in their allocation of resources. For a period of about 5-6 years things were very good and supported parenting programs were springing up all over the country. I found the request for me to come talk to people were coming from places far from Wisconsin. It was clear there was something in general that was looking more positive for vulnerable families.

What I've seen in the last couple of years is that the pendulum has swung farther back than it was when we started. We're leaner and meaner as a society. I think communities are closing ranks. People who are rich basically don't understand what the needs are. I think the middle class is too busy covering their own backs and the poor have been put in a position where they compete with each other rather than share with each other. Everybody is losing in this situation. The attitude that all of us need to do it on our own, and we don't need to support anybody is going to cost us all dearly in both financial and human terms.

Dolores: *I think back when I was a child growing up and how things were. If you needed assistance with something, your mom was sick, there was an uncle, a grandmother, the neighbor down the street, or a woman from the church able to step in to help you at the points you needed. I guess I don't see that so much today. People are moving more and are more isolated. The idea is that I should be able to do everything myself.*

Polly: I think we have lost a sense of community. And we are all going to suffer for that. I don't think we feel responsibility toward each other anymore.

Dolores: *And some of the supports that we all need at certain moments in our life don't seem to be there anymore.*

Polly: This is why the support offered to parents with cognitive limitations is so important. By providing community supports we have been able to show that the parents are better able to provide for their children and the children are happier and healthier.

Dolores Ullmer Liamba, CISW, has been involved with planning and evaluating supported parenting in Wisconsin since 1989. She grew up in a community where she knew several families headed by parents with cognitive disabilities who raised their children with the help of natural support systems of family, friends, and neighbors.

(608) 233-1331 Fax: 233-1636

E-mail: lolaliamba@hotmail.com

Moms’ Day Out

by Dolores Ullmer Liamba

Chuck Warner of "Contact" Radio in St. Louis, Missouri came to Wisconsin in June, 1998, to interview a group of six mothers with cognitive disabilities about their views of "Moms’ Day Out". The following are excerpts from his conversation with them. The radio program aired on stations throughout the United States on September 20, 1998. Polly Snodgrass introduces this article. She began the first "Mom’s Day Out" group in Green Bay, Wisconsin in 1985.

In the following discussion the moms talked about their involvement with the support group and discussed some of their experiences of living in the community with a disability. They talked with Chuck Warner, Dolores Liamba from the Supported Parenting Project at the University of Wisconsin-Madison, Netty Diaz who coordinates the Supportive Parenting Program in Rock County, and Mary Kay Blint and Kay DeuPree of the University of Wisconsin-Extension. They will be referred to as the “Interviewer” when asking questions in the following discussion. The names of the mothers have been changed to protect their privacy.

Introduction

Interviewer: *How did "Moms’ Day Out" get started in Wisconsin?*

Polly: Well, like all good ideas in supported parenting, it came from the parents themselves. They have taught us everything we need to know about what they need and how they function best and what would help the most. When I first started working with families, what struck me was how little they had in the way of ordinary life experience such as I had with my family, both when I grew up and as I raised my own children. They never got to do the ordinary things. Parents never had a break from their children. There weren’t the coffee clutches that were in my neighborhood, where moms sat around and talked and laughed and complained. And when you went home you realized every 2-year-old was just as obnoxious as yours and it had nothing to do with your parenting. There was someone there who had a 4-year-old who could reassure you that they won’t stay like this forever, they’ll turn into nice people again.

For the moms I was working with I found there wasn’t anybody to call when they were having a bad day. I took somebody out to lunch one day and she was so excited. I said, "it must have been a long time since you’ve been out to lunch." She said, "I’ve never been out to lunch." There were children who had never been to the library. There were families who’d never been to a museum. We started talking about what the moms would like to do for fun if they had an opportunity. We started to plan some family activities. What we found was that the mothers had a real need to have some time to spend as an adult woman with other adult women. So what they told us was that the dads get to go places all the time. They go hunting, they go fishing, they go to bars, they go bowling. They said, "We’re always stuck home with the kids."

Initially we only had "Moms’ Day Out" four times a year. They just wouldn’t hear of that. We made it once a month. Some programs meet once a week. Sometimes you don’t have to have everybody together, but you can have a number of small groups that meet. So "Moms’ Day Out" or "Moms’ Night Out" became an opportunity for them to get together, to learn together, to play together, to do nothing together and to make some friendships. It gave the moms an opportunity to get out of the house and to get away from their children for a little while. They had someone who would focus on them as a person, not just as a parent. Some programs that have groups focus on parenting skills. Others are for fun, just social time. I think they're essential. I think it is child-abuse prevention at its best. I can't imagine if I'd been stuck in the house with my children 24 hours a day and 7 days a week. There were days that I was close to the edge. But I had an outlet.

Planning Activities

Interviewer: *How do you plan the activities for the parents?*

Polly: We learned the hard way. We were told that parents won't show up for parenting classes. The obvious question seemed to be, "why didn't you come?" "You didn't come to the last event, why?"

The very first event that we planned we had a lot of children who were sick that winter. Everybody had an ear-infection, everybody had a cold. Parents would call and say my child is very sick and you'd get there and the child wasn't very sick, but parents didn't have the skills to sort out whether this was a serious problem. We decided we would have an evening with a public health nurse, a pediatrician and an ear specialist who would come and talk to parents about how to tell when their child is ill. We had 3 people sign up. We changed it to a Bingo-taco party and we had 38 people show up for it. We decided to have a Bingo-taco party and for 15 minutes a doctor would answer questions. We found that when we designed our events around what parents really wanted the problem certainly wasn't getting them there. The problem was being able to plan them often enough to meet their needs and desires. They would've come every week had we been able to get it together.

We found that when we designed our events around what parents really wanted the problem certainly wasn't getting them there. The problem was being able to plan them often enough to meet their needs and desires.

Interviewer: *What are some of the activities or topics for a "Moms' Day Out?" I know the program in Rock County focuses a lot on helping the moms learn some new skills about proper nutrition, food buying, and food preparation.*

Polly: I think that's a really smart approach to teach nutrition. When I first started I would find myself sitting on the sofa talking about the basic-4 food groups. Both they and I were falling asleep because it's a little dry. If you can get together as a group and go to the Farmer's Market or if you can plan and prepare and then share a meal together, that's a much more effective way to teach nutrition.

There are so many other things that are learned in that same setting when you're budgeting for food, you're also learning how to handle money for other things as well. When you share a meal or discussion about nutrition, you also share the social skills and just the good feeling about it. I think there needs to be recognition that eating together is about more than just eating food, it's about more than just nourishing your body. In our society most celebrations involve food. When people who like each other come together they do it just for the joy of being together and there is always food there. I think the idea that we would combine nutrition education and food and the "Moms' Night Out" concept is a wonderful idea.

There are many topics about nutrition that affect behavioral change. Nutrition isn't just about acquiring knowledge. It usually involves making some major changes in behavior as well. We all know what we are supposed to do to maintain appropriate weight. But, if we all did it, if it was that simple, just having the knowledge, there wouldn't be anybody overweight. We have to find ways to motivate as well as teach, to make the behavioral changes doable and desirable and to give the people support in order to do it.

The "Moms' Day Out" that focuses on nutrition is not all that different from the Weight Watchers concept where people gather and support each other and talk about good food and share good food. They then share it with their children and it helps parents understand how important basic nutrition is to their children. We tell mothers about some of the new brain research about how children learn. We show parents that what you feed to children and what you say to them and how you touch them makes the difference in learning when they're older.

Community Activities

Interviewer: *What are some of the activities that are planned in the community? Some mothers have talked about how they did some things that they had never done before. They mentioned that they didn't feel comfortable doing many things in the past because of the way others in the community had treated them or their children.*

Polly: We found that concept especially true in the schools when teachers would say they don't come for parent-teacher conferences. We would discuss how they felt when they came and they didn't look like the middle-class mothers. They weren't always welcomed. What they heard were all the problems with their children - not that the teachers were happy to see them because they have such a wonderful little children so they were really anxious to see what kind of a great parents they must have. Now I think if you say that to parents they'll come back the next time.

We did the same thing with the library story time. We started out with having a very good children's librarian who had a story-time just for our parents. When they got comfortable with that they started coming to all the story times. You have to start off in baby-steps, a place where you absolutely know they will succeed and be welcome. Then you can generalize that to many other things.

A Discussion with the Moms

Many supported parenting programs throughout the country offer support groups for parents. Some are offered for couples, some for mothers and their children, and others like this one in Rock County are for moms only.

Dorothy: There are things you can't talk about with somebody who hasn't been there. A lot of us have lost our children in one way or another. We can talk to somebody about it. Talking to people who haven't had that experience, they say, "we know how you feel," but they really don't. One way or another we've all been there somehow. That's why we can all get along so well, and that's why we can be so supportive.

Darcy came to the house and she asked how we'd like to get together with different women and do things together. I was all for it. It started out slow and then it got bigger. We go places or we do cooking.

Activities have included a trip to the zoo in another city, touring the Rotary Garden to see spring flowers, taking a sleigh ride to celebrate the holidays, and hosting a Mother's Day Luncheon.

Teresa: [At the Mother's Day luncheon last month,] we had ham and asparagus rolls with cheese on it. We had chicken, some kind of cheese cake with strawberries on top.

Interviewer: *Would you talk about your first time coming to Mom's Day Out?*

Nancy: The first time I came I was a little shy, cause I didn't know anybody. After I settled down and got to know the other people I started to open up more and talk more than I used to. I used to keep my feelings inside of me and they'd just keep building up.

Judy: For the first time I saw all these people and I just kind of looked at them and I instantly felt like I was going to cry. I didn't want any part of it because I knew I was going to be put on this hot seat and I was going to have to talk about what was going on with me and my life. I thought, no, no, this ain't me. But later on I found out that it wasn't that way at all. It was just something that I built up, and now I'm even getting more involved. I'm not scared to talk out. Before you couldn't get me to talk out. I'd back off. But now I'm getting to the point where I'm even willing to talk to you, Chuck.

Interviewer: *Can you tell about January when you decide about activities for the year?*

Dorothy: We sit down and plan our outings. We sit down and discuss it among ourselves and then tell Netty what we want to do. It's not they tell us, we tell them. It isn't that she throws out suggestions. We talk about it and we tell her if it's something we want to do.

Netty: Basically all I do is act as a facilitator. I get on the phone and see what they have available and what the costs are, then I let the moms know. I do the background piece of it. I do a mailing a month before the activity so they can tell me if they need transport or child care, and if they are going to be able to come. That way it also gives them a chance to plan if they have an employer. Everyone has been wonderful about making "Moms' Day" happen. We're improving it. I think it does help greatly with self-esteem.

Dorothy: We don't bring our kids to group or do anything with our kids because some moms don't have their kids with them and we don't want them to feel bad about it. If I was to bring my kids and someone else couldn't, they might feel bad about it. That isn't what it's for.

Interviewer: *Is there ever disagreement about an activity? What's that like?*

Dorothy: We vote on it. There were some of us that didn't want to go bowling. But we voted on it and bowling won.

Margaret: [Mary Kay signed and spoke for Margaret, who is deaf.]

Margaret says it's helped her at home. She has Heather who is 13 now. Sometimes it's hard to be in a group and being deaf, just a little bit, Margaret reads lips.

Dorothy: And that's why we're trying to learn sign language so we can communicate too.

Nancy: Well, we talked about it in the van this morning. We talked about learning sign language and that way she can understand us.

The first Moms' Day Out event was a holiday party.

Teresa: First one was at my house for Christmas.

Dorothy: We sat down and discussed it. We had a little party. We made our own dinner, cakes and sandwiches, and the ham and casserole.

Most parents with cognitive disabilities live on very limited incomes, often lacking the money to buy small things like a child's birthday cake. Cooking classes and other practical activities are very well attended.

Mary Kay: A lot of time when you go and buy a cake they can be very expensive. That was the purpose of that event. We made the cake from scratch. How can you make cakes for your children without having to spend a fortune?

Dorothy: We learned how to make cakes out of dolls. We made a cake and put a Barbie in it for a little girl's birthday cake. You go buy a Barbie doll. The angel food cake is the doll's dress. You put flowers on it and you decorate it. It was a lot of fun.

Mary Kay: Remember the dirt cake?

Teresa: Yeah, I remember that one. We put chocolate chips, vanilla stuff. pudding, Oreo cookies, gummi worms. I have a recipe at home called coffee-cake. It has coffee and mayonnaise in it.

One month the moms decided to go line-dancing at a local community center.

Netty: Melinda, you enjoyed that, and so did Judy.

Judy: Line-dancing is fun. It's a lot easier than doing some of the other dances you've seen because all you have to do is keep in a line. It's thrilling. It lifts you up, and not just because it's country and western. Somehow it's got a way of filling you so you don't feel so down and out. You don't feel left out.

Mary Kay: Margaret just said sometimes she will do it in her home, from the TV, and that's good exercise. They're also starting to put the line dancing on video tapes.

Interviewer: *How many were there?*

Mary Kay: We had 15. The community center here in Beloit has a nice wood floor. There was someone who volunteered. He brought the music and his boots and his hat.

Nancy: Our next is going to be touring our neighborhood Angel Museum in Beloit.

Dorothy: Oprah from the talk show donated her angels that she got from people when she said she'd never seen a black angel. So all these people were sending her black angels. She happened to donate some of them to Beloit. So they built a museum especially for it. Well it was a church and they just redid it. So we're kind of excited to go see them.

The event called "Pamper Yourself," was a day at the cosmetology school's beauty salon. This was a new experience for most of the women.

Netty: When we got there I think a lot of us thought "Oh no, what's going to happen to us at this place. Then, as we spend the day with the cosmetologists and the hairdressers, there were relationships that were built. It ended with everyone having lunch together with the staff at the salon. Remember trying to decide how to get your hair cut, Nancy? How did you feel after that experience?

Nancy: A little nervous.

Netty: How about afterwards?

Nancy: The person who did my hair did a really good job. I thanked her. We just had a really wonderful time. Seeing how these girls get tested for doing these different hairstyles.

Mary Kay: It was a new experience for them too because they were students at this cosmetology school. They didn't know what to expect as well as we didn't know what to expect.

Melinda: She [the girl who did my hair] said that was her very first time.

Interviewer: *So everybody was scared, on both sides. Did you get talking about other situations where you have to trust people? I'm thinking that's something you all deal with a lot.*

Judy: I know I deal with it a lot every day. I put up this barrier. I don't want to get too close. I feel uncomfortable. But yet since I started hanging with these women in this room that wall is starting to come down. They said you've got to learn how to trust. I said it's hard. When you grow up around an alcoholic family, that's been abusive to one another, you shy off from everything. And that's the way things are for me. So today, I'm even starting to reach out and go back to school. So this is a positive program!

> *I put up this barrier. I don't want to get too close. I feel uncomfortable. But yet since I started hanging with these women in this room that wall's starting to come down. They said you've got to learn how to trust.*

The majority of families headed by parents with cognitive disabilities in the United States live below the poverty level. They struggle to provide the basic necessities for their children. For one monthly activity, the group prepared a food budget.

Dorothy: We were preparing how much we were allowed for food and how long it was going to last. We went to one store and wrote down prices. We didn't compare stores. We were comparing how much [money] we had for food.

Mary Kay: We were using the thrifty food plan from the USDA. The USDA has a plan where they say for X amount of dollars a family of two, four, six, whatever, should be able to get by.

Dorothy: And we found it wasn't going to work.

Interviewer: *How didn't that work?*

Dorothy: The amount that they were allowing us to have and the quantity of the food was not enough to last us for the month. …not just the prices of the food, but let's say, how many glasses of juice would be in here and then times that for the month, how many glasses of juice can you have for the month to eat nutritionally. We were trying to eat nutritionally, but you couldn't do it, there's just no way you could do it.

Mary Kay: Margaret says it is very hard for her to get through the month with enough food to eat for her and her daughter.

Dorothy: I think that's a problem for a lot of us trying to get through the month. In fact you even take from one bill just to get groceries. Let's say you didn't pay the light bill this month because you need groceries. Well, OK, but you didn't pay it last month. Then they're going to shut your lights off.

Melinda: You know what they got in Rock County now, if you lose your power and lights you cannot get no help from Section 8 [housing].

Dorothy: And that's nothing, if you lose your lights they're going to take your kids.

Polly: When I first started working on budgets and after the first two or three I found myself saying, "Well, you just don't have enough. These are your basic expenses and this is your basic income and there is this huge discrepancy between them." So it was discouraging for me to try to figure out how to guide them out of this financial hole. I can't imagine what it was like for them. And they really don't see it in black and white. What they see is three weeks into the month, there's no money left and there's another week left before I get any money. We have to sometimes help them get to food pantries.

Interviewer: *Is there a phone-tree?*

Dorothy: We're trying to get that going. But a lot of moms don't have phones. So that's why we're trying to see if we can meet more than once a month.

Teresa: I don't have a phone number.

Dorothy: So the only time we see each other is when we're here.

Limitations in public services like transportation often make life more isolating for the moms.

Kay: I think one of the things happening here is how do you get around, how you get places.

Nancy: Mainly every place I go I walk. I use my two feet. When you're raised on a farm you have no transportation. You use your feet. I love using my feet. I leave at 5:12a.m. and I start school at 8:00. That's a long distance to walk. It takes me over two hours to walk to Blackhawk Tech.

Netty: Who wants to talk about waiting two hours for a bus.

Nancy: There's two hours waiting for a bus.

Dorothy: …or a cab will take 2-3 hours, you have to call way in advance.

Melinda: .... and now days it's not worth taking if you want to get somewhere. If you think which way is quicker. Nowadays for the price of a cab you are better taking a bus.

Dorothy: But it depends how close the bus will take you to where you're going, because with a little kid you just can't walk too far.

Initially, the women came to "Moms' Day Out" to participate in some of the activities. Over time, many came to value the chance to talk with the other women about issues and problems they were facing. An important part of the support group is being able to talk to others who understand these difficulties.

Interviewer: *How do your children and your children's friends respond to your disabilities?*

Dorothy: I don't think that's really an issue in my experience. Their friends come over and play and never made a big issue out of it that I know of, unless they said something to my kids and my kids just never said nothing to me about it.

Judy: With me and my son it's gotten to the point when he was at home with me... he would bring his school friends over. They would start playing and they kind of look at me funny and they started whispering to my son and the next thing I know he's on the floor fighting. I said, "What's going on?" He says, "Well mom, they say you're stupid and dumb." I say, "Let them say what they want." I say, "I'm not going to let it bother me." I say "Let it go. They're even younger than you are. Their parents are in the wrong for teaching their kids about handicapped people like that." I say to the kids, "If you can't get along with my son then you need to go home and not come back." And right now he's having that problem because he's just found out he has a learning disability. It's a struggle for him.

Dorothy: Kids can be mean to other kids, especially at schools. When they find out you're in a learning disability class then they make fun of you.

Nancy: There's even a waitress up the restaurant. She has a grandson who has a learning disability. She says the other kids are so mean, and here he's is only 5 years old. They're pushing on him, pulling on him, beating him up and calling him retard and everything else. He's not a retard. It's just the simple fact he has a learning disability, because his brain didn't function right.

Dorothy: That's like my twins... they are six, but yet they're like three [developmentally]. They're going to start regular school next year and I'm scared to death for them.

Interviewer: *Did you experience these things when you were growing up?*

Nancy: All the way up through high school I was in special education and I just hope my son doesn't have to end up being in special ed like I had to. It's sad, people called me names, talked behind my back.

Dorothy: I was slow all my life. I was put in special education in my 9th grade year. I suppose people talked about me behind my back, but nobody ever messed with me. I had too many sisters. I never experienced anything really bad in my school years.

Melinda: It was hard, they really did nag at you up there, in the school system. I mean, every time you walk in and out of the classroom, you got the kids in the regular grades, they're coming off, "look at that retard" and names like that you know. "Look at them, they're in special ed, ha ha, ha." Some of them will come up right to our face and call you that. It's tough.

Interviewer: *Did any adults stand up for you in those situations?*

Melinda: No. You stand and tell the teacher and they say just ignore them. They're not standing watching it, you know. You got to take a city bus back and forth, and you got them calling you names on the buses and stuff like that. You talk to the bus driver and they're not going to do anything. I had my mom switch me to a church school, I couldn't handle it any more.

Dorothy: I didn't have anyone call me names. I just never had any friends. I never got to go to any of the dances, or the games, or anything like that. I had my sisters.

Judy: I know what "loner" is. I've been there, all the way through school. When they started calling me names and I couldn't get the teachers to respond. I responded back in a hard way. Finally it got to the point I decided to drop out of school because I was hurting the kids literally. I thought that isn't the thing. I figured, well, if you're not going to listen to me and I'm hurting your kids, this ain't me. I got to leave.

Dorothy: I think that's where they get a lot of the "drop outs" because they felt that way. If you're going to call me names then I'm going to beat you up and then they're going to kick me out of school. Well, who wants to go back anyway? They're just going to make fun of me again. That's why I think they have so many "drop outs"

Interviewer: *Judy, talk about going back to school.*

Judy: Well, I was an alcoholic and violence was our main problem at home. Finally, I decided it's time for me to get straightened out... I decided it's time for me to go and get my treatment. I did that because I didn't want my son to see that kind of violence. And now I'm working hard in order to get him back home, to finish school, so I can support myself without being on any government aid. I'm going to keep doing it that way. I'm trying to stand on my own two feet, climb to the top of the mountain and say, "Hey I made it." I'm going for my GED, then job-training.

The support the women receive from each other helps the moms cope with living in the community and raising their children.

Dorothy: It's like we're all supportive of each other. If something during the month happens to somebody, we know that they're down, we've been there, we know what to look for. We try to bring them back up, cheer them up a little. If a crisis happens, you want to talk about it with your friends. A lot of us have become really close friends. But we only see each other once a month and it's hard.

Melinda: I've had a lot of help. I enjoy myself and it helps a lot. It gives me a break, a chance to meet other people.

Dorothy: These are the only friends we have and this is the only chance we can talk about our problems and we know it's just going to be among us. We talk and we know it isn't going to be written down on paper and put in a file. We don't get to see each other all the time, so it's a time to catch up.

Interviewer: *What's the one event you all hope never happens again? [laughter] Has their been one?*

Dorothy: I don't think so. I think the only one I hope never happens is we never have to say goodbye.

"Mom's Day Out" is sponsored by Developmental Disability Counseling in Beloit, Wisconsin. The coordinator of the support group is Netty Diaz.

(608) 365-8787 or FAX: (608) 365-1279

Chuck Warner has produced many programs for "Contact," a weekly radio program produced by the Sacred Heart Program. For more information call toll-free during regular weekday business hours at 1-888-7-CONTACT.

Dreams for Our Children

by Dolores Ullmer Liamba

At regional conferences for parents in Wisconsin we have facilitated a discussion about dreams. Parents were asked to write their dreams for their children and family on a piece of paper. Those parents that needed help with writing were assisted by a support worker. All dreams were then presented to the group. At some conferences a large wooden circle covered in yarn was used to attach the dreams to make a "dream wheel." A facilitator then read them all to the group. At one conference parents drew their hands on fabric and cut them out. They then wrote dreams on the hand. They were later sewn on fabric to make a "dream quilt."

Most of us have dreams for our families. It helps us to plan for the future. However, for many parents with disabilities this has been a luxury that few have had the time to think about. Few support workers have taken the time to discuss this with them. The presentation of dreams at the conferences has often been one of the first times many parents have had the opportunity to talk about their dreams with other parents. Just getting through a typical day has often been so difficult and frustrating that there has been little time left for dreaming. Here are some of the dreams that parents have expressed at their conferences.

Parents' Dreams

- *I want one day to get a job.*
- *I want my son to go to college some day.*
- *My dream would be to have my family off welfare.*
- *I want to buy a home.*
- *I want to raise happy and healthy children.*
- *I want that everyone could treat each other with respect.*
- *I want to get rid of crime in our neighborhood.*
- *My dream would be a safer world for children to grow up in.*
- *I want my children to be healthy and happy.*
- *I myself would like to get a good education, so that I could take care of my family.*
- *I want to become a good parent.*
- *I want a healthy happy baby and more peace in the world.*
- *I want to see my children finish school.*
- *I want to get married some day.*
- *My dream is that one day all my children and I will be together as a family and have a happy life together.*
- *I want to know that my daughter loves to read and learn.*
- *I want my son to be happy, healthy and can take care of himself.*
- *I wish that I could have a maid to help clean my house.*
- *I wish that my daughter would learn to read better.*

- *I want the future of my family to always be close and to never be far apart.*
- *I want my children to be healthy and safe.*
- *I would like to move to a different place.*
- *I wish my son to get better in his health and walk sooner than the doctors think.*
- *I would like a nice job, and make an honest good living.*
- *My dream is to have my daughter go through school and do really good.*
- *To keep my job.*
- *I wish that people in my family would understand each other and get along.*
- *To have a secure future.*
- *For myself to find happiness in life and have good friends.*
- *I wish for a better family life.*
- *To find a patient, caring, loving man to share my life and my family.*
- *To have a man that listens to me would help my dreams come true.*
- *I want my family to always be close and loving.*
- *I would like a job that I could do sitting down, and have child care provided.*
- *I would like to be able to drive.*
- *I hope my daughter always feels love so that she doesn't have to go elsewhere.*
- *I want my daughters to know how wonderful they are.*
- *I would like to see my daughter go to college.*
- *My dream is to have a better job.*
- *My dream is to be lucky in love.*
- *My dream is having a good position on my job.*
- *My dream is to get a lot of money.*
- *My dream is to move out of the city.*
- *I hope my children learn better in school than I did when I went.*
- *I would like to get my driver's license and get a car.*
- *My dream is to find a good man.*
- *My dream is for good health.*
- *Our dream is to get good jobs for us both.*
- *I dream to win the lottery.*
- *Like to be able to see my daughter get married and have a family.*
- *I wish I could have enough money to buy a house for my family.*
- *It would be nice not to have to depend on government money.*
- *My dream is to travel all over the world.*
- *I would like to own a house someday, and my daughter living with me.*
- *My dream is to get a new car.*
- *My dream is to be healthy and have healthy children.*
- *I wish my son had some friends to play with.*
- *My dream is for my children to move closer to home.*
- *My dream is to own a nice trailer.*
- *I hope to have my own house someday.*
- *I would like to be a teacher in the Birth-to-Three program where I live.*
- *My dream for me is to be happy and have a good future, and be the best parent I can be.*

Suggested Readings on Supporting Parents with Cognitive Disabilities

Accardo, P., & Whitman, B. (1990). Children of mentally retarded parents. American Journal of Diseases of Children, 144, 69-70.

Arcand, M. (1998). Family health care tool kit. Madison, WI; Wisconsin Council on Developmental Disabilities.

Booth, T., & Booth, W. (1994). Parenting under pressure. Philadelphia, PA: Open University Press.

Booth, T., & Booth, W. (1998). Growing up with parents who have learning difficulties. New York, NY: Routledge.

Booth, T., & Booth, W. (1998). Advocacy for parents with learning difficulties. Brighton: Pavilion Publishing Ltd.

Budd, K., & Greenspan, S. (1984). Mentally retarded mothers. In E. Blechman (Ed.), Behavior Modification with Women. New York, NY: Guilford Press.

Budd, K., & Greenspan, S. (1985). Parameters of successful and unsuccessful intervention for parents who are mentally retarded. Mental Retardation, 23(6), 269-73.

Dunst, C., Trivette, C., Deal, A., & Bell, P. (1988). Enabling and empowering families: principles and guidelines for practice. Cambridge, MA: Brookline Books.

Espe-Sherwindt, M., & Kerlin, S. (1990). Early intervention with parents with mental retardation: do we empower or impair? Infants and Young Children, 2, 21-8.

Espe-Sherwindt, M., & Crable, S. (1993). Parents with mental retardation: moving beyond the myths. Topics in Early Childhood Special Education, 13(2), 154-74.

Garner, R., & Pierotti, J. (1998). Fragile families. Madison, WI: Wisconsin Council on Developmental Disabilities.

Greenspan, S., & Budd, K. (1986). Research on mentally retarded parents. In J. Gallagher & P. Vietze (Eds.). Families of handicapped persons: research programmes and policy issues. Baltimore, MD: Paul H. Brookes.

Heighway, S., Kidd Webster, S., & Snodgrass, P. (1988). Supporting parents with mental retardation. Children Today, 17(6). Washington, D.C.: U.S. Department of Health and Human Services.

Heighway, S. (1992). Helping parents parent: A practice guide for supporting families headed by parents with cognitive limitations. Madison, WI: Wisconsin Council on Developmental Disabilities.

Hoffman, C., Mandeville, H., Webster, S. K., Heighway, S., Ullmer, D., Mincberg, B., Snodgrass, P., Murphy-Simon, K., & Wenger, B. (1990). The amelioration of health problems of children with parents with mental retardation 1987-1990, Madison, WI: Wisconsin Council on Developmental Disabilities and the Waisman Center on Mental Retardation and Human Development.

Kaminer, R., Jedrysek, E., & Soles, B. (1981). Intellectually limited parents. Journal of Developmental and Behavioral Pediatrics, 2(2), 39-43.

Keltner, B. (1994). Home environments of mothers with mental retardation. Mental Retardation, 32(2), 123-27.

Liamba, D. U., & Snodgrass, P. (Eds.) (1999). Supported parenting resource collection. Madison, WI: Wisconsin Council on Developmental Disabilities. (Distributed through Wisconsin libraries by Wisconsin public library system, 608-224-6160)

Llewellyn, G. (1990). People with intellectual disability as parents: perspectives from the professional literature. Australian and New Zealand Journal of Developmental Disabilities, 16(4), 369-80.

Llewellyn, G. (1995). Relationships and social support: views of parents with mental retardation/intellectual disability. Mental Retardation, 33(6), 349-63.

Mandeville, H. (Ed.). (1992). Building the foundation: public policy issues in supported parenting. Madison, WI: Wisconsin Council on Developmental Disabilities.

Mandeville, H., Anderson, L., & Lakin, C. (Eds.). (1998). Impact: feature issue on supporting parents who have cognitive limitations. Minneapolis, MN: Institute on Community Integration.

Ray, N., Rubenstein, H., & Russo, N. (1994). Understanding the parents who are mentally retarded: guidelines for family preservation programs. Child Welfare League of America, L23(6), 725-43.

Snodgrass, P. (1993). What's wrong with you?: Thoughts about helping families where parents have cognitive limitations. Madison, WI: University of Wisconsin-Madison.

Sweet, M. (2000). Discovering the parent's language of learning: an educational approach to supporting parents with mental retardation, 2nd edition, Madison, WI: Wisconsin Council on Developmental Disabilities.

Tymchuk, A., Andron, L., Bavolek, S., Quattrociocchi, A., & Henderson, H. (1990). Nurturing program for parents with special learning needs and their children, Park City, UT: Family Development Resources.

Tymchuk, A. (1992). Predicting adequacy of parenting by people with mental retardation. Child Abuse and Neglect, 16(2), 165-78.

Tymchuk, A., & Lutzker, In J. Lutzker (Ed.). (1998). The importance of matching educational interventions to parent needs in child maltreatment. Issues, methods and recommendations. Handbook of child abuse research and treatment, New York, NY: Plenum Publishing.

Walton-Allen, N. and Feldman, M. (1991). Perception of service needs by parents who are mentally retarded and their social service workers. Comprehensive Mental Health Care, 1(2), 137-47.

Webster, S.K. (Ed.). (1993). Preserving the bond. Madison, WI: Wisconsin Council on Developmental Disabilities.

Whitman, B., & Accardo, P. (Eds.). (1990). When a parent Is mentally retarded. Baltimore, MD, Paul H. Brookes.

Whitman, B., Graves, B., & Accardo, P. (1989). Training in parenting skills for adults with mental retardation. Social Work, 34(5), 431-34.

Order Form

Publications in the Supported Parenting Series

NAME OF PUBLICATION	COST	QTY	TOTAL
Preserving the Bond *Kidd Webster, 1993*	$5.00		
Helping Parents Parent *Heighway, 1992*	$3.00		
Building the Foundation: Public Policy Issues in Supported Parenting *Mandeville, Ullmer, 1992*	$3.00		
Cultivating Competence: 2nd Edition *Mandeville, Sweet, Snodgrass, Ullmer, 2000*	$6.00		
Entire Set of Supported Parenting Series	$15.00		
TOTAL COST		$	

Please make check or purchase order* payable to
Wisconsin Council on Developmental Disabilities (WCDD)
PO Box 7851, Madison, WI 53707-7851
Fax 608-267-3906

Send Order to:

Name: ______________________ Phone: ______________

Address: ______________________________________

City: ____________________ State: __________ Zip: __________

*FEIN 396006469
Photocopies of this form are encouraged.

For mailing, fold on lines, tape and stamp

PLACE
POSTAGE
HERE

Wisonsin Council on Developmental Disabilities
PO Box 7851
Madison, WI 53707-7851