

Governor's Planning Council
on Developmental Disabilities
Minnesota State Planning Agency
300 Centennial Building
655 Cedar Street
St. Paul, Minnesota 55155

FAMILY SUPPORT: TOWARD A NEW POLICY AGENDA
A STUDY OF
COMMUNITY RESPONSIVENESS IN PREVENTING HARM TO
CHILDREN WITH DEVELOPMENTAL DISABILITIES

Submitted to:

Developmental Disabilities Program Office
State Planning Agency
Capitol Square
St. Paul, Minnesota 55101

February 28, 1985

Submitted by:

Paul Kiley, Consultant
230 Oak Grove St.
Minneapolis, MN 55403
Phone: 612/871-2664

OVERVIEW/PURPOSE

Two years ago, a state-wide conference entitled, "Preventing Harm to Children with Disabilities" was held in Minneapolis. Much was learned and experienced on that day. Participants realized that getting help for parents and their children involves the efforts of many people in the community. A community where children can be safe and grow with the care of adult people does not just happen. It takes vigilance, a willingness to change whatever hurts children, and a commitment to be involved on behalf of children.

As a professional who works with these children or their families, or as a parent who lives with a disabled child, conference participants recognized that each was in a key position to be aware of how violence jeopardizes a family's future. Many people indicated in May 1982 that they had acquired knowledge and skills useful to work or home settings.

It became evident in 1984 that it would be helpful to current planning and programming efforts to understand what has happened in Minnesota communities during the past two years to prevent harm to disabled children. Two methods were used to gather this information.

- 1) Regional workshops were held in Mankato, St. Cloud and Rochester in the summer of 1984. Over 200 County social service, public health special education professionals, D.A.C. and residential staffs were invited to attend these meetings to offer their views on the status of preventing harm to disabled children. Thirty-seven professionals and parents attended these sessions.
- 2) A survey instrument was designed and distributed statewide to 400 people. This dissemination included all participants in the 1982 Conference, all 87 County welfare departments in Minnesota, and all special education districts in Minnesota. Twenty-four percent (97 people) answered the questionnaire.

What follows is a discussion of what was learned from these information gathering efforts. The report looks at the goals for prevention outlined in 1982, the current status of community responsiveness to disabled children at risk to abuse/neglect, the real possibilities for effective action, and future steps toward the goal of preventing harm to children with disabilities.

BACKGROUND

The 1982 Statewide Conference came about because of the voiced concerns of numerous professionals regarding the potential for abuse or neglect of handicapped children. The proceedings of the conference highlighted six factors that contributed significantly to the dynamics of stress + stress in families with disabled children. They were:

- cultural/social stigmatization
- social isolation
- prolonged and enduring sense of care for the disabled child
- attachment and bonding or the inability to grieve for the fantasized normal child
- the transition periods experienced around developmental milestones (e.g., puberty)
- the transition in services (e.g., children moving from pre-school to elementary school setting; the termination of physical therapy).

The awareness generated regarding these factors was further explored in regard to the child protection response, community service coordination and the emotional and practical obstacles to identifying and referring children at risk.

From these discussions there emerged six strategies that could be initiated or improved in local communities to attain the goal of preventing harm to

disabled children. They were:

- developing family member support groups especially for mothers and fathers and siblings of school age disabled children;
- providing or strengthening sex education programs and resources;
- strengthening parenting skills by affording parents consistent educational experiences that dealt with age-specific, disability-specific practical information that addressed their needs;
- developing respite care/in-home services;
- developing school policies/procedures and service coordination activities that speak to the needs of disabled children;
- planning and implementing training for professionals in identifying, responding, following through with families jeopardized by violence in their lives.

Basically, the regional workshops and statewide survey attempted to ascertain what has happened in regard to initiating these strategies during the past two years.

Status: Developing Support Groups

Although the vast majority of respondents indicated knowledge of the existence of a variety of support groups in their communities, few indicated awareness of group leader(s)/contact person(s) or average attendance. It was also suggested that families learn about programs principally by word-of-mouth and secondarily through professional referral. Local Associations for Retarded Citizens or pre-school (D.A.C.) programs were the most often cited as the prime source of offering ongoing active support groups for mothers and fathers together.

Significant concern was voiced by workshop participants as to the availability and viability of support groups for parents and siblings of elementary and secondary disabled students. In a number of rural settings even when parents got together they seldom stayed together because little wisdom about their experience was exchanged on a regular basis. Basically, they came to realize they had children with different disabilities, problems and needs.

Often cited obstacles to implementing a support group included:

- not knowing how to get started
- parent apathy
- lack of professional commitment
- parent travel time to meeting
- confusion about direction and focus of group
- stigmatization
- not knowing a contact person, a group exists or other parents having similar need for support.

Often cited helps to maintaining a group included:

- parent leadership and commitment
- parent activities and projects
- regular meeting time, place, purpose
- person skilled in group process
- meeting fathers' needs
- communication between parents and among professionals.

Support Groups: What's Possible/What's Happened Since 1982?

There are several exciting examples:

- 1) Forty-two people were cited as key resources/contact persons in operating support groups in Minnesota counties. They are based in all regions of the state. A list is attached.
- 2) In the St. Cloud region, educators in the special education cooperative have begun plans for initiating support groups for parents of school age children and support for themselves.
- 3) In the Rochester area, seven staff members at a residential facility recognized the need for a staff support group and are initiating activity to establish one.
- 4) In the Mankato area, parents of a cerebral palsied child brainstormed with area professionals on how to start up a parent support group. They explored the above cited obstacles and made plans to overcome them.
- 5) In the Metro area, parents of autistic children have initiated a supportive telephone help/hotline.
- 6) Also, a clearinghouse for family support organizations in Minnesota, sponsored by The Task Force on Children with Disabilities and Gillette Children's Hospital has been initiated to connect families with support organizations (phone K. Sandberg at 612/291-2848).

Support Groups: Future Steps Toward Goal

- 1) There is a need for communities in all areas of the state to identify the nature and extent of support group availability for parents and siblings of school age children.

- 2) In particular, professionals in the Metro, Northeast and Southwest areas of the state have indicated a preference for acquiring advice and skills in how to build support groups locally. This request ought to be met in the year ahead.
- 3) Communications between professionals and families needs to be improved.
- 4) Key change agents in counties need to be identified and worked with in building/maintaining support groups.

Status: Providing/Strengthening Sex Education Resources

Fifty-one percent (51%) of the survey respondents indicated awareness of the availability of sex education programs for disabled children in their communities. However, a majority of these respondents qualified their perspectives. Generally, sex education was seen as occurring in interactions between families and nurses, social service workers, mental health professionals, or school teachers acting on their own initiative. Sometimes, different resources were cited, such as local A.R.C. workshops for parents and the training provided by Planned Parenthood of Minnesota. Except for Metro and Southwest regions, awareness of sex education being offered to disabled children in the schools was low.

It was not clear whether disabled children participate in regular school sex education curriculum when it is offered or participate in curriculum designed to meet their special needs. Nor was it clear as to the extent to which either curricula was available and accessible to children. Part of the confusion stems from the difficulties perceived by people in providing sex education in the community. Most often cited difficulties included:

- awareness of availability of effective and appropriate materials and curriculum resources
- community mores (i.e., "prime job of parents not professionals")
- parental concerns or acceptance about children and their sexuality education
- lack of skilled instructors
- placing request for this form of social development in I.E.P.

For respondents, there seemed to be no short-term solution to overcoming these difficulties. Statewide community and parental acceptance of the expression of healthy sexuality among disabled adolescents is at best mixed.

Curiously, short-term/one-day sex abuse education efforts for the disabled have been implemented in the regions indicating strong lack of awareness or acceptance of reliable sex education programming. Although sex abuse education and prevention efforts are valuable in themselves, serious concern surfaced regarding their impact upon children with disabilities who have not previously experienced education about healthy sexuality.

Simply put: Does a community prefer children who are aware of and knowledgeable about their sexuality who can then make better choices about body safety and avoiding "bad touch" experiences; or does a community prefer children to know about body safety and "bad touch" settings and circumstances where attaining future knowledge about healthy sexuality is at best unclear and at worst nonexistent.

Sex Education Resources: What's Possible/What's Happened Since 1982?

Conference participants have been involved in a number of activities:

- 1) Conference participants from the St. Paul-Ramsey Medical Center Mental Health Program for Hearing Impaired developed a Health and Wellness program for the hearing impaired.
- 2) White Bear Lake Special Education Program is integrating a unit on sex abuse prevention (i.e., body safety) into ongoing and pre-existing sex education programs for disabled children.
- 3) Northfield Middle School has implemented a sex education program for T.M.H. students entitled "Being Me".
- 4) School District #916 is implementing sex education unit in Community Living Program for disabled students.

- 5) Ramsey County Mental Health Office offers a dating skills program for persons who are mentally retarded.
- 6) Several conference participants served as task force members/consultants to the Department of Correction's development of curriculum "Preventing Sexual Abuse of the Handicapped".

Sex Education Resources: Future Steps Toward Goal

- 1) Professionals from state regions (i.e., Metro, Southwest, Southeast) where the availability of sex education is perceived as most pronounced indicated a need for consultation and training to strengthen sex education programs.
- 2) Attention needs to be directed toward discovering what classroom sex education curricula are effective with disabled youth.
- 3) Communication among and between professionals who use sex education curricula and materials needs to be improved.
- 4) Local/regional key change agents need to be identified and worked with in order to find and plan long-term solutions in regard to sex education for disabled children.
- 5) The impact of short-term sex abuse prevention efforts upon the future living experiences of disabled children needs to be assessed.
- 6) Accurate sex education information should be available to parent and sibling support groups and parent education efforts in local communities.

Status: Parent Education

Thirty-three percent (33%) of the people surveyed were aware of the availability of programs which dealt specifically with the needs of parents to know about developmental stages of handicapped children. Very few respondents noted other informational resources addressing practical advice for parents.

Most often cited as providing parent education were pre-school programs (D.A.C.), public health nurses, mental health counselors and community education programs in local school districts. However, it was unclear what the nature of the program was with respect to meeting the needs of parents with child rearing concerns about their disabled child.

Oftentimes, respondents perceived these parents as gaining little practical wisdom from attending classes offered for parents of non-disabled children. There was a consensus that while a lot of information about parenting per se is available, what's lacking is clear, relevant educational advice and support delivered in a timely manner as needed on a year-to-year basis.

Parent Education: What's Possible/What's Happened Since 1982?

People noted these activities:

- 1) The St. Cloud AVTI Parent Child Program provides ongoing practical education experiences to parents of pre-school disabled children.
- 2) In Mankato, steps are being taken to investigate the potential for placing pertinent parent education material on Special Net microcomputer link, and for allowing parents access to Special Net information.

Parent Education: Future Steps Toward Goal

- 1) Key change agents need to be identified at local/regional levels to develop plans for addressing this serious unmet need of parents. Professionals surveyed in all but one region indicated the strongest preference for receiving consultation and training in implementing parent education programs.
- 2) Parent training resources that meet the needs of families with disabled children need to be identified and developed.
- 3) Computer aided instructional opportunities (i.e., software) need to be identified and developed to improve the availability and accessibility of practical parent information and education resources.

Status: Developing Respite Care/In-Home Services

Ninety-six percent (96%) of the respondents were aware of the provision of respite care services in their communities. However, only 27% of the people surveyed indicated that in their experience parents knew that respite care service was available to them. Word-of-mouth and professional referral were the most frequently noted forms of communication for parents to learn about respite care services.

Problems cited include:

- long waiting list of potential users
- parents don't get service when they really need it
- the inability to find a provider on short notice
- the need is larger than the resources available, so resources are disinclined to inform eligible people about services
- training of respite care providers.

Respite Care: What's Possible/What's Happened Since 1982?

- 1) Brown County Human Services regularly informs by letter all potential users of respite care in the county. Home visits also occur to ascertain family needs.

Respite Care: Future Steps Toward Goal

- 1) All counties should undertake a review of current policy to assure that all potential users are informed on a regular basis of the availability of services.

Status: School Policy and Reporting Procedure/Service Coordination

Sixty-three percent (63%) of the respondents were aware that their local school district had a policy regarding child abuse and neglect. The strength of this response is due in large part to the efforts of the State Departments of Education and Human Services to help schools formulate policies during the past five years. However 50% of those responding were not sure if the policy accounted for the special communication needs or problems of disabled children.

Interestingly, while 25% of the people responding indicated that their county's child abuse team had a member skilled in helping families with disabled children, 60% of those responding were not sure if such a person was a team member. A list of identified resources to teams is attached.

School Policy and Reporting Procedure/Service Coordination: What's Possible/What's Happened Since 1982?

- 1) Brown County identified county service worker skilled in helping families and brought him onto the Child Protection Team.
- 2) Twenty-five school districts have re-examined their school policy and reporting procedures in regard to meeting needs of disabled children.
- 3) In April 1984, the Minnesota Department of Education Office of Pupil Personnel Services developed and distributed to all Minnesota school districts a resource guide entitled Minimizing Abuse of the Imbalance of Power/A Capsule Look at Educator's Role in Preventing Harm to Children and Youth.

School Policy and Reporting Procedure/Service Coordination:
Future Steps Toward Goal

- 1) Local school districts can re-evaluate child abuse policy and reporting procedure to address needs of handicapped children. This should be done in consultation with local child protection unit of county welfare department.
- 2) County child abuse teams need to develop or identify resource persons skilled in working with families and encourage them to participate on local team.

Status: Professional Training

During the past two years, training for special education professionals has been of a hit-and-miss variety. Since the defunding of the State Department of Human Services' training efforts in 1982, it appears school districts have received very little beyond one hour workshop on the reporting law. Numerous conversations indicated that there is still a significant need for helping teachers explore the emotional and practical obstacles to identification and reporting and attain skills in checking out suspicions. Concern has been voiced about the current lack of preparedness of professionals, not trained since 1982, to respond to children's disclosures about physical or sexual abuse.

It was also perceived that county social service workers have had little substantive training in regard to improving skills in responding to families with disabled children, nor did plans exist for providing such staff training in the year ahead.

Professional Training: What's Possible/What's Happened Since 1982?

- 1) Child protection workers at regional sessions have realized that it takes more than sensitivity to respond adequately to these children and families when they experience abuse or neglect.
- 2) Workers gained awareness and understanding about improving the skills needed to intervene with families generally and child abuse situations in particular.

Professional Training: Future Steps Toward Goal

- 1) School districts can identify and use training resources that assist them in helping teachers deal with the emotional and

practical obstacles to identification and referral.

- 2) The Department of Human Services should develop as a priority the means for helping county workers use and be trained in Title XX Curriculum for Social Service Workers in Counseling Families with Developmentally Disabled Children (University of South Carolina, 1981).
- 3) Training should be provided to health care and rehabilitation professionals and residential program staff members.

SUMMARY

Many individuals from across Minnesota have moved ahead with implementing strategies that prevent harm to children with developmental disabilities, but more needs to be done. Increased efforts in parent education and building support groups and training professionals need to become priorities. Existing sex education curricula need to be effective in order to enhance future community living experiences of the disabled. More people everywhere need to become aware of the factors that contribute to stress + stress and the strategies that prevent or reduce its occurrence. The goal of preventing harm to children with disabilities is realizable. It is attainable when people are committed to working together on behalf of the futures of children.

ATTACHMENT A

Identified Support Group Contact Person(s)

NORTHWEST MINNESOTA

Marshall County

Leonard Olson, Warren, Minnesota

Ottertail County

C. Robinson

CENTRAL MINNESOTA

Todd County

Connie Keffe, Mary Hofer, Freshwater Special Education Coop., Staples, Minnesota

Douglas County

Betsey Schmidt, Association for Retarded Citizens; Jan Tompson, Developmental Achievement Center

Stearns County

Judy Hoening, United Cerebral Palsy Association; Cheryl Pennington, Association for Retarded Citizens; T. Durant, Minnesota Association for Children with Learning Disabilities; Dodi Ahles, Parent Child Center AVTI, St. Cloud

Morrison County

Gary Palo, Little Falls; Jean Ruff, Brainerd

Wright County

Judy Coley, Elk River

SOUTHWEST MINNESOTA

Murray County

Marge Mans, Marshall, Minnesota

Blue Earth County

Nancy Seep, St. Clair, Minnesota

SOUTHEAST MINNESOTA

Steele County

Judy Sirsen, People to People, Inc.

Olmstead County

Dorothy Betcher, Mayo Clinic, Rochester, Minnesota; Ann Haas, Rochester, Minnesota

Rice County

Casey Gordon, Jan Roberts, Nadine Steele

Identified Support Group Contact Person(s)

NORTHWEST MINNESOTA

St. Louis County

Char Miller, ARC, Duluth; Phil Garrison;
Dianne Maki; Lynn Engaar, Pilot Parents of
Northeast Minnesota; Angie Cvengros, Range
ARC; Inez Ericson, Arrowhead Epilepsy League

METRO AREA

Anoka County

Kathy Anderson

Carver County

Sue Hoffert, Ellen Kes

Dakota County

Leanne Lyles, Renee Sweetmilk

Hennepin/Ramsey Counties

Marilyn Bloom, St. Davids DAC, Minnetonka;
Annette Pantel, Courage Center; Ginny Meur,
Hearing Impaired; Jackie McDougal, Hearing
Impaired, ARC; Luanne Hientz, St. Paul, ARC;
Georgia Hiller, Twin Cities Society for Autistic
Children

ATTACHMENT B

Identified Child Protection Team Members with
Skills in Counseling Families with
Developmentally Disabled Children

NORTHWEST MINNESOTA

Hubbard County

Kathy Sunstrat, Director, Nursing Service
(218) 733-3812

Ottertail County

Lorina Rohr, N.Y. Mills (218) 385-2640

CENTRAL MINNESOTA

Todd County

Denny Dolan, Northern Pines Mental Health Center;
Connie Keefer, Freshwater Special Education Coop.

Stearns County

David Baraga, Mental Health Center

SOUTHWEST MINNESOTA

Brown County

Replacement for active member yet to be
named (6/15/84)

Lyon County

Harry Havik, Marshall Public Schools

SOUTHEAST MINNESOTA

Rice County

Karen Kempke, Northfield Public Schools

Goodhue County

Jean Currier, County Nursing Service 388-8261

Freeborn County

Fred Steen, County Social Services (507) 373-6482

NORTHEAST MINNESOTA

Cook County

Lois Johnson, Grand Marais (218) 387-2468

Koochiching County

Ruth Teeter, Northland Mental Health Center

Lake County

Dorothy Johnson, Human Development Center,
Two Harbors (218) 834-5520

ATTACHMENT B (page 2 of 2)

Identified Child Protection Team Members with
Skills in Counseling Families with
Developmentally Disabled Children

METRO AREA

Carver County

Susan Hoffert, Carver County Social Services
448-3661

Ramsey County

David Thompson, M.R. Child Protection 298-5001;
Jack Jones, St. Paul Ramesy Medical Center
221-3685

Anoka County

Ruth Parsons, Anoka County Social Services