

Developmental Disabilities Planning Council
&
Center for Development and Disability

PARENTS WITH DEVELOPMENTAL DISABILITIES
IN NEW MEXICO:
NEEDS AND SUPPORTS

SURVEY FINDINGS
WINTER 2005

■ Introduction

The New Mexico Developmental Disabilities Planning Council (NMDDPC), working with the Center for Development and Disability (CDD), initiated a survey of agencies / organizations providing services that potentially reach parents with developmental disabilities (DD). Its purpose was to help determine what parents with DD need in the way of supports and services to help raise their young children (under 18 years), and increase their independence, productivity, integration and inclusion into their local communities.

This was the first phase of a two-phase study, the second phase being three focus groups to be conducted in June 2005, attended by parents with DD themselves (report on the focus group findings, Summer 2005).

The information captured in this two-phase study will be used to help shape future projects in New Mexico to address the identified needs and desires of parents with DD.

■ Procedure

- On the basis of discussions between staff from both NMDDPC and CDD, a three-page questionnaire was created for the purpose of this survey (see Attachment 1, page 13).
- A comprehensive definition of ‘developmental disability’ was included at the beginning of the questionnaire to ensure that potential respondents were clear about which members of their client group they should consider in their responses.
- In January 2005, the questionnaire was mailed to approximately 500 agencies / organizations across New Mexico, along with a cover letter explaining its purpose. The mailing list was compiled from lists of DD and D&E providers, also independent living Centers. A “blanket-coverage” approach was taken in order to catch all potential respondents who fall into the target population. It was recognized that a large proportion of the surveys would reach agencies, which do not serve this population.
- Ninety questionnaires were returned, out of which 38 respondents stated that either parents with DD do not fall within their regular client group, or that they are not serving any parents with DD at present. There were 52 questionnaires returned from agencies / organizations who are currently serving the target population. Table 1 below shows how many returns came from each part of the State. Over half came from the Metro area, between 10 and 20 % came from each of the Northeast, Northwest, and Southeast, with just 6% of respondents coming from the Southwest.

■ Findings

1. Overview of Respondents

a) Type of Organization

Of the 52 responding organizations, 30 provided services to adults ranging from services particularly aimed at adults with developmental disabilities through to health care, home care, independent living services, or similar. Of these 30, one was government-based, eight were for-profit organizations, and 21 were non-profits. Other organizations included 13 companies offering therapies, two offering counseling, two university-based organizations, and five Early Childhood or Head Starts.

b) Family Situation

Table 1 below shows that respondents estimated that the majority (61%) of parents with DD have their children living with them. Although it was not asked as a specific question, several respondents commented anecdotally that this is often with the help of their own parents, the children's grandparents. One respondent remarked that her organization served four grandmothers who are themselves developmentally disabled but are acting as the main caregiver for the children of their own children with DD.

Respondents estimated that overall over half the parents received Supplemental Security Income (SSI) or Social Security Disability Income (SSDI).

It should be noted that all figures in Table 1 relating to numbers of parents are estimates. They provide a general picture but not an exact one.

**Table 1
Family Situation**

REGION	Number of Organizations	¹ Number of Parents Served		¹ Number of Parents whose Children are:				¹ Number of Parents Receiving SSI/SSD
		Mothers	Fathers	Living with Parents	Living with Extended Family	In Foster Care	Adopted	
Metro	27	117	37	83 (54%)	16	7	4	76 (49%)
Northeast	6	14	8	18 (82%)	15	-	-	15 (68%)
Northwest	5	16	2	13 (72%)	4	1	-	16 (89%)
Southeast	10	41	18	43 (73%)	8	8	-	33 (56%)
Southwest	3	3	2	1 (20%)	3	-	-	3 (60%)
New Mexico	52 ²	191	67	158 (61%) ³	46	16	4	143 (55% total) ³

Notes: ¹ Figures are respondents' estimates

² Total includes one survey in which region was not stated

³ Percent of total number of parents served (mothers + fathers)

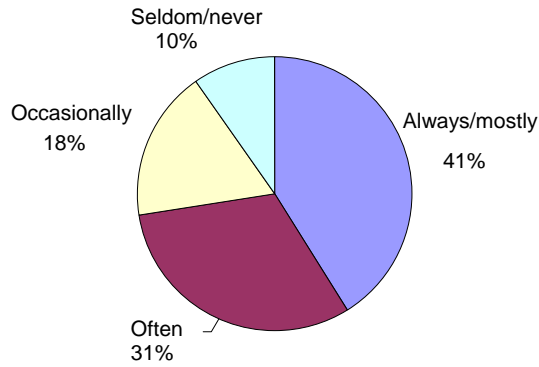
2. Sources of Support for Parents with DD

Respondents were asked where parents with DD might draw on support from within their social networks (see question 4, Attachment 1).

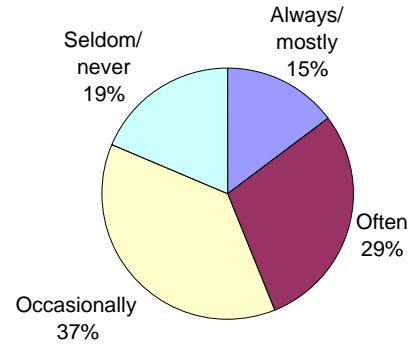
As might be expected, the respondents estimated that support mainly came from their family members. Figure 1 shows that 72% of respondents thought immediate family members (spouse, parents, children) provided support for their clients 'Often' or Always/mostly', leaving 28% who thought support was only 'Occasional' or 'Seldom/never'. Less than half of respondents (44%) thought support often or mostly/always came from extended family members (grandparents, cousins, aunts/uncles). Similar proportions saw support coming from a boyfriend/girlfriend (29%) or from other friends (23%).

Figure 1
Respondents' View of Sources of Support from Local Sources

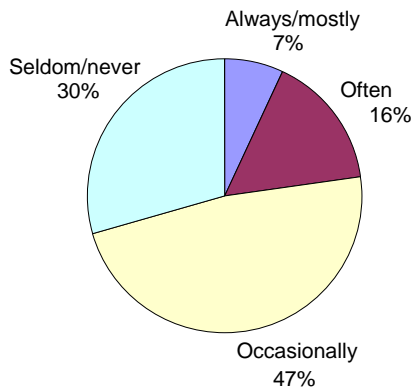
Support from Immediate Family



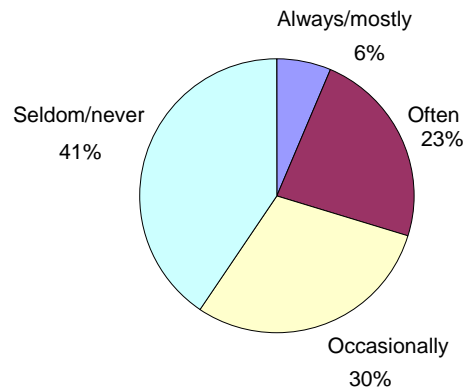
Support from Extended Family



Support from Friends



Support from Boyfriend/Girlfriend



The remaining sources of support are not represented in Figure 1. Ten percent or less saw co-workers, neighbors, church members or club members as providing support often or always/never.

Other sources of support mentioned by respondents were agencies' staff (e.g. DD Waiver staff, respite staff, therapists, etc.), whose job or vocation is to care for them or advocate on their behalf.

3. Difficulties for Parents with DD

Respondents were asked about some factors, which in their opinion, contribute to difficulties for parents with developmental disabilities (see question 5, Attachment 1).

Table 2 below lists the factors in descending order from the factors considered important by most respondents.

Over three quarters of respondents thought problems with financial management is a difficulty for parents with DD, with nearly half thinking it is mostly or always a problem.

Two general societal problems also face parents with DD, namely a lack of affordable housing and lack of employment. Sixty-two percent and 64% respectively of respondents believed these problems faced their clients often or mostly/always.

Between 60% and 70% of respondents also felt the three factors - limited expertise locally about developmental disabilities and parenting, lack of advocates, and lack of childcare – often or mostly/always affected parents with DD.

Nearly half the respondents (49%) thought that social isolation was often a difficulty, and a further 18% thought it mostly or always so.

Lack of family support (e.g. counseling, parent training) is believed often a difficulty (47%), with a further 10% of respondents believing it is mostly or always so. There are similar proportions for the linked factor, support systems burnout (44% and 13%).

A majority of respondents believe problems with abuse/neglect/exploitation are either occasionally (25%) or seldom/never (35%) a problem, leaving over 40% believing it is often or mostly/always.

Poor coordination between providers and too few of them is seen as a difficulty by around half the respondents.

Table 2
Factors Contributing to Difficulties for Parents with DD

DIFFICULTIES	<i>Proportion of Respondents who Consider It Contributes to Difficulties for Parents with DD</i>				<i>Total Responses</i>
	<i>Always/ Mostly</i>	<i>Often</i>	<i>Occasionally</i>	<i>Seldom/ Never</i>	
Problems with financial management	48%	28%	16%	8%	50
Lack of affordable housing	35%	27%	19%	19%	48
Lack of employment	28%	36%	21%	15%	47
Lack of advocates	27%	35%	27%	23%	48
Limited expertise locally about DD and parenting	24%	45%	25%	6%	49
Lack of childcare	20%	44%	22%	13%	49
Too few providers	20%	34%	24%	22%	50
Problems with social isolation	18%	49%	27%	6%	51
Poor coordination between services and providers	17%	27%	44%	12%	48
Support systems burnout	13%	44%	31%	13%	49
Problems with abuse / neglect / exploitation	13%	28%	35%	25%	49
Lack of family support eg counseling, parent training	10%	47%	35%	8%	49

Notes: 1. *Some respondents missed out questions. Percentages are calculated from total responses for each separate item.*
2. *Some rows do not total 100% due to rounding.*

4. Availability of Services for Parents with DD

Since the percentages in Table 3, column 2 (Number of agencies offering this service) are dependent on who responded to this survey, the more salient data is respondents' estimation of availability of services in their area.

Table 3 shows that less than two thirds of respondents believe that Life Skills Training, Respite/relief, Residential, and Family Preservation Services are available in their area for parents with DD.

The qualitative data in section 5 below expands on these issues.

Table 3
Availability of Services among Responding Agencies

SERVICES	<i>Number of agencies offering this service</i>	<i>Estimated number of parents receiving this service from agencies</i>	Service available in your community?
Counseling (family / individual / couple)	22%	38	84%
Case Management / Service coordination	47%	124	82%
Healthcare	16%	75	81%
Parenting Skills	34%	72	78%
Behavioral Health Services	16%	36	77%
Behavior Therapy	20%	27	71%
Nutrition	16%	36	76%
Housing	7%	7	76%
Employment Services	18%	22	74%
Prenatal Services	8%	7	72%
Transportation	27%	29	70%
Childcare	10%	6	69%
Domestic Violence Services	2%	2	68%
Life Skills Training	27%	63	66%
Respite / relief Services	27%	17	66%
Residential Services	22%	13	64%
Family Preservation	6%	12	61%

5. Suggestions for Improving the Quality of Life

The final question in the survey gave respondents the chance to write down their suggestions for improving the quality of life for parents with DD. The following long and thoughtful comment offered by one of the respondents encapsulates many of the problems faced by these parents:

“Though many of the supports and services listed above are available in this community, many parents are not able to access them. Synchronizing services (childcare, transportation, and financial services to get to counseling for example) is extremely difficult for some of our parents. Furthermore, the quality of services and/or level of training of professionals is questionable at times. Many of our parents rely on unsteady supports-partners and significant others, and when these become unavailable, their routines, schedules, finances, and most importantly their children suffer immensely. Waiting lists for HUD/ subsidized housing is more than 12 months long. Negotiating the system (income support Division/ HUD) requires much more literacy than some of our parents possess.”

Other comments from respondents confirm many of the points made in the above statement.

Six respondents commented on the need for more support groups for parents with DD, that should also include “*social opportunities other than a dance*”. The following two comments are examples:

“There need to be more vocational training and job opportunities. More parenting classes geared specifically to their needs; More support groups to draw on each others strengths and also socialization.”

“Perhaps there could be a support group in which DD parents can meet other DD parents. This group with some advocates could come together to a consensus on what supports they need to be successful in their lives and raising their children.”

More respite care (suggested by four respondents) would come under this support umbrella.

Without more support many parents risk losing their children, while some lose their children automatically because of their DD:

“They need increased support, supervision, and education, as well as advocacy, or they seem to lose parental rights.”

“The real problem seems to be attitudinal and results in the immediate removal of the child from the biological mother’s home, with on-going assumptions that restrict contact and involvement to the parent(s). Services are available, that limited in the greater context for everyone (e.g. childcare, transportation)”.

“The parent on my caseload is not her own guardian. Her mother is. Mother and father of parent have taken responsibility for the child. Parents were never given "privileges" of having a child.”

Two respondents pointed out that the parents’ children without DD also need special support:

“Affordable childcare and supports for children (such as) counselors. For example, if a parent has a disability and the child does not, adult has a support system (DD Waiver) but "normal" child does not – like someone to go to a doctors’ appointment with, etc.”

“The waiver needs an additional service so we can assist children “

A core problem seems to be in the quality of available help/support. The general impression is that it is often provided by poorly-trained personnel. Seven respondents commented on this, two of the suggestions are as follows:

“The community and providers working with children who have a parent with developmental disabilities need more education about their needs and how to work with this population.”

“Improved standards of care are necessary in residential services, day habilitation, respite care. CNA's or certification/training should be mandatory and certified workers should be paid more by the state to reduce turnover and poor care.

Two respondents spoke to the special needs of this group and that mentors or a central expert agency would be beneficial:

“We find that if there is no abuse or neglect in the home CYFD is rarely involved with these families. FIT service coordinators would benefit from mentors who could spend the time needed to help the family seek out and develop community supports that could sustain them through the years.”

The other comment was in relation to the dual diagnoses of drug dependency and DD:

“Ideally, there should be a central expert agency to act as consultants to programs dealing with this population. Case management is compromised by limited community housing, employment, and training opportunities for them.”

Several respondents came up with suggestions about life skills classes, including parenting:

“Parenting skills classes, social groups, increased in-home support for medical needs, cooking/life skills classes designed specifically for this population.”

“I feel there needs to be more planning for pregnancy education.”

One respondent came up with a practical solution to:

“Offer parenting classes in home for parents with no transportation.”

The final comment in this section describes in detail the ideal situation when a mother with DD gives birth. It concludes with the comment that services are less available in rural areas. This was also noted by three other respondents:

“Parents with developmental disabilities who have an infant hospitalized in the UNM_NCIU are routinely referred to their local New Mexico Early Intervention Program (Department of Health) due to infant-family risk factors. The early intervention programs provide a variety of support services to families. Parents with developmental disabilities who are doing well, typically have strong family/extended family support and in depth case management/service coordination in place at the baby's birth. Any weakness or limitations in these areas obviously will affect the parent and the child's stability. When support for parents with developmental delays is insufficient, the baby may require foster care placement. Consistent medical follow up for parent and child is a must, including general well baby care, family planning, or any special needs. Basic, ongoing infant and child care skills training is usually needed. Services in the rural areas tend to be less available. “

■ Conclusions

- Parents with DD need a strong support system to help them cope with the demands of parenting. This is often provided by family members, but otherwise they are mostly dependent on outside help. Without it they may not be able to keep their children with them.
- Respondents felt there are insufficient personnel in New Mexico trained to meet the special needs of parents with DD.
- Services are generally available but the special difficulties facing parents means they often cannot benefit from them. Such issues as transportation, childcare and social isolation often present hurdles.
- A well-trained mentor attached to a parent from the pregnancy stage to help them negotiate the available services and supports would help them.
- Classes in life-skills and parenting would add another layer of support. Parents often do not make use of what is available. Classes in the home might overcome some of the problems.
- Financial Management is a particular problem for parents.
- Services are less available in rural areas.
- The children of parents with DD also need a support system.

SURVEY ABOUT PARENTS WITH DEVELOPMENTAL DISABILITIES

In this survey, “developmental disability” means a severe, chronic disability attributable to mental and/or physical impairment, which manifests before the age of 22 and is likely to continue indefinitely. This type of disability results in substantial limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services.

What type of agency or organization do you work for? (please check)

Government Faith-based Non-profit School Other _____

Agency name _____

Agency Address _____

Name + job title of person completing this survey _____

Phone _____ Email _____

Please answer all the following questions only in relation to the parents with disabilities who you serve, who have CHILDREN UNDER 18 YEARS.

Note: A couple with developmental disabilities count as two parents:

1. How many do you serve (your best estimate)? _____ (mothers) _____ (fathers)

2. How many receive SSI / SSDI (your best estimate)? _____

3. To the best of your knowledge, how many have children:

Living at home with them? _____

Living with other family members? _____ (including extended family)

Living in foster care? _____

Living in another situation? (i) _____ (please specify the situation) _____ (give the number of parents)

(ii) _____ (please specify the situation) _____ (give the number of parents)

4. In general, do parents with developmental disabilities served by your agency receive support from:

	<i>Always / Mostly</i>	<i>Often</i>	<i>Occasionally</i>	<i>Seldom/ Never</i>
a) Immediate family members (e.g. Spouse, parents, children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Extended family members (e.g. Grandparents, cousins, aunts/uncles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Boyfriend/girlfriend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Neighbors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Co-workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Church members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Club members (e.g. Social / community / service / fraternal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Other _____ (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. In your opinion, which of the following contribute to difficulties for parents with developmental disabilities?

	<i>Always / Mostly</i>	<i>Often</i>	<i>Occasionally</i>	<i>Seldom/ Never</i>
a) Too few providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Poor coordination between services and providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Limited expertise locally about developmental disabilities and parenting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Lack of family support e.g. counseling, parent training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Lack of childcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Lack of advocates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Lack of affordable housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Lack of employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Problems with financial management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Problems with social isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Problems with abuse / neglect / exploitation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Support systems burnout	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Other _____ (Please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

continued

6. Please indicate the services your agency offers parents with developmental disabilities, and also indicate what services are available to them in your community if your agency does not offer them:

SERVICES	About your agency		Is this service available in your community? (Please check all that apply)
	Does your agency offer this service? (Please check all that apply)	Estimated number of parents receiving this service from your agency	
a) Case Management / Service coordination			
b) Behavioral Health Services			
c) Counseling (family/individual/couple)			
d) Behavior Therapy			
e) Healthcare			
f) Nutrition			
g) Family Preservation			
h) Parenting Skills			
i) Prenatal Services			
j) Childcare			
k) Employment Services			
l) Life Skills Training			
m) Residential Services			
n) Housing			
o) Respite / relief Services			
p) Transportation			
q) Domestic Violence Services			
r) Other: (Please specify)			

7. In the space below please write down your suggestions for improving the quality of life for parents with developmental disabilities in your area.

(Continue on a separate sheet if you need more space)

THANK YOU VERY MUCH FOR YOUR TIME

If you would NOT like to be contacted in relation to your survey responses, please check this box