

DOWN SYNDROME PLANNING GRANT  
THE ARC OF NEW MEXICO

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*Funded by The Arc of the United States through the Isabel Gonzales Trust Fund*

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## Greetings!

In 2011, The Arc of New Mexico received a grant from The Arc of the United States in Washington, D.C. to: 1) conduct a national search for best practices in the care, education and support of individuals with Down syndrome, 2) conduct a needs assessment for individuals with Down syndrome living in New Mexico to identify existing services and programs and gaps in services and programs, and 3) develop one or more project proposals that provide for the care, education, and support of residents of New Mexico with Down syndrome based upon the information gathered from the national research and statewide needs assessment.

Later in July, after receiving and reviewing numerous resumes, The Arc contracted with Ann Badway and Shannon Enright-Smith to administer the planning grant. In August both attended the 39<sup>th</sup> Annual National Down syndrome Congress Convention in San Antonio where they had the opportunity to attend numerous sessions, interact with family members and network with experts and leaders in the field.

In the following months, Ann and Shannon met with and interviewed family members, disability service providers, advocates, and health care professionals. They also had telephone conversations with experts from around the country and continued to research national best practices on the internet. One of the biggest challenges they faced was locating individuals with Down syndrome and their families around the state. They contacted several Down syndrome chapters and also received information and support from Randy Mascarella, Executive Director of New Mexico Special Olympics.

As the interviews continued, efforts were started to develop focus group questions and to identify contacts in various communities. In addition, work was started to develop on-line surveys with assistance from Cameron Crandall, M.D. and Lisa Broidy, Ph.D. both from the University of New Mexico. Two surveys were created, one for caregivers and one for family members.

In December, MaryEllen Garcia joined the project to provide administrative support. Several focus groups were held before the holidays. In January 2012, numerous focus groups were conducted in Albuquerque and in other communities around the state and the surveys were available on line via Survey Monkey.

This report contains the results of the interviews, focus groups, surveys and highlights national issues and trends. Key recommendations include:

- 1) *Develop a centralized clearinghouse of information regarding all aspects involved in the care, support and education of individuals with Down syndrome for families, caregivers and service providers*
- 2) *Establishment of a Down syndrome Clinic, attached to the University of New Mexico Hospital, Center for Development and Disability.*
- 3) *Training and education regarding all aspects involved in the care, support and education of individuals with Down syndrome for healthcare professionals, educators and service providers.*

This is an exciting opportunity for The Arc of New Mexico and The Arc of the United States to work together to develop programs of national significance that will enhance the quality of life for individuals with Down syndrome and their families.

Thank you for your participation and assistance.

A handwritten signature in black ink, appearing to read 'Randy Costales', with a horizontal line extending to the right.

Randy Costales

Executive Director

## **Introduction**

In 2011, The Arc of New Mexico received a planning grant to address the needs of individuals with Down syndrome from The Arc of the United States to identify the best practices in the care, education and support of individuals with Down syndrome, conduct a needs assessment for individuals with Down syndrome in New Mexico and develop recommendations resulting from these findings. As a result, The Arc of New Mexico put together a Planning Grant Team to assess the needs of individuals with Down syndrome in New Mexico and put forth recommendations.

This report aims to summarize the needs and service gaps for individuals with Down syndrome throughout New Mexico. This report is intended to provide general information about the methodology for the research conducted, results of the web-based surveys and focus group interviews, recommendations and information regarding national research and best practices.

## **Acknowledgements**

On behalf of The Arc of New Mexico, we would like to formally acknowledge the dedicated professionals who have lent their invaluable expertise to the Planning Grant for Individuals with Down syndrome in New Mexico. The Isabel Gonzales Fund of The Arc of the United States funded this project.

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Down syndrome Foundation of Southeastern New Mexico  
downsyndrome.com (permission to use photos)  
EPICS (Education for Parents of Indian Children with Special Needs)  
La Vida Felicidad  
Parents Reaching Out  
Rio Grande Down syndrome Network  
Special Olympics of New Mexico

Randy Moscarella, Executive Director of the Special Olympics of New Mexico, provided invaluable assistance and support for the Planning Grant, facilitating the identification of individuals with Down syndrome in our state, as well as community members and professionals involved in the care, education and support of these citizens.

*Dr. Broidy and Dr. Crandall generously donated their time and expertise throughout the Planning Grant, offering guidance, assisting in the creation of the online survey, and performing the data analysis.*

*If we have inadvertently left anyone off this list, please accept our sincerest apology.*

## Methodology

This report aims to provide an assessment of the needs and service gaps for individuals with Down syndrome throughout New Mexico. To this end, we conducted web-based surveys and focus group interviews with a sample of families/caregivers of individuals with Down syndrome who live or provide services in New Mexico. In addition, we conducted web-based surveys with healthcare and social service providers who work with individuals with Down syndrome.

Because there is no registry of Down syndrome individuals in New Mexico, we requested and obtained contact information for individuals with Down syndrome from Special Olympics of New Mexico (SONM). SONM provided membership contact information (names, phone numbers and addresses) for 276 individuals with Down syndrome and their caregivers residing in 21 out of 33 counties in New Mexico. Of the 276 individuals identified by SONM, 117 or 42%, reside in Bernalillo County (all but one of these lives in the Albuquerque metropolitan area).

Rather than contact all of these individuals, particularly since Albuquerque would be overrepresented, we initially selected 45 caregivers for initial telephone contact; 20 from the group in Bernalillo County and the remaining 25 from around the state. During telephone contact, we explained the grant purpose along with optional ways to participate: focus group, online survey, or individual interview. We asked interested caregivers to choose one method of participation.

Because the list provided by SONM may not have included all individuals with Down syndrome, we also provided grant project information to organized parent support groups, and advocacy and provider agencies and requested that anyone interested in participating in the research contact us directly. Though we reached out to families and others who care for individuals with Down syndrome through SONM and other support and advocacy groups, in the end, most of our participant volunteers were recruited directly, through informal contact with project staff. Staff spent time traveling around the state talking to those in the Down syndrome community about the project and most of those who took the online survey and participated in focus groups are individuals who staff met through these outreach efforts. In the end, 26 caregivers from New Mexico responded to the web-based survey and 91 participated in focus groups.

Though this is clearly not a random sample, as demographic information indicates, the respondents come from communities across New Mexico and care for individuals ranging from childhood through adulthood. As such, they are a useful group of key informants from which to learn pertinent information about the service gaps that individuals with Down syndrome and their families/caregivers face in New Mexico.

To identify potential providers who could complete the web-based survey, SONM provided contact information (including email addresses) for thirteen healthcare providers participating in the SONM “Healthy Athlete Program.” Details of the grant project and a web-link to the web-based survey were sent via email to, service providers and public school programs (e.g., transition, therapeutic recreation, special education, therapy).

We developed a web-based survey to identify the key needs and service gaps for individuals with Down syndrome in New Mexico. We created a separate survey for families/caregivers and for providers, with both relying on closed-ended Likert scale questions and open-ended response questions to capture key information. Family and caregiver survey questions measured their attitudes and perceptions about the need, availability and sufficiency of services in their community including: healthcare, education, social activities, and sources of information and support. Service provider survey questions measured attitudes and perceptions about their sources of information and support, their level of knowledge, education and training regarding Down syndrome, and the need and availability of local services. Both surveys also included an optional section where respondents could provide demographic information. Caregiver/family respondents were asked about their own demographic backgrounds (gender, income range, and education level) as well as the demographics of the individual with Down syndrome (age, gender and race). Providers were asked to report their gender, highest level of education, and length of time as a provider. The surveys were kept purposely short to encourage completion.

In addition to the web-based survey, we conducted thirteen focus groups and one telephonic interview with caregivers of individuals with Down syndrome. Focus groups met in Albuquerque (N=6), Farmington (1), Gallup (1), Rio Rancho (2), Roswell (1), Las Cruces (1), and Shiprock (1) with 91 participants in total. On average, focus groups had seven caregiver participants. Most focus groups met once, for about two hours. Two of the Albuquerque focus groups elected to return for an additional 90 minute meeting a month later to streamline their concerns and recommendations.

We digitally recorded all focus groups and one member of the research team also took written notes at each meeting. As optional measures, we asked participant caregivers to provide their socio-demographic information, including ethnicity, educational level, household income, outside employment, insured status and whether the individual with Down syndrome resided with the participant. To maintain respondent confidentiality, we separated the sheet with contact information from the document containing background or demographic information. Additionally, we collected no names or addresses that would link responses to individual participants.

We used a series of broad questions to frame focus group discussions and individual interviews and gain knowledge about the needs of individuals with Down syndrome:

- What is your primary role in the care, education and support of individuals with Down syndrome?
- What are the key things that make it difficult to provide care education and support for individuals with Down syndrome?
- What are the key things that make it easier for caregivers to provide care education and support for individuals with Down syndrome?
- What local agencies/people do you work with that help in efforts to provide care/support?
- What do you do to keep informed of existing or new services?
- What are the services that are needed but not available in the local community?
- What are some barriers to those services being provided?
- What age group is there the greatest need for services?
- What age group is there the best range of services available?

## Provider Web-Based Survey Results

### *Provider Respondent characteristics*

Forty-five providers from a variety of communities throughout New Mexico responded to the web-based survey. Every county in New Mexico had at least two providers who offer services to that county. The majority of respondents provide services in Bernalillo County (56%) followed by Taos and Lea Counties (16% each), Eddy and Valencia Counties (13% each), Sandoval County (11%). The remaining counties are each served by less than ten percent of respondents. The largest group of respondents identify themselves as educators (47%) followed by health care providers (24%) and social service providers (18%). About half (52%) of respondents report working directly with individuals with Down syndrome for over ten years. Though not all respondents offer services to the full range of age groups, together the providers represent a group that serves the full range of age groups from birth through late adulthood (see Table 1). Of those who provided their gender (N=32), 72% are female. Most provider respondents (61%) have an advanced degree.

Table 1. Age groups served by responding providers.

Age Group	Age range for which respondents provide services	
	N	%
Birth through 3 years	12	27%
4 through 12 years	23	51%
13 through 17 years	18	40%
18 through 22 years	14	1%
23 through 40 years	14	31%
41 years and older	14	31%
Don't know	—	—

### *Need and availability of services*

Over half of the providers who responded to the survey (60%) agree that “Individuals with Down syndrome are different enough from individuals with other kinds of developmental disabilities that there should be services designed to specifically address their needs,” while (24%) disagree with this statement. Most respondents (67%) report being well informed of the needs of individuals with Down syndrome in the community(ies) where they provide services. Over half (53%) also report being well informed of the services available to meet those needs.

However only 14% of providers agree that the services available in the community(ies) they serve are sufficient to meet the needs of individuals with Down syndrome. At the same time, 55% disagree and 31% are unsure whether their communities offer sufficient services. Of the available services, providers highlight early intervention and school based programs. When asked about non-health care service needs, provider respondents detailed caregiver services and transition to adulthood training as notably lacking.

Figure 1 shows respondents' sense of the age ranges with the best and the most limited range of services available to individuals with Down syndrome in the community(ies) they serve. In general, providers replied that younger age groups have a better range of services available, particularly up through age 17 years. Respondent replies were mixed because at the same time, providers also reported that the age group with the most limited range of services is 4 to 12 years. They also report a limited range of services for adults 23 years and older. It is also notable that over one-third of providers reported not knowing which age ranges have the best or most limited range of services available.

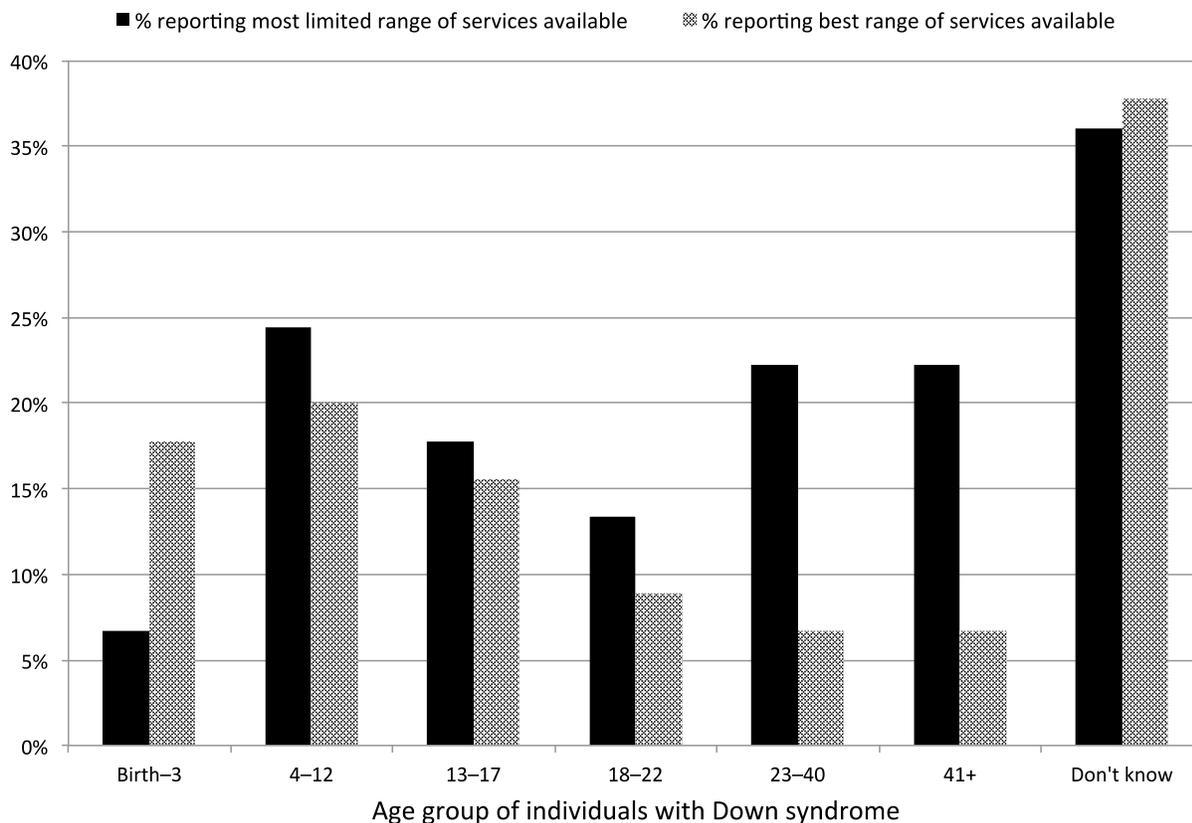


Figure 1. Age ranges with the most limited and best range of services available for Down syndrome as reported by providers.

The majority of provider respondents report moderate to high need for a range of medical services specific to individuals with Down syndrome (see Table 2). Respondents also report limited availability across the same range of services. The gaps in service (calculated by subtracting the availability reported from the need reported) are greatest for behavioral (60%) and mental health (58%). Although providers note significant gaps in all areas surveyed.

Table 2. Need, availability and gaps in health care services for Down syndrome.

	Moderate to high need		Moderate to high availability		Gap in services (Need minus availability)
	N	%	N	%	
Behavioral health	35	78%	8	18%	60%
Mental health	34	76%	8	18%	58%
Specialty health care	28	62%	8	18%	44%
Dental health	32	71%	14	31%	40%
Speech therapy	32	71%	15	33%	38%
Developmental pediatrics	31	69%	14	31%	38%
Audiology/Hearing	30	67%	13	29%	38%
Physical therapy	31	69%	16	36%	33%
Occupational therapy	31	69%	16	36%	33%
General child health	32	71%	19	42%	29%
General adult health	29	64%	18	40%	24%

### *Training and education about Down syndrome*

Only 16% of provider respondents report having received training or education specifically on Down syndrome within the past five years, 35% report never having received such training, and 47% report having received such training over five years ago. At the same time, the majority (70%) agrees that the formal training/education that they have received has been useful and up-to-date. Among the types of training respondents report having received, a number reported graduate school training in special education. Other training sources include continuing education courses and attending professional conferences. Providers also note the need for more continuing education courses and other ongoing training opportunities.

Providers report that they receive information about Down syndrome from a variety of sources. Most (60%) report using internet web searches. In addition, 27% have taken continuing education courses to learn more about Down syndrome. Another 24% report getting information from national Down syndrome organizations and the same percentage report obtaining information from professional medical organizations. Finally, 9% seek information from local support groups. Respondents also stated that they receive information from families

and other professionals with whom they work. In general, most respondents (67%) state that this information is useful and up-to-date, while 31% disagree.

## **Caregiver Web-Based Survey Results**

### *Caregiver Respondent Characteristics*

Twenty-six caregivers from various communities in New Mexico responded to the web-based survey. Parents of individuals with Down syndrome make up the majority (81%) of these respondents. The remaining respondents include one sister, two guardians and one “support person.” The largest group of respondents report living in Bernalillo County (33%). Eleven percent of respondents report living in Eddy County and another eleven percent in Sandoval County. Seven percent report living in Taos County. Chaves, Dona Ana, Grant, Lea, McKinley, Otero, San Juan, Santa Fe and Valencia Counties each has one respondent (4%). Of those who report demographic information (n=20), 85% are female. The majority of caregiver respondents (65%) report having a college degree or an advanced degree. Most (58%) work full-time outside the home, 26% work part-time while 16% do not work outside the home. Of the 17 respondents who report their annual household income range, 30% report an annual income under \$40,000 while the remainder is split between those making between \$40,000 and \$80,000 (30%) and those making above \$80,000 (25%).

### *Characteristics of the Individuals with Down syndrome*

Twenty respondents provide demographic information about the individual for whom they provide care. Of these, 45% report caring for a female. One half of the individuals with Down syndrome are Anglo/Caucasian, 35% are Hispanic and 15% are American Indian/Alaska Native. Figure 2 shows the age range of the individuals with Down syndrome. Half of the respondents report caring for an adolescent (13-17 years) or young adult (18-22 years). Most of these respondents report the individual for whom they provide care has at least one form of health care insurance, the most common being Medicaid (70%) or private insurance (50%) (see Table 3). Only one respondent states that the individual with Down syndrome does not have insurance. Forty percent rely on more than one form of insurance.

The majority of respondents (84%) report that the individual with Down syndrome for whom they provide care lives with them full-time. The remainder of respondents report that the individual for whom they provide care either lives with them part-time, with another relative or in a residential home.

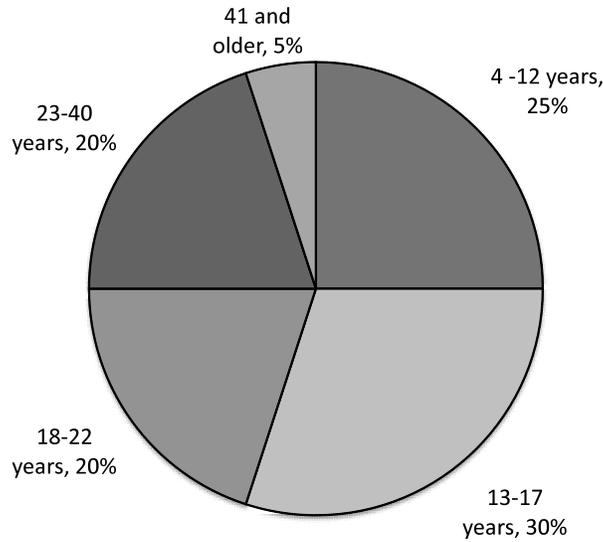


Figure 2. Age group of individuals with Down syndrome for whom respondent provides care.

Table 3. Health insurance type for individuals with Down syndrome.

Health Insurance Type	N	%
Medicaid	14	70%
Private insurance	10	50%
Medicare	4	20%
Public Health Service	2	10%
VA benefits	1	5%
Other	1	5%
None	1	5%

### *Need and availability of services*

Virtually all of caregiver respondents (92%) agree that “Individuals with Down syndrome are different enough from individuals with other kinds of developmental disabilities that there should be services designed to specifically address their needs,” while only 8% disagree with this statement. Most caregivers (92%) also report being well informed of the needs of individuals with Down syndrome. One half (50%) also report being well informed of the services available to meet those needs in their community. However, only 13% of caregivers agree that the services available in their community are sufficient to meet the needs of individuals with Down syndrome. At the same time, 84% disagree and 4% are unsure whether their communities offer sufficient services.

Figure 3 shows caregiver respondents' sense of the age ranges with the best and the most limited range of services available to individuals with Down syndrome in their community. Overwhelmingly, caregiver respondents indicate that younger age groups have a better range of services available, particularly up through age 12 years. Caregiver respondents also report a limited range of services for all age groups beyond age 3 years.

Respondents state that among the best services available to them are 1) early intervention programs and services and 2) Special Olympics. Respondents were also asked to provide detailed information about service needs in their community. Service needs fall into four primary categories: 1) education, 2) transition to adulthood, 3) health and 4) socialization experiences. With respect to education needs, respondents identify a lack of: inclusion services, special education teachers, and continuing and higher education opportunities for individuals with Down syndrome. During the transition period from adolescence to adulthood, respondents report a need for: occupation/job training, employment opportunities, access to housing, interim services/support while awaiting a DD waiver. With respect to health needs, respondents identify needs for: speech, behavior and physical therapy services as well as providers who have experience treating older individuals with Down syndrome. Respondents also note a lack of social activities and outlets for individuals with Down syndrome. In addition, more than one respondent notes the need for respite care services.

Respondents were asked to detail the specific things that make it difficult to access services for individuals with Down syndrome. Common responses note distance, inadequate knowledge of and lack of available of services. Respondents suggest that services are usually located in urban areas and families who live outside of those areas have to travel significant distances to access these services. This is particularly difficult for caregivers who work full-time. Respondents note that services are not well advertised and information about services is hard to access. In addition, many programs have long waiting lists and the bureaucracy can be difficult to navigate.

To help caregivers stay informed, many report using the Internet including Facebook, email, Internet search engines and specific websites (e.g., [www.disabilitycoop.com](http://www.disabilitycoop.com)). They also report sharing information with one another via support groups and informal networks.

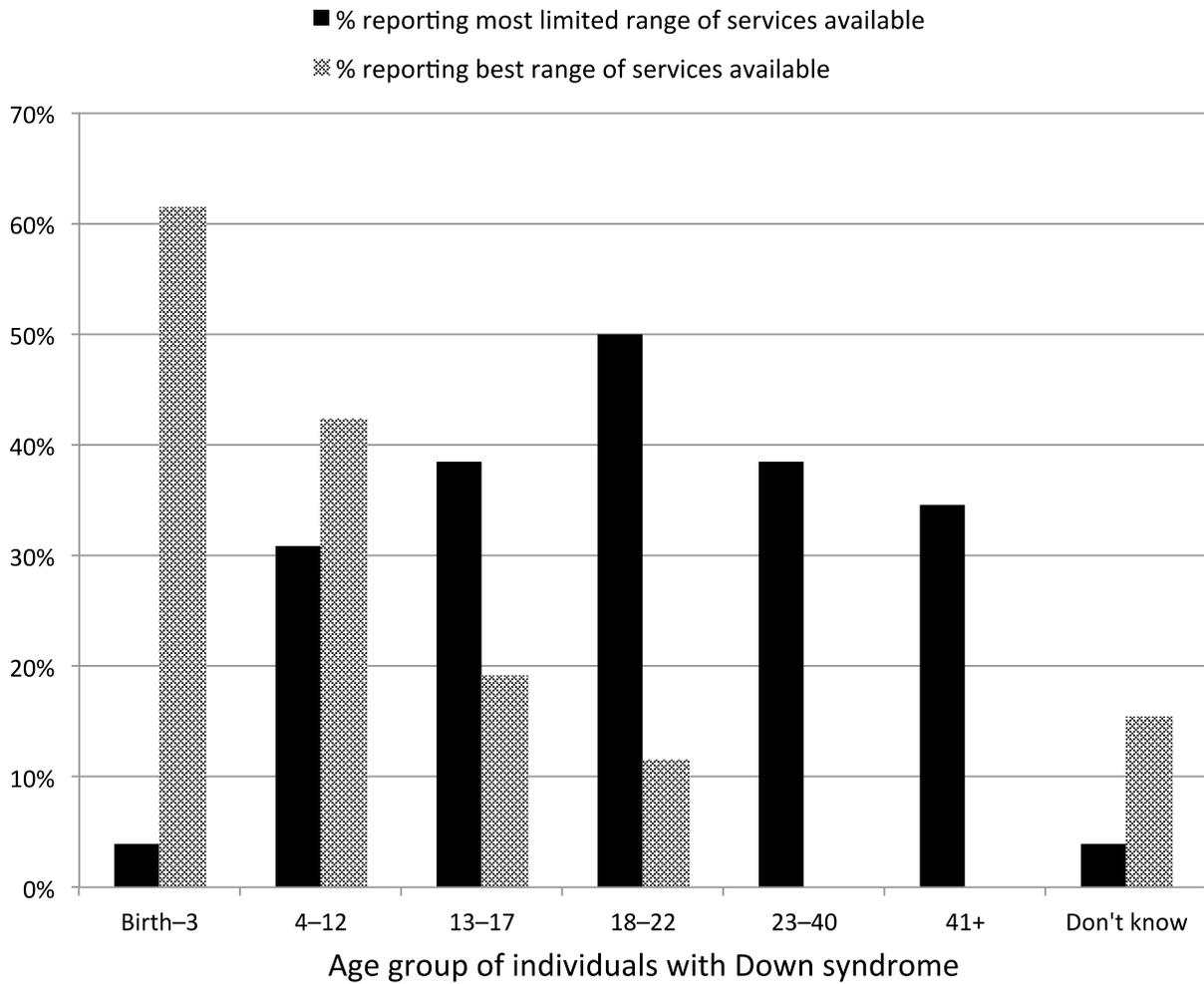


Figure 3. Age ranges with the most limited and best range of services available for Down syndrome as reported by caregivers.

Note: Throughout the sections detailing web-based survey results, percentages may sum to greater than 100% when respondents were able to select more than one response. In some cases, percentages may be less than 100% as a result of missing data or “Don’t know.”

## Focus Group Results

We conducted thirteen focus groups and one telephonic interview with family members and caregivers throughout the state of New Mexico. We held focus group meetings in Albuquerque (6), Farmington (1), Gallup (1), Rio Rancho (2), Roswell (1), Las Cruces (1), and Shiprock (1) with 91 participants (see Table 4 for a summary of participant demographics). On average, each focus group meeting had 7 participants. Two members of the project team attended each focus group meeting. One lead the discussion while another took detailed notes about key topics and issues raised by participants.

Most focus groups met once for 2 hours. However, two of the Albuquerque focus groups elected to return for an additional meeting a month later to streamline their concerns and recommendations.

### *Open-Ended Questions*

We elected to conduct focus group meetings to supplement survey data with more specific and nuanced details regarding the needs and service gaps facing individuals with Down syndrome and their families/caregivers. We used the following set of questions to a set of questions to frame focus group discussions around these issues:

- What is your primary role in the care, education and support of individuals with Down syndrome?
- What are the key things that make it difficult to provide care education and support for individuals with Down syndrome?
- What are the key things that make it easier for caregivers to provide care education and support for individuals with Down syndrome?
- What local agencies/people do you work with that help in efforts to provide care/support?
- What do you do to keep informed of existing or new services?
- What are the services that are needed but not available in the local community?
- What are some barriers to those services being provided?
- What age group is there the greatest need for services?
- What age group is there the best range of services available?

These open-ended questions, allowed for facilitated discussion to share experiences and opinions regarding these topics. Families were able to discuss what services they need, what has not worked and the barriers to providing the care, education and support of individuals with Down syndrome. Focus group discussions all keyed in on similar service and access barriers and identified a similar range of programming needs. Moreover, the discussions echoed the findings from the survey while providing more detail regarding the specific problems individuals

with Down syndrome and their families/caregivers face on a daily basis. In the following sections, we summarize focus group responses to each of these questions, highlighting illustrative quotes that express group sentiment.

Table 4. Characteristics of the family informants and the individuals with Down syndrome who participated in the focus groups.

Characteristics of the individuals with Down syndrome	N	%
<i>Age group</i>		
0-3 years	1	1%
4-12 years	25	34%
13-17 years	11	15%
18-22 years	13	18%
23-40 years	18	25%
41 and older	5	7%
No answer	—	—
<i>Gender</i>		
Male	34	49%
Female	35	51%
No answer	3	4%
<i>Race/Ethnicity</i>		
Anglo/Caucasian	40	58%
Hispanic	23	33%
American Indian/Alaska Native	12	17%
Asian	6	9%
Other	3	4%
No answer	—	—
<i>Health insurance</i>		
Private insurance	32	46%
Medicaid	32	46%
Medicare	10	14%
Public Health Service	3	4%
VA benefits	2	3%
Other	5	7%
None	2	3%
No answer	10	14%
<b>Characteristics of the family informants</b>		
<i>Gender</i>		
Male	17	25%
Female	50	72%
No answer	2	3%
<i>Education</i>		
Less than high school	1	1%
High school graduate	10	14%
Some college or university education	17	25%
College or university degree	21	30%
Some graduate education	3	4%
Graduate degree	11	16%
No answer	10	14%

Respondents may have selected more than one category for most questions. As a result, percentages will sum over 100%.

### *Description of Focus Group Themes*

#### ***What is your primary role in the care, education and support of individuals with Down syndrome?***

Participants described themselves as parents, teachers, advocates, caregivers, protectors, and fighters for their children. Participants expressed concerns that all parents share; however these concerns are intensified with their family member with Down syndrome.

A common theme was the additional time required to provide the care, education and support for a family member with Down syndrome. Participants remarked how rewarding and challenging it is being the parent of a child with a Down syndrome. Parents felt that their child with Down syndrome is “no different than any of the others kids, you work with them, teach them, play with them. It just takes longer since they develop at a different rate.” Many parents stated that they have to take a strong advocacy position for the needs of their children “we are the experts; we are the professionals because they are our kids.” A mother commented “I have to be a bear for my child.”

“We live in the boonies. I’ve thus become my daughter’s (who has Down [s]yndrome) best advocate. I spend a lot of time researching and reading about Down [s]yndrome.”

“As parents we face many everyday challenges”

“We have to always advocate for our children.”

***What are the key things that make it difficult to provide care education and support for individuals with Down syndrome?***

Participants noted how gaining accurate information and access to services is difficult and limits their ability to provide the best care for their family member. When discussing key things that make it difficult to provide care, education and support for their family member with Down syndrome, participants noted problems in three key areas: access to quality health care, access to educational services and access to good information about the various support services available to them.

***1) Access to quality healthcare***

Participants listed a variety of problems navigating the health care system and finding physicians with the expertise to care for Down syndrome patients. These problems are clearly magnified for those from rural areas. Not only do the rural communities have trouble with general practitioners for the entire community, but finding a provider with the knowledge and ability to care for their family member with Down syndrome is difficult. One family described difficulties with an audiologist. This practitioner wanted to fit their son with hearing aids because he could not pass the tests the audiologist conducted. The mother had to educate the audiologist about the difference in ear canals for individuals with Down syndrome. Her child did not require hearing aids.

Nearly all participants expressed the desire for “health care with Doctors specializing in the knowledge of Down syndrome and their potential strengths and possible health issues.” Families expressed the need for “pediatricians with knowledge” to

“medical providers with knowledge of older individuals with Down syndrome.”

## 2) *Access to education*

Focus group participants discussed a range of problems they encounter when to access the school system and also noted that providers lack access to education as well.

### School System

Focus group participants indicated that school systems vary, not only between cities and counties, but also within the same school system. Some parents described proactive teachers who ensure their child’s needs are being met. Others did not have the same response. Some of the major issues included:

- Individual Education Plan (IEP)- Parents would like to know their legal rights and their child’s legal rights. Parents did not know if their child received the right amount of therapy, or if the school was basing the therapy on their child’s needs as opposed to the budget. Parents wanted to know if their child qualifies for an educational assistant or the pros and cons of inclusion versus non-inclusion in school.
- Parents indicated that the transitions between kindergarten, elementary, middle and high school are very difficult. Participants felt that they spent great time and effort to navigate the system just to move to another school once you have figured it out.
- Parents commented, “There is little information in the high schools. “ This sentiment was expressed across the board from pre-school through high school.
- Parents also expressed the lack of information about post-secondary education for their child, many did not know of the program in Roswell at Eastern New Mexico University. Parents who learned about this through the focus groups expressed the “lack of access to post secondary education.”
- Parents expressed that “the schools are in need of change to support these children in helping them lead to an independent life.”

### Education of Service Providers

Participants described difficulties with medical service providers having the knowledge and information required to provide competent care for individuals with Down syndrome.

Much like survey participants, focus group participants also portrayed the general feeling that “Individuals with Down syndrome are different enough from individuals with other kinds of developmental disabilities that there should be services designed to specifically address their needs.” The majority of participants reported a high need for better range of services available for individuals with Down syndrome. Additionally, they reported that there is limited availability, particularly in the rural regions of the state.

Participants identified a wide range of medical providers who need training, ranging from nurses to physicians and dentists, generalists to specialists. Specifically enumerated medical specialists included obstetrician/gynecologists and cardiologists. Allied health providers, including geneticists and audiologists were also mentioned.

3) *Access to accurate information about services, including, the DD waiver, physical and occupational therapy, support services, socialization services.*

Participants discussed the problem that access to accurate information regarding all aspects in the care, education and support of individuals with Down syndrome is limited. Parents from numerous focus groups stated that there is “lack of information,” that “there are no services geared specifically for individuals with Down syndrome.” One of the most common themes was the varying information that is provided to families. One parent noted that “information not provided, I found out about Hypnotherapy from another parent and my Early Intervention Service provider did not mention it at all.” Parents noted that they learned about the DD waiver, therapy, educational rights and various other services through word of mouth or by ‘accident.’

Participants identified the following systems in which they had received inaccurate information or no information at all.

- Health Care Information
- Social Services Information
- School System Information
- Post Secondary/Life Skills Information
- Legal Information regarding their family members rights and their rights and responsibilities as caregivers
- DD Waiver
- SSI
- Needs planning for financial and legal services individuals with Down syndrome

“There are no services geared specifically for individuals with Down syndrome.

“Services available for individuals with disabilities are only accessible with the DD waiver.”

***What are the key things that make it easier for caregivers to provide care education and support for individuals with Down syndrome?***

Participants identified Special Olympics as one of the key resources in the state. This program allows parents social interaction with other families with individuals with Down syndrome and

the socialization that their family member needs. Participants attribute the success of this program to the mission; it is all about the “kids” the participants. Special Olympics focuses on the needs of those they serve.

Participants identified the DD waiver as a resource that makes it easier in the care, education and support of individuals with Down syndrome. Those who were on the DD waiver felt that what it provides their family member is better than not having it. “Without the DD waiver I cannot get my child into a program.” Those who were on the waiting list expressed the desire to have this. Participants felt that access to therapists, case management programs, and other resources such as “respite care is not affordable without the waiver.”

***What local agencies or individuals do you work with that helps in efforts to provide care and support?***

Participants in every focus group identified one person in their community that they often go to. This individual was either from a service provider or a parent of an individual with Down syndrome.

Participants identified Special Olympics as the agency that provides them the most information and assistance. Through the athletic programs that they offer families are able to connect with other families and gain valuable information for their family member. Often this is the only access to resources and referrals for families. Other services mentioned include:

- Arc of San Juan County
- Native American Disability Law Center
- DDPC Developmental Disabilities Planning Council
- PRO Parents Reaching Out
- The ARC of New Mexico
- The early intervention programs in their community, for example, Round tree, Tresco, La Vida Felicidad, etc.

***What do you do to keep informed of existing or new services?***

Participants described that the best way, and often only way, they are aware of existing or new services in their community is from other parents. Participants described this as ‘word of mouth.’ The ‘word of mouth’ referrals and information is often provided in the Special Olympics setting. Key comments from parents include:

“For me personally, I find a lot of information through Facebook.”

“I don't have any knowledge of any services.”

“I have a family friend that keeps me informed.”

“Talking to people on my child's Special Olympic team.”

“The Arc and the Internet Disability Scoop “

“Through my work with the school. Panels that I am on in our community.”

“Word of mouth from other Down syndrome families.”

***Are there services needed but not available in local community?***

Participants described a wide range of unmet needs in their communities. These needs had several common themes.

*Socialization*

Participants discussed the need for socialization and activities for their family members, other than Special Olympics. Which was often described as the only activity or resource for families. Ideas including Merry Makers (a dance program), fitness activities, social activities.

*Notification*

Participants described varying stories regarding how they learned their child had Down syndrome. Some participants were aware prior to birth via prenatal screening and others learned at birth. Participants describe the need for a more thoughtful process regarding how parents are initially informed about their child’s Down syndrome. Participants described wanting a welcome basket, number of another family to speak with or someone to meet them at the hospital.

One mother had to force the doctors to test her child and had to fight for the Down syndrome diagnoses. Doctors told her that her child was fine because her child was Asian they did believe her.

One family said that 22 years ago when they brought their child home from the hospital they got a knock on the front door and it was a mother and her toddler with Down syndrome. They have become lifelong friends.

One mother said the doctors and nurses were whispering around her daughter about her having Down syndrome and that is how she and her husband learned.

One mother said they told her that her child has Down syndrome, gave her a one-sheet information sheet and sent her home. No one told her about the small nasal passages of her infant and her child almost died because she didn’t know what to do.

One mother, Spanish speaking, said the doctors told her that they could help her get rid of her son. Have him adopted.

*Post-Secondary Transition:*

Participants described the transition between the educational system and adulthood like falling off a cliff. They identified an acute need for better independent living education and services for adults with Down syndrome. Parents often expressed a need for 'more' once schooling ends. Comments were extremely informative and included:

“Social gatherings for individuals with Down’s syndrome and awareness brought to the "normal" citizens of the community about Down’s syndrome.”

“There is information out there regarding early intervention and school, but what happens after high school – transition from school to adult world? We want our children to have a good quality of life like everyone else including friends, jobs etc.”

“Independent living skill classes once an individual reaches adulthood (school should be focusing on academic needs first then if appropriate address living skills), independent housing without DD waiver support, higher education possibilities and employment possibilities.”

“Minimal transition to adulthood supports/services. It's like dropping off the edge of the cliff once school ends.”

“My child has a complicated congenital heart defect, had three heart surgeries, and is currently doing well. She spent 4 months in the NICU when she was born, survived MRSA at 7 weeks, has hypothyroid, needs eyeglasses, has enlarged tonsils, had 5 different audiologists but today can safely confirm her hearing. Bottom line, I have a wonderful pediatrician who has helped manage her care and given great advice. While she requires many checkups throughout the year, can and has been hospitalized for respiratory viruses, I feel education after high school, employment opportunities, and care when/if she is older is most important.”

### *Down syndrome Clinic*

Participants identified a need for a medical facility in which they could receive specialized care for their family member. This clinic would not only provide this information, but also provide resources and referrals. Many participants expressed the need for a social worker in this facility who could provide accurate information. Participants want accurate information about social programs, medical information and various other referrals. Parents commented on numerous occasions that 'a Down syndrome clinic would be a great asset.'

### ***What are some barriers to those services being provided?***

#### *DD Waiver*

Participants frequently noted issues regarding the DD waiver. One family member described it as the "have and have not." Frequently participants described how they "stumbled on" to the DD waiver and were never told about it through any service provider or through the schools. Often families stumble on this very late in their child's school years and with the 8 to 12 year waiting list they often have adult family members with no access to services.

Information regarding the DD waiver and the Mi Via Waiver varied from group to group, and within each group. Participants would like accurate information about:

- What are the steps to sign up?
- When should you sign up?
- What are the eligibility requirements?
- What does the waiver provide for my family member?
- What are my family members rights under the DD waiver?
- What are the federal and state financial restrictions under the DD waiver and other assistance programs?

The DD waiver and issues surrounding the DD waiver was a constant theme. Parental comments included:

"The waiting time to get on the Medicaid DD Waiver. The Jackson lawsuit in New Mexico has eaten up money that could have gone to get more people on the DD Waiver."

"The ridiculously long wait (~16 years) to receive a DD waiver allocation. If a family can't self-pay for services, it is very difficult for individuals to participate in the community after they finish school."

“Many people do not know about available services including the DD Waiver.”

“There is limited to no access to services for individuals on the DD waiver waiting list. These services include; socialization with others, day hab, respite, training for employment.”

#### *Distance and rural barriers*

Many communities described the rural nature of the state a barrier to proper services for their family members. Communities have difficulty with getting and retaining providers for all services in their community.

The time to travel to Albuquerque, Lubbock or another urban setting is often time consuming and expensive. It is at least 6 hours round trip in addition to the visits. These trips are often overnight. Parents noted that the lack of local services and the geographical barriers often makes it difficult. “ I take my daughter for any medical needs to Albuquerque. Closer service would be very helpful.”

#### *Access to therapy or services*

Participants identified inability to access therapists for all age ranges. Many of the more rural communities described the difficulty in obtaining and retaining therapists.

Participants also identified inability to find services for their family members, especially non-health care related services such as:

- Living skills classes
- Transportation services
- Job/employment which will not jeopardize assistance
- Social Classes or Programs
- Sports Programs
- Dance Classes
- Art Classes
- Physical fitness programs

#### *Access to Accurate Information*

Participants identified the need to have accurate information provided. Many participants recognized during the focus groups that information they received about healthcare, schools, legal, DD waiver and other services was very different than what other participants were reporting.

### ***What age group is there the greatest need for services?***

As the survey results suggest, participants generally agreed that once their family member was no longer in the Early Intervention Program services declined. The needs of their family member changed dependent on what age range they fall in. Participants often described these age ranges as transitional periods. They often described that during the transitional period, when access to services is greatly needed, finding the services to meet their needs was difficult. Common transitional periods include.

#### Ages 4 to 6

- Continued access to the therapy that was provided in Early Intervention.
- Assistance for families during this time, including day care for their family member.
- Access to physicians that can work with individuals with Down syndrome.
- Milestones information: Participants identified the need for information about what milestones their child with Down syndrome should meet as opposed to a normally developing individual. For example, information about Potty training, walking, talking and reading.

#### Elementary/Middle/High School

- Therapy, which is mandated through schools, is limited and dependent on the school and school district. School systems across the state do not have an adequate number of therapists.
- Information about educational rights. How to successfully navigate the IEP (Individual Education Plan).
- Milestones information: Participants identified the need for information about what milestones their child with Down syndrome should meet as opposed to a normally developing individual. For example, puberty, reading, potty training and verbal communication.

“School Aged Children: Taos County doesn’t have any of the fun and enriching programs that Albuquerque has (Horseback riding, theater classes, etc.). All disabled kids in Taos County are lumped into one category. The only activity open to them is Special Olympics and for the Peñasco Community that started just this past year.”

#### Post-Secondary Needs

Participants often described this transition with increased difficulty. “Services drop off immediately after individuals leave the school system. Interim services/supports are

needed while people for a DD waiver allocation. Oftentimes, people are on the DD waiver waiting list for many years.” Participants expressed concerns about their family members transition from a school desk to the couch without access to services.

- Meaningful training or educational programs.
- Transitional living
- Independent living skills
- Adult respite
- Access to the DD waiver
- Guardianship issues
- Financial concerns
- Ability to earn income and still qualify for services

***What age group is there the best range of services available?***

Participants generally agreed that the best range of services, in each community, is the Early Intervention program, from birth to three. “Early Intervention services can help a parent learn how to provide care.” Early Intervention Programs provide:

- More therapists of all types
- Individual relationship w/family
- Programs and daycare to take children to
- Respite care
- PT-neck exercises, muscle tone, PT based in the needs of their family member
- Speech therapy
- Social interaction to develop skills

Although participants generally agreed that this was the best age group the services described between the various programs around the state varied widely. Parents commented that “early Intervention is very supportive. They help children with one on one and also help with supporting families in connecting to other services and families; when children get older there is little support in the schools along with low expectations and little opportunity for these children to live independently, contribute to society and be able to make real life friendships.”

One program, in a rural community, was spoken of highly throughout the state. Participants described this agency meeting with them within 24 hours of their child’s birth, providing accurate information about local and state resources, and accurate information about the DD waiver and other social services.

## Recommendations

The caregiver web-based survey, provider web-based survey, focus groups, personal interviews and national research identified several areas of need for individuals with Down syndrome in New Mexico. The findings from the surveys and focus groups closely echoed the information gathered through the personal interviews and national research conducted for this project. The findings result in three recommendations: centralized clearinghouse information regarding all aspects involved in the care, support and education, establish a Down syndrome clinic, and training and education for healthcare professionals, educators and service providers.

- 1) *Develop a centralized clearinghouse of information regarding all aspects involved in the care, support and education of individuals with Down syndrome for families, caregivers and service providers*

Caregivers, families and providers need to have access to accurate information. Information provided to families, caregivers and providers, regarding all aspects in the care, support and education of individuals with Down syndrome, is often missing information or inaccurate. This one-stop-shop, clearinghouse should have up to date, accurate and accessible information.

Participants from the focus groups described this either a web-based resource or a resource center with a social workers available. Many felt that having human contact would be helpful, providing a human connection. However, participants were concerned about the sustainability of a resource center. Participants broke down the topics that this centralized clearinghouse should have information on in the following categories:

- Families- lists of families in their community that other families with individuals with Down syndrome can contact.
- Transitional ages: Information pertinent to the following transitional ages: pre-natal, birth, ages 0 to 3, elementary, middle, high school, transition to adult, independent living, senior issues. Participants identified these groups as having unique needs.
- Legal Information: Information about families and individuals with Down syndrome legal rights, educational rights. Information about guardianship, financial information associated with access to the DD Waiver and social programs
- Medical Professionals- lists of medical professionals, who are trained, provide excellent care or specialized services.
- Social Service Providers: Agencies that can provide services such as respite care, assistance with obtaining case managers, and community services.

- Educators- information for educators who work with individuals with Down syndrome. Network list for families to learn of promising practices in the education of individuals with Down syndrome.
- Community information. General education for the community about individuals with Down syndrome.

2) *Establishment of a Down syndrome Clinic ,attached to the University of New Mexico Hospital, Center for Development and Disability.*

Establish a clinic, which could provide a multidisciplinary approach for individuals with Down syndrome from pre-natal through senior care. The clinic should provide general medical care, referrals and connections with specialists when needed and provide resources, advocacy, and supports to all families of individuals with Down syndrome, depending on their individual needs. The clinic should include medical professionals and social workers who can provide accurate information about resources and services available The Down syndrome Clinic should: establish programs that provide peer support throughout the state, establish programs that can provide healthcare (medical, physical therapy, etc.) and services that overcome the challenges of rural communities, and potentially be attached to the University of New Mexico Hospital.

3) *Training and education regarding all aspects involved in the care, support and education of individuals with Down syndrome for healthcare professionals, educators and service providers.*

Access to accurate information regarding all aspects in the care, education and support of individuals with Down syndrome is limited. One of the most common themes was the varying information that is provided to families. Families expressed the need for healthcare professionals, educators and service providers to receive accurate and up to date training and education regarding Down syndrome. Target audiences included: educators, the school system, doctors, nurses, therapists, various medical professionals, and social service programs.

These recommendations aim to address the needs and service gaps for individuals with Down syndrome throughout New Mexico. These recommendations are a direct result of the results of the web-based surveys and focus group interviews and information regarding national research and best practices.

## Quick Reference Matrix

Identified Need	Solutions/Promising Practices	
	Care/Coordination	Education
Need for Programs/practices to be supported by legislation (local/national) and funding. This need exists at every level – local, national and international		Legislators need to be educated by advocacy group sand constituents regarding needs of the Down syndrome Community.
Comprehensive Special Needs Planning to include financial and legal services for a person with Down syndrome at the poverty level. This has been consistently identified as a priority by families in the DS community.	Family advocates and trained care coordinators can educate individual families according to identified needs.	Workshops can be developed/offered to the DS community by local service organizations. Books are currently available on the subject.
Need for Programs/Practitioners and service providers to specialize in issues associated with Down syndrome. “Blind inclusion” vs. individualized services to accommodate and to take into consideration specialized needs (local) particularly with regard to advocacy services and medical services		Provide education and training to service providers regarding specialized needs of individuals with DS.  Create specialized Down syndrome care coordinator positions within service provider/advocacy organizations

<p>Need for services to accommodate/support family/siblings and caregivers (local/national)</p>		
<p>To assist in defining the scope of the problem including identifying persons with Down syndrome. “NM is blind to the data about individuals with Down syndrome. We can’t make people believe that we need more specialized services if we don’t have the data to back it up.” Knowing who the people are guides the research (and defines scope of the problem). Having a registry helps you find people who may benefit from the research and people who may participate in the research. This need occurs at every level - local, national and international</p>	<p>Centralized registry, database and Biobank</p> <p>Provide assistance to individuals with Down syndrome and their families and caregivers, health care providers in finding, evaluating, and using health research findings to help in prevention, diagnosis, and management of medical, psychological and oral health conditions to inform treatment decisions by individuals and their families</p> <p>Enhance visibility of Down syndrome research (i.e. /. Community and family partnerships)</p>	<p>Centralized registry, databank and Biobank</p> <p>Educate community about specialized needs/programs for individuals and families/caregivers in community</p>
<p>Need for focused and tested methods of providing educational services to persons with Down syndrome.</p>		<p>Special Needs Applications – ways to use the iPad and iPhone at home, in activities of daily living, in an educational environment and to support physicians with treatment and diagnosis throughout life span. Video modeling is an effective way of teaching this population from 3-18 years.</p>

<p>Community involvement in shaping the future for individuals with Down syndrome including pre-natal testing and medical care - awareness and education – impact we can all have by promoting positive aspects of Down syndrome.</p>		<p>Education and awareness campaign to health care professionals/training for medical personnel involved in caring for expectant mothers</p>
<p>Planning for transition from high school to adulthood – need for more specialized and supportive services and programs</p>		
<p>Need for networking and social support for individuals with Down syndrome that promotes quality of life and healthy social interaction</p>	<p>The “Cool Club” – to promote and create an environment for individuals with down syndrome and their families - to have a rich social life , social networking and interaction with other families by partnering with other parents and caregivers to create a “social club.”</p>	
<ol style="list-style-type: none"> <li>1. Need for medical services that are informed regarding the specialized needs of individuals with Down syndrome from pre-natal to death.</li> <li>2. Need for encouraging agencies and health care professionals to treat people with Down</li> </ol>	<p>Regional specialized clinics such as the Chicago DS Clinic at Lutheran or Sie Center for Down syndrome at Denver Children’s Hospital. There are 16 specialty clinics in the U.S., and others exist in the Middle East, the Netherlands, Slovakia, Sweden, Austria, Spain, Brazil, Argentina, Quebec, Japan, Nigeria, Israel,</p>	<p>Educate medical personnel regarding the identification and treatment of special medical needs occurring in the Down syndrome Community.</p> <p>Provide education and training to health care professionals in credible standards of care based on scientific evidence to individuals with Down syndrome</p>

<p>syndrome according to age and health needs – not just for their disability.</p> <p>3. Need to increase number of physicians, clinical psychologists, and allied health care professionals who have appropriate training and experience in treating adults, adolescents, and children with DS, including those from socioeconomically, culturally, rural, and linguistically diverse communities.</p>	<p>Pakistan, India, China, and Australia.</p> <p>Consult with individuals with DS, their families and primary and specialty health care providers to identify priority areas and develop standards of care for ensuring and improving the quality of their health care in their respective communities.</p>	<p>Expand education to other types of health care professionals used in providing healthcare to individuals with DS including geriatric, pediatric and other nurse practitioners and nurses, physician assistants, dental hygienists, and behavioral therapists.</p> <p>Support supplementary services to help physicians, dentists, psychologists, and other providers and organized health services in providing care to individuals with DS.</p> <p>Ensure that adaptive equipment and assistive technologies are available in urban, rural, and remote communities for use at clinical sites where individuals with DS receive healthcare.</p> <p>Identify multidisciplinary experts/advocate groups/family members/service providers working across systems to develop standards of care and education materials</p>
<p>Need for increased opportunities for parents, caregivers and individuals with Down syndrome to connect, interact, socialize and support one another on a regular basis</p>	<p>A statewide Coalition to improve care and coordination statewide by improving communication among families and service providers decrease</p>	

<p>(that also includes members from all Down syndrome statewide networks – and is financially supported</p>	<p>fragmentation of services and offer opportunities for socialization (to include assistance with transportation, food and activities. Coalition made up of a Board of Directors with a mission statement that involves community, inclusion and networking</p> <p>Host statewide DS conference</p>	
<p>“Change by design” – creating a better world for individuals with Down syndrome by applying a “human centered design” and putting the individual with Down syndrome first – rather than trying to “fit” them into systems that already exist but were not necessarily designed with them in mind.</p>		
<p>Need for focused and tested methods of providing educational services to persons with Down syndrome – this is a local, national and international need</p>		
<p>Establish local, regional and national awards that recognize excellence in providing services to individual with Down syndrome and their families</p>		

<p>The need to promote (and ensure continuity of care) healthy lifestyles for individuals with Down syndrome across the lifespan</p>	<p>Identify a package of healthcare/self-care/health promotion services for individuals with DS that will produce good outcomes in terms of health maintenance, management of illness, functionality, and life goals across the individual’s lifespan</p>	<p>Develop, evaluate, and disseminate continuing education curricula for service providers in the care of individuals with Down syndrome. Such curricula would be based on appropriate standards of care and include training opportunities that reflect understanding and respect for diverse cultures</p> <p>Support development and dissemination of effective training modules in interdisciplinary practice. Design modules should include social workers, family members, individual with DS, teachers, personal care attendants, job counselors etc.,</p>
<p>Make access to services for individuals with DS less complicated for their families and caregivers, whether in urban, rural, or remote communities (remove “unmanageable systems as constraints to service”).</p> <p>Need for better statewide and local service coordination, communication, less fragmentation among services/service providers, more information dedicated to</p>	<p>Ensure that independent service/care coordinators who work on behalf of clients to locate and ensure access to and coordination of services are available for individuals with DS who require such assistance</p>	<p>Support education of multidisciplinary teams, including mobile teams to bring services to individuals’ homes, schools and other non-clinical sites (to also address unique challenges in state including transportation and access problems in both urban and rural settings, lack of appropriately trained service providers, cultural and language barriers)</p> <p>Review eligibility to reduce</p>

DS, improved data		need for multiple applications and multiple determinations for eligibility for services. Promote the use of presumptive eligibility, once initial eligibility is established, for services through Medicare or SSI/Medicaid
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## Resources and Supplementary Materials

### Anecdotal Commentary

Melissa Ewer, attorney, Catholic Charities, (provides free legal representation to immigrants in New Mexico under the Violence Against Women Act). Challenges facing parent of disabled child: influence of language barriers on access to service, abuser blaming victim for having disabled child, lack of specialized programs in country of origin, lack of legal status and ability to access healthcare services for disabled child.

Dr. Jesus Galvan, DDS, Special Smiles, Delta Dental Plan of New Mexico; Special Olympics of New Mexico, Healthy Initiative Team. Dental care for individuals with disabilities and the Special Needs Certification.

Dr. Ray Lyons, DDS, FADPD, DABSCD, Dental Director, New Mexico Department of Health. Special Needs Dental Clinic." Hi Ann, I enjoyed speaking with you also and find your study interesting. Meaningful data is hard to come by in this field because responders, needs, and perceptions vary so broadly (from my own experience at a national level). I have attached what I believe is the current list of dentists who have completed the modules/training for certification with NM Medicaid for an enhanced fee when treating individuals with developmental disabilities. Also I have attached a "Best Practices" citation that describes the NM initiative that numerous states have looked to as an example for their own efforts. Oddly enough, I have been asked to provide training to more dentists out of NM than to those in state. Some dentists on our certified list have stopped seeing these patients due to hassles with Medicaid, or because they have become over burdened by patient access demands. I chronically receive complaints from practitioners as to the difficulties in dealing with agency and caregiver demands (paperwork, legal, noncompliance, etc.) and/or indifference. But I find the population to be challenging and enjoyable to treat. We NEVER have a boring day! If I can be of assistance please let me know.. DES34005NMspecialneedsdentalcode.pdf"

Tanya Baker-McCue, Director, Family Community Partnership Division, NM/LEND Faculty, Center for Development and Disability (CDD). The CDD is part of a network of 67 University Centers across the United States set up as part of Developmental Disabilities Assistance and Bill of Rights Act providing interdisciplinary education, distance learning and web-based courses, applied research, policy analysis, interdisciplinary healthcare and client services, and Information Network (providing comprehensive library services and community resource connections for individuals with disabilities their families, and professionals).

Nadine Maes, mother of son with Down syndrome, Family Specialist, CDD Information Network, Self-Directed Family Support Program. Current needs of families of individuals with Down syndrome; navigation, access and advocacy enhancing access to services by diverse populations; inclusive education; healthcare as a priority; education of healthcare professionals critical; prenatal diagnosis and access to accurate medical information and early contact with other families with members with Down syndrome.

Cristine Marchand, Executive Director, New Mexico Developmental Disabilities Planning Council. Using special needs apps, Smart phones, IPad technology for learning; Universal Design for Learning (design of instructional materials and methods that makes curriculum accessible to individuals with wide differences in their abilities).

Claudia Medina, Executive Director, Enlace Comunitario (a social justice organization led by Latina immigrants in Central New Mexico, providing direct services to Spanish-speaking victims of domestic violence and advocates for rights of Latino immigrants and their children).

Yoko Reece, mother of adult daughter with Down syndrome. Concerns raising disabled child: financial support after death of parent, education and transition training, lack of services without DD waiver; raising disable child in Japan; finding competent healthcare providers with knowledge about Down syndrome.

Nkazi Sinandile, Board member, New Mexico Women's Global Pathways (Empowering refugee women to gain self-sufficiency through education, economic development, and strengthened life skills). Presentation to Board on Planning Grant, September 7, 2011.

Sherry Spitzer, Executive Director, New Mexico Asian Family Center (provides comprehensive and integrated social services to the immigrant Asian population, facilitating access to educational, legal and social programs, clearinghouse of information and referrals). Asian, Middle Eastern, Pacific Islander, populations in New Mexico.

Jeanette Trancosa, Executive Director, EPICS (Education for Parents of Children with Special Needs, providing training, information, resources and support for parents, grandparents, family members and caregivers of Indian children with disabilities). Raising and supporting a child with disabilities in the Native American community; importance of training to educate and support parents in navigating education programs for children with special needs; access to, and influence of downsizing, in healthcare programs servicing Native Americans.

Ronalda Warito-Tome, Parent Training Specialist, EPICS. "Circle of Courage" and "Community Mapping" tools for assisting and training parents in identifying and utilizing community resources to support children with special needs; raising and supporting a child with a disability in the Native American community.

Johnny Wilson, Executive Director, Parents Reaching Out, (provides statewide networking opportunities for families with other families who have faced similar challenges with education and healthcare systems; training and mentoring for families in communities by volunteering; provide information and parent training in special education, advocacy, record keeping; Families as Faculty promotes family leadership skills and professional learning opportunities for future teachers and doctors). Challenges: meaningful inclusion with support system in place for students with disabilities, education and training for education assistants, developing and implementing successful transition programs in schools.

Kelly Hafer, Military Special Needs Network (network provides information and advocacy for military special needs families, assist families in navigating the military's Exceptional Military Family Program and the Extended Coverage Healthcare Option). "Military families in the more isolated regions, such as those stationed in New Mexico, may not be aware of the medical programs offered to families with dependents living with special needs. If these dependents are being treated by civilian healthcare, the healthcare providers themselves may not be aware of these programs...so military families struggle to find and afford specialized medical treatment in their area." As mother of two children with special needs, "...one of the reasons we are staying in the military is the services are so good." Access to information about programs at the earliest opportunity is critical.

Darcy Hanson, mother of adult son with Down syndrome. "It's about time someone is looking at this! We moved to New Mexico from Wyoming and Wyoming had its act together. Wyoming had the Governor's Commission on Disabilities. It was a paid position. You could call one number and get your questions answered."

Brian Chicoine, MD. Adult Down syndrome Center of Lutheran General Hospital. Discussed creation of The Adult Down syndrome Center, challenges, need for community support from Down syndrome Networks and parent advocates, medical apps for statewide use, and challenges with start-up funding. August 2011.

Dennis McGuire, PhD. Adult Down syndrome Center of Lutheran General Hospital. Discussed creation of The Adult Down syndrome Center and challenges in New Mexico regarding healthcare, rural nature of state, need for mental health services and expertise and introduced idea of "mobile health care unit." November 2011.

Mike Sullivan. Discussed creation of "Saving Downs" – advocate group in New Zealand for the life of people with Down syndrome from conception to natural death. Formed in response to New Zealand Government's new state funded eugenic antenatal screening program that targets and identifies unborn children with Down syndrome for selective abortion; challenges and fears. November. 2011.

Kilolo Brodie, Phd, MSW. Challenges of being a single parent of child with Down syndrome, particularly with regard to health care, medical needs of children with Down syndrome and direct correlation between service challenges and ethnicity and socio economic status. Discussed need for more community involvement and need for more cultural resources for children with Down syndrome and their families, National Down syndrome Conference. 2011.

Dr. Michael Brodie, Grandparent of child with Down syndrome. Discuss need for increased social promotion of individuals with Down syndrome, family support and medical and time challenges of raising a child with Down syndrome. Emphasized that family love and community involvement, education and support is "critically" important in raising a child with Down syndrome. National Down syndrome Congress Conference 2011.

Shari Cordova, President, Rio Grande Down syndrome Network. Discuss membership of Rio Grande Down syndrome Network, need for increased funding to improve local services and network involvement. 2011.

Janie Lee Hall, Special Olympics Region Coordinator for Western NM. Challenges of specialization, rural issues, educational, cultural, medical, transportation and socialization issues for families and children with Down syndrome in Western Region of state. October 2011.

Mark W. Leach, J.D. Parent of Child with Down syndrome. The state of Pre-natal testing, importance of education and social awareness about Down syndrome. Mr. Leach stated that, "according to report in Copenhagen Post, Denmark will be Down syndrome Free by 2030." 2012.

Kathy Olive, Former Chair, Advisory Board for Adult Down syndrome Clinic University of Alabama at Birmingham, Parent of Child with Down syndrome. Identified most important need of individuals with Down syndrome in Alabama to be medical care specialization and training, Parent Advocates Down syndrome (PADS) approached U of A, started Down syndrome Medical Clinic, funding, political issues, need for strong support by local DS network, parent challenges, education of healthcare professionals as a priority, and increased socialization for children and adults with Down syndrome. 2011.

Jenny Yates, Chair, Advisory Board for Adult Down syndrome Clinic University of Alabama at Birmingham, Parent of Child with Down syndrome. Group of parents, Parent Advocates Down syndrome (PADS) approached University of Alabama to be site for Down syndrome Clinic. Parent group (PADS) services 700 families - currently PADS provides fundraising for new clinic, guides clinic in practice, staff hiring, patient satisfaction and general direction of clinic development. 2012.

Dr. Jose Flores, Director (and Founder) Massachusetts General Hospital's Down syndrome Clinic for Adults and Adolescents with Down syndrome, Brother of sister with Down syndrome. Provider of all adult services to individuals with Down syndrome in New England (clinic now has 5 medical Doctors and other specialists - most difficult to find was a Psychiatrist). Mr. Flores is an Endocrinologist and researcher in genetics. Started clinic after realizing Individuals with Down syndrome not receiving medical care in young adulthood b/c of lack of healthcare specialization for adults with Down syndrome. Mr. Flores states, "people with Down syndrome have special needs from a specialty perspective, often primary caregivers not equipped to recognize medical issues particularly with adults so they often drop out of system of care when they become young adults. This clinic is an absolute necessity for adults with Down syndrome."

"NM is blind to the data about individuals with Down syndrome. We can't make people believe we need more specialized services if we don't have the data to back it up." – Taken from a telephone interview with individual who prefers to remain anonymous.

## **Telephone/Personal Interviews**

Brian Chicoine, MD. Personal Interview. Chicago Hospital .August 2011

Dennis McGuire, PhD. Personal Interview. November 2011.

Tanya Wheeler. Personal Interview. Springfield Mass. (Western Mass. Teaching Hospital). 2011.

Mike Sullivan. Personal Interview. Saving Downs, New Zealand November. 2011.

Kilolo Brodie, Phd, MSW. Personal Interview. National Down syndrome Conference. 2011.

Parents Reaching Out- Johnny Wilson, Andrea Leon, Project Coordinator/Dreamcatchers. 2011.

NM Asian Family Center- Sherry Spitzer. Personal Interview 2011.

Cristine Marchand-ED, NM Developmental Disabilities Planning Council. Personal Interview.  
2011.

Shari Cordova- RGDSN. Personal Interview. 2011.

Christine Vining, M.S. CCC SLP- Program Manager, Neurodevelopmental Services. 2011.

EPICS- Jeanette Trancosa ED, RONALDA WARITO-TOME. Personal Interview. 2011.

Nadine Maes, Personal Interview, 2011.

Yoko Reece, Personal Interview, 2011.

CDD- Tanya Baker-McCue, Personal Interview, 2011.

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## **Terms/Concepts**

**Blind Inclusion** – This phrase refers to including individuals with Down syndrome into already existing programs, without taking into account their specialized needs.

**Change by Design**- This phrase refers to creating/ designing programs to address the specialized needs of the consumer.