

# Nebraska Legislative Resolution 156

Addressing the Waiting List for Persons  
with Developmental Disabilities  
and Rate Methodology

December 2008

# LR 156 WORKGROUP MEMBERSHIP

The following members of the Legislative Resolution 156 Workgroup are thanked for their hard work and dedication to meet the goals of this project. Membership, as defined in the Resolution, included representatives from the State Department of Education, the Advisory Committee on Developmental Disabilities, the Developmental Disabilities Planning Council, people with developmental disabilities and their families, statewide developmental disability advocacy organizations, developmental disability service providers, and other interested parties. It is the commitment of individuals such as these that leads to positive outcomes for Nebraskans with intellectual and developmental disabilities and their families.

Laurie Ackermann  
Janet Anderson  
Mary Angus  
Bob Brinker  
Dennis Byars  
June Clapper  
Christi Crosby  
Glenda Davis  
Eric Evans  
Rene Ferdinand  
Sue Hamilton  
Kathy Hoell  
Seamus Kelly  
Brenda Kimes  
Anne Lauritzen

Maxine Lien  
Joan Marcus  
Carol McClain  
Dave Merrill  
Marlene Pedulla  
Kathy Peterson  
Kenneth Rood  
Sue Rood  
Jack Shepard  
Mark Smith  
Patty Smith  
Carla Sorensen  
Tammy Westfall  
Alan Zavodny

Special thanks are given to the technical advisors who provided expert guidance and resources to assist in the work of the group.

Mary Gordon, Nebraska Planning Council on Developmental Disabilities  
Terri Holman, Nebraska Planning Council on Developmental Disabilities  
Don Severance, NDHHS Division of Developmental Disabilities

Project Contractor:  
O'Hare Professional Consulting  
Mary O'Hare  
1205 S. 25<sup>th</sup> Street  
Lincoln NE 68502  
maryohare1@alltel.net  
402.475.8022

Project Sub-Contractor:  
Lloya Fritz  
1820 Kings Hwy.  
Lincoln NE 68502  
lloyafritz@alltel.net  
402.730.8469

# LR 156 EXECUTIVE SUMMARY

Nebraska is at a crossroads with its obligation to Nebraska citizens with developmental disabilities (DD)<sup>1</sup>. Several Nebraska Senators have recognized the urgent need to develop a strategic plan to address the current and future needs of citizens with DD and their families. Recent legislation (Legislative Resolution 156) appointed a workgroup to make recommendations for a strategic plan to incrementally reduce the number of persons on the waiting list and to review and make recommendations on the rate methodology established to fund said services. It is intended that this report will serve as a map for future efforts in that regard. The LR 156 Workgroup respectfully submits this report to the Governor, Legislature, and the Medicaid Reform Council.

The group identified challenges in meeting the needs of the eligible Nebraskans with 2,597 requests for services and currently waiting for services, some since 2003. The group used data and facts provided by the Health and Human Services Division of Developmental Disabilities, the expertise of the workgroup members, and input from Nebraska's DD providers to: analyze challenges facing the state in providing adequate services and supports to its citizens with DD; develop position statements and desired outcomes to guide system changes; and recommend specific changes to strengthen the system in meeting its obligation to its citizens with DD and their families. Some of the most pressing challenges facing the state include:

1. Nebraska needs to develop better methods for projecting current and future service demand.
2. Nebraska is challenged to redirect service demand into more economical service delivery alternatives.
3. The Rate Methodology is outdated and needs to be revised. State payments are not based on a realistic appraisal of legitimate provider costs and comparable market wages.
4. The current rate system is not flexible enough to address individuals' changing needs.
5. Quality measurements are not innovative, nor designed to measure outcomes for people.
6. The current billing and reimbursement systems are outdated and do not promote efficient and effective accounting practices for providers.

The LR 156 Workgroup spent considerable time and deliberation in developing desired outcomes and recommendations to address identified challenges. Specifically, position statements and desired outcomes are listed below.

1. Individuals with DD must have access to and receive necessary publicly funded services and supports with reasonable promptness.
  - a. A full range of quality DD services and related supports are available to all eligible people with developmental disabilities in all areas of the state.
  - b. Providers are funded at a rate and in a method that allows them to hire, train, and retain quality staff to serve current and waiting list populations.
2. Individuals with developmental disabilities must have a variety of quality service and support choices and providers must have flexibility in service delivery.
  - a. Services address all needs of the individual and are based on individualized outcomes and choice.
  - b. Flexibility in funding authorization, service delivery, and definitions is allowed.

---

<sup>1</sup> The term "intellectual and developmental disabilities (I/DD)" is the term preferred by the American Association of Intellectual and Developmental Disabilities. For purposes of this document, in keeping with current terminology in Nebraska State Statutes and regulations, the term "developmental disabilities" is used.

3. The developmental disability and supporting systems must promote effective and efficient delivery of services and supports.
  - a. The service rate methodology is adequate to support the current and future community service system.
  - b. Nebraska will strengthen the DD system infrastructure, at both the provider and state level, to support a growing community service system.
  - c. Capacity is expanded by developing a flexible system that allows for creativity in developing the supports and services for each person.
  - d. Gains made in public schools are maintained by seamless transition to appropriate services in the community.

Specific recommendations to reach the desired outcomes are presented throughout this report and summarized in the chapter entitled *Summary of LR 156 Workgroup Recommendations*. The recommendations are specific to waiting list reduction, rate methodology, and system changes. Of utmost importance are the two options (below) brought forward to reduce the waiting list. It is to be noted that Option #1 is the preferred strategy for reducing the waiting list. It ensures that funding will be available through upcoming years to fully fund the waiting list.

**Option # 1:** Appropriate funds, in the upcoming fiscal year, necessary to provide services for all eligible individuals with developmental disabilities who are past their need date. Once those individuals have been funded, provide funding for all eligible individuals as they reach their need date.

**Option #2:** Incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on their need date.

The workgroup is in agreement that the waiting list cannot be eliminated without an infusion of funding to better support Nebraska providers and changes to the rate methodology. The workgroup recommends that the rate methodology be revised and that a 15% increase be immediately allocated to support the development of needed statewide capacity to serve all citizens on the waiting list. Furthermore, the workgroup recommends that a rate methodology study be undertaken to modernize the current formula that was developed in 1992, as it does not reflect the current environment in which the providers must manage their businesses. Finally, the LR 156 Workgroup recommends that a committee or task force be appointed to monitor implementation and results of the waiting list reduction plan and systems recommendations presented in this report.

Funding the waiting list will not only provide improved quality of life for persons with developmental disabilities and their families, it will also provide thousands of jobs for citizens throughout the state of Nebraska. These are jobs that will put money into the pockets of Nebraskans, as well as stimulate communities by the purchase of goods and services needed to sustain individuals in their chosen communities. Providing services and supports for persons with developmental disabilities will allow them to become more independent, productive citizens, and decrease their reliance upon public support. The economic impact for Nebraska of this important initiative cannot be overlooked nor understated.

It is the sincere hope of the workgroup that Nebraska will follow through with its obligation to aid persons with developmental disabilities and their families to receive the assistance they need to live happy, healthy, and productive lives in their chosen Nebraska communities.

# Table of Contents

LR 156 WORKGROUP BACKGROUND .....	6
STATEMENT OF CHARGE.....	6
PROCESS.....	6
RECOMMENDATIONS .....	6
UNDERSTANDING THE WAITING LIST .....	8
SERVICE UTILIZATION .....	11
DIVISION OF DEVELOPMENTAL DISABILITY REGISTRY DATA .....	11
POSITION STATEMENTS AND DESIRED OUTCOMES .....	14
POSITION STATEMENT #1: ACCESS TO QUALITY SERVICES.....	15
POSITION STATEMENT #2: FLEXIBLE, QUALITY SERVICE DELIVERY AND INDIVIDUAL CHOICE	15
POSITION STATEMENT #3: EFFECTIVENESS & EFFICIENCY.....	16
WAITING LIST REDUCTION.....	18
WAITING LIST CHALLENGES.....	18
WAITING LIST FUNDING OPTIONS .....	25
WAITING LIST REDUCTION RECOMMENDATIONS .....	27
RATE METHODOLOGY .....	29
DD PROVIDER INPUT .....	29
RATE METHODOLOGY RECOMMENDATIONS .....	32
SYSTEM RECOMMENDATIONS.....	33
OVERSIGHT PLAN .....	35
WAITING LIST OVERSIGHT RECOMMENDATIONS .....	36
SUMMARY OF LR 156 WORKGROUP RECOMMENDATIONS .....	37
WAITING LIST REDUCTION RECOMMENDATIONS .....	37
RATE METHODOLOGY RECOMMENDATIONS .....	38
SYSTEM RECOMMENDATIONS .....	39
WAITING LIST OVERSIGHT RECOMMENDATIONS .....	40
RELATED DD SYSTEMS ISSUES .....	41
APPENDIX.....	43
APPENDIX A. LR 156 .....	44
APPENDIX B. SERVICE DEFINITIONS .....	46
APPENDIX C. PROVIDERS' INPUT .....	49
APPENDIX D. STATES' WAITING LIST INITIATIVES .....	56
APPENDIX E. RESOURCE LINKS.....	68

# LR 156 WORKGROUP BACKGROUND

## STATEMENT OF CHARGE

Subsection (3) of section 83-1216 in Nebraska statute (the Developmental Disabilities Services Act) states that: “It is the intent of the Legislature that by July 1, 2010, all persons determined to be eligible for services shall receive services in accordance with the Developmental Disabilities Services Act.” With a lengthy list of persons waiting to receive services and inadequate funding, Nebraska is clearly not on target to meet this intent.

Legislative Resolution 156 (LR 156) of the first session of the One Hundredth Nebraska Legislature established a workgroup to address two major issues related to the provision of services to persons with developmental disabilities. The charge for the workgroup, as defined in LR 156, is as follows:

- (1) Submit recommendations for a strategic plan to incrementally reduce the number of persons on the waiting list for developmental disabilities to meet the intent of the Legislature;
- (2) Consult with the Department of Health and Human Services to review and make recommendations on any revision to the rate methodology; and
- (3) Submit the workgroup’s recommendations on the strategic plan and revisions to the rate methodology in a report to the Medicaid Reform Council, the Legislature, and the Governor.

## PROCESS

Through a series of four facilitated meetings in the fall of 2008, the workgroup met to identify and develop a common understanding of the issues related to the waiting list and funding methodology. Reports and recommendations from previous state initiatives were reviewed and considered, with recognition given that these are not new issues.

A vast amount of data was compiled by the Department of Health and Human Services Division of Developmental Disabilities (DDD) and reviewed by the workgroup throughout the course of this process. This information included: current and future waiting list numbers, historical usage of funding, attrition figures, and projected numbers of students exiting high school. Additionally, information was provided and discussed regarding the current process for being placed on the waiting list, determining priority for receiving services, and other information regarding the waiting list and funding methodology. This data and information is presented throughout the body of this report and the appendices.

## RECOMMENDATIONS

As a final and culminating step, a set of recommendations to be used in the development of a strategic plan to address the waiting list and funding methodology was developed by the workgroup. The complete set of recommendations is included in the chapter entitled: *Summary of LR 156 Workgroup Recommendations*. A comprehensive strategic plan for the delivery of DD services will need to take into account the information and recommendations provided by this group, as well as the work of other initiatives related to the service system, e.g., the BSDC Oversight Committee, the Objective Assessment Process Workgroup, etc.

A draft of this report was presented to the Nebraska Planning Council on Developmental Disabilities for their review and finalization, with changes made as per their recommendations. This document is the final report submitted to the parties identified in the Legislative Resolution.

Recommendations are organized in this report as follows:

**Waiting List Reduction:** Funding options for reduction of the waiting list are provided for consideration, as well as recommendations that may have a direct or indirect impact on the waiting list.

**Rate Methodology:** Recommendations are made to address the rate methodology changes that the workgroup identified as necessary to support the current and future community service system.

**System Recommendations:** Recommendations are provided for systemic changes that would positively impact the developmental disability service system.

**Oversight Plan:** An oversight plan is recommended to monitor implementation and results of the LR 156 recommendations.

**Related DD System Issues:** As the workgroup conducted their activities, other critical issues related to the developmental disabilities service system were identified. While not directly related to the waiting list or funding methodology, the group felt that it is imperative that these are addressed in order to provide a comprehensive system of services for persons with developmental disabilities.

# UNDERSTANDING THE WAITING LIST

The following information is designed to assist in understanding how Nebraska offers developmental disabilities services to eligible individuals. It should be noted that The American Association of Intellectual and Developmental Disabilities (AAIDD) recommends the use of the term “intellectual disabilities” in combination with the term “developmental disabilities”. For purposes of this document, in keeping with current terminology in Nebraska State Statutes and regulations, the term “developmental disabilities” is used. As we move toward the change in terminology, the AAIDD definition of intellectual disability is provided as follows for future reference.

“Intellectual disability is the currently preferred term for the disability historically referred to as mental retardation. Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.”<sup>2</sup>

Much of the information presented in this section was adapted from the “Planning Better Futures Report on Nebraska’s Waiting List Initiative”, submitted to the Nebraska Unicameral by the Arc of Nebraska and the Nebraska Planning Council on Developmental Disabilities in 2000.

## **How does an individual become eligible for DD services?**

Any Nebraska resident who has a developmental disability (DD) is potentially eligible for services from Nebraska Health and Human Services. Eligibility for DD services is defined according to the Developmental Disabilities Services Act. The eligibility determination process is completed at the local DD Service Coordination office.

## **What is the Division of Developmental Disabilities (DDD) Registry?**

Once an individual is determined eligible, the individual or family indicates the date that services will be needed. This is commonly termed the individual's “need date”. It could be the same day or a date in the distant future. This information is placed on the DDD tracking system known as the Registry. Individuals and their families are encouraged to get an individual’s name on the DDD Registry as soon as possible, whether the need date is immediate or years away.

## **What happens when the need date occurs?**

The individual is considered to be on the waiting list when the stated need date has been reached or passed. The term “waiting list” is not an official term, but is used to refer to individuals with DD who have requested services, have a need for services, but cannot receive services primarily due to lack of funding.

Historically, as funding has become available for those on the waiting list, the order of selection has been by stated need date. In other words, those who have surpassed their stated need date in the most distant past receive services before those whose stated need date is more

---

<sup>2</sup> American Association of Intellectual and Developmental Disabilities: <http://www.aamr.org/>



current. Under special initiatives in the past, there have been instances where other priorities for funding have been established.

### **Who currently receives DD services?**

Individuals who are currently receiving services (either day or residential services), continue to receive services until they no longer need the services, choose to exit services, leave the state, or are deceased. Service Coordination is offered to all individuals deemed eligible. Services are also offered to:

- Nebraska youth who graduate from a Nebraska high school, are age 21, and are on the DDD Registry. These graduates are offered day services and Service Coordination. They typically do not receive residential services, even though they may need and have requested them. This is due to lack of funding. So, if they need services besides day services and have requested such, they remain on the waiting list.
- Eligible individuals demonstrating an emergency need (as defined in state statute).

### **What if there is an emergency situation?**

Based upon statutory language, Nebraska uses a system of authorizing services based upon emergency needs. Individuals in a situation that is deemed threatening to their health or safety, as defined by state statute, are termed as Priority One status. These individuals receive day and/or residential services based upon their assessed need.

### **What happens if an individual over 21 with DD moves into Nebraska from another state?**

Eligibility for services in another state does not mean the individual will be eligible in Nebraska. The individual must be determined eligible by Nebraska's standards and, if eligible, will be placed on the DDD Registry. Unlike individuals exiting a Nebraska high school, they are not entitled to day services, but could receive Service Coordination if requested.

### **How is the amount of services for each individual determined?**

The Objective Assessment Process (OAP) assists in determining the individual's level of need. The assessment is performed by using a standardized assessment tool, the Inventory for Client and Agency Planning (ICAP). Once the OAP is completed, a level of need is calculated and used to determine the amount of funding available for that person. The phased-in implementation of the OAP began in 1998. Individuals new to the system since 1998 receive the amount of funding determined by the OAP. Adjustments based on the OAP have not been made for individuals receiving DD system services prior to 1998.

### **What are the types of services offered?**

Services are considered to be either specialized or non-specialized. Specialized habilitation services are those designed to teach an individual skills as specified in their Individualized Program Plan and delivered by a certified DD provider. Non-specialized services are designed to provide support to the individual and are provided by individuals or agencies independently chosen and hired by the individual and his/her family. Further explanation of these services may be found in Appendix B.

### **Specialized Services**

Service Coordination: working with the individual and their family to develop plans for meeting the individual's needs.

Day/Vocational Services: services designed to assist in becoming employed. Services may range from supporting the person in a job in the community to teaching job skills in a sheltered setting.

Residential Services: services designed to assist the individual in living in the community. Services may be provided in the person's home or in supervised settings in the community.

Respite: service designed to provide occasional relief to the family from the day-to-day care and supervision of the individual.

### **Non-Specialized Services**

The Community Supports Program (CSP) is a system of self-directed services, planned by the individual and their family. CSP services are not based upon the habilitation (training) model, but rather upon a model of flexible services and support.

Services offered under the CSP include:

- Community Living and Day Supports
- Assistive Technology and Supports
- Home Modifications
- Personal Emergency Response
- Vehicle Modifications
- Respite

# SERVICE UTILIZATION

## Current Service Utilization

Nebraska's 33 public and private community-based providers serve 4,512 individuals in 70 certified programs.

## Historical Service Utilization

Figure 1. provides a breakdown of service utilization by service type since 2004. The number of persons utilizing each service type has climbed each year except for residential services, which decreased from year 2006 to 2007. The Community Supports Program currently supports 59 individuals and is not depicted on the graph in Figure 1.

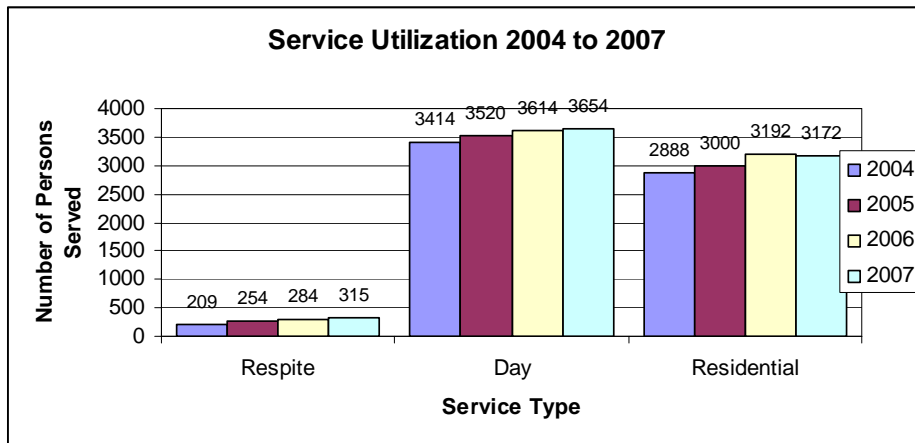


Figure 1. Service Utilization 2004 to 2007

## **DIVISION OF DEVELOPMENTAL DISABILITY REGISTRY DATA**

The Division of Developmental Disability (DDD) Registry Data can be most easily understood by conceptualizing the data into three categories. The data compiled for this report was current as of November 14, 2008. Service requests for 2009 and 2010 are estimates based on average service requests between 2003 and 2008.

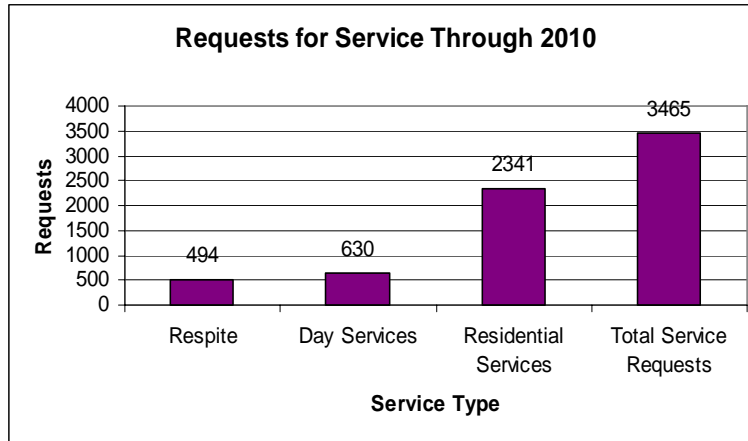
*The BIG Picture* data demonstrates requests by service type through the end of the year 2010.

*The CURRENT Picture* data demonstrates requests by service type of the individuals currently waiting for services or, in other words, past their need.

*The FUTURE Picture* data demonstrates requests by service type for the individuals who will reach their need date by the end of the year 2010.

## **The BIG Picture**

Registry data reported on November 14, 2008 indicates a total of 3,465 requests for service by individuals past their need date and reflects estimated requests for services in 2009 and 2010. The data indicates 494 requests for respite services; 630 requests for day services; and 2,341 requests for residential services, for a total of 3,465 requests. (Figure 2.)

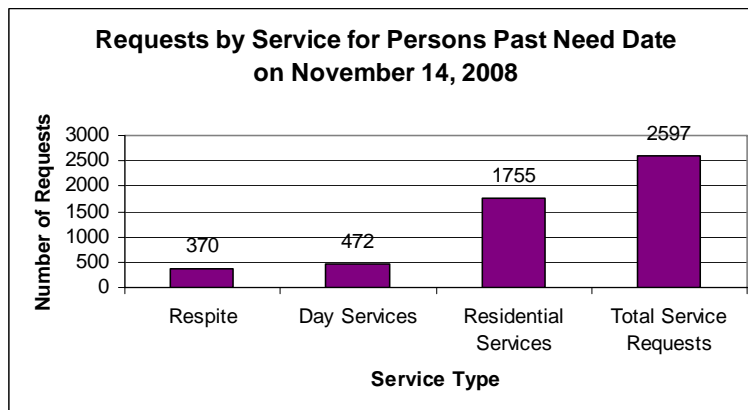


**Figure 2. All Service Requests Through 2010**

**\*Service Requests for 2009 & 2010 are Estimated**

## **The CURRENT Picture**

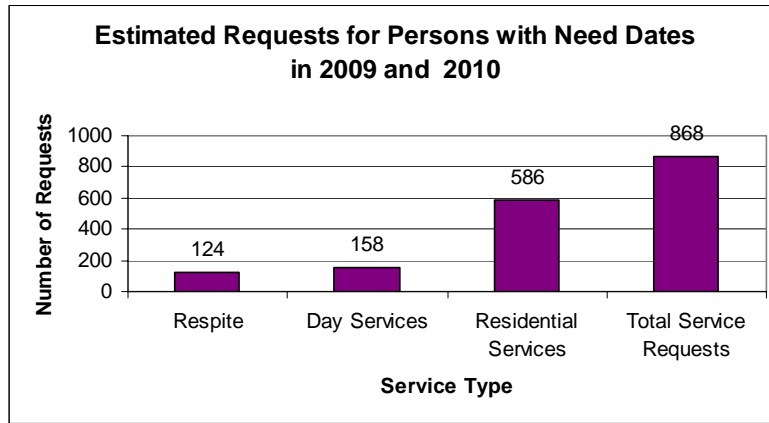
As of November 14, 2008 there are 2,597 requests for service on the DDD Registry from individuals who are past their stated need date and waiting for day, residential, and/or respite services. Some of these individuals have been waiting five years for services. The data indicates 370 requests for respite; 472 requests for day services; and 1,755 requests for residential services for a total of 2,597 requests for service. (Figure 3.)



**Figure 3. Service Requests for Persons Past Need Date as of November 14, 2008**

## **The FUTURE Picture**

Based on average service requests between 2003 and 2008, it is estimated that 868 service requests will be registered in 2009 and 2010. Estimates indicate that 124 individuals will request respite services; 158 individuals will request day services; and 586 individuals will request residential services, for a total of 868 requests for service. (Figure 4.)

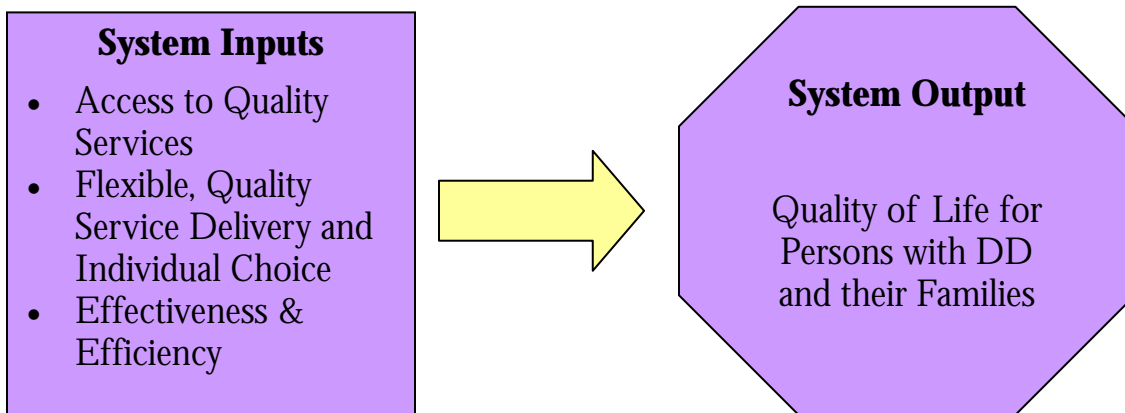


**Figure 4. Estimated Service Requests with Need Dates in 2009 and 2010**

# POSITION STATEMENTS AND DESIRED OUTCOMES

It is clear that Nebraska is underperforming in meeting its obligation to citizens with developmental disabilities. In response, fundamental system changes are necessary to improve Nebraska's performance in supporting this population and in meeting its enormous waiting list obligation. Absent change, system performance will not improve appreciably; the waiting list will continue to grow; individuals and families will not be served or will be underserved; and the entire system will deteriorate over time, resulting in undesirable outcomes for persons with DD and their families.

The LR 156 Workgroup spent considerable time and deliberation in analyzing the system's challenges and developing recommendations to address identified needs. The recommendations are key to fully funding the waiting list and redesigning the system to better meet current and future needs of this population. The recommendations are based on the premise that access to quality services; flexible, quality service delivery and individual choice; and system effectiveness and efficiency will lead to quality of life for persons with developmental disabilities and their families.



To that end, the workgroup developed three position statements and the desired outcomes for achieving the system changes required to meet the needs of individuals with DD in Nebraska.

## **POSITION STATEMENT #1: ACCESS TO QUALITY SERVICES**

*Individuals with developmental disabilities must have access to and receive necessary publicly funded services and supports with reasonable promptness.*

Currently, Nebraska has fallen significantly short of providing services and supports with reasonable promptness to citizens with DD. Data presented earlier in this report is evidence of the lack of progress in this area. The last year that individuals on the waiting list were offered services was 2006 and, at that time, the list was caught up to serve individuals who had been waiting since 2002.

There are 2,597 requests for services by eligible individuals who are past their need date on the DDD Registry. Some of these individuals have been waiting five years for services. Every year the waiting list continues to grow, so if action is not taken now, the problem will continue to significantly increase in future years. It is estimated that 434 service requests will be added to the DD Registry annually. The list only continues to grow.

### ***Desired Outcomes***

The workgroup identified the following as desired outcomes in providing access to quality services for persons with developmental disabilities:

- A full range of quality developmental disabilities services and related supports are available to all eligible people with developmental disabilities in all areas of the state.
- Providers are funded at a rate and in a method that allows them to hire, train, and retain quality staff to serve current and waiting list populations.

## **POSITION STATEMENT #2: FLEXIBLE, QUALITY SERVICE DELIVERY AND INDIVIDUAL CHOICE**

*Individuals with developmental disabilities must have a variety of quality service and support choices and providers must have flexibility in service delivery.*

The term “flexibility” was a major theme that continued to surface during workgroup discussions. Changes to promote flexibility in regulations, service delivery settings, individual use of funds to purchase supports in addition to habilitation services, and funding methodologies need to be explored, developed, and implemented. Such changes would offer a variety of quality service and support choices for individuals, as well as allow providers flexibility in methods of service delivery.

Individuals with DD often have complex needs that are not adequately addressed, particularly those individuals with behavioral challenges related to mental illness (also known as “dual diagnosis”). DD providers struggle to support individuals with a dual diagnosis and the behavioral health system and community law enforcement agencies are unprepared and, at

times, unresponsive to cries for help from families and providers. Cross-system responses need to be developed to better serve these individuals, as well as resources for persons with traumatic brain injury, medically complex conditions, and autism.

Individuals and their families often choose more expensive, assisted services in which they are assured a staff member is continuously present. Many of those who choose this level of service may be able to have their needs met by supported services in which staff are not continuously present. However, they tend to choose assisted services because “safety net” policies and procedures, which allow them to return to a more intense level of services if less intensive services do not work out, are not in place.

### *Desired Outcomes*

The workgroup offers the following as desired outcomes in order to provide flexible, quality service delivery, and individual choice.

- Services address all needs of the individual and are based on individualized outcomes and choice.
- Flexibility in funding authorization, service delivery, and definitions is allowed.

### **POSTION STATEMENT #3: EFFECTIVENESS & EFFICIENCY**

*The developmental disability and supporting systems must promote effective and efficient delivery of services and supports.*

An effective and efficient system is critical to the delivery of effective and efficient services and supports. The system is sustainable when it utilizes cost effective services and supports, builds upon the supports of families and communities, and effectively utilizes federal funding.

Capacity of providers to hire and retain a quality workforce to deliver services is an ongoing challenge. In order to serve additional individuals, providers will need a mechanism to access funding for start-up costs as they develop new services and supports for persons entering the system.

Capacity concerns are also an issue for the infrastructure of the entire system. As additional persons leave the waiting list and enter the service system, the demands at the State-agency level will increase. Additional Service Coordinators will be needed; administrative implementation and oversight needs will increase; education and training will need to be provided; and billing and tracking systems will need to be responsive to change.

The LR 156 Workgroup expressed strong support of the concepts of the Community Supports Program (CSP), but recommended changes to the program to allow for increased availability and flexibility for individuals and their families. Nebraska’s experience with this relatively new program has been quite positive and is supported by national trends regarding self-directed service models. Experience in Nebraska and other states show that the cost of CSP supports is significantly less than those in the traditional service models.

**The system is sustainable when it utilizes cost effective services and supports, builds upon the supports of families and communities, and effectively utilizes federal funding.**



Given the flexibility, affordability, and satisfaction with the CSP, it is strongly recommended that emphasis be placed on expansion and improvement of this service-delivery model.

Recognizing that the system cannot operate in isolation, recommendations are also made to support youth as they transition from school to community supports and services. Effective transition planning and partnerships between systems benefit young adults and their families and has been shown to decrease the individual's long-term reliance upon publicly-funded services, thus decreasing stress upon the system.

### ***Desired Outcomes***

The workgroup offers the following as desired outcomes in promoting effectiveness and efficiency.

- The service rate methodology is adequate to support the current and future community service system.
- Nebraska will strengthen the developmental disability system infrastructure, at both the provider and state level, to support a growing community service system.
- Capacity is expanded by developing a flexible system that allows for creativity in developing the supports and services for each person.
- Gains made in public schools will be maintained by seamless transition to appropriate services in the community.

# WAITING LIST REDUCTION

“It is the intent of the Legislature that by **July 1, 2010**, all persons determined to be eligible for services shall receive services in accordance with the Developmental Disabilities Services Act.”

## WAITING LIST CHALLENGES

Nebraska is seeking to live up to its obligation to persons with DD as stated in the Developmental Disabilities Services Act. This is a commendable goal and one that can be met with careful planning, systemic changes and, of course, political will. It is important to recognize that Nebraska has many challenges ahead that must be studied, understood, and addressed before a sound strategic plan to reduce the waiting list can be developed. These systemic challenges include:

1. Nebraska needs to develop better methods for projecting current and future service demand.
2. Nebraska is challenged to redirect service demand into more economical service delivery alternatives.
3. The Rate Methodology is outdated. State payments are not based on a realistic appraisal of legitimate provider costs and comparable market wages.
4. The current rate system is not flexible enough to address individuals' changing needs.
5. Quality measurements are not innovative nor designed to measure outcomes for people.
6. The current billing and reimbursement systems are outdated and do not promote efficiency and effective accounting practices for providers.

The challenges are discussed in the three sections which follow: Service Demand, Waiting List Projections, and Service Utilization Costs.

### Service Demand

“Most of the 5 million people with DD in the United States are supported by their families or live independently without specialized publicly-funded DD services.”<sup>3</sup> The majority of families care for their loved ones for as long as they can possibly do so, but publicly funded DD services are usually necessary at some point. On a national average, publicly funded DD service systems provide services and supports to a relatively small number of eligible individuals. It is estimated that approximately 20 to 25 percent of persons with DD actually receive services. Public systems focus primarily on people who have significant functional limitations, complex service needs, lack a support system, or require services over and above the supports that their family is able to provide. In most cases, once individuals access publicly funded services, they will need to do so throughout their lifespan. Therefore, public officials must plan for funding for them from year to year.

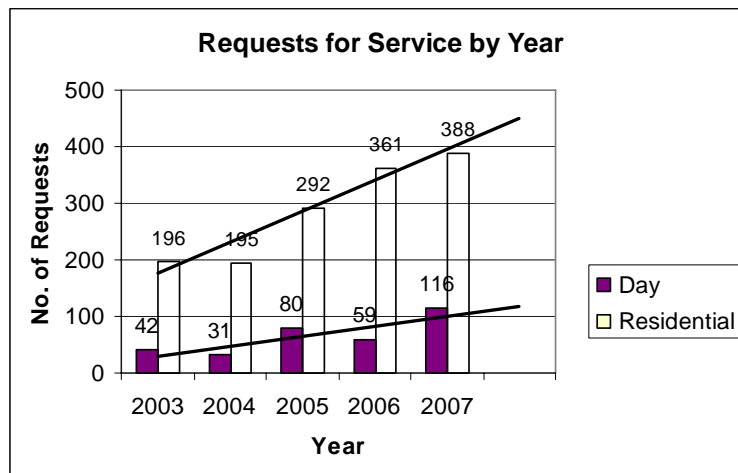
Each year the demand for DD services in Nebraska, as in other states, grows. The increased demand for services is generally a product of several factors. People with DD, like the general population, are experiencing increased longevity. As medical technology advances, all people are living longer. Therefore, an individual's need for DD services is extended over more years. Individuals are staying in the system longer. In addition, people with developmental disabilities

---

<sup>3</sup> Human Services Research Institute. (October 2008). *Closing the Gap in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. [www.hsri.org](http://www.hsri.org)

are outliving their parents or primary caregivers. On average, about 25 percent of people with DD currently reside in households in which the primary caregiver is age 60 or older. As caregivers age, their ability to support their loved ones decreases and the demand for publicly funded services grows.

The demand for developmental disability services is dynamic. That is, the demand is not a static one; it grows from year to year. Nebraska's service demand over the past five years is displayed in Figure 5. The average number of requests in any given year for day services is 79. In 2007, the requests for day services exceeded the average with 116 requests. The demand for residential services has increased even more dramatically over the past five years. Residential service requests range from a low of 195 in 2004 to an all time high of 388 in 2007.



**Figure 5. Requests by Service Year**

The increase in demand for day services is less dramatic than demand for residential services because DD eligible youth who graduate from a Nebraska high school and are age 21 or over are offered day services and Service Coordination. Separate funding for these services has been included in the annual appropriation for DD services. They typically do not receive residential services, even though they may need and have requested such. So, they are then captured on the waiting list for residential services, but not for day services. On average, 170 high school graduates request and receive day services annually. The average annual funding amount is \$12,000 per year per graduate, for a total of \$2,040,000 per year in state and federal funds.

**On average, 170 high school graduates request and receive day services annually. The average annual funding amount is \$12,000 per year per graduate, for a total of \$2,040,000 per year in state and federal funds.**

Serving only those with crisis or emergency needs and only funding day services for graduates has resulted in a huge backlog of individuals who need, want, and are eligible for services. Experts note that it is not uncommon to observe a year-over-year increase

in the expressed demand for DD services of four percent or more.<sup>4</sup> Clearly, Nebraska has not kept up with the demand for services.

“Federal court decisions have clearly indicated that responding to service needs with reasonable promptness means those individuals who have emergency or crisis needs must receive Medicaid-funded services within 90 days.”<sup>5</sup> Nebraska’s Priority One process is the avenue individuals and families resort to when they find themselves with emergency or crisis needs. Savings from those leaving services (attrition) are utilized to fund Priority One requests. It is questionable if this is the best method to fund the Priority One requests, rather than having a separate funding stream for such emergency situations and utilizing savings from attrition to fund other individuals on the waiting list. On average, 98 people are authorized to receive Priority One funding each year. The average annual cost for those in Priority One status is \$4 million dollars (\$2 million Federal/ \$2 million State).

**On average, 98 people are authorized to receive Priority One funding each year. The average cost for those in Priority One status is \$4 million dollars (\$2 million Federal/ \$2 million State).**

### **Waiting List Projections**

Nebraska’s DD service system operates under fixed funding limits. The annual appropriation does not accommodate all eligible Nebraskans requesting services. Therefore, capacity is determined by the annual appropriation and historically, as mentioned earlier, additional system funding only covers day services for graduates. Individuals who want more of a particular service; graduates requesting residential services; eligible individuals who move into the state; or individuals requesting services who have not previously had an immediate need are not served unless Priority One status is determined. These are the individuals who spill over onto Nebraska’s waiting list. Limited funding, coupled with rising demand for services, has resulted in the crisis Nebraska is facing today with a waiting list of 2,597 requests for service by eligible individuals past their need date.

**Limited funding, coupled with rising demand for services, has resulted in the crisis Nebraska is facing today with a waiting list of 2,597 requests for service by eligible individuals past their need date.**

The process used to formulate the waiting list poses many problems, especially in projecting how many individuals will accept services if offered and determining how much funding will be needed to serve those individuals once services are offered. Eligible individuals are asked to select services (day, residential, respite) they will need and the year they will need it. Based on their individual situation, individuals may request to receive day services in one year and residential services in another year. Individuals are determined eligible before they can be placed on the waiting list, but the level of service (number of units) they are eligible for is not determined at that time. The amount of services the individual needs is not determined until the individual is actually offered the service. This makes it extremely difficult to project how much funding is actually needed for those on the waiting list.

---

<sup>4</sup> Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2007). *Residential Services for People with Developmental Disabilities: Status and Trends Through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

<sup>5</sup> Human Services Research Institute. (October 2008). *Closing the Gap in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. [www.hsri.org](http://www.hsri.org)

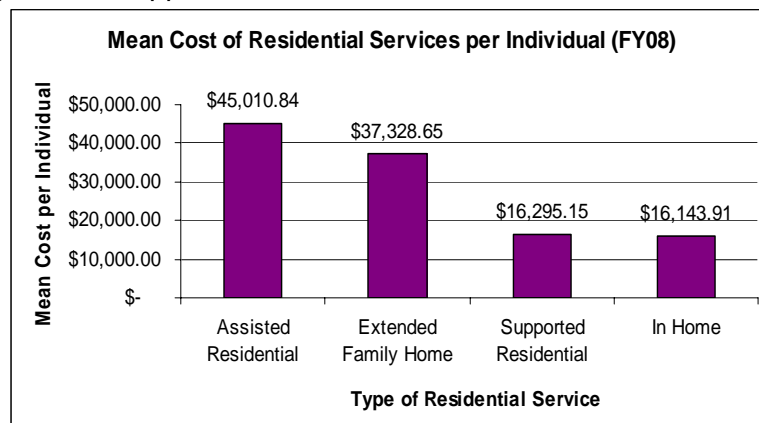
Historically, when offered, 60% of individuals on the waiting list accept day services; 80% of individuals accept residential services; and 70% of individuals accept respite services. The reasons individuals decline services when offered are varied and include: lack of service provider capacity; lack of providers in the home community; available services are not the level or type needed; and/or the individual/family has made other arrangements or adjustments to meet their needs. Of those who decline services, many still need the service but push the need date forward. A very small percentage of individuals turn down services altogether and remove their name from the waiting list. The coupling of the lack of knowledge about the individual's level of need and whether or not individuals will actually take the service once offered makes for a very inexact science when predicting the funding needed to eliminate the waiting list and meet future service requests.

**Service Utilization Costs**

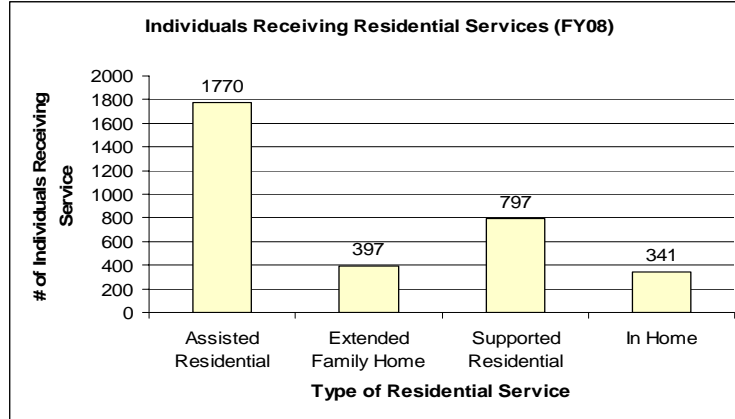
The most utilized services are assisted services, i.e., those where a staff person is always available. Supported and CSP services are much less expensive and chosen less frequently. Staff are not always available but provide intermittent services and/or support. Data regarding service utilization costs is broken down by residential, day, respite, and CSP in the discussion below.

Residential Services include: Assisted Residential, Extended Family Home, Supported Residential, or In-Home services. The various service definitions can be found in Appendix B.

- Assisted Residential services, primarily provided in a group home setting, are the most costly residential services.
- In the current fiscal year (FY08), 1,770 individuals are receiving Assisted Residential at an average cost of \$45,010.84 per individual per year. (Figure 6. and Figure 7.)
- Fewer individuals choose the less expensive types of residential services, which are Extended Family Home, Supported Residential, and In-Home services.



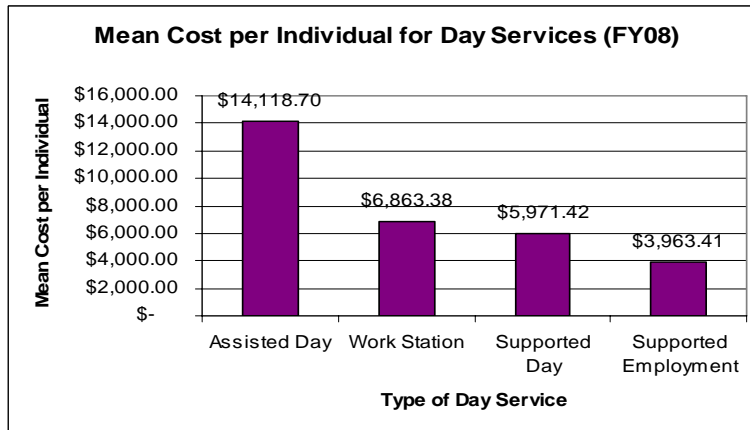
**Figure 6. Mean Cost of Residential Services per Individual (FY08)**



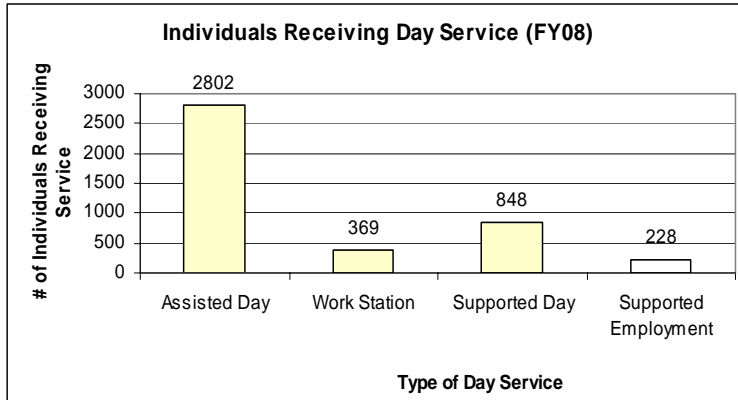
**Figure 7. Individuals Receiving Residential Services (FY08)**

Day Services include: Assisted Day, Work Station, Supported Day, and Supported Employment.

- The same phenomena holds true in that Assisted Day services, which are primarily provided in workshop settings, are the most expensive.
- The majority of the individuals receiving Day Services have chosen Assisted Day, with 2,802 individuals at an average cost of \$14,118.70 per person per year.
- Fewer individuals are utilizing the less expensive service types of Work Station, Supported Day, and Supported Employment. (Figures 8. and 9.)



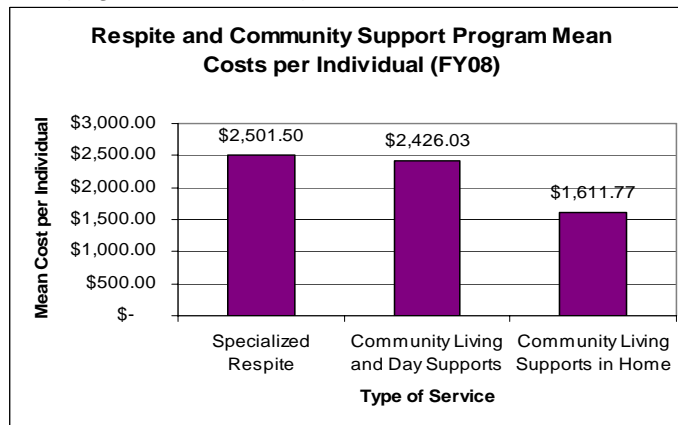
**Figure 8. Mean Cost per Individual for Day Services (FY08)**



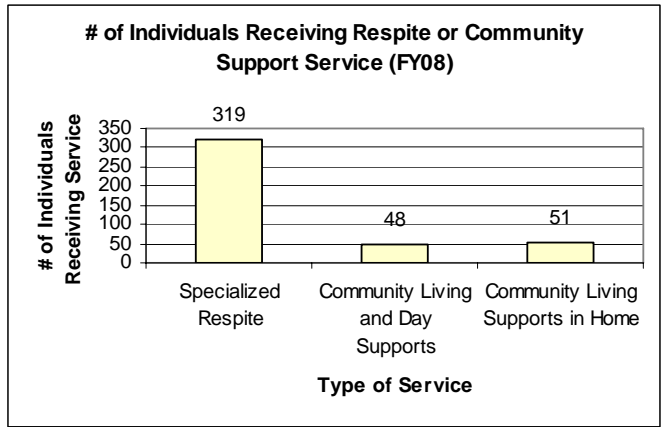
**Figure 9. Individuals Receiving Day Services (FY08)**

The Community Supports Program (CSP) and Respite services are less expensive and are selected less frequently.

- In the current fiscal year (FY08), 319 individuals are receiving Respite at a mean cost of \$2,501.50 per year per individual.
- The CSP is a relatively new program in Nebraska and offers an array of services, with Community Living and Day Supports and Community Living In-Home Supports being the two most frequently utilized.
- For the current year, 48 individuals receive funding for Community Living and Day Supports at an average cost of \$2,426.03 per individual per year; and 51 individuals are receiving Community Living Supports In-Home at an average cost of \$1,611.77 per individual per year. (Figure 10. and 11)



**Figure 10. Respite and CSP Mean Costs per Person (FY08)**



**Figure 11. No. of Individuals Receiving Respite or CSP (FY08)**

The CSP is an excellent lower cost service choice, and one that provides greater flexibility and control for individuals and their families. There are many reasons why individuals select the service types that they do. Typically, those with needs that are more extensive and who have fewer natural supports request Assisted Day and Assisted Residential services. Individuals with less extensive needs and/or more natural supports can typically be well served in the less expensive service types. Individuals often do not choose the less expensive, less intensive services because of the lack of flexibility and safety net assurances that would allow them to return to a more intense level of service if less intensive services do not work out.

**The CSP is an excellent lower cost service choice, and one that provides greater flexibility and control for individuals and their families.**

As previously noted, the CSP is a fairly new service option in the state and has yet to realize its full potential. It is anticipated that if more individuals and families, especially youth transitioning out of high school, were well informed about the CSP, they might find that it is a more desirable option than the typical group home and workshop setting.



## WAITING LIST FUNDING OPTIONS

As mentioned earlier in this report, some individuals have been waiting for services since 2003. Table 1. represents, by need date (in two-year increments), the number of individuals waiting for each of three service types: day, residential, and respite. Individuals can request one, two, or all three services. This data is based on data obtained from the Division of Developmental Disabilities through November 14, 2008.

Need Date	PROGRAM TYPE			
	Day	Residential	Respite	Total
2003 & 2004	142	698	82	922
2005 & 2006	173	631	110	914
2007 & 2008	157	426	178	761
<b>Total</b>	472	1755	370	2597
<b>Avg. Yearly Growth</b>	79	293	62	434

Table 1. Service Requests by Program Type by Need Date (as of 11-14-08)

The LR 156 Workgroup recommends consideration of the following two options for methods to reduce the waiting list as presented in Table 1. Option #1 is the preferred option.

**Option #1:** Appropriate funds, in the upcoming fiscal year, necessary to provide services for all eligible individuals with developmental disabilities who are past their need date. Once those individuals have been funded, provide funding for all eligible individuals as they reach their need date.

**Option #2:** Incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on their need date.

### **Option #1.**

As of November 14, 2008, a projection of \$62,544,700 State and Federal funds is needed to fully fund the waiting list. Taking into account the Medicaid match rate for waiver services and the historical average number of waiver eligible individuals in Nebraska, this results in an approximate 50/50 split for State and Federal funds. **These figures do not take into account any increased rates or changes to the rate methodology, nor do they take into account any additional infrastructure needs, i.e., Service Coordination, additional state level staff, etc. The funds cover only the costs for services calculated on the 2008 rates.** Any unexpended funds during any fiscal year would revert back to the general fund and be set aside for future use in reducing the waiting list. Continued appropriations for subsequent years are necessary to address ongoing need.

**Option #2.**

Option #2 is presented in Table 2. below. The proposed option is based upon the premise of providing needed funding for two years of service requests in each year from 2009 until 2014. **These figures do not take into account any increased rates or changes to the rate methodology, nor do they take into account any additional infrastructure needs, i.e., Service Coordination, additional state level staff, etc. The funds cover only the costs for services calculated on the 2008 rates.** This will need to be re-calculated each biennium to reflect current actual requests, as well as to reflect those who have changed their need date. The column titled 'New State and Federal Funding + Funding from Previous Year(s)' in the table reflects the funding appropriated in the previous year to fund those on the waiting list *plus* new funding for the year to fund additional people on the waiting list. Funding must be carried forward each year to continue services for those who were newly funded in the previous year.

The service requests are reduced by the percentage of individuals who typically accept services for the year requested, i.e., 60% of day services; 80% of residential services; and 70% of respite services. By the year 2015, the backlog of the waiting list will be eliminated and, from that year forward, individuals must be funded on their need date so that it does not build up to what it is today. The state funding total is calculated at 50% instead of the customary 40% because some individuals do not qualify for Medicaid funding and rely totally on state funding.

Fiscal Year	Years of Date of Need	Day: 60% of Requests	Residential: 80% of Requests	Respite: 70% of Requests	Total Requests Funded	New State and Federal Funding per Year	New State and Federal Funding + Funding from Previous Year(s)	State Funding Portion (50% of Total)
2009-10	2003-2004	85	558	57	700	\$22,995,784	\$22,995,784	\$11,497,892
2010-11	2005-2006	104	505	77	686	\$22,399,790	\$45,395,574	\$22,697,787
2011-12	2007-2008	94	341	125	560	\$17,159,125	\$62,554,699	\$31,277,349.
2012-13	2009-2010*	95	469	87	650	\$22,538,408	\$85,093,107	\$42,546,553
2013-14	2011-2012*	95	469	87	650	\$22,538,408	\$107,631,515	\$53,815,757
2014-15	2013-2014*	95	469	87	650	\$22,538,408	\$130,169,923	\$65,084,961
2015-16	2015*	48	234	43	325	\$11,269,204	\$141,439,127	\$70,719,563

**Table 2. Waiting List Reduction in 2 Year Increments**

\*Based on anticipated growth of the waiting list, not actual requests. Anticipated growth was calculated by averaging requests from 2003 until 2008.

## WAITING LIST REDUCTION RECOMMENDATIONS

1. **Funding:** Option #1 to appropriate, in the upcoming fiscal year, the funds necessary to provide services for all eligible individuals with DD is the ideal recommendation to fund the waiting list. Once all individuals on the waiting list are provided services, individuals will be funded as they reach their need date. Option #2 to incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on an annual basis is an acceptable option, but not the preferred option.
2. **Priority One Funding and Savings:** The workgroup recommends the appropriation of a separate fund to serve individuals determined to be Priority One status each year instead of savings from attrition being utilized for Priority One funding. The average annual cost for those in Priority One status is \$4 million (\$2 million Federal/\$2 million State funds). Savings from attrition or efficiencies in the system can then be used to fund individuals on the waiting list.
3. **Community Supports Program (CSP):** Revisions to the CSP to improve its usability and attraction to individuals and families include the following recommendations:
  - The current CSP caps funds available to individuals at \$20,000 or their OAP, whichever is less. Many individuals and family members report that this is too low to meet their needs. The workgroup recommends raising the individual cap.
  - Currently, the rates at which providers can be paid are capped at levels that are reported to be too low to attract and retain quality providers. These caps also limit the ability of individuals to hire specialized DD providers to provide services. The workgroup recommends raising or eliminating these caps.
  - The CSP has not been widely marketed. The workgroup recommends that extensive marketing and promotion of the program be provided to all interested stakeholders.
  - The workgroup recommends increased training and/or assistance to individuals, families, Service Coordinators, providers, and educators to increase the ability of individuals and families to identify and seek individualized services, self-direct services, and make informed decisions.
  - Currently, individuals in the CSP are not allowed to pay a non-legally responsible relative residing with them to provide their services. The workgroup recommends that CSP funds are allowed to purchase support from a non-legally responsible relative residing with the individual. It is also recommended that consideration be given to further changes to this requirement (in line with Federal Medicaid requirements) that might allow legally responsible relatives to be paid for the provision of services. Impact on other state programs would need to be considered. These changes may allow for a more cost-effective method of providing services.

4. **Incentives:** If Option #2 is chosen: provide an incentive for lower cost services by developing a phase-in process to allow individuals on the waiting list and past their need date by one year to choose either supported services or the CSP and receive services immediately. This process would continue until the slots on the associated waivers are filled. (Example: In the first year, all persons with a need date of 2003-2004 would be offered services. In addition, those with a need date of 2005-2006 would be offered the option of receiving CSP services or supported services). It is important that the changes to the CSP, as identified in point #3, be implemented in order to make this a more viable service option.
5. **Infrastructure:** The infusion of more than 2,000 individuals into the DD system over the next five years will result in a need for increased State agency administrative infrastructure to support increased capacity, e.g., Service Coordination, implementation and oversight needs, education, training, etc.
6. **Reporting:** The LR 156 Workgroup and other stakeholders have expressed confusion regarding waiting list numbers and processes. The workgroup recommends that the State develop a system for regularly reporting the status of the waiting list to interested parties, e.g., legislators, those on the waiting list, and other stakeholders.
7. **Safety Net:** Many individuals and their families do not choose the less expensive supported services (staff are *not* always present) over the more expensive assisted services (staff are always available) because they are fearful that if an emergency arises, they will not be able to access the assisted services needed to weather the emergency. The workgroup recommends that safety net policies and procedures be developed that allow individuals to choose CSP or supported services or even exit from those services *without* losing the option to access assisted services.

# RATE METHODOLOGY

An obvious concern is the need for revision of the rate methodology by which Nebraska pays DD service providers. Legislators recognized this need in the creation of LR 156, asking for recommendations for revisions to the rate methodology. This is critical, in that the methodology has not had significant review or change since its development in 1992.

## DD PROVIDER INPUT

The LR 156 Workgroup asked Nebraska DD providers to weigh in on the current rate methodology. The methodology has been a major source of tension within the service delivery system for many years. The following points serve as a basis for understanding the history of the rate methodology. Documents supplied to the workgroup by the DD providers can be found in Appendix C.

1. The basic premise of the funding methodology and intervention unit system was to provide "portability" so people could choose any provider and have the money follow the person.
2. People with higher need levels receive greater support than those with lesser need levels; the hope was to provide "no more, no less" than what a person needs.
3. Consistency is achieved by an Objective Assessment Process (OAP) using the Inventory for Client and Agency Planning (ICAP) to determine the number of intervention units. All providers are reimbursed at the same rates for the same services. How well this works in terms of individual equitability can be questioned, but it is a consistent process. It should also be noted that the OAP has not been implemented for hundreds of people who were "grandfathered" into the system when it was implemented for new people entering the system several years ago; therefore, consistency on how the amount of service each individual is receiving does not currently exist.
4. The Medicaid Waiver provides 59.54% federal funds and the state provides 40.46% of the funds when a person is served under a Waiver. Since not everyone is eligible for a Waiver, it averages to be a 50/50 split in costs. It is important to ensure that, when people are authorized for services, Waiver eligibility is immediately sought in order to maximize federal funding.
5. The direct personnel category of the funding methodology is based on 90% of the entry-level salary of a part-time temporary Developmental Technician I (DT I) at the Beatrice State Developmental Center (BSDC) instead of the average salary of a full-time Developmental Technician II (DT II) position. Current rates under the methodology are much lower than the 90% due to recent salary increases at BSDC. The major increased costs in human services have been in the area of benefits, due to increased cost of health insurance, worker's compensation insurance, and other benefits. Benefits originally computed at 20% of salary in the model are closer to 40% today.
6. The funding methodology has not been adapted for higher transportation costs, medical services support, issues around "sleep time" and increased regulation. In addition, there are issues regarding reimbursement for staff time in group homes for overnight

coverage. There are also higher costs for certifying medication aides and licensing of residential settings that impact the cost of doing business which are not reflected in past rate increases.

While there are many issues concerning the funding methodology and practices that affect the waiting list, the primary factors can be categorized as *funding adequacy*, *funding flexibility*, and *accountability*.

### **Funding Adequacy**

While it is clear that money is not the only barrier to staff recruitment and retention, it is perhaps the most critical factor. The current funding methodology includes reimbursement amounts for six different cost categories for each service: direct personnel, direct management, indirect management, non-personnel operating, transportation, and facility costs. When the rate methodology was developed, the Direct Personnel cost category was based on 90% of an entry-level salary position at BSDC. That entry position is now rarely used because of an inability to recruit for that position.

DHHS previously billed the Federal government at 100% of the methodology, but paid providers at 90% of the methodology. DHHS stated that providers came up with the other 10% through county funds and other sources. Recognizing that providers were not receiving 10% from the county or other funds, the State began billing the Feds at the 90% rate they were paying providers, effectively lowering the methodology by 10%.

There are two references to 90% in these discussions that may be confusing. The rate was built on 90% of the salary of BSDC's DTI position, with the idea that providers would be paid less than the State pays staff who deliver similar services at BSDC. Then, as noted above, DHHS said that 10% of the methodology amount was being provided by county funds and other sources so the State would only fund 90% of the methodology rate, further reducing the ability for providers to adequately fund their direct service positions.

In addition, recent salary increases at BSDC have caused providers to fall even farther below the 90% level. Funding should be based on the average BSDC's DTII salary, not entry level of DTI. Providers need to be able to recruit and retain quality staff for a quality service to be delivered. The methodology was developed to support people with DD through habilitation, i.e., training. The people supported today have broader needs than the funding for habilitation envisioned.

### **Funding Flexibility**

The current system of intervention units does not have the flexibility to respond to changes in individuals' lives due to health issues, behavioral issues, seasonal changes, and family situations. Because the State of Nebraska cannot afford to provide one-to-one supports for everyone who needs staff available at all times, some support is provided in groups. This demands flexibility of funding.

The current system offers a method, while less than ideal, to develop a more flexible method to address individual needs. It is proposed to multiply the rates by the approved units to develop a monthly rate for the supports provided to an individual. A monthly unit reimbursement system would assist providers to ebb and flow with individuals' lives. The idea of this is that providers would furnish

**The current system of intervention units does not have the flexibility to respond to changes in individuals' lives due to health issues, behavioral issues, seasonal changes, and family situations.**

supports that are more intensive during times when an individual has higher needs and back off when those needs lessen.

### **Accountability**

It is important to the Nebraska taxpayer and providers, as stewards, to provide accountability for the use of public funds. It is an equally important facet of stewardship to develop processes that are efficient and effective in delivering outcomes that are desired by the people who receive support and their families. While the State reimburses for each individual, they recognize the need for using staff effectively and the number of units are based on a number of individuals receiving support at the same time.

Accountability should focus on the person receiving supports rather than staff and the billing system. Innovative, efficient, and effective methods of delivering the outcomes that people want and need must be developed. Monitoring processes should focus on the use of mechanisms such as Service Coordination monitoring reports, Quality Review Teams, certification processes, critical incident reporting, family involvement, etc. to determine whether the supports have been provided in accordance with the Individual Program Plan.

### **Service Delivery System Capacity**

Service providers struggle to survive in the face of low payment rates that, in turn, result in major problems in meeting basic quality standards and maintaining workforce stability. There is broad agreement among Nebraska DD service providers that the rates that are paid for DD services are insufficient to ensure the delivery of high quality, effective support for individuals. These enduring low rates in Nebraska are a major source of discussion within the service delivery system.

The LR 156 Workgroup again turned to providers to address the issue of their capacity to serve individuals on the waiting list. Providers reached consensus that, if the following criteria are met, they could develop capacity to respond to an incremental plan to serve all of the individuals on the waiting list.

1. There is a 15% increase in rates to build capacity to serve additional individuals, as well as to attract and retain quality staff.
2. Authorizations for individuals are enough to meet their actual needs.
3. Behavioral health supports are available for dually diagnosed and/or behaviorally challenged individuals.

## RATE METHODOLOGY RECOMMENDATIONS

1. **Rate Methodology Study:** The current rate methodology was developed in 1992. It is way past time to develop a rate structure to meet the demands of today's economic environment. In addition, providers have increased demands which did not exist in 1992, including the provision of medical support services; issues around "sleep time"; and increased regulations. The workgroup recommends that the State pursue an independent contract to develop a more appropriate funding methodology and to develop funding alternatives. Among the changes to be considered are:
  - Development of a monthly rate for assisted services.
  - Development of a separate and distinct funding process that includes provider start-up costs to build capacity to serve people from the waiting list.
2. **Provider Rate Increase:** Whether or not a rate methodology study is conducted, providers will require extra funding if the more than 2,000 individuals on the waiting list through 2010 are to be served. The providers are strapped to pay direct service personnel a decent wage and cover the costs of employee benefits and transportation, which have increased tremendously over the past sixteen years since the rate methodology was developed. An increase of 15% in provider rates to build capacity and meet on-going costs of doing business is needed so providers can hire and retain employees and cover actual costs.
3. **Unexpended Funds:** There is a general belief that any DD funds not utilized during a fiscal year are returned to the General Fund. If this is the case, it is recommended that any unused funding allocated to the DD system should be applied to serving persons on the waiting list.
4. **Electronic Billing:** The current billing and reimbursement system needs revision and, if updated, could be a cost saver for the State and providers. An electronic billing and reimbursement system should be developed to reduce errors and provide effective tracking and reporting systems.



# SYSTEM RECOMMENDATIONS

This report has outlined specific recommendations to be used in the development of a strategic plan for addressing the waiting list and rate methodology. Through the workgroup process, other system recommendations were developed that are critical to achieving the ultimate goal of providing quality of life for Nebraskans with developmental disabilities. Those recommendations follow.

- 1. Service Models:** The current service models do not address the complex needs presented by some individuals. The workgroup recommends the development of service models to concentrate on the needs of all eligible people within the definition of DD, including those with traumatic brain injury, autism, dual diagnosis, and medically complex conditions. This should include utilizing resources such as Telehealth technology to promote access to specialized professionals, e.g., mental health services.
- 2. Assistive Technology:** Assistive technology is tremendously underutilized in our state. The workgroup recommends increasing access and use of assistive technology for all ages.
- 3. Transition Practices:** Transition planning for high school students is not always done in coordination with adult agency providers, resulting in missed opportunities for youth. The workgroup recommends increased partnerships between the education system, DD system, and Vocational Rehabilitation to provide seamless transition for students as they move from school to adult life. Schools, DDD, and Voc Rehab need to collaborate in the pursuit of real jobs for students during the last two years of school. It is also recommended that increased efforts are made to promote postsecondary education as an option for transition students.
- 4. Provider Employee Development:** Quality direct service workers are worth their weight in gold. The workgroup recommends the funding of a comprehensive system of provider personnel development to assist in direct service worker retention. This may include the development and funding of initiatives such as career ladders, employee incentives, and educational benefits.
- 5. Certification Procedures:** Certification processes are cumbersome for new, small providers to navigate. The workgroup recommends the revision of certification procedures to encourage the development of small and possibly single service providers.
- 6. Individual Use of Funds:** Individual use of allotted funding is tightly controlled. The workgroup recommends greater flexibility in the individual's use of their allotted funds to purchase supports to meet their needs and to receive services in settings that make sense for the individual, e.g., providing day services in the home.
- 7. Regulations:** It is a general perception that state regulations are often more restrictive than necessary, reducing flexibility in providing services. The workgroup recommends that state and federal laws and regulations be interpreted in a manner which allows flexibility (which in some cases promotes the use of less expensive services) whenever possible.

- 8. Pilot Projects to Promote Recruitment/Development of Services:** The workgroup recommends that requests for pilot projects that promote recruitment and/or development of services be sought. Innovative practices in service design and delivery to create a broader range of options to people with DD, especially those who are without services or have fewer options and resources, should be promoted.
- 9. Waiver Expansion:** Nebraska's Medicaid waivers favor services designed to promote habilitation. The workgroup recommends the current waivers expand to include services other than habilitation.
- 10. Objective Assessment Process:** The Objective Assessment Process (OAP) workgroup should be convened to address identified issues related to this process (see "Related DD Systems Issues" section of this report for further discussion).
- 11. Quality Monitoring:** Provider audits currently measure whether staff was present or not during a shift. The workgroup recommends that quality monitoring be measured by outcomes for people rather than whether staff was present. Monitoring should rely upon the use of Service Coordination monitoring reports, Quality Review Teams, certification processes, critical incident reporting, family involvement, etc. to determine whether the supports have been provided in accordance with the Individual Program Plan.

# OVERSIGHT PLAN

It is the consensus of the LR 156 Workgroup that an oversight plan is necessary to ensure that:

1. Decision-makers give proper consideration to the recommendations for addressing the waiting list and funding methodology;
2. A strategic plan for implementation of the recommendations is developed;
3. Rationale is provided for any recommendations that are not implemented; and
4. Ongoing monitoring of implementation of the strategic plan occurs.

## WAITING LIST OVERSIGHT RECOMMENDATIONS

- 1. Oversight Group:** It is the recommendation of this workgroup that the Nebraska Legislature appoint a committee or task force to monitor implementation and results of the LR 156 recommendations. Funding for the activities of this oversight group will need to be included, as it should not be the responsibility of these agencies to absorb the associated costs. Further, the workgroup recommends representation from the following groups as appropriate members of the oversight committee:

- Nebraska Planning Council on Developmental Disabilities
- Nebraska Advocacy Services
- Munroe-Meyer Institute

These three agencies, funded by the federal administration on Developmental Disabilities (ADD), are part of a national network to build capacity of states and communities to respond to the needs of individuals with disabilities and their families. The role of these three agencies to provide advocacy leadership at a state and federal level to interested persons in Nebraska is a natural fit for this work.

- 2. Technical Advisors:** Appointment of technical advisors representing the following entities is critical to the work of the oversight committee:

- Nebraska Developmental Disabilities Provider Network
- The Arc of Nebraska
- Nebraska Department of Health and Human Services Division of Developmental Disabilities (NDHHS)

- 3. Implementation:** Recommendations of the workgroup related to oversight of implementation include:
  - a. The LR 156 Workgroup report shall be posted on the NDHHS website.
  - b. Periodic status reports shall be provided to stakeholders to reflect:
    - i. decisions regarding implementation of recommendations;
    - ii. updates on waiting list numbers and costs; and
    - iii. steps taken to address the funding methodology.

# SUMMARY OF LR 156 WORKGROUP RECOMMENDATIONS

## WAITING LIST REDUCTION RECOMMENDATIONS

1. **Funding:** Option #1, which proposes to appropriate funds, in the upcoming fiscal year, necessary to provide services for all eligible individuals with DD who are past their need date is the ideal recommendation to fund the waiting list. Once all individuals on the waiting list are provided services, individuals will be funded as they reach their need date. Option #2 to incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on an annual basis is an acceptable option, but not the preferred option.
2. **Priority One Funding and Savings:** The workgroup recommends the appropriation of a separate fund to serve individuals determined to be Priority One status each year instead of savings from attrition being utilized for Priority One funding. Savings from attrition or efficiencies in the system can then be used to fund individuals on the waiting list.
3. **Community Supports Program (CSP):** Revisions to the CSP to improve its usability and attraction to individuals and families include the following recommendations:
  - The current CSP caps funds available to individuals at \$20,000 or their OAP, whichever is less. Many individuals and family members report that this is too low to meet their needs. The workgroup recommends raising the individual cap.
  - Currently, the rates at which providers can be paid are capped at levels that are reported to be too low to attract and retain quality providers. These caps also limit the ability of individuals to hire specialized DD providers to provide services. The workgroup recommends raising or eliminating these caps.
  - The CSP has not been widely marketed. The workgroup recommends that extensive marketing and promotion of the program be provided to all interested stakeholders.
  - The workgroup recommends increased training and/or assistance to individuals, families, Service Coordinators, providers, and educators to increase the ability of individuals and families to identify and seek individualized services, self-direct services, and make informed decisions.
  - Currently, individuals in the CSP are not allowed to pay a non-legally responsible relative residing with them to provide their services. The workgroup recommends that CSP funds are allowed to purchase support from a non-legally responsible relative residing with the individual. It is recommended that consideration be given to further changes to this requirement (in line with Federal Medicaid requirements) that might allow legally responsible relatives to be paid for the provision of services. Impact on other state programs would need to be considered.

4. **Incentives:** If Option #2 is chosen: provide an incentive for lower cost services by developing a phase-in process to allow individuals on the waiting list and past their need date by one year to choose either supported services or the CSP and receive services immediately. This process would continue until the slots on the associated waivers are filled. (Example: In the first year, all persons with a need date of 2003-2004 would be offered services. In addition, those with a need date of 2005-2006 would be offered the option of receiving CSP services or supported services). It is important that the changes to the CSP, as identified in point #3, be implemented in order to make this a more viable service option.
5. **Infrastructure:** The infusion of more than 2,000 individuals into the DD system over the next five years will result in a need for increased State agency administrative infrastructure to support increased capacity, e.g., Service Coordination, implementation and oversight needs, education, training, etc.
6. **Reporting:** The LR 156 Workgroup and other stakeholders have expressed confusion regarding waiting list numbers and processes. The workgroup recommends that the State develop a system for regularly reporting the status of the waiting list to interested parties, e.g., legislators, those on the waiting list, and other stakeholders.
7. **Safety Net:** Many individuals and their families do not choose the less expensive supported services (staff are *not* always present) over the more expensive assisted services (staff are always available) because they are fearful that if an emergency arises, they will not be able to access the assisted services needed to weather the emergency. The workgroup recommends that safety net policies and procedures be developed that allow individuals to choose CSP or supported services or even exit from those services *without* losing the option to access assisted services.

## **RATE METHODOLOGY RECOMMENDATIONS**

1. **Rate Methodology Study:** The current rate methodology was developed in 1992. It is way past time to develop a rate structure to meet the demands of today's economic environment. In addition, providers have increased demands which did not exist in 1992, including the provision of medical support services; issues around "sleep time"; and increased regulations. The workgroup recommends that the State pursue an independent contract to develop a more appropriate funding methodology and to develop funding alternatives. Among the changes to be considered are:
  - Development of a monthly rate for assisted services.
  - Development of a separate and distinct funding process that includes provider start-up costs to build capacity to serve people from the waiting list.
2. **Provider Rate Increase:** Whether or not a rate methodology study is conducted, providers will require extra funding if the more than 2,000 individuals on the waiting list through 2010 are to be served. The providers are strapped to pay direct service personnel a decent wage and cover the costs of employee benefits and transportation, which have increased tremendously over the past sixteen years since the rate methodology was developed. An increase of 15% in provider rates to build capacity and meet on-going costs of doing business is needed so providers can hire and retain employees and cover actual costs.

3. **Unexpended Funds:** There is a general belief that any DD funds not utilized during a fiscal year are returned to the General Fund. If this is the case, it is recommended that any unused funding allocated to the DD system should be applied to serving persons on the waiting list.
4. **Electronic Billing:** The current billing and reimbursement system needs revision and, if updated, could be a cost saver for the State and providers. An electronic billing and reimbursement system should be developed to reduce errors and provide effective tracking and reporting systems.

## SYSTEM RECOMMENDATIONS

1. **Service Models:** The current service models do not address the complex needs presented by some individuals. The workgroup recommends the development of service models to concentrate on the needs of all eligible people within the definition of DD, including those with traumatic brain injury, autism, dual diagnosis, and medically complex conditions. This should include utilizing resources such as Telehealth technology to promote access to specialized professionals, e.g., mental health services.
2. **Assistive Technology:** Assistive technology is tremendously underutilized in our state. The workgroup recommends increasing access and use of assistive technology for all ages.
3. **Transition Practices:** Transition planning for high school students is not always done in coordination with adult agency providers, resulting in missed opportunities for youth. The workgroup recommends increased partnerships between the education system, DD system, and Vocational Rehabilitation to provide seamless transition for students as they move from school to adult life. Schools, DDD, and Voc Rehab need to collaborate in the pursuit of real jobs for students during the last two years of school. It is also recommended that increased efforts are made to promote postsecondary education as an option for transition students.
4. **Provider Employee Development:** Quality direct service workers are worth their weight in gold. The workgroup recommends the funding of a comprehensive system of provider personnel development to assist in direct service worker retention. This may include the development and funding of initiatives such as career ladders, employee incentives, and educational benefits.
5. **Certification Procedures:** Certification processes are cumbersome for new, small providers to navigate. The workgroup recommends the revision of certification procedures to encourage the development of small and possibly single service providers.
6. **Individual Use of Funds:** Individual use of allotted funding is tightly controlled. The workgroup recommends greater flexibility in the individual's use of their allotted funds to purchase supports to meet their needs and to receive services in settings that make sense for the individual, e.g., providing day services in the home.
7. **Regulations:** It is a general perception that state regulations are often more restrictive than necessary, reducing flexibility in providing services. The workgroup recommends that state and federal laws and regulations be interpreted in a manner which allows flexibility (which in some cases promotes the use of less expensive services) whenever possible.

- 8. Pilot Projects to Promote Recruitment/Development of Services:** The workgroup recommends that requests for pilot projects that promote recruitment and/or development of services be sought. Innovative practices in service design and delivery to create a broader range of options to people with DD, especially those who are without services or have fewer options and resources, should be promoted.
- 9. Waiver Expansion:** Nebraska's Medicaid waivers favor services designed to promote habilitation. The workgroup recommends the current waivers expand to include services other than habilitation.
- 10. Objective Assessment Process:** The Objective Assessment Process (OAP) workgroup should be convened to address identified issues related to this process (see "Related DD Systems Issues" section of this report for further discussion).
- 11. Quality Monitoring:** Provider audits currently measure whether staff was present or not during a shift. The workgroup recommends that quality monitoring be measured by outcomes for people rather than whether staff was present. Monitoring should rely upon the use of Service Coordination monitoring reports, Quality Review Teams, certification processes, critical incident reporting, family involvement, etc. to determine whether the supports have been provided in accordance with the Individual Program Plan.

## **WAITING LIST OVERSIGHT RECOMMENDATIONS**

- 1. Oversight Group:** It is the recommendation of this workgroup that the Nebraska Legislature appoint a committee or task force to monitor implementation and results of the LR 156 recommendations. Funding for the activities of this oversight group will need to be included, as it should not be the responsibility of these agencies to absorb the associated costs. Further, the workgroup recommends representation from the following groups as appropriate members of the oversight committee:
  - a. Nebraska Planning Council on Developmental Disabilities
  - b. Nebraska Advocacy Services
  - c. Munroe-Meyer InstituteThese three agencies, funded by the federal administration on Developmental Disabilities (ADD), are part of a national network to build capacity of states and communities to respond to the needs of individuals with disabilities and their families. The role of these three agencies to provide advocacy leadership at a state and federal level to interested persons in Nebraska is a natural fit for this work.
- 2. Technical Advisors:** Appointment of technical advisors representing the following entities is critical to the work of the oversight committee:
  - a. Nebraska Developmental Disabilities Provider Network
  - b. The Arc of Nebraska
  - c. Department of Health and Human Services Division of Developmental Disabilities
- 3. Implementation:** Recommendations of the workgroup related to oversight of implementation include:
  - a. The LR 156 Workgroup report shall be posted on the NDHHS website.
  - b. Periodic status reports shall be provided to stakeholders to reflect:
    - i. decisions regarding implementation of recommendations;
    - ii. updates on waiting list numbers and costs; and
    - iii. steps taken to address the funding methodology.



# RELATED DD SYSTEMS ISSUES

As the LR 156 Workgroup conducted activities related to developing recommendations for a strategic plan to reduce the number of persons on the waiting list for DD services and to make revisions to the rate methodology, they recognized that there were other critical issues that need to be addressed by Nebraskans. Although these may not have a direct impact on the waiting list, they cannot be ignored. These issues are so connected that, without making needed changes to all, there is a risk of just transferring a problem from one area to another.

The following issues need to be resolved:

- Changes to the Objective Assessment Process (OAP) need to be considered. The current instrument used is the Inventory for Client and Agency Planning (ICAP). Although individuals are assessed using the ICAP, only individuals new to the system are given the units identified in that formula. Other individuals are authorized at their historical level of service, which may be higher or lower than the ICAP amount. Attempts to make the changes based on the ICAP were stopped, in part, due to concerns about the ability of the ICAP to predict costs of individuals with medical and behavioral health needs. The original plan did not allow for incremental changes, so there were concerns about people being placed at risk if their services were cut dramatically after years of receiving supports. A comparison pilot was done measuring the Supports Intensity Scale (SIS) against the ICAP and policies were put into place to insure safeguards for people losing services. However, the plan was never implemented. Currently, the DD Division has agreed, as part of a lawsuit settlement, to bring a workgroup together to look at this issue again and make recommendations. There are currently individuals in the system receiving fewer services than needed based on their assessments because there is not sufficient funding available to them. It is unclear whether moving people closer to their ICAP amount either up or down would result in additional costs, less costs or balance each other out. It is the recommendation of the LR 156 Workgroup that the OAP Workgroup be convened immediately to address these issues.
- The waiting list does not reflect everyone who is underserved. The waiting list only includes people who are not getting any service in that particular area (residential, day, and/or respite) for which they are on the registry. If an individual accepts any service in an area, they are no longer on the registry for that category of service. This is especially confusing for families who may think they are on the waiting list for a group home when they are getting some in-home supports. The services they are receiving are considered residential supports, so they no longer are on the waiting list in this category. They may be considered underserved and if circumstances change, they may become a Priority One and get the additional units needed to support a group home placement but they are no longer counted in the waiting list. The OAP issue discussed earlier also results in individuals being underserved but not on any waiting list as it is considered a separate issue. At this time there is no record kept at the state level of these “underserved” individuals.
- There are individuals who have a sufficient number of units authorized but because of the geography of where they live, their medical or behavioral health condition, or other factors are unable to find a provider for the needed services. Since the LR 156 Workgroup looked at service capacity issues, it is possible that some of their recommendations in this area will help solve this problem when implemented.

- There are two concerns about youth transitioning from school to the adult service system. First of all, individuals and families continue to lack the accurate information they need to plan for the services and supports that will be needed when they leave school. Although day services are an entitlement to students exiting special education at age 21, residential services are not. Individuals and their families must make appropriate plans for supports the persons needs beyond day services.

The second issue in this area is services for youth who are 18 to 21 years old. Health and Human Services has determined that DD day services are not available until a student reaches 21, regardless of when they graduate. Although this is not an issue for many students who stay in school until they are 21, there are some students who have completed their schooling and would like to graduate and begin paid employment. However, if they opt to do this prior to age 21, they are not eligible for job coaching or assistance in finding and keeping a job. This also limits services that may be provided by Vocational Rehabilitation prior to age 21. Proponents of serving this population maintain that by serving these youth at an earlier age, it is possible to divert them from long term service needs in the DD service system.

- The lack of appropriate and accessible behavioral health services for individuals with DD and mental health concerns is a growing problem in the DD system. Several factors make this a very difficult problem. There is a lack of mental health practitioners that are trained to diagnose and treat persons with DD. The regulations governing DD settings are focused on maximizing independence and so make it difficult to restrict individuals for their safety or that of the community in which they live. Some individuals with severe behavioral health problems function intellectually at the higher end of the scale for DD. The current assessment process measures their functional level and authorizes units accordingly, while it may not take into account the supervision and supports they need because of their mental health problems. As a result, it may be difficult to find qualified providers willing to serve them for the amounts offered. Finally, there is reluctance on the part of the Behavioral Health System and the Division of Developmental Disabilities to assume responsibility for these individuals. Both systems engage in conversations about identifying the “primary diagnosis” in order to say the person belongs in that system rather than trying to figure out how to blend funding and services from both systems to best serve that individual. If services to this population are not provided, it stresses the entire DD system and results in costly institutional placements and Priority One situations.
- Quality assurance must be an essential component of any changes to the community based DD system. The focus must be on insuring that individuals are reaching their identified outcomes. Individuals and families must be confident that the system is assuring basic safety, while being flexible enough to give people choices on how they want to live their lives. Quality assurance and monitoring by the state must allow for flexibility and not be concentrated on paper reviews, but rather observing to determine the quality of life and outcomes that people are achieving.
- Home and Community Based Waivers in Nebraska should be looked at to make sure that they reflect the best practices in the state and nation. They need to maximize federal funds by insuring that all needed services are included. Waivers should allow for self-direction whenever possible. In order to allow people to use the waiver best suited to their needs, eligibility should be based on meeting certain criteria and no waiver should exclude populations if they meet this criteria

# APPENDIX

## APPENDIX A. LR 156

LR 156 ONE HUNDREDTH LEGISLATURE  
FIRST SESSION  
LEGISLATIVE RESOLUTION 156  
Introduced by Johnson, 37;

**PURPOSE:**

(1) To examine and provide recommendations relating to the waiting list for people with developmental disabilities and to provide recommendations on any proposed changes to the methodology used for the payment of service providers. The waiting list refers to people who have been determined to be eligible for services, have set a date of need, but have not received services because of a lack of funding available. The waiting list has continued to be only partially addressed and communication, coordination, and collaboration are needed to develop an updated strategic plan based on incremental implementation if the intent of Nebraska law is to be met.

(2) Subsection (3) of section 83-1216 provides: "It is the intent of the Legislature that by July 1, 2010, all persons determined to be eligible for services shall receive services in accordance with the Developmental Disabilities Services Act."

In 2004, LB 297 amended section 83-1216 to include the establishment of a workgroup to provide a report to the Legislature and the Governor for the development of an objective assessment process to determine the amount of funding for the provision of services. The report generated by this workgroup was supported by unanimous consent of the workgroup. Further work is needed to develop a plan and additional study is necessary. Such study and recommendations for a plan shall include, but not be limited to, consideration of the following:

(a) A plan for the provision of services to all persons determined to be eligible for services in accordance with the Developmental Disabilities Services Act by 2010; and

(b) The incremental statewide implementation process for the provision of specialized services based upon:

(i) The number of persons who are waiting for services; and

(ii) The need to prevent any future development of lengthy waiting lists for services.

(3) The plan shall be based upon data provided by the Department of Health and Human Services and the State Department of Education to include, but not be limited to, the following:

(a) The historical usage of priority one funding for people with developmental disabilities;

(b) Attrition in specialized services;

(c) The projected and actuarial budgeted funding for students who are exiting high school; and

(d) Other information as needed.

(4) In addition, the Medicaid Reform Council has identified the need to review and revise the methodology used for determining the rates paid to intellectual and developmental disability providers.

**NOW, THEREFORE, BE IT RESOLVED BY THE MEMBERS OF THE ONE HUNDREDTH LEGISLATURE OF NEBRASKA, FIRST SESSION:**

To implement the purpose of this resolution, the Department of Health and Human Services shall establish a working group including representatives from the State Department of Education, the Advisory Committee on Developmental Disabilities,

**the Developmental Disabilities Planning Council, people with developmental disabilities and their families, a statewide intellectual and developmental disability advocacy organization, developmental disabilities service providers, and other interested parties. The working group shall:**

- (1) Submit recommendations for a strategic plan to incrementally reduce the number of persons on the waiting list for developmental disabilities to meet the intent of the Legislature;**
- (2) Consult with the Department of Health and Human Services to review and make recommendations on any revision to the rate methodology; and**
- (3) Submit the workgroup's recommendations on the strategic plan and revisions to the rate methodology in a report to the Medicaid Reform Council, the Legislature, and the Governor.**

## APPENDIX B. SERVICE DEFINITIONS

### Vocational

**Assisted Day/Vocational:** staff is on site and immediately available at all times.

**Supported Day/Vocational:** staff is periodically available and is not constantly on site/available. Services may be provided at work sites where persons without disabilities are employed or volunteer.

**Work Station in Industry:** workstations are located in a community business or industry where persons without disabilities are employed and where there may be several persons working on different job duties or contracts. Staff is available to people receiving these services at all times. The provider may contract with business or industry. Examples may include enclaves, workstations, or mobile work crews. Workstations do not include provider workshops.

### Residential

**Assisted Residential:** staff is available at all times-including sleep time. Services may be provided in group homes, apartments, or other living environments.

**Supported Residential:** Services are provided in a residential setting where the person is responsible for maintaining their own home, both financially and domestically, with periodic supervision/support from staff.

**In-Home Habilitation:** this service is provided to people living with their family to support the individual and family and to prevent out-of-home placements.

**Extended Family Home:** people receiving these services do not live with their natural families or in settings operated by a DHHS certified provider. Extended families provide service in their own homes and must be available to provide habilitation when the person is home (day and/or evening). Room and board is paid by the person with the disability and the board should include three meals each day.

**Home Teacher:** home teachers are employees of a certified provider agency. Individuals do not live in their natural family homes. Services are provided in a home teacher's home where a home teacher must be available during the day and/or evening, including sleep time. Room and board (three meals daily) are provided at the expense of the person with the disability.

### Respite

Respite services are available for persons living at home with their non-paid family or caregiver. Respite may be provided in the person's home or in a setting operated by a DHHS certified provider.

*Source: 2008 DDD Provider Profile*

## COMMUNITY SUPPORTS PROGRAM SERVICE DEFINITIONS

### **Assistive Technology and Supports (ATS)**

ATS includes devices, controls, or appliances that enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment they live in, thus decreasing their need for assistance from others. Approvable items are limited to those necessary to support individuals in their home and must be appropriate to the needs of the individual as a result of limitations due to disability.

### **Community Living and Day Supports (CLDS)**

Community Living and Day Supports provides the necessary assistance and supports to meet the daily needs of the individual. CLDS includes the following components:

- Assistance with hygiene, bathing, eating, dressing, grooming, toileting, menstrual care, transferring, or basic first aid.
- Supervision and monitoring for the purpose of ensuring the individual's health and safety.
- Supports to enable the individual to access the community. This may include someone hired to accompany and support the individual in all types of community settings.
- Supports to assist the individual to develop self-advocacy skills, exercise rights as a citizen, and acquire skills needed to exercise control and responsibility over other support services.
- Supports to assist the individual in identifying and sustaining a personal support network of family, friends, and associates.
- Household activities necessary to maintain a home living environment on a day-to-day basis, such as meal preparation, shopping, cleaning, and laundry.
- Home maintenance activities needed to maintain the home in a clean, sanitary, and safe environment. This may include heavy household chores such as washing floors, windows and walls, tacking down loose rugs and tiles, or moving heavy items of furniture.
- Supports to enable the individual to maintain or obtain employment. This may include someone hired to accompany and support the individual in an integrated work setting. Integrated settings are those considered as available to all members of the community. Payment for the work performed by the individual is the responsibility of the employer.

**Covered services do not include those provided in specialized developmental disability provider-operated settings, work stations, or supported employment services.**

- Supports to enable the individual to access services and opportunities available in community settings. This may include accessing general community activities, performing community volunteer work, and accessing services provided in community settings such as senior centers and adult day centers. Assistance with personal care needs or household activities is available only to those individuals who do not live with a paid caregiver. A paid caregiver is an individual or agency paid to provide services to meet the individual's daily needs. This does not include payments made for room and board.

The Community Living and Day Supports service is intended to provide necessary supports for the individual, but is not intended to duplicate or replace other supports available to the individual. Transportation to and from community activities is not covered as a separate component under this service. Fees, membership costs, and equipment costs related to social, leisure, and recreational outings are not covered under this service.

## **Home Modifications**

Home Modifications are those physical adaptations to the individual's home that are necessary to ensure the health, welfare, and safety of the individual, and/or which enable the individual to function with greater independence in the home. Examples of approvable modifications include:

1. Installing ramps, lifts, door levers, and grab-bars;
2. Building an accessible entrance into the home;
3. Widening interior doors to provide accessible routes of travel within the home to the bedroom, bathroom, and kitchen;
4. Modifying existing bathrooms to add roll-in showers, raised toilets, roll-under sinks; and
5. Adapting electric and plumbing systems to support assistive equipment, such as chair lifts and bathroom facilities.

Approvable modifications do not include adaptations or improvements to the home that are of general utility, and are not of direct medical or remedial benefit to the individual. Examples of home modifications that may not be approved include:

1. Home maintenance and repair such as carpeting or roof repair;
2. Access to the basement for use as a storm shelter or recreation;
3. Recreational pools and decks;
4. Remodeling not related to accessibility or disability-related needs;
5. New construction (exception may be made where a bathroom cannot be made accessible);
6. Restrictive modifications that replace supervision, such as half-doors, fences, and security items. Items which assist in supervision and are specifically related to the individual's needs due to disability may be considered, if necessary to ensure safety;
7. Central air conditioning; and
8. Adaptations which add to the total square footage of the home.

## **Personal Emergency Response Systems (PERS)**

PERS is an electronic device which enables individuals to secure help in an emergency. The individual may also wear a portable "help" button to allow for mobility. The system is connected to the person's phone and programmed to signal a response center once a "help" button is activated. PERS services are limited to those individuals who live alone or who are alone for significant parts of the day and have no regular caregiver for extended periods of time, and who would otherwise require extensive routine supervision.

## **Respite**

Respite is the temporary, occasional relief to the family from the continuous support and care of the individual. This service is available only to those who live with the usual non-paid caregiver(s). The term "usual non-paid caregiver" means a person who resides with the individual, is not paid to provide services, and is responsible on a 24-hour per day basis for the care and supervision of the individual. This service cannot be provided by members of the individual's immediate household. This may be provided in the individual's home or community.

## **Vehicle Modifications**

Modifications to vehicles may be made for purposes of accessibility when the vehicle is privately owned by the individual or his/her family and is used to meet the individual's transportation needs. The vehicle must be in good operating condition and modifications must be made in accordance with applicable standards of manufacturing, design, and installation.

*Source: CSP Consumer Handbook*



## APPENDIX C. PROVIDERS' INPUT

*To:* LR 156 Committee  
*From:* Dave Merrill, other providers on the LR 156 Committee  
*Date:* October 17, 2008  
*Re:* Funding Methodology and the Waiting List

---

### Overview of funding methodology and the interaction with the waiting list.

It is clear that the funding methodology and the practices adopted by HHS directly affect the capacity of the system to recruit and retain qualified staff to provide supports to address the waiting list. In addition, the funding system has a major impact on the capacity of the system to be flexible to the changing lives of people receiving supports. We have provided some basic points to consider about the funding methodology and practices that are relevant to the waiting list.

- \* The basic premise of the funding methodology and intervention unit system was to provide "portability" so people could choose any provider and have the money follow the person.
- \* People with higher need levels receive greater support; the hope was to provide "no more, no less" than what a person needs.
- \* Consistency is achieved by an Objective Assessment Process (OAP) using the ICAP assessment to determine the number of intervention units. It is important to use the term "units" rather than "hours" because according to people in the department at the time of development there was never an intent to apply the "face to face" criteria to assisted residential services. All providers are reimbursed at the same rates for the same services. How well this works can be questioned, but it is a consistent process. It should also be noted that the OAP has not been implemented for hundreds of people who were "grandfathered" into the system when it was implemented for new people entering the system several years ago.
- \* The Medicaid Waiver provides 59.54% federal and the state provides 40.46% of the funds when a person is served under the Waiver. Since not everyone is on the Waiver, it is about a 50/50 split for overall services. We should ensure that when people are authorized for services they go on the Waiver immediately to maximize federal funding.
- \* The funding methodology is based on 90% of an entry salary for a position (Tech 1) at Beatrice State Developmental Center that is paid to part time and temporary employees at BSDC. It should be based on the average salary of a Tech II position, since these are full time employees at the direct support level.
- \* Current rates under the methodology are much lower than the 90% due to recent salary increases at BSDC. The major increased costs in human services have been in the area of benefits, due to increased cost of health insurance, worker's compensation insurance and other benefits. Benefits originally computed at 20% of salary in the model are closer to 40% today.
- \* The funding methodology has not been adapted for higher transportation costs, medical services support, issues around "sleep time" and increased regulation. In addition, there are issues regarding reimbursement for staff time in group homes for overnight coverage. There

are also higher costs for certifying medication aides and licensing of residential settings that have not resulted in increases in rates.

While there are many issues concerning the funding methodology and practices that affect the waiting list, we have focused on three primary factors; adequacy, flexibility, and accountability.

#### Adequacy

While it is clear that money is not the only barrier to staff recruitment and retention, it is perhaps the most critical factor.

The funding methodology was based on 90% of an entry level salary of a position at BSDC that is now rarely used because of an inability to recruit. The State billed the Federal government at 100% of the methodology but paid providers at 90% of the methodology. (They argued that providers came up with the other 10% on their own.) Recognizing that this was not happening, they began billing the Feds at the 90% rate they were paying us, effectively lowering the methodology by 10%.

There are two references to 90% that may be confusing. The rate was built on 90% of the salary of the Tech I with the idea that the state would be paying providers less than they pay their own employees. Then the state said that 10% of the methodology amount was being provided by county funds and other sources so they would only fund 90% of the methodology rate.

In addition, recent salary increases at BSDC have caused providers to fall even farther below the 90% level. Funding should also be based on the average Tech II salary, not entry level of Tech I. We must recruit and retain quality staff.

The methodology was developed to support people with DD through habilitation. The people supported today have broader needs than the funding for habilitation envisioned.

**Recommendation: Restore the methodology to the 100% level and fully fund it. Modify the methodology to reflect the average Tech II's salary and the current percentage of salary to benefits. Do not return unused money to the general fund, but apply it to the waiting list.**

#### Flexible Funding

The current system of intervention hours does not have the flexibility to respond to changes in individuals' lives due to health issues, behavioral issues, seasonal changes and family situations. Because the State of Nebraska cannot afford to provide one-to-one supports for everyone who needs staff available at all times, we provide some support in groups that demand flexibility of funding.

The current system offers a method, while less than ideal, to develop a more flexible method to address individual needs. It is proposed to multiply the rates by the approved hours to develop a monthly rate for the supports provided to an individual.

Due to the congregate nature of supports, when an individual dies or leaves the system out of an assisted residential setting (group home), a compatible roommate from the extensive waiting list should be found, rather than forcing remaining roommates to move in order to match them with other people simply to have enough hours to provide 24/7 staffing. This does not apply when a person chooses another provider and takes their funding with them. We do not intend to promote group homes as the best choice for people, we simply recognize we may not be able to provide one-to-one support to everyone who needs 24/7 supports.

**Recommendation:**

- 1. Develop a monthly rate for assisted services. (These are services where staff are always available.)**
- 2. Develop a waiting list priority system that enhances capacity.**

Accountability

It is important to the Nebraska tax payer and all of us as stewards to provide accountability for the use of public funds. It is an equally important facet of stewardship to develop processes that are efficient and effective in delivering outcomes that are desired by the people we support and their families.

While the State reimburses for each individual, they recognize the need for using staff effectively and the number of hours are based on a number of individuals receiving support at the same time.

Accountability should focus on the person receiving supports rather than the staff and billing system. The state should become a partner in developing innovative, efficient, and effective methods of delivering the outcomes that people want and need.

**Recommendation: Use service coordination monitoring reports, quality review teams, certification processes, critical incident reporting, family involvement, etc. to determine whether the supports have been provided in accordance with the Individual Program Plan. Audits should measure outcomes for people rather than whether staff was present.**

**Implement electronic billing and reimbursement to reduce errors and provide easier tracking.**

# **White Paper on the Status of Developmental Disability Services in Nebraska**

June 30, 2008

## **Number of people needing support as of June 30, 2008**

\* There are approximately 4,567 people receiving specialized developmental disability services in the community and 270 people residing in state institutions at Beatrice State Developmental Center and the Bridges program in Hastings. There are also 239 people living in three private ICF-MRs in Beatrice, Axtell, and Grand Island.

\* There are 2799 people on a registry waiting for services across the state now or sometime in the future. Of those, 1,868 are past their requested date of need or have requested services by June 2008. Some people on the list have been waiting since January of 2003. The decision by several HHSS administrations to only fund day services for graduates has contributed to the waiting list.

\* It is difficult to estimate the number of people who are not receiving services and are not on the registry.

### **Additional Information**

\* Nebraska uses "means testing" to determine fees for individuals or families with minor children based upon financial ability to pay. These fees are collected by HHS.

\* HHS determines eligibility and funding for each individual, the individual and their family choose his/her provider. The person's funding follows the person if he/she chooses another provider.

\* The Medicaid Waiver provides a match for Medicaid waiver eligible people in the system. The match is 59.54 percent Federal, 40.46 percent state and local. These funds have provided the bulk of increases to the system over the last decade.

\* Providers are required to provide documentation of habilitation and must meet specified service needs that are driven by an Individual Program Plan (IPP).

\* Accountability is provided by a system of certification, regulation, complaint investigation, service coordination monitoring as well as oversight by local boards and advisory committees, advocacy groups and consumer satisfaction surveys.

\* Fiscal accountability is provided by statute and regulation.

### **Issues needing attention by the administration and legislature.**

\* Waiting list - There needs to be a plan to address the waiting list in a systematic way. There are several approaches that can be taken but we must have a measurable way of determining whether we are making progress, two possible measures include the length of the

waiting period or the percentage of eligible people served. The Developmental Disability Services Act stated the intent to address the waiting list but money has not been appropriated. In addition, the Federally mandated agency, Nebraska Advocacy Services has a current lawsuit against the state for the long waiting period and method of determining the amount of money allotted for each individual.

\* The funding methodology is based on 90% of a salary at Beatrice State Developmental Center that is not used as a base salary because of an inability to recruit staff into that position. With recent salary increases at BSDC current rates are much lower than the 90%. The major increased costs in human services have been in the area of benefits due to increased cost of health insurance and training to maintain a competitive wage to attract and retain qualified professional staff.

\* The basic assumptions of the funding methodology need to be examined. Changes in the last 14 years include increased transportation costs, medical services support, sleep time and increased regulation. The support needs of person receiving services have increased due to changes in eligibility criteria. In addition, benefits originally computed at 20% of salary in the model are closer to 40% today.

\* While the funding methodology is complex, the basic concept is that whatever percent increase state employees receive at BSDC should be provided to community based providers. Community providers face all the same issues of increased cost of insurance, difficulty in recruiting and retaining staff and increased demands through regulatory agencies. It still costs the state significantly less than if state employees were to provide the supports.

\* There needs to be a clearly understandable and fair way to determine the amount of support that the state will provide to an individual. While there is no perfect Objective Assessment Process (OAP), we need to agree on an effective assessment process that is flexible and changes with the needs of the individual.

\* Quality needs to be defined by people supported and families, as well as officials.

\* We need to remove the requirement for an elected official to be on the boards or advisory committee of certified providers. Public agencies are governed by county commissioners and need no additional representation on the advisory committee that has only the power to make recommendations. Private agencies find it cumbersome and ineffective to recruit an elected official.

## **Brief History**

Prior to the late 1960's, mental retardation was the term used to describe individuals with significant learning disabilities and the only option to families was the Beatrice State Home which is now called the Beatrice State Developmental Center (BSDC). The population at BSDC grew to over 2200 people and an investigation and federal lawsuit (Horacek vs. Exon) led to the growth of community services.

The state established 6 regions from Region I in the Panhandle to Region VI in the Omaha area. Governed by boards of county commissioners from each of the respective areas, they provided options for families across the state. In addition, Martin Luther Home and Bethphage Mission expanded their options from ICF-MRs, (small private institutions) to community based options. At approximately the same time, a change in the laws governing special education occurred, giving families the option of having their children remain in the community and receive an appropriate education.

The State of Nebraska has historically respected the views of family members in determining whether they will receive supports in an institution or the community and that remains true today.

In the past decade the number of certified providers has expanded to include over 30 different providers giving people with disabilities and their families significant choice of providers while retaining efficiency and the option of public community supports.

### **Acronyms**

AAIDD - American Association on Intellectual and Developmental Disabilities - (A national organization with a Nebraska chapter focusing on research, best practice, and professional networking.)

ACP - Association of Community Professionals - (An organization for people who work in the field of developmental disabilities.)

The Arc of Nebraska - (An advocacy organization for people who experience developmental disabilities and their families. It has local, state, and national affiliation.)

DDD - Division of Developmental Disabilities - (Division of HHSS devoted to specialized services for people with developmental disabilities.)

HHSS - Health and Human Service System - (State of Nebraska organization for human services)

NAS - Nebraska Advocacy Services - (A federally mandated advocacy organization.)

NASP - Nebraska Association of Service Providers - (An association of providers affiliated with the national organization American Network of Community Options and Resources, ANCOR)

NPN - Nebraska Providers' Network - (A voluntary association of Nebraska public and private providers with no fees or staff.)

PFN - People First of Nebraska - (Self Advocacy group originating in Nebraska, now international.)

### **Chronology**

1950s - Families begin to form programs to support their family members to fill the void between sending their children to Beatrice State Home and the lack of special education in the

school system and other supports in the community. In 1968, the Douglas County Plan formalizes this "grass roots" family movement.

July 1969 - LB 855 transfers the Office of Mental Retardation to the Department of Public Institutions from the Health Department moving away from a medical model.

1972 - The Horacek vs. Exon federal civil rights class action lawsuit is filed against the State of Nebraska. Due to this lawsuit, the population of the Beatrice State Home is reduced and the legislature appropriates funds for the development of community services and deinstitutionalization.

May 1973 - LB311 creates the six mental retardation regions in Nebraska, modified by LB302 in April 1974.

1974-1975 - Regions form governing boards of county commissioners. Advocacy groups feel county commissioners are able to offer local control and accountability and that public services are necessary to assure that low population areas of the state are adequately served.

Fall 1987 - Nebraska implements the Medicaid Waiver, capturing available Federal funds to supplement the State General Funds that had funded the system.

1991 - LB 830, the Developmental Disabilities Services Act is passed. After a study and much discussion, provider based case management services is transferred to state administered Service Coordination. It also transfers responsibility for waiting lists to the State of Nebraska, the state must authorize and approve funding prior to placement for a provider in order to receive state and Federal funding. In addition the federal definition of developmental disability is adopted, expanding the definition from the narrower mental retardation category.

1994 - LB 1136 provides additional funding to serve people in the community waiting for funding.

June 1995 - The Governor's Blueprint for Action contains a plan for eliminating the waiting list by requiring HHS to submit a plan to see that people leaving high school are offered supports, HHS interprets this to cover just day services so the waiting list continues to grow.

1996 - Medical service supports transfers back to providers from service coordination.

1998 - Administration and supervision of service coordination transfers from developmental disability Services (DDS) to the Health and Human Service System (HHSS) service areas.

## APPENDIX D. STATES' WAITING LIST INITIATIVES

### Annual Program Performance Report of State Councils on Developmental Disabilities 2007 Waiting List Narratives

#### AK

In conjunction with Senior and Disabilities Services and other stakeholders, the Council has been working to redesign the process by which people are drawn for home and community based services. An Ad Hoc Committee was formed to develop a new tool for determining placement on the wait list, and a new scoring system. The new tool was piloted at one urban and one rural provider agency during the last fiscal year, and the State began using the tool in the fall of 2007. The pilot demonstrated that the new tool is effective and improves the process and method by which people are drawn from the wait list. In addition, the group recommended numerous process improvement and recommendations for a tiered service delivery system were developed.

On September 30, 2007 there were 1,301 individuals on the wait list for services. After several years of flat funding for DD services, 136 people were drawn for services in FY07. Two groups of individuals were targeted, those over 40 years of age and who were likely living with aging caregivers, and those between 22 and 28 years of age, and who were transitioning from school to work. Of those, approximately 100 were interested, eligible, and have either begun receiving services, or are in process. Senior & Disabilities Services is committed to drawing 50 individuals per quarter doubling the number of recent annual draws, with the intent of eliminating the wait list or at a minimum, better managing the wait list so individuals and families don't wait more than a few months for services. The Alaska Housing Finance Corporation (AHFC) maintains a waiting list for Section 8 vouchers. Unfortunately, the process used to determine the number of people with disabilities waiting for services has been inconsistent over the past few years. Based on available information this year, AHFC estimates that number of people with developmental disabilities waiting for housing vouchers increased by 12 percent.

#### AL

Alabama continues to work at addressing the needs of persons on its waiting lists and to make it possible for people to access home and community-based services within a service system that is moving toward consumer driven/ person directed services. Currently there are 1743 persons waiting for services on the Waiting list. This number includes those waiting for services through the MR Waiver as well as the Living at Home Waiver. In FY 07, Alabama Department of Mental Health and Mental Retardation was able to serve 622 persons from the waiting list and provided 834 different services (279 residential, 319 day, and 236 supports). The division of Mental Retardation continues to manage the waiting list and prioritizes people based on assessment of the severity of their needs and the length of time waiting for services.

#### AS

During the fiscal year 2007 (October 1, 2006 to September 30, 2007), three requests came to the DD Council from families of children with disabilities to be housed at the Respite Care Center. Because of the limited space available at the Center, only one was accommodated. Two more are still on the waiting list.

#### AZ

The Arizona Department of Economic Security, Division of Developmental Disabilities (DDD) pulls wait list data from its management information system which identifies individuals waiting for one or more services by age (segregated by those over and under age 18). The wait list numbers reflect the number of people whose name appeared on the waitlist for one or more services for the timeframe October 1, 2006 through September 30, 2007. The wait list includes: 1) individuals who are unserved or underserved and are eligible for services provided through the long term system (Medicaid). Waiting for a service does not mean individuals are not receiving services; Medicaid-eligible individuals may be waiting for one or more services that are more difficult to obtain, including specialized services and/or services from a specific provider. An alternative service may be provided while the individual waits for a specific service and/or provider. Waitlist activity summaries generated from the Division's management information system report the number of individuals waiting for one or more services by age (segregated by those over and under age 19). Medicaid adults (Vocational) referred to Rehabilitative



Service Agency are not included in this count. The number of individuals waiting for one or more services is derived from reports for the requested timeframe. The waiting list is in constant flux. Barriers to service include limited appropriation for state only consumers and a statewide shortage of physical, occupational and speech therapists. The Division takes action to decrease the waiting list numbers by developing a network plan to address gaps in service throughout the state, rate increases for therapists and recruitment strategies to encourage development of rural therapy providers.

#### **CA**

There have been no changes to the information previously submitted.

#### **CO**

The demand for dd services is growing much faster than population growth and the State's ability to add new resources. The growth is tied in part to the baby boom cohort of persons with dd. This group increasingly requires state-funded services as their parents age. While Colorado is ranked 48th for fiscal effort for dd services, Colorado's dd service penetration and expenditures per person served are not far from the national average. Recent funding has targeted individuals transitioning from foster-care (who are not generally included on waiting lists); emergencies, based on current or imminent homelessness, an abusive or neglectful situation place the person's health, safety or well being in serious jeopardy, are a danger to others or a danger to self and the high risk persons that include 40 or older and living at home with parents or relatives, have a condition like dual diagnosis including mental illness, significant behavioral problems, non-mobile and/or medically fragile and those who have a functioning level of profound indicating a nearly constant level of daily care needs. One area that Colorado continues to struggle with is if there was enough funding in the system to cover the waiting list, would there be capacity. The interim committee heard testimony that low direct support staff wages, competing industries and high turnover make capacity an important correlated discussion with the Wait List. Recent surges in oil and gas exploration and development have created an even greater abyss for capacity in the rural reaches of Colorado. A coalition of advocates is exploring the potential for a targeted ballot measure for a sales tax increase to fully fund the existing wait list. A group of legislators that served on the summer interim committee have proposed a bill that would create a developmental disabilities cash fund with over 8 million dollars, growing each year incrementally and having the potential to roll over. With the pent up budget demand due to TABOR, Mental Health, Higher Education, Transportation and Education all have compelling needs that will no doubt tax the political will of the legislature, the executive branch and all Coloradans in setting funding priorities. The transformation of waived services into CMS's template and the expectation for Consumer Directed Services to be incorporated into the Comprehensive Service and Supported Living Service Waivers are all likely to have some impact on future wait lists.

#### **CT**

1. DMR's FY 2007 Appropriation funds \$4.1 million for the annualization of residential and enhanced family support, and Rent Subsidy Wait List placements, that were made in FY 2006, plus \$4.6 million to fund 150 new residential and 100 enhanced family support, and new Rent Subsidy Wait List placements, in FY 2007. The department's request for both annualization of services and new funding for services was included in new appropriations. 725 people were on the department's waiting list for residential services and 228 for day services. Appropriations provide for 66 people for residential services in FY 08 and 64 in FY 09, 79 for day services in FY 08 and 73 in FY 09, and 270 high school graduates in FY 08 and 245 in FY 09. There were also 192 people receiving services who were waiting for additional services plus 54 people in LTCs waiting for a service 2. Expansion of the KB waiver is allowable to 200 children. The Katie Beckett waiver was funded fully with 200 slots. The Council testified for additional appropriations. 3. 560 people are on the PCA waiver. State legislation enabled the expansion of the waiver to reach 698 people. New funds for additional people was appropriated for FY 08 and FY 09 but will reach only about 70 people each year. The Council testified for additional appropriations. 4. The Birth To Three list changes daily. The existence of a "waiting list" is disputed by the system but is generally known in practice. Appropriations fund expansion for eligible babies with very low birth weight, babies born at fewer than 28 weeks, children with significant delays in speech and biological risk factors and children with mild or unilateral hearing loss. 5. Since the start of the SNF Transition Project in June 2002, 311 people sought to transition. 127 have transitioned to the community. \$8.4 million was appropriated to implement a Money Follows the Person demonstration and increases from 100 to 700 the number of individuals to be served over a 5 year period. The Council testified for additional appropriations.

NOTE: States are now allowed to cover HCBS as a Medicaid State Plan option for certain individuals without requiring the person to prove that institutionalization would be the alternative. States may limit the number of people who can participate in this benefit AND ESTABLISH WAITING LISTS.

#### **DC**

The District of Columbia does not have waiting lists in its principle State Agencies responsible for service delivery to individuals with developmental disabilities.

#### **DE**

The DDDS Registry is a crisis based list that categorizes people by crisis severity and services are delivered based on that rating. Case Management services are offered to all clients of that Division. The DSAAPD Wait List was cleared this fiscal year with additional funds from the General Assembly with tobacco funds.

#### **FL**

The number of individuals with developmental disabilities on Florida's Waiting List for services under the Agency for Persons with Disabilities (APD) continues to grow, despite reports of over 900 people being newly enrolled in waiver services between October 2006 and September 2007. In October 2006, approximately 19,400 people were on the waiting list. Of this number, about one-third of the individuals (N=6,588) were served in the Family Supported Living Waiver (FSL) while waiting for services under the Home and Community Based Services Waiver (HCBS); one-third of the group (N=6,799) were receiving some type of state services such as state plan or pharmacy services; and about one-third of those waiting (N=6,083) were receiving no services. At the end of the reporting period and the most recent data available (October 1, 2007), the number of people on the Waiting List had increased by over 2,250 to 21,728. The status of those on the Waiting List includes 28 percent of the group (N=6,080) served in the Family Supported Living Waiver (FSL) while waiting for services under the Home and Community Based Services Waiver (HCBS); 36 percent (N=7,840) of those waiting were receiving some type of state services such as state plan or pharmacy services; and 36 percent of the group (N=7,808) were receiving no services. The number of people waiting for services and receiving no state services has grown from 6,083 at the beginning of the reporting period to 7,808 one year later, an increase of 1,725. Of the more than 15,000 individuals reportedly on the Waiting List as of October 1, 2007, excluding those enrolled in the FSL waiver, 30 percent of the group (N=4,741) have been waiting for 48 months and longer; 17 percent (N=2,770) have been waiting 36 to 48 months; 15 percent (N=2,316) have been waiting 24 to 36 months; 19 percent (N=2,995) have been waiting 12 to 24 months; and 19 percent (3,035) have been waiting for up to 12 months.

One potential avenue to increase access to needed services for those on the Waiting List has been a renewed emphasis on the use of state plan services and, in particular for children, access to services through the Early and Periodic Screening, Diagnosis and Treatment of Children (EPSDT). The most recent data available (9/1/06) on individuals on the Waiting List by age indicates approximately 60% are aged 3 to 21 years.

#### **GA**

The Legislature funded 1500 waiver services against the 2000 recommended by the multi-year funding plan, but expresses concern about the legitimacy of how the Division of MHDDAD tracks progress on the waiting list funding. In response, advocates have begun conversations with the Division about useful indicators that will record consistent progress from year to year. Advocates estimate that the waiting list grows by 1100 individuals each year, due to three primary reasons; population moving into the state, students graduating from high school, and people needing to move from their parents or caretakers homes because the care givers are aging or become disabled.

For the CCSP population (senior / disabled) the non-Medicaid waiting list has burgeoned due to individuals dropping off the Medicaid list because of the Estate Recovery practices put into effect. For the ICWP waiting list, 52 reflects the number of slots that the Georgia Advocacy Office reported this year, however, advocates are pressing for 500 slots, which more accurately reflects individuals identified in nursing homes who are appropriate, and desire transition to the community. Keeping a more accurate count of the need for ICWP services has become one of the priorities for the Unlock campaign.

#### **HI**

As a result of the settlement agreement in Makin II lawsuit initiated by Hawaii Disability Rights Center, there is currently no waiting list for services.

#### **IA**

The disability service delivery system in Iowa remains complex and fragmented with waiting lists that are inconsistently maintained or defined and which may not truly reflect unmet need. The state funds most services to children and partners with counties to fund services to adults (services to persons with MR and CMI are mandated). The locus of control rests with the counties who manage the funding and delivery of most adult services, including those provided through the HCBS/MR waiver. The state imposes few requirements on counties and the resulting inconsistencies and inequities extend to include waiting lists. Eligibility for services and the array of services varies among counties, as do county determinations about whether to maintain waiting lists for services or supports. Counties report who is being served with what services but do not report consistent information about waiting lists. New system improvements initiatives are exploring options to equalize access and reporting and to obtain and interpret statewide information. The state does maintain waiting lists for Medicaid HCBS waivers for which they pay the nonfederal share. On September 30, 2007 those lists had grown to 2,700 individuals among the state's seven waivers, with an average wait time for the Ill and Handicapped and Physical Disability waivers of just over one year. The 2007 Legislature did appropriate an additional \$2.2 million to reduce the waiting list for the Children's Mental Health Services Waiver but no new funds were appropriated to the state's other six waivers. Individuals who apply for services through Iowa Vocational Rehabilitation Services (IVRS) and are determined eligible are placed on one of three waiting lists: 1) Most Significantly Disabled (MSD), 2) Significantly Disabled (SD), and 3) Others Eligible. All individuals who are considered Most Significantly Disabled must be served before those on the Significantly Disabled list, and individuals on both the Most Significantly Disabled and Significantly Disabled must be served before those on the Others Eligible list. As of November 13 2007, IVRS had cleared the MSD and SD waiting lists through that date. Additionally, persons identified as Others Eligible through June 30, 2003 were cleared from the waiting list. Approximately 600 individuals remain on the Others Eligible list. Each month IVRS considers the number of individuals the agency has the capacity to serve, and serves those at the top of the list.

#### **ID**

The number of people awaiting extended employment services reduced from 250 to 153. This 39% reduction in the number of individuals awaiting services is reflective of program management practices by the Division of Vocational Rehabilitation. Administrative control of these services was transferred to the Division in 2004. The Division has given high priority to ensuring that all allocated funds are distributed to service providers. In turn service providers maintain full enrollments by moving people from waiting lists.

A price is being paid for the Division's financial efficiency. The individual budgeting process that is portable and allows individuals to select their choice of providers has disappeared. Individuals on waiting lists are required to select providers with available budget even though it may not be their choice of providers. While budgets are assigned to an individual, it does not follow the individual should there be a desire to change providers. A cadre of long term providers has greatly influenced these practices and new providers have experienced difficulty in acquiring funding.

During the 2007 legislative session the Division of Vocational Rehabilitation sought approval for rules that would have greatly restricted new providers from the service arena. The Council and its partners successfully argued against those restrictive sections resulting in 7 new providers being approved by the Division. The Division continued to address other points of contention by conducting two stakeholder meetings which resulted in much dialogue and no action to alter any Division administrative practices.

Finally the Division of Vocational Rehabilitation submitted a \$500,000 budget increase to allow individuals on the two waiting lists to be served. The Council reviewed the proposal and supported the increase in funding but limited its support for funding to serve only individuals awaiting supported employment. The Councils support was consistent with its segregated employment position statement. The request will be considered by the 2008 Idaho Legislature which begins January 7.

#### **IL**

P.A. 93-0503 required the Department of Human Services to compile and maintain a cross-disability database of Illinois residents with a disability who are potentially in need of disability services the department including those transitioning from special education. Nov. 1, 2004 was the launch of the IL PUNS system, which is a data collection process to determine needs. 11,800 individuals/family members have completed a PUNS as of December 4, 2007.

#### **IN**

Autism/ Developmental Disabilities were combined in 06 reporting but separated in 07. The AL list is no longer maintained since AL services have been folded into the A&D waiver.

#### **KS**

Small reductions (6%) in DD Waiting lists. The Legislative Interim Budget Committee recommended a 3 year phase in of WL reduction funds but it was not adopted during the Session. Increased funding was provided to decrease numbers but not a significant amount. A small rate increase for services was also provided. We are concerned that so many people wait for services, jeopardizing their safety, health and welfare. We plan a significant push for services in FFY08 to do a 3 year phase in of increased funds for services and rate increases to enlarge Kansas capacity. Our hope is that this or a version will be passed and we will have much larger decreases to our waiting lists.

#### **KY**

Only one waiting list exists in Kentucky for individuals with mental retardation and developmental disabilities. Although Regional Comprehensive Care Centers may retain a list for their specific purposes. Anyone can make application by submitting a completed application form that includes the signature of a physician or SCL,MRP confirming the diagnosis of mental retardation/intellectual and developmental disability along with

supporting documentation. Individuals are placed on a waiting list by date of receipt of their complete application and by category of need for support services. The Division of Mental Retardation who is under contract with the Department of Medicaid Services for the management of the Supports for Community Living (SCL) Waiver maintains the waiting list. When funding becomes available the applicant will go through an eligibility or Level of Care review for admission to the waiver. Kentucky Medicaid contracts with a Peer Review Organization (PRO) to conduct the eligibility test. Once the person is deemed eligible they should receive services within sixty days. Advocates continue to lobby legislators for increased funding. The continued growth in the number of individuals applying and being placed on the SCL Waiting List can be attributed to the notoriety brought by HB144. An additional 100 slots were appropriated in FY 07 bringing the total allocations available to 3301.

#### **LA**

Numbers for the NOW and Supports Waiver are current as of May 2007; OCDD & OMH Cash Subsidy, Elderly & Disabled Adult Waiver, and Adult Day Health Care numbers are current as of June 2007. As of Dec. 2006, Voc. Rehab. has no waiting list. Waiting list numbers for Children's Choice (a capped waiver limited to children) is combined with the NOW registry. 4,814 people on the NOW registry are simultaneously waiting for Children's Choice.

The decrease in the NOW registry is likely due to efforts by the Dept. of Health & Hospitals to validate the waiting list and may reflect a decrease in the state's population. Increased funding for NOW services passed by the State Legislature this year is expected to result in a decrease in the number of people waiting for this service. However, those funds would not have been implemented at the time the current waiting list number was reported in June 2007.

#### **MD**

DD Community Services Waiting List: The waiting list for community DD services has grown to 16,820 people  $\hat{c}$  nearly an increase of 1000 people over the past year. Individuals on the list are requesting over 30,000 services (residential, day and/or support services). 94% of them need at least one service now  $\hat{c}$  they are in the priority categories: crisis resolution, crisis prevention, or current request. 51% of the services requests fall in a  $\hat{c}$ crisis $\hat{c}$  category. Over 11,500 people on the list are not receiving any services. The others receive some services and are waiting for additional types of services. \_Only 6% of the people are on the list as  $\hat{c}$ Future Need. $\hat{c}$  The need for services grew in all parts of the state, with the growth ranging from 23%-200%. Funding was provided for approx. 600 transitioning youth, but other than that, there has been virtually no new funding. Some people on the WL are served when funds become available due to someone else leaving service. This is a relatively small number compared to the vast need.

The autism waiver has 900 children enrolled and 1236 on a waiting list. People get on the waiting list before eligibility is determined. Experience shows that approximately 60% on the waiting list will be determined for the autism waiver.

Section 8 Housing: WLs for Sect. 8 rental vouchers vary thru out MD and no jurisdiction reports intellectual and developmental disability specific data. Sect 8 waiting lists, in general continue to grow as need outpaces the availability of vouchers and national policy reduces the number of vouchers available to local jurisdictions. Maryland has implemented the second year of a pilot project that provides temporary

rental assistance specifically for people with disabilities (Bridge Subsidy) to address a very small part of the need.

#### **ME**

The waiting list for Vocational Rehabilitation services has been reduced by almost 40 percent from FFY05. Individuals receiving VR services are all in the category #1 classification (most significant disabilities). Their wait time on the waiting list has also been reduced from an average of 10 months in the previous year, to less than 4½ months by the end of FFY06. Individuals in categories #2 and #3 (significantly disabled, disabled) are not receiving services at this time. A continuing problem for category #1 VR clients is the lack of available funding for long-term job supports. (A pending Medicaid waiver request may improve this situation in the coming months.) Until then, any VR client whose employment plan indicates he/she will need long-term job supports does not receive further VR services due to the lack of funding.

Children with DD who do not meet medical eligibility criteria for the mental retardation/autism waiver and have not been identified as having mental health problems (with cerebral palsy, epilepsy, spina bifida, etc.) are not included in any waiting list, so the unmet needs of these children and their families, such as respite care, are not reflected in the lists.

The adult services waiver programs continue to be closed. The waiver for adults with mental retardation/autism is adding only individuals who are in Adult Protective Services status, usually due to the death/ill health of family caregivers. The waiting list of 117 is not in priority order persons ranked anywhere from 1 to 117 on the list may be moved onto the waiver program because their needs reach APS status. Other individuals will be put onto the waiver program due to emergent needs, without having been on the waiting list.

The consumer-directed physical disabilities waiver program, which provides funding for community services for individuals age 19-64, has been closed for many months, due to funding problems. The waiting list does not include individuals who need more service hours per week than the maximum authorized under the waiver at this time; those individuals have been forced to move into nursing homes rather than stay in the community. Some individuals are also forced into nursing homes because they cannot find in-home support services to meet their needs, due to the severe shortage of direct care workers in Maine. This population is also not reflected in waiting list numbers.

#### **MI**

DD Institutions: As of September 30, 2007, 115 persons with intellectual and developmental disability are in Mt. Pleasant, the state's sole institution for this population. This number is less than that of past years because the MI Department of Community Health is working to reduce the number of persons with developmental disabilities in the ICFMR by both working to transition current residents back to the community, and to reduce the number of new admissions. The Community Mental Health System is working to develop the capability and capacity of local providers to provide behavioral supports and crisis prevention/response to individuals with a intellectual and developmental disability. Additionally, MDCH has created

a virtual team to review cases of persons at risk of admission. They usually have problem behaviors. Another factor is that advocacy from disability groups has exerted pressure to close and/or reform the institution, and media has focused on allegations of abuse and neglect, including a suspicious death in a prior year, which is still being investigated.

Section 8 Housing:

976 is the waiting list number for vouchers currently, since the previous year was only 324, it has more than tripled. The likely reasons for the increase are Michigan's continuing economic problems and a substantial reduction in federal funding for Section 8.

#### **MN**

A total of 14,624 individuals are receiving services under the DD waiver (compared with 14,963 in FFY 2005 and 14,824 in FFY 2006); 313 individuals under the CAC waiver (compared with 245 in FFY 2005 and 276 in FFY 2006); 12,881 individuals under the CADI waiver (compared with 10,101 in FFY 2005 and 11,372 in FFY 2006); and 1,455 individuals under the TBI waiver (compared with 1,206 in FFY 2005 and 1,349 in FFY 2006).

During the past four years, the Minnesota legislature set limits on the number of people who could enroll in the CADI and TBI waiver programs. As of July 1, 2007, these waiver programs are available to all eligible individuals. First consideration will be given to individuals waiting for services and those under age 65 in institutional settings.

A total of 5,183 people are on the waiting list/in need of DD waiver services. Of this total, 285 people are living in ICFs/MR - all are receiving case management services, 5 people are receiving home care services, 1 person is receiving respite, 243 people are receiving day program services, 4 people are receiving job training services, 27 people are receiving education services. A total of 4,290 people are living in the family home, 274 people in foster care, 77 people in their own homes w/up to 24 hrs of supervision, 11 people in board/lodging, 14 people in MN Extended Treatment Options (under civil commitment, determined public safety risk, severe behavior issues), 2 people in nursing homes, 230 people are in other types of living arrangements. These individuals are receiving a range of services that may include case management, home care, consumer support/family support grant, respite, homemaker services, home modifications, SILS, other waiver services (CAC, CADI, TBI), education, day programs, and job training services.

#### **MO**

MO has a total of 8748 individuals in the 3 waiver programs; 200 in the Lopez or children's waiver, 1042 in the Home and Community Waiver and 7513 in the Residential Waiver. MRDD tracks those waiting for services, not those waiting for a waiver opening. The waiting list for residential services has decreased over the last year. This is partially due to increased case load growth dollars that helped lower the numbers, but it may also have been influenced by the Division's efforts to encourage providers to support people in their communities and homes. The In-Home services wait list has increased as more individuals and families have been identified who need services and the needs of many individuals on the list have increased. Identifying funds to meet the needs of those on the wait lists is further complicated as 46 of those waiting for residential supports and 52 of those waiting for in-home supports are not currently enrolled in Medicaid. The state recognizes the need to address the increasing needs of individuals and families and has continued to encourage partnerships with counties who have tax levies to provide the match for federal Medicaid dollars, allocating services based on needs, and allowing increased self-direction so individuals can use their limited funding in a manner that is specific to their needs and potentially lower the need for high levels of programmatic types of services. MRDD acknowledges that their current system does not allow individuals to access services prior to reaching a crises situation and is looking at developing a crises facility in St. Louis. However advocates feel that crises services are generally more effective when provided in the home and community. MRDD is also transitioning case management to willing county boards or other providers to decrease the numbers of state FTEs necessary and to lower case load numbers. This may encourage additional county boards to partner with the state to meet the service needs of those in their region. Advocates are concerned about moving to a county based system and even more so by a system in which private entities provide case management, but MO's legislature will not increase state funding for services or FTEs leading the state system to feel this is a viable option. Advocates know that this major system change will guide services for many years to come and that it will be difficult to bring the options from the previous system back once the transition is made.

#### **MS**

Changes have been small in number

#### **NC**

As we reported in the 5-Year NCCDD State Plan, NC doesn't maintain official waiting list data; however, a current analysis of the NC Support Needs Assessment Profile (NC-SNAP) indicated that 1456 consumers have gone to a LME and were screened for needed services; 205 consumers were receiving some services but needed additional services; and 1190 consumers were waiting for services that were not available. These figures total 2851. While the number does not reflect the total number of persons with ID/DD waiting for services, it is the best data available to us at this time. During this plan year, NCCDD sponsored a forum on waiting list data collection with Celia Feinstein, a national expert on this issue.

#### **ND**

North Dakota continues to not maintain formal waiting lists for services to persons with developmental disabilities.

#### **NE**

Nebraska has a current waiting list for services from the Intellectual and developmental disability System. As of June

30, 2007 it showed that 1436 people had requested services be provided on that date or earlier. However, several factors must be considered when looking at the waiting list. The list includes

individuals that currently receive a service but may want additional services or hours. People on the list are not evaluated for their eligibility for requested services until they are offered services. Because the list is long, individuals may put their names on the list to be sure they can receive a service when they need it. For example, residential services may be requested in anticipation of a parent not being able to care for the individual. However, when contacted about the availability of the service, the individual and family may turn it down or delay it since their current situation is working well. This is a marked increase in numbers of people on the waiting list from the PPR but it may be the result of when the report was run. Youth completing high school at 21 are entitled to day services in Nebraska. They would be on this registry while those services are being finalized after exiting school in the spring. It is possible that the numbers are slightly inflated in June since these youth may not have begun services yet. Nebraska's Aged and Disabled Waiver does not have a waiting list. It focuses on all people across the lifespan who are at risk for nursing home placement so it serves both children and adults. Vocational Rehabilitation does have an order of selection. Category 2 (those with a significant disability) and Category 1 (those with most significant disabilities) are all being served. Individuals with developmental disabilities would all be included in these two categories so there is no waiting list for them. Category 3 (those with a disability) has not been served for many years and it is unlikely that VocRehab would have the funds to do so. Therefore, no waiting list is maintained for this category.

#### **NH**

This past legislative session, a significant increase in funding, resulting from the advocacy efforts of the Council, families and other agencies, resulted in a reduction of the waiting list for developmental services, and a plan to eliminate it in three years. In September 2007 there was a net reduction of 132 people, resulting in the waiting list being reduced to 138 people from 270. At its peak, the wait list grew to over 400 in June of 2003. A legislative committee monitors the waitlist on an ongoing basis. While on the intellectual and developmental disability wait list, individuals are still eligible for other services from DHHS, including Medicaid services for acute care and rehabilitation.

#### **NJ**

There currently remains a Community Services Waiting List for placement in community residential settings and a separate Day Program Waiting List for adult day or supported employment served in the order in which their names were added to the lists. People living at home (23,800) often receive only case management services and are waiting for needed programs or supports. Real Life Choices, the self-determination effort in NJ, serves only 500-700 of those 23,800 people. The numbers reported are from the most recent waiting list report of the NJ Division of DD (2007).

The NJ Div. of DD has pledged to increase family-driven services in the next decade. [Real Life Choices and Family Support] This change of policy reflects a change in administration at the division during this reporting period, with expected emphasis on family supports and person-centered funding.

Despite pledges for improvement there is no foreseeable end to the delay between determination of eligibility and the delivery of community-based services for people with DD under existing protocols. A realignment of the Medicaid waivers used to create community programs is projected to allow greater flexibility in funding (family-driven) and a more streamlined process. This will require at least 12-18 months to initiate. The Council continues to work with its sister agencies to mitigate and resolve these issues.

#### **NM**

Currently, there is no waiting list for those joining or transferring to the MiVia Self-Directed Waiver. The traditional DD Waiver waiting list continues to grow, as does the Disabled and Elderly Waiver waiting list because allocations have slowed. The D&E Waiver has reached current funding level capacity. The DD waiver was a little less than 4 yrs in 2002 it is now official 7 plus year and families report being told as much as 9 years.

#### **NV**

Although the number of children waiting more than 45 days for eligibility determination increased slightly, 543 new cases were added to the count in state fiscal year 2007 which was a 21% increase in caseload. Additional staff and public/private contracts helped handle the increase.

In Developmental Services, the same is true. The number waiting has remained about the same, but the total number of individuals receiving services has increased dramatically.

#### **NY**

The NYS Office of Mental Retardation and Developmental Disabilities (OMRDD) maintains two formal

waiting lists, the NYS-CARES registration list for out-of-home residential services and a listing of children who are medically complex and need services under the Care at Home (CAH) Medicaid Waiver. Following the 2005 CMS approved increase in total CAH capacity to 600, OMRDD staff worked promptly to move children from the waiting list into the waiver and effectively eliminate the CAH waiting list. Through initiatives such as OPTS and Consolidated Support Services (CSS), OMRDD has strengthened its ability to provide individualized housing services. OMRDD is currently updating its NYS CARES waiting list to identify individuals whose housing needs have already been met but indicates that less than 6000 individuals are currently waiting for out-of-home residential services. NYS CARES III was approved to provide 1,000 new out-of-home residential, 200 new day and 2,500 new at-home residential habilitation opportunities over five years. By the end of the 2007-08 fiscal year, approximately 15,000 individuals will have been served through NYS CARES. Reviews of HCBS & ICF programs have found that they exceed federal standards. ICF reviews, while complimentary, have continually noted need for improvement in: individual privacy/confidentiality; coordination & follow-up in getting needed health care & adequacy of nursing supervision; incident management w/in prescribed timelines; implementation of active treatment plans; medication & behavior management; and better management of consumer funds. OMRDD continues to actively address these areas and to reinvigorate its Medicaid Service Coordinator program.

#### **OK**

The Oklahoma waiting list has long been a source of concern to Oklahoma advocates - including the professionals who administer the waiting list. While large and growing (though still substantially reduced from a recent high of 4258 in FY 2006), the list continues to experience significant movement. For an example, for the month of October, 2007, 63 persons were removed from the waiting list while another 93 were added.

The Developmental Disabilities Services Division and the Oklahoma Department of Human Services use all available funding to meet the expanding waiting list. A major effort of the past several years has been the extensive review of "Plans of Care," as DDS noticed the trend for these plans (for persons already being served) to grow more expensive without a major change in definable costs, such as direct support pay rates. While this has caused some concern among persons being served, the resulting savings have helped reduce the waiting list AND convince policymakers (including legislators appropriating funding) that the Plans of Care were as lean as they could be.

#### **OR**

The Support Services wait list data reported above is based on the original number of people identified in the Staley lawsuit settlement agreement who were estimated to be waiting for adult services, minus those who have been served since brokerage support services began in 2001, and adjusted with data from county case management rolls. A recent poll of Community DD Programs showed a large increase in people who are or will be eligible for services by the end of the settlement agreement. Meanwhile, 815 people on the wait list received support services in FY07. The waitlist data gathered does not currently include any projections of the type of services needed.

**Comprehensive Services:** Access to comprehensive services happens in two ways: through the 300 non-crisis comprehensive services slots available as a result of the Staley Settlement or through crisis services. 139 individuals were reported to have entered non-crisis comprehensive services in 2007. Each county maintains a semi-formal list of individuals needing comprehensive services and uses the list when non-crisis openings arise. Oregon has no formal, statewide crisis wait list, although at any given time, dozens may be needing assistance. Each Regional Crisis Committee is given a budget to meet the needs of individuals in crisis. Many of these individuals may ultimately receive comprehensive level services. At any time, there are at least 3 children waiting for every vacant slot in the children's residential services. The State will use the Supports Intensity Scale to capture wait list information for comprehensive services once the Restructuring Budgets, Assessments and Rates project is completed.

**Family Support Services:**

Oregon has 3 services that support families of children with DD living at home: a Medicaid waiver for medically fragile children, a waiver for children with behavior issues; and a state general fund Family Support Program. The Medical waiver programs do not have wait lists. Eligibility criteria are extremely narrow and many families with very significant support needs cannot get access to these waivers. Each county is required to maintain a list of families waiting for the county-based Family Support Services, but data are unreliable because each county defines both the service and the waitlist differently. Undoubtedly, there are children in case management who would be eligible for family



support but are not receiving it.

#### **PA**

There are now 4407 people in Emergency status, 9436 in critical status, and 7375 in Planning status. The situation has been helped by the Governor's budget initiative, hindered by the CMS requirement to provide additional services to those already in service. The Council is a member of a legislative task force created to devise long term solutions to this problem. There continue to be no other official waiting lists in PA.

#### **RI**

The Public Housing Waiting Lists do not contain a breakdown of individuals with developmental disabilities. Also, many towns combine Public Housing and Section 8 Waiting Lists. The total individuals/families on Public Housing/Section 8 Waiting Lists is 13,850, (3882 Section 8, 5526 Public Housing, and 4442 on combined lists). Among the local housing authorities, about 41% track the number of individuals with disabilities, and that is approximately 26%. Using prevalence rate for developmental disability, we might roughly estimate that 1.8% of the applicants, or about 250, probably have a intellectual and developmental disability with the range extending upward to include individuals with other disabilities to 3600 people.

While the RI Dept. of MHRH, Division of Developmental Disabilities reports that it does not have a waiting list for eligibility determination, the Council's experience in speaking with individuals and families who call for referrals and advocacy, as well as with provider representatives, is that some families determined eligible for DD services are contacting agencies and being informed that the agencies have insufficient funds and/ or insufficient workers to provide services to all who require them. For the foreseeable future, the Office of Rehabilitation anticipates serving customers who meet the first two categories only of its Order of Selection (Approx. 70% of individuals in each year are anticipated to be from Category 1, with the remainder from Category 2). The RI Dept. of Human Services has received a Robert Wood Johnson foundation Cash and Counseling grant called "Personal Choice". The program began taking new people as of January 1, 2006. This has alleviated the aged and disabled waiting list and added elderly applicants who wish to stay at home as an alternative to nursing home placement.

DMRS was taking people off the waiting list and putting them into Waiver services, but their budget ballooned and they have stopped. DMRS Waiting List is for Waiver HCBS (residential, day, and employment). Family Support is an incredibly flexible program, but is funded only with state dollars, so the waiting list grows. Family Support is for whatever the family needs the money for (respite, dental, home repairs). Options program serves aging and people with disabilities and is operated by the TN Commission on Aging and Disability. DRS is under an order of selection, but they have begun to serve some people who are priority category 2, so the number has decreased. This number is for all people with disabilities. The people are waiting for vocational rehabilitation services.

#### **UT**

DSPD has a current total waiting list of 1,835 (this includes people waiting for services on the 3 waivers listed). 1,684 is the number of individuals waiting who have intellectual and/or developmental disabilities. Usually the waiting list grows by about the same number that enter services each year so we have not had too much progress in getting the numbers of people waiting reduced.

The Governor's budget has targeted funding 1/4th of the Waiting List, and the Legislature appropriated in FY 2007 \$2,021,100 toward the Waiting List and \$599,800 for funds for mandatory additional services. The unduplicated head count of individuals being served is 4,674. This is an increase of 228 people since last year.

This report reflects the first year of the Supported Employment Pilot that targets the bottom half of the waiting list. 105 people were served and there were 5 successful closures. The SE Pilot was successful in reducing the number of people on the immediate needs waiting list for supported employment services. In many cases, non-participants asked to be removed from the SE waiting list because, when offered the services, they indicated that they no longer needed the service.

The Council supported a second year of a community coalition, the Disability Community Alliance (DCA), during the 2007 Legislative Session. The DCA was staffed with a coordinator whose salary was paid for by the Council and Council staff and members were very involved with this project. We attribute the increased attention and effort by the DCA in continuing to get the Legislature educated about the needs of people waiting and the need for additional appropriations to support the waiting list.

The Health Department has recommended transition funding in their budget for Legislative approval in

order to enable 16 people to move from the ICF/MR's to community waiver services. The actual number of individuals who get the opportunity to move into the community can vary based upon the fact that the money may not stretch to support all 16 slots if the individual cases are more expensive than average. This year 12 people moved from the institutions into the community. 6 people were moved from the Utah State Developmental Center into the community. But the census continues to remain about the same there year after year because people are admitted as beds open up.

#### **VA**

Data for the MR Waiver Waiting List, a total of the "Urgent" and "Non-Urgent" lists, is as of Sept. 10, 2007 (point-in-time). The DD Waiver List is an estimate, actual #s unavailable. Although legislative action has occurred to reduce Medicaid Waiver Wait lists specifically, additional funding for various Waivers, increases in some reimbursement rates, and a Northern Virginia rate differential increase - incremental allocations are not keeping up with growing needs. The DMHMRSAS now estimates that the MR Waiver list has grown by one person per day since FY 2004. Reimbursement rates remain low, a disincentive to expansion of community services. Demand for some services exceeds staff availability. Other factors impacting the growth of wait lists include the increase in Virginia's general population, greater public awareness of Medicaid Waivers, and increase in the number of children with disabilities. To effect system change, the Board significantly increased activities to influence state policies impacting persons with DD by making public comment on several significant regulations (DMAS & DMHMRSAS). The Board continues to advocate for person-centered supports, including appropriate Medicaid reimbursement rates for support services as well as coverage for preventative dental services for adults.

The number for the DRS Vocational Services Wait List is as of 9/28/07. Since July 1, 2004, the Department of Rehabilitation Services (DRS) has prioritized cases under the Order of Selection due to insufficient funding. In October of 2005, DRS opened Category III (persons with significant disabilities with one serious functional limitation) to services, and contacted those in this category on the waiting list. As a result, DRS production significantly increased, & case service expenditures rose, impacting the case services budget. In April of 2007, DRS closed all but Category I, individuals with most significant disabilities. In FFY 2008, funding will not be sufficient to serve all eligible individuals. The DRS Vocational Rehabilitation program served 24, 504 persons in state FY 2007. The current DRS State Plan estimates that the number of persons to be served in state FY 2008 will be 22,610.

#### **VT**

VT's system is based on its Developmental Disabilities Act of 1996, limited to those with a label of mental retardation (based on an IQ below 70) or pervasive developmental disorder, with an adaptive skills component. Services can include service coordination & community, employment, clinical/crises, family, home & transportation supports. It is driven by a System of Care Plan [SOCP] which sets "funding priorities" for 3-year periods; key priorities for FY08-10 to enter the system remained unchanged: homeless; danger to safety; & about to be institutionalized; death or loss of a caregiver; leaving child protective services, with limited funds for high school graduates with jobs & supports for parents with disabilities. Current priorities continue the increased age for transition employment supports. Closure of the caseload to new children continues to divert demand to other sources, such as Medicaid's EPSDT personal care program (which offers no case management), & Children with Special Health Needs' limited respite funding. LISTS: Regional designated provider agencies are the gateway to services & maintain 2 waiting lists to track the number of people eligible who do not receive developmental services. (This tends to discourage potential applications & undercount those not assisted to go further than an initial screening call.) APPLICANT LIST: Includes all people eligible for services based on their disability but do not meet the restricted Funding Priorities in the SOCP (outlined above) The list includes both new consumers and some existing consumers with minimal services. 233 people were on the applicant list in FY07 compared with 169 in FY04 and 106 in FY03. The total cost of addressing the Applicant List would exceed \$5.2 million. WAITING LIST: The waiting list includes all people (new consumers as well as existing consumers) who meet the restricted State System of Care Plan Funding Priorities, but for whom there are insufficient funds, either through legislatively-appropriated caseload funding or reallocation of existing resources. In the SOCP VT calculated costs to fund based solely on Flexible Family Funding @ \$1122 per family + admin (37,912) As of 12-21-06 there were 31 on this list compared with 9 in FY06 & 44 in FY 04. Given that SOCP priorities remained unchanged the 50% jump in the applicant list underscores the inadequacy of funding to meet needs even using a narrow definition.

#### **WA**

The State's Division of Developmental Disabilities (DDD) reports that about 36,000 people are enrolled in intellectual and developmental disability (dd) services. Of these, 20,000 receive services in the community and 943 are

residents of one of the 5 RHCs operated by the state. The rest, 14,000, may not have any other support than case management from the State's DD system. DDD maintains a list of 5,000 people who are waiting for state funded Family Supports.

For Waivers, DDD maintains that they do not operate a Waiting List. Instead, they enroll recipients in Waivers using an order of selection based upon legislative priority, emergent need (crisis) and qualification for Medicaid. On July 1, 2006, there were 9,748 people on one of the 4 Waivers. By June 30, 2007, the 4 Waivers had only 9,585 recipients. Apparently, people transferred among the Waivers, died, or moved to another state.

Although DDD is unclear about the use of a Waiting List, they acknowledge that about 11,000 people who have been determined eligible do not consistently receive paid supports. Given the estimated number of people with developmental disabilities in Washington State, 112,000, it is obvious that a huge pent up demand exists for people who may on any given day need dd services.

#### **WI**

Waiting lists overall continue to grow longer and longer (except for the Family Care counties and the Vocational Rehabilitation program). Some people have been able to come off of waiting lists in some counties and receive community services, while many others have had to move onto waiting lists. Some counties have smaller waiting lists, while the waiting lists in other counties have grown. Family Care will be expanded statewide over 5 years and significant funding was included in the 2007-9 approved state budget to enable those counties converting to Family Care in the next 2 years to eliminate waiting lists for long-term care. Funds were also included in the 2007-9 state budget to address the waiting lists for Family Support and Children's Waiver slots.

#### **WV**

The Medicaid A/D Waiver has no persons on a wait list.

#### **WY**

The waiting list for the Adult, Children's, and Acquired Brain Injury waivers was eliminated in March 2005. Starting in July 2006 the Developmental Disabilities Division had to begin a waiting list for waiver services. Throughout the year a number of children and adults have been funded. These numbers are not necessarily the same people waiting for services. The ABI waiver received appropriations to fund and their should not be a waiting list through the end of the biennium. Families have been seeking services for their children at a rapid pace. The average age of the child is 10.5 years.

Source: Data reported in the Annual Program Performance Report of State Councils on Developmental Disabilities and compiled by the Administration on Developmental Disabilities, ACF, HHS, 2007.

## APPENDIX E. RESOURCE LINKS

American Association of Intellectual and Developmental Disabilities: <http://www.aamr.org/>

Centers for Medicaid and Medicare Services Home and Community-Based Waiver Services:  
<http://www.cms.hhs.gov/home/medicaid.asp>

*Closing the Gap in Texas: Improving Services for People with Intellectual and Developmental Disabilities.*  
Human Services Research Institute. (October 2008). [www.hsri.org](http://www.hsri.org)

Nebraska Department of Health and Human Services Division of Developmental Disabilities:  
<http://www.hhs.state.ne.us/dip/ded/dedindex.htm>

Nebraska Planning Council on Developmental Disabilities: <http://www.hhs.state.ne.us/ddplanning/>