

**FAMILY SUPPORT  
FOR  
INDIVIDUALS WITH INTELLECTUAL DEVELOPMENTAL DISABILITIES**

**A REPORT TO  
CO-CHAIRS OF THE JOINT FINANCE COMMITTEE,  
THE CONTROLLER GENERAL,  
AND  
THE DIRECTOR OF THE OFFICE OF MANAGEMENT AND BUDGET  
Department of Health and Social Services**

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**Submitted by**

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**April 2014**

## **FAMILY SUPPORT**

### **Background**

Section 169 of the Epilogue of H.B. 200, the Operating Budget Act for State Fiscal Year 2014, stated the following: "The General Assembly is supportive of families who care for individuals with developmental disabilities in the community. The Department of Health and Social Services, Division of Developmental Disabilities (35-11-00) is directed to move forward with developing a plan to establish Family Support Waiver. The plan, including a review of necessary funding, shall be submitted to the co-chairs of the Joint finance Committee, to the Controller General and the Office of Management and Budget by April 1, 2014.

In order to develop a comprehensive plan for a family support waiver for individuals who are living at home with their family, the Director and staff of the Division of Developmental Disability Services (DDDS) reached out to a variety of family and self-advocacy organizations. Starting in August and ending in late November, the Division attended 12 forums:

People First	8/3/2013
Families Speaking Up	9/10/2013
Autism DE (Newark)	9/19/2013
Autism DE (Milton)	10/15/2013
DE Family Voices	10/16/2013
DD Council Partners in Policy	10/19/2013
Sussex open forum	10/21/2013
Kent open forum	11/5/2013
Downs Syndrome Association	11/15/2013
Leach School PTA	11/21/2013
Stockley Center Family Day	12/7/2013
New Castle open forum	12/9/2013

From those forums, we gathered the following information that will inform the design of a Family Support Waiver.

## **I. Where people live**

Currently, the Division of Developmental Disability Services serves approximately 3,775 individuals and their families. Of this total, approximately 980 individuals live either on their own with drop in supports, in neighborhood homes, townhouses, apartments, shared living, nursing homes or other institutions. DDDS provides supportive services to the majority of these individuals by operating a Medicaid Home and Community Based Services (HCBS) Waiver under the authority of section 1915(c) of the Social Security Act. An HCBS waiver is a cost effective alternative to placement in an institution. By operating an HCBS waiver, the State of Delaware shares the costs of the program with at least 50% of the cost borne by the federal government.

There are approximately 2,700 individuals eligible for DDDS services that are living at home with their families. The ages of the individuals range from 3 to 89. Services currently provided to these families include: a family support specialist, respite, family stipends and supported employment or day program.

## **II. What families want**

At each of the forums/ meetings, family members listed the following as the services that would be supportive to their family. The list is not in rank or preference:

### **A. Respite**

- Provided in a variety of settings
- Provided by well trained staff
- Provided by individuals selected by the family
- Easy to access
- Available immediately when a family crisis occurs
- Planned and unplanned
- Include opportunities for the individual with a developmental disability to have social time with their friends, i.e. weekend activities, trips; camps etc.

### **B. In-Home Support/Personal Care**

- Well trained staff to provide support to individuals with challenging behavioral or medical supports in the home with the family present
- Supports to the individual with significant needs to allow parents to spend more time with siblings
- Critical need to assist the family with supports on weekends
- Supports to develop independent living skills to prepare the individual to move out of the family home to a neighborhood home or to supported living in their own apartment

- Paid support hours available for individuals living in their own home or apartment to supplement supports provided by the family

**C. Stipend payments**

- Financial support to assist the family to stay together, including assistance with housing costs, utility payment etc.
- Payments for specialized physician services not covered by insurance or Medicaid
- Payments for dental services
- Payments for goods and services, such as specialized hygiene items, nutritional supplements, specialized therapies not covered by insurance or Medicaid

**D. Home and Vehicle Modifications**

- Provide funding to modify the family home to accommodate specialized needs of the individual, including ramps, adapted bathrooms, reinforced walls and specialized windows
- Provide funding to modify the family vehicle to accommodate for a wheelchair or other specialized adaptation for behavioral supports.

**E. Assistive Technology**

- Access to the vast array of new technology now available to assist individuals to be more independent
- Technology to assist with communication

**F. Behavioral Consultation**

- Provide clinical consultation to assist the family in the development of a behavior support plan to address challenging behaviors

**G. Nursing Consultation**

- Provide nursing consultation to assist the family with addressing medical issues

**H. Waiver Design /Flexibility**

- In the forums, families asked for maximum flexibility in the design of the waiver in order to meet the varying needs of many families. Some families would like a menu of services; others would like a capped budget allowing them to design their support needs. The design of the HCBS Waiver services

can be flexible and each state can design the program to meet the needs of the waiver recipients.

### **I. System Navigation and Information**

Listing and defining the package of services available in a Family Support waiver is only one piece of a comprehensive service system designed to support families. The essential element needed to support families is a quality case management system designed to understand and support the needs of individuals living at home and the support needs of the family.

At each of the meetings, the underlying issue of systems navigation permeated every topic. Families are not always in need of paid services but are desperate for information about resources and systems navigation. Since families are caregivers over the lifespan, the quest for information is continuous.



At each stage of the individual's life, the family plays a key and ever-changing role. As each family shared the story of their journey, the underlying thread of their story was the need for information and assistance in navigating a complex system of services, supports and cash assistance. The foundational elements in supporting individuals and their families are designed around a well-informed case management system focused on the family and a planning process designed to address the needs of the individual and the entire family. Currently DDDS provides little or no planning for families. Without the opportunity to plan for the future, many families shared their anxiety about not only day to day concerns but, overwhelmingly, what will happen to their loved one when they are no longer able to support them.

### **III. Use of Supports Waivers across the States**

Supports waivers, under the authority of Section 1915(c) of the Social Security Act known as Home and Community Based Waivers, have been used by many states to provide self-directed services while controlling access and costs into full 24 hour services, which are typically referred to as comprehensive waivers. The current DDDS HCBS Waiver is a comprehensive waiver. To date, 24 states have an approved supports waiver (Appendix A). Supports waivers can limit a state's financial risk by including a cost cap, limiting the benefits waiver members can receive and/or limiting the target populations who can receive waiver benefits.

States look to use supports waivers for individuals who can manage with less than 24 hour supports because they live with families or on their own with a network of natural supports. Supports waivers are an alternative to comprehensive waivers which typically include 24 hour residential supports, day supports and a variety of other essential services. A person who qualifies for a waiver service is entitled to all services in the waiver plan, based on assessed needs. For this reason, many states who want to offer a modest benefit to people living at home or on their own are concerned about entitling a group to a larger benefit and therefore create a limited "supports" waiver. As with other 1915(c) waivers, the number of people served in a supports waiver can be capped. In Delaware, having a family support waiver would help to delay paying for costly out of home placements. The annual all inclusive institutional cost at Stockley Center is approximately \$358,000 and the average residential costs for individuals on the DDDS HCBS Waiver is approximately \$80,000 annually.

Supports waivers can limit the amount of funds any person can use by limiting the types of services, the utilization or the duration of services. Most states with supports waivers have capped the amount of funds that can be spent per person per year but broaden the types of services and supports a person can purchase. By providing a flexible array of services, the waiver design can best respond to individuals and their families who can direct and customize services in a way that meets the needs they have at the time they have them.

#### **IV. General Features of Supports Waivers**

Since the intent of multiple states using supports waivers is to distinguish these services from full comprehensive services, the following attributes are common among supports waivers:

##### **A. Annual Financial Caps**

The most frequent features of supports waivers are capped annual budgets per waiver member (from \$13,500/IN to \$58,000/CT) It is important to have the benefits be sufficient enough to meet the targeted purpose such as covering day/employment services and access to family respite but not so broad as to open financial risk to the state.

##### **B. Target Group**

Supports waivers can target groups such as children, adults, high school transition age, etc. One common group in all states supports waivers are people who live in the family home. A state can set a limit of people to be enrolled and manage a wait list as long as that wait list is reasonable. Priority criteria must be specified in the waiver application for how the wait list will be managed as slots become available.

**C. Self-Direction**

Using supports waivers the state looks to partner with individuals and their families, having the person maximize supports that are part of the community before or along with public funds. The person and their family have the ability to control services by prioritizing the services that are needed, contracting or hiring the provider and managing the budget resources within the cap. States that have used capped benefits have found families and people with I/DD feel like partners in meeting their needs and the result is that they optimize natural and non-public funded supports and use only those waiver services needed over and above non-paid supports. Most often the actual cost per person is under the maximum available.

**D. Benefits or Package of Services**

Each state designs the set of benefits or array of services that will be available under the Medicaid 1915(c) waiver authority in a supports waiver. This can include all of the services that were presented by Delaware families at the forums: respite, in-home services, community inclusion, day services, supported employment, transportation, home modifications, services and goods and technology. When states have an overall financial cap on the amount of funds to be used, most States keep all the services on the table to allow flexibility and choice to meet individual needs.

**E. Service Coordination/Case Management**

Since most states use supports waivers to promote individual and family self-direction, the role of the service coordinator is important to facilitate and broker supports. The service coordinator assists the person in developing their plan, helps to identify what providers are available, works with the person to manage the budget and provides ongoing monitoring that the person is getting the outcomes they desired.

**V. The features of a Family Support Waiver that would benefit Delaware include**

Delaware families identified a number of supports that would assist them in creating a life for their family member. But most important, families and individuals expressed the desire to be able to design the services and in some cases self-direct those services. Self-direction is not a type of service but a way of thinking. It empowers the person to get supports and services based on individual needs, values and beliefs. The basic principles of self-determination that are incorporated in a supports waiver are:

- Freedom to plan a life with the supports what a person needs
- Authority to control supports dollars
- Responsibility for the use of public funds
- Responsibility to participate in and become a contributing member of the community

**A. Target Population**

Delaware could include both children and adults in the supports waiver. The benefit packages can be designed to fit age groups such as children, transition age youth, adults, seniors. There can be a smaller cap for children and services would not include employment or day habilitation support while the child was in school.

There are approximately 740 individuals with I/DD who are in day services paid for using the Medicaid State Plan Rehabilitation Option. Over time CMS has clarified what services are appropriate to be included under the State Plan Rehabilitative Services option versus an HCBS waiver. While day habilitation and prevocational service were previously approved by CMS in Delaware's Medicaid State Plan, more recent CMS guidance has indicated that these services are not appropriate under the State Plan Rehabilitation option. Using a supports waiver, Delaware could correct this by offering the same array of day services in a manner that is consistent with CMS expectations. The defined target population will include these individuals and the benefit package described below will include these day and employment services, so that they can be removed from the State Plan.

**B. Benefit/Service Package**

Delaware's Family Support Waiver can include a broad benefit/service package and let the financial cap be the control factor. Support Service Waivers must identify the services that can be utilized by any participant. The benefit/service package list can be inclusive and many states have the following list of benefits in their Supports Waiver:

- Respite
- In-home staff support
- Community inclusion
- Day services, non-work
- Pre-vocational
- Employment support
- Assistive Technology
- Home/vehicle modification
- Services and goods
- Behavior consultation
- Nursing consultation
- Family Network

Within the benefit/services included in the waiver, limits can be placed on individual services such as an annual or multi-year limit for home modification. The Delaware Family Support Waiver could consider an exceptional needs

category which allows services to be purchased above a financial cap for a limited amount of time under extraordinary circumstances.

**C. Financial Cap**

Delaware could establish both an annual financial cap and also cap individual services but allow a broad list of benefits for a family and person to utilize. Capping the amount of services a person can spend both empowers the individual and their families to self-direct to use what is needed at the time it is needed and provides some fiscal predictability for the state.

States that have used capped benefits have found families and people with I/DD feel like partners in meeting needs, optimize natural and non-public funded supports and use only what is needed. Often the costs per person are under the maximum available.

**D. Supporting Family Networks**

Throughout the state forums, the need for information and systems navigations was a common theme. Families are not always in need of paid services but are desperate for information about resources and systems navigation. This need can be met by supporting family-to-family networks as well by providing supports coordination. Family Networks are being established in a number of states (OR, MO, CT) where the premise is that when parents connect with other parents who share a vision of possibility, and help each other find strength, they break the cycle of loneliness and isolation commonly experienced by families of children with disabilities. In turn, their children are more likely to experience a trajectory of empowerment and success within and beyond the disability community.

**E. Supports Coordination/ Case Management**

Support Coordinators/Case Managers should be trained and immersed in person-centered and family-centered planning so they can identify, strengthen and expand all supports, whether they are natural supports or paid through public funds.

Support Coordinators/Case managers skilled in working with individuals living at home and their families, together with a comprehensive person-centered/family-centered planning process are the essential elements to a successful Family Support Waiver.

## **VI. Recommendations**

DDDS recommends that the following steps occur in FY 15 in order to prepare for the implementation of a Delaware Family Support Waiver:

1. In FY 15, DDDS will create a Targeted Case Management option in the Medicaid State Plan. The target group would be inclusive of individuals who will be enrolled in the Family Support Waiver. DDDS currently spends over \$1million in unmatched State funds on its family support specialist program. The majority of these activities the family support specialists perform would be Medicaid reimbursable, enabling us to draw down a Federal match to fund a targeted case management system making it within current budget the first year. Since this will be a State plan service as an entitlement to a target group, a budget request will need to be submitted each year to maintain caseload ratios as the target population grows.
2. In FY 15, design a planning process specifically designed for individuals living at home with their families. A solid planning process will be critical to the implementation of a waiver program, but more importantly it is the foundational piece to improving the overall support to individuals living with their families. DDDS FY '15 training funding can be used to develop this planning process.
3. DDDS will begin work on a Family Support Waiver application during FY15 (see tentative schedule in Appendix B).

## **VII. Next Steps**

### **A. Creating the application for the Delaware Family Support Waiver**

Since a Home and Community Based Services (HCBS) waiver is a partnership with Centers for Medicare and Medicaid Services (CMS), the application for the program must be approved by CMS. CMS uses a web-based application process based on the old paper application that has ten parts or appendices. The application addresses all elements of the operation of the waiver, such as how case management will be provided, how client services will be monitored, how the Division of Medicaid and Medical Services (DMMA) will provide oversight and, most recently, how states will come into compliance with the new CMS rule for the definition of community based services. The current DDDS waiver application is over 150 pages long. Development of a new application is an arduous process and will take several months to prepare before it can be submitted to CMS for review and approval. CMS initially approves 1915(c) HCBS waivers for a three year period, with renewals at five year intervals thereafter. Once CMS receives the application, they have 90 days to approve or deny it, but they can "stop the clock" at any time during this 90 day period by issuing a "Request for Additional Information". Past experience indicates that the CMS review and approval process for new HCBS waivers is likely to take at least

six months. Staff at DDDS in partnership with DMMA, have experience in this process. Upon approval to move forward, we will target a July 1, 2015 date for approval by CMS and implementation. A tentative schedule for planning and implementation is included as Appendix B.

Having a second HCBS waiver to operate and manage within DDDS will require additional personnel to perform activities that are required under the waiver such as level of care determinations, waiver enrollment, enrollment management against approved slots, management of any waiting list, financial controls, rate setting, monitoring utilization, quality assurance monitoring and waiver reporting. As of January 2014, the current approved comprehensive HCBS waiver has an active enrollment of 941 individuals. This second waiver is recommended to enroll 980 individuals in its first year and would continue to grow over time.

## **B. FY15 GF Start Up Costs Necessary for a FY16 Implementation**

Fiscal year 15 start-up cost necessary for a July 1, 2015 implementation is estimated at \$264,091. More information on these costs can be found in Appendix C.

### **Recommendations:**

1. DDDS has identified the need for six additional positions in order to manage and support this program. A new waiver cannot be implemented without additional staff to enable the division to comply with all of the CMS requirements around the operation of an HCBS waiver. The cost to add this essential staff is: \$89,113 for partial funding in FY15 and \$281,844 in annualization in FY16 for a total cost of \$370,956.
2. DMMA has identified the need for three additional positions in order to process the Medicaid waiver eligibility applications (assumes a caseload of standard of 330 cases per worker). The cost of these eligibility workers will be split 50/50 state and federal as a Medicaid administrative activity. DMMA cannot process these new applications within its existing staffing compliment. The cost to add this essential staff is: \$13,103 for partial funding in FY15 and \$65,513 in annualization in FY16 for a total cost of \$78,616.
3. In order to implement a new waiver, changes will need to be made to the Delaware Client Information System (DCIS), the Medicaid eligibility system and the Medicaid Management Information System (MMIS), the Medicaid claims processing system in order to enable the submission of provider claims for the services charged to the Family support waiver. The one- time state share of the cost for these changes is: \$121,875.

4. DDS will also need to engage the services of a consultant to develop Medicaid reimbursement methodologies for services not currently paid by Medicaid: \$40,000 state share one-time.

**C. Implementation for FY 16**

**Recommendations:**

**1. Propose the creation of two target groups under the waiver, as follows:**

- a. Target Group 1 - Individuals living with their family who receive State Plan DDS Day Services:

DDS recommends that the initial target group for this waiver be those individuals who are living at home and currently receiving Medicaid State Plan day services. Current Medicaid spending for these day services is \$12.5 million total funds. Available funds for these services will increase during FY 14, 15 and 16 based on additional funding appropriated for special school grads adding to that base. These funds are available to fund part of the overall capped budget for the new waiver, so the day services component of the capped budget would be cost neutral to the State, since the State is already paying for the services. Individuals would continue to have their choice of qualified providers. Individuals and their families would have more control over the expenditure of their funds by having control of their budgets.

The initial number of participants in Target Group 1 will start at 940 individuals with capped budgets of \$22,000 each for FY 16. The waiver application will propose additional participants of 100 new individuals for each of the next 2 years of the waiver (FY 17 and FY 18).

In addition to the Day Services, these individuals will be able to purchase any of the other options that families have requested, up to their annual capped budget. Families will get to choose the amount, scope and duration of each service within any individual service limits included in the waiver application, up to their capped budget.

- b. Target Group 2 - Individuals living with their family who do not receive State Plan DDDS Day Services:

These are individuals who are still in school or who may be receiving services from Vocational Rehabilitation so they do not need DDDS Day Services. These individuals will have a lower cap than Target Group 1 that will allow them to receive the full array of family support services other than the Day Services. The initial number of participants in Target Group 2 will start at 40 individuals with capped budgets of \$2,750 each for FY 16.

The waiver application will propose additional participants of 40 individuals for each of the next 2 years of the waiver (FY 17 and FY 18).

## **2. Home/Vehicle Modifications**

Individuals in both of the Target Groups under the Family Support Waiver would be allowed to access home or vehicle modifications related to accessibility or safety up to a cap of \$6,000 per person every five years. This cap is separate from the caps for Target Groups 1 and 2.

## **D. Funding for Waiver Service Costs - FY16**

Current Medicaid spending for State Plan DDDS day services was approximately \$12.5 million total funds in FY13. Available funds for these services will increase during FY 14, 15 and 16 based on additional funding appropriated for special school grads, adding to that base. These funds are available to fund part of the overall capped budget for the new waiver, so the day services component of the capped budget would be cost neutral to the State, since the State is already paying for the services.

DDDS proposes to add an additional \$1.2 million in State only funds currently being used to pay for respite and other family support services into this program to be matched with Federal funds and utilized toward the individual budget cap. This includes the \$715.5 that was appropriated to DDDS in FY14 for family support.

The total funds equivalent of this \$1.2M on state funds is approximately \$2.6M in SFY16.

The total service costs for the Family Support Waiver are projected to be as follows:

FY16: \$20,206,811  
FY17: \$22,156,872  
FY18: \$24,106,923

Over half of the costs above will be borne by federal Medicaid funds. Because of the combination of available Medicaid funds that are already being spent on State Plan Day services and the addition of DDDS state funding that is not currently matched the first year of the waiver (FY16) is projected to be cost neutral, assuming that the legislature continues to fund the special school graduates as they have done for the past 10+ years. The incremental costs in - FY17 and FY18 to cover additional waiver slots are as follows:

<b>FY</b>	<b>Total Incremental Funds</b>	<b>State Incremental Funds</b>
2017	\$1,946,872	\$898,481
2018	\$1,950,051	\$899,949

The federal Medicaid share is based on the most current available data. More information about the fiscal note can be found in Appendix D.

Over time, the number of participants and/or the capped annual budgets can grow as funding is appropriated by the legislature. Appendix D shows the fiscal impact estimate based on the anticipated number of participants and their capped costs. The fiscal note was developed assuming zero increase in the value of the annual caps. The fiscal note also assumes client growth for each fiscal year (17 and 18) is 100 for Target Group 1 and 40 for Target Group 2.

## **VIII. Acknowledgements**

DDDS would like to thank the many individuals, families and advocates who participated in the forums and acknowledge families as vital partners in supporting individuals to live fulfilling, inclusive lives in their community. DDDS looks forward to working with families to redesign the service system to better meet their needs and the needs of their family.