

APPENDIX B.

**STATE-BY-STATE CASE
STUDY RESULTS**

FLORIDA

Introduction

Florida's Family and Supported Living (FSL) Waiver was initiated in October 2005 with enrollment quickly growing to 2,650 recipients. The focus of these supports is to provide services to children and adults with disabilities living at home. Today there are 5,921 people enrolled in the supports waiver and 26,079 others served through the state's comprehensive waiver.

Method

In September and October 2006, the Human Services Research Institute (HSRI) staff visited Florida to conduct face-to-face consultations with key informants and also conducted discussions by telephone with additional informants. The individuals included in these conversations were: (a) state Agency for Persons with Disabilities (APD) staff including the state director, waiver manager and others along with personnel with the Florida Medicaid, Bureau of Medicaid Services, Developmental Disabilities Services Division; (b) representatives from interests outside the state agencies including the chair for community living and family committee from the Developmental Disabilities Planning Council and several families representing regional Family Care Councils; (c) service providers associated with the Florida Association of Rehabilitation Facilities; (d) independent support coordinators who perform service planning and monitor service delivery; and (e) staff of the Delmarva Foundation which manages Florida's statewide waiver quality assurance/improvement program.

Results

What follows are results of the conversations. First, information is presented to describe the policy goals of the waivers, information on waiting lists, and the fundamental waiver operations. Second, views offered by the informants are presented related to: (a) access to the waiver; (b) waiver operations such as budget allocations, service planning, service delivery, and safeguards; (c) outcomes; and (d) key issues in play.

Florida Policy Goals

Question: *What are the major policy goals of the supports waivers and how successful have the waivers been in meeting them?*

- Cost containment and budget related goals were a primary focus of the FLS waiver. The FSL Waiver employs a funding cap in order to serve more people with fewer dollars than would ordinarily be possible.
- Goals related to addressing the waiting list are also a primary focus. When the state settled the *Prado-Steiman* litigation, it committed to serving all eligible individuals who were on the waiting list as of June 1999. This goal was met, and the number of people receiving waiver services grew from 13,800 in 1999 to over 24,000 in 2004. Florida Governor Jeb Bush was instrumental in securing additional funding during this period and continues to support funding increases for developmental disability services.
- However, despite tripling funding for developmental disabilities during the period and substantial and necessary expansion of the comprehensive waiver, the waiting list climbed to 15,000 people. The FSL Waiver emerged as a means to support individuals and families who are on the comprehensive waiver waiting list by offering them a more limited package of in-home and other supports. In February 2007 the Florida legislature has continued its debate on the waiting list and additional potential future funding.
- Consumer-direction and person-centered planning goals are not primary goals of the FSL Waiver. The state is interested in flexible budget usage and improving its ability to assess individual support needs. Florida operates a pilot Centers for Disease Control and Prevention waiver that serves about 1,000 people and incorporates self-direction.
- Rebalancing the long-term care system and refinancing community services have not been primary policy goals.
- The state also is pressing for increased use of supported employment and supported living services.

Wait-lists

Question: *How many people are on the consolidated (i.e., all wait-lists for developmental disabilities services) wait-list?*

- In 2005, after a strong enrollment effort, 5,600 people were admitted to the waiver, reducing the wait-list to 6,200. To promote the waiver, 11,000-12,000 letters were sent to potential enrollees. But the wait-list has climbed back to about 12,000 due to: (a) continuing increases in the numbers each year who come forward seeking services; and (b) delayed impacts of population disruption and population migration due to hurricane impacts.
- State officials expect that there will be 9,000-10,000 people on the waiting list at year's end.

- In July 2006, the Florida Office of Program Policy Analysis and Government Accountability called for APD to improve its management of the waiting list with more regular review, updating, and identifying service needs. APD was encouraged to develop a multi-year plan for addressing the waiting list for waiver services that considers the length of time individuals have been on the waiting list, how soon the individual is expected to need waiver services, the expected level of services to be provided, and whether the individual is receiving services from other waivers or programs. In February 2007, the Florida legislature was weighing additional funding to help people move from the wait-list.
- People enrolled in the FSL Waiver may maintain their position waiting for the comprehensive Developmental Services Home and Community-Based Services (HCBS) Waiver (the comprehensive waiver).

Question: *How are wait-lists maintained?*

- Waiting lists are maintained for each waiver. State area offices process enrollment requests and maintain a consolidated wait-list that is also shared with the APD central office. Individuals apply for APD services and are later identified as potential waiver enrollees. A preliminary needs assessment is used by the state to select individuals who are on the waiting list for the FSL Waiver. When a waiver opening becomes available, the person is assigned a support coordinator. The central APD office keeps a running tally of the waiting list counts as information flows in from the area offices.

Question: *How long generally is the wait?*

- The average time on the waiting or interest list before an individual is enrolled is now five years or less, down from eight years in 2003. Some 81 percent of the individuals waiting are age 30 and under. Most of these potential enrollees have an intellectual disability. In January 2007, Florida's APD was anticipating a \$230 million deficit through the next year and a half. The Florida Legislature in February 2007 continued to examine the wait-list. Since then, Florida's new Governor Charlie Crist released his budget recommendations for FY 2007-2008 that includes \$119 million to cover the growing demand for waiver services through increased utilization from existing customers, and to provide waiver services to customers transitioning from the developmental services institutions.
- Governor Crist also earmarked funds to take care of citizens with developmental disabilities that find themselves in extreme need due to a caretaker or housing crisis. Over \$7 million will be used to care for 500 new crisis customers in the upcoming year and another \$6.7 million will pay for the crisis customers that will enter the program this year.
- In addition, the proposed budget provides \$6.6 million to allow the agency to serve more people in its Mentally Retarded Defendant Program and may take steps to reduce it.

Basic Operations

Question: *How are people selected for enrollment?*

- The enrollment process for the FSL Waiver is a step by step process that is coordinated by the central office and area office to track and guide applicants through the enrollment process. Interest letters are used by the area office with screening questions to check for HCBS eligibility criteria. A preliminary needs assessment is used to select individuals for the support waiver. Foster children with individual and other developmental disabilities (I&DD) and referrals with I&DD from the corrections system are covered by the comprehensive waiver but entry to the comprehensive waiver is now restricted due to funding limitations. In the current FY support waiver enrollment is also severely limited due to funding limitations. When the support waiver began, the enrollment process was controlled by the central office but this process has been moved to the area offices throughout Florida.

Question: *Is there descriptive information available on the people served in the supports waiver (e.g., age, primary disability, living arrangement, functional status, caregivers)? Is systematic information available regarding waiver impacts?*

- The APD annual report and brochures broadly defines profiles of those served in the supports waiver.
- More descriptive information is available to describe individual characteristics such as age, primary and secondary disability, and living arrangement.
- Systematic information about the impact of the supports waiver on is produced by the statewide quality assurance program.

Question: *How is quality assurance and quality management managed?*

- The same quality management architecture is employed for both waivers.
- Family Care Councils have been organized by region. The councils have many families of individuals who are relatively new to waiver services. The councils provide information to families and serve as a conduit of information and experience about the waiver among families. (See the booklet *Planning Ahead* which is available on-line at <http://www.fddc.org> or the brochure titled *Protecting Legal Rights: It's in Your hands!* available at <http://apd.myflorida.com>).

Question: *How are individual service plans developed?*

- Independent service coordinators meet with the person and their family or representative/legal guardian to complete needs assessments; identify supports needed and develop a plan to address stated needs.

- As a practical matter, the service coordinators often feel that if an individual wants a particular service or support, it can be submitted in the plan even though it may not be approved.

Question: *How are individual allocations set?*

- In September 2006, the waiver funding cap was increased to \$14,792, up from \$14,282. Previously, varying “soft caps” per person were applied but have been eliminated in favor of an overall total dollar cap per person. Exceptions are not made to the overall total support waiver cap.
- Individual assessments are conducted using a tool called the Individual Cost Guidelines. It determines the recipient’s specific resource allocation for waiver funds for recipients receiving supports.
- The individual has knows the funding allocation before planning starts. However, some informants expressed the concern that sometimes the amount of the funding allocation is not made known to families and individuals before a plan is created.

Question: *What decision-making authority do individuals/families have over the budget?*

- They can plan within capitated dollar limit and determine services and supports needed. Among people with two full years of plan development the average plan cost was approximately \$9,000 but the actual expenditures averaged about \$4,000. Understanding this pattern and the reasons driving it may take several years, in part because of the rapid growth and relative newness of the support waiver.

Question: *Who has **primary** responsibility for developing the service plan?*

- Individual support coordinators have primary responsibility.
- Among the service planners, the average caseload is 36 individuals per service planner, ranging from 18 to 42 individuals per planner.
- In Florida, people do not have paid outside assistance available to them during the planning process to help design the service plan.

Question: *Does the service planning include a distinct risk assessment process to identify and address identified risk?*

- Service planning does not include a distinct risk assessment process to identify and address identified risks and negotiated risk agreements are not used.

Question: *Is the process the same or different from that used in the comprehensive waiver?*

- Yes, it is the same process. The FSL Waiver has fewer services and supports and the resulting plans are often simpler but similar to the plans written in the comprehensive waiver.

Question: *What happens to individuals when they need more support than the waiver can offer, either by way of particular services and/or overall cost?*

- Individuals can apply for crisis enrollment on the comprehensive waiver. A specialized state committee examines individual requests and assessed needs. Sometimes Medicaid state plan services can help with portions of the problems presented.

Question: *What parameters govern transition from the supports waiver to the comprehensive waiver?*

- FSL Waiver participants retain their position on the comprehensive wait-list for potential future opportunities. Due to funding limits, at present enrollment in the comprehensive waiver is tightly controlled.

Question: *How might a person be disenrolled from the supports waiver?*

- An individual may be disenrolled from the supports waiver when the individual: (a) request such action; (b) is incarcerated; (c) no longer has a disability; (d) is no longer financial eligible; (e) moves out of state; (f) no longer meets level of care; (g) is admitted to nursing facility or intermediate care facility for the mentally retarded (ICF/MR); (h) is no longer eligible for Medicaid; (i) refuses services; or (g) fails to cooperate.

Question: *What if the individual wants to change their service plan, or wants to change providers?*

- The individual notifies his or her service coordinator that they wish to change, select a new provider, and set a date for new provider to begin providing services. The service coordinator works through the required notifications and new authorizations.

Question: *How is quality assurance and quality management managed?*

- The Quality Assurance System has produced a wealth of information with a uniform state system that measures the results of both the comprehensive and supports waivers. The system is contracted out to the Delmarva Foundation.
- The overall quality assurance approach has changed from an outcome perspective to quality assurance with “we are here to help you” theme. The

entire and extensive body of work is available on the Internet at <http://www.dfmc-florida.org>.

- Monitored elements have been reduced from 175 elements to 11 elements. These include five related to service process (e.g., background screenings, documentation for billings) and six tied to outcomes (e.g., health status, skills building).
- The implementation of policies by providers, not just having them, has been a key Florida discovery. The providers meet the extensive FSL Waiver handbook at 85-90 percent level but the quality assurance efforts stress a focus on the person and their outcomes.
- The Quality Assurance/Quality Management System for the FSL Waiver is the same as the comprehensive waiver. It is also the same provider network with 95-98 percent of the service providers the same. Next year the quality assurance system will differentiate between the FLS Waiver and the comprehensive waiver.

Question: *How are complaints resolved?*

- Individuals can file a complaint through a “Fair Hearing” process that is used to appeal a decision made by the state, or through a grievance available through the recipient’s chosen support and service providers.
- Where a grievance procedure is used, the grievant identified their grievance and proposed resolution. The provider responds to the grievance, this response can be appealed to the governing body. Grievance logs are examined by the state and must be maintained by providers.

Question: *What is the process that is used to monitor the health and well-being of individuals participating in the supports waiver?*

- The process used includes service coordination consultation, on site consultation, desk reviews, and follow consultations.
- On-site monitoring is performed a minimum of every six months.
- A primary difference between the approach to supports waiver monitoring and comprehensive waiver monitoring is that the comprehensive waiver requires monthly face-to-face visits.
- Service coordination follows up to resolve problems revealed by monitoring. Area offices track incidents and share them with quality assurance.

Opinions on Waiver Operations and Effects

Access to the Waiver

Explanation: *Access refers to how easily people can apply for and gain admission to the supports waiver.*

- Potential enrollees learn about this supports waiver program from current consumers, conferences, family care councils, printed matter and the website. Funding also shapes how people learn about the FSL Waiver. Many people are referred to the APD website for information. In the current year when new dollars for enrollment are very limited, some complain that people have been discouraged from applying for the consolidated waiting list.
- The supports waiver is not aggressively publicized. Word of mouth is probably the most common way families and individuals learn about this opportunity.
- It is “Very Easy” to apply. The demand for this FSL Waiver among people is increasing steadily. Personal documentation for some, however, may be difficult to provide. Cultural diversity issues in some locations in Florida make it harder to get and use services.

Service Planning

Explanation: *Service planning refers to the process to develop individual support plans for waiver recipients.*

- Some informants indicate individuals “somewhat” leads the planning process
- However, the state officials indicate that the FLS Waiver “very much” permits recipients to define their own service needs, and choose the agencies or support givers to offer the needed support.
- Informants note that the recipients “somewhat” exercise choice and control over service plans but this is shaped by the community they live in, provider issues that may limit it, sometimes parental control, and depends on the support coordinator. Others suggest that the supports waiver is inherently limited in choice because it does not offer as many services or dollars as the comprehensive waiver. Many indicated that they would like to see more services, no caps, and more flexibility for families and individuals.
- State staff feels that service planners get to know the individuals they are planning for “Very Well” while others would not go so far.
- Most agree that there are some very good support coordinators who know the individual and families well. Yet, there is a high turnover and some may be new and developing the necessary skill set. The state has tightened up qualifications and is examining competency-based certification and instruction for support coordinators.

Question: *What if the individual wants to change their service plan, or wants to change providers?*

- It is very easy is it for individuals to change service providers and this generally can be accomplished within days.
- Waiver participants cannot generally hire and manage their own support workers. While the workers are employed by an agency, participants often identify and refer potential workers to the agency and manage them on a day to day basis.
- Where “in-home” supports are offered to adults living home with family, the services are seen by the state as most often person directed; some feel that it depends on the individual and family.
- The services available through these waivers are generally broad enough to meet participant needs for individuals who do not have high needs or need to live in a group home.
- Informants indicate that it is “Somewhat Easy” for individuals to change their service plans. Regional offices can deal with emergency situations.

Service Delivery and Safeguards

Explanation: *Service delivery and safeguards refers to the services that individuals received and their operations, and the safeguards in place to assure health and well-being.*

- Once services are authorized, informants indicate that it is neither “Easy” nor “Hard” for individuals to get these services.

Satisfaction with Outcomes

- Generally, informants indicate that recipients are not living on their own or with friends, but are participating in community events.
- Informants indicate that there is “Some” emphasis on services to promote community integration versus services that are more traditional (sheltered work, enclaves, segregated activities...). Many individuals, however, use segregated services.
- Employment outcomes have been increasing from a 2,428 person baseline in 2004 to 4,441 people maintaining employment in 2006 with the five-year target of 5,842 people maintaining employment by 2009.
- To assure the health and well-being of participants, the safeguards in place are generally thought to be working well.

Key Issues in Play

Question: *What are the waiver’s greatest strengths?*

- A major strength of the FLS Waiver is the ability to serve a large number of services recipients at a predictable cost.

- Generally, many people report being satisfied with services and report being very happy.
- Governor Jeb Bush has invested significant sums in making waiver options available.
- The privately contracted quality assurance project is effective in documenting system change through statewide efforts.
- Many Florida applicants have come off the waiting list and are now receiving services.

Question: *What are the barriers to achieving the waiver's goals?*

- Workforce issues. Workers cannot be found easily and there is concern over what they are paid and the associated benefits.
- Some see shortcomings as difficulties in accessing professional therapies in some communities and the time it takes to get service authorizations approved.
- Many people, families and individuals, report a desire for increased self-determination with more choices and control over their chosen services, units, and activities.
- People are being taken off the waiting list but the list continues.
- Restrictions require the individual to leave the family home if they need a lot of care. Sometimes this seems neither less costly nor better for the individual.

Question: *Are there topics where there is disagreement or concern?*

- There is pressure to both add services and dollars to existing plans and also to take people off of the waiting list.
- The state has worked hard to get the supports waiver up and running and continues to seek refinements in practice as it gains experience.
- Like most states the individual (independent) Medicaid certified providers who are direct support workers look at the person served and their families as the employer of record. This creates problems in liability, workmen's compensation, routine paying of Federal Insurance and Compensation Act and other taxes that can create trouble for the employer in some situations.

Question: *What are the TOP THREE things that could be done to improve the waiver?*

- Increase flexibility. Allow people to use more of the funds for needs during the year (parallel funding for horizontal needs).
- Add a self-directed service option. In some cases people do not know how to use the services and supports.
- Remove cap limits on spending when a person needs more services to stay in their family home. Currently if they need nursing, therapies, or extensive care they have to leave their family home and join the comprehensive waiver. Some say that this is not always optimal for care or cost. Others feel like the cap should be flexible in some situations and that expenditures should be more in some individual situations.

- Add funds to adjust current plans and eliminate the waiting list.
- Many felt that the FSL Waiver should be expanded to include all or most of the services on the comprehensive waiver although it would need to have the same annual cap. Others suggest adding speech therapy, durable medical equipment, therapy for adults, and/or all the services in the comprehensive waiver.
- Find a way to enable environmental one time costs that hit once in a person's plan but wipes out most of their dollars for the entire year.

Question: *What other points should be raised?*

- Many parents, appreciative of the supports waiver, continue to desire additional service choices and sometimes more services overall.
- The need to eliminate any soft caps for services within the FSL Waiver and add supports for children, including needed behavioral supports.

Overall Impressions

All informants agree that the supports waiver is generally a positive development though early in its development. It has been effective at helping to reduce the wait-list and contain costs within a predictable budget. Still, many suggest that:

- The comprehensive waiver needs to continue to be available for those that “cap out” of the “supports waiver.”
- More service options might be added to this waiver to better tailor services and supports to needs.
- Many want more flexibility in the services and an increase in the range of choices that individuals and families could use.

Florida provides an excellent example of what can be done, in a relative short time, with what is already the second largest support waiver in the United States.

MISSOURI

Introduction

The Missouri Community Supports Waiver (CSW) for people with developmental disabilities was launched in 2003. Missouri built on its experience in furnishing state-funded, family-centered services in designing this waiver to underwrite alternatives to residential services. The waiver's major aim is to reduce the waiting list through the delivery of lower-cost services.

Method

In August and September 2006, HSRI talked with key Missouri informants to obtain more in-depth information concerning CSW. Informants included: (a) Division of Mental Retardation and Developmental Disabilities staff, including the Division director and senior program managers; (b) the director of the Missouri Planning Council for Developmental Disabilities; and, (c) personnel at the Institute for Human Development at the University of Missouri-Kansas City, the Missouri University Centers for Excellence in Developmental Disabilities. The Institute works extensively with individuals and families throughout the state.

Results

What follows are results from the key informant consultations. First, information is presented to describe the policy goals of the waiver, information on any service wait-lists, and the fundamental operations of the waiver. Second, opinions offered by the discussion participants are offered related to: (a) access to the waiver; (b) waiver operations, service planning, service delivery and safeguards; (c) outcomes; and (d) key issues in play.

Missouri Policy Goals

Question: *What are the major policy goals of the supports waivers and how successful have the waivers been in meeting them?*

- CSW was designed to serve as a low-cost alternative to the comprehensive waiver and as a vehicle to reduce the waiting list. CSW was not launched in response to a lawsuit.
- The CSW has been successful in relieving pressure on the mental retardation and other developmental disabilities (MR/DD) Comprehensive Waiver. Still, the overall number of people waiting for services continues to grow.

- Implementing self-direction and person-centered planning are seen as secondary goals. Presently, there is limited use of waiver self-direction opportunities.
- Rebalancing the long-term care system was not a policy goal. CSW permitted Missouri to refinance some state-funded community services in order to finance system expansion.

Wait-lists

Question: *How many people are on the consolidated (i.e., all wait-lists for developmental disabilities services) wait-list?*

	CSW	Comprehensive Waiver
2005	3,246	441
2004	446	1,540
2003	256	1,180

Question: *How are wait-lists maintained?*

- Missouri maintains a statewide waiting list. State service coordinators maintain the waiting list and track the status of individuals on the waiting lists. (Missouri maintains two statewide waiting lists, one for residential services and one for in-home services). However, some of the people on these lists are not Medicaid-eligible and others are eligible for Missouri Division of MR/DD Services but do not qualify for ICF/MR level of care. That is, eligibility for a waiver has not been determined for all individuals on these lists. Further, individuals may be added to the residential waiting list for “planning purposes.”
- Missouri uses a scored instrument to assess the urgency of need of people on the waiting list.

Question: *How long generally is the wait?*

- The average wait time is more than two years.

Basic Operations

Question: *How are people selected for enrollment?*

- People are selected for services by a utilization review (UR) committee based on waiting list score. Available funds are prioritized to support people who are experiencing an emergency or crisis.

Question: *Is there descriptive information available on the people served in the supports waiver (e.g., age, primary disability, living arrangement, functional status, caregivers)? Is systematic information available regarding waiver impacts?*

- There is no systematic information about the impact of the CSW on participants. By report, many people informally report that they are very happy with services and this result has been so common that more formal measures have not been used.
- Centers for Medicare & Medicaid Services (CMS) waiver reviews serve as the formal evaluations of the supports waiver.
- Missouri officials indicate that they know whether the waiver is effective by reviewing its impact on the waiting lists and by examining costs and reported satisfaction.

Question: *How are individual service plans developed?*

- State service coordinators meet with the person and their family or representative/legal guardian to complete a person-centered plan. Person-centered planning guidelines are posted on the state website.
- When the service plan is developed, a draft budget is also created that then goes to the UR committee. The committee considers the individual needs in the plan, any alternative means of meeting the needs, and the amount of service other individuals with similar needs receive in approving budgets.

Question: *How are individual allocations set?*

- The planning process identifies needs. A budget is drafted to meet the needs. The budget and plan are reviewed by the UR committee when it is the individual's first plan/budget and when there is a request to increase supports. The individual does have general knowledge of the allocation before planning if the person had a plan the previous year.
- Missouri does not have a budget allocation tool. Individuals receive a copy of their approved budget annually.

Question: *What decision-making authority do individuals/families have over the budget?*

- Individuals and families have input in the planning process where needs are identified and how the needs can best be met are proposed. The budget is developed. All new budgets or requests for increases in a budget must go through UR.

Question: *Who has **primary** responsibility for developing the service plan?*

- State employee service coordinators located at Regional Centers have primary responsibility; some SB-40 County Boards also employ service coordinators. Missouri uses targeted case management to finance service coordination. Service coordinators facilitate the planning process with the consumer and legal representative and others they request to participate.
- Each service coordinators supports 50 individuals on average. Service coordinators support a range of 40-70 individuals. Case loads have been growing due to budget limits.

Question: *Does the service planning include a distinct risk assessment process to identify and address identified risk?*

- Negotiated risk agreements are not used.
- The new service planning process in the renewal for both the support and comprehensive waivers provides for risk assessment for people who self-direct their services. The state also is using the Health Inventory Screening tool. Nurses ensure that health needs are addressed in the plan. There is a registered nurse in each region and this has worked well.

Question: *Is the process the same or different from that used in the comprehensive waiver?*

- The planning process is the same as that used in the comprehensive waiver.
- Individuals usually do not utilize paid outside assistance to help design the service plan. Community Specialists (waiver service) can assist in facilitating the development of the plan when an independent facilitator is requested.

Question: *What happens to individuals when they need more support than the waiver can offer, either by way of particular services and/or overall cost?*

- Service coordinators may authorize additional services. Regional directors are empowered to respond to emergencies in individual circumstances. Exceptions may be granted based on need. If the increased need is long-term, the person may be transferred to the Comprehensive waiver. In the renewal, the CSW cap was increased to \$22,000.

Question: *What parameters govern transition from the supports waiver to the comprehensive waiver?*

- In the last year, only 14 people moved from the CSW to the Comprehensive Waiver. People transition to the comprehensive waiver due emergencies and crises.

Question: *What if the individual wants to change their service plan, or wants to change providers?*

- The process that an individual must follow to change service providers includes notifying the service coordinator and over the course of 2-6 weeks the service plan is changed.
- The time it takes to change providers varies from days to months or more.

Question: *How is quality assurance and quality management managed?*

- The principle features of the waiver's Quality Assurance/Quality Management System include case management, statewide UR committee, and quality management committee. The Quality Assurance/Quality Management System for the supports waiver is the same as the comprehensive waiver. A score card system has been developed. This area is seen by some as not as open and transparent or designed for sharing as it could be.

Question: *How are complaints resolved?*

- The process that an individual must follow to file a complaint includes a Department telephone hot line (800-364-9687). Also, the state has consolidated its complaint processes and pulled investigations and consumer complaints into one unit. Investigators who live in local areas around the state have been consolidated into a pool. The system is able to investigate abuse and neglect but additional investigators are needed.
- It is generally thought that the community safety and health record is good but the state has shared only limited information about abuse and neglect. Most provider types are licensed or certified by the state or nationally accredited. Training has helped regional centers better monitor fiscal matters. Service coordinators and local quality assurance staff throughout the state often play a key role in resolving complaints that are not considered abuse and neglect.
- The Task Force also has called for a toll-free phone number for reporting suspected abuse and for the public to have access to completed investigative reports as long as patients' protected health information is not revealed.

Question: *What is the process that is used to monitor the health and well-being of individuals participating in the supports waiver?*

- The process includes service coordination and the quality assurance team. Monitoring is performed at least quarterly in CSW. In the Comprehensive waiver, service coordinators conduct monthly face-to-face monitoring for persons who receive residential (placement) services.
- One recent development is the emergence of self advocates and families excellence volunteer visits to homes. The state is recruiting volunteers.

- If there is a problem, service coordinators take immediate action. These situations are also reported to service coordinator supervisors and the Regional Center quality assurance team.

Opinions on Waiver Operations and Effects

Access to the Waiver

Explanation: *Access refers to how easily people can apply for and gain admission to the supports waiver.*

- The potential enrollees/families learn about this supports waiver program from service coordinators and other Regional Center or SB-40 County Board staff, with brochures and the new Network of Care website. Regional Center service coordinators perform intake and also explain services that are available.
- The supports waiver is somewhat publicized and individuals apply for services, qualify for the supports waiver waiting list, and are then enrolled by regional center service coordinators when openings become available through attrition or new funding.
- It is somewhat easy to apply for services but the demand for this waiver is growing quickly. Enrollment is dependent on identifying needs during the planning process and the scoring of the need through the UR process. The score determines the priority of the individual's need in comparison with others who have needs.

Service Planning

Explanation: *Service planning refers to the process to develop individual support plans for waiver recipients.*

- Overall, respondents indicated that the planning process "somewhat" encourages individuals to exercise leadership, define their own service needs, and choose the agencies or support givers to offer the needed support.
- Overall, respondents indicated that recipients exercise some choice and control over service plans but this varies somewhat by region and participants may not have funds to secure the supports that they want.
- Overall, respondents indicated that service planners "somewhat" know the individuals they plan for. Problems arise due of staff turnover and case load variations that is caused, in part, by rotating service coordinators.
- The waiver renewal provides for a supports broker to assist individuals who self-direct services. It is now possible to hire independent facilitator.
- A Missouri company currently operates fiscal intermediary services and is able to respond quickly to timesheets and payroll responsibilities.
- The services available through CSW are generally broad enough to meet participant needs. The waiver is written adequately but implementation of the

waiver is a challenge. Personal assistance varies a lot in the plans and there are frequent modifications.

- Overall, respondents indicated that it is “somewhat” easy for clients to change their service plans with variations among the different state regional centers.
- The strengths of the approach to individual planning are its ability to allow people to choose services and leave the waiting list.
- Some see shortcomings as difficulties in finding a more uniform experience in all of the regional centers for support waiver recipients.

Service Delivery and Safeguards

Explanation: *Service delivery and safeguards refers to the services that individuals received and their operations, and the safeguards in place to assure health and well-being.*

- Once services are authorized, respondents generally indicated that it is “somewhat” easy for individuals to secure services. Some rural areas present more difficulty but generally support waiver services are reasonably available.

Satisfaction with Outcomes

- Generally people do not seek/acquire/hold integrated employment but are quick to use segregated day habilitation. This is an aspect that the state is trying to change.
- Generally people do not live on their own or with friends and sometimes participate in community events.
- There is some emphasis in the waiver to stress services that promote community integration over services that more traditionally offer segregated options (e.g., sheltered work, enclaves, and other segregated activities). However, many participants are quick to use the segregated services.
- Waiver participants can hire and manage their own support workers. The addition of support brokers in the CSW renewal will help recipients manage workers on a day to day basis. About 200 individuals are managing their workers.
- Liability issues pertaining to these workers persist, as they do elsewhere. For instance, workers are not offered workers’ compensation.
- Fiscal intermediary support is adequate. This activity has been expanded in the newly renewed CSW.
- Where “in-home” supports are offered to adults living at home with family, the services are seen as most often as family directed rather than person directed. Family members probably manage the activities and workers 70 percent of the time.
- To assure the health and well-being of participants, the safeguards in place are generally thought to work well and families are helping to ensure the health and welfare of the waiver recipients.

- The more people in their lives who care for them the safer individuals are. Service coordination can often work well. But smaller service coordination case loads and more caring people in participant's lives would be an improvement.

Key Issues in Play

Question: *What are the waiver's greatest strengths?*

- A major strength of the CSW is its ability to serve more people at a lower-cost and take the pressure off the Comprehensive Waiver.
- The waiver renewal has added support broker and has additional waiver opportunities to help more people in the next couple years.
- The legislature has been more willing to listen to people and political direction may be changing.
- People have more hope of getting off the waiting list and receiving services.

Question: *What are the barriers to achieving the waiver's goals?*

- More flexibility is needed to better customize services and supports. Self-direction needs to be enhanced so that participants are not stuck with provider-managed model of supports.
- State leadership has turned over with three directors in three years.
- Achieving greater uniformity in recipient experiences at the 11 regional centers.
- Continued high growth in people seeking services.

Question: *Are there topics where there is disagreement or concern?*

- There should be more residential choices and more done to promote community employment.
- More funding is needed to meet the demand for support waiver services.
- The current prior authorization method sometimes interferes with structuring services to meet participant needs.
- Community providers are at capacity in some areas of the state. There is a need for more behavioral support with increased funding to meet the needs of some individuals adequately.

Question: *What are the TOP THREE things that could be done to improve the waiver?*

- Expand use of the newly added support broker service. This new service offers the potential of creating a renaissance in support efforts in Missouri.
- Supported employment rates need to be increased.
- Add funds to reduce the CSW waiting list.

Question: *What other points should be raised?*

- Increased self-direction currently translates into more work for regional center staff. This may explain why relatively small numbers of families and individuals have used this feature.
- The natural support networks are as critical as anything.

Overall Impressions

All informants agree that the implementing the supports waiver has been a positive development in Missouri. The CSW has helped people stay at home and secure respite or other needed supports within the overall waiver cap.

A key change was shifting to an annual individual cap versus applying caps to each service. In addition, the state has means for managing extraordinary requests or “exceptions.” State staff feel that such flexibility is essential to the successful implementation of support waivers.

Many feel too that additional improvements are possible because as a result of changes that were made in the CSW renewal. The changes concerned quality management, increased consumer choice, possibilities for self-direction, and the new support broker services.

Informants, however, pointed out that there is still much to do. The state lacks sufficient infrastructure, including technology for managing information, to make the supports waiver work as well as it might.

OKLAHOMA

Introduction

Oklahoma presently operates two In-Home Supports Waivers, one for adults and one for children. These two support waivers are currently being used by over 1,800 children and adults (who use 76 percent of the support waiver capacity) in Oklahoma.

Method

In August, September and October 2006, HSRI talked with people within and outside the Oklahoma system. These included: (a) state staff associated with the Developmental Disabilities Services Division, including the state director and others; and (b) representatives from interests outside the state agency including the state association of providers, the Developmental Disabilities Council, and the Center for Leadership and Learning at the University of Oklahoma.

Results

The results of the key informant conversations follow. First, information is presented to describe the policy goals of the waivers, information on any service wait-lists, and the fundamental operations of the waivers. Second, opinions offered by the consultation participants are offered related to: (a) access to the waiver; (b) waiver operations such as budget allocations, service planning, service delivery, and safeguards; (c) outcomes; and (d) key issues in play.

Oklahoma Policy Goals

Question: *What are the major policy goals of the supports waivers and how successful have the waivers been in meeting them?*

- Cost containment and related budget goals were a major policy goal of both In-Home Supports waivers in Oklahoma. Since 1999, both waivers have applied caps in spending per person to contain costs make waiver services available to more people than the comprehensive waiver could accomplish alone.
- Reducing the wait-list was also a major policy goal. At one time the wait for enrollment in the state's comprehensive services waiver had reached ten years, and the supports waiver presented significant opportunity to address this issue. The In-Home Supports Adult and Children Waivers help keep the number of people waiting and the length of time waiting much smaller than in the past. Presently, the current waiting for services is no longer than three years.

- Consumer-direction and person-centered planning goals are seen as less primary goals of the supports waiver. State officials note, however, that they will apply with CMS to change the supports waiver within the next 12 months during the renewal process with CMS to include self-direction opportunities to the waivers.
- Rebalancing the long-term care system and refinancing community services are not policy goals.

Wait-lists

Question: *How many people are on the consolidated (i.e., all wait-lists for developmental disabilities services) wait-list?*

- In recent years as much as 75 percent of new dollars for the In-Home Supports Waivers were used by existing service users for their plans.
- Wait-list figures are illustrated in the accompanying table:

2006	3,074
2005	3,853
2004	4,081
2003	3,494

Question: *How are wait-lists maintained?*

- Oklahoma maintains a statewide wait-list. Intake case managers maintain waiting lists and track the status of people who apply for waiver services but for whom slots are not available.
- The state observes a “woodwork effect” whereby when new funding dollars became available many new people who were not previously known seek waiver services. Referrals to other service systems to meet needs are often made.

Question: *How long generally is the wait?*

- Presently, the average time on the waiting or interest list before an individual is enrolled is more than two years but no one has been waiting for more than three years.

Basic Operations

Question: *How are people selected for enrollment?*

- People are selected for enrollment based on the order of requests for services, though emergency cases have priority. These emergency circumstances include people: (a) who no longer are able to care for themselves; or (b) individuals with caregivers who themselves are hospitalized, placed in nursing homes,

permanently incapacitated or have died. Some individuals periodically utilize Family Support Subsidy state funds.

Question: *Is there descriptive information available on the people served in the supports waiver (e.g., age, primary disability, living arrangement, functional status, caregivers)? Is systematic information available regarding waiver impacts?*

- There is descriptive information concerning the supports waivers participants. Additionally, an annual report and related brochures broadly describe profiles of participants.
- Oklahoma conducts satisfaction analysis annually of the support waivers.
- There is systematic information available about the impact of the supports waiver on participant costs with some limitations.
- The state has the capability to sort results by waiver but it is currently difficult. The state is making needed changes to improve its capacity to sort information by waiver.
- The CMS reviews and Quality Assurance surveys are the current formal evaluations of the supports waiver.

Question: *How are individual service plans developed?*

- State case managers meet with the person and their family or representative/legal guardian to complete need assessments; identify supports needed and include others as-needed to develop plan individual service plans.

Question: *How are individual allocations set?*

- The full annual cap of \$12,828 dollars a year for children and \$19,225 for adults is available to the recipient as long as they stay at or under the cap. These caps are increased based on service rate increases. Increases in the cap are possible if circumstances warrant and justification is provided and accepted.
- The individual does have knowledge of the allocation before planning.

Question: *What decision-making authority do individuals/families have over the budget?*

- Individuals with disabilities and their families plan within a capitated dollar limit and determine services and supports needed.

Question: *Who has **primary** responsibility for developing the service plan?*

- State case managers.
- Among the service planners the average caseload is 29 individuals per service planner in a year.
- The case load range the average service planner during this period is from 14 to 55 individuals per planner.
- In Oklahoma people do not have paid outside assistance available to them during the planning process to help design the service plan?

Question: *Does the service planning include a distinct risk assessment process to identify and address identified risk?*

- Negotiated risk agreements are not used.

Question: *Is the process the same or different from that used in the comprehensive waiver?*

- The comprehensive waiver uses a more detailed Individual Planning process. In the supports waiver, family members are often relied on to lead the process and address various risk factors. As a result, the planning is generally not as detailed or intrusive as that required when traditional community services are used.

Question: *What happens to individuals when they need more support than the waiver can offer, either by way of particular services and/or overall cost?*

- Case managers identify other alternatives when available. If none are available or identified, exceptions to increasing the cap can be approved and entry to the comprehensive waiver can be offered when slots are available. So far Oklahoma has been able to accommodate individuals as-needed in its comprehensive waiver.

Question: *What parameters govern transition from the supports waiver to the comprehensive waiver?*

- People may move to the comprehensive waiver when their critical support needs no longer can be met with the supports waiver, non-waiver services, or other resources as determined by the Developmental Disability Services Division (DDSD) Director or designee and funding is available.

Question: *What if the individual wants to change their service plan, or wants to change providers?*

- The individual notifies his or her case manager that they wish to change, select a new provider, and set date for new provider to begin providing services. The case manager works through the required notifications and new authorizations.

Question: *How is quality assurance and quality management managed?*

- The Quality Assurance/Quality Management System for the supports waiver is the same as the comprehensive waiver.
- The principle features of the waiver's quality assurance and quality management system include: (a) case management; (b) various surveys and reviews (i.e., consumer satisfaction surveys, provider performance surveys, critical incident reviews, medication event review, retrospective audit reviews); and (c) uses of oversight committees (i.e., statewide behavioral review committee, human rights committee, quality management committee).
- The state's Office of Client Advocacy (OCA) approves community provider grievance policies and procedures.

Question: *How are complaints resolved?*

- Individuals may file complaints by pursuing:
 - A Fair Hearing process to appeal a decision made by the Department. Complainants (and/or their representatives and witnesses) and Department representatives present their case. A Hearing Officer issues a written decision that can be appealed to the Director of Human Services, the Director's written decision can be appealed in District Court.
 - A grievance process through the OCA whereby local offices and providers retain "grievance coordinators" who assist recipients with the process. Complainants (and/or their representatives and witnesses) identifies their grievance and a proposed resolution. A local official responds to the grievance, this response can be appealed to the governing body, if not resolved there, the grievance moves to an independent administrative committee.
 - An administrative inquiry that can be initiated by calling, writing, or emailing the state Quality Assurance office with a complaint related to provider performance. After receiving a complaint, this office completes an investigation and issues findings which may include provider citations.

Question: *What is the process that is used to monitor the health and well-being of individuals participating in the supports waiver?*

- The process includes a mix of preventative activities (i.e., provider training, provider background and abuse registry checks, pre-employment screenings),

on-going monitoring (i.e., case management, provider monitoring, critical incident reporting), and look-behind review through consumer satisfaction surveys.

- Systematic monitoring of individual well-being is performed a minimum of every six months.
- When issues are uncovered, case managers are charged with following up and seeking resolution.
- A key difference the supports and comprehensive waiver is that the comprehensive waiver requires monthly face-to-face visits by case managers. For those in residential services, it also includes completion of the Physical Status Review (PSR) by the case manager and monitoring by DDSD registered nurses in accordance with the Health Care Level identified on the PSR.

Opinions on Waiver Operations and Effects

Access to the Waiver

Explanation: *Access refers to how easily people can apply for and gain admission to the supports waiver.*

- Some indicated that applicants and families must work hard to find out about services and that the new website is still difficult to navigate.
- Informants noted that the supports waiver is only “somewhat” publicized. Families learn about this supports waiver through brochures and word of mouth. In addition, applicants can learn about and apply for the program by contacting area office intake staff via telephone, mail, or through the Internet. Referrals may also come from staff of other service agencies, including from the statewide referral services, Outcome and Assessment Information Set.
- Informants indicated that it is neither “easy” nor “hard” to apply, and that individual experiences vary.
- Informants noted the demand for this waiver among people is increasing somewhat.

Service Planning

Explanation: *Service planning refers to the process to develop individual support plans for waiver recipients.*

- Overall, the planning process encourages individual to somewhat lead the planning process and somewhat define their own service needs. Families in some cases just need to be better informed and some say the state errs on the conservative side, so that participants do not always see the flexibility they seek in the program. Others note that the system is evolving and that in ten years that participants and families will be leading the planning process more.
- Overall, the planning process “Very Much” encourages individuals to choose the agencies or support givers to offer the needed support.

- Recipients do exercise choice and control over service plans, but may not have funds for all of the choices they make.
- Service planners “Somewhat” know the individuals they are planning for because of turnover in staff and case load variations.
- There is no supports broker or personal agent to assist individuals to put together the plan and/or negotiate services for the individual.
- It is very easy is it for clients to change their service plans. Informants note that it is a common occurrence.
- The strengths of the approach to individual planning are its ability to allow people to choose services and leave the waiting list.

Service Delivery and Safeguards

Explanation: *Service delivery and safeguards refers to the services that individuals received and their operations, and the safeguards in place to assure health and well-being.*

- Once services are authorized, it is neither “Easy” nor “Hard” for individuals to get these services. It can vary by location, given geographic differences, but generally the system responds well. For instance, some note that it can be difficult to get professional therapies in some communities.
- The services available through these waivers are generally broad enough to meet participant needs.
- Some informants feel that the release of “service authorization numbers” can be managed more promptly to reduce the time between authorization and actual service delivery.
- Informants note that it is “Very Easy” for individuals to change service providers. This generally takes a few days, up to 30 days.
- Waiver recipients cannot generally hire and manage their own support workers. Workers are typically employed by an agency. Recipients, however, often identify and refer potential workers to an agency and subsequently manage them day to day.
- There is “Some” emphasis on promoting community integration versus services that are more traditional (sheltered work, enclaves, segregated activities...). Many recipients, however, use segregated services.
- There is a pilot for a small group of 17 IHSW service recipients whereby they utilize a fiscal agent. Except for this pilot group, there is not a fiscal intermediary or payroll service available to help the individual control or manage the amount allocated for his or her services.
- To assure the health and well-being of participants, the safeguards in place are generally thought to be working well. Family members help assure the health and welfare of the waiver recipients.
- Where “in-home” supports are offered to adults living home with family, services are seen by the state as most often person directed. Others feel, however, that it depends on the individual and family and that it is instead often “family directed.”

Satisfaction with Outcomes

- Generally, many people report being satisfied with services and report being very happy.
- These waivers make services available that effectively support individuals to.
 - Generally seek/acquire/hold integrated employment.
 - Generally live with family, on their own or with friends.
 - Generally participate in community events.
- It is thought that recipients are basically safe and there is a good fit of supports.

Key Issues in Play

Question: *What are the waiver's greatest strengths?*

- To serve a large number of services recipients at a predictable cost.
- State leadership has been sustained and many believe that the state staff members are effective advocates. These circumstances have been an on-going strength of the system for the ten years.
- People have hope of getting off the waiting list and receiving services.

Question: *What are the barriers to achieving the waiver's goals?*

- Workforce issues. Only one company was found who was willing to offer worker's compensation to direct support workers involved with the supports waiver.
- Increased self-determination. Oklahomans believes in the power of local personal relationships, so many note that the supports waiver, which depends on such relationships, is a good fit for the state.
- People are being taken off the waiting list but the list continues.

Question: *Are there topics where there is disagreement or concern?*

- Some suggest that to save dollars support waiver recipients are being encouraged to room with other waiver recipients. Others argue that such practice is not state policy.
- One significant issue pertains to the amount of money service providers make and what amount they may retain as "profit."
- Another issue pertains to the use of paid family members. To the extent they are paid, the pattern may limit other service choices the recipient would have had otherwise.

Question: *What are the TOP THREE things that could be done to improve the waiver?*

- Add a self-directed service option.
- Add funds to adjust allow greater flexibility within current service plans and to eliminate the waiting list.
- Some feel that the waiver is inadequate to provide even the most basic services and is sorely under funded. In short, they feel that it amounts to a “band aid on a very large wound” and argue that more resources are needed to add new recipients and expand the service array.
- Some feel that being tied to Medicaid providers and products that can be purchased through Medicaid adds to costs. They noted that sometimes particular products can be purchase elsewhere (i.e., “off the shelf”) from discount stores, for instance, at a lower price. They argue that such skill and independence should be promoted. For example, a young man in a rural part of the state should be allowed to use the affordable local gym and exercise plan and not be forced to take the limited services of a physical therapist who must travel hundreds of miles to serve him.

Question: *What other points should be raised?*

- Many participants want increased self-direction within the waiver. While a relatively new concept, Oklahoma has some experience with the concept through its family support system.
- There is a need for an effective advocacy group in Oklahoma. Such groups tend to form on an issue and then disappear. The Tulsa Arc has been long standing but some offered that there is really no enduring and effective statewide advocacy organization.
- Transit options are available in two larger cities, but a significant issue elsewhere.
- Adults who are out in the community have “come off the radar” and are difficult to anticipate and count.
- The state has every kind of employment setting and some feel that vocational rehabilitation is not an active enough player in promoting systems change and community employment.

Overall Impressions

Although the supports waiver is early in its development (with a successful CMS recent renewal), all agree that it generally has had a positive impact. The waiver has proven to be financially predictable and as an effective tool for addressing the wait-list. There is some disagreement, however, over the need for dollars to fund existing plans versus the need for dollars to reduce the wait-list further.

The health and welfare of recipients has not been a problem due to strong family ties and family supports, and other mechanisms that the state has put into place. Most

people agree though that more can be done to promote self-direction. In response, the State plans on adding “self-direction” options in July 2007.

One major expansion for 2008 or later from the principle target group (i.e., people with mental retardation) involves the addition of people with autism. The planned expansion would include family mentoring and behavior analysis, use of TEACH techniques, and other methods.

OREGON

Introduction

Oregon's Supports Services for Adults Waiver (SSAW) was a direct outgrowth of the *Staley et al. v. Kitzhaber* lawsuit that was filed in January 2000. The *Staley* litigation was filed on behalf of over 5,000 people waiting for community services. The resulting settlement required that the state systematically address its waiting list. In doing so, the state proceeded in ways to promote self-direction, but also needed to work within a very difficult state budget climate. The SSAW was launched in July 2001.

Method

In August, September and October 2006, HSRI staff conducted face-to-face discussions with key informants on-site and follow-up conversations by telephone with additional informants. The individuals we spoke with included: (a) state staff associated with the Office of Developmental Disability Services Seniors and Persons with Disabilities (DDSPD), Oregon Department of Human Services including the state DDSPD director and others; and (b) representatives from interests outside the state agency including the Oregon Developmental Disabilities Council, the state provider association, experienced county program managers and managers of the support brokerages, and the Oregon Advocacy Center.

Results

The results of the discussions with key informants follow. First, information is presented to describe the policy goals of the waiver, information on any service wait-lists, and the fundamental operations of the waiver. Second, opinions offered by the consultation participants are related to: (a) access to the waiver; (b) waiver operations such as budget allocations, service planning, service delivery, and safeguards; (c) outcomes; and (d) key issues in play.

Oregon Policy Goals

Question: *What are the major policy goals of the supports waivers and how successful have the waivers been in meeting them?*

- Given the Staley court settlement, cost containment and budget goals were a major policy goal. This waiver survived the Oregon state budget crisis, though the settlement was modified. In particular, start-up actions were scheduled to end in 2007 but were put off to 2011 with a measured entry of 1,000 people per biennium.

- As part of the Staley litigation, the wait-list became a major focus of the supports waiver. Original goals, however, had to be modified due to the state budget crisis of the time, though the state is making steady progress on the wait-list.
- Consumer-direction and person-centered planning goals are cornerstones of the Oregon support waiver approach.
- Rebalancing the long-term care system and refinancing community services are not the primary policy goals associated with support services.
- The Staley settlement agreement in 2000 set the stage for the successful emergence of this supports waiver, and the success of the waiver appears to be ending the litigation.

Wait-lists

Question: *How many people are on the consolidated (i.e., all wait-lists for developmental disabilities services) wait-list?*

- The following table shows the number of people waiting for services from 2003-2006.

Adult Services Year	Comprehensive Waiver	Support Waiver	Total
2006	2,000	1,500	3,500
2005	2,000	1,500	3,500
2004	1,000	2,270	3,270
2003	1,300	1,000	2,300

Question: *How are wait-lists maintained?*

- The wait-list along with a great deal of other support waiver information is tracked by either the Community Developmental Disability Programs (CDDP), the support brokerages and state as part of the Staley settlement with careful periodic counts and Internet summary report postings. The wait-list has been monitored for years and is thought by most people that it will be eliminated as the roll-out of the settlement agreement is completed over the next several years.

Question: *How long generally is the wait?*

- Once the phase-in is completed in 2009, an eligible person requesting Support Services must be enrolled within 90 days. There will still be a wait-list for comprehensive services. Previously, there was a 20-year wait.

Basic Operations

Question: *How are people selected for enrollment?*

- Individuals apply for services through county offices.

- During the phase-in period of the waiver, Oregon uses a well-defined order of enrollment. First priority are those in “crisis”, with crisis defined as being at risk of civil commitment or at imminent risk of losing their homes. Next are a range of others including those with, aging caregivers, children transitioning from with existing support plans in programs such as family support, individuals “aging out” of educational system, and other wait-listed individuals. Enrollment is carefully analyzed to provide trend information as to the categories of individuals enrolling into support services. Waiting list rules are extensive and readily available.

Question: *Is there descriptive information available on the people served in the supports waiver (e.g., age, primary disability, living arrangement, functional status, caregivers)? Is systematic information available regarding waiver impacts?*

- Oregon conducts consumer satisfaction evaluations annually with all participants, includes questions regarding improvement in quality of life and identifies those improvements.
- The CMS reviews, consumer satisfaction surveys, and quality assurance surveys are the current formal evaluations of the supports waiver. The state relies on the involvement of parents and families.
- The state is also conducting reviews of the service brokerages in a manner that follows the CMS Quality Framework. Some brokerage directors, however, comment that some of the most innovative and imaginative support plans are not captured by the routine application of the framework.
- Oregon staff members indicate that they understand whether the waiver is effective especially in areas such as costs and reported satisfaction with services.

Question: *How are individual service plans developed?*

- County case management has a limited role. Counties perform eligibility reviews, approve the individual plan for Medicaid compliance, provide protective services, assist in crisis management, and bill under Medicaid administration.
- Oregon has established a network of independent “support service brokerages” throughout the state. Brokerages were selected by a competitive request for proposal process. Parents cannot be brokers to their own children.
- Support brokers called Personal Agents meet with individuals and their family or representative/legal guardian to develop a plan based on needs. The Personal Agent works with the individual to complete a customer goal survey. This survey guides the collection of information related to the individual’s available and needed supports as well as health and safety concerns in a variety of areas. Based on the customer goal survey a plan of support is developed.

Question: *How are individual allocations set?*

- Allocations per person are capped according to several benefit levels. The basic funding available to a Medicaid Waiver recipient is \$9,600 per year. If the individual's needs are significant, as measured by a standardized tool (Basic Supplement Criteria Inventory or BSCI), that amount may increase. A score of 60-80 on the BSCI allows access to \$14,400 per year while a score of 81 or greater allows access to funding up to \$19,999 annually for Medicaid waiver recipients. Non-Medicaid Waiver recipients receive a base benefit rate of \$3,840 or \$5,760 or \$8,000 per year depending on the needs as assessed using the BSCI.
- Individuals, along with Personal Agents and members of the individual's chosen circle of support identify supports needed and goals. They then develop an individual support plan (ISP) to address needs.
- Oregon has a 76 page handbook entitled *Rate Setting and Purchase of Self Directed Support Services from State Licensed or Certified Providers Organizations* that explains what can and cannot be purchased with support waiver funds. This guides the provider to reasonable and customary charges. This and the extensive, over 94 pages of rules that the state developed, have helped Oregon manage the Support Services for Adults.
- The State of Oregon has developed and made available a set of Expenditure Guidelines that explains to Personal Agents what can and cannot be purchased with support waiver funds. Additionally, a Rate Guidelines exists that sets reasonable and customary rates for services.
- Emergency crisis services are available and have in the current year been used more than anticipated.
- The individual has knowledge of the allocation BEFORE planning. The planning process is not geared towards spending the allocation, but rather identifies support needs first, then looks for ways to address those needs. Only when other options, particularly natural supports, cannot be found are support funds utilized.
- Individuals budget for an average of approximately \$800 a month but have actually expended an average \$630 a month. Consistently about 70-80 percent of the budgeted plan dollars are spent. For a number of years this has resulted in some dollars being returned to the state budget. Subsequently the state has changed its budgeting methodology to more closely align with the anticipated actual per person expenditure of plan costs.

Question: *What decision-making authority do individuals/families have over the budget?*

- Individuals can plan within the benefit level for which they are eligible and determine services and supports needed. Effort is made to change the commonly held perception that they "have a grant" and use the expenditure guidelines and training to assist individuals and families in making a problem solving ISP.

Question: *Who has **primary** responsibility for developing the service plan?*

- Personal agents have the primary responsibility for developing the service plan of care. This is a service as defined in the supports waiver. Currently there are 100 Personal Agents in Oregon employed by nine support brokerages.
- Personal Agents help set up the plan. CDDP case managers authorize the plan from a Medicaid perspective, but do not otherwise judge the ISP.
- Among the Personal Agents the average caseload is 40 individuals. It started at ten when the support waiver began and with current budget plans will end up at 45 individuals.
- The average case load range for a Personal Agent during this period is from 38-42 with a maximum average of 45 individuals per agent.

Question: *Does the service planning include a distinct risk assessment process to identify and address identified risk?*

- While there is not a formal risk assessment, the service planning includes elements of a distinct risk assessment process to identify and address identified risks.
- Negotiated risk agreements are not used.

Question: *What happens to individuals when they need more support than the waiver can offer, either by way of particular services and/or overall cost?*

- Brokers can look past “paid Medicaid” services and look out and connect people with other public or community resources.
- If the individual is in “crisis,” the brokerage and CDDP staff members work jointly to develop a plan.
- In Oregon people do not have paid outside assistance available to them during the planning process to help design the service plan.

Question: *What parameters govern transition from the supports waiver to the comprehensive waiver?*

- An individual may be disenrolled from the supports waiver if the individual: (a) is incarcerated for a defined period of time; (b) no longer has a disability; (c) is no longer financial eligible; (d) moves out of state; (e) no longer meets level of care; (f) is admitted to nursing facility or ICF/MR; (g) is no longer eligible for Medicaid; (h) refuses services; or (i) fails to cooperate with plan development. One emerging issue is recipients who engage in risky behavior or do not want to perform required planning activities. The technical bias of the support waiver is not to disenroll. However, not being eligible for the supports waiver does not exclude an individual from being eligible for supports services. The difference is the level of benefit the individual will be entitled to.
- Approximately 700 people have left the support service brokerages after initial enrollment. The following table suggests common reasons for termination

including the top two reasons moving to the comprehensive waiver or moving out of state. As shown, 38 percent of individuals who leave the supports waiver are moved to the comprehensive waiver if no other intervention is sufficient. The percentage of individuals refusing services has decreased significantly from the first year of the services to the current year. Individuals are now given more information prior to enrolling in services.

Termination Reasons	Percent
Refused services	22%
No longer eligible	4%
Moved from area	22%
Moved to Comprehensive Waiver	38%
Deceased	10%
Legal Rep withdrew	1%
Health/other issues	0%
Other/unknown	3%

Question: *What if the individual wants to change their service plan, or wants to change providers?*

- The individual must contact their Personal Agent. Individuals can terminate arrangements at will. It is very easy for individuals to change service providers. The time it takes to do this varies.

Question: *How is quality assurance and quality management managed?*

- Personal Agents work with individuals and families to develop a plan of support where non-traditional workers may be hired. In such instances, brokerages follow the Internal Revenue Service rules and process to become the “employer agent”. Direct service workers are generally determined to be domestic workers, but also may be bona fide independent contractors or supplied by a licensed agency individuals and families can acquire information on this matter by visiting the following website: <http://www.sdri-pdx.org/customers/index.html>.
- Fiscal intermediary or payroll services are available to help individuals control or manage the amount allocated for his or her services.
- State officials argue that quality assurance is not just for individuals, but that it is important to build in safeguards to maintain cohesion in thought and action among various system players, offer supports to the brokerages, maintain vigilant oversight to assure that policies are appropriate and decisions are acceptable. Staff members find that operational policies tend to be narrow and that increased flexibility is needed over time.
- State staff conducts field reviews and file reviews to oversee individual circumstances.
- The state uses the components of the CMS quality framework as a reference to assess its various waivers.
- The Quality Assurance and Quality Management System for the supports waiver differs from the comprehensive waiver. In part due to the settlement agreement

the SSAW routinely collects extensive information about recipient outcomes and group characteristics.

- The Staley Implementation Group has created a series of benchmarks to monitor services. Likewise, the state uses a series of personal indicators and support indicators covering 13 pages to see what is or is not working. The results have not been published yet as a statewide quality measure.

Question: *How are complaints resolved?*

- Individuals may file either an administrative complaint or a Medicaid Fair Hearing request.
 - A Fair Hearings request is processed according to the rules of the Department of Human Services. There has been one hearing to date.
 - An administrative complaint may also be filed locally with the relevant brokerage. Here, the grievant identifies their grievance and a proposed resolution. The matter is managed locally through a stated protocol within the brokerages. If not resolved at the brokerage level, the complaint may be forwarded to the CDDP level, and eventually the state level for resolution. Any corrections are carefully spelled out with detailed written specifications.

Question: *What is the process that is used to monitor the health and well-being of individuals participating in the supports waiver?*

- Personal Agents are active in pursuing health and welfare concerns and completing any necessary follow-up activities. Personal Agents may use a “well being assessment” to help understand the circumstances of the individual.
- Personal Agents contacts with individuals vary in frequency, based on the needs and desires of the individual. They review the support plan from a financial perspective quarterly to see if it is working however, these actions do not require a face to face contact.
- There is an adequate provider pool and over five years only three providers in Oregon have not continued support waiver services and two are not taking new support waiver recipients. However, concerns are being raised about the continuing adequacy of the provider pool, particularly as it relates to the current rate structure used within support services.
- Customer monitoring of quality can vary among brokerages and may involve personal agents’ use of periodic check-ins, satisfaction surveys or post cards, and use of “Quality Committees.” A Quality Committee is a group of recipients who meet to give feedback to the brokerage about how their supports are working and to suggest ways that their supports or the help they receive from their supports could be improved.
- A key difference between the supports waiver and comprehensive waiver is that the comprehensive waiver requires more intense monitoring by case managers.

Opinions on Waiver Operations and Effects

Access to the Waiver

Explanation: *Access refers to how easily people can apply for and gain admission to the supports waiver.*

- The potential enrollees and their families learn about the supports waiver with through the CDDP, printed matter, such as brochures, and related websites.
- In addition a 20 page publication, *A Roadmap To Support Services*, is available. This product, developed in cooperation by the Oregon Advocacy Center, the Oregon Council on Developmental Disabilities, and Oregon Department of Human Services, offers an understandable guide to the waiver. It is available in hard copy or by Internet http://www.ocdd.org/pdfs/Roadmap_2nd_edition.pdf.
- Respondents indicate that it is “Somewhat Easy” to apply and the demand for this waiver among people is increasing. People are referred to the support brokerage when they reach the top of the wait-list, based on their particular enrollment category.

Service Planning

Explanation: *Service planning refers to the process to develop individual support plans for waiver recipients.*

- Overall, respondents indicated that recipients “Very Much” lead the planning process and define their own service needs and, choose the agencies or support givers to offer the needed support
- Recipients do exercise a lot of choice and control over service plans, but may not have funds for all of the choices they make.
- Overall, respondents indicate that service planners generally “Know Well” the individuals they are planning for, though there are a few exceptions. Recipients may not always want to be known well. Assuring that planners know the people they are planning for is more of a challenge as case loads have grown.
- Overall, respondents indicate that the services available through this waiver are generally broad enough to meet participant needs.
- Respondents indicate that it is “Very Easy” for individuals to change their service plans. About 10 percent of costs change during the life of the ISP.

Service Delivery and Safeguards

Explanation: *Service delivery and safeguards refers to the services that individuals received and their operations, and the safeguards in place to assure health and well-being.*

- Once services are authorized, respondents indicate that it is “Somewhat Easy” for individuals to receive designated services.
- A protective service statute and mandatory reporting is part of the training for personal agents and it is working well.

Satisfaction with Outcomes

- Generally, respondents indicate that individuals do not seek, acquire or hold integrated employment but this is a currently a point of emphasis and promotion by the state.
- About 80 percent of support waiver recipients live with their families.
- Generally, respondents indicate that individuals do participate in community events.
- Respondents indicate that there is “Some” promotion in the waiver to promote community integration versus services that are more traditional (sheltered work, enclaves, segregated activities...) segregated services.
- Waiver recipients can generally hire and manage their own support workers. About half do.
- When “in-home” services are offered to adults living at home with family, the services are “Sometimes” family directed and “Sometimes” person-directed or both. This can be a point of friction.

Key Issues in Play

Question: *What are the waiver’s greatest strengths?*

- The waiver allows people to live at home with their families and to self-direct their services. Many supporters of the waiver characterize it as a “remarkable adventure.” Some feel that within Oregon the support waiver is will be seen in the future as an “entitlement.”
- Most agree that the self determination aspect of the support waiver is the “king of the world.”
- There is a feeling of shared success and ability to work through things with the state, support brokerages, advocacy community, and various stakeholder groups like the Staley Implementation Group. In general these parties speak well of each other and credit each other for the level of success Oregon has enjoyed. The support waiver roll-out survived the 2003 enrollment freeze.
- Most (71 percent) waiver recipients report they were “Happy” with the supports and services they receive. There is also an ease within families because someone else is involved in life event planning and in a supportive relationship with the recipient and family. Some report more frustration and dissatisfaction as they learn and become more informed overtime.
- The Oregon support waiver has numerous written products that are useful. For example, the 25 page *Handling Emergencies: A Guide to Personal Safety & Emergency Management* that came out in September 2006 is concise, understandable, and cogent. This is typical of 20 other written documents that have emerged within the Oregon support waiver.

Question: *What are the barriers to achieving the waiver’s goals?*

- Some see support waiver shortcomings as need for continued refinement in helping people throughout the state understand how they can better use the support waiver to make meaningful changes in their lives.
- There is a need to find “financial balance” between the comprehensive and supports waivers. The supports waiver has had the same fee structure since its beginning and it is not currently on the table for discussion. This threatens in several ways. For instance:
 - The \$37, five hour a day cap on day activities may limit future providers involvement. One provider, a college, has stopped enrolling waiver recipients and one community provider is talking with recipients to find ones that it is can afford to serve with that allotment.
 - The ability of the system to maintain a skilled and dedicated set of personal agents and other service workers without cost of living and other adjustments through the years may result in an unavoidable loss of quality services. Due to lack of funds, Personal Agents are forced to balance between health and welfare and self determination.

Overall, the state is struggling with the cost of growing numbers of crisis cases and the culmination of the roll-out of the Staley settlement with only the planned appropriations.

- Some say that the state has insufficient resources for overseeing the entire waiver system. They argue that the supports waiver has gotten a lot of focus, but challenges also exist regarding operations of the comprehensive waiver as well.
- Due to diminishing resources and the lack of cost-of-living adjustments over the past several years, the providers are struggling to maintain quality staff and facilities. Employee turnover runs at above 60 percent and providers complain about a lack of qualified applicants. Providers suggest that Oregon must significantly increase support of community providers or many will collapse. If the community system fails, in part or completely, the state will be forced to find alternatives that are either substantially more expensive, or poorer quality, or both. The Oregon Developmental Disabilities Coalition supports the DHS Policy Option Package that would increase funding to the system by \$63 million.
- Issues have been raised pertaining to direct support workers that individuals hire outside the traditional provider network. Issues pertaining to “employer liability” regarding these workers linger. These workers typically are not offered worker’s compensation or other benefits. Oregon has had litigation where the support brokerage was determined not to be the actual employer. One practical part of this challenge is in rural areas where over half of the support workers are family and 80 percent are direct service workers not employed by an agency.
- Oregon is unusual because direct support workers serving seniors and people with physical disabilities became unionized and acquired worker’s compensation and other benefits as a result. There is now a Home Care Commission, but the workers are not state employees, but as a result of a recent state initiative passed by the voters were allowed to unionized and bargain. This resulted in a large increase in worker’s compensation claims. Most feel that this employer liability is an Achilles’ heel of this type of waiver that could bankrupt support brokerages or result in successful litigation against the state.

- Some observe that operations involved with the supports waiver are much more involved, difficult, and risky than was commonly believed at the beginning. The need for a fiscal intermediary, for example, created a common understanding about certain forms of “risk” and the need to manage it.
- Most feel that the personal agent relationship is a pivotal piece of the support waiver and their skill, ability, reimbursement, and training will be critical to the continued success of the support waiver.

Question: *Are there topics where there is disagreement or concern?*

- One issue of tension involves the capacity of providers to request payment, even when circumstances result in a service not being delivered. This issue arises when an individual agrees to receive services but for whatever reason fails to show. The provider, as a result, may be left with expenses but having failed to deliver the service, cannot seek reimbursement. The state took a strong stand to refuse payment in circumstances like these. Providers objected, arguing that they could not bear the loss of such revenue. State officials, while pressing providers to factor in such occasional losses within their overall business plans are relying on intelligent and cooperative problem solving to resolve the issue. The system, however, is already stretched fiscally and the solution may simply require more money.
- Personal Agents wrestle with growing caseloads and extensive paperwork. One recent survey suggests that half of personal agent’s time is now engaged in necessary paperwork.
- The real challenge of changing service plans often rests with the need for CDDP reauthorization. Not all CDDP’s are county based; some are independent of the local county. Personal Agents are skillful at making needed changes without triggering a cumbersome reauthorization process.
- Reconciling the time sheets of direct support workers can pose a significant difficulty for fiscal intermediaries. Some report that the fiscal agent duties are costing them more than they are paid. Some report the duties are a helpful part of the overall support waiver economics.
- Individuals who are waiver recipients sometimes live “risky” lifestyles. Brokers are taught not to ignore these but assuring the health and well-being of such individuals is sometimes much more difficult.

Question: *What are the TOP THREE things that could be done to improve the waiver?*

- More funding is needed to improve training, raise service rates of pay, and provide additional needed services.
- Increase the flexibility in the services that can be purchased. The supports waiver sometimes lacks flexibility and injecting more flex would not always cost more. Some feel that state monies are necessary to pay for services that Medicaid cannot fund but would make a lot of sense in individual cases.
- More training for people and families to advocate for themselves.

- More structure, training, benefits for workers on supports waiver with more agency backup.
- Better training for personal agents about services in general and the many pieces they work with including services in general, food stamps, social security, mental health care, and alcohol and drug treatment.
- Some voices feel that the initial roll-out could have been more ambitious. More could have been done to identify millions of dollars were not used in support plans and returned to the state general funds. The state has not allowed any back fill for the vacancies that have developed. Others believe that the state has made “frugality” a cherished alter goal for the support waiver at the cost of forward movement.
- Many respondents felt that the Oregon state staff worked hard with others in the state to fashion a supports waiver that is well thought out and has many **superior features**. Respondents also indicated that they had learned much about its operations over the past few years and have made adjustments along the way. Participants expressed willingness to describe their system to others elsewhere and share their experiences.

Question: *What other points should be raised?*

- All informants argued that there is a great need to promote supported employment. The state launched a website promoting supported employment to illustrate successful employees (See http://www.dhs.state.or.us/dd/supp_emp/). Some note that Vocational Rehabilitation staff should move more quickly to identify when it can do no more, and allow the individual to move into the supports waiver instead of offering services at a “a glacial rate.”
- Oregon has diverse geographic areas. For example, one support brokerage covers 13 counties in Eastern Oregon and serves a geographic area greater than the rest of the brokerages combined. In rural parts of the state travel time can provide an economic challenge. Towns vary enormously on how much transportation is possible and available. Almost always recipients move to larger towns to get the supports and help they need, especially if they have mobility impairments.
- Some say that participants are not getting sufficient training, support and education so they can “play” a true self-directed role in their services.
- One dilemma for direct service staff members who are employed as “domestic workers” is that they are not paid for training time and can only be paid for direct face to face recipient services.
- One development worth noting is the emergence of “affiliated apartments” where parents may assist their son or daughter to move in with others who are receiving supports waiver services. Three of these apartments existed three years ago, and at least five more are in planning. These sites can be, unintended, almost facility like because of the high concentration of waiver recipients in one area.
- Overall there are nine brokerages. There are seven support waiver brokerages that are stand-alone and non profits. While most are strong, one has struggled

with providing progress reports in a timely way. Brokerage capacity can be expanded through a request for proposal process.

- Five years of policy work by the state continues to be revisited and sometimes old decisions are changed. Generally the state receives high marks for its forethought. Some decisions, usually revolving around funding limitations, are seen by some as being too directed.

Overall Impressions

The Oregon SSAW has increased in enrollment to ten times what it was when it began five years ago. It has served as an effective means for addressing the wait-list and to do so cost effectively. More than that, however, it has provided systematic means for the state to advance policy goals tied to self-direction.

The waiver was built on a commitment to self-direction and has steadily evolved to improve its associated policies, procedures, and operations. The state has identified and kept to seven core functions of self-direction, including: (a) assisting customers to determine their needs and plan supports; (b) assisting customers to find and arrange resources and supports; (c) providing education and technical assistance for customers; (d) providing fiscal intermediary services; (e) providing customer employment administrative support; (f) facilitating community building; and (g) assuring customer monitoring of quality.

With time, systems have been put into place to translate these functions into actual policy and practice. All agree, however, that in the doing that new, often unexpected, difficulties have emerged that press the system to redefine itself continually and reshape itself. State leaders and others often must challenge themselves to revisit and change standing policies. Other difficulties remain in play and defy easy solution. Issues pertaining to the workforce, for instance are not easily resolved. Likewise, assuring quality within a system that promotes diversification and self-direction is a challenging task.

Still, the Support Services for Adults Waiver has proven itself with most stakeholders and leaders in Oregon. It faces all of the challenges faced by the other support waivers around the nation and is threatened most by the future availability of necessary funding.

PENNSYLVANIA

Introduction

The Pennsylvania Person and Family Direct Support (PFDS) Waiver was launched in July 1999 to provide services that enable people with I&DD to continue living in their own homes or with their families. This waiver was developed in great part as a response to the state's waiting list. By the end of the current state FY, overall, the children and adults on the PFDS Waiver total of 7,930 are expected to be enrolled in the PFDS Waiver and another 15,340 in the comprehensive Consolidated Waiver.

Method

In August and September 2006, HSRI talked with key Pennsylvania informants to obtain more in-depth information concerning the PFDS Waiver. Informants included: (a) state staff in the Office of Mental Retardation (OMR), including the Deputy Secretary for Mental Retardation and others; and (b) representatives from interests outside the state agency including the Developmental Disability Planning Council, Temple University, the Training Partnership that works extensively with individuals receiving waiver services and their families in a statewide coalition, and Pennsylvania Protection and Advocacy.

Results

The results of the key informant conversations follow. First, information is presented to describe the policy goals of the waiver, information on any service wait-lists, and the fundamental operations of the waiver. Second, informant view are summarized concerning: (a) access to the waiver; (b) waiver operations such as budget allocations, service planning, service delivery, and safeguards; (c) outcomes; and (d) key issues in play.

Pennsylvania Policy Goals

Question: *What are the major policy goals of the supports waivers and how successful have the waivers been in meeting them?*

- While important, cost containment and budget goals are currently not the most emphasized goals. Since 1999, individual allocations within the PFDS Waiver have been capped, allowing the state to work towards its budget goals. Note that the cap was raised from \$22,083 for FY 2005/2006 to \$22,525 for FY 2006/2007.
- In 2006 the statewide mental retardation waiting list reached 24,927 people. People observe that use of a cap within the PFDS Waiver has helped the state to

serve more people than could have been served with only the Consolidated Waiver.

- State officials would like to accommodate all “emergency cases” identified within the wait-list but realize that such action will require additional funds. There is widespread agreement that the waiting list remains a major concern.
- State officials are striving to promote “consumer-direction” through both waivers. The intent is to work out various operational issues pertaining to self-direction involving how to set individual budgets, service planning, budget authority, and quality assurance.
- Rebalancing the long-term care system and refinancing community services are not primary policy goals. Overall 80 percent of services are financed through the waiver with the remainder paid for by county or state dollars.
- The state has two other goals which are both aimed at the use of more integrated settings. For example, state officials want to increase community employment, moving from sheltered work experiences to supported employment opportunities.

Wait-lists

Question: *How many people are on the consolidated (i.e., all wait-lists for developmental disabilities services) wait-list?*

- OMR uses the Prioritization of Urgency of Need for Services (PUNS) system to track wait-lists. In 2003, OMR began to collect PUNS information electronically; therefore the 2003 data may not accurately depict a full year of waiting list information. In addition, the PUNS form was revised in early 2006, which may have also affected the data. For these reasons, it is difficult to compare waiting list data across years. These limitations aside, this information tracking system allows the state to detect increased demand for its community waiver services over time.

Year	Emergency	Critical	Planning	Total
2006	3,274	9,999	11,654	24,927
2005	2,231	8,365	10,626	21,222
2004	1,920	7,463	10,181	19,564
2003	1,537	5,826	5,240	12,603

Question: *How are wait-lists maintained?*

- Local supports coordinators complete the PUNS with the individual and family and counties use the PUNS data for budgeting and planning. The state uses the PUNS system to maintain a comprehensive waiting list using its three categories of need.
 - The emergency category indicates a need within the next six months.

- The critical category indicates a need in more than six months, but less than two years.
- The planning category indicates a need in more than two but less than five years.

Question: *How long generally is the wait?*

- The average length of time for those in the *emergency* category alone is a year (369 days).
- The average time on the *planning* list before an individual is enrolled is 643 days. This includes people who seeking services at a future date, such as upon transition out of the special education system.
- People are selected for enrollment based on the categories of need, generally with emergency cases being chosen first.

Basic Operations

Note that OMR expects to apply to CMS to alter certain features of the PFDS Waiver within the next 12 months during the waiver renewal process. Currently Pennsylvania is moving away from program funding to fee-for-service payments. OMR is establishing new requirements on county administrative entities to increase waiver recipient control, choice, and to create more consistent waiver experiences for recipients across the state.

Question: *Is there descriptive information available on the people served in the supports waiver (e.g., age, primary disability, living arrangement, functional status, caregivers)? Is systematic information available regarding waiver impacts?*

- Individuals are generally described as younger and living on their own or at home with their families.
- More descriptive information is available in the state's Home and Community Services Information System to describe individual characteristics such as age, primary and secondary disability and living arrangement, though state officials plan to improve the available information.
- Systematic information about the impact of the supports waiver on participant costs is available with some limitations. Additionally, Pennsylvania conducts consumer satisfaction Interviews through an independent monitoring process. The process involves interviews with a sample of individual receiving services and their family and friends.
- The CMS reviews, quality assurance surveys, and the evaluation and monitoring of counties by the OMR provide formal evaluations of the PFDS Waiver.

Question: *How are individual service plans developed?*

- Local supports coordinators meet with the person and their family or representative/legal guardian to complete a needs assessment. Subsequently, an ISP is developed to address the identified needs.

Question: *How are individual allocations set?*

- Needs assessment is conducted every year as part of the planning process. Currently, there is not a consistent statewide needs assessment; however, OMR will begin implementing the Supports Intensity Scale as the standardized needs assessment tool starting in September 2007. The needs assessment results in the identification of support needs that are used by the planning team to develop an ISP. The ISP includes services and supports (including service units) to address the assessed needs. The individual budget is established after the planning process, based on the needed waiver services included in the plan.

Question: *What decision-making authority do individuals/families have over the budget?*

- OMR has instructed County Programs to provide participants with their individual budget upon request. Yet, informants note that some counties do not consistently follow this policy. State officials plan to develop and implement a more systematic protocol for setting individual budgets.

Question: *Who has **primary** responsibility for developing the service plan?*

- Local supports coordinators develop ISPs through a person-centered planning process.
- Among the supports coordinators, the average caseload is 50 individuals.
- The support coordinator caseloads presently range from 14 to 55 individuals.
- Participants may access personal support services to assist in developing the service plan.

Question: *Does the service planning include a distinct risk assessment process to identify and address identified risk?*

- ISPs are developed using a standardized format, which includes components related to risk, which are discussed during the planning process. However, the planning process does not include a distinct risk assessment protocol. Negotiated risk agreements are not used. OMR is in the early stages of developing a distinct risk assessment tool for use in planning.
- OMR utilizes additional mechanisms to identify and remediate risk. First, the statewide incident reporting system and policies generate standardized incident reports, which are reviewed by counties and OMR Regional Offices. The individual and systemic review of incident reports can result in the identification of

risk issues, as well as opportunities for improvement. In addition, OMR relies on inspections of licensed providers to reveal potential risk issues. Any identified issues are relayed to the provider, and are addressed through provider plans of correction. OMR reviews incident, licensing and other information as part of its Regional Risk Management teams, and reports findings to the appropriate provider and county.

- OMR expects providers and counties to conduct analysis of their risk management and review procedures. Generally, OMR believes that risk management is working well.

Question: *Is the process the same or different from that used in the comprehensive waiver?*

- The process is the same as that used in the Consolidated Waiver.

Question: *What happens to individuals when they need more support than the waiver can offer, either by way of particular services and/or overall cost?*

- Supports coordinators review other options that can be used, such as the community's natural supports or additional assistance using state dollars. State officials incorporate the potential for such cases within its budgeting process and transfer individuals into the Consolidated Waiver as necessary.

Question: *How might a person be disenrolled from the supports waiver?*

- An individual may be disenrolled from the PFDS Waiver when the individual: (a) requests such action; (b) is incarcerated; (c) no longer has a disability; (d) is no longer financial eligible; (e) moves out of state; (f) no longer meets level of care; (g) is admitted to nursing facility or ICF/MR; (h) is no longer eligible for Medicaid; (i) refuses services; or (j) fails to cooperate with waiver requirements.

Question: *What if the individual wants to change their service plan, or wants to change providers?*

- The individual notifies his or her supports coordinator when they need to change their plan or wish to change providers. The individual then selects a new provider and a date is established for the new provider to begin providing services. The supports coordinator works through the required notifications and new authorizations.

Question: *How is quality assurance and quality management managed?*

- The system used is the same as the Consolidated Waiver.
- Principle features include standardized monitoring forms used by support coordinators, independent monitoring teams, and on-going evaluation by OMR of local administrative entities that, with one exception, are counties.
- A strong feature of both waivers is the use of health care quality units and the use of certified investigators to investigate certain types of incidents at the state, county, and provider levels.
- The state participates in the National Core Indicators project that tracks approximately 100 consumer, family, systemic, cost, and health and safety outcomes -- outcomes that are important to understanding the overall health of public mental retardation agencies.
- The state will be stepping up oversight of ISPs and its oversight of administrative entities.
- One challenge for the implementation of standardized supports coordination monitoring is increasingly large caseloads that sometimes make the monitoring role difficult for the supports coordinators to fulfill.

Question: *How are complaints resolved?*

- Informal complaints can be made to OMR at its toll-free customer service number, or to the OMR Regional Offices. Informal complaints are also made directly to supports coordinators, supports coordination entities, counties, and providers.
- Many complaints come from people on the wait-list who want to acquire waiver services sooner.
- The formal complaint process (fair hearing and appeal) takes time and the state asks people to submit their request within ten days. Participants, however, have 30 days to appeal a decision. There are specified time lines and checks in the process that begin at the county level and move to the state level. It is felt by some that complaint handling has improved.
- OMR conducts a Service Review of certain waiver appeals for the purpose of evaluating county compliance with applicable policies and requirements. The Service Review results in state findings, which are distributed to the individual/family, the county, and the Department of Public Welfare's (DPW's) Bureau of Hearing and Appeals. Upon receipt of the Service Review findings, the individual/family can choose to continue on to fair hearing or withdraw their appeal.
- Some feel that the Fair Hearing process option is not always accessible for individuals and tends to be highly technical with hearing officers who are not versed in the rights and protections intended in the waivers. OMR is planning training for hearing officers in an effort to alleviate some of these issues.

Question: *What is the process that is used to monitor the health and well-being of individuals participating in the supports waiver?*

- The process includes mix of preventative activities (i.e., provider training, provider background and abuse registry checks, pre-employment screenings), on-going monitoring (i.e., supports coordination, local provider monitoring, and consumer satisfaction interviews).
- A key difference between the PFDS and Consolidated waivers is that the Consolidated Waiver requires more frequent face-to-face visiting.
- The Consolidated Waiver requires three face-to-face visits each quarter with one at the waiver participant's residence, one at the waiver participant's day service, and one at any place agreeable to the waiver participant.
- The PFDS Waiver requires face-to-face monitoring at least every six months with contact every three months for people living with a family member. The minimum frequency is increased for people living in their own homes, Personal Care Homes, or Domiciliary Care Homes to face-to-face monitoring at least every three months and contact at least once a month.
- Supports coordinators, and their supervisors, follow-up on issues to resolve them when monitoring reveals problems.

Opinions on Waiver Operations and Effects

Access to the Waiver

Explanation: *Access refers to how easily people can apply for and gain admission to the supports waiver.*

- Potential enrollees can learn about the PFDS Waiver in a wide variety of ways including: searching the blue pages in the phone book, local county assistance offices, informational fliers, and extensive statewide family training. Information is also presented by way of a 24 page guide to waiver services and through the DPW website. Local intake staff members also describe the services available and other sources, including educators in the school system, often make referrals.
- Informants note that the PFDS Waiver is "Somewhat" publicized and is well known within the system. Individuals apply for the program through contacting the local county assistance office, using the telephone, using the mail, or through the Internet.
- Informants note that it is "Somewhat Easy" to apply and that demand for this waiver among people is increasing "Somewhat."

Service Planning

Explanation: *Service planning refers to the process to develop individual support plans for waiver recipients.*

- Overall, respondents indicated that recipients “Very Much” lead the planning process, but “Somewhat” define their own service needs. OMR is firmly committed to the person-centered approach and uses a standardized format to develop the plan, which is entered into the state information system.
- Overall, respondents indicated that recipients “Somewhat” choose agencies or support givers to offer the needed support.
- Overall, respondents indicated that individuals exercise “Some” choice and control over support plans, but it depends a lot on the people involved. People can hire their own staff and act as “employer of record” (through Vendor Fiscal Intermediary Service Organizations (ISOs)) or hire an agency to manage this function (through Agency with Choice ISOs).
- Overall, respondents indicated that supports coordinators “Somewhat” know the individuals they are planning for because of high turnover and high caseloads. The state is increasingly professionalizing the role of supports coordinators and is in the process of developing a supports coordinator curriculum and increased credentialing.
- Individuals may access personal support services to assist them in putting together their plan and/or negotiating services.
- Informants indicate that the services available through these waivers are generally broad enough to meet participant needs.
- Overall, respondents indicated that it is neither “Easy” nor “Hard” for recipients to change their support plans because they can begin the process to change with a simple telephone call to their supports coordinator. However, the approval process can be cumbersome and it can take 30-60 days to make changes. There is currently an OMR-led work group that is currently working on improving this process.
- Statewide consistency regarding application of the PFDS Waiver has been an issue. Protocols pertaining to wait-list management, training, and plan formation have been or are being, standardized. Efforts are being made to increase the expectations of county performance and measure quality around the state in systematic ways.

Service Delivery and Safeguards

Explanation: *Service delivery and safeguards refers to the services that individuals received and their operations, and the safeguards in place to assure health and well-being.*

- Informants indicate that once services are authorized, it is “Very Easy” for individuals to receive services with only a few exceptions. Once the approval

process has been completed the only problem that emerges are the few times that agencies have been unable to hire or maintain staff.

- Informants indicate that services to promote community integration are emphasized over services that are more traditional (e.g., sheltered work, enclaves, segregated activities).
- Informants indicate that it is “Somewhat Easy” for individuals to change service providers and this generally takes weeks to months.
- Waiver recipients can hire and manage their own qualified support workers through vendor fiscal ISOs or with an agency with choice ISO serving as the “the employer of record.” Sometimes recipients choose an agency to hire and manage support workers. These options are being utilized a small percentage of the time but OMR expects the use of this option to grow.
- “In-home” supports utilized by adults living at home with family are most often family directed but sometimes are person-directed or both.
- Workforce issues related to liability have not been a concern to date.
- Informants generally indicate that the safeguards in place are working well. The active participation of families in the PFDS Waiver is helpful.

Satisfaction with Outcomes

- Generally, informants indicate that the PFDS Waiver encourages people to seek, acquire and hold integrated employment. There are two relevant services, job support and job finding, and OMR encourages people to utilize these services more. Across all of its mental retardation county services in January 2006 there were 2,366 people competitively employed, 2,768 employed through supported employment, and 7,565 in vocational programs. Others feel, however, that there is little opportunity for employment.
- OMR indicates that generally people live on their own or with friends. Some feel, however, that people do not live on their own or with friends often enough. There is shared agreement that people in the PFDS Waiver participate in community events.

Key Issues in Play

Question: *What are the waiver’s greatest strengths?*

- A major strength of the PFDS Waiver is its demonstrated ability to serve a large number of services recipients at a lower-cost.
- There is widespread agreement that the PFDS Waiver has been effective at addressing the wait-list.
- There is common agreement that the statewide training efforts are first rate with support from the highest levels. There are at least three highlights to this statewide training.
 - The “Partnership” is a coalition of five self-advocacy and family groups and Temple University’s Institute on Disabilities that has provided 250 training sessions in the last three years to over 5,000 people in each of the 67

counties throughout the state. This million dollar effort has led to a survey of topics that people have felt were needed and the formation of a series of two hour power points that are used by a train the trainer model to share with families and individuals across Pennsylvania. The curriculum currently includes eight topics for self advocates and seven topics for families and is also available to professionals.

- The College of Direct Support, available by Internet has attracted over 17,000 learners in the past four years. One new learning group that has appeared recently is comprised of direct support workers who provide PFDS Waiver services.
- The “OMR Academy for Administrative Entities” is managed by OMR and reaches County Programs/administrative entities to share information and standardize processes.
- There is agreement that the PFDS Waiver should increasingly emphasize integrated employment.
- The incident reporting system and self-advocacy efforts are commonly viewed by many as strong and a positive parts of the service system.
- The increasing emphasis of the PFDS Waiver on individuals directing their own services is considered by many as a strength.

Question: *What are the barriers to achieving the waiver’s goals?*

- The absence of sufficient funding inhibits efforts to increase access to the PFDS Waiver.
- There is a lack of consistency with PFDS Waiver policy and its application across the state that needs to be overcome.
- Some note that there are some unreported cases of abuse of waiver recipients who are minors. The reliance within the PFDS Waiver on families may leave individuals vulnerable to such abuse.

Question: *Are there topics where there is disagreement or concern?*

- One issue is how much control families and individuals have and how much is retained by counties and providers.
- There is no adult protective service system currently in the Commonwealth of Pennsylvania for people age 18-59. There is proposed legislation to add this protection and all agree that it creates undesirable risks for many individuals in the state as well as, unfortunately, some PFDS Waiver participants.
- One challenge that is frequently mentioned is keeping the PFDS Waiver “theory real in practice” across the state.
- Some feel that, to this day, the counties control the supports coordinators who in turn control the support planning and this leaves the waiver recipient faced with a county that essentially needs to balance its budget.

Question: *What are the TOP THREE things that could be done to improve the waiver?*

- OMR should move decisively to assure consistency in the application of waiver policies throughout the state.
- Pennsylvania is also eager to clarify policies and its expectations pertaining to self-direction, including issues associated with setting individual budgets and potential tensions over whether services are actually individual or family directed.
- There is a statewide push to standardize quality management across the state. In revamping quality management, OMR is stressing communicating better with stakeholders while it designs the final structure and identifies priorities.

Question: *What other points should be raised?*

- In Pennsylvania there is a constant tension between the need to address a large standing waiting list and improving service delivery.
- There is a need to improve information management systems to keep pace with changes in service design and delivery.

Overall Impressions

All informants agreed that the PFDS Waiver has helped people gain access to supports and move off the waiting list. There is also widespread agreement that the statewide training efforts that support individuals and families involved in the supports waiver are top notch. Meanwhile, OMR is working to achieve more consistency in the application of its waiver policies across the state. Overall, the PFDS Waiver is one of the tools that Pennsylvania uses to address its waiting list and contain costs. Added to that it seeks to explore and establish consistent practices that, from the onset of enrollment on, promote self-direction and community integration.

TENNESSEE

Introduction

The Tennessee Self-Determination Waiver Program (SDWP) is designed for children and adults with I&DD and was launched in 2005. Its major aim is to address the wait-list, but gives priority according to urgency of need. First priority for enrollment is afforded persons in the “crisis,” then with an “urgent” need, and finally to those categorized as “active.” Potential enrollees must have a non-institutional place of residence where they live with their families, non-related caregiver or in their own home, and have needs that can be met effectively by the combination of waiver services and other available supports. Presently, the SDWP waiver serves 800 participants, while the state’s comprehensive waiver serves 6,000 individuals.

Method

In August and September 2006, HSRI talked with key informants in Tennessee to obtain more in-depth information concerning the SDWP. Informants included: (a) state staff with the Division of Mental Retardation Services (DMRS), including the state director, manager, and others; and (b) representatives from interests outside the state agency, including representatives of the state Protection and Advocacy Agency and families.

Results

The results of the key informant consultations follow. First, information is presented to describe the policy goals of the waiver, information on service wait-lists, and the fundamental waiver operations. Second, the views expressed by the informants are summarized with respect to: (a) access to the waiver; (b) waiver operations, service planning, service delivery and safeguards; (c) outcomes; and (d) key issues in play.

Tennessee Policy Goals

Question: *What are the major policy goals of the supports waivers and how successful have the waivers been in meeting them?*

- There is strong agreement that cost containment was a major policy goal in launching SDWP. CMS had identified several major shortcomings with the state’s comprehensive waiver (i.e., Statewide Mental Retardation Waiver Program). CMS limited new waiver enrollment to individuals in crisis until those problems were resolved. In January 2005, CMS approved a replacement

comprehensive waiver and the SDWP and subsequently approved the resumption of waiver enrollments in March 2005. Since then, the SDWP has offered means for children and adults to receive waiver services in a more cost efficient way than through use of the comprehensive waiver alone.

- The SDWP waiver is viewed by all as cost effective and people generally report being satisfied with their waiver services.
- Tennessee also views the SDWP as a useful means for addressing its waiting list. Presently, 4,761 people are waiting services and state officials expect the demand for services to continue to scale up.
- While the SDWP waiver provides for consumer-direction, there has been limited implementation thus far.
- Rebalancing the long-term care system and refinancing community services were not major policy goals in launching SDWP.
- The SDWP was a direct outgrowth of the 2004 *Brown vs. Tennessee Department of Finance and Administration* waiting list lawsuit settlement agreement. The settlement provided for Tennessee to create a new waiver that specifically targeted children and adults with I&DD who were wait-listed for services and could be supported in the family home or other non-licensed living arrangements. SDWP waiver enrollment is expected to reach 1,500 persons in its third year.

Wait-lists

Question: *How many people are on the consolidated (i.e., all wait-lists for developmental disabilities services) wait-list?*

- The accompanying table shows the number of children and adults on the consolidated wait-list. Overall, about 1,000 individuals on the waiting list are inactive. The remainder includes 818 applicants in the “crisis” category and 422 who have “urgent” needs.

2006	4,761
2005	4,046
2004	3,660
2003	3,663

- The waiting list has grown by 1,300 people since the settlement but 1,900 people have been enrolled in the state waiver programs. People First of Tennessee has made the waiting list reduction its primary goal.
- Many, 43 percent now and 46 percent six years ago, of new waiver recipients come from school referrals. However, there are potentially 2,000 new children each year that are possible support waiver referrals and their presence is understated on the current waiting list.

Question: *How are wait-lists maintained?*

- State case managers maintain waiting lists and track the status of people who are seeking enrollment but for whom slots are not available by using a priority system that accommodates emergency cases first. There is a process enrollment committee that selects the absolutely most critical cases from the state's regions.

Question: *How long generally is the wait?*

- People in the "crisis category" can wait over one year and the wait for some can last up to 13 years.
- In the last several months there have been 10-15 people enrolled into the waiver a month, but given the resources available and the expected demand, the waiting list may reach 12,000-15,000.

Basic Operations

Question: *How are people selected for enrollment?*

- Applicants are selected by the eight person process enrollment committee.

Question: *Is there descriptive information available on the people served in the supports waiver (e.g., age, primary disability, living arrangement, functional status, caregivers)? Is systematic information available regarding waiver impacts?*

- The state does not have a systemized electronic data retrieval system for this purpose. The annual report and brochures broadly defines profiles of those served in the supports waiver. Some descriptive information to profile SDWP participants is available, however, resulting from various quality management activities. Such information is compiled on spread sheets, but is not easily available.
- Some information on the impact of the supports waiver on participant costs is available with limitations. The state has the capability to sort information by waiver, but these processes are new. The state is making needed changes to build better databases but there is still more work to be done. Informally, there are growing numbers of success stories from support waiver recipients.
- The CMS reviews and state administered quality assurance surveys are the current formal evaluations of the supports waiver.

Question: *How are individual service plans developed?*

- State case managers meet with individual recipients and their family or representative/legal guardian to complete individual service plans.

Question: *How are individual allocations set?*

- The full cap of \$30,000 for service components is available to the recipient as long as they stay at or under the cap. Increases in the cap are possible if circumstances warrant and justification is provided and accepted. The total budget for all waiver services, including emergency assistance services, may not exceed \$36,000 per year per participant.
- Individuals have knowledge of the allocation before planning.

Question: *What decision-making authority do individuals/families have over the budget?*

- They can plan within the funding limit and determine services and supports needed. The general allocation process has category limits but these can be worked around when necessary.
- There is a fiscal intermediary or payroll service available to help the individual control or manage the amount allocated for his or her services.

Question: *Who has **primary** responsibility for developing the service plan?*

- State case managers have primary responsibility for developing the service plan.
- Among service planners the average annual caseload is 50 individuals per planner.
- The case load range for service planners is from 35 to 50 individuals per planner.
- In Tennessee people usually do not have paid outside assistance available to them during the service planning process. Support brokers are available later to help recipients with the waiver processes and managing direct support staff.

Question: *Does the service planning include a distinct risk assessment process to identify and address identified risk?*

- The service planning includes a distinct risk assessment process to identify and address identified risks. Negotiated risk agreements are not used.

Question: *Is the process the same or different from that used in the comprehensive waiver?*

- The planning process parallels the process used in the comprehensive waiver.

Question: *What happens to individuals when they need more support than the waiver can offer, either by way of particular services and/or overall cost?*

- Other alternatives are identified by the case manager when available to meet their needs. If none are available or identified, exceptions to increasing the cap can be approved up to a point. Transfer to the comprehensive waiver is possible when slots are available. If slots were not available, the individuals would be placed on the waiting list.

Question: *What parameters govern transition from the supports waiver to the comprehensive waiver?*

- Only in the most extreme cases of need are individuals able to move from the supports waiver to the comprehensive waiver. So far, all such individuals have been accommodated.
- An individual may be dis-enrolled from the supports waiver if the health and safety of the individual or others cannot be assured or if the individual: (a) no longer manages his or her own service (support waiver); (b) is incarcerated; (c) no longer has a disability; (d) is no longer financial eligible; (e) moves out of state; (f) no longer meets level of care; (g) is admitted to nursing facility or ICF/MR; (h) is no longer eligible for Medicaid; (i) refuses services; or (j) fails to cooperate. Two individuals have been disenrolled in the past two years.

Question: *What if the individual wants to change their service plan, or wants to change providers?*

- The individual must contact his or her case manager and declare their want to change providers.

Question: *How is quality assurance and quality management managed?*

- The principle features of the waiver's Quality Assurance and Quality Management System includes: (a) use of a dedicated Quality Management Committee; (b) oversight by case managers; (c) consumer satisfaction surveys; and (d) use annually, and even monthly, of an extensive, standardized quality assurance tool.
- This system is the same as is used for the comprehensive waiver.
- Where problems are discovered, the state may fine providers or apply other sanctions, provide technical assistance or training.

Question: *How are complaints resolved?*

- There are units within the regional or central offices to manage complaints. To file a complaint, individuals make a formal complain through one of these offices. Staff pursue investigations, act to reach resolution and offer mediation though there have been very few mediations over time. Last year there were 52 complaints statewide.
- Individuals may seek a fair hearing through this complaint procedure or they may file a local grievance.
 - In Fair Hearings, a hearing is held before a Hearing Officer where the complainant requesting the appeal (and/or their representatives and witnesses) presents their case with the state presenting theirs as well. The Hearing Officer issues a written decision that can be appealed to the Director. The Director's written decision can be appealed in District Court.

- In the grievance procedure, the grievant identifies their grievance and a proposed resolution. A local official responds to the grievance. This response can be appealed to a local governing body. If not resolved there, the grievance moves to an independent administrative committee. If not resolved at this level, the grievance may remain unresolved. In administrative inquiries, quality assurance completes an investigation and issues findings which may include provider citations.

Question: *What is the process that is used to monitor the health and well-being of individuals participating in the supports waiver?*

- The process includes case management, provider training, consumer satisfaction surveys, provider monitoring, provider background and abuse registry checks, pre-employment screenings, and critical incident reporting. The standardized monitoring tool that Tennessee uses to sort categories of need for the waiting list also has a subset for monitoring health and well-being.
- In-person monitoring is performed a minimum of every six months.
- The differences between the approach to SDWP monitoring and comprehensive waiver monitoring is that the comprehensive waiver requires more frequent face to face visits by case managers. Quality management personnel accumulate individual studies for future action and looks over time for problem people and patterns.
- Case management is responsible for resolving problems identified through monitoring.
- The state expects to change the supports waiver within the next 12 month by increasing internal monitoring of state case management and increased technical assistance to support brokers. There is a request for proposal to establish a permanent fiscal intermediary combined with support brokerage.

Opinions on Waiver Operations and Effects

Access to the Waiver

Explanation: *Access refers to how easily people can apply for and gain admission to the supports waiver.*

- The potential enrollees and their families learn about this waiver through generally through contact with printed matter such as a “family handbook” or brochures, and through the website. Special educators also frequently make referrals.
- Informants indicate that the supports waiver is “somewhat” publicized and individuals apply for the program through regional state case managers.
- It is very easy to apply and the demand for this waiver among people is growing.

Service Planning

Explanation: *Service planning refers to the process to develop individual support plans for waiver recipients.*

- Overall, state staff indicate that individuals “Very Much” lead the planning process, define their own service needs, and choose the agencies or support givers to offer the needed support.
- In contrast, advocates believe that individuals are not in the driver’s seat during the service plan development process.
- Overall, respondents indicate that recipients can exercise choice and control over service plans and make decisions about trade offs. Financial administration has been good.
- Overall, respondents indicate that service planners know the person they are planning for “Well” or “Somewhat.” However, there is turnover in staff and case load variations. It is a mixed bag. After the lawsuit, the state progressed rapidly to institute the SDWP and case managers were put into place and trained on-the-job. This led to quality problems related to case management
- The services available through this waiver are generally broad enough to meet participant needs. There are few requests for upward migration to the comprehensive waiver.
- It is “Very Easy” for individuals to change their service plans.
- The strengths of the individual planning approach are its ability to allow people to choose services, hire staff, and decide on trade offs.
- Some see shortcomings as a lack of training and preparation for the support waiver case managers.

Service Delivery and Safeguards

Explanation: *Service delivery and safeguards refers to the services that individuals received and their operations, and the safeguards in place to assure health and well-being.*

- Once services are authorized, it is very easy for individuals to get the supports they need.

Satisfaction with Outcomes

Employment outcomes:

- Generally people do not seek/acquire/hold integrated employment though it is a support waiver option that is being encouraged. A broad coalition of support for *Employment First!* has led to an on-going commitment across the state to expand integrated employment. As a component of the *Employment First!* initiative, benchmark goals were developed to track state progress in increasing integrated employment placements. Providers are asked to report specific data on the

number of people in integrated employment, number of hours worked, wages earned per hour, and job title.

- The *Employment First!* Initiative boosted the number of individuals with I&DD employed in competitive jobs by nearly 40 percent in its three years of implementation. In 2002, when the Tennessee DMRS first launched the *Employment First!* Initiative, there were about 1,100 individuals employed in competitive jobs. That number grew to 1,542 by the end of December 2005.

Other outcomes:

- Generally, informants indicate that people can live on their own or with friends. However, families are very protective.
- Generally, informants indicate that people in the supports waiver participate in community events.
- There is some promotion in the waiver to promote community integration versus services that are more traditional (e.g., sheltered work, enclaves, and other segregated activities). However, many recipients continue to use the segregated services. Overall integration happens the most often with the family in regular community activities.
- There are currently 120 waiver recipients who hire and manage their own support workers. While the workers are employed by an agency, they often identify and refer potential workers to the agency and manage them on a day to day basis. Support brokers can help and assist them in evaluating workers and in filing the necessary forms.
- Where “in-home” supports are offered to adults living home with family, the services are seen by the state as most often family directed. This is true in the comprehensive waiver as well.
- To date, there have been no participants who have experienced major health, abuse, or neglect issues.

Key Issues in Play

Question: *What are the waiver’s greatest strengths?*

- Its ability to serve a large number of services recipients “in-home” while being cost effective with rapid deployment of the supports. Most people see the SDWP as early in its development with greater potentials for expanding self-determination.
- Generally, most individuals and families report being satisfied and very happy with services. There is flexibility of selection and potentially creative plans with enough services and components. People can stay home and the waiver reduces parental burnout.
- The state hosts eight town meetings each year and is working on better connections with school districts to help transitioning students become accomplished waiver recipients with more planning and fewer surprises for all parties.

- People have hope of getting off the waiting list and receiving services. The caps make people careful about what they select and careful what they buy.
- It allows for more flexibility and control for people with disabilities and family members in service delivery.

Question: *What are the barriers to achieving the waiver's goals?*

- Tennessee has a large waiting list.
- Self-determination is often seen by many as an all or nothing proposition. This can cause people not to want to pursue it.
- Improvements are needed in case management and support brokering. The support waiver needed to begin quickly which meant the case managers did not have as much time to be trained and oriented to the new waiver. Case management case loads have grown too large. Their comprehensive waiver counterparts have been organized and operating for some time. More training, mentoring, and monitoring is needed by the support waiver case managers and support brokers. They need more information about the possibilities the supports waivers offer and what people can do. The support broker role is new and offers an opportunity for recipients and their families to have much more help in individualizing and customizing their own supports and plan.
- Services offered by licensed clinicians and therapists might be delivered more cost effectively by professionally guided direct service workers.
- People need more information about how to utilize other sources of supports. The series of lawsuits and newness of the support waiver have left many stakeholders afraid, uncertain and not trusting communications and regular state information.

Question: *Are there topics where there is disagreement or concern?*

- People on the waiting list remain unserved and so are accorded no safeguards or support.
- Tennessee direct support professionals and Tennesseans with disabilities earn low wages, often have limited career paths, and have trouble finding affordable (accessible, and safe) homes to buy.
- Community providers have difficulty maintaining a stable workforce. Low ages in the community are a problem.
- There are difficulties concerning differences in service provision requirements for various therapies provided under the waiver as opposed to the state Medicaid plan. State officials are working to make these differences more apparent to reduce unintended errors.
- There is a need to continue to train and monitor state case managers.
- It is presently very difficult to monitor costs; millions of dollars can be spent before it is realized. Better information management systems are needed.
- More should be done to increase information sharing about the supports waiver, the opportunities it brings for self-direction and emerging best practices.

Question: *What are the TOP THREE things that could be done to improve the waiver?*

- Add funds to eliminate the waiting list or increase the existing cap on the support waiver, for example to \$50,000, to enroll people that would otherwise be in the more expensive and uncapped comprehensive waiver.
- More should be done to promote additional legislative and political support for the SDWP.
- Overall, there is a crying need for sharing information to help people obtain the supports they need.

Question: *What other points should be raised?*

- The SDWP is relatively new, and innovation should be encouraged.
- About five million new dollars is needed to bolster the existing comprehensive waiver. This is difficult choice because of the waiting list but is probably unavoidable.

Overall Impressions

All informants agree that the SDWP is making important contributions to supporting people with I&DD in the community, although it is still early in its development. CMS has influenced much of the decision-making to this point because of the shortcomings that it found in the operation of the comprehensive waiver. Now, however, it is time for state officials to step back and determine how the supports waiver can be best applied and shaped to improve the overall system of services. Clearly, the SDWP is a strong tool for containing costs and addressing the wait-list. Yet, much underlying infrastructure must still be developed, such as developing improved information management systems, assuring the presence of well-trained case managers and an agile provider community, and working out operational procedures to promote self-direction. Still, most agree that the SDWP has had a good start.

GAUGING THE USE OF HCBS SUPPORT WAIVERS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: FINAL PROJECT REPORT

Files Available for This Report

Main Report

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.pdf>

Appendix A. State-by-State Supports Waiver Profiles

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.pdf>

Appendix B. State-by-State Case Study Results

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendB.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendB.pdf>

Appendix C. Case Study Discussion Guides*

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendC.pdf>

* This Appendix is currently not available as an HTML file.