Understanding Self-Direction for People with Developmental Disabilities: A Choice for Change in Illinois

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The ***Campaign for Real Choice in Illinois*** is a grassroots, citizen action organization consisting of people with disabilities, family members, friends and professionals organizing for freedom and choice. We are founded on the premise of participatory democracy and the belief that meaningful reforms in the system of supports for people with disabilities will come only with active involvement of people with disabilities and their families.

Introduction

Throughout history, people with developmental disabilities have not had control—that is, substantial decision-making authority—over the services and supports that enable them to live a free and independent life. Instead, professionals and service providers have primarily managed such services, with individuals being relegated to the role of "cases" and passive recipients. People with developmental disabilities have not traditionally held the authority to decide what services and supports they receive in their daily life, who provides it, and how to spend the money that has been allocated for it. In recent years, several states have offered people with developmental disabilities an alternative to the "traditional" provider controlled model, which allows the individual to have more control over their services and supports. This alternative is called self-determination, or *self-direction*.

Self-direction is about choosing to be engaged in your life. People who have not before had the opportunity to make choices can select services and supports to help them connect to their community and enjoy greater quality of life.

For over twenty years, the federal Medicaid program has allowed state governments to waive certain rules. These waivers support individuals with developmental disabilities to live in the community rather than in institutions. All states now operate Medicaid waiver programs, such as the Home and Community Based Services 1915(c) waiver. But most of these programs do not allow people with developmental disabilities or their families or representatives to choose *how* government money is spent on their services. Choices about what services people receive and who provides their services are not made by the people these decisions affect.

Luckily, there is another option. Waivers in many states offer a self-directed option as well. Self-direction is based on the idea that the people being served are in the best position to know what they want and need in order to connect to other people and resources in their community. The self-directed waiver option utilizes features like

individualized budgets and service coordinators, which are perfectly suited for helping individuals plan and participate in the activities that will help them live a life of their own making. Self-direction puts the individual at the *beginning, middle AND end* of the service delivery process, so that they are both the authors and the finishers of a plan for their future.

Where is Self-Direction Already at Work?

A number of states are already using self-direction in various forms and with varying degrees of success. This paper will examine self-directed waiver programs in six states – Georgia, Oregon, Louisiana, Michigan, New Mexico, and Wisconsin – and offer recommendations for how a self-directed waiver program can be modeled in Illinois based on findings from these states. We compared each state based on these categories: 1) population; 2) background and development of the Home and Community-Based Services (HCBS) self-directed waiver; 3) eligibility; 4) the individualized budget including assessment tools; 5) services and supports that can be self-directed; and 6) service coordination.

Key Elements and Trends of Self-Direction

Writings and interviews with experts and people with developmental disabilities have revealed four key elements that make self-direction work. These four elements focus on the individual being served, but they are always backed by stable, capable, qualified support personnel filling various roles. The first element establishes individual control over preauthorized budgets that can be used flexibly to accommodate the needs specified by the participant, within budget limits. Individuals may act alone or in association with their family members or other concerned people, but decisions about what is important or needed should be left to the individual. The second is a personal advocate or service coordinator who helps participants develop and monitor their Individual Service Plan and ensures they have access to the supports and services they need. The service coordinator

also supports the participant in developing their individual budget and can request additional funding if directed by the participant.

The third element is a financial agent or fiscal intermediary who helps participants manage their money and meet administrative and legal obligations, such as approving purchases of goods and services, filling out tax forms for care personnel, processing employee payroll, and submitting monthly budget reports to the participant. The fourth element is a choice of services, where the individual can choose from current providers and/or general services that are offered in the most integrated setting. Providers and others act as authorized merchants, where participants may "shop". Participant-driven arrangements will spawn a market economy in which those providers representing the most value and quality will survive. People with developmental disabilities in Illinois have specifically stated they want service choices to include community employment with at least a minimum wage or above, individual directed goods and services, transportation, and personal support.

These four basic elements of self-direction can be found in nearly every one of the six states that we investigated, although some have developed them better than others. Some of the states are farther along in the implementation and refinement of their self-directed waiver and support services, while others are still in the early stages of development and working out the kinks. No one state is a perfect model of self-directed supports and services, however we should learn from the successes and mistakes of each state program as we move toward self-direction in Illinois.

For a complete breakdown of each state's self-directed waiver and program, please refer to Appendices A thru F.

Recommendations for Illinois

The Illinois Division of Developmental Disabilities 2010 Strategic Plan lays the foundation for self-directed services to be established in Illinois in the next seven years.

While the plan focuses more on shifting services to a person-centered philosophy, the option for self-directed services is prevalent throughout the Division's strategic priorities and goals to be achieved by 2017.

A shift to person-centered services in Illinois would indeed be an improvement over the current system of care and its over-dependence on institutional and bureaucratically controlled service delivery that essentially ignores the strengths, desires, hopes, and goals of the individual. However, even in a person-centered system of care, the individual is not guaranteed true power and control over the elements that are central to self-direction. Many of these decisions, while made with the inclusion and input of the individual, are still ultimately controlled by a support team, including family, friends and the provider.

Therefore, we recommend that Illinois develop a Self-Directed Supports Waiver for adults with developmental disabilities that not only places the individual at the center of his or her service delivery and coordination, but provides true individual power and control for the participant. We believe the new waiver must include the four basic elements described above and offer the following recommendations to be considered during waiver development.

Apply for Federal Funding through CMS

Illinois received funding through the CMS Independence Plus program to create the Cash and Counseling program to self-direct services for the aging in 2004. We recommend that the state investigate if there is still available funding through the Independence Plus program to develop a self-directed supports waiver or pilot program for developmental disabilities services. Since 2002, this program has been used to develop self-directed supports waivers and pilots in 14 states, including Georgia (Appx. A) and Oregon (Appx. B). Additionally, Illinois should investigate if CMS is still funding states through the Real Choice Systems Change Grants for Community Living program. Since 2001, this program has funded a range of state initiatives related to long-term care reform for people

with disabilities, including self-directed supports for people with developmental disabilities, such as the New Opportunities Waiver revision in Louisiana (Appx C).

Establish a Waiver Advisory Committee made up of Self-Advocates and Stakeholders

We recognize how committed the state has been to listening to the concerns and demands from self-advocates and stakeholders in the developmental disability community, particularly as we move toward revising the Illinois Adults with Developmental Disabilities Waiver. We recommend that the state continue to show that commitment by establishing a Self-Directed Supports Waiver Advisory Committee with a strong contingent of self-advocates, family members, and stakeholders who are dedicated to the development of a new self-directed supports waiver in Illinois. Furthermore, the state should continue utilizing the strength and leadership of self-advocates by making this committee permanent following the adoption of a new waiver. The committee would advise the state during the waiver implementation process, monitor the program and its outcomes, and make recommendations to address problems or challenges as they arise.

Offer a Flexible Individual Budget with Customizable Services

We are well aware of the financial strain being placed on the state these last few years, but we also recognize how committed the state has been to reforming and rebalancing the system of services for people with developmental disabilities in Illinois. Self-direction has been proven in other states to be at least cost-neutral to the status quo, and in some circumstances save the state money. A successful and effective self-directed program must have at its core a flexible and customizable individual budget, without strict or limiting allocation caps. We are not suggesting that Illinois offer a limitless individual budget. However, we do recommend that the state allow enough flexibility to participants to truly have choice of services, including customizable goods and services that are not traditionally covered under Medicaid.

Non-traditional Medicaid services are available to individuals in many states with self-direction, including Georgia, Michigan (Appx. D), New Mexico (Appx. E), and Wisconsin (Appx. F). What makes all the difference in these states is whether participants are truly offered the choice to purchase customizable goods and services through a flexible budget, such as in New Mexico where participants in Mi Via purchase 85-90% of their therapy services from "alternative therapy" options (see Appx. E, page 31). Or if individuals are forced to use most if not all of their allocation on the more traditional HCBS services even though they have the "option" of purchasing Individual Directed Goods and Services, which is the case in Georgia. If the state is going to commit to establishing self-direction in Illinois, we must demonstrate that commitment by not limiting choice or forcing participants to manage their lives under a rigid funding cap.

Use an Effective Needs Assessment Tool

Illinois should be utilizing a needs assessment that is the most effective tool for people with developmental disabilities currently available if and when the state adopts a Self-Directed Supports Waiver. Many states have already successfully adopted the Supports Intensity Scale (SIS; Georgia and Louisiana) or are moving toward adopting the SIS (Oregon and New Mexico) to determine a participant's needs, goals, and individual budget. Not only is the SIS the most effective needs assessment tool available, it can also save the state money by identifying individuals who are receiving a higher allocation then they realistically need and suggest a more appropriate individual budget. However, we should learn from the problems being experienced by participants in Louisiana who are regularly denied the full allocation of the individual budget determined by the SIS. Therefore, we recommend that Illinois commit to fully funding the individual budget that is determined by the needs assessment, even if that means developing an Illinois supplemental assessment, similar to the LA Plus in Louisiana.

A Fully Informed Participant

We believe that the individual should be fully informed of his or her funding and service parameters throughout the entire self-directed process, from assessment to development of the ISP to implementation. Some states, such as Michigan, use a method called Retrospective Budgeting (see Appx. D, page 26), which can offer a great deal of flexibility and customization for the participant, though there are some valid critiques of the method. Ideally we would want individuals to have access to virtually unlimited individual budgets and service options, and in states like Michigan with larger state Medicaid waiver funding that is not siloed or limited by State Operated Developmental Centers and ICF/DDs, this method can be very successful. However, the reality in Illinois is siloed and limited funding for developmental disabilities services in the community, which will most likely lead to some form of individual allocation caps.

If caps are going to be placed on a participant's individual budget, the individual should be fully informed of those limits while he or she is developing an ISP with the Service Coordinator. Retrospective Planning in combination with allocation caps can be disempowering to the individual. Therefore, we recommend that the state develop a method that lets the participant's needs and goals dictate the individual budget and ISP while fully informing the individual of limits or allocation caps to his or her funding and service options.

Use a Quality Fiscal Intermediary

An effective fiscal intermediary agency can operate basically in the background and ensure that the purchase of goods and services for the participant run smoothly and without too much daily interruption. However, an ineffective or unqualified fiscal intermediary can not only disrupt and potentially harm participants by failing to pay their personal support workers, for example, but can seriously damage a self-directed program by forcing provider agencies out of business if they are not paid in a timely manner. This has been the case in Georgia with their Financial Support Services Provider, Acumen.

Therefore, we recommend that Illinois commit to developing quality, trained, and educated fiscal intermediaries who have the resources and skills to handle the financial responsibilities necessary to protect both participants and providers from economic strain. We believe that both ACES$: Avenues to Consumer Services and $upport and Public Partnerships (which has an affiliate in New Mexico) have the potential to operate successfully under a new self-directed system in Illinois, however the state should investigate other fiscal intermediary options as well.

Use Quality and Independent Service Coordinators

No matter what they are titled in Illinois, a Service Coordinator must meet a standard level of education, experience, and training, such as the Consultants working under the Mi Via program in New Mexico. Similar to the fiscal intermediaries, an unqualified or incompetent service coordinator can seriously hinder a participant from developing the most effective and appropriate Individual Service Plan (ISP), which can lead to a low quality of life. The service coordinator is at the front line, working in conjunction with the participant and his or her family, spending countless hours to ensure that an individual has access to the goods and services that meet their needs, dreams, and goals. A quality service coordinator can save the state money by properly monitoring the individual budget and ISP to protect participants from purchasing unnecessary or potentially exploitive goods and services. Therefore, we recommend that Illinois develop a standard level of education, experience, and state-provided training in self-direction to be incorporated into the position's qualifications.

Additionally, service coordinators should be contracted with the state to operate as independent providers to avoid any conflict of interest and offer a true choice to the participant. Several states built independent service coordination agencies into their self-directed supports waiver, such as Georgia's Support Coordinators, Oregon's Support Brokerages, and New Mexico and Wisconsin's Independent Consultant Agencies. Whether Illinois develops a new statewide Service Coordination Agency or modifies the

role of the Pre-Admission Screening (PAS) agents, service coordinators must remain independent of agencies that provide other services to participants.

Establish an Additional "Support Guide" Role

In addition to the traditional Medicaid case managers and self-direction Service Coordinators, Illinois should establish a more direct supportive role, such as the Community Guide (Georgia) or Support Guide (New Mexico). While the Support Guide seems to be the most distinct and successful (see Appx. E, page 32), each of these states have attempted to establish an additional level of support for the participant. Unlike the service coordinator who handles most of the funding assessments, ISP development, and evaluation, this role would offer more daily operational support so the participant does not have to rely so heavily on the service coordinator for day-to-day assistance. This could include self-determination training, employee management education, community access, budgeting, and customized employment. This position would not require the same level of education and experience as the service coordinator.

There are several options the state could consider for this position. 1) It could be funded by the state, such as the Support Guide in New Mexico, and be available to all participants using self-direction through the Service Coordination Agency; 2) this service could be purchased by the participant, allowing the position to be an independent provider with proper training and education, such as a family member, close friend, or member of the community, or; 3) the state could develop a role for self-advocates to provide these services for each other in their community, again with training and education provided by the state.

Develop Peer Support Network Opportunities

Community is very important to the success of self-direction. As much power as a self-advocate has, a group of self-advocates surrounded by peers, family, and others who care is infinitely more powerful and capable of truly supporting individuals in achieving their

goals for a better life. Self-direction helps individuals participate in and contribute to their community's economic and social life. This participation helps the community understand how to meet individual needs and desires. We recommend that the state use self-direction to develop opportunities for people with developmental disabilities to connect with each other and their community, such as Human Service Cooperatives and Peer Support Networks.

Human Service Cooperatives are governed by the members and their families to support one another, share resources, and coordinate services and supports. Cooperatives for people with developmental disabilities bring together individuals who use community services and their families, empowering them to direct and control the services they need. Many states, including Georgia, are using cooperatives as a forum to promote the philosophies of self-direction and peer support. As Illinois moves toward implementation of self-directed services, cooperatives could offer an excellent opportunity to share information about self-direction among potential participants and develop a network of individuals and families to support one another as they begin self-directing their services.

Another way to bring together individuals with similar interests and life experiences in a community is Peer Support Networks. Less formal than Human Service Cooperatives, Peer Support Networks can offer mutual assistance for individuals and their families to support one another and build community. These networks would not necessarily need to coordinate services like cooperatives and could be organized by Service Coordinators, though the network should ultimately be shaped by the needs and preferences of its members. For example, a Peer Support Network could organize social activities for its members that are paid for out of their individual budgets.

Offer Different Levels of Self-Direction and Assistance

We do not believe that true self-direction and control over all services and budget related responsibilities will be appropriate or even desirable to every person with a developmental disability in Illinois. Therefore, we recommend that the state follow the

models of Michigan (Appx. D, page 28) and Wisconsin (Appx. F, page 36) by offering participants a range of options with varying degrees of self-direction and provider assistance. One end of the spectrum would be an option to use staff and services from a traditional provider agency with an individual budget and input on how, when, where and by whom services will be delivered. This option places more control and involvement on the service provider, and is commonly referred to as "Agency with Choice". The other end would give the participant near total responsibility and control over his or her services, staff, and individual budget, with support from a service coordinator and fiscal intermediary but little to no provider control. This option is commonly referred to as "Employer of Record". One or several middle levels of self-direction could offer compromises between these two extremes, such as the "co-employment" option in which the participant recommends workers to be hired by a provider or leasing agency but retains control over the individual budget with the support of a fiscal intermediary.

Conclusion

Now the choice is in your hands. By choosing self-direction, we will be giving people with developmental disabilities in Illinois the opportunity to get what they want and need for a full and meaningful life. The more that people practice self-direction and opt for services that support self-direction and community integration, the more these services will become available. It's a self-fulfilling prophecy, but we have to get it started.

In the end, self-direction is really about quality of life—would you be happier making your own decisions about things affecting your life, or would you rather someone else made them for you? Someone who may not know you well or even have your best interests at heart? Individuals have not had the chance to make this basic choice, much less choices about how they want to become part of their community. Let's put power in the hands of the people whose life it is. Let them determine their goals and how to meet them. Working together, we can make everyone's life a little bit brighter.

Appendix A

Georgia

As the Executive Director of the Georgia Council on Developmental Disabilities, Eric Jacobson, describes self-direction in Georgia, "It looks great on paper." But some significant problems have developed through implementation. We spoke with Eric and looked at several of the guides for individuals and families on self direction developed by the Georgia Council on Developmental Disabilities and commissioned by the Department of Behavioral Health and Developmental Disabilities (DBHDD). Currently, the state of Georgia developed both the New Options Waiver (NOW) and the Comprehensive Supports Waiver (COMP) to allow a self-directed option for adults with developmental disabilities who are eligible for these two HCBS 1915(c) waivers.

Population

- Total – 9,687,653 (2010 census)
- People with Developmental Disabilities – 8,977 (2008 State of the States) – 96,876 (1% estimate of total population)
- Individuals on NOW waiver – 7,720 (2010)
- Individuals using self-direction – 386 (5% estimate, no exact data)

Background of Waivers

In 2004, the Director of DBHDD, Dr. Stephen Hall, was funded by the federal Centers for Medicare and Medicaid Services (CMS) through an Independence Plus Initiative grant to amend the existing HCBS waivers to create a self-directed option for both the NOW and COMP waivers. The NOW waiver providers supports to people who do not need 24 hour care and is designed for people who live with family members or in their own home. The COMP waiver is for people who need more intensive, 24 hour support in their home or out-of-home services, or for people who are transitioning out of institutions into community living.

The movement toward self-direction in Georgia was the result of grassroots efforts by self-advocates, family members, and allies, such as People First and Parent to Parent of Georgia, as well as the Institute on Human Development and Disability and the Georgia Council on Developmental Disabilities, who conducted trainings and held conferences on self-determination across the state in the early half of the decade. Many of these advocates also participated in stakeholder groups during the development of the NOW and COMP waivers. Ultimately, the state was funded to take a serious look at amending their HCBS waivers to include a self-directed option through the CMS Independence Plus Initiative under the Real Choice Systems Change Grant Program. The waivers were approved by CMS in 2007.

Currently, the NOW waiver is the only waiver that has been fully implemented with a self-directed option. The COMP waiver has yet to offer self-direction to those who are eligible. This is most likely the result of problems the state has experienced in implementation of the NOW waiver, and thus have not been able to focus on implementing the COMP waiver self-directed option. We will provide several examples of issues experienced during implementation related to the various areas we examined.

Eligibility

Under the NOW and COMP waivers, both children and adults with intellectual and/or development disabilities are eligible for the self-directed option. These waivers apply to the entire state.

Individualized Budget

The NOW waiver has an annual budget allocation cap of $25,000 per participant, while the COMP waiver does not have a strict budget cap. A participant's budget is based on the results of the Supports Intensity Scale (SIS) and the Health Risk Screening Tool (HSRT), however the SIS cannot be used for children 15 or younger. The allocation also

reflects how much the participant spent on services in previous years. The SIS looks at 9 areas of need for support, which are:

1. Home Living
2. Community Living
3. Life-long Learning
4. Employment
5. Health and Safety
6. Social Activities
7. Need for Protection and Advocacy
8. 15 Medical Needs
9. 13 Behavioral Needs

The state of Georgia has experienced some significant challenges matching the SIS proposed budget with how much the state is willing to allocate to the participant. Many participants have received significantly lower allocations than the results of the SIS budget formula, even if the proposed budget is within the $25,000 cap. The state allows for just a 10% fluctuation from a participant's previous allocation to the budget results after completing the SIS.

Self-directed Services

Participants can choose to purchase services that meet their needs identified by the SIS and incorporated into their Individual Service Plan (ISP), but must stay within their budget allocation. Most of the traditional HCBS have an option for self-direction, although some services are specific to either the NOW or COMP waivers.

Covered services include:

Adult Occupation Therapy	**Adult Speech and Language Therapy**
Adult Physical Therapy	**Behavioral Supports Consultation**
Community Access – Individual or group; day evening or weekend	**Community Guide –** individual training on self-direction and community integration
Community Living Support – in-home support workers; hourly and daily	**Community Residential Alternative** – COMP only; *cannot be self-directed*
Environmental Accessibility Adaptations	**Individual Directed Goods and Services**
Natural Support Training – NOW only; training for unpaid support (family or friends)	**Prevocational Services –** life skills, problem solving, safety, social interaction skills

Respite Services – NOW only; hourly or overnight	**Specialized Medical Supplies**
Specialized Medical Equipment	**Supported Employment** – job development, job coaching, on the job supports
Transportation	**Vehicle Adaptation**
Financial Support Services*	**Support Coordination***

* Financial Support Services and Support Coordination are not taken out of the participant's budget

We want to highlight a few of these services that have not exactly met the expected goals when the waiver was being developed. The Community Guide was meant to complement the Support Coordination services and help participants think creatively about how to effectively self-direct their services and live a quality, fully integrated life in their community. This could include obtaining community resources, building supportive relationships, or getting involved with community and cultural activities. Unfortunately, the Community Guides became too wrapped up with Support Coordination, and lost their independent role, according to Eric Jacobson. It also became increasingly difficult for participants to purchase this additional service with their limited allocation, even if it was recommended by the SIS.

The Individual Directed Goods and Services is a common option in many states for participants who have needs that cannot be met by the traditional Medicaid covered HCBS waiver, with some exceptions. These customizable purchases are integrated into the ISP with help from the support coordinator and can include specialized appliances or furniture, assistive technology, alternative therapies, health-related services or equipment, and recreational activities. Again, because of limited allocations in Georgia, many participants are unable to purchase customized goods and services and are forced to stick with the more traditional services.

Service Coordination

Georgia uses Support Coordinators to assist all NOW and COMP participants with the initial intake and assessment, such as completion of the SIS and HRST. Support Coordinators are independent of service providers and are paid under a separate contract,

thus allowing for greater independence and avoiding a conflict of interest for participants purchasing their goods and services from providers. When participants and families choose the self-directed option, the Support Coordinators help complete the ISP and develop goals and objectives that reflect the self-determination model. Support Coordinators also develop and explain the individual budget, and can request an increase in the allocation if needed. In addition, Support Coordinators assist with the evaluation and monitoring of the participant and their ISP.

Support Coordinators then link the participant with the Financial Support Services provider, which in Georgia is Acumen. This provider conducts criminal background checks on prospective support workers, performs payroll and tax responsibilities, provides payment for approved goods and services, and tracks individual budget expenditures through monthly financial reports to the participant and family. Unfortunately, this system presented another challenge for providers and participants as the NOW self-directed program was being implemented. According to Eric Jacobson, Acumen was either delayed or failing to pay providers for performed services, forcing some providers to go out of business. Participants were also having a difficult time getting the funds needed to pay their support workers.

Appendix B

Oregon

In Oregon, we spoke with John Agosta with the Human Services Research Institute, and used the Oregon "Roadmap to Support Services" (3rd Ed., 2010), which was a collaboration of the Disability Rights Oregon, Oregon Council on Developmental Disabilities, and Oregon Department of Human Services – Seniors and People with Disabilities. We were also told that Beverly Herrin, director of the Resource Connections of Oregon support service brokerage in Salem, OR would be a good person to speak to on self-direction in Oregon. The state of Oregon developed the ICF/MR Support Services Waiver to allow a self-directed option for adults with developmental disabilities who are eligible for this HCBS 1915(c) waiver.

Population

- Total – 3,831,074 (2010 census)
- People with developmental disabilities – 5,312 (2008 State of the States)
  – 38,310 (1% estimate of total population)
- Individuals on Supports waiver – 4,000 (2010)
- Individuals using self-direction – 4,000

Background of Waiver

The state of Oregon received a grant from the Robert Wood Johnson Foundation in 1996 as part of their project to fund self-determination across the nation. A total of 19 states, including Oregon, were awarded grants to promote self-determination and consumer-directed supports, and many states followed by developing a self-directed waiver. Additionally, a settlement from *Staley v. Kitzhaber* in 2000 required the state of Oregon to develop the ICF/MR Support Services Waiver with a foundation of self-determination and person-centered planning. The settlement also effectively eliminated the waiting list at that time by requiring enrollment into the waiver within 90 days of application.

Eligibility

Under the Support Services Waiver, only adults (18+) with developmental disabilities who are not receiving comprehensive services under the Residential Waiver are eligible for the waiver and self-directed support services. This waiver applies to the entire state.

Individualized Budget

Under the Support Services Waiver, an individual's annual budget allocation is capped at $20,000. The allocation is based on the Basic Supplement Criteria Inventory (BSCI), which determines either a Basic Benefit or additional Base Plus level of funding. Most participants qualify for just the Basic Benefit. The BSCI will see if participants qualify for Base Plus by looking at long-term health needs, physical needs, need for behavioral supports, and caregiver circumstances. Participants can also request additional funding through the Activities of Daily Living Supplement (formerly Personal Care Service 20), if needed. Support Services are funded through the state's Seniors and People with Disabilities office along with federal Medicaid dollars.

Self-directed Services

Unlike Georgia, the state of Oregon only allows support services to be self-directed. Comprehensive services are covered under the Residential Waiver and cannot be self-directed. Participants can choose to purchase services that meet their needs identified by the BSCI and incorporated into their Individual Service Plan (ISP), but must stay within their budget allocation.

Covered support services include:

Assistance with Daily Living – chore services	**Community Living and Inclusion Supports**
Environmental Accessibility Adaptations	**Family Training**
Homemaker	**Occupational Therapy**
Personal Emergency Response Systems	**Physical Therapy**

Respite Care	**Speech and Language Therapy**
Specialized Medical Equipment and Supplies	**Special Diet**
Specialized Supports – behavioral, social sexual, and nursing consultation	**Community Access –** communication skills, budgeting assistance
Supported Employment	**Transportation**
Transition Planning – in addition to school and vocational rehabilitation support	

The waiver does not cover basic needs such as food, shelter or clothing, and can not be used for services that can be accessed through another governmental agency such as the Office of Vocational Rehabilitation, a High School Transition Program, SSI, or Section 8.

Service Coordination

Oregon uses a brokerage system to coordinate their support services. An individual will enter into the system through Community Developmental Disability Programs, who employ case managers to determine eligibility for the waiver. The participant will then be referred to a regional Support Brokerage to work closely with a Personal Agent who will assist with the development of an ISP through Person-Centered Planning and a Customer Support Services Survey as well as the individual budget, based on the results of the BSCI. Similar to Georgia, Support Brokerages and Personal Agents do not provide any direct support services, thus they can remain independent and avoid any conflict of interest. The Personal Agent will also help participants access community resources, select independent providers, provider agencies, or general business providers, and monitor and evaluate service outcomes. In addition, brokerages employ fiscal agents to ensure all the participant's costs are paid, including provider agencies and employer responsibilities, such as federal and state taxes and employee wages.

Appendix C

Louisiana

In Louisiana, we looked at several self-direction handbooks and waiver guides developed by the Office for Citizens with Developmental Disabilities (OCDD) over the last few years. We were also referred to Tammy Salter with OCDD, but were unable to speak with her. Self-direction in Louisiana is still in its infancy, both in its limited geographic coverage and scope of available services. A pilot was developed around the New Opportunities Waiver (NOW) to allow select self-directed options for children and adults with developmental disabilities and autism who are eligible for the HCBS 1915(c) waiver and living in certain areas of the state.

Population

- Total – 4,533,372 (2010 census)
- People with developmental disabilities – 8,368 (2008 State of the States)
  – 45,333 (1% estimate of total population)
- Individuals on NOW waiver – 4,800 (2008)
  - 14,768 people on NOW waiting list
- Individuals using self-direction – NA

Background of Waiver

As part of the Louisiana Rebalancing Initiative and a federal Real Choice Systems Change grant in 2004, the state began developing a pilot program to amend the NOW with principles of self-determination and person-centered planning. The revised NOW was approved by CMS in 2006 with the self-directed pilot beginning in 2007. The option to self-direct certain services under NOW was limited to those living in New Orleans, Baton Rouge, and the Hammon/Mandeville areas, essentially the major urban areas of the state. We were told that the plan is to take the pilot statewide sometime in 2011.

NOW participants currently living in the pilot area have the option to self-direct Individual and Family Support (IFS) services for both the day and night-time. A portion of the budget allocation is provided to the participant to operate as the employer of their personal support workers, while all other services are still controlled and funded through traditional service providers.

Eligibility

Under the NOW, children (3+) and adults with DD, MR, and autism living in New Orleans, Baton Rouge or Hammon/Mandeville are eligible to self-direct IFS services.

Individualized Budget

For everyone eligible for the NOW, the state of Louisiana uses the SIS along with a LA Plus supplement to assess needs and determine a level of funding. The self-directed portion of the participant's budget is based on the annual number of IFS hours as laid out in the participant's Plan of Care.

Self-directed Services

The NOW covers traditional HCBS waiver services with an option for participants to self-direct the IFS services (day & night) and function as the employer of their personal support workers. This includes:

- recruiting, hiring, and training workers
- determining workers' duties and schedule based on Plan of Care
- determining workers' wages and benefits
- scheduling workers
- orienting and instructing workers in duties
- supervising workers
- evaluating workers' performance
- verifying and approving time worked by workers
- terminating workers
- completing service documentation (progress notes) and reporting critical incidents

For a participant under the age of 18, the employer may be the parent, court appointed guardian, authorized representative, or the participant only if married or emancipated by the court. For an adult (18+), the employer must be the participant, with an authorized representative able to make decisions on behalf of the participant.

Service Coordination

The state of Louisiana uses Support Coordinators for everyone under the NOW waiver, and are further trained to support participants who choose the self-directed option for IFS services in the pilot area. When an individual chooses to self-direct IFS services, the Support Coordinator will educate the participant on self-direction and provide him or her with a *Self-Direction Employee Handbook* and Start-Up Packet. Following completion of the SIS and LA Plus assessments, the Support Coordinator determines what supports the participant will need to participate in self-direction (e.g. minimum number of workers needed, access to fax machine or internet, etc.) and includes these supports and services in the Plan of Care and budget allocation.

Once approved by the Self-Direction Program Manager and OCDD Regional Office Manager, the Support Coordinator and participant develop a Purchasing Plan which lays out allowable employment expenditures and allotted quarterly IFS hours. Additional employer training such as recruiting employees, developing job tasks and work schedules, as well as ongoing monitoring and evaluation is completed with the Support Coordinator. The participant is then linked with the fiscal/employer agent who processes payroll twice per month, sends budget reports, and completes necessary tax paperwork.

Appendix D

Michigan

In Michigan, we spoke with Dohn Hoyle, executive director of the Arc of Michigan, who has been one of the champions of self-direction in Michigan, along with the director of the Department of Mental Health and Substance Abuse (which includes Developmental Disabilities) Michael Head. Both men have been instrumental in crafting and implementing self-direction in Michigan, which is an option for people with developmental disabilities under the state's Medicaid Prepaid Specialty Mental Health and Substance Abuse Services and Combination 1915(b)/(c) Medicaid Prepaid Specialty Services and Supports for Persons with Developmental Disabilities program.

Population

- Total – 9,883,640 (2010 census)
- People with developmental disabilities – 39,000 (2010) – 98,836 (1% estimate of total population)
- Individuals on combination b/c waiver – 39,000 (2010)
- Individuals using self-direction – 3,900 (10% estimate, 2010)

Background of Waiver

Michigan was another of the 19 states funded by the Robert Wood Johnson Foundation to begin a self-directed pilot program in 8 counties in 1996. That same year, the pilot was strengthened by legislation that required person-centered planning for developmental disabilities services, as well as the adoption of a broader definition of developmental disability that matches the federal definition. When the pilot was deemed successful in 1998, CMS approved the combination 1915(b)/(c) waiver program, which "carves out" specialty mental health, substance abuse, and developmental disabilities services and supports and provides these services under a prepaid shared risk arrangement.

The state coordinates developmental disabilities services through 46 county-based Community Mental Health Service Providers (CMHSP), which already existed when the waiver was approved. The waiver established 18 Prepaid Inpatient Health Plans (PIHP) across the 83 counties to implement the managed care piece of the waiver. In 2002, the state adopted a PIHP Application for Participation that requires person-centered planning and a self-directed option. Then in 2003, the CMHSPs were required to offer a self-directed option as part of their person-centered planning for those who did not want to have their services coordinated by the PIHPs. Also of note, this new waiver effectively eliminated the waiting list for developmental disabilities services. This is in large part due to the state's closure of their state operated developmental centers and ICF/DDs around this same time period, which freed up funds for the counties to provide services to all eligible individuals.

Eligibility

The combination waiver covers multiple populations, including mental health, children with severe emotional disorders, and children and adults with developmental disabilities. The self-directed option is available for everyone who is eligible for the waiver, and applies statewide.

Individualized Budget

The state determines funding for each county based on a prepaid, per life calculation which looks at the number of Medicaid lives per county to allocate funding, with a minimum of 20,000 per county. The CMHSPs do not use any formalized needs assessments when developing an individual's budget. Some counties choose to use the ICAP or other assessments, but these are not used for budget allocations.

The state adopted a Retrospective method of budget planning, in which individuals do not have a capped allocation during the initial planning process. The ISP identifies specific arrangements the participant will use to control the budget and direct providers, but the

participant and Support Coordinator do not look at the cost of services or allocation limits until after the needs are identified and the ISP is completed. The Support Coordinator will then work with the participant to develop a budget based on the cost of services outlined in the ISP. The county CMHSP will determine the benefit amount, and at that time can place limits on the individual budget and set maximum amounts the participant can pay providers.

Self-directed Services

Similar to Oregon and Georgia, Michigan allows participants to self-direct most of the traditional, Medicaid approved HCBS waiver services, as well as additional non-Medicaid services that the state terms “B3 goods and services”. The more traditional services include personal support workers, transportation, peer mentoring, and adult OT/PT/SLT. Participants can also apply for housing assistance while pursuing other support, such as Section 8. The B3 goods and services are based on projected savings from the use of the individual budget that can be used to acquire goods and services that (1) increase independence, facilitate productivity, or promote community inclusion and (2) substitute for other forms of assistance, such as personal care in the Medicaid State Plan, community living supports, and other one-to-one support described in the B3 Alternative Service definitions. These are in addition to services that are “medically necessary”.

Service Coordination

Since the state operates on a county-based system of funding, each county has slightly different forms of service coordination. The majority of CMHSPs employ Support Coordinators, which operate in about half of the counties, and provide case management for all individuals on the waiver as well as service coordination for those who choose self-direction. Other counties allow individuals to hire an independent Support Broker who then completes training to provide service coordination. The Support Coordinators help participants develop the ISP, but again each county uses different formats for their

plan, such as the PATH or Essential Lifestyle Planning. So the state does not require a standard ISP format, only that it meets certain requirements, such as a health and safety plan. Many CMHSPs offer fiscal intermediary services as well.

Participants can choose from three methods of self-direction, which allow for various levels of individual control over the budget and services.

1. **Agency with Choice –** this arrangement uses staff from an agency within the county provider network with no fiscal intermediary services, placing more control and involvement on the service provider. The provider will employ the participant's staff, but the participant will negotiate with the agency about how, when, where and by whom their services will be delivered. The participant still has an individual budget and receives monthly reports from the provider showing how many units of service have been used, how many are left and how much the services cost.
2. **Purchase of Services –** in this arrangement, the participant chooses an agency that is not part of the county provider network to provide the services he or she is eligible for. The agency is still the employer of staff, but the participant has control over how, when, where and by whom services are provided. The participant has an individual budget and the provider will provide a fiscal intermediary to help manage it. Every month the participant reviews the documentation the employees are required to keep and verifies services were provided according to the ISP and that payment should be made to the agency. Once the fiscal intermediary has authorized payment and the agency has provided an invoice, the agency is paid for providing the services.
3. **Employer of Record –** this arrangement gives the participant the most responsibility and control over his or her services and who provides them. The participant recruits, interviews, hires, schedules, evaluates, and manages the employees who deliver their services. Employees must meet certain criteria, go through back ground checks, attend training, and sign employment and Medicaid Provider agreements. The participant has an individual budget and fiscal intermediary to provide support as an "employer agent".

Appendix E

New Mexico

In New Mexico, we spoke with Pat Syme, who is the Program Manager of Mi Via with the Department of Health. The department offers multiple self-direction guides and handbooks for individuals and families that we used in our research. The state of New Mexico offers a self-directed option under the ICF/MR 1915(c) waiver titled "Mi Via", which means my path, my way, or my road.

Population

- Total – 2,059,179 (2010 census)
- People with developmental disabilities – 3,446 (2008 state of the states) – 20,591 (1% estimate of total population)
- Consumers on ICF/MR waiver – 3,363 (2006) – 4,000 (2010 estimate)
  - 4700 waiting
- Consumers using Mi Via – 225 (developmental disabilities) & 70 (medically fragile)

Background of Waiver

In 2004, self-advocates and stakeholders came together to push for self-direction in New Mexico, forming a large stakeholder group (60-75 people) with smaller working groups. The state hired a statewide facilitator to coordinate the various groups. By 2005, the Mi Via program was originally planned to cover just the ICF/MR level of care waiver, which includes the developmental disabilities, medically fragile, and HIV/AIDS populations. But as the waiver was being written, stakeholders and self-advocates fought to expand it for the "nursing home" level of care (Elderly/Disabled, brain injury) waiver as well. The full waiver was approved by CMS in 2006. Today, both waivers and all 5 populations are eligible for a self-directed option under Mi Via.

Eligibility

Under the ICF/MR waiver, children and adults with developmental disabilities are eligible for Mi Via. Individuals currently covered by the ICF/MR waiver can transfer to Mi Via within 60 days of application, while newly eligible individuals may take up to 90 days to be enrolled in Mi Via. Mi Via applies to the entire state.

Individualized Budget

In New Mexico, Medicaid sets the individual budget allocation, which is similar for traditional ICF/MR and Mi Via waiver participants. The budget is based on level of care and age of the individual, and uses the Adaptive Behavior Assessment, which looks at activities of daily living, as well as an Abstract Assessment to determine eligibility. The state is looking at utilizing the SIS in the near future. The individual budget includes annual resource allotments which are a weighted average of needs, such as additional residential components.

The participant can request more funding with support from their Consultant and Financial Management Agent (FMA), but the state tends to be strict on approving budget increases, which must be approved by a third-party assessor. According to Pat, roughly 50% of increases are approved. The proposed budget may be considered for approval if all of the following requirements are met:

1. The proposed budget is within the participant's available budgetary amount
2. The proposed rate for each service is within the Mi Via Range of Rates for that chosen service
3. The proposed rate for each good is reasonable, appropriate and reflects the lowest available cost for that chosen good
4. The estimated cost of the service and/or good is specifically documented in the participant's budget worksheets
5. No employee exceeds forty hours paid work in a consecutive (7) day period

Self-directed Services

The Mi Via program allows participants to self-direct many of the traditional, Medicaid covered services, including:

Homemaker/Companion	**Adult Day Health**
Community Living	**Adult Day Habilitation**
Supported Employment	**Respite Care**
Assisted Living	**Behavior Support Consultation**
Environmental Modification	**Emergency Response**
Community Access	**Private Duty Nursing for Adults**
Skilled Therapy for Adults – physical, occupational, and speech therapies	**Nutritional Counseling for Adults**

Under Mi Via, all participants become the "employer of record" to hire and train their personal support workers. Participants receive training and education from their Consultant and FMA, however this has been one of the most challenging aspects of the program for both the state and participants. Many individuals and families have difficulty handling all of the responsibilities involved with managing their own staff, according to Pat. New Mexico is considering adopting a co-employment option for participants, similar to the Purchase of Services level of self-direction in Michigan.

Mi Via also covers additional Participant-delegated Goods and Services, including:

Transportation – nonmedical, vehicle modifications and repairs, equipment repairs	**Community Participation** – health club memberships, recreational activities, creative arts
Health-related Services, Equipment and Supplies – chiropractic services, non-covered medical and dental supplies, non-covered durable medical equipment, exercise equipment	**Technology for Safety and Independence –** Programmable or voice-activated phones, personal alarms, life lines, cell phones, assistive technology, memory-prompting devises, specialized toys
Alternative Medicine and Therapies – play therapy, hippotherapy (horseback riding), message therapy, native healing	**Household-related –** appliances, computers and costs related to internet access, adapted or specialized furniture
Resource Facilitation – educational opportunities not covered by other public programs	**Coaching/education for Parents, Spouse and Others Close to Participant**

Participant-delegated goods and services can be purchased from any vendor or business as long as the participant submits a Payment Request Form and valid invoice from the vendor to the FMA. These customizable goods and services are commonly purchased by participants. For example, only 10-15% of participants use traditional therapies. Many purchase alternative therapies, according to Pat.

Service Coordination

Mi Via is coordinated by Consultants who operate out of independent Consultant Agencies whose only function is to provide consultant services to Mi Via participants, although they also provide some Medicaid case management, but no other direct services. A provision of the 2009 rewrite of the ICF/MR waiver and Mi Via required a standard level of education and experience to qualify for a Consultant position. Participants can choose any Consultant from the Consultant Contractor Agency directory. Consultants are available up to twenty times per year at no additional cost to the participant. The Consultants and participants are aware of the Medicaid allocation prior to developing the Service and Support Plan (SSP) and individual budget. Consultants evaluate the SSP and budget annually, and can change the plan or revise services at any time at the request of the participant. New Mexico contracts with Public Partnerships to provide FMA services, such as employer responsibilities, payroll, taxes, and monthly budget reports for the participant.

A Support Guide provides additional daily support so the participant does not have to rely on the Consultant for day-to-day assistance. This includes some of the more customizable goods and services, such as self-determination training, budgeting, community participation, and job coaching. The Support Guide does not require the same level of education and experience as the Consultant, but is still employed by the Consultant Agencies and receives training from the state.

Appendix F

Wisconsin

In Wisconsin, we spoke with Dennis Harkins, who currently offers consultant services to developmental disability advocacy and provider organizations, but has been a champion of self-determination in Wisconsin and across the nation. The Wisconsin Department of Health Services (DHS) offers an extensive amount of information and guides for individuals and families interested in self-direction. The state offers a Self-Directed Supports 1915(c) waiver to those who are eligible, live in certain counties, and want to enroll in the Include, Respect, I Self-direct (IRIS) program.

Population

- Total – 5,686,986 (2010 census)
- People with developmental disabilities – 18,555 (2008 state of the states) – 56,869 (1% estimate of total population)
- Individuals on HCBS waiver – 14,037 (2006)
- Consumers using IRIS – 2000 (2010 estimate)

Background of Waiver

In 1999, Wisconsin developed a combination 1915(b)/(c) waiver, which created the Family Care managed care pilot program for people with developmental disabilities. The program operated in five counties for a seven year pilot period. In 2006, the governor announced a plan to expand Family Care statewide by 2013, but CMS directed the state to offer a self-directed alternative to managed care. Therefore, in 2007, the state created the IRIS program under the Self-Directed Supports waiver. However, IRIS could only be offered to individuals living in a county that currently offered the Family Care program, thus providing a fair choice between Family Care and IRIS. Wisconsin began implementing the IRIS program in January, 2008 and as of January 1, 2011, 56 of the state's 72 counties offer IRIS as a self-directed alternative to Family Care. The state still operates a more traditional 1915(c) waiver in counties that have not transitioned to

Family Care/IRIS, called the Community Integration Program waiver, but the plan is to have all counties transitioned by 2013.

Eligibility

Under IRIS, adults (18+) with MR/DD living in counties that currently offer Family Care are eligible for self-directed supports.

Individualized Budget

An IRIS participant's budget is based on the results of the Long Term Care Functional Screen (LTCFS), an assessment completed at a county Aging and Disability Resource Center (ADRC). The LTCFS estimates annual cost of needs, services and supports to calculate a budget allocation. The state does not appear to have a strict cap on an individual's allocation, although Dennis assures us that there is a limit. We have seen participants receive an annual allocation over $150,000 based on the needs identified by the LTCFS. However, the average annual allocation is around $40,000.

The state allows participants to adjust their budget to spend more or less in any given month during a 12 month period if necessary, or the participant can set aside unused funds for up to 12 months for larger purchases. Participants are also able to request additional funds by working with their Independent Consultant who can submit an Allocation Adjustment for annual increases or an Exceptional Expense request for larger, one-time purchases.

Self-directed Services

IRIS allows participants to self-direct many of the traditional HCBS waiver services, which include:

Adaptive Aids	**Adult Day Care**
Adult Family Home* – 1-4 beds	**Communication Aids**

Community-Based Residential Facility	**Consumer Education & Training**
Counseling & Therapeutic Resources*	**Customized Goods & Services***
Daily Living Skills Training*	**Day Services**
Home Delivered Meals	**Home Modifications**
Housing Counseling	**Housing Start-Up**
Self-Directed Personal Care*	**Nursing***
Personal Emergency Response System	**Pre-Vocational Services**
Residential Care Apartment Complex* - assisted living facility	**Relocation Related Services**
Respite Care*	**Specialized Medical Equipment & Supplies***
Support Broker	**Supported Employment***
Supportive Home Care*	**Transportation***
Vocational Futures Planning	

*A qualified spouse, relative or guardian may provide these items

Note the Customized Good & Services have certain requirements to qualify under IRIS.

The purchase must meet all four of these criteria:

1. The item or service is designed to meet the participant's functional, vocational, medical or social needs and also advances the desired outcomes in his/her ISP;
2. The service, support or good is documented on the ISP;
3. The service, support or good is not prohibited by Federal and State statutes and regulations, including the State's Procurement Code;
4. The service, support or good is not available through another source or experimental in nature.

AND

Must meet at least one of the following criteria:

1. The service, support or good will maintain or increase the participant's safety in the home or community environment;
2. The service, support or good will decrease or prevent increased dependence on other Medicaid-funded services;
3. The service, support or good will maintain or increase the participant's functioning related to the disability;
4. The service, support or good will maintain or increase the participant's access to or presence in the community.

Similar to Michigan, IRIS participants have several ways to obtain workers to provider services, such as supportive home care, respite, job coaching, or personal care under Self-Directed Personal Care services.

1. Be an employer of record and hire workers directly. The Financial Services Agency (FSA) serves as your employer agent and pays workers from submitted time sheets.
2. Manage the workers you choose with assistance from an Agency with Choice Provider, FSA pays agency
3. Recommend workers to be hired and managed by a co-employment or leasing agency, FSA pays agency
4. Use a provider agency to supply the services you need using the workers they have on staff; FSA pays agency, agency chooses, employs and manages workers

Service Coordination

Wisconsin uses a single-point of entry for all Family Care and IRIS participants, which is coordinated by the county ADRC. The ADRC completes the LTFS and notifies the participant of his or her individual budget. When an individual chooses to self-direct his or her services, the participant is referred to an IRIS Service Center and chooses an Independent Consultant and FSA from agencies that are independently contracted with DHS in each eligible county. The participant then develops a Support and Service Plan based on their individual budget and with support from the Independent Consultant. The IRIS Service Center will then approve the plan and send copies to the FSA.

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