# Sustainable Self-Directed Care in Pennsylvania’s Behavioral Health System

Prepared by: Kristin Ahrens, M.Ed Policy Director, Institute on Disabilities at Temple University, and Katharine Vengraitis, J.D., Legal Research Intern

June 1, 2015

Funding for this development of this report was provided through a SAMHSA Transformation Transfer Initiative Grant

Table of Contents

[Acknowledgements 1](#_Toc421859078)

[Purpose 2](#_Toc421859079)

[Background 2](#_Toc421859080)

[What is Self-Directed Care (SDC)? 4](#_Toc421859081)

[What Does Research Tell Us about Self-Directed Care? 5](#_Toc421859082)

[What is Experience with Self-Directed Care Nationally? 7](#_Toc421859083)

[Pennsylvania’s Service Delivery Systems for Self-Directed Care 12](#_Toc421859084)

[Consumer Recovery Investment Fund (CRIF) Program 13](#_Toc421859085)

[Existing Infrastructure for Self-Directed Care in Pennsylvania 19](#_Toc421859086)

[Funding for Self-Directed Care in PA’s Behavioral Healthcare System 22](#_Toc421859087)

[State Plan Home & Community-Based Services 1915(i) 24](#_Toc421859088)

[1115 Demonstration and Research 27](#_Toc421859089)

[Rehabilitation Option 29](#_Toc421859090)

[Conclusion 31](#_Toc421859091)

[References 32](#_Toc421859092)

[Appendix A: Current Eligibility Criteria for CRIF Project Participation 35](#_Toc421859093)

[Appendix B: Medicaid Authorities and Self-Directed Care in PA’s Mental Health Services System 35](#_Toc421859094)

[Appendix C: Abbreviations and Glossary of Terms 48](#_Toc421859095)

# ****Acknowledgements****

The policy analysis conducted to complete this report was made possible through the generous sharing of expertise of the following people:

Alison Barkoff, Director of Advocacy, Bazelon Center for Mental Health Law

William Boyer, Program Specialist, Office of Mental Health and Substance Abuse Services

Suzanne Crisp, Director of Program Design, National Resource Center for Participant-Directed Services

Ellen DiDomenico, Director, Bureau of Policy and Program Development, OMHSAS

Jonna Distefano, Administrator, Delaware County Office of Behavioral Health

Briana Gilmore, Director of Public Policy, NY Association of Psychiatric Rehabilitation Services, Inc.

Erme Maula, Program Manager, CRIF Self-Directed Care, Mental Health Association of SE PA

Deborah Neifert, Deputy Director, Pennsylvania County Administrators Association MH/DS

Rachel Patterson, Policy Manager, Association of University Centers on Disabilities (AUCD)

Joseph Rogers, Chief Advocacy Officer, Mental Health Association of Southeastern Pennsylvania

Angela Roland, Program Specialist, Office of Mental Health and Substance Abuse Services

Nina Wall, Director, Bureau of Autism Services, Office of Developmental Programs

Katherine White, Executive Director, Oregon Support Services Association

**All people with disabilities shall have the option to design, control and direct their own services and funding.”**   
—Pennsylvania Person Driven Services Coalition

# Purpose

Ultimately, the purpose of this paper is to identify options for scalable and financially sustainable self-directed care in Pennsylvania’s behavioral healthcare system. The paper begins with an overview of the status of self-directed programs nationally and in the Commonwealth of Pennsylvania. Because Medicaid funding will be critical for financial sustainability, self-directed care as defined by the Centers for Medicare and Medicaid (CMS) is explained and applicable Medicaid authorities are then analyzed in the context of Pennsylvania’s existing infrastructure and experience.

# Background

Participant-Directed Services (PDS), also known as “self-directed services” or “self-directed care,” have been an option in Medicaid[[1]](#footnote-1), therefore eligible for federal matching funds, since the 1990s. Major growth occurred in states using the PDS model when, in 2001, the Centers for Medicare and Medicaid revised the 1915(c) Home and Community Based Services (HCBS) waiver application to include participant-directed options. Currently, all states have at least one program that allows for self-direction.[[2]](#footnote-2) These programs serve people across the disability spectrum including people with intellectual and developmental disability (I/DD) and people who receive aging services. Though self-directed models of service are widely used across the United States, one population has been largely absent from receiving self-directed services, people with a primary diagnosis of mental illness.

In Pennsylvania, services for people with disabilities are mainly provided through 1915(c) home and community based waivers or institutional settings.[[3]](#footnote-3) Eight of the ten 1915(c) home and community based waivers in Pennsylvania allow for participant-direction. It is only the Autism and AIDS waivers that do not allow for any self-direction of services. Roughly 19,000 people in the Commonwealth currently self-direct at least one service.[[4]](#footnote-4) Pennsylvania has significant experience and infrastructure supporting a variety of self-directed models.

Though many states, including Pennsylvania, have extensive experience in providing services through self-directed models, there is relatively little experience in delivery of mental health services using these models. There have been a number of small demonstration or pilot self-directed care (SDC) models in mental health systems but nothing in any of these states has been scaled to statewide use capturing a full Medicaid match.

Self-directed services tend to be preferred over traditional models and have produced positive outcomes[[5]](#footnote-5). Further, SDC models are in natural alignment with the recovery paradigm. In line with Substance Abuse and Mental Health Services Administration’s (SAMHSA) definition of recovery, SDC models, by design, involve the person exercising choice and control in planning not only their goals for the future but their unique approaches to achieving the goals.[[6]](#footnote-6) Self-Directed Care models provide greater control over decision-making and service provision as well as and greater flexibility for how service funds are used. This increased flexibility and control could offer people the ability to better align services and supports with their recovery plans. In SDC, both individual budgets and employer authority are intended to provide a person with the opportunity to use non-traditional and non-specialized services which can allow for better community participation and opportunities for creativity and innovation. With this foundation rooted in choice and control, there is great promise for self-directed models in addressing some of the common complaints for people who use the mental health care system, namely, “restrictions on choice of providers and services, fragmentation of services and providers, inconsistent involvement of consumers in shared clinical decision-making, and inconsistent adoption of recovery oriented services and practices”[[7]](#footnote-7). In order to provide access to self-directed care models for Pennsylvanians with psychiatric disabilities (comparable to existing self-directed care models for people with other disabilities) and better align Pennsylvania’s behavioral health care system with the recovery-oriented principles adopted by the Office of Mental Health and Substance Abuse Services (OMHSAS) and the Substance Abuse and Mental Health Services Administration, self-directed options need to be made available to people accessing the behavioral health system in the Commonwealth.

## What is Self-Directed Care (SDC)?

In Self-Directed Care (SDC) people have some option to design, control and direct their own services and funding. For Medicaid payment for SDC, the Centers for Medicare and Medicaid (CMS) has specific features that must be part of a state’s program. Medicaid reimbursable SDC options involve a program design that allows for *employer authority* and/or *budget authority*. The CMS defines these terms as:

* **Employer Authority:** participants are afforded the decision-making authority to recruit, hire, train and supervise the individuals who furnish their services.
* **Budget Authority:** participants may also have decision-making authority over how the Medicaid funds in a budget are spent.[[8]](#footnote-8)

Medicaid reimbursable self-directed care models are generally characterized by a four key features: [[9]](#footnote-9)

1. **Person-Centered Planning Process:** CMS defines this as “The process is directed by the individual, with assistance as needed or desired from a representative of the individual's choosing. It is intended to identify the strengths, capacities, preferences, needs, and desired measurable outcomes of the individual. The process may include other persons, freely chosen by the individual, who are able to serve as important contributors to the process.”
2. **Service Plan:** A plan that addresses the needs and preferences of the individual and outlines the services and supports the person will receive. The Service Plan should also identify the services and supports that are needed to assist the individual to direct their services and supports.
3. **Individualized Budget:** The amount of funding available to the person to purchase needed goods and services. The budget should be developed to support the person’s needs and preferences as outlined in the service plan.
4. **Information and Assistance:** People self-directing should have access to services and supports to develop a person-centered plan and individual budget. Further, people should have access to support to both (a) recruit, hire and manage their workers and support and (b) manage their individual budget to most effectively meet their needs. Information and support is commonly provided through Financial Management Services and either a Supports Coordinator or Supports Broker.

## What Does Research Tell Us about Self-Directed Care?

Slade (2012) in *Feasibility for Expanding Self-Directed Services to People with Serious Mental Illness* summarizes the state of research on SDC in behavioral healthcare as follows:

One conclusion that is well substantiated by prior research studies is that most clients favor SDC compared to traditional mental health care. However, empirical data regarding the impact of SDC on quality of life, long-term clinical outcomes, and cost savings are largely unavailable. Small sample sizes across pilot sites, data quality issues, and weak evaluation designs have hampered prior assessments the impacts of SDC. [[10]](#footnote-10)

In the next few years, it is anticipated that research conducted on the demonstration in both Pennsylvania’s CRIF project and New York’s 1115 Demonstration project will contribute significantly to the body of evidence on SDC and outcomes. In terms of research on self-directed care models for other populations of people with disabilities, substantial research was conducted on the Cash and Counseling Demonstration in Arkansas, New Jersey and Florida.[[11]](#footnote-11) Lessons learned from this research that are particularly important for consideration of SDC in the behavioral health system are related to cost effectiveness, satisfaction and quality of life.

* After nine years of implementing a Cash and Counseling demonstration in Arkansas, the state reported a cumulative savings of $5.6 million. These savings do not reflect the additional savings the state reported from reduction of nursing home utilization.[[12]](#footnote-12)
* In another study of Arkansas’ Cash and Counseling program Dale, Brown, Phillips, Schore and Carlson concluded that initial expenses for person-driven models may be higher but that the temporary increase is offset by the reduction in later usage of expensive long-term care models.[[13]](#footnote-13)
* People directing their own care via programs like Cash and Counseling are overwhelmingly more satisfied with services than those who do not direct their own services.[[14]](#footnote-14)
* People participating in Cash and Counseling programs reported higher quality of life than people taking part in traditional care.[[15]](#footnote-15)

Research on the Cash and Counseling Demonstration provides some preliminary evidence that Cash and Counseling is effective for people with serious mental illness (SMI). Some of the demonstration programs included people with SMI as well as people with physical disabilities. Results from the Arkansas evaluation indicated that Cash and Counseling worked equally well for people with and without mental illness for the following outcome measures:

* satisfaction with paid caregiver’s relationship and attitudes;
* satisfaction with life;
* satisfaction with care arrangements and unmet needs;
* and adverse events, health problems, and general health status[[16]](#footnote-16)

These positive outcomes suggest that adapting the model for individuals with SMI is not only possible but will likely yield desirable results. Beyond the evidence from the Cash and Counseling Demonstration, in a SDC model in Florida that specifically targeted people with SMI, preliminary evidence showed positive outcomes for participants in terms of greater number of days in community settings and improved functioning as a result of the self-directed care option.[[17]](#footnote-17) Florida’s SDC model for people in the mental health system also showed reductions in expensive interventions like use of in-patient treatment and forensic involvement.[[18]](#footnote-18)

In addition to the accumulating evidence supporting the effectiveness of SDC models that include either employer and/or budget authority for those with and without mental illness, various studies have been conducted that support the integration of peer-based services as a vital part of self-directed care.[[19]](#footnote-19) Evidence supporting the improved outcomes in health and other aspects of recovery was validated in a study conducted by Druss, et al. (2010), which looked at peer-led interventions to improve medical self-management for persons with SMI. Other observed advantages to peer support included increases in physical activity, medication adherence, and the largest increase in reported physical health related quality of life.[[20]](#footnote-20)

In summary, though there is not a great deal of research on SDC for people with SMI, it does seem clear that, in addition to the model being a desirable model, it is a promising model in a number of areas. Research to-date tells us that SDC generally produces greater satisfaction with services, fewer unmet needs and people report a higher quality of life. Further, peer support appears to produce improved outcomes related to health and wellness.

## What is the Experience with Self-Directed Care Nationally?

Self-Directed Care programs are available in every state and the District of Columbia. [[21]](#footnote-21) There is considerable experience nationally with operating different self-directed models. The 2013 National Inventory includes data from 277 programs. From these data, several things are worth noting:

* Of 838,503 individuals using self-direction, 65,000 are in programs that only offer participant direction.
* Managed care is being used as a service delivery mechanism that includes self-directed care in 18 states.
* Fifty-three new programs started since 2010. [[22]](#footnote-22)

Self-directed care programs serving people with mental illness have been tried in a handful of states (Florida, Oregon, Iowa, Utah, New York, New Hampshire and Texas) usually on a smaller scale and as pilots or demonstration projects.

Table 1 summarizes the programs, other than Pennsylvania, that have continued beyond their initial pilot or demonstration period. Like Pennsylvania, other states have also not yet moved into statewide program implementation. With the recent approval of an 1115 Demonstration waiver, New York is poised to begin implementing a program on a statewide phase with a roll out to beginning in fall of 2016. In each of these models there is some kind of advisor, Recovery Coach or Support Broker role to assist the person with planning and managing an individual budget. Most models have an emphasis on budget authority (the exception is Michigan’s program) with funding available for participants to use flexibly to achieve the goals outlined in their recovery plans.

Table 1: States with SDC Programs in Behavioral Health

| **State** | **Size Served** | **Budget Authority** | **Employer Authority** | **Program** | **Funding Sources** |
| --- | --- | --- | --- | --- | --- |
| **Florida** | Jacksonville, Fort Myers  About 270 people | Yes | No | Participant can purchase clinical services or alternative modalities (wellness strategies to address clinical goals, productivity, employment).  Participants receive tiered amount of funding.  Everyone has a coach to assist with plan and budget. Coaches may be peers but it is not a required provider qualification.  Plans are developed in 3 month segments. Program is limited to 7 years participation. | State general funds |
| **Texas** | First pilot - 7 counties  Second pilot - Dallas county | Yes | Yes | Participants work with an SDC Advisor to develop person-centered plan (PCP) with individual budget, purchase services directly from community providers.  In first pilot, budget amount calculated based on the annual cost per person of outpatient mental health services (excludes expenses such as medications, emergency, and inpatient care, which remain available through the current service system.)  In second pilot, Dallas County – participants have $4000 or $7000 annual (meds, crisis and inpatient carved out) – SDC advisors assist participants.  Financial intermediary (FI), run through MCO, assist the individual by directly paying service providers and supporters hired by participants, and by providing vouchers for approved goods and services tied to the participant’s goals for mental health recovery. | State funded block grants to support peer specialists. Looking to  1915(b/c)  Transformation Transfer Initiative (TTI) grant |
| **New York** | The goal population size of pilot is a total of 500 leading into 1115 Demonstration to start fall 2016. The 1115 demonstration will have between 800 and 1,000 participants across 8-12 service settings by the end of a 2 to 3 year implementation period. | Yes | Yes | Not operational yet.  Supports Brokers assist with development of person-centered “Action Plan”. Participants may include allowable HCBS and non-treatment supports into their action plan.  **Services Eligible for Self-Direction:**   * Employment Support Services * Educational Support Services * Family Support and Training * Peer Services * Transportation (non-medical) * Psychosocial Rehabilitation * CPST   **Non-Treatment Goods and Services Eligible for Self-Direction:** Wellness activities like Gym/ health club membership, Smoking cessation tools/ education, Dental, Eyeglasses/care, Out of network health/BH/specialty services; Occupational/ skills development like Computer literacy, Interview preparation;  Transportation; In-home/ social/ community supports like housing start-up (down payments), non-recurring housing bills or costs related to home maintenance | Demo funded by Balancing Incentive (federal)  Beginning implementation of an  1115 Demonstration |
| **Utah** | Max 185 people  Salt Lake county | Yes | No | $1200 per participant average direct service dollars participants commit to 6 months  Voucher system with a fiscal agent  Based on recovery goals – reviewed monthly  Alternative treatment options can be purchased | Transformation Transfer Initiative (TTI) grant – |
| **Michigan** | Detroit/Wayne pilot – enrolling 20 ppl/ per month | No | Yes | Supports Brokers assist people with recovery planning.  Participants can hire peer specialists, family or friends using participant-directed services for the following:  Vocational assistance, housing assistance, planning, support with selecting and managing staff, sharing stories of recovery. | TTI grant covering cost for staff; 1915(b/c) managed care specialty waiver |

## Pennsylvania’s Service Delivery Systems for Self-Directed Care

### Utilization Rates of Self-Directed Care in Pennsylvania

Mirroring experience in other states, in Pennsylvania’s home and community based services system for people with disabilities (including the aging waiver), there is substantial use of the available participant-directed options. In the Office of Long Term Living HCBS waivers, 35% of waiver participants self-direct at least one service. This percentage ranges from 16% in Fayette County to 67% in Wyoming County. In the Office of Developmental Programs 13% of waiver participants self-direct at least one service. The range of use by county is from 0% in Cambria, Cameron, Elk to 41% in Forest, Warren, Huntington.

*Data Source: Office of Long Term Living Enrollment Date Q1 2014 and Public Partnerships, LLC Enrollment Data Q1 2014; Office of Developmental Programs Enrollment Data Q1 2014*

Office of Developmental Programs (ODP)

The Office of Developmental Programs allows some self-directed services for two of the three home and community-based waivers it administers. The Person/Family Directed Supports (P/FDS) and Consolidated waiver participants who live in private residences, (not paid residential settings), may elect to use “Participant Directed Supports.” This option allows employer authority and very limited budget authority (only the ability to determine workers’ wages from established wage ranges). The Autism waiver does not currently have any options for SDC.

Supports Brokers are a billable service under the P/FDS and Consolidated waivers for people who live in their own private homes and use a Financial Management Service. The intent of Supports Broker services is to enhance the individual’s ability to direct his or her own services. Though an allowable waiver service for over a decade, Supports Broker capacity is just being developed in Pennsylvania. As a result, there are very few people who use these services and very few providers who offer these services.

#### Office of Long-Term Living (OLTL)

The Office of Long-Term Living offers a SDC model in all of its waivers except the AIDS waiver. The primary service that is self-directed is Personal Assistance Services. Pennsylvania’s only option that offers both meaningful employer and budget authorities is the Services My Way program. Services My Way (SMW) is a Cash and Counseling program and is available for people in the Aging or Attendant Care waivers. In both the Aging and Attendant Care waivers, participants may also elect to use a SDC model that offers employer authority but not budget authority. These participants hire and manage their own workers using a Financial Management Service to assist with payroll and administrative functions. Though Services My Way is available state-wide (and a popular program in other states that have implemented it), fewer than 100 people have elected to use this model. This program has been poorly advertised and training for Service Coordinators has been inadequate.

#### Office of Mental Health and Substance Abuse Services (OMHSAS)

Pennsylvania's Medicaid State Plan includes Peer Support and all counties and county joinders are required to have at least two Peer Specialists available to consumers. Pennsylvania requires the certification of Peer Specialists who provide this service. The Pennsylvania Peer Support Coalition, sustained by the Pennsylvania Mental Health Consumers’ Association (PMHCA) and OMHSAS, support the networking and continuing education of Certified Peer Specialists.

#### Consumer Recovery Investment Fund (CRIF) Program –

The Delaware County Mental Health Office and Magellan Behavioral Health of Pennsylvania administer a consumer control pilot project which is operated by the Mental Health Association of Southeastern Pennsylvania (MHASP). The Consumer Recovery Investment Fund - Self-Directed Care (CRIF) project is a way of providing mental health services in which adults with serious mental illnesses directly control the funds spent on their recovery. In this project Certified Peer Specialists are trained to provide recovery coaching in a Self-Directed Care model. Participants, with the assistance of a Recovery Coach and the ability to flexibly use funds, develop a self-directed recovery plan. One of the key features of the CRIF model is that participants have access to “Freedom Funds” to assist in working toward recovery goals. The participant’s budget is based on use of behavioral health services in the two years prior to entry into the program. Any savings from reduction in use of clinical services is available to the participant as “Freedom Funds” to purchase non-traditional goods and services that support the recovery plan.

### Figure 1: CRIF Process for Person Centered Recovery Plan and Individual Budget

* Recovery Plan
* Participant meets with Recovery Coach and develops, implements, reviews, revises a person-centered recovery plan
* Individual Budget Amount Established
* Participant and Recovery Coach review 2 year historical spending on Behavioral Healthcare (doesn't include inpatient and crisis spending)
* Spending Plan to Support / Recovery Plan Established
* Within the individual budget, participant and Recovery Coach establish a spending plan to support the Recovery Plan
* Freedom Funds
* Any savings in use of in-plan services can be used to purchase non-traditional services. Care Manager at BH-MCO must authorize all expenditures

Table 2 provides a comparison of the self-directed models currently available in Pennsylvania.

#### Table 2: Comparison of SDC Options in Pennsylvania

|  | **ID Waivers (P/FDS and Consolidated)** | **Attendant Care and Aging** | **OBRA, COMMCARE, Independence** | **CRIF** |
| --- | --- | --- | --- | --- |
| **Target Population** | Ages 3+ with intellectual disability and ICF/ID Level of Care | Attendant Care: Physical disability ages 18-59  Nursing Facility level of care  Aging: Age 60+ Need Nursing Facility level of care | OBRA: 18-59 severe physical developmental disability requiring ICF/ORC Level of Care  Commcare: 21+ TBI and Nursing Facility level of care  Independence: 18-60 physical disability  Nursing Facility level of care | Delaware County HealthChoices adults and transition age youth with a SMI,  18 to 65 years of age, with 295 or 296 DSM IV-R diagnoses.  Utilization of Medicaid mental health and/or drug or alcohol services at least once every 3 months over the last 2 years  Legally competent to manage own affairs  Consenting to treatment and evaluation |
| **Funding Source** | 1915(c) HCBS Waiver | 1915(c) HCBS Waiver | 1915(c) HCBS Waiver | Traditional Services – Medicaid State Plan,  Freedom Funds - Non-Medicaid Reinvestment Funds |
| **Employer Authority** | Yes | Yes | Yes | No |
| **Budget Authority** | Yes – but limited to determining worker wages within state wage ranges | Yes – but limited to determining worker wages within state wage ranges  For people who opt for the Services My Way (Cash and Counseling) model - additional budget authority including the ability to purchase “participant goods and services.” [[23]](#footnote-23)  Note: This model is not being utilized to any significant extent in PA. | Yes – but limited to determining worker wages within state wage ranges | Yes.  The person develops and manages a budget for the recovery plan. Consumers may use their budget to purchase traditional mental health treatments and services as well as “alternative” (“Freedom Funds”) goods and services that directly support their personal recovery. |
| **Individual Budget** | No | Only for Services My Way participants | No | Yes |
| **Allowable Self-Directed Services** | * Home and Community Habilitation (Unlicensed) * Homemaker/Chore * Unlicensed Respite * Companion Services * Supports Broker * Supported Employment * Educational Support Services | Attendant Care: Participant Goods and Services, Participant-Directed Community Supports, Personal Assistance  Aging: Participant Goods and Services, Participant-Directed Community Supports, Personal Assistance, Respite | * Personal Assistance * Respite | Freedom Funds –non-traditional goods and services. |
| **Goods and Services** | No | Only for people who choose the Services My Way model | No | Yes |
| **Cash Disburse-ment** | No | No | No | Yes (restricted debit card) |
| **Information and Assistance** | Support Broker is an eligible service. Very few providers of the service statewide | Only available through Supports Coordination | Only available through Supports Coordination | Recovery Coach with specialized training in SDC |
| **Financial Manage-ment Services (FMS)** | Fiscal/Employer Agent (F/EA)  * Person is “common law employer,” also known as the “Employer of Record” of his or her staff. * Person responsible to recruit, hire and train staff; determine staff schedules and responsibilities; manage the daily activities of staff; and terminate staff when appropriate. * One statewide FMS agency (Public Partnerships, LLC or “PPL”). PPL responsible for withholding taxes, paying staff, providing workers’ compensation, conducting criminal and child abuse background checks.   **OR** AWC Model  * Person acts as the “Managing Employer” in a joint-employment arrangement with the FMS agency. * Person works with FMS agency to recruit qualified staff, train staff, determine workers’ schedules and responsibilities, and manage staff’s daily activities. * AWC is responsible for, hiring staff; processing employment documents; obtaining necessary criminal background and child abuse checks; paying staff; and providing workers’ compensation. | F/EA  * Person is “common law employer,” also known as the “Employer of Record” of his or her staff. * Person responsible to recruit, hire and train staff; determine staff schedules and responsibilities; manage the daily activities of staff; and terminate staff when appropriate. * One statewide FMS agency (Public Partnerships, LLC or “PPL”). PPL responsible for withholding taxes, paying staff, providing workers’ compensation, conducting criminal and child abuse background checks. | F/EA  * Person is “common law employer,” also known as the “Employer of Record” of his or her staff. * Person responsible to recruit, hire and train staff; determine staff schedules and responsibilities; manage the daily activities of staff; and terminate staff when appropriate. * One statewide FMS agency (Public Partnerships, LLC or “PPL”). PPL responsible for withholding taxes, paying staff, providing workers’ compensation, conducting criminal and child abuse background checks. | **Fiscal Agent**  The Fiscal Agent contracts with the County to manage Reinvestment Fund dollars used for alternative goods and services, while Behavioral Health MCO manages Medicaid claims for in-plan services.    Fiscal Agent services include:   * Payment for out-of-plan goods and services (may include debit card account – with established restrictions on purchases) * Tracking, monitoring and reporting of all expenditures |

### Existing Infrastructure for Self-Directed Care in Pennsylvania

Self-directed care models require a different infrastructure to deliver than traditional service models. Instead of per member per month, simple fee for service, or program funding, there is a need for managing and tracking individual budgets and expenses and, in many cases, providing a specialized payroll service that can also bill Medicaid. The 1915(c) waiver authority specifically requires states to provide certain key supports to participants who direct their services: financial management services and information and assistance.[[24]](#footnote-24) Pennsylvania has well-established infrastructure for delivering the financial management services for self-directed models that provide for employer authority.

#### Financial Management Services

In order for people to exercise employer authority, administrative support related to employer functions is necessary. Pennsylvania’s primarily uses a “Fiscal/Employer Agent” to perform this function. For both OLTL and ODP waivers, the state contracts with Public Partnerships, LLC (PPL) to perform this function on behalf of roughly 16,000 waiver participants. For people on the ID waivers, the state also offers an Agency With Choice (AWC) or co-employer model. The state contracts with over 20 local Agencies to provide this service.[[25]](#footnote-25) Through financial management services provided by the F/EA and AWCs, roughly 19,000 waiver participants self-directed at least once waiver service in 2014.

For both models of Financial Management Service, the Commonwealth pays a per member per month (PMPM) fee to the FMS and provides reimbursement for all authorized waiver services and supports processed by the FMS. In all of Pennsylvania’s waivers, FMS is an administrative service. Neither the F/EA nor AWC currently provides any cash disbursement as it is unallowable through 1915(c) waivers. Both models provide a specialized payroll service and have the ability to purchase approved vendors services.

#### Financial Management Services (FMS) supply the following in PA:

* Provider qualification
* Provider background check
* Payroll services (including filing all local, state and federal taxes)
* Obtain workers compensation on behalf of all employers
* Medicaid claims billing on behalf of the Commonwealth
* Provide monthly statements to waiver participants on utilization
* Provide reports to the Commonwealth

For the CRIF Project in Delaware County,the Fiscal Agent, the Mental Health Association of SE Pennsylvania, contracts with the County to manage Reinvestment Fund dollars used for alternative goods and services, while the Behavioral Health MCO manages Medicaid claims for in-plan services.

Fiscal Agent services include:

* Payment for out-of-plan goods and services (may include debit card account – with established restrictions on purchases)
* Tracking, monitoring and reporting of all expenditures

#### Information and assistance in directing services and supports.

When states opt to offer self-directed options, Medicaid match is available to reimburse the costs of individualized assistance to participants who self-direct their services and supports. This assistance may include:

* counseling participants about available services and supports
* support to build skills for developing and managing an individual budget
* help to recruit, screen, hire and manage their workers
* assisting them in locating services
* accessing other benefits and community resources.

States use various terms and models for this type of assistance, including: counseling, supports brokerage, supports coordination, or consulting. In Pennsylvania, this requirement is typically structured to be met by Supports Coordination. Stakeholders have expressed that this is an inadequate support structure as implemented[[26]](#footnote-26) Further, there is evidence that, in spite of program design and identified need for the information and assistance, approximately half of Supports Coordinators do not feel that it is their job to assist people in self-direction[[27]](#footnote-27)

#### Supports Broker/Recovery Coach in Self-Directed Care

Critical work is being done though Person Driven Services and Supports (PDSS)[[28]](#footnote-28) demonstration project and CRIF in the area of providing information and assistance for people who self-direct. Both projects have developed training packages, organizational structures and policies and procedures aimed at the development of providers of “information and assistance.” Through the PDSS project, Supports Brokers have been recruited, hired and trained to work with a cross-disability population. Through the CRIF project, Recovery Coaches have been recruited, hired and trained to work with participants in the behavioral healthcare system.

Information and assistance is an essential element for a robust SDC program. One of the barriers to people directing their own services is hesitancy or confusion about taking on the role of employer and managing an individual budget. Many people have never written a job description, managed a budget for services, had conversations about employee performance, discussed and weighed the value of the services they use, or done scheduling for support service workers. Support Brokers and Recovery Coaches in SDC are trained to support people with all aspects of exercising budget and employer authority.

Supports Broker and Recovery Coach services are intended to help blend paid and unpaid supports, to look at generic community services and supports before assuming specialized paid services are the solution to a need. In the CRIF project Recovery Coaches are Certified Peer Specialists with enhanced training for self-directed care. Part of the strength of the Recovery Coach model is that Recovery Coaches have lived experience in recovery and are rooted in community, not specialized, professional approaches. Recovery Coaching is about peers supporting each other to pursue self-directed plans. Recovery Coaches must “embrace self-determination as a cornerstone of successful recovery, and consistently convey this principle to consumers, family members and service providers.[[29]](#footnote-29) Both of these services are currently Medicaid billable services. Supports Brokering is an ID waiver service and Peer Support is a Medicaid State Plan service.

# Funding for Self-Directed Care in PA’s Behavioral Healthcare System

To expand upon the successes of the Consumer Recovery Investment Fund (CRIF) Project and create a sustainable SDC option in the behavioral healthcare system in PA, it is imperative that the program be designed to comply with Medicaid rules so that Pennsylvania is able to capture federal matching funds. With the 2010 passage of the Affordable Care Act there are some additional opportunities for states to serve people with mental illness and receive Medicaid matching funds. To this end, an analysis of applicable Medicaid authorities was conducted [see *Appendix B*]. From this analysis, three Medicaid authorities emerged as possibilities for sustainable funding. The 1915(i), 1115 Demonstration Waiver and “Rehabilitation Option” are all ways that SDC could be introduced statewide and obtain federal matching funds. Each of the options has advantages and drawbacks. Stakeholders need to weigh the below considerations for which option is the best for pursuit in the Commonwealth.

### Key Considerations for Medicaid Participation

1. PROGRAM DESIGN

* Is the program design *limited to budget authority* (like the current CRIF project) where a Recovery Coach works with a participant to develop a recovery plan and manage an individual budget that may include Freedom Funds if there are savings from reduced use of traditional services? OR
* Is the program design more expansive including *both employer and budget authorities*? Is the program design aimed at tackling other systemic issues like heavy reliance on Residential Treatment Facilities or high rates of unemployment by providing alternative service packages? Does program design promote self-determination to the greatest extent possible?
* Does the program design build on available infrastructure and strengths within DHS? or Does the program design require entirely new infrastructure?

1. POLITICAL FEASIBILITY

* How feasible is garnering administrative and/or legislative support for the option? What does the option provide in terms of promising practice, solutions to systemic issues? What kind of potential budget impact will the option have? What cost containment options are built into the option?

1. POPULATION THAT CAN BE SERVED

* Are there limitations on who can be served? Are these limitations acceptable or do they problematically compromise the intent of the program?

In Table 3, the key considerations for determining which Medicaid authority may be the most appropriate for expansion of SDC in Pennsylvania’s Behavioral Healthcare system are applied to the three most suitable authorities.

Table 3: Considerations Applied to 1915(i), 1115 and Rehabilitation Option

| **Consideration** | **1915(i)** | **1115 Demonstration** | **Rehabilitation Option** |
| --- | --- | --- | --- |
| **Budget Authority** | Yes, but no direct cash payments like CRIF Freedom Funds | Yes | Would be limited but could be defined |
| **Employer Authority** | Yes | Yes | No |
| **Promote self-determination to greatest extent possible for Behavioral Health** | Limited in scope | State has ability to design program and maximize opportunities | Limited in scope |
| **Ability to target broader systemic issues** | Yes, but not as a singular “package” and limited flexibility. Integration of 1915(i) services with existing services may be more difficult than with other MA authorities. | Broad design option allows | Narrow application |
| **Cost containment** | Creates a new entitlement to HCBS - could build in limitations on scope and duration to contain costs but all people eligible are entitled to receive | Requirement for budget neutrality | Population eligible to receive can be limited as well as scope, duration of service. |
| **Politically Feasibility** | Creating the new entitlement will be a tough sell | Because can define scope of coverage and program design could be aimed at tackling broader systemic issues, possibly. Budget neutrality could be perceived as an attractive safeguard for spending. | Narrow scope of change to PA’s Medicaid Plan may be the most attractive option |
| **Population that can be served** | All individuals eligible for Medicaid under the State plan up to 150% of Federal Poverty Level could access if they meet the functional needs/medical eligibility criteria.  May include special income group of individuals with income up to 300% SSI. Individuals must then be eligible for HCBS under a §1915(c), (d), or (e) waiver or §1115 demonstration program. | State determines | All Medicaid eligible individuals who meet diagnostic criteria outlined in State Plan |

## 

## State Plan Home & Community-Based Services 1915(i)

### Description

Under this Medicaid program, states can offer home and community-based services (HCBS) as part of the State Medicaid Plan instead of using the more traditional route of applying for a 1915(c) waiver which requires separate applications for different populations and regular renewal schedules. States can offer a variety of services under a State Plan HCBS benefit. People must meet State-defined criteria based on need and typically get a combination of acute-care medical services (like dental services, skilled nursing services) and long-term services (like respite, case management, supported employment and environmental modifications). Because it is part of the State Plan, there cannot be waiting lists for services under 1915(i) or caps on the numbers of people served.

**1915(i) State Plan HCBS: Options that States Have in Designing Program**

* Target the HCBS benefit to one or more specific populations
* Establish separate additional needs-based criteria for individual HCBS
* Establish a new Medicaid eligibility group for people who get State plan HCBS
* Define the HCBS included in the benefit, including State-defined and CMS-approved "other services" applicable to the population
* Option to allow any or all HCBS to be self-directed

### Considerations

1915(i) could be targeted to serve a specific population including people with mental illness. The federal rules regarding eligibility for 1915(i) are typically a little broader than many of the other Medicaid authorities. Through 1915(i) waivers, the Social Security Act allows states to provide home and community-based services (HCBS) to individuals who are ineligible for 1915(c) waivers because they do not require institutional level of care (LOC). Unlike with 1915(c) waivers, no determination must be made that “but for the provision of these services, individuals would require the LOC provided in a hospital, a nursing facility, or an intermediate care facility with individuals with disabilities (ICF/IID).” The state must set the medical eligibility criteria for the target population described in the application.

CMS allows states flexibility in establishing target group(s). In the final rule for 1915(i) CMS affirmed its suggestion in the proposed rule that “target population(s) could be based on diagnosis, disability, Medicaid eligibility groups, and/ or age.”[[30]](#footnote-30) The rule also allows states to propose more than one set of 1915(i) waivers, with each waiver targeted towards a specific population. A state can also propose a 1915(i) waiver that benefits multiple populations, and offer different services under the waiver to each defined target group. States do not need to target specific populations. Instead, a state may establish a 1915(i) waiver solely on needs-based criteria. Needs-based criteria can include both specific needs related to the targeting criteria, as well as general needs that apply across all populations eligible for 1915(i) services.

Like all Medicaid programs, in addition to functional eligibility, financial eligibility is also required for access to services available under a 1915(i) plan. All individuals eligible for Medicaid under the State plan up to 150% of Federal Poverty Level could access services outlined in the 1915(i) if they meet the functional needs/medical eligibility criteria. A state may also include a special income group of individuals with income up to 300% SSI. These individuals with income between 150% of FPL and 300% of SSI must be eligible for HCBS under a §1915(c), (d), or (e) waiver or 1115 Demonstration program (which would exclude people with a singular diagnosis of mental illness in PA).

### Who Could Be Served?

If Pennsylvania adopted 1915(i) to provide a sustainable SDC model, it could serve people with mental illness who met the criteria established by the state with income up to 150% of federal poverty level (FPL). Eligibility criteria similar to that established by CRIF could be proposed. Iowa has an approved 1915(i) targeting people with psychiatric disabilities which includes need-based and functional eligibility criteria like:

* “Has undergone or is currently undergoing psychiatric treatment more intensive than outpatient care more than once in a lifetime”
* “Has a need for assistance typically demonstrated by meeting at least two of the following criteria on a continuing or intermittent basis for at least two years:
* Is unemployed, or employed in a sheltered setting…
* shows severe inability to establish or maintain a personal social support system”[[31]](#footnote-31)

### Program Design

To use 1915(i) to fund a program design like CRIF, Pennsylvania could conceivably apply for a 1915(i) for a target population similar to that identified by CRIF with incomes below 150% of FPL. The HCBS that could be included would be (1) An equivalent of the Recovery Coach - specialized Supports Coordination or Supports Brokering and (2) “Participant-Directed Goods and Services” with a defined scope and duration. Participant-directed goods and services could be an alternative to the cash disbursement currently used in the CRIF program. No cash disbursements are allowable under 1915(i) however many of the same types of items could be purchased on behalf of participants. A Financial Management Service would be required to be used for the administering of the participant goods and services.

Pennsylvania could also use this option to provide a more expansive SDC program that includes both employer and budget authorities. In addition to the Recovery Coach Service and the Participant Goods and Services, typical HCBS-like habilitation, community integration, supported employment, respite, and family training could be available through this 1915(i) option.

### Key Challenges with 1915(i) as an Option for Sustainable SDC in PA:

1. Direct cash payment is not allowed in 1915(i). The current CRIF model of “Freedom Funds” as cash disbursements would not be allowable. Participant-Directed Goods and Services are allowable under 1915(i) and could be used as an alternative.
2. Politically 1915(i) may not be attractive because it could be seen as creating a new entitlement to services. 1915(i) adds services to the State Plan and all eligible people are entitled to receive them. Cost-containment strategies and perceptions of cost-containment could be difficult in this scenario.
3. 1915(i) was designed to make the administering of home and community-based services more streamlined for state and the federal government. Using 1915(i) to add a singular service (the goods and services that would substitute for Freedom Funds”) or to add goods and services and recovery coaching (as Supports Coordination or Brokering) for a targeted population may not be worth the administrative burden.[[32]](#footnote-32) If the adoption of 1915(i) HCBS services were aimed at additional systemic issues like high rates of unemployment or use of expensive services like Residential Treatment facilities, then 1915(i) may be seen as worth the administrative burden but still a potentially costly new entitlement.

## 1115 Demonstration and Research

### Description

The 1115 Demonstration provisions authorize the DHHS Secretary to consider and approve experimental, pilot or demonstration projects likely to assist in promoting the objectives of the Medicaid statute. The purpose of these demonstrations, which give States additional flexibility to design and improve their programs, is to demonstrate and evaluate policy approaches such as:

* Expanding eligibility to individuals who are not otherwise Medicaid or CHIP eligible
* Providing services not typically covered by Medicaid
* Using innovative service delivery systems that improve care, increase efficiency, and reduce costs.

In general, section 1115 Demonstrations are approved for a five-year period and can be renewed, typically for an additional three years. Demonstrations must be "budget neutral" to the Federal government, which means that during the course of the project, Federal Medicaid expenditures will not be more than Federal spending without the waiver.

### Options that States Have in Designing Program

* State can waive requirements for statewideness and comparability[[33]](#footnote-33) as well as other requirements.
* The state defines the eligibility group and criteria for eligibility.
* State decides what services are covered, subject to CMS approval.
* Participant goods and services are allowed.
* Cash benefits are allowed.
* State defines relationship to State Plan, waivers, and amendments, subject to CMS approval.

### Considerations

Using an 1115, a SDC program like CRIF could be demonstrated on a larger scale and receive federal matching funds for services and supports within the program during the demonstration period. The proposed demonstration could essentially take the CRIF program design including participant eligibility, the provider qualifications for the Recovery Coach, and the addition of “Freedom Funds” to the list of MA covered services and supports.

### Who Could Be Served?

The state proposes the eligibility group and criteria for eligibility and, because it is a demonstration, can determine to offer the model in certain geographic areas of the state or the whole state. Essentially, the state could propose the same criteria for eligibility that CRIF currently uses and define a number of areas of the state where it would be offered in order to conduct the demonstration.

### Program Design

The state determines how the 1115 interfaces with other Medicaid programs so conceivably an 1115 could be designed to replicate CRIF. As CRIF does now, the 1115 could essentially be used to work within the existing structures of Pennsylvania’s Behavioral HealthChoices, provide a Recovery Coach to assist with recovery planning, individual budgeting and budget authority as well as the use of Freedom Funds.

### Key Challenges with an 1115 Demonstration:

A few key considerations are: 1115 Demonstrations have a budget neutrality and program evaluation requirement and; if adopting a CRIF model, whether the use of an 1115 for the limited scope of the request for a waiver from Medicaid rules is the most appropriate Medicaid authority to seek.

1. In terms of the budget neutrality, most states use a per capita participant cap to ensure budget neutrality. Program design would have to address the budget neutrality which may be of concern given the preliminary research results indicating a lack of cost-savings from the CRIF project. Parallel to the considerations for the 1915(i), given the cost-neutrality restriction, it may make sense to design a program that includes an additional targeted approach to reduce use of high cost services like Residential Treatment and inpatient care and/or address reduction to costs through targeting employment outcomes. In addition to the CRIF “Freedom Funds” option, this program design could include more comprehensive self-directed care options like vouchers to purchase clinical and non-clinical services or a model that provides employer authority like self-directed personal assistance, companion or habilitation services, self-directed supported employment services, and transportation.
2. 1115 Demonstrations require strong evaluation component which would have to be built in to the program design.
3. Politically an 1115 Demonstration may be a more attractive approach than the 1915(i) because it requires budget neutrality, is aimed at addressing long term service system cost and design issues, and can easily be crafted to limit scale and scope and work in conjunction with existing service systems. However, the administrative burden of negotiating and implementing an 1115 may be a drawback.

### Rehabilitation Option

There is a provision within Social Security[[34]](#footnote-34) law referred to as the “Rehabilitation Option” which reads as follows:

13)[88] other diagnostic, screening, preventive, and **rehabilitative services**, including—

(C) any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.

Through this provision, Medicaid rules related to State Plan allow states some significant flexibility in designing their service packages to meet the needs of their populations. Rehabilitative services must be recommended by a physician or other licensed practitioner and be medically necessary.

### Considerations

In Pennsylvania we have a couple of uses of this provision that provide a good precedent for exploring this option to introduce the CRIF model into the State Plan. Peer Support Services are a rehabilitative service in the State Plan currently. The Adult Community Autism Program (ACAP) which is a managed care model uses this option in the federal statute to provide behavior specialist services. Further, in ACAP, there is a list of non-capitated items/services that the MCO can pay for as long as those things are identified in a needs assessment. These have included things like gym memberships.

### Who Could Be Served?

Pennsylvania’s State Plan currently outlines the eligibility for Peer Support Services. Similarly, the eligibility for the Recovery Coaching and Freedom Funds would be need to be described in the State Plan. The CRIF eligibility could be the proposed criteria.

### Program Design

Unlike the other Medicaid authorities, this option could allow for a more narrow or discrete (not creating a new Medicaid program using a new Medicaid authority) introduction of the CRIF model. Recovery Coaching and an accompanying benefit like “Recovery Promoting Goods and Services” (Freedom Funds) to fulfill objectives of a participant’s recovery plan would be new State Plan services available for people who need mental health rehabilitative services. The services would be administered through the existing managed care system.

#### Figure 2: Services Added to PA Medicaid State Plan with Rehabilitation Option

##### Recovery Coaching

* To include this option, the State Plan would require a modification to establish:
* Description of service, provider qualifications and limitations for the Recovery Coaching Service. This could be modeled after either Peer Support with additional training requirements in SDC models or Supports Broker in the ID system but either way would require a differentiation from Peer Support Services established in State Plan currently.
* It may also be prudent to include in this service description or provider qualifications the fiscal agent duties and requirements so there is an integrated mechanism to manage the Recovery Promoting Goods and Services.

##### Recovery Promoting Goods and Services (Freedom Funds-like benefit)

* An additional benefit that would prescribed in conjunction with the Recovery Coaching. This could be very similar to the current Freedom Funds.
* To incorporate this benefit, a description including the limitations related to the types of goods and services that could be covered as medically necessary to fulfill the objectives of the recovery plan and well as limitations on dollar amount and duration for use of this service would be also be detailed.
* The criteria for funds would need to be established and would require prior authorization through MCOs who would also monitor the expenditures. Cost containment could be managed through limitations on duration, scope or a yearly spending cap for both services.

#### Key Challenges with the Rehabilitation Option:

1. In order to gain support for this option a reasonable case will likely need to be made related to what costs are offset and what improved outcomes are expected (for example, greater levels of empowerment and community participation). Hard data in relation to inpatient use or individuals being at risk for inpatient care would be helpful for making the case for this addition in the State Plan.
2. A Behavioral Health Managed Care Organization rate adjustment may be needed depending on the expected utilization of the service. Substantial cost controls will need to be in place.
3. One of the compelling aspects of the CRIF model is the work that the Recovery Coaches do with participants to support them to develop a Recovery Plan, assess their utilization of behavioral health services, their satisfaction with those services, the extent to which those services promote their recovery and look at possible alternative approaches to meeting recovery goals. In the current CRIF project, it is this process wherein participants may achieve some savings that become Freedom Funds. Incorporating this incentive for savings into a State Plan “Recovery Promoting Goods and Services” benefit may not be feasible but it is worth pursuing the concept with the Office of Medical Assistance Programs and the Centers for Medicaid and Medicare Services.

# Conclusion

Self-Directed Care models are widely used in Pennsylvania and nationally for most populations of people with disabilities. People with psychiatric disabilities have largely been left out of these innovative practices. To-date, the handful of states that have tried SDC models have struggled to develop scalable and sustainable models. With changes in Medicaid policy instituted by the Affordable Care Act, states have additional options for coverage of services for people with mental illness and new options for self-direction. With these new opportunities, Pennsylvania’s infrastructure and experience with self-directed services for other populations, the experience of the Consumer Recovery Investment Funds Self-Directed Care (CRIF) demonstration, and a network of Certified Peer Specialists, the Commonwealth is poised for adoption of a sustainable, statewide SDC program for people with psychiatric disabilities.

Pennsylvania’s CRIF demonstration shows great promise as a recovery oriented approach to providing services in the behavioral healthcare system. There are several Medicaid authorities, the 1915(i), 1115 Demonstration and the Rehabilitation Option, which could work to introduce a CRIF or CRIF-like model of self-directed care statewide in Pennsylvania. With each of these Medicaid authorities, there are key decisions that will need to be made by stakeholders regarding the program design, integrity to a self-directed recovery oriented approach, and the feasibility of garnering administrative and political support.

Since the CRIF model operates using a budget authority but not employer authority and includes a limited introduction of new services (Recovery Coaching and “Freedom Funds”), unless a greater package of services were being added, the 1915(i) is not necessarily a good fit to accomplish this end. As well, managing the political perceptions of the creation of a new entitlement may be difficult and actually made more difficult if the package of services were to be expanded. Compromises in program design that would be necessary under 1915(i) are that no cash disbursement is allowed so recovery-oriented goods and services would need to be purchased through a financial management services.

The 1115 Demonstration model could allow for essentially adopting the CRIF model on a larger scale by identifying additional geographic areas where it would be replicated. Further, like the 1915(i), the 1115 would also support a more expansive program design. The 1115 could include more comprehensive self-directed care options like vouchers to purchase clinical and non-clinical services, or a model that provides employer authority like self-directed personal assistance, companion or habilitation services, self-directed supported employment services, and transportation. The biggest challenges with use of the 1115 Demonstration are likely the federal requirement for budget neutrality and negotiating the program design and administration of a new project.

To expand the CRIF model statewide and capture Medicaid matching funds, using the “Rehabilitation Option” in Social Security may be the most feasible option. Using this option would entail adding two benefits to the State Plan: the Recovery Coach and an equivalent to Freedom Funds, possibly something like “Recovery Promoting Goods and Services.” The major challenge with this option for Medicaid coverage is whether program design would allow for somehow connecting the savings from utilization of traditional services to the amount of funding available for Freedom Funds which is an important feature of the current CRIF program. Additionally using the Rehabilitation Option may require a slight rate adjustment for the managed care organizations.

# References

Brekke, J. S., Siantz, E., Pahwa, R., Kelly, E., Tallen, L., & Fulginiti, A. (2013). Reducing health disparities for people with serious mental illness: Development and feasibility of a peer health navigation intervention. *Best Practice in Mental Health*, 9(1), 62-82.

Carlson, B. L., Foster, L., Dale, S. B., & Brown, R. (2007). Effects of cash and counseling on personal care and well‐being. *Health Services Research*, 42(1p2), 467-487.

Cook, J.A., Russell, C., Grey, D.D., & Jonikas, J.A. (2008). A self-directed care model for mental health recovery. *Psychiatric Services*, 59(6), 600–602.

Centers for Medicaid and Medicare Services. (2008). Application for a §1915(c) home and community-based waiver [Version 3.5]: Instructions, technical guide. Department of Health and Human Services.

Dale, Stacy B. and Randall S. Brown. (2006). Reducing nursing home use through consumer-directed personal care services.” *Med Care*, 44(8): 760-7.

Dale, S., Brown, R., Phillips, B. Schore, J. and Carlson, B. (November 2003). The effects of cash and counseling on personal care services and Medicaid costs in Arkansas. *Health Affairs: Data Watch.*

DMA Health Strategies. (July 2009). Self-directed care policy and procedures manual: Consumer recovery investment funds.

Druss, B. G., Zhao, L., Silke, A., Bona, J. R., Fricks, L., Jenkins-Tucker, Sterling, E., DiClemente, R. , & Lorig, K. (2010). The Health and Recovery Peer (HARP) Program: a peer-led intervention to improve medical self-management for persons with serious mental illness. *Schizophrenia Research*, 118(1), 264-270.

Hall, R. Ph.D. (2007) Report on the effectiveness of the self-directed care community mental health treatment program. Florida Department of Children & Families, Substance Abuse & Mental Health Program Office.

National Resource Center for Participant-Directed Services. (September 2014) Facts and figures: 2013 national inventory survey on participant direction. retrieved from <https://nrcpds.bc.edu/details.php?entryid=445> April 13, 2015

Ng, T., Harrington, C., Musumeci, M., & Reaves, E. L. (Dec. 22, 2014). Medicaid home and community-based services programs: 2011 data update. Kaiser Family Foundation. Retrieved from <http://kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2011-data-update/>

Reinhard, S. Kassner, E. Houser, A., Ujvari, K., Mollica, R. and Hendrickson, L. ( 2014) Raising expectations: a state scorecard on long-term services and supports for older adults, people with physical disabilities and family caregivers. Retrieved from <http://www.longtermscorecard.org/~/media/Microsite/Files/2014/Reinhard_LTSS_Scorecard_web_619v2.pdf>

Sciegaj, M., Mahoney, K. J., Schwartz, A. J., Simon-Rusinowitz, L., Selkow, I., & Loughlin, D. M. (2014). An inventory of publicly funded participant-directed long-term services and supports programs in the united states. *Journal of Disability Policy Studies*.

Shen, C., Smyer, M.A., Mahoney, K.J., Loughlin, D.M., Simon-Rusinowitz, L., & Mahoney, E.K. (2008). Does mental illness affect consumer direction of community-based care? Lessons from the Arkansas cash and counseling program. *The Gerontologist*, 48(1), 93–104.

Slade, E. (2012). Feasibility for Expanding Self-Directed Services to People with Serious mental Illness. U.S. Department of Health and Human Services.

Spaulding-Givens, J. C., & Lacasse, J. R. (2015). Self-directed care: Participants’ service utilization and outcomes. *Psychiatric Rehabilitation Journal*, 38(1), 74-80.

Stakeholder Planning Team. (October 19, 2010). Power to the people summary and report: A summit on planning for services controlled by people with disabilities. Pennsylvania DD Council.

# Appendix A: Current Eligibility Criteria for CRIF Project Participation

## CRIF Eligibility Criteria[[35]](#footnote-35)

* Delaware County HealthChoices adults and transition age youth with a serious mental illness from 18 to 65 years of age, with 295 or 296 DSM IV-R diagnoses.
* Utilization of Medicaid mental health and/or drug or alcohol services at least once every three months over the last two years
* Legally competent to manage own affairs
* Consenting to treatment and evaluation

## Exclusionary criteria

* Individuals with a primary diagnosis of substance abuse
* Individuals who have been hospitalized in the previous six months
* Consumers who have used either far less or far more service than average in the seriously mentally ill population

# Appendix B: Medicaid Authorities and Self-Directed Care in PA’s Mental Health Services System

## 1915(b)(3) Reinvestment Funds Managed Care

### Description:

**1915(b) Managed Care Waivers are one of several options available to states that allow the use of**[**Managed Care**](http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/managed-care/managed-care-site.html) **in the Medicaid Program. When using 1915(b), states have four different options:**

* **[1915(b)(1)]** - Implement a managed care delivery system that restricts the types of providers that people can use to get Medicaid benefits
* **[1915(b)(2)]** - Allow a county or local government to act as a choice counselor or enrollment broker) in order to help people pick a managed care plan
* **[1915(b)(3)]** - Use the savings that the state gets from a managed care delivery system  to provide additional services
* **[1915(b)(4)]** - Restrict the number or type of providers who can provide specific Medicaid services (such as disease management or transportation)[[36]](#footnote-36)

### Considerations:

Pennsylvania’s current behavioral health care system is provided through 1915(b)(1)(2)(4) Medicaid authorities. PA does not currently participate in 1915(b)(3). In not participating in 1915(b)(3) Pennsylvania does not receive federal match (FMAP)[[37]](#footnote-37) for reinvestment or “savings”.

To use 1915(b)(3) to introduce SDC models into the behavioral healthcare system, BH-MCOs could be required to use at least some reinvestment funds to pay for Freedom Funds. It may be a cost-effective approach for the Commonwealth to include the 1915(b)(3) option to our managed care system because those funds would then be eligible for federal matching funds.

Challenges with this option:

1. There is a federal budget neutrality standard which may be difficult to comply with.
2. Reinvestment funds fluctuate so this would not be the most stable source of funding.
3. This option would probably be very politically unpopular. PA chose not to participate in (b)(3) because counties wanted flexibility beyond what was available under federal guidelines. County administrators are unlikely to give this flexibility up.

## 1915(i) State Plan Home and Community Based Services

### Description:

**State Plan Home & Community-Based Services 1915(i)**

Under this Medicaid program, states can offer HCBS as part of the state Medicaid Plan instead of using the more traditional route of applying for a 1915(c) waiver which requires separate applications for different populations and regular renewal schedules.

States can offer a variety of services under a State Plan Home and Community-Based Services (HCBS) benefit. People must meet State-defined criteria based on need and typically get a combination of acute-care medical services (like dental services, skilled nursing services) and long-term services (like respite, case management, supported employment and environmental modifications). Because it is part of the State Plan, there cannot be waiting lists for services under 1915(i) or caps on the numbers of people served.

**1915(i) State Plan HCBS: Options that States Have in Designing Program**

* Target the HCBS benefit to one or more specific populations
* Establish separate additional needs-based criteria for individual HCBS
* Establish a new Medicaid eligibility group for people who get State plan HCBS
* Define the HCBS included in the benefit, including State-defined and CMS-approved "other services" applicable to the population
* Option to allow any or all HCBS to be self-directed

### Considerations

1915(i) could be targeted to serve a specific population including people with mental illness. The federal rules regarding eligibility for 1915(i) are typically a little broader than many of the other Medicaid authorities. Through 1915(i) waivers, the Social Security Act allows states to provide home and community-based services (HCBS) to individuals who are ineligible for 1915(c) waivers because they do not require institutional level of care (LOC). Unlike with 1915(c) waivers, no determination must be made that “but for the provision of these services, individuals would require the LOC provided in a hospital, a nursing facility, or an intermediate care facility with individuals with disabilities (ICF/IID).” The state must set the medical eligibility criteria for the target population described in the application.

CMS allows states flexibility in establishing target group(s). In the final rule for 1915(i) CMS affirmed its suggestion in the proposed rule that “target population(s) could be based on diagnosis, disability, Medicaid eligibility groups, and/ or age.”[[38]](#footnote-38) The rule also allows states to propose more than one set of 1915(i) waivers, with each waiver targeted towards a specific population. A state can also propose a 1915(i) waiver that benefits multiple populations, and offer different services under the waiver to each defined target group. States do not need to target specific populations. Instead, a state may establish a 1915(i) waiver solely on needs-based criteria. Needs-based criteria can include both specific needs related to the targeting criteria, as well as general needs that apply across all populations eligible for 1915(i) services.

Like all Medicaid programs, in addition to functional eligibility, financial eligibility is also required for access to services available under a 1915(i) plan. All individuals eligible for Medicaid under the State plan up to 150% of Federal Poverty Level could access services outlined in the 1915(i) if they meet the functional needs/medical eligibility criteria. A state may also include a special income group of individuals with income up to 300% SSI. These individuals with income between 150% of FPL and 300% of SSI must be eligible for HCBS under a §1915(c), (d), or (e) waiver or 1115 Demonstration program (which would exclude people with a singular diagnosis of mental illness in PA).

Challenges with this option:

1. Direct cash payment is not allowed in 1915(i). The current CRIF model of “Freedom Funds” as cash disbursements would not be allowable. Participant-Directed Goods and Services are allowable under 1915(i) and could be used as an alternative.
2. Politically 1915(i) may not be attractive because it could be seen as creating a new entitlement to services. 1915(i) adds services to the State Plan and all eligible people are entitled to receive them. Cost-containment strategies and perceptions of cost-containment could be difficult in this scenario.
3. 1915(i) was designed to make the administering of home and community-based services more streamlined for state and the federal government. Using 1915(i) to add a singular service (the goods and services that would substitute for Freedom Funds”) or to add goods and services and recovery coaching (as Supports Coordination or Brokering) for a targeted population may not be worth the administrative burden.[[39]](#footnote-39)

If there were additional systemic issues that could be addressed like unemployment or over-reliance on expense services like Residential Treatment facilities and those could be addressed by adding Habilitation and a variety of employment services to the State Plan, then 1915(i) may be seen as worth the administrative burden but still a potentially costly new entitlement.

## 1115 Research and Demonstration Project

### Description

The 1115 Demonstration provisions authorize the DHHS Secretary to consider and approve experimental, pilot or demonstration projects likely to assist in promoting the objectives of the Medicaid statute. The purpose of these demonstrations, which give States additional flexibility to design and improve their programs, is to demonstrate and evaluate policy approaches such as:

* Expanding eligibility to individuals who are not otherwise Medicaid or CHIP eligible
* Providing services not typically covered by Medicaid
* Using innovative service delivery systems that improve care, increase efficiency, and reduce costs.

In general, section 1115 Demonstrations are approved for a five-year period and can be renewed, typically for an additional three years. Demonstrations must be "budget neutral" to the Federal government, which means that during the course of the project, Federal Medicaid expenditures will not be more than Federal spending without the waiver.

**Options that States Have in Designing Program**

* State can waive requirements for statewideness and comparability[[40]](#footnote-40) as well as other requirements.
* The state defines the eligibility group and criteria for eligibility.
* State decides what services are covered, subject to CMS approval.
* Participant goods and services are allowed.
* Cash benefits are allowed.
* State defines relationship to State Plan, waivers, and amendments, subject to CMS approval.

**Considerations**

The 1115 Demonstration allows states considerable flexibility in terms of scale, scope and program design.

The state defines the eligibility group and criteria for eligibility. States may combine service populations.

State estimates numbers served. Operates as an entitlement to all who are eligible.

State decides what services are covered, subject to CMS approval.

Participant goods and services as well as cash benefits are allowed.

State determines how the 1115 interfaces with other Medicaid programs so conceivably an 1115 could be designed to target a specific group within Behavioral HealthChoices group in Pennsylvania to offer a self-directed approach in-line with the CRIF demonstration project. The 1115 could essentially be used to work within the existing structures of Pennsylvania’s Behavioral HealthChoices.

Challenges with this option:

1. Budget neutrality - Budget neutrality must be maintained. Caps or benefit limits may apply for individual resource allocations or budgets. Services cannot in aggregate cost more than without the 1115 waiver.
2. Given the cost-neutrality restriction and the data from the CRIF project on cost, program design would likely need to include a targeted approach to reduce use of high cost services like Residential Treatment and inpatient care and/or address reduction to costs through targeting employment outcomes. In addition to the CRIF “Freedom Funds” option, this program design could include more comprehensive self-directed care options like Supports Brokering or Recovery Coaching from CPS with training in self-directed care models; financial management services and WRAP; self-directed personal assistance, companion or habilitation services; self-directed supported employment services; and transportation. 1115 also requires negotiation with the DHHS about program design and a significant evaluation component.
3. Politically this may be a more attractive approach because it requires budget neutrality, is aimed at addressing long term service system cost and design issues, and can easily be crafted to limit scale and scope and work in conjunction with existing service systems.

# 1915(k) Community First Choice (CFC) Option

## Description

Medicaid State Plan option that allows states to provide statewide home and community-based attendant services and supports to individuals who would otherwise require an institutional level of care (LOC). States taking up the option will receive a 6% increase in FMAP.

To be eligible for CFC services, beneficiaries must otherwise require an institutional LOC and meet financial eligibility criteria. CFC services must be provided statewide with no enrollment caps. Services can be provided under an agency-provider model (within which individuals must maintain the ability to have a significant role in the selection and dismissal of providers of their choice), a self-directed model, or other models approved by CMS. Specific services are determined following a face-to-face assessment of an individual’s needs and a person-centered planning process directed by the individual to the maximum extent possible.

CFC is a new State plan option to provide “person-centered” home and community-based attendant services and supports. Key features of the CFC options are:

* CFC is a State Plan option, NOT a waiver
* Because CFC is a State plan option, it must be offered to all those eligible for Medical assistance under the State Plan, who meet the benefit specific eligibility requirements
* Services must be provided on a statewide basis
* Cannot cap the number served, and cannot target
* CFC *requires* that states allow for the provision of services to be self-directed
* May provide for direct cash payments to individuals enrolled in CFC
* May use vouchers
* May provide financial management services-(but must provide this if individuals cannot manage the cash option without assistance)
* Must provide supports for self-direction

Required CFC services include: services that assist beneficiaries with activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, or cueing; services for the acquisition, maintenance, and enhancement of skills necessary for individuals to accomplish activities of daily living, instrumental activities of daily living, and health-related tasks; “self-direction” opportunities including voluntary training on how to select, manage, and dismiss direct care workers; and backup systems (such as beepers or other electronic devices) to ensure continuity of services and supports.

State selects from these for Self-directed Service Models:

1. Agency-provider model - Agency either provides or arranges for services. Individual has a significant role in selection and dismissal of employees, for the delivery of their care, and the services and supports identified in the person-centered service plan
2. Self-directed model with service budget which affords the person the authority to: recruit and hire or select attendant care providers, dismiss providers, supervise providers including assigning duties, managing schedules, training, evaluation, determining wages and authorizing payment, manage a Service Budget that was developed and approved by the State based on the assessment of functional need and person-centered service plan
3. Other models at state request and CMS approval

### Considerations

* CFC offers some of the greatest opportunity for self-direction. CFC does, however, primarily aim to provide assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (iADLs). Other types of services and supports can be included but with limits.
* There is a growing coalition around adopting CFC. This coalition includes the Centers for Independent Living. The Person Driven Services and Supports Coalition recently agreed to join other groups advocating for the adoption of CFC. The PDSS Coalition supports Community First Choice as a Medicaid option in Pennsylvania and will specifically advocate that the state design the plan to allow for maximum self-direction and control allowable under the federal regulations and adjustment of eligibility criteria to be more inclusive, specifically for people with diagnosis of intellectual/developmental disability or serious mental illness. Essentially, there will be a significant advocacy effort from the physical disability community and the cross-disability Person-Driven Services Coalition for the adoption of CFC including self-directed care options.
* Governor Corbett’s Long Term Care Commission recommended studying CFC as an option in PA. Governor Wolf’s Administration has commissioned University of Pittsburgh to study the costs of implementation.
* People who are eligible for CFC can use it in conjunction with other services. Someone accessing the behavioral health system who is also eligible could incorporate CFC services including goods and services or the cash benefit into their recovery plan.

Challenges with this option:

1. Though the CFC includes some of the best Medicaid provisions related to self-directed care models, eligibility limitations mean that many people with SMI would be excluded from participation unless they have co-occurring disabilities that require Nursing Facility or Intermediate Care Facility Level of Care.[[41]](#footnote-41)
2. Though the 6% FMAP (with no time limits) increase is attractive and CFC will likely reduce the use of facility-based care and therefore costs, the budget implications of CFC are unclear at this point. People on waiting lists for other services (13,500 waiting for ID services) would presumably be eligible for CFC and it is an entitlement. Further, people who participate in the capped P/FDS waiver (13,300) would also be eligible to access this service. Political opposition to CFC could be strong because it creates an entitlement to HCBS services and potentially has a large price tag.

# 1915(c) Home and Community Based Waiver

1915(c) waivers are the most commonly used funding stream to deliver home and community-based services. In 2011 more than 1.45 million were served through § 1915(c) waivers (47 states and DC)[[42]](#footnote-42) Within broad Federal guidelines, States can develop home and community-based services waivers (HCBS Waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.

States can operate as many HCBS Waivers as they want. Currently, more than 300 HCBS Waiver programs are active nationwide.[[43]](#footnote-43) Pennsylvania operates 10.

State HCBS Waiver programs must:

* Demonstrate that providing waiver services will not cost more than providing these services in an institution
* Ensure the protection of people’s health and welfare
* Provide adequate and reasonable provider standards to meet the needs of the target population
* Ensure that services follow an individualized and person-centered plan of care
* States can waive certain Medicaid program requirements under HCBS Waivers, including:
* Statewideness
* Comparability of services (Section 1902(a)(10)(B)): Lets States make waiver services available only to certain groups of people who are at risk of institutionalization. For example, States can use this authority to target services to the elderly, technology-dependent children, people with behavioral conditions, or people with intellectual disabilities.
* Income and resource rules applicable in the community.[[44]](#footnote-44) Pennsylvania currently sets the income limits for all 1915(c) waivers at 300% of SSI.

This waiver enables States to offer services to meet the needs of a particular target group. Within these target groups, States are also permitted to establish additional criteria to further target the population to be served on a HCBS waiver (e.g. target by age or diagnosis such as autism, epilepsy, cerebral palsy, traumatic brain injury, HIV/AIDS; etc.). Eligible individuals must demonstrate the need for a Level of Care that would meet the State’s eligibility requirements for services in an institutional setting. Target groups can be Aged or disabled; Intellectually disabled or developmentally disabled; Mentally ill (ages 22-64); or Any subgroup of these. States may also combine coverage for multiple target populations into one waiver to facilitate streamlined administration of HCBS waivers and to facilitate use of waiver design that focuses on functional needs.

States choose the maximum number of people that will be served under a HCBS Waiver program and are allowed to maintain waiting lists for services.

States can offer a variety of services under an HCBS Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), supported employment, day treatment or partial hospitalization, psychosocial rehabilitation services, homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose “other” types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.

1915(c) does allow for the purchase of individual goods and services, but does not allow for cash payments.

### Considerations

1915(c) waivers are typically designed as comprehensive long term services and supports for a target population. 1915(c) waivers can operate concurrently with a 1915(b). This means that Pennsylvania could offer some additional services for a target population and administer those services through managed care.

Eligibility requires that people meet institutional level of care.

A number of states have waivers for targeted groups that offer only a self-directed model of service in that waiver.

Pennsylvania has vast experience administering 1915(c) waivers and extensively uses two models of Financial Services Management for people who self-direct services in these waivers.

Challenges with this option:

1. Direct cash payment is not allowed in 1915(c). Current CRIF model of “Freedom Funds” would not be allowable.
2. Federal eligibility criteria for 1915(c) requires that to be eligible a person with mental illness would have to meet the level of care for an institutional setting and be ages 22-64. 1915(c) is limited and does not allow for children or transition age youth with mental illness to receive services.
3. Though Pennsylvania has a great deal of experience managing 1915(c) waivers, the administrative burden is significant and there may be resistance to taking on administration of another 1915(c).

## “Rehabilitation Option” in State Plan

### Description

#### Social Security Act Sec. 1905. [42 U.S.C. 1396d] (a) (13)(C)

“13)[88] other diagnostic, screening, preventive, and **rehabilitative services**, including—

(C) any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.”

Medicaid rules related to State Plan options allow states some significant flexibility in designing their State Plan services to meet the needs of their populations.

Rehabilitative services must be recommended by a physician or other licensed practitioner and be medically necessary.

### Considerations

In Pennsylvania we have a couple of uses of this provision that provide a good precedent for exploring this option to introduce the CRIF model into the State Plan.

Peer Support Services are a rehabilitative service in the State Plan currently.

The Adult Community Autism Program (ACAP) uses this option in federal statute to provide behavior specialist services. Further, in ACAP, there is a list of non-capitated items/services that the MCO can pay for as long as those things are identified in a needs assessment. These have included things like gym memberships.

Unlike the other Medicaid authorities, this option could allow for a more narrow or discrete (not creating a whole new Medicaid program using a new Medicaid authority) ntroduction of the CRIF model. The State Plan would require a modification to establish the requirements for the professional who would be conducting the needs assessment and recovery planning (could be modelled after either Peer Support with additional training requirements in SDC models or Supports Broker in the ID system but either way will likely require a differentiation from PSS established in State Plan currently) and the limitations related to the types of goods and services that could be covered as medically necessary to fulfill the objectives of the recovery plan.

The criterion for funds would need to be established and then prior authorization through MCOs who would also monitor the expenditures. Cost containment could be managed through limitations on duration, scope or a yearly spending cap.

Challenges with this option:

1. In order to sell this option will likely need to make a reasonable case related to what costs are offset. Will need hard data in relation to inpatient or individual being at risk for inpatient.
2. MCO rate adjustment may be needed – need to have significant cost controls in place.
3. Need to consider integrity to program model. Freedom Funds are currently connected to the recovery planning process and savings from reduction in use of traditional services. This may be difficult or impossible to implement using the Rehabilitation Option.

# Appendix C: Abbreviations and Glossary of Terms[[45]](#footnote-45)

* **ADLs**- Activities of daily living are the basic daily tasks that independently functioning individuals perform, including bathing, dressing, moving from a bed to a chair, eating, and toileting. An individual’s eligibility for long-term care supports and services is often linked to their inability to independently accomplish a certain number of ADLs.
* **BH-MCO** – Behavioral Health Managed Care Organization
* **FMAP** - Federal Medical Assistance Percentage, used to determine the amount of Federal matching funds for State expenditures for Medicaid.
* **FMS** – Financial Management Services are also called fiscal intermediary or fiscal agent services. FMS is an administrative service to support people to self-direct their services. FMS can provide payroll services as well as purchase goods and services on behalf of a person who self-directs.
* **HCBS** - Home and Community Based Services, including waivers, are designed to allow eligible individuals to receive services while remaining in their own home or community.
* **iADLs** - Instrumental activities of daily living are tasks that while not necessary for daily functioning, are essential to living independently, including doing light housework, preparing and cleaning up after meals, taking medication, shopping for groceries or clothes, using the telephone, managing money, taking care of pets, using communication devices, getting around the community and responding to emergency alerts such as fire alarms.
* **ICF/ID** - Intermediate Care Facilities for Individuals with Intellectual Disability.
* **ICF/ORC** – Intermediate Care Facilities for People with Other Related Conditions
* **LOC** - Level of care, this is the amount of assistance an individual needs to accomplish their daily activities. Individuals must meet a certain level of care to be eligible for long-term supports and services.
* **MCO** - Managed care organizations, which are health care delivery systems organized to manage cost, utilization and quality, providing Medicaid health benefits and services through contractual agreements between State Medicaid agencies and MCOs.
* **ODP -** Office of Developmental Programs, within the Pennsylvania’s Department of Human Services.
* **OLTL –** Office of Long Term Living, housed within the Pennsylvania’s Department of Human Services.
* **OMHSAS** -Office of Mental Health and Substance Abuse Services, housed within the Pennsylvania’s Department of Human Services.
* **PDS** – Participant-directed services or person-driven services are interchangeable terms with self-directed services. Self-directed are services allow participants to have decision-making authority and take direct responsibility over managing services with the assistance of available support as part of a person-centered planning process, as an alternative to traditionally delivered and manages services through an agency model. May include “employer authority” which is the decision-making authority to recruit, hire, train and supervise the individuals who provide the services, and/ or “budget authority,” which is the decision-making authority as to how Medicaid funds in the participant’s budget are spent.

**SDC** – see explanation for PDS.

1. Pursuant to section 1905(a)(24) of Social Security Act [↑](#footnote-ref-1)
2. Sciegaj, M., Mahoney, K. J., Schwartz, A. J., Simon-Rusinowitz, L., Selkow, I., & Loughlin, D. M. (2014) [↑](#footnote-ref-2)
3. The range for HCBS versus institutional setting ranges dramatically with just 6% of people with I/DD being served in institutional settings and 61% of new Medicaid aged/ disabled long term services and supports users receiving services in Nursing Facilities [↑](#footnote-ref-3)
4. Data Source: Office of Long Term Living Enrollment Date Q1 2014 and Public Partnerships, LLC Enrollment Data Q1 2014; Office of Developmental Programs Enrollment Data Q1 2014 [↑](#footnote-ref-4)
5. Slade (2012). p. v [↑](#footnote-ref-5)
6. <https://store.samhsa.gov/shin/content/PEP12-RECDEF/PEP12-RECDEF.pdf> Retrieved on April 1, 2015 [↑](#footnote-ref-6)
7. Slade (2012). p. iii-iv [↑](#footnote-ref-7)
8. Self-Direction Guidelines retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html> [↑](#footnote-ref-8)
9. Self-Direction Guidelines retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html> [↑](#footnote-ref-9)
10. Slade (2012). p. v [↑](#footnote-ref-10)
11. Definitions of Cash and Counseling vary but the main components can be explained like this:

    *Cash* - people with disabilities have the option to manage a flexible budget and decide what mix of goods and services best meet their personal care needs.

    *Counseling* - providing information and assistance to individuals who direct their own services. It is a key supportive service in self-direction programs. The goal of counseling is the same: to offer flexible and personalized support to ensure that self-direction works for the participants who choose it. (National Resource Center for Participant-Directed Services) [↑](#footnote-ref-11)
12. Dale, Stacy B. and Randall S. Brown (2006) p.760-7 [↑](#footnote-ref-12)
13. Dale, S., Brown, R., Phillips, B. Schore, J. and Carlson, B. (2003). [↑](#footnote-ref-13)
14. Carlson, Barbara Lepidus, et al. (2007) [↑](#footnote-ref-14)
15. Dale, Stacy B. and Randall S. Brown. (2006). [↑](#footnote-ref-15)
16. Shen et al., (2008). [↑](#footnote-ref-16)
17. Cook et al., (2008) [↑](#footnote-ref-17)
18. Cook, J. A., Russell, C., Grey, D. D., & Jonikas, J. A. (2008). [↑](#footnote-ref-18)
19. Brekke et al., (2013); Rosenick & Rosenheck, (2008). [↑](#footnote-ref-19)
20. Druss et al., (2010) [↑](#footnote-ref-20)
21. 2013 National Inventory Survey on Participant Direction [↑](#footnote-ref-21)
22. 2013 National Inventory Survey on Participant Direction [↑](#footnote-ref-22)
23. CMS defines Participant Goods and Services as: “[Services, equipment or supplies not otherwise provided through this waiver or through the Medicaid State Plan that address an identified need in the service plan (including improving and maintaining the participant’s opportunities for full membership in the community) and meet the following requirements: the item or service would decrease the need for other Medicaid services; AND/OR, promote inclusion in the community; AND/OR, increase the participant’s safety in the home environment; AND, the participant does not have the funds to purchase the item or service or the item or service is not available through another source. Participant Directed Goods and Services are purchased from the participant directed budget. Experimental or prohibited treatments are excluded. Individual Directed Goods and Services must be documented in the service plan.” Centers for Medicaid and Medicare Service & Cindy Mann. (Nov. 19, 2009). *CMS State Medicaid Directors Letter SMD # 09-007: Implementation of section 6087 of DRA - Section 1915(j)*. Retrieved from <http://downloads.cms.gov/cmsgov/archiveddownloads/SMDL/downloads/SMD111909.pdf> [↑](#footnote-ref-23)
24. Described on pages 5-6 [↑](#footnote-ref-24)
25. ODP Communication Number: Memo 044-14 [http://www.temple.edu/thetrainingpartnership/resources/pds/docs/044-14\_InfoMemo\_AWClisting.pdf](http://www.temple.edu/thetrainingpartnership/resources/pds/docs/044-14_InfoMemo_AWClisting.pdf%20) [↑](#footnote-ref-25)
26. Stakeholder Planning Team. (October 19, 2010). [↑](#footnote-ref-26)
27. Survey Report (September 24, 2014) Services My Way Survey Report. Temple University’s Institute on Disabilities. [↑](#footnote-ref-27)
28. [www.drnpa.org/person-driven-services/](http://www.drnpa.org/person-driven-services/) [↑](#footnote-ref-28)
29. DMA Health Strategies. (July 2009). p21 [↑](#footnote-ref-29)
30. States also have the option to create a new 1915(i) eligibility group based on the group(s) defined in 1902(a)(10)(A)(ii)(XXII) of the Act. [↑](#footnote-ref-30)
31. Iowa 1915(i) State Plan HCBS. Approved May 1, 2014. p.10 [↑](#footnote-ref-31)
32. Because the population is targeted in this scenario, the state would likely have to submit renewal applications every 5 years. For non-targeted 1915(i)s there is a one-time approval. [↑](#footnote-ref-32)
33. The comparability requirement states that medical assistance provided to eligible individuals “shall not be less in amount, duration, or scope than the medical assistance made available to any other individual[s].” Social Security Act, § 1902, 42 U.S.C. § 1396a(a)(10)(B)(i)-(ii)(2012) [↑](#footnote-ref-33)
34. Social Security Act Sec. 1905. [42 U.S.C. 1396d] (a) (13)(C) [↑](#footnote-ref-34)
35. DMA Health Strategies. (July 2009). Self-directed care policy and procedures manual: Consumer recovery investment funds. [↑](#footnote-ref-35)
36. Medicaid.gov. *1915(b) Managed Care Waivers*. Retrieved <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/managed-care-1915-b-waivers.html> [↑](#footnote-ref-36)
37. Medicaid is a Federal program administered by the States, and costs are shared between the Federal and State governments. CMS pays each state a percentage of its total Medicaid expenditures. This percentage is called the Federal Medicaid Assistance Percentage (FMAP). The rate for PA for 2015 is 51.68% [↑](#footnote-ref-37)
38. States also have the option to create a new 1915(i) eligibility group based on the group(s) defined in 1902(a)(10)(A)(ii)(XXII) of the Act. [↑](#footnote-ref-38)
39. Because the population is targeted in this scenario, the state would likely have to submit renewal applications every 5 years. For non-targeted 1915(i)s there is a one-time approval. [↑](#footnote-ref-39)
40. The comparability requirement states that medical assistance provided to eligible individuals “shall not be less in amount, duration, or scope than the medical assistance made available to any other individual[s].” Social Security Act, § 1902, 42 U.S.C. § 1396a(a)(10)(B)(i)-(ii)(2012) [↑](#footnote-ref-40)
41. To receive Community First Choice services and supports under this section, an individual must meet the following requirements: (a) Be eligible for medical assistance under the State plan; (b) As determined annually— (1) Be in an eligibility group under the State plan that includes nursing facility services; or (2) If in an eligibility group under the State plan that does not include such nursing facility services, have an income that is at or below 150 percent of the Federal poverty level (FPL). In determining whether the 150 percent of the FPL requirement is met, States must apply the same methodologies as would apply under their Medicaid State plan, including the same income disregards in accordance with section 1902(r)(2) of the Act; and, (c) Receive a determination, at least annually, that in the absence of the home and community-based attendant services and supports provided under this subpart, the individual would otherwise require the level of care furnished in a hospital, a nursing facility, an intermediate care facility for the mentally retarded, an institution providing psychiatric services for individuals under age 21, or an institution for mental diseases for individuals age 65 or over, if the cost could be reimbursed under the State plan. Eligibility, 42 C.F.R. § 441.510 (2014).   
     [↑](#footnote-ref-41)
42. Ng, T., Harrington, C., Musumeci, M., & Reaves, E. L. (Dec. 22, 2014). [↑](#footnote-ref-42)
43. Medicaid.gov. Home and Community-Based Services 1915(c). Retrieved from <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/home-and-community-based-services-1915-c.html> [↑](#footnote-ref-43)
44. Social Security Act, § 1902, 42 U.S.C. § 1396a(a)(1)(C)(i)(III)(2012). [↑](#footnote-ref-44)
45. Centers for Medicare and Medicaid Services. (May 14, 2006). Glossary. Retrieved from <https://www.cms.gov/apps/glossary/>. Glossary. Retrieved from <http://longtermcare.gov/the-basics/glossary/#Activities_of_Daily_Living_>(ADLs) [↑](#footnote-ref-45)