Research

Participant Direction for People with Intellectual and Developmental Disabilities in Medicaid Home and Community Based Services Waivers

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Abstract

Participant direction allows people with intellectual and developmental disabilities (IDD) and/or their families to direct services; in doing so, participant direction shifts participants from passive recipients to active consumers. Medicaid encourages, but does not require, states to allow participant direction. The aim of this study was to examine if and how states permitted participant direction in Medicaid HCBS 1915(c) waivers for people with IDD. We analyzed HCBS waivers from across the country to determine frequency of participant direction, expenditures directed toward participant direction, and states' goals for utilization of participant direction. Our findings revealed a disconnect between the large number of waivers that allowed participant direction, and states' extremely low goals for actual utilization of participant direction.

Keywords: Participant direction; Medicaid Home and Community Based Services (HCBS) 1915(c) Waivers; Intellectual and Developmental Disabilities; long term services and supports (LTSS)

Participant Direction for People with Intellectual and Developmental Disabilities in Medicaid Home and Community Based Services Waivers

Participant direction is a model that allows people with intellectual and developmental disabilities (IDD) and/or their family members to control and direct their services and supports (Crisp, Doty, Smith & Flanagan, 2009; Timberlake, Leutz, Warfield, & Chiri, 2014). Because of its basis in self-determination, independent living, and person-centered planning, research has found participant direction to produce increased choice (Heller et al., 2012), control (Heller, Arnold, McBride, & Factor, 2012; Swaine, Parish, Igdalsky, & Powell, 2016), satisfaction (Heller et al., 2012; Timberlake et al., 2014), quality of life (Heller et al., 2012), independence (Swaine et al., 2016), and empowerment (Heller et al., 2012). Participant direction can also result in better physical and emotional well-being, and fewer unmet needs (Gross et al., 2012; Heller et al., 2012).

Participant direction "transforms" people with IDD from passive recipients of services to active consumers who direct services (Kraiem, 2011, p. 4; Heller et al., 2012; Swaine et al., 2016) because of its basis on "three critical assumptions:"

> (1) people with disabilities are experts on their service needs; (2) choice and control can be introduced into all service delivery environments; and (3) consumer direction should be available to anyone with a disability, regardless of who is paying for their services…Rather than an agency telling a person with a disability the services that might benefit him or her, the dynamic switches to the agency listening to what the person with a disability wants and needs for services. (Swaine et al., 2016, pp. 464-465)

As a result of these benefits, the availability of participant direction as a service delivery model has grown in the past two decades throughout long-term services and supports (LTSS) and policy for people with IDD (Heller et al., 2012; Swaine et al., 2016; Timberlake et al., 2014; Walker, Hewitt, Bogenschutz, & Hall-Lande, 2009). States have a number of opportunities to provide participant direction through Medicaid, including through Home and Community Based Services (HCBS) State Plan Option (1915(i)), Community First Choice (1915(k)), Self-Directed Personal Assistance Services State Plan Option (1915(j)), and HCBS waivers (1915(c)) (CMS, n.d.-b). According to the Centers for Medicare and Medicaid (CMS) participant direction of waivers services is an alternative to provider management where participants or their representatives have the authority to "exercise decision making authority" over certain or all of their waiver services (Disabled and Elderly Health Programs Group et al., 2015, p. 193). As such, the waiver participant "accepts the responsibility for taking a direct role in managing them" (Disabled and Elderly Health Programs Group et al., 2015, p. 193). CMS notes, participant direction "promotes personal choice and control over the delivery of waiver services, including who provides services and how they are delivered" (Disabled and Elderly Health Programs Group et al., 2015, p. 193). According to CMS (n.d.-b) the following characteristics allow participant direction through all of the aforementioned authorities: person-centered planning; service plans; individualized budgets; information and assistance in the support of self-direction; quality assurance measures; and financial management services. Despite the benefit and availability of these features participant direction is considered an *optional* feature of Medicaid LTSS.

Although not required, CMS continues to encourage states to utilize participant direction. For example, the HCBS settings rule (CMS 2249-F/2296-F) mentions, because it maximizes

choice and control, “we have urged all states to afford waiver participants the opportunity to direct some or all of their waiver services, without regard to their support needs... states are encouraged, to whatever degree feasible, to include self-direction as a component of their overall HCBS waiver programs” (Medicaid Program, 2014, n.p.). In the technical guide for HCBS 1915(c) waivers CMS again emphasizes the benefits of participant direction, including as a cost-effective delivery method, and “urges that all states” allow participants the opportunity to direct services (Disabled and Elderly Health Programs Group et al., 2015, p. 191).

Despite the benefits of participant direction, and the encouragement by CMS, participant direction varies widely across states (Walker et al., 2009). As a result of the importance of participant direction, and the lack of reliable national data on participant direction of Medicaid HCBS waivers (Crisp et al., 2009), the aim of this study was to examine the application of participant direction in Medicaid HCBS 1915(c) waivers for people with IDD as 1915(c) waivers are the largest providers of LTSS for people with IDD (Braddock et al., 2015). To do so, 111 Medicaid HCBS 1915(c) waivers for people with IDD from across the country were analyzed to determine how states were allowing participant direction. This included analysis of frequency of participant direction, expenditures directed towards participant-directed services, and the types of participant direction allowed by states (i.e., employer and/or budget authority). Moreover, we also used states’ goals for the number of participants to be involved in participant direction as a metric to examine state priorities.

Methods

We collected waiver data for this study from the CMS Medicaid.gov website between June 2015 and March 2016. Our first inclusion criteria required waivers to be 1915(c); 1115 and 1915(b) waivers were excluded. Our next inclusion criteria required waivers serve only people

with IDD – intellectual disability (ID), developmental disability (DD), 'mental retardation' (MR), or autism (ASD). Although MR is an outdated term it was a necessary search term because it remains used by a number of waivers (see Friedman, 2016a).There were no age limitations imposed. Waivers for all other populations (e.g., brain injury, medically fragile, HIV/AIDs) as well as inactive or pending waivers were excluded during this stage. Our final inclusion criteria required waivers to be in effect for 2015. Fiscal year (FY) is used for consistency. Through these methods, we collected 111 FY 2015 HCBS waivers from 46 states and the District of Columbia.

Medicaid HCBS waivers are state projections made to the federal government, not utilization data. However, because of their basis on previous years' actual waiver utilization they are reasonably accurate proxies of services (Rizzolo, Friedman, Lulinski-Norris, Braddock, 2013). In waivers, CMS requires states to describe: assurances and requirements; levels of care; waiver administration and operation; participant access and eligibility; available services, including limitations and restrictions; service planning and delivery; participant direction of services; participant rights; participant safeguards; quality improvement strategies; financial accountability; and, cost-neutrality demonstrations (Disabled and Elderly Health Programs Group et al., 2015). If participant direction is permitted, states must note in *Appendix E: Participant Direction of Services* which features the waiver includes by detailing: employer and/or budget authority; election of participant direction (how the waiver is designed to support participant direction); participant direction by a representative; the services which allow participant direction; detail on financial management services; the inclusion of to help participant manage services; policies on voluntary and involuntary termination of participant direction; goals for participant direction; and, decision making authority (CMS, n.d.-a). We utilized this

information to examine the 111 waivers for application of participant direction. We used each of these sections to calculate trends using descriptive statistics. CMS requires states set goals for the number of unduplicated participants who will utilize participant direction a year; this information was analyzed with descriptive statistics to compare across waivers and states. We also used information in Appendix E to determine employer and budget authority – the participants' decision-making authority – across the states. Finally, we explored prioritization of participant direction by service category by comparing the services which allowed participant direction in Appendix E to the total service frequency and allocation in FY 2015 from Friedman's (in press) national analysis of expenditures.

Findings

Our examination of 111 FY 2015 HCBS waivers for people with IDD revealed that 72 out of the 111 waivers (64.86%) offered participant direction of approximately 600 services.

Goals for Participant Utilization

Waivers that allow participant direction are required by CMS to provide "goals for each year that the waiver is in effect for the unduplicated number of waiver participants who are expected to elect each applicable participant direction opportunity" (CMS, n.d.-a, n.p.). CMS explains,

> The information that is provided…will aid CMS in understanding the expected extent of the use of the waiver's participant direction opportunities. The use of the term "goal" is intentional – it recognizes that the use of participant direction opportunities depends on many factors, including primarily the choices that are made by waiver participants themselves. Over the duration of the waiver, the goal

may be over or underachieved. (Disabled and Elderly Health Programs Group et al., 2015, p. 213)

The 72 waivers that allowed participant direction in FY 2015, aimed to have a total of 76,063 participants direct their services; this accounted for 12.1% of the approximately 630,000 unduplicated participants served by HCBS waivers in FY 2015 (Friedman, in press). Figure 1 details participant goals for participant direction across waivers. Three waivers had goals of 100% participant direction: Montana Home and Community-Based Waiver for Individuals with Developmental Disabilities; New Hampshire In Home Supports Waiver for Children with Developmental Disabilities; and, Ohio Self Empowered Life Funding Waiver (see Table 1).

Employer and Budget Authority

We also examined which services provided employer and budget authority for these participant-directed services as they are a good measure of what type of participant direction is actually included. Employer authority allows the person with IDD or their guardian the decision-making authority over those who provide certain waiver services. CMS explains under employer authority, “the participant is supported to recruit, hire, supervise and direct the workers who furnish supports.” (Disabled and Elderly Health Programs Group et al., 2015, p. 194). In FY 2015, 85.9% (n = 506) of the participant-directed services from 71 waivers allowed employer authority. When waivers allow employer authority, the participant’s employer status can be as a ‘co-employer,’ ‘common law employer,’ or both. As a co-employer, the participant or their representative is “the co-employer (managing employer) of workers who provide waiver services. An agency is the common law employer of participant-selected/recruited staff and performs necessary payroll and human resources functions” (CMS, n.d.-a, n.p.). As a common law employer, the participant or their representative “is the common law employer of workers

who provide waiver services. An IRS-Approved Fiscal/Employer Agent functions as the participant's agent in performing payroll and other employer responsibilities that are required by federal and state law" (CMS, n.d.-a, n.p.). Of the 71 waivers allowing employer authority, in 43 waivers (60.6%) participants functioned as a common law employer, in 4 waivers (5.6%) participants functioned as co-employers, and in 24 waivers (33.8%) participants could function as both common law employers and co-employers. Under employer authority participants (or their representatives) had the ability to exercise the decision-making authorities listed in Table 2.

Budget authority allows the participant or their guardian the authority to direct the budget for certain waiver services. CMS details, under budget authority

> the participant has the authority and accepts the responsibility to manage a participant-directed budget…this authority permits the participant to make decisions about the acquisition of waiver goods and services that are authorized in the waiver service plan and to manage the dollars included in a participant-directed budget. (Disabled and Elderly Health Programs Group et al., 2015, p. 194)

In FY 2015, 86.8% (n = 511) of the participant-directed services allowed budget authority. Waivers allowing budget authority allowed participants the ability to exercise the decision making authorities listed in Table 2.

Projected Prioritization of Participant Direction

Out of the $25.6 billion dollars of HCBS waiver projected spending in FY 2015 (Friedman, in press), $5.3 billion dollars, or 20.9% was projected for services that allowed participant direction. However, the proportion of each waiver that allowed participant direction varied widely. Thirty-nine waivers (35.1%) included no participant direction. Thirty-one waivers

(27.9%) allocated between 0.01% and 20% of funding for services that allowed participant direction, five (4.5%) between 20.01% and 40%, 12 (10.8%) between 40.01% and 60%, 10 (9.0%) between 60.01% and 80.00%, and 10 (9.0%) between 80.01% and 99.99%. Four (3.6%) waivers allowed participant direction of all of the offered services – 100% of funding was directed towards services that allowed participant direction: Massachusetts Children's Autism Spectrum Disorder Waiver; Montana Home and Community-Based Waiver for Individuals with Developmental Disabilities; Montana Supports for Community Working and Living waiver; and, New Hampshire In Home Supports Waiver for Children with Developmental Disabilities waiver. Table 1 details what proportion of funding in each state was projected for services that allowed participant direction.

Twenty-percent of the approximately 2,850 services in FY 2015 (n = 589) could be participant-directed. As is shown in Table 3, the categories with the largest proportion of funding going toward services that allowed participant direction were: education (100%); family training and counseling (97.8%); individual goods and services (93.3%); financial support services (80.6%); and, respite (64.7%). The majority (52%) of transportation funding was also projected for services that allowed participant direction. The following services had a lower proportion of funding directed towards services that allowed participant direction, with rates of less than 50%: community transition supports; supported employment; health and professional services; self-advocacy training; supports for living in one's own home (companion, homemaker, personal assistant, supported living); day habilitation; specialized medical equipment and assistive technology; care coordination; prevocational services; and, residential habilitation.

Table 3 also reveals differences between the amount of funding projected for services that allowed participant direction, and how frequently service categories allowed participant

direction. The service categories that most frequently allowed participant direction were: education (100%); individual goods and services (90.3%); self-advocacy training (63.6%); financial support services (56.8%); and, community transition services (37.5%). The services with the lowest frequency of potential participant direction were: adult day health (2.7%); prevocational services (3.9%); residential habilitation (6.1%); health and professional services (13.0%); and, day habilitation (13.9%).

Discussion

> People with IDD's ability to direct services in Medicaid HCBS 1915(c) waivers represents a major paradigm shift in the delivery of publicly funded home and community-based services (HCBS). In the traditional service delivery model, decision making and managerial authority is vested in professionals who may be either state employees/contractors or service providers. Self-direction transfers much (though not all) of this authority to participants and their families (when chosen or required to represent them). (Crisp et al., 2009, p. 1-1)

Our analysis revealed the majority of Medicaid HCBS 1915(c) waivers for people with IDD allowed participant direction through both budget and employer authority of services. Under employer authority participants most frequently served as common law employers rather than co-employers. Most often participants were able to recruit, schedule, and supervise staff, determine staff duties, and set staff qualifications based on their needs and preferences. Approximately 21% of funding went towards services that allowed participant direction in FY 2015. This is a slight increase from FY 2013 (18.8%) and FY 2014 (19.7%) (Friedman, 2014; 2016b), indicating slight progress towards the expansion of participant direction for people with IDD.

Approximately one-fifth of services allowed participant direction. The service categories that most frequently allowed participant direction were education, family training and counseling, individual goods and services, and financial support services. However, those services categories most heavily funded by waivers also tended to offer less potential for participant direction. For example, residential habilitation made up almost half (42.3%) of all HCBS waiver spending in FY 2015 (Friedman, in press), yet less than 6% of funding was projected for residential habilitation services that allowed participant direction. Even supports for living in one's own home, which projected the most funding ($1.6 billion) for services that allowed participant direction, was only proportionally up to 30.2% participant-directed. Meanwhile, the category with the largest proportion of funding for services that allowed participant direction – education services – made up only .002% of total HCBS waiver spending in FY 2015 (Friedman, in press). Those categories with the largest proportion of funding for participant direction – education, family training and counseling, and individual goods and services – were actually some of the smallest categories in HCBS waivers; each of the four made up less than .1% of all total HCBS waiver spending. There appears to be an inverse relationship between total projected spending and projected spending for services that allow participant direction.

Moreover, states goals for the utilization of participant direction, particularly the number of participants that will utilize participant direction, were particularly low. Although goals varied significantly, overall in FY 2015 waivers aimed to only have 12.1% of participants direct their services. This mediocre goal mirrors past research by Prouty, Smith, & Lakin (2007) which found HCBS utilization of participant direction to be 5.8% on average in 2006/2007.

One limitation of our study should be noted; Medicaid HCBS waivers are state projections made to the federal government, not utilization data. However, because of their basis on previous years' actual waiver utilization they are a reasonably accurate proxy of services (Rizzolo et al., 2013). Moreover, analyses of waivers have resulted in findings that closely parallel expenditure analyses by Braddock et al. (2015) and Irvin (2011). We suggest future studies examine the relationship between projections and actual utilization for participant direction.

Our findings reveal a disconnect between the amount of services states allow to be participant-directed, and states' goals for the number of consumers involved in participant direction. Based on the bounds of our data we have no way to determine why states set the participant goals the ways they did – CMS does not require states to describe their decision-making process or design goals based on research or needs assessments. We suggest future researchers interview waiver administrators to explore these differences. Most likely states were basing these decisions on former goals, and previous utilization of services. However, basing goals on previous utilization of participant direction is problematic as many people with IDD have only recently been given the opportunity to direct services. Moreover, the ability to direct their HCBS services may not be known by waiver participants because it is not a widely-publicized feature. Swaine et al. (2016) found participants learned about participant direction opportunities through a patchwork of sources, including social services agencies, family members, brochures, doctors, and state rehabilitation departments. Widespread utilization of participant direction is unlikely to occur in the absence of concerted efforts by states to inform people with IDD of their right to direct their own services. Such efforts may depend more on the

leadership of state systems increasing their expectations about the potentials of people with IDD to direct services than the abilities of people with IDD to do so.

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Table 1

Participant-Directed Services by State

	Participants: Goal for Participant Direction			Projected Spending on Services that Allow Participant Direction		
State	*n*	% of total	Rank	Spending (Millions)	% of total	Rank
Alabama	30	0.5%	35	$1.78	0.6%	33
Alaska	0	0.0%	36	$0	0.0%	36
Arkansas	0	0.0%	36	$0	0.0%	36
California	16,674	15.2%	15	$377.19	13.5%	22
Colorado	0	0.0%	36	$0	0.0%	36
Connecticut	1,297	12.1%	20	$331.07	38.3%	11
Delaware	0	0.0%	36	$0	0.0%	36
District of Columbia	0	0.0%	36	$0	0.0%	36
Florida	0	0.0%	36	$0	0.0%	36
Georgia	3,235	20.0%	14	$259.44	48.1%	10
Hawaii	750	22.5%	13	$104.17	68.59%	8
Idaho	870	14.0%	17	$26.26	13.9%	21
Illinois	5,600	27.4%	9	$234.33	37.7%	12
Indiana	0	0.0%	36	$0	0.0%	36
Iowa	1,750	12.3%	19	$440.98	95.9%	4
Kansas	2,656	28.4%	8	$44.63	12.3%	24
Kentucky	5,416	36.8%	6	$95.5	17.3%	17
Louisiana	860	7.7%	26	$460.66	83.1%	5
Maryland	400	2.6%	33	$89.99	26.7%	14
Maine	0	0.0%	36	$0	0.0%	36
Massachusetts	820	5.7%	29	$148.91	12.7%	23
Michigan	962	11.0%	21	$484.49	99.5%	1
Minnesota	1,755	10.3%	23	$70.61	6.0%	28
Mississippi	0	0.0%	36	$0	0.0%	36
Missouri	667	4.6%	31	$23.77	4.5%	29
Montana	390	13.5%	18	$100.08	97.6%	3
Nebraska	1,570	25.0%	11	$32.06	15.8%	20
Nevada	0	0.0%	36	$0	0.0%	36
New Hampshire	1,120	23.5%	12	$212.56	98.9%	2
New Mexico	0	0.0%	36	$0	0.0%	36
New York	0	0.0%	36	$0	0.0%	36
North Carolina	335	1.4%	34	$683.3	56.0%	9
North Dakota	540	10.2%	24	$20.98	11.3%	26

Ohio	2,000	100.0%	1	$38.83	2.6%	31
Oklahoma	160	8.3%	25	$1.37	0.4%	35
Oregon	6,555	82.5%	3	$31.43	21.0%	15
Pennsylvania	3,600	10.9%	22	$378.88	16.9%	18
South Carolina	150	3.5%	32	$.25	0.4%	34
South Dakota	932	91.6%	2	$2.41	2.0%	32
Tennessee	628	34.9%	7	$24.42	3.6%	30
Texas	2,889	7.6%	27	$159.04	12.0%	25
Utah	1,200	26.1%	10	$26.13	16.4%	19
Virginia	1,675	14.1%	16	$59.54	7.9%	27
Washington	5,133	39.6%	5	$107.02	17.9%	16
West Virginia	2,990	64.5%	4	$102.28	28.6%	13
Wisconsin	264	4.8%	30	$83.4	82.6%	6
Wyoming	190	7.5%	28	$71.96	81.4%	7

Note. Rank is calculated by ranking the percent of total from highest to lowest.

Table 2

Decision Making Authorities

	%	*n* waivers
Employer authority		
Recruit staff	99%	71
Schedule staff	99%	71
Orient and instruct staff in duties	99%	71
Supervise staff	99%	71
Evaluate staff performance	99%	71
Verify time worked by staff and approve time sheets	99%	71
Determine staff duties consistent with the service specifications	99%	71
Specify additional staff qualifications based on participant needs and preferences so long as such qualifications are consistent with the qualifications specified	96%	69
Hire staff common law employer	94%	68
Discharge staff (common law employer)	92%	66
Determine staff wages and benefits subject to State limits	86%	62
Verify staff qualifications	75%	54
Obtain criminal history and/or background investigation of staff	72%	54
Refer staff to agency for hiring (co-employer)	47%	34
Select staff from worker registry	47%	34
Discharge staff from providing services (co-employer)	43%	31
Budget Authority		
Schedule the provision of services	75%	54
Determine the amount paid for services within the State's established limits	74%	53
Specify how services are provided, consistent with the service specifications contained	72%	52
Identify service providers and refer for provider enrollment	69%	50
Specify additional service provider qualifications consistent with the qualifications specified	68%	49
Review and approve provider invoices for services rendered	68%	49
Substitute service providers	65%	47
Reallocate funds among services included in the budget	60%	43

Authorize payment for waiver goods and service	56%	40

Table 3

Participant Direction by Service Category

	Service Category Rank	Frequency		Projected Spending	
		n	%	Spending (millions)	%
Education	17	2	100.0%	$.43	100.0%
Individual goods and services	15	28	90.3%	$9.91	93.3%
Self-advocacy training	16	7	63.6%	$.48	30.8%
Financial support services	13	25	56.8%	$38.71	80.6%
Community transition supports	9	39	37.5%	$222.59	49.3%
Family training and counseling	14	25	35.2%	$479.05	97.8%
Supports to live in one's own home	2	92	31.2%	$1,581.14	30.2%
Transportation	7	28	25.0%	$281.29	52.0%
Specialized medical equipment and assistive technology	11	83	23.6%	$37.45	17.8%
Respite	8	52	22.3%	$381.35	64.7%
Supported employment	5	45	19.0%	$297.98	44.5%
Care coordination	6	18	18.0%	$90.16	14.6%
Day habilitation	3	32	13.9%	$828.93	19.7%
Health and professional services	4	92	13.0%	$411.67	76.2%
Residential habilitation	1	17	6.1%	$617.51	5.7%
Prevocational	10	3	3.9%	$50.98	11.4%
Adult day health	12	1	2.7%	$.1	0.2%

Note. Rank of service categories calculated by total waiver projected spending (regardless of participant direction) -- the importance of the category -- with one being the highest.

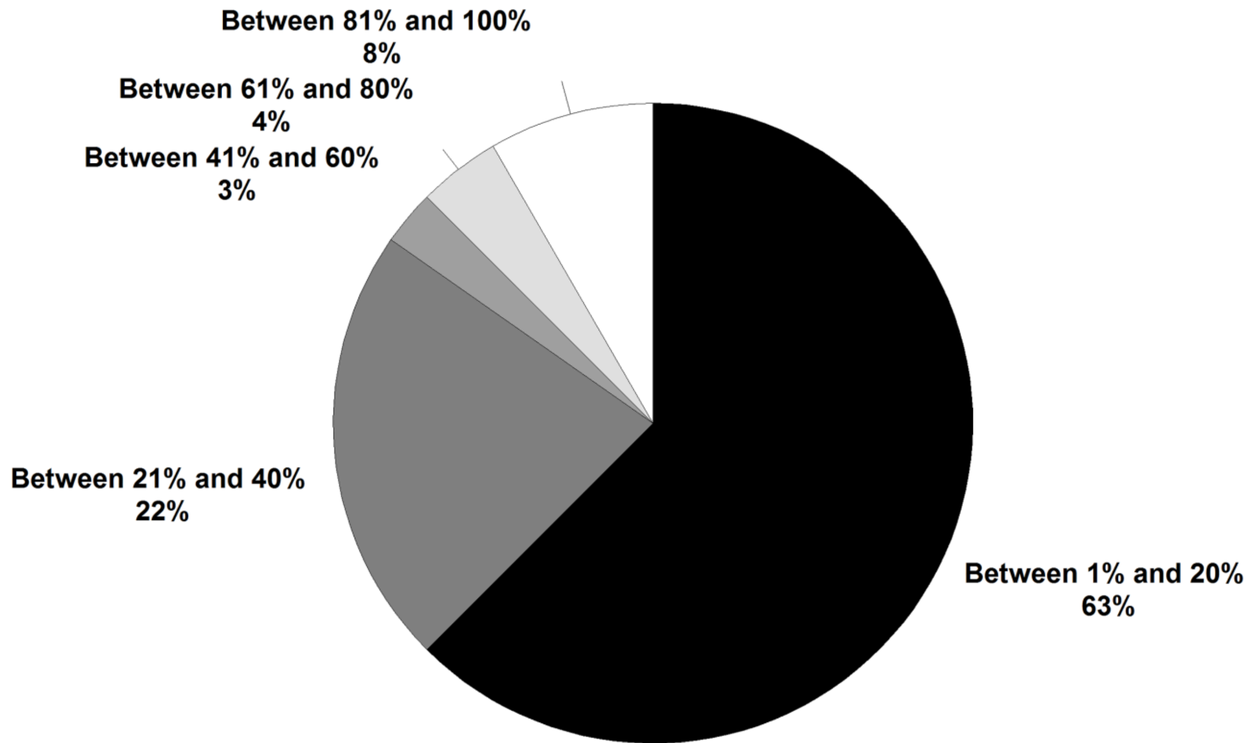

Figure 1. Goals for the number of participants involved in participant direction by waiver.