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Article *in* Intellectual and Developmental Disabilities · November 2016

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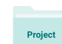

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Self-Advocacy Services for People with Intellectual and Developmental Disabilities: A National Analysis

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Acknowledgments:
This paper was sponsored in part by grants from United States Department of Health and Human Services, Administration for Community Living (ACL) (grant 90DN0296) and ACL National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) (grant 90RT5007-02-02). The content is solely the responsibility of the authors and does not necessarily represent the official views of the Department of Health and Human Services. Endorsement by the Federal Government should not be assumed.

Citation:
Friedman, C. (2017). Self-advocacy services for people with intellectual and developmental disabilities: A national analysis. *Intellectual and Developmental Disabilities, 55*(6), 370-376. https://doi.org/10.1352/1934-9556-55.6.37 .

Abstract

Self-advocacy plays an important role in facilitating the empowerment of people with intellectual and developmental disabilities (IDD), and helps people with IDD develop the skills necessary for the participant direction of services. The purpose of this study was to examine Medicaid Home and Community Based Services (HCBS) 1915(c) waivers across the nation to determine how states were utilizing self-advocacy services for people with IDD. Findings revealed approximately half of waivers provided self-advocacy services; however, less than .01% of waiver spending was projected for stand-alone self-advocacy services. States need to expand the provision of self-advocacy services as they aid people with IDD's ability to direct waivers services, and strengthen their ability to and exercise their rights.

Keywords: Self-advocacy; People with intellectual and developmental disabilities; Medicaid Home and Community Based Services (HCBS) 1915(c) waivers; long term services and supports (LTSS)

Self-Advocacy Services for People with Intellectual and Developmental Disabilities: A National Analysis

Self-advocacy is the civil rights movement of and by people with intellectual and developmental disabilities (IDD). Self-advocacy serves both as a source of empowerment for people with IDD and a method for grassroots organizing. As one self-advocate describes, identifying as a self-advocate,

> 'means knowing your rights and responsibilities. Self-advocate means standing up for your own rights. Self-advocate means speak for yourself and make your own decisions, being more independent, standing on your own two feet and sticking up for your rights.' (Shapiro, 1994, p. 209)

Priorities of the self-advocacy movement include closing institutions, ending subminimum wage, ending use of the word 'retarded,' and directing their services (Caldwell, 2011; Shapiro, 1994). According to Shapiro (1994) self-advocates "are saying they are willing to take risks like anyone else to live like other adults around them. They want places to turn to for support, but they also want the feeling of respect and self-confidence that comes from taking chances" (p. 192).

Self-determination, a key aspect of self-advocacy, includes knowing ones' rights and speaking out' about what one wants (Nonnemacher and Bambara, 2011). Self-determination also includes being in charge of daily decisions in order to reach ones' goals (Nonnemacher and Bambara, 2011). Because of this push for control by self-advocates, many IDD-related policies, such as long-term services and supports (LTSS), have become more person-centered (Heller, Arnold, McBride, & Factor, 2012). The Centers for Medicare and Medicaid services (CMS) has pushed states to expand the participant direction of their LTSS, which allows people with IDD and/or their families to direct their own services (CMS, n.d.; Disabled and Elderly Health

Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2015). Because of its basis on principles of self-advocacy and self-determination, participant direction results in improved choice, control, satisfaction, quality of life, independence, and empowerment (Crisp, Doty, Smith & Flanagan, 2009; Heller et al., 2012; Swaine, Parish, Igdalsky, & Powell, 2016; Timberlake, Leutz, Warfield, & Chiri, 2014).

A recent analysis of the largest provider of LTSS for people with IDD, Medicaid Home and Community Based Services (HCBS) 1915(c) waivers (Braddock et al., 2015), found that although the majority of waivers allowed participant direction by people with IDD, states' goals for the number of people with IDD who would participant direction were extremely low (Friedman, under review). Friedman (under review) suggests this discrepancy may relate to states' low expectations of people with IDD. The low utilization of participant direction may also relate to a lack of training programs that educate people with IDD on the self-advocacy skills necessary to direct their own services. For this reason, and because of the important role self-advocacy plays in facilitating the empowerment of people with IDD, the purpose of this study was to examine the provision of self-advocacy services within Medicaid HCBS 1915(c) waivers for people with IDD across the nation. In doing so we examined which states were providing self-advocacy services for people with IDD, and how self-advocacy services were utilized. We particularly analyzed the projected unduplicated participants, total spending, spending per participant, and annual service provision. We also examined waiver definitions of self-advocacy services in order to determine why states' motivation to provide these services, and how states described the usefulness of self-advocacy.

Methods

Medicaid Home and Community Based Services (HCBS) 1915(c) waivers were gathered from the CMS Medicaid.gov website over approximately 11 months (May 2015 to April 2016). Waivers that were not 1915(c), did not serve people with IDD (developmental disabilities developmental disabilities (DD), intellectual disabilities (ID), autism (ASD), and/or mental retardation (MR)), and were pending or inactivewere excluded. (Despite being an outdated term, MR continues to be used by a number of HCBS waivers and therefore was a necessary search term; see Friedman, 2016.) Waivers that did not include 2015 were also excluded; most often this was the state fiscal year (FY) (July 1, 2014 to June 30, 2015), however other states used the federal FY (October 1, 2014 to September 30, 2015), or the 2015 calendar year (January 1, 2015 to December 31, 2015). The term FY is used for consistency. Through this process we amassed 111 Medicaid HCBS 1915(c) waivers for people with IDD from 46 states and the District of Columbia.

CMS requires waivers to describe: CMS assurances and requirements; levels of care; waiver administration and operation; participant access and eligibility; participant services, including limitations and restrictions; service planning and delivery; participation direction of services; participant rights; participant safeguards; quality improvement strategies; financial accountability; and cost-neutrality demonstrations (Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2015). We utilized this information to determine which waivers provided any type of self-advocacy, particularly by going through almost 3,000 services and noting provision of self-advocacy services. This included bulk services (e.g., employment, residential habilitation, etc.) that included self-advocacy within the service as well

as stand-alone services that exclusively provided self-advocacy. The definitions of these services were then qualitatively analyzed for major and minor themes.

Unlike bulk services we were able to differentiate utilization and expenditures for stand-alone self-advocacy services. Therefore, we further analyzed stand-alone self-advocacy services quantitatively to determine the projected number of unduplicated participants, total projected spending, average spending per participant, reimbursement rates, and annual service provision per participant.

Findings

Service Definitions

Fifty-two waivers (46.8%) from 24 states provided self-advocacy through 74 services in FY 2015. Of those 74 services, 11 (14.9%) were stand-alone self-advocacy services, while 63 (85.1%) provided self-advocacy embedded within another service. It was most common for self-advocacy to be embedded in day habilitation services, supports to live in ones' own home (companion/homemaker/personal care/supported living services), and supported employment services; see Table 1.

Stand-alone services. Provided because of its ability to enhance a participant's ability to function in the community, stand-alone self-advocacy services were often described as a

> service provided to participants to promote self-advocacy through methods such as instructing, providing experiences, modeling and advising. This service includes assistance in interviewing potential providers, understanding complicated health and safety issues, and assistance with participation on private and public boards, advisory groups and commissions. (Colorado Supported Living Services Waiver (CO293.R04.00), n.p.)

Many of the stand-alone self-advocacy services also included peer support;

> Peer support is designed to provide training, instruction and mentoring to individuals about self-advocacy, participant direction, civic participation, leadership, benefits, and participation in the community. Peer support is designed to promote and assist the waiver participant's ability to participate in self-advocacy through either a peer mentor or through an individual/agency peer support facilitator. Peer support may be provided in 1) small groups or 2) peer support may involve one individual who is either a peer or an individual peer support facilitator providing support to a waiver participant. The one to one peer support is instructional; it is not counseling. (Massachusetts Adult Supports Waiver (MA828.R01.00), n.p.).

The majority of stand-alone self-advocacy services also allowed peer support to be provided over technology such as iPads, iPhones, and Skype.

Embedded services. States provided self-advocacy within embedded services for a number of reasons. Most commonly (*n* = 55, 87.3% of embedded services), the self-advocacy was provided for training and skill development. For example, Colorado Children's Habilitation Residential Program (CO305.R04.00) waiver's 'Habilitation' service described its provision of self-advocacy services as:

> Self-Advocacy Training and support includes assistance and teaching of appropriate and effective ways to make individual choices, accessing needed services, asking for help, recognizing abuse, neglect, mistreatment, and/or exploitation of self, responsibility for one's own actions, and participation in all meetings. (n.p.)

Many waivers (*n* = 15, 23.8% of embedded services) also embedded self-advocacy within their services in order to support participants as they exercise their rights. For example, Montana Home and Community-Based Waiver for Individuals with Developmental Disabilities' (MT208.R05.01) 'personal supports' service described its inclusion of self-advocacy as aimed at: "Assisting the individual to develop self-advocacy skills, exercise rights as a citizen, and acquire skills needed to exercise control and responsibility over other support services" (n.p.).

Instead of promoting self-advocacy as a general life skill, a number of waivers (*n* = 10, 15.9% of embedded services) also included self-advocacy training specifically to help participants advocate for their waiver services. For example, Wyoming Comprehensive Waiver's (WY1061.R00.00) 'Independent Support Brokerage' service explained, "other functions include assisting the participant in: conducting self-advocacy and assisting with employee grievances and complaints" (n.p.). Similarly, six services (9.5% of embedded services) included self-advocacy specifically for employment advocacy. For example, Indiana Community Integration and Habilitation Waiver's (IN378.R03.01) 'Extended Service' service included: "Job-specific or job-related self-advocacy skills training" (n. p.)

A number of embedded services (*n* = 8, 12.7% of embedded services) also described service provision aimed at providing opportunities for self-advocacy. For example, Tennessee Comprehensive Aggregate Cap Waiver's (TN357.R03.00) 'Support Coordination' service explains the support coordinator

> will provide the individual with information about self-advocacy groups and self-determination opportunities and assist in securing needed transportation supports for these opportunities when specified in the ISP or upon request of the individual. (n.p.)

Service Expenditures

In FY 2015, eight waivers provided 11 stand-alone self-advocacy services. These 11 services projected spending $1.57 million for approximately 2,000 unduplicated participants (see Table 2). However, both total projected spending and unduplicated participants ranged widely by service. While the average waiver provided stand-alone self-advocacy services for 324 participants, this ranged from 5 participants for Connecticut Employment and Day Supports waiver's (CT881.R00.02) 'Peer support per 15 minutes Agency' service to 1,090 services for Colorado Supported Living Services waiver's (CO293.R04.00) 'Mentorship' service. Moreover total projected spending ranged from $7,011 for Connecticut Comprehensive Supports (CT437.R02.01) and Individual and Family Support Waivers' (CT426.R02.01) 'Peer support per 15 Minutes individual' services to $1.05 million for Colorado CO293.R04.03 waiver's 'Mentorship' service, with waivers projecting an average total spending of $261,213. Spending per capita on stand-alone self-advocacy services was relatively low across the states, averaging at $0.07 per capita. Colorado had the highest spending per capita for stand-alone self-advocacy services ($0.19), Wisconsin the second highest ($0.05), and Connecticut and Massachusetts the lowest ($0.02).

Average yearly spending per participant on stand-alone self-advocacy services ranged from $293 for Massachusetts Intensive Supports Waiver (MA827.R01.00) waiver's 'Peer Support – 15 minutes' service to $1,476 for Connecticut CT881.R00.02 waiver's 'Peer support per 15 minutes Agency' service. The on average waivers providing stand-alone self-advocacy services projected $862 per participant per year. Figure 1 details average spending per participant further.

All stand-alone self-advocacy services were paid by a 15-minute reimbursement rate other than Wisconsin's Children's Long Term Support DD Waiver's (WI414.R02.01) 'Consumer Education and Training' service, which paid an hourly reimbursement rate of $64.00. The average reimbursement rate for 15-minute rate stand-alone services was $5.43 (which works out to $21.70 an hour). Six services (54.5%) had a 15-minute reimbursement rate between $3.50 and $4.00, two services (18.2%) between $7.00 and $7.50, one service (9.1%) between $7.50 and $8.00, and one service (9.1%) between $9.50 and $10.00.

The 15-minute rate services provided 162 15-minute units of stand-alone self-advocacy services per participant in a year on average (approximately 40 hours). One service (9.1%) provided 82 15-minute units (20.5 hours), one service (9.1%) 98 units (24.5 hours), 2 services (18.2%) 148 units (37 hours), and 6 services (54.5%) 190 units (47.5 hours). Wisconsin's stand-alone self-advocacy service provided on average 12 hours of services per participant per year.

Discussion

Approximately half of HCBS waivers for people with IDD provided some sort of self-advocacy service in FY 2015. Waivers explained they provided self-advocacy services because it helps people with IDD function in the community by building and strengthening their decision-making and advocacy skills, and exercising the rights granted to them as citizens. States also recognized the ways self-advocacy promotes general life skills, including those that help them advocate for waiver services.

Self-advocacy was provided through both stand-alone services and embedded within another service, most commonly day habilitation. Stand-alone services projected spending $1.57 million for approximately 2,000 participants in FY 2015. Although this may seem significant, it is less than .01% of the total HCBS IDD waiver spending projected for FY 2015 (Friedman, in

press). Spending per capita was also quite low across the states providing stand-alone self-advocacy services.

On average waivers projected spending approximately $900 per participant on stand-alone self-advocacy services in FY 2015, with the average participant projected to receive approximately 40 hours of stand-alone self-advocacy services a year. Although spending and annual service provision for stand-alone self-advocacy services varied widely by state, utilization was fairly low across the board.

In the current system, "self-advocacy services remain 'a hodgepodge of local, regional, and national schemes, largely uncoordinated and unregulated, and often relying on untrained and unpaid volunteers'" (Atkinson (1999) as cited by Redley & Weinberg, 2007, p. 769). Most self-advocacy organizations currently operate via a patchwork of small funds and volunteers. As such, services and supports are key (Caldwell, 2010). Lack of services and supports not only hinders opportunities to access the community but also to participate in self-advocacy. A self-advocacy leader in Caldwell's (2010) study "used the phrase 'fallen leaders' to describe individuals who could have grown into leaders, but did not have necessary and adequate supports and services" (p. 1009). As the most prominent providers of long term services and supports, Medicaid Home and Community Based Services waivers are the perfect vehicle to help promote self-advocacy by providing opportunities within waivers.

One limitation of our findings should be noted. Medicaid HCBS 1915(c) waivers are state projections provided to the federal government – not utilization. However, they are reasonably accurate proxies because of their basis on previous years' utilization. Moreover, previous analyses of HCBS waiver projections (Rizzolo, Friedman, Lulinski Norris, & Braddock, 2013) have revealed similar findings to utilization research by Braddock et al. (2015) and Irvin (2011).

In the 2014 1915(c) final settings rule, CMS noted,

> several commenters recommended that CMS include training as one aspect of employer-authority activities that self-directing beneficiaries may be allowed to exercise. A couple of commenters urged CMS to require states to offer training for individuals on selecting, hiring, supervising and firing service providers, in addition to service provider training. (Medicaid Program, 2014, n.p.)

CMS goes on to "agree with this recommendation" and suggest states utilize training programs to meet this requirement (Medicaid Program, 2014, n.p.). CMS's recommendation reinforces the importance of self-advocacy service provision by states. This is especially pertinent as Swaine (2016) found many people employed under participation direction felt they needed more job training from their employers with disabilities. Both the importance of self-advocacy, and our findings suggest states need to significantly increase their provision of self-advocacy services, especially as they redesign their waiver program in response to the person-centered planning requirements of the final settings rule (Medicaid Program, 2014). Self-advocacy is a vital tool that allows people with IDD to produce deeper senses of community, culture, identity formation, and disability pride. Service provision by the largest provider of LTSS for people with IDD should reflect the advances made by the movement by *actively* working to encourage it.

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Received 6/30/2016, accepted 11/17/2016

Table 1

Location of Self-Advocacy within Embedded Services

Service Category	*n*	%
Day habilitation	17	27%
Supports to live in ones' own home (Companion, homemaker, personal assistant, supported living)	10	16%
Supported employment	9	14%
Individual goods and services	6	10%
Community transition supports	5	8%
Financial support services	5	8%
Prevocational	3	5%
Residential habilitation	3	5%
Care coordination	2	3%
Family services	2	3%
Health and professional services	1	2%

Table 2

Stand-Alone Self-Advocacy Services in HCBS Waivers for People with IDD (FY 2015)

State	Waiver	Service	Unit	# Users	Total projected spending
Colorado	CO293.R04.00	Mentorship	15 Minutes	1,090	$1,048,972
Connecticut	CT437.R02.01	Peer support per 15 Minutes Agency	Per 15 Minutes	20	$27,854
Connecticut	CT437.R02.01	Peer support per 15 Minutes individual	Per 15 Minutes	10	$7,011
Connecticut	CT426.R02.01	Peer support per 15 Minutes Agency	Per 15 Minutes	20	$27,854
Connecticut	CT426.R02.01	Peer support per 15 Minutes individual	Per 15 Minutes	10	$7,011
Connecticut	CT881.R00.02	Peer Support - 15 minutes	Per 15 minutes	10	$7,429
Connecticut	CT881.R00.02	Peer support per 15 Minutes Agency	Per 15 minutes	5	$7,382
Massachusetts	MA828.R01.00	Peer Support - 15 minutes	15 minutes	87	$45,967
Massachusetts	MA826.R01.00	Peer Support - 15 minutes	15 minutes	66	$34,872
Massachusetts	MA827.R01.00	Peer Support - 15 minutes	15 minutes	269	$78,747
Wisconsin	WI414.R02.01	Consumer Education and Training	Hours	357	$274,176

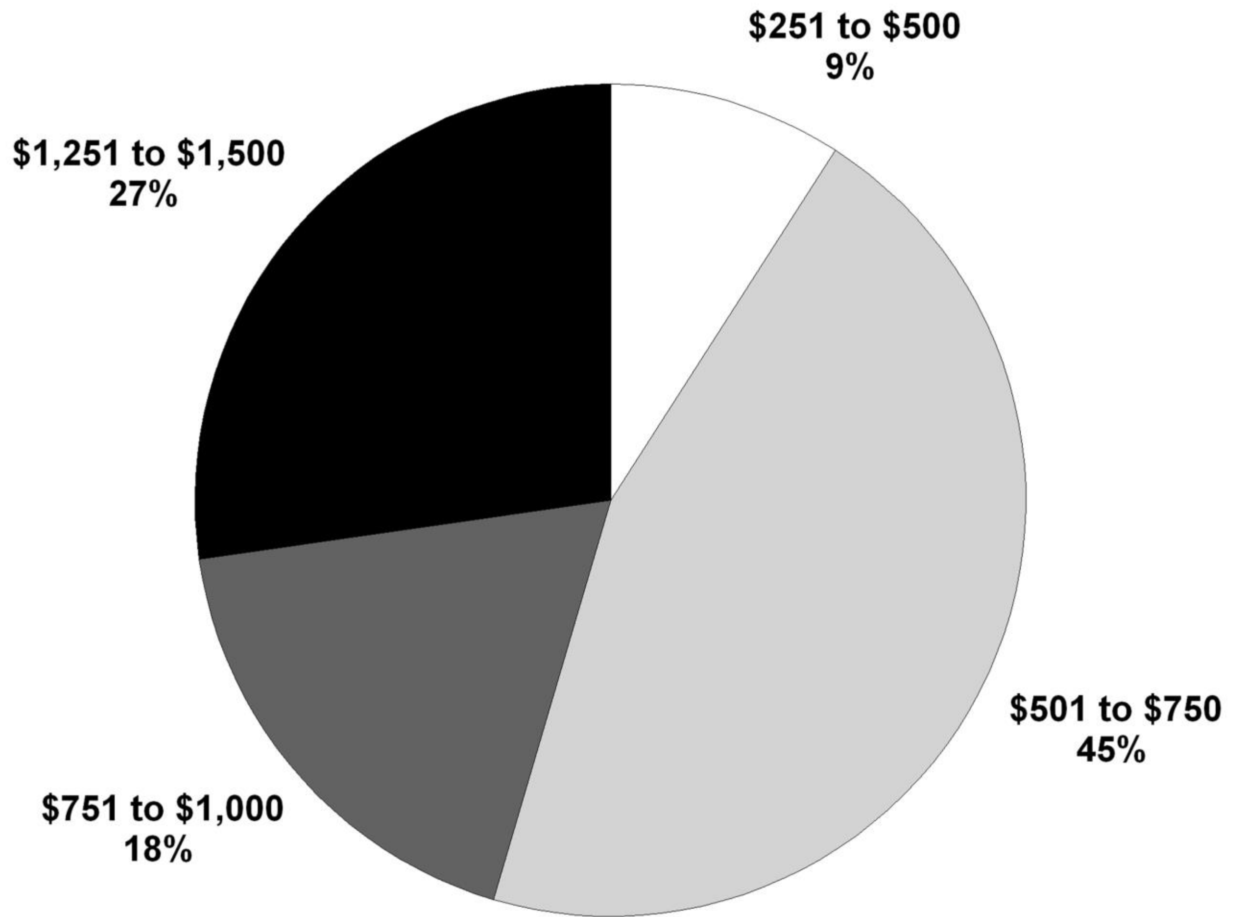

Figure 1. Average spending per participant for stand-alone self-advocacy services.

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