Research

Home and Community Based Speech, Language, and Hearing Services for People with Intellectual and Developmental Disabilities

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Research and Practice for Persons with Severe Disabilities

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Abstract

Speech language and hearing (SLH) services can improve people with intellectual and developmental disabilities' (IDD) health, autonomy, and community participation. The aim of this study was to explore how SLH services are offered to people with IDD across the nation, particularly in fiscal year 2015 Medicaid Home and Community Based Services (HCBS) 1915(c) waivers (n = 111 waivers). Findings revealed, unlike Medicaid state plans, HCBS waivers were often utilized to offer SLH services in alternative settings, like participants' homes, and provide long-term habilitative care rather than immediate acute care. Given increased risk for and under identification of communication and hearing disorders in people with IDD, adequate access to sufficient SLH services is essential to ensure the rights of people with IDD.

Keywords: Medicaid Home and Community Based Services (HCBS) 1915(c) waivers; intellectual and developmental disabilities; community living; speech, language, and hearing

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Communication is comprised of a series of complex and fluid interactions that include but are not limited to using and understanding facial expressions, body language and gestures, reading, writing, speaking, and listening. A communication disorder occurs when there is a disruption in any one or more of these interactions. Hearing is the sensory ability to detect and make sense of the sounds around us, including those sounds that are used for communication. Hearing is critical to understanding and using verbal speech. Disorders in hearing include deficits in detecting, processing, and making sense of sounds (e.g., hearing loss). Hearing and communication are closely related, and as such, deficits in hearing can negatively impact communication.

Speech-language pathology is a clinical profession that works towards the prevention, identification, treatment, and research of disorders in communication. Speech-language pathologists (SLPs) provide a variety of supports and services for people with intellectual and developmental disabilities (IDD) to improve speech intelligibility, language skills, and pragmatics; implement augmentative and alternative communication systems (AAC); and facilitate the communication of people with IDD through communication partner training (Hewitt et al., 2016). Similarly, audiology is a clinical field closely related to speech-language pathology that addresses the prevention, identification, treatment, and research of disorders in hearing. Unidentified and untreated disorders in hearing can lead to communication disorders or exacerbate existing conditions. Thus, the role of the audiologist in the diagnosis and treatment of hearing disorders is crucial for the communication skills of at-risk populations, like people with IDD.

Individuals with IDD are a heterogeneous group, and communication abilities vary depending on the individual and the context. While some people with IDD do not demonstrate communication disorders, many experience differences or difficulties with some aspect of comprehension, expression, or social engagement (Forster, 2016; Rice, Warren & Betz, 2005; Roberts, Mirrett, Anderson, Burchinal, & Neebe, 2002). While the exact number of people with IDD who have communication disorders is unknown, emerging data suggest a high comorbidity of IDD and communication disorders (Bhasin, Brocksen, Avchen & Van Naarden Braun, 2006). Additionally, people with IDD have a higher rate of disorders in hearing, specifically hearing loss, when compared to the general population (Herer, 2012; Park, Wilson, Stevens, Harward, & Hohler, 2012). The higher prevalence of hearing loss in people with IDD is significant given the symbiotic relationship between hearing and communication. Hearing is fundamental in the development of speech and language throughout childhood. Hearing loss in children affects speech-language development, academic achievement, and social functioning (American Speech-Language-Hearing Association [ASHA], n.d.-a). Specifically, hearing loss can result in delays in the development of receptive-expressive vocabulary, syntax, and articulation. In adulthood, hearing is central to comprehending the verbal speech of others. Hearing loss in adults has been linked to feelings of depression, anxiety, frustration, social isolation, and fatigue (Oyler, 2012). The substantial co-occurrence of communication disorders in people with IDD and their increased risk of hearing disorders underscore the key role of speech, language, and hearing (SLH) services for this population.

SLH services facilitate growth and expansion of the communication skills of people with IDD, including language comprehension, expression, and social interaction (Snell et al., 2010). One way in which SLH services support developing communication skills is through the

prevention, identification, and treatment of hearing loss. Studies documenting the high prevalence of hearing loss in people with IDD have found that the condition was seldom detected, and thus frequently untreated, prior to participation in said studies. For example, Meuwese-Jongejeugd et al. (2006) reported that 202 of the 424 (47.6%) individuals with IDD and hearing loss in their study were previously unaware of their condition. Many subsequently received treatment for hearing loss for the first time following the study, including medical management of conductive losses and acquiring hearing aids. Given the deterring influence of hearing loss on speech and language, SLH services can help people with IDD maximize their potential communication skills through prevention, early identification, and treatment of hearing loss. Studies show that hearing, and thus quality of life for people with IDD, improve with some traditional interventions, like hearing aids, cochlear implants, and bone-anchored hearing aids (de Wolf, Hol, Mylanus, Snik, & Cremers, 2001; Evenhuis, 1995; Kunst, Hol, Snik, Mylanus, & Cremers, 2006; McDermott, Williams, Kuo, Reid, & Proops, 2008; Phelan, Pal, Henderson, Green, & Bruce, 2016).

SLH services can also foster communication for people with IDD through the use of AAC systems. AAC includes all forms of communication other than verbal speech that are used to express thoughts, ideas, wants, and needs (ASHA, n.d.-b). AAC systems include manual sign language, writing, pictures, and computer devices with digitized speech output or speech generating software. AAC systems can be substitutes for verbal speech, or supplements to facilitate intelligibility. The implementation of a variety of different AAC systems for people with IDD has been shown to increase social interaction and language skills (Ganz et al., 2012; Meuris, Maes, & Zink, 2015) as well as increase speech output (Millar, Light, & Schlosser, 2006; Schlosser & Wendt, 2008).

SLH services may also address the skills and behaviors of communication partners, like teachers, family members, support staff, friends, and other community members. The goal of such services is to modify the ways in which communication partners approach and respond to people with IDD in order to facilitate communication. Communication partner interventions are highly effective across a range of participants, intervention approaches, and outcomes measures (Brady & Warren, 2003; Kent-Walsh, Murza, Malani, & Binger, 2015; Ogletree et al, 2016; Pierce & Schreibman, 1995). For example, when Goldstein, English, Shafer, and Kaczmarek (1997) provided direct instruction to preschoolers regarding their interactions with peers with disabilities, the communication of the students with disabilities increased overall and thus advanced their social interactions.

In addition to their general benefits, SLH services may improve the lives of people with IDD in more specific areas, such as health and community participation. The Communication Bill of Rights (Brady et al., 2016), developed by the multidisciplinary National Joint Committee for the Communication Needs of Persons with Severe Disabilities with the goal to ensure the communication rights of people with disabilities, states that all people, including those with communication disorders, have the right to influence the conditions of their own existence through communication. This means that people with communication disorders have the right to access supports and services that facilitate their equitable participation in daily communication interactions, including those impacting their health and medical services.

People with IDD have long experienced inequities in healthcare services, and subsequently more health problems than people without IDD (Emerson & Spencer, 2015; Ervin, Hennen, Merrick, & Morad, 2014; Hatton & Emerson, 2015; Llewellyn, Vaughan & Emerson, 2015; Lotan, 2016; Nehring & Lindsey, 2016). Such discrepancies in health and healthcare

services have been in part attributed to poor communication between people with IDD and healthcare service providers (Forster, 2016; Gentile, Cowan, & Smith, 2015; Nehring & Lindsey, 2016). Research suggests that improving the communication skills of healthcare providers can improve the access to and quality of health services for people with IDD (Chinn, 2017). Since SLH services have been shown to improve communication between people with IDD and their communication partners, these services are critical to ensuring the rights of people with IDD.

Given that participation in life is closely linked to successful communication (Costello & Shane, 2016), SLH services may improve the participation of people with IDD through enhancing communication interactions with others. For example, AAC instruction has been shown to increase the participation of preschoolers (Thomas-Stonell, Robertson, Oddson & Rosenbaum, 2016). Moreover, SLH services can also reduce the occurrence of challenging behaviors in people with IDD (Hutchins & Prelock, 2014). Sometimes people with IDD and communication disorders use challenging behaviors (e.g., self-injury, noncompliance, aggression, destructive, or disruptive behaviors) as means to communicate in the absence of other methods. Challenging behaviors may be misunderstood and mismanaged, resulting in isolation or separation of people with IDD and thus restricting full participation in their environment. The expansion of communication skills that result from SLH services can reduce the occurrence of challenging behaviors in people with IDD by improving mainstream communication skills or teaching alternative methods of communication and therefore, can increase participation in the community (Hutchins & Prelock, 2014). People with IDD often experience differences in communication that can negatively impact their quality of life and overall participation. By expanding the communication skills of people with IDD and their communication partners, SLH services are effective in enhancing the communication

interactions of people with IDD and therefore in facilitating their autonomy in the community (Chinn, 2017; Costello & Shane, 2016; Forster, 2016; Gentile et al., 2015; Hewitt et al., 2016; Kent-Walsh et al., 2015; Nehring & Lindsey, 2016; Ogletree et al, 2016; Phelan et al., 2016; Thomas-Stonell et al., 2016).

Given the high prevalence of communication disorders in people with IDD, that SLH services can successfully facilitate communication between people with IDD and their communication patterns, and the critical role that communication plays in the autonomy and self-determination of people with IDD, the aim of this study is to explore how SLH services are offered to people with IDD across the nation, particularly in Medicaid Home and Community Based Services (HCBS) 1915(c) waivers as they are the largest provider of long term supports and services for people with IDD (Braddock, Hemp, Tanis, Wu, & Haffer, 2017; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). Developed as an alternative to service provision in segregated institutional settings (e.g., intermediate care facilities for individuals with intellectual disabilities [ICF/IIDs]), Medicaid HCBS waivers allow states more flexibility to provide long term supports and services in the community by allowing them to 'waive' key provisions of the Social Security Act (U.S. Department of Health and Human Services, 2000). As a result, states are able to provide community-based services targeted for certain underserved populations, such as people with IDD. HCBS waivers have grown to become the largest provider of long term supports and services for people with IDD because of their benefits, especially in terms of improved outcomes and cost effectiveness of community living, and the preferences of people with IDD (Braddock et al., 2017; Hemp, Braddock, & King, 2014; Lakin, Larson, & Kim, 2011; Larson & Lakin, 1989; Mansell & Beadle-Brown, 2004). To examine the provision of SLH services by Medicaid HCBS waivers, fiscal year (FY) 2015 HCBS IDD waivers from

across the nation were analyzed to determine how SLH services were offered for people with IDD, particularly focusing on service utilization, projected expenditures, and trends across states and services.

Method

Medicaid HCBS 1915(c) waivers were obtained from the Centers for Medicare and Medicaid Services (CMS) Medicaid.gov website over approximately a one-year period (May 2015 to April 2016) (*n* = 498). Our first inclusion criteria required waivers be 1915(c) rather than 1115 (Medicaid demonstrations) or 1915(b) (Medicaid managed care) as 1915(c) are the largest funding mechanism of long term supports and services for people with IDD (Braddock et al., 2017) (*n* = 340). Our next inclusion criteria required waivers to have target populations of only people with IDD – intellectual disability (ID), mental retardation (MR), developmental disability (DD), and/or autism spectrum disorder (ASD) (*n* = 113). (It should be noted that although MR is considered an outdated term it was a necessary search term as a number of states continue to use it in their waivers; see Friedman, 2016.) Our next criteria required all waivers provide services for the year 2015. While the majority of waivers used the 2015 fiscal year (FY) (July 1, 2014 to June 30, 2015), some waivers used the federal FY (October 1, 2014 to September 30, 2015) while still others used the 2015 calendar year (January 1, 2015 to December 31, 2015). We use the term FY across year types (i.e., state FY, federal FY, calendar year) for consistency. This process resulted in the collection of 111 FY 2015 HCBS waivers for people with IDD from 46 states and the District of Columbia.

States provide HCBS waivers (often multiple) which offer a large number of services, such as residential habilitation, supported employment, day habilitation, or SLH. As part of CMS requirements all waiver applications are required 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). Waiver data about participant services (Appendix C-1/C-3: Participant Services – Service Specifications) were used to determine if and how each of the 111 waivers offered SLH services. This process resulted in the collection of 76 different SLH services offered through 52 of the 111 waivers (28 states and the District of Columbia) for people with IDD in FY 2015. Service definitions (Appendix C-1/C-3: Participant Services – Service Specifications) from these 76 services were next qualitatively analyzed using content analysis (Patton, 2002) to determine service trends and patterns.

Cost-neutrality data (Appendix J-2: Cost Neutrality Demonstrations – Derivation of Estimates) was then used to determine each waiver's utilization and projected expenditures for SLH services. It should be noted eight services from seven waivers from five states were excluded from the expenditures analysis because they combined SLH services with other therapies (e.g., occupational therapy, physical therapy, psychology) and it could not be determined what proportion of expenditures was directed specifically for SLH services. As a result, the final total included in the quantitative expenditure analysis was 68 services located within 45 waivers from 24 states and the District of Columbia. For the quantitative expenditure analysis, we examined cost-neutrality data of these 68 SLH services using descriptive statistics to compare total projected expenditures, total unduplicated participants, average projected service

expenditures per participant, average reimbursement rates, and average annual service provision per participant across the states and services.

Findings

Service Definitions

Speech/language services were generally defined similarly to Washington Children's Intensive In-Home Behavioral Support waiver's SLH service as:

> the application of principles, methods, and procedures related to the development and disorders, whether of organic or nonorganic origin, that impede oral, pharyngeal, or laryngeal sensorimotor competencies and the normal process of human communication including, but not limited to, disorders and related disorders of speech, articulation, fluency, voice, verbal and written language, auditory comprehension, cognition/communication, and the application of augmentative communication treatment and devices for treatment of such disorders.

Hearing (or audiology) services were generally defined similarly to Washington Community Protection Waiver's SLH service as:

> the application of principles, methods, and procedures related to hearing and the disorders of hearing and to related language and speech disorders, whether of organic or nonorganic origin, peripheral or central, that impede the normal process of human communication including, but not limited to, disorders of auditory sensitivity, acuity, function, processing, or vestibular function, the application of aural habilitation, rehabilitation, and appropriate devices including

> fitting and dispensing of hearing instruments, and cerumen management to treat such disorders.

Twenty-nine services (38.2%) offered both speech/language and hearing services, 42 (55.3%) services offered only speech and language, and 5 (6.6%) offered only hearing services. The majority of SLH services (61.8%; $n = 47$) offered *both* assessment/evaluation and therapy services. However, 22 services (28.9%) offered only therapy services. Conversely, seven services (9.2%) offered only diagnostics screenings and evaluation.

States often included in their SLH services definitions an explanation of the ways waiver services were different from the SLH services offered in their Medicaid state plans or other SLH services offered by the state. For example, 30 services (39.5%) specified that only adults could receive waiver SLH services because those under 21 would receive SLH through Early and Periodic Screening, Diagnostic, and Treatment (EPSDT). Twenty services (26.3%) explained SLH service provision was supplemental to exhaustion of Medicaid state plan services. Similarly, eight services (10.5%) specified waivers' SLH services were for exhaustion of EPSDT services.

Twenty-nine services (38.2%) generally noted that waivers offered SLH services that were not otherwise covered by Medicaid state plans. For example, frequently ($n = 24$; 31.6%) the waiver was utilized rather than the state plan so that SLH services could be offered in an alternative setting, such as the participant's home. The Washington Basic Plus Waiver explained this possibility saying,

> Speech, hearing and language services are available through the waiver when a Medicaid provider is not available in the area in which a child or young adult lives or when the service is not covered due to medical necessity, but is

> determined necessary for remedial benefit. An example of the need for these services as a waiver service would be to allow the therapy to be provided in the individual's home. State plan services are provided in clinical settings and few providers are willing to come into the home to provide service. Individuals on the waiver often require or benefit more from therapy provided in the home with the inclusion of family members or providers due to high anxiety and challenging behavior that prevents them from accessing the clinical setting. In-home services offer the additional benefits of the natural environment which allows therapy to be incorporated into individual regular household routines.

Other services (*n* = 20; 26.3%) explained SLH was offered in waivers rather than the state plan in order to provide long-term habilitative SLH rather than the short-term treatment for acute needs as offered in Medicaid state plans. For example, the New Mexico DD Waiver Program noted,

> Adults on the DD Waiver may access therapy services under the state plan for acute and temporary conditions that are expected to improve significantly in a reasonable and generally predictable period of time. Therapy services provided to adults under the DD Waiver are for maintenance and community integration purposes.

Another trend in SLH waiver service definitions was the allowance of training for caregivers or direct care staff. For example, one feature of the North Carolina Supports Waiver's SLH consultation service was to:

> provide expertise, training, and technical assistance … to assist family members, caregivers, and other direct service employees in supporting individuals with

developmental disabilities who have long term habilitative treatment needs. Under this model, family members and other paid/unpaid caregivers are trained by a licensed professional to carry out therapeutic interventions, which will provide consistency and increase the effectiveness of the specialized therapy.

Service Expenditures

In FY 2015, HCBS IDD waivers projected spending $23.1 million for SLH services. Projected spending varied widely by service, ranging from $18.75 (Indiana Family Supports Waiver's 'speech therapy' service) to $4.7 million (New Mexico Developmental Disabilities Waiver Program's 'speech therapy, standard (new)' service); average projected spending was $340,175 per service. Table 1 details total projected spending and spending per capita by state.

HCBS waivers projected providing approximately 13,000 participants with SLH services, ranging from 1 participant (Indiana Family Supports Waiver's 'speech therapy' service; Missouri DD Comprehensive Waiver's 'Communication Skills Instruction' service; Oregon ICF/IDD Comprehensive Waiver's 'speech, hearing and language services'; Pennsylvania Adult Autism Waiver's 'therapies – speech' service; Texas Developmental Disabilities waiver's 'audiology services'; and, Washington Community Protection Waiver's 'speech, hearing, and language services') to 2,255 participants (South Dakota Choices waiver's 'Other Medically Related Services - Speech, Hearing & Language'). The average service projected providing SLH services to 190 participants.

Figure 1 details average projected spending per participant by state. The projected spending per participant on SLH ranged across services from $18.75 (Indiana Family Supports Waiver's 'speech therapy' service) to $9,306 (Kansas Autism Waiver's 'Interpersonal

Communication Therapy' service) (see Table 2). On average services projected spending $1,730 per person for SLH in FY 2015.

SLH services were reimbursed at a number of different rates (see Table 3). Rates included 15-minutes (*n* = 32, 47.1%), hourly (*n* = 19, 27.9%), session/procedure/visit (*n* = 13, 19.1%), and daily rate (*n* = 4, 5.9%). The average 15-minute reimbursement rate was $17.47 ($69.88 an hour), hourly rate was $63.05, session rate was $81.18, and daily rate was $226.06. Those services with 15-minute reimbursement rates projected providing 134 15-minute units (approximately 34 hours) per participant on average in a year, hourly rate services 42 hours on average per participant, session rate services 63 sessions on average per participant, and daily rate services 89 days on average per participant.

Discussion

SLH services can be critical to expanding the community participation and inclusion of people with IDD. However, our examination of SLH services offered by Medicaid HCBS 1915(c) waivers across the nation found that only 28 states and the District of Columbia offered SLH services for people with IDD in FY 2015. Unlike Medicaid state plans, HCBS waivers were often utilized to provide SLH services in alternative settings, such as participants' homes, and provide long-term habilitative care rather than immediate acute care. Many states also saw waiver SLH services as supplemental to the services people with IDD received in childhood through EPSDT, or to the acute care offered Medicaid state plans.

In FY 2015, HCBS waivers projected $23.1 million for the SLH services of approximately 13,000 people with IDD. Although it may seem like a significant amount of funding, this amounted to only 0.09% of all FY 2015 HCBS IDD waiver spending (Friedman, 2017). In FY 2015, HCBS SLH services were projected for only 2.1% of participants; whereas,

the prevalence of SLH disorders is estimated as 10% in the general population (Morris, Meier, Griffin, Branda, & Phelan, 2016). Moreover, our findings also revealed large variance across states and services in terms of total projected spending, spending per participant, reimbursement rates, and annual service provision. For example, average annual spending per participant ranged from $19 to $9,306. The wide variance found across SLH services is a hallmark of the HCBS waiver program and its services (Friedman, 2017). The wide berth allowed to states in designing customized programs also results in large differences across states and services (Friedman, 2017). Unfortunately, other than requiring allocation be equal to or more cost effective than institutional funding (cost-neutrality), CMS does not require states to explain in depth their decision-making for reimbursement rates and other service expenditures.

Despite the variation in reimbursement for SLH services through HCBS IDD waivers, the majority of services were reimbursed at rates insufficient to provide the SLH services described compared to existing benchmarks, for example Medicare. Medicare, Medicaid, and many other health care plans use Current Procedural Terminology (CPT®), a set of descriptive terms and identifying codes which serve as uniform medical nomenclature, to report and describe medical procedures (American Medical Association, n.d.). When compared to reimbursement of common and comparable SLH services described in the Medicare Physician Fee Schedule (MPFS), average reimbursement rates within HCBS waivers for SLH services are constantly and significantly lower. For example, according to the Medicare Fee Schedule for Speech-Language Pathologists (ASHA, 2015), which provides national reimbursement averages according to CPT® codes of outpatient speech and language services, evaluation of speech (CPT® Code 92522) and language (CPT® Code 92523) are reimbursed at $93.51 and $195.98 respectively (per 45-60 minute session), and evaluation for speech generating AAC systems (CPT® Code 92607) at

$127.55 (per hour). Intervention for speech and language (CPT® Code 92507) is reimbursed at $79.90 and intervention using speech generating AAC systems (CPT® Code 92609) is reimbursed at $111.78 (per 45-60 min session). These services are comparable to the SLH services described by the HCBS waivers; however, on average, Medicare reimbursed at $121.74 an hour for such services, which is anywhere from 1.5 to almost 2 times more than that reimbursed through HCBS waivers in this study. Medicare reimbursement rates are often used as a guideline when negotiating reimbursement rates for private insurances; however, they may be below competitive market rates due to budgetary constraints (ASHA, n.d.-c). Given that the MPFS typically sets the minimum reimbursement standards for SLH services, and that MPFS rates are generally considered to be below that of third party payers (McCarty & White, 2009), the reimbursement for SLH services within many HCBS waivers are below said standards and thus insufficient for actually providing the services described.

While the reason for such a discrepancy in reimbursement between standards like the MPFS and HCBS waivers is to our knowledge not discussed in the literature, one possible explanation includes the prioritization of services offered. Although reimbursement for services described in the MPFS includes those offered "regardless of setting," Medicare services are often rendered in hospital-based settings (like inpatient or outpatient rehabilitation) or according to hospital regulations, standards, and customs (like home health services). Such services are typically "provider centered," placing the power to direct care in the hands of the professional as opposed to the person with a disability and their support network. HCBS waiver services, on the other hand, offer a more collaborative and integrative approach to treatments, even when compared with Medicaid state plans. Given these differences in philosophy, and the fact that waiver services are mostly aimed at long-term habilitative care rather than immediate acute care,

it is possible that provider-centered services taking place within the medical setting have traditionally been considered more valuable and thus are funded accordingly; another possible explanation is that the newer community-based model of service provision has fewer benchmarks to help set reimbursement rates.

In light of the insufficient funds allocated to SLH services for HCBS waivers, it is unlikely that people with IDD utilizing waivers are able to obtain adequate SLH services from waivers themselves. The services rendered through HCBS waivers would at best be insufficient in supporting long-term change due to infrequent services, and at worst not even enough to obtain an evaluation. Furthermore, the SLH services described in this study are provided by the same professionals (speech-language pathologists and audiologists) with the same degrees (Master's degrees and clinical doctorates) and qualifications (licensing and certifications) as those who provide services to Medicaid and Medicare recipients despite the discrepancies in reimbursement rates. Additionally, those clinicians providing community-based services, like those offered through the HCBS waivers, have the added financial and temporal expense of traveling to participants. Given the poor reimbursement rates and these added expenses, it is unlikely that many clinicians enroll as providers of SLH services through HCBS waivers, rending them even more inaccessible to people with IDD.

HCBS services are effective in supporting community-based living for people with IDD, and are preferred over other service delivery models (Braddock et al., 2017; Hemp et al. 2014; Lakin et al., 2011; Larson & Lakin, 1989; Mansell & Beadle-Brown, 2004). Similarly, SLH services are established in their improvement, advancement, and expansion of communication for people with IDD. Given the crucial role that communication plays in key aspects of independent living, like interpersonal relationships, safety, and employment, SLH services

offered through HCBS waivers are an essential element of equitable access to autonomous living for people with IDD. Despite this, current allocation of SLH services through HCBS waivers are not only unreliable from state to state, but are insufficient overall when compared to national bench markers, like the MPFS, which serves as a standard for reimbursement by third party payers. Such a discrepancy in reimbursement reflects a depreciation of SLH services offered in community-based settings.

Limitations

A number of limitations should be noted when considering our findings. First, HCBS waivers are projections made to the federal government, not expenditures. However, they are reasonably accurate proxies as states base them on previous years' expenditures. Moreover, Rizzolo et al.'s (2013) analysis of FY 2010 HCBS IDD waivers revealed similar findings to expenditure analyses conducted by Braddock et al. (2011). Rizzolo et al.'s (2013) analysis found waivers projected spending $23.5 billion, which was highly representative of Braddock et al.'s (2011) analysis of projections ($25.1 billion). Braddock et al.'s (2011) figure included $1.38 billion of spending from two 1115 and 1915(b) waivers and two managed care programs, which accounts for the slight difference between Rizzolo et al. (2013) and Braddock et al.'s (2011) figures.

Second, a recent CMS revision (Home and Community Based Services Waivers [CMS-2296-F], 2011) allows states to combine target populations (e.g., IDD and physical disability). There were four waivers in FY 2015 which combined IDD with another target population. These four waivers were excluded from the analysis because service provision and expenditures between people with IDD and the other target groups could not be differentiated. Although these waivers likely would have produced similar trends, this exclusion should be considered when

interpreting our findings. Finally, as is typical, the waivers' FY in this study do not always align exactly – some states utilized the state FY, others the federal FY, and still others the calendar years; however, all waivers included the year 2015.

Implications for Research and Practice

Based on waiver data alone there is no way to determine why there are such large differences across states and services. While some of these differences are likely due to state characteristics, such as demographics, and size, these large differences still existed even when state population was controlled using spending per capita calculations or using average spending per participant. The large differences in reimbursement rates and annual service provision are particularly concerning considering they can impact the quality of SLH services people with IDD receive, as well as result in service disparities.

The CMS technical guide for states explains both average reimbursement rates and annual service provision should be based on,

> the most recently approved CMS-372(S) [annual waiver expenditure report]… In the case of new waivers or when additional services are being added in a waiver renewal… the source may be a state study, utilization of similar services in other waiver programs, or experience in other states. (Disabled and Elderly Health Programs Group et al., 2015, p. 277)

The technical guide also notes CMS reviews estimates to ensure rates are "consistent with economy, efficiency, and quality of care" (Disabled and Elderly Health Programs Group et al., 2015, p. 277). CMS also explains, "a state may be required to provide additional justification if the amount of the payment appears to be *excessive* in light of experience with waivers that provide similar services to like target populations" (emphasis added; Disabled and Elderly

Health Programs Group et al., 2015, p. 277). Not only does the CMS technical guide only mention contacting the state prior to waiver approval if the proposed rates are too expensive – not when they are not sufficient – it is also unclear how strenuous and critical these reviews are given there were a lot of low rates across SLH services, especially when compared to national benchmarks. This is particularly concerning given low reimbursement rates are not uncommon across different waiver service types (Friedman, 2017).

While states may be basing rates on previous years' rates, if the original rates were not sufficient or if they do not grow with industry standards, it is unclear if and how states would be pushed to expand their waiver estimates prior to approval. However, this lack of clarity also provides for fruitful opportunities for future research. Future research should examine states' decision-making processes in depth regarding utilization and allocation, as well as examine if and how CMS critiques these decisions. Another potential future research direction is an analysis of the changes CMS does require of states prior to approving their waivers. The research about changes CMS requires will help ensure people with IDD receive services of equal quality, regardless of location.

SLH services are provided through a patchwork of systems (e.g., Medicaid state plans, Medicaid HCBS, Medicare, early intervention) with little existing research on how states fill in gaps in SLH service provision across these services. Moreover, utilization trends of SLH services by people with IDD through the HCBS waivers have yet to be explored in the literature, making examination of service expenditures a fruitful avenue for future research. It would also be beneficial to explore the demographics of SLH service recipients – who benefits most from HCBS waiver services as well as if there are any service disparities. Doing so would be helpful to guide future health promotion efforts based on disparities, as well as to identify any barriers

and facilitators to accessing SLH services through HCBS waivers, in order to best meet the needs of all people IDD and communication disorders.

Given the existing literature on the benefits of SLH services for people with IDD and the poor reimbursement rates for these services within the HCBS waiver system, the results of this study have implications for advocacy efforts in future practice. One goal of advocacy efforts would be to achieve sufficient reimbursement rates so that participants in HCBS waiver programs across states have equitable access to services. Adjusting reimbursement rates may be leveraged by raising public awareness of the increased prevalence of communication and hearing disorders in people with IDD, the communication outcomes of SLH services within this population, and the often insufficient reimbursement rates for SLH services within HCBS waiver programs. Campaigns increasing awareness of these issues should target not only the general public, but specifically the IDD community and their support networks. Self-advocates, families, and service providers (like SLPs) can be strong allies in pushing for adequate reimbursement rates through their national organizations like The Arc, NADD and ASHA, which directly correspond with legislators, policy makers, and politicians regarding issues important to their membership. Collaborative and interdisciplinary advocacy efforts are a critical part of obtaining adequate reimbursement rates that reflect appropriate value for the vital role of SLH services in ensuring the rights of people with IDD.

Moreover, given the variability not only of reimbursement rates for SLH services across states, but also of the inconsistent provision of SLH services themselves, it is unlikely people with IDD, their support networks, and their service providers receive clear, streamlined information regarding the availability of SLH services through HCBS waivers, ultimately leaving people with IDD and communication disorders without communication services

adequate to meet their needs. Increased awareness of SLH services could be achieved through knowledge translation via mass media, social media, and state and national organizations serving the aforementioned groups.

Clinical education programs for future service providers, like SLPs, should also educate students about Medicaid HCBS waivers. Expanding clinicians' knowledge of this alternative funding mechanism may be particularly beneficial when the people with IDD they serve have utilized the maximum amount of SLH permitted by Medicaid state plan services for services that are not covered in state plans or in cases where community-based services are more appropriate than those provided in the medical setting.

Conclusion

Despite the clear need for and benefit of SLH services in the lives of people with IDD, projected funding for SLH services through HCBS waivers varies significantly from state to state, and includes insufficient reimbursement rates, and service provision. Given increased risk for and under identification of communication and hearing disorders in people with IDD, adequate access to sufficient SLH services is essential to ensure their right to a self-determined autonomous life through communication.

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Table 1

Waiver Spending on Speech, Language, and Hearing Services (FY 2015)

State	*N* services	Total projected spending	Spending per capita	Rank	Total projected participants
Alabama	3	$70,957	$0.01	16	42
California	1	$333,171	$0.01	19	185
District of Columbia	1	$885,000	$1.32	3	300
Florida	2	$3,016,447	$0.15	10	733
Georgia	2	$81,519	$0.008	20	46
Illinois	1	$29,600	$0.002	22	200
Indiana	2	$76,021	$0.01	17	20
Kansas	1	$567,677	$0.19	8	61
Kentucky	2	$2,775,462	$0.63	4	434
Louisiana	1	$3,240	$0.001	24	12
Maine	2	$30,740	$0.02	14	33
Massachusetts	4	$376,959	$0.06	12	424
Mississippi	1	$9,275	$0.003	21	5
Missouri	5	$192,785	$0.03	13	146
Montana	2	$1,454	$0.001	23	9
New Mexico	7	$6,394,709	$3.07	1	3,069
Oklahoma	5	$671,061	$0.17	9	571
Oregon	1	$396	$0.0001	25	1
Pennsylvania	2	$145,873	$0.01	18	35
South Dakota	1	$1,633,666	$1.90	2	2,255
Tennessee	5	$2,634,885	$0.40	6	1,827
Texas	9	$2,004,441	$0.07	11	1,341
Washington	4	$129,228	$0.02	15	57
West Virginia	1	$723,598	$0.39	7	535
Wyoming	2	$343,751	$0.59	5	100

Note. Rank is spending per capita from highest to lowest.

Table 2
Projected Spending per Participant on Speech, Language, and Hearing Services

Projected Spending	*N*	*%*
$1 to $1,000	24	35.3
$1,001 to $2,000	24	35.3
$2,001 to $3,000	9	13.2
$3,001 to $4,000	5	7.4
$4,001 to $5,000	4	5.9
$6,001 to $7,000	1	1.5
$9,001 to $10,000	1	1.5

Note. N = number of services. States could offer more than one waiver; waivers could also include more than one SLH service.

Table 3
Reimbursement Rates and Annual Service Provision

	n (%)			
	15 min (*n* = 32)	Hourly (*n* = 19)	Session (*n* = 13)	Daily (*n* = 4)
Average reimbursement rates				
$0.01 to $10.00	3 (9.4)	--	1 (7.7)	1 (25.0)
$10.01 to $20.00	21 (65.6)	1 (5.3)	1 (7.7)	--
$20.01 to $30.00	7 (21.9)	1 (5.3)	--	--
$30.01 to $40.00	1 (3.1)	2 (10.5)	3 (23.1)	--
$40.01 to $50.00	--	--	1 (7.7)	--
$50.01 to $60.00	--	6 (31.6)	2 (15.4)	--
$60.01 to $70.00	--	1 (5.3)	--	--
$70.01 to $80.00	--	7 (36.8)	4 (30.8)	--
$160.01 to $170.00	--	1 (5.3)	--	--
$280.01 to $290.00	--	--	--	1 (25.0)
$290.01 to $300.00	--	--	--	1 (25.0)
$320.01 to $330.00	--	--	--	1 (25.0)
$450.01 to $460.00	--	--	1 (7.7)	--
Average annual service provision per participant				
0 to 25	4 (12.5)	11 (57.9)	8 (61.5)	--
26 to 50	1 (3.1)	4 (21.1)	3 (23.1)	--
51 to 75	4 (12.5)	--	--	--
76 to 100	9 (28.1)	2 (10.5)	--	1 (25.0)
101 to 125	6 (18.8)	1 (5.3)	--	--
126 to 150	2 (6.3)	1 (5.3)	--	--
201 to 225	2 (6.3)	--	1 (7.7)	--
251 to 275	--	--	--	--
326 to 350	--	--	--	3 (75.0)
351 to 375	1 (3.1)	--	--	--
401 to 425	--	--	1 (7.7)	--
525 to 550	1 (3.1)	--	--	--
701 to 725	1 (3.1)	--	--	--

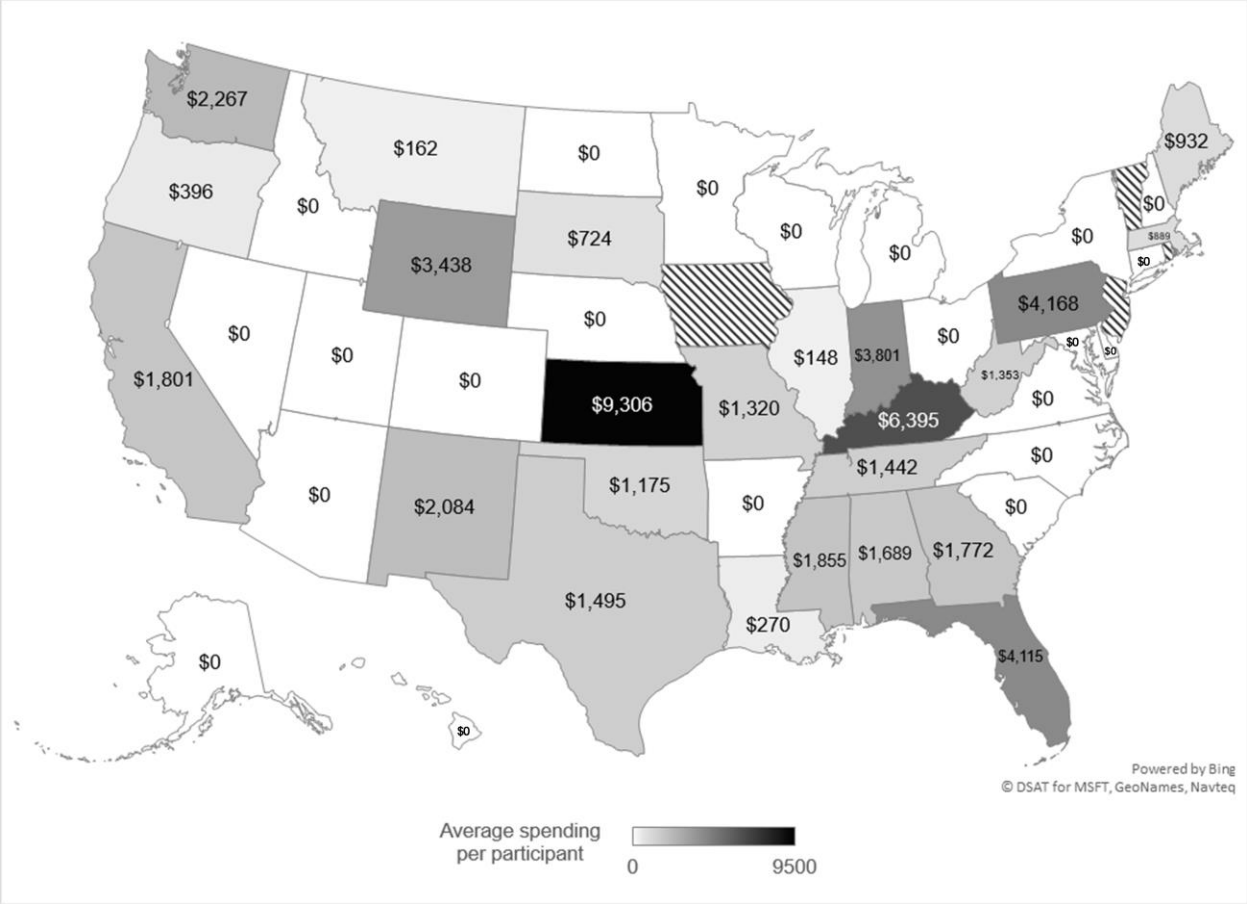

Figure 1. Average projected SLH service spending per participant by state for FY 2015 waivers. States detailed "$0" included no waiver funding for SLH. States with stripes were those states not included in our sample because they did not have FY 2015 IDD waivers, or waivers that were accessible via CMS (see Friedman (2017) for more information).