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## Language Deprivation Is a Game Changer for the Clinical Specialty of Deaf Mental Health

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## **Language Deprivation Is a Game Changer for the Clinical Specialty of Deaf Mental Health**

### **Abstract**

In this paper, the medical, social and historical forces resulting in much smaller numbers of deaf children having quality access to natural sign languages are presented. These forces mean that people who work in the clinical specialty of Deaf mental health are seeing more clients with atypical or dysfluent sign language. An historical overview of the development of this clinical specialty is outlined, followed by a discussion of how the problem of language deprivation is a “game changer” for the work of mental health clinicians, interpreters, communication assessors, and administrators of Deaf mental health services. Special attention is given to the proposed new condition called language deprivation syndrome (LDS). Knowledge about LDS is presented along with current research questions. Some innovative clinical, interpreting, communication assessment, and administrative practices relevant to work with deaf people with language deprivation are presented.

*Keywords: Deaf, Language deprivation, Deaf mental health, Language deprivation syndrome*

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## **Language Deprivation Is a Game Changer for the Clinical Specialty of Deaf Mental Health**

### **Introduction**

Language deprivation is a game changer for the clinical specialty of Deaf mental health. Because medical, social, and historical forces are resulting in much smaller numbers of deaf children having quality access to natural sign languages, the language and communication abilities of deaf people are changing. With this come challenges for which mental health providers working with deaf people and ancillary helping disciplines — including sign language interpreters, teachers of deaf children, and program administrators — are called upon to address. Throughout this paper the upper case “Deaf” will be used when there are specific references to Deaf culture, the Deaf community, Deaf mental health, Deaf education, Deaf interpreters or culturally Deaf or signing people. When deaf people are referred to generally, or when the reference is to hearing loss, the lower case “deaf” is used.

Deaf children may have normal intellectual potential, but often grow up without native language abilities in any language (Hall, 2017). This is not just because many are unable to hear sufficiently to acquire spoken language as hearing children do, but also because they may not be exposed sufficiently to natural sign languages to allow them to acquire native signing abilities. Natural sign languages “are bona fide linguistic systems, with structures and rules and the full range of expressive power that characterize spoken languages.” This is distinguished from systems created by educators that attempt to represent the spoken language manually by borrowing and adapting signs and imposing a way of manually representing the spoken language grammar (Sandler & Martin, 2001).

For children who are severely to profoundly deaf, acquiring spoken language skills requires great effort and is sometimes not possible; whereas acquiring native sign language skills can be natural and effortless, providing the right environment is present (Humphries, Kushalnagar, Mathur et al., 2012). Without native abilities in either spoken or sign languages, deaf children can develop a host of cognitive, socio-emotional, and behavioral challenges, discussed in this article in relation to the proposed condition of “language deprivation syndrome” (LDS) (Gulati, 2019; Hall, Levin, & Anderson, 2017).

Historically, attempts by mental health professionals to assist deaf people have essentially used three paradigms to guide their work. Over roughly a century, a distinct clinical specialty called Deaf mental health has been evolving which, in the years before it had a name, focused upon the disability of being unable to hear. Remediation of hearing loss and its consequences was the first paradigm for this work. Then, with the rise of Deaf pride and the Deaf cultural movement, the mental health paradigm shifted towards what has been called a “culturally affirmative” model of mental health care (Glickman & Gulati, 2003; Glickman & Harvey, 1996; Leigh, 2010) The shift was essentially from the medical-pathological to the cultural view of Deaf people as applied to mental health (Baker & Cokely, 1980).

The shift represented a profound paradigm change. More recently, the decline of Deaf residential schools, rise of mainstreaming, and the influence of a cochlear implant industry which often promotes an oralist philosophy, along with other socio-historical developments discussed

below, means that there are growing numbers of deaf children who lack native language skills in either sign or spoken language (Cogen & Cokely, 2015). This in turn means that the Deaf mental health specialty must maintain a dual focus on cultural affirmation and the disabilities associated with language deprivation; in essence, a third paradigm. (Glickman & Hall, 2019).

In this article, we also discuss some of the ways that growing attention to language deprivation is affecting the work of Deaf mental health and allied professionals. We discuss the proposed diagnosis of language deprivation syndrome and then note some of the implications of language deprivation for sign language interpreters and mental health clinicians (Glickman, 2009; Gulati, 2019; Hall, Levin, & Anderson, 2017). It is one matter, for instance, to work with Deaf people who are proudly culturally Deaf and who use sign language fluently. It is with those people that a culturally affirmative model of work is most applicable. It is quite another matter to work with deaf people who are culturally marginal (Glickman, 1996; Leigh, 2009) and who are dysfluent in even their best language (Crump & Hamerdinger, 2017). Some of these people, mentioned in the latter group, may have LDS, a profoundly disabling condition. Deaf mental health professionals are now increasingly realizing that growing numbers of their clients are language deprived and that they have to adapt their work accordingly (Glickman & Hall, 2019).

Finally, we discuss some of the administrative challenges of setting up and running a statewide continuum of mental health services for diverse deaf people, and the pivotal role that a knowledgeable and skilled Director of Deaf Services plays. The large knowledge base for state directors incorporates both cultural and disability concerns including guiding service providers in addressing the enormous diversity of communication skills and deficits among deaf people. The focus of their education and advocacy goes beyond what is legally required by laws like the Americans with Disability Act (ADA) and Title VI of the Civil Rights Act because neither law is a perfect match for the complex intersection of cultural and disability concerns of deaf people.

## **A Brief Historical Overview of Three Paradigms**

### ***Paradigm One: Culturally Uninformed Clinical Practice and the Presumption of Disability***

The modern era of specialized mental health treatment of deaf persons arguably began with the 1975 Conference on the Functions, Competencies, and Training of Psychological Services to the Deaf in Spartanburg, South Carolina (Levine, 1977). This conference was organized by Edna Levine, one of the founders of the Deaf mental health field. In the early 1970s, she conducted a survey of psychological service providers working with people then broadly labeled as “hearing-impaired” and found that most providers were practicing without special training or knowledge, including in sign language (Levine, 1981). This conference was likely the first professional venue where advocates asserted that providers who work with deaf people should, at a minimum, sign. Conference attendees also discussed qualifications, training, and whether the nature of counseling with deaf people was different than with hearing people. These kinds of questions persisted as the clinical specialty of Deaf mental health developed (Glickman, 2013).

These themes were echoed in the first text to be published about counseling deaf people, a short monograph by pioneering deaf psychologists Allen Sussman and Larry Stewart, *Counseling with Deaf People* (Sussman & Stewart, 1971; Williams & Sussman, 1971). This monograph

contained chapters describing the social and psychological problems found among deaf people, the then-status and principles of counseling deaf people, the role and function of the counselor, and counselor preparation. The main theme was that counseling with deaf people was possible provided the counselor was adequately trained and skilled, and the key component of such training was developing sign language abilities.

The first specialty mental health programs for deaf persons in the United States and Great Britain were established in the 1950s and 1960s (Pollard, 1992). A mental health program for deaf people was established at the New York State Psychiatric Institute by Franz Kallman, John Rainer, and Ken Altshuler (Glickman, 2013). This was followed by the St. Elizabeth Hospital unit in Washington, DC, founded by Luther Robinson, a program at the Michael Reese Hospital in Chicago founded by Roy Grinker, McCay Vernon, and Eugene Mindel, the University of California San Francisco's Center on Deafness founded by Hilde Schlesinger and Katheryn Meadows-Orlans, and a psychiatric inpatient program for deaf people in Manchester, England, established by John Denmark. These programs all focused on the most severely disturbed deaf people. They provided the first contexts in which psychotherapy with deaf adults was discussed (Glickman, 2013) Bringing deaf people together into distinct mental health programs was a crucial step in considering their special service needs.

In the first half of the 20<sup>th</sup> century in the United States, research occurred into the psychological functioning of deaf people (Pollard, 1992). After the first world war, over 80 papers, reflecting the interest in newly developing intelligence tests, were published comparing deaf and hearing samples on intelligence and personality (Pollard, 1992; Pollard, 1998a; Vernon, 1995). Rudolf Pintner, the author of many of the papers, strove to do psychological testing of deaf people appropriately, even calling for the creation of new, specially developed psychological tests (Pollard, 1992). Most of his colleagues, however, were less cautious. Using highly biased measures such as written English tests that were administered without signing or interpreters, they found that the evaluated deaf people had lower intelligence and greater psychopathology than the hearing people they studied. Their conclusions on the relative intellectual inferiority of deaf people were reinforced later by Helmer Myklebust, whose own studies of deaf people using English-based personality tests such as the MMPI, concluded that deaf people showed greater psychopathology (Myklebust, 1964; Pollard, 1992; Vernon & Daigle-King, 1999).

It is easy to criticize these early pioneers for not understanding what half a century of research and cultural change regarding deaf people now allows us to take for granted: the need for mental health providers working with deaf persons to be appropriately trained and qualified. One could fairly argue that their early mistakes set the stage for a more culturally affirmative and respectful practice.

Prior to the 1970s, while there were psychological research and mental health practice among deaf people, they were generally not conducted by competent signers, nor informed by objective research, and were certainly not guided by sensitivity to American Sign Language (ASL) and Deaf culture, nor administered by trained Deaf professionals. Such developments had to wait till the discovery during the 1960s that ASL was a language distinct from English (Stokoe, Casterline, & Croneberg, 1976), and the burgeoning Deaf culture movement of the 1970s and 1980s. The period up until this time should be considered overall one of mostly uninformed

practice where notions of deafness as a profound disability, with many implications for impaired functioning, were assumed. The bias is easily summarized in the old idea of a “psychology of deafness,” in which sensory-deprivation (the inability to hear) is presumed to cause psychological problems (Lane, 1992). The paradigm is predominantly that which Baker and Cokely (1980), in their groundbreaking first grammatical text of ASL refer to as the “medical-pathological” view of deaf people. However, as noted, the seeds of change were being planted.

### ***Paradigm Two: Cultural Affirmative Mental Health Practice***

The second phase took its roots in the 1970s, but only took off in the last two decades of the 20th century. For the shift to a culturally affirmative model to occur, the dominant paradigm through which deaf people were understood had to shift from the medical-pathological model to the cultural model in which Deaf people were viewed as linguistic minorities with a community and culture (Baker & Cokely, 1980). Genuine ASL classes, as opposed to classes where people learned sign vocabulary began with the “Green Books” by Baker and Cokely (1980).

This shift to the Deaf cultural paradigm enabled mental health professionals working with deaf people to change the foci of their work from how deaf people adjusted to a hearing loss to all the elements of cross-cultural and culturally affirmative mental health care (Glickman, 1983, 1986, 2003; Glickman & Harvey, 1996; Leigh, 2009, 2010; Sussman & Brauer, 1999). This new thinking set the stage for the creation of the mental health counseling track in the Gallaudet Department of Counseling along with the university’s clinical psychology doctoral program. In essence, a culturally affirmative model of mental health care emerged as part of the new recognition of Deaf communities and culture. It was founded on the recognition that ASL was a real language and that members of the Deaf community were minority language users.

The culturally affirmative model of mental health care for deaf people has some recognized components. First and foremost, it includes ensuring that providers have appropriate communication skills (a topic itself of much greater complexity than initially appears). Of course, it is often much easier to tout the importance of sign language skills than to find qualified providers, and the signing skills of providers vary enormously. Nonetheless, there has been growing recognition that providers need these skills, and that the skills should be evaluated with objective measures. Secondly, there has been a growing commitment to developing and hiring competent deaf people in all aspects of programs and services and in leadership roles. Thirdly, culturally affirmative sensibilities increasingly inform clinical practice in such matters as how deaf and hearing staff relate to one another and how established psychotherapies are adapted for deaf people with varying communication abilities (Glickman, 2013).

There have been numerous innovative Deaf treatment programs, with ground-breaking research and new practices emerging from places like the Deaf Wellness Center in Rochester, New York. There have also been innovative Deaf-centered addiction programs, beginning with probably the most influential program, the Minnesota Chemical Dependency Program, which provided specialized services for several decades until 2020. Other elements of an emerging clinical discipline, such as professional organizations like ADARA, professional conferences sponsored by ADARA and Breakout, professional journals like the JADARA and JDSDE, new books and videos, the latter taking advantage of emerging web-based technologies, have appeared. Alongside the development of culturally affirmative mental health and rehabilitation practice for

deaf people have been pioneering practices in mental health interpreting, such as those taught at the annual Mental Health Interpreter Training (MHIT) program offered by the Alabama Office of Deaf Services, with which the second two authors are affiliated.

Competent Deaf treatment providers, services, and programs need to have a great deal of communication expertise, exquisite sensitivity to the Deaf experience, and a variety of specialized intervention skills. A culturally affirmative perspective continues to be the foundation for Deaf mental health. Whenever one starts a new service, the first order of business is always, or should always be, assuring that staff have the needed linguistic and cultural competencies (Glickman, 2013).

### ***Paradigm Three: Deaf Mental Health and the Integration of Culture and Disability Considerations***

The third phase of Deaf mental health is one in which a culturally affirmative perspective is not adequate to guide the field (Glickman, 2013; Glickman & Hall, 2019). There is ample evidence at this point of the kinds of self-awareness, knowledge, and specialized skills required of practitioners in this field to make a solid claim that Deaf mental health is a distinct clinical specialty even without considering the growing attention to the problem of language deprivation (Glickman, 2013; Glickman & Hall, 2019). Note that “Deaf mental health providers” refers to providers in the discipline, regardless of whether they are Deaf, hearing, hard-of-hearing, Deaf-blind or have other statuses.

The move beyond a pure culturally affirmative model is occasioned chiefly by the fact that language deprivation forces upon the field a new consideration of disability-related themes, especially the disability of language deprivation syndrome or LDS. Deaf mental health differs from the culturally affirmative model in this incorporation of both cultural and disability perspectives. Many Deaf people object to any notion of being deaf as a disability (Bauman & Murray, 2014; Lane, 1996; Padden & Humphries, 1988). The cultural model of the Deaf community teaches that Deaf people consider themselves members of a community that has a language and culture(s) at minimum. Even so, the world for deaf people is changing to the point where the cultural lens on Deaf people is increasingly inadequate as a sole framework for Deaf mental health.

First, a focus upon culturally Deaf people often minimizes the experiences of the much larger group of people with hearing loss, including those deafened later in life, who do find their hearing loss to be disabling, and for whom hearing loss may well be associated with psychological conditions like depression and anxiety (Fellinger, Holzinger, & Pollard, 2012; Kvam, Loeb, & Tambs, 2006). Indeed, people who are hard of hearing or late-deafened have many unique psychological challenges related to experiencing life as an outsider or as between worlds (Harvey, 1998, 2001). Such non-culturally deaf people must also be served by providers in Deaf mental health programs.

Beyond that, numerous social-historical and cultural trends are impacting the mental health of deaf people. As described in a recent report for the National Interpreter Education Center, the profile of deaf people served by sign language interpreters, and also by implication mental health professionals, has changed substantially, and increases the likelihood that professionals in both

Interpreting and Mental Health disciplines will see more deaf people with atypical or dysfluent sign language (Cogen & Cokely, 2015). Atypical sign language refers to signing that is “deviant from the established and recognized norms used by competent and fluent ASL users.”

“Dysfluent” sign language is a subset of atypical sign language and refers specifically to sign language marked by grammatical errors (Witter-Merithew, 2017). See discussion later in this article.

The identified trends below, cited in Cogen and Cokely (2015), impacting the language skills of deaf people relevant to this study are:

- An unprecedented growth in racial and ethnic diversity across the United States, including among the deaf population. This growing diversity includes a dramatic increase in the numbers of deaf people from families that use a foreign language in the home. There are more deaf people who are linguistic minorities within linguistic minorities.
- An increasing number of deaf children, youth, and adults who have one or more medical, physical, emotional, cognitive, and/or developmental conditions that impact communication, a condition sometimes labeled as “Deaf-plus” (Christensen, 2000). Commonly, the syndromal conditions that cause the deafness also cause some of these other conditions (Crump and Hamerdinger, 2017).
- A growing majority of deaf children educated in mainstream settings, often without sufficient language or academic supports. In 2006, for example, the U.S. Department of Education reported that 87% of deaf children were enrolled in mainstream education.
- An increasing number of deaf individuals using cochlear implants, particularly among the population of deaf children. The results of cochlear implantation are highly variable, and dependent upon factors other than the medical procedure itself such as whether the child has other disabling conditions and the quality of parental support for language and emotional development. Discouraging early childhood sign language exposure, as proponents of cochlear implants all-too-often do, is a high-risk strategy, and can produce children with neither a solid sign nor spoken language foundation (Gulati, 2019; Humphries, Kushalnagar, Mathur et al., 2016; Spencer & Marschark, 2010; Szarkowski, 2019).

All these trends indicate that many more deaf children will not have access to culturally affirmative understandings of being Deaf. This likely means they will bring a medical-pathological understanding of hearing loss to themselves, viewing themselves as “hearing impaired” instead of members of a linguistic and cultural minority. Many are likely to experience themselves as “between worlds” and to struggle over identity (Glickman, 1996; Leigh, 2009; Leigh & O'Brien, 2020). Many will experience their hearing loss as a source of shame, embarrassment, depression, anxiety, and trauma (Kvam, Loeb & Taub, 2016). Some will find support through exploration of sign language and Deaf culture, much as other oppressed minorities develop self-esteem by exploring culturally affirmative identities and communities, but many will not choose this path as opportunities to do so decline. Their challenges are better understood within a disability perspective, and this too must be a focus of Deaf mental health.

Additionally, there is little doubt that language deprivation can be profoundly disabling. The most extreme instances of language deprivation result in essentially alingual deaf people; that is, people with minimal or no formal language skills in any language. Susan Schaller, in 1991, wrote *A Man Without Words*, a book about a community of alingual and semi-lingual deaf people. Most hearing people have never met any such people and may find it hard to believe that human beings with normal intelligence can be, essentially, languageless. Inside the Deaf community, however, the problem of severe language deprivation is well-known. Programs and specialists that serve deaf people usually know many alingual or semi-lingual deaf people, and these programs commonly struggle to serve them (Glickman, 2009).

In the United States, alingual deaf people are often found among immigrants from third-world countries where they likely received minimal education, or among people who have an additional neurological basis for language impairment. Alingual deaf individuals can also be found in rural, isolated American communities or where they have been hidden from the larger world. One such case that gained national attention was Donald Lang, the subject of a movie, “Dummy” (Perry, 1979). Many states have alingual and semilingual individuals identified in either their state departments of mental health or correctional systems.

While, in the United States, it is relatively rare to find truly a-lingual deaf people, if the actual language abilities of deaf signing people are appropriately assessed, one often discovers how signing can mask many language difficulties. People who appear, on superficial examination, especially by non-signers, to be communicating fluently may actually lack very basic language abilities, such as the ability to describe clearly who did what to whom and when. Providers who do not attend with sufficient expertise to the actual language abilities of their deaf signing clients may make assumptions that prevent them from tailoring interventions to the actual cognitive and language abilities of their clients.

Language deprivation is a primary cause of language dysfluency in deaf persons, but not the only cause (Crump & Hamerdinger, 2017). There are both medical and psychiatric causes of language dysfluency, and language and learning problems are associated with many of the causes of deafness. Deaf people may show dysfluent sign language, for instance, due to severe mental illness, traumatic brain injury, or developmental and learning disabilities, and all these may occur in the context of language deprivation, creating a very complex set of unique communication skills and deficits (Crump & Hamerdinger, 2017). A cultural perspective on Deaf people, in which knowledge and skill in ASL is considered the prime qualification for work in this clinical specialty, doesn't begin to capture the true complexities of serving people with these communication and clinical challenges.

With this new paradigm, specialists need to balance expertise in both the cultural and disability aspects of the D/deaf experience. The complexities of culturally affirmative mental health care intersecting with the equally complex disability considerations imply that considerable specialized professional training is needed to do this work effectively.

## A Closer Look at Language Deprivation Syndrome

Language deprivation, with resulting delays and impoverishment in language development, does not occur without accompanying problems. The new focus on language deprivation in Deaf mental health has resulted in a hypothesis regarding a condition involving language deprivation and associated symptoms.

Mental health specialists working in designated Deaf treatment programs have reflected upon the presence of a significant subgroup of deaf patients who have a combination of language and cognitive problems, low levels of psychosocial functioning and independent living, poor emotional self-regulation skills, and behavioral problems (Glickman, 2009). Different researchers have attempted to understand and codify what they observed with terms like *primitive personality disorder* (Vernon & Miller, 2005), *surdophrenia* (Basilier, 1964), and *developmental disorders of communication* (Denmark, 1985, 1994) Even the literature on vocational rehabilitation has described a subgroup as *traditionally underserved deaf*, an intended upgrade on the then commonly used pejorative term, *low-functioning deaf* (Dew, 1999).

Based on a literature review and research conducted on the Westborough (Massachusetts) State Hospital Deaf Unit, the term, *language deprivation with deficiencies in behavioral, emotional and social adjustment*, was proposed to describe this condition (Glickman, 2009). Research from Gulati (2019) and Hall, Levin and Anderson (2017) offered the more eloquent diagnostic label of *language deprivation syndrome*.

Even so, research on LDS is in its infancy. There is no consensus, for instance, regarding diagnostic criteria. Even the term “language deprivation” is difficult to operationalize. What kind and degree of language deprivation would meet diagnostic criteria? How dysfluent must a person’s language be? How are language abilities evaluated? What are the necessary additional components of the diagnosis? Can one have LDS without showing severe behavioral problems? When language problems have medical causes, would the diagnosis still apply? Despite these questions, this promising concept explains a great deal of the unique challenges encountered in Deaf mental health.

### ***Knowledge About LDS***

Studying a large deaf caseload, Gulati (2019) listed characteristics of persons with LDS as preliminary findings or research hypotheses. A person with LDS:

- May superficially appear to use sign language fluently, but on closer examinations shows characteristic linguistic deficits.
- Struggles with the concept of time.
- Struggles with cause-and-effect.
- Lacks awareness of a conversational partner’s need for context, and more generally lacks “theory of mind.”
- Struggles with abstract concepts.
- Has difficulty learning.
- Struggles with emotional regulation.
- Struggles in relationships.

- Shows reduced fund of information but may be quite “street-wise.”  
“Acts feelings out.”

Gulati (2019) further described LDS structurally as incomplete neurodevelopment. He based this on research involving brain scans of deaf people with delayed language, which examined both brain structure and functioning (Mayberry, Chen, Witcher, & Klein, 2010; Penicaud, Klein, Zatorre et al., 2013). Language-deprived people suffer from “underdeveloped neural language processing that has failed to grow forward in the adult brain due to an absence of language experience during critical moments throughout early brain development” (Mayberry, as quoted in Gulati, 2019, p. 38). The fact of demonstrable neural correlates of language deprivation is strong evidence for the condition and raises the intriguing question of whether brain scans can become an important part of the diagnostic procedure.

Children with delayed exposure to a first language can develop into adults who function like people with a developmental disability (Gulati, 2019). That is, one can see significant impairment in academic, vocational, social, and independent living domains. Gulati conceptualized LDS primarily as an environmentally-caused developmental intellectual disability stemming from inadequate neural development in the language processing parts of the brain. He also drew upon the notion that language deprivation impacts development of theory of mind or the ability to appreciate that other people think differently than you do (Meristo, Morgan, Geraci et al., 2012; Tomasuolo, Valeri, Di Renzo, Pasqualetti, & Volterra, 2013). This, in turn, can impair the ability to acquire a cognitive skill such as the ability to appreciate point of view, and a social-emotional skill such as empathy.. The inability to appreciate how other people think and feel impairs social relationships. Thus, this poor language development creates poor cognitive development which in turn creates emotional, social and behavioral problems.

LDS likely can be co-morbid with any psychiatric condition, including schizophrenia, but people with LDS are probably not prone to hallucinations or delusions, nor do they fit the usual developmental pathways for schizophrenia (Glickman, 2009). They may well have disorganized thinking, but this is different than that of persons with psychosis; research studies of this are also in their infancy (Glickman, 2007). For instance, people with LDS may have difficulty referencing time, something not generally found in persons with schizophrenia. They may omit key grammatical aspects of their best language (such as proper sign/word order and inflection), which, again, is not usually found in people with schizophrenia. The language usage of people with schizophrenia is often considered illogical or bizarre by other people, whereas for persons with LDS, it is more likely be perceived as impoverished. Incorrect or poorly formed ideas which are due to language and information deprivation may superficially resemble delusions, but it could be a serious clinical error to confound them, especially if that error results in administration of unnecessary psychotropic medication.

If one does not work regularly with deaf people with mental illness, one could easily confuse LDS with schizophrenia because the language, social-emotional, and behavioral problems, and poor real-world functioning, resemble, in some ways, what one finds in people with schizophrenia. It is, therefore, hard to see how one could work skillfully in diagnostic assessment of deaf people without a deep understanding of the implications of poor language development for many deaf people.

### ***LDS Complicates Psychological Work with Deaf People***

The possible presence of LDS complicates mental health assessment and intervention in a multitude of ways. To begin with, many of the problems that mental health clinicians see and normally treat can be caused, or exacerbated, by language deprivation. For instance, poor ability with emotional self-regulation indicates that the person lacks the skills for recognizing and managing internal experiences like feelings, impulses, thoughts, and physical sensations. The person may not be able to recognize and name, or manage, conditions the therapist would identify as depression, mania, anxiety, anger, or trauma-related dissociation. This means that a person with LDS and unrecognized depression, for instance, would not be self-aware about this condition. They would not say, or think, something like “I’m depressed,” and, lacking any schema for mental health treatment, would not seek out a counselor or therapist.

Notably, individuals with LDS are not unique in lacking psychological insight or in having problems with emotional self-regulation, but one can hypothesize that severe language deprivation intensifies psychological problems as well as making them more difficult to treat. For example, the lack of tools for understanding one’s experience, or seeking appropriate help, presumably makes people with LDS and depression more vulnerable to self-harm and suicide. This seems reasonable to assume, and a pioneering study has found just that.

Noting the crucial role that language plays in the development of emotional and behavioral regulation, researchers studied pre-lingually deaf adults receiving treatment in a substance abuse program (Embree et al., 2017). They hypothesized that “those who acquired language later in life (after age 10) would have higher rates of past suicidal behaviors compared to those that acquired language early in life. Their sample included 63 men and 44 women with a mean age of 39.6 years, and they found that “the lifetime prevalence of suicide attempts increases with mental illness and delays of language acquisition.... Each of these factors (prevalence for suicide attempts, comorbidity of substance use disorder and co-occurring mental illness) was amplified among the participants with significantly delayed language acquisition” (p. 11).

Although the sample in this study is not representative of deaf people generally, the findings raise an important research question. When one is researching any dependent variable related to psychosocial functioning in deaf people, (e.g., negative conditions like depression, anxiety, anger, self-harm, aggression, or substance use, or positive conditions like self-esteem, educational or vocational achievement, social skills, the presence of friendships and intimate relationships, etc.) if one adds an independent variable such as age of acquired language or perhaps a measure of language abilities, will one find that those with later language acquisition, or poorer language abilities, have higher rates of psychological or social dysfunction? Language abilities, of course, should be evaluated in the person’s best or preferred language. Ample reason exists to hypothesize that the answer is yes for most or perhaps every dependent variable. In other words, while people with language deprivation can experience every known form of psychopathology, it is very likely that the language deprivation worsens the psychopathology, and that severe language deprivation worsens it severely.

Indeed, in Gulati’s study of language deprivation in 99 consecutive referrals of deaf children to Deaf Services at Cambridge Hospital, he found that “half of the variance in these deaf

psychiatric patients' aggressive behaviors seemed attributable to problems with language" (Gulati, 2019). This provides more evidence that psychological research with deaf people should include measures of age of language acquisition and language abilities. This is itself a research game-changer. More attention to delayed language acquisition in both spoken and sign language is highly likely to support a robust understanding of LDS. This should also provide a strong scientific basis for critiquing the high risk strategy of denying deaf children access to natural sign languages (Humphries, Kushalnagar, Mathur et al., 2016).

Secondly, a person with LDS who struggles in relationships is likely to have numerous conflicts with other people and may lack even a conceptual model for problem-solving, communication, and conflict resolution skills. They may lack, for instance, such common notions as "people see things differently," "compromise," and "win-win." Again, one does not need to experience language deprivation to have interpersonal problems, but it can be hypothesized that language deprivation and interpersonal problems correlate strongly.

People with LDS are often referred to mental health services because of problematic behaviors, interpersonal conflicts, and sometimes trouble with the law. Typically, the individuals who experience LDS do not refer themselves. Someone else refers them perhaps with the well-intentioned, but naïve, notion that all they need is a "therapist who signs." Even if the therapist signs, that therapist will probably still struggle to bridge the chasm between the world of a trained mental health clinician and that of a person who lacks the most rudimentary notions of mental health or counseling. Needless to say, the naïve hearing clinician who lacks any knowledge of the lived experiences of deaf people, or language deprivation, but conscientiously arranges for an interpreter, will have little idea of the depth of the cognitive chasm that likely still separates them from the person they hope to serve.

Thirdly, a person with LDS who "acts feelings out" is likely to be impulsive, make poor decisions, and get into trouble (Glickman, 2009). The lack of well-established coping and social skills indicates that they may be vulnerable to use of addictive substances for self-regulation, and these create problems of their own. The lead author, who was the director and psychologist on the Westborough Deaf psychiatric inpatient unit for 14 years, remembers the program serving many deaf people who fit this LDS profile, some of whom struggled with addictions. The author can remember staff struggling to help these patients understand the connection between their addictions and their lack of good coping skills. The emphasis the program came to put on simple coping and social skills was one attempt to give these people practical life strategies, in simple language, to aid in their recovery (Glickman, 2009). We found that it was not just that these people needed better coping and social skills. They needed the *notion* of coping and social skills as a means of answering the question, "how do I make my life better?" Teaching this notion of coping and social skills to people who lacked a conceptual map for "getting better" became an important part of the "pre-therapy" approach described below.

Fourth, the reduced fund of information, and difficulty learning and acquiring new information, that Gulati postulates as one component of LDS implies that standard educational and therapeutic approaches may be inaccessible (Glickman, 2009). Consider, for instance, the common cognitive behavior therapy (CBT) interventions of doing "behavioral experiments" in order to "examine the evidence" related to possible "cognitive distortions." Educational

experiences that includes exposure to the scientific method (e.g., what is the nature of evidence), are necessary to understand these concepts, and the presence of an interpreter, or excellent signer, cannot make up for the educational deficits which preclude use of such “evidence-based” strategies.

It is easy to come up with other examples of evidenced-based therapies that are not evidenced-based for deaf people with LDS. For instance, 12-step programs depend on highly abstract concepts like “powerless over alcohol” and “higher power” and capacities to do such complex tasks as “taking a fearless and searching moral inventory.” CBT-based relapse prevention work requires the ability to anticipate problems before they happen as well as consider internal and external triggers and other risk factors. These abstract notions may not be accessible even when they are fluently translated into ASL (Guthman & Sternfeld, 2013).

CBT also commonly involves tasks like completion of a mood log or daily record of dysfunctional thoughts. This usually requires some ability to read and write, and more importantly, requires some established ability to introspect. Pictorial aids designed for non-literate people can help considerably with CBT self-monitoring techniques, but when people lack practiced experience with introspection, it is likely that self-monitoring will need to focus on concrete behaviors (e.g., negative behaviors like hitting or positive behaviors like deep breathing) and perhaps secondarily on the more obvious feelings like anger, sadness and happiness. Self-monitoring of more subtle feelings, like embarrassment, shame or guilt, or of thoughts, which are mostly dependent on language, may need to be developed slowly and may not always be possible. (Glickman, 2017). Indeed, the ability to be “meta” to one’s own thoughts — that is, to observe and evaluate one’s own thoughts — seems to be tied to language skills. Therefore, many common cognitive therapy techniques involving monitoring, evaluating and changing thoughts and beliefs, may be inaccessible to people with LDS (Glickman, 2017).

More recently, when working with people judged as not ready for mental health, rehabilitation, or medical interventions, clinicians have been advised to use “motivational interviewing,” a form of counseling designed to help people resolve their ambivalence about change (Miller & Rollnick, 2002). However, motivational interviewing also assumes cognitive abilities such as identifying and weighing pros and cons of addictions and other problem behaviors. More broadly, it assumes the ability to do a self-assessment to determine what one needs and then consider alternatives. Clinicians use motivational interviewing to help clients who are considered “pre-contemplation” or “contemplation” with regard to their readiness to change; that is, they haven’t given the need for change much thought or don’t see enough reason to give up a problem behavior (Prochaska & DiClemente, 1992). People with LDS may be pre-contemplation also, but the bigger barrier is likely to be poorly developed thinking abilities such that they cannot rationally evaluate what their problems are and whether they want to pursue help for them.

Experienced clinicians in Deaf mental health will recognize, for instance, the problem of trying to serve persons with LDS who have sexual behavior problems but lack even a rudimentary understanding of their bodies and relationships, much less sexuality. These clinicians may appreciate the challenge of trying to help people who lack the cognitive structure of cause and effect, or theory of mind (e.g., how do other people think?; what is their point of view?; how do they experience me?) understand the impact of their own behavior on other people. They will

also appreciate how difficult it can be to help deaf people with limited language skills, plus other cognitive and educational deficiencies, negotiate something as complex as a sexual encounter.

Similarly, clinicians will recognize the challenge of sending persons with LDS to group therapy programs based on a 12-step or CBT models. Beginners in Deaf mental health, or well-intentioned advocates, may think the problem is a lack of interpreters. Indeed, anyone working from a purely culturally affirmative model, who thinks the only treatment barrier is a lack of interpreters or perhaps, signing clinicians, will have difficulty understanding that even when one has obtained these resources, treatment may still be inaccessible. Experienced Deaf mental health practitioners will understand how much more is required to make treatment accessible than interpreters, regardless of how skilled the interpreters are. Competently signing clinicians are desirable, of course, but these clinicians must also have a considerable knowledge and skill base about language deprivation and adaptations of mental health interventions (Glickman, 2019b).

Fifth, LDS can be, as noted, and often is, co-morbid with more familiar conditions like major depression or post-traumatic stress disorder. It can even be co-morbid with psychotic disorders. However, quite often, the more familiar clinical problem, the one that has a DSM or ICD diagnosis, is not easily treatable because the LDS problems are more salient (Glickman, 2009). For instance, a therapist may want to help a person with depression, anxiety, trauma, or anger-related disorders, but may first, and for quite some time, have to focus on such “pre-therapy” considerations as “What’s wrong?,” “Why are you here (in this program)?,” “What is counseling?,” “What does getting better mean?,” “Why should you talk to me?,” and “What do we talk about?” Even more fundamentally, the therapist may have to help the person tell a story (such as “What happened today?”) and then teach fundamental problem-solving techniques as identifying a problem, considering cause and effect, considering the point of view and feelings of other people, evaluating options, and accepting consequences (Glickman, 2017). All this teaching must be adapted for the cultural, linguistic, and developmental needs of the person. Depending on the extent and nature of language deprivation, learning these concepts, and then doing traditional psychotherapy, may not always be possible, even when the therapist signs fluently.

An additional challenge is that people with LDS are not typically empowered individuals who believe they can make changes to improve their lives. Some of these people have a learned passivity and dependency whose notion of help is that other people do things for them. Others have discovered that what they cannot achieve through communication and negotiation, they may be able to get through aggressive threats or behaviors. Both learned dependency (e.g., “other people need to fix things for me.”) and threats of aggression (e.g., “I’ll force you to do what I want.”) contain radically different schemas than the schema that psychotherapy usually depends upon (e.g., “I need help with a problem that I have; the therapist will help me make changes in my life.”)

### **Pre-Therapy**

Because of the difficulty of providing standard psychotherapy to deaf people with language and learning challenges, Glickman (2017) created a staff training program and manual called “pre-therapy” at the Westborough State Hospital Deaf Unit and Pahrtners Deaf Servcies outside Philadelphia. This program is designed to bridge the gap in thought worlds between the

therapist or staff and such deaf and hearing clientele,. The staff training manual contains 12 lessons with three key components:

1. **Improving the therapeutic alliance:** Relevant workbook lessons teach empathic communication, a strength-based framework, and a “one-down” interactional style based mainly on asking good questions, rather than giving directives. Glickman argues that the common practice of telling people with language and cognitive challenges what to do does not teach the core developmental task of learning to think and solve problems. To do that, skillful questioning works better.
2. **Adapting CBT:** The principal CBT adaptation is to provide a simple, clear and practical map or notion about how one gets better. The notion used is “learning skills,” which is itself a simplification of CBT. The actual skills must include developmental simple coping and conflict resolution skills that also can be easily represented with pictures. Beyond that, lessons teach how to adapt CBT self-monitoring procedures using pictorial tools. They teach how to draw on the simplest cognitive therapy techniques for changing self-talk. They also on the Narrative Therapy technique of “externalizing” (White & Epston, 1990), in which thoughts, feelings and symptoms are personified by imaginary creatures. Thus, one would learn positive self- talk, for example, by talking back to an anger or depression monster. Verbalizing these thoughts to something, like a creature, is a step towards learning to think these thoughts intentionally.
3. **Operationalizing Deaf-friendly counseling and psychotherapy:** Lessons teach five Deaf-friendly counseling methods: a) mindful attention to language and communication, b) using teaching stories and examples, c) using visual aids and art, d) role -playing and e) drawing on the desire of community members to help and teach each other. (Glickman, 2017)

This pre-therapy approach is not research-validated, but it is the first systematic attempt to describe how to adapt evidence-based therapy approaches for deaf people with LDS. This pre-therapy model draws upon widely understood common factors in psychotherapy success as well as research-validated (for the general population) CBT techniques (Wampold, 2001). As serving deaf people with variants of LDS becomes an increasing focus in Deaf mental health, practitioners will inevitably have to build upon it. Standard psychotherapy practices, even done by a “signing therapist,” or a therapist using interpreters, are unlikely to work unless the chasm of understanding and thought-worlds between the therapist/ therapeutic team and clientele is bridged. Growing numbers of potential deaf clients unprepared for psychotherapy, and of psychotherapists unprepared for work with such clients, will likely increase the necessity and utility of such a concept.

### **Training interpreters to work with deaf consumers with atypical and dysfluent language in mental health settings**

Awareness about and competence in serving deaf people with language dysfluency is becoming a game-changer for the profession of sign language interpreting. As more has been done to

understand the impact of language deprivation and as interpreters are seeing more deaf clients with poor language skills in their best language, the field has seen the need to respond and change (Crump, 2012; Crump & Glickman, 2011; Glickman & Crump, 2013; Glickman & Hall, 2019; Pollard, 1998c; Solow, 1988).

Direct communication between a therapist and client who share the same language and cultural framework is recommended. However, mental health services are still provided through interpreters given the lack of sufficient clinicians who sign fluently to meet demand (Hamerdinger & Karlin, 2003; Landsberger & Diaz, 2011). The field of interpreting has grown since the 1960s when Registry of Interpreters for the Deaf (RID) certification came with the assumption that the certified interpreter could reasonably work with most deaf people (R.I.D., 2020). Practitioners recognized that not every interpreter was a good fit for every deaf person (Burke, 2017), but acknowledging that one was not qualified to work with a deaf individual was considered by some to be an admission of a general lack of competence. The idea that one couldn't work with everyone was endorsed in theory but often shunned in practice.

In the interpreting professions' early years, many believed that imperfect interpreting was better than no interpreting at all. This led to interpreters, or signers, accepting assignments beyond their ability level. Interpreters who cannot easily understand their deaf clients can find themselves unsure whether the problem lies with their own inadequately developed skills, the signing abilities of their deaf clients, or both (Hale, 2007; Schick, Williams, & Kupermintz, 2006). Ironically, it takes a highly competent language user to recognize and work well with a poor language user (Glickman & Crump, 2013). The following story illustrates the common dilemma faced by interpreters unprepared to work with dysfluent deaf signers.

Mary, a 60-year-old deaf female, was not a fluent sign language user. She had a doctor appointment in which her chief complaint was stomach pains. During the pre-Americans with Disabilities Act (ADA) years, doctors would generally not pay for interpreters. Mary called a local agency but there were no certified or qualified interpreters available. The agency then called to see if Samantha, with approximately one year of sign exposure, would assist. Samantha was hesitant but was assured by the agency that she could handle the assignment. They also let Mary know that Samantha was her only option. Mary reluctantly agreed. Predictably, Mary produced a significant amount of sign language that Samantha was unable to understand. She understood broadly that Mary's stomach hurt but could not understand or convey the details.

Samantha was dysfluent in sign language because she had not yet developed competence in the language. Mary was dysfluent for other reasons, including language deprivation, though this was not recognized at the time. Years after this encounter, Samantha's signing and interpreting improved significantly. One day, she was chatting with a seasoned interpreter and a Deaf individual when Mary walked over to them. Samantha remembered Mary and watched as Mary engaged in a brief conversation with the other two highly skilled signers. Samantha realized that she still did not understand Mary. After Mary left, Samantha asked the two individuals whether they understood her. They both shrugged and acknowledged that they did not. Looking back, Samantha now realized that neither she nor Mary had been fluent signers during her assignment years ago. She also realized that the agency which hired her had failed to see how the two

communicators were a poor linguistic match. Samantha's poor interpreting had not, in fact, been better than no interpreting. It had probably made a challenging situation worse.

Historically within the field of interpreting, there were no established set of standards related to working with individuals who were deaf and language deprived or who exhibited other types of atypical signing. In the absence of any formal training, experienced interpreters would often tell novice interpreters just to voice the signs that they understood. This fit with the machine model that was commonly utilized as the interpreting standard during the earlier years of interpreter professionalization (Baker-Shenk, 1991). It was also common for interpreters to share observations such as "the person has strong ASL," "the person is a grass roots signer," or "they don't understand fingerspelling well." These comments could serve as a subtle code for the observation that the deaf person appeared to be an unskilled signer. Interpreters knew about consumers who were difficult to interpret for, but they did not meet as professionals with the purpose of analyzing language patterns, considering strategies, or developing techniques for these challenging assignments.

In the field of interpreting the realization has grown that, as with other professions, further sub-specialization is needed. The early areas of specialization resulting in national certifications were reverse skills, legal, performing arts, and oral transliteration. Recently, the specialization of mental health interpreting has developed (Crump, 2012; Glickman & Crump, 2013; Hamerdinger & Karlin, 2003). Increasingly, language dysfluency has become a vital part of the discussion in mental health interpreting (Glickman & Crump, 2013; Thacker, 1994, 1998). For instance, psychiatric illnesses effecting thought content and processes create additional language dysfluency challenges. The Alabama Department of Mental Health has addressed these training issues through establishing standards and a certification process for mental health interpreters (Alabama Department of Mental Health, 2003).

The Center for Atypical Language Interpreting (CALI), associated with the interpreter training program at Northeastern University, focuses on training interpreters for atypical sign language they may encounter. CALI uses "dysfluent language" as a subset of atypical language associated with medical, developmental, and psychiatric causes for impaired language use. The CALI program is mostly available on-line. (<https://www.northeastern.edu/cali/>).

This emergent focus upon atypical or dysfluent sign language illustrates a primary distinction between foreign language and sign language interpreting. Foreign language interpreters can generally assume that the people they are interpreting for are native speakers of their respective languages. Sign language interpreters cannot assume this. Indeed, as discussed earlier, as the numbers of deaf children educated in Deaf schools decline, sign language interpreters will work increasingly with signers who are not fluent in their best language (Cogen & Cokely, 2015). This, again, is the reason that the growing attention to language deprivation is a game-changer for interpreters

Within mental health interpreter training, interpreters are cautioned against "fixing" dysfluent language, making the dysfluent signer appear more linguistically competent than they are (R.I.D., 2007). The goal to produced clear narratives may be well intentioned, as interpreters are usually conscious of the concern Deaf people express that articulate signing can be poorly

interpreted and cause the Deaf person to appear less intelligent. It may also be due to the interpreters' own self-doubts about their abilities, especially since it is difficult to assess language abilities in another person if one is less than a native user of the language.

There are dangers beyond that of covering up clinically significant language dysfluency. In a forensic context, it can lead the examiner to conclude that the deaf defendant has a better understanding of the legal issues they face than they actually do, resulting in an inappropriate finding about competence to stand trial (Pollard & Fox, 2019). Even in a therapeutic context, misrepresenting the deaf person's language abilities can prevent the clinician from adapting an effective therapeutic approach. Covering up or fixing language errors can also disguise the fact that the additional resource of a Deaf interpreter is needed.

One of the early interpreting techniques identified for responding to language dysfluency was "glossing," or the repetition of a string of words signed by the deaf individual that held a common representation of a sign. Interpreters who gloss when they do not understand hope that somehow the hearing person will be able to make sense of the message anyway. However, the use of glossing, without providing the clinician any explanation about what one is doing, is fraught with problems. This technique can make the most articulate Deaf signer appear faltering, unintelligent, or thought disordered, and it can unfairly intensify this impression with deaf clients who do have language difficulties. Clearly, if one is going to use glossing, there is a need for a discussion with the clinician about the language abilities of the deaf person and the bias introduced by this approach. Traditionally trained interpreters have been reluctant to assume this kind of educational role for fear that it disempowers the deaf consumer (Hamerdinger & Karlin, 2003; Glickman & Crump, 2013; RID, 2007).

There are also many situations where conversation with the hearing clinician about interpreting process is indicated. For instance, the more dysfluent the consumer, the more likely that a consecutive interpreting approach should be used. When the consumer is not understanding information, the interpreter may have to use creative interpreting techniques such as role-playing, drawing, and the use of toys or other manipulatives, to achieve understanding (Wattman, 2019). Interpreters with dysfluent consumers may recognize and advocate for the additional resource of a Deaf communication specialist or interpreter. This person might also work with the consumer outside of the interpreting context to help them understand the relevant content. This might occur in a forensic context where considerable additional education of the consumer is necessary for them to demonstrate legal competence (Pollard & Fox, 2019).

Increasing awareness about dysfluent language is one reason that the need for a Certified Deaf Interpreter (CDI) has developed. Deaf interpreters often have greater abilities to match the language needs of deaf people than hearing interpreters, who may have learned ASL as a second language or for whom sign language is not a personally lived experience. However, there is more to this task than simply matching language abilities. Interpreting for dysfluent language users requires a solid understanding of linguistics, language development, language deprivation, and interpreting theory and practice.

Even without additional resources, the interpreter(s) may need to ask the clinician to rephrase the question, provide examples, role-play, draw, or use some other teaching strategy (Wattman,

2019). Subsequently, there is a clear need for pre- and post-session meetings. All these decisions require considerable interpreter training and preparation.

At the frontier of new knowledge in the study of atypical or dysfluent sign language, questions are being raised as to whether the specific nature of the dysfluency might provide clues as to the etiology. If the interpreter observes, for instance, that the deaf person is not able to reference time, or organize information sequentially, that strongly suggests language deprivation as a cause. If the deaf person is unable to use the personal pronoun “I,” or repeats the same phrase in each conversation, that suggests a developmental disorder along the autistic spectrum (Overweg, Hartman, & Hendriks, 2018). Other sign language errors are associated with strokes in the Brocas or Wernike’s area of the brain (Poizner, Klima, & Bellugi, 1987). A seemingly bizarre idea, like the belief that aliens are communicating to the person through their iPhone, suggests a psychiatric problem (Glickman & Crump, 2013).

The study of specific sign language errors, and their likely etiology, is in its infancy, but properly trained mental health interpreters are more likely to be aware of this issue than mental health clinicians untrained in Deaf mental health. An important emerging discussion in the mental health interpreting domain is to what extent, and in what manner, the interpreter should be sharing this knowledge, as well as their own observations of specific language patterns, with the clinician (Crump & Hamerdinger, 2017; Trumbetta, Bonvillian, Siedlecki Jr., & Hasins, 2001). Ideally, there is a specific communication evaluation, discussed below, to reference, but that is still a rarity, leaving interpreters as the main people likely to hold this vital knowledge relevant to psychiatric assessment and treatment (Pollard, 1998a, 1998b; Wattman, 2019).

Awareness of the multi-faceted impact of language dysfluency and the complexity of work in mental health with individuals who are deaf is resulting in a paradigm shift in how interpreters are trained for this work. One recommended new technique is the utilization of norm-referenced communication assessments. This developing practice is discussed next.

### **Communication Assessments: An Emerging Best Practice**

Another response to deaf people with atypical or dysfluent language has been to develop and draw upon highly specialized communication assessments. While there have long been multiple assessment tools for assessing English skills, norm-referenced tools for assessing ASL abilities are relatively new. Assessing ASL abilities can be more challenging because it is a visual form of language without a standardized written form, and because there are few qualified assessors. The gold standard, not yet easily available, is a communication assessment procedure with well-established validity and reliability, and with intervention implications clearly correlated with assessment findings (Henner, Hoffmeister, & Reis, 2017; Henner, Reis, & Hoffmeister, 2019).

In Alabama and South Carolina, a protocol and tool referred to as a Communication Skills Assessment (CSA) is required for any person who is deaf and receives mental health services (Alabama Department of Mental Health, 2003; South Carolina Department of Mental Health, 2014; Williams & Crump, 2019). Training interpreters and others to produce, utilize, and apply information gleaned from the CSA is a state-of-the-art practice being pioneered in these two states. This assessment, currently undergoing validation, provides a detailed descriptive

understanding of the deaf person's language skills and deficits, and recommendations for adapting interventions to fit language abilities.

The CSA incorporates a review of educational and communication history and the demands of the current communication environment. Historical considerations include the etiology of deafness, possible causes of dysfluent language, and the quality and frequency of family and social communication. Importantly, it provides an assessment of various types of communication and evaluates both competencies and dysfluencies. The CSA also includes recommendations for meeting and advancing the communication abilities of the client as well as for adapting therapeutic approaches to fit with these abilities.

An example illustrating the effectiveness of the CSA can be found in Luther's story. Luther was a 65-year-old African American male who was congenitally deafened due to unknown causes and has a diagnosis of schizophrenia. He was communicationally isolated for significant periods of his life both before and within the mental health system. In psychiatric inpatient and residential treatment, he was treated in facilities that did not provide adequate, or at times, any language access for him and was misdiagnosed as intellectually disabled. Additionally, because Black Southern ASL is not widely known by practitioners who work within the Deaf and mental health field, it was important for communication evaluators to be careful to not confuse atypical language variants with actual language errors. There is not yet any instrument perfectly designed, and easy to implement, that validly capture all the variances of ASL.

Luther eventually came to be treated within a group home for individuals who were deaf and had mental illness, in which all the staff were Deaf and fluent sign language users. The CSA revealed that he was expressively slow, relying on repetitions of signs and sign phrases, and that he used idiosyncratic signs that staff did not initially recognize. The assessment also found that he perseverated on a few topics, making comments that did not seem reality-based, and that he had an extremely limited fund of information on every topic assessed.

One sign combination used to express his desire for an oatmeal creme pie was a gesture similar to washing dishes (with an open B-handshape), the ASL sign for WHITE, the initial gesture repeated, a sign for CIRCLE, a gesture for eating, and the sign PLEASE. Staff working with him knew the meaning of the signs and informed the communication team. Luther also used repetition when he wanted something. If he wanted a cigarette, for example, he used the same simple sign phrase again and again until he got it. He wasn't capable of departing from this strategy, nor could he focus on other matters until his request was met. A therapist made the clinical mistake of trying to help him delay gratification in those moments, but Luther did not understand what the therapist was attempting to do. He thought she was denying him cigarettes, and he responded aggressively.

The communication assessors advised the therapist to make sure he understood and agreed to this task before proceeding. They also made recommendations for building his verbal reasoning skills, such as more extensive use of role-playing, a counseling technique widely used in Deaf mental health (Glickman, 2017), and practice of delayed gratification at times when Luther wasn't so narrowly focused on the one thing he wanted. The therapist, while competent as a clinician and gaining experience in working with deaf people, was not a skilled signer. She

needed the communication assessment to understand the nature of his language limitations so she could draw upon simpler and more active counseling strategies.

Therapy is much more likely to succeed when the client and therapist are aware and in agreement about what they are doing (Wampold, 2001). Because the therapist did not make the effort to help Luther understand why she was encouraging him to accept a delay in getting cigarettes, he thought she was refusing his request. The communication assessment, then, became an important therapy resource because it helped the counselor understand her client's thought-world. It also served to caution the therapist not to assume Luther had language and cognitive abilities such as the ability to narrate a clear story organized to make a particular point.

While the communication assessment team performed this assessment, they interviewed several local Deaf senior citizens, including some who were African American, to determine whether Luther was using older, regional, or Black ASL signs. One of the signs utilized by several members of this older Deaf group was a sign for "brown," the same initial hand-rubbing gesture that Luther himself utilized when describing the oatmeal cream pie. From these interviews, the assessors realized that many of Luther's seemingly idiosyncratic signs were signs once used by members of the older Deaf population who attended schools for the deaf. Knowing this made him appear less psychotic; he hadn't invented these signs, nor were they evidence of a thought disorder. Staff then learned more of these older, regional signs and used them with Luther. It was much easier for them to learn these older signs than for Luther to learn more standard and contemporary ASL.

As one might expect, staff matching his way of signing strengthened these therapeutic alliances and helped take stress off Luther, decreasing behavioral incidents in the process. His clinical team began to appreciate that Luther made more sense than they had previously thought. They shifted their view of him from being a person whose primary problem was schizophrenia to a person whose primary problem was communication deprivation and trauma, coupled with language use that appeared atypical to the team working with him.

Spitz and Kegl (2019) described promising communication development strategies with deaf language-delayed people. Studying a community of deaf people in Nicaragua and elsewhere who did not have sign language exposure until after the critical window for language acquisition had closed, they asked game-changing questions about late language development, characteristics or qualities of deaf people who are more successful late language learners, and the optimal pedagogical methods for late language and communication development. They found, for instance, that it is often easier to teach vocabulary than grammar, that different kinds of language development are possible, at least for some people, even if they never become native language users, and that it is possible to carefully craft methods and tools for teaching one language feature at a time to language deprived deaf people.

With this game-changing attention to language deprivation, more attention and resources must be devoted to improving and validating the tools available for communication assessment as well as establishing standards and credentialing for communication evaluators. A related skill, as exemplified by the work of Spitz and Kegl (2019), is developing best pedagogical practices for language and communication skill development in language deprived deaf individuals.

Key to all these interpreting, teaching and counseling strategies is a humble willingness to accept that *our* language abilities may not be enough. When one considers how varied the communication abilities of deaf people are, and how severe the impact language deprivation can have, it is best to think of Deaf mental health work as involving a team. It is rare to find any one person who has all the clinical and communication skills necessary to do this work. The common practice of hiring a Deaf mental health specialist in clinical settings, as if one such specialist could be all things to all deaf clients, is a set up for burnout. A good communication assessment can guide a Deaf mental health team as to what kind of communication competencies are needed to create an effective clinical response. This is likely an evolving best practice.

### **Language Deprivation and the Organization of Deaf Mental Health Services**

Since language deprivation creates both developmental and behavioral health challenges, and because there is language, cultural, and disability elements to this work, it isn't obvious how services should be organized, especially at the state level. In particular, it isn't obvious whether a cultural/language or disability framework should be used to conceptualize and organize these services. There needs, therefore, to be someone within state government, such as a Deaf services director, who can help the state human service system conceptualize and organize Deaf mental health services, especially in considering language deprivation. This section is devoted to describing that role and laying out recommendations for how that Deaf services director might guide state services to address both the cultural and disability aspects of this work. It supplements an earlier discussion of that topic (Gournaris, Hamerdinger, & Williams, 2013).

Public mental health services are normally organized within a state's mental health authority. States provide services like psychiatric hospitalization, outpatient and residential care either directly or through vendor agencies with whom they contract. Some states may place services for people with developmental disabilities in a separate agency. Deaf people in those states may be served by one or both agencies, depending on whether they are thought to have developmental disabilities, and depending, sometimes, on what is considered their primary disability. States may also have separate departments or commissions serving deaf people, and these may or may not include mental health services. A further complication is that treatment for addictions may be organized through yet another agency. Deaf mental health services, then, if they exist at all, are often scattered across multiple agencies, with some doing better than others in meeting the complex cultural and disability needs of diverse deaf people.

Deaf mental health should be seen as a clinical specialty, one that encompasses not only mental health, but also the developmental issues that are part and parcel to serving people with language deprivation. Viewing deaf people with language deprivation as both a both a cultural/ linguistic minority and people with a developmental disability may create an uncomfortable tension that complicates service provision. Deaf people sometimes state that because they are best understood as a cultural and linguistic minority, they are most likely to get appropriate specialized mental health services under Title VI of the Civil Rights Act of 1964. Title VI is a basis for culturally and linguistically appropriate service (CLAS) standards, which are regulations promulgated by the Federal Department of Health and Human Services (<https://thinkculturalhealth.hhs.gov/clas/standards>). Deaf people with language deprivation,

however, present a greater challenge than language access, and this important civil rights act does not quite address their complex needs.

LDS is a proposed developmental intellectual disability (Gulati, 2019) that could also be considered a psychiatric disorder beginning in early childhood. Language deprivation affects development, and in its most extreme forms, can create a functional developmental disability. In addition, there are many possible causes of poor language skills in deaf people, and some of them are medically or neurologically based (Crump & Hamerdinger, 2017), so it is not uncommon to find deaf people who have developmental disabilities, language deprivation, and multiple other challenges. In the real world, comorbidity is the norm, and pure cases of LDS, with no other problems, are rare, if they exist at all. LDS, as conceptualized here, does not fit neatly, therefore, into a cultural minority model. In sum, deaf people with language deprivation likely have a functional developmental disability, comorbidity with other psychiatric disorders, and other behavioral challenges (Glickman, 2019a; Gulati, 2019). They are likely, therefore, to need assistance from multiple state agencies or programs.

When deaf people are served within state departments of mental health, many will have language deprivation. This was the norm in the Westborough State Hospital Deaf Unit in Massachusetts, where more than half of the patients exhibited symptoms and behaviors consistent with current understanding of LDS, alongside more familiar conditions like schizophrenia, bipolar disorder, post-traumatic stress disorder, mood disorders, substance use, and other developmental disorders (Glickman, 2009). The same has been true in Alabama, where the Bailey Deaf Unit served 87 people between 2005 and 2011 when it closed. Of those 87 people, only approximately 15 were not, in some way language-deprived (Hamerdinger, personal communication, November, 2011). Most also had complicating co-morbid issues, ranging from medical and/or neurological problems to substance use disorders.<sup>1</sup>

Understanding LDS as a developmental, intellectual disability does not mean people should not be served within state departments of mental health. Rather, it means that such departments must develop the communication and clinical sophistication to address the comorbidity. They may want, for instance, to treat a problem like schizophrenia, but they will be unable to avoid the fact that language deprivation interferes in many ways with the ability to deliver accessible and meaningful mental health treatment for schizophrenia, apart from medication. It can even interfere with medication if the language deprivation means the person cannot give informed consent to the medication or use it as an informed consumer. Providing interpreters alone won't resolve the problem, especially in cases of more severe language deprivation, because the therapy will likely have to be highly adapted, along the lines of pre-therapy discussed above (Glickman, 2017). In addition, clinicians unfamiliar with language deprivation are quite vulnerable to making diagnostic errors, and interpreters cannot compensate for their ignorance of this topic (Glickman, 2007).

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<sup>1</sup> Information based on a review of census data and clinical records for former patients of the Bailey Deaf Unit by the Director of the Office of Deaf Services, Alabama Department of Mental Health.

### ***The Pivotal Role of the Deaf Mental Health Services State Director***

To meet these challenges, personnel with specialized cultural sensitivity, a unique knowledge base related to psycholinguistic issues among deaf people and a variety of specialized skills are needed (Glickman & Hall, 2019; NAD, 2008, 2014). The specialized skills include language skills that go well beyond “knowledge of sign language.” Indeed, evaluating the language and communication abilities of personnel is likely to be just as important as evaluating those of clients. The effective statewide Deaf Services Director has the responsibility of assuring that programs and services are both culturally and clinically competent for the highly diverse deaf population, including the large cohort of people who are not fluent language users.

In a few states, this responsibility has been assigned to an administrator, usually in the state department of mental health. One notable exception to this is Minnesota, where the responsibility is held within the Minnesota Department of Human Services (DHS) Deaf and Hard of Hearing Services Division, separate from the state mental health authority, which is also housed under the larger DHS umbrella. This position has various titles; the Director (Alabama, Georgia, Minnesota and Missouri), Program Manager (North Carolina), Program Administrator (Kentucky) and sometimes Coordinator of Deaf Services (Illinois.) For the sake of simplicity, we refer to it here as the state director of Deaf mental health services, or more simply, the state director, and the entity that person works in as the state Deaf mental health authority, recognizing that it is not always within the legislatively recognized state mental health authority.

As the public mental health continuum of care varies by state, the state director’s responsibilities vary also, but all such positions should have some basic responsibilities in common. They should be able to drive policy, administrate directly or contractually the provision of clinical services, set minimum standards for provision of Deaf mental health services, and regulate who is qualified to provide those services, including—and perhaps especially—interpreters. Thus, it is necessary that this oversight authority is invested in an administrator who understands the cultural, clinical, and disability aspects of Deaf mental health and can provide quality assurance and accountability.

This is particularly critical in the case of services that purport to treat deaf people with language deprivation. Apart from a very few free-standing, Deaf-run mental health programs in the country, services for deaf people with language deprivation are provided by agencies that are hearing-run. Such agencies are prone to a category error regarding deaf people, mistakenly thinking that all deaf people have the same service needs, and specifically that the provision of interpreters or of clinicians who sign will suffice. The knowledge, training, and experience in working with consumers who have language deprivation brought by the director will determine the overall competence and effectiveness of the services. Programs led by clinicians who are both fluent in ASL (a necessary but insufficient pre-requisite) and experienced in working with deaf people who have language deprivation are more likely to address all the language, cultural and disability aspects of this complicated clinical work.

An example of this is Alabama. There are specific requirements embedded at various levels in both Alabama Department of Mental Health’s policies and in the state code that governs how mental health programs in the state are certified and operated. These policies define ASL fluency

in a measurable way, specifically advanced or better on the American Sign Language Proficiency Interview (ASLPI), and they set ways to ensure that these policies are enforced.

For deaf people with language deprivation, one of the more important components of this oversight function is requiring communication assessments. The CSA discussed earlier is one; and validated ASL assessments are another approach (Henner, Hoffmeister, & Reis, 2017; Henner, Reis, & Hoffmeister, 2019). In Alabama, a section of the state code, also known as the Program Operations (Chapter 580-2-9), require that this CSA be in the clinical file of every deaf individual receiving mental health services in the state, and that the treatment plan address issues raised in the assessment. This can mean, for example, a requirement that a communication specialist be used in conjunction with an ASL-fluent clinician or a Qualified Mental Health Interpreter in the case of services, like psychiatry, when an ASL-fluent clinician is not available.

Other states, such as Minnesota and South Carolina, have similar policies and guidelines. (Gournaris et al., 2010). Some of these were discussed in Gournaris, Hamerdinger, and Williams (2010), where the state models for Deaf mental health services are compared. The political landscape exigent in each area determines which model and approach will be used.

Having ASL-fluent clinicians is only one part of the service array that needs to be available. The other part must look at how the system responds to language deprivation and dysfluency. A culture that emphasizes a team approach, consisting of clinical and communication experts, will lead to more successful outcomes, as described earlier in this article. The communication assessment should spell out the kinds of language skills staff need to possess, and that may or may not be available in signing or interpreting staff. Often, a person, like a Deaf communication specialist, who has a higher level of communication competence, will be needed. The state director should be at the forefront of not only building the Deaf mental health treatment culture, but also working with funding streams to ensure that services of communication specialists are covered.

The state director should have specific qualities and qualifications. Unless the state director is fluent in ASL, it is unlikely that the director will understand the linguistic complexities of the population served. Equally important, without fluency in ASL, the Deaf community is less likely to view the state director as credible. The state director also must be an extremely effective communicator in English, especially when working with state-level bureaucracy. Furthermore, when the state director is also deaf, there are challenging cross-cultural issues to work through (Gournaris & Aubrecht, 2013).

The state director is most effective when clinically trained and experienced in working with deaf people with mental illness who also have language dysfluency. An effective state director not only understands clinical practice, but also has experience in working with deaf people with atypical and dysfluent language. There must exist a deep understanding of causes of language dysfluency and knowledge of how to assess the impact of, and then ameliorate the barriers to treatment caused by that dysfluency.

## **The Catchment Area Issue**

Another potential barrier for deaf people with language deprivation is living in the wrong place. Generally, a state is divided into several service areas, each consisting of a roughly equal number of clients. This is intended to spread out services more evenly through the system. . This catchment area design can create a barrier when specialized services exist in catchment area but a deaf consumer lives in a nearby area without such services.

For deaf people generally, and people with language deprivation especially, the catchment area should be statewide, as in South Carolina and Alabama. This mitigates the possibility that deaf people are unable to access programs simply because of geographical boundaries. Optimal service programs for deaf people with language deprivation are so rare that it can be enormously frustrating not to be able to draw upon them because of an arbitrary boundary, especially when they are nearby. Deaf people with language deprivation are unlikely to understand why they can't make use of an accessible service simply because it is in another town. They may just think they are being unfairly denied the service.

## **Different models of state service delivery**

An important consideration is how the state mental health authority itself is set up. In many states, the state mental health authority, what is usually called a "Department of Mental Health," is part of a larger human services cabinet level agency. This is a trend likely to accelerate with the shift in philosophy toward integrated health care, which includes medical and what is often called behavioral health, often encompassing mental illness, substance use disorders and developmental disabilities.

Mental health services may be combined with developmental disability services in one agency or separated into various agencies. In Massachusetts, for instance, there is a state Department of Developmental Disabilities that is separate from the state Department of Mental Health. Sometimes mental health and developmental disability services are combined with other service needs into one large behavioral health agency such as the Georgia Department of Department of Behavioral Health and Developmental Disabilities. Generally, as more services are combined in one agency, any state director of Deaf services will find themselves further down in the hierarchy, and the lower one is in a departmental hierarchy, the more difficult it can be to advocate for specialized service needs. Consider, then, the challenges that a state director of deaf services, who is low in the agency hierarchy, may have in advocating not just for deaf constituents but for the even smaller, and less understood, subgroup of deaf people with language deprivation. Having already struggled to help hearing bureaucrats understand Deaf culture, the State Director must now, unhappily, complicate this for them by introducing the disability of language deprivation.

Minnesota is a state where all services for deaf people are organized within one state agency. This has the clear advantage of concentrating deaf-related expertise in one place and fostering a relatively seamless, tension-free service provision system. This model makes it easier to serve deaf people with language deprivation because it is more likely that the staff will understand this issue, and there will be no struggle over resources for people who have both functional

developmental disabilities and comorbid mental health problems. It also avoids the problem of substance abuse services being relegated to some other agency.

The disadvantage of such a model is that state agencies for serving people with behavioral health and developmental disabilities can be freed from the expectation that they accommodate deaf people. In addition, specialized mental health, rehabilitation, and developmental disability expertise found in such agencies is less available to deaf consumers. In practice, it is difficult for one set of staff to have all the diverse kinds of expertise (mental health, developmental disability, addiction rehabilitation, cultural and language competence, etc.) that deaf people may need. Deaf services agency staff should understand Deaf culture and hearing loss, but will they also understand all they need to about mental illness, developmental disability, addictions, and any other issue that impacts deaf people?

In other states, such as Alabama, South Carolina, and Missouri, the mental health authority is a cabinet-level department, though the design within departments vary. For example, both Alabama and Missouri include mental illness, substance use disorders, and developmental disabilities under the Department of Mental Health, while South Carolina has three separate departments. The state directors of these programs usually have access to the highest levels of decision-making, and can often influence substantial policy changes. This was how Alabama implemented the nation's first regulation on mental health interpreting, even with an interpreter licensing law already in effect. By mandating the use of specially trained and qualified mental health interpreters, preferably working in conjunction with a Deaf interpreter, the state has been able to address risks that occur when an uninformed clinician encounters a deaf client with language deprivation.

The Alabama Office of Deaf Services state director created the Communication Access Team (CAT). The CAT's influence on the process of treatment cannot be understated. When people with language deprivation are working with clinicians who have little to no experience in language deprivation, and with the proposed LDS concept, sometimes all that stands between the deaf person and a catastrophic clinical error is the CAT. Establishing policies that require the use of qualified mental health interpreters and communication specialists is one large impact a state director can have on the care of deaf people with language deprivation. The state director can also ensure that the staff serving deaf people get all the specialized trainings unique to work in Deaf mental health.

North Carolina uses contracted direct services in addition to interpreters. Under the supervision of a program manager primarily responsible for contract monitoring and invoice processing, some direct services are provided by a single entity with a quasi-statewide presence. In this case, RHA Health Services is the agency charged with serving deaf people with serious mental illness (<https://rhahealthservices.org/deaf-and-hard-of-hearing-program/>).

As of 2020, that program is directed by a deaf person who is a licensed clinical social worker and an experienced administrator. Such a model has the potential to be effective in serving deaf people with language deprivation, provided a few safeguards are built in. There must be flexibility in the contract, so the provider is not limited to a certain set of permitted services. Deaf people with language deprivation come with widely varying needs and the contract must

allow for meeting those needs, many of which have no parallel working with hearing consumers. For example, pre-therapy is not yet recognized as a billable service in most places. A common way of limiting costs is to either pay fixed rate per person per month, a form of managed care, or to designate a specific set of services that are billable. The state director can be very influential in defining billable services and establishing rates, which in turn allows more flexibility in meeting the specialized needs of deaf people with language deprivation.

Illinois provides another example of a how many states address Deaf mental health care. According to the Illinois Division of Mental Health webpage, (<https://www.dhs.state.il.us/page.aspx?item=30458> ), Deaf mental health care is largely limited to “ensuring language access by providing language assistance services, including interpreter services at no cost to each customer at key points of contact, in a timely manner.” This adopts the most clinically naïve position that the provision of interpreters is required and *sufficient* for serving diverse deaf people.

The policies of Illinois and similar states towards mental health services for deaf people, imagining that all that is needed are sign language interpreters, ignore entirely the communication, developmental, and clinical needs of this population. Deaf people with serious mental illness generally will fare poorly using this model, and deaf people with language deprivation may be lost entirely.

A central conundrum in advocacy for Deaf services is this: often, the first and major focus of advocacy is around obtaining interpreters. Both the ADA and Title VI of the Civil Rights Act can assist with this. Such advocacy is no small task. It often takes lawsuits and years of tireless effort. Having “won” interpreters, how do advocates then say, “yes, but interpreters are not enough.” The truth is that service provision through interpreters alone is a grossly inadequate model. Quality Deaf mental health services require a much higher standard, one that goes well beyond the ADA and Title VI, that establishes culturally and disability informed Deaf mental health programs.

Arguably, a model like Illinois’ is less effective because the state director has limited ability to influence direct service provision, and because the only special accommodation recognized for advocacy is interpreting. Each of the other models has strengths and weaknesses, but they create more appropriate Deaf services given that the qualified and empowered state director in place has influence over the nature of provided services.

This State Director can promote accommodations beyond just providing interpreters. In some models (Minnesota being the clearest example), the state director is directly responsible for multiple kinds of service provision. In other states (North Carolina being the best example), the program manager has more of a contracting and oversight role with vendor agencies. In still other states, (Alabama, South Carolina, and Missouri), the state director has a hybrid role, responsible for some direct service provision but overseeing contracting and policy development. As long as the state director is knowledgeable about both the cultural and disability aspects of Deaf services, and they have institutional power to influence service provision, many models can work.

What does not work is having no qualified person at the helm or having a qualified person with no power. It is probably fair to say that the more de-centralized the provision of Deaf services in a state, the more uneven the quality of services, and the more there is a need for some qualified leader in state government holding and promoting the standard of quality Deaf mental health care.

### **Conclusion**

People who have experienced severe language deprivation comprise a minority of people seen in Deaf mental health programs, though they may require a grossly disproportionate allocation of resources to serve. Less severe forms of language deprivation and dysfluency are more common, but Deaf mental health clinicians should be on the lookout for language and communication difficulties, with all their implications, in their clientele. This, again, is where a good communication assessment can be invaluable. Thus, while the absence of a “therapist who signs” or interpreters appears to be the obvious problem in service delivery, it is just the tip of the iceberg in regards to the true challenges involved in serving deaf people with language deprivation in mental health settings.

As Deaf mental health specialists come to understand the full implications of language deprivation for cognitive, social, and emotional development, they realize how much more knowledge and skill they must acquire than just signing. It then becomes increasingly obvious to them that this work requires clinical specialization well beyond acquisition and use of a minority language. It also requires a team of clinical and communication specialists.

Deaf mental health is a clinical specialty involving both cultural and disability themes and competencies (Glickman, 2013; Glickman & Hall, 2019). The cultural themes have to do with work with members of a cultural and linguistic minority group. The disability themes have to do primarily with the profound impact of language deprivation on deaf people, sometimes creating a functional developmental intellectual disability, as well as various kinds of comorbidity. They also have to do with the fact that being deaf or hard of hearing is experienced and conceptualized by many as disabling.

Deaf mental health providers also have advocacy roles: wherever they can, they need to advocate for deaf people to have quality ASL-based learning and service environments as resource options, even if many of them will not choose such services. They especially need to advocate for careful language assessments of deaf children, in both spoken and sign languages, and for the provision of quality signing educational options for deaf children. This advocacy to insure language acquisition is part of current nationwide LEAD-K initiatives (Holmes, 2019; Payne-Tsoupros, 2019).

What makes language deprivation a game-changer for the Deaf mental health field, however, is that providers will increasingly work with such culturally marginal, language-dysfluent people. This calls for a greatly expanded toolbox drawing upon both cultural and disability frameworks, including research into all the implications of late and inadequate language exposure. Following Gulati (2019) and others, more such research will enable us to acquire a science-informed consensus as to an operational definition and diagnostic criteria for Language Deprivation

Syndrome. For many Deaf mental health providers, as for many D/deaf people, this may not be the world they wish for, but it is the world they now inhabit.

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