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Support Service Providers (SSPs) for DeafBlind Texans 86th Texas Legislature Session

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Governor's Committee on People with Disabilities
January 5, 2017
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FACT SHEET

Small defined population (approx. 2500 per the Helen Keller National Center) of Texans who are DeafBlind with largely unmet service needs that may be addressed through a reasonable investment by the Texas legislature.

MAIN ISSUE – Need for Support Service Provider (SSP) Program for DeafBlind (DB) citizens of Texas.

- People who are DB have dual hearing and vision loss resulting in isolating effects in their community.
- The Health and Human Services DB Medicaid waiver program provides intervener services and requires participants have three co-occurring disabilities, deafness, blindness and an intellectual disability. The state's Vocational Rehabilitation (VR) program may provide very short-term services similar to an SSP specifically related to employment. No Service currently exists in Texas that meets the SSP needs of Texans who are deaf and blind to help them live independently in the community.
- SSPs are the gateway for maintaining independence for DB adults
- Independent DB adults need this program to participate in their community and make informed decisions.
- More than 20 states already have an SSP Program.

VIABLE SOLUTION – We respectfully request the Texas Legislature's support to enact as SSP program (a high impact solution for the needs of a low-incidence disability population.)

- An SSP program would allow DB Texans to maintain their independence and not exclusively rely on scarce volunteers to perform daily tasks.
- The HHSC Office for Deaf and Hard of Hearing Services has the infrastructure and expertise to run an SSP program.
- Administrative costs would be minimal due to the small population needing these services.

COLLABORATIONS

This issue is championed by the Texas Governor's Office, Committee on People with Disabilities and is in the Committee's past biennial report. This issue is supported by all Texas deaf stakeholder groups and organizations:

Alliance of and for Visually Impaired Texans (AVIT), American Association of the DeafBlind (AADB), Coalition of Texans with Disabilities (CTD), DeafBlind Camp of Texas (DBCTX), DeafBlind Citizens in Action (DBCA), DeafBlind Multiple Handicapped Association of Texas (DBMAT), DeafBlind Service Center of Austin (DBSCA), Deaf Grassroots Movement (DGM), Texas Association of the Deaf (TAD), Texas Deaf Grassroots (TDG)

For more information, check out <https://txssp.info/bill>

Service Roles within a Diverse Texas DeafBlind Community

Deafblind adults want to navigate their environment, participate in the community, make autonomous decisions and live independently, with greater quality of life, safety, and community access.

There is a gap in existing services to the estimated 2,500 deafblind adult Texans who face barriers in addressing basic needs such as shopping, errands, reading mail and safely traveling to and attending public events, including voting, business, and health services. Professional **Support Service Providers (SSPs)** fill the gaps that sign language interpreters and interveners do not cover.

Deafblind people have a wide range of individualized needs, depending on the impact on hearing and vision, onset of deafblindness and communication modes used. Deafblind children receive services while in school, and those with an additional disability can receive lifelong intervener services through a Medicaid waiver program. Language-proficient autonomous deafblind adults living in their own homes are not eligible for these services.

Interpreters provide language access for certain scheduled events, but that alone does not create true access due to mobility and information-gathering barriers. SSPs cover a range of situations that sign language interpreters do not.

The chart below highlights the roles of these three professions.

	SSP	Intervener	Interpreter
Works with autonomous deafblind individuals who do not need guardians.	✓		✓
As a primary job duty, describes visual environmental info, including area layout, non-verbal responses, movements and actions of people, to the autonomous deafblind person using his/her preferred mode of communication	✓	✓	
Offers professionally trained human guide services to deafblind individuals.	✓	✓	
Accompanies autonomous deafblind individuals to access basic services such as shopping, business errands and health services.	✓		
Briefly facilitates unscheduled communication needs (eg: cost of groceries, travel delays, inquiring the location for something).	✓	✓	

	SSP	Intervener	Interpreter
Interprets for autonomous deafblind individuals in scheduled community events (eg: religious, social, life events, public presentations, medical settings, appointments and meetings).			✓
Interprets in educational settings for deafblind individuals who use conventional* language.			✓
Provides customized services to deafblind individuals who have developmental delays and/or additional disabilities.		✓	
Facilitates learning and development of concepts, social skills, emotional awareness, sensory efficiency, self-determination, functional communication and independent living.		✓	
Is part of the IEP/ARD team, communicates with all team members, including parents, and provides input for IEP/ARD meetings.		✓	
Are paid for their services.	✓ (Not in Texas)	✓	✓
Keeps all information confidential according to laws, agency standards and ethics.	✓	✓	✓
National certification available for this professional role		✓	✓
Certification, licensure requirement for this professional role			✓

Compiled by Heather Pavey, Nancy Riley, Heather Withrow, and members of the Texas SSP Coalition, March 2019.

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Note: Conventional language includes spoken English, visual or tactile sign language.

References

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10 SSP BASICS

Katherine Gabry & Mark Gasaway

Presented at 2018 Deafblind International Conference

What is a very basic definition of a Support Service Provider (SSP)?	1	A SSP acts as the eyes and/or ears for a person who is DeafBlind. The SSP takes in information not seen or heard by the DeafBlind person, and conveys it in an unbiased, objective manner.
What specific activities does the SSP do to meet this definition?	2	The SSP: 1) provides access to visual, situational and environmental information; 2) serves as a human guide, thereby providing safe, efficient and effective access to the community and transportation; and 3) provides assistance for short exchanges of spoken and/or signed conversations. In all, the SSP does <i>with</i> , not <i>for</i> , and the SSP does not leave the DeafBlind person alone without his/her consent.
Where are services provided?	3	In home, recreational, vocational and community settings. Note that some programs may restrict certain activities.
Who do SSPs work with?	4	SSPs provide 1:1 services to DeafBlind people who are self-directed and who have an established language system. Note that SSPs are not teachers or interpreters, nor are they advocates. They remain impartial, and respect the choices and decisions of the DeafBlind person.
How does the SSP provide information?	5	The SSP uses the DeafBlind person's preferred mode of communication, relaying this information as clearly and completely as possible. Communication modes can include sign language, tactile communication, speech, print, Braille and technology, among others.
How are SSPs trained?	6	At present, there is no national standard or curriculum for SSP training. Each program has its own requirements. Nonetheless, the professional SSP realizes that learning never ends, and continually strives to improve through interaction with the DeafBlind community and through formal workshops and training programs.
What are some necessary skills and characteristics of SSPs?	7	The ability to effectively communicate, to accurately and objectively describe environmental information, to provide safe and efficient mobility (including human guide), to communicate efficiently and effectively, to think "on his or her feet," and to maintain personal boundaries. SSPs respect consumer choice, are patient and flexible, are punctual, and, generally have a knowledge of DeafBlind culture.
Is there a Code of Ethics?	8	Some SSP programs have adopted a Code of Ethics, but there is no national standard. Nonetheless, SSPs and DeafBlind people treat each other with respect and dignity, and both parties respect each other's privacy, integrity and confidentiality.
How can the relationship between the SSP and the DeafBlind person be described?	9	The SSP and the DeafBlind person form an interpersonal partnership. Both parties must be open to honest communication, and the SSP must be willing to accept guidance and direction from the DeafBlind person.
Overall, why is the SSP important?	10	Professional SSPs are a link to information. When DeafBlind people have information, they can make informed choices, more fully engage in their communities, communicate with others, and, ultimately, enjoy life with greater independence.

A Report on Support Service Providers (SSP)



Texas Governor's Committee on People with Disabilities

January 5, 2017

The Committee on People with Disabilities

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Support Service Providers (SSP)

On May 4, 2016, during their nationwide rally, members of the Deaf Grass Roots Movement (DGM) met at the Capitol with the Executive Director of the Texas Governor's Committee on People with Disabilities to express their concerns on not being able to independently access the community due to a lack of support services for Texans who are DeafBlind. Later this year, on September 30th at the Texas Association for the Deaf Symposium in New Braunfels, representatives from several deaf advocacy groups restated these same concerns over having no program in Texas to deliver Support Service Providers for Texans who are DeafBlind¹.

The Individuals with Disabilities Education Act (IDEA) identifies a category of severe disabilities known as "low incidence disabilities." People who are both deaf and blind fall into this category. According to the Texas Health and Human Services Commission, DeafBlindness is a chronic condition in which a person not only has deafness, with their hearing impaired severely enough so that most speech cannot be understood with amplification, but who also has legal blindness, where their visual acuity is 20/200 or less in the better eye with best correction or their visual field is 20 degrees or less. In other words, DeafBlindness is a combination of sight and hearing loss that not only affects a person's ability to communicate or access information, but significant and unique adaptations may be required for the individual to maintain independence and move around in the world. DeafBlindness is a unique and diverse condition that may impact a wide range of sensory capabilities, include the presence of additional disabilities, and vary at the age of onset for vision and hearing loss. Estimates indicate that there are approximately 70,000 people in the United States who are DeafBlind. It is estimated that 2,486 Texans are DeafBlind according to the Helen Keller National Center's (HKNC) database.

So how can the critical needs of persons who are DeafBlind who want to live more independent and productive lives within their communities be met? Support Service Providers (SSPs), or Interveners, may be able to assist these individuals with their challenges.

Research Summary on SSPs

Support Service Providers (SSPs) are specially trained professionals who enable people with combined vision and hearing losses (commonly referred to

¹ DeafBlind is the spelling adopted by the [American Association of the DeafBlind](#) (AADB) to reflect the dual disability of a hearing and vision loss for the cultural community of the DeafBlind

as persons who are “DeafBlind”) who communicate with American Sign Language to access their environments and make informed decisions. SSPs provide individuals who are DeafBlind with visual and environmental information, sighted guide services, and communication accessibility. Presently, Texas does not have a mechanism to pay for SSP services.

Research gathered by the Helen Keller National Center in March 2016 on SSP programs/services in other states is summarized as follows. More in-depth information on state SSP programs/services provided by the HKNC and other sources can be found in Table 1.

- Most services are provided locally in metropolitan areas, not statewide;
- Most services are funded by grants and/or donations or for vocational rehabilitation (VR) clients through the state’s VR agency;
- The number of people served per year vary from 5 to 80+ based on the 30 states who responded to inquiries on services provided;
- Most SSP services requested are shopping, errands, reading mail, attending community events, employment related tasks, attending appointments and transportation to events;
- The number of service hours provided per month vary across the country from 4-80; and
- **Most SSPs volunteer their services.**

The HKNC does not claim to have counted everyone in the information gathered. There are children in K-12 programs, adults in rural areas, and individuals who are unidentified by the HKNC and may be unaccounted for.

Interveners

The Texas Health and Human Services DeafBlind with Multiple Disabilities (DBMD) waiver program “provides home and community-based services to people who are DeafBlind with multiple disabilities as a cost-effective alternative to institutional placement. The program focuses on increasing opportunities for consumers to communicate and interact with their environment.” Services are intended to enhance, rather than replace, existing informal or formal supports and resources. Residential habilitation, respite, intervener, supported employment, employment assistance, and support consultation are available through both the consumer directed and the traditional agency option.

An intervener is defined in [Texas Administrative Code §42.103](#) as “a service provider with specialized training and skills in DeafBlindness who, working

with one individual at a time, serves as a facilitator to involve an individual in home and community services and activities, and who is classified as an "Intervener", "Intervener I", "Intervener II", or "Intervener III" in accordance with [Texas Government Code, §531.0973](#). The services of an Intervener are not to be confused with those of an SSP. Although both providers help people who are DeafBlind access the community and environment around them, they each provide additional services that are different.

SSP vs. Intervener

Jackie Souhrada, DBMD Program Specialist for the Texas Health and Human Services Commission, explains that both Interveners and SSPs help someone who is DeafBlind connect to the world around them. Both provide the person who is DeafBlind "with access to clear and consistent sensory information." However, the knowledge, skills and abilities needed for each type of job are different based on the level of services provided.

An Intervener is typically a paraprofessional who has received in-depth, specialized training in DeafBlindness. Working with people of all ages who are DeafBlind, the Intervener works closely in a one-on-one relationship with the person who is DeafBlind to gain intimate knowledge of the person they are working with in order to help them "reach out and connect with the broader world." The role of the Intervener is to provide specific intervention in three areas: access to information; access to communication; and access to social and emotional development. The Intervener's personal connection with a person who is DeafBlind reduces any sense of isolation or disconnection from the world and helps them to build a bond of trust. The Intervener may be the one person in the DeafBlind person's life who can help him or her begin to interact with others, express preferences, make choices, solve problems, and develop self-esteem. An Intervener is paid for the work they do and has an occupational career ladder.

On the other hand, Support Service Providers (SSPs) are typically unpaid volunteers who receive informal training of short duration (typically a two-day overview with some experiential opportunities). SSPs generally act as a sighted guide and communication facilitator. According to the American Association for the DeafBlind, "An important aspect of the relationship between the person who is DeafBlind and an SSP is that the former makes all decisions. The SSP can provide information to the individual to assist in considering options, but at no point should the SSP make choices and decisions. The professional SSP strives to be helpful but objective, supportive yet empowering, and sparing in expressing their personal preferences while

providing services.” Services typically provided by SSPs include transportation to the store, communication in a social setting, serving as a human guide while walking, etc. While persons who are DeafBlind may have their favorite SSPs, some may never have met the SSP who is assigned to provide a needed service for them. Overall, the SSP’s role does not have the depth nor the same level of expertise as that of an Intervener. In Texas, SSPs are usually volunteers as the state does not have funding or a strategy to pay for SSP services.

Haley Broadway, a DeafBlind constituent, explains the following about SSPs, many of whom are deaf themselves:

SSPs can:

- Serve as a guide when escorting a person to or from a meeting room, a restroom in an office, or through a lunch line during a workshop;
- Provide visual and environmental information which can take several forms: describing the activity, mood or who is in a room; reading the menu if the print is not legible and voicing/interpreting that information; or locating food items in a grocery store; and
- Provide support to the DeafBlind in their homes, at their place of employment, in their community or elsewhere.

SSPs cannot:

- Provide personal care, e.g., bathing and grooming;
- Run errands alone for the person who is DeafBlind;
- Make decisions for the person who is DeafBlind;
- Teach or instruct;
- Should refrain from formal interpreting in medical, legal, business, or other settings; and
- An SSP who is also a professional interpreter should be careful to differentiate which role they are assuming in any particular situation.

Funding

Based on GCPD’s research, SSPs are funded by other states in the following manner: private donations, grants, local taxes, vocational rehabilitation service funds, and/or state Medicaid dollars.

Recommendations

Providing SSP services in Texas communities can have an enormous impact by allowing greater independence, self-determination, and a higher quality of life for Texans who are DeafBlind. This would be especially true in small and rural communities where limited or no services may be available to these citizens. Therefore, the GCPD proposes the 85th legislature implement the following recommendations:

1. Establish an SSP program that includes training for SSPs so that services are provided in a standard and consistent manner. The HKNC can assist with training information for SSPs as can a number of DeafBlind community members who have been formally trained as SSP Trainers.
2. Establish a pay rate for SSP services with a graded scale of wages similar to that of the Interpreter I, II and III career path. Pay should be based on SSP-level training requirements and American Sign Language (ASL) fluency. A proposed wage of \$20 per hour is recommended. As a note, the 2016-2017 State of Texas Salary Schedule published by the Texas State Auditor's Office reflects the beginning salary for an Interpreter I is approximately \$17 per hour.
3. Establish a voucher program to pay for SSP services. The Specialized Telecommunications Assistance Program (STAP) administered by the Texas Health and Human Services Commission (HHSC) to provide assistive technology equipment is a voucher program that could be a model for an SSP voucher program. This may lessen the demands on state resources to administer this program. The state of Tennessee operates its SSP services as a voucher program and has provided GCPD with information on its voucher operations.
4. Establish the funding source for the SSP program, noting any inherent obligations that may be associated with the source of funds (e.g., Medicaid funds, general revenues, etc.)
5. Establish an initial proposed budget of \$5.808 million for the SSP program. This cost is derived as follows:
 - a. Estimated maximum number of hours per month for services to (1) individual (e.g., personal business, grocery shopping, attendance at a community event): 5 hours per week or 20 hrs per month = 240 SSP service hours/year per individual.
 - b. Estimated 44% of the estimated 2,486 people who are DeafBlind will need SSP services (many in this population are school age (K-12), already receiving Intervener services, are adults in the DBMD waiver

program, or have enough vision or hearing to function without an SSP): 1100 individuals served.

- c. Calculation for cost of program: 1,100 individuals x 240 service hrs/yr = 264,000 hrs/yr x \$20/hr = \$5,280,000/year.
- d. Administrative Costs for SSP program: \$5,280,000 x 10% = \$528,000
- e. Total Program Cost: \$5,280,000 + \$528,000 = \$5,808,000

Estimates for SSP Program Participant Costs

Number of Participants	Times	Yearly Hours	Times	Hourly Rate	Equals	Annual Cost
1,100	x	240	x	\$20	=	\$5,280,000

Estimates for Total SSP Program (Participant Plus Administrative Costs)

Program Costs	Administrative Costs	Total Costs
\$5,280,000	\$528,000	\$5,808,000

Establish the fee for service in rule to facilitate future changes.

7. Designate a state agency to run the SSP program.

Resources

Molly Sinanan, molly.sinanan@hknc.org, Helen Keller National Center

Andrew Cohen, Constituent who is DeafBlind

Haley Broadway, Constituent who is DeafBlind

To obtain a copy of the full report which includes the data regarding the SSP Programs of other states, go to <https://gov.texas.gov/organization/disabilities/gcpd-reports#Review>

By: Watson

S.B. No. 704

A BILL TO BE ENTITLED

1 AN ACT
2 relating to the provision of certain support services to persons
3 who are deaf-blind.

4 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

5 SECTION 1. Section 81.001, Human Resources Code, is amended
6 by adding Subdivision (1) to read as follows:

7 (1) "Commission" means the Health and Human Services
8 Commission.

9 SECTION 2. Chapter 81, Human Resources Code, is amended by
10 adding Section 81.014 to read as follows:

11 Sec. 81.014. SUPPORT SERVICES PROGRAM FOR PERSONS WHO ARE
12 DEAF-BLIND. (a) In this section:

13 (1) "Communication mode" includes communication
14 through:

15 (A) auditory amplification, such as through a
16 personal hearing aid or assistive listening device;

17 (B) American Sign Language or Signed English; and

18 (C) tactile American Sign Language.

19 (2) "Deaf-blind support services" means services
20 provided to a person who is deaf-blind that assist the person with
21 accessing the person's environment and allow the person to make
22 informed decisions. The term includes providing visual and
23 environmental information or sighted guide services and assisting
24 with communication accessibility by communicating in the preferred

1 language and communication mode of the person who is deaf-blind.

2 The term does not include performing any of the following for the
3 person:

4 (A) providing personal care services to the
5 person;

6 (B) completing ordinary errands for the person;

7 (C) making decisions for the person;

8 (D) teaching or otherwise instructing the
9 person; or

10 (E) interpreting for the person in a formal
11 setting, including a medical, legal, or business setting.

12 (3) "Program" means the deaf-blind support services
13 program.

14 (4) "Provider of deaf-blind support services" means a
15 person who is specially trained to provide deaf-blind support
16 services.

17 (b) The commission shall operate a statewide deaf-blind
18 support services program through which:

19 (1) deaf-blind support services are provided by
20 providers of deaf-blind support services; and

21 (2) the commission reimburses the providers for the
22 provision of the services.

23 (c) The executive commissioner by rule shall establish
24 reimbursement rates to be paid to a provider of deaf-blind support
25 services under the program. The reimbursement rates must use a
26 tiered wage scale that is based on the provider's:

27 (1) level of training in communication modes for

1 persons who are deaf-blind and in sighted guide-mobility
2 techniques; and

3 (2) fluency in communication modes for persons who are
4 deaf-blind.

5 (d) The commission shall ensure that quality deaf-blind
6 support services are provided under the program by:

7 (1) monitoring the compliance of providers of
8 deaf-blind support services with program rules;

9 (2) developing funding sources for the program that
10 are in addition to state sources and will reduce reliance on the
11 state sources for continuation of the program; and

12 (3) providing funding and technical assistance for
13 training programs for:

14 (A) providers of deaf-blind support services
15 under the program; and

16 (B) persons who are deaf-blind to enable those
17 persons to effectively use the services offered under the program.

18 (e) The executive commissioner may establish an advisory
19 committee to advise the commission in developing and operating the
20 program, including operating the program in a manner that ensures
21 the efficient use of state money. Subject to Section 2110.002,
22 Government Code, the executive commissioner shall determine the
23 number of members serving on the advisory committee, which must
24 include persons who are deaf-blind and other stakeholders.

25 (f) The executive commissioner may adopt rules necessary
26 to:

27 (1) operate the program in a manner that is efficient

1 and maximizes the number of persons served; and

2 (2) ensure that providers of deaf-blind support
3 services receiving reimbursement under the program have adequate
4 training to provide those services.

5 SECTION 3. Not later than September 1, 2020:

6 (1) the executive commissioner of the Health and Human
7 Services Commission shall adopt rules necessary to implement
8 Section 81.014, Human Resources Code, as added by this Act; and

9 (2) the commission shall begin operating the program
10 required by that section.

11 SECTION 4. This Act takes effect September 1, 2019.