

# ADVOCATING FOR STATEWIDE CO-NAVIGATOR SERVICES IN TEXAS A HISTORY

**Important Note: With more DeafBlind (DB) leaders actively involved in advocating for independent living services, DeafBlind services philosophy and terminology is evolving. “Support Service Provider” (SSP), has become regarded as culturally insensitive, in that it implies an imbalance of power in the working relationship with the DB individual. In its place, “Co-Navigator” (CN), has been coined by many DB leaders, who reason that the job title is more culturally sensitive, as well as more clearly descriptive of the actual process of the work. But for practical reasons, these two terms of art—CN and SSP, are used interchangeably.**

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## **1990s**

- **In Texas, SSP services were available to only a small population of DeafBlind adults, who were either (1) residing in state-sponsored independent living programs, or (2) receiving time-limited vocational rehabilitation program services. Since most DB adults in Texas were not eligible, or did not otherwise participate in either of these two programs, they faced many barriers to living more independent and productive lives. DB individuals and allies began, therefore, to advocate for SSP Services, by encouraging Texas’s rehabilitation agency for individuals who are blind, then called the Texas Commission for the Blind, to expand SSP services to the general population of autonomous DeafBlind adults. DB people and allies also visited SSP programs in other states, attended DB conferences to learn more about how to establish a program, and worked on developing a model for Texas.**

## **2005**

- **The DeafBlind Service Center of Austin (DBSC-A), was formed to be part of the National SSP Pilot Project affiliated with Seattle’s renowned DeafBlind Service Center (DBSC). Initially, this pilot project’s goal was to develop a nationwide training curriculum, provide SSP training, and fund two pilot SSP projects. Cities would be chosen that had a sizable DB population, but did not already have SSP services—Austin being one. Kris Cué, a DeafBlind individual, traveled to Washington, DC, to meet with both Texas**

senators and a couple of representatives to request support for the legislation to fund these two pilot SSP projects. Most unfortunately, this funding provision did not pass.

- Since 2005, DBSC-A has provided SSP and DB consumer training when funding is available, using the curriculum that was ultimately developed by DBSC. DBSC-A has also coordinated SSP services for the local DB community, again when funding allows. For example, it contracts with the Texas School for the Blind and Visually Impaired's DB Outreach Team, to provide SSP services for regular meetings of the Interagency Task Force on DeafBlindness, as well as other sponsored events.

## 2008

- In April, Texas's then rehabilitation agency, Department of Assistive and Rehabilitative Services (DARS), held a public forum for the disability community to express their views on improving existing services. Several stakeholders testified about the need for SSP services, including DeafBlind individuals Kris Cué, Kim Powers, Erik Hammer, Richard Garrett, & Juli Wilhite; along with allies Mark Seeger, Nancy Riley & Jacque Orr. Although there was widespread support within the DARS administration, our effort to persuade DARS to begin providing ongoing SSP services (through its independent living program) was not successful—due to the timing of DARS' reorganization, along with nationwide economic challenges.
- Over the next several years, after submitting unsuccessful grant proposals and holding limited fundraisers, DBSC-A set forth a plan to personally visit Texas legislators to educate them regarding the vital need for statewide SSP services, as detailed below.

## 2015

- Then state Representative Elliot Naishtat previously supported and authored the DeafBlind Multihandicapped Association of Texas's Intervener Services bill. Therefore Kris Cué and Jacque Orr met with his Legislative Director Nancy Walker, to educate her about the need for statewide SSP Services for autonomous DeafBlind adults.

**They then provided Ms. Walker with a two-year SSP pilot project proposal, and apprised her of the Louisiana statute that enabled funding for Louisiana's statewide SSP program through its Universal Service Fund, commonly referred to as the Telecommunications Tax.**

**Ms. Walker then took our proposal to staff at the Texas Public Utility Commission (PUC), to ask their legal opinion as to whether PUC's Universal Service Fund could be used to fund an SSP program—much like Louisiana and several other states. PUC's lawyers gave their consent, therefore, Rep. Naishtat forwarded a proposed bill for CN services, to be paid for by Texas's Universal Service Fund, to House attorneys for their approval. The House attorney(s), however, did not approve the bill, and it is not clear why.**

**2016**

- On May 4, during their nationwide rally, members of the Deaf Grassroots Movement (DGM), met at the Capitol with staff of the Texas Governor's Committee on People with Disabilities (GCPD) to express concerns about DeafBlind Texans' inability to independently access the community—due to the lack of SSP services.**
- On Sept. 30, at Deaf Sympo, representatives from several Deaf advocacy groups restated these same concerns over having no program in Texas to provide SSP services for autonomous DeafBlind Texans.**
- Subsequently, DeafBlind individuals Hayley Broadway & Andrew Cohen, and Helen Keller National Center's Regional Representative Molly Sinanan worked closely with GCPD's Executive Director Ron Lucey and (then) Disability Rights Coordinator Randi Turner, to conduct research to formally document the need for statewide SSP services in Texas. GCPD then voted unanimously to recommend establishing an SSP Services program to the Texas Legislature.**

## **2017**

- **In January, the GCPD issued “A Report on Support Service Providers (SSP)” to the Legislature. This much appreciated achievement provided us with sorely needed documentation to validate and enhance our efforts to get CN legislation passed. The report estimated approximately \$5,808,000.00 (\$5.8 million+) per year in costs that the state would have to incur, which totaled to \$11,616,000.00 (\$11.6 million+) for the biennium.**
- **In March, Kris Cué, Kim Powers & Jacque Orr met with (former) Senator Kirk Watson’s Senior Policy Analyst—Ryan Alter, to share a proposed bill for statewide SSP services. Since it was very late in the session Senator Watson pared down our proposed bill to that of a pilot project (SB 1997). This bill was filed right before the bill filing deadline. As such, it died in committee.**
- **In the summer, Kris Cué, Kim Powers & Jacque Orr met with GCPD’s Ron Lucey and Randi Turner to offer feedback regarding their SSP Report, and to discuss how to proceed going forward with our legislative efforts.**

## **2018**

- **In the fall, GCPD sponsored a meeting with DB community members and then Texas Association of the Deaf (TAD) President Mike Swoboda to strategize our legislative effort for 2019. GCPD’s Ron Lucey & Randi Turner encouraged and educated us on best practices for advocating for a CN bill. Armed with GCPD’s Jan. 2017 report—solid documentation to support our effort—we quickly formed a coalition to harness momentum and strength in numbers. At that time we called ourselves the “SSP Coalition of Texas.” DB individual Hayley Broadway led the way, DB individual Andrew Cohen created our website, and DB individual Heather Pavey set up our Facebook page. In addition, many SSPs (mostly volunteers) co-navigated the maize of the Capitol while visiting with legislators, and donors purchased T-shirts & tote bags for us, with our logo (“SSPs for DeafBlind Texans”) clearly displayed.**

**2019**

- **Around the third week of January, our coalition began meeting weekly at the Capitol to advocate for statewide SSP services. (We were not eligible for formal assistance from TAD during this session, as TAD members had already prioritized the issues they wanted their lobbyist to pursue.) Early on we found a sponsor for our proposed SSP bill—again Senator Kirk Watson, who filed SB 704, as well as Representative Gina Hinajosa, who filed a companion bill in the House (HB 1564).**
- **On April 16—with great excitement—the House Committee on Human Services held a hearing on our bill. (We had never reached this far in the legislative process before.) Twelve coalition members (most of whom were DeafBlind) personally testified that day, several coming from out of town. And twenty-one individuals registered (but did not testify) in support of our bill—including TAD’s Mike Swoboda and TAD’s lobbyist Aaron Gregg. Other allies assisted by donating time and money toward transportation, lodging, and meals for our out-of-town coalition members.**

**In spite of our great turnout—a very, very logistically challenging endeavor to say the least—our bill “died in committee.” According to Representative James Frank, the committee’s chairman, our bill was not voted favorably out of his committee because of its seemingly high costs. Rep. Frank did, however, vote favorably out of his committee HB 3991, which related to increasing the number of slots available in the “Deaf Blind with Multiple Disabilities” (DeafBlind Waiver) program—one that also had a very high fiscal note. But, this bill subsequently died in the Senate Committee on Health and Human Services.**

- **During the summer of 2019, Heather Pavey and Jacque Orr joined forces to begin making our coalition’s website more user-friendly, and hopefully more accessible to DeafBlind users.**
- **The Texas Health and Human Services Commission (HHSC), provides independent living services to people with disabilities, and the coalition feels strongly that HHSC’s Office of Deaf and Hard of Hearing Services (DHHS), is ideally suited to administer a statewide**

**CN Services program. And other states administer their SSP/CN programs through their comparable Deaf and Hard of Hearing Services departments. During the summer, fall and winter months of 2019, therefore, coalition members met several times with various HHSC administrators to advocate for that agency to include a CN program on their next Legislative Appropriations Request (LAR), due the following fall of 2020. This would greatly facilitate getting our CN bill passed, as an LAR budget item could preclude the need for an arduous fiscal note.**

- **In December and then January of 2020, HHSC held "listening sessions" across the state to gather input from disability advocates about what services and supports should be funded for 2022-23. Coalition members personally testified, both in person and online, about the need to prioritize statewide CN services. There was reportedly support for CN funding, but due to the advent of the COVID pandemic and other economic issues, no such funding appeared in HHSC's final LAR. Still, several coalition members made their feelings known to HHSC personnel.**

## **2020**

- **Through the spring and summer of 2020, coalition members made follow-up contacts with staff within HHSC. But we were greatly stymied by the barriers created by COVID: mainly the inability to meet in person, and the ineffectiveness of video conferencing for people with vision issues.**
- **From August 7- 9, coalition members participated in TAD's Deaf Sympo—a biennial meeting that usually precedes each legislative session by a few months, in order to prioritize issues to address. Hayley Broadway spoke about the critical need for CN services for DeafBlind Texans, then moderated the discussion that followed. When the membership voted on the 9th, enough votes were cast for our DeafBlind CN issue to obtain formal TAD support going into the next legislative session. This was wonderful news—quite an accomplishment!**
- **During the early fall Hayley Broadway, Nancy Riley & Jacque Orr worked with GCPD's Randi Turner and Research Specialist Monica**

**Villarreal to revise its SSP Legislative Report. The revision was intended to recalculate the estimated costs for a statewide CN program—costs that more accurately reflected the actual number of DeafBlind individuals who would likely be both eligible for, and actively use CN services.**

- **In December, GCPD published its revised SSP Report, titling it “Report on Support Service Providers (SSPs) / CoNavigators (CNs).” GCPD’s budget estimate was reduced to \$584,400.00 (\$ .5 million+) per year—meaning \$1,168,000.00 (\$1.1 million+) for the biennium. This much, much lower estimate meant legislators would hopefully be receptive to passing our bill. This revised report was very encouraging news! It is available on the “Research” page of our website at [texascn.org](http://texascn.org).**
- **In mid-December, TAD’s CN legislative sub-committee (core group being DeafBlind individuals Hayley Broadway, Sarah McMillen, Kris Cué & Sheryl Hunt, and ally Jacque Orr) began collaborating with TAD’s lobbyist Aaron Gregg. The need for interpreters and transportation fees made it too expensive to meet in person as a group. Co-chairs Hayley Broadway & Jacque Orr and Aaron Gregg decided, therefore, that going forward the three would meet virtually through zoom and VRS every other week, as well as as-needed texting for updates and guidance, then report back to other sub-committee members and TAD as a whole.**
- **On Dec. 14, Hayley Broadway and Jacque Orr began working with volunteer ally Jeff Harper on creating our new and greatly improved website at [texascn.org](http://texascn.org). Jeff has also graciously volunteered to be the administrator. Note: At this point in time, our website has not been formally announced for public use, because we need to have braille users evaluate its accessibility. We hope to accomplish this soon.**

**2021**

- **In January, the CN sub-committee sent our proposed bill to Aaron Gregg, who in turn forwarded it to the Texas Legislative Council for official drafting.**

- The GCPD issued its “2022-2023 Policy Recommendations Report to the 87th Texas Legislature.” This report included a recommendation that legislators establish “a formalized support service provider (SSP) / co-navigator (CN) program within the HHSC, including training for providers,” at a projected cost of approximately \$584,000.00 per year.
- On Jan. 12, the 87th regular Texas Legislative session began.
- On Jan. 22, we received very good news! Aaron Gregg advised us that once the official Texas Legislative Council’s bill draft was completed, it would be filed by Representative Mary González from El Paso. Mr. Gregg then announced that another lobbyist, Kate Goodrich, who was interested in our CN advocacy efforts, hoped to join our cause. She subsequently formally affiliated with the DeafBlind Service Center of Austin, a strong supporter of our CN advocacy efforts. Ms. Goodrich has an invaluable working knowledge of the Senate Health and Human Services Committee, as well as relationships with key legislative staff members—greatly enhancing our legislative strategy.
- In early March, Representative Mary González filed our CN bill (HB 3287), and Senator Bryan Hughes filed companion bill SB 1715.
- Our coalition worked hard to expand our DB Coalition, amass more support for our bill, and strategize our legislative contact efforts. Eventually, however, our lobbyists told us to stop contacting legislators because the sheer volume of our emails and phone calls had overwhelmed them. Smile
- On April 13, the House Committee on Human Services held a public hearing on our bill. Due to COVID restrictions, only two DB constituents were allowed to testify in person. To review this testimony go to [texascn.org/legislative-information](https://texascn.org/legislative-information). A transcript is included. The committee reported our bill favorably out of committee, after which the full House passed our bill to engrossment.
- On May 21, the Senate Committee on Health and Human Services held its public hearing on our bill, only this time—again due to



**COVID restrictions—no testimony was allowed, other than that of Ron Lucey, Executive Director of GCPD, as a “resource witness.” The Senate committee quickly reported our bill favorably out of committee.**

- **May 26 was the last day that House bills could be passed in the Senate, and our bill was near the top of Senator Hughes’ stack for final passage. Most regrettably, however, in spite of working through most of the night, the full Senate did not reach our bill for a vote. Indeed, Senators were unable to pass many of the 121 bills on their “Intent Calendar”—due in no small part to political gamesmanship. But oftentimes, a bill does not get passed on its first, second or even third attempt. But this time we came so very, very close to final passage, so we have reason to be quite optimistic that our Co-Navigator bill will pass during the next legislative session in 2023.**

**Acknowledgments:**

**A very special thanks to Kris Cué, Chairperson of the DeafBlind Service Center of Austin and Nancy Riley, a strong ally for individuals who are DeafBlind, for contributing to this history.**