

An Impact On All

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When IL Hands & Voices GBYS (Guide By Your Side) kicked off in 2009, it was built on the premise of “build it and they will come”. A strong foundation of communication and partnerships was built, but it was not as sustainable as we believed.

The partnership adhered to continuous quality improvement principles and was fueled by commitment and passion. Both parties desired to partner so that referrals could be received directly by GBYS from the Early Hearing Detection and Intervention (EHDI) program. Challenges with formal agreements, infrastructure, and funding were obstacles to the shared mission. It took time, patience, and finding others who understood the need to finally put a plan into place. But giving up was not an option. Over a decade after the state’s GBYS launch, a signed DBA (Doing Business As) agreement became a reality. Today, the Illinois EHDI program can make direct referrals to GBYS and the gates have been opened for other meaningful quality improvement opportunities.

The rainbow at the end of the 10-year shared vision includes:

- Greater likelihood of providing parent to parent support within the national benchmark.
- Family data including time of enrollment, resources sought and what type of amplification (if any) the family has chosen freely communicated with the EHDI Program.
- Renewed sense of purpose that fosters IL guides to feel more effective, impactful, and connected to the parent professional role.
- IL GBYS connecting families to the next steps of Early Intervention (EI) and clarifying the roles of the EI providers appropriate for a child who is deaf or hard of hearing.
- IL families receive knowledge of national, state, and local resources as well as access to the private online social support group.
- Most importantly, IL families have a parent-professional to talk with and gain a better understanding of the journey ahead.

Through the shared undertaking, Illinois rolled out our direct referral process in July 2020, during the pandemic. In October 2020, a Transition Specialist was incorporated into the IL GBYS program through quality improvement processes to the program partnership. The specialist follows up with families transitioning out of Part C/ EI and into Part B (U.S. special education services under IDEA.) The specialist documents EI enrollment status and history, educates the family on the upcoming transition, answers questions and provides resources. The transition specialist asks the family to answer two questions on a scale of 1-5 (5 being the highest). For the first question, 81% of families reported a 1, 2 or 3 related to Individualized Education Plan (IEP) preparedness. The other question rates helpfulness of the outreach. To date data shows, 87% of the families reported a 4 or 5. In February 2021, the third role, Lost to Follow-up (LTF) Specialist, was introduced to our EHDI parent support team through a COVID 19 pilot project. Due to the impact of COVID 19 Illinois’ GBYS Program was able to facilitate follow up with families. The specialist asks if the family has a follow up appointment scheduled, helps families find a testing site, answers questions and provides support for parents navigating the process with insurance. One of the first families the specialist encountered shared that her family did not see the need to follow up because she saw her child responding to sounds. The specialist empathized and shared that she responded similarly with her own child, however, follow up testing determined that her

daughter was hard of hearing. The mom expressed appreciation for the input and was then ready to set an appointment. Mom closed by stating that she would feel awful if she delayed a diagnosis and was thankful for the call.

It may have taken over 10 years for the unicorn to land, but the numbers do not lie. The DBA has allowed Illinois' continuum of EHDI care to assist more families sooner (often while parents are still on maternity or paternity leave, leading to more connections with fathers) compared to as an opt in program. Before direct referrals, the program connected 40 families to support and resources in 2019 compared to 122 families in 2020, a 205% increase. Prior to our direct referrals (from Jan. - June 2020), 29 families were enrolled in parent-to-parent support. After the DBA was implemented, (from July - Dec.) the number tripled to 93 families! And the demographics of the families have changed by serving more families with children who have unilateral, mild, and conductive losses, more rural families who may straddle borders for care, and families who identify as other than Caucasian increased from 36% to 52% of families. The collaborative impact is shown in the significant increase from 2019 to 2020 ... and that was during the pandemic! Direct referrals assist programs to meet national benchmarks, revitalize parent guides and most of all serve families earlier in their journey.

As program collaborations between the parent-to-parent support organizations and the state EHDI program evolve, NEVER GIVE UP. Continue to share the rainbow and unicorn dreams, educate one another, accept each other's current circumstances and be willing to work outside of the box. The personal investments by all can pay off at unpredictable times.