

## Michigan Parent Involvement in 1-3-6 (1)

When the HRSA grant came out, Michigan Hands & Voices proposed to Michigan EHDI that we would 1) operate a robust Guide By Your Side program, and 2) train parents to be involved in efforts to improve outcomes related to the 1-3-6 goals. The latter is called our 1-3-6 Parent Representative program.

The mission of our 1-3-6 program is to use Parent Stories to help improve the Michigan EHDI medical and educational systems. In the first two years, this is what we have accomplished:

For Goal 1 - screen by 1 month of age:

- 25 parents are now trained to share their newborn screening and diagnosis stories.
- 33 meetings included parents sharing their stories in small staffings, webinars, and presentations for diverse audiences including managers, bedside staff, and students.
- 100% of respondents of one presentation said the speaker was effective. One Attendee's reaction: "Personal story really accentuated the importance of follow-up."

For Goal 3 - diagnose by 3 months of age:

- We are scheduling visits along with EHDI staff to ENT offices where we will discuss the challenges parents face in completing the diagnostic process.

For Goal 6 - intervention by 6 months of age:

- 7 meetings have included parents this year in Local Interagency Coordinating Councils, which are advisories for local Early Intervention programs.
- Parents represent the needs of children who are deaf or hard of hearing, and professionals can immediately put the shared information to use.
- Examples of what parents have shared:
  - "Brought up the need for reaching more families with Unilateral hearing loss and getting them plugged into Early On<sup>®</sup>."
  - "I talked about the 1-3-6 initiative and our interest in improving early intervention. I also talked about the value of teaching empathy and inclusiveness, so even if a meeting topic does not directly impact families, they can still benefit from any discussion at these meetings."

In addition to the local engagement efforts, our Parent Reps are involved in statewide and regional collaboratives/advisories, at a rate of about 12 meetings per year.

As we have worked in collaboration with EHDI to build this program, we have enjoyed successes and learned lessons. We are grateful for our close relationship with EHDI staff. It has helped us through the transition from a 1 parent consultant model to a having a seat at 36 meetings and presentations per year!