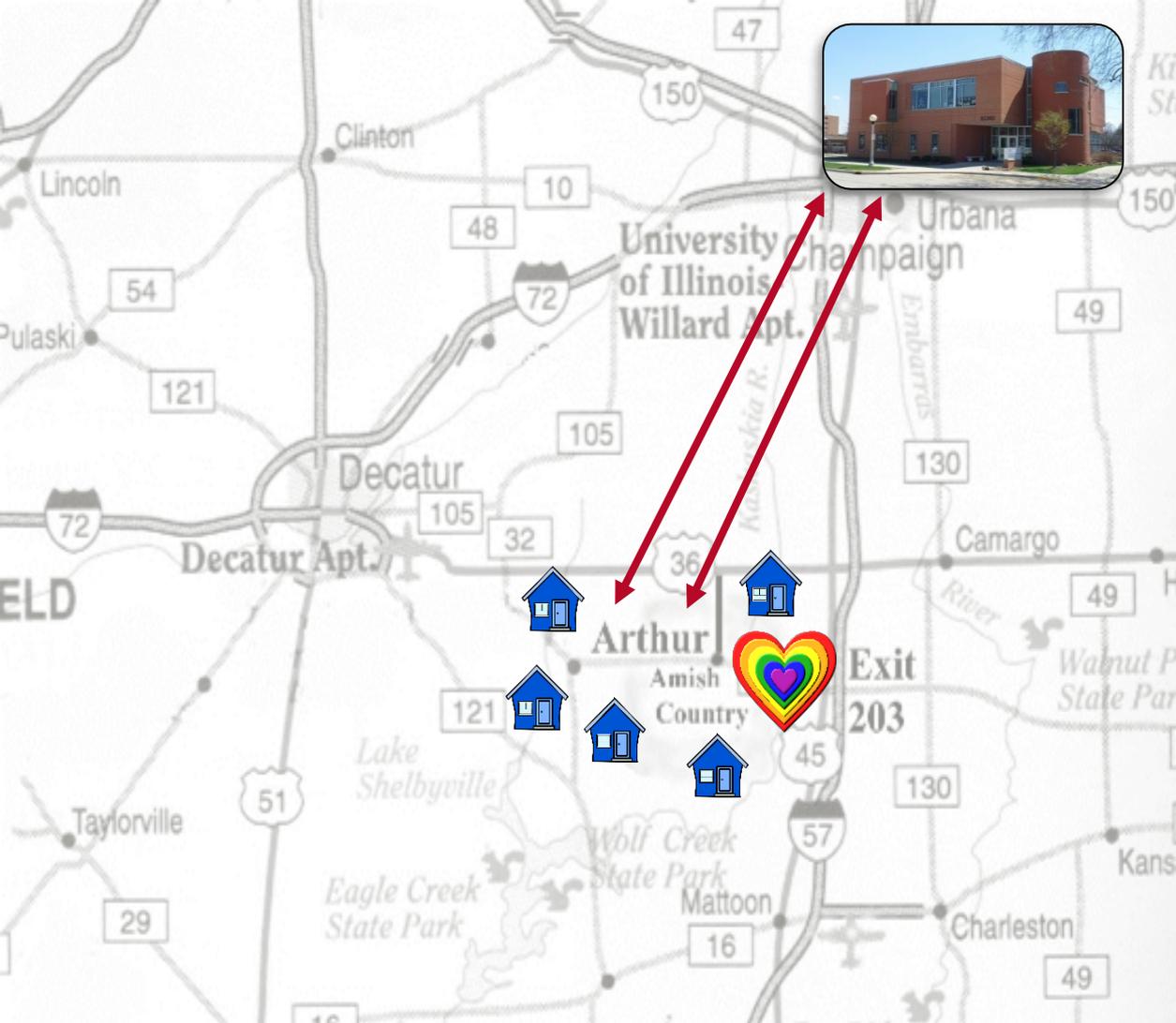




Supporting Children who are Deaf or Hard of Hearing in the Amish Community

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Carle Foundation Hospital ECHO (Expanding Children's Hearing Opportunities) Program



Community Model

- Arthur Amish Community
- Services by Carle ECHO
 - EI providers travel to patient's home for home visits
 - Amish families travel to ECHO for audiological services
- Rainbow Heart School & ECHO
 - ECHO therapist & outreach coordinator travel to support teachers and provide weekly therapy services
 - EI speech/play group is provided for 2 year olds in the Amish community twice a month

Anita's Reflection

“Before I started working with the Carle ECHO program, children who are deaf or hard of hearing, I had been teaching special education at 1st and 3rd grade levels. I had no experience with children who are deaf or hard of hearing. We as an Amish community do not feel it necessary to pursue a formal education higher than 8th grade. As special education teachers, we are very thankful for individuals willing to enable us to help our students achieve their greatest potential.

I actually had no training beyond the 8th grade. I mean I had, I...I had 8th grade promotion, and that was all.



My journey with deaf and hard of hearing began only 3 years ago by visiting ECHO once a week and also being allowed to work alongside the students and therapists. And observing the therapists, I was working really alongside the therapists, but I was work, I was observing them. Later on, we were allowed, we were able to allow a student to attend a private school within our community while still allowing her to receive the same therapy she needed by the same therapist she had at ECHO. I was her teacher and by allowing her to attend a private school within our community she was able to learn both of the languages she will be using throughout her life.

One of the common ideas among the Amish is that it is impossible for deaf individuals to be bilingual. So mostly they would focus on learning English and not the Pennsylvania Dutch we normally use at home. We incorporated both languages throughout the therapy, in the classroom, and at home, and she is now able to switch back and forth between the two languages correctly. Most Amish children are just being introduced to their second language at age 5, this gives deaf and hard or hearing children a small advantage against their normal hearing peers as they begin attending 1st grade.

If I had the privilege of meeting another deaf or hard of hearing teacher in our community, I would highly recommend working alongside ECHO. I would really like for them to have the same chance to visit the ECHO classrooms as I did.

They were more, they were geared more toward, toward little children of course because we had, we had been working with, like I said 1st and 3rd graders, so they had been working lesson. They had been working paper, books, things like that. And I noticed, one thing I noticed, in the classroom that I was mostly visiting, they only had like, they had a very open plan. They were geared towards small children. They really, I could tell, they really were working on their language goals, where as they would, they would just play with the children.

And that, that also, made me realize that a lot of learning can be done while playing. That was something I did not, fully realize at that time. I always thought that learning goes hand in hand with papers; papers and books and writing; and doing things, sitting actually! I always thought learning happens while you're sitting. And now, now I know that it doesn't it. It really, it really happens while everyone is engaged and playing, and yeah, sometimes working. Yeah.

Additionally having therapists willing to drive out to a private school was a great help in allowing us as an Amish community to keep our students within our community schools. One thing I never expected to see when I began working with ECHO and with deaf and hard of hearing children, was a child so far behind in her language and speech coming to the point where she exceeds the language and speech of others her age and this all in despite of her hearing loss.

I also did not expect ECHO to be so generous in providing help.

I, I had always imagined hearing loss to be a pretty severe disability, where the only thing, the only way to communicate was between sign language or lip reading. I never, I never imagined that a deaf person could effectively communicate by using their voice. I always thought that anyone communicating with deaf people would need to have the special training, the special schooling for sign language and things like that. I never imagined they could just talk like anyone else.

I, I have, I have a helper, a teacher helper in my room beginning this term, and I can definitely see myself in her where she is not quite sure how. Yeah, I see it over and over again where she doesn't, doesn't understand that she, she does need to just, just talk. She's like, "well I don't know how to say it, I don't know how to do this." And I see how I, I mean, I can see myself, I know that I was like that too. I, I also thought I have to do this differently. I have to do this differently. And some things did need to change, but just by, just by doing it I was able to see what needed to change. But most of the things could still proceed like normal.

If I would ever have to start over again, I would probably ask a lot more questions. At the beginning, I know I did ask questions, but I think I would, I would want to ask a lot, LOT more questions. Something else I would want to do is learn the cued speech and sign language before beginning to teach deaf and hard of hearing individuals. That was, is kind of hard, without working without those two, will probably work for the preschool aged students, but once they reach the 1st and 2nd grade level, when they're reading and writing, cued speech is really, really needed. It makes it a whole lot easier.

One really big benefit is his spelling. He's been able to go like from memorizing half of his spelling words correctly to knowing how to spell all of his spelling words. And it has been, it has been helping him; we don't normally use it to sound out words, but in writing words definitely. I mean, that's the only thing we are using right now is spelling words. But it really, really helps. It helps him, it helps him visualize it and know that this is, this is what is happening."

Strategies

Parent Empowerment / Train the Trainer



Parent Empowerment

- This family wanted the child to learn to talk because they don't sign, so we helped them find the communication mode that supported the family's needs
- We gave the family strategies for the development of spoken language (family included: grandmother, older cousins, aunts, and close friends – not just the parents)
- We also gave the family strategies to help keep the devices on so the child could have access to sound:
 - headband with hearing aids (Ear Suspenders)
 - costume tape with the hearing aids and CIs
 - experimented with different CI cable lengths and wearing options

Train the Trainer

- Initially, Anita came to CAOS with the child who would be in her classroom at Rainbow Heart
- She observed in the classroom and therapy settings at CAOS
 - Emphasis on use of the hearing devices and access to sound
 - Strategies used to develop audition, language, and speech skills
 - Method of teaching (play-based intervention)
 - Use of peers as models
- At Rainbow Heart, the teacher of the deaf went into the classroom
 - Observed,
 - Co-taught, and
 - Coached Anita in supporting listening, language, and literacy development

Strategies

Culturally Responsive Intervention



Planning Based on Child's Environment

- Consider vocabulary we teach the children needs to be related to their environment
- Consider lack of access to technological resources, such as internet, Facebook groups, texting other parents, all communication by phone is leaving a message
- Understand that they cannot take part in tele-therapy so we need to find ways to see them onsite in their community or at the ECHO Program
- Had to be creative when getting them to the ECHO program:
 - paid private taxis
 - public transportation
 - appointment coordination
- Responsive to the Amish not wanting their picture taken, for example: for home and school projects (something we usually do to build vocab concepts)

One family shared, “They haven’t tried to push us to do things that are against our beliefs and have helped us find ways around the obstacles.”

Strategies



Simultaneous
Bilingualism

Simultaneous Bilingualism

- Parents are bilingual in this community
- Pennsylvania Dutch is the language used by the Amish Community
- It is not a written language
- Simultaneous bilingualism in therapy may look like:
 - Therapist speaks in English
 - Then the parent or teacher will immediately repeat the message in Penn. Dutch
 - This will go back and forth throughout the session
 - When the child responds in Penn. Dutch, then the parent/teacher acts as the interpreter and the therapist provides the English equivalent

Simultaneous Bilingualism: Parent Perspectives

- “I feel it is important that they learn both. Pennsylvania Dutch; so the family and her peers can communicate as usual and she doesn’t miss out. English; because they need that at school and beyond.”
- “I think its important, but I think its challenging for her too. In the later years it will really help her, but now it seems like she is trying to get two languages in. But I just think she’s, that it kind of puts her back too.”

Strategies



Check
your
Biases

Check your Biases

- Don't assume they will automatically reject hearing aids and cochlear implants
 - Families knew that their community would support their choice in using hearing technology if that was something the family wanted to do
 - One family with a child with CIs, uses a solar powered system to recharge their rechargeable batteries
- They do have phones; although they are in a separate space from the house
- While they do have Amish doctors, they also see medical professionals out of their community for specialized services
- We have found the Amish Community to be very warm, open, and welcoming!

“I say we are very blessed to have a program that feels like family to us. And we feel like we can talk about anything, and yeah, it means a lot to have people to talk to that understand hearing loss and everything.”

Community Support



How has the Amish community been supportive?

A Mother's Response

“I don’t know. Right after we found out about the hearing loss, I had gotten a lot of letters from people, like those were, some were from out of state, there was one from around here. Then I had some ladies come over for, spend an hour or two in the forenoon just talking about it and that they’ve gone through and experience hearing loss (with their own children). With their own, yeah. (was that helpful for you?) Yeah it was cause it was very new for us to start out in knowing which way to go and what to do.

We had written or put this like in a certain paper the Amish get from all over states, we put in for information, like for people with hearing loss or that had implant, cochlear implants or had this meningitis, that we would like to hear back from them so they would write us and we put our address in.”



Anita's Response

“Yes. I, I know that there have been, in earlier years before, maybe twenty years ago, I would say most of the, most of the deaf and hard of hearing children, which are now adults, we don't have any deaf and hard of hearing adults within our community....possibly for various reasons. But there have been children earlier, but they have not, they have not grown up to be, feel accepted within the Amish community. And that is something that's really, really sad because they, they did not, they did not get the understand, they did not receive the understanding that just anyone else does because, well they can't hear. They can't communicate with anyone supposedly.”



Anita

“I would say the response would be, umm, they’re always interested. They’re always asking what we’re doing, how, how we’re doing it and things like that. The response to it, they’re, they’re really interested. And I think, they’re surprised, they’re always surprised if I say that I don’t know very much sign language. I only know what my students have taught me.

I think, I think they’re thinking the same thing I did. I think they’re thinking that deaf and hard of hearing children do not communicate in any other way than by sign language. So they’re, they’re really, really surprised. I would say in the last year or so, there’s not been as many surprised people because it’s more, probably more common. They have talked with me and they know that it’s different. And I think that creates more awareness and they, they know that they can, they can come up to a deaf and hard of hearing child and talk to them and know that they will be able to understand them for the most part. And it makes the children feel much more included (definitely) if they, if they can give and take wherever they go.”



Questions and Reflections

For continued discussions
or questions, please
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THANK YOU!!