

Fathers' involvement in education, learning, and development for children with CHARGE syndrome

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Introductions

- Parent involvement in their children's education is an essential element for their success, especially for families with CHARGE syndrome (Olivos, Gallagher, & Aguilar, 2010).
- In addition, very little is known about families with children with CHARGE syndrome. CHARGE syndrome is a disorder that affects multiple parts of the body. CHARGE is an abbreviation for coloboma, heart defects, atresia choanae, growth retardation, genital abnormalities, and ear abnormalities (Genetics Home Reference).
- Research on parent school involvement has conventionally focused directly on mothers, thus little is known about the experiences of fathers in school settings, specifically for fathers of children with disabilities (Pancsofar, Petroff, Rao, & Mangel, 2019).
- When fathers are involved in their students' education, they do not feel part of the educational team, which ultimately makes them feel as "the odd man out" (Mueller & Buckley, 2014).
- When fathers are at meetings, they described their feelings as not fitting in with the education team, which made the process feel overwhelming and daunting (Mueller & Buckley, 2014).
- Although there has been a few research on fathers' experiences of students with disabilities conducted, it is important for professionals to assist fathers with children with deafblindness. Thus, it is essential that educators explore fathers' perspectives in special education (Petroff, Pancsofar, & Shaaban, 2019).

What is Individualized Education Program (IEP)?

- The Individualized Education Program, also known as the IEP, is a legal document under United States law that is created for each public-school child receiving special education.
- It creates a chance for teachers, parents, related services professionals, school administrators, and students to collaborate to improve educational outcomes for children with disabilities.
- The IEP team sets measurable and specific annual goals for the child with disabilities to reach.

Method

- Transcriptions of interview data from 24 fathers of children with CHARGE syndrome. CHARGE syndrome causes congenital deaf blindness among many complicated health issues.
- Open-ended interviews were conducted in Summer 2019 at the annual National CHARGE syndrome conference.
- Analysis of the interview data involved a three-step inductive approach of open coding, axial coding, and selective coding.
- Fathers live in several different states across the United States. Twenty-two of the fathers were Caucasian, while one was Asian or Pacific Islander, and another was Puerto Rican. Twenty-one of the fathers identified their role as a father, two identified as the step-father, and one identified as the grandfather.

Results

Emerging Themes Preliminary Findings

Through the coding of interview transcripts, there were several emerging themes around fathers' attendance at the Individualized Education Program (IEP).

There is an overarching theme that most fathers attended IEP meetings and spoke about attending these meetings.

- "Yeah, I would go to the IEP meetings. I did three 12-hour shifts a week, so we would always schedule it when I had a day off, and I pretty much went to all of the IEP meetings." (Transcript George).
- "But I have attended – if I've missed an IEP meeting in the 14 years that he's been in the school system, I would say it's probably been one or two out of that 30-odd IEP's." (Transcript Henry)
- "So I would sit in these meetings and soak up everything I could. I'd write it down if I didn't, if I knew I wasn't going to remember it and then I could go back in armed going." (Transcript Mike)
- "Usually for something for like that we're advocating, it happens in the IEP and we both went together and we talked about it before and sort of organized more together." (Transcript Issac)

Next Steps for Research

- Coding analysis of interview transcript data will continue through Fall 2020.
- We will continue to research father's experiences on IEP teams.
- We will explore whether there are trends of father's experiences on IEP teams depending on the student's age.



<https://www.chargesyndrome.org/>

Father Experiences with IEP Preliminary Findings

After coding the interview transcripts, we were able to find out fathers' experience with the IEP. We found a divide between fathers' positive and negative experiences at these meetings. In addition, we are in the process of finding the meaning within these negative and positive fathers' experiences. Some of the fathers' experiences include:

Some fathers had positive experiences at the IEP meetings

- "We've never had to fight an IEP, we really haven't, and when you're just open and sincere, our experience, they wanna work with you. If you go in shields up, then the fight happens. And we always say what we want before we go in, and we haven't had issues. (Transcript Anthony)
- "Yeah, I feel like they all went good. I felt like there's a lot, a whole team of people that really wanted to help." (Transcript Larry)
- "They do – we have IEPs on an annual basis, and we set goals, and actually the folks that we work with, they manipulate the system, so she gets as much time as she can." (Transcript Nathan)

Some fathers had negative experiences at the IEP meetings

Fathers had to fight for services

- "Well, it's just that we had to push for things. Again, we would walk out of these meetings thinking, God, what about parents who don't know what to ask for?" (Transcript George)
- "So we moved down here, we moved to rural Northeast Texas. There wasn't much services out there. We battled the school district quite a bit." (Transcript Mike)
- "When you know that they exist and you ask for them, their representatives aren't really that happy to give them. So you kind of need to fight for them." (Transcript Ethan)

Fathers felt like IEP was useless

- "Even though they talk about education, okay, the educators aren't educated enough for whatever." (Transcript Patrick)
- "Right, exactly, they don't know, really – they don't know what the real needs are. So you need to inform them, and sometimes schools don't like that, okay." (Transcript Yusuf)
- "But there has been a real struggle where there was a couple years where they rewrote all the goals and then just wiped out everything. You're like, 'Well what was the progress?' (Transcript Daniel)