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Systemic knowledge at school entry: learning from disabled children and their families

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ABSTRACT

This article presents practical interpretation of an institutional ethnography, which examines the organization of young disabled children and their families. The article begins with an understanding that the experiences of young disabled children can teach us about the ways in which we organize around ability, and the power that is held by the institutions that claim to 'support', 'help' and 'care for' children. The authors present recommendations for educators that are grounded in research evidence as well as their own lived experience.

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Introduction

Entry into schooling is a significant milestone in the life of children, marked with excitement and anticipation for new development, learning and relationships. However, for many children, registration in kindergarten programs is not the beginning of their journey. Disabled children and their families may have been working toward these educational goals since they were born. The experiences of disabled children and their families have a lot to teach us about transition into school and how disability shapes our social vision for education.

Through research, our team have been talking to families once per year since their children were 2 years old or younger. The families who we have been working with have managed services for their children who have diverse disability and deaf identities including neurodiversity, blind and low-vision, language impairment, and physical and intellectual disabilities.

In this article, we share interpretation of the research from the standpoint of disabled young people and two adult researchers. The IECSS project has taught us that young people and their families hold a tremendous amount of knowledge about how education systems work. The authors recognize that disability is a diverse experience but holds some common experiences.

Procedures and systems

Experiences of disability are often accompanied by interactions with healthcare, early intervention and clinical professionals. There is a strong belief in Western medicine that

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early identification and intervention are necessary for the success of disabled students in school.

As a result of this philosophy, many children and their families spend the first years of a child's life engaged in the procedural and programmatic activities of early intervention. Educators should know that not all disabled students require special education or early intervention, and it is important to understand disability from the perspective of children. However, if a child has been part of early intervention services they hold knowledge about their own learning and requirements for support, unlike other students.

Many children have been part of a system that includes referrals, wait times, and relationships with professionals, as well as appointments, consultations and therapy. The effects of this experience are not just developmental. Disabled children are impacted by their early experiences just like other children. However, while disabled children are attending extra appointments, their friends might be socializing. Accessing services affects socialization and participation in different activities.

This system can be very complicated. Reflecting back on this experience, young adults note that for young children it can be confusing to see many different people for different services. It is important to talk to children about why they are participating in these services, what the goals are, and how those goals and supports might be transitioned into schools.

We have found that it is common for children in early intervention programs to be pushed into multiple programs and services with similar goals, leading to repetition and exhaustion. For example, occupational therapy is accessed through multiple agencies, such as community early years programs, clinical developmental services, and health care settings. Yet families and young adults note that the services from one agency to the next are often identical and each requires its own intake and assessment processes. This happens with other service as well, such as speech and language, physical therapy, and children's mental health services.

While early intervention can be repetitive and lack efficiency, in our experience, many children and families also find these services crucial to development, participation and growth. Early intervention and clinical services are valued by disabled children and their families. Both young adults and families see the possibility for impairment specific health care, intervention and support in order to *live a good life*. This is possible when the services do not take over a child and families life.

They also saw a discrepancy between public and private agencies. Providing more publicly funded services to children and understanding their adaptive needs can better support the inclusion of disabled children within educational settings. These services can be the difference between young children feeling included or excluded from their new school. It is therefore imperative that there is equity in access to the services that children want and need.

Key Messages for educators:

- Families and young people want disability specific services, including special education.
- Disability specific and special education services should not interfere with students' participation in other activities.
- Special education services should recognize that disability is not a universally understood concept.

The work of families

Early intervention, education and care systems require work on the part of families such as medical appointments, relationships with professionals, filling out forms, and finding funding. This work is essential for access, and families do not have the same resources (including money, time and relational capital) to do this work.

We have heard from families that participating in this system also exposes them to systemic discrimination including on the basis of race, citizenship status, custodial status with their children, and disability discrimination. Further, the western medical assumptions underlying this system, evident in the diagnosis and referral mechanisms, serve to reinforce western practices of medicalizing childhood.

Families also require support for themselves throughout this process. Rather than relying solely on medical professionals for advice, speaking with disabled youth and other parents with disabled children can be beneficial. This could help parents learn more about the struggles their child may encounter, and can help children to connect with people who have shared experiences. Educators could also use this strategy to gain a better understanding of how to support their students.

Overall, our research indicates that parents and adults have a critical role in the lives of disabled students, but ultimately, it is critical that children are listened to directly. The best way to understand what someone is going through is to ask them directly to learn about children's day-to-day lives, what they need, and how they define themselves.

Key Messages for educators:

- Children and families who have participated in early intervention programs should be recognized for the work they have done and the knowledge they have of the system.
- Because this system is a lot of work, educators should consider how much they ask of families.
- While families are an important source of information, children should also be asked about their experiences.

Disability identity

Diagnosis, identification and designations of special needs, health conditions and impairment are central to gaining access to services in school and early childhood care and intervention programs. However, experiences of disability are much more than these official declarations. In our experience disability is often only referenced within these procedural discussions.

Children are rarely included in procedural discussions about their education, especially when they are very young. For this reason, many young people report that no one really talked to them about disability in their early years. More importantly, disability is rarely included in conversations about diverse identities.

Children need to be told about their health and development, as well as any diagnostic information that is available. It is important for adults and peers to recognize that disability identities can be positive. Being different from other people can be a gift that allows you to see the world in new ways. However, in our experience most people do not see disability this way and are reluctant to discuss it for that reason. Educators can change that viewpoint.

We believe that how young people see themselves is often at odds with how others view them. Educators, children, and other people make assumptions about disabled children. Families in our study described talking to their children about disability. In our experience, other adults, including educators, often avoided or were uncomfortable talking about disability.

Peers often have a difficult time talking to their friends about disability. It is important to allow young kids to ask questions without the fear of being disrespectful. These conversations can help to change rude or disrespectful actions such as staring and awkward behavior around disabled people. We believe that the classroom is one place where these conversations should take place from a young age. Positive representation of disability is needed at all ages if young children are going to hold positive views of themselves.

In addition, the services themselves are often designed with deficit views of disabled students embedded in them. Our special education systems, and supports in early childhood education and care, tend to focus on the present moment and supporting disabled children to participate at a given time, neglecting to focus on the future. Assumptions that disabled students will not progress in education and employment in the future are evident in services that lead to segregation, life skills education that replaces academic content, and programs that treat disabled children as needing help but not as providers of help.

Finally, it is critical consider that disability identity is always situated within the context of other forms of identity including culture, language, gender, race, age, class, geographic location, migration, etc. The Youth Advisory Committee of the IECSS project identified the need for all forms of equity across the country and the need for politicians to recognize diversity if education is going to be inclusive. The IECSS project, as well as many other research studies, have identified the intersection of inequality in access to services, and in outcomes for disabled students.

Key Messages for educators:

- Positive representations of disability are needed in conversations with all children.
- Adults and children should ask more questions about disabled people's lives so they do not make inappropriate assumptions.
- Recognizing disability as one part of identity is important for equity.
- Disability rights are interconnected with other forms of discrimination.

Conclusions

Special education needs to shift its focus from creating systems that are reactive to developing responsive approaches that are designed to maximize participation.

We need to start talking to young people about disability as a legitimate identity not just a category for bureaucratic purposes. We need to recognize the value of disabled experiences and in order to do that we will have to get more comfortable with talking about disability in early childhood, and directly with children and their families.

Further, we need to stop asking families to do the work of inclusion and adaptation. While families are very knowledgeable, they don't necessarily have all the answers, and they are likely to be engaging in many more professional interactions than other families.

Rather than asking families, educators should spend more time getting to know children and asking them about what they need. These conversations can also be helpful for other children so that they are more sensitive and knowledgeable in their interactions with disabled people.

Finally, disability or diagnostic categories do not necessarily mean that young children need more services. We encourage educators to engage with children first before deciding what they need. However, if children have already qualified for services or figured out what they need in earlier years, educators should honor the work that was done to make that determination and reduce the procedural barriers to getting the support that is the right of the child, and that will allow them to fully participate.

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