

A photograph of two young women, one with dark hair and one with light brown hair, both wearing light purple shirts. They are smiling warmly at each other and holding hands. The woman on the left is wearing a plain purple t-shirt and jeans, while the woman on the right is wearing a ribbed purple t-shirt. The background is a plain, light-colored wall.

**Hospital Experiences of Children
with Intellectual Disabilities,
their Parents and Nurses**

A QUALITATIVE RESEARCH STUDY

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Executive Summary

The present study highlights the experience of hospital visits for children with intellectual disabilities (IDs). Children with IDs often encounter increased hospital visits and have unique challenges to overcome when in this setting. Mothers, nurses, and the children themselves provided the researchers with personal stories and narratives highlighting their successes and challenges. They provided suggestions for change as well as praise for many hospital practices.

Nurse (n=17), mother (n=12) and child (n=8) participants took part in semi-structured interviews in their home or at the health centre. Child participants often had a parent, guardian or caretaker present to assist with the interview process. Mothers and children provided stories of their hospital visits; what they did, who they saw, and what worked or didn't work. Nurses described their care practices; what they did differently, challenges they had and stories of success. Each individual's experiences were qualitatively analysed paying close attention to personal, social and institutional discourses and practices.

Findings from the study suggest that many hospital experiences for these children and their families were positive and successful however, some challenges were identified as well. Mothers described many successful relationships that were established between themselves and healthcare professionals but also identified a heavy reliance on them when their child was in hospital and felt stigmatization and labeling still impacted their child and themselves in many ways in the hospital environment. Child participants were generally happy to visit the hospital and any fear or discomfort they described was associated with medical procedures (ie. needles, x-rays). Nurses expressed a strong desire to develop relationships and help make hospital experiences positive for both children with IDs and their families but also expressed a lack of knowledge and education associated with caring for children with IDs which often left them feeling unsure or uncomfortable.

Recommendations for improving the healthcare experience for children with IDs are identified. Particular attention is paid to the institutional setting and how it impacts the care experience for nurses, parents and the children themselves.

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Introduction

This report was developed based on a research study conducted at the IWK Health Centre in Halifax Nova Scotia from 2010-2013. The study aimed to better understand hospital experiences of children with intellectual disabilities (IDs) in the hopes of learning better ways to support children with IDs and their families in the healthcare setting. Children, parents and nurses were interviewed as part of this project and each participant provided the research team with personal stories of both positive and challenging healthcare experiences. The research team has utilized these stories to better understand the healthcare experiences of children with IDs and the hope is that findings will guide future healthcare training, education and planning.

Children with IDs are socially and institutionally constructed as different because they are often unable to fit into what mainstream society constitutes as 'normal'. The social construction of 'normal' comes from a particular set of dominant values that places higher value on a certain way of doing things such as communicating, moving and interacting. When an individual is unable to operate or engage in these ways they are viewed as different and are marginalized. This is the position of children with IDs.

Children with IDs often have more hospital admissions and increased healthcare experiences overall (Balogh, Hunter & Ouellette-Kuntz, 2005; Frid et al., 2002; Mahon & Kibirige, 2004; William et al., 2005). However, previous studies have shown that individuals with IDs are treated differently in the healthcare setting. Lewis and Stenfert-Kroese (2010) completed a study of nursing attitudes towards individuals with IDs and found that nurses had more negative attitudes towards individuals with IDs than individuals with a physical disability. Nurses also identified being more likely to segregate individuals with IDs and less likely to explain treatments and ask if they were in pain. Several other studies have identified similar findings (Gibbs, Brown & Muir, 2008; Matziou et al., 2009; McConkey & Truesdale, 2000) highlighting a clear differentiation between the healthcare experiences of 'mainstream' patients and patients with IDs.

Research which has focused on the *personal* experience of individuals with IDs further supports this finding with many studies highlighting patients with IDs or their care givers feeling discomfort and worry when in the hospital setting (Brown & Guvenir, 2008; Gibbs, Brown & Muir, 2008; Guidelines and Audit Implementation Network, 2010; Webber, Bowers & Bigby, 2010) as well as a significant reliance being placed on individuals with IDs, parents and caregivers (Avis & Reardon, 2008; Brown & Guvenir, 2008, Cumella & Martin, 2000; Gibbs, Brown & Muir, 2008). Communication between healthcare professionals and patients with IDs has also been highlighted as a source of tension (Avis & Reardon, 2008; (Cumella & Martin, 2000; Scott, Wharton & Harnes, 2005). Avis & Reardon's (2008) study of 12 parents of children with IDs identified communication with healthcare staff as their most important theme and highlighted that parents "placed high value on 'direct' communication between the nurse and their child" (p 12) as well as the nurse and themselves as the parent.

While all of this research portrayed a clear picture of a different hospital experience for children with IDs, the present study focused on the **how** and **why** of these differences. Participant experiences were closely examined in an effort to determine the individual, social and institutional scenarios that helped to create these experiences. Feminist poststructuralism and discourse analysis guided this exploration and provided an appropriate tool for gathering an in-depth, well-rounded understanding of the child with an ID's hospital experience. Four themes emerged from this analysis.

Labels: What's in a name?

Impact of ID on relationship establishment

ID information sharing

Reducing stigma through education and knowledge

Research Process

Ethical approval was obtained through the IWK Health Centre Research Ethics Board to ensure the rights and protections of study participants. The research study took place over a 2 year period (March 2011 – May 2013) and ethical approval was received annually.

Participants

Nurses

Twelve nurse participants were recruited through study posters situated throughout the health centre and on the internal health centre website. Inclusion criteria required nurse participants to have worked with a child with IDs at the IWK Health Centre within the past 2 years.

Nurse Participants (n=12)

	Average	Minimum	Maximum
Years Employed as a Nurse	17.5 years	2 years	41 years
Years Employed at the IWK	12.5 years	1 year	41 years

Parents

Seventeen parents of children with IDs were recruited through mail out packages as well as posters and postcards distributed throughout the health centre and local support organizations. While fathers were eligible to participate, all parent participants were mothers. Parents were able to participate if they had a child with IDs who had obtained care at the IWK Health Centre within the past 2 years.

Parent/Mother Participants (n=17)

	Average	Minimum	Maximum
Age of their Child	10	3	16

Children

Eight child participants were recruited through mail out packages and recruitment posters and postcards throughout the Health Centre and local support organizations. Inclusion criteria for child participants included a mental age of at least 7 years old (as reported by a parent/guardian) and the child must have obtained care at the IWK Health Centre within the past 2 years.

Child Participants (n=8)

	Average	Minimum	Maximum
Age of Child	12	8	18

Methodology

Feminist poststructuralism provided the framework for the present study guiding the project from its inception (Butler, 1992; Cheek, 2000; Foucault, 1983). This methodology focuses on interactions between personal, social and institutional discourses and offers a means for close examination of power relations and negotiations. The concept of power within feminist poststructuralism is not associated with any one party having “power over” but rather operates under the belief that all individuals have power that they choose to negotiate, utilize or withhold based on a range of factors such as institutional settings, social structures or personal beliefs. Using this methodology we were able to better understand the healthcare experiences of children with IDs.

Data Collection

Informed consent was obtained from all participants prior to their participation. Parent authorization was received from the parent or guardian of child participants and child assent was obtained as well. Individual, semi-structured interviews were completed with all participants as well as a brief demographic survey. Interviews were roughly 30-90 minutes and were audio-taped and transcribed verbatim with identifying information removed and pseudonyms included.

Data Analysis

Analysis took place simultaneously throughout the data collection phase to allow for on-going understandings of emerging themes. Interview transcripts were analyzed through a dual process of discourse analysis and thematic coding. Discourse analysis was the main analysis tool with thematic coding being supplementary. All three members of the research team reviewed and analyzed the first few transcripts and came to consensus about initial emerging themes and relations of power. The research coordinator then continued to analyze the transcripts using discourse analysis and thematic coding. Nvivo 8/Nvivo 9 software was used to organize the data into themes. These themes remained fluid during the analysis process and were merged and expanded throughout the course of the analysis. All members of the research team worked together on the final analysis.

Discourse Analysis

Discourse analysis involves the identification of personal, social and institutional beliefs, values and practices. Individual transcripts were closely reviewed in order to identify participant's unique beliefs and values and how they interact with the institutional and social value systems around them. Participant's beliefs, values and practices were initially examined on an individual basis and categorized into themes. Once reviewed individually, analysis took place across all transcripts within participant groups by reviewing common themes for further and more in-depth review of personal, social and institutional discourses. Foucault's (1983) concept of relations of power was a significant part of discourse analysis and was used to understand the subject positioning and agency of participants' experiences.

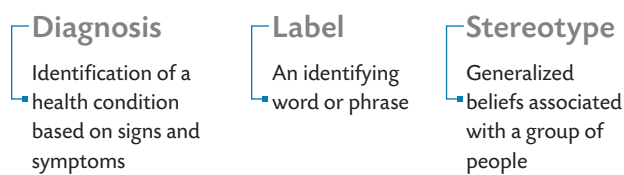




FINDINGS

Diagnoses, Labels and Stereotypes

Diagnoses, labels and stereotypes emerged as three important terms/concepts that impacted a child's access to care and experience of stigma. By paying close attention to how each participant used these words to describe their experiences and the meaning they placed on them, we were able to better understand how care was organized in the hospital and the healthcare system.



At times the three terms had distinct meanings and at other times they overlapped. In particular, the term label was used interchangeably with both diagnosis and stereotype, which signified moments where medical, social and institutional constructions of meaning and healthcare practices converged. These were the moments that caused us to stop, reflect and question the everyday, common and assumed meanings that had historically been attached to these words and examine the impact they had for participants.

The Helping and Hindrance of Diagnoses and Labels

Many mothers in the study spoke about the importance of having an ID diagnosis assigned to their child because this helped to manage their child's health condition as well as their utilization of support services, programs and funding.

I think having a diagnosis in terms of helping get appropriate teaching techniques in place and stuff was really important. (Mother)

[...] once we got the diagnosis then they'll start coming to your home but before that we were going to them [...] (Mother)

However, when discussing access to services, we noted that the term label was often used as well.

[...] the whole necessity of labels. There's a necessity for it in order to access resources and what happens is [...] some opportunities that would benefit somebody who doesn't have that specific label just aren't open to them because they don't have that label. (Mother)

So whether he has that label or not I think it's actually getting him further than if he didn't. (Mother)

While mothers understood that diagnoses were associated with medicine the term label seemed to shift the experience to that of social supports which extended beyond traditional medical care.

For the majority of participants, receiving a diagnosis such as autism provided access to many necessary services. However, one child who was given a diagnosis of a rare condition did not have the same results because supports were often contingent on having very specific, and common, diagnoses.

[...] we haven't really gotten a lot of services. I find if Janey was autistic she would get more but [...] I have to really dig deep to get services here for her because she kind of falls through the cracks (Mother)

I didn't really [...] feel like she kind of fit into a group like that. (Mother)

Many mothers also described diagnoses as allowing individuals who worked with their child to better understand their child's needs and tendencies.

Sometimes labeling helps [...] sometimes it's a benefit because the last time somebody said 'what is this kid stupid?' 'No, he's intellectually challenged, he has a learning disability.' (Mother)

When we didn't have a diagnosis [...] she was all, looked like stern and annoyed because he wouldn't sit down and stay in her office and roaming around. (Mother)

All mothers in the study were aware of the need to use diagnoses or labels to navigate the system and believed they were essential to their child's care and access to services and supports.

When Labels Shift to Stereotypes

Through the interviews it became apparent that there were certain assumptions and stereotypes that were associated with diagnoses and labels. Although a diagnosis could be defined using medical terminology there were also social meanings that were attached to the diagnoses and labels that were based on fear and misunderstandings. For example, many mothers and nurses described how children with IDs were often stereotyped and assumed to be poor communicators, disruptive or difficult. Parents were also sometimes negatively labeled or stereotyped as bothersome, difficult or bad parents.

Stereotype: Children with IDs are poor communicators

I would tell people, you know, you can talk to Tim. Don't talk in front of him, don't talk to him like he's a subject and he's not here. He understands [...] (Mother)

Stereotype: Children with IDs are disruptive or difficult

People will look at him and either just think he's misbehaving or that we're bad parents and the comments you get even from qualified medical staff, you kind of get the impression that [there are] some who really don't understand. (Mother)

Stereotype: Parents of children with IDs are bothersome, difficult or bad parents

I found as soon as I started to talk and say what Tim's meds were, what his seizure activity was, that he was non-verbal, I didn't stop [...] and it was just like all of a sudden 'well she's a know-it-all' [...] and that's not my intent, my intent was so that people knew Tim. (Mother)

It was evident in our study that there continued to be a variety of negative beliefs and values associated with children with IDs that have been historically constructed through dominant social discourses. These beliefs and values manifested as labels and stereotypes. All of the mothers and some of the nurses were aware of and concerned about these stereotypes and shared examples of how they challenged the negative and oppressive beliefs and practices.

I'm really careful not to label because the parents feel very guilty. (Nurse)

One mother described how she helped to teach a healthcare clinician to challenge the belief that children with IDs are unable to communicate.

I turned into being a bit of a teacher with one because he'd come and introduced himself [...] and I'd point him to Tina. He'll go 'oh hi Tina' and I'll say 'you know if the child is old enough to understand, you should go to the child first, they're why you're here [...]' (Mother)

She went on to suggest that all healthcare clinicians should have sensitivity training to help them understand that an ID diagnosis does not mean a child cannot communicate.

A little sensitivity training [...] Tina can talk you know, ask her first [...] don't assume because they have an intellectual disability that they don't understand. (Mother)

This mother had clearly experienced stereotyping associated with her child's ID and chose to help challenge this assumption by both drawing attention to the issue and helping to teach clinicians a more appropriate way to interact with children with IDs.

Being cognizant of the difficulties experienced by children with IDs and their parents due to stereotyping and labeling is the first step to begin to question, and hopefully challenge, these oppressive beliefs.

Understanding and Embracing Difference

Mothers and nurses in this study spoke about the difficulties they encountered when children with IDs were positioned and described as being 'different'. Perceptions of difference predominantly led to negative assumptions and stereotypes. In particular, children with IDs were compared to mainstream children and in an attempt to be inclusive and caring many nurses spoke about how they believed a child with IDs should be '*treated as any other child*' and '*no longer seen as different*'. These statements suggest that if care is equalized between children with IDs and mainstream children this may improve care for children with IDs who noticeably continue to be negatively stereotyped. While the intent of treating everyone equally was meant to reduce or eliminate stigma, it may unintentionally contribute to harm. If equality is interpreted as 'sameness' amongst children, this could lead to overlooking an individual's unique needs.

We suggest that rather than striving for equality we should be striving for 'equity', which shifts the value system from treating everyone the *same* to treating everyone *fairly*.

I think first of all remove that barrier of someone being high need or special need and just realize that [...] everyone's different, so nobody's different (Nurse)

This nurse highlights this point by speaking about the necessity of focusing on the unique needs of *all* children including children with IDs. She challenges the concepts of both sameness and difference by suggesting that each child in the healthcare setting needs to have their unique needs met whether they're the same or different from other children's.

Conclusion

It was clear that diagnoses and labels were a necessary part of the process of care for children with IDs. Medically, diagnoses helped healthcare professionals attend to physical and intellectual concerns. Diagnoses and labels were also helpful to parents and children as they navigated services from an institutional and social point of view. However, it was also important to note that diagnoses and labels could hinder access to care as well as cause negative stereotypes and stigma. Stigma towards children with IDs is not new, but we did find participants describing moments of empowerment when they were able to identify the stigma, question the problematic attitudes and behaviour and then challenge these moments. These moments provide us with excellent examples of how nurses and mothers worked to change practices. Moments of tension should be interpreted as opportunities for change.

FINDINGS

Impact of IDs on Relationship Establishment

Children with IDs need to be comprehensively assessed physically, mentally, socially and culturally. Not only are they admitted to the hospital more often than mainstream children, but they may also have multiple health concerns including higher levels of anxiety. As discussed in the previous section, stigma is still associated with children with IDs and therefore they may be marginalized in western culture because they vary from what 'mainstream' society considers 'normal' (Matziou et al., 2009). This variance from 'normal' often includes communicating in a non-mainstream way or interacting socially in ways that would contradict the status quo. All of these factors can impact the relationship development process..

Establishing effective and therapeutic relationships is an important part of care with any child and family member. However, establishing a relationship with a child with IDs and their parents/guardians often requires different or additional skills by nurses and healthcare professionals. It is imperative to establish supportive relationships that will also help to minimize experiences of marginalization and allow a child with IDs and their parents/guardians to feel safe and secure in their healthcare environment (Cohen et al., 2011).

The 'Valuing' of Relationships

Mothers, children and nurses all placed significant personal value on relationships between healthcare professionals and children with IDs.

Most of the people there are, like are nice and stuff. I don't know they just like, they were really cool. (Child)

However, we found that it was not always easy to establish this relationship for a variety of reasons. A hierarchy between medical care and taking the time to establish therapeutic relationships was a predominant theme that created tensions for mothers and nurses. More support was given for physical and medical care compared to support for relationship building. Institutional structures and practices required that more time, education and resources be prioritized for medical interventions.

I think a lot of parents know that nurses are competent to check a blood pressure and stuff but it's more [...] are you confident enough to communicate and interact with my child and make sure they get what they need? (Nurse)

The practice of spending more time on physical treatment and procedures rather than relationship development created a certain dichotomy and tension for nurses when they had to prioritize care. Ultimately it appeared that institutionally more value may have been given to physical care.

Some nurses, however, did provide examples of their challenging of this dominant value system. One nurse described a time when she ensured she was able to make a connection with a child with autism.

I remember one of our patients, he came as a new admission on my night shift [...] he was another autistic child but not high functioning [...] and I remember when he came he was very, very low functioning and non-verbal so as soon as I found out that [...] I found out who his dad was, I zoomed right in and said 'what does your son like [...] I know you're tired but in a nutshell, let me write down real quick, what does your son like?' [...] and as soon as he said 'oh my god he loves to play balls.' [...] I called labour and delivery and got the big birthing ball for him [...] he loved it! (Nurse)

This nurse recognized the importance of relationship establishment with this particular child and chose to place high value on this piece of the child's care. This act went beyond ensuring the child was physically and medically cared for and helped to ensure the child felt comfort and security while in the healthcare setting.

Challenges to Relationship Development

Three main challenges to relationship development were identified by both nurses and mothers.

- ▶ Communication
- ▶ Time
- ▶ Fear

Communication

Our research found that many of the nurse participants identified themselves or other nurses feeling like they could not communicate as effectively with a child due to their ID.

[...] you couldn't tell them we're trying to help[...] you need to have this. You couldn't even explain this cut needs to be closed so it doesn't get infected. You couldn't tell them any of that right [...] (Nurse)

I find the best thing to do, well at least with this little guy, was talk to the mom and find out what really works cause he's not very verbal, he's very, like lots of sign language and just, you can't really sit him down and have a conversation with [...] (Nurse)

[...] a lot of the kids are just kind of almost catatonic like they're just kind of lying there and I don't feel like I really have a relationship with them like I try and be kind of gentle and kind of stroke their arm when I'm doing something. (Nurse)

Interviews with mothers also supported this finding with several mothers describing healthcare professionals as not talking to their child and *'talking down'* to them, presuming that they were intellectually at a lower level.

I especially find people [...] sort of talk down to him. So, I have noticed that. (Mother)

Very few of the nurses would actually talk to Tim like he understood or was a person that was listening[...] they would tell us what they were going to do [...] they would say 'okay Tim we're going to put the IV in' but they'd be looking at us and talking to us. (Mother)

We can ascertain from these examples that the stereotype that suggests a child with IDs will be unable to communicate effectively existed. Children with IDs *do* generally communicate, however it may not be in a 'mainstream' way and this can be uncomfortable and frustrating for people. Some might interpret this as an inability to communicate when it could also be interpreted as a variant way to communicate. Communication is considered to be an important factor in the development of relationships (Bronwyn et al., 2012; McCabe, 2004) and was noted by all participants in our study. Verbal communication is the dominant way of initiating and fostering relationships and therefore adaptations need to be identified and encouraged to assist with this relationship establishment.

Time

Nurses described time as a factor in their ability to develop working relationships with children with IDs. Some nurses described not having enough time to develop the relationships that they would like with their patients.

We try to [develop relationships] but normally have about a maximum of 5 minutes to do it [...] So it really can be difficult. (Nurse)

A healthcare professional's understanding of the importance of time when building relationships was further articulated by a parent who described a dentist who brought a child in for regular appointments many years before he had to treat her to allow her to get to know him.

[...] we went down, to see the dental department and Julie was about 5 and he said 'I'm not going to have any work to do on Julie until she's about 14 or 15 and then she'll be doing surgery to straighten her jaw' [...] but, he said, 'nobody wants a stranger' so 'I want her to come in so she can get to know me' (Mother)

This dentist placed high value on relationships and understood that parents and children valued this as well. His beliefs and values shaped his practice as he suggested that the child *'get to know me'* because *'nobody wants a stranger'*.

Another mother described a similar experience with a nurse.

She's warm [...] when we came here for the first time I had a lot of questions and I said 'I don't mean to hold you up, this is a real stupid question.' She said 'no it is not, there's no such thing' and she always has time [...] always, she listens and she talks [...] she's such a gift. (Mother)

We can see through both mother and nurse excerpts that *'having time'* was viewed as an essential factor in their ability to develop relationships with their patients and their families. Unfortunately, the dominant healthcare discourse did not support large amounts of time between patients and healthcare professionals. Priority and value was placed on getting medical procedures done with less emphasis placed on developing supportive relationships.

Fear

Both mothers and nurses discussed the concept of fear as it related to children with IDs. Children with IDs are seen as *'different'* and this can be scary to people because it goes against what they consider *'normal'* and perhaps what they are comfortable with. Mainstream refers to dominant ways of doing things or *'the status quo'* that have been historically, socially and institutionally constructed and embedded in practice. When something is different from this it may create fear or uncertainty.

I know a lot of nurses down here feel kind of like 'uh-oh, what are we' [...] it's not the same. (Nurse)

This nurse identified where she believed the uncertainty came from when she said *'it's not the same'*. She suggested that she and her colleagues were accustomed to working with the mainstream population (and were likely trained to work with the mainstream population). When a patient who was not *'the same'* as what they were used to presented in their healthcare area they were unsure of how to proceed and felt a sense of *'uh-oh'*.

Mothers were very aware of the potential for people to feel fear when working with their children and suggested that this fear came from a place of unknowing and uncertainty.

[...] when you haven't had much exposure to people with intellectual disabilities it's kind of scary for some people because they don't know how they interact with them. They're not really sure how to do or go about any of those things. (Mother)

This fear may impede a nurse's willingness or ability to try to develop a meaningful relationship with a child with IDs. They may be fearful of saying something wrong or insulting or they may be scared that if they try to communicate it may not work. Whatever the specific fear is, we suggest that it comes from a place of not knowing and not understanding. Education and knowledge have the potential to shift a person into knowing and understanding and break down any fears which can negatively impact the ability and willingness to develop meaningful relationships with children with IDs.

Challenging the Status Quo and Developing Positive Relationships

Our research found that many times positive relationships were developed between healthcare professionals and children with IDs and their families, regardless of the above mentioned challenges. Mothers provided several examples of when relationships worked and these examples allowed us to look closely at the practices that fostered relationship development. When mother's described their personal relationships with their child's healthcare providers they identified practices such as giving them *'support'* and *'telling us what was going to happen'*.

[She] was really, really supportive. She would come and sit with us and talk to us about Todd and all his good points. (Mother)

Going for the operation first thing in the morning Jason and I and our daughter went down and we went in and the nurses that were there attending were wonderful. Very great about telling us what was going to happen. (Mother)

These parents described their healthcare professionals as *'wonderful'* and *'great'*; Terms which suggest that relationships were developed.

When discussing successful relationship establishment between healthcare professionals and their children mothers further identified appreciating when healthcare professionals took the time to interact with their child and learn appropriate ways to communicate with them.

I remember a nurse working in Cardiology [...] she was really good with Monique. Like I mean they talk to her like she was her age [...] and try to find positive ways to occupy her while they had to do whatever it was. (Mother)

These mothers provided distinct examples of when nurses and other healthcare professionals were able to overcome and challenge the many institutional, social and personal barriers that have the potential to impede relationship development with a child with IDs in order to develop a relationship that they believed was essential to quality care.

Conclusion

Our research has shown that children with IDs, parents and nurses valued positive and supportive relationships and believed these types of relationships made a difference to care. However, we have also identified that the dominant healthcare discourse has not been constructed to easily support the development of effective relationships with children with IDs and their parents. These contrasting value systems created tensions for the nurses and mothers in this study and ultimately many mothers felt unsupported. We suggest that a shift in institutional practices that better supports the development of relationships with children with IDs and their parents, could lead to a more holistic and positive healthcare experience for this population.

FINDINGS

ID Information Sharing

Findings from the present study suggest that information pertaining to a child's ID was not always effectively documented or shared. For example, nurses identified that common conditions such as autism would typically be recorded in a child's medical file and would be understood by most healthcare professionals. However, when children had an ID diagnosis such as 'developmental delay' or 'global delay' these were not always recorded in the file and when they were in the patient's file many nurses described not understanding what those labels actually meant.

When people say global developmental delay I'm like really? I just feel like that label gets put on a lot of kids who have a lot of different conditions and it would just be nice [to have] a little bit going into what that really means[...] (Nurse)

Not having information and not having it passed on [...] I think it's as important as the allergy protocol [...] it's not something to be taken lightly. It's to be recognized [...] (Nurse)

Most of the nurses identified a need for additional information regarding childhood IDs. Some nurses described not feeling 'prepared' for caring for a child with IDs. While others suggested wanting to know what an ID diagnosis 'really means'. Diagnoses such as global delay and developmental delay can mean very different things for each child that receives them and as noted by many nurses in this study, it was essential to have specific and additional information to understand how the 'delay' impacted a particular child's care, communication and interactions.

Parents echoed nurse suggestions by also identifying a need for better communication and accessibility to their child's ID information within the healthcare setting.

[...] I think there should be a clear page on the front of each file to say, just bullet points about the child and how to interact with them. So that anyone who picks up his file will know what he has and how to deal with him. (Mother)

It should be with the allergy chart [...] a big red thing that says 'how to talk to child!'. (Mother)

One mother described her frustration when she came to the hospital with her child due to a seizure and was then

asked to explain to health centre staff why her daughter wasn't talking.

[...] once I went in there, it was just after she had a seizure [...] I still had to explain to them all about her history and about why she's not talking and if that was something I needed to talk to somebody about. I just found it really frustrating because [...] I've already been dealing with it [...] I don't feel like I should have to explain all about her disorder every time I go in there. (Mother)

Parents believed that having detailed information about the impact of their child's ID in their medical file would help healthcare professionals understand how to 'interact' and 'talk' with their children. Similarly, nurses felt that this information was 'helpful' and provided them with an opportunity to 'prepare' and understand 'how to deal' with a particular child.

Nurses Question, Challenge and Provide Solutions for Information Sharing Practices

Many nurses discussed the importance of sharing and documenting ID information unique to each child. However, the process of sharing this information at the time of the study was problematic. For many nurses in the study, the institutional and medical practice of using general diagnoses for children with IDs and charting with minimal information created a difficult situation. For example, 'developmental or global delay' did not provide enough information and therefore nurses needed to search for more specific information about a particular child's condition. The lack of information also created a sense of devaluing a child's condition because it had not been legitimized through documentation. As a result of this reoccurring situation, many nurses found ways to work within the system by finding alternative ways to give and receive ID information about a child.

Nurses gave and received ID information through:

- ▶ Informal sharing of ID information
- ▶ Seeking ID information from parents
- ▶ Choosing to document ID information

Informal Sharing

Many nurses discussed the importance of sharing information amongst themselves not only to provide appropriate care for the children with IDs but also to help educate each other. They would 'ask' each other about a child's 'demeanor' and 'what has helped'. Most of the time, the nurses shared information through informal verbal communication amongst themselves and other healthcare professionals.

[...] a lot of the kids that we do see have been seen before. They're long term follow-up kids so [I] ask the other nurses, do you know this child? What's their demeanor? Are they combative or are they pretty good? Are they calm?' (Nurse)

We talk about it with day surgery nurses[...] they'll normally pass on the child's characteristics, what they've noticed already [...] and we in turn pass on how the child went to sleep to the recovery room nurse so they can know what to expect when he wakes up. (Nurse)

This appeared to be a 'normal', 'everyday' practice as well as a common moment of tension and therefore we further deconstructed the experience using discourse analysis. During our analysis it became apparent that the historical everyday practice of informally sharing information about child patients may have been informed by common practices associated with 'mainstream' children. For example, with 'mainstream' children nurses would probably not formally document whether a child was cranky, moody or angry. This type of information would likely be discussed informally during a report at shift change and would be associated with a child's personality and characteristics. While this may be an appropriate practice when working with a 'mainstream' child we suggest that the same practice may not be effective and may actually be oppressive to a child with IDs. When the same type of behaviour occurs in a child with IDs the reason for the behaviour may be very different than that of a 'mainstream child.' For example a child with IDs who is unable to verbally communicate their pain may instead experience outbursts or anger when in pain. Having this type of information documented in a child's medical file would allow healthcare staff to prepare for this and understand the meaning behind the behaviours. A child with IDs behaviour needs to be understood as more than just their 'demeanor' or 'characteristics' and instead understood to be a possible manifestation of their ID or way of communicating. The nurses in this study recognized that this information was a significant aspect of a child's ID and spoke about the importance of sharing this information

even if only informally. Because of the importance that nurses placed on this information, we suggest that further dialogue is needed to better understand why this information is important and how it impacts care.

Seeking ID Information from Parents

When information pertaining to a child's ID was not provided in the charts or from other nurses/ health care professionals most nurses described seeking and receiving information from the child's parents.

One of the first things I ask parents is generally how does your child communicate if they're non-verbal. Are there words or gestures that I need to know throughout the day if you're not in the room that are really important things to know and also are there things that I can be doing to help calm them down or soothe them [...] (Nurse)

The majority of mothers described a similar approach to healthcare professionals obtaining information about their child's ID and identified often being asked to explain their child's ID and its impact. While many mothers were very willing to *support* healthcare professionals in communicating and getting to know their child, some mothers identified aspects of this practice as '*frustrating*' and felt that all of the necessary information should '*be in the file*'.

[...] sometimes they'll just say 'briefly tell me about Jane and why you're here and what brought you here' [...] So then I'll have to go through the whole thing [...] I just feel like if we're at the IWK [...] it should all be in the file. (Mother)

But we're not the experts, we're the experts with him and knowing his needs most of the time but I think we come to the IWK for the experts. (Mother)

The initial statement described by the first mother of '*tell me about your child*' is likely a very common question to ask a parent whose child has come to the hospital. However, we saw through our interviews with mothers that this type of question may not always be appropriate when working with children with IDs. Children with IDs medical history is often very extensive and it can be exhausting and frustrating for parents to feel it is their responsibility to explain this history to the healthcare professionals caring for their children. Mothers valued healthcare professionals who were knowledgeable about their child's disability, needs and communication methods. This information allowed healthcare professionals to take the lead in a child's medical care and relieved the pressure on parents of children with IDs.

I felt like I was a doctor [...] I mean I wanted to be involved in the decision making but I wanted them to lead the way. (Mother)

Choosing to Document

Some nurse participants chose to challenge the dominant practice of not documenting ID information by choosing to document anyway. Nurses described tracking down additional information about a child's ID and also writing ID information on a child's Kardex. One nurse in particular described her frustration when working with a child without knowing that she had an ID.

All she was doing was scribbling and I said 'you can make a nice line across straight like that' and she's like nothing and she just didn't get this concept at all.[...] If I would have known ahead of time, I would have handled the situation differently [...] I would have asked the father how he's getting along, is she in a school program [...]

This nurse chose to challenge the dominant institutional practice of only documenting medical diagnoses by tracking down the information she felt she needed and sharing this information in the child's care plan.

[...] when I seen this report I'm thinking mother of god, this would be helpful information to have every time she comes in. We should know this. [...] I put a note on this care plan to read 'please read'. Instead of saying 'she's developmentally delayed' [say] 'please see psychological assessment' so you understand what that means for her. (Nurse)

The practice of choosing to document ID information can be seen as nurses challenging the dominant or mainstream approach to recording healthcare information. While many nurses described informally passing ID information amongst themselves, these nurses chose a different practice and instead ensured that this information was recorded and available for all healthcare professionals as well as themselves. This practice shows their understanding and belief that ID information should be formally passed and shared.

Conclusion

We can see through the identification of a desire to have ID information by both nurses and parents that the current institutional approach to sharing this information was not meeting the needs of those directly involved in a child's care. We suggest that the dominant healthcare discourse places value on certain types of information sharing practices and documentation. Medical information such as blood pressure, test results, allergies and disease identification was routinely documented within medical files; this information was highly valued in the dominant healthcare discourse. Other information pertaining to a child's ID such as the way they expressed themselves, how they communicated and what helped to comfort them was not routinely documented and was perceived to be supplemental information rather than pertinent.

The dominant practice of documenting, sharing and valuing a certain type of healthcare information further marginalizes children with IDs. By institutionally not requiring certain ID information to be shared in a formal and written way, a perception and belief might be created and perpetuated which suggests that this information is not as important as information that is documented.

We believe that formally sharing and passing ID information allows for easier access and shifts the institutional value system placing more value on ID information which will ensure that differences and needs are acknowledged and approached respectfully and appropriately.

FINDINGS

Reducing Stigma through Education and Knowledge

Children with IDs may express themselves, communicate, interact and socialize in ways that are different than the mainstream population. Higher levels of anxiety disorders have also been found in children with IDs (Nelson & Harwood, 2011; White et al., 2009) and IDs are often comorbid with other physical disabilities (Matson & Cervantes, 2013). Because of these complexities and differences, healthcare professionals should require unique education and training when working with this pediatric population. However, nurses in our study did not identify receiving any formalized education associated with IDs.

The dominant healthcare discourse focuses on education and training associated with a mainstream population. This statement was supported by nurses who discussed their understanding of educational priorities within the healthcare setting.

It might be that okay if you're going to learn about chemo and central lines today you're not going to have time to learn about autism spectrum disorder, right. (Nurse)

Not that it's not important but I think there's so many education topics people want that it's more the acute emergency stuff [...] (Nurse)

Because children with IDs have more frequent and longer hospital stays than mainstream children, it is increasingly important for healthcare professionals to have a foundational understanding of appropriate ways to work with children with IDs.

A Desire for Knowledge

Many nurses described a need and desire for more education and training regarding childhood IDs.

I think there does need to be some education at the undergraduate level [...] I think though that the hospital does need to [...] spend some time, whether it's in-services or just part of orientation that just has a session that talks about it. (Nurse)

It would have been really actually nice in the orientation to have something on children with autism because I have zero experience with it. (Nurse)

I think more education would be good [...] just some knowledge about what's different about them. (Nurse)

Mother's also supported the need for healthcare professionals to have more education pertaining to children with IDs.

[...] honestly I think it's really just having the training. Everyone has to learn [...] but if you're going to send someone in who's going to take background information for the doctor they need to be aware and they need to actually know the patient. (Mother)

This identification by both mothers and nurses further highlights and supports the need for additional education and training for healthcare professionals in this area.

Parent Reliance

Nurses who did not have knowledge regarding childhood IDs often relied on a child's parent to provide them with information about the child and to help them communicate and interact with them. This was a practice described by all nurses to varying extents.

[...] normally our kids and their parents are there and they're able to tell us what makes them comfortable, what makes them uncomfortable, what position they like to lay in, which they don't. (Nurse)

Down here it's really based on what the parents are kind of telling you and just kind of deferring a lot of the questions back to the parents. (Nurse)

Parental reliance within the pediatric hospital population is likely a very common practice given the age and abilities of the children being treated. However, several nurses described this reliance as being more significant on parents of children with IDs.

I always think those parents tend to stay in the unit at the bed side maybe more, take shorter rest periods than say the parents of the child who if they needed something could tell you clearly. (Nurse)

We are really reliant on them and if they're like 'well you know his vital signs might be fine but I'm telling you something's wrong' like I think they really need us to listen to that and I think they do get listened to more than say the kid who comes in and parents are like 'he's just off'. (Nurse)

Both nurses and parents suggested relying on parents to provide healthcare professionals with ID information may be *'too much'* or *'exhausting'*.

I just find it's just exhausting like because I've been so involved in her medical care. (Mother)

Maybe the parents would think that was nice too that we're not completely like 'so what do you think?' (Nurse)

While parents of all children might expect a certain level of reliance on them, increased reliance has been shown to be placed on parents of children with IDs in our study as well as others (Avis & Reardon, 2008; Brown and Guvenir, 2009; Scott et al., 2005). We suggest that this additional reliance could be minimized by educating and training healthcare professionals to work with, understand and care for children with IDs.

"Learn As You Go"

As a result of having minimal formal educational opportunities regarding childhood IDs nurse participants described a process of 'learning as you go'. This was done through personal and professional experience, other nurse interaction and informal learning opportunities

It's the children with multiple issues and co-morbidities that you see in house more often than not so it's been just you learn as you go. (Nurse)

One nurse described an informal learning opportunity that she and another colleague were introducing called 'tea talks' which provided a forum for nurses to discuss any topics they felt required some additional learning.

[...] we call them tea talks. At 2 in the afternoon it gets quiet, sit around the desk kind of throw in topics of interest and then make a schedule. We'll talk about this, we'll talk about that. (Nurse)

Another nurse identified going to a video series associated with autism that was offered by a local university.

It was a learning series [...] I have gone to quite a few of them. So I've watched quite a few autistic movies, movies with autistic kids in them, and then there's a panel afterwards [...] so that's how actually I've gotten a lot of information. (Nurse)

These nurses gave examples of how they challenged the healthcare discourse regarding what was institutionally considered to be priority education. They chose to create and attend to their own learning opportunities in order to obtain knowledge and information pertaining to childhood IDs. They learned from other healthcare professionals and through their personal experience how to best work with and care for children with IDs. The practice of nurses seeking out their own ID knowledge identifies their desire for more information in this area. These nurses wanted to better understand children with IDs and their needs.

The Impact of Minimal ID Education

Nurses within our research described discomfort amongst themselves and their colleagues when working with children with IDs. They believed this discomfort came from a lack of knowledge and training.

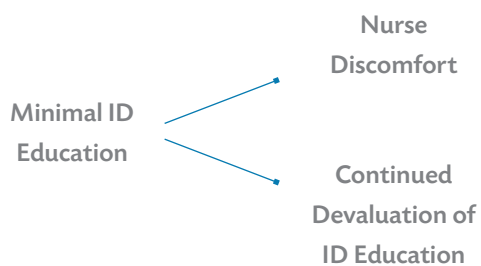
[...] the care that they get is still going to be exactly the same it's the care provider, just the comfort level would be so much better if we had some more education surrounding it. (Nurse)

All nurses in this study believed that they were competent when providing medical care, procedures and treatment to children but many worried that they might be missing something specific to children with IDs. Many believed that if they had more education they would be able to deliver care with more confidence and comfort, thereby improving the experience for nurses, children and parents. This common lack of comfort and skills while providing care for children with IDs suggests that ID education and training was not seen as a priority within the dominant healthcare discourse.

Conclusion

It is important to examine how mainstream healthcare training, professional development, education and teaching has been constructed and delivered. Because the predominant focus has been on mainstream pediatrics and ID education has not been included to the same extent, there is an appearance that ID education is less important. While this is more than likely not intentional it continues to perpetuate the social belief that education in this area is not as important or even necessary. This dichotomy between mainstream and ID education created tensions for the nurses and mothers in this study and ultimately led

to nurses and mothers recognizing that some of the needs of children with IDs continued to be marginalized as well as the educational needs of nurses.



Both nurses and mothers in our study were aware of the need for additional training and education regarding childhood IDs. The dominant discourse on institutional training and education did not include a focus on children with IDs. This exclusionary practice marginalizes individuals who are not able to 'fit' within the mainstream ways. ID training and education can allow healthcare professionals to feel confident and comfortable when working with children with IDs. In turn, the marginalization of children with IDs will be minimized and their healthcare needs can be more adequately met. Nurses in our study used their agency to find ways to work around, and challenge present practices.



Final Outcomes and Recommendations

The present study provided the researchers with a multi-level understanding of the healthcare experiences of children with IDs. By collecting stories from nurses, mothers of children with IDs and the children themselves we were able to identify both challenges and successes associated with the unique healthcare needs for children with IDs. We identified feelings of discomfort, uncertainty and fear from the nurses. As well as frustration associated with a lack of ID education and differences of opinion on whether to treat children with IDs the same or differently from other children. Nurses also described not having the time to develop the relationships they wanted with these children and a lack of documentation regarding the unique impact of an intellectual disability on each child.

We also highlighted feelings of uncertainty amongst mothers of children with IDs who were concerned that healthcare professionals would not know how to communicate with their child because they did not have enough knowledge or education about IDs. Mothers also felt there were too many expectations on them to be an expert on their child's care and too much pressure to tell their child's complex story to multiple healthcare professionals repeatedly with some mothers suggesting their child's story should be documented in the medical chart. Mothers were frustrated with access to services being reliant on specific diagnoses that would often change or shift throughout their child's care – this created barriers and complicated service access. They also noted that stereotypes and stigma did exist in the healthcare setting through unintentional fear, practices and misunderstandings.

However, in amongst these challenges we found numerous stories of nurses and mothers challenging dominant healthcare discourses. Both nurses and mothers spoke about overcoming obstacles and forming relationships and strong bonds. Nurses challenged the obstacles by creating their own learning opportunities, completing continuing education, documenting ID information and seeking out mentors. Through their everyday practices nurses gave examples of how they were able to overcome and question

stigmas associated with children with IDs. Mothers were also able to challenge the stigma by collaboratively suggesting ways that healthcare professionals can communicate with their children.

Overall the experiences for most participants were positive. Nurses wanted to feel confident when working with children with IDs and had a strong desire to know more about this population so that they could improve the healthcare experience for them. Mothers often felt supported and comforted by the healthcare professionals who worked with their children and the children themselves were able to overlook any negative or painful healthcare experiences and overwhelmingly told positive stories about things like receiving popsicles and visiting the gift shop. The children's stories and experiences were not about feeling judged or treated inappropriately but were rather about the excitement of getting a finger puppet after a needle or a treat after an x-ray.

Recommendations

- 1) Healthcare professionals need to understand how diagnoses impact access to care.
- 2) Children with IDs should be treated equitably (or fairly) not equally (the same as everyone else).
- 3) Healthcare professionals and parents should collaboratively work together to challenge and eliminate stigma towards children with IDs.
- 4) Healthcare professionals need to be able to recognize the invisible practices of stigma when working with children with IDs.
- 5) Building caring relationships should be given high priority and be just as important as physical care and tasks. This would provide a holistic healthcare experience.
- 6) Healthcare professionals should be supported in overcoming fears and misunderstandings associated with IDs.

- 7) Intellectually disabled children's mood, expression and communication style (both verbal and non-verbal) need to be formally documented in a child's medical chart. This will allow healthcare professionals to understand the child's needs, make visible the invisible, challenge the status quo and shift the meaning from supplemental to pertinent.
- 8) More education regarding IDs is needed in graduate and undergraduate programs as well as continuing education within the healthcare institution.
- 9) Sole responsibility should not be placed on the parent to educate healthcare professionals on their child's IDs and care. The term "expert" should be clearly understood and agreed upon by parents and healthcare professionals.
- 10) Parents need help navigating the system.

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