

Hospital Experiences of Children with Intellectual Disabilities: Child, Parent and Nurse Perspectives

STTI Conference
24th International Nursing Research Congress
Prague, Czech Republic
July 22 – 26 2013

Dr. Megan Aston
Emily MacLeod
Dr. Lynn Breau



Purpose

Explore hospital experiences from the perspective of children with ID, their parents and nurses who cared for them



Methodology

Feminist poststructuralism

- Relations of power
- Discourse analysis
- Question everyday, taken-for-granted practices
- Uncover invisible experiences of participants

Participants

Children (n=8)

- Self selected with parental approval
- At least one hospital experience in past 2 years
- ≤ 18 and mental age > 7
- Diagnoses such as autism, global developmental delay and non-verbal learning disorder

Parents (n=17)

- Self selected
- Child had at least one hospital experience in past 2 years
- Parent with child ≤ 18 and any mental age

Nurses (n=12)

- Self selected
- Provided care to at least one child with ID in the past 2 years

Data Collection & Analysis

- **Individual, semi structured interviews audio-taped and transcribed verbatim**
- **Discourse analysis**
 - Individual experiences of beliefs, values, practices
 - Language and meaning
 - Personal, social and institutional discourses
- **Identified common and unique experiences**

Findings

- **Labels: What's in a name?**
- **The Impact of ID on Relationship Establishment**
- **ID Information Sharing**
- **Reducing Stigma Through Education and Knowledge**



Labels: What's in a name?

The terms *diagnosis*, *label* and *stereotype* have been socially and institutionally constructed

Parents used the term 'label' when referring to ...

Diagnosis

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

Stereotype

*Certainly not **labeled**. In fact, quite the opposite... quite often when you come out of a meeting or whatever you feel like wow autism's really cool (Parent)*

Labels: What's in a name?

Diagnostic labels helped children access services

Having a diagnosis in terms of helping get appropriate teaching techniques in place and stuff was really important (Parent)

That's one sad thing about this whole, 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. (Parent)

Once we got the diagnosis then they'll start coming to your home but before that we were going to them and that was in (community) (Parent)

Labels: What's in a Name?

Diagnostic labels experienced negatively when assumptions were made about a child's quality of life

(Child) was diagnosed at 4 and half months with infantile spasms which lead to a diagnosis of (condition)... We were told at that time that (child) wouldn't know us, my husband or I, from anyone else. We were told he probably wouldn't live until his 1st birthday and we were told that the best thing would be just to walk away.
(Parent)

Diagnostic labels can lead to fear because of lack of understanding

There is that fear factor, you know, seeing, hearing about children that have intellectual disabilities, especially those with severe, more severely disabled kids.
(Nurse)

When you don't know kids with, 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 um I guess how to do or go about any of those things. (Parent)

Labeling: What's in a Name?

Labels sometimes carried stereotypes and stigma

- Children with ID are unable to communicate**

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

- Children with ID and their parents are difficult**

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

The Impact of ID on Relationship Establishment

Relationship building vs medical tasks

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. It might just be that it gets pushed back and you do it on a case by case basis.

(Nurse)

Challenges to relationship building

- Time
- Fear
- Communication

I think they're mostly afraid because ... they don't know how to communicate or what he may need (Parent)

The Impact of ID on Relationship Establishment

Positive relationships possible when nurses overcame challenges

I remember when he came he was very, very low functioning and non-verbal so as soon as I found out who his dad was I zoomed right in... and said 'what does your son like, can you just tell me. I know you're tired but just 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 cause he was really agitated and upset... dad said 'oh my god' because he loved it, loved it. (Nurse)

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

I talk to her about my life and then she measures me and she weighs me... she's awesome. (Child)

ID Information Sharing

Medical diagnosis is not enough

You might not recognize what the disease is but it's how it affects the child and what level their delay is. (Nurse)

Need more specific information

- Details of diagnosis
- Abilities
- Personal characteristics

Mainstream approach to charting healthcare information was problematic for children with ID

ID Information Sharing

Nurses challenged the way ID information was documented and shared by . . .

- Increased documentation
- Seeking out additional information
- Informal communication between nurses

...for her to communicate her pain it's mostly behavioural cues...So I get to actually see some over a period of several days. I get to see these behaviours and get to know the patient better... and also it gives me the opportunity to spend some time with the nurses to educate them on what these [behaviours] are. (Nurse)

Reducing Stigma Through Education and Knowledge

Nurses recognized their lack of knowledge and education about IDs

I think more education would be good.... just some knowledge about what's different about them. Not even just intellectually but how say blood work might be different or just the physical part but also how can we assist this family... (Nurse)

Parents recognized nurses lack of knowledge regarding IDs

Undergraduate and continuing education primarily focuses on mainstream children

Reducing Stigma Through Education and Knowledge

Nurses challenged mainstream approach to education

- Relied on parents

Involved in the decision making? Yes – too much so – but yes... 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. (Parent)

- Learn as they go

... no nothing formal... just things you've kind of learned over the years or whatever. (Nurse)

- Informal ID education

...we call them tea talks. Like at 2 in the afternoon it gets quiet, sit around the desk kind of throw in topics of interest ...we'll talk about this, we'll talk about that. (Nurse)

Research Conclusions

- **Experiences of labeling are complex**
 - Labels = services, supports and resources
 - Labels = stereotypes, judgments and stigma
- **Relationship development more difficult because of fear, stigma and lack of time**
- **Healthcare professionals need better access to information about a child's ID**
- **Increased education = reduction in stigma, labeling, stereotypes and fears**

Thank You!

Questions or Comments?



megan.aston@dal.ca

emily.macleod@iwk.nshealth.ca