

Dr. Bea Staley

Lecturer, Special Needs & Inclusive Education

Charles Darwin University

“It’s always an adventure”

**Parental experiences of disability
in the Darwin area**



“It’s always an adventure”

Parental experiences of disability in the Darwin area

- **PEOPLE: CHILDREN EMBEDDED IN FAMILIES..**
- **PLACE: FAMILIES EMBEDDED IN COMMUNITIES..**
- **POLICY: COMMUNITIES SHAPED BY NATIONAL POLICY..**

The study..

- Early Intervention (EI) services are an **educational priority** for Australian children with developmental delays and disabilities aged birth through six years of age.
- Given parents are the conduit between their child and clinical services being accessed, I wanted to understand the perspectives of parents, and the supports and constraints they experience in accessing and implementing EI services.
- This study is designed to broadly understand the way parents experience the EI system in Darwin (and around) - for many EI is the bridge between their worlds of medicine (early hospital) and education (preschool and Transition).
- This research is ultimately interested in the supports and hindrances families experience as they navigate these systems.

Aims and significance

- Through this research we seek to:
 - (i) Understand caregiver perspectives about their time in EI Services and the perceived benefits and inconveniences.
 - (ii) Give caregivers an opportunity to share and discuss the issues and challenges they have had to face in their interactions with EI systems
 - (iii) Identify themes that arise across caregiver narratives to inform the professions, and help clinicians/agencies to better tailor service provision to families.
- Most of the literature is about efficacy of service models (e.g. does it work?) not experiences of families.
- National Disability Insurance Scheme (NDIS) - Darwin starting July 2018.

Narrative Inquiry

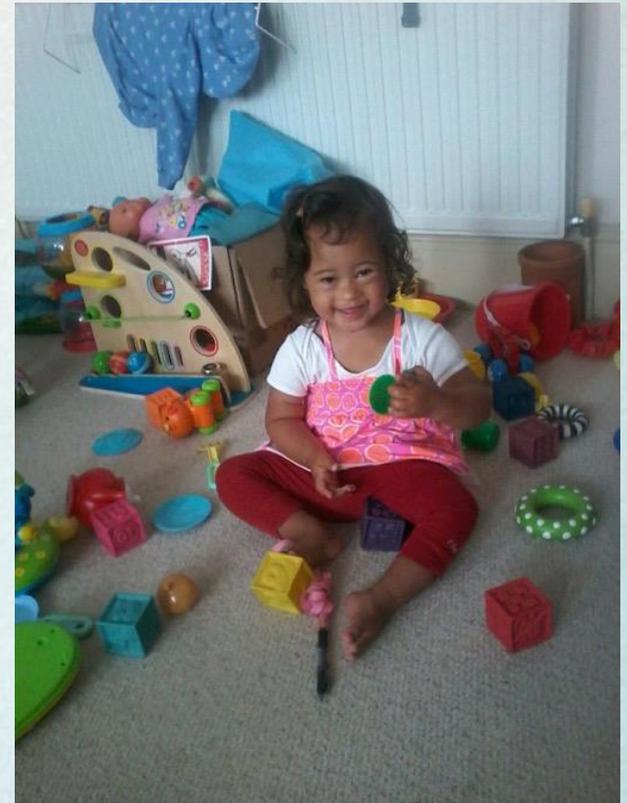
- Narrative inquiry is a methodological approach that involves the collection, description, and analysis of stories, or narratives, that people tell about themselves and about their lives or “stories lived and told” (Clandinin & Connelly, 2002, p. 20).
- Narrative inquiry is an entanglement between researcher and participants who are, simultaneously, living, making meaning, and collaborating—they are, in fact, living stories in spaces and places over time. The researcher enters and departs the research narrative whilst the living continues—changing, shifting, being interpreted, and being reinterpreted (Clandinin & Connelly, 2000).



Research Methods

- Using open ended/conversational interviews
 - (shortest interview 18 minutes, longest 90 minutes)

- Snowball sampling



Alice, with parental permission

People: The Families

26 families/interviews

- 1 interview with both parents
- 25 interviews with 1 parent
- 1 foster carer
- 3 fathers, 24 mothers
- 33 children/teens
- 7 families have 2 children with diagnoses
- 25 in Darwin/Palmerston, 1 in Alice Springs



<https://www.flickr.com/photos/katgrigg/>

**** plan is to interview 50 families**

People: The Families

Their children

- 33 children/teens
- 9 females & 24 males

Average: 5 years 11 months

Age range of children:

3 years – 13 years

Adjectives parents use:

Delightful, lovely, clever,
adorable, such a great kid,
cheeky, happy, very loved by his
family..



<https://www.flickr.com/photos/kamaljith/5135306732>

Diagnoses

	Sample	Australia
Autism Spectrum Disorders	24 (73%)	1:100
Cerebral Palsy	1 (3%)	1:500
Down Syndrome	3 (3%)	1:1100
Global Developmental Delay (or other) - Trauma? - Speech/language issues (ASD?)	3 (3%)	--
Prader Willi	1 (3%)	1:25,000
Cleft Palate ** recent ASD diagnosis	1 (3%)	1:50,000

** Wonder if moving forward I should actively recruit families with experiences not related to ASD

Notable themes: The news

... something is different (at birth)

“I’ve never even seen a child like Grace* in my country. When Grace just came out from my tummy, I see she’s different from all my kids.”

“She was diagnosed at nine weeks after having some issues at birth and having genetic testing... it’s sort of a bit of a rollercoaster I think...but yeah, I think when she first got diagnosed I was pretty devastated and had a lot of grief and loss and for babies, there’s so much there. I find that kind of gets re-triggered when she has different health issues.”



<https://www.flickr.com/photos/seattleye>

or.. the realisation

Noticing something is different

“ We knew something was not right... We knew that there were signs and things because they used to ask lots of questions; he doesn't look up and playing with hands and things, being systematic and at that time he would have lots of tantrums with his routine. We used to just do things and we didn't know about that, like what to do. I think that was a big challenge for us as well.”

Other people's concerns..

“nobody actually told me that this could be autism or it could be something else. They just said we'll keep an eye on him. The girl that initiated that assessment left the childcare and nobody really followed up on it. It wasn't until he was about three years old that they refused to move him out of the toddler's room and I said that's not really good, what's going on?”

The grief

Get that grief, put it in a box, crack on. Bury that shit deep, deep down.

A child psychologist actually in the early stages.. said to me... you know that someday you're going to have to do some grieving about this process and I said yep, that's fine, today is not that day...I have to get on with it. I don't have time to fall apart this week.

Notable themes: Assessment

“I always describe it as like a two-year process...”

“I knew it was an assessment, a development assessment but I felt it was very clinical and there wasn’t a lot of .. empathy ... I almost felt like it was, like I kind of had to justify why my child needed service. I had to put a case forward of why my disabled child needs help. I just felt like maybe that wasn’t my ideal experience coming into a new service.”

“No, it’s been a while going on but some of the places we’ve been to, they just forget to ring you back and get you to finish or all the people leave so then they forget to pass onto the next person who comes in so we’re going through someone else now.”

“That was horrible. It was really long-winded, I guess the hardest part for me was to take my child to somebody that didn’t know them and basically point out everything that’s wrong with him and have them sit there and judge him. That part I found really difficult. It was assessment after assessment after assessment.”

**** This is definitely an area that clinical providers can respond to in the future.**

Places: Services

- 22 of the children seen at Carpentaria Kids
- Most children have interacted with one or more service provider in Darwin including: psychologists, speech pathologists, occupational therapists.
- For example: OT for Kids in Palmerston came up frequently.

Notable themes: Services..

- Parents will take bad services over no services.
- Services are difficult to navigate.
- Very few people are sure about the assessment process.
- The route through assessment is often fraught, it can take families up to a year to get a diagnosis and it often comes at considerable cost.
- Parents wish there were more options and often aren't sure of their available options anyway.
- If your child has Autism there is an advisor to help families navigate services in Darwin.



<https://www.flickr.com/photos/jeremymiles/2793449565>

Notable themes: Services..

“I guess the never-ending appointments and non-stop, taking time off work. I’m lucky that I have a boss that’s very understanding in a job that I can work around and do stuff from home so that helped but it was just the never-ending appointments and keeping the files and all the paperwork to do with it...it just gets so relentless and you just want to throw your hands up at certain points but you’ve just got to take a deep breath and keep going and look at the bigger picture.”

“His interventions were just so helpful and they were so needed. They really, really had a very significant impact on our daily lives. That was amazing. We’ve definitely done the full spectrum. I felt from our first experience it’s been really positive.”

NDIS

The model suggests you have a range of services to pick from and that you know what the options are.

That doesn't seem to be true for many families in Darwin. In the Autism community

Families on the whole just aren't sure what to do about NDIS.

Places: Schools

- 12 mainstream public schools
- 2 Catholic schools
- 1 Special School

Schools..

- Despite starting this research in an Early Intervention Service, most of the families have children enrolled in schools and interact with the Northern Territory Department of Education in some way (e.g. Student Services)
- Teachers and administrators in schools make life much easier or much harder
- Many of these children are in special schools (27%) and their parents love these schools
- When children are in mainstream schools, parents worry most about friendships. They want their children to have friends (They want this badly).



Major Themes: Schooling

“We had two awful day care experiences prior to that so I went into the planning assessment ready to fight and advocate. I was ready for a battle and they were just wonderful. I didn’t have to fight for anything and I felt really listened to. Everything has just gone really smoothly”

“it’s such a relief because if school doesn’t work, nothing else works. If she is anxious about one thing, everything else is a lot harder so it’s really important that it went well and it has.”

“we’re lucky at [his school] they're wonderful. They know James* now, they can see he’s a bright boy and his teacher is just, she’s never allowed to leave, in fact we’re going to have to make sure she’s his teacher forever until year twelve, I don’t care if she’s only doing early childhood or lower primary. She’s going to have to pick up some skills on the way.”

What advice do you have for teachers?

“I think one of the more practical things would be just when you’re interacting with children, just to really come down on their level and speak quietly and use really clear as possible language. And keep it simple. That’d be one thing but I mean on a bigger level, it’s just seeing the child as a whole individual really and looking for their strengths as well as their challenges I guess.”

“I know they're busy ..sometimes if they could just give you a couple of minutes. Most of the teachers I’ve got are awesome with doing that but early on it felt like I was doing something wrong with his first teacher like I wasn’t able to control him and ...that I’d gone wrong somewhere and ..I would say to her what do I do?”

“I think as parents we need to realise that’s not the only student in the class but I think teachers need to realise that that’s our priority and we want to know...”

Being in the community

“Sometimes it’s a challenge because sometimes he’ll do unusual things. Yesterday we went for lunch outside and he left our table and he was just running around other tables.”

“Look, he’s not always enjoyable. It’s quite, very structured; I’ll take him to certain places I know how he’ll behave. I know how he’ll react. I can predict his behaviour. Some things we just do and we see what happens. Shopping is at a few places and he gets very excited but he’ll want to grab everything from the aisle or he’ll want to go to that certain toy and he’ll get one of those little bouncy things. I mean, I’m pretty structured and I try to just, you know, to make it easier for all of us.”

**** This is definitely an area that clinical providers can respond to in the future.**

Families need to connect with each other..

“Yeah, just being around other kids that are different but on the spectrum is really, really awesome. I’ve connected with one family and we do a lot together because of that but that’s been the major help I think.”

“The little playgroups were good. Even if James didn’t get anything out of it, I did, meeting other mums which I think is a huge part because you do feel quite alone, even though you know in theory there are other parents out there actually meeting them is a huge thing. You know, some of the mums I’m still in contact with.”

Including older students:

- We hear very little about teenager with disabilities and yet these parents can provide some useful insight into how life changes (and improves) when it is no longer about issues such as toilet training.
- Some of the stressors of having little ones appear to lessen (or perhaps they just change?).

Where to next?

- There is certainly data here that speaks to the necessity for community services to support families become advocates for their child.
- Some parents are already good at this, but all parents will have to advocate for their child's needs and services with NDIS

Summary

- This work reminds us about the human aspect of having a child with special needs. The stresses but also the joys.
- We hear the strategies some schools use to make families feel welcome.
- We also hear about the unkind things educators say and do and how much hurt that causes.



Contact:

Dr. Bea Staley

Bea.staley@cdu.edu.au