Outcomes for Families of a FASD Diagnostic Service

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AIMS

- Qualitative approach to evaluate the FASD assessment process for families of children assessed using the Australian Guide to the Diagnosis of FASD
- Aimed to identify how families experienced the FASD diagnostic process, and to provide insight into the ongoing difficulties for families following diagnosis
- Capacity for the family to engage in a post-diagnosis management plan also investigated

Diagnostic Process

- Children referred to CDS by GP if concerns regarding behaviour or development.
- PAE investigated/assessed as part of the FASD assessment process.
- The CDS MDT conducted FASD assessment over three phases:
  - (1) conducting the assessment;
  - (2) diagnosis:;
  - (3) follow-up.

Team Member	WK 1	WK 2	WK 3	WK 4
Clinic Magement	Arrange next client	Contact previous client regarding follow-up	Confirm appointments	Arrange feedback session
Paediatrician	Measurement of Sentinel Features	-	Formulation and draft report	Final report and provide feedback to the client
Social Worker	Initial intake interview; assess prenatal alcohol exposure	Provide support if needed	Formulation and draft report	Final report and provide feedback to the client
Psychologist	Assessments and observations	Further assessment and report drafting	Formulation and draft report	Final report and provide feedback to the client
Speech Pathologist	-		Formulation and draft report	Final report
Occupational Therapist	-	Assessments	Formulation and draft report	Final report
Physiotherapist	-	Assessments	Formulation and draft report	Final report
All: Case Discussion	Patient Summary	Discuss results from assessments	Develop case formulation	Discuss upcoming clients

Design

- Phenomenological approach
- Qualitatively assessed families' lived experience of engaging with a FASD diagnostic service, and the outcomes associated.
- Utilised a convenience sample
- Retrospective demographic data was gathered from medical charts
- Phone interviews were conducted with caregivers
- Qualitative information was transcribed

Materials

- Semi-structured phone interviews - approximately 15 to 30 minutes in length
- Phone interviews were conducted and audio-recorded
- Interviews were then transcribed verbatim: all identifying information removed

Procedure

- Ethics was obtained from QLD Health and USC HREC's
- Thematic analysis was conducted using Braun & Clarke's (2006) 6 step model
    1. Data familiarisation
    2. Initial code generation
    3. Theme searching
    4. Reviewing themes
    5. Defining and naming themes
    6. Producing the report.

Participants

- Participants were recruited from the patient sample of children who attended the Sunshine Coast CDS for an assessment of FASD.
- Inclusion criteria for the chart review was that participants were assessed in the clinic from January 2016 to December 2017.
- A total of 37 children were referred for assessment; 17 received no FASD diagnosis
- 20 with a FASD diagnosis were contacted to be included
- 13 families consented
- 7 caregivers completed the phone interview
- Small sample although adequate for phenomenological study (Creswell, 1998; Morse, 1994).

Participants

Caregivers

- Aged from 23 to 65 (M = 40.0; SD = 17.13)
- Either employed, semi-retired, or a fulltime carer
- Interviewee
  - 42.9% (3) biological mother
  - 14.3% (1) biological father
  - 14.3% (1) maternal grandmother
  - 28.6% (2) paternal grandmother
- Ethnicity
  - 14.3% (1) identified as Aboriginal
  - 71.4% (5) identified as Caucasian
  - 28.6% (2) unknown ethnicity
- Legal Guardianship
  - 85.7% (6) had legal guardianship of the child
  - 14.3% (1) under guardianship of Department of Child Safety

Children

- 85.7% (6) were male
- Ages ranged 4 to14 (M = 8.4; SD = 3.87).
- All children received a FASD diagnosis except for one who received an at risk of FASD diagnosis
- Facial Features
  - 14.3% (1) showed no facial features of FASD
  - 28.6% (2) showed one
  - 42.9% (3) showed two
  - 14.3% (1) showed all three
- Sever neurodevelopmental impairment ranged from 3-6: 5 children (71.4%) had 4 domains
- 85.7% (6) received a co-morbid diagnosis of ADHD (combined type)
- Additional co-morbid diagnoses:
  - Intellectual Disability
  - Specific Learning Disorder (Numeracy)
  - Speech language Disorder
  - Speech Sound Disorder

Results

1. Receiving a FASD Diagnosis had a Positive Impact	2. Caregivers' Evaluation of Assessment Process	3. Positive Support Services Relative to FASD	4. Ongoing Difficulties Regardless of Diagnosis	5. Need for Societal Knowledge of FASD
School feedback session created understanding of child's needs.	Positive experience with CDS staff.	Helpful supports accessed or implemented.	Barriers accessing supports and unhelpful recommendations.	Lack of caregiver prior knowledge of FASD.
Caregivers' positive regard for child and aspirations for child's future.	Receipt of diagnosis as positive.	Support for caregivers seen as positive.	Difficulties with mainstream schooling.	Lack of societal knowledge and recognition of FASD.
Acknowledgement of child's capability.	Need for delivery of recommend supports to be clearer and accessible.	Family support seen as positive.	Behavioural and social difficulties.	Feelings of apprehension about the child's future.

Results

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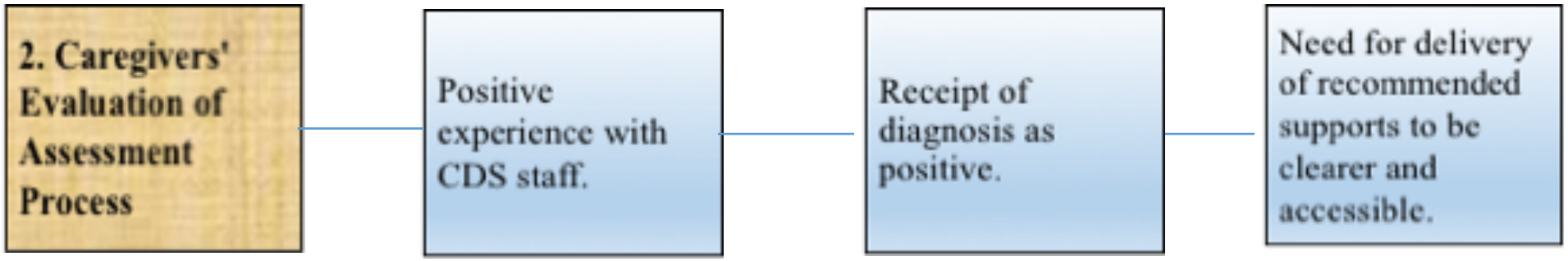
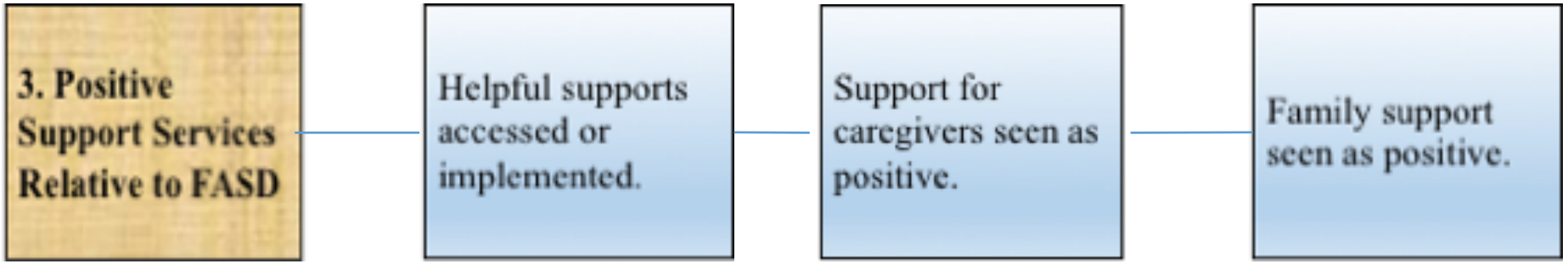


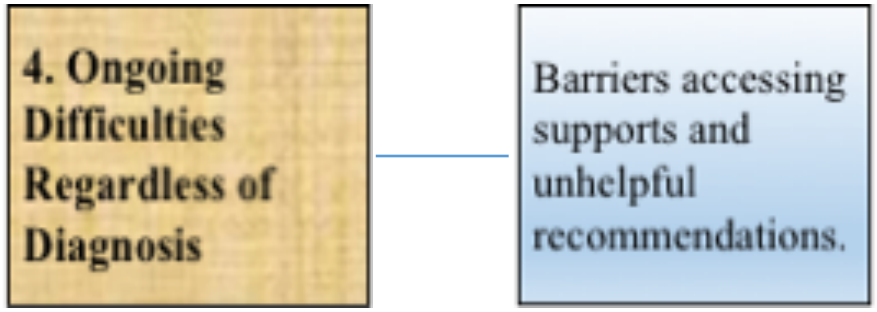
- "I did not feel judged at all. By any of the team because, you tell them the truth about your children and when you do, that's the last thing you wanted… to feel horrible about it" (P012)
- "Hearing about the diagnosis ... made me ... make sense of everything ... In his eyes nothing's different .... But, for us, we can put a name to what's going on" (P015).
- "Not really. They [CDS staff] probably did point it out at the meeting ... it's a lot of info to take in though" (P006).

Results



- "He gets a lot of frustration out in that boxing. The lady who takes him boxing says, "Has he had a bad day?" She says, "Oh, he's punching very hard today." .... we're sort of gauging emotions even in his boxing". (P011)
- "I've already been in groups back when [the child] was about four, a women's health centre... it's somewhere that [I can go] if I do need to go" (P012).
- "Yeah, I think ... I don't look for it [support] as much as I should. I think probably because we do have that support [through family]" (P012).
- "We share [the caring load] ... My husband shows him building things and they do things in the shed" (P006)

Results



- “They [the recommendations] weren’t ever an option ... being, a young family ... [the child] and my husband have disabilities. So, I'm a full-time carer ... being a low- income family, we didn't have that [the recommendations] as an option. (P001)”
- “We’ve got many forms here that .... They go through them, of course, but, yeah [it’s a lot to take in] ...” (P006).

Future Directions

- **Improvement to communication of post-diagnostic recommendations**
- **Establishment and promotion of social/family supports**
- **Overcoming barriers to support through service provider networks**

Thank you