An Evaluation of the Barriers to Health and Social Care for “Hard to Reach” Groups enrolled in an Integrated Care Initiative in Sydney, Australia

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Introduction: Vulnerable Families

• Social disadvantage – Impaired ability to access resources and participate in economic and social aspects of society
• Complex and enduring needs
• May suffer trans-generational disadvantage and psychological trauma
• Can become invisible to health and social services and policy makers
• Particularly vulnerable to fragmented care
Background: Healthy Homes and Neighbourhoods Integrated Care Program

• Long term care coordination for vulnerable families with complex health and social care needs, who are disconnected from key services and require multi-agency support to have these needs met.

• Aims to keep clients and their families safe, and connected to society.

• District wide (Central/Inner West Sydney) with foci in two identified “hotspots” of disadvantage.
Aims / Objectives

• Realist evaluation of HHAN Program
• “What works for whom and why?”
• Analysis of the contexts, mechanisms, interventions and outcomes underlying the program
• Barriers to health and social care examined as part of contextual exploration
Methods

• Semi-structured interviews: 12 HHAN Care Coordination clients, 21 professionals

• Clients: “Can you tell me a little bit about your situation and why you think you were referred to HHAN Care Coordination?”, “Have you found it easy to get the help you need?”

• Professionals “Do you think that vulnerable clients are able to access the care they need?” “What do you think are the barriers optimal to health and social care?”

• As research progressed, more targeted questions based on previous responses.
Participant Characteristics

- **Clients**: all female caregivers, 3/12 grandmothers, 9/12 birth parents.
- Caring for children aged newborn to teenagers.

- **Professionals**: Variety of backgrounds, mainly social workers/healthcare workers.
  - 4/21 HHAN, 4/21 local health district or general practice, 4/21 NSW Department of Family and Community Services (Housing and Child Protection), 2/21 NSW Education services, 5/21 partner NGOs.
### Characteristics of Clients Interviewed

<table>
<thead>
<tr>
<th>Medical/Social Comorbidity Experienced by Family</th>
<th>Number of clients affected (N = 12)</th>
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<tbody>
<tr>
<td>Mental health issues (including postnatal depression, significant grief or psychological trauma)</td>
<td>11/12</td>
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<td>Migration/Visa issues</td>
<td>2/12</td>
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<td>Domestic violence</td>
<td>5/12</td>
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<td>Significant relationship difficulties</td>
<td>11/12</td>
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<tr>
<td>Financial stress</td>
<td>7/12</td>
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<tr>
<td>Single</td>
<td>5/12</td>
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<tr>
<td>Substance misuse</td>
<td>3/12</td>
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<tr>
<td>Single parenting</td>
<td>5/12</td>
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<td>Involvement of child protection services</td>
<td>6/12</td>
</tr>
<tr>
<td>Child with behavioural or mental health difficulties</td>
<td>4/12</td>
</tr>
<tr>
<td>Significant physical health difficulties in caregiver</td>
<td>7/12</td>
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<tr>
<td>Problems with security or standard of housing</td>
<td>5/12</td>
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Results

Intrinsic Factors

Extrinsic Factors

Barriers to Health and Social Care
Results: Intrinsic Factors

- History of trauma/depression (often intergenerational)
- Competing priorities
- Distrust of services/professionals
- Concerns about confidentiality and disclosure

“So a lot of our clients, especially if there’s domestic violence, which is 45% of our clients… So while she’ll be focusing on the little one’s health needs, her health needs are nowhere to be seen” – Social Worker

“..If I had to go to someone. (not that I would have a problem with going to someone like), but I just sit there and it’s like more of an effort when I’m feeling down…I’m like I can’t do it” – Client

“We had a lot of issues with…children who need dental care and, you know, some of the families, their priority; it is to help their child but they can’t actually get them to the Dental Hospital, even though it’s close, but that’s because themselves, they’re having a really hard time and they need support… some of them need hand-holding and confidence is a huge problem; like we see parents when they first come here, they’re quite withdrawn and hollow and it’s like an institution…” – Preschool teacher

“...And I guess it also takes time, you can’t just expect people to trust you overnight, and trust you with everything…” – Client
Results: Accessibility/Economic

“...these little things like paediatrician and it’s not little but seriously $280 for a consultation..... So all the GP does is refer you – I don’t know if she’s the only GP that does it or someone else but they’re all specialists and they just cost my shopping like one weeks shopping every time.” – Client

“I’ve had the experience of ringing (for a service) and being asked what side of the street they are on, the number and you just go, yeah... this is not ok.” – Social Worker

“(some providers) are not comfortable with (vulnerable patients) because they actually take a lot of time and they are not really very lucrative patients even though they are coming back and they’re bulk billing and often they don’t turn up you know any times....Do they really use these appointments for patients which we don’t get paid for?” – Doctor

“..A young mother, had a six month old baby, she had depression, anxiety and suffered from domestic violence....because she had to look after her baby, she couldn’t actually go to the psychiatrist herself...is there any service that can help her to look after her baby so she can actually work on her issues?” – Case Worker

<table>
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<th>Economic Barriers</th>
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<td>Lack of Medicare incentives</td>
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<td>Perceived or real costs for services – Clients not referred to bulk-billing providers</td>
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<td>Indirect costs to attend services – Childcare, transport costs</td>
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## Results: Misalignment of Service Provision with Client Needs

<table>
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<tr>
<th>Misalignment of Service Provision with Client Needs</th>
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<tr>
<td>Assumptions about needs, rather than consultation</td>
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<td>Care plans not realistic given client’s social circumstances</td>
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<td>Frequent turnover of case workers/healthcare staff → Unstable service relationships</td>
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### Client

“..That’s the main thing, instead of just assuming what people need, actually ask them what they’re after and people end up getting a lot further in actually helping someone and in the right way” – Client

### Clinical Nurse Consultant

“..Sometimes you see the discharge summary, with a follow-up appointment at 9am… you know the carer’s been up with them all night and that appointment is just not going to happen” – Clinical Nurse Consultant

### GP

“One of my patients who’s really difficult was doing great when he had a case worker…. Four months later he just DNAs again, I can’t get hold of him and it’s because the case worker changed… I would have loved them to call me and let me know…then the patient ends up in Concord and then it can take six months to recover from those sort of setbacks” – GP
Results: Communication Issues

“..XX (An NGO) just recently changed everything…they won’t take referrals by fax...they don’t take it by phone. You have to do an online form and it’s not… doesn’t even integrate with our software and we’re told that sending things electronically is not safe. It can be very frustrating.” – Doctor

“As GPs, there’s a lack of understanding what services are out there and what they will do.” – GP

“This patient told me ‘I am seeing M and they’re helping me sort that out’...I kept asking “who is M and where are they from?’. But the patient wasn’t sure” – Case worker

Clients misunderstanding services of different service providers

Technological barriers hindering communication e.g. incompatible electronic referral systems
Discussion

- Despite evident need, data suggest that inequities between advantaged and disadvantaged children and families in Australia are increasing.
- Studies from OECD countries (including Australia) demonstrate that the least advantaged members of society are less likely to access specialist care.
- Vulnerable clients are often characterised as “hard to reach” – Implies fault rests with the families themselves.
- However, this study highlights the endemic issues within health and social care systems that act as barriers to care.
- Our findings align with those reported in previous studies, although this study presented a unique client perspective within our health district.
Conclusion / Lessons Learned

- Families with complex needs face multiple barriers to care.
- The findings of this study present opportunities at both individual provider and system levels to enhance engagement.
- In particular, this study’s findings highlight the necessity for integrated care initiatives, which encourage reorientation to address social determinants of health and create enabling systems for integration/communication between professionals.
Limitations

• Study was based in one Local Health District and findings may not be applicable to other settings.
• The most vulnerable society members may still have been missed; further exploration of their views could enhance our understanding.
Future Research

• Ongoing research from our group to determine “what works for whom and why?” so that correct interventions can be implemented in appropriate situations.

• Ongoing consultation with community members to ensure that solutions are appropriate.
References

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