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

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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.

FAMILY DISADVANTAGE
Number of times the SA1 was located in a hotspot for an indicator of disadvantage
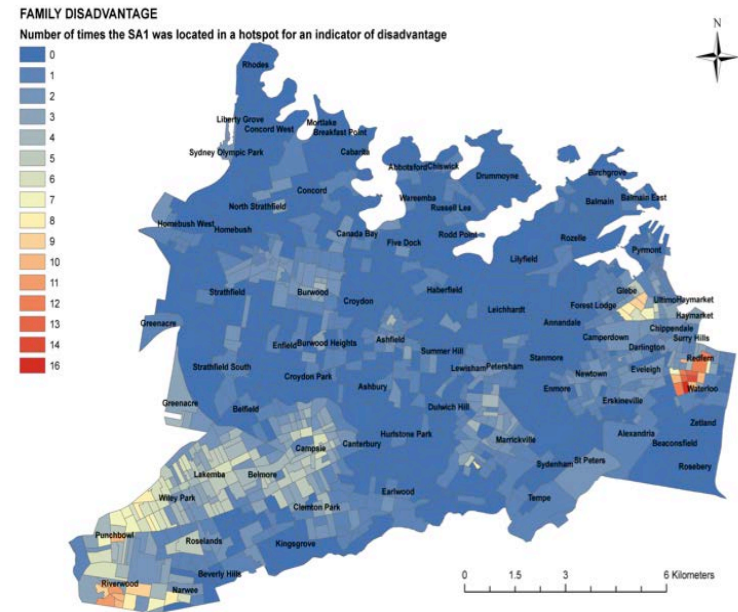
Aims / Objectives

- 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

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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.

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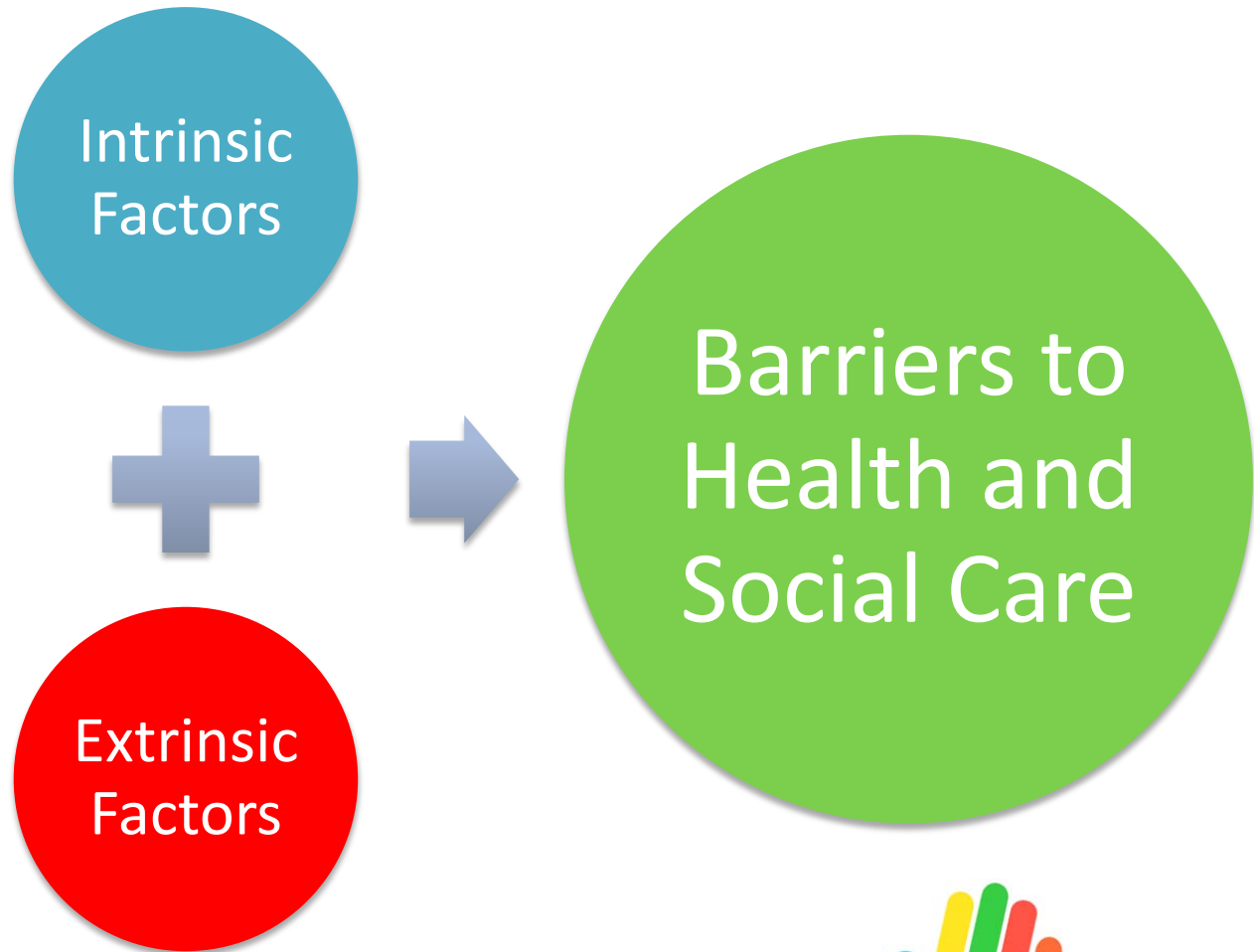and neighbourhoods

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.

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Characteristics of Clients Interviewed

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

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Results

Intrinsic Factors

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Extrinsic Factors

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Barriers to Health and Social Care

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Results: Intrinsic Factors

"..If I had to go to someone, (not that I

"So a lot of our clients, especially if there's domestic violence (which is

""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

- Competing priorities
- Distrust of services/professionals
- Concerns about confidentiality and disclo

"…And I guess it also takes time, you can't just expect people to trust you overnight, and trust you with everything…" – Client

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Results: Accessibility/Economic

...mic Barriers

...providers) are not comfortable with (vulnerable patients) ...ey actually take a lot of time and they are not really very ...ive patients even though they are coming back and ...ey're bulk billing and often they don't turn up you know ...ny times....Do they really use these appointments for ...atients which we don't get paid for? " – Doctor
...ck of Medicare incentive...
Perceived or real costs for services – Clients not referred to bulk-billing providers
Indirect costs to attend services – Childcare, transport costs

"... 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 ... just wonder are ...go, ...k." –

...train line and there's sort of a bus which doesn't come very often..." – Client

"..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

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Results: Misalignment of Service Provision with Client Needs

Misalignment of Service Provision with Client Needs

Assumptions about needs, rather than consultation

Care plans not realistic given client's social circumstances

Frequent turnover of case workers/healthcare staff →Unstable relationships

"..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

"..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

"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

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Results: Communication Issues

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

"..XX (An NGO) just re[...] take referrals by fax...they [...] do an online form and it's not… [...] even integrate with our software and we're told that sending th[...]gs electronically is not safe. It can be very frustrating." – Doctor

Clients misunde[...] es of different service providers

Technological barriers [...] eding communication e.g. incompatible electronic referral systems

"..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

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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.

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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.

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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.

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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.

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