

Service provider perspectives on supporting people with intellectual and developmental disability from Iraqi and Syrian refugee backgrounds

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Syrian and Iraqi refugees

- ❖ 15 million Syrians and Iraqis fled war
- ❖ Since 2006, 25,000 settled in south western Sydney
- ❖ 2012 Australia streamlined health waiver
- ❖ Refugees with disability eligible to come to Australia
- ❖ 2015 Australia accepted 12,000 Syrian and Iraqi humanitarian entrants



Refugees from Syria and Iraq have experienced....

- ❖ War and violence
- ❖ Poverty and dislocation
- ❖ Trauma
- ❖ Likely to experience high rates of cognitive, mental, physical and sensory disability.

Refugees with disability face specific barriers to service access

- ❖ Lack of assessment and support in country of origin
- ❖ Stigma and discrimination
- ❖ Reduced capacity for community and social support in settlement country
- ❖ Poor health literacy and 'disability' literacy

What is known about refugees with disability coming to Australia?

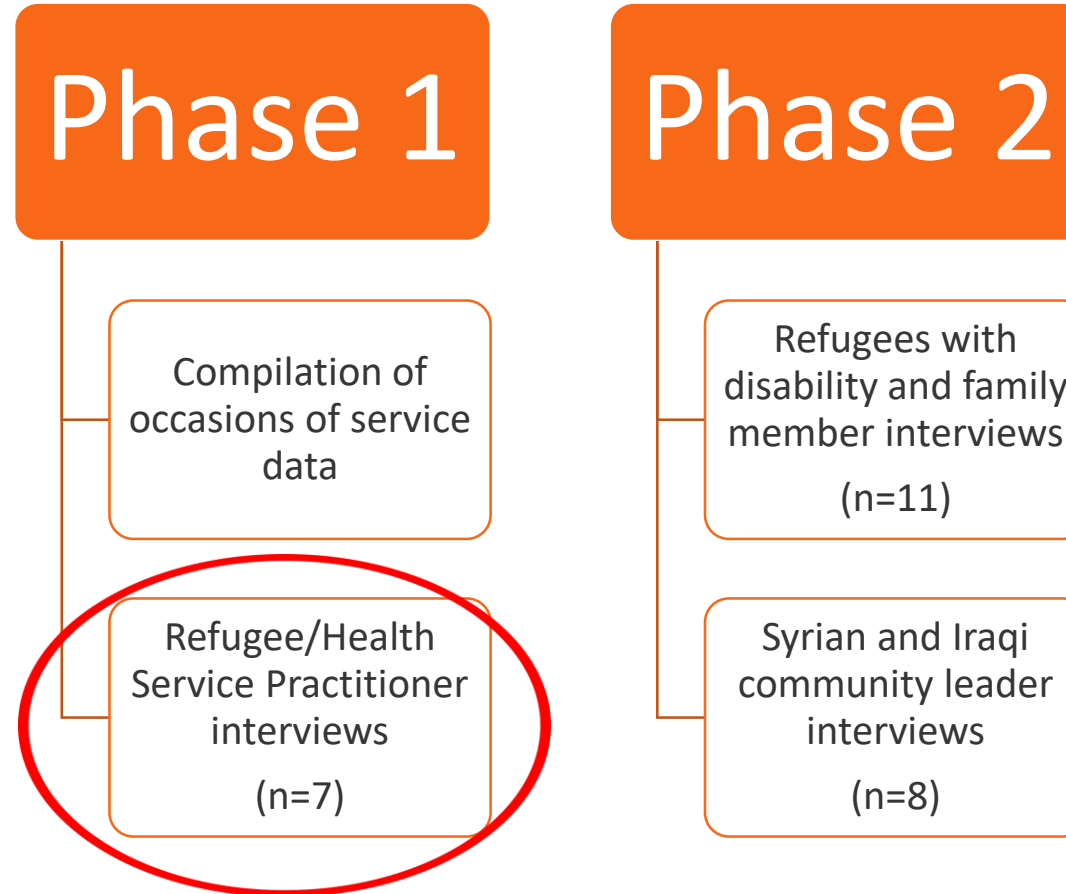
- ❖ Limited knowledge about numbers
- ❖ Limited understanding of people's circumstances
- ❖ **What does this mean for refugees with disability and for service providers?**

Disability in South Western Sydney: Experiences of the Iraqi and Syrian refugee communities

- ❖ Collaborative research project South Western Sydney
- ❖ Academics and service providers with
- ❖ Expertise in refugee, disability & mental health fields
- ❖ Small study funded over 12 months (2018-2019)



Study Design



Phase 1: Practitioner Interview Participants

7 practitioners from

4 refugee and health agencies

Employed as: social workers, nurses, counsellors, early childhood workers, occupational therapists, paediatricians

Interviews conducted and analysed by UNSW academic team members



What disability-related issues do practitioners see?

“The whole gamut: intellectual, cerebral palsy, genetic defects, birth defects due to protracted and difficult labours, meningitis leading to brain damage, traumatic injuries from war casualties, traumatic brain injuries, psychosocial disability. Not that many people arriving with severe chronic mental illness (e.g., schizophrenia) because they just don't make it here.”



A practitioner relayed this account.....

“I recently worked with a young man in his early 30s with cerebral palsy, very severe physical impairments. His elderly mother put him in a wheelbarrow and wheeled him from Iraq to Syria. He was all curled up and so contracted that his fingernails were dug into the palms of his hands and he hadn't had his teeth brushed for 30 years because he had such a bad gag reflex, his mother was afraid she would drown him.”



“People are survivors, they are resilient”

Themes

Organisations' response to disability

Cultural understanding of disability

Experiences of NDIS



Theme 1: Organisations' response to disability

- ❖ Pre-arrival information and responses
- ❖ Establishment of disability-specific supports and services
- ❖ Overcoming language barriers
- ❖ Resettlement issues
- ❖ Gaps in service provision
- ❖ Referrals and networks

Establishment of disability-specific supports, Overcoming language barriers and Resettlement issues

Due to the increase of people with disabilities, in last two years, [service] has set up a disability support team - three nurses and the social worker. This is in recognition of the increased numbers and complexity of people with disability from refugee background.

Some [service] nurses are language proficient or they work with qualified health care interpreters. The bilingual community educators do community-based education and health orientation when refugees arrive.

Getting people in intense resettlement phase so only so much they can take on board. We think about immediate needs in the first 12 months and focus on what the family can handle at any one time.

Theme 2: Cultural understanding of disability

- ❖ Gender issues
- ❖ Attitudes to disability
- ❖ Family and community
- ❖ Seeking viewpoint of the person with disability

Gender Issues and Attitudes to disability

We usually try to match those on 'women at risk' visas with a female nurse because they have often been subjected to violence. But [for other women] it is a fantastic opportunity to demonstrate to families that things are different in Australia and there are male nurses.

Generally, people don't have an understanding of disability – haven't had it explained to them. People are looking for a cure and expect Australia may be able to provide this - medical services very good, first world country, going to school will 'cure' intellectual disability. Understanding of disability in general is a big learning step.

There are lots of myths and misconceptions around disability for example told the other day by a mother "baby was normal until doctor came to the village and put a needle into the child's spine" so equating a spinal tap for meningitis with causing the disability.

Another practitioner's account.....

“Boy with cerebral palsy and intellectual disability. It took some time to establish a diagnosis. Family really struggled with NDIS. Disability Support team made appointments, but family did not show up. Social Worker needed to take family to appointments. Parents hadn't come to terms with child's disability as permanent...it took a few sessions to explain to the family the nature of the disability. Lots of health education.”



Theme 3: Experience of NDIS

- ❖ Access to NDIS information
- ❖ Eligibility to NDIS - access costs and constraints
- ❖ Need for case management
- ❖ NDIS planning

Access to NDIS information, Eligibility to NDIS and Need for case management

Social worker had to re-visit because the plan was all in English. Local Area Coordinator gave family the plan and a list of services in a spreadsheet from the website which included services throughout NSW and was in English! Lots of families get things in the mail and don't know what it is about.

Many refugees with intellectual disability have never had a diagnosis, psychometric or OT assessment, and that is the language of functionality that the NDIS needs

People need a consistent case manager who is overseeing case planning and progression. The NDIS model is missing someone to work with the family to make a case plan re where to next. These families definitely are not armed with the knowledge to do this. Families don't know what to ask for.

Implications for service provision

This study has important implications for understanding the ways in which organisations support the complex physical and mental health and social needs of people with intellectual and developmental disability from Iraqi and Syrian refugee backgrounds.

Research partners



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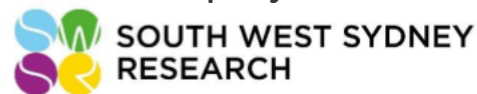
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