

The experience of disability in refugees

by Angela Dew

The Life-History research I have been conducting uses an interviewing method, that records autobiographical history from an ordinary person's perspective. Most of my research is qualitative, participatory-action research, with co-designed and art-space methods, it aims to improve people's lives.

I have focused on people with complex support needs facing many intersecting barriers due to disability, refugee background, geographic location etc. The research involved in-depth interviews with two Syrian men with disability, and two mothers of sons with disability, one from Syria and the other from Iraq.

I wanted to explore their refugee journeys and trace their experiences living with or caring for somebody with disability in their countries of origin, transit countries (their countries of first asylum), and then resettled in Australia. I employed a Syrian-born woman, also with a disability, to conduct the interviews in Arabic, to be transcribed and translated into English.

Each person participated in three, two-hour interviews, covering their lives in reverse chronological order. In the first interview they spoke about what life was like in

Australia, in the second about leaving their country of origin and spending time in transit, and in the third about growing up in their country of origin and the outbreak of war. This was done deliberately to build rapport with participants as the interviews progressed because we knew the discussions about living in their country through war would be emotional, as they proved to be.

To inform and analyse the interviews, I use G. Benezer and R. Zetter's 2015 refugee journey framing. I use narrative and thematic analysis methods, enabling me to look at the data in different ways. I reflect on that in this presentation.

Names have been changed for this presentation. Daoud a middle-aged man whose chronic health condition resulted in disability. Grigis is also middle-aged, deaf and has a brain injury from an accident as a child. The two mothers of sons with disability: Hana was from Syria and she was the mother of Tariq who was in his late twenties and had an intellectual disability. And Amira, from Iraq, is the mother of Rami, a teenager with congenital physical impairments.

Four themes were developed to explain the life-course experience of these participants. The first encapsulated participants' experiences growing up with disability in Syria

and Iraq. (There were three sub-themes: limited access to services early in their lives; being included within their communities as children and young adults; and exclusion and discrimination within the broader community.)

The second theme related to their experiences of being at war and seeking refuge in a transit country. Also spoke about not being employed in Australia despite each working in Syria and the transit country. The mothers spoke about some of the difficulties they experienced as a carer in a new country, as well as the positive aspects.

The fourth theme was about how people felt, their sense of belonging and inclusion within the Australian society.

I've drawn on four conceptual theories. The first is the Life Course theory, first proposed by American sociologist Glenn Elder. The second, perhaps more familiar, is the Ecological Theory, developed by educationalist Uri Bronfenbrenner about 40 years ago. The third is the Social Capital Theory, and the fourth is Benezer and Zetter's Journey Framing Theory. These theoretical frameworks offer complementary viewpoints to understand the experiences of people with disability from refugee backgrounds.

Professor Elder developed the Life Course Theory in the 1970s to describe how living through the Great Depression of the 1930s and World War II influenced the lives of a generation. Elder proposed five intersecting principles, the first being life span development. Elder said the experiences people have throughout their life affect their development as individuals and their subsequent life experiences. We are all products of where and how we live.

The second principle is historical time. It demonstrates how global, national, subsequent and individual events have an impact on individuals. His focus seemed to be on people who had lived through the 1930s and the 1940s, but his work is really timeless.

The third principle is about social time and place. Elder wrote that where and when you are born, and when and where you live, have an impact on your experiences.

The fourth principle is about linked lives. People who are important in a person's life also have an impact on what happens to him or her, reflecting interrelationships.

The fifth principle is human agency, that is, people make choices. Even though we are a product of where we are born, the time we're born and the relationships we have, we still can make choices and changes and alter what happens in our lives.

Understanding how these interrelated factors influence a person's life allows us to explore and explain individual life experiences in the larger context of history, place, time and relationships.

This Life Course approach provides a holistic

understanding of lives over time and in changing social contexts. I found this useful in framing the journeys people with disability have made as refugees.

Bronfenbrenner's Ecological Theory—seeking to explain the effects of an individual's microsystem, mesosystem, exosystem and macrosystem on child development—has been used a lot more broadly than in health, disability, education etc. I find this useful in describing and interrogating the intersection of individuals and their broader social influences. The theory explains the interaction between the micro (individual level), the meso level (which connects the individual to the services and systems structures with which they have direct contact) and the exo, the broader social system in which the individual may not be directly engaged but is still influenced by it. The macro system comprises the outermost level of influence, and includes cultural values, customs laws and regulations. The theory describes a series of nested, interdependence systems.

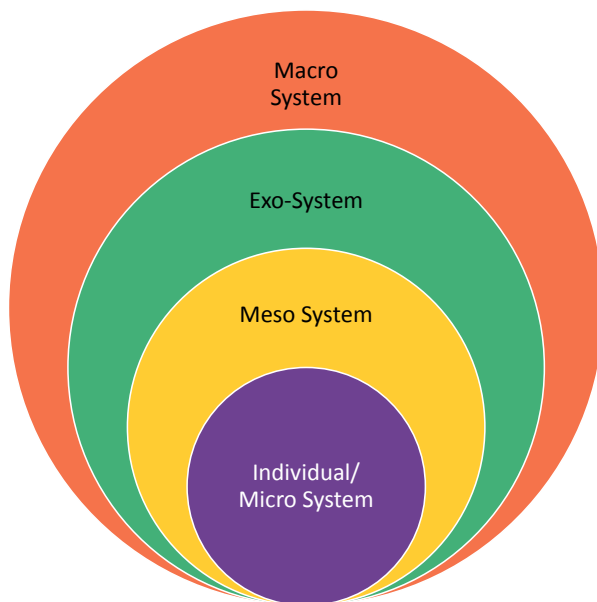
American sociologist Nan Lin describes the social capital theory as the social connections and relationships that are critical for individuals, social groups, organisations and communities to achieve goals. There are three types: bonding, bridging, and linking. Bonding networks are non-hierarchical and involve well-known and trusted members who provide direct assistance to an individual. Bridging networks reflect the connections made with a broader network, to which an individual is typically connected by members of the bonding network. Given the relationship with the referring network member, there is still a degree of trust and familiarity within a bridging network. Linking networks on the other hand, are described as hierarchical, involving connections with people and structures outside the person's known and trusted contacts.

The Benezer and Zetter Journey Framing Theory proposition is that exile and forced migration are a process and a journey involving the why and how of life changing experiences. It identifies four conceptual challenges in understanding the refugee journeys, the characteristics of what they call the "Wayfarers". These are individual and group demographic characteristics, temporal characteristics, covering when they consider their journey to have started and ended. Often those journeys start long before people leave the home country and go on for much longer after arriving and getting settled in a new country.

Drivers and destinations are about the reasons and motivations for the journey. What really makes people to leave their country of origin? There are wide-ranging issues concerning the process and content of the journey. What, for example, happened during a person's refugee journey? All of these influences are compounded.

In my Life History research with people with disability

Bronfenbrenner's Ecological Theory



A series of nested and interdependent systems



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and family members from refugee backgrounds, I brought these four theories together to help me gain a deeper understanding of the impact of the refugee journey on individuals' lives. The accompanying figure depicts elements of the four theories within a representation of Bronfenbrenner's Ecological Model to situate the individual with a disability, their family and friends in that central micro level within the meso services and network level, the broader Exo system level and the Macro geopolitical environment level.

If we look at that innermost purple circle, this figure incorporates what Benezer and Zetter described as the characteristics of the Wayfarers, such as intersections of age and gender, disability, country of origin, relationship status, religious affiliation, minority status etc. This inner circle also corresponds with what Elder describes as linked lives, highlighting the interdependency of family relationships with families, friends and colleagues in the course of a life.

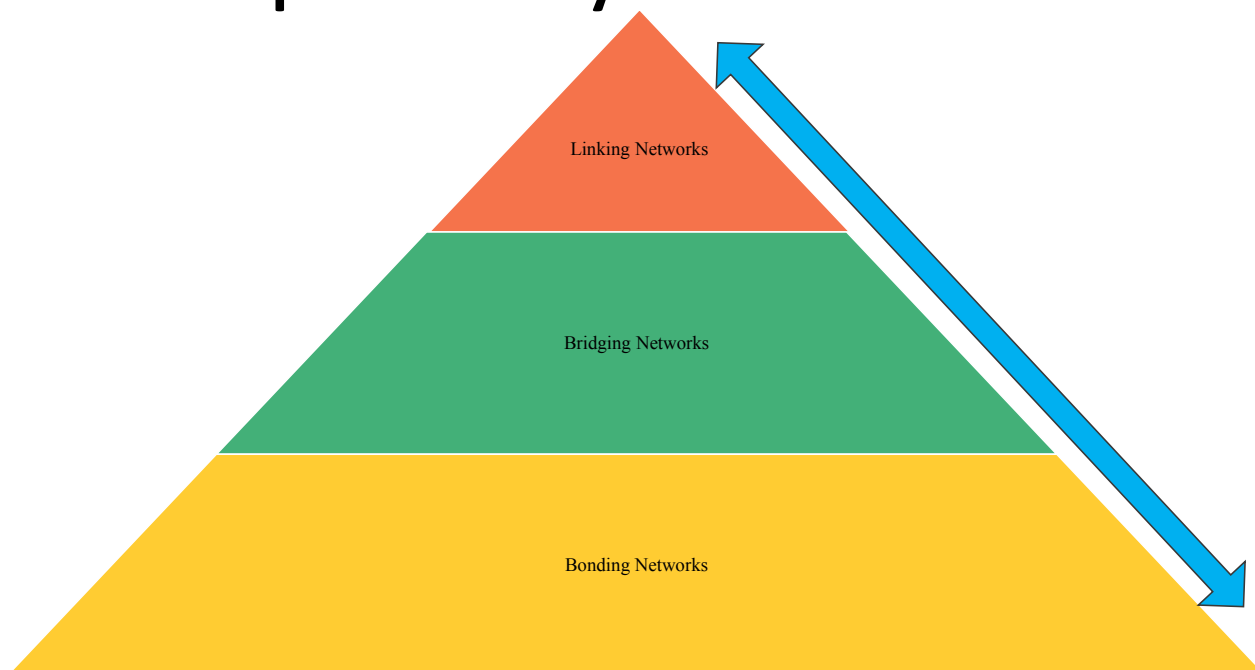
Human agency at the micro level represents the choices people make. We might think that people who are refugees don't have a lot of choice in what happens to them. In fact, this Life History research shows people are constantly

making choices about whether they leave, when they leave, who goes with them, who they leave behind, what they leave behind. Agency is a big part of that journey. The next, the yellow layer of the Ecological Model, the meso level depicts the connection between those in the inner circle and the broader services and networks with which an individual and their inner circle interact via bridging networks, potentially gaining access through a person's micro level contacts. Many of the people who come to Australia, and certainly the people who I interviewed, had relatives already living in Australia, who provided them with important links to other networks.

The third, green circle represents the exo or broader system, with which an individual might not feel they interact directly, but which nonetheless has an impact on their life. And that would be things like the education, employment, the disability sectors etc. And the fourth, orange outer circle represents the macro level or geopolitical environment. Obviously for people who have come as refugees, the journey has been very much informed by what happened at the geopolitical level. Each of these layers can be referred to the life history interviews.

The four theories highlight the interdependent nature

Social Capital Theory



of people's lives, the network of shared relationships that is fundamental to survival and thriving, especially through times of war and relocation. Elder referred to this as the principle of linked lives. Bronfenbrenner situated individual and family connections at that central micro ecological level and it was foundational to all the other levels. Relationships are integral to bonding and bridging networks in the development of social capital. Benezet and Zetter described the Wayfarers interrelationships as central to understanding the refugee journey.

Take the example of Tariq, in his late 20s, with an intellectual disability. Mother Hana is his main carer in the family, which also comprises his father and two brothers.

Tariq has depended on this family and Hannah in particular to take care of him throughout his life. Looking after Tariq, as well as ensuring his brothers had educational and work opportunities, was a driving force in the family leaving Syria and coming to Australia. In Syria, Hannah reported that Tariq had strong connections with their neighbours and extended family, who looked out for him and included him in activities. Such connections, part of bonding networks, are indicative of the ways in which people's lives are linked, as described by Elder. At the meso

level, bridging social capital networks are important, as they ensure the individual knows about and has access to services and support beyond their immediate connections. This is particularly important when a person with disability and their family come from a refugee background to settle in a new country, in doing so losing their understanding of and connections to people and services in their country of origin.

The whole family, all those in that inner circle, may be starting from scratch in developing new networks in a new country and may rely on a broader circle of extended family and acquaintances living in Australia to introduce them to new services, supports and networks – this again reflects Elder's principle of linked lives. Before Hana and Tariq came to Australia about eight years ago, Tariq had lived a pretty sheltered life with just his family in support. Hannah and Tariq by chance met a woman who spoke Arabic and, learning that Tariq had no paid support here, helped Hannah to register him for the NDIS. Tariq now receives speech pathology, is learning to use an iPad to communicate and has someone who takes him out into the community, which has given Hannah a break. This illustrates the benefits of developing new and broader networks, providing

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additional knowledge of and access to services.

The exo level relates to the broader systems within which the individual and their meso connections operate. At this level the connection could be to a funding body providing financial support for a service provider used by an individual. In this example, the way a funding body's guidelines account for the intersections of age, cultural background, language, gender, religion etc, can have a huge impact on the quality of support then provided to the individual. Here, linking networks can be influential, for example, in advocacy for equitable service delivery and funding models. Given the importance for people with disability and family members from refugee backgrounds to connect to services, this level also aligns with Benezet and Zetter's process and content elements of the refugee journey.

The examples from the life history research: the attempts by Daoud and Grigis to get employment. Both men had working lives in Syria, then had employment in their countries of first asylum before coming to Australia. In Australia, both had struggled to find work –sufficient work and work they wanted to do. Through contacts of relatives in Australia, Grigis got part-time manual work.

But as he gets older, he's finding this hard, made harder still by the combination of his deafness and brain injury, his lack of Auslan (Australian sign language) and his refugee background. He has connected with the deaf community in Australia and members of his faith and these links have provided him with broader community contacts.

Macro level involves national and global human rights, disability, refugee and settlement policy, among them the 1948 Universal Declaration on Human Rights, the 2006 United Nations Convention on the Rights of Persons with Disabilities and the 1951 Convention relating to the Status of Refugees and the 1967 Protocol. Such instruments – while seemingly having no direct impact on the lives of people with disability and family members from refugee backgrounds –are actually foundational in ensuring people seeking asylum, including those with disability, are treated fairly and humanely. They provide a fundamental underpinning of the refugee journey, drivers and destinations, in part assuring people seeking asylum there is an internationally recognised and agreed process that is responsive to their personal journeys. We all know it's not perfect, but there is a system in place. This level also aligns with Elder's time-and-place principle of historical events having an undoubted impact on the lives of individuals.

Amira and teen son Rami furnish another example. Instability in Iraq 16 years ago meant Rami likely did not receive the best care for his congenital impairments. The family did not receive support to manage Rami's physical and psychological needs. The war scattered Amira's parents and siblings all over the world, removing support that she had received from her mother and sister in particular. The war had a global effect but also a profound, long-lasting impact on Amira and Rami's lives.

In conclusion, applying these four theoretical frameworks to the experiences of people with disability from refugee backgrounds provides a conceptual understanding of the impact of those experiences on their journeys. Life history interviews reveal that on the long and complex refugee journey, people with disability and their family members experience ongoing marginalisation and discrimination, exacerbated by war. There is no doubt that people from refugee backgrounds with disability require specialised support and services in their resettlement country.

Further, we need to conduct more research to fully understand people's experiences and how best to support them in their refugee journey. This body of research, now spanning more than seven years, is one of the first in the world to explore the challenges and benefits experienced by this group in their journeys and settlement in Australia. R