

Sammendrag av doktorgradsavhandling

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Everyday geographies of disability, care and forced migration in the South-East of England

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This doctoral thesis explores everyday experiences of disabled asylum seekers and refugees and family carers (kin and non-kin carers) with disability and care. The thesis draws on perspectives on disability and care. Studies on everyday experiences of disability amongst asylum seekers and refugees are rare and little is known about the experiences of those who provide them with informal support, such as family and friends. The literature suggests that legal status and limited entitlements to support result in social exclusion and poverty for disabled asylum seekers and refugees (Roberts and Harris 2002). Poor support contexts impact on family carers as they then take on significant caring responsibilities. Research on family carers of black and ethnic minority background suggests they face multiple barriers to formal support (Trotter 2012). Few studies have explored experiences of families of asylum seeking and refugee background.

Qualitative semi-structured interviews were conducted in three urban areas with 15 adult asylum seekers and refugees with diverse impairments and legal permits (8 females and 7 males aged 25 to 84), 13 family carers (kin and non-kin carers, 7 females and 6 males aged 13 to 78) and 17 professionals (4 males and 13 females, 11 from statutory and 6 from third sector social care and health services). Interviews were audio-recorded, transcribed, coded and analysed thematically.

The thesis includes an introduction, two chapters on theoretical perspectives, one chapter on research methodology, three findings chapters and a final chapter with a summary and discussion. The first findings chapter, chapter 5, discusses personal and social experiences of disabled asylum seekers and refugees with disability and chronic illness, describing a range of personal and social experiences. Becoming disabled and coming to terms with it often occurred during a period characterised by multiple losses and difficult social conditions for participants, during migration and including structural barriers related to their immigration status. These experiences influenced how participants embodied their experiences as disabled people on an emotional, physical and social level. Their experiences demonstrate that legal status, including migration and settlement experiences, intersect with age, gender, ethnicity and other social identities, alongside impairment and chronic illness to shape their personal and social experiences. These intersections result in multiple forms of social exclusion and immobility, but also facilitate opportunities for peer support, belonging and social participation. Disabled asylum seekers and refugees drew on a range of place-specific resources and networks, including family and community networks.

Chapter 6 discusses family carers' and disabled asylum seekers' and refugees' experiences of providing and receiving care. Informal caring practices were shaped by an intersection of circumstances such as disability and chronic illness, disruptions in family forms and household structures, gendered and generational norms of care, cultural expectations and shared memberships and identities in communities, and legal status and entitlements. Disruptions caused by disability and chronic illness, mi-

gration and settlement and lack of entitlements caused shifts in family roles at which time partners, children and young people in households or non-kin members in communities took on significant caring responsibilities. Family carers provide support through a diverse range of high level care activities. They were disposed to care based on empathy, socio-cultural, gendered and intergenerational values of care and caring relationships were characterised by reciprocity. Caring affected family carers emotionally, physically and socially. Young people's education, peer relationships and transitions to adulthood was affected. Their identities and emotional wellbeing were also affected by social stigma surrounding their parents' impairment, poverty and legal status. However young people were resilient in their aspirations and hopes for higher education and well paid jobs.

Chapter 7 explores disabled asylum seekers and refugees' and family carers' experiences of formal support, drawing also on experiences of professionals. Limited support resulted in poverty and refugee and ethnic organisations were a key source of support. Restrictive legal environment constrains professionals in statutory social care who experienced ethical tensions when unable to meet needs of clients. Third sector professionals commented on a lack of family approaches in statutory social care and statutory professionals reported difficulties applying family approaches, because of legal constrains. They also commented on the "hidden nature" of carers in communities, which made it difficult for them to identify carers. Third sector professionals observed their organisations struggling to meet a rising number of asylum seekers and refugees with complex needs. Statutory and third sector professionals reported that working arrangements between them were rived with tensions, yet identified effective partnerships as being key in their efforts to influence support outcomes for clients.

The findings are an important contribution to knowledge, policy and practice, indicating the need to recognise disability amongst asylum seekers and refugees as a personal and social experience and to engage with needs of family carers. The research raises profound questions about the potential and limitations of current policies, provision, and practice as a means of social protection and support in fulfilling the human rights of disabled asylum seekers and refugees and their families.

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