



Disabled asylum seekers and refugees and access to social care in South-East England



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Abstract

Little is known about everyday experiences of asylum seekers and refugees with disability and social care (Harris, 2003). This paper discusses experiences of disabled asylum seekers and refugees and their access to social care. Qualitative semi-structured interviews were conducted with 15 adult asylum seekers and refugees with diverse impairments who had lived in the UK between 1 to 12 years (8 females and 7 males aged 25 to 84), 13 kin and non-kin carers (7 females and 6 males aged 13 to 78) and 17 professionals working in social care (4 males and 13 females, 11 from statutory and 6 from third sector services). The findings revealed that disabled asylum seekers and refugees experienced social exclusion and lack of access to social care related to their impairment, legal status and rights to support. They, however, resisted exclusion by drawing on a range of alternative resources in their families and communities. Their experiences provide insight into 'lived experiences' of disability and access to social care and suggest a need for a human rights approach in policy and services.

Keywords: asylum seekers, refugees, disability, social care.

Útdráttur

Þekking sem snýr að reynslu fatlaðs flóttafólks af félagsþjónustu er af skornum skammti (Harris, 2003). Í þessari grein er fjallað um reynslu fatlaðs flóttafólks af aðgengi að félagsþjónustu. Eigindleg hálfstöðluð viðtöl voru tekin við 15 hælisleitendur og flóttamenn með ýmsar skerðingar sem höfðu búið í Bretlandi í 1 til 12 ár (7 karla og 8 konur á aldrinum 25 til 84 ára), 13 ættingja og vini sem veittu þeim stuðning (6 karla og 7 konur á aldrinum 13 til 78 ára) og 17 fagaðila í félagsþjónustu (4 karla og 13 konur, 11 frá sveitarfélögum og 6 frá félagasamtökum). Rannsóknarniðurstöður benda til að fatlað flóttafólk upplifi félagslega útskúfun og erfitt aðgengi að félagsþjónustu og að þetta tengist skerðingum þeirra, lagalegri stöðu og réttindum. Flóttafólk brást við erfiðu aðgengi með því að nýta sér ýms óformleg úrræði í nærsamfélagi sínu. Reynsla þeirra varpar ljósi á „lifaða reynslu“ af fötlun og reynslu af aðgengi að félagsþjónustu. Niðurstöðurnar undirstrika ríka þörf fyrir að mannréttindasjónarmið séu höfð í forgrunni löggjafar og réttindareglna sem snúa að flóttafólki.

Lykilorð: hælisleitendur, flóttafólk, fötlun, félagsþjónusta.

Introduction

Research on disabled asylum seekers and refugees and their experiences with disability and access to social care is limited. Disability in this group is overwhelmingly understood as primarily a medical issue and as the outcome of migration (Pisani & Grech, 2015). The limited available literature which engages with social experiences of disability highlights multiple barriers to support, including legal status and limited entitlements, cultural values of disability, family traditions of care and inadequate professional and institutional approaches in targeting disabled asylum seekers for support (Harris, 2003; Harris & Roberts, 2004; Ward, Amas & Lagnado, 2008). There is a gap in the literature regarding 'everyday experiences' of disabled asylum seekers and refugees; how people negotiate their needs for support and the kind of resources they may draw on when facing barriers to support. In this paper I use the term 'disabled asylum seekers and refugees' to refer to asylum seekers and refugees with limited entitlements to support and who have diverse impairments and chronic illnesses that, in interaction with attitudinal and environmental barriers, hinder their full and effective participation in society on an equal basis with others (UNHCR, 2014). I use the term 'carers' to refer to kin and non-kin individuals who are in supportive relationships with disabled asylum seekers and refugees, providing them with significant support in activities of daily living (ADL) and/or instrumental activities of daily living (IADL). In this article I discuss PhD research findings on experiences of asylum seekers and refugees with impairment and care in the South East of England (Ottósdóttir, 2015). I begin by giving an overview of knowledge pertaining to disability, asylum and social care. I then discuss the research aim and methods,



followed by a discussion of key findings and, finally, I reflect on their contributions to academic knowledge and policy.

Understanding disability and asylum

Historically, disabled people have been understood from a medical model, a model which defines impairments as abnormalities and a clinical condition of body or mind of individuals (Gleeson, 1999; Oliver, 1990). The medical model views disabled people as incapable of participating in social life on an equal basis with 'normal' people, assuming that social problems faced by them are best resolved by medical interventions (Oliver, 1990). The 1970s Disability Rights Movement resisted such views, raising concerns over the lack of opportunities disabled people experienced in their lives. The movement highlighted the effects of the medical model on policy and services to disabled people, contributing to their poverty, dependence and social exclusion and called for a social perspective on disability, emphasising the role of societal structures and negative attitudes in the lives of disabled people (Oliver, 1990). The social model focuses on changing society in order to facilitate the inclusion and participation of disabled people and has had great impact on enhancing equal opportunities and rights of disabled people, particularly in the global north (Priestley, 2003). Among scholars there is a growing recognition of the need to engage with diverse personal experiences of disabled people, such as in the global south, where the majority of disabled people live and are denied the recognition of being 'disabled' because their rights and needs for medical support are not recognised (Meekosha & Soldatic, 2011). Disability continues to be debated and contested among scholars.

The UN and WHO endorse a combination of the medical and the social model, viewing disability as an outcome of physical and social influences and address disability as a human rights issue, recognising personal rights and the choices of disabled people, including people in displacement processes (WHO, 2015; UNHCR, 2014). The UN 'Convention on the Rights of Persons with Disabilities' requires member states to protect and promote equality and the capabilities of 'persons with disabilities' and to respond to their 'special needs' for social protection and participation (UNHCR, 2014). Still when it comes to migrants, disability policies usually exclude them and immigration policies also lag behind by excluding disabled people (El-Lahib & Wehbi, 2012).

In the global south the incidence of poverty amongst disabled people is high (Groce, Kembhavi, Wirz, Lang, & Trani, 2011) and studies claim a cyclical relationship between disability and poverty (Pisani & Grech, 2015). The majority of asylum seekers and refugees in the global north come from the global south. Disabled people are likely to be among them but no official statistics are currently available about their numbers. The literature on disabled asylum seekers understands disability as threefold: As the outcome of birth, poverty and/or of traumatic migration and settlement experiences (Mirza, 2014). The literature also highlights a complex nature of disability among asylum seekers who often have multiple impairments and intertwined social and medical needs (Rechel, Mladovsky, Ingleby, Mackenbach, & McKee, 2013; Ryan, Kelly, & Kelly, 2009).

Literature in social work in the UK has explored the social impact of poverty and lack of rights to support on disabled asylum seekers. Disabled asylum seekers hold limited rights to social and health care and are unable to access the same level of care support as other disabled citizens and this may increase their negative experiences of disability, poverty and access to social care (Harris, 2003). The literature highlights multiple barriers to social support, where legal status and limited rights intersect with cultural, social and economic barriers. In some communities, disability and certain illnesses carry social stigma and families may not be accustomed to public provided care and rely on family traditions of care (Chambra, Ahmad, Hirst, Lawton & Beresford, 1999; Trotter, 2012). When these barriers are combined with poverty and limited rights to formal support, disabled asylum seekers face great challenges in accessing support, usually resulting in their social isolation and difficulty for social care professionals to target their needs (Humphries, 2004; Robinson, 2014).

In the UK, asylum seekers and refugees who hold limited entitlements are not entitled to specialised health and social care unless they fulfil criteria of having 'disability' and 'care needs'. Care assessments involving asylum seekers are particularly complex because of raised thresholds by local authorities and because their medical and social needs are so interwoven (Ottósdóttir & Evans, 2014). Access to social care for these groups tends to be strictly based on the medical model of disability and they are deprived of any reference to their social rights and agency as disabled people (Newbigging et al., 2010).



Methods

The research was conducted in 2011–2012 and examined experiences of disabled asylum seekers and refugees and their kin and non-kin carers of disability and care. Qualitative semi-structured interviews were conducted with 15 adult asylum seekers and refugees with diverse impairments and national backgrounds who had lived in the UK between 1 to 12 years (8 females and 7 males aged 25 to 84), with diverse statuses as asylum seekers or refugees with limited entitlements attached to their permits, 13 kin and non-kin carers (7 females and 6 males aged 13 to 78) and 17 professionals in social care (4 males and 13 females, 11 from statutory (4 were social workers) and 6 from third sector services). The research aim called for diversity of backgrounds and participants were recruited by purposive sampling method. Considering the research criteria and the social vulnerability of participants, refugee and ethnic organisations were used as gatekeepers to help recruit participants (Padgett, 2008). English was spoken in all interviews except five where interpreters were used. Interviews were audio-recorded, transcribed, coded and analysed thematically. Summaries of each interview were written to assist in reading across the data. Pseudonyms are used throughout this paper.

Findings

Experiences of disability and access to social care

Interviews with disabled asylum seekers and refugees revealed diverse circumstances in which impairments had emerged as well as personal and social experiences of living with disability and accessing social care. The majority identified with having several impairments, often including mental health, physical and/or sensory impairments. A large portion of participants spoke of pre-migration circumstances and/or difficult journeys to the UK, where they had become injured. The majority credited their mental health impairments to distress, including poverty and lack of entitlements experienced during migration and settlement.

Disabled asylum seekers and refugees identified having complications associated with their impairments which affected them physically, emotionally and socially. The majority of them described the process of becoming impaired as emotionally difficult, because they experienced it as a form of multiple losses, t.i. loss of health, identity, social status and loss of place and belonging. Becoming impaired had often occurred within the context of multiple losses over the migration

process, whereby people had lost their homes, relatives, income and social status.

Social meanings given to impairments in communities influenced how people felt about their status as ‘disabled’ as people feared rejection from relatives and communities and the impact their impairment would have on their lives and the lives of their relatives. The stigma of disability was internalised in some people’s perceptions of themselves, which in turn had a negative effect on their identities as men, women, parents etc. because of the association made between those identities and being healthy and able-bodied. Sabeen, an older woman and asylum seeker from Iraq with low income described that before her impairment she had enjoyed a high socioeconomic status. Following her impairment and settlement in the UK she had “lost herself” and claimed she “didn’t feel happy anymore”. She explained:

Before the stroke happened I was very concentrated and everything and I could live very easily, but after that everything changed, for my memory is gone and for me as a person! I am gone.

Impairments were found by disabled asylum seekers and refugees and their kin carers to have significant impact on their families, and how other people in their communities perceived them and treated them and their families consequently. Impairment when combined with limited access to social care, poverty and stigma of disability served to isolate them and their relatives from communities and needed support. Stigma also hindered them from disclosing to relatives back home about their impairment, unemployment or lack of support. They were however resilient in the face of difficult personal and social experiences. Parenting roles were a source of resilience in the face of lack of entitlements, poverty and uncertain legal status. This was described by Lana, a disabled mother from Somalia, who explained that “you manage differently with your impairment when you have children”. Disabled asylum seekers and refugees also referred to their aspirations of a better life in the UK as helping them to stay resilient during difficult legal experiences, such as when awaiting decisions on asylum claims or renewing refugee permits.

Disabled asylum seekers and refugees described experiencing great moral anxiety over being poor and unable to provide financially, such as sending remittances, and those in parenting roles of being unable to



guarantee when their children could be reunited with their family. Thus, transnational family interactions were significantly restrained by the legal context of disabled asylum seekers and refugees (Madziva & Zontini, 2012). Impairments also had implications for intimate relationships, with disabled asylum seekers and refugees experiencing moral anxiety, because of social and cultural norms and seeing their bodies as ‘unhealthy’, unfit and ‘abnormal’ and as obstacles to performing intimate relationships (Loja, Costa, Hughes & Menezes, 2012; Shakespeare, Gillespie-Sells & Davis, 1996).

Many of them had experienced negative social interactions within their ethnic community. Lana, a disabled woman from Somalia, described how in the UK she felt socially excluded from her ethnic community, because she was unable to eat with her right hand due to her amputation resulting from an attack during war in her home country. Eating with the left hand was considered a taboo in her community and regarded as unclean. For Lana, interacting with her ethnic community had become a significant source of emotional pain:

Me and my daughter are going sometimes to weddings and weddings are not yet finished and I just feel I can't do it. I try to go outside even when my heart is heavy but I don't feel good.

Despite negative social experiences disabled asylum seekers and refugees also described positive experiences which served to enhance their sense of emotional and social security. Older people drew support from friends and people in mosques and churches because of the cultural value placed on supporting elderly people. People supported by kin and non-kin carers characterised their caring relationships as based on interdependence and reciprocity, drawing support from kin carers but also providing them with support as part of their family roles and identities. Reja, an elderly woman from Iraq, considered her caring role of her disabled adult son as part of her role as a mother stating, “I have been caring for him since I was 16 and I will continue to do that”, when referring to her unwillingness to accept an offer of respite care from the local authority social services. Her view reflects a gendered preference of care and a family and cultural tradition of care but also the failure of social services to address cultural needs.

Interviews with disabled asylum seekers and refugees revealed mixed experiences of accessing

social care support. Only a few reported that they had been through a social care assessment and been successful. This experience was confirmed by views of professionals in third sectors of social care who stated that social departments were often slow to intervene as “asylum seekers were not high on their priority”. Kencho explained that as a disabled person living with multiple impairments he had had difficulty receiving support from local authorities because of his asylum-seeking status and his experience highlights the height of assessment thresholds when qualifying for care support from local authorities:

I had to appeal lots of times. It was a lot of, long time process. Even my doctor wrote a letter to them but they did not listen to that [...] I used to get help from (local refugee organisation) and also like food every week. That was the best they could do.

It was apparent from the accounts of disabled asylum seekers and refugees that when they found it difficult to cope with their impairments support from local authorities had been late or not available at all. In some instances they had not been referred at all to local authorities by third sector organisations, such as refugee and ethnic organisations they had been in contact with, highlighting that their needs for support went unrecognised. The lack of their access to support from local authorities may however also have been influenced by their lack of entitlements and the availability of relatives and people in their communities to provide them with support. It may also have been influenced by whether or not their impairment had been recognised by health authorities as ‘disability’. For example, Lana described at the time of the interview she was only just now managing to negotiate access to disability benefits following an assessment after trying for 11 years as a refugee with permanent residence permit to gain recognition of her disability status.

Interviews with social workers in social care departments revealed that they faced great challenges in responding to disabled asylum seekers and refugees with limited entitlements because of their binding legal and funding environment and high care assessment thresholds. They explained that care assessments involving asylum seekers were complex and required them to disentangle social needs from medical needs. They reported that impairments that were “socially visible” in communities were ‘much easier’ to identify



and respond to than invisible impairments, such as sensory and mental health impairments common in refugee communities. Disabled people often failed to come to the attention of social workers because they did not present for support in the first place or not till late and refugee organisations not identifying their needs. They also reckoned that clients feared authorities and that language barriers, stigma of disability and negative values attached to receiving public support would prevent disabled asylum seekers and refugees and those supporting them to seek support. These views were confirmed by professionals in third sector organisations.

Social workers commented on experiencing great ethical tensions in their roles because their professional environment required them to try balance their personal and ethical values with the legal and funding environment they worked within. Marge, a social worker, commented on a pattern where social workers got “bogged down” in bureaucratic procedures and lost sight of fundamental human rights principles and holistic approaches in social work. The restrictive funding and legal environment surrounding social care to asylum seekers was considered by social workers and professionals in third sector organisations to indeed undermine their roles of support and create conflicts between professionals in different sectors about whose responsibility it was to provide support. Professionals in third sectors observed that responses from local authorities were inconsistent and based on informal practices. Edna, a senior adviser in a refugee organisation, commented: “Some of their staff can be quite helpful but it’s purely on an informal basis [...] I would say these kinds of responses are rare because the resources are not there anymore.”

The findings revealed that most of the participating refugee organisations lacked holistic approaches, targeting asylum seekers and refugees as a homogenous group and failing to identify diverse needs, including those of disabled people and kin carers. Professionals referred to organisations being strained by lack of resources commenting that they were mostly “managing destitution”. A few of the professionals surprisingly commented that their organisations seldom came in contact with disabled people and carers, while this was in stark contrast with their statements about the majority of their clients being affected by complex impairments and social needs. One of the professionals stated, “we don’t work with disabled people, these are just persons that are a part of the whole community

of refugees and asylum seekers that we work with”. Her view confirms the experiences of disabled asylum seekers and refugees of their specific needs not being identified.

Interviews revealed that refugee and ethnic organisations were, however, a key source of social support to disabled asylum seekers and refugees and their carers when formal support was not forthcoming. Disabled asylum seekers and refugees highly valued the efforts made by some professionals who despite legal barriers tried to assert their influence on the outcome of care assessments, advocating on their behalf.

Discussion and conclusion

The findings confirm the link established in academic literature between poverty, poor health and disability and lack of entitlements and rights in societies in which asylum seekers settle (Dwyer & Brown, 2005; Groce et al., 2011; ICAR, 2006; Oliver, 1990). The findings reveal a complex nature of disability (Ryan et al., 2009; Ward et al., 2008). Disability intersects with legal status, migration and settlement processes as participants faced significant social barriers being denied rights and access to support based on their dual status as disabled people AND as migrants. The findings confirm a multiple nature of social barriers in lives of disabled asylum seekers and refugees (Chambra et al., 1999; Harris, 2003; Trotter, 2012).

Support needs of disabled asylum seekers and refugees and their rights to social support are indeed on the margins of policy and provisions for support. The findings call for the need for policies and services based on a bio-psychosocial understanding of disability and which recognise a human rights approach to disabled asylum seekers and refugees and those who support them. The findings raise profound questions about the potential and limitations of welfare policies, provision, and practice as means of social protection and support in fulfilling the human rights of disabled asylum seekers and refugees. ‘Good care’, as conceptualised by Tronto, based on ethics and a recognition of rights of disabled people, is hard to achieve in circumstances where professionals lack resources and face institutional and policy barriers (Tronto, 2010). My point here is that policy of access for disabled asylum seekers and refugees who hold limited rights to support needs to be underpinned by human rights principles first and foremost.



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