

# *Disability and chronic illness*

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# **Disability and Chronic illness**

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## **Abstract**

This chapter discusses the situation of migrants with disability and chronic illness and their access to health, social care and welfare support in settlement countries. The links between disability and migration have been generally neglected in the literature to date; often disability is only referred to as a potential outcome of migration because of the association between poverty, poor health, housing and employment conditions amongst migrants. This chapter provides an overview of key conceptual understandings of disability and chronic illness and the policy context. The links between migration, disability, chronic illness and care support are complex, due to shortfalls in existing knowledge and the lack of policy engagement with asylum seekers and refugees with disability and chronic illness, despite their often high care needs. The chapter pays particular attention to the situation of asylum seekers with disability or chronic illness who often have limited entitlements to health, social care and welfare support, drawing on our empirical research on disability, HIV and caring relations among asylum-seeking and refugee families in the UK. Such families face major barriers in accessing appropriate health, social care and welfare support. The unmet care needs of disabled asylum-seekers also impact on informal family carers, including children and young adults, whose substantial caring responsibilities, combined with their restricted entitlements to support, affect their wellbeing, education and transitions into adulthood.

## **Introduction**

The World Health Organisation (WHO) estimates that 15% of the global population are disabled people (World Health Organisation and World Bank, 2011). The majority of disabled people live in the global South and the incidence of poverty amongst disabled people is higher than in the general population in this region of the world (Mitra et al., 2013). This is due to limited rights to public welfare support, greater health-related expenditure and barriers to participation in employment and education (Groce et al., 2011), which are influenced by wider national and global processes and inequalities which constrain government spending

and public welfare systems. In much of the global North disabled people's rights to participate in social life and to receive support are recognised in policy and designated support may be provided. Yet despite considerable advances in international and national policies and the greater involvement of diverse groups of disabled people in decision-making processes, disabled people globally continue to experience multi-dimensional inequalities and disadvantages in their life chances and opportunities (Mitra et al., 2013; Groce et al., 2011).

Disabled people may become displaced as a result of extreme poverty and lack of social protection, environmental disasters or war. Approximately 2.3 to 3.3 million internally displaced persons are estimated to be disabled people (UNHCR, 2014). However, disabled people may be left behind during displacement, because they lack social protection, support and the power or resources needed to negotiate migration routes (Straimer, 2010). To date, there are no official statistics about the numbers of disabled people involved in migration across international borders (Shivji, 2010; Simmons, 2010). The vast majority of disabled people face significant structural barriers, as well as barriers to migration (Grech and Pisani, 2015; World Health Organisation and World Bank, 2011). This is because of negative connotations associated with disability and assumptions in national immigration policies that disabled people are 'unproductive' and will not contribute economically or socially to their country of settlement (El-Lahib and Wehbi, 2012). Disabled people tend to be ignored in migration policy and interventions and have restricted rights to employment and welfare support because of their status as migrants in receiving countries; they are often unable to access the same level of health and social care support that other disabled citizens in receiving countries are entitled to, which further compounds negative experiences of disability and social exclusion. This applies particularly in European countries where migrants from countries outside the EU, asylum seekers and undocumented migrants, have unequal entitlements to support (see Harris and Roberts, 2004; The European Migration Network, 2014).

The links between disability and migration have been generally neglected in the literature to date; often disability is only referred to as a potential outcome of migration because of the association between poverty, poor health, housing and employment conditions amongst migrants (Rechel et al., 2013; Ryan et al., 2009). Migrants are considered at higher risk of

becoming chronically ill or disabled than the general population because of poorer living conditions and limited entitlements to welfare support (Sole-Auro and Crimmins, 2008; Sundquist, 1995). Migrants with a marginalised legal status, such as asylum-seekers or those with insecure or no legal status, may be more likely to experience disability, chronic illness or other physical or mental health problems (Allsopp et al., 2014; Jayaweera, 2014; Raphaely and O'Moore, 2010). The few available studies of disabled migrants' experiences offer important insights into how disability intersects with cultural, social, economic and global processes to constrain participation and shape the agency of disabled people involved in migration (Grech and Pisani, 2015). At the international scale, the situation of disabled migrants has only recently been acknowledged, following the establishment of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008. Given the lack of statistical evidence, knowledge about disabled migrants' experiences and the lack of policy engagement with such critical issues, the picture of disability and migration that we discuss is rather complex.

In this chapter, we first provide insight into key conceptual understandings of disability and chronic illness. We then discuss the policy context of migration, disability and chronic illness. We focus on the specific situation of asylum seekers with disability or chronic illness and provide a case study of the UK context, drawing on literature, policy and our own empirical research on disability, HIV and caring relations among asylum-seeking and refugee families.

## **Understanding disability and chronic illness**

A 'medical model' of disability dominated approaches to disability in the global North until relatively recently and continues to exercise a significant hold over attitudes and responses to disability globally. The 'medical model' regarded disability as largely an 'individual misfortune' or private 'tragedy' or 'abnormality' that needed to be treated, cured or prevented by medical intervention alone (Oliver, 1990; Gleeson, 1999). The disability movement, led primarily by activists and allies in the UK and the USA from the 1970s onwards, rejected such medical, rehabilitative models of disability and developed instead a 'social model' of disability to highlight the socio-cultural, economic, political and environmental barriers that prevented disabled people's participation in society.

The 'social model' focused on changing society to facilitate the participation and inclusion of disabled people, rather than on efforts to 'rehabilitate' individuals and overcome biological constraints of the body. Political lobbying and campaigning underpinned by a social model approach to disability have led to significant changes in disabled people's access to education, employment, health and social care and welfare provision (Priestley, 2003). Disability activists and allies demanded disabled people's rights to participate in all aspects of society on an equal basis with non-disabled people, under the often cited slogan, 'Nothing about us without us'.

The social model has, however, come under increasing criticism in recent decades for being gender-, race- and class-blind, speaking mainly of the experiences of white middle class men with physical impairments in the global North. It paid little attention to the experiences of women and others from socially disadvantaged backgrounds with diverse impairments and the majority of the global population of disabled people who live in the global South (Imrie and Edwards, 2007). Feminist disability scholars highlighted the failure of the social model to recognise personal, embodied experiences of impairment and chronic illness as part of people's diverse experiences of disability (Butler and Parr, 1999; Dyck, 2010; Morris, 1991). Wendell (2001) argues that social model proponents' resistance to the idea of identifying disability with 'illness' (due to its association with the medical model) in fact served to prioritise the experiences of 'healthy' disabled people and neglect the diverse experiences of people living with pain or other physical (or mental health) complications linked to impairment which affect their health. The call of some disability scholars to 'bring the body back' into disability studies is not merely for theoretical reasons but also to respond to the real support needs of disabled people (Loja et al., 2012; Kröger, 2009).

Indeed, conceptualising chronic illness as 'disability' poses a fundamental challenge to the social model of disability, which seeks to distance itself from medical discourses. Those living with chronic illness may choose to identify according to their biomedical diagnosis rather than according to a more generalised notion of 'disability'. Hughes (2009) notes that the interests and concerns of such 'biosocial' groups and the disability movement diverge in a number of ways: biomedical diagnosis and impairment are central to the identification of 'biological citizens'; biosocial groups are likely to 'gather and embrace the specialised medical and scientific knowledge associated with their condition' and medicine is perceived

as a 'potential ally' in contrast to the rejection of medical approaches by the disability movement (Hughes, 2009, p. 678). Identification as a bio-social group however may limit access to entitlements under disability legislation and potentially perpetuate the stigma surrounding both disability and some chronic (often life-limiting) illnesses (Evans et al., in press).

People living with HIV can be regarded as such a bio-social group, who do not identify as 'disabled people' and are often not defined as such in law or social policy unless they have specific long-term impairments, although the UK and Australia are notable exceptions, according protection to people living with HIV under national disability legislation (Evans and Atim, 2011). The activism and advocacy of networks of people living with HIV in the global South have been crucial to securing free access to life-prolonging anti-retroviral medical treatment in many resource-constrained contexts. Nevertheless, the continuing stigma surrounding HIV which is often gendered, combined with a lack of entitlements to support, may lead to significant experiences of discrimination, destitution and insecurity among migrant women living with HIV in the UK (Evans and Becker, 2009).

An increasing body of literature has shown that socio-cultural constructions of disability and 'healthy/ ill' bodies and the ways that people are treated vary cross-culturally and are shaped by personal, embodied and collective experiences, as well as by social differences (such as gender, class, race, ethnicity, socio-economic status), and wider structural processes such as national and international policies and welfare provision in different geographical and historical contexts.

Recent international policy acknowledges the interaction between biological, psycho-social and environmental dimensions of disability. The UNCRPD, rapidly ratified by many countries after it was introduced in 2008, demonstrates a renewed global commitment to recognise disability as not merely a personal matter but as a bio-psycho-social and human rights concern. The bio-psycho-social model endorsed by the UN and WHO arose from a growing concern about the seeming lack of attention to 'impairment' and global differences in the experiences of disabled people within social model approaches. The bio-psycho-social model endorses a human rights approach to disability, while recognising that disability is a medical, personal and a social matter. The Convention aims to 'ensure and promote the full realization

of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability' (UN, 2008).

## **Disability, chronic illness and the UN's position**

The UNCRPD and UN Refugee Agency (UNHCR) have sought to address the situation of disabled people in migration processes. The UNCRPD refers to migrants in Article 18 on the liberty of movement and nationality:

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:
  - (a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;
  - (b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;
  - (c) Are free to leave any country, including their own;
  - (d) Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country; (UN, 2008)

Nation states that have ratified the UNCRPD are obliged to promote and develop policies on disability which provide equal access to opportunities for welfare, health and social care, and any other support required in order for all disabled people (including migrants) to participate fully in society. Yet despite ratifying the Convention, the UK, Malaysia and Thailand have maintained a reservation on Article 18, excluding immigration policies from the Convention's obligations. Australia recently lifted the reservation it had on Article 18 (UN, 2015).

Furthermore, the UNHCR launched its 'Conclusion on refugees living with disabilities and other persons living with disabilities protected and assisted by UNHCR' in 2010 in order to demonstrate the UN's commitment to specifically address the situation of disabled asylum

seekers, refugees and other migrants who have been displaced (UN, 2008; UNHCR, 2010). The Conclusion focuses exclusively on disabled people in need of humanitarian protection following displacement and includes men, women and children who have become displaced internally and across nation states because of a variety of environmental, political and social reasons endangering their lives. Yet it has been criticised for lacking any further guidelines concerning how to respond to disabled asylum seekers in receiving countries (Straimer, 2011). Disabled asylum seekers, as well as migrants who hold limited entitlements to support, may be denied status as a disabled person in receiving countries if, for example, their disability is not visible or they do not qualify for a care assessment on the basis of having visible 'care needs', which further marginalises those with 'invisible' chronic illnesses, mental health problems or other disability (Harris and Roberts, 2004).

In reality, the ratification of the UNCRPD and UNHCR's Conclusion have not necessarily translated into actual rights for disabled people. In many countries, disabled people continue to be devalued and stigmatised due to socio-cultural constructions of the problematic, 'abnormal' nature of disability, and because of legislation, public policy and service provision which are based primarily on medical model approaches to disability (Groce et al., 2011). Furthermore, despite significant improvements to legislation and service provision in many countries, including the UK, disabled people continue to experience inequality and marginalisation in the labour market, education and other aspects of society (Hughes, 2015). Disabled migrants with limited entitlements to welfare, health and social care are even more likely to face poverty, inequality and destitution than other migrants (Ward et al., 2008). Their situation has been exacerbated in recent years by increasingly restrictive immigration policies, austerity and cuts to public welfare services following the global financial crisis in 2008, despite the adoption of laws and policies underpinned by a social model and/or human rights approach to disability in many receiving countries in Europe and elsewhere in the global North.

## **The policy context of migration, disability and chronic illness in settlement countries**

The introduction of the UNCRPD has been broadly welcomed among disability organisations and in theory at least, appears to have positive implications for the human rights of disabled migrants. In reality, migrants with disability or chronic illness face challenges in gaining

acceptance of their status as disabled people and in gaining entry because of increasingly restrictive immigration policies in many receiving countries (Straimer, 2011). Disabled migrants face significant structural barriers in accessing health and social care support because of ever tightening criteria used to determine eligibility and definitions of disability and 'care needs'. Coupled with language and socio-cultural barriers and limited resources to address diverse needs within migrant and Black and Minority Ethnic (BME) communities, disabled migrants often experience multiple barriers to support which prevent their participation in society on an equal basis with non-disabled people (Trotter, 2012; Cole and Burke, 2012).

As noted earlier, knowledge about the needs of migrants with disability or chronic illness is very limited. In migrant studies, disability is usually only referred to as a medical condition that a migrant may have been born with, or which may have developed during settlement. Many disabled migrants come from low income countries where disability and poverty are intrinsically linked; while some individuals may have been born with impairments, many impairments are caused by poor living conditions in the country of origin and difficult experiences associated with migration and settlement (Straimer, 2011; Harris, 2003). Poverty, insecure housing and hazardous employment environments negatively impact on the physical and social health of individuals, which can result in disability (Zimmer, 2008). Further barriers to accessing support in receiving countries include socio-cultural barriers related to negative personal and social experiences of disability and inexperience in receiving welfare support in the global South, combined with a failure of services and policy to address migrants' diverse support needs (Groce et al., 2011; Lamichhane et al., 2014). Due to these structural inequalities, comparative research between European countries suggests that migrants that are relatively 'healthy' on arrival are at a much higher risk of developing chronic impairments and poorer health outcomes than other groups in receiving countries where they have settled (Rechel et al., 2013; Sole-Auro and Crimmins, 2008; Sundquist, 1995). Sole-Auro and Crimmins conclude that, 'there is little evidence of the "healthy migrant" in European populations' (Sole-Auro and Crimmins, 2008, p. 861).

Statistical evidence about chronic illness among migrants has several shortcomings. No reliable figures currently exist about the prevalence of chronic ill health among the migrant population in the UK, for example, although 'non-UK born' migrants, particularly those from

South Asia (especially Pakistan and India) and Sub-Saharan Africa, are disproportionately affected by infectious diseases, such as TB, Hepatitis B and C and HIV than 'UK-born' people, which may be due in part to the higher prevalence of these infections in their countries of origin (Health Protection Agency, 2006; Health Protection Services, 2011; Jayaweera, 2014). The majority of cases of TB, HIV in heterosexuals, malaria and enteric fever reported in the UK were found among migrants (Wagner et al., 2013). Unlike for infectious diseases, however, evidence by country of birth for non-communicable diseases is limited. Jayaweera (2014) concludes that a comprehensive overview of the health of migrants in the UK is hindered by the fact that much existing evidence on health includes ethnic group but not migration variables, such as country of birth, length of residence in the UK, or immigration status, which often reveal significant differences.

While BME communities are likely to face a multitude of structural barriers to health and social support which they may share with migrants, studies in the UK often pay little attention to migrants' differential position and specific needs in accessing welfare services. Moreover, disabled migrants tend to be overlooked in policy and research on BME disabled people and those who care for them (Carers UK, 2014; The Children's Society et al., 2012).

Migrants in many receiving countries also face increasing public hostility and stigmatisation due to unfounded media portrayals of migrants as 'health tourists' (Jayaweera, 2014). This notion is often used to question migrants' access to healthcare and the welfare system, with the claim that migrants are a 'burden' to national economies. The UK Department of Health's (2013) recent public consultation for example, emphasises the need to regulate migrants' access to National Health Service healthcare by introducing fees for migrants from states outside of the European Economic Area (EEA). Research suggests, however, that migrants from within (rather than outside) the EEA enter the UK for medical purposes and health tourism produces financial gains rather than a drain on the NHS (Hanefield et al., 2013). The Department of Health's emphasis on the role of front-line health services in identifying chargeable migrants means that health care professionals, such as general practitioners (GPs), are under pressure to not only deliver clinical practice, but also to control entitlements to health services (Ottosdottir and Evans, 2014, p. i59). Indeed, Pussetti and Barros (2012) highlight the racialised nature of European countries' public health and social care policy, which often constitute migrant populations as 'unsanitary citizens'. Following this overview of

the policy context of migration, disability and chronic illness, we now discuss the specific situation of asylum seekers with disability or chronic illness in receiving countries.

## **Asylum seekers with disability or chronic illness**

An estimated 3.5 to 5 million of the global population of displaced people are disabled people (Pisani and Grech, 2015). Research with asylum seekers has focused on the physical and mental effects of conflict and war in countries of origin; trauma associated with migration and settlement processes, including isolation, loss of social status, poverty and insecure legal immigration status; and the impact of government policies such as detention and dispersal in the receiving society (Roberts and Harris, 2002; Ward et al., 2008; Jayaweera, 2014). Asylum seekers and refugees are likely to have higher health needs than other migrant groups. Studies in the UK and systematic reviews of studies across European countries point to higher rates of depression and anxiety among asylum seekers and refugees compared to the national population or other migrant categories (Raphaely and O'Moore, 2010; Jayaweera, 2014). Children and women who have suffered sexual and physical abuse are regarded as particularly vulnerable groups (Women's Refugee Commission, 2014).

The majority of research on disabled asylum seekers is based on health studies informed by the medical model of disability. Research examines the impact of forced migration on an individual's physical and psychological health and 'functioning', painting a general picture of complex impairments in forced migrant populations, with a high prevalence of mental health problems (Mollica et al., 1999; Silove et al., 1998). In their study of Bosnian refugees in Australia for example, Momartin et al. (2003) found that a high proportion of participants suffered from mental health problems, showing clinical symptoms of post-traumatic stress disorder.

Only a few studies have examined the situation of disabled asylum seekers and refugees from a social model of disability perspective, highlighting the detrimental material and social conditions generally found in settlement countries (Ruiz-Casares et al., 2010; Steel et al., 2006; Roberts and Harris, 2002). Asylum seekers in many countries in Europe experience prolonged periods of insecure immigration status and limited levels of subsistence support;

they may be subject to deportation or detention processes; and are highly vulnerable to poverty and destitution, which significantly impacts on their health and wellbeing (Ryan et al., 2009). While the focus is often on barriers to care support, research is usually conducted with non-disabled people and disability is viewed as a mere outcome of the migration and settlement process (ICAR, 2006; Crawley et al., 2011; The Children's Society, 2012). Straimer (2011; 2010) comments that European national policies on asylum and disabled asylum seekers tend to be based on the medical model and do not seem to take on board the recommendations made by the UNHCR on the situation of disabled people in forced migration contexts. Disabled women and children in particular, face significant barriers to social support and fulfilment of their rights to equal participation in settlement countries (Women's Refugee Commission, 2014).

The little available literature reveals multiple legal, cultural, policy, language and information barriers to accessing formal care facing disabled asylum seekers (see Harris and Roberts, 2004; Sales and Hek, 2004; Roberts and Harris, 2002; Guhan and Liebling-Kalifani, 2011; Humpries, 2004). In comparison to other disabled people, disabled asylum seekers appear to have heightened vulnerability to poverty and social exclusion because of their legal status, restricted entitlements to health, social care and welfare support, raised thresholds in care assessments and the failure of refugee organisations, disability organisations and local authorities to adequately address their needs (Roberts and Harris, 2002).

### **Case study: asylum seekers with disability and chronic illness and informal carers in the UK**

Given the limited evidence about the situation of disabled asylum seekers in receiving countries, in the remainder of this chapter, we draw on available literature and our own empirical studies to provide a case study of disabled asylum seekers and carers' access to welfare support, health and social care in the UK.

Asylum seekers in the UK have a recognised legal status (unlike 'undocumented migrants') and are granted limited entitlements to public welfare support, although this is only approximately 70 per cent of the public benefits (such as Income Support Allowance) that are available to British citizens or those who have been granted refugee status (Home Office,

2014; UK Government, 2014). Asylum seekers and 'undocumented' migrants face additional structural barriers to accessing employment, education and health and social care support in the UK because of their limited or lack of entitlements and lack of, or illegal, access to the labour market (ICAR, 2006; Harris, 2003). Furthermore 'irregular' or 'undocumented' migrants have very limited entitlement to healthcare within the NHS and often lack the resources to fund alternative treatment (Medical Protection Society, 2015). Both of these categories of migrants (asylum seekers and undocumented migrants) continue to be relatively hidden within research and policy on disability, care and migration, despite their often acute experiences of destitution and marginalisation (Harris, 2003; Roberts and Harris, 2002; Ward et al., 2008). Furthermore, although refugees whose asylum claims have been upheld and who have been granted indefinite leave to remain in the UK have the same legal entitlements to welfare support as British citizens, they may continue to experience structural inequalities (such as in entering the labour market), ongoing chronic illness or disability which may have resulted from extended periods living in poverty and destitution as an asylum seeker and socio-cultural barriers to accessing health and social care support (Fell and Fell, 2013; Harris and Roberts, 2004; Yeo, 2015).

In UK asylum support policy, no reference is made to the needs and rights of disabled migrants other than the use of the term, 'care needs', which is used to determine eligibility for care support for all disabled people (UK Government, 1999; 1990). In order to qualify for care support, disabled asylum seekers and people with 'No Recourse to Public Funds' must have 'critical needs' which result from impairment or age and not merely from their living conditions (SCIE, 2010; 2013). Furthermore, disabled people are regarded as 'vulnerable' rather than considering them as social actors with capabilities (Katsapaou, 2013). Hence, social care and housing may be granted only to disabled asylum seekers with significant impairments who are deemed to be in need of assistance with activities of daily living (SCIE, 2010; 2013).

Ottosdottir's (2015) study of asylum seekers and refugees with disability and chronic illness in the South East of England confirmed these findings. Despite the option to use human rights assessments to provide social care for asylum seekers with limited entitlements, social

workers explained that local authorities usually sought identification of 'critical needs' , rather than their assessments being informed by human rights principles:

'You need to have care needs first, yeah! [...] You have to have an eligible care need for us to provide a service [to asylum seekers whose claims or appeals have been rejected]. The care need is the gateway into the service with us' (Ronalda<sup>1</sup>, social worker in a local authority).

Professionals in statutory and third sectors that provided health and social care support struggled to respond to the care needs of disabled asylum seekers because of the strict eligibility criteria required for care assessments, and the conflictual nature of social policies designed to meet the needs of 'vulnerable adults and children' and immigration policies that applied to those in the asylum system (Grady, 2004; Sales and Hek, 2004; Robinson, 2013; Ottosdottir and Evans, 2014). Statutory sector professionals, such as social workers, experienced tensions between the legal framework governing the situation of asylum seekers and their efforts to address their human rights and care needs (Ward et al., 2008; Newbigging and Thomas, 2011; Ottosdottir and Evans, 2014). In Ottosdottir's (2015) research, social workers expressed frustrations about the ethical dilemmas they faced when they were under pressure from the local authority to withhold support to asylum seekers with limited entitlements because of funding constraints. Support must be negotiated between local authorities, the Home Office and even the NHS, and social workers felt that they were at risk of losing sight of fundamental human rights principles and their professional ethics of care (underpinned by a holistic approach to the person's needs) when they became involved in such negotiations (*ibid*; Ottosdottir and Evans, 2014).

In the light of multiple barriers to formal support, disabled asylum seekers in the UK often rely on informal sources of support, such as children, relatives, friends and others, to provide sometimes substantial, regular care to meet their needs. Ottosdottir's (2015) study revealed that most family and friends interviewed who were caring for disabled asylum seekers had not received a carers' assessment or support as carers from the local authority, the third sector or

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<sup>1</sup> Pseudonyms have been used throughout the case study section to protect research participants' identities.

from the NHS. Carers may also keep their caring role hidden due to a fear of deportation and discovery of their family's insecure immigration status. As Charlotte (aged 21) from Uganda, who cared for her mother with HIV, explained:

'My mum always used to tell me stories about her friends that had been, been sleeping at their house and immigration came and just took them, you know because they did not have leave to remain. Not that they were illegal but they did not have the confirmed status. So she always used to worry about that they would suddenly appear...My mum used to say, 'Listen you are not like any of these children. If your friends are going wherever and start to have fun, you should think that for you that is not normal because for one, you don't have Leave to Remain and you don't have the money', so always those two things'.

Disabled migrants and carers may therefore 'remain hidden' from services or be considered 'hard to reach' by professionals due to such fears, which may prevent them from seeking support (Harris and Roberts, 2004). Other reasons cited for the invisibility of disabled migrants and carers within statutory and third sector social care and support services included a lack of policy implementation, limited professional efforts to engage with the specific needs of migrants with disability or chronic illness and the fact that migrants assume caring roles on the basis of expected socio-cultural norms of family roles and relationships (Ottosdottir, 2015). The scarcity of research and knowledge about families' experiences of disability and care further hinders the development of appropriate support (Roberts and Harris, 2002; Harris and Roberts, 2004; Trotter, 2012; Yeo, 2015).

In the UK, third sector organisations are beginning to recognise the potentially high levels of caring that young people in asylum seeking families and in families 'Without Recourse to Public Funds' take on (The Children's Society, 2013). Young carers in asylum-seeking families may be more likely to experience higher levels of caring responsibilities than 'young carers' in non-migrant families because of the unmet needs of their disabled parents/ relatives, in addition to the often lengthy periods of insecure legal status and limited entitlements to health, social care and welfare support.

Evans' (2011) research with African migrant mothers living with HIV and children caring for them who were seeking asylum or who had been granted refugee status/British citizenship,

suggested that young people's regular responsibilities for household chores, childcare and provision of emotional support were interspersed with periods of more intensive care for their parent during episodes of ill health or hospitalisation. Many mothers living with HIV expressed feelings of frustration, sadness and guilt that they had to rely on their children to care for them when they were ill.

For young people from asylum-seeking families, the emotional impacts of supporting a parent/ relative with a life-limiting illness were exacerbated by pressures associated with their insecure immigration status and a sense of isolation and lack of alternative support (*ibid*). Crystal (aged 15), who cared for her mother and brother with HIV in an asylum-seeking family from Uganda, emphasised the need for security for her and her family's future:

'To know that we can settle down because the Home Office is not replying to us and mum can't work and I can't get a part time job and no one, it's just we need to have that assurance that yes we are going to stay in this country, that we don't need to be worrying about every time they're sending people to their country that it's going to be us next or something. We just need security' (Evans, 2011, p.354).

The profound sense of insecurity mothers and young people felt about whether they would be allowed to remain in the UK was linked to a fear of deportation and potential loss of access to life-prolonging anti-retroviral therapy that returning to their country of origin would entail (Evans, 2011, p.348). Caring relationships and young people's and mothers' mobility and access to support at the local level were thus influenced by wider structural processes such as global inequalities in access to HIV treatment and restrictive immigration policies (*ibid*).

Young adults carers (aged 18-24) in asylum-seeking families also face significant challenges in their transitions to adulthood because of their caring responsibilities, as well as their legal status and sustained periods without entitlements to employment and education (The Children's Society, 2013; Becker and Becker, 2008). Ottosdottir's (2015) research suggests that young adult carers in asylum-seeking families faced major barriers in making the transition into university education. Young adult carers with different legal status than the rest of their families faced great difficulties. Susan (aged 21) from Zimbabwe who had a different legal status from the rest of her family and who cared for her mother with HIV, explained that

she would not qualify for reduced university fees until she had gained 'Indefinite Leave to Remain', despite having lived in the UK for ten years on consecutive limited 'Leave to Remain' permits:

'I will probably be near 30 years old then you know. I mean I want to do my education now! Unfortunately it is not going to work for me so I am hoping to get a good job that pays me well so that I can put myself through school'.

Migrant young people from non-EU countries struggled to pay the much higher university fees than home/EU students and may postpone higher education, further compounding structural inequalities and discrimination they may face in the labour market and in their future life chances.

In addition to these barriers, a lack of cooperation between refugee and mainstream disability organisations in supporting disabled asylum-seekers has been noted in the UK (Ward et al., 2008). Refugee organisations often carry the burden of support, and disability support organisations do not appear to be involved in supporting disabled people from forced migrant backgrounds. In addition, carers organisations, including those providing young carers support services, are often not in contact with young people or other family members providing informal care in asylum-seeking and refugee families (Evans and Becker, 2009; Greenwood et al., 2015).

While many local authorities emphasise diversity and family-focused approaches, a recent UN report suggests that many strategies have failed to reach families or meet the diverse support needs of children and adults in the UK asylum system (UNHCR, 2013). Limited evidence was found of 'good practice' in social care with forced migrant families; professionals and agencies struggled to identify care needs, including those of disabled people, young carers and adult carers (SCIE, 2010). The 'complexity' of care needs among asylum seekers with disability or chronic illness; professionals' lack of awareness of entitlements; difficult interagency partnerships between organisations who work with asylum seekers and those 'Without Recourse to Public Funds' were cited as key issues which had a negative impact on professional interactions with forced migrant families with care needs (*ibid*).

## **Conclusion**

In this chapter we have analysed the complex linkages between migration, disability, chronic illness and care support. We provided an overview of key conceptual approaches to disability and chronic illness. We then discussed the policy context of migration, disability and chronic illness, highlighting the shortfalls of existing knowledge and the lack of engagement with asylum seekers and refugees, despite their often high care needs. The specific situation of asylum seekers with disability or chronic illness was discussed through a case study of the UK context, drawing on available literature, policy and our own empirical research on disability, HIV and caring relations among asylum-seeking and refugee families. Our analysis of the situation of asylum seekers with disability and chronic illness revealed that this group faces major barriers in accessing appropriate health, social care and welfare support. The unmet care needs of disabled asylum-seekers also impact on informal family carers, including children and young adults, whose substantial caring responsibilities and their legal status and limited entitlements to support affects their wellbeing, education and transitions into adulthood.

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