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Restrictive practices on refugees in Australia with intellectual disability and challenging behaviours: a family's story

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Abstract

Purpose – The purpose of this paper is to explore the experiences of a refugee family navigating complex disability and restrictive practice service systems. Living with disability, or caring for someone with disability can compound the disadvantage and marginalisation already experienced by refugees. The nexus between disability and refugee status, particularly intellectual disability and restrictive practices, has received little scholarly attention and almost nothing is known of people's experiences in this situation.

Design/methodology/approach – Thematic analysis of a case study is used to illustrate the experiences of a refugee family in this situation. The case study presented was part of a larger ethnographic study exploring the experiences of people of refugee background living with disability.

Findings – There were numerous barriers to accessing appropriate services. The family experienced high levels of stress simultaneously navigating the resettlement process and the disability service system. They were poorly informed and disempowered regarding the care of their loved one and the use of restrictive practices. Experiences in the country of origin, employment responsibilities, and unfamiliarity with the service system were key factors in this family's difficulty in safeguarding the rights of their family member with disability.

Originality/value – This case study examines the complexity experienced when disability intersects with refugee background. Areas for additional research and significant gaps in service provision are identified. The case study clearly demonstrates the importance of understanding people's pre- and post-settlement experiences to inform policy and service provision.

Keywords Intellectual disability, Refugees, Family, Barriers, Trauma, Restrictive practices

Paper type Case study

Introduction

It is estimated that 7-10 per cent of refugees (Mirza, 2012) have some form of disability. In 2014 there were 19.5 million refugees worldwide (United Nations High Commissioner for Refugees, 2014). Whilst the exact percentage who live with disability in Australia is unknown, it is thought to be high; as has been demonstrated in studies undertaken in other countries of resettlement such as the USA (Huang et al., 2011; Yang et al., 2012). The diversity amongst people from refugee backgrounds makes it challenging to identify common experiences of disability, although research has identified they may be exposed to stigma, discrimination, and marginalisation in their country of origin (Albrecht et al., 2009).

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Similarly, people with intellectual disability in Australia and their family members often experience exclusion, marginalisation, stigma, and prejudice (Commonwealth of Australia, 2009). Soldatic et al. (2015, p. 509) argue that it is well established that people of non-English speaking background experience institutionalised racism from disability service providers. Concomitant to this barrier, resettlement services are poorly equipped and positioned to adequately assist regarding disability related matters (Soldatic et al., 2015).

People of culturally and linguistically diverse backgrounds have substantial challenges in understanding and navigating Australia's complex health systems (Beauchamp et al., 2015), social service systems (Soldatic et al., 2015), and financial systems (Zuhair et al., 2015). For refugees it is likely these challenges are further compounded given the nature of their experiences prior to migration. There is limited Australian research into the impact of disability on the refugee experience, nor is adequate data collected regarding the intersection of disability with migrant or refugee status (Albrecht et al., 2009; Bogenschutz, 2014; Soldatic et al., 2015). An extensive literature review conducted by the authors identified that the majority of the disability literature relevant to people from refugee backgrounds focused on mental health with little attention explicitly paid to disability, including physical, sensory, and intellectual disability – a pattern also noted by Soldatic et al. (2015). This lack of knowledge renders refugees with non-psychiatric disability invisible, and leads to significant difficulty in adequately understanding the experiences of this group and advocating for appropriate policy and service responses (Soldatic et al., 2015). Yet, it would be reasonable to expect that the intersection of disability, particularly intellectual disability, with a refugee background would substantially compound disadvantage, and create additional challenges to the resettlement process (Bogenschutz, 2014; Mirza, 2012).

A further complicating factor for people from refugee backgrounds who live with disability is when they also exhibit behaviour that is considered “challenging”. Challenging behaviour (CB) is defined as:

Culturally abnormal behaviour(s) of such intensity, frequency and duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit the use of or result in the person being denied access to ordinary community facilities. (Emerson, 2001, p. 3).

Understanding the contextual reasons behind the behaviour, for example, difficulty communicating pain or environmental stressors, and developing proactive support plans are essential to providing quality care (Jones et al., 2013). Behaviours experienced as challenging may include self-injurious behaviour, aggression, leaving the premises without the carer's knowledge, verbal and physical assault, inappropriate sexual behaviour, and pica (Brylewski and Duggan, 2004). Estimates of the prevalence of CB vary depending on the study context, however, it has been estimated that 7-15 per cent of people with intellectual disability will display behaviours that have the potential to cause harm to others or self (Webber et al., 2008). A qualitative study in the UK, conducted with family carers of adults with intellectual disability from diverse ethnic backgrounds, explored their perceptions of CB and found that families from minority ethnic communities were more likely to report

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negative experiences (Hatton et al., 2010). This highlights the need to innovate and develop programmes and services that support the needs of people with intellectual disabilities from immigrant backgrounds (including refugees) and their families (Raghavan et al., 2009). In Queensland, people with disability living in supported accommodation, aged care or mental health facilities, hospitals, schools, or group homes who exhibit CB may be subject to restrictive practices (Australian Law Reform Commission, 2014). “Restrictive practices” refers to chemical, social, physical, mechanical or seclusionary interventions by service providers that have “the effect of limiting the rights or freedom of movement of a person with disability, with the primary purpose of protecting the person or others from harm” (Australian Law Reform Commission, 2014). The report entitled “Challenging behaviours and disability: a targeted response” (Carter, 2006) was a catalyst for reforms to Queensland’s restrictive practices regime (Department of Communities, Child Safety and Disability Services, 2013). The report identified that service providers were over-reliant on restrictive practices to reduce CB, and the use of restrictive practices for adults with intellectual disabilities potentially violated international human rights obligations (Department of Communities, Child Safety and Disability Services 2013, p. 1). In response, the Queensland Government adopted, amongst other reforms, multidisciplinary assessment and individualised positive behavior support plans (PBSP). A PBSP is a requirement of the legislation (Disability Services Act, 2006 s.123L, p. 158-159). Whilst the reforms are important, human rights violations continue to be of concern.

Australia has ratified both the United Nations Convention relating to the status of refugees, and the United Nations Convention on the Rights of Persons with Disabilities (Crock et al., 2011). Thus, Australia has a responsibility to ensure that these human rights are maintained by the refugee and disability service systems. Research such as that described here provides an insight into the service and knowledge gaps that leave people of refugee background with disability, and their families, vulnerable to human rights violations.

The experience of disability is embedded in a socio-cultural context which influences the construction of identity, help seeking behaviour, and the responses to the disability by family and community (King et al., 2014; King and King, 2011). For refugees, an understanding of the context from which they have fled is critical as experiences of torture, trauma, or expectations of punitive government responses will further shape their engagement, or lack thereof, with formal service systems. The following case study was selected for presentation due to the complexity arising from the person living with an intellectual disability with CBs, and a suspected history of torture and trauma in their country of origin.

Bashir, Makeen, and Amira

Pseudonyms from the same country of origin have been used to protect confidentiality.

This case study explores the experiences of Makeen, a man whose intellectual disability resulted from a war-related injury during childhood, and who has been subject to restrictive practices in Australia. The informant was Makeen’s brother, Bashir. Their mother Amira also features in the case study. Neither Makeen or Amira were present at the interview and thus,

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it is Bashir's perceptions of the family's experiences represented in the case study. These experiences provide a clear example of the range of challenges involved in navigating the complex disability service landscape for people of refugee background.

Data collection and analysis

The story of Makeen, Bashir, and Amira was collected as part of a larger qualitative study (n=10) of refugees with disability conducted in Brisbane, Australia in 2014. The project had ethical clearance from the Queensland University of Technology Human Research Ethics Committee.

An in-depth interview was conducted with Bashir, who provided informed and voluntary consent. This method was used to gain a thick, in-depth description of the lived experiences of the family (Seidman, 2013; Rice and Ezzy, 2000). The interview, lasting 140 minutes, was conducted by the study's primary researcher, who has considerable cross-cultural experience. The interview protocol was informed by an extensive literature review and consultation with an advocacy service for people with disability of culturally and linguistically diverse backgrounds. The schedule of questions is provided in Box 1.

Bashir's interview was audio recorded by the primary researcher with his permission and transcribed verbatim by another research team member. Spot-checks were undertaken by the primary researcher to ensure accuracy. Table I provides an overview of the process of the thematic analysis.

Box 1: Schedule of questions

Can you tell me your story?
 Can you tell me about how disability is viewed in your culture?
 What does it mean to you to live with a family member with disability?
 Are there differences in the way disability is experienced here in Australia compared to your home country?
 What impact does having a family member with disability have on you and your family?
 How does your community in Australia respond to your disability – what support is there? (probe for stigma, inclusion, exclusion, any services, or other assistance)
 What support do you get from services provided by the Australian Government?
 What do you know about your entitlements?
 Can you tell me how you have accessed these?
 What other support or resources do you need?
 Is there anything I have not asked that you think is important I know?

Table I. Overview of the thematic analysis process.

Phase	Description
1. Data familiarisation	The primary researcher reviewed the transcript and field notes taken during the interview
2. Initial generation of themes and insights	The primary researcher and two additional research team members reviewed the transcript for emerging themes
3. Open coding	Coding of the themes by the primary researcher and team
4. Final coding	The transcript was re-examined line-by-line and codes were generated and themes established

Case outline

Country of origin experience

Makeen was born without disability in the Middle East. Bashir recounted that the family was “really wealthy” and lived in a “perfect area”. When war broke out, a wave of bombing shattered all the glass in the family’s house, and Makeen collapsed bleeding from the ears. Upon regaining consciousness, it was believed Makeen had lost his hearing, though his family noticed that Makeen was becoming unresponsive, and they suspected other injuries. They travelled extensively over a number of years to obtain a clear diagnosis; however, despite theories ranging from brain injury to autism no absolute diagnosis was made.

In 1999 Bashir and his mother Amira were forced to flee their Middle Eastern country after being chased from “one city to another”, and seek political asylum. They were unable to care for Makeen and left him at a Red Cross clinic in their country of origin, for lack of better alternatives. After a period of time the Red Cross was no longer able to operate in the country and the government took over the clinic. Bashir and his mother had no contact with Makeen for a period of six years and are unclear of what happened to him during this time, although they have had reports of torture:

Where he was they used to tie him to the window so they don’t give him food, you know. And they torture him, they used to hit him on the head. And his teeth were like, all broken. And he was tortured for years, and they were giving him drugs and all these kinds of things.

The search for Makeen

Bashir and Amira arrived in Australia in 2005 after being recognised by the UNHCR as refugees. They were driven to a residential unit by a settlement service provider and told that as they spoke English they would do well. Bashir stated that they received minimal

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relevant advice. After finding employment and saving some money, Bashir and Amira began searching for Makeen. Their extended family had also left their country of origin, which exacerbated the difficulties in locating Makeen. Eventually, someone was found who was willing to look for Makeen at the centre where he was left and take him into their care if he was found. This came at great financial expense to Bashir and Amira.

Makeen was found, but was not “in a good shape” and was taken to live with relatives. Makeen was granted a visa to come to Australia in 2007. There was significant difficulty in securing Makeen’s escape from the country and the carers who were now financially dependent on Bashir and Amira; however, eventually Bashir managed to bring him to Australia.

The family’s experience of disability service provision

A resettlement service contacted a disability service who assessed Makeen as being eligible for support due to his high support needs and Bashir and Amira’s full-time work commitments. Bashir and Amira had no understanding of how the broader disability service system operated. Makeen was invited to move into a supported residential service with three other men. Bashir and Amira agreed.

Medical assessments arranged by the residential service provider led to different diagnoses, including epilepsy. Bashir and Amira did not think he had epilepsy, but were working a number of different jobs, and attempting to establish themselves in a new context. The family had very limited involvement in the medical assessment and prescription of medication for Makeen and at the time of interview believed that a definitive diagnosis had still not been made. They trusted the new service: “We trust, we saw how nice Australians were as people, and we thought, you know [...]”. They compared their situation to their country of origin where “[...] governments, they treat people so badly, the system was so bad – people were disadvantaged by the system”.

After a period of time, the service provider informed the family of their intention to move Makeen to a house, almost 40 kilometres away from Bashir and Amira. This distance was “nearly impossible” for Bashir and Amira to travel, and they were worried and unhappy. The service provider said “[...] it’s happening, and if you don’t like it take him out of the service”. Bashir did not know who to contact, and was referred from one service to another. He waited three to four weeks for a call-back, during which time Makeen was relocated. The service undertook to drive Makeen to Bashir and Amira for visits; however, this happened less and less frequently. Bashir noted that when Makeen came to visit, the amount of medication he was required to take had increased. The service provider reported that Makeen’s behaviour was increasingly challenging. Bashir asked the service to provide him with activities, to teach him skills. The service said there was no funding.

The service provider applied to the Queensland Civil and Administrative Tribunal (QCAT) for an order to appoint a legal guardian for restrictive practices. Bashir and Amira were acting as informal decision makers for pro re nata (or as needed) medication; however, a change in

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legislation required a formally appointed decision maker. Bashir stated that the service provider had said “we are applying, we are filling all the forms, you like it or not” ... “the service where my brother is, they treated us very badly”. The family did not fully understand what chemical or physical restraint entailed, nor did they understand the QCAT process or role of the legal guardian. Bashir reported being fearful of the consequences for Makeen’s care if they challenged the use of restrictive practices by the service. This fear was driven by their experiences in their country of origin and information that alternative care providers were not available. Thus, they were unable to effectively advocate or represent themselves in the tribunal process and a legal guardian for restrictive practices was appointed by QCAT for Makeen. Bashir felt that after this appointment Makeen’s life became worse, and there was no assistance in addressing his behaviours.

The situation continued to escalate with Makeen being required to pay for any damage he caused to his home, which he could not afford to pay. As the situation escalated so did Makeen’s CB. Around this time the family were referred to an advocacy agency which provided much needed information, and intervention. Makeen was relocated to temporary accommodation with a new service provider, unfortunately it was almost three-and-a-half hours away from his family. Permanent accommodation and resolution of Makeen’s care needs had not been obtained at the time of the interview; however, the advocacy agency was experienced as providing “[...] some light at the end of the tunnel [...]”.

Thematic analysis

A number of key themes emerged from the story told by Bashir. These include the isolation of people with disability in his country of origin and in Australia, the issues surrounding the family’s difficulties understanding and negotiating complex service systems, their unsatisfactory interactions with both government and non-government services, and their struggles to safeguard Makeen’s human rights. The lived experiences of the family influenced their interactions with service systems in Australia, demonstrating the criticality of understanding context.

Isolation

For people from refugee backgrounds settling in a new country, constructing social bonds with members of like-ethnic groups facilitates the sharing of cultural practices and customs, allowing for the easy sharing of information, and reduced isolation (Ager and Strang, 2008). Social contact and support are critical in maintaining individual and familial well-being (Simich et al., 2005, p. 259) and may provide a “buffer” between individuals and stressful life events (Sonn, 2002, p. 7), support major transitions such as immigration in the lives of families, and enhance and develop familial and individual coping skills (Simich et al., 2005, p. 259). A lack of social support may result in alienation and isolation from the broader community and poor mental health outcomes (Albrecht et al., 2009, p. 264). Yet, where disability is present, the community may be a source of stigma and shame. Makeen and Bashir both spent their formative years in a Middle Eastern country, where people with disability attracted feelings of pity from the community, and shame from family members. For Bashir, this meant denying Makeen’s existence when asked about having siblings:

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[...] when I was a kid at school they asked me “do you have any brother or sister”, I say no, I am an only child. And this is the norm [...].

Bashir explained that it was typical to put the person with disability in their room whenever guests were present. People in Bashir’s community from lower socio-economic backgrounds hide their family members in basements and tied them up in a room. Disability was also seen by some to be a result of spirit possession. However, for Amira, disability was seen to be a medical issue. Multiple doctors were consulted in places such as Spain and Morocco in the search for a diagnosis for Makeen. Bashir reported that there was still a tendency within his resettled ethnic community to isolate and exclude people with disability:

They just want to isolate them and not get them involved in things [...].

It has been Bashir and Amira’s active choice to establish themselves in the wider Australian community rather than developing networks with like-ethnic communities. However, it may be that this has limited their access to the informal supports such a community can provide. Isolation from community was also evident within Makeen’s second residential placement. He was, at this time, living 40 kilometres from Bashir and Amira. Bashir implored the service provider to provide Makeen with some activities:

He can understand both English and Arabic, and you know if you teach him skills, take him to work, please get him out. And they kept saying there’s not enough funding, there’s no funding.

Bashir questioned whether this lack of service provision was connected to a lack of funding, laziness, or whether the staff were getting paid enough to provide quality services. He also speculated whether something “fishy” was going on behind the scenes.

Restrictive practices

The reported increase in Makeen’s CBs caused Bashir and Amira considerable concern. Bashir and Amira, who were working seven days a week, saw Makeen less once he was moved further away. At the same time, the family noticed his medication was increasing:

[...] his Webster pack, that’s the packet where he takes his tablets from, start to get bigger and bigger and bigger with more tablets and tablets.

There was also questions for Bashir and Amira concerning why Makeen had been diagnosed with epilepsy. This diagnosis resulted in the prescription of Epilem; however, the family remains unconvinced:

[...] we don’t think he has epilepsy at all. And for all these years since 2007, he’s been using Epilem [...] the tablet. But we always said he never had epilepsy, I don’t know why you guys diagnosed him with epilepsy.

Significantly, Bashir and Amira were accepting of the use of chemical restraint for Makeen:

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[...] the chemical restraining we didn't have much problem with it at that time.

Bashir perceived the application to QCAT for a legal guardian for restrictive practices proceeding regardless of whether the family approved or not. He felt that his lack of understanding of how the system worked meant that the organisation could:

[...] get away from many, many things and they just wanted to do anything they want.

For the family, who did not have an established understanding of the system or legislation associated with chemical and physical restraint, the application to physically restrain Makeen affected them emotionally. Amira questioned whether Makeen would be hit or tortured. Bashir did not know the answer:

And I said I don't know, it's a grey line, if he was angry or tried to push the staff away and the staff couldn't communicate with him, there are so many things happening with the service provider [...].

There was fear that the person managing restrictive practices for Makeen would be a stranger appointed by the tribunal unless the family filled this role:

[...] the way they said it, they said if you don't like it they will get a complete stranger to look after his matters. And you will never even see him, they said to us. They were really abusive. You will never see him, you will never have anything to do with the matters to do with his life, have nothing to do with him. So that's why I was really scared. I said what are they talking about?

Bashir and Amira also feared that if they challenged the decisions made by the QCAT, then the service provider would refuse to care for Makeen:

If you have anything, go to the tribunal and try to challenge it. But we were worried if we go to the tribunal the service will say if you don't say these things we will kick him out. You go and take him – and where do we take him?

The appointed guardian for restrictive practices had little communication with Bashir and Amira:

Interviewer: *"[...] do they let you know what's going on with your brother?"*

Participant: *"Zero, nothing. To answer that question, absolutely nothing. Only contact when the tribunal the time and that's it. Nothing at all [...]."*

The family's interaction with services

Within many refugee communities there is a general lack of understanding of the functions and services provided by health care facilities (Davidson et al., 2004, p. 567; Sheikh-Mohammed et al., 2006, p. 595; Woodland et al., 2010, p. 3). This lack of understanding was evident for Bashir and Amira. Whilst Bashir and Amira were encouraged by the resettlement service to take time to learn how the system worked before seeking employment, they felt a sense of urgency to gain employment and "catch up" as they had "missed so many things".

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They had little idea of any service infrastructure. For example, to find out how to hire a lawyer to help bring Makeen to Australia, Amira walked from one end of the city to another, asking people in businesses for help. Eventually, she found a service which provides free legal advice for refugees, who agreed to assist her.

Services did not communicate well with Bashir and Amira, and given their previous experiences in their country of origin and their fear of retribution from services in Australia, they struggled to effectively advocate for Makeen. Bashir had particularly poor experiences with the private disability service provider. He related concerns about staff turnover, moving his brother to accommodation further from the family, the lack of stimulation for Makeen, and the application to QCAT for a legal guardian to be appointed for restrictive practices. He experienced government staff as reluctant to help:

[...] and the lady on the phone was very unhelpful [...] Every time I say to her, ask a question, she said so what do you want me to do to you?

Further difficulty arose when Bashir tried to lodge a formal complaint about the disability service provider, “forms and forms and forms” presented as an insurmountable barrier. Their feelings of helplessness about achieving change were exacerbated when a government representative agreed the service was “awful” but questioned what she could do about it:

I know exactly what you say [Bashir], and the service provider they are awful, but what can I do? She would say to me like this, she would say they awful [...].

These experiences caused considerable stress for Bashir and Amira:

And it’s very stressful to my Mum, so I have to do it. And it was really, really, stressful, like I can’t explain to you. And, eventually, I don’t know, we were just going around in circles. Bashir speaks English fluently, but he spoke about the difference between speaking to service providers and communicating with them. Despite his fluency, he felt that his situation was:

[...] really dark, and you don’t know where you are going, and you don’t know what to expect and what’s happening.

It was also evident that this service provider had little understanding of the context and background Makeen had come from. Little or no investigation had been conducted regarding his mental health and his experiences before he came to Australia. Staff in his supported accommodation made little attempt to communicate with him. An understanding of his history of torture, abuse, and deprivation of liberty in his country of origin would have assisted in understanding his behaviours and the family’s fears regarding physical restraint. A key point of difference was the family’s experience with the advocacy agency:

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So the advocacy service started to take a lot of that burden off my back, my mum's back, a lot of it [...] because like when [service provider] comes in and say no to me, I would hang up the phone and just go do nothing and my mum go cry. But with the advocacy service, no, because they were more specialised in this thing, and they would go and search and say no, we have contacted certain people and instead of giving us a no, why don't we go to do this and this and this [...].

Discussion

This is the story of one family and as such is not representative of the diverse experiences of people from refugee backgrounds with disability. Nonetheless, it does demonstrate the complexity and difficulties that may accompany the negotiation of systems in a new country for people with disability from refugee backgrounds. The family's interaction with Queensland's restrictive practices regime adds an additional layer of complexity.

Makeen, Bashir, and Amira's experiences are shaped by both their country of origin and country of resettlement contexts. Their gratitude for services that did not torture or harm Makeen positioned them to be accepting of practices that they did not fully comprehend. Their fear of retribution, desperation to rebuild their lives financially and secure their family's future, and lack of understanding of the service system and their rights led to them not being able to have a voice in Makeen's care. They have spent much of Makeen's time in Australia confused about his diagnosis, medication, behaviour management, and care needs. Of great concern is that they have genuinely feared for his well-being whilst in the care of a funded service. Government, non-government and private services appear to have failed to understand both the historical and current context of the family; assuming their knowledge, skills, and capacity to navigate a foreign complex system. Of particular note, is that these difficulties were experienced despite Bashir's fluency in spoken English. This suggests that these issues would be further compounded for people with less fluency. A key turning point for this family has been their introduction to an advocacy agency that has helped them understand the service system, how to navigate it, and how to more fully exercise their right to advocate for Makeen's well-being. The introduction of this agency upon Makeen's arrival in Australia may have made a significant difference to the standard of care he received and the possibility of the family working in partnership with the provider.

Conclusion

This case study explores the experiences of a family where intellectual disability with CBs intersects with the lived experience of being of refugee background. It highlights the isolation from community of origin and mainstream society that this intersection creates. For Bashir and Amira this isolation is due to the dual stigma of having a family member with disability and their refugee status, as well as the financial burden of rebuilding ones lives and the isolation that long working hours creates. Makeen was isolated in supported accommodation, with little activity and community engagement due to poor service provision, funding constraints, and limited access to his family due to his location and their limited means.

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The case study also brings to life the contentious nature of restrictive practices. The family were providing consent to chemical restraint without fully understanding the medical need or implications; and the service provider was resorting to these practices without fully understanding Makeen's history and possible behavioural triggers. Without such an understanding it is difficult to comprehend how an effective personal behaviour management plan could be devised. Only the fear of physical restraint prompted the family to challenge the need for restrictive practices.

De-contextualised, poor communication with the family from a range of service providers is evident throughout the family's resettlement experience. The case study suggests that simple steps such as seeking to understand people's country of origin experiences, orienting people to relevant service systems, informing them of their rights, providing clear and detailed information that does not assume pre-existing knowledge, and linking them with suitable advocacy services early in their resettlement journey may assist in avoiding much of the distress experienced by Makeen, Bashir, and Amira.

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