
2-12-2024

Online Bilingual Co-Design: Developing Resources with People with Disability and Family Members from Refugee Backgrounds

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Recommended APA Citation

Dew, A., Murad, M., Smith, L., Watson, J., Robinson, K., Higgins, M., Preston-Thomas, C., Stow, M., Culos, I., Coello, M., Momartin, S., Astourian, C., Johnson, K., Lenette, C., & Boydell, K. (2024). Online Bilingual Co-Design: Developing Resources with People with Disability and Family Members from Refugee Backgrounds. *The Qualitative Report*, 29(2), 577-593. <https://doi.org/10.46743/2160-3715/2024.6377>

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Abstract

People with disability from Syrian and Iraqi refugee backgrounds living in Australia have limited access to information and resources in Arabic language. Our study aim was to use a co-design process to create a suite of Arabic-language resources to increase information access and build capacity of people with disability and family members from refugee backgrounds to use services, and of disability and refugee services to provide relevant support. Following a rapid literature review about access to supports and services for people with disability from refugee backgrounds, workshops were held with 38 people with disability and family members from Syrian and Iraqi refugee backgrounds to identify service access barriers. An online bi-lingual co-design group involving six people with disability and family members, six service providers and four researchers then developed resource content and formats to address identified barriers. Professional video production companies developed the visual resources. A co-developed dissemination plan ensured the resources reached target audiences. This paper details the PAR bilingual co-design method used and explains how using this method resulted in an active and equitable partnership through which all members' capacity and understanding was built resulting in a range of practical resources for use by those who reported a need but limited access.

Keywords

co-design, participatory action research, bilingual, refugee, disability, carers, community accessibility, support

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Acknowledgements

We acknowledge the resilience of people with disability and family members from refugee backgrounds and thank all those who took part in the workshops and co-design groups. We pay our respects to the Traditional Custodians of the Lands where this research took place and acknowledge that sovereignty has never been ceded.

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Online Bilingual Co-Design: Developing Resources with People with Disability and Family Members from Refugee Backgrounds

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People with disability from Syrian and Iraqi refugee backgrounds living in Australia have limited access to information and resources in Arabic language. Our study aim was to use a co-design process to create a suite of Arabic-language resources to increase information access and build capacity of people with disability and family members from refugee backgrounds to use services, and of disability and refugee services to provide relevant support. Following a rapid literature review about access to supports and services for people with disability from refugee backgrounds, workshops were held with 38 people with disability and family members from Syrian and Iraqi refugee backgrounds to identify service access barriers. An online bi-lingual co-design group involving six people with disability and family members, six service providers and four researchers then developed resource content and formats to address identified barriers. Professional video production companies developed the visual resources. A co-developed dissemination plan ensured the resources reached target audiences. This paper details the PAR bilingual co-design method used and explains how using this method resulted in an active and equitable partnership through which all members' capacity and understanding was built resulting in a range of practical resources for use by those who reported a need but limited access.

Keywords: co-design, participatory action research, bilingual, refugee, disability, carers, community accessibility, support

Introduction

This paper reports on the use of co-design to create a suite of resources to increase information access and build capacity of people with disability and family members from Syrian and Iraqi refugee backgrounds to use services, and of disability and refugee services to provide relevant support.

The need for Arabic language resources was identified in previous research and by service providers due, over the past ten years, to an increasing number of people with disability and their family members settling in Australia on Humanitarian Visas (Dew, 2023; Dew et al., 2021; Dew, Lenette et al., 2022; Dew, Watson et al., 2022; Duell-Piening, 2018; Smith et al., 2022; Soldatic et al., 2015; Wells et al., 2021). Article 1 of the United Nations Convention on the Rights of Persons with Disabilities defines disability as: "...long term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder [the person's] full and effective participation in society on an equal basis with others" (United Nations, 2022). In Australia, people from refugee backgrounds who receive Humanitarian Visas are eligible to access income supports and community services that promote disability, health, and educational inclusion (Dew, Lenette et al., 2022). There is evidence that gaining access to these supports and services is challenging for many people in this situation (Dew, Lenette et al., 2022; Hirsch et al., 2019; King et al., 2016; Soldatic et al., 2015). Reasons for these challenges include failure to provide the often-complex service information in community languages and to support navigation of these systems (Dew, Lenette et al., 2022; Hirsch et al., 2019; King et al., 2016; Soldatic et al., 2015).

The National Disability Insurance Scheme (NDIS) was introduced progressively across Australia from 2013 to provide individualised funding for eligible individuals to purchase "reasonable and necessary" supports (NDIA, 2022b). The first hurdle to access NDIS funding is to prove "significant and permanent" impairment (NDIA, 2022a). People with disability from refugee backgrounds may not have received a formal diagnosis in their country of origin or may have fled without explanatory paperwork (Smith-Khan et al., 2014). For people from non-English speaking backgrounds and for those unfamiliar with Australian service systems, the online NDIS application process is difficult to navigate without assistance (Dew, Watson et al., 2022). Our previous research with people with disability and family members from Syrian and Iraqi refugee backgrounds highlighted these difficulties (Dew, 2023; Dew, Lenette et al., 2022; Dew, Watson et al., 2022; Dew et al., 2021; Smith et al., 2022; Wells et al., 2021).

Our current project is informed by the seminal work of Penchansky and Thomas (1981) in which they postulated a theory of access incorporating five dimensions: accessibility, availability, acceptability, affordability, and adequacy (or accommodation). The 'fit' between these dimensions in relation to the service user and the service provider is critical in determining access. The better the fit, the better the access. Our earlier work identified a poor fit in terms of access to services for people with disability and family members from refugee backgrounds.

Based on a longstanding partnership between refugee settlement and support providers, disability service providers, people with lived experience of disability from refugee backgrounds, and academics, the authors engaged in a participatory action research (PAR) project using co-design methods to create resources to assist Arabic-speaking people to understand and access disability supports including NDIS funding. This paper describes the co-design method we used to develop these resources. Conducting the research during the COVID-19 pandemic and associated restrictions meant we adapted the method for online delivery. The complexity of doing this was compounded by bilingual and bicultural considerations. The paper identifies the benefits and challenges of using a PAR online bilingual co-design method to create a range of resources in Arabic language including videos and postcards.

PAR involves engagement between researchers and co-researchers - people with lived and/or professional experience of the topic under exploration - to find practical solutions to identified, often complex, challenges about which there is little empirical evidence (Hughes, 2008; Lenette, 2022; Reason & Bradbury, 2008). Co-researchers may include people with disability, family members, practitioners, and policy makers (Collings et al., 2021) and,

according to Lenette (2022, p. 2), co-researchers are “active agents in the co-production of new knowledge.” Lenette (2022) noted that it is this participation by people with lived experience throughout the research process that sets PAR apart from other broader participatory research approaches which may not include people with lived experience of the phenomenon in co-researcher roles. PAR typically involves an iterative, cyclical process of planning, action, observation, and reflection (Hall, 2005; Lenette, 2022).

The term co-design is a relatively recent addition to PAR vocabulary focussing on the design aspect of the research process to create innovative solutions (Masterton et al., 2022; Rolleston et al., 2022). In their systematic scoping review mapping the definitions of co-production and co-design in health and social care, Masterton et al. (2022) noted that the term co-design, originating from the 1970s Scandinavian participatory design movement, has emerged as a distinct concept from the broad umbrella term of co-production. Rolleston et al. (2022, p. 2) described co-design as an “equitable collaboration between researchers and communities using culturally centred, creative participatory methods” and they highlight the benefits of bringing together researchers, funders, and community members to collectively understand and build solutions to identified problems. McKercher (2020, pp. 14-15) identified four key principles for co-design: (a) share power in research, decision-making, design, delivery, and evaluation; (b) prioritise relationships, building trust and social connections; (c) use participatory means to facilitate self-discovery and encourage active partnerships; and (d) build capacity recognising everyone involved has something to teach as well as something to learn. Sigg Pallesen et al. (2020) and Howard and Thomas-Hughes (2021) also commented on the importance of developing and maintaining a positive team climate in co-design projects to equalise the power between researchers and co-researchers. Rolleston et al. (2022) noted that “authentic co-design” takes longer than traditional research approaches and is often logistically complex with implications for complying with grant application guidelines, research budgets and the potential of “conflicting philosophical approaches” (p. 3). Similarly, Sigg Pallesen et al. (2020) reported the need for continuous feedback in co-design supporting the emergent nature of the process. As with PAR generally, reflexivity for all involved in co-design is crucial and there is evidence that pre-existing relationships between researchers and co-design members will likely result in better and more sustainable outcomes (Howard & Thomas-Hughes, 2021; Rolleston et al., 2022).

In-person PAR and co-design are typically considered best practice due to the interactive and relational nature of the processes (McKercher, 2020). The impact of the COVID-19 pandemic meant that many research activities were necessarily shifted online. The project reported in this paper, conducted in 2021-2022, was affected by pandemic restrictions and lockdowns meaning an online approach was used for data collection and the co-design activities. One of the only published papers describing co-design online due to COVID-19 is by Fails et al. (2022). They noted that conducting co-design activities online rather than in-person allows for greater diversity of those able to participate including participants from diverse cultures, languages, and abilities. According to Fails et al., online also removes some of the logistical barriers to in-person meetings such as transportation and venue access which are important considerations for many people with disability.

Fails et al. (2022) also reported that while online participation can be less intimidating for some people, others may feel alienated and disengaged online due to perceived power imbalances and the need to request support from others to participate. While the pandemic provided opportunities for some people to enhance their digital literacy skills, those with limited access to equipment and connectivity and limited skills to problem solve when technical issues arose, were disadvantaged (Fails et al., 2022). Additionally, Fails et al. (2022) noted that conducting co-design activities online can present challenges for rapport and building trusting

relationships, identified as crucial to co-design by Rolleston et al. (2022), Howard and Thomas-Hughes (2021), McKercher (2020), and Sigg Pallesen et al. (2020). This may be particularly challenging when group members have not previously met in-person. Engaging in co-design online can make it difficult for those managing the sessions to identify when participants are disengaged or uncomfortable particularly if cameras are switched off. Fails et al. suggested a range of strategies for overcoming some of the barriers to online co-design. These included being prepared to improvise and be spontaneous in response to group dynamics and needs, being patient and providing additional time, using break-out groups and assistance for people to transition to these, and considering the length of sessions to ensure participants maximise engagement. They suggested including pre-session support to check participants' technology and digital skills ahead of time. Our experience mirrored Fails et al.'s findings as we incorporated into our project many of the strategies reported in their paper along with additional consideration for the need to conduct research and co-design work in two languages through engagement of bilingual co-researchers.

The Federation of Ethnic Communities' Councils of Australia (FECCA) published a report into the training qualifications and career pathways of bilingual and bicultural workers (FECCA, 2017). According to the report, bilingual and bicultural workers have linguistic skills and share similar cultural backgrounds and understandings as the populations with whom they work. They also bring training and professional skills relevant to the goals of the service employing them for example, health care, aged care, or disability support. Many workers are proficient in multiple languages. In the project described in this paper, bilingual/bicultural workers were involved in data collection and co-design and hence were integral to the research contributing their cultural knowledge and language skills. Squires (2009) reviewed literature to describe the methodological challenges in what she described as "cross-language qualitative research" where there was the "use of a translator or interpreter at any point during the research process" (p. 278). Squires identified two main challenges in conducting cross-language research: (a) the need for the translator/interpreter to provide an accurate translation of the concepts discussed in the research which can be problematic when, for example, a word or phrase to describe a particular concept may not exist in a language, and (b) the need for translators/interpreters to have credentials and experience to ensure the translation accurately reflects what participants said. Squires noted that failure to attend to these issues may affect the credibility and reliability of the cross-language research and should, at the very least be acknowledged as a research limitation. In our project, the involvement of bilingual workers employed in partner organisations ensured existing knowledge of the topics discussed, and common words used. Not all bilingual workers had translation credentials. However, they were all employed in roles that required daily use of translation skills.

Method

Ethics clearance for this PAR co-design project was received from Deakin University Human Research Ethics Committee. Information about the project was provided verbally and in writing, in both Arabic and English as needed/appropriate, and all participants provided either verbally recorded or written consent to participate.

PAR and co-production principles informed the initial project design, its implementation, and the co-design of the resources as at all stages people with lived experience of disability and refugee status and those who support them were integral. The full project team included eight academics from two universities in Victoria and New South Wales (NSW), the project manager (MM) who is an Arabic-speaking man with a disability from a Syrian refugee background, and representatives from the seven partner organisations who included people with lived experience of disability, family members, and providers. The project team met every

six weeks online over the life of the project to update project progress and provide guidance and feedback.

Procedures

The project was conducted over four stages. Stage 1 involved a rapid evidence assessment of peer-reviewed and grey literature about access to supports and services for people with disability from refugee backgrounds. In Stage 2 workshops were held with people with disability and family members from Syrian and Iraqi refugee backgrounds living in Australia's two most populous states, NSW and Victoria, which have the highest numbers of people from refugee backgrounds. Stage 3 involved an online bi-lingual co-design group to develop resource content and formats. The groups worked with professional video production companies to develop the visual resources. In Stage 4, a dissemination plan was co-developed and implemented to ensure the resources reached the target audiences. Each stage is described in detail below.

Stage 1 - Rapid Evidence Assessment

Stage 1 involved an initial search of previously collected peer-reviewed and grey literature related to people with disability and family members from refugee backgrounds. This literature was collected over a five-year period (2018-2022) by the academics on the research team during previous research involving this population (Dew, 2023; Dew, Lenette et al., 2022; Dew, Watson et al., 2022; Dew et al., 2021; Smith et al., 2023; Wells et al., 2021). A Web of Science search was also conducted to add any recently published peer-reviewed articles. The abstracts and keywords of all articles were scanned by the first author to identify references to disability service access for people from refugee backgrounds. Only articles that referred directly to service access issues were retained. A Google™ and organisational website search was conducted to find additional recent grey literature including reports discussing service access. Project team partner organisations reviewed the list of documents and contributed additional materials. In line with the inclusion criteria stated above, six peer-reviewed articles (Dew, Lenette et al., 2022a; Duell-Piening, 2018; Hirsch et al., 2019; King et al., 2016; Mirza & Heinemann, 2015; Soldatic et al., 2015) and five reports (Culos et al., 2020, 2021; Department of Social Services, 2017; Foundation House, 2019; The Federation of Ethnic Communities' Councils of Australia et al., 2019) were included.

These documents were deductively analysed (Armat et al., 2018) by the first author according to Levesque et al.'s (2013) five dimensions of service access: a) approachability; (b) accessibility; (c) availability and accommodation; (d) affordability; and (e) appropriateness. Levesque et al.'s work further develops these service access dimensions based on the seminal work of Penchansky and Thomas (1981) described earlier. A spreadsheet was created to align aspects of access described in each document across each of the five dimensions. This spreadsheet was shared with the full project team who verified the analysis and collectively developed a one-page plain language overview which was translated from English to Arabic. Figure 1 is an English-language version of the one-page plain language summary sent to workshop participants as a conversation starter.

Figure 1*One-Page Summary of Barriers to Accessing Services***Co-Designing Resources to Increase Access to Information and Services: Syrian and Iraqi People with Disability from Refugee Backgrounds and Service Providers****Workshop to talk about barriers to accessing services**

People with disability and their families from refugee backgrounds can find it hard to get information and services in Australia. We want to create some resources to make getting information and services easier for people with disability from Syrian and Iraqi refugee backgrounds. Before we do this, it is important we understand what makes it hard for people to get the information and services they need. Information and services may be related to housing, transport, hospital and healthcare, disability support services, allied health, education, employment, English-language classes, support in the home, and assistive technology such as wheelchairs.

We know a little about this already. We have learnt what we know by talking to people with disability and family members from refugee backgrounds, and information from services that support people and other researchers.

We hope that this summary will help you to think about your own experiences before the workshop.

It can be hard to know about services and how to contact them. For example,

- Sometimes there is not enough information about services and what they can do to help
- Information isn't in my language and dialect or easily available to me
- It can be hard to find someone to help me get the right service
- There can be long waiting times to see services and get help
- Sometimes I am embarrassed to ask for help
- I don't know how to ask for other help if the service isn't right for me or my family member

My culture is not always understood. For example,

- Some cultural differences are not understood, such as the importance of family, shared language and dialect, food, religion, the roles of men and women, and attitudes to disability or minority groups
- Communities and services don't always understand what I have experienced including the challenges of fleeing war and conflict and how these impact on my life now
- It can be hard to find and use translating and interpreting services

Services don't always take my, or my family member's, disability into account. For example,

- Housing and transport aren't available or physically accessible
- Services aren't in the area where I live
- I don't get the equipment, technology and help I, or my family member, need
- I find it hard to get an education, learn English, and find a job because of my disability or, as a family member, because I am busy caring for a person with disability

Services cost too much. For example,

- Housing rent is too expensive
- I don't get enough money to pay for the services I, or my family member needs
- Medical and specialist doctors and therapists are expensive

Services don't meet my needs. For example,

- Some staff lack experience working with people with disability
- Some staff don't stay in their jobs for long

- I find some services don't share information with each other, so I often have to repeat what I tell them
- There isn't enough long-term support for me, or my family member with disability

Stage 2 - Workshops

Using purposive sampling methods (Etikan et al., 2016), participants were recruited to workshops via the networks of author MM and partner organisations using Arabic-language flyers distributed via email and social media. Snow-ball sampling also occurred as information about the workshops was passed between potential participants (Creswell & Plano Clark, 2011). Inclusion criteria were adults (18 years +) who either had a disability (defined in line with the United Nations definition of disability provided in the introduction) or were the family member of a person with disability from a Syrian or Iraqi refugee background. It was considered important to include both people with lived experience and family members as they may hold different views and experiences of accessing services and supports.

The purpose of the workshops was to inform the co-design of resources by exploring the views of people with disability and family members from Syrian and Iraqi refugee backgrounds about their access to services and supports and issues impacting on them. The Arabic language summary of access gaps/barriers developed in Stage 1 was sent to participants prior to the workshop and used to promote discussion (see Figure 1). The workshops provided an opportunity for people to reflect on the information and resources that were useful to them, to discuss gaps and barriers to service access and use, and to suggest useful strategies and approaches to filling these.

Five workshops involving 38 participants were conducted in Arabic by co-researcher MM along with one non-Arabic speaking member of the research team (MH, LS, JW, or AD) and a visual documenter, an artist with lived experience of disability and Arabic language skills. Each workshop had between four and eleven participants. Conducted during November and December 2021, four workshops were online due to COVID-19 restrictions, and one was held in person at one of the partner organisation's premises in a location convenient and accessible to participants. Each workshop ran between 60 – 120 minutes. In recognition of their time and input, each participant received an \$100 gift card. Table 1 provides information on workshop participants.

Table 1
Workshop Participant Information (N = 38)

	No.	%
Gender		
Female	23	60
Male	15	40
Age range		
31-40	21	55
41-50	5	13
51-60	12	32
Person with disability	14	36
*Carer		
Carer for	25	64
Son/daughter	13	34
Spouse	9	24
Sibling	3	8

Country-of-origin		
Iraq	26	68
Syria	12	32

Notes. One participant identified as both having a disability and being a carer of a person with disability.

With participants' permission, workshop discussions were audio-recorded, transcribed, and translated into English language using a professional accredited transcription and translation service. The visual documenter's illustrations captured the key elements of the workshop discussions and, as well as being a visual record, were used in the resources developed in the Stage 3 co-design groups. An example of the illustrations is provided in Figure 2.

Figure 2

Illustration of Physical Access Barrier Discussed at a Workshop



Preliminary analysis of the English-language versions of the workshop transcripts was undertaken by the first author using content analysis to identify commonly described access barriers and priority areas for resource development (Hsieh & Shannon, 2005). Each workshop transcript was analysed separately with 10 barriers identified as commonly occurring across all five groups:

1. Lack of information, and confusion, about Australian systems and rights.
2. High cost of living expenses and inadequacy of income support.
3. Language barriers to asking for and accessing services including access to interpreter and translation services.
4. Housing availability, accessibility, affordability, waiting times, tenant rights, and stability.
5. National Disability Insurance Agency (NDIA) – confusion about NDIA role, how funding is determined, how to get information about access to the NDIS in Arabic language.
6. National Disability Insurance Scheme (NDIS) funded service providers - unqualified workers, lack of cultural awareness, not using interpreters or translators, lack of follow-up and continuity.

7. Health – cost of out-of-pocket payments, communication with health care providers, lack of understanding of referral system, lack of free or low-cost dental care, and long waiting times for specialist services.
8. Family stressors – financial, single parents, impact on non-disabled siblings, psychological stressors, lack of extended family support, lack of respite services, and inability to work due to caring role.
9. Lack of holistic family approach including respect for language, culture, religion, gender; need for cultural support groups to share information.
10. Transport – cost, availability, and accessibility.

Through discussions with the full project team, these ten barriers were condensed to highlight three overarching concerns that the team felt could be responded to within the co-design groups: (a) lack of information, (b) language barriers, and (c) family culture. The team considered cost issues to be outside the scope of the project because they require longer-term systemic changes. Within the three overarching concerns, four priority areas were initially identified as needing resource development: (a) housing, (b) NDIS, (c) health, and (d) impact on family.

Stage 3: Co-design Group

Co-design group members were recruited from two sources: (a) people with disability and family members who participated in the Stage 2 workshops, and (b) staff working for partner organisations including those who were bilingual in Arabic and English languages. During Stage 2, workshop participants were informed that the aim of the project was to co-design resources and invited to indicate their interest in being part of the co-design group. Workshop members who became co-design group members were given a \$200 gift card per co-design meeting in recognition of their time and expert input. Partner organisations distributed recruitment information to their employees who then indicated interest in taking part during their paid work hours and role. The final make-up of the co-design group included 16 people: six workshop participants (three people with disability and three family members), six partner organisation representatives (practitioners), the project manager (MM), and three academic team members (AD, LS, and JW).

The co-design group met online four times in successive weeks for two hours each time. An agreed-upon structured approach to the meetings was developed, with the full group meeting for the first 30 minutes with an accredited bilingual practitioner who was paid to interpret this part of each meeting. During that initial half hour, the group discussed common issues identified across the sub-groups such as the main issues to address in resource development and the most appropriate formats to use. The group then split into three online sub-groups for one hour working intensively on resource development. Each sub-group included a person with disability, a family member, two practitioners, one of whom was bilingual and interpreted for their sub-group, and an academic team member. Co-design group members self-selected to the sub-group topic they were most interested in. Each session closed with a 30-minute full group recap and to set the agenda for the following week. Members of each sub-group connected via email and completed work ‘out of session’ to bring to the next meeting. Author MM ensured that the inter-meeting communication was provided in Arabic as well as English.

The co-design group decided to further focus the development of resources, addressing three of the four identified priority areas: NDIS, (oral) health, and impact on family. By the end of the four sessions, each sub-group had a plan for the resources they would lead the

development of. Due to time and resource constraints, the fourth priority area, housing, was explored through a presentation at one of the meetings by a representative of a tenancy rights group who spoke about the services provided to people from culturally and linguistically diverse backgrounds. Other people with specialised knowledge were invited to provide input into the co-design group meetings, for example around carer supports and specialist dental care for people with disability. This input was provided to the full group during the initial half hour and was informative for all and useful for the specific sub-groups in considering resource development.

Stage 4 - Resource Dissemination

Resource dissemination was discussed in the final co-design group meeting and with the full project team. A knowledge translation/dissemination plan was co-produced by the project team detailing strategies, key stakeholders, and timeframes. The group agreed on a 'trusted places and spaces' approach relying on local knowledge and contacts. Strategies included providing information about the resources for local Arabic-language newspapers and radio stations, distribution of links to the resources through places of worship (mosques and churches) and local community centres. Additionally, the project team used their organisational networks and communication strategies to disseminate information about the resources. Conference and meeting presentations and journal publications were also planned.

Discussion of the Benefits and Challenges of the Online Bi-lingual Co-design Process

Each stage of this multi-stage project contributed to the successful outcomes achieved. There were several challenges that, in large part, were successfully navigated due to the highly collaborative nature of the team reflected in the PAR and co-design method and built on the previous relationships between partner members. The importance of this collaborative approach in co-design work was highlighted by Rolleston et al. (2022), Lenette (2022), McKercher, (2020), and Siig Pallesen et al. (2020).

The first stage of the project enabled us to distil evidence about service access for people with disability from refugee backgrounds from peer-reviewed literature and reports and provide this in an accessible (translated into Arabic language), succinct format to stimulate workshop discussion (see Figure 1 for English-language version). Applying Levesque et al.'s (2013) five dimensions of service access provided us with a framework for unpacking and understanding service access in a systematic way. Sharing the distillation of this evidence with the Stage 2 workshop participants provided a springboard to the discussions which then 'put flesh on the bones' of the evidence with real life examples. Conducting the workshops in Arabic rather than via an interpreter facilitated the free flow of discussion within and amongst the group members and helped to build trust and rapport within each group (McKercher, 2020; Squires, 2009). Content analysis of the translated workshop data identified the priority areas for resource development in the Stage 3 co-design group (Hsieh & Shannon, 2005). In keeping with PAR methods, including multiple perspectives from workshop participants, practitioners and academics in the co-design group added veracity to decisions made about resource priorities, content, and format (McCormack & Dewing, 2012).

As discussed by Fails et al. (2022), conducting our co-design activities online rather than in-person allowed for greater diversity of those able to participate and removed some of the logistical barriers to in-person meetings. This flexibility was a key element in the success of the project. Also, of critical importance to the success of the co-design process was the bilingual facilitation by practitioners experienced in interpreting and knowledgeable about living with disability and Syrian and Iraqi culture due to their own lived experience (Squires,

2009; FECCA, 2017). With one exception, these bi-lingual workers were not accredited translators as recommended by Squires (2009) however, their daily work roles involved translation and interpreting.

The methodological challenges of the co-design process were two-fold: language challenges and the need to conduct the co-design groups online due to COVID-19 restrictions in place at the time. As described by Squires (2009), working across English and Arabic languages poses challenges to an inclusive PAR approach. Except for MM, the research team do not speak Arabic, but are experienced in refugee- and disability-inclusive research. MM was contracted to facilitate the Stage 2 workshop discussions as well as translate for the non-Arabic speaking academic staff member who attended. The real-time production of illustrations of participant statements by the visual documenter also supported the non-Arabic-speaking staff member to follow the discussion, however it was more difficult than had been anticipated for these staff members to assist with and support the discussions. This extended the length of the online workshops and extensive post-workshop debriefing was required. The flow of the workshops became smoother as MM became more familiar with, and took on feedback about, strategies for promoting discussion.

In Stages 3 and 4, project team partner organisations were crucial in bridging the language divide, supporting bilingual staff to participate in the co-design group and act as interpreters (Squires, 2009). Author MM played a vital role in connecting with and supporting participants throughout the project and, due to his shared experience and language, MM developed trust and rapport with participants which greatly enhanced the success of the project (McKercher, 2020). The experience of working across languages was different between the co-design sub-groups. Author LS was the only non-Arabic speaker in her sub-group and so group discussions largely occurred in Arabic with occasional pauses to fill LS in on the direction of the discussions. LS noted that this way of working represented an example of power sharing whereby the researcher was the person 'left out' of discussions – a common experience of non-English speaking research participants in other settings. LS also noted that during later co-design meetings to develop a script for a video, the group members used English more frequently perhaps feeling more comfortable with LS and not so concerned about 'making mistakes' in English.

Another challenge to the project was the need, due to COVID-19 density restrictions, to conduct most of the Stage 2 workshops and all the Stage 3 co-design group meetings online using videoconferencing. As described by Fails et al. (2022), videoconferencing technology was problematic for some workshop participants meaning MM provided significant support to several people for them to be able to use the technology. Our reliance on technology meant some people were not able to take part in the online workshops and unfortunately, we did not have the capacity or budget to hold individual interviews which were requested by some potential participants. An advantage of being online was that people from NSW and Victoria and from metropolitan and regional areas were included. This enabled us to overcome an additional logistical barrier (geographic distance) to those identified by Fails et al. (2022). Being online also meant we convened one co-design group rather than one in each State as originally proposed. Moving the co-design work to an online format with the added complexity of working in two languages compounded the logistical challenges inherent in cross cultural co-design work identified by Rolleston et al. (2022). The bilingual practitioners were essential to making this work as they were experts in working with people with lived experience as they themselves were from Arabic-speaking refugee or migrant backgrounds (FECCA, 2017). In keeping with Fails et al.'s (2022) recommendation, using small sub-groups in the co-design process enabled a smooth flow of Arabic and English language discussion between group members which was harder to achieve in the larger group.

Outcomes and Outputs of the Co-design Process

The main aim and outcome of the project was to improve the access of people with disability and family members from Syrian and Iraqi refugee backgrounds to community services and supports. A further outcome was enhanced knowledge about barriers to accessing services from the perspectives of both people with disability and family members to better target resources to their specific needs.

These outcomes were achieved through the production of a range of practical resources identified, planned, and created using a co-design process. Co-design members overwhelmingly felt that Arabic-language videos were the most appropriate format for several reasons. Videos can be distributed via social media channels regularly used by Iraqi and Syrian communities. They are also accessible for people with low literacy skills who will not read information sheets and brochures. Short, animated videos are engaging without taking a lot of time to view and there is an emerging evidence base showing their effectiveness for knowledge translation (Boydell & Croguennec, 2022). Across the three identified priority areas six short, animated Arabic-language videos were produced providing tailored information about the NDIS and one on supporting families. A postcard with information about oral hygiene and regular dental care for people with disability, tips for this care and information about where affordable dental care for people with disability can be obtained in each Australian state/territory was also produced. The final videos were produced by media companies and the postcard was designed as part of an assignment by visual design students from Deakin University. Illustrations from the workshops and additional commissioned images were used in the resources.

As identified in Stage 4, dissemination of the resources is key to their uptake using the approach of ‘trusted places and spaces’ used by people with disability and family members from Syrian and Iraqi refugee backgrounds. In line with the co-produced dissemination plan, partner organisations committed to disseminating the resources through their various channels and networks using websites, Facebook pages, WhatsApp groups, Viber, community newspapers and radio. Places of worship and community centres were also identified as ideal dissemination venues along with general practitioner clinics. This dissemination is ongoing with 350 video views recorded within the first month of dissemination. We also received feedback from several co-design group participants: “It was my absolute pleasure to be able to help with this fantastic project. After all, this project will help my community.” (Co-design group member, bi-lingual practitioner) and “I really like to learn new things – this [project] gave me a sense of hope.” (Co-design group, carer) The project team and resources were awarded the inaugural New South Wales Multicultural Health Communication Refugee Resources Award 2023.

Transferability of the Project Method

This paper describes the application of a PAR co-design method using an online bi-lingual approach. In publishing this paper, we hope that other researchers will find the description of our adaptation and application of this method to be useful in planning future projects involving participants from culturally and linguistically diverse backgrounds in PAR co-design.

Limitations

This project was conducted over a relatively short period of 10 months due to grant funding requirements. This meant we condensed the co-design groupwork to weekly meetings

over a one-month period with email communication in-between. This was an impost on co-design members' time and required a high level of commitment. Being able to spread the co-design work over a longer period may have been beneficial although the upside was that people retained their interest and momentum evidenced by the retention of co-design members for the duration of the project.

Working with commercial media companies to produce the animated videos was also challenging especially as COVID-19 impacted on the media companies' staff time and continuity. The production of the videos took much longer than anticipated in part due to the complexity of producing them in Arabic-language and our commitment to employing people with lived experience as visual and voice-over artists. The video production companies were only involved in the project towards the end of the co-design group meetings and were not necessarily culturally aware, meaning some of their design assumptions relied on stereotypes that were inaccurate, for example, presuming that all Syrian and Iraqi women were Muslim and wore hijab. Many of our participants came from Christian minorities or were not religious and not all Muslim women choose to wear hijab. We were able to address these issues with the companies to include a range of images, but this required additional scrutiny and time. The effort paid off with one co-design member commenting, "I liked the idea of being inclusive to have men and women showing in the video and woman with Al-hijab and without. Well-done to all, very impressive!" (Co-design group member, bi-lingual practitioner)

We included people with a range of disability in the workshops and co-design group. We acknowledge that people have a range of access issues related to their specific impairment and participation in an online forum may be more difficult for some people than others, for example, people with intellectual or cognitive impairment and those with complex communication needs who may have been excluded due to this. Conducting the co-design groups online also meant we had people with disability and family members in the same group. During the planning stages the project team discussed the pros and cons of running separate sessions for these groups to minimise feelings of discomfort or constraint and to allow people to speak freely from their own perspective. Having a mix of people with disability and family members in the online groups was however unavoidable and it is difficult to know what impact this had on the outcomes. Although not articulated by participants, the mixed makeup of groups may have been preferable to some due to the highly relational nature of their family structure, an aspect of middle eastern culture identified by Danga et al. (2022) and Shahnava (2023).

Conclusion

Our previous work identified a gap in knowledge about how people with disability and family members from Syrian and Iraqi refugee backgrounds access disability and other community services and supports (Dew, 2023; Dew, Lenette et al., 2022; Dew, Watson et al., 2022; Dew et al., 2021; Smith et al., 2022; Wells et al., 2021). This paper reports on a PAR project that engaged people from this group alongside bilingual practitioners to co-design a suite of resources to address service access challenges. In so doing, this paper adds to the limited literature on bilingual co-design methods. We concur with Fail et al.'s (2022) recommendations that using co-design methods with bilingual participants requires a commitment to responding and adapting to challenges as they present, ensuring additional time and fluid structures so all can participate, and offering pre-session and ongoing support with technology. Employment of a person with lived experience and language proficiency was crucial as we could not have recruited or maintained the engagement of participants in workshops and the co-design group without this. Our experience using a PAR bilingual co-design method resulted in an active and equitable partnership through which all members'

capacity and understanding was built resulting in a range of practical resources for use by those who reported a need but limited access.

Implications for Future PAR Co-design Research

Our adaptation and application of a PAR co-design research approach using online bi-lingual methods has implications for others considering research with similar cohorts and using similar methods. Our work highlights the importance of genuine and respectful co-design engaging people with lived experience at all stages of research design, implementation, and dissemination. Our work also showcases the value of academic and practitioner collaboration to ensure both rigor in research method and real-world application of research results.

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Wells, R., Murad, M., Higgins, M., Smith, L., Lenette, C., Lappin, J., Dew, A., Boydell, K., Bibby, H., Cassaniti, M., Isaacs, D., Raman, S., & Zwi, K. (2021). Exploring the intersection of human rights, health, disability and refugee status: An arts-based approach. *Australian Journal of Human Rights*, 26(3), 387-404.
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Acknowledgements: We acknowledge the resilience of people with disabilities and family members from refugee backgrounds and thank all those who took part in the workshops and co-design groups. We pay our respects to the Traditional Custodians of the Lands where this research took place and acknowledge that sovereignty has never been ceded.

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Article Citation

Dew, A., Murad, M., Smith, L., Watson, J., Robinson, K., Higgins, M., Preston-Thomas, C., Stow, M., Culos, I., Coello, M., Momartin, S., Astorian, C., Johnson, K., Lenette, C., & Boydell, K. (2024). Online bilingual co-design: Developing resources with people with disability and family members from refugee backgrounds. *The Qualitative Report*, 29(2), 577-593. <https://doi.org/10.46743/2160-3715/2024.6377>
