

Co-Designing Access Information with People with Disability from Syrian and Iraqi Refugee Backgrounds

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On behalf of the research team



Original artwork by Mr Nasan Asber



Acknowledgement of Country



I acknowledge and pay our respects to the Elders, past and present, of the Aboriginal and Torres Strait Islander peoples on whose unceded lands this research was conducted.



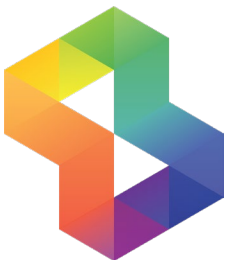


Syrian and Iraqi Refugees



- ❖ 15 million Syrians and Iraqis fled war
- ❖ 2015 Australia accepted 12,000 Syrian and Iraqi humanitarian entrants
- ❖ 2012 Australia streamlined health waiver
- ❖ Refugees with disability eligible to come to Australia

Australian Government, 2012; Refugee Council of Australia, 2017a, 2017b, 2019





People with disability from refugee background

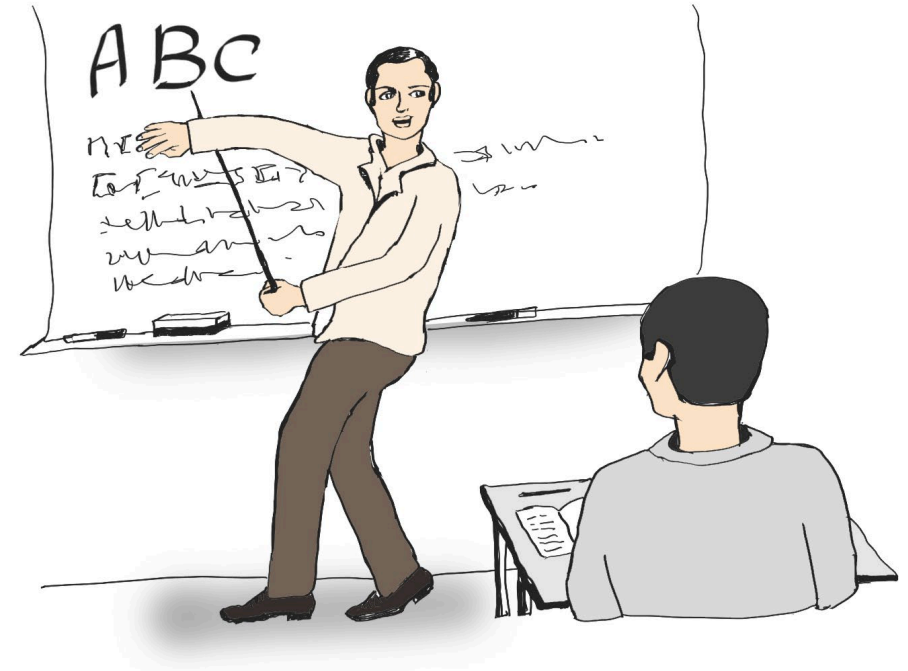




Eligibility and access to supports and services

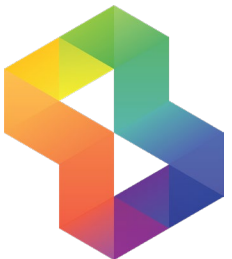
Humanitarian visa recipients are eligible to access Australian supports and services

- ✓ Disability services
- ✓ Health services
- ✓ Education
- ✓ Welfare entitlements



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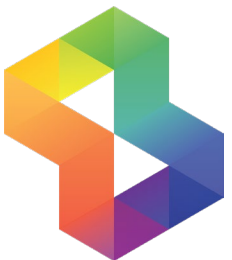
Soldatic et al., 2015; Crock et al., 2017; Dew et al., 2022a, 2022b, 2020, 2021; Refugee Council of Australia, 2019; Smith et al., 2022; Wells et al., 2021





“I have spent a long time in Australia learning how to ask and search for services. I support others in my community to do this. I have observed that many people from refugee backgrounds are focused on getting basic needs and do not have any expectation that they will receive [disability support], so they do not ask for it.”

(Murad cited in Wells et al., 2021: 387)





Partnership grant to develop resources



Funding provided by the National Disability Research Partnership, hosted by the University of Melbourne and funded by the Department of Social Services.





Project Aim

Co-design 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;
- services to provide support.



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Step 1: Desk based:
Identify information
and resource access
gaps and barriers:
previous research;
literature review

Step 2: Arabic-
language Workshops:
38 service users to
identify information
needed to access
services and supports

Step 3: Co-design
group: online bilingual
group (n=16)
Graphic designers and
video companies to
create resources

Step 4: Knowledge
exchange – “trusted
places and spaces”



Participatory Action Research and Co-design

Equitable collaboration between researchers and communities.

Using culturally centred, creative participatory methods.

Co-researchers: active agents in co-production of new knowledge.

Iterative, cyclical process - planning, action, observation and reflection.

Create innovative solutions.

Four key principles for co-design:

1. **Share power** in decision-making, design, delivery and evaluation;
2. **Prioritise relationships**, building trust and social connections;
3. Use **participatory means** to facilitate self-discovery and encourage active partnerships;
4. **Build capacity**: everyone has something to teach as well as something to learn.





Co-designed Resources

Oral Health Postcard



الصحة الفموية مهمة جدًا لصحتنا واحترامنا لذاتنا ونوعية حياتنا

تعد الصحة الفموية الجيدة جزءًا مهمًا من الصحة العامة لكل شخص.

- يمكن للضم النظيف والصحي أن يساعد الشخص على أن يبدو ويشعر بتحسن تجاه نفسه.
- قد تؤدي الصحة الفموية السيئة إلى الشعور بالألم وتغيير في المذاق والنوم المتقطع وصعوبة في الأكل ومشكلات سنية أخرى.

من المرجح أن يعاني الأشخاص من ذوي الإعاقة من سوء الصحة الفموية مقارنة ببقية أفراد المجتمع. هذا لأنهم قد:

- يجدون صعوبة في تنظيف الأسنان والشفاه
- يعانون من انخفاض السمع والبصر
- يجدون صعوبة في فهم التعليمات المكتوبة
- يعانون من الغثاس (مرض الارتداد الحمضي) الذي يسبب الحموضة
- يتناولون أدوية يمكن أن تضر الأسنان
- يعانون من مشاكل في الوصول إلى خدمات الأسنان العامة

يحتاج الأشخاص من ذوي الإعاقة إلى دعم إضافي للحصول على خدمات العناية الفموية.

تتوفر المعلومات باللغة الإنجليزية فقط في باقي الولايات والقلم

NSW

National Disability Insurance Scheme Information Videos



Families with Disability Video (funded by NSW Refugee Health Service)



<https://youtu.be/aQHrkDgtdrY>





Challenges

Challenges

- Bridging language and cultural differences
- Connecting with the communities
- Gaining trust & power sharing
- COVID restrictions
- IT challenges
- Timeframe for project – condensed co-design

Solutions

- Bi-lingual approach Arabic privileged / English secondary
- Leveraging our partners
- Employing people with lived experience
- Conducting workshops and groups online
- Trouble-shooting and support
- Maintained momentum between group sessions



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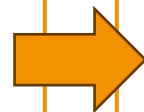
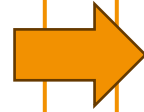
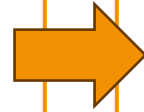




Implications

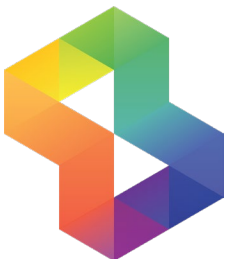
What we'd do again

- Conducting research in participants' language not via an interpreter
- Including multiple perspective at all stages
- Online workshops and co-design groups
- Bi-lingual co-design group facilitation by practitioners
- Visual outputs and resources



Why we'd do it

- Built trust and rapport
- Added to veracity of decisions made
- Allowed for greater diversity across geographic locations
- Brought personal and professional knowledge
- Accessible, engaging, easily shared





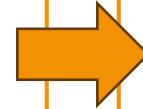
Dissemination: “Trusted Places and Spaces”

➤ YouTube videos



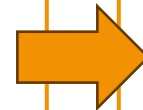
Links distributed via partner organisation and universities social media

➤ Oral health postcards



Distributed via partner organisations and Disability Oral Health Consortium (Deakin led) Resources registered with NSW and Victorian multi-cultural health resources

➤ Presentations

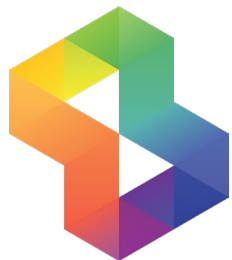


Presented at 5 conferences (including one in Miami USA in Feb 2024); university staff and student presentations; STARTTS Master class

➤ Publications



Bi-lingual co-design method, *TQR*, 29(2), 577-593. <https://doi.org/10.46743/2160-3715/2024.6377>.





Related publications

Crock, M., Smith-Khan, L., McCallum, R., Saul, B. (2017). The legal protection of refugees with disabilities: Forgotten and invisible? UK: Edgar Elgar.

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. Open Access. <https://doi.org/10.46743/2160-3715/2024.6377>.

Dew, A., Watson, J., Smith, L., & Murad, M. (2022a). *Small changes could bridge communication and cultural gaps for people from refugee backgrounds who need disability support*. The Conversation. <https://theconversation.com/small-changes-could-bridge-communication-and-cultural-gaps-for-people-from-refugee-backgrounds-who-need-disability-support-185405>

Dew, A., Lenette, C., Wells, R., Higgins, M., McMahon, T., Coello, M., Momartin, S., Raman, S., Bibby, H., Smith, L., & Boydell, K. (2022b). "In the beginning it was difficult but things got easier": Service use experiences of family members of people with disability from Iraqi and Syrian refugee backgrounds. *Journal of Policy and Practice in Intellectual Disability*, 20(1), 33-44. DOI: 10.1111/jppi.12424. Special Issue on Family Support Interventions in Culturally Diverse and Low-Resource Communities. Open Access.

Dew, A., Lenette, C., Smith, L., Boydell, K., Bibby, H., Lappin, J., Coello, M., Raman, S., Velkou, K., Wells, R., Momartin, S., Blunden, H., Higgins, M., Murad, M., Barry, J., & Mohammad, Y. (2021). "To the Arabic community disability is not normal": Multiple stakeholder perceptions of the understandings of disability among Iraqi and Syrian people from refugee backgrounds. *Journal of Refugee Studies*, 34(3), 2849-2870. DOI: 10.1093/jrs/feaa111.

Levesque, J-F., Harris, M., & Russell, G. (2013). Patient-centred access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, 12:18. <http://www.equityhealthj.com/content/12/1/18>

Refugee Council of Australia (2019). *Barriers and exclusions: The support needs of newly arrived refugees with disabilities*. Surry Hills, NSW

McKercher, K.A. (2020). *Beyond Sticky Notes. Doing co-design for real: mindsets, methods and movements*. Sydney, Australia: Beyond Sticky Notes. ISBN 978-0-6487875-0-1

Smith, L., Chester, I., Dew, A., Higgins, M., Lenette, C., Wells, R., & Boydell, K. (2022). Key characteristics of the refugee journey for Iraqi and Syrian family members who support someone with disability. *Disability & Society*. Ahead of Print 1-23. DOI: 10.1080/09687599.2022.2045189. <https://doi.org/10.1080/09687599.2022.2045189>

Soldatic, K., Somers, K., Buckley, A., & Fleay, C. (2015). 'Nowhere to be found': Disabled refugees and asylum seekers within the Australian resettlement landscape. *Disability and the Global South*, 2(1), 501-522.

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. DOI: [10.1080/1323238X.2021.1882044](https://doi.org/10.1080/1323238X.2021.1882044).

