



Government of **Western Australia**  
Department of **Health**

# **Multicultural Health Diversity Café 8:** **‘Improving health equity for people from** **culturally and linguistically diverse** **backgrounds with disability’**

29 August 2018

**Cultural Diversity Unit**  
**Chronic Disease Prevention Directorate**  
**Public and Aboriginal Health Division**

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## Executive Summary

**‘Improving health equity for people from culturally and linguistically diverse (CaLD) backgrounds with a disability’** was the theme of the Multicultural Health Diversity Café Diversity Café 8, which was held at the Bendat Parent and Community Centre on 29 August from 9 am to 12 pm. Diversity Café 8 brought together 50 staff from within the WA health system, government agencies, not-for-profit organisations and a number of consumers.

The health status and needs of CaLD people with disability are similar to those of the rest of the community. Culture, religious beliefs, conceptualisation of disability, gender and language spoken, however, can impact on their health outcomes. These and other factors such as stage of life, type and complexity of impairment and diversity within this population group need to be considered when planning and implementing health policies, programs and services.

**In this Café, a carer, a clinician and staff of a CaLD disability advocacy support organisation** shared their perspectives and experiences around improving health equity for CaLD people with disability. Challenges and concerns for service providers, staff and consumers were also discussed. The three speakers were:

- Maha Rajagopal, Carer perspectives
- Dr Siyat Abdi and Christine Grace, Providing systemic advocacy
- Jenny Campbell, Applying the Disability Health Framework

**The speakers’ presentations were followed by buzzing sessions** in which tables of participants engaged in conversations guided by questions related to the preceding presentation. The main points from each table’s buzzing sessions were recorded via GroupMaps and shown on the screen for everyone to see.

**The Diversity Café series** seeks to bring together staff from the WA health system, other government agencies, nongovernment and community organisations and consumers to share knowledge, connect ideas and ask questions about health matters as they relate to people from CaLD backgrounds.

**Diversity Café 8** was organised by the Department of Health (DoH) Cultural Diversity Unit (CDU) in collaboration with the Ethnic Disability Advocacy Centre (EDAC) and the Health Networks.

**The Café was facilitated by** Ruth Lopez, DoH.

*The Multicultural Health Diversity Café series offers other learning opportunities for service providers on their ongoing journey to cultural competency, specifically around providing equitable access to safe and high quality health programs and services for people from culturally and linguistically diverse (CaLD) backgrounds.*

## Presentation 1

### Maha Rajagopal, Carer Perspectives

Maha's presentation was about her own perspective as a carer, and as someone who provides a strong supporting role to her sister, Praha, whose daughter Shanti has Down Syndrome. Shanti is a 21 year old woman who loves life, is very sociable and relates very well with people around her. She has, however, like many young people with disability, faced numerous health challenges growing up. Maha stressed that Shanti is fortunate for having a Mum who is assertive, speaks English and who wants the best for her daughter. Shanti needed a voice and someone who could take her on her life journey and this came in the form of her Mum. She also has an excellent GP who listens and responds to her health needs and oftentimes, coordinates her healthcare.

Maha spoke about taboos as well as cultural and religious perceptions around people with a disability, for example, beliefs that 'Past bad karma may bring punishment in the form of a disability to a family', or that 'A cripple will never enter paradise.' Due to these perceptions, parents often do not encourage their children to develop their skills and talents. Her advice was to change this perception into something less fatalistic. Parents and carers need to realise that people with disability, when provided with appropriate and adequate supports, can learn, develop, be engaged in many activities and are able to explore a lot of possibilities. Shanti has had care and support from her Mum, her nuclear family and her extended family, which has enabled her to pursue, among others, her love for dancing and singing and participating in performances. She is also learning independent living skills like cooking.

Maha cited challenges faced when taking a person with a disability to hospital. Hospitals are very frightening places and very complex to navigate, particularly for someone with a disability who is often anxious about appointments. Long waits may make the situation worse and often people are not informed of what is going on. Transitioning from paediatric care to adult care is also a big issue. In the community, GPs are seen as not interested in providing extra support to CaLD people with a disability and their families. Shanti and her family often encounter these challenges themselves but have found ways to deal with and face them head on.

Maha encourages parents and carers to 'Read up, inform yourselves. Get a notebook. Write your questions so you are prepared when you go and see a health professional. Ask for an interpreter if you need one. Seek the support of an advocate. Become assertive.'

In addition, for health professionals, she has this reminder. 'Care for the carers. Ask them how they are as they may have their own medical issues, too.'

## Buzzing Session 1:

### What is your understanding of the health status and needs of CaLD people with disability?

#### *Health status*

- Whether one is from a culturally or linguistically diverse background, or has a disability or not, we have similar health issues. The difficulty lies in navigating the system.
- Economic migrants have different needs from refugees with a disability.
- Traumatic backgrounds and low expectations may result in not seeking a range of services, not accepting different services or understanding relationships of different services, for example, seeing many doctors for different reasons.
- The concept of early intervention is foreign.
- Stigma is associated with disability and the complexity of issues is increased when one is from CaLD background.
- Acknowledge the complexity and intersectionality of disability and CaLD and that everyone is an individual.
- Some medical diagnoses do not exist in certain cultures.
- A big variance exists between children of CaLD background born in Australia vs those who migrated at a later stage in life.
- Constructs of disability can vary across cultural groups.
- Disability is seen as a curse by some cultures.

#### *Needs of CaLD people with disability*

- CaLD people with disability have complex needs.
- Limited or no health literacy.
- Cultural barriers, information translation, assume low literacy.
- Accessibility and transport.
- Differences in expectations.
- Need for multicultural support groups.
- Limitations of understanding and use of technology.
- Lack of empowerment from the system.
- Information and who to contact.
- Misconceptions about support structures for family and community; oftentimes don't know what support systems are available, or support is not culturally appropriate.
- Poor access to health services.
- Mental health issues.
- Support is very ad hoc, there is a need for systemic support.
- A CaLD person with a disability always needs an advocate as there is a lack of knowledge and understanding of the health system.

### *For Service Providers*

- Service providers must share information about the health situation and resources for the whole family to enable better understanding. Consider holistic approach to health care.
- Some service providers have to improve capacity to deal with non-verbal patients from CaLD backgrounds.
- Service providers need to undertake training on how to engage interpreters to dispel reticence/fear about how to use them, and where to access them 24 hours a day.
- Consider flexible health delivery with comprehensive health teams.
- Some service providers need to understand the importance of effective communication and cultural norms.
- Video and verbal translations can be helpful, graphs, maps, visual aids.

## Presentation 2

### Dr Siyat Abdi and Christine Grace, Providing systemic advocacy

**Dr Siyat Abdi spoke on how cultural practices**, religious beliefs and conceptualisations of disability impact on CaLD families' engagement with the health system. He argued that culture plays a huge part in a person's understanding of health, that perceptions of physical and psychological wellbeing vary widely across societies and that communities have different beliefs about the causes of illness, behaviours when ill and expectations as to how illness should be treated.

Cultural perceptions of disability and health can lead to positive and empowering or negative and harmful views, particularly around causes of disability. Transgressions of accepted social conventions such as inappropriate family relations including extra-marital affairs and incestuous relationships may invoke a curse; supernatural forces may affect the child during prenatal and postnatal period of care as would fate, nature, the will of God or destiny, unexplained events and biomedical factors.

Alternative treatments are often sought. The use of amulets to protect against evil spirits (Jinn's) and traditional herbs may be preferred as opposed to conventional medicine. Other practices may include consulting traditional medicine men for interventions or practicing ancestral appeasement like sacrifice, seeking divine intervention to influence how an individual might resolve matters of chronic illness and disability and acupuncture or cupping.

Positive practices from country of origin, however, may no longer be observed post migration to Australia. For example, providing filial and collective care duties to members of the family; eating traditional healthy diets due to lack of access to cultural food ingredients; decrease in incidental physical activity if one is unemployed or living a more sedentary lifestyle; non-comprehension of easy-to-read or translated information; and feeling that cultural interpretations and treatments are dismissed, irrelevant or not accepted by health professionals.

He stressed the importance of a health system that is able to acknowledge cultural difference, which promotes the development of cultural competency among health providers and which pro-actively engages with community.

**Christine Grace shared examples of health system advocacy** undertaken by EDAC on behalf of CaLD clients with disability, as follows:

A client had a stroke prior to coming to Australia. The Humanitarian Entrant Health Service made an appointment for him to attend the Neurology Department of a major public hospital. On the day of his arrival, however, he presented at the Emergency Department and was discharged without further assessment, referral to Neurology or access to rehabilitation programs. After a period of time without receiving any health care, EDAC came to know this client and advocated on his behalf for access to required equipment, regular and continuing therapy (OT, physio and speech) and further assessments by a specialist therapy team.

A 40 year old woman was referred by her GP to a Rheumatology Clinic at a public hospital. Upon receipt of the appointment letter, she contacted the clinic to request for a female doctor for cultural reasons. She was told by hospital staff that she could not choose her doctor and that she had to accept whoever would be attending on the

day. She sought EDAC's help. EDAC informed her of her health rights, the role of hospital patient liaison services and assisted her to contact them. The client has now been allocated a female specialist and is waiting for an appointment to be made.

The parents of a 14 year old boy diagnosed overseas with autism were required by the Disability Services Commission (DSC) to get Australian confirmation of the child's diagnosis. He could not access any therapy while waiting for an appointment with a developmental paediatrician which could take more than 12 months up to 18 months. EDAC advocated with the family and liaised with a mental health service provider who was able to confirm the child's diagnosis fast tracking registration with DSC and access to ongoing supports.

Christine stated a few factors that impact on clients getting an outcome: appointment letters in English which clients may not be able to read and do not have extended networks who can assist resulting in appointments being missed and being taken off the list for future appointments; clients not aware of available services within the health system; long waiting lists for appointments especially for children who have been referred to Child Development Services; health professionals reluctant to provide reports to clients (for NDIS or Centrelink purposes); staff not accessing interpreters when it is required; lack of follow up to ensure that clients are clear about their treatment plans and transport issues.

## Buzzing Session 2:

**Given that culture, religious beliefs, conceptualisations of disability, gender and language spoken can impact on health outcomes, how would you empower people from CaLD backgrounds with disability to enable self-advocacy?**

### *Organise forums that promote self-advocacy*

- Convene forums for people with disability, their families and carers, on how to self-advocate.
- Establish support groups to enable self-empowerment that comes from when one is exposed to those who have the same lived experience as oneself. They help give you a voice.
- Support peer groups, peer led workers.
- Have more community groups to empower and educate those in the community.
- Create an environment for people to feel confident to say what they are thinking and want.

### *Develop community skills and knowledge*

- Practice deep listening, not with the intention of trying to persuade or change.
- Assist people to tell their story, develop a script, so that they can rehearse their script.
- Important to allow people from CaLD backgrounds with disability to engage in their own cultural practices, if not deemed harmful. This can be complementary to Western medical treatment and supportive to their mental health and wellbeing.
- Explore “slow medicine” emerging from Scotland - educating people to look at all options, starting with the least interventionist and giving people a choice.
- Spend quality time with patients who have specific needs and take time to explain in ways they can understand.
- Share knowledge to navigate health services, need to keep reinforcing and teaching.
- Educate CaLD people about the fact that it is okay to change their health service provider if not happy with current one, and that it is also okay to get a second opinion.
- Health service providers must lead by example.

### *Develop, promote and use appropriate resources/Collect CaLD data*

- All health agencies need to collect and use CaLD data for best practice.
- Develop new resources, for example, visual resources to assist with communication.
- Develop and promote resources for primary health providers so they can increase knowledge, become skilled to ask questions and identify appropriate care. For example, disseminate information about WAPHA’s HealthPathways.
- Book longer consultations to give patients’ sufficient time.
- Promote knowledge of the health system at different levels and in different modes.
- Acknowledge your own personal beliefs and how they might impact the consultation.
- Build rapport/develop relationships. Give time.

*Use interpreting services and multilingual resources*

- Provide correspondence in preferred language and follow up patient through the help of an interpreter to explain appointment times and other details.
- Provide interpreters and subsequently educate patients about the importance of asking for interpreter.
- Check out assumptions and ask clients what needs to be met.
- Get involved with advocacy organisations or peak bodies that assist in navigating the health system.

## Presentation 3

### Jennifer Campbell, Applying the 'Disability Health Framework'

Jenny introduced her presentation by talking about the Disability Health Network (DHN) whose goal is to provide a better health experience and better health outcomes for people with disability, their families and carers. This is done by providing better access to appropriate services, delivering health services that meet individual needs and coordinated care. The DHN is a partnership between the then Disability Services Commission and the Department of Health and has been running for over 5 years.

Some of the drivers for the Disability Health Network's work at local, national and international levels include the UN Convention on the Rights of Persons with Disabilities; National Disability Strategy 2010-2020; WA Disability Services Act 1993; Patient stories; Clinical Senate recommendations; Health disparities for people with disability.

Jenny then discussed the Disability Health Framework which is a guide for service planning and delivery to ensure the inclusion of people with disability. The framework supports the 'social model of disability' by placing the person at the centre of improvement initiatives and provides opportunities for partnerships and collaboration through common enablers. Jenny then showed the Disability Health Framework Animation, a resource that the Network is very proud of, available on this link <https://www.youtube.com/watch?v=Otcacj-ykDw> .

She highlighted that it is important not to group all people with disability together as people do not fit pre-determined stereotypes, delivering person centred care needs consideration/ recognition of conditions, needs and aspirations of individuals, focus on supporting people with disability, their families and carers to develop knowledge, confidence, skills and behaviours to achieve the best possible health. The health and wellbeing of carers of people with disability is also important. Research indicates that carers report a 59 per cent decline in physical health and two-thirds decline in mental and emotional health.

Shift to mainstream health providing services to people with disability needs to be matched with developing a health workforce with the appropriate values, skills and behaviours to provide inclusive health care. Workforce capability can be enhanced by people with disability and their families and carers sharing their stories. Initiatives to increase workforce capability should include all services related to social determinants of health.

People with disability are more likely to experience discrimination and barriers in health care provision including prohibitive costs, limited availability of services, physical barriers and inadequate skills and knowledge of health workers. Barriers to inclusion can only be identified and mitigated effectively by the inclusion of people with disability, their families and carers in health care planning and design. Strengthening continuity of care is important as people with disability may also have increased health care requirements and access multiple service providers.

### Buzzing Session 3:

**One of the goals of the Disability Health Framework is ‘improve the quality, accessibility, inclusiveness and coordination of services necessary to meet the health needs of people with disability.’ How would you apply this for CaLD people with disability?**

- Improve coordination and explore idea of virtual health. For example, use technology and apply telehealth principles to get two or more Specialists participating.
- Explore a mixed methods approach of delivering information, for example, translated letters, phone calls, texts, home visits.
- Provide compassionate care and kindness.
- Broaden communication between government and non-government stakeholders.
- Implement health promotion/ prevention strategies for those with a disability, for example, obesity.
- Try different methods to connect, change policies and processes in organisations to assist with trying different approaches.
- Share information across organisations.
- Create forums to educate CaLD people with disability about their rights because so many come from cultures where they do not complain or assert themselves.
- Minimise documentation.
- Invest in support for CaLD communities to improve health literacy, increase confidence and develop peer support.
- Acknowledge the client's understanding of what disability is in their own culture and that they are experts for themselves.
- Health professionals must communicate health risk factors and social requirements in referral and discharge information.
- Extend time of appointments for people with disabilities.
- Workforce capability - increase awareness related to inclusivity for all diversity
- Conduct training for health workers in the use of interpreters.
- Pictorial guides / no language in the accessibility documents to CaLD clients
- Like previously; assumptions, language barrier, attitudes need to be addressed. A language app can be created?
- CaLD people with disability their families and carers participating on health and disability boards and Advisory Committees.
- Documentation of use of interpreter (and patient's English proficiency) should be a KPI.

## The Presenters

**Maha Rajagopal** is a carer for her niece Shanti, who has Down Syndrome. She has been assisting her sister provide a supportive and nurturing home and family environment for Shanti. Together, they have successfully encouraged Shanti's love for singing and dancing resulting in Shanti's participation in public performances and connected Shanti to organisations that have helped her develop and acquire independent living skills, such as cooking. Maha has played a key role in figuring out difficult to navigate systems such as the public health system, particularly around transitioning from child and adolescent health services to the adult health system.

**Dr Siyat Abdi** has more than 20 years' experience working in the disability and community development sectors. He first trained as a teacher overseas and taught in high schools and tertiary levels for many years. He completed a PhD in Community Rehabilitation (Disability Studies) at Flinders University, registered as the first blind teacher in South Australia and has been working as a systemic advocate at EDAC. He is also a human rights activist

Siyat has worked extensively with migrant communities in Western Australia and South Australia, particularly refugees, women and people with disability and has served as representative on various diversity groups and advisory committees in both States. He has so far published a book and written articles on CaLD people with disability and continues to undertake research in this area.

**Christine Grace** is a Systemic Advocacy Officer at EDAC. Her background is in Community Services which includes disability advocacy, inclusion support for childcare centres and staff to provide inclusive programs for children with disability, intensive case management for adults with mental illness, family and domestic violence outreach and disability advocacy for people from CaLD backgrounds. She has a keen interest in social Justice and equity issues and supporting people to make positive changes to their circumstances. She is passionate about providing a welcoming and inclusive community for all people. Having raised a child with an intellectual disability, she understands the difficulties and barriers faced by families when trying to navigate difficult pathways and processes.

**Jenny Campbell** is currently the Co-Lead of the Disability Health Network and the A/Chief Health Professions Officer at the Department of Health WA. She has a clinical background in Occupational Therapy and has extensive experience in health as an allied health practitioner and leader. Having worked in a variety of positions both within WA health and overseas, Jenny has experience in project management and policy development in different health and disability contexts.

## The Multicultural Diversity Café 8 convenors:

<b>Ruth Lopez</b> , Senior Policy Officer Cultural Diversity Unit Department of Health	<b>Rosita D'Adamo</b> Service Manager Ethnic Disability Advocacy Centre
<b>Kelli Monaghan</b> , Policy Officer Cultural Diversity Unit Department of Health	<b>Marlene Parry</b> , Senior Development Officer Senior Development Officer Health Networks, Department of Health

## Appendix A: Program

8:30 am	Registration	
9:00 am	Introduction to Diversity Café 8 Acknowledgement of country	<b>Ruth Lopez</b> , Senior Policy Officer, Cultural Diversity, Public and Aboriginal Health Division, Department of Health (DoH)
9:10 am	Welcome address	<b>Wendy Rose</b> , Chief Executive Officer, Ethnic Disability Advocacy Centre (EDAC)
9:15	Introduction to group maps	<b>Kelsey Gill</b> , Health Networks
9:20 am	<b>Session 1</b> Consumer and carer perspective <b>Q &amp; A</b>	<b>Maha Rajagopal</b> , Carer
9:40 am	<b>Buzz session 1:</b> What is your understanding of the health status and needs of CaLD people with disability? Identify 3 key points and input on Group Map Look at collective input, grab coffee, take a quick break	
10:10 am	<b>Session 2</b> Providing CaLD disability advocacy <b>Q &amp; A</b>	<b>Dr Siyat Abdi and Christine Grace</b> , Systemic advocates, EDAC Facilitated by <b>Rosita D'Adamo</b> , Development Manager, EDAC
10:30 am	<b>Buzz session 2:</b> Given that culture, religious beliefs, conceptualisations of disability, gender and language spoken can impact on health outcomes, how would you empower people from culturally and linguistically diverse backgrounds with disability to enable self-advocacy? Identify 3 key points and input on Group Map Look at collective input, grab coffee, take a quick break	
11:00 am	<b>Session 3</b> Applying the WA Disability Health Framework <b>Q &amp; A</b>	<b>Jennifer Campbell</b> , A/Chief Health Professions Officer, DoH
11:20 am	<b>Buzz session 3:</b> One of the goals of the Disability Health Framework is 'improve the quality, accessibility, inclusiveness and coordination of services necessary to meet the health needs of people with disability.' How would you apply this for CaLD people with disability? Identify 3 key points and input on Group Map Review collective input, grab coffee, take a quick break	
11:50 am	Summary	Key ideas from the conversations
12 noon	Close	Thanks and Close

## Appendix B: List of Participants

Below are the Café participants who gave permission for their name and organisation to be listed in the Summary Report.

First Name	Second Name	Agency
Dr Siyat	Abdi	Ethnic Disability Advocacy Centre (EDAC)
Rehab	Ahmed	Ishar Multicultural Women's Health Centre
Mikala	Atkinson	Cancer Council WA
Steve	Banks	WA Police
Sarah	Beasley	Cancer Council WA
Brianna	Bendotti	Notre Dame
Karla	Benitez	Umbrella Community Care
Jennifer	Campbell	Department of Health (DOH)
Clare	Chamberlain	Community Health Refugee Health, Child and Adolescent Health Service (CAHS)
Dr Sarah	Cherian	Perth Children's Hospital (PCH)
Christine	Grace	EDAC
Karen	Crossley	Osborne Park Hospital
Rosita	D'Adamo	EDAC
Rose	Dale	EDAC
Marie	Deverell	DOH
Udani	Dhanojanan	Office of Multicultural Interests
Ljiljana	Djordjevic	South Metropolitan TAFE, AMEP
Barbara	Edwards	DOH
Jason	Ellis	Youth Mental Health Services, North Metropolitan Health Services
Kelsey	Gill	Health Networks, DOH
Jennifer	Gordon	EDAC
Mary	Gurgone	Fortis Consulting
Lesley	Harland	Sir Charles Gairdner Hospital (SCGH)
Damian	Hart	WA Country Health Service
Lanny	Hoskin	WA Cervical Cancer Prevention Program (WACCPP)

First Name	Second Name	Agency
Iren	Hunyadi	Consumer
Dr Le	Jian	Epidemiology Branch, DOH
Bizunesh	Kebede	Community Health, CAHS
Colleen	Koh	Epidemiology Branch, DOH
Nerissa	Le	Foodbank WA
Karen	Lipio	Health Consumers' Council
Ruth	Lopez	DOH
Katie	Lux	PCH
Diana	Mitchell	Special Needs Dental Clinic, North Perth
Kelli	Monaghan	DOH
Emily	Moore	WAPHA
Kay	Morton	WACCPP
Marlene	Parry	DOH
Maha	Rajagopal	Carer
Mark	Ravenscroft	Lifeplan
Wendy	Rose	EDAC
Debra	Royle	WAPHA
Jessica	Saayman	Community Health Refugee Health, CAHS
Tamarai	Selvam	Special Needs Dental Clinic, North Perth
Monica	Taylor	Armadale Mental Health Service
Shalini	Vincent	Ishar Multicultural Women's Health Centre
Craig	Webster	Balga Senior High School
Lorraine	Wilson	Child Development Centre, CAHS
Catrina	Wold	Injury Matters
Stacey	Weiske	DOH

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