Enable Equality
Disability and Diversity in Australia
The magazine of the Federation of Ethnic Communities’ Councils of Australia (FECCA)

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Welcome to the winter edition of Australian Mosaic magazine entitled Enabling Equality: Disability and Diversity in Australia. In choosing the theme for this edition we endeavoured to bring together the different perspectives of our contributors and to create a vision of a more equal Australia for all. The theme of this issue celebrates the various layers that constitute a person’s identity including their culture, language, abilities, talents, goals and achievements.

In light of the above, this edition’s articles focus on exploring what exactly works for people with disability and what is needed for their empowerment and self-determination. The message that we aim to promote through this compilation of perspectives is that the Australian society as a whole needs to shift away from victimising, discriminating or stigmatising people with disability. It needs instead to look at the best ways to enable them to fulfil their potential and to build confidence in their talents and abilities. Our expectations from people with disability need to rise to allow them to be equal contributors to our society who also have equal opportunities.

At FECCA, we have been advocating for change and improved outcomes for people with disability from culturally and linguistically diverse (CALD) backgrounds because we acknowledge the additional barriers that their backgrounds can pose in their lives. We have been pursuing to build strong working partnerships with organisations such as the National Ethnic Disability Alliance (NEDA) to strengthen our advocacy efforts and to better promote the interests and concerns of people from diverse ethnic backgrounds with disability at a national level.

Through its dedicated Disability Advisory Committee, FECCA has been advocating for improved access of CALD people with disability to services, including those facilitating education and employment. We have been systematically arguing for more inclusive national disability policies that consider and address the specific needs of people from CALD backgrounds with disability, while also calling on the Australian Government to implement its international human rights obligations as a signatory to the United Nations Convention on the Rights of Persons with Disabilities.

As part of our efforts to advocate for a fairer society for CALD people with disability we have decided to create, through this edition of Australian Mosaic, a platform where we could hear from advocates, policy makers, academics, service providers, visionaries and people with disability themselves about the best ways to empower, enable and engage with people with disability, their families and their carers.

Dwayne Cranfield, the CEO of NEDA, introduces us to the concept of ‘dignity of risk’ and the right of a person with disability to personal choice and self-determination, regardless of their age, culture, religion or type of disability. Focusing on the right to personal choice, Bruce Bonyhady, the Chair of the National Disability Insurance Agency (NDIA), provides an insight into the development of the National Disability Insurance Scheme (NDIS) as a fair an inclusive disability policy that engages every part of Australian community through an individualised approach and has the capacity to meet the complex needs of CALD people with disability.

Christian Astourian, the former Chair of the FECCA Disability Advisory Committee, reflects on the journey towards equal opportunities for and empowerment of people with disability and raises some concerns about those people with disability that fall through the cracks and are not eligible for the NDIS. Mark Bagshaw, a lifelong disability advocate, continues the praise for the NDIS as a new business model and a positive vision for building a new system of disability support but warns that the ‘Grand Design’ for a disability reform cannot be complete without also removing the infrastructure barriers. Craig Wallace, President of People with Disability Australia, discusses the journey from tolerance to identity for people living with disability, shifting from the image of people with disability as recipients and victims and putting them in control of the support they need.

Yvonne Gritschneder from Carers NSW looks at the experiences of CALD carers with the reforms happening within the disability sector, including the need for tailored information and training, and the impact the NDIS has on them. While the economic benefits of tapping into the talents and skills of people with disability seem to be overlooked by the Australian private and public sector, Suresh Rajan, Chair of
NEDA, is showcasing the social success of an Indian company employing only people with disability, as well as highlighting the significant entrepreneurial benefits such an inclusive approach can bring to businesses. Gulnara Abbasova, our Acting Director, analyses the results of a survey conducted by FECCA to find out how multicultural organisations around Australia engage with CALD people with disability and highlights the role of such organisations in bridging the gaps in culturally appropriate service delivery.

Zeliha Iscel, the Chair of the FECCA Disability Advisory Committee, discusses the unfair treatment of people with disability and their families in the Australian migration system, underlining its inconsistency with Australia’s human rights obligations. Addressing the issues faced by those few refugees with disability that are granted a visa, Sandy Eagar, of NSW Refugee Health Program, provides an insight into the development of the Refugee Health Nurse Program and its role in helping overcome some of the basic barriers.

Esther Simbi, a political activist, highlights the challenges faced by people with disability from non-English speaking backgrounds in Australia, as the second biggest group in the disability community, around education, employment and domestic violence. Norhawa Bee Mohamed Ismail from NEDA tells us the stories of two resilient women who overcame the barriers imposed by their disability. Lola Payenda, a young woman with Afghani heritage, talks about the importance of family support in overcoming everyday challenges and in fostering a sense of empowerment.

Ace Boncato, Systemic Advocate at the Multicultural Disability Advocacy Association of NSW, herself living with a disability, has focused her energy on becoming an advocate for the rights of people with disability in Australia and internationally.

I wish to commend all the contributors for their valuable insights and for joining us in our journey towards enabling equality for all Australians. We hope that this edition raises some important questions about the future of the NDIS and the broader reform needed in the disability sector, paves the way towards changing attitudes and recognising the amazing potential of people with disability, and stresses the need to foster equality and social inclusion by eliminating all forms of discrimination against people with disability.

Lastly, I wish to thank our partners from NEDA for their input into this edition and I commend their unconditional commitment to ensure that the interests of CALD people with disability are represented through a cohesive voice at a national level.
Dr James Jupp AM, FASSA, has been a regular contributor to Australian Mosaic for several years. He is an Adjunct Professor at the Australian Demographic and Social Research Institute at the Australian National University in Canberra. He is the author of many articles and books on immigration and multiculturalism. Most recent publications include From White Australia to Woomera (2007), The Encyclopedia of Religion in Australia (2009) and Multiculturalism and Integration (with the late Michael Clyne, 2011). He emigrated from Britain to Australia in 1956 and has taught political science at universities in Melbourne, York (UK), Waterloo (Canada) and Canberra.

The Commonwealth Budget was not very well received this year. It was followed by a big shift in support for the major parties, with the Australian Labor Party (ALP) ahead of the Liberal/Nationals and Bill Shorten ahead of Tony Abbott. One unfortunate feature of this shift is that it might slow down the much needed organisational and policy reforms of the ALP, which is showing its age. It also needs to discipline its politicians to avoid the destructive careerist battles which were the main cause of Labor’s defeat. Winding up the factional system might liberate some energy for restoring the party.

This sudden change suggests that the overexcited articles following the last election about the impending collapse or even death of the ALP, were off the mark. Major political institutions (in this case with more than a century of history) do not just die in Australia, whatever may happen elsewhere. Smaller parties like Pauline Hanson’s One Nation, or the Democratic Labor Party do. Even then it is worth noting that the current Greens hold up their support quite well, both in opinion polls and actual voting.
They are the only party to oppose current asylum policy. Greens follow in a longer tradition, which goes back to the Democrats and to defections from the Liberal Party of its more liberal members. What this will all mean for Clive Palmer’s new party is hard to say. But its Senate result reflects the large scale funding which is available to it, rather than a broad national movement.

When we look towards two of the world’s largest democracies – India and the European Union – we are looking at a different and more worrying situation. In India the Congress Party and the Nehru family, which led it since independence, were decisively defeated by a Hindu nationalist movement which mobilised the largest social elements in Indian society. News media in Western democracies took some pleasure from this, without asking whether or not this was progress. Hinduism is a very varied religion which has many conservative and reactionary aspects surviving in rural and small town electorates. Having seen the Tamil minority crushed in Sri Lanka by the Sinhala Buddhist majority, there is a danger that a similar if less drastic fate might befall India’s large Muslim minority and possibly its much smaller Christian communities. These have been protected to some extent by Congress, as have liberals in the major cities. But Indian politics have always based on multi-party coalitions, which is not true for Sri Lanka. None of this need worry Australia much, but it might reinforce the widespread Indian belief that Australia is a racist country, based on the old White Australia policy and our present refugee and immigration policy.

Corruption and incompetence have been the bane of Indian politics and caused the downfall of Congress.

Bureaucracy and local nationalism have started to eat into support for established mainstream parties in the European Union. Each member state has begun to show national variety in its response to Europe’s economic problems and to rising national resentments. France veered dramatically to the Right, with the National Front emerging as the leading party; Greece moved the other way with the new Left party coming out on top and the older Pasok falling away. Greece still gave a reasonable vote to its Communist party, the Kommounistikó Kómma Elládas (KKE). Hungary gave large support to the Right Jobbik, and so on through all the varied results.

The British result of the EU elections raised serious questions about the stability of one of the oldest democratic party systems. The Liberal Party, which is currently allied with the Conservatives, disappeared off the map back to its minority status of fifty years ago. The Conservative Party lost support to the UKIP (United Kingdom Independence Party) which wants to leave the European Community altogether. Voting
behaviour was quite different between the suburban and rural south, which split the Conservatives with UKIP; London, which remained Labour; and the Industrial north, which was also Labour.

Of considerable interest was the strength of nationalist parties in Scotland, Wales and Northern Ireland. On the face of it there is instability in British politics. However Conservatives go back to the 1850s and Labour to 1906 and it is only the Liberals who look like dying – as they have often done before. Most unsettling is that UKIP attracts the strong racist and anti-immigrant element who might otherwise drift towards very unpleasant parties like the English Defence League and the British National Party.

All of this makes Australia look quiet and remote from the real world. However our refugee policy remains controversial, both here and internationally. In effect we no longer implement the United Nations Refugee Convention, of which we were an early signatory. The boats have been stopped by using the Navy, sending asylum seekers to Nauru and Manus islands, denying even genuine refugees any chance of settling in Australia if they came by boat, and desperately looking for other much poorer countries to take over our rather small “burden”. Those who once were termed “boat people” have now been tagged as “transferees” because we hold them pending getting rid of them to somewhere else. The overcrowded and insanitary facilities on Nauru and Manus have been condemned several times and suffer regular riots.

The short official answer to such criticism is that this is what Australians want.

The recent Lowy Institute annual poll lends credence to this. Their sample shows 71 per cent favour turning boats back when safe; 59 per cent favour offshore processing in Nauru and PNG; limited temporary protection visas 48 per cent; no asylum seeker coming by boat should be allowed to settle in Australia. These all conform with the official Liberal policy. However there are also majorities of the 1000 adults respondents who disagree with “no asylum seeker should be allowed to settle in Australia”. Polls are useful but not always very refined. To answer “yes” to this question is to deny any support for asylum, whether by boat or otherwise.
Dwayne Cranfield is currently the Chief Executive Officer of the National Ethnic Disability Alliance and the sitting Chair of Advocacy for Inclusion. He has lived in the ACT since 1989 and has worked within the welfare sector since 1984 by advocating for the rights of disenfranchised people, both in Australia and abroad.

He has also worked with refugees in Sweden as well as with young male sex offenders in the USA. He has held several positions on the Minister’s Disability Advisory Council within the ACT and holds qualifications in both Disabilities and Community Sector Management. Dwayne is also a sitting member of the Alfred Deakin High School Board and a member of the curriculum committee at the Canberra Institute of Technology within the Alcohol and Drug faculty.

Most of Dwayne’s working life has been spent within the area of child protection, substitute care and homeless youth; the last few years he has gravitated towards the areas of homelessness, adult mental health and disability. This change in direction towards the disability sector was facilitated by an assault that Dwayne sustained from a client in 1999. This assault left Dwayne with an acquired brain injury, which he lives with on a daily basis.

The term ‘dignity of risk’ is nothing new. It has been around for a long time but in Australia within the disability community it is something new. Not for the practitioners and people working within the disability community, but for the consumer it is a relatively new concept as this part of our society has for some time existed on a process of ‘manna from heaven’. It has been a system of handouts and people living with disability have been reduced to accepting charity; not a very dignified existence, not much in the way of “choice and control”. “The concept of dignity of risk, is the right to failure.”

It is also somewhat of a new concept for the government and the political sector, that is the people we appoint to represent us at the highest levels. Recently I sat with a Senator, who I will not name, and talked about the dignity of risk. The Senator was engaged and at the end stated that she had never heard of the term before. Her response was interesting as it seemed that the concept was a revelation; an epiphany of sorts. I gave her a reading list and some web links hoping that she might do further research.

The concept of dignity of risk has the bulk of its history from within the mental health community and was championed by the self-advocate movement, i.e. people living with mental health concerns and the subsequent peer support networks. Dignity of risk is an important concept; it places an emphasis on personal choice and self-determination, two concepts that are central to recovery. This is the premise from a mental health standpoint, but it’s not a difficult reach to bring it into the framework of the disability community.

The difference between the mental health and the disability frameworks is as already mentioned; the mental health sector infuses dignity of risk with recovery and recovery based processes. From within the disability community the possibility of recovery is for most not an option and very remote. Within this framework dignity of risk is about living
well, self-determination and the new catch cry within the National Disability Insurance Agency (NDIA) and the National Disability Insurance Scheme (NDIS), choice and control.

Every endeavour has an element of risk, and every opportunity for growth carries with it the potential for failure. All people learn through a process of trial and error. Often learning as much from their mistakes as from their successes, this is a process that the able bodied community often take for granted.

As children we grew up making choices and engaging in risky behaviour; most of us learnt from our mistakes. Trial and error, it is how we learn our limits, what we like and what we do not; this is what personal growth is about. The often said joke is “why do learning experiences have to be so painful”. Supporting people through failure can assist them to develop resilience and give them a benchmark to work from, a reference point that will support development; how do we know what we like if we do not know what we don’t?

Part of the problem is that we as persons who care for loved ones living with disability have this overwhelming need to protect them, keep them safe, away from harm or the possibility of harm, wrapping them in a safe cocoon. How do we as people living with disability learn our limits, how do we learn our personal strengths and weaknesses, how do we learn to self-determine without failure and the permission and ability to take risks?

From where I stand working within the sector and as a person living with a disability it is the central core value of why I do the work that I do; and if the Government is truly committed to the rights of all people including those of us living with disability then this concept has to be the foundation-stone that all is built on.

Of late the catch cry of the Government disability community, i.e. the NDIS and the NDIA has been “choice and control”. If this is true and the NDIS is a vehicle for those who live with disability to live well, then the underlining premise has to be that of dignity of risk. William A. Anthony (2000) states: “the notion that one has options from which to choose is often more important than the particular option one initially selects”.

Within the area of the culturally and linguistically diverse (CALD) community this is paramount. Last year I was asked by SBS radio “why is choice and control important within the NDIS and why is it important for the ethnic people living with disability?”

My response was to give a brief case study. I asked the reporter to think about the needs of a young Muslim woman possibly living with cerebral palsy, confined to a chair, she is a practising Muslim and cognisant without cognitive deficits. She should be able to determine who takes care of her personal needs, who washes and cleans her, who prepares her meals and what social activities she engages in that mesh with her life and religion.

This is only the starting point of choice and control, this issue deals with the most basic of human needs without taking into account the overarching aspect of self-determination with regard to all aspects of one’s life, the parts that many able bodied people take for granted.

Finally, as suggested by Petersen, Maier & Seligman (1995) within a mental health context,

“Environments are a barrier to the dignity of risk. When consumers are in institutions, hospitals or group homes, often their capacity for choice is severely limited. Choices as simple as when to get up, what you’re going to eat or who you are going to spend your time with are taken away. We need to ensure that appropriate accommodation and support exists in the community so that people living with a mental illness can exercise their right to make choices, take risks, participate in and potentially thrive in the sometimes scary and unknown outside world.”
Hope is central to recovery. Every choice involves both the possibility of failure or success. Over-protectiveness, taking away people’s choices, not allowing them to take risks or try new things crushes hope. This can be seen in many people who have been institutionalised or hospitalised for any great length of time. It can also lead to learned helplessness, which is often more debilitating and disabling than any illness itself.

This is as true for the mental health community as it is for those people living with disability. All people should have the right and the opportunity to self-determine, to take risks, to be given the opportunity to fail, to learn from these failures and to celebrate their triumphs, to sometimes do things within their life that are not tethered to a therapeutic return, just for the hell of it! And if they stuff it up then hopefully they will learn from that experience and extend their knowledge base. Personal growth, choice and control and the notion of dignity of risk should never be taken for granted no matter your age, culture, religion, or the significance of your disability.
NDIS — FAIRNESS FOR ALL PEOPLE WITH DISABILITY

Bruce Bonyhady is the current Chairman of the National Disability Insurance Agency. He was formerly the President of Philanthropy Australia and the Convenor of the independent panel appointed to advise the Productivity Commission and the government during the inquiry into long-term care and support for Australians with disability. He was a member of the Disability Investment Group and the Reference Group for the Pension Review, the Deputy Chair of the National Disability Insurance Scheme Advisory Group to the Council of Australian Governments, and the Chairman of Yooralla.

Mr Bonyhady has also held a number of senior positions in the funds management industry and insurance industry in Australia and internationally. He is the father of three adult sons, two of whom have disabilities. Mr Bonyhady was appointed as a member of the Order of Australia in 2010 for services to people with disabilities, their families and carers and to the community.

It was a heartfelt plea for help, and my response should have immediately put her mind to rest. In retrospect, a conversation in 2006 with a mother who had immigrated to Australia and settled in Dandenong set in motion a chain of events that would lead to the development of the National Disability Insurance Scheme (NDIS). I was then the Chairman of Yooralla, a disability service provider, and at the time, the Victorian Government was forcing Yooralla to supply early intervention services to more children with the same amount of money, even though it would mean many would receive inadequate support. So when she asked “how can I get the services my son needs?”, I explained our dilemma instead of offering a solution. Those words would haunt me — and become my driving force — for the days, weeks and years to come.

As I walked away from that conversation, I was horrified to realise that I had been defending the status quo — an unfair, underfunded and broken system. I remember thinking, “that is just an appalling answer” and reflected on what it must be like to be living far from extended family, to have a child with a disability and to have no influence or power. I resolved to find a better way, and I met with former Deputy Prime Minister, Brian Howe. He suggested looking at disability support through an insurance model rather than traditional social welfare means.

It was a light bulb moment, and through the work of a lot of different people over many years, the NDIS is now a reality. For the first time in Australia, fairness is at the centre of disability policy design. The NDIS does not discriminate based on a person’s background or their ability to self-advocate, the type of disability, or how, where or when it occurred. It gives people with disability and their families the choice and control over the implementation of their reasonable and necessary supports. This flexible, individualised approach means cultural factors can be taken into account. Put simply, the NDIS will ensure everyone with a significant and permanent disability will get the opportunity of a good life.
It is thought that 25 per cent of people with disability are from culturally and linguistically diverse (CALD) backgrounds, yet it would appear only a fraction receive disability support under previous State or Federal systems. Many may have opted out, preferring not to engage with a system that has posed so many challenges and, from their first contact, did not reflect them.

The NDIS is a once-in-a-lifetime opportunity to address the challenges and chronic underrepresentation of disability support for people from CALD backgrounds. The key to its success is the engagement with every part of the Australian community. We need to work together to find solutions and empower friends, family and colleagues to get the support they need — and deserve. So read on, learn about the NDIS and help spread the word. I often wonder what happened to that mother and her son from Dandenong. I could not help her at the time, but her predicament has become the catalyst for great reform and change that is already benefitting thousands of others.

**LAUNCH**

In 2011, the Productivity Commission called for an NDIS after conducting its largest inquiry ever. It compiled a 1400-page report and — in language perhaps unusually colourful for economists — labelled the existing disability support system unfair, fragmented, underfunded and inefficient. The case for an NDIS was clear and it received support from all governments and all sides of politics. It is the biggest and most complex social policy change in 30 years. It is being trialled in sites across the country so the experiences and lessons learnt can be applied to full-scheme rollout.

The NDIS launched at four sites on 1 July last year: Tasmania (for young people aged 15-24), South Australia (for children aged 0-14), the Barwon area of Victoria and the Hunter area of New South Wales (for adults up to 65). From 1 July this year, the NDIS will commence throughout the Australian Capital Territory, the Barkly region of the Northern Territory, and the Perth Hills area of Western Australia. Rollout of the full scheme across the rest of Australia will commence progressively from July 2016.

**HOW IT WORKS**

The scheme works on an insurance principle, the idea being that anybody can be affected by disability. It might be from birth or it might be acquired later in life. The scheme covers all Australian citizens, permanent visa holders and those holding protected Special Category Visas with a **significant and permanent** disability that substantially reduces their ability to participate effectively in activities or perform day-to-day tasks or actions.

The NDIS does not discriminate based on cause or type of disability or where or how a disability occurred. Need determines support. Once a person has been determined as able to access the scheme, an NDIS planner will listen to their goals and aspirations, and work with them to develop an individualised disability support plan to help achieve these goals. Plans are designed to enable participants to engage in education, employment and their community and become independent, to the best of their abilities, and receive necessary equipment.

For example, plans might include intensive, one-on-one lessons about handling money or cooking, or help identifying and entering employment. The participant has the freedom to choose the service provider that best suits their needs, and when and how their support is implemented. If a person does not meet the access requirements for an individual plan, NDIS planners and local area coordinators will help them find and connect to community supports, activities and organisations.

People aged over 65 will be covered by the aged-care system and will not be able to access NDIS support. Those who are under 65, when they make a successful access request, will be able to choose whether to stay with the NDIS or transfer to the aged-care system when they turn 65. Assistance is also available to people who have difficulty accessing the NDIS or cannot manage their own disability supports independently.
WHAT THE NDIS MEANS FOR CALD COMMUNITIES

The most important point is that the individualised approach of the NDIS has the capacity to meet the needs of people with disability from CALD backgrounds. It is not about making people fit into fixed support options. Instead, under the NDIS, participants are informed consumers making individual choices that can be tailored to their preferences and cultural needs. Of course, an ambitious national reform has its challenges and many of these are particularly relevant to CALD communities — for example, service delivery in remote areas, the interaction between disability and mental health sectors, lack of self-advocacy and communication skills, and varying attitudes and language around disability.

There is also a lack of reliable data about CALD people with disability because of underrepresentation in previous systems. This is a problem the NDIS has inherited and is working to correct. The National Disability Insurance Agency (NDIA), which is responsible for implementing the NDIS, is therefore working with the disability community and experts to navigate these challenges. The NDIA itself needs to be culturally competent in terms of its policies and staff, because this will be reflected in the scheme itself. Central to the solution to these challenges is establishing the NDIA as a learning organisation and recognising that everyone from participants to service providers and subject experts have a valuable contribution to make to its co-design.

We need to work together to make the NDIS the best it can be. The first steps have already been taken, with the NDIA convening a group of leading CALD and disability advocates — including the Federation of Ethnic Communities’ Councils of Australia and the National Ethnic Disability Alliance — from every State and Territory to develop a CALD strategy for the NDIS. The CALD Disability Advocacy Network Roundtable on 26 May 2014 focused on building sector capacity, building cultural competency within the NDIS, and CALD community engagement and capacity building. It was a productive exchange of ideas, and roundtable members have committed to drafting a strategy — which will be put out for discussion — and building ongoing community dialogue.

ACCESSING THE NDIS AND FURTHER INFORMATION

The NDIA website, www.ndis.gov.au, is the first port of call for information about the NDIS. It outlines when the scheme will roll out in each area and the My Access Checker allows prospective participants to check their ability to access the scheme. The website is continually updated with new information so check in regularly or, even better, sign up for our newsletter. Your ideas and input are welcome — and needed.

There are many challenges but we now have a once-in-a-lifetime opportunity to build a disability system, through the NDIS, which meets future as well as current needs and this includes finding the best ways of supporting CALD people with disability. Help make a real difference by spreading the word and getting involved. Together we can bring to life the unique goals and aspirations of every person with disability across this great culturally-diverse country.
CASE STUDY

For Nepalese woman Sancha Subba, the NDIS has provided a long-awaited opportunity to develop skills and make new friends. Sancha, who has learning and physical disabilities, has never attended school or received disability support. The 22-year-old and her family migrated to Tasmania a few years ago and speak little English. NDIS Tasmanian site manager, Sue Ham, said a Nepalese interpreter from the local migrant resource centre helped Sancha, her family and NDIS staff to develop an individualised disability support plan.

“Through the interpreter, we were able to ask Sancha and her family what needed to be considered in terms of cultural, linguistic and religious factors,” she said. “It was important the family were comfortable with all aspects of the plan and service providers entering their home.” Sancha now has an individualised plan in place that provides funding for dance, music, art and cooking classes to develop skills and interact with others that share her interests. “Her plan also has funding for the translation of printed material such as relevant, up-to-date health information.”

Sancha and her family chose not-for-profit organisation Able Australia as their service provider. Able Australia northern area manager, Jamie West, said incorporating cultural and linguistic factors into service provision was not as difficult as expected. “It’s been a very positive, educational experience for us too and we are planning an event to celebrate the cultural diversity of participants,” he said. “Sancha’s family have put a lot of trust in us and she is thriving — her smile makes everyone’s day.”

New skills and social interaction bring a smile to Sancha’s face. NDIS participant Sancha Subba (centre) with Jamie West and Shannon Bland from service provider Able Australia. Photo credit: Scott Gelston/The Examiner.
There is no doubt that we are living in very interesting times when it comes to people with a disability in terms of providing them opportunities for a decent quality of life with support to achieve their short and long term goals in life. The National Disability Insurance Scheme (NDIS), to be administered by the National Disability Insurance Agency (NDIA), will achieve the above when fully implemented across Australia in five years’ time. So far the Government seems to be committed to implementing the NDIS within the existing timeframe and in full. Even though this scheme will bring the biggest change and improvement to people with a disability like never before, we should not forget the eligibility criteria for this scheme only covers people with a severe and profound disability requiring support in their everyday lives.
Since a bit more than 700 thousand people are going to be eligible for the NDIS, what will happen to the 3.3 million people who are not considered as having a profound and severe disability but still require some form of support? We need to keep in mind that without this scheme in place, the level of support and opportunities for people with a disability depends pretty much on where you live (which State or Territory, city or country area) and how you have acquired your disability (born with it, car accident, workplace accident, or otherwise). There is still no answer to what support will become available for people with a disability who are not eligible for the NDIS.

The other very important issue here is that even having the best system in the world in place to support people with a disability is not enough because people need to be empowered to have control over their own lives and believe in themselves and what they can achieve with the right support in terms of their life goals. Why do people with a disability need empowerment so much? Because they have been denied everyday life opportunities and kept in isolation for too long.

Today, less than 40 per cent of people with a disability in Australia will finish year 12 or equivalent and it will be nearly impossible to get an education in a private school because of narrow-minded attitudes or extra costs involved in supporting students with a disability. The labor participation rate of people with a disability stands at around 50 per cent. Within the public sector system, 30 years ago more than 5 per cent of the workforce was made of people with a disability, today this rate has dropped to approximately 2.6 per cent. Australia has one of the highest rates in the Western world of people with a disability living below the poverty line.

Therefore if we compare the way people with a disability used to live 40 and 50 years ago when they were secluded in institutions away from family and friends, living in places that looked like jails, then we can say that things have really improved today. Still we are a very long way away from living in a society that provides opportunities to people with a disability as equal members of society.

A very important aspect of advocating and implementing changes within society to create equal opportunities for people with a disability should come from people with a disability themselves, demanding changes and being empowered to believe in themselves and implement their rights. Compared to other marginalised groups, disability advocacy has been very slow in raising awareness and creating changes in society. The reason for this is primarily the fact that, people with a disability have never been united enough as a movement in the past. People without a disability have advocated and lobbied on behalf of people with a disability a lot of the time, which is great too, but does not change community attitude towards people with a disability and what they should achieve for themselves as much as they can.
Empowerment needs to start at home, within the family environment where the person with a disability is treated equally like any other family member. Being treated equally does not mean denying the fact the child has an impairment. It is about acknowledgment and providing the right support as a family to overcome the impairment. In the process of empowerment, a person with a disability needs to be able to grow and experience life as much as everyone in society, including making mistakes. This may sound like a silly concept but in reality when you live in a world where family, society, system and service providers tend to overly protect the person with a disability from any dangerous or difficult situations in life, effectively there is a denial of opportunities for growth, maturity and responsibility for that person.

It is paramount for people with a disability to experience life as much as everyone because this is what makes the person to become more independent in life. Being independent does not mean at all to be able to do everything on your own; it is more about knowing what you want in life and knowing how to get it. Society in general still believes today that people with a disability will never have the same opportunities as everyone else for education, work, career and relationships. Such limitations do not come from the disability or impairment that the person has, but from society’s attitude and the low expectations for people with a disability. Most of the time people with a disability can achieve as much as (if not even more than) people without a disability, if only they are given an opportunity to do so.

Another important thing related to creating opportunities is that quite often a person with a disability needs to create their own opportunities in life because, simply sitting and waiting for an opportunity to come does not provide an outcome. The best way for people to create opportunities is by making themselves known and showing their skills. Society can do its part too by acknowledging that people with a disability are productive members of society that need to be treated as such and given the same opportunities to contribute and make a difference for themselves and others.

We have come a long way through the journey in the last 50 years for people with a disability to be considered as equal members of society with rights and responsibilities, but I still believe that we are only half way through this journey to achieve real equality, which happen when all members of society get involved to provide their contribution.
AUSTRALIA’S GRAND DESIGN FOR DISABILITY REFORM

MARK BAGSHAW

Dr Mark Bagshaw is the Managing Director of the innov8 Consulting Group, and a lifelong advocate for the disability reform. He worked for 28 years in IBM in a range of senior management positions, and has particular skills in strategic change management.

For most of that time Mark has also undertaken many national and international leadership roles in the social development area, including leadership of the Australian Disability Training Advisory Council, the NSW adult and community education sector and the Social Entrepreneur movement. His current roles include Co-founder of The Able Movement; Deputy President of the Australian Council of Social Service (ACOSS); a member of the Centre for Social Impact Advisory Council; Trustee of the New Zealand Be. Trust and others. In 2013 Mark was inducted into the Disability Employment Hall of Fame.

He has used a wheelchair for mobility since the age of 16 when a spinal cord injury caused through a diving accident resulted in quadriplegia.

One of my favourite television programmes is Grand Designs. We are introduced to a couple who excitedly share their vision for their dream home. We see a model of what it will look like and then we follow them through the inevitable and often enormous highs and lows as they bring their dream to life. At the end of each program we visit them a year or so later and, with few exceptions, we find that they have created something truly remarkable – and they love it.

And so it is with Australia’s approach to disability reform, and the hottest disability topic in Australia at present – the National Disability Insurance Scheme (NDIS). Australia has the vision and, it would seem, the commitment and determination to build a new system of disability support that truly is a Grand Design.

How far we have been from that vision was left in no doubt by the Productivity Commission when it said the current system was “…underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in the community”.

Let us start by taking a look at the NDIS and where it fits into the big picture of disability reform.

At the core of the vision for the NDIS is a new business model. Unlike the old system, it will put people with disability at the centre. They will not be told what support they need, but they will decide that themselves.
Why is this so important? Because the most disabling thing for a person with disability is not the disability itself, but the debilitating and demotivating effect of a society that does not expect much from them and makes decisions on their behalf. This saps people’s confidence and for many, it makes their Grand Design for a full and productive life just a dream. Second, it will be a market-driven system. We know that in most cases the best products and solutions are developed when an efficient supplier responds to the needs of an informed consumer. And third, there will be an extra $8 billion every year for disability support. A big number, yes, but as the Commission pointed out very strongly, the cost of not doing this is much greater.

The NDIS is currently being trialled in the Hunter region in New South Wales, the Barwon district in Victoria and for young people with disability in South Australia and Tasmania. Full rollout of the scheme around Australia is currently planned for 2018. All of the other States and Territories have also signed up for the NDIS.

This is all great news for people with disability. But it is only half the story.

The NDIS will prepare people with disability with the tools and supports they need to be part of our world. But the NDIS on its own will not create a level playing field for people with disability. It is not going to make all public transport accessible. It is not going to make websites accessible to people with visual impairments. It is not going to make our education system welcoming of all people with disability; and it is not going to break down prejudices across the community and in the workplace in particular.

And that is the other side of the story. We need the world to get ready to welcome people with disability, and to do that we must focus on a single objective: creating a smooth pathway from the beginning to the end of every day for every person with disability. The average person in Australia opens their front door each morning and expects the day to work out okay. And they can do that because we have a wonderful country, with a great infrastructure, that offers opportunities for most Australians, encourages and supports them – and expects them to make a contribution. They are travelling on the superhighway of life.
In contrast, people with disability are travelling on the back roads. For many, every day feels almost like a war zone. It is hard work living with a disability, and just like a real war zone, it is often only the most resilient and determined people with disability who make that critical decision every morning to open their front door and go out into the world.

A really important part of creating a smooth pathway is about practical things. It is about designing and building our world with the needs of people with disability firmly in mind. It is about making all of our public transport accessible, not just the 40 per cent that is currently accessible. It is about making every form of communication accessible to people with sight and hearing impairments. And the list goes on.

Let me illustrate using my own personal experience: I use a wheelchair for mobility and have been working full-time in demanding jobs all my adult life. But I am often late for meetings, and sometimes I cannot get to them at all, because I cannot rely on public transport and access to buildings. Is it my disability that is the problem here, or the fact that all of the buses are not accessible?

We need to do two things here: put a lot more resource and effort into removing infrastructure barriers, and from today onwards never build infrastructure that excludes people with disability. No ifs, no buts.

Creating this smooth pathway is important. But there is an even more challenging task that we simply cannot ignore. It is our community’s belief in the capacity of people with disability. I often ask people in our community: do you truly believe that a person with a disability is as capable of participating in, and contributing to, our society as anyone else? Some do. But as the 40 per cent difference in workforce participation for people with disability in Australia shows clearly, most employers are not willing to give a person with disability a job. We need to change that. We need to raise the bar on our community’s belief in the capacity of people with disability – and that includes many people with disability themselves.

We must all truly believe that, by preparing people with disability to participate in our nation through the NDIS, and by preparing our nation to welcome their participation, people with disability will be ready, willing and able to contribute their passion, their wisdom, their drive and their skills to building our wonderful country. If we do not believe that, then we will have squandered our best opportunity ever to unlock the enormous untapped potential of people with disability in our nation.

Raising the bar on Australia’s belief in the capacity of people with disability is what The Able Movement is all about. It is a new organisation of people who passionately believe that people with disability are far more capable than most people believe. Our key objective is to create a new social movement across Australia that drives real change on the ground in local communities.

For culturally and linguistically diverse (CALD) communities, who include the highest numbers of people with disability in the country, this challenge is particularly significant. But so are the opportunities. CALD communities have a strong sense of community spirit, and a reputation for working together for the benefit of all. Marshalling that community spirit is at the core of disability reform, and the rest of our nation has much to learn about the power of that community spirit.

One thing is certain: we will not build our ‘Grand Design’ unless we all work together. I wonder what advice people sitting in their dream homes at the end of each Grand Designs episode would offer us as we embark on our journey towards our vision of a world in which people with disability are participating in everything our society has to offer? I think it might go something along the lines “never lose sight of your vision, be willing to try new ideas and make mistakes, and never give up – it is well worth it in the end”.

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This is a pivotal moment for disability in Australia and a good time to be talking about disability, culture and identity in a publication like the Australian Mosaic. While the focus of the public mind has been on the National Disability Insurance Scheme (NDIS), pensions and the Budget, the reality is that there is a more profound shift in the undercurrent on disability in Australia that mirrors the conversations that we have had for decades about culture and identity on our island. A conversation that has moved from unhappy notions of assimilation, towards tolerance and then celebrating identity.

As Australians from culturally and linguistically diverse (CALD) communities would know, cultural change for a demographic group is not a linear journey, but one which can zigzag on the way to a better destination.

Almost a decade ago when Gerard Goggin and the late Christopher Newell wrote Disability in Australia: Exposing a Social Apartheid, they named disability as a form of apartheid similar to the treatment of refugees with exclusion across all dimensions. At the time the book stood out as an oddity. Disability as a policy priority was dead. The major parties took no disability policies to the election just a year before and the disability peaks did not even crank out an election platform. Given that people with disability represent around 18 per cent of the population this was a bad place to be.

Disability rights have historically suffered from being unable to find their place between a response to a medical diagnosis, a plea for charity or a progressive ‘cause’ championed by those who recognise the great Australian tradition of rooting for an underdog. None of these positions were ill intended, but neither did they cut through and mark the ground that multiculturalism, feminism or gay rights staked out decades ago.

That is a point where disability is a held identity – a stitch in the ‘Australian Mosaic’ that adds vibrancy to the whole. That is a place that we have started to
reach in 2014 and we can build on if we try. There are good groups working to cross bridges which include the National Ethnic Disability Alliance.

Binding this effort at a high level was the United Nations Convention on the Rights of Persons with Disabilities. The Convention is a remarkable thing. It came out of the developing world and was initiated by Mexico. Australia ratified the Convention in 2008.

It is comprehensive with eight principles and 50 articles covering a range of issues in the lives of people with disability from education, access, employment, right to life and bodily integrity, and personal freedoms.

The Government’s National Disability Strategy supports obligations under the Convention. Conventions mean little when people lack basic supports and the NDIS pushes the paradigm shift from tolerance to identify. Instead of imagining people with disability as supplicants or recipients, it is puts us in control of supports.

The fact that the NDIS has been boosted in the Budget with some of the toughest cut backs in public spending and transfer payments since World War II speaks to the new presence of disability as a mainstream issue. There are broader issues to which the successful delivery of the NDIS is entwined – the National Disability Strategy is pivotal to these.

Our urban landscape remains littered with barriers; workplaces remain inaccessible and hostile to anyone outside the ‘young and hungry’ mould; and business has yet to grasp the potential of customers with different needs, treating us as an obscure niche. As things stand now, we cannot get onto coaches, trains and planes; we cannot get into shops; we cannot use public toilets; we cannot travel safely on footpaths; we cannot get jobs; and people are remanded in jail without trial; locked up, restrained and abused.

Addressing these basic barriers, creating jobs and retaining a decent underlying safety net are key to economic emancipation and the profile and presence of people with disability. The job is far from over, but we are at the end of the beginning.
CALD CARERS EXPERIENCES WITH DISABILITY SECTOR REFORMS IN NSW

YVONNE GRITSCHNEDER

Yvonne Gritschneider is a Policy and Development Officer at Carers NSW. Yvonne has worked in the social and public health policy field since 2006 in both government and non-government organisations in the UK as well as Australia. After joining Carers NSW in March 2013, Yvonne has focused on representing the diverse needs of carers across many areas of policy and practice.

Prior to joining Carers NSW, Yvonne worked as Policy Researcher at the British Heart Foundation and the UK Health Forum in London, UK. Before living in the UK, she worked as project officer at the Department of Health and Ageing and as programme officer at the Federation of Ethnic Communities’ Councils of Australia in Canberra. Throughout her career, Yvonne has focused on advocating for the recognition and support of the diverse needs of CALD people in the social and public health policy field.

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers have been identified as being particularly likely to experience financial stress, burnout, isolation and lack of assistance.

Those from culturally and linguistically diverse (CALD) backgrounds not only share many of these experiences, but may also face additional impacts that cultural issues and conflicts can have on this demanding role. We know that CALD carers are less likely to identify as carers and may not be receiving the support they need in their caring role. They are often acting as health interpreters and have particular needs which health providers should be sensitive to.

In a previous issue of Australian Mosaic, Carers Australia CEO, Ara Cresswell, wrote about the common problems of CALD carers accessing support services in Australia. This article will look in more detail at issues identified by CALD carers in NSW in relation to major reforms in the disability sector, introducing more person centred approaches (PCAs) and individualised funding arrangements.

In a person centred system, the rights of people with a disability, and their families and carers, to make choices about their own lives are respected. Instead of government telling people with a disability what support service they will receive, they can decide what services they want. People with a disability, their families and carers can decide how these services are delivered, how often, and by what service provider. Individualised funding is a common funding delivery model in PCAs. It allocates a particular sum of money to an individual for funding their services and supports. The amount is usually determined by an assessment, and...
the individual is usually involved to some extent in the planning for how to spend the funding. The funding is then subject to regular review. Examples of individualised funding in disability programs operating in NSW include the Supported Living Fund and the National Disability Insurance Scheme (NDIS).

These changes have the potential to positively transform the caring experience for all carers, especially CALD carers, as they allow for diverse values and preferences to be considered in service delivery and provide greater choice of service types and providers. However, it is important that organisations such as Carers NSW continue to advocate for the consideration and inclusion of all carers, especially those from CALD backgrounds, as these reforms become reality.

The NDIS is being rolled out in the Hunter region of NSW since 1 July 2013. Carers NSW has received feedback from carers of people with a disability transitioning to the NDIS in the Hunter trial site. Carers have highlighted issues such as inadequate information and preparation for families and carers prior to their NDIS assessment; constant policy and procedural changes during the trial causing confusion and stress; and effectively reduced choice of services in some circumstances.

Findings of the Carers NSW 2012 Carer Survey show that families and carers of people with disabilities have only a limited understanding of PCAs and need tailored information, resources and training to engage with PCAs and individualised funding packages. Only 40 per cent of survey respondents had heard of PCAs, and just over half had heard of individualised funding. Awareness was particularly limited among carers from CALD backgrounds. Although roughly half of the respondents to our 2012 Carer survey believed that PCAs would lead to improvements for both carers and the people they care for, many carers raised concerns about the potential implications of PCAs for carers.

Further, our 2012 Carer Survey found that the most common type of support carers felt they might need if they were to manage their own funding was an information session. When asked which type of resources would be most useful in making the most of PCAs, most respondents to a small survey of Carers NSW Carer Representatives on resources about PCAs selected ‘training, e.g. workshops, seminars’. As well as information, we believe that carers will require interactive training which gives them an opportunity to develop and practice relevant skills.

Given that individualised funding often involves the option of self-management, Carers NSW also believes that all carers need practical resources such as checklists, toolkits and templates to assist them with tasks such as managing a budget and hiring staff. Any information and resources should be provided in appropriate and accessible formats (e.g. online and in printed form) and in simple English and community languages. These will also need to be effectively promoted and distributed so that diverse groups of carers, such as CALD carers, Aboriginal and Torres Strait Islander carers, lesbian, gay, bisexual, transgender and intersex (LGBTI) carers, young carers and older parent carers, can access the information.

Carers NSW has recently delivered information and capacity building sessions to people with a disability, their families and carers as part of the Supported Living Fund program, which delivers individualised funding to some people with disability in NSW. We have found that the understanding of PCAs among carers remains varied, with many carers - particularly those from CALD backgrounds - requiring further assistance to confidently engage with PCAs.

Our case study below demonstrates how specialised support of CALD carers and family members can empower them and their families.
CASE STUDY:  
A HOLISTIC APPROACH TO PERSON CENTRED PLANNING

In early 2013, Carers NSW visited the family of a CALD young carer, Julian*, to support his mother Maria* to complete a Supported Living Fund (SLF) application. Maria has a physical disability and Julian has been caring for her since he was four years old. Now in his late teens, Julian is her primary carer and he helps his mother with a whole range of everyday living tasks, including personal care, cooking and cleaning. Julian’s mother does not speak English, and he also translates for her. Julian is a member of our Young Carer program, but the family does not receive external support and Maria relies on support from her family and community, particularly those from her local church.

Our staff sat with Maria and Julian to discuss their hopes for the future. As well as considering Maria’s needs and wishes, we also spoke with Julian about his wishes, including his desire to go to University. Maria wants Julian to have more time to himself, to “find a good wife”. By speaking with the family and encouraging Maria and Julian to have their say, we were able to get the full picture of the current care arrangements and future support needs. We helped the family put together an SLF proposal that was sustainable, considered the family’s wishes, and reflected the importance of family and community in their culture.

*names have been changed

While the recently updated operational guidelines for the NDIS provide some scope for recognising and supporting informal care arrangements, Carers NSW continues to advocate that all carers should have the right to their own assessment as is the case in the UK. We believe that this should be independent from the assessment of the person with disability, as well as formal, comprehensive and nationally consistent. The carer assessment should take into account the willingness and capacity of the carer to provide the current level of support as well as the carer’s own goals and support needs. Subsequently, carers would need to be able to access their own person centred supports and individualised funding packages allowing them greater choice and flexibility in the support they receive in their caring role.
“I’M NOT AN ADVOCATE FOR DISABILITY ISSUES. HUMAN ISSUES ARE WHAT INTEREST ME” – AIMEE MULLINS

Suresh Rajan

Suresh Rajan is currently the President of the National Ethnic Disabilities Alliance and the former president of the Ethnic Communities Council of Western Australia. He is a regular contributor on the subject of multiculturalism to media in Perth. Suresh is also an Ambassador for people with disabilities. His career began with the Australian Taxation Office (ATO) in Perth and over a period of seven years he managed various sections of the Taxation Department, in both Perth and Canberra. He was responsible for the conduct, before the Boards of Review and Supreme Courts, of cases that involved disputes between taxpayers and the ATO.

Suresh Rajan has an accountant’s background and has regularly appeared on television and radio as an economics commentator. Suresh has a Bachelor of Commerce and a Masters of Business Administration Degree from the University of Western Australia. Suresh’s passion has always been the better integration of migrant communities with Aboriginal communities. He continues to work towards that end.

This could well have been the mantra of the directors and founders of the company Vindhya E-Infomedia. Who is this company? A Google search of the details of the company reveals the following:

“Vindhya e-Infomedia Private Limited provides information technology and information technology enabled services in India and internationally. It offers data entry, data conversion, data processing, and document management services. The company also provides image scanning and indexing, optical character recognition, and adobe portable document format services. Vindhya e-Infomedia Private Limited was founded in 2006 and is based in Bengaluru, India”.

DISCLAIMER: This article was first published by The Stinger on 25 May 2014 and it is reproduced with the permission of the author. The original article is available at http://thestinger.com.au/im-not-an-advocate-for-disability-issues-human-issues-are-what-interest-me-aimee-mullins/#.U4ZtyfMSyvJ
More detail of this company can be found here: http://www.vindhya.info/. But there is more to this company. I was made aware of this company by a childhood classmate of mine from Bishop Cotton’s Boys School in Bangalore (now Bengaluru), Pradeep Esteves. Pradeep and I went to school together there in the early part of the 1970’s. We have now become reconnected on Facebook in recent years. Like me, Pradeep has morphed into an advocate for various groups. In a recent discussion on my Facebook page he pointed out to me that:

“Of late, at least in India we find some business enterprises who show passion, it could be a personal experience or there is this case of a couple who came to Bangalore City from the rural areas and struggled for 4-5 years because their passion was to start an enterprise employing only people with disabilities (they themselves were not disabled) and no investor believed in them, they didn’t give up, after the long struggle, today it is a big business in software and employs only people with disabilities, equal gender balance is maintained and very successful... some light.”

The most fascinating part of the company from my perspective was this detail about the Managing Director (when reading this bear in mind that in India the language that is used in the disability sector may not be as refined or nuanced as it is here in Australia):

“Vindhya, a socio-economic venture started by her, is India’s first & only and arguably world’s first & only for profit organization which employs only people with disabilities as 100% of its production staff. Its production staff comprises only physically challenged, hearing impaired and border cases of spastic.

Starting as a first generation entrepreneur she has been able to grow the company from five people with disabilities to close to 150 people with disabilities and are currently in the process of increasing by another 500 people with disabilities to serve a new customer.

Her vision is to employ 5000 people with disabilities by 2015. Vindhya serves customers who are one of the top three in their respective domains.

A plan to employ 500 of them in the current financial year has already been underway. Work of Pavithra through Vindhya has been highly appreciated by all channels of Media throughout India and also been the recipient of Shell-Helen Keller Award from National Centre for Promotion of employment opportunity for disabled people, a government of India body, and Outstanding Customer from then Honourable Finance Minister Mr. P Chidambaram on behalf of Canara Bank one of the largest national banks in India.”

The CEO’s bio-data online is also revealing:

“Ashok has been inducted into world economic forum’s Young Global Leader community for the year 2009-2010. As the Young Global Leader from India, he will be involved in development programs across the world including leadership program at the Harvard University.

He has been on the regular guest lecture list of various management institutions in India for promoting the social-economic ventures and has been advising various large organization on inclusion of people with disabilities on a larger scale for providing better dignity of life through equal employment opportunity.

Prior to starting Vindhya, Ashok was in senior positions (Director) at R2K Inc, and Network Solutions (an IBM company) & Trivium Inc (an Intel funded company) responsible for their operations in Asia region. He has demonstrated result oriented leadership capabilities taking the organisations to the next level.”
This is a company that by any measure of business success is successful. The business is run like any other profit venture. However, it has a very low attrition rate (around 10 per cent). Most of the employees that started with the company at inception are still there. As the CEO Ashok Giri explains it:

“We hire people from different sources. The selection process is divided into three rounds. The first thing we look for is attitude... if a person has an attitude to do something in life, he can achieve anything. Second, we look at skills such as typing speed, and we have a written test with English and computer related questions. Finally, there is an interactive session.”

Giri runs Vindhya e-Infomedia like a regular business, with weekly and monthly performance incentives for the best workers. “The top performers get a cash prize and recognition.” But does he fire people, like in a normal business? “Just one or two since inception,” says Giri, “and only for behavioural concerns”. “We try and help employees improve their performance and skills,” says Giri. The two-storeyed office was designed for the differently-abled. And its customers vouch for the success of the company. Abhijit Ray, Director and Co-founder of Unitus Capital, who has known the company for the last 18 months highlighted:

“Theyir business model addresses both commercial and social needs and yet is successful with timely delivery and quality. The company also stands out in the way it treats its employees, particularly the rural manpower that it hires and brings into the mainstream.”

There is much that we can learn in our business community from the experience of this company. Those of us who are familiar with the Business Services Wage Assessment Tool (BSWAT) issues in Australia and the practices therein could do worse than to study the example of this company in India. In simple terms, BSWAT is an assessment tool that is used to assess the reduced wages that would be paid to people with disabilities. As the Department of Social Services website explains it:

“Internationally, there are precedents where people with disability are paid a reduced wage. In Australia, this occurs in conjunction with a range of other supports and benefits including income support payments and employer incentives including wage subsidies and workplace modifications. These strategies are in place to encourage mainstream employers to engage a diverse workforce and to provide people with disability opportunities for economic participation.”

This company is bucking the trend of a reduced wage for people with disabilities and it is reaping the huge benefits from doing so. Maybe it is time for us to be re-evaluating these strategies and thinking far more broadly and inclusively.
Gulnara is currently the Acting Director of the Federation of Ethnic Communities’ Councils of Australia. Prior to moving to Australia two years ago, Gulnara spent 10 years working in human rights, both at grass-root level and in international policy and diplomatic environment, with a particular focus on indigenous peoples and ethnic minorities. Gulnara is proud to have worked alongside outstanding community advocates from across the globe who shaped her vision of social justice. Gulnara joined FECCA to make a contribution to the organisation’s commitment to promoting fairness and inclusiveness in Australia’s multicultural society.

Given that one quarter of Australia’s population is born overseas (and nearly as many having a parent born outside of Australia), it is inevitable that the Federation of Ethnic Communities’ Councils of Australia (FECCA) works on a broad range of issues affecting various cohorts of people from culturally and linguistically diverse (CALD) backgrounds. Specific focal areas include women, youth and older people, established and newly emerging communities, and people with disability. FECCA’s policy and strategy on disability is driven by a dedicated advisory committee and I have been privileged to support the work of these committed advocates.

Last year, the committee conducted a survey to find out how multicultural organisations, including FECCA’s members in States and Territories, engage with people from CALD backgrounds living with disability, either through employment or service delivery. The other objective was to scope multicultural organisations’ understanding of the issues facing ethnic community members with disability to better align FECCA’s national advocacy priorities with the needs and aspirations of its constituency.

44 multicultural advocacy organisations and service providers with diverse capacity and extent of engagement with people with disability participated in the survey. 40 per cent indicated that their engagement with people with disability needed improvement, while 45 per cent believed it was adequate. Only 14 per cent rated it as excellent.

Survey participants told us that FECCA’s role should focus on promoting greater awareness to the community Australia wide of the issues impacting on people from CALD backgrounds with disability, their families and carers. Feedback also highlighted that community attitudes sometimes
frame disability as an impediment to education or employment, and may pose significant barriers. Similar assumptions may exist within organisations. Lack of organisational awareness about cultural and disability issues was identified as yet another barrier that may discourage CALD people with disability to engage. Limited awareness of cultural sensitivities and availability of appropriate models of care among service providers may result in CALD people with disability fearing that their needs would not be understood or accommodated, which often causes them to turn to their families for care.

The survey outcomes also raised expectations that FECCA should work towards increasing awareness amongst people from CALD backgrounds with disability and their carers about access to programs and services, including the National Disability Insurance Scheme. Broadly, lack of awareness of services and their availability, and its impact on CALD people with disability, was one of the fundamental findings of the survey. Often CALD people with disability are not aware that services exist for them, which is largely due to limited information made available in languages other than English or in accessible formats.

Overall, equitable access to services, including culturally appropriate services and access to language services, was highlighted as an important area for FECCA to pursue, particularly in rural and regional contexts. The survey results also revealed the need to focus on specific groups that people from CALD backgrounds living with disability may identify with, including age and gender, as such cohorts have their individual needs that need to be taken into account.

Most of the barriers identified through the survey are not unfamiliar – for instance, the limited systemic and organisational capacity of multicultural advocacy organisations and service providers, which impacts on their responsiveness to the needs of CALD people with disability, and is exacerbated by structural barriers, such as language, systems knowledge, and stigma in the community. Striking, though, was the clear call for reinforcement of collaboration between multicultural and disability sectors, in view of its importance for enhanced ability to support, and engage with, CALD people with disability.

While multicultural or ethno-specific organisations’ capacity to engage with CALD people with disability may often be limited, we learned that major gaps in culturally appropriate service delivery could be addressed through their enhanced partnerships with mainstream services, including through co-location of disability services and collaboration with specialist employment services. An overwhelming majority of the responses emphasised the need for a stronger focus on sharing information and knowledge through such collaborations.

When it comes to FECCA’s role, supporting the multicultural sector’s development was emphasised as vital to effectively serving the diverse needs of CALD people with disability. Given its position in the CALD sector, FECCA can be instrumental in working with the government to strengthen multicultural organisations’ capacity and facilitated access to information to deliver disability services.

Recognising the importance of productive engagements, FECCA’s disability advisory committee aims to collaborate, among other organisations, with the National Ethnic Disability Alliance as the peak body for representing the rights and interests of people from a non-English speaking background with disability, their families and carers. This edition of Australian Mosaic magazine is one of the first joint actions, and we hope to see our engagement enhance through collaborative advocacy strategies.

It is critical that FECCA plays an active role in responding to the challenges faced by people from CALD backgrounds, including people with disability and their carers, in all areas of Australia’s policy and practice. The extent of the challenges is such that they can only be addressed with the commitment and collaboration of the partners within and across the sectors, underpinned by effective multilateral communication and dialogue.
PEOPLE WITH DISABILITY TREATED UNFAIRLY IN THE AUSTRALIAN MIGRATION SYSTEM

ZELIHA ISCEL

Zeliha Iscel was born blind and arrived in Australia with her family in 1981. She completed her degree in Politics and Government at Edith Cowan University and has been an active advocate for people with disability from culturally and linguistically diverse backgrounds since 2006. Zeliha’s roles have included Senior Policy Officer at the National Ethnic Disability Alliance and producer/presenter of ‘EthnicAbility’, a radio program on disability and ethnicity funded by the Ethnic Disability Advocacy Centre in Western Australia. Zeliha currently chairs the FECCA Disability Advisory Committee and also the Women With Disabilities WA. Zeliha also runs her own business, Inclusive World - a consultancy service on disability and diversity.

The migration authorities have always been weary of who becomes an Australian and who should not be given the privilege. While it is fair to say that this is the due responsibility of governments, often it leads to the discrimination of certain groups as happens with people who apply to immigrate to Australia and have a disability.

THE HEALTH ASSESSMENT

As the White Australia Policy was wound down in the 1960s, Australian citizenship was extended to non-Europeans, but continues to exclude people with disability. This is primarily done using the Health Assessment which most migration applicants are required to undergo. In its paper entitled No Right to
Discriminate, the National Ethnic Disability Alliance (NEDA) highlights four key problems with the Health Assessment in relation to disability:

First, that it is a barrier to fairness. While people with disability are not expressly listed for exclusion in the Health Assessment, the assumed cost of a person’s disability, with no consideration of that person’s contributions or that of their family, indirectly discriminates against people with disability.

Second, the Health Assessment creates a barrier for social inclusion. This refers to the ‘one fails, all fail policy’. That is, if one family member has a disability, the whole family is refused entry into Australia. At times, this has led to families failing to include a person with disability – usually the most vulnerable person – in their immigration application, engendering guilt among family members and thus possibly reducing their productivity in the Australian economy. The amount of money that leaves Australia as family members hire support for the loved one they leave behind and the regular visits they are obliged to make to check on the person also needs to be considered.

Third, the Health Assessment causes a barrier to refuge. This relates to Australia’s stringent screening of refugees to ensure that only fit and healthy people are permitted to enter into Australia. It mainly applies to off-shore refugees as those who manage to reach Australia’s shores are often more successful.

Finally, the myth of the healthy migrant - NEDA cites a report commissioned by the Australian Government which states: “A prosperous Australian society requires a stock of people who are capable of economic and social participation. In the first instance, this means people of sound physical and mental health [...]”. The erroneous assumptions here are that firstly people with disability all have health issues, and secondly that people with disability do not contribute to society economically, socially or in any other way.

The impact of the Health Assessment on people with disability and their family can be very harsh.

A blind man – I will call him Ali - and his non-disabled nephew arrived in Australia on a student visa in 2002. They both completed their studies successfully and applied for their permanent residency. The nephew obtained his permanent residency without much difficulty; Ali however, is still fighting to obtain his permanent residency today. Ali has always been in employment since completing his studies, providing for his wife and two children. He is active in the community and goes about his daily life with very minimal support for his disability. Yet he continues to be denied permanent residency in Australia merely because he is blind.
DISABILITY DISCRIMINATION ACT

The Disability Discrimination Act was introduced in Australia in 1992. This Act has been in place to protect discrimination against people with disability. Essentially, it means that people with disability and their families, friends and carers can use the legal system to address instances where they feel they have been treated unfairly because of disability. However, the Disability Discrimination Act does not apply to the Migration Act 1958. Migration authorities therefore, have the mandate to make decisions at their discretion, and people often have little recourse for appeals. There is anecdotal evidence of people being coerced to sign papers declaring they would not seek migration outcomes for their family member with disability in order to gain entry into Australia.

NEDA, FECCA and other organisations argue that the Disability Discrimination Act should be applied to the Migration Act. In so doing, every person with a disability who applies for Australian citizenship or permanent residency will not automatically be guaranteed a visa but the application will be assessed more fairly. In cases where it may be too difficult to grant a visa for a person with disability, the Disability Discrimination Act ‘unjustifiable hardship’ clause can be exercised. The government has not considered this proposal favourably.

UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Australia signed the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008. CRPD is an international document which provides guidance on the basic rights and freedoms that are inherent for people with disability. Article 18 of CRPD grants liberty of movement and nationality for people with disability. However, the Australian Government has taken an interpretive clause on Article 18 so it is effectively not required to adhere to this article.

Notwithstanding, NEDA sought legal advice in 2008 to verify whether the treatment of people with disability in the Migration Act 1958 complies with CRPD, and the advice highlighted great inconsistencies. While no direct discrimination was found in the Migration Act, it was deduced that the Health Assessment can give rise to indirect discrimination on three crucial points:

First, there is currently a significant cost threshold of $40,000, established by the Australian Institute of Health and Welfare. Essentially this means that if the cost of supports and services for a person with disability is deemed to be more than $40,000 in a period of five years, the person will not be granted a visa. The refusal occurs regardless of whether people actually use all the assumed supports and services for their disability. On the other hand, there are concerns that the $40,000 threshold over a five year period may be too low.

Second, indirect discrimination may also occur due to weak evidence requirements in the health assessment. Only one Medical Officer of the Commonwealth (MoC) is required to assess the cost of a person’s disability, and it is assumed that this person has full knowledge of a condition and its associated costs. Applicants also do not have a right of review so the MoC’s word is final.

And lastly, the health assessment analysed under the CRPD, promotes indirect discrimination of people with disability by failing to take into account the family or individual’s wealth that they will transfer to Australia. They may have enough resources to pay for their supports and services without relying on the Government, but this opportunity is currently denied.

So where to from here?
THE NET BENEFIT APPROACH

Following its Inquiry into the treatment of people with disability in the migration system in 2009, the Joint Standing Committee on Migration released its report, *Enabling Australia*, in 2010. This report recommended that the government takes the net benefit approach when processing the application of a person with disability. Essentially, the financial and social contribution of an individual and family would be weighed against the costs incurred by a person with disability. The Government then agreed to investigate into the net benefit approach in 2012. However, in 2013 the disability assessment approach shifted back to the Ministerial waiver.

THE MINISTERIAL WAIVER

Currently the Minister for Immigration and Border Protection has the authority to intervene in a case (or override) the decisions derived from the health assessment. Many people have gained entry into Australia through this process - a recent example being the Kabir family - but it is inconsistent and time consuming as this is the measure of last resort. It assumes a scornful attitude toward people with disability suggesting that their fair treatment is a privilege rather than their right.

A health waiver is also sometimes available which is an override mechanism that can be administered by the Department of Immigration and Border Protection. However, these waivers are only attached to a small number of visa sub-classes, with the majority of cases rejected on health grounds needing to go all the way to Ministerial intervention. While guidelines for health waivers exist, there is no transparency behind the decision making process used by the Minister when using the Ministerial intervention power. Ideally the *Disability Discrimination Act* and CRPD should be applied. The breadth of visas that are accompanied by a health waiver also needs to be expanded to all visas.

CONCLUSION

In conclusion, the health assessment incurs an unfair treatment of people with disability. Neither the *Disability Discrimination Act* nor CRPD has afforded relief for migration applicants with disability and their families. While the net benefit approach is favoured to process applications of migrants with disability, it is understood that the government favours the Ministerial waiver approach. In this instance, the government must apply the tools that protect the rights of people with disability when considering the Ministerial waiver and permit waivers for all visa categories if the Australian migration system is to be fairer for people with disability.
Despite Australia’s proud history of resettling refugees, refugees with pre-existing disabilities were often excluded from resettlement programs. Disabled refugees and other would-be immigrants were denied Australian visas if they were suffering from or were diagnosed with conditions or diseases that would likely result in undue costs to the community, or place further pressure on health care and community services that are already in short supply in Australia. This was referred to as ‘prejudice to access’. Examples of the prejudice to access conditions included the need for an organ transplant or the need to undergo radiotherapy.

In 2010 a Joint Standing Committee report, Enabling Australia: Inquiry into the Migration Treatment of Disability, challenged the philosophy and ‘significant cost threshold’ that had been used to exclude refugees with disabilities. It also challenged the government to reconsider the ‘one fails, all fail’ criterion that excluded whole families from being granted a visa due to disability issues with one family member.

As a result of these changes, more refugees with disabilities are now being granted humanitarian visas. The numbers are not huge. The NSW Refugee Health Nurse Program has assessed over four thousand newly arrived refugees since October 2012. As a result of the screening we have only identified 12 individuals with disabilities that require everyday assistance. These individuals include a four year old with Down syndrome, a 15 year old boy with acquired brain injury caught in a bomb blast in Iraq, and a 35 year old man with cerebral palsy.
All of these refugees have arrived in Australia as part of a family group. All of them have been competently cared for by their family members and are, of course, loved and cherished. Indeed, the standard of the care given to them prior to their arrival, often in the most primitive of circumstances, is a testament to the dedication and support of their carers.

One of the roles of the NSW Refugee Health Nurse Program is to link newly arrived refugees into health and other services based on individual needs. Most health and health-related service providers are familiar with the needs of newly arrived refugees or recognise that a refugee client will require intervention or catch-up. Waiting times for treatment can be challenging, particularly dental, however, we are generally able to escalate care based on the urgency of need.

So based on the premise of need, we approached disability service providers with the same expectations of our other service partners. We quickly realised, however, that due to the historically low numbers of refugees with disabilities, many service providers had no experience with refugee clients or their need for quick intervention.

So why give refugees priority for access?

It is our experience that refugees often arrive with meagre possessions and resources. Their disability equipment may consist of a pack of incontinence pads. They do not have or were forced to leave behind any equipment, aids or appliances that we would take for granted if providing care for a family member/loved one with a disability: a wheelchair with a foot rest, a commode chair to allow toileting with some dignity, a shower extension hose to maintain hygiene.

One of the issues that complicate referrals is that newly arrived refugees have no service history in the system.

So get them into the system, I hear you say! The first problem is which system? Let us go back to our 35 year old man with cerebral palsy who was our first case of a refugee living with a disability. Do we refer him to the NSW Family and Community Services or to the Cerebral Palsy Alliance? Or perhaps the local health district intake team? What about appropriate accommodation? Is there any disability accommodation in the rental market in Sydney?

In this case we made enquiries with all of the services to ascertain waiting times for assessments and services provided. We were advised that all services had long waiting lists and an urgent referral was classified as three months. In addition we were advised that the wait for an Occupational Therapy assessment in the local health district could be 14 months! The wait to get into the system was clearly unacceptable.

We then turned to the Department of Immigration and Border Protection Complex Case Support Team. The Complex Case Support Team assists high-needs refugees and humanitarian visa holders with additional and complementary support. Our client certainly met the criteria and was entered into their case management system. Via this team the family were supported in securing appropriate accommodation, and aids and appliances that assisted in daily living activities were finally delivered. The delay in the delivery of services however was still about six months.

Knowing that we were likely to receive more refugees with a disability, we explored several options to highlight the needs of this vulnerable group.
A Disability Forum was held in Sydney in May 2013 co-hosted with the NSW Family and Community Services Department. Unsurprisingly, many service providers, having never dealt with a refugee with a disability, were confused about residency status, Medicare entitlements and the settlement process. We were careful to explain the difference between a refugee and an asylum seeker for example, and the Forum highlighted the extreme vulnerability of asylum seekers with no Medicare entitlement as the majority of services are provided only to Australian residents. This very successful forum brought together a swathe of service providers and interested groups and highlighted some of the issues and challenges. Service providers acknowledged the unique and immediate needs of newly arrived refugees and committed to exploring pathways to early assessment.

Following the Forum, we followed up with these and other service providers and support agencies with offers of additional education and information for their staff. We also became proactive about referrals for disability assessment. Whenever possible we refer clients prior to their arrival in Sydney. We actively seek as much medical information about the client as possible (usually from the Visa Medical) to allow activation of the case. We have commenced a case management approach whereby we meet face-to-face with settlement and disability services to plan approaches and regularly evaluate outcomes. We practise ‘assertive follow-up’ which entails following up referrals with phone calls and email enquiries. In short, we advocate, advocate and advocate!

Affordable housing is already a huge challenge for newly arrived refugees in metropolitan Sydney. Trying to find affordable rental housing suitable for a wheelchair-bound person in metropolitan Sydney is almost impossible. As mentioned, these clients are well cared-for by their families, but it is the aids and appliances that are lacking. We have therefore sourced reasonably priced short-term equipment loan pools to bridge the gaps between arrival and service assessment and provision. This equipment decreases the physical burden on carers such as lifting, transferring etc., and goes some way to modifying their home environments. Considering the relative small number of refugees living with a disability in Australia, we can make a huge difference to their lives when we combine effort and expertise. We are all in this together…
EMPOWERING CALD PEOPLE WITH DISABILITIES:

CHALLENGES FACED BY PEOPLE WITH A DISABILITY FROM NON-ENGLISH SPEAKING BACKGROUND IN AUSTRALIA

ESTHER SIMBI

Esther Simbi, Dignity for Disability’s 2014 Upper House lead candidate at the South Australian election, embodies determination. She contracted polio as a young child in Sudan and today has post-polio syndrome. Esther came to Australia in 2005 after 19 years in a refugee camps in Uganda, having survived extreme hardships. For Esther, an important turning point came from the respectful words of one man, an Italian Catholic priest who saw her ability and gave her the encouragement and support she needed to attend school. This involved a shifting of perception within herself and those around her and resulted in her gaining an education.

Through this experience, Esther gained a strong belief that access to an education gave her the opportunity to establish her career as a social worker, and now, through an ongoing emphasis on education, Esther wants to spread the message that disability is not inability. Her resilience and perseverance in relation to her own story assists her in working towards overcoming inequality and disadvantage for people with a disability.

People from culturally and linguistically diverse (CALD) backgrounds are the second biggest group in the disability community, after women with a disability. Despite this, both disability and mainstream health, education and other services in our community often have little consideration for the additional access needs of people who do not speak English as a first language, and have disability related requirements too. Let us look at some of the challenges, and possible solutions.

Accessing education is very difficult for CALD people with disabilities particularly women, due to language barriers and physical impairment, in addition to cognitive impairment on occasion. CALD people with disabilities find it challenging to advocate for themselves due to language and cultural barriers. It is important to remember some CALD women come from oppressive backgrounds where they have faced limited access to decision making and educational opportunity.
The added social stigma attached to disability that women from African backgrounds face compounds disadvantage – I am sure some from other cultures see this too – particularly where war and refugee backgrounds have meant people have had to fight for their right to education at every step due to resource pressures. If advocates and translators were provided in educational settings, this could assist people from non-English speaking backgrounds, particularly women, realise their goals. It is essential that teachers, lecturers and others involved in the delivery of education are aware of these concerns and approach the challenges with an open mind to ensure opportunities are maximised.

Some CALD people with disabilities may require a modified curriculum to suit their educational needs. Accessing the required resources or services may be difficult due to pressures on disability access support staff at schools, TAFEs, universities and in other further education settings. It should be remembered that once education and skills are developed, people in CALD communities with disabilities are hopefully able to secure employment, and reduce dependence on welfare payments.

A significant economic argument posed by the Productivity Commission for the introduction of the National Disability Insurance Scheme (NDIS) is the benefit Australians with disability could bring to the economy when they are able to access employment – and contribute as tax payers while also enjoying the benefit of careers in their chosen professions.

This brings me to the issue of employment. Unfortunately, Australia has a dismal story to tell in the realm of employing people with disabilities when compared with our cousins in the Organisation for Economic Co-operation and Development – we rank very poorly. This is the case in both public and private sector employment. I have not seen statistics on specific challenges faced by people with disabilities in CALD communities, but anecdotally, this situation is even more of a trial.

Firstly, we need the government at all levels to provide leadership in this area. Employing people with disability, especially CALD women, requires the government to be far more innovative in this realm. While physical access and workplace supports such as a screen reader, or an accessible toilet, are important to ensure people with disability can get into a workplace, the cultural and attitudinal change required is the real barrier. The focus needs to be not on whether someone needs a desk that fits their wheelchair under it, or instructions explained clearly and slowly because English is a second language, but instead on the skills and experience that person can bring to the workplace.

With a progressive, solution-focused approach, employing CALD people with disabilities does not need to be the great drama it is made out to be. In fact, research has repeatedly shown that people with disabilities are excellent employees – often it has been so hard to secure employment, once we do have a job we stay around for longer in the same workplace (we are more loyal) and we take less sick days.
The government needs to show leadership in the area of employing people, we will then see improvement from the community and the private sector. It is not about charity when it comes to employing CALD people with disabilities; improving diversity in a workplace in Australia has been shown to improve productivity and wellbeing. We human beings are not a homogenous bunch – and our diversity, whether it is disability, interest, ethnicity, language or culture, should be celebrated, as it brings out the best in all of us.

Workplace bullying is a critical area that needs to be monitored. CALD people can sometimes find themselves bullied in the workplace – with little understanding of how to deal with it, including options for complaint and counteracting the bullying. It can feel like after pushing so hard to gain employment, and then being confronted by bullying and harassment, you have nowhere to go and that no one will believe you. It is crucial that workplace managers, Equal Opportunity Commissions and other relevant bodies run awareness campaigns that target bullying in the workplace.

Finally, to the issue of domestic violence. Research indicates that CALD women with disabilities are more likely to experience physical, emotional, psychological and financial abuse as well as neglect by their partners or carers. Cases of abuse for people with disabilities in Australia are not often reported and additional physical and financial dependence of disabled people make them even more vulnerable to ongoing abuse.

In this instance information and awareness campaigns are also essential. Schemes such as the Community Visitors Scheme in South Australia will help people with disabilities in supported residential situations, but not women with disabilities living independently in the community. Out there, CALD people may not report abuse to police due to language barriers and more significant cultural issues. They may fear losing their partner, accommodation and financial stability. Many women that are newly arrived in Australia will not be aware of their rights in this area – particularly if they have come from countries where violence against women is often tolerated by society and legislation. As you can see, there are significant challenges for people with disabilities from CALD communities in the Australian society, but also positive solutions and gradually improving public awareness. I look forward to the day that a CALD person with disability faces no more discrimination or daily challenges than anyone else in our community.
Disability and Diversity: Personal Stories of Resilience

At FECCA, we believe in the power of telling personal stories. We believe that they can spark emotions and they allow us to see the bigger picture through the lenses of those who are directly affected by the policy. Personal stories have the power to inspire and empower, as people feel that they are not alone in facing their barriers and they can learn from others’ experiences with their own challenges.

In this issue Norhawa Bee Mohamed Ismail, Policy Officer at the National Ethnic Disability Alliance, tells us the stories of two resilient women from culturally and linguistically diverse (CALD) backgrounds who overcame the barriers imposed by their disability. Their stories go to the heart of the issue of disability and empowerment, and how their journey has transformed them to be inspirational women today.

Lola Payenda, is a young woman with Afghani heritage, who speaks about the importance of family support in overcoming everyday challenges and in fostering a sense of empowerment. Ace Boncato, Systemic Advocate at the Multicultural Disability Advocacy Association of NSW, tells her story about living with disability, and how she has focused her energy on becoming an advocate for the rights of people with disability in Australia and internationally.

FECCA would like to thank Norhawa Bee Mohamed Ismail for interviewing Lola Payenda and Ace Boncato. We would also like to thank Lola and Ace for kindly sharing their personal stories with us and our readers. We hope that you enjoy reading them.
LOLA PAYENDA’S STORY

I was born in Australia and I identify as an Australian. My parents migrated from Afghanistan to Australia in 1986. While my parents brought us up with cultural traditions and values, they were progressive as well as supportive of living in a Western society. I was never expected to wear a hijab, or pray five times a day. I am one of four siblings.

I had been bullied in school since I was 11. Being from an Afghan background and of Arabic appearance I faced discrimination at high school, due to the vilification of Islam after the September 11 attacks. I was being bullied in school even though I was born in Australia. I always kept it to myself for most of the time as I felt that I could not speak to anyone about how I was treated or even looked at.

I started to feel isolated and alone. I remember hiding in the restroom during recess because I felt different from my schoolmates and everyone was staring at me. I had a few friends at school, and at times I found it hard to feel motivated. It got worse and I started to feel depressed, thought about death and even about ending my own life.

I knew I was depressed and suffered from anxiety, but I did not know who to talk to at school. One of my teachers suggested that I go and see a counsellor and I was put on medication, however the discrimination continued. I wished my teachers and peers were more supportive in school.

I would explain to my parents what was going on in school. However, things at home were getting worse for my family as my parents were separating. I suffered from depression and anxiety between the age of 13 and 17, and suffered from agoraphobia too. I started to have a fear of public places and at times, I would get up and feel like I could never leave my room. I have lived in fear and it was quite debilitating at times.

It got to a stage where I did not want to get out of bed and I simply wanted to stay at home and sleep because I felt that there was nothing to look forward to. While there was a lack of support from my peers in school, my older sister helped me overcome my issues and continuously encouraged me when I went into a dark place. I was very fortunate to have the encouragement from my siblings who fully supported me throughout my mental breakdowns.

My partner has been a great support and he has never given up on me even when I doubted myself. They have both been people I would turn to for strength and resilience, especially on days when I feel like I could not even step out of the house. I think it is important for people with mental health disorders to have family and loved ones to support
Women with disabilities often face multiple discriminations and may be denied the right to exercise their human rights. Approximately 300 million women and girls around the world with an intellectual, mental, sensory and/or physical disability are likely to face double discrimination based upon gender and their disability. These barriers are magnified for women from culturally and linguistically diverse (CALD) backgrounds with a disability. In most cases, they are invisible within their own communities and at a higher risk of facing domestic and/or family violence.

In my experience as a Policy officer with the National Ethnic Disability Alliance (NEDA), I have developed the passion to ensure that policy makers include the participation of women from CALD backgrounds with a disability in social policy, taking into consideration their knowledge and expertise. Ms Ace Boncato, the Systemic Advocate and Policy/Projects officer for the Multicultural Disability Advocacy Association of NSW Inc, is an example of such a policy.

Ace is an inspiring, hard-working and highly motivated woman who I greatly admire for her positive attitude and resilience. Ace was born in Australia and both her parents are from the Philippines – a beautiful country and a place that Ace visits as often as she is able to. Ace has been lucky enough to be part of an incredibly supportive family who has always encouraged her to be what she aspires to be. Ace mentioned, “when I was growing up, the term can’t did not exist in my family’s vocabulary; if you wanted to do something, you would find a way”.

ACE BONCATO’ STORY

Narrated by Norhawa Bee Mohamed Ismail

Women with disabilities often face multiple discriminations and may be denied the right to exercise their human rights. Approximately 300 million women and girls around the world with an intellectual, mental, sensory and/or physical disability are likely to face double discrimination based upon gender and their disability. These barriers are magnified for women from culturally and linguistically diverse (CALD) backgrounds with a disability. In most cases, they are invisible within their own communities and at a higher risk of facing domestic and/or family violence.

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Ace is an inspiring, hard-working and highly motivated woman who I greatly admire for her positive attitude and resilience. Ace was born in Australia and both her parents are from the Philippines – a beautiful country and a place that Ace visits as often as she is able to. Ace has been lucky enough to be part of an incredibly supportive family who has always encouraged her to be what she aspires to be. Ace mentioned, “when I was growing up, the term can’t did not exist in my family’s vocabulary; if you wanted to do something, you would find a way”. 
Ms Boncato never really liked labels, nor did she like to use them on herself or anyone for that matter. She said, "it is only when you come across people on the train, who feel that it is appropriate to ask you how old you are, or what you are doing “out at this time of the night” (i.e. 6:30pm on my way home from work on a week-night!), that you realise, that whether you like it or not, you are being labelled in society".

In talking about culture and disability, Ace highlighted how the Filipino culture has very interesting views on how one acquires disability. She recalls, “I remember during one visit, a friend of our family stated that my mum ate too many crabs, resulting in me having brittle bones”. She further mentions that “unfortunately, if one happens to have disability in the Philippines, opportunities are stunted; and with the lack of infrastructure and support for people with disability, it is evident that the predominant attitude is that people with disability don’t work, socialise, get married, have kids or even go out of their houses. Unlike the Philippines, Australia is developed enough to have the resources to create a society where everyone can have full participation, regardless of disability, ethnicity, cultural background or gender”.

For this to happen, Ace strongly believes that “the voices of Australia’s diverse people need to be heard, for which understanding disability and attitudes towards disability when culture and gender are major factors, is essential in making sure the appropriate support is available”. Who would be best placed to provide advice on these issues, but those who have first-hand experience and Ms Boncato trusts that everyone has something valuable to contribute; it’s just a matter of finding a way to do it.

More recently, I saw an opportunity advertised by the Australian Human Rights Commission to nominate emerging young leaders in the disability sector to attend the 7th session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities in New York, in June this year. On behalf of NEDA, I submitted a nomination for Ms Boncato and she was one of the six young disability rights advocates to represent the sector at the United Nations. NEDA is positive that Ace, being a young woman from a CALD background with disability will bring into the dialogue a uniquely Australian perspective concerning the barriers and issues faced by people from CALD communities with disability, their families and carers.

This is an excellent opportunity for Ace and I do believe that there should be more opportunities for young women from CALD backgrounds with a disability to take on leadership roles. While there are role models of women with a disability who continuously promote and advocate the rights of persons with disability, I feel that there is a need to promote gender equality and empowerment of women from CALD backgrounds with disability.
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PO Box 798 Hobart TAS 7001
P: 03 6231 5067
F: 03 6231 5069
E: mctotassie.net.au
W: www.mctot.org.au

VICTORIA

Ethnic Communities’ Council of Victoria
Statewide Resources Centre
150 Palmerston St Carlton VIC 3053
P: 03 9349 4122
F: 03 9349 4967
E: eccv@eccv.org.au
W: www.eccv.org.au

Diversitat (Geelong Ethnic Communities’ Council)
153 Pakington Street
Geelong West VIC 3218
P: 03 5221 6044
F: 03 5223 2848
E: diversitat@d diversitat.org.au
W: www.diversitat.org.au

Ballarat Regional Multicultural Council
Golden Point Cultural & Learning Centre,
Cnr Grant & English Sts
Golden Point VIC 3350
PO Box 1418 Bakery Hill VIC 3354
P: 03 5332 5941
F: 03 5332 5944
E: admin@brmc.org.au
W: www.brmc.org.au

Sunraysia Mallee Ethnic Communities’ Council Inc.
38-40 Madden Avenue Mildura VIC 3500
PO Box 1213 Mildura VIC 3502
P: 03 5022 1006
F: 03 5021 2450
E: dean@smecc.org.au
W: www.smeccin.com.au

Ethnic Council of Shepparton & District
158 Welsford St Shepparton VIC 3632
PO Box 585 Shepparton VIC 3632
P: 03 58312395
F: 03 5831 3764
E: ec shepp@mcmedia.com.au
W: www.ethniccouncilshepparton.com.au

Gippsland Ethnic Communities’ Council Inc.
PO Box 3492
Gippsland Mail Centre VIC 3841
P: 03 5126 2091
F: 03 5126 4027
E: gippslandEEC@gmail.com
W: www.gippslandethniccommunitiescouncil.webysite.com.au

North East Multicultural Association
47B Reid Street Wangaratta VIC 3677
PO Box 417 Wangaratta VIC 3676
P: 03 5721 2090
E: nema@nema.org.au
W: www.nema.org.au

WESTERN AUSTRALIA

Ethnic Communities’ Council of Western Australia
20 View Street North Perth WA 6006
P: 08 9227 5322
F: 08 9227 5460
E: eccwainfo@gmail.com
W: www.eccwa.org.au
FECCA is the national peak body representing Australians from culturally and linguistically diverse (CALD) backgrounds. We provide advocacy, develop policy and promote issues on behalf of our constituency to government and the broader community. FECCA supports multiculturalism, community harmony, social justice and the rejection of all forms of discrimination and racism.

FECCA’s membership comprises state, territory and regional multicultural and ethnic councils. FECCA has an elected executive committee and a professional national secretariat implementing policies and work programs on behalf of its membership and stakeholders.

For more information and to read more about FECCA’s policies and program, please visit our website: www.fecca.org.au. Alternatively, please contact the FECCA office on (02) 6282 5755, or email: admin@fecca.org.au.
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