

One Step Forward Two Back

*Service provider experiences of
implementing Aged Care Reforms and
the National Disability Insurance
Scheme (NDIS) across South West
Sydney*

FINAL REPORT
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This project was commissioned by Macarthur Disability Services in Sydney, Australia.

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Disclaimer

This report presents the results of work carried out from February till July 2017. The information presented was the best available to the knowledge of the consultants at the time of writing the report. Every effort has been made to present the views of all stakeholders.

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Acronyms

ACHA	Assistance for Care and Housing for the Aged
ACSA	Aged and Community Services Australia
ADHC	Ageing, Disability and Home Care
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
CHSP	Commonwealth Home Support Program
CoS	Continuity of Supports
FACS	Family and Community Services NSW
FECCA	Federation of Ethnic Communities Council of Australia
HCP	Home Care Packages
ILC	Information, Linkages and Capacity Building
MAC	My Aged Care
MDS	Macarthur Disability Services
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Services
SWS	South West Sydney
TIS	Telephone Interpreter Service

Executive Summary

The ageing and disability services landscape is changing, with older people and people with disabilities being positioned as active participants. The scale and pace of change across the ageing and disability sectors, for older people, people with disability and their allies and government is unprecedented.

In February 2017, Carrie Hayter Consulting was contracted by Macarthur Disability Services (MDS) to identify how service providers across South West Sydney in ageing and disability were progressing with the implementation of the National Disability Insurance Scheme (NDIS) and the aged care reforms. Five consultations were held between February and June 2017 across Bankstown, Liverpool, Fairfield, Macarthur, and Wingecaribee to explore what is working, what is not working and what needs to change to build on what is working.

Like many regions of Australia, service providers across South West Sydney are adjusting to changes across both sectors which is creating adaptive leadership challenges for their organisations, NDIS participants, people with disability, older people and their carers or allies. Heifetz and Linksy (2002)¹ argue that adaptive leadership is the activity of mobilising people to tackle tough challenges and thrive. They demonstrate that adaptive leadership challenges are those for which there are no simple, painless solutions – problems that require us to learn new ways. In contrast, technical problems are well defined and the solutions are known and those with adequate expertise and organisational capacity can solve them. Adaptive leadership problems are entirely different, the challenge is complex and not so well defined; and the answers are not known in advance.

The diversity of South West Sydney poses significant challenges for these communities and organisations working to implementing the NDIS and aged care reforms. The 2011 census data showed that 36% of residents were born overseas² with significant demographic differences between LGA's. For example, 53 per cent of people in Fairfield were born in another country, while less than 16 per cent in Camden, 12 per cent in Wollondilly and 15 per cent in the Wingecaribee LGAs. Furthermore in 2011, there were 6881 people who identified as Aboriginal and Torres Strait Islander with 7% reporting a severe or profound disability.³

¹ Heifetz, R., & Linksy, M. (2002). *Leadership on the Line - Staying Alive through the dangers of leading* Boston, Massachusetts: Harvard Business Review Press

² ABS, Census, 2011 <http://www.swsphn.com.au/multiculturalhealth>

³ Aboriginal Affairs NSW

<http://www.aboriginalaffairs.nsw.gov.au/pdfs/profiles/region/South-West-Sydney.pdf>

Methodology

The project methodology included:

- an on-line survey for providers that was live for four months from 20 March 2017 to 21 June 2017. Approximately 44 providers completed the survey (33 were disability funded, 34 aged care funded and 34 services had registered for the NDIS) across all LGAs covered for this report in South West Sydney;
- Five consultations with service providers across South West Sydney in Bankstown, Fairfield, Liverpool, Macarthur and Wingecarribee LGAs with 112 service providers represented including 55 disability services and 57 ageing service providers.

The project methodology is at Section 1.2 of this report.

Background to aged care reforms and NDIS

In 2011, the Productivity Commission completed inquiries into ageing and disability which led the path for significant reform for the funding and organisation of disability and aged care services across Australia⁴.

In response to these inquiries and lobbying by key stakeholders in the ageing and disability worlds, the external ageing and disability funding landscape is changing dramatically as part of the personalisation and individualisation of funding. Central to these changes are the concepts of choice and control for the people (participants or consumers) who use services reflected in the changes to community aged care and the National Disability Insurance Scheme (NDIS). As part of these changes, funding is shifting from block or program based to individualised funding.

Section 2 describes the key challenges in implementing the NDIS and aged care reforms. These include the pace and scale of change for all stakeholders, using on-line portals and funding systems, educating and empowering participants and consumers to understand the changes, supporting and sustaining the aged care and disability sectors and adaptive leadership challenges for organisations.

⁴ Productivity Commission. (2011). *Caring for Older Australians, Report no 53, Final Inquiry Report* Canberra Australian Government

Productivity Commission. (2011). *Disability Care and Support, Productivity Commission Inquiry, Volume 1*. Canberra Productivity Commission

Key Issues and Recommendations

This report affirms many of the existing issues for providers in implementing the National Disability Insurance Scheme (NDIS) and the aged care reforms across South West Sydney. However, it does highlight serious concerns about information, access and empowerment for people with disability, older people and their families from Culturally and Linguistically Diverse (CALD) in understanding the NDIS and how to navigate and engage with a changing aged care system.

The design of reforms and systems across the NDIS and aged care reforms has not created a culturally inclusive system. In fact, providers reported difficulties for people from diverse backgrounds and their families to access, navigate the NDIS and aged care reforms.

Recommendation One

That the South West Sydney Disability and Ageing Networks write to the Australian Government to suggest the establishment of a multi-lingual line⁵ for My Aged Care and the NDIS and feed this information to key peak agencies including National Disability Services (NDS), Aged and Community Services Australia (ACSA) and the Federation of Ethnic Communities Council of Australia (FECCA).

The key issues and recommendations for government, sector support and development workers and for providers across South West Sydney is in Section 3.

Across NDIS and aged care reforms

The scale and pace of change for providers, participants, older people and their families, carers and allies in adapting to the NDIS and the aged care reforms was a consistent theme. Providers reported significant technical issues but also adaptive leadership challenges in adjusting to the My Aged Care (MAC) Portal, the NDIS My Place portal as well as administrative demands in engaging with these technical changes to assessment, intake and payment systems.

⁵ The Department of Human Services operates a Multilingual Phone service, people can speak to bilingual service officers about Centrelink payments and services, see <https://www.humanservices.gov.au/individuals/contact-us/extra-assistance-when-calling-us>

Furthermore, providers expressed deep concern about the participants experiences of NDIA planning processes with some participants not having their reasonable and necessary supports met under the NDIS. Similar stories were reported for older people and their allies with tremendous difficulty in navigating MAC, Regional Assessment Services and getting access to the right support at the right time, particularly for people from a Culturally and Linguistically Diverse (CALD) background.

The scale and pace of reform for providers in implementing the NDIS and the aged care reforms shows the critical importance of Sector Support and Development funding and positions in supporting ageing and disability services in South West Sydney to adapt to the external environment. Section 3.1 outlines these key issues in more depth.

Recommendations

Recommendation Two

That Sector Support and Development Workers across South West Sydney work collaboratively and use the ageing and disability network to support providers in managing the adaptive leadership challenges in their organisations. This could include the creation of a collaborative network across all Sector Support and Development Workers in Bankstown, Fairfield, Liverpool, Macarthur, Wollondilly and Wingecarribee to facilitate strategic conversations across South West Sydney.

Recommendation Three

That Sector Support and Development Workers (including the Multicultural Access Project Workers and the Aboriginal Sector Support and Development Workers), Ageing and Disability Workers in Local Government continue to work collaboratively and promote attendance of services at regional ageing and disability network meetings and evaluate the outcomes of network meetings to meet service providers expectations.

Recommendation Four

That the Sector Support and Development Workers across South West Sydney continue to promote opportunities for training and skill building of services and Boards in adapting to the reform environment.

In consultations providers reported the importance of being an 'adaptive' leader and responding to issues as they emerged on a weekly or daily basis. The opportunity to connect with other managers to share experiences was a powerful part of the facilitated workshops across South West Sydney with people sharing ideas about how to adapt, evolve and adjust in a changing environment.

Recommendation Five

That an adaptive leadership program for people working in community organisations including ageing and disability organisations is developed in partnership with local Councils and other key stakeholders.

Providers across sectors reported that carers were struggling to make sense of reforms and were often invisible in the planning or assessment process. Some carer support projects across South West Sydney were undertaking capacity building projects with carers.

Carers

Recommendation Six

That the funded carer support projects across South West Sydney work together to develop and build on the carer capacity building initiatives in the NDIS and aged care reforms.

Aged Care Reforms

Section 3.2 identifies the key issues for providers in implementing aged care reforms. The most commonly reported issue from providers was about educating and empowering older people and their carers, particularly people from CALD backgrounds to know how to access and engage with the aged care system. Providers working in CALD communities reported that people are saying “it is too hard to access MAC” so there is no point in attempting to get services.

While the Multicultural Access Project Workers are undertaking pop-up MAC information sessions run by bilingual workers across different communities (including religious places, shopping centres, GPs, local councils), further work is needed. In the Fairfield, Liverpool, Bankstown consultation the *Know the Aged Care* bilingual educator program that had been developed in using bilingual educators to educate a range of communities about the aged care system was discussed. Other suggestions included the creation of a connector program with people who have used the aged care system working to connect people in their community into the aged care system.

Recommendation Seven

That the MAPS and Aboriginal Sector Support and Development Workers continue to initiate capacity building with local communities and work in partnerships with local Councils to reach communities that may not access or know about My Aged Care.

Recommendation Eight

That Sector Support and Development Workers across South West Sydney work collaboratively to redevelop a bilingual educator model and a community connector model to support CALD communities accessing MAC across South West Sydney.

Participants raised many issues with MAC including being able to contact MAC on behalf of an older person, carer or family member. MAC would request further documentation and providers reported it was extremely difficult to contact MAC on behalf of a person. Health professionals also reported difficulty in getting people through MAC and providers expressed concern that some health professionals including GPs and some Primary Health Networks do not know how MAC works. The issues raised by service providers reflect issues raised nationally and MAC is introducing a number of changes from 3 July 2017 (see Section 2.2). These include procedures for people to be a registered person who can speak on behalf of an older person or carer (provided they consent), as well as improving access to information for allied health professionals.

Recommendation Nine

That the ageing forums monitor the proposed changes to MAC and develop a systemic process for providing feedback on key issues to ACSA and representatives of Health Connect.

Recommendation Ten

Sector Support and Development Workers across South West Sydney work with Primary Health Care networks, GP's and representatives from South West Sydney Local Health District to educate staff about MAC and aged care reforms.

Participants also raised issues about delays in people getting access to services including long waiting lists for Commonwealth Home Support Program (CHSP) services and for level 3 and level 4 Home Care Packages. In Macarthur providers reported long wait lists for Home Care Packages, Therapy Services, Domestic Assistance and Lawn Mowing. As part of this providers also expressed concerns about the ability of people to pay who are financially disadvantaged.

Recommendation Eleven

The Sector Support and Development Workers across South West Sydney monitor the current waiting lists for packages and CHSP services across the region and provide this information to ACSA and the Australian Government.

For people who are over 65 years and currently accessing FACS or ADHC disability and/or community care supports, it was unclear as to how the Continuity of Support (CoS) program will be rolled out across South West Sydney.

Recommendation Twelve

That the South West Sydney Ageing and Disability Network clarify with the Department of Health about the roll out of the Continuity of Support program for people 65 years and over who are currently accessing FACS/ADHC disability and community care supports across South West Sydney.

Specific issues in relation to the interface between Regional Assessment Services (RAS), providers, older people and their allies and using the provider portal were raised in the Macarthur ageing consultation. There appeared to be some disinformation between all stakeholders and it was suggested that a local working group be established to work through some of the technical issues between RAS, MAC and providers in Macarthur.

Recommendation Thirteen

That the Sector Support and Development create an Assessment and MAC working group with service providers, Regional Assessment Services and representatives from health to identify ways of improving and streamlining assessment processes. This information could be shared across networks in South West Sydney.

National Disability Insurance Scheme

Section 3.3 outlines the key issues for providers in implementing the NDIS. These included educating and empowering participants and families about the NDIS, planning including some people not getting their necessary and reasonable supports met after undergoing an NDIA planning process, poor communication with the NDIA, NDIS prices and the financial viability of services; workforce issues in recruiting and retaining staff; and the administrative burden of the My Place Portal on providers.

In regards to educating and empowering participants and families to make the most of the NDIS, there appears to be a disconnect between the capacity building initiatives funded by the NSW Government (eg Ability Linkers, My Choice Matters, the First People's Aboriginal network), NDIA and the impact at a local level. It is possible that providers are confused by the different capacity building initiatives that are funded by the NSW Government and the National Disability Insurance Agency (NDIA). A central information point for

all these initiatives would support providers to refer people to these initiatives.

Recommendation Fourteen

That the South West Sydney Disability networks promote capacity building initiatives for people with disability, carers and families. This includes collating all capacity building initiatives including CALD communities, Aboriginal communities and other initiatives and promoting this information on the South West Sydney sector support website.

Recommendation Fifteen

That Sector Support and Development Workers undertake further engagement with the Aboriginal communities across South West Sydney to identify issues with the NDIS implementation.

Service provider consultations and the survey data outlined the deep frustration of providers working with participants, families and carers about planning processes and the quality of these plans. Plans are being developed without adequate planning conversations and the goals are not matching the supports that are funded under people's plans. There is a significant risk that planning processes are not meeting people's reasonable and necessary supports.

Recommendation Sixteen

That the South West Sydney Disability Networks raise concerns about the poor planning processes including people not getting access to their reasonable and necessary supports with the NSW Department of Family and Community Services, National Disability Services and to the National Disability Insurance Agency at a regional level.

Service providers across all consultations reported poor and inconsistent communication with the NDIA with limited visibility of NDIA staff across South West Sydney. Providers reported that they could ring the NDIS National Access Team (NAT) twice in one day and get two different answers to the same question.

Recommendation Seventeen

That South West Sydney Disability networks develop better working relationships with the NDIA across the region.

Service providers reported confusion with the reduction of the FACS/ADHC funding as people with disability transition to the NDIS.

Similarly, there was significant confusion about continuity of support arrangements for people under 65 years not eligible for the NDIS or people receiving less support under the NDIS than under the specialist state based system.

While Schedule D of the NSW Bilateral Agreement for transition to the NDIS outlines that continuity of support arrangements will be put in place to achieve similar outcomes prior to the introduction of the NDIS, providers are not clear on what the continuity of support arrangements are. There has been a lack of clear information provided across South West Sydney about the Continuity of Supports arrangements.

Recommendation Eighteen

That individual organisations continue to make representations to FACS and where required the South West Sydney Disability networks make representations to the NSW Department of Family and Community Services to clarify the transition funding arrangements for disability and community care services as people with disability transition to the NDIS.

Recommendation Nineteen

That the South West Sydney Ageing and Disability Network make representation to FACS to clarify:

- *the continuity of supports arrangements for people with disability under 65 years who are accessing FACS/ADHC disability and community care supports and are not eligible for the NDIS.*
- *the continuity of support arrangements for people with disability under 65 years who are eligible for the NDIS whose reasonable and necessary supports under the NDIS are less than what was provided under the state based system. This arrangement should address the 'gap' in supports.*

Recommendation Twenty

That the South West Sydney Ageing and Disability Network make representation to the Australian Department of Social Services to clarify continuity of support arrangements for people not eligible for the NDIS and currently accessing Commonwealth programs that will cease when the NDIS is introduced. For example, for carers under the National Respite Disability Program and the Personal Helpers and Mentors program (PHaMs) for people living with mental health issues.