

ETHNIC LINK SERVICES
Pathways to Multicultural Access and
Participation to the NDIS Project
CALD Connect and Navigate Model

UNITING
SA *Together
we can*

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The Pathways Project Evaluation Report and CALD Connect and Navigate Model were produced as part of the ILC funded Pathways to Multicultural Access and Participation Project undertaken by Ethnic Link Services, a division of UnitingSA.

The reports and their recommendations are intended to be used as reference documents to provide insight and guidance for working with people with disabilities from CALD backgrounds, their families/carers and their communities.

Proper acknowledgment of UnitingSA and author Maria Eliadis must accompany any reproduction of the report's contents.

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1. Pathways Project: Connect and Navigate Model

The NDIS is a significant social reform that has changed how disability supports are funded and provided.

The aim of the NDIS is to fund reasonable and necessary supports for people living with disability while strengthening their choice and control over these supports.

The *Pathways to Multicultural Access and Participation* Project was funded by the NDIA under the ILC Grants Program to trial a communication strategy to deliver information about the NDIS in a linguistically and culturally appropriate manner, eroding the stigma that is often associated with disability within CALD communities and reaching those who are socially and geographically isolated.

One of the objectives of the Pathways Project was to, ‘...pilot a ‘Connect & Navigate’ Model for potential CALD participants which addresses barriers to access and participation and supports optimal service outcomes for this population group, (which is significantly under-represented in the NDIS uptake)’.

What the Pathways Project has learned is that Choice and Control is only realised when people living with disability have the social capital they need to effectively engage with the changes to the system and the changes in roles and responsibilities of key stakeholders, including themselves.

The consumers and carers stories demonstrated that social capital is strengthened when people are; well informed and understand what is going on, and; they stay motivated when they experience progress and feel they are achieving outcomes. Continual system setbacks, delays in communication and inconsistencies in process drained people of their resolve and confidence to pursue their goals.

Navigation Models

Systems navigation approaches provided by individuals or teams have emerged since the 1990's as a strategy to reduce barriers to health and social care.

Local Area Coordination was introduced in the late 1980's to enhance support for people with disabilities and has evolved as a core element of disability service strategies in Australia, the UK and Canada.

Navigation Models are intended to improve the experiences of complex clients with health and social support needs in primary care who often experience fragmentation and gaps in service delivery.

In an article by Carter et al (2018) the researchers, who undertook a meta-analysis of research and reports on Local Area Coordination models, found that there was still great diversity in models and definitions of roles.

Patient navigation is intended as a method of barrier reduction, bridging gaps in service which serve as pitfalls for complex patients. (Carter et al, 2018, p1)

These objectives are reflected in the NDIAs Partners in the Community model and Local Area Coordination approach to NDIS participant support and application of the information, linkages and capacity building.

Source: Navigation delivery models and roles of navigators in primary care: a scoping literature review, Carter et al. BMC Health Services Research (2018) 18:96



2. Co-designing the Connect and Navigate model: Engagement and approach

The Pathways Project's engagement with consumers and carers was based on the principle that the Project would support consumers and carers to 'achieve' the outcome they wanted and through that process learn about connecting to and navigating the NDIS. The Project Team engaged with all consumers that came in contact with the project.

Engagement was self-selecting and achieved through community outreach, referral from other agencies or through the Community Forums. The engagement process evolved organically and was not restricted to a set number or type of consumer/carer participants other than they needed to be from CALD backgrounds.

The stories captured as part of the Project's work were also self-selected based on Consumers and Carers providing permission for their stories to be captured and referenced. Aware of the need to ensure diversity in the Consumer and Carer cohort, the Project monitored the profiles of the Consumers and Carers engaging with the project and were pleased that self-selection had provided a broad spectrum of profiles and experiences.

The Project Officer engaged with each Consumer and Carer individually, working within the following guidelines:

- Everyone that came in contact with the Project would be supported as required,
- The aim of the support was to keep them connected, to assist them with information and provide 'advocacy' support to navigate the system,
- Each person was made aware of the Project's aim to learn from their experiences and attempt to draft a Connect & Navigate Model for people from CALD backgrounds,
- Each Consumer and Carer was asked for their permission for their stories to be used to inform the Project and were invited to actively participate in co-designing the Connect & Navigate Model.

3. The Consumers and Carers who shared their stories

The Connect & Navigate Model was informed by the experiences of the eleven consumers and carers who gave permission for their stories to be collected and shared. These same consumers and carers expressed interest in more actively contributing to the co-design process and were invited to meet as a peer group. The group met twice.

At the first meeting they shared their stories with each other and provided feedback on how they 'interpreted' their experiences and what they thought was going on.

Of the seven people who attended that first meeting only one had a positive story to tell. This carer was quite upset that no-one else had a positive story and feeling that maybe the others weren't doing the right things or didn't know what to do she asked them a series of questions. What became clear was that all six were experiencing system fails: delays in approval for capital supports, inconsistent advice from the NDIA, poor communication and follow through by the NDIA/LACs, or provider 'resistance' to understanding concerns and failure to do anything about people's concerns or in one case a request for a new support at the plan review time.

This first meeting was held in February 2019 after several of the community forums had been held and when the relationship between the Project Team and the LACs had strengthened. This made it possible to involve the LACs to act as navigators and work with consumers and carers to identify 'fails' and provide solutions.

Over the time of the Pathways Project the NDIA addressed many 'system fails' and barriers that were raised by the consumers and carers. Some of these included NDIS/LACs having more face to face meetings with participants and prospective participants, the NDIS and several ILC projects starting to release materials in different community languages, and there was an increased (but still inconsistent) use of interpreters. The most intractable issue being faced was the delays in approval and delivery of Capital Supports and this had nothing to do with barriers traditionally identified as experienced by people from CALD backgrounds, this experience was universal across NDIS participants. It was also not easily 'solved' by the LACs.

The NDIS is a new system, a new way of thinking about disability and of deciding on supports and regardless of recent developments many barriers still hindered the consumers and carers from realising the full potential of the NDIS. These included:

- Not being 'heard' by providers and funds being expended on services and supports that were not agreed or that were no longer required, while other supports were poorly delivered,
- A lack of choice of providers. This was the case for those living in regional SA but was also experienced by those who would have benefited from providers that were culturally more aware and sensitive and willing to use resources designed for CALD participants,
- Struggling to translate the concepts underpinning the NDIS hence they continually failed to 'say the right thing'. The translating refers specifically to impact of a disability/impairment on functionality and the way goals 'cascade' into everyday activities and what supports enable these everyday activities and hence achievement of long-term goals,
- While it wasn't a 'significant' barrier in the case of the consumers and carers involved in the Pathways Project community accessing the NDIS, community attitudes and stigma towards disability was raised. Even participants from more established communities mentioned the lack of support for people in the communities living with disability.

4. Impact of stakeholders on experiences of connecting and navigating the NDIS

Another important learning from the consumer and carers stories was a better understanding the roles of key stakeholders to consumers and carers and the impact they had on positive experiences and positive outcomes.

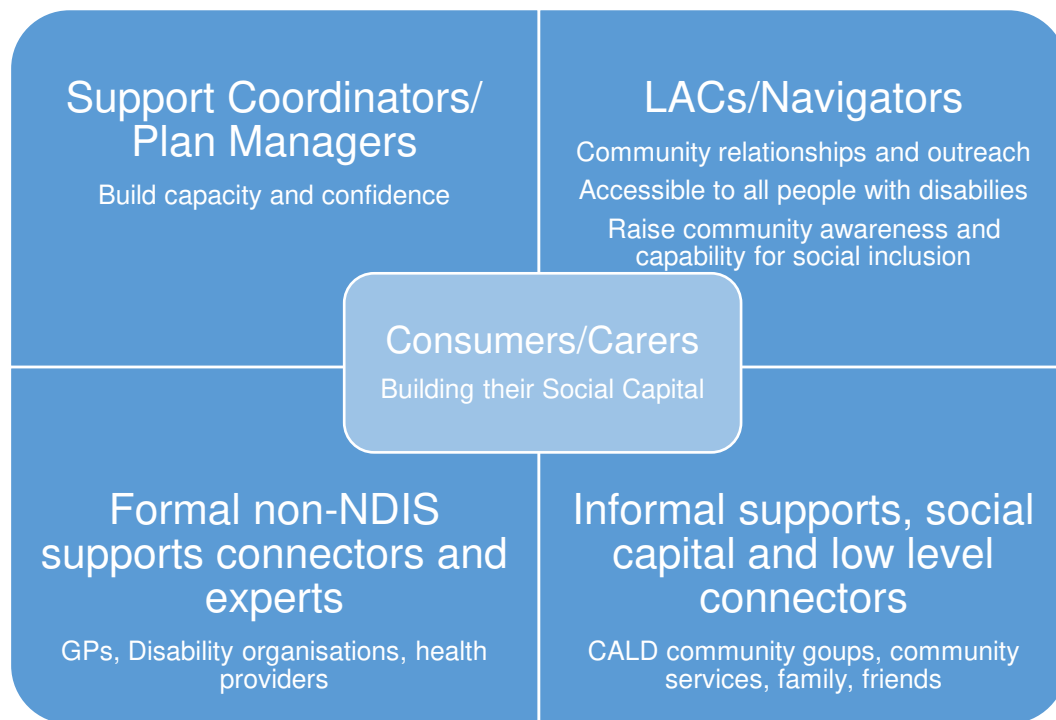


Figure 1 Interrelationships between stakeholders and Consumers and Carers

The more social capital they can build up, the more confident and capable they are to 'converse' in the NDIS language, the more control they have over what they achieve through the NDIS. The above figure demonstrates the different but critical roles each stakeholder contributes to the consumers and carers having a successful NDIS experience.

This was evidenced at the Pathways Program Symposium during the panel session with three of the Consumers and Carers, each of whom when asked what advice they would give people accessing or 'navigating' the NDIS all three said - 'don't give up', 'persevere', ask as many people as you can, get as much help as you can. NB they also referenced the Pathways Project itself as having made a significant positive difference to their experience.

Consumers' and Carers' sense of having Choice and Control was boosted once they understood how to 'translate' the NDIS (not just navigate it). Extrapolating lack of function from disability and 'translating' the impact of this on their everyday lives; setting goals that would inform what supports they might get and appreciating the inverted relationship they now have with support providers is new and for many without a history of engagement with the disability sector very new and quite confusing.

What most influenced the Consumers and Carers was;

- The suggestions or 'nudges' from professionals "...you should apply for the NDIS" or "...you need to get ready for the NDIS...",
- Their strong sense that they deserved to try, but this was questioned when they faced repeated challenges,
- Their connection to the vision of '...a better life...' and to have more choice and control over the quality of their life.

5. Core interventions, their impacts and what we learned

Core areas of activity	What we learned about Connections	What we learned about Navigation	Success Factors	Considerations
<p>Ethnic media</p>	<p>5EBI was a very effective connector to many language programs however each CALD community has a unique media profile,</p> <p>5EBI will collaborate and advise on strategies that 'invite' people to connect,</p> <p>Language is not the only consideration as some language groups have diverse community profiles (ref case study of the Spanish speaking communities),</p> <p>Different media mediums are effective for different communities i.e. print media for Chinese, social media of the newer African and Middle Eastern communities, radio and community TV for others,</p> <p>Many smaller social/cultural community organisations use informal newsletters and e-newsletters to communicate.</p>	<p>Media such as radio, newspapers etc. are best used to raise awareness and curiosity.</p> <p>For navigation in the broad sense to 'work' there needs to be a simple and clear call to action.</p> <p>A direct reference to LACs as Navigators and information about how to contact them would be very useful for consumers.</p> <p>Most consumers that connected with the Project needed personal advice and support from a LAC as opposed to general 'first level' awareness raising.</p>	<p>Co-design engagement and communication strategies with the experts, the communities themselves,</p> <p>Don't assume one strategy reaches all sectors of one language or ethnic group and don't assume one strategy will be effective with all communities – co-design.</p> <p>Link announcements to a clear call to action</p> <p>Timeframes should be short/urgent, a blitz a week or two before an 'event',</p> <p>Link to social media and include interviews that can be turned into podcasts or YouTube videos & photos to make it personal,</p> <p>Place 'regular' notices on community TV, and in newspapers and newsletters in community languages</p>	<p>No one approach works best for all communities so try to build an integrated strategic communications strategy.</p> <p>As the NDIS addresses system fails and the Partners in the Community establish the service models and build their community profiles ethnic media can be used to expand or 'build' messaging. For example, focus on implementation, announce drop in or outreach initiatives etc.</p>

Case Study: Spanish Speaking Community

Leaders from Spanish speaking communities were actively involved in both the English language forum and hosted a dedicated forum in Spanish and contributed to the evaluation of the Forums. The feedback from the leaders of the Spanish speaking communities was echoed by the leaders from the Arabic and Swahili speaking communities.

They welcomed an information Forum on the NDIS in Spanish and recommended that subsequent approaches to engage the Spanish speaking communities recognise them as a diverse group with different origin stories and that they may not share social networks. They recommended using outreach strategies to connect with the wide range of existing groups and to use methods that focused on storytelling and sharing to help contextualise information. They believed that building capacity within the communities through a network of peer 'mentors/ambassadors' would address a particular issue they saw in their communities of people feeling they did not 'deserve' to apply or believed they would not be eligible. Radio was highlighted as a great connecting medium as the population that needed the information most was often older and listening to the



Core areas of activity	What we learned about Connections	What we learned about Navigation	Success Factors	Considerations
<p>CALD Communities</p>	<p>Community Leaders were willing to act as 'connectors' to information about the NDIS and navigators like the LACs as well as to develop social support and programs for those living with disability and their carers. The potential for them to be connectors became obvious but was again unique for each community.</p> <p>Leveraging existing relationships and rewarding collaboration is important.</p> <p>The impact of the forums was immediate with all communities interested in 'what next' and many communities not included in the initial series requesting forums for their communities.</p>	<p>LACs' involvement in all Forums was a 'game changer',</p> <p>LACs were available and willing to deal with personal queries at the Forums and to take individual referrals from the Project Officer,</p> <p>The role of the LACs at the Forums and the relationship between the Project Officer and the LACs demonstrated how navigation can work and importantly the positive impact it can have for consumers.</p>	<p>Co-design an outreach strategy for communities,</p> <p>Connect with community leaders but also 'look' for informal representatives and 'lay' leaders such as women's groups, community liaisons, faith leaders etc.,</p> <p>Invest in building relationships with community leaders and increasing their understanding of things like human rights framework, impairment and functionality, goals and supports, support planning and implementation,</p> <p>Be prepared to subsidise the costs to communities. Especially smaller and newer communities.</p>	<p>Peak or 'umbrella' organisations are good initial connectors, however successful outreach requires building relationships directly with communities and then to even drill down to smaller communities. This is true not only for small and newly arrived migrant communities but also for the larger and more established communities.</p> <p>Priority should be given to the vulnerable communities that come together for social/cultural sharing and receive no outside financial support. These communities are often identified as hard to reach but just require external connectors to reach out to their 'grassroots'. The leaders themselves are keen to connect.</p>



Case Study: Vietnamese Community

The Vietnamese Women's Association SA hosted an NDIS information Forum and contributed to the evaluation of the Forums. Of the communities that hosted Forums they were the only organisation that is also registered as an NDIS provider. Their feedback provided insight into the pivotal role CALD service organisations play for their community members in assisting with all sorts of queries and providing support, advice and referral.

As an organisation they reported they would benefit from more information and training sessions for their staff especially on topics about the more practical aspects of supporting community members to connect with and navigate the NDIS; such as effectively preparing for Plan meetings, managing support funds, understanding plans, activating plans and connecting to MyGov/MyPlace,

Core areas of activity	What we learned about Connections	What we learned about Navigation	Success Factors	Considerations
<p>Mainstream, Community Services and Disability Organisations</p>	<p>These sectors played a valuable 'primary connector' role for all the Consumers and Carers. They all provided the initial 'nudge' or advice to 'apply for the NDIS' and provided significant assistance.</p> <p>The quality of their 'connecting' depended on how well they themselves understood the NDIS and how 'empathetic' they felt towards the consumer/carer.</p> <p>GPs and health sector professionals were pivotal in assisting the most vulnerable consumers to connect with the NDIS.</p>	<p>The capacity of these stakeholders to act as navigators was inconsistent and at times seemed to strain resources and go beyond responsibilities leading to referrals to the Project Officer.</p> <p>The interventions of these stakeholders were strengthened and more effective when they understood how they 'fit in' to the NDIS system and how, where and when to refer people.</p>	<p>Provide these sectors/organisations with a Connect and Navigate Model. The more they know about the NDIS the more they can assist and refer.</p> <p>Disability and CALD Services sectors need support to understand each other's sectors and how they can best either grow their service models or collaborate for improved outcomes for consumers and carers.</p>	<p>CALD is marginal to mainstream, community and disability services and disability is marginal to CALD service providers.</p> <p>As soon as the Project started its outreach work and was 'known' it started to receive 'referrals' and requests for 'help' with disability clients and the NDIS, but also from consumers wanting help with employment and other 'connections'</p>

Case Study: YWCA

The YWCA offers support to African women through their Growing Horizons program. A worker supporting participants on this program connected with the Pathways Project requesting support with navigating the NDIS on behalf of one of her program participants; a woman from Eritrea who arrived in Australia a couple of years ago, had limited English language skills and was an amputee.

The woman was on a six-month journey experiencing major delays and barriers in connecting with the NDIS. The YWCA worker attempted to assist her by contacting the NDIS and/or LACs and trying to set up a Plan meeting with an interpreter, but the situation was not 'progressing'. When she heard about the Pathways Project, she contacted the Project Officer hoping to refer the woman.

The Project Officer was able to connect directly to the relevant LAC and set up a meeting with the Eritrean woman. It took another 4 months but the young woman from Eritrea finally got an approved plan and received her prosthetic leg. She is now waiting for the home modifications.



Core areas of activity	What we learned about Connections	What we learned about Navigation	Success Factors	Considerations
<p>Consumers and Carers</p>	<p>All consumers and carers were 'nudged' to apply for the NDIS. Even those that were already using disability services were prompted to get ready and find out more.</p> <p>Connections made through GPs, allied health professional, health/hospital staff and workers in disability organisations were pivotal to consumers knowing about the NDIS and deciding to apply.</p> <p>The most vulnerable consumers were connected to the NDIS via GPs and/or health sector professionals.</p>	<p>'Navigation' (as defined in the report) was the determining factor in Consumers and Carers experiencing positive outcomes. The Project 'walked' alongside Consumers and Carers and supported them as they resolved their problems.</p> <p>While most issues were able to be resolved by the LACs those where Consumers and Carers were not fully satisfied involved language barriers or delays with receiving capital supports.</p> <p>In some cases, even if issues were not fully resolved Consumers and Carers felt better because they felt more in control, understood their choices better and had the LAC and Project Officer to refer to for advice and support.</p>	<p>Establish a user friendly 'navigator' referral model so 'connectors' can refer PWD to LACs,</p> <p>The more personal the better – i.e. face to face meetings, home visits etc.</p> <p>Should be simple/one touch and responsive to CALD barriers to avoid issues down the track,</p> <p>This worked well during the pilot for referrals to ECEI services, NDIS needs to continue to build language resources, disseminate them and LACs capabilities to maximise them,</p> <p>Promote the above to mainstream and community services, LGAs,</p>	<p>'Navigation' was experienced differently by all the Consumers and Carers and they all experienced difficulties with 'navigation'.</p> <p>While many ILC projects have successfully developed NDIS information in community languages, these resources need curating and to be more easily accessible. As the Scheme 'matures' so too does the level of information available in community languages.</p>

Case Study: Margaret and John*

Margaret lives in Whyalla and cares for her 28-year-old son John. John is diagnosed with multiple disabilities and has been receiving support from Disability SA since he was a child. Mum and carer Margaret made it her business to find out as much as she could about the NDIS when she heard about it. She talked to support staff she knew at the local disability provider organisations as well as John's doctors. She attended all the information sessions she could and took away all the information they made available. When John received his invitation to apply for the NDIS and Margaret received the call from the local LAC for a plan meeting she was ready.

She was advised by the LAC and disability support workers about how to prepare for John's Plan meeting, she had close relationships with health professional that assisted her to describe the impact of John's disabilities and supports that would improve his quality of life and she knew what would most positively impact on her sons quality of life and personal goals.

The NDIS has improved John's quality of life significantly and Margaret speaks positively about the experience, but she 'warns' it is a lot of work, you have to bug a lot of people, you need to be very organised and you need to not give up! She knows she would not have the outcome for John she has without A LOT of advice and support. Living in a regional centre she is well connected in her community and has a close 'personal' relationship with the local LAC. (*Not their real names).



6. Guide for LACs, Mainstream and Community Services and Disability Organisations

CONNECT

Mainstream/Community Services and Disability Organisations

The National Disability Strategy clearly outlines the responsibility for mainstream services to provide accessible and responsive services to people with disabilities.

Stakeholders:

- General Practitioners
- Allied Health Professionals
- Early childhood and early education institutions
- Medical Specialists/nursing staff in Health System
- Disability Organisations
- Community Support and Services Sector – i.e. welfare, LGA, migration and settlement services

How to Strengthen Effectiveness:

- Increase their awareness of the NDIS,
- Educate them about the role they can play,
- Involve them in a navigator referral pathway,
- Develop empathy by building cultural awareness and competency levels,
- Increase confidence by sharing best practice for working with people from CALD backgrounds.

CALD Consumers and Carers

Consumers and carers get the best outcomes from the NDIS when they engage based on their personal circumstances, what is relevant to them and when they know what is expected of them – what they think about and need to do.

When someone explains this and assists them to navigate the process, they experience better results and feel better about themselves and the outcomes they experience.

The factors that ‘trip’ them up most are:

1. Their frame of reference is the current welfare or health system,
2. They don’t know what they don’t know about the NDIS and disability reform,
3. They don’t understand the new ‘language’ of the NDIS about functional impact of disability on everyday lives, personal goals and how to meet them with supports,
4. They can ‘fail’ even if they do everything that’s asked of them and they don’t understand, they blame themselves.

NAVIGATE

Local Area Coordinators

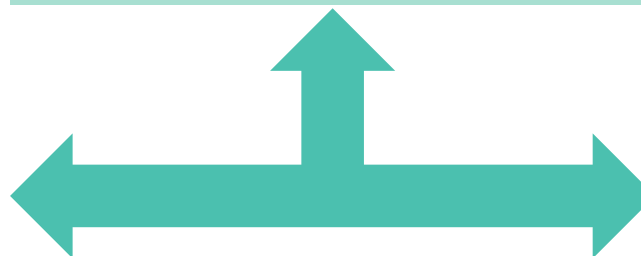
The LACs play a key role as navigators, assisting people with disabilities and the communities they live in to maximise the disability sector reforms and the NDIS.

As the NDIA’s Partners in the Community, LACs are responsible for realising the five priorities of the NDIA’s Cultural and Linguistic Diversity Strategy (2018):

- Engage with communities,
- Make information about the NDIS accessible,
- Increase community capacity and broaden consumer choice
- Improve approach to monitoring and evaluation,
- Enhance cultural competency within the NDIA and its Partners in the Community,

How to strengthen effectiveness:

- Do outreach and connect with CALD community’s infrastructure and activities,
- Resource communities to address stigma and attitudinal barriers,
- Don’t assume rather co-design with consumers and communities,
- Build relationships with communities and build on existing relationships,
- Develop empathy and confidence by building cultural awareness and competency levels.



7. Navigating the NDIS Guide for Consumers and Carers (7-64YO)

If you are a 7 to 64 years old:

- You are an Australian Citizen or permanent resident or hold a Humanitarian VISA
- You or your child has a Profound and Permanent Disability
- You or your child needs support with everyday tasks and to achieve your personal goals



What you need to do:

- Call the NDIS for an Access Request Form,
- Call the local LAC for help.

Next you need to:

- Start to collect evidence of:
- Your disability and how it affects you doing things to be independent or to work or go to school, to go out into the community, socialise and make friends,
 - Think about what help makes the biggest difference for you



If accepted call LAC for a plan meeting and for help to prepare.

- Prepare your participant statement using the Booklet 1
- Start to think about your goals and who you want to help you,
- Do you need help to find and manage this support or to pay for the supports?

If not accepted to the NDIS:

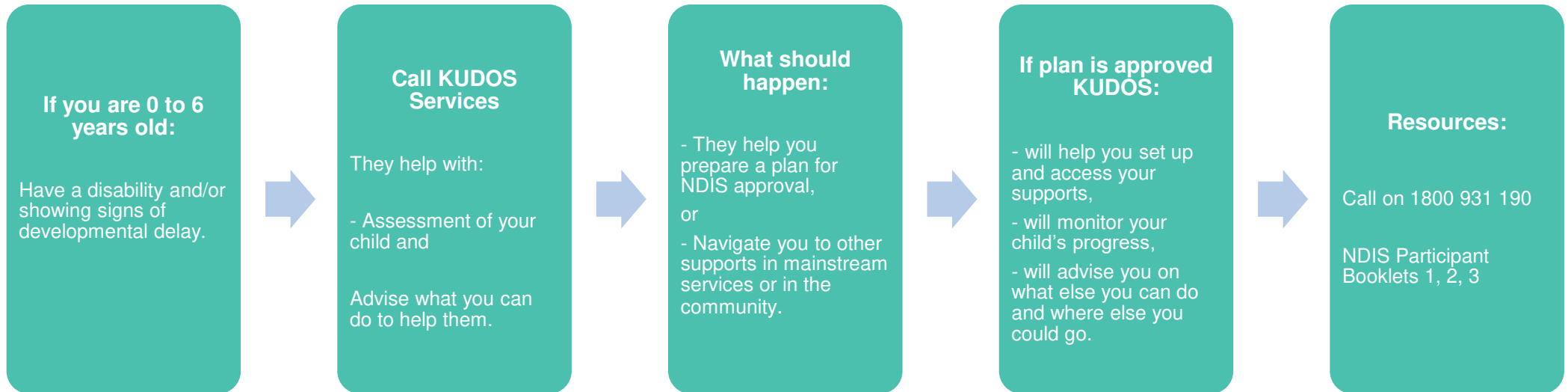
- LACs will connect you to other supports.
- You can appeal the decision at the Appeals Tribunal
- You can wait 3 months and try again.



Resources:

- For evidence – GPs and medical specialists, current therapists and service providers, disability organisations.
- Preparing for plan meeting – NDIS Booklets 1 & 2
- For implementation of your plan – NDIS Booklet 3.

8. Navigating the NDIS Guide for Consumers and Carers (0-6YO)



9. Navigating the NDIS Guide for Consumers and Carers (Do's and Don'ts)

Do's	Don'ts
<ul style="list-style-type: none">- Be proactive and confident, everyone has the right to apply if they are eligible,- If you need help with English, ask for an interpreter or a LAC that speaks your community language,- Only agree if you understand, ask questions,- Ask for and look for information in your community language- Go to the LAC/NDIA office or ask for a meeting,- Look for people in your community that can help; for example, your doctor, child care workers or teachers, hospital staff or specialist, settlement support services, go to the relevant disability organisations i.e. Royal Society for the Blind, Autism SA, Acquired Brain Injury SA, Downs SA	<ul style="list-style-type: none">- Don't wait, don't give up, don't think you are the problem, the system is new, and everyone is learning,- Don't do it alone bring a support person with you to meetings,- Don't ignore the help from the LACs and other supports,- Don't talk on the phone if it is not easy for you,- Don't think you don't deserve it,