Down Syndrome
Western Australia

2018
-
2019
ANNUAL REPORT

Annual Report contents

Down Syndrome Western Australia

Cover image: Jack McKevitt, one of our DSWA Ambassadors

Down syndrome Western Australia acknowledges the Whadjuk people of the Noongar nation, the traditional custodians of the land on which we stand, and we pay our respect to the elders past, present and emerging.

Down syndrome WA - our purpose

Down syndrome WA (DSWA) is an NDIS provider providing support to people with disability and their families. DSWA is a community resource for people with Down syndrome, families, teachers, support workers, child care workers, researchers, students and many others.

OUR VISION

People with Down syndrome live a life of their choice and make their contribution to the community.

OUR PURPOSE

To provide services to support people with Down syndrome to achieve their goals.

WE VALUE

- **Human rights:** Ensuring the rights, dignity and equality of opportunity for each individual.
- **Person-centred services:** Placing the person at the centre of services in building their capabilities and opportunities.
- **Our unique lived experience:** A service culture drawn from empathy, knowledge and understanding of our lived family experience.
- **Responsiveness:** Listening, supporting and responding sensitively to the needs of individuals and their families.
- **Collaboration:** Working in partnership with the community, service providers and decision-makers in providing the best outcomes for our consumers.

DSWA provides services built on specialist knowledge, understanding and lived experience of people with Down syndrome, their families and carers.

- Provide peer-based support to people with Down syndrome and their families.
- Provide registered National Disability Insurance Scheme services to people with Down syndrome and their families, focused on the experience and expertise of DSWA.
- Work in collaboration with other organisations including NDIS providers, in developing individualised services in areas of additional complexity and disadvantage in Western Australia.
- Engage in national initiatives to provide individualised services using the strengths of national partners and expertise of localised service providers.
- Progressively extend the range and reach of individualised services in Western Australia especially into regional and remotes areas.
- Provide activities and events that promote inclusion for individuals and families at the community level.

Down Syndrome
Western Australia

Executive Officer report

Welcome to a summary of another great year for Down syndrome Western Australia (DSWA).

KEY HIGHLIGHTS

As NDIS providers we are slowing maturing our business in the NDIS space while keeping a strong focus on our core business of providing information and services to our families and local community.

NDIS workshops are continuing to roll out. Please ring our office for information as you may be currently involved in pre-planning for your NDIS plans.

Grant submissions have moved from a State level to Federal NDIA. Down syndrome Australia is becoming more federated with six states combining and streamlining resources, so we will be applying for many of our ILC grants federally as opposed to State. We feel this is timely given the changing landscape and our success is linked with Federal funding. Information and access to resources will continue as part of our core business to families and NDIS participants.

The Traineeship Certificate II in Customer Engagement is beginning to become a reality. We have placed three people as trainees into local government and local businesses.

We were successful in securing the last State ILC Grant *Getting Ready for Work.*

We plan to work with school age students in years 10, 11 and 12 as well as mature age (17 years plus) and, in particular, those in ADEs who wish to transition into open employment

Our social groups are increasing so please be aware you can access Aim High, FrienDS for Life, weekend camps, parent training and employment supports with your NDIS plans.

Disability Support Awards. L-R: Dennis Liddelow, husband of Minister Stephen Dawson; Jacqueline Armstrong, Regional Manger of Status Disability Employment Services; Margaret Lawlor, Executive Officer DSWA; Hon. Stephen Dawson, Minister of Disability and Environment; Andrew Domahidy, HBF employee; John Van Wielan, CEO of HBF

WA COMMUNITY RETREAT FOR FAMILIES AND CARERS.

DSWA has been working in a collaborative partnership with Carers WA and HelpingMinds to bring together an established place for a break away - a place to take that time out for oneself, recharge the batteries, learn new coping strategies and connect with peers. Post-retreat, two of the organisations have services that offer continued ongoing support.

The final Business Case can be found on our webpage www.dsawa.asn.au

OTHER NEWS

Relationship building is important for our young people and we plan to resource grants in the mental health and health space to assess what programs, creative projects or pilots where we can collaborate and submit community partnership strategies.

I would like to give a heartfelt thanks to our outgoing Chair, Nick Gray, for his positive and inspiring contribution to the Board and myself. I am delighted to hear that he will be staying on as a Board member. A big thanks to the team at DSWA for working together to produce programs, information, advice and advocacy, all leading to better choice and control for the DSWA community.

Margaret Lawlor

Margaret Lawlor
Executive Officer

Upcoming events

You will note that we have changed our Ball night to a Gala Dinner which was held on Saturday October 5th - as this report was going to print. We will have lots of photographs on our website and in next year's Annual Report. Family and friends of DSWA paid tribute to a fantastic night and are looking forward to future Gala Dinners.

StepUP! is coming up (October 20th) and a great family affair for all. Thanking you in advance for your generosity, time and fundraising for this day Nikki Schwagermann, Emily McCain and Caleb LeCras.

Chair report

In the past 12 months we have seen our Association grow from strength to strength. We are now substantially funded by the WA Government for the first time in the Association's history. This has come with a lot of hard work, diligence and relationship building with a number of our WA State Ministers.

The Association's strategy was recently refreshed which spells out four primary objectives in i) Services to Individuals and Families, ii) Information and Advocacy, iii) Innovative Research and Program Development, and iv) Governance and Organisational Capability.

We are looking to further extend our services and programs in 2020 beyond the current milestones of babies and toddlers (Playgroup), high school students (FrienDS for Life) and young adults looking for greater social inclusion and independent living skills (Aim High).

In the past three months we have launched a new open workplace Traineeship Cert II in Customer Engagement, 15 hours per week on the job, completed over an 18-month placement. This is a very exciting development as, this time last year, we were lobbying three WA Ministers to get this program off the ground with some funding. This is now a reality and shaping up to be very successful. This work experience and education model can be extended in future to a range of other open workplaces (beyond local councils), across any number of industries.

The Association is well engaged in the NDIS rollout across WA, both with providing information and awareness through an ILC grant and as a registered NDIS service provider. We have seen a new revenue stream come into the organisation for the first time in the past 12 months related to providing an NDIS service to families.

We will continue to move towards a more financial sustainable model with this sort of revenue enabling more programs and services for our members and community.

From a governance and Board make-up perspective, we have a number of new Board members who have joined us from a variety of industries, including research in the area of Down syndrome and areas of the community.

Finally, a big thanks to Margaret, our Executive Officer, and all the staff and volunteers at DSWA. I love to hear the pulse of our members and also from the community about the work we do.

I received this quote from one of our families gaining the benefit of the FrienDS for Life program. It sums up the Association's past 12 months wonderfully.

"FrienDS for Life has been fantastic, after many years with little contact from DSWA, it has been wonderful to reconnect. For our daughter Holly, the group provides fun and friendship. As Holly moves through her teens we realise how important it is for her to have own social life. Many thanks to Nikki, Emily and all the amazing volunteers."

Nick Gray
Chair

Treasurer Report 2018-2019

The year ending 30th June 2019 has been a busy time for DSWA with significant expansion to our services, as we progress and transition into the NDIS.

We had a strong focus on developing a Certificate II into a Traineeship which was a lengthy process and proved successful when we applied for asubstantial ILC grant *Get Ready for Work* from Minister Dawson of $231,000 to date.

Fundraising/event income remained steady, with the Board and community deciding to let go of the Ball as it was too expensive. We now have a Gala Dinner (October 5th) to celebrate the successes and achievements of those in the DSWA community. $20,000 was raised among our stakeholders and patrons and we were able to offer the tickets at a cost of $50 per head. We hope this will be the first of many Gala Dinners.

REVENUE

StepUP! for Down syndrome continues to grow, with the 2018 event bringing in over $27,000 - a great result. Donations on a small and large scale are continuing to come in from businesses, and the community.

As with the previous financial year, grant funding has been our most significant source of revenue.

Transitioning into the NDIS space, Down syndrome WA will be applying for NDIA grants which will span over a three-year period as opposed to our current yearly grants.

State ILC grants have been finalised and we now apply to the NDIS for grants.

Overview:

- Received NDIA DPFO for peer support NDIS information
  $117,800
- Received ILC grant State *'Get Ready for Work'*
  $231,000

  We are currently managing these two grants
- We were successful in securing our Telethon Grant of **$40,000** to assist with our playgroups.
- We were successful with NGCS allowing us to run two educational conferences for Professionals in the Education Sector and for Families.
  $35,000

We committed to a Business Case joint venture with Carers WA and HelpingMinds to hopefully create a WA Community Retreat for Families and Carers. The case is currently been lobbied with Commonwealth and State governments, Lotterywest and philanthropic groups. The project has been in progress for two years and we hope Hon. Christian Porter and Hon. Ben Morton will champion this project into reality.

We plan to submit a grant to HBF to engage a project officer to run FrienDS for Life.

EXPENDITURE

Not surprisingly, our largest cost is wage-related. Grant funding has allowed us to effectively subsidise this cost in the 2018-2019 financial year.

Future projects will involve working closely with Down syndrome Australia to procure funding at a national level.

In the changing space that is NDIS, the Executive Officer has informed the Board that they will be looking at State grants in the area of Health and Wellness.

The intention is to collaborate with other small organisations to produce programs that relate to building healthy relationships.

It is suggested that, with the increase in external funding, especially Government funds, that the Board implement an ongoing review program of governance. All staff and Board members should participate and be aware of their personal responsibilities in this regard.

Stephan Pollard
Treasurer

Board and Staff
2018-2019

BOARD

Chair	Nick Gray
Treasurer	Stephen Pollard
Minute Secretary	Julie Jalawadi
Board Members	Frances Moon Pauline Abordi Jess Jalawadi Andrew Domahidy Katherine Salt Katie Gothard-Leigh Lynne Nixon

STAFF

Executive Officer	Margaret Lawlor
Family / Education Support / NDIS	Julie Ireland
New Parent Support	Nikki Schwagermann
Office Coordinator / Communications	Caleb LeCras
Program Manager / Training / Open Employment	Emily McCain
Financial Controller	Dee Ede

PROJECT STAFF

Playgroup	Janette Cook
Assistants	Katie Rodwell, Claudia Rodriguez
Aim High	Suzanna Olsen

A message from our Chief Executive Officer

I am pleased to be able to provide you with an overview of the work of Down Syndrome Australia in the 2018-2019 financial year. Down Syndrome Australia (DSA) has continued to play an essential role in advocating for people with Down syndrome, providing information about Down syndrome to range of audiences and tackling the stigma associated with intellectual disability.

ADVOCACY AND POLICY DEVELOPMENT

Over the past year we have provided important advocacy on key issues in partnership with people with Down syndrome.

The Down Syndrome Advisory Network (DSAN) continues to play an active role in our advocacy work. The DSAN (https://www.downsyndrome.org.au/advisory_network.html) is made up of people with Down syndrome from across Australia who provide information and advice to the DSA Board and CEO. It is thanks to the support from the Sherry-Hogan Foundation that we were able to develop, and are able to continue to support this network.

DSAN meet every month to discuss a range of topics that are important to them and to provide input into DSA's advocacy work. This year the network has provided important input on a range of issues including:

- Prenatal screening
- NDIS
- Education
- Ageing
- Social Media
- A new App for down Syndrome

One of the highlights this year has been that was done in partnership with the DSAN to develop a national advocacy platform for Down Syndrome Australia: Leave No one Behind. This document sets out eight key action areas which are the priority advocacy issues for the organisation. The document provides a clear overview of each issue, an overview of the evidence, and how change can be achieved. We also created an Easy Read version of this document, as well as a toolkit to assist those who want to get involved in supporting our advocacy.

> One of our key calls to action which has been a focus of work this year has been prenatal screening. The technology that enables genetic screening is rapidly advancing and becoming more widely available. DSA believes it is unethical to provide screening without access to balanced information about Down syndrome.

We know that families who participate in pre-natal screening often don't get all the information they need and don't have access to suitable counseling before and after screening. We have continued engaging with Government, the Medical Services Advisory Committee (MSAC) and other stakeholders on this important issue. In March, we launched a petition to lobby the government for a funded, co-ordinated approach to pre-natal screening. You can view and sign the petition here. DSA will continue to advocate for a national funded information campaign to ensure families get access to the information they need.

Access to equitable health care has continued to be a concern for people with Down Syndrome. This year, we were involved in a national campaign about Health and Intellectual Disability which was led by Inclusion Australia. The movement was a push to address inequalitites in access to health for people with an intellectual disability. We were pleased to partake in a national Roundtable to consider the changes required to improve health care for people with intellectual disability. We look forward to working with the Government on the promised "Roadmap" to address barriers to appropriate health care.

We have been working with the National Disability Insurance Agency on issues that affect our community including advocating for automatic eligibility to the NDIS, addressing problems with planning meetings and the knowledge of planners, addressing barriers to accessing services and supporting information about the NDIS.

To inform our advocacy, we conducted a National Survey on peoples experience with the NDIS and received more than 400 responses. We have utilized the results of the survey to inform our advocacy and discussions with the NDIA. One of the key messages that came out of the survey was concerns around the planning experience and the knowledge and attitudes of planners. As a result, we worked with the NDIA on improving training for planners including developing a factsheet and videos on Down syndrome.

Discrimination within the immigration system continues to be an area of concern for our organisation. Families are being turned away from Australia simply because they have a child who has Down syndrome. We have been calling for changes to the migration laws to end the discrimation against people with disabilities attempting to migrate to Australia. As part of this work, we have provided support to a number of families while also working on the issue with Government and other partners.

We have continued to have engagement with key Commonwealth Government Ministers and the Opposition as well as senior bureaucrats in relevant Government departments. DSA has also continued to strengthen its relationships with other peak bodies in the disability sector, including the Australian Federation of Disability Organisations (AFDO), Inclusion Australia and others. We are also pleased to be able to work closely with our international organisations including Down Syndrome International (DSI) and the Asia Pacific Down Syndrom Federation. We have also had opportunities to collaborate more closely with collagues from China and Canada.

COMMUNITY AWARENESS AND PROFILE

DSA works continuously on raising community awareness and understanding about Down syndrome and promoting inclusion.

As part of this work we developed a social media campaign for World Down Syndrome Day that included 21 stories about people with Down Syndrome in the countdown to World Down Syndrome Day on 21st of March. This year we asked people with Down syndrome to talk about their passions and interests and share their pride with the world. It was our most effective campaign to date, with an estimated audience reach of 1.2 million people. We also held a very successful event at Government House hosted by our Patron, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd) Governor-General of the Commonwealth of Australia and Lady Cosgrove.

His Excellency addressed our audience of politicians, families and organisational members.

We have continued to provide a quarterly national e-newsletter to provide updates and information about the work of Down Syndrome Australia. This initiative has been very successful with each newsletter reaching more than 1000 people. You can sign up to our newsletter here: https://www.downsyndrome.org.au/

We also continue to produce our fabulous magazine *Voice* and excitingly this year, we launched our new digital platform to complement the journal.

This allows us to share more information and more stories with our community than what is able to fit into our journal each issue. The DSAN has had key role this year in improving the content and accessibility of our national magazine. As a result of the feedback from our members, we have increased the content developed by people with Down syndrome and are producing more Easy Read versions of stories in each addition.

INFORMATION AND RESOURCES

Community Inclusion toolkits

We have continued to build on the Community Inclusion toolkits that were released last year, and enjoy hearing stories about how they have been used to support people in the community. In April we were pleased to launch our animation *We're all different but we're all the same – so let's all be friends!*. The animation was developed especially to speak to kids about inclusion and being different and yet being the same. The animation was based on drawings done by a person with Down syndrome. We hope this message of inclusion will help support conversations about friendships, inclusion and the importance of celebrating diversity in schools, sporting fields and the playground. The full toolkit is available at: www.communityinclusion.org.au.

Over the next year we will continue to further develop the materials in the toolkits. Work is also well underway to create a fully accessible app that provides an opportunity to get advice from people with Down syndrome and hear them share their stories about their lives, as well as provise a link to information about Down syndrome and community inclusion.

Information for Life Resources

The Information for Life Resources which we launched last year have continued to be well regarded and utilised.

Each month we have more than 1000 downloads of these resources from our website, as well as providing more than 5000 hard copies of the resources over the last year.

We have also been contacted by a range of international organisations who have asked to be able to adapt our resources for their country. These resources will be reviewed on a regular basis to ensure that they remain up-to-date and informed by the latest evidence. These guides are also available for download in the new Resources section of the website: www.downsyndrome.org.au/resources. We also have some of the resources available in other languages including Cantonese, Mandarin, Hindi, Arabic and Vietnamese https://www.downsyndrome.org.au/resources/translated_resources.html

New Publications

We have also released two new important publications this year.

Down syndrome and Mental Health provides information and tips for people with Down syndrome and their families to help maintain good mental health. The publications also helps people and their families identify when professional support might be required. People with an intellectual disability, including Down syndrome, are two to three times more likely to experience mental illness than people without disability, therefore it is an important issue that we want to provide support for.

Supported Decision Making and Down syndrome provides suggestions and advice on how to support people with Down syndrome to be involved in decision making.

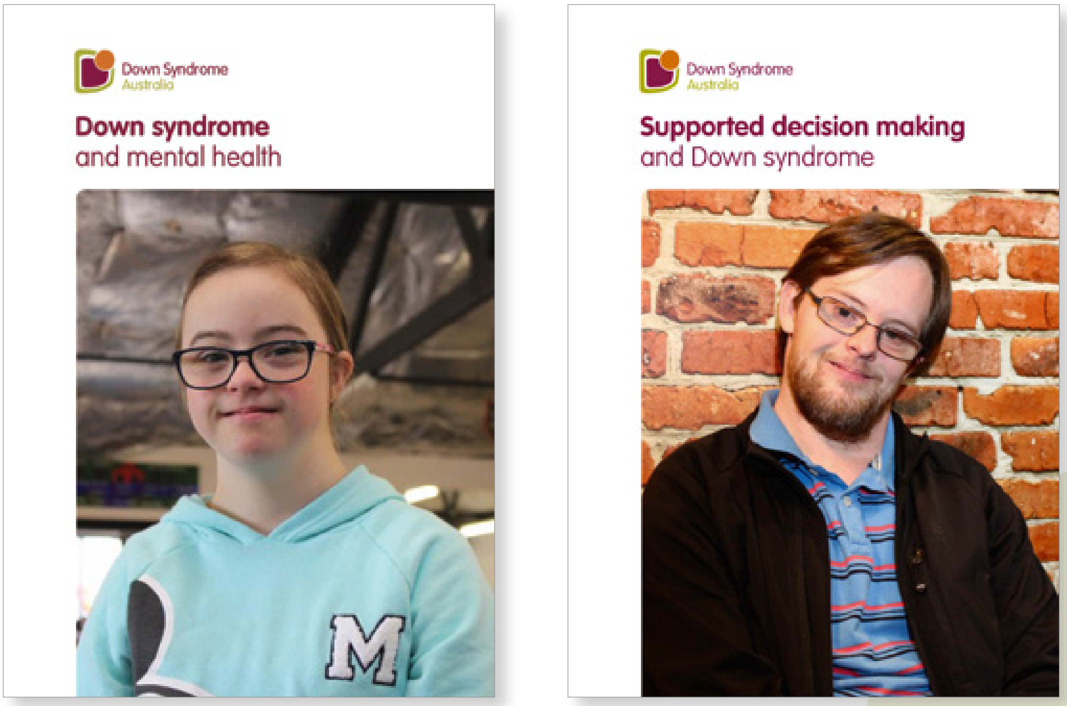
We are pleased that both publications have been widely shared and utilised.

WORLD DOWN SYNDROME CONGRESS

Down Syndrome Australia is looking forward to hosting the World Down Syndrome Congress in Brisbane in 2022.

We were pleased to participate in the 2018 World Down Syndrome Congress in Glasgow in July. This was a fabulous opportunity to promote the 2022 Congress as well as to be part of presentations about the work of the Down Syndrome Advisory Network. We were pleased by the level of interest and enthusiasm about our 2022 Congress. The Congress in Glasgow was also a fantastic opportunity for DSA to learn about how the WDSC's are run and to meet with our colleagues from Down Syndrome International and to discuss our joint expectations about the 2022 Congress.

This year we were fortunate to finalise our Patrons for WDSC 2022: Air Chief Marshal Sir Angus Houston AK, AFC, (Ret'd), family Patrons Michael and Nick Hogan, and Ann Sherry AO and finally,



Down Syndrome Australia
Down syndrome
and mental health

Down Syndrome Australia
Supported decision making
and Down syndrome

The new Down syndrome and Mental Health *and* Supported Decision Making and Down syndrome *resources, both available at www.downsyndrome.org.au under the 'Resources' tab*

The Honourable Dame Quentin Bryce AD CVO. We are honoured to have such pillars of the community represent us for our World Congress.

We also announced on World Down Syndrome Day, Tasmania's Matt Hoori and Texan resident Charlie French as the joint winners of the WDSC 2022 logo competition. The winning logo brings together two creative minds from opposite sides of the world. Down Syndrome International (DSi) executive director Andrew Boys said the winning logo expresses the excitement and the ethos of World Down Syndrome Congress.

We will continue work on developing the congress over the coming year, and are looking forward to hearing from the community about what they would like to see at their congress.

New Initiatives

Over the coming year DSA will be working on a number of key projects including:

- Finalising the new national website
- Developing a national data management system (CRM)
- Finalising a Down Syndrome App which will be a platform for sharing stories and experiences
- Development of new resources including ones on social media and relationships
- A national campaign on Disability and Migration

I look forward to being able to report on the progress of these initiatives in next year's annual report.

Dr Ellen Skladzien
CEO
Down Syndrome Australia

DSA highlights

The following represents an overview of some of this year's highlights and ongoing programs which serve to improve the profile of Down syndrome Australia, our state and territory associations and the support of people with Down syndrome.

StepUP! for Down syndrome

StepUP! for Down syndrome is held in Perth on October 20th 2019.

As Australia's largest annual Down syndrome fundraising and community event, *StepUP!* is dedicated to supporting people with Down syndrome. Every dollar raised by *StepUP!* helps your local association provide support, services and information to empower people with Down syndrome and their families.

The countdown to *StepUP! for Down syndrome* 2019 might be on, but we're already looking forward to *StepUP! for Down Syndrome* 2020. Get your teams ready to start raising much-needed funds for the 2020 events across the country. Go to: www.steupfordownsyndrome.org.au for more information.

voice

We are seeking your feedback on *Voice*, the journal of Down syndrome Australia. This information will be used to help us evaluate our work and areas for improvement. The survey will take about five minutes to complete and all your responses are anonymous.

Go to https://www.surveymonkey.com/r/DSAVoice to complete the survey.

If you need help with the survey, please contact info@downsyndrome.org.au.

If you are interested in contributing to Voice you can contact the editor at Voice@downsyndrome.org.au.

NATIONAL ROADMAP ON HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITY

In early August 2019, The Department of Health held a Roundtable on *Intellectual Disability and Health*. This Roundtable was a result of the advocacy of NSWCID and Inclusion Australia as part of the *Our Health Counts* campaign.

At the Roundtable, Health Minister Greg Hunt called on stakeholders to work together on a national roadmap to improve the health of people with intellectual disability. The roadmap outlines what needs to be done to improve the health of people with intellectual disability.

Down syndrome Australia was a strong supporter of the *Our Health Counts* campaign and looks forward to working with the government on these important issues.

DOWN SYNDROME ADVISORY NETWORK (DSAN)

The DSAN is made up of people with Down syndrome from across Australia who provide information and advice to the DSA Board and work with the DSA CEO to ensure that we are representing the voices of people with Down syndrome. It is thanks to the support from the Sherry-Hogan Foundation that we were able to develop this new network.

In August 2019, DSAN came together to talk about how to best support people with intellectual disability to be leaders and have their voices heard. The outcomes of this workshop will be used to develop training materials to support self-advocacy.

DSAN meets every month to discuss a range of topics that are important to them and play an important role in DSA's advocacy work.

Services and programs

DOWN SYNDROME HELPLINE

The Helpline provides people with direct contact with DSWA either by phone, email, social media or via website contact. During the past year, people contacted us for practical and emotional support such as prenatal and new parent support, and help to find information on a wide range of issues for people and families at all ages and stages of life. These included health and medical concerns, queries about development, behaviour, education, recreation opportunities, ageing and mainstream services in the community. Increasingly, we are getting calls about the NDIS, plans and implementing plans. We also met with people face-to-face to help with information and support. **The Helpline number is: Freecall 1800 623 544.**

DISABILITY SUPPORT ORGANISATION (DSO) GROUPS

DSWA has run peer support groups for more than 30 years. This now includes our new parent group, playgroups, FrienDS for Life, Aim High, as well as groups in Albany, Busselton, Bunbury and the metro area.

These groups are designed to bring families together to share information, strategies and resources about any topics of interest. Lately the NDIS has been the most sought-after information. We will be continuing these groups during the next year and information about meeting dates will be posted in our Facebook groups and our e-news. If anyone would like to be involved in setting up or running a group (even if it is just a one-off event) then please contact us. These groups are supported by an NDIS ILC grant.

WORKSHOPS

DSWA has run a number of workshops this year, offering families information and support for various life stages.

This has included an education conference for families with sessions focussed on two age ranges; 0-6 years and 7-12 years. This conference covered many areas of interest including education options, behaviour management, social skill development, sexuality and protective behaviours. Some of the conference presentations are available online.

We have also run sessions on the NDIS and what to include in your plan as well as providing individualised support for planning. There are a range of resources on our website which are available for download. NDIS workshops will continue to be run in the next year.

TRAINING AND CONSULTANCY

DSWA offers a range of training and consultancy services. Every year, we run a full day professional development workshop for teaching staff. Sixty-one educators came to our workshop in March 2019. We also ran training sessions throughout the year in both metropolitan and regional schools, and for staff in disability service provider organisations. As well as group sessions, DSWA provides consultancy services for trouble-shooting and classroom or workplace strategy development. All training and consultancy is delivered on a fee-for-service basis, with quotes available. Email Julie Ireland on julieI@downsyndromewa.org.au for more information.

COMMUNITY AWARENESS AND DEVELOPMENT

At DSWA, we actively work to create a more informed and inclusive community. This takes many forms, from providing information resources, to talks and presentations to various groups, and regular information and engagement through our DSWA Community Facebook page. Annual events include World Down Syndrome Day, National Down Syndrome Awareness Week, and the national *StepUP!* walk as well as other fundraising events.

This year we have also been developing an online resource on how to access mainstream and community services as well as information, strategies and training for businesses and government departments to promote inclusion in all aspects of the community. This resource has been funded by ILC grants from the WA Department of Communities.

I support the ndis

DSWA AND THE NDIS

DSWA is now a registered service provider, with both state Disability Services and the NDIS. This means that people with Down syndrome and their families can use their individual funds to purchase some DSWA services and supports. Our aim is to continue in our areas of expertise in peer support and training, as well as group supports (FrienDS for Life, Aim High), Health and Wellbeing breaks away and *Finding and Keeping a Job*.

Events such as this are vital in promoting community awareness and development

DSWA AND YOUR NDIS PLAN

Given the recent rollout of the NDIS environment, we feel that reiterating the following information will help when planning and reviewing your NDIS Plan.

Down Syndrome WA is recognised as the natural point of contact for people with Down syndrome and their families, as well as general community members wanting information about Down syndrome. **DSWA is seen as the expert source of information and support.**

As we move into the NDIS environment, our values, services and programs will remain, but the way that these services are funded will change.

In the past, DSWA has fundraised or obtained grants to maintain our services. While we will still seek grant funding, DSWA is now able to fund our direct services through individual NDIS plans.

This means that when you are planning for or reviewing an NDIS plan it would be useful to think about your goals and how any DSWA programs or services might be funded within that plan. In this way you are able to access our programs with the funding in your NDIS plan, and DSWA is able to continue to provide the services valued by you.

DSWA is a registered provider for NDIS in the following areas:

- **Assistance with life stage, transition**
- **Assistance with social and community participation**
- **Social and community participation**
- **Assistance with personal activities**
- **Innovative community participation**
- **Group/Centre activities**
- **Assistance to access/maintain employment important to put into your NDIS plan so DSWA can assist.**
- **Assistance with travel / transport**

This means that Aim High, FrienDS for Life, weekend camps, parent training, and employment supports may be accessed through your plan.

If you are **self-managed,** then DSWA will provide an invoice to be paid.

If you are **plan managed,** then DSWA will provide an invoice to be paid.

If you are **NDIA-managed,** then DSWA will claim from your funding allocation on the NDIA portal.

If you are engaging DSWA for our services, a meeting to discuss your plan and a service agreement will be made.

Some of our services, such as new parent support or peer support groups, are unable to be funded directly in an individual NDIS plan. Rest assured, we will continue to apply for grant funding to maintain these areas as we see these as vital to our core values and reason for existing.

Financial memberships are welcome as we keep you up-to-date on all DSWA matters. Financial members receive a copy of our National Magazine which is an excellent production by Down syndrome Australia.

Please contact Julie Ireland, Family and Education Support officer, with queries about the NDIS or any other support needs and if you would like an NDIS workshop in your area.

Contact admin@downsyndromewa.org.au for more information.

FRIENDS FOR LIFE

This is our group for children aged 11 to 17 years and their families, funded by a CBA grant. FrienDS for Life has had 12 activities over the 2018/2019 financial year. We now have 34 members, with an average of 20 coming to each event. Two DSWA staff, who are also parents, along with ten active teen volunteers, coordinate and run the events.

Activities so far include Music Rocks, Razzamatazz show, hip hop, karaoke, pizza night, movies, Sculptures by the Sea and surfing.

The group has continued to be very well received by both the teens and their parents. We are seeing lots of friendships being built between the teens and also between the parents.

AIM HIGH CLUB

Our Aim High program is for young adults with intellectual disability of 17 years of age and over.

We offer 3-hour workshops covering a wide variety of topics. There is a mix of recreational, sports and formal learning with practical applications.

- Grooming
- Communication skills and decision-making
- Budgeting, shopping, feeding yourself and safety
- Rights and responsibilities
- Getting and keeping a job
- Accessing services in the community – doctor, dentist, chemist
- Transport
- Relationships and sexuality
- Dealing with loss and grief
- Further education

Many of our Aim High participants are Ambassadors representing DSWA and we are very proud of the work they do on behalf of the association.

Examples of some of our DSWA staff member-supervised events include:

Dinner at Outback Jacks, Northbridge, 6.30pm - 9.00pm. Cost $15

Warwick Super Bowl, Warwick, 12.00pm - 3.00pm. Cost $15 plus $17.20 for two games - total $32.20.

NEW PARENT SUPPORT

DSWA provides information and support to new families including hospital and home visits, follow-up calls and a new parent information kit.

During 2018-19, DSWA was involved in supporting the families of 17 new babies.

DSWA also provided prenatal information and support. There were 10 calls and three prenatal visits.

DEVELOPMENTAL PLAYGROUP

DSWA has two playgroups. Both are run by staff with lived experience as parents. We have regular volunteer helpers including three adults with Down syndrome.

Playgroup provides specialised developmental activities for babies and toddlers, with a focus on fun and success. It also offers parents a relaxed environment for peer-to-peer support and sharing information. There are also occasional guest presenters on topics of interest.

The playgroups were sponsored by Telethon this year and have more than 55 members between both playgroups. Both groups have run weekly - the south on a Monday and the Perth metro on a Friday.

Contact Nikki Schwagermann for more information about the Developmental Playgroup nearest you on nikki@downsyndromewa.org.au

TRAINEESHIP

At DSWA, we have established a traineeship pilot program to overcome two significant barriers that are often put before people with Down syndrome - barriers to vocational training and open employment. We have taken a customised employment approach and have had three of our Ambassadors successfully placed in a traineeship program, working at HBF, Town of Cottesloe and City of Perth, and all earning an award wage.

The traineeship is a Certificate II in Customer Engagement and is for an 18-month period. The person undertaking the traineeship is supported by the Disability Employment Support (DES) Provider, Status and the training organisation that provides the on-the-job assessment, Fremantle Education Centre and Chamber of Commerce.

The traineeship involves working a 15-hour week and part of that employment involves upskilling on the job.

The trainee is not expected to read and write lengthy training material. The assessment is done through observation and verbal discussion and Fremantle Education Centre will ensure the performance criteria for the qualification are being met. The qualification is flexible and has been relatively easy to apply to various office administration type roles.

Diverse workplaces have the competitive edge

Businesses which seek to recruit and retain people with disability are getting a competitive edge by drawing from the widest pool of candidates to find the right person for the job.

Visitors to HBF's head office are in no doubt that Andrew De Domahidy, pictured, is perfectly suited to his role on the front desk.

As a business administration assistant, Andrew's duties include welcoming customers, distributing the mail and organising name tags for guests.

Andrew, who has Down Syndrome, applied for the position with the support of Down Syndrome WA Employment and Training Officer Emily McCain.

"Andrew is amazing at remembering people's names and he has great people skills," HBF chief executive officer John Van der Wielen said. "You only have to follow him around the office to see that he is very popular and good at his job.

"He has enriched our workplace and added value to the company by making people understand that you can have diversity and different perspectives among the people working in your organisation."

According to Emily, Andrew's potential to fulfil the role was quickly embraced by HBF.

"It's an approach which benefits everyone and shows that big organisations like HBF with so many employees can be at the forefront in really changing mindsets and erasing stereotypes."

Andrew, John and Emily will speak about customised employment opportunities for people with disability at the NDS WA State Conference.

The article above appeared recently in the The West Australian

DSWA 's partnership program includes Fremantle Education Centre RTO; Status is our Disability Employment Provider. Status will be assisting with on-the-job support.

DSWA will assist Status by providing training in two areas:

- How best to work with the successful candidate and will be delivered to staff members where the person is placed
- DSWA will provide a one to two-hour session fee for service to the organisation on *Diversity Training* and information about Down syndrome

Please contact Status Disability Employment Support Regional Manager Jacqueline Strong on 0424 244 887. Alternatively, please contact Emily McCain, Manager Training and Employment on emily@downsyndromewa.org.au or (08) 9368 4002.

The following 2 pages illustrate the range of services offered by Status which may be of assistance to jobseekers.

Status

Disability Employment Support

> “Status understood my aspirations for the future. They made it possible to open new doors and create opportunities that I didn’t know existed.”

Status offers an individualised service to people with a disability seeking employment. We provide DES services across South Australia, Victoria and Western Australia in the following locations:

South Australia
Adelaide
Elizabeth
Gawler
Kilkenny
Marion
Modbury
Noarlunga
Norwood
Port Adelaide
Salisbury
Torrensville

Western Australia
Cannington
Fremantle
Mandurah
Midland
Mirrabooka
Rockingham

Victoria
Sunshine
Frankston
Preston

We offer assistance to look for suitable and meaningful employment through a variety of methods which have allowed us to consistently place a high percentage of our clients into work.

Corporate Head Office

Level 6 – Office Tower
Westfield Shopping Town –Marion
297 Diagonal Road
Oaklands Park SA 5046
T: 08 8377 0101
F: 08 8377 3911
E: status@status.net.au

PO Box 75
Oaklands Park SA 5046

ABN 63 096 880 563

Training Services Head Office
RTO Enquiries

Freecall: 1800 681 131

WA State Office

13 Pattie Street
Cannington WA 6107
T: 08 9451 8017

PO Box 112
Cannington WA 6107

VIC State Office

Tenancy 4, 153 Harvester Road
Sunshine VIC 3020
T: 03 9364 7791

PO Box 393
Sunshine VIC 3020

status.net.au

Empowering people, powering business

STATUS

Disability™ Employment Services

AN AUSTRALIAN GOVERNMENT INITIATIVE

One-on-one Support

We understand the importance of fully engaging participants in the return to work process. Our clients receive regular one-on-one appointments with specialised Employment Consultants who offer personalised career counselling and advice.

Through their Employment Consultant, our clients have access to funding assistance for suitable work-related clothing and travel costs, a FREE TABLET* (provided by Status) to use for job searching and staying connected, and on-the-job and employment-related support once placed into work.

Job Club

Status Job Clubs offer an interactive session to support participants to develop their Job search and employability skills. These clubs are designed to build self-efficiency, and include training in resume and cover letter techniques, navigating the application process, and interview techniques.

The group also discuss how to increase opportunities for employment through social media and networking, and skills for cold canvassing.

Most importantly, our Job Clubs focus on maintaining mental health whilst job searching, and building a routine that sets expectations for the workplace.

*Please see information sheet available on Status website for further details.

Employer Contacts

Status Business Networking Breakfasts are held quarterly to build new and stronger employer contacts. Our clients are invited to attend these events to network with local employers.

Through their Employment Consultant our clients are able to take advantage of our extensive employer database with ongoing vacancies and employment opportunities. We are also able to offer government wage subsidies to employers to increase employment opportunities for eligible participants.

Dress for Success Adelaide

In 2015, Status became the founding patron and sponsor of Dress for Success Adelaide, an affiliate of Dress for Success Worldwide. Dress for Success is a global movement for change empowering women to obtain safer and better futures.

Providing personal presentation advice, corporate attire, interview preparation, volunteering opportunities, and a professional women’s group for ongoing mentoring and support in the workplace, we have been inspired by the work of Dress for Success Adelaide in making our community stronger.

Participants in our WA and VIC sites are able to access similar services through our partners.

Access to Training Services

Our clients have access to fully funded education and training packages to upskill and improve employment options, including the Government Skills for Education and Employment (SEE) initiative aimed at improving the Language, Literacy, Numeracy, and Digital Literacy skills of individuals.

We are also able to support our clients to access Federal and State Government funding options allowing participants to study, either online through an e-learning platform or in the classroom, and to commence traineeships in areas of interest, opening further pathways for employment.

For youth aged 17–24, we can also assist with access to internships via the Youth Jobs PaTH program across Australia.

Centrelink Advocacy

Status Employment Consultants are able to provide Centrelink Advocacy for our clients, and offer assistance with the re-assessment process.

We can offer assistance throughout the re-assessment procedure, supporting our clients to obtain up-to-date medical information within the Centrelink guidelines, providing a support person during the Centrelink assessment, and helping to understand the Centrelink requirements throughout the process.

Community awareness and profile

2019 CALENDAR

Our 2019 Calendar has sold out, raising vital funds for our programs. We are looking forward to launching the 2020 calendar shortly. These beautiful images feature some of our stars in the 2019 issue. Enjoy.

Eli

Oscar

Tyler

Daisy

Hannah

Tracy, photographer for our DSWA yearly calendar is available for individual and groups sessions. Please contact Tracy Joy Bicker on 0421 813 726

VOICE

Voice, the journal of Down Syndrome Australia, is a place for news information and stories from the Down syndrome community. We publish articles on current research and work relating to Down syndrome and intellectual disability more broadly. We keep you updated on the work that DSA is doing and we publish stories from the associations around the country and keep you up to date on events and activities.

But most importantly, this journal has become a place for people with Down syndrome to tell their stories in the way that best suits them. In recent years we have shifted our focus to ensure that people with Down syndrome are at the centre of we do and are not limited by their means of communication when telling their story.

It is incredibly important that people have an opportunity to say what they want, how they want to. Whatever works for you, we can get creative and make it work for *Voice*.

We now have an interactive website where you will find digital versions selected of articles from the current and back issues of *Voice*, right back to the first issue in 2013 when *Voice* became a national journal. You will also find bonus content such as video, photo galleries and interviews related to the articles featured in the print journal.

https://downsyndromevoice.org.au

Voice continues to be a benefit of membership for West Australians, so get behind DSWA and become a direct member to receive *Voice* as well as all the other benefits of membership including access to many of the services we provide. Learn more and sign up here:

http://www.dsawa.asn.au/support-us/membership/

AMBASSADOR GROUP

As part of one of the WA ILC grants, DSWA has brought together a team of young adults with Down syndrome to be a part of our Ambassador Group. This is a group of people with Down syndrome, aged 18 or over, who help DSWA tell other people and organisations about why and how to include people with Down syndrome.

Our ambassadors meet regularly and have been involved in many exciting projects. On World Down Syndrome Day they were invited to afternoon tea at Parliament House in Perth with the Honourable Stephen Dawson MLC, Minister for Disability Services and two of our ambassadors travelling to Canberra to Parliament House to meet with the Governor General, the Honourable Sir Peter Cosgrove.

Minister for Disability Services, Hon. Stephen Dawson MLC at Parliament House, Perth, on World Down Syndrome Day (March 21st) with our Ambassador Group representing Down Syndrome WA

They have also been involved in a mental health research project by Consumers of Mental Health WA (CoMHWA). CoMHWA is a non-profit, community-based organisation dedicated to supporting mental health reform and recovery of people with lived experience of mental health issues. CoMHWA is lead by consumers, for consumers. CoMHWA coordinates, promotes and supports the consumer voice within mental health services and the wider community through consultation, systemic advocacy, supporting peer support and services, and partnerships and relationships.

Development of an app for Down Syndrome Australia, as well as playing a significant role in the planning and coordinating of the Gala Dinner held in October 2019. Many of our ambassadors have had public speaking opportunities, including speaking at parliament house and speaking at education conferences to both staff and parents.

Each ambassador has a profile which can be found on our website, with each of them telling their story of their achievements or something they are proud to have been a part of.

We are always looking for new people to be involved, so if this sounds like something you may be interested in being a part of please contact the office.

We are proud to include three of our Ambassadors' stories in the following pages. We hope you enjoying seeing their success as much as we do.

Anna's STORY

“I recently went on the tall ship *Leeuwin* for 4 nights and 5 days.

I didn’t know anybody so I was feeling nervous plus I had never been on a ship before. Once I met my group, I felt better but was still a little unsure. I was in the white team and our watch leader was Cody, who was a sailor.

On the first day before the ship left, we did some training. We pretended to steer the ship and wore our harnesses which kept us safe. We had to wear our harnesses when we were on deck so if we fell overboard we wouldn’t be lost. We learnt about the ropes and sails and then we sailed just off the coast for the night. Many times during the trip we had to ‘number-off’ to make sure we were all there. My number was 10.

The other people on board were so nice and we learnt about each other’s experiences. At night we all sang along with a guitar and played card games like UNO which I loved. There was a lot of laughs.

Cody taught us how to climb the mast, but first we had to pass the ‘hang test’. This meant that our feet were dangling above the deck and we had to hang on to a mast for 15 seconds. One of the instructors had a timer. I was nervous at the start, but I was fine. When we got to 15 seconds the instructor yelled “DONE”! Phew, now I could climb the mast.

On day 3 in the afternoon we all had a go at climbing the mast. I was sooo scared. Cody was beside me the whole way and told me it would be scary for a bit, but I would get the hang of it! I asked him if I was going to die and he said there was nothing to be worried about because I had a harness and he told me I could do it. I climbed up to the platform and touched it. I felt really happy and excited and everyone clapped and cheered for me because I was really brave. I was really proud of myself.

Cody also taught us how to clean the decks with scrubbing brushes, about the braces which are pulling the ropes, so the sails go up and down. In the olden days the crew would say “2 – 6 – HEAVE”, so we did this too. We laughed a lot.

Another time I went on the roped net at the bow of the ship. (I learnt some seafaring words!) It was scary because there was only ocean below the net, and I could see the blue as I climbed on it. We had to fold a sail and we did it. I conquered my fears.

One very cool activity was where we had to make a special aircraft with an egg in it so when we dropped the aircraft from half way up the mast the egg landed safely. We put newspaper around ours and taped it with sticks as well. Our egg won as it didn't smash. Some people had hard boiled eggs. We worked as a team and won a small bar of chocolate. We broke it into bits and gobbled it up.

Happy hour was cleaning. We had to clean downstairs on the starboard side, the midship area and the port side with a cloth and make sure the bunks were clean. It was great fun because there was loud music like *Here Comes the Sun*, and opera too. I started singing opera and everyone told me I should be an opera singer.

I slept on a skinny little bunk bed with two bunks above me. There were five other people in my room. I really wanted to do the night watch so I could get some fresh air! We all worked as a team and helped out with dishes and drying after dinner, so good team work. The food was so nice. Roast beef, pasta, pizza and salad. One breakfast we had pancakes with maple syrup and berries. I felt fine and happy with not one bit of sea sickness. The weather was good, sunny and one morning it was cloudy.

We did a lot of feedback at the end of the day and everyone gave me feedback. My shipmates said I was friendly and really funny and made people laugh a lot, especially Cody.

I learnt about being a good team member and being responsible with the ship and looking out for the people around me. Also I learnt to be brave. We had a brain storm about challenges, and I learnt to have faith in myself and to have a go at challenges. Mine was 'don't be afraid of heights' and I did it. I climbed the mast. It made me feel so good about myself.

I would recommend the *Ultimate Challenge* on the *Leeuwin* to others because it is all about having a go at something new and challenging yourself. Being on the ship was hard work but it was fun. It also goes toward the adventurous journey part for my Silver Duke of Edinburgh award. I would love to do it again.

Joe's STORY

Swimming for my school, my club and my State.

My proudest achievement is my swimming, which I work very hard at. I go to training three times a week at HBF Stadium and train with my club *Superfins*. Training is for 90 minutes and I try never to miss it.

I swim freestyle, breaststroke, backstroke, butterfly and the individual medley which is the four strokes in one race. This is hard as each stroke has a different touch at the end of the lap and different turns and so sometimes this gets confusing.

I have been in many competitions. At school I loved swimming for my house Loreto at our school carnival. I would get a house point for every race I did and my house would cheer me on. I was the first student at my school with a disability who swam in the ACC inter-school competition. I was so proud to swim for my school.

With *Superfins* I have competed in club swims as well as State Championships. I have also done Open Water swims in Coogee and South Beach. I also went away with *Superfins* to Busselton and swam in a team of four for the Busselton Jetty Swim and to Rottnest where I did the Rottnest Swim Through.

In 2017 I went to Geelong and swam in the Down Syndrome National Competition representing Western Australia. This year I am going to Brisbane to Swim in the Down Syndrome National Competition again. I am very excited about this and am training hard. My goal is to get selected for the Down Syndrome Worlds in Turkey in 2020.

Brooke's
STORY

“Hi my name is Brooke and I am 24 years old with a great and full life.

I currently work at Royal Perth Hospital and it's very rewarding meeting lots of interesting people. I have been at RPH for just over 4 years and still enjoy it.

Volunteer work is a big part of my life. Currently I volunteer at Ronald McDonald House and the Perth Children's Hospital. I really like volunteering and giving back to the community.

Traveling is my passion. So far I have been to the Gold Coast, Bali, Brisbane, Adelaide, United Kingdom, Singapore, Vietnam, and Thailand. With my most recent and exciting trip to Canberra for the Down Syndrome Awareness Day as a young Ambassador visiting and having afternoon tea with the Governor General Sir Peter Cosgrove and Lady Cosgrove.

In 2016, I became a home owner. My life changed because when I get home from work and volunteering I have to do all my own cooking, cleaning and laundry. I love having my own house and all my family are close by. Things are different in my own place but all the changes are for the better. I love having people over for dinner and have friends and family over for sleepovers – so much fun.

All of the above couldn't be achieved without the loving support of my family, friends, work colleagues and support people – thank you.”

Down Syndrome
Western Australia

Proudly funded by:

Government of **Western Australia**
Department of **Communities**
Disability Services

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