

EBL QUARTERLY NEWSLETTER • SUMMER EDITION • JANUARY 2019

In this edition

Welcome Our New Chair	1
New Respite Service at Andrews Farm	1
Christmas Party	1
Note from The Chair	2
A Word from Wendy	3
EBL Advisory Group	4
EBL Carer Forum	5
From Our Carer Information Kit	6
EBL Innovation Committee	8
Governance & Risk Committee	9
Introducing Jeremy Moore	9
NDIS Quality and Safeguarding Commission & Complaints Processes	10
No "opt out" for NDIS Participants	12
Challenging & Complex behaviours: the ABC approach	14
Defining Intellectual Disability	15
Siblings Australia	16
Supported Independent Living	17
We will miss you Brian, Alyshia turns 21	18
Christmas Party	19
NDIS Lindates Autism Workshops	20

Christmas Party

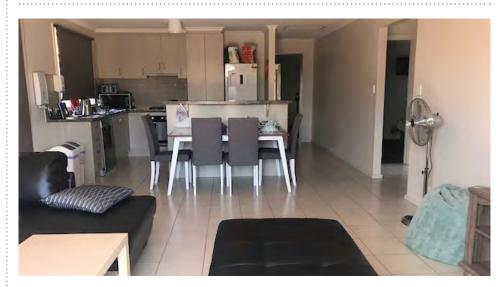
As always, everyone had an amazing time at the EBL Annual Christmas Party! Thank you to everyone who came along, it was absolutely fantastic to see so many smiling faces come together to celebrate another wonderful year!



Welcome Our New Chair



e are thrilled to welcome EBL Disability
Services' Board Chairperson, Sue Chapman.
Sue is incredibly passionate about EBL and brings
with her a plethora of experience when it comes
to advocating for and working with people with
a disability. Sue joins our inspirational carer-led
Board, and together with our wonderful staff and
EBL community, we are all very excited to see what
2019 will hold.



New Respite Service at Andrews Farm

Located on a quiet street, our new respite service is situated in Andrews Farm. This 4-bedroom home is being used for smaller groups of people with a disability and allows for those who don't do so well in larger groups, to flourish.

At this stage, the house is set up for adults, and with the expansion of our Day Options program, we will also be using the house for our cooking program and life-skills program where people can learn everything from washing clothes, ironing, general cleaning and more.

In addition to the lovely garden outside area, incorporated in this home is a "Sensory Chill Out Space" using one of the lounge rooms with the hope to have feature assistive technology for controlling lights and music, so stay tuned for that one!



A Note from The Chair

appy New Year. I hope 2019 is a fulfilling and enjoyable year for us all. For those of you who were not at the AGM in October, elections for all Board positions were held, and at the Board meeting in November I was appointed the new Chairperson. The full Board now comprises: Sue Chapman (Chairperson), Dawn Brodie, Phil Donaldson, Tracey Edwards, Judith O'Donnell, Andrew Sterzl, Chris Streeter, Betsy Tang and our CEO, Wendy Warren.

I have previously held positions with the Innovation Committee and the Carers' Advisory Group of EBL, and I hope to also continue with those roles. I have an adult son with Autism and intellectual disability, and my husband is profoundly disabled due to the ravages of Multiple Sclerosis. Everyone's story is unique, but in some respects I (and several other Board Members) have walked the walk, and can talk the talk, from personal experience.

2018 was a very challenging year for EBL. I congratulate Wendy and all of her staff in rising to meet all those challenges, and staying the course with conviction and perseverance. The NDIS is still not completely rolled out in South Australia, and EBL still has many clients to support in this area - I know they will make sure that all clients are prepared as much as possible for their first plan meetings or reviews, as the case may be. While EBL continues to grow at a modest level, the need to manage funds, and especially cash reserves to cover the NDIS teething problems, is uppermost in our minds.

In 2019, I want to meet as many carers as I can. I will be attending EBL's Carers Forum on 28th February, and I hope many of you will be also be able to attend what should be a very interesting day. The Board wants to have a good understanding of what EBL's clients need most.

One of the areas we intend to look at this year, is trying to increase respite availability. I hope that we can provide more information in that regard later in the year.

While things are busy and there seems to be lots to do, I am very excited for the future, and keen to work with our new Board, Wendy and her staff.

Sue Chapman

Chairperson EBL Disability Services



A Word from Wendy

appy New Year and welcome back to our quarterly newsletter! It is hard to believe we are already well into 2019, with no signs of slowing. As always, the team at EBL have been busy and we have so many exciting things in store this year.

First of which is the inaugural 2019 EBL Carer's Forum! This free event will be held at Technology Park on Thursday 28th February and is dedicated to informing, sharing and answering your questions around advocacy, legal planning, housing and navigating a world under the NDIS. Not only will you hear from a range of knowledgeable speakers on the day, you will also be treated to lunch and the sweet sounds of the Sisters of Invention. On top of that, everyone who attends will go into a draw to win a weekend away in the Barossa staying at the exceptional Barossa Novatel, including 2 x nights respite for your child. This amazing opportunity to take some well deserved time off is not to be missed, so be sure to RSVP to admin@eblds. org.au and book your space now!

Secondly, we congratulate and welcome Sue Chapman to the position of Chairperson. Sue is extremely passionate about EBL and supporting people with disabilities. She has been involved with the disability sector for many years, advocating on behalf of the families of those with a disability, both to service providers, Disability SA and The Minister. She sat on the Board of the Autistic Children's Association of SA (now Autism SA), is a member of the Family Forum group of Highgate Park (formerly Julia Farr), and for the last 11 years, has been a Board Member of the Harrow Trust (Harrow Housing P/L). Also, a member of the EBL Carer Advisory Group. I am sure you agree, the support

and experience Sue brings to EBL Disability Services is invaluable. Please join me in extending a very warm welcome to Sue in her new role as Chairperson of our inspirational carer-led Board. Together with the EBL team, we will strive to create the best possible opportunities for people with a disability.

We are thrilled to have our new respite service up and running in Andrews Farm. This 4-bedroom home is being used for smaller groups of people with a disability and allows for those who don't do so well in larger groups, to flourish. We are also using the house to cater for the expansion of our Day Options program allowing people to benefit from the programs on offer. Incorporated in this home is a "Sensory Chill Out Space" using assistive technology. We will be sure to keep you updated on this!

I would also like to take this opportunity to introduce Expresident of the Guardianship Board of South Australia, Jeremy Moore. Jeremy is a strong advocate for those living with vulnerabilities. His expertise in helping our organisation develop robust strategies and advocacy practices focused on individual consent and capacity has been invaluable as we enter the new safeguarding framework of the NDIS. Jeremy will also be speaking at our upcoming Carer's Forum on the topics of Legal/Advanced Care Directives.

In this edition, we will also be hearing from our Innovation Committee
Convenor, Phil Donaldson and head of the Governance & Risk Committee,
Betsy Tang on the incredible work they are currently undertaking. We work very hard in both of these areas to ensure that not only are we leading the way when it comes to

(continues on next page)

2 EBL QUARTERLY NEWSLETTER

EBL QUARTERLY NEWSLETTER

A Word from Wendy (continued from previous page)

innovation in the disability sector, we also have a robust safeguarding framework in place with standards that are second to none.

This edition of the newsletter also showcases a number of different articles covering topics on how to find supported accommodation for your child, ethical service provision, behavioral management strategies, health management for associated healthcare conditions, sibling workshops, as well as links to healthcare resources that may also be of benefit and an update on all things NDIS.

Looking forward, we want to ensure your voice is always heard and your questions answered. Should you have anything you wish to discuss with us at any time, please be sure to visit our complaints portal on the contact page of our website under 'Feedback & Complaints' or call us directly on 8252 1000. You can also arrange to speak with EBL Chairperson, Sue Chapman or the Convenor of our Carer Advisory Group, Dawn Brodie on the same number. We welcome your feedback.

Last but not least, there were smiles all round at the Annual Christmas parties at EBL and Harrow House. Thank you to everyone who came along and enjoyed in the celebrations, it was uplifting to see our community coming together to celebrate another wonderful year!

And finally, I want to extend a heart filled thank you to absolutely everyone at EBL for their hard work and dedication in 2018. As we head into another year, I have no doubt that the amazing staff, our new carer-led Board and the wider EBL community, will make 2019 our best year yet as we work together to do all we can to ensure those living with a disability continue to live rich and meaningful lives.

Wendy Warren

Chief Executive
EBL Disability Services

EBL Carer Advisory Group



November newsletter contained information on the new board members and their

profiles and I am thankful to be one of those members. I look forward to working with the new board in 2019 and supporting Wendy Warren in her role as CEO. The 2018 AGM had the largest attendance we have ever had and I would like to thank everyone who attended and the many families who took the time to send in proxy votes. Wendy and the EBL team are committed to providing the best service possible while dealing with the changes under NDIS. Your attendance at our AGM is one way of showing that they are supported and appreciated. It is also an opportunity to collect a report which informs you about the previous 12 months

including how well EBL are doing financially. I hope you might consider attending the 2019 AGM to meet fellow carers and get to know who your Board members are. The Board and Carer Advisory Group would enjoy the opportunity to meet you in person.

I would like to thank the EBL Foundation for supplying the funds for the Christmas party last December. A hearty meal in a good venue, music to dance to and of course the most important person at this time of the year, Father Christmas. The clients seemed to enjoy the day with some artistic face painting and a present to take home as well. If you have not attended the yearly Christmas party before, I am sure the person you care for would have an enjoyable time, so please consider it this year.

There will be information in this newsletter and an invitation sent out concerning the "Carers Forum" to be held in February. EBL will do their best to inform you with information you requested in the carer survey in 2018. There will be limited places, so please book in early.

The Carers Advisory Group will continue the morning tea meetings this year. We have tried different days of the week and will continue this in hope that you might find a day that suits you. The next 4 dates are below, so you can insert into your diary now. A further invitation will be sent closer to the date.

Friday 15/02/19

10.00am - 12.00pm

Wednesday 08/05/19

10.00am - 12.00pm

Tuesday 13/08/19

10.00am - 12.00pm

Thursday 21/11/19

10.00am - 12.00pm

Nawn Brodie

Convenor

EBL Carer Advisory Group

Inaugural Carer's Forum

This brand-new event will be held at Technology Park on Thursday, 28th February and is dedicated to informing, sharing and answering your questions around advocacy, legal planning, housing and navigating a world under the NDIS.

This is an event not to be missed, so be sure to RSVP to admin@eblds.org.au now!

Together We Can!

EBL CARERS FORUM

Thursday, 28th February 2019 10am-3pm - Technology Park, Mawson Lakes

Join us for this **FREE** event dedicated to informing, sharing and answering your questions around advocacy, legal planning, housing and navigating a world under the NDIS!

Hear from parents and key people within the industry. Ask your burning questions, be treated to the sweet sounds of The Sisters of Invention and enjoy lunch on us!

Everyone who attends will go into a draw to win a weekend away in the Barossa staying at the exceptional Barossa Novatel, including 2 x nights respite for your child. This amazing opportunity to take some well deserved time off is not to be missed! To be eligible for this prize, you simply need to RSVP to this event and be there on the day when we draw the lucky winner.

Here's a sneak peek into what you can expect on the day.

Learn more about:

NDIS Readiness

Respite

Day Options

Harrow House

Housing & Assistive Technology

Legal/Advanced Care Directives

Disability Advocacy

Assisted Holidays

Disability Services, Community Services and Access

Benefits of Ambulance Cover

Hear from:

The Sisters of Invention - Be uplifted and mesmerised by the sweet sounds of The Sisters of Invention

Come along to this event as we join hands to listen, learn and connect at what is sure to be a memorable and informative day!

KSYP to:

EBL Contact at admin@eblds.org.au or phone 8252 1000 by Friday, 15th February.



4 EBL QUARTERLY NEWSLETTER 5

Alone we can do so little; together we can do so much.

- Helen Keller

From our Carer Information Kit

What is important to you?

We understand the most important thing to you is protecting, caring and providing for your child living with a disability.

To assist, EBL Disability Services Inc. (EBL) has prepared this Carer Information Kit for general information purposes.

Disability affects us all

It's more common than you think. Almost all Australians are touched in some way by disability.

People with disability are part of every section of our community: men, women and children; employers and employees; students and teachers; indigenous and non-indigenous; customers; and citizens. No two people experience their disability in the same way.¹

Over 4 million people in Australia have some form of disability. That's 1 in 5 people.

- 19% are men and 18% are women.
- 43% of people over 55 years have one or more disabilities.
- 2.2 million Australians of working age (15 64 years) have disability.

People with disability are twice as likely to be in the bottom 20% of gross household incomes.²

Some harrowing statistics:

- •1 in 6 Australians are affected by hearing loss.
- 357,000 people in Australia are blind or have low vision.
- 10% of the population are dyslexic (some 2 million Australians).
- 45% of the population will experience a mental health disorder during their lifetime.

Furthermore, the likelihood of living with disability increases with age.

- some 31% of 55-64 year olds are living with disability.
- almost nine in ten people aged 90 and over (88%) have a disability.
- 39% of complaints lodged with Australian Human Rights Commission are against businesses and related to disability.³

There are a lot of people with disability that need help. Many are unemployed and need a chance, while others are, unfortunately, unemployable.

This Carer Information Kit aims to point you in the right direction to find the advice and resources you need to make the most important of decisions – caring for your child.

It's aim is to help you think about making the right legal arrangements for your circumstance.

There are a lot of complex legal terms that need to be understood. It's sometimes difficult to plan ahead – planning for illness and death may seem morbid, or to be inviting bad luck, especially, when you are already busy with the many demands of caring it may seem like a lot of extra work.

It's worth it though. Once arrangements are made you can stop worrying and have some sense of security and peace of mind about the future. It may help you avoid difficult situations, especially at times of crisis or emergency

What is in this carer information kit?

Summarised and helpful information to get you started.

Please note that nothing in the Carer Information Kit constitutes or is intended to constitute investment, financial, property, mortgage or legal advice and should not be relied upon by any person as a substitute for professional advice.

We strongly encourage you to seek independent legal and financial advice before making any decisions.

1. WHAT IS DISABILITY?

2. GOVERNMENT ASSISTANCE

- 2.1 National Disability Insurance Scheme
- 2.2 Disability Support Pension (DSP)

3. PLANNING AHEAD

- 3.1 Carers
- 3.2 Guardians
- 3.3 Bank Signatories
- 3.4 Powers Of Attorney
- 3.5 Advance Care Directives
- 3.6 Wills
- 3.7 Superannuation

4. TRUSTS

- 4.1 Discretionary Trusts
- 4.2 Testamentary Trusts
- 4.3 Special Disability Trusts
- 4.4 Injury Compensation Trusts
- 4.5 Life Insurance Proceeds Trusts
- 4.6 Child Maintenance Trusts

To get your copy of the Carer Information Kit, contact the team at EBL on

(08) 8252 1000.

We lead by example, treating all in our community with genuine respect and equity.

6 EBL QUARTERLY NEWSLETTER 7

¹ Australian Network on Disability

² Australian Bureau of Statistics, Survey of Disability, Ageing and Carers 2012

³ Except where stated otherwise, data is taken from Australian Bureau of Statistics, 2012, Survey of Disability, Ageing and Carers (SDAC).

EBL Innovation Committee

The Innovation committee which is convened by Board member Phil Donaldson in working under the auspices of the Board and its members include Sue Chapman - Board Chair, Tracey Edwards - Foundation Chair, Chris Streeter - Board member, Wendy Warren - CEO and Board member and EBL Executive staff members Glenn Stanton and Matt Heading.

The Innovation Committee has drafted a new charter for presentation to the Board which embraces the idea of the committee as being a co-creation think-tank to generate opportunities for consideration of the EBL Board to further enhance the lives of its clients, carers and staff relating to innovation ideas across (but not limited to):

- Core service delivery
- Potential future and emerging client services and support
- Marketing plans, growth and competitive position
- Emerging care and technology trends in the disability services sector
- Intellectual property strategy and development
- Community values and social responsibility

As a result, the Innovation Committee will:

- 1. Deliver an annual business plan of ideas and action for the Boards consideration
- 2. Assist in EBL demonstrating innovation leadership in the disability services sector.

Already the Committee has provided some initial leadership supported by the EBL Board and the EBL Foundation to apply for an NDIS ILC grant. The project aims to increase organisational efficiencies and capacity through developing game-integrated management solutions to enhance people with complex Autism Spectrum Disorders ability to communicate, engage and improve quality of life.

It is hoped that this will also provide an avenue to a full exploration of innovation and the business models needed to create sustainable income generating activities that can feed into supporting the other parts of EBL, its clients and its carers.

The grant outcomes will be known in May/June 2019.

As we move into 2019 we will continue to look for opportunities that assist in EBL demonstrating innovation leadership in the disability services sector, to further the aims and objectives of EBL and to deliver excellent outcomes for the people and the organisation.

We look forward to the contribution of the EBL community into the innovation committee as we co create our future in this area. Innovation is part of who we are, how we operate and how we provide benefit to the EBL community now and into the future.

Kind regards and best

Phil Donaldson (Convenor)

EBL Disability Services Board Innovations Committee

Introducing Jeremy Moore

EBL Disability Services has had the pleasure of working alongside Jeremy Moore on various projects involving advocacy, capacity, legal administration and guardianship for people with disabilities. Jeremy is a strong advocate for those living with vulnerabilities. His expertise in helping our organisation develop robust strategies and advocacy practices

focused on individual consent and capacity has been invaluable as we enter the new safeguarding framework of the NDIS.

Jeremy is the Ex-president of the Guardianship Board and will be speaking at our upcoming Carer's Forum on the topics of Legal/ Advanced Care Directives.



Governance & Risk Committee

A s many of you may know, EBL has a new Board of Directors following the AGM in October last year. This led to the reshuffling of sub-committee members. I have put up my hand for the role of Convenor of the Governance and Risk Sub-Committee.

I will admit that I am a new kid on the block in regard to this role and it is a steep learning curve for me. However, I do have a strong compliance background and lots of experience in ensuring compliance with the law having worked as a Commonwealth public servant for more than 30 years. I have taken on this challenge with a view to ensuring EBL has a strong Governance and Risk Framework that will stand up to scrutiny.

Under NDIS, there is a new Quality and Safeguarding Framework that applies to NDIS participants effective of July 2018. Compliance with the Framework is imperative.

There is a requirement that service providers like EBL must achieve accreditation status issued by the Australian Service Excellence Standards (ASES), to exist under NDIS. EBL received this accreditation and was described as a quality organisation in November 2018. This is the result of EBL meeting the high exacting standards of ASES in areas including clinical care and governance, service delivery, worker safety and the like. To quote ASES in their feedback to the CEO, "Your achievement is a culmination of hard work and dedication by the people within your services to create a quality organisation." Anyone who is involved with EBL should be so proud!

I will work with members of this sub-committee to ensure EBL continues to be committed to quality and continuous system improvement.

While I learn the ropes, I would welcome any feedback and input you, as clients of EBL, have to offer. I strongly believe that client feedback is an invaluable source of information which can be used to improve the standards of how we operate as an organisation. Please feel free to send me an email to **BetsyT-BOD@ebIds.org.au**. Alternatively, you may ring **8252 1000** to arrange a time to chat. Anyone who knows me knows that I am into coffee diplomacy!

Betsy Tang

Convenor,
Governance & Risk Committee

independence, with support and individual choices

We encourage people

to believe in their

ability to achieve

8 EBL QUARTERLY NEWSLETTER

NDIS Quality and Safeguarding Commission & Complaints Processes

What is The NDIS Quality and Safeguards Commission?

The National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission (NDIS Commission) is an independent government body that works to improve the quality and safety of NDIS services and supports.

What they do

You can contact The NDIS Quality and Safeguards Commission if you feel unsafe or unhappy with your NDIS supports or services.

We encourage you to talk directly to your provider first to see if you can resolve your concerns. All registered providers must have an effective complaints management system. If you are not confident to speak to the provider or you are not satisfied with the result, you can talk to them.

It's always okay to speak up. Their complaints service is independent and free.

Making a complaint can lead to improved services, communication and changes to the way supports are delivered.

How to make a complaint

Who can make a complaint

Anyone can complain about NDIS funded services provided to a person with disability. This includes NDIS participants, other people with disability, friends, families, carers, advocates, workers, or any other person who wishes to make a complaint.

What complaints they take

You can make a complaint to the NDIS Quality and Safeguards Commission about the quality or safety of supports and services provided by any NDIS provider. They take complaints about whether NDIS services have been provided in a safe way and to an appropriate standard. You can also make a complaint to them about how an NDIS provider has responded to a complaint. If you or someone making a complaint on your behalf is concerned about how you will be treated, you can make a confidential complaint. This may influence how the NDIS Commission can take action.

What complaints they don't take Complaints about the NDIA, access and participant plans are managed by the NDIA. You can also complain about the NDIA, or the NDIS Commission, to the Commonwealth Ombudsman.

The NDIS Quality and Safeguards Commission handle complaints about NDIS services in places in which they are operating. This is because the NDIS Commission is being rolled out gradually.

The NDIS Quality & Safeguards Commission are available from:

- •1 July 2018 in New South Wales and South Australia
- 1 July 2019 in the Australian Capital Territory, Northern Territory, Queensland, Tasmania and Victoria
- •1 July 2020 in Western Australia.

If you are not sure who to contact, the NDIS Quality & Safeguards Commission can help to connect you with the right organisation.

Where to go with a complaint

I'm not happy with NDIS funded services



The NDIS Commission



1800 035 544

1800 800 110

I'm not happy with the NDIA's actions or decisions

NDIA or Commonwealth Ombudsman

www.ndis.gov.au www.ombudsman.

gov.au

I'm not happy with a service provided by another agency or body



Your state or territory complaints body

Find links on the **NDIS Commission** website www. ndiscommission. gov.au

How the NDIS Quality and Safeguards Commission handle complaints

The NDIS Quality and Safeguards Commission will acknowledge your complaint and may ask for more information. You can let them know your preferred method of communication. In helping to resolve a complaint, they may:

- request information and documents to help clarify the issues
- help you to talk to the NDIS provider
- with your consent, speak to the NDIS provider about the issues
- talk to you about the information we receive from an NDIS provider

Sometimes a complaint may be referred to conciliation or investigation. A conciliation meeting helps people to understand the issues and reach agreement on how a complaint can be resolved. An investigation may be conducted if the issues raised in the complaint involve serious concerns or risks to people with disability.

As part of this, they may request further documentation, contact people involved in the complaint, visit the service provider or talk to other people affected by the issues including other people with disability and staff. If a complaint raises a serious compliance issue, they have powers to take action.

You may withdraw a complaint at any time by letting the NDIS Quality and Safeguards Commission know.

If you're unsure about who to contact or what to do about an issue, the NDIS Quality and Safeguards Commission can give you advice or help you find the right place to go.

Make a complaint

Call: **1800 035 544** (free call from landlines)

Complaint contact form: www.ndiscommission.gov.au National Relay Service: www.relayservice.gov.au then 1800 035 544 Translating and Interpreting Service: 131 450

We deliver quality

support individuals

10 FBI QUARTERI Y NEWSI ETTER

services that

positive health

and wellbeing

to achieve

outcomes.

No "opt out" for NDIS Participants

By Lee Archer - January 5, 2019 NDIS Opinion

y Health Record has been all over the news, with the federal government scrambling to allow extra time for consumers to deliberate over whether their privacy is at risk and to decide exactly how much of their personal medical information they want to share. The concept of privacy as a right for consumers and citizens of Australia isn't always awarded the same seriousness for people with disability. For some people, the NDIS planning process and provider engagement has increased the privacy intrusion into their everyday life that would not be acceptable to most Australians.

Commodifying your inner self to buy a plan

The intention of the NDIS is noble- that people with disability have the same rights and opportunities as all Australians to live an 'ordinary life.' This encompasses all the same life milestones, trials, tribulations and successes that most Australians take for granted. So big tick NDIS. That is exactly what we want the Scheme to do. Moreover, the notion of an 'ordinary life' is a conceptual winner when explaining to the broader Australian community what the NDIS is all about: the NDIS should be removing the barriers that disability that can present in living an ordinary life.

The experience of formulating an 'ordinary life' through the NDIS can be a far cry from an 'ordinary' experience, especially when compared to how Australians access other supports and services. The idea of 'goals and aspirations' is embedded in NDIS legislation and is compulsory for all Participants. Conceived to address the systematic disenfranchisement of people with disability, it is designed to provide the tools for people with disability to take control over the direction of their own lives. For some people with disability, this may be the first time that they have been asked how they want to live their lives.

So what is the issue? The personal cost of this system is not one that most of us using government services have to pay. I have used health, physiotherapy and other services all my life. Not once have I been asked to cough up my broader life goals, and if I had been asked, I would have probably told them to mind their own damn business.

People with disability can have a very different experience of privacy to most Australians. Unfortunately, people with disability can be quite used to being directed and intruded upon. This historical lack of agency has led to an acceptance that as a person with disability, you don't own your life or that this is the sacrifice you have to make in order to access the services you need.

It is not unreasonable to expect people to be required to provide some information about themselves in order to access services, but the NDIS expectations of what needs to be given are, as the young people say, next level. In order to capture the biggest dataset about disability in the world, the NDIA is asking Participants benchmark questions about their health, household income, and family dynamics. This information helps us understand the effects and efficiency of the Scheme, but how does this balance against the privacy intrusion? Do Participants feel they can say no? And how does it compare with what other Australians are asked when utilising similar services?

The intrusion gets particularly pointy when it comes to housing. A huge number of resources are being pumped into Specialist Disability Accommodation (SDA). The NDIA is under enormous pressure, as this could break the Scheme if it goes wrong, but stories from advocates indicate that this has led to some particularly dodgy stuff happening around goals. Anecdotally, DSC has heard that Participants seeking SDA have been pressured to change their goals from something like 'I want to live independently' to 'I want transitional housing.' So, is this still the Participant's goal? Or has it morphed into the NDIA's goal for that person? If goals are to be so fundamental to the Scheme, then they need to be authentic and belong to that person.

Provider engagement

The intake process for some providers can be extensive, and sometimes take the form of intake documents 10-30 pages long. This is an unnecessary, risk-averse practice which reflects the provider's desire to make sure they cover all the bases. But for the person with disability, this can have the compounding effect of eroding the person's agency, giving them less control of their history, their lives and the relationship with the provider. As the NDIS market heats up, providers should start thinking about what is it that they really need to know and do away the aspects of their intake processes that may ask too much of Participants.

Who owns your dreams?

Capturing goals and aspirations is a legitimate framework for administering a complex Scheme. However, goals need to be captured in a sensitive and authentic way that recognises the intrusion this represents to some people. Capturing data should not go beyond what people experience in mainstream services. If the NDIA are serious about an 'ordinary life,' then this needs to translate into an ethical approach to data collection. A person's goals, dreams, aspirations and identity are their own, not the NDIA's to grab. They are that persons to give - willingly, and consciously.

That is the ultimate choice and control, baby.

Source: www.disabilityservicesconsulting.com.au/resources/no-opt-out

The word 'respite' has definitely gone out of fashion.

People reject the implied assumption that people with

disability are something that you need to take a break from.

12 EBL QUARTERLY NEWSLETTER

EBL QUARTERLY NEWSLETTER

Health Management for Associated Healthcare Conditions + Links

Defining Intellectual Disability

Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society.

The use of the term intellectual disability in the context of the WHO initiative "Better health, better lives" includes children with autism who have intellectual impairments. It also encompasses children who have been placed institutions because of perceived disabilities or family rejection and who consequently acquire developmental delays and psychological problems." (WHO)

Positive Behaviour Management Strategies for Family Members

Challenging & Complex behaviours: the ABC approach

It can be very stressful dealing with behaviour issues, but the ABC model is a handy way to understand what is happening, and respond instead of just reacting. It involves looking at the:

- Antecedents (what happened before the behaviour?)
- Behaviour (what is the actual behaviour?)
- Consequences (what happens afterward?)

This is an effective technique for taking the emotions away from challenging behaviours, analyzing these behaviours, then creating effective responses. When creating a behaviour support plan, it will be important to work out which strategies you will use. These strategies are not to be used occasionally, but will need to be applied consistently by everyone who encounters the targeted behaviours. While they may be difficult at first, your chosen techniques will eventually become second nature.

Antecedents

What occurs before the behaviour (and may have triggered it)?

The antecedents are simply all the relevant things that happened before the behaviour occurred. They can also be considered as triggers for the behaviour, such as:

- things that other people did or said
- emotional state (e.g. depressed, tired, anxious etc.)
- the environment (e.g. hot, noisy, cramped, smell, bright lights).

Managing these antecedents, or triggers, is a proactive way to avoid behaviours occurring in the first place. Here are some useful strategies:

- Build and maintain good rapport
- · Avoid or minimize known triggers
- Sometimes a distraction or redirection away from the trigger may be all that is necessary
- Involve the brain-injured person in discussing triggers
- Work together on possible coping strategies in dealing with triggers
- \bullet Suggest and encourage these strategies when a trigger occurs.

Graduated exposure to the antecedent

This is useful when antecedents can't or shouldn't be avoided. With time and patience, it can be a powerful technique. For example, Kirsten starts screaming in supermarkets due to sensory overstimulation. Her mother says they will just stand outside the supermarket for 30 seconds then go home. The next time, they go in for 30 seconds then go home. This is gradually lengthened until Kirsten has adapted to this difficult environment.

Preparing for the antecedent

An inability to cope with chaos, unpredictability and lack of routine is common after a brain injury. For example, if Chris finds the activity and noise of a supermarket unpleasant, it can help to talk about expected reactions and ways to cope before the event.

Behaviour

What happens during the behaviour (what does it look like?)

Before you respond to an actual behaviour, the key is to understand the purpose of the behaviour and what it may be expressing about unmet needs. Although emotions can be running high, there are still strategies that can prove useful during the behaviour itself:

- Stay calm and speak in an even tone
- Give simple directions and prompts about coping mechanisms
- Use non-threatening hand gestures
- Manage your personal safety and remember the strategies agreed on for dangerous incidents
- Recognize when it's time for disengagement/exit strategies for crisis situations.
- Ignoring the behaviour

In some cases, behaviour occurs to get attention, so the best strategy may be to ignore it. As with many of these techniques, tactical ignoring is best linked with positive reinforcement. For example, a child is ignored during a tantrum, but is rewarded with praise, a treat or favourite activity once the tantrum is over.

Consequences

What are the immediate and delayed reactions from everyone involved?

The consequences, or our responses to a challenging behaviour, are very important. For example, a pleasant consequence can simply reward the behaviour, while a negative consequence may discourage it.

Pleasant consequence: "When I yell everyone gives me what I want".

Negative consequence: "When I yell everyone ignores me completely".

When we use the ABC technique to analyse behaviour, we tend to stop reacting emotionally in ways that often make the situation worse. A consistent response from everyone to challenging behaviour can have a very strong effect over time.

Snapshot Of Causes Of Id In Australia

- Down syndrome 12-15% of all Australians with ID (Bittles & Glasson, 2004)
- Autism spectrum disorder

 (causing severe or profound
 limitation) 0.5% of Australians
 with 71% experiencing severe or profound limitation (Australian
 Bureau of Statistics, 2014a)
- Cerebral palsy (with ID) 0.07-0.2% of Australians (Australian Cerebral Palsy Register, 2013
- Fragile X (with ID) <7,000 Australians (Brown, 2010)

Defining Quality Of Life

The World Health Organisation defines Quality of Life as "individuals" perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships personal beliefs and their relationship to salient features of their environment." (World Health Organization, 1997, p. 1).

Source: www.nds.org.au/images/ LearnNDevelop/Chronic-Illnessand-People-with-Intellectual-Disability.PDF

Our vision is to passionately support individuals and their families to lead fulfilled lives.

14 EBL QUARTERLY NEWSLETTER
EBL QUARTERLY NEWSLETTER

Siblings Australia

Siblings Australia, a unique national organisation, was established in 1999 by Kate Strohm, with the assistance of Dr Jon Jureidini, in the Department of Psychological Medicine at the Women's and Children's Hospital in Adelaide, but later became an independent entity. The organisation's focus is on siblings of children and adults with disability or chronic illness, and over a period of 20 years it has developed a national and international reputation for its work with families and professionals.

The organisation Mission Statement says it all. *Siblings: Acknowledged, Connected, Resilient*.

Siblings can often be overlooked, which can lead to feelings of isolation. If this continues, children can become vulnerable to a range of emotional and mental health problems. However, if siblings are acknowledged, and connected to sources of support, they are likely to become more resilient and family relationships are likely to be stronger

For more information about Siblings Australia visit:

http://siblingsaustralia.org.au/

Supported Independent Living

How to find housing

Here is a simple step-by-step guide to find private rental housing that will suit your budget, needs and preferences.

Here are some things to consider before you begin:

- Do I have enough money to move?
- How will I move all of my belongings?
- What can I afford?
- Do I have enough money to live on my own or will I need to share?
- Where do I want to live?
- Are shops, work and places to eat close by?
- Are sports and leisure activities close by?
- Do I need to be close to friends and family who can provide support?
- Will I have access to community services that I may need?
- What is local public transport like?

What sort of residence will I need?

- How many bedrooms will I need?
- Will my residence need to be physically accessible for myself or others?
- Does it have stairs?
- Are the doorways wide enough for a wheelchair etc.
- Do I have enough furniture to move into an unfurnished residence?
- Do I need particular floor coverings according to my mobility needs?

What sort of housing am I eligible for?

- Public housing
- Community housing
- Private rental.

If Government housing is not suitable or available for you, then your next step is to look for housing through private rental. This can be a much more expensive means of accommodation, and you must evaluate your finances to ensure that you are able to afford a rental property.

How to apply for private rental

How can you find private rental properties? You can search for private rental properties by either visiting the real estate offices in your area or by searching on the internet.

Each real estate office will have a list of private rentals in their area - this list is updated as often as every few hours - much more frequently than the internet.

Finding private rental properties online

- Go to www.realestate.com.au if you are in Australia
- Click on the "Rent" tab at the top of the page
- Choose your State on the map of Australia
- Enter suburb name(s) or select suburbs from the list provided that you are interested in
- Select a weekly price range from the list provided, or enter a weekly price range
- Select the number of bedrooms you need to have in your rental property, from the list provided
- Select the property type from the list provided (i.e. house, unit etc.) explanations of the different types of housing are provided by clicking on the link titled "Property Type Definitions"
- Click "Start Your Search" to view the results.

How can I view a private rental property

There are several ways you can arrange to view a property you are interested in:

- You can inspect the property yourself but you'll often need to provide photo ID and a deposit to get a key from the real estate
- The property owner may like to meet you, so they can supervise your inspection
- Sometimes the existing tenant may be able to show you through the property
- An open house may be arranged if there are multiple people interested in a property



For disability specific housing options in South Australia visit The Housing Hub at: www.communityhousing.

com.au/housing-hub/

Feedback & Complaints Portal

t EBL, we want to ensure your voice is always heard and your questions answered. Should you have anything you wish to discuss with us at any time, please be sure to visit our complaints portal on the contact page of our website under 'Feedback & Complaints' or call us directly on **8252 1000**.

I think whatever we can do, the more people who can help, the better.

16 FBI QUARTERLY NEWSLETTER

We will miss you Brian!

A fter 20 years of volunteering at EBL, Brian Whiteburn has retired, much to our displeasure..... only joking, but he will be terribly missed!!

Brian diligently tended to the gardens and yards at the Yarnbrook Street and Ventura Street homes and was always there to lend a helping hand to a multitude of odd jobs that forever popped up and needed attention.

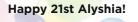
We will all miss Brian and his bright smile and wealth of knowledge around the beautiful gardens he created.

We would like to take this opportunity to wish you all the best in your retirement and thanks again for being part of the EBL family for all these years.

Alyshia turns 21!

A lyshia turned 21 on the 30th of November. Alyshia has been with us for some years, first in the children's house and upon turning 18, the adults house.

We would like to recognise Alysha's milestone of turning 21 and hope to share many more birthdays with her.





EBL Christmas Party

veryone had an amazing time at the EBL Annual Christmas Party! Thank you to everyone who came along, it was absolutely fantastic to see so many smiling faces come together to celebrate another wonderful year!



NDIS Commission coming soon to Vic, Qld, Tas, ACT and the NT

Posted on 16 January 2019

The NDIS Quality and Safeguards Commission will roll out across Vic, Qld, Tas, ACT and NT from 1 July 2019. The NDIS Commission began operating in NSW and SA on 1 July 2018, WA will transition from 1 July 2020.

NDIS participants have the right to be safe and receive quality services from NDIS providers. The NDIS Commission is an independent agency established to improve the quality and safety of NDIS supports and services.

It ensures a nationally consistent approach to NDIS quality and safeguards. This helps participants access services and supports that promote choice, control and dignity.

The NDIS Commission works to promote safety, quality services, prevent harm, resolve problems and identify areas for improvement.

Until the NDIS Commission is in place in each jurisdiction, NDIS participants are covered under their state or territory's existing quality and safeguards systems.

If you receive supports in NSW or SA, you can raise concerns with the NDIS Commission about:

- services or supports that were not provided in a safe and respectful way
- services and supports that were not delivered to an appropriate standard.

For more information about the NDIS Commission, including how to make a complaint, visit: **www.ndiscommission.**

gov.au/

You can also complain directly to the NDIA by phone or completing a feedback form here: ndis.gov.au/about-us/contact-us/feedback-complaints. The NDIA will make sure that your complaint is directed to the NDIS Commission where necessary.

Autism Workshops

Autism SA offers a range of different workshops for families and professionals. These workshops aim to develop participants understanding of a particular area relating to the autism spectrum for families, and to increase awareness and understanding of autism, along with provide a range of practical strategies that may be beneficial when working with individuals on the spectrum in a range of settings, for professionals.

Family workshops are presented by experienced professionals from across different teams within the organisation for participants to develop a greater understanding through these interactive, engaging and practical workshops. The general workshops for professionals are a useful introduction for people who have not attended previous Autism SA workshops.

To find out more about these workshops, visit: www.autismsa.org. au/training-workshops

Contact details

- t (08) 8252 1000
- **f** (08) 8255 1066

w eblds.org.au

e admin@eblds.com.au

EBL Disability Services

Endeavour House, Module 5, 11 - 15 Fourth Avenue, Mawson Lakes SA 509

We partner and advocate for our community to overcome challenges to fulfill aspirations and provide peace of mind