



Aspiehelp / The Aspire Trust September 2017 Newsletter

Edited by Anna Melling

Aspie Round Up bookings now open, upcoming sausage sizzles, Altogether Autism's survey results, Mad Poets Society, Why I Don't Have 'High-Functioning' Autism

The Aspie Round Up

Friday 17th and Saturday 18th of November

The website is now online!

<http://www.theaspieroundup.co.nz/>



We will be partnering with the University of Canterbury Disability Resources Centre to host workshops. The planned location is the Undercroft Seminar Room, below the Central Library at University of Canterbury.

Dr Stephen Mark Shore, Clinical Assistant Professor in Special Needs and Autism at Adelphi University USA, will appear in a video "The Awesomeness of Autism".

Stephen is himself Autistic. He is also the Patron of Aspiehelp / The Aspire Trust.

Book now!

Visit our Fees and Registration page to book your ticket:

<http://www.theaspieroundup.co.nz/fees--registrstion.html>



Use coupon code **EarlyBird** and register by the 1st of October to get 20% off!

Submissions are open:

If you would like to present a workshop, please get in touch. We aim to have workshops by people with lived experience on topics such as life, education, work, community and empowering people on the spectrum.

We would love to hear your stories of facing and overcoming barriers and challenges in your quest for living a meaningful life - either as a person with ASC or someone who supports people with ASC.

The deadline for submissions is Thursday the 21st of September.

For more information, visit the "Submissions" page on the website linked above. We look forward to receiving your submission!

Facebook page is online:

<https://www.facebook.com/theAspieRoundUp/>

Don't forget to like and follow to keep up to date with developments!



In Our Office

It has been a busy month, with visits and visitors. Several new clients and several sausage sizzles!

Leith has sustained various injuries from falling (and in a separate incident), hitting herself on the head with the boot lid and really, really, cannot do a whole day cooking sausages any more! But we do need someone to take on organising the roster, buying the provisions etc.

We are going to be applying to be a DPO (Disabled Persons Organisation) in order to be able to apply for funding from Te Pou o Te Whakaari Nui.

We have a new Trustee, Charlotte West, who is a Clinical Psychologist since Rowie Millar moved and resigned from the Board.

We are going full steam ahead on the Aspie Roundup- very exciting!

We are awaiting the arrival of Rod Wintour, from Auckland, as new staff member with many years experience in helping children on the spectrum.



*Our staff, clockwise from top left:
Leith, Olivia, Julie, and Anna*

Social evenings

Our regular social evenings are on the first and the third Wednesday of the month, at a venue near Church Corner at 7:30pm. (Please contact Leith for the exact location). We have board games, hot drinks and biscuits, and a selection of books from the Aspiehelp library available at every meeting. Please bring a \$2 donation.

The next meetings are on the 20th of September and the 4th of October. You are welcome to attend. (New members should contact Leith or Julie first.)

Conversation group

Our Aspiehelp conversation group meets fortnightly on Tuesdays at 2pm.

A get-together for people affected by Asperger's Syndrome.

The next meetings are on the 26th of September and the 10th of October.

Please contact us if you're interested in attending.

Our Patron is Stephen Mark Shore, PhD.

The Aspire Trust, Inc is a registered Charitable Trust. Charities Services registration number is CC46192.

phone (03) 337-6337 or email info@aspiehelp.com
support us at givealittle.co.nz/org/myaspiehelp
www.aspiehelp.com

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Upcoming Fundraising Sausage Sizzles

We will be holding more fundraising BBQs over the next few weeks at Fresh Meats Barrington (Barrington Mall):

30th of September - Fresh Meats Barrington

7th of October - Fresh Meats Barrington

14th of October - Fresh Meats Barrington

21st of October - Fresh Meats Barrington

If you're in the area, come and visit, say hello and perhaps buy a sausage! We are very short of volunteers to help out with the sausage sizzles. Leith shouldn't have to be standing over a BBQ for 6 hours on a weekly basis. Please offer even for 2-3 hours now and then. The more volunteers who offer, the less each person will have to do.

Quote Corner

The most interesting people you'll find are ones that don't fit into your average cardboard box. They'll make what they need, they'll make their own boxes.

- **Temple Grandin**



Altogether Autism...

altogetherautism.org.nz

For those who are unaware of what Altogether Autism do, "Altogether Autism is a free, nationwide autism spectrum information and advisory service provided as a partnership between Life Unlimited Charitable Trust and Parent to Parent New Zealand". They put out a quarterly journal full of interesting articles, which you can read online or request to receive by post free of charge.

They have a lot of information on their website, and they also offer a free (government funded) personalised information service!

In the July newsletter, I linked to some surveys being run by Altogether Autism on Autistic Talent Search and Employment Experience. The results of these surveys are now available at the following link for anyone who is interested. These results are presented as anonymous statistics.

https://drive.google.com/file/d/0B0UkYJ_oSLT4UWZLeTFHY1RLV2M/view?usp=sharing



Writers Group and Mad Poets Society

Some of you may be interested in these events run by MHAPS - Mental Health Advocacy and Peer Support (www.mhaps.org.nz)

The Mad Poets Society is back with some new events for people interested in creative expression to get involved in. Check out the posters attached and information below. Feel free to print and display posters, and circulate this email around to people who might be interested J

Writers group

People with personal experience of mental illness, distress or addiction who write are welcome to come along to our new Writers Group. We meet monthly from 1-3pm, usually on the first Saturday of the month. Writers of all kinds welcome – poetry, short stories, novels, memoirs, songs, come along! You can opt to just have an audience (no feedback), encouragement only, or some editing suggestions to improve your work. Get in touch to find out details. Our next writers group meeting is this Saturday 2nd September from 1-3pm. These are free to attend. Following dates are 7th October, 4th November and 9th December.

Mad Poetry Open Mic Nights

Mad Poetry open mic nights are starting back up next month. We are back at Beat St Café from 7pm on Friday 15th September, 20th October and 10th November. Come along to listen to some fab poetry and music, and have a go at reading some writing that inspires you or some of your own work. Open mic nights are welcoming to anyone who wants to come along, and are an openly supportive space for people whose writing deals with themes of mental health, illness, and recovery. After our Spring Series we will be taking a break for Christmas and then back for Summer 2018. Hope to see you at an event soon!

If you would like to find out more about Mad Poets Society events, please email us at awareness@mhaps.org.nz or call 366 8288. We are also available to come and talk to groups about Mad Poets Society and answer any questions people might have about coming along.

Lipstick Dreams

The Riccarton Players are a not-for-profit recreational theatrical society. You may be interested in their upcoming play:

By Helen O'Connor & Simon Hopkinson

A must see play full of laughter, tears and fun, with toe-tapping songs from the Swinging 60s that will have you dancing in the aisles!

Directed by: Doug Clarke

Choreographer: Annette Searle

Dates: 5th – 14th October

7.30pm Nightly (except Mon & Tue) **Plus** Matinee 4pm

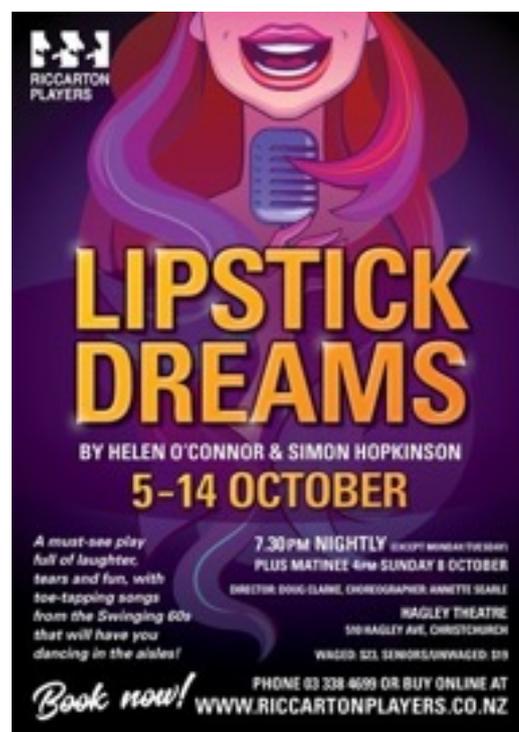
Sunday 8th October

Admission prices: \$23 waged and \$19 Seniors /Unwaged. Concession Tickets available for Groups of 10 or more.

Venue: Hagley Theatre, 510 Hagley Avenue, Christchurch

Bookings: Phone 338 4699

or via website: <https://www.riccartonplayers.co.nz/current-production>



Why I Don't Have 'High Functioning' Autism...

Republished with permission from Jeanette Purkis

<https://jeanettepurkis.wordpress.com/2017/08/04/what-i-dont-have-high-functioning-autism/>



A colleague told me many years ago that a fellow employe had told her 'Jeanette shouldn't say she has autism. She is very mild'. Aside from the inherent rudeness in such a statement about me to a third party, that little statement encompasses one of the most significant issues Autistic people can face: 'Mild' and 'high functioning.' These are labels applied to us, usually by non-autistic people, which apparently describes many Autistic people's experience of Autism on their behalf and often ascribes a bunch of judgements and assumptions along the way.

The idea of high or low functioning Autism probably started to gain traction when Asperger syndrome was included in the DSM IV diagnostic manual which was published in 1994. I was diagnosed with Asperger Syndrome shortly after that. As I went through life and more people learned about Autism and Asperger's I got given the 'high functioning' label. There were expectations with my 'high functioning' which I quickly noticed were very different to the expectations given Autistic people who had more need of support with day to day life and / or those who did not speak.

To my understanding there is no clinical descriptor called 'high functioning' and 'low functioning' Autism although some diagnosticians use them as a sort of rather unhelpful shorthand.

So why do I – and many other Autistic people – struggle with the high or low functioning labels? Well I can't speak for others but my issues are many and varied. I will use the example of a friend who has two Autistic sons. The younger son does not speak much and requires assistance for practical things. He is a lovely boy. His older brother, also a lovely boy, is more like me – articulate, speaks a lot and doesn't need assistance for most practical things so much, but struggles with anxiety and being bullied. My friend says that almost universally, her younger son is underestimated and her older son has his difficulties dismissed. These functioning labels and the expectations which so commonly go along with them are really unhelpful for her sons. They mean that the younger boy is likely to struggle to get the opportunity to do all that much even if he is capable and the older boy will be expected to not ask for – or be given – much assistance, even when he needs it.

My thoughts on some of the specific issues in this are:

- Functioning labels privilege experience. The experience of the 'low functioning' person is usually viewed poorly and the skills of the 'high functioning' person are praised but their challenges missed or dismissed. For some people they may be twice exceptional / gifted but be utterly miserable, destroyed by anxiety, the cruelty of others or self doubt. Gifted people still need support. The fact they have unusual skills in one area does not necessarily equate to the capacity to manage other elements of life. I spent some time in gifted programs when I was in primary school but I ended up in jail when I was 20. That may be an extreme example but for me all I thought about being gifted when I was informed about it was that bullies harassed me at school because I was a nerd. I wanted to have less intellect so I could be like the other kids but there I was reciting poems about the end of the world in year seven!

- Functioning labels can also be used as a divisive thing. I have been told on a few occasions ‘You can’t speak for my child. You are high functioning.’ (thankfully this doesn’t happen a lot). I prefer to support commonality rather than focus on division. And no Autistic advocate really speaks on behalf of another Autistic person. We share our experience and knowledge in the hope that others – Autistic people, parents, clinicians, educators etc – will draw some insight and awareness from our knowledge.
- Low functioning labels in particular can be incredibly misleading. Many non-speaking Autistic people are highly intelligent. And many non-speaking people describe the experience that before they had an effective method of communication, they were observing the world and experiencing things as others who speak do. I am horrified to imagine what some people must have witnessed in terms of put-downs, insults, disrespect and ableism said right in front of them.
- I always think functioning labels come from the basis of ableism and discrimination. The functioning labels model seems to be based on deviation from a notion of ‘normal functioning’. In such a model a non-autistic person is the yard stick for measuring Autistic capability. In this model presumably there is the ‘norm’ represented in the neurotypical person, then the ‘Aspie’ who seems more ‘normal’ and then the ‘low functioning’ person who supposedly is the least ‘normal’ of the three, on the outer edge of capability. I’m sorry, but from a perspective of neurodiversity and inclusion and as someone captured in this model this horrifies me. What is this ‘normal’? And why am I and other Autistics based in terms of deviation from this? In my mind, we all have skills and attributes and difference is certainly not ‘less’.

One issue with the functioning labels is that many people find them a neat shorthand to describe their child, their student or client or sometimes themselves. I think though that this shorthand is problematic as the high and low functioning descriptors don’t exist in the diagnostic literature, Now bear with me here. I do not subscribe so much to the medical model of disability so I am aware a description in a diagnostic manual does not actually define our experience. But the clinicians and from them educators and all others who support Autistic people at some point in their journey have the diagnoses listed in the DSM 5 diagnostic manual. So if they use this additional ‘high functioning’ or ‘low functioning’ which isn’t in fact defined anywhere people think it is official. But there is no definitive list of high or low functioning. The descriptions are arbitrary and subjective. Each person applying these labels is just applying them based in their own individual beliefs. So while the medical model of disability is problematic in describing our Autistic experience, the functioning labels are even more problematic as there is no way to determine what they actually mean other than the ‘feel’ or ‘vibe’ of the person applying them!

I would love for us to get rid of the functioning labels. Each Autistic child or adult is a unique individual. We fit within the broader umbrella of the Autism spectrum but beyond that we are all different. Rather than clarifying understanding of how best to support us, the functioning labels are likely to do the exact opposite.

