



## **2018 CHAIRPERSON'S REPORT: NOVEMBER 2017 –NOVEMBER 2018**

2018 has been a very significant year for the autism community in this country as the NDIS continues its roll out and nears its full implementation nationwide. People on the spectrum have consistently accounted for approximately 30% of all users of the NDIS since its inception and yet there has been a lack of engagement with the sector by the NDIA. This year this changed with the formation of the NDIA Autism Advisory Group and the Australian Advisory Board on Autism Spectrum Disorders was at the forefront of this dramatic shift.

### **Backbone Organisation for the Australian Autism Alliance**

The Australian Advisory Board on Autism Spectrum Disorders has continued to play its role as the backbone organisation for the Australian Autism Alliance formed in August 2016, the first comprehensive Australian network of autism-specific organisations comprising self-advocacy organisations, service providers, advocacy organisations and research organisations.

In the interests of supporting this broad and representative network of the autism community, the Board again contributed up to \$20,000 along with a contingency fund of up to \$10,000 to assist its operations in the financial year 2017- 2018. The Board also managed a separate bank account on behalf of the Alliance for the receipt of income specific to the Alliance and approved all expenditures. It should be noted that the Advisory Board is not itself a member of the Alliance, however, Member organisations of the Board are all Members of the Alliance in their own right.

The value of the Australian Autism Alliance was seen earlier this year after an Alliance member noted the NDIA had without notice changed the eligibility for the NDIS for people on the spectrum on its website, making it much more difficult for people on the spectrum to access the scheme. The Alliance quickly sprang into action and within 24 hours the NDIA had retracted the changes and shortly afterwards decided to formally engage with the autism community through the formation of the NDIA Autism Advisory Group. This was the most significant step forward by the NDIA in relation to the autism community since its inception. From the outset the Advisory Board was represented on the Advisory Group by its Chairperson, however initially there was no formal representation from the Alliance.

To strengthen and formalise the leadership of the Alliance, the Advisory Board recommended the establishment of two co-chairs to lead the Alliance. The Alliance endorsed this recommendation and subsequently, following their election, the two co-chairs, Paul Micallef and Terry Burke, were added to the membership of the NDIA Autism Advisory Group, making it an even more representative group. Other members of the Advisory Group were Fiona Sharkie from Amaze, Andrew Davis from the Autism CRC and Katharine Annear from ASAN.

The Advisory Board also:

- committed to supporting the Alliance as its backbone organisation for the foreseeable future rather than year by year so that the Alliance could with confidence be the voice for the autism community, and
- supported the development of a secretariat involving people on the spectrum as well as neurotypical participants while further refining the existing facilitator's role to a more specialised consultant role to the Alliance.



These changes have provided the Alliance with a firmer but leaner structure which should assist in it becoming sustainable in the longer term.

### **The Advisory Board & the NDIS**

The Advisory Board has been represented by Fiona Sharkie on the NDIS CEO Forum which has operated for a number of years. Through this connection, Fiona and I were able to meet with Rob De Luca, Chief Executive Officer of the NDIA and one of his Deputy CEOs, Vicki Rundle to discuss the Advisory Board's concern that the NDIA be more responsive to the needs of people on the spectrum using the scheme, or trying to access the scheme.

The value of this meeting was soon overtaken by subsequent events resulting in the formation of the NDIA Autism Advisory Group outline above, which importantly has provided an ongoing place for the Chairperson of the Advisory Board to engage with the senior management of the NDIA.

Also the Advisory Board's representation on the NDIA CEO Forum continues with Fiona.

### **The Asia Pacific Autism Conferences**

#### APAC 19

In 2017 the Board, which convenes the Asia Pacific Autism Conference, appointed the Autism Resource Centre in Singapore [ARC(S)] to host the Asia Pacific Autism Conference 2019 (APAC 19). This would be the first time an APAC conference was to be held off shore.

Planning for APAC 19 is now well advanced. The conference will be on 20 – 22 June 2019 at the Resorts World Sentosa, Singapore. The conference theme is *Thriving with Autism*. The Conference will be preceded by two days of Learning Journeys and Workshops on 18 – 19 June.

The Organising Committee for APAC 19 is chaired by Mrs Denise Phua, President of the ARC(S) and supported by Mrs Stephenie Khoo, the Deputy Executive Director of the ARC(S). Adrian Ford is the Australian Advisory Board on Autism Spectrum Disorders' representative on the Organising Committee.

The confirmed invited speakers include Patricia Howlin (UK), Peter Vermeulen (Belgium), Damian Milton (UK), Mark Brosnan (UK) and Christine Bigby (Australia).

The partner organisations working with the ARC(S) to support the conference are Autism Association (Singapore), AWWA, Rainbow Centre and St Andrew's Autism Centre.

The conference streams are *Physical Health & Well-Being, Lifelong Education & Learning, Social Relationships & Participation, Independence & Employment* and *Families & Autistic Individuals*. The call for papers closes on 17 December 2018 and applicants will be notified by the end of January 2019. Early Bird Registration for delegates closes on 15 March 2019.

#### APAC 21

In regard to future APAC conferences, the Board resolved that the aim of these conferences was for them to be accessible to practitioners and people in Australia while also developing opportunities for it to be held in the Asia-Pacific region. As a result it was resolved that every other APAC would be hosted in Australia. This meant APAC 2021 would be hosted in



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Australia while APAC 2023 would be open for tender to organisations both in and outside of Australia.

As a result of this decision, expressions of interests from member organisations of the Board were called for APAC 21, resulting in the decision that the host organisation for that conference would be the Autism Association of Western Australia.

### **Financial Health**

In 2018 the Advisory Board continues to maintain a solid financial position generating a surplus of \$10,413 from a turnover of \$49,496 with accumulated funds of \$121,246 on its balance sheet. It has been able to maintain its sustainability while still investing in the Australian Autism Alliance.

### **Conclusion**

My thanks to all members of the Board for their continuing support of the work of the Board and particularly my thanks go to Joan McKenna Kerr, the Deputy Chairperson and Terry Burke, CEO of Autism Tasmania who again carried the joint roles of Honorary Treasurer and Company Secretary. All the work undertaken by the directors is additional to their demanding permanent positions in their own organisations so their commitment to the Advisory Board is very much appreciated.

I have decided not to stand again as Chairperson having carried the role for four years. (This was also the second time I have been in this role after being chair from November 2006 to January 2010 when the governance of the organisation was significantly updated.)

The most significant development over the past four years for the Board has been its leadership in forming and supporting the development of the Australian Autism Alliance. The Board has become the backbone organisation for the new Alliance by providing financial and governance strength. The timeliness of the creation of this new organisation was seen in its capacity to effectively intervene with the NDIA earlier this year resulting in the formation of the NDIA Autism Advisory Group.

The other major development has been in the Board clarifying its role in relation to the APAC conferences. Its role has changed to that of the conference convenor which appoints the host organisation to run the conference in recognition of the reality that the host organisation takes all the risk in managing the conference. The Board has also simplified the fee to be paid by the host organisation by requiring an agreed upfront fee to be paid in two parts prior to the conference itself.

Both of these developments have been underpinned by the Board's reliable financial position after recovering from a \$79,000 loss in 2013- 2014. The decision to have upfront fees for hosts of APAC significantly strengthened the position of the Advisory Board. This and the ongoing careful management of funds has allowed for the responsible investment in the Alliance – which has become the one strong voice for autism in Australia.

Adrian Ford  
**Chairperson**

13 November 2018