



SIDE BY SIDE ADVOCACY ANNUAL REPORT 2016-2017

Side By Side Advocacy Incorporated
Shop 1, 30-32 Herbert Street West Ryde NSW 2122
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Vision

We envisage world where people with disability
are equal and valued;
where diversity is celebrated, needs are fulfilled
and opportunities realised.



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Statement of Purpose

Side By Side Advocacy promotes and upholds the rights, needs and interests of people with intellectual disability to enable full and meaningful participation in the community.



STATEMENT OF VALUES

1. Each person's life is of equal and inherent value and worth.
2. People with disability have the right to advocacy and to protection from devaluation, neglect, abuse and the denial of human rights.
3. People with disability have the right to be treated as individuals, and not in terms of their disability.
4. All people are entitled to comprehensive and appropriate support to ensure full inclusion into the community.
5. All people have the right to make decisions about their own lives.
6. All people should be treated with dignity and respect.
7. All people have the right to be safe, valued and accepted.
8. All people have the potential to grow and develop and should be provided with opportunities.
9. All people regardless of gender, age, ethnicity, sexuality or religion have the same human and legal rights.
10. People with disability are to be treated in accordance with the UN Convention on the Rights of Persons with Disabilities.



ABOUT SIDE BY SIDE ADVOCACY

Side By Side Advocacy Incorporated is a community based, not-for-profit organisation with the status of a charity. We are located at Shop 1, 30- 32 Herbert Street, West Ryde. We promote and uphold the rights, needs and interests of people with intellectual disability. We do this through advocacy. A voluntary management committee, known in the organisation as “the Board”, is responsible for the governance of the organisation. Our five members of staff, led by the Executive Officer, deliver two distinct advocacy programs, being individual advocacy and citizen advocacy. This is now joined by the Appeals Support to the AAT,

Side By Side Advocacy originated as **Citizen Advocacy Ryde-Hunter’s Hill** (CARHH) and our citizen advocacy program continues to operate in the local government areas of Ryde and Hunters Hill. In 1989 a steering committee was established to investigate the feasibility of setting up a citizen advocacy program to address the unmet needs of people with intellectual disability living in the Ryde and Hunter’s Hills local government areas. One of the driving forces of the steering was John Roarty, a resident of Weemala. He wrote forcefully about his experience of being institutionalised in his book *Captives of Care*. The steering committee was successful and the association, known as Citizen Advocacy Ryde Hunters Hill was incorporated in 1991.

In 2006 the constitution of CARHH was changed to enable the organisation to add a second model of advocacy. This form of advocacy is called Individual Advocacy and is delivered by members of staff, whom we call advocates. In 2006 we also changed our name to **Side By Side Advocacy**. Our name is significant on a number of levels. It is indicative of the structure of our organisation in that we have two distinct advocacy models working side by side. It is also reflective of our advocacy style as we work side by side with the people for whom we are advocating.

The **Citizen Advocacy Program** is offered in the Ryde and Hunter’s Hill local government areas. Our **Individual Advocacy Program** is available to people with intellectual disability who reside in the local government areas of Hornsby, Hunter’s Hill, Manly, Mosman, North Sydney, Lane Cove, Pittwater, Ryde, Warringah and Willoughby. We are funded by the Department of Social Services, and there is no cost to people who receive assistance from Side By Side Advocacy.



WHAT IS CITIZEN ADVOCACY?

The Citizen Advocacy movement originated in the USA in the 1970s and follows the principles of social role valorisation (SRV) enunciated by Wolf Wolfensberger (1972). SRV brings people with intellectual disability into the general community by recognising each individual's role as a valued member of society rather than categorising people because of their disability.

Our Citizen Advocacy program is available to people with intellectual disability in the Ryde and Hunter's Hill local government areas. Our Citizen Advocacy Coordinator finds vulnerable members of the community whose needs are not being met and recruits them into the Citizen Advocacy program. We call this person a *protégé*. The protégé is then matched with a caring, proactive person in the general community who becomes a citizen advocate. Together the protégé and the citizen advocate form a citizen advocacy match – a one to one freely given relationship that may last for many years. The function of Side By Side Advocacy is to make and support the match between a person with unmet needs and a caring person in the community, who freely gives their time in an unpaid capacity.

WHAT IS INDIVIDUAL ADVOCACY?

Individual Advocacy is provided by our experienced and qualified staff and focuses on the rights, needs and interests of our clients. Individual advocacy assists eligible people with one to support when they are facing challenging situations, dealing with uncertainty or being treated unfairly. Some examples include: problems at work, home or with neighbours; dealing with government departments; accessing educational opportunities; negotiating and navigating Guardianship and Public Trustee matters.

Priority is given according to the relative need of the person and considers factors such as physical and emotional harm, homelessness, incarceration, hunger, poverty, and vulnerability. Individual Advocacy is without cost and is available to people with intellectual disability that live in the local government areas of Hornsby, Hunter's Hill, Lane Cove, Manly, Mosman, North Sydney, Pittwater, Ryde, Warringah and Willoughby.

WHAT IS APPEALS SUPPORT AT THE AAT?

Appeals Support is provided by our staff (ASO) to ensure that the best possible case is presented to the Administrative Appeals Tribunal after internal reviews are exhausted.



CHAIRPERSON'S REPORT

I always find the task of writing this report to be a difficult one. It is challenging to describe in words the functions of the Board without sounding repetitive or tedious. As we go about our duties of governance, the tasks that we undertake and the way in which we carry them out are, on the whole, repetitive, predictable and cyclical. These qualities are necessary as we demonstrate due diligence and transparency in fulfilling our roles as voluntary members of the Board of Management. Our efforts and methods have again been effective, as demonstrated by the attached favourable financial report and our successful audit against the National Standards for Disability Services in September.

Similarly it is difficult to describe and celebrate the achievements of the organisation. Our two advocacy programs, Citizen Advocacy and Individual Advocacy, are held in high esteem in the community and within the disability sector. Our dedicated and professional members of staff work relentlessly to “promote and uphold the rights, needs and interests of people with disability”. Through the establishment of freely given relationships, or by addressing issue based advocacy matters, Side By Side Advocacy makes a significant and positive difference to the lives of people with intellectual disability. However, the need for advocacy only exists because people with disability continue to face abuse, neglect and discrimination. While we are proud of the way in which we deliver our advocacy programs, we will save our celebrations for the day when people with disability are able to lead “a good life” with appropriate supports and without barriers.

The most significant thing that has affected Side By Side Advocacy this year has been the roll out of the National Disability Insurance Scheme (NDIS) in our funded LGAs – and across Sydney. Like asking for pony for Christmas, the roll out of the NDIS has been a long in coming and eagerly anticipated. Making individual funding available to eligible people with disability to pay for “fair and reasonable supports to enable people with disability to achieve their goals” certainly sits well with the values of our organisation. However the “pony” has also brought with it some unanticipated responsibilities and some surprize negative consequences.

The resources of the Citizen Advocacy program have been stretched to the limit as Deb Maio supported program participants to negotiate the brave new world of the NDIS, in addition to her usual duties as Citizen Advocacy Coordinator. Deb, as always, has proved to an asset to the program and the organisation through her dedication, enthusiasm and passion. The Individual Advocacy program was also affected by the NDIS roll out, and by February we noticed a steady increase in the number of advocacy matters related to the NDIS. Our Individual Advocates, Sian Williams and Amanda Chui quickly gained the necessary skills and knowledge to enable them to advocate effectively on NDIS matters. After Amanda left in February, Preeti Thadani was appointed as an Individual Advocate. Her passion, dedication and attention details ensured that she fitted in well with the established team.



Side By Side Advocacy was approached by our funder to provide support to people with disability who wished to appeal a decision of an NDIS provider at the Administrative Appeals Tribunal (AAT). Deciding whether or not to accept this funding was perhaps the most importance and challenging decision the Board had to make this year. It certainly knocked us out of the realm of repetitive, predictable and cyclical. We had to consider such things as whether this role would be compliant with our constitution; how did it sit with our strategic plan; was the project in accordance with our values; would it have negative affects on our current programs and stakeholders; did we have the capacity to provide such supports; does the project dilute our advocacy..... or to name but a few. After much discussion, we decided to take on this funding and offer such support as a project of the organisation. We decided to “silo” the project and evaluate it in two years’ time. In this way we feel that we can offer support to people wishing to take an appeal to the AAT and protect the integrity of our current programs. After a rigorous recruitment process, Siam Williams was successful in being appointed as our first Appeals Support Officer. We have yet to fill the Individual Advocacy position she has thus vacated.

As well the consequences of the NDIS roll out, we have had two other major challenges to manage this year. Our EO, Gary Goodship experienced significant health issues this year. While we were obviously concerned for Gary’s health and well- being, his leadership and sound management of the organisation were sorely missed while he was on leave. His absences were managed through the dedication and selflessness of both staff and board members, who worked above and beyond to ensure that functions of the organisation continued without interruption to our clients and participants. I am very pleased to report Gary has returned to full heath, with his drive and passion for defending and upholding the rights, needs and interests of people with disability as robust as ever.

Our other challenge is the one I seem to write about on an annual basis – and that it is in regard to our largely futile attempts to grow our support base in the community. We continue to engage with the community through participation in such events as the Granny Smith Festival, City of Ryde Community Festival, and our annual cocktail party to celebrate International Day of People with Disability. We seek to publicise our purpose and being through our website and our newsletter. In spite of these things we continue to struggle to recruit new board members and new members of the association. This is a challenge that we will continue to address.

We were very happy indeed to welcome a new board member this year. Angela Talarico has been attending board meetings for a couple of years in a support role. We were delighted when Angela agreed to join the Board. As the mother of a person with disability she brings a lifetime of personal insight to this role. Steve MacDonald moved out of Sydney and so did not nominate for the Board this year. Steve started his relationship with Side By Side Advocacy as a volunteer in 2008, generously providing ITC support to the organisation. He joined the Board in 2012, and served as vice chair in 2014- 15, and 2015-16. We are very pleased that our relationship



with Steve will continue, as he we have engaged Steve to again provide ITC. Preeti Thadani's resignation from the Board was a bitter sweet. Preeti was a thoughtful and thorough board member and vice chair. However, she resigned from the Board to enable her to apply for a position on staff as an Individual Advocate.

You may have noticed how many times I have mentioned the word "challenge" when describing the past year, and may possibly wonder why a group of volunteers would take on such demanding and time consuming roles. Each and every member of the Board is passionate and dedicated to the purpose of the organisation, fulfils their duties with due diligence and more, and their lives according to our values. We do not shy away from robust discussion and do not always have the same point of view. However, we enjoy friendly, supportive, respectful and cooperative relationships as we work toward a common goal. It gives me great joy to be associated with this group and I am proud of the function that we serve and the way in which we operate.

Coralie Jensen
Chair
Side By Side Advocacy

COMMITTEE OF MANAGEMENT - "The Board"

CHAIRPERSON – CORALIE JENSEN

Coralie has a background in education and a passion for inclusion and social justice for people with disability. As a mother and carer of a person with disability, she gained firsthand knowledge and experience in advocacy. After eleven years as a volunteer to the organisation, Coralie joined the Committee of Management in 2003, and has served in the position of chairperson since 2007. Coralie has been deeply involved in the organisation of our events, quality assurance and in promoting and lobbying for the organisation and disability issues in general. Coralie continues her dedication to Side By Side Advocacy, as a living memorial to her son Finley.

VICE CHAIRPERSON - STEPHEN MACDONALD

Steve is originally from the UK and has lived and worked in Australia since 2004. He has 15 years' experience in various IT roles, including technical support, training and project management, and now provides IT support in the school system. Steve began volunteering with Side By Side Advocacy in February 2008, and became a board member in 2012. Steve was elected Vice Chair in 2014. Steve did not renominate for the board due to relocating



TREASURER – MICHAEL SLINN

Michael is a professional accountant. Without Michael and his commitment we would be poorer in many senses. Michael gives many hours to Side By Side Advocacy and is also active in other organisations, using his skills to help build better lives for people with disability and those who are disadvantaged. Michael and his wife live at Bullaburra in the Blue Mountains and have two children, two grandchildren, and two foster grandchildren.

SECRETARY – RUTH PERRAM

Ruth has a background in psychology and education. She retired in 2013 after a 22 year career as a high school teacher. Ruth has a strong sense of community and speaks up and out on various issues when she feels that justice is not being served. She is the mother of three adult daughters, loves travel and lives in Eastwood with her husband. Ruth was elected to the Board in 2013 and became secretary in 2014.

MEMBER – MICHELLE DONELLY

Michelle is one of the founding members of Citizen Advocacy Ryde-Hunter's Hill and has been actively involved in the organisation for over twenty years. Michelle ensures that people with disability are included as valuable members of society. She has an academic, professional and personal commitment to educating people about disability. Michelle has provided extensive SRV oriented training and assistance to staff.

MEMBER – FIONA GIVEN

Fiona joined the board of Side By Side Advocacy in November 2013. Since graduating from Macquarie University in 2004 in Arts Law, she has worked in a range of legal settings including as a paralegal and solicitor with the Crown Solicitors Office, and as a policy officer with the Australian Centre for Disability Law. Fiona is a person with cerebral palsy and complex communication needs and uses various forms of AAC and various other forms of assistive technologies. She is currently a part time member of the Guardianship Division of the NSW Civil and Administrative Tribunal. Fiona is passionate about protecting the rights of people with disability. She is the President of the AAC Voice, and sits on the board of the Independent Living Centre.

**MEMBER – ANGELA TALARICO**

Angela ,was born in Italy has lived in Australia for 50 yrs., she is the mother of 4 sons ,grandmother of 8,her young son has down syndrome, he’s 34 years old and lives in a l`Arche community, she has lived experience of disability.

Angela is passionate about people with disability living a good life, she originally joined SBSA as a volunteer supporter for 1year, she then joined the board as a member .

LIFE MEMBER – GEORGE GRAY

George is our only life member having served on the Board of Management for ten consecutive terms. He is a fine speechmaker and a consummate networker and has wide social contacts over the northern Sydney area. George also provides assistance in recruitment of staff as required. George lives in the Ryde area.



EXECUTIVE OFFICER'S REPORT

I must admit to somewhat of an advantage over Coralie when writing my report for our AGM , as I do get to read her report before commencing mine. For me personally the year has been very difficult health wise, and accordingly this did adversely affect our organisation at a very sensitive juncture for the people we support. We did get through the difficulties with superhuman effort from staff and board members, for which I am extremely grateful.

The complete rollout of NDIS has changed the focus of our Advocacy greatly from mainly housing issues to more complex family support related issues. This change in focus along with staff movements has certainly provided us with learning opportunities as both individuals and the organisation.

A further complication has been the offers to us and other National Disability Advocacy Program (NDAP) providers to “take on” the NDIS Appeals to the Administrative Appeals Tribunal (AAT) previously titled External Merits Review. After much soul searching and negotiation with Department of Social Services (DSS) the board decided to accept the offer and employ an additional staff member as NDIS Appeals Support Officer, Sian Williams (Individual Advocate) was quick to put in her application for the newly created position and was successful in her application. We were very fortunate to employ Preeti Thadani as an individual Advocate on Amanda’s leaving and Preeti’s resignation from the board, Preeti brings both strong qualifications and experience to the position while also being very much part of the local community.

We have been fortunate to have been able to recruit such formidable staff for each of our programs and hope to maintain this high level in recruiting for the vacant Individual Advocate position, and others into the future.

I would be very negligent to not mention the extra burden that the NDIS places on Advocates within our Citizen Advocacy program, and must reiterate that in many cases this is not what they signed up for, the level of complexity of the NDIS is often extremely confronting and confusing, Deb Maio spends much of her time now supporting the Advocates and Protégés through the hurdles and mazes presented by the NDIS, I must say she does it with great success alongside her CA coordination duties, obviously even the CA program will evolve into the future as the coordinator necessarily becomes more “hands on” in supporting relationship , this supports the longevity as some of our older relationship possibly would not withstand the additional impositions of the NDIS.

In closing I would once again like to thank the board and staff for their ongoing support in this year, a year that was mostly very trying but also very exciting to be a part of.

Gary Goodship
Executive Officer



STAFF

EXECUTIVE OFFICER – GARY GOODSHIP

Gary Joined Side By Side Advocacy in November of 2008 after a number of years working in senior roles within service provision for people with disability, across Greater Sydney. Gary has a passion for providing social justice to people living with intellectual disability, and certainly enjoys the variety of roles that he is able to enact on a daily basis within Side By Side Advocacy.

CITIZEN ADVOCACY COORDINATOR – DEB MAIO

Deb joined Side By Side Advocacy in May 2013. Her experience in disability is as a parent, guardian and professional. She has worked in both Individual Advocacy and in Citizen Advocacy and spent many years in the education sector working to provide equal access to mainstream education for students with disability. Deb values the opportunity to support advocates to speak up for people with disability their right to a full and inclusive life in their community.

INDIVIDUAL ADVOCATE – AMANDA CHUI

Amanda took up the position of Individual Advocate at Side By Side Advocacy in November 2013. She has always been passionate about the protection and promotion of human rights and is committed to her professional role in an area of human rights that is often overlooked. Amanda left us in February 2017

INDIVIDUAL ADVOCATE – SIAN WILLIAMS

Sian (pronounced SHARN), joined Side By Side Advocacy in April 2016. She is studying Law at Macquarie University. Sian has worked on the frontline of support in disability services and through this experience has developed the passionate view that people with disability should be provided with equal access to their communities.

INDIVIDUAL ADVOCATE – PREETI THADANI

Preeti joined the Board of Management in 2015. She has an extensive work background in Dispute Resolution. After resigning from the Board, Preeti commenced working as an Individual Advocate in March 2017. She is passionate about the protection and promotion of human rights and is committed to giving people with disabilities a 'fair go'. She has assisted other organisations and worked to help improve circumstances for disadvantaged people from CALD backgrounds. Preeti and her family have lived locally since 1979



FINANCIAL REPORTS

2016-2017



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