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Self-Advocacy and Inclusion
A Summary of the Study
'What can be Learned from Speaking Up over the Years'?

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Self-Advocacy and Inclusion – A Summary of the Study 'What can be learned from Speaking Up over the years'.

Self-advocacy literally means 'speaking up on one's own behalf' (Poetz, 2003). The independent self-advocacy movement aspires to 'work together for justice by helping each other take charge of our lives and fight discrimination' (Oregon People First 1991). It seeks to change the collective social position and experiences of people with intellectual disability in society through individual empowerment and participation in policy debates and campaigning (Ward, 1998; Hayden & Nelis, 2002; Goodley & Ramcharan, 2005). These aspirations suggest the potential significance of self-advocacy to achieving multiple dimensions of social inclusion through building social relationships, fostering participation in civic organisations and engaging in political structures and processes. However, there is little evidence in Australia or abroad about the impact of self-advocacy on the lives of people with intellectual disability or its contribution to their broader social inclusion.

Self-advocacy in Australia has been characterised by a trajectory of decline, government neglect and low levels of support and resources. This compares poorly to the expansion experienced in the UK and US during the 1990s and early 2000s. In Australia, only a handful of independent self-advocacy groups exist. When this study commenced in 2006, little was known about the development and activities of such groups. Indeed, there were only two published papers about Australian self-advocacy (Romeo, 1996, Bramley & Elkins, 1988).

This study, *Self-advocacy and inclusion: What can be learned from 'Speaking Up' over the years* was a collaboration between academics from La Trobe and RMIT Universities and members of Reinforce. Founded in 1980 Reinforce is the oldest self-advocacy group in Victoria. The group was interested in writing it's history, both to capture the organisation's achievements and see what might be learned from the past to ensure the group's future survival. Meanwhile, the academics wanted to explore links between self-advocacy and social inclusion, understand the relative underdevelopment of self-advocacy in Australia and put into practice inclusive research methods.

The collaboration lasted from 2006 until early 2014. For three of these years research was funded by a Linkage grant from the Australian Research Council, with cash and in kind contributions from the following Industry Partners: Reinforce, annecto, Jewish Care, St John of God Accord, Office of the Public Advocate and Office of the Senior Practitioner, DHS.

As the application stated, 'This research undertaken *with* self- advocates aims to examine the significance of self-advocacy in building the individual, social and political inclusion of people with intellectual disability'. The project had several strands: 1) investigation of the history of Reinforce, through interviews and document review using inclusive research methods; 2) examination of the impact of self-advocacy group membership on individual identity in Australia and the UK, through a PhD study that used constructivist grounded theory; 3) exploration of the life stories of self-advocates using oral history methods, and; 4) refinement of inclusive research methods through continuous reflection.

A final seminar and book launch for *Reinforce Self Advocacy: Speaking up over the years* in February 2014 marked the end of the study. The book tells the story of Reinforce in an accessible way with words and pictures. As Amanda Hiscoe wrote in the introduction;

> This book is about the history of Reinforce self-advocacy group in Melbourne, Victoria Australia…You will learn about this group and about self-advocacy when you read this book. We wanted to put this book together as a legacy of our work in self advocacy—this means we wanted to leave something behind for other people to learn from. Doing the history project was important for us, it gave us the chance to look at what we had done…We have gathered everything we could find—photos, papers, videos and talked to a lot of people who were involved, then we thought about what it all meant. The book gives a picture of self-advocacy past and present and will hopefully make people think about what the future will be. It was important to us that we did this properly, that is why it took so long and why we worked as a group to do it. As we have said "we are the history, we know it, we made it".

In addition to the book, findings from the study were presented by the self-advocates and academics – in various combinations – at more than 16 Australian and international conferences. Other outcomes include 4 published academic papers with several more papers still under review, a book chapter and a PhD thesis, Each of these publications details rich new knowledge about specific aspects of self-advocacy or inclusive research methods. This paper aims to provide an overview of the methods we used, and synthesise findings from the first three strands of the project by drawing out common themes about features of self-advocacy groups and their impact on individuals and broader society. Finally, this paper explores the implications of these themes in the context of the National Disability Strategy (Commonwealth of Australia, 2011) and reforms to the disability service system thorough the introduction of the NDIS (2013).

Overview of Methods

The study focused on the way that self-advocacy is experienced or perceived by its various stakeholders which includes self-advocates, supporters, and people who hold formal positions in organisations responsible for funding or policy making. The study was situated within a theoretical paradigm of social constructionism and qualitative methods were used in each strand to collect and analyse data from documents as well as open ended interviews.

The history of Reinforce

The History Group, comprising 5 self-advocates and 3 academics, studied the history of Reinforce. We used an approach framed as 'a collaborative group method' (Bigby, Frawley & Ramcharan, 2014) that adapted methods of interviewing and analysis to take account of the strengths of different group members. The group shared the research tasks and met regularly together to review progress, conduct interviews and discuss data. The academic members also met separately to reflect on strategies for ensuring the inclusion of self-advocates and to plan the study.

Sixteen past paid workers and unpaid supporters of Reinforce, three government officers involved in decisions about self-advocacy funding, and twelve Reinforce members shared their perspectives about Reinforce and self-advocacy. They were recruited through a reunion held in 2007 and participated in semi-structured interviews conducted jointly by history group members. A book depicting the 'Key Moments' of Reinforce was used in the twenty-seven interviews to prompt reminiscences about self-advocacy. Interviews often took the form of a dialogue as self-advocate history group members responded to interviewees with their own memories. In addition over 200 documents such as committee of management minutes, project and annual reports were reviewed (see Frawley & Bigby, 2015; Henderson & Bigby, under review for more details).

Data were analysed inductively, first by the academics who used coding and constant comparison to develop abstract conceptual categories. Later themes were discussed with self-advocate history group members, which often led to further data as they reflected on the initial findings. The initial findings were then tested and refined through presentations at several self-advocacy conferences.

Sian Anderson's PhD study "We just help them, be them really" Building positive, included identities: engagement in self advocacy groups by adults with an intellectual disability

This strand sought to compare the experiences of self-advocates in the UK and Australia and

consider the effects of self advocacy group membership on social identity. Participants were ten paid supporters and 24 self-advocates from four independent self-advocacy groups in the UK, two from Australia, and three experienced commentators on self-advocacy from the UK. All the groups were self-governing but varied in size, location and accessibility to resources in the form of paid support work and operational funding (further details see Anderson, 2013; Anderson & Bigby, under review).

Through semi-structured interviews, self-advocates talked about the kinds of activities in their group and outlined the highlights of their experiences. Supporters were asked similar questions about the activities of the group as well as about the type of support they provided. Grounded Theory methods (Charmaz, 2006) were used to analyse the interview transcripts and to develop a model of the ways in which self-advocacy groups work to build more positive social identities for people with intellectual disabilities.

Life stories

The life story work was conducted by a historian using oral history methods and built on the life story work undertaken by Dorothy Atkinson (1987). Each of the history group self-advocate members and the president of Reinforce (at that time) met several times over an extended period with the historian and decided upon the aspects of their lives they wished to explore. Their stories were written by the historian and reviewed by self-advocates before each one was published in book form. The process of generating each individual's life story and the role of the historian were made explicit to avoid the invisibility of the writer, which is often a feature of this type of life story work (see Henderson & Bigby under review for full details and reflection on this method).

Main Themes from the Study

The history group delved deeply into one Australian self-advocacy group and the PhD study explored the experiences of self-advocates from six groups from Australia and the UK. Meanwhile the life story work explored the lives of six Australian self-advocates. Despite the differing perspectives of each enquiry, similar themes echo across the study.

Self-advocacy Groups – Places of Owned and Controlled by Self Advocates

Self-advocacy groups are places where people with intellectual disability feel they belong and have a strong sense of ownership and control. They are real rather than virtual places that usually include office spaces where members spend time together working on the business of the group. A core group of members are in these offices regularly and are heavily involved in

paid and unpaid work. The atmosphere is one of collegiality, where people with intellectual disability are free to be themselves and feel respected. In the case of all the independent groups in this study, group members controlled each organization through an elected committee of management that was made up solely of people with intellectual disability. Holding an elected office was valued within groups, bringing status and power to members.

Members join and attend groups on their own terms. There is no compulsion and no eligibility assessments. There are, however, expectations about behaviour which are agreed upon collectively and hold sanctions if transgressed. Many members are longstanding, while others come and go over shorter periods. Some groups are so popular that members are encouraged not to stay too long or sub-groups are formed to expand opportunities for participation.

Members rely on paid staff or unpaid supporters to scaffold their participation in the group and manage certain aspects of internal operations and external relationships. There is however, a strong sense of equity between supporters and group members, which is different from the social distance often found between staff and people with intellectual disability in disability services.

Self-advocacy Groups – Places of Activity and Opportunity

Self-advocacy groups support their members to participate in a broad spectrum of activities. The types of activities are broadly similar across all groups although scope and scale depends on the size of the group and it's resources. Some groups are internally focused, concerned with governance such as committee work or managing the organization. Many groups run educational sessions for members about anything from intimate relationships to pet care. Most groups conduct 'speak out' sessions where members can gain confidence in sharing experiences and talking about issues in their lives. Other activities are externally focused and involve members running community education and training programs for schools, professional groups or mainstream services to raise awareness about intellectual disability. Some groups are more political than others. These groups are more involved in representing the interests of people with intellectual disability on advisory committees or reference groups. They consult with government bodies or lobby and campaign about specific issues. Specific projects involve research, developing training packages, making audio-visual materials and speaking at conferences.

Activities vary over time and are often shaped by external agendas and the availability

of funding for specific projects. For example, the activities of Reinforce during the 1980s and 90s might be considered more radical and externally focused than in recent times. By contrast, in the UK, the Valuing People policies of the 2000's offered significant opportunities for self-advocacy groups to be involved in community education and representation on consultative bodies.

Participating in the activities of self-advocacy groups created many opportunities for change in the lives of self-advocates such as: developing skills and self-confidence, having fun and new experiences, travelling to different places, and participating in meaningful paid or volunteer work. Being part of a group often meant that self-advocates made friends with other members in the group as well as acquaintances outside the group with people in other self-advocacy groups or the broader advocacy and disability sectors.

Self-advocacy Groups - Promoting Positive Identities and Individual Social Inclusion

For the participants in this study, membership of a self-advocacy group has extended their horizons. Membership has also led to greater self-confidence and engagement with the community outside the narrow and often segregated world of disability services. For some members, participation in self-advocacy has changed their self-perception and become a catalyst for new and more positive identities. Most common among these was an identity as a self-advocate; and significantly not as a person with intellectual disability but rather an 'expert' about intellectual disability in the eyes of others. Some people who held management committee positions, or worked on projects, in the office or as a community educators took on the persona of workers or people with a business like identity. For others being a self-advocate became their occupation. Though less common, some self-advocates took on identities as independent people who lived – with friends or partners – away from their parents.

Through group membership, self-advocates became involved in civic society and political activities often in partnership with other organisations with different constituencies who have similar interests in social justice and social change. They became people who contributed to the community as well as people who received support.

Self-advocacy Groups – Creating More Inclusive Communities

Self-advocacy groups have been influential in changing the lives of their individual members and also furthered the social inclusion of people with intellectual disability. This is no longer so much through the radical social action, such as squats and campaigns that characterised the

early years of Reinforce. Rather, more recently, it has been through positive imagery and the demonstration that people with intellectual disability are adults and citizens, and through increasing their visibility in the community and illustrating the roles they can play. As Anderson and Bigby (in press) wrote;

> It seems likely that creating opportunities for individuals to change the way they perceive themselves will have spillover effects in changing the way they are perceived in the broader community and that that will lead, over time to a breaking down of some of the negativity and stigma surrounding the intellectual disability identity. Self-advocacy groups have a vital role to play in facilitating this important process.

By their very existence, self-advocacy groups create a source of expertise and a readymade pool of volunteers with information about discrimination, the aspirations of people with intellectual disability and their lived experiences that others may draw upon. The existence of self-advocacy groups has contributed to expectations that governments and others would consult with people with intellectual disability and include them as representatives on reference and advisory groups. For example, members of Reinforce have been invited to become representatives of such groups, such as the appointment of David Banfield to the first National Disability Advisory Council in 1983. How influential self-advocates have been on these bodies, and whether their contribution has been symbolic rather than meaningful is difficult to ascertain. Indeed there are some examples where the available support enabled little more than a presence at the table. Nevertheless, self-advocacy groups have certainly been a part of the broad powerful coalitions for social change, which have in turn influenced governments and social policy.

Sources of Strength – Relationships, Commitment and Supporters

Commitment to self-advocacy and strong relationships between members, and alliances between groups and supporters have been significant sources of strength for self-advocacy organisations. In Reinforce for example, shared experiences and friendships among the small core group have given the organisation a sense of continuity and secured its existence through internal and external political upheavals. Reinforce owes its inception in the early 1980s to beliefs of parent advocates and young professionals in social justice and their commitment to creating ways to release the inherent power of people with intellectual disability speaking out about their experiences.

The continuing importance of external relationships was evident in the range of

partnerships that groups had with other organisations that facilitated funding, and helped to secure contracts and invitations to collaborate on projects. For example, some UK groups have established strong relationships with local government partnership boards. Meanwhile, the links Reinforce has built with philanthropic bodies and senior bureaucrats, who hold power and the purse strings, has served the organisation well over the years. Philanthropy has been a significant source of funding for Reinforce. Meanwhile co-location with other small social justice focused organisations has helped many groups establish supportive partnerships.

Support from paid staff or supporters to scaffold the participation of people with intellectual disability is critical to the operation, strategic planning, and good governance of self advocacy groups. Many groups have paid staff who work for them and provide day to day support for operations. Just as importantly, these supporters lead strategic planning to help secure the funds that keep the group solvent. The type of facilitative and organisational work supporters do is highly skilled but often poorly paid. And more often than not, such supporters are employed on a part time or casual basis. Like funding for self advocacy groups, the employment of support staff is usually structured around short term contracts. Notably, funding for paid support staff varies quite significantly between self advocacy groups, though generally it remains at a lower level in Australian than in the UK.

The impact of limited or ineffectual support was evident in some groups by the degree of dis-organisation in offices, problems with disseminating final products from their projects, internal conflict and low morale. We also uncovered evidence of how vulnerable some groups are to exploitation by paid staff who hold a lot of power but are subject to limited oversight. In this respect, alliances with other organisations that can offer some measure of independent support with finances and bookkeeping have proven valuable.

Much of the support for self-advocacy groups has come from the good will of others in the form of time and resources donated by, or borrowed from other organisations such as parent advocacy groups, universities and government or disability services. One of the problems associated with such an ad hoc arrangement is the uncertain and serendipitous nature of this type of support. And in recent years this type of support has been harder to find as organisations everywhere strive for greater accountability.

Self-advocacy groups have also been strengthened by the opportunities available for members to join representative bodies or be part of consultations. These opportunities have,

for the most part, come about due to the growing expectation that public bodies and government include people with intellectual disability as members of civic society. However, the support for such endeavours has often been too thinly stretched to encourage meaningful participation.

Challenges for Self-advocacy – An Uncertain Place in Policy and Reliance on Support

In the UK and Australia, self-advocacy groups have occupied an uncertain place in the eyes of successive governments, which have, for the most part failed to fully grasp the value and purpose of such groups. Exacerbating the problem is the fact that government perceptions of self-advocacy have changed over time. For example, in the 1984 report of the Victorian Committee on the Legislative Framework for Services to People with Intellectual Disabilities self-advocacy was included with advocacy, which it said required independent funding;

> provision should also be made for the funding of advocacy organisations...they will need funding and independence from government and other providers....The funding should have few conditions and advocacy organisations should not be subject to the degree of regulation specified for service agencies (Rimmer, 1984 p. 78).

By contrast, the 1988 report on a Ten Year State Plan for Intellectual Disability Services cast Reinforce as a community education program and suggested it should be funded along with other specialised resources in the community such as the Social Biology Centre (Neilson, 1988). From 1992 responsibility for advocacy and self-advocacy has been shared between states and the commonwealth under the various iterations of the Commonwealth State Disability Agreement. The advocacy program funded by the Commonwealth has been reviewed numerous times in search of guidelines and outcome measures. The state program on which Reinforce has relied has been subject to similar vagaries, primarily through changes of government and constant re-organisation of funding responsibility.

The ability of self advocacy groups to secure and adequate funding has had deleterious consequences on groups of people with intellectual disability who rely on skilled support to navigate complex social environments. For instance, over the thirty years of its existence Reinforce has expended significant energy securing small amounts of funding on an ad hoc basis. Uncertain funding renders self-advocacy groups vulnerable to being used to serve the agendas of others. As one of the founding members, the late David Banfield explained: 'to a certain extent [the Department of] Community Services have possibly used Reinforce over the years for different things'. It was a simple statement that probably means

more than one thing. First, it may mean that Reinforce has been used symbolically by governments, enabling them to tick the box of consultation or representation when in fact something more tokenistic took place. Second, it may mean that one off funds offered at the end of a financial year has allowed the government to set its own agenda for Reinforce. Indeed, there is little doubt that in providing funds to undertake specific projects (determined by the needs of the Department or the ideas of its bureaucrats rather than Reinforce) the government has, at times, diverted energy away from Reinforce's own priorities. In a similar way, ad hoc and limited funding has at times meant that simply 'keeping the door open' has consumed the organisation's energies. Even some attempts by governments to strengthen self-advocacy have inadvertently misfired. For example, the attempts to establish a People First Resource Centre in 1986, actually weakened Reinforce by dividing members' time and loyalties and drawing skilled self-advocates away from the grassroots organisation.

Implications for Self-advocacy in the Future

This study has demonstrated the significant contribution that self-advocacy groups make to the social inclusion of individual members and in furthering the inclusive capacity of communities. Self-advocacy groups are hybrid organisations with few parallels.

- They are not simply about advocacy - standing up for the right of their members or supporting people to speak up and stand up for their own rights.
- They are not simply peer support or self-help groups – sharing experiences of occupying a common social position and fostering the emotional growth, skills and well-being of members.
- They are not simply one of the many clubs or societies that make up civic society and constitute the glue that binds communities together - offering membership to those with common interests or shared passions, opportunities to meet people and make friends and a sense of belonging and participation in meaningful activities.

Self-advocacy groups do all of these things well and they are fundamentally important to the social inclusion of people with intellectual disability. They have the potential to transform individuals' lives and contribute to social change in society. Based on rich qualitative data from a small number of groups, this study has provided the evidence for these claims.

Independent self-advocacy groups are run by and for people with intellectual disability. They are governed by committees of people with intellectual disability rather than mixed boards of professionals and family members. They find it hard to be self-sustaining,

despite at times being able to charge fees for training and community education services. And in order to function successfully, self-advocacy groups require skilled support. Perhaps unsurprisingly, only a small number of self-advocacy groups in Australia have managed to survive the indifference of governments and the serendipitous and ad hoc funding regime to which they have been subjected.

Self-advocacy organisations are participatory, and rely on the availability of sufficient roles or tasks so that all members have the opportunity to participate. In an organisation like Reinforce, which is small and close knit, it has been difficult to accommodate new members without displacing others. Well intentioned suggestions by others about growth or membership renewal have held inherent dangers in destabilising of groups. Moreover, much energy has been wasted on attracting new members who find it difficult to break into tightknit groups. With this in mind, and drawing on the experience in the UK, it would seem that a large number small, though networked groups is preferable to a small number of large groups.

By uncovering the history of self-advocacy and its significance in achieving social inclusion, this study has highlighted it's potential roles into a future where significant reform of the disability service system and Australian society is envisaged by the National Disability Insurance Scheme (NDIS) (2013) and the National Disability Strategy (NDS) (Commonwealth of Australia, 2011). The challenge will be to develop ways of providing continuity of skilled support to existing self-advocacy groups and seeding the development of new ones. Both the NDIS and NDS have outlined, in their aims, a commitment to building more inclusive communities and to developing the social networks and inclusion of people with disabilities. If, as this study suggests, self-advocacy groups are a means of facilitating the achievement of such aims for people with intellectual disability, the question is where they fit and how they can be supported as part of the NDIS. Recognising the evolutionary nature of the NDIS, at present there are many possibilities to secure the future of self-advocacy groups.

The most problematic possibility is for self-advocacy groups to adopt a user pays model. This might be feasible, if members or potential members were eligible for an individualised funding package (IFP) under tier 3 of the NDIS, and funds for community participation were included in the package. But this type of funding may be too unstable and variable over time to ensure continuity of support for good self-governance and of the group's activities. A user pays model where members become consumers may dramatically

change the key characteristics of self-advocacy groups by undermining their collegiality and the members' sense of ownership and control. It is also likely that not all self-advocacy members or potential members will be eligible for IFP's and they will therefore be unable to fund their own membership.

Tier 2 of the NDIS, now reframed as Information, Linkages and Capacity Building (ILC) holds more promising possibilities for self-advocacy groups to flourish in the future. Applicable to all people with disabilities and their families, the proposed purpose of ILC is to invest in capacity building that sustains and 'strengthens informal support and promotes social and economic inclusion for people with disability' and ensures societal change (Department of Social Services, 2015). Self-advocacy groups readily fit this purpose by doing many of the things that ILC aims to achieve, aligning well with all five of the suggested streams. For example,

> Stream one; Information, linkage and referrals - self-advocacy groups provide peer support and education for people with intellectual disabilities;

> Stream two; Capacity building for mainstream services - self-advocacy groups provide community education to a wide range of organisations in the community and participate in teaching programs for professionals and others about the lived experiences of intellectual disability;

> Stream three; Community awareness and capacity building - self-advocacy groups provide opportunities for social and civic participation of people with intellectual disability benefitting both individuals by building identity and social networks but also increasing their visibility in the community as citizens playing valued roles, contributing to changed social attitudes;

> Stream four, Individual capacity building - self-advocacy groups provide peer support, friendship, skills develop and meaningful occupation for people with intellectual disability;

> Stream five, Local area co-ordination - self-advocacy groups play many of the anticipated functions to be carried out local area coordinators, especially building social networks and connections for people with disability with each other and other members of the community.

The ILC appears to hold considerable promise for future funding of self-advocacy groups if existing and embryonic groups are able to gain sufficient support to prosecute their case for

funding. It will be important for bodies such as NDIA, DSS, State or local governments to reach out to groups and support applications, remembering that self-advocacy groups are small and local. Self-advocacy groups are not services and do not have the corporate infrastructure to respond quickly to opportunities or compete well for funding. In this time of significant change, government must recognise the contribution of self-advocacy groups to its own agenda for the social inclusion and participation of people with intellectual disability. Just as the passion and commitment to social change of professionals and others supported the development of the first self-advocacy groups in the 1980s, it may now be time to muster the support of powerful allies, such as the Industry Partners in this study, to secure a place with the new policy regime which will enable it to flourish and contribute to the transformation of people's lives.

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