

Miriam Stevenson, March 2010

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***Flexible and responsive research: Developing Rights-based Emancipatory Disability Research methodology in collaboration with young adults who have Down syndrome.***

*Abstract*

*This paper examines the development of the Emancipatory Disability Research (EDR) paradigm; principles defined by various groups and authors within the disability movement which are intended to ensure the integrity of disability research design and practice. It is argued that these principles are commensurate with the tenets underpinning the United Nations Convention on the Rights of Persons with Disabilities (2008). The paper then relates the principles of EDR to participatory research involving people with an intellectual disability, drawing both on existing studies and the author's ongoing research project which is conducted in partnership with young adults with Down syndrome and other key stakeholders.*

*The author advocates for the ongoing development and adaptation of the EDR 'model' in respect of people with an intellectual disability. This requires the academic researcher to embrace their position as a Human Rights activist, and render the research process flexible and continuously open to diverse forms of participation by co-researchers who have an intellectual disability, if they are to influence the research process and outcomes and their voices are to be heard.*

***Introduction***

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*The methodology of disability research and, in particular, research involving people with an intellectual disability, raises vital philosophical, political and practical issues. As a non-disabled researcher; what is the moral justification in my undertaking this work? What 'standpoint', framework and principles if any, can guide me? How can I ensure participation in formulating research questions, gathering and analyzing data and presentation of findings? What conclusions can those with a disability draw and how can they and society benefit? The purpose of this paper is to explore, the United Nations Convention on the Rights of Persons with Disabilities (which entered into force in May 2008), the Social Model of disability, the Emancipatory Disability Research (EDR) paradigm and the work of other critical researchers in relation to how these might guide the position and practice of the non-disabled researcher and effective inclusion of people with an intellectual disability in the research process. In so doing, I also reflect on experiences from my own research journey alongside young adults with Down syndrome.*

### **The language of disability**

Before I begin, an important note about terminology; the language of disability is always complex, controversial and constantly evolving. There are global and cultural preferences to be considered and respected. The term 'people (or person) with an intellectual disability' will be used here as the term chosen by Australian self-advocacy groups, despite some inconsistency with the social model of disability (UPIAS, 1976; Oliver, 1998).<sup>1</sup> In addition, inclusive research itself has 'spawned a new language' and diverse terms have been used to describe inclusive researchers (whether they have a disability or not) and those who would have been 'subjects' in non-inclusive research (Walmsley, 2004). For the purposes of this paper, and aligned with the perspective I develop, I refer to inclusive researchers as 'non-disabled researchers' and people who might have been research subjects as 'co-researchers'.

### **The Rights of People with an Intellectual Disability to be Researchers**

Rather than ask the question “Can I research people with an intellectual disability?” it is better to start with a justification as to “Why?” Personally, I have always enjoyed working with people with an intellectual disability because I find their perspectives and insights very interesting and those people with an intellectual disability I have come to know well over the years have struck me as remarkably intuitive. However, there is a moral justification for why I might involve them in research. The United Nations Universal Declaration of Human Rights (1948) is designed to benchmark standards, entitlements and codes of behaviour by which we should be treated as human beings. Human Rights do not deny individual and cultural differences; rather, they assert inherent entitlements due to all of us, regardless of such differences, by mere fact that we are human. Our basic Rights, therefore, should be unassailable in the face of cultural and individual differences. What logically follows is less frequently discussed but equally as important; a Human Rights framework bestows a means of perceiving and relating to other people which dignifies us as humane and requires us to value others as equal to ourselves, regardless of any mutual differences. The universalism of Human Rights means that rights advocacy for one person’s Human Rights is, in effect, advocacy for everyone’s Rights and vice versa.

The rationale for Human Rights is a vital discourse and, as a consequence, has been the subject of extensive debate for centuries. Post-Kantian philosophers such as Gewirth (1981) use deductive logic to cogently argue that ‘absolute rights’ exist. This means certain basic moral rights, namely, ‘the rights to freedom and well-being’ are necessary for human agency. Such Rights cannot be culturally ‘relative’ and are non-negotiable. Other authors such as Ife (2001) do not wholly support this view and hold that Human Rights ‘are not static’ and will ‘change over time’. For the purposes

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of this paper however, I apply the United Nations Universal Declaration of Human Rights (1948) and the United Nations Convention of the Rights of Persons with Disabilities (2008). I hold that such Rights are global, universal, enduring and, ideally, should underpin the agency of all people (with or without a disability) in all social spheres and activities, including research.

The assertion of the 'non-negotiability' and reciprocity of basic Human Rights is critical, particularly for disadvantaged and marginalized social groups. In the history of Human Rights violations, there are few social groups who have endured the discrimination and abuse as have people with an intellectual disability. Eugenics, sterilization programs (Kempton & Khan 1991; Hubbard, 2006) and forced institutionalization have been widely perpetrated upon this group, often justified in the name of 'welfarist' paternalism (Ramcharan, 2006). In the face of this history, the need for ongoing resistance to the oppression and devaluation of people with an intellectual disability, and in advocating for their social inclusion and equality, clear Rights instruments are required. The United Nations Convention on the Rights of Persons with Disabilities confers no new Rights but was passed due to the delayed recognition of the Human Rights of people with disabilities relative to other disadvantaged groups. The 'guiding principles' of the Convention emphasise respect for dignity, autonomy, independence of persons, non-discrimination, full participation and inclusion in society, respect for difference and acceptance of human diversity, equality of opportunity, accessibility, gender equality, respect for the right of children with disabilities to preserve their identities and for their 'evolving capacities' to be respected (UN Enable website, Guiding Principles of the Convention).

It is evident that the existence of human and civil rights alone cannot ensure inclusion and equality for people with intellectual disabilities. Whilst we might try to address their social disadvantage

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through legislation, regulation and positive rights (positive discrimination), this tends to progress no further than providing an agenda aimed at meeting the basic needs of people with an intellectual disability and protecting them from harm (Young & Quibell, 2000). A variety of 'enabling' strategies are required to progress inclusion. One avenue of determining the best strategies to use is to involve people with an intellectual disability about matters which concern them through research.

### **The characteristics of the 'activist' social researcher**

If you come here to help me, you're wasting your time. If you come here because your liberation is bound up with mine, then let's work together.

Lilla Watson

Australian Aboriginal Organiser, Academic and Visual Artist

Having recognised that Rights advocacy is not about charity or benevolence but legitimate activity designed to preserve the dignity of humanity, we need to ask; "What makes an activist researcher?" We have established that a Human Rights perspective orients disability researchers towards an activist approach; but, how do we further define this position and how do we determine a grounded and credible model of engagement?

Healy (1996) gives us a useful starting point when she explicates the concept of 'activist social work' and identifies four defining strategies for 'change orientated' social work. My additions (in italics) render this typology congruent with features of the "activist researcher":

- a) A commitment to standing alongside oppressed and impoverished populations  
(Leonard, 1994, p.17)

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- b) The establishment of practice relations in which workers/researchers and clients/ co-researchers work as co-participants engaged with and still distinct from one another (Fine, 1992, p. 220)
- c) The worker/researcher adopts a self-reflexive and critical stance (Fine, 1992, p. 220) in that the worker/researcher is alert to those barriers within the practice/research context and beyond that which serve to disadvantage clients/co-researchers and deny possibilities for dialogue between workers/researchers and participants/co-researchers (Leonard, 1994, pp.10-15)
- d) A commitment to the 'study of change, the move towards change and the provocation of change' (Fine, 1992, p. 220). In particular this involves an orientation to the transformation of those processes and structures that perpetuate domination and exploitation (Leonard, 1994,p.17; Yeatman, 1994, p. 9)

Healy's third point concerning 'disadvantaging barriers' leads the non-disabled researcher strongly in the direction of the social model of disability, (UPIAS, 1976: Oliver, 1990) and the emancipatory disability research paradigm ( Oliver, 1992; Barnes, 2001); both of which have been largely developed by people with a disability and have enormous credibility and impact globally. Given the subject matter under discussion it is instructive to clearly explicate these at this stage.

### **The Social Model of Disability**

The social model of disability has been in existence for over three decades. It was developed from a structural perspective and argues that 'disability' is socially constructed. This model asserts that it

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is not impairment which disables a person but the social and economic exclusions which people with impairments face in societies, (UPIAS, 1976; Finkelstein, 1980; Oliver, 1983; 1990; 1996). Therefore the social model of disability more specifically defines impairment and disability as a twofold classification:

Impairment: lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body;

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of activities (UPIAS, 1976, pp.3-4).

The social model has been criticised generally for its neglect of the very real impact of impairment (Morris, 1991, French 1993 and Crow, 1992); its simplistic separation of the impairment (medical) from disability (social); the subsequent denial of the complexity of the lived experience of individuals with a disability, and the impossibility of a “barrier-free utopia” (Shakespeare, 2006 pp. 200-201). However, the above definition does not deny the impact and individual complexities of impairment. There is scope within the social model for discussion and exploration of these issues which Thomas (1999) refers to as ‘impairment effects’. The personal narratives of individuals have inherent value and validity whether impairment is present or not. The lens of the social model (i.e. the cultural, historical and material context of individual experience) can only enrich the analysis of experience (Barnes, 2001). Criticism of the social model on the basis of a supposed ideal of a ‘barrier free utopia’ seems unfair. Would we criticise a Human Rights model on the basis that its utopian ideal would be a world where no-one’s rights were ever violated? As we all know, an ideal is typically on an ever-receding horizon.

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The strength of the social model is that it seeks to overturn medical and individualized models of disability which perpetuate a focus on the deficits of disabled people and the 'personal tragedy' brought about by their impairments. Its logic can be easily understood, interpreted and applied by both academics and non-academics alike. If the worth of any political model can be measured by its influence in the broader community, the social model has undoubtedly had the most impact (Barnes, 2001). It has been used in anti-discriminatory legislation (Disability Discrimination Act, UK, 1995) and has influenced the World Health Organisation to develop an International classification of Functioning, Disability and Health (WHO, 2001) to replace its individualistic and discredited antecedent: the WHO International Classification of Impairment, Disability and Handicap (Wood, 1981).

Whilst writers such as Finkelstein (2002) have asserted that the social model is not a rights model, I would argue that one underlying epistemological assumption of the social model of disability, or certainly its strategic use, is that all people, including people with impairments, are complete people, of equal value as human beings and have Human Rights. This universalistic presupposition is essential to the radical project of the social model otherwise there would be no basis for resistance against 'disabling' cultures and practices, or reason to assert that discrimination on the grounds of impairment is unacceptable. The fact that the social model has been so widely recognised and applied also resonates with global 'civil rights' agendas. Its influence is again evidenced in the United Nations Convention (2008) which supports a global 'paradigm shift' in attitudes and approaches to people with disabilities and advocates:

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[a movement away from] viewing persons with disabilities as “objects” of charity, medical treatment and social protection towards viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on free and informed consent as well as being active members of society (UN Enable website, Convention on the Rights of Persons with Disabilities section, para. 2).

Oliver (2004) described the social model as a ‘practical tool’ and as such it has proved an important vector for the realisation of Human Rights on many levels. The UN Convention 2008 similarly declares itself as a “Human Rights instrument with an explicit, social development dimension” (UN Enable website, The Convention in Brief section, para. 3). Though academic debate will no doubt continue, for an activist researcher, there is little tangible to gain from a ‘disarticulation’ of the social model from Human Rights advocacy.

### **The Emancipatory Disability Research model: critique, defence, development**

The social model forms an important cornerstone of Emancipatory Disability Research (EDR), which began to develop in the 1980s as researchers with a disability and non-disabled researchers began to draw on people’s own experiences of disability to illustrate the complexity of the process of disablement with reference to environmental and social forces (Barnes, 2001). This research paradigm emerged alongside the research and writing of critical theorists, black writers and feminists who aligned themselves with oppressed groups (Truman, Mertens, & Humphries, 2000). Different forms of research based around social power-sharing such as Participatory Action Research (Friere, 1970; Fals-Borda & Rahman, 1991) gathered momentum and credibility. It is of note once more that Healy’s (1996) typology is reflected in the social/historical preconditions of this

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paradigm, linking oppression and activist workers/researchers/writers to the development of liberationist research models.

The emancipatory disability research paradigm was identified in 1991 in a set of seminars funded by the Rowntree Foundation. Presentations from the seminars were published in the *Disability, Handicap and Society* (now 'Disability and Society'), Special Issue; 'Research Disability' 1992 (C. Barnes, personal communication, 21<sup>st</sup> October 2009). Barnes (2001) reiterates seven emergent core principles which can be summarised as follows:

- Control: Unlike conventional approaches, (EDR) must fully involve disabled people throughout the research process. Non-disabled researchers may be involved but they must be accountable throughout the entire research process to a research advisory group or committee controlled and run by disabled people.
- Accountability: Research processes and practices must be open and explained to research participants and participating organisations. The findings and implications of research must be disseminated in appropriate formats to all relevant audiences, including disabled people.
- Practical outcomes: EDR must attempt to leave disabled people in a better position to confront the disabling barriers in their lives and must not exploit their experiences for career benefits to researchers. EDR should produce knowledge, understanding and information that will have some meaningful practical outcomes for disabled people in their struggles to overcome the barriers they face in disabling societies.
- The social model of disability: EDR should adhere to the social model of disability. This reflects the growing demand by disabled people for a more holistic approach to the problems

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commonly associated with disability. EDR focuses on the economic, environmental and cultural barriers encountered by disabled people and their families.

- The 'problem of objectivity' and need for methodological rigour: Researchers must ensure that they openly state their ontological and epistemological position and their choice of research methodology and data collection strategies must be logical, rigorous and open to public and academic scrutiny.
- The choice of methods: Whilst EDR has generally been associated with qualitative rather than quantitative data collection strategies; the choice of methods must adequately reflect the needs of the project concerned and the wishes of disabled people.
- The Role of experience: Discussions of disabled people's experiences, narratives and stories should be couched firmly within an environmental and cultural context in order to highlight the disabling consequences of societies increasingly organised around the needs of a mythical, affluent non-disabled majority (Adapted from Barnes, 2001; BCDP website, 2007).

Barnes (2001) explains EDR as a dynamic process so there is no suggestion that the above model is written on a tablet of stone and cannot be further developed. Fundamentally, however, researchers must explicitly represent the politics and practice of their research activity. Critically, disability research methods need to be reconstructed to bring about a shift in the 'social relations' of disability research production and not replicate and perpetuate the oppression of people with a disability (Oliver, 1998).

The EDR model presents a very clear set of principles, which can not only be used as a guide to ensure (or at least improve) the integrity of disability research production but also assist in determining its validity and trustworthiness. Taken at 'face value', however, EDR presents

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'compliance' issues for independent research production and control by many people who have an intellectual disability and also for non-disabled researchers seeking to involve people with an intellectual disability. The answer to these problems, I would argue, is not to exclude people with intellectual disabilities from research nor attempt to abandon the principles of EDR. We need to remember that its main progenitor, the social model of disability, was first developed by people with physical disabilities. Disabling cultures have conspired to give articulate people with a physical disability a stronger voice in its creation. Very different 'impairment effects' (Thomas, 1999) are likely to exist between people with a physical disability and people with an intellectual disability and indeed between these groups and people who may have both a physical and intellectual disability. The EDR model principles need to be enriched and augmented iteratively via analysis, reasoned debate and the dissemination of messages from intellectual disability research. I believe there are two major issues in realising this; 'control and agency' and the 'myth of homogeneity'.

### **Control and agency**

Primarily for EDR is the issue of the 'control' of research by people with intellectual disabilities. Some people with intellectual disabilities may be fully capable of initiating, controlling and conducting all aspects of research, however, some would not. Due to their intellectual impairment their 'rights bearing agency' i.e. their ability to independently assert their Human Rights, may be compromised. To prohibit them from research production on this basis would be a Human Rights violation and an act of 'disablement'. 'Evidence- based' policy and practice is rapidly developing as a 'new paradigm' in the social care field (Howard, McMillen & Pollio, 2003) and it would be negligent to exclude evidence from people with an intellectual disability. For example, if I were creating services to provide assistance to people with intellectual disabilities, should I not try to find out from them how, what, when, where and so on such services should be provided? Within our

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contemporary social structure the groups and individuals who have the power to initiate and facilitate participation in research for people with an intellectual disability are mostly non-disabled people. I maintain that their action in supporting others to access their Rights is permitted by the universalistic principle of 'other advocacy equals self advocacy'. Interconnected with this rationale, it can be argued that some legitimacy of agency is given to the activist researcher as discussed earlier (Healy, 1996).

### **The myth of homogeneity**

Fawcett and Hearn (2004) in their discussion of researching 'others' assert that it cannot be assumed that all disabled people identify with other disabled people or that having an impairment is the most important aspect of a person's identity or social position. Should EDR engage in 'false universalising' by assuming there is homogeneity of opinion, perception, type of impairment/s and so forth? Even in groups of people with the same disability label (e.g. Down syndrome) caution should be exercised as 'all categories mask differences'. Ironically, perhaps one of the disabling effects of the medical model has been to facilitate the stereotyping of people according to their disability labels. The continued widespread practice of IQ testing for example, although largely discredited (Gould, 1996), has done much to generate an almost universal 'assumption of incompetence' in respect of people with an intellectual disability (Richardson, 2000). Having impairment, being a relative of a person with impairment, or being part of a specialist organisation dealing with disability issues does not necessarily produce activism or advocacy. There are many documented and anecdotal accounts of 'internal politics', power-plays and self-interest within specialist disability organisations (e.g. Humphrey, 2000), which can detract from wider enabling agendas for people with a disability, including their meaningful participation in research (Moore, Beazley, & Maelzer, 1998).

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I have established thus far that; people with intellectual disabilities have the right to be involved in research; their voice in matters which specifically concern them is essential; many people with an intellectual disability will require support to instigate, and participate meaningfully in research; and simply having an impairment does not automatically guarantee a disability rights perspective or even the identification of the self as 'a person with a disability'. Logically it seems that in disability research, the integrity and ideology of the researcher (regardless of whether they have a disability or not), the ethical framework of the research, its methodological transparency and a clear commitment to shift the 'social relations' of disability research production, are the most important factors. So how is this achieved in the context of research practice?

### **Bringing down the barriers: Involving people with intellectual disabilities in research**

Academic justification aside, successful self-advocates such as Aspis (2000) and Harrison, Johnson, Hillier, & Strong (2001), have argued that researchers should share their skills with people with an intellectual disability. There is now a small but significant body of research where people with intellectual disabilities are identified as co-researchers/researchers and are appreciably involved in research processes which traditionally engaged only university academics; tasks such as ethics applications, the development of research questions and hypotheses, collecting and analyzing data and the distribution of findings.

One major 'inclusion breakthrough' is recorded in the work of Ham, Jones, Mansell, Northway, Price, & Walker (2004) where a group of self advocates and university based researchers collaborated from the inception of the research on an application to an ethics committee. Self-advocate volunteers and academic researchers together decided on the approach to the study

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(focus groups). Information and consent forms were developed using accessible language, symbols and photographs and produced a 'user-friendly' version of the ethics application (usually a long and complex document) for access by all the team. The team practiced their presentation with a 'mock' committee. When the ethics committee gave their approval for the research the self-advocates were clearly acknowledged as 'researchers' both within the research team and externally. Practices such as this may help to combat some barriers to inclusive research created by well intentioned but sometimes over zealous 'ethical protectionism' (Iacono, 2006; Ramcharan, 2006) on the part of some ethics committees.

In terms of gathering data from people with an intellectual disability, Richardson (2000; 2002) in his participatory study with six people researching aspects of their own lives notes the use of focus groups which were largely unstructured and hence allowed participants to select topics for themselves. This allowed the research to be self-directed and themes to be emergent and non-intrusive. Regular weekly meetings over two years also allowed for data analysis and member checking by participants. It is also quite possible that this reasonable time span allowed the growth of trust and confidence between Richardson and his co-researchers who were also included in the distribution of research findings via co-presenting at conferences.

Inclusive research can be challenging; the examples above illustrate the pursuit of inclusion and enablement through transparency, consultation, flexibility, accessible resources and prior training/practicing for roles (where possible). So what have I learned thus far on our 'Voices for Change' research journey?

### **The Voices for Change journey**

The 'Voices for Change' study takes place within 'Up, Up and Away', a 'circles of support' project, hosted by a registered charity in Australia. Up, Up and Away was brought into being when a group of approximately 25 young adults with Down syndrome (18-25 years) were consulted about what they wanted out of life for the future. The messages were loud and clear; they want access to the same opportunities and lifestyle choices as their non-disabled peers, they also want to make a meaningful contribution to community life. Their voices for change can be heard in this 'summarising' statement which became the main endeavour of the project. It can also be interpreted as a plea for equal citizenship rights:

[We want] "To do stuff in our life like everybody else; like getting a job, moving out, seeing friends, going out, having a relationship and helping others"

These young people also recognised the need for moral and practical support in achieving these rights. The consultation process identified family members, friends, community members and disability agencies as being potentially key social supports and hence the concept of a 'Circle of Support' or 'Team of Champions' was adopted in the construction of the project model (Stevenson, 2007).

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The opportunity for research was presented by the flexibility of the project's structure and its initial funding lifespan of 3 years. Participatory action research (PAR) was especially appropriate for our project as it is congruent with activist approaches to research (Healy, 2001), with the social model of disability (UPIAS, 1976) and EDR, all of which set out to challenge barriers to participation. Exponents claim that PAR is educational and empowering (Friere, 1970; Fals-Borda & Rahman, 1991), data collection methods are flexible and attuned with local, cultural, economic and political conditions i.e. are context specific. The research is necessarily iterative and unfolds in accordance with the development of each project as new understandings and insights are gained. The Up, Up and Away project had been crafted via the collective voices of young people which gave them clear 'ownership' of the enterprise from the outset. Participatory research within the project would be informative and potentially enrich the project experience for the young people. Combined with this, circles of support are becoming increasingly popular as self-directed support for people with a disability and their families; research into their effectiveness is therefore warranted.

Because I was the project coordinator and the project had already commenced when the idea of academic research was mooted, there were obviously issues of consent which needed to be dealt with by both the host organization and the University-based Human Research Ethics Committee (HREC) in the course of my ethics application. Due to ethics requirements I had to be reasonably clear about the direction and purpose of the research, however, these had already been determined to an extent in the initial strategic preparation for the Up, Up and Away project. Within the research plan I presented to HREC, the committee did allow for the flexibility that participatory action research requires within a carefully considered ethical framework (Stevenson, 2007). A research steering group was set up to oversee the research which was inclusive of people with

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Down syndrome, their parents and other stakeholders with knowledge and experience of the disability field.

The primary endeavour of the research is to discover what aspects of a circle of support model assist young adults with working towards/achieving their life goals. The 'emancipatory' agenda of the research has taken on its own significance and hence is the focus of discussion here. From the outset, my co-researchers presented at conferences and university seminars with me. These presentations were very well received and I noted that quite a few of the participant group had a flair for, and really enjoyed, public speaking. We developed a proposal which was eventually funded by a member of the host organization and seven young people were recruited and paid to work with specialist consultants to become trainers in Down syndrome and disability issues. They have since developed workshops for undergraduate social and health care professionals. The young people use presentation software and DVDs (very enabling technologies), as well as role play exercises with students, to augment and enrich their communication and messages. Thus from an initial process of research inclusion has blossomed an interesting and affirmative role for some young people with an intellectual disability and, equally, some memorable learning for university students.

In aspiring to the EDR and PAR models, all the young adults with Down syndrome involved in our research were regarded as potential co-researchers hence, exploring their potential for decision making and participation in research activity was a key feature of my methodological approach. Semi-structured interviews have been conducted across 7 'cases'. Each case consists of; a participant of the Up, Up and Away Project who has Down syndrome; a parent or main support person (or two parents if both were willing to be interviewed); and the facilitator or 'team coach'

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matched to each young person. The interview questions were based around what Up, Up and Away participants, parents/main supporters and facilitators thought about the project and how it had impacted upon them and were carefully constructed by myself (then checked by research participants) so as to be 'non-intrusive'. I was interested in eliciting their views and opinions about their experience of being part of Up, Up and Away rather than prior 'life experience' information. One young man with Down syndrome who was employed within the Up, Up and Away project as 'Team Voice', a representative of young adults with Down syndrome on the project reference group, expressed an interest in conducting some of the interviews with his peers (with Down syndrome) alongside me. We worked out a 'team strategy' whereby he would read out the interview questions which his peers would answer. If I wanted to ask a supplementary question, I would indicate by raising my hand and he would give me space to ask the question. This system worked very smoothly and engendered mutual respect and power sharing. Flexibility has been a key feature of this methodology; having been interviewed themselves, two young women with Down syndrome (on separate occasions) decided they wanted to conduct their own interviews, one with myself, the other with the Team Voice. Each formulated their own questions. Their interviews have yielded further data, provided by myself and the Team Voice, and from the pertinent issues raised within the questions that these young women decided to ask both of us as co-researchers. This development is acceptable in the context of PAR approaches. These young women effectively challenged the traditional binary positions of the 'researcher' and the 'researched' and the corresponding potential for replication of oppressive social relations therein (Oliver, 1992).

In terms of analyzing the data, I have looked at different ways of involving young people with Down syndrome. On one occasion, I gave a de-identified transcription to one young woman and asked her to underline what she saw as the important points that were made by the interviewee. She

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underlined words and phrases and made notes in the margin such as 'importance of my culture', 'opportunities for leadership', 'paid work' and 'friendships'. Through this, I could see a primary coding of data was emerging, determined by one of my co-researchers. I have since received a small amount of funding for three young people to assist me with the data analysis on campus in a room provided by my University. We plan to co-author a paper when analysis is completed.

### **Reflections**

Action research methodology appears to be a particularly enabling for the young people, providing a 'live' and dynamic field of inquiry. Data is harvested from contemporaneous views and opinions on their shared and individual experiences of being Up, Up and Away project participants rather than necessarily having to reach back into the past. In terms of other positive factors of note, the long term nature of the research project, which has been running from March 2007, has enabled myself and my co-researchers (including families) to get to know and trust each other which has undoubtedly enriched our research partnership. We can be open and honest with each other. The opportunity to offer paid work to co-researchers gives them some acknowledgement of their contribution, after all, how many university based academics work for free?

These are just a few examples from our research journey thus far. Through a flexible approach to the research, building relationships over time with my co-researchers, listening, observing and presenting opportunities for them to participate in different ways, I have discovered a range of research abilities, interests and talents amongst my co-researchers which, had the research design been more rigid, more preconceived, I may never have become aware of. Importantly, I have had faith in the notion that my co-researchers have capability, can develop competence and must be engaged in matters which intimately concern them. As a collective, we have achieved some

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compliance with the emancipatory paradigm which places emphasis on 'participant validation' (Barnes, 2009), i.e. the contribution of people with a disability to traditionally academic research processes. Due to time factors (most of my co-researchers had other jobs); it was not viable for all to be involved in every research activity. There are still some issues of control to be addressed and explored (Zarb, 1994).

Writers such as Walmsley (2004) advocate research training, pre-planning and role definition which are desirable, appropriate and achievable in some research situations with specific groups of co-researchers with an intellectual disability who have the time and space in their lives to do this. Opportunities for inclusive intellectual disability research studies, however, are (so far) limited, not least of all due to the continuing dominant status of the medical/health paradigm in the allocation of research funding and corresponding demand for large scale disability studies (Oliver, 1998: Walmsley, 2004). Furthermore, it is difficult to generalise about such a diverse group of people and thus be prescriptive as to exactly how individuals can, and should, be involved in research processes. I would argue that opportunities for small scale inclusive projects need to be embraced. Intellectual disability research methodology is still developing, and, beyond the establishment of ethical integrity, an over-proliferation of 'rules' could be counterproductive to some researchers and disability groups getting involved in developing innovative research practices and adding to our knowledge in the area.

### **Conclusion**

'Nothing about us without us'

Motto, International Day of Disabled Persons 2004

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The 2008 UN Convention on the Human Rights of Persons with Disabilities invites us to re-double our efforts to include our fellow disabled citizens in all aspects of civil society. Although many people with intellectual disabilities will need appropriate support and encouragement to participate in research processes, it is their Human Right and non-disabled researchers need not step back from the challenges of partnerships in this area. Although a variety of approaches are taken by different researchers, the common theme of our work is that the research experience has been enriched through the inclusion of people with an intellectual disability as co-researchers in the research process. Human Rights awareness and an activist position on the part of the researcher have facilitated both challenging and affirmative messages in relation to methodology and findings from co-researchers. I have discovered thus far that by keeping the research processes continuously open to diverse forms of participation by my co-researchers, their voices are continually in earshot, their presence is felt and hence their influence is being brought to bear at most stages of the research journey. Using an enabling approach, our co-researchers can be consulted and their opinions valued as different but equal. This can (and arguably should) occur within any field of academic inquiry which concerns them. Within a clear ethical framework, non-disabled researchers can ensure that co-researchers participate as far as they can (and wish) in research processes. We can listen while our colleagues express their own ideas about how they would like to do things and support them in entering new territory. Non-disabled researchers can work to de-mystify academia (a world which ritually excludes people with an intellectual disability) and share our power and privileges. We can make sure our co-researchers have meaningful, dignified and interesting experiences in the course of research.

Although we would be deceiving ourselves to think we can transform 'the social relations of research production' with our colleagues who have an intellectual disability overnight (if ever), we

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can strive towards that ideal. Above all, in accordance with EDR principles, non-disabled researchers need to acknowledge and own the 'political nature' of their work. This way, we protect everyone's rights to participation in research production, not just our own.

### **Notes**

<sup>1</sup>This paper is concerned with the development of Emancipatory Disability Research which is underpinned by the social model of disability (UPIAS, 1976; Oliver, 1990). Central to the political project of the social model is its claim that the term 'Disability' describes the 'mechanisms of social oppression that all disabled people face', rather than their impairment. This assertion impacts upon the language of disability. The social model recommends that in terms of disabled people as a group, irrespective of impairment, we should use the term 'Disabled people' (Carson, 1999). Self advocacy groups however, tend to prefer people-first language. In some ( but not all) settings in the UK, self-advocacy groups use the term 'people with learning difficulties' e.g. People First and Values into Action, hence reserving the term 'disability' to describe social oppression. In Australia, self-advocacy groups prefer the term 'people with an intellectual disability' and so, in respecting their wishes, the term 'people with an intellectual disability' is used in this paper. Such linguistic inconsistency with the social model is problematic, however, and I do have the concern that 'people with an intellectual disability' simply translates as 'people with an intellectual impairment'. Hence impairment and disability, once again, can become synonymous and the social model definition of 'disability' can be lost.

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