

NNDR Conference Nyborg, Denmark 2nd -4th April 2009

Keynote Address

Inclusive Research with people with intellectual disabilities: Potential and Pitfalls

Introduction

The Keynote address reflects upon 'inclusive research' six years on from the publication of the book I wrote with Kelley Johnson on Inclusive Research in 2003 (Walmsley and Johnson 2003). I aim to:

- Define Inclusive Research
- Reflect on its history, and what it has achieved
- Consider some fundamental questions it raises about the nature of intellectual disabilities
- Inspire and inform!

I should perhaps apologise for focussing on developments in the UK and Ireland, as this is where my experience has been since I write the book-and before. But I will make a virtue of necessity, and ask you to use the Q and A session which follows to make those connections

In particular, I will explore the following questions:

Is there a tension between the purpose of research for people with intellectual disabilities as a route to new skills, knowledge and power-or an adjunct to the service industry?

How far can the environment be manipulated, barriers reduced, to solve the limitations learning disability impose? In other words, does true inclusive research reflect an agenda which maintains that to take part in society on equal terms, people with learning difficulties must heroically rise above the impairment and join in a conspiracy to deny that their intellectual impairments matter? (Walmsley, 1997: 12).

Is learning disability, as normalisation theory has it, the result of labelling, creating a cycle of stigma and devaluation, to be remedied by the promotion of 'valued social roles' including that of researcher?

How far does inclusive research go to remedy the real disadvantages experienced by people with learning disabilities – do the outcomes repay the effort and resources required?

And, finally-where does theory fit?

Defining Inclusive Research

Inclusive research sees people with intellectual disabilities change from the passive beneficiaries or objects of research to the people who frame and ask the questions

Defined in 2003 as:

A term which embraces participatory and emancipatory approaches to research

Its characteristics are research that:

- Is owned (not necessarily initiated) by people with intellectual disabilities
- Furthers the interests of disabled people, researchers are on the side of people with intellectual disabilities
- Collaborative
- People with intellectual disabilities exercise control over process and outcomes
- Outputs are accessible

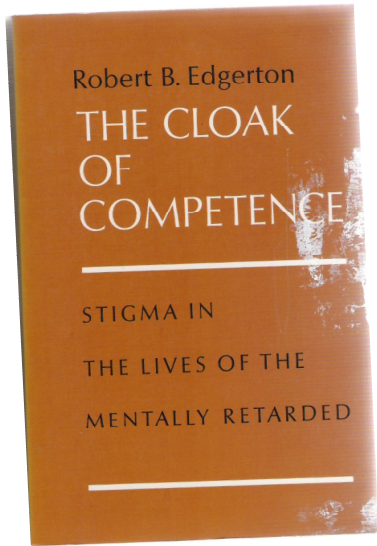
(Walmsley and Johnson 2003)

Since our book was published Carlisle Research Collaborative, a group of researchers with and without learning difficulties, has come up with a definition of 'person led research' which goes beyond our original definition:

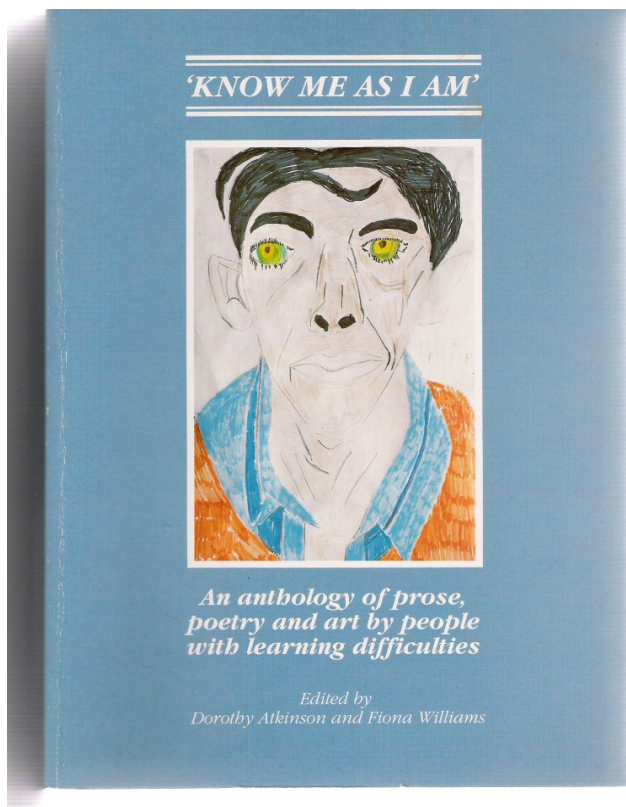
- Person led research is research started and controlled by people who have learning difficulties
- Rejected research is where people with learning difficulties are not part of the research when it is about them... Where they are not completely included they are rejected

(Townson et al 2004 page 73)

A brief history of inclusive research: From Academic Gaze to Speaking for yourself



Robert Edgerton, 1967



Atkinson and Williams (eds) 1990

Robert Edgerton was one of the first researchers to examine the lives of people with intellectual disabilities (Edgerton 1967). Using ethnography, he reported on the ways people managed after leaving Pacific State, a large West coast of USA institution. He found that people could flourish if they found 'benefactors' to guide and support them. However, he was the interpreter of their actions, he exercised the 'academic gaze'. This is very different from research in which people speak for and represent themselves, such as Atkinson and Williams' 1990 anthology 'Know Me As I Am', and many subsequent collections (eg Johnson and Traustadottir 2000, Traustadottir and Johnson 2005, Atkinson et al 2000).

We can usefully reflect upon some dichotomies to trace the history of inclusive research. Then (pre 1980s)

- Researchers decided on the questions to ask, and the methods
- People with learning difficulties were the objects of research
- Reports not accessible

Now

- People with learning difficulties help decide the questions, and methods
- People with learning difficulties do research
- Research as a tool to support what might broadly be termed self advocacy and service improvement
- Accessible reports are required for research which involves learning disability topics.

Of course, this is a gross over simplification, but it serves to make the point.

Inclusive Research: part of a wider rights movement

Inclusive research cannot be taken in isolation. It is part of a rights movement which asserts 'nothing about us without us' (Aspis 2000). This has affected assumptions about the degree to which people with learning disabilities are involved in activities which impact on their lives. At the same time, in the wider world, we have witnessed a shift to 'engagement' and 'co-production' as requirements for public services, not only intellectual disabilities, but also in health care, housing, policing, schooling (Bovaird 2007).

Inclusive research may seem to be rather an esoteric topic. However, it is a very useful mirror as it faces the challenge common to many 'user led' movements of reconciling two barely compatible objectives. Organisations set up *by* users have the aim of 'empowering' a particular client group through service provision, campaigning or participating in political structures. At the same time, they have to set up organisational processes (management of the group and sustaining the organisation in practical ways, within the law pertaining to such issues as employment, health and safety etc., budgets and so on)

(Tilley 2006). The need to do this can distract from their fundamental objective of empowerment. I imagine we have all seen so called user controlled organisations which are, in practice, controlled by others in the name of efficiency or effectiveness. Or simply through concealment. Research relationships allow this to be addressed in microcosm, to explore the minutiae of developing relationships between non disabled people, and people with intellectual disabilities. INCLUSIVE RESEARCH is a route to reflection upon some very fundamental issues in the struggle for citizenship. If we can get it right in research, then research has some very useful lessons for the wider system, of people with intellectual disabilities, and those who seek to support them in becoming self realising to the maximum of their potential.

INCLUSIVE RESEARCH: A personal journey

I became interested in what I later named 'Inclusive Research' back in the 1980s, at a time when the transformative potential of self advocacy for people with intellectual disabilities was just beginning to be realised in the academic world. For almost 20 years I, and other academics struggled to work with people with intellectual disabilities in a variety of collaborative ventures – teaching (Open University 1989, 1996), research (my PhD Gender, Caring and Learning Disability 1995), Conferences (Social History of Learning Disability group, Walmsley 1993), co-authoring (Walmsley and Downer 1997, Atkinson et al 2000).

Awareness of 'Nothing About Us Without Us' inhibited any academic theorising – we were driven by values, seeking within the world of research to redress some of the wrongs we perceived as having been inflicted on people.

In order to make sense of these exciting, but frequently bewildering experiences, and not without considerable hesitation, Kelley Johnson and I set about writing the book which explains my presence here today.

Our stated reason was:

A frank and open debate about some of the difficulties of undertaking this kind of research, as well as its advantages, will assist in developing methodologies and approaches which offer a middle way between trivialising and puppeteering (page 16)

We were not alone. Others writing on a topic, advocacy, also associated with empowerment, identified similar confusion.:

What is striking is that...there is surprisingly little written on the subject of advocacy. One of the consequences of this neglect has been that the meaning and purpose of advocacy have not been subjected to sustained critical examination with the result that discussions relating to advocacy tend to occur in a conceptual fog...If there is a genuine commitment to providing people with learning disabilities with the means to express their views then there has to be more informed debate about how this can most effectively be achieved (Gray and Jackson, 2002: 13).

We were both worried that stepping out of line, to voice our own dilemmas, would be regarded as a betrayal of some core values-‘nothing about us without us’ - that had both driven us and constrained us in our work to date. Again, we were not alone. Liz Tilley, who researched two advocacy organisations in the UK for her PHD thesis, explored why this might be so:

Citizen advocacy, which was probably the first model of advocacy to become established in the UK, has an inherent suspicion of academic research. It is felt that to research advocacy is to treat it as an “intervention” and to “clientise” those it supports, thereby thwarting a key aim of citizen advocacy, which is to promote partners’ access to and acceptance within, the life of the community. Second, the stress laid upon confidentiality by all models of advocacy has led to an understandable reluctance to discuss actual advocacy processes in the public arena

The same could be said of Inclusive Research. Stepping away, exercising the academic ‘gaze’, was seen as a betrayal, particularly if you did not have the label of intellectual disabilities. But if you did have the label of intellectual disabilities, stepping back and reflecting or theorising in your own space, was not a luxury you are likely to be able to manage, without very skilled support. A conundrum.

Preparation for this Keynote has prompted me to consider whether our book, published in 2003, has actually achieved what it set out to do, to clarify some of the confusion, and what it missed, a reflection both on process, and purpose.

Inclusive Research: Influences

In our book we identified three major influences on inclusive research, one of which, Participatory Action Research, came from community development approaches, the other two, Social Role Valorisation(srv) and the social model of disability, came from within the disability movement.

Participatory Action Research (PAR)

Kelly Johnson identified PAR as one parent of inclusive research, with its emphasis on research which prompts change (improvement) in people’s lives

In which not only the research itself prompts change, but that those who take part are empowered, ‘that the process itself reflects a more just and fair society in microcosm’ (Walmsley and Johnson 2003 p.32)

Where the boundaries between researcher and research participant are broken down, and where the participants develop new skills.

Where the outcomes are real improvements in people’s lives

The second parent social role valorisation –

Active Research involvement is a valued social role, being a researcher even more so.

Being a researcher ticks all the boxes laid out by Wolf Wolfensberger (1998):

Valued participation

With valued people

In valued activities

Take place in valued settings

Furthermore, being a researcher brings with it the opportunity to develop 'valued' skills, and, possibly, paid employment

SRV makes sense of the researcher's role as akin to a citizen advocate – there to enable devalued people to find a voice, and to act as a bridge into association with people who are socially valued

The researcher in this model has the duty to promote a positive image of people with intellectual disabilities

Emancipatory Research

The third parent, emancipatory research, most closely identified with the disabled people's movement, originating in the UK, argued for a change in the social relations of research production (Oliver 1992)

In this model, disabled people choose what needs to be researched, decide on the approach, and receive and control the findings. Disabled people do not necessarily do all the work, rather:

'researchers as the expert servants of disabled people who must put their knowledge and skill at the disposal of their research subjects for them to use in whatever ways they choose' (Walmsley and Johnson 2003 p.?).

Co-production

If I were writing it now, I would add a fourth, 'co-production' or 'engagement', defined as

the provision of services through regular, long-term relationships between professionalized service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions (Bovaird 2007 page 847)

Co-production, while drawing on ideas developed in the disability movement such as individuals controlling their own budgets and commissioning their own services, is essentially service oriented –engaging people in their own health care for example, will lead to better outcomes and lower costs. I will cite some examples of this later in my address. It is increasingly a mantra of policy makers, observed, at least in the Statutory sector in the UK, more in rhetoric than practice.

Theories of Change

If we consider inclusive research as a way to address the disadvantages experienced by people with intellectual disabilities, then we can portray these four parental influences as 'theories of change' which lay out assumptions

about the nature of a social problem, what its solution is and how particular action will lead to the solution. The tables indicate how the four different parent theories play out as change strategies.

PAR

Assumption about the nature of the problem	Communities know what they need but lack the resources to address their problems through research
Intervention	Researchers support communities to define what matters to them, find 'brave new paths', solutions which fit their context
Expected Outcomes	Practical solutions to people's real problems Skilled people in communities
Success Measures	Increased Capacity in communities and groups to identify and tackle problems of real concern

SRV

Assumption about the nature of the problem	Labelling leads to societal devaluation, denial of access to valued social roles
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Intervention	Involvement in research provides valued social roles in valued settings with valued people
Expected outcomes	Increased social value for people with intellectual disabilities, both as participants, and as role models for others
Success Measures	Societal perceptions of people with intellectual disabilities change

Social Model of Disability

Assumption about the nature of the problem	Disablement is the result of barriers in society - to full participation, citizenship, and inclusion
Intervention	Change in the social relations of research production. Disabled people in charge of research, deciding the questions, designing the process, receiving and using the results

Expected outcome	Research that is framed around disabled people's concerns, finding solutions which reduce barriers to participation and inclusion
Success Measures	Fewer barriers, greater inclusion

Co-production

Assumption about the nature of the problem	People are the most important resource for health and care, but professionals do unto, rather than work in partnership to release potential
Intervention	Research partnerships between professionals and people who need to use services to research real needs people have of professional support
Expected Outcomes	Service users empowered, professional roles changed from relieving to enabling

Success Measures	Professionals as enablers Improved service outcomes Lower costs
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Using a 'theory of change' makes it clear that the four parents of inclusive research lead to different strategies, different roles for researchers without disabilities, and frequently, confusion of ends and means

To take just one aspect, if power is defined as the ability to make a difference:

In PAR power is shared ostensibly equally, a relationship of interdependence between researchers and 'communities'

In srv, it is the nondisabled person's duty to further the disabled person's access to power, to be silent, self effacing

In emancipatory research, the researcher is the servant, the expert consultant, the employee.

In co-production, there is a gradual handover of power, the professional/researcher shifts role from reliever to enabler

In the intervening years we have seen something of a resolution and fulfilment of these different strands through the development of inclusive research

Inclusive Research: Achievements

In describing the achievements of inclusive research since 2003, I have grouped the discussion as follows:

- ***Creating Inclusive spaces for research***
- ***Practising Inclusive History: Moving on from 'nothing about us without us'***
- ***Defining the contributions people with intellectual disabilities can make to research***
- ***The developing role of research funders***
- ***Back to Basics: Research and empowerment***

Creating Inclusive spaces for research

Since the 1990s, the Social History of Learning Disability group (<http://www.open.ac.uk/hsc/lds/site/>) at the UK's Open University has been running annual 'inclusive history' conferences, where researchers, people with intellectual disabilities, family members and practitioners come together to discuss the history of intellectual disabilities. From tiny beginnings in the mid 1990s, this has become a major event,

attracting international contributors with and without intellectual disabilities to the extent that this year for the first time, we have extended it to two days in recognition of the quality of papers submitted.

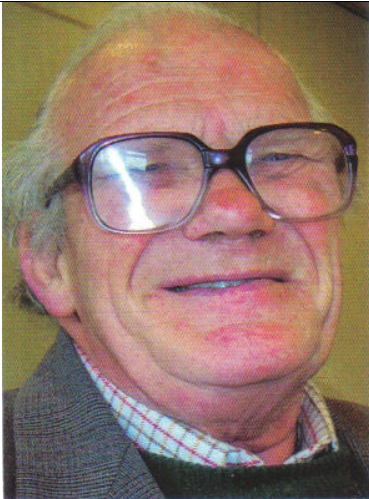
The Group aims are:

- To encourage historians, researchers and people with learning difficulties to work together on the history of learning disability
- To develop methods of historical inquiry that combine oral history, biography and archive research
- To find ways and means of making history available and accessible to all who are interested
- To make links between the history of learning disability and broader social policies.

At the conferences, the life stories and experiences of people with intellectual disabilities sit alongside scholarly papers, creating an inclusive forum where mutual understandings can be forged, and disagreements acknowledged.

Juxtaposing individual experience with scholarly research papers creates the potential of a creative dialogue between people with intellectual disabilities and researchers. Below are two examples from 2009 abstracts submitted.

Victor Hall's Conference Abstract 2009



I want to tell you my life story.

I have had hard times and good times. I am a survivor of institutions. It is important to hear my story to

stop things like people having to live in hospital happening again.

I have done well in my life because I have always worked hard and always kept trying.

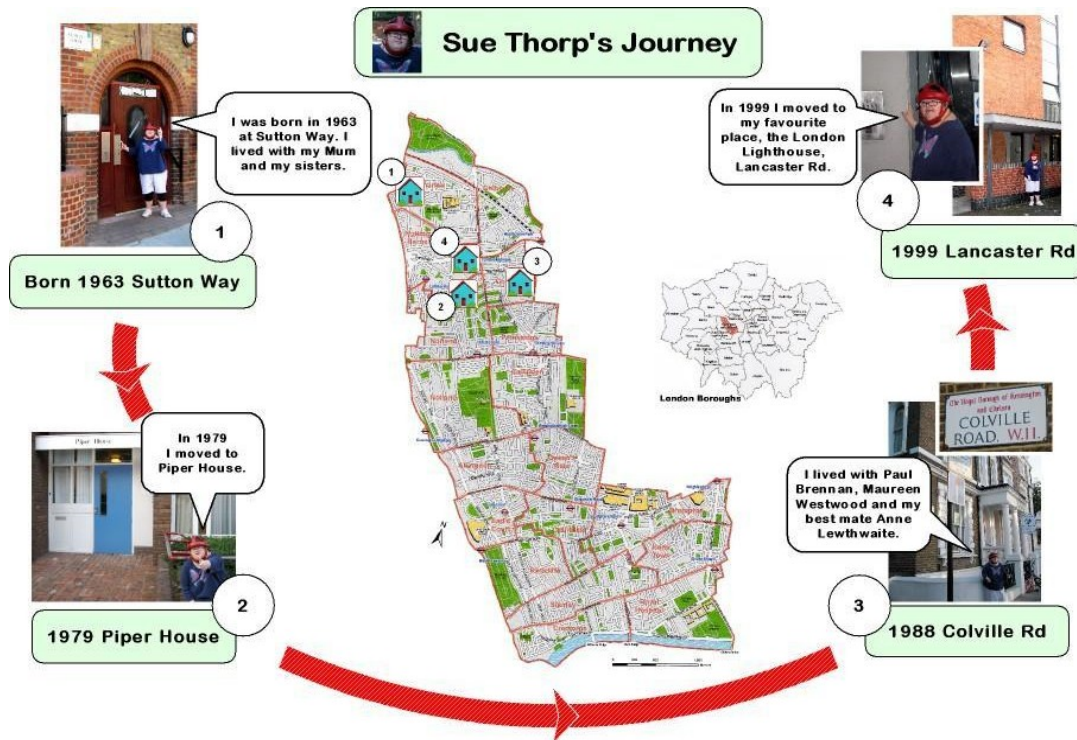
Zoe Hall's Conference Abstract 2009

Title: Caring or cared for? An Irish perspective on the family relationships of people with intellectual disabilities.

Currently in the National Institute for Intellectual Disability, Trinity College Dublin, there is a project underway to collect the life stories of older people with intellectual disabilities. So far 22 stories have been collected, and one of the emerging themes from these stories is that of the role of family carers.

However, the caring was not done by family members for their intellectually disabled children or siblings, but rather a distinct pattern has emerged of the storytellers caring for *other* family members due to bereavement, illness, physical impairment and other reasons. A second and related theme is that of the sense of loss and unhappiness felt by these carers when forced into residential care themselves, when their 'usefulness' as carers for other family members had passed.

The work of this group has primarily been with people with relatively mild disabilities, people who, quite literally, have a voice. However, Sue Ledger in her PhD work has pioneered life history methods which include people with more profound impairments, and challenging behaviour, using the device of mobile interviews. She drives people to places they have lived, records any responses, and records their life journeys on specially designed maps



(Ledger, in progress)

Getting the balance right to create inclusive spaces has taken time and experimentation. I believe that this idea, of creating inclusive spaces where researchers, people with intellectual disabilities, practitioners, can leave their roles behind and debate on reasonably equal terms is of great and, as far as I know, unique value.

Practising Inclusive History: Moving on from 'nothing about us without us'

At the core of our book were questions about the relationships between researchers and people with intellectual disabilities. We were finding our own voices, and challenging some of the euphemisms and cover ups that researchers had employed to hide their own power in the process, detecting the hidden hand.

On the one hand researchers may be trying to implement the values of inclusive research and allow people with learning difficulties to lead and take control whilst not imposing these values on the group members. On the other, they are aware that managing a research project involves making decisions, achieving day-to-day deadlines and completing the task. Mack (2001) writes 'the line between drawing ideas from people and telling them what to think is thin and hard to locate'. Can researchers be accountable without being controlling?

Since we wrote, researchers have become bolder in exposing some of the tensions, again taking the space to find their own voices

Val Williams and Ken Simons have added to this debate, concluding in a reflexive article about working on a funded research project that 'inclusive research is something new, with its own hallmarks and styles' (2005 p.7)

Val, the paid nondisabled researcher, identified

The central task of handing over ownership of the research must count as the most difficult of the issues that faced me as a research supporter (2005 p. 12)

She coined the idea of 'researcher in residence' as a way of describing her role, akin to the 'artist in residence', people can be in control, they can also be supported to do the research.

So far, so good, the model promises the best of all outcomes in the best of all possible worlds. But in another reflexive piece, Alex McClimens describes the struggles he has had with co-authoring with a group of people with intellectual disabilities, to finally withdraw and produce a 'minority report' of his own. He points to three issues with which his group struggled:

- The words –actually putting these on the page invariably devolves to the 'academic'
- Attribution of authorship – whose name goes first, how many authors
- Acceptance that there will be disagreements between the different parties, that the academic (although he does not say this in so many words) has a right to disagree, just as do the authors with intellectual disabilities.

'Whose knowledge, the professional academic or the person labelled with learning disability is valued more, and by whom' (2007 p. 275) sums up the core dilemma in his article.

Chapman (2005) tackled the great 'missing link' of support in self-advocacy, which had escaped scrutiny in the literature for a number of years. Interestingly, this PhD project was conducted using inclusive methods – and the combined voices of both Chapman and the research team successfully contributed to a highly revealing piece of work.

Support is a role that bridges the gap between what people want to be doing, and what they are rejected from doing by the way things are (2004 p.84)

In subsequent work the Carlisle Research Collaborative have explained why they moved from being a self advocacy group, in which only the members with intellectual disabilities had a voice, to being a collaborative, where everyone has a voice-including researchers and support workers (Towson et al 2004).

Craig Dearden, non disabled Director of a Cambridge user organization, expresses this view in relation to self advocacy work more broadly:

We believe that a partnership between people with and without learning difficulties is far more effective than a situation in which people with learning difficulties are left to do everything on their own...In my experience, those types of organisations often struggle to deliver, and hit problems in the medium and long term . . . I think that is an incredibly slow approach in a competitive charity environment (Craig Dearden, quoted in Mack, 2001).

Effective partnerships between people with intellectual disabilities and those who seek to support them appear to be the key to moving forward. As ever, relationships are at the core of the enterprise.

Clarity about added value

In our book, we reflected upon the purpose of inclusive research. Undoubtedly, we argued, it added to the value for those involved – new skills, new status, in short valued social roles, and in some (all too few) cases, payment, even a route to paid employment.

It also added to knowledge –insider accounts more readily elicited when people with intellectual disabilities ask the questions than when professors do so.

And it extended knowledge about how people with learning difficulties experience the world, their perspectives, desires, contributing, for example to inclusive history in which the views of all stakeholders are represented

We were then unsure what else inclusive research contributed to research.

Since the book was published there has been an increase in sophistication in delineating the roles of people with intellectual disabilities in major research projects.

The National Survey of Adults with Learning Difficulties in England and Wales, 2003/4 (Emerson et al 2004), conducted in the wake of Valuing People by the University of Lancaster, BRMB, and Central England People First, an advocacy organisation controlled by people with learning difficulties. Central England People First contributed to the research design, the training of the research team, and the final report which is available on line, with an audio commentary.

The research team developed a comprehensive set of tools to access the views of people with quite limited communication abilities, for example show cards to ask

questions:

How happy do you feel about your
life at the moment?

45101680



1

Very
happy



2

Quite
happy



3

Sometimes
happy,
sometimes
unhappy



4

Mostly
unhappy

SHOWCARD 1

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4120033

The Report is unusual in that it was only produced in an accessible version. It used the familiar device of reporting in plain language with line drawings, but also included a commentary from the self advocates involved, as in the illustration:

A Place to Live



We think too few people (less than one in seven) live on their own or with a partner. Too many young people still live with their parents and too many older people live in supported accommodation. Living independently makes many choices possible but, just like everyone else, people with learning difficulties worry about safety in the area they live in. We don't think this should stop people living independently. They should have the choice of being independent and safe.

We were not surprised that so many people's privacy was not respected and that most people in supported accommodation did not have a choice about who they lived with and where. As people with learning difficulties the right to have choice about a place to live and to privacy are very important.

Ian Davies & Karen Spencer

We asked people about where they lived and who they lived with.

Just over two in three people (69%) were living in private households. This means that they were living alone, with a partner or with their parents or other relatives. Just under one in three people (31%) were living in some form of supported accommodation.

Of the people living in private households:

- o nearly three out of four people (73%) were living with their parent(s)
- o one in six (17%) were living with other relatives



27

It is worth noting that this was the product of organizational partnerships, whereas most early examples of Inclusive Research had been between individual academics and individuals with intellectual disabilities (see for example Atkinson and Williams 1990, Atkinson et al 2000)

Involvement in Inspection of Services: Experts by Experience

The involvement of people with learning difficulties in inspections of services has also been developed. The Commission for Social Care Inspection, the English regulator for social care services until April 1st 2009 commissioned, through a competitive tendering process, Experts by Experience. Three of the six organisations commissioned are people with intellectual disabilities –they accompany inspectors, their role being to ask questions of the residents or users who, it is assumed, will offer more honest responses than if an inspector asked the same questions.

My final example might fall into the co-production category – involving users and carers to decide on research priorities for improving health.

The developing role of research funders

In 2003, funders for inclusive intellectual disabilities projects were hard to find. We have seen a pendulum swing-now it is the case that many funders insist upon involvement in research related to intellectual disabilities. And have become more sophisticated in spotting 'client' relationships, where inclusion is a fig leaf for researchers seeking to 'use' people with intellectual disabilities as a route to obtaining money.

The Heritage Lottery Fund, a national funder which supports preservation of the UK's heritage, has extended its definition of heritage from landscapes and great houses to people's own memories. It has funded at least 20 projects like this one, where people with intellectual disabilities are funded to record their own heritage:

Sandwell People First's Our Hidden Lives Project

We are supporting ten young people with learning disabilities to explore and research their heritage. The young people will focus on archive research dating back to 1800 and contemporary oral history from 1950's onwards. The oral history will particularly focus on the lives and experiences of individuals and staff who worked in long stay institutions.

www.hlf.org.uk

In parenthesis, I might add that some funders have been so convinced of the value of inclusive research that they insist on it – when it may not be appropriate. And work with a rigid model which assumes that people will be the principal researchers. There is now work to do in getting funders to understand that people with intellectual disabilities will need highly skilled support to carry out their own research projects to a high standard, and may need the resources to pay their own experts-a consultancy model not incompatible with the Social Model philosophy.

Back to Basics: Research and empowerment

So far I have ranged around some of the more sophisticated elements of Inclusive research. I now want to return to some rather less exalted and 'professional' aspects of inclusive research.

There is ever a tension in self advocacy between the political work of the collective, and meeting the needs of individual members (Buchanan and Walmsley 2006). Only a few people are genuinely likely to be able to develop skills and knowledge to become 'real researchers'-the opportunities are not that many, and not everyone wants to be a 'real researcher', even if they have the potential. However, if we

regard inclusive research as a tool for supporting self advocacy, then it has a far more significant contribution.

In Ireland, a country where self advocacy lacks any infrastructure, my co-author, Kelley, has inspired people to use 'inclusive research' to

- identify why research is important to them and how research can be used to improve their lives
- Encourage people to become researchers, and
- Help people undertake projects which are important to them.

If researching together is a success people with intellectual disabilities who take part will have

- New skills and information
- New friends and contacts
- The chance to speak up about what matters to them, and to learn about what matters to other people
- And, sometimes, more power, for example to undertake campaigns and make changes in their lives.

In County Clare in the west of Ireland, the Brothers of Charity who run services have appointed an Inclusive Research Officer to foster research amongst the people who use their services. The Brothers supported inclusive research:

- To show how people can have more control over their own lives
- To ensure that people have the power to make changes.
- To enable people with intellectual disabilities to put issues on the agenda for services

In Clare, inclusive research is a tool to foster empowerment. The Clare Inclusive Research Group has produced

- The Garden Story preserving the memory of a Garden where people had worked in words and pictures

Lance Cooney's Story 'I'll come back here again'



Lance in the garden

I was one of the very first ones here when they first built [the workshop]. None of you were around that time. I think none of you existed that time. Another thing, Danny Montgomery is my best friend. He is the very first one I met here. And Mark White. Ger Doohan, Martin O'Connell. All the others. There was a lot of us. [Now] most of the fella's have left.

- The Coffee Shop: market research into a community run enterprise in a small Irish town

- Researching the Travel Challenge
- Researching Relationships

Marie took on the travel challenge. She researched into a journey to a hotel, and then did the trip with friends and a staff member. She reported 'my first trip on public transport since 1992, 17 years. My parents didn't think it was doable enough for me, and I didn't think it was either'

'It was great'.

The Inclusive Research Group use drama to present their research findings:



Marie presents her findings

The differences between travel training, familiar in services, and researching one's own travel needs may be semantic, but they are also significant. Travel training implies the role of a recipient of information, a student role, all too familiar to people with intellectual disabilities, and to staff. A researcher is an active role, defining one's own travel needs, and gaining the wherewithal to pursue them. Also, make some mistakes on the way And learn from them.

Possibly equally important was the response of the worker who supported this adventure-'it is the first time I have ever done anything like this. It's been great for the clients, it's been great for me too. It's shown me a different way to work with people' (Personal communication 2009)

At the present state of our knowledge, there appears to be no real substitute for independent and skilled human support.

Progress?

I have reviewed progress. It is a patchy story, not a continuous improvement, not necessarily sustainable and certainly not universal but evidence that some of the challenges we posed in 2003 have been addressed:

- More honesty
- Greater clarity about 'added value', the contributions people with learning disabilities make has been named and recognised
- A move away from personal to organisational relationships
- A recognition that people with learning difficulties need knowledge and skills, as well as their life experience to bring to the party, that the researcher may also need to be a teacher
- Researchers have had permission to claim their own space, and that has helped immeasurably in moving things on
- And really heartening gains in self confidence and opportunities, as represented in the Clare travel training and the abstracts to our 'Inclusive History' Conferences

Pitfalls

In concluding this address I return to the questions about the nature of intellectual disabilities I posed at the outset

How far can the environment be manipulated, barriers reduced, to solve the limitations learning disability impose?

Is ability, as Dan Goodley put it in 2000 'a reflection of support networks, rather than some individual quality or deficiency'-In other words, it is our (researchers') responsibility to make research accessible and meaningful for people with intellectual disabilities.

I believe that the strides made in inclusive research indicate that there is an enormous amount that can be done to change the environment from barriers to enabling. Indeed, when we wrote the book, I was worried that Inclusive Research taught us more about process how the research was done, than it did about content, what it said. I now tend to believe that this is Inclusive Research's greatest contribution as a set of findings. If Goodley is correct –and there is overwhelming evidence that he is right to see

skilled support as the core of empowerment, then what inclusive research has to offer is models of support which, as Rohlfs Chapman argues:

Support is a role that bridges the gap between what people want to be doing, and what they are rejected from doing by the way things are (2004 p.84)

Great ingenuity has been displayed by researchers in finding ways to make research inclusive. People with intellectual disabilities have initially been in the role of responders, but there is evidence that some people are now taking the lead. Even Alex McClimens' dilemma was partially resolved: the Burton Street Gang published their own article (Abell et al 2007)!

However, once we leave the cosy world of research, things do get more difficult. The issue of payment is important to many would be researchers with intellectual disabilities. But, as we have all found, pay is usually only forthcoming when you do what the payer wants done. And that is not often writing your own life story, researching your own travel needs or asking your friends' views about labels, relationships and bullying.

As for a career, the traditional route via University is blocked by the need for academic qualifications.

We all know people active in the self advocacy movement whose private lives remain little changed from that of a 'traditional' service user, going home to mum, back to the group home, exercising precious little of the skills and energy developed for research

Is learning disability, as normalisation theory has it, the result of labelling, creating a cycle of stigma and devaluation, to be remedied by the promotion of 'valued social roles' including that of researcher?

Marcus Redley and Daniel Weinberg's (non inclusive) work challenges us to consider 'to what extent can a group of service users, whose very entitlement to state sponsored assistance is justified by putative intellectual impairment (low IQ and deficits in social functioning) be empowered according to an exclusively liberal model of citizenship that presumes and requires as its very defining features, intellectual ability and independence' (Redley and Weinberg 2007 p. 768)

They argue that to regard intellectual impairment as a technical issue that can be minimised under the rubric of access, jargon free documents etc. aims to minimise the consequences of people's impairments (p779-80)

I think I have shown here today that success in inclusive research goes beyond technical to human aids, that imagination and commitment together have overcome many of the barriers we perceived in 2003. However, it is also the case that inclusive research has included only a small minority of people to date. Even service based approaches like the Inclusive Research Group in County Clare are rare and fragile. There is undoubtedly a danger that inclusive research creates an elite, people with relatively mild impairments, and leaves others on the margins. Jani Klotz reminds us that there are many people with more profound impairments whose experiences and life worlds are not included in the activities we

describe here, all of which rely to a great extent on creation of a shared language. Her challenge to us to accept seemingly meaningless actions as 'legitimate, meaningful and purposeful', rather than 'making them conform to normative social practices and behaviours for their inclusion and acceptance' (2004 p. 101) is a reminder that the origins of inclusive research do lie in social role valorisation, and that there are other ways to recognise people's contributions

How far does inclusive research go to remedy the real disadvantages experienced by people with learning disabilities – do the outcomes repay the effort and resources required?

My response to this pretty fundamental question is that it goes some way to addressing disadvantage. We do, as a result of inclusive methods and approaches, know more about what really matters to people with intellectual disabilities. Issues such as bullying, health care have moved up the agenda a result. We also know more about creating a shared language. Roshss Chapman et al's definition of support has helped to 'name' some of the qualities that make for the most effective support,

Support is a role that bridges the gap between what people want to be doing, and what they are rejected from doing by the way things are (2004 p.84).

But this should not distract us from the very real material disadvantages people experience. The English National Survey (Emerson et al 2004) found that poverty, isolation and feeling unsafe were common experiences. Inclusive research has done little to address these problems. It was ironic that as I left County Clare, one of the persons working in the service told me that their car allowances had been withdrawn. In a rural area like Clare that is an enormous blow. People have their nice homes, their sea views, support from staff and a research group –but not the wherewithal to go anywhere not even to the shops, unless staff use their own vehicles at their own expense. In the current economic climate this won't be an isolated example. We must not let 'inclusive research' be a fig leaf which distracts from campaigning for more equal distribution of money and the good things in life.

And then there is theory....

And, finally-where does theory fit?

It had been one of our frustrations in 2003 that theorising as we understood it was impossible if we adhered to 'nothing about us without us'. In their research into the role of support workers in self advocacy organisations Chapman (working with the Carlisle Research Collaborative) concluded:

'theory was imposed rather than worked through and understood, based on the members' individual needs and requirements' (Chapman 2005: 288).

This raised an uncomfortable conflict regarding the extent to which consciousness-raising in self-advocacy groups was being directed, if not controlled, by advocacy workers.

It is possible to find examples of theorising purportedly by people with intellectual disabilities. The People First (London) website provides one:

- People First promotes the social model of disability. This is a way of thinking about disability that says it is society that needs to change to include disabled people. We should not have to change to fit in with society. We are against the medical model of disability, which is the view that being disabled means there is 'something wrong' with you. Doctors and teachers and other professionals put labels on us marking us out as different from everyone else.
- It is these labels which get in the way and stop us taking part the same as anyone else, for example people labelled as having a learning difficulty get sent to special schools and then on to day centres when what we would really like is to get a job; we get put in group homes to live with other people with the same label, with whom we didn't choose to live, when we would prefer to live on our own with support or with a boyfriend or girlfriend.

<http://www.peoplefirstltd.com/> accessed 28/11/08

This statement clearly draws on srV (labeling) and on the social model of disability (the medical model) as its theoretical underpinnings. However, I doubt that it represents the authentic 'voice' of the organisation's grass roots members (Clement 2003). As a call to action, it may be adequate, but as an analysis of the real problems people experience it is not.

There is evidence that Inclusive Research can develop theory as a collaborative effort between disabled and nondisabled researchers, for example, the definition of support quoted in this paper was the outcome of the Carlisle Group's joint efforts. This is an area of potential as yet only partially realised.

Towards a new Theory of Change

I opened this paper by considering four 'parental influences' on Inclusive Research, and presented them as 'theories of change', noting that there is potential for confusion and conflict as the analyses they present lead in different directions, with a range of potential roles for non disabled researchers, from partner to advocate, expert consultant to educator.

I argued that the value of inclusive research was as a microcosm in which relationships could be explored. As I reviewed progress, the significance of relationships both interpersonal and organisational was reinforced. It seems fitting to end this review with an alternative theory of change which puts relationships at its core, and bridges the gap between the often esoteric world of inclusive research and the far more significant enterprise of improving the lives of people with intellectual disabilities.

<p>Assumption about the nature of the problem</p>	<p>How to bridge the gap between what people want to be doing, and what they are rejected from doing by the way things are</p>
<p>The Intervention</p>	<p>Inclusive research to experiment with different models of personal and organisational support relationships, and spread the results to policy makers and to services</p>

Expected Outcome	Improved understanding of what constitutes effective support to be used to train and develop staff, volunteers, and advocates to work alongside people with intellectual disabilities
Success ?	People are supported to bridge the gap as they define it

If inclusive research has taught us anything, it is that relationships are fundamental.

Jan Walmsley

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