"Self-advocacy: forming reliable alliances"
Keynote address, ASSID 40th Annual Conference, 10th
October 2005, Auckland, Aotearoa.

Author information
Professor Dan Goodley
Manchester Metropolitan University
Research Institute for Health and Social Change
Division of Psychology and Social Change
Elizabeth Gaskell Campus
Manchester Metropolitan University
Hathersage Road
Manchester
M13 0JA
Tel: (+44) 0161 247 2000
Fax: (+44) 0161 247 6842
E-mail: d.goodley@mmu.ac.uk

ABSTRACT
This paper reflects the views of an ally, without the label of intellectual disabilities, with ten years of researching and supporting self-advocacy. It is hoped that this paper supplements, in some small way, the huge and significant body of literature that has already been produced by the self-advocacy movement. This literature needs to be at the fore of any analysis of disability activism and self-advocacy. This paper draws upon a number of resources: a documentary history of an English People First group; an examination of performing arts on the participation of people with intellectual disabilities; a long-term study of the lived and enacted realities of self-advocacy; the life story of the self-advocate Gerry O'Toole; a research project about the experiences of parents of disabled babies. These resources demonstrate the *power* of self-advocacy to work alongside people with intellectual disabilities, professionals, service providers, policy makers and researchers to challenge conditions of disablement, exclusion, discrimination and alienation. Yet, they also remind us of the *barriers* that threaten to stifle efforts to form reliable alliances with self-advocacy. It will be argued that in order to

understand, realise and release the potential of self-advocacy, we need to interrogate the three key concepts sloganeered in the title of this conference: (1) co-operation; (2) collaboration and (3) creativity. Only when we meaningfully engage with these concepts can we start to talk about forming reliable alliances with self-advocacy. Finally, it is suggested that as conference delegates, who are brought together under the banner of the study of 'intellectual disability', we need to unearth and question the very assumptions that underpin our understandings of this concept. *Rejecting deficit assumptions* is a key component of forming alliances with self-advocacy.

Introduction

Tēnā tātou katoa! I hope that means a collective and inclusive WELCOME to you all. I want to thank the conference organisers for inviting me here to speak. In this paper I want to argue that self-advocacy provides opportunities for creating reliable alliances in relation to the following projects:

- Theory - Understanding and challenging the conditions of disablement: the exclusion of disabled people (inc. people with intellectual disabilities);
- Services - Developing enabling services through bringing together the ambitions of self-advocacy and the human services;
- Practice – Enhancing practitioners to promote self-empowerment and interdependence of the people they work with;
- Politics – Contributing to disability politics as a global phenomenon: that recognises the glocal (the local and global).

The paper draws upon a number of research projects that I have been involved over the last 10 years: an ongoing documentary history of an English People First group; a project on the performing arts of people with intellectual disabilities (Goodley and Moore, 2000); a long-term study of the lived and enacted realities of self-advocacy (Goodley, 2000); the life story of the self-advocate Gerry O'Toole (Goodley et al, 2004); a research project about the experiences of parents of disabled babies (http://shef.ac.uk/inclusive-education/disabledbabies). These resources demonstrate the *power* of self-advocacy to work alongside people with intellectual disabilities, professionals, service providers, policy makers and researchers to challenge conditions of disablement, exclusion, discrimination and alienation. But, they also remind us of the *barriers* that threaten to stifle efforts to form reliable alliances with self-advocacy.

I will argue that in order to *understand, realise and release* the potential of self-advocacy, we need to interrogate the three

key concepts sloganeered in the title of this conference: (1) co-operation; (2) collaboration and (3) creativity. Only when we meaningfully engage with these concepts can we start to talk about forming reliable alliances with self-advocacy. A recurring theme of this paper is that of 'our assumptions': the ideas we hold about the phenomenon of 'intellectual disabilities'; the principles on which research, service provision and practice are based and the philosophies that underpin the support of self-advocacy. A fuller version of this paper, with related references and research projects is available at the following website:

http://www.shef.ac.uk/applieddisabilitystudies/

This is the website for new research Centre of Applied Disability Studies (COADS) at the University of Sheffield.

1. CO-OPERATION
Co-operation refers to working together for a common purpose with commonly agreed-upon goals and methods. It hints at a *starting point*: a willingness to be working with others: to be flexible, open, willing and, significantly, able. Marginalised people, like those labelled with intellectual disabilities, may well benefit from the co-operation of others to further their development. Yet, for self-advocacy to embrace and be a key element of co-operation, it is crucial to deconstruct this concept. I want, therefore, to look at two areas:

1. The dilemmas and risk raised by the state sponsorship of self-advocacy in England and Wales following the 2001 White Paper 'Valuing People';
2. Ways in which we can understand and promote support of self-advocacy groups towards meaningful co-operation.

AGAINST CO-OPERATION IN ENGLAND AND WALES?
One of the biggest threats to a meaningful agenda for co-operation between practitioners and people with learning difficulties is when the agenda is being set from above rather

than below (Goodley, forthcoming). The Valuing People (2001) White Paper introduced by the British government, has given rise to substantial funding of advocacy and self-advocacy organisations across England and Wales. Indeed, Values Into Action – formerly the Campaign for the Mentally Handicapped in the 1970s – has combined its role of campaigning organisation with being the recipient of Department of Health funds that were awarded to self-advocacy groups throughout England. This has permitted the funding of under-represented self-advocacy groups in rural locations; promoted black and ethnic foci and supported self-advocates with 'complex needs'. Simultaneously, the White Paper's emphasis on People's Parliaments has, arguably, further strengthened the representation of people with learning difficulties in debates about their lives and the services that they access. Self-advocacy is now accepted as a given in services: both in consultation and provision.

Historically, of course, many organisations of disabled people have pushed for an independence from government lobbying groups (Oliver 1990; Campbell and Oliver, 1996) and critical voices have been raised about the place of the Disability Rights Commission in the politicisation of disabled people in Britain. There sometimes appears to be an almost unquestioned assumption that the bankrolling of self-advocacy – post-Valuing People – is a good thing. Indeed, the White Paper says many supportive things about the crucial place of (self) advocacy in the lives of people with learning difficulties (see Valuing People, 2001, page 49 for example). Yet, questions remain about the types of self-advocacy group that are valued in the climate of Valuing People and the dangers of homogenising groups to fit an acceptable face of self-advocacy. To what extent does Valuing People promote models of empowerment and self-advocacy that are less to do with embracing the resilience of people with learning difficulties and more to do with normalising the enactment of self-advocacy? People's parliaments, for example, appear to have the potential to give the kiss of life to service-focused self-advocacy groups that were widely criticised by the People First movement in the 1980s and 1990s (see for example,

People First of Washington State and University of Oregon, 1994). Just as Page and Aspis (1997) warned against the domination of self-advocacy by issues of service provision, the contemporary promulgation of self-advocacy by the White Paper threatens, yet again, to promote a service-oriented vision of self-advocacy: clinical and conservative in outlook. But is this really that threatening? After all, isn't disability activism and self-advocacy a broad church, welcoming different members with varying belief systems and organisational aims? Is it not better that the government are funding self-advocacy groups, whatever their group type, than no funding at all?

More tricky issues remain about whose voices and whose actions are dominating the empowerment and the self-advocacy agenda in these times of the Valuing People. Just at the time when England enjoys the highest number of independent self-advocacy groups that it has ever had, many aspects of the political agenda for people with learning difficulties are being shifted by people without learning difficulties. The nagging concern I have relates to the ways in which self-advocacy is conceived; does the policy-led agenda and business like structuring of forms of self-advocacy groups, post-Valuing people, correspond with the actions and ambitions of the existing self-advocacy movement? To ensure that policy makers, service providers and professionals are not redefining self-advocacy in ways that are in contrast to the self-advocacy movement, we need to engage with the ways in which self-advocacy groups respond to and promote the resilience of people with learning difficulties.

HOW CAN SELF-ADVOCACY BE SUPPORTED IN WAYS THAT PROMOTE MEANINGFUL CO-OPERATION?
Question: What makes for a good supporter in the self-advocacy movement?
Self-advocacy groups are normally made up of people with learning difficulties – sometimes called 'self-advocates' – and supporters or advisors who aim to help the membership to promote self-advocacy. The role of the supporter is a difficult and, in many ways, complicated one. A few years ago I

carried out some research with self-advocacy groups (Goodley, 2000). One of my main aims was to understand how self-advocacy groups worked. A key issue emerged: that self-advocacy groups prosper not only from the activism of people with learning difficulties but also from good support on the part of advisors. But what makes for a good supporter? Previous literature and research *on* self-advocacy – and *by* self-advocacy groups – has tended to understand support in one of two ways:

1. Good supporters are good people.
2. Good supporters are independent of services.

The first explanation suggests that some people are simply just good at supporting people with learning difficulties. Perhaps they have thoughtful dispositions, caring personalities and positive attitudes which make them able to support self-advocacy in useful and empowering ways. The second explanation is based on the idea that self-advocacy groups must be independent of services. If supporters are professionals or staff within services and also supporters of self-advocacy groups, then a conflict of interests will often arise. So, if a group wants to criticise a day centre for not offering its 'users' enough opportunities, and the group's supporter is a member of staff of that centre, then the supporter will feel pulled between his/her commitments to the group and his/her place of work.

It seems to me that these explanations do not go far enough in questioning what constitutes 'support'. In addition, I think good and bad support are directly linked to assumptions held by the people who enact support. But these assumptions are not just individually owned things – they are often reflected in society's view of disabled people. I think you can be a good supporter and be a professional. I also think you can be a good person and a bad supporter. But good support reflects particular assumptions about people with learning difficulties. Let me give you some stories to illustrate what I mean.

David is a thoughtful man. He has been supporting a People First group for many years. But, you see, the problem David has with self-advocacy, so it seems to him, is that people with learning difficulties really cannot do it that well. Indeed, he thinks that really, he can advocate far better for people with learning difficulties than they can self-advocate for themselves.

Julia walked into the meeting of the self-advocacy group. Peter, one the members, was angrily shouting 'I hate the staff in my group home – they are always telling me what to do'. Julia asked Peter to quiet down. She recounted the story to her friend June in the pub, later that evening. 'You see', Julia reflected, 'the thing with Peter is that he really does have challenging behaviour'.

Kath had been working with Asif for a number of years. Asif did not speak. He tended to communicate with movements of his arms and legs. During their time together, Kath had developed a way of communicating with Asif. 'Circles' was almost like a game, where huge pieces of paper cut into circles were bluetacked to the floor. A circle in the middle had a smiley face and the word 'happy' written below it. Another, this time to the right of the room, portrayed an angry face. One day, Kath and Asif lay on the floor, circles all around them. When Kath asked Asif about how he was finding the Day Centre, Asif moved himself slowly but with determination across the room until he lay across the circle title 'unhappy'.

Three stories of support. For me, they reflect different assumptions – on the part of the supporters – about people with learning difficulties. David's belief about people with learning difficulties could be termed a deficit perspective. As Tim and Wendy Booth say in their 1994 book about parents with learning difficulties, supporters who hold a deficit perspective assume – often immediately, sometimes for a long time – that people with learning difficulties are unable to think and do for themselves because they are not able enough. Julia appears to hold an assumption that people with learning difficulties are what they are because of their impairments. So,

when a person without the label of learning difficulties gets angry then this is because they are, well, angry. May be they are an angry person. But we would probably want to ask how or what made them angry: a crap day at work? An irritating person? When a person with learning difficulties gets angry then this is often interpreted as a direct consequence of that person's 'impairment' or 'learning difficulties'. Contrast these assumption with those held by Kath. We could term Kath's outlook as one of a capacity perspective. Kath holds the strong belief that Asif does know his own mind. That he has things to say. That he has strong opinions. However, she knows that they have to work together imaginatively to ensure that his views are voiced. Kath's assumptions are based on the idea that just because someone has an impairment then this does not make them a passive person devoid of thought and ambition. She conceives of Asif as someone capable of co-operation.

But note this – the assumptions held by David and Julia reflect dominant viewpoints of society. We live in a disabling society that understands disability as the product of someone's impairment. Kath's assumptions are different – people like Asif are disabled by a society that makes no effort to try and engage with people whose voices are difficult to access. Therefore, we need to change the environment, make it more accessible and inclusive, and work to bring out 'difficult to hear voices'. Kath's view is very similar to the viewpoints expressed by the disabled people's movement: disabled people are disabled not by their impairments but by a society that excludes people with impairments. Change society; challenge disability.

I am often thrown by some of the supporters that I meet who say things about people with learning difficulties that reflect very negative, inward looking and 'disabling' assumptions. Many of these people are good people: they care about others and want to make lives better. Many of them work outside of services. But what they demonstrate, when they say such things, are assumptions about people with learning difficulties that will inevitably give rise to bad support. They are doing

support in a way that fits with a disabling society and the viewpoints that dominate. In contrast, good support seems to be based upon assumptions about people with learning difficulties which are optimistic, emphasise capacity over deficit, consider the impact of environments rather than 'impairments' and, crucially, take people as people first.

What makes for good support? The answers are in the assumptions we hold. We will return to assumptions at a later point, but for now, I would like to turn to collaboration.

2: COLLABORATION

Collaboration appears to infer some form of active participation and partnership: some doings together. How collaboration is enacted will influence how reliable an alliance self-advocacy becomes. Policy makers, practitioners and researchers of disability must ensure meaningful collaboration with organisations *of* disabled people such as self-advocacy groups. Indeed, a vision of self-advocacy as a reliable alliance has been promoted in contemporary disability research. I will, firstly, turn to examples of this work in order to tease out some element/aims of collaboration and then, secondly, consider the conditions under which collaboration could be made.

RESEARCH COLLABORATION: INCLUDING SELF-ADVOCATES AS RESEARCHERS

Collaboration in research has been embraced in a number of participatory approaches to research. In England, we can point to the pioneering work of researchers in the School of Health and Social Welfare at the Open University and The Norah Fry Institute at the University of Bristol. Both of these research centres have benefited from long-held working links with organisations of disabled people: particularly People First groups. In North America, the work of the Centre on Human Policy at the University of Syracuse is pertinent here. Drawing on interpretivist theories, people with learning difficulties have featured centrally in the work of associated authors such as Robert Bogdan, Steven Taylor, Phillip and Diane Ferguson, while research has attempted to include people with learning difficulties and their People First organisations in the process

of research production (see http://soeweb.syr.edu/thechp/). One possible way of thinking about collaboration is in terms of participation and/or emancipation. This might be considered as a *continuum*:

Knowledge	Shared Knowledge Research	Action
Non-participatory Emancipatory	**Participatory**	
Researcher-led researchers	Researcher invites participants into research	Co-

A key emergence of participation is, and for many should be, emancipation. The field of disability studies has a long history of promoting research practices that work alongside and with disabled people (Special issue, *Disability, Handicap and Society, 7, (2)* 1992; Zarb, 1992; Barnes, 1997; Oliver and Barnes, 1997; Clough and Barton, 1998; Stone and Priestley, 1996; Goodley and Lawthom, in press). The underpinning assumptions of the British social model of disability have led to a number of core research issues, including:

- *Inclusion* – more and more disabled researchers involved in academia
- *Accountability* – the disabled people's movement demands researchers and academics to be accountable to the experiences and aims of disabled people, reflected in the slogan 'Nothing about us, without us';
- *Praxis* – theories of disability emerge from an engagement with the changing nature of disabled people's lives;
- *Dialectical* – research *draws* and *builds* upon the social model of disability;

- *Ontological knowledge* – disabled people understand the conditions of disablement and impairment;
- *Disablement rather than impairment* – disability research should engage with the material, social, cultural, relational and political conditions of disablement;
- *Partisan* – research/ers are on the side of disabled people.

(see Goodley and Lawthom, forthcoming, conclusions)

These issues are, of course, contestable and have provoked major debate in the disability studies literature. Ethically sound research is not simply about following professional guidelines on anonymity, confidentiality, withdrawal and the avoidance of distress in research. Ethical research is also about promoting an ethically sustainable vision of disability. Ethics brings with it considerations of values and politics in which the disabling world is changed to give way to more equitable social relationships. Any research endeavour that attempts to work with people with intellectual disabilities benefits from reviewing itself in light of these issues. In a recent text I have edited with Geert Van Hove entitled 'Another disability reader? People with learning difficulties and a disabling world' (Goodley and Van Hove, 2005) and a special issue of the *British Journal of Learning Disabilities* (2004, Vol. 32, No. 2), a number of contributions reflecting participatory approaches hint at a number of emancipatory consequences. The first consequence to mention is *criticality:*

> peer review is when people double check an article to see if its good enough.We don't think University people should double check this article. No disrespect to university people, but they don't know what its like to be learning disabled (Docherty *et al*, 2005, p31)

This chapter by researchers with intellectual disabilities raises many questions about the criteria against which research is judged. Docherty et al (2005) suggest that in order for research to include then it must address a number of common barriers including:

- Information which isn't accessible;

- Jargon and offensive terminology;
- People's negative attitude (you can't …);
- People not listening to us;
- People being patronised;
- People who don't want to know and just walk away;
- People who want to know you but just drop you afterwards.

The second consequence of participatory research is the identification and development of *organic intellectuals.* This is crucial in addressing Chappell's observation in 1996 that while a number of disabled scholars have further analyses of disablement, the analytical hand of people with learning difficulties remains largely absent. Carlisle Research Cooperative's 2005 paper, for example, aims to tease out good practice in relation to participatory research. In an imaginative and thoughtful analysis, authors of the Cooperative define their model of research as *person led research*, which is research started and controlled by people who have learning difficulties. This contrasts with *rejected research,* where people with learning difficulties are not part of the research, though the research is about them. This sets up real challenges in terms of disability studies ensuring that research has a strong commitment to inclusion and equality in the research process.

The third consequence of this type of research to mention is the *deconstruction of researcher/professional practice.* An ongong debate in the International People First / self-advocacy movement is how non-disabled allies can support the self-empowerment of people with learning difficulties. In the same Journal issue as the Carlisle co-operative's paper, Chapman and McNulty explore this role of support in the movement by reflecting on their interventions when working with the Carlisle Research Cooperative. They recognise that in order for people to be meaningfully supported in the research process then non-disabled researchers / supporters need to render explicit – and often change – their agendas, preconceptions and assumptions. Such a need is, of course, relevant to current considerations of professional practice

throughout the human, social, health and education services used by people with intellectual disabilities. The recent increase in the take up of direct payments by people with intellectual disabilities in the UK and elsewhere takes meanings of professional practice to very different levels: consumers with intellectual disabilities directly accessing and paying for the services of chosen professionals. How enabling this transformation is to those consumers remains to be seen: but many lessons can be learnt from examples of participatory research practice like those I have cited here.

CONDITIONS OF COLLABORATION: INTERDEPENDENCE AND DISTRIBUTED COMPETENCE

Any attempt to collaborate will be based upon the assumptions held by the social actors implicated. In writing this paper I was reminded of the story of a Maori Phd student who, on submitting their Phd thesis, wished to put their genealogy on the title page of their thesis, below their name. This story captures something potent about collaboration: the inter-connected nature of self. Take the following vignettes from an ongoing documentary account of an English People First group:

> *A reality: Margo and Thomas have just moved in to a small house. It is located up the lane from Thomas's old flat. Margo has moved out of the latest in a long list of group homes. Their now house as two bedrooms. The guest bedroom is situated in the attic – 'so that people can visit and stop over', Margo informed me. A little garden requires weeding and a bit of loving care. Support workers visit in the mornings and evenings to help with food and cleaning the house. Best of all, though, by 7.30pm, Margo and Thomas are left to watch the TV, share a beer (or three) and put their feet up after busy days working.*

> *A dream: Paul longs for a time when he has his own flat, with a wide screen TV, pet dog, no garden, easily placed in relation to the market in town and not too far from his Mum's house. He would decorate it mostly white, maybe*

some brown and hopefully with a few chrome fixtures.
Weekends would be chilling out time – doing nothing –
maybe a few DVDs and a take-away pizza.

These pictures of domesticity are particularly important for Paul, Margo and Thomas. They are also of great relevance to people with the label of learning difficulties and their supporters. The White Paper Valuing People (2001) is a clearly articulated strategy for policy and practice in relation to the life chances of people with learning difficulties post the 1995 Disability Discrimination Act and following the agitations of the International Disabled People's movement. The paper boasts a number of overlapping key concerns, including the promotion of legal and civil rights; independence; choice and inclusion. Key to these concerns is the issue of independent living:

> Government objective: To enable people with learning disabilities [sic] and their families to have greater choice and control over where and how they live (DoH, 2001, p70)

For many people with learning difficulties, adulthood is accompanied by group living with parents and siblings in family homes or peers in group homes. Most people live with their families. If not then they live in supported contexts, such as local authority group homes. In addition, Valuing People reports 3000 living in 73 village and intentional communities. The extent to which people with learning difficulties have a say in their own housing and accommodation is explicitly cited as a major concern by the White People. In 2001, there were over 4 million existing homes in the social rented sector alone, which could have been used for the possible accommodation of people with the label of learning difficulties (DoH, 2001). Clearly, at least, some of the resources are there.

Yet, for many, a chosen home remains a distant dream. The importance about people with learning difficulties having a say about where they (want to) live – as a key element of self-advocacy – has been strengthened by recent controversial

news stories about private care homes / specialist units being built to house people with learning difficulties with mental health problems and complex needs. Such 'humanitarian' interventions threaten yet again to segregate people with learning difficulties from mainstream life. There is a real threat of many potentially active members of the self-advocacy group languishing in group hostels, small institutions, privately owned Trust homes and family homes. Moreover, the increased professional input into the lives of people with learning difficulties may well increase the hurdles that people have to jump in order to reach a level of professionally assessed 'competence'. Add to this, the culture of risk experienced by professionals, family members and people with learning difficulties alike, and many self-advocates face incredible difficulties in convincing others that they are 'capable' enough to live in a place of their choosing.

Margo and Thomas have known each other for over 20 years. Yet, it is only now, when they are both over 50, that they have 'achieved' the level of competence and maturity deemed appropriate for independent living by professionals and family.

Paul still plans for a life of solitary living – away from the institutional settings of group homes and the lack of privacy offered by 24/7 staff surveillance. That said, he would appreciate some help with preparing his tea.

Margo, Thomas and Paul demonstrate not only the ambitions of people to live where they want to live, but of the **inter-dependence** that underpins any good living. Living independently is never living alone. We all require the services and skills of others to make living worth living. As a contributor to a book by Jane Campling put it many years ago, 'Not many of us cut our own hair – we all need help'. Independent living also means supported living: by friends, family, the community. It is therefore important that the self-advocacy

movement continues to support self-advocates' choices about where they want to live; and to identify the support necessary for such living.

In this sense, then, collaboration demands the pooling of resources, skills, expertise, drive, ambition, passion and commitment. I particularly welcome this theme of the conference because it seems to at least implicitly demand the enactment of inter-dependence. In doing so, we trouble notions of 'independence' which sound more like neo-liberal and conservative ideas of personhood which, let us be honest, have dominated thinking at the very least in the UK. Who wants to be independent? Interdependent sounds safer, more human, social, community based and more achievable.

3. CREATIVITY
Creativity challenges the maxim "There's no need for change: It's how we do things around here". Self-advocacy is a hot-bed of activism, theorising, life-style creating, embracing diversity. Sometimes we need to be creative in seeking out its creativity. We need to be *rhizomatic* (but more of this later). Often self-advocacy takes on different shapes, practices and forms. In so doing, it disrupts taken for granted ideas and common senses about people, society and identities. I want now to talk about creativity in three different ways:

1. Contextualised activism;
2. Self-advocacy via the performing arts;
3. Understanding intellectual disabilities: becoming rhizomatic

The aim here is to supplement ideas for co-operating collaboratively through thinking creatively.

THINKING CREATIVELY ABOUT PEOPLE (WITH INTELLECTUAL DISABILITIES): CONTEXTUALISED ACTIVISM
As I mentioned earlier, a key task of working in collaboration with others involves assuming competence rather than incompetence. In 2000, Michele Moore and I asked; 'how far

is academic research drifting away from the contextualised practical and theoretical work prioritised by disabled people'? Our involvement with people with the label of 'learning difficulties' highlighted the urgency for rethinking not only the origins of theoretical development, but also the destinations. Academic debate so often separates itself off from everyday practices: the academy is where theory is generated in and where development often stays. This separation will stay in place as long as artificial - and problematic - distinctions between theory and practice can be sustained through divisive (and elitist) governance of research production. A real alternative is to work from the 'bottom up': taking a direction to research as located in the lives of disabled people themselves (see for discussions Atkinson and Williams, 1990). We felt it appropriate to work with dialectical notions of practice, where contextualised examples of activism can be explicitly recognised as practical and theoretical spaces, constituting arenas for meaningful praxis-oriented developments. An example from field notes highlights the theoretical qualities of contextualised activities:

> Khadam phoned me on Wednesday night. He told me that a chap was coming down to the self-advocacy group on Saturday to visit.
>
> 'Is he a member of staff from the local Day Centre', I asked?
>
> 'No'.
>
> 'Is he a friend of yours from the market where you work?'
>
> 'No'.
>
> 'Does the person have 'learning difficulties'?
>
> 'I don't know, I haven't asked him', replied Khadam.

Khadam's response – as a person labelled as having 'learning difficulties' and challenging this through involvement with a self-advocacy group – practically captures the socially constructed and contested nature of 'learning difficulties' as a naturalised impairment. The social model of disability informs and is informed by points of analysis raised by personal and

political *activists* such as Khadam. To see his resistance as an incidence of activism signifies political and theoretical potency. While the vignette of his actions is not the product of a piece of emancipatory research, we can understand these actions as intrinsically emancipatory. Here then is another side to emancipation within disability research where we aim as researchers to capture the theoretical and political qualities of contextualised actions. Similarly, our work with performers with learning difficulties has meant that conventional ways of expressing theoretical and practical outcomes have become inadequate. If we go along with conventionality then research worlds and everyday life are threatened with disconnection. We are dubious about the prospects for progressing disabled people's own agendas for research if current distinctions between the academy versus activism, theory versus practice, researchers versus non-researchers and abstracted versus accessible findings, remain in place.

In relation to the analysis of biographical accounts of people with 'learning difficulties', Whittemore, Langness and Koegel (1986, p7) argue that in the course of the critical review of the interface between life events and their personal interpretation, the researcher comes to understand the individual in a way that the individual him or herself probably cannot. While Khadam may not view his responses to stupefying questions as theorising the socially contested nature of disability, and we say this not without a hint of irony, we feel a responsibility to capture the importance of his responses – to affirm a sense of significance in light of his involvement with self-advocacy. Simultaneously, researchers also need to be sensitised to such potentially revolutionising actions.

SELF-ADVOCACY OUTSIDE THE MEETING ROOM: PERFORMING ARTS
Our account of Khadam, is still very much our account: our attempt to be creative (and we have been told that we have failed!). A clear example of creativity, which furthers the reliable alliances of self-advocacy to the development of

empowering service provision and practice, has been demonstrated through the performing arts of people with learning difficulties. The following is taken from our account of a theatre production by people with learning difficulties that we presented to audiences including users of a local Adult Social Education Centre and members (from Goodley and Moore, 2000):

Paul stands and walks to the front of the room. He tells the audience, 'Right, we're now going to show you our second review should be'.

Three members of staff enter, a physiotherapist, a social worker and keyworker. Each are introduced by Paul as he shows them to their seats.

Paul: Is the first person ready to come in?

The client, played by Rosa, enters stage left with her mother Julie, who asks Rosa if she is 'ready for this'.

Rosa: Yeah, but there are things that I might say but don't be offended will you?

Mother: Don't worry about it dear, this is your review.

They sit down - Rosa on one chair, her mother joining a chair at the end of the row of professionals. 'Oh, if you'll excuse me, I haven't got the right file', admits Paul. He leaves to get the right documents. He is away for a short while. Nothing is said in the room. When he returns, Rosa's mum asks if they can start. 'NO', shouts Paul, turning from chairperson to audience instructor. 'Now', he reminds us, 'Let us not forget the two people listening at the door who shouldn't be listening'.

Enter Alf, broom in hand, and Tina [stage right].

Alf: What are you doing?

Tina: Shhh… I'm listening.

'And let us not forget there's two people in the Garden', points out Paul.

Enter Paula and Peter who appears to be looking into the room through binoculars [stage left].

Paula: What's going on in their Peter?

Peter: There's an interview on.

'Now can we start', asks Rosa's mother, impatiently. 'We may. Carry on', instructs Paul as he takes his seat – Rosa on one side and the professionals and her mother on the other.

The professionals talk among themselves.

Physiotherapist: I hope this doesn't go on long

Social worker: [Tuts] I have to go to another boring review.

Mother asks 'Pat' [Rosa's stage name], 'Are you ready?'

Pat nods.

Mum: Ok. Can we start talking about Pat.

Physiotherapist: [To mother] Well, Pat has been doing physio over the last 12 months. She's finding it hard to do and she's not handling those things that are available for her to do.

Mother: What is there exactly for her to do?

Keyworker: Different courses, sewing, computers …

Social worker: … caring for old people, childcare.

Mother: [Leaning over to physiotherapist] Well, as her physio, what would you suggest?

Physiotherapist: Well… she might find it difficult and things hard to do.

Mother: Well, this is it. She really can't do these things can she?

Enter tea lady, 'I've brought a cup of tea'. Mother takes tea [mimes drinking from a cup].

Flashpoint (on 2minutes 35seconds)

Pat [Rosa]: STOP! [Stands up, arm raised] Why are you talking to each other? [Shouts] WHY AREN'T YOU TALKING TO ME? I'm sat there [points to chair] sat like a stuffed dummy.

Mother: Calm down love.

Pat: NO! [Stands forward and points] Its my review after all and I'm sat there listening to you muttering to one another. [shouts] NONE OF YOU ARE TALKING TO ME.

Mother: Okay, okay, what would you suggest? How would you like it to be?

Pat: Right, I'll show you [turns to the audience and shouts] LADIES, I'LL SHOW YOU HOW I WANT MY REVIEW.

Pat tells the physiotherapist, 'I don't want you, you can go'.

Physiotherapist shakes hands of staff and mum and leaves.

Pat gets rid of tea lady, 'Ill have my tea later'. Asks her mother to move her chair. Moves her and her chair by her own chair. Social and keyworker, chairs in hands, are waved forward. The four chairs now form a square. She tells Paul, 'I'll sort you out later'.

Audience laughs.

Paul plays to the audience, 'Let me know when you are ready!' Pat does. She kicks him out, 'Can you leave please'.

Then she turns to the onlookers and listeners. First, Alf and Tina.

Pat: And what are you doing? You can go! [Audience laughs]

Then Paula and Peter.

Pat: And what are you doing? You can go! [Audience laughs] [turns to face audience] And this is how I want my review, in a nice little square, at home [sits down].Now can we get started? Thank you. Soon we get it done the better.

Mother: Shall we find out first what suggestions the keyworker and social worker have?

Pat: Yeah.

Mother: Give us some things that Pat might want to do please.

Keyworker: There are different courses, sewing, computers …

Social worker: … caring for old people, childcare.

Mother: Which of the would you like to do? [addressing Pat]

Pat: Old people – I don't like children they get on my nerves.

[Mother and audience laugh]

Mother: What for five days of the week?

Pat: No. Centre for two, go to the old people's home for three.

Mother: I suggest you get in touch with your keyworker and set up a timetable. How does the keyworker feel about this?

Keyworker: Fine. I'll go along with it [Smiles at the audience]

Mother: Is there anything else?

Pat: Eh…

Mother: Is that it?

Pat: Yeah.

Mother: Is there anything else you'd like to put forward?

Pat: No.

Mother: Are you sure while we're here?

Pat: No. I'm sure.

Mother: Okay. Shall we thank these people for coming?

Pat: Hmmmm… Yeah.

Pat and her mother shake the hands of the two professionals. The chairs are moved to the side of the room. Mum and the two staff leave stage left. Rosa, stepping in and out of role makes a speech to the audience:

'And this is how I want it to be, I don't want it in any public place. I want it in my own home, where it is quiet and you get some peace'.

She walks off to 'There's no limit'.

I have suggested elsewhere that self-advocacy is the public recognition of the resilience of people with learning difficulties (Goodley, 2000). Such public displays – not only through the campaigning activities of the People First movement but also through other creative for a such as performing arts – are crucial. Why? because acting differently is so important when lives are so constantly surveilled:

Someone told me a tale the other day. It got me thinking. Pauline and Micheal have split up. Ending 15 years of marriage. They met in their twenties, at the local Day Centre,

courted for a few months and were married by the winter in a little registry office in the village where Pauline's family lived. Their years together seemed so wonderful to us, from the outside. Unlike many of their friends they did not automatically move from family to group home. They rented their own flat above the chippy on one of the main arterial roads into Manchester. Michael worked in a factory about a mile away from their flat and Pauline would meticulously and lovingly keep the home. By five, every week night, they would be snuggled up on the sofa, eating TV dinners and chatting away about their day. Pauline would sometimes pop into the Day Centre to see her old mates. She would be weighed down with shopping. In amongst the vegetables would be a little something for Michael – a keyring, classic car magazine, a chocolate bar. Always a little something for 'him indoors', she would tell her friends with a glint in her eye. As a couple they would represent their self-advocacy group. An appearance at a conference, an impressive presence at a services consultation event and a constant reminder that there was more to life than centres, sheltered workplace, IPPs and segregated homes. Their lives were rich. Close friends at the working men's club that they met up with at the weekend. Weeks in Blackpool at their favourite guest house. And a shared sense of self. It always made people sit up, when Michael would say, 'my wife and I'. So formal, so loving.

But, you see, Pauline and Michael have split up. Pauline met with Matt – also member of their self-advocacy group and an old friend – over coffee in the train station. 'I have had it with him', she explained. She opened up her heart and spoke of the times, again and again, of Michael lashing out at her, in the heat of an argument. A punch on the arm, deadening it. She hit back, but Michael did not even flinch. Until that day, that day when she bumped into Matt – a chap she used to go out with before Michael – and told him what had happened. Michael and her had had an argument and he had punched her in the arm. Matt was not happy, 'You shouldn't let him do it, you know, it's not right'. As one coffee turned into three, she had made up her mind. Matt had convinced her. She rang Michael and told him she was never coming back, 'I have my

own life to lead. And I want to spend it with Matt'. She spent the night on Matt's settee. Matt had his own flat, a new one, he had just moved in. The next morning, she waited until Michael had gone off to work, and let herself into their place – the place she used to live – and filled a bin liner with clothes. Before closing the bag, she carefully put in her favourite photo of their wedding. She was back at Matt's place by lunchtime, but he wasn't alone. Standing outside the door, a face as grim as any she had ever seen, was her Mum. Her sister was also there. She looked disappointed and teary. 'You're not living in sin with him … with Matt. You need to get back to your husband', shouted her Mum. It took a bit of convincing but eventually Pauline, her Mum and her sister Tracey were sat silently together in Matt's living room. Matt had done as he was told by Tracey. He had fucked off out of the flat, taking a wander around the block. The women spoke for a good hour. They listened to Pauline explain her unhappiness at being with Michael, of his mood swings, his temper. They listened to Tracey suggesting that Pauline and Michael get together to sort things out. 'These things happen in marriages, you know'. But Pauline's mind was made up. 'Please go, I am happy here'. And her two favourite women in the world stormed out of the door, just as Matt was returning from the chippy. Michael meanwhile had fled the marital home and was back in his beloved Rochdale. Their flat lay empty.

This story has really happened. In many ways it is a common tale of relationship breakdown – sad but not rare. However, it raises concerns for the right of people with learning difficulties to simply break up a relationship. I have met Pauline, a couple of times, at conferences and events. I also have met Michael, I like him, I like them both. I am sad that they are not together. Concerned that Michael was hitting Pauline. But even more troubled about what happens next. Because, you see, at the time of writing, the talk is that Pauline will be moved into a group home. Her social worker and family are concerned that she cannot live independently. I have heard that certain professionals and family members believe that Pauline and Matt are a match made in hell – they are both, as one professional put it, 'just not capable of looking after

themselves, never mind each other'. By splitting up their relationship, for good reasons I am sure, Pauline has put herself at risk: of losing the independent living she shared with Michael and gaining the dependent and potentially limiting experience of life in a group home. This says much about the ways in which society and its institutions treat people with learning difficulties:

- Everything in life is potentially open to surveillance and, consequently, control;
- Even personal relationships and private matters can become ward of the state;
- Relationships are open to risk assessment and professional interference;
- The independence of women with learning difficulties is often seen as a product of the 'competence' of their partners;
- Breaking up is hard to do – particularly when others are mapping the terrain of what happens next.

What is a complicated and often heart-breaking experience for many, becomes a question of professional control and assessment. The tale of Pauline and Michael reminds us that power never leaves the lives of people with learning difficulties. Hence, the need for self-advocacy.Hence, self-advocacy as a reliable alliance.

UNDERSTANDING INTELLECTUAL DISABILITIES: BECOMING RHIZOMATIC

As conference delegates, we are brought together under the banner of the study of 'intellectual disability'. There is a need, I would maintain, to unearth and question the very assumptions that underpin our understandings of this concept. *Rejecting deficit assumptions* is a key component of forming alliances with self-advocacy, as we have seen earlier when thinking about co-operation and collaboration.

First, we need a sociology of those who study mental deficiency ... second, we badly need a sociology of those who work in institutions ... third, we need to see mental

defectives in terms of the general theory of social problems (Dexter 1956, pp10-11).

This call for a sociological imagination – for thinking creatively - has been taken up since the 1950s, with the following quotations capturing some of the attempts to redefine intellectual disability:

What should concern us is the mystifying fact that so many social scientists ... do not regard mental retardation as a social and cultural phenomenon. I say mystifying, because nothing in the probabilistic world of social scientific reality is more certain than the assertion that mental retardation is a socio-cultural problem through and through (Dingham, 1968, p76).

Mental retardation [sic] is, in fact, a socio-political not a psychological construction. The myth, perpetuated by a society which refuses to recognise the true nature of its needed social reforms, has successfully camouflaged the politics of diagnosis and incarceration (Bogdan and Taylor, 1982, p15).

It means no one will hire me on a job unless they hear from a rehab counsellor or social worker. Get what I mean when I say it's hard for handicapped people [sic] to find a job? (Larry on what learning difficulties means in Langness and Turner 1986, p71).

If someone else whispers a lot during the play people might ignore it or get angry. If we whisper it is because we are retarded [sic]. It's like we have to be more normal than normal people (Martin Levine, self-advocate, in Freidman-Lambert 1987, p15).

What is retardation? It's hard to say. I guess it's having problems thinking. Some people think that you can tell a

person is retarded by looking at them. If you think that way you don't give people the benefit of the doubt. You judge a person by how they look or how they talk ... but you can never tell what is inside the person (Ed Murphy, in Bogdan and Taylor, 1976, p51).

Clearly, though, understanding intellectual disabilities as a product of society and its practices is a leap of faith too far for some. Recently, Vehmas (2005) has suggested that we need to ask serious questions about humanity, personhood and access to human rights that are raised by the existence of very real, organic, embodied intellectual disabilities. 'What about people with profound intellectual disabilities?' is a question I have been asked many times when espousing the virtues of self-advocacy, 'does self-advocacy really represent these people?' At the heart of these questions is an assumption: that self-advocacy, empowerment, theory and research, co-operation and collaboration is incapable of touching those whose identities are imprisoned by severe impairments of mind. It is a key reason why people with intellectual disabilities have remained marooned from certain developments in the social model of disability: the social model cannot cope with something so unmovable asocial and material as the severely impaired brain.

These assumptions and associated rejections risk marginalising people with intellectual disabilities from debates about their services, rights, professional practice and self-advocacy. While I have attempted to look at just a few examples of the ways in which self-advocacy can exist as a reliable alliance to the furthering of these debates – via co-operation, collaboration and creativity – I want to end by suggesting that in thinking through our assumptions – how we understand learning difficulties – we may well want to look at the foundations on which they are based. In a current study 'Parents, professionals and disabled babies', colleagues and I have been talking with parents of disabled babies about their experiences of health and social care. One key research question relates to the ways in which parents and

professionals negotiate and construct understandings of impairment. The following extract is from an interview with a parent:

> I have this booklet written by the mother of a special needs child. It's called Welcome to Holland. She talks about the wonderful dreams we attach to pregnancy, birth and having the child and likens it to going on a journey to Italy. It's what you've always dreamt of, you get on the plane and you're all excited. And then you get on this plane after a couple of hours later or whatever, you've now landed in Holland. And you were expecting this fantastic place, Italy, and you're just so disappointed. But if you look carefully and don't let go of Italy you'll see the beauty that's in Holland, the beautiful tulips, the canals. It will have certain things Italy may never have. You'll meet people that you wouldn't meet if you were going to Italy. And you might not get Italian wine but, hey, they've got some really beer in Holland (Rebecca Greenwood).

This parent's understanding of her child's disability raises interesting ideas associated with fluidity, movement, flux, change and uncertainty. My colleague Pamela Fisher has drawn attention to the ways in which parents draw upon different narratives to make sense of their children (Fisher, 2005). These include linear narratives, with beginnings, middle and ends, some with more focus on the hopelessness of impairment others associated with struggling for their child's rights. Another narrative is the one hinted at here, which we have termed the narrative of the 'philosophy of the present' (Fisher and Goodley, forthcoming) or 'the parent as becoming' (Goodley, forthcoming). It is to the latter I want to turn.

A way of understanding parents' engagement is located in Deleuze and Guattari's (1987) understanding of 'becoming'. By this, we are not referring to 'how the human being is constructed' (Lawlor, 1998) but to how subjects transcend the given (Buchanan, 1997): *to become* or to engage with places of *immanence*. To create action and results rather than

establish transcendentals. Not being but always becoming. To become rather than to be. For many of parents, becoming is infinitely preferable to some of the expected demands placed upon them:

> Rebecca Greenwood: You see, I can't keep chasing the normal. I mean I've done so much to try and make my son normal but I can't keep that up. It really does detach you from life. I need to accept him in the ways that he is and just enjoy them and him. I must stop pressurising myself

One take on this would be that they lack a reflexive vocabulary that allows them to talk of themselves as subjects. They are uncertain and this is bad. It could also be argued that some parents apparently contentedly reflect on the present, with seemingly scant regard for past and future. An alternative reading is provided by Deleuze and Guattari (1987). They suggest that natural history and social science is based, in part, on genealogical understandings of progression that tend to think in terms of relationships (between A and B). Instead, they argue, thinking should be and actually is enacted in terms of production (from A to Z). Here then, becoming, is not based around relational binaries (becoming a good parent rather than a bad parent) nor is it about constructing a particular human subject (the good mother). Instead, becoming produces nothing other than itself. What is real is becoming – embracing the becoming of parent/ing (Ibid., p263)

> Becoming is a rhizome, not a classificatory or genealogical tree. Becoming is certainly not imitating, or identifying with someone; neither is it regressing-progressing … bands, human or animal, proliferate by contagion, epidemics, battlefields and catastrophes (Ibid., pp265-266)

Here 'being' is best understood as pure difference or becoming. Here we need to embrace Deleuze and Guattari's nomadic rhizomatic thought as the means through which to refute the urge to impose forms, order and subject:

Write to the nth power, N-1, write with slogans: Form rhizomes and not roots, never plant! Don't sow, forage! Be neither a One nor a Many, but multiplicities! Form a line, never a point! Speed transforms the point into a line. Be fast, even while standing still! Line of chance, line of hips, line of flight. Don't arouse the General in yourself! Not an exact idea, but just as idea (Ibid., 1987, p 27).

The rhizome is a figurative visual term, used by Deleuze and Guattari (1987), to describe and prescribe non-hierarchical networks which may be seen in politics, cognition, desire, love, parenting and so on. Rhizomes are oppositional to trees which symbolise hierarchies, linearity and extreme stratification. Ignore trees. Think, instead, of weeds, grass, swarms and packs.

To think creatively about intellectual disabilities, then, may involve an engagement with uncertain assumptions and ideas, not yet properly formed, not yet rooted, that allow us to think outside the box of the tree-like structure of 'intellectual disability'. For self-advocacy to be a reliable alliance then it requires allies and supporters to think again about the question, 'how do I understand intellectual disabilities'.

CONCLUSIONS
This conference offers an ideal opportunity to take to task these three key concepts, phenomena, entities and practices. The question is not:

Is self-advocacy a reliable resource?

But what conditions need to exist to allow self-advocacy groups, researchers, policy makers and practitioners to make reliable connections? The answers to these questions are clearly, it seems to me, bound up in the assumptions and expectations that we hold.

Thank you.