

Telling the History of Self-Advocacy: A Challenge for Inclusive Research

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Background This paper tells the story of Central England People First's (CEPF) History Project.

Method This was an inclusive research project, owned and controlled by members of CEPF which sought to chart its 21-year history, 1990–2012.

Results It illustrates both the strengths of such a project and some of the challenges.

Conclusion It concludes that using inclusive research methods enabled the story to be told, but that it was less successful in addressing questions about why the organization grew and prospered in the 1990s, only to struggle in its later years, and what this tells us about the conditions which enable self-advocacy to flourish. The paper was collaboratively written by the CEPF History Project team and an academic ally. Different fonts differentiate the contributions, although it is acknowledged that lots of the ideas were shared.

Keywords: history, inclusive research, intellectual disabilities, learning disabilities, self-advocacy

Accessible Abstract

This paper explores issues in telling the history of self advocacy using inclusive research methods. It explains how and why CEPF recorded its history, what we found out, and some of the questions we have had to think about:

1. whose voices we hear
2. what to include, what to leave out
3. what parts of the research people with learning difficulties can do
4. what self advocacy means to different people
5. how to make use of research other people have done.

It raises some new questions about directions for inclusive research. The Paper was written by the CEPF History team – Craig Hart, Ian Davies, Angela Still and Catherine O'Byrne - working with Jan Walmsley. We wanted to make it clear what were Jan Walmsley's ideas and what were our ideas. We have done this by writing our ideas in a different font. BUT lots of the ideas belong to all of us.

Introduction

We wanted to do this project to remind ourselves how far we have come as individuals, as an organisation and as a movement. It is important that groups like ours are celebrated. Especially when a lot of them are closing. People have forgotten how important we are, hopefully this will help them to remember. (CEPF & Walmsley 2012)

This paper describes how and why Central England People First (CEPF), a leading English self-advocacy organization based in Kettering, Northamptonshire, recorded its 21-year history in 2011/12, and some of the issues it raised about telling the history of self-advocacy.

This was an inclusive research project, led by members of CEPF, with help from a project worker, and CEPF 'friends' including Jan Walmsley who wrote this paper with the CEPF History Project Team. Jan Walmsley wrote the chapter using the research we have done to record our history and explaining how our history fits in with the history of self-advocacy. She then met with us, discussed what she had written, then made some changes.

The paper is written so that it is clear when CEPF members are 'speaking' and when Jan Walmsley is speaking. CEPF words are in a different font to make them stand out. Some of the ideas are shared – this is indicated by using the term 'we'.

Self-advocacy is a term used for the individual or collective voice of disabled people. Self-advocacy

organizations developed alongside the deinstitutionalization of people with learning disabilities, and their appearance is associated with an increasing recognition of the rights of disabled people during the last quarter of the twentieth century (Ward 1998; Buchanan & Walmsley 2006).

Self-advocacy has been international. It has appeared in many developed countries – western Europe, North America, Japan and Australasia since the 1970s (see *British Journal of Learning Disabilities Special Issue* 2006). It has developed differently in different countries, with some national movements being fostered by parents' associations, while others have developed within services or as a result of advocacy by powerful allies. Other than in Denmark (Bylov 2006), the recent history of self-advocacy has been poorly documented. There is a danger of information being lost given the ephemeral nature of many self-advocacy organizations and the ageing of some of the leaders of self-advocacy (Caldwell 2010). This is why CEPF bid for money to record its history.

Literature review – what we know about self-advocacy's history

Self-advocacy developed in the later twentieth century, alongside, and intimately related to deinstitutionalization and new ideas – normalization, the social model of disability – which redefined people as citizens, with rights, rather than victims and beneficiaries of the charity of society (Williams & Schoulz 1982). Its early history is told in many places – see, for example, Bersani 1998; Goodley 2000. Buchanan & Walmsley 2006 following Chapman (2005) point out that in its early days, it was the creation of advocates, people without learning disabilities who encouraged 'speaking up' events. There is some evidence that people with learning disabilities were speaking up long before the history was conventionally recorded. Ledger and Shufflebotham uncovered 'songs of resistance', composed and sung by residents of long-stay hospitals, which predate the flowering of self-advocacy in the late twentieth century (2006). There is documentation of riots in hospitals (Open University 1996) and of repeated absconding (O'Driscoll & Walmsley 2010). Walmsley (2005) unearthed a letter from a resident of Bromham Hospital Bedfordshire, England, which used the term 'standing up for myself', a term familiar in the later self-advocacy movement (Simons 1992), in a letter written in 1943. However, no dedicated research has charted this earlier history of resistance unlike that for other disabled groups (Campbell & Oliver 1996; Goodley 2000), and conventional wisdom has it that self-advocacy

began in Sweden in the 1960s and spread via the USA into the Western world. Lots of groups were set up in the UK in the 1980s and 1990s.

Our group, CEPF, began in 1990. It was then called Northamptonshire People First. Like lots of other groups we were funded with the help of Mencap.

Self-advocacy has been described by many people with and without learning difficulties. The CEPF History Project described it as:

For us self advocacy has meant lots of things. When we were first set up it was about learning to speak up for ourselves and making people listen to us.

There are two important strands

1. Developing the skills and confidence to speak up as an individual and making people listen. This was the emphasis in the early days of self-advocacy (Open University 1986; Buchanan & Walmsley 2006);
2. Campaigning and representation: this is more of a collective activity. People have campaigned on many issues, including language – fighting the label 'mental handicap' and advocating for more 'People First' language (Chapman 2005), in the UK the use of the term 'people with learning difficulties' (Goodley 2000).

The collective activities of self-advocacy have developed in different directions, such as reviewing the quality of services (Scourfield 2009), consultation (Aspis 1997), campaigning (CEPF 2012), research (Atkinson 2010), recording the history of institutions (Potts & Fido 1991; Manning 2008) and, most ambitiously, self-advocacy as a 'new social movement' (Bersani 1998; Goodley 2000).

In the UK, and North America, 'independent' self-advocacy in which people with learning difficulties employ their own support workers has been long seen as better than service-based self-advocacy (Williams & Schoulz 1982; Ward & Schoulz 2000; Buchanan & Walmsley 2006). This is the position adopted by CEPF (originally Northampton People First) throughout its 20-year existence.

However, self-advocacy's history has not been served well by researchers. Much that is written about self-advocacy is 'claims making' (Clement 2003), saying it is important while not explaining the conditions that support its success, nor its challenges and difficulties. For example, Hank Bersani called it a 'new social movement' and said:

A social movement writes its own history and defines its own roots (1998 p. 63)

Dan Goodley echoed this ambitious view. He wrote:

Self advocacy constitutes a political activity with potentially massive impacts upon the lives of people with learning difficulties (2000 p. 6).

However, in 2012, there was little evidence that people with learning difficulties were writing their own history, other than through individual life stories, and in projects such as that described here¹

The only extended and scholarly history of self-advocacy is by Frank Bylov, published in full only in Danish (Bylov 2006, 2008). He identified 3 'Generations of Movements' in Danish self-advocacy:

1. 'Movements of Cultural Role Transgression': clubs run by professionals for sports, theatre, art, festivals – usually in segregated settings, always under the control of professionals;
2. 'Movements of self-advocacy': developed from the late 1980s, under the wing of the Danish parents' organization with the purpose of recruiting and educating a new generation of self-advocates. People with learning difficulties occupied symbolically powerful positions but because they relied on money and help from LEV they could be ignored when they said things LEV did not want to hear;
3. 'Movements of political empowerment': began when ULF, the national organization, was set up in response to cutbacks which reduced the wages of people in sheltered workshops, showing they really did not have any power (1993). ULF leaders still work with LEV when it increases their influence, but also act independently, calling themselves 'developmentally hampered', developing a pride in their disabled identity and working out for themselves what they want and how they will get it (Bylov 2006).

Bylov suggests this idea of 'generations of movements' could help chart the development of self-advocacy internationally. But that has yet to happen beyond Denmark.

More of the history of self-advocacy has been recorded through life stories. Goodley recorded the life stories of six leading self-advocates in the 1990s. One of them, Joyce Kershaw, explained what self-advocacy meant to her:

People First teaches you how to stick up for yourself and we do, you don't hear as many people calling us now (2000 p. 230).

Mabel Cooper, once Chair of Croydon People First, says that telling one's story is also 'speaking up':

It's still advocacy but it's doing it in a different way ... it's letting the world know what it's like now and what it was like then Atkinson *et al.* (2006) p. 19.

Some work has been published about leadership in self-advocacy. Again, this is largely life story based. Nancy Ward, leader of US-based Self Advocates Becoming Empowered (SABE), wrote of the struggle she had had in building confidence (Ward & Schoulz 2000). In 2006, Karen Spencer, at the time a leading light in CEPF, reflected on her experience of leading CEPF. The title she gave the chapter 'I've had enough of the everyday thing' gives a sense of her exhaustion with being at the head of a federated self-advocacy organization, with problems of governance and managing employees (Spencer and Walmsley 2006), a task that would have challenged most people without having also to contend with learning difficulties. Recent research in the USA into the leaders of self-advocacy is based on analysis of the stories of 13 leaders, partly inspired by the recognition that as these leaders are growing older, they are not being replaced (Caldwell 2010). This approach only goes a limited way to explain *why* there are few new leaders.

Individual histories are important. They show what a difference self-advocacy can make to individuals, which is, of course, important (Atkinson 2010). But they are only individual stories and do not help to explain the ways in which wider social, economic and political contexts in different countries may lead to different ways of doing self-advocacy or affect its impact.

Simone Aspis, who terms herself 'a disabled women with learning difficulties' (Aspis 2000b p. 70), commented on the importance of women with learning disabilities understanding the discrimination they face and their relationships with other groups in society: she argued that telling individual stories does not help them with a political analysis of their situation (Aspis 2000b p. 71). Similarly life stories alone cannot explain why grass roots user led self-advocacy flourished in the 1990s and now appears to be declining (National Forum 2012; Roberts *et al.* 2012).

This echoes concerns we have, that we are not finding new people to come in and learn to lead our organization. Other

¹At the time that CEPF were writing their history, Reinforce in Victoria, Australia, were carrying out a similar project.

than funding problems, we do not know why so many self-advocacy groups in England have closed recently.

Who should tell the story of self-advocacy?

One major issue in recording the history of self-advocacy is who should do it. Although he is not disabled, Frank Bylov had the full support of ULF in researching and writing about their history. Nor did he try to put this in accessible language when he published it. But some self-advocacy leaders believe that only people with learning difficulties should tell this story.

'Nothing about us without us' has been an important slogan of the disabled people movement in England (see Campbell & Oliver 1996), and Simone Aspis used it to challenge the right of non-disabled people to have any say in the history of learning disabilities (Aspis 2000a). If there is this level of controversy over telling the history, then recording the story of disabled people own movement as an outsider is even more controversial. And this may explain why it has not been attempted.

In our project, we asked Jan Walmsley to write the history of self-advocacy – we only recorded Central England's history. This was because we had not read the books and papers that Jan Walmsley had read.

Possibly a result of Aspis's challenge is that there has been no detailed history of self-advocacy in England. Those academics interested in self-advocacy are frequently also committed to 'inclusive research', 'nothing about us without us' (Walmsley & Johnson 2003; Townson *et al.* 2004; Chapman 2005). They may be hesitant to push for a scholarly history of self-advocacy because of the difficulties in making it inclusive. The result is that it is difficult to come to a fuller understanding of the conditions which enable independent user-led self-advocacy to flourish, or the reasons for its recent decline, a decline CEPF have experienced as an organization.

This was the situation when CEPF began to write its history.

Materials and Methods: The History Project: How We Did It

How it started

Central England People First had been thinking about writing our history for several years. We knew there was a lot to say as we had been around since 1990 and had done many important things. We knew it was urgent because we had lots of funding problems which almost forced us to close, we kept having to move offices and we never had the time or knew how to store

our papers safely. As some of our founder members left, they took their memories with them. CEPF has always been led by its members, and we wanted to do the history ourselves. But after lots of discussions, we decided we could not do it all ourselves and that we should bid for money to:

1. Employ a project worker with oral history skills to work alongside us;
2. Buy equipment – video cameras, digital recorders, new computers and printers;
3. Set up a History Project website – with help from experts;
4. Write a booklet;
5. Hold an exhibition;
6. Run workshops for our members to help them learn about archives, oral history, interviewing, website development, scanning, Skype and writing up what we found out.

We were really excited when the Heritage Lottery Fund gave us the money in 2010. We interviewed for the project worker job and gave it to Catherine O'Byrne who was with us throughout the project, and started work at the end of 2010.

Central England People First has always made sure people with learning difficulties run things, so the project was led by one of our members, Craig Hart, supported by the project worker, and seven CEPF members – Ian, Mark, Angela, Stephen, John, Philip and Louise.

Instinctively, because of a long tradition in CEPF of people with learning difficulties doing the work themselves, this was always going to be an 'inclusive research' project, although this is not language its members use. It met Walmsley and Johnson's 5 criteria of inclusive research:

1. A research question owned by disabled people;
2. Furthers the interests of disabled people;
3. It is collaborative – disabled people involved in the doing of the work;
4. Some control exercised by disabled people over process and outcomes;
5. Question, reports and outcomes must be accessible to people with learning disabilities (Walmsley & Johnson 2003 p. 95).

Doing the work

Much work was sorting out documents and scanning them so they could be on the website.

More work was finding photographs, scanning them and working out who was in them, where they were taken and when. Once this was complete, we could almost tell our story just by photographs.

We agreed and recorded a timeline of the big events in our history.

We held 'memory lane' sessions with members and with people who had worked with us during our 21 years, and recorded these.

We did interviews with some people who were important in our history and who have left CEPF.

Results and Discussion

New Skills

Along the way we learnt many new skills.

We recorded what we did with photograph stories: here is one from our visit to the Northamptonshire Archives office (Figure 1).

We bought new computers with touch screens and learnt how to use them.

We learnt how to scan photographs and documents and to make sure we put titles and dates on them.

One thing it forced us to do was to tidy our office – it has never been so well organized, and we took the opportunity to buy some new furniture and to get the office redecorated.

Challenges

So far so good, with help from friends of the organization on the Project Advisory Group, from a website company, Northamptonshire Archives, Paul Bingham, our photographer, and the East Midlands Oral History Association, we worked hard and got lots of material into the website.

But we had lots of challenges on the way.

Money, people and time

At the time we got the grant, we had lost some long established support workers, and we were in financial difficulties. This meant we could not concentrate only on the history project because if



Figure 1 Members of the project team visit Northamptonshire's archives.

we did, the organization might fold. We had to get out and get grants and then do the work and this took us away from spending as much time as we wanted on the project. Fortunately, the funders agreed that we could spend more time as long as we did what we had promised and kept within the budget.

Who does the interviews?

When we started, we expected that members of the History Project Team would do all the interviews. This was in keeping with our principle that people with learning difficulties lead the work. But some people who had left CEPF – people who had once been very important in the organization – did not want to answer questions from their old colleagues. We decided to ask an outsider to do these interviews for us. This was not really satisfactory, and it was not what we said we would do originally. But it was the only way to get their stories.

Who is it for?

In the funding bid, we said the project audience was:

1. Our members and people who had worked with CEPF;
 2. Other people with learning difficulties in Kettering;
 3. The people of Kettering – who don't know much about our organization;
 4. Other people with learning difficulties;
 5. Professionals and academics.
- This meant producing our history in different ways
6. For other people with learning difficulties who do not understand self-advocacy, we had an exhibition and launch to encourage them to record their own histories;
 7. For professionals and other important people, we need to influence we needed to write something that helped explain self-advocacy. We knew that they might want more detail than would normally be in an easy read document. This was a difficult decision but we decided that with help we could write something that we couldn't write by ourselves but that we could understand;
 8. For academics, we wanted to explain how our work fitted in with the story of self-advocacy. We could not tell this bigger story so we asked Jan Walmsley to write this for us. We decided to organize this in a booklet with Jan Walmsley words on one side of each 2 pages and our story on the other side. We had lots of meetings to agree what was written and what photographs to use. We called it '21 years of CEPF – A journey and a celebration' (CEPF & Walmsley 2012). We tried to use both the simple language that we like and the detail and background funders like. We learnt the importance of this the hard way. We have had applications for funding turned down because funders thought that we had not included people with learning difficulties – they just did not get it!!!

Whose voice counts?

When we had almost completed the booklet, we showed it to two people who had worked for or with CEPF in the past. Both said we had left out some really important things in the booklet:

1. The pioneering work CEPF have done in IT, being the first self-advocacy group to have its own website;
2. Using IT to keep contact with people in other countries;
3. Influencing the local council;
4. Carrying out consultations with people in other areas to find out what they think;
5. The big conferences we have run – on leadership and on Valuing People;
6. An IT network for self-advocacy internationally;
7. Having our own company car (email correspondence 17 January 2012).

These are not what we thought had been most important. They are in the timeline, but for us it was more important to record in the booklet the things members remember. It was hard to think of anything we didn't remember as being important. We talked about the things that we remembered the most being the most important. But we wondered whether this was true or whether the things that we remembered most were the most fun/horrible or the most interesting.

It was also hard for us to think about things that other people did for the organization as being important because we weren't there to see it, or to know what happened. We could only say what was important to us as individuals.

We have always debated whether support workers should have their own voice, and on the whole, we have said they shouldn't. We sorted this by doing an interview with the support worker and putting it on the website. We also included some of the things he thought were important in the timeline and the booklet. So his voice is there too, alongside ours. That seemed fair.

The things [the support worker] said are more the backdrop but the most important things are those that people have personally been involved in the things they have achieved. – Ian Davies.

Conflict – what can and cannot be recorded

We were unsure how to record disagreements. It's OK to write about disagreements between support workers and members. Joyce Kershaw told the story about how supporters were excluded at the 1993 People First Conference in Canada, for example (Goodley 2000), but no one ever talks in public about when members fall out, or worse, when members bully other members. But this was the reason some people had left, and if we were recording the history, we really should talk about that.

However, we knew this would hurt people. So we left it out. We are too close to it, which was really good for some things but when it got to the hard stuff, it meant it was more difficult.

We had some bad partnerships. One university would not include people who could not read in their research. This meant we couldn't say they were working in partnership with us. But we have decided not to name them – it is enough that you know these things happened, you don't really need to know who it was. By keeping some of this private, it means that we can talk about the bad things rather than ignoring them altogether. We feel comfortable with this way of doing it.

You want to forget the battles. Yes they are important but... well they were hard and things have changed. – Ian Davies.

We think this will make it more difficult to make sense of what happened to self-advocacy but we are still in it.

Self-advocacy is not history, we are still here we just have a history. If we dug into this, we really would be history because we would not be able to carry on. If we have to carry on working together, we can't dig things up too much, it's all water under the bridge.

What we found out

A lot of what we found out we knew already, but it was not written down. You can see everything we have done in the timeline on our History website (add web reference).

It did remind us just how much we have done, not only in Northamptonshire but across the world. We achieved a great deal. Some things really stand out.

It also told us how much has changed, and we've put this in a then and now table.

Then (1990s)	Now (2012)
The County Council talked with us all the time, and we influenced the Community Care Plan and the race equality strategy	The only time we talk to the council is when we tender for money against other organizations or when they issue a consultation. We do not know the people at all.
We had core funding from the council, which meant we could exist as an organization as well as doing specific projects	We fund ourselves by asking members to pay to come out of their direct payments or by bidding for money to do projects. This makes it very difficult to recruit new members

Table (continued)

Then (1990s)	Now (2012)
We talked a lot with other self-advocacy organizations in England and worked in partnership with them, for example to run the England People First Conference in 1994	We have little contact with other organizations except through the Regional and National Forums, and these are controlled by the government
We came close to getting a national England People First owned by people with learning difficulties in 1994/1995 after the England People First Conference which we hosted	We have a National Forum owned and run by the government
We had regular contact with self-advocacy groups across the world, and there were international conferences every 4 years run by self-advocates	We have some contact with self-advocacy groups in other countries for special projects including research.
User-led self-advocacy groups like ours were seen as the best way to do self-advocacy	Organizations that are mainly run by paid support workers are getting the contracts
We were led by Ian Davies, Karen Spencer, Nigel Lott, Chris Shane, Angela Still, Craig Hart	We are led by Ian Davies, Angela Still and Craig Hart – the same people but fewer of them
We had branches across Northamptonshire and in neighbouring counties – in Milton Keynes, Peterborough, Wolverhampton	We are a small organization with just one office
We paid members for their work	Members pay to come, and we cannot afford to pay them for their work

This looking back has been important to us as an organization and pushed us to think about what the future should look like. We have come up with lots of ideas:

1. A social enterprise to help people employ personal assistants;
2. Working with schools to educate people about transitions as they leave school, where their future is going to lie;
3. Offer work experience to young people and mentoring;
4. Offering buddying to people when they go to see the doctor or to hospital appointments
5. Research to find out how to run our organization better so that we run efficiently but still make sure people with learning difficulties are in charge.

We would like to be able to pay people for this work in future.

Our first step is to visit other self-advocacy groups to find out how they manage some of the things we are finding difficult.

An 'inclusive research' approach

This was an inclusive research project. It met all the criteria for inclusive research set by Walmsley & Johnson (2003). Members of CEPF actively chose to do the project, were in charge of key decisions and carried out much of the work. It was a team approach. Non-disabled people played a hugely significant role, as supporters, advisors and expert consultants – it could not have happened without them – but decisions remained in the hands of the CEPF project team.

In this sense, it demonstrates the viability of an inclusive research approach to a substantial project. Undoubtedly, it took longer than a comparable professionally run project. Compromises were made over:

People with learning difficulties carrying out all the field work interviews proved not to be viable. Emotions were too raw, members of CEPF too close to former members for this to work. However, this is the sort of decision any research team has to make – who is best placed to carry out particular tasks.

Dissemination: not everything was fully accessible, if such a thing were possible (see Redley & Weinberg 2007; Walmsley 2009 for extended discussion). Undoubtedly, this will prove controversial; however, it was a shared and conscious decision, made for sound reasons.

We were not keen to have things which were not in easy read, but we understand that sometimes it is important to make exceptions to our rules.

Recording the history helped members learn about information technology, scanning documents, the importance of keeping records with dates, helping people tell their stories, what you can and cannot say in public and how different voices – of supporters and academics – can find a place in an inclusive research project.

The inclusive research approach worked well to record major achievements and milestones. Working in an inclusive research way may have been successful because being led by members has been central to CEPF since its very early days, as discussed below.

Discussion: Contribution to Telling the History of Self-Advocacy

The CEPF History Project is important as the first sustained attempt to record the history of a self-advocacy

group in the UK. The project demonstrated that CEPF had been an important thread in the story of self-advocacy in England and beyond. CEPF remained in the forefront of developments in self-advocacy for 15 years and came close to setting up a national organization.

We tried very early on to work with other self advocacy groups to set up an England People First. We held a conference and lots of people came. We tried to get a man and a woman from each area. Some people were experienced self advocates and some had never spoken up before. We designed our own t-shirts and we spoke about things that mattered to us. But we did not succeed. It was the politics. People are trying to set up a people first England again and we have shared our experiences of what happened last time. We need to share our history so that people can learn from it.

Central England People First members were the first to address an IASSID International Conference as keynote speakers in Helsinki in 1996. CEPF pioneered new forms of governance in the 1990s, such as a company run by people with learning difficulties, with people with learning difficulties as signatories to company cheques; setting up a federated organization with branches across central England. And CEPF arguably influenced self-advocacy on an international stage, by attending international conferences and pioneering IT-based networking across the world.

It is possible also to infer that CEPF had a distinctive and influential position on self-advocacy. It began in 1990 under the auspices of Mencap, a parents' representative organization, however, unlike its Danish equivalent rapidly distanced itself from parent and carer lobbies, so that within 2 years of its foundation, by 1993, it was taking a distinctive position on the Community Care Plan and the development of learning disability services, and developed 'The Wheel' as a campaigning instrument (Figure 2).

We came up with 'The Wheel' which is a chart that shows all of the important things that people need to live well in the community and how they affect each other. We still use this a lot as we think it is really important.

It also developed a rhetoric of being 'user-led and controlled' well summarized in this quotation from an project interview with a former support worker (paid employees without learning difficulties):

The way we worked was very much as a set of equals, all involved. I might be wrong but I like to think I did not make decisions without people

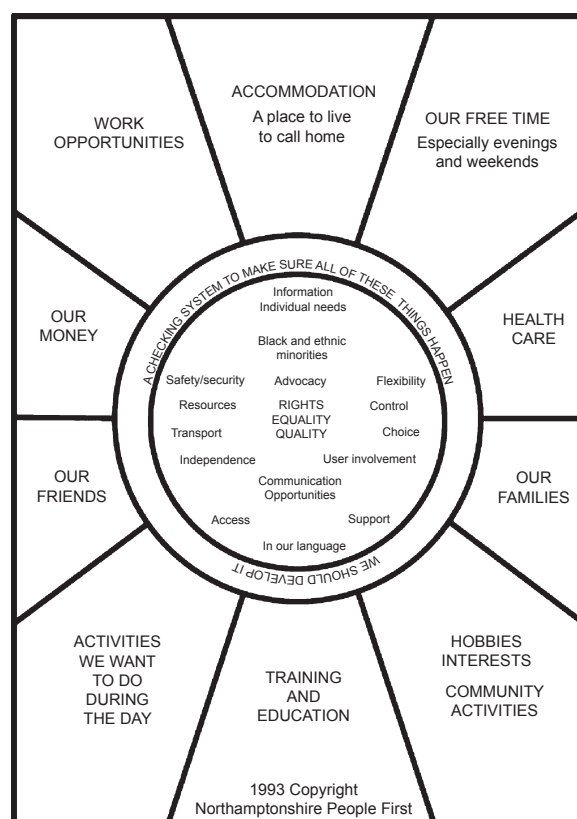


Figure 2 The Wheel: Central England People First's contribution to thinking about Community Care 1993.

being involved, more than consulting.... You had access to everything I had, reading all the post that came in, taking all the phone calls, you knew more than I did because you were talking to people, that set the whole process over how we worked. (interview with former CEPF Support worker Feb. 17th 2012)

The position articulated here has remained highly influential in thinking about UK self-advocacy (Townson *et al.* 2004; Chapman 2005), although has been challenged more recently as impractical, idealistic and excluding people with more complex disabilities (Dearden Phillips & Fountain 2005; Redley & Weinberg 2007)

What CEPF recorded in their history project makes it possible to reflect on its past within the framework set out by Bylov. The trajectory is different. Like the Danish movement, it began under the wing of a parents' organization. Unlike it, CEPF rapidly distanced itself from Mencap. It is as if CEPF skipped Bylov's second generation where its members were coached, but also

stified, by parents' organizations, and leapt to the third generation, characterized by Bylov as 'movements of political empowerment'.

The CEPF History Project is the most recent of many important achievements. The questions it did not answer are:

1. Why Central England was so significant for so long;
2. Why no national organization was established in England;
3. Why People First organizations rarely meet to exchange ideas, develop campaigns, learn from each other as they did in the 1990s;
4. Why user-led self-advocacy of the type championed by CEPF seems to have declined since *Valuing People* was published in 2001;
5. Why younger people are not joining groups like CEPF.

It points to a limitation of inclusive research to date that sophisticated analysis is beyond its scope (Walmsley & Johnson 2003). What the research has done is to stimulate CEPF members to think about these questions and to provide evidence that these are questions which need answers – the next step in telling the story of self-advocacy.

What of the survival of self-advocacy in England? It is of enormous symbolic significance if we are serious about citizenship and rights to have organizations which can represent people's views. And as segregated services disappear so its social function becomes ever more important. It is a challenge for self-advocacy and commissioners alike to find ways it can adapt to the changed external environment in which it finds itself.



The last word goes to Ian Davies with a reminder of why it is important that self-advocacy flourishes.

Never, did I think that I could go from having no choices and being forced to attend a day centre to speaking at international conferences, running my own company and forcing organisations to making things better for people like me. But I did.

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