

Learning from the experts: people with learning difficulties training and learning from each other*

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Summary

This article is about a training project run by Central England People First (CEPF). CEPF has been doing workshops, conferences and other training for over 10 years. It seemed like a good idea to help other people with learning difficulties to learn how to be trainers. This would help them to speak out about their lives and the services they want. CEPF asked the Department of Health for some money to design a 'training for trainers' programme, and try it out. The Department of Health agreed, and CEPF set up the National User Training Development Project. The training team designed a 2-day programme, and asked people in different parts of the country to try it out. Eight organizations agreed, including a care village, another People First group and two social services departments. Eighty people with learning difficulties and support people took part. The project team told them about what training is for, and how to organize it. They also had the chance to try out their own ideas. They practiced 'role plays', 'speaking up', doing quizzes and using video recorders. At the end, the people who took part filled in evaluation sheets, so that the team could find out if the training was useful. Most people said that they had enjoyed it, and that they had learned something. At the end of this project, we think we have learnt two things:

1. People with learning difficulties can be good trainers, because they are experts about services and the things that are important in their lives.
2. Using training can be a good way of helping people with learning difficulties to speak out about how they want to be treated.

Keywords *Empowerment, evaluation, leadership, skill-sharing, speaking out, user-led training*

*While this article is written according to academic conventions, it should be acknowledged as a 'co-production', which depends very substantially on the input and practical experience of the project team, comprising four members of the self-advocacy organization, Central England People First (CEPF).

Introduction: recognition and empowerment?

The wider context for this account of one particular training initiative is defined by a growing interest in involving service users in the planning, management and delivery of services. A significant movement has emerged in recent

years, which has created a strong impetus towards user-participation, and even user-control across a range of care services, including those for people with learning difficulties (see, for example, Beresford & Croft 2001). In England, which is the geographical setting for the initiative discussed here, this has clearly influenced the publication of the White Paper *Valuing People* by the government (Department of Health 2001), and the establishment of a substantial implementation programme in support of the policies set out.

Whilst the central theme is very much one of improving the quality of life for people with learning difficulties, it is important also to acknowledge that the approach taken reflects a commitment to user participation in the delivery of change. The White Paper itself, for example, drew heavily on a consultation process organized by people with learning difficulties, although the extent to which this was truly representative has been questioned sharply:

Our idea of partnership working is somewhat different from the views of the Department of Health. We want real partnership. People with learning difficulties need to be involved right from the beginning. People with learning difficulties should be paid consultants doing consultation work. (Spencer *et al.* 2001)

The *Valuing People* initiative has clearly not been without its critics (see also, Davies 2001, for example), but it does seem to demonstrate a new understanding of the relationship between state, statutory agencies and recipients of goods and services. Partnership and consultation have, at the very least, become embedded in the rhetoric of official documentation and policy statements.

Alongside these developments, we have also seen a significant growth in user-led and user-controlled organizations which have developed both expertise and influence in promoting positive improvements, both in terms of service delivery and wider systems which affect the quality of people's lives. This is typified by the rapid increase in the number of People First and similar organizations which organize, provide support and lobby on behalf of their members (Goodley 2001). The origins of this movement can be traced back over a number of years, and this current period of growth coincides with broader and currently fashionable concerns about 'social exclusion' and those groups which are consistently marginalized, socially, politically and economically (Social Exclusion Unit 2000).

People with learning difficulties are now making clear their expectations of being given rights to participate fully and equally in the life of the community [Central England People First (CEPF) 2001]. The challenges ahead lie in moving on from this mood of confidence and expectation to finding practical ways in which effective solutions can be delivered. In the context of this article, this concerns the changed relationship between people with learning difficulties, and those responsible for supporting them and

providing services. The focal point is a training initiative where people with learning difficulties have taken the lead, and shown how they can act as educators in their own right.

New opportunities: participation and change

There are already many concrete examples of changes which have resulted in a stronger role for people with learning difficulties, both in influencing service planning, and in exercising a degree of control over decision-making and service delivery. As Coles (2001) points out, such changes have been associated with a broader move to embrace the 'social model' of disability. He identifies the emergence of empowerment strategies in service provision for people with learning difficulties which have afforded them a degree of control over key aspects of their lives and their services. In addition to specific developments in practice, we have seen evidence of user participation at all levels, from involvement in job interviews, to membership of strategic planning bodies, such as 'Partnership Boards'. Despite this, people with learning difficulties do not always feel fully involved through these changes (Fyson & Simons 2003).

In the academic context, we have observed trends towards a new research paradigm, based on principles of 'working with the experts' (Atkinson & Walmsley 1999; Knox *et al.* 2000; Walmsley, 2001). From this, it is perhaps not too great a step to the idea of 'learning from the experts', and the allocation of a central role in the provision of training and skills development to people with learning difficulties themselves.

Given this range of opportunities opening up, there is understandable interest in the development of a wider range of change strategies. The role of self-advocacy organizations in promoting and, indeed, exploiting these opportunities is especially significant.

Central England People First was established in 1990, and now has a strong tradition in representation, advocacy, service development, research, consultancy and training. Its members can boast a wide range of expertise and experience, and some examples of the organization's work demonstrate its ability to carry out an important educative role with staff and managers, in changing attitudes and practices which have disadvantaged and discriminated against service users. One such exercise (CEPF 1999) involved a consultation led by CEPF which reviewed services and the experiences of people with learning difficulties in one local authority area, which was used as the basis for policy change and service development.

Central England People First has been keen to work in partnership with policy-makers and statutory bodies, despite the risks involved, in order to promote members' interests. At the same time, the organization has managed to remain challenging and critical when it feels this is justified

(for example, Davies 2001). Thus, CEPF has been willing to negotiate places on Partnership Boards on its own terms, it has developed a role in the administration of direct payments, and it has been willing to seek funding from statutory bodies for initiatives such as the one reported here. Members of CEPF do not feel that they have had to compromise their principles to undertake these activities; rather, the extra resources have helped them to get the views of people with learning difficulties heard more effectively. They also feel that they have been able to use the opportunities provided to improve their own skills as advocates, researchers, consultants and trainers.

The role of training in creating change

With growing levels of interest in ensuring that service users have a role in the organization and management of services, there has also come a concern to reflect this principle at the level of staff training and development. A number of previous examples can be identified of attempts to ensure that training does, at least, incorporate a user perspective. For example, in the field of mental health, service users have participated in the production of course materials for the Open University (Reynolds & Read 1999). In the context of learning difficulties, research has demonstrated that training intended to increase sensitivity to user views can be beneficial in changing staff attitudes (Binney 1992); and there have been examples of service users themselves taking the lead in developing training programmes (Lordan 2000).

The previous experience of organizations such as CEPF in using consultancy and training as a vehicle for change also finds wider support from sources such as Freire (1972), who has identified the enabling and liberating potential of participative education. As he demonstrates, training and education with oppressed groups must be seen as a process of dialogue and empowerment:

We must never... provide the people with programmes which have little or nothing to do with their own preconceptions, doubts, hopes, and fears... It is not our role to speak to the people about our own view of the world, or to attempt to impose that view on them, but rather to dialogue with the people about their views and ours. We must realise that their view of the world, manifested variously in their actions, reflects their *situation* in the world. (Freire 1972, p. 68)

There appear to be clear parallels between the liberationist arguments of those involved in educational initiatives with poorer communities, and the transfer of power and expertise associated with user-led training.

This kind of argument opens up more far-reaching possibilities regarding the role of training, not just as a means of improving technical abilities, or promoting changes in attitude and behaviour, but in changing power

relationships between providers and users of services. In other words, training initiatives developed and provided by service users can have a 'political' as well as a practical role.

The CEPF training project: preparing the ground

The training project reported here was developed as an idea from the prior experience of CEPF in the use of training and consultancy to influence agency policies, service planning and service delivery. One of the strengths of the project was its ability to use the existing skills of people with learning difficulties who had already worked as advocates, consultants and trainers in a number of different settings. Over the years, CEPF has gained substantial experience and expertise as a user-led organization, as a provider of training and consultancy to statutory service providers and others, including service users (CEPF 1999). This expertise, it was felt, could be shared and built upon through the development of programmes and materials which would enable people with learning difficulties more generally to offer training to staff and managers in service agencies, as well as others who might have a relevant interest, such as transport providers. As the project bid stated, the proposal was based on:

years of experience as a leading self-advocacy organisation with a strong commitment to, and extensive experience in, partnership working. (CEPF 2001)

It was this track record which enabled the project team to develop a programme which would be participative, enabling, and directly relevant to the concerns of service users with learning difficulties. CEPF recognized that for people with learning difficulties to take on a training role, they must be ready to do so. The project's initial consultation with service providers indicated a real concern that trainers should be properly equipped, and should not be placed in a potentially exposed position through lack of preparation.

The CEPF team's own extensive experience as trainers put them in an ideal position to take the lead. The process of preparing the training materials involved pooling the ideas from the team, using flip charts and discussion, with help from the project support person and external consultant. This enabled a coherent draft programme to be put together, which combined an introduction to the principles and possible uses of training, with a chance to experience a series of training techniques. The programme was designed to ensure that delivery would remain in the hands of the CEPF training team, who would call on additional support only when needed. In the event, this proved to be the case.

The intention of the programme was to provide participants with skills and practical knowledge which they could use in turn to provide training for agency staff and policy-

makers. For example, one exercise was planned to illustrate the value of role-plays as a means of drawing attention to everyday problems and concerns for people with learning difficulties. Participants might choose to enact 'attending a planning meeting', or 'challenging a decision'.

The 2-day programme therefore combined opportunities to practice specific skills, such as speaking in public, or using a video camera, with workshops designed to enable people to use their own experience as the basis for training activities which they could lead (see Day 2 timetable, Appendix 1).

Delivering the programme

The application for funding proved successful, and on the basis of the Department of health grant provided, the National User Training Development Project (NUTDP) was able to pilot and deliver the 2-day programme in eight locations in England. The training team was made up of four members of CEPF, with support from a CEPF employed member of staff and a project advisor. The programme itself was delivered in its entirety by the four team members with learning difficulties. As Freire (1972, p. 89) observes, the ability to use and draw on common experiences is an important source of knowledge and awareness.

Participants were usually recruited from local authority services for people with learning difficulties, although delivery sites also included a 'care village' and another user-led organization. The training events were enthusiastically received by participants, who welcomed the opportunity to see themselves in a new and more powerful role, potentially as trainers of those providing services for them. They understood this as enabling them to play an active part in 'speaking out' about the issues and experiences that mattered to them; and at the same time, they could see themselves as educators of those who were perceived as having considerable power over service users (see, for example, 'The Road', Appendix 2).

Especially popular was the chance offered by the programme to learn how to design and perform a role-play. One such opportunity resulted in a powerful presentation of the experience of being bullied on the bus, and, importantly, how to challenge this.

Evaluations completed by those attending showed that they found all aspects of the training of value, including both the practical skills development, and the chance to develop their own ideas.

For example one participant in Carlisle reflected on the practical skills acquired, in response to the question: 'What did you learn from the training days?' The answer was: 'How to do the role-plays'. This participant also stated: 'Now I will be able to train other people'. Another person said: 'I liked all of [the activities], specially the warm up and "speaking up"'.

A participant in the training event in Staffordshire said: 'The workshop[s] were good', and that the programme was 'very good and very interesting', whilst another individual at the same event said that it would help her/him 'to run the problem solving'. Of course, like any training programme, some comments were less positive. For some the days were 'long', and someone complained of not being able to: 'get a word in edge ways'. In general, however, the comments were positive, and reflected increased confidence amongst participants, in their own abilities as 'trainers'.

Thus, at the conclusion of the pilot programme, it was possible to identify a number of positive outcomes. In an immediate sense, the training events proved popular and worthwhile for around 80 people with learning difficulties who took part. In addition, the fact that the training was directed and presented by a user-led organization such as CEPF meant that the wider potential value of developing a user-led training strategy was confirmed. It is clear that there is great scope for utilising such an approach in generating a wider sense of empowerment for providers and participants alike.

User-led training: strengths and weaknesses

In documenting the significant achievements of the NUTDP, it is important not to convey an over-simplistic impression of unqualified gains. In order to get the most from initiatives of this kind, we need to be realistic about what they can and cannot achieve, and how they might be improved upon. There are, for example, a number of potential weaknesses which must be acknowledged.

First, it is not necessarily the case that people who have experience of using services will be skilled in offering staff training. Skills have to be acquired and developed, and for some this will neither be desirable nor achievable. Much time was taken up in the project on developing and improving skills, both within the team, and as part of the pilot training exercises. It is important, here, to distinguish between the very real value of drawing on direct experience as a training 'input', and the wider range of skills required in organizing and delivering a training programme as a whole.

Secondly, it must also be recognized that there are some areas of knowledge and expertise, for example in welfare benefits, where people who use services may not be best equipped to provide training. This is not necessarily a shortcoming, but a matter of being realistic about the limits of one's knowledge.

Thirdly, the project has identified that there are likely to be additional costs and resource implications of providing user-led training, for instance, in ensuring that appropriate support, communication and media facilities are provided. This area of concern was identified in the project's initial

survey of staff training interests, and it does seem important in order not to inhibit the quality of delivery.

Finally, and again perhaps self-evidently, training provided by service users cannot automatically be assumed to achieve its objectives, simply because it is seen as a 'good thing'. It must be properly targeted and presented, recipients must be clear about the aims and purposes of the training, and it must be fairly and robustly evaluated. It would be unhelpful, for example, if evaluation responses were based on patronising assumptions about what could be expected.

Despite these possible shortcomings, there are a number of powerful strengths which can also be associated with user-led training based on the experience of the project whose experience is presented here.

It provides a clear and relatively unthreatening basis for dialogue and sharing, away from the service setting. Mutual understanding can be built up much more easily in this sort of context.

In addition, there are specific aspects of learning, such as improvements in communication, for which user-led training is particularly appropriate, in contrast to those more 'technical' issues such as welfare benefits or the law. Agency staff responses to the survey carried out by the project indicated that this was an area where they would particularly value input from people who use services.

Furthermore, the development of skills and expertise, and the role reversal involved in service users taking the lead in training, are in themselves both empowering and of practical benefit for people with learning difficulties, who may not have thought of themselves as taking this kind of 'leadership' role previously. Those who participated in the training for trainers programmes delivered by the NUTDP generally felt that they had gained from the experience in this respect.

And finally, despite the cautionary note already sounded, the evidence from the pilot exercises carried out by the project team suggests that user-led training is able to deliver, in the sense of achieving its learning objectives, consistently and to a high standard.

In this technical sense, then, the experience of the project would suggest that any potential shortcomings of training programmes provided by people with learning difficulties can be offset by the significant gains identified. There are clear intrinsic benefits, aside from the wider achievements which this kind of initiative represents.

Learning from the experts: wider horizons

For the project itself, its initial success has opened up the very real prospect of taking this training model further. The 2-day programme which formed the core of the initiative is now well established, and is capable of being delivered to people with learning difficulties who are interested in becoming trainers on a much wider scale.

In addition, the project has generated a range of training materials which should enable other groups to develop training skills for themselves (Smith, 2003). This material is designed to be accessible and realistic, and it retains an underlying commitment to principles of empowerment and taking control.

We can perhaps conclude that the NUTDP 'works' on a number of levels:

- It is a concrete demonstration of the skills and potential of people with learning difficulties who have developed and delivered an effective and well-received training experience.
- The training model realised here has the potential to be replicated elsewhere, thus reinforcing the achievements of the project, and improving the capacity of people with learning difficulties generally to train staff.
- The model promotes a reversal of roles, and an explicit commitment to the principle that power and expertise lie with those conventionally seen as passive and powerless recipients of services.

This was a pilot project, which points the way for future development. Also required is a more thorough evaluation of the impact, both for those providing and those receiving training of this kind. For instance, it is important to ask to what extent those who gain training skills are then enabled to put them into practice. Despite these concerns, the early signs from participants' feedback are that they enjoy being involved, they feel that they have acquired new skills and confidence, and they want to go on and put what they have learnt into practice. In this way, the project has clearly contributed to the aim of achieving empowerment through learning (Adams 1998; Freire 1972).

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Appendix 1 (from CEPF 2002)

Training Programme

Day 1

2.00 PM–2.30 PM

Training activities – Louise

Introduce and describe the following workshops:



- Role plays – Chris



- Quiz-Fiona



- Using equipment – Craig video, TV
- Speaking in public – Louise



2.30–2.45 PM

Tea and Coffee



2.45–3.30 PM

Workshops



3.30–3.45 PM

Tea and Coffee



3.45–4.30 PM

Workshops



4.30–4.45 PM

Talk about the next day, and thank you for coming.



Day 2

10.30–1 1.00 AM

Feedback from the day before – Craig

11.00–11.30 AM

Choose your training method and choose your topic –

Fiona

- problem solving
- what people want
- how to listen
- different views of 'users' and 'carers'
- how to improve services



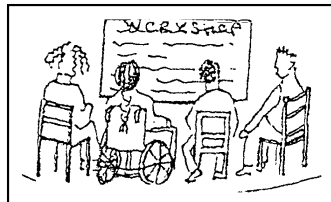
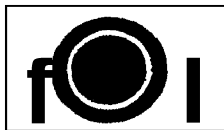
11.30–12.30 PM

Planning your activity around your topic and rehearsal –

Fiona.

12.30–1.30 PM

Lunch

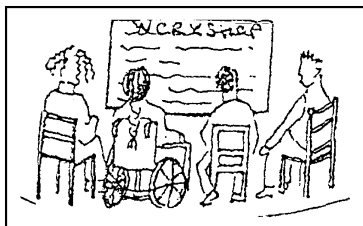
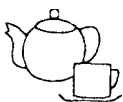


1.30–2.30 PM

Do your training activity with the whole group – Chris.

2.30–2.45 PM

Tea and coffee



Appendix 2 (from CEPF 2002)

The Road

First ask a person from the group if they would like to draw a picture of a road, or how they would like the road to look.



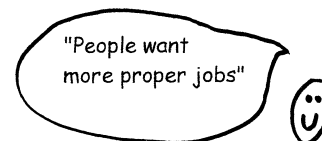
Draw the road across a flip chart sheet.

Have lots of pictures handy.

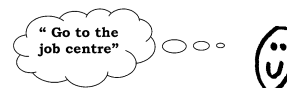
Ask People

What do people with learning difficulties need in their life?

Use pictures to show this for example



What steps can you take to get what you want?



What stops this from happening?



Use a picture of a cross

How can you break down these barriers?

“Speak to the Government”

Use a picture of a Hammer to knock down the barriers.



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