

Centre for Participation
Centre for Participation
at Cambridge
at Cambridge

*New Challenge -
New Opportunities*

Centre for Participation

New Challenge, New Opportunities

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Section One: The Proposal

Some Background

Late in 2002, the advocacy agency Speaking Up!, the University of Cambridge, the Cambridgeshire Learning Disability Partnership and the Department of Health's Valuing People Support Team agreed to work together in partnership to explore the idea of a jointly run "*Centre for Participation*" based in Cambridge. Between March and April 2003 an initial proposal document was circulated amongst key figures and opinion formers in the learning disability field. There was considerable support and enthusiasm for the concept and the proposal developed further based on the inputs of key players in the learning disability field.

The Aims and Objectives in Brief

The aims of the "*Centre for Participation*" would be to foster **innovation**, conduct **investigations** and **disseminate** new and useful knowledge about the most effective ways of empowering excluded people in the shaping of their lives. Importantly, the Centre would hope to be a powerful tool for people with learning difficulties – researching areas that people with learning difficulties highlight as important to them.

The Centre would publish the lessons learned from research in ways that are accessible and of practical use to those (including people with learning difficulties) seeking to improve life-outcomes for this group. Furthermore, the Centre for Participation would hope to offer developmental opportunities to enhance services, practice and knowledge through consultancy and training delivered by the partner organisations.

Three Partners and An Advisor

The proposed *Centre for Participation* is a collaborative venture between partner agencies representing a range of perspectives (self advocacy, academia, statutory bodies). Each partner is able to directly contribute to moving the work of the Centre forward and can commit resources, time, and opportunities to the joint work of the Centre. Each organisation brings unique strengths and skills, but share the goal of wanting to increase participation for people with learning difficulties in society.

A strong initial partnership has been established in the Cambridgeshire area between a self-advocacy organisation, an academic institution, and a local statutory body. In addition, a central government delivery team is involved in an advisory capacity. As the Centre for Participation develops, additional partners are likely to be established to best meet the aims of the Centre and to maximise the value of the initiative to a wide audience.

The Centre for Participation will be a “virtual organisation” – a collaborative use of the resources and capabilities of different partners. The Centre will be a new entity that is neither an academic institution, a self-advocacy organisation, or a branch of government but rather, it will encompass all three.

As such it will have:

- ❑ the passionate belief in empowerment and the commitment to full citizenship brought by the self-advocacy organisation.
- ❑ the commitment to academic rigour and excellence brought by the University
- ❑ the applied understanding of empowerment brought by those at the coal-face in local statutory bodies and provider organisations

The Centre for Participation would attempt to distil elements from each of the collaborators, put them together in a new way that results in a new and creative chemistry that cannot be achieved by organisations acting alone.

Going In: Resources and Capabilities of the Initial Partners

The partners who have initiated the Centre for Participation bring tremendous skills and experience to the collaboration:

(i) *Speaking Up!*

- ❑ Speaking Up!, the advocacy agency for Cambridgeshire, is a leader in developing creative new ways to enable people with learning difficulties to control their own lives.
- ❑ Speaking Up!’s innovation in supporting people with learning difficulties to participate in service development and also to deliver training and research would enable them to contribute to initiating and participating in the work of the Centre for Participation.
- ❑ Speaking Up!’s networks and credibility within the advocacy sector would enable them to disseminate the useful findings from the centre to other advocacy organisations.

(ii) *The University of Cambridge.*

- ❑ The university has an impeccable world-wide reputation, and would ensure the dissemination of findings of the Centre for Participation within the global research community.
- ❑ The recent award of the Health Foundation Chair to the University held by Anthony Holland has enhanced learning disability research at the university. Specifically, the multi-disciplinary research group into learning disabilities (that includes clinicians, social and biological scientists and academic lawyers) would be a huge asset to the project.

- In addition, the Faculty of Education has a long and well-established reputation for teaching and research in the field of young people and adults with learning disabilities.

(iii) The Cambridgeshire Learning Disabilities Partnership (CLDP).

- Recognised by the IPPR Public Involvement Awards in 2002, CLDP is one of the most progressive public bodies in the UK in terms of its user involvement.
- CLDP will enable the Centre for Participation to examine its own processes and decision-making mechanisms in depth in terms of how far they empower users of services.
- It will provide a good “laboratory” to explore how new approaches such as Person Centred Planning can be improved.

Additionally, valuable facilitation and advice is provided by:

(iv) Valuing People Support Team (VPST).

- VPST has the dissemination capability to ensure that the practical lessons learned are spread in clear and effective ways to public and other bodies providing services to people with learning disabilities.
- VPSTs strong links into Government mean that the learning from this project can be shared with other agencies working with excluded groups.

Cumulative resources and capabilities of the initial partners:

- Participation of people with learning disabilities in the project
- Leading edge user involvement work going on within the local area
- Academic skills and credibility
- Access to the daily realities of statutory services in operation
- Ability to translate key messages to a wide range of audiences: academic, service providers and people with learning difficulties.
- An approach to key questions that brings together the knowledge and experience of all three sectors in a new way.
- Influence within an area that is still not well understood.
- Information, consultancy and training

Outcomes

With strong inputs into the Centre through its partners, the potential services and benefits that could be generated are significant.

Research and Innovation

The Centre plans to offer people with learning difficulties, and those who provide them services, leading edge research on 'what works' in participation. A fundamental aim of the Centre will be to evaluate existing approaches and formulate brand new ways of working to promote the full involvement of people with learning disabilities in research.

Dissemination

Importantly, as well as conducting research, the Centre for Participation would also seek to be the vehicle for spreading knowledge on best practice. This dissemination would include both a geographical spread of information throughout the learning disability sector in the UK and internationally, but would also develop knowledge on empowering other excluded groups. Understanding what does and does not work in involvement could lead to valuable learning for other groups marginalized in society.

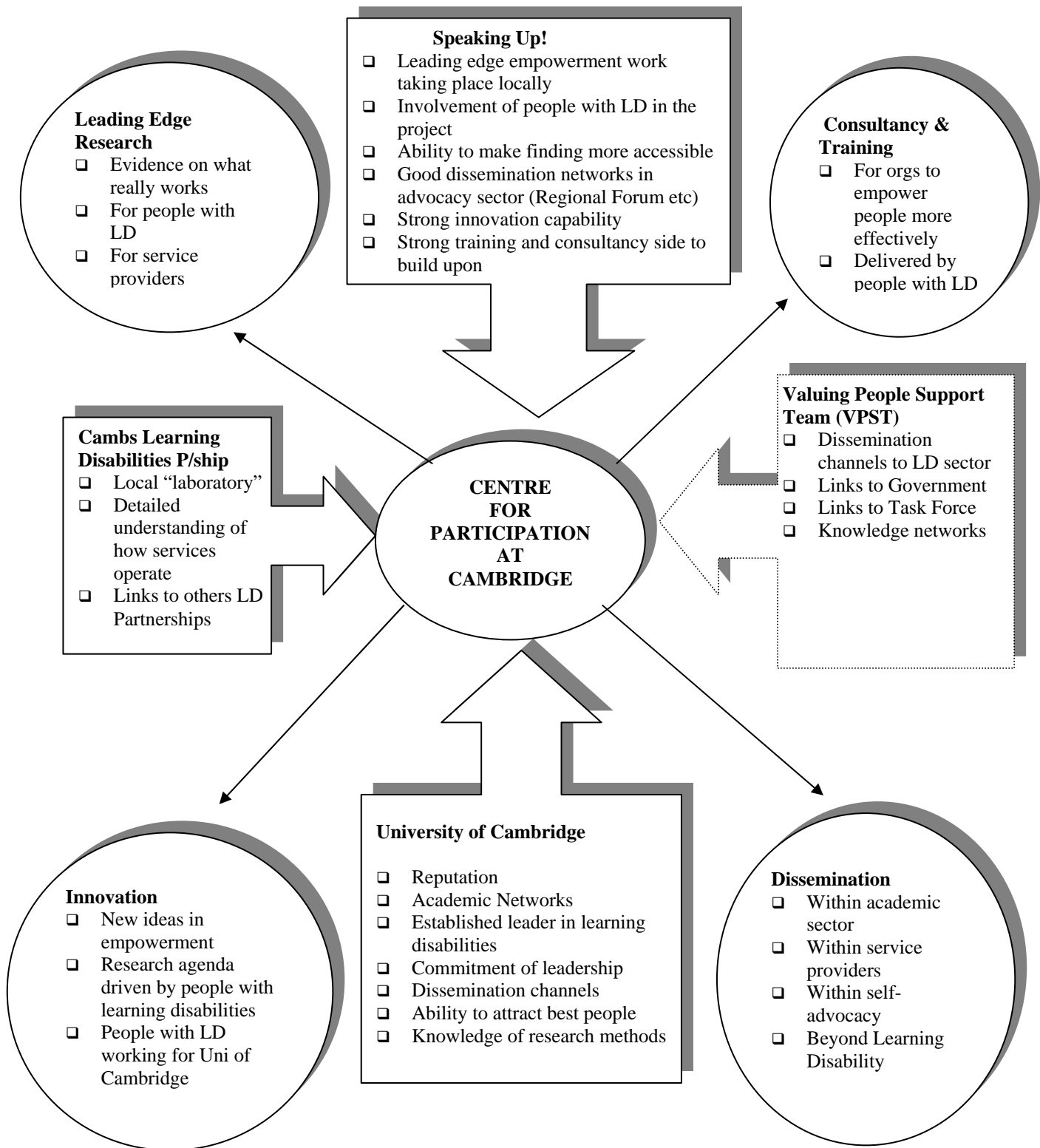
Training and Consultancy

In order to truly make a difference, the Centre for Participation would also aim to take dissemination a step further by offering training and consultancy on implementing the findings of research. Again people with learning disabilities will be supported to play a key role in conveying the messages and new learning to professionals and peers. This transition from research to practice would see the Centre for Participation driving service provision forward.

People with learning disabilities leading the march towards positive change in participation

- ✓ Research Agenda driven by people with learning disabilities
- ✓ Best Practice disseminated to people with learning difficulties, academics and service providers through an excellent combination of channels (by a respected self-advocacy organisation, University, Government Support Team)
- ✓ Training and Consultancy on implementing effective changes delivered by people with learning disabilities.

Fig.1: Centre For Participation - Initial Inputs & Outputs from the Centre



The Gap in the Market

It is recognised that collaborations between interested parties are common in the learning disability field. Work between universities and local authority bodies in particular are common, notably with the University Affiliated Programme (UAP) approach which is well developed in the USA.

Some good work is being done already which is making a useful contribution to knowledge and understanding. Whilst acknowledging these existing bodies, it is important to emphasise the different perspective offered by the Centre for Participation's partners. For example:

Norah Fry Research Centre, at Bristol. The Norah Fry does bring researchers and service users together. However, as the researchers are not practicing clinicians, they are not as intimately linked to local services as the University of Cambridge academics are to local services. The social scientists at Cambridge University conduct clinical work and the link is emphasised with Tony Holland being a member of the LDP Board.

Tizard Centre, University of Kent at Canterbury. Whilst some of the researchers at the Tizard are clinicians too, they are not always consistently linked with 'local' services. The work the Tizard conducts with service users tends to be under more of a 'consultation model' than a partnership approach.

In the main, the proposal for a Centre for Participation is different in that it seeks to add the crucial dimensions of self-advocacy and 'live' services to ensure that its research is completely relevant to the real experiences of people with learning difficulties.

The Centre for Participation will seek **useful** and **genuine** involvement of people with learning difficulties in shaping and delivering research and training.

Useful and **genuine** involvement means people with learning disabilities:

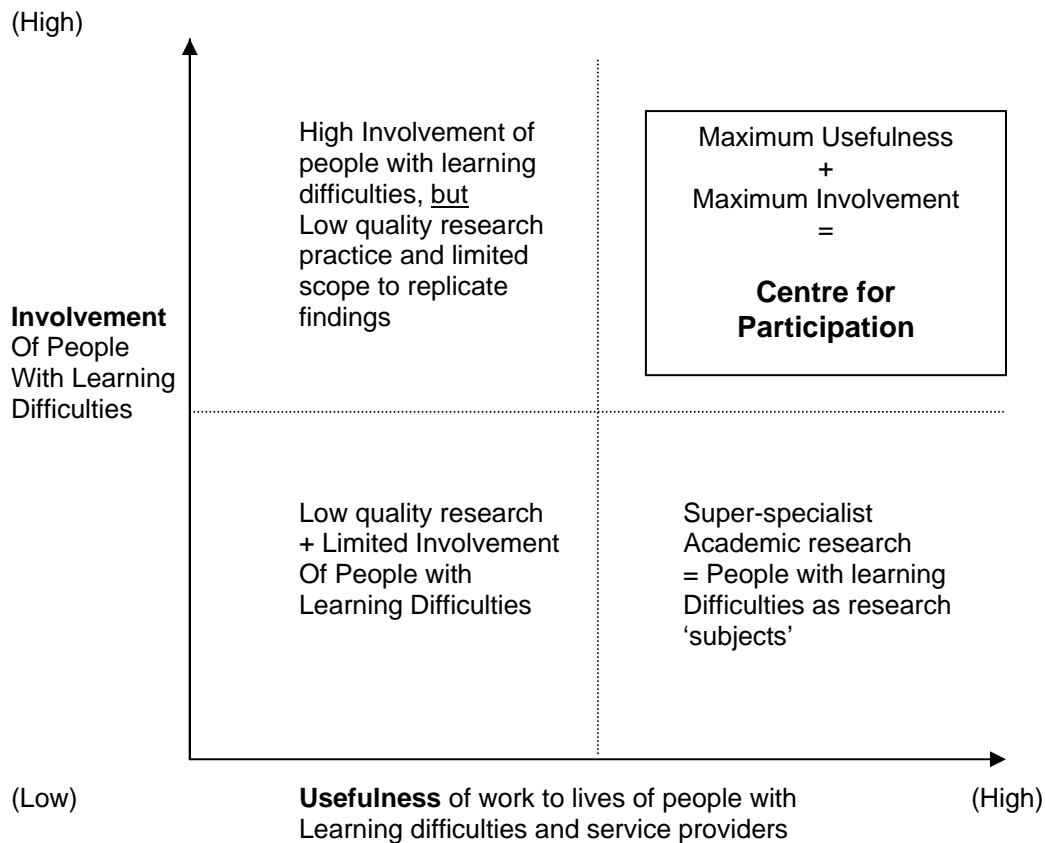
- * determining what research is to be undertaken.
- * taking a more active role in research than simply being 'subjects'
- * potentially being employed as research assistants by the University of Cambridge.

The Centre for Participation would seek to be lead in its choice of research topics by the expressed interests of people with learning disabilities. For example, the Cambridgeshire Service Users Parliament could commission the Centre to explore issues of interest to them. Arguably, the direct involvement of people with learning disabilities in establishing the research agenda, conducting the research and monitoring the outcomes will help to secure the relevance of the research and its impact on people's lives.

Moreover, the areas to be explored by the Centre will seek to **challenge** existing theories of involvement and provide evidence on what really makes a difference to the lives of excluded people. A further challenge for the Centre for Participation is to make top quality research beneficial (and accessible) to the lives of people with learning disabilities.

It is felt that too often academic research can be impenetrable to people with learning difficulties and of limited value to those providing services and support. Likewise, some efforts to involve excluded people can result in token involvement or lead to minimal usefulness to those it seeks to empower. The Centre for Participation would seek to involve people with learning difficulties in a way that ensures the output of the work is of maximum added value to those delivering and receiving services and support.

Fig. 2: The Gap in the Market



Foundations of Success

While the proposed Centre for Participation represents an entirely new venture which poses fresh challenges, it is important to highlight the track record of success brought by the partners in the field of involvement. This includes examples of effective partnership working between the key players.

Speaking Up! (Winners of the Guardian Charity of the Year Award, 2002), supported by the other partners, have already begun exploring innovative ways of involving people with learning difficulties, including:

- Service User Parliaments originated in Cambridge, proactively supported by the CLDP, and the model has now spread to a number of other areas, with Speaking Up! offering consultancy on establishing a new parliament.
- 'Training Partners' a project lead by BILD which seeks to develop the skills of people with learning difficulties in delivering training. The aim is to support those who have never done training to a level that they are able to deliver formal training on the experience of having a disability. Speaking Up! were selected as one of four partner agencies in the project, supported in their work by the University of Cambridge.
- Training by people with learning difficulties employed by Speaking Up! delivered to teachers and other professionals on Continuing Professional Development courses at the University of Cambridge Faculty of Education.

Additional Successes to be added here:

Examples.....

➤ Tony's Centre and CLDP

➤ Faculty of Education

Section Two: The Constitution

How the Partners Will Work Together

One way of conceptualising the virtual nature of the Centre is to see that the Centre for Participation is the **brand** under which the partners will work together on specific projects. Accordingly, the brand will:

- ❖ **Enable us to secure research money** by demonstrating to potential funders the commitment and unity of the partners to working together
- ❖ **Provide clear definition to collaborative work between the partners**, ensuring focus for work being conducted as the Centre, whilst protecting each partner's additional roles and responsibilities
- ❖ **Support the dissemination of findings**, especially as the Centre's reputation grows, as outputs can be marketed under a single, consistent, identifiable brand.

Perhaps in time and with a track-record of success behind it, this collaboration may spurn a true Centre with a physical base and its own workforce. For now (at a time of uncertainty in funding these sorts of initiatives) this initial 'virtual' set up, enables the viability of this level of partnership to be explored and tested at minimum to nil risk to the individual partners. The potential achievements that could come from trying to work together in this way remain considerable, however.

What will the Partners start work on?

At the outset, the Centre will engage in both Proactive and Reactive work streams.

Pro-Active Role: The Centre for Participation will not respond to competitive tenders, but instead seek to set the agenda for research into participation. Significantly, people with learning difficulties themselves will play a role in identifying the questions that are of importance to them.

Reactive Role: There will be elements of the work of the Centre for Participation that could be described as more reactive. This may include offering consultancy to other projects who approach the Centre. Consultancy should only be considered if the project in question is about either participation or relevant to local services. Another reactive workstream could be exploring how the findings from projects conducted by other agencies can be disseminated in more accessible, and ultimately more effective, ways.

Alternatively, the reactive role may be when the cumulative resources of the Centre come together to act as advisors on a project being conducted by one of the partners away from the Centre. The Centre for Participation partners will be able to work as a 'focus group' of sorts supporting, informing and guiding

The reactive work of the Centre is important as it may inform the proactive projects.

Example: Reactive leads to Proactive

Speaking Up! are considering bidding for a competitive tender to consult people with learning difficulties on what should be included on a website aimed at young people at transition and their families. Speaking Up! consult the other Centre partners on the project. A frank and honest discussion follows, out of which comes not only guidance for Speaking Up! on the specific tender, but wider questions for the Centre:

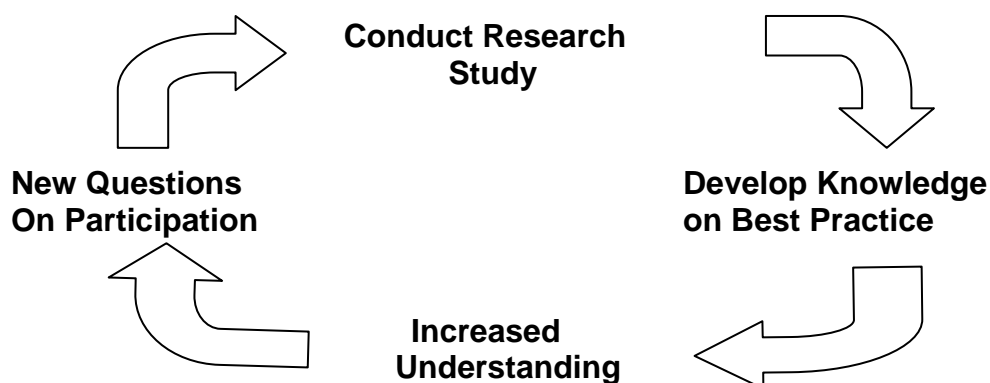
- How many people with learning difficulties have easy access to a computer or the internet?
- How should websites be used to convey information to people with learning difficulties?
- What are the most effective ways of disseminating information to people with learning difficulties?

Pro-active work should be the ultimate goal of the Centre, however, and it is envisaged that there will be two strands to this:

- 1) **Evaluation of Local Services:** With a strong link to the Service User Parliament members and areas they would like to see evaluated
- 2) **Research Into Participation at a broader level:** How is it helpful, how can it be unhelpful, how does it work best...

It is foreseen that these two strands will be complimentary and exploring one area will generate questions for the other.

Figure ? – The Cycle of Answers and Questions



For example, the Service User Parliament may express an interest in evaluating participation of people with learning difficulties on the local Partnership Board. A research study into this may generate information on what works and what doesn't work, which in turn may lead to broader questions on the role of Partnership Boards generally.

Likewise, the Centre may choose to explore issues around participation of people with learning difficulties in the electoral process in this country. In turn, this may raise questions of how local people are being supported and encouraged to engage in political processes.

This combination of local and more general research both plays to the strengths of the Centre and ensures evidence-based research that has relevance beyond one County.

The importance of the connection with a live, local environment cannot be underestimated. Indeed, it is the close link of all the partners to real, local service provision that sets the Centre for Participation apart from other collaborations. Without the research skills of the university, the Centre would never prove or fully understand anything. Without the direct links to self-advocacy and local services, the Centre would be nothing more than an academic venture.

“A Guinea Pig with a State of the Art Hutch?”

It is important to acknowledge the impact the Centre could have in Cambridgeshire. Whilst the County may be used as a testing ground for theories of participation, in return people with learning difficulties (and the services that support them) will have access to leading edge knowledge on best practice.

What is expected of the Partners?

A formal agreement or constitution will need to be negotiated to formalise the workings of the Centre for Participation.

Some of the questions to be answered will be:

- What commitment will be expected from each partner in terms of money, resources and time?
- How will the partners agree on the proactive projects to bid for?
- How will decisions be made as to how the work required in a project of the Centre will be divided amongst the partners?
- What will be the process for partners to bring their own projects to the Centre for input? Is there a limit to the number of approaches that can be made in a year? Will there be a set format for responding to these approaches?
- How will decisions be made as to whether or not to take up a consultancy role on another project?
- How will the Centre respond if the projects brought by one partner become an imposition to the Centre?

Section Three: Starting to Work Together

Testing and Strengthening the Partnership

Engaging in reactive work, particularly advising on each other's separate projects, will enable the Partners to test their collaboration. An immediate need exists, therefore, to agree protocols for bringing projects to the Centre for discussion. In particular, decisions must be made as to whether this work can be conducted without the need for specific funding.

This reactive work will lay the foundations for the larger-scale, proactive work that the Partners want to conduct together.

Initial Funding

In brief we have two options for securing funding for proactive projects from here onwards...

- ❖ Make a bid for, say £5000, with which to develop this business case, to engage with the Service User Parliament, and firm up what the Centre wants to be ahead of beginning to bid for funding for an initial research project.
- ❖ Go straight in for a research project exploring, ideally an issue of interest to the Service User Parliament.

Funding for an initial research project will need to be sufficient to cover the costs of completing the research project, disseminating the findings and exploring opportunities to offer training and consultancy based on the outcome of the research. Built into the project costs will be an element of funding to support the evaluation and next stage of development of the Centre for Participation. Any earned income from training and consultancy will also be directed back to further fund the development of the Centre.

Potential funders discussed by the partners include the Community Fund, Cadbury Foundation and venture philanthropy in general.

First Moves: The Cambridgeshire Service Users Parliament

A central feature of the Centre for Participation is for the proactive research and development agenda to be set by people with learning disabilities, rather than the Departments of Health or Education, or university academics.

To this end, an offer will be extended to the Cambridge Service Users Parliament to identify an area of participation that they would like to be researched.

When the Service Users Parliament was established in 2000, it was set up to mirror central government processes in many ways. MPs (all people with learning disabilities) were elected by their peers to represent them for a set period of office. In June 2003, the Service Users Parliament completed its first three-year session. With hustings and new elections running in the summer of 2003 and looking into the second three-year session, there is much focus on identifying the learning from the first three years to improve the Parliament in its second term.

The Parliament may therefore request that the Centre for Participation conduct an evaluation of the Service Users Parliament as its first research project. The scope of such a project could seek to evaluate the workings of the Parliament, measure the qualitative impact of the Parliament on the lives of people with learning difficulties (both who have been involved in the Parliament and those unengaged) and could compare the effectiveness of the Parliament with areas where there are no such attempts at participation, for example long stay hospitals.

Alternatively, the MPs could raise another issue of significance to them. Possibilities include:

Partnership Boards

What impact are Boards having on service development and the lives of people with learning difficulties?

Are Partnership Boards encouraging collusion in service cuts?

How do people with learning disabilities get the most out of attending a Partnership Board?

Person-Centred Planning (PCP)

What difference, if any, has PCP made? What works best and what is less beneficial? Does PCP actually lead to a more needs-led service? Is PCP right for everyone?

Inclusion

What contributions are inclusive schools and colleges making towards the social inclusion of people with learning disabilities in adulthood? What impact do inclusive settings have on people with learning disabilities in terms of personal, social and educational outcomes? Does inclusion enhance citizenship? Is inclusion right for everyone?

Full details of the research technique for any project will be devised by the University academics in conjunction with people with learning difficulties.

The first step is for an approach to be made to the Parliament explaining the Centre and carefully positioning the research offer to them. A Powerpoint presentation may need to be devised to summarise this proposal.

Partners will have to decide whether they need to bid for a small grant to fund the further development of this business-case and the consultation with the Parliament, or whether this can be built into a bid to fund the ensuing research project.

Looking Forward: Potential Areas for Research

Beyond this initial piece of work, the potential areas for research and enquiry are extensive. The areas that are selected for review should depend largely on the interests of people with learning disabilities and their supporters.

The Centre must develop a clear set of guidelines on what it will and will not research, and how it will select the next project. Guidance of this nature is likely to include a view that the research focus will be timely and contribute to current thinking and debates in wider society. As such there could be a focus on issues of citizenship and learning disability. Work could be done, for instance to explore voting and people with learning disabilities. Links could likewise be made to current strategies such as local regeneration.

The possibilities are considerable. The underlying approach would be to review existing practices, highlight the true impact of certain approaches and ensure full participation of excluded people in all aspects of their lives.

Conclusion

The Centre for Participation represents a new challenge – a challenge to bring together people with learning difficulties, academics and service providers to work together for a joint aim. It also presents a challenge to existing practices that do not empower people with learning difficulties. Poor practice can be exposed, best practice can be shared.

Through these challenges there are tremendous opportunities. Opportunities for people with learning difficulties to influence research, opportunities for service providers and academics to focus on the issues that really matter to people with learning difficulties, opportunities to reduce exclusion.

A Centre for Participation is all about a 'New Challenge and New Opportunities'