Real Power? An examination of the involvement of people with learning difficulties in strategic service development in Cambridgeshire

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Summary

Securing meaningful involvement in service development and provision can be seen as a particular challenge for people with learning difficulties. The National Health Service & Community Care Act [(1990) HMSO, ISBN 0105419907] and more recently Valuing People [Department of Health (2001) Valuing people: a new strategy for learning disability for the 21st century, Cm5086] have stressed the importance of statutory providers working in partnership with people with learning difficulties, without giving any clear guidance on how to achieve this. This paper is written from the perspective of Speaking Up – a voluntary organisation that has developed the ‘Parliament’ model to give people with learning difficulties a strong collective voice. Through self-advocacy taking the leading role in shaping the way people with learning difficulties and statutory providers communicate, it is argued that the Parliament model enables people with learning difficulties to genuinely influence services. After considering the link between self-advocacy and user-involvement, this paper describes the Parliament as it has developed in Cambridgeshire and discusses whether what has been achieved represents a real increase in power for people with learning difficulties. It concludes with a short assessment of the potential for replicability of the Parliament as a model for other areas of the UK. Craig Dearden-Phillips is Chief Executive of Speaking Up and Rob Fountain a Project Leader with the organisation.

Keywords Advocacy, empowerment, learning difficulties, parliament, partnership, power

User-involvement, self-advocacy and the parliament model

Whilst the idea of involving recipients of services in decisions affecting them promises empowerment, the practice for service users has often been very disempowering. Croft & Beresford (1995) have written scathingly of the ‘painful’ practices of service providers co-opting users views to legitimate their own agenda. When calls for participation come from the providers, the result is often a diluted experience on the terms of those in power.

Involvement has often in reality stopped at ‘consultation’ with a justification that ‘listening to someone speaking of their own direct experience can be a most effective way of keeping the real world in our minds’ (Whittaker 1993, p. 328). Whilst consultation does give people a voice, it does
not give them the power to ensure that their views will be heeded (Arnstein 1969).

Self-advocacy is speaking up for oneself and has had a positive impact for those with disabilities. As Atkinson (1999, p. 6) has concluded, the impact for people with learning difficulties has been to ‘speak out; to have a voice, and to have a means by which that voice may be heard’. To build upon this tradition when looking at user-involvement would seem common sense.

Moreover, it is also clear that self-advocacy most often occurs in groups – speaking up with and for other people with learning difficulties. Such collective self-advocacy has been seen to help shift the balance of power between people with learning difficulties and those who hold control over their lives such as parents and staff (Cooper & Hersov 1986).

Recent research has identified several conditions necessary for meaningful involvement of people with learning difficulties in decision-making processes. Aichison et al. (2001) came up with six building blocks to successful engagement in service development including communication, leadership and independent advocacy. Partnership was another key element identified, with ‘principled pragmatism’ highlighting a need for a culture of partnership from both sides. If achieved it is held that not only can professionals empower people with learning difficulties, but also that people with learning difficulties can in turn empower professionals.

Looking at involvement in voluntary organisations in particular a report by the Joseph Rowntree Foundation (2003) concluded that positive involvement came when: the agenda for involvement was shaped by users, there was clear engagement with the process by those in senior positions, and the emphasis was on building strong relationships between those in decision-making roles and those seeking to have more influence.

These findings support many of the aspects of how the Cambridgeshire Parliament has developed.

Description of the Parliament in Cambridgeshire

The Parliament is a partnership between a voluntary organization and local statutory body. Speaking Up is a self-advocacy charity that seeks to create positive choice for disabled people through training, involvement and advocacy projects. The Cambridgeshire Learning Disability Partnership (CLDP) is the combined Health and Social Services body responsible for the care and support of 1500 adults and a budget of £35 million.

Originally set up in 2000, the Parliament is now in its second 3-year session. There are currently 23 ‘MP’s’ – people with learning difficulties selected by their peers to represent them at the bi-monthly Parliament – and seven Cabinet Ministers who specialize in a particular area, such as transport or high support needs. There are MPs representing users of individual services (such as Larkfield Day Service in Ely) and an ‘independent’ MP to represent those people who do not access services. Candidates volunteer to stand and have to go through hustings and competitive elections to become MPs.

The MPs determine the topics for each Parliament based on issues they feel are most important to their ‘constituents’. Recent sessions have focussed on Direct Payments, Bullying and Being Person-Centred.

Main Parliament meetings are attended by CLDP’s senior managers – crucially, though, they attend as invited guests of the MPs. People with learning difficulties run the Parliament sessions (with support from Speaking Up staff).

As well as the CLDP, there are other invited guests from relevant agencies for the issue. For example, at a Parliament covering transport, representatives from Stagecoach, WAGN trains and the Transport and Highways section attended. This brings people with learning difficulties into dialogue with these mainstream groups – and in an environment that might surprise those who have limited contact with people with learning difficulties. It also brings together the full range of agencies responsible for the well being of people with learning difficulties.

It is this involvement on the terms of the service users, and where people with learning difficulties out-number ‘professionals’ and those without disabilities which is key to the model’s success.

Approach

The Parliament seeks to embed the opinions and influence of people with learning difficulties into the system for shaping services in three main ways.

1. By obtaining and conveying ‘Key Messages’ from users of services to senior managers.
2. By fostering an atmosphere of accountability between senior managers and the people they serve.
3. By developing people with learning difficulties as leaders.

Key messages

At the Parliament, we say what we really mean. We get together with the managers and tell them what we’re about – Michael Speed, MP, Cambridgeshire Parliament

Parliament works by giving people with learning difficulties the space and support they need to convey their views to senior managers. It also encourages a dialogue between the two groups, an opportunity for managers to explore, in small group situations, precisely what people with learning difficulties think.

The bi-monthly Parliament meeting is the culmination of a lot of work – Speaking Up now employs three people in running the Parliament (a full-time project leader supports
two employees with learning difficulties who served as MPs in the original Parliament).

Accessible materials are produced that enable MPs to learn more about how services and budgets work, and support them to think about what they think, feel and believe about issues. Smaller ‘Action Groups’ are held in between Parliaments to review what happened and what is coming up next. This gives MPs a chance to digest the issues, better understand the context and prepare what they have to say.

The principal output of the Parliament sessions are ‘Key Messages’, often with associated action points. MPs are therefore enabled to contribute views on the ‘big picture’, rather than on the details of particular decisions.

Sometimes detail is necessary, such as an occasion when MPs had the opportunity to cross examine a Chief Executive of a Primary Care Trust on the implications of a cut in proposed investment in learning disability services. On these occasions, staff from Speaking Up who volunteer time to offer independent support to MPs at the main meetings take on the role of interpreting situations and presenting them in a way that makes sense to the MPs. While this is an imperfect process, it does enable the MPs to then respond and take part in a way which they otherwise would not.

**Accountability**

I report our progress to the Parliament and when it sits all my senior team attend. It is part of the way we work – Sheila Forrest, Lead Commissioner, CLDP.

The whole idea of the Parliament is to create a more open environment in which issues are shared early. The atmosphere is generally conversational and collaborative, not confrontational. At each Parliament meeting, the CLDP report back to MPs on their progress since the previous Parliament and asks MPs for their thoughts on current difficult issues.

Genuine openness from the CLDP has been displayed and is immensely powerful. For example, in July 2002, a proposed cancellation of significant planned expenditure was discussed as a possible solution to budgetary pressures within the council as a whole. The Assistant Director for Adult Services passed this on immediately for discussion at the Parliament the following day so that MPs could react quickly to this key development.

The Parliament does not replace Partnership Board meetings, but complements these. MPs are supported to participate at the Partnership Board as part of their wider responsibilities.

**Personal development of MPs**

I stood in an election and people chose me to be the MP for Wisbech. That means I say what people want. I’m their man – Peter Auckland, MP, Service Users Parliament

Extensive support is given to MPs to help them develop their own presentation, representation and influencing skills. New MPs receive 3 days training on assuming their role and the project team offer on-going mentoring. The Parliament also aims to develop in MPs a pride and a strong sense of civic purpose in their roles.

The term ‘Parliament’ was chosen mainly because of its prestige and standing. ‘Forum’ or ‘Committee’ fail to catch people’s imagination in quite the same way. Events have corroborated this. The status and prestige of being an MP gives identity - a valued social role – and its import to people with learning difficulties is evident in the passion and commitment shown in elections.

The MPs for the current term of office were chosen through an election in which 73 people stood as candidates and in which more than 600 people voted. Elections are vital to the process as MPs are expected to represent the views of others. Making this happen is one the biggest challenges for the Parliament model.

**Real power? Reflection on the impact of the Parliament**

We are part of the way things get done now. We don’t always get our own way, I don’t think we ever will but we are involved and there is communication there – John Woodhouse, MP, Service Users Parliament 2000-03.

Measuring the impact of the Parliament is difficult given the complexity of the service-commissioning and budgetary system of which it is part. A link has been made with Cambridge University for detailed evaluation of the Parliament’s impact both on service development and the MPs themselves.

The MPs can point to some definite successes, though. Complaints brought by two MPs in 2002 about the quality of a local residential home set off a chain of events that led to the removal of its manager. MP’s feelings about the way GP surgeries often treat people with learning difficulties made a significant contribution to the decision to train 100 GP receptionists in learning disability issues. Individual MPs have also made major personal contributions on local planning groups around day services, the protection of vulnerable adults (No Secrets) and Person Centred Planning.

But it is the impact on the way that the CLDP operates that is perhaps of greatest interest. Further research will reveal how decisions have changed because of the parliament. What is evident from Speaking Up’s perspective is a new atmosphere of accountability, involvement and communication between CLDP and service users. This represents a major shift in culture in a relatively short time.
Real power...or window dressing?

This cuts straight to the question of how power operates in our world. At its simplest, power is the ability to make things happen – or stop things happening. A ‘radical’ reading of how power operates in learning disability services suggests that power lies with service managers in the statutory system, not users. Empowerment, therefore, is about somehow wresting power from statutory agencies and handing it to users. This is a view commonly found in the disability movement which has pioneered Direct Payments as an example of how this might happen for individuals. The Parliament, in the view of the ‘radical’ is unlikely to represent real power for two reasons. First, it is not seeking to displace senior managers and accepts the fact that managers, not users, ultimately have to make the key strategic decisions. Secondly, power in disability services reflects the unequal distribution of power in society, making the Parliament open to manipulation by powerful managers whose first concern is to be seen to be involving service users.

The ‘pluralist’ view, to which Speaking Up would subscribe, admits the traditional weaknesses of service users as a political force – but sees the answer in boosting the knowledge, lobbying skills and access of this constituency. It also recognises the limitations on the power of senior managers who themselves are at the confluence of innumerable pressures in which they have to mediate the demands of central government, their own managers, as well as local politicians. This analysis sees power as more diffused, a set of ‘poles’ rather than a single source which dominates all others. The Parliament is viewed as an attempt to create another ‘pole’ of power. This is real power, not in the sense of a defining, seismic shift from professional to service user, but in terms of ensuring that influence of the constituency of service users is ‘in the mix’ that produces eventual outcomes.

Partnership not confrontation

The Parliament is built on partnership, the idea that building trusting and supportive relationships with statutory authorities is the most effective way to secure influence. This contrasts with the adversarial, ‘Westminster’ style of working where one group sets out to embarrass the other into changing a policy or approach.

Critics of partnership working say that this kind of arrangement tends to favour the more powerful agency. All too often, partnership is about what statutory agencies want, not users. Our experience suggests that, yes, statutory agencies are powerful players but that it is the quality of relationships with statutory agencies that most affects how a partnership works.

The approach Speaking Up favours is not a friendly, convivial relationship in which differences are papered over in the interests of harmony. Rather, we believe in a mature relationship in which major differences of opinion are expressed and in which difficult issues are regularly broached. The partnership between the MPs and CLDP goes through both harmonious and difficult phases. At times, it has been strained almost to breaking point. At others, they have acted in concert to put pressure on other agencies to recognize the needs of learning-disabled people. But one important part of this mature relationship is a refusal to personalize issues or demonize senior managers. This would destroy the political process because it results in the withdrawal of one side and leaves the other in the wilderness, without a voice.

Replicability

Is it possible to reproduce the Parliament model elsewhere? The answer to that question is positive because Parliaments or similar bodies have now been set up in at least five parts of the country. However, our experience suggests that the following factors need to be in place if these initiatives are to succeed:

**Statutory buy-in**

Senior managers must embrace the idea and participate fully in all Parliament sessions. Furthermore, they need to be willing to demonstrate how the Parliament has influenced their approach to particular issues.

**Advocacy buy-in**

Not all advocacy organisations see partnership with statutory agencies as they way forward and would not willingly go into an arrangement in which they could be seen as legitimising the oppressive practices of statutory agencies.

**A strong advocacy organisation**

Speaking Up organises the Parliament which is a complex logistical operation involving a range of tasks.

**Funding**

Running the Cambridgeshire Parliament costs around £60 000 a year.

This list does not, we believe, make the Parliament one of those projects that succeeds because of unique local conditions. It does, though, show that important factors need to be in place to re-create the Parliament elsewhere.
Conclusion

The Parliament has built on self-advocacy to develop an advanced model within an emerging culture of user involvement in learning disability services. The notion of ‘Parliament’ has a clear resonance with many people who have a learning difficulty and has been an excellent way to attract people to serve as representatives. While its direct influence is not always easy to gauge, it has integrated the voice of people with learning difficulties into the wider system of service planning and delivery. How meaningful this is in terms of real service user power depends largely on one’s approach to this whole issue. If a pluralist, you will see the Parliament as an important additional force in the shaping of services. If a radical you will see it as a sop to real user power which involves seizing power from professionals and handing it to service users. The extent to which the Parliament idea is adopted elsewhere will depend to a large extent on the capacity of user groups in local areas, their attitude to working closely with statutory agencies and the commitment of those agencies to invest time, energy and finance in such initiatives.

‘Real Power!’ is a video and training pack on the best of what is happening in user involvement across the UK. ‘Real Power!’ is available from Mental Health Media, The Resource Centre, 356 Holloway Road, London N7 6PA on 0207 700 8171.

References


