

# Taking Person-centered Planning Seriously

John O'Brien and the Breaking Boundaries in Berkshire Group

*A person-centred approach will be essential to deliver real change in the lives of people with learning disabilities. Person-centred planning provides a single, multi-agency mechanism for achieving this....*

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*Development of a person-centred approach requires real changes in organizational culture and practice. Achieving these changes should be a priority*  
—Valuing People

## Who we are

Members of the Breaking Boundaries in Berkshire group are service workers who have been honored by four people with learning disabilities who have allowed us to form four planning teams, one around each of them. Our teams have worked with these four people over the past eight months in order to learn-by-doing about the foundations of person-centered planning. We have developed our skills with Frances Brown's guidance and with managerial and personal support from Jo Welch. As part of our training we have been working with the four focus people to implement the plans we made together in a three day workshop in March 2001. We also gather regularly with Jo and Frances to reflect together on what we are learning as we implement and revise each person's plan. On 14 November, 2001, John O'Brien, who studies positive changes for people with disabilities, joined us for one of these meetings and we gave him our permission to write this paper as a reflect on what he heard from us.

Our experience shows that person-centered planning is a powerful way to generate commitment to change for people with learning disabilities.

Because many people wonder about whether person-centered planning can be relevant to people with substantial disabilities, it is worth saying that the four people we are learning with receive 24-hour support and have considerable need for day-to-day assistance and that some staff who work closely with them predicted that they would not be able to participate in person-centered planning. This prediction has proven false for all four people. By following their lead, we have been able to accommodate their preferred ways of communicating and participating in their team's work.

9 December 2001

## How person-centered planning could weaken our system

We welcome the recent Government White Paper, *Valuing People*. As we have listened carefully to the people who focus our teams' work, we find validation for *Valuing People's* principles and objectives. The people we are learning with, and those who know them best, want them to have homes that reflect their individuality, meaningful things to do during the day, and lots of opportunities to experience community life. Our experience also validates what the White Paper says about people who have the chance to participate in person-centered planning calling on our service system\* to make deep changes in culture and practice.

We can report what it is like to be in the midst of this process of culture change. The work of committed staff is one key resource in implementing *Valuing People*, and our initial experience of person-centered planning shows its power to generate commitment. Over the

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past eight months we have come to know the people who have allowed us to plan with them in new ways. As we have grown to know them, we have come to care much more that they have the chance to live their lives as they choose.

We have witnessed growth in their sense of themselves as worthwhile people. This growth in confidence comes from positive changes in the way other people treat them. These positive changes emerge from respectful listening and give them the experience of having real influence over some aspects their own lives. Though we have come to feel a greater sense of positive possibilities for the people we plan with, we feel more uncertain about the ability of the service organizations we work for to make the changes that people require. Our commitment to the people we support has grown but so has our impatience and dissatisfaction with the service system we work in. Right now, we are more optimistic than ever about what people with learning disabilities will achieve if staff and managers listen respectfully and modify services to match what clearly works to make a person's life better. But we are not yet confident that our service system will be able to act on what person-centered planning reveals.

Because our learning process does not stop at holding meetings or writing plans, and because some of us have a role in people's day-to-day support, we have been able to identify and achieve some positive changes within the scope of our immediate influence. Achieving these initial goals has increased the four focus people's trust in us, deepened our understanding of that matters to their quality of life, and strengthened our desire to work for further changes. This positive

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\* As we use it here, "service system" includes NHS and Social Services commissioners, care managers, service providers, and staff and the formal and informal ways they interact. We take this whole set of interactive parts to be the focus of the changes in culture and practice required by *Valuing People*.

cycle of growing trust, growing understanding, and growing desire to take positive action builds up tension as we come up against more and more barriers to positive change rooted in the way our service system currently functions. Leadership from system managers will translate that tension into guidance and energy for the sort of culture change that *Valuing People* requires. Failure of leadership from managers will translate that tension into frustration and cynicism.

If our service system can adapt to requests for change from the people we are planning with, we believe that its capacity to realize *Valuing People's* principles will expand, people's options to pursue improved quality of life will increase, and our morale will flower. If our service system cannot make practical responses to people's newly strengthened voices, the gap between *Valuing People's* words and our capacity to deliver will grow, people's options will stagnate, and our morale will wither. We appreciate that changing systems takes time, but, unless there are clear markers that a genuine cultural change process is happening in a way that will reach the people we plan with, we cannot trust that the passage of time alone will realize the White Paper's principles of rights, independence, choice, and inclusion. If increased investment in person-centered planning is not paced by increased responsiveness in the way services are provided and funded, person-centered planning will alienate its participants from the service system.

We have found a better way to understand what matters to people and it has made us hungry for the deep changes that *Valuing People* requires.

## Shared challenges

We are part of the culture and habits of practice that *Valuing People* calls on to change and we share responsibility for that change. Not only can system managers defeat the White Paper's promise by failing to provide leadership, we can too if we withdraw behind the barriers our service system throws up and wait for managers to make our way smooth. Such a retreat into powerlessness and dependency would belie a central responsibility of those who do person-centered planning: to find ways to generate positive actions with whatever is at hand.

Engagement in person-centered planning means more than recording a list of goals or specifying a care package. It means working with people over time to make positive changes happen. Our willingness to accept our share of the work necessary to change the culture of our services has a common source: person-centered planning becomes personal for everyone who joins in. Of course, each of us maintains

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an organizational and professional role, but, done well, person-centered planning shifts the way we inhabit these roles because it brings us into a more personal relationship with a person we support and with one another around that person. This shift draws new boundaries for us and these new boundaries generate some of the conflicts that energize change.

- Our perception of our job role and what we believe we should be doing in our work changes but our organization's perception of us has not changed. This difficulty seems most pronounced for people with direct support roles.
- By design, person-centered planning teams are a way that people with learning disabilities authorize action on their behalf. When this is successful, we become the person's agents, especially when people need assistance or interpretation to speak for themselves and family or non-service worker allies are missing. This can put us in the position of working for changes that don't match the current practice or change agenda of our organizations. It also introduces multiple points for originating an action agenda into organizations with a tradition of unitary, top-down authorization for action. The managers who assign us to practice person-centered planning will need to develop new ways to deal with the variety of individualized actions and priorities that will result.
- Person-centered planning is a process for building common understanding, so involvement in person-centered planning gives us a different kind of understanding of a person than non-participants have. This gives us a dual responsibility: to work hard to communicate messages that can be hard for those without experiential knowledge to appreciate; and, to pay attention to less engaged people's different perspectives and positions. It is particularly difficult to respond to reasonable questions about how we know that a change will suit people who have very limited communication. The temptation for us to feel superior to non-participants is as strong as their temptation to dismiss us as "over-involved" or "imposing our agenda on the person" or "unrealistic".
- Competent person-centered planning creates a shift in point of view for team members. We come to adopt our best sense of the person's point of view. Practices that have seemed good, or at least good enough, can come to seem unfair, even abusive, when we try to look at them through the person's eyes. This gives many person-centered

planning team members a greater sense of urgency for change than those in authority have. The inability of people with authority to understand this urgency or to act on their understanding can make us impatient and angry because someone we care about continues to suffer or to live with the costs of missed opportunities. Discomfort with our urgency or anger can lead those in authority to discount us as extreme in our views. This escalates the conflict by reinforcing the assumption that “managers don’t really care about change”.

- Everyone can applaud positive changes that do not disturb existing arrangements. But some of us have concluded that, for the person we plan with, these changes simply soften the negative effects of a living arrangement that is wrong for the person from the ground up. Life is better, but for us the improvements that seem to be enough for others only strengthen the case for major change.

Person-centered planning means working with people over time to make positive changes happen. It is not just meetings and written plans.

- Our service system has sought uniformity and standardization as a way to insure fairness and improve quality. Person-centered planning often reveals important variations that routine solutions have masked. Some of these variations imply big changes -people assigned to live with one another on the basis of professional judgments of compatibility reveal a strong preference to live apart. Other changes seem smaller -people scheduled for morning showers are more comfortable and relaxed with evening baths. Both raise the issue of how much accommodation to individual differences is reasonable and competent person-centered planning provides strong advocates for greater individualization and thus more variety and less uniformity. It means that people with strong and capable person-centered planning groups have better chances at good lives than people who lack such groups. Because it will take time to build up enough teams to offer everyone this advantage, it doesn’t seem fair. But keeping people stuck in mediocre or poor services when person-centered planning makes it clear what would suit them better doesn’t seem fair either.
- Over time, the cycle of telling people what’s important and having people respond by providing different kinds of assistance builds trust between the focus person and the members of the person-centered planning team. Trust also grows from meeting and talking regularly in a place especially set aside for listening and planning action.

This can lead people with learning disabilities to new confidence and strength. It can also bring up issues that are difficult to hear and difficult to handle, issues that raise questions about risk or abuse that our system now deals with in formalized ways that take people themselves out of the center of the decision making process. There must be fair and systematic ways do deal with people’s vulnerability to neglect or abuse, but it doesn’t make sense to take important decisions about people’s lives completely away from themselves and those who know and care about them.

- Person-centered planning often carries a considerable weight of emotion. Many people with learning disabilities have experienced unfair treatment and some have suffered unconscionably. The burdens and set-backs –often imposed by ignorance, prejudice, and discrimination on attaining even simple things can be hard to fathom and the achievement of simple things can bring a sense of celebration that could seem disproportionate. Our service system wants to function on the basis of objectivity, but objectivity can’t mean denying the problems that become apparent as people trust us enough to tell us about their lives and the everyday things that they want for themselves.

Leadership will translate tension into guidance and energy for culture change. Failure of leadership will translate tension into frustration and cynicism.

These changes in our understanding of role, authority, hierarchy, perspective, evidence, urgency, variety, and emotion can be the ferment for cultural change if people with responsibility for building the service system’s capacity to realize *Valuing People’s* principles and people gathered to assist people to have greater choice over how they live find productive ways to engage one another. One thing is sure: we have found a better way to understand what matters to people and it has made us hungry for the deep changes that *Valuing People* requires.