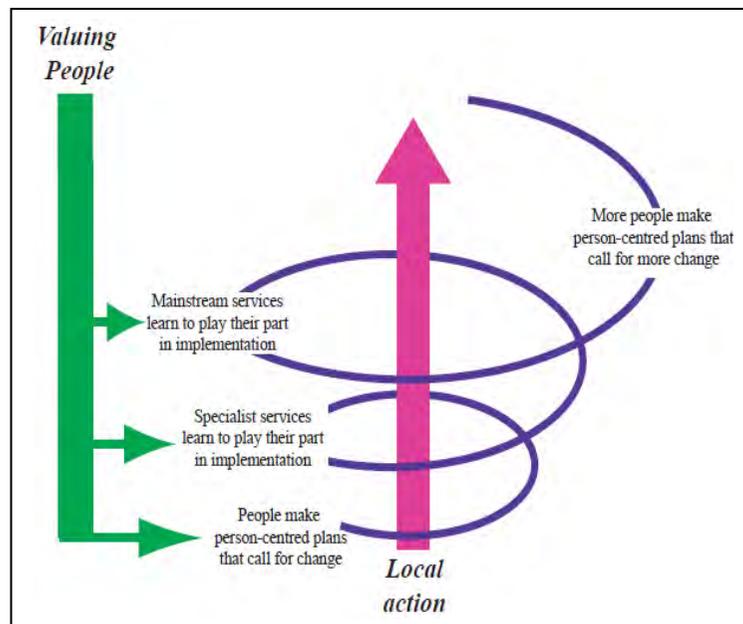


## Person Centred Planning And Transformative Change

### *Rediscovering illuminating contributions in the John O'Brien archives*

David Towell writes: *Citizen Network* is currently publishing a series of articles celebrating the lifetime contributions of John O'Brien and exploring the continuing relevance of his work to the challenges we face now in 'building communities that work better for everybody'. In the course of editing this series, I have been searching out articles and pamphlets that John produced during his many years of visiting the UK. When John took part in a workshop or met a local network, he frequently took the trouble to write up accounts of the discussions and make them available to participants. Often this meant a circulation of no more than 30 or 40 people. These documents are a treasure trove but a lot of the material is now hard to find.

This paper summarises three of these important contributions where I am listed as 'co-author'. Their main theme is an exploration of *how person centred planning could become an important tool of local system change*.



The 2001 government White Paper *Valuing People* made person centred planning (PCP) a pillar of improved services for people with learning disabilities. John is sometimes described as the 'father' of PCP and certainly, with many colleagues, was a key innovator in this field. In its original conception, PCP was intended as a 'disorganiser' i.e. a process for helping people break out of the assumptions often made about them in bureaucratic services so as to create new possibilities.

Accordingly I think John was open-minded but sceptical about a national policy that mandated PCP on a large scale.

Against this background we invited local teams from a number of places to join us for three workshops (held at Cranfield University) at roughly annual intervals between 2003 and 2005 to explore how the *Valuing People* mandate could become a positive tool for helping people 'get more of life'. Here are the three reports on these events. (Of course, 20 years on, most of the links within the three papers are now out-of-date but the messages are not!)

April, 2003: *Person Centred Planning In Its Strategic Context: Towards a Framework for Reflection-In-Action*

[Cranfield whole document.pdf](#)

January, 2004: *Building Local Capacity for Person-Centred Approaches*

[Cranfield II.pdf](#)

March 2005: *Getting More of Life: Improving the Timeliness of Person-Centred Approaches*

[Cranfield III screen.pdf](#)

In the early 2000s, the 'can do' spirit in these papers and indeed among the participants in the three workshops was inspiring. People with learning disabilities and their families that I know now typically experience inspiration like this hard to find. Loss of *Valuing People* momentum, the years of austerity and growing public intolerance of difference have taken their toll. I hope you agree that these 'Cranfield papers' are worth rediscovering.

# Person Centred Planning In It's Strategic Context

## Towards a Framework for Reflection-In-Action

John O'Brien and David Towell

In response to *Valuing People*, the number of people with learning disabilities experiencing person-centred planning is growing, and the number of people learning about person-centered planning is growing even faster. David Towell invited 28 people to spend two days at Cranfield University on 10-11 March 2003 thinking together about the kinds of changes in specialist and mainstream services that would significantly increase ... the benefits that people realize from their involvement in person-centred planning and ... the numbers of people who benefit from person-centred planning.



Some of us are people who are the focus of person-centred planning, some of us have children or relatives with disabilities, others facilitate and teach person-centred planning, others manage service provision, others manage service commissioning, others are involved in the activities of Partnership Boards, others have

national responsibility for assisting the implementation of *Valuing People*. Many of us have more than one of these roles.

We worked together in small groups and shared some of our learning with the whole group. As a whole group, we also listened to brief and powerful presentations by four people who are making important changes in their lives. Our discussions fell under four headings:



- Based on our experience, what “big picture” issues are emerging around the early implementation of person-centred planning?
- What has to happen locally to create the conditions under which person-centred planning can help large numbers of people to have better lives?
- What are the lessons from our discussions for national policy and implementation?
- Where and how can each of us contribute?

John O'Brien wrote these notes to summarize the large group discussions. He worked from the graphic record prepared and checked with participants during the whole group discussions. Because much of the work happened in small groups, every participant will have talked about many things not reflected here.

These notes are **not easy to read**. We are still exploring ideas that are complicated for us to understand. We want to work with people with learning disabilities to find more accessible ways to talk about these things. We hope that people who find this hard to read will work with others on their team to figure out what we've said and tell us what they think.

**Our Question**  
**What will it take for person-centred planning to lead to better lives for big numbers of people?**

### What do we mean by “Strategic Context”

The word **context** points our attention away from the details of how person-centred plans get made to the environment in which person-centred plans get implemented. The word **strategic** points our attention to capacities that must be developed on purpose, over time, if person-centered plans are going to lead to real positive differences in lots of people's lives.

So thinking about person-centered planning in its strategic context means identifying what needs to change in specialist services and what needs to change



in mainstream services (like housing, transportation, education, benefits, and services that help people get into jobs) if big numbers of people are going to be able to turn good plans into better lives. These changes will only happen if people work together across the boundaries that separate services. It will be some time before new ways of working become widely enough established to make it easy to gather the resources to implement a person-centred plan without a good deal of creative problem solving and negotiation.

Some people who make person-centred plans show the kinds of changes in specialist and mainstream services that are needed to make people's lives better: they either find ways to make existing services work to support the life they want for themselves or clearly identify the barriers that have to come down and the new capacities that must be created.

As people who have authority to change specialist and mainstream services figure out –through Partnership Boards– how to shape their services to match what *Valuing People* says, it will get easier to implement person-centred plans. Then more people will want to make plans that make the principles in *Valuing People* real for them. To make these principles real, Partnership Boards need to think about the services available now from two points of view. Partnership boards will do good work if they look at and change local realities...

... from the point of view of the principles and priorities identified by *Valuing People*.

... from the point of view of the growing number of people who use person-centred plans to identify the ways they chose to live and the way they want to use their fair share of available resources to help them to live that way.

## What results do we want?

To focus our thinking, we identified three results we want to achieve and assigned each a symbol and a color. We use the word **capacity** to stand for all that it takes to do something well, including people's knowledge and skills, authorization, time, and investments of money.

**First**, we want to develop local capacity to give people with learning disabilities and the people who know them best the assistance they need to say how they want to live their lives and to specify the sort of opportunities and assistance that will make a positive difference to them. This is the function of person-centred planning. So far, most Partnership Boards have put most of their attention on increasing the numbers of people who know about person-centred planning and developing facilitators for person-centered plans.



**Second**, we want to develop local capacity to adapt specialist services so that they can deliver needed assistance in ways that respond effectively to the requirements that arise from person-centred plans. We see this as a systematic process



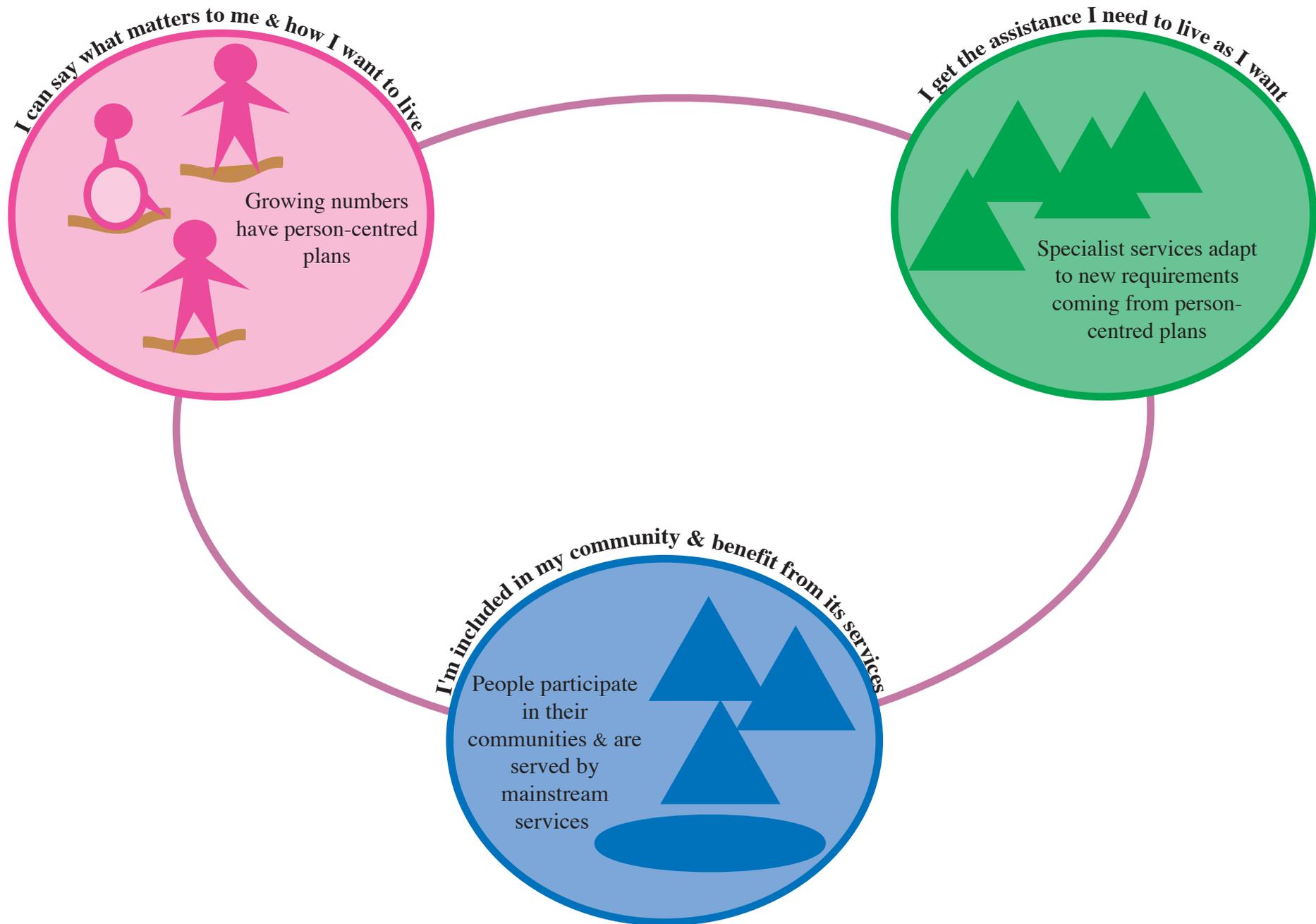
of changing both the kinds of services offered and the culture of services. This process involves creating an account of required adaptations to specialist services from the experience of the initial group of people who engage in person-centred planning and combining this with an assessment of existing local services in light of *Valuing People* to plan and learn to make necessary changes.

Third, we want people with learning disabilities to participate in and contribute to their communities. This kind of active participation allows people to share in the responsibilities and opportunities that come from being a friend, a good neighbor, a supporter of local activities, a member of groups, a worker, and sometimes an activist for change (as when adults with disabilities reach out to educate school children about disability or work with the police to increase the security of our streets). We also want to develop local capacity in mainstream services so that people with learning disabilities benefit from the services to which their citizenship entitles them. *Valuing People* identifies mainstream services and benefits as a major source of the resources necessary to assure that people can participate in and contribute to the life of their communities.



The relationship among the capacities to produce these three results creates the strategic context for person

## The Strategic Context for Person-Centred Planning I



centered planning, as suggested by the diagram on the previous page. Each capacity constrains the other two:

- Weaknesses in regularly summing up what people are calling for in their person-centred plans and changing services to meet the variety of requirements for individualized supports reduce the ability to implement person-centred plans and discourages people from investing in plans that say clearly what matters to them and the kinds of assistance that work best for them. Specialist services that fail to change to assist individuals to access and successfully use mainstream services will limit mainstream services opportunities to include people with disabilities. They will also suffer from greater scarcity of resources than *Valuing People* intends by its call on mainstream services to include people with learning disabilities in the same benefits they offer to any other person.
- Weaknesses in mainstream services capacity to include people with learning disabilities and offer them the same benefits as other citizens leave specialized services with the burden of paying for and providing services that others people receive from mainstream sources while it increases the number of problems that people must deal with as they work to implement their person-centred plans.
- Weaknesses in person-centred planning decrease the numbers of people with learning disabilities with the information and support they need to take up mainstream services while depriving efforts to change the culture of specialist services of information about necessary changes and concrete opportunities to learn new ways in partnership with individual people and their allies.

Investing too much in making person-centred plans and too little in culture change in specialist services and opening access to mainstream resources will frustrate

the implementation of *Valuing People*. An effective strategy will balance investments so that each growing capacity strengthens the others. Because both specialist and mainstream services have to figure out how to deal with many competing priorities under different local conditions, it will be hard to move smoothly to get this balance right. A lot depends on how effectively Partnership Boards work together and how much power partnership boards can claim in local areas by building good relationships among people with knowledge and people with influence. There won't be a perfect strategy, a "good enough" strategy will do.

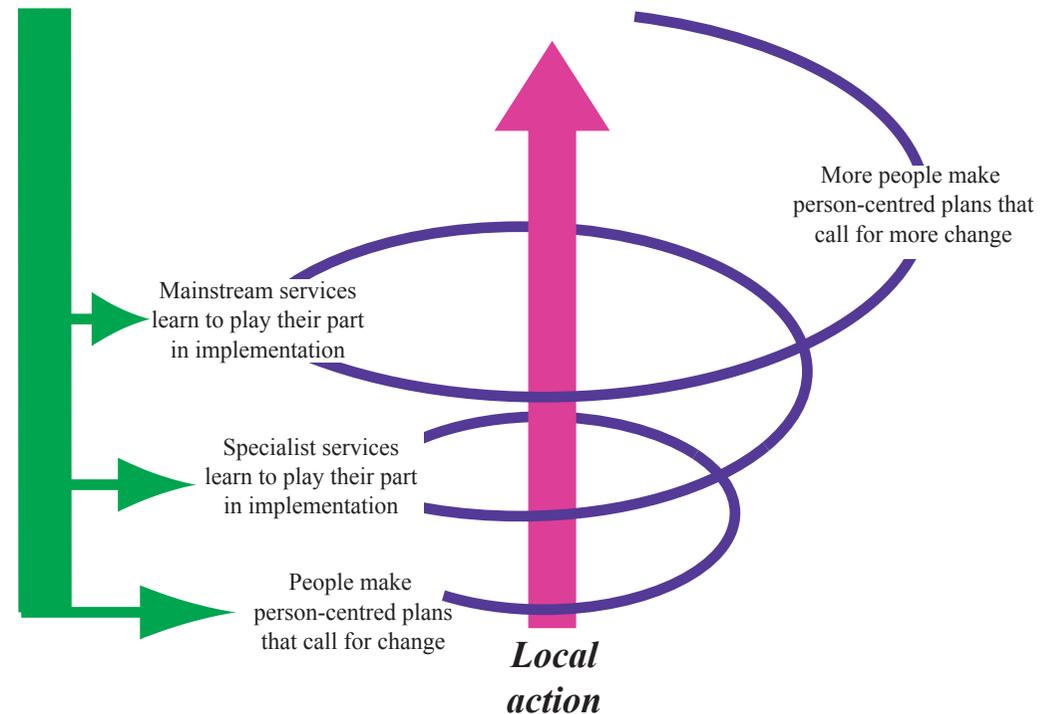
### How will a good enough strategy contribute to positive changes for people and services?

An effective strategy will allow growing numbers of people to implement plans that reflect considered choices about how they want to live and what assistance will work best for them. As specialized services learn to accommodate a greater variety of requirements for individual support based on the plans created by early adopters of person-centred planning, it will become easier for the next wave of people to implement

their plans. As more plans incorporate mainstream resources, it will become more beneficial to plan and more people will choose to do so. As more people make plans that refine the adaptations of specialist services and access mainstream services, more people will have better lives.

This strategy generates a positive spiral. From the top down, *Valuing People* makes plain the kinds of changes the Government wants local specialist and mainstream services to make, and it identifies person-centred planning as one of the ways to direct these changes. From the bottom up, mainstream services will learn how to include people with learning disabilities

### *Valuing People*



and specialist services will learn how to assist people to have the lives they want by responding to what they request based on their person-centred plans. More people will have a good chance to have better lives.

### Why a “good enough” strategy?

Making *Valuing People* real would be easier if...

... the Government had attached a substantial amount of new money.

... policies for modernizing mainstream services explicitly assigned very high priority to including people with learning disabilities.

... policy changes in other areas of specialist service provision harmonized with the values and principles of *Valuing People*

... managers and local political decision makers had only a manageable few priorities for change and plenty of time and money to support the change process.

However, local governments and mainstream services are dealing with many priorities for modernization and many perceive an overall scarcity of resources; Partnership Boards themselves feel rushed to respond to many requirements; some important initiatives for modernizing mainstream services don't explicitly refer to the inclusion of people with learning disabilities; there are potential disharmonies among policies (e.g. possible negative effects of implementing the Care

*“We are not sure that Government as a whole is giving enough priority to people with learning disabilities. We have not yet seen much to prove that all parts of Government have accepted Valuing People and that this means they need to change how they work so that people with learning disabilities are included when they make new plans and change things. Unless they also change, the lives of people with learning disabilities will not get better.”*

– *Making Things Happen: First Annual Report of the Learning Disability Task Force*

Standards Act on supported living); and many people think that the funding available for specialized learning disability services is insufficient to keep up with growing demand.

It would also be easier to implement *Valuing People* if necessary changes in specialist services were simply a matter of adopting new procedures and techniques. However, the change needs to go deeper, to shift a culture shaped by beliefs that services exist to gather people with learning disabilities together and control them for their own good. This culture makes too little room for recognizing that people with learning disabilities have the same rights and responsibilities as any other citizen and encourages services that are inconsistent with the nation's social inclusion agenda. It has created and then covered-up many problems. For example,

- Many people were re-settled from large institutions into group living arrangements that are smaller and often physically much better than the institution but still leave people outside their community and under staff control. Agreements between health or social service authorities and housing associations can lock people into these “part-way to-a-full-life” services, unless commissioners and providers can find ways to bridge into more individualized forms of services.
- The “professionals know best” assumption still shapes many relationships between people with learning disabilities, their families, and services. People with disabilities and family members are

uncertain that they will be heard; professionals are uncertain that they can respond to what people and families have to say. This difficulty in finding effective ways to communicate can even effect Partnership Boards, whose members have to learn how to listen to each other and work together to make and implement plans to change the culture and systems that contain them.

These conditions make it hard to imagine getting agreement on and smoothly implementing a coordinated strategy that deals with all the potential difficulties before people take action. A good enough strategy will allow people to clarify their purpose, find as many openings for positive action as possible, and support people to reflect on and revise as things change.

### The personal context for planning

Our work focused on the strategic context for person-centred planning so that we could think about how to improve the chances for big numbers of people to have better lives. However, we also reminded each other that people with learning disabilities and their allies have used person-centred planning to make positive changes before service cultures and practices have decided to change.

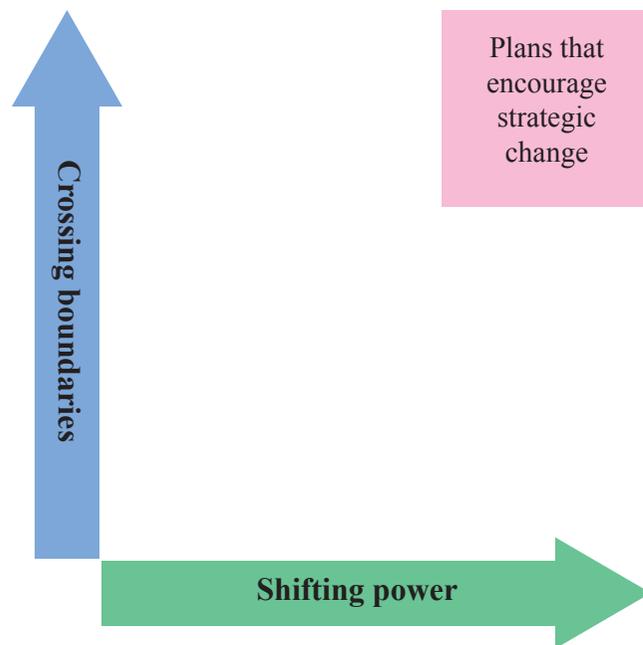
One way we heard that this has happened is through the involvement of ordinary people in active Circles of Support. Sometimes this has resulted in people finding home-grown solutions like the following. Local specialist and mainstream services may be a long way from assisting people with learning disabilities into a proper job, but local people may know who is hiring and support a person's application. Transportation policy may make it hard for people with disabilities

to get where they need to go, but local people may be able to figure out how to arrange a ride. This kind of action begins with the planning question, “How would anyone else around here accomplish this?”

Because *Valuing People* expects that people with learning disabilities will draw on ordinary, informal resources (“natural supports”) as they live the lives they choose, it’s important to remember this ordinary context for person-centred planning. One aspect of the culture change needed in specialist services is to make room for ordinary solutions and informal supports rather than reaching reflexively for a formal service solution, whether specialist or mainstream.

### Two dimensions of change

The local conditions for implementing person-centered plans develop as two kinds of changes happen:



- It becomes easier for people with learning disabilities to cross the boundaries of mainstream services so that they receive the same benefits as any other person does and it becomes more common for people with learning disabilities to participate in ordinary community life.
- The culture of specialist services changes so that power shifts from services and their staff having control over people with learning disabilities to people with learning disabilities and their families taking responsibility for choosing how they want to live with the resources and opportunities available to them and how specialist services will offer them the greatest assistance.

Those people who have the support and the courage to make and act on plans that push cultural change and move them into the use of mainstream services will be encouraging strategic changes, changes that can benefit more people than themselves by creating new patterns of services, opening new doors for people with learning disabilities, and showing new possibilities. Because this sort of plan stretches both specialist and mainstream services, it will take time, creativity, courage, persistence, and plenty of help from other people interested in real change. And even then, there is a real risk that desired changes will not happen as people wish. The people who make this kind of plans are pioneers.

Of course, progress on the rest of the Partnership Board’s agenda determines how far it is possible for pioneers to travel and how many people will be able to follow the paths that they open up. One common way that systems resist change is to create exceptions to accommodate a few individuals, then say “We’ve done that.” and leave everyone else pretty much where they are.

Identifying these pioneering plans as making a strategic difference is not to put down person-centred plans that lead to real improvements in people’s lives without connecting a person to mainstream services or working for a different, more individualized form of service. It is just to underline the importance of encouraging those who make and support person-centred plans to reach as far as they can in the direction that *Valuing People* points. Often people who have not experienced being heard by service workers will start small and then they will move on to a bigger change when small steps succeed,

Making change in these two dimensions calls for five kinds of action:

- Encourage responsibility for positive action.
- Check for evidence of results in peoples lives, in cultural shifts in specialist services, and in greater inclusion in mainstream services.
- Generate knowledge of mainstream service sectors.
- Generate local knowledge of the communities people live in.
- Discover and broadcast what is being learned about how to get better results from specialist and mainstream services.

These actions will move forward as new connections and relationships grow.

### The shapes of change

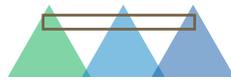
People organize themselves in different ways for different purposes. Shifting the context to allow more people to make person-centred plans that result in better lives involves developing relationships and connections that take each of these different shapes.

Two shapes reflect formal organizations.

- Formal organizations divide and control work through a hierarchy of tasks and reports. In the public sector they offer defined services and implement policies. Social Services Departments are formal organizations; so are Government Departments and service providing organizations.

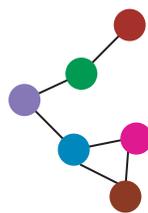


- When formal organizations plan, they often create official advisory groups in order to consult representatives of those with a stake in their services. The Learning Disability Task Force is such a group. When they collaborate with one another, they often create formal cross-organizational groups to make plans in response to requirements. A Partnership Board is such a group. These formal groups serve the agenda of the authorities that commission them.



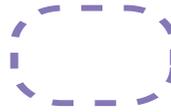
Three shapes reflect some of the many ways that people choose to create connections and relationships that support things that matter to them.

- People maintain and extend their networks in order to gather and pass on information, reach new people through introductions from those they already know, exchange help, and define possible deals.
- Circles gather those who share a concern for encouragement, emotional support, practical help, and personal exchanges. A circle may form around one person. They are people who believe in the



person, deserve the person's trust, and provide help. A circle may form as a group of like minded people who gather to support and encourage one another.

- Communities of practice are created when people who share a passion (for example, a passion for person-centred planning or advocacy for human rights), and who come from different locations, come together occasionally to exchange information, expertise, and knowledge.



Networks, circles, and communities of practice are important settings for making cultural change in specialist services and making the boundaries into mainstream services and community life easier to cross. Each, in its own way, connects people and creates conversations and exchanges that serve as sources of knowledge and energy to take action.

Formal organizations can't command or control these important ways that people organize themselves. They can support their emergence by investing their employee's time and by offering some practical support. The Valuing People Support Team is assisting the development of communities of practice around person-centred planning and a number of authorities and organizations are allowing their staff time to participate.

No reasonable attempt at significant change will depend solely on formal structures. Those who want change will need to invest in building their networks across boundaries, in gathering strength through circles, and in expanding skills and knowledge through communities of practice.

## Responsibility for action

The more people simply identify problems and wants and wait for formal systems to solve the problems and deliver their wants, the more bogged down in resentment and confusion the process of cultural change will get. It's easy for staff who feel overwhelmed and people with learning disabilities and family who feel like services never listen to find others to blame. The problem with this desire to blame isn't with accuracy: most staff are overloaded and few people with disabilities and family members feel respectfully heard. The problem is with what it will take to make progress on the deep changes that *Valuing People* calls for: more people –staff, managers, politicians, family members, people with disabilities, ordinary members of the public—who see themselves as responsible for finding ways to move things along.

A specialist service culture shaped by the belief that “professionals have all the answers” can trap anyone. Staff can be trapped into controlling the people they assist. People with learning disabilities and family members can be trapped into thinking that positive changes will happen if only they can persuade, petition, or push the system to deliver what they want (a position that assumes that they **do** have the answers and simply won't deliver) .

The signs of being caught in this trap sometimes show up in people's imaginings about person-centred planning. Some staff and managers worry that if people say what they want in their life, it will be staff's responsibility to deliver all that people want. Some people with learning disabilities and family members are reluctant to get involved in person-centred planning until they have proof that “they” (staff and managers) will actu-

ally deliver on what people call for in their plans. Both of these reasons to be reluctant about person-centred planning are expressions of the specialist service culture that *Valuing People* wants to change. They leave people with learning disabilities and family members passively waiting for staff to deliver rather than reorganizing things to make room for partnerships in which everyone takes responsibility for action.

Specialist services do have a duty to provide services that meet people's assessed needs. Mainstream services do have a duty to provide for eligible people, including people with learning disabilities. There is no excuse for treating people disrespectfully. And, the culture of specialist services has to change. This calls for new learning that has to be done in partnership. And, mainstream services have to find ways to open their doors to people they have been accustomed to seeing as the responsibility of specialist services. This calls for new learning which has to be done in partnership.

This learning will take place as more staff, more managers, more people with learning disabilities, more family members break out of existing patterns and find new ways to relate to one another. There are at least two starting places for responsible action.

The first way begins with the confidence that comes from recognizing that people with learning disabilities have much to offer and that it is often exciting and rewarding to play a part in making the changes called for by *Valuing People*. This way involves...

- Saying clearly what we want more of, focusing on creating more of what we find positive.
- Asking, "Who do we want to join us and how do we ask them?"

- Finding ways to communicate the benefits and the excitement of creating more individually responsive supports and more inclusive mainstream service and communities.

Sometimes the message to mainstream services and community members is a straightforward one. To get what we want, all that is necessary is that others see the person with a learning disabilities as a person like anyone else and do the same for them as they would for anyone else. Sometimes people with learning disabilities may need mainstream services to make some adjustments. Whatever the message needs to be it is important to frame it as much as possible in terms that make sense to the people we are inviting to join us.

The second way to positive change responds to blocks and barriers.

- Ask, "What exactly is getting in the way of good work?"
- Clearly identify the changes that would increase effectiveness and make whatever change is within our ability.
- Negotiate with others who need to make changes.
- Identify and pursue alternatives if our negotiations for change are unsuccessful.

Whichever way we choose, there are four guides to follow:

- Take time to build personal connections.
- Minimize blaming.
- Invite people to get involved in a helpful way.
- As much as possible, work with those who are willing; some reluctant people will become more willing when they can see what happens for others.

## Look for evidence of results

Person-centred planning is a process, better lives are results. The deliberations and documents of Partnership Boards are processes, increases in social inclusion are results.

Both person-centered planning and Partnership Boards are positive and hopeful processes and there are many things to learn in order for them both to properly involve people and plan together effectively. But it's important not to let our concerns for getting the process right take our attention away from results that improve people's lives and contribute materially to important national agendas.

Much that matters to people can't be measured in numbers, but there are numbers to indicate the rate at which a locality is progressing.

Because not everyone will want the same thing, it makes sense to look at results in terms of proportions of the whole population of people with learning disabilities. Not everyone will want a job in the open labor market, but some people do, and *Valuing People* calls for a significant increase in the numbers of people at work. So, tracking the percentage of people at work from year to year would be good information for people who facilitate person-centred plans to think about. They can ask themselves how the plans they are facilitating help people move into work.

Some indicators of progress on crossing boundaries into mainstream services might be:

- The percentage of people with learning disabilities who live in their own homes with needed assistance, the amounts of publicly available money people use to pay for housing, the amount of equity people are building in their property.

- The percentage of people with learning disabilities at work in the open labor market, the amount of money they earn, the amount of taxes they pay, the value of the benefits they continue to receive.
- The percentage of people earning qualifications.
- The percentage of people receiving adequate primary health care.

Some indicators that power is shifting in the direction of people with learning disabilities might be:

- The percentage of available funds for specialist supports expended through direct payments.
- The percentage of available funds expended on commissioning supports to individuals and families.
- The percentage of available funds redirected from congregate housing and congregate day services to supports for individuals.
- The number of people with learning disabilities who facilitate person-centred planning for other people.
- The number of family members who facilitate person-centred planning.
- Etc.

As often as possible, the results of changes for people with learning disabilities should be clearly linked to other important agendas:

- Social inclusion.
- Welfare to work.
- Connexions.
- National Service Frameworks for health.
- Etc.

## Generate knowledge

Two kinds of knowledge are necessary if people with learning disabilities are to take their place in community life and in mainstream services. Call one kind “local knowledge” and the other “sector knowledge” (as in the “housing sector” or the “health care sector”).

Both kinds of knowledge are generated in the same ways: by extending personal networks to include people from the other side of the boundary; by inviting people to cross the boundary and join our circles; by joining communities of practice with mainstream agendas (e.g. people interested in local economic development or improving further education opportunities); and by finding ways to take some action together that benefits each interest.

These two questions indicate the attitude that has the best chance of generating useful knowledge:

- What does the world look like through the other person’s eyes?
- How could we help the other person pursue something that is important to them that would also have benefits to us?

**Local knowledge** is specific to particular neighborhoods, villages, workplaces, etc. As local knowledge grows, people have better answers to questions like these:

- Who around here knows... (... who is hiring, who might be a good assistant for a person with learning disabilities, how to join the community theatre, how to raise tropical fish, a good plumber)?
- Who around here is interested and active in... (...line dancing, trains, local history, woodworking, supporting name your favorite football club)?

- Who around here do others look to for help?
- Who around here do people respect for their opinions?
- Who around here is active in politics?
- Who are the champions for this community and what is their agenda?

**Sector knowledge** concerns different mainstream services (housing, economic development, education, benefits administration, employment programs, primary health care, etc.). Some of this knowledge is local, but much of it applies across the whole country. As sector knowledge grows, people have better answers to questions like these:

- What is the history and identity of this mainstream service?
- What jurisdiction does this mainstream service have?
- What are its geographic boundaries and subdivisions?
- How does money flow to and through this mainstream service?
- What language do people in this sector speak: vocabulary, jargon?
- What kinds of reasons and arguments persuade people in this sector?
- What is the current agenda?
- What do people inside this service see as problems, pressures, and the leading edge of innovation?
- What does the organization chart look like?
- How do the procedures work?
- Who gets things done?
- Who influences the people in charge?

Generating knowledge is like learning to speak a new language. It takes time. It takes the ability to not know the correct answers and to ask questions. And the best way to learn is in conversation with native speakers; only some of what's necessary to know can come from books.

The best learning, and the most change, comes when people with learning disabilities cross the boundaries into a new sector and get involved in combining their agenda with that of the people inside. We heard of a group of self-advocates who have gotten involved in London Transport's efforts to improve public transportation. They joined in because the rules for using their bus passes didn't allow travel before 9:00 am and this made people late to their jobs. This issue has been resolved, and along the way the group has received funding to develop training for London Transport. Members of this group are coming to know the public transit sector from the inside out.

There are many reasons to take actions that will benefit people with learning disabilities. By reaching out to link our agenda with those of mainstream services, and by making the effort to learn their language, it is sometimes possible to make positive changes without requiring mainstream services to adopt our whole agenda.

### Sharing what is learned

Generating knowledge is a lot of work. That's why it makes sense to invest in ways for people to say what they have learned and share it with others. Some of this can be done in writing and in videos and on the internet. But some of it takes the kind of occasional face-to-face contact among interested people that communities of practice offer.

As people who are passionate about person-centred planning start to exchange mainstream service sector knowledge at their gatherings, that will be a sign that person-centred planning is influencing its strategic environment.

### Afterthoughts: Another view of the strategic context

The conference stimulated many of us to keep thinking after we left. The picture on the next page points toward another way to define the strategic context for person centered planning, based on David Towell's post-conference reflections.

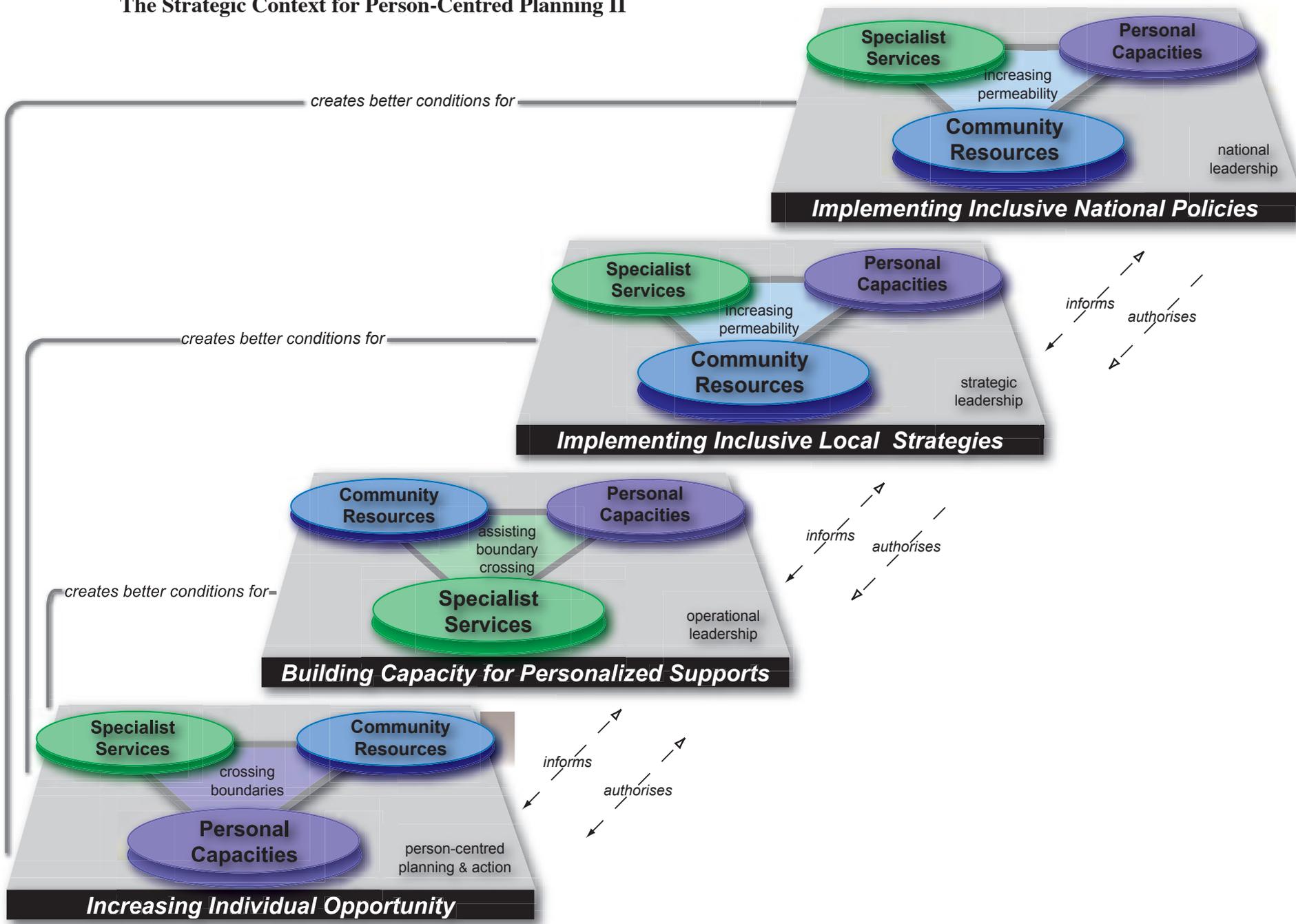
This diagram indicates that the conditions for successful person-centred planning and action are set by performance at **four different levels of action**.

- At the personal level, the focus is on **increasing individual opportunity** through person-centred planning and action. In order to shift power toward people with learning disabilities, specialist services must recognize that the need to have control of one's life and services is as legitimate as people's need for practical help; and mainstream services must recognize people with learning disabilities as bearing the same rights as any other citizen. In order to promote social inclusion, all those working at the personal level must cross boundaries that typically lead to the exclusion of people with learning disabilities from community life and mainstream resources.
- At the service level, the focus is on **building capacity for personalized supports** that include growing numbers of people with learning disabilities through the exercise of operational leadership. This

means that specialist services aggregate information about changing individual demands, consider the requirements of *Valuing People* and learn to offer an increasing variety of different combinations and types of assistance in ways that increase people's ability to exercise effective control of their lives. It also means that specialist and mainstream services negotiate their respective roles in ways that make it possible to assist more and more people with learning disabilities to cross the boundaries between specialist and mainstream services. It also means that people with learning disabilities and family members play an active role in operational leadership, considering not just their personal circumstances but the capacity of specialist and mainstream services to effectively support and include bigger and bigger numbers of people whose interests and needs may differ from their own.

- At the local authority level, the focus is on **implementing inclusive local strategies** by exercising strategic leadership so that all local public investments develop capacity for social inclusion and increase the personal capacities of all local citizens. Some of these strategies involve shifting the culture and practices of local specialist and mainstream services so that boundaries are more permeable, allowing excluded people to move more easily into mainstream services. Others strategies involve building local social capital. People with learning disabilities and family members play an active role in the administrative and political decision making for their whole locality.
- At the national level, the focus is on **implementing inclusive national policies**, exercising na-

# The Strategic Context for Person-Centred Planning II



tional leadership so that more and more of the government's investments join-up to promote social inclusion and build personal capacities. In addition to building social capital, national policies will improve the conditions under which local authorities implement inclusive local strategies. People with learning disabilities and family members have an important role to play in the planning and advisory bodies that influence national leadership.



Each level offers three points of view on action:

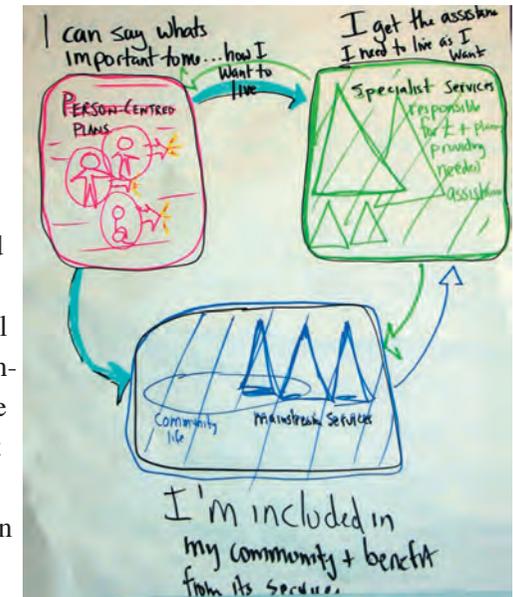
- Positively affecting the **personal capacities** of people with learning disabilities including people's experiences and knowledge and skills, people's needs for specialist assistance, people's use of mainstream services, and people's connections to other people and groups in their communities.

- Positively affecting the fit between **specialist services** and the individual requirements of people with learning disabilities for assistance and control; and positively affecting the division of responsibility between specialist services and community resources.



- Positively affecting the fit between **community resources** and the eligibilities and interests of people with learning disabilities; and positively affecting the capacity of specialist services to achieve a clear and coherent focus on the individual needs of people with learning disabilities by allowing them to attend to the things they are uniquely qualified to do without duplicating the work of mainstream resources.

The better each level performs, the stronger will be performance at other levels, provided that there are effective ways to communicate among levels. Higher levels do create conditions for performance at lower levels, and performance will be strengthened to the extent that different levels align around investing



in social inclusion and the creation of greater personal capacity. However, even while higher levels are learning, there is plenty of room for action closer to people with learning disabilities. No one has an excuse to opt out of taking some action that will move things along in the direction indicated by *Valuing People*.

We look forward to future opportunities for developing this framework through sharing in further reflection on the experience this action generates.

# Building Local Capacity for Person-Centred Approaches

John O'Brien and David Towell

**“Development of a person-centred approach requires real changes in organisational culture and practice. Achieving these changes should be a priority...”**

–*Valuing People*

## Who We Are and What We Did

At David Towell's invitation, teams from Bexley, Bury, East Kent, Oxford, and Poole gathered at Cranfield on 17-18 November 2003. Teams included people with learning disabilities, family members, managers of service providing agencies, and commissioners of services. There was also a team with national responsibility for assisting in the implementation of person-centred planning. This was the second such workshop in what we plan to be a series of similar events, to be continued in 2004. In the Spring, we had worked with a similar cross-section of stakeholders in the delivery of *Valuing People*, but invited as individuals. The lessons from this workshop can be found in *Person-Centred Planning In Its Strategic Context* (available from david.towell@iahsp.fsnet.co.uk ). In particular we learnt from sharing and reflecting on experience across England that success in delivering *Valuing People* objectives requires a balanced investment in the three main areas –helping people make and act on person-centred plans, shifting the culture of specialist services and opening up access to resources in the mainstream – and continually exploring the links between these three areas of development. Taking this core idea seriously, we also were able to see how, starting small, it might be possible to establish in each locality a positive spiral of change which would

ensure increasingly large numbers of people get individualized opportunities and support consistent with *Valuing People* principles. And in meeting the many challenges involved in achieving positive progress, we identified the importance of maintaining a focus on the twin outcomes of people with learning disabilities

crossing the boundaries of mainstream services and wider community life (inclusion) and gaining power over their own lives (self-determination).

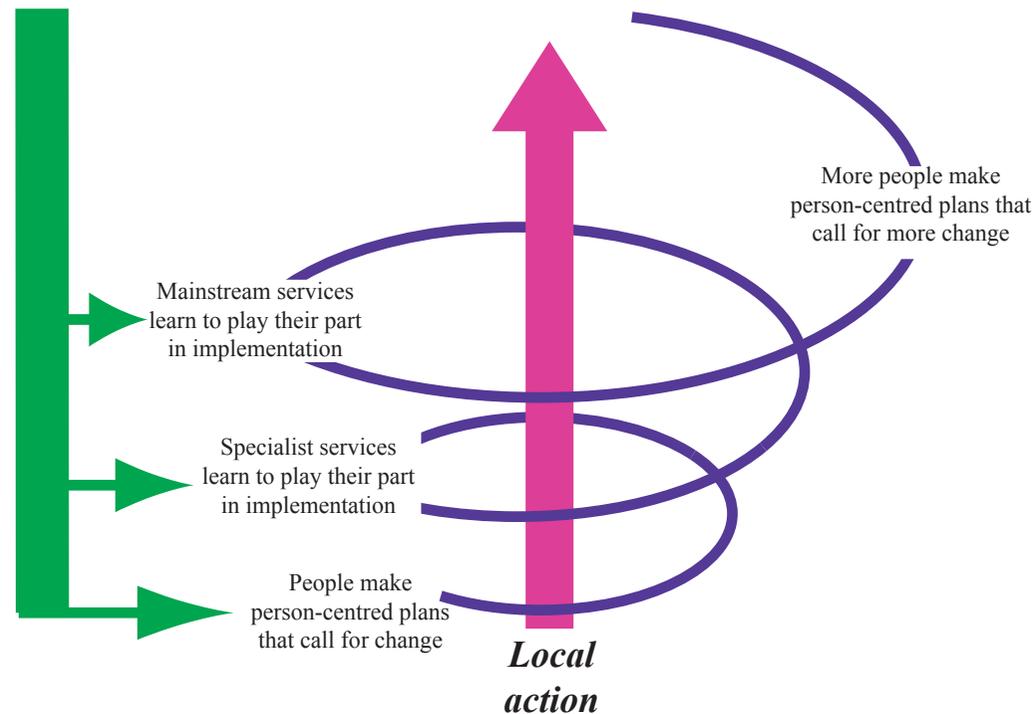
These ideas formed the backdrop to the second workshop but with the important difference that this time we invited people in local teams who, working and learning

together, would be better able to act on their diagnosis of their own situation so as to strengthen local strategies for systemic change.

Each team made its own record and was able to take home a locally-tailored workshop report to share with colleagues and inform action.

Rather than writing our own workshop report we reflect further on some of the key ideas discussed in the large group and start to sketch some 'thinking tools' which might be useful to

## *Valuing People*



teams in developing local action plans which support a positive spiral of sustainable change.

We appreciate that this paper is not easy to read. We are still exploring ideas which can be difficult for all of us to understand. We want to continue to work with people with learning disabilities to find more accessible ways to talk about these things. In the meantime we hope people who find this hard to read will work with others in their teams to figure out what to take from this to assist their own local efforts.

Our purpose was to explore **what needs to happen locally if person-centred planning is going to be a key part of delivering the kinds of supports described by *Valuing People***. We worked in teams, in groups constituted by role, and in a large group to answer four questions:

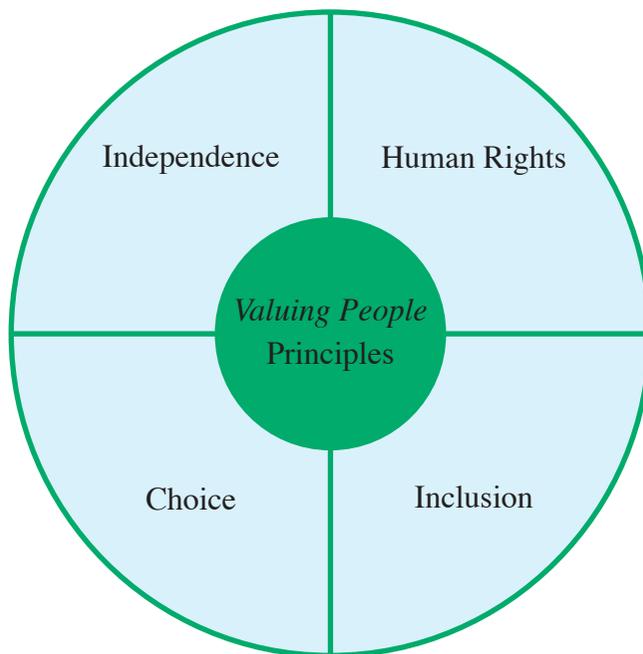
- What is the big picture in our locality: what is happening around the implementation of *Valuing People* and how does person-centred planning fit it?
- What needs to happen locally to make person-centred planning effective?
- What contributions to this agenda do our different roles make possible and what do we need from others in order to make those contributions?
- Based on our answers to the first three questions, what is our team action plan?

This paper represents work in progress. We welcome comments from those who use these ideas. We hope also to continue this process of learning from local experience through further workshops with a mix of local teams – next time perhaps nominated by local Partner-

ship Boards – and thus to further develop ideas and tools which assist principled local action.

### ***Valuing People* calls for deep changes**

*Valuing People* is based on clear principles. Organizing and delivering services consistent with these principles to the large numbers of people who deserve them calls for deep change of two kinds.



**The ways that people with learning disabilities receive services** need to change to embody the principles so that...

- ...Mainstream services accommodate people with learning disabilities alongside other citizens.
- ...People and families receive individualized assistance in ways that respect their identity and their choices about how they want to live.

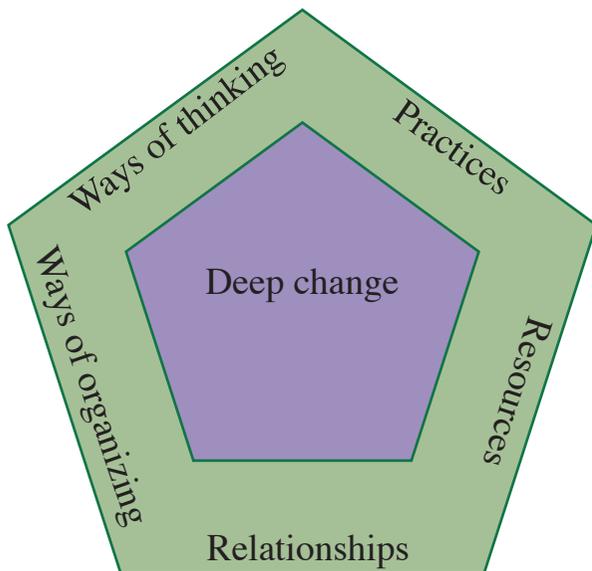
- ...Many more people have more income from paid jobs.
- ...People have life-long opportunities for learning.
- ...Many more people live in their own homes.
- ...People contribute to the life of their communities in ways that reflect their interests and gifts

**The ways that changes are made** need to embody the principles, so that...

- ...People and their families get the support they need to play an active role in defining, planning, steering, and evaluating changes in their own lives (This is where person-centred planning comes in.)
- ...Some people and families play an effective role in representing service users' point of view in planning, implementing, and evaluating changes in the delivery of specialist and mainstream services.
- ...Action for change in mainstream services includes the concerns of people with learning disabilities and actions for change in specialist services are informed by the concerns of those reforming mainstream services.
- ...Changes demand an investment in learning how to think and act differently: better understandings of disability, effective practice, and community life emerge and are widely shared.
- ...Local networks of people committed to the principles develop trust and mutual help based on shared action.

Deep change\* is a shorthand term that underlines the seriousness of the work of changing the culture of specialist and mainstream services. It calls for people and systems to identify settled patterns of working

\*See R. E. Quinn (1996). *Deep Change*. London: Jossey-Bass



that do not serve *Valuing People's* principles and to purposefully challenge them in order to discover new relationships, new ways of thinking, new resources, new practices, and new ways of organizing. Top down control of the details of deep change is impossible because these dimensions of deep change influence each other and create new interdependencies, which generate new possibilities and new problems. Some examples:

- Listening to people's preferences about how they would like to live calls for new practices to support people's decision making, new ways to think about risk.
- Thinking about everyone as a choice maker highlights the need for staff learning how to better understand people who do not use words and how to assist people with very limited experience to get a real sense of their options.

- As people draw on different funding streams and more people take up direct payments, contracting practices need to evolve.
- As mainstream primary care assumes responsibility for health care, specialist services need to consider their continuing responsibility to monitor and assist people to maintain good health and how to organize to meet that responsibility effectively.
- As mainstream housing resources become more available to people with learning disabilities as individuals, some service providers will face decisions about how to deal with property that they own.
- Groups with responsibility for planning and policy implementation are challenged to develop ways of discussing issues and making decisions that encourage genuine participation. Members with disabilities and family members are challenged to find ways to overcome what may have been a painful history of being ignored or disregarded and make the most of their opportunity to be part of the planning process.
- Because new capacities take time to develop and often depend on making the most of local circumstances, access to better opportunities will be patchy, at least during the time it takes to develop effective practices for disseminating competence from place to place.

These are interesting and important problems because their resolution will bring both specialist and mainstream services into better alignment with the principles of *Valuing People*. Positive changes in the lives of a growing number of people with learning disabilities demonstrate the practicality and the benefits of deep

changes in services. However, reflection on these changes shows that accepting risk and the responsibility to deal with real difficulties are part of the cost of improvements. This will be so at least until a new pattern of community expectations and services and supports stabilizes around *Valuing People's* principles.

**Necessary changes are not only deep but also broad.**

Especially in early efforts to cross the boundaries of mainstream services, people and their families will need to trust themselves and the people who support them to deal effectively with the many potential problems of relying on a new and different system. A person whose family feels secure with the day centre's bus may face a test of their trust at the prospect that a person will use public transit to pursue an individualized schedule of activities. Their capacity to support change will depend, in part, on their confidence that the person will re-



ceive adequate assistance to learn to use public transit. A person with a paid job in view needs confidence that the people she counts on have accurate information and willingness to help with potential benefits problems.

There is no single family voice or staff voice. Different voices represent very different estimates of the benefits and threats of change. Person-centred planning provides an important forum at the individual level for making sense of new possibilities, figuring out how to deal with problems, making agreements about action, tracking progress, and making adjustments and renewing direction.

Staff and their managers will find new demands around how and when they are available to the people they assist. The central management of service providing organizations face new strategic issues around what to provide and how to pace changes in their service offerings. Commissioners need new processes for assuring the adequacy and appropriateness of services because they can no longer rely solely on simple and impersonal professional assessments to judge the fit between services provided and people's preferences about how they want to live.

### Shared themes in social policy raise uncertainty

Deep changes in learning disability services –both in the way services to people with learning disabilities are delivered and in how necessary changes in the system of services are made– resonate with a set of themes common across current reforms in social policy. These themes –social inclusion, citizenship, increasing choice

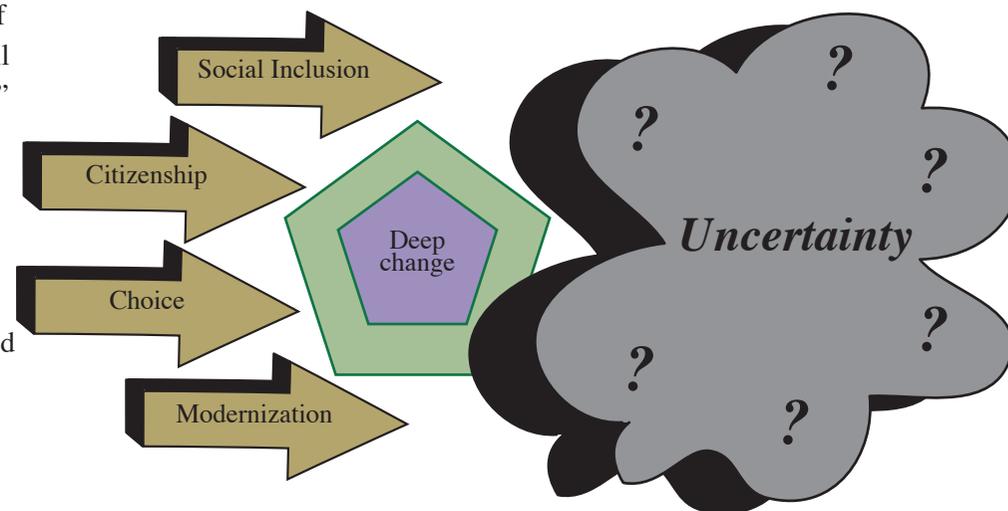
and involvement in the way services are provided, and the demand for fundamentally different approaches to service delivery– underline the importance and enrich the definition of the *Valuing People* principles. The breadth of their application means that people throughout local government and across mainstream service provision will recognize the intent of *Valuing People*, especially if those of us who are serious about its implementation learn to frame our proposals in ways that clearly express these themes.

So there is promise in the widespread call for deep change. But there is also a drawback: a further increase in uncertainty.

- People count on specialist and mainstream services while those services are changing. Not everyone who is affected would choose significant change in familiar arrangements in either specialist or mainstream services. A commitment to participation and responsiveness disallows ignoring those who want most to avoid the disruption of deep change. How will voices for “no change” be acknowledged and accommodated?
- These themes give people in other systems good reasons to respond to action based on *Valuing People's* principles. However, people with learning disabilities may not

figure in their planning unless people with learning disabilities and their families and allies actively represent their concerns.

- Other sectors face their own challenges of deep change. They may see people with learning disabilities as integral to their mission or they may see people with learning disabilities as an unwelcome distraction. Learning with people with different organizational cultures takes effort to cultivate relationships and understanding. This takes time and introduces even more demand on our capacity to learn outside familiar boundaries.
- Themes like social inclusion and citizenship are topics for controversy and much conversation as well as for the multiplication of initiatives. This may promise a stronger platform for joint action, but keeping up requires considerable effort.



## Avoiding distractions

Situations of high uncertainty generate at least three predictable distractions from the work of deep change:

- **Focus on task over principle.** We get busy holding meetings and training sessions, and submitting papers in compliance with external deadlines, and dealing with the inbasket. Busy-ness provides both a feeling of change and a good excuse for avoiding deeper changes in relationships, resources, practices, and ways of organizing. Person-centred planning can be a tempting busy-ness trap when the goal becomes simply increasing the number of people who attend training and the number of plans filed.
- **Narrow options under stress.** The changes required to implement *Valuing People*'s principles call for a significant increase in the variety of resources accessed and supports offered. The stress of uncertainty may lead us to lock-in to single solutions at just the time that we need to be exploring a wider horizon. A set of person-centered plans that all call for small variations on more of the same things that people already get signifies a fall into this trap.
- **Denial.** Reducing the demand for deeper change can be accomplished by simply re-labeling current practices as exemplars of principle, or by claiming that expressions of satisfaction with current arrangements mean that no further opportunities need be explored, or by resigning from responsibility for taking any action until some other external change happens.

Developing the capacity to implement *Valuing People* for large numbers of people and not just a fortunate few

calls for leadership that will keep people from mistaking the walls of distracting traps for the horizon of possibility. This leadership is as important among commissioners and senior managers of services as it is among the participants in person-centred planning.

## Creating tools for strategic change

Everyone who wants to play a constructive part in meeting the challenge of deep change needs to improve their ability to think and act as strategists. Our discussions sketch the outlines of three kinds of tools for better strategic thinking.

There are important conditions to enable good use of these tools:

- Time to get together
- Support for reflection (good places to meet; capable facilitators and recorders)
- Inclusion of people with diverse perspectives
- Shared commitment to continually improve ability to listen to different points of view and to present a true picture.

### 1. Sharing a big picture

It's easy to focus on a single family of tasks and miss a big picture of the context for all the different changes necessary to implement *Valuing People*. Taking the time occasionally to construct and revise a shared picture of the environment gives people with diverse interests and perspectives the chance to discover opportunities for shared action and to consider priorities. Answering questions like these provides a useful background for using the other tools outlined here. Choosing key points

and considering the relationships among them defines the art of constructing a useful big picture.

- What can we say about the larger environment that contains our work?
  - What national trends and forces do we need to monitor and connect with?
  - What is happening in our local area among mainstream services and in communities that we need to monitor and connect with?
  - What is happening at more senior levels of any provider organizations that also work in other areas as well as ours?
- How would we describe the current effectiveness of people with disabilities and their families...
  - ...in influencing the services that they receive themselves?
  - ...in gaining support from other people with disabilities and their families to inform and implement positive changes in their own goals and lives?
  - ... in influencing the implementation of *Valuing People*?
- How would we describe the current state of coordination among the services in our area?
- How would we rate our history of collaboration with mainstream services?
  - What has worked?
  - What has not worked?
  - What are our current assets to promote collaborative work?
- How would we rate our history of change within specialist services?

- What has worked?
- What has not worked?
- How do we transfer what has been learned in one setting to others?
- Where are the strengths to build on in our specialist system?
  - Good examples of individualized assistance to people and families?
  - Assistance to people using mainstream services in a way that promotes choice and personal inclusion?
  - Ways that the voice of people and families is strengthened?
  - Sources of system flexibility such as support for use of direct payments, service brokerage, incubators for new initiatives?
  - What are our current assets to promote better alignment with Valuing People’s principles?

## 2. Checking the balance of strategic investments

Achieving a better capacity to plan and work in a person-centred way requires investment in a variety of activities. From time to time, partnership boards should set aside time to check the balance of their investments by describing how much time, talent, and money they are investing, then judging how good the balance is along at least the five dimensions described in the table below, and then adjusting their investments to gain a better balance. There is no single correct proportion of investment, only the requirement to be thoughtful about the balance as circumstances change.

Focusing “inside” on improving our own specialist services	Focusing “outside” on developing opportunities in mainstream services and community resources
Helping people to form and express their aspirations	Supporting people to pursue their aspirations
Focusing on people’s current preferences about how they want to live	Supporting people and families and allies to learn about new possibilities
Taking more local action within local communities and particular services	Shaping wider policies
Refining the techniques for planning with people	Improving service capacity to assist people in individualized ways
Focusing on people and family members and direct support workers	Focusing on managers and commissioners

## 3. Refining understanding by developing and testing systems of measurements

An effective system of measurement accomplishes at least four things:

- It provides a credible account of the results of service investments in terms of Valuing People’s principles.
- It allows comparisons across groups of people and through time that identify situations to learn from.
- It offers one means of translating people’s experi-

ence of barriers into useful messages that stimulate problem solving and policy change.

- It improves understanding of the meaning of the principles.

The process of developing measures and systems to assure that monitoring is effective in the ways described above provides a good opportunity for people to improve their understanding of what *Valuing People’s* principles mean.

- What information would credibly indicate an increase or decrease in inclusion; choice; independence; promotion of human rights?
- What is the least intrusive, least expensive way to collect and analyze this information?
- How can the monitoring process increase the individual influence people and families have over the way services are provided?
- How can the monitoring process improve the effectiveness of Partnership Boards?
- What information is it best to analyze for groups of people in order to surface areas that call for focused change efforts? (Examples might be trends in income from wages from open market jobs or rate of uptake of direct payments by people with substantial needs for assistance.)

## 4. Learning from storytelling

Deep change requires that both singly and together we sustain the effort to learn from reflection-in-action about how to do better. Stories are a powerful way to communicate the possibilities opened by *Valuing People’s*

principles. Honest, clear stories can broaden people's sense of what is possible and encourage and guide action. Building skills in telling stories with purpose and in listening to stories to guide further action creates important resources for deep change.

Because aligning services with the principles calls for significant change in how services assist people and families, we need to invite stories about key results, including these:

- People working for fair wages in open employment with support from their co-workers.
- People secure in their own homes.
- People substantially increasing control over their own daily lives.

- People benefiting from the use of assistive technology and supports to communication, mobility, productivity, and independence.
- People making valued contributions to ordinary community associations and activities.
- Mainstream providers demonstrating competency in serving people.

Because change needs to happen broadly, we need to invite stories of change at different levels of the system. For example, we need to know what it means to a person to finally be able to have their own front door key. We also need to know what it took to make it possible from the point of view of direct service workers, and managers, and mainstream housing providers. And simi-

larly across the whole range of issues which contribute to a full life, we need to learn to tell and listen to stories that communicate possibilities and stories that communicate know-how and stories that serve as springboards to the kinds of action that will result in the deep changes required to offer ever larger numbers of people with learning disabilities opportunities for choice and independence and inclusion based on respect for human rights.

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## Getting More of Life

### Improving the Timeliness of Person-Centred Approaches

John O'Brien and David Towell

#### Who We Are and What We Did

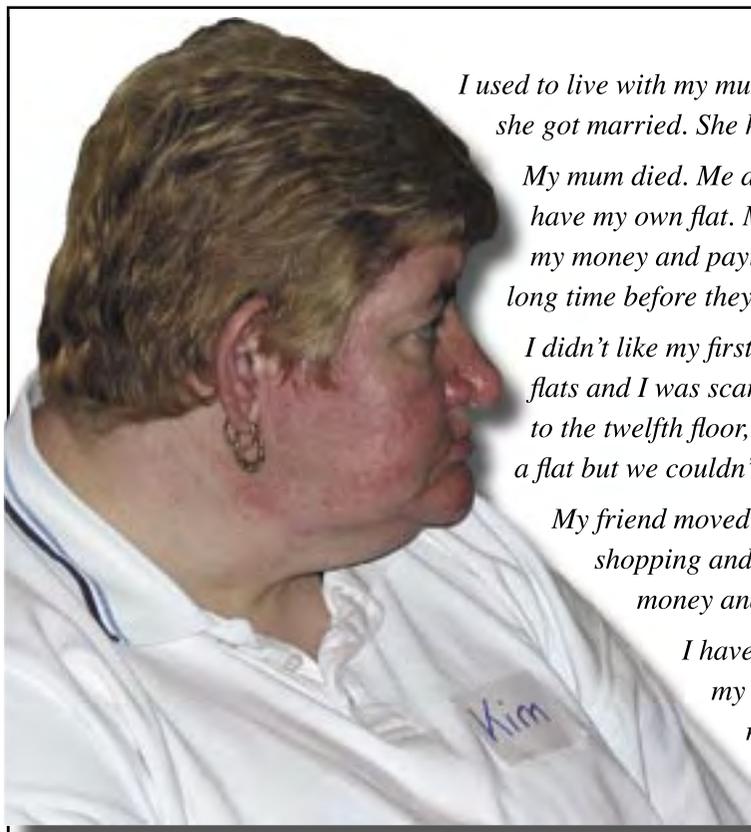
Kim's story –which she shared with teams from Bristol, Cumbria, Kent, the Northeast, and Worcestershire who gathered at Cranfield on 7-8 February 2005 at David Towell's invitation– expresses the principles that shape the implementation of *Valuing People*. Exchanging sup-

port with friends, Kim's independence has grown as her choices have grown. Her choices have grown as she and her allies –firmly convinced of her rights– have negotiated the changing terms of her inclusion in mainstream housing and adjustments in the assistance she uses.

We came together to learn more about how to build the local capacity to offer many more people the kinds of opportunities that Kim experiences. These are everyday choices about where and with whom to live and with what support. But offering the opportunity for everyday choices calls for complex adjustments in the beliefs, relationships, and practices of specialist and mainstream services.

The group included people involved in self advocacy, person-centred planning coordinators, managers of service providing agencies, and commissioners of services. This was the third workshop in what we plan to be a series of similar events. The records of the first two workshops are available at [www.bris.ac.uk/Depts/NorahFry/Strategy/papers.htm](http://www.bris.ac.uk/Depts/NorahFry/Strategy/papers.htm) or from David Towell at [david.towell@inclusion.demon.co.uk](mailto:david.towell@inclusion.demon.co.uk).

The core question in each of our three workshops has been, **What will it take for person-centred planning to lead to better lives for big numbers of people?** This question grows from a twofold realization. Committed people can create remarkable results by working in person-centred ways, as Kim and her friends have done. And, many people will be excluded from access to these results unless there are deep changes in the culture of specialist and mainstream services.



*I used to live with my mum and dad and my sister. When my sister was young she got married. She had two children. They live independently now.*

*My mum died. Me and my dad were upset. I wanted to move out and have my own flat. My dad and my sister said I could not manage with my money and paying my bills. They were worried about me. It took a long time before they said it was alright for me to move out.*

*I didn't like my first flat. It was next door to the doors of my block of flats and I was scared someone would break in. Then they moved me to the twelfth floor, which is better. Me and my friend wanted to share a flat but we couldn't.*

*My friend moved in to the flat next door to me. That was nice. We go shopping and out for meals together. I help my friend with her money and her cleaning.*

*I have lived in my flat for five years now. I can manage my money. I go to my dad's on Sundays and we go to my sister's for tea. They are proud of me.*

*–Kim Norman*

*Bristol and South Gloucestershire People First*

In our previous workshops we learnt from sharing and reflecting on experience across England that success in delivering *Valuing People* objectives requires relentless focus on the twin outcomes of people with learning disabilities crossing the boundaries of mainstream services and wider community life (inclusion) and gaining power over their own lives (self-determination). This calls for a balanced investment in three main areas – helping people make and act on person-centred plans, shifting the practice of specialist services, and opening up access to resources in the mainstream – and continually exploring the links between these three areas of development. As this diagram, which has appeared in each of our workshop reports, suggests, we see the task

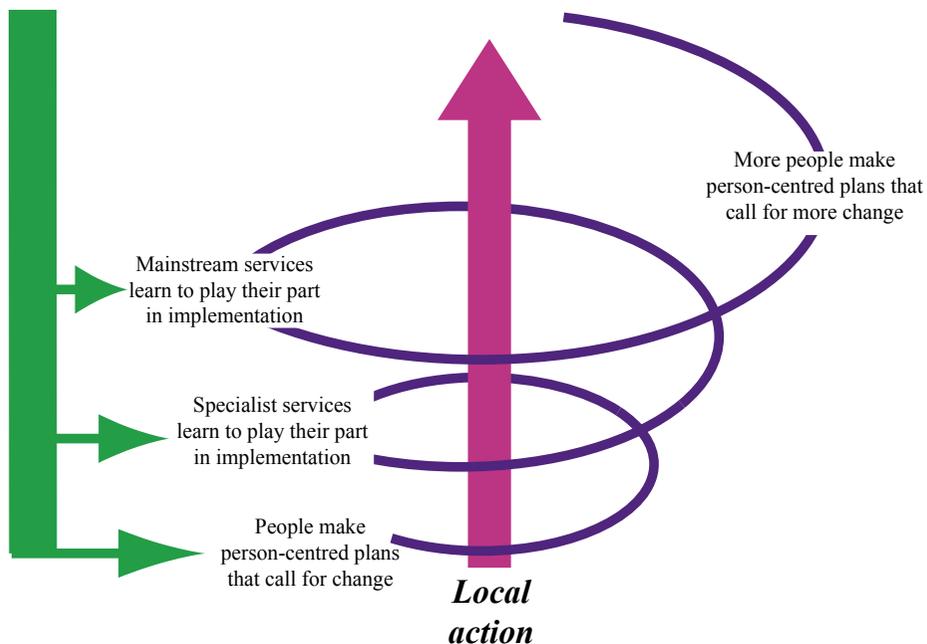
as harmonizing local action with national policy in such a way that a positive spiral of learning through action and reflection develops.

Our purpose in this workshop was to explore **what needs to happen locally if people with learning disabilities are to play an active part in opening doors to inclusion in community life.**

We worked in teams, in groups constituted by interest, and in a large group. In search of promising possibilities, we reviewed what we have learned that increases the number of people who experience more of life and can say...



## Valuing People



- ... I am part of a growing **network** of ordinary relationships which help me and the others who belong to the network to make useful contacts and get things done.
- ... I have the **home** and home life that I want
- ... I have a **job** that I value
- ... I have **good things to do** as a member of my community
- ... I have the **transport** I need to get where I want to go
- ... I am maintaining my **health** and get good health care when I need it

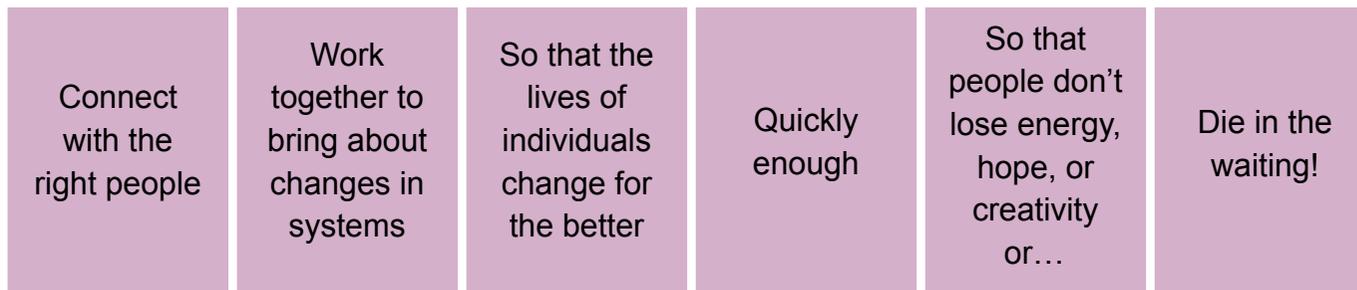
Each team made its own record and was able to take home a locally-tailored workshop report to share with colleagues and inform action. Rather than writing our own workshop report we reflect further on some of the key ideas discussed in the large group

We know that this paper is not easy to read. We are still exploring ideas which can be difficult for all of us to understand. We want to continue to work with people with learning disabilities to find more accessible ways to talk about these things. In the meantime we hope people who find this hard to read will work with others to figure out what to take from this workshop report to assist their own local efforts.

### Contact

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## Timeliness as a Key to Strategy

One team included the sequence of pages above in their report of what they have learned in the process of implementing person-centred approaches. Their message highlights the importance of timeliness in making change.

The power of *Valuing People* (and of the recently released *Improving the Life Chances of Disabled People*) lies in the call to actively pursue values that are both compelling and difficult to realize under current conditions. The move from the role of passive recipient of professionally controlled and controlling services to active chooser of a personal path to inclusion requires energy, hope, and creativity.

Person-centred approaches have released energy, hope and creativity as local areas have experienced growth in...

... capacity to listen carefully to people's aspirations and preferences and take action to change the way people experience specialist services based on what staff hear; this includes a growing number of ways to respond to people with limited communication and limited life experiences.

... ownership of the person-centred planning process by people with disabilities and their family members, as shown by the increasing number of people and family members making and facilitating plans, teaching about person-centred approaches, and developing person-centred ways to plan and act.

... the number of available models of people making positive changes in their lives, sometimes through the use of direct payments

Listening and acting together builds commitment to the possibilities identified by *Valuing People*. Positive results lead many people to higher aspirations and more courageous action. This virtuous circle can be broken, and even crash into demoralization and cynicism, if people lack positive ways to deal with the delays that they meet.

Conserving energy, hope, and creativity through the time it takes to shift power to people and their families and re-negotiate the boundaries of mainstream services and ordinary community life draws attention to the importance of improving timeliness.

**Timeliness means that people believe that they have enough of what they need, when they need it, to continue working for a positive change in their lives.**

In a changing system delay is inevitable, but timeliness has broken down when people feel they can do nothing but wait passively for change to come to them. Looking at local strategy from the point of view of timeliness suggests three questions:

- How can we minimize delays imposed by the specialist service system?
- How can we minimize delays imposed by mainstream services?
- How can we support people with disabilities and their families to experience timeliness in their move to greater power and greater inclusion?

## Minimizing Delays in Specialist Services

The first step is identifying where delays occur and accepting responsibility for reducing them. Taking responsibility for reducing delays means more than assigning responsibility for the delay to someone else and waiting for them to resolve the problem. It means trying other ways.

Questions that uncover and challenge limiting assumptions reveal ways to reduce delays. Examples:

- A growing number of people who want to make personal plans are waiting for one of a small supply of staff facilitators. How could more people with

disabilities and family members facilitate their own plans? How could more people with disabilities and family members facilitate plans for others? Who else could plan with people effectively?

- A growing number of people are waiting for an intermediary to move things along a decision-making chain –perhaps a busy social worker with a large caseload. How could more people “go direct” rather than waiting for the intermediary? Could some approval steps be eliminated altogether? Could some approval steps be managed by exception, with approval assumed on notification except under certain specified conditions?
- Some people are waiting for a service provider who is willing and able to provide the assistance they require in the way that they prefer. How could the tools and structures that are developing through the *In Control* projects ([www.selfdirectedsupport.org](http://www.selfdirectedsupport.org)) help more people use direct payments to organize their assistance?

### Reducing Delays in Mainstream Services

Some mainstream service delays result from scarcities or inefficiencies that affect everyone who uses them. Other delays result from difficulties in mainstream service providers recognizing people with learning disabilities as eligible for their services and lack of reasonable adaptations to their impairments.

Experience among those at our workshop shows that people with learning disabilities and their allies usually have a better chance of influencing

mainstream services and community developments when they join in with mainstream planning efforts and improvement projects as contributing participants than when they try to recruit those responsible for mainstream services to join in Partnership Boards. As one team put it, “It is easier for us to get a seat at their table than it is to get them to our table.”

The team from Swale, in Kent, reports a positive experience in joining in regeneration planning for their community. They describe what they have done as “crossing the river” from a focus on specialist learning disability services to a wider concern for their community as a whole. By making the journey, people with learning disabilities and their allies have a voice in the disposition of a significant investment in community regeneration, they have considerably expanded their network of useful contacts, and they have learned a new and effective way to help people plan cooperatively. Called *Planning for Real*<sup>®</sup>, this approach seems to them like “person-centred planning for a whole community”, with its use

of imagery and three dimensional models to support people in exploring how they want their communities to be. Learn more from *Neighbourhood Initiatives*, the originators of *Planning for Real*<sup>®</sup>, at [www.nifonline.org.uk](http://www.nifonline.org.uk).

Taking an active role in other’s work means looking at issues of importance to people with learning disabilities from a new angle, a perspective that shows how an issue of importance to a larger group of citizens can be resolved in a way that works for people with learning disabilities. To participate effectively, people concerned with learning disabilities need to put themselves inside the heads of people concerned with community development, or housing, or transport. The collages below were created by people in Bristol as a way of exploring the ways that four major themes in planning for the whole community connect with their concerns. This effort to learn other sector’s languages makes us more effective in influencing their plans.



Being well represented in the forums that guide the whole community's future is important, but implementing plans to improve safety, or jobs, or housing, or transport is as complex as implementing a Partnership Board's plans. Instant results for large numbers are not an expectable part of any significant change.

There are at least four good reasons to contribute actively to the work of improving other sectors of community life:

- Plans and the changes they lead to will be better for everybody if they include careful consideration of the issues of access and adaptation for people with disabilities.
- By their active participation, people with learning disabilities and their allies will educate other concerned citizens and officials about themselves while they build useful contacts. As one team put it, "In some ways, the tea breaks can be the most important parts of the meeting. That's when you can meet people and build connections."
- Many people with learning disabilities care as much as any other citizen does about community issues and they have as much responsibility as any other citizen to put their caring to work as part of the solution to important community problems. There is no way to join-up thinking and action across the sectors that influence community life if people don't make the effort to join-in with one another.
- Involvement across sectors of the community produces timely knowledge about what is happening and where there might be opportunities for people with learning disabilities.

## Supporting People to Experience Timeliness

People experience timeliness when they judge that they have enough of what they need, when they need it, to continue working for a positive change in their lives. When people see delays as part of a process that they play an active part in improving, timeliness is maintained even when progress is slow. When people are waiting passively for someone else to deliver improvements to their lives, timeliness has broken down and feelings of helplessness, cynicism, and resentment entangle the capacity for positive action.

**Not being alone.** Being and feeling in company with others who have a common purpose is the most important antidote to helplessness. This makes it urgent to resist the temptation to reduce person-centred planning to a paper exercise conducted for the convenience of busy staff and managers looking for target numbers of plans done. Done right, person-centred planning invites the engagement of a person and allies in discovering a common purpose that they are willing to work together to achieve. This requires that Partnership Boards assure that there is sufficient investment in person-centered planning to allow people to own their plans as a source of positive action, and that this investment results in a growing number of plans that carry people over the boundaries of specialist services into positive roles as included members of their communities. If every plan leads back to specialist services, it is time to think more deeply about person-centered planning.

**Getting Organized.** Two levels of organization help people avoid the state of waiting passively by encourag-

ing continuing positive action, even when the path to important goals is long and rocky.

A circle of support organizes allies at the personal level. It supports people to make sense together, over time, of where there are opportunities for the person to make a contribution and benefit from social exchange and how to access them. It allows people to risk the pursuit of ambitious goals. Many people with a history of involvement in specialist services have no or very few allies who are not current staff members, and sometimes no staff members have the kind of personal relationship and commitment to action that would identify them as allies. It is important that staff notice people's isolation and respond thoughtfully by finding ways to strengthen existing relationships and extend people's contacts.

Advocacy groups bring together people who share a concern for change and support them to work together. Advocacy groups might be ad hoc or well organized. They might be groups that include people with learning disabilities, or family members, or staff and other citizens or they might be groups, like VIA ([www.viuk.org](http://www.viuk.org)), that bring people with all of these identities together. What matters is that people are taking action together, not waiting for an "advocacy service" to get around to them.

Being a member of an active advocacy group multiplies people's opportunities for positive action. The longer the delay that people encounter and the more systemic the cause of the delay, the more important belonging to a group committed to changing the conditions that create delays can be.

Investments in courses like *Partners in Policymaking* and in supports to advocacy groups are important parts of a Partnership Board's change strategy.

**Seeking the most direct route.** The fulfillment of timeliness is arriving at an important goal: starting a good job or moving into your own home. People with learning disabilities and their families and allies can increase their chances of living in ways that make sense to them if they practice seeking the most direct route to their goal.

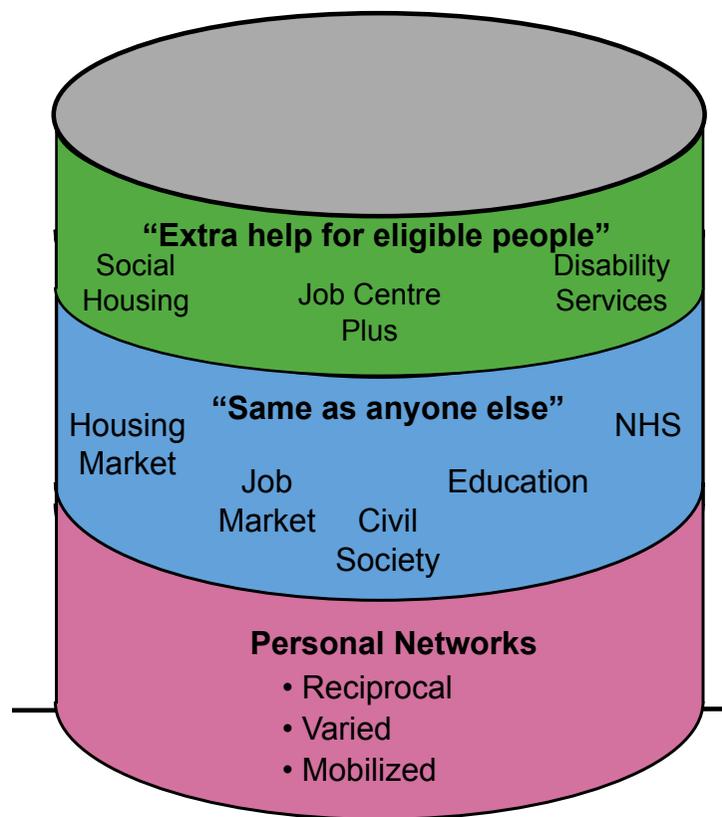
The diagram may help in thinking about seeking the most direct route. It shows three levels of support that are available in any community. *Personal networks* are the range of connections people have available to them to gather information, mobilize support, and make new connections. "*Same as anyone else*" are the opportunities available to any citizen through the associations of civil society, the job market, the housing market, the education system, the health service. The sectors in this layer need to learn how to welcome people with learning disabilities and adapt in order to successfully include them. "*Extra help for eligible people*" is a range of services for people who are excluded from the opportunities available to anyone else because of the consequences of poverty or impairment. Many of the services in this layer need to learn how to overcome a history of paternalistic control over and segregation of their clients and move to actively supporting people's transition to being in control of their lives as included citizens.

Seeking the most direct route to an important goal is more often a process of discovery by trying than it is

simply looking up and following a route map.

Discovery will come easier when people have strong personal networks, built up among a variety of different people who themselves have different connections and based on a history of exchanges. A person's search for a job that matches their interests and capacities will mobilize a strong network and may offer the shortest route to work: "I know a place that is hiring and I think it would suit you. Let me give the person I know there a call so you can arrange to check it out."

When people have the means to participate in the same



way as anybody else, and when market actors, community associations, and mainstream services will do the work of figuring out adaptations to people's impairments, the shortest route to an important goal leads a person direct to the same places that anybody else might look. Self-directed supports, capable benefits counseling, and an accessible housing market can bring a person home. A local theatre group whose members share a person's enthusiasm for musicals may be able to directly solve the problem of rides to rehearsals and performances.

Services that offer "*Extra help for eligible people*" can be a significant source of delays. They may be over-subscribed and have waiting lists. They may see people with learning disabilities as outside their purview or as unfairly competing for resources with other people who lack access to the benefits and services that people with learning disabilities have. They may lack sufficient knowledge and skill to assist people with learning disabilities. They may hold low or stereotyped expectations of people with learning disabilities.

Partnership Boards and advocacy groups can help people in their search for the most direct route.

- Collect and make available stories of the different paths that people have followed to important goals.
- Encourage people and families and their allies to pursue multiple paths at the same time. For example, when seeking a job, mobilize personal networks, make direct approaches to interesting employers, and apply to Job Centre Plus simultaneously.
- Share honest estimates of how long it takes to follow different paths.

- Use and further develop the tools available from the *In Control* project.
- Analyze the current state of all three levels of community support and look for ways to smooth direct paths to goals that are likely to be in demand: open market jobs, educational opportunities, and homes that reflect people's choices and interests.
- Invest in strategies that work directly to multiply the options available to individuals at the "Same as anyone else" level. Don't get stuck in the assumption that the "Extra help for eligible people" level is the only or the best route to participation in the job market or the housing market. Think about strategies that will increase capacity for reasonable adaptations for individuals rather than strategies for groups of people with learning disabilities. For example, prefer individualized adaptation and assistance for participation in further education to programs operated for groups of people with learning disabilities in further education establishments.

### Building a Culture for Connection

In a society where the life chances of people with disabilities are improving substantially, the role for specialist services is to provide people and families with the specific assistance that they require to define the way they want to live and to pursue the most direct route to goals that are personally important and meaningful. But at present much specialist service money remains sunk in providing services that compensate

people with learning disabilities for social exclusion and control them in the name of managing risk. This limits demand for reasonable adaptation from the "Same as anyone else" layer of community life while it retards people's ability to form a strong foundation for positive action by building varied social networks based on their contributions to other's well-being. Moreover, a number of people with learning disabilities and family members find benefits in services that congregate and control. They experience efforts to modernize familiar services as a threat rather than an opportunity to embrace new goals and discover new paths.

Building a culture for connection gives specialist learning disability services the best chance to play a positive role in the move toward a more inclusive society that is supported by systems capable of collaborating with people with learning disabilities and their families to produce more personalized assistance.

Connection is the organizing idea because the variety, strength, and quality of connections available to a people influence

...the level of confidence they have in setting and actively pursuing personally important goals, especially when those goals require finding a way to inclusion in ordinary life and mainstream services

...the opportunities available to them

...their resiliency to disappointments and difficulties

As the diagram says, there are three themes in building a culture for connection: encouraging personal responsibility for connections; developing practical ways to make and support a growing variety of connections, and dealing responsibly with vulnerability.

**Encouraging personal responsibility.** Connections have to be made, based on shared interests and mutual exchanges. Everyone has a role to play. People with learning disabilities need their families and allies to recognize their gifts and capacities and encourage them to find ways to bring these gifts to the ordinary life of their communities. Family members, especially



family members who may have lost regular contact with a person, need encouragement to hold high expectations and act with and for the person to realize them. Direct support staff and professionals who assist people need to be thoughtful about changing conditions that contribute to people's passivity and isolation. Partnership Board members and managers need to develop policies and investments in new forms of assistance that will make it easier for people to use mainstream services and play valued roles in ordinary life.

In promoting responsibility for connections it is important to build enthusiasm for action by celebrating and learning from people's attempts and achievements. Policies, procedures, and routines need to be audited to ensure that they focus staff on working actively to make connections that will allow them to get more of what they want in life.

**Developing practical supports for connection.** The idea of adaptation of ordinary environments to support the successful participation of people with disabilities opens a vast space for invention. People need assessments that let them specify and negotiate for the adaptations and assistance that they require to pursue important life goals. They need a variety of strategies for negotiating access and adaptations. They need the effective use of assistive technology and ways to integrate powerful technologies for instruction and self-control into everyday routines. They need a range of supports that makes it easier for them to self-direct the personal assistance they need.

Jobs in ordinary employment are a particularly fruitful setting for these inventions.

To develop these inventions, staff, especially professionally trained staff, need to discover effective ways to collaborate with people with disabilities and the people they interact with as co-workers, members, and citizens.

**Dealing responsibly with vulnerability.** People with learning disabilities are vulnerable to discrimination, exclusion, neglect, and abuse. This vulnerability is compounded when attempts to manage people's lives to extinguish risk limit their ability to pursue important goals and participate in ordinary life.

Being responsible in this important area means thinking carefully about actual people in real situations. Hypothetical discussions of what might go wrong can spin off into a caution so excessive as to freeze people inside the boundaries of specialist service settings.

Decision making around risk needs to include the person and those who know the person best as primary voices. It is important to figure out how people can get the information and support they need to make good decisions and how they can manage conflicts among themselves over what is acceptable.

Policies regarding risk make a good subject for organized, system-wide reflection. Where do people with disabilities and their allies encounter "risk" as a barrier to taking desired action rather than as something to be thoughtful about while pursuing what matters to them? Do direct support workers understand risk in a way that

enables action or in a way that discourages them from supporting positive experiences? Does senior management understand risk in the context of actively promoting new experiences and opportunities? If so, do direct service workers have the same understanding?

Discussions about risk need to keep purpose in view. The reason for specialist services is to support people in experiencing more of life. This means working out ways to minimize the risks involved when people do what matters to them. It does not mean stopping people from doing things or making contacts that would be reasonable for people who do not depend on services.

We need to analyze the lessons of success in enabling people to deal with the risks involved in pursuing positive goals .

A full life includes disappointments, failures, difficulties, losses and suffering. Friends sometimes let people down, or move away, or die. These are difficult and even regrettable facts of life. They are not risks that can be managed away but ordinary experiences that people need support to be resilient to. Resiliency is a matter of having the support of others. Resiliency grows as people become more deeply connected to a more richly varied network of people.

The task of specialist services is to assist people to live full lives.