

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 or from David Towell at 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

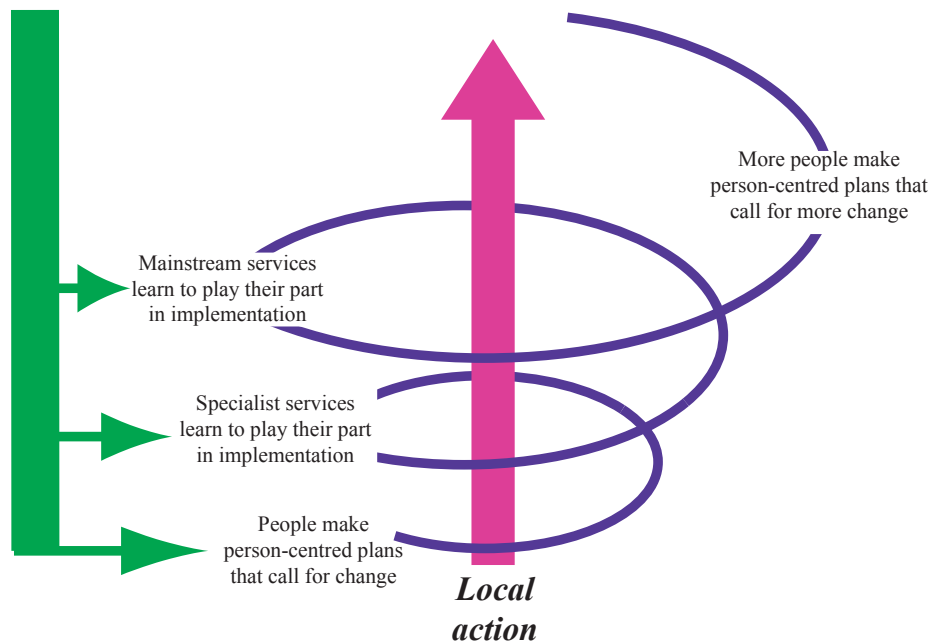
as harmonizing local action with national policy in such a way that a positive spiral of learning through action and reflection develops.

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

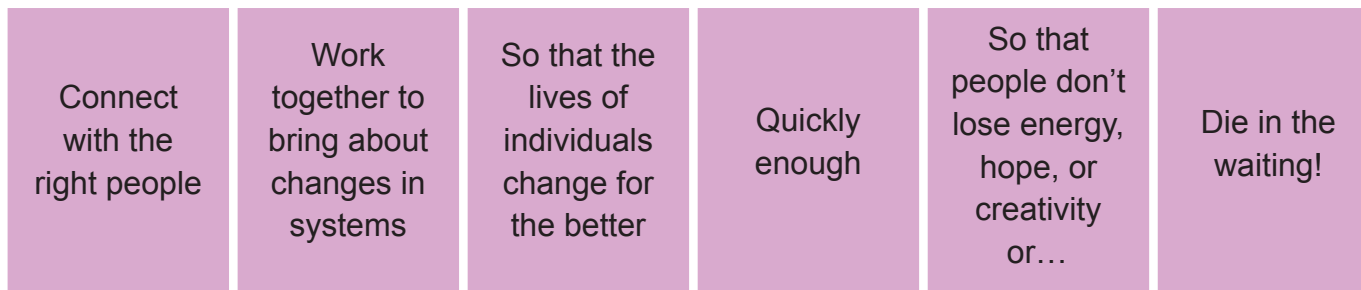
Each team made its own record and was able to take home a locally-tailored workshop report to share with colleagues and inform action. Rather than writing our own workshop report we reflect further on some of the key ideas discussed in the large group

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.

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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) 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*[®], 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*[®], at 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.viauk.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.

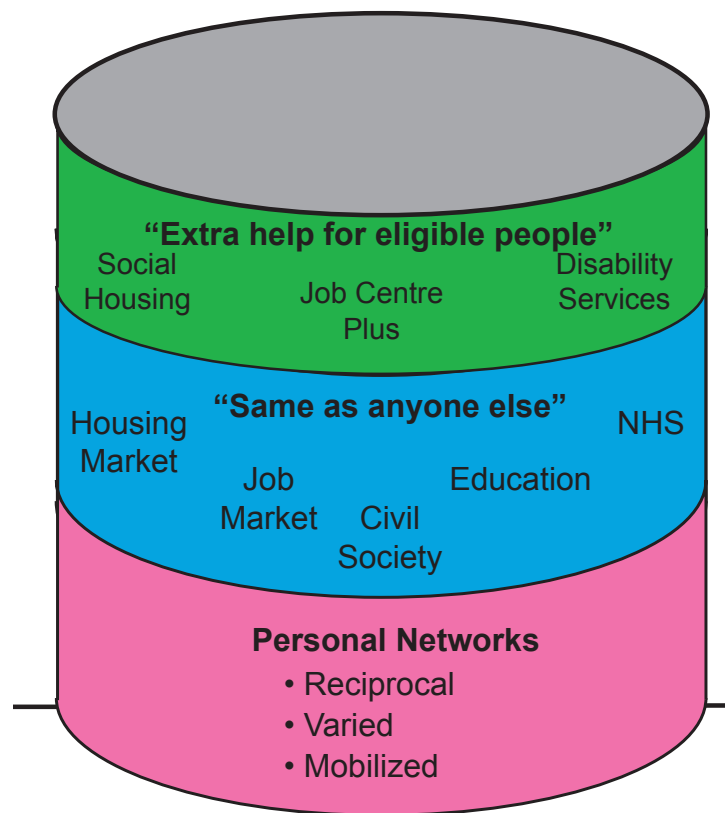
The diagram may help in thinking about seeking the most direct route. It shows three levels of support that are available in any community. *Personal networks* are the range of connections people have available to them to gather information, mobilize support, and make new connections. "*Same as anyone 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.