"We are clear that the position of disabled people in European society is beginning to change. This is primarily as a result of the demands of disabled people that their full rights as citizens should be recognised & protected."

–EUSE Quality Standards
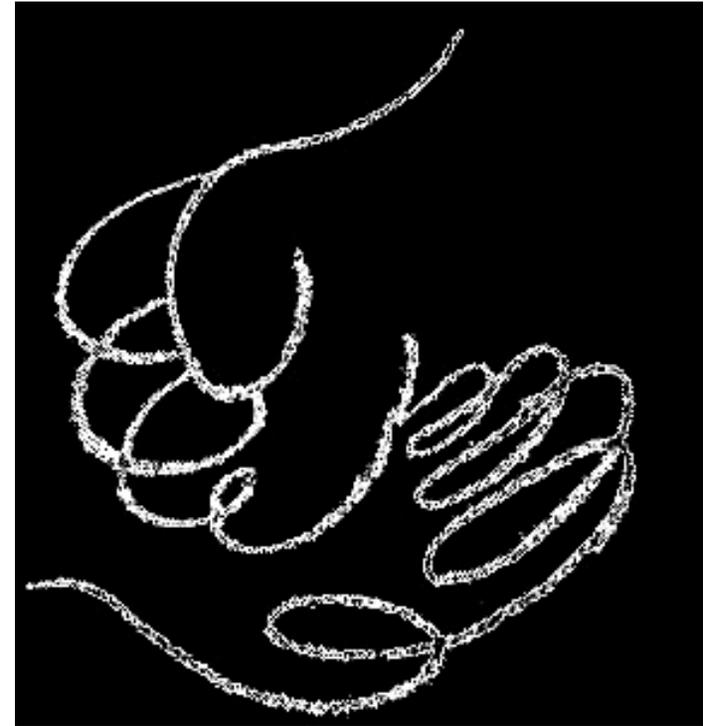
7th EUSE Conference

17 June 2005
John O'Brien

The Center on Human Policy

Syracuse University

rsa770@earthlink.net

www.inclusion.com

http://thechp.syr.edu/

Over the past 60 years, activist disabled people & their allies –chiefly family activists and personally engaged professionals– have fought hard for and won significant policy victories. Their efforts have re-framed political & professional discourse and are beginning to influence the direction &, more slowly, the level of public investment. There is increasing agreement that public policy & professional practice should deliver…

…access to every dimension of political, cultural, & economic life

…adequately funded, individualised active support for inclusion that is controlled by disabled people (with necessary assistance when intellectual impairment limits decision making ability)

As the number of policy victories grows, the gap widens between policy & practice, especially level & direction of public money. Reducing this gap should be the priority for all who practice supported employment. It playing our part, we can draw energy & inspiration from the well-springs of supported employment.

One way of assessing changes in policy & practice is to think about their likely effects on the lives of people who are most likely to be excluded from ordinary life.

As I think about employment related policies or programs, I ask myself, "Will this raise or lower the odds that my friend Andre will have a real job with a real wage in a workplace where people value him."

Andre brings gifts & skills to other people. He also has multiple impairments: he requires very substantial amounts of highly skilled instruction to master new tasks; despite extensive effort by skilled professionals he communicates with only a very few, concrete signs; he is paraplegic & has limited use of his hands; his sight is very limited; while he can partially participate, he requires personal assistance with every daily task.

End institutionalization & redirect the money

Design for access

Make the most of "reasonable adjustments"

An active role in shaping local & national life

Build a climate of higher expectations

shaping the future of equality

discussion paper

the disability debate

Disability Rights Commission

Take positive action to promote human rights

Put disabled people in-control thru individual budgets & IL

Reform benefits to encourage work & asset building

Promote positive relationships with non-disabled people

In some nations, we are two words away from prevailing in the policy struggle

CabinetOffice

Prime Minister's Strategy Unit

Improving the Life Chances of Disabled People

January 2005

A joint report with:

Department of Work and Pensions
Department of Health
Department for Education and Skills
Office of the Deputy Prime Minister
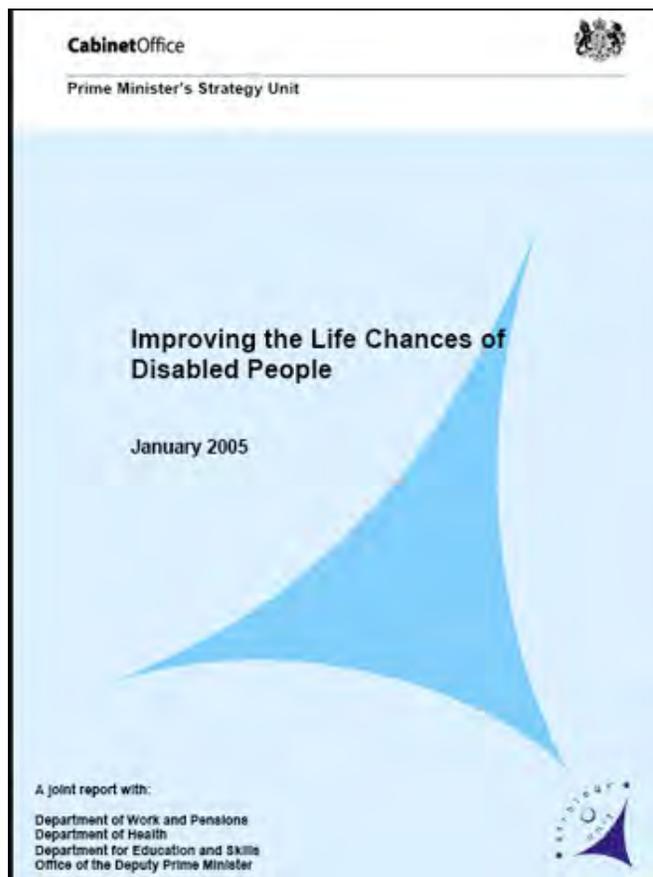
30 years

"…any disabled person who wants a job, and needs support to get a job, should be able to do so ~~wherever feasible.~~"
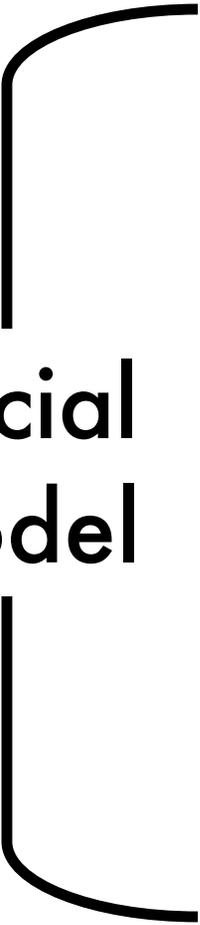
Social
model

Supported
Employment

Social
Inclusion

Andre's odds for employment go up with the real world implementation of every one of these policies.

Taken together they would transform the life chances for people with significant disabilities.

But implementation will be complex...

"…any disabled person who wants a job & needs support to get a job, should be able to do so…"

Prime Minister's Strategy Unit

Office of the Deputy Prime Minister

Department of Work and Pensions

Improving the Life Chances of Disabled People

Department of Health

Department for Education and Skills

They say all this has to work in a joined up way!

Employer Engagement Project

New Deal for Skills

Apprenticeships

Employer Training Pilots

Learning and Skills Council & Training Providers

Information, Advice and Guidance (IAG) partnerships

Jobcentre Plus

Pathways to Work

WORKSTEP

Connexions

System of Systems Charged with Implementing the Employment Strategy Set Out in *Improving the Life Chances of Disabled People*

Employers' Forum on Disability

Incapacity Benefit

New Deal for Disabled People (NDDP)

Working Tax Credit

Access to Work (AtW)

Job Brokers

Disability Employment Advisers (DEAs)

Broadcasting and Creative Industries Disability Network

6,700 pre-employment programs sponsored by 2,500 local governments & NGO'S

While SE lacks legislation & core funding in most nations

Non- work & segregated work alternatives hold the majority of resources & continue to grow

At least 2 multi-national corporations are in the business of work re-entry & placing or assisting big employers to recruit socially excluded people into entry level jobs; at least 1 is a large scale partner with national government.

What happens if we lack the courage to imagine better & act together?
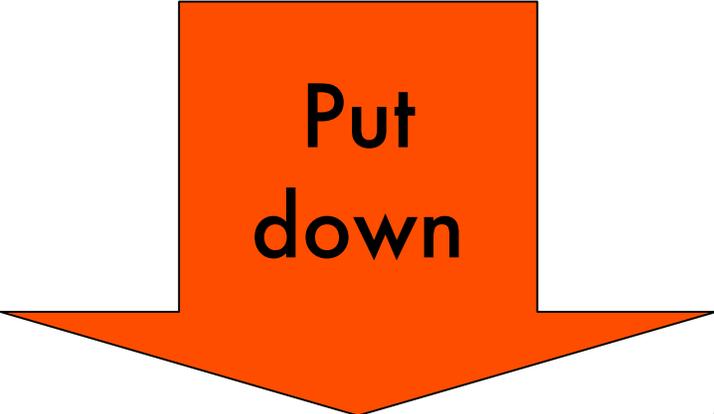
Put down

Andre disappears from ordinary life & makes a life at the margins of society. Odds of work = 0
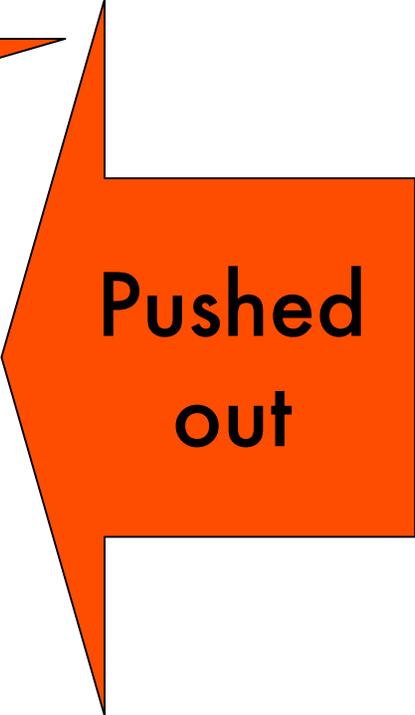
Pushed out

It is acceptable in professional & political discourse to say change is…

…too costly

…impossible

…too risky

…not desirable

What happens if we have the courage to imagine better & work together?

Odds of work go up with every move

Shifting power
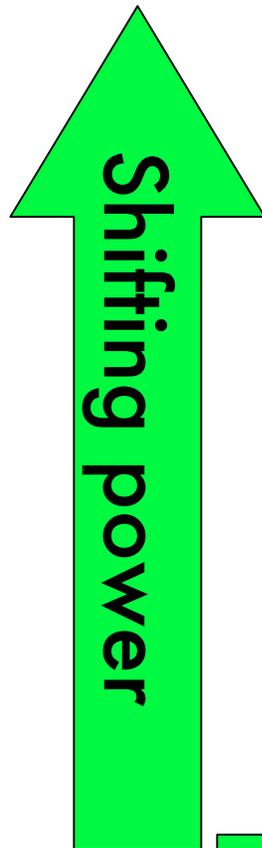
More possibilities for citizenship & contribution

More choices

More uncertainty

Crossing Boundaries

It is easy to feel too
small for the task.

We need to draw on the same well-springs that gave the originators of supported employment the strength to bring us as far as we have come.

Impossibly high expectations

Close personal partnership with disabled people

Priority on those least likely to have the opportunity to work

Relentless hope

Opportunism

Fanatic commitment to show & tell

Commitment to learn & willingness to abandon outmoded structures

There are only two feelings. Love and fear.

There are only two languages. Love and fear.

There are only two activities. Love and fear.

There are only two motives, two procedures,

Two frameworks, two results. Love and fear.

Love and fear.

–Michael Leunig

What people who build social inclusion do is understand & emphasize the centrality of relationships & interpersonal connections to achieving their objectives. They pay particular attention to bridging relationships.
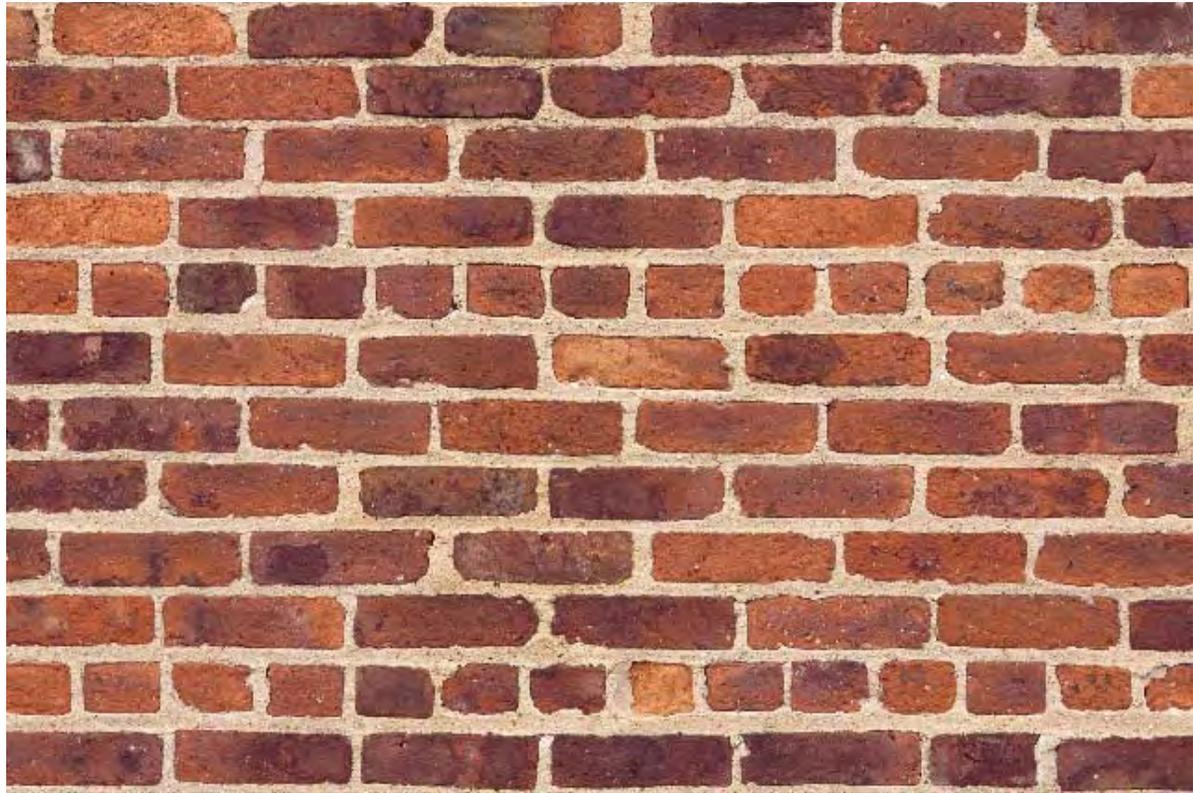
That is, they become artful at walking through walls.

Genuine relationships, that can contain real differences but allow sustained work at the political, the systemic & the personal level, greatly improve Andre's odds of work.

Building a network of such relationships is the task of those who walk through walls and learn to build human castles*

Disabled Activists

Family Allies

Committed support workers

Enrolled workers, employers & trade unionists

*apologies for the mixture of metaphors.

If these resources are orchestrated, work becomes a real possibility

Workplace Resources

Personal Assistance*

Personal resources:

Capacities & connections

Supported Employment Resources*

Organizing, Design, Creative problem solving,

Mainstream Employment Supports
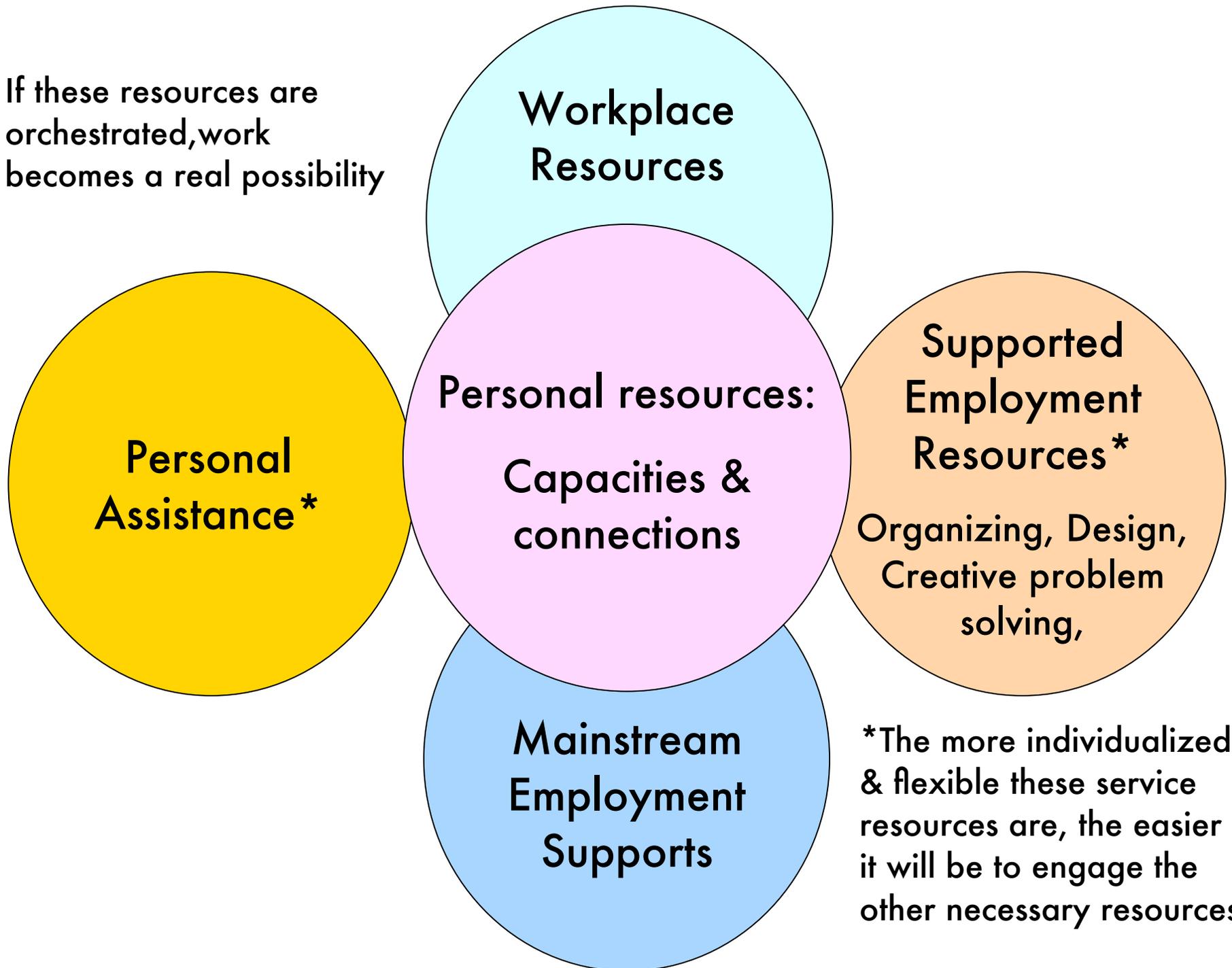
*The more individualized & flexible these service resources are, the easier it will be to engage the other necessary resources

A circle of support – all but two of whom are unpaid people has gathered around Andre and his mother– they provide practical help, creative problem solving, and encouragement. This has allowed the orchestration of multiple resources and resulted in Andre (who is 24) holding several jobs -beginning at age 16 and most recently at age 21 adding a job at the county prosecutor's office where he performs an individually tailored job doing office tasks.

For Andre, the key is an individual budget, directed by circle members on his behalf, that makes the personal assistance he requires portable. To be safe & healthy in any setting –even an institution- he would need a high & costly level of staff support. Less than extensive & expensive support would put his health at risk. Making the funding for that support portable makes it possible for him to work. His 24 hour supports cost no more than institutionalization would cost.

Moreover, the authority responsible for paying for his services spends less on many people who require less costly support at work than they would receive in segregated facilities because of an individualized combination of personal responsibilities, natural supports, and carefully targeted paid assistance.This allows the system flexibility to invest more in people who require more paid assistance to be successful.

Many people might attain employment through the application of impersonal, "objective" methods.

For Andre & others with substantial impairments to have good chances to work at real jobs, we must work generatively, from our hearts, to build the relationships that will realize the policy victories that disabled people & their allies have won with so much effort. To lose heart would be false to their victories.
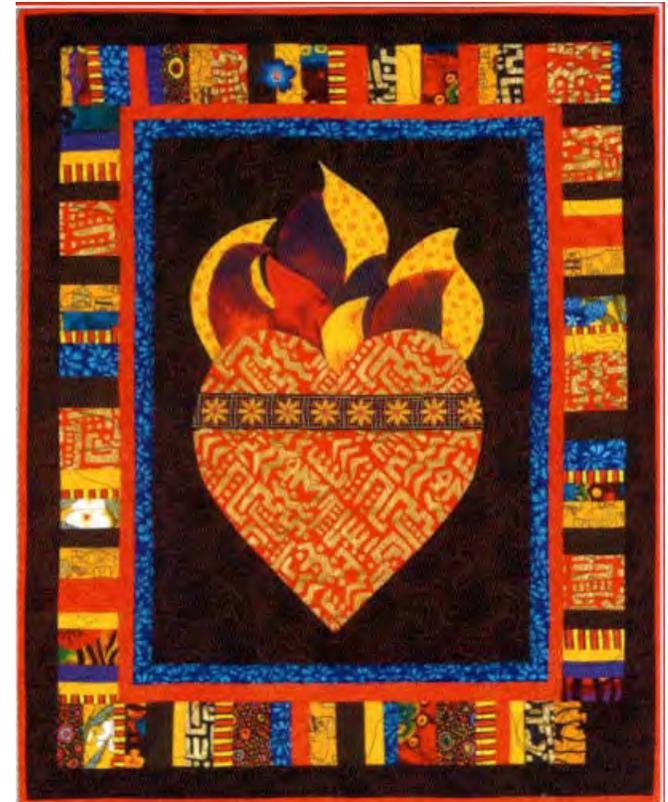
For books, videos, and training on person-centred work:

Inclusion Press www.inclusion.com

Training Resource Network www.trninc.com/

For downloadable papers on policies and service designs that support person-centred work:

The Center on Human Policy http://thechp.syr.edu/