

Community Safeguards Coalition
Campaign 2007

my Life



my Home



my Solution



Like other Queenslanders,
people with a disability want to choose:
where they live
who they live with
where they go and when
what they eat
who works for them.

about the

Community Safeguards Coalition

The Community Safeguards Coalition is a network of people including people with disabilities, families, friends, advocates and allies of people with disabilities who are committed to safeguarding the human rights of people with disabilities in Queensland.

For more information

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Parents and allies

Carol and Tim Holt
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Our message

1. People with a disability are being coerced to live in group situations that are not appropriate, despite the Queensland Government's rhetoric about options.
2. Coercing people with a disability to live together is not the best solution.
3. When people with a disability can take control of their own housing and their own lives, just like everybody else, they create better solutions.
4. We call on the Queensland Government to implement new ways to give people with a disability control of their lives, their housing and their support arrangements.

People with a disability are being coerced to live in group situations that are not appropriate, despite the Queensland Government's rhetoric about options.

Gary's* Story

past:

After Gary's family discovered he had been abused at the Basil Stafford Centre he returned to live with his parents. However, his behaviour and health deteriorated to the point where family life was untenable for everyone.

present:

Gary has received short-term funding to live independently for one year. He rents a house and receives flexible support from a local service. His aggression is gone, his health has improved and he is enjoying life.

future:

The government is seeking a co-tenant to live with Gary despite his disabilities making it unsuitable for him to live with others.

- In 2003, 834,000 people with a disability lived in Queensland (22% of the population) according to the most recent survey of people with a disability.
- Approximately 279,100 of these people live with a severe or profound core activity restriction (7.6% of the population). This means they need significant support in self care, mobility and/or communication.
- In 2003, approximately 158,700 people under 65 years of age in Queensland had a severe or profound core activity restriction. (4.8% of the state's population).¹
- More than 1,400² younger people (under 65) currently live in aged care residential facilities in Queensland. The Queensland Government and the Federal Government have funded strategies to help younger people find alternatives to living in nursing homes.
- In a survey of users of disability services in 2004-05, 58% of Queensland service users with a disability lived with family, 25% lived with others and 12% lived alone³.

Living with family is not an option for many people with a severe disability, for example because of the extent of their needs, their lack of family, the age or health of their family or lack of appropriate support. These people mostly rely on Queensland Government funding programs to pay for housing and support so they can live independently.

A minority of people with a disability receive individual funding packages, where the funding follows the person. This type of funding is not being encouraged in the 2007 Disability Services Queensland funding reforms, *Growing Stronger*. Congregated care, ranging from small group homes to large complexes is emerging as the dominant model for accommodation and support for people with a disability.

Examples include:

- construction of a large-scale congregated care facility at Wacol on the site of the former Basil Stafford Centre for people with challenging behaviours
- registration of 48 accredited supported accommodation boarding houses in Queensland⁴, where residents receive some assistance from on-site staff. Most hostels accommodate 15 to 30 people, although some house more than 100 people
- Department of Housing and Disability Services Queensland are working on a Memorandum of Understanding to facilitate shared tenancies for people with support needs – despite the fact that no other public housing tenants are required to share with strangers
- the maximum amount of funding through an individual funding package is only ever granted to people with extremely high support needs. However this funding is not sufficient to meet their individual support needs and to provide capacity to participate in community life. This forces people to pool their resources and share accommodation with other people with a disability, usually through a community-based service provider.

*"This is the vision we are heading back towards, with some of the old congregated solutions being re-established, promoted, strengthened and condoned by current policy and practice"*⁵. Queensland Parents for People with a Disability

Coercing people with a disability to live together is not the best solution.

Melissa's* Story

past:

Melissa had bad experiences with incompatible co-tenants in group homes, leading to conflict, violence and self-mutilation. According to her psychiatrist, her behaviour was triggered by her home environment.

present:

Melissa's family cared for her at home until they had to return to work. For the short term, she is living in an informal care arrangement with a family friend.

future:

Melissa's future is very uncertain – she has applied for funding to live independently.

“Close regard should be had to the research which strongly suggests that large or clustered accommodation facilities are more likely to be counter productive in addressing behavioural issues and that greater emphasis be given to more dispersed, smaller and more intimate design which provides separate and private space at the same time providing the capacity for social interaction as the individual desires”⁶.

Hon W.J. Carter

Group living infringes people's rights to accommodation and support that they control. Whether it's with one other person or in a clustered setting with many more, forced group living:

- doesn't cater for individuals' needs – in practice tenants usually lose the ability to make independent decisions about their leisure activities, transport arrangements or even what they eat and when
- forces incompatible people to live together – for example for some people with autism, living with others can trigger severe behavioural and psychological problems
- is driven by short-term cost-cutting at the expense of quality of life for people with a disability – providing less funding up-front looks like good value until you consider the cost to the individual, their family and the wider community from crises and hospital admissions
- leaves people vulnerable to abuse including physical and sexual assault⁷.

“People with a disability have the same human rights within their families, communities and cultures as other members. Strategies to prevent the abuse, neglect and exploitation of people with a disability include the reduction of isolation and the enhancement of social connections.”⁸

Disability Services Queensland

“Key to the prevention of crime against persons with disability ... the following strategies are central: Elimination of models of supported accommodation that congregate unrelated persons with disability together in groups. Particularly problematic in this respect are residential institutions, boarding houses and nursing homes, but so-called group homes have the potential to be equally inductive of crime.”⁹ Phillip French

**Names have been changed to protect the identities of vulnerable people*

When people with a disability can take control of their own housing and their own lives, just like everybody else, they create better solutions.

Samantha's* Story

past:

Despite her family's contribution to establishing and maintaining a family-run group home for their daughter and six to eight other people, Samantha had no secure tenure in the facility when her health began to deteriorate.

present:

Thanks to short-term emergency funding, Samantha has been able to recruit extra support to help her live in the group home.

future:

For a long-term solution, Melissa has applied for public housing and individual support funding, like many other Queenslanders with disabilities. The likelihood of success is limited.

In Britain, over 1,200 people with a disability have been allocated a personal budget so that they can plan and implement their own housing and support strategies. An evaluation of the *In Control* program shows that this approach helped people with a disability to avoid expensive, crisis-driven service solutions.

Early indications are that overall care costs have decreased using the In Control model. For example, the plans people made increased their own tenancies by 900%, increased employment of personal assistants by 175%, decreased days in day centres by 22% and decreased use of registered care homes by 100%.¹⁰

*"Interestingly consultation evidence suggests that, on a macro-economic level, independent living is a cost effective option ... independent living will permit far more disabled people to contribute tax and national insurance payments and ... simultaneously, the benefits bill will also be reduced. Moreover, in the long term, the demands on other public services, particularly the health service, is expected to be considerably less."*¹¹ Evaluation of independent living programs in Britain.

Human rights indicators

The current system in Queensland means that the basic rights of many people with a disability are not being met.

| Indicator | Right here, right now, for many |
|---|---------------------------------|
| Persons with a disability live in the community with choices equal to others | X |
| Persons with a disability are included and participate in the community | X |
| Persons with a disability are able to choose their place of residence on an equal basis with others | X |
| Persons with a disability are not obliged to live in any particular living arrangement | X |
| Persons with a disability have access to a range of in-home, residential and other community support services necessary to support living and inclusion in the community and to prevent isolation and segregation | X |

Indicators are from Article 19 of the United Nations Convention on the rights of people with a disability, 2007

We call on the Queensland Government to implement new ways to give people with a disability control of their lives, their housing and their support arrangements.

Kate's* Story

past:

Kate left the Basil Stafford Centre just after her 20th birthday, thanks to a concerted campaign by her family and supporters to obtain secure housing and funding for long-term support.

present:

Ten years after moving into her own home, Kate is supported by seven women of various ages who assist her to do the things she enjoys. She does her own shopping and regularly invites friends over for dinner. She goes to friends' houses regularly and meets up with her family once a week for dinner. Her life now is filled with potential, thanks to the benefits of living in her own home, surrounded by family, friends and neighbours, going about the business of ordinary life.

future:

Kate's home and funding look secure for the future. The circle of support which has developed around her is a strong safeguard for her future. Kate's friends and family share her vision and values, want to be part of her life and are ready to support her in the years to come.

The Queensland Government has provided non-recurrent funding to a number of small-scale projects to provide customised solutions for the support needs of people with a disability. Recent examples include:

- the Collective Action Project, an innovative response to the need for individuals to have real lives, real autonomy and to live firmly embedded in community
- increased flexible funding and a partnership between Disability Services Queensland and the Department of Housing, to assist people with spinal cord injuries to return to living in the community
- some family-driven small scale responses to the needs of adults with a disability, such as Building Informal Networks and the Homes West Association, funded from non-recurrent Innovation grants.

Our call to action ...

We call on the government to go further. We recommend that Disability Services Queensland develop and implement a program based on the principles identified in the UK In Control model, to provide individualised flexible funding direct to individuals so they can be supported to develop a plan for their own support needs.

"An individualised and flexible approach which provides for and specifically addresses the person's specific needs and the circumstances of the individual case is the unequivocal key element in the proper care and support for the person with intellectual disability and challenging behaviour"¹². Hon W.J. Carter

1. The Survey of Disability, Ageing and Carers (SDAC) conducted in 2003 by the Australian Bureau of Statistics (ABS) cited in Disability: A Queensland Profile, 2005, Disability Services Queensland
2. Multiple Sclerosis Society
3. The Commonwealth State/Territory Disability Agreement (CSTDA) National Minimum Data Set (NMDS), Queensland, 2004-05
4. Office of Fair Trading
5. The Pendulum is Swinging Back: An Evaluation of the Challenges in the Lives of People with Disabilities, Queensland Parents for People with a Disability, 2005, p. 4
6. Challenging Behaviour and Disability: A Targeted Response, a report to the Minister for Communities Disability Services and Seniors by the Hon W.J. Carter Q.C., 2006, p. 13-14
7. Australian studies cited in Queensland Disability Housing Coalition, (2005) A Home of My Own, sheet 16A
8. Preventing and Responding to the Abuse, Neglect and Exploitation of People with a Disability Policy, Disability Services Queensland, June 2007
9. Disabled Justice: the barriers to justice for persons with disability in Queensland, by Phillip French for Queensland Advocacy Incorporated, 2007
10. <http://www.in-control.org.uk>
11. The costs and benefits of independent living, Jennifer Hurstfield, Urvashi Parashar and Kerry Schofield, 2007, U.K.
12. Challenging Behaviour and Disability: A Targeted Response, a report to the Minister for Communities Disability Services and Seniors by the Hon W.J. Carter Q.C., July 2006, p. 9-10

Gary's Story



Forced co-tenancy looms for Gary

Gary* is a motor racing enthusiast (Go Holden!). He's partial to Meatloaf's music, devours block buster animation movies and doesn't need any persuasion to follow the football.

At 30, he happily rents a house in a friendly South East Queensland neighbourhood.

Gary looks like an average sort of bloke, but he has severe autism, cerebral palsy, epilepsy, intellectual disability and cannot speak.

Past

...Gary and Jacinta stay home alone, windows and doors locked, phone off the hook so that there is less risk that noise and disturbance will trigger a violent outburst from Gary.

Let's wind the clock back six years. Gary loves motor racing, Meatloaf, movies and football. He has been living at home happily joining in family life but fairly suddenly, things change. He is highly anxious, frustrated, has virtually stopped sleeping, eating or drinking and subjects himself and others to distressing outbursts of rage in between endless pacing. His Mum Jacinta can see that he desperately doesn't want to be living at home with her and his step father and brothers, although she thinks there may be a medical problem as well. Gary has to be hospitalised – a trauma for him, Jacinta and hospital staff. He is re-hydrated but tests don't reveal any sign of an underlying medical problem.

It's Christmas time and Gary is very agitated. It's a hard decision but the family decide to pack up the Christmas tree and trappings and head off to stay elsewhere for Christmas while Gary and Jacinta stay home alone, windows and doors locked, phone off the hook so that there is less risk that noise and disturbance will trigger a violent outburst from Gary. Life seems very grim and Jacinta, badly sleep deprived, manages to keep going but only because there is no other option.



Present

Jacinta draws hope from each visit she makes to Gary's place, finding him relaxed, and full of delight and pride with his new home and new life. Gary's aggression has disappeared.

There is no other option because Jacinta promised Gary she would never again put him in a respite care facility. She made this promise when she discovered that Gary was being abused at Basil Stafford residential institution where he lived away from home for four nights a week between 1987 and 1991, whenever he was well enough between increasing bouts of severe illnesses like amoebic dysentery. Jacinta's discovery of Gary's abuse was confirmed in the Criminal Justice Commission Inquiry into Allegations of Official Misconduct at the Basil Stafford Centre.

There is no other option because the allocation of personal care funding from Disability Services Queensland (DSQ) will not permit Gary to live away from home, alone, with the 24 hour support he requires. It is obvious to Jacinta that Gary wants to move out of home but that he cannot cope with living with another person with disabilities. A professional assessment concludes that Gary's decline is consistent with post-traumatic stress disorder as a result of his time in Basil Stafford.

Jacinta, with support from her husband and disability advocates, decided that she had to persevere so that Gary could try living alone. After three years of phone calls and letters and refusing to give up on the many occasions when government staff moved on and phone calls weren't returned, DSQ agreed to one year of funding for independent living.

Although there is no certainty for the future, Jacinta draws hope from each visit she makes to Gary's place, finding him relaxed, and full of delight and pride with his new home and new life. Gary's aggression has disappeared. He has been able to stop medications like anti-depressants and if he does need to see a doctor, he is relaxed enough to wait in the waiting room like anyone else. Both Gary and Jacinta are very confident in the quality of flexible, individualised care the local support service has been providing.

Future

The department is seeking a co-tenant to live with Gary, despite his unsuitability to live with others. Gary's situation looks very uncertain.

Disability Services Queensland has indicated that it is not economical for Gary to live alone long term. The department is seeking a co-tenant to live with Gary, despite his unsuitability to live with others. Gary's situation looks very uncertain.

Given recent experience, expecting a co-tenancy arrangement to be economical may be a mistake. If Gary's anxieties escalate then problem solving may involve things like support from the State's Behaviour Support Team, higher support staff turnover and repeated staff training, support from advocates and meetings with various officials, more health services and medications.

The question of whether forced co-tenancy actually saves money is well worth careful investigation.

** Identities have been changed to protect vulnerable people*

Samantha's Story



Insecure group home tenure shakes Samantha's world

The pay's not good at 67 cents an hour, but 35 year old Samantha* loves her work in a mail centre. As for many of us, work is a crucial part of her sense of worth and meaning.

Because Samantha has severe disabilities, certain things need to be in place to ensure she can take her place as a citizen, worker, friend, daughter and sister. When Samantha's accommodation arrangements unravelled recently, she and her family learned how uncertain life can be for people with a disability in Queensland. They also learned from the experience about what Samantha really needs: independence with appropriate support so she can make the choices and take the risks the rest of us take for granted.

Past

When Samantha's accommodation arrangements unravelled recently, she and her family learned how uncertain life can be for people with a disability in Queensland.

The story began almost 25 years ago when, to provide an alternative to life in an institution, some parents of people with disabilities created a large, purpose built house for a group of seven to nine people with disabilities to live together near their families. It was a huge effort to raise the funds needed and a huge step forward in comparison to life in large institutions.

Samantha's parents joined in the project and Samantha has lived there for over 15 years. For this very sociable young person it was a pretty good arrangement, although with just one support worker to assist seven people with disabilities, there was not a lot of scope for each individual's pursuits and aspirations.

** These stories are true, but identities have been changed to protect the confidentiality of vulnerable people*



Present

They discovered that Samantha had no tenancy rights to give her secure tenure in her home.

Fast forward to 2007. Samantha's disabilities mean that her health has deteriorated and she is prone to frequent unpredictable seizures. In the last two years she has fallen while having seizures and sustained very serious injuries several times. While this is alarming for all concerned, there is not a lot to be done to remove this risk other than living in cotton wool. And as Samantha's mother Rhonda says, 'Samantha deserves to live with the dignity of risk.'

However the group home management decided otherwise and laid down several requirements before Samantha could return home, for the good of staff and other residents. Samantha's family were shocked to see decisions being made about their daughter's own life that were about others' needs and not Samantha's. They also discovered that Samantha had no tenancy rights to give her secure tenure in her home.

Samantha went from hospital to her family home to recuperate while negotiations took place with the group home. Over 25 weeks she continued to pay out \$5,000 in board and lodging in the hope things would be resolved.

A resolution is in the pipeline. In the short term, some of the board money is being refunded and the State Government has allocated 32 emergency support hours/week for 12 weeks so that Samantha can return to her group home four days each week.

Future

Samantha wants a more ordinary life, where she can decide on the simple things.

For the long term, Samantha and her family have agreed that she is overdue for a chance to live independently. She wants a more ordinary life where she can decide on the simple things like what food to eat and when to eat it; when to play the best country and western music in the world and at what volume; and when to go shopping and what to buy.

To achieve this dream, Samantha has applied for public housing and individual support funding. If she is successful, the funding won't be enough to allow Samantha to live on her own, but if she can find one other compatible person with support funding, their combined support hours will permit a life that is much more about their own choices and the things most of us take for granted.

While acknowledging her needs are increasing, Samantha is optimistically embracing change and hoping for a more sustainable future.

Melissa's Story



Will Melissa be happy again?

Melissa's photo album from her teenage years looks like many others stashed in bedrooms around Queensland – lots of happy photos of a vibrant young woman! Today's photographs of 30 year old Melissa* tell a different story. The smile is mostly absent and so are signs of vitality. Melissa's story is typical of many Queenslanders with a disability, who have little control over their home environments and their housemates.

Past

For 18 months Melissa lived alone, and blossomed. She was relaxed and adventurous.

As a young adult, Melissa moved out of home into a church-run house with support staff to help her and two other young people, all with disabilities of different kinds. Melissa has an intellectual disability, autism and epilepsy. The three housemates didn't get on well, and when the church bought another house, Melissa moved there. That house became a 'drop in centre' for clients living elsewhere with their support staff, which caused some anxiety for the tenants. Again the house mates did not get on well.

After a series of changes, it happened that for 18 months Melissa lived alone, and blossomed there. She was relaxed and adventurous enough to holiday in Melbourne and Sydney with a trusted friend.

That period came to a sudden end when the church moved in another woman with disabilities. There was conflict and Melissa became increasingly anxious. One day the tension became too much: Melissa trashed the house. Melissa's family was not contacted but a doctor gave her an injection to which Melissa had a bad reaction. She was sedated but pulled out her hair and mutilated herself.

Melissa was able to stop the medication and settled down for a while until another explosion happened. Melissa's mother Tania took her to a psychiatrist who felt Melissa's intense reactions were triggered by the environment she lived in. He offered to visit there to look at the dynamics in the household as a way to offer some help. The church agency refused permission for this visit but stressed that Melissa should be medicated. Again the medication had side effects and Melissa's behaviour deteriorated. An agency official threatened to call the police if there was more trouble and have Melissa admitted to a psychiatric hospital where her medication could then be reviewed.

Tania approached the state government's Disability Services Queensland (DSQ) to express her alarm. The department introduced Tania and Melissa to a disability advocacy service, where they discovered that Melissa had no support funding of her own – the funding for support staff was attached to the church agency, not to Melissa. However she could apply for individual support funding.



Present

There was no standard tenancy agreement for Melissa's accommodation. Instead there was a residential services agreement which seemed based on the assumption that Melissa only needed a room. This was a surprise given that Melissa's family had furnished the house, fundraised, and repeatedly replaced electric jugs, irons and other appliances over the years.

Meanwhile, Melissa remained distressed in the group home environment. During an outburst of frustration one day she seriously injured herself and subsequently lost her ability or desire to dance. She became hyper-sensitive to noise and all sensory stimulation. There were staff conflicts, Melissa's money was stolen, the church refused to involve police, staff brought clients Melissa didn't know into the house, there were mistakes with medication, the tension mounted and Melissa once again exploded. The agency decided they would have to evict her and so DSQ provided some emergency support funding so she could stay until an alternative could be found. One day after a weekend outing, Melissa told her mother that she would never return to the agency house.

Looking back, Tania can see how unhappy Melissa was in the group home. "That place just drove her crazy in the end."

Melissa lived with her parents for eight months, while they were also caring for an elderly parent at home. When her parents had to return to work, Melissa was left with no secure home and no support funding package. Fortunately she lives week to week in an informal arrangement with a woman (trained in direct care) and her family who live very quietly and have so far been prepared to make some changes to their habits to help Melissa feel comfortable. Melissa's loving parents live nearby.

Melissa doesn't do a lot now, doesn't have contact with friends, doesn't pursue her old love of dancing and doesn't go out much. But she's calm and happy to be where she is.

Looking back Tania can see how unhappy Melissa was in the group home. "If I had the time over I'd get her out much sooner," she said. "That place just drove her crazy in the end. I hope the old Melissa comes back to us one day, and she is happy again."

Future

Melissa's future is uncertain. She has applied for public housing and individual support funding...

Melissa's future is uncertain. She has applied for public housing and individual support funding to allow her to live independently in secure accommodation where, for the first time in her life, she would be in control, with support from her family. If these applications fail, what will happen?

**** Identities have been changed to protect vulnerable people, whose accommodation and support needs are still being negotiated.***

An Alternative Approach:

A new UK approach to service delivery for people with intellectual disabilities called *In Control* has the potential to transform traditional approaches of congregated care and case management without costing more money.

The model could apply to people with any kind of impaired capacity.

control

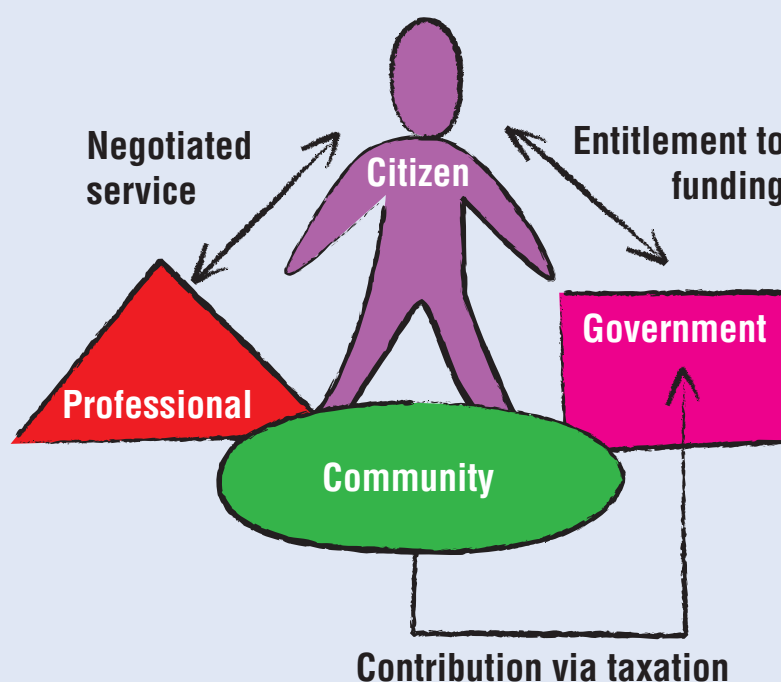
This approach began in 2003 and an evaluation showed highly significant increases in satisfaction across all measured factors – self-determination, planning, support, money, home and community life.

This included results such as a 55% increase in satisfaction with self-determination and 29% increase in satisfaction with home.¹³

The 'Citizenship Model' of *In Control* (illustrated below) is characterised by:

- a personal budget for individuals – set indicatively as early as possible
- self-assessment and support planning led by the person or those closest to them
- a high degree of flexibility in how money can be used.

The 'Citizenship Model' of *In Control*¹⁴



Citizens Take Control

success

Part of the success so far seems due to the fact that the individual with a disability and their chosen co-planners are focused on their specific needs, rather than a definition of the need based on knowledge of existing services.

For example, knowing local day respite centre places are available may skew care planning to include day respite even if it's not really linked to an individual's goals.

Interestingly, comprehensive assessments were not a success factor because there were none. Also, people found that if they knew their budgets and had information early enough to plan well, they were able to avoid expensive, crisis-driven service solutions. Early indications are that overall care costs have decreased using the *In Control* model.

The plans people made increased their own tenancies by 900%, increased employment of personal assistants by 175%, decreased days in day centres by 22% and decreased use of registered care homes by 100%.¹⁵

model

The model enshrines six keys to citizenship:

1. **Self-determination** – the ability to control your own fate and make decisions for yourself
2. **Direction** – a unique sense of purpose by which to identify your role within your community
3. **Money** – the means to independently meet your needs without being dependent on others
4. **Home** – a place of your own in the community where you are seen to belong
5. **Support** – being able to offer others the chance to help and be useful to you
6. **Community Life** – to make a contribution to the community by your meaningful presence and participation.¹⁶

13. <http://www.in-control.org.uk>

14. Diagram adapted from *In Control* www.in-control.org.uk

15. <http://www.in-control.org.uk>

16. *In Control*, Simon Duffy MA DMS FRSA PhD, Valuing People Support Team, National Co-ordinator of *In Control*, Edited version of article published in the *Journal of Integrated Care*, Volume 12 - Issue 6 December 2004

