

# **Ethel Temby Study Tour Award**

**September/October 2005**

**Person Centred Planning and its Implementation  
for Families with Children with Disabilities**

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## 1. BACKGROUND

***“We have to always keep in mind that person centred planning is not our goal. The plan is not the destination. It is the vehicle.”<sup>1</sup>***

***“If you only focus on the quality of the plan without focussing on the quality of the implementation you are doing yourself and the person a disservice.”<sup>2</sup>***

The purpose of my study tour was to visit individuals and organisations involved in person centred planning with families of children with disabilities in England and to learn more about implementation of plans. Throughout my trip I met a range of people from different organisations who were inspiring, supportive and encouraging. There was always an exchange of information, experiences and views between us. I learnt much about person centred planning and implementation but much much more.

I learnt more broadly about the social care system for families, children, in particular disabled children and adults in the U.K. I learnt about the breadth and depth of the person centred approach, its philosophy and its inter-relationship with direct payments, circles of support, empowerment, inclusion, multi-agency approaches, training, new initiatives in particular, “In Control”.

The study tour enabled me to develop my knowledge and understanding of the person centred approach, it enabled me to create new working relationships with key individuals in England who are lead professionals in person centred planning and/or service delivery and it acted as a catalyst for action, change, and the development of new projects and new ways of working within my current practice.

## 2. THE PERSON CENTRED APPROACH

2.1 I visited Clive Acraman, Manager of Sure Start Waterbridge based at Colne, East Lancashire as Clive had co-authored a paper with Helen Sanderson “Person Centred Approaches and Family Essential Lifestyle Planning Plans.” Family Essential Lifestyle Plans recognise what is important to each family member, and identify the support that the child and each individual family member needs.

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<sup>1</sup> Sawell, Sanderson et als Essential Lifestyle Planning for Everyone 2005 p159

<sup>2</sup> ibid

As Sarah a Social Worker with Sure Start Waterbridge said:

*“Continuity of care, and understanding a particular child’s needs, wishes and feelings is something we, as a profession often mess up. It is time that Care Plans and Looked After Children (LAC) documents are our tools for ensuring needs, wishes and feelings are considered, and to some level these tools are effective. What Family Essential Lifestyle Plans offer however, is a true voice for the child to express what is important to them, from their perspective within the context of the family.”<sup>3</sup>*

In addition to learning about Family Essential Lifestyle Planning I also learnt about the Sure Start Program, the way in which it was developed from the bottom up, i.e. an extensive community consultation was held to inform the services about what families in the area wanted. Sure Start Waterbridge is a program that very much involves families in its operation, half of the Board of Management are parents and carers.

Sure Start is a government scheme designed to improve the health and well being of families and children before and from birth to four years by providing: outreach and home visiting schemes to families with young children; support for families including parent projects; good quality play, learning and child care; community health and advice; support for those with special needs including support in accessing specialised services; support to strengthen community involvement.

Sure Start Waterbridge impressed me as a vibrant program with much emphasis on family support and education. As a U.K. program I understand Sure Start is currently undergoing some scrutiny, however at Sure Start Waterbridge with a staff of 28 the program after 3.5 years has delivered services to over 1000 children. Another organisation I visited, Wigan and Leigh Scope also provided a Sure Start program which specifically focussed on 85 families of children with disabilities and disabled parents including a project to link families together to provide support with each other.

Using a person centre approach means working in a way that reflects the values underpinning person centred planning. Practical tools called person centred approaches are different ways of gathering information about what is important to someone, what they want for their future, what support they need. These approaches are different from the traditional form of assessments.

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<sup>3</sup> Acraman, C., and Sanderson H, The Potential of Family Essential Lifestyle Plans, [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)

All the staff team at Sure Start Waterbridge were trained in person centred approaches. Sanderson and Acraman state:

*“Family Essential Lifestyle Plans are not an assessment, and unlike any other tool that is used to plan with families we are aware of, the plan is owned by the family and not the service. However they do create and present, demonstrably fuller and richer information, and insights into family behaviour and functioning than traditional assessments provide.”<sup>4</sup>*

Clive talked with me about the relevance of the approach with families of children with disabilities with families driving their own family plans.

In addition I was introduced to the application of person centred planning to team development. Clive Acraman has developed this approach with Helen Sanderson and applied it to the team at Sure Start Waterbridge.

*“A person centred team is a team with a shared sense of purpose who know what is important to and for team members. In a person centred team roles and tasks are allocated based on team member’s strengths and interests and the team regularly reflects on and shares, what they are learning.”<sup>5</sup>*

All of this is recorded and updated in a person centred team plan.

- 2.2 Helen Sanderson of Helen Sanderson Associates discussed with me the extension of Essential Lifestyle Planning, one type of person centred approach to using it as a framework for assessments of prospective foster caregivers, adoption applicants, organisational reviews and strategic planning. Her consultancy has used this approach in her review of Looked After Children in Northern Ireland; She has recently written “Good to Great” with Michael Smull which uses the person centred approach with organisations as a means of organisational review and change.

Helen has been most encouraging to me and offered to informally mentor me in my application of the person centred approach to my work at MacKillop Family Services.

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<sup>4</sup> ibid

<sup>5</sup> Acraman, C., Sanderson, H., Person Centred Teams. The Experience of Sure Start Waterbridge and Possibilities for Health and Mulitagency Teams, at [www.helensandersonassociates.com.uk](http://www.helensandersonassociates.com.uk)

### 3. ROLE OF FAMILIES

- 3.1 Families Leading Planning U.K (FLP) is an organisation established on July 7, 2004. Its work centres around the development of Families and Person Centred Planning. FLP takes an active role in conducting training programs for families to learn about developing a plan for a family member.

I was fortunate enough to spend two days with Barbara Coles the Executive Officer of FLP. During this time I spent one day attending a training day for families and the other talking with Barbara about the needs of families and the work of FLP. Apart from the content of the training day attended, it was very evident that the group of parents doing the course were learning from each other. None of them had known each other before the course and it was obvious they were re-considering what was occurring for their son/daughter as a result of learning about the situations of other parents' children, young adults. For example, one parent had never considered the idea of her daughter living independently to the family but as a result of hearing about what was occurring with other participants' young people, she was now considering this. Partnership Boards and Valuing People were supporting the training provided by FLP.

Families Leading Planning states:

*"A person centred plan is only a means and not an end. The life that the person wants is the outcome, not the plan that describes it. Good plans are rooted in what is important to the person while taking into account all the other factors that relate to the person: health, safety, disability, views of those who care about ( and know) the person and resource issues".<sup>6</sup>*

Valuing People has said that:

*"family members and friends are full partners in planning and should be offered the opportunity to learn about leading plans for the people they love should they wish to do so".*  
(Dept of Health, UK 2002).<sup>7</sup>

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<sup>6</sup> Taken from "What is Person Centred Planning?" Handout from Families Leading Planning

<sup>7</sup> Department of Health, UK Valuing People, 2002

In “Families leading person centred planning, How are they doing? Where are we going – Good Practice Ideas for Partnership Boards”, Barbara Coles, Caroline Tomlinson, Helen Sanderson and Alison Short the authors write:

*“It is clear that we need to inform families in a variety of creative ways about person centred planning. Many families feel strongly that they should be able to expect assistance with planning whilst others wish to learn how to plan (as advocated in the Department of Health Guidance). Families are excited about how together with the people they love, and people that support them and/or deliver services, that the plan leads to action now and in the future for their relatives.”<sup>8</sup>*

- 3.2 I was also fortunate to learn about the Partners in Policymaking Course which develops leadership and empowers participants with advocacy skills. Partners in Policymaking was created in Minnesota USA by the Governor’s Council on Developmental Disabilities in 1987. Partners is an innovative, competency based leadership training program for adults with disabilities and parents of children with developmental disabilities. The purpose of the program is two fold: one, to teach best practices in disability, and two, to teach the competencies of influencing public officials.

Since 1987, Partners programs have been implemented across the U.S.A, Netherlands, United Kingdom. More than 13,000 Partners graduates are part of a growing national and international network of community leaders serving on policy making committees, commissions and boards at all levels of government.

The Circles Network and Wigan and Leigh Scope both offer these courses when they can. Whilst spending time at Wigan and Leigh Scope I was privileged to spend an evening with four parents and two people who had disabilities who wanted to give me feedback about what the course had meant for them and how it had changed their lives. Some of the comments were, from Parent 1 “I fell in love with my 8 year old daughter again” – I realised that I might not be able to change a number of things but I learnt to see her differently; from Parent 2 “it has turned my world around. I thought I knew it all, I knew my son better than anyone and would always care for him” – now he is about to move into his own accommodation next door, I am working and my husband and I are starting to get to know each other and have a social life (which is a struggle – I don’t know how I’ll go); from Parent 3 I am fighting to get a lift installed in our home, it has not been easy but this course has equipped me with understanding about the system and policy making and I have now brought the U.K. Government into the matter.”

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<sup>8</sup> Valuing People Support Team: Person Centred Approaches: Next Steps, Page 4

The Partners in Policymaking course is resource intensive and is certainly not for everyone but it has much about it which is attractive – the mix of adults with disabilities and parents of children with disabilities together, the combination of development of knowledge, skills, personal development and support and friendships gained by participants doing the course.

Many of the people who have completed the Partners in Policymaking course in the UK have gone on to make other contributions, for instance leading family person centred planning, being family mentors for other families, developing service options, working in the field, providing disability education courses for schools, working on developing inclusive opportunities for people with disabilities.

- 3.3 At Wigan and Leigh Scope I had the wonderful experience of attending an evening with about 40 people. These people, a mix of children, teenagers, young adults, parents, interested adults were all involved with a group of teenagers who were undertaking the Silver level of the Duke of Edinburgh Award, having already achieved their bronze. At least eight of the participants had moderate and severe disabilities.

The evening was held in a community centre and the group met weekly during school time working through the challenges of the Award. The night I attended the group were looking at photos which had been taken during group activities through the year and were making decisions about a calendar for 2006 which was going to form the community service component of the award. It was a wonderful experience which taught me that if a few people have an idea and have the motivation to stick with it much can be achieved. This activity was supported by Wigan and Leigh Scope and was a great example of inclusive practice.

Wigan and Leigh Scope is a voluntary organisation which provides information, advice, support, training, person centred planning and a personal advocacy service for local disabled people of all ages and their families. It works in partnership with other agencies to provide innovative new solutions which enhance the quality of life for all disabled people and their families. Its mission statement is:

*“we actively promote and support inclusion, opportunity and choice for all disabled people and their families who live, work or use services in the borough of Wigan and Leigh. Seeing the world as a brighter place by celebrating difference, after all together we are better.”<sup>9</sup>*

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<sup>9</sup> Annual Report 2005, Page 4, Wigan and Leigh Scope

I spent three days at Wigan and Leigh Scope, my program was organised by Caroline Tomlinson, Service Manager at Wigan and Leigh Scope. I went on a home visit with a field worker to a mother of a boy who had acquired a psychiatric disability at the age 7 years. I visited a new day program for young adults, I met other staff of the organisation, I attended a meeting of the Parents Council, which is an advisory group of parents. At the Parent Council meeting parents were very concerned about a reduction in respite services for families with children with disabilities and were considering what action they could take. This was an issue I could identify with as it is very relevant for families I am involved with.

## **4. SUPPORTS FOR FAMILIES**

### **4.1 “In Control”**

With Caroline Tomlinson I attended a meeting in Derby involving the Assistant Manager of “In Control” and a staff member from the Valuing People team who was responsible for involving families/carers in the work of Valuing People. The meeting was to discuss plans for involving family leaders from across England in an all day forum around “In Control” and Family Leadership as it related to “In Control”.

“In Control” has been piloting a radically different way of organising social care that fundamentally changes where the power lies and should leave people who use social care services fully in control of their own lives, funding and supports. It has at its core personalised budgets and places emphasis on families in the lead.

The key to the approach is one stop assessment and resource allocation. This means the aim is to pull together all potential sources of support for the disabled person, achieving ultimately a single process and outcome. Under the Scheme being trialled in Wigan, resources are allocated in three bands – up to £10,000, £20,000 and £30,000 a year – and it is true that disabled people and their families may spend the money as they choose, provided statutory requirements such as the minimum wage are met. Many of the “In Control” families in Wigan have done the Partners in Policymaking course.

“In Control” is a project of Mencap (the leading learning disability charity in UK) run in partnership with Helen Sanderson Associates, the North West Training and Development Team and Paradigm and supported by the Valuing People Support Team.

An evaluation of the pilots will soon be completed and it is worth noting an In Control Conference is being held on March 9, 2006. More information can be found at [www.in-control.org.uk](http://www.in-control.org.uk) and [www.paradigm.org.uk](http://www.paradigm.org.uk)

#### 4.2 Direct Payments

A number of the parents I met during my trip, including Caroline Tomlinson of Wigan and Leigh Scope and Barbara Coles of Families Leading Planning had direct payments for their sons. Both employed teams of personal assistants for their sons which included providing a 2:1 ratio. Direct payments are cash payments made to meet people's community care needs in lieu of traditional services. They allow anyone assessed as eligible for a community care service to make their own arrangements for the provision of that service. In doing so they (or in the case of children, their parents or guardians) become employers, deciding whom to employ as well as the terms and conditions of employment.

Early 2005, 870 families in England were in receipt of Direct Payments with the number rising. Some Local Authorities have been slower than others to develop schemes but, as pressure from both central government and families increases, take up is certain to accelerate. Direct payments and traditional support do not have to be mutually exclusive. Some individuals may decide a mixed package – with part of their assessed needs met by Direct payments, part by traditional care – best suits their needs.

*“A huge advantage of Direct Payments reported by parents is that of regaining control over family life, allowing them to decide who comes into their homes, what they do, and how long they stay. Parents greatly appreciate being able to use that control to build relationships based on mutual trust and respect, with a small number of people they can train to do things in ways that work for them.”<sup>10</sup>*

#### 4.3 Circles of Support

I spent two and a half days at the Circles Network and met staff from all over the U.K. as it was the time they met as the Project Management Group. I joined in training on personal, social and augmentative communications and learnt much about the range of work the Circles Network is involved in and its funding.

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<sup>10</sup> Direct Payments for Families Pippa Murray Circles Network UK 2005

A circle of support is a group of people who meet together on a regular basis to help a person accomplish their personal goals in life. The circle acts as a community around that person (known as the focus person) who, for one reason or another, is unable to achieve what they want in life on their own. The members of a circle who may include friends, family, neighbours and interested members of the community are not paid to be there. Service providers may also be involved but the emphasis is on people who share common interests with them.

Circles of support help the person build bridges and make connections to the wider community, so that individuals who were unconnected – to society, to services, to friends and new opportunities – become connected, sometimes for the first time in their lives. Circles have at their core person centred planning and use a facilitator to get things started. Usually the facilitator can train a member of the circle to take over his/her role once the circle is operating well.

I spent time with the Co-ordinator of CREDO, Nadine Jay, a project worker of the Circles Network. Nadine talked with me about a specific inclusion project she had established which involved non-disabled and disabled teenagers getting together, how she had gone about starting it and how it is working now. Since I have returned I have heard that an additional 3 years of funding for the project has been obtained.

## **5. LOCAL AUTHORITIES**

### **5.1 West Berkshire**

I spent a day with the West Berkshire Local Authority at Newbury. My time involved visiting a newly completed respite facility 'Castle Croft' for children with disabilities and children with complex medical needs and talking with the Team Leader of the Disabled Children's Team, Marjorie Taylor. The new respite facility had been recently redeveloped and involved combining targets of both the Health Department and Social Service. There were two beds for children with complex medical needs and four beds for other children with disabilities.

Four staff were rostered on duty and at night staff were on active night duty and included a nurse. The facility was based opposite the local Special School that many of the children attended. It had beds for six children and worked with 40 families. It was likely this would increase to 60 families. The standard of the facility was high and it was very well equipped. For instance staff could talk through an intercom with each child in his/her room.

It was apparent that the nature of services provided for families of disabled children varies considerably from one local authority to another. Whilst the importance of person centred planning is recognised particularly as a result of Valuing People, the priority this approach is given will be dependent on the management of other pressures such as demand for service provision.

Marjorie Taylor talked with me about the importance of the Children's Act and that children were seen as children first and disabled second. So children receive a common assessment and then it is considered they have an entitlement to the services identified from the assessment. Considerable funding goes into universal children's services so that those children referred to the disabled children's team have high support needs.

## 5.2 Devon

At Devon County Council I met with John Shaw, who is leading a new joint agency team for children with special needs. This involves a joined up approach with health, education, social care departments. Policy and Protocols are being established with the partners of the scheme and funding is being pooled. This is the first local authority in England where this has occurred. When a child is referred an integrated assessment occurs. If, as a result of the assessment, the child does not need more than two services, then a referral might be made to community service providers. If more than two services are required a key worker will be appointed from the most appropriate partnership organisation.

## 6. IMPLEMENTATION OF PERSON CENTRED PLANNING

A primary aim of the Study Tour was to learn more about the implementation of plans. I learnt that a detailed plan clearly included an action plan listing tasks and who the person responsible was as well as provision for people coming back together to consider areas of difficulty which may have arisen during the implementation of a plan.

In order for this to occur however, it required a key person to take the initiative and this would often be the parent. The opportunity for parents to participate in training, (for example courses run by Families Leading Planning), learning to develop a person centred plan for their son/daughter had considerable merit and contributes to the parent's motivation in the plan being implemented as well as providing the opportunity to learn skills through the training which will assist the parent in ensuring implementation occurs.

When talking with Alison Short of Helen Sanderson and Associates about implementation, I learnt about Design Days which are held to educate service providers about person centred planning. These one day workshops aim to get service providers "on board" and committed to the notion of person centred planning. This is

crucial as often plans will require service provision e.g. a support worker to assist with getting a young person with a physical disability showered and dressed, and it is vital that service providers are committed to the philosophy of person centred planning if they are providing a service to a client who has been through this process.

Circles of support are an example relevant to the implementation of person centred plans. Circles are created frequently in order to implement an individuals plan. The philosophy of person centred plans is at the heart of the development of a circle. Family mentors, people there to support families in the implementation of a plan are another example of a means by which plans can be enacted. Again, Families Leading Planning provides training for and supports family mentors.

Helen Sanderson et als write about Implementation Groups:

*“The implementation group has two very practical and visible tasks: to inform people about person centred plans and to ensure that there is capacity to facilitate good plans for people who need and want them. The group has two more open ended tasks: to do what it can to help people’s plans become reality and to develop the ‘community of practice’ around person centred plans.”<sup>11</sup>*

The community of practice is very important and links to the notion of design days and it is evident to me that in order for implementation of plans to occur service providers, practitioners, planners must be fully committed, skilled and knowledgeable about person centred planning – the philosophy and process. It is worthwhile noting that a community of practice has been recently initiated in Melbourne by Person Centred Learning Services.

## **7. OPPORTUNITIES – WHERE TO FROM HERE?**

As a result of my study tour, I am committed to developing person centred planning in the work undertaken by Bayview Disability Services, MacKillop Family Services. In doing this, I am aware I have a network of support from the contacts I have made during my tour.

In 2006:

- (a) I intend to seek funding from Government/Trusts to develop circles of support in the Barwon-South West Region.
- (b) I intend to ensure training for the Bayview Disability Team in People Centred Plans occurs.

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<sup>11</sup> Ritchie, P., Sanderson, H., Kilbane, J., Routledge, M., People, Plans and Practicalities, 2003, Page 104

- (c) I intend to ask three team members to develop people centred plans for several of their clients (Helen Sanderson places emphasis on starting small in order to achieve).
- (d) I intend to explore and look to implementing training in people centred plans being available for families.
- (e) In 2007 I am keen to develop a program which involves young people in the Duke of Edinburgh Awards.

I am also keen to provide information about my learnings to professionals working in disability services. I have given a presentation to the Disability Partnership Team at Department of Human Services, Barwon South West Region; the Child and Youth Sub-Committee ACROD (Vic); Program Managers, MacKillop Family Services and Bayview Disability Team, MacKillop Family Services.

In 2006 I will be giving a presentation to the Statewide Group of Flexible Support Providers and will continue to use opportunities I have to inform people about my experiences. I will also be presenting to other staff groups within MacKillop Family Services.

I intend also to post this report on the website of MacKillop Family Services.

As stated in my introduction, the Study Tour was a wonderful experience, full of new learnings. It has inspired me to develop my own practice and to drive service improvements in my own organisation and the broader disability system.

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## **BIBLIOGRAPHY**

Ritchie, P; Sanderson H; Kilbane J; Routledge, M “People, Plans and Practicalities” achieving change through person centred planning, SHS Trust 2003.

Smull, M.W. and Sanderson H., “Essential Lifestyle Planning for Everyone” The Learning Community – Essential Lifestyle Planning, 2005.

Short A. and Sanderson H., “Looking to the Future” Families Leading Planning, 2004.

Wertheimer, A (ed) “Circles of Support”, Building Inclusive Communities, Circles Network 1995.

Mount, B and Zwernik, K., “It’s never too early, It’s never too late” A booklet about personal futures planning, Minnesota Governor’s Council on Developmental Disabilities, 1989.

Murray, P., “Direct Payments for Families”, Circles Network, 2005.

Murray, P. and Penman, J., “Let Our Children BE”, A collection of stories, Parents with Attitude 1996.

Murray, P., and Penman J (ed) “Telling Our Own Stories”, Reflections on family life in a disability world, Parents with Attitude, 2000.

Mount, B., “Imperfect Change” Embracing the Tensions of Person-Centred Work, Communitas 1990.

Valuing People Support Team – “Families leading person centred planning. How are we doing? Where are we going? Good Practice Ideas for Partnership Boards”. (Written by Barbara Coles, Caroline Tomlinson, Helen Sanderson and Alison Short.

## **WEB ADDRESSES**

[www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)

[www.paradigm-uk.org](http://www.paradigm-uk.org)

[www.familiesleadingplanning.co.uk](http://www.familiesleadingplanning.co.uk)

[www.partnersinpolicymaking.com](http://www.partnersinpolicymaking.com)

[www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)

[www.wiganandleighscope.org.uk](http://www.wiganandleighscope.org.uk)

[www.surestart.gov.uk](http://www.surestart.gov.uk)

[www.devon.gov.uk/disc](http://www.devon.gov.uk/disc) Devon Information Services for Children

[www.westberks.gov.uk](http://www.westberks.gov.uk)

[www.in-control.org.uk](http://www.in-control.org.uk)

[www.valuing.people.gov.uk](http://www.valuing.people.gov.uk)

## **RESOURCES**

- Videos
  - “Circles of Support, Circles Network, 1995
  - “Hello You” The Voice of Young People Who Are Perceived as Having Profound and Complex Impairments” Circles Network.
- Pamphlets from the various organisations I visited.
- Annual Reports:     Circles Network  
                              Wigan and Leigh Scope
- “Don’t need the sun to shine to make me smile” A Consultation Report collating the views of children and young people with disabilities about Wigan Social Services Summer Playschemes. Wigan and Leigh Scope, February 2003
- “Transition”, Wigan and Leigh Scope.
- “The Parent Council”, Wigan and Leigh Scope, 2004.
- “Complex Needs”, A consultation with families, Wigan and Leigh Scope, 2002
- Girsch, M. and Girsch, C., “Fanning the Creative Spirit”, Creativity Central 3<sup>rd</sup> ed. 2003.