PARTNERS in CHANGE

NEW MODELS FOR SUPPORTING CHILDREN AND FAMILIES AND EXPLORING THE LOCAL AREA CO-ORDINATION MODEL

PARTNERS IN CHANGE WORKSHOP

GLENROTHES

12 DECEMBER 2001

LOCAL AREA CO-ORDINATORS'
TRAINING WORKSHOP

ERSKINE

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ABOUT PARTNERS IN CHANGE

Partners in Change is a programme of work funded by the Scottish Executive and co-ordinated by Scottish Human Services Trust. The development of the Partners in Change programme was highlighted in Scottish Executive's Health Plan (Our National Health) published in December 2000, and it is part of the on-going Involving People Programme which takes forward the range of activities and aims outlined in section 5 of the Plan.

SHS's task in delivering the Partners in Change programme is to:

- gather ideas and experiences from both people in communities and people who work in services on key areas in the planning and delivery of services in the NHS
- identify locally based groups and create opportunities for these groups to work together with services to share information and ideas
- facilitate the design of local Partners in Change projects. These individual projects aim to extend the ways people are involved in specific service areas locally, and in time lead to improvements in the ways services respond. Together, these local projects will form an extensive programme of Partners in Change projects throughout primary care, acute care, screening services and community care services which will involve the people who use these services
- introduce people to ideas and practical experiences that have been developed in other places.

FOREWORD

Why we held the event in Glenrothes

The main part of this report was prepared from notes taken during a Partners in Change workshop held in Glenrothes on 12 December 2001.

Our National Health is a strategy for improving the health of people in Scotland.

‘A healthy Scotland means:

- services and communities planning and working together
- individuals taking a shared responsibility for their own health
- working in partnership, across traditional boundaries and across a range of different organisations
- tackling inequalities between rich and poor, including those who are currently excluded, and bringing about social justice.’

(Our National Health, page 13)

The workshop which launched the Partners in Change programme looked at the factors that influence our health and wellbeing - such as our behaviour, our environment and our social networks - and how health services could work with communities to complement what each other was best placed to achieve.*

The links between health services and communities are particularly important for children and young people, older people and people who have long term relationships with the NHS. The Scottish Executive has also identified projects involving these groups of people as priorities for the local projects in the Partners in Change programme.

The workshop at Glenrothes brought together several elements which

***Communities and Health**
‘Communities and Health: What will the outcomes be from greater partnership between people who use health services and the people who work in services?’ A report from the Partners in Change workshop with John McKnight, Glasgow, 2 May 2001

NHS Boards and other people and organisations might find useful in developing services which enable people to have a more active role in their own health:

- the ideas and experience over 10 years from the Local Area Co-ordination model from Western Australia
- the experiences of parents and families in looking for support
- the experience of people who are working in services
- the ideas people had about how these approaches could be used in Scotland - for anyone who uses services to support them living as part of their community but especially for families and for older people.

The training workshop in Erskine

In April 2002 SHS Trust ran the first training workshop in Scotland for Local Area Co-ordinators. The workshop brought together people who had been recently appointed as the first 6 Local Area Co-ordinators in Scotland, parents and people who are part of planning and/or managing Local Area Co-ordination in their areas, and families and staff from other local authorities and NHS Boards which were considering this approach. The people taking part included people who had participated in the initial event in Glenrothes.

The course was delivered by Eddie Bartnik, who developed the approach, Anne Cross from the Queensland scheme, and SHS Trust staff. It covered:

- understanding the problems that Local Area Co-ordination is designed to solve
- principles and values that underpin the approach
- practical aspects of working in this way
- how to ensure high standards
- taking Local Area Co-ordination forward in Scotland.

Several participants have gone on to link the development of Local Area Co-ordination to the network of local Partners in Change projects and to other local arrangements to extend the participation of people who use services and families in developing and implementing health care and related services.

DETAILS OF THE GLENROTHES WORKSHOP

The workshop speakers were:

Stephen Williamson
A parent from Perth and Kinross who is a graduate of the Partners in Policymaking programme co-ordinated by SHS Trust. Partners in Policymaking is an 8 month leadership development programme for adults with labels of disability and parents of children and young people labelled disabled under the age of 19.

Eddie Bartnik
Assistant Director of Metropolitan Service Co-ordination at the Disability Services Commission in Western Australia. Eddie developed the Local Area Co-ordination model and has been managing, evaluating and developing the model for 15 years.

His presentations around Scotland in 1999 and 2000 exposed people to the Local Area Co-ordination model and the adoption of the model is now one of the four key recommendations in the Scottish Executive "Same As You?" strategy document for people with learning difficulties.

Tricia Cox
Head of pre-school Educational Home Visiting Services in Fife. Tricia is involved in a process of developing new approaches to working with families in Fife.

Workshop outcomes

Following the presentations, one group of participants explored the application of this model to children's services. A second group explored its application to services for older people. The recommendations from these groups in included in the Where Next? section of this report. A third group worked with Tricia Cox to identify ways to extend the participation of parents and children in developing the next stage of the new Fife service.

WHAT KIND OF SUPPORT DO FAMILIES LOOK FOR?

Stephen Williamson introduced himself as a parent from Perth and Kinross and a graduate of the Partners in Policymaking programme co-ordinated by SHS. His youngest son Kim has a label of disability.

A year ago I would have introduced myself as ‘just a parent’. However, having completed the Partners in Policymaking leadership programme I now realise that as a parent I am one of the most important people to come into contact with my son.

I feel very strongly that parents, families and adults with disabilities have to take up their responsibility and play an active role in designing the services and supports they need to live full lives. There is no point in endlessly complaining that services don’t work, or are no good. Families and individuals have to play their part in explaining to service systems what support would work for their family and then work with services to ensure that this support is delivered.

About Just Imagine - designing creative family support

During the Partners course the participants heard about family support.* Along with a number of the other participants on the programme, I was impressed by the concept that support should be to the family, not just directed towards fixing or removing the child with the disability. We were also inspired by the idea that the support should be supportive and preventative, not in response to crisis.

*__Family Support__
Lou and Emily Nisenbaum from Massachusetts Families Organising for Change presented on the Partners in Policymaking programme. As a group of families, this organisation had actively campaigned for Family Support services to be provided in their State. Ten years ago their State had a respite-only model, which involved removing the child with the disability from the family in times of stress or crisis. Now their State provides a whole range of family directed supports and assistance.

The guiding principle underpinning the family support model is "what ever it takes". Realising that responsive family support would, by definition, mean different things for every family, a number of Partners formed a group called Just Imagine and did just that. Partners sat with their families and wrote down what would work for their own family or individual situation. We then produced the Just Imagine brochure containing some of those stories.

Leslie's story (taken from the Just Imagine brochure)

> *"Our family dynamic is that our two sons Aaron, twelve, and Callum, six, both have learning difficulties and need support and supervision at all times. I am partially sighted and only being able to see out the centre of my left eye restricts the amount that I am able to do with my boys. This often leaves Amanda, my fifteen year old daughter, lost in the shuffle. We have no family to help us, as our parents are elderly and sister and brothers have opted out of any support issue. Ian and I are the only carers for our sons at present.*
>
> *We would love a family friend or fill in parent. Someone who could fill in for either Ian or myself to look after the boys when needed, or help during the school holidays when Ian is at work. It would be great to have a friend who could take me and the boys out and help keep an eye on them, or to look after the boys so myself and Ian could go out together, or with Amanda, or take one of the boys to a local group.*
>
> *To have someone who really knows the boys well would help Ian and I and we'd feel more appreciated, as that person really starts to care for our gifted children, all three of them. We would like to have control of the pay and of the hours worked, so cutting down on the phoning and waiting for a reply scenario that you get now when asking for any help." Leslie Stalker*

The loss of control and the endless waiting referred to in Lesley's story is a common experience for families. Families feel like we are lost in the shuffle and always waiting for someone to get back to us. The Just Imagine group is about trying to get parents and professionals to work more closely and effectively together.

The need to be listened to and taken seriously

I want to give an example around the issue of working with health care professionals by telling a personal story about Kim's recent experience in a hospital.

Kim's story

> *"Kim had to have yet another MRI scan. This was the third one that he'd had, so Kim knows hospitals very well. He knows surgeries very well. He knows what a white coat means; he knows the whole bit.*
>
> *Kim and I had to go to hospital. We had to be there for half past ten. We sat in the ward at half past ten. Kim always has a nap in the afternoon, but that day in the hospital Kim wouldn't go anywhere near the bed; he wouldn't even sit on it. So he sat on the chair while I sat on the bed; because if he sat on the bed he wasn't quite sure what would happen to him. There was no way that he was going to have a nap, so the poor child sat there. His eyes were going together but there was no way that he would go for a nap.*
>
> *There was nobody in the ward to suggest something for us to do. The play area was actually closed that day, which I didn't quite understand, but even if it had been open there was nothing there that was appropriate for Kim. He doesn't play with toys, Kim's favourite toy in our house is the vacuum cleaner. There was nothing for Kim to do except sit there.*
>
> *Kim got more and more anxious. He is of an anxious nature anyway. He wasn't allowed lunch because he was going under general anaesthetic. At one point we attempted to leave the ward because I thought if nothing else we can go for a walk. I was stopped at the door and told we couldn't leave because 'he's not allowed to eat anything'. I said he wasn't going to eat anything and I was told 'you can't take him up to the mall because there is food there and he would only want it'. I pointed out that we had talked it through with Kim and explained it, he knew it would make him sick if he ate and he doesn't want to be sick.*

The nurse said 'oh no, 'cause it would be my responsibility and I don't know if I can let you' and I said 'well I will remove that responsibility from you'. We left, much to this nurse's dismay, and we came back at one o'clock.

Eventually they came and put the 'magic cream' on. Kim is used to that, he knew what was coming. We learned very early on that if you allow Kim to see what's happening it's not a problem. Kim has an extremely high pain threshold. Our dentist recently took a tooth out (it was hanging by a thread albeit) but without anaesthetic because there is no way that Kim would have let him put a needle in. Kim is not worried about pain. He is worried about not seeing what is happening. So he knew what the magic cream was because he had seen that, he knew that then he would get the little needle in and the whole bit, so he knew what was going to be happening and that really wasn't a major problem.

The problem came when two and a half hours later, after the cream had stopped working, we were taken down to the MRI unit and we sat outside it for another half hour because there was a backup of patients. When we did eventually get in, there were six people all with white coats. Another thing Kim knows about is white coats and he knows that he doesn't like them. One of them tried to hold Kim's head away while the other tried to put the needle in, I kept saying 'no let him see what you're doing' but they totally ignored me.

The cream wasn't working so he could feel pain and he didn't understand why. It ended up that the six of them couldn't hold him down and he was screaming 'daddy, daddy, stop it, stop it' and I had to listen to that. In the end I had to make the decision that somebody was going to get hurt, possibly Kim, possibly one of the staff. I then had to help these people. I had to go against everything that I believed in.

I can get quite upset just talking about it. I had to hold my own child down while they anaesthetised him. There was, and this is a dreadful thing to say, more interest from the staff in how I felt, how I was doing, than in how my son

> *was, or at least that's how it appeared to me. I had nurses putting their arms round me because I was blubbing like a baby.*
>
> *I think it was the most traumatic experience I've had, blubbing like a baby and this nurse is going 'are you alright, are you going to be OK ?' I said 'yes I'm going to be OK, but my son won't. I know what's happening. I know why it's happening but he doesn't. All he knows is that six people held him down and did things to him and he's going to wake up feeling shit. He's not going to understand, and the next time we have to come back here for something it's going to be worse.'*
>
> *I complained and was told that it shouldn't have happened and there is a nurse on the ward who is appointed to special needs, but unfortunately it was her day off that day. I would like to ask you what difference you think it would have made if she had been on that day? Because I don't think it would have made any. She didn't know Kim, there had been no contact with us beforehand, there was no provision made to meet Kim's needs while he was there. Yes, you end up having to wait. You all have to wait for various things, sometimes it's beyond our control, sometimes it's not. But it could have been different".*

This experience summed up for me the phrase I no longer wanted to use - "just a parent". Parents are often treated as if they had no skills or understanding. I want to see things done differently and I consider listening to be one of the most important skills in making that difference real.

It is important that parents listen and it is important that we tell professionals what we hear. Professional needed to listen while asking the right questions and trying to really probe and push and hear what the person is saying. It is only through listening that you get it right.

Parents are important. We are ordinary people. We don't all have degrees or skills or credentials that are recognised, but we do know our children and professionals could use that knowledge. Parents are more than happy to talk about what they know when they are genuinely asked.

Final comments

In response to questions Stephen referred to circles of support* and PLAN Scotland. Stephen explained that he was on the Steering Group for PLAN Scotland, a new organisation which has been formed as a sister organisation to PLAN Canada**. One of the key aims of the new organisation was to facilitate the building of relationships around individuals with labels of disability and their families to ensure that these people were both safeguarded and included in community life. The PLAN facilitator would use person centred planning approaches to try and build up a rich picture of what was important to the person and then work to engineer connections with the local community.

The circle of support could also assist the person in shared decision making, with different members of the circle having lead responsibility for different areas of the person's life, for example, health care, or daily support, or money and legal issues, etc.

*** Circles of support**
*Circles of Support were first written about in "From Behind the Piano" (Jack Pearpoint, Inclusion Press, Canada). The book catalogues the personal story of Judith Snow's escape from an institution to live in friendship and community. In the process, a circle of support was formed that not only supported Judith, but transformed the lives of everyone involved. The key message was none us of can deal with life alone and the concept of conscious circle building has been used a model to try and safeguard vulnerable individuals in the community.

****PLAN**
**PLAN Canada have produced a book entitled "A Good Life for You and Your Relative with a Disability" (Al Etmanski ISBN 0-9680 462-1-5). This book is available for purchase from SHS Trust. Also contact PLAN Canada website at: http://www.plan.ca/about/index.html

LOCAL AREA CO-ORDINATION IN WESTERN AUSTRALIA

Eddie Bartnik began his presentation by explaining that he had spent the last 25 years of his life working in the management of service delivery systems. His aim this morning was to share with the audience what he and his colleagues had learned over that period about how to do better job of supporting individuals and their families. He would refer specifically to how this knowledge has contributed to the evolution of the Local Area Co-ordination model.

Eddie's current job title was Assistant Director for Metropolitan Services Coordination at the Disability Services Commission in Western Australia. In his post he was responsible for managing two Disability Services programmes. One was a traditional, community based support system including therapists, psychologists, recreation and care workers. The other was the Local Area Co-ordination programme. As he was responsible for both, he could confirm that the Local Area Co-ordination programme was a completely different type of programme.

Key values and beliefs which underpin the Local Area Co-ordination model

I want to start by highlighting that although I and my colleagues work for government, we know we do our best work when we stand alongside individuals and families. There are a number of dominant beliefs and values that make the Local Area Co-ordination model work.

- The approach is person and family centred, giving people choice and control over their lives.
- It is preventative rather than crisis orientated. The approach is based on working with people when they are still strong. If you wait until families have blown themselves apart, you end up simply throwing large amounts of money at the problem. Working with people and families while they are strong helps to develop their strengths.
- It believes that most progress is made when people who use the services are involved in running things and where a shared idea of where things are going is developed. Governments can use lack of clarity about the best solution to avoid doing anything.

However, when everyone involved with a family has worked out what they really want and they are saying the same thing, it is harder for Governments to do nothing.

- The current scope of Local Area Co-ordination in Western Australia is support to children and families and to disabled adults, as this was the span of responsibilities of my Department in the local authority when we started to develop the model. In other parts of Australia the Local Area Co-ordination model now also supports older people and people with mental health problems. The experience has been that the values and the practical aspects of the Local Area Co-ordination approach make it effective in all these situations.

Guiding principles for a Local Area Co-ordinator

Get to know people well over time

We know that services, however brilliant their assessment tools, can spend huge amounts of money trying to meet people's needs and still get it wrong. We have learned over the years that the better the Local Area Co-ordinator actually knows the person over a long period of time, the better the job they do. This may sound simple, but most human service systems are designed to discourage staff from getting to know the people they are paid to support.

Build connections to the local community

Like many places we sometimes have moves to centralise all government staff in big buildings. However, we have found that if we are truly trying to build a good life for people in the community, government staff need to go out into local communities and work alongside people, getting to know them. This is how we start doing a better job of connecting with them. The idea of truly developing a local connection and being part of the community is very central to the role.

Have positive values and assumptions around individuals, families and communities

Many traditional services are focused on cataloguing what people can't do, recording their "needs" and their problems, identifying their deficits. The traditional paradigm is that services are there to 'fix' people's problems. This way of thinking about people is as debilitating for the service providers as it is for the people concerned. It leads to limited thinking.

Local Area Co-ordinators focus on what people are good at and what their strengths are. Valuing their contributions helps the Local Area Co-ordinator get to know them better. Trusting people a bit more takes you to a very different place. Your assumptions about what you're dealing with, what the problems are and what you're trying to do, undergo a change.

People working in services have to undergo a paradigm shift. They have to move away from the idea of "providing a service" and move towards building capacity and strength. The Local Area Co-ordinator has to leave things stronger than when they first intervened. I want to stress that this is the most important element - to build something that is stronger for the person, and the family in the community. This is very different from providing services to fix and manage people's perceived and assessed 'deficits'.

History of the Local Area Co-ordination model

In the 1980s in Western Australia we were having service delivery problems because people in rural areas were travelling to Perth to receive services. One group of professionals traditionally assessed people's "needs" and other people provided services to meet those "needs". For many people this meant children leaving their families and local communities to be displaced in residential services.

In the late 1980s we heard about families and individuals in Canada* who were taking their children out of institutions and supporting them in their community. We also heard about people getting their own funding to manage their own support and new ways of working with people to help them design the supports they needed to live the life they wanted to live.

***Canada**
Eddie is referring here to the early work by Marsha Forest and Jack Pearpoint on inclusive education and person centred planning and Judith Snow's achievement of being the first person in Canada to receive direct payments from the Government to manage her own personal assistants.

All of this would mean that supports and services had to be more personal, more local and more accountable to individuals and families. It also changed the role of the paid worker, from assessing and allocating the person to pre-determined support solutions, to helping the person imagine what good support would look like, then helping them access that support and manage it.

The ideas that were influencing me and my colleagues at the end of the 1980s were echoed by demands from family members who were on the Local Board of Management of the Disability Services Commission. One member said “I don’t want more and more services or more professional workers. I want a real life for my son. I don’t want him spending his life just living with people with an intellectual disability, working with people with a disability, being friends with only people with disabilities.”

This parent had a vision for her son of his own life, his own home, of him maybe getting married. When you put families in the driving seat you gain a very different view of the world and its opportunities for people.

The first Local Area Co-ordination project was set up in one community and focused on the goal of placing one person back in that community. Over thirteen years, the initiative has expanded from one project to an approach that has now spread throughout the whole of Western Australia.

There are now 120 Local Area Co-ordinators working in the community. As well as assisting people to think through the kind of support they needed and help them access and manage this support, the Local Area Co-ordinator also has a responsibility to identify gaps in current service provision to enable these gaps to be filled.

One project that started off with a different way of doing things has now been developed and continuously evaluated (there are six major evaluations of the system to date). It shows that real change often comes from a bunch of people with a good idea setting about doing it in a thorough way. Before you know it, you’ve just about changed the world!

A Local Area Co-ordinator's statement of purpose

I have already talked about the need for Local Area Co-ordinators to work to some key guiding principles (to get to know people over time, to build connections with community and to hold positive assumptions about families and individuals with disability).

These principles are part of the Statement of Purpose included in the job description for the post. This stated explicitly that the Local Area Co-ordinator is there to:

- to be supportive of people and their families
- to allow and assist people and their own families to identify their own needs
- to help people determine which support services they wish to use (which may involve designing new service responses and access community resources)
- to give people and their families control over the resources to the extent they require to pursue their chosen lifestyles.

In order to fulfil this purpose, the Local Area Co-ordinator has to:

Firstly - absolutely believe that individuals and families are in the best position to know exactly what is important in their lives. The National Authority in Western Australia now uses this in its documents, talking about "...families and people being experts about their own lives".

I have a long history of running a traditional service system, with group homes and hostels and day programmes. As a government bureaucrat, it took me a while to really believe this approach could work - but it absolutely does work. I believe we need to do a better job of putting individuals and families into the driving seat, because they are the ones who really know what's important.

Secondly - give people choices and assist them to make choices. Stephen Williamson (first speaker) spoke very clearly about wanting to control the money, the people who are involved as carers, etc. It is true that not every family supported through Local Area Co-ordination wants to exercise that control, but they should have the choice

The key point here is that it is the choice that is really important. People are all really different. What might work for some people, may not work for others. You make real progress when you offer choices to people as opposed to saying ‘this is the answer’.

Thirdly- assist people to pursue their chosen lifestyle. Given that there are a million combinations of what people might be able to do, the idea of building up a vision of what they want in their life is very important. This is a life-long process, because people change all the time. People gain access to new ideas and opportunities. They meet other people. They try things out, they change, they take a little bit of this and a little of that. This is a dynamic and creative process, not a static, form-filling assessment process.

The goals of **inclusion, dignity, and empowerment** in the community permeate the model. Close personal knowledge of individuals and families in their local community is essential to achieve these goals. Community and family **self sufficiency** is also critical. Local Area Co-ordinators are working with families to jointly develop solutions that are useful to people with disabilities and useful to families.

Equally significantly, these solutions also **teach the community to accept all of its members**. A lot of the old ways of working, e.g. providing residential respite for someone to give the family a break, didn’t teach the community anything at all about including all the members of its community. Local Area Co-ordinators have developed ways of working that are good for the person, good for the family and encourage the community to learn about including all of its members.

The importance of the geographical locality base

The model is completely locality based. We have found that one Local Area Co-ordinator should work with about fifty people in their immediate neighbourhood. The approach is not disability or client specific, as are most service response systems in Britain.* Local Area Co-ordinators work with whoever is in their local area. This will of course be a range of people: young people, older people, people with learning difficulties, people with mental health issues, people with physical or sensory impairment, homeless people, some with big problems and others who are getting on with life.

This means that the same principles of self determination, capacity building and community connectedness apply to older people as well as children. It means that transition from one service system to another, as with the transition from childrens' services to adult services, is not an issue.

Why do we need this approach?

Let me explain why we need this alternative to traditional assessments by recalling a story from back in the late 1980s, when one family moved into my area. As with other "new referrals", the family were to be assessed by a Senior Social Worker or Senior Psychologist. A very experienced Social Worker when to see them and when he returned, he said to me "I met with the family and these are the things that they need..."

***Client specific services**
Health and Social Services in Britain are generally organised along client specific lines - older people, children and families, people with learning difficulties etc. The Western Australian Local Area Co-ordination model eradicates all these divisions and works with everyone. Whether the model adopted in Scotland will mirror this approach is as yet unclear, but there are concerns that the model may become restricted to one client group. For example it may be misunderstood as only being applicable to people with learning difficulties because it has been recommended in the Same As You? strategy document for people with learning difficulties.

I was confused by the list of needs. I knew the family had no relations close by and no local friends. I thought that there would have been issues relating to those types of support, but meeting people and being connected to the local community were not on the list. The Social Worker explained "I didn't ask them about that. All I asked them about were the things that we could help with".

We all know that people in formal human services typically stop asking people what they really want, because if they are not in a position to help them, they don't want to open themselves up to that distress. The more I reflect on and learn about that sort of behaviour, the more convinced I am of the need for a different approach.

New ways of providing information, advocacy and support

The Local Area Co-ordinator has to also provide information, advocacy and support. Traditionally, this was translated as the professional people giving out information about services and professional guidance. However, I and my colleagues have learned that people seem to learn an awful lot more from other people who have been through the same thing. In fact, there are some things that people can only learn from other people in the same situation.

Stephen Williamson mentioned PLAN (Planned Lifetime Advocacy Network). This organisation actively networks people who are in the same situation and facilitates them learning from and supporting one another. PLAN is about families assisting other families to think about planning for the future, to develop personal networks around the individual with the disability and to do some things in a 'family business' rather than 'government business' way.

I want to stress that there are a lot of specialist people doing a fabulous job in services. But the key thing is to work out the right relationship between specialist services and families, and recognise the things that services can't do. There are good services that can help people get the things that are important in their lives. But there are times when services get in they way.

Making real connections with the community

The Local Area Co-ordinator has to connect people to their local community, access ordinary community resources and, in the process, teach the community to include all its members.

Local Area Co-ordinators connect families to ordinary resources and involve them in the development of new projects, like school holiday programmes which do a great job of including all of the children in a family, including those who may have specific significant disabilities. This is in stark contrast to traditional responses, which would have been to set up a "special" school holiday programme to run in parallel with the real school holiday programme.

Individualised funding

In Western Australia we have been working away, trying to make services more individualised for nearly ten years now. Since 1992, all the money for Local Area Co-ordination goes to named individuals for specific, detailed supports services. This is dramatically different from traditional block funding for projects, where it is very hard to track money distributed to providers to run group services. In the old system it was difficult to calculate how much it costs to support an individual, but the money in the Local Area Co-ordination system is completely transparent.

The Local Area Co-ordinator funds a person or a family. The person or the family can decide whether the money goes to an agency to provide a service for them, or whether they manage the money themselves. Agencies tend to be used to provide trained staff. However, parents can also provide care, or they may feel the people next door could do it, or the people down the road. This level of control doesn't suit everybody. Some people feel safe about choosing their own support staff and trusting people, others don't - but they have the choice.

The Local Area Co-ordinator system in Western Australia has two different sources of funding: Direct Consumer Funding and Discretionary Monies.

Each Local Area Co-ordinator gets $8,000 from the **Discretionary Monies** fund. This enables them to make decisions, costing up to thousands of dollars, on the spot, to assist people who have urgent needs. This discretionary funding is used quite sparingly but is very important.

The **Direct Consumer Funding** scheme is more formal. People are also assisted to buy their own supports and money is provided as required. The Local Area Co-ordinator develops a funding plan, with a budget, with the person. The paperwork for this is simply a one-page agreement. This application then goes to a panel for approval and people are assisted to manage their money on an ongoing basis.

At least once a year the funding plan is reviewed to see how people are doing. It is important to note that only one in three people in the system actually use money and between 5% and 10% of all the money in the system is returned by families in any one year because they say, "I'm doing OK, I don't really need it." This is the only government budget which can count on an under spend annually due to returned funds from families. In my experience provider agencies never return funding!

The lesson here is that as soon as you show you trust families, then families start trusting you. People think that families are going to run off with the money, but the exact opposite is true. If anyone knows how it feels to struggle, it is other families. If you put money in the hands of families they take a very responsible approach to the situation.

Evaluations of the Local Area Co-ordinator model

There have been many evaluations of Local Area Co-ordination. The findings have been pretty consistent over the years:

- families find it useful, and they find the support from Local Area Co-ordinators valuable
- people feel that they have more control over their lives, and
- people are more positive about the future.

A lot of work has also been done on the training and supervision of Local Area Co-ordinators. There has also been a focus in the past few years on investing in families and family leadership training. In the early days it was thought that good staff with good training would generate lots of good ideas that would then lead to great things with families. This was only partly true. The really great things start to happen when you invest in leadership training for families and then work with them.

In the last few years we have supported a lot of activity in local areas, where individuals, families and Local Area Co-ordinators are working together, developing ideas which lead to even better connections within the community.

Our experience confirms that the money itself just buys you the same old stuff. What is really critical is the investment in thinking about what's possible. The more we bring in new ideas and bring in families and individuals who have done things in different places, the more people have a chance to see new possibilities.

I think we're learning an awful lot about what families and informal networks can do for people. This is a family I know quite well and they are very happy for me to share their story.

Carly's Story

> *"Cheryl and Dennis live in a place in the North West of Australia and they have a daughter, Carly, who has a learning disability and is now a young adult. They have always struggled; they put her in a local school to keep her life as ordinary as possible and out of the special system. They were telling me about what happened the year before she left school.*
>
> *The school was trying to be very helpful. Staff there organised a meeting about a post school options program. People came and told Cheryl and Dennis that when Carly left school, they could get her into an employment program for people with disabilities. They also talked about another program, a day community access program, where a paid person can come and take her out for coffee.*
>
> *The parents flipped big time about the idea of someone being paid to take their daughter out for coffee. They got*

loads of their friends round and had a Barbecue. They spoke about Carly and her ambitions for life and they asked, "how do people get a job in this city anyway?"

Some of the responses were:
" there is a big pearling festival called the shindu festival - get Carly involved with the organising community for the festival, that way she will get to know a lot of folks and make a lot of connections". Other friends said "get involved in the local markets because you can develop ideas about things they can sell and make".

All these ordinary folks started generating ideas about how to get a job in their city, none of which were dependent on the person receiving a disability pension.

From my point of view it was just amazing because this family, like a lot of families, decided that they didn't want to go into the disability services at all. They just wanted to do it completely differently."

ADDITIONAL INFORMATION ON LOCAL AREA CO-ORDINATION

How does Local Area Coordination work in Australia?

The Disability Services Commission website describes their work on this subject. http://www.dsc.wa.gov.au/content/faq.asp

Local Area Co-ordination leaflet text
We have also included over the page, for your information, text from the Western Australia Disabilities Services Leaflet on Local Area Co-ordination.

This leaflet also points out that more than 6,240 people in Western Australia were registered with Local Area Co-ordinators for services and support. The concept is also being adopted by the Western Australian Aboriginal Affairs Department and the majority of Australian States and Territories, as well as overseas.

WHAT IS LOCAL AREA CO-ORDINATION?

The Disability Services Commission has developed a unique program to assist and support people with disabilities and their families throughout Western Australia.

The Local Area Coordination network began in the bush as a pilot project to assist people with disabilities living in rural and remote areas. It has proved to be so successful that the network now covers the entire state.

Local Area Co-ordinators operate from local offices and work within the community to assist people with disabilities and their families and carers to plan, select and receive the support and services they need.

Currently, there are twenty-two local area coordination offices in country regions, and twenty-four offices in the metropolitan area, staffed with up to five Local Area Co-ordinators. Each LAC provides support to between forty and sixty people with disabilities, ensuring a personalised and responsive service.

The LAC operates as a service coordinator rather than a service provider. In this way, he or she helps clients to make decisions about which support and services they want and then helps them to choose who will provide those supports and services.

By being placed in communities, Local Area Co-ordinators are able to:

- get to know local people with disabilities;
- assist people to identify their own needs, choose their own supports and plan future goals;
- connect people with local community members and community groups to explore ways in which needs can be met;
- support people to approach community groups/agencies who may be able to provide needed services;
- identify with individuals, families/carers and the community, gaps in local services and help people to explore possible responses;
- help to identify grants that will enable people to purchase their own supports;
- monitor with individuals and their families the quality and quantity of services provided to local people with disabilities; and
- complement and support the services provided by other parts of the Disability Services Commission and DSC funded organisations.

DEVELOPMENTS IN CHILDREN'S SERVICES IN FIFE

Tricia Cox, Head of the Pre-school Educational Home Visiting Service in Fife closed the morning by talking through a development process their team were undergoing at present.

Why the service had to change

The aim of the Educational Home Visiting Services was to:

- support and 'be with' parents when they might otherwise feel unsupported
- help parents promote their child's development and quality of life
- provide information and help parents find the answers to questions
- help parents integrate and co-ordinate services.

When I talk about supporting families, I do not just include the nuclear family of mum, dad and children, but also the extended family and family supports such as friends, neighbours, work colleagues, and, as they are developed, circles of support.

While many professionals in the service try to achieve the above aims, they don't always succeed. All services can become uncoordinated, with professionals not knowing who else is involved, not communicating with one another, not co-ordinating appointments, and sometimes disagreeing on diagnosis and approaches to treatment, therapy and teaching interventions.

When services are uncoordinated it causes problems for families and professionals. Some families prefer to have visits co-ordinated on one day, others don't. Families have to deal with conflicting advice and the professionals have to rely on the families to tell them who else is involved.

The Educational Home Visiting Service had been concerned for many years that the system for accessing services for families of very young children with special needs was less than perfect. It was acknowledged by colleagues in health services that referrals were often made in an apparently ad hoc fashion, depending on the professionals involved and without families being fully aware of which services were available. Often assumptions would be made regarding the needs of families without them being consulted. Whilst there were examples of existing good practice in joined up working, this was often dependent on individuals and was not universal.

The process of change

Fife Primary Care NHS Trust and Fife Council had commissioned an external consultant to conduct an audit of parents' and staff views on the services provided through the Child Assessment Units and the Forth Child Development Centre. He consulted widely with parents and staff and reported back with recommendations for co-ordinated services.

A multi-agency planning group (unfortunately, without parent representation) had been set up to consider these recommendations. The model that was proposed was based on 3 Teams.

- Each child would have a Core Team, working directly with that individual family and co-ordinating the professionals who worked most closely with the family.
- A Community Team, taking referrals and co-ordinating services: there would be several community teams in local areas with representatives from the main agencies usually involved and bringing in the services - such as housing - as necessary.
- A single Management Team, taking responsibility for strategic planning and an overview. This would have a parent representative.

We are now at implementation stage. The planning group has been replaced by an implementation group of six, including senior managers from health, education and social work, and parent representation is to be sought.

There is agreement to appoint a co-ordinator for two years to set up the new system. There will be more consultation with parents and professionals over the first year to work out the details of the system, before implementing and evaluating it in the second year.

This is an unfinished story, a work in progress. The implementation group still have to 'troubleshoot' the proposals by consulting the people involved and ask for the 'ah, buts...'. That is the next step. I have heard a lot during the morning presentations which gives me cause for reflection and a re-examination of the model we are currently pursuing.

Closing discussion

During the afternoon session a group of people worked with Tricia to identify how families will be involved in developing the service. There was a strong feeling in the group that parents should have been and should now be actively involved in this development process. It was suggested that information packs for families about the new model might be useful. The independence of the key worker was questioned and the point was made that creative services need not necessarily be more expensive.

Update

By the end of April 2002 the services was not yet underway. Three parents were part of the implementation group.

WHERE NEXT? NOTES FROM WORKSHOP GROUPS

Applying the Local Area Co-ordination approach to services for children and families

This discussion group brought together parents of children who had special needs and people who worked in a range of services as managers or delivering care. The group talked about their concerns about the present system and how it could work better. From their experience, these issues also arose in services for adults who have a disability or health problem.

Issues affecting current service delivery

- **Funding:** multiple sources of funding seemed to be a serious barrier to the development of co-ordinated services. Joint budgets, like the LAC budgets which covered all people, irrespective or age, disability or need, within the locality, would work more effectively.
- **Training:** there was a need for joint training for staff to break down barriers between professional groups. This training should involve people who used services.
- **Policy:** people who used services were not involved at policy development level and it showed.
- **Service design:** involving people who used services in all levels of service design would improve service design.
- **Lack of co-ordination:** participants had experience of services not being well co-ordinated for individual families. They also knew of poor co-ordination across the services that were provided in a community, and of specialist services not linking well with the ordinary supports in a community that families use.

Could the LAC model make things better?

The Local Area Co-ordination model, with its emphasis on co-ordination, family control and forward planning, was seen as a good way to address the problems with present services. Other changes that would help the present arrangements, and also fit well with Local Area Co-ordination, included:

- looking at ways in which families and other people who use services can most usefully be part of worker recruitment panels and training schemes

- exploring options for families and people who used service kept their own records and documentation
- more opportunities for the staff who work with families to get involved in planning services - frontline staff as well as mangers, and staff from related services, not just the specialist services.

Where next?

- All local areas should look at ways to get families more involved at all stages of planning and providing services.
- Start looking at how Local Area Co-ordination can be provided in Scotland for everyone who can benefit from it - not just for adults who have a learning difficulty.

Applying the Local Area Co-ordination approach to services for older people

The people who came to this workshop included some people who are active in older people's networks. Their interest in the workshop was two-fold. One role was to help them contribute to the wider discussion in Scotland about ways to support older people in more flexible ways. Another was as members of extended families and of the wider community who had an interest in services for children.

Could the LAC model make things better?

This group were very positive that the philosophy of Local Area Co-ordination was eminently transferable to older people. Older people use a wide range of services, so co-ordination was important.

The group felt that if Local Area Co-ordination model was implemented correctly there would be better access to services and support, providing much more flexible support for individual people. This was not the same as seamless provision - the problems there lay in thinking that services can do everything.

Making this happen would require tapping into people's experience and ideas to shape the provision. The need to recreate a sense of community in some of our urban and suburban areas was seen as key to this development. There was a need to look at what is good about communities, and then to find ways to reconstruct it. The group knew of small examples where this already happened in particular projects or services, so it is possible.

They also thought that paying attention to the ways in which communities support older people would also benefit the children and their families whose stories we had heard at this workshop and other people and families whom they knew.

The group thought that, in line with the Australian Local Area Co-ordination experience, this would reduce reliance on central service provision and would strengthen the development of strong supportive communities. The structures developed to support Local Area Co-ordination would have the added benefit of also fitting in with this style of work.

Where next?

- Start thinking about how Local Area Co-ordination can be introduced to support older people. Perhaps a few areas in Scotland could try it as a pilot and then share their experience with the others.
- Start talking to older people about what aspects of communities they find supportive - now and in the past. Encourage a dialogue that involves older people and younger people about what is a supportive community.

TRAINING WORKSHOP ON LOCAL AREA CO-ORDINATION IN SCOTLAND

Erskine, April 2002

This event was the first training in Scotland on the practical implementation of Local Area Co-ordination. The participants decided that it would be helpful to have leaflets and other material about Local Area Co-ordination, and this is available from SHS Trust. We have included in this report sections from the short brochure and other feedback and ideas from people who took part in the training workshop.

SHS Trust is running a second national training course in November 2002. Family members will be encouraged to attend as members of teams including staff from local authorities and NHS Boards.

How the model is working in Scotland

In Scotland all 32 local authorities and NHS Boards have been asked to plan jointly for the introduction of Local Area Co-ordination. In May 2002, six local authorities are employing Local Area Co-ordinators.

The model will be implemented differently in different areas, but the defining features are:

- No-one is “too disabled” or “not disabled enough” to access a Local Area Co-ordinator.
- Each Local Area Co-ordinator works with 50 people/ families and works with both children and adults. If they work with too many people, they cannot support them. If they work with too few people, the Co-ordinator starts doing for the person, not doing with the person.
- Co-ordinators are there by invitation, they can not tell people what to do.
- Community development and capacity building is as important as giving people money or linking them to services.
- Prudent and flexible use of funding to enable families and individuals to create their own solutions.
- It’s local - Co-ordinators work to get to know one geographical patch and the 50 or so families in that area.

- Co-ordinators work within a focused, supportive management structure with explicit values, regular supervision and appraisal to ensure those values are being reflected in practice.

In some areas the focus on Local Areas Co-ordination is on people who have a learning difficulty, reflecting the initial scope of the 'Same As You?' document. In other areas there are now plans to extend the range of Local Area Co-ordination to all people who can benefit.

Features of Local Area Co-ordination which are essential

The participants believe it is important not to lose sight of these key features as the model is being developed across Scotland.

Local Area Co-ordination means

- getting to know individuals and their families well over time
- being invited in to help
- knowing that individuals and families are in the best position to determine their own needs, goals and plans for the future
- having a positive attitude towards and high expectations of, individuals with the label of disability and their families and the community in general
- leaving individuals and families stronger
- building the community's capacity to include every one of its members
- developing partnerships with individuals, families, other community members and agencies
- listening to individuals and families
- enabling individuals and families to use community resources (NOT just services)
- networking families and individuals with one another
- helping families access diverse sources of funding
- finding creative and inclusive solutions to problems
- providing timely and accurate information, advice and advocacy
- knowing who's who locally
- being friendly and accessible - in a local shop front or community place, rather than a local government office
- managing money creatively, effectively and prudently
- working with all ages and labels

What the advantages of Local Area Co-ordination could be in Scotland

> *"As a parent of a child with labels, we have had hundreds of questions to ask about a thousand different things, i.e. will my son go to school? how will he be supported at school? who helps support him? will he have a social life outside of school? who with? will he be safe? what happens when his schooling is over? will he have a life? will he have a home? etc etc etc.*
>
> *An LAC would be able to help our family with these, plus the hundreds of other questions we have, as they are a person who lives amongst us and lives in our circles. They are available when it suits us, they are independent of the 'system', they are a friend."*

> *"What would an LAC mean? I always say that when Douglas was born and diagnosed I expected the doorbell to ring and someone to come and give me information and support, to ask me how we were coping, to explain the strange and wonderful world that is disability. Douglas is now 11 year sold and I am still waiting for that doorbell to ring.*
>
> *Maybe now with a Local Area Co-ordinator, other parents won't have to wait and wonder if the door bell is ever going to ring."*

> *"Local Area Co-ordination is an exciting approach that enables families and individuals to live their life in a typical way in the real world."*

"A Local Area Co-ordinator would be a link to finding out what is really possible for our son and where to access it. He would really know him and therefore we could find the sort of service which would make a real difference to him and it would not necessarily be from within the traditional services.

An LAC could be doing all the things social workers want or need to do but just don't have either time or knowledge of the community, family or individual to do. We would feel connected with a professional person who really knows us and what our needs are. They could also help us identify non traditional ways of solving support needs."

"The LAC approach makes sense because it starts where people are, it builds on the strengths they've already got, and it fits in with families, rather than making families fit into someone else's idea of a good life."

"As someone who works in the system, Local Area Co-ordination has reaffirmed for me the value of inclusion in all areas of life."

" I can see this approach enabling me to support older people in doing what they want to do – stay at home, as part of their community."

"The LAC <u>is</u> the person that users and carers have wanted to assist them to obtain a good life."

"LAC could help the big service providers to work in different ways with people – be alongside the staff who are changing their roles."

> *"LAC would make the other big policy changes that are coming along be easier to put into practice. It is the thread that can link all the changes around 'client groups'."*

What would help local areas implement Local Area Co-ordination

> *"Sharing the vision with families and colleagues in my area."*
>
> *"We need to get office bases that are in the community – where people can find us."*
>
> *"There needs to be more discussion between local authorities and the NHS about how this approach can help all sorts of people and help solve the problems both organisations face."*
>
> *"I've learned a lot from talking to the parents and the other colleagues who were on this course. They are going to be an on-going source of support for those of us who are putting it into practice."*
>
> *"A proper job description for the Local Area Co-ordinators."*

What the Scottish Executive and other organisations could do to help

> *"The Scottish Executive could take the lead in getting people to work to the same structures – better guidelines"*
>
> *"Encouragement, or prompting, for the areas that still are not introducing Local Area Co-ordination, and more positive encouragement for the ones that are getting started."*
>
> *"Encourage people in local areas to think about Local Area Co-ordination beyond the scope of Same As You and people with learning difficulties."*
>
> *"Set up an evaluation for Local Area Co-ordination nationally."*

NEXT STEPS

If you are interested in contributing to the development of Local Area Coordination in your part of Scotland and wish further information you can contact us at the address below or visit our website.

Scottish Human Services Trust
1a Washington Court
Washington Lane
Edinburgh, EH11 2HA

Tel: 0131 538 7717
Text tel: 0131 4773684
Fax: 0131 538 7719
Email: general@shstrust,org,uk

www.shstrust.org.uk

Further information is also available on the Disability Commission of Western Australia's website; http://www.dsc.wa.gov.au

PARTNERS in CHANGE

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