

# **Partners in Policymaking: The first UK course**

Chris Gathercole & Lynne Elwell

## Acknowledgements

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## Summary

Partners in Policymaking is a leadership training programme for disabled adults and parents of disabled children up to school leaving age. It began in Minnesota in 1987 since when most of the United States have taken it up. The first course outside the USA was held in the NW of England from January to September 1996 attended by 29 participants from many parts of the NW.

The aim is to invest in users of services who will have the competence and confidence to work with policymakers at national and local levels.

The course takes two days a month over eight months. It is held at a hotel with an overnight stay. It describes state of the art practice. Assignments between sessions give participants opportunities to practise skills of finding information, making contact with policymakers and people who work in services, presenting their views, learning how decisions get made and how to influence them. They are provided with packs of books, articles from journals and other documentation at each session, to form the basis of their own libraries.

The main framework of the course designed in Minnesota, was used with little need for change. Major adaptations were required to the sessions on policymaking at national and local levels.

The course has been sponsored by The North West Training and Development Team, The Home Farm Trust and The National

Development Team, with funding provided by The Department of Health, HFT and NWTDT.

The course has more than fulfilled our expectations and aspirations.

The Partners in Policymaking programme translates extremely well to the British scene. We have established that there is interest among disabled adults and parents of disabled children in the course and that it is greatly appreciated by them. They have rated their experience of the course very highly, consistently reporting each session as making a significant contribution to their development.

Participants have been active in a wide variety of ways. Despite, or possibly because of, the very demanding nature of the course, participants have pursued the course with vigour and enthusiasm.

A number of lessons have been learned which will help us to improve future courses. In recruitment, we have learned that we need to work hard to attract fathers for future courses as well as participants from an Asian background. We need to recruit mentors to assist participants with limited educational backgrounds to pursue assignments.

Having established that Partners in Policymaking is an excellent programme we are exploring how to run the course each year in the NW and how to disseminate it elsewhere in Britain. Information days are being held for people from elsewhere in the country interested in the possibility of running courses in their regions. Course accreditation is being explored as a possible safeguard for quality.

## Why a new course?

People with disabilities and their families have always been the true experts on what they need and what they want in order to have positive, successful lives. Historically, however, systems and governments have dictated what people with disabilities receive, which may or may not be what is needed. People with disabilities were faced with, 'This is what we have, take it or leave it.'

A course which telescopes the experience of enlightened parents and users of services who have gone before will help develop a new generation ready to play a much more active role in deciding the future lives of themselves and their children.

It is now a requirement of health and social services that those who use services should be not only consulted but much more closely and actively involved in policymaking, (see section below on The policy context for partnership). Users of services need preparation for this role. They need to think about what good practice is and also how they can contribute to policymaking.

Users of services start out from their own experience. Many have difficulty in seeing beyond their own situation to the wider policy implications. This course helps participants to relate their personal experiences to the systemic and policy implications for service design and provision.

## Course description

### Course aims

The course aims to provide information and skills training so that people with disabilities and family members can pursue their own agendas.

The course is intended to enable participants to:

- be aware of options and possibilities in different areas of people's lives so that they are as knowledgeable as the supposed experts on state of the art thinking and practice

- contribute to policy making and implementation in wider service development, locally and nationally
- become real partners with the professionals and the policy makers
- have the confidence and competence to influence decisions about services and negotiate much more successfully when decisions are made about what is needed
- make informed decisions on what help, services and resources they need for themselves or their children
- support and guide other service users and carers
- contribute to the training of service purchasers, providers, planners and policy makers
- prepare participants for the battles ahead with much greater chances of success.

### Who is the course for?

The course is for:

- parents of children with disabilities, including learning disabilities
- adults with disabilities, including learning disabilities.

### Values

Partners in Policymaking is built on critical values relating to the inherent worth of disabled people<sup>1</sup>. The values are the underlying thread woven throughout the course.

- People with disabilities are **people first**. They are not 'the handicapped' or 'the disabled'. Using People First Language is a must - no labels.
- People with disabilities need real **friendships**, not just relationships with paid staff.
- People with disabilities are entitled to the right to free speech. The opportunity to **communicate**, in whatever form, must be available to every person with a disability.

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<sup>1</sup> From *Partners in Policymaking Co-ordinator's Handbook* 1995

- People with disabilities must be able to enjoy full **mobility** and **accessibility** that allows active participation in community life.
- People with disabilities must be assured **continuity** in their lives through families and neighbourhood connections.
- People with disabilities must be treated with **respect** and **dignity**.
- People with disabilities need to be in positions to **negotiate** to have their wants and needs met.
- People with disabilities must be able to exercise **choice** in all areas of their lives.
- People with disabilities must be able to live in the **homes** of their choices with the supports they need.
- People with disabilities must be able to enjoy the benefits of true **productivity** through employment and/or contributions as members of their communities.

## Course outline

The course started in January 1996. There was a two day, residential event once a month for eight months (excluding August). Each event started in the late morning on day one (Fridays) and finished about 3 pm on day two (Saturdays) (see Appendix 1 for the programme).

Participants learned about principles of service design and effective strategies for change through lectures, readings, small group exercises and assignments.

They gained practical experience of finding out how to influence policy making and planning: talking with purchasers, providers, planners, policy makers; writing letters; presenting the case for change; lobbying and what it takes to become an activist. They learned how decisions get made.

At the start of each session participants were given packs which included books, reports, copies of articles, information leaflets and other documentation. The eight packs provided an extensive library on which participants could draw subsequently for reference.

Topic areas of the course included:

**History** Includes history of the ways disabled people have been treated, history of services, history of the self-advocacy, parent and independent living movements. This first session provided context for the later sessions.

**Education** Benefits of including children with disabilities in mainstream schools. Outlines strategies for including disabled children.

**Whole life planning** Looking ahead and thinking about what children and adults with disabilities will need as they get older. Includes person centred planning, circles of support, supported living, what it takes to create a positive home environment community building and exploring community resources.

**Employment** Describes how people with disabilities, even substantial disabilities, can be enabled to do a job with appropriate training and support. Includes transition from school and children's services to adult life and services for adults.

**Policy development** How decisions on service provision get made at national and local levels, and how to influence them. Includes parliamentary processes, how an Act gets on the statute book and local government processes.

**Assistive technology** How technology can help mobility, communication, self-care and employment. Includes modules on positioning for people with physical disabilities for optimum functioning in education and employment. Also switches, computers and software.

**Advocacy** Developing a vision for the future, knowledge of relevant legislation, how to change policies, meeting officials, use of the media, developing alliances, community organising, advocacy organisations. This last session focuses on change agency and includes meetings procedures.

Between sessions, participants were given assignments such as: reading; making contact with key people such as their local MP, local councillor, supported employment service manager; visiting services; getting hold of policies such as the LEA Special Educational Needs policy. These assignments gave opportunities to practise finding information,

speaking to officials and learning how policy and decisions are made.

After the last session participants each did a six month project to practise these skills further.

## Staffing

The work of developing and running the course in the NW has been shared between Chris Gathercole as course organiser and Lynne Elwell as course co-ordinator. Lynne's experience as a parent of a daughter with disabilities was invaluable in bringing an understanding of the needs and situation of disabled people and family members to the running of the course. Paul Taylor acted as consultant in devising parts of the programme.

## Speakers

A variety of people were invited as speakers, facilitators, or panel members (see Appendix 2). Partners were able to meet key influential people on whose friendship and expertise they can draw in the future. Biographies of all guests were given to Partners in their information packs to assist the networking process.

Speakers were recruited who are national or international leaders in their topics.

Over a third of the guests have personal experience of services as disabled people or family members.

## History

Partners in Policymaking originated in Minnesota. It was devised by Colleen Wieck, Executive Director of the Minnesota Developmental Disabilities Council and the first programme was run in 1987. Subsequently interest grew in other States and it now operates in over 35 States. Over 4000 people have graduated across America.

The 1996 British course was the first held outside the USA.

## Preparation

Contact was made in 1994 with the originator of the course, Colleen Wieck, Executive

Director of the Minnesota Developmental Disabilities Council who made available a handbook for coordinators.

Later in 1994, Colleen ran three workshops at a conference in Manchester arranged by Peter Kinsella for the National Development Team. At the end of this conference a decision was made by the North West Training and Development Team and the National Development Team to seek funding to run a course in Britain.

In September 1995 Lynne Elwell visited Dallas, Texas and Minnesota to learn about running Partners in Policymaking. Lynne attended the first session of the Dallas course and the last session of the Minnesota course, gaining first hand experience of being a participant. She met course participants, graduates from previous courses, course coordinators and administrators, speakers and helpers. This visit gave invaluable lessons and insights into the reasons why the course is designed the way it is. It also enabled Lynne to form warm relationships with people who have subsequently been able to advise us as we developed and ran our own course.

Electronic mail has been a great aid to rapid communication for us. We have been able to send a query to American colleagues and usually get a response within a day, sometimes within the hour.

We decided that our central aim would be to run a model Partners in Policymaking course, using the framework and guidance provided in the Co-ordinator's Handbook. This would require us to adapt the course to take account of differences in legislation, and policymaking at national and local levels. However, we aimed to make any adaptations in the spirit of the originators of the Partners programme in order to retain its essence.

There have been a number of examples of innovative programmes being taken over and changed, sometimes out of all recognition. We felt that it was important for us to safeguard the essential character of the Partners programme.

We anticipated that following our first course there would be interest in running it elsewhere in the country. We therefore wanted to

accumulate experience and learn lessons that would be useful to others. In gaining that experience we aimed for the highest standards we could achieve.

## Participants

### Eligibility

The course is for disabled adults and parents of disabled children up to school leaving age. Although parents of grown up sons and daughters might get a lot out of the course, they are not included as a major aim of the course is to invest in new blood and especially young parents to become leaders of the future. This is a controversial issue as many older parents are keen to take part.

Defining disability is an important step in deciding who is eligible for the course. In America, Developmental Disability is the term which identifies the target group for Partners programmes. We do not use this term in Britain.

The focus of the work of the three sponsoring organisations is learning disabilities. However, a key feature of the Partners approach is to recognise the common issues which are of concern across the range of disabilities. The term Partners refers not only to partnership between users of services and policymakers but between people with different kinds of disabilities.

We adopted the following definition of disability in determining eligibility for the course.

A person is considered disabled who:

- has an intellectual, physical or sensory impairment, or a combination of these, which began before adulthood
- which is likely to continue for a long time, sometimes for life, and
- who may need help and support with three or more of the following activities in their daily lives:
  - \* self-care

- \* talking, listening, joining in conversations (receptive and expressive language)
- \* learning
- \* mobility
- \* making decisions about the future (self-direction)
- \* will need more than the usual support from other people in their lives (capacity for independent living)
- \* having enough money, or being able to take care of their own money (economic self-sufficiency).

Of the disabled adults on the course two thirds had learning disabilities and one third physical disabilities.

The majority of the disabled children of the parent participants had learning disabilities with many diagnoses represented.

Including disabled adults and parents on the same course may raise questions for some readers. Again this is part of the Partners philosophy to build alliances. Many parent participants on the course expressed appreciation at sharing the course with disabled adults. They felt that this was a very important part of their learning.

### Recruitment

Participants were recruited between September and November 1995. 4000 leaflets were circulated throughout the NW, and notices placed in appropriate newsletters. The course co-ordinator Lynne Elwell was invited to meetings of self-advocacy and parent groups to talk about the course and answer questions.

32 participants were selected from 51 applicants. The aim was to achieve a balance of genders; ethnic minorities; urban, suburban and rural; spread across the region; kinds of disability. We had difficulty recruiting from the Asian community. Eventually we compromised by including an Asian parent whose son is beyond childhood (he was aged 24). We also did not attract as many fathers as was hoped.

Three participants dropped out in the early sessions leaving 29 participants.

## Age

Average age of the parents was 38 years. Average age of the disabled adults was 34 years. A third of the parents had pre-school children.

Ages	Children of parents	Parents	Disabled adults
0-4 years	8		
5-9 years	7		
10-19	9		
20-29	1	3	1
30-39		11	4
40-49		7	1
50-59		2	
Total	25	23	6

**Table 1**  
**Age spread of participants and their disabled children**

## Gender

There were two men and 21 women among the parents and 3 men and 3 women among the disabled adults.

## New Blood

One of the aims of the course is to invest in new blood, people who had not been active in advocacy. Although a few had some limited experience as members of self-advocacy or parent organisations before starting the course, most had very little.

## Geographical Spread

Participants came from many diverse localities across the NW.

Bolton	1	Manchester	1
Bury	1	Oldham	1
Cumbria	1	Rochdale	1
Glossop	1	Sefton	1
Knowsley	5	Tameside	1
Lancashire	8	Wigan	5
Liverpool	1	Wirral	1
		Total:	29

**Table 2**  
**NW localities from where participants came**

In future courses in the NW it is hoped that there will be a greater focus on smaller areas. For example, it would make sense to focus separate courses on Greater Manchester, Merseyside, Cheshire and Lancashire.

## Attendance

Attendance, at 94%, has been remarkably high considering the difficulties participants have had in getting away for two days each month.

## The policy context for partnership

The Government is laying great emphasis on involving users and carers in policy development.

## Health

One of the six medium term priorities of the NHS Executive is:

‘Give greater voice and influence to users of NHS services and their carers in their own

care, the development and definition of standards set for NHS services locally and the development of NHS policy both locally and nationally.<sup>2</sup>

‘Health Authorities should have a strategic plan for, and be engaged in early, systematic and continuing communication and consultation with local people, users and carers’ groups, community health councils and other representative and voluntary groups, about plans to respond to local health needs and to developing local services. They should be able to demonstrate the impact of that consultation on their plans and how its outcome has been fed back to the local community.’<sup>3</sup>

A Department of Health initiative, *Local Voices*,<sup>4</sup> emphasised that local people need to be listened to, kept informed about issues on which their views will be sought, involved in discussions about options and constraints and informed of decisions (and the reasons for them) taken on their behalf.

## Local Authorities

Guidance to local authorities on planning services for adults with learning disabilities states that ‘Carers and user groups..... should be consulted’.<sup>5</sup>

The Community Care Act 1990 (Section 46) requires Social Service Departments of local authorities in preparing Community Care Plans to consult with, among others, voluntary organisations representing users and voluntary organisations representing carers.<sup>6</sup>

The Children Act 1989 requires Social Service Departments to have clear policies for the

inclusion of voluntary organisations in planning local services.<sup>7</sup>

## Joint Commissioning

The Department of Health guidance on joint commissioning includes as parties to joint commissioning:

‘**Users and carers.** Contributing to building a picture of need, broad strategy and options for service development through regular involvement in planning, monitoring and review activities.’<sup>8</sup>

‘User and carer involvement is a safeguard against joint commissioning becoming an inward looking bureaucratic process. They should be involved in identifying need, and providing input to monitoring and review. Commissioning authorities should be clear about the overall process, and the role of users and carers within it.’<sup>9</sup>

## Concerns of partners

Each participant on the course was selected on the basis of information provided in their application form. Some of the concerns stated in their application forms are listed below.

- I have had to fight to get help for my child which at times has been frustrating and demoralising. My son’s problems won’t go away and there are many more years of battles ahead.
- I believe it is important that professionals who work with disabled people talk to them and their parents/carers as we all have working knowledge that can assist them in making decisions about the services they provide.
- I need to become more aware of how to deal with people in authority and not be afraid to let professionals know what I think!

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<sup>2</sup> NHS Executive 1996 *Priorities and Planning Guidance for the NHS: 1997/98*.

<sup>3</sup> NHS Executive 1996 *Priorities and Planning Guidance for the NHS: 1997/98*.

<sup>4</sup> Department of Health 1992 *Local Voices* NHS ME.

<sup>5</sup> Department of Health 1992 *Social Care for Adults with Learning Disabilities (Mental Handicap)* LAC(92)15.

<sup>6</sup> Department of Health 1990 *Caring for People: Community Care in the Next Decade and Beyond: Policy Guidance* HMSO.

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<sup>7</sup> Department of Health 1991 *The Children Act 1989 Guidance and Regulations, Vol 6, Children with Disabilities* HMSO.

<sup>8</sup> Department of Health 1995 *An Introduction to Joint Commissioning* page 5.

<sup>9</sup> Department of Health 1995 *An Introduction to Joint Commissioning* page 7.

- Information pertaining to our son's future, his rights, and what is available for him is very difficult to obtain.
- Having fought this far to get the best available services for my son, I am fully aware that the fight will go on for the years ahead.
- We have become very disillusioned with the lack of communication with current services, and their continual denial of our rights as parents to have an active say in our child's future.
- I have become increasingly aware of the need for partnerships and advocacy with professionals, as important as they are, but more importantly is the need for them to listen, and hear our needs, whether adults or children.
- I want to be able to attend meetings and say clearly what I want for my son and not come away feeling I have only said a third of what I wanted.
- I am concerned at the fact that our children don't have rights. I feel that children should have the right to be educated alongside their peers.
- From the day my son was born I seemed to be fighting different agencies to make life as full and productive as possible for him. I found gaining information on what was available extremely difficult. Most information in the end came from fellow parents.
- My main concern is the lack of information on the choices you have available to both the carer and child.

## Evaluations

The course is intensive and demanding. Participants give up their valuable time. It is important to discover whether they considered the sacrifices worthwhile.

The views of course participants were sought to discover how they responded to each session. At the end of each session an evaluation form was completed by each partner. They were

asked to rate aspects of the sessions on a five point scale.

Responses indicated that Partners' reactions were positive (average 4.8) and the course consistently met their expectations (average 4.6).

Other questions concerning the detail of each session were used to give us feedback so that we could adapt the course, as we went along, to be as responsive as possible. Responses were generally very positive.

In addition, open ended questions were asked to elicit comments and suggestions. Following is a selection of comments from the eight sessions.

### **The thing I most liked about this session was:**

- Really inspired me.
- We have got 'real' life inclusion here today and we need to go out and show others what can be achieved by 'true and equal' partnership.
- Gave me an insight into my own capabilities which surprised me!
- The contacts and information offered were varied and covered a wide range of issues, the presenters made sense of very complex issues.
- The speakers without exception provided us yet again with a vast amount of information and a lot to think about.
- It was an eye opener.
- Realising that inclusion works and that it can be achieved if there are enough people - both professionals and parents who agree on inclusion working together.
- I never dared to imagine my child could be included in a mainstream educational situation.
- I thoroughly enjoyed the whole session and enjoyed the role play review.
- The personal stories were inspirational and showed that inclusion can happen!
- The enthusiasm of the guest speakers and their willingness to pass on their experiences and help.

**The session would have been better if:**

- I don't see how you can improve on a session that was interesting, informative and educational.

**In what ways will the knowledge and skills gained this weekend be useful to you?**

- This course has given me so much information and knowledge that I have gained the confidence to go out and question people at a higher level about what they are providing - how they would change and what they will do for the future and, do not feel anymore, inadequate or a feeble parent with no power.
- Learning presentation skills, which will be invaluable to me.
- Added confidence in realising that we can present our views in a way that will have impact and bring the results we desire.
- I have realised that I can't change everyone's opinions today! But how to plant seeds, water them and watch them grow.
- The information will be invaluable to myself, other parents and groups.
- It has made me very uncomfortable about my son's school which I have felt for a long time but now I want to start doing something about it.
- I was under the impression that you got your child where you were told and mainstream was just not a possibility for anyone with multiple difficulties.
- The knowledge I have gained this weekend will be extremely useful and has given so much valued information that will help me with the statementing of my child.
- I will be using the knowledge in the fight for my own child and will attempt to influence policies locally in at least one school.
- I now have the information I need to go and ask questions at both my daughter's special

and prospective mainstream school ultimately to achieve my goal, i.e., inclusion for my whole family.

- Knowledge is power - the more we get, the more power we gain.
- It has made me even more determined that inclusion is right for my daughter.
- More aware of services available and be able to pass the information to others. It has given me the interest to find out what is available in my area, what is going on and what way could be improved.
- I have the knowledge and confidence to now go out and question what is happening.
- Able to have the confidence in how to approach professionals.
- Share information with anyone willing to listen.
- I have information to pass on to others and is there for me when the time comes.

**Other comments**

- Look out world, here come the partners!
- Once again you've challenged issues, emotions, the system and us. Challenge and change is an essential part of our growth and you have given us the opportunity to grow. Thank you.
- Another brilliant weekend.
- An excellent course - very sorry that it is coming to an end.
- The Partners course has taught me a great deal.
- The general variety of partners which have been chosen for the course I feel is good.
- I feel that I've met others who have taken a first step on a very long journey, like all journeys the company makes it worthwhile.
- I cannot believe the positive outcomes the course brings about for individuals and hopefully as a group of partners ultimately will influence change.

- The information given is now my most treasured possession.
- I have found the weekend challenging and disturbing in some respects and have enjoyed meeting and getting to know other people.
- Brilliant weekend!
- When I get in touch with professionals I always now make enquiries for the whole range of disabilities instead of simply the group that my child fits into, which must be positive.
- I have left with new ideas and imagination and always share the weekend with the support group I am part of.
- All the information I've been given in the whole of the course has been great. I didn't feel that this month would be really interesting to me personally but I've been very pleasantly surprised.
- I found the session very challenging and life changing. The more I seem to find out, the more there is to find out.
- It really has opened my eyes.
- An excellent, inspiring weekend. Thank you once again!
- It has been my first experience of partaking in a structured information programme regarding disability issues and has certainly awoken my grey matter.

## Outcomes

Below is a record of some of the activities of participants during the first six months of the course.

- As a member of this Partners group I have learned more than I ever imagined, however, I do not think I am alone as Partners truly is an experience which changes your whole perspective on life, reinforcing the power that a group of people have as opposed to an individual - but you still keep your own individuality.
- I am aware that I have been able to help different people, on different matters, with a confidence which is unbeknown to me, I just know it keeps popping up to enrich my life as well as those around me.
- I am glad Partners has become a part of my life, it is a bit like learning to live again.
- Coming on to the Partners course, on receiving the application details, I had to think very hard about the time commitment, and whether I wanted or needed a course such as this. Thank goodness I did.
- I feel the last six months has not only given me a great deal of knowledge and confidence, but has been a time of personal growth and experience, as well as making some wonderful friends and allies.
- I now know that I have a right to voice my opinions. I detest writing but have recently discovered that if I feel strongly enough about something I can overcome my intense hatred of putting pen to paper and let somebody know what I think. That's amazing for me, and it's only come from the course.

## Conferences - presentations

- Given my first speech in public.
- I have spoken on 'Right from the Start' to the Community Health Care Council at their conferences in Harrogate. The presentation I gave was a parent/professional perspective.

- Guest speaker at a conference for parents and professionals from the 5 boroughs organised by all of the Parent Partnership Coordinators.
- Guest speaker and workshop leader for Contact a Family day for parents and professionals.
- Spoke to a group of dentists re-Inclusion.
- Gave a talk about the Partners course at a 'Sharing Day'.
- Spoke on inclusion at an INSET day for teachers at a local primary school.

## **Services**

### ***Education***

- I am involved with the LEA Special Needs Consultation Committee, so that I can have my voice heard before the policies are passed. As my son is now becoming involved in education, I feel this is a very important time for both of us.
- Had an interview with LEA head of special needs about inclusive education. I did this with three other partners.
- Interviewed SEN Advisor re-integration into mainstream schools for children who have severe learning difficulties and physical difficulties.
- Attended School Governors Forum - spoke about difficulties faced by our school with regard to SEN children who live out of our borough. Discovered we are not the only school with this problem. Have agreed to co-ordinate action group of Governors to address this problem.
- I have phoned, written to and interviewed Head of Special Needs educational services and Principal Psychologist to discuss policy and procedures in meeting special educational needs.
- Meeting with head teacher of special school to discuss how he is promoting inclusive education from within the system.
- I have had contact over the phone with the SENCO at the local college about the lack of provision of course and support in the colleges for people who have a learning disability, particularly communication problems.
- I talked with the SENCO at our local college to discuss why they are unable to offer any courses for people with a disability other than dyslexia.
- Had meeting with Director of Education to discuss policy on inclusive education.
- Correspondence with Director of Education and SEN officer about inclusion.
- Supported mum at a review.
- Supported mum for more integration into mainstream school which meant a meeting with the statementing officer and the Assistant Director of the LEA, which was successful and starts more integration in September.
- I have encouraged a mum to ask for more integration for her child which she has done and now is very interested in inclusive education.
- Attended review at Special School supporting parent of child in Nursery who was requesting mainstream education. Made quite good progress.
- I've attended review meetings of a Statemented child, along with other professionals, including the Area Special Needs Officer, and provided written evidence to support the full inclusion for this child in a mainstream school.

### ***Social Services***

- Made contact with Social Services re-Joint Strategy Group planning services for our area 1996-2000. Asked to join in meetings to put forward my hopes for the future.
- When I arrived home on the Saturday afternoon of the first session of Partners a report on 'The review of services to children with a disability' had arrived in the post. By Sunday morning I had read through the report and had written a letter to the social services department, commenting on the contents of the report.

- I have been in contact with social services and the library about support groups and I have received a copy of the current Joint Community Care Plan.
- I have phoned, written to and interviewed the manager of our supported employment scheme.
- Visited our local supported employment scheme.
- Volunteered myself to take part in the service users group of Social Services Department.
- Joined the social services users group to be involved in the changes currently planned for respite. Instigating inclusive leisure provision.
- Meeting with head of learning disabilities social services on transition planning. Was asked to provide information on 'transition' for the local planning group - which I did. Also I was asked to become involved in the children's planning group for learning disabilities.
- In company with other carers identified areas of concern in the local Community Charter and submitted written comments.
- Attended meeting of Joint Services Planning Group as representative of the Carers' Network (we attend in rotation).
- Attended a joint Health and Social Services strategy meeting to discuss meeting the needs of people with a learning disability in our area: 1996-2000.

### **Health**

- I have been invited to help, as a parent, improving our local Primary Health Care Service for adults with learning disabilities. My role will be one of looking at and improving what happens, health wise, when our children have left school.
- Met with Head Paediatrician re-Joint Strategy Group, answered questions on what we as parents wanted from them for the future.
- Involved in planning with our health authority of services for children with disabilities and their future.
- I have received a copy of guidelines on 'Sharing the News'.
- Trying to establish peripatetic speech therapy service. Four letters to Chief Executive of health authority. One letter and face to face meeting Chief Executive, of our health authority
- Interview with the Public Health and Research and Resource Centre, Salford University, along with other parents of children with disabilities about consumer view of services.

### **Housing**

- Letter to a Housing Association asking for their policy relating to people with disabilities and complaining about the attitude of one of their sales team.
- Letter to Housing Association asking why their homes were not accessible.
- Letter to house builders asking why they built inaccessible homes.
- Invitation by Housing Association to stand for committee supervising management of homes and ongoing development programme of new housing for people in need.

### **Children**

- Developing inclusive service in play.
- Joined the local 'under 8s forum', specifically joined to ensure that the needs and views of children with special needs and their families are heard. Already I have raised issues on inclusive leisure activities and integrated summer playschemes. The group has agreed to add weight to a campaign for integrated leisure opportunities.
- I have managed to secure funding from the National Lottery (£51,220), for a youth club for all young people, which I am starting. Although this is from the Support Group of disabled children, it is providing the opportunity for a social get together for all young people in the local community,

and not a club for disabled children. I have made contacts with quite a lot of people while collating together the information etc., for the club, which always provides an opportunity for the right message to get across People First, Inclusion for All, etc.

- Spoke to respite carers for children about inclusive play opportunities and they are currently going to receive a training package/day on inclusive play.
- I worked closely with Leisure Services Play development officer in drafting criteria for play grants, training and publicity etc. One of the criteria for obtaining a play grant was for groups to demonstrate how a child with a disability would be integrated into a play scheme and over the summer myself and the development officer will visit as many of the schemes as possible to see if this criteria is met.
- I have spoken to my son Thomas' nursery workers, about the Partners course, and what I have gained from it.
- I have been short listing candidates to be interviewed for four child care posts in the new nursery.
- I approached the Information Officer at the local Disability Information Service and suggested that someone who had knowledge of children's issues would be an asset to his organisation. They also have an in-depth information computer system called 'Inches', which holds as much information and contacts etc., to do with disability issues that they could compile. The Disability Information Officer was keen for me to share his facilities, in return he hoped I would provide information in specific areas, (largely to do with the under 16-19 years age group) which would be of practical use and to be stored on the 'Inches Information Service'. Resources were made available to me, such as stationery, postage, phone, and word processing facilities, inclusion on mail shots if required, research documents and journals etc. The aim of the Information Officer's project is to provide the most extensive disability service as possible in

our area. As I work for a support group of children with disabilities (voluntarily) I use this time with the Disability Information Service on a Wednesday as a base for the group, for any parents who need help/advice on problems they are encountering (and I have to say I have had a couple of success stories) as well as providing a service to the general public, I obviously come into contact with the associated different departments involved with children, such as Health, Education and Social Services, and have had dealings with various members of these. The information and personal experiences learnt from Partners in Policymaking could provide this service to all counties in the country, as everyone has a Disability Information Service.

- Together with three other mums liaised with the Children with Disabilities Team to set up and run an information table for parents of children with a disability as part of a large exhibition held in our local hospital. There were over twenty tables for charities and agencies and the Mayor opened the exhibition which was part of our activities for Carers Awareness Week. I also helped at an information table in Boots Store.
- A new parent group is submitting written comments on the Children's Services Charter and gaps in services which have been identified.
- I have become involved with the Register of disabled children that is being formed in our area. I am hoping to make this a true partnership. The register is to enable services i.e., health, social services and education to plan for the future.
- Have been contacted by Contact a Family with regard to services for children, as they start to set up in our area.
- Assisted SN children at youth games, the events were integrated this year. five boroughs represented. Persuaded swimming coach to visit Special School to work with children and staff improving their skills.

- Spoke out at Activity Club meeting and subsequently they changed wording on consent form for Club as previously it was very misleading as to who was responsible for our children.
- Encouraging each local play forum in our area to address the needs of children with disabilities.

### **Libraries**

- Asked libraries to buy the books I wanted, i.e., all the books I have got on the course.
- Assisted Library Service in planning and purchasing of books aimed at special needs children. All local libraries now have ordinary books (chosen by me and advisor) put to one side in Libraries exclusively for the use of SN children. I must point out that this is not obvious and you must ask. There is not a separate section saying 'SEN Books Only'. They have been very good about this.

### **Equipment**

- Visited Aids to Living. Gathered information on aids available and distributed information to others.
- Aids To Living - we were given both a welcome and information on available products, also the opportunity to test just how comfortable some of the products were.
- Visited a local company which specialised in equipment for the disabled with two other partners. My son is a wheelchair user and it affected me very strongly that he has a standard NHS wheelchair which I don't think is suitable, so I have approached the OT and he is going to take it further.

### **Media**

- I was interviewed on camera for a promotional video for Family Link (they offer short term respite for Special Needs children and their families). I have been affiliated with them for a number of years now and it was good to have the opportunity to say how good they have been and tell others.

- Interviewed for video being produced by Education dept featuring special needs provision in the borough. Giving a parent's perspective of both mainstream and special.
- Negotiated the inclusion of a disability awareness column in the Catholic Pictorial news paper which will cover a different subject each month starting in January 1997.
- Local paper published a letter I had written to them about the new supermarket trolleys for children being piloted in the local Sainsbury's store. Said how good they were for my daughter as shopping was quite difficult with a child who has learning difficulties.
- Published articles/letters to editors.
- Informed a friend who works for a local newspaper of some very positive news re: inclusion. (A little girl who spoke for the very first time in an inclusive play situation - published in the local paper).
- Spoke to representative from Scope. Fairplay and Mencap. Have maintained contact with the individuals from the groups and have been asked to write an article for Fairplay's newsletter.
- As a member of a Carers Network I was appointed Editor of the Network Newsletter which is quarterly and funded by Social Services. I am at present working on the third issue which at present is printing 750 copies.

### **Joined or set up organisations**

- Visited borough solicitor re-constitution for support **group**, had tour of council offices and chambers.
- Joined Steering Group formed by Save The Children Fund as their funding had been dramatically reduced and they could no longer operate the Toy Library. We had to arrange for someone else to take it on or to dissolve the operation and spread the resources fairly amongst users in the borough.

- I recently have formed a core group of people interested in working on the possibility of setting up an integrated summer playscheme for summer 1997.
- During a recent parent partnership day, I spoke out and called for parents to demand better services for their children and unite together to fight for them. Following this several things happened. I was approached afterwards by the chairperson of the local sub planning group: learning disabilities and invited to join the group. I have now become involved in the group, have attended my first meeting and was able to confidently participate in all discussions. When 'transition' was brought up I was able to speak to the group about good practice.
- Became Secretary of local support group for preschool SN children and their families. Wrote aims and objectives and the constitution (no-one else had any idea of what they were supposed to do). Organised AGM, empowered and enabled Chairperson.
- Joined Network 81.
- I am on the same governing body as the secretary of the local Mencap Society and have received dates of meetings and the groups that are supported by them through leaflets and information. published by the society.
- I have been appointed to be a member of the working committee for the now integrated nursery which has just been built which connects an existing primary school with a newly built special school.
- Since starting Partners I have attended Network 81, have re-applied to become a school governor, participated in workshops.
- I was elected as Deputy Chair of the Disability Action Group (DAG) run by the local council Chief Executive's Department. DAG includes officers and councillors as well as community representatives. The Deputy Chair becomes Chair in the following year.
- As Secretary of Homelife (North West) Limited, great stress, at the moment, on obtaining finance for houses. Numerous meetings, correspondence etc., with our MP, Fylde Local Authority Housing Department to raise our profile and prove the great need for schemes like ours in the locality.
- Have obtained a place on Fylde Housing Forum where we can input the needs of young disabled adults.
- I am a member of a steering committee and I was one of the panel who interviewed and appointed our Carers Advocate.
- The steering committee which set up a Carers Network has adopted a constitution and appointed a committee of which I am the Vice Chair. The Network seeks to draw together existing groups under one umbrella which focuses on the needs of the carer and therefore improves the lot of the person cared for.
- Presently a new group is being formed amongst parents of children attending my son's school. The LEA is just beginning to acknowledge that children with autism need staff with extra training to meet their needs.
- Through my involvement with the local sub planning development group, the local chair person of Mencap, who is also a member of the group, has invited me to become a member of the executive committee of Mencap.
- Invitation by local Scope to stand for committee.

### **Language and images**

- Spoke about how I thought that the symbol on the bus passes should be changed. This has now been changed thanks to our self advocacy group and Partners in Policymaking.
- Made a fellow school Governor 'think' about language following a conversation when she pointed out that her godson was 'a mongol'.
- Words are powerful weapons and Partners has given me the confidence and

information to speak out during conversation with service people, family members and friends who tend to use words like 'handicapped' , 'mong'.

- Continuously encouraging people first language.
- Trying to get Marks & Spencer to use models with disabilities - three letters so far.
- Talked about people first language to parents at Portage meeting.

### **Individual - personal/family**

- Attending Partners gave me the confidence I needed to start my son in mainstream school. The Head Teacher wasn't keen on the idea with him having severe learning difficulties, but with the advice and encouragement Partners gave me I achieved this. My son was the first child with severe learning difficulties to be accepted in our local school.
- Met with Headteachers of special and mainstream schools that my children attend re- inclusive education for my daughter. Subsequently written to Director of Education requesting full re-assessment of statement to be done in mainstream setting to get a clearer picture of her needs.
- Met with Speech Therapist on several occasions. Discussed my daughter, we disagree on a lot of things but have found a way of working together so that we all have our needs met.
- My son's assessment for the procedure of transition from children's services to adult services began at the end of last summer, I feel more confident and assertive towards the end of the assessment in asking for my son's abilities to be considered rather than his disabilities and not just steer him into the established centre.
- I attended a review for my son, on my own. After the review one of the people who was at the review said to me, I felt very proud of you, you handled the meeting very well and I liked the way you stood up for yourself, and this course has helped me do

that and to help others stand up for themselves.

- I have fought with the LEA to keep my daughter in mainstream school, I received the draft statement which was not satisfactory, so I had a meeting with the statementing officer, who could not promise me what I wanted. After writing to her after the meeting I have received a new draft statement: full time in mainstream school with extra funding from the LEA for extra support.
- I have had interviews with teacher, SENCO, and teacher with responsibilities for equal opportunities.
- Called on my extended network to support my request for a powered wheelchair for my son when we were dismissed by the service providers.
- Tried to persuade my son's OT and physiotherapist to change from a segregated to an inclusive group.
- My son is now attending an inclusive holiday care provision.
- Met with Integration Support Worker assigned to my daughter and discussed inclusion.

### **Contact with other parents**

- Made and received numerous phone calls from parents wanting support/advice covering all aspects of disability. They are too many to list here.
- Currently arranging setting up of support group for parents interested in inclusive education.
- Started a Parent Support Group.
- The first Tuesday after each Partners weekend, I meet up with a group of parents/carers to share what we have learned on the course. Hopefully, it will continue as a Parent Support Group after the course ends.
- Through what I have learned on the course and following the 'Sharing Day' I have become involved in starting up a Supported

Living Group. It is at its very early stages at the moment.

- Supported family when meeting Headteacher of Comprehensive school following an incident when their son was assaulted by a teacher.
- Name on list of people awaiting Named Persons Training.
- Trying all the time to get other parents to think positively about their children, and how it helps to use language that respects them as individuals.
- I have received information via phone and letter from the Carer's Centre.
- I have a lot of mums who now approach me for advice concerning integration and benefits.
- Encouraging parents of children with disabilities to become more informed of choice.

### **Contact with disabled people**

- Visited and interviewed resident of a group home with regard to her supported employment. Also interviewed person in charge of the local authority run home which is several doors away from where I live.
- Taught a friend's son how to fill in job application forms and helped him to meet the Disability Employment Adviser.

### **Person to person**

- Expanded my network to include people who believe in equality for all and who are prepared to work together to achieve human rights and justice for all.
- Throughout the course I have made several phone calls i.e. Education, Disability Services, Learning Disability Services, Special Schools, Libraries, DASH, other Partners. The one call that I feel uncomfortable with is one made to a group home. I was disturbed by the attitude of this lady the way she put down everything I said to her - anyway this lady may have

forgotten me but she hasn't heard the last of me.

- Phoned various other parents, CVS, MPs and councillors, social services departments, play scheme co-ordinators, health visitors, learning disability teams, speech therapist, physio, teachers, home teaching teachers, parents I have not met but have got my phone number from someone - in fact, anyone who will listen to me.
- Talked about disability in conversation e.g., family, friends, hairdresser, neighbours, financial advisor, policemen, community policemen, CVS outreach worker, church members, social workers, etc., again, anyone who will listen.
- Since starting the course I have spoken to numerous individuals about a wide range of disability issues e.g., inclusion, equal opportunities, supportive living, education, equipment, communication aids, benefits etc., and have given advice to numerous parents about statementing, advocacy, inclusive education, how to complain etc.

### **Letters**

- I have written to the Head of Special Needs, thanking him for his time and information which he had given us, using this letter as a voice to strengthen myself.
- Written many letters.
- I have written to the school, requesting information on Transition within the school, and The Brothers of Charity, I intend to write an article for the Brothers' International Newspaper.
- Wrote personal letters to friends in Canada who are teachers etc., about the Partners in Policymaking course, and Judith Snow in particular, telling them if they get an opportunity to listen to her talk - to take it.
- Letter written to local councillor with regard to threat of closure through lack of funding for a playscheme.

### **Training/Education - workshops, conferences, courses**

- Attended Inclusive Education workshop held at Scope.
- Attended Inclusion Workshop.
- I have just completed an application form for a joint initiative of Manchester University, Mencap and the Royal Schools for the Deaf (Manchester) for a course at certificate level titled 'Working with Children and Adults who have Severe or Profound Learning Disabilities and Sensory Impairments'.
- Have attended and completed a Counselling Course in basic listening skills. I see this as a useful tool in helping others and will be undertaking the next level in September.
- Currently attending training courses run by our Carers Development Worker, who is helping us identify 'who's who' in social services and what the functions of various committees are. Also key people to contact.
- Attended course run by CVS on 'Effective Meetings'. Other courses on 'letter writing' etc., to follow.
- Started a course at our local college for trainers on Disability Awareness.
- Have been accepted on a degree course - Disability and Community Studies and Applied Social Sciences.

## Church

- Sunday School classroom changes will be made to enable children to mix /be taught with their peers and consideration for a stair lift has been taken to Church Council. These changes have come about since I raised the issue of disability awareness at a Sunday School meeting.
- Letter to church eldership expressing concern of attitudes shown to people with disabilities within the church.
- Negotiated and diplomatically raised the awareness of the local clergy in regard to the way disabled children are disregarded and ignored within the catholic community. After negotiating, got my son included with the other children as an alter server.
- Meeting with church minister expressing concern at lack of inclusion of people with disabilities and discussion of people first language.
- Talk to seven people at church house group on people first language.
- Talk to Sunday school leaders about inclusion.

## Elected Representatives

- I spoke on 'Right from the Start' in the House of Commons to the All Party Disability Group of MPs and Peers as part of a Scope initiative. The recommendations were that compulsory training be given to student nurses and medical students on 'Right from the Start'. Also that money be found from health for a facilitator's post, to train, health care workers already in post.
- Went to Westminster with a Scope/NUT delegation to meet MPs about school access for disabled children.
- Wrote to MP, regarding why my LEA has not taken part in teacher training with regard to epilepsy, when a course has been designed specifically to address this important issue.
- I have written to my MP and hope to attend his surgery.
- Saw my MP about access to schools.
- I saw my local councillor. This was to see if we could get any help for my husband to claim DLA.
- Interview with MP. Reason - the FEFC were withholding vital funds from our son's college. Consequently, our MP communicated our concerns to James Paice, a minister in the Department of Education. The problem is ongoing. Our MP continues to voice our concerns.
- Meeting planned with MP in July for an update on the problem, at his request.
- In contact with my local MP - ongoing.

## Job

- Got a job. Now Development Assistant for Contact a Family in their new office. Visited CaF offices in London. Met staff, discovered who does what, how the organisation is run.
- Since undertaking the course I have been promoted to a 'paediatric community nursing sister'. A great many of the children I nurse on a daily basis have disabilities. Already my colleagues seek my advice about matters concerning children with special needs and I hope that eventually it will become a recognised part of my remit.

## Adaptations

We were able to use most of the course as it stands. However, legislation and policymaking at national and local levels in Britain are obviously different from the USA. The two sessions on national and local policymaking had to be constructed anew.

There is space in the programme to include matters of local interest. Topics in the NW which are of pressing concern are to do with support for families with pre-school disabled children.

Sharing the news with parents at the time of diagnosis of their child's impairment has been a development in the NW since 1989, an interest shared by Scope in their national campaign Right from the Start. Face to Face is a way of introducing new parents to parents who have experienced learning of their child's impairment. This scheme is being introduced in Greater Manchester currently. Inclusion for pre-school disabled children in mainstream provision is another major interest in the NW. These three topics were introduced into the course.

A minor adaptation to the course has been in the timing. We started at 11.30 am on Fridays with a half hour presentation by someone who has been on the receiving end of services as a disabled person or a parent, telling a story of their personal experience relating to the topic of the session. This helped to orientate participants to the topic of the session from the point of view of a single person. As the session

broadened out to raise systemic and policy issues participants could relate the wider picture to the life of one person as well as to their own situation.

## Lessons

The first conclusion is that the Partners in Policymaking programme translates extremely well to the British scene. We have established that there is interest among disabled adults and parents of disabled children in the course. The section on Evaluations shows the appreciation of participants for the opportunity to take part.

Despite, or possibly because of, the very demanding nature of the course, participants have pursued the course with vigour and enthusiasm. Early on in the course, participants began to emerge as activists. The section on Outcomes illustrates the range and depth of their activities.

The course has more than fulfilled our expectations and aspirations.

In recruitment, we have learned that we need to work hard to attract fathers for future courses. We will have to develop ways of gaining their interest so that we get more applications from fathers.

We will also have to work hard to attract participants from an Asian background. There are several towns in the NW with sizable Asian communities. Preparatory work will be needed to discover what are the potential barriers for them.

We were not able to give adequate support to participants whose educational experience had been limited, especially those who had difficulty reading and writing. During the sessions helpers were available to assist those who needed help with reading and writing. For a future course we would discuss with each participant, arrangements for linking up with a mentor to assist with assignments, and working through the packs of reading materials provided at each session.

## Costs

Participants were not asked to pay fees. Costs of the course venue, including overnight

accommodation and food were covered. Also costs of travel to the venue and support for family members as needed were covered.

For this course of 29 participants the cost per participant amounts to £1625. For 35 participants the cost per participant is £1512 (see appendix 3). This covers: books; participant expenses such as travelling, family support and personal assistance; speakers fees and expenses; venue and accommodation for participants, speakers, course organiser and co-ordinator and helpers; course co-ordinator's salary and expenses, printing of recruitment leaflet. Administration and course organiser's salary are paid by NWTDT and are not included in the above figure.

## Dissemination

Having established that Partners in Policymaking is an excellent programme it is clearly necessary to disseminate it elsewhere in Britain.

A major consideration in this process is to safeguard quality. Two approaches to safeguards are being pursued. The first is to identify key colleagues around the country who could take the role of patron in their localities. They would be provided with the Co-ordinator's Handbook, attend an information day to learn about the course and clarify what would be needed to get a course going. They would then, if interested, work out a strategy to raise awareness and funds, appoint a co-ordinator and oversee the development of their local course.

This approach is intended to ensure the growth of a network of colleagues who are ready to learn from each other and committed to safeguarding the essence of Partners in Policymaking. In order to begin this process information days have been held in June 1996 and September.

In thinking about who to invite we identified the following characteristics. People:

- likely to share commitment to the values of Partners in Policymaking
- with experience of running events - conferences, seminars, workshops, courses
- with experience of presenting at events
- with a good understanding of a wide range of issues concerning disability
- with a wide range of contacts for potential speakers - locally, nationally, internationally
- with good judgement to make sound decisions
- who are held in good respect by their colleagues.

We feel a duty to do what we can to ensure that Partners in Policymaking is developed as effectively as possible in Britain. We are, therefore, anxious that whoever takes responsibility to make it happen should be very capable and appropriate.

As national publicity increases, it is likely that we will be approached by people who are unknown to us who wish to start courses. With our network in place, enquirers will be able to link up with our key contacts locally rather than us attempting to vet people from a distance to see if they are suitable.

The second approach is to develop a system for accrediting courses. This would provide a mechanism whereby courses could apply to be recognised as meeting agreed standards. This approach will be agreed with Colleen Wieck as the originator of the programme. Benefits from accrediting Partners in Policymaking courses would include gaining the support of potential funders and helping to recruit applicants.

In running this first course we have developed a range of materials which may be of help to other course organisers in Britain. These materials will be made available to course co-ordinators.

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## Appendix 1 Programme

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### Session 1: History January 12-13 1996

Avant Hotel  
Windsor Road, Manchester Street,  
Oldham

#### Friday, January 12, 1996

11.00 am-11.30 am	Registration - <i>Conference Suite</i>
11.30 am-12.00 pm	Welcome <b>June Maelzer, Lynne Elwell, Chris Gathercole</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-3.00 pm	History of Services and Perceptions of Disabled People <b>Paul Taylor</b>
3.00 pm-3.30 pm	Break
3.30 pm-5.00 pm	History of Independent Living Movement <b>Dave Gibbs</b>
5.00 pm -5.30 pm	Social Time
5.30 pm-7.00 pm	Dinner
7.00 pm-8.00 pm	What is Partners in Policymaking? <b>Chris Gathercole and Lynne Elwell</b>
8.00 pm-9.00 pm	Introductions

#### Saturday, January 13, 1996

7.30 am-8.30 am	Breakfast
8.30 am-9.00 am	People First Language <b>Lynne Elwell</b>
9.00 am-11.15 am	History of the Parent Movement <b>Liz Dyer</b>
11.15 am-12.00 am	Ground Rules <b>Lynne Elwell</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-2.30 pm	History of People First Movement <b>Bridget Whittell</b> A Personal Perspective <b>Brian Jones</b>
2.30 pm-3.00 pm	Evaluations

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## Partners in Policymaking Programme

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### Session 2: Education - Inclusion and Quality February 9-10, 1996

Avant Hotel  
Windsor Road, Manchester Street,  
Oldham

#### Friday, February 9, 1996

11.00 am-11.30 am	Registration - <i>Conference Suite</i>
11.30 am-12.00 pm	Two parents' experiences <b>Pat Dolan and Sue Thomas</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-2.00 pm	Why Inclusive Education? <b>Sue Thomas and Pat Dolan</b>
2.00 pm-4.30 pm	Strategies and How to Do Inclusive Education <b>Stephanie Lorenz</b>
4.30 pm-5.45 pm	Preparation for Education Roundtable <b>Chris Gathercole</b>
5.45 pm -6.00 pm	Break/Social Time
6.00 pm-7.00 pm	Dinner
7.00 pm-9.00 pm	Roundtable with Oldham Local Education Authority panel <b>Dave Tweddle, Adviser</b> - Policy Development and Resources <b>Claire Ward</b> - Early Childhood Education, <b>Tony Brady</b> - Secondary/Transition <b>Diane Risk</b> - Statutory Assessment, Making and Maintaining Statements <b>Dorice Johnson</b> - Register of Named Persons <b>Ian McPhail</b> - Multicultural Issues.

**Saturday, February 10, 1996**

7.30 am-8.30 am	Breakfast
8.30 am-9.00 am	Video - Whose School Is It Anyway?
9.00 am-11.30 am	Statementing <b>Stephanie Lorenz</b>
11.30 am-12.00 am	A parent's experience <b>Sylvia Alty</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-2.30 pm	National and North West Perspectives on Education National: <b>Linda Jordan</b> NW: <b>Stephanie Lorenz</b>
2.30 pm-3.00 pm	Wrap-up and Evaluations

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## Partners in Policymaking Programme

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### Session 3: Supported Employment

**March 8-9, 1996**

Avant Hotel  
Windsor Road, Manchester Street,  
Oldham

#### **Friday, March 8, 1996**

11.00 am-11.30 am	Registration - <i>Conference Suite</i>
11.30 am-12.00 pm	Experiencing Supported Employment <b>Carol Tobin</b> with <b>Diana Bridge</b>
12.00pm-1.00 pm	Lunch
1.00 pm-5.00 pm	Supported Employment <b>Doug Cresswell</b> with <b>Julie Caddick</b>
5.00 pm -5.30 pm	Break/Social Time
5.30 pm-6.45 pm	Dinner
6.45 pm-9.00 pm	Speaking Up <b>Chris Gathercole</b>

#### **Saturday, March 9, 1996**

7.30 am-8.30 am	Breakfast
8.30 am-9.30 am	Change Agency <b>Chris Gathercole</b>
9.30 am-12.00 pm	Transition from School to Adult Services <b>Martin Routledge, Anne Hilton</b> and <b>Julie Stansfield</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-2.30 pm	Sharing the News and Face to Face <b>Chris Gathercole</b>
2.30 pm-3.00 pm	Wrap-Up and Evaluation

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## Partners in Policymaking Programme

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### Session 4: Whole Life Planning, Supported Living, Service Co-ordination, Building Inclusive Communities April 19-20, 1996

Avant Hotel  
Windsor Road, Manchester Street,  
Oldham

#### Friday, April 19, 1996

11.00 am-11.30 am	Registration - <i>Conference Suite</i>
11.30 am-12.00 pm	Experiencing Community Living <b>Lewis Smith</b> with <b>Lilian Nelson</b>
12.00pm-1.00 pm	Lunch
1.00 pm-5.00 pm	Personal Futures Planning, PATH, MAPS and Circles <b>Judith Snow</b> and <b>Frances Brown</b>
5.00 pm -5.30 pm	Break/Social Time
5.30 pm-6.45 pm	Dinner
6.45 pm-9.00 pm	Supported Living <b>Peter Kinsella</b> and <b>Vic Riley</b>

#### Saturday, April 20, 1996

7.30 am-8.30 am	Breakfast
8.30 am-12.00 pm	Building Inclusive Communities <b>Judith Snow</b> and <b>Frances Brown</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-2.30 pm	Service Co-ordination <b>Owen Cooper</b>
2.30 pm-3.00 pm	Evaluations

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## Partners in Policymaking Programme

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### Session 5: Legislation, and Policymaking at National Level May 10-11, 1996

Avant Hotel  
Windsor Road, Manchester Street,  
Oldham

#### Friday, May 10, 1996

11.00 am-11.30 am	Registration - <i>Conference Suite</i>
11.30 am-12.00 pm	Personal Experience of Influencing National Policy <b>Joe Steen</b>
12.00pm-1.00 pm	Lunch
1.00 pm-1.45 pm	What's Important to Know About the Legislative Process? <b>Anne Leonard</b>
1.45 pm-2.00 pm	Preparation for questions and discussion with Alf Morris <b>Paul Taylor</b>
2.00 pm-3.00 pm	Influencing Legislation and National Policy <b>Alf Morris, MP</b>
3.00 pm-3.15 pm	Break
3.15 pm-4.00 pm	The Disability Discrimination Act <b>Anne Leonard</b>
4.00 pm-5.15 pm	Scope's Experience of Influencing Legislation and National Policy <b>Anne Leonard</b>
5.00 pm -5.30 pm	Break/Social Time
5.30 pm-7.00 pm	Dinner
7.00 pm-9.00 pm	An international perspective <b>John O'Brien</b>

#### Saturday, May 11, 1996

7.30 am-8.30 am	Breakfast
8.30 am-11.30 am	Practical Lessons from Experience of Influencing at National Level <b>Philippa Russell and John O'Brien</b>
11.30 am-12.00 pm	Influencing the European Union <b>Philippa Russell</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-2.30 pm	Experience of the National Development Team at National Level <b>Margaret Flynn, and Margaret Pearson</b>
2.30 pm-3.00 pm	Evaluations

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## Partners in Policymaking Programme

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### Session 6: Physical Disabilities, Assistive Technology and Challenging Behaviour June 7-8, 1996

Avant Hotel  
Windsor Road, Manchester Street,  
Oldham

#### Friday, June 7, 1996

9.30 am-11.30 am	Exhibition of equipment - <i>Conference Suite</i>
11.00 am-11.30 am	Registration - <i>Conference Suite</i>
11.30 am-12.00 pm	Update and Assignments
12.00pm-1.00 pm	Lunch
1.00 pm-5.00 pm	Positioning for People with Physical Disabilities <b>Joan Bergman</b>
5.00 pm -5.15 pm	Photos
5.15 pm-5.30 pm	Break/Social Time
5.30 pm-7.00 pm	Dinner
7.00 pm-9.00 pm	Supporting Positive Behaviour Change <b>Herb Lovett</b>

#### Saturday, June 8, 1996

7.30 am-8.30 am	Breakfast
8.30 am-12.00 pm	Assessing Technology Needs and Demonstration of Devices <b>Jenny Taylor, Lesley Rahamin and Roger Dyer</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-2.30 pm	Aids and Appliances Services <b>Bernie Gibbens and Sue Thomas</b>
2.30 pm-3.00 pm	Wrap-Up and Evaluation

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## Partners in Policymaking Programme

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### Session 7: Policymaking at Local Level - Local Authorities and Health Authorities July 5-6, 1996

Avant Hotel  
Windsor Road, Manchester Street,  
Oldham

#### Friday, July 5, 1996

11.00 am-11.30 am	Registration - <i>Conference Suite</i>
11.30 am-12.00 pm	Personal Perspective <b>Tony McDermott</b>
12.00 pm-1.00 pm	Lunch
1.00 pm-1.30 pm	Introduction to local policymaking <b>Paul Taylor</b>
1.30 pm-1.40 pm	Introduction to voluntary agency services
1.40 pm-2.10 pm	Voluntary agencies <b>Robina Mallett</b>
2.10 pm-2.40 pm	How Local Authorities work <b>Nick Harris</b>
2.40 pm-2.50 pm	Introduction to education
2.50 pm-3.20 pm	Education <b>Dave Tweddle</b>
3.20 pm-3.40 pm	Break
3.40 pm-3.50	Introduction to Social Services
3.50 pm-4.20 pm	Social Services <b>Andy Kilpatrick</b>
4.20 pm-4.30 pm	Introduction to Health Services
4.30 pm-5.00 pm	Health Services <b>Andrea Campbell</b>
5.00 pm-5.15 pm	Photos
5.15 pm -5.30 pm	Break/Social Time
5.30 pm-7.00 pm	Dinner
7.00 pm-9.00 pm	Devising local strategies <b>Nick Harris</b>

**Saturday, July 6, 1996**

7.30 am-8.30 am	Breakfast
8.30 am-9.45 am	Revising strategies
9.45 am-10.00 am	Introduction of panel <b>Don Rowbottom</b> <b>Pat Martinez-Williams</b> <b>Godfrey Travis</b>
10.00 am-10.30am	Presentations
10.30.am-10.45 am	break
10.45 am-12.15 pm	Presentations and response from panel
12.15pm-12.30 pm	Summary and reflections <b>Paul Taylor</b>
12.30 pm-1.30 pm	Lunch
1.30 pm-2.30 pm	Projects and sharing
2.30 pm-3.00 pm	Evaluations

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## Partners in Policymaking Programme

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### Session 8: Strategies for Advocates and Self-Advocates - Community Organising September 6-7, 1996

Avant Hotel  
Windsor Road, Manchester Street,  
Oldham

#### Friday, September 6, 1996

11.00 am-11.30 am	Registration - <i>Conference Suite</i>
11.30 am-12.00 pm	Update, Assignments and Graduation Announcements
12.00pm-1.00 pm	Lunch
1.00 pm-3.00 pm	Personal Styles <b>John Loble</b>
3.00 pm-3.15 pm	Break
3.15 pm-4.45 pm	Using the Media <b>Jim Williams</b>
4.45 pm-5.30 pm	Campaigning <b>Joe Whittaker</b>
5.30 pm-7.00 pm	Dinner
7.00 pm-9.00 pm	Community Organising and Advocacy <b>Chris Gathercole</b>

#### Saturday, September 7, 1996

7.30 am-8.30 am	Breakfast
8.30 am-9.30 am	Feedback on community organising strategies
9.30 am-11.45 am	Meetings <b>Paul Taylor</b>
11.45 am-12.00 pm	Evaluations
12.00 pm-1.00 pm	lunch
1.00 pm -3.00 pm	Graduation/Reception
3.00 pm	Fond Farewells

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## Appendix 2 Speakers

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**Sylvia Alty** works as an Advocacy Development Worker in Preston; started ALPHA, a parent support group in Londridge; chairs All Children Together, a parent support group in Lancashire.

**Joan Bergman** is a physical therapist; Professor Emerita of the University of Alabama; and has served on the Board of Directors of United Cerebral Palsy Associations.

**Diana Bridge** works with Training into Employment, a supported employment agency in Oldham.

**Frances Brown** works as an independent consultant and trainer with a special interest in Person Centred Planning; is an Associate Consultant of the National Development Team.

**Tony Brady** is Head of Learning Support at a secondary school in Oldham.

**Julie Caddick** works at the City of Liverpool Community College.

**Andrea Campbell** is Director of Community Care at Sefton Health Authority.

**Owen Cooper** manages the Learning Disability Service of Oldham Social Services.

**Doug Cresswell** has a special interest in supported employment; he manages the learning disability day services for Stockport Social Services.

**Pat Dolan** was a pioneer in getting her daughter into mainstream primary and later secondary school; founded PASSPORT, a group based in Stockport to promote inclusion.

**Roger Dyer** attends his local mainstream school and has an interest in assistive technology.

**Liz Dyer** is training to be a teacher; has been active in a parent support group in Bury which she started.

**Lynne Elwell** is an independent consultant and trainer; has worked as a parent support group

co-ordinator and citizen advocacy development worker; is now Partners course Co-ordinator.

**Margaret Flynn** is a researcher; writer and Assistant Director with the NDT.

**Chris Gathercole** is a member of the North West Training and Development Team; Partners course Organiser.

**Bernie Gibbens** was a physiotherapist before becoming a manager with the Manchester Joint Learning Disability Service.

**Dave Gibbs** is a member of the Derbyshire Coalition of Disabled People and works with the Derbyshire Centre for Integrated Living.

**Nick Harris** works with Manchester Health Authority; has had wide experience of voluntary agencies; worked in welfare rights and Manchester Community Health Council; was on Manchester City Council for 15 years.

**Anne Hilton** is active in promoting inclusion in Oldham.

**Dorice Johnson** is the Parent-Partnership Co-ordinator in Oldham.

**Brian Jones** is Chair of Wigan and Leigh Free Speech, a self-advocacy group and also a board member for the National Development Team.

**Linda Jordan** was active in getting a policy of inclusion adopted in Newham, London. She subsequently became Chair of the Education Committee and was instrumental in seeing through its implementation.

**Andy Kilpatrick** is Service Co-ordinator with Knowsley Social Services Department.

**Peter Kinsella** is a Purchasing Manager with Liverpool Health Authority with a special interest in supported living.

**Anne Leonard** works at the Campaigns Department of Scope national office; is an experienced Parliamentary lobbyist; has worked on education projects, housing initiatives and campaigns around improving how parents learn that their child is disabled.

**John Lobley** works at the Practice Development Centre, Calderstones NHS Trust as a staff trainer.

**Stephanie Lorenz** is: SEN Advisor for Bury Education Authority; on the Independent Panel for Special Educational Advice (IPSEA); appointed by the Department for Education to the Special Educational Needs Tribunal; a Distance Learning Tutor to the Advanced Certificate in Education (Autism) at Birmingham University; and lectures widely on inclusion issues.

**Herb Lovett** is an independent consultant from Boston, USA, with an interest in people who are difficult to serve and autism.

**June Maelzer** is a staff trainer with Manchester City Council.

**Robina Mallett** works as Carer Support Officer with Home Farm Trust; is active in Supportive Parents for Special Children, a parent group in Bristol; is on the Advisory Group for Partners in Policymaking.

**Patricia Martinez-Williams** is a Commissioning Manager for Wigan and Bolton Health Authority; Councillor in St Helens; school governor.

**Tony McDermot** is Chair of Trafford Forum for People with Learning Disabilities; Chair of the Community Health Council and Chair of the Council for Voluntary Services in Trafford.

**Ian McPhail** is General Inspector with Oldham Local Education Authority.

**Alf Morris** is MP for Manchester (Wythenshawe); promoted the Chronically Sick and Disabled Act (1970); was Britain's first Minister for the Disabled.

**Lilian Nelson** is a manager with the Learning Disability Service of Oldham Social Services.

**John O'Brien** is an international leader, writer and teacher from Georgia, USA.

**Margaret Pearson** is Policy Consultant with the National Development Team having previously been a civil servant at the Department of Health with experience of government from the inside.

**Lesley Rahamin** is a teacher from London with a special interest in information technology.

**Vic Riley** is the Development Worker with the Federation of Local Supported Living Groups.

**Diane Risk** is Head of the Statutory Assessment Service with Oldham Local Education Authority.

**Martin Routledge** is Development Manager with the Learning Disability Service of Oldham Social Services.

**Don Rowbottom** is Community Care Development Officer with Lancashire Social Services Department.

**Philippa Russell** is Director of the Council of Disabled Children at the National Children's Bureau; advises ministers and civil servants on policy and legislation; is an Associate Director of the National Development Team.

**Lewis Smith** lives in Oldham, having lived for 51 years at Brockhall Hospital.

**Judith Snow** is an international leader in the disability movement, philosopher, writer and teacher from Toronto, Canada.

**Joe Steen** is an Assistant Director with Liverpool Social Services and active in Mencap.

**Jenny Taylor** is an independent consultant with an interest in information technology and education; and takes part in Ofsted inspections.

**Paul Taylor** is a member of the North West Training and Development Team; an associate consultant with the National Development Team; an independent consultant and trainer.

**Sue Thomas** campaigns for inclusion in education and community life; founded PASSPORT, a group based in Stockport to promote inclusion.

**Carol Tobin** has been successful in finding paid employment with the help of Oldham's Training into Employment service having previously attended a day centre for many years.

**Godfrey Travis** works with Barnardos and manages the joint service to disabled children in Salford on behalf of Social Services.

**Dave Tweddle** is an Assistant Director with Oldham Local Education Authority.

**Claire Ward** is Head of the Pre-School Special Needs Service with Oldham Local Education Authority.

**Joe Whittaker** is a Senior Lecturer at Bolton Institute for Higher Education.

**Bridget Whittell** was an advisor to Wigan and Leigh Free Speech.

**Jim Williams** is deputy editor of the Oldham Evening Chronicle.

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## Appendix 3: Costs

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The figures below are based on the costs of the 1996 course. They give an indication of the likely costs for a course for 35 participants.

Each of the figures will vary from one course to another. Participant expenses can vary considerably depending on their own and their family support needs

	£
Books	4123
Participants' expenses	2285
Hotel accommodation*	22596
Speakers' fees and expenses#	5102
Flyer#	800
Co-ordinator's fees and expenses#	18000
Total	52906
Cost per participant	1512

\* Includes: accommodation for participants, speakers, organisers and helpers, meeting rooms, audio-visual aids, and is based on overnight stay for each of the eight sessions.

# These costs do not vary with the number of participants.