

# PARTNERS IN POLICYMAKING

The way to make a  
difference

a leadership development programme

Report to the Scottish Executive  
Tuesday 23 October 2001



## ABOUT SHS

Scottish Human Services Trust (SHS) is a consultancy, training and development company specialising in the field of community care. We are independent, not for profit and values led. We believe that people of all ages and abilities have the right to the supports and services they require to enable them to participate fully in their communities.

The work we do brings us into contact with:

- individuals and families on a one to one basis
- user led groups and community organisations who want to change things at a local or national level
- staff from service providers working in the statutory, private or charitable sectors - for example: social workers, care managers, support and care staff, nurses and health associated professionals, advocates, day centre staff, supported employment workers
- policy makers at local and national government level.

As part of our work we design and run training courses, conferences and seminars. We publish articles, research papers, books and policy statements and we undertake a range of development work in fields such as advocacy, user involvement, person centred service design, and capacity building in local communities.

Much of the material and the philosophy is indebted to the work undertaken over the last 25 years by our colleagues in the UK, North America and Europe - particularly Wolf Wolfensberger, John O'Brien, Kristjana Kristiansen, Marsha Forest, Jack Pearpoint, Judith Snow, Alan Tyne and John McKnight.

At the core of all our work is a commitment to the values of inclusion - the belief that communities are healthier, stronger and better when they learn to include everyone; the belief that social exclusion is both damaging to individuals and detrimental to the community as a whole.

## CONTENT OF THIS REPORT

Introduction and background to this report

About Partners in Policymaking

The background to the programme

The course composition

The course design

The course curriculum and materials

Some stories to illustrate the kinds of changes Partners has made to people's lives

What we would like you to do to safeguard the programme

Appendix I

1999-2003 Geographical analysis of participants

Appendix II

1999-2001 List of presenters

Appendix III

1999-2001 Books, publications and videos (excluding copies of handouts and leaflets)

Appendix IV

1999-2001 List of organisations Partners graduates are involved in

Appendix V

2000-2001 Programme costs

## INTRODUCTION AND BACKGROUND TO THIS REPORT

On Friday 15 June 2001 Trevor Jones, Head of the NHS in Scotland, attended the graduation weekend of the second Partners in Policymaking course to run in Scotland. After the presentation by the Partners, Mr Jones asked SHS to organise a further presentation to the Minister for Health and other relevant Scottish Executive Ministers. He believed that what the Partners had to say would be of interest.

A presentation by Partners Graduates from the first two national programmes has been scheduled for Tuesday 23 October 2001, in Edinburgh. This report has been prepared to accompany this presentation.

This report has been produced for the attention of Scottish Executive representatives who attend the presentation on 23 October 2001 and their colleagues, who are unfortunately unable to attend. The content of the report, particularly the individual stories, are personal and confidential. This report can therefore not be reproduced for public distribution without the full prior consent of both SHS Trust and the individuals whose stories are included.

## ABOUT PARTNERS IN POLICYMAKING

Partners in Policymaking is a leadership development programme. It is designed for adults labelled disabled and parents of children labelled disabled.

The overall aim of Partners in Policymaking is to increase social inclusion and achieve social justice. It specifically aims to do this for people who are at risk of social exclusion due to labels of disability.

It achieves this aim by recruiting, educating and training the next generation of leaders. It provides these new leaders with

- a strong values framework,
- a clear and coherent analysis of why things are currently organised the way they are,
- a different and expanding vision of what's possible,
- many of the tools and skills they need to make change happen for themselves, their own families, their local communities and at a national level.

Partners in Policymaking invests in the capacity of the people who have the greatest stake in creating a better future. Partners believes in the energy and creativity of people and trains them to invent and design new solutions, for themselves and others. We know that to do this well, you need to invest in imagination and belief. You need to see the best before you can imagine better.

Most importantly, Partners brings a new energy for change to the policymaking table. The criteria for success is not "is it better than it used to be?" Rather, "is it the best we can possibly imagine?" It intends to make parents and adults with labels of disability real partners in policymaking. Partners make a contribution.

By the end of the programme Partners have had the privilege of a better education than many of the professionals they are working with. We know this because professionals tell us.

We regard Partners graduates as a national asset.

## THE BACKGROUND TO THE PROGRAMME

The programme was originally developed in 1986 in Minnesota, USA. Colleen Wieck, the course originator, was an official for the Governor's Council on Developmental Disabilities. She was acutely aware that the families who had pioneered service developments during the 1960's and 1970's were becoming less able and less willing to work for innovative change in the service system. Young disabled adults were also missing from the policymaking arenas.

Colleen has continuously and relentlessly improved the programme over the last 15 years. Partners now runs in all but 4 States in the US and some 8,000 people have graduated. England has run a number of regionally based courses and organisations in South Africa, Holland and other European countries are keen to host the programme.

The delivery of the programme is licensed and in 1996 Colleen Wieck invited SHS to run the programme in Scotland. It took 3 years to secure funding for the first national course, which ran from October 1999 through to May 2000. SHS then secured partial funding from the National Lottery Charities Board for a three-year programme, commencing September 2000 and running through to June 2003. SHS has to secure funding from other sources to meet the shortfall.

The second course graduated in June 2001 and a total of 75 graduates are now active around Scotland. Forty two new participants start the third programme in November 2001.

## THE COURSE COMPOSITION

To date we have had 281 applicants for the 122 places offered for the 3 programmes. All participants are selected on the strength of their personal statements and their references. When scoring applications we look for evidence that people are willing to work hard, take up leadership positions and use their learning for the benefit of their local communities. The level of learning support, childcare, travel costs or personal assistance required by individuals is irrelevant in the selection process.

Having short listed the strongest applications, we then structure the course to meet a number of criteria. We want the make up of the course to mirror the national population and Appendix I gives an analysis of participation from different localities to date. We aim to build up small groups of Partners in each locality.

The final course group is also engineered to reflect a composition of, on average, 30 parents and 10 adults. Twenty of these 30 parents must have children under the age of 10 years old. When selecting the adults we give priority to people under the age of 35 years and we seek to have a mixture of adults with physical impairment, sensory impairment and learning difficulties.

Of our 75 graduates, 19 have been adults with labels of disability and 56 have been parents. Of the 19 adults, 10 have been under the age of 35. Of the 56 parents, 10 have been fathers. These parents represent a total of 64 children with labels of disability and 47 of these children are under 10 years old.



## THE COURSE DESIGN

The course runs over 8 residential monthly weekends. The course is residential for many reasons:

- **Geography:** We include people from all over Scotland, from as far apart as Orkney and Shetland to Stranraer, from the Western Isles up to Inverness, from rural Aberdeenshire to central Glasgow. The participants on the programme mirror the geographic distribution of the population and this helps us keep an outward looking focus.
- **Intensity:** The Friday session runs from 11.00 am through to 9.00 pm. The Saturday session runs from 8.30 am through to 4.00 pm. Over the 8 months participants will be exposed to between 80-100 presenters. All the graduates stress the need to be able to carry on talking informally on the Friday night to debrief, to argue about the ideas and to develop their thinking.
- **Networking:** The residential nature of the course ensures that people have a safe and comfortable place to share their experiences, support one another on their individual journeys and build up strong and powerful support networks.
- **Equality:** For many adults with labels of disability, the course may be the first time they have had an opportunity to be out of residential care and spend time with other non-labelled adults, as peers. For many parents, it might be the first good night's sleep in years. The act of organising the support you need to be away is also part of the course curriculum.

## THE COURSE CURRICULUM AND MATERIALS

Over the 8 weekends we work through a comprehensive syllabus covering philosophy, history, independent advocacy, civil rights and legislation, system design theory and systems change theory.

Partners in Policymaking insists on raising expectations. The most highly regarded, innovative and challenging teachers, writers and practitioners from around the world present on the programme. They are invited to talk about best practice in inclusive education and learning, independent living and personal assistance, family support, employment, person centred planning, up to date research and independent funding alternatives. A list of presenters to date is included as Appendix II.

We combine theory with practical application, vision with technical expertise and imagination with competency based learning. Once we have helped someone work out what they want to say, we teach them how to get their message across to professionals, service systems, the media and their own families.

The programmes for the weekends, as most graduates will confirm, are intense and demanding. Participants are set monthly assignments and encouraged to start working in local groups.

Participants work their way through 8 monthly folders of handouts and, on average 40-50 books, publications, videos and training manuals. A list of publications issued to date is attached as Appendix III.

Materials are provided in the format requested by the participants. To date this has included audio tape, Braille, MP3 CDs and computer text. Signers and note takers have also provided support to the programme. People often work in teams on assignments and the second group of Partners have been systematically connected to the first group of graduates.

## SOME STORIES TO ILLUSTRATE THE KINDS OF CHANGES PARTNERS HAS MADE TO PEOPLE'S LIVES

The whole programme is currently being independently evaluated and a full report will be available by the end of November 2001. This evaluation will identify quantifiable outcomes as well as including the views of graduates on the impact of the programme.

However, in my role as Partners Co-ordinator for the last 2 years, I have been in contact with Partners on a daily basis. I can offer personal testimony about the impact of the programme on both the individuals who attend and those closest to them.

Every Partner has a story of change to tell. Each participant has made some change in their life as a result of the programme. For some this has been finding or changing employment, for others it has been changing how they or their children are supported.

People have changed where they live, how they live, who they live with and how they are supported. I would also submit that every participant has changed, or at least clarified, what they believe to be true about disability. Each has a different view of what is possible.

I know from regular telephone contact with Partners that they are also active change agents. Many are changing nurseries, classrooms and schools across Scotland. Many are either involved in local groups or have set up new groups and organisations. Many are playing key roles in local authorities working with them and advising them on policy development and service design.

Many are involved along side health, social work and educational professionals improving local service delivery. They do this by giving talks, passing on materials or by actively working with those professionals on the design and delivery of new types of services.

A number have already presented to the Parliament on a range of issues, from education to accessible ferries. As well as creating a strong network within themselves, the Partners are also active in many national and local groups. The organisations they represent are listed in Appendix IV

In this section of the report I want to include a small number of stories to just give you a flavour of the kinds of changes people have made.

PARTNERS IN POLICYMAKING  
the way to make a difference

#### 4. Support the programme financially

With an initial subsidy of £29,850 from the Scottish Executive (then Scottish Office) in 1998, SHS has managed to secure a further £350,904 in funds to run the programme on a national basis. The programme for year one cost £110,000 and the programme for year two, including a graduate programme, cost £130,000. We anticipate that the next two courses will also cost in the region of £130,000 per annum, giving us a total budget for the 4 year period of approximately £500,000. For this sum we would aim to have trained in the region of 155 graduates at a cost of just over £3,200 per person.

The costs of the programme are detailed in Appendix V. The course is free to participants. We cover the full costs of the residential stay and reimburse all travel, childcare, personal care and other support costs. We pay for all the training materials and publications and fund the conversion of many of these materials into accessible formats. We provide signers, note takers and other learning supports and we are in regular contact with all participants both during and after the programme. We reimburse presenter fees and we work to subsidise the costs of overseas speakers by arranging other events for them to deliver when they are here.

The current shortfall in the budget for the third and fourth course is in the region of £130,000 over the two years. We are intending to approach each local authority, health board and trust to seek sponsorship on an individual basis, but this is a long and time-consuming process with no guarantee of success.

We ask for the Scottish Executive's support in securing this shortfall by whatever means they have at their disposal, whether this be direct sponsorship or by commending the programme for local authority and health board support.

We would also ask the Scottish Executive to give a long term commitment to the continuation of this work. Initially this can be through dialogue with SHS Trust about ways to secure continuation funding for the existing programme once the National Lottery Charities Board funding runs out in June 2003.

5 Question your existing perception of who disabled people are and what they have to contribute

The Partners course has changed the way the participants and their families view the relationship between themselves and the world of services. This has meant that they have had to question their old patterns of behaviour and develop new ones. They are dealing with the service system in a new and creative way. The focus is on capacity, not incapacity. The tenor of the conversation is one of self respect and equality, not self doubt and indebtedness.

We know that the Scottish Executive recognise that true partnership is a two way relationship. If the Partners can develop new ways of working with the system, the system also has to develop new ways of working with people.

We ask the Executive to review the values and beliefs it holds about people with labels of disability in Scottish society. We ask the Executive to evaluate the impact these values and beliefs have on the current service design and delivery system. We need the Executive to develop a coherent and principled approach to the development of generic legislation, strategy and policy guidance which addresses the rights and needs of all citizens.

We finally ask the Executive to give serious consideration to ways in which they can promote greater opportunities for adults, families and professionals to gain the education they each need to become effective partners in policymaking for the 21st century, in the true sense.

Heather Anderson  
Partners In Policymaking Co-ordinator  
Scottish Human Services Trust

# APPENDIX I

1999-2003 Geographical analysis of participants

| Health Boards       | No of places<br>over 4 years | Local Authorities   | % pop       | Target over<br>4 years | Actual<br>1999-2000 | Actual<br>2000-2001 | Actual<br>2001-2002 | Balance*<br>2002-2003 |
|---------------------|------------------------------|---------------------|-------------|------------------------|---------------------|---------------------|---------------------|-----------------------|
| Argyll and Clyde    | 10                           | Argyll and Bute     | 2%          | 3                      | 2                   | 1                   | 2                   |                       |
|                     |                              | Renfrewshire        | 3%          | 4                      |                     | 1                   | 1                   | 2                     |
|                     |                              | Inverclyde          | 2%          | 3                      | 1                   |                     |                     | 2                     |
| Ayrshire and Arran  | 10                           | South Ayrshire      | 2%          | 3                      | 1                   | 1                   | 1                   |                       |
|                     |                              | North Ayrshire      | 3%          | 4                      | 4                   | 1                   |                     |                       |
|                     |                              | East Ayrshire       | 2%          | 3                      |                     | 1                   | 1                   | 1                     |
| Borders             | 3                            | Scottish Borders    | 2%          | 3                      |                     | 2                   | 3                   |                       |
| Dumfries & Galloway | 4                            | Dumfries & Galloway | 3%          | 4                      | 1                   | 2                   |                     | 1                     |
| Fife                | 11                           | Fife                | 7%          | 11                     |                     | 5                   | 3                   | 3                     |
| Forth Valley        | 9                            | Stirling            | 2%          | 3                      |                     | 1                   | 2                   |                       |
|                     |                              | Falkirk             | 3%          | 4                      | 2                   |                     |                     | 2                     |
|                     |                              | Clackmannanshire    | 1%          | 2                      |                     |                     | 1                   | 1                     |
| Grampian            | 17                           | Aberdeen City       | 4%          | 7                      |                     | 1                   |                     | 3                     |
|                     |                              | Aberdeenshire       | 4%          | 7                      | 2                   | 2                   | 2                   | 1                     |
|                     |                              | Moray               | 2%          | 3                      |                     |                     |                     | 3                     |
| Greater Glasgow     | 28                           | City of Glasgow     | 12%         | 19                     | 2                   | 3                   | 5                   | 5                     |
|                     |                              | East Renfrewshire   | 2%          | 3                      |                     | 2                   | 1                   |                       |
|                     |                              | East Dunbartonshire | 2%          | 3                      | 1                   | 3                   | 1                   |                       |
|                     |                              | West Dunbartonshire | 2%          | 3                      |                     | 1                   | 1                   | 1                     |
| Highland            | 7                            | Highland            | 4%          | 7                      | 2                   |                     |                     | 3                     |
| Lanarkshire         | 20                           | North Lanarkshire   | 6%          | 10                     | 2                   |                     | 3                   | 3                     |
|                     |                              | South Lanarkshire   | 6%          | 10                     | 2                   |                     | 1                   | 3                     |
| Lothian             | 25                           | Edinburgh City      | 9%          | 14                     | 8                   | 2                   | 2                   | 2                     |
|                     |                              | East Lothian        | 2%          | 3                      |                     | 1                   |                     | 2                     |
|                     |                              | Mid Lothian         | 2%          | 3                      |                     |                     |                     | 3                     |
|                     |                              | West Lothian        | 3%          | 5                      | 4                   | 3                   | 2                   |                       |
| Orkney              | 1                            | Orkney              | 0%          | 1                      |                     |                     | 2                   |                       |
| Shetland            | 1                            | Shetland            | 0%          | 1                      | 1                   |                     | 1                   |                       |
| Tayside             | 13                           | Dundee City         | 3%          | 5                      | 1                   | 2                   | 3                   |                       |
|                     |                              | Angus               | 2%          | 3                      |                     | 1                   |                     | 2                     |
|                     |                              | Perth an Kinross    | 3%          | 5                      | 1                   | 2                   | 3                   |                       |
| Western Isles       | 1                            | Western Isles       | 0%          | 1                      |                     |                     | 1                   |                       |
| <b>Totals</b>       | <b>160</b>                   |                     | <b>100%</b> | <b>160</b>             | <b>37</b>           | <b>38</b>           | <b>42</b>           | <b>43</b>             |

\*The allocation for year 4 will obviously have to be readjusted depending on the level of local authority support

## APPENDIX II

### 1999-2001 List of Presenters to Partners in Policymaking

(in order of appearance)

#### International speakers

1. Michael Kendrick, Massachusetts, USA - international writer, presenter and policy advisor in the field of social inclusion.
2. John O'Brien, Georgia, USA - international writer, researcher, presenter and policy advisor in the field of social inclusion.
3. Jan Nisbet, New Hampshire, USA - Director of the Institute on Disability/University Affiliated Program - leading author, teacher and policy advisor in field of inclusive education and natural supports in the workplace.
4. Lou and Emily Nissenbaum, Massachusetts, USA - founding members of Massachusetts Families Organising for Change, pioneers in the development of individualised family support. Also Directors of the Nemasket Group, a day support service provider.
5. Doug Watson, New Hampshire, USA - founder of the first supported living agency in Britain and veteran of policy and systems change in field of social inclusion.
6. Nancy Hansen, Canada - advisor to Statistics Canada on employment options for disabled people.
7. Judith Snow, Toronto, Canada - international writer, philosopher and campaigner for social inclusion. Key teacher on development of circles of support.
8. Colleen Wieck, Minnesota, USA - course originator, Governor's Council on Development Disability and lifelong campaigner for social inclusion.
9. Jack Pearpoint, Inclusion Press International, Toronto, Canada - leading writer and teacher in field of social inclusion and, together with Marsha Forest and John O'Brien, co-designer of person centred planning tools.
10. Carol Tashie, New Hampshire, USA - Institute on Disability/University Affiliated Programme, author, teacher and one of the first Inclusion Facilitators for school systems in New Hampshire, 10 years ago.
11. Sharon McGovern, New Hampshire, USA - Institute on Disability/University Affiliated Programme, teacher and inclusion facilitator specialising in the inclusion of children with the label of autism.

12. Enrico Barone, Pisa, Italy - parent and founding member of the Equity Group.
13. Rose Galati, Toronto, Canada - teacher, parent and tireless campaigner for school and social inclusion. Involved in development of peer support syllabus in Toronto High Schools and played lead role in establishing supported employment opportunities.

#### National speakers

1. Pete Ritchie, Edinburgh - Director of Scottish Human Services Trust, author, teacher, policy advisor and systems change analyst. Established the second supported employment agency in Britain, played key role in the implementation of the All Wales Strategy, and has spent the last 8 years writing, teaching and directing the work of SHS, the only organisation of its kind.
2. Alan Tyne, Essex - author and teacher in field of social inclusion. Played key role in hospital closure programme in England 20 years ago and founded the Campaign for Mental Handicap Education and Research Association (CMHERA), a sister organisation to CMH, which became VIA (Values into Action).
3. Lynne Elwell, Rawtenstall - Partners in Policymaking Co-ordinator, England.
4. Joe Whittaker, Bolton - lecturer and action researcher, Bolton Institute, England.
5. Jan Tyne, Essex - policy advisor on inclusive education.
6. Vic Riley, Wigan - Founding Director of the Federation of Supported Living Agencies, England.
7. Don Braisby, Clwyd, Wales - independent facilitator.
8. Monica Hunter, Edinburgh - Partners Graduate and Chairperson, People First Scotland.
9. Jaynie Mitchell, Saltcoats - Partners Graduate.

#### Scottish presenters (50 in total)

1. Anne Harkes, Edinburgh - parent and founder of the Inclusion Alliance.
2. Gillian Morbey, Glasgow - Director of Sense Scotland and parent.
3. Peter Brawley, Glasgow - Director of the Centre for Independent Living.
4. Denis Rowley, Fife - then playing key role in Gogarburn closure programme.



5. Alison Closs, Edinburgh - Moray House Institute of Education.
6. Lorraine Dilworth and Cathy Flynn, ISEA, Scotland.
7. Robin Burley, East Lothian - independent consultant on barrier free housing and previously Director of Edinvar Housing Association.
8. Julia Fitzpatrick, Edinburgh - Director of Ownership Options in Scotland.
9. Maureen Sofio, Edinburgh - independent welfare rights advisor and member of Lothian Coalition for Independent Living.
10. John Leggate, Director of Shared Care Scotland.
11. Amanda Brown, Barnardos West Lothian Family Support Team.
12. Margaret Malley, Edinburgh - author of Special Schools and Now We Are Different (People First Scotland publication).
13. Chris Jones and Jeremy Weston, SHS, on supported employment research.
14. Sylvia Crick, Edinburgh with Irene Waters and Sharon King, Inclusion Alliance.
15. Margaret Stirling and Ed Reid, Averyron Project, Hamilton, Scotland.
16. Norah Smith, Manager, Woodlands Centre, Fife.
17. Michael Evans, Employment Disability Unit and Chair of the European Federation of Supported Employment Agencies.
18. Liz Hawksford, Margaret Scott, Emma McKendrick, Playback Group, Edinburgh - on children's advocacy.
19. Marcia Ramsay, Director, Advocacy 2000, Scotland.
20. Bill Gray and Brian Rosie, Fife Disability Equality Trainers, Scotland.
21. Brian Cavanagh, Edinburgh - independent consultant and campaigner for social justice.
22. Kate Pryde, Head of Adult Provision, Falkirk Council.
23. Cindy Wallis and Donna Walker, Lomond and Argyll Primary Care NHS Trust.
24. John Payne, Community Care Implementation Unit, Scottish Executive.
25. Jimmy Black, Dundee - Scottish Federation of Housing Associations Press Officer.
26. Graham Sharrock, Edinburgh - Forum Interactive Training - acting coach.

27. Neil Todd, Education Officer, RNIB, Scotland.
28. Drew Hunter, Edinburgh - Equity Group.
29. Dorothy McDonald, Isle of Bute - Partners graduate and Director of Achievement Bute.
30. Finlay McDonald, Inverness - Partners graduate - moving out of residential care.
31. Suselle Boffey, Independent Living Quality Assurance Officer, City of Edinburgh Council.
32. Kirsten Lawrie, Sylvia Lawrie and support staff, Edinburgh - living in your own home with support.
33. Helen Chandler, Ownership Options in Scotland, Scotland.
34. Joan Murphy and Lois Cameron, AAC Research Unit, University of Stirling.
35. Sheilis Mackay, Inclusion Implementation Team, Edinburgh City Council.
36. Hector Mackenzie, Health Gain, Scottish Executive.
37. Lindsey Davey, Disability Rights Commission, Scotland.
38. Jean Bareham, Edinburgh - independent consultant on parliamentary procedures.
39. Doris Adens, Head of Strategic Policy and Performance, Scottish Borders Council.
40. Ian Kerr, Social Work Services Inspector, Scottish Executive.

SHS staff involved in design and delivery of the programme

1. Heather Anderson - co-ordinator.
2. Julie Barclay - graphic design and material production and adaptation.
3. Heather Simmons - person centred planning facilitation and weekend support.
4. Pat Black - person centred planning facilitation and presenter.
5. Andy Smith - person centred planning facilitation and presenter.
6. Jo Kennedy - person centred planning facilitation.
7. Helen Wilson - person centred planning facilitation.
8. Liz Hardy - person centred planning facilitation.
9. plus a team of SHS administrative and financial support staff.

### APPENDIX III

1999-2001 Partners in Policymaking - Books, publications and videos  
(excluding copies of handouts and leaflets)

1. Principles of Normalisation - Tyne and O'Brien, Via Publications.
2. What's really worth doing and how to do it - Judith Snow, Inclusion Press.
3. From behind the piano - Jack Pearpoint, Inclusion Press.
4. Action for Inclusion - O'Brien and Forest with Pearpoint, Snow and Hasbury, Inclusion Press.
5. People, Plans and Possibilities - SHS Trust with support from Joseph Rowntree.
6. A Little book about person centred planning - O'Brien and Lyle O'Brien, Inclusion Press.
7. Numerous extracts from SHS training packs and materials on person centred planning.
8. Circles of Friends - Robert and Martha Perske, Abingdon Press.
9. All my life's a circle - Falvey, Forest, Pearpoint and Rosenberg, Inclusion Press.
10. Skills for Inclusion - SHS Trust - tapes of programme to train new people working in field of social care.
11. Teachers are for all children - restructuring teacher education for today's diverse classrooms - University of New Hampshire.
12. Equity and Excellence newsletters - University of New Hampshire.
13. Daring to Dream - University of New Hampshire.
14. Treasures: A celebration of Inclusion - University of New Hampshire.
15. Changes in Latitudes, Changes in Attitudes: the role for the inclusion facilitator - University of New Hampshire.
16. From Special to Regular, from Ordinary to Extraordinary - University of New Hampshire.
17. Petroglyphs: the writing on the wall - University of New Hampshire.
18. Special Schools and now we are different - People First publication.
19. The Parent's Guide to Special Educational Needs - Enquire Pack.

20. Life at school and choices at 16+ - Enquire Pack.
21. Disability Equality in the Classroom: a human rights issue - Rieser and Mason, Disability Equality in Education.
22. Lives in Transition - stories from New York - Lyle, O'Brien.
23. Your Move - SHS Trust publication on independent living.
24. Crossing the Boundaries - Shared Care Scotland.
25. Extracts from Community Living: Implication for people and agencies - SHS Trust.
26. Information on the Disabled Person's Living Service.
27. Information on Glasgow Centre for Independent Living.
28. Information on Lothian Centre for Independent Living.
29. Direct Payments - the impact on choice and control for disabled people - summary findings - Witcher, Stalker, Roadberg and Jones.
30. An Easy Guide to Direct Payments - Department of Health.
31. Supported Employment in Scotland - Pete Ritchie and Kirsten Stalker, SHS Trust, (Disability Studies Seminar - Dec 99).
32. Baking Cakes at 60, young disabled people in transition- AccessAbility Lothian.
33. Making your case - Partners in Policymaking publication.
34. Extracts from Changeover training materials - SHS Trust.
35. Supported Employment for people with complex needs, choosing, getting and keeping a job - Phase 1 research findings - SHS Trust.
36. Ways to Work - SHS Trust.
37. Creating Diversity - Bruce Anderson and Margaret Andrews.
38. A good life - Al Etmanski, PLAN Canada.
39. Just say Know - Dave Hinsburger, Diverse City Press Inc.
40. Behaviour Self! - Dave Hinsburger, Diverse City Press Inc.
41. How We Do It - Policies and Procedures for the staff of personal assistants working for Judith Snow - Judith's staff team.
42. Playback Video Resource Pack - the Playback group.
43. Scottish Advocacy Video.

44. Directory of Advocacy Groups in Scotland - Advocacy 2000.
45. Summary of Scottish Health Plan - Scottish Executive.
46. Patients, People, Power - Empowerment Audit tool and video - SHS Trust.
47. Independent Advocacy - a Guide for Commissioners, Scottish Executive.
48. Extracts from Advocacy 2000 Key Ideas Kit.
49. Partners video box set - SHS Trust.
50. Getting a life; a short introductory video to person centred planning - SHS Trust.
51. Do no harm - Extract from the Careless Society - John McKnight, Basic Books.
52. Community building in Logan Square - John McKnight, Asset Based Community Development Institute, Institute for Policy Research, Northwestern University.
53. The Same as You? - Copies of summary document - Scottish Executive.

## APPENDIX IV

### 1999-2201 List of organisations Partners Graduates are involved in

1. Achievement Bute, Isle of Bute
2. Achievement of Deaf Children in Scotland
3. ADHD Support Group, Aberdeen
4. Adult Basic Education, North Ayrshire
5. Advocacy 2000, Scotland
6. Advocacy Into Action, Falkirk
7. Advocating Together, Dundee
8. AFASIC - Communication Difficulties, Scottish Branch
9. Artlink, Scotland
10. ASSIST, Scotland
11. Autism Support Group, Argyll
12. Autism Support Group, Dunblane
13. Autistic Spectrum Support Group, Fife
14. Berwick Borough Disability Forum
15. British Deaf Association, UK
16. Children with Disabilities Project Group, Dumfries and Galloway
17. COMPHI, Scottish Borders
18. Cross Party Scottish Parliamentary Group on Autistic Spectrum Disorder
19. Deaf Children's Society, East Scotland
20. Deaf Education Group, Glasgow
21. Disability Equity Trainers Group, Fife
22. Dumbartonshire Deaf Association
23. Dumfermline Advocacy Initiative
24. Dunfermline Advocacy Agency
25. Education Advocacy, West Lothian
26. Enable, Argyll & Bute
27. English Down's Syndrome Association
28. Equal Say Citizen Advocacy, Glasgow

29. Equity Group, Scotland
30. Family Futures Consortium, Scotland
31. Fife Advocacy, Kirkcaldy
32. Forth Valley Joint Learning Disabilities Strategy Group
33. Glasgow Learning Disability Initiative
34. Grampian Service Brokerage (direct payments)
35. Greater Glasgow Health Board
36. Greater Pilton Carer's Resource, Edinburgh
37. Joint Commissioning Team for Learning Difficulties, Dumfries & Galloway
38. Just Imagine, Scotland (new group to develop family support)
39. Kings Park, Special Needs School, Dundee
40. KITES (Kids inclusion through education and support), Dumbartonshire
41. Lanarkshire Advocacy Forum
42. LEAD Scotland
43. LINK support group, West Lothian
44. Lothian Autistic Society
45. MELDI, Edinburgh
46. NAA, Stirling
47. National Autistic Society, UK
48. National Autistic Society, Glasgow Issues Group
49. National Deaf Children's Society, West of Scotland
50. North and East Ayrshire LEAD
51. North Ayrshire Community Care Forum
52. North Ayrshire Access Panel
53. North Ayrshire Advocacy Service
54. North Ayrshire Community Care Joint Planning Group
55. North Lanarkshire Council Consultation Forum
56. Oasis, Perth
57. Open Minds, Perth

58. Ownership Options in Scotland
59. PAMIS, Scotland
60. Parent Forum, Dunbartonshire Council
61. Parent Network, Aberdeenshire
62. PDA contact group, Glasgow
63. People First, Edinburgh Women's Group
64. People First Scotland
65. PHAB, Scotland
66. Post 16 Working Group, Dumfries and Galloway
67. Rainbow House Special Needs Parent Support Group, North Ayrshire
68. Rhins Machars Support Group, Dumfries and Galloway
69. Scotland Yard Adventure Playground, Edinburgh
70. Scottish Down's Syndrome Association
71. Scottish Executive Implementation Group (Same as you review)
72. Scottish Executive User's and Carer's Group
73. Scottish Society of Autism
74. SEN Forum, Stirling
75. SLEEP Scotland
76. Spina Bifida, Glasgow West
77. Stepping Stones, East Dunbartonshire
78. Strathclyde Autistic Society
79. User Care Services, Irvine
80. Visually Impaired Unit, Galashiels
81. VOCAL, Edinburgh
82. West Lothian Inclusion Network
83. West Scotland Deaf Children's Society
84. Worker's Educational Association, Aberdeenshire
85. Yorkhill NHS Trust Patient Public Forum, Glasgow



## APPENDIX V

### 2000-2001 Programme Costs

| <b>Detail</b>   | <b>Total</b>      |
|---|-------------------|
| Residential costs (inc VAT)<br>(from Friday 11.00am - Saturday 4.00pm)  | 41,495.26         |
| Participant expenses (including travel, childcare,<br>personal assistance, nursing provision, signers,<br>note takers, work cover)                          | 19,988.51         |
| Books, materials, videos, adapted materials   | 9,918.28          |
| Equipment, telephone, office running costs<br>and material production   | 9,398.09          |
| Speaker fees and expenses (international speakers<br>subsidised by other events)  | 8,388.77          |
| Graduate Programme<br>(4 sessions - Michael Kendrick, Rose Gelati,<br>John McKnight, Al Etmanski and Vickie Cammack)  | 8,311.00          |
| SHS direct staff costs<br>(Co-ordinator post 3 days per week, admin<br>support 3 days per week, plus additional<br>graphic design and financial management) | 31,965.35         |
| <b>TOTAL</b>  | <b>129,465.26</b> |



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**COMMUNITY  
FUND**  
*Lottery money making a difference*

## BEING IN SCHOOL

Jannai and Hannah are identical twins. When they were born in 1993, their mum, Karen, was told they would have very different lives. When they were 5 years old, Hannah went to be educated at the local primary school. Jannai was sent to nearest special school to have "all her needs met." All of her special needs, not her ordinary needs.

Hannah never understood why her sister didn't come to school with her. In January 2001, Karen finally let Hannah have her way. Using all the knowledge, skills and courage she had gained from the Partners in Policymaking programme, Karen moved Jannai into her sister's Primary 3 class.

Jannai is now being successfully included, making friends and learning. We have a parent who is willing to teach a school about how to support her daughter. We have teachers and staff who are willing to learn, and children who don't understand what all the fuss is about.

As Karen says, "we have to remember that everyone's need for support is someone else's need to support."

## BEING AT HOME

Kyle used to live at home with his mum and go to the local primary school. However, for much of the last 4 years, he has lived in a residential special school over 60 miles away from his home. Both he and his mum, Carina, were in considerable distress because of the separation. Both were living split lives.

In 2000, with the knowledge and vision she had gained from the Partners in Policymaking programme, Carina began to dream of a different future for her and her son. She had seen inclusive education working, but Partners had introduced her to the idea of individual family support.

With additional practical assistance from the Family Futures programme, Carina designed a new family support package. She convinced the local authority to transfer their funding from a segregated, out of area placement to home based family support. This is the first package of its kind in Scotland.

In autumn 2001 Kyle finally came home. The local authority now pay for support staff to help out at home and also accompany Kyle to his local school, where he has been welcomed back with open arms. Both he and Carina are whole again.



## BEING WITH FRIENDS

Paula has two daughters, one who attends the local primary and one who visits one morning per week. The family are still negotiating with the local school to make sure that Victoria becomes a full member of that school community.

However, there is one place where Victoria fully belongs - the local Girl's Brigade Company. As a result of being on the Partners in Policymaking programme, Paula realised that her daughter never went anywhere without either her mum, her dad or her gran. She realised that she had to learn to let go and let Victoria find her friends.

Paula phoned up the local Girl's Brigade Captain and asked if Victoria could go along. The Captain said they had never had a child like Victoria before, but they would see how they got on. Victoria joined the Company in 2001 and is now fully included.

She is completely supported by the girls in the troop and the Captain says she is an asset to the company. In June 2001 she marched with her troop in the local Beltane Festival and her Explorer's Certificate is proudly on display on the mantelpiece.



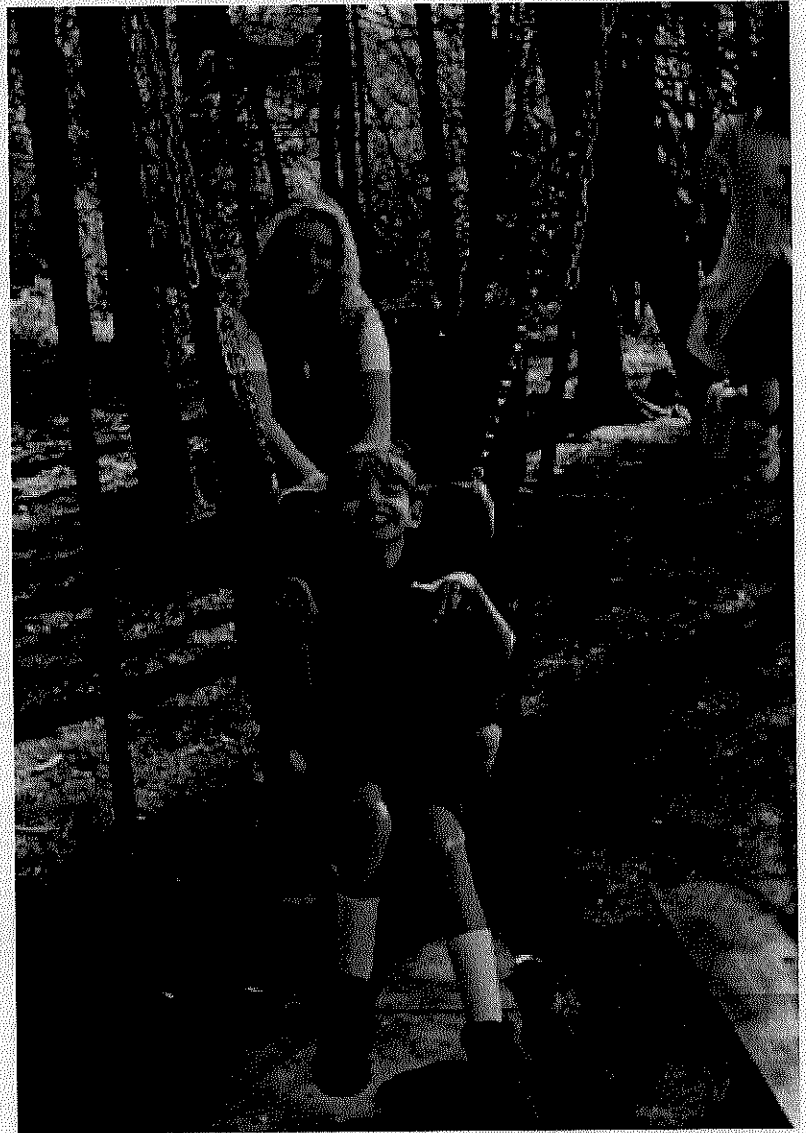
## BEING IN THE PARK

Zara was watching one of her mum's videos from the Partners course and decided to take some action. When Zara was younger, she had been trapped in a swing. Her mum had been unsuccessfully negotiating with the local Parks and Recreation Department for 4 years to get them to put an accessible swing in the local park.

With her mum's support, Zara approached the local MSP and got their support to raise the issue with the local authority. She helped choose a swing and within weeks the swing was installed. The whole solution cost £96.

Zara can now hang around with her friends at the park. And like the other kids, she sometimes has to wait her turn - because the swing is busy.



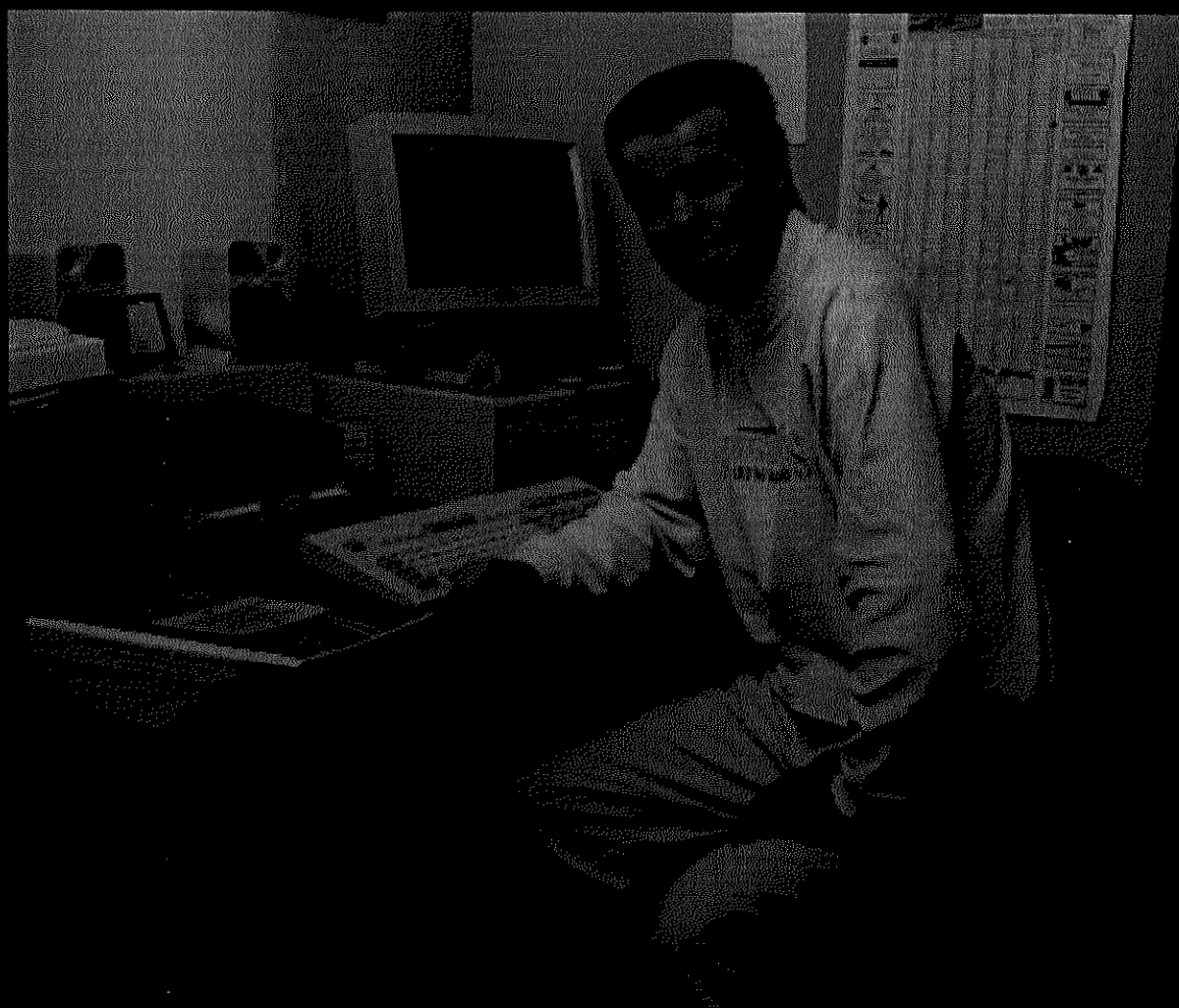


## BEING AT WORK

Steve used to be a volunteer advocacy tutor at the local college. He used to turn up and run his class and worked hard at preparing the material he used. After being on the Partners in Policymaking programme, Steve could no longer see why he didn't get paid, while everyone else did.

He approached the Head of Department and said that he wanted to be treated the same as everyone else. It was time for them to take his work as seriously as everyone else's. He awaited their response.

Now Steve is on the payroll. He is paid for his work and is a member of the department staff team - and he has doubled his class numbers!



## BEING INDEPENDENT

Fiona's husband had been her personal assistant for years. When she was on the Partners in Policymaking course she heard about direct payments and found out about employing personal assistants.

In May 2001, with support and encouragement from other Partners, Fiona managed to secure a direct payment from her local authority. She advertised for a personal assistant. She then designed the interview process and recruited her first PA. Fiona says her new-found independence is wonderful - and most importantly she feels like she has her husband back. "It is like we are on honeymoon again!"

Fiona is now starting her University career.



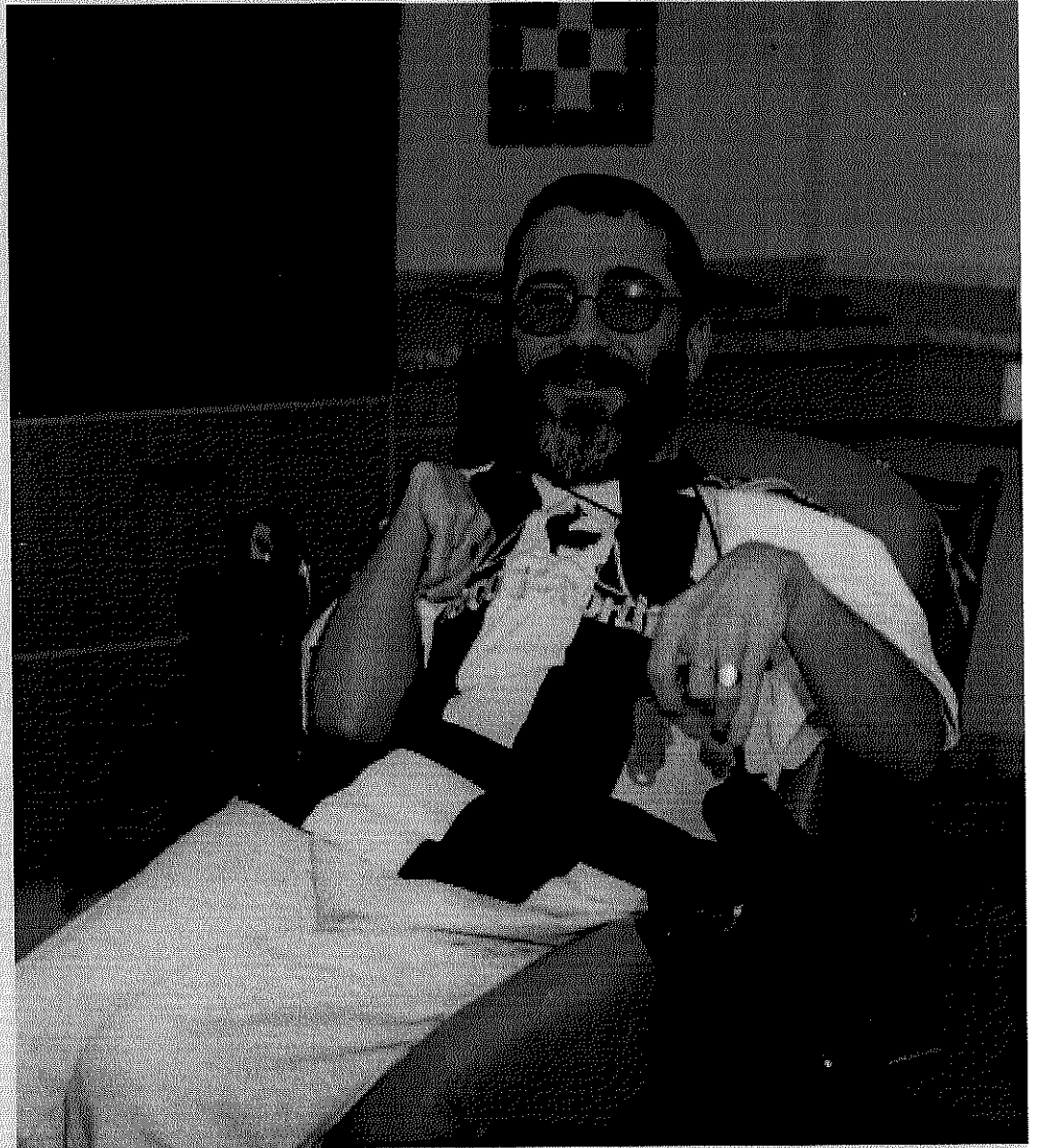
## BEING YOUR OWN PERSON

For 27 years of his life, Finlay has lived in residential care, often with 20 or more people. When he was on the Partners in Policymaking course, Finlay began to believe he could have his own place and employ his own support staff.

With the network of support provided by the Partners, Finlay has worked away on this dream. In November this year Finlay moves into his own new house in Inverness. He has taught the local authority about individual support packages and he is in the process of recruiting his own staff.

As someone in his planning meetings said, "you and Nelson Mandela have served the same time - and your freedom is as important!"





## WHAT WE WOULD LIKE YOU TO DO TO SAFEGUARD THE PROGRAMME

### 1. Recognise the importance of leadership development

Over the last 8 years SHS have invited many visitors from the States, Canada, Europe and Australia to Scotland to expose people to new ideas and ways of working. We always ask these people what they think makes the greatest difference in the struggle for greater social inclusion for people with labels of disability. They always tell us it is family or consumer leadership training.

As an organisation totally committed to increasing social inclusion, SHS can confirm that there have been more significant changes in the last couple of years than the previous five years. We, in part, attribute this increase to our capacity building approaches in Partners in Policymaking, Family Futures, Allies in Change and Partners in Change.

We now have 75 teachers around Scotland directly changing the lives and beliefs of the people around them. Things we, as an organisation, only dreamed about happening are now happening on a daily basis.

We know that the Executive are committed to greater public involvement and consultation. We know that the Parliament is committed to the principles of social inclusion and social justice.

We would therefore ask that the Scottish Executive publicly endorse the work the Partners are doing and encourage their involvement in public life. We also ask that the Executive publically recognise the importance of ongoing leadership development.

### 2. Validate the quality of the programme

Investing in the people who have the greatest stake in the quality of life for people with labels of disability improving may now seem obvious. Doing this on a national scale in a systematic way is hugely powerful.

We know that people will always say that you can do this cheaper, faster and smaller. Yes, of course you can. But it won't be Partners, it can't be called Partners and it won't deliver the same outcomes. The system outputs mirror the system inputs.

We know that the programme is 8 months long and over 8 residential weekends. This is because, over 15 years, this has proven to be the most



effective and efficient way of producing the changes we are seeing. People need that length of time to get through the material and see the changes happening in their own lives.

We know that we have a packed syllabus and we know that the participants need all of it. For example, parents who have 4 year olds need to know about the employment piece of the jigsaw and the adults need to work with parents on the education piece. Partners need to see the big picture. They need to think through how a decision at one point can impact on a life path.

We know that parents and adults need to listen to one another and work together. We know that crossing the usual disability boundaries and not being impairment specific is hugely liberating. We know that the basic principles of independent advocacy and generic, civil rights based legislation affects everything. We know that once you have this information, you need training to help you communicate it successfully to others.

We ask the Scottish Executive to publicly endorse the scale and quality of the programme.

### 3. Commit to the Graduate programme

As part of the National Lottery Charities Board funding for the current 3 year programme, we have nominal funding to run a graduate programme. We know that once Graduates have completed the programme, the real work starts. Many are recruited onto committees, panels, working groups. Many are inundated with requests for talks and presentations. Some are asked to undertake staff training, produce policy documents and evaluate strategic plans. This is generally unpaid work in their own time.

At this point Graduates are very vulnerable. They are often working on personal changes and they have lost the monthly direct support of the Partners course. We believe it is essential that we continue to invest in these people by continuing to offer training and support. We believe a combination of content specific training sessions and capacity development workshops is necessary to ensure that the initial investment is not lost.

People are also keen to be regularly contacted by phone, to receive news updates from other partners and to continue to have opportunities to gather and simply learn from one another in a structured way.

We ask the Scottish Executive to consider sponsoring an ongoing graduate programme.