



Community
Living
Development
Team

INFORMATION EXCHANGE ON **SELF-ADVOCACY** AND **USER PARTICIPATION**

Services to people with learning difficulties



No. 4

NOVEMBER 1992

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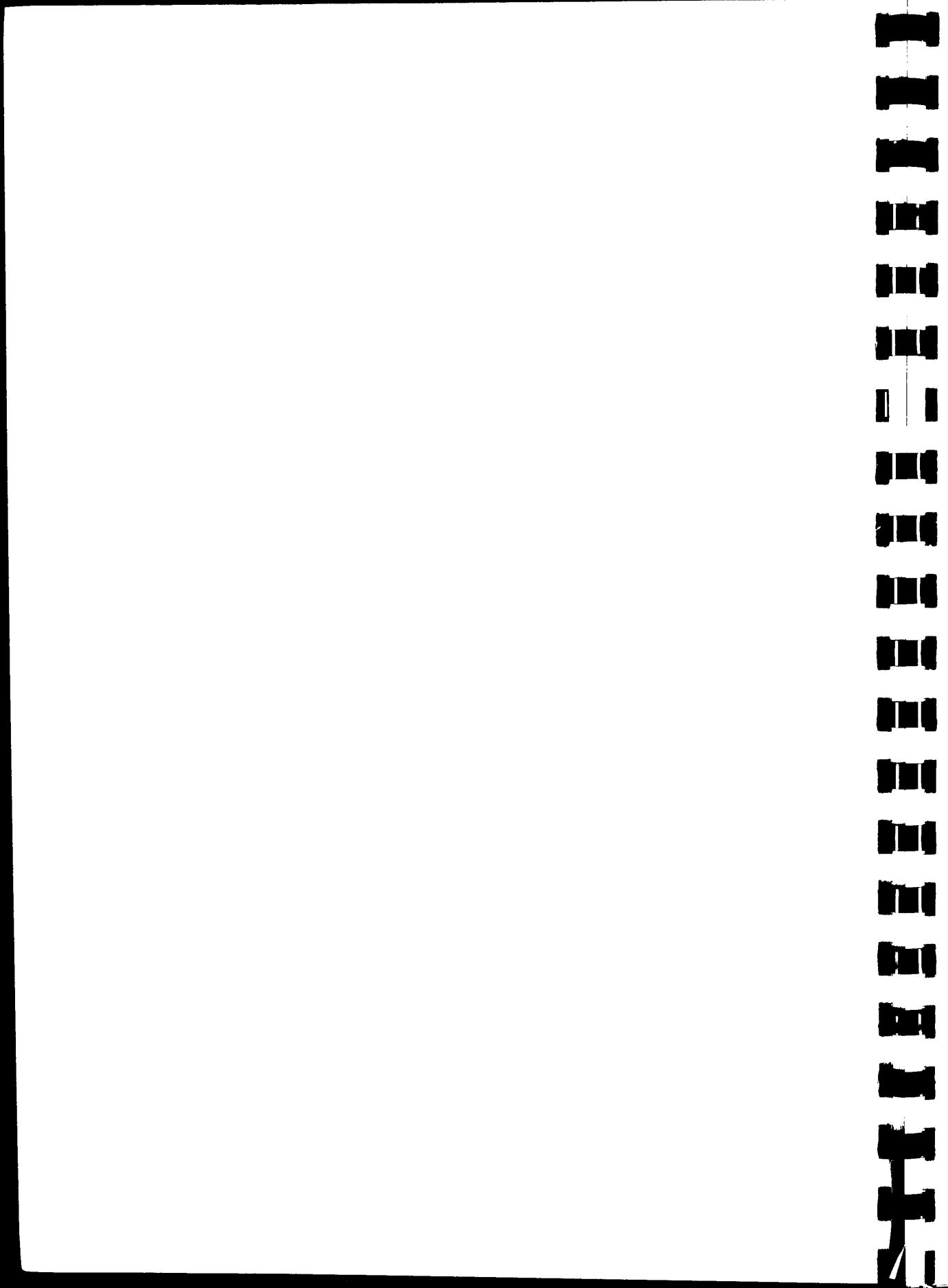
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EDITORIAL

Once again, we very much appreciate receiving readers' contributions, particularly as it is clear that the topic for this issue - conflict of interest - was not necessarily easy to write about and some people with stories to tell were finding it difficult to decide whether to make them public. The stories illustrate a range of situations which are likely to confront both people with learning difficulties and their supporters.

Although conflict can be seen to have its positive side - for example, as a sign of growth in a group or organisation - it can be very tough for the people concerned at the particular time of conflict. It emphasises again the great need there is for people to have support - particularly the opportunity to share experiences informally with people in similar circumstances. To facilitate these opportunities a little, we publish in this issue a list of people who are on the information exchange network -arranged by county to help you get in touch with people nearest to you. If people in the London area would find occasional meetings helpful, Annette McDonald (see her story this issue) is offering to be a contact point in Southwark and I would be pleased to hear from people north of the river who would find it useful to meet at the King's Fund Centre.

If any readers have other ideas about how we might strengthen support please get in touch.

NEXT ISSUE

Consulting users about community care plans

This is a subject on many people's minds as April 1993 approaches. Most authorities have already undertaken a 'first round' of consultation though reports indicate a wide variation in how seriously and thoughtfully the process was undertaken. What is happening in the 'second round' for people with learning difficulties in your area? Please send us your experiences -whether it is a story of consultation completed or one which is still being planned.

Involving users in Management Committees

People with learning difficulties are now being invited to join a wide variety of management groups and a number of readers have asked for more information. So much has been said and written about this, that many people will have some pretty good ideas about how people can be involved effectively - in theory anyway. But what happens in practice? What has worked well in your area and why? What are the barriers?

Please send in your experiences on these two topics by **Friday 26th February 1992**. The enclosed questionnaires are intended only as a framework or guide for your thoughts. If you want to tell the story in a different way please do so.

Andrea Whittaker
November, 1992

Address update

Please use the enclosed contact list to check we have your correct address and let us know if any changes should be made

CHANGING THE NAME

Breakaway's
Contact: Gwen Baker, Valerie Parsons, Fairways Day Centre,
Knowle Green, Staines, Middlesex. Tel: 0784-450211

What was the situation?

We wanted to change the name client to student.

When did conflict of interest start to arise?

When we did a survey to see what other people thought.

How did you go about tackling the issue?

A member looked up addresses of other day centres.

Sent survey to everyone in all Surrey Day Centres and asked them to send survey on to Director of Social Services.

Sent letter to Director of Social Services telling him about our survey and about wanting to change our name.

Director of Social Services wrote to us and invited us to his office for tea.

Went to tea at Director of Social Services offices. Talked to him about not liking the name "client". He said that in future we could be called what we liked.

How far have you resolved the conflict?

We are now called students.

What were the difficulties?

Problems with staff not wanting change. Arguments with advisor and other staff about this issue. Advisor picked on - so were members.

What were the successes?

We kept going and ignored sarcastic remarks.

Is there anything you would have done differently?

No

PRINCIPLES v. PRACTICE

Brian Didsbury Users Committee

Contact: Harold Roberts, Brian Didsbury Centre, Didsbury Close, East Ham, London, E6. Tel: 081-552-8948.

What was the situation?

Our committee had no money of its own. If we needed money we had to ask Chris who looked after the Centres Amenities Fund. We decided to raise our own cash.

We belong to People First and do not like to be called mentally handicapped.

When did conflict of interest start to arise?

Some raffle tickets came from Mencap. We could keep half the money raised for ourselves. The prizes were very good and the tickets easy to sell. But Mencap means mentally handicapped.

How did you go about tackling the issue?

We talked about this at the Users Committee and we decided to sell the tickets because we need the money and Mencap does a lot of good work.

We wrote to Mencap to say we didn't like its name. (We had written before about Little Stephen.)

We are selling the tickets now.

We will go on trying to get Mencap to change its name.

How far have you resolved the conflict?

We haven't changed Mencap but we do not feel guilty about the money.

What were the difficulties?

Getting some people to buy the tickets because of the name.

What were the successes?

We will get our own petty cash.

Is there anything you would have done differently?

No

* * * *

PAID SELF-ADVOCACY WORKERS NOT EMPLOYED BY THE GROUP

Southwark Unity

Contact: Annette McDonald, c/o People First, Instrument House, 207-215
King's Cross Road, London, WC1X 9DB
Tel: 071-713-6400.

What was the situation?

My conflict of interest is one experienced by most paid self-advocacy workers who are not employed by a group/organisation of people who have learning difficulties: that of supporting, enabling and facilitating fully the views, ideas and actions of the group when it is in conflict with the directions of the employers. A particularly no-win situation which results in:

- a) losing the trust, interest and respect of the group by building up their aspirations based on your support of their actions, then being unable to carry it out fully;
or
- b) endangering your personal financial position and employment by entering into direct conflict with your employers; further resulting in grievance, or disciplinary action, resignation or dismissal.

I have knowledge of both of these situations happening in employment projects.

When did conflict of interest start to arise?

Self-advocacy development work, based on the practices and beliefs of People First is the facilitation of self awareness and understanding of people who have learning difficulties about themselves, their rights, responsibilities and capability to have their own voice and be listened to; to influence, comment on and change their service provision, their lives and the attitudes and awareness of people around them. After much discussion with the group, it was decided that to be able to do this the group members must have control to decide how their funding was spent and the freedom to tell their worker what to do. At this point political, financial and employment agendas entered the picture:

- a) It is politically correct to support fully the spirit of self-advocacy, but do service providers really want their users to be empowered to the point of being able to challenge them? Personally, I think not.
- b) We are all in financial crisis. Statutory and voluntary bodies are fighting for ever decreasing amounts of government and private funding. One way to survive is to jump on this year's 'in' issue, a new project can bump up a struggling organisation's available money, and is hard to let go of.
- c) Independence for the self-advocacy group effectively means a transfer of the worker's contract of employment, without which the conflict of interest cannot be resolved.

This results in a very strange situation of approaching the funders to request a change in your employment, management and financial status. Given point (a) and taking into account the real belief of service providers and others about the abilities and capabilities of people who have learning difficulties, as a worker you can be seen to be saying; I don't like what my employers are asking me to do. I would still like a job and the funding, so how about you giving the money to this group of people with learning difficulties who I know I can manipulate far easier than my present employers and get on with what I want to do.

Answers: a) work out a way to show the funders that it is the requests and directions of the group, not your own personal interests you are fulfilling.

b) resign.

How did you go about tackling the issue?

Consult, discuss, inform and educate the self-advocacy group on all options regarding their future development taking into account responsibility to monitor and assess the use of current funding.

Clarify and define exactly what your role as development worker is: there are many options but make sure the one you choose has clearly defined boundaries.

Listen to, and believe in the request of the group: look at your role as facilitating the reality of achieving the request. Believe, be clear and be strong in your own ability to do it.

Identify, gather and inform your support: borough organisations, individuals, self-advocacy workers, People First etc. Form a strong "Management Committee" and self-advocacy group.

Document justifications, structures, policy and procedure. Do the background work and find facilitation for the group to do the negotiation. Remove yourself from the discussion process.

How far have you resolved the conflict?

In my ninth month of employment I have effectively removed the conflict from my mind; I now know that my role is to follow and facilitate the directions of the self-advocacy group. This I am doing.

What were the difficulties?

Endless!! But the core of the problem is the quandary over the role of the paid self-advocacy worker. With this clarified to my satisfaction the group can move forward towards independence and control with confidence and support.

What were the successes?

- a) One of our funders is soon to enter into direct contract negotiations with the self-advocacy group.
- b) We have begun to achieve credibility and be taken seriously as a self-advocacy group in the Borough. PEOPLE ARE LISTENING TO US.

Is there anything you would have done differently?

Not taken the job!? No, this has been a process of exploration, investigation and working out the way forward in an area that is untested and without precedent.

Further

The content, views and beliefs in this report are those of Southwark Unity and myself, supported by People First. Some of the issues may be new, contentious or thought to be totally wrong. I certainly think it raises more questions than I would care to put down in writing at the present time. I welcome questions, comments and discussion both from workers in similar situations and from anybody else involved in self-advocacy. I would especially welcome an open meeting to discuss further the subject of employment conflict of interest - in whatever situation you may find yourself as a paid worker; interested people can contact me through Southwark Unity or People First London Boroughs.

* * * *

SELF-ADVOCACY GROUP v. THEIR FUNDERS

Advocacy in Gateshead,
Contact: Sally Young, 75 Coatsworth Road, Gateshead NE8 1QL, Tel:
478-6472

What was the situation?

Last year as part of a budget decision, Gateshead Social Services decided to charge users £1.50 per week for attending day centres. Users already pay transport charges, meal charges and have recently lost their free travel pass.

When did conflict of interest start to arise?

Residential home staff asked me to talk to users to explain what was happening. The users asked me to write a letter on their behalf to Gateshead Social Services Department. Gateshead Social Services Department are our main funders. The Chair of Social Services was very unhappy about this.

How did you go about tackling the issue?

I ensured I used only the words spoken by users and did not try to influence them in any way.

I informed my Management Committee - they were very supportive and saw this as an opportunity for advocacy in action.

I spoke informally to Senior Management 'off the record' - they were supportive of the action.

We ran a larger scale campaign - letters to the press, TV. and radio coverage, letters from carers/users to councillors, lobbied meetings.

I ensured there was user involvement throughout the campaign so any criticism of the project manipulating people was unjustified.

How far have you resolved the conflict?

We have regular (quarterly) meetings with Social Services Management to let them know about general areas of work. We participate in planning groups and induction and training for staff.

What were the difficulties?

Ensuring I did not 'manipulate' people to put my own personal views onto them.

What were the successes?

The involvement of users - people realising they had a voice which was potentially powerful. We ensured the service was debated in public, and a guarantee was given that the charge would be frozen for this year.

Is there anything you would have done differently?

Set up a campaign committee/group - but the timing was too difficult.

* * * *

PERSONAL LIFE v. SELF-ADVOCACY WORK

People First of Yeovil

Contact: Fiona Wright, c/o Fiveways Centre, Ilchester Road,
Yeovil, Somerset. Tel: 0935-823292 or Sylvia McGrady Tel:
0935-22111

What was the situation?

I was unhappy with attending the centre. I left and stopped attending the self-advocacy group. I was so busy being chairperson that it stopped me sorting out my own life.

When did conflict of interest start to arise?

About 18 months ago.

How did you go about tackling the issue?

I stopped going to the centre. I spoke to Ian Pugh my social worker about the problem.

The social worker and the advisor set up a number of meetings to help me get self confidence and to think about my own life.

I joined the adult learning centre and local weightwise gym.

I started going back to group meetings but as a helper not as chairperson.

How far have you resolved the conflict?

Sorted out quite a bit.

What were the difficulties?

Making the effort to do things for myself. Sadness that I was not chairperson any more.

What were the successes?

Getting to do things for myself, not just for self-advocacy.

Is there anything you would have done differently?

Would have liked more help. Trying to get to the centre more often to sort things out, not just stop going.

* * * *

NOT BEING PROPERLY CONSULTED

People First of Yeovil
Contact: Fiona Wright, c/o Fiveways Centre, Ilchester Road,
Yeovil, Somerset. Tel: 0935-823292 or Sylvia McGrady Tel:
0935-22111

What was the situation?

We were not asked about the building of a new centre - right next door to our centre - until the plans were made. Staff and management and Mencap parents were all consulted early in the planning but not the self-advocacy group.

When did conflict of interest start to arise?

It's always been like it. People who go to Fiveways Centre don't get a say in how it is run. Self-advocacy is not liked by some of the staff and they don't understand what we are trying to do.

How did you go about tackling the issue?

Tried to get training for staff. John Hersov came to speak to them.

We asked to go to staff meetings.

Spoke to manager at the centre.

How far have you resolved the conflict?

Nil

What were the difficulties?

Staff don't want to change. Staff don't think we can be good at managing the centre. Adults at the centre don't get the help they need to do this.

What were the successes?

Some of the staff have good attitudes now and try to help and stand up for us.

* * * *

AVOIDING CONFLICTS

Mike Leat, Advocacy Worker, Residents Committee,
Greenlaws Day Centre, 65 Cranley Road,
Guildford, Surrey GU1 2JW, Tel: 0483-36435

What was the situation?

Fortunately no conflict of interest has yet arisen in my work. Conflict of interest was a subject we thrashed out right from the start. We spent a lot of energy ensuring that staff, managers and users of services understood clearly the nature of my role so misunderstanding could be avoided. We drew up the following ethical guidelines to deal with any conflicts of interest which may arise. I also have my own independent support network of people who do not work for the Health Authority whom I consult with regularly when difficult issues do arise. Ultimately it is down to myself and the service to discuss carefully the role I play. At times these discussions can be very frank and the issue of conflict of interest has to remain foremost in everyone's mind.

* * * *

Ethical Guidelines Re Advocacy Co-ordinator

The aim is for the post of Advocacy Co-ordinator to become an independently funded and managed post.

It is recognised that for the interim period whilst the advocacy co-ordinator is directly managed by the learning disability service many ethical issues need to be addressed.

1. Many of the objectives of the advocacy co-ordinator must be user led and therefore the traditional managerial objective setting will not be appropriate for much of the advocacy work.
2. Should conflicts arise between users and managers of the service the advocacy co-ordinator must remain free to support the users voice.
3. A monitoring system is required to ensure that the advocacy co-ordinator is objectively helping users put forward their views and not views coloured by the advocacy co-ordinator's own.
4. The boundaries of the advocacy co-ordinator are set within the following priorities:-

| | | |
|--------------|---|---|
| 1st Priority | - | Clients of the learning disability service |
| 2nd Priority | - | Other people with learning disabilities living within the S.W.S.H.A. area |
| 3rd Priority | - | Staff and Management of Learning Disability Service |
| 4th Priority | - | Staff and Management of other services for people with learning disabilities within S.W.S.H.A. district |
| 5th Priority | - | Other local groups, services and users developing advocacy initiatives. |
5. An independent arbitration process must exist to ensure that any ethical problems can be dealt with fairly and effectively.
6. The advocacy co-ordinator post should attain independence as soon as is practically possible.

* * * *

King's Fund Centre

SELF-ADVOCACY AND USER PARTICIPATION INFORMATION EXCHANGE

CONTACT LIST

November, 1992

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G Wallington

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| SURREY Shelagh Collier | Chairperson, People First in Cranleigh, Aeolian House, Horsham Road, Cranleigh, Surrey |
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Silim Khan, Jan Ritchie

Ms Julie Hammond

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Chairperson, Thamesdown People First, 48, Priory Green, Highworth, Swindon, Wiltshire
Trowbridge People First Group, Ashton Street ATC, Trowbridge, Wiltshire, BA14 7EU

Social Worker for Learning Difficulties Team, Area Office, Bromsgrove Street, Kidderminster DY10 1PE

Secretary Students Committee, Lindley House SEC, Bowling Hall Road, Bradford, West Yorkshire, BD4 7SY

Secretary, Huddersfield People First, Huddersfield SEC, Swallow Street, Huddersfield, Yorkshire

Ravensthorpe SEC, Havelock Street, Ravensthorpe, Dewsbury, W. Yorkshire, WF13 3LU

Secretary Speak Up, 14, Beevers Road, Kimberworth Park, Rotherham, Yorkshire
Chairperson, Members Committee, Scarborough Training Centre, Salter Road, Scarborough, North Yorks

Assistant Director, Northern Ireland Council on Disability, 2, Annadale Avenue, Belfast BT7 3JR

Self-Advocacy Group, Dingleton, Melrose, Roxburghshire
Lothian Rights Group, 45, Ashgrove, West Lothian, Scotland
Ark Housing Residents Committee, 'Arkbrae', 51, Fairies Road, Perth
Larchfield Residents Meeting, Larchfield, Maugh Road, Blairgowrie, Tayside, PH10 7JB
Barnardos Advocacy Service, Co-ordination, 235, Corstorphine Road, Edinburgh, EH12 7AR

S. Brecknock Rural Skills Centre, Gwernyfed School Farm, Three Cocks, Brecon, Powys
Secretary, Glanrafon Self-Advocacy Group, Glanrafon Day Centre, Chester Road, West Queensferry, Deeside, Clwyd
c/o Peter Roberts, Trelai Centre Trainees Committee, Trelai Centre, Caldicot Road, Ely Cardiff

King's Fund



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| Ann Walford | Chairperson, Tremorfa Self-Advocacy Group, Tremorfa Centre, Pengam Road, Tremorfa, Cardiff |
| Mr Aneurin Williams | People First S. Wales Region, Sandbrook Day Centre, Queens Road, Thomastown, Merthyr Tydfil, Mid-Glamorgan |
| Ms Beryl Woodfine | Dr. Richard Advocacy Group, Dr. Richard Centre, Pool Road, Newtown, Powys |
| Ms Deborah Sanderson | West Glamorgan Forum, 142, Walter Road, Swansea, West Glamorgan |
| Mrs Sonia Liggett | D.A.R.T. New Pointers, The Friary, Cardiff, CF1 4AA |
| Mr David Roberts | Colwyn Advocacy Group, 12 Llwyn Morfa, Abergele, Clwyd, N. Wales |

