

King's Fund Centre
Community Living Development Team

INFORMATION EXCHANGE
ON
SELF-ADVOCACY AND USER
PARTICIPATION

Services to people with learning difficulties

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This information exchange relies on its readers for its existence! Any comments or suggestions about how it should operate will be very welcome. Individual contributions - not necessarily related to the chosen topic(s) of a particular issue - will also be welcome.

In developing the information exchange, we are keeping in close touch with People First's London office, bearing in mind their role in providing a link with groups around the country and producing a national newsletter. We want to make sure that the work of the information exchange complements and does not overlap the work of the People First Office. The information exchange will concentrate on service development issues. It will not, for example, cover the type of self-advocacy group news which is contained in People First's national newsletter.

The information exchange is produced particularly for supporters and advisors of self-advocacy groups and people with responsibility for developing effective ways of working in partnership with users in planning and delivering services. However we hope that many service users will also read it, and we will be continually striving to find ways of producing it which will make it readily accessible, whoever is using it.

EDITORIAL

Thanks again to those who have contributed written material for this issue and also for positive comments about the usefulness of the exchange.

INVOLVING SERVICE USERS IN THE PLANNING AND DEVELOPMENT OF SERVICES

Three stories are included, each with its own particular points of interest. There must be many more stories to be shared: perhaps people are so busy doing it, there's no time for writing about it!! If these stories prompt you to put pen to paper - or voice on a tape - please do so, we welcome accounts of your experiences at any time and will include them in a future issue.

COMPLAINTS PROCEDURES

It may not be a surprise to readers that we were not exactly inundated with examples of user-friendly complaints procedures! Most of the responses were along the lines of 'we are working on it'. It is good then, to be able to enclose the attached examples from Somerset and from Ravenswood in London. The contributors wish to emphasise that these leaflets are very much in the draft stage and are now being piloted. The Hillingdon Social Services leaflet is an example of trying to make a complaints procedure accessible to the general public - not specifically people with learning difficulties.

In order to broaden my own knowledge in this area, I decided to do a quick (!?) telephone survey to colleagues around the country who might reasonably be expected to know the current state of play. My thanks to all of them for their time and for further suggestions of people to contact. A total of 22 different contacts yielded the following information:

- * No further user-friendly examples. Most people agreed that although a lot of thought is being given to producing accessible material, most people are still at the stage of developing the basic procedure. It was also pointed out that producing a 'user-friendly document' is only the beginning. People still need to be helped to understand how to use it.
- * Two citizen advocacy schemes - Avon and Hereford and Worcester - have obtained funding to set-up a complaints advocacy service to assist people who wish to make a complaint. The schemes are not yet in operation.
- * The Social Services Inspectorate organised a series of workshops in March and a report will be produced. I understand that several examples of procedures using pictorial materials to make them more accessible were

brought to these workshops. Hopefully these will be included in the report. Contact Judy Downie - 071-972-2000 Ext. 4265.

- * NISW held a conference on the subject on 18th May. Further information from Tessa Harding - 071-387-9681
- * Gateshead Social Services are providing resources to produce a video and tape of their complaints procedure, particularly for people with learning difficulties. The working group consists of representatives of a local advocacy group, parents, and people with learning difficulties.

NEXT ISSUE

Conflict of interest

As the self-advocacy movement grows and begins to tackle issues which are more likely to 'rock the boat', we are hearing more about difficulties arising from situations involving some sort of conflict of interest. For example, a group tries to influence a major change at a day centre and comes into conflict with management; an advocacy worker finds him/herself caught between loyalty to the group for whom the project was set up, and the management group or funders.

Some of the factors contributing to these tensions seem to be:

- Lack of real understanding of self-advocacy
- The band wagon effect - everyone wants to be 'doing it'
- It seems relatively easy at present to get funding for 'advocacy projects' - on the face of it, a positive factor - but linked to.....
- Short time-scales on projects - often only one or two years - can create pressure to achieve 'measurable' results in an unrealistic time
- Advocacy projects are being set-up which seem to attempt to be 'all things to all men', glossing over the differing needs and aspirations of different groups of people and making unrealistic demands on (often) lone workers.

Some of the difficulties can occur when a group or project is part of another organisation or group of organisations for example:

- operates within one of the statutory services,
- is part of one larger 'parent' organisation,

- is linked to an umbrella group of voluntary organisations,
- is linked to an umbrella group of disability organisations.

Whenever a group is not independent, there is potential for conflict of interest. And when large amounts of money are involved, the challenges can become even greater. So, for the next issue we feel it might be helpful to share experiences of dealing with such difficulties. For example, can a clear management structure help? Is building good relationships the most important factor? What has worked for you? What didn't work for you?

Please use the enclosed questionnaire if possible, but if you just feel like writing in your own words about any current or past situations, we'd still like to hear from you. Anonymity will be preserved if that is what you prefer.

Please send in your contribution by Wednesday, 30th September 1992.

Andrea Whittaker
June, 1992

BEING INVOLVED IN A DISTRICT JOINT PLANNING TEAM

Annie Ferguson or Carol Ann Clarke
Speak Up
12 Meadow Close, Dalton, Rotherham, SG5 4HF
Tel: 0709-852383

We have just been accepted on the District Joint Planning Team.

How did it come about?

We invited a manager from the planning team to come to one of our meetings. We asked her a lot of questions.

We said to her that there was no one with learning difficulties on the planning team and we asked to be represented by one of us.

The manager wrote back this week to say there was whole-hearted support for a representative from Speak Up to be invited to future meetings.

How are service users supported?

The Joint Planning Team will supply Speak Up Committee with tapes of their meetings. Speak Up Committee members come from various self-advocacy groups. They will use the tapes to write Information Sheets to take back to their groups, so that Speak Up members and other people with learning difficulties can say what they think.

What have been the difficulties?

We don't know yet but we hope that the managers will speak to us without lots of jargon so that we can understand and make decisions for ourselves.

Any other comments you would like to make?

We hope that managers will listen. Our representative can't read but speaks out well. We hope they will use signs, symbols and tapes to help Robert do a good job at feeding back.

* * * *

ACCESS AND DISABILITY ADVISORY GROUP

Harold Roberts,
Chairperson,
Brian Didsbury Users' Committee,
2 Didsbury Close, East Ham, London, E6
Tel: 081-552-8948

Invitations to meetings and regular consultation with
Newham's Access and Disability Advisory Group

How long has it been going on?

First letter. 11.1.1991

How did it come about?

We had a letter from the Chief Executive of the Town Hall
Department telling us about the group.

We had to phone or write in to the Equal Opportunities and
Human Resources Group to get dates and times of meetings.

We are sent dates, times and agendas of meetings and
consultation papers. We send in our comments.

How are service users supported in this involvement?

We work on what we want to say in our Users' Committee
with back-up from the Education Department.

What have been the difficulties?

Getting to the meetings.

* * * *

WORKING TOGETHER GROUP

Mike Leat, Advocacy Worker
Maureen Booker, Residents Committee (Chair)
Greenlaws Day Centre, 65 Cranley Road,
Guildford, GU1 2JW, Tel: Mike - 0483-36435
Maureen - 0483-427263

A quarterly meeting between the chairperson and secretary of the residents' committee and the residential service manager and business manager.

How long has it been going on?

First meeting held in February 1992, second meeting April 92.

How did it come about?

Managers were very keen to hear the views of the residents' committee and the committee were keen that their views were heard.

Managers and residents met together to discuss ways this could be achieved and agreed on a formula of working together at meetings (see Minutes).

It was agreed that the meetings would also be used to work together on making decisions and taking action about the subjects discussed.

How are service users supported in this involvement?

Support is given by the advocacy worker who attends the meetings as a secretary and advisor.

What have been the difficulties?

None so far as the structures of both the residents' committee and the management group are well established. These meetings were the next logical step.

What have been the successes?

Residents and managers able to sit round a table and thrash issues out on an equal basis.

Any other comments you would like to make?

This is the final block in place of hopefully an effective system of user representation in the planning and control of the service. See diagram overleaf.

We are talking about having wider 'working meetings' of staff, residents and managers working together to produce

- a) Bill of Rights (charter)
- b) Complaints procedure

* * * *

SOUTH WEST SURREY HEALTH AUTHORITY

WORKING TOGETHER

Notes of a meeting held on 28th February 1992

Present:

Wendy Williams	-	Business Manager
Joan Ashdown	-	Residents Committee (Secretary)
Raj Mungar	-	Residential Service Manager
Maureen Booker	-	Residents Committee (Chair)
Mike Leat	-	Advocacy Worker

It was agreed by everyone that it was important for the managers and residents to meet together regularly. The meetings would be called "Working Together" and would be held quarterly in March, June, September and December.

The meetings will be used as a chance for the chairperson and secretary of the residents committee to share with the managers some of the views of the residents committee.

The business manager and the residential service manager will use the meetings to share with the residents some of the views of the management team.

The meetings will also be used to work together on making decisions and taking action about the subjects discussed.

The advocacy worker will come to the meetings as a supporter and to act as the secretary. The advocacy worker will stop coming to the meetings when it is agreed that support is no longer required.

The meetings will be held at Buryfields Clinic. Everyone agreed that other meetings could be held occasionally in between the quarterly meetings when needed.

It was agreed that Maureen and Joan would share with the residents committee, what is talked about at the Working Together meetings and that Wendy and Raj would share this with the management team.

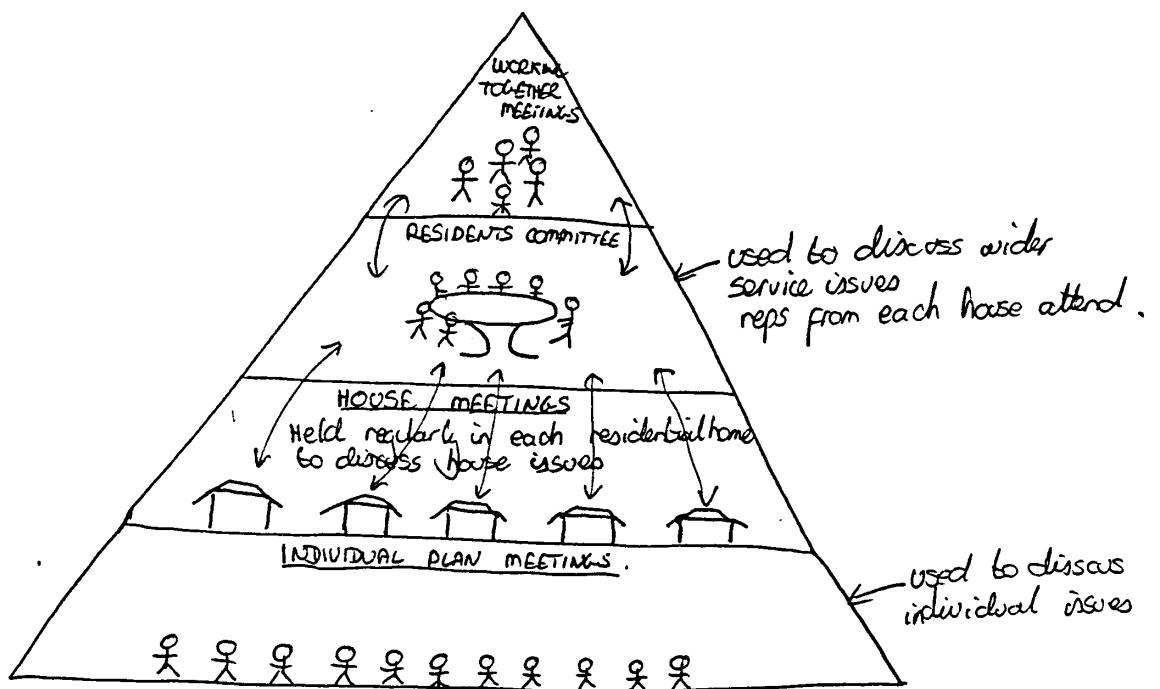
Meeting closed.

ML/DI
03/03/92

WORKING TOGETHER

South West Surrey H.A.

Structure of meetings



Contact: Jane Jones
Speech & Language Therapy Dept.
Dene Barton,
9 Dene Road
Norton Fitzwarren
Taunton. Somerset
tel: 0823 433 540

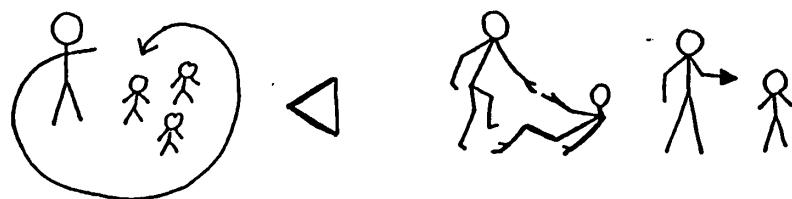
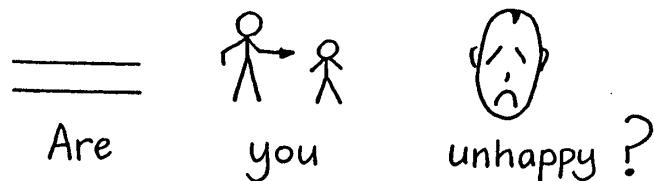
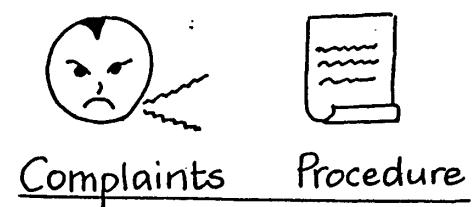


for People with Learning Difficulties
Social Services Department
Somerset County Council
County Hall
Taunton
Somerset TA1 4DY

Phone: (0823) 333451

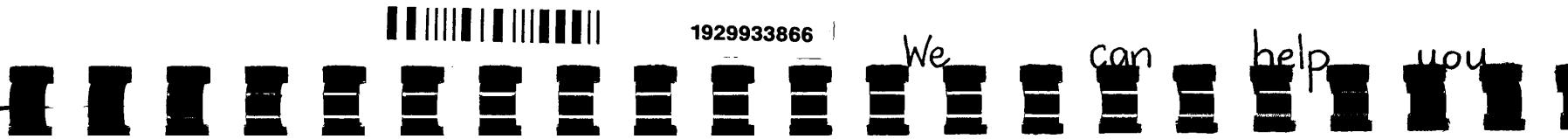
-9-

Somerset County Council
Social Services



1929933866

We can help you





Name



Address



Unhappy



Help

from

Name  worker

Name  Social worker

Name  Manager



I



am



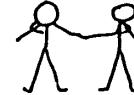
unhappy about



:-



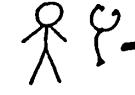
Money



Friends



Work



Keeping well



Living



Leisure



Moving about



Holidays



Communication

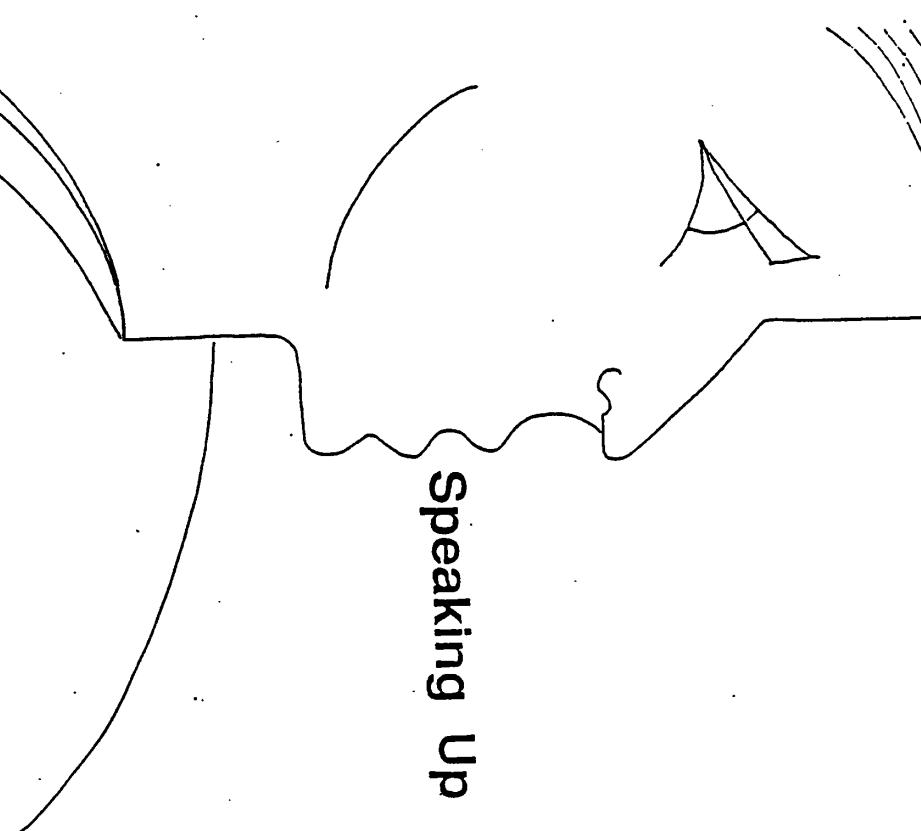


Other



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Contact: Jacquie Billis
Ravenswood
17 Highfield Road
Golders Green,
London. NW11 9DZ tel: 081 905 5557



Speaking Up

PEOPLE WITH LEARNING DISABILITIES

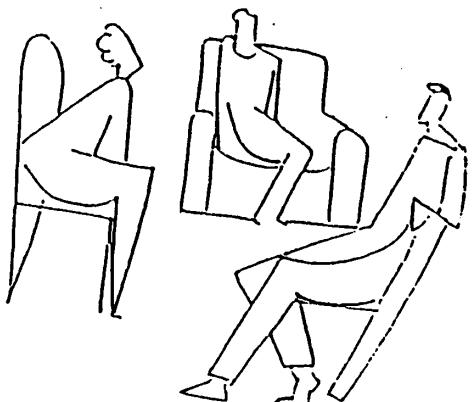
MAKING A COMPLAINT

YOU HAVE A RIGHT TO SPEAK UP

If you think you have been unfairly treated or worried about something and want something done about this but don't know how to go about it.

THIS IS WHAT YOU DO:

One place to talk about things that worry you is your Self Advocacy or Residents Group.



If you are not happy after this you have a right to go to the Social Service Registration Department in your own Authority.



HEADS OF SERVICE:

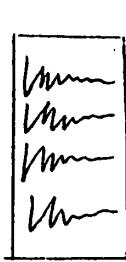
Village;	Sheena Davies
London Homes:	Marian Janner
Unity;	Jamie Easton
Kennedy Leigh:	Karen Carr
Deli:	David Hart
Social Work Team:	Vivienne Freeman

6.

FORMAL COMPLAINT

ASK TO SEE A DIRECTOR

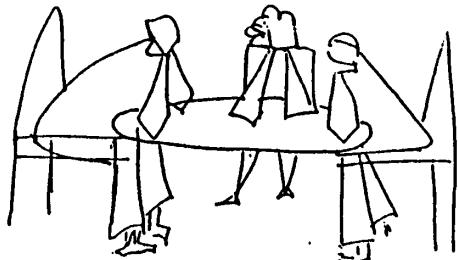
Your complaint will have to be written down and there is a special form



ASK FOR HELP IF YOU NEED IT

13 You should have a decision in 7 days.

4. If your problem is still not solved, the Director will arrange for you to see the Executive Director Norma Briar who will arrange a meeting with you and your friend to discuss the problem and try to sort it out. You should have a decision in 7 days.



3.

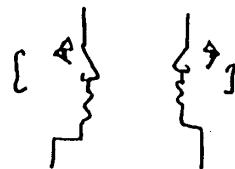
However if you have a personal worry which you do not want to talk about in a group and you want to complain;

THIS IS WHAT YOU DO:

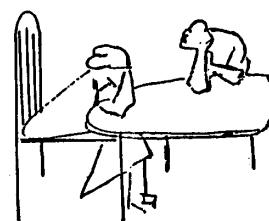
1. Tell a friend whom you can trust. This may be someone you work or live with. If not, you may want to speak with a relative. They could help you to take your complaint to the person responsible.

OR.....

Ask to speak to your Head of Home, Centre or Club. You can take another person with you if you want. They will try to sort out your problem.



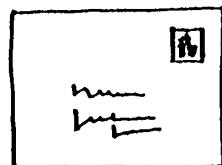
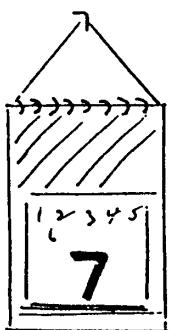
OR You might want to complain about the Head of the Home, Centre or Club so..... Take your complaint to that persons manager who is the Head of the Service.



4.

If you want help to know who that person is
The Complaints Coordinator Ruth Hinton can help
you. She is at 17 Highfield Road, London NW 11
9DZ. Tel: 081- 905 5557

2. They should have sorted out your problem in
7 days from the day you spoke to the person in
charge. Someone will write to you, phone or
come and talk to you about what they will do
to sort it out.



If your problem is now sorted
and you are happy with the
decision that is fine.



5.

IF NOT:

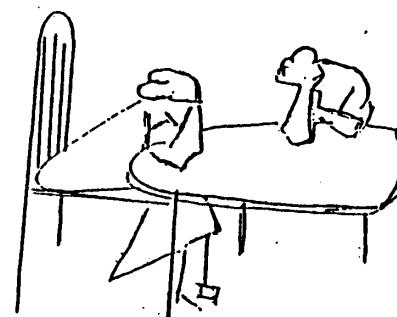


3. You have the right to put your
problem to the next person in
charge, called the Head of Service
and have a decision in 7 days. A list of
these people is put at the end.
If you are not happy after speaking to this person
SAY SO.....

-14-



You have a **RIGHT** to take your problem to a Director.



For further information about the complaints procedure or Advocates, contact your local Social Service Office, the staff in your unit or the Complaints System Manager, Tel. 0895 50111 ext. 2198 or write to:

The Complaints System Manager
Social Services 2S.08
Civic Centre
Uxbridge
UB8 1UW

To improve the quality of our services, we not only need to deal with your complaints, but the Complaints System Manager will also be pleased to receive your 'good news' so that we know which standards are satisfactory.

-15-

Contact: Sylvia Sheehan
Complaints Systems Manager
Hillingdon Social Services
Inspection Unit
Dingon Hill Close
Coldharbour Lane
Hayes. UB3 3HN tel: 081 569 3804

**Are you
satisfied with
the quality
of our services?**

**Social Services
are ready to
help with your
Complaints**



Q. What is this about?



A. From 1st January 1989, Social Services have a better way of dealing with your complaints as part of its aim to listen to its customers and improve its services.

Q. What is a complaint?



A. It can be a concern or problem about a service, a disagreement about a decision, or a feeling of dissatisfaction by any individual user of our services.

Q. Can I have help in telling Social Services about my complaint?



A. Yes, you can choose a friend, someone you trust or select from a list which is in the Social Service Offices. The person who helps you is called an ADVOCATE.

Q. Does this prevent me going to a Councillor or the Police?



A. No. You can go to your Ward Councillor at any time, and if you think an offence has been committed against you, you can go to the Police.

Q. If I have a complaint, what do I do about it?



A. Firstly, if you have a Social Service Worker, you should take it up with her/him and try to sort it out.

Q. If I don't feel it is sorted out, what do I do?



A. Ask for a meeting with the manager of the team, home or day unit. This should take place within 10 working days. Don't forget, you can bring your Advocate.

Q. If I am still unhappy, what do I do?



A. Register your complaint, by telephone or letter, with the Complaints System Manager at the Civic Centre, Uxbridge, Tel. 0895 50111 Ext 2198.

Q. If I can't talk to my Worker or I lack confidence in the Manager, can I go straight to the Complaints System Manager?



A. Yes, but the Complaints System Manager will ask if you have tried to sort it out and may ask the Manager to talk with you before making the complaint formal.

Q. What happens when I register?



A. An Officer is appointed to investigate. (S)he will interview all concerned, including your Advocate (if you have one), and read records and procedures. (S)he has 15 working days to make a report.

Q. Does (S)he judge the complaint and make a decision?



A. No. (S)he reports to a senior officer who will decide and write a reply to you explaining the decision, whether it is in your favour or not.

Q. If I do not accept the outcome, is that it?



A. No, you make an appeal to a panel of Councillors through the Complaints System Manager. The decision of this Panel is final within the London Borough of Hillingdon. Further complaints would need to be referred to the Local Ombudsman.

Q. Does this procedure deal with every complaint?



A. No. Some decisions are made in court and you need to discuss with a solicitor and decide whether to make an appeal. Other complaints may be covered by legislation or local authority procedure and so you will need to get advice to find the right course of action.

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