

Action for independent living: A guide to getting involved and making a difference in your local area



supporting blind and
partially sighted people

What is “independent living”?

Independent living means disabled people enjoying the same choice, freedom, dignity, control and opportunities as people who are not disabled – at home, at work, and as members of the community. It does not mean individuals having to do everything for themselves, but it does mean that any practical help people need should be based on their own choices and aspirations [Source: Disability Rights Commission (DRC)].

Why is social care support so vital for many blind and partially sighted people?

Access to high quality social care services at the time they are needed can really help to improve the quality of life of blind and partially sighted people. Social care refers to a range of services and support that enables the person to live their life with dignity and in the way they want. It can range from help at home with everyday tasks such as shopping and cooking, to providing care in a home for those who require a lot of support. **It's not just an added extra – for many people it's essential.**

What is the problem?

Support and services are provided and funded by local councils. But financial pressures mean that local councils are making huge cuts to their services. Recent research has revealed that almost three quarters of councils now only provide services for people who have the highest needs. Those of us with sight problems do badly out of this, often because the people who assess who is “eligible” do not understand the impact of sight loss. **This is unacceptable. It means people don't get the support they need to lead their lives independently.**

Sheila Martin is 60 years old and registered blind. For 27 years, she received a care package of five hours a week. Her “carer” assisted her with household tasks such as washing, cleaning, making beds, vacuuming, ironing and checking use-by dates on food. In June 2006, the council decided to cut her care package from five hours per week to one and a half hours per week.

The reason given for this cut by the council was that their eligibility criteria prevented them from providing the assistance Mrs Martin needed, because it was not substantial or could be met by family members. In fact, the tasks which Mrs Martin required assistance with were those where the family were either unable to help or were part of Mrs Martin's family/domestic role and she therefore wanted to perform them independently of other family members.

The Council's decision reflects a general underestimation of the amount of assistance that Mrs Martin requires in her day-to-day life and the impact that a lack of assistance will have on her independence.

Sadly, Mrs Martin's experience is not unique. Up and down the country we are hearing similar stories that reflect the fact that the care system is failing blind and partially sighted people. In too many cases, not providing the right support when it is needed means a person needs more expensive care and support later on as a result.

For example, a person with sight problems who has difficulty crossing the road is more likely to limit their travel plans, and may not even venture out at all. This could result in:

- dependency on others to do their shopping
- higher food bills (due to having to use corner shops or convenience stores, which are expensive)
- an increased reliance on less healthy "ready meals"
- lack of exercise
- social isolation.

Taken together, these outcomes could lead to a lower quality of life, financial problems, and worse health from poor diet and lack of exercise. However, an assessor might not fully understand these implications, and he or she might not know that basic mobility training by a rehabilitation worker could resolve the problem. This lack of awareness could result in the person being more likely to abandon the struggle for independent living and opt for residential care instead. This outcome might not be in their best interests and would be expensive for the individual or the community at large. People should not be forced into making this choice due to lack of support [Source: Improving Lives Coalition, (2005), "Facing FACS"].

Getting better services

RNIB has produced a good practice guide, called **Good practice in sight: How excellent services for blind and partially sighted adults can boost the overall performance of local authorities**. This shows local councils how they can meet their own performance targets by providing a good service for blind and partially sighted people. The recommendations focus on nine areas that make up a good service. The campaign will ask councils to make these a reality for everyone who experiences sight loss.

1. **Emotional support** – making sure that there is a broad range of support such as support groups and counselling provided by a qualified counsellor.
2. **A flexible referral system** – ensuring that people can “enter the system” when they need it. There need to be good links between health and social care workers and a different ways of being referred (eye care professionals, GPs, family or friends) including being able to self-refer.
3. **Information and advice** – to ensure people are able to make better-informed decisions about the services they want. This should include information about services to help with daily living skills and also information about access to benefits, housing, leisure activities as well as seeking and staying in work if appropriate.
4. **Assessment** – this should identify all possible support needs an individual blind or partially sighted person has to make sure they receive appropriate support at the time that they need it.
5. **Equipment** – this must be made available to ensure blind and partially sighted people are able to lead more independent lives safely. This must include a minimum level of equipment (magnifiers, liquid level indicators, white canes) but should also include more sophisticated items such as computer software and equipment that allows people with sight loss to read ordinary print.
6. **Training** – should be available where a person needs it, in the use of equipment, in orientation and mobility, independent living skills and communication skills, and low vision enhancement.
7. **User involvement** – a good service will ensure people are empowered to make the right choices about the contents of their own individual care package. They will also be able to play a key role in deciding what services are provided and how they should be delivered.
8. **Complaints** – a clear complaints procedure needs to be in place which people know about and are encouraged to use. People must be confident that any problems they have will be taken seriously and solved at the earliest possible stage.

9. **Inter-agency working** – to ensure health and social services have a “joined-up” approach, including links with other groups which provide services in the area such as charities, to provide a seamless service to blind and partially sighted people.

Campaigning – what do we want to achieve

RNIB is sending **Good practice in sight** out to all councils who have social services responsibilities. At the same time, you can help by taking action in your local area to make sure local councils:

- recognise the severe impact that being or becoming blind or partially sighted can have on a person’s life, and
- understand what a good service is and improve what is on offer to blind and partially sighted people in their area.

The three key messages that we want to get across to local council staff are:

1. The effects of sight loss can be devastating – leading to loneliness, social and economic deprivation and poor health.
2. Local authority staff need to recognise the severe impact of sight loss and the need for appropriate levels of support.
3. Local authorities need to take prevention seriously. Even where blind and partially sighted people have low or moderate support needs these should be met to help blind and partially sighted people reach their own potential for independent living and avoid the need for more expensive support at a later stage.

How you can get involved

1. Work together

Many areas have a **local society** for the blind who may be interested in working with you on the campaign. The National Association of Local Societies for Visually Impaired People (NALSVI) should be able to tell you if there is a local society in your area. Contact them on 01302 571 888 or at nalsvi.org. Your area may also have a **Low Vision Services Committee** which works to support people with low vision living in an area. Other organisations such as your local Age Concern may also be interested in getting involved. Contact your RNIB Regional Campaigns Officer who will be able to put you in touch with groups in your area.

2. Get the facts

Does your local authority provide good services in the nine areas described above? Find out what official inspections have said about services in your area. Ask your RNIB Regional Campaigns Officer who'll be able to help you. Your local society or Low Vision Services Committee may also be able to help you answer these questions. You may decide that you want to focus on one or two of the nine benchmarks of good practice rather than all of them.

3. Then ask the real experts – people who use the services

Host a coffee morning and carry out a survey of people's experience of local services. Try to get least ten people to take part if you can. Your local society may be able to help host this and you could put together a short report of your survey findings, highlighting good and bad areas and examples of what people have experienced. We want to highlight the experiences that people have had (both good and bad) of services in their area. This will help to create awareness and understanding of issues relating to visual impairment. Your RNIB Regional Campaigns Officer has a template of a survey that you can use and would be really keen to hear the results of your investigations.

4. Write to your councillor

Draw your councillor's attention to **Good practice in sight** and ask them to show support for the campaign within the council. Remember to include the three key messages outlined on page five and include examples of real life experiences – they are a very effective way of getting your message across. Follow this up a week or two later with a phone call (or an email if you have access to the internet) to make sure they got your letter. RNIB can provide a template of a letter covering the main points.

5. Say it with poetry!

Contribute to the campaign in a more creative way. RNIB's annual creative writing competition is usually only open to members but this year we're widening this so everyone can get involved in the campaign. The theme of the competition will be:

"This is what my independence means to me"

The winner will get a cash prize of £100 and have their poem published in the RNIB member's magazine **Vision** in June 2009. There will also be prizes for runners up in each region. We'll use the winning poems to raise awareness in your area and nationally and will really help to bring home the message.

Poems will need to be entered from October by the end of December. Submission criteria will be published in **Vision**, in October or can be obtained from Blase Roccisano on 0207 391 2243 or by email at blase.roccisano@rnib.org.uk

6. Write to your local paper

Tell them if services for blind and partially sighted people are failing to provide the necessary support to allow people to live independent lives. Your local councillors and local MP really care about what the local paper says! Getting a story into the local paper or talked about on local radio is a really effective way to raise awareness amongst decision makers where you live. Please contact the RNIB Campaigns team for a template letter and help and advice on taking forward media work in your area.

7. Be our “Core voice”

We are also always looking for people who are willing to be part of RNIB’s “Core voice” – a group of blind, partially sighted and some sighted people who share an interest in supporting RNIB’s work with the media.

You would need to be willing:

- to talk to journalists from the TV, radio and/or newspaper, or
- to let us use your story in an anonymous way in campaign literature

If you are interested and think you can help, contact Bill Alker for further information on 020 7391 2223 or 0115 987 1522 or at bill.alker@rnib.org.uk

Contact us

RNIB has a network of regional campaign staff who can provide support and advice for your campaigning and offer other ideas for how to work in your local area to bring about positive change. We are really keen to hear what you plan to do to get involved in the Action for Independent Living campaign. Please contact the RNIB Campaigns team in any of the following ways to tell us your plans and we can put you in touch with your Regional Campaign Officer:

Write to:
RNIB Campaigns team
105 Judd Street
London
WC1H 9NE

Campaigns hotline: 020 7391 2123

Email: campaigns@rnib.org.uk

If you or anyone you know could benefit from free advice and information on any issue related to sight loss, please contact RNIB Helpline on 0845 766 9999 or email helpline@rnib.org.uk