



Nov/Dec 2004

HAPPY CHRISTMAS

The Board of Trustees

Cathy Magill - Chair
Judith Littleboy - Vice Chair
Joe Magill - Secretary
John Beadman - Treasurer

Dave Abbot
Carolynne Beadman
Hughie Bollan
Richard Lees

I know our festive wishes seem a little early but Christmas is only just around the corner and we really wanted to send our warmest wishes for a Happy Christmas and a healthy and accessible New Year to all of our members as this will be our last newsletter for 2004.

So where has the year gone, it seems to have flown by. However when we look back it is very encouraging to see the progress that SAIN has made in 2004. The office is now manned by Michelle on a regular basis and she has worked hard to ensure that systems and procedures are in place to promote the activities of SAIN and keep our members informed of our activities and opportunities for involvement. This has seen an increase of 30% in our individual membership and more than 100% in our Associate members meaning that we are reaching far wider and becoming an even stronger force to be reckoned with. In 2004 Richard has been working hard to ensure that SAIN has been in-

involved in more consultation exercises than ever before, which has had real and lasting impact on the decision making process, this has included The Home Care Re Tender project, Supporting housing projects, Passenger transport strategies, Highways Planning, access auditing and UK Passport service to name but a few.

We have seen the involvement of old and new members who have participated in these projects and we would like to thank each of them for their time and commitment. We have secured more consultation work for 2005 and will be looking for interested parties to take part, so please keep your eyes on the "Networker" in the new year for more details.

As always we have been representing disabled people on many panels and boards throughout the county. It is testament to the hard work of all SAIN representatives that we been invited to be involved in new groups such as the Advocacy Working Group, The

Best Value, Property Services group and the East Somerset Partnership against Racial Harrasment group. We have also recently secured service provision contracts in the form of Direct Payments support for Children and Families in Wiltshire, it is our intention to increase the volume of service provision in 2005 as we continue to develop as one of the key disability organisations in Somerset. Most recently we have had our AGM and conference where our new board of Trustees were elected (See page 2) and various workshops and presentations were delivered. We would like to thank all of those who attended and hope that they agree that this was a very enjoyable and informative day. So as you can see we have had a busy year and are looking forward to the challenges that 2005 bring. Again we send you all our warmest wishes
Cathy Magill and all at SAIN



RADAR keys
RADAR keys to access disabled toilets are now available from the SAIN office at a charge of £2.25 if you intend to visit the

office to purchase a key, Please call before hand to ensure that the office is manned when you intend to visit



Please remember to let us know if you change address, telephone number or email so that we can stay in touch.

Trustees Re Elected

At our recent AGM on Saturday 20th November 2004, we are pleased to announce that the following people were re elected to form SAIN's Board of Trustees. David Abbott, Carolynne Bead-

man, John Beadman, Hughie Bollan, Richard Lees, Judith Littleboy, Cathy Magill & Joe Magill (Pictured left to right). The Trustees will now appoint a Management Committee to manage the day to day activities of

the organisation. The Trustees are keen to hear from anyone who would be interested in joining the Management Committee and would ask that you contact the office for more details if interested.



Mentoring opportunities for Disabled People

Disabled people are being given the unique opportunity by staff at Hinkley Point B power station, where they and their colleagues throughout British Energy are offering to share their skills and experiences with disabled people.

The mentoring scheme is part of the company's year long partnership with RADAR and locally nominated charity SAIN. The

partnership is about more than just raising funds and signing cheques. British Energy is offer-

ing disabled people the chance to partner with individuals throughout its business to help them develop their own career opportunities.

Gary Perrett and Iain McCall from Hinkley Point B are just two of the many employees throughout British Energy who has signed up to the scheme.

"Everyone in the company has really risen to the challenge of raising money but the mentoring allows us to see the real immediate benefits of our efforts"

Once the employees have been through an initial training programme they will be paired up with a mentee from outside of the company.

"We are really looking forward to getting started and would encourage anyone who thinks they

may benefit from this scheme to contact the helpline"

The scheme is open to all disabled people over the age of 18. The first mentor/mentee pairings will begin soon with regular contact meetings being established over a period of at least one year. There is no official closing date for applications, but British Energy would encourage applicants to contact them as soon as possible.

If interested please contact Maxine Wells on 0800 3760676 or email maxine.wells@british-energy.com or write to her at British Energy Communications, Barnett Way, Barnwood, Gloucester, GL4 3RS. Phone lines are open Monday to Thursday from 8.30am—4.30pm.



Supporting People Consultation

In the past month SAIN have been working on a Consultation project looking at the Supporting People Service.

This has involved our consultation worker carrying out detailed interviews with users of the service in South Somerset and bringing together a focus

group of non users from the Mendip area to find out their views on how the service could be developed.

We are now in the process of analysing all the information and drawing up a report to be forwarded to the Supporting People Service. We will bring you more details of our findings soon. We would like to take this opportunity to thank all those

who took part in the interviews and the focus group and would like to say a particular thank you to Dorothy Church and her colleagues from Day Services for all their support .

For more information on this or other consultation projects please contact Michelle at the office

SAIN are pleased to welcome, new Associate members, The Lupus Western Group, to the network. As one of our main aims is to ensure that as many disabled people as possible have the chance to have their say, then it is always encouraging to welcome on board organisations, through whom we can make contact with those, we may not otherwise have been able to reach

Systemic Lupus Erythematosus - Hard to say Harder to live with

Lupus is an auto-immune disease, whereby the patient's immune system creates antibodies which instead of protecting the body from bacteria, viruses etc, attack the persons own

body tissue. This causes symptoms of extreme fatigue, joint pain, muscle aches, anaemia, increases the risks of miscarriage and possible destruction of vital organs. Most Lupus sufferers are also sun sensitive.

Although there are many possible manifestations of lupus, those listed above are some of the more common. Lupus is a disease which can present many different facets, rarely do two people have exactly the same symptoms and this can make an early diagnosis difficult.

There is no cure, for most sufferers with Lupus this means a lifetime of medication and frequent visits to hospital.

The cause of lupus is not positively known though research has provided evidence implicat-

ing heredity factors, hormones and infections including viruses. Some 50,000 may have Lupus in the UK, a large percentage of these are women, although men and children can also be sufferers.

The Lupus Western Region, covers parts of Gloucestershire and Wiltshire, the whole of Somerset, Bristol and Bath, has set up a network of contacts (who have Lupus themselves) throughout the region, so that sufferers, their families and carers can ring to gain information and support. The Western Region also organises meetings around the area, has fund raising events, and generally helps to spread awareness.

If you would like more information on Lupus, please ring 01935 840132

Shaping Health

The Health Advocacy Partnership (HAP) Launches its Website.

www.hapforums.co.uk

HAP is not-for-profit company, formed to provide support to the voluntary members of recently established Patient and Public Involvement (PPI) Forums

The new website will enable you to register your views on health issues and give you more information on what PPI forum can do and how to get involved.

Following is a list of public meetings where any member of the public can go along

and raise any health related issues or concern with a member of the forum.

Meeting are subject to change, if you have special needs for accessing a meeting please contact James or Luisa at the Health Advocacy Partnership on 01225 701120

Taunton and Somerset PPI Forum

25-Nov-04, Taunton Library, Meeting Room, 12.00pm

PPI Forum (RUH Bath)

14-Dec-04, New Oriel Hall, Larkhall, Bath. 12.30pm

South Somerset PPI Forum

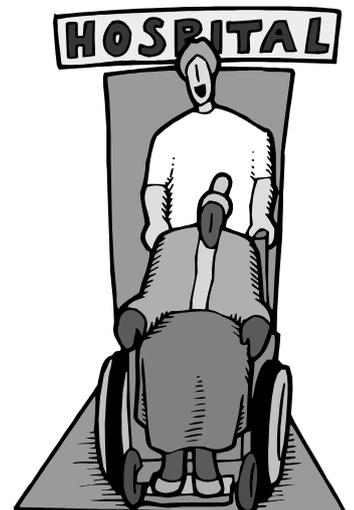
12-Jan-05 Venue and time to

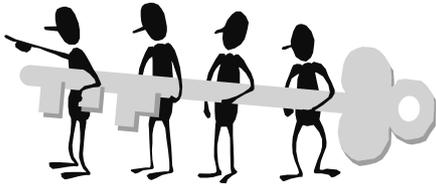
be confirmed

Somerset Partnership PPI Forum

19-Jan-05 Venue and time to be confirmed

Other forums have yet to set dates for the new year, please visit the website or call the SAIN office if you would like to know more about a forum in your area





Making Britain Open 4 All

Do you still find it difficult to get access to some services. As a disabled person you have rights of access to goods and services. Disabled people already have important rights under the Disability Discrimination Act (DDA) when it comes to using services or accessing goods.

From October 2004 these rights have been extended and service providers will have to consider making changes to physical features which make it unreasonably difficult for disabled people to use their services

What are "goods and services" under the Act?

Anyone who provides a service to the public or a section of the public is a service provider. There are a few exceptions: private clubs that have a meaningful selection process for members, transport (but only the transport vehicle, not everything else connected with it such as stations, airports and booking facilities) and education. Not all manufactured goods are covered. The maker of a bathroom suite does not have to make the bath accessible for you but the shop selling it has to make it's services accessible. So disabled people have rights to all kinds of services. That includes going to a restaurant, shopping for clothes or food, to using the local library, going to church or visiting your solicitor or doctor. All of these people provide services and are covered by Part III of the DDA.

The 2004 duties say that service providers should make reasonable adjustments to

physical features but what is a physical feature?

Here is a long but not exhaustive list: steps, stairways, kerbs, exterior surfaces and paving, parking areas, building entrances and exits (including emergency escape routes), internal and external doors, gates, toilet and washing facilities, public facilities (such as telephones, counters or service desks), lighting and ventilation, lifts and escalators. It is important to realise that these features aren't just buildings or indoor facilities. They include seating in the street or a pub garden, stiles and paths in a country park, or fixed signs in a shop or leisure facility.

How should a service provider deal with a physical feature that is making it difficult for me to use a service?

Once a service provider has identified the physical features that may make it difficult for you to use their service. They can remove that feature, alter it, find a way of avoiding it or provide the service in another way.

What to do if you are discriminated against

Your positive persuasion will usually convince an organisation or business to make adjustments and alterations to physical features. If you don't get a response to your initial enquiries or the response you get is unsatisfactory, you may want to consider taking matters further. This could include taking a legal claim.

Your first step to taking a claim is to gather enough information to be able to assess whether you have a claim under the DDA. And also whether that claim is likely to be a strong one or a weak one. There is a model letter recommended by the DRC which will help you to gather the relevant information (Available from

www.drc-gb.org/open4all/rights/selfhelp.asp or by contacting the SAIN office). Remember, as well as gathering information to help you make a legal claim this letter is also part of an on-going process of trying to persuade the organisation or business providing the service to make adjustments, without the need for legal action. So keep an open mind to the possibility of a negotiated solution that is satisfactory to you and the service provider. If when you get a reply (or in the absence of any response), you decide you want to take matters further contact your local access group, Citizens Advice Bureau, law centre or the DRC Helpline for advice on taking a claim.

In summary:

- This letter shouldn't be a first step - positive persuasion should come first and can often result in a practical and innovative resolution
- If you don't get a satisfactory response then use our suggested standard letter
- Once you've sent the letter, keep the lines of communication with organisation open. Once they realise how seriously you take this matter (and that they have legal duties) they may be ready to make changes.
- If you want to take matters further (including legal action) then seek advice
- Remember there is a six month time limit for legal action from the incident of discrimination under the DDA.

For more information on how these changes affect you and what to do if you feel you are being discriminated against and to Vote for the "best" and "worst" service providers visit www.drc.org.uk/open4all/ or call the SAIN office for advice.