

Support and social groups for people with acquired deafblindness. A formula for success?

A very common request from deafblind people and their families is that they meet and have contact with others in a similar situation. This workshop is about the formation of a new group which has, as one of its aims, the breaking down of the isolation caused by acquired deafblindness. We will discuss the setting up and running of a social and support group for hearing aid users with sight impairments. We will be looking at the Hearing and Sight Impaired UK (HSI UK) group as an example but I hope that you will have the time and opportunity after the presentation to talk about any group you are involved in or maybe your plans for starting a similar group in your locality.

1. The need for a new group

It is only over the last ten to fifteen years, in the UK, that people with Usher Types 2 and 3 have been diagnosed in larger numbers. Usher awareness amongst both ear and eye specialists has been much higher for Type 1, probably because the profound deafness of Type 1 is more recognisable. Historically, therefore, groups for visually impaired sign language users, most of whom have Usher Type 1, were set up before groups for visually impaired hearing aid users.

In 1995, Sense organised a residential weekend entitled “Usher Identity” which was for all people with Usher. However, it became apparent over the weekend that the fifty or so Usher people present split into two groups, based on their communication requirements. With the best will in the world, people with Usher Type 1, who relied on their remaining vision to communicate using sign, found it almost

impossible to communicate with those who had Types 2 or 3 who used speech, lip reading and hearing aids. Similarly, people with Types 2 or 3 could not communicate with sign language users who had no useful hearing.

Since our existing Usher group at that time consisted almost exclusively of sign language users, the first stirring among Usher hearing aid users to start a group for their own segment of Ushers can be dated back to 1995.

I should make it clear that there has never been any ill feeling or split between people with different Types of Usher in the UK; the new hearing aid users' group was based purely on the need for a group which had a common base for communication.

The communication parameters for the new group at its inception were that its members would use speech, lip reading, hearing aids or cochlear implants (or would be hard of hearing with no hearing aids) and would have English as their first language.

2. First steps in forming the new group

Following the Usher Identity weekend, four Usher hearing aid users (3 Type 2s, 1 Type 3) decided to set up a meeting for interested Usher people with the aim of starting an Usher hearing aid users' group. With some background help from Sense regarding publicity, speakers were arranged and a large room booked at the Royal National Institute for the Blind (RNIB) in Central London.

The meeting, which took place in 1996, was attended by about thirty people and, by the end of the afternoon, the Usher Hearing Aid Users (UHAU) group had been formed. The names, addresses and phone

numbers (this was before email was used!) of everyone present were taken and, with the help of Sense, a mailing list was set up.

3. The original aims of the group

As a group, Usher hearing aid users, along with many people with acquired deafblindness, are isolated because they have a low-incidence disability which affects their ability to travel, as well as their access to communication and information.

The aims of the group at that time were three-fold: to provide mutual support, to share information and to organise social activities. These three aims are still the bed-rock of the group, although they have expanded and matured over the years. More about that later!

To be honest, I can't remember much of the early meetings but there was a very successful residential weekend conference for this group, "Adapting to Change" which was held by Sense in 1998. After that conference, the group really took off in a new and revitalised way.

4. How UHAU evolved into HSI

As time went by, many new hearing aid users joined the group, which was still meeting and socialising primarily in London, either at the Sense head office in North London or at the Sense South East office in Norbiton, Surrey. The socials were supported by Sense but the UHAU Steering Group organised the speakers. This Steering Group consisted almost exclusively of Usher hearing aid users. Usher Services at Sense was still involved with running the mailing list and providing support to UHAU but an increasing number of decisions regarding the group were made by the Usher people themselves.

Members of the Steering Group at that time were being approached by other blind and visually impaired people who wore hearing aids. These people were finding it hard to follow hearing blind groups because of their hearing loss but also felt excluded from UHAU because they did not have Usher.

By now, in around 2000, the UHAU group was gaining in confidence and the Steering Group felt that it was time to open up the group to other visually impaired hearing aid users. A vote was held regarding the name of the new group, using the contacts on the mailing list and, as a result, UHAU became HSI (Hearing and Sight Impaired).

5. Becoming a branch of Sense

The newly-named HSI was, as UHAU was before it, an independent group of Usher people and, now, other visually impaired hearing aid users, supported on a practical level by Usher Services at Sense. It had no funds of its own. HSI was not a formal group with a formal constitution and the Steering Group was formed of volunteers, not elected members.

Sense has a membership scheme and a network of branches, which are usually local or regional groups of parents and families of congenitally deafblind children and adults. These branches receive a proportion of the Sense membership fee for each Sense member who is also a member of that branch.

In about 2001, the Sense Membership Team suggested to HSI that they might like to become a branch, not in the sense of belonging to a region but as a national branch consisting of a particular group of people, in this case hearing aid or cochlear implant users, usually non-signers, who also had a visual impairment. This would mean that the group would receive a small set-up grant as a new branch and would receive a proportion of the membership fees for each Sense member who was also a member of HSI. However, the group would then have to have a formal constitution and a proper committee and it would, of course, have to be accountable to Sense for its plans, decisions and finances.

After much consideration and discussion, HSI became a branch of Sense in March 2002 and also changed its name to HSI UK.

6. Expansion of HSI UK

Since HSI UK is now a branch of Sense, the Steering Group has become a committee and an Annual General Meeting is held each March or April. We have a subsidiary branch (should we call this a twig?!) in South Wales and two subsidiary branches in the North and North East of England. We have several international contacts, including Usher and other people in Australia, New Zealand and South Africa, as well as here in The Netherlands and throughout the UK.

7. The current situation

It has been my privilege to be involved in HSI UK from its inception over ten years ago and to witness at first hand how it has grown, both numerically and, even more importantly, in confidence, during that time.

Since 2002, we have been organising socials twice a year, with speakers ranging from a Hearing Therapist, a cochlear implant specialist, a member of staff involved in Sense's Usher research and an Usher person who is also a Sense Trustee. More recently, our Treasurer has discovered a talent for organising outings, which are becoming a well-attended and popular social feature. In fact, we are getting people coming along to the outings who have not been involved in any other Sense or Usher events previous to that.

Finally, we must mention the now famous (or infamous?) Christmas Social, held on the first Saturday in each December. We compete in answering sometimes quite difficult questions in a general knowledge quiz, a member of the group provides music and we have plenty of food. This is a party not to be missed!

8. Challenges

A main challenge for a group such as HSI UK is the difficulty which some of our participants have in getting to the meeting or outing. Not everyone lives near good transport links and, even then, a communicator-guide may be needed, particularly if the deafblind person's sight is very poor. It has been relatively easy to get people to an event in London but, in other parts of the country where population is more sparse, it is almost impossible to travel unless one has access

to a lift by car or taxi. Public transport, even if available, may not be accessible to a deafblind person.

Information needs to be available in a range of formats which makes preparing a mailout more complicated than usual.

There is always a risk of communication breakdowns, even between two or more hearing sighted people. As you can imagine, there is even more potential for misunderstandings between people with a dual sensory loss! These mishaps of communication can need sensitive handling.

9. Equipment and helpers required for the running of the group

Our main request is for is a clear, loud and reliable loop system and good lighting; also an accessible venue which is easy to find, with good signage. These requirements are much harder to come by than one might imagine! Some of our members need guiding from a mainline station, or from home, to the venue and we have links to some volunteers who will help with this. Information and committee papers are available in various formats as preferred.

10. Personal and group development as a result of taking on responsibility

It has been very encouraging to see how committee members have developed in skills and confidence as they have taken on responsibilities in running the group. Our current secretary, who has been in post for about five years, was fairly newly diagnosed as Usher Type 2 before becoming involved in HSI UK. She was very shy and lacking in confidence. Over her time as secretary, she has increased her already considerable organisational skills and has blossomed as

an Usher person, despite her narrowing visual field. She can be relied on to produce whatever paperwork is needed on time and she is able to contact new, or potential, members as required.

Our Vice-Chair, who has Usher Type 2, is very committed to his role, although he continues to work full time, and often emails everyone late at night because that is his only free time. His wife, who started her role as Treasurer very hesitatingly, is now sure enough of her role to stand up to quite difficult situations with the bank and has turned out to be a very good general advocate for hearing and sight impaired people.

HSI UK, led by our able Chair, no longer focuses entirely on itself. It has become a campaigning group, both on a national and on a local level. HSI UK also liaises with other organisations, such as the Royal National Institute for the Blind (RNIB), the Royal National Institute for Deaf People (RNID), the Retinal Awareness Group (RAG), Hearing Concern (a national organisation for hard of hearing people), the National Federation of Blind People and TAG, an umbrella organisation which concentrates on telecommunications issues for deaf, deafened, hard of hearing and deafblind people.

The committee consists of 8 people plus a note taker. Only one member of the committee, apart from the note taker, has full sight and hearing and she is the Treasurer mentioned above. We have three Usher Type 2s, one Type 3 and three other hearing and sight impaired members who do not have Usher.

11. Support needed by HSI UK from Sense

The main role of Sense now is to provide a suitable venue and the mailing list for sending out information about forthcoming events.

Since HSI UK is a branch of Sense, we have to write a branch Action Plan each year and we are invited to take part in the Sense Forum, as well as have access to relevant training events.

Sense therefore plays a background and back-up role; both major and day-to-day decisions concerning the running of HSI UK are taken by the committee.

12. The way forward

So, where do we go from here? Although much has been achieved over the last ten years, the bulk of the “happenings”, with the exception of South Wales and the North of England, are still very much located in London and the South East. We need HSI people in the rest of the UK to be similarly inspired to set up local HSI “twigs”, with support from the main HSI UK committee as required.

As well as our social commitments, we need to continue to look outwards and extend our campaigning role and our interests in equipment for HSI people. This would include input into appropriate telephony; broadcasting, both television and radio; hearing aids; alert systems; environmental issues and maximising sight. We are planning to start an e-group, as this is a wonderful way of breaking down the barriers of isolation.

13. Conclusion

Groups such as HSI UK grew from four people, hearing aid users with a dual sensory loss who saw the need for an exchange of ideas with others and decided to do something about it. Professional organisations that provide services for deafblind people should encourage these groups if they already exist, or supply the means for

the setting up of such groups. Recently diagnosed people with a dual sensory loss can be put in touch with an appropriate group where help from their peers is available. Also, helping to run a group can be enormously beneficial to someone's confidence and self-esteem. We have seen people grow and change as a result of being a committee member and taking on and holding down the responsibility of an Officer.

Although the setting up and running of HSI UK has been successful in the main, there have been some challenging times in the past and we still have a long way to go.

I hope that our experiences have been of interest to you and will inspire you to think about setting up a group or network in your locality. Maybe these questions will enable you to come up with some suggestions and ideas of your own.

Thank you

Marylin Kilsby, National Usher Coordinator, Sense

Questions (to start off the discussion)

1. What are your experiences in running and /or being part of a group for people with acquired deafblindness?
2. How would you publicise your group?
3. What would be the aims for your group?
4. Do you know of any appropriate volunteers? What do we mean by "appropriate"?