

## Factsheet 17

### A SENSE OF HISTORY

Sense was founded in 1955 as a self-help and support group for the parents of children whose disabilities were neither recognised nor provided for. The children were born deafblind as a result of their mothers catching rubella (German measles) in pregnancy. 'The Rubella Group', as it was known, was founded by Peggy Freeman MBE and the late Margaret Brock MBE, whose daughter and son respectively were born with congenital rubella syndrome.

The Group began with ten founder families and assets of £2.5s.0d (£2.25). Today, Sense is the UK's largest voluntary-sector provider of services to people with sight and hearing difficulties. It employs over 1,500 staff and meets the needs of thousands of dual-sensory impaired people from babyhood to old age.

This factsheet charts the history of Sense. The first part describes some key milestones and acts as a summary of the Sense story. The second part explains some of the major issues Sense has grappled with.

#### Sense - the key milestones

- 1955** Sense is set up as **The Rubella Group** with ten founder families. There is no provision for deafblind children other than one small unit. The Group begins by sharing information and pressing for services to meet the needs of pre-school and young children, and their parents.
- 1956** 23 families are in touch through the Group.
- 1961** The Rubella Group registers as a charity. There is a further epidemic of rubella. The founders visit schools around the country, hoping to encourage special units for children.
- 1966** The Group becomes **The National Association for Deafblind and Rubella Handicapped Children**.
- 1970** Rubella immunisation for schoolgirls begins.
- 1974** The Association drops the word 'children' from its title as the beneficiaries are growing up. The first holiday programme is held.

- 1975** The first head office is set up in Coventry and the Association begins lobbying for training and housing provision for young adults.
- 1980** The Magpie Appeal on ITV raises funds to open Manor House near Peterborough, the first UK centre of its kind for young adults, providing housing, training and education.
- 1981** The Association's first Director - Rodney Clark - is appointed. The Association begins discussions with the Government about the release of deafblind people from mental hospitals, where many have been cared for.
- 1982** The Ealing Family Centre opens to assess young children and support parents, and the Family Advisory Service is launched. The head office is moved to London and begins fundraising to extend its services.
- 1983** The Association becomes **Sense** and begins to provide services to a new group of people, those with Usher syndrome.
- 1985** Services begin in Scotland. The first group home opens in Market Deeping, Peterborough to provide supported independence to young adults.
- 1986** Sense becomes the sole trustee of the Royal School for Deaf Children in Birmingham and develops further education and residential facilities for young people. This becomes Sense Midlands. Sense opens its first shop, in Petts Wood, Kent.
- 1987** The Overbridge Continuing Education Centre opens in Glasgow. Sense's income tops £1 million for the first time. Sense, as part of a consortium, produces a ground-breaking report 'Breaking Through' which still influences social services planning.
- 1989** After years of Sense campaigns, the Government publishes the first guidelines on the education of deafblind children. HRH The Princess Royal becomes Sense's patron. Sense South West is set up.
- 1990** Sense is established in Northern Ireland.
- 1991** The Glasgow Family Resource Centre opens.
- 1992** The first intervenor service begins in Lincolnshire, providing weekly support to families at home. The Advocacy project is launched, helping deafblind people to express their views.
- 1993** Sense Cymru is launched in Wales. The Family Resource Centre in Bristol opens.

- 1994** Sense has 38 group homes. Communicator-guide services are set up, providing regular one-to-one support for mainly elderly people. Sense International is set up to share Sense expertise with projects around the world.
- 1995** Sense South East is set up.
- 1996** Sense North is set up and opens Melton House a day service for deafblind adults.
- 1998** Sense acquires its first residential care homes for older people. The Horizon employment project starts, training young people for possible entry into open employment. The first deafblind member of Council is appointed.
- 1999** Sense organises its first mass lobby of Parliament at which over 200 deafblind people and their supporters argue for more support under the banner 'Yes to Access'.
- 2000** Sense launches the 'See the Person' campaign to encourage service providers - shops, restaurants, banks - to meet the needs of deafblind consumers. Sense rebrands with a new logo to reflect its work more accurately.
- 2001** Success for the "Yes to Access" campaign, with the introduction of new Section 7 Guidance requiring local authorities to assess deafblind people's needs and provide appropriate services. Recognition of Rodney Clark OBE, who retired after 20 years of leading Sense, with the opening of the Rodney Clark Resource Centre in Leeds – offering educational opportunities and a ICT centre for deafblind people in the region.
- 2002** Sense sets up two new Saturday Clubs for deafblind children and their families in Barnet and near Leeds, as well as new summer play schemes in Sense Northern Ireland and Scotland. Sense sets up the Hearing and Sight Impaired Group for hearing aid users with impaired sight.
- 2003** Sense is playing a key role in the Early Support Pilot Programme, a Government initiative to improve services for families with disabled children under three. With much excitement - and some sadness - we closed the Princess Royal Centre in Birmingham to move to new premises. The new Birmingham resource centre houses teaching rooms, Sense Online (our ICT Learning Centre) and office accommodation.
- 2004** Sense launches the **National Collaborative Usher Study** with the Institute of Child Health and the Institute of Ophthalmology . The study is aimed at linking information about the severity and type of hearing, balance and vision loss in people with Usher together with the particular gene that causes their disorder.
- 2005** Sense celebrates its 50<sup>th</sup> anniversary. Commemorative events include a hugely successful family weekend and conference as well as a series of

prestigious lecture at the Royal Institution.

- 2006** Sense launches the **Fill in the Gaps** campaign aimed at securing the support needed by older people who have developed a dual sensory loss.
- 2007** A new children's service is launched in the North working with 42 children and young people and their families.
- 2008** Sense hosts the Deafblind International Co-Creating Communication with Persons with Congenital Deafblindness Conference in Leeds. Speakers and delegates came from all over the world to share expertise and innovative practice.
- 2009** Sense launches its new Five Year Plan, "It's in our hands", aimed at addressing the changing face of social care provision. The government reissues statutory guidance about services for deafblind people and circulated it to local authorities with a Local Authority Circular document.

### **The first priority - pre-school provision and the needs of parents**

When Sense was established in 1955, rubella epidemics were a common occurrence and hundreds of babies were born with congenital rubella syndrome. Rubella children typically had feeding problems, sleeping difficulties and many other behavioural difficulties, in addition to the communication problems inherent in dual sensory loss. Many children lacked any means of communication (signing was frowned upon at the time) and most were developmentally delayed; for example, few children learned to feed themselves or even accept solid food until they were seven or eight. Yet there was virtually no help for parents, no provision for pre-school children and little understanding of the impact of rubella syndrome.

Sense's first priority was to set up a newsletter (still going strong as *Talking Sense*) to share information about their children's needs and how to cope with them. They also began campaigning for help for parents and young children. By the late 1950s, the founders had established some allies in the then Ministry of Health who enabled health visitors and welfare clinics to receive some training in the needs of deafblind children. A successful Sense conference in 1961 attended by parents and many professionals did much to raise awareness of the issues, and by the following year Sense were fundraising to train a teacher to help pre-school children. In 1965, a day unit was set up in Hither Green Hospital which showed how special training could help two- to six-year olds. In Birmingham, another pre-school group was launched, run by Jessica Hills, initially a teacher of the deaf. Jessica went on to be a long-serving chairperson of Sense.

After many years of fundraising and lobbying behind the scenes, the biggest breakthrough came in 1982 when funds from the Magpie Appeal enabled Sense to open the Family Centre in Ealing, West London. Staffed by fully qualified teachers, the Centre provided Monday to Friday schooling for children, day and weekend courses for parents, and training for teachers and other professionals. It was enormously successful, both in demonstrating what deafblind children could achieve given the right training, and showing how parents could be skilled and supported to help their own children. The school unit closed in 1983, but the Family Centre went

on to provide assessments of deafblind children and continued its work with parents and professionals. A second Family Centre was opened in the Midlands in 1987, followed in 1991 by another in Glasgow and a Family Support Service in Sense East, and in 1993 by the Woodside Centre in Bristol.

Now, Sense is the biggest provider of support to pre-school deafblind children and their parents in the UK. We support families and children through the Family Centres and all seven Sense regional offices. A network of 13 branches helps parents to keep in touch with and support each other. Another group, the Family Network publishes its own newsletter, runs events, and keeps families in touch with each other and informed on the latest developments.

## **Battling for a decent education**

When Sense was first launched, specific educational provision for deafblind children was virtually non-existent. There was one special unit at RNIB Conover Hall School in Shropshire with places for five children, later expanded to 15 places. Some rubella-handicapped children were placed in schools for deaf or schools for visually impaired children, where some managed to cope if their hearing or sight was sufficient to enable them to communicate. But some of these placements failed and many children were labelled ineducable; and with severe developmental delay because of their dual sensory loss, many children were thought to be 'mentally handicapped', as the term then was. These children became the responsibility of the mental health services and were placed in Junior Training Centres (later to become schools for children with severe learning difficulties). Although the children were well cared for, their special needs, especially their communication needs, could not be met and few children in these centres reached their potential.

In the 1960s, Sense began a long campaign to persuade the Department of Education and Science (DES) to recognise the special needs of dual sensory handicapped children and to set up appropriate provision. The 1970 Education Act was the first breakthrough. It paved the way for special units to be set up, mainly in residential schools, though there was, as yet, no special training for the teachers. A postgraduate teacher's course was started by the University of Birmingham in 1988, and became a mandatory qualification in the following year.

The 1981 Education Act was a step forward in that it introduced the concept of 'special needs'. These were to be assessed and documented in a 'statement of needs' which specified the provision required. But despite Sense's representations, the DES once again decided that deafblind children were best placed in schools for children with severe learning difficulties. Sense continued its campaigns and by 1989 won a partial victory when the DES published a policy document which, for the first time, obliged local education authorities (LEAs) and special schools to consider the specific needs of dual sensory handicapped children. LEAs were also obliged to collect statistics on the numbers of deafblind children.

By the 1990s there were fewer rubella-handicapped children as the result of immunisation, so Sense extended its work to include all children with dual sensory disabilities, whatever the cause.

Though there is still no national provision, many special services have been set up

since 1986, some in Sense itself. Sense's achievement has been to demonstrate to Government both the special needs of deafblind children and the value of parents as partners in the education of their children and the shaping of public policy. Today, Sense still helps families to get the best possible education for their child and is an acknowledged expert on educational policy.

## **Towards independence - homes, work and leisure**

By the 1960s, the children in whose name Sense was founded were growing up and the founders were becoming concerned about their fate when they left school. At the time, there was no provision for them other than Adult Training Centres (ATCs) run by the mental health services. Placements in ATCs were often unsuccessful because there were too few staff who had no training in this field.

There was also the issue of housing. Rubella handicapped young people could not live independently of their parents, but what would happen when the parents were too old to care for them? It was clear that the next priority was to set up appropriate training centres and hostels. By 1974 Sense were fundraising to set up an experimental centre and, after the successful Magpie Appeal on ITV, Manor House in Market Deeping, Peterborough was opened in 1980.

Manor House opened with 12 students, who quickly showed their potential. Not only did the training centre produce excellent craft work, but the students developed in unexpected ways as a result of skilled further education. Some learned to read and write, others learned to sign, and all began to acquire many independent living skills. Manor House led to the development of 'group homes' - ordinary houses in the community where deafblind people would have greater independence. The move towards this type of provision was encouraged by the Department of Health and Social Security whose 'Care in the Community' document of 1982 envisaged the transfer of patients from mental hospitals to social services provision. In 1985 our first group home opened in Market Deeping, to be followed in 1987 by others in the Midlands when Sense Midlands was launched at Edgbaston, Birmingham. The Edgbaston site also included another training centre offering further education and craft skills to its students.

The late 1980s and 1990s saw enormous expansion in our housing provision for deafblind people. By the end of 1999, Sense had 73 group homes throughout the UK, providing supported housing and further education for 314 deafblind people who will be able to live there for as long as they choose. Sense is now extending the range of housing provision, including self-contained flats where residents have even greater autonomy.

In 1998 Sense moved its Edgbaston training centre to a new site in Oldbury where young people are being trained in a workshop environment for possible entry into open employment. Some are already working part of each week in local companies.

## **Holidays**

Sense holidays began in 1974 when the Brown family took a small group of children and young people on holiday, giving them an opportunity to sample new activities and giving their parents a welcome break. Sense now runs holiday programmes

every year for at least 120 holidaymakers of all ages, supported by over 200 volunteers.

## **Serving people with Usher syndrome**

Usher syndrome is a major cause of sight and hearing difficulties. People with Usher are born deaf or partially hearing and gradually lose their sight as teenagers or young adults as a result of an eye condition called Retinitis Pigmentosa. Their needs are obviously very different from people with congenital rubella syndrome. Sense began providing services for people with Usher in 1983, offering support and advice, especially on communication, and raising awareness of the condition, which was often not diagnosed. This work has resulted in the emergence of Usher UK in 1995, a self-help network, mainly for people who use sign language. Usher UK now runs its own meetings and newsletter. Another group, Hearing and Sight Impaired, for people who use hearing aids, is now getting off the ground with Sense's support.

## **Meeting the needs of older people**

The majority of people with sight and hearing difficulties are in older age groups. Over half of people over 60 have some degree of hearing loss and one in twelve has serious sight loss, while a minority lose both sight and hearing. Sense began working for this age group and for others with acquired deafblindness in 1994.

Communicator guide schemes, also established in 1994, help mainly older people to maintain their independence. Communicator guides offer one-to-one support, for example helping someone to get to a hospital appointment, deal with the bills or go shopping. Sense also trains and support other professionals. Between 1998 and 1999, Sense acquired three residential care homes for older people to extend services for this age group.

## **A world player**

By the 1990s, Sense was an acknowledged expert in its field and Sense International was set up in 1994 to share that expertise worldwide. In many parts of the world, services for deafblind people and their families are non-existent and their situation is often desperate. Sense International began work with partners in Latin America in 1995. The Sense International Professional Development Programme started in 1996, training people to work in their own countries. In 1997, a Development Manager for India was appointed and the first Indian project was launched in the following year. In February 1999, a second Development Manager was recruited in Romania and already several projects have been established.

By early 2000, Sense International has twelve staff in four countries and has worked with programmes in more than twenty countries.

### **1. A Sense of the future**

Sense has achieved a great deal since its modest beginnings in 1955 but there are still challenges ahead if deafblind people and their families are to receive all the services they need. We have recently published A Sense of purpose: our strategic plan for 2004-2009 which lists our main priorities. We plan to place the emphasis on

putting the individual first, enabling them to overcome barriers. We will help deafblind people to develop their own voice. To give added weight to our work and campaigns we will continue to develop our understanding of deafblindness.

## **2. Further reading**

*Good Sense: The National Deafblind and Rubella Association 1955 - 1995*; by Peggy Freeman. Sense, 1996.

## **3. Where can I go for help?**

If you:

- would like to find out more about deafblindness or the services for deafblind people in your area
- require information in alternative formats including braille, large print, audio or disk - or would like this factsheet to be translated into your first language -

please contact Sense's Information Team.

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