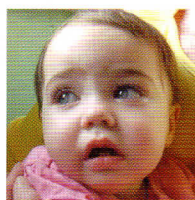




Association for Spina Bifida and Hydrocephalus

STRATEGIC PLAN: 2006 - 2011



Introduction

It is my great privilege to be the chairman of ASBAH as it celebrates its 40th anniversary. For 40 years the Association has worked determinedly and with great passion and indeed success, to fulfil its vision of a future where everyone with spina bifida and/or hydrocephalus can get the most out of life.

That vision remains as clear and as appropriate today as it has been at any time in the last 40 years. ASBAH is also equally clear about its own role and purpose in working to achieve that vision.

It is appropriate that in this anniversary year ASBAH also sets out its own strategy for the next five years. In this Strategic Plan we are signalling ASBAH's determination to continue our strong tradition of giving direct, high quality support to individuals, whilst also responding to changing times. Policy developments in health and social care are under way that will lead to more government-funded support for people with a range of long-term neurological conditions. We at ASBAH will influence these developments to ensure that our service users benefit, and that their needs and experiences are reflected in new services.

We will continue to provide skilled ASBAH Advisers and other staff to work directly with disabled people and their families. Also, reflecting the changing policy environment, a strong theme of this strategy is to influence and inform service-planners in the NHS and local authorities, to create a better quality of service for everyone who has spina bifida and/or hydrocephalus. We will ensure that our staff have the information and skills required to undertake this changing role. ASBAH agrees with the government report 'Improving the Life Chances of Disabled People', which emphasises helping disabled people increase their independence, improving support to children, and improving transition to adulthood.

Richard Astle, ASBAH Chairman

Vision

ASBAH's vision is a future where everyone with spina bifida and/or hydrocephalus can get the most out of life.

Mission

ASBAH works with people who have spina bifida and/or hydrocephalus (SB/H), their families and carers to promote individual choice, control and quality of life.



Activities

Aim 1

To improve and inform public attitudes towards disabled people, and those with spina bifida and/or hydrocephalus in particular, so that society becomes inclusive. We aim to:

- consult and involve people with SB/H, their families and carers, in formulating the policies and priorities.
- join forces with other agencies, umbrella groups and partners to lobby effectively.
- campaign at national and/or regional level to influence government policies and priorities.

Aim 2

To influence and inform professional workers, agencies and government about SB/H, so that a comprehensive range of support is provided, through health, education, social, employment and other services. We aim to:

- maintain a skilled Adviser team to inform and support service users and their families in achieving their aims.
- consult with leading experts and professionals in relevant fields.
- influence government-led initiatives in health and social care and social inclusion to ensure that the particular needs of people with SB/H are better understood and catered for.

Aim 3

To value people with SB/H and involve them fully in the Association. We aim to:

- listen to disabled people and their families and learn from their experience.
- promote and encourage events and experiences which will empower disabled people to take control of their lives.

Aim 4

To be widely recognised and known as the leading source of information and expertise on hydrocephalus and spina bifida. We aim to:

- disseminate high quality information and broaden awareness of our presence as a source of expertise and support.
- support local ASBAH Associations and encourage them to be affiliated.
- initiate a telephone Helpline and Information Service, supported by wide publicity, to make ASBAH more accessible to potential service users.
- promote and encourage research in our field and disseminate results.



In addition to these aims, ASBAH will also undertake to uphold the following:

ASBAH as Influencer

The realisation of the Association's mission of bringing individual choice, control and quality of life to people with SB/H depends on a wide variety of high quality services being available from a range of providers, throughout the disabled person's life. It is the duty of society to provide or procure these services but because of the complex nature of the impairments many agencies and professional workers do not have a good understanding of SB/H. ASBAH will work to correct this deficit by providing good information to influence agencies so that they can fulfil their duties to service users.

ASBAH's aim is to mobilise skilled services from agencies responsible for health/medical care, education and lifelong learning, benefits, equipment/adaptations, housing, training, employment support, leisure, transport etc. Where ASBAH can help to develop good practice and demonstrate excellence, opportunities will be created to show effective ways of working with the responsible agencies.

ASBAH will further develop the capacity and skills at national and regional level to influence and campaign on key policy matters and will work with local partners to improve local service planning and commissioning.

The Social Model of Disability

In pursuing its vision and mission, ASBAH asserts the right of all disabled people to full inclusion in society, whatever their physical, sensory or learning impairments. ASBAH believes that the degree to which any person's impairment is disabling depends on the extent of societal barriers, be they economic, environmental or cultural. ASBAH therefore promotes the elimination of barriers, through the provision of services and adjustments, and improvement of attitudes. ASBAH aims to create and enhance opportunities

for full participation in society for those whose impairments are spina bifida and/or hydrocephalus.

In communicating realistic information and publicity about SB/H, the particular challenges and needs will be described in a manner which emphasises opportunities, the scope for realisation of ambitions, and the right to a good quality of life.

ASBAH will promote positive messages and images which will improve public attitudes to the disabilities.

Prevalence and Trends

Research undertaken for ASBAH gives the UK incidence of spina bifida pregnancies (all neural tube impairments) at more than 1,200 per year.

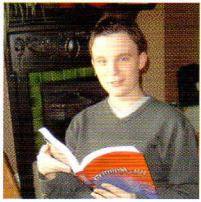
The UK live birth incidence for neural tube impairments is now about 1 per 5,000 births, having fallen dramatically during ASBAH's lifetime because of elective abortions, improved vitamin intake, and possible other factors.

Conversely, more children today are surviving with hydrocephalus owing to better medical/surgical interventions. Because reporting is patchy and inconsistent, incidence statistics are unreliable, but for ASBAH this is likely to be a significant growth area in our work.

The life expectancy of people with SB has increased dramatically over this period, so that the needs of adults with SB form a large proportion of the demand for ASBAH's support, where a neural tube impairment is involved.

Better survival of babies with hydrocephalus, including very premature infants, means that the largest proportion of ASBAH's work with children concerns the health and educational issues that are associated with hydrocephalus.

Many individuals with SB/H need additional help to develop the organisational skills necessary for



independent living. Many live as adults, with parents, in the family home, but require more support to prepare them for greater autonomy, as their parents grow older. ASBAH will work to encourage service developments to meet this challenge.

It is now recognised that some older people develop hydrocephalus late in life, showing symptoms akin to senile dementia, which can be treated by implanting a shunt. Efforts will be made to make ASBAH's information and support available to this group of potential service users.

ASBAH's Compact with Local Associations

ASBAH aims to support affiliated Local Associations so that they are accessible and effective for people in their local area, and well informed about local services and facilities. ASBAH encourages all Local Associations to enter its mutually agreed Compact, which sets out basic standards and expectations on both sides. ASBAH will work particularly with Local Associations which are part of the Compact. Local Associations have an important role in influencing local service planners and commissioners to address the needs and wishes of people with SB/H.

By speaking with a united voice, national and local ASBAH can better inform and influence other providers. ASBAH aims to make joint bids, with Local Associations, to statutory service commissioners, to assist the funding of Advisers and other services.

ASBAH will work with interested groups and individuals and support them with information and guidance, to help them act as champions for service improvement.

Information, Support and Advocacy

Some people with SB/H are prevented from participating in society by a range of constraints, and need to be empowered through skills and

confidence to realise their potential.

ASBAH recognises the need of disabled individuals and their families for contact with an informed and empathetic person who listens, offers relevant information, and can advise or point towards sources of expertise. Whilst it is beyond the resources of ASBAH to employ Advisers who can offer a continuous service for everyone in our beneficial area, we will provide a team of professional Advisers whose skilled interventions can help service users to reach decisions and benefit from the range of voluntary and statutory services available.

Advisers will, where possible, use their expertise to influence local service planners and commissioners of health and social care services, to deliver better services in our field.

When necessary, ASBAH staff will act with service users as advocates for them, for defined purposes.

Recognising the importance of education, ASBAH will offer support to children and parents in addressing educational choices and problems and obtaining the best possible service from schools. The interests of the individual child will always be our primary concern. Lifelong learning opportunities are of particular importance to young people and adults who have SB/H and will be promoted.

ASBAH will strengthen its information and advisory services by setting up a national Helpline and Information Service which will respond to telephone calls, e-mails and letters, issuing high-quality information and, if appropriate, signposting to other sources of expertise. A wider range of information leaflets and bulletins will be made available for electronic or hard copy distribution.

The Helpline will be widely publicised at relevant information points, through websites, and in directories. This will help to inform all potential service users of ASBAH's existence, and allow them to access our services.



ASBAH will continue to invest in "Link" magazine to ensure it remains up-to-date and a lively, attractive magazine for members.

Forum of Disabled Members

ASBAH will continue to encourage membership and participation in the work of Your Voice, the disabled users' forum, through which the expertise of disabled people helps to serve others, particularly young adults, whose talents will benefit the Association and its future work. The number of participating Your Voice members will be increased by offering attractive events and activities which are seen as relevant by service users. ASBAH will continue to fund the Your Voice forum and seek support for its work from outside sources.

The Your Voice forum, and its elected committee, acts as a source of ideas and critical support in the development of appropriate policies.

Research

Medical research will be encouraged and financially supported where possible, to increase knowledge of the causes and complexities of SB/H. As well as the possibility of primary prevention, studies into treatments and interventions which may minimise impairment and improve the quality of life of disabled people will be supported. ASBAH will encourage improvements to reporting and statistical methods so that a true understanding of the prevalence of SB/H can be achieved.

Social and educational research will be supported or commissioned when necessary, both to inform campaigns and to bring the benefits of enhanced knowledge and expertise.

The views and ideas of disabled people will be sought so that research studies and activities are appropriate and relevant to them.

Raising Funds

ASBAH will continue to create fundraising opportunities on a broad front, while monitoring the success and cost-effectiveness of each activity. This will include telephone appeals, mailings, an individual donor scheme, charity shops, community and sponsored events, large project bids, applications to trusts and companies, and the development of legacies. Regional initiatives will be pursued in collaboration with Local Associations where practical.

Corporate partnerships and sponsorship will be sought, to support publicity, publications and marketing, and other appropriate objectives.

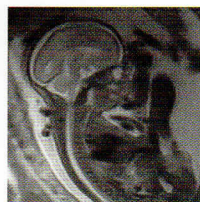
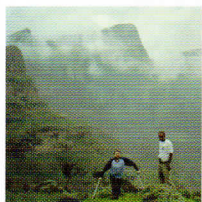
A specific appeal will be undertaken to set up and run a new Helpline and Information Service, attracting the support of leaders in the world of business, sports and media.

Governance

ASBAH will ensure that a strong and diverse national Board of Trustees is enabled to exercise high quality governance. Induction and orientation of newly elected Trustees, training on selected topics, periodic audits of Trustee skills, and active maintenance of a Key Trustee scheme by which individual Trustees assume specific areas of interest, all result in a well-informed and forward-thinking Board. Meeting agendas will be strategic in nature, with reports designed to summarise information and present choices clearly, allowing the Board to monitor current activity, take decisions and form future plans.

Trustee Activity

As well as functioning as Board members, Trustees may at times take a leading role in representing ASBAH in a variety of contexts, acting as ambassadors towards member groups, officials, funders and other stakeholders.



Management

ASBAH will effectively manage staff and resources, acting as a good employer, demonstrating full accountability to its elected Board of Trustees and to the public. Its advisory services will work to the Community Legal Services (CLS) Quality Mark, and other activities will conform to PQASSO Level 2 as a minimum.

An annual Business Plan will be agreed by the Board of Trustees, against which performance will be measured.

The committee structure through which members monitor activities will be periodically reviewed through the Board.

Staff will be offered relevant in-service training, and be kept informed of key developments through regular briefings. Staff salaries and pension provision will be regularly reviewed. Formal communication will be maintained with a Staff Joint Negotiating Committee, ensuring that policies and procedures are up-to-date and responsive to current needs.

Finance

Approximately 80% of ASBAH's expenditure relates to staff costs, signifying a heavy commitment to staff and, through them, to service users. A balance will be sought between using income to achieve the Association's aims and retaining a responsible level of reserves. The Board has set a target of holding six months costs as free reserves.

Modern and effective financial and administration systems using appropriate IT will be operated in active communication with professional advisers to ensure full compliance with the SORP and other charity best practices. Regular reviews of banking, insurance, audit, suppliers and investments will be made.

Our Commitment

The Trustees and senior staff commit themselves to furthering ASBAH's distinguished record of improving the lives of people with spina bifida and/or hydrocephalus, their families and carers. This commitment extends to all those with a stake in the Association, including members and service users, staff, funding bodies and supporters, and professional colleagues in our field, all of whose dedicated efforts we gratefully acknowledge.

About ASBAH

ASBAH has been working for 40 years to improve the life opportunities of people with spina bifida and/or hydrocephalus. The Association's work embraces a span of activities that require a diverse range of professional skills, including the support of health, educational and social needs, as well as influencing policy and furthering research.

ASBAH is committed to supporting over 15,000 individuals, with 400 new contacts asking for our help annually. ASBAH acts as a central resource for 34 affiliated Local Associations, which offer local support and information.

As well as a national office in Peterborough, we have five regional teams of community advisers covering England, Wales and Northern Ireland. A forum of disabled members influences ASBAH policy and encourages user participation. ASBAH sponsors social and medical research into spina bifida and hydrocephalus.

ASBAH's Trustees include service users who have spina bifida and/or hydrocephalus, parents of children who have spina bifida and/or hydrocephalus and professionals from a range of disciplines.



**Spina Bifida
Hydrocephalus**

HELPLINE

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ASBAH
1966-2006 Challenging the future
Association for Spina Bifida and Hydrocephalus

Registered charity number 249338

Community
Legal Service



ASBAH works to the quality
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and holds the CLS Quality Mark