



Special Needs Information Point Annual Report 2002 - 2003

“Snip believes that accurate, accessible, timely information can improve the quality of life for children with special needs and their families”

Patron's Message



" I never thought I'd write the words Snip: the movie, but there it is. I've just finished watching the video and for some reason it seems like a tremendous milestone. The work of snip and the work of so many people put into Snip has always been very real, so why seeing it on screen should make a difference, I don't know. But it does. I watched it and it felt like Snip had come of age and...maybe it's my hormones (!) but...I had a lump in my throat. Just sitting on the very outer edge of the circle, I feel very proud of what Snip does."

Kaye Adams

Snip Patron Kaye Adams

Snip is a voluntary organisation based at the Royal Hospital for Sick Children in Edinburgh. It is managed by a committee of parents of children/young people with special needs and professionals working in the field. Some of the staff have personal experience of parenting children/young people with special needs.

Snip aims to:

- Promote information to families and carers of children with special needs, the children and young people themselves and the professionals who work with them
- Provide emotional support to parents/carers
- Educate professionals in the statutory and voluntary sector about the needs of families of children and young people who have chronic illness or are disabled
- Link with other information and support services in the statutory and voluntary sector, making and receiving referrals as appropriate
- Raise the profile of the needs of disabled children and their families in the wider community

- Provide input into policy at local and national level with regard to children and young people with special needs

These aims translate into three distinct areas of work for Snip:

- **Information, advice and support**
- **Education and training**
- **Consultation and policy**

In addition, Snip's employment policies and practices mean that we enable parents of children and young people with special needs to work for the organisation. This is very important, since research carried out by the Joseph Rowntree Foundation and the Family Fund shows that only 0.3 % of mothers of severely disabled children work full time, which is well below the national average for all mothers.

Information, advice and support

Thanks to our Patron's 'Celebrity Who Wants to be a Millionaire' win last year we have been able to extend our staff team by two part-time Information & Support Workers, Sharon Dunlop and Jane Stewart, to work in the wards at the hospital and on the telephone helpline.

Wards

Repeated and long stay admission to wards at the Sick Children's hospital are sadly a regular feature of many families' lives. In addition to the worry about their child, parents have to manage other children and work commitments. It is a hugely disruptive and stressful time. Recognising this, Snip has always provided information and support to families on the wards. With the appointment of these two new workers we have been able to reach more families. This increased visibility has led to a huge rise in demand for the service.

Of the people we worked with this year, **231 were parents who received intensive emotional support at the hospital** either when their child or young person was in Intensive Care, the High Dependency Unit, Neonatal Unit or on the Wards. Because the hospital is now the intensive care specialist centre for the East of Scotland, many of the families are a long way from home and this leads to even more stress than if they were from the local area.

Some of the comments we got from families about this support are as follows:

'Without Snip we would have been completely lost, when our baby first became ill we had no idea where to turn'

'Sharon supported me at a meeting on the ward about my son and asked questions that I would not have known to ask but needed the answers to'



Telephone Helpline

Very few parent callers to the helpline actually have a particular question. Parents come to Snip with a wide variety of circumstances and our job is firstly to listen to them and identify with them what information might enable them to deal with those circumstances more effectively. They are often distressed about their situation and do not know where to turn or what to do next.

The staff at Snip are skilled at listening and asking open questions which enable the caller to identify what their main issues are and what they need to know to deal with these issues. Staff are then able to draw on their own personal experiences and professional expertise to provide information and guidance.

Many parents needed information about:

- Benefits and Trusts
- Conditions and impairments
- Support groups/Counselling
- Activities for their children
- Holidays and associated issues such as special travel insurance etc
- Education

Often the families need to have systems and processes explained, such as:

- How to make a claim for Disability Living Allowance and other benefits
- The roles and responsibilities of the various professionals involved with their child
- How to go about accessing learning support for their child at nursery and school
- What can they expect from review meetings and multi-disciplinary team meetings (MDTs)

Between the helpline and the wards we answered no fewer than 1474 enquiries over the year, an increase of 20% on last year.

This increase was also partly due to our new ground floor premises, which we moved into in September. It means that families can now drop in and have a coffee and a chat when they are at the hospital. We have also seen an increase in nursing and other colleagues calling in, now they don't have to climb to the attic any more! Our sincere thanks go to staff at the hospital for generously swapping rooms. Four hundred and fifty-eight professionals from health, education, social work and the voluntary sector used Snip this year. We were delighted that Gail Peterson of the Royal Bank of Scotland Marketing Dept carried out a market research project on our behalf to get professionals' views of the service and its future direction – this is some of the feedback we received:

'Excellent service and extremely helpful'

'Very effective team working, highly skilled and motivated staff, informative organisation and compassionate'

The market research revealed a high awareness of Snip and its services and 83% of respondents had used Snip, 24% using its services between 6 – 10 times in the last twelve months. 94% said they would recommend Snip to other organisations and 72% had referred families to Snip.

Website

A big 'thank you' goes to Mike McLean for his voluntary work on the web-site over the past few years. We wish Mike well in his new job. We are delighted that our new Information Assistant, Helen Edmond, has web-site development skills and she has now taken on this role.

Newsletter

The newsletter 'Snippets' now has a circulation of over 1000 copies per month. We are flattered that articles from Snippets are regularly reproduced in other publications. A number of members receive the newsletter in alternative

formats, including electronically. This is in addition to the range of Snip publications available for download from our website.

Therapeutic Support Groups

The City of Edinburgh Council Social Work Dept has provided funding for Snip to run therapeutic support groups for parents of children with special needs. These groups offer parents the opportunity to talk in confidence with other parents about the emotional implications of caring for their children and are facilitated by an experienced and qualified counsellor, Maggie Harris. The funding also provides five sessions of 1:1 counselling for parents who are unable to use the group.

Participants in the groups have generally found the experience to be very positive and helpful and comments include:

'..finding out I am not alone with experiences and emotions has been an enormous help'

Education and training

In September we were delighted to promote Claire Edwards to a new post of Information and Training Manager. She is the day-to-day supervisor of the two new Information and Support Workers and designed their induction programme. Claire is primarily responsible for developing Snip's rapidly expanding training role. Her work over the last year in promoting Snip as a training organisation has resulted in a number of commissions throughout Scotland. A major commission has come from the Redesign Project within Lothian University Hospitals NHS Trust to design and deliver training on Key Working next year.



Professor Sheila Riddell shares an informal moment at the care co-ordination Conference.

Claire and Shirley have also delivered a number of workshops on a range of issues including:

- 'Breaking Bad News'
- 'Emotional Implications of Caring for a Child with Special Needs'

Snip's role in the education of healthcare professionals within the Royal Hospital for Sick Children in Edinburgh has been further developed through the formal inclusion of a variety of modules in the undergraduate and post-graduate training programme for junior doctors. Claire has worked to formalise existing training commitments with the colleges and universities within Edinburgh as well. Healthcare professionals have told us that the parental perspective is a valuable addition to their training and that our input will significantly influence their practice in the future.

Snip conference

A major highlight of the year was our first ever conference which attracted no fewer than 120 parent and professional delegates from all over the UK. The theme of the conference was Care Co-ordination and Keyworking for disabled children and their families. The day was chaired by Professor Sheila Riddell of the department of disability studies at Glasgow University. Shirley Young opened the day by explaining the current legislative framework in relation to Care Co-ordination. Professor Trisha Sloper of the Social Policy Research Unit at the University of York spoke to current research in the field and a parent from Leicester gave a very moving and eloquent account of her struggle to co-ordinate her severely disabled child's care. In the afternoon there were a variety of workshops where delegates could learn about and share their experiences of good practice. To enable parents to attend the conference free places were provided and there was a crèche.

Feedback from the day was extremely positive and included such comments as :

' The most welcoming atmosphere I have ever known at a conference' – Parent

'Excellent day – let's hope we can put things into practice soon!'

'Very informative and enjoyable day. Great for networking.'

'Very useful, thought provoking day.'

Consultation and policy

Care Co-ordination

Snip has lobbied for better co-ordination of services for families of children with special needs for many years and Shirley is the Scottish Trustee for the Care Co-ordination Network UK.

Another highlight of the year therefore is the commissioning of Shirley to lead the Care Co-ordination Action Team as part of the Lothian Universities NHS Trust's Community and Therapies Re-design Project. This exciting, major piece of work has involved Shirley in leading a multi-agency team, including parents and the voluntary sector, in establishing four Care Co-Ordination pilot schemes in North East and North West Edinburgh, Midlothian and East Lothian.

In addition to our commitments to a wide ranging of forums at local, Scottish and UK levels, Shirley and Claire have also contributed to the following reviews and consultations –

- SEN and Disability Discrimination Act
- Scottish Executive – Review of practice - Schools Division
- Additional Support Needs legislation

Committee Profile

We are delighted to welcome Shona Moyes as a new parent member of the Management Committee.

The remainder of the committee are as follows:

Chair: Miranda Harvey - Parent
 Vice Chair: Rachel Wilson - Parent
 Treasurer: Sue Mclean – Parent
 Joy Blakeney – Professional
 Lesley Mount – Parent/Professional
 Louise Jarman - Professional

Once again, the Committee have had a busy year overseeing the operations and management of Snip. At the annual Development Day we were delighted to hear the feedback of the market research survey, presented by Gail Peterson. We agreed that in view of the huge rise in demand for Snip's services we should increase the hours of one of the Information & Support Workers to full-time.

As usual, Committee members have undertaken a number of training courses to improve their skills. Miranda, together with Shirley the Project Manager, attended a day delivered by the Directory for Social Change on 'Managing Organisational Change'. Other members have attended sessions on Equal Opportunities, Best Value and Service Level Agreements.

Treasurer's report

The excitement of the "Who wants to be a millionaire?" win crossed over into this year. The money won by our generous patron Kaye Adams and her friend Ross Kelly has enabled Snip to reorganise and expand its services. In September we were joined by three new members of staff. Families on the wards and callers to the helpline have benefited greatly from this enhanced service.

Our thanks go to Edinburgh's Royal Hospital for Sick Children for providing us with a new fully accessible office and for continuing to cover our telephone and postage costs.

We are grateful to everyone who has so kindly donated money and benefit in kind this year. We continue to receive support from the Community Fund, Lloyds TSB Foundation, Midlothian Council, Lothian Health and the City of Edinburgh Council. Ian Rankin once again deserves special thanks, as do the regulars at Swany's and Oxford bars, the Margaret Black Trust, Psymetrix, NSA Club, British Association of Accident and Emergency, Wisconsin Scotland Trust, National Library of Scotland and indeed everyone who has put money in our collection cans. We are also grateful to John MacAulay for organising an excellent fundraising dinner in collaboration with FACE. Proceeds from



this event will be received in the next financial year.

All donations, large or small, are always welcomed and thanks must also go to our G.A.Y.E donators.

The hard work of all our staff is reflected in the increase this year of the income generated from commissioned work, training and speaker's fees. The success of Snip's first conference in March is also a tribute to all our staff (The majority of conference fees were still outstanding at the end of the financial year and so there will be a net profit, rather than the loss reflected in these accounts.) The conference was the launch pad for Snip's keyworker training role, which we anticipate will become a reliable source of income. Friends and well wishers continue to support our fundraising events which include our annual ceilidh and raffle, the RHSC Street Fair and our Santa letters.

As expected, we have used some of the 'Millionaire' money from last year's surplus to meet the shortfall between income and expenditure – expressed in the accounts as a deficit. As funding from the Community Fund and the Lloyds TSB Foundation end in June 2003 a funding strategy, including the appointment of a fundraiser is being actively pursued by the Management Committee. Another essential element of the strategy will be to use the soon to be completed promotional video, fronted by Elaine C Smith, to encourage corporate giving and Give As You Earn.

Anyone interested in discussing how they can contribute to the work of Snip should contact the Snip office.

Sue McLean
 Treasurer

ACCOUNTS SUMMARY

Special Needs Information Point

Income & Expenditure Account Incorporating a Statement of Financial Activities For The Year Ended 31 March 2003

	Notes	Unrestricted Funds £	Restricted Funds £	Total Funds £	Total Funds 2002 £
Incoming Resources					
Donations & Membership		2,666	-	2,666	118,887
Activities in furtherance of the charity's objects	2	19,579	50,768	70,347	77,725
Activities for generating funds	3	17,279	-	17,279	7,494
Investment income – bank interest		4,978	-	4,978	851
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Total incoming resources		44,502	50,768	95,270	204,957
Resources Expended					
Fundraising costs	4	396	-	396	264
Cost of activities in furtherance of the charity's objects	5	47,833	49,229	97,062	73,842
Support costs of activities in furtherance of the charity's objects	5	6,071	-	6,071	3,118
Management & administrative costs	5	4,355	-	4,355	1,451
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Total resources expended		58,655	49,229	107,884	78,675
Net (outgoing)/incoming resources for the period		(14,153)	1,539	(12,614)	126,282
Fund balances at 31 March 2002		141,551	9,435	150,986	24,704
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Fund balances at 31 March 2003		127,398	10,974	138,372	150,986

All the results of the charity relate to continuing activities.

There were no other recognised gains or losses other than those included above.

The accounts for the year ended 31 March 2003 were approved and signed on behalf of the Committee on 1 September 2003.

Sue McLean Treasurer

Full accounts and independent examiners report available from SNIP office on request.

Special Needs Information Point
Royal Hospital for Sick Children
14 Rillbank Terrace
Edinburgh EH9 1LN
Helpline/ Fax 0131 536 0583 (10am - 4pm Mon to Fri)
Office/ Text phone/ Fax: 0131 536 0360
E-mail: snip@btinternet.com
Web-site: www.snipinfo.org

Scottish Charity No: SC000264

Agents, Advisors and Supporters

Bankers: Royal Bank of Scotland, University Branch, 61 Forrest Road, Edinburgh

Payroll Advisors: SCVO

Independent Examiner: James Anderson & Co. Chartered Accountants

Collating Team: Pefferbank Co-operative

