



**SNIP**– supporting children, young people and families  
Annual Report 2004-2005





**Kaye Adams**  
**SNIP'S Patron**

'The capacity that SNIP has to constantly reinvent and reinvigorate itself as an organisation never ceases to amaze me. The notion that, after fifteen years, SNIP would just 'tick over' is inconceivable. The training arm goes from strength to strength and is showing real potential to provide a substantial income stream.

The role of the Youth Worker in exploring the very particular needs of young disabled people, 12 and over, is very exciting. It is hoped that funding will be found to continue this work next year.

Yet again, the number of families supported by SNIP has increased year on year. Those are just the headlines; there are countless initiatives on-going at various stages of development and thanks to the commitment, enthusiasm and energy of all those involved with SNIP, there doubtless always will be'.

*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. Four out of the five staff are also parents of children and young people

who are disabled and they draw on their own experiences to inform their work with parents and professionals.

### **SNIP aims to:**

- **Promote information to families and carers of children with additional support 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**

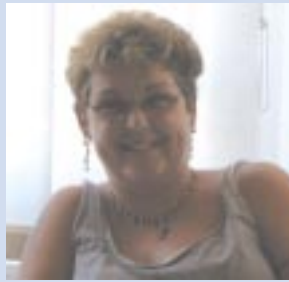
the needs of families of children and young people who have chronic illness or are disabled

- 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 additional support needs.

These aims translate into three distinct areas of work for SNIP which result in many positive outcomes for children and young people with additional support needs and their families:

- **Information, advice and support.**

Our Information & Support workers, Sharon and Veronica, carry out the



Sharon



Veronica  
Information and support workers

following two main areas of work:

### Providing Information and Advice

### Giving Emotional Support

Both of these aspects of work are carried out either face to face in the SNIP office, on the wards of the hospital or via the telephone help-line. As a result of SNIP's involvement this year parents have:

- **Accessed around £100,000 in benefits**
- **Successfully secured**

around £4,000 in grants from trust funds

- Received grants and a range of items such as washing machines, driving lessons and holidays etc from the Family Fund.

Parents have used these funds to meet the significant extra costs associated with caring for a disabled child/young person. Research carried out this year by the Family Fund and Contact a Family shows that families need to find on average an extra £10,000 a year to bring up a disabled child. **SNIP continues to play an important part in ensuring that families get to hear about funding sources they may be eligible to access.**

In providing information and advice we draw on our experience as parents and the organisation's knowledge built up over the past 15 years. Because of the emotional impact of discovering that their child has some additional needs parents often need support to make sense of the services, systems



and processes that may be of help to them and their families. **They tell us that having an opportunity to talk to people who are going through similar experiences is one of the most helpful aspects of our service.**

*“Over the years SNIP has been so helpful to me and my family, always ready to listen and point us in the right direction – the fact that some of the staff have been through similar situations makes a real difference too”*

## Emotional Support

We see the giving of emotional support as a key element in supporting parents. The value of acknowledging where a parent is emotionally, at any given point in time, should not be underestimated. Often people rush to offer practical solutions to families. These may well be welcome, but without the space to

express their feelings in a safe and non-judgemental environment, many parents struggle to adapt and adjust to the reality of their situation.



Adam

## Website

The website continues to be an extremely popular way for people to access our service. Just under 10,000 people from all over the world downloaded information this year.

## Enquiry Statistics

Once again we have had a record number of enquiries – 2,607, with a 70:30 ratio parents to professionals.

## Information for Children and Young People

Thanks to the generosity of a number of trust funds we have been able to extend our service to young people (12 and over). Sharon took on the role of Youth Worker to explore the level of need and the type of enquiry amongst this age group. She has supported a number of young people in the following ways;

- Direct Payments
- Planning for college
- Benefits
- Moving onto independence
- Co-ordination
- Leisure activities.

In addition we received funding which allowed us to ensure that the information we provided to the young people was available in a range of formats, including CD-Rom.

We are pursuing further funding to enable this service to continue and develop and

we would like to appoint another person to take on this specialised role.



Jordan and Danielle

## Fife Outreach

We have been approached by a group of parents and professionals in Fife to consider establishing an outreach service locally. They secured funding from Fife Health Improvement fund to survey demand and to raise awareness of SNIP.

In order to ensure the survey reached as many people as possible, 2000 questionnaires were sent out via Fife schools and professional groups, with the request to pass them on to relevant parents and professionals. A further 1000 questionnaires went out to those on the RNIB mailing list.

A total of 278 questionnaires were returned, 192 from parents, 78 from professionals, 1 from a carer and 7 unspecified. Of these 273 (98.2%) felt there was a need for an information point in Fife, and 262 (94.2%) would use such a resource. As a result of the survey there was a large increase in telephone and e-mail enquiries from the area this year, which further underlines the benefits of us having a physical presence in the area.

Tricia Cox, one of the professionals involved in the Fife group has since been co-opted onto our management committee and we are in negotiations with Fife Council and NHS Fife to secure a venue and possible funding.

## Counselling and Therapeutic Support Groups

Sometimes parents need more than emotional support and SNIP receives funding to offer 1:1 counselling or Therapeutic Support groups for such parents who live in

Edinburgh and Midlothian. We use independent, fully trained and accredited counsellors for these services to keep them separate from our other support functions.

In March we held our second 'Therapeutic Day' at the Engine Shed in Edinburgh giving parents the chance to try out, for free, a range of complementary therapies such as massage and Reiki. It was also a chance for them to meet the counsellor and hear more about what she can offer. Next year we hope to run a similar event in Midlothian.

We continue to seek funding to extend these services to families from other geographical areas.

## 'Therapies on the ward'

This year we were delighted to be able to offer for an 8-week period over the summer, free bedside therapeutic massage for the parents and carers of children on the neurological ward.

We recognise that the hospital



environment creates its own unique pressures for parents – such as the stress involved in waiting for test results; children taken to and returning from surgery. A reluctance to leave the child's bedside; a change in sleep, diet and routine as well as juggling family commitments all add up to additional stress for parents or carers.

The therapist, Susan McLean is a fully qualified I.T.E.C (*International Therapy Examination Council*) therapeutic massage therapist.

Parents who used this service were extremely positive about its benefits and we hope to be able to continue it next year.

## Education and Training



Claire Edwards  
Training Manager

The training arm of SNIP has three aims:

- First and foremost to improve the service families receive from the professionals who work with them
- Secondly to support the professional development of those working with families
- Thirdly to provide an income to support other aspects of the service.

The past year has been enormously successful for SNIP, with a real consolidation of our position as the leader in the field for providing tailor-made training courses developed and delivered by parents. Courses and sessions have included –

- Emotional implications of caring for a child/young person with special needs
- Impact of childhood disability on family functioning
- Including children with specific conditions into after school clubs and play schemes

- Breaking 'bad' news
- Childhood Disability Equality
- Communicating with families.

Participants have ranged from junior doctors to hospital consultants, out-of-school-care staff to senior Educational Psychologists. Some of the feedback we have received in evaluations is as follows:

*"All professionals involved with disabled children should go on this course"*  
*"The trainers' use of their own stories and experiences bring this training alive – this way of exploring the issues is highly effective"*

## Key Worker Training

For the second year running The City of Edinburgh Council has used some of its 'Changing Children's Services Fund' money to commission SNIP to train professionals to become 'key workers' for families of children with additional support needs as

part of the move to a 'care co-ordination' approach.

The objectives for the training are –

- To emphasise the importance of developing self awareness in the role of Key worker
- The identification and promotion of attitudes, values and skills needed for effective working
- To stress the need for regular reflection and review of practice
- To promote the accessing of support and supervision for all practitioners carrying out this role
- To encourage ongoing professional development

## 'Training for Trainers - Key Worker Course'

Following on from the first year's successful delivery of Key Worker training we have developed a five day 'Training for Trainers' course. The course is targeted at:

- Managers wishing to establish Care Co-ordination and Key Working in their local areas
- Practitioners wishing to develop training skills
- Trainers wishing to add Key Worker training to their portfolio.

We developed the course for the following reasons:

- To increase capacity for the wider delivery of Key Worker training
- To ensure that the training is delivered with full reference to and appreciation of the principles of Care Co-ordination and the core skills, values and attitudes
- To ensure that the Key Worker course addresses specific local needs
- To ensure that this training is delivered to a consistent standard.

This course was delivered in September to a group of parents and practitioners from Northern Ireland, Leicester, Fife and Edinburgh.

*"As an experienced trainer already I welcomed the opportunity to have time to reflect on my training style and the course methodology of deconstructing the material was a really helpful way of working that I will incorporate into my own approach"*

## Additional Support for Learning – City of Edinburgh Council Implementation

We are delighted that SNIP has also been commissioned to support The City of Edinburgh Children & Family's department in their implementation of the Additional Support for Learning (ASL) act. This is a major legislative change for Scotland and has wide-ranging implications for all agencies working with children, young people and their families. SNIP facilitated a number of awareness-raising seminars and will be delivering a



training programme for practitioners next year. In addition, Claire has been seconded to the Development Team (ASL) for the City, to support the work of developing guidelines and procedures for effective practice and implementation.

The Council has also acknowledged our existing role as information providers by funding a leaflet about our service to be distributed throughout the Children and Families Department's education settings.

## Consultation and Policy

This year, as usual, SNIP has been at the forefront of promoting improvement in the way families of children with additional support needs are treated in Scotland:

### Care Co-ordination and Key Working –

Claire has now replaced Shirley as a Trustee of the Care Co-ordination Network UK. This organisation promotes the development of Care Co-ordination

schemes throughout the UK. A highlight of the year is that the DfES in England endorsed the CCNUK standards for Key Working in its National Service framework for children.

Shirley continues to chair the Scotland group, which supports the Scotland Development Worker, Laura Ewen.

### Education -

SNIP continues to influence local and national policy development in this area with Shirley sitting on the Advisory Group to the Scottish Executive's Additional Support for Learning (ASL) Act Implementation Team. The team have been busy drafting the Code of Practice in preparation for the Act's introduction in November.

### Social Work -

SNIP is represented on the Strategy Development Group sub-group for disabled children for the City of Edinburgh Council and **provides valuable parental input into this planning body.** This group also

oversees the projects for disabled children funded through the Changing Children's Services Fund.

A new development this year has been the invitation for Shirley to sit on the newly established **Respite Allocation Panel** for Edinburgh. This is a great opportunity to contribute to this very worthwhile initiative, which sees respite providers from across a range of agencies negotiating to ensure that children access the most appropriate setting and that allocation of resources is made according to the greatest assessed need. Again, the council recognised the unique experience and expertise SNIP has to contribute to this panel, both from the parental perspective and as an organisation that works with parents of children and young people with a wide range of impairments.

## Highlights of the year – Chair’s Report

### Working Families Employer of the Year Awards 2004 – Special Commendation Received

The committee were delighted that SNIP was short listed for an Employer of the Year Award. Shirley and Claire went to London for the ceremony and discovered that SNIP was the only small charity on a shortlist that included the Scottish Courts Service. The Special Commendation was made *‘for proving how a small organisation can improve service delivery by employing carers’*. Training, recruiting and retaining staff even in a small organisation is costly both financially and in meeting the targets of the work place. SNIP employs parents of disabled children and young people because of the talents and experience they bring to their employment. However in order to support the staff to continue to work in the organisation policies have

had to be developed in order to retain staff.

Flexibility regarding working hours with core hours that must be covered allows staff to work the hours required but also allows them to meet their family commitments. ‘Carers leave hours’ allows staff to attend to their family needs without feeling they are letting the organisation down in some way.

Supervision, both clinical and management, is accessed by all the staff and provides both a way of supporting them and also ensuring a quality service is given. Training issues can also be highlighted and built into SNIP’s development plan. We believe that this approach towards our staff enables them to continue to deliver the best service possible to families and practitioners.

### Kids Zone Comic

A quarterly comic aimed at children and young people is being produced. Danielle Dunlop who has recently moved into high school is helping with the production and this allows SNIP to keep

in touch with this age group.

### Development day

A successful day was held with Alison an external facilitator and previous SNIP chair facilitating the day. The management committee mapped the future for SNIP in 10 years time and then made plans as to how to move forward on a variety of issues.

### Director’s post

Shirley Young previously Project Manager has taken on many varied roles since the organisation began. The team working in SNIP has grown considerably and in order to reflect her new roles and responsibilities a rescoping exercise took place. This included updating her job description and changing her title to Director.

### Income from Training

Claire Edwards has directed her considerable talents towards developing and extending the training SNIP offers. The income derived from training has grown considerably and now helps to support the service.



In order for Claire to devote more time to training a further Information and Support Worker is to be employed.

## Committee News

The AGM in October saw the retiral of Rachel Wilson as Chair. Shona Moyes also stood down as Treasurer and Joy Blakeney came to the end of her term of membership. Lesley Mount stood down due to pressure of work. We are extremely grateful to them all for their hard work and commitment over the years and they were presented with tokens of appreciation at the AGM.

Shona has stayed on the committee as vice-Chair and Mary Russell, our first grandparent on the Management Committee, joined as Treasurer. Louise Jarman, Vice Chair, stepped into the Chair. Billie Hurst, a physiotherapist and parent joined as Secretary. During the year Carrie Upton, Chaplain at the Royal Hospital for Sick Children

and Tricia Cox, Pre-school Community Teams Co-ordinator in Fife were co-opted.

During the year the committee have formed the following sub-committees:

- Fundraising
- Policy
- Recruitment.

The full membership is therefore as follows:

Louise Jarman – Chair  
Shona Moyes – Vice Chair  
Mary Russell – Treasurer  
Billie Hurst – Secretary  
Jillian Allett  
Gail Peterson  
Marlene Snodgrass  
Tricia Cox - Co-opted  
Carrie Upton – Co-opted

### Treasurer's Report

This year we have used Fundraising Consultants to help generate income from Trust Funds and have re-established a fundraising sub-committee to develop a three-year fundraising strategy. This is very important for the continued success of SNIP as the wonderful "Celebrity Who

wants to be a millionaire?" money won and donated so generously by our patron Kaye Adams and her friend Ross Kelly is fast being used up. As expected after the success of last years conference there has been an increase in SNIP's income from the delivery of Key Worker Training for Dumfries & Galloway, West Lothian Healthcare, City of Edinburgh Council, Lothian University Hospital NHS Trust and Fife Council. This has also been reflected in requests for us to carry out commissioned work, speaker's fees and delivery of other training programmes. (As the majority of the conference fees were outstanding at last year's financial year-end they will show in this year's account). Increased training activity and the trip to London to collect the National Information Forum award led to higher than usual staff travel expenditure this year.

This year we have been able to extend our "Therapeutic Support Groups", due to continued support from the

City of Edinburgh Council and Midlothian Council, which we know has been a real "lifeline" for some parents and carers.

Our thanks go to the Royal Hospital for Sick Children for their continuing support by providing us with our fully accessible office and for covering our telephone and postal costs. Due to our increase in staff numbers they have also very kindly provided separate office space for Shirley Young, our Director.

We also continue to receive support from the City of Edinburgh Council and Midlothian Council. Our final payment from the Community Fund, for 2002 – 2003 was received in this financial year.

We give special thanks to Ian Rankin who so very generously continues to support SNIP along with the regulars at the Swanny's and Oxford Bars, the BP Harding Committee, the Scottish Crisis Society, the Margaret Black Trust, the Russell Trust and to everyone who raised or donated money including

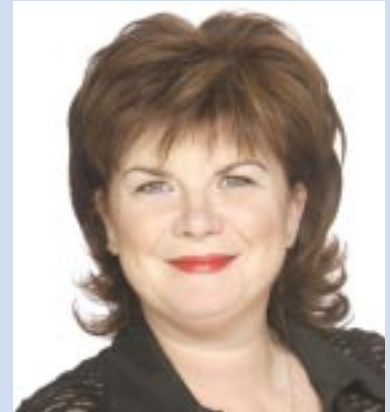
our G.A.Y.E donators.

We are very grateful to have been supported by friends and members this year with the continued success of our annual ceilidh and raffle, the book signing Ian Rankin carried out at the RHSC street fair and our wonderful Santa letters.

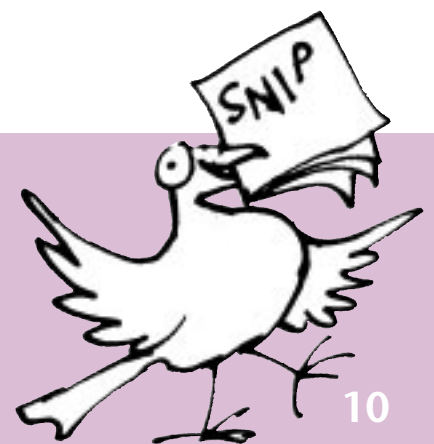
The SNIP office would be delighted to hear from anyone who would be interested in contributing to the work of SNIP or in becoming involved in our Fundraising sub-committee. Our aims for the coming year are:

- Secure Trust Fund donations to contribute to help-line and youth work costs
- Increase Give as You Earn Donations
- Increase spread of collecting cans
- Develop more fundraising events and projects such as a Snip Car Boot Sale, Christmas card etc
- Encourage existing donors to give on a more regular basis

- Target more local authorities
- Continue to extend income generation through training.



Elaine C. Smith  
Patron of SNIP



## Accounts Summary Year Ended 31 March 2005

	Unrestricted funds £	Restricted funds £	Total Funds £	Total 2004 £
Income	77,919	73,998	151,917	86,891
Expenditure	112,893	45,023	157,916	149,582
Fund balances 31/3/04	75,681	0	75,861	138,372
Fund balances 31/03/05	40,707	28,975	69,682	75,681

### How SNIP spends its money

Fundraising costs	9%
Costs to carry out the work of SNIP	89%
Management and administrative costs	2%

This report should be read in conjunction with the annual audited accounts.

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](mailto:snip@btinternet.com)  
Website: [www.snipinfo.org](http://www.snipinfo.org)

Scottish Charity Number: 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



**Addendum : this replaces the printed Treasurer's Report in the SNIP Annual Report 2004/05**

**Treasurers Report**

This year has been the most successful year for us financially since our Patron, Kaye Adams and her friend Ross Kelly donated £115,000 to us from their "Who wants to be a millionaire?" win in 2001. As reported last year, we have expanded our income from training and thanks must go to our Training Manager, Claire Edwards, for her excellent work in developing our new Keyworker 'Training for Trainer's' course, which is receiving interest from people throughout the UK. In order to continue to build our capacity to deliver training we are intending to employ another Information and Support Worker next year to free up more of Claire's time.

Another new development has been a commission by the City of Edinburgh Council to help them implement the Additional Support for Learning Act. Much of the work for this will be carried out in the next financial year.

Once again we have been able to provide "Therapeutic Support Groups" and 1:1 counselling for parents due to continued support from the City of Edinburgh Council and Midlothian Council.

Our thanks go to the Royal Hospital for Sick Children for their continuing support by providing us with accommodation, telephone and postal costs. We also continue to receive support from the City of Edinburgh Council, Midlothian Council. This year we are delighted to have also received a contribution to the service from East Lothian Council for the first time. Fife Health Improvement Fund kindly provided money for us to carry out a feasibility study in the area with regard to us establishing an outreach service.

We give special thanks to the following individuals, groups and organisations that have supported SNIP so generously this year:

- Provincial Grand Lodge of Edinburgh and the Caledonian Lodge
- Brian Williamson who donated his 40<sup>th</sup> birthday present money
- Ian Rankin and the regulars at the Swany's and Oxford Bars
- Margaret Black Trust
- Lloyds TSB Foundation
- Robertson Trust

We are also grateful to a large number of Trust Funds who have enabled us to work with young people for the first time this year. We will seek to consolidate this next year.

Thanks also to friends and members this year for their continued support of our annual ceilidh and raffle, the RHSC street fair and our wonderful Santa letters.

The SNIP office would be delighted to hear from anyone who would be interested in contributing to the work of SNIP or in becoming involved in our Fundraising sub-committee.

Shona Moyes Treasurer to October '04 and Mary Russell Current Treasurer