

Branching Out

The Newsletter of Sense Scotland
www.sensescotland.org.uk

Hi Folks!

Welcome to another issue of Branching Out. No longer under the care of John Calder but hopefully still heading in the right direction because of the strong foundations laid during the many years of his capable stewardship. Thanks John! You'll be hearing from John in future issues though and we are currently planning what that regular column would focus on. Let us know what you want us to cover about computers, the Internet ... whatever.

Inside these pages there is the usual mixed bag of snippets, current affairs, inside news, commentaries and so on. A bit special this issue is our feature on our Perfect Day competition. Printed in full are all the prize winners and a promise to post one of the entries on our web site very soon. You'll enjoy this one. You'll also enjoy our first fiction review from a young friend of the organisation.

On a more serious note, our lead story has gone into quite a bit of detail on what we think about MMR and why we support

the current immunisation programme. We had also hoped to say something about the Scottish Parliament's Health Committee report on this topic but the session was held in private. The report will be published during the week beginning 26 March.

Our second lead story is an important one about requirements being placed on local authorities in England and Wales to provide a range of appropriate services for deafblind children and adults, including those who have multiple impairments. Along with Deafblind Scotland, we have raised this with MSPs and with the Health Minister. Let us know what you think and how you feel you could be involved in any campaign about this.

If you fancy getting active and raising some money, turn to the fundraising pages. There are loads of fun events to take part in.

We are also saying good bye to some very important people in this issue. Sheena Tulloch has been an active member of committees and a tireless campaigner for deafblind people for the last twenty-five years or so. Sheena has been a member of our National Council for a number of years and while she recently retired from it, I do believe I heard her say she wanted to get back to work locally! We are also saying good bye to Rodney Clark who retires at the end of May as the UK Chief Executive after twenty years of spirited and inspiring leadership. Thanks, Rodney.

Read on and do tell us what you'd like us to cover in the next issue – it might even be a story from you. All the best.

Joyce

Joyce Wilson

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Measles, mumps and rubella (MMR)

We know that there has been a lot of media coverage of MMR recently and that some of you may have questions or know other people who have concerns. You might just want to know where Sense Scotland stands. Here is an extract of a paper we recently sent to the Minister for Health and other Members of the Scottish Parliament. Call Linda Long directly if you still have questions.

Sense Scotland began in 1977 as a self-help and support group for parents of deafblind children whose disabilities were caused by congenital rubella. Rubella infection during pregnancy can cause deafness, blindness, heart defects and other impairments. This combination of effects is known as congenital rubella syndrome. Sense Scotland is now a well-established charitable organisation and continues to provide support to individuals who, for whatever reason, are affected by sensory impairments and complex support needs.

Because of the catastrophic effects of rubella, Sense Scotland supports immunisation programmes aimed at its prevention. Rubella was a common childhood disease, prevalent amongst youngsters aged 4 - 9 years. Prior to the introduction of MMR, any unimmune adult women were susceptible to contracting the disease, particularly if in contact with children (their own included). The rubella component of MMR is essential in preventing the circulation of rubella amongst children and thus, preventing congenital rubella syndrome.

Sense Scotland fully supports the MMR immunisation programmes. We know that the use of MMR has been effective world-wide in reducing the incidence of rubella, measles and mumps – and associated complications. Scottish incidence figures for cases of these diseases in 2000 are the lowest ever recorded.

We are aware of calls for making single antigen vaccines available and, having considered the weight of evidence available, conclude that the introduction of single antigen vaccines would lead to an increased

incidence of congenital rubella in addition to increases in the disabilities caused by measles and mumps infections.

Sense Scotland strongly endorses the continued use of MMR to advance the eradication of rubella, measles and mumps. We know the devastation these diseases can cause. The implications of a resurgence in rubella are clear: children will once again be born with deafblindness and additional complex health needs, requiring lifelong support. We encourage policy makers and practitioners to keep the complexity of these issues in mind when considering the issues surrounding MMR.

Improving Services

New guidance or local authorities in England and Wales, section 7 guidance, has just been issued by the Department of Health. The guidance is significant as it says what should be done in response to the support needs of deafblind people (note that this includes children and adults). There are no similar arrangements in Scotland and we are raising with the Health Minister, Susan Deacon, and her MSP colleagues just what the Scottish Parliament intends to do in this area. We will keep you posted of progress but in the meantime here are the main points of the guidance:

Authorities in England and Wales are asked to take the following action:

- identify, make contact with and keep a record of deafblind people in their catchment area (including those who have multiple disabilities including dual sensory impairment)
- ensure that when an assessment is required or requested, it is carried out by a specifically trained person or team, equipped to assess the needs of a deafblind person – in particular to assess need for one-to-one human contact, assistive technology and rehabilitation
- ensure services provided to deafblind people are appropriate, recognising that they may not necessarily be able to benefit from mainstream services or those services aimed primarily at blind people or deaf people who are able to rely on their other senses
- ensure they are able to access specifically trained one-to-one support

workers for those people they assess as requiring one

- provide information about services in formats and methods that are accessible to deafblind people
- ensure that one member of senior management includes within his or her responsibilities, overall responsibility for deafblind services

We understand from our London colleagues that this is the strongest sort of guidance the Department issues. The local authority can only get out of doing what the guidance says if it has a very strong reason. All decisions are open to judicial review.

Let us know what you think.

Just a perfect day – special feature

In the December issue we told you about the winners of our Perfect Day competition. Here we have reprinted some of the entries. You will find a nice colour version posted on our web pages just as soon as we can get it up there.

My perfect day by Daniel Martin, aged 12, Glasgow

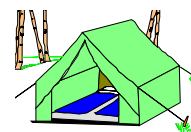
My perfect day would be to go to Spain for a day and go on the banana boats and paragliders. I would like to go to Portaventura and go on the roller coasters. I would like to go into the Freddy Kruger house for fun and horror. I would want to go on a jet-ski and speed boat because I like going fast on water. I would like to fish for a Spanish red tuna. I would go to the discos at night time for a while. I would really enjoy going go-karting and motor biking. To finish off my perfect day I would compete in a speed boat race. I would be exhausted so ... I would want to come home.

(Runner up)



My Favourite day with the Family by Minty Sainsbury, aged 9, Devon

Go on holiday to Scotland in the car with Louis. We will camp there. It will be beside a lake which has fish in it. Louis could swim in it, me and dad could fish in it, Daisy could paint it. We could go on a picnic in the woods and make bonfires. Go out with dad in the wood and shoot some grouse for supper. Me, Daisy, mum, Louis and dad all go horse riding. (Louis's favourite thing is riding). Go out picking blueberries to make nice jam and drink. Mum, Daisy, me and Louis all have races when dad's resting. Me, dad, Daisy and mum would go fishing. We would have to catch two each but Louis would be beside the boat swimming. When we had caught something, we would all jump in! Me, Daisy and Dad will go out painting the wood. We would drive to Sense so Louis would be looked after so we would do something fun. We would sit round a camp fire drinking tea and eat cake. Then before we went to bed we all jumped in for Louis sack. When we were all tired we would go to bed. (at this time it is 10).



(First prize aged 10 and under)

Minty's story was presented as a series of pictures each illustrating parts of the story. We have not been able to give you a full flavour of the story, sorry Minty, but maybe you'll like the way we have posted it on the web pages. Let us know.

My Perfect day would be ... by Daisy Sainsbury, aged 12, Devon.

To wake-up with the sun shining brightly through the caravan curtains. Me, my Mum, my Dad, my Sister Minty and Brother Louis would be on the west coast of Scotland where every day would be as hot and sunny as the day before! Fantastic!

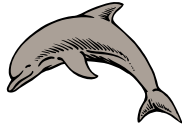
We would all get-up and have a lovely breakfast of Mr Honey's Bacon, Rice Krispies and slightly toast with Mr Davison's Honey.

After that Mum would propose to take Minty and Louis to an adventure playground leaving me with Dad. So they would go out

leaving Dad and Me planning what to do for the morning.

Suddenly Dad gives a cry of exclamation "Why don't we go to the Royal Shakespeare Theatre we could get a private jet!" I would immediately agree. We would grab some sweets and jump on a private jet.

We would watch a lovely play of Macbeth and when it had finished we would have a shop in Harrods and have some lunch at Fortnum and Masons! After that we'd drop by and have tea with the Queen! Then to finish the morning off would have a quick sing song with Tom Jones!

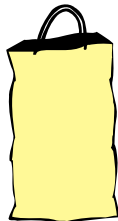


Later we would all go to the beach. We'd swim with the dolphins and seals and build sandcastles big enough to live in. And to top the whole day up, we'd eat our barbie in front of a beautiful Pinky sunset.

(Runner up)

My Perfect Day by Fayona Brown, aged 11, East Kilbride.

My perfect day would be on 20th January (my birthday). I would get on my magic carpet and fly to the United States. The first thing I would do in my perfect day in USA, I would go to Disney World with a wrestler called The Rock. We would ride all the rides in the park and visit the Warner Brothers Studios. Then we have lunch there. After all of that we would go to Rodeo Drive and The Rock would buy me anything I wanted. I would buy fancy clothes and fancy shoes. We would go from one shop to another and come out of each with loads and loads of bags. (Of course The Rock would carry them all since he is a WWF wrestler.) Once we have been in every shop possible we fly back to Scotland (it only takes 20 minutes by carpet) we collect everyone I know and then fly back to the USA. The carpet takes us to the Hard Rock Café. Everyone would be wearing clothes I picked out for them in Rodeo Drive. We would have a full 3 course meal which none of us would pay for. After a lovely meal my magic carpet would take whoever wanted to



come to a wrestling match in which The Rock would wrestle and win. After the wrestling the magic carpet would then take everyone who went to the wrestling match and dinner back to The Beverly Wiltshire Hotel where the film "Pretty Woman" was filmed. In the morning the carpet would take us all home.

(Winner aged 11 and over)

A day in the life of ... by Ross Gibson, aged 12, Dundee

I was just nineteen when I was practising my footie skills in the back yard. My mum shouted to me Ross. I came in. It was Dick Advocaat saying "they had signed me for £4.5 million".



My first game was against Celtic. I was playing RCF. It was a dream first half. We were three-nil up in 12 minutes with me scoring a hat-trick. I continued my scoring after in the game. In the sixty-first minute I netted my fourth goal of the game from a thirty yard free kick. We went out 6-0 winners with Miller scoring two at the end. Dick was delighted with my performance and said my weekly wage would be up to £14,000 for that marvellous game.

Dick said in the next day in training I would be getting a Scotland call-up along with Billy Dodds and Barry Ferguson. And I was named in the Scots squad for the trip south to San Marino.

I was in the starting line-up for the match, forward with Billy Dodds. I couldn't had got a better five minutes scoring two goals in the third and fifth minutes. It remained that result all through. Craig Brown, my Scotland place will be kept.

(Second prize, aged 11 and over)

My perfect day by Thomas Michael Spence, aged 6 years, West Calder

My perfect day is Thursday. On Thursday nights I go to my signing class.

Last week it was Deaf Awareness Week and it was like a party. That night I learnt new signs from a video.

I was so greedy I ate a meringue. Some

cocktail sausages were hard to get because they were stuck in a melon. I did manage to get some. When I did eat them some of the bits fell off.



On my first day at signing class I liked my signing teacher.

I am going to signing to learn to sign to my wee sister. On the first day I learnt a sign for game.

On Friday morning I show my sister the new signs I've learnt but I am very tired at school and need a rest.

Signing classes are so much fun I wish they were everyday.

(Second prize age 10 and under)

This story has also been published in DCS News – the Newsletter of East Scotland Deaf Children's Society, March 2001. Well done Thomas!

My Perfect Day by Helen Murray, aged 12 years, Glasgow

My name is Helen Murray and I am 12 years old. I am writing this essay on what my perfect day would be in the hope of winning one of the prizes.

My perfect day would be on a Saturday because that's my favourite day of the week. I'd wake up on a Saturday morning to find enough money in front of me to go on a shopping spree. I'd gather my friends up and we'd all go on a shopping trip. I'd buy loads of outfits and have a really good laugh. When I returned home with my friends and all my outfits, there would be a make-over artist sitting in the living room ready to give us a all make-overs. I would get dreadlocks put in my hair and my friends would get whatever they wanted. After we'd all had a make-over we'd get ready to go on a night out to the Archaos (and under 18s night club in the town). A limo would arrive outside my house at 4.30 pm to take us to the Archaos. When we got there, Alice DeeJay (my favourite singer) would be standing outside waiting to greet me with free tickets for me and my friends to get in. When we eventually got in we would have a brilliant laugh and a really good time. At the end of the night the limo would be waiting outside to take us home. My mum decided

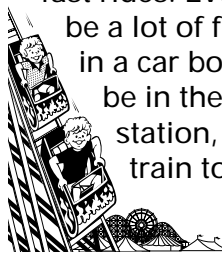


all my friends could stay overnight so when we got home mum had organised a surprise sleepover for us. We watched videos, listened to music and stuffed our faces with food all night and eventually we all fell asleep. That would have to be my perfect day.

(Runner up)

My perfect day by Pamela Martin, aged 14 years, Glasgow

My perfect day would be a day away with all my friends to Alton Towers. The reason I think this would be a perfect day is that myself and all my friends love the shows and we haven't yet been to Alton Towers, we have only been to Strathclyde Park and Loudon Castle and from what I have seen on TV and heard about it from people I know, it looks and sounds absolutely brilliant and it would be the perfect day for people who really like fast rides. Even the journey there would be a lot of fun because instead of sitting in a car bored for hours you would only be in the car until you got to the train station, then you would be getting a train to England, then a bus to Alton Towers.



(Runner up)

Snippets

Cast your votes

With the election looming, it's probably just a bit late to register if you aren't already registered but you can check by calling your local council on 08456 062062 for a form and to enquire about postal votes. For future reference, registering for a vote is now much simpler than ever. You can register at any time. A new register begins on the first day of the month.

It looks like it will be a May General Election. Like last time, let us know how you get on – remember if you need assistance to cast your vote at the polling station, you should be allowed to take someone to help you.

Holidays 2001

You'll have heard about the holiday programme for 2001 – just a reminder of dates, venues and the limited number of places. Let Margaret Bamford at Newark Drive or one of the advisory team know if you are interested.

14 July to 21 July Trefoil Centre, Edinburgh for those needing a bit more support

28 July to 4 August Haven, Craig Tara, Ayr under sixteens activity holiday

11 August to 18 August Pontins, Blackpool over sixteens activity holiday

Margaret is based at 15 Newark Drive, Glasgow G41 4QB (0141 424 3222).

Easter family fun day

The Sense Scotland Easter family fun day is on Saturday 7 April at the day services resource base Unit 5, 39 Durham Street in Glasgow from 1 pm till 4 pm. Hope you can all make it.

Get online and chat

Chatability is a new online Internet chatroom for disabled children recently launched by Capability Scotland. The project is funded by a Scottish Executive Innovation Grant. The chatroom is being piloted by children in five specialist schools across Scotland but you can log on at www.chatability.org.uk if the adult who is responsible for the computer you are using agrees.



Easter magic show

The National Deaf Children's Society is hosting an Easter magic show at Norfolk Street in Glasgow. Contact the NDCS office on 0141 420 3388 by 30 March if you are interested in finding out more.

Rodney Clark

After twenty years of courageous, creative and spirited leadership, Rodney Clark has decided to retire as Chief Executive of Sense UK at the end of March 2001. In many ways, Rodney made Sense his life and we are all the richer for that. If you have any message for Rodney, we'd be delighted to pass it on

or you can send your good wishes directly to Sense, 11 - 13 Clifton Terrace, Finsbury Park, London N4 3SR.



John and Sheena with Chairman Roy Cox

The Sense Scotland Award

The Sense Scotland Award is for very special occasions. It has been awarded only once before in 1989 to Sr Ailish Massey on her retirement as head teacher at Carnbooth School for deafblind children in Glasgow. In February 2001, we were delighted to make the Award again, this time to Dr John Tulloch and Mrs Sheena Tulloch, both of whom have made a significant contribution to taking Sense Scotland to where it is today. As well as a specially commissioned art piece completed splendidly by the smart group the honour was given to John and Sheena for their:

Special and long-standing contribution, both as individuals and as a family, to the establishment and development of Sense Scotland; an improved understanding and awareness of deafblindness and multi-sensory impairment in the wider community; the recognition of the unique needs of and development of services for families and people who are deafblind or who have multi-sensory impairment.

John was the chairman of our first Executive Committee and Sheena has served on a number of committees over the years. Both, of course, have done much more than that. Thank you John and Sheena.

Birthday news

You'll all be pleased to know that Eleanor Ross of our advisory team had a baby girl, Eilidh, on 11 February. Lots of love to big sister Morven and proud mum and dad.

A book review

Although *The Raging Quiet* is set in the Middle Ages, the underlying theme is something that will never change – how difficult it is to be different.



The villagers in Marnie's village don't trust her because she lives alone after her husband died just after they moved there. They don't trust Raven because they believe that he is mad. However, after a while Marnie realises that he's not mad – he's deaf. She makes up rudimentary sign language so

that she can communicate with him.

The villagers though aren't impressed. Already suspicious of the pair, they think that the hand symbols are spells and try Marnie for witch-craft.

The villagers' ignorance and xenophobia, Marnie's frustration when she runs out of signs and Raven's anger when he cannot make himself understood are all things that are still experienced today. So, many outcasts and deaf people will identify with this book. But whoever you are, it is an enjoyable read anyway.

The Raging Quiet by Sherryl Jordan, published by Simon and Schuster, £7.99
Book review by C Macquarrie, a 12-year-old friend of Sense Scotland.

From Westminster

Budget 2001

Reports are that families are the main winners from Gordon Brown's recent budget. Here are some headline items:



- guaranteed minimum income for severely disabled people on benefit of £142 a week
- children's tax credit be paid at £10 per week
- from June the child care tax credit will pay up to 70% of child care costs – instead of £100 per week as at the moment
- families receiving the higher children's credit and maternity pay will be up to £2,240 a year better off
- two weeks' paid paternity leave to be introduced
- maternity pay will be increased from £60 to £75 next year and then up to £100 in 2003
- statutory obligation to pay maternity pay will be raised from 18 weeks to 26 weeks
- minimum wage to be increased to £4.10 per hour from £3.70

Welcoming the Budget, Scotland's First Minister, Henry McLeish, said:

"Today's budget offers a tremendous boost for Scotland. Scotland will receive £200 million of the Budget's additional spending on key public services over three years. This comes on top of the SR2000 increase. The Scottish Executive will determine how these extra resources are allocated."

And we anticipate that will mean spending on hospitals and the anti-drugs strategy and the implementation of free personal care for elderly people.



Disability benefits

Along with this issue of Branching Out we are sending a copy of Battling for Benefits which is the report on the survey some of you took part in last summer. A common theme was the problem in making successful claims for disability living allowance and the delays in getting claims settled. Hope you find it interesting, thanks to those who took part. As ever, get in touch with our advisory team if you have any specific benefits problems.

Child disability benefits and other sources of help

This eight page leaflet from Contact a Family provides useful information for families who have a disabled child or children and covers these topics:

- advice on benefits
- buggies and wheelchairs
- working families tax credit
- housing benefit
- council tax benefit
- social fund
- income support
- jobseekers allowance
- disabled persons tax credit
- fares to hospital for treatment
- nappies and incontinence aids
- grants guide
- mobility costs
- other sources of help such as the Family Fund

You can get hold of the leaflet either by phoning the Scottish Branch: Contact a Family Scotland; Norton Park; 57 Albion Road, Edinburgh EH7 5QY 0131 475 2608 Or by contacting the head office direct: Contact a Family; 170 Tottenham Court Road London W1P 0HA 0207 383 3555 email: info@cafamily.org.uk

Disabled child credit

From 3 October 2000, you can claim a disabled child credit if you get working families tax credit (WFTC) and you have

a disabled child who gets DLA or is registered blind or has recently been taken off of the blind register. The disabled child credit can add another £22.25 per week to the maximum payment of WFTC or could bring you into eligibility for the first time. There hasn't been much publicity about this change so you may not know about it.

Note that the WFTC is a means-tested benefit paid through the wage packet.

Children's tax credit

Also, bear in mind that if you have a non-disabled child or children, you can claim a children's tax credit from April 2001 – claim this on top of WFTC (which includes a child care tax credit that is a completely different thing).

Ring 0845 300 1036 or 0800 072 2020 for claim forms and information.



From the Scottish Executive

Adults with incapacity legislation

Included with this issue of Branching Out is a leaflet outlining the main provisions of the act, what it might mean for you and who to ask for information and advice. An implementation team is sited at the Scottish Executive for your queries on 0131 240 6861.

An improved hearing aid service?

Susan Deacon, Scottish Health Minister, recently announced the development of guidance on hearing aid and fittings services by the Medical Research Council's Institute of Hearing Research. She claims this will improve hearing aid provision no matter where you live, putting an end to the postcode lottery.

The guidance also comments on the use of digital hearing aids and makes it clear that when a patient requires, and can benefit from a feature which is only available in digital instruments, that these should be provided. A wide-ranging review of audiology services will be undertaken soon.

The Royal National Institute for Deaf People have welcomed this as a significant step forward. Let's hear from you about how you get on with your hearing aid services.

Contact Linda Long

Our National Health – a plan for action, a plan for change

So what is the health plan? This is the Scottish Executive's vision for creating improvements in our national health. Though the Plan does not spell out many specific targets or initiatives, it gives a flavour of what the Government would like to see happen. The onus is on individual health boards to put the policy into practice. The emphasis throughout is on achieving higher standards of health for all and reducing inequalities – between the rich and poor as well as between differences in availability of services and treatments across the country.

The plan calls for health boards and local authorities to work together for public health and focus resources on the neediest communities. There are some references to health agencies working together with voluntary sector organisations but there is no specific detail of how this process will be encouraged. However, we are actively involved in a network of health-related voluntary sector organisations which is pressing health boards to appoint staff with a remit for engaging with the voluntary sector on health issues.

There will be an end to "empire building" by individual NHS trusts (trusts were set up to competitively run and deliver services in certain hospitals or communities for specific populations). Instead, each of the 15 health boards will manage all of the health services, including hospitals, clinics and primary health care, within their geographical area. This streamlined management is intended to work to improve the current unevenness of standards of care

or the "post code lottery" in which individuals in different locations receive different treatments or quality of service.

There are some specific goals:

- appointments should be available with someone at your GP practice within 48 hours
- by 2003, maximum waiting times for non-urgent hospital care is to be reduced from the current 12 months to 9 months
- pharmacists will be able to renew prescriptions without you necessarily having to see your GP
- 24-hour helpline will be made available for round-the-clock advice on health and health services.

These are just some of the main points. We would be interested to hear of your experiences and what changes, if any, you come across. We would be particularly interested in hearing what improvements you think would make a difference to you. Please let me know of any health news or issues of concern to you. You can read the entire NHS plan by visiting the web-site www.scotland.gov.uk or let me know and I can send you the short guide or a copy of the full publication.

Linda Long

The Millan Report – New directions

The long awaited review of the Mental Health (Scotland) Act 1984, chaired by Rt Hon Bruce Millan, was published recently almost two years after the committee was set up in February 1999. This promises to introduce the most radical shake up of mental health legislation for many years. We need to take note of what the proposals are because mental health legislation can apply to people with learning disability. The Committee heard representations from us and from other organisations that this category should be removed from the legislation but members felt that it would be premature to do so. Instead, the Committee has called for an expert review of learning disability within mental health legislation.

The major points are:

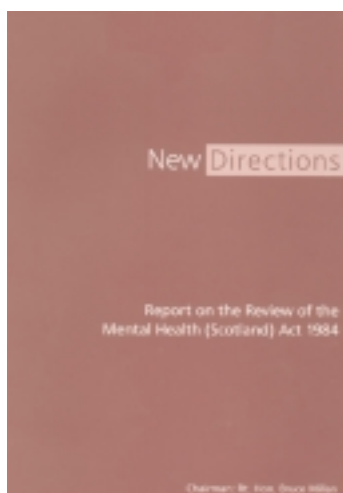
- the rights of service users to advocacy, information and services need to be strengthened and clarified

- the rights of carers need to be strengthened
- the rights afforded by the Act should apply with equal force to people with particular needs such as members of ethnic minority communities, children and disabled people

The Committee has called for a new Act which should be based on principles similar to the arrangements for the Adults with Incapacity Act 2000, including:

- non-discrimination
- equality
- respect for diversity
- reciprocity (where an obligation is placed on an individual there should be a similar obligation on services)
- informal care (wherever possible, treatment and support should be provided without recourse to compulsion)
- participation respect for carers
- least restrictive alternative
- any intervention should be of benefit
- the welfare of the child should be paramount

To implement the proposals will require more resources. There is documented under-investment in in-patient services, no area in Scotland has a comprehensive range of mental health services for adults and services specifically for children are woefully inadequate. The Scottish Executive has welcomed the report and has indicated that it will "carefully consider the whole range of measures recommended in the package". Susan Deacon, Health Minister, has said



there will be changes which will both strengthen rights and will protect the wider community.

The full report is lengthy but there is a 28 page summary which we can copy to you – just let Joyce Wilson know.

Freedom of information

The first ever legally enforceable right of access to information held by public authorities was announced at the beginning of March by the Deputy First Minister, Jim Wallace. A fully independent commissioner appointed by Parliament will have the legal authority to require disclosure of certain types of information by Scottish Public Authorities. Commentators have said that the arrangements go much further than those proposed south of the border.

The Bill is out for consultation until 25 May 2001 and covers:

1. A legal right of access for all to information held by a broad range of Scottish public authorities including the Scottish Executive and its agencies, local authorities, the NHS in Scotland, educational institutions, and the police.
 2. A fully independent Scottish Information Commissioner with strong powers to promote and enforce the legislation. The Commissioner would be appointed by the Queen on the Scottish Parliament's recommendation, independent of the Scottish Executive.
 3. The Commissioner would monitor the overall operation of the legislation ensuring that as much information as possible is available to the public. Where he or she considers that information should be disclosed there would be legal power to order disclosure.
 4. A limited set of exemptions, providing safeguards against the disclosure of sensitive information. In most cases, authorities seeking to withhold information would need to show that there would be "substantial prejudice" if the information was released, and be required to consider the public interest in disclosure.
- Legislation is unlikely to be on the statute books until 2002.

From the Scottish Parliament

Scottish Parliament Education, Culture and Sport Committee report on special educational needs (SEN)



The Inquiry was set up 18 months ago and considered:

- diversity of provision
- effectiveness of current integration strategies
- effectiveness of transition arrangements
- requirements of special needs families

The report's recommendations centre around:

- support for inclusion of children and young people in mainstream schools
- revising the whole process of recording child's special educational needs
- improving arrangements for training of teachers and non-teaching assistants
- improving multi-agency working

We don't think that the report has done enough either to fulfil its original four point

remit nor to reflect the diversity of views expressed to the Committee.

Those who followed the reports of the Inquiry meetings will have noticed that early on, members became convinced of the case for inclusion of all children with SEN into mainstream schools and of the need to uproot the Record of Needs system. Members began to visit a range of provision across Scotland and reports became more muted about the advantages of inclusion. Parents were concerned about the loss of a legal basis through which to record their child's needs.

It is interesting to speculate why the diversity of view was not reflected in the final report. One possibility is that Committee membership changed substantially during the lifetime of the inquiry.

Stuart Aitken

From across Sense Scotland



SENSING ART & MUSIC

Arts Development Programme

As we told you in the last issue, we have been awarded a grant from the Scottish Arts Council National Lottery Fund to fund a three year arts project, Sensing Art and Music — SAM. This is an inclusive three year development project of the arts and the senses. This user-led innovative arts programme offers new opportunities for individual growth and expression, bringing together the arts and disability.

There will be three main phases:

- introducing skills and techniques through 'taster workshops' in a wide range of music and visual arts media
- developing further skills in participants' chosen media
- create and share work with others through exhibitions at local venues within Scotland

There will be opportunities to create, perform and exhibit work in a range of national venues throughout Scotland. Get in touch with Mike Nolan at head office if you want to know how you can take part.

Standards in education of children who are visually impaired

RNIB Scotland and Sense Scotland have been funded by the Scottish Executive Education Department (SEED) to produce a revised and updated set of education standards based on the document Vision for the Future – a framework for minimum standards in visual impairment education first published in 1995.

Funded for two years under SEED's Innovation Grants Awards, the project will establish a set of minimum standards which local authorities can use as benchmarks for their own education services. Areas covered by the standards (subject to change) will be:

- information
- identification
- referral
- assessment
- working with others
- placement
- access to curriculum
- individualised education programme (IEP)

Standards will be written in simple straightforward language offering a checklist format that is easy to follow. This sort of format will be designed so that it is easy for parents and others to use as a checklist of services. Support materials and examples will also be given.

All 32 local authorities have expressed an interest in either corresponding with the group or attending meetings to give feedback on the proposals. Key people in the writing team are Stuart Aitken from Sense Scotland and Neil Todd from RNIB Scotland, both of whom were part of the original editorial group in 1995.

Stuart Aitken

Getting organised

We have been working with Glasgow colleagues at pamis (profound and multiple impairment service) to develop a personal organiser for people who depend on support service provision. The organiser aims to help them keep records of the many people who can be involved in

delivering services. People using services can open a file on any individuals who work to support them. The file could hold:

- pictures and contact details of people (such as the GP, advocate, teacher or care manager)
- summaries of meetings about them and their planned questions to ask at the next meeting
- their copy of any plan that service providers have made with them

It is easy to forget the detail of what was said at a meeting, especially if the information is all held in your head. And when people are moving between services and from child to adult provision, there can be more people involved that you can know! The personal organiser is where all of this information can be filed and easily picked up when you need to remember something or have an appointment with a service provider.

Work on the personal organiser has been funded by Glasgow City Council Learning Disability Services. The personal organisers are being piloted at the moment with about 12 users of services across the city. Researchers from Glasgow University will be involved in finding out how useful they are and what changes we could make to improve them.

If you want to know more about the development and pilot of personal organisers or want to try using one, call me at head office.

Linda Long

Staff development

We recently received a grant from the Abbey National Charitable Trust that allowed us to develop a set of distance learning materials for our staff team. These are aimed at new staff and provide a range of support materials to help them settle into the workplace as well as developing the key skills they need to be successful. This includes communication, planning activities, mobility and guiding as well as risk assessment. The grant allowed us to set aside time to write the material as well as purchase a stock of presentation folders. We will be able to deliver these core modules in this way for the next three years.

The core modules link directly into our training workshops which we offer 8 times per year in Glasgow, Dundee and Glenrothes. As we develop more projects in the North of Scotland, we may also deliver workshops in Aberdeen or Inverness. These workshops include topics such as moving and assisting, client protection, epilepsy awareness etc. We have been interested in opening up our Induction Workshops to a number of other people and one suggestion that came from Eleanor Ross of the advisory team, was that we make places available to family members. There are usually spaces available on our courses and we are particularly aware of the needs of families in relation to moving and assisting, for example.

Perhaps in the course of this year, we may offer dedicated workshops aimed at families and carers. I'd be interested in your views on this. And if anybody is interested in joining any of our workshops at the moment, then please feel free to get in touch with me at head office.

Paul Hart

The Ten-2-Four Transition

As many of you will know, the Ten-2-Four pilot project in Dundee came to an end in early December 2000 after a year of operation. This was clearly a difficult time for both clients and staff with a lot of uncertainty about the future and sadness that something we'd all enjoyed so much was going to finish. As there was to be a closure conference, involving carers, Sense and local authority staff, clients and staff channelled their energies in the last few weeks into the production of a presentation and video. These would show evidence of the great work we'd all done, the impact it had had on people's lives and, we hoped, would also sow seeds about what future service providers could learn from what Ten-2-Four had achieved.

All clients and staff took part in the production of the video being interviewed in sign and speech and having activities recorded. The Wedderburn Video Production Facility very generously gave a great deal of their time and hard work – thanks for that.

On the day of the conference, some

clients chose to speak about their disappointment that the service wasn't continuing and some parents and carers voiced similar concerns. Everyone emphasised the value of the pilot and what had been gained. Everyone was assured that a great deal had been learned and established about what clients and carers need from a community enabler service.

On another level, senior staff worked flat out and liaised with other services to ensure that clients had placements to cover for the days they were losing from Ten-2-Four. We also provided an end of service review and a package for all clients to take forward like personal passports and communication guidelines. Some clients moved smoothly on to other placements but for others the process was more complex or difficult. By the time the pilot closed, all clients had alternative placements secured.

It was clear that some clients old and new needed a similar service to the one they had from Ten-2-Four. And although that service no longer exists, a new Sense Scotland service has evolved with many similar characteristics – the Community Enabler Service. A few clients who used Ten-2-Four, and some new clients, are using this enabler service. It's currently a smaller project than Ten-2-Four but is attracting no less interest. It looks set to become well-established if not expand over the next few months. We are already extending into evenings and weekends.

Another exciting development is the attachment of a short-term children's project to run mainly over the holidays and the month of April – including day support and adventure weekends away.

All in all, the Ten-2-Four project may have ceased to operate but in reality this is much more of a transition than a closure. We have a team that is expanding and what is now evolving looks as though it can and will provide a greatly needed and valued link to the community for many clients both present and future.

Jess Kerek

John Smith Gardens

There's been a lot happening in John Smith Gardens since a new friend and housemate moved in last summer. It took only a very short time for him to settle into his new home and familiarise himself with the environment. Due to his sensory impairments he has had to learn his way around by using touch and smell alone. However, it didn't take him very long to be able to find his own way to the most important thing in the house, the kettle.



We are going on more social activities – trips to football matches, theatre, restaurants and local leisure facilities such as cinema and ten-pin bowling. Everyone has been very welcoming and each has greatly benefited from him moving in. When asked how they felt about their new housemate, others signed: “He is an old friend and also a nice man”. And, “I like him, he's nice”.

Changes are not only to do with the people who live here but about the environment itself. Our lounge has had a facelift and the change seems to be a hit with everyone as it is bright and uplifting. Bedrooms have all been decorated and everyone enjoyed being involved in the process. The kitchen is in the middle of being revamped as I write and we are all looking forward to seeing it take shape, especially since we recently passed an environmental health check with flying colours.

Finally, due to funds raised last summer by staff who ran a half-marathon, and a donation of £1000 from McDonalds, we are delighted to be developing a “quiet room” full of sensory equipment and entertainment equipment.

Laura Houston

Auchtermuchty

Four people live here at Orchard Court. Like other groups, they are very busy. Some go to Dunfermline for country dance lessons, all four enjoy the relaxing environment created by snoezelen sensory equipment used in the house and the weekly sauna, steam and jacuzzi

experiences at the local health centre. Everyone enjoys the visits every fortnight from a music worker who explores recall, musical interests and use of instruments on a one-to-one basis. We also like to go to concerts and have seen the Scottish singer, Ally Bain, The Amoebas, Scottish Fiddles and Country and Western singer Charlie Landsborough. We like to keep in touch with friends and join folks at Temple Lane in Dundee for some of their parties.

Maureen d'Inverno

Finglassie

There are seven people living in two apartments here in Finglassie. The house is all on one level and was purpose built by Fife Council. It has superb space and amenity allowances. It also has a huge garden which we are delighted to say is now all planted and establishing well with lots of sensory plants. Many of the bedrooms have ensuite facilities and staff are now helping to personalise each of them. For some of the people here, this is their first experience of living in the community. One person came with no history of speaking and she is now learning a phenomenal amount and using words at the same time. Everyone is also planning a holiday this year – the only problem is deciding where to go!

We are expecting a very important visitor soon. We'll say more about it in the next edition!

Gwyn Morrison

Fundraising

Top Marks for fashion

Over four hundred people attended the Sense Scotland and Marks & Spencer Fashion Show held in the splendid setting of Glasgow City Chambers in February. Marks & Spencer staff from the Glasgow Argyle Street store and their children turned into models for the night and displayed a wide range of fashions from the spring and summer collection.

Following the fashion show, Stageworks entertained the audience with music from west end musicals and the evening was



rounded off with an excellent buffet provided by the City Chambers.

Our thanks to all at Marks & Spencer, in particular Guy Riddell and Alison Divers, David Greer and the cast from Stageworks, the staff at Glasgow City Chambers and all the members of the Sense Scotland fundraising group. The amount raised from the evening was £11,500 which will help towards this year's holiday programme.

Bill Mitchell

Events 2001

The fundraising department is always on the lookout for new ways of raising money. Here is a list of fun events planned for 2001 – we hope you or people you know will want to take part.

March to October – Jump from the sky

A series of parachute jumps from 2, 3 or 10 thousand feet. Full training given and no prior experience is necessary. For an information pack contact John Brady.

February to November – Ride the Rapids

A series of white water rafting adventures on the River Tay near Aberfeldy. You can take part as an individual or as a group. Full training is given and no prior experience is necessary. For an information pack contact John Brady.

All Year Round – From Dead Sea Level to the Top of the World

A breathtaking range of adventure treks and cycles in some of the world's most exotic locations including Peru, Cuba, the Great Wall of China and the Everest base camp trek in the Himalayas. For a free comprehensive brochure contact John Brady.

One off Events

20 May – It's a Knockout, Strathclyde Country Park

A real fun day with plenty of running about and getting covered in foam and water. Teams of 10 to 12 will compete in events based on the popular television programme. Everyone will be sponsored to raise money. We are trying to get at least one Sense Scotland team made up of staff and family members. Call Sara Bannerman if that could mean you!

24 June – Great Scottish Walk, Edinburgh

A 12 mile walk in Edinburgh, including Holyrood Park and Meadowbank Stadium. A shorter 6 mile route is also available. For further information contact Jim Ellis.

30 June and 1 July – Abseil, University of Abertay, Dundee

Participants will drop 140 feet from the tower at the Abertay University. For full details contact John Brady.

15 July – Abseil in Inverness

Take part in a 120 foot abseil at Raigmore Hospital in Inverness. For full details contact John Brady.

20 August – Golf Day, Turnberry Hotel, Turnberry

Teams of 4 will take part in a day's competition. A meal and presentation follows in the evening. For further information contact Jim Ellis.

12 September – Golf Day, Gleddoch House Hotel, Langbank

Teams of three compete for a trophy but the event is real fun day. A meal and presentation follows after the golf. For further information contact Jim Ellis.

18 November – Ladies Lunch, Marriott Hotel, Glasgow

Enjoy a champagne reception and lunch followed by cabaret entertainment. Tickets are £25. For further information contact Jim Ellis.



The views expressed within Branching Out are those of the authors and do not necessarily reflect those of Sense Scotland.

If you have any comments to make about the content of Branching Out or any other aspect of the work of Sense Scotland, please contact us. Copy for the next issue should be sent to: Joyce Wilson, Sense Scotland, 45 Finnieston Street, Glasgow G3 8JU by: mid May 2001.

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