

The PROFESSIONALS

and how they can help children
with Down's syndrome



Information for parents, carers,
professionals and students

SCOTTISH

Down's Syndrome

ASSOCIATION

helping people realise their potential

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Who NEEDS professionals?

The professionals we are talking about are those who provide our health, education and social services. Everyone makes use of professional help at some time or another. In addition, there are specialist services available to people with learning disabilities and their families.

Parents who have a child with Down's syndrome (DS) will come into contact with a wide range of professionals, many of whom visit all families with children and some who are specialists.

At times it can seem an imposition. It can feel like hard work to have all these appointments with new people introducing themselves, perhaps at a time when you are just getting to know your new baby, and would appreciate some time to yourselves.

'I was so tired, and still quite low after Ewan was born. It was one visitor after another to see the baby. I suppose I know why they came, but I didn't want them then. I did keep a note of their phone numbers though.'

You needn't cut off lines of possible help. If you are being overwhelmed by appointments, let the professionals know, and arrange another visit. There may be other times you would welcome professional help.



'Brian was a young man in his own right. He wanted to leave home as much as we wanted the place for him. He certainly needs support, but he's happy and busier than he was with us. We worry less about the future now.'

DO YOU NEED THEM?

The amount of contact any family has with professionals will always depend on their own needs and wishes. Some families prefer little advice or assistance other than at critical times, such as to do with their child's health or schooling. Other families prefer to have constant support.

Families are all different, and there is no one correct way. You have to make the system work for you, by letting the professionals know what will suit your particular family.

Most parents want to make use of some professional help, to the best advantage of their own family. Ideally, this can be done by working with the professionals, in partnership.

Professionals as PARTNERS

PARENTS' EXPERTISE

Parents are experts on their own children. They have the best understanding of the ways their children behave and communicate. They know their children's likes and dislikes, and what is likely to motivate them.

Many parents also become very knowledgeable about the special needs of their children, through their own experience and through talking with other parents.



Professionals can suggest ways of helping children, but parents are the ones who will know which activities will suit their particular household, and fit in with the family's timetable.

Parents must make their wishes clear to the professionals they are working with. If you are not happy with the service that is being offered you must say so, and ask for what you need.

You will not always agree with advice you are given. It's worth listening to suggestions

with an open mind though, and sometimes you might even change your views. On the other hand, if you consider new ideas and still disagree, have confidence in your own opinions.

'You have to be firm in what you believe in. It's okay to be a 'pushy parent'. You have to be assertive, not aggressive, and tactful but firm.'

THE PROFESSIONALS' CONTRIBUTION

Professionals have a background of training, knowledge and experience in assessment and planning for people with learning difficulties. They can help parents to solve specific problems and improve parents' own coping, caring and teaching skills.

Professionals rely on parents to give them observations and information about their children. But, no matter how skilled parents are in the care of their own child, there may be times when a trained person standing outside the family circle can give a useful objective view.

There must be give and take between parents and professionals, respecting each other as equally important partners in the care of the person with DS. Children with disabilities benefit most when parents and specialists share information and responsibility, and work together.

Things that DON'T HELP

Children and adults with DS are entitled to the same health care and consideration as anyone else. If you feel dissatisfied with what you are offered, remember that you can seek a second opinion.

Parents often do become very knowledgeable about DS. Some professionals who are not specialists may know considerably less about DS than the parents they are advising. They may still have useful advice to give, but should respect the parents' knowledge and show a willingness to educate themselves.

'He seemed to think he'd be failing somehow if he didn't give an answer there and then. If he'd just said he wasn't sure, and he'd find out, I'd have been happy with that. Maybe he was worried that he wouldn't have looked 'expert' enough?'

'Too much is put down to DS. It's not the most important thing about Sean. He's not a 'Down's syndrome boy'. He's a little boy, he's my son, he also has DS. Some things about him are because of DS, I know, but plenty is just because he's Sean.'



'They'd listen to half of what I'd got to say, and then dump us in a category. But they might just have missed the most important part! We're not all text book cases, and they miss a lot by not listening.'

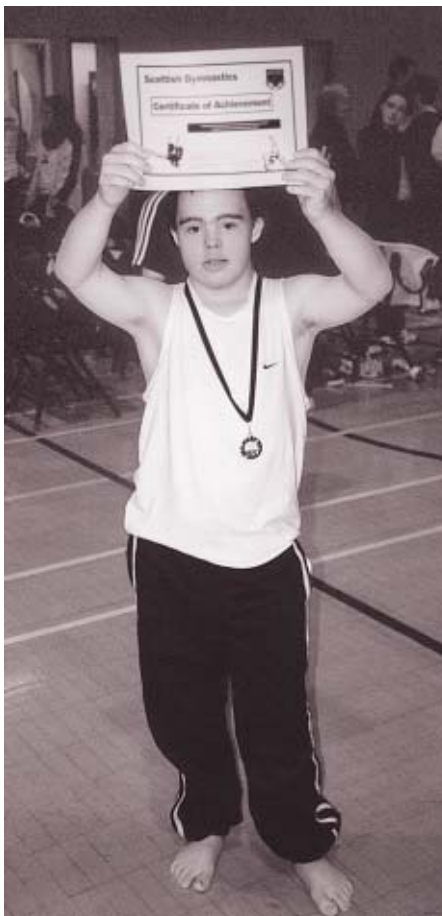
'It was a real struggle to get across town for so many appointments with such a young baby, and when I got there the staff were so abrupt. It really upset me. I needed looking after in those early days.'

'I was always made to feel that I was making a mountain out of a molehill, and that there was a queue of other patients out there waiting, all more important than me.'

Things that DO HELP

A POSITIVE APPROACH

Good professional practice will always mean treating people with respect, and as individuals. In SDSA's experience parents have found that:



'A positive attitude really helps. That's what parents like us really do have to teach the professionals. Let's not talk about failure all the time. Let's talk about what our children can do.'

'The GP's good. She says 'Hello Daniel, how are you?' ... just like with the other children. She doesn't talk to him any differently and that's important.'

'She said right at the start she knew nothing about DS, but that she would find out about anything I asked. She was being honest. It's been a learning process for both of us.'

'They always keep me fully informed. They explain what each test is for, and let me know the results even when all's well and it could wait until the next appointment. It stops me worrying unnecessarily.'

'If I'm worried about something it's always taken seriously and investigated. They accept that I'm her mother, and that if I think there's something wrong there probably is.'

LISTENING to people with Down's syndrome

Valuable advice can come from people with DS, speaking for themselves. People with DS react like anyone else to unhelpful attitudes:

'People have always shoved me aside, as if I didn't matter. They'd say, 'Oh, you're fat', 'you're lazy'. I get upset.'

'I'm so fed up with being spoken to like a child. They'll comment on the way I dress, they'll ask, 'Have you been shopping for your mummy?.'



'It's nice when they say, 'You're looking well'. A wee comment like that makes you feel well!'

'I like my doctor because he's friendly and he's never in too much of a hurry.'

The transition from childhood to being an adult can be difficult, not only for young people but for their parents as well:

'I'm an adult, living independently for a long time now, but they still say, 'Paul, go and sit down' or, 'No, you don't need the toilet now.'

The views of adults with learning disabilities themselves are being taken into account more and more. People with DS are involved, with their carers and professionals where appropriate, in choosing their own services. Adults with DS in supported accommodation should have the right to choose their own support workers and to have a say in the overall running of their home.

'As parents we tend to be over protective and we shouldn't be. I do want Amy to have a life of her own.'

How to CONTACT the professionals

Should you decide that you would like some professional help, the next stage is to get in touch. Some professionals will come to you, whereas others have to be sought out. For example, if you have a new baby there is never any difficulty contacting a health visitor, she will come to your home.

On the other hand, parents of an older child may have a problem and not know who to turn to. Services vary considerably across the country. They are continually changing and it can be difficult to keep up to date. Parents often have to work very hard to secure the services they require.

Speaking to other parents is often helpful, as is speaking to professionals who have experience and knowledge of the local situation.

To contact a particular professional, you can sometimes approach the appropriate office directly. Alternatively, some referrals must come through another professional such as your GP, health visitor, or educational home visitor.

Parents often come to find one particular professional contact helpful, and will use him/her to reach others and build up a network. Most professionals who are easy to contact and approachable will be happy to be used in this way. However, there may be times when you will have to be prepared to persevere.

'I knew there was a problem, but nobody else seemed to take it seriously, or knew what to do. In the end I just sat in the waiting room, refusing to leave until the paediatrician saw us! I'm so glad I did now.'



In order to see many professionals you may have to speak to administrative staff first. In most instances all staff will be understanding and helpful. If you feel that you are not being given the assistance you require the answer is not to be put off, but to calmly insist on making the appointment that you feel is necessary.

More PRACTICAL advice

KEEP A NOTEBOOK

List useful addresses and telephone numbers in a notebook. Try to keep a diary, recording the results of any formal assessments, and your own observations. Keep any letters sent to you, and copies of any letters you may send. Ask for a copy of any report or letter that you feel would be helpful.

When you go to an appointment, note any questions you may have beforehand and take the list with you. It's all too easy to forget at the time. During the consultation, jot down anything important that might otherwise be forgotten. It can be useful to ask for written advice sheets or a summary of the information that's been given.

There is rarely one correct answer. You will at times be given different and occasionally conflicting advice, and keeping this kind of record can be helpful when it comes to clarifying issues.

TAKE A FRIEND

It can be useful having your partner or a friend attending appointments with you. A friend being there can give you the confidence to remember to ask all your questions. Sometimes it will be easier for you if your friend asks the questions.

He or she will be able to discuss what was said during the meeting with you afterwards. Having someone to talk to will also make any waiting times seem shorter.

Friends can also help if you are having difficulty filling in a form or writing a letter. A friend, or someone you trust, can help you find the right words. If your child has a Record of Needs, your Named Person may fulfil this role. Further information about the Record of Needs can be found in other booklets in this series.

ASK UNTIL YOU UNDERSTAND

Don't be afraid to say that you don't understand if any particular point isn't made clear to you. Ask questions until you feel informed enough to make choices. You need to have the facts in order to be properly involved, and every professional should provide these facts in plain language.

'The jargon they use gets me down. Why use big words when little ones would do? It's off-putting. It creates such a distance between 'them' and 'us'. And if they have to use big words, why not just explain them?'



SECOND OPINIONS

If you are not happy with treatment or advice you are given you can ask for a second opinion. It can be awkward if you need a GP's referral to see a particular specialist, and your GP disagrees. If you cannot reach an agreement, you are entitled to go to another GP.

It's important to trust the professionals you are working with. You must be able to discuss treatment and services and ask questions without feeling intimidated or embarrassed.

Some of the contacts you have with professionals will last for years. It is worth making sure that these long term

relationships are comfortable. Personality clashes do happen. If you really cannot get on with one of the professionals allocated to you, ask to work with someone else. In many cases this will be possible.

WAITING

You should never have to wait more than half an hour at an appointment. Arrive on time, but not early, and take plenty for you all to do while you wait. It helps to pass the time and prevents you from becoming anxious. Once again, having a friend with you can be helpful.

If you are kept waiting too long, you have every right to complain. If ever you do complain it's worth doing so in writing.

The professionals A–Z

This list is not intended to be comprehensive. Services will vary depending on where you live.

Some of the professionals described will be familiar to all parents, while others work mainly with people with learning disabilities. In some situations parents prefer to use the ordinary services, while at other times there can be good reasons for seeking specialist advice.

The professionals involved will also depend on the age of the person with DS. For example, paediatricians and

educational psychologists work only with children and young people. At a certain age, perhaps on leaving school, there will be a change to new professionals and adult services. These transitions can prove difficult until new channels of support are found.

No one family is likely to meet all the professionals listed. You may find that the professionals you do meet work individually, or as a team, or as a combination of both. For more information about multidisciplinary teams see page 18.



IN HEALTH CARE

Audiologist

An audiologist is a doctor who runs services for people with hearing disorders. Most Health Boards have an Audiology Centre where people with hearing difficulties are sent for diagnosis and advice about treatment. Hearing is very difficult to test in children, and traditional methods are not always reliable. If you are concerned about your child's hearing, make sure it is being fully investigated, and ask your GP or health visitor about referral to Audiology.

Cardiologist

A cardiologist is a doctor who specialises in disorders of the heart. Heart disorders are relatively common in children with DS, so this is the specialist many parents are likely to meet. It is important that your child should be seen by a paediatric cardiologist, that is a cardiologist who specialises in working with children. Paediatric cardiologists are based in Edinburgh and Glasgow, but out-patient clinics are held in other centres.

Community Nurse (Learning Disability)

Community Nurses have specialist training in the field of learning disability, and can offer advice, support, assessment and therapy.

Some community nurses work with children, while others only cover the 16 plus age group. Those who deal with all ages provide a useful link between child and adult services.

Community nurses are often attached to Community Learning Disability Teams and can be the most accessible source of referral to them. These multidisciplinary teams aim to co-ordinate services to meet the needs of individual clients.

Dentist/Orthodontist

Like everyone else, people with DS should see a dentist regularly. In some areas there are specialist services for people with learning disabilities.

Children with DS have a small upper jaw which can lead to overcrowding. If you are concerned about the spacing of your child's teeth, it is worth being referred to an orthodontist.

Dietician

Dieticians are experts in nutrition who give practical advice about eating healthily. People with DS may become overweight, so exercise and diet are important. Children with DS are also prone to constipation. Most dieticians are based in hospitals, but some are available in health centres. Referrals are usually made through a GP.

General Practitioner (GP)

GPs give a general medical service and may not have specialist knowledge of DS. They can though make referrals to other professionals and organisations that provide specialist help.



A supportive GP can be a great source of strength, being readily available, and having the benefit of knowing the whole family.

Clinical Geneticist

Some parents who have a child with DS wish to see a clinical geneticist before they have more children. This is a consultant specialising in genetic disorders and who generally has some experience of working with people with learning disabilities. These specialists are based in four regional genetic centres in Scotland, but they travel to clinics held in local hospitals. They can be contacted directly, or through your GP.

Health Visitor

The health visitor is a nurse with specialist training in advising families with babies and young children. She visits all children under 5, and works in close consultation with the GP.

The health visitor carries out a series of valuable developmental checks. These appointments provide an opportunity for parents to express any worries or doubts they may have. If problems do occur, the health visitor may advise that your child is seen by a specialist.

Occupational Therapist (OT)

The OT looks at any activities your child may have difficulties with. She will break these activities down into small separate steps that are more manageable. The steps are then built up gradually, using play to develop the skills, until the whole activity is mastered successfully.

The OT can work with you on activities such as dressing and feeding, and the general areas of co-ordination, muscle control, touch sensitivity and bodily awareness.

In working with adults the same step by step principles are used, primarily in the area of independent living.

Ophthalmologist

The ophthalmologist is a doctor who is an eye specialist. People with DS may have problems with focusing correctly, because they tend to have small eye sockets. If there is any doubt about your child's vision, you can ask to be referred to the ophthalmology clinic. If you are not referred to the eye department of a children's hospital, ask to see an ophthalmologist who deals frequently with children. Your own optician may also offer helpful advice.

Paediatrician and Community Paediatrician

A paediatrician is a doctor specialising in the care of children. He or she confirms that a baby has DS by taking a blood sample and having it sent for analysis. This is usually done in hospital just after birth.

The paediatrician goes on to monitor the child's developmental progress and general health. Initially you may meet the paediatrician in the maternity hospital. As your child gets older, a paediatrician in the community may be responsible for his/her follow up.

Community paediatricians work closely with parents and colleagues in education and social work to ensure that your child's developmental and medical needs are met. This may be in children's centres, nurseries and schools. They will ensure that your child's medical and therapy needs are incorporated into the Record of Needs, and provide a school-based review and advice service.

There are certain tests and check-ups that should be routinely done for all children with DS. For more information see *What is Down's Syndrome?* in this series. These tests can be carried out by your community or hospital-based paediatrician.

Physiotherapist

A physiotherapist works with the child's development of posture and movement. Babies with DS are helped by being stimulated, talked to and played with while placed in many different positions. This helps their muscle tone and balance to develop, and helps them to explore their environments.

The physiotherapist can help with advice on handling and positioning the baby, and also later on if the child is having difficulty in achieving any particular stage of motor development. The role of the physiotherapist diminishes once the child is walking.

Speech and Language Therapist

The speech and language therapist is concerned with communication. Communication is crucial for relating to other people, to be able to say what you want and how you feel. Communication happens through spoken language, gesture, eye contact, facial expression and tone of voice.

The speech therapist will suggest ways of promoting the development of communication and listening skills. She may also give advice on feeding and swallowing difficulties if they arise.

Most children with DS have delayed speech and language development, but nevertheless do learn to communicate effectively from an early age.



EDUCATION

Careers Officer

Careers officers provide information and advice about continuing education, training and employment options for young people leaving schools, colleges and training programmes. Most authorities have specialist staff who work with young



people with additional needs. They offer independent advice and support, liaise with other agencies, and work closely with school staff and parents.

Educational Home Visitor

The educational home visitor is a trained teacher attached to the regional psychological services. She works in the home with young children with special needs and their parents. She has knowledge of pre-school, primary school and special school provision.

The educational home visitor works with parents on a regular basis, planning an educational programme for their child. She helps with the child's early cognitive abilities, such as matching and sorting shapes and colours, and the skills that eventually lead to reading, writing and number work.

The role of the home visitor changes as the child grows. At the start all visits will be at home but later she will also visit playgroup, nursery and then link with school. Transition from one placement to the other can be made smoother with the support and practical advice of an educational home visitor.

Educational Psychologist

Educational psychologists have knowledge and experience in the areas of child development, children with special needs, families, and schools of all kinds. They work with families, teachers and other professionals, and particularly in the case of pre-school children, with the educational home visitor.

The educational psychologist will give advice about learning and behaviour as your child progresses through school. He or she will assess a child's special educational needs whenever this is required, for example at school entry.

Teachers (and playgroup leaders)

Many children with DS attend mainstream playgroups, nurseries and schools. Teachers in mainstream who have a child with special needs in their class often have the back-up of a learning support teacher.

Learning support teachers assist and advise class teachers in developing teaching materials and methods, and by teaching the pupil directly. They might also be the ones to make contact with relevant

agencies, such as SDSA. The SDSA can provide class teachers with information and support tailored specifically to Down's syndrome.

In special schools, class teachers usually have specialist training, and experience of working with children with DS.

Auxiliaries and special duty attendants are non-teachers appointed to support some pupils. They work as assistants to the class teacher, helping with practical tasks, and looking after any other special needs the child may have, such as with dressing, toileting, or at playtime.



IN SOCIAL SERVICES

Occupational Therapist

Occupational therapists are based within the Social Work Department as well as in hospitals.

Social Worker

Some parents maintain regular contact with a social worker while others call on them only when they are seeking a particular service, such as short breaks or help with claiming benefits. Information on benefits can also come from other sources, such as a welfare benefits advisor, the citizens advice bureau or SDSA.

All families suffer from stress at times, and social workers can provide valuable support and counselling.

Local Social Work Departments and Health Boards play a key role in the provision of services for adults with learning disabilities. Services are now arranged after social workers (or local area co-ordinators) assess the needs of individuals and their carers.

An adult with learning disabilities in supported accommodation often has his or her own 'key worker' who offers support in achieving an independent lifestyle and can encourage self advocacy skills.

OTHERS

Complementary and alternative therapists

Some parents feel that what they are offered locally by 'traditional' services is inadequate, and search elsewhere for alternative forms of treatment and support. Some GPs are more sympathetic to alternative medicine than others, and the picture is constantly changing. For example, homeopathy is now widely respected. There is information about more controversial treatments in *What is Down's Syndrome?*, in this series.

If you are looking for a second opinion or private assessment, in this country or abroad, it can be most useful to speak to other parents first and gain from their experience. The SDSA keeps up-to-date information about most of the therapies available.

Research

You may at some time be asked whether you and your child might like to take part in research into DS. Typically, projects are aimed at increasing knowledge of the health, social and educational needs of children and adults with DS.

Parents should never feel any obligation to take part, but many enjoy helping in research, knowing that they are contributing towards a better understanding of DS.

MULTIDISCIPLINARY teams

In multidisciplinary teams, professionals work together to plan services for individuals and families. Working in this way helps communication and the efficient exchange of information.

When the meeting is about a child, parents are often invited to attend and to participate. It can be useful for parents to see the professionals together, but if meetings become too big, they can be intimidating. Having a friend with you is often helpful.

The aim is to enable parents to meet with representatives from education, health, social work and the voluntary sector and to plan individual care in a co-ordinated and effective way.

Multidisciplinary teams have different names and systems in different areas. They can be led by health, education or social work departments.



Voluntary ORGANISATIONS and SUPPORT groups

Voluntary organisations play an important part in supporting people with disabilities and their families. Increasingly, they also provide direct services. Many organisations in addition offer advice and information to professionals and students.

The SDSA is a national organisation offering advice, support and information to people with DS, parents, carers and professionals on all aspects relating to Down's syndrome. SDSA provides support through networks of local parents and, in the early stages, through links with maternity hospitals. For more information see *Your Baby has Down's Syndrome*, in this series.

SDSA has a helpline that offers support and information about issues ranging from antenatal screening through to child development, health, adolescence, adulthood and ageing.

'Having other parents to talk to has meant support, care, and real friendship for us. At every stage it's been crucial to meet people who've been through it and understand. At the start it was all to do with coping with the baby, then there was school... and now all we talk about is 'letting go!'

Individuals with disabilities themselves have formed advocacy groups, and self advocacy groups. National and local organisations are increasingly raising the profile of people with learning disabilities with many encouraging the involvement of people with DS or other learning disabilities on their management committee.

Campaigning is another important function for voluntary organisations. Individually or together, they lobby on issues of concern to people with learning disabilities. Parent groups like SDSA also help members with individual problems.

'It's pressure from parents that gets things to change. You have to speak up and let them know if you're not happy. Otherwise, how can you expect things to get better?'

Some organisations also offer specialist information and advice, for example, on legal, educational or benefits issues.

The voluntary sector is important in other areas, such as providing short breaks or leisure activities. Some national organisations and locally based groups provide direct services in housing, employment and training.

In CONCLUSION

All the various professionals you will come across as a parent are experts on some aspect of child development, but as a parent you are the expert on your child. No one knows your family better than you.

The professionals can give help, guidance and support to parents and people with DS of all ages. It is worth working with them. Make sure you are informed and involved, and don't underestimate the value of your own opinions.



‘They were talking about my son as just another name or number. Eventually I just thought, “Hey, wait a minute. You’re not getting away with this. I’m a parent, he’s my son, and I’m going to get the best for him”.’

‘It’s only as a joint effort between professionals and families, working together and learning from one another, that we can provide a better future for our children with disabilities.’

References

FURTHER READING

Sticking up for Yourself: Self-advocacy and people with learning difficulties.
K Simons, Norah Fry Research Centre, University of Bristol, 1993

What is Down's Syndrome? Living with Down's Syndrome.
SDSA, 2001

USEFUL ADDRESSES

The Action Group

Norton Park
Edinburgh EH7 5QY
0131 475 2315

British Institute of Learning Disabilities

Wolverhampton Road
Kidderminster
Worcestershire DY10 3APP
01562 850251

Down's Syndrome Association

155 Mitcham Road
London SW17 9PG
020 8682 4001

Down's Heart Group

17 Cantilupe Close
Eaton Bray, Dunstable
Beds. LU6 2EA
01525 220379

ENABLE

7 Buchanan Street
Glasgow G1 3HL
0141 226 4541

Key Housing Association

Savoy Tower
77 Renfrew Street
Glasgow G2 3BZ
0141 332 6672

Ark Housing Association Ltd

The Priors
Canaan Lane
Edinburgh EH10 4SG
0131 447 9027

LIVING WITH Down's Syndrome

This booklet is one of a series produced by the Scottish Down's Syndrome Association for people with Down's syndrome, parents, carers, relatives, students, professionals and anyone who has an interest in Down's syndrome.

The booklets are designed to help with the thoughts and questions that occur to parents and to answer some of the general queries we receive about Down's syndrome.



Some points to bear in mind while you read:

- The term Down's Syndrome has been shortened to DS.
- People with DS are described as having a learning disability.
- In some of the booklets we refer to the person with DS as 'she' or 'her', while in others we refer to 'he' or 'him'. All the information applies equally to both sexes.
- We have written from a Scottish viewpoint, but the issues covered will be of relevance to readers elsewhere.
- For details of other titles in the series, or any further information, please contact SDSA at the address on the back page.

SCOTTISH

Down's Syndrome

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helping people realise their potential

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The SDSA provides support, advice and information to people with Down's syndrome and their families, carers, professionals and the general public in Scotland.

It also seeks to raise awareness and understanding of the potential of people of all ages with Down's syndrome.

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