

Health  Champions

Report from
the Health
Champions
project

Acknowledgements

We could not have reached this stage of a final report without input from many people – too many to mention, but you all know how much you contributed to this project.

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Cath McHattie

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All of us need the NHS – but some of us need it more than others.

Scottish Executive: *Our National Health*, 2000, page 67

“It’s a good clinic with staff who are interested in their patients.”

**“The doctor didn’t look at him.
Asked me questions, then the usual come back in 6 months.”**

Quotes from the diaries

Part 1

Introduction

The Health Champions project began as a Partners in Change initiative as part of the Scottish Executive's commitment to involving people. The project brought together families of people who had learning disabilities and staff who worked in a range of NHS settings.

We want to share what we have learned with other people, as part of the learning across the NHS system and with local partners.

What we did

The Scottish Executive launched the Partners in Change programme in *Our National Health*, as one of the ways to extend the involvement of patients, their families and communities in the NHS. In Ayrshire and Arran, a Partners in Change Steering Group was established in 2001 and several workshops were held across Ayrshire to explore enthusiasm for developing projects that would enable change and improvements. Discussions at the workshops helped shape the idea of the Health Champions project. Cath McHattie, who is the mum of a young person who has additional support needs and was a member of the steering group, led the project. Cath linked with another member of the

A patient-centred NHS must not just be a slogan: it must become a way of life. We want to work with the NHS to ensure that a patient focus is embedded in the culture. To make this happen we will ensure that listening, understanding and acting on the views of local communities, patients and carers is given the same priority as clinical standards and financial performance.

Scottish Executive: *Our National Health*, 2000 page 50

steering group and together they developed the idea of gathering information that would help improve hospital and health services for people with additional support needs. The steering group agreed a proposal for 10 people who use services and/or their relatives to complete diaries. Regular feedback was provided to the steering group as well as to the Improving Hospital Services for Patients with Special Needs Group, chaired by the Director of Nursing and of which Cath is a member.

Our method

It took some time for the diaries to be produced. Much care and thought went into what the content should be and how this should be presented. The final list of headings for the diaries is attached at the end of this report. During this time, Cath established links with the Community Learning Disability Team co-ordinators who linked with school doctors to seek advice and help to recruit volunteers to contribute to the project. Volunteers were then invited to meetings held in a range of locations across Ayrshire to distribute the diaries and provide advice and support to contributors. Cath offered ongoing support for contributors.

We asked people to keep diaries of their contacts with the NHS. The diaries were based around the practical and emotional impact of these contacts for the people and their families,

rather than on the clinical outcomes. We also wanted to see how the various contacts with different services came together for that person and family. So we asked people to keep the diaries over a period of a year until March 2004. Clearly the number of contacts that people had varied.

Once we had all the diaries, Outside the Box Development Support helped us with putting the report together, identifying possible ways to improve services, and with planning what will happen next.

The experiences of the people who took part illustrate what services are like for patients and their families, and what it is like for some families who are living with disability in Ayrshire and Arran. They complement the information and feedback the NHS has from other sources.

We are very grateful to those families who contributed to the project: they have helped more people to understand what can improve access and quality of health care for disabled people and their families, and especially for people with learning disabilities. We hope that the information in this report will provide the evidence and opportunity for action within the health system to make those improvements and extend the good aspects of care.

How to use this report

The experiences which are described here – both the good ones and those where things could have been better – happened in a wide range of services and locations, largely within Ayrshire and Arran. These are experiences that can happen anywhere.

If you work in the NHS or a related service, you can use this report to help you consider implications for your service. Our suggestions on ways to make the services better are at Part 6 of the report, but here are some ideas to start you thinking.

Think through your service from a patient perspective. Walk through it.

- **What is likely to have happened before the person ever gets to your office or clinic?**
- **How would it be if you had to wait here for half an hour? For an hour?**
- **What could it be like if you were in a wheelchair, or couldn't see or couldn't hear?**
- **Are the people who come here being treated with respect?**
- **Are you and your colleagues reassuring people who are anxious?**

We believe there is a need for a more coherent approach within NHSScotland to meeting the needs of disabled people. In this European Year of Disabled People, we will extend the principles set out in Fair for All [the policy to ensure the needs of people from ethnic minorities and refugees are met] across the NHS to ensure that our health services recognise and respond sensitively to circumstances of people's lives.

**Scottish Executive:
Partnership for Care,
2003, page 20**

Many health professionals and healthcare teams are involving patients in the design and delivery of services. Many parts of the NHS are harnessing patient feedback and translating that into improvements in the delivery of care.

**Scottish Executive:
Our National Health,
2000, page 51**

You can also use the report to help you think about the ways individual people and their families contribute their experiences and ideas, for both their own care and for services overall.

- **Are there easy ways for people to feed in ideas, including staff?**
- **Are there easy, user-friendly ways for staff to get feedback from patients in a structured way?**
- **Are there ways to highlight to staff, across the whole health system, an individual's needs e.g. "Lucy hates a busy room and becomes very anxious"?**
- **Are staff empowered to create change where it is felt that it would benefit that individual?**
- **Are families helped to voice an opinion?**

If you are someone who uses health services, or has a relative or friend who has frequent contact with the NHS, the experiences described here might help you think about how you can also feed in your ideas and suggestions.

- **Are there any particular things which staff do which you find helpful?**
- **Are there things that you can see which could be improved?**

Life expectancy for people with learning disabilities is lower than for the rest of the Scottish population.

People with learning disabilities have a higher number of health needs, and more complex health needs, than the rest of the population.

People with learning disabilities have a higher level of unmet health needs than other people.

There is a need to increase capacity within generic services [those used by everyone] to meet better the health needs of people with learning disabilities, and also to increase capacity within specialist learning disability services.

Family carers play a crucial role in supporting the health needs of their relative with learning disabilities. Their own health needs are often not adequately supported.

People with learning disabilities and family carers are a valuable resource for educating professionals and paid carers.

It is explicitly unlawful in Scotland to discriminate against a person on the basis on their disabilities; reasonable adjustment must be made so that services are accessible. However, in addition to experiencing exclusion, people with learning disabilities experience both overt and more subtle forms of discrimination in NHS Scotland. This cannot continue to be tolerated.

**NHS Health Scotland:
Health Needs Assessment, 2004**

Part 2

Why this matters

'He has a huge smile, and when he laughs you have to join in.'

'His attention span is about 3 minutes.'

'..very caring to others, but she can be uptight in crowds and noisy areas.'

'A really chatty, happy girl ... sociable.'

' ..a typical teenager'

'..has no mobility and not much speech...enjoys company and has a fun sense of humour.'

'He has limited understanding and cannot sit unaided, walk or talk. He is generally a happy contented boy.'

'She is really good company. Loves to be out and about.'

Quotes from the diaries

The people who were at the centre of the experiences described in the diaries covered a range in terms of their ages, disabilities and family situations. Their ages ranged from 11 years to 47 years, but they are typical of many disabled people.

- There are younger children.

- There are teenagers, who are at school, making friends and fitting in the interests that many teenagers have.

For both, there are other children and young people in their families, and parents who work, so the arrangements for fitting in clinic appointments could sometimes be complicated. When extra treatment or visits are needed because of delays or poor co-ordination across parts of the NHS, this may mean more time off school for the young person and time off work for their parent.

- There are people in their thirties and forties, who are looked after by a parent who is now elderly.

People with learning disabilities are now living longer than in previous generations, as a result of improvements in health care.

- Some people need other people to take extra time to listen to them and understand what they are saying.
- Some people use a wheelchair to get about.
- Some people use equipment to help them communicate.
- One young person is deaf and communicates by signing.
- For some people, a change of routine or being in noisy places is not good for them.
- Some people are reassured when they can

feel or see a particular thing which is familiar to them.

- All of the people go to many different clinics and doctors because there are several symptoms or disabilities as a result of their health condition.
- The impact of illnesses such as chest infections can be higher than usual for some people, so they sometimes need urgent attention.
- For several people, the person who is their main carer is not in good health.

Many studies have highlighted the poorer health of people who are carers – their mental health and well being; physical injuries caused by lifting or working with poor equipment; generally neglecting their own health because other people have to come first. In addition it could be expected that a carer's energy levels may lessen as they grow older, particularly as the physical demands of their family member increase.

The NHS staff looking after the person with the disability may have no awareness of the health problems of the carer. Here, this included some situations where the carer had a long-term condition which sometimes made it difficult for her to cope with travelling a distance, for example. One person fell and broke her shoulder, and this has had an impact on looking after her family, two of whom have special needs.

Part 3

General Overview

The experiences which are described here – both the good ones and those where things could have been better – happened in a wide range of services and locations across Ayrshire and Arran, and at clinics at Yorkhill and Southern General hospitals. These are experiences which can happen anywhere.

Many of the good features of care are examples of the kinds of practice set out in statements of good practice and policy documents, including the NHS Quality Improvement Scotland standards and in the recent Health Needs Assessment by NHS Health Scotland.

These are also features of good care for anybody who uses the NHS.

Looking at services from a patient's point of view underpins everything that we are seeking to do in the health service. Patients are concerned about the quality of care; treatment at the right time and in the right place; being treated with dignity and respect; having their say in decision making; having their feedback taken into account; and getting clear explanations at every stage.

Scottish Executive: *Partnership for Care*, 2003, page7

Positive features throughout the diaries are:

- **Staff treating the person with respect**
- **Reassurance, and getting good care and helpful advice**
- **Keeping people informed about the reasons for any delays and giving apologies**
- **Staff looking for ways to make things easier for people, and giving people choices**
- **Buildings which are comfortable and easy for disabled people to get around**
- **Facilities where there is enough accessible parking.**

Common features which were poor are:

- **Staff behaving in ways that are disrespectful**
- **Poor communication with people by some staff**
- **Insufficient car parking for disabled people at some NHS locations**
- **Physical layout and other features of hospital design and maintenance which are unhelpful or not suitable for disabled people**
- **Lack of equipment to assist disabled patients in treatment rooms or wards**
- **Delays in getting care**
- **Delays/waiting when clinics or other services ran late.**

Part 4

What was good

Respect for the person

The people completing the diaries particularly noticed when the staff showed courtesy, consideration and respect. They also commented on staff who showed an interest in the person – finding out what she was interested in, making real conversation. For some people, there was a contrast with previous experiences or with current contact with other parts of the NHS.

‘The dentist spoke directly to her.’

‘It was good to see him treated with respect.’

‘The doctor came downstairs to see us, tried to make it easier for us.’

‘It was people I knew. All the staff were very friendly and helpful.’

‘The physiotherapist is really nice. She asked me loads of questions about myself - she seems to be interested in what I do. She doesn’t say I’m just a patient.’

‘It’s a good clinic with staff who are interested in their patients.’

Quotes from the diaries

Reassurance

A frequent good feature of the contacts was the quality of the care people received, and the reassurance which staff gave them.

There were examples of staff explaining the reasons for things that someone was finding to be a problem, and involving the person in discussing what to do about it.

There were also examples of situations which someone had previously found uncomfortable, but was now described as a good contact because the staff were reassuring and engaged with the person.

‘She spoke to [my daughter] throughout, explained what she was doing and why.’

‘Same person as last time, so [person] was relaxed and treatment was easier.’

‘She was relaxed and happy – talking to staff she knows well.’

‘Staff chatted away to him about ordinary things.’

‘She showed what the equipment did.’

‘great support’

‘excellent visit’

‘ I was anxious about it before, but the staff were really nice.’

Quotes from the diaries

When someone was quite ill it helped a lot to see a GP or hospital staff they know. Carers also praised staff who took steps to reassure them.

'She gave us her number so we could get in touch quicker if it happened again.'

'They told us not to worry, just phone and they will come to the house.'

'The theatre staff were lovely.'

Quotes from the diaries

For some families, the reassurance was around the day-to-day situations – for example, practical suggestions on how to handle particular situations, a prompt response at the start of someone becoming unwell. People commented on examples of staff being interested in the other members of the family and giving advice or suggestions that helped the whole family.

One mother said of a psychologist: 'She also made me feel good about myself, and that I had done a good job working with my daughter.'

'great support and help...makes us all feel relaxed'

Quotes from the diaries

Parents and carers often need moral support. Often there can be low esteem as a result of what is perceived as constant negativity. Having a supportive relationship with, for example, a health visitor who is sensitive to the family's needs, can help boost the carer's self-esteem.

Appointment times

People noted it as a good experience when they were taken on time. In the contacts described in the diaries, and in the families' previous experience, waits of around half an hour beyond appointment times were fairly common, so being taken on time was something to note.

All the diaries commented on the information people were given when there was a delay – explanations about the reason for the wait and apologies were both listed as good features of visits.

Staff looking for ways to make access to health care easier, and giving people choice, were praised.

'She said she would refer us to Crosshouse so we didn't have so far to travel.'

Quotes from the diaries

People noted as good when there was a choice of equipment, where possible, and making it as 'normal' as possible – for example, choosing the boots to go with splints.

Buildings that are comfortable

The families who completed these diaries had many problems with buildings, including new ones, which were not well-suited to the needs of people who use wheelchairs. When they were in a building which had wider corridors, larger rooms or pleasant places to wait in, they commented on these features positively.

Car parking that is easy

Car parking was often a problem for the families. When it was easy, both the patient and person with them were more relaxed.

'new disabled parking – what a difference!'

Quote from the diaries

Part 5

What was not so good

Staff behaving in ways that were not respectful, and did not create reassurance

The families felt strongly about staff who did not treat disabled people or their carers with respect.

‘The receptionist totally ignored my daughter, she spoke directly to me.’

‘The doctor didn’t look at him. Asked me questions, then the usual come back in 6 months.’

Quotes from the diaries

Another aspect of care which added to the difficulties for some people was the large number of staff involved – for example, when different staff carried out different stages of an admission or assessment. This was contrasted with the situations where a few members of staff worked with the person and got to know how to communicate with them.

‘ It would have helped if just one or two doctors had treated her. She was exhausted coping with so many people.’

Quote from the diaries

Communication

Several people encountered significant communication problems in these contacts, especially when a parent is trying to take in information *and* deal with her child's distress.

They noted that the impact for someone of news or options around treatment was influenced by previous bad experiences of treatment or of hospital stays. There were examples of staff not appearing to anticipate this or take account of it.

One mother described a doctor saying that further surgery was needed, when her daughter was present and there was no prior warning to let her discuss the possibility with her daughter.

'[it is very difficult]trying to discuss things with a doctor when you are with a child who wants you to sign [use sign language] to him and tell him what is going on'.

Quotes from the diaries

Car parking

Everyone commented on difficulties in getting access to buildings. Specific problems were:

- lack of parking spaces for disabled people
- delivery vans in those spaces, and/or blocking entrances
- non-disabled people using spaces designated for disabled people
- cars getting damaged by other drivers or by barriers which do not accommodate vehicles which are higher than most cars.

'Problems with getting parked made us late.'

'We were rushed and anxious by the time we got there.'

'My daughter was upset by the incident in the car park.'

'..drove round for nearly 20 minutes before I found a space.'

Quotes from the diaries

The consequences were usually that the patient and carer were anxious and upset by the time they got to their appointment. So the rest of the contact could be affected in many ways, including how they both responded to the staff they met and the person's physical reactions to treatment.

This is an example of the ways the various aspects of a contact with services interact with each other. When the next person they saw at the clinic or unit was reassuring and helped calm them, things got back onto a good footing. If the next person was not welcoming, the contact could continue to go badly.

Physical environment: the size of rooms and waiting areas

The main features of buildings which people described as poor are:

- rooms which are very small and do not have enough space both for a wheelchair and for someone accompanying the patient
- waiting areas and treatment rooms that were hot and uncomfortable, especially for someone who can't easily get up and move.

The small rooms were in places like eye clinics, but also for consultations with physiotherapists and other staff who could be expected to see people who use wheelchairs or need more space to move in.

'The room was small, leaving no space to lift [person] and no room for a hoist.'

'The waiting room was too small for us, so we ended up in the corridor'.

'It's a pain when you have to keep asking someone in a wheelchair to move. You feel as if you are in the way all the time.'

'A bit clinical – not great to take a child into.'

Quotes from the diaries

Equipment in the treatment areas

Another problem with the buildings was the lack of equipment suited to the range of people who used that service.

- Several people had experiences where there was no hoist for someone transferring from a wheelchair to a treatment chair or table.
- It was usually left to the person's parent or carer to lift them or help them transfer, although on some occasions staff did offer to help.

Again, this included settings where many of the patients were disabled or older people.

A mother whose child was in hospital for a planned stay found that the bed was not safe for that child, there were no suitable bathing aids, and there was no chair which could be positioned safely. She had to hold her 12 year old on her knee for several hours. Eventually a nurse came who helped her sort out a suitable bed with secure sides.

'It took 3 hours to get her wheelchair fitted. I was tired with all the lifting I had to do, moving her in and out of chairs. It would have helped if there had been a hoist.'

'I was lifting in a confined space – makes things more difficult.'

'She couldn't use it [diagnostic equipment] because it was on a table that could not be adjusted to the height of a wheelchair.'

'They have nothing for children with mobility problems.'

Quotes from the diaries

Delays and other difficulties in getting treatment or equipment

There were examples of people going for tests, but these were not all done at the one appointment as arranged. Consequences included:

- having to take another day off school (for patient) and work (for parent)
- the patient being nervous the second time because she knows it will be uncomfortable
- results not available in time for the appointment with the consultant to plan the next stage of treatment.

There were also examples of delays and poor communication causing ill health. For one person, the result of a poorly fitted wheelchair was further treatment which at best would be uncomfortable and involved another series of hospital visits.

‘[consultant] said the wait for 8 months in getting a wheelchair fitted properly was undoing what had been achieved in surgery last year.’

‘Pleased that the consultant got things moving straight away – but why had they ignored my phone calls for all these months?’

‘I am desperate for the shoes as we have to glue the soles back on the ones he is wearing to get him to school.’ When the mother called to collect the new shoes: ‘The office had only one pair, although 2 were ordered. So it is another trip in a couple of weeks time.’

‘Poor communication between specialist staff and staff at local surgery resulted in an inaccurate label on the prescription bottle – standard dose for most people, which is too little for [patient]. It means we can’t let her take the medicine to school or respite, as the staff must follow the printed instructions.’

‘Constantly phoning is exhausting.’

‘When we arrived the equipment wasn’t there. The staff phoned to see when it would come. Why couldn’t they have phoned me before? It’s a 45 mile round trip.’

Quotes from the diaries

There were examples of people finally getting equipment, but some parts were not right and new ones had to be ordered. So the person was expecting another long wait before the equipment could be used properly, and/or would have to make arrangements – which were difficult – for another visit to collect the equipment.

There were also examples of staff working from out of date notes: the patient or relative knew what had happened at a recent visit to another hospital or specialist but it wasn't available to the staff here, and the treatment or examination could not go ahead until the information had been checked. Valuable time was wasted for staff and for families alike.

There were also situations where the wait was for a referral or getting an appointment with someone. Once the family got to the right person the care was very good – so the frustration was in not getting that support or treatment earlier.

People also described their frustration at being bounced between several community staff – for example, when trying to get incontinence pads for someone who needed these occasionally.

'Spent next few days trying to phone the health visitor – always not available'. A week later – ' it is uncomfortable and embarrassing. Washing and changing the bedding is easy, but not the bed'. Finally 'got 30 pads delivered. I could manage with less, but it seems it is 30 or nothing.'

Quotes from the diaries

Delays – waiting at clinics or for other care

Waits of around 30 minutes at clinics after the appointment time were fairly common and on a few occasions people waited for over an hour. This added to the distress for patients, and in some situations made the subsequent treatment or examination more difficult and for some impossible.

'She got more anxious waiting.'

after a wait of half an hour: 'He is anxious as he doesn't like hospitals.'

'What was not so good? Waiting so long in a hot room with a child who is anxious.'

Quotes from the diaries

It also caused difficulties for carers who were juggling other responsibilities – getting home to make dinner for the family, caring for another disabled member of their family.

One person had to attend Accident and Emergency late one evening. Although she was seen 15 minutes after arrival, she then was left for over 30 minutes: in all, the visit took 2 hours. The arrangements, which appeared to be routine for all patients, did not suit someone who was uncertain about what was going on and got anxious.

Another person faced a delay of over 3 hours when being admitted for planned surgery. In part, this was because a bed and other equipment suited to their needs had not been arranged on the ward.

There were also situations where the carer was waiting for treatment, and where it appeared that her role as a carer was not taken into account in planning the care or setting priorities.

‘My last appointment was at 10.45 and I still hadn’t been seen at 1pm.’

‘I had to ask a friend to come in and help when I was ill.’

Quotes from the diaries

Part 6

Suggestions for ways to improve the services

This section brings together suggestions on action which the NHS can take to improve services for people with learning disabilities and their families. They include those from the families who completed the diaries and ideas from NHS staff who read the diaries and this report.

Work towards the most inclusive and best practice you can with the money available and ask disabled people about priorities, about what they want and about how the service can be provided in a different way.

**Lynn Welsh, Disability Rights Commission,
February 2003 Conference Report**

All staff

Think about the ways in which you treat the patients and families you meet – are you respecting the dignity and identity of everyone, including people who have learning disabilities?

Talk to people about what would help them – acknowledge that you don't have all the answers but show that you are trying to help.

The people who you meet are probably anxious, and may already be upset or stressed by the effort of just getting there. Think about what you can do to help relieve their anxiety. Is there anything which may be adding to their anxiety, which you can change?

Are you doing what you can to make it easier for disabled people to get access to services? For example, by not taking or blocking car park spaces for disabled people.

If you know that work is planned (or underway) to improve things, make a point of keeping up to date with progress so that you can pass that information on to patients and their families.

Service Redesign Committees and Service Redesign Teams #

Make disabled people, and their particular and various needs, part of your redesign of all health services – not just of specialist services.

Remember the range of disabilities. You will never be able to anticipate the needs of every patient who will use that service. So build in enough flexibility to let staff adapt to the needs of the individuals.

Use this report as a prompt on the points you need to think about.

Work with people who have learning disabilities and other disabled people in your local area when you are working on a service redesign project.

Service Redesign Committees were introduced in Partnership for Care. Each NHS area has a Redesign Committee.

Service managers and people planning services

Use the experiences and views of people with learning difficulties and their families to help you plan services which will work for everyone. Use resources such as this report and, most importantly, talk to people in your area.

Have more local outreach clinics.

Consider joint working with local Councils to support vulnerable families e.g. for the NHS to take account of families' respite needs. For people with learning disabilities, this can be part of your Partnership in Practice agreement.

Look at the scope for practical support such as a 'meet and greet' person to meet patients at the reception door, to enable the vehicles to be parked and prevent undue stress at the start of the appointment.

Walk through your facilities, from the car parking and bus stop, into the building, to the reception and on. How would it work for someone who is not very mobile, or who has difficulties understanding what is going on around them? Ask disabled people and their families what would help.

Get together with the local Volunteers Co-ordinators, families and disabled people, to explore ways in which volunteers can contribute.

Estates staff

Think about the design of waiting areas, and how convenient they are for people with a range of disabilities. Examples suggested by the families are

- Rearrange the seats in the waiting room –

take a few out, so there are spaces for wheelchairs.

- Remove fixed tables, or have smaller ones which are easier to manoeuvre a wheelchair around.
- Have something for teenagers to do while they are waiting – for example, like the teenbooth at Yorkhill.

Think about the range of people who might use that service, and the facilities or equipment they may need. Suggestions from the families were

- Have hoists available for people who have to transfer between chairs or onto equipment – especially in situations where the NHS knows there will be people in wheelchairs, but also available for all settings.
- Make sure there is space in at least some rooms for extra equipment and extra people.

Walk through your facilities, from the car parking and bus stop, into the building, to the reception and on. How would it work for someone who is not very mobile, or who has difficulties understanding what is going on around them? Ask disabled people and their families what would help.

Primary Care staff

Think about the design and layout of your buildings – look at the suggestions for the Estates staff.

Do a review of GP practices in a local area and let people have a list of what is easily accessible e.g. can people be seen downstairs?

When the GP is referring someone with a disability or a relative who is one of their carers to another part of the NHS, think about how you can alert the services to what this person will need.

Ask the person and/or the carer whether they would like their contact number included in the referral letter, so that staff can readily get in touch to confirm arrangements.

Avoid calling somebody for whom access is difficult for different things on different days – and if they come to see you, check whether they are due a recall for anything soon and deal with it there and then if you possibly can.

Could community nurses make a visit to take blood samples at home, if these are necessary, to avoid a double trip to a surgery?

Specialist units providing services for disabled people

Think about how you organise your services – how convenient is this for the people who use your services and their families?

Could you have more local outreach clinics?

Will the equipment you provide start making a positive change to the person's life straight away?

- Have a wider range of the usually small parts – such as straps – which make equipment fit properly.
- Give people a choice around collecting equipment, such as asking a friend to collect it or staff posting it out to them.
- Telephone when equipment comes in, in case the person needs it urgently.

Community Health Partnerships

Think about how you can share the ideas and suggestions in this report with the members of the Community Health Partnership in your area.

Think about how you can involve people with learning disabilities and their families when you are setting up the Community Health Partnership.

Discuss with them how these patients, families and staff – just as for the other patients, too – can have a continuing relationship that is positive and constructive.

Clinical staff in all settings

Think about the needs of the patients you know will be attending for care before the clinic or admissions.

- If someone has a disability, has someone asked them what would make the contact easier for them?
- What equipment would help them? Is it ordered?
- Is the usual location for the service the best place for this person, or would somewhere else be more convenient?
- What time would be best? For some people, an early appointment may mean a terribly early start, when they need a long time for washing, dressing, eating and having their medication. Other people may prefer an early appointment, when the place is less busy.

Families value continuity and getting care from someone whom the person knows.

- What can help you have continuity in the care for this person?
- If you are going to be away next time, what information do you need to leave for colleagues and for the person or family?

- Is there room for flexibility in the timing of repeat visits to ensure continuity?
- Could you provide a brief note of a visit for families so that if they are attending a different clinic in the near future, they are able to give clear information to the staff there?

People appreciate it and are less anxious - and so respond better to treatment - when staff show an interest in them as people. Is it easy for the staff in your team and your patients just to have a chat?

For patients who are relatives or carers of people with disabilities, are you taking account of this when planning their care?

- Ask patients what they need to help them in their role as a carer - times of the treatment, support at home when recovering.
- Ask them if it is ok to involve other services, such as respite services.

Receptionists, administrative staff

When someone is disabled, think about what appointment arrangements will help them.

- Consider what steps have had to be taken to get the individual to an appointment e.g. transferring person and equipment into a vehicle, meals, personal hygiene.
- Appointment times could be extended for people with special needs.
- Appointment times could be negotiated individually, so that particular times can be avoided e.g. busy car parks, too many people about.
- Think about the totality of the patient's needs – is it possible to avoid multiple recalls?
- Could you have someone to 'meet and greet' some people, to be with the patient while the vehicle is parked, and to make sure they are booked in for their appointment in good time.
- When you know someone needs extra space for their wheelchair and/or a carer, flag this up in their notes, so arrangements can get made at the time of their next appointment.
- Think about what can help this person feel at ease – being valued, acknowledged.

- Think about how you can keep patients informed about delays when clinics run late.
- Think about what could make waiting times less difficult for patients with additional support needs and their families. Ask them for suggestions.

Training and development for all staff

Help staff reflect how they would like themselves and their family to be treated.

Work with disabled people and their families to plan staff training.

Involve disabled people and their families in training staff.

Annex 1

Headings from the diaries

About the person:

- Age of the person
- Male or female
- Please tell us something about them

About each visit or experience:

- Department/clinic visited
- Date/time of appointment
- Actual time when seen
- What was good about the visit?
- Anything not so good?
- What effect did this have on the person/family?
- What would have made it easier for you?
- Any other comments?

The families knew that what they said in the diaries would remain anonymous.

Annex 2

Policy and practice context and other sources of information

- **Scottish Executive Health Department: Our National Health, 2000; HMSO**
- **Scottish Executive Health Department: Partnership in Care, 2003; HMSO**
- **Scottish Executive publications are at: www.scotland.gov.uk/publications or www.scotland.gov.uk/library/health**
- **NHS Quality Improvement Scotland: Quality Indicators – Learning disabilities, February 2004**
<http://www.nhshealthquality.org/nhsqis/files/Learning%20Disability%20Quality%20Indicators.pdf>

- **NHS Health Scotland: People with learning disabilities in Scotland - Health Needs Assessment Report, 2004**

A summary is at: <http://www.phis.org.uk/pdf.pl?file=pdf/LDSummary.pdf>

- **Disability Rights Commission, NHS Forth Valley, NHS Quality Improvement Scotland, Scottish Executive and SHS Trust: Improving disabled people's access to health provision, 2003; conference report, SHS Trust**

- **SHS Trust and Scottish Executive: Service for All – Making it Happen, 2003; conference report; SHS Trust**

The reports published by SHS are at: www.shstrust.org.uk/publications_reports.htm

- **Mencap: Treat Me Right, 2004. This report describes the experiences of people with learning disabilities when using health services. The Mencap website also has examples of useful material and links to other sources of information for people with learning disabilities on health matters, and for staff who work in the NHS.**

The report is at: www.mencap.org.uk

- **The Health Challenge Bulletin, Scottish Consortium for Learning Disability, 2004. This is a list of many useful sources of information on health for people with learning disabilities, their families and for staff who are treating or supporting people with learning disabilities.**

www.sclld.org.uk

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