

You have heard from the experts. You have listened to the voices of experience. You have discussed facts and figures, new developments and old problems. I am not an expert. I am a politician – one of those who can often be part of the problem but who can sometimes help find the solution. So my task is to bring commitment and to try to put into words the spirit of this occasion.

Look around you. This room holds some 300 people. Imagine it filled with children. Now treble the size of the room and the number of children.

That roughly is the number of children we welcome into our world every year, who are born deaf or with hearing impairment.

Now split that number in half, and one half of those children at the age of one and a half were until recently undiagnosed and half of those remained undiagnosed at the age of three.

Now watch those children grow and watch them struggle with inappropriate or uncomfortable aids and equipment and see their families struggle to get the best communications system to suit them.

And keep watching while school age comes and educational opportunities are missed because access to supported mainstream education or to specialist classrooms and teachers are not available or not affordable.

Then imagine that small number of young people who have come through all that and qualified for further or higher education but find choice of college and course limited and restricted by the lack of physical and human support.

And so it will go on – into the world of work: and the world of holidays: and the world of hobbies: and the world of sport: and the world of transport: and the world of home.

Most children with deafness or hearing impairment probably start life with that challenge; as the years go by, more and more will lose the faculty as a result of illness or accident or chance; and later hearing will, as my 99 year old mother puts it, be one of the "bits that wear out" with advancing years.

And whether hearing is never there or whether it is impaired or "wears out", there is an added burden that children, young people, adults and elderly have to bear – and that is discrimination – stigma – the lack of understanding, the lack of patience exhibited by the rest of us, that too often leads to the slow, disappointed, sad slide into isolation and loneliness.

That is the down side of what we are here yesterday and today to address; that is part of the reality that we who are policymakers must understand and be spurred by into action.

If we do not put in place the right policies and adequate resources for children at the very start of life, we cannot be surprised if they face increasing difficulties as they progress through that life.

But there is another reality we must also understand. We are not here to speak in sombre hushed tones, because so many of the people who live with hearing loss or impairment – and especially the children – are not themselves sombre and they certainly don't speak in hushed tones! So let us start by celebrating their achievements; because they are achievers in so many ways in their personal and public lives.

This is not then a day for a theme of "There but for the grace of God go I"; but for the football chant "Here we go; here we go; here we go!"

Gathered here are doctors, scientists, teachers, therapists, carers and advocates and policymakers. All of you I salute and thank for what you do.

But today the real stars of our drama are the children themselves. The rest of us are the supporting cast, the stage managers, the scenery designers, the backroom boys and girls. It is our child stars who invite parliaments, press, public and professionals to share, as in any theatre, the emotions – the joy, the tears, the laughter – and the pride of performance. They are wonderful performers. They achieve so much. They demonstrate courage, determination and humour.

They are a pleasure to live, learn and work with; and they give so much to the rest of us. They cope, they adapt, they are resilient. Disabilities may not disappear – perhaps they rarely do – but they do not have to prevent someone living life to the full. Beethoven I suppose is a classic case – in every sense. But what about the young dancer who trained at the Ballet Rambert School and went on to dance with the Portuguese National Ballet? I remember asking how someone with no hearing could do that and was told it was by feeling the rhythm through one's feet. And there are countless other examples in sport and the arts, in business and professions and journalism, that stand as role models.

But so too do the every day achievers in their daily lives – not least as children.

And it is as children that we should first and foremost see them. Not as labels or categories. And certainly not as "them" and "us". There should be no "two nations" concept of normal and disabled. The road through life and disability is a seamless one and often one of degree. We do not cross over into a world of disability; we all have various abilities and various areas of difficulty. We need to understand how close those areas are.

Children with hearing impairment – however profound – do not classify themselves. Any more than I do when I take my glasses off. I am a man; a husband, father and now grandfather; I am too big, sometimes too slow,

sometimes too stupid, I am a politician, but even that does not set me aside – I hope – from the rest of mankind. I do not classify myself as "sight impaired", although I am now helpless in terms of reading my notes! No more do I say I am a diabetic, even though that is a condition the pain in my feet often reminds me I live with.

So first a child and then one who lives with a physical problem – deafness.

- That child – and I – can function and live our lives;
- if we have the benefit of good scientific advice;
- if we have the support of physical aids, devices and perhaps medication;
- if we have obstacles removed and access ensured;
- and above all if we have a little understanding from our friends, family, neighbours and from our colleagues or fellow students.

Understanding starts young – during or even before school days. If children with hearing problems are enabled to mix with other children in their neighbourhood, at playschool and then through the school system, they are not only understood better by them but are protected by them; and the other children learn about disabilities that they might not otherwise meet until adulthood.

Many disabilities, like deafness, are not visible and that can make other people uneasy. If someone has a wheelchair or a white stick, the condition is immediately seen and understood. But if there are no such outward signs, the result can be unease and then impatience and then rejection; and that in the past has led to policies of people being sent away and institutionalised and forgotten. Much less of that happens if as children they are together early with their hearing impaired playmates and school chums

That is why I personally endorse and have always tried to facilitate mainstream education for children with disabilities. I know it is not always possible and I know it is not always what parents want, but to me it is a fundamental right for a child to have access to the fullest possible educational experience, whenever it is possible and the additional support can be provided. And I believe the cost of that support must be afforded and provided. Likewise it must be afforded for the centres of excellence and for specialised units.

Overall policy for deaf children should be the same as for any other children – but with some extras to ensure a disability does not become an impossibility. This week we have been celebrating Deaf Awareness Week. The question is how do we ensure that awareness across Europe and how do we translate that awareness into action by Europe and all its Member States.

- I believe our European agenda for action should be to find and share best practice;
- to establish a European Framework for Children with deafness and hearing impairment;
- to invest in research and to ensure the human rights of those children.

- We need a programme by the governments and local governments of Europe, to cover health, education, training, transport, social security and social services, to enable children with hearing difficulties and their families to cope and to achieve;
- we need to expand opportunities and to remove obstacles;
- and we must involve children and their carers, whenever possible, in the planning, implementation and monitoring of services.
- We will need legislation, codes of good practice, users charters, and resources.

Now, I may say that and believe it. But I need your help, if we are to achieve it.

I need your help in persuading my fellow politicians and especially those in government and Commission, who hold the purse strings and decide policy priority.

And let me give you some tips:

- Don't use a megaphone – I will cover my ears and wait for you to go away;
- Don't try mass mailing – you will all get a standard reply;
- Don't mass e-mail me – you will be lost among the spam for Viagra and the enhancement of bits of my body you don't even want to think about – and we know where the delete button is now;
- Do write to me in your own words, as a constituent;
- Do come and see me (briefly) in my constituency and invite me to come to a local support group or clinic or research centre;
- Help me to feel you are my deaf children's group or family or specialist and I will fight even more for you.
- And do say thank you afterwards: it's worth its weight in gold.

I always remember an advocate for another disability area; she used to come and see me when I was a Health Minister. My officials would always be firm with me: "Remember Minister the answer is No" and she would enter my room, preceded by her warmest smile, assure me I was her dearest friend and ally, thank me profusely for all I had achieved with her; and as I glowed, I hardly noticed the reference to one or two new ways she thought I could help her, I just said of course. And afterwards my officials would shake their heads "And how are we going to pay for that, Minister".

I exaggerate a little but the advice to win people before arguments, which is often given to politicians, applies no less to lobbyists. And five letters from constituents to every MP means several hundreds to Ministers and the Prime Minister will soon want to know what you are doing to calm this campaign.

If we are to raise the profile of deaf and hearing impaired children, so that we can put their needs higher on the agenda for research, treatment and care, we need to understand. Only those who live with a disability themselves can really understand what it means and what would help. But we can listen; we

can hear; we can empathise. We all, I believe, need to do more listening. It applies to all disabilities and disorders and to people of all ages, but especially perhaps to children. Parents need to listen; health and care professionals need to listen; service managers need to listen and policy makers certainly need to listen.

So often when I was a Minister I was astounded at the eloquence and force of children with a health or social care problem; and so often they gave me the piece to complete the jigsaw of service provision. The boy who stopped me on the stairs of a psychiatric hospital and told me: "I know when I am going to be ill, but people won't listen to me and my GP says I am not ill enough to be referred. And so I wait and then I am really ill." He taught me about one of the gaps in our health service. No professional or manager had told me that truth before.

Of course, sometimes you get more than you bargain for. It was a colleague of mine who said he once asked an elderly patient what extra provision she would most appreciate, to which she replied that a case of Guinness each week would be very welcome.

But it was another elderly lady who taught me another lesson. I had called on her and found her sitting watching television with the sound off. I asked her why and she explained her hearing was very poor. I said I would put her in touch with the hearing aid people, but she said oh no, a nice lady had come and given her a new hearing aid, but she had arthritis in her fingers and could not adjust its volume control. So she sat there rather depressed because we did not have joined-up action and support from the different agencies and services on which she depended.

Let me take a third elderly person, my own mother, whose hearing started to go in her eighties. It was becoming more and more difficult to communicate over the telephone, despite the adaptations to it and she was beginning to think she could no longer live independently, as she wished. So we bought her a fax machine and she was able to send and receive letters and send us her shopping list every fortnight and she was well into her nineties before she left that home. But fax machines are only available to those who can afford them.

Now she is in a nursing home and not very happy because no-one in the system has the time or the patience to sit with her and communicate, telling her about the day's news or reminiscing over the past. We can do that when we visit but the rest of the time there is nothing and no-one to stimulate her perfectly active mind.

All these are examples from older people but the lesson applies no less to children.

It is to listen and observe. It is then to engage all the services, to provide the aids and gadgetry, which children are so adept at using, and to have the

patience and the skill and the commitment to communicate and stimulate the bright person and brain that is within the child. If we listen, we are able to hear from that child his or her needs, his preferences, his likes and dislikes, his frustrations, his imagination and his ambition. Then that child is having a real input into decisions that directly affect him.

Of course it can be even more difficult to achieve, if the child has multiple disabilities. The work I have seen done with children who are both deaf and blind is always moving and often amazing. To help such a child communicate by touch and movement is work of skill and inspiration. Likewise I have often seen the work done with children who are hearing impaired and have learning difficulties. Then, for example, it is much more difficult to judge when a child is comfortable with, say, a hearing aid. But we have specialists and centres that have been able to do just that. Such teams are never cheap and cannot always be local but their continued existence must be a priority for the public purse.

Behind all this is the too often undervalued and under resourced area of research. Research into the causes, treatments, reversals, implants and possible cures, including stem-cell and genomic research and research into the technologies of medical devices and environmental aids. This is where so much hope for the future is invested but Europe is lagging behind America and Japan and, if we are to keep our research teams, in government research establishments, in industry and in the great charitable research foundations, we must double our research budget.

In Europe that has been acknowledged as a fundamental requirement for the so-called Lisbon Agenda – designed to dramatically increase Europe's competitiveness – but we have to ensure that doubling is realistic and achieved. Over the coming months we shall be considering the Commission proposals for the 7th Research Framework and every European Government needs to look at its own research funding too.

Europe of course does not run health services or social services. Indeed the Treaties preclude it from doing so. But it has a major role on public health, on environmental health, on pharmaceuticals, on professional qualifications and now, as a result of court judgements, on patients' rights to mobility – to go to another EU country for treatment, if there is undue delay in one's own country.

We also have a Health Action Programme, with the three strands of Health Information, Health Emergencies and Health Determinants. Our most effective role is in finding and sharing best practice and setting Frameworks for different diseases and disorders.

One key message from good practice is the theme of this conference – and Services working together is always one of my themes – Health, Education and Social Services are, or should be, the obvious collaborators in support of a deaf child, but every area of policy making has a part to play.

Under the Treaty of Amsterdam we brought in a policy of greater emphasis on the area of Health Promotion. Early diagnosis policies are clearly a part of that, but so are illness, disorder and disability prevention policies. I often think we should rename our Departments of Health as Departments of Illness. They invest very little in policies for good health. Yet investment in the prevention of deafness and research into the removal of causes of deafness must surely be as important as policies for those who are already deaf. Europe is bringing in Health Impact Assessments to apply to all major new policies. It cannot be left to Health departments alone, when it may well be traffic noise, or chemical pollution, or literally the sound of gunfire in the army that bears the responsibility.

And if you are looking for good practice in improving the lives of children with hearing impairment, where better to turn than to the arts. I don't mean just the role model artists I referred to earlier; I mean the opportunity to participate in an art form. Children often express themselves through painting – as art therapists know – and a problem bottled up inside can find expression. They can gain enormous self-confidence and self-respect through performance arts. And many will go on to use the arts, professionally or as amateurs, to contribute to helping other people and to giving pleasure to millions.

Then there are the opportunities that must be enhanced to attend and enjoy art forms, with loop systems, signing performances and so on.

I remember once reading a booklet about a child with a disability attending school. It described the help, support and participation and the real friendships with other children. Everyone worked together, played games together, went on outings together. At the end, it said the school did not yet exist but all the elements were taken from a school somewhere and all the thoughts and feelings the child expressed were those of a real child somewhere. The booklet was called “Nothing Special”.

When it is nothing special to have a disability, because you are accepted as a full member of your community,

- and when we give support in such a way that that book's theme was too much the story of everyday life to be published,
- and when we all realise that the opposite of ability is not disability and that disability has no connection with inability
- then children will be children and not classified and separated. That is my ambition.

It is my ambition because too often in Britain, in Europe and around the world, I have seen children let down by us the people who have it in our power to make a difference for them. And never is that more painful than when it is a child with a disability that he or she could overcome with a little help. Children with hearing impairment are like all children.

Remember those words of Shakespeare's Shylock? His “difference” was not deafness but being Jewish, but the message is the same.

“If you prick us, do we not bleed? If you tickle us, do we not laugh? If you poison us, do we not die? And, if you wrong us, shall we not revenge?”

In the same way, deaf children are children, with all the feelings and emotions of other children. They must not be wronged by us. The opposite of wrong is right. We can right wrongs by giving rights. The rights that we should seek for deaf children are the right to opportunity, to achieve to the limits of ones potential; the right to the technical and human support that enables one to contribute to society; and the right to care and love. Perhaps one cannot demand always to be loved – perhaps one has to earn that. But one earns it by first being understood; so let us have a right to understanding.

If we find understanding, we also defeat discrimination and stigma. And I want to end by focussing on that. Stigma applies to too many types of physical and mental conditions. It is always wrong. It is certainly wrong when it applies to deafness and it is doubly wrong when it applies to deaf children.

Stigma is evident in all our countries and stigma is a human rights abuse

- unintentional, born out of fear and ignorance,
- but just as damaging to a child as any other form of abuse.
- We all contribute to the stigmatisation of children who, if they had a visible physical problem, would receive our sympathy and support.
- Yet with deafness we so often turn away and hope someone else will cope. Living with deafness is tough enough, without having added to the burden of the condition, the pain of discrimination and rejection.
- We must confront stigma for what it is. It is prejudice. Prejudice means literally pre-judging. It neither uses logic nor facts. It is based on ignorance mixed with assumption and emotion.

*To tackle it, we could start by listening to and learning from children themselves and their families. They should be partners in all our service planning and practice.

*We need to change the attitudes and assumptions and categorisations in our political, social and health systems.

*We have charters of rights for patients, tenants, rail users, shoppers; so why not for children with hearing impairment?

*We need to educate and inform so we can break the cycle of prejudice and ignorance that links public, media and policymakers.

To professionals in health, education and social services I would say:

In your hands are the skills of healing and teaching and care but you cannot remove that added burden of stigma on your own.

Carers and advocates can speak up and help to persuade by sharing their experience.

The media can help by spreading truth and destroying myth.

Politicians can listen, learn, understand and then act to provide better services and to help others overcome fear and ignorance and prejudice.

But none of us can do it alone.

Yet together we can overcome.

And we must, because none of us are immune from illnesses and disabilities that carry stigma and nor are our children and grandchildren.

When I speak of stigma, I think of the words of Stefan Heym. I was in East Berlin a few years ago and came across a photograph from November 1989, when he addressed that vast crowd in Alexanderplatz. They had come together to oust a repressive regime.

‘Wir haben in diesen letzten Wochen unsere Sprachlosigkeit ueberwunden und sind jetzt dabei, den aufrechten Gang zu erlernen.’

‘In these last weeks we have found our voice again and have learned once more to walk with our head held high.’

Discrimination is just such a repressive regime. Stigma stills our tongue and makes us hide our head. It destroys our confidence. It spoils our childhood.

Our declaration throughout Europe and our individual commitment, on behalf of Europe’s children, must be that those who are deaf or hearing impaired will, with our help, find their voice, their dignity, their self-respect and walk into a future of hope and achievement with their heads held high.