



BEYOND DISABILITY

The Emotional and Social Development
of Disabled Persons



Health
Education
Bureau

BEYOND DISABILITY



Published by the Health Education Bureau

“Beyond Disability”

The proceedings of a summer school held in St. Patrick's College, Drumcondra, Dublin, July 13th-17th, 1981, on the theme, *The Emotional and Social Development of Disabled Persons*. This course was attended by professionals from the fields of health and education and was organised and sponsored by The Health Education Bureau.



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Introduction

The publishing of the proceedings of this Summer School, "Beyond Disability", concludes successfully the organisational aims of this conference. It is, indeed, a pleasure to have available, in book form, the papers and recommendations arising from the conference to meet the many demands we have received for information. Those attending the conference encouraged the publication of the proceedings since they considered that much of the discussions which ensued from the papers sought to break new ground in furthering the professional training of those who work with disabled persons. The papers, without exception, draw attention to the underlying emotional and social needs of those who live with disabilities. All professionals, including teachers, psychologists, doctors, nurses, social workers, occupational therapists, speech therapists and those working in residential care, will find in these chapters sensitive and informed insights into the personal world of the disabled person. We hope that this contribution to the further development of the professional worker will result, not only in enhancing the quality of services, but, also, removing the now recognised constraints which have hindered, in the past, the full and emotional development of each disabled person.

The Summer School was organised with the full support and co-operation of the Department of Education. The following were of great assistance to the Health Education Bureau in advising us on the content and structure of the conference: Mr. Michael O'Mordha, Department of Education; Dr. Jim Ledwith, Bawnmore Assessment Service; Dr. Roy McConkey, St. Michael's House, Stillorgan; Prof. Desmond Swan, Department of Education, U.C.D.; Mr. Sean Glennane, Department of Education; Anne O'Sullivan, St. Patrick's College; Frances Mannion, Irish Wheelchair Association and Sean Buckley, St. John's Special School, Dublin. In particular, we wish to acknowledge the contribution made by our Chairmen, Group Leaders and Rapporteurs and the help given by Anne O'Sullivan in editing the proceedings.

As course organiser, I wish to acknowledge, also, the co-operation of the other members of the Health Education Bureau team who administered

behind the scenes, namely: Celene Craig, Secretariat; Harriet Duffin, Public Relations Officer; Claire Devlin, Exhibition Organiser; John Heuston, Rapporteur and the many other staff who helped throughout the proceedings.

EUGENE DONOGHUE,
Education and Training Officer,
Health Education Bureau.

Foreword

The role of the Health Education Bureau in realising the objectives for the International Year of Disabled Persons will go far beyond December 1981. The further training and education of professionals who work with disabled persons is an important component of our work. This Summer School, "Beyond Disability", was part of our investment in that process. This publication records for us, and for all those interested, professional insights and recommendations for action, aimed at achieving the long term objectives of this special year. It will serve us, and all those involved with disabled persons, as a basis for planning future action.

DR. H. D. CRAWLEY,
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CHAPTER ONE

Emotional Needs of Disabled People

Keynote Address: Professor Peter Mittler

The title of the Summer School, "Beyond Disability", puts the essence of the problem rather better than the title, of this paper. We are trying to get beyond disability, to see the disabled person as a person first and as disabled second.

As a psychologist and as an educationalist, I am more comfortable talking about educational matters, emphasising what positively can be done to help handicapped and disabled people to learn and to develop their skills and abilities. The better we become at teaching, at helping handicapped people to develop skills and abilities, the more important it is to remember their needs as individuals, their personal needs and their emotional needs.

Our ideas on how services for disabled people should be organised are achieving a greater degree of unity and consensus. There are differences of emphasis but, on the whole, the kind of philosophical assumptions about the direction in which they should be moving are very much more unified than they used to be. In general terms, we seem to be agreed that we need a shift of emphasis from a health model towards an educational, social and developmental model. But the health model is clearly still there and it has a very important contribution to make. We are talking very much more about multi-disciplinary or inter-disciplinary forms of assessment in which people come together from different professions and in which the disabled person, the person with the disability, is himself or herself included as a member of the inter-disciplinary team.

The first question we need to face is clearly, why do we need to talk about the emotional needs of the disabled at all? Are their emotional needs in any way different from those of anyone else? Don't they vary as much as in any group of people? Isn't the very title, "Emotional Needs of Disabled People" a reflection of the very kind of discrimination or segregation that we want to avoid? If their needs are basically the same, we can consider the

kind of obstacles that prevent or distort the emotional development of disabled people. These obstacles exist in the environment, they exist in the disabled persons themselves but more usually they are found in a complex interaction between the disabled person and the environment. The environment clearly includes significant other people — close family, the immediate environment of family and home and neighbourhood and also peers, workmates, casual social encounters etc. You cannot separate the emotional needs of the individual from the needs of significant other people in that person's environment: parents, family, peers, workmates, casual contacts and so on. To work with a disabled person, therefore, is to work intimately with all those with whom he comes into contact.

PARTICIPATION AND EQUALITY?

The theme of the International Year of Disabled Persons is participation and equality. It is worth constantly asking ourselves during this year and future years, to what extent disabled persons with whom we work and for whom we work, enjoy participation and enjoy equality. What are the obstacles to their enjoying a greater degree of participation and equality? In what way can we help, step by step, to remove or sidestep some of these obstacles? The answers can only lie in the work that each and everyone of us does with, and for, disabled people, but I do want to suggest that however good we believe our own service to be, there are very large obstacles to the participation and equality of disabled people and, furthermore, that the removal of these obstacles lies within the grasp of every single one of us. It is no good blaming faceless administrators, the politicians, those who allocate resources. In the end, certain important steps do fall to them. There are small ways in which a great degree of participation and equality can be insured by everybody working in the service, no matter how young, how junior, how inexperienced, how low their position in the hierarchy. It is not always a matter for other people.

Equality

Let's take first equality as citizens, with equal rights to those of anybody else in the community. How many people with disabilities are still living in hospitals? How many still receive inferior education? How many receive little or no education at all? How many are denied access to the ordinary services that the rest of us use? How many are prevented from forming relationships with the opposite sex? How many have no home of their own and no prospect of any home of their own? How many have no job? How many have little or no leisure or recreational skills? How are we helping disabled people to reach these goals? What are we doing in our own service to remove these obstacles?

Participation

How many people with disabilities are actively involved in helping to

plan services at local and national level? How many representatives of disabled people are sitting on the various committees to consider the needs of disabled people and to plan actively for them, both at local and national level?

The second level is the more individual level — the participation of disabled people as equals in plans for their own rehabilitation and their own treatment. One of the worst sins of professionals is that we feel we know it all. We have worked with disabled people for a long time. We claim to have a lot of experience but we don't have the experience of what it is like to be disabled and we are so busy rushing from one person to another than we don't really listen. The participation of disabled people in plans for their own rehabilitation, the need for them to be consulted, the need for them to be able to express an opinion on the quality of the services which are being made available for them, is a very important aim for the next decade and we have hardly started to reach it yet.

What I would like to do now is to tackle the question of emotional development a little bit more chronologically and to begin with very young children and the needs of their families because the emotional development of young children is clearly the root of emotional development in the adult. We always say the first five years are very important and we have to ask ourselves a number of searching questions about the extent to which way we organise our services now meets the emotional needs of handicapped and disabled young children. What kinds of obstacles are put in the way of the emotional development both of the child and of the family? The point I made at the beginning that the needs of the disabled person and those of the people in his immediate environment cannot be separated is, of course nowhere more true than in thinking about very young children. The emotional development of young children is inseparable from the emotional needs of their families.

A list of needs of young children has been put forward by Dr. Mia Kelmer-Pringle. The list is not exclusively concerned with children, it has to do with the needs of all of us.

THE NEEDS OF CHILDREN

- *the need for love and security*
- *the need for new experiences*
- *the need for recognition and achievement*
- *the need for responsibility*

Those who know the story of Christy Brown will recall that Christy was one of twenty-one children and that his parents had taken him from doctor to doctor, had been told that he was an imbecile, that he would never respond to education, that there was nothing there in that very twisted body. This happened in the very early 1930's, but we have to ask ourselves, would such a gross misdiagnosis occur today? What kind of help would

Mrs. Brown be getting in the Dublin of today, in the London and in the Manchester of today, were she there, and were the story to be repeated all over again? Can we be sure that young, severely physically handicapped children are not mistaken for severely mentally handicapped children? Can we be sure that a child who is severely mentally handicapped would be getting the education, the developmental stimulation, the kind of parental support programmes that we now know to be essential?

Love and security

Love and security for a handicapped child must depend on the extent to which parents and the wider family circle can help that child to feel loved and to feel secure. The essence of this now is that we try to take parents into partnership with professionals. The 1970's, in many countries, has been the decade of parents. Parents have come forward, not only demanding better services which on the whole they have been able to secure, but also demanding a share and demanding partnership with professionals in securing means of helping a child to grow and develop.

Christy Brown's mother had no information; in fact, the information she had was grossly inaccurate. There needs to be regular discussion between parents and professionals, and a planned programme of visits to the home so that we don't expect parents to come to specialised centres, however excellent they may be. We must find some means of taking the service to the parent, and to the child, rather than always expecting them to come to us. Above all, the seventies have shown us that parents can use opportunities to share in discussions about goals for the child and actively adopt a teaching role for their child in partnership with professionals. This isn't just parents of children before they go to school, it is also parents of children who are already at school who are developing new forms of partnership with teachers.

From the parents' point of view, the most important need is that they should be valued, that they should be helped to feel a sense of confidence, that they are competent, that they can meet the child's needs. Partnership with professionals should result in families and parents having a sense of their own expertise and worth.

We are tending to put aside now the models and assumptions on which some of us were trained; for example, that parents of handicapped people feel guilty about having produced a handicapped child, that they spend the whole of their lives mourning the normal child that they never had, that they need adjustment, that they need to be taught to accept the child's handicap, and so forth. It is true that some parents experience these emotions and these attitudes, just as any of us would, but this is not the rule. Generalisations about parents' feelings are very dangerous and parents are all too easily labelled. Many parents do feel, however, that experts know best. They trust experts to an amazing extent, considering how unhelpful experts and professionals often are. But if you believe, as a parent, that there are other people who know more about your child's handicap than you do and who have more experience and longer years of training, then of

course you are going to feel doubly disappointed if those professionals don't give, don't communicate, don't share with you.

In terms of the development of services, I have indicated already a major change of emphasis from a model where the parents came to the professionals to one where the professionals are now increasingly visiting families in their own homes. In the field of mental handicap in particular, these developments have been really quite impressive. One programme, which will be known to many of you, the so-called Portage Programme, is essentially a system of parents helping children to achieve weekly goals in their development. These programmes are delivered by professionals who are not high-powered psychologists or doctors, but people with relatively little training who in a matter of five to six days can themselves be trained to use these particular materials to assess, together with the parent, where the child is developmentally and to learn to set goals. All this is done in the child's own home and this is just one example of the change of emphasis of our services towards one that is very much more home-based. There is still a need for specialised services and for centres of excellence and somehow we have to strike a balance between them. We are making our programmes for handicapped young children very much more systematic and, as I had indicated earlier on, the more systematic our programmes become, the more skilled we become in helping children to achieve short-term goals, the more important it is to keep their emotional needs in mind and also those of the parents. Sometimes I feel that we are so busy training parents to be teachers, speech therapists, psychiatrists and physiotherapists, that there isn't much time left for parents to be parents. Psychologists and educationalists are particularly guilty of this. We are so intoxicated with our own success in helping parents to be teachers that the emotional side of their development and of the child's development is often at risk of being neglected. As far as the child is concerned, it is obvious that the child needs to have experiences of success rather than failure hence the behavioural approach which emphasises small goals, small steps and skilled teaching is in fact designed to contribute to the child's feeling of worth.

Need for new Experiences

We have cause for some doubt about whether we are making new experiences available in as rich a way as we might. We all need new experiences to help us to grow and to develop, but to what extent are these experiences made available to children with handicaps and disabilities? What are the obstacles to the provision of new experiences?

Firstly, handicapped children are often sheltered from ordinary everyday experiences; for example, a child who is very severely physically handicapped is often not taken out, usually for very good reasons: we don't have the right means of transport; the children are getting heavier, there are really very difficult physical problems in taking such children out sometimes. But by not taking the child out, that child is missing out on a whole host of very ordinary, everyday social encounters with shopkeepers, with casual social contacts, and so on, which are, for any child, an

indispensable aspect of his learning.

Another obstacle has to do with too much routine: if you are working with a very severely handicapped child, you struggle and struggle to find the best method of doing things, of feeding that child, of positioning him, of trying to get him to communicate, but the danger of routine is that it becomes too much of a ritual and it means that you are in danger of depriving the child of new experiences because you've found a *modus vivendi* of getting something done in a particular way. One has only to go around a hospital for the mentally handicapped, for example, and watch the very small numbers of staff that are available in such hospitals feeding children when it is quite obvious that some of those children at least could be taught to feed themselves, if there were enough staff there with the skills and resources to do it. But because it is quicker to go round with a spoon, feeding one child after another, or to dress the child, or undress the child, or bath the child, when in fact he has the ability to do these things for himself, we necessarily deprive the child of new experiences that are essential for the growth of anyone of us.

Related to this is a third obstacle and this is the one relating to lack of demand. In the education of very severely handicapped children, we tend to follow the slogan, and it is only a slogan, that you get out what you put in — everything that you want a mentally handicapped child to learn, you will have to teach him, because very little learning goes on except through skilled and systematic teaching. If we don't make demands, we don't get a great deal back.

In particular, a lack of language demand is a very serious obstacle to growth and development. How often, when we are trying to get a child to communicate, do we engage in the "what's that?" kind of dialogue? We hold up an object and we say, "What's that?" and the child says, "Watch"; we say, "Good boy!" and reward him, when we could be stretching his language by asking questions in such a way that he's producing, say, a two-word utterance, or a verb rather than a noun when in fact he has the ability to do that. So, these aren't special teaching sessions, these are the ordinary everyday social encounters that adults, not just teachers, have with handicapped children.

We can all of us, I believe, think usefully about the kind of demand that we make of a handicapped child to produce skills or to interact with us in any way at all. So we have to ask ourselves constantly, how far can we provide new experiences for this individual, even individuals who are very severely handicapped indeed? The skill of the educationalist — and we are all educationalists in the sense that we are all concerned with growth and development — lies in knowing when the time has come to move on developmentally, when the time has come to make new demands. The more severely handicapped the child, the more we tend to settle for one particular level of development. If a child produces a single word response when we ask him to do things, we tend to ask him to say the same thing over and over again and we tend to forget that we have been doing this now for a year or more and that it is time to think of the next stage of development and how we can help the child to reach that.

All these questions are really very ordinary. They are not questions for specialists with extra training in special education, they are questions for all of us, whether we are selling newspapers in a shop and a handicapped child comes in, whether we are parents, whether we are teachers, doctors encountering a child for ten minutes.

Let's consider the physically handicapped child with, shall we say, cerebral palsy who can't open his hands because of the spasticity of the muscles in his hands. Think of the new experiences that are closed to that child when he can't feel shape or texture, the whole world of sensory development through touch is closed to him.

We know from research what we perhaps didn't know so clearly from experience, that even very young babies are able to exercise choice, are able to discriminate sensory input to a far higher level than we previously suspected. I'll just mention one piece of research in which we are involved in Manchester, which is being carried out by my colleague, Dr. Sheila Glenn. She has rigged up a very simple device which consists of two loudspeakers, each with a large yellow knob protruding from it. If the child just touches one knob, he gets one kind of tape recorder switched on; if he touches another one, he gets a different one. So you can choose between whether you hear your mother's voice or another woman's voice, you can choose whether you hear your mother's voice speaking, singing a nursery rhyme, or speaking in a very flat, unintonated way. So, by a piece of not very complicated technology, which could be rigged up with relatively little expense, you can work with normal children as young as six months and mentally handicapped children who are only at a six-month level of development, and demonstrate quite simply that they are able to choose, to discriminate, to express an opinion, if you can call it an opinion.

Now this relates to the question of participation and giving an opinion about the environment in which you are functioning at any one time. There are other examples of people with severe impairments in their ability to communicate showing through the use of a simple piece of technology that they have ideas of their own, that they can make perceptual discriminations of which we did not think them capable.

Need for recognition

Recognition and achievement can be given for every small step that is taken in a child's development. We know now, that no matter how profoundly handicapped a child may be, no matter how limited or how helpless he may seem to be, he is capable of taking a small step forward in his development, provided we study that child's development and provided we work out goals and steps that are very small and that are related to the unique individual needs of that child.

In using these methods, we tend to use principles and practices of reward training. We may begin with rewards that are extrinsic — whether it's music or a food reward — but we try to work increasingly towards rewards that are intrinsic, where the reward lies in the completion of the task rather than in some external reward system. Systematic teaching along

behavioural lines can help the child to take the initiative in his own learning and help to motivate the child to seek out new experiences which other people may not be bringing to him.

Clearly, parents are going to need a great deal of help in bringing that kind of stimulation, that kind of demand, to a child who can't easily seek them out for himself, and here again, a number of technological or semi-technological breakthroughs have taken place in the very recent past. In particular, there has been a real breakthrough in the field of sign languages for the mentally handicapped and for other children and adults who, for whatever reason, are unable to communicate themselves. Various adaptations have been made from sign languages for the deaf to make them suitable for people who are not speaking, both children and adults, and in the last three or four years, something like 75% of schools for mentally handicapped children in England and Wales are now using some formal system of non-verbal communication. This isn't just a piece of technology. You can see that by giving a child a bridge between himself and the outside world, just like the piece of chalk in Christy Brown's toe, you're building a bridge that helps the child to see that something that he does, brings him rewards and satisfactions and also satisfactions from the people who care for him and who love him. So, the revolution in the development of formal systems of non-verbal communication for non-speaking individuals, is of fundamental importance, not only in teaching them to communicate but also for their emotional development.

The need for recognition and achievement can also be looked at in relation to the key-concept of choice. Let's ask ourselves how often, when working with handicapped children, whether they're in schools or in residential care, or in our own homes, do we give them a choice in terms of what they eat, or the clothes they're going to wear? If a child has a severe difficulty in dressing himself, we tend to lay the clothes out for the child and we just decide what it is he should wear or that it is time to change his clothes. How often do we present him with a choice? Even if that child can't talk, we can at least put one in one hand and one in the other and try to indicate to him that the onus is on him to choose whether he has this one or that one. Just as a very small baby can make a choice between listening to Bach or listening to the Beatles, so a much older child has no difficulty making a choice in whether he's going to wear a yellow sweater or a brown sweater. Similarly, we tend to put food down in front of children because it's more convenient to do it that way, but there are many simple situations such as the choice between tea and coffee, where it is possible for us to offer choice. Much later when we are talking about vocational training, it is possible to have a dialogue with someone who cannot speak in order to try to explore what that person's preferences are for the kind of things that interest him. Similarly, in the field of leisure and recreation. By doing this, you are recognising the worth of the individual in front of you, treating not the disability but trying to get behind the disability, to looking at the person because even very severely handicapped people are able to express choice and have, as we say, a mind of their own. Very often, in the day to day way that we work with them and treat them, we tend to deny that individuality,

not because we don't care about their emotional needs, but because we are very busy, there aren't enough of us and it's quicker and easier to get into a certain kind of routine.

Need for responsibility

Responsibility for one's own actions is again a matter of choice gradually taking responsibility for doing more and more for oneself and becoming less dependent on other people. This can be done with people of all ages, starting with really quite young children and also still working with adults. There are innumerable examples of people with disabilities who, for example, are not using public transport when in fact they have the ability to do so. It needs time and patience and staff resources which are often not available to teach, for example, a mentally handicapped adult to use a public transport system but it's easier to have him collected in a minibus or in a coach. But in fact it respects the worthwhileness of the individual much more to teach him to use the public transport himself. The technology of teaching someone to learn to use a public bus is now pretty well known. There are books and manuals and lots of case histories on how to do it. The methods are not complicated, they don't require a Ph.D. in rehabilitation technology. They can be done by a volunteer, and by a parent, and yet somehow, there are in every community, hundreds of people who are not using these skills when they could be trained to use them. The example of public transport is merely one of many that can be given.

Common Needs

Having looked at these four needs, let's just very briefly look at what they have in common.

First of all, the recognition that we're dealing with a child or an adult first and handicapped or disabled person second.

Secondly, the question of balancing ordinary needs of that individual with special needs that arise from the handicap. This is a very difficult balance to strike because we cannot deny the handicap and pretend it doesn't exist under the banner of normalisation. We have to balance ordinary needs with special needs because handicapped people do have special needs that other people don't have. What we mustn't do is to neglect the ordinary needs which all of us have.

I've also stressed the constant awareness of the need for growth, and the danger of underestimating abilities.

I haven't stressed the myth that because an individual is limited in one area, he's necessarily limited in all. Somebody can be mentally handicapped but that doesn't mean to say that he is mentally handicapped in all areas of his development. We all of us have special skills and abilities; in the same way, mentally handicapped people, although affected fundamentally, very often show particular strengths in one area of their development. Somehow we have to find out what those strengths are and to work on them rather than constantly attacking weaknesses. In particular, in the field of language, it's very often assumed that because somebody is mentally

handicapped, very little language development can be expected but we know from work in mental handicap that language development tends to get out of step with the rest of development and there are people who are functioning at a far lower level of language development than you would expect, given their level of skill and competence in other areas.

INTEGRATION

The central question of emotional development is closely related to the extent to which a handicapped child is in contact with other children and with ordinary, everyday experiences. The big question in special education is how to make ordinary education special and how to make special education ordinary — another of those balances that we try to strike. Nobody questions that integration of handicapped children is anything other than a desirable goal. Nobody questions that integration of handicapped children is likely to produce enormous social benefits for the handicapped child and for the ordinary children with whom he or she comes into contact. What is in dispute among people working in this field, is how far a child with severe handicaps is going to benefit *educationally* and here is our other balance — the balance between the educational needs of the child and his social needs: this balance is going to be different from one child to another. Social development and emotional development are obviously beset with obstacles if children's experiences and contact with normal children are going to be unnecessarily restricted: but what is unnecessarily? How do you define it? Do you do it as a matter of dogma and say, all children should be educated in normal schools or do you try to meet the needs of the individual by carrying out a detailed assessment of the needs of that particular child?

Integration is neither easy nor cheap. It is very hard work to make integration work. Christy Brown spoke of a glass wall. Another educational researcher working with the deaf also spoke of a glass wall that existed in London schools between a unit for children with hearing impairments and other children in the rest of the school. It's not difficult to have a class of handicapped children in a normal school if you can overcome questions of resources, attitudes and so forth. What is difficult is making integration work so that there is real social, educational and emotional contact between children with special needs and children in the rest of the school. It is not enough simply to place handicapped children in the normal school and feel that you've done your best in the name of integration. That is only the very first step.

So, even at the level of social integration there has to be a great deal of planning and a great deal of thought. The paradox here is that the harder you work at ensuring integration of handicapped children, the greater is the risk of singling out the handicapped child from his normal peers. I can well recall going into one primary school where there was one of the earliest attempts at integration of severely mentally handicapped children. As part of this programme, two children from the class for the severely

handicapped were put into a normal infant reception class who were being told a story. The teacher had all the children sitting round her and said, "Now I'm going to ask you all a question but I want none of you to answer except Johnny and Stephen because, you see, they don't know the answer and I want you all to keep quiet while they give the answer". She wanted to give those children something to achieve but in doing so, she singled them out as totally different from the other children. Were they integrated or not integrated?

ADOLESCENTS AND ADULTS

However sound the foundations of emotional development and however good the services that are being developed during childhood, adolescence usually brings special stresses and strains. We don't have to assume that these stresses and strains are inevitable but neither can we assume that the absence of the obvious signs of strains and stresses means that they aren't there and that we've been spared them.

In most developed societies, the problems of adolescence are compounded by a sudden and often dramatic deterioration in the quality and the quantity of services that are provided for school-leavers. In fact, there's a glaring, obscene contrast between the quality of what we do for children and the absence of adequate services for meeting the need of adolescents and young adults. The extent to which this happens varies in different societies but in most European countries and in North America, several things happen at the time of school leaving.

First, there is a loss of established routine. There is a danger of a loss of status and a sense of place in society even if that place has been sheltered. There is a loss of friends and social relationships. There is a lack of leisure outlets and there is isolation of the young person from his contemporaries and from his peers.

A survey which we have done in the Greater Manchester area of 214 handicapped school-leavers, pinpoints yet again their isolation from their friends, their lack of leisure interests and opportunities and the lack of services for this population. Thousands of handicapped adolescents are leading very bleak and empty lives to-day and as the recession bites deeper, the situation will undoubtedly get worse.

So let us look briefly at needs and the kind of services which could be provided to meet particularly the emotional and social needs of adolescents.

First of all, a need for *continuing and continued education*. The youngsters can either stay at school or go to further education colleges but this calls for a great deal of thought about the kind of education that should be provided, either in schools or further education colleges. In the last few years in England, further education colleges have opened their doors to handicapped students but very much with the physically handicapped student in mind. This is of course an excellent development but they have been preoccupied with ramps and special facilities in toilets for the wheelchair students; they've not thought sufficiently about the learning

difficulties of the wheelchair student when he or she gets into the college. Someone with cerebral palsy might not be able to write sufficiently quickly and to take notes, might not be able to read a board or be able to cope with the speed and style of presentation of the kind of teaching that goes on in a Further Education college.

So, it's not a question of physical access, it is also a matter of educational access.

We need in all countries, a programme of staff preparation for meeting the needs of handicapped and disabled students. Integration can be mindless and thoughtless in the F.E. college as much as anywhere else but I feel very optimistic about political developments in the field of further education, except that the recession in my country is now so severe that there is every sign that handicapped young people are being forced to leave school at 16 rather than remaining at school until 19 which it is their legal right to do; this is an example of discrimination which we all want to avoid.

Secondly, *vocational training*. This is a difficult subject to talk about at the moment when we are facing massive unemployment on a scale that we've not known since the 1930's. What do we feel about the common assumption that's made that disabled people should have lower priority in the job market? What do we feel about the statement made by a minister from my country which said, "it is insulting to the disabled to assume that they should take anything less than their fair and equal share of the country's economic difficulties and therefore, that it is inappropriate to seek a vocational training and job opportunities for disabled people at a time when so many non-disabled people are unemployed". These are moral and ethical choices that face us but if we want to look for factual evidence, we have some factual evidence that even very severely handicapped people are capable of responding to vocational training and are able to enter work. I mention just one example from Britain of the Pathway Scheme which has shown that it is possible to find work for mentally handicapped young adults, if a particular placement officer is employed for the purpose, whose job it is to match the job to the person. We have to argue, I believe, for some degree of positive discrimination because special needs demand special measures. Why should disabled people have less right to work than anyone else? We know from such evidence as we have that some mentally handicapped people are able to work well and that they are particularly highly motivated to do so. If our theme has to do with emotional and social development, it's pretty obvious that work is essential for social integration and for emotional development.

Housing has been the biggest and most exciting single development in the field of changing attitudes of people who provide services. The clear need for a home of your own is now undeniable and much less contested than it used to be. So where do we stand in relation to the large numbers of our people who are in hospital, who are in large communities and who are suffering from some degree of emotional starvation! Most of us do not live in large hospitals. Very few of us, if we became mentally handicapped as a result of a severe head injury on leaving this hall this afternoon, would wish to live in the mental handicap hospitals and in the large institutions which

are found in every western society. We accept, philosophically, the need for independent living, for everybody, including the mentally handicapped and now we're beginning to see that this is possible.

The use of ordinary housing has been something of a breakthrough in attitudes because it's increasingly accepted that it is possible for mentally handicapped people to do this, provided that they are helped systematically and carefully to be prepared for more independent living. So in schools and in adult centres, they are being trained in cooking, in budgeting, in social skills and in coping with a wide range of situations which they are going to meet if they are going to be able to live independently. We are faced with something that people call the residential assumption. The residential assumption is the assumption that because you're severely handicapped, you're necessarily going to need residential care. That assumption is now beginning to be stood on its head and we're asking what kind of services does this family need or does this individual person need, so that he or she can continue to live in an ordinary house, not necessarily with their parents but with others, with similar needs?

We assume as a society that parents are going to look after their handicapped son or daughter until they become physically incapable of doing so by reason of old age or death. But why make that assumption? Most of us left our own parents' homes when we were in our late teens or early twenties and yet our services are based on the assumption that handicapped people will continue to live with their families. Why isn't it possible to plan alternative residential accommodation which is homely and domestic and involves the use of ordinary housing and the freedom of choice that an ordinary house gives you long before there is a crisis? Parents obviously need help at this stage to let go and to gradually work towards a greater degree of independence.

Central to the use of ordinary housing is the ability and freedom to have *personal relationships including sexual relationships* in the same way as all other members of society and for two people who are handicapped, to live together and to marry, and for disabled and non-disabled people to live together and to marry. Fortunately, the sexuality of handicapped people is now being discussed in a much more free and open way than was the case even five years ago, but I have to ask you this: Whose problem is this? Who knows best? Who decides what? The sexuality of people with disabilities has to be recognised as something that is there and will not go away if we don't talk about it. They have the same needs for the development of lasting personal relationships as any other person does. The problems lie, equally distributed, among the disabled, among the staff and among families. We all of us need to discuss these issues openly. Staff who work with disabled people need opportunities for discussion, not just occasionally but regularly, programmes of discussion on education for personal relationships, not merely the sexual aspects of these relationships. Secondly, we need not just liberal platitudes but discussion of the physical aspects of sexuality as well and more and more organisations are offering this kind of help — the Family Planning Association, the SPOD organisation (Sexual Problems of Disabled People) are actively considering the needs of disabled

people. Similarly, parents are going to need help in understanding the sexual development of adolescents and young adults, and skilled and sensitive counselling is going to be needed for people with disabilities themselves to be able to discuss these things with those who are involved with them, either as partners, parents or professionals.

PARTICIPATION

I want to return to the theme of participation, because I think it is perhaps the single most important task for us to try to grapple with in the next decade. We need, I believe, to ensure a much greater degree of participation of disabled people in making decisions about their own lives. It is beginning to happen. In America, the movement is known as consumerism and it takes a pretty radical and sometimes almost violent form. I attended last year, an international conference of Rehabilitation International and there, people in wheelchairs were making demonstrations which were primarily anti-professional. They felt that they had had enough of being treated as second class citizens, of not being involved in decisions about their own lives and their own programmes of rehabilitation.

Even in the field of mental handicap, mentally handicapped people are beginning to speak and to demand that they be listened to. In the United States, there's a movement called People First who regularly hold conferences, who regularly have speakers about the quality of the environment that's being offered to them, about the kind of life that they're leading. In England, we've had conferences organised for mentally handicapped people by Campaign For the Mentally Handicapped and these have resulted in publications such as *Listen*. In a number of adult training centres, you find student committees, in hospitals and in hostels, you find committees of mentally handicapped people and, believe me, they are not just the most articulate ones. Sometimes, people with severe speech disorders, people with relatively limited powers of communication, are able to express an opinion about their environment and about what is being done for them. Clearly, there are many obstacles to this. The parallel has been drawn by some writers in terms of the civil rights movement in the United States. Parallels have been drawn between the disabled and other oppressed minorities. There are parallels in these movements where a group of the population have felt that they are being discriminated against and gone to legislation so that it became illegal to discriminate on grounds of race, illegal to discriminate on grounds of sex, equally, it could be argued it should be illegal to discriminate on grounds that an individual is disabled.

The consumerism movement is closely related to another movement which the professionals have in fact insisted on, and that is the movement of accountability. Increasingly, in our services, we are seeing a demand coming from staff themselves for a greater degree of accountability in what they do. If someone is being admitted to a hostel or to a sheltered workshop, what are you trying to do for that person? The suggestion has been made that anyone being admitted to a facility for disabled people should have, as a

right, a written statement of the goals of that service for the particular person. Similarly, accountability, in terms of a programme, can be expressed along more professional lines as well.

Does one really have to make a case for the participation of disabled persons themselves? How many of us still feel that we, with all our years of experience, know best? How many of us professionals feel that disabled people tend to be unrealistic — that we shouldn't raise their expectations too high, that they'll only be disappointed at the end of the day if their plans don't materialise?

This right of disabled people themselves to participate in decisions about their lives, and about their futures, is all the more important now that professionals are becoming so much more skilled at methods of teaching and methods of rehabilitation are very much more effective than they used to be. These methods are prescriptive in so far as they involve step by step progress towards particular goals.

But, who is to say what is an appropriate goal? Do all disabled people want to be integrated into the mainstream of society? Do all disabled people now living in our hospitals for handicapped people want to be rehabilitated into the community? I don't know the answer to these questions, but I think we can at least begin to ask. The essence of the participation approach on the part of professionals is very much rooted in this word "choice". I believe that we can teach children from a very early age to express choice in very simple matters, like choosing what to wear, choosing what to eat, and we should always be very wary of imposing choice from above.

We need to remember that disabled people are individuals with needs and personalities that vary as much as they do among any other group of people. When we begin to recognise the individuality of each person with a disability, when we finally stop prescribing for their needs as if we know best and when we finally involve them in the process of integration and participation, then I believe, we shall have begun to meet their emotional needs.

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CHAPTER TWO

The Early Years: Family and Community

1

Dr. Anne T. McKenna

Policy making for the care and welfare of infants and young children takes as its first principle the growth and maintenance of attachment between infant and mother. Most professionals concerned with working with young children regard their role as one of ensuring that wherever the infant may be, he or she experience a continuous relationship with a mother or adult figure, believing that if this emotional attachment is not experienced, the child's ability to feel any emotion is impaired. Indirect support for the mother, when and where she needs it, is the best help towards letting her get on with the job which she and she alone does best. The goals of helping agencies are in the main the reduction of anxiety, the removal of harassment, and where possible alleviation of any other obstacles which hinder the mother in this task. This first relationship has an important effect on all future relationships, and its quality is decisive in determining the warmth and genuineness or otherwise of later friendships and loves.

Maternal instinct and the disabled child

The attachment of mother and infant which is seen as so important for later development occurs naturally and inevitably under a wide range of environmental conditions, the mother taking to the infant as instinctively as the infant takes to the mother. Perhaps we might say that the mother takes to the infant because the infant takes to the mother. The infant emits a large range of behaviours such as eye-to-eye contact, rooting, smiling, motor excitement on hearing the human voice or seeing a face, all of which go to "hook" the mother to the infant and keep the flow of reciprocal behaviour coming from the mother, gazing back at the infant, orienting of mother's

body to the infant's, smiling and talking. But although these bondings occur under a very wide range of conditions, this range is nevertheless limited and circumstances can arise which can serve to make the process difficult and improbable. The blind infant who cannot scan the mother's face, the deaf infant who cannot respond to her voice by quieting or becoming still, the paraplegic infant who cannot root or cuddle the mother, these infants are failing to give out signals, signals which normally increase a mother's instinctive orienting to her infant, which keep the smiling, talking and stroking coming from the mother, and in turn elicit more attention from the infant. The mother in such situations requires the help of what might be called "remedial parenting", analogous to "remedial education" where the mother is taught a number of strategies to ensure a close attachment in the first months of life. What was instinctive in the mother-child relationship becomes raised to the level of conscious awareness, so that the mother may take upon herself to provide planfully what she might give to another child unthinkingly.

There is a school of thought which considers that one should not educate parents on how to bring up their children, as this is taken to affect their natural confidence and assurance and so diminish their sure-footed effectiveness in handling problems as they arise. And it is true that most parents have a relatively accurate understanding of the norms of child development without ever having received any formal instruction in the discipline of Child Development. As an example of this I might cite a recent study in the Department of Psychology, in University College Dublin, where parents of three and four year old children were asked how any child of this age might perform on a number of linguistic developmental tasks, including vocabulary, syntax and imitation of adults. Whereas they could predict some items better than others, overall they had a high level of accuracy when estimating the level of development, more accurate in fact than that of final year students in a Teachers' College, who had been studying Child Psychology for a number of years. This accurate model of the parents had presumably been built up from experience rather than tuition, experience with this child and others of their children developing at a normal pace.

The question we must ask however is whether parents of disabled children can gauge the responses of their child in the same way, predicting with the same accuracy how they might perform on a variety of tasks which they had not previously encountered. Experience and common sense indicate that this is most unlikely. What I am suggesting is that they do have a need for a system of specialised parent education to make up for their own inevitable lack of experience in dealing with this handicapping condition.

Video and other types of recorded observations between a mother and her disabled child have shown us the form such parent education might take, and enabled training programmes for parents to be assembled. For some time now, parents of deaf children have been taught to bring objects up to their face whilst mouthing the name of the object, in order to encourage lip reading skills. Recent discoveries stressing the importance of facial gestures in communication have further resulted in a training

program for both parents and teachers of the deaf. The deaf child is trained to follow the adult's line of vision before any word is uttered, thus ensuring that the child and the adult are concentrating on the same topic, or that what has been called "inter subjectivity" has been established. Without ensuring a common topic for both, comment is superfluous and no communication is possible.

So, too, the instinctive behaviour of eye-to-eye contact between the mother and the young child may be disrupted, when the mother's intuitive responses have as it were dried up, as sometimes happens with the parents of mentally handicapped children. Under these circumstances, a mother may be made aware of the need for and the importance of her maintaining such contact by seeing a video tape of herself and her child, or another mother and child pair. Thus the mother may observe that non-verbal children may use such eye-to-eye contact when they have finished a task in order to look for the approval in the parents' eyes; or the child might be taught to use such contact as a monitoring device in order to read from the mother's face whether what he has just done is correct, and thus how to proceed — but only if the mother trains herself to be already looking at the child in readiness. Observing this occurring on video tape gives a mother a keen appreciation of her role in the child's learning process, as well as a set of prescribed behaviours which she can be assured are effective in the child's development. Such parental training programmes can also help the parent to focus on more constructive and forward looking behaviour of the child. Where the need for protection is strong and highly visible, as in many a disabled child, this can totally take over the parents' repertoire of activities towards the child; the impairment can define the child's personality for the parent and thus become even more disabling.

Need for mastery

It is indeed a characteristic of parents and teachers of disabled children to protect them from failure of any kind, which often leads to a tendency to control the child and to over-direct their behaviour. When observed interacting with such children, they tend to intrude into the child's activities, often manipulating for him the material he is working on. In their desire for the child to succeed, they often try to solve the problem for the child themselves, seeing the correct solution as more important than the child's own efforts in reaching towards that solution. The same tendency has been observed in young student teachers or allied professional staff in in-service teaching, and it probably arises from an anxiety about what other people think, plus a lack of appreciation of the child's need to experience a sense of his own mastery over his abilities and disabilities. No matter how small or imperfect the result may be in absolute terms, the child must not be deprived of the right to give of his own abilities rather than be controlled by another, no matter how loving. The attitude sought should be one of detached support, and it is known that parents who support rather than intrude into their child's behaviour, induce in the child a sense of being in control of themselves as well as an increased ability to persist in any given

task — qualities we are anxious to engender in our disabled children.

Another error often made by parents and teachers in training is to pass on to a new task as soon as the child has succeeded in the old one. Instead of allowing the child to repeat the task successfully over and over again, and to experience success and mastery, they present him with the next problem in which failure is assured, at least in the first instance. If we as adults would just dwell for a moment on our own pleasure in doing things we are good at, we would be more aware of the child's joy in his own mastery of a task.

Need for company of other children

Appreciation of what goes on between a mother and child, or an adult and child, should not blind us to the fact that children need and respond in a special way to other children. It is now recognised that children from as early as six months of age find another child, near in age, a most compelling stimulus and one which can induce rapt attention, wonder and hearty laughter. We used to consider that children did not need the company of their peers until four or five years of age, but a number of considerations have altered our perceptions. First of all, when families were larger with two or three children under school age, children *did* have company of other little ones, and interactions took place which were unobserved and almost certainly life-enhancing for the child. In the second place the social competence of young children went unnoticed in the privacy of their own home, and it was not until such times as there were sufficient numbers of young children in groups—outside their homes and under the care of a professional that such behaviour was actually chronicled. From close observation of groups of young children and of their verbal and social interactions, it is clear that their group play is governed by rules, some of them quite intricate, which the children carefully observe. The apparent casualness and almost aimlessness of a group of toddlers will reveal, for example, rules of language for exiting and re-entering group play. It will also show that the child makes a clear distinction about temporary and permanent ownership, between her coat and lunch box for example which are always hers, and a chair in the classroom which is hers for the duration of a story or singing time, but which reverts as it were to public ownership at the end of a specific activity.

Whilst some might regard a group of 20 two or three year olds as being in some way unnatural or even wrong, seeing toddlers ideally as a unit in a family, nevertheless children at this tender age can, as we have seen, produce friendly and cooperative behaviour, which would be unlikely to be elicited otherwise. The fact that disabled children are dependent or partially dependant on adults for a longer time can minimise their chances of mixing with other children, able or disabled. Training for social competence can begin at almost any age, and for the disabled, the earlier the better. This is all the more so since we know that achieving things for yourself, the mastery that we talked of above, follows on the heels of social competence; children who can manage their own age group happily and competently tend to be better at gaining control of their own physical and intellectual development

than children who are withdrawn and cannot play with their peers.

Need for early intervention

In what has been said concerning the emotional development of the young disabled child, it is clear that the child and the parents need the support of the community in the form of parental education and early educational intervention. The parents, in the first years of life need professional help in understanding the child's unique developmental problems, in classifying and naming the areas of child behaviour, in recognising what behaviour to reinforce by approval and encouragement, what to discourage and what to ignore. The normal family home is a place of strong emotions, both positive and negative, and these are often exaggerated when there is a disabled child in the home. A detached but interested nurse or social worker can help to cool a hothouse emotional atmosphere, and bring anxiety levels down to manageable proportions and hopes for the future back to realistic levels. And this affects the child's eventual intellectual competence as well as his emotional stability. No psychologist today would predict the future level of cognitive functioning without taking into account the environmental influences at work on the child; child rearing practices affect the acquisition of specific developmental skills, in ways that we can now spell out. I have attempted to show how this works in the area of the child's feeling of being in control of himself, and how over-manipulation of the child can deprive him of this constructive experience.

It is also essential that the disabled child be afforded an opportunity to enjoy the company of other children, to develop competence in getting along with them and becoming more competent in getting on with his own life. For this reason, and for many other good reasons (which we have not discussed here today), pre-school facilities are essential for our disabled children in the eighties, and these facilities should be integrated into day nurseries and nursery schools and play groups wherever possible. As you know, it is now a matter of legal necessity in U.S.A. to provide integrated pre-school services for the handicapped — to the level of those existing for other children. And there lies the rub. The network of nurseries and kindergartens in any country tends to be dependent on the number of married women with young children who are out at work. Ireland happens to be at the bottom of this particular international league table for many reasons, with the result that there is a relatively underdeveloped pre-school network and consequently reduced opportunity for integration of the handicapped pre-schooler. As a psychologist in early child development with a strong belief in the efficacy of early intervention, I would encourage professionals in this field to make the provision of early integrated education programs one of their priorities in their work for the disabled. We might also recall in this context that whereas we in Ireland may seem to be short of community facilities for the education of our pre-schoolers, nevertheless our state schools do accept children two years before the statutory age, and that this facility is very widely availed of by the

community at large. If we add to this the fact that the Irish National Teachers' Organisation, representing the bulk of the primary teachers in Ireland, proclaimed in their annual congress in Galway in April of this year a steadfast commitment for the integration of the handicapped into the primary school system, it would appear that the teaching profession are on the side of the disabled, and of their integration into the community of school. And there is little doubt that this is the road forward for acceptance of the disabled as persons into the community, rather than as members of a category of paraplegics, blind or deaf, where the impairment describes — and circumscribes — the personality. As long as the segregation of the disabled child has the effect of making the handicapped child a rare and strange sight, reacted to with embarrassment by members of the community, the more will the parent compensate by making them more dependent and therefore less competent, and the vicious circle will continue. Changes on the part of the able-bodied, changes which can best begin at the pre-school level, will bring about changes in parents' attitudes to their children, beside which all the benefits of technological innovation will pale into insignificance.

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2

Criona Garvey

"No man is an island, entire of itself . . . any man's death diminishes me because I am involved in mankind."

(J. Donne 1623: Devotions XVII)

The above statement is as true today as it was in the 17th century. Our attitude to handicap derives from our philosophy of life, and a caring society can no more discriminate against the handicapped than it can against those who differ in race, religion, colour or sex. Who are the handicapped or the disabled? (One of my friends talks about the *hardly able* and the *just about able!*). Not only does any man's death diminish the community but any man's handicap diminishes it also, *because we are all involved in mankind and therefore we must care.*

Ar scath a cheile a mhaireann na daoine.

My interest is mainly in the pragmatics of handicap. Because of many years of practical day-to-day work with many types of handicap, the emphasis for me has been on trying to lessen the burden of handicap and to integrate the child into his own family, that is, into the first community he experiences, in preparation for integration into the ordinary community. However, if handicap could be prevented, or lessened, it would be even more valuable than trying to lessen the results of handicap.

1. The Prevention of Handicap

There have been a number of developments in the prevention of handicap e.g. PKU, Rubella vaccination, genetic counselling to mention but a few. The figure, generally accepted, i.e. that 65% of handicap is environmental and therefore preventable, in theory at least, and 35% genetic should stimulate research and education in every concerned community and country.^{1, 2}

2. Telling the bad news

There is a large volume of evidence to show that there is a sad lack of psychological skills in giving the news about handicap.³ One mother I know was told bluntly — "Mrs. — your child is severely mentally and physically handicapped." Mrs. Maher said "I felt like putting myself and my handicapped son under the nearest bus." It was not the best time to tell the

mother, just three weeks over a pregnancy and without the father being present. A counsellor should be available for the family *immediately*, in maternity hospitals, in the community care offices, in children's hospitals etc., when the bad news is given.

3. Stress

There is considerable evidence of stress in the families of handicapped children.⁴ It has been suggested that the trauma related to being told the bad news about a handicap is like being told that one has a terminal disease. There are several stages in this trauma. After the initial shock and numbness wears off, the first stage *Denial* begins, "No, it isn't true — not my child."

The parents may go around seeking reassurance from friends or other professionals that the bad news is not true. The second stage is *Anger* — *Why me?* God, the in-laws, husband, wife, everybody and everything, in or out of sight, is blamed. The third stage — *Bargaining* involves trying to do a deal with God, "I'll give up smoking, drinking. I'll be a better Catholic/Protestant/Christian Jew, husband, wife, mother, father — if my child can be all right."

The fourth stage *Depression* develops when the person is beginning to see that the facts are true — the child is handicapped and is not going to be cured. The fifth stage, *Acceptance*, is where the parents have to some extent come to terms with the facts and begin to do something about the situation. There is always hope, fortunately, and taking action is a positive step for parents — they want to do something practical to help the child. Not all parents go through all of the above stages, but it is necessary to emphasise that it is normal, not pathological, for parents to deny, shop around, be angry, depressed. People dealing with parents, during these stages, should not get angry themselves and write off the parents as difficult, disturbed, or won't accept the diagnosis. Professionals must be trained to accept the anger and hurt of parents, not add to it by their own insecurities. Later on, if parents, especially mothers, say that they wish the child had died, or they felt like killing the child, getting moralistic and angry at the parents does not help. Parents of handicapped children are always vulnerable and need reassurance, not rebuke.

4. The special status and the self concept of the handicapped child as being different or other

There is no doubt that the child's concept of self will depend largely on the attitudes of parents and others.⁵ If the parents feel that because the child is handicapped, he must be loved more than the other children, given special treats etc., the seeds are sown for difficulties in upbringing. There is evidence that ordinary infants of 10 days old "know" how long to cry to get the attention of mothers. Add to that the mother's anxiety about a handicapped child and very soon there can be situations where the entire family revolves around one small child and is controlled by infantile demands. One example of this is where a 3 year old boy with mild cerebral palsy and severe/profound deafness had established firm control over a

family of five others — father, mother and three sisters. If John did not like what was on the table for Sunday lunch he pulled the tablecloth and everything on it to the floor. When his sisters did their homework, he tore up their copies. If one of them sat on a chair that he suddenly took a liking to, he screamed or kicked or hair-pulled until the girl left the chair. If he woke up at 3 o'clock every morning as he did and if Mammy and Daddy did not instantly have fun and games with him, he screamed the night away. The rest of his repertoire included spitting, biting, pinching and throwing things. In the case of other children additional techniques were eye-rolling, blue fits, asthmatic and pseudo-epileptic attacks and the "*Daddy — Mammy hit me*" trick.

If the child discovers that screaming works, then he has a very useful method of controlling his world. Logically then, if he is expected to do exercises for a therapist he screams if they seem a bit hard or hurting, or if he does not like the exercises, or the therapist. In his lifestyle, anything not liked or difficult is not done, so he goes through home, school, work and life with the firmly established idea that "other" people do anything difficult or not liked by him. There are other masters as well as political ones! One child like this in a family can cause serious problems. There is an added stress in the family, the father and mother may become stressed because of continued lack of sleep, the other children resentful and irritable, everybody at loggerheads with one another. As well as the stress of the original handicap, there is now an additional stress associated with fatigue, a sense of incompetence, perhaps hopelessness. The handicapped child, meanwhile, has firmly established that he is special, that the rules for other members of the family do not apply to him, because he is different.

5. Behaviour Modification

Behaviour modification simply means changing behaviour. The idea is not new but some of the methods are. People and governments have used various methods to change or to control the behaviour of human beings for many centuries. Animals and reptiles also change the behaviour of their own species and of man e.g. snakes and mice. The basic principle of Behaviour Modification is that we repeat behaviour which is rewarded and behaviour which is punished or ignored is not repeated.⁶ If a child, who is in good health, screams for attention and gets it, either always or sometimes, he is rewarded, so he will scream again for what he wants. If he bites, pinches, spits to punish somebody, and it works, he is rewarded by his success. If he sees that a blue fit or asthmatic attack or pseudo-epileptic attack, sends his parents into a dither to conform with his wishes, he has already established control of his kingdom.

6. What to do about these Problems

After a thorough check up by a paediatrician, and if there is no evidence of epilepsy, convulsions, etc., parents are advised to ignore blue fits — i.e. say nothing, do nothing, look passive, or look out the window, and under no circumstances is the child to be given what he put on the blue

fit for. At other times, when the child is well-behaved, he should be hugged, cuddled, kissed. This reinforces and rewards, "good" behaviour. The same techniques apply to pseudo-epileptic attacks, whining, day screaming and night screaming. For biting, pinching, spitting, kicking, time out is recommended. This involves putting the child outside the door or in an unstimulating room immediately and every time he bites, spits, kicks etc. The mother or the father should not start a long reasonable, logical explanation of why the child is being put out, because this attention given to the child may be rewarding in itself. The secret is to do the time out instantly, without comment and consistently.

Time out works also for whining and screaming behaviours. If anybody e.g. other parent or grandparent interferes with the system, it does not work, so both parents are counselled together about the system. Again, as in the case of ignoring blue fits, "good" behaviour should be rewarded at ordinary times by praise, hugging, cuddling, kissing etc.

In my experience, Behaviour Modification with parents is successful about 95-99% of the time. Fortunately, parents are *for* their children and are most co-operative when they are given sensible, simple instructions. It helps when all of the supporting services and therapists agree on behaviour modification techniques because then one therapist is not working at cross purposes with another, to the confusion of everybody!

I am very lucky in my clinics and schools in that I get full support from all the staff, teachers, therapists, doctors etc. The quality of these professional people is remarkably high, as is that of the parents.

The child's integration in the family and community will depend on his ability to relate to others and on the others' ability to relate to him. I have described the handicapped child and the family and how to ensure that the child fits into his first community in preparation for integration into the larger community.

Constraints

The constraints are man-made i.e. negative attitudes, prejudices and behaviour of the public in general, the caring organisations and people in some organisations and institutions.

RECOMMENDATIONS

1. Education of the minds and hearts of people, the public in general and professionals in particular. Professionals should give away knowledge.
2. Recognition that parents are *people* too and will clearly in some cases know more than the professionals. All parents are equal and some are more equal. The use of parent resource groups is strongly recommended.
3. Legislation for the care, education and employment of the handicapped.
4. Regional centres with specialists in the various areas relating to

handicap. Psychologists should be involved in counselling in such centres.

5. An enhancement of the role of teachers and psychologists in policy and decision-making, especially in the area of special education.

6. Generosity and humility of mind, heart and spirit, if these virtues are still respectable!

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3

Dr. Noreen Buckley

Speaking as a parent, there are some points of view I would like to put before you.

Acceptance

The whole future of a handicapped child depends on the degree of acceptance given by parents. If the parents reject the child they may also reject the services available within the community. This is why it is so important that parents are seen early by the professional and told with sensitivity and kindness about their child. In this way, they will be helped towards acceptance.

Acceptance does not always come easily. The birth of a handicapped child can bring, instead of joy and pride, pity and sadness, and the very real fear of being unable to cope.

For parents, a whole new dimension is added to their lives. The presence of a handicapped child within a family may make parents insecure and leave them more vulnerable to all the other difficulties of life. Normal fears take on a new sense of importance e.g. what if one of the parents becomes ill? What if the husband loses his job?

I think the most important step to acceptance is the way parents are told. This is the first thing they remember and it colours their view and affects their outlook. They need to be told kindly and gently, and accurately. At this stage, timing is of the essence in telling parents about their child's handicap. They will only take in part of what they are being told. They go home, think things over, they have worries, they will want to come back to ask all sorts of questions. For example, they will want to ask about the present, about feeding, about how they are going to cope, and most of all — why did it happen? They need to know the answers to these questions early on in order to be able to come to terms with the facts and plan for the future. Where possible, parents should be told together. Honesty in telling is always best. Parents can appreciate the difficulties, at that point in time, of predicting an accurate future.

Time and care, kindness and sensitivity, at this stage, are all important. Sometimes it happens that if parents are not carefully handled, they will not accept the handicap and will go from place to place, doctor to doctor, looking for confirmation of their belief that their child is normal. This is the path to eventual heartbreak.

Help in the Community

When parents are seen and told by the paediatrician in the hospital, they should be referred immediately to a Child Study and Assessment Centre for mentally handicapped. This is usually attached to a centre for mentally handicapped, and so, parents have the benefit of feeling that they are being tied into a comprehensive service and so feel less isolated.

At this centre, a team approach to diagnosis, involving the parents in physiotherapy and stimulation of their child, helps them to feel that something is being done and that care and attention are available to them. After the first few months, a more accurate prognosis will emerge. Secondary handicaps will be diagnosed and treated early, thereby minimising their effects. Parents come to know the services and will begin to feel secure knowing that help is available in times of crisis.

Within the community, public health nurses and also counselling nurses will be visiting and bringing special knowledge of services for the handicapped. This community care is necessary to educate parents and give them the support they need. Problems of neighbours relating to the situation can cause further isolation for the mother. Frequently, young mothers come home with their child and relatives, neighbours and friends, instead of rushing in to see the baby and saying "how is the child?" and "how are you?", are afraid and do not know how to handle it. The support services, within the community, of nurses, counsellors and social workers, will assist young parents in overcoming these difficulties. *The basic aim for parents is to make their child as independent as possible, within his means.* This should be kept in mind at all times. If they start with this aim at the beginning and keep working at it, they will have a child whose potential has been developed and who is as independent as possible.

The Family

It is important that parents be helped to accept their handicapped child early because they do not stand in isolation but are part of a family. It has been said that a "handicapped child makes for a handicapped family", but this is only true when things have gone wrong and the family dynamics are totally upset. Families make up the community and, therefore, the community must strive to serve the family and cater for its needs. When things go wrong in a family, there must be help in the form of "crisis intervention". Here, I would like to pay tribute to the new Break Away Scheme, launched by social workers this year, which has given much needed breaks to many families, and which holds out promise of greater potential in the future.

Parents must look at the total needs of their family because there is always danger of neglecting their normal children. Parents need to remember that all their children are entitled to their love and care. Parents very often expect their children to accept a handicapped child as normal within the family. However, it may have taken parents themselves time to accept the child and parents cannot expect normal children to accept a handicapped child immediately. Siblings need explanations and their questions

answered. Also time for adjustment is needed. Without forcing, mothers can expect the whole family to get on well together. Problems will arise but nothing that is impossible to cope with e.g. if a hyperactive child persists in turning on and off the television, the other children will get very frustrated. In this situation, a mother must realise that the only thing to do is to take the child out of the room until the programme is over, letting her normal children watch the television in peace.

The mother of a handicapped child has two options — either to accept the child and allow him become part of the family, or she can devote all her time to the child and isolate herself from her other children. This is not good for the family dynamics; it is not good for the child; it is not good for the mother. The one that it rebounds back on most is the handicapped child. Children are normal — they will resent the amount of attention the handicapped child is getting and, consequently, will take it out on him. So, one must always look at the child in the context of the total family.

Parents must also be careful not to put on their children too much responsibility for the handicapped child. It is not fair to place responsibility on young children for the actions of the handicapped child. No young child wants to be called "big" if it means added responsibility and less love and care.

If one has an extended family, they should certainly be involved. Uncles, aunts and grandparents are very useful and helpful. Normal children need them, but the handicapped child needs them much more. A quiet Downs' Syndrome child is much less trouble to babysit for than a normal child. Relatives, friends or neighbours should be willing to babysit because young parents with a handicapped child need to get out together, more so than in other families. I know families where parents have not gone out together for 3-4 years. This is wrong, because they get into the habit of not going out and they will not allow their children to be looked after by anybody else. This is a great disadvantage to the child. Ordinary children get out and mix in the community and so why not expose handicapped children to relatives, friends and the community. In this way, parents will enlarge his world and make him less dependent.

The other children in the family can help the handicapped child in many ways e.g. through play, speaking etc. These normal children may also need special help at times themselves. School teachers can play a big part in looking out for signs of insecurity. Such signs as lack of concentration, boldness, aggressiveness, lying, stealing and other changes in pattern. If these are recognised as such, the teacher can then give that little bit more attention to help them through bad patches.

It is obvious from this that parents need preparation in carrying out their roles. In some countries, there is large-scale involvement with parents e.g. the Belgians have special inservice training where professionals are trained and counselled to help parents. When a handicapped child is born, parents are counselled, initially at the hospital, and then in the home by a local counsellor. This service is provided all through the early years. This service has been very successful and is now government subsidised. In Ireland, we have had, in the last year, a counselling course for nurses for the

handicapped, who we expect will be able to give great help during the early years. We also have parent groups run by voluntary bodies who provide services. These are run mostly for the same age group i.e. babies, pre-school child, school child etc. Often parent groups meet and exchange views. They are also given specific talks on the problems that are relevant to the children at that particular period.

With regard to the family, there are one or two more points I would like to make. Firstly, young parents have special problems. They will possibly wonder about future children. Suddenly, life will become very serious — they have to grow up and mature overnight. By contrast, if the handicapped child is the last child in a family, it is very often easier because there are older children who can help out. The parents are a lot older and more mature and have a lot more parenting experience.

My second point concerns whether the child is quiet or hyperactive. A quiet little Downs' Syndrome child will need care and attention and extra stimulation, but he or she will be relatively easy to manage. However, when a child is hyperactive, needs little sleep and is continually on the move, he naturally causes disturbance within the family. These children, of course, take up much more of their parents' time and are much more exhausting. Another factor which makes a very big difference to the family is the number of secondary handicaps which the child has. Some of these are: failure to thrive; heart murmurs; blindness; deafness; epilepsy and orthopaedic difficulties. Many small children who are handicapped suffer from repeated respiratory tract infections and also other illnesses in the first few years. These parents will also need special preparation for their roles.

Conclusion

Parents of handicapped children can experience great support from religion. We, in Ireland, are lucky in this respect. We owe a great debt to these religious who have run services so successfully in the past for our children.

Finally, it is important to remember that parents suffer much more than their handicapped children. The handicapped child, nurtured in a loving and caring environment, will happily go through life to a glorious and immortal future. Though parents suffer they can take consolation in this.

Dr. Noreen Buckley

She has been active in the National Association of the Mentally Handicapped for many years and is a former president.

CHAPTER THREE

The Disabled Child and the School

1

Professor Desmond Swan.

"Some aspects of the emotional and social development of handicapped children and their implications for teacher training."

We cannot define handicap except by reference to the normal, while we use the integrity of mind and body to affirm our adequacy as persons to others. Besides, our self-concept is centred on the physical self at its core. Both in the spheres of motor and mental skills therefore, in the worlds of ideas and of artefacts, the person who is handicapped physically or mentally, is continually being defined as inadequate. And yet every one of us is handicapped in some way.

THE CONCEPT OF HANDICAP-LABELS AND ASSESSMENTS

The concept of handicap therefore is by no means clear or simple, so for my purpose here I shall define as handicapped anyone who suffers from a disability which of its nature or due to its degree of severity, places him at a marked disadvantage compared with others in similar circumstances.

Prevalence must depend on definition, but even in favourable circumstances it is estimated that at least one child in six has a disability of some magnitude; indeed the Isle of Wight survey (Rutter, Tizard and Whitmore, 1970) found this to be the percentage of children with a chronic handicap of moderate or severe intensity, and requiring some form of special attention, while in the sphere of scholastic achievement a similar prevalence has been found for children who are retarded in reading (Swan 1978).

Now we could attempt to classify the most prevalent handicaps on several parameters e.g. according to origin (congenital or environmental); according to the major professional specialism implicated (e.g. medical or

educational); according to their supposed location in the personality (e.g. motor, sensory, emotional or intellectual) etc. But it is always we who attach the label — despite the frequency with which a given child's problems refuse to fit neatly into these categories e.g. the Isle of Wight survey found that 24% of the intellectually retarded also had marked emotional and behavioural disorders.

The very visibility of certain physical handicaps may well lead to their earlier detection and thus to a labelling by such physical syndromes as deaf, blind, cerebral palsied etc. with all the determinism and simplicity that these may connote as well as their frequent stigma. Despite the absence of a direct relationship between physical and intellectual however, there has occurred a carry-over from the medical to the sphere of intellectual retardation which, however useful it may have been in the past, is now quite counterproductive. "No other stigma is as basic as mental retardation" wrote Goffman, "in the sense that a person so labelled is thought to be so completely lacking in basic competence. Other stigmatized persons typically retain some competencies, limited though they may be, but the retarded person has none left to him. He is, by definition, incompetent to manage any of his affairs" (Goffman, 1963). Fortunately there is evidence (Carroll, 1980) that the stigma suffered by former pupils of Special Schools may be decreasing, but we must ask is it right at all to risk this price in order to provide a child with an education appropriate to his special needs.

The time has come for us to replace the rather simplistic medical model of illness diagnosis and cure with the more appropriate educationally based model of assessment (cf. Wall, 1980). A diagnostic approach to teaching (cf. Swan, 1973) the problem pupil, aided by valid and reliable standardized test results, information from parents and from any other relevant source — all these combining to yield an individual pattern of strengths and weaknesses, is the appropriate educational model of assessment. But to do all this will require the closest collaboration of teachers and educational psychologists. I insist that it is unjust both to pupils and to their teachers for the Department of Education to continue to shuffle off responsibility for assessment onto the Health Board in each area, while withholding the establishment of a psychological service within the primary schools. To do so, is to define educational problems in medical or pseudo-medical terms; the question is no longer one of ensuring that the patient will survive, but that as a person the pupil be enabled to live at the fullest level which he can reach and this is essentially an educational need. It is all too easy to define needs in terms of existing services, rather than in terms of personal problems whose amelioration may demand a reappraisal of those services. It is only when we place the central responsibility for solving educational problems back in the school, with the help of whatever educational, medical and paramedical specialists are appropriate, that we will properly cater for the major needs, emotional, social and intellectual of handicapped children.

EMOTIONAL DIFFICULTIES OF THE HANDICAPPED CHILD

The human personality is all of a piece. We may describe a child with a

low I.Q. as a slow learner — but to leave it at that is to ignore the fundamentally emotional aspect of all learning. Emotion and value constitute the dynamics, intelligence provides the structures of learning, but the two are in reality inextricably linked with the physical and with each other. This said however, it must be pointed out that healthy emotional development is the cornerstone of the healthy personality, while adequacy in one's personal relationships is another *sine qua non*. I propose first to look at some emotional and social problems of the physically and of the intellectually handicapped, and then go on to discuss some implications for teacher training.

From the perspective of the individual we may ask, what are *his* reactions to his handicap? How does he see it, and what in fact is going on "deep inside in that silent place where a child's fears crouch?"

Perhaps the most salient feature of any handicap is that it belongs uniquely to an individual — not to a cripple or an epileptic or an idiot or anyone defined by membership of a group, but to a child whose fate has decreed that he must come to terms with his experience of it. Second, that a handicap entails failure in some sphere of life — whether in learning, in physical activity, or in social popularity, and that unless this barrier is somehow overcome the failure will become cumulative through time. The experience of failure is an intensely personal one, but most of us can disguise these intense feelings sufficiently by highlighting our successes. The visibly handicapped child however has a constant public reminder of his inadequacy. Since bodily integrity is ordinarily fundamental to a sense of well-being and self acceptance, it will be difficult for the handicapped person not to develop a negative self-image.

An important research finding here however is that the chief determinant of the child's attitude to his handicap is the attitude of the parents to it (Allen & Pearson, 1928). If they are anxious about it, he is most likely to be so too; if they are matter-of-fact then he will usually adjust to it more easily. Reynell (1974) maintains that the distress of the parents at having a handicapped child is probably the earliest and most persistent stress that a child with a congenital physical handicap has to experience. They may feel guilty at having produced a "damaged" child, sometimes they may be mourning the normal child whom they had hoped for — and of whom they now have a perpetual living reminder — and usually at the same time attempting to love, accept and live with their handicapped child. This background resulting for instance in over-protection, could indeed have a distorting effect on the child's emotional development. Additional burdens such as the disruption of family life, financial strain or poor health in parents, any of which may result from the handicap, can place the individual in a vicious circle of stress, often with no end in sight.

This brings us to the notion of stress itself by which I mean the experience of negative feelings sufficiently serious and prolonged, to militate against healthy emotional development. Of course there are degrees of stress which are positive and maturing in their effects. Here however we are discussing its adverse effect.

The research on the emotional problems of handicapped children is inconclusive due to the lack of scientifically based methods of measuring

stress and its outcomes. There is however agreement (1) that the handicapped child is generally more vulnerable to stress than the non-handicapped, and (2) that there are certain stages of development when this vulnerability is likely to be greater.

CRITICAL PERIODS OF EMOTIONAL VULNERABILITY

The first of these stages to concern us here is the phase of entry to formal schooling. Even in the most favourable conditions this is an event that needs careful management. In the case of the handicapped child however he may now be exposed to the unpredictable demands of a less protective and a less accommodating environment than he has been used to. Most handicapped children go to ordinary schools, and these are designed for average children, not for the atypical. The dread of any child of being perceived by his peers as different or inferior is all too likely to be realised therefore, outside the classroom if not inside.

Changes of school are also likely to be stressful, especially the transition from primary to post primary, although 20% of Faughnan's sample of Irish Wheelchair Association members, never in fact made this transition (Faughnan, 1977). At least in primary school one was usually in a single room with one teacher, throughout the day. Old relationships on which the handicapped pupil may have become unusually dependent are now liable to be disrupted, and new peer reactions apprehensively anticipated; the dread that one's first presentation of self will be greeted with ridicule by some thoughtless individual most loom large in the child's apprehensions. There is probably no child who makes the adjustment from the more pupil-centred primary school, to the impersonal kaleidoscope of new teachers and new subjects in post-primary, without experiencing some strain. For some handicapped pupils it can be a traumatic transition. Nevertheless many do navigate it successfully and go on to acquit themselves well academically and socially in this new arena. It is hazardous none the less and even the flexibility of the comprehensive school, in accommodating individual differences, can be offset by its unavoidably large size.

An increasing source of stress at the secondary level is the urge to be academically competitive by way of passing the public examinations, although this may overtax the resources of the handicapped pupil. It may besides challenge the priorities of the individual teacher and is now becoming a major problem in several special schools. For instance a recent study carried out in U.C.D. Education Department of the motivation of deaf pupils in a special school found that 88% of them rated "To pass exams" as their chief motivation in attending secondary school (McDonnell, 1980).

The experience of adolescence can exacerbate the actual impairment of certain pupils. Aside from the frustration of the boy who is unable to compete athletically or the girl whose deformity marks her down in what we might call the "boyfriend" stakes, there is the likelihood that established control of epilepsy, diabetes or asthma for instance, may temporarily slip, or that irregular growth may place an extra strain on a weak limb (cf. Varma, 1974).

Schooling, whether of the physically or intellectually handicapped must concentrate on facilitating the maximum independence and autonomy of which the young person is capable, whilst enabling him to accept his difference without, if possible, feeling inferior. In Special Education at least, we try to create a caring environment for the individual, but this while necessary, can also be counter-productive where it creates dependency or "learned helplessness". It is as easy for parents or teachers to be under-demanding as it is to be over-demanding; once the range of the handicapped individual's capacities has been accurately ascertained, it must be insisted upon that only the best in that range will be acceptable. All of us have to learn that objective standards exist and that the price of independence is to measure up to these. It would be too easy to allow the handicapped youth to use his impairment as an excuse for not making an effort.

Again, it is at least as important to the handicapped person to prove himself capable of reaching normal standards in some field of endeavour. If this cannot be in formal academic achievement, the imaginative teacher or parent is almost bound to find an appropriate outlet in one of the numerous range of hobbies now within reach of all young persons — and frequently it is in the avocation that one's true vocation is eventually discovered.

PROBLEMS OF SOCIAL ADJUSTMENT

Much of what I have been saying applies to social adjustment as well as to emotionality. If we take maladjustment as a separate entity we realise that it is by no means confined to those who are otherwise handicapped, although it may be more prevalent among them and may find somewhat different forms of expression among them. Anderson's research (1973) found however that physical handicap *per se* was not an important correlate of overall social adjustment within the ordinary school, but that neurological abnormality (especially cerebral palsy), intelligence level, social class, family size, and sex of pupil did differentiate levels of adjustment; while O'Moore (1980) in a carefully drawn sample of children with normal intelligence and visible physical handicaps, found no significant differences in the overall social and emotional adjustment of disabled children in ordinary day, special day and special residential schools. She also found that physically handicapped children in ordinary day schools were able to cope as satisfactorily as their normal peers in their social and emotional lives.

However, we must also be concerned about the adjustment of the disabled to the workplace, and here again is a major stress point in their development. Increasing age and capacity extend the exposure of the individual to new environmental conditions, and thereby increase the risks. The vocational guidance of the young person must begin well in advance of school leaving while his attainment of maturity, of realistic self-assessment and of independence are all now put to the test unless he has been directed towards sheltered training or employment. A skilled counsellor or social worker who knows both the individual and the new working environment can also be a crucial determinant of success or failure here.

A recent study by Hastings and others (Hastings et al, 1978) of disabled trainees in AnCO training courses who had been assessed as suitable for open employment, found that in fact they had considerably greater difficulties of social adjustment than their normal workmates. Their learning problems tended to stem not from a lack of physical or mental capabilities but from a lack of social skills, and were judged to arise from a preoccupation with, or an exaggerated view of their own disability. But the fact that psychiatric histories were prominent in this handicapped group must weight heavily in interpreting the main finding here.

TEACHER TRAINING FOR THE EDUCATION OF HANDICAPPED CHILDREN

It would be naive to assume that more and better training of teachers for work in this field would solve the major problems. Nevertheless, the teacher is the key figure, next to the parents, while public and administrative attitudes are also important.

Scarcely a generation ago, in 1938, the following statement was made by an anonymous educational official in Dublin:

“After all this is a world for the average man, and if there are funds available, the bright child who will be an ornament of the state, and become a useful citizen, should be helped. I think it is a waste of time trying to teach children who can never learn and never be taught to learn.” (cited in Byrne, 1979).

While we can point to at least a twenty-fold increase in special educational provision since those dark days, and a seven-fold provision in the past twenty-five years alone, as well as a marked improvement in its quality, we cannot afford to be complacent. I am not certain that traces of the attitudes underlying the above quotation have entirely disappeared.

What are the issues now facing those involved in the Teacher Training area?

1. Do we attempt to train a limited number of specialists to a high level or to equip every teacher in training with some limited knowledge and skills?

I believe the answer will be both, though in fact we do not yet do both, for both the primary and post-primary sectors. Probably all of our initial training courses do now include greater or lesser inputs on Special/Remedial Education, while specialized training courses in both U.C.D. and St. Patricks College do train specialist teachers, the former of the Deaf, the latter for the Mental Handicap, but neither in sufficient numbers.

2. Is it better to provide Specialist Teachers by way of separate initial training or through in-service courses?

In Germany and Holland for instance one finds specialized pre-service courses exclusively in Special Education. I feel however that much can be

gained by way of a full-time in-service course which would recruit already experienced teachers into this very demanding work; a firm framework of experience with ordinary pupils can be invaluable, despite some risk of inflexible attitudes.

Here I share with you an open secret that we in the Education Department at U.C.D. have been ready, willing and able for two years past to mount such a full-time training course for teaching at the post-primary level. But when we requested that the Government Department release teachers to take it, they refused to do so. I find this disappointing, especially in the absence of any other course catering for this level.

3. How to modify a procrustean subject-based curriculum at second level so as to make schooling a more meaningful experience for handicapped and deprived children?

I can only raise this as a question of fundamental importance and while we are carrying out research on aspects of it, I do not have any ready solution.

It may be true that the post-primary school finds it difficult to adapt to the needs of handicapped pupils; nevertheless the structure of this school does lend itself in certain ways to the introduction of a "pupil specialist" who will work in collaboration, or in parallel, with the existing subject specialists. But given indications of a tendency for Special Education to isolate itself from the mainstream, added to the relative unpopularity of this work and its very demanding nature in some schools, the more closely the special teacher is integrated with the rest of the school staff the better for both.

Such teachers need to develop to a high level the skill of pupil observation as a basis for diagnostic teaching. They need the adaptability to set firm, realistic objectives, differentially planned, for differential needs (See Ainscow and Tweddle), and the organisational ability to lead their colleagues in a concerted attack on these neglected problems. They need confidence in themselves, and the skill to imbue their colleagues with confidence in their capacity to cope immediately with a range of different problems or to know where to turn for immediate help; confidence too in and setting the norm for the formation of pupils' attitudes in general to peers who differ from themselves. They need to have an orientation to ongoing research, so as to engage in small-scale studies in their own schools or to participate in "major" projects like the comprehensive survey of the Visually Impaired which is going on at present and for which the collaboration of teachers is vital.

Another area where the teacher of the handicapped needs particular skill is in pupil counselling, towards entering into meaningful relationships with difficult or alienated young persons. Lastly, they need a bouyant and optimistic outlook on their work to counteract negative attitudes of colleagues and even more negative attitudes among their own pupils.

There is nothing sacrosanct about IQ 70. We do not have handicapped, deaf, maladjusted or cripples in our schools, but children with special needs. The sooner we are enabled to prepare specialist teachers to cope with the actual range of pupils capacities in the post primary school the better.

We must stop trading in labels and start from pupils needs, accurately perceived. There is a world waiting to be born under our footsteps. . . .

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2

Sean Glennane

"The Influence of School Experiences on the Emotional and Social Development of the Disabled Child".

The views expressed here are personal ones, and not necessarily those of the Department of Education.

Before considering the position of the disabled child we should first ask what provision our school system makes for the emotional and social development of children generally. Rarely will one find any overt reference to it in the written curriculum. The first chapter of the handbook on the Primary School Curriculum makes a number of statements which suggests that the school can provide for the emotional development of children. In it we find statements like "each (child) is entitled to an equal chance of obtaining optimum personal fulfilment".

The twin aims of the curriculum are: –

1. To enable the child to live a full life as a child.
2. To equip him to avail himself of further education so that he can go on to live a full and useful life as an adult in society. There is also a recognition that children are complex human beings with varying needs, physical, emotional, intellectual and spiritual. Finally it is stated that each child as an individual deserves to be valued for himself and to be provided with the kind and variety of opportunities towards stimulation and fulfilment which will enable him to develop his natural powers at his own rate to his fullest capacity.

We can take all these statements as a declaration of intent that the school should provide for the emotional and social development of the children.

In practice the degree to which emotional and social development is made a priority depends very much on the individual school. It is not an area which can be legislated into the school system nor is there a minimum standard which can be laid down. Schools probably mirror the attitudes of the society which they serve. It is sometimes felt that the so called cultural subjects, like Art, Music and Drama, have the effect of promoting emotional development. It is more likely that the manner in which subjects are presented has a far greater effect on emotional development than the content. It is possible to distinguish between the *manifest* curriculum and

the latent curriculum. The *manifest curriculum* includes all those areas which are timetabled.

The *latent curriculum* may be much more important for emotional development. It includes values implicit in what is included in and excluded from the curriculum. The methods of teaching, organisation (e.g. mixed ability as against streaming) have an effect on the perception which the individual child has of himself within the school. The systems of motivation, discipline and incentives will also influence the attitude of the individual child. The relationships which exist within the school, between the children themselves, between the children and staff and between the various members of staff will produce a climate which will affect the emotional and social development of the pupils.

The school has a crucial role to play. Its effects will be most beneficial when its values reflect those of the home. It is probably time to say that our schools over many years were best suited to the needs of children who approximated most to the average level of their peers in intellectual emotional and social development and found it difficult to accommodate themselves to the needs of exceptional children at both ends of the spectrum. Until recently it was only in special schools catering for a particular handicap that the individual needs of the disabled child could be assured of attention.

If children are to develop to their fullest potential they need experiences during their school years which are challenging and in which they can feel secure. They need to have a good image of themselves, to feel that they have a valuable contribution to make to the group, to be acceptable to and accepted by the other members of the school community. If they or their families feel alienated from the school community they may reject the system and become emotionally unstable.

All the points which I have raised so far are applicable to all children. Even the best adjusted children may encounter problems from time to time. Disabled children are likely to encounter even greater problems. I would like to consider these problems under three headings, family, school authorities and peer group.

The family of a disabled child will have encountered many difficulties in the pre-school period. When the child comes to school age many agonising decisions may have to be made about educational placement. Depending on the nature and degree of the disability a decision may have to be made about sending the child away to a residential special school, to a day special school, many miles from home, to a special class in a school not attended by other members of the family or to the local school to an ordinary class. Only in the latter case will the child be using the facilities ordinarily available to the family. Whatever decision is made problems will arise in relation to emotional and social development.

The first need of the family is to have available well-informed and objective professional advice. It is important for the child's emotional well-being that the parents are fully involved in all decisions and that adequate counselling is available to them whatever placement is decided upon, it should be fully understood and accepted by the parents, the other children

in the family and, as far as possible, the peer group in the immediate environment. If parents feel guilty or hostile about the child's educational placement it will adversely affect his attitude towards school.

Whatever educational placement is decided upon, the disabled child will have some special learning needs, depending on the kind and degree of the disability. Most disabled children miss out on the informal learning experiences which ordinary children have in the pre-school years. They tend to be absent from home for medical treatment and even while at home they are sheltered and are usually precluded from reaching the same level of maturity in making relationships as ordinary children of the same chronological age. The transition from home to school may therefore produce greater emotional trauma than for other children. If they have missed out on informal learning experiences they are less likely to have reached the same readiness for formal learning as their non-handicapped peers. Results of research, however, suggest that where there is not a serious intellectual deficit involved, children with sensory and physical disabilities eventually catch up on their non-handicapped peers. It is essential, however, that they have teachers in those early years who are sensitive to their needs and who structure the learning experiences to take account of their disabilities.

Inevitably the question of integrated versus segregated education arises. I would suggest that many of the arguments put forward for and against integration generate more heat than light. It is not my intention here to discuss the merits or demerits of integration. I would rather like to point out some of the difficulties which can arise either in an integrated or segregated environment. As a general principle, however we could probably all agree that as far as possible all children should be educated with their own age peers. All children share the same basic intellectual, emotional and social needs. Indeed the arguments for and against integration do not hinge on the identification of needs but rather on how those needs can best be met.

In the case of children with certain physical or sensory disabilities, special aids, apparatus or adaptation of buildings may be necessary in order that the child can avail of facilities in ordinary schools. Over the past number of years the Department of Education has given sympathetic consideration to requests for grants for such aids or adaptations. Physically handicapped children who find it difficult to attend school every day or for the whole of the day can avail of supplementary home teaching. I have personal experience of the working of this scheme for the past twelve years and have seen children with severe physical disabilities pass through the entire educational system whose parents a few years earlier would have had to choose between a residential school and not sending them to school at all. In general the ordinary schools have been very accommodating of such children. Particular praise is due to many of the smaller rural schools who have accepted these children fully. Where difficulties about toileting and medical care have arisen, the parents, older brothers or sisters or public health nurses have come to the aid of the school where this was necessary. In general where the disabled child comes to school from an early age he is accepted by his peers and given help where necessary.

In the case of the hearing and visually impaired children the Department operates Visiting Teacher Services. The teachers attached to these services

have authority to visit homes of pre-school children at the request of parents. Thus they form a trusting relationship with the family over many years and are able to give advice which is trusted when the time comes for educational placement. Where a child with a hearing or visual disability is attending an ordinary school the visiting teachers call to the school to advise the teachers, to liaise with the family and to ensure that the child is using efficiently whatever hearing or vision he has left. The existence of these services has ensured that the strengths of the families are fully harnessed to enhance early development and that the disabled child receives in school the special help required. I have first hand knowledge of the work of the Visiting Teachers of the Visually Impaired since their appointment. I am often amazed at the range of services which they provide. They are clearly welcomed by parents and teachers and indicate that there is goodwill towards disabled children in an increasing number of schools.

For many children with serious intellectual, emotional or physical disabilities the only realistic option is placement in a special school. Such schools are staffed by teachers who have developed very sophisticated skills in dealing with the learning and management problems of the children in their classes. They also have ready access to the expertise of other specialised disciplines. Often the children in these schools have more than one disability and it would be quite difficult to provide adequately for them in ordinary classes. Additionally the presence of some of these children in an ordinary class would pose serious management problems for the teachers. Either the disabled child would get insufficient attention or so much attention would be diverted from the other children that their learning needs would be neglected.

Protagonists on both sides of the integration/segregation debate can usually agree that the more handicapped the child is the more likely it is that his total needs will be best served in separate special schools. The vast majority of children suffering from the various disabilities might be classed as being less severely handicapped if we work on the principle that in a normal curve of distribution the closer one comes to average the greater the number will appear in any categorisation band. One has to ask the question is it necessary to send to separate special education all those children who are at present so segregated? If children are being prepared for a life of independence and for full participation in community activities, can we justify educating them separately from ordinary children? This is an issue which must be faced by all in ordinary and special education.

In relation to the emotional and social development of the disabled children, different sets of problems exist in ordinary and special schools.

If the child is placed in an ordinary school, care must be taken that he is not placed in destructive competition with his abler age peers. When I speak of destructive competition I am referring not only to intellectual areas. Clearly the handicapped child at play in games and in social relationship may be at a disadvantage, either temporarily or permanently, and due allowance must be made for his disability. Whereas the teacher may be willing and able to make allowance, the other children in the class may not be so accommodating. Children at school age tend to be outspoken and direct, even to the point of cruelty. At a practical level there is probably a necessity to introduce some

ideas on the concept of disability into courses on Civics, Religion, Social Studies and Human Development. Ordinary pupils and students must be taught to strike a correct balance between challenge and caring in their dealings with the disabled. If disabled people are to take their places in society as adults on a basis of full participation it is as important to educate the able bodied in the needs of the handicapped as to try to adapt the disabled to the norms of society. A fate even worse than destructive competition is where the disabled child in the classroom is either ignored altogether or is so insulated and protected that he is excluded from forming normal relationships. Where the disabled child is placed in the ordinary school, therefore, it is important that the right attitudes be formed in members of staff and pupils.

Placement in an ordinary school, then, makes certain demands on the child and on the school. The success or failure of the disabled child in coping with the demands of ordinary schooling is very much an individual matter. Essentially he must adapt himself to a dominant subculture where the majority of others in it do not suffer from that disability. He must be able to form reciprocal relationships with his peers; he must be able to join in a meaningful way in the majority of classroom and extra curriculum activities. He must be able to endure a certain modicum of the teasing in which ordinary children indulge and he must be able to cope with occasional hurtful remarks. The frontline staff in the school and the other children, must, for their part, be prepared to make some adaptation in their behaviour to accommodate the disabled. In the case of a physically disabled child, it may mean assistance in writing, mobility or going to the toilet. In the case of a visually impaired child it may mean tolerating the presence of awkward apparatus and some slowing down of normal classwork. In the case of learning disabled children, it may mean occasional special groupings, withdrawal to a resource room or special class for certain periods or the omission altogether of certain aspects of the curriculum. In the case of the emotionally disabled it may involve (perhaps most difficult of all) the application of standards of conduct different from those which would be tolerated of the majority.

It is sometimes argued that disabled children in ordinary schools have not the same access to specialised medical or other expertise. This may not be such a disadvantage. I would hasten to add that I am not in any way decrying the necessity for specialist services for disabled children. At certain critical periods of their lives, medical attention and care may be far more important than education. However if disabled children are being continually treated during school hours, is there not a danger that they will be singled out still further from their ordinary peers? I am a little worried by those who say that placement in an ordinary school is only appropriate where the facilities in the ordinary school are comparable to those of the *best* special schools. This begs the question, what are the *best* special schools? I would suggest that the *best* schools are those where the frontline staff have the right attitude towards the disabled. I use the term *frontline* staff advisedly. These are the teachers in the classroom, the child care assistants, where they exist, or those other members of staff, (e.g. cleaners, bus drivers etc.) who are in daily contact with the children. The development of community care services throughout the country should ensure that professionals in the various specialist disciplines

will be available to a far wider range of children than in the past. If community resources are used it will have the effect of demythologising the concept of handicap.

I have dwelt at some length on the disabled child in the ordinary school. What of the special schools and special classes? The majority of our special schools have been purpose built over the past twenty years. The capital grants come out of the funds available for the building of Primary schools generally. The planning data for special schools have been updated in accordance with developments in mainstream education. The most modern of our schools provide accommodation on a truly generous scale. Very large percentages indeed of the capital costs come from public funds and the voluntary agencies do not meet insurmountable difficulties in providing the local contributions.

The special schools have available to them a wide variety of resources both human and material. The teachers in them are highly qualified and provide a caring secure atmosphere for the children, and ensure that all the children however complex their disabilities, are treated with courtesy, dignity and respect. The voluntary agencies which provide the local management provide the additional financial resources where there is a shortfall between amounts received by way of state grants and the full running costs. The fact that they are all national schools means that they are to some extent part of the mainstream of general education. As far as my colleagues in the inspectorate are concerned, all of us have considerable connections and duties in ordinary schools. Indeed the manner in which special education is administered shows the degree of flexibility which can be accommodated within the national school system.

The historical fact is that separate education was provided for groups with common medical or psychological characteristics as a necessary first step for those for whom no provision at all had been made previously, and it was possible to channel scarce resources in a readily identifiable way to those who needed special attention most. Undoubtedly for many of their pupils, the special schools continue to provide the best climate for social and emotional development. The difficulty arises, however, with those children who aspire to a life of independence in the community as adults. Placement in a special school can be seen as placing them in a social system largely comprised of those who are similarly handicapped. It can lead to a loss of contact with normal peer groups and children can lose neighbourhood contacts. They can be a sense of stigma. Furthermore there is a real danger that the environment of school will be too protective and that the learning experience will not be sufficiently challenging. This is a particular danger for children of average or above average ability who suffer from a physical or sensory handicap.

To guard against the dangers referred to in the above paragraph it is vital that children in special schools maintain contact with ordinary children on a structured basis. This can be achieved in a variety of ways. Opportunities for social contact arise in school journeys, outings, concerts with neighbouring ordinary schools. At second level there is a case for including special school children in social and sporting activities of local schools. Often the local schools have major resources in practical subjects. Some of the pupils from special schools could join classes in neighbouring postprimary schools for

those subjects. Indeed the provision of practical work areas in special schools may have had an adverse effect on the maintenance of contact with ordinary schools. In many schools with which I have been associated, there was far more co-operation when the special schools were in inadequate temporary accommodation.

Whether the disabled child is enrolled in an ordinary school or a special school the following three questions may be asked.

1. Does the placement help to compensate for the handicap?
2. Does it reinforce the handicap?
3. Does it increase the handicap?

I would suggest that the answer lies not so much in the kind of school in which the child is placed, but rather in the attitude of the school population and the disabled child's perception of that attitude.

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CHAPTER FOUR

The Disabled Person during Adolescence and Young Adulthood

1

Dr. Paul McQuaid

"There is a tide in the affairs of men which taken at the flood
leads onto fortune; omitted, all the voyage of their life is bound
in shallows and in miseries."

(Julius Caesar, Act 4)

The converse of disability should be what concerns the delegates at this Summer Course. The Medical-biological model does not, however, in its primary task address compensatory and healing aspects of the individual although, of course, no investigation, assessment or diagnosis can but have implicit in its effect the requirement of succour and healing.

Increasingly as the 20th century draws to a close the role of primary health care distributors is becoming more obvious. This is most clearly seen in the increasing public demand for change of emphasis on a clearer definition of responsibility for psychiatric services and psychiatric patients. The new mental health bill is a case in point in that the rights of patients are more clearly defined, the legal safeguards against hypothetical mismanagement of patients strengthened and the regulation and restriction if not actually incarceration of patients carefully delimited. Likewise, the whole thrust of the Final Report of the Task Force on Child Care Services is in favour of support and minimal intervention. The point of these observations is that the public is demanding now that more and better treatment should be provided in the setting of community and family life.

General Considerations

It is of critical importance that professionals working with young people understand that there *are* important differences between the sexes reflected in the different aspects of development and functioning. The main headings used are physical, emotional, psychological and social. Boys are different from girls in all sorts of ways and there are many studies now, some of more recent origin which distinguish between the sexes on psychological and emotional factors. The developmental task accomplishments demanded of young people progressing from the pre-pubertal stage through to early adulthood have to be accomplished within a time space of some ten to fifteen years, depending upon the rate of the different areas of maturation. Girls usually reach maturity earlier than boys, on average about 2 years. Furthermore, they appear to be less likely than boys to have problems particularly problems of behaviour of an aggressive antisocial type. Girls usually begin to menstruate nowadays about the age of 12, this being a good deal earlier than was the case a century ago and boys too have their first nocturnal seminal emission by the age of 14, these two events being the so-called "markers" for the arrival at the stage of adolescence. Of course, for some time beforehand the family and those most immediately concerned with the young person in question will have become aware of his or her increasing size and sometimes disproportionate change of shape as well as of the emotional and social characteristics of the young person beginning to be adolescent. There are often changes in the quality of hair, the beginning of growth of hair in the pubic and axillary areas and not infrequently a change in the texture of the skin with spots, pimples and sweatiness becoming more of a problem. There is often an increase of interest in pursuits of adolescents, in this generation pop stars, the rock and punk music scene, football, tennis stars etc.

Throughout adolescence the different areas of development may not be in phase and can, as a consequence, cause difficulties for the individual who although not suffering any specific or handicapping disability but whose out-of-phasesness at that time is felt at least as a discomfort and indeed sometimes as a "handicap". For example, take the girl of 15 who has not yet begun to develop physically or who has only rudimentary breast and other secondary sexual characteristic development and who has not yet menstruated; who is nevertheless intelligent and aware of the difference between herself and her peers who are perhaps already beginning to socialize and go to discos in groups, beginning to talk in terms of dating and "going steady" etc. and who have for perhaps three years been menstruating. Likewise, the physically mature twelve year old boy who has already achieved an advanced state of adolescent physical development may be considerably socially disadvantaged, with his, as yet, physically immature peers. That same individual may by the age of 16 be passed out physically by his contemporaries and may then subsequently feel disadvantaged by virtue of the fact that he has been displaced as the biggest boy in the class, the one who is most sought after on team games etc. Parents and others may gain some sense of expectation of the young person's approach to adolescence by the so-called

growth spurt which is marked in the year before menstruation or seminal emission.

For those who are not intellectually retarded or handicapped the final period of cognitive development begins to emerge. This is what Piaget has called "formal operations". The major task in this period is for the young person to learn how to think about ideas as well as objects and consequently to be able to classify and organise ideas and manipulate them. In addition, another important feature of this stage is the young person's ability to search out systematically and methodically for answers to problems. The importance for young people to be able to proceed to this stage is exemplified by the experience of secondary education. Method in problem solving becomes critical and the trial and error approach of younger children, those still in the phase of "concrete operations" is clearly unsatisfactory. Thus, the intellectually handicapped, dull or slow child is delayed in the acquisition of the ability to use formal thinking operations perhaps permanently and as a consequence cannot be expected to cope with the intellectual tasks of secondary education. This is particularly important in the change from inductive to deductive logic. There are well known studies which show that many young people do not reach the stage of formal operations at all. This has clear implications for those working with young people, in schools, secondary, vocational and comprehensive and in training and work situations.

On the social and emotional aspects of development during this period, young people congregating in groups are more clearly seen to be mixed-sex rather than same-sex groups with for most teenagers individual coupling beginning to emerge towards the middle of the stage. Many commentators have accepted the idea of breaking adolescence up into three stages, *early*, *middle* and *late* with the last stage being represented by more intimate relationships between the sexes and the adoption by the young person of a personal identity, definition of an appropriate role and role-behaviour system. Sexual identity and sex roles become very obvious and, with boys, sex-role stereotyping emerging. The sex differences in incidents of atypical development have been categorised as follows.

Type of problem	Approximate ratio of males to females
School problems: Children testing below grade level in basic subjects	3 to 2
Physical handicaps —	
Visual problems	1 to 1
Hearing problems	5 to 4
Speech defects	3 to 2
Emotional Problems —	
Conduct disorders	5 to 1
Anxiety-withdrawal	2 or 3 to 1
Estimated number of children of all diagnoses seen at psychiatric clinics	2 to 1

At one time adolescence was believed by many commentators and professionals to be a time of exceptional difficulty and turmoil. Studies however indicate that this is not the case and while there is certainly a small absolute increase in the prevalence of emotional and conduct disorders in adolescence, the increase is not of very great significance. Allied to this finding was that of the reflection and exacerbation in adolescence of problems already in existence. The distinction was made that problems of an aggressive or other type of behaviour abnormality in adolescence are likely to be taken more seriously by society in general and parents and the police in particular because of the increased size of the individual concerned and the possibly more dangerous nature of their behaviour. The conclusion to be drawn from this work is that young people of 8 to 12 years already giving trouble can be expected to give trouble in adolescence if not attended to and the problems brought to the notice of their parents and guardians. Another study by Rutter has shown that difficult youngsters are more likely to be criticised by parents but a protective feature for young people is a strong secure relationship with a parent or another adult. This type of attachment preferably occurring early offers security and appears to "buffer" the child against later problems.

What happens to children and young people who are emotionally disabled? The concept of vulnerability, how children might be predicted to be vulnerable and how that vulnerability might manifest itself was a feature of the professional literature in child psychiatry of the '60s and '70s. The work of Bowlby on separation of young children from their care-givers, work of the Robertsons on the effect of traumatic experiences on young children by virtue of hospitalisation or other naturally occurring events in family life, and the studies of the neonatologists and infant researchers more recently, resulted in a dramatic change of orientation to the emotional welfare of very young children and infants and a number of follow-up studies of children who were at risk for emotional and social deviance because of lack of bonding or attachment to their mothers or care-givers early in life, and the presence of temperamental or actual organic and physical disabilities which might be expected to give rise to trouble later on. The studies clearly show that there is a risk attaching to early life problems; bonding failure, early and prolonged separation etc., but that these difficulties do not necessarily give rise to permanent and irreversible emotional and social disadvantage and that indeed the flexibility and plasticity of young children's minds and bodies is the more remarkable feature.

Other studies of importance in the last two decades have been the Temperament and Personality studies of Thomas, Chess and Birch, Graham and Rutter and others which have shown on the basis of prospect of longitudinal studies that there are temperamental differences between children which are observable in infancy and which are persistent. The definition of a "difficult" temperamental profile has been of great assistance in permitting the detection and understanding of irritable, emotionally labile, arbitrarily responsive young people who are frequently a trial to their parents and others. The interacting effect of the presence of such a child in a socially and materially disadvantaged family with punitive and rejecting parents

provided the recipe for serious behavioural deviance and psychopathology. The longitudinal study of Lee Robins revealed that conduct and behaviour disorders in young people was significant in discriminating between those who had poor adult life status outcome from those with good adult status outcome. Other studies (Malmivara A., et al, Weissg et al) show that poor concentration, impulsive cognitive style, difficult behaviour and specific learning disabilities which are sometimes found, produce academic failure, problems with teachers and peers and usually school failure. This contributing towards poor self-esteem and decreased motivation causes further problems and lack of expectation of approval and success.

Psychiatric Statistics

Studies of adolescent emotional disorder and "turmoil" show that the absolute increase of emotional and psychiatric disorder in adolescence is not great although present and that the vast majority of adolescents who have emotional and psychiatric problems, have already given evidence of such in their middle childhood. The Isle of Wight population was subsequently used again (Graham and Rutter 1973; Rutter et al 1976) when the total population of 2,000 14 and 15 year olds was screened on much the same basis as the younger children, using parent and teacher questionnaires. Psychiatric assessments were carried out on all who had a deviant score on the questionnaires and on a randomly selected group. The previous study also made available psychiatric assessments on 10 year old children and in addition, there were assessments made of the parents of the adolescents. What emerged was that psychiatric disorders were slightly commoner in adolescence than in middle childhood and the rates for adults were higher. The prevalence was estimated to be of the order of 10-15% and the researchers drew attention to the necessity to include adolescents who self-reported psychiatric symptomatology but who passed unnoticed by their parents and the school authorities. They suggested that when these young people were included, the prevalence would rise to around 21%. Chronic physical handicaps, especially including neurological educational retardation even higher. Other studies, which are remarkably few, indicate that in one Australian town, some 10% of children, 16% of adolescents and 24% of adults were diagnosed as showing psychiatric deviance and in Blackburn, in the north of England, serious disorders, resulting in clinical referral, were found to occur in 21% of boys and 14% of girls. Whole or representative figures for Ireland are not available. Some studies have shown that certain sections of the population, particularly those containing disadvantaged groups, have higher rates of childhood psychiatric disorder. Long-stage institutions, Children's Homes, Special Schools and the like have been studied and found to admit exceptional numbers of disturbed youngsters (McQuaid 1971, Barnes and O'Gorman 1978). These studies on boys in an Industrial School, St. Laurence's, Finglas, revealed that a high proportion of the boys had serious behaviour problems and/or psychiatric disorder in addition to below-normal physical characteristics and intellectual and academic attainment retardation. In common with the findings of Graham

and Rutter (1975), those of Warren (1965 a, b) show that the majority of psychiatric problems in the British adolescents were anxiety-states, depression or other affective abnormality, behaviour disorders and mixed behaviour and neurotic disorders. Significantly, and this is the experience of practitioners in Ireland, only a small number of young people in the population have psychotic disorders and do not tend to be found in any substantial numbers, even in mental hospitals. In the study of one year's admission to an Industrial School, McQuaid found a number of boys with a serious disturbance of thinking and affect, sufficient to warrant the diagnosis of psychosis. It is unlikely that such severely disturbed young people would now be missed in the pre-committal assessment which takes place in the Assessment Centre at Finglas.

Drug Abuse

Statistics for drug abuse in Ireland suggest that there is a small problem but one which is steadily growing. Characteristically, the features of drug abuse here are not unlike that of countries close to us, although happily, we do not have the more obvious and severe expression of the problem as is observed in the larger industrialised cities of North America, particularly amongst the disadvantaged and racially discriminated against. Of more importance here, perhaps, is the increasing amount of alcohol being consumed by younger adolescents of both sexes. The Stardust Disaster last Spring clearly demonstrated how under age drinking in groups in seemingly socially approved situations can occur, with disastrous results. Automobile accidents and other dangerous behaviours are all too frequently a consequence of such misuse of alcohol and the admixture of alcohol and drugs such as tranquillisers and stimulants are again increasingly a feature of teenage "drinking" in Ireland. As one who was working with some of the survivors and their friends and families of the Stardust Disaster, a feature of the general social mores and customs surrounding the event was the bland tolerance of excessive alcohol consumption.

Questioning a young person who drinks regularly and excessively, or uses drugs alone or with alcohol as to why they do so, a simplistic answer is usually forthcoming with seemingly not much thought to it. The young person will usually say that they enjoy drinking with their friends and that it gives them a sense of pleasure and relief. Behind that usually lies a considerable if not intense preoccupation with and fascination for the social scene which includes drinking and drug using. For many of these young people, the behaviour is a consequence of learning that a large number of unpleasant emotions such as depression, anxiety and guilt can be alleviated by use of various drugs. All of us who use drugs, including alcohol, for recreational and social purposes have to exert strong control over the tendency to use such agents for emotional and stress relief. It is precisely such control that the adolescent and particularly the young adolescent lacks. For that reason, traditional societies have imposed limitation and controls of impulses which are seen in adolescents — examples of this are the legal age for driving, for purchasing alcohol both in pubs and off-licensed premises, for leaving school etc etc. Anna Freud has pointed out

that, at puberty, "the danger which threatens the ego is that it may be submerged by the instincts; what it dreads above all is the quantity of instinct". (Freud A. 1936). The essential function of and progression through adolescence is to produce consolidation of the ego or that part of the personality which is in contact with reality which permits increasingly appropriate expressions of various instinctual needs. The developmental tasks of confronting adolescents, as already mentioned, include achieving independence from the parents, developing the capacity to feel love and be tender to others and eventually achieving a sense of identity which leads to productivity and a sense of belonging to a useful society which cares for its members. That type of eventual outcome of adolescence does not usually occur until the late teens and so, from early adolescence until that time supervision, support and structure have to be provided by the adolescent's care givers.

Some of the features of adolescent alcohol and drug abusers include premature separation and alienation from their parents with a seeming capacity for independence which covers great anxiety and insecurity. Throughout this time, parents tend to provide food, shelter, clothing and other necessities but the older the adolescent, the more likely they are to have shed such limitations on their freedom. Often they have moved away from the family home to live in communes, group situations or on their own with or without having achieved some measure of employment. The continuing control parents have over young adolescents in providing the necessities of life coupled with a clear and firm determination to know where the young person is, with whom, what they are doing, when they will be home, and forming, with other parents, a type of "psychological link-fence" around the group of same-age adolescents has been shown in the States to be an important intervention strategy to deal with early adolescent drug and alcohol abuse. The programme became known as the "DeKalt Families in Action". In Atlanta, Georgia, parents had become concerned about their children's deterioration in school performance and, because their children all attended the same school, were able to fairly quickly link up with each other. The basic ingredient of their programme was *firm external control* of the drug seeking behaviour of their children. They agreed on a strong stand against drug use and the children were told by their parents that they would not be allowed to use the drugs and this was followed by intensive surveillance. A common set of rules was developed by the parents which covered most social activities of the young people. In addition, they offered the children "constructive alternative recreational activities which did not involve drug use".

Anorexia Nervosa

This unusual condition, a self starvation syndrome, is increasing in the developed countries of the world. Treatment programmes vary from family-based family therapy intervention and support to full scale hospitalisation, massive restriction of the individual and application of Behaviour Modification techniques. Early onset of the illness, before 14 years, the presence of vomiting, laxative abuse, somatic complaints, obsessive,

compulsive traits and depression, longer duration and fixed personality problems have all been noted. In addition, poor childhood adjustment, disturbed family relations and bulimia were found significantly associated with poor outcome. However, Hilda Bruch has said that the outcome of the treatment is "entirely dependant on the therapist's capacity to understand one of the, perhaps, surprising features of anorexia nervosa outcome is that very often a sense of improvement, an appreciation of having been helped is not correlated with good outcome with persisting low weight, anorectic pattern of eating and other problems, particularly in the area of intrafamilial relationships". Depression and continuing anorexia has been demonstrated. The general trust of research findings is that the adolescent's capacity to master adolescent development tasks is a fairly accurate reflection of the likely outcome. Working with anorexics in units in which there are other adolescents and in which there is a developmental and psychotherapeutic approach as well as strong underlining of sociability would appear to be the best milieu to promote health after the initial danger of starvation has passed. However, fatalities occur. Separation from parent figures and quite lengthy treatment stays in residential units is the other important aspect of hospitalisation.

Attachment, loss and depression

Bowlby has already been referred to. His recent multi-volume publication on Attachment and Loss has great relevance to those who work with children and families in permitting recognition of the essential task for all humans. That is, to be able to cope with, on the one hand, the requirement for closeness and bonding which form the basis for personality development and, to tolerate separation and loss from and of the loved one on the other. Such loss may be psychological in the sense that the toddler experiences the departure of his or her mother or principal care-giver for any length of time or actual as the case may be for the individual who loses a parent, sibling or other "important other". Individual differences apply and for some the depth and intensity of attachments are very considerably greater than for others. The indications are that just as intelligence is distributed, the capacity to be hypersensitive or insensitive lie at opposite ends of the dimension in the middle of which the greater majority are to be found of those who have a capacity to feel which is average and therefore shared with the majority. Consequently, when one speaks of sadness, a sense of emptiness and loneliness, psychological pain, "separation-anxiety", the angst of being and the terrible fear and sadness that have to do with bereavement, most of us will know what that feels like. At around the age of 10, most children begin to be aware of the meaning of death and to have some sense of not being. At this time the anxious, sensitive or obsessional individual may begin to develop significant phobias and death phobia may be concealed by School Phobia or School Refusal. Earlier, anxious-clinging and other anxiety reactions to separation may be noticed as a common behavioural form and neurotic feature. Young people deprived of a parent have been shown to be at greater risk for depression in later adult life although they may not at the time have

shown any significant depression although exhibiting other behavioural or developmental deviations. Consequently, it is important for children who lose a parent to have available to them a counsellor or mental health professional who may be able to assist them in Grief Work. As the individual progresses through adolescence and into adult life, the psychological risk attaching to bereavement is lessened but by no means eliminated. Delayed grief reactions are a common experience of those who work with depressed individuals and those who are showing various other problems following the death of a loved one. The four phases of reaction to a bereavement — denial, anger and despair and assimilation are well known. Individuals having difficulties in coping with the departure of a loved one are usually those who have had a conflictful or ambivalent relationship with that individual and have denied and repressed the negative aspects of that relationship subsequently. Grief work and the treatment of those with unresolved grief reactions has to do with uncovering such conflictful emotional areas and to often prevent the idealisation of the departed so as to permit a more realistic combination and acceptance.

Intervention Strategies

The essential function of any helping agent or programme is firstly to clearly delineate the problem and define that in meaningful terms for the young person and the family. This commonly now requires the integrated approach of an Assessment Team comprising professionally trained social worker, educational or clinical psychologist and a child psychiatrist. The approach increasingly has a family bias and may include the additional input of speech and language consultants — therapists, school counsellors and teachers, and background referral data from family doctors, public health personnel and, in special cases, juvenile liaison officers, welfare officers of the Department of Justice, child care workers, religious and others who have contact with the young person in the first instance. Crisis Intervention is quite common resulting from the immediacy of self-poisoning, attempted suicide, drug and alcohol abuse, anti-social behaviour with law enforcement agent contact and other immediate and demanding circumstances. Many of the young people referred have been badly handled, either as a function of spoiling, sometimes covert and, on many other occasions, overt rejection, or excessive control and suppression. Enhancing of self-esteem, increasing competence, exploring new coping strategies, developing emotional resources, extending one's emotional boundaries and conscious awareness are all part of the treatment dispositions which have to be evaluated in the light of the individual and his family's capacity to stabilize and adjust. The homeostatic mechanism whereby a family reintegrates following disequilibrium, may allow for growth, or, on the other hand, premature closure of the "system" again, without the development of really useful life enhancing skills. Many "therapies" are extant and while those which pertain principally to adults are more obvious, they are also more widely practised in North America and flourish in North America increasingly.

Family Therapy techniques, Effectiveness Training Programmes,

Outward Bound Exercises, Group Therapy in its various forms, recreational activities and importantly, team games, well run Youth Clubs and related Youth Programmes and Guidance Counsellors are all part of the intervention model. Guidance Counsellors vocational assessment services such as the City of Dublin Vocational Education Committee Psychological Service, the National Rehabilitation Board with its connections with the Rehabilitation Institute and other vocational training centres, AnCO and its work preparation and training courses and many other similarly vocationally concerned operations are of tremendous benefit to young people. There are hazards now attaching to young people in Ireland by virtue of being young and in such numbers because of the economic climate, persistent and all pervading recession and the risk of loss of self-esteem and increasing frustration and apathy at the inability to find something useful to do. Such circumstances call upon all of the resources, enthusiasm and initiative of young people. We should enthusiastically help young people to promote their own interests which are so often to be seen in their caring for and work with others who are less well situated than themselves.

Behaviour and Character Disorders, those young people with anti-social manifestations, drug abusers and psychopathic personalities generally require a more structured and specific style of intervention and usually require in some way to be singled out and separated from their peer groups. It can be extremely difficult to intervene in some cases, particularly where there is a lack of parental interest or supervision or where the family relationships are so disorganised, skewed or absent as to be ineffective. There are some families who do not want the sort of help described above, there are some who say they do but don't and there are some who do, and try very hard to benefit but fail for all sorts of other reasons, many of them relating to "professional distance", dis-interest or failure of continuity. Some young people are vulnerable anyway, constitutionally and by virtue of heredity and there are social groups which defy all middle class control. The best hope for our young people lies in the continued enthusiasm, concern and dedication of so many professionals and others who work for their future welfare and who retain an optimism which may border on the delusional.

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2

Anne Lyons

The period of adolescence and young adulthood encompasses what is probably the most critical step in the life of the handicapped youngster — the transition from school to the adult community. This brief paper will focus on transition, with particular reference to social and emotional development as a vital component of successful adaptation. I will attempt to pinpoint some of the gaps in provision, rather than detail the excellent work that is going on.

It is generally accepted and well researched that social competence and personal maturity are an all important ingredient of adult adjustment, including work adjustment. For young people entering on a rehabilitation programme, it is just as important, or more important to teach skills that will maximise social and personal functioning, as it is to teach work-related adjustment skills. To date, however, the emphasis has been on work. While a number of centres have excellent programmes, in many, this facet of the rehabilitation process has been dealt with on a laissez-faire basis, or ignored altogether. Approaches to social development lack the precision, the structure, the tools and the resources devoted to work adjustment and preparation.

What are the outline elements and pre-requisites of such a programme? I would suggest that such a programme should contain three overlapping elements:—

- (i) social adjustment — imparting the skills which will enable the young person to participate effectively as a member of a group in various social settings;
- (ii) personal development and adjustment — development of essential skills of decision-making, self awareness, self acceptance, as well as areas such as appearance, mannerisms;
- (iii) community adjustment — imparting the skills which will enable the youngster to use community resources as effectively as possible.

I would identify a tendency in many centres and schools to concentrate on the last of these — community adjustment — and devote little time and resources to the first two.

PRE-REQUISITES FOR EFFECTIVENESS

1. Reality-Testing

Social training programmes which take place entirely within the confines and environment of a rehabilitation setting, school or institution run the risk of failure. The need for such programmes to take place, or at least to be tested out, in non-sheltered settings and with the participation of non-handicapped young counterparts has been well documented. Feedback on the usefulness and the direction of the programme is essential, and difficult to get in any other way.

2. Parental/Family Involvement

While reasonable efforts are made to inform parents about programmes and goals, I would identify a much greater level of involvement as being essential to success. Even if professionals had the time and the willingness to involve parents in training programmes, this remains a complex issue. Parental expectations may well have been shaped through earlier experiences into adopting a passive role, dependency may have been fostered to the extent that parents may be unwilling to accept a new and higher level of involvement during the teenage years. As well, there would be particular difficulties to be solved. Nonetheless, if family involvement is crucial then these problems must be tackled and solved.

3. Readiness to participate.
4. Programmes planned to meet individual needs.
5. Programmes which take account of the particular community environment: e.g.
 - inner city children;
 - young people in remote rural areas;
 - young people who have been in trouble with the law.

6. Importance of follow-up programmes into the community

This very important aspect of provision is the one that suffers most, in the Youth Employment Service, when staff resources are tight. This limits the chances both of picking up problems in time and of giving essential feedback to schools and centres.

CONSTRAINTS

What are the constraints on achieving a balance between programming for social/emotional development and work programmes?

1. Resources — availability of staff resources.
2. Availability of training in adjustment techniques pertinent to the

needs of the handicapped adolescent, and to specific groups — mentally handicapped, deaf, cerebral palsied, epileptic.

3. A clear vision of the type and level of resources needed, nationally, for this work is essential. Do we need more counsellors or a greater emphasis on social development in training courses for rehabilitation and educational personnel? Even in the States, where adjustment counselling, as an independent profession has been developing apace for many years, there is still much dissatisfaction with the slow development of the profession. We may not wish to take that particular road, but we must take some road.

The task of the rehabilitation agencies will be made much simpler if educational programmes have given a high priority to social and personal development. The programme elements and pre-requisites for effectiveness already outlined have equal application at this level. Much excellent work is being done, particularly in schools for the mildly handicapped, where good social and pre-vocational programmes are in operation in many schools. Work experience, and other types of reality testing are built into these programmes. In planning for integrated education, then, every effort should be made to guarantee that an equally high priority be given in curriculum planning and resource allocation for social and personal development in the normal school.

It has been our experience that young people whose needs have not been met in this area present an extremely difficult challenge to the Youth Employment Adviser. Their level of passivity and dependence makes them unable to participate meaningfully in the process of vocational planning. The Youth Employment Adviser is then faced with the choice of entering on a lengthy process of attempting to motivate the young person, to interest them in taking responsibility for their own lives and decisions, or else to re-inforce the earlier experience by being very directive, in the hope that the next stage of the process, the training centre, will build the lacking personal skills.

1st RECOMMENDATION

That a working party, representative of educational, rehabilitation and consumer interests be set up to recommend a framework for social development programmes and services. The working party might examine successful programmes at home and abroad, up-to-date techniques, staffing needs, staff training needs. The working party would take account of particular regional and local factors.

I would like now to refer to another dimension of integration, which is particularly relevant to the disabled school leaver — that of the need for a much closer integration of educational and vocational planning.

A recently published British study examines the educational and vocational experience of handicapped school-leavers in nine local authorities and measures to assist them into work. This study suggests that

they may be better off if they have not been integrated into normal schools.

The most employable of those leaving special schools are more likely to find and keep jobs than handicapped children leaving comprehensive schools. They even do better than those in the ability range above them in the remedial streams. The study concludes, not surprisingly, that this is almost certainly because more specialist help is provided in special schools. The study which is the British submission for the O.E.C.D. project "The Handicapped Adolescent" deserves close examination.

The finding, is not necessarily an argument against integrated education, but it is certainly an argument for the closest co-ordination between specialist vocational agencies and those planning for integrated education. This is essential if very praiseworthy but short-term educational and social goals, are not to cut across longer-term goals of vocational and social adjustment in adult life.

2nd RECOMMENDATION

That the need for formal structures aimed at co-ordinating planning for education and rehabilitation services be examined by the relevant agencies.

A recent working paper emanating from Brussels entitled — "Foundations and Guidelines for a Community Action Programme on the Lifelong Education and Training of Handicapped People", gives great ground for optimism.

This paper sets out in detail the basis for a new community action programme on the education and training of the handicapped, which it is planned to launch later this year and implement from 1982 onwards.

The document refers to the recent allocation of education to the portfolio of the Commissioner responsible for employment and social affairs. It suggests that, as a result of this development there exists "at least the potentiality of the Community's being able to take the lead in coherent treatment of two domains, the segregation of which has been for so long a source of frustration and failure throughout the community".

This exciting breakthrough at European level adds urgency to my recommendation, if we are to take full advantage of the proposed action programme.

As well as the need for a planning mechanism which would integrate planning for education and vocational training of disabled young people we should look carefully at the benefit which could accrue to them if existing and proposed planning structures were extended to take account of their needs. I mention a few:

- the curriculum council proposed in the recent White Paper on Education. Its aim is to extend the framework of consultation available to the Department of Education. There is a strong case for extending that consultation to take account of the curricular needs of disabled students.

- Youth Employment agency, being established by the Government. Its structure must allow for representation of the interests of the disabled school leaver.
- The Manpower Consultative Committee; this committee recently published a report on youth employment. The value of having the interests of disabled young people represented on these wider planning fora is exemplified in this committee. One of its major recommendations was for a Youth Pledge Scheme, whereby young people unemployed for one year will be regarded as priority clients for training and work experience programmes. A commitment was sought and got that N.R.B. would be involved at the planning stage in order to ensure equal opportunity for disabled young people. While this may not seem a major step, it is nonetheless a step in the right direction.
- The Training and Educational Liaison Committee, set up by the Department of Education and Labour. A number of educational projects could usefully be geared to take account of disabled students.
- The proposed Preparation Programmes for working life referred to in the White Paper. "The Department will initiate, on a pilot basis, career orientated courses which will aim at providing a range of basic career skills." All such alternative courses should have elements of general education, social and personal development and work experience, or observation.
- The Spiral Programme, being undertaken by the Curriculum Development Centre, Shannon. This is an action research programme whose central theme is to facilitate transition, through planned interaction with the local community.

Underlying most of what I have said, and indeed underlying most of what is said and written about every aspect of integration, there is the assumption that exists out there beyond the school and beyond the training centre, a workplace and an active community into which young people can and wish to integrate. The work ethic in particular underpins the philosophy of schools, rehabilitation facilities, and other august and influential bodies such as the European Social Fund. The strength of the work ethic in our society is one of the reasons why work adjustment has eclipsed social and personal adjustment in rehabilitation services to the extent that it has.

For those severely disabled young people who have, in spite of their difficulties, coped successfully with education and examinations in a normal school, with its inbuilt expectation of jobs for all at the end of the day, the intensity of the crisis of transition to a life without work and suddenly cut off from peers defies description. The Youth Employment Adviser, faced with the task of counselling youngster and family towards an acceptance of the stark reality of an ever more total dependence on the State, is doomed to failure. Even if sheltered employment is available, the

very notion is anathema to a youngster used to a measure of community living. Day care — the very term emphasises their dependence and limitations. This group, whose number is small but whose need is very great — may ironically, benefit from the growth in numbers of young unemployed in our post industrial society. The ethos of schools and training strategies may change to take account of the need for what the Warnock Report termed “significant living without work”.

While most would agree that the acquisition of personal skills leading to expanded personal independence are legitimate goals which can be, and for this group, must be independent of vocational placement, there is little recognition of this in the structure of services.

Imaginative alternatives for their post-school provision and educational programmes relevant to their life situation need to be provided as a matter of urgency. This leads to the third and final recommendation.

3rd RECOMMENDATION

That the particular educational and post-school needs of handicapped young people unlikely to find open or sheltered employment be examined jointly by the agencies concerned with their welfare.

OTHER AREAS OF PROVISION

There are a number of other areas of provision for the handicapped young person which warrant examination. These will be mentioned briefly:

1. Further education provision for handicapped young people.
2. Provision for the early leaver, the 15 year old, or indeed the 13 or 14 year old, too young to avail of any rehabilitation facility, and with little hope of getting work.
3. (a) Take-up of third level education by handicapped students;
(b) Facilities at third level to meet their special needs.

In summary, I would refer again to the three recommendations made. These recommendations overlap to some degree. The common factor is the need for integrated thinking on many issues concerning disabled young people on the part of the many agencies planning and providing service. This, along with full and meaningful consultation with the “consumer”, I would see as pre-requisites for effective action.

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3

Desmond Kenny

Most of the thoughts I shall present in this paper have had their origins in my own experiences as a disabled person, and in my own impressions of how disability has influenced the lives and the life-styles of other disabled people with whom I have talked. "The disabled" or "The handicapped" is a term used to embrace all disabled people because of their common need for help or intervention services. The way the term is used at times conveys a false impression of common needs and a common psychology for people from diverse backgrounds, experiencing the full range of disabilities or impairments of function we label handicap or disability.

I am not denying that there is a common ground of sorts existing between all the categories of disabled groups, and I would number myself among those people who would advocate greater recognition of this fact with a view to the increased acceptance of a need for generic services — but I will not accept that all disabled people should be compounded into a common denominator which suggests a unique group-psychology for disability and fixes all disabled people as living in quasi-ghettos of a disability type or classification. Of course being disabled makes a difference for the person or his or her family. But so also does a teenage pregnancy, drug abuse and the other elements of happenings which are not regarded as being normal — and "normal" is the calvary on which difference is too often crucified as a deviant strain.

Without contradicting my own logic regarding the absence of a group-psychology for disabled people and denying the existence of quasi-ghettos, I shall be talking about them in this paper where I believe such special characteristics to exist. However I shall be regarding them as being artificially imposed. My impressions and comments relate substantially to a minority of disabled people (perhaps a large minority) a minority who go through special schooling and who have either physical or sensory disabilities.

At the time of adolescence a sense of urgency and a state of anxiety co-exist and conflict in the maturing person. This growing stage of being not quite a child and not quite an adult is made the more emotionally acute when it is accompanied by the realisation that one is also not quite normal. All young people have a right to the excitement of fantasy. They have a need to burn their fingers on the sun before they are satisfied with the reality of constraints. In one way or another our society generally has a tolerance for teenage escapology..

Disabled teenagers, on the other hand, are given very little manoeuvrability in terms of day dreams and make-beliefs. The intervention structures we design for them can (and do) at the same time both support and arrest the growth of individuality. Nowhere is this more obvious than in the special school, particularly the special school which students attend to the age of eighteen years. Special schools, it would appear to me, emphasise or lay stress on those parts of the curriculum which the teaching staff regard as being "appropriate" to the employment scope open to specific disabilities. There is a sense of total awareness of what is or is not possible in employment terms, and this reality is conveyed to teenagers when they are becoming aware of their social identity as it revolves around employment and marriage. Potential is pitched in its ultimate at proven levels of achievement of others with a similar disability. Potential, therefore, is replaced by a processing capacity, with people being directed towards the employment rather than the employment considered after the person's learning potential has been fully developed — idealistic perhaps. But adolescents are naturally idealistic and will refuse to achieve if objectives fall below the idealism threshold.

The further segregating of disabled students on grounds of sex makes sexuality an additional consideration of normal adolescent development which special schools in the past have ignored. For some disabled people to whom normal heterosexual relationships may be impossible, alternative sexual expression should be recognised as being legitimate within certain bounds.

So we have an adolescent disabled person in a special school who is being steered in a given direction dictated by known realities. There is a little bit more, however. The disabled person knows he is being steered and why he is being steered, but cannot accept the pattern of logic of what is being done on his behalf. Few people can imagine the storm of frustration which buffets the disabled adolescent as he comes to terms with himself as a new physical being who for the rest of his conscious existence will be made aware of his disability and have limitations put upon his ability. This placing of limitations on ability was probably happening for a long time before adolescence, but only at such a critical time does it start to take on any significant importance.

If the special school is a residential one, the significance and importance of limitations being imposed may be less acute for the time being because of the protective insular nature of all boarding schools. In a residential school, it is easy for a disabled person to see himself in a new importance in relationship with his fellow-disabled students. I believe that an awareness of one's disability can accelerate the psychological, developmental process, leading to an early maturity where the person is more serious and more sensitive than his able-bodied peers. Equally, however, awareness of one's disability can cause a retreat into the world of one's disability type. You might call them quasi-ghettos. Whatever the name given to this mental retreat, it cannot be denied that comfort and companionship can be had from one's own kind. Disability becomes the normal and the able-bodied are regarded as being the "outsiders". This

form of group-identity can slow down the maturing process, for in a small, insular world it is easier for a one-eyed man to become a king in the valley of the blind. Weakness plus weakness does not equal strength but it can equal security and that in itself is a form of psychological support.

Care must be taken to help disabled people leaving special schools to ensure that they are adequately supported when adjusting into the post-school community. A disabled school-leaver, coming from a closed and sheltered environment, can find himself dropped suddenly from the ladder of relative success to the floor of a poor-achiever. I have met people who between the ages of eighteen and twenty-three have had to seek psychiatric help in coming to terms with themselves and their new roles as employees in jobs not measuring up to the expectations and as members of a society in which they felt alienated from the social life of their able-bodied peer group. It may be readily known to those of us involved in the provision of support and intervention services that a network of services is available, capable of meeting most if not all the help-requirements of disabled people, particularly at times of major cross-roads in their lives. I would suggest that the same panoramic view of inter-locking services is not shared by young disabled people. Nor do the same young people share the same appreciation of delays we have come to regard as normal time-lapses as movement is effected between the various stages of help.

I have heard people talk of the expressed frustrations of disabled people in a disparaging way as though frustration shouldn't exist — as though disabled people manufactured annoyance or aggression out of a perverse sense of malice. The disabled person may be referred to euphemistically as "having a chip on his shoulder". People forget that being done-good-to also hands the recipient of help a magnifying glass of questioning purpose. Allied with the cynism from disappointments and broken promises, this casts those of us in the delivery end of services in a dubious light. The disabled person may have difficulty seeing whether we are there for his assistance or he has come to be one of the many who assist us in retaining the job that helps them but never adequately attends to him. Disability can sometimes result in the accelerated psychological development of a young person. For the helper to ignore that possibility will result in his being unable to establish a true rapport with the disabled person.

Young disabled people may experience one of two forms of frustration. The frustration which is the inarticulate confusion of purpose and direction that attempts to find a language of meaning is mainly the experience of the less-mature disabled person. The other form of frustration stems from an over-maturity or imbalance of maturity caused by my suggested acceleration of the psychological cycle in some disabled people who have a high degree of "uncertain self-image" which seeks recognition and approval before it can become confident. However, frustrations are not viewed generally in such important terms and that is why we too readily write them off as the manifestations of "chips on shoulders" and so forth.

Before making my concluding remarks on the disabled person during adolescence and young adulthood, I want to go back to segregation and

specialisation. I touched on it in passing when I mentioned a need for greater recognition of the value of generic services. Specialisation in specific disabilities does undoubtedly allow a service to apply all of its resources to meeting needs and wants associated with a specific disability. However, I am convinced that at a certain stage (I don't know when it is arrived at) the need to compensate or provide compensatory disciplines for a disability comes into conflict with emotional wants that exclusive specialisation cannot meet.

If a disability is not sufficiently severe to prevent a disabled person living most of his life outside of an institution or formal disability servicing structure, why at certain times take him into these structures instead of seeing the provisions of exclusive services as having the capacity of being met in inclusive disabled/able-bodied settings? I believe that you cannot take disabled children out of society without paying the price of integration difficulties when they are re-introduced to society as disabled adolescents or young adults.

In my concluding remarks I must make some observations on my own observations and leave some brief recommendations on how we should go about helping disabled people through their emotional difficulties. My first recommendation would be to avoid as far as is possible segregating disabled people from non-disabled people. However, in pursuing a policy of integration, discreet support services may be required, and these should at all times be provided off-stage to the performance of the integrated activity.

Secondly: where specialisation must remove disabled people from mainstream society for purposes of intensive training, such exclusive services must be more aware that they are dealing with a whole person by making more provisions for the emotional development of disabled people — not as a clinical exercise, I would add, but as an integral philosophy of approach in the delivery of all aspects of services.

Thirdly: while it might be infinitely more practical to tell or counsel disabled people as to what they can or cannot achieve in terms of optimum job-opportunities, it might be of more benefit to them in the long-term were they themselves to be given the opportunity of applying reality to their aspirations. I would suggest that services "explore" with disabled people the viability of their ambitions by initiating "work-experiment" schemes that would allow disabled people to test their own capabilities or lack of them. The conclusions they arrive at may ninety-nine times out of a hundred concur with what we could have told them. But the discovery for themselves will make for better job-satisfaction in the work found for them. There is that 1% which could lift the job-opportunities horizon by surprising us all.

Fourthly, and lastly, I would urge those of us involved in the provision of services to remember that the confidence of a disabled person is more fragile than it sometimes appears to be. The reason for this is, I believe, that the more successful a disabled person becomes in objectively mastering the limitations of his own disability, the more subjectively critical he becomes of his own achievements which would have been greater but for the limiting factor of his disability. There is always a feeling of loss arising from being

disabled, and the more one has to compensate for the limitations arising from disability, the more one becomes aware of that feeling of loss and requires reassurance and encouragement which the exterior surface of confidence belies as a requirement.

It is difficult to talk about the period in the lives of other disabled people without recognising that it is only now that I can put a sense of proportion on the "hell" of my own adolescence and young adulthood. I have not named all the devils of that period but the devils I have named I have put forward in this paper as influences surrounding a vulnerable time for us all and a time of such magnitude in the life of a disabled person.

Des Kenny

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CHAPTER FIVE

Sexuality and Disability

1

Liam A. O'hEigarta

It seems necessary to set down a number of basic biological facts if we are to view man from the perspective of his sexual nature. There appears to me to be a danger that unless the biological basis for sexuality is brought into proper focus, it may be lost sight of under the cloud of accumulated wisdom, personal opinion and emotion which can sometimes characterise debates on this particular topic. The facts are simply stated. All living things need to have the ability to reproduce if their species is to survive. Some organisms perform this necessary function asexually. Their reproduction is not dependent on the fusion of separate male and female sex cells. Asexual reproduction occurs throughout the plant kingdom. Primitive unicellular and multi-cellular plants propagate themselves in this fashion. Even higher flowering plants, which have specialised to reproduce sexually, have also adapted to reproduce asexually. Common examples of this are strawberries propagating by means of runners, daffodils by means of bulbs, and potatoes by means of tubers. Most forms of animal life reproduce sexually. One exception to this rule is the unicellular amoeba which creates new life by the seemingly simple expedient of splitting in two. A rather odd example of asexual reproduction in a more highly developed animal is the planarian or flat worm. This curious creature reproduces by attaching itself to a fixed surface and pulling itself in two: the part which contains the tail proceeds to develop a head and the part containing the head grows a tail. You may think this procedure rather strange — I wonder what the flat worm might think of our system. The existence of hermaphrodite forms of life, each organism containing both male and female sex organs, some self-fertilising and others cross-fertilising, adds yet another string to Nature's bow. Earthworms, for instance, are hermaphrodites and when they couple, each earthworm fertilises the eggs of the other.

Man, in common with all mammals, reproduces sexually. He does not split in two, send out runners, grow bulbs or tubers or tear himself apart in

order to ensure the survival of his species. His survival depends on the fusion of separate male and female sex cells, each produced by a different parent. Put in another way, the human race may be divided into two distinct groups, male and female, in accordance with the role each plays in the process of reproduction. One wonders why Nature thought it necessary to develop male and female, if reproduction can be brought about equally successfully by asexual means. The same question must have been troubling Lord Chesterfield when he stated that sexual activity wasn't really all it was made out to be, on the grounds that "the pleasure is momentary, the position ridiculous, and the expense damnable!" Despite these understandable reservations, however, it must be stated that, from a biological point of view, sexual reproduction has made a major contribution to the evolution of species. It has led to far greater genetic variation among offspring, thereby ensuring adaptation to changing environments by some individual members and, therefore, to the survival and development of species. Anybody who has experienced a sexual relationship must also agree that it makes life so much more interesting and enriched. How dull life would be without love songs, the Mona Lisa, falling in love, falling out of love, weddings, honeymoons, christenings!

Man may share a common physical sexuality with many other living organisms. There, however, sexual similarity stops and enormous differences between the sexuality of man and the sexuality of other animals emerge. Man is the most highly developed creature ever to have trod the earth, not in physical terms but in terms of his ability to adapt. He spans the earth from Pole to Pole, surviving in all the extremes of environmental conditions. He has shot himself into space and walked upon the moon. His success is not due to his physical development, but mainly to his ability to reason, to draw conclusions, to foresee the outcome of his actions, to solve problems, to communicate in sound symbols, to record and pass on to succeeding generations the accumulation of his wisdom. He is also an animal who feels, who is capable of experiencing a wide range of variety of emotions and whose feelings can affect his behaviour. He has worked out codes of values by which he lives, being able to judge his actions as being "good" or "bad" against the yardstick of his value-system. He is a gregarious being, who likes living in groups and so as to maintain order and stability within his social groupings he has developed sets of rules by which his social behaviour is regulated. He has even projected the existence of a higher state of life beyond the human and terrestrial to which he aspires after his inevitable death. He is physical, certainly, but he is also intelligent, emotional, moral, social and sometimes religious. Man's sexuality cannot validly be considered in isolation from all these diverse but complementary aspects of his functioning. In suggesting ways as to how his sexual development may be advanced, these factors must also be taken into account. It is not simply a matter of ensuring that he develops to full physical sexual maturity, allowing him to discover or telling him the facts of life and letting him get on with it. Development as a sexual human being must also imply development as an intelligent, emotional, social, moral and, perhaps, religious sexual being. In order to function as a mature sexual human being, therefore, one needs to understand the biological basis of sexuality, to anticipate the outcome of one's sexual actions, to give and receive love in a stable relationship, to

conform to a code of behaviour determined by an inbuilt value-system, to make provision for the upbringing of children in a secure and caring environment. Sexuality in man has the dual aims of reproduction and self-fulfilment. Placed in this perspective, sexual development is a complex process indeed. It is in this context that the sexual development of disabled is a complex process indeed. It is in this context that the sexual development of disabled persons must be viewed.

The family, itself a social unit which has grown directly out of man's sexual nature, and out of the long term dependency of children, is the primary agent for promoting sexual development. In this setting, learning can continue over a long period as is required by the slow maturation of the human young, the child's changing needs being met at varying levels as he grows to maturity. The family constitutes a social entity of which the child himself forms a part, where man's sexual nature in all its aspects is given full expression. Here, the young child is made gradually aware of male and female differences. He comes to realise that he belongs to one of these groupings. He learns to identify with and model himself on the parent and on other people of the same sex as himself. He learns to become a person capable of giving and receiving love, through the experience of his parents' love for him and his reciprocated love for them. He comes to appreciate that a special relationship exists between his father and mother. He is free to observe their outward signs of affection for one another and to accept these as a natural part of human behaviour. He notes the complementary roles which they play in maintaining the fabric of the home and family. He internalises a system of values by which his behaviour, including his sexual behaviour, comes to be governed. During his adolescent years, the family provides him with the security and the stability which he requires as he begins to assert himself, to search for self-identity, and alternately to accept and to reject the demands which he sees are about to be made on him by his impending adulthood. Good relationships and an open approach to sexual matters will enable him to come to terms with, to control and to rechannel his sexual drive during these difficult years.

In a family which accepts its responsibility for promoting sexual development, the child's natural curiosity about sex is satisfied by answering his questions always truthfully and in such detail as he requires at the various stages of his development. Questions might be prompted by, for example, observation of physical differences between males and females within the family, development of primary and secondary physical sexual characteristics, pregnancies and births of young to domestic, farm or wild animals could be used to provoke discussion. Suitable opportunities, such as bedtime or bathtime could be availed of to develop the child's insights. The child should not be left with the impression that sex is a taboo subject. Frank, open discussion on an on-going basis, where possible involving both parents and perhaps even a number of children together, is considered to be the most natural and effective approach. The sudden walk in the woods with father or the sit-down session with mother for a "Talk" with a capital "T" may serve only to confirm the child's view of sex as being taboo, if the groundwork has not been properly laid and the atmosphere for frank, open discussion already created.

When to begin, where to begin, and how far one should go in imparting information on the physical aspect of sexual behaviour are questions with which many parents experience difficulty. It is now widely accepted that children should know the basic facts of human reproduction before the onset of puberty. This is particularly relevant in teaching girls about menstruation. This approach enables them to view the facts objectively as not yet relating to themselves, and their consideration of them is not clouded by an overlay of emotional barriers. Parents and other educators have found it helpful to conceptualise the physical processes in the form of a cycle, extending from pregnancy and birth, through growth to physical sexual maturity, to mating, fertilisation and conception. The young child's questions are likely to arise from the experience of pregnancy and birth, at which stage he is given such information as he is capable of understanding on the growth of a baby in the mother's womb, and on birth. Later, as he notes the development of male and female sex organs, he can be informed of their function in such detail as he might require. At this stage, he would not need to understand the mechanics of sexual intercourse: he would be told that when the father and mother feel loving towards one another in bed, seed passes from the father's body to the mother's, which may or may not cause one of her eggs to grow into a baby. At a later stage still, when he is thought to have reached an appropriate level of intellectual and emotional maturity, or when he poses the question, he would be told in more detail, about sexual intercourse. Emphasis would be placed on the loving nature of the relationship and he would be led to understand that this activity gives the man and woman great pleasure and that it is one of the ways in which they show their love for one another. It should be engaged in only by married couples who are in a position to provide a family unit for the children who might be born of the union. Parents often experience difficulty in what they see as "confessing" to their child that they themselves regularly engage in sexual intercourse. In a family where sex is presented and accepted as an integral part of life and love, the child readily comes to terms with the fact that his parents should express their love for one another physically as well as in the many other ways which he has observed as he grows up.

The school may be seen as the second main agent in the fostering of sexual development. Its proper role is to complement, not to replace, the home. Unfortunately, possibly in decreasing numbers, some homes are either not capable or willing to fulfil their responsibilities in this area. This means, that, in such instances, the full onus of responsibility falls on the school where the school is willing to accept such responsibility. The school has a peculiar and specific contribution to make to the sexual development of pupils, different from that of the home. It provides the pupil with a setting where he discovers that he is not alone in wishing to gain enlightenment into his sexual nature. He can share his problems and difficulties of adolescence with his peer group in a setting which is less emotionally charged than the home. An informed, responsive teacher can do much to allay the doubts and fears of the maturing young person, provided that the structure for such interaction is properly devised as an

integral part of school activity. The pupil can gain clarification of facts only partially understood or possibly not fully explained in the home setting. In mixed schools, or in single-sex schools where special provision is made (e.g. inter-school discos, debates, social work, shared facilities), he can learn to interact socially with members of the opposite sex outside of his own family.

Whether schools should embark on programmes in sex education must remain a matter for decision by each school authority. Many post-primary schools provide such programmes in Ireland. I know of no primary school which does but, no doubt, some do exist. Some special schools have made very promising advances in this area in recent years.

I will confine myself to enunciating a few general principles which I see as being necessary if the school is to fulfil its role properly.

1. Because the family is the ideal setting for promoting sexual development and the parents the primary educators, a school should not embark on a programme without first consulting parents. They would be informed of the school's objectives and the approaches to be adopted in order that these objectives might be realised. They would be invited to co-operate insofar as they are able in supporting the work of the School in the home setting. Very often, parents welcome an initiative from the school in that it acts as a catalyst which provokes more open discussion on sexual matters in the home. When parents express the wish that their child would not participate in a sex education programme, their wishes should be respected. Skilled counselling may enable such parents to gain an insight into the desirability of having home and school co-operating in advancing their child's sexual development.
2. Sex education in schools should not be a once-off affair. It should not merely consist of a "talk for the senior pupils" nor of the mere showing of a film or the playing of a cassette tape. It could involve all of these, but should be an on-going, cumulative process which would meet the changing needs of the child as he develops to maturity. The physical facts of sexual behaviour would be gradually unfolded over a period of time, taking perhaps two or three years to cover in the desired detail the cycle from pregnancy and birth, through physical development and on to sexual intercourse and fertilisation. Decisions as to the detail and the order in which these facts are to be presented at any given stage can be taken only in the light of the particular circumstances of each school and of its pupils. Sex education seen as an on-going, cumulative process has clear implications for school organisation.
3. Sex education in schools is not simply a matter of describing the physical facts. Biology alone is not sex education. Biology has been decried as "sex education for rabbits". If pupils are to be

enabled to develop into mature sexual human beings, then their sex education must take account also of the emotional, social and moral aspects of their sexuality. In schools where religion forms a part of school programmes, a religious dimension can be given to sexuality by presenting human love as an extension of God's love and procreation as a sharing in God's creative powers. Even in schools which are totally secular in outlook, sex education implies the development of a sense of the sacredness of life and of wonder at man's ability to recreate new life from his own mortal body and the realisation that the unborn child is alive and has the right to life. If schools are to acknowledge the multi-dimensional nature of sex education properly presented, additional organisational implications follow. Post-primary schools have succeeded in giving recognition to this principle by involving a team of teachers (e.g. school counsellor plus biology teacher plus teacher of religion) in this process.

The immediate concern here is the sexual development of disabled persons. Disabled persons are persons first. Their disablement is a secondary consideration. Nowhere more than in the field of sexual development does this hold true. As persons, they are either male or female. Those who work with and for disabled people may consider it unnecessary to emphasise such an obvious truth. Yet, it is sometimes difficult to escape the conclusion that disabled people are seen as a sort of "third sex" — men, women and the disabled. One hears them described as homogenous: "They"; "They like..."; "They prefer...". Many share my concern that the individuality of each disabled person can be swamped under the wave of the all-embracing "they". I am suggesting that it should also be a source of concern to us that their sexuality, their maleness or their femaleness, may be lost sight of and ignored in our well-intentioned enthusiasm to cater for them as a separate social sub-group.

Furthermore, the secondary consideration that they are disabled in one way or another may serve to overshadow the fact that the majority of them do develop to sexual maturity, in the physical sense at least. One readily understands the difficulty some parents may experience in accepting that their otherwise dependent adolescent is nevertheless sexually physically mature. It does the disabled no service to regard them as a group of sexless Peter Pans. If we accept that they have a right to achieve their potential in other aspects of their development, it is at best inconsistent, at worst inequitable, that we would not equally seek to foster their development as sexual persons. Because of intellectual, emotional, social, economic and moral limitations, only the few can hope to aspire to the fulfilment of a full sexual relationship. This minority are entitled to expect the full backing of society in endeavouring to attain this goal. All disabled persons, however, should be assisted to attain the level of proficiency in which they are capable of: —

1. Seeing themselves as either male or female.

2. Identifying with and modelling themselves on suitable models of their own sex.
3. Inter-relating socially with members of the opposite sex.
4. Understanding the biological basis of sexuality.
5. Coming to terms with the physical and emotional implications of their sexuality.
6. Behaving responsibly and with dignity in sexual matters.

The means of bringing about the realisation of these objectives by disabled persons are, I suggest, quite the same as those already advocated for the abled in this paper. Clearly, modifications will need to be made so as to take account of intellectual, emotional or physical impairments. Nevertheless, I would propose that the principles already expounded above in respect of the abled, apply with equal validity to the sexual development of the disabled. These may be summarised as: -

1. The home is the primary agent for promoting sexual development.
2. The school's role is to complement the work of the home.
3. In both home and school, any approach designed to foster sexual development would need to be (a) ongoing or cumulative and (b) multi-dimensional.

This short paper has attempted to outline the background against which the sexual development of disabled persons might be viewed. It has endeavoured to set sexual development in the context of overall development. It has sketched out in broad detail the complementary roles of the home and school in the process. It has suggested that whatever approaches we may devise to fostering sexual development should be both cumulative and multi-dimensional. It has proposed that these principles should also be applied to the sexual development of disabled persons.

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2

Sean Buckley

*A Programme of Human Relationships — St. John's Special School,
Augustine St., Dublin 8.*

1. St. John's is a day school for boys and girls aged 4-18 years. All of our pupils have learning difficulties in the 'mild' range. (I.Q. terms 50-75 approx.)

2. The Warnock Report (1978) defined the aims of education as follows: —

"To enlarge a child's knowledge, experience and imaginative understanding and thus his awareness of moral values and capacity for enjoyment. To enable him to enter the world, after formal education is over, as an active participant in society, a responsible contributor to it, and capable of achieving as much independence as possible."

In order to make this possible, we need to have facilities and programmes which will make available to our pupils a wide range of experiences and opportunities for self-development. Non-disabled people of average learning ability and over have these opportunities available to them through: —

- a. The ordinary school system — primary, post-primary, third level.
- b. A variety of courses and training programmes.
- c. Various clubs, groups, organisations, interests etc. which they join.
- d. Their ability to avail of all the facilities and services etc. which they can join.
- e. Their ability to choose, and to cope with difficulties and failures.
- f. Their own capacity for independence.

Our pupils are clearly disadvantaged in these areas and thinking in terms of equality and participation, we must try to give our pupils the opportunities necessary for the development of their full potential. The area of development which this paper deals with is that of human relationships and personal growth.

A basic human need and a basic human right is to have opportunities

of freely meeting other people; of meeting people of the opposite sex; of forming friendships; of falling in love and, perhaps, of forming a much closer and more lasting relationship.

In thinking of a programme of human relationships and sex education, we must firstly look at what opportunities the young people, boys and girls, have of meeting together, sharing views, ideals, difficulties, confidences etc., and of sharing leisure activities together.

'New Experiences', which are essential for all areas of personal growth, are nowhere more important than in the area of relationship. A mixed school has great advantages in this regard.

It is through being involved together in this way that: -

1. Boys and girls get to know one another in a real and natural way.
2. Each can come to some understanding and acceptance of (a) themselves in relation to others, (b) of their own sex and (c) of the opposite sex.
3. They can come to understand that boys and girls can share interests/have interests that differ; can share ideals/have different priorities; that boys and girls can often see different aspects of the same situation and that they have different strengths and weaknesses.
4. Together they can compliment and improve immeasurably the quality of life for each.
5. They can find friendship and love.

It is these encounters which provide the reality and the range of experiences in a relationship which will help to make a programme of sex education meaningful and it is through these that the young person's developing ideas and personality will find its direction. The school can help and support the home in providing these opportunities.

Related School Programmes

We cannot, therefore, isolate the sex education programme in the school from other school programmes.

The quality of the response to the sex education programme and the level of responsibility towards self and others in boy/girl relationships will be no different than the quality of relationship in all areas of school life and home life.

The values which the person develops and respects in all areas of life are those which he/she will bring to the sexual relationship; the person who develops kind, thoughtful, considerate, caring attitudes and values towards others will bring these values to sexual relationships, while those who have problems in these areas will bring these same problems into sexual relationships e.g. aggressions, lack of responsibility, exploitation etc.

1. Programme of Moral Formation.

We need to have definite expectations of behaviour and to lead our pupils towards accepting for themselves the highest values and ideals of relationship.

2. Religious Education

Christian values and ideals are those which can guide people towards the happiest and most real relationships.

3. Opportunities For Relating With Others

Class work — all subjects.

Physical education, swimming, games etc.

Outings, trips.

Clubs, discos etc.

While they need guidance, our pupils need also to be trusted and to be given as much responsibility as they can cope with.

Through these and other opportunities, the young person can develop responsible and caring values and attitudes towards others.

4. A sound basic knowledge of various bodily systems is very important before the introduction of sex education: the digestive system; excretory systems; circulatory systems etc.

One point which I would like to stress is that a sex education programme is not the answer to deviant sexual behaviour. Deviant or inappropriate behaviour of this sort is an indication of deeper problems and needs, and requires a much wider approach. Clearly, a way must be found to contain the immediate problem while efforts are proceedings towards finding a more long term solution. We had a boy of 17 years of age in our school recently who illustrates this point very clearly. He was a very strong aggressive person who repulsed all efforts at friendship. He masturbated openly in class and made aggressive sexual advances to the girls at every opportunity. He was avoided by the other pupils and the staff found it extremely difficult to like him. All our efforts to help him to improve his behaviour failed. We decided to make a special effort to get to know him, to find the things at which he could succeed and to build up his self-image and his standing with the others in the class. We took a special interest in his swimming and football and he improved dramatically. Little by little, his confidence improved. By the end of the year we discovered that all the outward signs of his sexual problems had disappeared and he related happily with other pupils. Of course, the same problems might well re-emerge when the supports, structures and security which he needs are removed. But his case still shows us that a sex education programme would not be the answer to his problems.

Some Notes With Regard To The Programme

Principles behind the programme:

1. The Christian view of human sexuality and the family is the one which can lead us to finding real happiness and personal fulfillment in our lives.
2. Since we are sexual beings, our sexuality influences all areas of our lives and all our relationships.
3. Human beings are happy only when they are trying and choosing to be loving and responsible e.g. a person who is selfish, who jeers, fights etc. is not happy.
4. When a person sets out to do his best, not only will the situation or service benefit, but he himself will be happy and fulfilled e.g. the man who is happiest at his work will be the one who does a good job.
5. Young people are naturally idealistic and have a great feeling for what is "good" and "right" and "loving".

Format of Programme

1. The programme tries to take into account the need to educate on the quality of relationship and on other ways of expressing sexuality, rather than just on the sexual act.
2. We set out to give a wide perspective of human sexuality before coming to discuss the young people's own development in that area. If too much attention is drawn to their own developing bodies rather than giving a wider perspective of human sexuality, the difficulties which young people have in coming to terms with "growing up" may be greatly increased.
3. We use the story of a couple through which we explore many aspects of a developing relationship. This allows more freedom of discussion, as it takes away the immediate pressure of the different situations being applied directly to the individuals in the class. It also helps us to see situations from a different perspective.

Involvement of Parents

Parents are involved at all stages of the programme. The pupils take home discussion forms and questionnaires which offer an opportunity to parents to join with the young people in the programme. At some suitable stage in the programme, the parents are invited by their children to tell the story of their own relationship.

People Presenting the Programme

The people presenting the programme should have opportunities of

exploring their own views and attitudes to the various sections. They should feel "at home" with all aspects of it. Ideally, two adults should be present with each group session, preferably male and female. They should, I think, be people who are well known to the pupils and have a good relationship with them. Experts, parents etc. can be invited to speak to the group if considered desirable at various stages.

Class Groups

Most of the programme is followed by the entire class together. At "sensitive" areas, we take groups of girls on their own and groups of boys. This emphasises our attitude of respect towards the indignity and personal nature of these areas.

In a sex education programme, we must try to educate young people to the genuine meaning of love. We must try to open them to the moral inspiration to love better, be more protective, more considerate and to respect all that is open and good and healthy. This is what being in love is all about — not stimulating passion, but longterm happiness.

ST. JOHN'S SPECIAL SCHOOL *Human Relationships — A School Programme*

SECTION 1

Plant Life, Animal and Bird Life, Insects and Fish Life etc:

Aims:

1. To develop awareness of God's Plan of creation for all living things and how all have an active share in that plan.
2. To experience the beauty and wonder of nature.
3. To develop interest in and sensitivity to all living things.
4. To promote an understanding of the process of growth and reproduction e.g. in flowers, plants etc.
5. Awareness of needs and habits of various species.
6. Care of young — feeding, protecting, playing etc.
7. Our responsibility towards the world of nature.

Creation — God's Plan — all living things have an active and continuing part to play.

- A. Plant Life, Trees, Flowers etc — all contribute — beauty and food value. All can absorb food and water; grow; reproduce; die. They can also adapt to their environment and have various means of protection and of fertilisation and dispersal of their seeds.
- B. Animal, Fish, Bird, Insect Life — all contribute — beauty, food value, work for us, pets etc. things they can do for themselves — feed, grow, move, reproduce, die.

Habits and instincts of various species — each suited to own needs and in accordance with its inner plan.

Stories of animal families and their care for young — wide differences in needs e.g. lions, kangeroos, turtle, frog etc.

Some suggestions for project work and integration with other areas of curriculum:

1. Story of creation from Bible.
2. "Nature Table" — grow plants and flowers from seeds, bulbs etc.
3. Scrap book or other display of leaves, flowers, grasses etc.
4. Pictures of mammals and non-mammals.
5. Babies, babies, babies — photographs and pictures of baby animals etc.
6. Write stories of animal families with pictures etc.
7. Story of food.
8. Stories and pictures of animals which help us.
9. Collection of fruits, vegetables etc.
10. Seed collage, rubbings, leaf prints etc.
11. Plant school garden.
12. Care of environment — what I can do.

SECTION 2

God's Plan of Creation — Human Beings

Aims:

1. To show that loving and life-giving can take many forms in our everyday lives whether we are married/single/young/old/ etc.
2. To show some ways in which we can share in creation. Only human beings can *choose* to love.
3. To give some opportunities to discover the beauty, excitement and personal fulfilment of choosing to contribute to be loving and caring to be responsible.

The meaning of human sexuality can be expressed in the two values *love and life*.

We can be loving and life-giving through: —

A. Personal Development — all areas

- a. All that I can do to develop my own potential.
- b. How I can become more loving, more caring.

B. People need help, friendship, company, understanding, care, love etc.

- Thinking of others, sharing, kindness, good humour, forgiveness, loyalty etc.
- Helping at home, loving my family, playing with brothers and sisters etc.
- Helping at school, being loving towards all others in school etc.
- Visiting, helping and doing shopping for old, lonely, sick.
- Being a true, loyal friend.
- Being helpful and courteous, crossing road, bus queues etc.
- Saving money for those in need.
- Being friendly and cheerful in meetings with people.

C. People need food, services — People have problems

Work: We contribute to the needs of others by providing food, shelter, services and conditions necessary for life and those which improve the quality of life.

Satisfaction and personal fulfillment come from deciding to give the very best service possible.

Preparing for work — what is important.

Different kinds of work — how do they contribute?

Taxes: by our taxes, we contribute to social services, health services, education etc.

D. Different kinds of love

— family — mother, father, brothers, sisters, relations.

— friendship.

— “falling in love” — special love between two people — they want to share their love and lives together — leading to commitment, marriage, family.

— Christian love.

Suggested written and project work etc:

1. Story of creation from the Bible; Jesus teaches us to love — New Testament and Children of God series.
2. “People of Love” scrapbook of photographs/pictures of family, friends etc.
3. “Growing Up” — list of all the things I can do.
4. “My Best Friend” story, pictures etc.
5. “We Care For Others” — stories and pictures of what pupils do for others.
6. “What People Can I Make Happy?”
7. “Why I Want To Work?”
8. “My First Job On Leaving School.”

SECTION 3

Pupil's Present Attitudes to “Growing Up”, to Relationships and to Sex

Aims:

1. To awaken interest in the whole area of interpersonal relationships and so to serve as an introduction to the following sections.
2. To encourage a personal involvement in the programme.
3. To show the need to explore responsibly for solutions to the many questions which arise.
4. To guide pupils towards understanding that parents' attitudes arise out of love for them and the desire to protect them.

5. That because sexual matters are so *personal and private* (not furtive or secret), many parents have difficulty in discussing these matters with their children.
6. Because sexual matters are so *special and personal and private*, we should have responsible attitudes at all times and respect for ourselves and for others.
7. Involvement of parents through discussion questionnaires sent home to be filled by pupils and parents.

Pupils attitudes and feelings with regard to relationships are explored through questions like the following:

Do you think parents (or teachers) trust you?	Why?/Why Not?
Do you think parents understand you?	Why?/Why Not?
Are you allowed enough "freedom"?	Why?/Why Not?
Are you allowed out at night?	Why?/Why Not?
Should parents know where you are and with whom?	Why?/Why Not?
How do you think parents feel about boy friends or girl friends?	
Are you allowed to watch any programme you like on T.V.?	
Parents attitudes to certain films, books, magazines etc.	
Did parents ever talk to you about where babies come from?	
Did you ask? What results? What do you think would happen if you did ask?	

Through these discussions, pupils can begin to see and appreciate that parents' rules and regulations and attitudes arise out of love, caring and concern for them. Also pupils need to develop and grow in responsibility.

Suggested written and project work etc:

1. Responsibility and love for parents and others — New Testament and Children of God series.
2. Discussion forms e.g. questions which arise from discussions —
 What time I think I should go to bed? Why?
 What time parents think I should go to bed? Why?
 T.V., films etc. — What I think I should watch? Why?
 What my parents think I should watch? Why?
3. My favourite pastimes.
4. Friends — things we like to do together.
5. Friends — things to avoid.

SECTION 4 (a)

Story of Relationship of Boy/Girl Leading to Marriage

Aims:

1. To show that relationships between two people which bring happiness and fulfillment involve the whole person and are based on the two values

of love and life. These include such qualities as caring, sensitivity, understanding, patience, thoughtfulness, gentleness, loyalty, commitment, permanency.

2. To offer opportunities for discussion of all that is involved in a relationship leading to marriage.
3. Parents' involvement at all stages: —
 - a. Discussion forum which pupils take home;
 - b. Parents share their own story.

The story can be built by pupils giving opportunities of exploring various aspects of a developing relationship. At all times it is the most loving and the most responsible attitudes and decisions which are sought.

Names, ages (usually 17, 18), pictures.

Where each works — wages etc.

Where they met, how, what was said etc.

Falling in love.

Dating, how often, where do they go, cost, who pays, how late etc.

Meeting parents.

What qualities boy likes in girl/qualities girl likes in boy.

Interests they have in common/individual interests.

Do they have any "rows", "break it off" etc. What were the causes etc?

Engagement — why did they decide to become engaged (commitment etc)?

— When? Where? Who asked? How long before engagement? Why? What is changed in the relationship now? Why? How long before marriage? Why? Preparation for wedding.

Marriage — wedding day — When? Where? Story, pictures. What changes are there now in the couple's lives? Housework, money, meetings, friends, going out at night, pastimes and interests.

Parents' Story — at some suitable stage — ask for parents' story, where they met, how? Who made the first approach, first date, development of relationship, funny stories etc.

Baby — our couple would like to start their family.

Pregnancy — very special time for couple — special needs — relationship grows — tenderness, understanding etc.

Changes in their life-style — difficulties.

Preparing for new arrival.

Visits to doctor etc.

Suggested written work, project work, integration with other areas of curriculum:

1. Jesus teaches us to love — love, marriage, New Testament, Children of God series.
2. Discussion forms to be filled (with help from parents) at all stages of developing relationship.
3. Make out a budget for boy/girl — wages, deductions, expenses, food, rent, savings, spending.

4. Economics of starting a home — saving, house prices, loans etc. Cost per month. Can they afford this?
5. Preparations for baby — make out a list and find how much these cost.
6. Cost of wedding and honeymoon.
7. Story of couple — scrapbook with pictures, stories etc.
8. What to do on a night-out.
9. Most important qualities in a husband/wife. What I would look for. ("The kind of boy/girl I would like to marry").
10. Wedding days — photographs of parents' wedding.

SECTION 4 (b)

Story Of That Baby

Aims:

1. To show that this is a special sharing in God's Plan of Creation.
2. To present the information necessary for the understanding of human sexuality.
3. To experience some of the wonder, beauty and mystery of new life.

Loving and Life-giving

In this section, we are talking about the mother's body, father's body and how their love for each other, expressed through their sexuality and the sexual act, result in their sharing in God's Plan of Creation in a very special way — the creation of new life — a baby.

Reproduction, Conception, Development of Baby, Birth

1. Show slides of developing baby in mother's womb. Talk about this development.
2. How this life began. Reproductive systems. Father's body. Mother's body. Use diagrams, slides, film strips etc. "An Ovum leaves the Ovary" — story of its journey — a. unfertilised, b. fertilised. How sperm is produced, stored, leaves the body. How sperm unites with ovum.
3. Conception — a new life begins.
4. Back to slides of developing baby. Follow the development.
5. Birth of baby.

SECTION 4 (c)

Family Life

Aims:

1. To show the joy of the couple at the new arrival and their love for each other which they now share with the baby.
2. To discuss some of the changes and difficulties which the couple now face and how they might deal with these.

The following and other topics might be discussed in this section:

1. Visiting mother and baby in hospital.
2. Choosing a name.
3. Returning home with baby.
4. This might be a good time for pupils to ask parents about their birth, homecoming, choosing names etc.
5. Caring for baby — breastfeeding, bottle feeding, changing, bathing, dressing etc..
6. Family planning.
7. New changes and challenges to life of couple.

Suggested written and project work for Sections 4(b) and 4(c)

1. Outline drawings of male and female reproductive organs. Name various parts and describe purpose of those parts.
2. Story of developing baby from conception to birth.
3. "Look how I've grown". Let each pupil bring a photograph of himself as a baby and a photograph of himself as he is now. There can be a lot of fun in matching these pairs of photographs. — Mount in pairs on a wall display.
4. Family Tree: Let children trace their family tree with help of family. Let them check what physical characteristics appear to have been passed on from one generation to the next e.g. colour of hair, eyes, height etc.
5. "Find the likeness" photographs of parents' wedding — put in box. Which parents belong to which child?
6. Story of my childhood.
7. How I am like my mother and father.
8. Story of my birth.

SECTION 5

Adolescence — Growing Up

Aims:

1. To help pupils to understand the changes that are taking place in their bodies and the meaning of these changes.
2. To help them to understand why we must respect our own bodies and have respect for others.
3. To help them to question responsibly the different relationships they may encounter — "Is this the right thing for me to do?" etc.

The pupils will have some knowledge of reproduction from previous sections so that they can look at adolescence from a wider perspective. In all discussions, the guiding principles, with regard to relationships, will be love and responsibility: —

"What is the most loving thing to do in that situation?" — Why?

"What is the most responsible thing to do?" — Why?

“Am I loving somebody if I use that person for my own pleasure?”— Why not?

The following areas are discussed among others:

- Changes — boy/girl — physical and emotional, interests and independence etc.
- Relationships with parents.
- Attitude to authority.
- Teenage relationships.
- Personal care and hygiene.

Suggested written and project work:

1. List of leisure time activities “I like”.
2. Each pupil get information on some leisure time activity, write down information, present to class, make wall display. Information: place type of activity, cost, time available, joining, travel etc.
3. What community projects or groups can I join? Find information on these.
4. How I contribute to my local community.
5. What I mean by love:
6. The kind of man/girl I would like to marry.
7. My best friend.
8. Interests I can share with my parents.

SECTION 5 (c)

Some personal and social situations will have arisen already in discussions. Others may not have arisen but the terms will be familiar to the young people and need to be discussed: masturbation; extra-marital sex; single parents; divorce; separation; annulment; couples “living together”; contraception; abortion; homosexuality; rape; venereal disease; prostitution etc. These can be discussed in terms of the same principles of love and life and the other qualities listed earlier. We can also discuss how we, our community and our government, can help those people who need help and those people who have problems or who are lonely, rejected and unloved.

SECTION 6

It is useful to collect information with regard to services and help available in the community and benefits to which people are entitled. The pupils will have experience of some of these already.

Services

Health; marital; housing; educational.

Sean Buckley, N.T., Dip. in Special Education.

Principal of St. John's Special School for pupils with learning difficulties.

3

Corry de Jongh

There is an increasing awareness that disabled people have emotional and sexual needs just like other people. This paper will refer mainly to aspects of physical disability although some of the comments are equally applicable to mentally handicapped people. The range and diversity of physical disability is enormous and therefore there is always a certain danger in generalisation. Thus, I would like to emphasise that we have to look at disabled people as individuals, with different backgrounds, with different personalities, with different needs and with different views on life. We have to look at disabled people as persons who happen to be handicapped. Like other people, disabled people are aware of their emotional and sexual needs but we also have to recognise that their condition makes them different — different in the sense that their participation in social life and relationships is made difficult for them — different in that in a society that is itself still inhibited in matters of sex, the disabled often are ignored as sexual beings. Witness, for example, what a 25 year-old girl has to say, "nobody imagines that a girl in a wheelchair is pining for love. People say that I am not unattractive and that I have an affectionate nature. I am a very emotional person and I am so keen to be happy. Whenever I see a man, my impulse is to get up and fly to him if I could. I am longing for love, how can I keep it to myself?" This girl is pining for love, she wants to love, to be loved, to touch, to be touched, to give and to receive love, warmth and affection.

In what way is she different from her able-bodied friends? She is different because she happens to be disabled and she is in a wheelchair but she is no different from non-disabled people in her feelings and emotions. We do not know anything about this girl, how severely disabled she is, what disability she has, but we can well imagine that she has encountered some of the following problems — over-protection by well meaning parents or caretakers, who wanted to protect her from the hurt of falling in love and being rejected. This could well have resulted in a lack of confidence in herself, in a lack of confidence to express her own needs to other people because she might not have had the opportunity of experience. She may have physical problems. Perhaps a speech problem which makes it difficult for her to communicate, she may have a physical deformity which makes her perceive herself as undesirable although other people say she is attractive. She may be socially isolated because of lack of transport or because of lack of finance to move around freely or because she is frowned

upon if she enters a pub or a disco. Perhaps she may think that people reject her as bad when she expresses her emotional and sexual needs openly. She gives an indication in this direction by saying that "nobody imagines that a girl in a wheelchair is pining for love". She could be right. Many times have I heard people saying, after reading an article or listening to a talk on sexuality and disability, "Gosh, I had never thought about that! How could they when the image in the media of sexuality is one of romance, glamour and of beautiful and perfect bodies? How could they if the attitudes towards the disabled unfortunately are like this. I would like to quote from Louis Batley's "The Chatterley Syndrome".

"The cripple is an object of christian charity, a sociomedical problem, a stumbling nuisance and an embarrassment to the girls he falls in love with. He is a vocation for saints, a livelihood for the manufacturers of wheelchairs, a target for busybodies and a means by which prosperous citizens ease their consciences. He is pitied and ignored, helped and patronised, understood and stared at. But he is hardly ever taken seriously as a man. . . ."

There are many disabled people, who feel good about themselves and about their bodies, who have intense and satisfying relationships, who do get married and perhaps have children and lead a totally fulfilling life.

In what way does a physical disability affect the phycho-sexual development of a growing individual? Let us look for a moment at what Norman Rae has to say in his report on "Sexuality in Handicapped People". He states "those people, whose learning, development, social behaviour, ability to communicate verbally, or whose psychomotor capacity are affected in one-way or another, as a result will have difficulty in coming to terms with their own sexuality and of those around them".

1. Children who are handicapped from birth (for example, children with cerebral palsy and spina bifida) have limited experiences of the normal process of growing up. They are often not allowed to choose for themselves, to make decisions for themselves and to learn, by making mistakes. In the family, disabled children are the focus of attention of the parents who often are inclined to indulge their child as if they want to compensate for the handicap and cover up guilt feelings about producing a handicapped child. In such a family, the disabled child is made so special that there might be too few opportunities to learn to give and take and to learn to share with the other children. As a result, these children may remain self-centred and preoccupied with themselves and they may find it difficult later in life to find deep and lasting relationships.
2. With regard to their physical development there is evidence that disabled girls start to menstruate earlier and that boys reach puberty at an earlier age than their non-disabled peers. These children may very well be ill prepared for these changes, they may be emotionally and socially less mature than others of the same chronological age. For parents, this obvious onset of adulthood

can be shocking as many parents find it difficult to envisage their children as adults with sexual roles.

3. Another factor, one that is often overlooked, is the implication of regular treatment and physical care by parents, therapists and staff in institutions. Particularly in the case of the more severely disabled, regular treatment and handling of the disabled part of the body may become a preoccupation, while the normal parts including the sexual areas of the body can be overlooked and under-emphasised. The disabled child is being dressed, undressed, washed, stimulated and treated with exercises. This regular handling of the body involves a certain intimacy and this physical contact and intimacy can lead to confusion for the caretaker and the growing-up child.
4. These young disabled people often have limited or no opportunities to explore their own bodies, including their genitals and that is a pretty normal thing to do! They have little opportunity also, to experiment with either boy or girlfriends, which is a pretty normal thing to do too! They may not have the privacy or opportunity to do so. We know that it is important that young people have these experiences in order to come to terms with their own sexuality and to have good relationships later in life. Thus we can see that disabled youngsters are in many ways disadvantaged in comparison with people who become disabled at a later stage of their lives.

To summarise the effect of disability on psychosexual development of a disabled child, 1. Puberty starts earlier, 2. They are less prepared for these changes, 3. They are emotionally and socially less mature, 4. They have less opportunity to learn about their own sexuality.

How then do these young people learn about and recognise their own sexuality and how much help and information do they receive from peers, parents and teachers?

Sex education is as important for disabled as for non-disabled children. Most teachers have come across questions like: "can I get married?" and "can I have children?" How does one deal with these questions? What is one's own view on sexuality, relationships and marriage? I think it is important to be aware of one's own values in discussing these topics with other people. In my own view, and this is supported by what I see around me, the expression of one's sexuality is by no means confined within the limits of marriage or solely to relations with the opposite sex. We have to recognise that there are people who have sexual relationships outside marriage and that some people feel more attracted to their own sex than to members of the opposite sex. Disabled people are no exception.

In relation to disabled people, we see that they have a limited choice of partners and we see that there are many disabled people, particularly the more severely disabled, who will never get married. Should they be told to suppress their feelings? Or do we try to help them find a way to express their

sexual feelings? If a disabled person finds himself a partner but has no prospect of marriage, could we deny him or her some pleasure and happiness in life? And if a disabled person is unable to have intercourse, do we judge alternative ways of lovemaking as abnormal or perverse, I am well aware that these questions touch on sensitive and moral issues and I think it is important that we are guided by the disabled people themselves, by what they need and want for themselves.

Marriage

Of course, disabled people also wonder, "will I get married?" "Will I marry a disabled partner or a non-disabled partner?" Marrying a non-disabled partner means sacrifice and dedication and also a greater flexibility about sex roles. For example, the wife might go out to work while the disabled husband stays at home. On the other hand, it is said that if two disabled people marry, they will understand each other better because they share the same situation. But it also might mean a greater need for outside help in activities of daily living. All these advantages and disadvantages and mutual expectations will have to be discussed with the couple and after an open and honest discussion, it is only the couple themselves who can take a decision.

Most disabled women are able to conceive and many disabled men are able to father children, thus the question arises, "will we have children or not?" For disabled women this seems a particularly difficult decision, as many long for motherhood. Disabled people should have a choice, they should know the facts and implications, they should know the possibility of and the risks of pregnancy and the problems of having children in a household where one or both of the partners is disabled. On the basis of these considerations, they will make up their own minds and of course, methods of contraception should be discussed with the couple. If it is impossible to have children, then perhaps adoption could be considered. (I don't know if it is possible in Ireland for disabled people to adopt children).

Let us look at some of the research in the area of disability in marriage. Norman Rae concluded that no prognosis can be made for satisfaction in a marriage merely on the grounds of seriousness of handicap. Goodman carried out research on 1,500 paraplegic patients in Stoke Mandeville Hospital and he found — that more handicapped women tend to marry handicapped men and that handicapped men more frequently marry non-handicapped partners — that the divorce rate after handicap is not higher than in the general population and in cases of divorce, sexual frustration is not the main reason for the divorce — that over 50% of his patients were fertile. He concluded that there is no reason for undue pessimism as regards sexual functioning of the paraplegics.

What kind of sexual problems do disabled people encounter? I will give a general outline of the problems. (For further information, I recommend an excellent book called "Not Made Of Stone," by Dr. Herlingaetal). Broadly speaking, three types of problems can be found and in many cases there is an overlap of problems.

1. Physical problems — there can be impairment of sexual functioning itself: the inability to have an erection, inability to have an orgasm, lack of sensation and sterility. These problems can occur with conditions like spinal cord injuries, multiple sclerosis and spina bifida etc.

Other physical problems that can make sexual intercourse difficult are pain, weakness in the limbs, lack of motor spasms and the important problem of incontinence. These problems can occur in conditions like muscular dystrophy, cerebral palsy, arthritis etc.

2. There can also be psychological problems, fear of rejection, fear of pain, fear of transmitting a disease, inhibition and a poor self image or body image.
3. Relational problems: stigmatising, isolation, feelings of inferiority, dependency, fear of sexuality, or a parent/child or nurse/patient role instead of equal partnership.

How many disabled people do have sexual problems? Let us look at Bill Stewart's research of 212 disabled people with a wide variety of handicaps. He found that over 50% of the interviewed people had some kind of sexual problem and a greater proportion of men than women. Although his definition of sexual problems was rather wide and although we have no similar research data in Ireland, it shows us that problems are frequently found. This percentage seems very high but we should not forget that non-disabled people can also have psychosexual problems and also receive little help. It has been the experience of SPOD in England that with information, advice and counselling, many disabled people can improve their situation and overcome some of their problems.

The view of the disabled themselves in Stewart's study was that the ability to satisfy a partner was as important as personal satisfaction. Witness a married paraplegic man describing his experience:

"I think we enjoy sex just the same. It's very, very difficult for an able-bodied person of the same sex to understand but you need the same satisfaction mentally. If you don't get it sexualwise, feeling wise, whatever it might be mentally, mental-wise if you can satisfy the other parts, whichever it may be, whether it be a man or woman, then that is the main thing. Mentally, you're satisfying your partner. I think that is the great thing as regards the sexual side of it."

In Bill Stewart's research interviews, it transpired that 40% said that they had no idea of any source from which help might be available and that they would welcome a counselling service. It is amazing to see that such an important aspect of life was not discussed at all with many of the disabled interviewed. Susanne Quin in her follow-up study of 30 paraplegics in a large rehabilitation centre in Ireland reports similar findings. For the majority of those interviewed, the sexual aspect of the disability was never discussed automatically with them. She remarked that given the general

level of ignorance and inhibition the disabled people themselves were very willing and sometimes even eager to discuss sexual matters.

So, what can be done to help the disabled with these problems? Like Susanne Quin, it has been our experience in SPOD, Ireland, that the disabled themselves are often very willing to discuss their sexual problems and that it is more often inhibition on the part of the staff that prevents a more open discussion. This seems to be a widespread phenomenon and information and counselling has not been available to many disabled people who have needed it. Just because the disabled person does not ask questions, it does not mean that he or she is quite satisfied with the situation. If it is true, as Bill Stewart found in his research, that many disabled people encounter sexual problems at some stage in their lives, then information, advice and counselling ought to be available. We, as professionals, have the duty and the obligation to provide this whenever necessary. It is because of this lack in services that a group of professional people set up the SPOD resource group in Ireland. We have found that there have been many requests for information leaflets and personal counselling. We see counselling, and this includes counselling on physical, psychological, relational problems and genetic counselling, as a way to help the disabled person to understand their own position and reach their own conclusions. I think it is important that we as professionals dealing with disabled children and adults become aware of our own attitudes. It is important that we are prepared to take the time to listen to the disabled — to what they want and what they feel — and that we are not afraid to broach the subject if we are given the opportunity.

I am optimistic about the future. Attitudes are changing and more and more sexuality is seen as an integral part of being human. More and more disabled people are coming out in the open and demanding from us that they be seen as people with equal rights. I have seen in the few years of SPOD's existence in Ireland, a great amount of interest from disabled and non-disabled. We have talked openly about sexuality and disability in meetings, on radio and television, we have written articles for papers, we have published several newsletters and we have received very few negative reactions. This gives me hope that in the future, the disabled will indeed be able to lead a truly human, satisfying and fulfilled life!

Perhaps we feel we have to know all the answers. This is not so. We can inform ourselves by reading and discussion, we can help the disabled to find relevant information, we can encourage the disabled to be sure to get answers to their questions from doctors and specialists. We can help the disabled to make decisions and to take initiative. Most importantly, we should involve the disabled themselves in advising and counselling disabled in a similar position. This has proven to be very useful.

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During 1976-78 she worked with the Irish Wheelchair Association and worked as a psycho-sexual counsellor with the Irish Family Planning Association before taking up her present position.

She was co-organiser of S.P.O.D. Ireland, a working group for sexual problems of the disabled.

CHAPTER SIX

Being Special?: The Role of the Professional in Contact with the Disabled

1

Dr. Roy McConkey

Over the past twenty years there has been an impressive development in services for disabled people. Although many fine new buildings have been erected, the most significant advance has been in the number of people employed full-time; I would guess there are around 5,000 professionals involved with some 30,000 disabled people. In 1981, the Government will spend approximately £100 million on services for handicapped people. This represents an average spending of £3,400 for each disabled person derived from a levy of £150 on each taxpayer. Thus there has been a marked, even rapid transition from a charitable to a professional service.

Yet the essence of professionalism lies not just in money. In this paper I want to examine some essential attributes of professionalism; attributes which transcend the specific skills and training of the individual specialist. In short, what do (or should) teachers, nurses, therapists, doctors, psychologists have in common that warrants the appellation — "*they're professionals*".

The professional is an evaluator

Professionals should be able to stand back and make an objective evaluation of their service; free from vested interests or personal prejudices. And more importantly, they should go on to make decisions and changes in the light of their evaluations.

In Ireland, we have a growing tradition of service evaluation. During the past ten years the results have been published of six major surveys into

the lifestyles of people who are deaf,¹ blind,² physically handicapped,³ mildly mentally handicapped,^{4,5} and moderately and severely handicapped.⁶ I should like to present some of the findings on the social maturity of disabled people in Ireland today.

Arguably there are three main indicators of a socially mature person within our society—

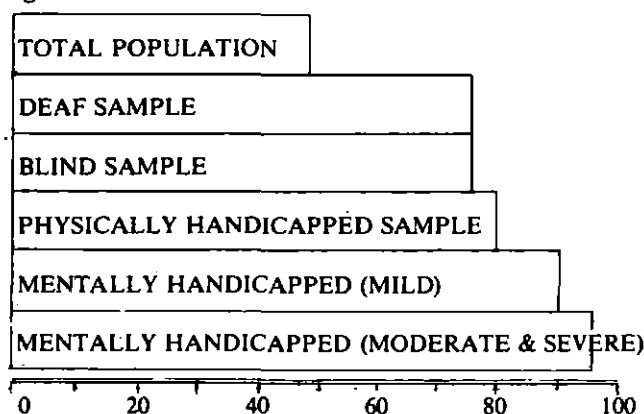
- (1) *marriage* — which involves establishing and maintaining a close relationship with another person;
- (2) *employment* — which enables the person to earn money that covers necessities and a few luxuries;
- (3) *own home* — living away from parental home so that the person can develop his/her own life-style and individuality.

Figure 1 gives the percentages of people with different disabilities whose social maturity matches up to that generally found within our society?

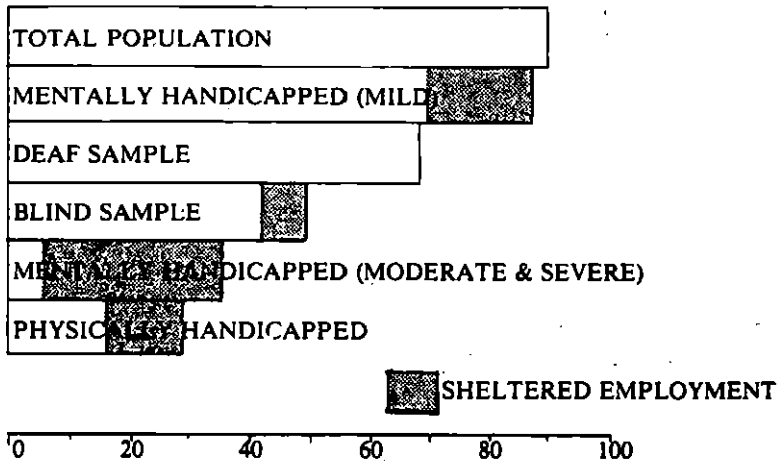
Social Isolation — Across all three areas the picture which emerges is that disabled people are isolated and dependent; mostly single and living in their parental home with only a minority earning a living wage. These findings stand in marked contrast to the 3rd article of the United Nations Declaration of Human Rights of Disabled people — “(they) have the same fundamental rights as their fellow-citizens of the same age, first and foremost, the right to enjoy a decent life, as normal and as full as possible”. In the Ireland of today, that right is not a reality for most disabled people.

FIGURE 1
Results of Surveys into the Lifestyles of Disabled People

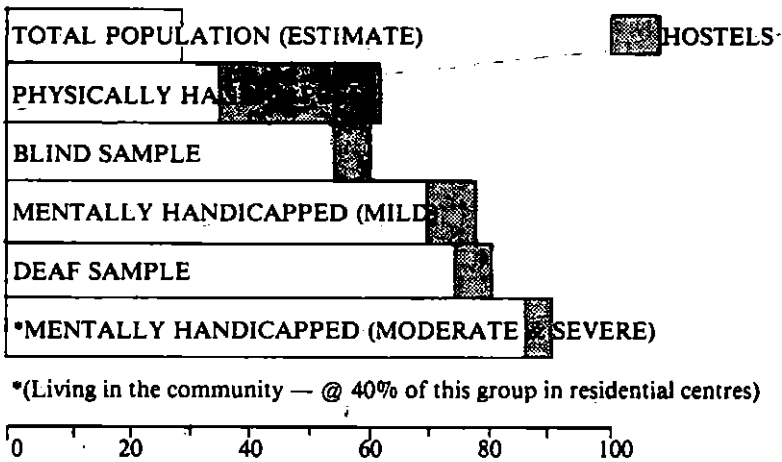
Percentage Unmarried



Percentage Employed



Percentage Living in Family Home



Why not? The blame can easily be placed on an unwelcoming society or more often on disabled people themselves, but surely we professionals must shoulder some of it — after all we are being paid to help them. Their failures must reflect back on us. Should those findings not cause us to reconsider the way we organise our services? It seems a curious logic to withdraw handicapped children from the local community for education and then ten or fifteen years later wonder why it is difficult to get them back into society.

Our current models of service delivery — even day services for children and adults living at home — are still strongly influenced by two traditions. First, *separation* — with the connotation of protection both of the disabled and for society — and secondly, *hospitalisation* — with an emphasis on disability as an illness that is treated by “specialists”. It is very hard for all of us — professional and disabled alike — to shake off the notions of protection and illness which surround disablement. We know of course that over-protective parents can stunt and spoil their able-bodied offspring’s emotional and social development. The risk is no less with handicapped children.

Yet I am only too well aware that our specialist centres — be they schools, workshops, or residential homes — will not disappear overnight. Nor will the integration of specialist services into our community service network be achieved through polemics. Indeed debates on integration are frequently tempered more by rhetoric than reality.

Integration for all — Rather than viewing integration as a prescription for all, to be taken immediately by all, it is best seen as *an aim for each disabled person*. It then goes without saying that all the professionals helping that person will be attempting to further this aim. Viewed in this way, integration is no longer a subject for academic debate but a plan of action. There is much that each of us can do to reduce the social isolation of disabled people.

For example, take the area of leisure pursuits. Surveys of mentally handicapped adults living in the community have shown that most of their recreational activities are centred on the home and involve the family. Of 500 mentally handicapped adults living in Dublin — average age 25 years — $\frac{2}{3}$ spend their leisure time with their parents; just $\frac{1}{3}$ go to any community event (cinema, pubs) and only one in five would have a non-handicapped friend.⁸ This is a markedly different pattern from that of able-bodied people.⁹

And this pattern is present in childhood. In a survey of the play activities of 67 mentally handicapped children — average age 6 years — only two played daily with a neighbourhood friend. Their regular playmates were invariably mothers, siblings or fathers.¹⁰

As professionals working in services, have we given any thought as to how our disabled people spend their leisure time? How well do we try to prepare them to participate in community activities? How much experience do we give them of “getting on” with others? Surely all the data emerging from our evaluations should challenge our presumptions and cause us to redefine our role.

The professional is a mediator

One outcome, I would foresee is that the professional needs to become a mediator between disabled people and the community.

In a survey of over four hundred, 15 to 17 year olds attending second level schools in Dublin, we asked how frequently they had come in contact with mentally handicapped people.¹¹ Around 30% mentioned some contact

during the past fortnight; another 35% had some contact in the past year, but over one third had had no contact at all in the year past.

More significantly though, when we enquired as to the form of contact, most young people reported seeing them on T.V. or around the city. Less than one quarter had had the chance to meet or talk to a mentally handicapped person.

When asked how they would react to meeting a mentally handicapped person, they reported feeling more uncomfortable — “embarrassed, awkward, disturbing” — and more lacking in confidence — “not knowing how to react or what to say” — that if they were meeting a stranger of their own age for the first time. Interestingly their reactions to meeting a deaf/dumb person were the same as for the mentally handicapped person.

Thus our young people — indeed most of our people — have been isolated from disability and understandably show some unease at the prospect of meeting handicapped people. Of course the consequence is as predictable as it is sad — avoidance. But what are we professionals doing to remove these fears — fears which we know to be totally unfounded?

Preparing the community — During the past year, St. Michael's House Research, in conjunction with the Health Education Bureau, has been involved on an education project into community attitudes to retarded adults. In the first phase we have been focussing on pupils in second level schools. Project staff have gone into schools and taken a series of six class periods; amounting to some 3 hours of pupil contact. Throughout, the bias is more to *involvement* than no information. Indeed the highlight is a visit of a group of mentally handicapped adults to meet the pupils in *their school*. This meeting occurs in the fourth period of the course and the young people are gradually introduced to the idea, by among other things, viewing videotapes which implicitly give them examples as to how they can act with handicapped people.

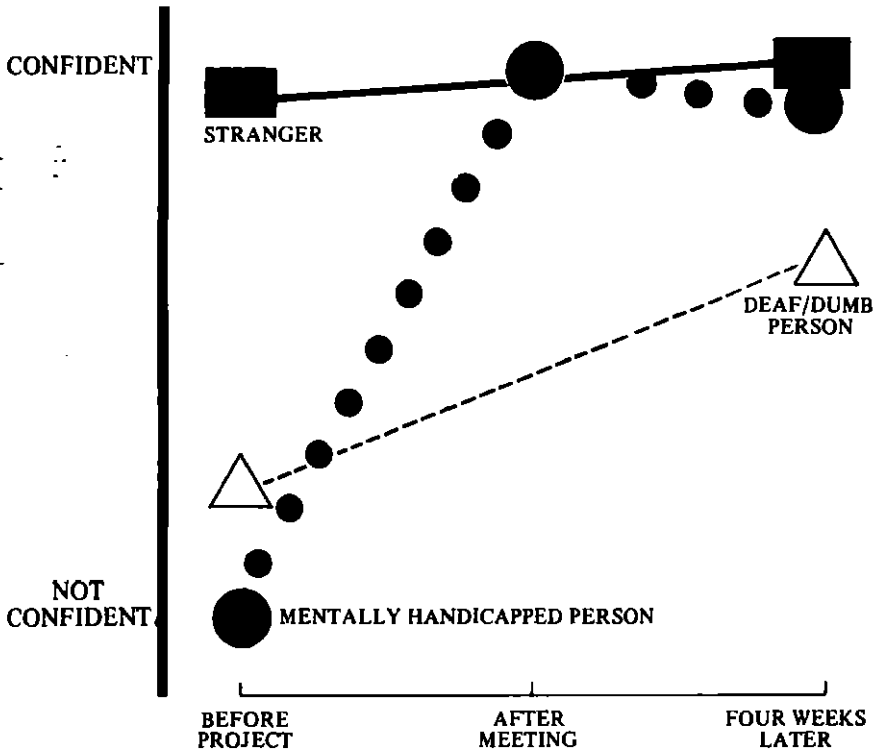
The meeting occurs in the context of club activities — darts, table games etc. — which are laid out in a spare classroom, and two pupils usually pair off with one handicapped person. This contact period usually lasts for half an hour, yet even in this short time there is a marked change in the young peoples perceptions as to how they would feel on meeting a mentally handicapped person. See Figure 2. Nor was this just a halo effect following the first meeting — the change was maintained 4 weeks later.¹²

But this is not just a project for specialists. Subsequently the staff in St. Michael's House workshops and Adult Care Units (nurses, supervisors, teachers) have gone on to use the package in their local secondary schools and with just as much success. Thus a relatively small investment of time — only 3 hours in this instance — can effect significant changes.

Arrangements to meet — This project though is built around a very simple idea — mentally handicapped adults visit the local school. Nothing earthshattering or complicated to arrange, yet the novelty of this suggestion is symptomatic of the invisible barriers which we professionals have coddled with society in erecting around disabled people.

Of course we often arrange outings for disabled children and adults — but they go to the zoo, the beach or to shops, sometimes even to Lourdes —

FIGURE 2
Young Peoples' Reactions to Meeting a Handicapped Person



but rarely do our visits have the explicit aim of meeting people. Indeed we may even try to choose places and times when this is least likely to happen.

But why not plan regular trips to your Local National, Secondary and even other Special schools? Why not take them to visit day centres, playgroups, hospitals, community centres, factories and colleges — all with the aim of having them meet people and letting people meet them.

Once the barriers to contact are broken in this simple way, other developments become possibilities — could not some disabled young people provide voluntary help, say in old people's homes; could not a group of disabled adults do their contract work within the supplying factory rather than in a special workshop?

In all these various ways and many others besides, we professionals can start dismantling the barricades that have surrounded disability but like all good mediators we need to prepare *both* parties for getting along with each other. Only then will the aim of this International Year — 'Full of participation and Equality' — start to become a reality.

The professional is a sharer of information

This third characteristic follows on naturally from the above discussion. But as well as sharing information with the community, we professionals would do well to look within our services and ponder how forthcoming we are in sharing our expertise with others. I want to highlight three main dimensions of information exchange — among professionals; in service training and with disabled people and their families.

Inter-professional exchanges — The plethora of professionals involved in handicap services is a constant reminder to each of us of our own inadequacies. The ideal — one professional with all the necessary expertise — is an unobtainable dream. Yet what saddens me is that many of our so-called multi-disciplinary teams do not act as a *team* but rather as a collection of individuals and sometimes egotistical ones at that. How often do you see one of your colleagues working with a child or teaching a class? What practical tips and guidelines have you been given, or could you give, on helping a disabled person? Surely if we know a technique that works we should share it with everyone — good news needs to travel fast. Of course the root problem is that we ourselves are not at all convinced that our expertise is effective. Instead we shelter behind our specialist training and fuel the myth of professional omnipotence.

When faced with disability and its sometimes unpredictable consequences it is no shame to ask for help. This openness is the hallmark of teamwork; the sharing of experiences based on mutual respect that leads on to joint planning of actions which then become the *team's responsibility* to implement.

In-service training — Much has been learnt already about ameliorating the effects of disability and research currently ongoing around the world will further extend our knowledge. Yet we still have to evolve satisfactory ways of transmitting this information to all people in our services. The model of once-and-for-all initial training which is standard for most professionals in most countries is patently inadequate for the rapidly changing world of disability and remediation. There is urgent need for some form of "in-service" training.

However, existing models for such training are not immediately practical for a small country such as ours. For example, a one year, seconded training course for special education teachers in a College of Education or University can cost upwards of £15,000 per participant. Nor is it just a matter of finance, although that is obviously a limiting factor on the number who can participate at any one time. It is questionable whether training that is given away from the daily place of work is the best way to effect changes in what professionals actually do in the classroom, clinic or work. And secondly, it is dubious whether an eclectic course can ever be sufficiently specific to be practically useful. (Of course such training courses can bring other benefits but the debate is about priorities and I would argue that the shortcoming noted above should be our priority for in-service training.)

There are alternative models for organising "refresher" courses for

staff. One approach we have used within our research programme at St. Michael's House is the concept of videocourses.¹³ This consists of a series of five video-tape programmes (lasting in total for about 2½ hours) centred around a particular topic — e.g. the early language development of handicapped children. Staff taking the course, view the programmes in their own centres on a once-a-week basis and in the intervening days they carry out set practical activities with the children in their group.

Thus this approach embodies the priorities noted earlier. However such courses do require quite a bit of effort to produce and if they were only available to staff working in St. Michael's House service they would not be cost-effective. Therefore we have recently trained tutors from other mental handicap services around the country — 11 services in all — and during the last 4 months, over 100 front-line staff from Galway to Dublin, Cork to Dundalk have taken the course in their own centres.

Such courses are both practical and economical. To launch them, all that is needed is for a small group of professionals with sufficient confidence in their knowledge to put a course together and present it in a transmittable form to others. In short, you could do it for the staff in your service and later you could train others to use it with the staff in their services. Such an hierarchical model is the most effective way of achieving speedy and widespread transmission of knowledge.

Disabled people and their parents — Although I come to this last, there is no doubt in my mind that in all our sharing of information this should have priority. The fact that it has to be mentioned explicitly and that it cannot be taken for granted is a sad reflection of the gulf between us as servants and those whom we serve. How can we spend an hour or more "assessing" a disabled child or adult and not share our thoughts or conclusions with him or his family? Little wonder some disabled people have asked — "are you doing this for me, or am I doing it for you?"

The explanation I suspect lies in a lack of confidence which I know team-building and inservice training would do much to remove. But I do want to make some specific comments on the involvement of parents in our services as I detect a great reluctance among professionals to have close links with families. For instance, the videocourses I referred to earlier are used within St. Michael's House with staff and parent alike. Indeed, course organisers frequently find that parent groups are much more enjoyable and rewarding. We made this point strongly when training the tutors from other services and encouraged them to run the course with a parent group. But without exception, all opted to use it first with staff. They may have had good reasons for doing this but it does reflect the relationship, or rather the lack of it, we professionals have with many parents.

As I see it, there is no need to debate the pro's and con's of parental involvement. The fact is, it is their's by right and they *are* involved anyway in that they see far more of the child than we do. Rather it is up to us to take it one step further and nurture their interest and involvement in *our work*. We can do this by: (a) establishing links when the child is young or with older children, whenever a change occurs in their routine — moving to a new class or to a new service setting; (b) by issuing personal invitations

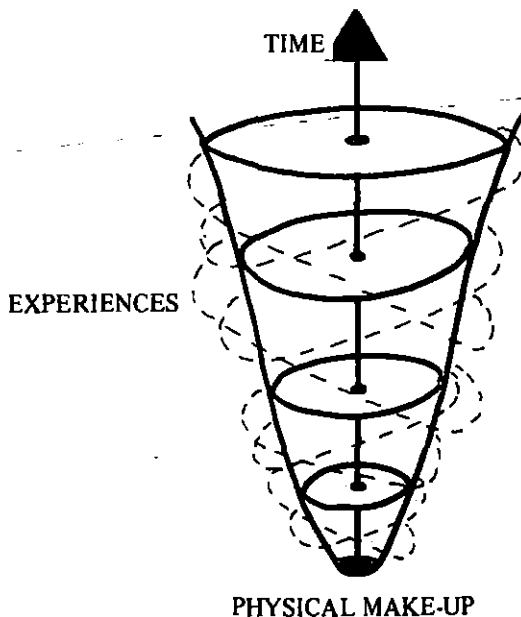
which outline specific reasons for your coming together and; (c) ideally by meeting parents on an individual or small group basis. All the evidence is that when approached in this way, parents are interested, co-operative and supportive to you. There are of course, some exceptions but my guess is that they occur with about the same frequency as the disinterested and unco-operative professionals with whom we have to deal as well.

The professional is a giver of hope

Of all the characteristics, this is probably the one which embodies the essence of professionalism. For many disability is synonymous with despair. Thus the role of "giver of hope", is a crucial and continuing one. But it should not be at the level of unrealistic platitudes. Rather meaningful plans for action are needed that will result in changes for the better.

Yet I sometimes wonder how convinced we are that our hopes are justifiable. I suspect that we still harbour very simplistic notions of human development. For example the analogy is made to a seed; as long as it has food, heat and light it will grow into a mature plant — otherwise we are helpless to determine its growth.

FIGURE 3
A Transactional Model of Human Development



DEVELOPMENT IS —

- * Upward
- * Outward
- * Discontinuous

IT IS AFFECTED BY—

- * Previous Development
- * Current Experiences
- * Physical Make-up
(lessening with time)

This may well be true for plants but then humans are not vegetables and certainly current models of human development emerging from recent psychological research bear little relation to this concept of growth.¹⁴

Figure 3 attempts to synthesise our current understandings of human development. The essential feature of this model is that development results from transactions between the developing person and the experiences (especially people) surrounding him/her in everyday life. Note that development is represented both upward and outward — new skills have to be generalised to all contexts — and it is also shown discontinuously. There is a growing acceptance that at least in some aspects of development, children can show marked and sudden advances; moving rapidly from one stage to another — and equally there will be periods — sometimes referred to as plateaus — when seemingly there is little change or advance taking place.

These new notions of development will take some getting used to — not least by those professionals who are asked to make predictions about an individual's future development. Discontinuities make prediction a risky business.

Influences on development — However the beauty of this model is that it also highlights the influences on further developments. The most important being the individual's present level of development for it is this which determines the extent to which he can contribute to, as well as benefit from, the experiences around him. This model recognises that, to an extent, we are masters of our destiny.

Secondly, development is channelled by *current* experiences. There is a great temptation to look back into the past and search for explanations but more often the answer lies in the present. We know that human development once started is robust and vibrant and that it can overcome many traumatic deprivations.¹⁵

Lastly, development is influenced by the physical make-up of the person — the nervous system, genes, hormones and sensory receptors — but this influence *decreases over time* as it is overlaid by the acquisition of skills and behaviour patterns. Yet I suspect that the common man, not to say some professionals, would still cite this as the pre-eminent influence on an individual's development or they will use it to account for immaturity. They see only the damaged individual — the deafness, blindness or brain disorder — none of which can be cured, and so they often despair. They are wrong.

True handicaps — Our model of human development puts the disability into perspective, it is of *decreasing* importance as the person matures. Thus a person fails in open employment, not because he's deaf, but because he cannot communicate fluently or because he is too pig-headed or because he cannot travel alone on the bus. These are the true handicapping conditions and each can be removed. Therefore we have every right to be hopeful.

But we have failed to get this message across to the community, maybe because we do not want to believe it ourselves. It places on us a tremendous responsibility — we can influence every individual's development by what

we do, or more significantly, by what we fail to do. In such circumstances it can be more comforting to think that it is beyond our control.

The spirit of professionalism

These then are just some of the attributes of professionalism; no doubt you could add others. All are high ideals but it is no shame to admit our shortcomings. We professionals are a relatively young body; a product mostly of the 1970's and as pioneers we are allowed the luxury of making mistakes — provided we learn from them.

It is very hard to capture the essential spirit that should characterise professionalism in the context of disablement. I think the late President Kennedy came closest during a speech he gave on a visit to Dublin some 5 months before his assassination. Although he was talking about the problems facing the world community in general, his comments can be paraphrased as follows —

“the problems of disabled people cannot possibly be solved by skeptics and cynics whose horizons are limited by the obvious realities. They need professionals who can dream of things that never were.”

May you dream dreams.

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A multidisciplinary approach is essential in the management of a child who is physically handicapped or who has multiple handicaps.

The doctor has a particular role to play in the overall management. He sees the child at an early stage and will seek help and advice from the physiotherapist and the occupational therapist. He is also likely to consult the speech therapist about sucking and feeding difficulties, which may result in speech disorder. The role of the speech therapist in speech and language development allied here to the psychologist and teacher in a common cause and indeed each achieves considerable expertise in their colleagues' fields by close association.

Hence the doctor is usually the prime mover and at first guides the therapists. Later he is likely to be guided by the psychologist and by the teacher.

A discussion on who is to be the team leader is outside the scope of this brief paper, but there should only be one leader.

One must stress, however, that the parents are the most important members of the team, particularly with regard to decisions about treatment and education and, arguably, their general practitioner is secondary in significance only to the parents.

Successful involvement of the parents in the treatment and educational systems at an early stage may depend upon their previous experiences. They have sometimes been given misleading or, perhaps, through misguided kindness, wrong information about their child. They are often told that the child is a little stiff or backward. This may be interpreted by them as meaning that with a little advice from the medical profession and some effort from themselves, the child will turn out to be perfectly normal.

How to tell the parents initially that their child is not normal is very difficult. One's professional training is inadequate for the task. There is a great difference between the armchair, academic, adviser and the individual who has to face both parents and tell them that their child is permanently handicapped.

One cannot plan for the future and enlist the full co-operation of the parents, in the correct management of the child, unless the truth is told. All of the truth need not be told on the first visit; but what is said should be sufficiently clear to enable the parents to make realistic provisions for the future. A good feedback arrangement with therapists can ensure that inadequate or poorly phrased explanations may be changed and incorrect

diagnosis or opinions modified.

The doctor must deal as best he can, with the help of others, in the management of the handicapped child and the family. However, his principal role should be orientated more and more towards the prevention of handicap. This should involve genetic counselling in relation to conditions such as Down's Syndrome. There is clear evidence that if mothers cease having babies after 35-36 years of age, the incidence of Down's Syndrome and other chromosomal abnormalities would be diminished by 50/60%. In the proper management of pregnancy itself, early referral and good ante-natal care are essential. Cigarette smoking should be greatly reduced or eliminated as smoking during pregnancy leads to smaller babies. Heavy alcohol consumption during pregnancy doubled the incidence of congenital malformations. Good nutrition of the pregnant woman is mandatory. The place of confinement should be adequately staffed and equipped to care for mother and child should any emergency arise.

A very important aspect of prevention is in the field of nutrition. Ireland shares with Scotland the dubious distinction of having the lowest consumption of fruit and vegetables in the developed world and the Irish also have about the highest consumption of sugar. In Ireland there is a relatively low intake of essential components of the Vitamin B Complex, including Folic Acid, Vitamin B12, Pyridoxine and Pantothenic Acid.

The incidence of Cerebral Palsy is twice as high in this country as in Sweden and the prevalence of Spina Bifida in Ireland is probably the highest in the developed world and many times higher than in the Scandanavian countries. Spina Bifida has been referred to as the "curse of the Celts". Certainly there is a strong hereditary component. However, the Irish who go to live in the USA have a lower incidence of Spina Bifida amongst their children and this incidence declines with the passage of time, indicating that there must be an environmental factor present in Ireland.

It is believed that this environmental factor may be dietetic. Certainly we could with advantage increase our intake of wholemeal and rye bread and of fruit and vegetables.

Management of the handicapped child involves integration of all the available skills. The term in America for integration is "mainstreaming" and in Scandanavia "normalisation". In the words of the Snowden report, integration of the disabled means a thousand things: It means the absence of segregation, it means social acceptance, it means being able to be treated like everyone else, it means the right to work, to go to cinemas, to enjoy outdoor sport, to have a family life and a social life and a love life — to contribute materially to the community, to have the usual choice of association, movement and activity, to go on holidays to the usual places, to be educated up to University level with ones unhandicapped peers, to travel without fuss on public transport.

The integrated approach might be examined at 4 levels:

1. With the Mother.
2. Into the Family.

3. Into the School.
4. Into the Community.

I will deal very briefly with the first and second of these and not at all with the fourth.

1. Integration with the Mother

The importance of bonding cannot be overstressed. It is very important that the mother and baby should be together immediately after birth, even for a very short period, to cement a relationship that may be crucial at a later stage.

2. Integration into the Family

The second phase of integration is with the siblings and this can be achieved by early referral. Early referral enables one to incorporate the handicapped child into the family unit by stressing his or her normality — there may, of course, be a few additional problems.

“There is general agreement that the younger the age that children with physical, mental or emotional disabilities are discovered and fully assessed, the more hopeful is the prognosis.” — Mary D. Sheridan.

3. Integration into the School

The third level of integration is into the school. This should be preceded by a psychological assessment and occasionally the psychologist will devise a special learning programme for particular children. This assessment may be further implemented in the Pre-School Nursery Class.

The Nursery is a most valuable assessment area and an almost perfect example of integrated activity. It is the common meeting place of Parents, Teacher, Psychologist, Speech Therapist, Physiotherapist, Occupational Therapist and Social Worker. The Nursery serves as an extended Assessment Area to ensure correct school placement.

It is also most important for mothers (and fathers) who have previously felt themselves to be in a uniquely unhappy position.

Meeting others with similar problems may permit some emotional outlet or, more important, a sharing of experiences in management.

The Department of Education in Ireland has the policy that all children should be integrated to ordinary schools — if possible. At present there are more than 100 Special Schools and more than 150 Special Classes in the country.

Most of us would agree that Special Schools or Classes are bad if you don't need them, but integrated education is not a cheap alternative to segregated education. Since it is essentially concerned with the improved quality of education, it is likely to be more expensive. It is certainly more expensive to make all school buildings suitable for the handicapped and to demand more professional expertise from all teachers. The necessary financial resources are not always available.

However, more and more handicapped children are being integrated

into the ordinary school system and this trend is likely to continue. Transfer should only be arranged after full consultation with parents and the new teachers. Such children should be carefully monitored and there should be a built-in arrangement to take them back to the Special School if this is considered to be in the best interest of the child.

In our school, we have experience of physically handicapped children with good intelligence who are illiterate and enumerate after spending three to five years in good primary schools.

To be effective, efforts towards integration at any of the levels discussed must involve good communication. In the Central Remedial Clinic, this communication is largely achieved at four weekly meetings.

One is a general staff meeting at which all the teachers, therapists, social workers, visitors and doctors attend. Decisions are made about new entrants, about school leavers or about children being transferred to other schools. Children with special problems are also discussed.

(Some parents often have more difficult problems and these may be best resolved by a special meeting between parents, teacher, psychologist, therapists and the doctor.)

The other three meetings are: one between the heads of departments, another concerning vocational training and placement, and the fourth about therapy. No meeting lasts more than thirty minutes.

Summary

It is not enough to provide services, it is also necessary to make sure they reach the people who need them most. It is important that one person have overall charge as without active leadership, a wide variety of well intentioned services may easily end up adding to the family's burdens.

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Brian P. Malone

In addition to those functions for professionals so correctly proposed in Dr. McConkey's paper, there is another whose appreciation could lead to massive benefits. To the disabled, the professionals encountered are also the licensed and much respected *representatives* of that society to whose value system the disabled are expected to adjust.

This paper considers the selling and acquisition of the self concept of being "disabled" — its typically unplanned introduction, its unmanaged development and re-enforcement. An empirical Irish study isolating the effects of being "disabled" on the goal-setting behaviour of young adults is noted.

It is suggested that society has three approved roles available to the person embarking on being disabled. The promotion of the best option of these three, if undertaken by the front line professionals and other opinion leaders, would lead to a significant improvement in the reality of what it is to be disabled.

THE MAKING OF DISABLED PERSONS

The layman, by and large, thinks of disability as something you acquire in hospitals. You may go in after a road accident, or with a virus, or just for tests, but after an interval you emerge fully kitted out as a Disabled Person — looking, acting and feeling the part. But hospitals do not see themselves as holding lead responsibility as society's main disability makers or shapers. After all, the main thrust of your hospital, and of the medical and para-medical professions it shelters, is to bring the consumer to the stage where he or she can be sent back out to what we laughingly call the normal world, *there* to rejoin the rest of humanity or civilization. The community is whatever is *out there*. It is a something whose time has not yet come until one is "discharged" into the less sterile air outside. Inside it *is* a different world. Through every sense organ, countless routines and special behaviours, your typical hospital is clearly a place apart.

This over-simple medical and marriage model of being "in sickness or in health" reinforces an artificial dichotomy of two separate worlds, in only one of which is found the community. That is just as foolish as believing in eternity but thinking of it as a one-way street, open-ended only at the *far end* and somehow choosing to ignore the present and the past as a

legitimate part of that same eternity. "For ever" does not start with death, and the community does not stop at the hospital door but extends inwards and backwards to wherever there are people. The fact is that it is that section of the community who happen to be employed in hospitals from whom the newly disabled learn their new status and against whom they must try out their new unwelcome identities. While neither patients nor professionals arrive free of massive pre-conditioning, the final stance of our survivor can be importantly and very helpfully shaped by the emotional and social trials, errors *and successes* lived through at this formative period. The technical contribution of the professions is obvious and appreciated. The human relational input of even being available as a model for reality testing by a personality in the course of reconstruction is arguably more important in determining the final nature of this "born-again" man. But this goes unrecognised, existing almost despite the professional and clinical systems. When a disabled person leaves hospital it is already, for the most part, too late to be moulding any new identity.

The Year of the Disabled is so concerned with educating the *general public* to a more positive awareness of what disability entails, that the important question of how their "disability" is sold to your actual newly disabled consumer is hardly considered at all. In fact, hardly any positive selling or counselling is done for that person. In there it is all unaided buying as the unreal twilight zone between the former and the future self has to be traversed with only the approval or disapproval in the faces and reactions of the significant others, to steer by and let you know what you are permitted to be and do in this new state.

Whether in or out of hospital, the condition of disability itself acts as a socio-psychological stimulus. The reactions to it are in turn to be seen as important influences experienced by both parties, and clearly expressed in:

1. The value-system of society.
2. The Socialisation of the disabled individual.
3. The rehabilitation situation.
4. The rehabilitation process.

We can briefly consider each of these in turn.

1. The Value-System of Society

We commonly allocate a positive and high value to the possession of a pleasing appearance and a good physique, and to be markedly deficient in either of these areas is to be disadvantaged, not only in a physical sense, but also in terms of social status.

Such a judgement the authors Barker and Wright classify as a prevalent social-psychological fact, saying of the person concerned that he is regarded as inferior not only with respect to his specific limitation but as a total person. "He may feel shame, inferiority, even worthlessness . . . it is also felt that, like a member of other underprivileged minority groups he "ought" to feel inferior, that he ought to know and feel his place." Those of relatively high value, the non-disabled or normal majority may be

unconsciously obliged to devalue the disabled and depict them as suffering a misfortune or loss, if their own relative position is to retain any meaning for themselves or for others. It is not the objective loss a person suffers so much as the value system of the judges that determines the degree of devaluation that will result. A classic "catch 22" situation operates here. The disabled person who does not acknowledge the misfortune of his condition and who makes an apparently good adjustment will be regarded as feigning his indifference, or else, as being an exceptional case. Here, it is society's reaction to the handicapped which constitutes the main source of maladjustment.

The operation of this influence was noted by Adler. He wrote "children with imperfect organs are overburdened. They may become discouraged by comparing themselves with those around them and their feelings of inferiority may be stressed by the pity, ridicule or avoidance of their fellows . . . they may consider themselves personally humiliated by the world".

Unemployment, a common consequence of disability, is a further source of devaluation in a culture where a person's work and worth may be judged as interchangeable measures. The achievement of some form of economic independence is a well documented "core problem" for the disabled. An extreme admiration of achievement, productivity, vigour, health and youth prevails, and the problems of the disabled are greater because of this basic distortion of the structure and of the value system of society itself. "Such a system of values moulds and reinforces an elaborate social hierarchy. The disabled are as much the inevitable victims of this system as the young professional and managerial groups are its inevitable beneficiaries." (Townsend)

Experiencing the operation of such value-systems the disabled person perceives a devaluating social distance between the non-disabled majority and himself. The uneven relationships necessary to such common attitudes as pity or patronage confirm to the disabled person the widely accepted inequality of status.

As a result the physically disabled person might be expected to have more modest ambitions and to set a lower level of aspiration in his endeavours than his non-disabled counterpart.

2. The Socialization of the Disabled Person

The values of the individual, that he has internalised and made his own, are based upon what is presented to his mind as he exists in society. He cannot remain uninfluenced by these, and they partly equip him to be the kind of person that he is. "Man is a social animal" and is dependent on society for the content of his thoughts, his dreams, his ambitions, even many of his illnesses of mind and body. . . . It is only because they are part of society that individuals are endowed with interests, with aspirations, with goals. There is as much truth in this for the disabled as for the non-disabled individual.

To the extent that he internalises, identifies with, and adopts as his own

the value system of the broader society, and to the extent that that society devalues the disabled, the disabled person will support society's devaluation of himself. He will feel that his non-acceptance by others is largely justified. He will agree that a non-injured person is more valuable, more likeable, more worthy. He will suffer keenly that he happens to be on the wrong end of the relationship but he will see it as an unavoidable and natural fact to be supported as morally valid . . . the emotional devaluation of him must prevail. Such a person wishes then to be accepted by the non-disabled whose ideals and values he shares, but at the same time he feels that he ought not to be accepted.

Involved in the socialisation of the disabled individual is the emergence of the "looking-glass self". By this process the emergent self is said to pattern itself, where it may, according to what it can perceive, mirrored in important others, as society's expectation for it. Conformity to the expectation of the esteemed society is given high priority. Resignation may be paraded as a virtue and the victim is active in his own devaluation.

Those with congenitally or early-acquired disabilities are liable to acquire this outlook in the course of their normal development in society. Those with disabilities acquired later in life but who once tacitly supported the devaluation of the disabled, now transfer to an expected lower status role regarded by them as operating naturally and inalterably. *Has there ever been so clear an opening and a task to challenge preventive health education?*

3. The Rehabilitation Situation

It has to be said that the positive public image and professionalism of rehabilitation may obscure the fact of its essentially remedial nature. Rehabilitation offers a substitute means and its function is to cater to clients with acknowledged and abnormal problems. It is the inability to progress normally that causes clients to merit rehabilitation in the first place. Though aimed to equip its clients for eventual integration in the open community, the vocational rehabilitation situation itself is an experience in segregation based on disability. In an establishment catering exclusively for the disabled, the client experiences a constant confrontation with disabled fellow workers. Now there are widely varying differences between and among the handicapped, and it is recognised that their occupational acceptability is enhanced and the prejudice against them is reduced to the extent that they can be viewed as unique individuals — not members of a herd apart!

The rehabilitation situation, counter to this, allows an opportunity for the public to consider, and the disabled to identify with, a separate category of "disabled persons", and according to Festinger's "Process of Social Comparison" much group behaviour is concerned with associating with and becoming even more similar to those who are relatively similar to oneself.

The physical and social separateness of rehabilitation facilities increases the perceived deviancy of the disabled person, already inherent in his condition. He may become an easier target for discrimination and

avoidance because he has been made more readily recognisable and different from his fellowmen.

The rehabilitation situation includes also the professionals who largely determine what its content and quality shall be. In this they are influenced by the official concept of the disabled client as "an individual whose prospects of securing and retaining suitable employment are substantially reduced as a result of physical or mental impairment". Such clients, to be eligible for rehabilitation, will have been judged, by those controlling the situation, to have substantially reduced prospects in comparison to their non-disabled peers. This is compounded by the likely social distance between the rehabilitation worker and the handicapped person and by the worker's prevailing concepts and class stereotypes.

It has been well established that professional rehabilitators — working on the disabled — have measurably more negative attitudes towards disabled persons than do fellow employees working alongside or with the disabled. In addition the rehabilitee's own interpretation of his situation may reflect some negative, if realistic, elements. He experiences at least a marginal awareness that he has reached a dead end where it is beyond his power to overcome his milieu. For those whose role hitherto had not been clear-cut, considering themselves neither disabled nor normal, the rehabilitation situation may, paradoxically, confirm them in their role as disabled persons. The relief is gained of having to observe less demanding standards, but any status beyond that of a tolerated minority-group member, may be forfeited. Whether up and about or in bed, disabled veterans feel their inability to earn a living much more strongly at home than at a hostel where, in a community of fellow-sufferers, everybody is in the same position. The presence of the client in the rehabilitation situation may have a lowering influence upon his status valuation in public attitudes, in the attitude of rehabilitation workers, and in the attitude of the client himself.

4. The Rehabilitation Process

The relationships and procedures operating in the process of rehabilitation may also contain elements damaging to the confidence and self esteem of the client. The worker-client relationship tends to be an asymmetrical one, with the professional person occupying the higher status position and the disabled person may easily feel in a dependent position. It is just such an atmosphere, of a wise and powerful one on the one hand and a dependent suppliant one on the other, that so easily can nourish the feelings of inadequacy and personal inferiority that true rehabilitation seeks to avoid.

The client may also feel that he is being bounced around from one service to another.

An internal report described clients, after intake to rehabilitation as "routinely sent on rounds of assessment procedures, the meaning and importance of which, to him, were probably obscure and confusing". Professional workers are cautioned to de-emphasise the power of their own

FIGURE 1

**A Comparison of the Aspiration Level of Disabled and Non Disabled Subjects
(In terms of Initial Goal Discrepancy of Reality Index)**

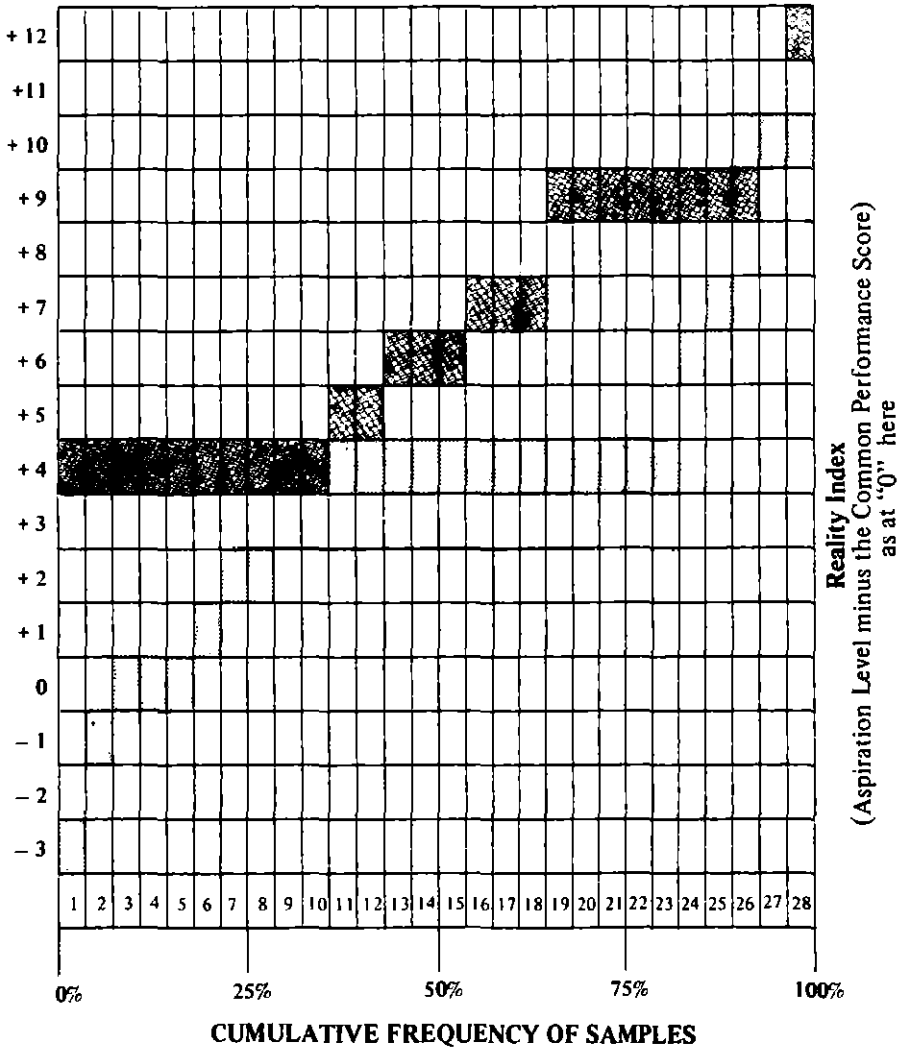




Figure 1

 Disabled N = 28
 Non Disabled N = 28

roles and that of the rehabilitation machinery, lest the client abdicate responsibility for solving his own problem — the aura of authority and power must not lead the client to expect that the agency will resolve his problem. Failure to achieve the clients involvement and participation results in his becoming passive and dependent in the rehabilitation process. The most common means of securing his participation — the vocational case conference — can, for the low-status client, be a stressful confrontation with a high prestige professional team, and, under these circumstances, client participation may more often be described as acquiescent rather than truly active. The majority of rehabilitation clients come from lower-level socio-economic groups. As a result, the preconceptions of the professional-level worker, and in practice his unilateral decisions on rehabilitation goals, may be quite inappropriate and may provide a negative psychological climate for a productive relationship and outcome.

To the extent that the rehabilitation situation is perceived as conferring a lower status upon the disabled client, and to the extent that the rehabilitation process is an occasion of passive and dependent client behaviour, there will be reasons to expect a lowering of the disabled person's self esteem, ambition and level of aspiration.

Local experimental findings serve to show that the effects here suggested have a reality more substantial than mere speculation. Concrete results from a study of disabled and of non-disabled Irish apprentices, matched closely for age, intelligence, family economic status, and occupational prospects, demonstrated a statistically significant difference in their goal-setting behaviours although measured after identical attainments. (See fig. 1):

While still in hospital, patients probably exhausted themselves allaying the ill-concealed anxieties of their visitors — who is comforting whom? This continues into the wider community where far too much scarce energy has to be expended in masking the disabilities — “shamming” so that one can hopefully “pass” as if belonging completely among the non-disabled — *and* so that the real non-disabled are not left feeling too uncomfortable.

The identity problem already agonised personally with the disappointment of zero to limited recovery, is now echoed outside in the insistent questions of others — “but you will get better, won't you?” This simple all-or-nothing demand on physical health where one must be classed as belonging either to the ill or the well leaves precious little room for the disabled seeking a tenable and credible middle-ground for existence in the broader community at home, club or workplace levels. While neither sick nor yet recovering to full health, a desperate onus is on the person who is disabled to prove by demonstration and by argument that *many* important aspects of his existence and personality can still be regarded as conforming to the normal.

The second traditional option is just as extreme but made easier to swallow with the nostalgic flavour that everyone knows where they stand. Involved here is the emotional and financial cashing in on the dependent state of disability for all it is worth. Throwing in the towel in this calculated act of submission may leave the thinking public confused as to what status

the disabled wish for themselves. Such parading and trading certainly triggers some curious natural reflex in the community to the great profit of those still going for this easiest option of "turning professional". Sadly, one is reminded of how well rewarded is the act of submission in the animal world, even among wolves.

The remaining option, at once modern and mature, is the one to be advocated more forcefully for the disabled themselves and to be accommodated more generously by the community — hopefully led by its enlightened professionals. Here folk will simply be themselves, and proud of it.

Without undue hang-ups, they neither hide nor exploit their disability which they rightly regard as just *one* dimension of the multi-dimensional self. Different but equal their charity too begins at home, inside their own heads, and comfortable in a proper self-regard, they can increasingly let the world — their world too — come to terms with them.

Expanding the notion and practice of a common or shared citizenship is probably one of the main bits of business of the Year of the Disabled. The recent Snowdon Report spoke of there being "two nations" present, so great was the social and economic deprivation experienced by the disabled. In fact many could not be classed as part of the common society at all. The point has not been made well enough or often enough that the disabled are *not* some self-contained others or "out-group" requiring special category status. So do let's "Smash H Block" indeed where "H" means a separate Handicapped block in society. There is hardly a family in the Country without a member or a relative disabled in one way or another. It is also inescapably true that with accidents, illness or simple ageing over 60% of the population are destined for a disabling condition at some stage of their lives. Altruism and all the nobler motives apart, enlightened self-interest should be sufficient cause to stir us to improve the physical environment and the psychological climate on the very good insurance probability that many of our families, our friends and ourselves will reap a direct benefit.

FOOTNOTE:

Figure 1 is taken from "The Aspiration levels of Persons with a Physical Disability". Malone, Brian, M.A. (N.U.I.).

Brian Malone, B.A., M.A.

A counsellor with the Schools' Psychological Service, Dublin City Vocational Education Committee. He is Chairman of the Irish Wheelchair Association and Chairman of their Educational Working Group.

He studied applied psychology at University College Cork. His M.A. thesis was entitled: "The Aspiration Levels of Persons with a Physical Disability".

CHAPTER SEVEN

Full Participation and Equality

*Edited transcripts from tape of presentation on conference overview by
Prof. Vida Carver, The Open University.*

The Health Education Bureau encouraged me to be a little fly on the wall during the Conference and to follow the proceedings in my own way. I listened hard; I listened to every lecture; I attended groups; I talked to individuals. What I've tried to do is to pick out certain recurrent themes. I shall try to deal with the major themes and some hidden themes which seem to me to be important as we went along.

The word that buzzed around almost more than any is a word which I suddenly took a dislike to in the course of the conference. The word is integration. The word integration is opposed, and I think in false opposition, to something called segregation. I think that sometimes, those of us who speak the anglo-saxon tongue, are a little ready to rush into the latin end of it and sanitise our ideas, to take the reality out of them by using a word like integration which has got no feeling, no reality in it. Integration becomes a nonsensical notion once we have fully accepted that there ought not to be segregation. To be talking about integration now implies that we've erected a false barrier in our minds and we build real barriers in the real world to match it. But now, the barriers, mental and real, are crumbling. So, when we try, as we did in this conference, to define integration, we are talking about something which really ought not be necessary to define.

The real title of the conference is "Beyond Disability" and beyond disability, there is simply a human being, an individual human being. Somebody in one of the groups said we ought to be able to define normal and when you get faced with that sort of remark you realise the essential nonsense of the two concepts, integration and segregation. I thought rather frivolously about how one defines a human being and I've come up with a sort of definition not to be taken too seriously. What do we know about a human being? Well, the first thing, in fact the only thing, the only immediately obvious thing, is that a human being is not a God. Therefore,

with some rather dodgy logic, we conclude that a human being is a creature of imperfections, with blemishes and weaknesses. Indeed, human beings come in a rich variety of shapes and sizes, colours, sexes and so on, so varied that the imagination boggles at the notion of what we could possibly mean by an average human being. Well, we all know how to calculate averages, add up the individual instances and divide by the number you first thought of. I began to think of how you define a human being in that way. So far as colour, the average human being is perhaps a yellowish-brown with a few streaks of red here and there, and a little speck of faint pink to represent the European races. For shape, he probably has 1.999 legs and 1.99 arms and 1.99 eyes. When you come to sex, it gets even more comical. I suppose, we would have to say that a statistically average human being would be a hermaphrodite with only one breast. Really, I've only said this to point to the stupidity of trying to set something normal against something different.

Beyond disability there is a human being, there are millions and millions of us — any single one of which compared with the highest of the lower animals is complex, rich in experience, able to do all kinds of things and all sorts of feelings and emotions and potentials that the rest have not got. Now, that I think is perhaps the most important theme that I saw coming out of this series of lectures and discussions. But what we are into now is not averages, nor average disabled people, nor average non-disabled people, but ordinary individuals with individual problems. Also, when we talk about his emotional-social problem, we are talking really about functions of the whole person — not separate functions which are apart from his learning, his intelligence or anything else — we are talking about a whole person. That is what this conference was about: whole, individual people, not statistics.

The second thing which seems to me to have come over loud and clear is, that the individual is asking to be treated in just that way — as a person who can and will take responsibility for his own life. Such a person needs information above all else and some practical help to remove the barriers which, at present, separate him from the rest of us. A major theme arising is that the revolution is underway — it's all begun. The disabled people have raised their banner. They are marching in front of the rest of us and we have just got to keep up with it, like a great river in full spate.

This came home to me very forcibly when the discussion took place on sexuality and there were three very interesting and thought-provoking lectures on this subject. At the end, there were questions coming forward; perfectly reasonable questions, and they took the form: should we allow young people to do this, to do that, should we allow mentally handicapped people to behave in this or that way? And I suddenly thought what on earth are we talking about? How could we stop them? The only way we could stop them now would be to take a massive step backwards and pass new legislation to go back to the old days, push them all behind bars in the workhouse. What do we think they have been doing?

When I tried to grapple with the rather complicated statistics, it seems to me that there are now far fewer places and facilities for adult mentally

handicapped people than there are for children in special schools. Places, I mean, where we might have any influence at all on their behaviour: training centres; clubs; take the lot, there are far fewer of them. How can we stop the people from doing what they choose? How could we in fact, ever have stopped them? They have been doing what they chose for a long time.

Children are selected for special schools, still largely on the basis of something called an intelligence quotient, which, if it measures anything, and I think it does, measures scholastic ability. It says nothing about feelings, it says nothing about loyalty, capacity to make human relations at all. It doesn't even say if you can boil an egg properly, which is the sort of thing which happens in ordinary life. Now, probably there is no stage in life when higher demands, intellectual demands, are put on you than when you are at school. At school, we make heavy intellectual demands on the children and my suspicion is, supported by some research, that the majority of mildly and possibly of moderately mentally handicapped young people do the same as other children when they leave school. When they have moved away a little way from the influences of school, and melt back into the general population according to their natures, or according to the way they have been taught while they were at school, they get married, find jobs or they may do dreadful things, like have illegitimate babies or they may end up in jail with many rich and clever people. They behave according to their own particular natures and we can't do anything about this, except, as I said, put them behind bars or take on the sort of programme which was suggested during the discussions on sexuality: that is, use the time when they are at school to assist them to understand their own feelings, assist them with advice, with guidance, set the problem in context for them, and trust them to make what they can of it. Our problem is to help and advise while we have got the opportunity, to help them to talk it through and then, whether we like it or not, they will do what they find appropriate, what they find fits into their own life pattern and their own nature.

I used that particular subject area to develop this theme because that is where it seemed to me to come over most strikingly. The fact that it is all happening now and what we have to do is to catch up with what is happening.

On the first day of the Conference Peter Mittler, in his very comprehensive keynote address, analysed the needs, as he saw them, of disabled people and their families from infancy right through childhood and adolescence, up to adult life. He spoke about obstacles in their path and I remember somebody in the discussion later questioned his use of the word obstacles on the grounds that obstacles are something immovable. I thought about that but it seems a good word to me. I think there are obstacles, concrete physical obstacles, and social attitudinal obstacles still standing in the way of disabled people — and they are real obstacles. I remembered the old obstacle races at school when we had sports day and we faced a long row of unpleasant objects put there just to torment us. We had to climb over them or scramble under them in order to get to the goal at the end with rather sore knees. But all those obstacles had actually been put there by our teachers to please themselves really, because they thought an obstacle race

was good for the girls. At the end of the day, we went home with our sore knees. I am comparing those obstacles to the stairs, which could be replaced by a ramp, the machinery which could be adapted for a blind worker and the unsuitable housing and kitchen equipment which make it difficult for a disabled housewife to get on with her job. They were all designed in the first place to please non-disabled people. As far as the disabled were concerned, it was good for them to "come to terms" with their disabilities — even if it gave them sore knees, or worse. Some of the obstacles are even more solid and substantial; like the walls around some schools and institutions, those solid buildings which hold people apart, and one day I think somebody will go along there in a wheelchair, with a stick of dynamite, since that is the fashionable way of solving such problems, but I hope it won't come to that. These are the obstacles of the physical environment. There are other obstacles of course and, in a way, even more intractable and they reside in the minds of other people — social obstacles on the road to integration — I'll come back to that theme a little later.

It was on the second day of the Conference that I became aware of two hidden themes, which, because they didn't receive any comprehensive treatment in the main lectures, seemed to cry out for explicit treatment.

It began with the short quotation at the beginning of Desmond Swan's very sensitive analysis of the stress points in a child's career. He spoke of "that silent place where a child's fears crouch". In our schools there are children, each living an individual life, each facing his own personal problems, not just when the teacher is there or when the psychologist is busy assessing, but when the doors are closed. Behind the teachers and in all the private times in the playground, at home in bed at night, and even, in the classroom where the eyes may be fixed on the blackboard, but the mind might be quietly preoccupied with its own concerns. One element in that privacy, according to Desmond Swan, could be fear.

Words sometimes detach themselves from their immediate context and seem to repeat and repeat in another context and all through that second day, I found myself noticing that word "fear" coming up in new contexts — it was quite spooky. In a group session, a teacher in an ordinary school spoke of her fears for the disabled child who might suddenly appear in her classroom as part of an integration programme and of her fears for herself too. Would she know how to cope with his special problems? Another teacher was afraid for the other children in her class who might not get the attention they deserved, if she found herself distracted by a handicapped newcomer. Later in the day, fear came out again, the parents' fears as they wait to be told what is wrong with their child and the fears of the professional telling the parents the truth as he sees it. All incidentally, according to somebody else, compounded by the fear of becoming handicapped oneself.

Now, the only thing to do with fear, as soon as you realise it is there, is to face it, and then try to look at what is causing it and see if it is justified.

The second hidden theme, for me, emerged when Des Kenny spoke. For the first time at this conference, we had a disabled person speaking boldly and frankly about his own experience of his own disability. It was an

individual statement.

Disability, said Des Kenny, is a label suggesting one psychology for a homogeneous group. Yet disability has many causes and the disabled are a group only in so far as the services surrounding them give them group identity. At that point, I realised that if we were honest, we had only been talking at second hand and in a generalised way about the needs, feelings and problems of disabled people. We were talking rather about the problems that "they", the disabled people, created for "us" in the services. This is, of course, a perfectly legitimate thing for us to be doing, since there are problems which we have to solve and we are the services, but we do have to remind ourselves that our problems and the child's or the adolescent's problems don't always coincide precisely and the major concern of a conference like this should be to bring them into closer coincidence.

Des Kenny didn't speak of fears, but he did speak of a sense of bewilderment in adolescence, of long delays and broken promises and in a vivid phrase "of being hit by a storm of frustrations".

Later in the conference, Brian Malone also took up this hidden theme and gave another personal testimony from the stand point of a disabled person. It was at this point that I began to conceive the idea of cheating on the kind people who had paid my fare to come here, and to offer, not an overview of the conference, but rather a kind of underview, from the experiences of disability: a commentary upon our themes from the standpoint of disabled individuals. I remember that we did have in Peter Mittler's opening address one such testimony when he read the story of Christy Brown and his first lesson in writing. I think that this reading came over as an experience which excited everybody at the Conference — it was something that we listened to but we didn't analyse. So what I want to do now is to try and draw out something of the total picture in which Christy Brown had developed and what must have gone before, because Christy Brown's ability to write the letter "A" wasn't something that suddenly came out of the skies. I tried to think of what the preconditions were. To anyone outside the family, the infant Christy may have been perceived as an almost totally disadvantaged child and, yet, he had some very real advantages. Firstly, his parents loved him unquestionably and they cared for him and ensured his full integration into a large family, and, secondly, in the environment of an affectionate, if overcrowded home and sunlit garden, all Christy's unaffected senses, sight, hearing, smell, taste and touch, were continuously stimulated. His mother, in particular, and the other family members, if you remember, talked to him continuously and by the age of five his understanding of spoken language was already well advanced. If he had been thrust aside behind a barrier, this sort of thing could not have happened — could it? He couldn't have understood language in the way that he did. He had even been introduced to books early in life and his sisters and brothers provided him with a model, which he was very ready to copy, in the use of writing materials.

Now, of course, most importantly, Christy himself had the natural ability and the motivation and the determination in his own unanalytic way, because he was only five years old, to take advantage of his assets, and he

had obviously already unconsciously prepared himself for this first lesson in writing by acquiring some control over the movements of one limb and he also had the untaught ingenuity to substitute the use of his toes for his fingers when his chance came. One last thing that I think is also important, was that his achievement was recognised and reinforced by the family as an occasion for general rejoicing.

So really, it wasn't quite such a simple story as told by Christy in his first chapter. We might say that Christy's success was a triumph for total, unquestioned integration.

Now, I can't apply this type of analysis to all the things I want to say, but I do want to pick up some themes from statements that disabled people have made about various points in their lives. None of them are typical, I am not doing typical things, I'm doing a rather difficult thing in trying to throw individual things and leave you to come to conclusions about them, which I hope will not be to say "Ah, now we know how disabled children feel on these occasions".

We can take another episode from Christy Brown's childhood story actually, because it wasn't a 100% success story; a much shorter episode which shows how the common experiences of childhood can in certain instances be made much more stressful for a disabled child and how isolated such a child can be when he is facing them. One of the urgent hidden problems that face all children is the development of a stable self concept, which is a long and gradual process, punctuated sometimes by sudden revelations, some pleasant some unpleasant. These for a handicapped child will include the incorporation of the concept of "handicapped" into his own idea of himself. One part of this process will involve his own direct observations and comparisons of his own activities in a situation, in comparison to those of other children. A second will come to him from how other people treat him and from what they say to him about himself, and as he grows older he may, like other children and adolescents, experience conflict about his identity when his image of himself seems at variance with what he is learning about other people's. In the case of a handicapped child, this conflict may be intensified if the behaviour of some of the people he meets betrays prejudiced attitudes towards his ability.

Now this short episode from Christy Brown's story illustrates how painful the realisation of his own disability may be for a handicapped child. Although Christy couldn't walk, you remember, his handicap in boyhood was much reduced by a rusty old go-cart, known in the family as his chariot, in which he regularly ran the streets with his brothers and in which he also fulfilled a special role of guardian of scrunped apples. On one of these occasions, he even taught himself to swim. But, one day when he was ten years old, the axle of the go-cart snapped irreparably and he says "Everything was changed. I was thrown upon myself at last. The queer idea that there was something wrong which had entered my mind sometimes — now loomed larger. A few days later, I was sitting in the front garden playing with toy soldiers, with my brothers, when along came some of my pals carrying fishing nets and jam jars on a string. There was a rush for fishing nets and tackle and everybody was excited. They all crowded at the

gate ready to go. As Tony was going down the path, I looked up at him dumbly, appealing silently. He stopped. This was the first time he had gone anywhere without me. "Sorry Chris", he said, not looking at me, "we will bring you back a lot of pinkeens". He moved away quickly. I was left alone in the garden. I looked down at my hands — twisting and twisting — the bottom had just fallen out of my world. I was now ten, a boy who couldn't walk, speak, feed or dress myself, I was helpless, but only now did I begin to realise how helpless I was. I still knew nothing about myself. I knew nothing beyond the fact that I was different from others. I didn't understand what made me different or why it should be, but I just knew that I couldn't run about or play football or climb trees or even feed myself as others did. I couldn't reason this out. I couldn't even think clearly about it. I could only feel it, feel it deep down in the very core of me like a sharp needle that worked its way through all the fancies and dreams of my childhood till it tore them to shreds — leaving it naked and powerless to avoid this stark reality that I was a cripple. Until then, I had never thought about myself."

Now, after that experience, Christy reports that he went through quite a long period of deep depression and even when his parents managed to replace the go-cart with a proper invalid chair, with a nice padded seat and rubber tyres, he refused to leave the house, except occasionally. But he did recover his self possession later when somebody gave him a box of paints and he started to paint. But was that long agony really necessary? Perhaps it was. Perhaps there wasn't anybody who could have talked to Christy or explained things better before. Perhaps his very acceptance in his family made that a barrier but there is some interesting evidence that children, at least in British schools, are going through this same sort of experience now.

Madge and Fassam (1982) made a systematic study of the experience of disability in school children by asking the children themselves. They talked to physically disabled children in a special school, both juniors and seniors, and to seniors recently integrated into a co-educational secondary comprehensive school. They also talked to non-handicapped children about their attitudes and feelings about disability.

In general, the children talked very freely and without hesitation and were extremely frank and objective. One of the authors told me that if any child showed the least hesitation they stopped all questions. Very often the children came back to them and said they wanted to talk. So they got a great deal of very frank information and it is difficult to give the flavour of this, but it was quite clear that the children themselves thought a great deal about their disability. They were able to describe its functional effects in considerable detail. For example, one junior boy could say this: "I seem to loose my strength when I pick up chairs. It sort of hurts, when I go upstairs. I go up so slow dragging my feet. It hurts my back when I bend, when I jump, and I can't jump very high. When I walk I kind of start to drag my feet along the floor — I have to take a rest. I keep thinking I haven't got a proper heart — that is what I keep thinking, the way I lose my breath and everything."

Now, of course, he is a very ordinary kid. He doesn't use the splendid

language that Christy Brown used as an adult looking back on his own childhood. But yet, that child, who could tell so much about his functional disabilities, about the things he could and couldn't do, and could do it in so much detail, had no idea of the cause or the nature of his disability because nobody had ever talked to him about it. This sort of ignorance was very wide-spread in the school. The children worried frequently after information and that was one of the reasons why they were eager to talk. Yet very few ever discussed their disability with anyone. In fact, only about quarter talked even to their parents about it and very, very few mentioned confiding in anybody else, including a teacher or a minister of religion. They talked a little bit, some of them, to brothers and sisters, but not a great deal.

Now this was not necessarily for bad reasons. A few it seems were so secure at home that they said "the subject never crops up" and I think that may have been the case with Christy. But I think it is something we ought to be alerted to — if it is going to create a crisis later for the children. One girl showed a rather sad maturity when she said that she wouldn't talk like this to her mother for fear of upsetting her. But, on other occasions the reason really did seem to stem from the parents' unwillingness to talk.

This is a girl, of about thirteen, an integrated pupil at the comprehensive school. She said that her mother is "like them here, she don't care. I say she don't care, I don't think she does. If I talk to her she just don't bother listening, I tell her people tease me at school, she says it is good for me — you just get the feeling she don't care. So everytime there is a meeting at school, I just forget about it cos I know she ain't goin' a come". A boy at the special school said he hardly ever spoke to his parents, because when he was worried "they are too busy and they say 'What are you on about?'"

So we mustn't assume it is all easy at home for these children. It is also quite clear that these children are facing, in their schools, continuous stigma and rejection, on top of the disability itself. They usually don't even think of actively seeking support.

A boy spoke of "people teasing me. Boys you know copy the way I walk and the teachers shout at me when I don't do nothin'. Say somebody done somethin' and she, the teacher, caught me looking, she thinks I done it, but I never and then I sort of shout and lose my temper and sort of swear and stuff like that — I don't mean to, its just they don't understand."

Well, we are looking at a child's eye view. We don't know what the teacher's view would be of that, but after all, we are reporting on how people feel, not on facts or situations, and it is how people feel that we are concerned with here.

Now, it is interesting that some of the older and more sophisticated pupils, particularly at the integrated school, were really beavering away at trying to get information about their disability and they got wise to the idea of pressing the doctor. One girl, for instance, a girl of seventeen, the oldest girl in the whole group, had worked very hard to find out, first the name of her disability, "sickle cell anemia", and then a little bit about it. She describes how she is working on this and she is seeking for new information.

Notice how she feels she has to go about it rather cunningly: "I'm trying to find out what they can do about my limp and what they can do about fitting me with a new joint, because at the moment I can't bend my leg, because the joints in that leg are stiff. They explained to me that if they gave me an artificial joint and it got infected then they would have to take it out and then they would have to fuse both bones together because they can't put the bone they took out back, so my leg would be even shorter. I have only found that out recently. They don't approach you — you have to ask them. You have got to go on asking. It is only because I talked about it a great deal recently and told them "Look, I have a lot of pain. What is going to happen to me when I start working?" that they decided to start some treatment."

We have heard this story before, haven't we? With mothers worrying about "what is the matter with my baby?" I think this is a very common theme that has been running right through the conference. The need for information, hard information to help people just to know what is going on as a starting point for making their own decisions, if for nothing else.

Still, the other very positive side to all this, which I think does need pointing out, is that in the face of a multiplicity of problems, these children seem to show great resilience and have perpetually asserted their independence.

A fifteen year old girl with spina bifida, for instance, spoke about getting dressed at home, "My Dad used to do it up to when I was about twelve. Then one day I said no, I've got fed up with this, I'll do this myself now, so he stood and watched me do it. Then he let me do it on my own. 'Cos up to the time I was twelve, my mum was washing my hair and ironing my clothes and one day I thought this is a bit stupid, she can't do it all my life so I might as well do it myself. So one day, she went out and when she came back I had ironed all the clothes and she said 'Cor, you're getting good'."

I would like to give you one more quotation, since integration, in the narrow sense of bringing all children into the one school, is very much in people's minds here. This is a remark of an integrated pupil, one of the older girls in the comprehensive school, when asked about her reactions to her school. They are more positive than negative, but she weighs it up in rather a sophisticated way and I think you would like to hear this — how the children themselves are weighing up the advantages and disadvantages. "Well, I wouldn't like to say I *like* it, but then I don't *hate* it. The thing I like about it is you've got a chance to express the way you feel. You've got a chance to do what you like. Like at the old school, the games and your friends, they are just like you, handicapped. You have got more range of lessons here. At the old school you're sort of taught maths, English, cookery, but here you have French, all the different languages, Greek and things like that. It is harder work because at the old school I sort of took it for granted that's what we would be doing here. You know the sort of easy work, and I thought if I was good at it and attended to my books I'd get a good job at the end of it. Now I'm here, I am realising that it is a bit different. You have got to really study more and lots of things you've got to know. At the old school, they just sort of taught you — I didn't think you

would ever need to know more until I was here."

You can see the various perspectives that the child is facing, quite rationally working out for herself. I have given these quotations because they do make it very clear, at any rate to me, that these ordinary disabled children, even while they are still at school, in England anyway, have problems and anxieties that go far beyond any that these parents and teachers are aware of and that the children are active in trying to solve them for themselves. Like the adults, their problems are made worse because they just can't get hold of the information that would help them to put it together or the opportunity to express their feelings to someone who cares in an individual way.

Now, obviously, I don't know how these problems are handled in special schools in Ireland. This may be one of the lots of things you just do better than we do. But knowing about them is certainly part of the information that ordinary schools need when they are expecting to receive disabled children. Good information is the worst enemy of fear for teachers as well as for children.

If preparing children for life in the world they will inhabit in the future is a legitimate part of schooling, along with the 3R's, then a chance to talk their problems through should be built into the school curriculum and not only for the disabled children, but also for those who will be their neighbours in the community in the future.

Surely such questions should take precedence in thinking above some of the short term problems that are worrying people about toileting and ramps. Toileting and ramps matter of course, but as the problems they raise become clear, they should be quickly solved by human ingenuity, and the children themselves, provided they are asked, have no difficulty about telling what they need in the way of aids.

Any disabled person will be glad to help you, if you want to collect feelings and attitudes about disability. Particularly, if you tell him you are approaching him as a learner and you want him to be your teacher. You know disabled people get as fed up as anybody else of always being on the receiving end of instruction and good works.

The themes which predominate are the main themes of the conference — that beyond disability there is always a human being who is much more like other human beings than he is like anything else in the universe. He has interests, feelings, ambitions and strivings and he too has a continuing consciousness, and independence which persists, and I think this is, for some of us, the crunch, which persists right outside the context of any contact with the professional services. If we leave a question unanswered, we can't assume that the person who asked it or the parent or whoever it is will say, "right, I'll remember to ask him that when I come back in 3 months". He or she will go on beavering away in his own way, collecting as the doctors might say, old wives tales. But if the doctor won't tell him, he may have no other recourse but to his mother-in-law to get the sort of information he is going to use to try and help him get on with the job of living.

Secondly, what he really wants from us is not the ready-made solutions

which it would be so convenient to give. You know we all have a stock cupboard of solutions, sometimes material solutions, aids which don't quite fit at times, advice which was useful in the case of Mrs. Jones which ought to do for Mrs. Brown because her case is rather similar, this kind of thing. But they don't want ready-made solutions which solve *our* problems as experts and helpers — they want good hard information to help them solve *their* problems in their own way and they want access to the practical resources to which we hold the key.

Thirdly, it seems to me, and this is an individual feeling, that the way to respond to an individual and to forget one's fears of his difference, if one has such fears, is to respect his essential sameness, his right of equality and participation.

Now I am trying to answer the question who gives the information, which again seems to me to be a very odd question. I say who gives the information you do, I do. The individual human you to the individual human person. If it is incomplete, or you're not sure, you tell him so, you tell him what authority you have or what authority you don't have for saying it. You tell him as you would frankly to any friend and you try to show him where he can get better and more complete information if what you are telling him is not complete. I am afraid that this may sound rather a simplistic answer but for all except some very complex problems to which we have to say "This one is too difficult for one. Let's try and find out together." I think really that the basic starting point is here for all the rest. And do remember that the revolution is already advanced. The river is in full spate and we have got to swim very fast if we are going to keep ahead of the flood.

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Prof. Vida Carver, B.A., Ph.D.

A psychologist with the Open University. She was responsible for the development of two courses: "The Handicapped Person in the Community" (jointly with Prof. T. Williams) and "An Ageing Population".

She has acted as Chairman for the Open University's Co-ordinating Committee for Disabled Persons and she served as a founder member of the Executive Committee of the National Bureau for Handicapped Students.

Her recent publications include: "Disability and the Environment" (with Michael Rodda).

Rapporteur's Report

John Heuston

Health Education Bureau

In order to facilitate the gathering and presentation of the many recommendations made in the course of the conference, the participants formed a number of working groups. These groups then considered the major constraints which impede the proper integration of disabled persons. The constraints were then grouped under a number of headings (educational, political, economic, demographic, psychological, sociological etc.) and were presented to the conference during the final session with suggested recommendations to overcome them.

EDUCATIONAL GROUP

Group Leader: Frances Mannion

Constraint 1

Poor communication between groups of professionals and between members of the same professions.

Recommendations:

1. The full team of professionals dealing with the disabled child/person should be present at all case conferences, including parents, at decision making stages. When appropriate, the disabled person himself should be present.
2. In the case of referral of a disabled child to the psychological or other specialist services, a child should be seen by the psychologist in the classroom environment so that his interaction may be observed and discussed with his teacher.

Constraint 2

The lack of pre-school services available for the emotional and social development of the disabled child.

Recommendations:

1. It is recommended that the Departments of Education and Health should give serious consideration to further extending pre-school services by providing finance, staff training, transport and other back-up services.
2. When appropriate, disabled children should be accommodated in the general pre-school system.
3. Existing domiciliary services for pre-school children be intensified and diversified.

Constraint 3

The present examination system places the disabled person at great disadvantage.

Recommendations:

1. The present structure of the examination system should be completely revised to include on-going assessment of particular individual differences. Also, the present "once-off" "make or break" method of examination should be totally abolished.
2. Third level institutions should review their entrance requirements to take account of the special circumstances of some disabled students.
3. Disabled young people, unable to achieve group cert level, should be assessed on their own merits for entrance to training courses.

Constraint 4

Inadequate adult education provision for disabled persons.

Recommendation:

The particular needs of the disabled in the area of adult education should be considered by the bodies providing these services.

Constraint 5

Teacher training, in relation to the special needs of disabled persons, is deemed to be totally inadequate in this country at the present time.

Recommendations:

1. Inservice training courses should be urgently made available for second and third level teachers who teach disabled pupils.

2. The basic training of all health and educational personnel should include a compulsory module relating to disability and handicap.
3. Relevant in-service training should be available to all personnel involved in the service of the disabled.
4. Proper training courses be provided for teachers of the blind.

Constraint 6

The lack of a programme to meet the needs of young disabled persons leaving special classes in primary schools, with which they can continue into second level education.

Recommendation:

Provisions should be made in second level schools to meet the needs of all disabled pupils.

Constraint 7

Frequent poor relationships between parents and teachers.

Recommendations:

1. Parents should be encouraged to approach teachers e.g. by means of "open days" in schools and clinics as well as formal parent/teacher meetings.
2. Home visitors should be appointed to act on links between home and school.

Constraint 8

Inadequate training in developing social skills in disabled children.

Recommendations:

1. Expeditions to settings outside schools and clinics should be arranged aimed at improving awareness of the everyday social environment.
2. The facilities of AnCO, N.R.B. and community centres throughout the country should be better utilised to provide training and social skills.
3. The disabled should have the opportunity to avail of situations where they give of themselves in terms of time and work.
4. A unified training programme in social skills should be developed.

Constraint 9

Inadequate preparations of disabled persons for leisure activities.

Recommendations:

1. Hobbies should be encouraged in order to develop better use of leisure time.
2. A comprehensive programme of education for leisure should be developed and implemented.

INSTITUTIONAL GROUP

Group Leader: Eamon O'Murchú

Constraint 1

The lack of suitable accommodation for adult handicapped persons.

Recommendation:

Suitable facilities and services should be made available to enable adult handicapped persons to reside in the community rather than in institutions.

Constraint 2

A lack of appropriate placement facilities for persons with multiple handicaps.

Recommendations:

1. Residential and assessment centres should be provided to ascertain which is the primary handicap and to ensure appropriate educational placement.
2. All institutions which cater for multiple handicapped persons should be provided with adequate finances and the necessary resources and personnel.

Constraint 3

The impersonal nature of large institutions and the general lack of privacy in such places.

Recommendations:

1. Disabled persons residing in institutions should be in a position to exercise choice in matters of clothing and domestic arrangements e.g. personal laundry facilities for small items, facilities for hygiene and grooming.
2. No disabled person should be based in a unit accommodating more than four people.
3. If disabled persons are accommodated in a ward setting, curtains should be fitted between all beds.

4. Travel vouchers should be available to relatives of disabled persons at the institutions.

Special recommendations with regard to disabled children in residential care:

1. The experiences which the child in the open community enjoys should be made available in residential care.
2. Children should be allowed to exercise choice in matters of clothing.
3. Children should make their own beds and should assist in washing up and cleaning kitchen and bedroom areas.
4. All children should be accommodated in family size units of four children complete with kitchen and bathroom facilities and managed by a house parent.
5. All staff working in institutions catering for children should have specific training in child development.
6. Facilities should be made available for parents to stay overnight at residential centres.
7. Regular periods of play should be arranged with non-disabled children.

Constraint 4.

Attitudes of some religious and clerical managements in relation to segregation of the sexes in institutions.

Recommendations:

1. All institutions (including schools) should cater for both sexes.
2. In segregated institutions, every opportunity should be used to allow the disabled person to interact and socialize with the opposite sex in the local community.
3. A balance of male and female staff should be appointed to all institutions for the disabled.

PSYCHOLOGICAL GROUP

Group Leader: Pat O'Keefe

Constraint 1

Attitudes of some professionals.

Recommendations:

1. More specialists should be trained and recruited to allow sufficient time in their work for appropriate and sympathetic counselling.

2. Training in a particular skill is not sufficient. Training in communication in relation to that skill is also required.
3. Jargon should be avoided at all times.
4. Training in the principles of team work should be given when the approach is multi-disciplinary.
5. Appropriate privacy should be possible whereby the professional can meet and discuss with parents and/or other professionals.
6. Child care assistants should be allowed supervise a class while a teacher is meeting with a child's parents or other professional.

Constraint 2

The lack of counselling and support services.

Recommendations:

1. The counselling public health nurse service should be made available nationwide.
2. A person skilled in counselling should be available to inform parents of a child's handicap soon after birth.
3. Trained personnel from each voluntary agency dealing with handicap, should be available to counsel parents and families of children with the appropriate handicap.
4. The advice services of a person skilled in the area of play therapy and early learning activities should be made available to parents of pre-school handicapped children.
5. Screening services for children at the age of two should be seen to be available nationwide.
6. Use should be made of national television to provide suitable morning programmes for young children and mothers.
7. Contact should be maintained at all times between specialists from the different agencies dealing with the family of a handicapped child.
8. Parents should become familiar with the appropriate special school or service when it is seen that the child will be referred there.
9. Every special school should have a liaison officer working between the home and school.
10. Counselling on sexuality should be available to the parents of the disabled adolescent.
11. Flexibility in home help schemes should allow for help to parents who need it. The possibility of making available creche facilities was mentioned in this regard. As was the possibility of second-

level students undertaking such work.

12. Counselling facilities for the parents of disabled children should be made to siblings of the disabled.
13. Professional youth workers should be employed to work with school leavers in their social and recreational lives.

ECONOMIC GROUP

Group Leader: Joan Delahunty

Constraint 1

Poor financial support from the state resulting in voluntary organisations spending valuable time and effort in fund-raising.

Recommendations:

1. Fund-raising should be carried out sensitively, taking into account the self esteem of those who are to benefit.
2. All disabled interest groups should act together in exerting pressure for the provision of greater resources.
3. The image of the disabled should be carefully fostered in order to attract effective sponsorship by commercial interests.

Constraint 2

Current policy regarding the disabled is dictated by economic rather than the real needs of the disabled.

Recommendation:

Those working in the field at a community level with the disabled should be involved in the identification of their true needs, in terms of both health and education and, having identified the needs, should have some effective channels through which their views may be put to the relevant planning authorities.

Constraint 3

The emphasis on care of the disabled rather than prevention of disability.

Recommendation:

The education of the public concerning preventive measures is recommended since this would be of major long-term economic benefit to the community.

Constraint 4

Poor employment opportunities for disabled persons.

Recommendation:

More funds should be allocated to the infrastructure of rehabilitation e.g. accessibility to public transport, buildings, education of employers, in order to aid employment of the disabled in the community.

ETHICAL GROUP

Group Leader: Bob McCormack

Constraint 1

The fear of loss of rights of disabled persons.

Recommendations:

1. The disabled have a right to open and honest consultation with professionals.
2. Clear, simple language should be used by professionals in all consultations with disabled clients.

Constraint 2

Inability of some disabled persons to adequately represent their own interests.

Recommendation:

Those who are in the primary caring role e.g. parents, frontline care staff, should participate at all levels of decision making with and on behalf of the disabled person.

POLITICAL AND LEGISLATIVE GROUP

Group Leader: Ann McCarthy

Constraint 1

The lack of opportunities for disabled persons to express their political will.

Recommendations:

1. Disabled persons should be given the opportunity to exercise their franchise by means of a postal ballot.
2. Legal advice should be provided to families and clients as a normal part of the service.
3. Disabled persons should not have to 'beg' for legal rights and entitlements e.g. medical cards.
4. All residential institutions should be reviewed regularly by an independent body.

5. Caution should be exercised so that legislation does not become "segregationalist".

SOCIOLOGICAL GROUP

Group Leader: Maura Moran

Constraint 1

Poor level of public education generally regarding sexuality in relation to the disabled.

Recommendations:

1. Open and honest discussion on "sexuality and the disabled" should be encouraged.
2. The rights of disabled adults to give expression to their own sexuality should be actively promoted.

Constraint 2

Poor public attitudes towards disabled persons.

Recommendation:

The Health Education Bureau should carry out a campaign on public attitudes towards disabled persons.

DEMOGRAPHIC GROUP

Group Leader: Esther Lyng

Constraint 1

Poor spread in terms of location of residential care centres throughout the country. (Facilities tend to be clustered in or near large centres of population.)

Recommendation:

Special residential care units should be attached to local ordinary schools and community facilities.

Constraint 2

Lack of information for parents and professionals.

Recommendations:

1. A booklet should be produced indicating the services available for different handicaps. Such a booklet should also include a list of grants available and bodies offering such grants.
2. The services of community care teams should be better publicised at local level.

Constraint 3

Poor transport services for the disabled.

Recommendations:

1. C.I.E. should extend its system of free travel to include the parents of handicapped children travelling from country areas for consultation purposes.
2. An escort system should be introduced for young mentally handicapped who are travelling to workshops on the public transport system.

Constraint 4

There is a serious shortage of speech therapists in rural areas.

Recommendations:

1. More speech therapists should be recruited to work in rural areas.
2. In-service courses should be provided for teachers to train as speech correctionalists.

Constraint 5

Inadequate screening services for disabled children.

Recommendations:

1. Screening services should be provided for infants, with follow-up in local clinics.
2. An annual medical examination should be provided for every child, not just for those in certain classes, as at present.

Constraint 6

Lack of advisory service to teachers.

Recommendation:

Consultants should be made available to schools to advise on programmes, materials, behavioural guidelines etc.

ADMINISTRATIVE GROUP

Group Leader: Niamh O'Doherty

Constraint 1

Bureaucratic delays and constant re-direction of enquiries.

Recommendations:

1. One person in each government agency should be nominated to deal with a specific area of concern to disabled persons.

2. Bureaucratic structures should be improved in order to streamline delivery of services. The responsibility of each government department should be clearly defined in order to avoid confusion.
3. Care units should be set up for those not already catered for under existing services e.g. autistic young persons.
4. A continuous on-going service should be provided for those leaving special schools for moderately mentally handicapped at 18 years of age with a direct transfer to a vocational training centre.
5. School leaving age for moderately mentally handicapped should be raised to 20 years of age in appropriate cases.
6. It is strongly recommended that the medical and educational models be suitably combined with reference to the multi-disciplinary units. The leader of a team should define different areas regarding all aspects of a client's development and appoint each member of the team to his/her tasks.
7. It is strongly recommended that the Schools Psychological Service be extended to primary schools and that a direct service be made available to special schools.
8. There is a need to improve the relationship between voluntary groups and state agencies to maximise resources. Voluntary bodies should be recognised as being valuable assets to the community in economic terms. Furthermore, they are often seen to be more humane than governmental institutions.

Finally, it is recommended that the Health Education Bureau be asked to develop guidelines for co-operation and communication between institutions and organisations in the field of disability.