

The Inclusion Assistant

**A training course for supporters of young people with
high level support needs within mainstream education**



Published in 2007 by the
Alliance for Inclusive Education

This pack is based on the thinking of young disabled people with high level support needs, with contributions from young people at George Green School to whom we are indebted for their welcome and assistance in thinking about the need for an Inclusion Assistant.

Our thanks also to:

Lucy Mason who supported young people to think about what they wanted.

Chris Goodey for talking to disabled adults and other parents helping us to focus on the need for this role.

Developed and written by Micheline Mason and Christine Burke.

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You can order more copies of this pack from:

The Alliance for Inclusive Education
336 Brixton Road
London SW9 7AA

Tel: 020 7737 6030
Email: info@allfie.org.uk
Website: allfie.org.uk



Contents

Introduction:

The Building of Inclusive Communities	5
Why an Inclusion Assistant?	17
How to Use this Pack	21
Aims of the Training Course	23
Definitions	24

Module 1.

The Right to be Valued	30
------------------------	----

Module 2

The Right to a Positive Future	41
--------------------------------	----

Module 3

The Right to Be Safe	58
----------------------	----

Module 4

The Right to Have our Physical Needs Met.	70
---	----

Module 5

The Right to Have our Communication Needs Met.	83
--	----

Module 6

The Right to Have our Learning Needs Met.	91
---	----

Module 7

The Right to Have our Emotional Needs Met.	104
--	-----

Module 8

The Importance of Friendship	117
------------------------------	-----

Module 9

The Right to Have a Voice Within the School	133
---	-----

Useful Contacts	140
-----------------	-----

Further Training	141
------------------	-----

Appendices

1 The TA Debate	143
2 Direct Payments	145

Contents

Introduction

The Building of Inclusive Communities

There are many training courses for Learning Support Assistants and Teacher Assistants within schools. However, this is the first to be written from the perspective of disabled people and the Independent Living Movement.

The desire to write this pack came from our observation that a particular group of young people - those with impairments which required the one-to-one assistance of a non-disabled person in order to be safe and to function - were in danger of being left behind in segregated settings whilst their more able peers were being encouraged to join mainstream society and to help develop inclusive practices. This we felt was bad for the children concerned who are finding themselves in ever more restricted environments, surrounded by adults and unable to communicate with their classmates, and we felt it was bad for mainstream schools which were not being challenged to change their policies and practices sufficiently to cause the 'paradigm shift' from integration to inclusion. This in turn is leading to some parents and teachers questioning whether mainstream schools could really be for all children and, mistakenly in our view, campaigning for this vulnerable minority to be educated separately.

It also came from the realisation that the world outside school is moving on, especially with regard to the technological and financial support for disabled people to live independent and productive lives out of the residential homes, sheltered workshops and day centres which have been our lot for so many generations. Young disabled people and often their parents need to be connected to real life and all these new opportunities, and this needs to start in school.

Our History as a Minority Group

The history of the world has been one of a continual ebb and flow of oppression and resistance. A State system which gives free education to all children regardless of race, nationality, class, gender, religion or ability will inevitably bring together groups of people under one roof who have been oppressing or resisting each other for hundreds, if not thousands of years. This is true of children, their parents and teachers. We do not start on a 'level playing field'. Some will traditionally have had far greater access to resources and the means to represent themselves than others. The need to address these issues head-on has been clearest with gender issues as girls and boys are more commonly educated together, and on the issue of racism and multi-culturalism within our increasingly rich and diverse school communities. This has gone some way to help raise the self-esteem of girls and black and ethnic minority children, to help them have pride in their histories, identities and in their cultures. It has educated boys and white children about the roles they have been

conditioned to play towards others and the reality of the lives of such people. It has helped humanise all parties.

Within a few inner-city schools, some attention has been given to classism as very wealthy and very poor children are taught together as 'equals,' although there is a long way to go on this. There has been very little recognition that the same work needs to be done around the oppression and resistance of disabled people around the world. Consequently many disabled children feel deeply ashamed of their impairments and want to hide them, deny them or draw attention away from them. They do not want to seem different to their non-disabled classmates and this is because they feel that having an impairment leads to being de-valued and ultimately excluded by the 'normal' world. Or it makes disabled young people want to 'huddle' with other disabled young people, afraid of the ignorance and taunts of children who think of themselves as 'normal'. They grow up without positive role models and knowledge of their own history as a group. Although research has shown that young disabled people in mainstream schools have higher self-esteems than their counterparts in special schools, it is still lower than their non-disabled classmates (and that is often pretty low in itself!)

Disabled people do have a terrible history of rejection, institutionalisation and wasted lives. However, we also have a wonderful history of survival, resistance, self-organisation and emancipation. Everyone should know about this. It will help everyone to have a clearer picture of reality, especially how powerful disabled people can be.

The Legacy of the Medical Model

There are many good things brought about by the effort to fund research and treatment of impairments. People know and understand a great deal more about impairments - what they are, how they affect each person, how to treat it and sometimes cure it. Many children now live who would have died. Many children are now virtually 'cured' of their impairments by surgery, e.g. cleft palates and harelips (still a huge problem in poor countries). Many children are protected from catching disabling illnesses through vaccination, e.g. smallpox and polio. Many children have their lives prolonged and made much more comfortable by careful medication, e.g. children with diabetes, cystic fibrosis, epilepsy, sickle-cell anaemia, haemophilia and childhood cancers.

Speech therapy, physiotherapy and occupational therapy have helped many children to learn to manage their conditions with less pain, discomfort, frustration and boredom. Technology has transformed the lives of many disabled children, especially powered wheelchairs and trikes and speech aids which have literally given a child mobility and a voice. The health service is now creating all sorts of packages of care for children who are technology dependent, e.g. need a respirator to live outside of a hospital at home and going to school.



This increased knowledge has also helped dismiss the myths and misunderstandings about the effect of particular impairments on the potential of the child. Where once it was thought that all children with impairments had learning difficulties, now it is understood that many do not. And while it was thought that all children with learning difficulties were forever stuck at age-related stages of child development, now it is understood that all children grow up and continue to learn and develop throughout their lives - given the opportunity.

All this is good and to be valued and welcomed. However, much about the Medical Model is not good, has caused immense harm and needs to stop. Many disabled children will grow into disabled adults. Their impairments are a permanent part of them. The main difficulty is caused when the Medical Model overrides a child's 'ordinary needs' for love, closeness, touch, security, fun, laughter, friends, stimulation and play, hope and a sense of being wanted (as they are). The past practice of institutionalisation, based on a eugenic philosophy, relied on breaking the love-ties between children and their families and consequently with the whole of society. Both sides were heavily conditioned to believe that we did not need each other, and if left together would bring harm to each other.

All systems which perpetuate segregation, even in its most 'benign forms', e.g. a State of the Art Special School; a special club for disabled children, feed into these deeply held attitudes. They make disabled people, especially children, feel unwelcome, burdensome, ashamed, afraid of being abandoned or sent away, and these feelings and fears are often a life-long legacy of what happens to us when we are young.

The Medical Model can also make disabled children feel that they must become 'normal' to be accepted. 'Normal' usually means appearing to have the same needs as non-disabled children and denying or hiding their real needs. For example, many disabled young people give up wanting to do things which they know will require the assistance of an adult (or older child) in favour of not 'standing out' or being different from their non-disabled peers.

For many children, therapies dominate their early lives, with little time being given to a real education or other childhood experiences from which they could learn and develop friendships. Known to be of paramount importance to non-disabled children, friendships are not considered to be of any real importance to disabled children, resulting in almost complete social isolation.

When operated at full power, the Medical Model is a self-fulfilling prophecy. It creates adults who are uneducated, isolated, immature and unable to direct their own lives without many years of rehabilitation.



The Medical Model also harms society by denying ordinary people the opportunity to connect with and learn from disabled people. This leaves a fear of impairment and disability in everyone. People associate these things with a loss of status and power, with rejection and isolation, with pain, suffering and death. Non-disabled people are led to believe that they do not have the skills to 'help' a disabled person unless they become professionally trained (the biggest rationale of teachers to exclude disabled children from mainstream schools). The sight of a significantly disabled person reminds people of their own vulnerabilities, mortality and ineptitude and they do not want to feel those things.

It is clear however from observing young children in early years, inclusive settings that none of this is 'natural'. Young children are excited to learn about each other, long to be useful to each other, and make connections across all divides of race, class, language and ability. They grow up free of fears which truly 'disable' others who are not so lucky.

“Natasha is more sparkly when she knows William will be in school. She gets up and says 'It's a William day today'. She never wants to miss school when he is there, even when she is ill. They have a special friendship”

For more information on the Medical and Social Models, see Sheets 2 - 4 at the end of 'How to Use This Pack'.

Charity and the Media

The way we think about disability and disabled people is largely shaped by the images created by large charities and by the media.

Charities for disabled people are one of the biggest legacies of the Medical Model of Disability. Many of them were set up primarily to fund medical research into specific impairments in order to develop better treatments and even cures. Other services for people with that impairment are usually secondary.

Charities are traditionally set up and funded by white, middle or owning class, non-disabled people in their efforts to do good. This puts disabled people in a permanent role of beneficiary, having to be grateful for whatever they tell us we need. Because many charities rely on public donations of money and volunteers, they have to create images which will make people want to part with their hard-earned cash - i.e. pity, guilt and self-interest. These images have filled our billboards, magazines and post-boxes for generations and have sunk into our subconscious minds.

Charities still run special schools, residential homes, work centres and special services for disabled people. They still provide much of the essential equipment we need such as powered wheelchairs and augmentative speech aides. They pay for washing machines and holidays for families in which there is a disabled child.

Introduction



Disabled people have been challenging this for many years. Much of the motivation for the Disabled Peoples Movement was to create alternative organisations which reflected our own views of who we are, what we need and how we want to live our lives. Most of these are not charities and rely on Local Authority or Central Government funding, but this also brings problems. Nowhere yet do we have a right to an independent voice or to the aids and adaptations we need. Meanwhile many millions of pounds are still channelled into large charities. For some disabled people the struggle is now to 'take over' these charities, changing their policies to support the social model of disability. All this is largely lost on the general public however, who still associate charity with 'poor people who can't help themselves'.

This view of disability still dominates the media in general. Negative images of suffering, such as the Diane Pretty case - a disabled woman fighting for the right to assisted suicide - recently received many hours of media attention, including the television news with its millions of viewers. The struggle of the majority of disabled people to the 'Right to Life' raises only minimal interest.



Disabled characters in soaps and in drama generally are almost absent. Even the specialist television programmes highlighting issues of disabled people such as LINK or SEE HEAR have all but vanished. This leaves everyone, including young disabled people, unaware of the reality of the lives of disabled people in contemporary society. Inclusive schools need to help educate their staff and pupils about all these issues. Local disabled people who belong to the Disability Movement could be asked to help.

Film

Stereotypes of disabled people have long been used by filmmakers to the detriment of our place in the world. This is a subject of great interest in itself. (See <http://www.diseed.org.uk/Pages/Disabling%20Imagery.htm>)

Introduction

Books

Too few books have been written by disabled people about the reality of our lives. Many traditional children's books portrayed disability in very 'Medical Model' ways. The happy ending often involved the child 'getting better' e.g. *The Secret Garden*, *Pollyanna*, *Heidi* etc. This is gradually changing with more positive images and true-life stories e.g. *'A Different Life'* by Lois Keith. Adults who live or work with disabled young people would do well to familiarise themselves with these books and other positive images.

The reason this is so important is because of the internalised shame many disabled young people feel so deeply. Many disabled young people and their families are also afraid of the future because they are not seeing positive role models to help them have courage and hope that they could live a full life, just the way they are.

The Disability Movement

Up until the late 1970's the interests of disabled people were almost entirely represented by parents, charities and professionals who were not themselves disabled people. The prevailing view was that disabled people were child-like and in need of managing and being protected by others for the whole of their lives. This view was often challenged by individual disabled people, but alone no individual could bring about the change of attitude and services which were needed to allow disabled people some level of autonomy and control over their own lives. Inspired by the Civil Rights Movement in the USA, disabled people in the UK began to come together as a political movement in the 1980's, led by educated people with physical impairments. It has grown to represent hundreds of user-led coalitions and campaigning groups of people with physical impairments, long term illnesses, learning difficulties and survivors of the mental health system. 'Disabled People' is the chosen umbrella identification.

The Medical and Social models of Disability were a product of the innovative thinkers of the early days of the movement, and they have provided a political and philosophical base which binds members together within a common framework and vision. Not every person with an impairment allies themselves to the Disability Movement, but many thousands do.

The Movement has worked out together basic demands which have broad agreement amongst a diverse membership (See 'What Disabled People Want'). In the UK there is an umbrella organisation of user-led organisations called The UK Disabled People's Council. It in turn is represented internationally at the UN through Disabled People's International (DPI) and is part of a world-wide movement.

Disability Arts

This is a development which evolved from the growth of the disability movement. Self representation has many forms, one of the most powerful being through the Arts. It is only in the last 20 years that disabled people have begun to explore their identity and experience of living with an impairment in an oppressive system. There has been an explosion of music, drama, film, poetry, writing, photography, painting, drawing and sculpture done by disabled people about their experiences. Theatre companies have been formed and new art forms such as signed song have become established. Some would argue that this has made possible the concept of a disability culture through which disabled people can express and communicate a unique world view. For many disabled people, like all other minority groups, the use of the Arts can be the beginning of a positive, collective identity, a source of pride and a way to combat stereotyping and prejudices of the non-disabled world.



The Crystal Fountain by Nancy Willis

The Need for Allies

Many young people see themselves as a minority group without rights and in the control of adults who may or may not have their best interests at heart. They recognise their relative powerlessness and the lack of respect with which young people in general are treated.

Some have learned about young people around the world, issues of poverty and disease, child labour, child soldiers, sexual exploitation and vulnerability to abuse in all its forms. They recognise that many of the issues which adults find difficult around young people - fighting with each other, bullying, addiction to cigarettes, alcohol and drugs, promiscuity and teenage pregnancies, roaming the streets and engaging in low-level crime,

are all the result of their oppression as young people. Young people are increasingly saying they need adult allies to help them deal with this in positive ways without blame or reproach, but holding out the possibility that they could treat themselves and each other well and to be advocates for them when they need it. Young disabled people are saying that they want their Assistants to be allies:

"So what is really good in schools are allies. An ally is somebody who is not a young person themselves, but has spent a lot of time committed to young people and has a clear picture for their liberation, and a clear passion for it. Within a school situation I would say they need to be someone primarily who has access to the culture and experience of being a young person. Being able to be in touch with how that felt and re-evaluating their experiences having looked at their own childhood, their own teenage years and young adulthood and the way that they were treated. And who doesn't need to be constantly sharing those experiences, not going to be remembering their own childhood the entire time. Their attention can be completely on the young person and they have a resource outside of that relationship in which they can talk about their feelings and what is coming up for them. And that they also have good attention from the other adults that are working with that young person. Often what will happen is that teachers and support staff of the young person will use that young person's attention quite unfairly to talk about their feelings around being a young person, or around disability or around how hard their job is or how overworked they are. It's not really appropriate for the young person and there needs to be someone who can facilitate that really. Realistically, while all this stuff is happening young people are going to have huge feelings about it and the impact it has on their assistants so there does need to be people there who can be that resource for the other staff. People that are particularly clear themselves. It needs to be someone who has good knowledge of the social and medical models of disability, someone who realises that the relationships of the young people is central to their job, so supporting friendships between young people is really very key. Participation is at the centre of what they are doing, that they have particular skills to do with having access to things like facilitated communication, interpreters, they don't necessarily have to go through all these things themselves, but they will be connected to people that do and will know about these systems and independent living and personal assistants. They have good attention for the young people themselves to work things out however challenging it gets. They are committed completely to the young people. Their role has to be there for the support of the child and the dreams of that young person" Lucy Mason

The role of Inclusion Assistant is new within the education system. It has great potential for modelling being an ally to young people because its goal is to help young people create a different and better world, based on

real connections, learning through experience, dispelling ignorance, facilitating communication, empowering and respecting people who have had little such support, and helping to give young disabled people more choice and control over their own lives.

Working with Parents

Children with high level support needs will usually have most of those needs met by their parents. The individualised training you will need in personal care, communication needs, equipment, supporting therapies, health and medication etc will be provided by the child and their parents. They will be the experts on this. The parents may also know a great deal about the child's learning style, strengths and weaknesses. They will have a broader view of the progress the child is making than those who only see her or him in the school setting and it is likely they will be the ones fighting for resources for their child's wellbeing. It is essential that parents are seen as team members, bringing expertise and feedback, and not as 'enemies' "putting their one child's needs above all the others". At the same time, some parents may also have a lot to learn about being an ally, the social model of disability and 'letting go'. They do not all have access to training, resources and contacts which may be available to professionals*. They may have cultural or language issues themselves. They need to be included as much as possible in the learning process of creating inclusive schools and communities both as teachers and as students.

Some young people with special educational needs will not have parental support, and this may be part of the cause of their difficulties. For these young people a meaningful relationship with just one adult in a school can make an enormous difference. It has been found that young people will not put themselves in a position where exclusion from school is possible where such a relationship exists. The Inclusion Assistant may well be that person.

*It is emerging from the personal histories of disabled adults that the dominating influence of the medical model over their parents was the major barrier to a sense of equality and self respect as young people.

"My parents had issues about my impairment. There was lots of animosity and blame. One wanted the best for me, the other couldn't see the point. My Mum felt guilty. She spent all her time trying to prevent the inevitable. There was lots of surgery. I knew it was wrong. I was not consulted. A tortuous experience. She couldn't let me be the person I would have been." A.K .

"Sadly my mother's shame at having a disabled child has never abated. During my time at home the only time I ever went out of the house was to visit relatives or to go to church. My mother did everything she could to hide my impairment which at the time I didn't challenge because I didn't want to upset her - upsetting her might mean that she and my father would leave me back at Chailey never to return!" T.F.

Conversely, the enlightenment which followed exposure to the 'Social Model' is what enabled their parents to become true allies:

I wrote this poem after two weeks of being in an inclusive community where gifts and differences were valued. When I first met my daughter after this experience I was struck by how differently I experienced her:

I looked into Annie's Eyes this morning

*I looked into Annie's Eyes this morning -
In this morning I looked into Annie's eyes.
My daughter's eyes.*

*I searched for what was wrong. What is her disability?
As I looked into her eyes, at her hair blown by nights tossing and turning,
she smiled and smiled. My heart hurt with sensations all over. Where is it?
I could find no wrong with Annie in her beauty playing with her dog this morning.*

*Polly danced and barked. Annie sprayed water at Polly's barks.
They danced round the room.
I felt like I was coming through a thick fog this morning.
I cannot see anything wrong with Annie.
I cannot feel anywhere in my body that tight almost nauseous feeling I
always have when I think I have seen what's wrong with Annie.*

*In this morning my body feels no tightness, no nausea as I look, and look
at Annie.
She is simply a beautiful, joy filled child having morning spraying love and
water at her barking dog, Polly.*

*I sit this morning feeling a trembling in my belly.
How precious is this moment of me seeing Annie as she is.
I am angry for all the labellers who have sought to steal my daughter's life.*

*I am sad that I have so many times taken their lies inside me
seeing Annie as retarded or organic brain damaged or disabled or
whatever.
I have often seen my child with eyes of guilt and shame.
I have been robbed of the present.*

*It is so obvious at this moment that there are only children.
People filled with gifts and possibilities.*

*I feel my belly calm, warm, my heart trembling, my eyes with tears, my
smile soft.
I see Annie so clearly this moment of dog spraying laughter.
I know I do not have to live the Labellers lie.
I know in this morning the truth.*

Mike Green.



The Right to Make a Difference in the World

Disabled people, especially those with high-level support needs do not often fulfil the expectations of a capitalist society and its' values. We are not always able to earn our own livings, we constantly need help from others, and we are not always clever. Yet we are fully human and want to be included.

We want the right to make a difference to the people we love and who love us, to our families and friends, and to the wider community.

Inclusion has often been resisted because it requires things to change. The fear is that the change will be for the worse with everyone getting less resources and being held back, but everywhere it has actually happened people report that it was a change for the better. People have learnt new skills, more resources were made available, systems became more flexible and responsive, and everyone felt less judged and more able to be themselves without fear of exclusion. The children with the biggest 'needs' brought the greatest change. They made a positive difference to their world. This we believe is a fundamental human right.

The Role of the Inclusion Assistant

The Inclusion Assistant is a new role within mainstream nurseries, schools and colleges. It is a development of the Teacher Assistant (TA) or Learning Support Assistant (LSA) but is specifically aimed at supporting the inclusion of young people who have high-level support needs. These can be physical, emotional or intellectual, or a combination. Young people who need such support may be labelled as having 'Severe' or 'Complex' or 'Profound' impairments, and will need one-to-one support in any environment if they are to be able to be safe and to participate in whatever activities are happening. This need will probably extend into adult life where such support will come from personal assistants employed under the Direct Payments Scheme (see Appendix 2) as well as family, friends and partners. This role can be helpful to all children but our focus in this pack is children with high level support needs for whom the role is essential for their participation.

The Inclusion Assistant is not simply a 'carer'. Within a school community their job is to help make connections between their focus child and their peers, teachers and other members of the community.

The role is also about helping the focus child learn how to manage their support in ways which empower them and give them increasing control over their own lives. Disabled adults have fought long and hard for the independence which can only come about when we have support which we can direct ourselves. Without this, people with high-level support needs are trapped within a life dominated by services and institutions. This is the 'nightmare' we are trying to avoid.

All children are required to go to school by law. It seems fair that children can expect some basic rights to be honoured within such schools. These apply to all children, but have particular significance and implications when we are considering children with high-level support needs. These seem to be fundamental:

- ▶ The right to be valued
- ▶ The right to a positive future
- ▶ The right to be safe
- ▶ The right to have our physical needs met
- ▶ The right to have our communication needs met
- ▶ The right to have our learning needs met
- ▶ The right to have our emotional needs met
- ▶ The right to have friends and allies
- ▶ The right to have a voice within the school

An Inclusion assistant and his/her managers will need to pay attention to all these issues. He/she will also have rights which include being part of a team, being valued and supported and given appropriate training, status and remuneration in order to do the job well.

This training course is aimed more at the 'why' of these things than the 'how', although we will make suggestions on each area for further learning.

Further reading:

Incurably Human - Micheline Mason. Available from Inclusive Solutions

BCODP Manifesto 2005 - Available from UKDPC (formerly BCODEP)

Disability Politics: understanding our past, changing our future - Jane Campbell and Mike Oliver (1996) Published by Routledge

Disability Equality in Education - a Human Rights Issue - Richard Rieser and Micheline Mason. Available from DEE

All contact details found under Useful Contacts, page 140

Useful Materials:

The Inclusion Assistant Report and Video

What Disabled People Want

Both available from the Alliance for Inclusive Education

Why an Inclusion Assistant?

Inclusive Education is essentially about the de-institutionalisation of disabled people. It is part of a much bigger struggle initiated by disabled people in the 1970's and 80's. At that time most disabled people lived in residential homes, attended day centres or sheltered workshops, were prevented from marrying and having children and had little say or control over their own lives. This situation is slowly changing but there are still many disabled people who are forced to live this kind of separate, parallel life. The argument still seems to (mistakenly) centre on where to 'draw the line' - what level of impairment should trigger segregation? The education system is charged with making this decision for disabled children and young people through the Statementing process.

Disabled children do not yet have an absolute right to mainstream education, and those most vulnerable to exclusion are children who have a level of impairment which requires assistance from an adult for several hours a day. These young people we have called 'children with high-level support needs'. This group includes children who are blind, deaf, deaf/blind, have severe physical or intellectual impairments, chronic illnesses, are neuro-diverse, have mental health issues or behaviour difficulties. Some children may have more than one of these conditions. They are commonly called children with 'complex needs.'

In a world which values people almost exclusively for their potential productivity within the work force, it can seem difficult to imagine a valued adult role for such people within mainstream society, and therefore it is being argued that there is a continued and permanent need for special schools (and adult institutions) for this group of people. Disabled people themselves strongly disagree with this. We know that nobody would choose an institutional life over a supported life within the community. We have continually regarded inclusion as a human right regardless of the support we need to achieve this. This is especially true in the rich, developed world.

One of the biggest breakthroughs for disabled people came with the legalising of the power of local authorities to issue money in lieu of services to disabled people with high-level support needs (Direct Payments). This means that disabled adults can stay in their own homes and buy in the staff they need to provide personal and domestic care. For some this means a team of six assistants providing 24 hour care.

The advent of 'Access to Work', a government service, has enabled many people with high-level support needs to become part of the labour force by providing their employers with technological support, adaptations to the workplace, personal assistants, readers and interpreters, drivers, vehicles or taxi fares to get to work.

Supported Employment Schemes have likewise enabled many people with learning difficulties to become employed in the open market by providing on-the-job training and supervision. As the Disability discrimination Act becomes more effective, all these opportunities are expanding

The social skills learned (on both sides) in inclusive schools are allowing long-term friendships to form between disabled and non-disabled young people. As a result disabled young people are studying, following their own interests and hobbies, enjoying gap years, travelling with friends, falling in and out of love, learning to use the now accessible transport system or to drive, finding part-time or full time work, leaving home to live alone or with friends, managing their own Direct Payments or appointing an advocate to do so. Life has never been so hopeful for disabled people. (see 'Where Are They Now' the Alliance for Inclusive Education 2005).

Our research has found however that the experiences of childhood will shape to a large extent the degree to which a young disabled adult will be able to use these new opportunities or will remain dependent on family and statutory services for the rest of their lives. The single most defining factor is the degree to which the child's parents are able to become allies - reject the medical model, embrace the social model and fight for social and educational inclusion. Disabled people feel this dependency on parents is too great. It leads to vast inequalities between disabled young people. We think that all disabled children should have the same opportunities. Children with high-level support needs should be accommodated in mainstream schools (and other children's services) as a matter of course, without the need for parents to fight.



Workshop with students from George Green School

Introduction

At present the restructuring of non-teaching staffing in schools has led to the withdrawal of the role of Learning Support Assistant and the development of the role of Teacher Assistant. In this re-structuring we discovered that children with high-level support needs were not being considered. In fact it became clear that the expectation was that they would go to special schools. Even where such children were included in mainstream schools the need for one-to-one support was seen as a barrier to inclusion. Untrained staff had been appointed in the past as 'minders' for disabled children and, sometimes, they were. Children themselves felt too 'different' and rejected the help, but then often found themselves struggling without the facilitation they needed to access either the educational curriculum or the social activities. No work was done with

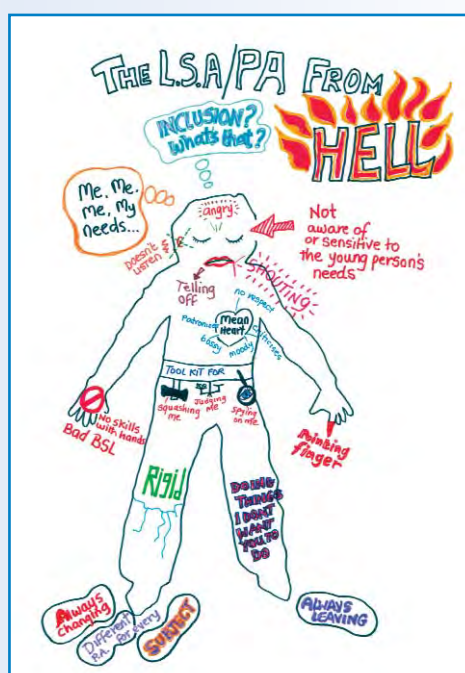


Workshop with students from George Green School

the non-disabled children and situations occurred where bullying and isolation were happening without being challenged in a useful way. Parents became concerned and felt they had to withdraw their child and find them a 'refuge' within special schools.



Introduction



Full size versions of these pictures are on pages 27 and 28

Disabled adults however, having developed very good models of self-directed support within the Independent Living Movement, are certain that a new role could be incorporated into mainstream schools which would bridge the gap between infancy and adulthood. We envisage a team of people in every school who would be specially trained in the social model of disability, in personal care and facilitation, in accessing the curriculum, and in the tools of inclusion. They would work one-to-one with children who need such support, and would also work with teachers and the non-disabled children to facilitate disability equality and inclusion. This pack is designed for the training of such people in the role our young people requested be called 'The Inclusion Assistant'.

The goal is to prepare all young people to live together in a diverse mainstream community as adults. This will inevitably change the nature and culture of school and of society for the better.

Introduction

How to Use this Pack

The aim of this training is to equip individuals with the ability to support one or more young people with high level support needs to participate in and contribute to daily life in a mainstream school. The main emphasis of the training is about seeing the world from the point of view of a young disabled person, living in the 21st Century, in the developed world, with the expectation of living their life, however long or short, in meaningful communication with their families, friends and local communities. It endeavours to show the trainee how they can become an enabler of both the focus child/young person, and of their teachers and classmates in building an inclusive school community.

The pack does not include basic skills training in First Aid, lifting and handling or computer literacy. All these are needed in addition to this training. The pack also cannot teach the individual care needs of each child or how to operate and maintain any specialist aids/equipment they use. This can only be done by the child themselves, their parents and their current assistants. Time will need to be set aside for this essential training. Every child will be different, even if they have the same impairment. Likewise, the pack does not include communication skills such as Makaton, BSL or Facilitated Communication. These are additional skills which may or may not be needed.

Finally, the pack does not include differentiation of the curriculum as this is clearly a role for trained teachers working in collaboration with TAs, Inclusion Assistants, therapists and peer supporters.

For each module you will find:

1. Introductory notes which you will need to read and possibly copy as preparation for delivering that module. These notes include a 'suggested reading' list and 'useful resources' where appropriate.
2. A Module Programme which can be copied for participants.
3. The Aims of that module which can also be copied.
4. Detailed guidance notes for the exercises listed in the module programme.
5. Guidance notes for any suggested presentation for that module.
6. Sheets relevant to that module which you can copy for participants or make into overheads.
7. Module Outcomes.

Please add your own personal material to each module. We have given you the elements of the programme we feel are essential to be included. The pack requires an understanding of the issues, it is not written for someone with no knowledge or training skills.

You may also find Sheets 1-6 at the end of this section useful for copying and using in your training sessions.

We recommend that you start each session with a summary of the previous module and ask participants to say what they learnt from that module.

Similarly we recommend that you end each session by asking them to reflect on what they have learnt from the session you have just delivered.

We also recommend you ask participants to use a learning diary to record their feelings, thoughts and learning throughout the programme.

The times indicated for exercises are intended as a guide only.

Module Outcomes

The Module Outcomes are a tool to help you evaluate your students progress through the course. You will find them at the end of each module section.

The outcomes could be developed in different ways to meet the requirements of awarding bodies such as the Open College Network, Higher Education Institutions etc and so enable people studying the programme to gain nationally accredited qualifications and facilitators to access training funding.

These outcomes could also form the basis of extended written work between training sessions.

Help to deliver the pack

The Alliance is able to offer a training package which includes the pack itself and training on implementing the pack in a range of settings. Please contact us for more information (details on page 2).

Aims of the Training Course

1. To learn how young disabled people experience the world.
2. To understand that life can be exciting and rewarding for any young person, despite any needs they have, if they are welcomed and given the right support.
3. To help envisage a positive future for young people with high-level support needs.
4. To identify the barriers to achieving this future in school and in the wide world.
5. To develop strategies for removing these barriers.
6. To help foster relationships between young people with high-level support needs and their teachers and peer learners.
7. To enable the young person to take increasing charge over their lives, including managing their own support.
8. To help raise awareness within the school of the important roles disabled people play in the world.



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Definitions:

Oppression

The systematic mistreatment of one group of people, by another group of people, which is REINFORCED by the laws and institutions of their land.

Segregation

A legal system through which a disabled child, from the age of two, can be placed by non-disabled people, including parents, in educational and/or residential provision separate from the mainstream for up to 52 weeks a year.

Integration

Disabled and non-disabled people sharing a common space or activity, usually initiated, designed and controlled by non-disabled people.

Inclusion - 'All for One and One for All'

A philosophy which views diversity of strengths, abilities and needs as natural and desirable, bringing to any community the opportunity to respond in ways which lead to learning and growth for the whole community and giving each and every member a valued role. Inclusion requires the restructuring of schools and communities.



Definitions:

The Medical Model

Disabled people, once organised in a movement, identified two Models or ways of explaining disability. One created by doctors and other health professionals sees the "problems" in disabled peoples lives as a result of their impairment. The solution is the treatment or cure of the individual. This is the Medical Model.

The Social Model

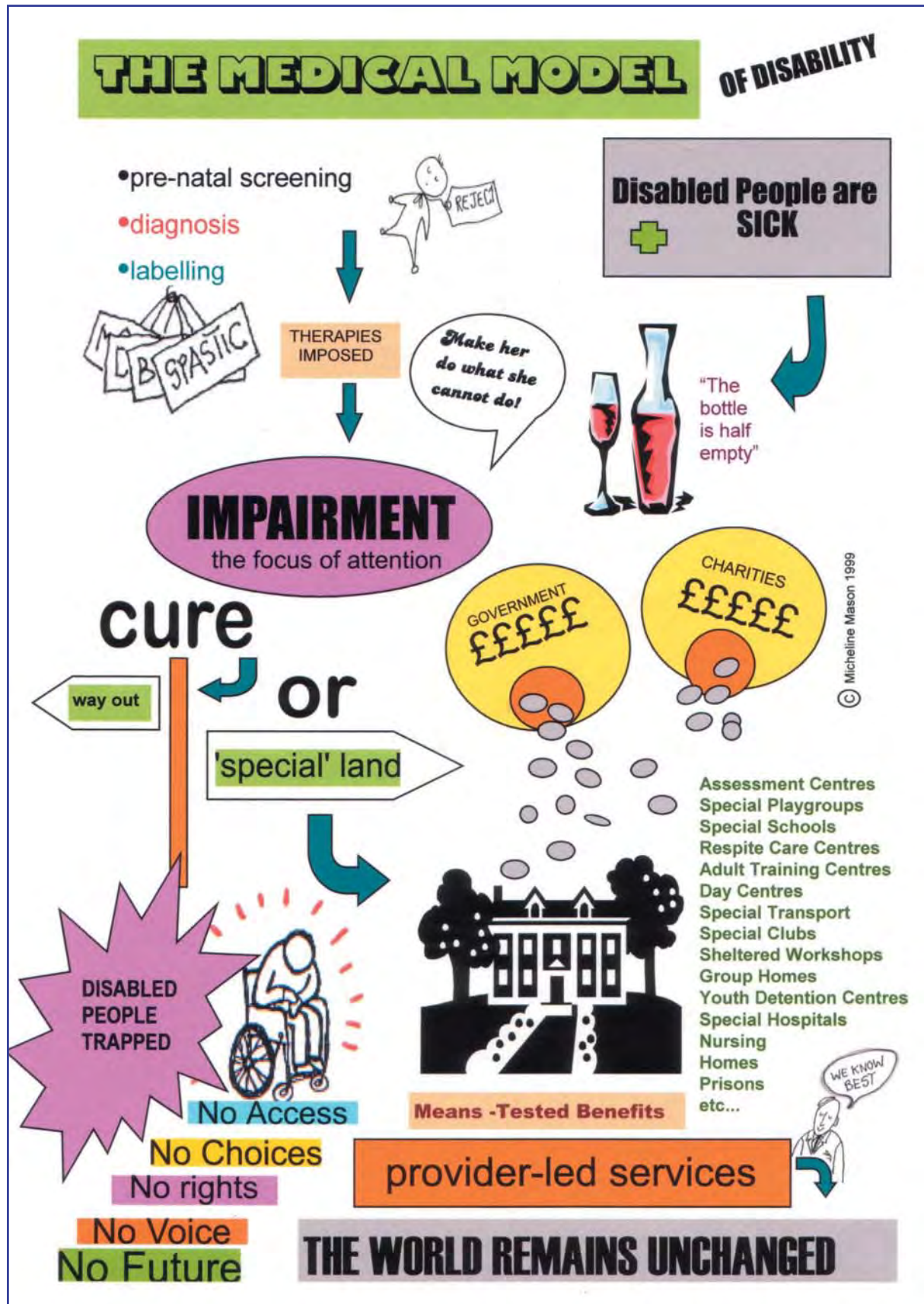
The second model, created by disabled people, sees the problem caused by the way society responds to their needs. By creating barriers in buildings and structures or by not producing information in different formats such as Braille, people with impairments are disabled. This is the Social Model.

Independence

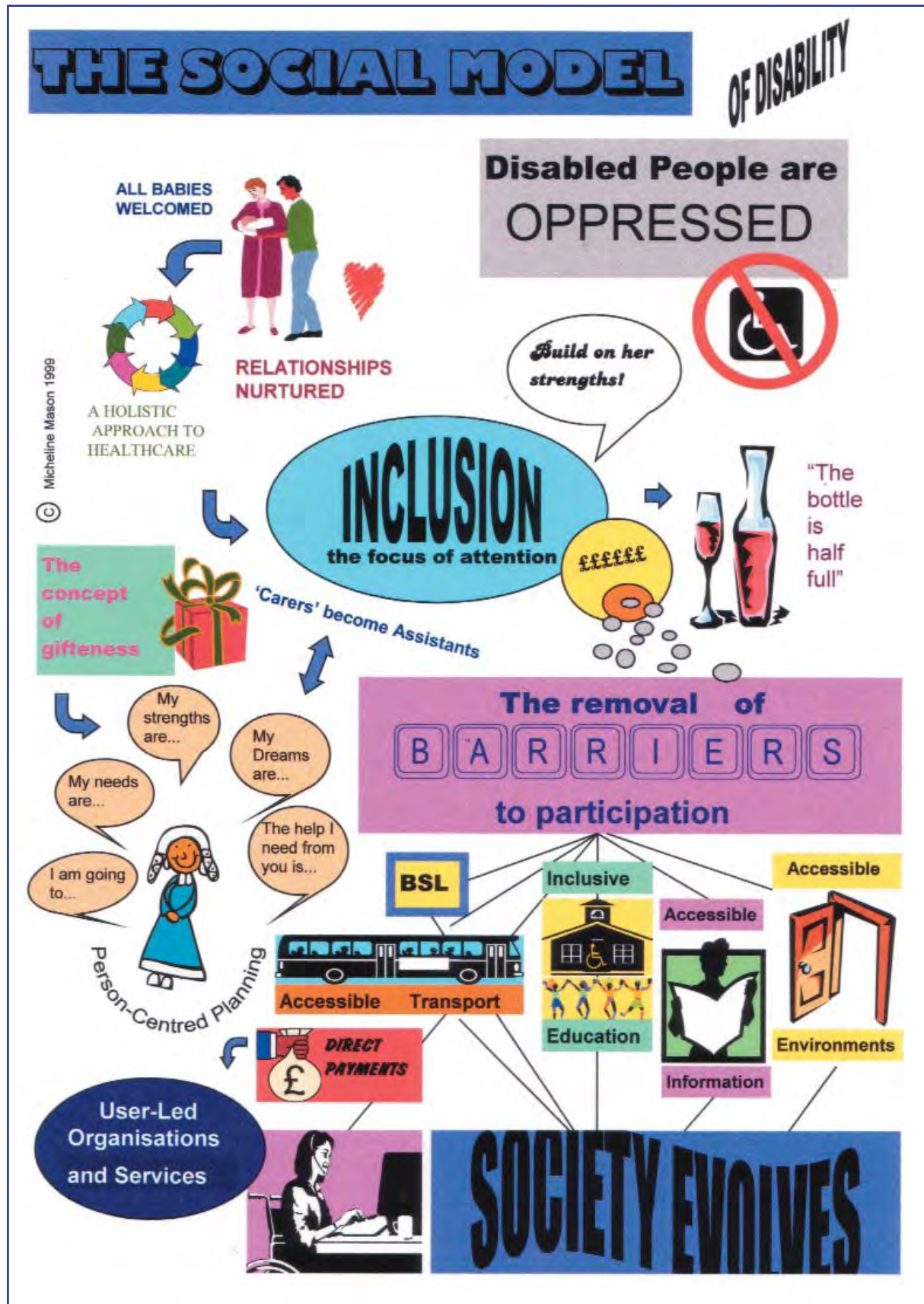
Independence is not doing things alone but being able to direct your own support.



The Medical Model



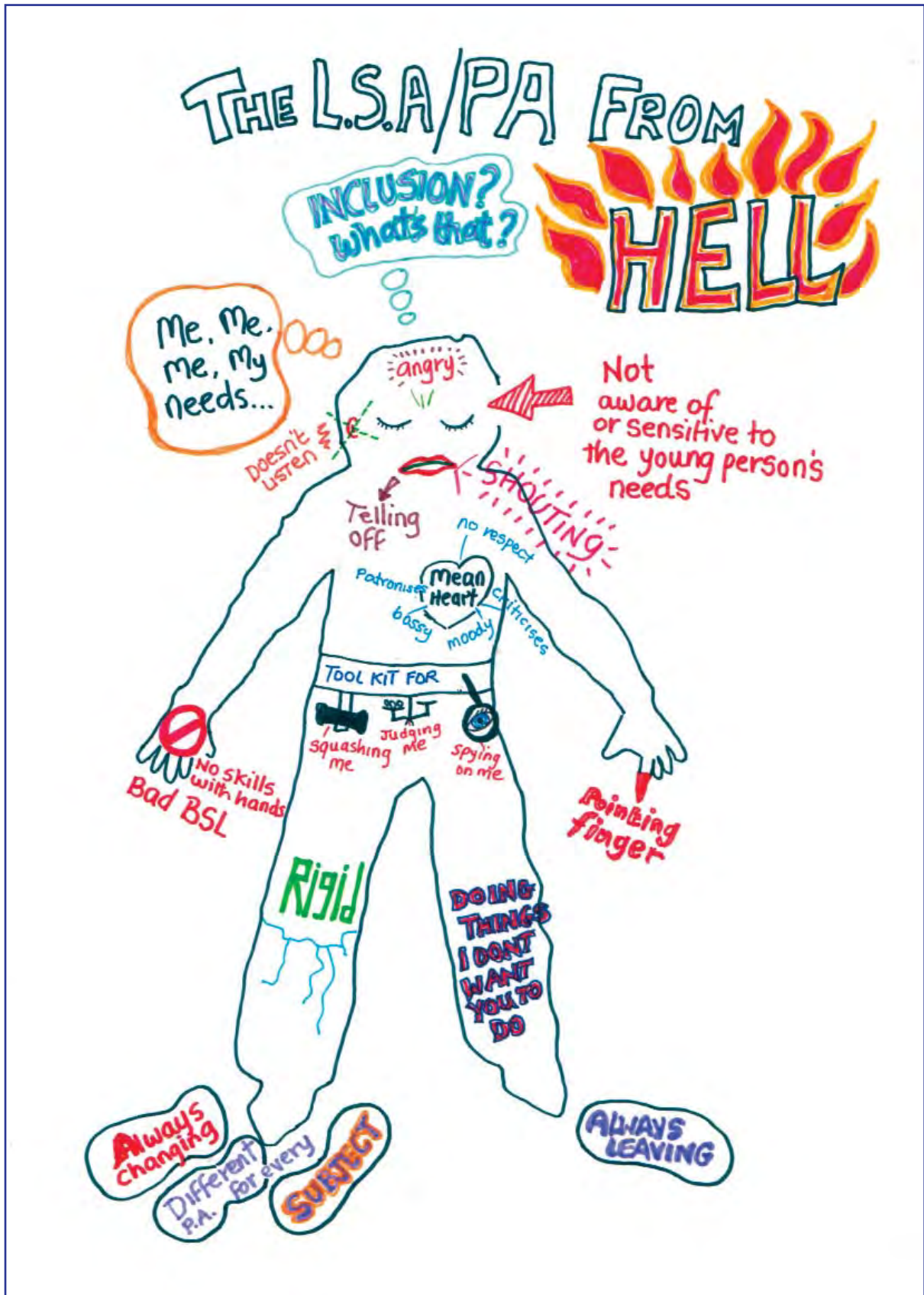
The Social Model



The LSA from Heaven



The LSA from Hell



Module 1

The Right to be Valued

Nurseries and schools have an almost unique chance in our societies to be idealistic - to ignore or contradict the judgements which are made about the comparative worth of people, and to reach for something bigger, however challenging that may be. All this is based on sound psychological and educational theory and practice. We learn better if we are happy, and we are happy if we feel good about ourselves. Comprehensive education was founded on an idealistic principle that all children, from all backgrounds should be given an equal chance to succeed. Inclusive education is only a re-statement of this principle. The challenge has been re-training non-disabled adults to take their attention off the things which we cannot do, and to celebrate and develop those which we can. Children do not seem to have the same difficulty.

"What we most enjoy at playtime is when we push William up the hill in his wheelchair and come down really fast - we run down all holding on because we must not let go or he will roll off and get hurt. We hold on really tight in case he gets frightened. We enjoy reading with William. We hold out two books and he looks at the one he wants. We follow his eyes. He likes Kipper books. Lucy and Vita hold the book and turn the pages. Natasha reads the words. When he is out of his wheelchair he lies down to take part in activities and we lie down with him. When William goes to soft play a group of us go with him and we all roll around together. The best thing about having William in the class is his hugging and giving big cuddles." Child, Davigdor Infants School

An Inclusion Assistant will need to find ways to help everyone value children who have historically only been seen in a negative light, as problems and drains on the resources of society. This may even include the child's parents who may have had years of negativity from medical professionals. The current system's need to assess a child's difficulties and failures as a means to acquiring resources (Statementing) is a major barrier to creating a positive identity as a disabled young person.

Values, Ranking and Status

We are all born into a world which values people differently. Some are Kings and Queens, some are born into destitution. Wherever we start on the road to inclusion we are faced with the issues of ranking and status. This not only affects how others treat us, but also how we feel about ourselves. How we feel about ourselves will affect, in turn, how we treat others.

We are not born with such judgements about the value of different people, we learn them from our families, the television, our friends and from the social systems we engage with, especially school. As we grow older we learn them from the media and from literature, music and the arts.

When asked to rank categories of people in terms of how the world values them, people seem remarkably sure and consistent about who matters and who doesn't. For example (in Britain) film stars and famous sports people are often top of the list, gypsies, criminals and disabled people are usually at the bottom. White people are always perceived as above black people and the class system speaks for itself. This is one of the challenges of inclusion. The majority of children who are segregated from or excluded from school represent groups of people who have very little status in society. It is not automatic that this will change simply by bringing these young people into a mainstream setting. The behaviours which people have developed towards such people will play themselves out in the new setting - in fact this is exactly why parents of disabled children want to protect their children by sending them to 'special' schools. Unfortunately even segregation does not answer the problem. People with low status in society internalise these values. We believe them about ourselves and we believe them about people like us. The ranking and mistreatment of each other in special schools is often even more malicious than when we are 'diluted' by integration.

"There was a hierarchy of impairment at school. People who were incontinent and 'smelly' were at the bottom. I remember being asked to help to 'get so and so'. I used manipulation to get him into a classroom where the others were all waiting to beat him up. It was a way to vent my anger. This goes on onto adulthood. Disabled people can treat each other very badly." A.K.

"I was left alone with people I was told were 'autistic'. I spent all my time changing their routines to upset them. I remember persuading one boy, Mark Masters, to throw some tennis shoes, which belonged to a teacher I hated, into a stream. The teacher went berserk. Mark turned pale and fainted with fright. I was his biggest tormentor. I am ashamed of that now, but not then. I was fuelled by anger and boredom." J.C.

It is important to acknowledge how we have learned to rank people, and where we place ourselves in relation to others. We then need to look at how we know who goes where. What are the indications that a person, or group of people is valued. E.g. what resources are they given? How much attention are they allowed? Is their opinion asked for? Do you want to be their friend?

Inclusion is about examining all these pre-conceptions, habits, irrational feelings and the systems which support them. We need to learn to do things differently if the concept of equality is to mean anything.

The most effective tool against prejudice is finding out the truth about people who are different to yourself, and about your own history.

Written from the perspective of disabled people and the Independent Living Movement.

Programme

1. Welcome and introductions
2. How we will work together
3. Module 1 Aims
4. Exercise: The Children of Jowonio poem
5. Exercise: The Line of Invisibility
6. Exercise: Being Valued
7. Presentation: Being Valued
8. Concluding Remarks



Aims of Module 1

1. To explore how humans rank each other in value and status.
2. To think about the valuing of young people who have historically been given little status in society.
3. To challenge common stereotypes of disabled people.
4. To understand that inclusion means learning to value all people (young and adult) equally.



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Exercises:

1. Jowonio Poem

- ▶ Hand out or show overhead of the Children of Jowonio poem (Sheet 1.1)



- ▶ Ask trainees:
What made you feel valued or not valued as a child?

2. The 'Line of Invisibility' Ranking Exercise

- ▶ Make a horizontal line on a blackboard or a wall using ribbon/string etc.

- ▶ Call this 'The Line of Invisibility'

- ▶ Distribute pre-labelled cards to trainees which include: Lawyer, Doctor, Film Star, Politician, Plumber, Refuse Collector, Bus Driver, Nurse, Cleaner, Media Representative, Director of Multi-National Company, Teacher, Sales Assistant, Sports Personality, Traveller, Asylum Seeker, Disabled Person, Person with Learning Difficulty, Prisoner.

- ▶ Give each trainer a blank card also and ask them to write their name on it.

- ▶ Give them all blu-tac and ask them to stick the cards on the wall relative to the 'Line of Invisibility' (where society does not value you) and in relation to each other. Ask them to put themselves on the wall in relation to the other cards.





- ▶ Ask them:
How they know where to put people?
How do we treat people differently according to their status?




- ▶ How do young people show they value each other?
How do teachers value young people?


3. Being Valued Exercise

- ▶ Describe how children choose or value each other, for example, which group or gang they belong to (Punks & Rockers, Townies & OutofTownies, Grungers & Chavs, Pink Ladies, Black or White, Fat or Thin etc)
-  ▶ Ask the group to think aloud about the grouping that existed when they were at school.
- ▶ Ask the group to discuss what it would be like for a child that cannot do their own hair or dress themselves. A child that does not choose their own clothes. What would that be like for them? How can they belong to a group? What would help a child who is not 'cool'?
- 

Note: You may wish to purchase a song called 'Courage' for this exercise. It is part of an audio tape called 'Starting Small' by Bob Blue and is available from DEE (contact details on p142)

Presentation: Being Valued

1.  Share Sheet 1.2, either by making an overhead or handing out. Ask the group if these assumptions are based on reality or prejudice.

2.  Below are some questions based on the background notes at the beginning of this module. We suggest you use these to promote a discussion which relates to the module aims.

- ▶ How do we show people that they are valued?
- ▶ How can we show these things to every child (and member of staff) in a school community?
- ▶ If we treat people the same, is that the same as treating them of equal value?
- ▶ Do we value people for their achievements and abilities, or for their qualities and humanness?
- ▶ How have we learned to judge the worth of another?
- ▶ Who get parts in school plays?
- ▶ Who gets picked to represent the school?
- ▶ Who gets on the school brochure?
- ▶ What makes children in or out of the in crowd?

Module 1 Outcomes

Demonstrate the ability to:

- ▶ Review the impact of societies' views of value and status on the lives of disabled young people.
- ▶ Reflect on common stereotypes of disabled people and discuss how these can be challenged.
- ▶ Make effective links between the concepts of inclusion, value and equity.



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What the Children of Jowonio Know



Jowonio (an Onondagan word that means "to set free") was the first school in the USA to systematically include children who were labelled as 'autistic' within regular classrooms with 'typical' children. The administrators, teachers, parents and students at Jowonio are solidly supportive of inclusive communities and of the importance of many kinds of children learning to play and work together. This poem was written by Mara Sapon-Shevin to thank them all for what they have taught her.

WHAT THE CHILDREN OF JOWONIO KNOW

The children of Jowonio know - not because they have been told - but because they have lived it :

That there is always room for everyone – in the circle and at snack time and on the playground – and even if they have to wiggle a little to get another body in and even if they have to find a new way to do it, they can figure it out – and so it might be reasonable to assume that there's enough room for everyone in the world

The children of Jowonio know - not because they have been told - but because they have lived it:

That children come in a dazzling assortment of sizes, colours and shapes, big and little and all shades of brown and beige and pink, and some walk and some use wheelchairs but everyone gets around and that same is boring – and so it might be reasonable to assume that everyone in the world could be accepted for who they are

The children of Jowonio know - not because they have been told - but because they have lived it:

That there are people who talk with their mouths and people who talk with their hands and people who talk by pointing and people who tell us all we need to know with their bodies if we only listen well – and so it might be reasonable to assume that all the people of the world could learn to talk to and listen to each other

The children of Jowonio know - not because they have been told - but because they have lived it:

That we don't send people away because they're different or even because they're difficult, and that all people need support and that if people are hurting, we take the time to notice, and that words can build bridges and hugs can heal – and so it might be reasonable to assume that all the people on the planet could reach out to each other and heal the wounds and make a world fit for us all.

From 'Because we can change the world – a practical guide to building co-operative, inclusive classroom communities', by Mara Sapon-Shevin

Some common assumptions about disabled children:

- ▶ They can't do much
- ▶ They are not intelligent
- ▶ They are 'babies'
- ▶ They need special teachers and special things to play with
- ▶ They are spoilt
- ▶ They try and 'get away with things'
- ▶ They will not lead a normal life
- ▶ They have lots of problems
- ▶ They cannot answer their own problems
- ▶ They do not know what they need or want (only professionals know this)
- ▶ They want to be able-bodied
- ▶ They have no right to be angry
- ▶ They get everything they need free and without a struggle (wheelchairs etc)
- ▶ They like being with other people 'like them'
- ▶ They do not have an inner life - an emotional life
- ▶ If they can't speak, they can't understand



Module 2

The Right to a Positive Future

This pack is beginning with a goal, a desired outcome for all the work that is entailed in building inclusive communities and supporting people with high-level support needs to be part of that process. Unless a positive future is imagined, we will not know why we are doing certain things, or why we should be trying to bring about change. We will not be able to judge success or failure.

Our Main Criteria for a Successful Outcome:

The person is:

- ▶ In meaningful relationship with more than just family.
- ▶ Has interesting things to do.
- ▶ Has an outlet for talents and gifts, including paid employment if desired.
- ▶ Can see a purposeful future for him/herself (in their own terms).
- ▶ Is still learning.

It is still true that many disabled people with high-level support needs do not live positive lives:

"Young people were interviewed who are effectively being 'warehoused' in residential provision: they have little opportunity for making friends, being involved in their local community, or doing anything meaningful during the day. To a large extent the scope for any personal development has ceased." Joseph Rowntree Foundation 'Findings': Transition to Adulthood for Young Disabled People with Complex Health and Support Needs 1999

Developing a positive future is something that needs to be the focus of growing up. Experience shows us that many disabled people end up leading segregated lonely lives. Ending up locked in services they have not chosen or desired. This focus is essential to make sure the disabled young people like their peers are able to look forward to a life which is meaningful and within the mainstream of life.

"Paul left school with little hope for the future. No discussion about work or chosen career or what he wants to do or how to live his life. It is taken for granted that he will graduate into the local day centre. He is now 50+ and has been in the same day centre since leaving school and has been enrolled year after year for the last fifteen years in the same computer class".

Module 2

What is new is that it can be shown that this is not a direct and inevitable result of the impairment, but the sum total of the attitudes, experiences and opportunities which were available to that person when they were young. Some disabled people with high-level support needs lead very active lives, engaged in their communities, in close relationship to others, and in control of their support, systems and resources.

Joe was born in 1981 and was one of the first children with learning difficulties to go to a mainstream school with a learning support assistant. He went to a primary school in London and then moved with his parents to Aberdeen in Scotland when he was twelve, where they continued to battle for a mainstream secondary school.

"I'm 22 now. I left college last year when I finished my NVQ in Catering in 2003. This college is brilliant. I give them a 10 for Inclusion.

I have five jobs. The first job is part time and I do this with my dad teaching nurses about special education. I teach them that we're not different. They always give me the best evaluations. It's a fun job.

The second job is DJ'ing. My name is Joe90 and my business is called JK Entertainment. I do karaoke and disco's at functions and DJ at pubs. I DJ any music except Gareth Gates and Will Young. The business was set up with my cousin Paul, but it's my business now. It's been good. I want to carry on DJ'ing, it's my best interest.

The third job is two days a week as assistant manager for a restaurant.

My fourth job is recycling aluminium to keep the environment clean. I also recycle computer chips.

My fifth job is as vice-chair for People First. It is an organisation run by people with learning difficulties about speaking up. I have been a member since I was 16. We are all bosses.

I just bought my own home. It's amazing really."
Excerpt from 'Where Are They Now'

The main factors which made the difference for this young person were:

- ▶ Loving and empowering parents/allies
- ▶ Inclusive Education
- ▶ Positive vision for the future
- ▶ Direct Payments
- ▶ Greater opportunities in mainstream life

Too much currently depends on a child being fortunate enough to have the first of these - parents who are positive, get to learn about the medical and social models of disability, have the resources to wrestle with systems, (Health, Social Services and Education) and can imagine a better future for their child than that which is usually expected.

Parents have a lot of power over their children, and parents of disabled children in particular are still legally allowed to 'choose' a segregated, even residential school placement for their child. How they exercise this power will depend greatly on their access to information and their own self-confidence, beliefs and prejudices. It will also be heavily influenced by the responsiveness of mainstream provision to the needs of their child. Obviously, the greater these are, the more concern the parent will have. Research has shown that parents of disabled children almost always want inclusion as their first choice. It is only after rejections, hostility and incompetence that they seek refuge in the segregated system, having to put the 'now' before the idealism.

The role of well trained inclusion assistants for children with high-level support needs within mainstream schools and classrooms could transform this situation. Despite the smaller classes and higher ratio of staff, children in special schools do not get this kind of support:

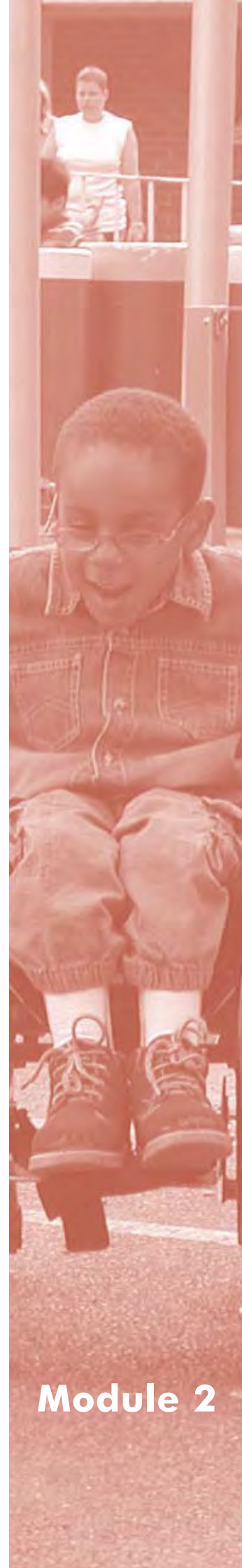
What Happens in Special Schools?

As a SEN Advisory Teacher, I have had the opportunity to observe special schools in action on a number of occasions. These have been schools for children with the label of severe, profound and multiple learning difficulties. I haven't visited them on special occasions or as a special visitor. I have been on normal days with a child who is visiting or to free up a teacher for a visit to a mainstream school.

My overwhelming feeling on these visits has been of long swathes of time spent on preparing for things to happen rather than things happening. This is not anyone's fault. It is the result of having a school comprising exclusively children with a very high level of need.

First, lots of time is spent arriving at school. The logistics of getting large numbers of disabled children off buses and into their classrooms and into their chairs is not easy. So nothing much may happen until about quarter to ten or later. Then there will be not much happening after two thirty when everyone has to be seated, dressed and taken to sit with their bus groups ready for the return journey. So we have a seriously shortened school day.

Taking a group of children to the toilet, many of whom have to be hoisted, and changed, is another long time-consuming ritual, that has to happen twice a day or more. Getting hands washed, drinks drunk



and snacks eaten for this group is again a long business with so many severely disabled children. Going outside at playtime involves getting coats on, transferring into different seating and then the same thing in reverse.

In between all this kind of activity there are windows of learning. There may be a morning welcome routine involving registration/weather/day of the week. This is usually a multi-sensory activity. There will typically be a literacy activity sharing a big book. There will be other group lessons over the week relating to different areas of the curriculum.

A class at this type of school is usually made up of some children who have little movement and may have little option but passivity and some children who are mobile and challenging. Apart from the morning welcome routine, the content of the lesson tends to be aimed at the more active children and a lot of energy is spent trying to make them sit and behave. If there is a child with more ability to understand than the others, this child may well be asked a lot of questions.

The passive children are strapped into different positions and the focus of the lesson is not on them, although they may be given an object on their tray which links with the lesson.

There are sometimes more exciting lessons like hydrotherapy, soft play, light stimulation, visits out of school, possibly even trampolining, but again a high proportion of time is spent getting ready for these activities.

There are also windows of time when the children will do individual work relating to their individual education plan. The more physically disabled children will need an adult to enable them to derive any meaning from this activity, but the more challenging children will inevitably tend to take up staff's time.

There tends to be a lot of assessments and recording material, which needs to be filled in to show that the children are working on their targets. Like most of this kind of paperwork, it takes up a lot of staff time, which might be better spent interacting with the children.

If the day is seen as a house, it is a house with an awful lot of bricks and not many windows. It is not anyone's fault. It is the nature of segregation.

SEN Advisory Teacher, Northwest of England

Inclusion Assistants have the chance to help create a new model of education which will give all disabled children the same opportunities as the lucky minority.

Written from the perspective of disabled people and the Independent Living Movement.

Module 2

Programme

1. Welcome and introductions
2. How we will work together
3. Module 2 Aims
4. Exercise: Shield
5. Exercise: Challenging Expectations
6. Presentation: The Right to a Positive Future
7. Exercise: Barriers to Inclusion
8. Concluding Remarks



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Module 2

Aims of Module 2

1. To see inclusive education in the context of the whole life.
2. To understand the difference between segregation and inclusion.
3. To compare different lifestyles
4. To focus on the barriers to inclusion.
5. To consider ways to make inclusion possible.



Module 2



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Exercises:

1. Shield Exercise.



- ▶ Copy Sheet 2.1 and hand out. Ask participants to complete on their own.



- ▶ Ask them to feedback. This will help people to get to know each other and focus on their own school experience.

2. Challenging Expectations Exercise.



- ▶ Write the following on a flipchart and ask participants to answer the question in pairs and then feedback:

“X’ is a child who has cerebral palsy affecting all four limbs. She has little voluntary movement and cannot speak. She is incontinent. She has been assessed in the past as having a developmental delay of over 6 years. She also has diabetes. How do you imagine her life when she is 25?”

- ▶ Read out the following statement and follow with presentation.

“The person described in this case history is now 20, studying English at University with a package of support which is paid for and managed by her mother under the direct payments scheme. Some of the Assistants have learned to facilitate her speech and written work using Facilitated Communication. She is also part of a group of young people who offer training to mainstream schools and colleges on inclusion, for which she gets paid. Her assistants are trained by her mother to manage her diabetes”.

3. Barriers to Inclusion Exercise.

(For this exercise you will need blutack)

- ▶ Make copies of Sheet 2.2 (bricks and wall breakers)
- ▶ Split group into 3 or 4 people depending on size of group and room used.
- ▶ Hand out a few bricks per group.

- ▶ Ask the group to write on each brick one barrier to inclusion within their institution.
- ▶ Ask the group to stick bricks to form a wall of barriers and discuss.
- ▶ Hand out wall breakers and ask the group to consider the discussion on barriers and come up with possible solutions to each barrier. They can choose as many as they want, then write each solution on a wall breaker.
- ▶ Stick wall breakers on each brick and discuss.



Module 2

Presentation: The Right to a Positive Future.

- ▶ Share Sheet 2.3 and explain why the points are important for inclusion.
- ▶ Share Sheet 2.4 - Joe's story.
- ▶ Share Sheet 2.5 - Paul's story and compare outcomes with Joe's Story.
- ▶ Explain what helped Joe's story to be different from Paul's by showing Sheet 2.6

Module 2 Outcomes

Demonstrate the ability to:

- ▶ Reflect on the role of education within the wider context of individuals' whole life experiences.
- ▶ Identify the key differences between segregation, integration and inclusion, comparing the different lifestyles these promote.
- ▶ Identify the main barriers to inclusion and suggest solutions for overcoming these.

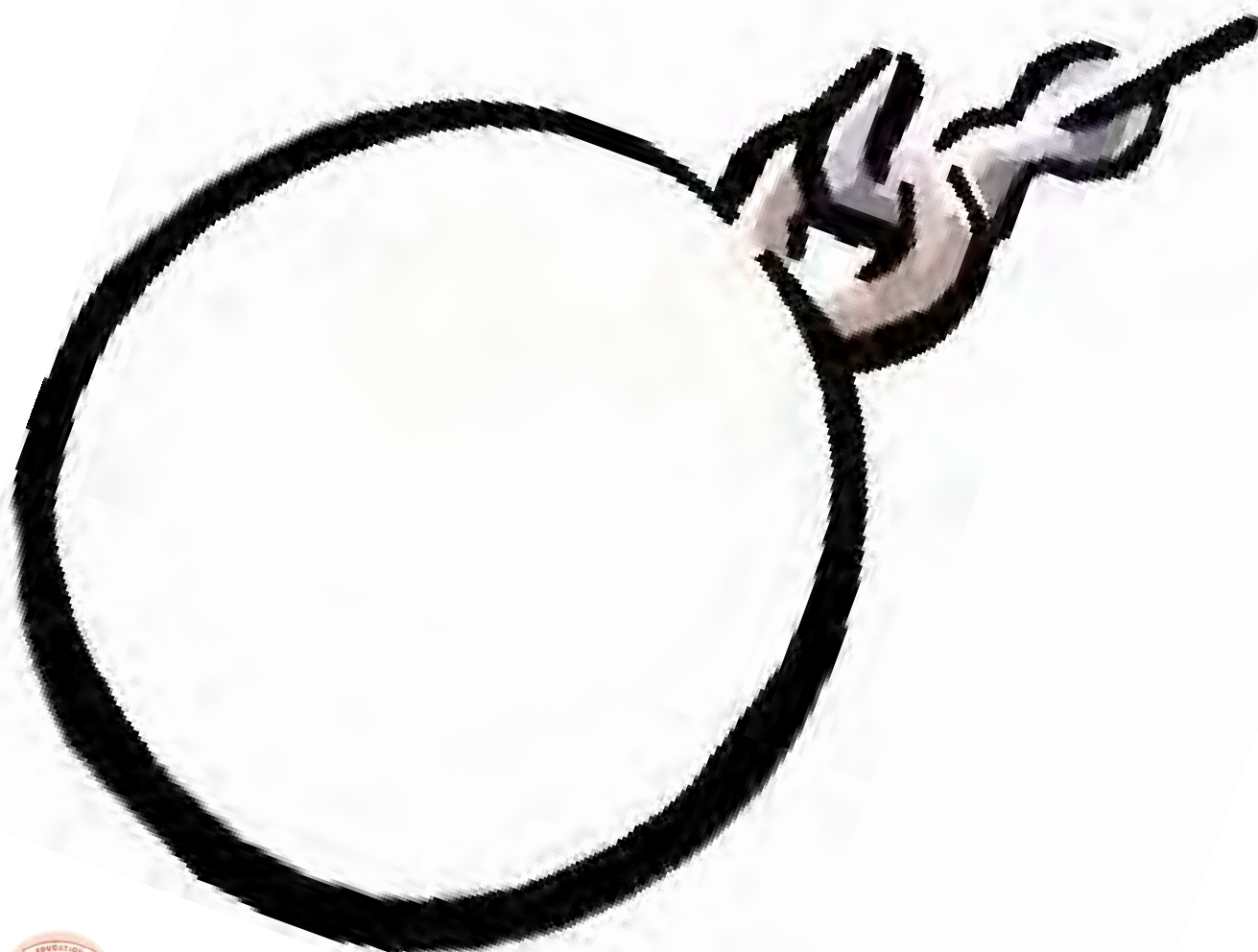


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Module 2

Something I was really good at at school	My Best school memory
Something I'm proud of from school	Person I remember from school





What Makes an Inclusive Lifestyle:

The person:

- ▶ Is living in a non-institutional setting.
- ▶ Is in a meaningful relationship with more than just family.
- ▶ Has interesting things to do.
- ▶ Has an outlet for talents and gifts, including paid employment if desired.
- ▶ Can see a purposeful future for him/herself (in their own terms).
- ▶ Is still learning.



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Joe Gault



"I have five jobs. The first job is part time teaching nurses about special education. I teach them that we're not different. They always give me the best evaluations. It's a fun job.

The second job is DJ'ing. My name is Joe90 and my business is called JK Entertainment. I do karaoke and disco's at functions and DJ at pubs.

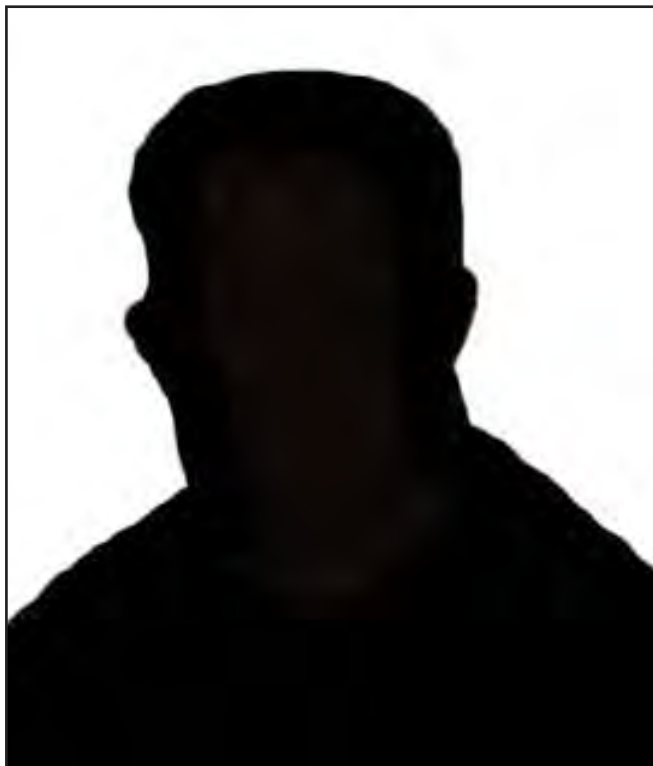
The third job is as assistant manager for a restaurant. I work two days a week.

My fourth job is recycling aluminium to keep the environment clean. I also recycle computer chips. When I leave college I will try and get a 2nd placement recycling so I work 2 days a week.

My fifth job is as vice-chair for People First. I have been a member since I was 16. It is an organisation run by people with learning difficulties about speaking up. It is disabled people run and we are all bosses.

I just bought my own home.
It's amazing really".



Paul

“Paul left school with little hope for the future. No discussion about work or chosen career or what he wants to do or how to live his life. It is taken for granted that he will graduate into the local day centre. He is now 50+ and has been in the same day centre since leaving school and has been enrolled year after year for the last fifteen years in the same computer class”.



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The main factors which made the difference for this young person were:

- ▶ Loving and empowering parents/allies
- ▶ Inclusive Education
- ▶ Positive vision for the future
- ▶ Direct Payments
- ▶ Greater opportunities in mainstream life



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Module 3

The Right to Be Safe

Although many young people would not choose to go to school if it were not compulsory, it is still a sad fact that many children feel safer at school than at home. At least no-one hits them, and there is regular food. There are adults who seem to care about them some of the time. It is structured and consistent. Children whose lives are full of inconsistency and chaos are often the children who bring the biggest headaches to teachers. Their unmet emotional needs can lead to all kinds of difficult behaviours. However an increasing number of schools are now accepting that they have a duty of care towards all their pupils and are not justified in excluding them into a world where they will be in danger. Some of these young people may only be contained within school with the support of a one-to-one assistant for a period of time.

Protection from Abuse

However careful we are, children are vulnerable to abuse from people bigger and stronger than themselves. There are many people around who have been left with patterns of physical, sexual or emotional violence, who are compelled to continually seek opportunities to play out these behaviours. They will gravitate to places where vulnerable people can be found, preferably on their own. Disabled children are particularly vulnerable because of our need for physical and intimate care, because sometimes we cannot speak, and because our testimonies are often considered unreliable, especially if we have been labelled as having learning difficulties. We are sitting targets. This can be from people who are paid to look after us, or sometimes from older pupils. It is impossible to prevent all these people from getting near their victims, however stringent we are about police checks etc.

Many disabled adults who were sent to residential or segregated day schools, just like children in Local Authority Care, have memories of serious abuse which was never acknowledged or dealt with:

"We were told when to go to the loo. I remember going on an outing to Bognor with the school when I was about 15. When the coach arrived there we were all told we had to go to the toilet. There was no accessible toilet and what they wanted to make me do was line up with the others in an alleyway and go to the toilet outside. We were using bottles and things with no privacy at all. They said if I didn't go I would have to sit in the bus all day, so I sat in the bus all day."

"Looking back I realise I experienced sexual abuse at school. I needed more help going to the loo at the time I reached puberty. Then we had female Welfare Assistants helping both the girls and the boys. One welfare assistant commented on my newly sprouting pubic hair. I was very shy then and in my Asian culture we do not speak of these things so I

was shocked. She looked aroused, excited and she said "What I do sometimes is shave it all off. If you ever want to do that I'll help you". I was overwhelmed with embarrassment but I thought it was normal behaviour. My friend at school bragged about this woman doing him little sexual favours. She vanished from school one day, right in the middle of term. Ever since I have been very selective about my PAs. You get a feel about people. It us an instinct. We must be given a choice." A.K.

"We used to freeze in the winter and boil in the summer. I wouldn't go to the loo at school because I was afraid of the dinner ladies who used to take us. They took our knickers down in full view and then sat us on the loo and left us for about twenty minutes. The whole of the dinner break went like that. I was very skinny and bony. Only weighed 31/2 stone. It was so uncomfortable. There was no gentleness. No kindness. Very degrading. They ignored our impairments. Quite cruel." J.C.

"We all experienced constant ridicule and torment from people who were supposedly employed to 'care' for us. I remember one young boy being dragged down two flights of stairs because he had wet the bed. On another occasion I remember a group of three or four 'care' staff standing round a young boy (who had a significant speech impairment), as he ate his food, laughing at him because swallowing made him drool more." T.F.

This case of a teacher in a Special School taken to court on several counts of cruelty towards a disabled eight year old girl, is one of the few which come to light because of the fear of 'whistle blowing' amongst staff:

Press Release January 27th 2005

JUDGE EXCUSES ABUSE OF DISABLED CHILDREN

Disabled people and their allies were horrified to read the pronouncement of Judge David Hale in response to a teacher of disabled children admitting that she had assaulted her pupils. He said:

"I take the view that people who do as she has done for many years need the patience of a saint with children like this. One can understand that the pressures on occasions are such that one can behave inappropriately in frustration or for whatever other reason".

This 'inappropriate behaviour' was perpetrated in Dee Banks Special School in Chester. It included hitting a small girl, who was in a wheelchair, with a pointer stick across the face; holding the girl by her cheeks after her teeth had been removed and lifting her bodily; holding a boy's head under water during a swimming session; smearing spaghetti in the faces of two boys during a cookery lesson and throwing a ball in the face of one of them. A further five cruelty charges, denied by the teacher Beryl Thompson, were allowed to remain on the file after her trial on January 14th.

Module 3

One of the main safeguards for disabled children is being surrounded by non-disabled children. Their presence will inhibit most abusers, and if one manages to mistreat a disabled child, it is likely that their friends will tell and will be taken seriously. This alone is enough to make an argument for inclusive schools rather than herding all the most vulnerable children together, out of sight, with numerous adults in places known to attract abusers.

"When you are 13 it's a real drag for your birthday to fall on a school day. But for my daughter Clare this was to turn out to be a blessing in disguise. I couldn't have foreseen what a powerful and illuminating moment was going to occur in the local burger bar where she and her friends had decided to assemble that Tuesday after school. They had settled down to munch into their choice of fries and shakes, when one of them said, "Diana, Clare has something important to tell you." They all went a bit quiet, and turned to Clare. Clare was a little hesitant; she has learning difficulties and a speech and language impairment. This wasn't going to be easy. But with their gentle help and encouragement the story unfolded of how her current LSA was mistreating her. Ignoring her in class - even reading a magazine if she could get away with it and most devastatingly had hit Clare on the way back from swimming one day. I just had the presence of mind to reassure Clare, and all of them that action would be taken immediately, but most of all to thank them for making sure that Clare told her own story and not gone behind her back. They had made sure that this behaviour, carefully hidden from the teachers, had been exposed and Clare got to understand how wrong it was. Their actions and thoughtfulness led to changes that empowered Clare for the rest of her school days. No LSA was ever again recruited unless Clare gave the go ahead at the interview and was completely comfortable with them after a few weeks trial. All this was possible because her friends had witnessed some wrong doing and been able to deal with it the way they would have wanted for themselves. Respectfully. There is no greater protection in life than having friends that can look out for you." D.S. Parent

Another important safeguard is that every child should choose who carries out their intimate care procedures. Most children, even with the most severe impairments, can and do indicate when they are not happy with the care they are receiving from certain people. It is as important as being able to choose when and who to have sex with. In fact it is probably how we learn to make these sorts of choices as adults.

It is also a fundamental principle of the independent living movement and was one of the major changes in our lives as disabled adults that we took back the power to choose who should be our personal assistants. When we won the right to recruit our own help, pay them and become their employers, we achieved a huge step forward in living safely in the world.

Written from the perspective of disabled people and the Independent Living Movement.

Module 3

Programme

1. Welcome and introductions
2. How we will work together
3. Module 3 Aims
4. Exercise: What makes you feel safe?
5. Exercise: Protection and Risk
6. Presentation: Risk Versus Safety
7. Exercise: School Policy
8. Concluding Remarks



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Aims of Module 3

1. To focus on issues around personal safety.
2. To understand risk.
3. To learn from the perspective of disabled people.
4. To understand what makes us safe.
5. To understand possible conflict between personal safety and school policies.



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Module 3

Exercises:

1. What Makes You Feel Safe Exercise

- ▶ Ask participants to work in pairs and to take 5 minutes each to listen to each other about what makes you feel a) safe b) unsafe.



- ▶ Bring group back for feedback. Write issues arising on flipchart.

Note: For this exercise you need to highlight the issue that people feel safe if they are in control, e.g. the thought of growing old may be scary because we could not guarantee we would be in control.

2. Protection and Risk Exercise

- ▶ Read out the following scenario:

Amanda is a child in a mainstream primary school in a busy inner city area. She is six years old. She has a condition called Osteogenesis Imperfecta, or 'Brittle Bones'. This results in small stature, weak muscle tone and fragile bones. She cannot walk but can crawl. She is just starting to use a powered wheelchair. She also has a lightweight manual wheelchair. Her mother has the same condition.



- ▶ Ask the group to work in pairs and to think of the situation and spend 10 mins writing down: What would you do to protect the individual and staff concerned?



- ▶ Ask group to feedback and write main points on flip chart.



- ▶ Ask pairs to now think of the same scenario and ask the question: How would you promote independence?



- ▶ Bring group back and ask for feedback and discuss the issues of risk.



- ▶ Share Sheet 3.1 (Amanda's Story) and discuss.

3. **School Policy Exercise.**

- ▶ From what they heard, ask groups of 3-4 to draw up a list of what constitutes good practice.
- ▶ Feedback.
- ▶ Compare list to what is school policy in reality.

Note to trainer: Bring with you a sample of school policies on safety.

Presentation: Risk Versus Safety

1. Using the introductory module notes as a starting point, discuss the issues raised by disabled people. E.g.:

- ▶ Vulnerability to abuse
- ▶ Safety in numbers (Clare's Story, p58)
- ▶ Choosing your own helpers



2. Share Sheet 3.2 and ask: Can you be too safe?



Module 3 Outcomes

Demonstrate the ability to:

- ▶ Identify and discuss key issues concerning personal safety and risk, using a range of perspectives.
- ▶ Reflect on potential areas of conflict between individual personal safety and school policies.
- ▶ Apply perspectives of disabled people to risk and safety policies in your own work setting.



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Module 3

Amanda's Story

At school Amanda had a full time LSA who stayed in the background much of the time. She also had an escort (another parent) who pushed her to school. The LSA and Amanda were issued with a 'walkie-talkie'. This allowed the LSA to be occupied with other tasks but always ready to respond to Amanda's call. Amanda was always the priority.

Amanda's mother had a 'bleeper' by which she could be summoned in an emergency (this would now be a mobile phone). The LSAs were trained by Amanda's mother and by Amanda herself. They also sought the advice of a specialist O.T. from the Brittle Bone Society. She reinforced that Amanda's safety depended on Amanda being in control at all times of her physical being. This especially meant:

- a) Not lifting her or moving her without warning
- b) Asking her how to handle her, every day
- c) Believing her if she said she had a fracture and could not be moved

The main reason is that Amanda's needs could change at a moment's notice, as could her level of pain. The only person who could know that was Amanda. Modelling this 'Stop and Ask' approach helped the children in the class know how to keep Amanda as safe as possible.

All staff were warned that total protection was not possible. Amanda may have fractures however careful everyone was. Emergency procedures were taught to the LSA and the class teacher. They were reassured that, short of gross neglect, they would not be blamed or sued if an accident occurred.

Amanda was enabled to get out of her chair and play on the floor with the other children. She was also encouraged to take part in Gym with her LSA under 'voice control'. This was to help Amanda's physical strength to develop as well as her social skills and sense of closeness to the other children.

The children in Amanda's class were given some straightforward information about Amanda's condition. They were trusted to be aware of her needs once this information was given.

Amanda was helped by her LSA to go to the toilet and to get her outdoor clothes on. She was helped to transfer from outdoor chair to indoor chair.

Amanda was included in all school activities including school trips and journeys. If needed, extra funding was sought for her LSA to come to assist her. The school policies reinforced her right to inclusion by stating that if any activity was not accessible for any one child then it would not happen. A replacement activity would be sought.



Risks

To laugh is to risk being a fool
To weep is to risk being sentimental
To reach out for another is to risk involvement
To show feelings is to risk showing yourself

To place your ideas, your dreams
Before a crowd is to risk their loss
To love is to risk not being loved in return
To live is to risk dying
To hope is to risk despair
To try is to risk failure

But risks must be taken because the greatest
Hazard to life is to risk nothing
Those who risk nothing do nothing, have nothing
And are nothing

They may avoid suffering and sorrow
But they cannot learn, feel change
Grow, love, live

Chained by their certainties, they are slaves
They have forfeited their freedom
Only a person who risks... is truly free.

Anon

Module 4

The Right to Have Our Physical Needs Met

All children deserve to be sheltered and adequately fed every day of their lives. They need suitable clothes and access to the means to keep themselves clean. It cannot be assumed that every child in any school will have this at home. School is a very important safety net for many children.

Children with additional physical needs will only be safe if they have one or more people available to them at all times who know how to meet those needs. Every child will be different and their individual needs will have to be taught by the child, the parents or other regular assistants together with advice from professionals such as paediatric OTs, and aids advisors. These skills can range from lifting and transferring, dressing/undressing, assisting with the toilet, assisting with eating and drinking or tube feeding, use of specialist equipment such as standing frames, wheelchairs, speech machines, back-braces, portable ventilators, etc.

Some children will need some form of therapy on a day-to-day basis and the Inclusion Assistant may well be trained in this by a physiotherapist or speech therapist. He/she may work under their supervision or in partnership with the therapist themselves.

Some children will have medical needs and their Assistant will need to know about any medication they take, and what to do in an emergency. For children who are often away from school, at home or in hospital, the Assistant will have an important role in maintaining continuity and organising work whilst they are away, and making sure the child is welcomed and helped to catch up when they return. It may be necessary for the Assistant to work with the child in other settings.

However physically dependent a person is on help from another person, they still can be in control of their lives, independent and able to keep their dignity. This depends entirely on how the help is given. The goal is for the young person to be more and more 'in charge' of their support, more directive and assertive as they grow older. This can pose a challenge to adults who are used to being in control. It takes a particular sort of maturity, but there are an increasing number of people who now work with disabled adults who have a lot to teach about this empowering role.

Some young people with learning difficulties, autism or compulsive behaviours may have difficulties keeping themselves safe. They may get lost around the school, or be unaware of some of the dangers of equipment or machinery. Some may put themselves in vulnerable positions regarding sexual relationships, and some may have a tendency to run away. These needs are very individual and may need very close supervision at all times. These children are safest when their needs are known by everyone, not just their Assistants, so letting everyone know what to look out for and how to help will be an important role for their Assistant.

It should not be assumed that all these needs must be met by adults. Children with such needs often prefer them to be met by their friends, especially as they grow older. Children can be taught how to help with eating and drinking, putting on jackets, setting up equipment, taking notes, pushing wheelchairs and much else. Enabling this to happen is an important role for the Inclusion Assistant. Children are usually very clear when they do not feel big enough or strong enough or responsible enough to be taking on particular tasks. Adults should not convey any feelings they might have that helping a disabled child is burdensome or exploitative. Children do not naturally feel this way. They like to be needed and useful towards each other. Some children may find they are needed and valued by someone for the first time in their lives and it can be transforming.

Independence

Most of us think this means doing things without help, doing things alone. It is something we think of as good and desirable from a very young age. We associate dependence with childishness and independence with growing up. However, many people with high level support needs will always need help to function. Disabled people have worked hard to create services which allow both support and autonomy. They have re-defined 'independence' to mean being in control of the assistance they receive, i.e. working out what they want to do and then getting the help to do it. This is the opposite of service-led support where the 'help' available is designed and delivered by the providers, and the disabled person accepts it or goes without. Direct Payments is a 'service' fought for and won by disabled people. After assessment, a sum of money is given to the disabled person to hire and fire their own staff who become 'Personal Assistants'.

For a young person with high level support needs, learning to be self-directive can be very difficult. Most young people do not have to deal with constant adult attention, and most do not want it. In a school environment where all the pupils are highly controlled, strict rules and sanctions are in place and there is a culture of 'Doing What You Are Told', every 'individual' child has to develop their own relationship to authority. This is part of maturing and becoming autonomous. To belong to young peoples' culture and community usually involves some degree of resistance to rules and adult control. It is a right to be 'naughty'! It is easy to see why this is a controversial idea for young people who need constant facilitation by an adult. The adult may well see their job as keeping the young person 'on task' all the time, making them behave, finish their homework, avoid all risk and be a 'perfect' student. A wise manager will think beyond this. Some balance will need to be achieved between support and control. This is not to say that a disabled child should be exempt from school rules. The staff who normally manage school discipline should include all the children in their jurisdiction. The extra person, in the form of the Inclusion Assistant, should not be seen as an alternative and constant supervisor.

The details of this relationship need to be carefully thought about or an important piece of the child's learning may be prevented from happening. Some unsupervised time when young people are left alone with each other seems vital for real inclusion to happen.

Independent Living

We live in the West - the so-called Developed World - under the illusion that we move rapidly from a state of total dependency at birth, to total independence at about 20 and that this is normal and desirable. We fear 'dependence' and the concept of being a burden on others. This most often shows itself as we get older. A great deal of our fear of disability is of this notion of dependence on others and becoming a burden, or becoming burdened with having to look after someone.

Because of our particular history, the State's response to this fear has been to institutionalise people and turn 'caring' into a form of employment. This has reinforced all our fears about disability and old age. It is disabled people themselves who have challenged all this. The first group of disabled people to come together, united to fight against the restrictions placed on their lives were young adults with physical impairments living in residential homes. They said that:

- ▶ They had abilities which were being wasted
- ▶ They did not want to spend their lives in an institution
- ▶ They wanted to make their own decisions about day-to-day life, e.g. what to eat, what to wear, when to get up and go to bed, who to mix with.
- ▶ They wanted to be in control of their 'carers', rather than the other way round.

This last demand was the most controversial at the time, but the one which is gradually changing the lives of disabled people. It recognised that the need for assistance did not mean that they could not be independent as long as they were in charge - the support was there to help them follow their own goals, not those of an institution or of their carers.

Some of those people experimented with new ways of living in adapted housing with a 'Care Package' organised by their local social services. Eventually however, it became clear that the goal of a supported independent life would not become a reality unless the 'client' became the employer, recruiting, training, managing and paying people to help them in the individual and flexible ways they required. Disabled people fought and won a battle for 'Direct Payments' in which Social Services transfer an agreed amount of money each week for the individual to buy-in their support. The new role of 'Personal Assistant' was born.

Suddenly a whole world of possibility has opened up to disabled people who need personal care. We have been able to travel, study, get jobs, make friends, have love affairs, get married, have children, do voluntary work, become politicised. We employ people who can help us get up, dressed, washed, shaved, make phone calls, facilitate our speech, set up and use equipment, drive us about, help with domestic chores and childcare. They can help us pursue studies, hobbies, relationships and self-advocacy.

The legal right to direct payments also now applies to people with learning difficulties, to young disabled people aged 16-17, and to parents of disabled children. (see Direct Payments, Appendix 2)

With children comes the added challenge of adultism, or the general view that adults should control a child's life for their own safety etc. We need to work out how to gradually reduce this control and gradually increase the child's autonomy and right to set their own goals as they grow into maturity. The role of non-teaching assistants in school could be very much a part of developing this increasing autonomy without abandoning the child to manage alone. For this to work the assistants, their managers, the parents concerned and the child's friends and classmates need to learn from disabled adults how we live our lives.

Lifting and Handling

This pack does not cover training on personal care or facilitation of individual young people. However whilst there are no regulations around issues such as 'dressing and undressing', there are now very clear guidelines as to how to lift children and adults in schools and other settings. This has often been misinterpreted and used in ways which work against the autonomy, dignity and even safety of the 'lifted' whilst seeming to protect only the rights of the 'lifter'. It is important therefore in this pack to comment on good practice in this area. The law says that when a person needs to be lifted or moved by a paid 'carer', there must be a 'Risk Assessment' to see how techniques and equipment may help minimise any risk of strain or injury to the lifter. Many institutions have reacted to the consequent fear of litigation by issuing blanket 'No Lifting' policies. However many disabled people find hoists painful and restrictive and prefer to be moved by human beings who are trained in lifting techniques and who have the physical strength to do so. A case was taken by the DRC on behalf of a disabled person and the ruling was that blanket policies are illegal. These issues are especially relevant for children who love to be in physical contact with each other - on the floor, in the ball pond, on the grass and in many situations where mechanical equipment is just not appropriate. The reliance on equipment also teaches a message which is very anti-inclusion for young people. Most children do not live in houses with ramps, adapted toilets or portable hoists. If their disabled friends are to visit to play, eat together, even have a sleep-over, then their

parents, their friend's parents, their big brothers or sisters or their PAs will need to lift them. If children do not see this happening at school then they will come to believe it cannot happen, and much of the point of inclusive education will be lost. Everyone's needs must be balanced with lifting techniques taught and used, low-tech aids developed (e.g. sliding boards,) and most importantly, the disabled person involved in the decisions about lifting and handling.

Written from the perspective of disabled people and the Independent Living Movement.



Module 4

Programme

1. Welcome and introductions
2. How we will work together
3. Module 4 Aims
4. Exercise: Who helped you today?
5. Exercise: Mosquitoes
6. Exercise: Positive Help
7. Presentation: Developing independence and understanding interdependence.
8. Presentation: Lifting and Handling - the Dignity of Risk.
9. Exercise: Being directed by young people
10. Concluding Remarks



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Module 4

Aims of Module 4

1. To explore areas of independence and interdependence
2. To explore definitions of independence
3. To understand the History of Disablism
4. To learn about issues of personal care from the disabled child's point of view
5. To start to address changes needed in school culture



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Module 4

Exercises:

1. Who helped you today?

- ▶ Ask the group to individually write down everybody upon whose labour you depend to live your particular lifestyle, from waking up this morning and arriving to this training.



Note: Ask them to include use of heat, light, water, food, clothing, transport, telephone etc.



- ▶ Feedback

Notes:

- ▶ We are all dependent on many hundreds of people. Life for the majority of people is so organised that their support is invisible.
- ▶ If someone needs someone to come and get them up in the morning that is only one more person.

2. Mosquito Exercise

- ▶ Ask group to imagine that there has been a mosquito epidemic which causes everybody infected to become paralysed from the neck down for six months. You have all been infected.

- ▶ Describe yourself as the Director of a support agency that will send them supporters for their care.



- ▶ Ask group to work in pairs and record for each other what type of person they want to offer them support, personal care and meeting their physical needs.



- ▶ Say that the epidemic has been more severe than expected and a lot of your staff have been infected, so there are less people to help. Ask them in pairs to list their top 3 requirements.



- ▶ Ask for feedback and support a discussion, highlighting issues around what makes good support.



3. Positive Help Exercise

- ▶ In pairs ask them to take 5 mins each and listen to each other. Ask them to think of a time when someone was really helpful to them when they needed it. What made it good?
- ▶ When they have both said what they felt ask them to take a further 5 mins each to think about a time when someone tried to help but it was not useful.



- ▶ Ask pairs to feedback main points.

4. Being directed by the young person Exercise.

- ▶ In pairs for 5 mins each ask them to discuss how it would feel to be directed by a young person. They need to be encouraged to be honest about how they would feel.



- ▶ Ask them to feedback main points.



- ▶ In a big group discuss how young people directing fits into the culture of the school.

Notes:

- ▶ Most schools are fairly authoritarian
- ▶ Adults firmly in charge
- ▶ Young people not directing
- ▶ Asking for culture change to allow more control in line with peoples feelings from the above exercises
- ▶ Disabled adults with high level support needs will increasingly be employing their own personal assistants in order to live an independent life. Skills needed to do this need to be practiced as a child grows up.

Presentations:

1. Developing independence and understanding interdependence.

- ▶ Share Sheet 4.1 and use along with introductory notes as a guide.
- ▶ Present under each of the headings.



(You might want to do your own research and bring stories, photographs, etc.)

2. Lifting and Handling - the Dignity of Risk

- ▶ Please refer to Module 3 and summarise main points and the relevance to lifting and handling.



- ▶ Also refer to the introductory notes on this Module.



- ▶ Discussion: When working out a lifting policy for an individual child how can we make sure that everybody has been heard including the child and their parents.

Module 4 Outcomes

Demonstrate the ability to:

- ▶ Identify the differences between independence and interdependence, reflecting on their impact on disabled people's experiences.
- ▶ Discuss the impact Disablism has had on past and current practice.
- ▶ Utilise individual pupil's views when planning for their personal care requirements.



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Module 4

Developing independence and understanding interdependence.

Definition of Independence:

“Independence is not doing things alone but being able to direct your own support”

History of Disability:

- ▶ Needs met in institutional setting
- ▶ No control
- ▶ Disabled person as patient (Medical Model)

The Now:

- ▶ Disability Movement developed another view
- ▶ “The natural state of humanity is interdependence”
- ▶ We all need help but can be independent
- ▶ Being in control of how I am supported



Module 5

The Right to Have Our Communication Needs Met

It is fundamental to our human nature to engage in two-way communication with each other. This is not as simple as it sounds. In large schools, particularly inner-city schools where children and staff come from many varied backgrounds, speak many languages and represent all class backgrounds there is much room for miscommunication and mis-understanding.

Some children are particularly vulnerable to this because some children have impairments which affect their ability to hear, understand and use language. Unfortunately there has been a long history of mistreatment of these children based on the false idea that the inability to speak is the result of an inability to think or understand. Because of this children have been left in silent places, under stimulated and not spoken to. For example Deaf children were labelled as Deaf and Dumb, their manual (sign) language dismissed as primitive gestures, and locked up in long stay mental handicap hospitals. The same treatment was given to people with cerebral palsy, Down's syndrome, autism and many other conditions which made talking with their voices difficult. Thankfully, things are changing in our understanding of physiology - what particular impairments mean our bodies can and cannot do; in attitudes as deaf and disabled people fought back; in the development of communication systems using other functions of the body, and in the development of augmentative technology such as talking computers.

Every effort should be made to give every child a communication system, even if that can only involve body language. Body language can be 'read' and used as a form of communication - in fact most of us used that for the first two or more years of our lives with great success! A dependable 'yes' and 'no' can also make a big difference to the exchange of information between two people. A communication system can only work if everyone can use it, not just the focus child and their therapists or 'carers'.

Once established, communication systems should be used as much of the time as the disabled child wants, taking into account the amount of effort they can be to use. Having access to children without communication needs is vital for any child to develop their capacity to make relationships to their fullest ability. Even a silent child can learn a great deal from the chatter of their classmates and friends.

Learning how to use speech technology is a vital skill for many Inclusion Assistants. Speech therapists do not just teach people to talk anymore. They often have developed great expertise in the development of communication systems and the use of technology for speech-impaired children. Their input is very important.

Some children will require sign language to communicate. Many inclusive schools are now teaching the whole school basic sign language skills such as Makaton and the first stage of British Sign Language. For the inclusion of profoundly deaf children however, Assistants need to be fluent signers/interpreters and as in the adult world of interpreters for the deaf, they need to work in teams with adequate time to rest.

Facilitated communication is now becoming more accepted within the education system. This involves physically assisting a child with a movement disorder to achieve the control to point to letters on a letter board, or to type. It is a skill which can take up to nine months to learn, but has released many disabled young people from a prison of wordlessness.

Some young people thought to be 'uneducable' have taken public examinations using this system and have progressed to university. Like BSL it needs great concentration and can only be done for limited periods of time, so more than one person must be trained to assist a child in this way. There are a growing number of people able to deliver this training, but it often relies on assistants and parents passing their skills to each other on a one-to-one basis.

For further information on Facilitated Communication see:
Communication and Learning Enterprises: www.contactcandle.co.uk

Written from the perspective of disabled people and the Independent Living Movement.

Programme:

1. Welcome and Introductions
2. How we will work together
3. Module 5 Aims
4. Presentation: What is communication?
5. Exercise: Learning to listen
6. Concluding Remarks



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Module 5

Aims of Module 5

1. To explore the complexity of communication
2. To understand the basic need for two way communication
3. To think how to establish the maximum communication possible between young people with High Level Support Needs and their peers, teachers and assistants.
4. To create some awareness of the augmentative technology and facilitation which is available to help disabled people who are non verbal to communicate



Exercises:

1. Learning to Listen Exercise.

In pairs:




- ▶ One person cannot use words. Partner has to draw their favourite house. How did that feel? How well did they do?



- ▶ One person can only say yes and no - partner find out what they think about God.

Presentation: What is communication?

1. Show The Inclusion Assistant DVD. Ask the group:
 - ▶ How many different communication systems are being used?
(Spoken english, BSL, Facilitated Communication, use of 'Liberator', Hero's own individual system)
 - ▶ What others have you used? Discuss
 -  ▶ How can you learn these things?
2. If possible, find examples of communication technologies, communication aids, assisted communication etc. and elaborate on how they are used. Also include local information as to where they can go for advice.

Note:

Please remember to reinforce learning from the child and their family.

Module 5 Outcomes

Demonstrate the ability to:

- ▶ Review a range of augmentative technology and facilitation that is available to aid communication.
- ▶ Reflect on the complexities of enabling effective communication.
- ▶ Establish effective communication between young people with High Level Support Needs and others.



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Module 5

Module 6

The Right to Have Our Learning Needs Met

The State Education System is primarily set up to make children become productive, employable adults. The learning that children are compelled to engage in during class-time however, is only a small part of what children learn at school. Children learn about the world outside their family at school. They learn about the diversity of people, ideas, histories, circumstances, religions and beliefs, who they are in relation to others. They learn to have and be friends, to relate to many different adults, to accept rules and restrictions on personal freedoms. They learn sometimes to fight, to defend themselves, to take risks, to defy authority, to overcome shyness, to understand and be part of youth culture and much else. It is often incidental that they also learn to read and write. Much of this learning happens outside of the classroom. All children have a right to this whole experience not just that proscribed in the national curriculum or their Individual Education Plan, although these are important.

An Inclusion Assistant is different to a Teacher Assistant because they are concerned with the whole picture - what happens in the break times, the after-school clubs, the journeys home, the evening and weekends.

There is still a lot to be learnt about accessing learning for children with high-level support needs. For some it is just a matter of enlarging the print, or interpreting the teacher's words, or scribing for a child who has difficulty writing. For some pairing the child up with a non-disabled classmate who can lend their strength and ability to a co-operative task is enough. The child themselves, and their parents will often know exactly what is needed. But for some the challenge is much greater. Most children with 'severe' impairments have been dogged by low expectations and limited life experiences. The developmental curriculum, popular with special school practitioners, has often served to focus on what a child cannot do rather than their strengths and gifts. The desire to measure progress by the use of tools such as the P-Scales has again limited children to areas in which they can demonstrate some new physical skill or competence, but disabled adults have testified over and over again that there was much more going on inside than could be shown on the outside. It is wise therefore to adopt an attitude called 'The Least Dangerous Assumption' (See sheet 6.1)

All children, including children with high-level support needs, learn most of what they learn at school from other children. An Inclusion Assistant will help facilitate peer tutoring and mentoring rather than thinking that their job is to do it all themselves.

For young children play is their 'work'. It is how they learn. Play is not the same as therapy, however much adults try to make it fun. Play is self-directed and has a different goal - the child's own learning goal.

All children need lots of opportunity to play and for children with high-level support needs this is no different. However, their lives may be so full of therapies and daily living activities such as dressing and feeding that their families may have precious little time or energy left to facilitate play. Whilst some children are easily over-stimulated, especially children with autism, or hyperactivity patterns, it may seem that some disabled children don't know how to play. That might be mistakenly put down to their level of impairment, but it is more likely to be that they have already begun to learn to be passive and 'shut down' because of too little stimulation which is fun and stress free. Other children are often the motivators - the ones to 'wake the child up' in a mainstream setting, or to calm one down. The Inclusion Assistant needs to find lots of ways to facilitate these relationships.

An Inclusion Assistant should also not seek to replace the role of the ordinary classroom teacher, even if the teacher wants them to. The Assistant is there as much to help the teacher to teach as the child to be a student. The teacher should plan their lessons to include all their pupils and have given thought to how the lesson might need modifying, adapting or accessing for each child. They need to be familiar with every child's IEP, their current state of health, any big issues in their lives, when and for how long they may be away from their classes, any particular problems they might be having with each subject area. They need to think of how to reward each child for effort or for a special achievement, and how to dole out sanctions according to school rules when appropriate. These things should not be delegated. The Assistant's role is to make sure that the teacher has the necessary information about the child, to make sure the child is comfortable, has understood what is expected of them, has all the resources they need and has the physical help they need either from themselves or a fellow pupil.

Homework

In a mainstream school young people are expected to work very long hours. In secondary school the average school day is seven hours. It is then expected that each child will do 2-3 hours of homework every night and several at weekends. Given the current inaccessibility of mainstream school buildings many young disabled people are still being 'bussed' or 'taxied' to school from far away, adding 1-3 hours daily travelling time. This is a longer working day than many adults have to manage. Disabled pupils have other pressures as well - necessary therapies, or dealing with fatigue, pain or hospitalisation. Time away from school nearly always means 'catching up' as well as keeping up with the work. In school the child may have an extensive support network, but at home, there will usually only be family members to help. This raises serious issues of inequality for young people with high level support needs. Teachers can do a lot to help by paring down homework to essential learning points, preparing the assignments in accessible formats (e.g. on a computer disc with answers

to fill in) and giving the pupil notes etc in electronic formats. Children could be resourced to tape their 'essays' instead of writing them and so on. Managers could also organise it so such students could stay in school for homework clubs at which their support system could continue. This will need funding and extra hours of assistance bought in. The Inclusion Assistant may also be needed out of school, at home or in hospital when continuity is very important, as is liaison with the student's teachers and friends. All this needs to be decided at policy level and before the 'Job Description' is drawn up.

Q. What do you think about a child being required to work up to a 50 hour week?

Written from the perspective of disabled people and the Independent Living Movement.

Programme

1. Welcome and introductions
2. How we will work together
3. Module 6 Aims
4. Presentation: Everyone can learn
5. Exercise: Best Play Memories
6. Exercise: The Least Dangerous Assumption
7. Exercise: Individual Education Plans
8. Exercise: Supporting an IEP
9. Concluding Remarks






Aims of Module 6

1. To tackle any assumptions about the ability to learn of people with High Level Support Needs, especially those which affect the ability to speak.
2. To explore the nature of play as self-directed learning.
3. To understand the difference between play and therapy.
4. To become familiar with the role of an IEP in the life of a pupil with High Level Support Needs.
5. To be clear about the difference between the role of the teachers and the role of the Inclusion Assistants.




Exercises:

1. Best Play Memories

- ▶ Tell the group to get into pairs and divide ten minutes into two five minute sessions. For the first five minutes the first person answers the question: What is your best play memory?
- ▶ The other person listens and encourages details.
-  ▶ They then swap places for the second five minutes.
- ▶ The group then comes together to share their memories.
- ▶ The trainer draws out common threads. These usually include: no adult supervision, taking risks, being 'naughty', making a mess. Sometimes it includes supportive 'playful' adults joining in.
-  ▶ The trainer then reminds participants that play is how children learn, that it must be self-directed and not confused with therapy.
-  ▶ Ask the question: How could you facilitate a child with High Level Support Needs to have similar play experiences to your own?

2. The Least Dangerous Assumption

- ▶ Share Sheet 6.1
-  ▶ Read and discuss.
(We will not be covering curriculum issues and differentiation as this is covered elsewhere in your training. This is set to help you think about your role in enhancing or limiting a child's learning.)

3. Individual Education Plans (In groups of five)
 - ▶ A child you are assisting with High Level Support Needs is transferring from primary to secondary school. He or she will need a new IEP.
 - ▶ What needs to be in it?
 - ▶ When should it be written?
 - ▶ Who should be involved?
 - ▶ How will you facilitate the child's contribution?
 - ▶ Write on sheets of paper
 - ▶ Feedback using sheets and discuss
4. Supporting an IEP
 - ▶ Give out Sheets 6.2 and 6.3 as handouts and allow time for participants to read.
 - ▶ Ask people to work in pairs and answer the questions:
 - ▶ What is the role of the Inclusion Assistant in supporting Eleanor?
 - ▶ What support or information will they need?
 - ▶ Ask for feedback and discuss.



Presentation: Everyone can learn.



Use the introductory notes for a presentation, bringing out some of the points below:

- ▶ Bring out the difference between the teacher and the assistant.
- ▶ The range of ability in a classroom is huge and individual differentiation of curriculum is the job of the teacher. From learning colours to preparing for university, all children need their learning facilitated.
- ▶ The role of the Inclusion Assistant in this is to introduce the child to the teacher and to liaise with them. To facilitate the implementation of the child's IEP. To help with homework. Play. Facilitate the child's learning. Help with friendship and social aspects of school.
- ▶ However, access to the curriculum is the role of the Inclusion Assistant. This could involve making large photocopies for a partially sighted child, inputting information to make it accessible through the computer, explaining things with pictures.
- ▶ Most children with High Level Support Needs do not simply follow the regular timetable for lessons. They have an Individual Education Plan. Explain what this is.
- ▶ Give an example that you know as an OHP or handout.

Module 6 Outcomes

Demonstrate the ability to:

- ▶ Discuss the role of play and therapy in the lives of young people with High Level Support Needs.
- ▶ Review how an IEP can be used to identify effective support and provide challenging learning experiences.
- ▶ Reflect how the differences between the roles of teachers and Inclusion Assistants apply to working with pupils with High Level Support Needs.



The Least Dangerous Assumption.

"Least dangerous assumption" states that in the absence of absolute evidence, it is essential to make the assumption that, if proven to be false, would be least dangerous to the individual. Consider it this way. If I were to go fishing for a week and not catch any fish, there would be two assumptions that could be made. First, I could say "there are no fish in the lake since I did not catch any, and I know what I am doing." Or, second, I could say simply that "I did not catch any fish that week, and I will keep on trying." The first assumption seems rather arrogant, while the second one is more realistic and respectful). The same holds true for students with disabilities. Imagine a child who does not talk with the spoken word and moves around using a wheelchair. Her teachers have worked with her for a month and have not yet seen any evidence of what she understands. In fact, they wonder if she knows or is aware of anything at all. These teachers can make one of two assumptions. They can assume that "what you see is what you get" and that this child does not know anything, that her brain is as empty as that lake. As such, they can educate her in a way that reflects those assumptions (perhaps segregated classes or regular classes with low or no expectations). Now imagine her as she graduates and uses a communication device to say, "Why did you treat me so poorly?" I am smart and you wasted twelve years of my life!" A very dangerous assumption was made, with results that none of us would desire.

Now, consider the second assumption. These same teachers can recognise that her movement differences are differences and not deficiencies. They can assume that she knows lots and just isn't currently able to show what she knows. Her brain is as full of knowledge and potential as that lake is of fish, but they just have not been able to reel anything in yet. As such, her schooling would reflect these high expectations and she would be considered and respected as a valued member of her school and classes. Now again, imagine her twelve years later at graduation, using her communication device to say, "Thank you from the bottom of my heart to all of my teachers who believed in me and made me feel as if I truly belonged and treated me like all of my classmates." This is the least dangerous assumption, one that results in a young woman who can celebrate her full and fulfilling life.

But consider a third scenario as well. What if we never come up with a way for this young woman to communicate her intelligence? What if, after twelve years as a valued and respected student in all general education classes, we still do not know exactly what she has learned and knows? What harm was done? What was lost? Nothing. And that truly is the least dangerous assumption.

All people are people first. Everyone belongs to this wonderful life. No one should have to conform to someone else's standards before they are told that they are "good." We all belong. We all have strengths and weaknesses and our own individual potential to be great people and to live the lives we want. We can all lead happy and fulfilling lives, supported by those around us to be successful adults. It is up to all of us to examine our own core beliefs and to spread the word of the least dangerous assumption. We can no longer allow the justification of a prejudice that is so dangerous. Now is definitely the time to believe that all people are valued individuals with limitless potential. Keep on fishing - the lake is overflowing!!!!

Rossetti, Z. & Tashie, C.

University of New Hampshire (A longer version of this piece can be read at www.inclusive-solutions.com)



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At the meeting were Eleanor's Mum and Dad, Eleanor's personal assistant, and two family friends. Also in attendance were Eleanor's current teacher, her educational psychologist, her speech and language therapist, two local authority officers, her social worker and the Assistant Head Teacher from Eleanor's new mainstream school.

Eleanor's mother went through the plan on the wall and after discussion it was agreed that:

- ▶ Eleanor will have a core curriculum of music, art and sport every day with the other pupils.
- ▶ Each day there will be some time for reflection, therapy, reinforcement and individual learning.
- ▶ Other options such as design technology, food technology, citizenship will be explored.
- ▶ There will be a team of four teachers working with Eleanor, Angela (the year head and head of PE), Eric the music teacher, Vicki for Art and Debbie for technology and as her tutor group leader.
- ▶ The LEA will employ two learning support assistants who will work in schools and will also help her to attend two after-school activities per week (1.5 FTEs). Eleanor's parents will be part of the interview panel.
- ▶ The LEA will find some EP time to come in and help set up a circle of friends within Eleanor's tutor group.
- ▶ The school will allocate staff development time for Eleanor's parents to talk to the school about her gifts, ambitions etc.
- ▶ Eleanor will be invited to join the 'Jonah' programme with other children who are not from St. Hild's catchment area to help introduce her to the school.
- ▶ Eleanor will have her own timetable. Each period will include learning goals set by the teacher. From these Eleanor's progress will be measured.



Module 7

The Right to Have Our Emotional Needs Met

The Medical and Social Models of Behaviour

Children and young people who are labelled as having 'Social, Emotional and Behavioural Difficulties' evoke a different response from those considered to be disabled - a response far harsher and more punishing. They are the one group of children most teachers reserve the right to permanently exclude from their schools and this is increasingly condoned by government and the media. Inclusive education however means all children.

'Behaviour' is a wide term which covers several different 'groups' of children, each of which needs its own response:

1. Children who challenge authority and do not have any impairments,
2. Children who become disruptive because their needs are not being met,
3. Children with mental health difficulties who need help, e.g. children who have been bereaved or traumatised, or who are depressed,
4. Children whose challenging behaviour is part of a condition, e.g. Tourettes Syndrome or Autism,
5. Children whose lives are impossible for them to manage e.g. Chaotic home-lives, ill parents, abuse and fear,
6. Children who have had little exposure to socially acceptable behaviour,
7. Other groups or situations in which the child may be labelled as the problem rather than their circumstances.
8. Lonely or insecure young people wanting to gain status in the eyes of their peers.

The medical model of behaviour will tend to see the entire problem as within the child, a medical condition such as ADHD, or a personality problem which calls for an individual behaviour modification programme. The social model will however look for fundamental causes and social solutions which may involve the whole school, support for the family, different government policies.

Fundamental Causes

It could be argued that the Education System is not now (perhaps it never was) designed to meet the needs of children. It is designed to meet the needs of the economy. As the needs of the economy have changed from one largely based on manufacturing to one largely based on services, the

skills needed have changed, with a much greater emphasis on literacy and numeracy skills and familiarity with IT. Society itself has speeded up and the market place has become ever more competitive and controlled by distant forces (globalization). Increased centralised control from government over the education system has narrowed down its goals to one of higher 'standards' in set subjects rather than nurturing healthy, thinking, whole young people. A child-centred pedagogy has been blamed for our economic 'failure' and is considered flawed and outdated.

Children have always been without power in this country, having very few human rights of their own. Children, like adults, will resist their own oppression, and this can lead to labelling. As the Service Economy has an insatiable need for 'clients' children are easily targeted by professionals, labelled as in 'need', and passed from one 'Provider' to another. It could be said therefore that it serves the economy well to create problem children, by disabling people with impairments, medicating people in distress, de-skilling people by a curriculum too rigid for real people and therefore impossible to teach to all children, or provoking children to resist authority by unjust treatment. It is unlikely that this would be a conscious intention.

The difficulties within the system are not the fault of children, parents or teachers. The culture of blame is totally unhelpful. Children in particular are often considered guilty until proved innocent.

Teachers do not go into education to damage young people, but to do good. Many teachers do in fact create good practice in this area despite all the lack of support and resources, but this good practice is not publicised or systematically spread from school to school. Some of this good practice includes the insights that:

- ▶ Teams are essential
- ▶ Collaboration and restitution are better than blame and punishment
- ▶ Children should have more power over who, where, what, how and when they learn
- ▶ Emotional Intelligence should be part of the core curriculum with plenty of time and resources attached to it. It should permeate the rest of the curriculum.
- ▶ Children can tell teachers what they need through speech, scrap-books, and many other ways.
- ▶ Social skills should be actively taught in all schools (mediation etc)

- ▶ Needs should be checked out and addressed early enough
- ▶ Play should be reclaimed as children's primary method of learning (until they are quite old!)
- ▶ Lifelong learning should be remembered (there is time)
- ▶ Restorative Justice should be used as a tool for inclusion
- ▶ Teachers should have training in dealing with children's emotions during their initial training
- ▶ It should be recognised that this will not be a strength for all teachers.
- ▶ All adults should be encouraged to look at their own emotional needs. (Not only children are bullies, insecure or anxious)
- ▶ Circle time should be used to manage conflict
- ▶ Health, Social Services and the Youth Justice Service all need to be involved in planning for inclusion
- ▶ Teachers need personal support to manage difficulties they experience with children
- ▶ Talking about emotional needs is more useful than talking about SEBD

Disabled Children and Emotional & Behavioural Needs

Children with High Level Support Needs have the same emotional needs as every other child.

The history of disabled people has shown that the Medical Model which has dominated services for the last 2-3 hundred years, largely ignored the emotional needs of disabled people, especially children. They were separated from their families and often surrounded by adult staff who related to them as figures of authority, not as loving parents. The eugenic drive to prevent disabled people from reproducing led to a denial of the sexuality of disabled people, or the possibility of their becoming parents themselves.

The move to inclusion is based on the realisation, made clear by disabled people, that we need access to a rich variety of experiences and potential relationships, balanced by security and constancy in order to fully develop as adults. This includes the scope to express sadness, anger, frustration, excitement, hope, love and affection. One of the unhappy consequences of segregation has been the unnatural dependence on paid helpers to fulfil

these emotional needs. And it must be said that many 'helpers' have as great a need to be 'needed' in this way. It is important to recognise that an Inclusion Assistant should not become a child's 'best friend', but find ways to enable them to make friends with other young people.

Physical closeness and touch is at least as important to disabled children as to any other group of children. Children with physical impairments often experience a good deal of touch which is not particularly pleasant e.g. physiotherapy, being washed and dressed, being hoisted etc. The opportunities for the ordinary touch of friends need to be created and supported as much as possible for these children.

Impairment Based Behaviour

Some impairments lead to unusual behaviour, aspects of which may be considered unacceptable, or 'against the rules' e.g. the compulsive swearing of a child with Tourettes Syndrome, or over-reaction to stress in children with autism. Inclusion does not mean treating all children the same, but treating children appropriately. Part of the learning process for non-disabled people is to know about and understand what lies behind our own and each other's behaviour. This is part of gaining 'Emotional Intelligence'. Rigid adherence to rules will always lead to the potential exclusion of disabled children who display such behaviours. It is part of building an inclusive school culture to look at school policy and practice in this area.

Written from the perspective of disabled people and the Independent Living Movement.

Further Reading

Touch - Our First Language by Micheline Mason. Available from the Alliance for Inclusive Education.

Programme

1. Welcome and introductions
2. How we will work together
3. Module 7 Aims
4. Exercise: Different ways you can support children's emotional needs
5. Exercise: Forthcoming marriage
6. Exercise: Case Study
7. Presentation: Having Our Emotional Needs Met
8. Concluding Remarks



Aims of Module 7

1. To understand that all our behaviours are in response to external conditions or events.
2. To adopt a helpful rather than judgemental approach to difficult behaviour.
3. To explore strategies that have been used successfully to support children with High Level Emotional Needs to remain included.
4. To think about the emotional needs of young people with High Level Support Needs.



Exercises:

1. Supporting Children's Emotional Needs



- ▶ Get the group to look at list on Sheet 7.1 and write down the different ways you can support children's emotional needs.



- ▶ Put responses on flipchart.



Discuss

▶ 2. Forthcoming Marriage.

Your son or daughter has announced their intention to get married. Their chosen partner is a wheelchair user, has impaired speech which you find difficult to understand and needs two personal assistants every day to help with personal care and driving.



- ▶ What is your reaction?



Discuss



How would this affect your support of teenagers with High Level Support Needs

▶ 3. Case Study.

Photocopy Sheet 7.2 and handout to all students.



Give 5 mins to read it.



Ask: 'What were the strategies used which resulted in the successful outcome of Steven's story?'



In groups of 2-3 discuss and write down your suggestions (15 mins)



Put up Sheet 7.3 as an overhead



Discuss (10 mins)

Presentation: Having Our Emotional Needs Met

Please use introductory notes for your presentation and link to the aims of this module.

Key Points:

- ▶ Teams are essential
- ▶ Collaboration and restitution are better than blame and punishment
- ▶ Children should have more power over who, where, what, how and when they learn
- ▶ Emotional Intelligence should be part of the core curriculum with plenty of time and resources attached to it. It should permeate the rest of the curriculum.
- ▶ Children can tell teachers what they need through speech, scrap-books, and many other ways.
- ▶ Social skills should be actively taught in all schools (mediation etc)
- ▶ Needs should be checked out and addressed early enough
- ▶ Play should be reclaimed as children's primary method of learning (until they are quite old!)
- ▶ Lifelong learning should be remembered (there is time)
- ▶ Restorative Justice should be used as a tool for inclusion
- ▶ Teachers should have training in dealing with children's emotions during their initial training.
- ▶ It should be recognised that this will not be a strength for all teachers.
- ▶ All adults should be encouraged to look at their own emotional needs. (Not only children are bullies, insecure or anxious)
- ▶ Circle time should be used to manage conflict
- ▶ Health, Social Services and the Youth Justice Service all need to be involved in planning for inclusion
- ▶ Teachers need personal support to manage difficulties they experience with children
- ▶ Talking about emotional needs is more useful than talking about SEBD

Module 7 Outcomes

Demonstrate the ability to:

- ▶ Interpret behaviour as a response to external conditions and events.
- ▶ Reflect upon the emotional needs of young people with High Level Support Needs and how these may be supported successfully.
- ▶ Explore strategies that can be used to include young people with High Level Support Needs.



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'Behaviour' is a wide term which covers several different 'groups' of children, each of which needs its own response:

1. Children who challenge authority and do not have any impairments,
2. Children who become disruptive because their needs are not being met,
3. Children with mental health difficulties who need help, e.g. children who have been bereaved or traumatised, or who are depressed,
4. Children whose challenging behaviour is part of a condition, e.g. Tourettes Syndrome or Autism,
5. Children whose lives are impossible for them to manage e.g. Chaotic home-lives, ill parents, abuse and fear,
6. Children who have had little exposure to socially acceptable behaviour,
7. Other groups or situations in which the child may be labelled as the problem rather than their circumstances.
8. Lonely or insecure young people wanting to gain status in the eyes of their peers.



Case Study

Steven is twelve years old. He is looked after in the care of the local authority. His natural father left home when he was a baby and his mother was a registered drug addict who was frequently hospitalised. Steven's siblings were also in care but they often found themselves in separate foster accommodation. His step father died prematurely when Steven was eleven.

Although he began his schooling in a mainstream primary school, Steven's teachers were initially concerned about his learning needs but even more so by his erratic bouts of angry behaviour. He would destroy equipment, his own work, and that of others. He could be abusive and threatening to both staff and other children. He was assessed and became the subject of a statement of educational need and placed in a junior school for children with emotional and behavioural difficulties. Unfortunately his behaviour went unabated and he was excluded from his special school and placed in another SEBD junior school in a neighbouring borough. By this time he was subject to a full care order and was living in foster care.

Steven was excluded from the second SEBD special school and returned to his home borough where he was now old enough to attend the secondary age SEBD special school. He was subsequently excluded from this, his third special school, for destroying the headteacher's office.

There were now considerable concerns regarding Steven's education and welfare needs. However, with the failure of three special school placements and what eventually became an extended period out of school, a placement for Steven appeared increasingly elusive. During the period of exclusion, Steven's foster placement changed and he found himself living opposite a mainstream middle school. Both he and his carers were confident that given appropriate levels of support he should be allowed another chance in mainstream, despite his previous record of special schooling. Not surprisingly the staff at the middle school were concerned about his possible placement and Steven remained off-role until the LA had no option but to direct the school to take him.

Steven began to attend the middle school for what was the last two terms before he would transfer to the high school. It was agreed that he would initially have full assistant support (25 hrs), with a view to him being re-assessed as soon as practicable. The LA support service agreed to work with all groups involved in the case including Steven, his carers and his social worker. Most importantly though, the support teacher focussed her efforts on encouraging and supporting key staff within the school in order to demonstrate that Steven was able to achieve in mainstream. This work included close liaison with the special needs co-ordinator, the support assistant, the class teachers and the head teacher.

Steven's reintegration from long term exclusion and special school provision into a mainstream context was not without difficulties. He was excluded twice for short periods, and was involved in a number of incidents. However, Steven's supporters worked collaboratively, acknowledging his small successes, and responding consistently to poor behaviour.

A year since initial referral and Steven has been successfully supported from middle to high school. He no longer requires the high level of support initially provided. The high school team do not regard him as a particularly difficult pupil and he no longer carries the stigma of the long-term excluded troublemaker. Most importantly of all, his foster placement has been sustained and his emotional and welfare needs are more stable than ever before.

Giles Barrow, Head, Behaviour Support Team, Merton, London. November 1996.

Note: Every year 10,000 young people of secondary school age lose a parent
(Dealing with bereavement (1996) National Youth Agency)

Steven's is an extreme case in exceptional circumstances. However, the strategies adopted to maintain him in mainstream are no different to those used for dozens of less problematic cases:

The Key Principles of Success were:

- ▶ A flexible approach in providing support
- ▶ The concerns of the mainstream staff were taken seriously and acted upon
- ▶ Regular levels of communication were maintained between home, school and LEA
- ▶ A belief that Steven had the capacity for change

Giles Barrow, Head, Behaviour Support Team, Merton, London. November 1996.

Module 8

The Importance of Friendship.

Can you imagine a world without Friends? The answer to this question is usually no and yet there are many in society that crave friendship. A companion to hold your hand or to call and say hi. Someone that is going to call you and say "Are you well? I have missed you."

Society has become a very fast place to be. We drive to large impersonal supermarkets to buy our food. We drive into large petrol stations to fill up with petrol. We communicate with colleagues via e-mail. All this activity is marked by one thing - we do not really have to connect with anyone. We do not need to speak or build a relationship with anyone. Loneliness and isolation were words that used to describe mainly people who may be disempowered, disabled or elderly. Increasingly we find that because of our new way of life there are more and more people who are lonely and seek friendship.

Children who have been labelled as having SEBD, are nearly always lonely children. It is likely that relationships have broken down in their lives due to family trauma, separation of parents, death of close adults or siblings, a parent going to prison, sudden upheaval such as running to a refuge to escape domestic violence, or being the victim of bullying or exclusion. Some will be living in Local Authority Care or with foster families. Their response may result in behaviour which makes them unpopular and exacerbates the problem. They may seek companionship in gangs of other disaffected young people. By the time a child's inclusion depends on a one-to-one assistant, the problem has become very serious, but the solutions are not essentially different than those for any other child with high-level support needs. The main goal will be to help re-connect the child with others in positive and mutually rewarding ways.

For disabled people the picture of loneliness is always a danger as isolation has become a characteristic of the way our lives are organised. From a young age we are excluded from the mainstream of life and sent to special schools in a special bus. This builds a barrier between us and our neighbours, our local community and any chance for families to become connected at the school gate.

This becomes further marked by attending residential special colleges. This means that any connections we may have had have now moved on and we come back to a community that is unfamiliar to us. We come back as strangers.

For young people school is the place where they make friends. It is through these friendships that they develop a sense of identity. Schools however are not designed to create friendships. Their objective is academic excellence, the imparting of knowledge based on standards and a national curriculum based on competition. Children find their way in school and become connected by accident. We only have to remember

our first day at school to consider how we got involved in the school community and its culture. This culture determines which children are at the top of the hierarchy. The cool children, the popular child, the child that is good at sport, and those at the bottom of the hierarchy, the geeks, those that are different. Their difference being that they are new, of a different culture or race, from a disadvantaged group such as travellers or disabled children. One might argue that children with high-level support needs can be found at the bottom of this secondary hierarchy. This group of young people are vulnerable to exclusion because of their impairment, behaviour, state of health or mental health.

Structures within school that have been created to support children's inclusion can be found to further isolate them and act as a barrier to them becoming linked to other children and opportunities of friendship. One of these structures is that of the development of Learning Support assistants/Teaching Assistants. At present it is perceived that the role is one that isolates the child and creates a friendship with the assistant rather than with other children. It is not 'cool' to have an adult perched on your shoulder all the time.

Changing the role of these supporters in school could be instrumental to the development of inclusion, friendship and feeling of belonging and in turn well being. The role of the Inclusion Assistant could support the child to become connected with other children and create the opportunities for relationships to be built with other children. If schools had a larger focus on friendship and the development of relationships as a main objective this would create an environment that promotes the happiness and well being of all children and adults within the system. A happier place for all children.

The experience of disabled young people in mainstream schools reinforces this argument. Young disabled people are very clear as to what is there in schools that either hinders or could help their inclusion and sense of belonging.

The building of children's skills in how to make friendships is instrumental to the development of an inclusive environment.
(See Sheet 8.1 'The Importance of Friendship')

This has given rise to the development of the idea of Circles of Support. This is artificially bringing together a group of people that the focus person chooses to think about the persons life and lifestyle. This eventually becomes a natural process of friendship without the need for meetings.

The first circle was that of Judith Snow whose life was very different before her circle. Her parents were elderly and the only way she could become independent was to live in a nursing home for the elderly as this was the

only place she could get her physical needs met. The development of her circle, her "Joshua Committee" made it possible for Judith to develop a lifestyle rather than an existence. Her circle members became her friends, her companions, the people that would help her think about her life and help her to change it. From a life of isolation and dependency her life changed to one where she was independent, had power and control of her life and friends that she relied on and in turn relied on her.

Many disabled people have become further disempowered by the systems that have been developed to support them to live their life. These systems have resulted in them becoming prisoners within a world where there is only paid staff and no community. A world where you have little power and control over your own decisions. In fact paid staff becoming gatekeepers to their whole life.

Friendship between children who have been traditionally kept apart benefits both sides. It is the foundation upon which we can learn to build a society in which everyone has a part, and everyone is cared for. Non-disabled people do not learn to be afraid of disability or disabled people, but remember the connection - what they gave to each other. This is part of a quiet revolution that has no precedent in society. It will lead to a different world.

Dealing with Name Calling and Bullying

As much as having friends can make school a happy and enjoyable place to be, being disliked, excluded or bullied by other children (or staff) can make the experience of school deeply unhappy. Bullying has led to a lifetime of insecurity for some, and even suicide. Many parents of disabled children are frightened that their child will get bullied at school because



Module 8

they remember how they treated the 'bus' children themselves when they were at school. In our experience, ignorance is the cause of most bullying of disabled children. Trusting children with good information is the main antidote. The 'Medical Model' has tended to treat information about impairments as some sort of shameful secret which will stigmatise the child and should be treated with the utmost confidentiality. This is not a helpful attitude. It has even led to the disabled child themselves having little knowledge about their impairment and consequently no chance of illuminating anyone else about it. It just becomes 'The thing that is wrong with me'. A circle of support is an excellent forum to give good information about why a child behaves the way they do - they have been traumatised by some event at home; they have a hidden impairment such as dyslexia, dyspraxia or Asperger's Syndrome; they have a physical impairment which affects the way they move or speak; they are ill or in pain - all these things need explaining to children and children nearly always want to help. Even if it doesn't stop every child from making upsetting comments or laughing inappropriately, the disabled child will find themselves protected and defended by their friends and will learn to deal with negative reactions in a positive way.

Written from the perspective of disabled people and the Independent Living Movement.

Further Reading:

Circles of Friends - Inclusive Solutions

Circles of Adults - Inclusive Solutions

Building Community through Circles of Friends - Christine Burke,
Foundation for People with Learning Disabilities

All contact details on pages 140 -142

Programme

1. Welcome and introductions
2. How we will work together
3. Module 8 Aims
4. Presentation: Supporting Friendship
5. Exercise: Do a relationship map
6. Presentation: Circles of Friends
7. Exercise: Using Circles to develop friendships
8. Concluding Remarks

Module 8





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Aims of Module 8

1. To understand the centrality of friendship to the concept of inclusion.
2. To think about children with hidden impairments.
3. To look at the different kinds of relationships which are essential for a 'normal' life.
4. To learn about Circles of Support.
5. To begin to learn how to set up and facilitate circles.
6. To think about extending the circle beyond the school gates.



Exercises:

1. Do a relationship map.
 - ▶ Give each person a copy of Sheet 8.2
 - ▶ Tell them that what they write is confidential, but some will be asked to volunteer to share what is in their circles
 - ▶ Ask them to fill in the circles from the middle outwards:
 - A) Those people closest to you - people you cannot imagine living without
 - B) People who are still close, but for whatever reason did not make it into the middle circle
 - C) Acquaintances and colleagues - people with whom you share activities or interests, who learn from you or from whom you learn. Include groups such as the Church, Sports Clubs, Unions, evening classes, tenants associations, etc
 - D) People who are paid to be in your life - e.g. doctors, social workers, your boss.
- 
- 
- ▶ Ask for 2-3 people to read out their circles.
 - ▶ Ask everyone to guess the total number of people in ALL circles
 - ▶ Ask if there will be changes in the future - were changes from 10 years ago
 - ▶ Ask what made the difference between circle A and B
 - ▶ Ask how differently they feel about people in A and people in D
 - ▶ Explain that they have drawn out a 'normal' life. Circle C is very important. Like a marketplace for new ideas / relationships or to have a 'voice' in the world.
 - ▶ Next show Sheet 8.3. Explain that this is a typical map



of a child with High Level Support Needs and their family.

- ▶ Ask how would you FEEL if this was YOUR circle
Put words onto a flipchart
- ▶ Ask how you might BEHAVE if this was your circle
Put words on flipchart
- ▶ Explain how the medical model and segregation help create this isolation, especially the empty circle C.

2. Using Circles to develop friendships

- ▶ Tell the group to think about the relationship map (Sheet 8.3) and imagine there are now eight young people in Circle C.
- ▶ How could they be used to help develop relationships. For example, making connections with other children which could be developed into true friendships.
- ▶ Ask the group to consider how the circle in school could be supported beyond the school gate. For example, joining in community activities like brownies.

Presentation: Supporting Friendship

- ▶ Share Sheet 8.1 'The Importance of Friendship'
- ▶ Discuss

- ▶ Share Sheet 8.4 'Children with hidden impairments'
- ▶ How can we foster empathy and friendship for these children?
- ▶ Discuss

Presentation: Circles of Friends

Circles of Friends is a tool developed originally in Canada to help children to welcome and include children who were coming to their schools from segregated schools, units and classes. The point is to gather a number of young people around a focus child to help them to make friends and to feel included.

This presentation needs to be developed using the trainers own experience of Circles.

***Please note:**

This presentation and the following exercise is simply an introduction to developing Circles in the classroom. You will need to have further training in Circles of Support which includes hands on experience of developing Circles in the classroom which is mentored and evaluated before you can actually facilitate a circle.

For further training, either contact somebody from within your own Local Authority or contact Inclusive Solutions (page 142)

Module 8 Outcomes

Demonstrate the ability to:

- ▶ Justify the importance of relationships to the concept of inclusion.
- ▶ Describe the strategies for setting up an effective circle of support.
- ▶ Find further training in order to facilitate a circle of support both within, and outside of, school settings.



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Module 8

The Importance of Friendship.

I think that when you don't have friends you can't experience real life because real life is how you get on with other people. I can't do anything on my own so I am completely dependent on people helping me, so if I am not going to be surrounded by only personal assistants, I have got to find a way of making friends.

I have had some good friends in the past when I was younger, and I know there are people who would like to be my friend now, but everything seems to be against us.

I have been to all types of schools, in the special school I was treated as if I didn't understand anything. I tried to make friends but we were all so badly treated that it was impossible to ever talk to each other. I don't want to see those people now because I get so sad.

When I went one day a week to Junior School, I really did make some friends but they moved on to a different secondary school and I don't see them now. When I went to School I was in a special unit, so I was like a museum specimen, and I was told that the kids weren't ready to come to my house, so when I wrote notes to them, the teacher would not allow them to be given out. Then I was at home for a few months and had a home tutor, and I got really lonely and depressed. Now I am at a different (Comprehensive Secondary) school which is better, and I am beginning to get to know a few people.

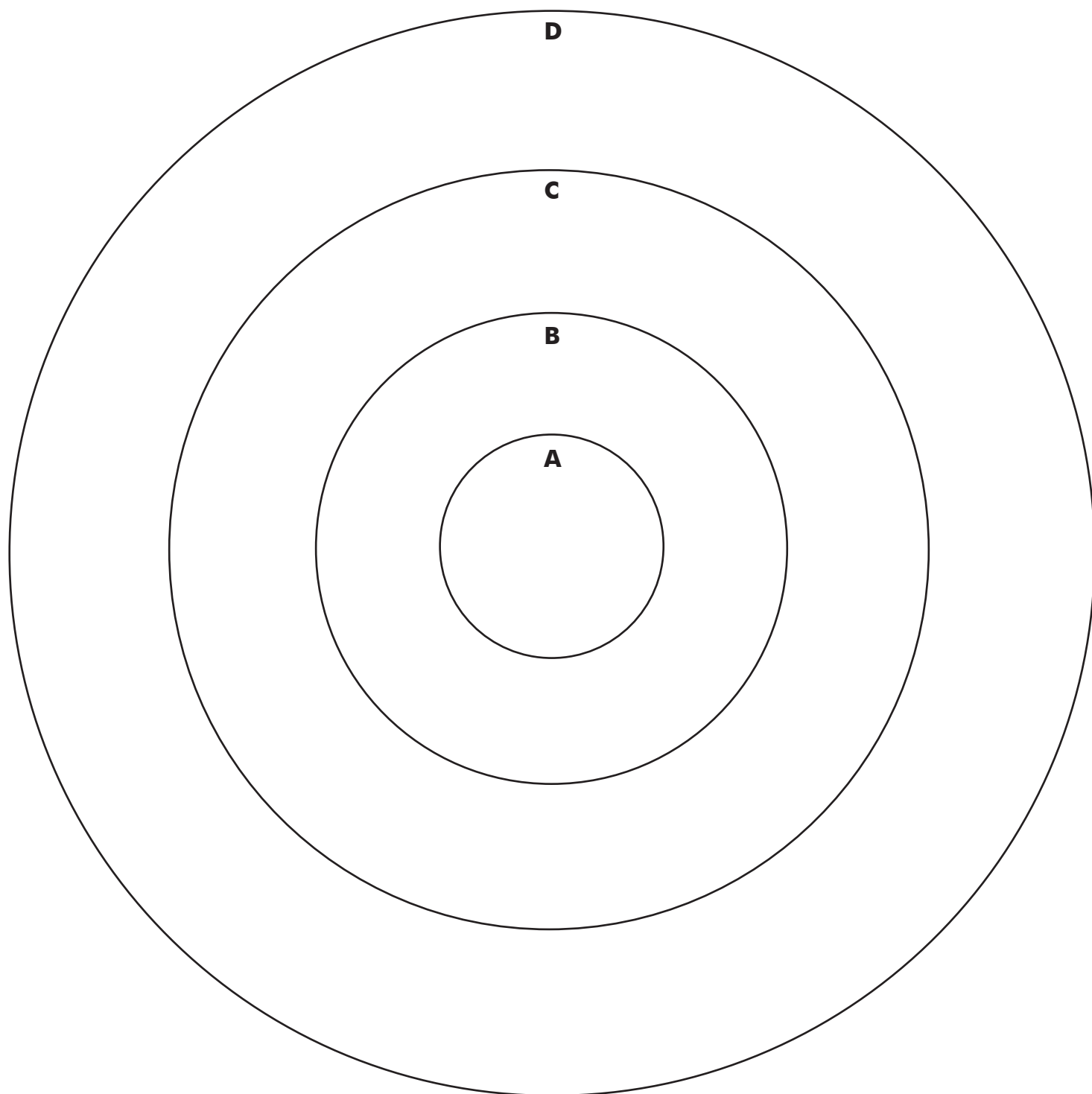
I think it is so hard when we have to spend so much time trying to do things adults think are important, like work or getting ready. Why can't we have time to really talk to each other. It is so hard because I need people who can help me and they are not always there when I want them. So we need time when we are all together so we don't have to keep making arrangements.

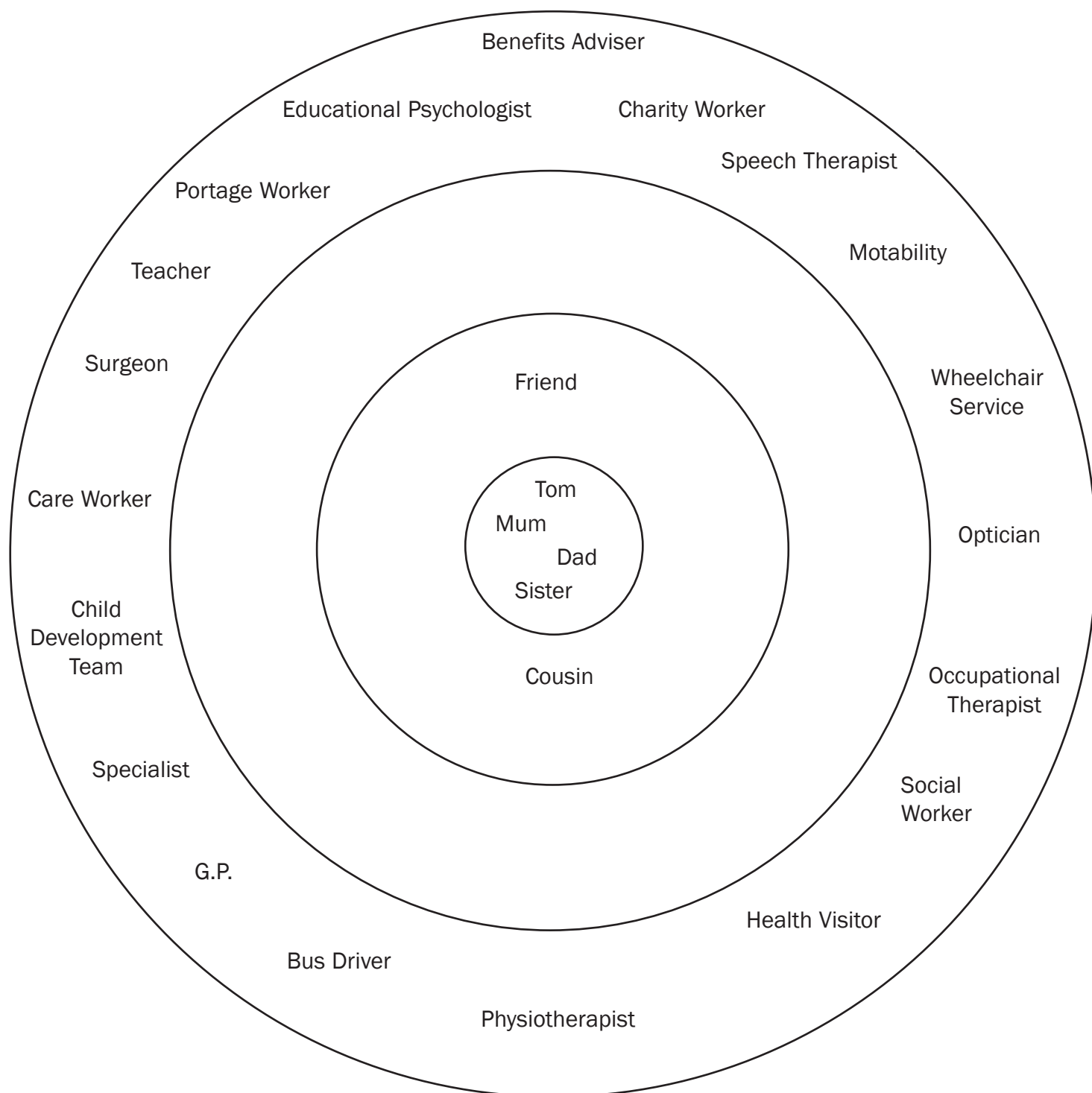
I would like to see schools take more time to help people get together so they have real time to get to know each other and then become friends.

I want a life where people really want to be with me and we can work things out together.

Maresa MacKeith









Module 9

The Right to Have a Voice Within the School

"If anyone were to ask me what message I might have for others I would tell them that they should listen to, believe and respect young people. In my experience it is very difficult to tell anyone how you feel when they won't listen. If you are not believed then you stop believing in yourself. If you are not respected then you lose self respect and everyone needs self-respect."

'Charlotte' from JRF Findings - Transition to Adulthood for Young Disabled People with Complex Health and Support Needs, 1999

"Young people are always supposed to listen to adults, we are seldom taken seriously. We are the ones who have to go through school, we are the ones who will have to deal with conflict when we are adult. We have to try out our ideas and practice ways of resolving conflicts. We want to make friends in our own way. We have to do that if we are going to learn about how to relate to each other. We want help from adults but on our terms. I think that all young people need things to change, not just disabled kids."

Maresa Mackeith

One of the ways to build inclusive school communities is to make sure everyone gets a chance to share their thinking, their experiences and the things they would like to change. This is especially true of children who come from groups which are not well treated within the wider society - black children in predominately white schools, traveller children, children of asylum seekers etc. There is an increasing emphasis on school democracy and the learning of citizenship. Children with high-level support needs often have unusual perspectives on things and can make very important contributions to everyone's picture of the world. If there is a school council it is important that inclusion is a regular item up for discussion and collective problem-solving. If a child is truly unable to represent themselves on such a council, their circle members could bring forward their issues and be their advocates.

Written from the perspective of disabled people and the Independent Living Movement.

Programme

1. Welcome and introductions
2. How we will work together
3. Module 9 Aims
4. Exercise: How to ensure a child shares their thinking
5. Exercise: Power and control
6. Exercise: Jackie's Story
7. Presentation: Having a Voice



Aims of Module 9

1. To imagine what it feels like to have no voice in society.
2. To think about how to encourage young people with High Level Support Needs to develop opinions and express them.
3. To think of ways in which they can share their thinking with their friends, class, tutor group and whole school.
4. To ensure that the young person's voice is central to any decisions that are made about them.



Exercises:

1. How would you ensure a child shares their thinking?



- ▶ Ask group to share ideas

- ▶ Share different ideas on a flip chart. (Tutor groups, newsletter, news boards, school council, circle time, black history week, student complaints, students union, disability history week)

2. Power and Control

Following a child's instructions. (Important particularly in choosing who you want to be with, particularly for personal care)

- ▶ In pairs take 10 mins each to direct the person to make you a cup of tea. Swap.



- ▶ How did it feel? How would it feel to follow instruction from a child?

3. Jackie's Story

- ▶ Read out the following:

Jackie is 15 and determined to leave school at 16 and go to college. Her mother is equally determined that she will not because she fears that her daughter will not be protected in the same way at college as at school and that it might affect benefits to the family.



- ▶ Ask the group to work in pairs and answer:
What is your role as an Inclusion Assistant in this?

- ▶ Also: How will you create good team work that ensures that the child, his/her allies (including friends), the family and the school are all included to listen to the child and to support the best outcome.



Note to trainer:

Highlight the importance of developing good teamwork. refer to the DVD to reinforce the importance of supporting the young person's voice.

Presentation: Having a Voice

- ▶ Use the module introductory notes to highlight the importance of supporting the child's voice and link to the aims of the module.

Note: For this presentation you may wish to purchase the Cleves School Song, available from Cleves Primary School, Arragon Road, London E6 1QP

Module 9 Outcomes

Demonstrate the ability to:

- ▶ Reflect on the importance of young people with High Level Support needs having a voice in society.
- ▶ Explore strategies to enable young people with High Level Support needs to share their thinking with others.
- ▶ Devise and justify strategies that will ensure that the views of young people with High Level Support Needs are central to decision making concerning them.



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Module 9

Useful Contacts:

The Alliance for Inclusive Education

336 Brixton Road
London
SW9 7AA

Telephone: 020 7737 6030
Email: info@allfie.org.uk
Website: www.allfie.org.uk

The UK Disabled People's Council

Email: info@ukdpc.net
Website: www.ukdpc.net

Foundation for People with Learning Disabilities

9th Floor
Sea Containers House
20 Upper Ground
London
SE1 9QB

Telephone: 020 7803 1100
Fax: 020 7803 1111
Email: fpld@fpld.org.uk
Website: www.learningdisabilities.org.uk

People First (Self Advocacy)
Unit 3.46 Canterbury Court
Kennington Park Business Centre
1-3 Brixton Road
London
SW9 6DE

Telephone: 020 7820 6655
Email: general@peoplefirstltd.com
Website: www.peoplefirstltd.com



Useful Contacts

Human Scale Education

Unit 8, Fairseat Farm
Chew Stoke
Bristol
BS40 8XF

Tel/Fax: 01275 332516
Email: info@hse.org.uk
Website: www.hse.org.uk

School Councils UK

Unit 5, The Quadrangle Centre
Nacton Rd
Ipswich
IP3 9QR

Telephone: 01473 321141
Fax: 01473 321188
Email: info@schoolcouncils.org
Website: www.schoolcouncils.org

Further Training:

The Alliance for Inclusive Education

336 Brixton Road
London
SW9 7AA

Telephone: 020 7737 6030
Email: info@allfie.org.uk
Website: www.allfie.org.uk
Training on 'The Inclusion Assistant'

Parents for Inclusion

336 Brixton Road
London
SW9 7AA

Telephone: 020 7738 3888
Helpline: 0800 652 3145
Email: info@parentsforinclusion.org
Website: www.@parentsforinclusion.org
Training for parents on the Social Model of Disability



Further Training

Inclusive Solutions

49 Northcliffe Avenue
Nottingham
NG3 6DA

Telephone: 0115 9556045 or 9567305 9498550

Email: inclusive.solutions@me.com

Website: www.inclusive-solutions.com

Training in Circles of Support and other 'keys' to inclusion

Communication and Learning Enterprises (Candle)

32 Market Place
Kendal
Cumbria
LA9 4TN

Telephone: 08456210708 (local rate call)

Email: contactcandle@btinternet.com

Website: www.contactcandle.co.uk

Training in Facilitated Communication

National Centre for Independent Living

Unit 3.40
Canterbury Court
1-3 Brixton Road
London
SW9 6DE

Telephone: 0207 587 1663

Fax: 0207 582 2469

TypeTalk: 18001 020 7587 1663

E-mail: info@ncil.org.uk

Website: www.ncil.org.uk

Info and training in Direct Payments and other Independent Living issues



**Further
Training**

The TA Debate

In the early days of integration disabled children were only allowed into mainstream schools if they brought a "minder" with them in the form of a full time LSA. They generally took complete responsibility for the physical care, safety and to a large degree for helping the child do their work by adapting it etc. The teachers took varying degrees of responsibility for planning their lessons so that the child was included. Some left all of that to the LSA, the SENCO, and any specialist advisory teachers. Depending on the personality and understanding of the LSA and the child, they could act also as the child's "friend", spending all their time close by, or they could act as facilitators of friendships, drawing children into collective activities and standing back when peer relationships started to form.

The good side of this was that parents were confident that children who had high level support needs and could be very vulnerable in a school situation would be cared for. The LSAs often became very skilled at meeting individual needs, including the use of specialist equipment, administering medication, implementing therapies such as physiotherapy or speech therapy (under the guidance of a qualified professional). They often learnt "emergency procedures" and when to recognise that they were needed. All together this made possible the integration of children with a range of impairments including those labelled as severe, complex or profound.

The difficulty is that it did not lead to the real inclusion of children, especially those with high-level support needs. Teachers did not necessarily include them in their lessons; if the LSA was away the child was told to stay at home; if the LSA/child relationship was not good, they both became very unhappy; it was exhausting and isolating for the LSA and there was a very high turnover of staff.

The most common criticism was that the LSA became a barrier to the child becoming part of their peer group. It singled them out and made them feel "different".

Disabled people would like to bring in a missing piece of the picture - thinking developed by adults with high-level support needs in the independent living movement.

Our fight has been against the Medical Model of Disability which has seen us primarily as patients, in need of treatment, cure, or institutionalised care. The independent living movement grew from an "uprising" of young adults living in Cheshire Homes. They felt they had no control over their lives and were being made to waste their time. They identified the main barrier they faced as having no financial means to buy in the physical support they needed to leave the homes and live in ordinary houses in the

community. They invented the role of PA (Personal Assistant), and fought for the right to choose either a statutory service to provide care, or money in the form of direct payments to hire and manage their own staff.

This battle was won and all Local Authorities now have to provide a Direct Payments scheme for those who choose it. Recently the entitlement was extended to disabled young people aged 16-17 and to younger disabled children via their parents. This has allowed many "severely" disabled people the chance to live full and exciting lives outside of institutional walls or control. The role of PA is now also used by young people with learning difficulties to explore life in ways which are unique to this era and generation.

(The Government also provide similar support to disabled people at work under the 'Access to Work' Scheme. This can include help with transport, equipment, adaptations to the workplace, and personal assistants/drivers) The benefits for us are that we choose who gives us support, and we direct the nature of that support and the goals to which we are working. For disabled people with the highest level of need, PAs are part of a package of carers, often including parents and other relatives.

It is often not understood by the non-disabled world how tiring it is to have to keep training new people to meet your basic needs, or how insecure we feel when we do not have reliable and familiar helpers, or how vulnerable to abuse we are when we have no say over who provides intimate care. The skill to manage PAs is one which needs to be learnt. It is a life skill of utmost importance for disabled people.

In a school situation it is a challenge to think about a young person "directing" an adult, but the change of role from "minder" to "assistant" or facilitator, is what needs to happen.



Appendix 1

Direct Payments

A direct payment is money given to an individual by a social services department to buy the support they have been assessed and agreed as needing.

The purpose of direct payments is to give control over to people eligible as an alternative to social care services provided by a local council. A local authority has to offer a direct payment to all that are eligible that want it.

The direct payment gives the person flexibility to plan their own life and buy in what they want or need rather than settle for the range of service solutions offered by social services for certain housing, employment, education and leisure activities.

The aim is to increase opportunities for independence and social inclusion.

Who can get Direct Payments?

- ▶ Disabled parents
- ▶ Parents of Disabled children under 16
- ▶ Disabled young people aged 16 to 17 (including young people with learning disabilities)
- ▶ Disabled adults (including adults with learning disabilities)

The Department of Health provide several guides to Direct Payments, available from :

Department of Health Publications
PO Box 777, London SE1 6XH

Tel: 0870 155 54 55

Email: dh@prolog.uk.com

Website: www.dh.gov.uk (search 'direct payments')



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Appendix 2