

An Inclusive Education Guide for Families



Education and Culture DG

Lifelong Learning Programme

*Family Partnerships for
Inclusive Education*

The Partnership

This toolkit has been created by the six partners involved in the 'Family Partnerships for Inclusive Education' project, funded by Grundtvig. The project partners are:



Alliance for Inclusive Education (UK)



APF-Association des Paralysés de France (France)



UNAPEI (France)



Associazione DarVoce (Italy)



Associata RENINCO (Romania)



Sjalfsbjörg ISF (Iceland)

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An Inclusive Education Guide for Families

Family Partnerships for Inclusive Education

Welcome to you

You have looked here because you have a disabled child; you may have some worries about supporting their health right now and some fears about the future but remember, the most important thing is:

YOUR CHILD BELONGS IN YOUR COMMUNITY

and their life - short or long - is of great value. That is no different from any other child.

We are parents of disabled children too, and we want our children included in ordinary school and ordinary life.

We have been part of a project in Europe to look at inclusive education in our 5 countries - France, Italy, Iceland, UK and Romania. We have been making our study in the company of disabled and non-disabled professional and family member delegates. We have had the chance to observe what each country has made possible in mainstream schools which have welcomed us in to see what they are doing and we have also learned from each other's experience and thinking across the barriers of language, with a lot of goodwill and collaboration, the key to inclusive practice anywhere.



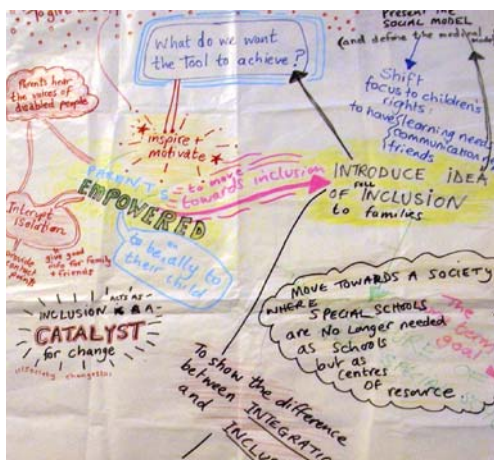
Schoolchildren
in Romania

United Nations Convention

Our wishes for our children's full inclusion are supported by the United Nations Convention on the Rights of Persons with Disabilities, article 24 (extract) :-

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

- a. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- c. Enabling persons with disabilities to participate effectively in a free society. (Full text of article 24 can be found in Appendix 1)



What Do We Hope This Guide Will Do?

- Inspire, motivate and empower parents
- Support you to be an ally to your child
- Strengthen your expectation of a positive future for your disabled young person and yourselves
- Introduce to you our idea of full inclusion and give you the tools, support and information you need to move towards it

Shift the focus onto your children's rights in education - to be equally valued, to have their learning needs met, their communication needs met, to have friends, to have a voice about their school

Show and explain the difference between integration and inclusion

Let you hear the voice of disabled people (see Disabled people's guide) and give you a different way of thinking about what disables a person - the social and medical models of disability

Show you that you are not alone and provide some contact points (see contacts list at end of report and useful contacts page at: www.allfie.org.uk)

Give good information you can pass on to other family members and friends about how they can support you (see Appendix 3)

Show that inclusive education acts as a catalyst for change in society

Move towards a society where special schools are no longer acceptable or needed as schools, but instead become centres of resource - training, skills and equipment - for the benefit of all learners

Ways of Thinking About Disability

Our partnership with the disability movement has expanded our understanding of what disability is. Our child's impairment is just a part of who they are, which can't be separated from the rest. There is no version of them without that feature, and it's not a problem for them. An impairment does not disable a person whose access needs are fully met.

The Social Model of Disability

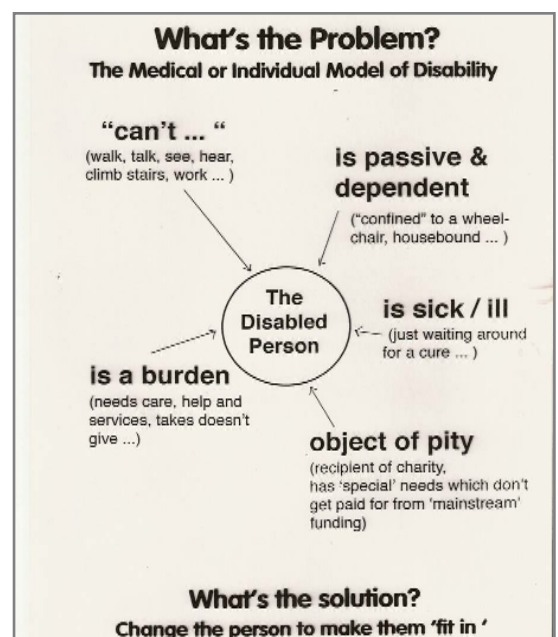
What disables a person is negative attitudes in society towards people with impairments or differences, lack of access, and barriers to participation in the things non-disabled people take for granted. Therefore what needs to change is that all barriers need to be tackled and overcome including negative attitudes and provision needs to be made for whatever adaptations and support are required by a disabled person for them to have equality of opportunity, and determine their own life choices. This is called the social model of disability: those who adopt the social model require systems and services to change and be flexible to accommodate the diverse needs of all those who use them.

This way of thinking about disability forms the basis of our approach and our findings in this guide.

The Medical Model of Disability

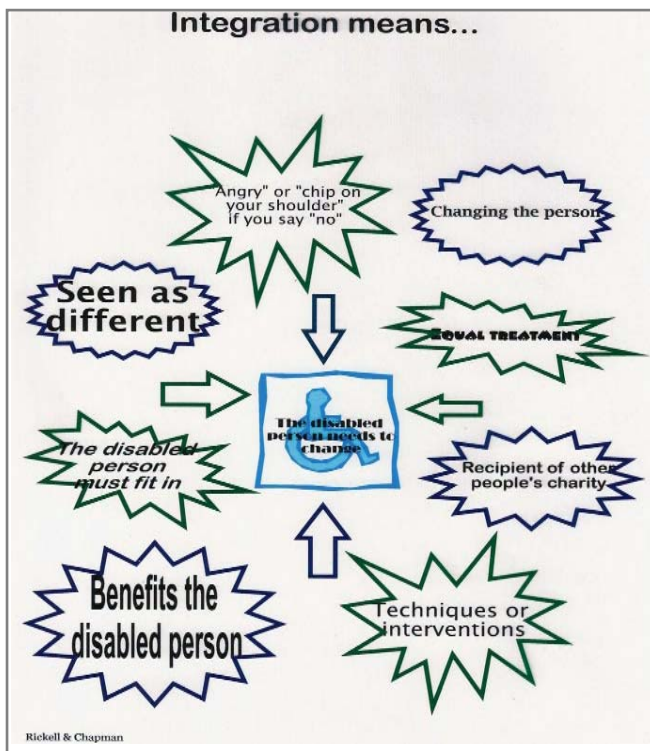
The medical or individual model of disability by contrast sees the person with an impairment as faulty, seeks to focus on the things that person cannot do, and makes a priority of cure or management of the impairment (often overlooking a person's strengths, gifts, ordinary needs, and desire for empowerment, self-determination and inclusion).

The medical model reinforces the view of the impairment as a tragedy for the individual and their family and anything they accomplish is seen as triumph over adversity. As parents, we reject this view of our children.



Integration and Inclusion

Integrating our children is not enough: we want our children to be included. To really include someone, the system must be flexible and adapt to the child. The process of working out how to do that teaches us all how to live with one another in a diverse society, identifying barriers to one another's participation and removing them. It helps us get to know each other and build inclusive, collaborative communities.



Integration requires the child to adapt themselves to the system. It is usually a first step towards inclusion but if it stops there, it can teach some children that they don't fit in, and can never fit in. This has a serious impact on those young people and their communities. Integration has to be followed up by intentionally seeing what needs to happen in order for a person to be fully accommodated.

What is Inclusive Education?

We say it is:

One system of education for all

Individualised for each child or learner

It is child-centred, and listens to all perspectives

A system which meets the particular needs of my child and every other child

A system capable of modifying itself to respond to the needs of the most vulnerable

A system where every child has equal opportunity

It is not static, it's a process which continually develops our understanding of how we can best accommodate each person.



To define inclusive education further, our group agreed to adopt the 7 principles of inclusion put forward by the Alliance for Inclusive Education in the UK:

Diversity enriches and strengthens all communities

All learner's different learning styles and achievements are equally valued, respected and celebrated by society

All learners to be enabled to fulfil their potential by taking into account individual requirements and needs

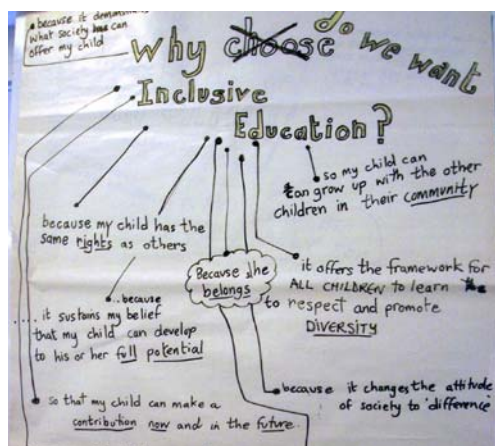
Support to be guaranteed and fully resourced across the whole learning experience

All learners need friendship and support from people of their own age

All children and young people to be educated together as equals in their local communities

Inclusive Education is incompatible with segregated provision both within and outside mainstream education

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Why Do We Want Inclusive Education?

Some of our thoughts about this:

So that my child can learn and make friends and allies

Because my child belongs

So that my child can grow up with the other children in their neighbourhood and community

Because it demonstrates what society can offer my child

So that my child can make a contribution now and in the future

Because my child has the same rights as others

Because it sustains my belief that my child can develop to his or her full potential

So that my child can have a sense of purpose

Because it offers the framework for ALL children to learn to respect and promote diversity

Because it changes the attitude of society to 'difference'

Because it takes an active role in interrupting all oppression and discrimination



What is an Ally?

Someone who is on your side

Someone who is willing to support your views and perspectives (even if they don't agree with you)

Someone who will let you use their skills and strength without taking your power

Someone who holds your dreams and visions and supports you when you are tired or discouraged

Who can be your Ally for Inclusion in your local School?

Someone who can do the above and is convinced by inclusive education



How do we Measure Inclusion? How Inclusive is your Local School?

Inclusive education means in your local community whenever possible - the school nearest to your house. Sometimes that local choice doesn't work out and we talk about that further on. But keeping the wish for each child to attend their local school as the goal, what can you do to try to assess that school's willingness and ability to accommodate your child well. Here are some guidelines that might help you.

Try not to make assumptions - keep in mind that it is possible to include your child well. Don't rule it out in advance

Find an ally (see definition of ally above) and take them with you when you go to look at the school and meet the staff. Observe well, ask questions if you don't understand what you see, but be aware of the feelings of the students who might overhear your questions. Ask your ally to help you with this, if you are in doubt. They may also have questions that will help.

Open questions will give you more information - ones that require a thoughtful answer rather than just yes or no, for example - how do you meet the learning needs of a mixed ability group?

If you can, ask other parents, what do you love about this school? Is there anything that could be done differently? (Just listen, don't discuss)

If possible get to know the parents in the school, join the parents' organisation if there is one.

If there is a choice of schools in your neighbourhood, make this initial visit to each of them, and aim to listen and assess how physically accessible the schools are, how open and friendly the staff, how happy the children appear to be, whether there are any disabled children in any of the classes you see, how they are accommodated by staff and children, how diverse the school community is - ethnically and socially.

If you have an older sibling already at the school, inform the school early that you have a disabled child who will be joining them and when, so that they can plan ahead, in partnership with you

Get to know the legislation that supports your child's right to be included, which is different in each country, and find organisations who can support you with that knowledge (UK - Parents for Inclusion 0800 652 3145, Allfie 020 7737 6030)

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Here are some questions you might want to ask the school:

How many students are there in each class?

Do you have students with difficulties in learning, communication or behaviour in this school?

What do you do to support those students to have friends and be included?

Who differentiates the learning materials for visual and other learning styles, and what is the role of subject teachers in the planning of these materials?

What opportunities do you offer to students to have a voice in the school? How do you ensure that disabled students, including those with learning difficulties have an equal opportunity to express their views?

What do you do to demonstrate that you welcome cultural and social diversity in your school?

Do you have any disabled students at the present time, and if so, how old are they?

Can you give some examples of reasonable adjustments you have made in the last year or two to accommodate the needs of students with physical, sensory, learning and behavioural impairments in the school.

How is the partnership of families with the school organised to support the best interests of the student?

What have you done to adapt the curricula and methods of assessment to meet the learning needs of all students?

What do you do to ensure that all students can participate in school activities including day outings, residential trips and extra-curricular clubs and opportunities?

How do you make it possible for children to work together?

How many support teachers do you have in your school, and how are they used to support the students' learning and participation?

What is the Role of the Parent in Inclusive Education?

To be an ally to our own child and to others

To recognise our expertise about our own child, and our child's expertise

To adopt and model the social model of disability when giving information about our child to the school (see below for one page profile)

To look for and establish mutual support with other parents in the school - try not to tackle issues alone

To work in partnership with the school to develop the inclusive practice around our children, appreciating what is going well and identifying barriers to their participation in school, working together on the solutions, and keeping the channels of communication with the school open.

To keep happy, rested and supported enough ourselves to do all this and still enjoy our families!

Making a one page profile of your child with a few simple statements about what their future dreams and goals are, what they want to do now, what their strengths are, what they need, and what help they need from others can be a great help in getting their support right in school, and is best done as a class exercise, so that all the students do a profile for themselves, and all contribute to each other's.





What Can You Do if Things Go Wrong?

What if the school says no, or fails to meet the child's needs, or other problems arise?

See problems as issues of access and support

Approach the school, explain the issue and ask to work together to find solutions

Get support from your allies - other parents, staff, governors, local authority personnel, organisations

Know the legislative framework underpinning your child's rights and how to use it

Be willing to go to legal process, if you are able to (UK - IPSEA 0800 018 4016)

Remember that this is a struggle for human rights against a long-established culture of disability discrimination. And like any struggle for social justice, we will continually set our sights higher, as we discover more and more that is possible. So our goals are unattainable in the sense that they always grow, and we continually strive to make it better - and that's a good thing, because there ought to be growth.

If you don't succeed in the most local school, don't give up, try another mainstream school in your general area with the support of your allies, and look for recommendations from other parents. This is not ideal, but it is preferable to no school, school with a negative culture towards your child, or special school.



Young people take the message 'We Know Inclusion Works' to the DFES in the UK with parents and allies.

How Can Parents Work Together to Lobby for Better Inclusive Practice?

Join an organisation that is rooted in the social model of disability, and informed by the leadership and voice of disabled people, with an emphasis on rights.

Keep informed about local, national and international initiatives to promote disability equality and inclusion.

Seek out allies in other rights movements and local and national political activism.

Form a parents' support group at your child's school to add weight to your views and concerns.

Project School Visits



During our school visits in our five countries we were privileged to see schools developing their ability to offer equality of opportunity to disabled students. We made a list of all that we had observed during our 5 visits which we felt to be good practice in inclusion, or which we felt to be a barrier to participation and belonging. We have attached the full list at Appendix 2 as a reference point for your own observations. Not all schools will manage to adopt all the good practice suggestions, some are related to the culture of a country, or its legal framework or local policy but taken as prompts, this list might help you to contribute your thinking when a change is needed in what is being provided for your child.

We offer you our findings and our vision of inclusive education to support you and your child on your journey to the future. May your fears melt away and your dreams come true.

Useful Contacts and References

Contacts

Alliance for Inclusive Education - UK based campaigning and information sharing network led by disabled people - www.allfie.org.uk

APF-Association des Paralysés de France - National disability organisation - www.apf.asso.fr

DarVoce - Association of associations set up to support and promote volunteering - www.darvoce.org

Parents for Inclusion - UK organisation supporting parents who want an inclusive education for their children. www.parentsforinclusion.org

RENINCO Association Romania - National Information and Cooperation Network for Community Integration of Children and Youth with Special Educational Needs - www.renincor.ro

Sjalsbjorg ISF - National organisation of disabled people - <http://gamli.sjalsbjorg.is>

UNAPEI - National Federation of Representation and Advocacy for People with Intellectual Disabilities and their families - www.unapei.org

World of Inclusion - <http://www.worldofinclusion.com/resources.htm>

References

Charter of Fundamental Human Rights of the European Union 2000 -

http://www.europarl.europa.eu/charter/pdf/text_en.pdf

EU Thematic Key Words for Inclusive and Special needs Education - Glossary of Terms (Revised 2009) -

<http://european-agency.org/publications/ereports/thematic-key-words-for-inclusive-and-special-needs-education/THEMATIC-KEY-WORDS.pdf>

Index for Inclusion (Centre for Studies on Inclusive Education)

www.csie.org.uk/publications/inclusion-index-explained.shtml

Manifesto for Inclusive Education - Campaigns -

www.allfie.org.uk

Salamanca Statement and Framework for Action on Special Needs Education 1994 -

www.unesco.org/education/pdf/SALAMA_E.PDF

United Nations Convention on the Rights of the Child

1989 - www.unicef.org/crc/

United Nations Convention on the Rights of Persons with Disabilities 2007 - www.un.org/disabilities/

UK Laws

Equality Act 2010 -

www.legislation.gov.uk/ukpga/2010/15/contents

1981 Education Act - www.legislation.gov.uk/ukpga/1981/60

1996 Education Act -

www.legislation.gov.uk/ukpga/1996/56/contents

Special Educational Needs and Disability Act 2001 -

www.legislation.gov.uk/ukpga/2001/10/contents

APPENDIX 1

Extract from the United Nations Convention on the Rights of Persons with Disabilities

Article 24 - Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

- a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

- a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
- b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
- c) Reasonable accommodation of the individual's requirements is provided;
- d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

APPENDIX 2

Solutions / Facilitating Aspects Towards Inclusion:

School space is accessible and attractive, with plenty of open space

The local authority involved itself in the process of inclusion (beyond its statutory obligations)

Adapted materials provided for a disabled child are available to everyone

Students moved as a group from special school to mainstream school, at their own request

All services (local social, health and educational teams) working in partnership to achieve inclusive objectives

All students having access to the same curricula appropriately adapted to meet their access needs and learning style

Teachers being creative in their approach, taking risks and trying things out; the curriculum is not too prescribed (there is freedom to teach what makes sense for the individual)

Education is individualised for every student

Therapists are available inside the school or therapeutic approaches and exercises are built into the general curriculum classes, with teaching or support staff trained to incorporate these approaches for all students or those who require it

Where the schools are already responding to the needs of families in deprived areas it is easier to accommodate the needs of the disabled pupils because the school have already developed their ideas, attitudes and resources

Flexible staff learning from feedback

Positive social attitude is encouraged with a positive mindset and school culture is relaxed, with an open and free philosophy

The school is seen as a resource for the community which makes it easier to respond to the needs of families and children

A multi-cultural school community welcomes diversity

Thorough training of all teachers and extra study for teachers to adapt to different learning needs and styles

Partnership approach between school, child and family

Involvement of parents in the design of education

Growing through differences: diversity encourages society to evolve

Head of school understands the social model of disability and sees that it is implemented

Equality of opportunity is a priority: more favourable treatment of disabled children is accepted as necessary to make equality possible

Respect for children and parents is a requirement

Creating and supporting friendship groups beyond school is a school priority

Extra teaching support is available

It is important that resources are available - staff, tools, space

Inclusive practice requires the strong belief that every child can progress and that teachers can accommodate every child - a "can do" attitude

School has a positive mission statement and friendliness

Special needs is not only about disability - school is responsive to the needs of every child

Extra curricular activities are made accessible for all pupils

Celebrating successes throughout the school and making sure that disabled pupils are represented in the school magazines, prospectus, website etc

Families are reassured that professionals have the opportunity to share best practice

Parents have the opportunity to share best practice and support each other

List of barriers observed during our school visits:

Inaccessible buildings and inaccessible design, no ramp, lift was locked, no lift to upper stories

Inadequate space even in accessible toilets

Large complicated early years building with lots of rooms confusing for some children

Lack of accessibility in communication and education resources - need for differentiated materials in the school library, accessible information on the school walls, and easy read careers information

Poor attitude of some professionals

Lack of specialist teacher training

Lack of training in the social model of disability

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Lack of recognition by professionals of parents' expertise and need to increase partnership working between them

Parents vulnerable to the medical model of disability, leading them to see their child's impairment as an over whelming obstacle in their life, provoking feelings of shame and/or guilt

Medical model of disability discourages parents from looking for their child's abilities and focuses on deficits

The existence of special education creates the demand for it, due to the strength of the special education lobby

Focus on competition and meritocracy within the education systems

General societal adherence to medical model and deficit rather than a child's potential and strength

Lack of disabled role models within the school staff

Absence of images of disabled people in the print and display materials

Invisibility of disabled people in the media and society

Families who are less well resourced in terms of education and money may be less able to fight for their children's rights to be included

Segregation/integration/inclusion: a school may believe they're including a child because the child is present in the school, but they don't recognize the difference between segregation, integration and inclusion

Empowerment of young people is not always a school priority

Lack of priority given to intentionally building and supporting relationships and making circumstances in which friendships can be developed, especially for students with communication differences or difficulties

Lack of use of peer support in and out the classroom, or peer tutoring, small group work, circles of friends or buddy schemes

Lack of sufficient funding and staff

Lack of understanding of the social model of disability on the part of the school's leadership

Inclusion not a priority in the school

Not enforcing laws that support disabled children's rights

Lack of empathy for feelings of disabled young people e.g. discussing disabled students impairment, access needs or level of study in front of them in medical model terms

APPENDIX 3

Family and Friends Information Sheet

When a baby is born one of the first questions most people ask is "are they alright?" This can be a difficult question to answer, if your baby has an impairment or a medical condition.

Friends and family can make statements and assumptions that are painful to hear, and that do not reflect the long term dreams and wishes of the parents. These statements and assumptions can begin to damage the tender connection being made with a new child.



The least dangerous assumption for you to make is that this is a precious new life, wanted and loved by his or her family, and that his or her impairment will not be a problem for them, and shouldn't be for anyone else. It isn't a tragedy or a disaster, just something new and different, an opportunity to learn. The new arrival needs to be celebrated and welcomed like any other baby. Expect him or her to have a good full positive life amongst all of their family and friends. Even if their life will be short, they still need to be welcomed and honoured.

He or she may be a little different than you imagined but this is nothing to be afraid of. The parents and family may all have a difficult time initially whilst any pressing health concerns are dealt with, especially if the new one's life is in danger. There will be new information to absorb and get used to.

Parents may well be in need of more practical support than before, especially if the baby needs medical care, or lots of extra feeding or attention, or doesn't sleep, and if there are other siblings to care for. You could offer to help them out with the washing or the ironing, do some shopping, taking siblings out for a treat, read to them, help with homework, Hoover, cook, wash up, take the dog for a walk! Whatever you can manage.

Parents may be worried, anxious or upset sometimes. Try not to join in with that, but do listen if you can do so in a relaxed way and still hold out a positive view of their new baby. Understand if they can't see you, or haven't time for a phone call - it's practical, not personal.

If you have any uncomfortable feelings about the new family member, please remember that we have all grown up in a world which hasn't always treated people who are different with respect and equality, so it isn't surprising to sometimes have some tension and feelings around that - your feelings are unlikely to be about the new child, you may experience those feelings before you've even met. Try to find someone who can listen to you without

judgement and without joining in, and express these thoughts and feelings so that you can be relaxed with the baby and the family whenever you are lucky enough to get introduced. It is not helpful to them to have to listen to your disappointment, worry, or anxiety and it will not be good for their relationship with their baby. Discourage other friends and family from expressing negativity when they hear the news, for example saying "I'm sorry".

This baby may also need you to learn how to accommodate their different ways of doing things as they get older - this would be a good time for you to start to learn about their access needs. He or she belongs in their community amongst family and friends, in the same nurseries, schools and colleges as all the other children of that community - any kind of separation of him or her from other children is not necessary, and will not help him or her to learn to be part of society. But the parents will need help to get those nurseries, schools and colleges ready to support, educate and include him or her.

Different ways of thinking about disability

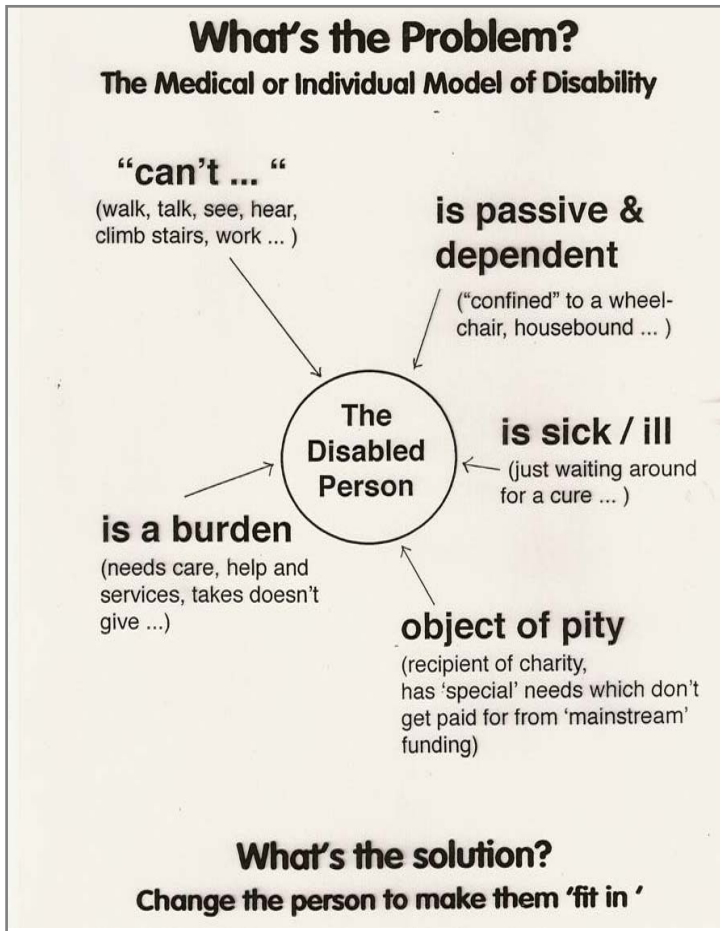
There are different ways of thinking about disability - most of us have grown up with the Medical or individual Model, which sees disabled people as a problem, people with something wrong with them.

Things have changed. Now many disabled people reject this way of thinking about their situation in society, and have redefined disability as an experience of barriers to participation in the things that non-disabled people take for granted such as education and pupil voice, friendship, sex and relationships, work and career, public office etc because of lack of accessibility and negative attitudes to disabled people. This lack of access needs to be addressed from the start of someone's life.

This is called the Social Model of Disability, and it is a model which invites us all to join in the process of overcoming the barriers to participation and inclusion identified by disabled children and adults and their allies.

A child's impairment is just a part of who they are, which can't be separated from the rest. There is no version of him or her without that feature, and it's not a problem for them. An impairment does not disable a person whose access needs are fully met.

The Medical Model reinforces the view of the impairment as a tragedy for the individual and their family and anything they accomplish is seen as triumph over adversity. This model is often adopted by parents at the birth or diagnosis of their disabled child inadvertently because of the constant focus on problems, and causes damage to the bond between parents and child. Supporting parents to adopt the Social Model helps to repair this damage.





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