



LEIDEN UNIVERSITY MEDICAL CENTER

# *Disabilities and Handicaps*

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**Maastricht**



- Impact
- Definitions
- Parents and siblings
- Services
- Education
- Transition and independence
- Legislation

*NOW, CLOSE YOUR EYES*

Think back to when you were anticipating the birth of your child.

Who (or what) was this child to have been for you?

## *Dreams of parents*

- Parents who are rich or poor, educated or undeducated
- Pregnancy unplanned, or planned, first or tenth.
  
- Parents attach to children through dreams, fantasies, illusions, and projections into the future.
  
- Parents have a dream, hope, wish , expectation of having a child who
  - will be healthy and happy
  - grow up to reach his or her full potential
  - on reaching adulthood will be able to function independently

*Excerpts of parents' hopes and dreams for their children  
at Early Childhood Education and Family Center*

- To be successful at whatever he chooses to do in life.
- I want her to overcome any obstacle that comes her way.
- To be able to speak so that her wants and needs can be voiced.
- To be a happy and healthy child.
- To know that she is loved.
- 
- To gain independence and confidence to be all she can be.
- To live life to its fullest.
- To concentrate on herself yet be respectful and tolerate others.

- To live her life to improve the world around her.
- To make changes as well as to gracefully accept changes.
- To develop her skills and use them accordingly.
- I don't want her to say "I can't" until she's given her best effort.
- That she'll have more joys than sorrows.
- May she be fortunate enough to have sincere friendship in her life.
- To love and be loved by others.
- That he always will be as happy as he is now.

*NOW, OPEN YOUR EYES*

- You have just heard that your much wanted and awaited child has a problem
- You have been told that your child has a disability

## *A child with a disability*

Disability shatters the dreams, fantasies, illusions, and projections into the future that parents generate as part of their struggle to accomplish basic life missions.

Parents of impaired children grieve for the loss of dreams that are key to the meaning of their existence, to their sense of being.

The impairment, not the child, irreversibly spoils a parent's fundamental, heart-felt yearning.

Recovering from such a loss depends on one's ability to separate from the lost dream, and to generate new, more attainable, dreams.

As disability bluntly shatters the dreams, parents face a complicated, draining, challenging, frightening, and consuming task.

They must raise the child they have, while letting go of the child they dreamed of.

They must go on with their lives,  
    cope with their child as he or she is now  
    let go of the lost dreams  
    and generate new dreams

To do all this, the parent must experience the process of grieving.



"You never expect this and you're never prepared."

"For a brief moment your hopes vanish and you're left holding your fears literally ... But then all you feel is love: the worry, the guilt comes later but so does the joy and the pride - all you really have is a child, not a child who is this or that, but a child."

## *Grieving*

Grieving is an unlearned, spontaneous, and self-sufficient process.

It consists of states of feeling that provide the opportunity for self-examination, leading to both internal and external change.

The grieving states that facilitate separation from a lost dream are:

- denial
- anxiety
- fear
- guilt
- depression
- anger

The word "states" is used, instead of "stages," to emphasize grieving is not a step-by-step process that evolves through discrete stages.

## *Disability*

- A disability may develop at any moment in time
- May be either short term or long term
- A child who has a disability has, almost always, as an adult, some consequences of this or it may even be more severe
- An adult who has grown up without a disability will be different to an adult who has grown up with a disability
- An individual may qualify as disabled based on a personal or group standard or norm



## Measuring Children's Disability via Household Surveys: The MICS Experience

By

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Paper presented at the 2005 Population Association of America (PAA) meeting.  
March 30 - April 2, 2005, Philadelphia, PA.

The Multiple Indicator Cluster Surveys (MICS) measurement of disability falls within one of the main components of the ICF part of function and disability:

activity limitations and participation restrictions, which are identified with an implicit assumption of performance and capacity as qualifiers.

MICS also collects data related to the contextual factors of the ICF framework, particularly on the personal factors representing the background of an individual's life and living (age, gender, ethnic background, education, household wealth, nutrition, health, etc.).

The idea here is to use the collected data to explore associations between existing impairments in children's activities and participation in life situations, and their contextual factors.

**Proportion of children 2-9 years of age with at least one impairment according to type and country. MICS2 2000-01**

TYPE OF DISABILITY	COUNTRY						
	Cameroon	Iraq*	Jamaica	Lesotho	Madagascar	Sao Tome & Principe	Suriname
Development	3	1	1	14	15	11	3
Vision	2	1	1	6	3	3	4
Hearing	3	1	1	7	4	7	4
Understanding	4	1	3	12	6	10	5
Movement	2	1	1	4	2	5	2
Crisis/Fits	4	1	1	4	5	14	3
Learning	3	1	2	5	2	8	3
Speaking	7	2	2	9	4	15	3
Mental	6	1	3	11	11	3	4
<b>TOTAL</b>	<b>23</b>	<b>4</b>	<b>9</b>	<b>40</b>	<b>34</b>	<b>44</b>	<b>20</b>

\* Three governorates only: Dohouk, Suleimaniya and Erbil.

**TABLE 6. DEMOGRAPHIC INDICATORS**

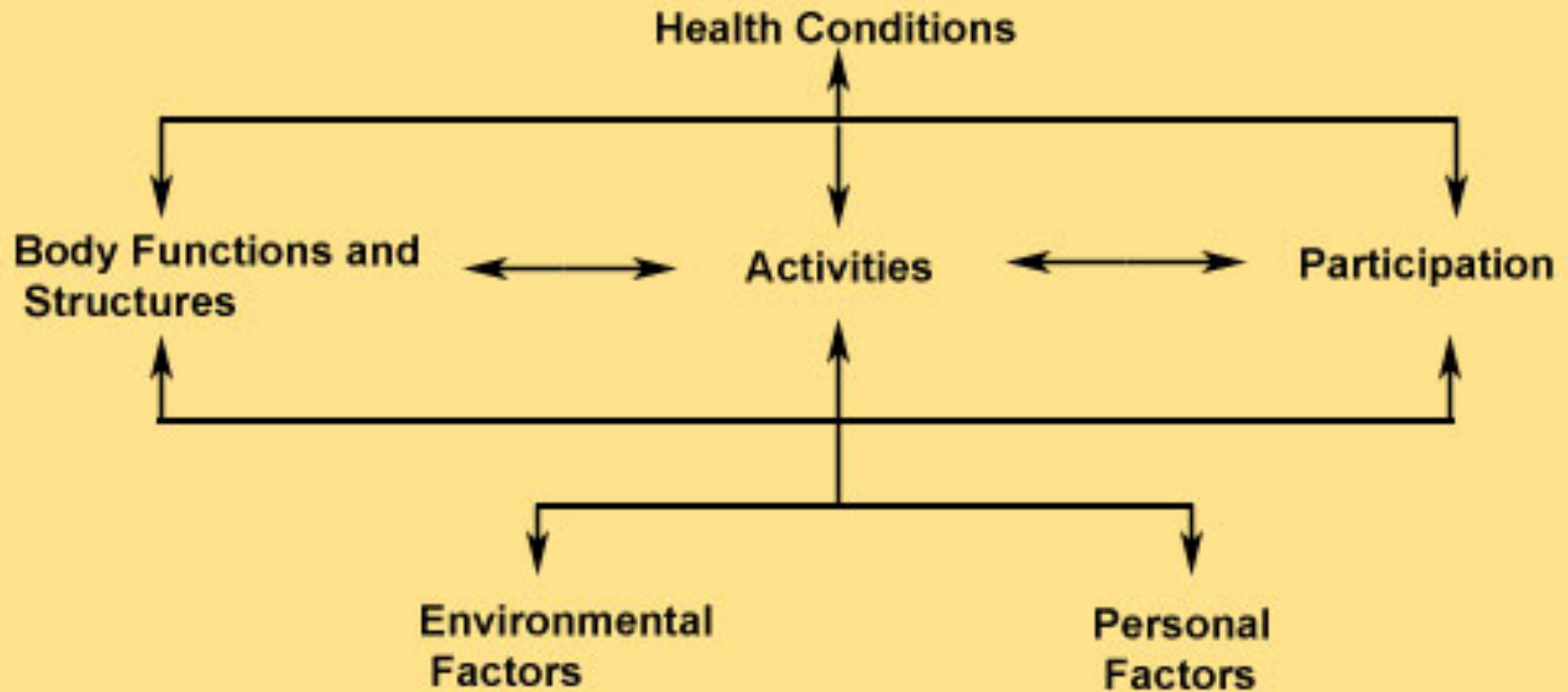
	Population (thousands) 2009		Population annual growth rate (%)			Crude death rate			Crude birth rate			Life expectancy			Total fertility rate 2009	% of population urbanized 2009	Average annual growth rate of urban population (%)		
	under 18	under 5	1970-1990	1990-2000	2000-2009	1970	1990	2009	1970	1990	2009	1970	1990	2009			1970-1990	1990-2000	2000-2009
	Netherlands	3562	943	0.7	0.6	0.5	8	9	8	17	13	11	74	77			80	1.7	82
New Zealand	1063	290	0.9	1.3	1.2	9	8	7	22	17	14	71	75	80	2.0	86	1.1	1.4	1.1
Nicaragua	2420	679	2.7	2.1	1.5	13	7	5	46	37	24	54	64	73	2.7	57	3.3	2.5	1.8
Niger	8611	3280	2.9	3.3	4.1	27	24	15	57	56	53	38	42	52	7.1	17	5.7	3.9	4.2
Nigeria	75694	25426	2.7	2.5	2.7	24	20	16	47	46	39	40	45	48	5.2	49	4.9	4.4	4.0
Niue	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	37	-2.0	-1.3	-1.4
Norway	1108	296	0.4	0.6	0.9	10	11	9	17	14	12	74	77	81	1.9	79	0.9	1.1	1.2
Occupied Palestinian Territory	2204	708	3.4	3.8	3.8	19	7	4	49	46	35	54	68	74	4.9	74	4.5	4.4	3.7
Oman	1067	297	4.5	2.6	2.1	17	4	3	50	38	22	49	70	76	3.0	73	8.5	3.4	2.1
Pakistan	78786	24121	3.1	2.5	2.5	16	10	7	43	40	30	54	61	67	3.9	36	4.2	3.3	3.0
Palau	7	2	1.4	2.6	0.7	-	-	-	-	-	-	-	-	-	-	82	2.2	2.6	2.5
Panama	1196	345	2.4	2.0	2.0	8	5	5	37	26	20	65	72	76	2.5	74	3.0	4.0	3.1
Papua New Guinea	3112	961	2.4	2.7	2.8	19	11	8	42	37	31	43	54	61	4.0	13	4.5	1.4	1.9
Paraguay	2563	739	2.7	2.3	2.1	7	6	6	37	33	24	65	68	72	3.0	61	4.0	3.6	3.0
Peru	10591	2969	2.5	1.8	1.4	14	7	5	42	30	21	53	66	73	2.5	77	3.4	2.4	1.8
Philippines	37033	10800	2.7	2.2	2.1	11	7	5	40	33	24	57	65	72	3.0	49	4.6	2.1	2.1
Poland	7166	1832	0.8	0.1	-0.1	8	10	10	17	15	10	70	71	76	1.3	46	2.9	-1.1	-1.0
Portugal	1971	531	0.7	0.2	0.6	11	10	10	21	11	10	67	74	79	1.4	60	1.8	1.5	1.6

Disability is not something that happens to only a small number of people

## UN Convention on Disability

Disability is defined in the Convention on the Rights of Persons with Disabilities (2007) as including persons "who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

## The ICF model of functioning and disability

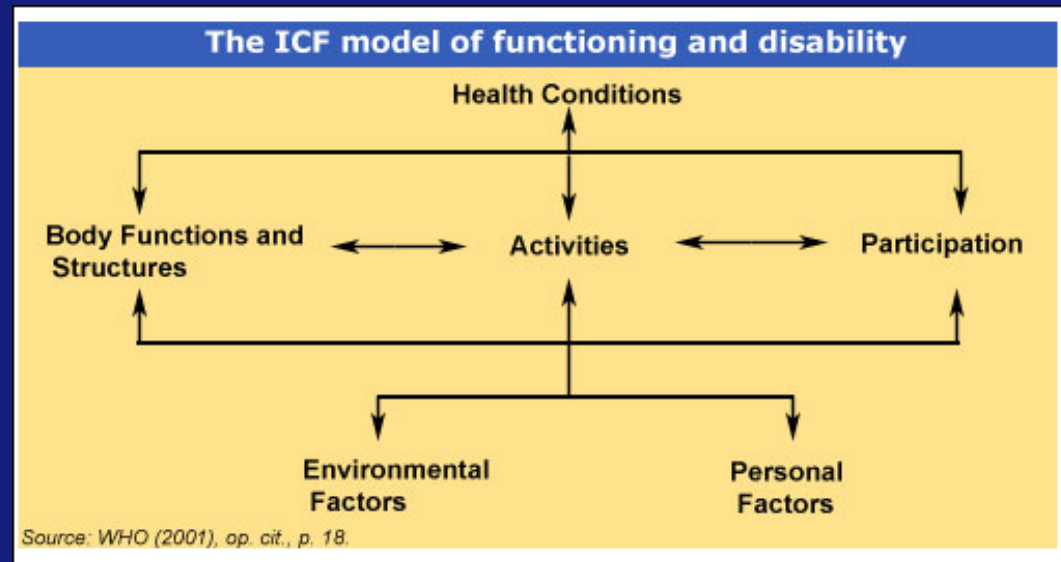


Source: WHO (2001), *op. cit.*, p. 18.

- Impairment problem in body function or structure
- Activity limitation is a difficulty encountered by an individual in executing a task or action
- Participation restriction problem experienced by an individual in life situations

# ICF Classification of health and health related domains

- Perspective
  - Body
  - Individual
  - Society
- 2 lists
  - body functions
  - structure
- Domains
  - activity
  - participation
- Environmental factors



## *Physical disability*

- Any impairment which limits the physical function of limbs or fine or gross motor ability
- Some disabilities can improve over time while others may not.
- A physical disability may result from:
  - genetic/congenital problems
  - complications during birth (cerebral palsy, etc.)
  - invalidating diseases (polio, tuberculosis, etc.)
  - accidents (road accidents, war injuries, child abuse etc.)

## *Sensory disability*

- Impairment of one or more of the senses
  - sight
  - hearing
  - smell
  - touch
  - taste
  - spatial awareness



## *Cognitive disability*

- The concept of cognitive disabilities is extremely broad, and not always well-defined.
- In loose terms, a person with a cognitive disability has greater difficulty with one or more types of mental tasks than the average person.
- Broad concept ranges from mental illness, retardation to mild or specific cognitive deficits

## *Mental health and emotional disabilities*

- mental health conditions – including schizophrenia, bipolar disorder, depression
- epilepsy, alcohol and drug use disorders, child and adolescent mental health conditions
- psychological or behavioral patterns generally associated with subjective distress

## *Mental health and emotional disabilities*

- Despite their vulnerability, these people have been largely overlooked as a target of development programmes.
- This is despite the
  - high prevalence of mental health conditions,
  - their economic impact on families and communities,
  - the associated stigmatization, discrimination, and exclusion.

## *WHO: Mental health conditions*

- Mental health conditions affect millions of people
  - 151 million people suffer from depression
  - 26 million people from schizophrenia
  - 25 million people are affected by alcohol use disorders
  - 40 million people suffer from epilepsy
  - Circa 844,000 people die by suicide every year.
- 
- In low-income countries, depression represents almost as large a problem as malaria



*Invisible handicap*

- Chronic disorders such as
  - congenital heart disorder
  - diabetes
  - asthma
  - obesity

## *Asthma*

- is the most prevalent chronic disease in childhood
- affects about 150 million people world-wide
- relatively low fatality rate, draws less attention than other respiratory conditions
  
- High prevalence of childhood asthma during the last decades predicts the growing prevalence of asthma in the near future unless appropriate preventive measures are undertaken.

## *Childhood Obesity and Overweight*

- 15% of children are overweight and another 15% are at risk of becoming overweight.
- two thirds of these will become overweight adults
- significant health consequences of childhood overweight and obesity (often do not become apparent until adulthood)
  - cardiovascular diseases (mainly heart disease and stroke)
  - diabetes
  - musculoskeletal disorders, especially osteoarthritis
  - certain types of cancer (breast and colon).
- At least 2.6 million people die each year as a result of being overweight or obese.

## *Injury-related impairments resulting in disabilities*

- Physical and/or cognitive limitations due to neuro-trauma
- Paralysis due to spinal cord trauma
- Partial or complete amputation of limbs
- Physical limb deformation resulting in mobility impairments
- Psychological trauma
- Sensory disability such as blindness and deafness

## *“Special needs”*

### Definition:

is an umbrella term underneath which many diagnoses may be placed

Children with special needs may have

- mild learning disabilities or profound mental retardation
- food allergies or terminal illness
- developmental delays that catch up quickly or remain entrenched
- occasional panic attacks or serious psychiatric problems.

The designation is useful for

- getting needed services
- setting appropriate goals
- gaining understanding for a child and stressed family.

## Definitions “Special needs”

"Special needs" are commonly defined by what a child *can't* do:

- milestones unmet
- foods banned
- activities avoided
- experiences denied

These hit families hard, and may make "special needs" seem like a tragedy.

Some parents will always mourn their child's lost potential, and many conditions become more troubling with time.

Other families may find that their child's challenges make triumphs sweeter, and that weaknesses are often accompanied by amazing strengths.

- The persons name should come first and the descriptions of the impairment or disability should be used so that the impairment is identified but is not modifying the person
- Adaptive equipment should be described functionally as something that assists a person, not as something which limits a person





**The impact of childhood disability on family life**

Barbara Dobson, Sue Middleton and Alan Beardsworth

15 June 2001

<http://www.jrf.org.uk/publications/impact-childhood-disability-family-life>

Approximately 300 families with severely disabled children took part in this study.

Of these, 182 parents returned completed diaries and questionnaires which form the basis of this report.

The families were identified through the Family Fund Trust Database and lived in four areas of the country: Leicestershire, Birmingham, Derbyshire and Nottinghamshire.

## *Diagnosis and adjustment*

Central to the process of adjustment was the way in which parents received a diagnosis of their child's disability.

The diagnosis was important to parents for many reasons. It was often the point from which parents could begin to contemplate their futures and to understand the nature of their child's disability.

For this to happen, parents needed information which they could understand and relate to.

This process did not happen instantly but for many parents the diagnosis represented a turning point from which they started to regain some control over both their own and their child's lives.

Diagnosis was also crucially important because it was often the gateway to services, including the entitlement to financial benefits.

## *Parent or carer?*

Parents of disabled children often have two roles:  
parent and carer.

Many parents did not differentiate between their role as parent, and the tasks they performed to care for their child.

In their experience, they did whatever was necessary to look after their child and the only difference was that their child had specialised health needs.

The researchers conclude :

the challenge for policy and indeed for medical and social services is to recognise these dual roles and to accord each one the respect they deserve.

However, parents described how often their parental or caring roles were denied.

In some instances, the specialised knowledge that they had acquired about their child's condition was ignored

In others, their role as parents was overlooked as professionals discussed their child with them in cold clinical terms.

All parents strived to spend enough to meet the needs of their children. To achieve this they spent less on themselves and made other savings wherever they could.

Excluding spending on food, parents spent on average one fifth of the total family income per week on items and services for their disabled child.

In order to allow for this level of spending, parents developed ways of coping financially.

These included:

- parents going without
- relying on help from families when it was available
- going into debt
- economising whenever and wherever possible.

While the majority of parents were creative and careful money managers, achieving the required results took time and energy - two things that for many parents were in even shorter supply than money.

## *Family aspects of childhood disability*

They stressed that it was not “*just doom and gloom*”, nor was it about only giving.

But parents also talked about the emotional costs and described how they, their families and friends reacted and adjusted to the needs of their child.

The findings suggest that, as parents struggle to reconcile costs with needs, they must also confront new and unexpected experiences which redefine their family life.

## *Difficulties for parents*

A particular difficulty for parents was that they were suddenly exposed to the attitudes that many disabled people experience all the time: they were marginalised and ignored by some friends and family.

As a result many parents became very isolated.

It was only as parents grew in confidence that they were able to challenge the way in which they and their children were treated by society.



Many parents of disabled children become used to being stared at in public or the topic of other people's or professionals' conversations.

Yet despite this public profile, parents reported how as a family they remained invisible. They were not regarded as an 'ordinary' family, with the same aspirations and rights as families who did not have a disabled child.

While families reported that the physical exclusion was hard to deal with, it was the change in attitudes by society, including professionals, that devastated them. Their experience was that they as a family no longer evoked positive feelings but were instead pitied.

By being treated as a 'matter of regret' they were stripped of their family status and denied the same emotional and social worth as 'normal' families.

## *Siblings*

- Brothers and sisters, along with their friends and spouses, will have longer relationships with a disabled child than parents, grandparents, aunts and uncles.
- While it is important that parents and other adults in the family find time to spend with each child independently of other siblings, it is important that they learn to appreciate and enjoy one another



## *Siblings*

- It is important to remember that relationships between siblings are complex, distressing, and inspiring whether one of them has a diagnosis or not.
- Nowhere else is it so obvious that children with special needs are more like their mainstream peers than they are different from them , than at home, with their families, in the middle of a sibling row.

Sisters and brothers of children with disabilities grow up to be energetic and effective advocates

siblings with special needs often contribute immeasurable support and encouragement for their mainstream siblings

whether they choose or are able to have close relationships as adults or not, they should have had every opportunity to enjoy one another and to coexist peacefully as they grow up.

## *Siblings contact with others*

- family participation in outings or holiday events
  - siblings can observe older children with the same disability
  - and other brothers and sisters their age
- 
- Understanding the diversity of individuals with the same diagnosis can be as reassuring to siblings as it is to parents.

programmes available through advocacy organizations that specifically address the needs and concerns of brothers and sisters growing up with a sibling with special needs.

Often the focus is on social activity and games, with a short discussion of some topic in common, or an occasional adult speaker who has a specific diagnosis and wants to share his or her lifestyle and relationships with the group.

Mainstream resources and support for maintaining and improving sibling relationships have a wealth of information that can benefit families of children with special needs

Staying integrated in the mainstream of communities means that not only can experiences be shared with families who have only typically developing children, but they can share theirs.

Some of the greatest obstacles are the same that challenge every parent.

All children are unique and wonderful, perplexing and delightful.

## *Sibling Support and Rivalry - Childhood Disability*

- Growing up with a brother or sister who has a disability can give siblings
  - a greater richness of experience and better quality of life
  - bring out positive traits in their characters,
  - help them develop better senses of humor and fairness
  - introduce them to the best aspects of inclusive communities
  
- These benefits are more likely to be realized if all children in a family are encouraged to develop their potential in a warm, loving and safe environment.

Children interact with one another on many levels at home.

squabbles and conflicts must be mediated  
cooperation and congeniality encouraged.

birth order helps determine some aspects of sibling relationships

Active parenting demonstrating fairness, plus showing interest and delight in each child, helps to alleviate tensions that develop in everyday life and especially stressful situations.

## *Turning points*

- Assistance of others, abilities, beliefs and personal characteristics
- Receiving a diagnosis
- Medications and remedies
- Services received, opportunities and experiences in life
- Devices and wheelchairs
  
- Hindering
  - Lack of support from others
  - Attitudes beliefs and behaviour of others

- Listen to people with disabilities and their parents
- Speak directly to the children themselves and choose your words carefully
- Deal with the family as a whole
- Provide services with acceptance and respect
- Focus on individual needs, as each person is different

## *Natures of services required*

- Support parents of children with disabilities to encourage their child's independence
- Encourage opportunities for children to know others with similar disabilities as well as those without disabilities
- Provide vocational guidance for realistic jobs
- Ensure services extend beyond childhood, decentralised and accessible
- 
- Prepare for adulthood, plans that will help in all aspects of life
- Provide information to ensure that people know of available services



*10-year plan for supporting  
Queenslanders with a disability –  
consultation report*

Published by Department of  
Communities (Disability and  
Community Care Services),  
Queensland Government

July 2011

© The State of Queensland,  
Department of Communities, 2011

1. raising community awareness about the issues, barriers and rights of people with a disability is fundamental
2. everybody needs to work together to bring about change in our communities
3. education, valued roles and employment are key determinants of a 'good life'
4. health should be a priority in its own right

5. inclusion should happen from birth or at point of diagnosis
6. it is important to recognise and celebrate diversity, not just focus on disability
7. no more 'silos'; government agencies and services need to work together better
8. universal design in places and spaces will be better for everyone

9. mainstream services should be accessed first and disability services when required

10. people with a disability should be able to access services, supports, aids, equipment and communication support as a 'right'

11. technology and innovation are important enablers to participation

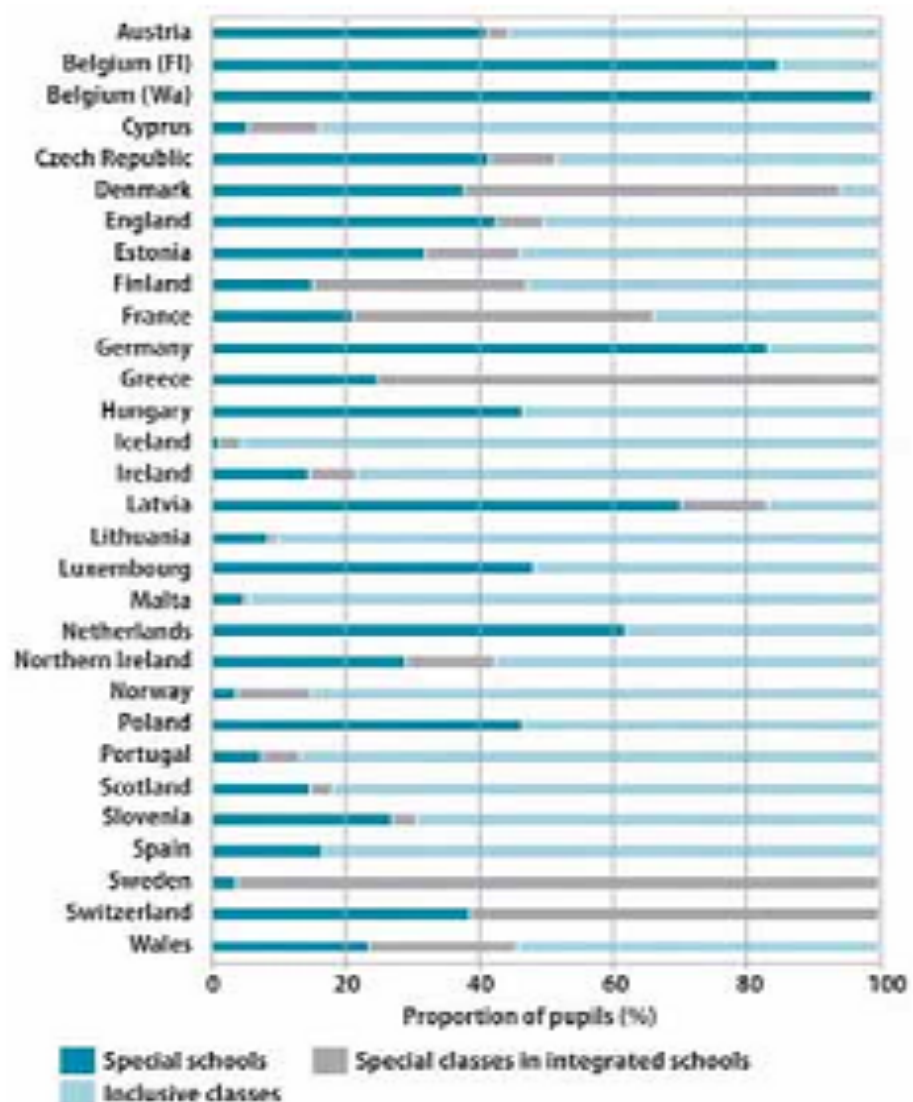
12. disability services must aim to enable and support people with a disability to equally participate in the community through strategies such as flexible and self-directed funding

**Table 7.1. Education outcomes for disabled and not disabled respondents**

Individuals	Low-income countries		High-income countries		All countries	
	Not disabled	Disabled	Not disabled	Disabled	Not disabled	Disabled
<b>Male</b>						
Primary school completion	55.6%	45.6%*	72.3%	61.7%*	61.3%	50.6%*
Mean years of education	6.43	5.63*	8.04	6.60*	7.03	5.96*
<b>Female</b>						
Primary school completion	42.0%	32.9%*	72.0%	59.3%*	52.9%	41.7%*
Mean years of education	5.14	4.17*	7.82	6.39*	6.26	4.98*
<b>18-49</b>						
Primary school completion	60.3%	47.8%*	83.1%	69.0%*	67.4%	53.2%*
Mean years of education	7.05	5.67*	9.37	7.59*	7.86	6.23*

*Unicef report 2011 The state of the world's children*

**Fig. 7.3. Delivery of education by type of model f**



*Unicef report 2011 The state of the world's children*

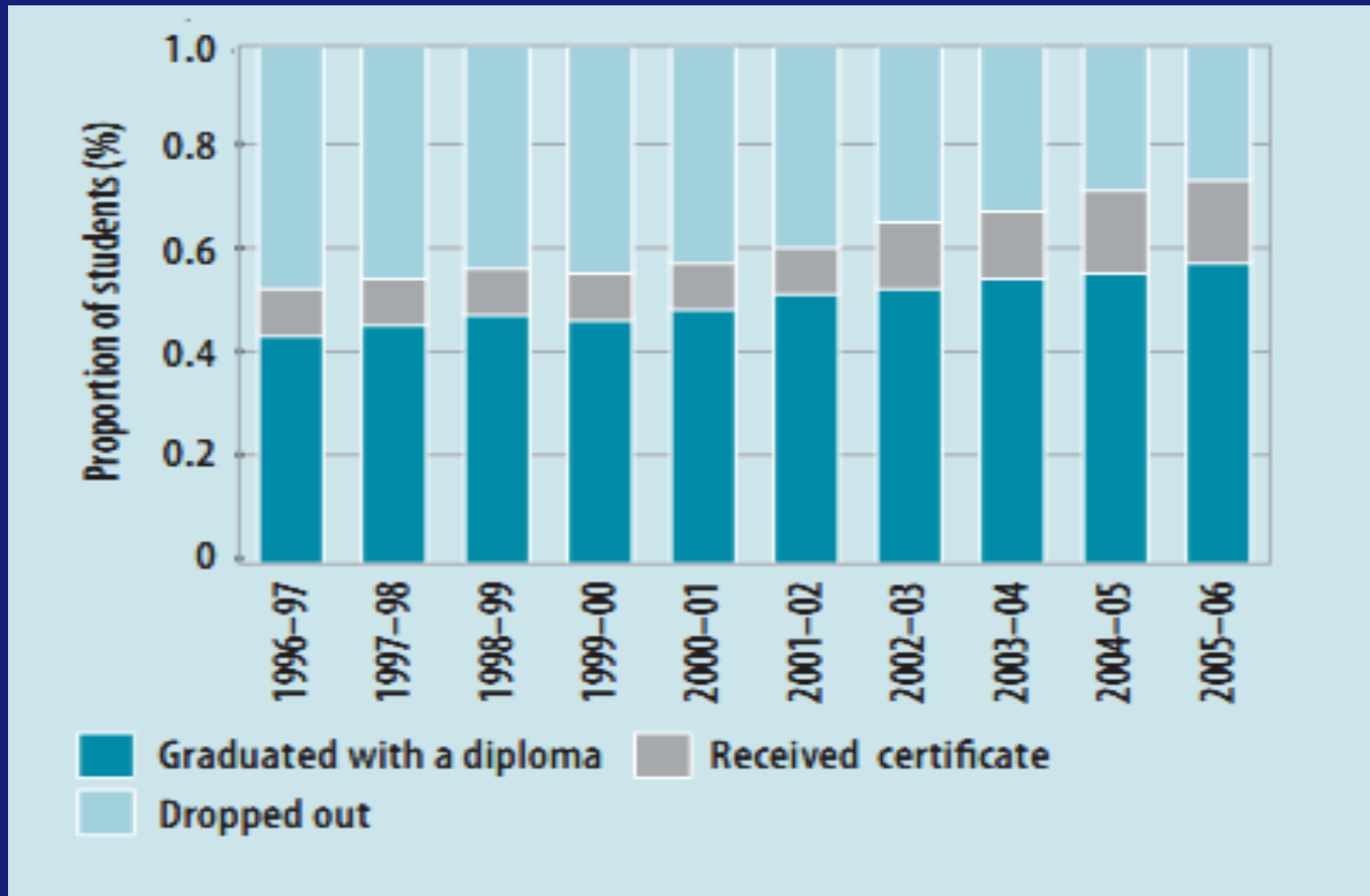
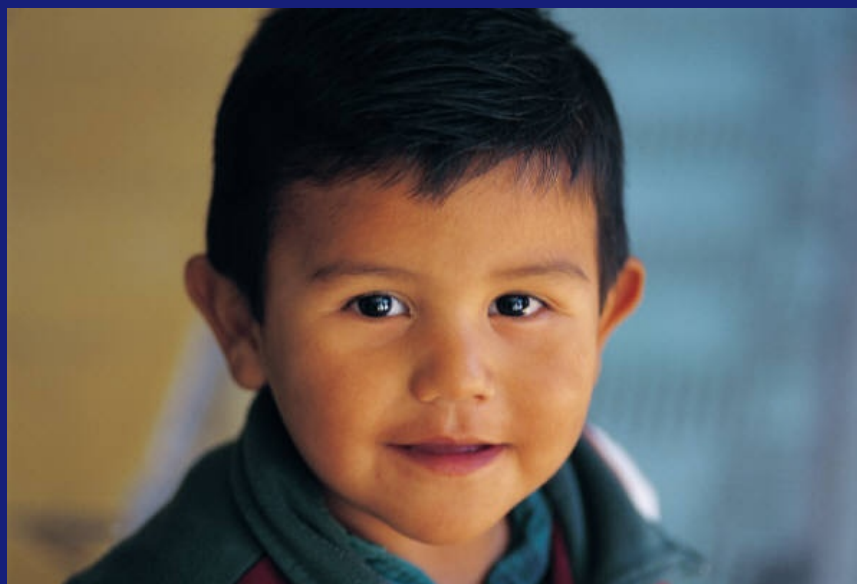


Table 4-3. Students with disabilities served under IDEA, Part B, in the U.S. and outlying areas who exited school, by exit reason, reporting year, and student's age: 1995-96 through 2004-05. Rockville, Data Accountability Centre, 2009 ([https://www.ideadata.org/tables30th/ar\\_4-3.xls](https://www.ideadata.org/tables30th/ar_4-3.xls), accessed 16 October 2009).



## *Increased risk: need for sex education*

People with a disability experience all forms of abuse, including sexual abuse, at higher rates than the rest of the population.

Without adequate sex education and an understanding of protective behaviours, they may also be at increased risk of sexually transmissible infections and unplanned pregnancy.

## *Increased risk: need for sex education*

People with an intellectual disability have the same range of sexual thoughts, attitudes, feelings, desires and fantasies as people without disabilities,

they often have fewer opportunities to engage in age-appropriate sexual activity than their same-age peers.

Yet, when people with an intellectual disability express their sexuality, it is often seen as a ‘problem’.

Sex education is sometimes withheld, even though people with an intellectual disability experience STIs, unplanned pregnancy and sexual abuse at higher rates than the rest of the population if they do not learn protective behaviours.

## *Reasons for this increased risk*

Lack of knowledge about sexual issues

Misinformation about sex from peers, rather than books or other reliable sources

Lack of intellectual ability to understand the changes happening to their bodies

Misplaced trust in others due to increased dependence on others for assistance

A tendency to be overly compliant, particularly those children requiring a high level of support

Lack of assertiveness training or skills

An overprotected lifestyle and limited social contact.

[http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Sex\\_education\\_for\\_children\\_with\\_intellectual\\_disabilities?open](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Sex_education_for_children_with_intellectual_disabilities?open)>Sex education for children with intellectual disabilities - Better Health Channel</a><br/>



ACYI

Transition Planning Protocol for Youth with Disabilities  
Your Guide To Reaching New Heights

[http://www.seniors.alberta.ca/disabilitysupports/documents/  
TransitionPlanningProtocol.pdf](http://www.seniors.alberta.ca/disabilitysupports/documents/TransitionPlanningProtocol.pdf)

- Begin early (13-16 years of age)
- Involve and support youth and their families as key players
- View the youth as a member of the community rather than a client of a particular service
- Be flexible in allowing youth and families to express wishes, dreams and new opportunities
- Be a natural and seamless progression from youth to adulthood
- Be a collaborative responsibility of youth/family, the key ministries and the government programs available to youth and adults with disabilities, government-funded agencies, service providers and relevant community partners.

## *All areas of transition to adulthood*

- Adult services
- Education
- Employment programs and opportunities
- Living arrangements
- Community life
- Financial independence
- Relationships (making friends)
- Social/Leisure
- Health care and medical management.

## *Areas*

- **Cultural Considerations**
  - Specific needs and desires
  - Activities and groups
  - Other considerations
  
- **Education, Training**
  - Post-secondary education or training options
  - Need for educational supports
  - Need for financial support for education/training
  
- **Employment or Career Development**
  - Work experiences
  - Employment interests
  - Employable skills
  - Need for supportive employment
  - Volunteer experiences, opportunities and interests

- **Income and Finances**
  - Banking
  - Long-term financial plan
  - Life insurance
  - Income sources
  - Funding currently available or expected to be available
  - Support required to manage finances
  
- **Living Arrangements**
  - Whether to continue with current living arrangement
  - Examination of types of housing
  - Semi-independent or independent living
  - Short-term and long-term plan for housing
  - Rent or own

- **Personal Management**
  - Household management including meal preparation
  - Hygiene/personal care
  - Sexuality and birth control
  - Social skills
  - Money management
  
- **Service Requirements**
  - Services and supports currently used, needed and anticipated for adulthood
  - Services currently accessed that the youth will no longer be eligible for as an adult
  - Eligibility for adult services
  - Awareness of information requirements and length of process involved in some areas of transition into adult services
  - Resources

- **Social, Recreational and Spiritual Development**
  - Hobbies and interests
  - Pets
  - Sports and fitness activities
  - Religious and other spiritual groups
  - Volunteer activities and interests
  
- **Transportation**
  - Independent (bus, walk, cycle, etc;)
  - Assisted (parents or family)
  - Specialized accessible transport
  - Equipment needs

## *Transition*

- **Guardianship, Trusteeship and Personal Directives**
  - Guardianship status: partial, full or independent
  - Trustee status: formal, informal or independent
  - Personal directive in place
  - Self-advocacy
  - Wills/trusts
  - Other legal considerations
  
- **Health Status and Care**
  - Technological and adaptive equipment
  - Health supports, equipment and supplies to maintain health
  - Psychosocial and cognitive development supports
  - Medical services and resources



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A HANDBOOK ON THE HUMAN RIGHTS  
OF PERSONS WITH DISABILITIES

# Understanding The UN Convention On The Rights Of Persons With Disabilities

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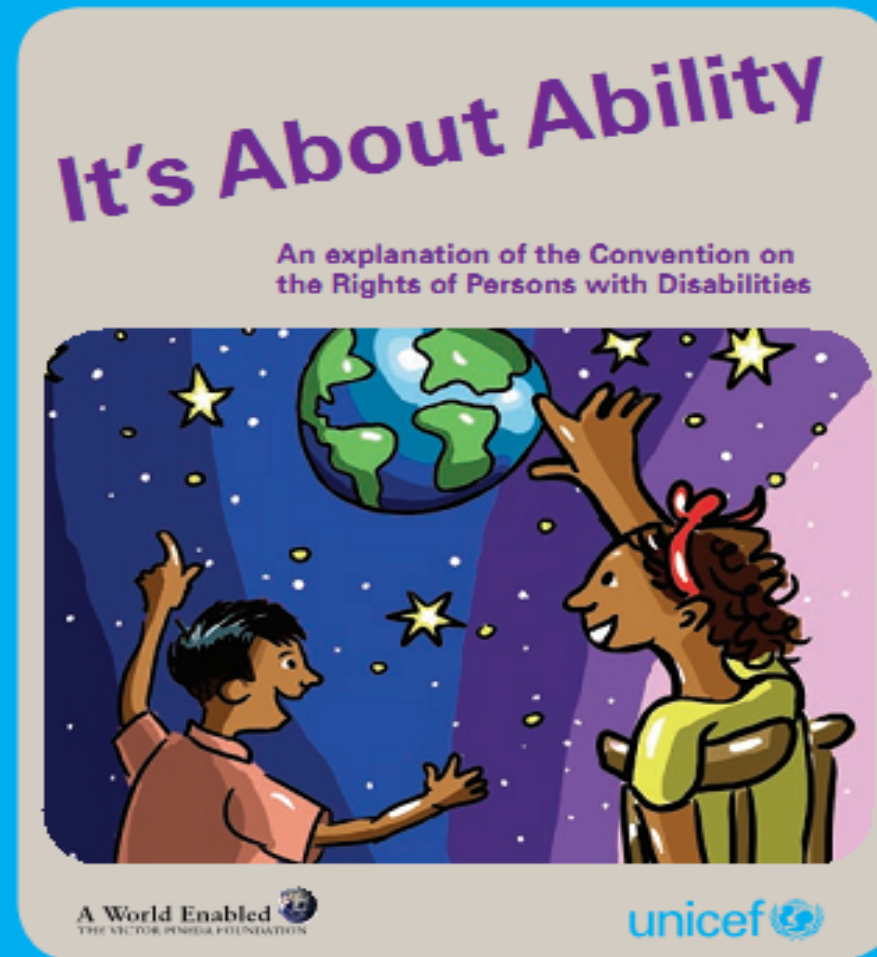
# *UN meeting*



## Article 7

### Children With Disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.



The final text incorporates a lot of Convention on the Rights of the Child (CRC) language, in particular the concept of ‘best interest of the child’,

Article 3 CRC. The right to express views freely, which derives from Article 12 CRC, is included.

Language from Article 23 CRC was also used.

There are several references to children with disabilities throughout the text, e.g.:

“Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child”

The General Obligations, Article 4 Para 3 refers to the need to consult children with disabilities in the development and implementation of legislation and policies implementing the Convention.

Freedom from exploitation, violence and abuse, Article 16, highlights the need for child-focused legislation and policies.

Article 18 on liberty of movement and nationality underscores the need for children with disabilities to be registered immediately after birth, and reinforces the right to have a name from birth, acquire a nationality and the right to know and be cared for by their parents.

## *Birth registration*

- Children with disabilities are disproportionately vulnerable to non-registration at birth.
- Without birth registration they are not recognized in law and they become invisible in government statistics.
- Non-registration has profound consequences for the enjoyment of their human rights, including the lack of citizenship and access to social and health services and education.
- Children with disabilities who are not registered at birth are at greater risk of neglect, institutionalization, and even death.

## *Early childhood*

- In early childhood disabilities are usually identified and the impact on children's well-being and development recognized.
- Young children should never be institutionalized solely on the grounds of disability.
- Equal opportunities are necessary for full participation in education and community life, including by the removal of barriers that impede the realization of their rights.
- Young disabled children are entitled to appropriate specialist assistance, including support for their parents (or other caregivers).
- Disabled children should at all times be treated with dignity and in ways that encourage their self-reliance.

More often than not, adults with and without disabilities make policies and decisions related to children with disabilities while the children themselves are left out of the process.

It is essential that children with disabilities are heard in all procedures affecting them and that their views be respected in accordance with their evolving capacities.

This should include their representation in various bodies such as parliament, committees and other forums where they voice views and participate in making the decisions that affect them as children in general and as children with disabilities specifically.

- Engaging them in such a process not only ensures that the policies are targeted to their needs and desires, it is also a valuable tool of inclusion since it ensures that the decision making process is a participatory one.
- Children should be equipped with whatever mode of communication to facilitate expressing their views.
- Furthermore, States parties should support the development of training for families and professionals on promoting and respecting the evolving capacities of children to take increasing responsibilities for decision-making in their own lives.

Article 23, in ensuring respect for home and the family pertain to children with disabilities:

right of children with disabilities to retain their fertility

and the right to equal respect of family life, including the right to adopt children.

Article 23 Para 4.

children are not to be separated from parents with disabilities against their will

*Transportation and access, para 39.*

The physical inaccessibility to public transportation and other facilities is a major factor in the marginalization and exclusion of children with disabilities and markedly compromises their access to services, including health and education.

And although this provision is mostly realized in developed countries, it remains largely un-addressed in the developing world.

All States parties are urged to set out appropriate policies and procedures that make public transportation safe, easily accessible and free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, to children with disabilities.

Article 24 para 2, rights of children with disabilities is education, sub a.

children with disabilities shall not be excluded from free and compulsory primary education, or from secondary education on the basis of disability.

Article 25 health provision and Article 30 on participation in cultural life, recreation, leisure and sport

“children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system.”