

Daily Life with a Retarded Child



Sexuality

Healthy Food

Mental Handicaps

A Practical Handbook for Parents,
Teachers, Pedagogues and the Family



Daily Life with a Retarded Child

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Daily Life with a Retarded Child

A Practical Handbook
by H.W. Gade

To Lukas

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Preface

I play with my beloved son. His face is close to mine. I look into his eyes, his beautiful, pale blue eyes. Then we play for long having fun. But in the middle of the play, I'm struck by a boundless bleak despair, and my eyes fill with tears. We shall never read French poetry together. We shall never see modern operas or go to classical concerts. We shall never go on the grand tour to my favourite city, Rome. We shall never...

Then I realize that my son is looking at me: "I want to play with mom", he says in an offended tone. "Papa don't want to play!" And then we play for very long, and my boy won't go to bed, because it's such fun.

And his father cannot sleep because his heart is full of tenderness and great sorrow. It is hard to learn how to be a good father to a beautiful little boy with an IQ of 40. And I love him so much. This is all my fault. Let me be a good father, let fall my pride and vanity. Let me be a good father.

*Henrik W. Gade
Broenshoej 10 April 2005*

1. Introduction

The core of retardation is the lack of one or more layers of a normal human's inborn intelligence and logic. Therefore it is necessary with intensive intelligence testing of the child to find the right education and the appropriate therapies.

What is Intelligence?

All living creatures have a consciousness. This goes for bacteria, insects, fish, turtles, horses and humans. Our subspecies of the primates have achieved an astounding intelligence through an unpredictable and geologically extremely fast development.

Compared to the chimpanzee, which is our closest relative, we now possess a number of new layers in the intelligence, probably developed in the below order:

- ❑ *An spoken abstract language* with past, present and future. This type of advanced language is unique for the homo sapiens species (us). Our unconscious sign language and mimics, however, are common to all highly developed apes. [The language probably came about 100,000 years ago].
- ❑ *A superego* The Freudian idea the “superego”, generally speaking, covers the ability of seeing yourself from outside, i.e. watching how you act and behave as if you were watching another person. Through having a superego, modern humans obtained a much higher degree of self-control and understanding of their own behaviour. Especially an understanding of their own shortcomings and a desire to learn from mistakes. [The superego was maybe developed about 40,000 years ago at the same time of the first religions.]
- ❑ *A written language*. With the written language (to be able to read and write), the humans could suddenly remember their myths and learn from the past. [About 5,000 years ago].
- ❑ *Math*. By counting and measuring, the humans became able to develop sophisticated tools and methods of cultivation suited for small and urban towns, contrary to the life of our nomad ancestors. [About 5,000 years ago].
- ❑ *Empathy*. The ability to – consciously – sympathize with and understand other people is relatively new in the development of the development of mankind. [About 2,000 years ago].

Being retarded means that the various new parts of the human intelligence apparently fade away, first the latest layers, then the older layers, one by one. The first layer to go is the *empathy*, i.e. the understanding of our fellow beings. This occurs in both lightly and moderately retarded children. Math becomes extremely difficult or impossible to learn, and reading and writing is a major problem. A lot of the children are almost completely word-blind.

The moderately retarded children can read a little, but on a very basic level. They cannot do calculations, only learn by heart, The superego is not present anymore, and the very lack of a superego hinders a “normal” behaviour, as the child cannot see itself from “outside”. Most moderately retarded children have a language, but usually with speech defects and little understanding of what is being said to them. The child might use a grammatically correct language, but use it mechanically without a deeper knowledge of what they are saying.

The severely retarded children normally have no language, no superego or any other part of the new layers of the human intelligence.

NOTE The suggested age of language is built on newer linguistic theories placing the age somewhere between 100 to 150,000 years. The age of the superego is pure guesswork, but would be a natural condition for the visual art and the religions which came about 30 to 40,000 years ago. The age of empathy is also a guess, built on the assumption that the manifest advent of compassion took place about 2,000 years ago. The age of the written language and math is known rather precisely. Both spoken language, math and written language are partly inborn and can thus be "lost" through retardation or brain injury

The Intellectual Abilities of a Child

Mental age is the intellectual age of a child compared to children of the same physical age. Originally, IQ was the mental age divided with the physical age multiplied with 100. today, the intelligence of a child is estimated according to how age appropriate the child thinks and acts. The IQ is then estimated accordingly. A normal IQ is 100. A deviation of +/- 15% is allowed.

The limit of the IQ 100 is moving upwards all the time. The definition of retardation is therefore a "standard" deviation of more than 30% below 100, i.e. a relative number. Intelligence is always an approximation and most children have strong points, where they function above IQ 100, including retarded children.

Many mentally handicapped children are very musical, and retarded kids can be masters of the computer. It is essential to use and strengthen the gifts of the child, to give it a sanctuary without defeats and frustrations.

There are Many Types of Intelligence

Modern psychiatry differ between various types of intelligence:

- 1** *Body / Motor Intelligence* - A problem for a lot of retarded children.
- 2** *Visual / Spatial Intelligence* – although retarded children are strongly dependent on visual impressions, spatial intelligence is a weak area.
- 3** *Logical Intelligence* functions very badly in retarded children.
- 4** *Linguistic Intelligence* is often substandard, even if the language sounds normal. Severely retarded children often have no spoken language, although they do understand a bit of what is being said.
- 5** *Musical Intelligence* For unknown reasons, musicality is seldom touched by a mental handicap.
- 6** *Self-controlling Intelligence* is weak, but can be trained through therapy.
- 7** *Social Intelligence* is weak among retarded children.

Intelligence Tests for retarded Children

There are many kinds of intelligence tests for retarded children. Often the parents have no idea what the tests are all about. It can be very frustrating to be presented with a report on your child built on an intelligence test you have never heard about. Here are a few typical intelligence tests.

Bayley's Developmental Test

Used to test children with moderately retarded development, e.g. a 6-year old child with a mental age of 2. Bayley's test has 3 scales, a mental, a motor and a behaviour scale.

Wechsler's Intelligence Test for Children (WISC)

The WISC scale for children and the similar test for adults are some of the most widespread tests in the world. The WISC test is used for children between 5 and 15 years old. There is also a scale – the WPPSI scale – for children between 4 and 6 years old. The children are tested for verbal IQ, functional IQ and complete IQ.

Stanford Binet's Intelligence Test (SB 4th Edition)

The French doctor Binet and the American ditto Stanford were two of the pioneers of intelligence testing. The latest version of the test can be used on children/teenagers between 2 and 23 years old. It consists of 9 to 15 subtests with linguistic and comprehension tests, sense of space, comparing objects etc.

Flexible Behaviour

Throughout the childhood, the child is taught and rehearses socially acceptable behaviour in various situations. Retarded children often have great problems behaving "normally". Their lack of understanding rules and "general behaviour" restrains their contact with other children and grownups.

The psychologists have made a list with typical examples of social behaviour, which are difficult to many retarded children. By focusing on the unique problems of each child, you slowly develop a key to solving the problems, behavioural therapy and rehearsing "correct" social behaviour.

Intellectual understanding:

- Flexible and expressive language
- To read and write.
- Understanding the use of money.
- Independent, logical acts.

Social understanding:

- Social relations with others.
- Being responsible.
- Self respect.
- Nativity / victimisation.
- Can observe rules and laws without being helped.

Practical knowledge:

- To be able to eat, dress and go to the toilet yourself.
- To be able to cook food, take medicine and use the telephone yourself.
- To take care of yourself, ride on the bus and go to the supermarket.

These things do not come natural to a retarded child. Lightly retarded persons will be able to learn most of the above, but a moderately / severely retarded child will have great problems with the majority of the tasks.

It is hard to Understand

It is so hard to understand for parents like us, that our moderately retarded child is not like us. There must be a way to evoke the “sleeping” intelligence reserves, it just a passing problem, he will learn in school. But there’s but emptiness, where the logic and the conscious actions reside in “normal” persons like us. There is but emptiness. And it is so hard to understand for a parent who loves his child. There is but emptiness, and you child cannot live on your false hopes. Surrender to the sorrow, but it is a grief for your own dreams. Your child live in a dreamless day occupied by the little and the near, repetition, safety. There are no plans, no grand dreams. There are only the fleeting days, daddy and mommy.

When the Superego is Absent

Without a superego, all actions become impulsive and illogical. The actions of the child are not necessarily meaningless, but seldom driven by a conscious wish of carrying out a certain task. As the child does not understand himself, it often loses contact with his body and actions. It can be heard in the language, when the child calls himself by name and seldom use “me” or “mine”. He recognizes the words, but he does not understand their deeper contents, as he doesn’t understand himself.

Your child lives in a word that resembles your own. But this is only on the surface; you will never be able to fully understand the world of your child. You share nothing but the Love.

Retardation

AAMR, the leading American society for retardation states in its definition of retardation that one should take into consideration both the social environment of the child, physical handicaps, strengths and weaknesses and the possibilities to develop the skills of the child. Being professionally supported over a longer period strengthens the development of all retarded children.

Retarded children are slow learners of walking, talking and being clean. Besides the learning problems, many retarded kids have comorbid diseases (side effects), e.g. reduced hearing and sight, spasticity, epilepsy, ADHD, Tourette’s syndrome and autism. The moderately retarded children are especially prone to comorbid diseases.

What is the Cause of Retardation?

Organic Impairment

25% of all retarded persons suffer from inborn organic impairments, for example:

- Fetal Alcohol Syndrome (FAS – the mother drinks during the pregnancy, ***DON'T!!!***). FAS is the single largest cause of retardation in Europe and the USA.
- Down's syndrome.
- Rare diseases like fragile X syndrome (autism), Cri du Chat syndrome, Rett's syndrome (autism), PKU (a metabolic disorder) and other diseases.
- Acquired physical injuries could be head lesion, German measles, measles, lack of oxygen during birth or meningitis, all are common causes of retardation.
- Pollution and various poisonous substances, lead for example, may cause damage to the brain.

Unknown Factors

Retardation without any obvious cause totals almost 75% of all retarded person. Life in a socially strained family without the strength to look after the small children may be the cause of permanent mild retardation too. Refugees with war trauma might also develop retardation. Children of retarded parents often become retarded themselves. They “learn” to be retarded.

Mental Retardation among Children of Emigrants

Marrying your cousin is a social and medical problem for many children of emigrants. A growing number of children in the special schools are retarded partly because of the close family relation between the parents. This goes for small isolated villages and farmers too.

Degrees of Retardation

A retarded child is defined as a person with an IQ of 70 or below. You can divide retardation into 3 (4) degrees, all individual groups with very different needs.

- Lightly retarded: An IQ between 50-55 to 70 [85% of all retarded persons].
- Moderately retarded: An IQ between 35-40 to 50-55 [10% of all retarded person, including the son of the author].
- Severely/deeply retarded: An IQ from 20 to 35-40 [5% of all retarded persons]. WHO's definition also uses a 4th degree, ”deeply retarded”, for children with an IQ below 20.

How many People are Retarded?

1-3% of the population has an IQ under 70.

Boys and Girls with Retardation

About 3 out of 5 retarded kids are boys/men. The disproportion between boys and girls is also present by most other handicaps, as boys – in general – are more psychically fragile than women.

Diagnose

The latest WHO classification of mental retardation is ICD-10 from 1994. The text is quite lengthy and therefore not reproduced here (read the text on: www.who.int/classifications/icd/en). To receive the diagnose “retarded”, the following must be present:

- An IQ below 70.
- Problems with non-flexible social behaviour.
- The disease started before the 18th year.

Contrary to the American classification systems WHO insists that cognitive, linguistic, motor, social and other aspects of flexible social behaviour are used to describe the degree of intellectual impairment. WHO also supports the notion that a retarded person can have mental handicaps and psychic diseases along with the retardation.

Besides the previously mentioned degrees of retardation, WHO uses “other mental retardation”, where physical problems make it difficult to identify the degree, and “unspecified mental retardation” if a baby, for example, cannot be diagnosed with sufficient certainty. Unless the child has severe retardation or Down’s syndrome, a diagnostic investigation should only be carried later.

DECLARATION Due to the absence of courses in mental handicaps during the education of psychologists, doctors, teachers and pedagogues, there’s a fatal lack of knowledge of e.g. ADHD and autism among these professional caregivers. This presents a serious political problem all over most of the world. As the teachers can’t teach and the doctors can’t really diagnose handicapped children, the kids suffer and the governments loose substantial amounts on wrong treatment and social disasters. The politicians should feel ashamed of themselves.

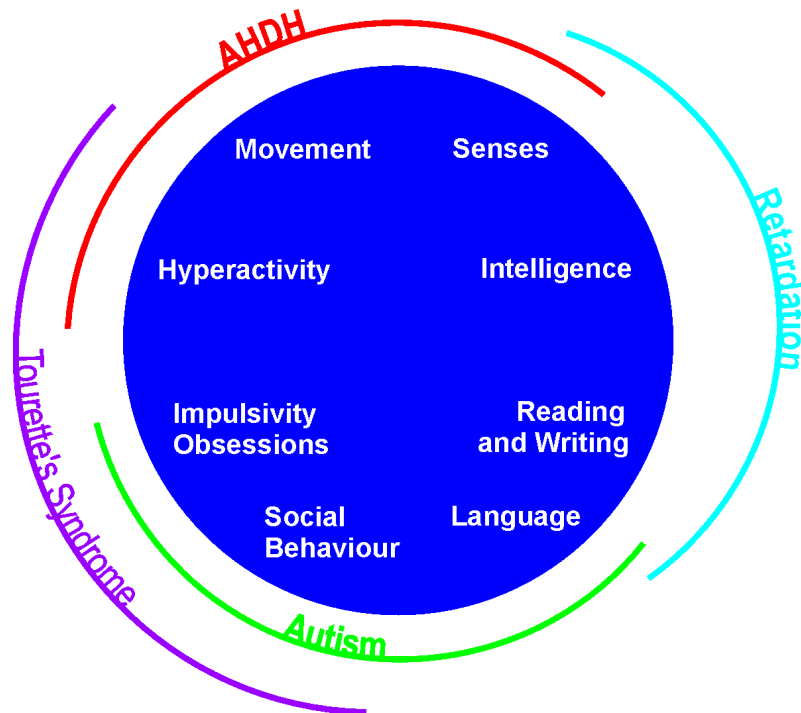
And the normal citizens should start changing their negative attitude towards our children – they have come to stay!

Retarded / Delayed Development / Morons / Nuts / Imbeciles / Idiots/ Changelings

One handicap – many names. Since Luther suggested drowning all retarded children, humanism – thank God – has come a long way. But the many tabooed names disclose the widespread fear for those who are different. Petty racism thrives in a world of computers and “tolerance”.

The Correlation between Various Mental Disabilities

The following drawing shows the overlaps between retardation and other related mental disabilities:



Retardation: Deficient intelligence, lightly to severely. Socially unacceptable behaviour caused by the child's lack of understanding the ways of the world. Massive problems learning to read and write.

Autism: The child is locked up in its own world, some times without language and communication. Autism is a severe disorder, probably the most serious of these four very common mental disorders.

ADHD (Hyperkinetic Syndrome): Massive problems with the perception of the outer world lead to hyperactivity and deviating behaviour.

Tourette's syndrome: Verbal and motor tics. Obsessions and compulsions. Risk of depressions and other psychic disturbances.

All four disorders are caused by a physical or genetic / chemical brain damage, and they are all incurable.

The School

Education of Retarded Children

Educating a retarded person is a lifelong project, which not only involves the school but also the parents, the family, friends and neighbours. And the education continues for life. Even if the retarded child is unable to develop on its own initiative, he can be trained to develop far beyond expectations through intense supplementary assistance. To reach this goal, you need:

- ❑ To realize the indicial needs of the child. *Everyone* engaged in the child, must know these needs and how to take care of the child the right way.
- ❑ To develop the ability of the child to carry out the basic daily needs: Put on the clothes, go to the toilet, wash the hands, brush the teeth and eat.
- ❑ To teach the child according to the mental and physical ages of the child.
- ❑ To work out a tight structure, supporting the weak sides of the child with the help of its strong sides.
- ❑ To strengthen the social skills of the child.
- ❑ To strengthen and collect the emotional and intellectual sides of the child.
- ❑ To educate the parents and the staff for better understanding and support of the child.

Lightly Retarded Children

Attending school is no different to a lightly retarded child than to a “normal” child. But it is absolutely necessary to consider the child’s lack of knowledge and skills compared to the rest of the class.

Moderately Retarded Children

Children with moderate or severe retardation should primarily be taught to be independent in the ordinary, everyday skills mastered by “normal” children but *not* by a retarded child. It is important not to overestimate the retarded children, because you tend to believe they are like you. But it is equally important not to underestimate the children, balancing the actual needs and the running development of the children’s skills.

Teaching subjects like reading, writing and math must follow the normal demands of the school, adjusted to the abilities of the child, while the ability to cope with life as a child and later as a grownup always will be the most important subject for a moderately to severely retarded child.

Special School or Normal School?

When the child is in-between lightly and severely retarded, it can be hard to choose the best kind of school. Some parents find it humiliating to send their child to a special school. But the parents should consider the heavy mobbing of “stupid” kids in the normal schools, where your child quickly becomes a victim not a student. A special school will almost always be the best choice, if the child cannot come to grips with the school. And you will be surprised how much your child can learn when placed in inspiring and safe surroundings suited for children with lack of social and practical skills.

Normal School with Special Classes

If the child is up to the elementary demands of the normal school, it should – of course – stay there. The child should, however, receive special education in challenging subjects like reading, writing and math. The lightly retarded children normally do well in practical subjects. The teacher should always try to visualize and explain everything very clearly. The education should have more pauses than normal – this will also be a benefice to the “normal” students.

PLEASE NOTE Retarded children, as a rule, cannot understand abstract language.

Make sure that the retarded children have understood the basic part of the subject. Always repeat the points at least 5-10 times to enable the child to understand them. Never scold the child but take it serious and praise him/her when the child finally has understood what you told the other kids one hour ago.

You might use a mobile phone with Dictaphone or a tape recorder to record the teaching. The child can then take the recording home and let daddy and mommy help.

If there are especially gifted students in the class, it should be considered to let these highly intelligent kids help their retarded classmates learning to read and write. This would be an advantage for the retarded kids as well as “professors” – who are often mercilessly teased due to their intelligence – giving both of them a little more prestige in the class.

It is necessary to have dedicated special classes to the difficult subjects. If the children have for example ADHD or Asperger’s syndrome, they should be in the special class most of the day.

The premises (rooms) of the special class must be organized to let the children sit in small groups, a little isolated to avoid mutual distraction between the groups.

The behaviour of the children must be surveyed and interpreted by the school psychologist. If (when) there are major problems, the parents and the special doctor of the child must be called for immediately. The school does not have the necessary resources to solve a retarded child’s behavioural problems, as they can be caused, not only by the retardation, but by ADHD, early deprivation or other side diseases.

Daily Life in the Special School

In the morning, your child will be driven to school by the school bus. In the special school, things are almost like in a normal school, but the special needs of the children are taken care of all the time. The classes are small with teachers, pedagogues and helpers. Most of the special schools have the school and youth centre in the same building to integrate the teaching and playing in one place. The teachers, pedagogues and helpers do their best to change the life of handicapped children, and the normal school could learn a lot from these enthusiastic and patient professionals who have dedicated their lives to special kids– our kids!

2. Light Retardation

The border between "normal" and lightly retarded can be fluent. A "normal" child understands a sentence and keeps on talking. A lightly retarded child, however, does not always understand the sentence but pretends to do in order to avoid being laughed at. As the content of the sentence is the basis of the whole conversation, the lightly retarded child is now mentally offline. And nobody notices, as it is hard – even for professionals – to see if a lightly retarded person has understood what has been said.

The closer the child is to a "normal" child, the harder it is to help it without making him/her look like a fool to the other kids. When the retardation comes closer to moderate retardation, nobody's in doubt. It is in the grey zone between these two states that the school and the home must learn to navigate, helping the child without making it look "stupid and odd". It is really difficult, but can be done.

At Home

Parents of small children with retardation has an acute need of help. They feel isolated and misunderstood, as family and friends keep telling them all the time that their child will soon be "normal".

To proceed, the parents have to take the destiny of their child in their own hands with the help of experts in handicapped children. Depending on the mental level of the child and the economy of the family, they could for example try:

- To frequently meet with other handicap parents in parent / child groups.
- To work with the social behaviour of the child.
- To have an experienced, paid consultant supervise the child a couple of hours a week to work out an effective pedagogy that suits the needs and capability of the child.
- To set up a number of main and part objectives including deadlines.

Unless the child is severely retarded, the family should use the local kindergarten to train the child in being together with other kids before starting in the school / special school.

The School

Especially for teachers / pedagogues: All children with retardation have different problems. Therefore you must make yourself fairly acquainted with the specific problems, gifts and shortcomings of the child in question. Read the diagnosis and all the documentation on the child, you are allowed to read by the authorities. The more you know the background of the child, the easier it will be to anticipate and handle the odd social situations and conflicts.

All experienced teachers know the weak and strong sides of retarded children. Therefore it is important that young teachers coming directly from the training college should have one of old teachers as a mentor, before they start teaching

special classes. It is of course less expensive for the school to let the young teachers start head on, but eventually this will create a lot of problems for the kids and the young teacher who risks overreacting in desperation over these “hopeless” kids who don’t understand anything! 1-2 weeks of supervision with an experienced teacher can save the school a lot of turbulence not only among the retarded children but also in the whole class. Inadequate education of weak students unintentionally turns them into scapegoats for the “normal” children. And of course easy victims of harassment, as they cannot defend themselves intellectually.

What is the Background of the Child?

For a start, the special teacher must make a throughout investigation into the history of the child, weak sides – and strong sides. It is just as important to know what the child’s weaknesses and strong points are. Here are some typical challenges for lightly retarded kids:

Weak Sides

Cannot understand abstract ideas and complicated language with foreign words. Cannot understand when the teacher speaks very fast or addresses the whole class. Cannot read what is written on the blackboard.

Takes everything literally. Has very little awareness of other people’s feelings (lack of empathy). Clumsy and unpredictable in social situations.

Has great difficulties in learning “simple” things. Is better at learning by heart than understanding the contents.

Can be very aggressive if teased or if they feel socially isolated. Do not understand irony and take jokes literally, sometimes leading to violence.

Strong Sides

To the teachers and pedagogues: See the next chapter “Moderate Retardation” to read a couple of good advices for teaching retarded children. Many of the methods in the next chapter are also useful for lightly retarded kids.

In general, retarded children are straightforward and happy. They have a light view on life and are take things as they come. If you are able to coordinate it well, the joy and enthusiasm of the retarded kids will come off on the other kids in the class.

Most retarded children have one or more points, where they are better than their “normal” schoolmates. Typical strong points are playing music, being small geniuses on the computer or being good at cooking food. Use the strong sides of the retarded kids to improve their image and strengthen the bonds between the retarded and the normal children.

Life as a Lightly Retarded Child

Work?

In Western Europe, that is no longer a tradition of sending retarded adults out on the open labour market. The old industries with simple physical work tasks that didn't require reading or mathematic skills, thus being suited for retarded people, have almost disappeared. The very few remaining physical jobs all require special knowledge and that the employee can work independently, which are both unlike to find with retarded grownups.

What is left is the traditional jobs for retarded persons, disability retired patients, addicts and other minority groups with various problems. The jobs are normally within:

- Open workshops and farming
- Sheltered workshops

Both job types are based on financial support from the government or the local community. The open workshops are by probably the best offer for well functioning lightly retarded persons, but almost all retarded people will feel at home in the many group homes and sheltered workshops. In other words, there are a lot of relatively good work for the retarded grownups, but of course the work is offered at the mercy of the politicians, not as normal "on demand" jobs.

A Normal Life?

What is a "normal" life? Many lightly retarded persons can live a life as a disability retired patient almost without problems, but as soon as the retardation becomes more severe, more and more help is needed from the authorities. At the border of moderate retardation, a sheltered accommodation is necessary.

Seemingly, it is very easy to get a place to live and a paid job . But this is make-belief only. Actually, it can be hard work to secure a flat for a handicapped person with visible retardation.

IMPORTANT Contact the local handicap centre while your child is as young as 10-.12 years old, to plan for a future home for your kid. This is not only wise but also absolutely necessary.

Besides securing the home, the parents must plan for a new life with the child visiting in the week and on vacations. Long term planning including the death of one of the parents must be made. Young parents are as we all know immortal, but this unfortunately doesn't apply to old parents.

Sexuality

Like any other living species, humans – *including handicapped humans* – are born with a sexuality. You cannot separate sexuality from the other parts of a person's physical and mental state, as the behaviour and urges of man comes from many sources, not least sexuality.

Retarded Kids and Sex

If you are retarded, you will need help from your parents to understand what sex is:

- You often have problems with other kids, and you have difficulties in social relationships. Before you can even think of dating a girl / boy, you must learn to understand the feelings of your future partner. He/she maybe sees the world quite differently than you.
- You must learn to control your problems with being close to another person or being touched by a “stranger”. That takes a lot of control and a lot of preparation.
- As you are retarded you must learn everything slowly and in small portions.

Ask your parents to make role-plays of meeting a boy / girl. Look what other people are doing when they kiss or walk hand in hand. They are not strangers anymore, they are friends. What is a real friend?

The section on sexuality is an edited excerpt from the book “Sex – An Apology for Love” by Tom Carter-Smith released on Digital Books™, 2004. The text has been reproduced with the permission from the publishing house and the author. www.nordisc-mental-aid.com.

Problems

If you think that all your problems are over when your child has a home of his/her own and a job in a sheltered accommodation, you are slightly overoptimistic.

The advantage of light retardation is an almost ”normal” life. But freedom and independence have their price, especially when you are naïve as all retarded people are.

Bad company, violence, abuse of all kinds and babies - oh yes, I said babies – because the existence and use of condoms are unknown to your child. Or he/she simply forgets them. Here is a row of serious problems for lightly retarded adults. The moderately and severely retarded persons do not have these problems as they are always surrounded by support personnel.

Father, Mother and Baby

Not long ago, retarded parents were locked up and castrated if they had children. Many retarded women spent their whole life in an asylum due to committing the unspeakable crime of having a child. This is only 30 years ago, but most of us have already forgotten ☹.

- Today, retarded persons have the right to have children. But can they fulfill the obligations of being parents?
- It is very difficult to judge the future of a retarded couple from their IQ and diagnoses alone. But social problems – many retarded mothers are alone – and a chaotic childhood is foreseeable.
- Another delicate question is the fear of having a child with early deprivation. The care of the mother is reduced by her lack of empathy and not understanding the needs of the child. A “normal” childhood may not be possible and the child risks forcible removal to avoid the terrible mental disorder “early deprivation” (severe attachment disorder due to lack of care). The disorder is incurable and ruins the life of the child.

Today, arguments for denying retarded persons with an IQ below 55 for example to have children is hard to find. But this is not a question for the author to answer. What would I do, if our boy became a father ten years from now? I have no idea!

Drugs

A small but visible group of retarded adults has problems with especially alcohol and light drugs. The parents must go all the way to stop these abuse problems. You cannot let your child down by ignoring these serious problems.

Crime

Strange as it sounds, more than a few retarded grownups actually commit various types of crimes ranging from shoplifting to sexual abuse of small girls in the street. They get tempted by sweets in the supermarket, small girls in the street or in other situations where the lack of impulse control and common sense lead to acts, they cannot hold back. If criminal incidents occur, you must contact the local police to agree on the some sensible measures to avoid that your child breaks the law again. Major crimes committed by retarded people are rare, but what if your child committed one?

3. Moderate Retardation

Many people only know of lightly retarded children. Consequently, they believe that all retarded persons are really normal, but slightly “behind”. Most people remember the pictures of retarded contestants from the Handicap Olympics, happy faces from ecological farms and the sweet looking girl sitting with her boyfriend spelling the headlines in the paper. That’s all very positive and correct. But it doesn’t remotely look like the ways of my moderately retarded son (the degree “moderate” is an obvious misnomer).

In this chapter, I will draw on my experiences with my own child, who at the time of writing is 10½ years old. He is a lovely child, our light and joy. But he is certainly not “normal” now and never will.

At Home

The practical circumstances around the moderately retarded child’s first year are about the same as for the lightly retarded children. Please see the section “At Home” in the previous chapter.

In the case of moderate retardation, there is no doubt about the seriousness of the problem. Shortly after the birth, problems of all sorts appear in the small child. Most moderately retarded children have a series of comorbid (side effects) illnesses, and my son has six serious disorders and syndromes. But even without these disorders, a child who is so deeply retarded will be affected by a long row of other specific problems caused by the malfunctioning brain during its first 4-5 years. These problems are so numerous and complicated that it would take 2-3 books to describe them shortly.

See a row of examples later in chapter “Severe Retardation”.

Parents of a moderately retarded child must prepare for a huge task. But a huge task, which has its own reward in the happiness beaming from the child. The love of your child grows love and in love the problems give way to joy and trust. The joy and trust that will carry you through the life with a severely disabled child.

What the Child cannot do

There are many things your child cannot do. We have now unmasked the false hope, and we walk the road together, the bitter road all handicap parents share. Here is the real world.

No Self-awareness

Your child does not know himself; he doesn’t even know he is a human being. He is a name, a touch, the taste and feel of food, the hot water in the bath, mother’s embrace, the strap in the school bus, the smell of the classroom, all the confusing sensory impressions he receives during a long day. But he is not an idea, the idea of a human being. He is an open book for the world to write in, immediately erasing his transient memory, leaving the boy in the dark.

He is a presence, a constant wonder – who am I? Where am I?

Where is my Hand?

The boy sits in the bathtub looking around him, surprised: "Where is my hand?" he asks. His hand is covered with water and he cannot see it. And if you cannot see something, something does not exist.

We ride on the bicycles. Father and son ride behind mother. With his eyes sharply watching his mother's neck, the boy asks: "Where is mommy?" If you cannot see mother's face, mother does not exist.

Mother goes to the kitchen. "Where is mommy?" asks the boy. If you cannot see mother, mother does not exist.

Are you my Mommy?

"Are you my mommy?" asks the boy. Again and again. It's so obvious that it hurts. We feel like screaming: "Here's mommy – she's right here!" But the boy does not know whether my wife is his mother. He doesn't know who he is himself. He doesn't know who his mother and father are.

Frustration

Often the existential disbelief of the boy turns into frustration. And the frustration turns into a furious anger. He strikes us hard, beats, kicks and throws his little fist at us. He's so insecure, so confused. Who am I? Where am I? Do I live here? Are you my daddy?

All answers are received with a big smile and forgotten one second later. Now it is our turn to be frustrated. But we are big and grownups and able to handle this situation. And if we can't, too bad for us, because we will *HAVE* to handle it.

What the Child can do

If the great confusion is painful and exhausting, the relief comes from the things our child actually *can* do. In spite of the serious emotional harm done to him by his biological mother, the little boy has so many feelings and longings within him. When he finally embraces us and we feel his little hand caressing his parents, much too old as we are, we are dizzy with happiness. He means it; he loves us for real. We believe. We hope. We know.

Feelings

Embracing us, when he awakes. Blazing smiles when we meet after a long school day. Hopeless tears for hours when mommy travels abroad. Senseless happiness, when he sees mommy's face in the doorway one week later. Feelings we thought we should never see. The joy we thought was gone forever, obscured by the problems and the fear. The trying love, the timid attachment. The Light.

Music

Our boy has a great talent better than his age, music. He sings all the old children's songs with a beautiful, clear voice, and the latest pop hits. This is *his* gift, the gift each moderately retarded children have: Each child his gift, often music or computer. Our boy is fairly good on the computer, too.

Daily Activities

Clothing, Eating, Going to the Bathroom

We use a lot of energy on teaching him all the ordinary things that “normal” kids just do. But this is a necessary part of his lifelong education in being a “normal” person.

Slow Learner – and so what?

A moderately retarded child is not only a slow learner, he is EXTREMELY slow. Our boy finally learned to spell “dad” and “mom”. We went mad with joy. It is now three years ago, and even if he makes the occasional small progress, it goes terribly slow. He can spell single part words, but he cannot really read. A boy that cannot sense himself cannot read because a text is a total of single words, and he’s not good at totals, he prefers the details.

Calculation is always learned by heart. He cannot count, and he will never be able to learn. Gymnastics and music is primarily therapeutic. Art is popular in the class, but our boy prefers photographs. Advanced disciplines like reading aloud are carried out by the teachers, the children cannot do it. But all the kids love to listen to stories.

And the children are actually taught all the subjects found in “normal” schools. It’s rather amazing that it is possible. Just watch the special teachers and pedagogues do their magic 😊 !

The School

Excluding the special problems around e.g. autism or early deprivation, you can set up a few checklists, which contains the essence of teaching retarded children, who are capable of being taught. Most retarded kids are!

<i>To the parents</i> Please read along with the teachers – the checklists are valid at home too!

Checklists to the Teachers and Pedagogues

Here are a couple of checklists:

From - to

- From simple to complex.
- From unknown to known.
- From concrete to abstract.
- From part to whole.

Activities during the Day

- Morning meeting, meals, breaks.
- Change in activity: Preparing, understanding.
- Developing the behaviour: Learn by playing with other kids.
- Group plays: Role-plays.
- Art: Music, theatre, visual art.
- Body-consciousness: Physiotherapy, gymnastics, sport, dance.

Learning Strategies

- Learning: Repeats, again and again.
- Preserve what we have learned / experienced.
- Analyses of tasks.
- Form: Is it the right form? Do the children understand the contents?
- Instructions to the children – active help and conscious moving back.
- Intensify the development.
- Role models: Class mates.
- Yearly events: Birthdays, Christmas, Easter, summer and other holidays.

Therapeutic Methods

Music Therapy

Baby rhythmic is a well-known technique nowadays, but music therapy for retarded children is still not that common. Through playing and listening to music, the children can develop their senses and consciousness by using a channel, music, that reaches the parts that thoughts and emotions cannot reach. The “healing” power of music has never been scientifically proved but is a happy side effect of a lovely time with singing and playing.

Physiotherapy

Physiotherapy is an area that is economically neglected in many special schools. The children really need to learn the whereabouts of their body. If the money to the physiotherapists dries out, the retarded will be deprived of an excellent tool for developing the body, i.e. developing the mind.

The harder the children are hit by comorbid illnesses as spasticity, blindness, deafness etc., the more important it is to provide physical therapies. Motor dysfunctions are the gravest problem. See the section on motor dysfunctions in the next chapter “Severe Retardation”. Many of these dysfunctions can be found in moderately retarded children as well.

Light Therapy

Light Therapy is known from the so-called winter depressions, which are cured by means of special lamps. Light Therapy has a great effect on retarded children in connection with the “invisible” depressions”, troubling many handicapped persons. The therapy must be carried out by a medically trained specialist/doctor.

Water Therapy

Water Therapy is one of the oldest medical remedies in the world known from healthy mineral water, the saunas of the shamans or the cold showers of the 1950'ies. Retarded children love to bath and swim. Bathing in hot or cold water relaxes the muscles and dampens the agitation. Swimming strengthens the muscles and the lungs. A hot bath before the child goes to sleep is wonderful and healthy

Life as a Moderately Retarded Child

Work?

All grownups with moderate retardation either live in a sheltered accommodation or with their parents. They cannot be alone. Only a few have the resources for a work carrying out very simple jobs on a sheltered workshops. But it is always good to have social contact with other retarded adults.

Health Problems

The lifetime of retarded people is now almost the same as for “normal” people. This means that the authorities suddenly realise that many retarded adults are extremely overweight – or the opposite. Neither condition is especially healthy. Smoking and drinking among retarded persons are an increasing problem after the close down of thousands of psychiatric departments in favour of local sheltered accommodations without decent medical surveillance.

The lack of exercise and workout is a major problem contributing to the increasing numbers of deaths due to malign (severe) stomach illnesses. Many older retarded persons eat no fruit or vegetables, leading to a generally bad physical condition.

When a retarded grownup visits the special doctor, he/she should be accompanied by a family member to make sure that the retarded person understands what the doctor tells him and to help buying correct medicine.

Talking of medicine: The medication is often too heavy and advice from psychiatrists with expertise in special medicine is generally needed to reduce over medication and serious side effects.

Dementia

Older retarded persons frequently develops dementia and Alzheimer, especially if they have Down’s syndrome. Recently, it has been discovered that the risk of dementia and Alzheimer is significantly reduced if the retarded person has a good social life with many excursions and daily contact with other retarded persons and the family. Daily exercises and workout is also important to keep the mental health. This is another good argument for strengthening the social life and the workout in the group homes!

Violence

Retarded persons have a partly undeserved reputation for being violent. Usually the violence does have a reason; it could for example be a conflict where the retarded person reacts in despair when the pedagogue won’t allow him to watch television after bedtime. He reacts exactly like a little child, and it would be wise of the staff to realise that a moderately retarded person is not “just as” a little child – they *are* small 7 year olds kids mentally. If you imagine the person as a little child, it is much easier to avoid violent episodes.

Unfortunately, many young pedagogues take the violent episodes with the patients very personal. As they have never learned to work with handicapped people during their time at the training college, they can’t handle the retarded adults lack of social sense of occasion. They sincerely believe the violence was a personal attack. In the worst case, the pedagogue sees the violent retarded person as an en-

emy and treats him/her badly and arrogantly, which in turn can produce violence in itself, a literal catch 22.

An even worse way delusion is that the retarded person *planned* the violence. As the retarded person cannot plan beforehand this is an unethical (and silly) way of thinking. The retarded person reacts impulsively, and if you are just a little smart, you can dampen down the episode in seconds by distracting the angry person with an alternative pleasure or by sitting down with him quietly to talk about what has happened. You must *never* yell or use *fast movements* with your hands. Otherwise you've asked for it...

If the patient has ADHD, the possibility of impulsive violence is obvious. You should learn to foresee potentially violent situations and how to distract/stop them. See the author's book "Caring for a child with ADHD" in the literature list in the back of this book for general advice on these situations.

4. Severe Retardation

On the border between moderate and severe/deep retardation, the last layer of a human being's unique intelligence, the language, disappears. The child is now pure being. The longer down the IQ scale the child comes, the more abilities and organs it loses. At the bottom of the scale, the child cannot move, cannot eat, cannot hear, cannot see. The little child lives, but he/she is already with God or in the Eternity, depending on your religion.

At Home

The love of your child never dies out. I talked to the mother of a deeply retarded child at a special school. She was heartbroken – her son used to smile at her when she bathed him in the swimming-bath. Now he was completely unresponsive and loose. Her face was dark with sorrow.

But maybe there is a hope. Some severely retarded children do learn to walk as grownups, and might understand a little bit of what is being said. Maybe they can even eat themselves. There is always hope.

The emotions are the last sense to disappear. It is the mammals' inner core separating us from more primitive animals; our mutual feelings. Small glimpses of life still flash in the dark, which seems to enclose the child. My son sits down stubbornly refusing to take his medicine at the school. A little boy sits beside him in a wheelchair, his head on one side and upturned eyes. Finally, we succeed in tricking my kid to take the pills. Everybody smiles. Suddenly the little deeply retarded boy starts clapping his hands and laughing. Everybody hold their breath in surprise – most of the pedagogues had never heard him utter a sound before. There is always hope.

The Special School / The Institution

Physiotherapy

Most of the mental and motor dysfunctions with retarded children are due to deficits in the central nervous system. It can be both inborn and induced deficits. Lack of muscle control, bad balance and coordination of the limbs are but a few of the many deficits that may reside in the body and mind of the child.

What the Child cannot do

Hypotonia (weakened muscle tension), *hypertonia* (spasticity), *cramps*, *epileptic seizures*, *hydrocephalus* (water in the head), *hyperkinesia* (hyperactivity), *stereotype movements* with the hands, *involuntary movements of the tongue*, *drooling*. *Delayed growth of the bones*, *hyper-flexible joints*, *deform hands and feet*.

Heart/lung problems delay the motor development. *Pneumonia*, *hyperventilation* and *sleep-apnea* all radically reduce the life quality of the child.

What the Child can do

In the case of Down's syndrome, you can strengthen the child by neutralizing the decomposition of the muscles (see the special literature on Down's syndrome). By severe retardation, you should strengthen the flexibility of the child's body to avoid stiff and malformed limbs.

The motor development is influenced by and influences the mental abilities of the child. To be able to walk yourself strengthens the *social abilities*, the spatial senses and the *emotions*. Research has indicated that the development of self-awareness is intimately related to being able to walk.

The use of a wheelchair or a rollator can successfully replace physical walking if the legs of the child don't have the sufficient strength. The physiotherapists say that the child should start using these remedies at a very early state.

The child should not lay down more than absolutely necessary, as the upright position strengthens the child's ability of interacting with the surroundings.

Life as a Severely Retarded Child

All severely retarded children eventually come to live in sheltered accommodations as adults. There will be looked after them and the parents can visit them as often as they like, taking them home for weekends and vacations. Just like the parents with moderately retarded children.

5. Support

Caring can be many things. It can be the responsibility of looking for a job, the responsibility of developing new ideas or the responsibility of minding a retarded person. This person might be your own child or a child in your special kindergarten. No matter if you are a parent or you get paid for minding a person, you render your *support* to the retarded person. And support – responsibility and love – is what this chapter is all about.

Support – a Lifelong Project

Through a careful strategic support you can come a long way even with moderately retarded kids. Clothing, eating, bathing, confidence and friends are but a few of the small victories the retarded person can enjoy with the help of his/her supporting friends. Here are a number of examples:

Human Development

- ❑ Support the development of general and fine motor skills through various exercises with hands and feet. Use toys or balls. Start with the general skills and proceed with fine motor skills.
- ❑ Play with the words – without using foreign words or abstract language – and let the retarded kids fly into new exciting worlds. Use pictures, sounds and role-plays to learn about the things that surround us, to develop the fantasy. Use Paddington, Peter Pan, Alice in Wonderland, Hans Christian Andersen – all the great, funny and different storytellers, preferably with good illustrations to talk about and point to.
- ❑ Meet and play with other people – normal or retarded – in safe surroundings. Rehearse the difficult art of being sociable and thinking of others. It is not that easy.

Education

- ❑ Use the computer and the Internet to play with word and things, colours and form. Train colours, words and forms.
- ❑ Look at signs and spell the road names. Read the newspaper headlines and look at the photographs. Read (good) comic strips. Why can the dog speak? Can real dogs speak? “Head-master’s street” – do you know anybody who lives in Head Master’s Street? Do you live in Head Master’s Street? Do you live in Foot Master’s Street? Don’t forget to speak slowly, quietly and clearly without overdoing it. Learn to laugh without letting the common laughter turn into aggression (this is *not* easy!)
- ❑ Play grocer’s shop and learn to pay. Play the captain of the pirate ship – or the little, sneaky pirate who shoots all the good guys. But then they all have a pill and get well again. And the little, sneaky pirate becomes a nice doll again. Learn empathy.
- ❑ Use the methods of the school at home. Read the contact book and talk to the teachers and pedagogues more than once a week to make sure you know what they are doing in the school. Do the same activities at home.

Cleanliness and Food

- ❑ *Learn to go to the bathroom on you own.* Remember to wipe your hands in the towel. And remember to turn off the light. That was good – you could do it!
- ❑ *Learn to put on your clothes.* First you must take off the pyjamas. It's a little difficult to take the pyjamas off, I'll help you. Then you must put on the under-pants and shirt. That's a little difficult, too. Now you must put on the trousers – and the slippers – you can do that all by yourself! That was fine, now mommy must see it!
- ❑ *Learn to eat.* Watch out, the food is a little hot! Blow on it – wait a while until it has become colder. Now we cut the meat into small pieces. Be careful – the food shouldn't fall on the carpet. That was the beef – now it's ready to eat for big boys. Do you want ketchup? You can pour the ketchup yourself, but be careful. My! You have already finished your plate? You are very clever!

Mission Impossible Before the reader starts laughing at the silly tone of the author please think about, whom I am talking to. It could be a big boy, physically 16 years old, but mentally only 5. All handicapped children should be praised all the time, the wilder the better. And everything should be explained as simple as possible – a “normal” kid would run away screaming after 2 minutes. A moderately retarded child begins to get to the point after 10 min.

Much of the meaning is conveyed in the way I speak to the boy. I am calm and slow with an almost monotonous, kind, clear voice, insisting but without making the boy nervous. Neutral but firm in the intention of carrying a task through that might be impossible under other circumstances, in another tone.

Outside the Home

- ❑ *Learn to drive by bus or in trains.* Sit with the child by the window. Get used to everybody smiling sheepishly, shaking the head or scolds you for talking down to your child. If you are really “lucky”, they will call the police (yes, I have tried it all!). When you have learned to ignore those who hate handicapped children, you can count bus stops and other bus lines. Is that a number 5? And number 2? There are many number 5 busses today! Should we count the busses with the fingers? Let the child pay the ticket. And press the stop button.
- ❑ *Teach the child to play “normal”.* Walking down the street without being “funny”. Not talking to anybody you meet, when we are on a big, dangerous road.
- ❑ *Learn the traffic rules* for bicycles and pedestrians, red light / green light and turning to the right / left (with the hand).

Healthy Food and other Healthy Ideas

- ❑ *Eat healthy and nurturing food with many vegetables, pasta, rice or potatoes and a little meat.* Drink lots of clean tap water. Avoid soft drinks and milk which both happen to be unhealthy (milk? Oh yes, you didn't know, but many kids get ADHD like symptoms by drinking milk). Avoid chips and sweets. Eat fruit six times a day.

- ❑ *Workout is very important.* Run for 1/2 hour with the retarded child or take 1 hour on the 2-wheeled bike or the tandem bike. That should be enough for 1 day, but of course it doesn't hurt to include an afternoon run while you are both in the mood.
- ❑ *Play football and basketball* to get rid of the aggressions.

Family and Friends

- ❑ *Learn to be social.* Why should we always talk to people I don't know? Why must I sit at the table while we eat? I want to go home! But look now see what the other kids are up to! Do you want to join the fun?
- ❑ *Play with your cousins.* Tell the cousins that the child is very good at playing on the computer, although he's not so bright as they are. Sit beside the children while they play (if you leave them alone, the 1st World War will start while you are on the toilet).
- ❑ *Invite the schoolmates home.* Tell the child that the schoolmate may play with the cars. And tell the schoolmate that he should not throw the cars at your child. Prepare some fruit and juice and talk with the father and/or mother of the schoolmate, while the children play. Don't let the children out of sight while you talk. Trust is fine, but two happy kids without bruises and juice all over are better.
- ❑ *Teach the child to help other people.* Let him/her help clear away the table. Remember, only 1-2 desks at a time, unless you want to renew your chinaware! Divide the work in small steps: first the desks, then knives and forks, then glasses – one at a time.
- ❑ *Learn from other parents.* Get new friends with handicapped children. Let the children play together, watch them and learn. Discuss with the parents and share your experiences.

At home with Mommy and Daddy

It is very important to create fixed structures in the home, especially around breakfast and dinner. But the fixed structures including the bath in the evening and the activities in the weekend and on holidays must always be predictable. The child needs to have a small world to develop through minimizing the unrest caused by unstructured surrounds

Morning

Wake up the child at the same time every day, including the weekends and during vacations.

Evening

Home from the School

- ✂ When the child returns from school, he/she should sit quietly playing a computer game or watching a (peaceful) video before dinner.
- ✂ Make a plate with fruits like oranges, apples, bananas or cucumbers, carrots for the kid to eat before dinner. Avoid chips and sweets, which may agitate the child.

Prepare for Bedtime in Advance

✂ Explain to your child *"now we eat, we watch some TV, then we bath and then you we go to bed and sleep "*. Do not use the normal *"you must go to bed at 8 o'clock"*. As the child has little sense of time, 8 o'clock means NOW or in two weeks time in the child's head. Stick to the concrete list of activities before the child goes to sleep. A retarded child likes it that way and feel much safer through having a firmly structured bedtime schedule.

Bath

✂ The bath should be a quiet moment together with the child. If possible, it should be only mother and child, i.e. only two persons, in order to slowly lower the tempo of the child. After the bath, which could be 1/2 hour or more, the child is wrapped in a soft, warm bathrobe and on its way to bed, calm and relaxed. The change from the bath to the bed should be carried out slowly and softly.

Bedside Story and Sleep

When the child has been dressed for the night, it could be time for a bedside story, a little relaxing classical music (known to the child!) or playing with the Gameboy. Take your time, but keep the deadline: the fixed sleeping time. You may have to ask the child, gently and neutrally: *"Now put your head on the pillow and turn off the Gameboy, now mother wants you to sleep. Tomorrow the school bus will come and both you and mother are both tired."* Use concrete words only and shortly explain the reasons behind your "order".

Make sure that there is a pilot light or a garland of soft lights in the child's room, so that the child will not be afraid of "lions" in the dark corners.

Normal Brothers and Sisters

✂ If the child has "normal" brothers and sisters, it is a good idea that the parents occasionally split up, one taking care of the retarded child and the other taking care of the "normal" child/children.

The Relief Institution

Even if it can be a source of both sorrow and bad consciousness to the parents, you **must** send the child for a relief institution once a week. It's normally the local municipal authorities that are supposed to pay, and sometimes they decide **not** to pay. And even if they do, there might not be **room** in the institution. This is all very strenuous. And when the kid finally comes home after a night where you couldn't sleep for worries about your child, he says: "Why didn't you come and pick me up at school? Do I still live here?" Cheer up, it can be much worse ☺ But you get used to be the wicked parents. Surviving the rainy days in spite of the everlasting pressure and the endless worries. No handicap family can live without a regular relief arrangement.

Weekend

✂ Make a plan for Saturday and Sunday, for example: **Saturday** mother and the child go shopping in the supermarket. Then we make lunch (father is the cook), and in the afternoon father and son/daughter go to the playground. Meanwhile, mother prepares the dinner. When you have eaten, it's television time until 8 o'clock. That is, if the child is interested in television – some retarded kids are

not, bad luck! At last, mother takes the child to the bath and put it to bed. **Sunday** repeats Saturday with the shopping replaced by a long bicycle ride with both mother and father. The playground is replaced with a visit to the library, where we read good books that catch the interest of the child.

Vacation

✂ Vacations should be planned in all details well ahead. The child must hear all the details many times. If the child can read, make a laminated sheet with all the vacation details, preferably with a photo of the place where the vacation takes place.

Restrict your vacation (abroad) to once a year, and always to the same place. This guarantees a peaceful, happy child who thrives both at home and on vacation.

Responsibilities of the School / Institution

Education of Retarded Children

- ✂ Use the strong side of the child in the education.
- ✂ Be concrete and literal. Show the child what you want with the hands and mimics. Use pictures rather than words. Let the child try itself – it works better than long explanations.
- ✂ Divide long sequences into smaller steps. Let the student carry out one step at a time.
- ✂ Use **sign-to-speech** to autistic children without language. Other children with an insufficient language may also benefit of the sign-to-speech language.
- ✂ Praise the kid and tell him/her why you are praising him/her. Don't get sentimental; retarded kids are very musical and they can hear even the false notes you cannot hear yourself, be careful!
- ✂ Train the child in correct social behaviour without lifting a finger or moralizing directly or indirectly. Simply correct the child and tell it: "that's how to do it – now we rehearse it, until we can do it."

Practical Advice

- ✂ Most retarded children benefit from pictograms showing what to do during the day. For example a picture of a schoolbag, a bus, the school, a lunchbox, the youth centre, a child who plays, the bus again and finally a picture of mother hugging the baby in the doorway.
- ✂ Be concrete in your language. Avoid abstract notions. Irony is totally forbidden and results in an immediate, violent conflict.
- ✂ All persons who are in touch with the child must have a basic knowledge of retardation and the "12 most important rules". See later in this chapter.
- ✂ Don't scold the child and avoid power struggles with the child. This could lead to conflicts. Use distractions instead, a motivation activity, that the child likes.

<p>REMEMBER The strategies used by the special teachers in the school should also be used at home – the school and the home is one coherent system.</p>
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The ABC Model

The ABC model stands for **A**ntecedent **B**ehaviour **C**onsequences. The method is used to explain “bad” behaviour.

Antecedent

An analysis of the child’s reason to go berserk.

- ✂ When do the problems usually arise? When the teacher hasn’t got the time for the “annoying” child? During the lunch break?
- ✂ Does the problem come when another child is teasing him? Does it always happen at the same place? Is it always on the playground or in the hall? Or at home?

Behaviour

What happens when the child starts reacting?

- ✂ How often does the inappropriate behaviour occur?
- ✂ How often does each fit take?

Consequences

What happens after the unfortunate incidence?

- ✂ How do the children and grownups around the maladjusted child react after the episode?
- ✂ How does the episode affect the child itself and the other children and grownups?
- ✂ Does the child get anything ”positive” out of its behaviour?

Various Instinctive Strategies of the Child

- ❑ *Looking for attention.* Everyone wants to receive attention. And if they can’t get it by following the rules, bad attention is better than no attention.

Is the reason for the child’s bad behaviour that it wants to have contact with the teacher?

- ❑ *Self-stimulation.* Especially retarded autists begin rocking and socking the thumb, when they are bored.

Should the child be activated – or calmed down with a quiet activity?

- ❑ *Escape.* If the child don’t want to go to school or is confronted with a task beyond its unable to perform, the child sometimes resorts to weeping to escape the unwanted activity.

The weeping must be stopped immediately: “This is just nonsense, you already come hone from school at 5 o’clock!” It’s an easy task for you, I will help you!”

- ❑ *Lack of social understanding.* The child wants something from a schoolmate and takes it without asking.

The child must be trained through small role-plays, preferably with dolls or through exciting stories about a child who tries to steal from another child. The

story must end well, and the children become friends again. Otherwise you are back again where you started.

Morning Meeting / First Lesson

The first lesson can be a trial both to the child, the other kids, and the teachers / pedagogues. The child will always be nervous due to the many kids and the change from the bus to the school.

Avoid Noisy or Unknown Surroundings

If the surroundings are very noisy or new to the child, you must pay special attention to the anxiety provoking effect that may have on the child.

Motivation

Motivation is the Message

✂ All retarded children are turned on by a goal / a reward. If this inner motivation is present, the child will thrive. But motivating the child is a question of knowing the interests and gifts of the child. So carefully plan your activities with the child to involve his special talent(s) in order to support the learning process and the self-esteem of the child.

Misunderstandings

There are many – too many – silly misunderstandings around retarded children. Here are a few:

”Retarded persons cannot have a psychical disease”: Retarded persons, especially moderately retarded persons, are more vulnerable to psychical diseases than normally gifted persons.

”Retarded persons have no feelings. They are like vegetables”. All retarded people have intense feelings. The intellectual expression they lack is replaced by strong emotional eruptions. Retarded people are happy, in love, sad and afraid like any other person.

”Retarded can be moved around as one wishes. They don’t care where they are. All handicapped are extremely sensitive to any kind of change; new rooms, new pedagogos, new meeting hours, new furniture etc. Changes are always an important source of unrest and problems.

The 12 Most Important Rules

- 1** Remember that a retarded child's "stupidity" and odd behaviour are due to an incurable inborn brain damage.
- 2** Be one step ahead of the child. Learn to understand the child's way of thinking.
- 3** Conflicts can only be stopped by motivating the child into an exciting or funny activity.
- 4** Common sense and reprimands do not work on a the socially unacceptable behaviour of a retarded barn.
- 5** Prepare the child for the activities of the day. Unforeseen changes in the activities of the child are a source of anxiety and stress.
- 6** Never give a negative order like: "*You mustn't do that*". Instead, use a positive and concrete argument: "*If you play with the car on the television, the television can be damaged*".
- 7** Do not start arguing with the child when the difficult conflicts arrive. Digressions are the only things that work.
- 8** Always praise the child, when he/she has been clever, carried out a task well or just did what you told him/her to do. A retarded child can *never* have too much praise.
- 9** If the child has behaviour problems, punishment never works. Although the child – sometimes – actually *does* understand the connection between action and punishment, he/she is unable to stop the bad behaviour. Punishment of mentally handicapped children is a regular cruelty to the child.
- 10** Safe surroundings are the main factor in stopping conflicts. The child needs peace and predictability and fixed routines, day after day, even in the weekend and on holidays.
- 11** Strictly adhere to the fixed bedtime and the other daily routines. The unrest of the child is subdued if the days feel secure and predictable.
- 12** Use the humour and fun as motivation and comfort, if the child feels bad. Humour can relieve the sorrow and the feeling of defeat.

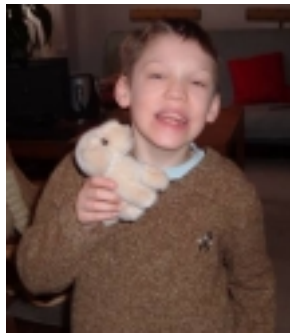
6. Sorrow and Joy

Life with a Handicapped Child

You have now fully realized that your child is handicapped. Many thoughts, prejudices and self-reproaches pop up in the confused and sorrowful mind of yours. What will become of our child in distant future? Why have we born a child, which is not normal? Why us – we are not handicapped!

Then comes the anger and finally the hopelessness. In the following months and years, your family must stand the greatest test of your life.

Don't get divorced. The divorce rate for parents to a handicapped child is sky high. The child will need you both later in life. Don't let your family go to pieces. When you have received the diagnosis of the child, be it good or bad, the darkness will be replaced with light. A light that lives within the child and you, love. You will still have your child in the morning, smiling and cuddling. You will still have a child playing cowboy and Indians. He / she will still be a normal child in spite of the symptoms of the mental disorder. And you will have learned to handle the problems. You will still be a family and your child will have a good life surrounded by loving and knowing parents.



General Thoughts about Handicaps

Conflicts

A normal child can be enormously irritating and downright hopeless. But the morning after, all is forgotten. Not so with a mentally handicapped child. The conflicts come in waves; they are numerous and unbearable for days and weeks, but then all of a sudden they have vanished. Slowly you start believing, that you *do* have a normal child. Then comes the next wave.

To loose your Baby

Everyone who has a child knows that he's not for the keeping. We are happy for a short while, then we must restrain from our own happiness to secure our baby's future and happiness. This will be a day of sorrow for us, as we love our child. We are sad not being able to fill our part anymore, sadness mixed with a deep joy to have found the best place possible for our beloved boy/girl.

That day comes, if not tomorrow then the day after tomorrow. We await that day with horror and the conviction that this is the best for our child. All the hopes and worries we have ever had, was all about this day, the day where our little man leaves his home to seek other protecting angels than us. Gone are the meetings, the medicine, the school, the bus, bedtime, bath, bicycle rides. We are alone.

But we don't lose the little one. We still have him in the weekend, on vacations – we will never lose him. And then we lose him anyway. He was not for the keeping.

Nobody who has lived with a handicapped child will ever return to the old life. We will see a threatening emptiness, a meaninglessness far bleaker than being out of work or very ill. There is no need for us any more, we feel. And then comes the black depression, which always waits for us when we open our hearts to the loneliness and the feeling of being totally helpless.

When that time comes – the day after tomorrow – we must be ready to fight not only the authorities and the politicians' narrow-minded cutting down the budgets, but fighting emptiness. We must keep the love of our son, our little Peter Pan who never grows old. We will still be there, now behind the scene.

Can we make it? We must make, we know. Love rules.

The Eternal Child

The first couple of years with a handicapped child are the most difficult. When all the diagnoses are in place, when the special school has become routine and all the false friends have disappeared – you will be surprised how few real friends you have, when you become the father and mother of a handicapped child. But the safety suddenly returns. Not the cosy, self-assured safety without a child, the empty safety. Now it's a meaningful safety, a real life. We don't understand how we have been able to live for so long without our little child. They disappeared like dust in the wind, when you came, little boy.

Now you fill our life and give us a meaning. You are the joy and happiness, the light and the real world. When you are happy, we are filled with your joy. When you are afraid and scared, we open our hearts for you, embrace you with body and spirit and protect our fragile child against the darkness that comes from within and from outside.

We take care of you, little child. You are our child, our life, our eternity. And you will always be inside us, where your smile has crushed the pettiness, the respectability and the fear of losing face. We stand naked and shiny as the trees not broken in the storm. We are strong and beautiful. You make us beautiful little child, our eternal child.

7. Medicine and Diseases

There is no “cure” for retardation. All medicine given to retarded children are for comorbid diseases or to dampen unrest.

WARNING Vitamins, oil and mineral cures have become very popular in the do-it-yourself families. But these types of “herbal medicine” have never been tested scientifically, and it can be risky to use them in expense of the officially recommend medicine types. Don’t be your child’s doctor, not even if you *are* a doctor. Leave the medicine to the experts.

You should wait as long as possible before medicating your child. But as many retarded children have one or more comorbid diseases, medicine is often unavoidable, if for example for example Tourette tics become a nuisance to the child.

When choosing a medicine for your child, the advantages of a medication should always outweigh the possible disadvantages.

Many of the medicine types are, by the way, only tested on adults, as the kid’s market is too small to pay off the investment of testing it on children. So instead the children become involuntary guinea pigs ☹.

In addition, the medicine types often have many side effects, which ”unfortunately” aren’t mentioned in the Instructions for Use and long-term side effects, showing up 20 years later.

It is extremely difficult to choose the right medication, and if your child has both ADHD and Tourette, which is rather common, it becomes almost impossible. Medication working against ADHD very often increases the Tourette – and vice versa. Or the medication dampens the tics and the hyperactivity, but provokes regular depressions.

IMPORTANT! The parents of course cannot choose the medicine themselves. Medication is for highly skilled neurologists and psychiatrists only.

General Unrest

Psychoactive Drugs

Haloperidol

Description The oldest and most widely used medicine against tics.

Passing Side Effects Involuntary muscle movements.

Chronic Side Effects Dry mouth, walks like an old man, constipation, ”stone face”, the feeling of being a ”zombie”, trembling, tiredness, weight gain. Other known side effects are school phobia, restlessness, depression.

Pimozid (Orap)

Description Another well-known medicine against tics. Resembles haloperidol.

Passing Side Effects Involuntary muscle movements.

Chronic Side Effects A little fewer side effects than haloperidol.

Risperidon (Risperdal)

Description Antipsykotisk, dampening medicine. widely used today.

Passing Side Effects Almost like Ritalin.

Chronic Side Effects Weight gain, tarditive dyskinesia (stone face, involuntary movements of the mouth).

Olanzapin (Zyprexa)

Description Ligner risperdal.

Passing Side Effects Unknown

Chronic Side Effects Unknown

Central Stimulating Medicine

Methylphenidate (Ritalin)

Description Used against hyperactivity and general restlessness.

Passing Side Effects Stomach-ache, sleeplessness, headache, no appetite. Cries without any reason. Should not be given to the child before bedtime. The medicine must be stepped down before the main meal.

Chronic Side Effects General decrease in growth. It is important to regularly check the height and weight. Increased blood pressure and pulse.

Ritalin Concerta

A brand new depot plaster dosing the medicine slowly and steadily.

Dexamphetamine

Description Used against hyperactivity and general unrest.

Passing Side Effects Resembles Ritalin, but are not so tough.

Chronic Side Effects Resembles Ritalin, but does not take the appetite away.

Depressions and OCD

Tricyclic Medicine

Tricyclic medicine types work on OCD by effectively blocking the stream of surplus impulses.

Clomipramine (Anafranil)

Description Newer anti-depressive drug. Very effective against OCD.

Passing Side Effects Should be taken together with food to avoid digestion problems.

Chronic Side Effects Fatigue, dry mouth, dizziness, tremors, constipation and lack of potency.

Other Tricyclic Medicines

- Fluvoxamin [Fevarin™]
- Fluoxetine [Fontex™, Prozac™]
- Paroxetine [Seroxat™]
- Sertraline [Zoloft™]
- Citalopram (Cipramil™)

IMPORTANT! The depression of a Tourette child is sometimes disguised as crossness and aggression. Be aware of that! Depressions can easily be treated with Fontex® and similar drugs.

Comorbid Diseases

The medical world is divided between doctor believing that a retarded child cannot have a “normal” handicap like ADHD or Tourette’s syndrome, and doctors who knows that the earth is not flat. A group of doctors from the last category have researched the spreading of comorbid diseases. The number in parenthesis is the percent of all retarded persons and the number of normal persons with these mental handicaps.

- ADHD, Tourette’s syndrome and OCD (17-52% against 6%).
- self-destructive behaviour [primarily severely retarded children] (3-15% against 0,1%).
- Schizophrenia (3% against 0,8%).
- Manic depression [bi-polar disease] (3-6% against 1-2%).
- Autism, depressions, OCD, angst and ODD (violent behaviour).
- Reduced hearing and sight [50%].
- Spasticity and/or epilepsy [20%].
- Stomach problems, reflux and constipation.

Epilepsy

Almost all retarded children have epilepsy. The dysfunction in the brain causing the retardation also triggers the epileptic symptoms.

The Yearly Examination with the Special Doctor

Children with retardation must be examined at least once a year by a neurologist specialising in handicapped children. The areas medicine, behaviour, learning/school and family advice must always be a part of the examination. It is your responsibility to remind the doctor of the four main areas.

8. Resources and Literature

Websites

General Websites

- Diagnostic Criteria for mental handicaps from WHO
www.who.int/classifications/icd/en/
- American society for retarded children and grownups.
www.aamr.org/
- American organisation for retarded children.
www.thearc.org
- General site on retardation.
http://kidshealth.org/kid/health_problems/birth_defect/mental_retardation_p3.html
- Really good Indian website on retardation
www.ourspecialworld.com
- Psychiatric website with a fine section on retardation.
www.psychiatry.com
- Mental handicaps, sexuality and healthy food.
www.nordisc-mental-aid.com
- Interesting article on the history of retarded children.
www.uab.edu/cogdev/mentreta.htm
- Medicine for handicapped persons.
www.emedicine.com/neuro/topic605.htm

Comorbid Diseases

Fetal Alcohol Syndrome

- Fine website on fetal alcohol syndrome (FAS).
<http://fasalkoholembryopathie.freesevers.com>
- Large, professional site on FAS, fetal alcohol syndrome.
www.fasworld.com/home.ihtml

ADHD

- Large American ADHD society.
www.chadd.org
- Parents' site for ADHD
www.adhd.com

Tourette's Syndrome

- Very good general website
www.tourette-syndrome.com
- Really good Tourette website
www.tourettesyndrome.co.uk

Autism

- The National Autistic Society (NAS) is in the UK
www.nas.org.uk
- General autist website
www.autism.org

Rare Diseases

- ❑ Information on rare syndromes and orphan diseases
www.cafamily.org.uk

Various

- ❑ Good site for siblings with handicapped brothers and sisters.
www.mhasp.org/coping
- ❑ Special education.
www.cloudnet.com/~edrbsass/teachingaboutmr.htm
- ❑ Resource site for teachers of handicapped children
www.teachers.net/mentors/special_education
- ❑ Award-winning music therapy site
www.musicworkshop.org.uk
- ❑ American BARC has worked for over 50 years to help retarded persons to a job.
www.barc-inc.org
- ❑ General website on biofeedback – computer aided therapy.
www.bfe.org

Literature

The titles can all be found on www.amazon.com or www.nordisc-mental-aid.com. This is only a few titles out of the huge selection on amazon.com.

- ❑ Mary Beirne-Smith, et al: **Mental Retardation**
- ❑ Nina Galerstein, et al: Age **Appropriate Activities for Adults With Profound Mental Retardation** A Collaborative Design by Music Therapy, Occupational Therapy and Speech Pathology
- ❑ Arthur E. Jongsma Jr., et al: **The Mental Retardation and Developmental Disability Treatment Planner**
- ❑ **Torey L. Hayden**'s moving stories are quintessential reading for parents and professionals around retarded children:
 - Beautiful Child
 - The Tiger's Child
- ❑ www.nordisc-mental-aid.com, Digital Books™. Other books by the H.W. Gade:
 - Caring for a Hyperactive Child (ADHD)
 - Daily Life with Tourette's Syndrome.

9. Index

Use the Index! By looking up in the index you can find your child's symptoms or the explanation of a strange medical name.

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Daily Life with a Retarded Child

The border between "normal" and lightly retarded can be fluent. A "normal" child understands a sentence and keeps on talking. A lightly retarded child, however, does not always understand the sentence but pretends to do in order to avoid being laughed at. As the content of the sentence is the basis of the whole conversation, the lightly retarded child is now mentally offline. And nobody notices, as it is hard – even for professionals – to see if a lightly retarded person has understood what has been said.

The closer the child is to a "normal" child, the harder it is to help it without making him/her look like a fool to the other kids. When the retardation come closer to moderate retardation, nobody's in doubt. It is in the grey zone between these two states that the school and the home must learn to navigate, helping the child without making it look "stupid and odd". It is really difficult, but can be done.

The first couple of years with a handicapped child are the most difficult. When all the diagnoses are in place, when the special school has become routine and all the false friend have disappeared – you will be surprised how few real friends you have, when you become the father and mother of a handicapped child. But the safety suddenly returns. Not the cosy, self-assured safety without a child, the empty safety. Now it's a meaningful safety, a real life. We don't understand how we have been able to live for so long without our little child. They disappeared like dust to the wind, when you came, little boy.

Father to a moderately retarded 11 years old boy



Daily Life with a Retarded Child

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