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ISSN 1729-8997

(Online Edition)

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Children Speak

Vol 6, No.24, June - July 2007

A Newsletter of the Organization for the Protection of Children's Rights

Message from the President

We know that all children are special. They are so because they bring joy to their parents, friends and family just because they are there to share special moments as well as everyday experiences with us. All children, just like all adults, are different. Each one of us has different sets of capabilities and skills, likes and dislikes in addition to a varied array of knowledge and understanding.

It is refreshing that we do not speak of "disabilities" anymore. We use the words "differently abled" because children with intellectual and physical challenges are not "disabled" but simply have a different set of skills that can be used in productive ways. You will be able to read all about it in our article entitled "Special Children Special Lives".

Our respect for one another and especially for others who are intellectually or physically challenged will help determine the kind of world that our children will inherit from us. If we demonstrate that everyone can find his/her place in society no matter what their abilities are, then we have shown our children that we accept and respect those who are different.

It is up to all of us to tap into this diverse rainbow of colors and extract the best qualities that everyone has to offer in order that our society can benefit from the different talents and gifts that all individuals have to put forward. ■



Riccardo Di Done



Special Children. . .

Exploring the world of these differently-abled children with Maitri Porecha

Every parent dreams of having a perfect baby with expressive angelic eyes, a tiny puckered nose, rosy pink lips, a pair of attentive ears and some hair. In reality, there are things that could happen during the birth process, which can affect the development of a child. As a matter of fact, three out of every 100 children born across the globe will be intellectually and/or physically challenged.

An intellectually disabled individual is one who displays intellectual functions that are well below average and who has trouble adjusting to life during his/her developmental period of growth. The mental progress of such an individual is 70% or less of the expected rate at his/her physical age at that moment. Poor social

skills, self-care and communication further hinder the individual's growth. Mental progress is usually determined by the Intelligence Quotient (IQ), in order to provide parents and teachers with a realistic idea of what to expect from the child as he/she grows. Lower intellectual abilities however, should not be considered as a sole factor to determine the child's poor academic performance. Children with lower IQs can do extremely well in practical areas such as imitation and repetition. They often tend to bridge the gap by exhibiting advanced social skills and relating well to their parents, relatives, friends and society at large.

Intellectually challenged children are broadly classified into 4 categories on the basis of IQ. An individual with an IQ between 51 and 70 is mildly intellectually impaired. This is often discovered when the child cannot perform well in a regular school program. Nevertheless, they are educable, can benefit a



A Class comprising mixed age groups from the POSAT School for Special Children, Mumbai

"No one needs to stop learning when their so-called mental levels go off. Does one quit learning once their mental age reaches 15 or 16 or whatever normal adult mental age is?"
- Dr. Nanavati

great deal from special education and generally get along on their own in life. Children who are moderately intellectually disabled (IQ between 36 – 50) are trainable, they can learn to take care of their basic personal needs and can be trained for useful work. Some severe cases (IQ ranging from 21 – 35) are also trainable. Some children with profound mental disabilities (IQ 20 or below) will never learn to walk or feed themselves. Others will learn to walk, feed themselves, use the toilet and do simple tasks at a much later stage in life than normal children.

A normal human being's physical and emotional development halts after a certain age as maturity settles in. Just like a fully grown tree keeps growing new branches and sprouting fresh green leaves every season, after a certain point of time, a human being stops growing upward and begins to expand the endless horizons of learning outward. Similar is the case with a mentally challenged person.

"No one needs to stop learning when their so-called mental levels go off. Does one quit learning when one's mental age reaches 15 or 16 or whatever normal adult mental age is? In the case of special children, mental growth retards at a certain age, but this does not mean that they stop learning. Learning is a life-long process," explains Dr. Maya Nanavati, a Mumbai based physiotherapist and a social activist.

A developmental disorder can be caused by a number of things ranging from genetic defects (Down Syndrome & Fragile X Syndrome are amongst the major causes) or an injury/illness to the mother during conception or lack of proper nutrition to the womb during pregnancy.

. . . Special Lives

different from the rest. An underlying guilt or the "Why me?" question haunts them early on after the child's birth. This gradually transforms into slow acceptance through interaction with similar parents in local communities and at schools. Special Schools for these children contribute a lot to the holistic development of the child.

We visited a number of special schools around Mumbai to find out more about the educational facilities that are available for these special children. The schools are divided into 6 broad categories to which the child is admitted after having ascertained the child's level. There are no more than 20 students in each class since this makes it easier for the teacher to cater to the individual needs of each child. The classrooms are full of vibrant colorful paintings and pictures to hold the children's attention. The attention span of such children tends to be extremely low as they are unable to concentrate on one thing for long periods of time. Thus, the activity and teaching sessions are limited to fifteen-minute blocks each. Alternative methods of teaching along with play empower these children to grasp concepts. A normal study session with an intellectually challenged child at Junior Basic and Remedial Classes included writing through tracing alphabets and numbers, matching the object with the picture, grouping, puzzles and activities that increase dexterity as well as exercises which increase hand-eye co-ordination and association. Cards, board games and building blocks form an essential part of their study at this level.

Children whom the teachers feel are capable of sitting for normal school grade examinations are put into Basic and Senior Academic Classes. Apart from academics, pre-vocational training and occupational therapy sessions form an integral part of the child's daily routine. In the



TOP: Children engrossed in solving an association exercise at POSAT School for Special Children, Mumbai; BOTTOM: A typical classroom at Shartul Gurukul School for Special Children, Mumbai

second half of the school time, the children are engaged in learning computer operations, office skills (viz. filing, punching, and accountancy), gardening, cooking, packaging, labeling, candle and paper bag making, dancing and art. They are increasingly taught in the school to become independent right through the early stages of their lives.

A child who is intellectually challenged often exhibits other behavioral problems such as extreme hyperactivity or he/she can be excessively non-reactive to the surroundings. Occupational Therapy (OT) in such cases enhances and hones the muscle movement, flexibility, head neck control, and brings the motor skills of the child near normalcy. Therapies include ball-pressure exercise, association and co-ordination exercises and color, music as well as dance therapies. A triangled approach to the whole scenario with the child at one end, the therapists, special educators and teachers at the other end, and the parents at the top end, if implemented can do wonders to the child's life.

An intellectually disabled child deals with the 5 concrete sensory powers of touch, smell, seeing, hearing and smelling out of which, the sense of touch and smell is advanced while the level of abstract thinking is usually low. Mentally challenged children have to be taught repeatedly to notice, observe and associate in order to learn. General goals in educating these special children revolve essentially around self-sufficiency, economic usefulness, satisfying human relationships and imbibing civic responsibility.

There have been people with intellectual disabilities since the beginning of the human

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A Convenient Truth

By Peter Singer

Melbourne, Australia: CAN it be ethical for a young girl to be treated with hormones so she will remain below normal height and weight, to have her uterus removed and to have surgery on her breasts so they will not develop? Such treatment, applied to a profoundly intellectually disabled girl known only as Ashley, has led to criticism of Ashley's parents, of the doctors who carried out the treatment, and of the ethics committee at Seattle Children's Hospital in US, which approved it.

Ashley is 9, but her mental age has never progressed beyond that of a 3-month-old. She cannot walk, talk, hold a toy or change her position in bed. Her parents are not sure she recognizes them. She is expected to have a normal lifespan, but her mental condition will never improve.

In a blog, Ashley's parents explain that her treatment is not for their convenience but to improve her quality of life. If she remains small and light, they will be able to continue to move her around frequently and take her along when they go out with their other two children. The hysterectomy will spare her the discomfort of menstrual cramps, and the surgery to prevent the development of breasts, which tend to be large in her family, will make her more comfortable whether lying down or strapped across the chest in her wheelchair.

All this is plausible, even if it is also true that the line between improving Ashley's life and making it easier for her parents to handle her scarcely exists, because anything that makes it possible for Ashley's parents to involve her in family life is in her interest.

The objections to Ashley's treatment take three forms familiar to anyone working in bioethics. First, some say Ashley's treatment is "unnatural" — a complaint that usually means little more than "Yuck!" One could equally well object that all medical treatment is unnatural, for it enables us to live longer, and in better health, than we naturally would. During most of human existence, children like Ashley were abandoned to become prey to wolves and jackals. Abandonment may be a "natural" fate for a severely disabled baby, but it is no better for that reason.

Second, some see acceptance of Ashley's treatment as the first step down a slippery slope leading to widespread medical modification of children for the convenience

of their parents. But the ethics committee that approved Ashley's treatment was convinced that the procedures were in her best interest. Those of us who have not heard the evidence presented to the committee are in a weak position to contest its judgment.

In any case, the "best interest" principle is the right test to use, and there is no reason that other parents of children with intellectual disabilities as profound as Ashley's should not have access to similar treatments, if they will also be in the interest of their children. If there is a slippery slope here, the much more widespread use of drugs in "problem" children who are diagnosed as having attention deficit hyperactivity disorder (ADHD) poses a far greater risk than attenuating growth in a small number of profoundly disabled children.

Finally, there is the issue of treating Ashley with dignity. A Los Angeles Times report on Ashley's treatment began: "This is about Ashley's dignity. Everybody examining her case seems to agree at least about that." Her parents write in their blog that Ashley will have more dignity in a body that is healthier and more suited to her state of development, while their critics see her treatment as a violation of her dignity.

But we should reject the premise of this debate. As a parent and grandparent, I find 3-month-old babies adorable, but not dignified. Nor do I believe that getting bigger and older, while remaining at the same mental level, would do anything to change that.

Here's where things get philosophically interesting. We are always ready to find dignity in human beings, including those whose mental age will never exceed that of an infant, but we don't attribute dignity to dogs or cats, though they clearly operate at a more advanced mental level than human infants. Just making that comparison provokes outrage in some quarters. But why should dignity always go together with species membership, no matter what the characteristics of the individual may be?

What matters in Ashley's life is that she should not suffer, and that she should be able to enjoy whatever she is capable of enjoying. Beyond that, she is precious not so much for what she is, but because her parents and siblings love her and care about her. Lofty talk about human dignity should not stand in the way of children like her getting the treatment that is best both for them and their families. ■

Peter Singer, a professor of bioethics at Princeton University, is the author of "Writings on an Ethical Life."; Published: January 26, 2007 in NYT, Op-ed

Profile

Italy Practises Full Inclusion

By Anna Zambon Hobart

While the world has grown more sensitive to the needs of children with disabilities and has looked at providing incentives like special schools and increased health care to its disabled citizens, the other side of the spectrum for certain countries like Italy is as bright. For almost twenty years in Italy, all the children between the age of three to fourteen with a disability, be it mental or physical, have been included in the compulsory school system.

Special schools and Nursery Schools for the disabled have all but disappeared, and self-contained classes for the disabled in public schools were finally eliminated in the 1980s. Legislation dating back to the 1970s limits class size to 20 children, including one child with a disability. Supplementary support

teachers and therapists, physical therapists and psychologists are provided for these children.

The law assigns local responsibility for co-ordination between the schools and the local public health units. The shift from special schools to inclusion also entailed changes in objectives and methods of the entire educational system.

Today, twenty years down the line, people with disabilities in Italy are more a part of the community than anywhere else in the world. Full inclusion has proved to be a mutually enriching experience

for people with disabilities and for the rest of Italians as well. ■

Based on "Down Syndrome - Living and Learning in the Community"- Paper presented by Anna Zambon Hobart, 1995

News

Special Olympics Celebrates 39th Anniversary

July 20, 2007: The spirit of the Special Olympics was first given life on 20 July 1968, at Soldier Field in Chicago, Illinois (USA). One thousand athletes with intellectual disabilities lit a Special Olympics cauldron to proclaim their vision of sport - a vision marked by skill, courage, sharing and joy. It is a vision that has swept the world.

Today the spirit of Special Olympics is alive in more than 2.5 million athletes, almost 200,000 coaches, and millions of families and volunteers in 165 countries. It is foremost a spirit of joy, but also one of courage, integrity, pride and



Athletes strive for the finishing line in a 200m race at the 2003 Special Olympic World Summer Games in Dublin, Ireland

respect. It is a spirit of acceptance that transcends geographic, social and political

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Increasing Attacks on School Children in Conflict Areas

June 29, 2007: Recent incidents in Asia, the Middle East and Africa show increasing attacks on school children in conflict areas. Citing incidents, two school girls were killed, another three students and a teacher were injured at a girls' school in Afghanistan, while in Gaza, one student traveling to national college entrance exams was killed, and in a separate incident another was injured, in crossfire.

"In parts of Iraq parents remain justly concerned about the risks involved in sending their children to school, and insecurity has closed schools in the Central African Republic, in Nepal and in Sri Lanka," the agency said in a news release.

At the same time, UNICEF cited evidence that where an education system continues to function, students will face real risks to take advantage of the opportunities that education provides. In the occupied Palestinian territory in June, some 60,000 students in both Gaza and the West Bank made it through 10 days of entrance exams, despite the current crisis.

"Children have the right to a safe learning environment at all times, even under the most difficult of circumstances," UNICEF Executive Director Ann Veneman stated. ■

UN Welcomes Child rights bill in Sierra Leone

The National Child Rights Bill, approved by the Sierra Leone Parliament in West Africa offers for the first time, an opportunity to align the country with international rights standards for children.

Non-discrimination is one of the guiding principles of the Bill - it provides the overall framework for ensuring adequate standards of care for all children in Sierra Leone. These include prohibition of early marriage, of conscription of children into the armed forces, the right to a name and nationality, free and compulsory education, protection against domestic violence and child trafficking, structures and systems for the protection of children at village and chiefdom levels, as well as protection against harmful traditional practices affecting children including female genital mutilation. ■

(Source: UNICEF)

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Special Olympics Celebrates 39th Anniversary

boundaries. It is a spirit that inspires everyone!

In neighborhoods and communities around the world, Special Olympics athletes come together to experience the simple gifts of teamwork, competition, triumph and perseverance. In 21,000 competitions each year, Special Olympics provides the rarest gift of all: a chance.

For so many more people with intellectual disabilities, the spirit of Special Olympics has yet to touch their lives. More than 190 million people with intellectual disabilities live without being given a chance to enjoy even the most basic freedoms - the chance to be part of a family, the chance to go to school, the chance to have a job, the chance to make a friend.

On the occasion of its 39th anniversary, Special



Special Olympics offers children and adults with intellectual disabilities year-round training and competition in 30 Olympic-type summer and winter sports

News

Special Olympics celebrates the hope of a future when every person with an intellectual disability will have a chance, when every athlete will cross the finish line with the words, "I am a winner." ■

(www.specialolympics.org)

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Special Children Special Lives

race. In ancient Greece and Rome, for example, infants with obvious disabilities including intellectually challenged babies were often killed at birth. By the middle ages, however, Churches in Europe were beginning to set up places in order to care for and protect such children. In the Renaissance period, greater value was placed on human life and using death as a "treatment" for intellectual disabilities began to fall out of favor.

In 1975, the US federal government passed a special education law: Public Law 94-142 (*Individuals with Disabilities Education Act*, IDEA) which requires all children with disabilities to receive an education tailored to their unique needs. This law gives children with disabilities, unprecedented opportunities to learn and become contributing members of the society. The *Americans with Disabilities Act* of 1990 prohibits discrimination on basis of disabilities in just about every public arena. The United Nations General Assembly's *Declaration on Rights of Mentally Retarded Persons* of 1971 and its

Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care of 1991 ensures the fundamental freedoms and basic rights of the differently abled. It includes the protection of minors, right to determination of cause of mental illness and appropriate medical examination and proper standards of care for the mentally disabled.

An intellectually challenged child has the same emotional requirements as other children, perhaps more - to be loved, accepted, cared for, respected and treated in a dignified manner. Children with intellectual disabilities today have a much better chance than ever before of achieving their potential, what with early diagnosis and schools working closely with parents in educating such children. Together the parents, teachers and the children can explore and push the limits of the child's potential. As the society's mindset continues to broaden and the children receive constant motivation and support, their future will continue to brighten. □