REPORT OF ONE DAY SEMINAR

ONE DAY SEMINAR
21st March World Down Syndrome Day
Under the theme of
“RIGHT TO WORK”
Thursday, 21st March 2013
Hotel Mehran, Shara-e-Faisal, Karachi

Report by: Abid Lashari
President
Pakistan Down Syndrome Association (PDSA)
SUMMARY

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1. Introduction & Background

Pakistan Down Syndrome Association (PDSA) was established in 2009. The purpose of this DPO was to raise awareness about rights of Down Syndrome children in Pakistan. People are unaware about the Down syndrome & its identifications. There are hundreds of Down syndrome children in Pakistan, they are not visible. People have hidden their children with Down syndrome in their homes. PDSA Pakistan is committed to raise awareness about Down Syndrome children and promotion of rights of children.

VISION

Our mission is to improve quality of life for people with Down syndrome in Pakistan and promote their inherent right to be accepted & included as valued and equal members of their communities.

Objectives

1. Provide information, support & resources to people with Down syndrome, their families and careers and the professionals who work with them.

2. Represent people with Down syndrome with a single global voice and encourage international communication & cooperation.

3. Raise awareness about Down syndrome and the potential of people with Down
syndrome to be valued members of their communities.

4. Conduct bespoke outreach training programmes in partnership with national and International NGOs like Down Syndrome International (DSi) to disseminate the information.

**Background of 21st March**

World Down Syndrome Day (WDSD) is observed on 21 March. On this day, people with Down syndrome and those who live and work with them throughout the world organize and participate in activities and events to raise public awareness and create a single global voice for advocating for the rights, inclusion and well-being of people with Down syndrome.

This year at the United Nations the World Down Syndrome Conference 2013 will be organized on 21 March under the theme "The Right to Work". This year's Conference will focus on the rights of persons with Down syndrome to work in open, inclusive and accessible environments. It will help raise awareness on the importance of promoting early development and education, proper medical care and providing for independent living in communities.

The date for WDSD being the 21st day of the 3rd month was selected to signify the uniqueness of the triplication (trisomy) of the 21st chromosome which causes Down syndrome. The original idea was proposed by members of the European Down Syndrome Association and Down Syndrome International.

On 19 December 2011, the United Nations General Assembly declared 21 March as World Down Syndrome Day. The General Assembly decided to "designate 21 March as World Down Syndrome Day, to be observed every year beginning in 2012;" and "invites all Member States, relevant organizations of the United Nations system and other international organizations, as well as civil society, including non-governmental organizations and the private sector, to observe World Down Syndrome Day in an appropriate manner, in order to raise public awareness about Down syndrome;".

The Secretary-General of the United Nations Ban Ki-Moon said on 21st March 2012 "On this day, let us reaffirm that persons with Down syndrome are entitled to the full and effective enjoyment of all human rights and fundamental freedoms. Let us each do our part to enable children and persons with Down syndrome to participate fully in the development and life of their societies on an equal basis with others. Let us build an inclusive society for all."
Pakistan Down Syndrome Association (PDSA), member of DSi since 2011, is engaged to raise awareness about Down Syndrome children in Pakistan. The purpose of formation of PDSA was to award separate identity representation of people with Down syndrome in Pakistan. PDSA is only internationally & national level recognized organization of Down syndrome in Pakistan.

In Pakistan wide gap exists to understand Down syndrome, PDSA has proposed national level seminar on account of World own Syndrome day on 21st March 2013, under title “THE RIGHT TO WORK” to create awareness in the public for understanding Down Syndrome.

**Overall Objective:**
This Seminar will focus on the rights of persons with Down syndrome to work in open, inclusive and accessible environments. It will help raise awareness on the importance of promoting early development and education, proper medical care, and providing for independent living in communities.

Observance of the Day provides opportunities for participation by all stakeholders, the parents, Governments, the UN system, civil society and organizations of persons with disabilities – to focus on issues related to the Down syndrome children.
Pakistan Down Syndrome Association (PDSA) in collaboration with UNESCO commemorated World Down Syndrome Day in a local hotel in Karachi. A large number of activists for the Rights of Persons with Down syndrome, parents, representatives of media and Civil Society organizations participated at the event.

The United Nations has declared 21st March as ‘World Down Syndrome Day’ in 2012 and it was the first time that this day has been celebrated in Pakistan by UNESCO and Pakistan Down Syndrome Association. PDSA is linked with Down Syndrome International- DSI, which is globally engaged in raising awareness about the rights of people with Down syndrome.

While reading the message of UNESCO’s Country Director to Pakistan, Mr. Kazi Ayaz Mahessar, Provincial Coordinator of UNESCO in Sindh, highlighted the importance of early intervention through Early Childhood Care and Education in the development of children with Down syndrome. He said that persons with disabilities are often seen as the objects of pity and misfortune and are often left helpless on their own or with their parents. However, referring to the Convention on the Rights of Persons with Disabilities, adopted by United Nations in 2006 and ratified by Pakistan in 2011, he said that Convention embodies a paradigm shift in which persons with disabilities are no longer regarded as objects of charity and welfare, but as persons with equal rights and dignity who can make an enormous contribution to society.

While emphasizing the importance of inclusive education, early intervention for children with Down syndrome and their education in mainstream education system, he said that after the ratification of CRPD, it is now the responsibility of State to provide equal opportunities for
learning and for work to the persons with Down syndrome and disabilities. He said that UNESCO, being the specialized Agency of United Nations, is working for the well-being and human rights of all people.

Mr. Abid Lashari President Pakistan Down Syndrome Association (PDSA) acknowledged the sponsorship made by UNESCO, HANDS & SAFWCO Sindh to organize national level seminar. He said that a congenital impairment caused by having an extra 21st chromosome; results in a flat face and short stature and mental retardation. It is named after John Langdon Down, the British physician who described the syndrome in 1866 who first described the syndrome as impairment/Disability. Mr. Lashari said Down Syndrome children are unnoticed in Pakistan, there is dire need to declare Down Syndrome as 05\textsuperscript{th} category of Disability in Pakistan. He said disability is not issue or problem but a different life style. The society must accept disability & ensure accessible environment & equal partnership in all walks of Life. Mr. Lashari told that the theme of the day is “Right to work”, Down Syndrome children should be offered equal access of work options, should be engage in work opportunities.

Mr. Ghulam Nabi Nizamani, Chairperson, CBR Asia Pacific Region, stressed the importance of engagement of Right-based organizations in raising awareness about the persons with Down syndrome and disabilities. He called the attention of Government for ensuring equal treatment and fundamental rights of persons with disabilities.
Mr. Nizamani shared physical characteristics that persons with down syndrome have excess skin at the nape of the neck, flattened nose, separated joints between the bones of the skull (sutures), single crease in the palm of the hand, small ears, small mouth, upward slanting eyes, wide & short hands with short fingers. He shared developmental characteristics that these children have Impulsive behavior, poor judgment, short attention span & slow learning.

He suggested some solution regarding well-being of persons with Down Syndrome that the more awareness raising programs may be organized to sensitize public, Parents and families of people with Down Syndrome networked and mobilized, on job trainings should be provided, They don’t be treated as children forever and to promote good practices of these people at work place promoted.

Mrs. Iffat Sultan mother of baby with Down syndrome shared her experience that her baby is doing all routine life activities, she responds as is guided. She said that her baby has potential to grow up but unfortunately equal access and opportunities were not offered in education system, no institution is willing to offer standard educational environment, the speech therapy, occupational therapy and physical therapy are too expensive to afford a common family. He suggested Government, INGOs, NGOs and other stakeholders to support the cause of persons with Down Syndrome that they may be enable to enjoy the right of education, right to work/employment and others.

Mr. Dileep Kumar of HANDS Pakistan lauded services of PDSA & UNESCO for organizing such national event first ever in the history. He said HANDS is also engaged towards rehabilitation of persons with disabilities, to make them able to earn livelihood & offer work opportunity. He said HANDS offer its possible support to PDSA to expand its programme in rehabilitation & well-being of persons with Down syndrome.
Mr. Muna Bhai President Awareness Pakistan assured his full support to PDSA in awareness of Down syndrome in Sindh especially in Karachi. He said that stigmatization on disability has discouraged persons with disabilities; he said society must encourage PDSA cause.

Mr. Ghullam Muhammad from CSR Department NBP lauded services of PDSA and assured future collaboration for the rehabilitation of persons with Down Syndrome.

Regional Director Special education Hyderabad region Mr. Manzoor Ali Mastoi said that Special education department is fully committed to deliver services to children with special needs. He said Down syndrome children are treated in all centers of department which are fully equipped to facilitate Down syndrome children. DPOs like PDSA are playing their role to achieve their rights, the department will fully cooperate with DPOs to remove stigma on disability.

On the occasion Ms. Amna Shaikh from Darul Sukoon, Ms. Amna Khan & Ms. Shahla Fayaz from Makaz e Umeed, and Ms. Samina Almas from The Education Foundation also spoke on the occasion.

**Conclusion with Recommendations**

1. It was recommended to declare Down syndrome as 05\textsuperscript{th} category of disability in Pakistan.
2. It was recommended to promote social inclusiveness of persons with Down syndrome in all walks of life.
3. It was recommended to offer decent work for people with Down syndrome as per UNCRPD article 27.
4. It was recommended to ensure early childhood education of children with Down syndrome.
5. It was recommended to implement CRPD with soul & heart.
6. It was recommended to ensure parliamentary participation of persons with disabilities.
7. It was recommended to provide equal opportunities at all spheres of life.
8. It was recommended to provide equal opportunities to disabled peoples’ organizations in project management.
9. It was recommended to promote inclusive development through Community Based Inclusive Development.
Invitation Card

PDSA in Collaboration with UNESCO
cordially invite you to attend one day seminar on occasion of the Observance of
World Down Syndrome Day
Under the theme of “RIGHT TO WORK”
Thursday, 21st March 2013 at 11:00 am
Hotel Mehran, Shahra-e-Faisal, Karachi

R.S.V.P
Abid Lashari
President
Pakistan Down Syndrome Association (PDSA)
03003211876

PROGRAMME
SEMINAR ON WORLD DOWN SYNDROME DAY
21st March, 2013

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<th>Time</th>
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<tr>
<td>11:00</td>
<td>Registration</td>
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<tr>
<td>11:30</td>
<td>Recitation by Mr. Hafiz Mumtaz Dehnaj</td>
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<td>11:45</td>
<td>Welcome Remarks by Kazi Ayaz Mahesar, Provincial Coordinator, Sindh, UNESCO</td>
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<td>12:00</td>
<td>Orientation of Seminar by Mr. Abid Lashari, President PDSA</td>
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<td>12:30</td>
<td>Role of Parents of Down Syndrome Children by Iffat Sultana</td>
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<td>13:00</td>
<td>Identifying and removing of barriers and suggestions for Down Syndrome children to access their right to work by Ghullam Nabi Nizamani, Chairperson, CBR Asia Pacific Region</td>
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<td>13:45</td>
<td>Speech by HANDS representative</td>
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<td>14:00</td>
<td>Keynote Speech by Secretary Special Education, Ministry of Special Education, Government of Sindh</td>
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<td>14:15</td>
<td>Vote of Thanks</td>
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