

July 5, 2007

DPI/NGO BRIEFING
AUTISM: RAISING AWARENESS, CHANGING ATTITUDES

Thursday, June 28, 2007, 10:00 AM – 12:00 PM

1. This week's briefing focused on Autism, a disorder that severely inhibits neurological, emotional and intellectual development. They estimate that one in one hundred and fifty children are affected by this disorder worldwide. While Autism remains increasingly researched but misunderstood, autistic children still may experience difficulty with language, communication, social interaction and the perception of their environment. This leads to their isolation. This briefing looked at the current research underway and the social challenges that are posed by Autism. The panelists discussed their efforts to raise the awareness of Autism in order to eradicate the stigmas and misconceptions surrounding this disorder. Their purpose was also to raise funds for research to find better treatments and a cure.

Moderator:

Juan Carlos Brandt, Chief, DPI/NGO

Speakers:

Ms. Susan Wright, Co-founder, Autism Speaks

Dr. W. Ian Lipkin, Greene Infectious Disease Laboratory

Mr. Eric Olsen, Focal Point on Family, Social Integration Section,
Department of Economic and Social Affairs, United Nations

2. Video –“Autism Everyday A Decade For Autism” was screened at 10:00 AM. This video showed the exposures of children and what their families face. In the film, mothers speak of their problems. These mothers had to quit their jobs in order to take care of their affected children.

They are running scared. What happens when the affected child runs out the door? They indicated that they cannot keep the child quiet. We must have compassion for both the child and the mother. The film indicated that affected children are placed in special education courses. It is difficult for the mother of the affected child to have a life.

Insurance companies do not cover these special expenses incurred with affected children. The mother is up all night with the child for many nights. The mothers dream that it might get better but it does not. The mothers write up all medical details of the affected child in case something happens to her. They have no thought of surrender. They are never going to quit. These mothers must have dedication.

3. The Moderator, Juan Carlos Brandt, welcomed everyone and introduced each of the speakers with their backgrounds. He stated that children world wide do not have the support of the family as in the United States.

Mr. Brandt spoke about his son, Jacob, who was also affected and cured of Autism. This raised his awareness of Autism.

4. The first speaker, Ms. Susan Wright, has a BA degree from Sara Lawrence College. Her grandson is also affected by this diseases. She indicated that one million children are affected world wide. This a world wide crises.

Ms. Wright indicated that we need to galvanize action on Autism world wide. Public knowledge is nonexistent. She had proposed that her Ad Council "Public Service" advertise the urgency of combating Autism. In nine months they have received 47 million dollars for Autism.

5. The second speaker, Dr. W. Ian Lipkin, is a professor of health at Columbia University and has a BA fro Sara Lawrence College and an MA degree from Minnesota University. Since 1974 he has worked full time in research on infectious disease.

He asked the question what is Autism? He has been trying to get answers in order to be able to affect early detection and possible cures. The critical are;

- Unlikely to be a single disorder
- Children affected vary with age and causes
- To solve the problem we must address a worldwide solution
- We must recognize that each child is unique

The Autism epidemic increased dramatically over the last twenty years. Dr. Lipkin was trained in Neurology which helped him to diagnose Autism. The increase in Autism does not eliminate the genetic cause of the disease.

Dr. Lipkin indicated that to solve this problem we must address a worldwide solution. Each child is unique. He indicated that the Autism epidemic increased dramatically over the last twenty years. He believes that there is a correlation between the environment and Autism.

We may never be able to truly determine the causes. He hopes that as we gain knowledge of Autism we may be able to increase our understanding of Autism. Dr. Lipkin has a twenty one year old with Autism. It is an increasing social and economic problem for Autism families. He ended by saying that we must try to address this problem.

6. The last speaker, Mr. Eric Olsen, joined the United Nations in 1993. He has been in the United Nations Department of Social Affairs since 2004 and is a member of the Focal Point Program. He has a BA degree from Rutgers College.

Mr. Olsen serves as an assistant member in the area of family policy addressing family issues. He works with member states in the area of the family and policy addressing family issues. He works with family partners, governments, NGOs and other United Nation agencies.

The International Day of Families was instituted on May 15, 2007. This was a convention on the rights of persons and families with disabilities. This United Nations charter;

Includes the rights in the Preamble

- Article 8, Awareness Raising
- Article 22, Respect for Privacy
- Article 23, Respect for home and the Family

The speaker provided A few aspects of the family and Autism as follows;

- Autism can have a high impact on families and family life.
- Mothers take extended care of the Autism child.
- Parents also need emotional support for the Autism child.
- Community awareness is also important.

Additional aspects provided by the speaker;

- Respect is important.
- Support and assistance by the community to the individual and his or her family is also important.

The World Health Organization of the United Nations issued a global advisory on vaccine safety in 2003.

More information on this subject can be found on E-Mail: olsone@un.org.

7. Juan Karl Brandt indicated that World Observance Day will be at the United Nations on November 26, 2007. He indicated that we should do the same for Autism awareness.

8. Questions/Answers:

8.1 Mr. Eric Olson; United Nations member states must prepare a paper on the topic of Autism for National Day at the United Nations. They can write to affected families on this. He will be meeting in three weeks on this subject to bring it up in October 2007 to have a national day at the United Nations in 2008.

8.2 Dr. W. Ian Lipkin; He indicated that it is difficult to determine the factors causing Autism.

8.3 Ms. Joan Kirby; She indicated that she will bring up the subject to the Executive Committee to add Autism to the September 5 –7, 2007 60th Annual DPI/NGO Conference.

8.4 Ms. Suzanne Wright; She indicated that it is very limited on what public schools can do on Autism. It is very difficult but more needs to be done.

8.5 Dr. W. Ian Lipkin; Indicated that his son had excellent care in schools since they moved to New York City. It was difficult for New York City schools to do this.

8.6 Ms. Suzanne Wright; Her organization is using many methods listening to every voice on Autism.

8. Questions/Answers (Cont'd):

8.7 Dr. W. Ian Lipkin; Requirements differ in the management of Autism. Not All methods work on a given Autism affected child. There are a number of different manifestations that make a difference. They are still looking at leads that affect an Autism child. His profession is trying to apply rigid modes for Autism as is done with cancer.

This requires a very sophisticated analysis of the Autism affected child. He Indicated that they need to focus on each condition of an Autism affected child worldwide.

8.8 Ms. Suzanne Wright; She indicated that her organization is working on a system to support Autism affected children when they grow up.

8.9 Ms. Joan Conner; Speaking from the audience gave her success story with her diagnosis of some Autism affected children including her own, some twelve years old. She gave a history of good and bad support and stumbled on parents with the same issue.

She slowly learned her rights and got them to provide a home program. It took seven years with full service for her affected child. Her child is now in high school and wants to go to Sara Lawrence College. From this experience she has become a special education advocate.

8.10 Dr. W. Ian Lipkin; He indicated that we must focus on parents to try to determine the contributing factors that affect Autism affected children. We have to take a broad scientific view. There have only been limited studies of abnormalities of the brain, etc, of affected children. With the new imaging techniques now available may be able to do more. They do not know if the environment or vaccines affect genetics.

8.11 Mr. Eric Olson; Families have been changing issues like homes, partners or divorced partners remarry. It is difficult to track. The United Nations is doing a review of vaccines and related issues. UNESCO is dealing with the education issues and UNICAP is dealing with the child issues.

8.12 Ms. Suzanne Wright; Her organization is working on a video glossary showing a child with Autism. Films are a great way of moving forward on this problem. The video will be available to everyone. She stated that next year we will have a Day of Autism at the United Nations.

NETWORKING SUB-COMMITTEE

Thursday, June 28, 2007, 1:15 –3:00 PM

Moderator:

William Gellerman, Chair

1. Mr. Gellerman opened the meeting and introduced a new representative from Russia. She just graduated as a doctor and joined us for this meeting. She is taking courses in a New York City college on humanitarian studies, etc.

2. Moses Williams, Co-Chairman, talked about his college in New Jersey (Rutgers) has collected book donations for needy areas in the Gulf Region and other areas. They have collected 3000 boxes filled with books.

He indicated that many areas in the Gulf area of Indian tribes have received no government help after their areas flooded resulting from storms. He recommended that we should contact Dr. Joseph Garcia, president of the National Congress of American Indians in Washington, D.C. for additional Information.

He stated that in September he will be working with New Jersey grade schools to teach the students of what we are doing. Moses Williams stated that he will be meeting with PSG on this week. PSG might take the lead in contacting other areas in the United States on this.

Moses Williams also recommended that libraries in each area should be contacted to see what or who can be contacted on this in the Gulf region. He will be contacting the American Library Association this week on this.

3. The subject of the planned breakfasts for the Conference was brought up. It was indicated that eight to ten tables will be required, one for each group. This information will be passed onto the Planning Committee.

4. It was indicated that we must now plan to network between other networks to Facilitate communication after the Conference.

5. It was recommended that we provide Moderators at the Conference with topics for their sessions. It was recommended that we have a session on topics before the September Conference. This can be by E-Mail to each of us on this Sub-Committee. This would raise question to address.

6. After the end of the September Conference, everyone attending, NGOs, etc, should have a Declaration for them to pick up as the final Declaration.
7. Our goals are to have a network of aligned networks, a revised vision as a basis of alignment and a rationale for alignment of a shared vision. There must be a process for achieving this alignment among networks and networks of networks.
8. We must encourage the Moderators to facilitate the alignment process.
9. The following strategies were recommended to be forwarded to the Planning Committee:
 - Solutions on problems in Africa
 - Create a measuring monitor to detect the global warming and early signs of danger

The world's leaders must see these early warnings early. The United Nations must have these monitors to be seen by member nations. They need to remember when dealing with people the level that they are at and deal with them at that level not on their own.

PLANNING COMMITTEE MEETING

Thursday, June 28, 2007, 3:00 – 5:00 PM

Moderator:

Juan Carlos Brandt, Chair, DPI/NGO

1. Moderator, Juan Carlos Brandt opened the meeting and welcomed everyone.

Adoption of the Agenda

- a. Motion was made and the agenda was approved

Minutes of the last meeting

- a. Approved without change

2. Media Sub-Committee

Joan Levy indicated that information on the Conference is being sent out.

The independent press and the student journal has both been contacted to participate.

The Chinese NGOs have submitted workshop papers. If needed they will be added to the workshops. The Chinese proposals were excellent. There are two from China but they can be combined.

Proposal made and agreed to have include China

We are planning on having 32 Mid-day workshops.

We will support proposals from other nations into our Conference. We are planning to use rooms at the United Nations and the Church Center. We are looking at UNCEF if we can get rooms there. We have a deadline that has to be met.

Ms Levy indicated that they are extending the deadline for overseas speakers to respond.

3. Internet Sub-Committee

They are reviewing all the material and content. They are also working on the September 6 screening date. Within the next week they will be providing the content for the internet.

4. Networking Sub-Committee

The sub-committee is working with students, schools and churches on the Conference. They are showing them the networking and how it can Improve Climate Change.

The sub-committee is also showing how people can bring in utilities on this important subject. Their goal is a network of aligned networks and a Conference Declaration framework for action.

The view of the sub-committee is that there should be an actual deliverable to come out of the Conference and bring together the leaders of the Conference. Networks will work with each of the Conference moderators to come up with an effective document.

The goal is to end up with a document that can be agreed to on the last day of the Conference. They plan to have a breakfast on the last day of the Conference to allow participants to talk with each other.

Networking recommends the use of a calendar to set up agreements of each topic to the September Conference and prepare agenda items. They also recommend that Conference participants be informed of their ability to confer before the Conference.

They recommend that we must integrate the Networking planned web site with the United Nations regional Conference web site. All Conference must be told that they can provide inputs to the web site. The Outcome Document will be presented to all member nations after the Conference on Climate Change.

5. Multigenerational Sub-Committee

They are moving forward on preparing their video for the Conference. They have two families from Africa who have agreed to participate. One is from Tangier the other is from Africa. The head of the second family has a Doctors degree from Rutgers.

They have also made contact with an individual from Algeria. They are also looking into areas. They need to make contact with students and teachers in high schools and college. They recommended that a Web site be set up for this. They already have a youth page on their Web site.

6. Program and Thematic Sub-Committee

Fifteen speakers have been confirmed and will participate in the Media Workshops at the Conference. These include Chinese speakers. Chinese NGOs are also planning to come to the Conference.

Attendees are asking how much their expenses will be and will they be able to get a daily subsistence allowance. They are being told to try to get funding from other sources. We do not have a budget for funding. If anyone can host an individual they should notify this sub-committee.

PDC George Weinstein
National UN Chairman