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Dear Friends,

Europe is still undergoing a severe financial crisis. The austerity measures that have been taken by members of the European Union in attempts to cut public spending have had an immediate impact on social protection policies. Throughout Europe, the member associations of Autism-Europe are questioning the budget cuts and freezes of certain welfare measures. In particular, several organisations and projects for people with Autism have experienced budget cuts or delays, such as delays in the creation of new residences, as well as cuts to funding for disability organisations more generally.

Autism-Europe is concerned about these developments and calls for further engagement to ensure that people with Autism, and people with disabilities in general, are not the first to bear the brunt of the crisis. Many steps are needed to develop their full participation in society and respect for their fundamental human rights.

In this context, it is essential to hold national governments and the European institutions accountable to their obligation and their commitment to pursue the full implementation of the United Nations Convention on the Rights of People with Disabilities. We must ensure that the rights of people with disabilities, and people with Autism in particular, are effective and that these people are not further excluded from society.

Fortunately, the support for people with Autism is unwavering and the cooperation of organisations representing people with Autism at the European and international levels has intensified. At the last General Assembly meeting of Autism-Europe, the following associations have become members: FEDRA (Romania), the Icelandic Association of Autism, Inspire Foundation (Malta), Autism Cymru (United Kingdom) and the Autism Center of Kuwait. We welcome these new members into our network and look forward to our future cooperation.

Sincerely,

Evelyne Friedel
President

Aurélie Baranger
Director
Annual General Assembly of Autism-Europe
Athens, Greece, 17 April, 2011

Yannis Vardakastanis recalled that an effective implementation of the UNCRPD requires a proper governance structure. To that end, Article 33.1 of the UNCRPD obliges the States Parties to designate one or more focal points within government for matters relating to the implementation of the UNCRPD, and to give due consideration to the establishment of a coordination mechanism to facilitate related action in different sectors and at different levels. Mr Vardakastanis highlighted the fact that the focal points should be at the highest possible level, and that one focal point can be enough. The UNCRPD is a mixed agreement, meaning that the matters it covers fall within the responsibility of Member States and or the European Union.

Article 33.2 of the Convention obliges States Parties to maintain, strengthen, designate or establish a framework, including one or more independent mechanisms to promote, protect and monitor its implementation. The Convention also lays down specific provisions on the full involvement and participation of persons with disabilities in the monitoring process. It is a new situation for institutions at national and international levels and therefore it requires a change of mindset and a ‘paradigm shift’ for all the stakeholders, including DPOs. The involvement of DPOs is key, and to this end an innovative approach is necessary and new mechanisms have to be put in place in order to enable better results.

The President of EDF also introduced the European Disability Strategy which is a framework of policy initiatives designed by the European Commission to promote the implementation of the UNCRPD. Eight areas have been identified; accessibility, participation, equality, employment, education and training, social protection, health and external action. This strategy identifies actions at EU level to supplement national ones, and it determines the mechanisms needed to implement the UN Convention at EU level, including within the EU institutions. It also identifies the support needed for funding, research, awareness-raising, statistics and data collection. EDF tries to correlate the European Disability Strategy with the Strategy 2020 (the larger strategy for EU policies for the next decade). This presentation echoed the presentation made by Evelyne Friedel of the draft leaflet produced by AE in 2010 to highlight the main aspects of the UNCRPD for persons with autism and their families. The leaflet will be made available in the coming months on the AE website.
Report on activities in 2010 and priorities for 2011

Delegates received information about the major activities implemented in 2010 by Autism-Europe and the priorities that have been established for the coming years.

The success of Autism-Europe’s ninth International Congress, ‘A Future for Autism’ held in Catania, Italy, in October 2010 was highlighted, and Autism-Europe President, Evelyne Friedel, thanked Vice President, Donata Vivanti, for her dedication in organising the congress on behalf of Autismo Italia, and her continuous efforts to achieve such a great result.

The large attendance (over 1200 participants) reflected that Autism-Europe is considered to be the most influential advocacy organisation in the field of autism in Europe. Prominent researchers were present as keynote speakers. Autism-Europe was also proud to welcome speakers from international organisations, such as the European Commission and the World Health Organisation. All the videos of the sessions are available on the congress website and on YouTube: http://www.youtube.com/user/AutismEurope2010.

Autism-Europe has managed to build a solid and trusting relationship with the scientific community, the professionals working in the field of Autism Spectrum Disorders (ASD) and the decision-makers at the EU level. It allows a fruitful cooperation aiming at enhancing the rights-based approach to care and intervention for persons with ASD in Europe. This contributes to promoting inclusion and anti-discrimination of persons with ASD in Europe.

Other landmark activities were the events held on the occasion of the World Autism Awareness Day, as well as the ongoing contacts that were fostered with the European institutions and other European NGOs such as the EDF and the European Social Platform.

As the priorities for next year’s activities were highlighted, the issue of ageing of persons with ASD is becoming a global concern for all our members. In the preparation of the European Year 2012 on ‘Active ageing and intergenerational solidarity’, Autism-Europe would like to prepare a report to raise awareness and share good practices for responding to the specific needs of elderly persons with autism. We therefore encourage you to share any valuable information you may have on this issue. AE would also like to consider the issue of multiple discrimination (including on the basis of ethnicity and gender) and how this can affect access to proper care, and to determine which forms of action can be promoted to address this issue. Once again, AE will encourage the sharing of good practices and experience between its members.

During the meetings, workshops were organised to improve AE’s internal and external communications as well as to share good practice on the issue of European Structural Funds.

Networking and welcoming new members

The AGA was also the opportunity for participants to network and learn more about the respective activities of their counterparts from other countries, and notably the work achieved by the Greek Association of Autism. During the meeting, new members were elected, and AE is delighted to announce that FEDRA (a Romanian Federation for autism) and the Icelandic Society for Autism have become full members, while the Inspire Foundation (Malta), Autism Cymru (United Kingdom) and the Kuwait Center for Autism have become associated members. We would like to welcome them to the AE network and provide you with the opportunity to learn more about them in this edition of LINK.

Finally we would very much like to thank the Greek Association of Autism for their very warm welcome and all their support in the organisation of these successful meetings.
Global bell ringing ceremonies and numerous celebrations honoured World Autism Awareness Day throughout Europe.


Duncan Niederauer, CEO and Director of NYSE/Euronext, and parent of a child with Autism, has generously given the honour of ringing the opening bell at the New York Stock Exchange to Autism Speaks each year since the inception of WAAD. To help raise awareness of the global impact of Autism, Autism-Europe and its members joined Autism Speaks and participated in bell ringing ceremonies in Amsterdam, Brussels, Lisbon and Paris.

UN Secretary-General’s Message for 2011

The number of children and people with autistic conditions continues to rise – in every nation and in every racial, ethnic and social group. Although the recognition of autistic conditions among the scientific, health and care communities is improving, public awareness remains low. The annual observance of World Autism Awareness Day thus takes on ever greater importance as an opportunity to mobilize for action and assistance.

Children and persons with autistic conditions face major challenges associated with stigma and discrimination, as well as a lack of access to support. Many struggle with multiple barriers in their daily lives. Far too many suffer terrible discrimination, abuse and isolation, in violation of their fundamental human rights.

Autism is a complex disorder. But in many cases the right treatment early on can bring improvements. That is why it is so important to raise awareness about the signs of autism and provide services as soon as possible.

It is also critical to support parents, create jobs for individuals with autism based on their skills and strengths, and improve public education to better meet the needs of students with autism.

Taking these steps will benefit society as a whole, enriching people with autism, their loved ones and others alike. As the mother of one child with autism said, “Although my daughter has walked a long way, I have walked a longer way.”

Together, let us travel this road toward a more caring and inclusive world.

Ban Ki-moon, 2 April 2011

World Autism Awareness Day 2011

Autism-Europe and its members stand up for Autism!

• France - Evelyne Friedel, President of Autism-Europe, rang the closing bell at NYSE/Euronext in Paris
• Belgium - Jean-March Delizée, Secretary of State for Social Affairs, with the portfolio responsibility for people with disabilities, and Aurélie Baranger, Director of Autism-Europe rang the opening bell at NYSE/Euronext in Brussels, with representatives from the Belgian associations APEPA and VVA.
• Portugal - Isabel Cottinelli Telmo, President of Federação Portuguesa de Autismo and President of APPDA-Lisboa, rang the opening bell at NYSE/Euronext Lisbon
• USA - Suzanne and Bob Wright, co-founders of Autism Speaks, the world’s largest Autism science and advocacy organisation, were joined by Duncan Niederauer, CEO of NYSE/Euronext in ringing the opening bell at the stock exchange in New York.
• Netherlands - Fred Stekelenburg, Director of the Dutch Autism Association (Nederlands Vereniging voor Autismie) sounded the closing gong of the stock exchange in Amsterdam.
Throughout 2010, NGOs Autism Overcoming, Children First and the International Child Development Centre engaged in the development of a project aiming to create a separate centre for social therapy to provide secondary/vocational education for youths aged 14 and over who have Autism. This programme will serve as a model for the introduction of analogous institutions all over the Republic of Armenia. The project was introduced, and will be supported, by the Government of the Republic of Armenia, and is currently in the preparatory stage.

**BELGIUM**

Between March 28 and April 1, interviews with people who have Autism and their parents were broadcast on Flemish radio and television. These are available on www.autismevlaanderen.be

**ARMENIA**

VVA, APEPA and Autism-Europe participated in the bell ringing ceremony on April 1 at the stock exchange in Brussels. The staff of several organisations and companies wore the WAAD button in the week preceding World Autism Awareness Day. A sound tower stood in the central station in Antwerp on April 1 and 2, in which travellers could hear how people with Autism experience the sounds of a train station. Participants in the sound tower also received a WAAD button.

**CANADA**

During the Autism month, the Autism and PDD Society of Laval organised a range of activities such as conferences and information sessions on Autism, an exhibition of artwork created by people with Autism, an Autism awareness walk, a visit to an organic farm run by persons with Autism and of Peguy’s House, a respite house for people with Autism and Pervasive Developmental Disorders.

**CROATIA**

This year the Croatian Society of Autism launched a huge awareness campaign, which was largely promoted on television and in the media. The launch event was generously supported by the President of Croatia and honored by the First Lady’s attendance. In their respective towns, our member associations held information stands and organised balloon releases together with people with Autism, parents, teachers, the media and anyone who wanted to join in. Iconic buildings including city halls, theatres and churches were lit up in blue. The Zagreb Society celebrated the opening of the first residential house for adults with Autism in Croatia. The whole campaign was a huge success.

**CYPRUS**

Cypriots participated in the Light it Up Blue Campaign, with several banks in Nicosia lit up in blue.

**CZECH REPUBLIC**

Czechs participated in the Light it Up Blue Campaign. In the capital city of Prague, for example, LBBW bank and KPMG buildings were lit up blue. Other businesses, schools, organisations and individuals also joined the campaign by wearing a blue t-shirt. APLA arranged a press conference, an exhibition of artworks made by people with Autism and a ‘Charity Zumba’ event involving celebrities.

**FINLAND**

The exhibition ‘Hop in! - Getting from Bangladesh to Finland on an Autism Rickshaw’ opened on April 2, on World Autism Awareness Day at the Helinä Rautavaara Museum in Espoo. The idea was for visitors to discover the daily life of Bangladesh and of people with ASD through their senses: listening, feeling, smelling and seeing. The exhibition was open during April and was visited by more than 5.000 people. The Helinä Rautavaara Museum exhibition might be over, but the Autism Rickshaw continues its journey as a global education campaign all over Finland, spreading global awareness of Autism.

**FRANCE**

**AUTISM CONSORTIUM**

On World Autism Awareness Day, the Autism Consortium, including Autisme France, the Sésame Autisme Federation and Pro Aid Autisme held a press conference to launch their campaign on educating children with Autism in ordinary schools. The campaign was given coverage in the local and national press and on television.
**GERMANY**

The president of Autism Germany, Maria Kaminski, and Prof. Dr. Christine Freitag of the University Hospital Frankfurt (a member of the scientific advisory council), were interviewed by the Deutsche Presseagentur. The interview was published in many media outlets. Additionally, numerous activities of our regional organisations were held, for example, informative events on the topic of Autism, exhibitions, cinema and much more.

**GREECE**

GSPAP celebrated WAAD in the cities of Athens, Thessaloniki and Ioannina, where professionals addressed large audiences on issues of sensory integration, obstacles to community inclusion, parents’ psycho-social education and the validity of new ‘therapies’ for people with Autism. The celebrations were concluded with a performance by young people who have Autism and by showing the film *The Boy Inside*.

**HUNGARY**

Hungarians also took part in the Light It Up Blue Campaign; the Hungarian Parliament in Budapest, the local music palace in Kaposvár, the fortress of Tata and shopping windows in the centre of Szombathely, among others, shined in blue.

In Székesfehérvár, the ‘ Más Fogyatékos Gyermekékért Foundation’ organised an ‘A for Autism’ programme at the local mall and lit the local theatre up in blue. Numerous other events took place across Hungary on WAAD: Run for Autism, awareness walks, broadcast of the film *Rain Man*, an exhibition of arts and crafts made by people with Autism and a ‘common tea event’ which was open to everyone.

**ITALY**

In Turin, the film Festival CinemAutismo2011 took place from March 31 to April 2, organised for the third year by Associazione Museo Nazionale del Cinema and M. Mastino and G. Torrej, with the support of Gruppo Asperger Onlus and ANGSA Piemonte Onlus, and the patronage of Fantasia Federation. The festival was attended by 450 people in four sold-out events with films and short films about Autism and Asperger Syndrome. In Rome, the XV Municipality of Rome in collaboration with the Library of Corviale and the sponsorship of Gruppo Asperger Onlus and ANGSA Lazio Onlus, showed the film, *Temple Grandin*.

**ICELAND**

There were two big events held in Iceland on April 2. First, the opening of ‘Specialisterne’, a company owned by the Icelandic Autistic Society and a few members of our organisation. Specialisterne trains people with ASD and helps them develop skills to search for employment. This company is based on the same model as Specialisterne in Denmark and was developed with their help. Second, the Icelandic translation of the book *Freaks, Geeks and Asperger Syndrome* by Luke Jackson was published. Close to 300 people came to celebrate with us that day.

**LUXEMBOURG**

The Autism Foundation of Luxembourg ([www.fal.lu](http://www.fal.lu)) held a conference on the theme ‘Autism – Improved awareness for improved support’ on April 2. Two professionals in the field, Dr Eric Willaye and Dr Stephano Lassi, were invited to give presentations. The aim of the conference was to raise public awareness about Autism. The conference was a success and families were made aware of the services offered by the Foundation and given the opportunity for discussion with one another.

**MACEDONIA**

On April 2, the Macedonian Scientific Society for Autism (MSSA) organised an event in Skopje hosted by Zoran Ljutkov, a famous Macedonian actor, in which numerous Macedonian singers, including children’s choirs, also took part. During the programme, children with Autism and parents shared their experiences. MSSA’s President, Prof. Dr. Vladimir Trajkovski, talked about the issue of Autism in the Republic of Macedonia. Jasmina Troshanska, Vice-President of MSSA, addressed the diagnostic aspect of Autism, and Zoran Ljutkov presented on the rights of persons with Autism. The event benefitted from the generous support of Mrs Maja Ivanova, the Macedonian President’s spouse. Television and radio stations broadcast information about Autism and on the events held on April 1 and 2.
PORTUGAL

Awareness postcards and events were organised in various towns of Portugal.

POLAND

To celebrate and commemorate the World Autism Awareness Day, the SYNAPSIS Foundation in Poland joined the Light it Up Blue Campaign. On April 2, the Palace of Science and Culture, the most characteristic skyscraper in Warsaw, turned its lights blue. The Grunwaldzki Bridge in Krakow was also lit up in blue. It was a great opportunity to draw the attention of both society and the media to the issue of Autism in Poland, where the level of Autism awareness is low and where the national care system is still inadequate. The campaign was widely promoted on the Foundation’s website, on Facebook and in the Polish media.

ROMANIA

Autism Romania also joined the Light It Up Blue Campaign. Thanks to their participation, the Romanian Parliament building – the biggest building in Europe – as well as other representative buildings in Bucharest (the Arch of Triumph, the National Theatre and educational institution buildings) turned blue on April 1 and 2.

SPAIN

AUTISMO ESPAÑA

Autismo España commemorated the World Autism Awareness Day 2011 with the projection of a movie untitled Maria and I in Madrid (the film’s website, María y yo: http://www.bausanfilms.com/EN/69/movie/home), which attracted over 200 people. During this event people with and without Autism, as well as representatives of the disability collective in Spain, participated. The film was shown simultaneously in 24 locations in Spain. These cinematographic events were all organised by Autismo España’s member associations.

MAS CASADEVALL

On April 2, the Mas Casadevall Foundation in Serinyá (Girona) held information stands in 5 Catalan towns to raise awareness on the difficulties that people with ASD are confronted by, and to voice their demands. Products made by residents were also presented. The film entitled Maria et Moi was also projected in Girona and Barcelona. It features, with a touch of humour, the story of a famous cartoonist and his autistic daughter, Maria.

SLOVAKIA

From 30th March to 2nd April, the Bratislava Castle in Slovakia was lit up in blue (as part of the Light It Up Blue Campaign). SPOSA organised the so called ‘Water Ball Day’ in the city centre of Bratislava on April 1, with special guests, Mrs. Gasparicova, wife of the President of the Slovak Republic, and Mr. Ptacnik, Mayor of Bratislava. One of the Water Ball Day attractions was a falcon show by a group from Banska Stiavnica.

UNITED KINGDOM

The UK based service provider, Spectrum, marked World Autism Awareness Month with two lectures on the triggers leading to challenging behaviour, given by Robin Gunson, Spectrum’s Head of Developments. The lectures, which were held in community halls and free to the public, were organised by Mark Hilley of the Devon & Cornwall Autistic Society (DCAS), a charity offering support to families in Cornwall who are living with ASD. For information on Spectrum and the DCAS please see www.spectrumasd.org and www.dcas.eu or contact Deborah Moore at deborah.moore@spectrumasd.org.
My late brother Mark was autistic and I noted the things that affected him, such as bright light, unpredictable sounds and heat, as well as his obsession with detail over the bigger picture, order, sameness, stimulation, stability and calm. I completed a thesis on building for people with autism whilst at college and since practicing as an architect I have designed a number of buildings for children and adults with autism, as well as continuing my research.

“As we know autism is a complicated disorder that affects communication and the senses. We also know that a ‘one size fits all’ approach on the basis of a shared label of Autism Spectrum Disorders (ASDs) may not be effective in helping these individuals” (Donna Williams).

I have taken some simple concepts which, if used in the design of buildings, can have beneficial effects for people with ASDs without being specific and therefore marginalising them into bespoke buildings that are equipped for special needs.

Calm, Order and Simplicity

Complexity can cause stress if it is not harmonious. For people with autism the effects of complexity are much greater, they are unable to discern separate noises, shapes, etc, easily, which can lead to tension. If a building or set of buildings are planned in a simple and clear manner the user will require little effort to use and enjoy the building. A clear layout and organisation of spaces can help a person use a building without confusion as to the location of rooms. A building that has a sense of clarity and order has a calming effect on the user; whether they are autistic or not, the stimulation is reduced. To provide a calm ‘back drop’ for people with autism can assist in reducing some elements of stress which is helpful for their well-being.

Fig 1 : Newcastle school

This is a plan of a school I designed in Newcastle, United Kingdom. The idea was that the junior and senior schools are separated by the main communal and administration departments. The classrooms for each school are located off a courtyard, defined by the ‘Golden Spiral’. It is this courtyard that provides a constant source of reference when you circulate around the building or exit a classroom. The intention is that you are always connected with this source of reference and able to locate yourself easily at any point within the building, therefore providing a source of calm, order and clarity.

Calm and order is not confined to a building’s plan and section; it can also be observed in the use of materials. The Cistercians reflected the austerity of their faith in their architecture. The plain simplicity of the stone walls, floors and roof vaults is uninterrupted by the complex distractions of adornments and embellishments. This Abbey and its concept is over 800 years old, yet it is a perfect example of simplicity, calmness and order. The same material is used everywhere.
This is a more contemporary example of a space I designed that used similar materials for the walls, floors and ceilings. The limited pallet of materials assists clarity and makes for a calmer space.

"Maintain a stable, ordered and secure environment. The autistic child simply cannot function if there are too many daily changes... The autistic child is unable to bring order to his world. You must provide that order in his environment. Autistics might march to a different beat but that beat can be meaningful." (Temple Grandin).

It is not always easy to limit the use of materials, but I feel at least the application of restraint should always be in the forefront of one’s mind when designing spaces for people with autism.

**Minimal Detail and Materials.**

Complexity in the detail of a building can cause visual distractions and sometimes obsession. People with autism can become absorbed with such detail, therefore you should design out any elaborate or unnecessary detail using a limited pallet of materials, and reduce hard edges which in turn will provide a less distracting, more restful solution.

"Every morning I had to catch a bus and tram for the long journey to this new school. It certainly was a new school as everything in it seemed new. There were shiny red banisters and curved tinted windows. There were indoor carpeted staircases everywhere, the whole place was a mass of corridors; a puzzle in which you had to choose the right door. I liked the banisters, which led to hallways with red doors running off them. I was constantly going into strange classrooms and sitting down before being escorted out and pointed in the direction of my own class... On lunch breaks I would wander through the school watching various colours which disappeared under my feet and I would stop sometimes and stare at something for the entire break, like the polished floor of the gym or the reflection in the curved tinted glass windows.” (Donna Williams).

**Proportion**

Ancient proportional systems resonate with something within the human mind or heart which recognises beauty in a very direct and intuitive manner. When we see a natural form such as a sunflower we automatically see its beauty. These proportional systems are derived from, and abundant in, nature.
The diagram below shows the golden spiral in operation, creating a series of rectangles which can be used in plan and section. This proportion can help to achieve well balanced spaces.

Some years ago I designed a small building which derived its proportion from the Fibonacci series of proportion, this is a proportional system which is close to the numbers of the golden ratio. The Fibonacci numbers are 0 1 1 2 3 5 8 13 21 34 55....

This is a Children’s Centre I designed which again uses the Fibonacci numbers as well as a limited pallet of materials.

This is a school designed by architects, Greenhill Jenner, which shows the use of sandblasted glass that diffuses the natural light providing evenness which is less powerful and distracting.

Fig 7

Natural Light

“The key is light and light illuminates shapes and shapes have emotional power.” (Le Corbusier).

Natural light that enters into any building will uplift the spirit. Introducing light into a building needs very careful thinking with autism in mind. Too much variety may startle, too much shadow may create repetition as visual stimulation.

A chapel designed by Tadao Ando which for me has very strong emotional power.

Fig 10

Fig 12

At Ronchamp in France the introduction of light is much softer.

Fig 11

At Ronchamp in France the introduction of light is much softer.

Fig 13

Good levels of even natural light will help make and clarify a space, how it falls onto walls and floors will help a person come to terms with a space. As Le Corbusier states, it has emotional power. It is how much power we should introduce into a space that we need to consider for people with autism.

Proxemics

Proxemics is defined as the branch of knowledge which deals with the amount of space that people feel it necessary to set between themselves. Proximity is the condition of being near or close. This personal space surrounds the body. Most people guard this space to some degree. With autism this personal space can be greater and more sensitive. During a normal day this space is often infringed. In a building, spaces are defined by ceilings and walls. If they are too close, the space is limited. To provide generous circulation space in a building will help reduce the impact of this infringement.


**Containment**

It is important that a child with autism is "contained" for their own safety, but it is important that they are able to wander freely, or certainly feel that they can. Equally, it is important that the carer is comfortable that the child can wander in safety. How we provide a safe place within which this child can wander is the essence. History and nature shows that this can be achieved in a subtle manner.

A Zen enclosed courtyard which does not give the feeling of restriction.

"All of us need a private place. Autistic children need their secret places too, in which they can hide and retreat to their own world. After all autism is a 'withinness' disability and autistic children need the security of their own hideaways. I had mine and it was a place for me to think and recharge myself." [Temple Grandin].

**Observation**

We need to be able to easily observe the movements of children with autism for reasons of safety and well-being, but it is important that this person does not feel as if they are being watched all the time. To feel free is important for children with autism. If we provide uncluttered internal and external spaces, this will assist observation. If there are known secure boundaries that cannot be seen, but are known, this allows the children with autism to escape from view.

**Acoustics**

"Sometimes I heard and understood and other times sounds and speech reached my brain like the unbearable noise of an onrushing freight train. Noise and confusion at large gatherings of people overwhelmed my senses." [Temple Grandin].

All people are sensitive to sound to varying degrees. My understanding is that people with autism struggle to discriminate different sounds and are more sensitive to sound. A building’s construction needs to respond to this in terms of impact sound, flanking and reverberation transmission. This can be achieved in the type of construction, from grass roofs to limit impact from rain, to mass wall construction and good sound absorption of materials.

A school I designed in Hereford uses a grass roof to help reduce impact noise from the elements, such as rain, as well as being sustainable.

I was asked to design a classroom for Newcastle City Council that responded to the needs of the child with autism. The designs embody some of the concepts discussed in this paper.
In 2008 I was invited by an independent government organisation to present proposals for a new Autism Centre in Abu Dhabi. Our proposals were based on the ideas set out in this paper and also from personal experience and projects completed to date. The designs were met with universal approval and the practice was commissioned to design the centre in 2009.

During development of the design, another criteria entered the process; namely that the concepts should not only be about autism and architecture, but also culture and tradition.

Firstly, I would like to explain the design proposals and then explain how culture and tradition had a further impact on the research and design.

The design for the centre is for an all-through school for children with autism from the ages of four to 16. The centre also has an early intervention centre, adult workshops and respite facilities. Similar to other schools we have designed, the classrooms for each age group are distinct and separate from each other, as well as being gender separate due to the culture of the United Arab Emirates (UAE). The spaces are located around the communal spaces including courtyards, food bar and drama theatre. This communal form provides an easily identifiable still point that will be a source of reference and location in the building.

All the departments in the centre are accommodated in easily identifiable forms that are embraced by a single lightweight roof and acid printed glass screen. This roof and screen acknowledges the harsh environmental conditions in the UAE and provides protection from heat gain and sun glare which is important to avoid for people with autism. The acid printed glass screen also diffuses the natural intense light therefore softening the shadows and light entering the building.

What became apparent during the development of the design was the need to embrace the Emirates’ culture and tradition. This was important because it would give the children and stakeholders of the centre some personal cultural identity, making the children feel less alienated and allowing the building to be part of their culture.

The people of the Emirates hold very strong family values and the children using the centre are cared for by the family outside schools hours. With this in mind we approached the building first with autism in mind, then moulding the overall plan to historic and natural forms. The overall plan, section and elevation is based on the ‘Golden Spiral’ giving all the forms and spaces good proportion which in turn will provide good quality acoustics, particularly improved by the use of sandblasted limestone for the all the walls.

All the independent forms are held together by a uniform acid screen printed glass brie soliel. This screen will have prints originating from arabic calligraphy. The highly recognised artist Mohamed Mandi will be developing the designs in workshops with the children at the local autism centre and it is hoped that their participation will provide a form of cultural ownership of the building. Below is an early model of the centre. The school is due for completion in September 2012.

Fig 21

Conclusion

The intention of these concepts is to hopefully provide a framework, or menu if you wish, to assist designers developing projects for people with autism. If we remain committed and connected to the overriding simple concepts then the approach to ASD design can not only be subtly specific, but also universal. Always remember it is not what you put into the design, rather, it is what you do not do that has the effect. The power of restraint.

• Simon Humphreys RIBA FRSA

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My experience in voluntary activities

2011 is the European Year of Volunteering, as declared by the Council of the European Union, because: “volunteering is one of the key dimensions of active citizenship and democracy, putting European values such as solidarity and non-discrimination into action, and as such contributing to the harmonious development of European societies”. I contribute to this occasion by sharing my experience in volunteering activities as a person on the autism spectrum.

I am a man of nearly forty years and I have received a diagnosis of Asperger Syndrome (AS) only five years ago. Meanwhile I have been a volunteer for thirteen years. When I was young I never thought that I would be able to become a volunteer; for me to stay in close touch with people was unimaginable because of all my difficulties in communication and social interaction (which only many years later I understood to be features of the autistic spectrum condition). I’ve always been very shy, in kindergarten I never talked with other children or with the schoolteacher; it was very difficult for me to talk to new people, both my peers and adults, and I would only begin to interact after I had seen them for a long time, but even then I always barely interacted at all. Also, to see people in trouble or in need of help was very annoying to me and I always avoided such situations.

In 1997, while I was still a college student, I became a conscientious objector to military service for ideological reasons, rejecting all forms of violence and weapons, so I did civilian service instead of military service, which at that time was still mandatory in Italy. This was my first experience with the world of voluntary activities. I worked in accompanying children of Roma camps to school, along with social workers. At first I was not convinced that I was able to carry out these activities, especially since the children were ‘live wires’ and I had no experience and no predisposition to work with children, but I had a strong motivation to continue.

Slowly I was able to adapt, social workers followed me closely and the parents of the Roma camp gave me confidence because they knew that I was unable to scold or mistreat their children, even when they were a bundle of mischief, and the children themselves preferred to be in my company rather than that of the social workers because I never reproached them. Moreover, since they...
were very lively and alert, they themselves began to interact with me and stimulate me. Eventually I felt so at ease that when the twelve months of compulsory civilian service came to an end and I resumed my university studies, I continued for another six months in the same Roma camp as a volunteer. I found a lot of gratification in what I did; the experience has enriched me a lot and changed me as a person, dramatically improving my social and communication skills.

In 1998, then I entered into an international organisation of volunteers who are dealing with human rights and social, cultural and political projects. In particular, I participated in campaigns for human support in third world countries and I have travelled many times in sub-Saharan Africa. Here, as in the experience of civilian service, I was surrounded by sensitive people who appreciated my virtues, strengthened my strengths and helped me to overcome my weaknesses and difficulties - unlike in my previous domains of schools and university, where people around me had a competitive spirit, exalting my flaws, mocking me and not enabling me to experience much personal growth. I felt particularly at ease in my travels in Africa because the relationship with the African people, especially in villages, is more direct and explicit than in western countries; there are fewer barriers and less filters, it is obvious how they feel and what they need, and it is easier to relate to them.

Meanwhile, I dropped out of university and I started working in a computer company. I put those skills to good use in Africa, working with computer literacy and opening an internet centre. I turned my difficulties into strengths; after one week the other Italian volunteers who travelled to Africa with me began to miss Italy, friends, relatives and Italian food. They wanted to go back, but I was very focused on my task and for me, eating rice for lunch and dinner for weeks was not a problem because it’s my favorite dish. My longest trip lasted two months.

Finally, five years ago by accident I discovered Asperger Syndrome. After that I received the diagnosis and I started to participate in associations of families, professionals and workers in Autism Spectrum Disorders, and I compared myself with other people in the spectrum like me. All this has made me fully aware of my situation and provided additional tools for me to continue my journey of personal growth. I immediately started to do voluntary activities in associations in the field of ASDs; participating in projects, giving talks at conferences and connecting with people with AS and their families.

Recently, my responsibilities have increased; in 2009 I became Vice President of Gruppo Asperger, a non-profit organisation, and in 2010 I became a member of Autism Europe’s council of administration as a self-advocate. Voluntary activities have become the main activity of my life and also the one that gives me the most satisfaction and benefit for my personal growth. I discovered with pleasure that many other people on the autistic spectrum have undertaken a path in voluntary activities similar to mine, mainly by giving accounts at conferences, becoming a councillor of associations of families who are dedicated to autism, or founding organisations or communities made up of people in the autism spectrum. I can not list them all here, in the literature and on the internet it is easy to find biographies of these people in the spectrum and on these organisations and communities. I would love to mention Marc Segar; though, a young English man with ASD that died young in an accident; he was the famous author of *Coping: A Survival Guide for People with Asperger Syndrome*, which was published in 1997, and he was also a volunteer in Africa and active in associations of families dedicated to autism.

• Pietro
‘ACEbook’ project helps adults with Autism across Europe to make friends

Results from a research project have shown that Facebook can be used to help adults with Autism to establish social connections and make friends.

So far, the results have been very positive. Another project participant, 38 year-old Scott Burdon from the United Kingdom, described his experience of the project: “I have found the experience of meeting new people on the project very educational. This project has given me the opportunity to travel to places I would never have seen otherwise and learn about new cultures”.

Parents of the young adults have also been interviewed to gauge the project’s effectiveness.

“Parents have reported significant positive changes in their sons’/daughters’ independence, mood, social skills and communication which they attribute to the project,” explained Dr Lawson.

“The preliminary results from interviews with parents also show that the project has challenged their sons and daughters to overcome certain fears, and that the resulting feelings of pride and achievement have had significant influence on other social aspects of their lives, including the parent-child dynamic,” he remarked.

Another researcher associated with the project, Dr. Maddalena Fiordelli, added: “One of the most important findings is that the friendships formed are stronger if people have been meeting regularly in person. This confirms previous research on online social networking which tells us that social networks foster previously existing connections. From interviews we discovered that participants like to use Facebook to stay in contact with their two or three close friends during the time between meetings”.

People with Autism often have a strong need for structure and an aversion to change in their everyday lives, and as Dr. Fiordelli explained, the research also found that “Autistic adults can benefit from a structured environment like Facebook for their relations.”

The project’s final event, in which project participants discussed their achievements through the project, was held in Ljubljana in September. A documentary called ACEbook – the real social network was also made during the project, and is available for viewing. For copies, contact the Center for Autism Slovenia: +386 1 620 7734 +386 3 147 0187 - info@avtizem.org
In 2008, the Welsh Government announced the implementation of its 10 year Autism Spectrum Disorders Strategic Action Plan for Wales. In doing so, it became the first government in the world to deliver a national strategic policy for autism and over these past three years have supported its implementation with £7.1million of ‘ring-fenced’ funding for autism. This article describes what this strategy has achieved to date. It also serves to tell the story of the pivotal role that Autism Cymru, a small Welsh autism charity, has played in bringing about these major changes for people with autism, their families and supporters, as well as its role in setting up a world class research agenda for autism in Wales.

Wales has a population of just over three million people and since 1999 has had its own government, but until Autism Cymru was founded (following a grant from the Shirley Foundation) in 2001, Wales did not have its own national charity for autism. The combined energy of a new national government and a new national charity for autism came together in 2001-2002 and the outcome of discussions was a partnership between the Government and the charity to develop a national strategy for autism. As Autism Cymru’s Chief Executive, I was asked to chair the development of the strategy and this involved many practitioners, parents and people with autism. The strategy was launched in April 2008 by the Welsh Government and I was seconded to the Government as ASD Implementation Manager for Wales to drive forward the delivery of the strategy.

It is now three years since delivery of the autism strategy in Wales began and an evaluation of progress made was published in March 2011. So, what impact has been made by having a dedicated autism strategy in Wales?

Wales now has a formal infrastructure for autism – each of the 22 local authorities in Wales has a lead ASD officer and an ASD stakeholder group consisting of people with ASD, family members, charities, practitioners, etc (totalling over 400 members across Wales). There is also a national stakeholder group operated by the Welsh Government. Each of the 22 local authority areas has a local ASD action plan, based upon the national plan. During 2009-2010 alone, 22 new collaborative projects benefiting people with autism, their families and those who work with them were developed and funded via the Welsh Government funding for autism and as a result of local ASD action plans. Wales now has a national ASD practice and learning web resource and an ASD learning improvement network led by a national coordinator.

Another of the benefits has been a big increase in autism awareness-raising and over 5,000 people in Wales attended autism training courses delivered in Wales during the 2010-2011 period.
19 of the 22 local areas in Wales reported a big increase in awareness of adults with autism over the same period. In 2009, the Welsh Government commissioned research into the needs of older people with autism with Bangor and Glamorgan universities, and as a result, a series of recommendations have been made regarding the improvement of recognition, practice and research in this increasingly important area of work.

In December 2010, the Welsh Government appointed the Wales Autism Employment Ambassador, Robert Lloyd Griffiths, and Robert’s role is to promote the positive benefits of employing people with autism to business. In February 2011, the Welsh Government also published a wide range of autism awareness materials for schools, doctor’s surgeries, homelessness services, employers, older persons with autism and so on, and these can be accessed directly from the Welsh Government website.

Back in 2007 Autism Cymru sought the support of the Welsh Government to create a world class research facility in Wales and the charity pulled together a funding partnership with Cardiff University, Autistica, Autism Initiatives, the Welsh Government and others to raise £750,000 to recruit the United Kingdom’s first named Chair in Autism Research to Wales. In April 2009, Professor Sue Leekam was appointed as Chair in Autism and Sue became the Director of the Wales Autism Research Centre launched in September 2010 at Cardiff University.

Persuading government and academia to engage so fully in autism in Wales and to support service developments with major financial resources has been Autism Cymru’s BIG achievement (a peak not yet reached by charities in England and Scotland, although some significant strides have been made recently by Autism NI in Northern Ireland). However, there is so much more to Autism Cymru’s work, including our training throughout Wales, the world online autism conference run by a member of our staff, Adam Feinstein, our employment programme in partnership with the Irish Society for Autism [reported upon in the last issue of the Link magazine], and our fourth Wales Autism International Conference in Cardiff City Hall attracting speakers and delegates from throughout the world. Autism Cymru is also a member of the Celtic Nations Autism Partnership with our friends in the Irish Society for Autism, Scottish Autism and Autism Northern Ireland. For all of you who have small autism charities across Europe, bear this in mind, as you can achieve a great deal more than the big charities by thinking strategically – and we in Wales are proof that this is so! For those who wish to learn more about Autism Cymru’s approach in Wales and the impact of the Welsh Government’s ASD Strategic Action Plan for Wales please contact me by email (hugh@autismcymru.org).

Hugh Morgan
Chief Executive Autism Cymru and Expert Advisor for Autism to the Welsh Government
Maltese foundation joins Autism-Europe

Inspire - the Eden and Razett Foundation - is a leading voluntary organisation in Malta which specialises in providing inclusion services for persons with physical, learning and intellectual disabilities. Inspire aims at providing a holistic range of programmes and services to children and adults with disabilities, and championing their inclusion and equal opportunities in civil society. Through dedicated staff and volunteers, Inspire provides various services to over 1,000 children and adults with different needs and potential. These services address the educational, therapeutic, social and recreational needs of the people who Inspire helps, with a focus on ability and potential.

Inspire is Malta’s largest provider of specialised educational programmes for children with Autism Spectrum Disorders (ASDs). Inspire’s programmes are also the leading accredited programmes recognised by the education division of Malta’s Ministry of Education, Employment and the Family. Inspire works closely with this ministry to support children and teenagers with autism in Malta and Gozo. Through the partnership with the Ministry, an increasing number of children and their parents are supported at home, in school and within Inspire’s programmes. Inspire’s programmes support mainstream education and, together with the education division’s ASD support team and other specialist teachers, they work towards ensuring that students exhibiting autism are enabled to participate and progress.

Inspire’s ASD programmes, STEP and STYLE, are offered through a team of tutors who are supported by speech and language pathologists, occupational therapists and the programmes’ psychologists. Parents are considered to be key members of the multidisciplinary team and work alongside tutors and the other professionals. Their commitment and cooperation is considered to play a major role in the child’s progress. Parents are an integral part of their child’s assessment and teaching, constantly providing information about their child’s needs, behaviour, interests and dislikes, and also voicing their own concerns and priorities for their child.

Inspire works with the parents through providing the opportunity to observe sessions, feedback, parent support and discussion groups. Links are maintained with schools through Inspire’s participation in the regular reviews and through delivery of specialised programmes for the remaining children in the mainstream classroom. Inspire’s staff members carry out school visits, whilst the learning support assistants working in various schools visit the Inspire programmes to observe specialised teaching strategies and techniques within a highly structured environment. This is followed by a discussion with the specialised tutor providing the opportunity to enhance liaison. Autism specific strategies adopted by Inspire include the consistent use of visual structure, low arousal approaches, strong sequencing, high levels of predictability and individualised practice. Individual and group sessions are organised to offer choice, variety and opportunities in coping with change and problem solving.

Apart from offering educational programmes, Inspire is also actively engaged in carrying out research and promoting the rights of persons with ASDs within society at large. Inspire has been successful in creating employment opportunities for adults with autism, providing them with job coaching and supported employment. Inspire has also participated in EU projects facilitating the exchange of best practice and knowledge regarding autism in a range of EU countries.

Inspire is also currently working on developing outreach support in order to create opportunities for children with autism to participate in mainstream sports, theatre and music.

Inspire continues to seek learning opportunities for its staff and opportunities to share best practices with local and overseas organisations that work in the field of autism.

“With an increasing number of people diagnosed with autism around the world, it is crucial that we continue to innovate and work in partnership with parents, government and other NGOs to ensure that best practices are shared. It is also imperative to network with organisations overseas, in view of facilitating further the exchange of best practices, research and policy advocacy at local and European levels”, says Nathan Farrugia, Chief Executive of Inspire.

It is in this context that Inspire has recently sought to join Autism-Europe as an associate member. Indeed, the organisation looks forward to collaborating with members of Autism-Europe, exchanging best practices and ideas on policy development, as well as piloting socially innovative projects for the benefit of persons with autism and their families.

INSPIRE is officially registered as an association of volunteers, under the name Eden and Razetti Foundation.
The main mission of the Kuwait Center for Autism is to spread Autism awareness and ensure an accurate educational program to children with Autism, a lifelong disability, for improving their educational, social, and conceptual abilities. The program takes into consideration individual differences and supports students' vocational talents and fosters their integration within society. To achieve this purpose, teachers, parents, specialists, and workers in the Autism field are provided with continuous courses and special training (including lectures, workshops, and international conferences) to improve their efficiency and keep pace with international developments in this field. In addition, a series of publications are being added to Arabic literature to enhance awareness of Autism, and a bimonthly magazine called Silent Scream (in Arabic) is published with local and international events in the Autism field.

The programs, activities and services presented by the Center are:

A. The Educational Training Program is presented on a scientific and educational basis that suits the Autistic child’s abilities. The program evaluates the child to determine the level of his or her abilities, an individual education plan is set to assess the improvement of the student all through the year and he or she joins the class that fits his or her age and abilities.

B. The Early Intervention Program is an intensive rehabilitation program for children from age 3 to train in basic skills such as work behaviour, work skills, and enhanced communication. Behaviour modification plans are established and families are assisted to design self-help programs.

C. The Friends Club Program is an entertainment program to enable children with Autism to spend weekends with siblings and other children in a pleasant atmosphere of fun, entertainment, and structure under the supervision of specialised persons.

D. The Summer Camp is arranged during summer holidays (with 8 summer camps held so far), giving the children a mixture of entertainment, training, and amusement at a structured environment. This Camp is open to all students with Autism and Down Syndrome from different schools and establishments within and outside of Kuwait.

E. The Swimming Club Program is an afternoon program set up every year during summer holidays for children with Autism and special needs and their brothers and friends under the supervision of trainers. It is an essential step to join autistic children with normal and external society in such clubs teaching them many interaction and communication skills.

F. The Youth House Program aims to train youths suffering from Autism and Pervasive Developmental Disorder (PDD) in self-help skills, such as communication and social interaction, through several activities and programs specially planned to achieve these goals.

G. Conferences and Workshops are held for families, teachers, and workers in the field of Autism and special needs, also all those who have relationships with people who have Autism in and outside Kuwait. The first international conference in the region was held in 2000 and the second was held in 2003.

H. The Occupational Program for people with special needs to find a suitable job to secure a better life began at the center by employing one young man with Autism and another young lady with Down Syndrome.

I. The Evaluation & Diagnosis Unit studies the main problems and difficulties of each child in cooperation with genetic centers for medical tests and performs academic and psychological evaluations. Finally, the parents receive a detailed psychological report with recommendations.

J. Consultation and Training is provided by specialists in the field of Autism who are invited from countries around the world, for continuous information on the latest developments in the field of Autism.

K. Publication series have been available since the establishment of the center. Understanding and awareness of Autism is spread by composing or translating specialised books into Arabic language (more than 50) to overcome the clear shortage of such books, audio, and video in Arabic libraries.
The Center which was previously functioning in a small rented building, has now moved to a new building (built on 10,000 square metres) as a result of the benevolence of the generous people of Kuwait. To acquire proper land took many years of continuous efforts through determination, a lot of meetings with ministers, congress men and many others. Further efforts were then required to raise donations for the building which cost $11 million. The design of the building aims to provide an integrated service for people with Autism at one location which is also the first of its kind in the entire Middle East. Many Autism professionals from the United States, United Kingdom and other countries who were invited for its opening ceremony in January 2011 (under the auspices of His Highness the Amir Sheikh Sabah Al-Ahmad Al-Jaber Al-Sabah) congratulated Dr. Samira Al-Saad for achieving this unique construction which they had not seen before, even in their own countries.

For further information please email to kwautism@qualitynet.net (until our website is renewed).

L. Silent Scream magazine (since 1997) is the first scientific specialised magazine in the Middle East concerned with Autism. It speaks for those who are suffering from Autism and other difficulties, with many translations, research articles, interventions and updates on scientific research in this field.

M. Gulf Autism Union established in 2002, brings together the professionals and institutions in the field of Autism in the Gulf region. It will soon be called the Arab Autism Union.

N. Maintenance of the ISO 9001:2000 certificate acquired (in 2005 and 2008) to ensure the quality of service provided and also to improve the efficiency and productivity of the services provided.

O. Autism Accreditation Status was awarded to the center in 2010 by National Autistic Society Accreditation, United Kingdom for quality Autism provision.

P. The Medical Unit provides fast and professional care to the students of the center in case of accidents and emergencies.

Q. The Research Unit has a study hall and research hall to continue research currently being conducted between Harvard University, Faculty of Medicine and Kuwait University, and will begin or collaborate more with other researchers to identify the causes of Autism. The Center has so far published many research articles in scientific journals and international conferences and will continue to do so.

R. The Training Center trains parents, teachers and other workers in this field through workshops conducted by international professionals and therapists in the Autism field. Autism diploma courses for teachers and professionals have also been conducted at the center in cooperation with the University of London.
Autism-Europe
International Congress X
Budapest, Hungary, 26-28 September 2013

The Hungarian Autistic Society is pleased to inform you that they are organising the next International Congress of Autism-Europe which will be held in Budapest, Hungary on September 26 to 28, 2013. The event will be open to everyone (people with Autism, their families and professionals in the field of Autism) and will be an occasion not to miss, with a program including the latest scientific advances in relation to all aspects of Autism Spectrum Disorders.

The 10th congress will also mark the 30th anniversary of Autism-Europe.