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Autism-Europe

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Autism-Europe Campaign

« Break barriers together for autism »

Abbey Brooke

“No matter the challenges you face, your dreams are valid”

The ESIPP project

Parent education improves the quality of life of autistic people and their families

Prof. Andrew McDonnell

Understanding the Low Arousal Approach

Register



now for the AE's 12th International Congress in Nice!

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Cover: Abby Brooke is a young self-advocate who leads the initiative "Walking Autism", started in 2011 to raise awareness on autism and other disabilities in remote rural areas of Kenya and other African countries. In this picture, Abby is saying "hello" to Baloo, one of the camels which had walked along the continent with her. Picture by Walking Autism Africa for Autism-Europe.

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Dear friends,

Welcome to this new edition, in which you will find information about some of AE's activities, including the continuation of its campaign: "Break Barriers Together for Autism". This year, we had the honour of being welcomed by President Tajani and MEP Estaras to the European Parliament, where we presented our photo exhibition and shared testimonies collected from all over Europe shedding light on the daily obstacles encountered by autistic people and their families.

Improving understanding of how autistic people can participate fully remains a priority in fostering an inclusive society for all. In line with this theme, you will discover the challenge of a young autistic woman, Abby Brooke, of informing her fellow citizens in Kenya by means of a long awareness-raising walk, through which she connects with various communities across the country.

Having Abby on the cover of this issue is also symbolic and a sign of hope in light of the fact that, on the occasion of the 2 April 2018, the United Nations called for the empowerment of girls and women on the autism spectrum. Indeed, this group is still all too often ignored and invisible. It is therefore crucial to be aware of, and take action to combat, the additional discrimination they suffer and to encourage their participation in decision-making that concerns them.

One way to strengthen this empowerment is, for example, to provide access to training that enables families to have a positive approach to autism in order to better understand and meet the needs of their children. This was the focus of the ESIPP project, in which participating parents reported that it also helped to lift them out of their isolation and allowed them to meet allies.

Indeed, it is also by uniting forces that we can make our voice heard and gain visibility. It is therefore with great pleasure that AE has welcomed five new member associations from all corners of Europe, with whom we look forward to cooperating. You will discover more about two of the new member associations in this issue.

Informing, meeting and interacting with people from all walks of life and from all countries is also the goal of our International Congresses, which take place every three years. The next one will be held in Nice (France) from the 13 to the 15 September 2019. You are cordially invited to submit your proposals for presentations, as well as to register in the coming weeks. We hope once again to see many of you there so that all together, as autistic people, families, professionals, researchers and other stakeholders, we can collectively call for and contribute to a "New Dynamic for Change and Inclusion", in accordance with the ambition of this AE's 12th Congress.

Happy reading,



Zsuzsanna Szilvasy
President



Aurélie Baranger
Director



From left to right: Autism-Europe President Zsuzsanna Szilvasy, European Parliament President Antonio Tajani and MEP Rosa Estaràs.

Thousands across Europe and beyond break barriers together for autism

Around World Autism Awareness Day (2 April), associations from more than 22 countries and thousands of individuals responded to the call launched by Autism-Europe (AE) and joined the second phase of its awareness campaign “Break barriers together for autism- Let’s build an accessible society”. In 2018, AE is stepping up its call for decision-makers to act to remove the barriers that hinder autistic people’s inclusion in society and enjoyment of their rights.

It is only by listening to the needs of autistic people and working together that society can remove those barriers and promote inclusion for all, so that no one is left behind. In order to provide a concrete picture of the barriers faced by autistic people and their families across Europe, Autism-Europe gathered testimonies to illustrate the many daily hurdles they experience in various fields of life.

AE published some of these testimonies in a document entitled “Fostering a barrier-free society for people on the autism spectrum”. It includes 18 testimonies from 16 European countries together with examples of good practices and policy recommendations that can foster a more inclusive society in nine key areas. They highlight widespread difficulties linked to access to diagnosis, education, employment, transport and public spaces, lifelong support, life in the community, access to justice and the right to vote. These testimonies outlines key structural

barriers and present some policy recommendations and examples of good practices to tackle them.

Backing the campaign for a strong European Accessibility Act

In 2018, the issue of accessibility for persons with disabilities is high on the EU agenda. The European Accessibility Act, proposed by the European Commission, is currently in the trilogue stage of the EU decision-making process, meaning we are approaching the moment at which the Act’s final form will be decided.

AE has been actively voicing the needs of autistic people and their families since the initial stage of the elaboration of the Act. This year is a crucial time to bring to the forefront the access needs of autistic people, and to make decision-makers understand how they can improve the lives of the EU’s 5 million autistic people.

President Tajani welcomes the campaign photo exhibition to the EU Parliament

The 10 April 2018 saw AE’s exhibition make its way to the European Parliament in Brussels. The exhibition, titled “Break Barriers Together for Autism” was officially opened at a ceremony where guests were welcomed by hosting MEP Rosa Estaràs Ferragut, and President of the European Parliament Antonio Tajani.

Welcoming guests to the vernissage of AE’s campaign exhibition, Tajani and Estaràs Ferragut underlined the role the European Parliament can play in removing barriers, and supporting autistic people and their families both in reaching their full potential, and in enjoying their full human rights.

“This event, which marks World Autism Awareness Day, helps us to become aware in order to overcome the difficulties faced

The UN calls for the empowerment of autistic women and girls

On the 5th of April, the United Nations held its 2018 Observance of World Autism Awareness Day at the United Nations. The event focused on the importance of empowering autistic women and girls and involving them and their representative organisations in policy and decision-making to address the challenges they face.

Through dynamic moderated discussions with experts and advocates, the observance examined the particular challenges faced by women and girls with autism. Autism-Europe's President Zsuzsanna Szilvasy attended the United Nations events in New York.

Building momentum through Europe and beyond

AE's members throughout Europe have symbolically broken barriers and called for a more inclusive society for autistic people in Europe. People from every corner of the continent joined forces to spread the campaign's message.

(see picture below)

by autistic people. It is important that we continue working so that thousands of people with autism across Europe can be fully integrated into society (...) Each man and woman is important and is a gift to society; this is why I think that it is important to embrace that gift", said Tajani.

President of AE, Zsuzsanna Szilvasy highlighted the issue of accessibility, which is central to Autism-Europe's campaign. She made reference to the role of the European Parliament can play in fostering greater accessibility for autistic people, not least by supporting a strong European

Accessibility Act (EAA) which is currently nearing its final negotiations between the European Parliament, the European Commission and the Council of the European Union.

"The EAA is a key piece of legislation to remove some key barriers for millions of citizens with disabilities in Europe. AE has been actively voicing the accessibility needs of autistic people and their families since the initial stage of the elaboration of the Act. For them, it is essential that accessibility of communication is properly addressed in the EAA. For autistic people, and others, it is key to consider easy-to-

read and easy-to-understand accessibility requirements, not to leave anyone behind", Szilvasy said.

The pictures on display were taken by three photographers from the UK (Graham Miller), Poland (Michał Awin) and Luxembourg (André Weisgerber), all aiming to help people understand what accessibility means for those on the autism spectrum and what kind of obstacles they face in their everyday lives. The exhibition was made possible thanks to the support of Photohonesty, and AE members the JiM Foundation and *Fondation Autisme Luxembourg*.

Collage of pictures taken in 12 different countries in 2018. The collage features supporters from Portugal, Slovenia, Serbia, Spain, France, Luxembourg, Malta, Hungary, Belgium, Italy, the UK, Syria, Iran, Russia, FYR of Macedonia, Cyprus and Croatia.





Overview of the General Assembly meeting.

Autism-Europe gathers 70 representatives from 23 countries for its Annual General Assembly in Rotterdam

From the 11 to 13 May 2018, more than 70 representatives of European autism organisations from 23 different countries attended Autism-Europe (AE)'s Annual General Assembly and Council of administration meetings to discuss and vote on issues related to AE's activities and membership.

The meetings took place in Rotterdam (Netherlands) and coincided with the International Society for Autism Research (INSAR) Annual Meeting. Prior to the governing meetings, participants also had the opportunity to attend a discussion panel and meet with representatives of the Dutch Autism Association (*De Nederlandse Vereniging voor Autisme - NVA*) and other Dutch self-advocacy organisations.

Highlights of the meetings included participants welcoming the following five new member associations: Autism Spectrum Information Advice and Meeting Point (AslAm) from Ireland, Autism Regions from Russia, the Association of Non-Government Organisations for Autism of Slovenia, Tohum Foundation from Turkey and AT-Autism from the UK. The Council of Administration was also renewed by half after a vote by the General Assembly. Furthermore, updates about the projects and platforms in which AE is currently involved, discussions about AE's next International Congress in Nice in 2019 and on future priorities were also on the agenda.

Discussion on key priorities related to education

General Assembly participants took part in a workshop discussion to share their insight concerning the main barriers to quality inclusive education across the EU. They also discussed the possible scope of AE future recommendations. The added value of cooperation at the EU-level to foster better access to education for autistic people was highlighted.

Many common challenges were identified across Europe:

- lack of information and specific training for teachers at all levels (which constitutes a violation of Article 24 of the UN Convention on the Rights of People with Disabilities);
- need for adequate transition towards inclusion across the different education models to avoid trauma in autistic children;

- lack of safe educational learning environments and of networking opportunities for parents;
- lack of adequate accommodation and empowerment of children in need of a high level of support;
- lack of awareness among teachers, peers, parents, and professionals;
- need to redefine concepts like education, success, and inclusion.

To tackle these issues, members suggested a wide range of recommendations, including: transnational cooperation and exchange of best practices; training on different disabilities for professionals at all levels with a focus on the attitude of the educator; professional approaches focused on children-specific needs, abilities, and profile; playing on talents and e-learning; considering inclusion as a teaching goal; fostering organised cooperation between health professionals and learning environments; reducing the number of students per class, etc.

During the second half of 2018, AE will launch an online survey to gain a more comprehensive overview of the state of play and challenges at stake regarding access to education for autistic people in Europe.

Technology demonstration area

As a side-event, Autism-Europe organised a technology demonstration area in which participants could test two different ICT devices in relation to autism.

AE members had the opportunity to play with the first prototype of a humanoid robot designed by the DE-ENIGMA consortium funded by the EU Horizon 2020 programme, in partnership with AE. Zeno the robot is being developed and tested for an emotion-recognition and emotion-expression teaching programme addressed to school-aged autistic children. This approach combines the most common interests of children of school age: technology, cartoon characters (which Zeno resembles) and socialising with peers. During the project, which will run until 2019, Zeno will go through several design phases, getting ‘smarter’ every time.

AE member SPOSA from Bratislava (Slovakia), also presented the “Autism Simulator”. This virtual reality experience allows people to experience certain sensory issues that some people on the autism spectrum may face in different contexts, like in a coffee shop, at school or on public transport. It has been designed to support awareness-raising and training of a broad range of stakeholders on the impact that sensory overload can have on the lives of autistic people.

Involvement of autistic people in the Netherlands

Prior to AE governing bodies meetings, our full member, the NVA, organised a panel discussion at the Erasmus MC – Sophia Children’s hospital of Rotterdam.

NVA representatives introduced their association, which this year celebrates its 40th anniversary, and counts more than 11,000 members, of which 40% are adults on the autism spectrum. They stressed the importance of working for and with the active participation of autistic people. Several self-advocacy

organisations from the Netherlands were also present. Then, Sander Begeer, Associate Professor at the Department of Developmental Psychology at the *Vrije Universiteit Amsterdam*, presented the Dutch Autism Register. The register collects data anonymously and looks at a wide range of topics relevant to autistic people so as to provide a picture of their situation in the Netherlands.

The panel continued with the speech of self-advocate Diederik Weve from PAS Nederland, who presented autistic-lead initiatives in the Netherlands such as self-advocacy, mail-groups, forums, speaker academies, networking events and conferences, autism ambassadors in private companies or administration, etc.

The last part of the event was devoted to a panel discussion with seven self-advocates from various countries that discussed a range of issues, such as the double empathy problem (when both autistic and non-autistic people experience difficulties understanding each other when communicating), the challenges linked to diagnosis and, finally, the relevance of the social model vs the medical model of autism.





The non-profit association *Vanuit autisme bekeken* (VAB) is a coalition that works for the emancipation of autistic people towards an inclusive society. It is supported by the Ministry of Health, Welfare and Sport and the Ministry of Education, Culture and Science.

The core of Monique’s work within the VAB team is to establish the use of experiential expertise, from the start as an integral part of processes, as a standard. In relation to education, VAB supports the cry, ‘listen to the youth and give them a voice’ without prejudice. In practice, this means that the youth is actually allowed to speak.

More information:

<https://www.vanuitautismebekeken.nl/>

“Not wanting to be lonely is what links us”

Monique Post, Representative of NVA and board member at Autism-Europe. Monique supported the organisation of the panel of autistic advocates in Rotterdam during AE’s last General Assembly meeting.

“**E**verything in my life seems to be changing. I am experiencing a period of extreme development and self-awareness at the moment. There are countless reasons for this both in terms of my work and private life (...).

Working with the *Vanuit autisme bekeken* (VAB) or the “Coalition Looking From Within Autism” in English, gave me the opportunity to work my way out of benefits and also to learn a great deal about politics and the dynamics of working together. It also taught me how difficult it can be to open people’s eyes to new ideas and integrate this. I am referring to the approach of my mentor and teacher Martine Delfos where she looks at autism from a developmental perspective.

I was also given the chance to represent the NVA as their European Ambassador within AE. I seriously underestimated the degree of positive impact this would have in my life. In addition to this I was given the opportunity to accompany Delfos to Latvia for a second time to attend and experience treatment sessions. This was an experience that I will never forget (...).

My experiences over the past weeks, where I met with people from Latvia, Wales, the Netherlands (during the autism awareness week) and Luxembourg have had quite an impact on me personally. Because of being given the opportunity to experience how working from a developmental perspective can impact a family. One of the most impressive examples I’ve witnessed is of a 39 year-old man, trapped in stress and trauma, who is now being able to talk. This has resulted in me gaining a different degree of courage for my journey within the world of autism.

(...) Each and every person is different, but what connects us together is the feeling that we do not want to be lonely. Stress is an underestimated problem which deserves to be given far more attention... ”

The content on the left-hand side is a condensed version of the article “Not wanting to be lonely is what links us”, written by Monique Post – a young woman with an autism diagnosis and a consultant - and originally published in the issue for summer 2017 of the “Autisme Magazine”, produced by Autism-Europe member the Nederlandse Vereniging voor Autisme (NVA).

A full version of the article can be found on our website: <http://www.autismeurope.org/blog/category/interview/>



Art workshop set up at the *Diversamente Onlus* office

AutisMovie: The Short Film Festival Dedicated to Autism

Cinema is a good media to raise awareness of autism. Now in its fifth edition, the AutisMovie Festival, conceived and organised by Autism-Europe member *Diversamente Onlus* from Italy, in collaboration with the organisation *Inmediazione*, took place in the CineTeatro S. Eulalia in Cagliari, from the 1st of June to the 3rd June 2018. The three-day event, which was free to attend, included screenings of the short films competing for the Festival's top prize, round table discussions, and dedicated workshops.

The Festival was opened with the *AUTISMART* event, open to all and particularly relevant for art teachers, educators and autism support professionals. The event took place at the *Via Stoccolma* Highschool in Cagliari, on the Italian island of Sardinia. *Diversamente Onlus*, with the collaboration of *Inmediazione*, Autism Burgos (Spain), *Autismisäätiö* and Autism Film Festival (Finland), brought together participants to explore the role art plays in the lives of autistic people. Among the speakers were Laura Esteban, a Spanish illustrator who has worked on creating fairytales and stories to explain autism to children, and Susanna Salonen, an art teacher for autistic people at the Autism Foundation in Helsinki.

Guests were also shown extracts from the short films “*Luigi il macchinista* (Luigi the mechanic)” and “*Il silenzio di Camillo* (Camillo's Silence)”, produced by *Diversamente* and *Inmediazione* and inspired by the books illustrated by Laura Esteban. Orjo Pättiniemi, president of the Autism Film Festival in Helsinki, and Finnish organisation *Autismisäätiö*, then presented their work as part of the series «Adventurous heroes» run by Joannis Clementides, member of the *Sininen Sirkus* (Blue Circus), a collective of Finnish artists who are all on the autism spectrum.

On the morning of the 2nd June, an art workshop was set up at the *Diversamente Onlus* office, curated by Laura Esteban, and targeted at young autistic people, to demonstrate how illustration and art

can also act as a channel for communication and expression for people on the autism spectrum. In the afternoon of the same day, participants were treated to a screening of the documentary film «*Ocho pasos Adelante* (Eight steps forward)» by Selene and Sabina Colombo, an award-winning film about the lives of five autistic children and their families living in Argentina. The short film, which was also screened at the United Nations, wants to underline the importance of early diagnosis and has contributed to the introduction of mandatory screening in the first 3 years of life for children in Argentina.

The 3rd June saw the closing of the Festival, with the screening and the presentation of awards for the AutisMovie short film finalists. The short film «*Bumblebees*» by Jenna Kannell, winner of the 2016 edition of AutisMovie, was also screened. The version presented to guests was newly dubbed in Italian by voice-over artists with Asperger's syndrome as part of the «*Aspie Dub*» project of the *Teatro 8* association in Turin.

The short films screened this year are the result of a collaboration between AutisMovie and the ASFF Film Festival in Rome. The AutisMovie jury was made up of parents, operators in the audiovisual sector and autistic people. The first prize was given to the film «*Delivery Boy*» of Vinicius Saramago. The second prize was given to the film «*Circles*» by Micah Levin and Jesse Cramer, and the third prize went to «*Godhead*» by Gaston Connor.

Abby raises awareness of autism and other disabilities in remote rural areas of Kenya and other African countries.



Abby Brooke, Kenyan self-advocate and leader of the initiative “Walking Autism”

“No matter the challenges you face, your dreams are valid”

To date, Abby has completed a 400Km, one-month long walk around Mt Kenya, speaking at 5 public community events on the challenges and opportunities autism presents, reaching over 500 parents, professionals, teachers and carers. Her next project is a 2000Km, four-month long walk across Kenya, where the level of understanding and support for autism is very minimal, and during which she will seek to change this through her actions and talks. Abby, born in Nairobi, was diagnosed with Asperger’s Syndrome at the age of 13 while living in England for her school education.

Autism-Europe: Can you explain to us a bit more about the initiative “Walking Autism”?

Abby Brooke: It is a project to raise awareness, acceptance, understanding and support of autism, done by walking. Walking is how I personally like to meditate I can say. So it is walking with camels carrying the bags. Walking is a much more personal way of dealing with such subjects, and it is a very personal issue for me. Walking and connecting with people on a one-to-one basis, not just driving to a place. And the people I meet on the way they asked me “What are you doing?”, “Why are you doing this?” You meet so many people, not just at workshops but on the road too.

I walk with three camels and two guys who help me with the animals and with the bag and keep me company. We started this walk one month ago. Sometimes people can join a walk for a weekend, or they can accompany us the whole time.

AE: What is the biggest impact you have had so far with your awareness raising?

AB: I help people. On the last walk, the one where we walked around a mountain, towards the middle of the walk, people beyond our planned route said to me “I heard what you are doing. Can you help me? Can you give me a contact for the EARCs (Early Assessment resources Centers) in that particular area?” So just by being able to help and doing what I

can, I think that this makes a big impact.

For the parents who ask me, I give them little tips about things that they can do. In the evening, people who look at me and talk to me during the walk, they just come to me and say “you need to camp, come here with us!” and there we are able to talk longer about how you can help, what you can do and why education and support are important, and just little things like self-understanding, self-esteem, supporting a person in their development, and not just looking at the negatives.

AE: What are your next projects?

AB: I am still looking for sponsorship for my next walk. But it is a 2,000km walk

that will take 4 or 5 months. In certain towns that I'll pass through I will be joined by Autism Awareness Kenya (AAK) and SEP (Special Education Professionals), my two partners. During my previous walk, they came up and we gave workshops to the communities, talks on autism, disabilities and inclusion. These are rural areas that do not get much support, nor much education and awareness on any disability.

AE: What were the topics raised during those workshops and the profiles of the people who attended?

AB: They need to be more aware definitely, and accepting, of course. We address questions such as "What is autism?" "How can I be helped?" What can we do? Just general questions like that. We meet a lot of parents, teachers and professionals, that's mainly the audience. I am sure that we have had people who might be given the diagnosis or persons who are on the spectrum and they don't know.

AE: Are you in touch with the autism community in Kenya?

AB: I have volunteered for AAK, doing events like World Autism Awareness Day events and awareness projects with them and with SEP just by myself talking about my thoughts. There are very few people who are open about their Asperger's, but I know a few. I am sure that there is a big community. But it is not really a topic of discussion. No one really talks about it. By walking, I want to set up a support group for adults with Asperger's. Sadly people look so much at helping the children that there are very few services for adults.

AE: What challenges do you face in your daily life as a person on the autism spectrum? And, in general, what are the main challenges faced by autistic people in Kenya?

AB: There is a lot of non-understanding. There are certain things I wish I was better at or better at coping with. Lack of understanding. This is also why I wanted to do something here, to show the real side of it. It is about a real person, not what you see in films like "Rainman". In Kenya, there is a lot of stigma, very much a lack of awareness and lot of discriminations still happens. And of course lack of support. Support is coming, it is growing, but sadly a lot of the time it is based on people's level of income, and the majority of Kenyans are poor. So even if they have support they cannot afford it. So support is growing here but a lot of people just can't afford it.

AE: How did social media help you to recover your self-confidence and start to advocate for autism?

AB: Firstly that was just a name for me "autism". I knew that name "autism" but... My mother had books about this but they were written by doctors and professionals using almost negative wording. It was so much not like me. It was after I came home from Australia in 2011, aged 27, that

I really started looking into understanding my diagnosis. Until then I had never really wanted to "accept" it. Having hidden it, and it being my secret through most of my life due to the stigma and discrimination that came with being different in Kenya, I joined a few groups online.

I made some amazing friends and I got to realise that there is not one set way with autism, it is a whole. Everyone is different and not all the people are the same. It doesn't mean you can do anything. It means you will have problems but just maybe, with more understanding and with more acceptance, those problems become smaller. And there are so many self-advocates now. That also gave me the courage to speak and tell my story because every story helps. When I was still learning about autism and Asperger's syndrome I read stories from other people and that helped me. It is passing the torch in a way.

AE: Do you have a message for other autistic people out there?

AB: Just accept the challenge. For me autism is a constant challenge, and I would like to think that I can beat it all. It doesn't define who I am. I have problems but I can get through them.

Autism and other disabilities in Africa

Support for disability in Africa is still lacking, more so in the rural, poorer areas, where the means of education, support and understanding are lacking. Often a child born with disabilities will not receive any schooling.

Stigma and discrimination are high in some areas. False beliefs surrounding people with disabilities may favour "harmful practices", sometimes linked to witchcraft.

You can support Abby's initiative by sponsoring 5, 10 or 20 km of her next walk "Summit to Sea"; a 2000km, 5 month long walk within Kenya.

More information: <https://gogetfunding.com/sponser-a-kilometre-summit-to-sea-a-2000kms-walk-in-kenya-for-autism/>



As part of the project, Abby organises workshops for parents and professionals.



Interview with
Andrew McDonnell by
professionals from
Studio 3.

Professor Andrew McDonnell (Clinical Psychologist and CEO of Studio 3) was interviewed by and Simone Kendall (Assistant Clinical Psychologists, Studio 3) about the concept of the Low Arousal Approach.

Understanding the Low Arousal Approach

The Low Arousal Approach was first established in the late 1980's in the UK. Its philosophy emphasises a non-confrontational approach in crisis situations. In 1992 Professor McDonnell established a training company called Studio 3 Training Systems Ltd. Over the last 25 years, Studio 3 has expanded and now provides its services across Europe.

Studio 3: What does the Low Arousal Approach mean, what does it have to do with stress and why is it relevant to autistic people?

Andrew McDonnell: The Low Arousal Approach is a collection of behaviour management strategies which focus on effective crisis management. As a young psychologist trained in Positive Behaviour Supports, I was always asked to produce plans but was also asked to give advice about what to do in a crisis situation. Autistic people in my experience are often 'highly aroused' and good stress management needs to be applied in these circumstances. The phrase I like to use is 'when you are drowning, that is not the best time to learn how to swim'. The

people we support can accumulate stress to the point that they experience 'shutdowns' and 'meltdowns'. So teaching supporters how to behave in these circumstances is vital in my opinion.

S3: Can the Low Arousal Approach be applied in the family home and in schools? Can the Low Arousal Approach be used by parents and families?

AM: Yes! We are proud of the fact that parents can be trained in Low Arousal Approaches. Indeed a good number of parents and family members have completed training and have successfully implemented it into their family home. Linda Woodcock, a parent of an autistic person, has written an excellent book on Low Arousal called 'Managing Family Meltdown'. On a personal note, it is a priority for me and Studio 3 that families receive training in Low Arousal Approaches.

S3: Within the approach you discuss minimal use of physical intervention only when imminent risk of harm is apparent. Why?

AM: Too much training in this field contains physical interventions as a way of managing behaviours of concern. At Studio3 we have always reduced the number of physical interventions taught on our training courses. This is because we are quite radical in our perspective as we have banned many methods of physical restraint for our international programmes. This is because many methods of restraint are quite frankly dangerous. In addition to our training differing from other companies due to our philosophy, our method of training also differs. Often people forget what they have learnt in the classroom in stressful situations, our training is not limited to the classroom. Instead we are able to provide specialist on-the-ground training and support.

S3: Is there any advice that can be given to parents/carers who support people who self-injure?

AM: Self-injurious behaviour is a very common problem, however this is nonetheless extremely distressing for the individual and those who support them. In my experience, self-injurious behaviour is often triggered due to the individuals' sensory differences. Therefore the use of proactive sensory strategies can often be very successful in reducing occurrences of self-injurious behaviours. In addition, designing relaxation programmes from a sensory perspective can also be beneficial. To give you an example, an individual will nearly always have smells which will relax them. Using this strategy can not only relax the individuals in times of stress, but can also reduce this person's heart rate. Self-injurious behaviour is highly complex and can have many functions for the individual. Nonetheless in addition to using proactive strategies, in times of extreme stress, parents will also need to use reactive strategies. For example, parents may benefit from being taught how to physically distract a person when their self-harm is causing significant physical damage to themselves.

S3: How long does it take to learn your method and what preliminary qualifications are required to participate in the training?

AM: We routinely train supporters (including families, carers and staff teams) on a core three day training course. This course is delivered in over 14 countries including Sweden, Denmark, Germany, the UK, Ireland and Canada. We also provide Train the Trainer courses to organisations to enable their employees to

become Studio 3 affiliated trainers. I do need to stress however that potential trainers must have completed the core three day training course regardless of their experience. We additionally set very high standards for our trainers and in some cases people have failed to complete our training courses.

S3: What does the future hold for the Low Arousal Approach and Studio 3?

AM: Whilst the Low Arousal Approach is conceptually very strong, there is still a need for a stronger empirical evidence base. This is becoming even more relevant as training programmes are appearing to be increasingly popular. In addition, the specific behaviour needs of autistic people needs a much stronger emphasis within future Low Arousal work. This would certainly include a stronger voice for the people we support within the training we provide. Finally our main goal at Studio 3 is still to support restriction and restraint-free lives for the people we support.

*Written by Tarendeep Kaur Johal and Simone Kendall,
Assistant Clinical Psychologists at Studio 3 Clinical Services
Ltd on February 2018.*



More information about Studio 3 Training Systems and its services:

<http://www.studio3.org/training-systems-for-managing-difficult-behaviour/>

Schools from Kalamata visited a photo exhibition on the subject of sibling relations in autistic families

International research builds knowledge on sibling relationships

Sibling relationships play a central role in family life and are a powerful components of child development. Their dynamic interactions have a large impact on socio-cognitive development. Despite this, the experiences of siblings who grow up with an autistic brother or sister have received very little research interest. Researchers from the Lifespan Learning and Sleep Lab (LiLAS), at the UCL Institute of Education (IOE), in May 2017, hosted an event at the Centre of Arts and Education in Kalamata, Greece, that aimed to teach local communities about autism through focusing on sibling relations.

During the week-long event, the IOE researchers hosted a photo exhibition, gave talks, and showed video screenings around their research activities. The subject of sibling relations in autistic families was also broached through panel discussions raising questions such as “What is it like to grow up with an autistic brother or sister?” and “Can we democratise family research and family intervention in families with complex needs?”. The event demonstrated the need for more participatory research, which would include focusing on traditionally neglected voices.

The event concluded with a talk from IOE Senior Teaching Fellow in Psychology, Georgia Pavlopoulou, who was joined by four sisters who shared their stories on what it means to grow up with an autistic sibling during adolescence. In her talk, Pavlopoulou explained that there is little research on young adolescents growing up with an autistic sibling, especially concerning sisters’ experiences. She discussed the ways that siblings’ experiences can be complex and often difficult to capture using traditional research methods, as they are often habitual and taken for granted.

Pavlopoulou’s PhD research at the IOE explores relationships and environmental settings in the life of neurotypical sisters growing up with a preverbal autistic sibling. She works closely with the families to examine how strategies in research and intervention may shift the balance between vulnerability and resilience for families raising an autistic child and enhance siblings’ wellbeing.

Dr Dagmara Dimitriou, Reader in Developmental Science and Director of LiLAS Lab, further explains this research area: “We can only understand issues and opportunities of wellbeing within the families if they are active participants. In the current study, sisters were in the centre as agents and we have learnt a great deal from them. This research is promising for future changes in policy and in relation to both quality improvement and cost containment of therapy services. For example, the sisters commented about aspects of life that have not been addressed adequately at research and intervention levels; these include problems at school, sleep difficulties and respite time.”

In the study sisters reported their environmental settings and relationships in their family, school and their local community. Researchers found that the descriptions given by the participating sisters elicited descriptions about their experiences of wellbeing and struggle that went beyond the contribution of the presence of autistic behaviours. This message is important for both parents and professionals, as it moves away from the notion of the pathologisation of the families of autistic children (without lessening the difficulties faced by the sisters) or the narrow focus on the autistic child excluded from other family members. This may contribute to an emerging change of the negative narrative relating to families living with an autistic child with associated learning difficulties.

In a post-study group, participants and researchers developed action items together based on the sisters' expressed needs and perspectives. The items of this plan were shared with local press and trustees of local autism charities at a national level, but were also shared with a few university researchers and a siblings' research advisory group in the UK.

Among the key needs identified as part of this exercise were promoting acceptance, educating local communities, educating autism researchers and professionals, raising awareness of sisters' experiences, needs and priorities at a national level, and validating and refining themes across different cultures by applying the same or similar positive methods.

Researchers from the Lifespan Learning and Sleep Lab (LiLAS), at the UCL Institute of Education (IOE).

The proposed action items to address such needs included sharing research results with local mainstream schools, disseminating the key points from the study on the websites of NGOs and using study data to increase funding through additional grants for research in this area. Participants in the post-study group also recommended incorporating photos and multimedia video stories approved by the sisters involved in the study, to bring home the message behind the findings, and work with sisters from at least 3 different countries in the future through master and PhD students.

Kostas Saravelakis, Head of a local educational authority in Kalamata, and one of the event participants, said of the event: “[It] makes the local community think about what it means to grow up with an autistic sibling and how we can improve our services. We expect teachers, therapists and local community to challenge the borders and spaces between their clinical planning and teaching, promoting empathy and autism awareness in our local society. Such initiatives empower families and communities and create meaningful partnerships that may serve as mini community interventions.”

This event was part of a self-funded PhD study conducted by Georgia Pavlopoulou. The exhibition was kindly funded by the Greek Parents' Association, Municipality of Messinia and supported scientifically by LiLAS Lab Director: Dr Dagmara Dimitriou. Reader in Developmental Science at University College London.



ESIPP: Parent education improves the quality of life of autistic people and their families

Established in 2015 to develop locally appropriate Parent Education Programmes, the Erasmus+ project ESIPP is drawing to an end, demonstrating the very positive impact of this initiative on the lives of children on the autism spectrum and their families in south-east Europe.

Research shows that providing accurate information about autism to parents and teaching them to adapt their parenting using good autism practices, helps to improve outcomes for autistic people and their families. However, such support is extremely limited or non-existent in some European countries. To help fill the gap, the ESIPP project was established in 2015. Its purpose is to develop parent education in autism, tailored to the needs of families and autistic people in the FYR of Macedonia, Cyprus and Croatia.

Running until August 2018, the project is funded by the European Commission's Erasmus+ Programme, Key Action 2: Strategic Partnerships in Adult Education.

Led by the University of Northampton (UoN), the project brings together academics, professionals and parents from eight other partner universities and autism organisations, including Autism-Europe. Those involved come from various backgrounds – both national and cultural – and have a wide set of skills.

Dr David Preece, project coordinator from the UoN: “The ESIPP project was developed to make parent education about autism available to families who otherwise could not access such knowledge. This project has shown the benefits of providing accurate information and effective strategies to parents in these countries. They feel more confident about supporting their children, and

more able to respond to their needs. And family life has become happier too.”

Impact of the ESIPP project

Since 2016, the ESIPP project has delivered 19 training sessions to 335 parents in nine different cities in Croatia, the FYR of Macedonia and Cyprus. Moreover, nine local trainers have been trained in those countries in order to ensure the sustainability of the project after its lifespan.

Throughout 2017 and the beginning of 2018, a total of 450 parents, professionals, academics, students, decision-makers, journalist and other interested parties attended the four different ESIPP



©ESIPP Project

Image taken at the 2nd ESIPP parent training session delivered in Skopje in 2016

multiplier events held in Zagreb, Northampton, Skopje and Limassol, aiming at raising awareness about the importance of parent education in autism and sharing the work and expertise of the project partners to a wider audience.

Before each of these events, project partners held roundtable discussions with national, regional and local key stakeholders (such as representatives of the government, the municipality, NGOs, trade unions, universities, institutions for education and/or disabilities etc.), to discuss the importance of sustaining the legacy of the ESIPP training after the project's completion.

The project has been largely covered by the media (including television, radio, internet, press, specialised media, etc.) both among the targeted countries and abroad. ESIPP has also been presented in several international congresses and conferences in Europe and overseas, including in Brazil and India. In 2017, the Erasmus+ UK National Agency praised ESIPP for its exemplary use of the Impact+ Exercise and how it supported better impact of the project.

ESIPP Parent Education Programme

The ESIPP project has the core aim of developing and disseminating a training programme for parents of autistic children living in south-eastern Europe. The Parent Education Programme (PEP), entitled "Positive approaches to autism" is freely available on the project website and consists of six modules. Each module is designed to increase parents' knowledge, building upon the information learned in previous modules and extending it further. The content presents the latest best practice as recognised by autism practitioners and experts in the field. It is hoped that participation in the modules will develop parental confidence, assisting them in making and implementing self-help strategies that will go some way toward easing the great demands that caring for children with autism can require.

The PEP promotes the use of positive strategies, and is based around the following topics: an introduction to autism spectrum conditions, behaviour, the use of visual structure, sensory issues, communication challenges and the building of social skills. In addition, three non-core modules were added to meet requests for information on issues linked to puberty, sleeping and eating. This was created due to requests from parents on the initial feedback forms from the first round of training.

ESIPP recommendations for policy-makers

Supporting families is of paramount importance and is also an obligation, according to the Preamble and Article 23 of the UN Convention on the Rights of People with Disabilities - ratified by the European Union and all its Member States.

To mark the Global Day of Parents 2018, June 1, the ESIPP project released recommendations for policy-makers, together with a short video, to call on them to foster parent education to improve the quality of life of autistic people and their families.

ESIPP strongly recommends that European countries ensure the development of effective parent training to foster a "positive approach to autism" and respond to the support needs of millions of families across Europe. In line with the project's findings, this will contribute to the full implementation of the UNCRPD.

.....
Parent training is an effective way to empower families and people on the autism spectrum as well as to improve their quality of life, outcomes and inclusion in society.

ESIPP findings highlight the fact that:

- Parent training noticeably improves the quality of life of autistic people and their families and should therefore be supported and further developed;
- Autistic people and their families face many structural obstacles – having a significant impact on access to rights as well as their quality of life – that should also be addressed.

.....
For more information and to access the various modules of the parent education programme, please go to: <http://esipp.eu/>

Testimonies from parents who took part in the training:

"I would definitely recommend this education to other parents and family members"

"I wish I had the opportunity to attend this education when my child was diagnosed"

"I really liked when we had opportunity to ask about our children and about specific problems so they showed us how to communicate with them..."

"Spending time with other parents was really valuable for me, we can understand and help each other with our experiences"

« "We learned more things in two days than we did in 5 years. We take our son to so many therapies and nobody has told us as many details and ideas as you did. Thank you so much for this training"

Register for the Autism-Europe's 12th International Congress in Nice!

Autism-Europe's 12th International Congress will take place in Nice, France, between the 13 and 15 September 2019.

It will be hosted by Autism-Europe member, Autisme France.

The theme of the 12th edition of the Congress is "A new dynamic for change and inclusion".

More than 1,500 delegates are expected to attend this three-day event.





©Acropolis Nice

Exterior of the Acropolis Palace

Autism-Europe's international congresses are dedicated to sharing advances in practical and scientific knowledge about autism to as wide an audience as possible, including self-advocates, researchers, professionals and parents.

Ce congrès d'Autisme-Europe portera sur les développements les plus récents dans le domaine de l'autisme, y compris le diagnostic, les interventions, l'éducation, le soutien tout au long de la vie, l'emploi, les droits et les politiques.

The Congress will focus on the most recent developments in the field of autism, including issues related to diagnosis, interventions, education, life-long support, employment, new technologies, rights and policies.

The theme of the 2019 Congress is "A new dynamic for change and inclusion". It is intended to share state of the art knowledge and experiences that will make it possible to progress towards an inclusive society for autistic people. This three-day event will feature keynote speeches, three parallel session per day with symposia and oral communications, poster sessions and workshops.

Keynote speakers are stakeholders who have contributed significantly to the understanding of autism and fostered a better quality of life for autistic people.

Confirmed keynote speakers so far:

- **Prof. Simon Baron-Cohen** (UK)
- **Prof. Stanislas Dehaene** (France)
- **Prof. Hilde Geurt** (Netherland)
- **Prof. Ami Klin** (USA)

- **Prof. Eric Willaye** (Belgium), Director of SUSAs, Mons.
- **Dr. Monica Zilbovicius** (France), Directeur de Recherche-U797, INSERM, et Service de Radiologie Pédiatrique, Hôpital Necker Enfants Malades, Paris.

The Scientific committee

- **Prof. Frédérique Bonnet-Brilhault** (France) – Chair – Head of Department, University Center for Child Psychiatry, UMR930 INSERM / CHRU Tours.
- **Prof. Sven Bölte** (Sweden), Director of KIND, Karolinska Institutet, Stockholm.
- **Ms. Stéf. Bonnot-Briey** (France), Network & Quality manager for AFG-AUTISME. Belongs to AFFA & PAARI non-profit associations. Autistic person.
- **Prof. Tony Charman** (United Kingdom), Professor of Clinical Psychology, King's College London.
- **Dr. James Cusack** (United Kingdom), Director of Science at Autistica. Autistic person.
- **Dr. Djea Saravane** (France), Regional Center for Pain and Somatic Care in Mental Health and Autism, Etampes.
- **Dr. Donata Vivanti** (Italy), former President of Autism-Europe, board member and former vice-President of the European Disability Forum.

Call for abstracts

A call for abstracts will be launched in the third quarter of 2018. Researchers, autistic people and professionals, and any other interested stakeholders are invited to send proposals for contributions to the scientific committee through the congress website.

The venue

The Congress will be held at the Acropolis Convention Centre. In the heart of Nice, just 7km from the Nice-Côte d'Azur International Airport. Acropolis ranks among the world's most famous conference and exhibition centers.

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More information:
www.autismeurope-congress2019.com
.....

Registration

Registrations will be open in September 2018! Register early and benefit from the best rates!



©Acropolis Nice

AsIAM aims to provide a one-stop shop for the autism community in Ireland

Autism Spectrum Information Advice and Meeting Point (AsIAM) is a national autism charity that was founded in 2013. They work to educate, empower and advocate for the autism community in Ireland and to engage with all strata of Irish society to build a more understanding, accessible Ireland for their community.

The organisation was founded by Adam Harris, a young autistic person, and a group of professionals who have children on the autism spectrum. The group established the organisation based on shared experiences of the isolation, misunderstanding and exclusion, which so often follow diagnosis. The aim was to create an online vehicle to share information, advice and support and to use it as a platform to reach out and educate society, online and offline.

In 2014, Adam won a Social Entrepreneurs Ireland Elevate Award, which helped to kick start the organisation and attract additional media attention and financial support. In early 2015, they began to significantly expand their range of community supports and awareness programmes. Today, AsIAM has a team of seven staff working across 11 projects or areas of work and engaging a cross-section of society from secondary school students to public servants. They also hold regular events and programmes to empower the autism community and build its capacity to work for change.

Building an autism-friendly society

AsIAM believes that four pillars are essential in establishing an autism-friendly society: Community Support and Empowerment; Public Awareness and Training; Public Policy; and Effective, responsive services and supports.

Their strategy is unique in several areas:

- 1) At the core of all pieces of work will be a strong online presence – including the development of a range of high-end, online training packages to complement their work on the ground and increase their reach.
- 2) The strategy proposes that AsIAM takes the lead in pro-actively driving change in the space through the creation of best practice guidelines and standards for organisations which serve autistic people.
- 3) Throughout the strategy is a focus on sustainability measures, including earned income, to ensure they can focus their efforts on delivery and impact.

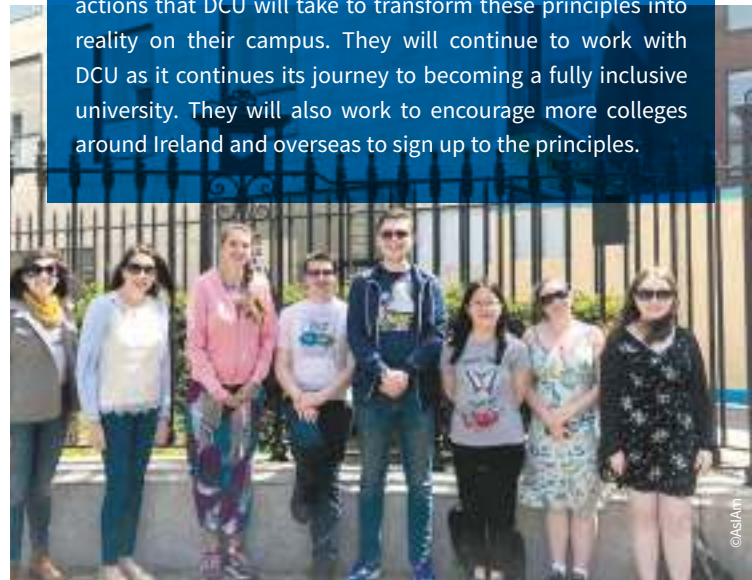
Bottom photo : Participants of the YouthHub campaign, aiming at engaging young people and gaining a greater insight into what it is like to live with autism.

Below photo : The talk “The Autism Experience” is part of the YouthHub campaign, supported by the Irish Department of Justice & Equality. In the picture, the talk given at Dublin City University in June 2018.

The world’s first autism friendly university

Among the numerous activities undertaken by AsIAM in the field of education, they recently accredited Dublin City University (DCU) as the world’s first autism friendly university through a collaboration between DCU, AsIAM and Specialisterne Ireland (a specialist consultancy that recruits and supports autistic people). This followed 3 years of research, strategic planning and fundraising. In their work with DCU, AsIAM have developed 8 principles which any university can adopt and work towards implementing.

Working with the university, they have agreed on over 50 actions that DCU will take to transform these principles into reality on their campus. They will continue to work with DCU as it continues its journey to becoming a fully inclusive university. They will also work to encourage more colleges around Ireland and overseas to sign up to the principles.



AsIAM is a full member of Autism-Europe.

Fostering a holistic approach and lifelong support in Slovenia



Since May 2015, Zveza nevladnih organizacij za avtizem Slovenije (the Association of Non-Government Organisations for Autism of Slovenia) has been working towards advocating for a holistic approach for persons on the autism spectrum and lifelong support in all areas, including health, education, social care, employment or care for a better quality of life.

In April 2014, more than 400 persons on the autism spectrum and their families, professionals, and other stakeholders, met in Ljubljana at the event “All-Slovenian Initiative for Equal Opportunities for Persons with Autism”. This initiative highlighted the importance of connecting organisations in the field of autism to try to achieve common goals. The following year, nine non-government organisations from different Slovenian regions established the Association.

In 2018, the Association counts a total of 11 member organisations which are very active not only in Slovenia, but also at the international level. Its governing bodies are made up of a total of seven parents and five professionals. Through their work and common efforts, they advocates for the needs of autistic persons at different levels:

- Pooling NGOs supporting autistic people;
- Pooling people on the autism spectrum, their parents, and professionals working in this field;
- Raising public awareness about the challenges of autistic children and adults and their families;
- Monitoring legislation in the fields of health, education, work, and social protection, and taking part in modification of legislation;
- Providing support for adults and children with autism in their social inclusion;

- Providing support for families and active involvement in improving the quality of life of adults and children with autism and their families.

The organisation believes that its membership in Autism-Europe “is of great importance to their future work and that it will greatly contribute to the quality of the Association’s programmes and, indirectly, the quality of life of persons with autism in Slovenia”.

Among the future plans, the Association foresees: establishing continuous communication with policy-makers, encouraging autistic people to embark upon self-advocacy, addressing the need for early intervention and taking part in establishing an effective system, offering support to schools by implementing the “Autism friendly school project”, supporting high school autistic students, educating personal assistants for adults on the autism spectrum, addressing the needs of autistic adults who are currently without any support, helping families of autistic people, and raising public awareness.

Zveza nevladnih organizacij za avtizem Slovenije is an affiliated member of Autism-Europe.

In April 2018, the Association organised an autism awareness campaign, including a walk with balloons in different Slovenian cities. During this month there was also a presentations of organisations working in the field of autism in the capital, at the Faculty of Education in Ljubljana. The Association also prepared the project “Autism friendly school”, aiming at motivating schools to be more inclusive and supportive towards autistic children and their families. In Domžale, a centre for young autistic adults was opened and member organisations also published an online magazine, Vox Alia, written by autistic adults.



Last April, the Association organised an autism awareness campaign, including a walk with balloons in different Slovenian cities.

Member Associations of Autism-Europe

FULL MEMBERS

(national associations of people with autism and parents)

BELGIUM

Association Pour l'Epanouissement des Personnes Autistes (A.P.E.P.A.)
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Vlaamse Vereniging voor Autisme (V.V.A.)

Groot Begijnhof 14
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Fax: + 32.9.218.83.83
E-mail: vva@autismevlaanderen.be
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CZECH REPUBLIC

Národní ústav pro autismus, z.ú. (NAUTIS)

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www.facebook.com/nautis.cz
Website: www.nautis.cz

CROATIA

Croatian Society For Autism (S.H.P.A.C.)

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DENMARK

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FINLAND

Finnish Association for Autism and Asperger's Syndrome

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E-mail: autisme.france@wanadoo.fr
Website: www.autismefrance.org

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GREECE

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Autism Spectrum Information Advice and Meeting Point (AsIAM)

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LITHUANIA

Lietaus vaikai (Rain Children)

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MALTA

Autism Parents Association (APA)

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SPAIN

Asociación de padres de niños y niñas autistas de Bizkaia (APNABI)

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Website: http://www.apnabi.org/

Autismo Burgos

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Website: www.autismoburgos.org

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