

# DIVERSITY

DENIZLI AUTISM SOCIETY (DOD) – ISSUE 1



DOD is in Europe  
**GERMANY AND  
HOLLAND**

Examples From  
Abroad  
**PROGRAMS IN THE USA**

Pioneers' Story  
**MOTHERS TELL  
ABOUT AUTISM**

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This project is funded by the European Union.

Bu proje Avrupa Birliđi tarafından finanse edilmektedir.



**HAKLARA DESTEK**  
İnsan Hakları Örgütlerini Destekleme Programı

*"This magazine was created within the scope of Support to Rights programme and funded by the European Union. Its contents are the sole responsibility of Denizli Autism Association and do not necessarily reflect the views of European Union and/or Support to Rights programme."*



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# ***Autism rights are human rights!***

As the Denizli Autism Association (DOD), we set out to ensure the individuals with autism and their families to lead a life worthy of dignity and fundamental human rights, and are very excited to release our first publication! With this publication that we prepared as part of the Haklara Destek Institutional Support for Human Rights Programme, we aim to draw attention to the problems of individuals with autism, propose solutions for these problems and advocate for equality of rights and opportunities.

Individuals with autism and their families are subjected to discrimination in all aspects of life, and we carry out numerous activities of advocacy, awareness raising and collaboration. In Turkey, civil society for autism has been working to change the fate of people with autism for many years, and we have come a long way thanks to their great efforts. Although these efforts hold great importance, much to our regret, it is not possible to suggest that they have been sufficient enough in granting their rights to people with autism.

An Autism Action Plan was launched after a commission of investigation had been established at the Grand National Assembly of Turkey, followed by a laboriously prepared report. However, as a mother of a child with autism, I can safely say that all these works have not been reflected in our lives. There are still fundamental failings in every area of services, such as education, employment and involvement in social life. For instance, according to the data of 2019 from the Turkish Employment Organisation, only 28 individuals with autism were registered at the organisation. Today, very few of individuals with disabilities in Turkey can have access to education. And for those, who can, the quality of education is a matter of debate. As for the case of adults with autism, it is our biggest open wound.

In Turkey, there is only one organisation where autistic individuals are provided with residential services in Istanbul, and it is affiliated to the Turkish Ministry of Family and Social Policies. However, some news and images related to the problems experienced at this facility hit the press.



News often appeared on the media reporting that, mentally handicapped residents were chained and kept behind the bars, harassed and raped. A system that accommodates four autistic individuals in one room, ties their hands or put them behind the bars is not acceptable in any country. Autism is part of human diversity.

It is our duty to create facilities, which provide care to autistic individuals, and are worthy of human dignity. Therefore, on our first issue, we cover the facilities providing care to autistic adults in Germany, Holland and the USA.

Just as in other parts of the world, campaigning for autism rests on mothers' shoulders in Turkey. Therefore, in order to give voice to both individuals with autism and their mothers, we asked mothers and wrote what they told us on this issue. We also cover some eye-opening articles on autism, ableism, creative drama and family counselling. As we are opening the door slightly on this issue, this is just a beginning and there will be more...

***Dudu Karaman Dinç, DOD's Communication Coordinator***

# NEW TERM

# NEW OBJECTIVES



*The Denizli Autism association has been working non-stop in spite of the COVID-19 pandemic, in order for individuals with autism and their families to lead a better life and have access to their rights. On our new term, we have taken considerable steps in achieving our main objectives as a renewed DOD!*

## **Human Rights and Dignity First**

Denizli Autism Association (DOD) was founded by parents of children with autism in 2014, and describes itself as a right struggles and advocacy oriented association. DOD conducts activities aimed at ensuring a complete integration into society to help individuals with autism lead a life with dignity and fundamental human rights.

DOD conducts activities of awareness raising, advocacy, collaboration and policymaking aiming to be an international counselling centre. Having conducted child and family based activities locally; DOD collaborates with various NGOs in policy making for autism around Turkey. Furthermore, it has become a member to Autism-Europe.

All the activities of our association and its relations with collaborators are carried out in line with the principles of participation, benefit making, being solution oriented, accountability,



anti-discrimination and sustainability. To help children and teenagers with autism integrate into social life, DOD conducts summer clubs and workshops, and implements reverse mainstreaming practices.

## **New Term, New Steps**

DOD took significant new steps in areas, which were among our main objectives in 2020. We achieved concrete results in creating awareness, advocacy, developing collaboration and networking, and fundraising. Although some of our activities have had to be interrupted due to COVID-19 pandemic, we have renewed ourselves and developed new strategies.

## **Our corporate capacity is improving**

We continued to work on developing our organisational and corporate capacity in 2020. We participated in a total of 107 meetings and trainings in 2020 in order to improve our corporate capacity, number of our collaborators and advocacy skills. We prepared a DOD Directory of Governance and DOD Constitution of Communication within the BIRLIKTE: Local CSOs Institutional Support Program.

We identified basic orientations for fundraising, and communicated with social enterprises as a crowdfunding method. Our application for the Iyilik Kazansin fundraising platform was accepted.

The support that we took within the Local CSOs Institutional Support Program, conducted by the STGM and funded by the European Union, was completed in August 2020, and we were selected as a grant beneficiary of the Haklara Destek Program. Our works within this program began in July 2020. The basic objectives of this project are to increase DOD's corporate capacity, develop connections with international networks and improve fundraising skills.

Our applications for the Etkiniz EU Programme and South Aegean Development Agency (GEKA) were accepted. We completed the project "Denizli Autism Association (DOD) Is Overcoming Prejudices". The members and volunteers of the DOD both got training for writing Erasmus+ Project, and wrote three projects in practice under the supervision of their mentors.

### **Monitoring human rights and disability rights**

Among DOD's main objectives is to increase the capacity of monitoring and reporting human rights and disability rights. We work for establishing a monitoring system at a local level. The Etkiniz Programme provided us with a long-term expert support. With the help of our expert, we designed a monitoring programme for individuals with autism in Denizli. On January 2020, we started working on monitoring the discrimination, to which children with autism and their families are subjected in education.

### **Covid-19 pandemic and its effects**

We organised workshops for our autistic children with the participation of our voluntary child development teachers and their students. We also provided the parents of autistic children, who joined these workshops, with a counselor support. Thus, the students gained the experience of facilitation at the workshops. And the parents had the chance to spare time for themselves during which their children were at the workshops.

One day after DOD's General Annual Meeting on 15th March, activities conducted at associations were interrupted due to COVID-19 pandemic. Therefore, we had to suspend our activities at our centre.

We could not run our annual reverse mainstreaming summer club due to COVID-19 pandemic. We had to provide our educational and family counselling services over the phone during which the COVID-19 cases increased. At the beginning of the pandemic period, we invited civil society for solidarity by writing an infographics titled "Solidarity Keeps You Alive" and released it to public.

### **Children with autism could not have access to education**

The fact that schools, rehabilitation centres and sports centres etc. were closed due the COVID-19 pandemic caused disruptions to autistic individuals' routine; particularly, autistic adults faced numerous problems. The pandemic caused real problems in many areas, notably access to education. Due to the lockdown, majority of children with autism could not have access to education, as they were not able to benefit from online education. All these problems increased the worries of parents who already know that institutions, where their children can live humanely do not exist, if anything happens to them.



# What We Did In 2020?

## **One-to-one counselling support**

Educational and family counselling that we conduct face-to-face at the DOD centre started again in July. Between July and January, we had provided one-to-one educational and family counselling for 29 families. One family came from İzmir, another from Uşak and the rest from Denizli city centre and various districts of Denizli.

We submitted petitions to some public bodies and local authorities to find solutions for the problems caused by COVID-19 pandemic. We gave support to the works of the umbrella organisations in which we are included. We supported campaigns when schools were reopened. We provided support to the campaigns of the Platform for Right To Employment of Persons with Disability, Community of Turkey's Mothers of Children with Autism and Platform for Equal Rights in Education.

Thanks to family counselling, parents of children, who were newly diagnosed with autism, could reorganise their families much more easily. Our educational support helped them learn different methods, such as how to play with their children, scientific and interactional approaches and what to consider while choosing educator and institutions.

## **DOD's window**

The majority of DOD's advocacy, awareness raising and visibility activities included media works. We were on eight live TV programmes on local television channels, 2 radio programmes, and covered on a national news bulletin. We appeared on 62 news in total. On these news and programmes, we both explained the activities of our association and advocated for autism and disability.

We had to suspend our awareness raising seminars that we conducted at schools for families and educators due to pandemic. We began our online DOD's Window programmes to create awareness, advocacy and collaboration. DOD's Window started on 3 December 2020 and covered good examples with a total of 14 programmes.

*·We participated in a total of 107 meetings on increasing corporate capacity, education, collaboration and advocacy.*

*·We organised a workshop on Right-Based Disability Journalism on the Right-Based Journalism Workshop conducted by ESHID (Association for Monitoring Equal Rights) for local journalists from all around Turkey.*

*·We organised inclusive education seminars "Life Is Beautiful When We Are Together", and exhibited the works produced at the art workshops that were conducted as part of the Mikro-fon project.*

*·We did DOD's 3rd Ordinary General Meeting.*

*·We completed the BIRLIKTE: Local CSOs Institutional Support Programme.*

*·We prepared a DOD Directory of Governance and DOD Constitution of Communication.*

*·We were admitted to the Haklara Destek Institutional Support for Human Rights Programme.*

*·Our applications for the Etkiniz EU Programme and South Aegean Development Agency (GEKA) were accepted.*

*·We organised 4 workshops in which children with autism and typically developing children participated.*

*·We delivered food aid and clothing gift cards to the families who lost income due to COVID-19.*

*·We provided 29 families with educational support and family counselling.*

*·We joined 8 live TV programs on local television channels.*

*·We joined 2 broadcasts by Medyascope and STGM, a TV news program and 2 radio programs.*

*·We appeared on 62 Internet sites.*

*·DOD's Window programmes began.*

*·Our application for the Iyilik Kazansın Fundraising Platform was accepted.*

*·We became member of the Partnership Network To Prevent Violence Against Children.*

*·Our application to become a member to Autism-Europe was accepted.*



## Reorganising families requires multiple supports

*İbrahim Dinç, DOD's Member of Board,  
father of an autistic boy and family counsellor  
suggests that families need to be  
given support from the initial diagnosis  
for full and equal involvement of autistic individuals in life.*

Just as many other mammals, parents in homo sapiens care for their offsprings from their birth onwards. The infancy and childhood periods of human offsprings take much longer compared to other mammals. Since typically developing children can learn many skills and behaviours through natural interactions in day-to-day life with their families, they won't need additional supports to get these achievements. However, these processes become challenging for autistic children and their families, and they often need various methods to learn many skills. Regrettably, we do not have experts or institutions that provide support to families after their children are diagnosed with autism in Turkey.

Many children with autism suffer from additional problems, such as sleeping and digestion disorder, and hyperactivity. All these problems decrease life quality leading to learning difficulties and parental fatigue. Parents often get confused as an interdisciplinary collaboration and each discipline offer different opinions from their perspective. Thus, parents often have to make intuitive decisions. And making hasty and intuitive decisions mostly causes financial and emotional losses.

***Parents often get confused as an interdisciplinary collaboration and each discipline offer different opinion from their perspective. Thus, parents often have to make intuitive decisions. And making hasty and intuitive decisions mostly causes financial and emotional losses.***

After the diagnosis, it is extremely essential that families determine a road map taking all financial and social resources into account, and accept in advance that this will be a very long road. Also, the most rewarding resource for parents is getting support from the extended family members at the beginning of this road...

Parents' working life change, and mostly one spouse will have to quit work. Siblings of autistic children are also greatly affected by the new diagnosis. Parents face even bigger challenges when siblings are younger and also need caring. Therefore, getting support from their extended family makes parents quite fortunate in dealing with their challenges.

Mother's burden of responsibilities may take a toll in more traditional families. Therefore, division of labour should be rearranged in an equal way in the reorganisation of the family. Parents should not overburden siblings with responsibilities and make sure that they are least affected by the situation.

Families determine their road map making changes by their own means; however, they also need guidance and support. And unfortunately, neither local authorities nor social services exist in our country to offer functional guidance to families. I believe that local authorities particularly should collaborate with associations working in this field and start operating guidance centres. Furthermore, local authorities should immediately include children with atypical development in sports activities, vocational courses, art workshops and so on.

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# I OWE WHO I AM TO AUTISM



***Deniz İşçi, a university student and activist, who describes herself as an autistic person and have more than one neurodivergent categories, told us about herself, autism and Merhaba Spektrum.***

**Could you briefly tell us about yourself and when you were diagnosed with autism?**

My name is Deniz, and I am 24 years old. I am autistic and have more than one neurodivergent categories. I am a university student and activist. My family and I always knew that I was different when I was a child, but never had the chance to find solutions for it due to the reasons beyond our control. When my parents divorced, I moved to Antalya with my mother and began seeing a psychiatrist there. It was right after my first year in high school. Since I was mostly nonverbal at the time, the psychiatrist soon diagnosed me with autism. As I have autistic relatives, the diagnosis did not surprise us at all.

**How did being autistic affect your life?**

Being autistic affects my life in many good and bad ways. I am very happy, even proud of being autistic, but it does not mean that I don't face challenges. I find it difficult to live in a world that is not organised for people like me. Our society often doesn't accept different individuals, and therefore, we are subjected to discrimination and ableism. I was marginalized a lot since I was autistic and different during the times I did not love myself. Because I couldn't manage being normal in the past, I blamed myself for when I faced with wrongdoings. But now I love myself and try letting people, who accept me for who I am, into my life. Being autistic has made me skillful. Since autism has affected my outlook on everything, I owe who I am to autism. I think and perceive differently from the people around me. I feel and behave differently from the people around me. This natural diversity of humankind is astonishing and praiseworthy. And there are numerous people like me in autistic community. We have our own rich culture, a common language and similar experiences. Being a member to this community makes me very happy.



## **How did you start expressing yourself through social media?**

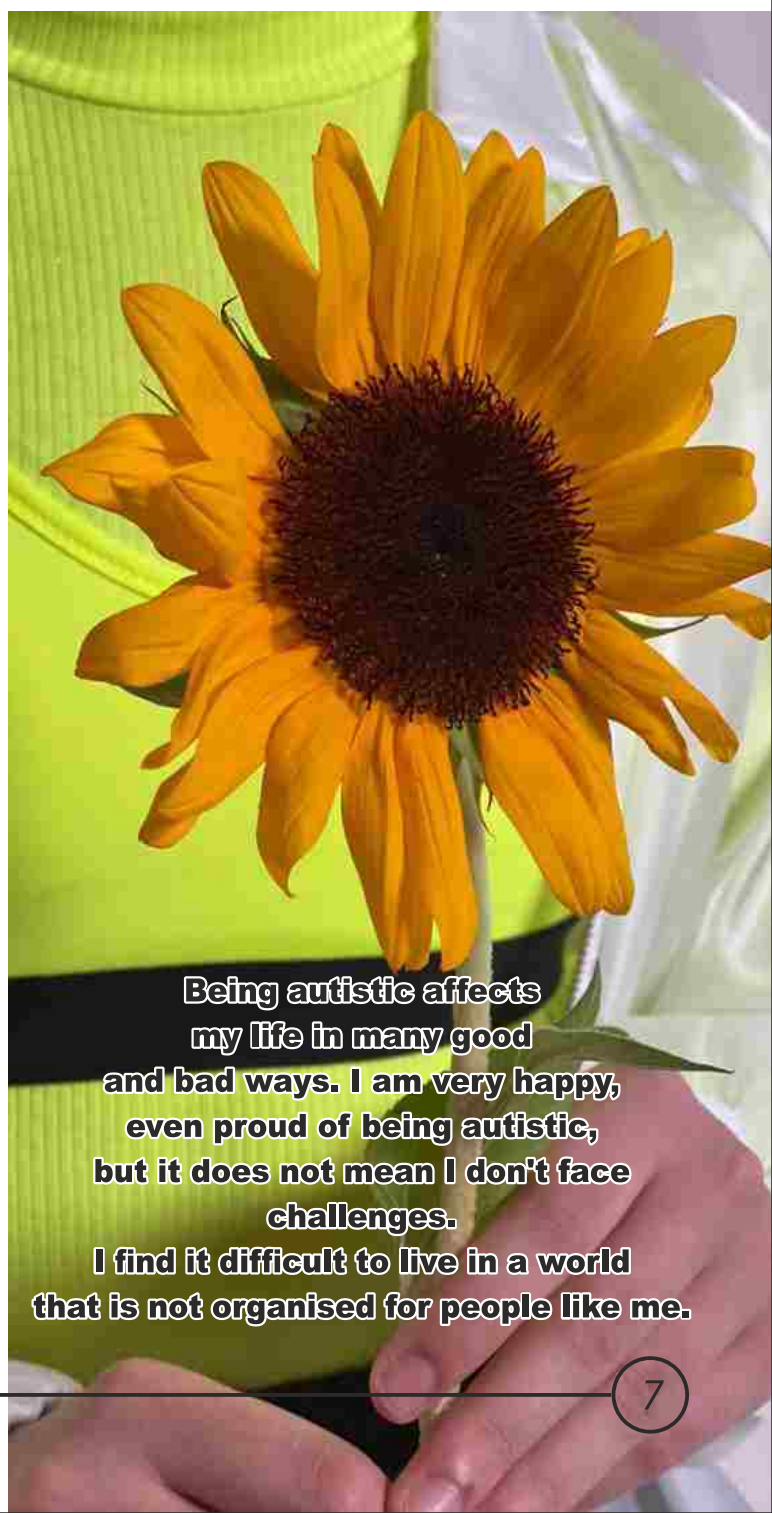
I have been on online platforms related to autism for a long time. Before I decided to start doing this myself, I had been in contact with autistic people from other countries on the Internet. However, I felt quite alone as an autistic person who lives in Turkey. I sought for an opportunity and online platforms where I could meet with other autistic people in Turkey for a while, but I couldn't find any. I also looked for people, who came out autistic, but again I couldn't find many. There was neither a platform for autistic people or anyone representing them. And I decided to do something about this instead of just getting mad at it. I first shared posts on Facebook, but they weren't exactly well received. Then I opened an account on Twitter. I was impatient at first and deactivated and then reactivated my account a few times. I eventually managed to keep my account active and began writing about autism.

## **Could you tell us how the Merhaba Spektrum team get together? What are the goals of your team?**

After I had begun writing on autism on Twitter, a young man with autism, whose current username is @llhanizm, joined Twitter. I considered all the reactions I had received until then, and decided to give support to him. I sent a message to him and that is how we met. He is a wonderful, knowledgeable person with a high level of self-consciousness at such a young age. He also began writing about autism on Twitter. Another member of our team wrote to us and said he is autistic. Then, we came across the videos about autism shared by a person with the user name @vinsstimming and met this person. After some people had written inferior and groundless things about us, we decided to write our manifesto as a response to the reactions we received. We adapted Vin's already existing website "merhabaspektrum.com" to activism and our team. Recently, a high value member of our team, Alaz has joined us and begun working at full speed.

We have many goals, but give priority to make the Merhaba Spektrum website an autism resource that has the largest and most recent information in Turkey. We aim to promote neurodiversity movement and help people accept that neurodiverse and autistic people exist. We strive to fight against ableism, and wish to correct the common misconceptions about autism.

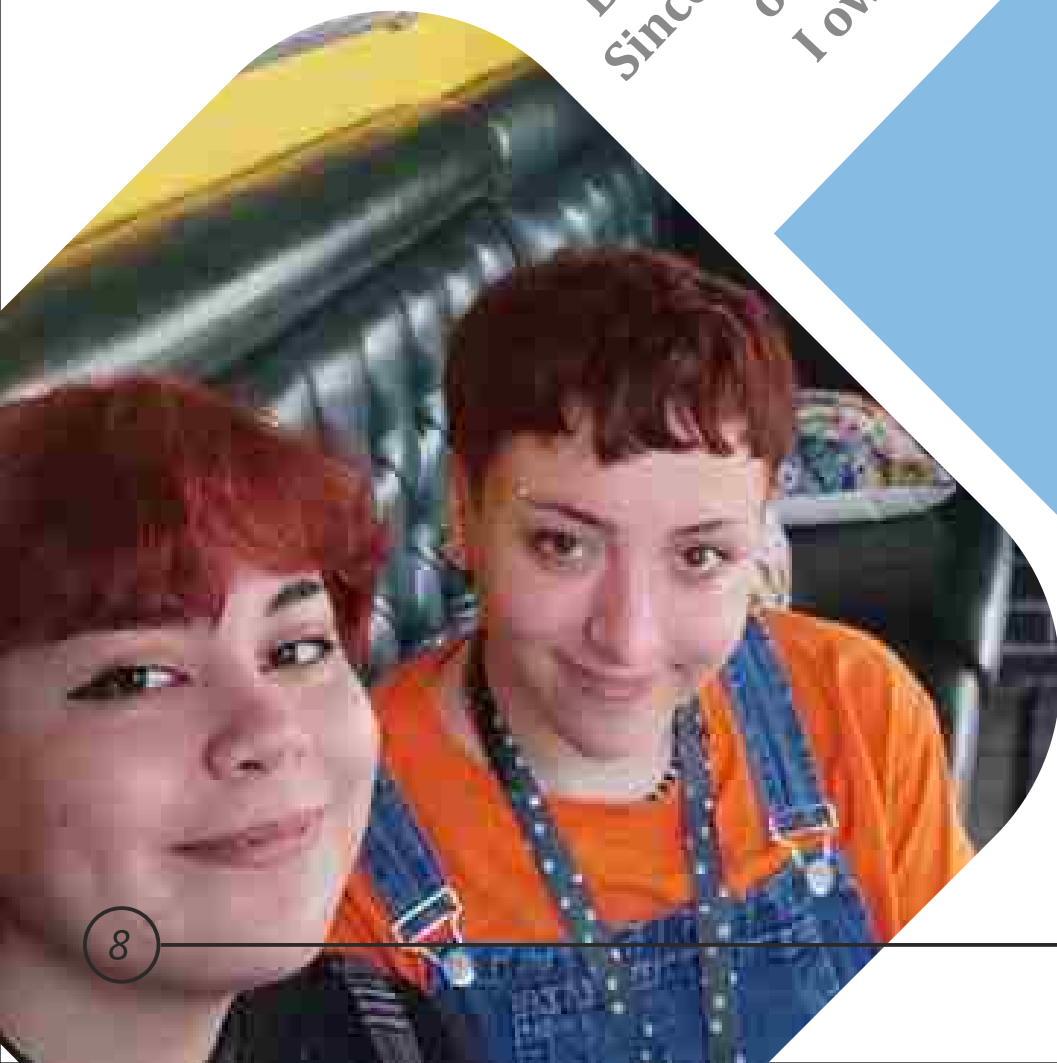
We work on changing the ableist language and perception towards autism, and creating a beautiful, autism-friendly environment for existing and future autistic people. We want everyone to know that autism is a necessary and beautiful human diversity, and needs to be recognised instead of being wiped out. We strive to provide information useful for autistic and all other people. We try to help families and other people better understand us, and wish autistic people to get the support they deserve and be able to stop the current injustice. We have many more similar goals. I believe that we can easily reach our goals thanks to those who listen to us and be instrumental in making us heard.



**Being autistic affects my life in many good and bad ways. I am very happy, even proud of being autistic, but it does not mean I don't face challenges. I find it difficult to live in a world that is not organised for people like me.**



**Being autistic has made me skilful.  
Since autism has affected my outlook  
I owe who I am to autism.**



### **Could you share your views on neurodiversity and ableism?**

Neurodiversity is about the fact that human neurological system develops in various ways, and it deserves appreciation. Neurodiverse people have made undeniable contributions to human progress, and still continue to do so. Ableism is about discriminatory mentality of non-disabled people towards people with disability, and its reflections on actions. There are many types of ableism that we face, and they are turned a blind eye. People find our autistic characteristics odd, and may react to our presence in public places. Ableist people believe that autistic people and autism should completely be wiped out rather than being supported. Moreover, they may speak this up not knowing or uncaringly how this will be so disrespectful for people with autism. Ableist people also use everything related to disability as an insult, because they see being disabled as degradation. There are numerous examples to the types of ableism, because ableism is a terrible thing that penetrates in every cell of a society. So much so that even disabled people may act in ableist ways towards themselves. We need to become aware of that we are ableist, and question and improve ourselves constantly by listening to people with disabilities.

### **What do you think about the status of autistic people in Turkey?**

I think that they are extremely subjected to injustice. Since autism is not well known in Turkey, autistic children turn into traumatised autistic adults. As neither families nor children can get the necessary and appropriate support from early childhood, things become irreversible. And therefore, parents have serious concerns about the future of their children.

Autistic children may often be denied access to education. And those, who can enrol at schools, may not attain academic achievement since they cannot get the appropriate support. The fact that fields of employment are not often suitable for us prevents autistic adults from having financial independence.

### **What are needed in order to ensure autistic adults to gain employment and lead an independent life?**

From the moment when a person is diagnosed with autism, it is necessary to work on how this person can lead a happy and healthy life as an autistic individual.

Trying to “cure” autistic people or prevent their autistic characteristics is a waste of time, and can end very badly. It is vital to discover the autistic characteristics of autistic individuals and act accordingly; for instance, using AAC (Augmentative and Alternative Communication) systems for a person, who is non-verbal or needs support for communication. Apart from that, each autistic individual differs greatly from one another; therefore, an individual support plan should be made. If a system that accepts autism instead of wiping it out and aims to support autistic people is developed, they can reach their potentials through an individual support system. When they are provided with appropriate fields where they can go for their areas of interest and find employment, they can have financial independence. If schools are accommodated for autistic students, and teachers are trained to work with autistic people, then they can attain academic achievements.

### **Do you have any recommendations for families with autistic children?**

Please listen to other autistic people about autism. They need to accept that autism will not disappear. Parents, who want to treat autism, become vulnerable to exploitation by false treatment sellers; treating autism is not possible! As autism is not a disease, it does not have a treatment. In fact, autism is not something like a tumour that affects a “normal” brain adversely; autistic brain is wired differently. In order to wipe out autism, either the autistic person needs to be wiped out or their brain needs to be changed. You should accept that your child is autistic and this will never change, and it is not a bad thing. Majority of the hardship you and your autistic child experience occur because you live in an ableist society. Autism has nothing to blame, and there is no need to fight against autism. And please make sure to use AAC for your autistic children and pay attention to their needs.

### **What do you think would provide an easier life for autistic people in Turkey?**

The system for autism in Turkey needs to be rebuilt. Misconceptions about autism needs to disappear, and everyone, who will come across an autistic individual, needs to be trained on autism with up-to-date information to make the lives of autistic people easier. Also, living environments need to be adjusted for us without expecting us to stand aside or put up with it.

# Pioneer Mothers Tell...



*Nejla Arslankurt's son Alper is 44 years old; Nevin Aktulga's son Cemil is 37 years old and Fatma Tabanlı's daughter Merve is 31 years old. Their stories are somewhat equivalent of listening to the history of autism in Turkey. Pioneer mothers, who paved the way for other mothers while they give battle for their own children, explained...*

We see that campaigning for autism rests on mothers' shoulders both in Turkey and around the world. We talked with Nejla Arslankurt, the founder and the president of Igi Autism Association, Nevin Aktulga, the writer of the book, "Altını Çizmezsem 1 Düşmez mi?" (If I Don't Underline It, Wouldn't 1 Fall?), and Fatma Tabanlı, the founder and the president of the Foundation for Supporting Individuals with Autism about what they have been through since the first diagnosis of their children and the current situation of autistic adults.

## **Early diagnosis and intervention**

Alper was first diagnosed with autism around 40 years ago. Since there was very limited information about autism and special education during those years, people faced many challenges. Although there has been some progress, similar challenges still continue after all those years. Nejla Arslankurt told us about the early days of first diagnosis: "When Alper turned 3, we came to Çapa Medical Faculty in Istanbul. He had an interest in numbers and learned how to read and write by watching TV adverts. The initial diagnosis period lasted around a month. When the doctor told us that he was disabled and there was nothing to do, I burst into tears, but I don't remember what was said afterwards.

Then we went to see Ülker Yaşın at GATA (Gülhane Military Medical Academy). Alper got improved quite well there, and received his first diagnosis for autism at Haydarpaşa Hospital in 1980.

We had to relocate often because of my husband's job, and it affected us a lot. I had been through a lot during the first three years of my life with child. My son couldn't start special education until 1987. He attended a mainstream primary school. Early diagnosis and intervention is crucial but regrettably, Turkey has not had access to early diagnosis and eligibility for intervention yet. After we had moved to Ankara, founding Igi Autism Association became a turning point in our life."

## **We told everyone about autism**

Nevin Aktulga says that Cemil received his autism diagnosis in 1987 and tells us about those days: "I was working at the Student Selection and Placement Centre (ÖSYM) at the time. My daughter was born in 1977, and my son in 1984. My son was a calm baby. I felt the difference in him, but couldn't name it. On the recommendation of a student from the Psychology Department at Middle East Technical University, we went to Ferhunde Öktem, and Cemil was diagnosed with autism in 1987. At that moment, I thought that I had never had hardship before in my life.

I was done with everything, my worries were over and a sense of calm came over me. I soon made my peace with the new situation and began telling everyone about autism. I enrolled Cemil at the nursery at my work. He both got special education and went to a mainstream school. We had lived in Ankara until we moved to Istanbul in 1990 due to my husband's assignment. During that period, we had worked a lot at Ilgi Autism Association."

A teacher of readygarment, Fatma Tabanlı says that she quickly noticed the differences in Merve even though she was her first baby as she studied child development at the middle school: "Merve was born in 1990. She was a beautiful, calm baby. She had problems with sucking during breastfeeding. We went to the Ege University Hospital when she was 8 months old. All the tests came back clear, and we went back there after a year. We were told that she had hearing loss and needed speech therapy. I observed that Merve behaved differently than children with hearing disability. In fact, I diagnosed her with autism with the help of my teacher friends before the doctor's diagnosis. A psychiatrist diagnosed her with autism in 1993. Since there was not any place for her special education in Balıkesir, where we lived at the time, I began to take her to Alev Girl's rehabilitation centre in Izmir two days a week. After she had cried for two months during her education, she began making eye contact for the first time."

### **Critical times and turning points**

Their children's autism diagnosis became a turning point for all three of these mothers. And they moved on having seen the glass half full. They pushed all their boundaries to ensure that their children can get access to education. Nevin Aktulga, who said that she focused on her children by putting all her own projects aside, says: "As an older sister, my daughter bears an extra responsibility. She, too, had to learn autism. She needed to know why I gave priority to my son. My mother was the biggest chance I had. I went to all sorts of therapies. Nejla always supported me at all levels. I learned that having high morale was very crucial. I went to the concerts of the symphony orchestra every Saturday. My son began to listen to Mozart. Music has changed him."

Nevin puts an emphasis on the fact that she has never compared her son to his peers. She had acted as the President of Ilgi Autism Association during the two years when Nejla Arslankurt had been in Egypt. She says that the association did really good works in Ankara, and touched the lives of many children with autism and their families. She also points out that she had never seen a civil society organization similar to Ilgi after they had moved to Istanbul.

"When my son received his diagnosis, we thought that we would assume the full responsibility of our son as we had brought him to the world. I am not the kind of person who whines; I am a fighter," says Fatma Tabanlı. After the diagnosis, they first gathered the whole family and informed them of the diagnosis. She says that they got the support of both her and her husband's families at all levels. Also, their neighbours and friends supported them. They did everything for Merve to be able to get access to special education and peer education. "We were 3-4 people in Balıkesir, and after great struggles, we managed to ensure that a special education classroom was opened at a school. However, none of the teachers had the knowledge of autism. We sponsored a teacher and sent him to the Autism Centre at the Ankara University for three weeks. We equipped the classroom with our own means. We had some materials made at my husband's workshop. We have always struggled since the first diagnosis of Merve."

Nejla says that she loves sharing and believes the power of unity. "I have come to realise something in due course: When my daughter died, I visited a professor of theology, who said that everyone chose their own roles. I really believe that we seek for these roles. I do not say any bad words to anybody, even to those who deserve them. We are trying to do our best."

### **The government must fulfil its responsibilities**

Ilgi Autism Association was founded by families, who were affected by autism, in 1988 in Ankara. The rehabilitation centre established as part of Ilgi was opened in 1992. Ilgi has carried on its activities as a Public Benefit Association since 1996. It is an autism association that has achieved significant projects, and changed the lives of many autistic individuals and their families so far. Nejla Arslankurt has put so much of herself at each stage of this association.

Since the day it was founded, Ilgi Autism Association has provided thousands of children with quality education, ensured that hundreds of children to lead an independent life by minimising their needs for special education, conducted parent trainings and contributed to the training of many support staff and educators. Majority of the professors working in this field today have all been trained at Ilgi during their university years. Along with all these, the association has conducted autism awareness activities aimed at people of all walks of life. They have done everything that a civil society organisation can do through their own means. However, all these activities should be carried out as a social state policy all around the country. That is how we can talk about justice and equal opportunities in education.



Although civil society activities for autism began in Turkey's capital Ankara in the 90s, same activities began in the city of Balıkesir by another mother taking action. The Association For Supporting Individual With Autism was founded in 2011, and the OBIDEV in 2016. After Merve had been diagnosed with autism, her mother Fatma Tabanlı had shuttled among Izmir, Eskişehir and Ankara. Everything began with Fatma eventually saying, "Having access to good education and living humanely are our children's right in Balıkesir too!" They also have run many projects in favour of children with autism, and these projects enabled parents to take a break. They still continue to work non-stop in order to achieve their goals. They constantly work overtime together with other mothers in other cities to ensure that children lead a life worthy of human rights and dignity.

### **Individuals with autism need inclusive solutions**

Mothers suggest that mainstreaming is a vital need in terms of social integration. According to them, the approaches offered as a solution to this problem at the Autistic Children Education Centres ("OÇEM") are far from being solutions for the problems. They also state that permanent solutions are needed for life-long learning, employment and independent life.



## **Without us, our child would be abandoned**

**Nejla Arslankurt:** We can say that autistic adults are in the hands of their families for now. And the government does not do much about it. And what the government is already doing for us is insufficient. Vocational schools seem to operate for the sake of appearances; we do not find them efficient at all. Parents are trying hard to create the appropriate circumstances for the improvement of their children. Civil servants, school directors or bureaucrats do not have such problems as they think they are already fulfilling their responsibilities. They don't really care about what is really needed.

My child would be abandoned without us as his parents. Our children are in God's hands, because there is not a system for them. If my son is enrolled at an institute today, I don't believe that his needs will entirely be met. Alper can meet his own personal needs by himself. He is verbal but cannot look after himself when he is on his own. He can only lead an assisted life and there are no organisations or people that can provide it for him if we weren't around him. When I visited elderly care centres, I saw some sights of suffering. Besides, disabled people are not taken by elderly care centres.

My dream for my life is to ensure that my son lead life as a happy and satisfied person. I have always wished to be able to leave a solid institute, residential care centre where he and his friends can live after I'm gone. I tried and worked hard for this, but establishing a rehabilitation centre requires so much money and effort that I have lived out my life for it. I would really wish that some other people would lend a hand to me, but that has not happened and we could not institutionalise enough to make my dreams come true. As mothers, we have the dream of seeing suitable environments are created for our children to live in humane conditions with or without us around them. Living spaces ensuring these conditions should be made. The government must take the responsibility of care services and extend them all around Turkey.

# FOCUS ON WHAT YOU CAN DO

**Nevin Aktulga:** Cemil used to work before the pandemic. He entered data at the IPSOS Research Company. He used to get up at 6 A.M., made a salad, boil an egg for himself, and have them, get dressed and listened to music until his shuttle bus to work arrived. He used to leave house half an hour before the time of the shuttle bus, and went the bus stop. He used to come back home from work at 17:30, make a salad, eat it, and then go to the gym nearby to exercise for an hour. He would then come back home, have a shower, have his dinner and go to bed. Since he started working from home after the pandemic, he now spends his time at home. He gets up early and has his salad, listens to music and sings along the songs. We then have breakfast together. He reads his newspaper (only one specific newspaper, Gözcü) and then goes for a walk. He helps his grandmother, and does the daily chores like throwing the bin, emptying the dishwasher and sweeping the floors with a broom. He watches TV if the Parliament Live is on. He also watches basketball and football matches regularly. He got used to watching football on his father's smart phone. By the way, his father and I got divorced, but we always work together as co-parents for the sake of our children.

## **What are your dreams for yourself and your child?**

On this path of my life, I have learned not to plan ahead, try to go with the flow and string along with what happens. I dream that my son can live on his own by his own will surrounded by good people. He has been working for 15 years. Although he has already been entitled to pension, I want him to continue working and remain healthy. Maybe it is about my age, but all I want from life is to remain healthy and peaceful altogether.

## **What would you tell yourself at the time when your son was newly diagnosed?**

Believe me, I don't have anything to say. I think I would be in two minds again when we get a new diagnosis, because each incident is new and different. My emotions then were all humane feelings. I can't think of many things that I could say had I done things differently. Above all, I would choose acceptance, but not to do nothing after acceptance but focus on what I can do after acceptance."

## **How does Merve spend her days?**

We need to minimise our uncertainties in order to spend our day. We use activity schedules for Merve for this. Initially, it was hard for her to accept the unavoidable changes in her programme. Then she learned to tolerate them. We use an annual datebook for specific dates, such as religious festivals, birthdays, and the dates when his brother Yekta comes back to Balıkesir. Merve creates the calendar. Since using the datebook copes with uncertainties, it makes our life so much easier. We have monthly and daily activity timetables. They were in written form initially, but now we use them verbally, but if repetitions increase, we save and follow them on our phones.

Merve goes to OBIDEV's educational institution everyday. She joins hourly programs that include special education, sports education and occupational education. And she helps administrative and kitchen staff during the remaining hours from her lessons. She can express her needs by communicating with the staff at the institution. Apart from her routine programs, she makes plans to have coffee and meal 2 or 3 times a week with the people in our inner circle with whom she enjoys spending time. She enjoys socialising with people she likes by having meals a lot. She sometimes stays over at her sports teacher, aunt or granddad's at her own accord.

She can independently manage her self care, and stay at home on her own during the day. She can express her pains when she has health issues, such as toothache or menstrual pain. She can tidy her room. She puts objects where they belong after she uses them. She is aware of possible hazards in the house. She can enter the house using her key. She can look after her personal belongings. She chooses her outfits for her various activities, can prepare her bag if she has a sports lesson.

She loves being in contact with people. She chats with people through WhatsApp on her mobile in order to make plans with them throughout the day. In her spare times, she follows the posts of the people she cares on social media on her mobile. She saves those posts and reflects some of them on her life. She sometimes watches cooking videos on YouTube. If we have the ingredients at home, she does the preparations and asks me to finish cooking. Merve usually spends her day to the full within a program that mainly includes her choices but we form within our means. In the evenings, she chats with us a little after dinner, then lets herself into her room and usually goes to bed early.



# The smiling face of autism in Antalya

There are hardly any day centres where autistic adults attend in Turkey. Founder of ANTOBDER, Perihan Bal, who established a centre that touches the lives of autistic individuals and their families in Antalya in cooperation with civil society, public and local authorities, answered our questions.

**Could you tell us about yourself and your acquaintance with autism?**

I was born in 1968 in Antalya. I am married with two sons. I graduated from the Vocational School of Construction at the Akdeniz University and Department of Social Services at the Anadolu University. I worked as a substitute teacher for many years. I currently write at three local newspapers. My elder son, Cenk has autism. He was born in 1992 and diagnosed with autism in 1997.

The early years of Cenk's life were spent in the east of Turkey during the time when my husband worked as an army member. We thought that our son could not develop relationship with his peers as he was brought up in environments with no children. And we lost my husband's mother and sister in a tragic car crash during the same period. My son shut himself away totally after that incident.



*"Our main objective is to ensure that our young adults with autism become both productive and happy by having a good time."*



**Can you tell us about the process of the foundation of your association, and works you have done?**

I had been the president of the Sports Club for Autistic Individuals in Izmir for 11 years. We moved to our hometown, Antalya after my husband's retirement in 2009. As there was not an association for autism in Antalya, we founded Antalya Sports Club for Autistic Individuals (ANTOBDER). I currently act as the president of our association whose main objective is to help autistic people and their families adapt educational, health and social life and claim their rights, and introduce autism to society and large masses.

**There are only a few places where autistic adults can go in Turkey. You developed a model for the entire country in cooperation with civil society and public and local authorities. Can you tell us how this idea was born and brought into life?**

There were no place to which autistic youth could go after school age in Antalya, and we all suffered from it. One day, my phone rang at 3:15 in the morning. "What have we done to deserve to be sentenced to life imprisonment at home?" said a woman, burst into tears. She had nobody else than his autistic child, and was alone in this big city. Having heard this mother's despair speeded up our works. As ANTOBDER, we began to seek solutions to ensure our youth with autism over the age of 18 lead a better life. Young people on the autism spectrum, who have finished their compulsory education, are sent back to their homes after their graduation.



Since they cannot find anything to do at home, both themselves and their families faced a difficult situation. And we increased the pace of our solution seeking by having meetings with various authorities. At the end of our meetings with the Antalya Provincial Directorate for National Education, we transformed an abandoned village school into an education centre for young people with autism. After we had made a protocol with the Antalya Provincial Directorate for National Education, we had the school renovated, and opened courses affiliated to the Public Education Centre of handicrafts, painting, sports, agriculture and cooking.

The school building had gone to ruin over the years, so we first renovated it. The support of the Municipality of Konyaaltı is truly remarkable. Our teachers come from the Public Education Centre, and the municipality provides the shuttle service and lunch for our students.



*"I hope the number of autism villages like ours will increase throughout all our cities and districts so that our youngsters with autism won't have be stuck at home!"*

We broke new ground in Turkey by putting a project into practice in collaboration with civil society, public and local authorities. We have been operating since the 2018-2019 school year. We have a total of 42 autistic students between the ages of 18-45. We provide our services between 09:20-15:20 during the weekdays.

**You give agriculture and sports lessons thanks to your large building and garden. How do your students like these lessons?**

We call this project and place, “Our Autism Village”. Our place is in the Akdamlar village within the Konyaaltı Municipality. We are located in a beautiful place at the foot of the Beydağları Mountains, amongst orange trees with plenty of oxygen away from the traffic and city noises. For facilities for autistic individuals, usually places surrounded by nature are chosen in other parts of the world. The fact that we have a large building and garden in an orange orchid affects positively all our education and sports lessons. First thing in the morning, our students do their routine walk by taking 5 laps around the walking track as they arrive at the school before they start their lessons. We create the necessary circumstances for the youngsters to be happy above all. We ensure that they release their energy through the activities that work for them and go back to their homes more peacefully and calmer.

During the sports lessons, they do activities, such as basketball, table tennis, walking, gymnastics and rhythmic dance. Agriculture classes include planting and caring plants, landscaping and flower care. In cooking lessons, students learn how to make pastry, preparing simple meals and fruit juices. Handicrafts lessons teach appropriate handicraft tailored to the ability each student. Our main goal is to ensure that young adults with autism are both productive and happy by enjoying their times spent here.

**You are constantly in collaboration with your students' parents. What do they say about it all?**

As parents, we are happy as long as our children are happy. Seeing our autistic child peaceful and happy is all our priority. Every person spends quality time when they have interests and hobbies, and do not disturb the peace around them.

*“At the end of our meeting with the Provincial Directorate for Special Education and Rehabilitation, we transformed an abandoned school building into an education centre for young adults with autism.”*



Absence of facilities where autistic adults can do activities affects the psychology of both these adults and their families, and their improvement adversely. Since these youngsters enjoy themselves during the time they are at Our Autism Village, we get really positive feedbacks from the families. I hope the number of similar autism villages will increase throughout all our cities and districts so that our youth with autism won't have to be stuck at home!

*Meetings with the Antalya  
for National Education,  
transformed village school into  
helping people with autism.”*



### **What are your dreams for yourself, your son and association?**

Our Autism Village has been an efficient project that responds to the needs of these people in terms of spending quality time throughout the day. However, we are only saving the day here; what we want is to be able to establish residential facilities for our children by the same philosophy and spirit of Our Autism Village. There is an inverse correlation between our children and us: As they grow up and get stronger, we get older and run out of strength. As parents of children with autism, our ultimate goal is to create safe residential and occupational centres by developing projects in collaboration with our government and local authorities.

As the civil society organisations of autism, we must join forces by developing good projects. We already bear heavy burdens of life as families of autistic children, so we should make our lives easier, instead of being a burden to one another. We must continue seeking our rights uniting together by converting our energy to create a positive synergy.



*We already bear heavy burdens of life as families of autistic children, so we should make our lives easier, instead of being a burden to one another.*



## Reading Susan Sontag , the woman who looks all the sufferings of the world through herself

*General Secretary of Ceviz Autism Social Defense  
and Research Association, older sister to autistic  
Güneş, Attorney Deniz Yazgan wrote about  
autism imagination through Susan Sontag readings.*

**According to Sontag,  
using cancer as a metaphor is  
incitement to violence. Unfounded metaphors  
for autism will either make the autistic  
individual celestial or subhuman.**

**In the sky and underground,  
autism has no place.**

**It is a matter of accepting  
the autistic person is human.**

A fine arts enthusiast, obsessed moralist, and bigoted serious as self-defined, Susan Sontag was born in 1933, in New York. As she graduated from high school at the age of 15, she entered the Berkeley University. She had many corporate successes, but far beyond these, she was an exotic and colorful woman. At the age of 18, she graduated from the Department of Philosophy at the University of Chicago and a year later, she had embraced her son David, to whom she dedicated a book that we will talk about in this article later. Receiving international honor scholarships, she conducted research and lectured at the science-creating universities of the USA, called the Ivy League. She was a prolific on very broad spectrum. She left her mark in many parts of the globe. In her article 'Trip to Hanoi', which she wrote after the US visit to Hanoi during the Vietnam invasion; she protested the occupation, using the unfortunate metaphor of "the white race is the cancer of human history. She criticized and put it in an unusual way. She took photographs, made films, wrote plays, essays, columns, screenplays, stories and novels. And she advocated in all of them.

She lost her father to tuberculosis when she was 6 years old and her mother to lung cancer when she was 43 years old. She had her own cancer diagnosis in her 40s. In her book *Illness as Metaphor*, the leading role was for tuberculosis and cancer. In this broad-spectrum literary-philosophical assessment that she wrote while she was being treated for breast cancer, there was almost no "I" language, but the clarity of her own experience dominated the ninety-odd pages that made up the narrative. Before Sontag, metaphors of illness were scarcely critical. Sontag, as she always does, was able to influence and direct the thinking of the next century with her criticisms. When we talk about the social model that explains disability, we unconsciously talk a little bit about Sontag. Because Sontag says from the beginning, at page six of *Illness as Metaphor*; "Any illness that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are the object of practices of decontamination by members of their household, as if cancer, like TB, were an infectious illness. Contact with someone afflicted with an illness regarded as mysterious malevolency inevitably feels like a trespass; worse, like the violation of a taboo."

Most people who find out they have cancer will be demoralized as long as a particular illness is seen not just an illness, but as an evil, invincible predator. According to Sontag, the way out is not in giving up saying the truth to cancer patients, but in correcting the very concept of the illness, in purifying it from myth.

Knowing that there may be a scandal that jeopardizes one's love life, promotion chances, or even whole career, cancer patients may tend to be extremely secretive, if not downright mysterious, about their illness.

Going a little further in the reading, Sontag makes another crucial point in quotation marks. Perceiving illness as a punishment.

It is also included in this problem to state that the illness is a feature that reveals the character of the person who has the illness, as in tuberculosis previously and now in cancer. Or more accurately, that the character of the person itself causes the illness, as the pretentious, passionate, ambitious person harms himself down to his deepest cellular recesses.

Sontag continues with a reference to Georg Groddeck'; The sick man creates her own illness. Groddeck goes further in *The Book of It*, published in 1923.

Over time, only one of the theories about cancer survived, which is cancer leads to the exact stages of death. I mean, it's not cancer that isn't deadly. From this, you might conclude that I have no hope of a new method to treat cancer.

Sontag reports that Kafka also wrote in his diary in September 1917, when he was diagnosed with tuberculosis: The infection in the lungs is just a symbol. It's a symbol of an emotional wound, an inflammation called Felice. The illness speaks for me because that's what I wanted it to be, he says. And he writes to Felice, "I think it's not tuberculosis, at least it's not actually tuberculosis in essence, it's rather a sign of bankruptcy in general."

Frightening illnesses are marginalized and made hostile. As the illness is demonized, the body that carries the illness, and thus the patient himself, is perpetuated. The patient begins to make rapid tours at the two poles between perpetrator and victim.

Although awareness studies for autism are carried out with the slogan of difference, not an illness, the main point of view is to treat the autistic individual in very toxic ways. As autism is depicted with a jigsaw puzzle, in each moment in front of an autistic, we are directed to what is missing, to what needs to be sought, to something lost and mysterious. And as Sontag said and quoted by autistic individuals from Turkey, parents do not bring autistic children together with their children just because they "infect" their autism.



*Frightening illnesses are marginalized and made hostile. As the illness is demonized, the body that carries the illness, and thus the patient himself, is perpetuated. The patient begins to make rapid tours at the two poles between agency and victimhood.*

After the diagnosis, some families do not talk about autism. Then starts discourses based on specialty, on special; such as our daughter/son is different. Instead of facing society's mislabeling, we stick with one more mislabel. The word autistic comes hard, we pick to say, 'person with autism'. We claim that autism is only one trait. However, the human brain and the way it works cannot be just a trait. This is obvious as day.

According to Sontag, using cancer as a metaphor is incitement to violence. Unfounded metaphors for autism will either make the autistic individual celestial or subhuman. In the sky and underground, autism has no place. It is a matter of accepting the autistic person is human.

Cogito [Review] devoted its 87th issue, published in 2017, to "Vulnerability". Judith Butler says in her interview, "There are intolerable, insurmountable forms of vulnerability that cannot be tackled alone. This is exactly why there is a need for an ever-expanding community, network or alliance. If it fails to expand and grow, the vulnerability is exacerbated. The forms of alliance diffusion must become diverse, resilient, and ever-expanding. This means that those of us who are less vulnerable must take on the task of generating and maintaining these networks and alliances.

Talking on behalf of the autistic person who does not express herself in a typical way cannot and should not be of making humiliation, pitying him and making him pitiful a common phenomenon.

As Sontag says, "Metaphors, however, do not become ineffective simply because we avoid them. For this reason, metaphors need to be exposed, revealed, criticised, and even slammed down and erased from their existence purposefully."

Sontag also talks about the stigma coefficient, the capacity to create a ruined identity. "I had the experience of being obsessed with photographs in the past. And because almost all important aesthetic, moral, and political issues had found their

way into the relatively short history of photography. In terms of the evolution of sensitivity, the invention of the camera was perhaps even more important. Of course, what makes photography so interesting and so powerful is the different uses of photography in our culture, consumer society." She says.

Capturing the autistic individual while he is in a state of emotional meltdown and then presenting it on display is nothing but voyeurism, just as Sontag mentioned. But right at this point, looking loops. As it is shameful to look at it, refusing to be aware of this situation also makes one feel bad. To cite my dear friend, Attorney Zeynep Alacakaptan, " Being a spectator of photographs in which human dignity is trampled underfoot has an offensive and embarrassing aspect to one's being human. But this gaze also expresses a certain awakening and awareness. The choice that can be made in the opposite direction, that is, choosing not to look at the suffering and thus turning away from these sufferings (and the victims), will mean leaving the subject of the photograph whose rights have been violated alone, in a sense, and will eliminate the possibility of taking action on the subject."

On the other hand, comes the accommodation to violence. Thus, autistic becomes the other one. When the narration of the image is also experienced due to autism, surreal perception is reiterated, identified with autistic savagery, and the responsibility for autism is lightened.

It is time to reveal the post-truth perception. Unconditional love is the duty of parent; but it is not the unconditional love that society should feel for autistic and for neurodiverse in general. As Sontag says compassion and sympathy are feelings and not related to action. Autistic should live as a human being, not as an angel.

# Drama is the rehearsal of life

Ayşegül Odabaşoğlu, DOD's Member of Board and Modern Drama Teacher, wrote about the effects of creative drama on the lives of individuals with autism.

There are many scientific studies revealing that social ties have profound effects on the lives of individuals. Those, who improve their social ties with their social circle, have a higher quality of life, tend to lead independent lives, catch adult diseases less often, have a better mental performances and self-confidence. Individuals with stronger social ties are considered to have social competence.

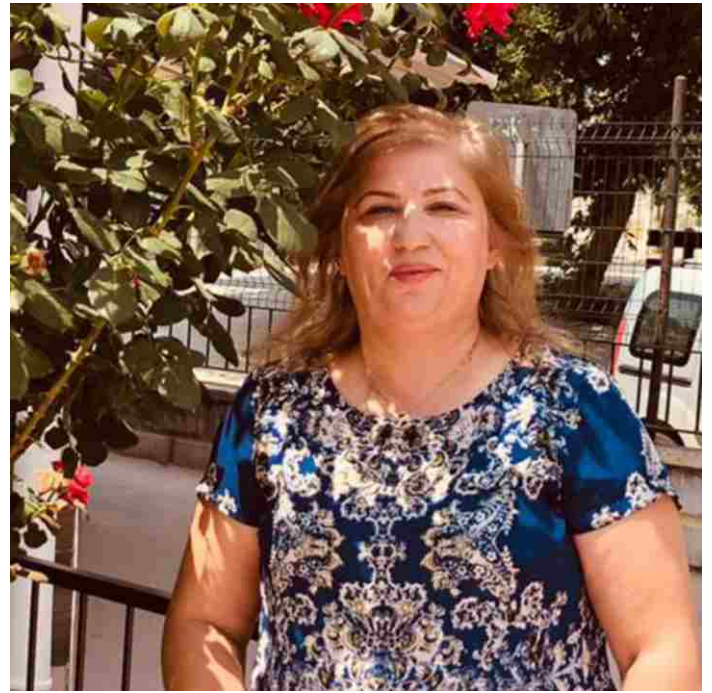
Modern education aims to use an approach based on teaching students how to reach knowledge rather than how to store it. This approach plays a role in developing many learning models and teaching methods that enable students to discover knowledge on their own. Creative drama keeps individuals active in learning processes, enables them to learn by doing and experiencing, makes a contribution to them to be productive, in short, develop in all aspects. It is a method that sits at the very core of people's lives.

In creative drama when used in education, individuals interpret and perform an experience, event, idea, sometimes an abstract concept or behaviour in "play like" processes by reviewing them all. All these are preformed in a group work taking advantage of theatre or drama techniques, such as improvisation, role-playing and so on. (San, 2002).

Creative drama has a great significance in education. If used as a teaching method in education, drama aims to improve sensory, cognitive and behavioural abilities. Moreover, it helps learners gain qualities, such as confidence, self-knowledge, creativity, critical view, excelling oneself and producing ways of problem solving in entertaining ways.

Use of creative drama as a method in education allows modern individuals to shape their social relationships, gain self-awareness, produce and present their existence. Events and situations, and connections between them can easily be learned through creative drama. It is narrated in an indirect way, therefore, it allows individuals to observe others' and their own behaviours at a safe distance. Today's problems can be searched in the past, present and future. A situation is discovered through both concrete and abstract expressions. It is an active method that includes experiencing course of events. Thus, it sheds light on the events by making notions concrete. When looked from a sociological perspective, individuals can have a better knowledge about the past, present and future of not only theirs but also their society (O'Neill&Lambert, 1995; San, 1996; Adıgüzel, 2006).

Individuals with autism are defined as people, who exhibit repetitive behaviours and utter repetitive words, differ from their peers and also experience delays and limitations in terms of cognitive development. Autistic children often have difficulties in communicational skills and are unable to use verbal and nonverbal communicational skills. And all these difficulties affect their language development adversely. Limitations in communicational skills also have negative impact on their social skills,



and find it difficult to communicate with their peers and adults around them. Drama, at this point, should be an integral part of autistic individuals' lives. Drama workshops offer creative, fun and interesting opportunities in order to improve social skills in a safe environment.

There are many techniques that support theatre and improvisation techniques to use drama for autistic adults. It will both be possible and encouraging for autistic individuals to join many activities that are seen impossible for them to join. Drama is very necessary for autistic individuals to challenge barriers they face during their lives. Many researches reveal that drama is effective in improving anger management and social interaction, and improving skills. Also, it will be very useful if those, who work and live with autistic individuals, receive training for creative drama. Thus, it will be easier for autistic individuals to improve their social integration and skills to live peacefully.

**Drama should be an integral part of autistic individuals' lives.**

**Drama workshops offer creative, fun and interesting opportunities in order to improve social skills in a safe environment.**



# Holland and Germany

*Denizli Autism Association visited various rehabilitation centres and schools in Germany and Holland in order to make on-site observations for the living conditions of individuals with disabilities in Europe.*

Use of “habilitation” plays a significant role in integration of individuals with disabilities in society becoming widespread in Europe. As part of Sivil Düşün Mobility and Networking Support, Board Members of DOD, Dudu Karaman Dinç, Sümra Çelik, Zeynep Yamacı and Burcu Bilik paid a working visit to Germany and Holland under the supervision of Adem Kuyumcu between November 3-9th in 2019. DOD visited Artan Pflegedienst that provides individuals with disabilities with home care services, Shtiftung Pflegedienst Habilitation Centre, Albrecht-Schnitter-Schule Vocational School, where individuals with atypical development attend in Munich, Germany; and in Holland, the Aveleijn Habilitation Centre in Denekamp and a Spar shop where people with mental disability work.

## Home care and health services

**Artans Pflegedienst**, located in Munich, provides individuals with disabilities with home care and health services. Artans offers services such as temporary home care, cleaning, nursing care and training relatives to give care with its expert staff. In Germany, home care services are covered by insurance. In order to use this service, an expert report is prepared for the condition of the individual. People can get this service within the region of their residence, and everyone can have access to basic services. For each individual with disability, a care level is identified from 1 to 5 for mobility, cognitive and communication skills, patterns of behaviours and psychological problems, self-care, ability to do the requirements of treatment and manage daily routine. Fees paid to companies that provide these services are determined based on the level of care. An appropriate support is provided in accordance with the expert report. For instance, if individuals cannot manage their self-care, they are assisted in getting dressed, bathing, taking medicines, and so on. If needed, they get support for cleaning and shopping.

Habilitation is a care technique that offers services to people with disability to meet their individual and social needs, and lead an independent life, along with ensuring them to gain physical, social, mental and occupational skills.



**Stiftung Pfeningparade** is a habilitation centre where individuals with disabilities are helped to lead an independent life, guided for their education and ensured to integrate in social life. Funded by the church and supported and inspected by the government, this centre has two buildings organised for disabled children and adults respectively. These buildings are located in the city centre and fully accessible.

**Services for adults:** On the first floor of the first building are common spaces and workshops, such as dining hall, cafeteria and spaces for sports activities. And also there is a unit that provides home care services in the bottom floor of the building.

Upper floors of the building include 2-bedroom flats where individuals with disabilities live with their families or alone. They can have access to any health or care supports without leaving the building. Also, the building has full accessibility for all types of disabilities. Those, who reside in the building, can join workshops, such as weaving chairs, woodwork, cutting and packing. They get paid for what they do in the workshops.

**Services for children:** The second building is a school where students of all types of disabilities from pre-school to high school attend. Each classroom has 14 students, includes a teacher and assistant to give support for the self-care of children. If needed, an assistant is employed for each autistic child.

The building has full accessibility. Classrooms are well lit and spacious. Each classroom has a large and transparent door. There is a swimming pool in the ground floor, where children's various needs, identified by doctors and other experts, are met. Supports, such as speech and occupational therapy are provided and necessary adjustments for the use of medicines are done. Families do not make any additional payments for anything. All services and supports are provided free of charge based on the individual's need, family's demand and expert report.



*Stiftung Pfeningparade is a habilitation centre where individuals with disabilities are helped lead an independent life, guided for their education and ensured to integrate in social life.*

**Albrecht-Schnitter-Schule:** Specialised in learning, Albrecht-Schnitter-Schule is an occupational school that supports individuals with atypical development. The school provides education in 12 disciplines (metalwork, woodwork, business/administration, hairdressing, gardening, etc.) and 25 areas of occupation. Students, who cannot succeed in other schools, are admitted in this school. The school had 513 students aged between 15-35 in 2019.

**In Germany, home care services are covered by insurance. People can get this service within the region of their residence, and everyone can have access to basic services.**

Education is offered between 08:00-16:00. Each classroom has 8 students, and classes last 1 hour 45 minutes. School has workshops along with classrooms. For instance, the automation department includes a garage equipped with all the necessary technological tools. Those who finish this department can get employed in the mechanics industry as an expert.

In Germany, companies are subject to a quota of 4% of disability employment. The school signs a contract with the related companies that employ individual with disability. Students attend the school for two or three days depending on the class term, and take a practice exam in their field of education in order to graduate from the school. This exam is the same one taken by the students in other schools; the only difference is that a different curriculum is used for students to succeed in their lessons. Moreover, students learn all the skills by experience and practically. For instance, students of cookery make all the meals in the kitchen. Service department students gain experience by serving their friends at the school cafeteria, and that gives them self-confidence for their future work life. Success rate of the graduates is 98%.



*Families do not make any additional payments for anything. All services and supports are provided free of charge based on the individual's need, family's demand and expert report.*





### Step by step to an independent life,

Avelijn in Denekamp in Holland offers services for individual with autism and mental disability with care, treatment, education, assisted and independent living, and so on. Individuals over 18 are also admitted here. The oldest person in the centre is 72 years old and autistic. Those with multiple disabilities can also stay here as long as they are in the mentally disabled group. Personal rights of individuals are respected here, and also families can visit their children at any time they want.

The centre includes 52 two-bedroom flats, each of which has an area of 70-meter square, a bedroom, a study room, a lounge with an open kitchen, a bathroom and toilet. The building is heated with a central heating system. 60% of the residents are male. These types of facilities were built outside the city centres in the past, but moved to the centres as it encouraged discrimination and prevented from social integration.

The buildings have two floors, and different parts were painted in different colours so that those who have good visual memories can find their flats. In each part, there are staffs that work in three shifts. The centre is never vacant. Flats have cameras to maintain security. However, individuals with disability live on their own in their flats. There is a file for each resident, and his or her individual education and support programs are designed according to the file.

The residents of Avelijn prepare their breakfasts and sandwiches for lunch, and have dinner prepared at the centre. If an individual is on a special diet, the menu is prepared accordingly. In order to make a contribution to sustainability, meals are sold to the consumers outside the centre, and the income is used for the centre.

### James's house

We visited James's flat in Avelijn. James is 28 years old, has autism and Dawn syndrome, and lives on his own. He has the mental capacity of a three-year-old, and is non-verbal. He is interested in music, and has a guitar in his room. He loves riding a bike.

There are many photos hung on his flat's wall. Majority of these photos belong to his elder sister who died of cancer. He has his favourite CDs in his bedroom. He tidies and arranges his house by himself. The building is heated with biofuel and an underfloor heating system due to safety reasons. And there is a control system for the use of fuel.

James uses a timescale in order to manage his daily routine. The timescale is prepared with him and saved in his iPad. Since he is illiterate, he uses his timescale with pictures. He is provided with all sorts of supports based on his needs at the centre. Assistants wake him up when he cannot wake up, and has his dinner from the centre's kitchen. There are spaces where he can socialise with his friends. A sex therapist comes to see him on Wednesdays. Along with all the education he has received, his likes and dislikes are also recorded in his file since his childhood. All this information guides the staffs at the centre to provide him with the necessary support. James follows a programme based on the plan prepared with him and his file.



*The Sparo shop we visited employs 27 individuals with disability including autism, Dawn Syndrome and mental disability, who work full time and under the guidance of three supervisors.*

A culture centre was rented near Avelijn in order to help residents get employment and socialise. Individuals with mental disability work in the library, cleaning of the theatre and restaurant of the culture centre. Also, this building includes workshops of cake and cookie making, packaging toys, and paper folding and tearing. Here, autistic individuals work based on their skills. Their work targets are created with the help of their supervisors and everyone is included in the production process.

We also visited a SPAR shop in a town about 20 minutes away from Denekamp. Only individuals with mental disability work at the shop. 27 individuals with autism, Down Syndrome and mental disability work full time and under the supervision of their consultants. We saw that individuals with autism and other disabilities contribute to production and are supported for their social integration and independent life everywhere we visited. In order to achieve all these, all the necessary steps begin from the childhood years of the individuals.

*Avelijn in Denekamp in Holland offers services, such as care, treatment, education, assisted and independence life for individuals with mental disability and autism. To see similar facilities of this centre, where every single detail is considered, in our country, too, has become our biggest dream!*



# Our story is just beginning

DOD's Vice President, educator and Musa's mother, Sümra Çelik wrote about her impressions after the Holland visit...

We have many journeys we have taken in our life. However, the hardest journey is the one we take to our hearts. During the visit I did to Holland in 2019, I took a journey to my heart. Do we need to go to thousands of miles away to take a journey for self-discovery? I think sometimes we do. Isn't humanity is made of an odd paradox? Aren't contradictions the most beautiful form of art?

The best rule of taking a true beautiful journey is to take it with your fate mates and comrades. Everyone's journey has its own reason, such as vacation, business, etc.; our reason was autism. I took the road as a mother after I purified myself from everything... I set off with my fate mate Dudu and comrades Burcu, Zeynep, Adem and the cutest of all comrades, baby Okyanus for our journey to Germany and Holland. Each mile of this journey took me to the depths of my heart, because we were visiting residents, schools and so on for people with disability and autism. Each one of the places we visited was impressive; everything from the workshops to designs was studied in detail...

Our last stop was Avelijn in Holland. The director of the institution welcomed us. He patiently answered all our questions. He was patient, because we had to ask the same question over and over again as we were greatly amazed. Not because we did not understand or hear well, but could not believe what we heard. The centre was a cosy place including detached houses with flower gardens in their yard. The first thing that caught my attention was that high walls, wire fences, doors, etc. did not surround it. I just could not believe it! I thought that autistic individuals would escape from there remembering the facilities surrounded by walls and wire fences in our country. I asked the director, Sander, "Don't they run away, at all?" He gave a humble smile and said, "No, they don't." In 5 minutes, Dudu asked the same question, and he repeated the same answer. And when Burcu asked the same question 10 minutes later, he looked at us astonishingly, probably thinking that we did not understand him well. Having noticed his look, we had to explain that our children constantly attempt to run away, so we could not believe that theirs do not, and had to ask over and over again. "We do not aim to keep them here as prisoners. They have the right to live freely wherever they want," he said. He explained that people with disability are seen as an individual from the moment they receive diagnosis, and get prepared to live an independent life. And the reason why they do not run away is because they are educated and trained. I think this was the gist of our journey.

After we had chatted for a while, Sander took us to the apartment of a 28-year-old man with the mental capacity of a three-year-old, autism and Dawn syndrome. He emphasized that they took his permission before they opened the door. Yes, a door was opened in my life, and maybe in my heart... James lived there alone. He could visit his family whenever he wanted.



He could have guests in his flat if he wanted. We first entered a lounge with an open kitchen. The programmes for his daily routine were saved on TV to make his life easier.

The residents have their dinner altogether in the communal dining hall, but prepared their breakfasts and lunches by themselves. There was a cooker in the apartment. While I was baffled by it, I found out that he could cook his favourite meals. We went to James's bedroom. He had a small obsession. He apparently neatly orders his CDs in a line on his bed. It was his little routine. I wondered if I could put an order to my problems as he did with his CDs, and thought I could maybe sort my life out if I started lining my problems like those CDs. Then Dudu and I caught each other's eyes, which were filled with tears. We did not talk. Perhaps we had the biggest silence in our lives, but this silence told each other a lot. I think we both took James for our sons Musa and Deniz. They maybe strolled that apartment with us. As I said, it was our biggest silence ever, but biggest screams were hidden in it. And as I wrote at the beginning, the best side of a journey is that you take that journey with your fate mates. The study room and the other parts of the apartment were all beautiful. In fact, the most beautiful thing here is the message given: Autistic rights are human rights. The fact that Musa and all other children in Turkey are autistic does not make any less of them. They, too, have the right to live freely, equally, humanely and with dignity like anyone else. When someone goes somewhere, he or she would never come back as the same person. Journey brings us around, says Albert Camus. And five autism volunteers, our baby volunteer, Okyanus came back to our country. We all came in different dates, but looking through the same perspective: Autistic rights are human rights.

"All great stories begin in two ways: Either someone takes a journey or a stranger arrives at a city," says Tolstoy. We took a brave journey, and are now a stranger in the city we came back to. Yes, maybe the time is limited and the road long, and we are tired, but our story is just beginning. We will fight to the end to make change... We will fight to have places like those facilities in Germany and Holland in Turkey, too. We will work hard to finish this story greatly...



**Can you tell us about your works that you conducted for adults with autism at Tohum Autism Foundation?**

We have a programme called Career Development and Life Skills Programme for the continuation of the services provided from early childhood to adulthood. Within the scope of this programme, we work on revealing workforce potentials of autistic adults through supported employment programmes, and their employment in various fields, such as cleaning, food industry, data entry, jewellery design, and textile warehouse attendance. Thus, autistic adults find the opportunity to improve skills of using money, creating spare time activities, social integration and so on. This programme supports the independence of individuals along with their career development, enabling them to improve their daily life skills and integrate into areas of social life. Two young people with autism were employed at the Akbank-Bilkay Company from these services before the pandemic. They started working on operation completion and data entry.

Apart from supported employment programmes, we conduct workshops to help them learn various work skills and create workforce within our foundation. A workshop for making wristband was founded at our school in collaboration with the Pour La Bonte brand. Our autistic adults produced 2,554 wristbands in 2020 and they were put up for sale pioneered by the brand.

## Autistic adults and practices in the US

*Aylin Sezgin, the Vice President of Tohum Autism Foundation explained her views about the autism centres they visited in the US, and their own works with autistic adults at the foundation.*

*Many of the adults who have been benefiting from the full time programmes at the PCDI (Princeton Child Development Institute) also use the residential services of the institute. There are apartments called group homes where a few autistic individuals and their life coaches live together.*



### **Can you tell us about the institutions that you visited in the US and their services?**

Our school has been offering various services for adults with autism as the dissemination arm of various institutions, notably PCDI (Princeton Child Development Institute), Alpine Learning Institute and Melmark since 2006. We have often visited PCDI for many years. We also had the chance to see some other institutions, observe their services and obtain information at different times. We saw that the common goal of these institutions are to support independent life for adults with autism, teach them social and daily life skills and improve their spare time skills. Moreover, adults with autism are provided with the opportunity to gain employment through supported employment. In these institutions, young people over 18 are provided with in-house programmes, community living programmes or half-day programmes. Regardless of the type of the programmes, an individualised programme for each adult is developed, and these programmes are conducted based on data in a systematic way.

### **Can you give us an example for the skills targeted for adults with autism?**

Various skills are targeted based on the interests, needs and personal learning characteristics of the adults. As skills for preparation for employment, they learn cleaning, warehouse tasks, office skills, such as using computer and printer. Daily life skills include folding laundry, food preparation, ironing and playing the piano. And their skills for social independence include shopping, drawing money, ordering at a restaurant and planning appointments.

### **Can you tell us about community living programmes?**

Majority of the adults who benefit from the in-house programmes at PCDI also use the community living programme. There are apartments called group homes where a few autistic individuals and their life coaches stay together. While some of the adults, who stay in these homes, improve their skills by going to the institution in the daytime; some others are employed full time or part time. Apart from the group homes, there are apartments where 2 or 3 adults with autism stay together. These adults can lead an independence life.



However, their life coaches periodically visit their apartments or workplaces to supervise them.

**What types of services are provided for autistic adults with severe behavioural problems?**

There are not many institutions that provide services for autistic adults with severe behavioural problems in the US. Kennedy Krieger Institute is a very good example among the organisations we visited. Located in the Baltimore State, this institute has been offering its services for about 75 years. It was founded with the support of John Hopkins University, and is also a research centre offering various services to various disability groups.

Kennedy Krieger Institute has a separate department for autistic individuals with severe behavioural problems. There are a lot of applications for this centre that gives 2-6 months of live-in services. The centre provides its services to no more than 15 individuals at the same time. Their individual characteristics are all taken into account. For some severe cases, live-in period can be extended to 12 months. Children or adults (up to the age of 21) with the diagnosis of autism or secondary diagnosis can make an application at the centre. Both educational implementations based on applied behavioural analysis and medical services are provided together at the centre. Educational processes continue during the day. And in the evening, nurses working in a 24-hour shift do their follow-up. Nurses work in three shifts.



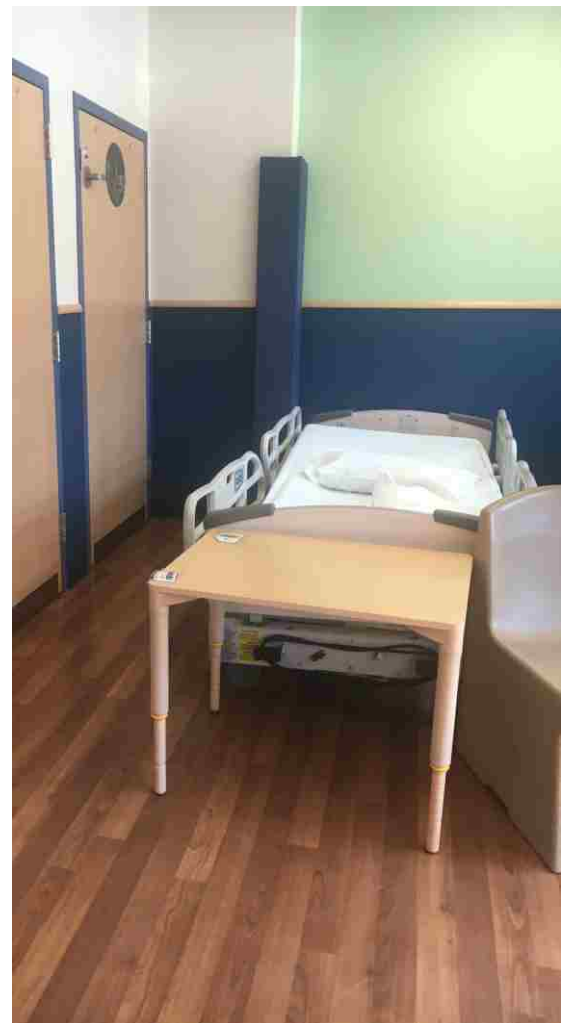


## What are the educational and treatment implementations at the institute?

Educational interventions applied for the individuals with autism who gets live-in services at the centre are planned tailored for each individual, and experts provide consultancy to the therapists. Each individual is provided with programmes based on systematic data. The physical environment is arranged in a way that severe and harming problem behaviours would not harm individuals. Sharp edges in the rooms are covered with soft materials. There are safe rooms furnished with soft cushions so that the individuals are calmed without being harmed during their severe problem behaviours. The room is equipped with communication systems in case the individuals ask support from outside the room. These rooms can also be monitored from monitoring rooms or with cameras. Door handles are placed high enough so that children cannot reach. Toilets and bathrooms are built fairly large for carers to enter if needed. Hospital beds are used in the rooms. Some special outfits and hardhats can be used in order to protect individuals and therapists. Teaching is conducted by the use of visuals during educational implementations. Individuals gain self-care skills such as having a shower and brushing teeth by using activity schedules.

## To which institution are those, who complete their services, referred?

Individuals whose services end in this centre either go back to their families or placed in nursing homes. There are not institutions that give services to individuals over the age of 21. Regardless of the severity of their cases, they can stay at the psychiatric services of hospitals for a week. They are then discharged and again, go back to either their families or nursing homes. In short, in the US, the number of supportive living and learning environments, where autistic individuals over the age of 21 can improve themselves, integrate into social life, contribute to production and lead an independent life is very few.



## We need a change in the perception of the autistic

I graduated from the George Washington University where I completed my Master's degree in 2012 and began seeking a job. I was admitted as a special education teacher at the Community School of Maryland within the Community Services for Autistic Adults and Children (CSAAC). CSAAC is an NGO that is located in Maryland State and provides autistic individuals with intense early intervention, school programme, independent life and work schedule. As opposed to the mentality suggesting that autistic people should be "cared" in a remote and separate part of a city, this institution maintains that autistic individuals can lead an independent life, exist in work force in accordance with their areas of interests and skills without being alienated and marginalised. I have always felt lucky to work at such an organisation with this perspective in my first professional experience of working with autistic individuals.

I had students at the ages of 17, 20 and 21, and teaching assistants who give them one-to-one assistance during and outside the school hours. Although their personal characteristics appears to be difficult, I had three autistic students with whom I enjoyed working most.

My 20 and 21-year-old students (one male and the other female) resided in group houses, where 4 people accommodated, and went to work during the school hours in certain days and times. The houses they lived were rented in the centre of the city next door to neurotypical people. Each had their own room and private belongings that they brought from their family homes. Lounge and kitchen were the common spaces for four housemates. Lounges were furnished based on the residents' interests. While some had table tennis, some had a huge table top of which was filled with jigsaw puzzles or colourful knitting yarns. They went to shopping either together or in turn, and shared house works, such as cooking, cleaning, laundry or dish washing.

All three of my students were employed based on their interests and skills. We gave them all the necessary supports so that they achieve their works. While I worked on their academic and behavioural skills at school, their work coaches supported them at work. One student, who was nonverbal, worked at a restaurant, one at a shop and the other delivered newspapers. They worked, spent effort, paid for their work and proudly spent their earnings. Above all, they felt useful and a part of society, and it was a worthless feeling both for them and me.

Although all these sound "impossible" or like a "dream" in Turkey's circumstances, I have seen that individuals with autism could "lead a life worthy of human dignity and human rights" when the necessary arrangements are done and supports are provided.

After I had returned to Turkey, I worked as a teacher at various organisations, and had the chance to make some observations. I was totally astonished by what I saw after my experiences in the USA. Although my astonishment has been replaced by disappointment in time, when my path crossed with people, who believe that we can make real changes in autism in our country, I have devotedly

**Burcu Bilik, DOD's Chairwoman and Education Coordinator, wrote about her working experiences with autistic adults in the US.**



continued my works.

Stereotypical behaviours, which were allowed to a certain extent for students to calm and regulate themselves, were seen as problem behaviours, and never allowed here in Turkey. I saw that when a child entered a classroom by swinging arms (there are many people who swing arms when walking) was taken out of the classroom several times to ensure that he/she entered again without swinging arms; or when a child with many social skills was sent to a special education school on the grounds that "he had not had all nursery school skills yet" while he could both enjoy himself and learn a lot from his peers with typical development...

Not to mention the houses where autistic individuals lived or their works for it is among the bleeding wounds of the autism concerns in our country. Of course, we have good examples in this field, but they are no more than a handful, and made possible solely with the efforts of autistic individuals, their families and civil society organisations.

Although I thought at first that the difference between the two countries resulted from social policies, educational methods and economic conditions, I have come to realise that it is due to the difference in the "perception of the autistic". Perception of the autistic in Turkey includes correcting them; likening them to "normal" people, and perceiving them as "individuals who need care" in a scolding way rather than seeing them as individuals. Therefore, studies and works conducted for autism are way far from protecting the right to live equally and in dignity for autistic individuals.

It does not matter from where we bring the examples of good practices, expensive educational programmes, and state-of-the-art systems. What really matters is making a "change in the perception of the autistic". As long as we can't change it on a social level, all the policies developed and practices conducted will continue marginalising and seeing the autistic as a passive object.

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