Autism Awareness Society
Kyrgyzstan
St. John’s College
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Project Summary

Through the Autism Awareness Society, I will print and distribute autism identification booklets in Kyrgyz to kindergartens and primary schools in rural regions. I also plan to create social media content on autism awareness on the official AAS page in the Kyrgyz language to initiate open discussion of autism in Kyrgyzstan. The goal is to bring awareness and information to a population that does not speak Russian and English in rural regions and support the parents of the children in those areas.

Background

According to the Soros Foundation-Kyrgyzstan there are approximately 630 children with autism in Kyrgyzstan. They further report that 34,000 children with disabilities are registered in the country. That is 1.1 percent of the population under the age of 17. Experts estimate that more than 20,000 children in Kyrgyzstan have autism spectrum disorders. The estimation calculated by experts is significantly higher than the reported sum of children with Autism in Kyrgyzstan. This demonstrates the lack of awareness around the topic of autism and that parents do not have enough institutional help to diagnose and help their children. In addition, due to colonization, all academic publications and information about autism in Kyrgyzstan are printed in Russian and not Kyrgyz. Not only does the language barrier create a challenger for Kyrgyz parents with special needs children to find effective learning techniques, but also creates ignorance of neurological disorders in the population.

In Kyrgyzstan, autistic children suffer neglect and maltreatment due to the lack of information in the Kyrgyz language that could help parents give the children essential education and care. Neurological disorders are still not taken seriously at schools and in the population, which makes it difficult for autistic children and their parents to feel welcome and comfortable in public places. Due to the lack of mental health and neurological specialists that can offer their services in Kyrgyz, parents and their autistic children feel isolated with their issues.

I came to the idea of forming the foundation from having a brother who has severe autism spectrum disorder. We always knew that my brother has special needs. Only when we moved to England for a year was my brother diagnosed with autism. When we came back from England my parents could not find any therapist or any information in Kyrgyz that we could use to understand my brother's diagnosis. Very few psychiatrists in the capital city could give my parents basic guidance and prescribe necessary medicine. The language barrier due to colonialism makes it difficult for native Kyrgyz people to diagnose autism, as most neurologists in Kyrgyzstan are trained in Russian.

Preliminary work

I discovered the institution “Ruka v Ruke” when my parents brought my brother there and paid for private classes. I volunteered there to learn more about caring for children with autism. However, as it is a private institution, the fees were more than any average family in Kyrgyzstan could pay, so after some time, we had to take my brother out of the classes. Outside of private institutions that charge a high amount for their services, there is a complete lack of support from the government. Through AAS I aim to give parents a platform to communicate the difficulties of autism to the population and the government, so that educational and work-placement institutions could be made available for people diagnosed with autism.

Out of frustration of not feeling like my brother did not fit in, my parents and I started an Instagram account, @storiesbek, to document his learning process. The account gained a lot of attention from many parents, and many are finding out about autism for the first time through the account. The account currently has 18,200 followers. All announcements of events for the parents of children with autism will be established through my brother’s well-established Instagram profile. Many parents in Kyrgyzstan follow this account as it provides information in Kyrgyz about the experience of living with autism spectrum disorder. @Storiesbek will be a constant social media support figure in the project as he is my brother, and my parents are interested in advertising the project on his social media page.
Before the start of the association, I will dedicate a month-long research period to determine the best articles and issues to raise in the conversations in the AAS.

**Project objectives**

1. Promote peace by creating an environment of inclusion and awareness in primary schools for children diagnosed with autism in rural villages of Kyrgyzstan through children’s literature.
2. Tackle the language barrier and make information about special needs children’s education available in Kyrgyz.
3. Encourage empathy and understanding in teachers and educational institutions.
4. Provide information and mental health support to Kyrgyz parents of autistic children in their native language.
5. Create a platform for parents to meet, discuss and plan future AAS events and projects.
6. Publish and translate publications into Kyrgyz, from the well-established source for parents with diagnosed children: [autismspeaks.org](http://autismspeaks.org).
7. Create interest and demand for neurologist and psychologist education in Kyrgyz.
8. Hold mental health support sessions weekly and provide a professional psychologist to talk to parents.
9. Create an online platform to collect data on children with autistic children in the Kyrgyz language, making it accessible to native Kyrgyz people.
10. The association will play an active part in the formation of tolerant and favorable public opinion about children with autism through media (social media, books, short clips).
11. Through the online platform, collect opinions and stories to highlight the issue. The social media account is going to be funded for a year to be active in supporting parents and shining light on the overlooked children diagnosed with autism spectrum disorder.

**Partnerships**

I plan to collaborate with the private school “Sapat” in Kyrgyzstan and distribute the published resources to the multiple campuses that they have around Kyrgyzstan ([https://sapat.edu.kg/en/glavnaya-english/](https://sapat.edu.kg/en/glavnaya-english/)). I attended high school there and have contacts to the Sapat network. I would also like to distribute published literature to orphanages and the crisis center “Sezim” that takes care of women and children who suffered domestic violence ([https://sezim.org/bashky-bel/](https://sezim.org/bashky-bel/)). My mother has a long-standing relationship with the crisis center, being a medical journalist, she has collaborated with them in the past. I will invite experts that are currently working in the organization *Ruka v Ruke* in aiding the project events with their expertise. I have previously volunteered in this organization, so I have connection to the therapists and neurologists there. Additionally, the AAS will have a mental health counseling meetings for parents on a regular basis for 2 weeks. This will encourage friendship and resource sharing between the parents of children with autism spectrum disorder. The organization [autismspeaks.org](http://autismspeaks.org) has been contacted to collaborate with AAS to translate the most relevant and useful articles on the website.

**Long-term objectives**

- To create awareness in youth that will foster a welcoming environment for children with special needs in schools.
- Motivate youths into studying more about autism and creating interest in the subject. Ideally, from the interest universities will begin to offer training for specialists in autism spectrum disorder.
- Through the active social media account, which is planned to be funded for a year with the social media stipend, to show demand for education catered for children with special needs to the government.
- Create an online platform (website and social media page) for parents to communicate and plan future events through the association.
- The created association being the largest resource for parents in Kyrgyz.