

# Families of People with Autism on Curaçao Need Support

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### Background

On Curaçao, a Small Island Developing State (population 150.000) and since 2010 a constituent country within the Dutch Kingdom, support systems for people with autism are still developing. Over the years, a lot has been done by local healthcare institutes. Governmental and non-governmental care organizations have initiated and enhanced care for people with autism. Several local psychiatrists, speech therapists, psychologists, and other professionals dealing with autism became more experienced and knowledgeable about the support needed. Also schools, especially special education, have taken steps to facilitate children with autism.

Despite the apparent improvement in care and support, there are indications that (families of) people with autism still lack support. Therefore, this study looks at a wide range of issues, with a focus on problems experienced in the diagnostic process, treatment, housing, education, work and leisure, socializing and wellbeing.

### Objective

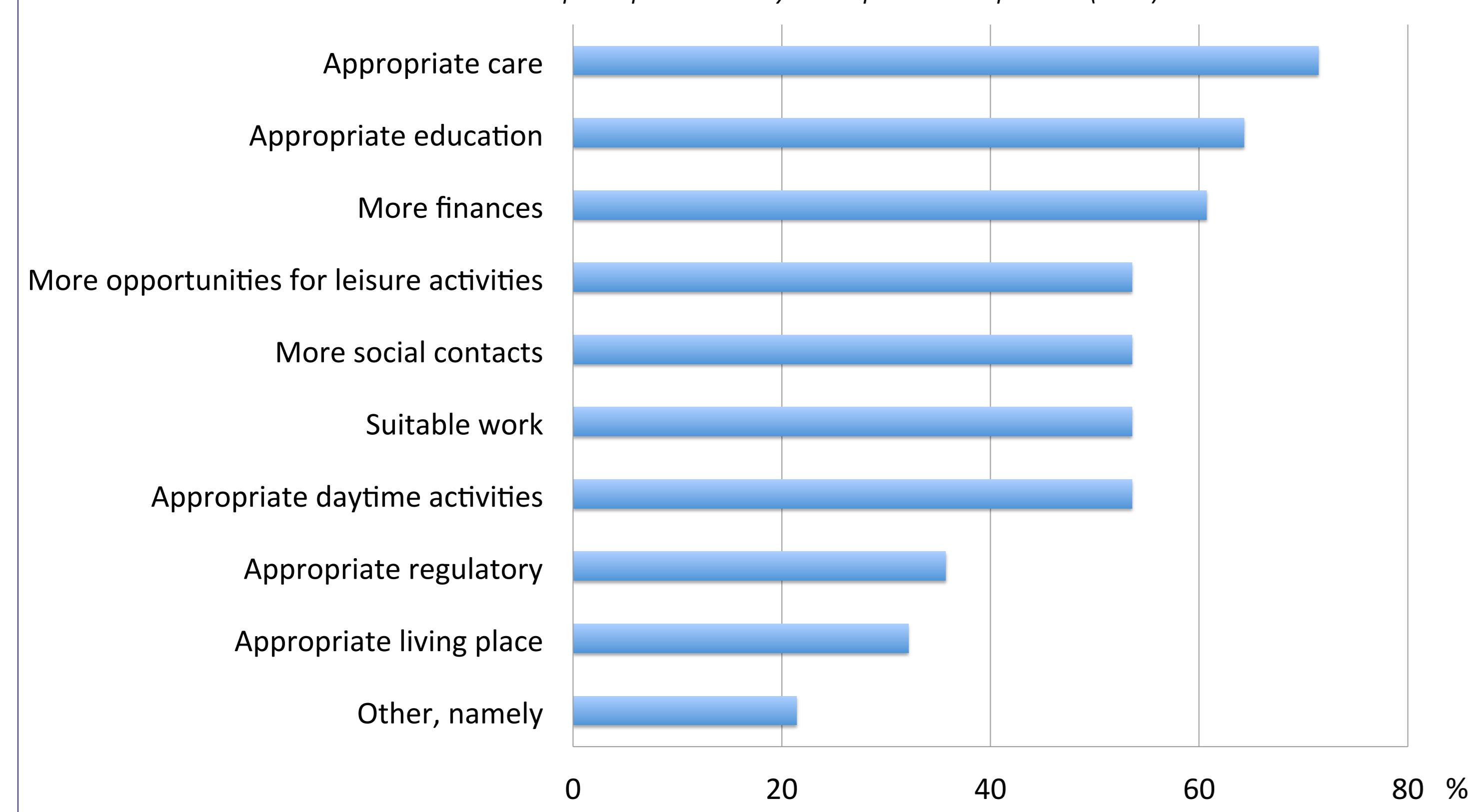
The objective of this study was to gain insight in the need for professional support in people with autism living on Curaçao and their families, to identify the gap between this need for support and the availability of resources and facilities. The local parents' association 'Asosiashon pa Autismo Curaçao' (AAC, founded in 1997) initiated this study and will use the results to bring the needs experienced to the attention of social organizations and the government.

### Methods

Using a mixed method approach, first a focus group (qualitative research) was held consulting 7 parents from the AAC concerning their needs for support for their children with autism. Next, these results were used as a local input for the construction of a questionnaire (quantitative research) based on the Dutch Society of Autism 2013 questionnaire (Begeer, Wierda & Venderbosch, 2013). 37 parents and caregivers (30 mothers, 4 fathers, 1 sister, 1 teacher and 1 therapist) of 32 individual children with autism (age 5-30) filled out the survey online or hardcopy in the Dutch or Papiamentu language. Response rate of the AAC members via email was 34%, this was complemented with 17 non-members reached via other institutions.

#### Needs of families of people with autism on Curaçao

What would be required for the person with autism to be able to better participate in society? Multiple answers possible (n=28)

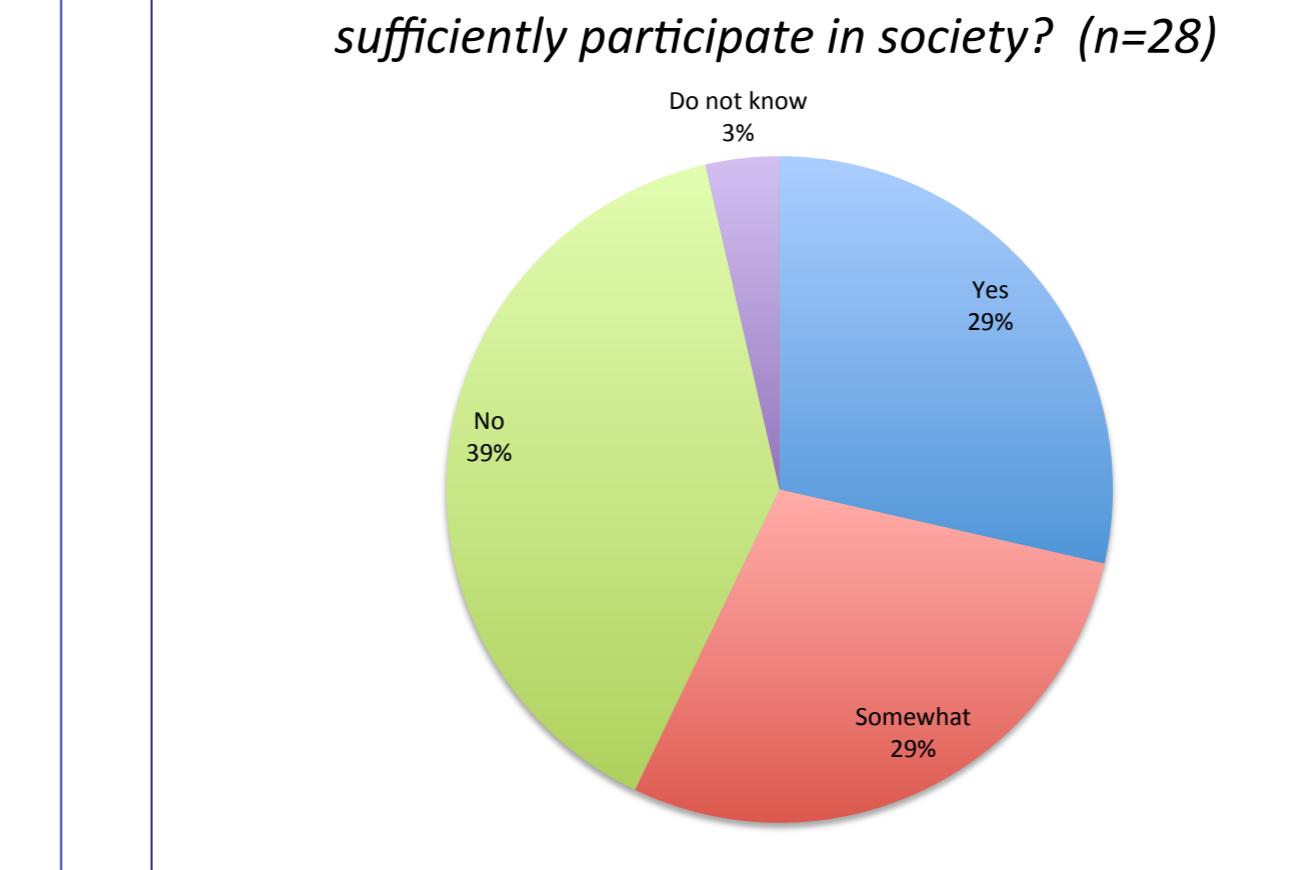


### Results

The study reveals that the diagnostic process takes long (average of 20.5 months) and in many cases parents still need to go abroad to get a correct diagnosis. Parents express the need for a multidisciplinary team and for case managers. After diagnoses, parents experience that there is no care or treatment plan and no guidance to the right support and facilities. Only a few schools have the means to support people with autism; in some cases children are rejected at all primary schools and are not able to receive any education. Parents perceive housing facilities to be scarce; although in the small community family provides a strong safety net, there is a huge need for assisted living, as parents fear for the time that they will no longer be around. The respondents are aware of leisure facilities on the island, but they refer to the much broader range of possibilities in e.g. Venezuela and the Netherlands. A job coach could improve job opportunities. Many parents experience financial difficulties. Furthermore, parents perceive there is still a taboo on autism in the Curaçao community; they fear that a lot of children stay undiagnosed and might end up on the wrong pathway. They see a role for the government.

#### Participation in Society

Do you think that the person with autism can sufficiently participate in society? (n=28)



"I had to pay a caretaker just to help me get him into the classroom for school. She would sit with him until he was able to go inside or else I would lose my job."

"We need professionals. Volunteers in the foundations really are angels. Add two specialized people and you can get so much more out of these children."

"Here on Curaçao we do not have special education for these children. This is a huge problem. We miss out on guidance and activities. We need materials and professionals to work with the children."

### Conclusions

To improve the professional support on Curaçao for (families of) people with autism, institutions should collaborate to facilitate the route from first diagnosis to integrated support for care, education, living, work and wellbeing.

### References

Begeer, S., Wierda, M., & Venderbosch, S. (2013). *NVA Enquête 2013: Allemaal Anders, Allemaal Autisme* (NVA report). [Dutch Association Survey 2013: All different, all autism] Retrieved from [http://www.autisme.nl/media/55246/NVA\\_Onderzoeksrapport\\_2013\\_LR.pdf](http://www.autisme.nl/media/55246/NVA_Onderzoeksrapport_2013_LR.pdf)



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