

**Name of Study:** Measuring Quality Adjusted Life Years (QALY) in Children with Autism Spectrum Disorders

**Location:** Massachusetts General Hospital, Boston, MA, USA

**Eligibility Criteria:** Parents of children or adolescents between the ages of 3 and 19 who have been diagnosed with an Autism Spectrum Disorder

**Principal Investigator:** Dr. Karen Kuhlthau

**Contact Information:** Ms. Dianali Rivera, Research Assistant; phone: (617) 643-4585 or Ms. Jennifer Delahaye, Research Coordinator; phone: (617) 724-1938.

Dear Parent,

We are writing this letter to offer your child an opportunity to participate in a research study that is focused on children and adolescents with Autism Spectrum Disorders (ASDs). Any parent who has a child that has been formally diagnosed with an ASD and is between the ages of 3 and 19 will be asked if they would like to participate.

This research study is focused on measuring quality-adjusted life years in children with ASDs. Quality-adjusted life years (QALYs) essentially measure how much a disease weighs down your life. This measure is used by insurance companies, health care centers, and economists to decide whether the benefits of a treatment outweigh the costs of the treatment. In other words, will the person treated see significant enough improvements in his/her quality of life to justify the financial consequences of the treatment? If the answer to this is yes, then the treatment is worth doing. If the answer is no, then an alternate form of treatment will be sought. No one has studied whether the current questionnaires used to find out this information are applicable to children with ASDs. To our knowledge, QALYs have never been measured for children with ASDs. Figuring out the best way to determine QALYs for children with ASDs will allow this information to be used in order to advocate for better treatments.

Participation in this study involves taking part in one focus group meeting. The meeting will take about half a day and will be held at MassGeneral Hospital's main campus in Boston. All parents who choose to take part in this research will be given \$50 for their participation. There is no charge to participate in this study.

If you are interested in participating, please contact Dianali Rivera at (617) 643-4585 or Jennifer Delahaye at (617) 724-1938.

Thank you in advance for your consideration of this study. We wish you and your family all the best and we look forward to working with you in the near future.

Sincerely,

Dr. Karen Kuhlthau  
Associate Director  
Center for Child and Adolescent Health Policy  
Massachusetts General Hospital

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