# AGENCY OF HUMAN SERVICES

# REPORT TO THE LEGISLATURE OF THE STATE OF VERMONT

# **Regarding Implementation of ACT 158:**

An Act Relating to Health Insurance Coverage for Early Childhood Developmental Disorders, including Autism Spectrum Disorders

Addendum – Autism Speaks Parent Survey

Submitted to:

Senate Health and Welfare House Health Care March 2014 Autism Speaks sent out a survey to parents of children with ASD in Vermont in late December, 2013; 75 parents responded to the survey.

#### Insurance

- 60% of parents indicated that their child's primary insurance was private insurance
- 37% said Medicaid
- 3% were unsure

# How did the parents hear about Act 158

- 34% from another source such as a friend, provider, media, or parent organization.
- 27% via e-mail or listsery
- 22% said it was the first they had heard about it
- 17% heard about it through a workshop
- 8% through a medical professional
- 2% through school

## When asked if their child was receiving therapy outside of school

• 51% of parents indicated that their child was not

Of those who said their child was receiving therapy outside of school

- 16 % through their Medicaid insurance
- 13% through private insurance
- 13% said they paid for it out of pocket
- 3% was paid for through Medicaid Home and Community-based Services funds
- 3% through a flexible option under Medicaid Children's Personal Care Services

### When asked about how easy it was to navigate getting therapy for their child

- 29% said they had trouble getting information, but eventually succeeded
- 29% said the process is confusing, but they are still trying
- 18% said they got frustrated and gave up
- 14% said they have no idea where to begin
- 10% said it was easy and straight forward

Parents indicated that they have difficulty finding therapists with ASD background who will accept their insurance, there are waiting lists for therapists, they have trouble finding information and navigating insurance process.

83% of parents indicated that it was extremely important that their child receive therapies outside of school.

Parents made some additional comments. A few parents who had been able to access ABA services were very happy with the progress their child made through the therapy. Others were frustrated that they could not find ABA providers or could not get their private insurance or Medicaid to cover the service.