

Easter Seals' Living With Autism Study

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Schedule

- Introduction
 - Easter Seals
- Living with Autism Study: Categorical
 - Data
 - Potential Solution
- Family Life
- Information Stream Preferences

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Introduction: Easter Seals

- \$1.3 B (2007)
- Trusted brand
- Organizational Structure:
 - National Headquarters in Washington DC and Chicago
 - Affiliates (78) in United States
 - Collaborative relationships in Canada and Australia
 - 550 Service Sites
 - 23,000 staff
- Served 1.6 million individuals with disabilities and their families in 2007
- Diversity in diagnosis and across the life span

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Introduction: Easter Seals

- Adult and Senior Services
- Assistive Technology
- Camping and Recreation
- Inclusive Childcare
- Early Intervention
- Medical Rehabilitation
- Mental Health
- Residential and Housing
- Respite
- Workforce Development

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Living with Autism Study

- Made possible by MassMutual Financial Group
 - Disclosure statement

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Living with Autism Study: Objectives

- Call attention to critical lifetime challenges among families living with autism
- Provide support for resource development and legislation:
 - School to work transition
 - Employment
 - Residential and community support
 - Financial planning for future

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Living with Autism Study: “Question(s)”

- How do the experiences and expectations of parents of children with autism differ than that of parents of typically developing children?
- How do parents of children with autism prefer to obtain information?

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Living with Autism Study: Methodology

- Content Development Expertise
 - Health
 - Education
 - Medical anthropology
 - Finance
 - Families

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Living with Autism Study: Methodology

- Harris Interactive
 - expertise in survey design
 - On-line implementation

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Living with Autism Study: Methodology

- Subjects
 - Parents of Children with autism under age 30 - n = 1650
 - Easter Seals
 - Autism Society of America
 - Parents of typically developing children under age 30 – n = 950
 - (other groups attempted)

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Living with Autism Study: Methodology

- Participants
 - Diagnostic Division
 - Autistic Disorder
 - Pervasive Developmental Disorder – Not Otherwise Specified
 - Asperger’s Disorder
 - Childhood Disintegrative Disorder
 - Retts

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Living with Autism Study: Methodology

- Content
 - Employment
 - Housing
 - Education
 - Financial Well Being
 - Quality of Life
 - Health

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Living with Autism Study: Results / Employment

- Employed
 - Autism: 22%
 - Typical: 75%
- Have never looked for work
 - Autism: 59%
 - Typical: 12%

Participants over the age of 16

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Employment: Solution

- Expectation of employment
- Effective transition planning from high school
 - Point of Transition Service Integration Project
 - 75% employment rate (national average is 13%)
 - Nancy Henn (video)

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Living with Autism Study: Results / Education

- Education adequate to prepare for life
 - Autism: 19%
 - Typical: 56%
- 69% spending at least ½ time in segregated education environments

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Education: Solution

- Learning Experiences - An Alternative Program for Preschoolers and Parents (LEAP)
 - peers as young as 36 months taught to facilitate social and communicative initiations with their peers with autism
 - use of facilitative strategies result in higher rates of communicative interaction for preschoolers with autism



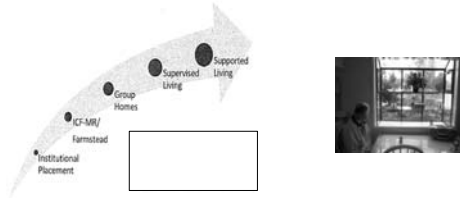
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Living with Autism Study: Results / Housing

- Will always have a place to live
 - Autism: 29%
 - Typical: 60%
- Living at Home between age of 19-30
 - Autism: 79%
 - Typical: 32%

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Housing: Solution



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Living with Autism Study: Results / Financial Well Being

- Incurred debt to meet family needs
 - Autism: 61%
 - Typical: 46%
- Have financial independence
 - Autism: 13%
 - Typical: 49%

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Financial: Solution

- Financial literacy for children and youth
- Pursue expert advice

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Living with Autism Study: Results / Quality of Life

- Have friends in the community with whom he/she shares interests
 - Autism: 57%
 - Typical: 17%
- Have a spouse or life-partner
 - 51%
 - 9%

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Quality of Life: Solution

- Direct Instruction in Socialization
 - Young Children
 - Youth
 - Adult (Sperry & Mesibov, 2007)
 - Relationships at work
 - Developing and maintaining personal relationships
 - Appropriate behavior around members of the opposite sex
 - Personal perspectives on having autism

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Quality of Life



One doesn't need to be on the autism spectrum to be mystified by what is involved in dating.

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- Advice to Parents:
 - Take an active role in learning more about the subtleties of adolescence and relationships.
 - Encourage your child to get involved with activities of interest that involve interactions with other people either in group or club-like settings.
 - Teach your children how to interact with others when a romantic interest is present.

Living with Autism Study: Results / Health

- Have a primary care physician that understands needs
 - Autism: 23%
 - Typical: 47%
- Health insurance that adequately covers needs
 - Autism: 18%
 - Typical: 42%

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Health: Solution



National Medical Home Autism Initiative

- identify and demonstrate how principles of the medical home can be applied to achieve early identification and intervention for children with autism spectrum disorders

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National Medical Home Autism Initiative



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Living with Autism Study: Family Life

- Daily routines
- Time together
- Divorce rate

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Living with Autism Study: Accessing Advice

- Interventions **47%**
- Health **41%**
- Emotions **33%**
- Family life **30%**
- Stress management **26%**
- Diet **25%**
- Finances **22%**
- Tax planning or estate planning **22%**
- Spirituality **20%**
- Employment **18%**
- Life insurance **17%**
- Entertainment **16%**
- Shelter **8%**
- Clothing **6%**
- Retirement **6%**
- Sexuality **6%**
- End-of-life issues **4%**

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Accessing Information

- **PROFESSIONAL**
 - Local autism support centers 26%
 - Pediatricians 15%
 - Developmental Pediatricians 22%

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Living with Autism Study: Accessing Information

- **INFO SOURCES**

- Search engines (e.g., Google, Yahoo, etc.) 40%
- Specialty websites 49%
- Online news (e.g., CNN, MSNBC, FOX, etc.) 11%
- Television news 8%
- Magazines 13%
- Newspapers 6%

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Living with Autism Study: Accessing Information

- **PERSONAL**

- Support groups 29%
- Friends or family 24%
- Religious organizations 7%
- Other families who have children with special needs 53%

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