

# Prediction in ASD: Families' views

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# PRO AID AUTISME

- Parents' Association created in 1985 for the creation of institutions
- Information for public authorities, professionals and parents
- Organization of symposia (Sorbonne, Senate, Ministry of Health, Institut Pasteur)
- Training for the TEACCH program (Paris, IDF and province)
- Trained consultants or practitioners approved by the University of North Carolina, USA



Sophie Biette  
Administrateur Référent Autisme

# UNAPEI

- A political movement bringing together 550 family associations including 350 ESMS managers, from early childhood to the end of life.
- Date of creation: 1960.
- 200,000 people accompanied, 94,000 professionals.
- Audience: mental disability, autism, psychic disability, polyhandicap.
- 60,000 people with ASD (estimation).

## ELENA cohort : Families' questions (1)

- Multicentre study (coverage of the territory)
- Diagnosis in France: early diagnosis
- Diagnostic criteria used : homogeneity
- Age of persons with autism (2 - 16 years)

# ELENA cohort : Families' questions (2)

- Mode of intervention (management), French position :
  - Integrative psychotherapy (psychoanalysis?)
  - Educational approaches based on neurodevelopment (Denver, ABA, TEACCH, Exchange Therapy and Development)
  - Schooling (AVS, SESSAD, UE, UEE)
- Results analysis:
  - Sufficient number of families in different age groups
- Communication (scope of the study):
  - Towards families (associations)
  - Professionals
  - Public authorities and government agencies (ministry)

# Expectations of families: identification of predictive criteria (1)

- Definition of developmental profiles of autism (improvement of intervention proposals)
- Improvement of diagnosis of persons with autism:
  - Severe autism, high functioning, borderline ...
  - Presence of comorbidities
  - Inclusion, follow up of 16-years old individuals in the study
- Better understanding of ASD

# Expectations of families: identification of predictive criteria (2)

- Accompanying modes?
- Educational approaches used?
  - Intensity?
  - Duration?
  - The best?
  - Specificity in relation to the developmental profile of the person?
- Involvement of parents? (Parental guidance, training ...)
- Follow up of siblings
- Better understanding ASD
- Support for dissemination of results (analysis of documents)



# Expectations of families: identification of predictive criteria (3)

- Other lessons from :
  - Genetic data (classification) :
    - Mutation (monogenic, multigenic)
    - Polymorphism
    - Number of gene copies (duplication, deletion)
  - Brain imaging (MRI)
  - EEG
  - Comorbidities
  - Other features to avoid:
    - discouragement (burn out families and professionals)
    - over-cost / over-investment in a "heavy" approach not needed
  - Definition of a better profile.

# Expectations of families: impact of the ELENA study

- Study without direct benefit (difficulties to explain)
- Quality of life
- Help for solicitation:
  - Government agencies
  - Ministries
  - Mecenat
- Relationships with other families (identification of the same characteristics of autism)

# Perspectives: support from family associations (1)

- Increased cohort size
- Extension of the study to 10 years and more
- Promotion of further translational studies
- Inclusion in other national, European cohorts
- Participation in European research projects
- Obtaining Grants

# Perspectives: support from family associations (2)

- Lessons to be learned from a cohort of children and adolescents:
  - Best information for the choice and the intensity of interventions (according to the profiles ...) for the families and professionals (establishments and services)
  - Extension to adulthood
  - Participation of families in the creation of an adult cohort
  - Lessons to support social participation, housing, inclusion in the world of adult work?
  - Predictive medicine (based on evidence)