

SPARK for AUTISM University of Utah



What is the purpose of SPARK?

SPARK aims to help scientists find and better understand the causes of autism.

This is done by studying DNA from people with autism and their family members.

Health and other information that can impact health, behavior and lifestyle is also studied.

There are currently 31 clinical sites nation wide working to obtain this information from 50,000 families affected by autism.

The University of Utah is the only clinical site in Utah



Enrollment in EASY!

It is all done online and takes only about 30 minutes

After consenting, surveys are completed

Each participant sends in a saliva sample for DNA analysis

Since new autism genes are discovered every year, each family's genes will be re-analyzed every year and rechecked for results.

**Anyone with a professional diagnosis of
AUTISM can join SPARK**

Please join the University of Utah and SPARK!

You can refer anyone you know who has a diagnosis of autism to join SPARK.

Please give us your contact information and we will contact you

CONTACT US:

sparkforautism@hsc.utah.edu

1-833-474-7092

www.SPARKforAutism.org





Medical Home Portal

www.medicalhomeportal.org

Pediatrics TeleECHO

Parents Perspectives on ASD



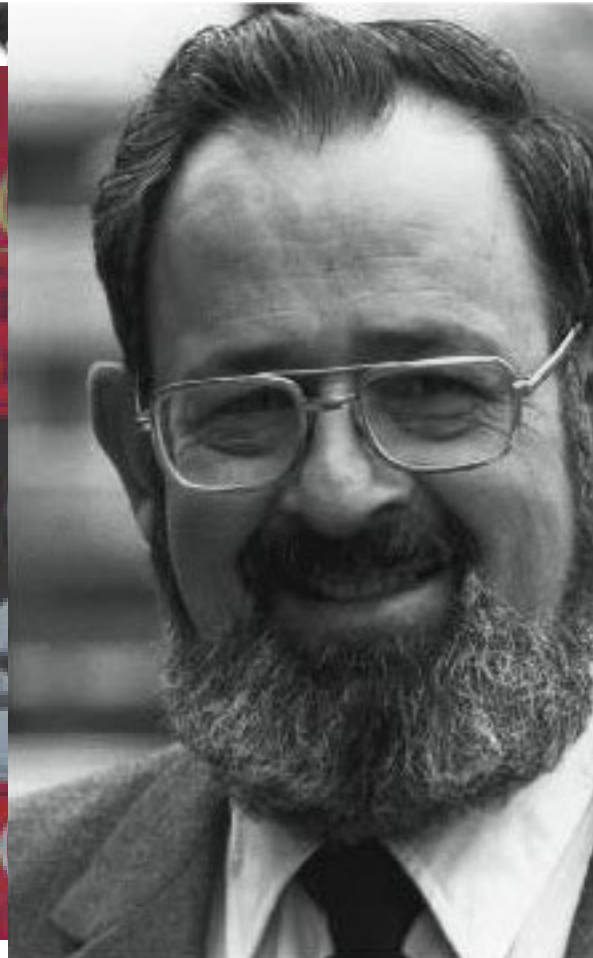
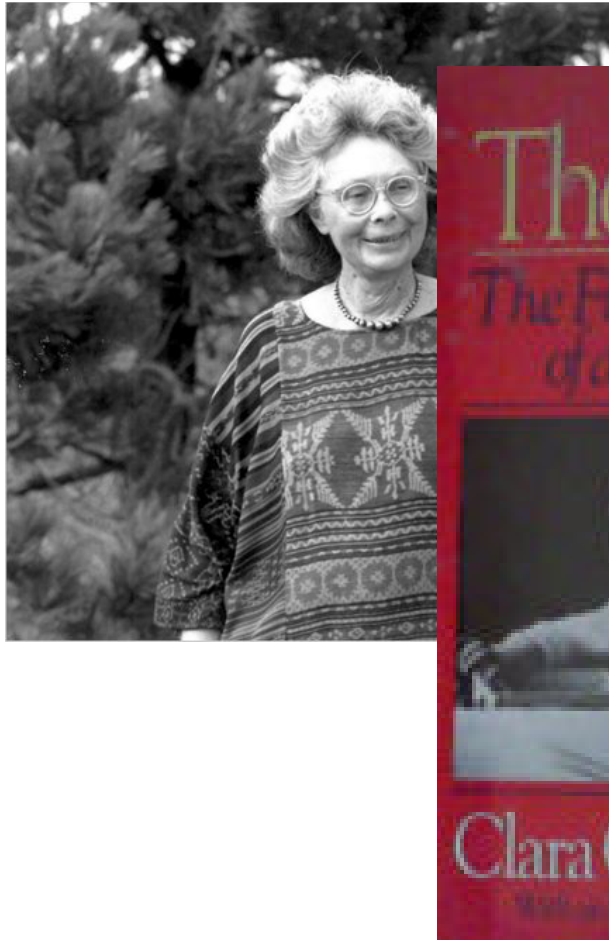
Paul S. Carbone MD
Associate Professor of Pediatrics
University of Utah

“Refrigerator mothers”



“The precipitating factor in infantile autism is the parent’s wish that the child should not exist.”
-Bruno Bettelheim

The tyranny of expertise





Parents of children with ASD and medical care



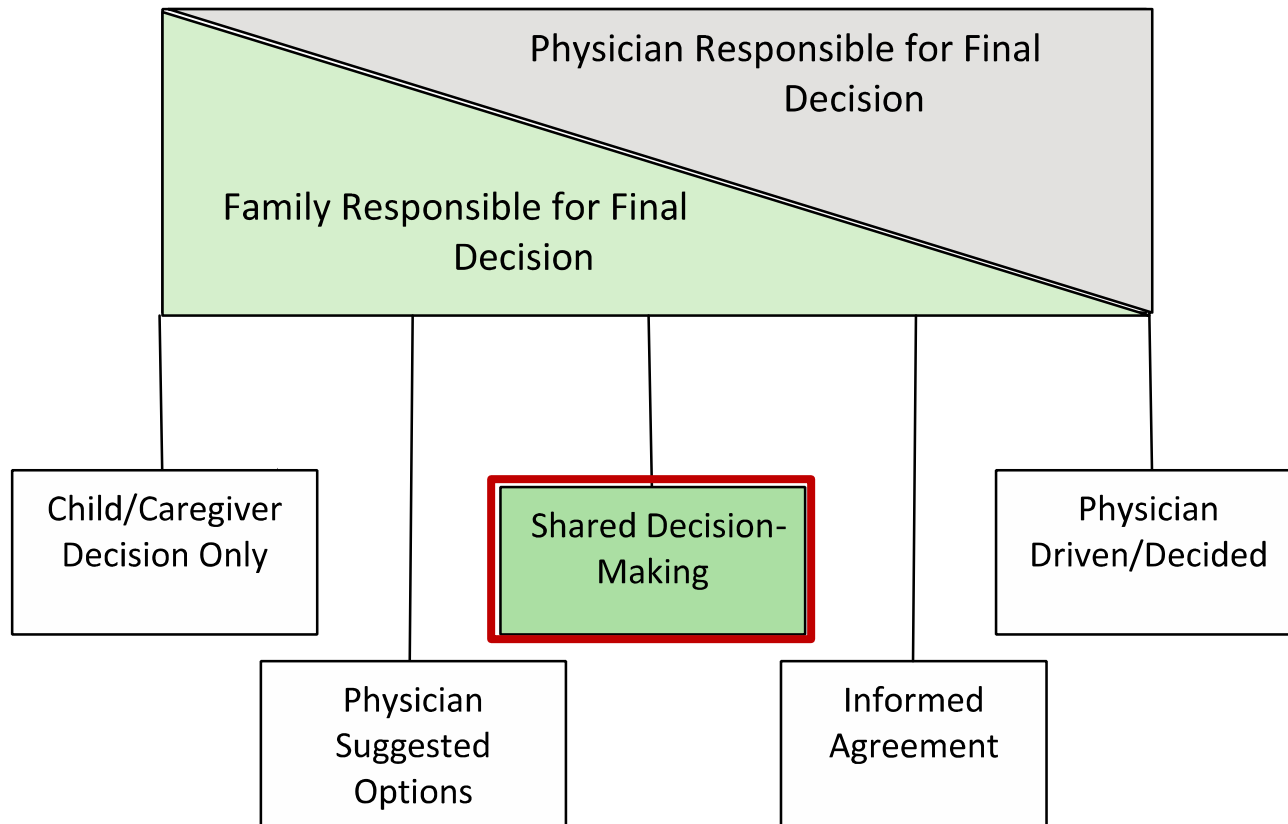
- Dissatisfaction with medical care
- Care is less family centered
- Care is less coordinated
- Difficulty accessing specialty care
- Higher out of pocket expenses and financial problems
- Less likely to receive care within a medical home

Definition of family-centered care

Partnership is the foundation

- Work together
- Mutual respect
- Trust
- Open Communication
- Decisions are made together
- Negotiate





(Consumerism) ← **Autonomy** ← ----- → **Beneficence** → *(Paternalism)*

FIGURE 1

Continuum of decision-making.

Adams, R. C., et al. (2017). "Shared Decision-Making and Children With Disabilities: Pathways to Consensus." *Pediatrics* **139**(6).

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