

**How parents of children with autism navigate intervention: A grounded theory**

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**Outline**

- Methodological aspects & relevance of findings
- Analytic grounded theory findings
- Implications and generic relevance

- Grounded theory
- Constructivism
- Symbolic interactionism

**METHODOLOGICAL ASPECTS & RELEVANCE OF FINDINGS**

**Grounded theory**

**Aim:** Develop a substantive (local) theory to explain a social psychological process

**Data:** Primarily in-depth interviews; some documents, occasionally participant observation

**Design:** Largely iterative, theoretical sampling, etc.

**Analysis:** Constant comparison, coding, memos, etc.

### Constructivism (QUAL research)

- Social reality depends on meanings people construct (constructions):
  - 1) Individuals, construct personal meanings.
  - 2) Groups construct socially shared meanings that are often hidden, taken for granted
  - 3) People are behaviorally *influenced by* these individual and shared meanings, and
  - 4) People contribute to constructing them.
 → Social research should access constructions.

### Symbolic interactionism – Methodology

- Goal: reflect empirical world from *bottom up*
- Most valid understanding from:
  - Studying people directly in their real world settings
  - Avoiding preconceptions
  - Adjust / Respond to the data collected
  - Avoiding importing ideas/theory without verifying applicability

“the scholar who lacks that firsthand familiarity is highly unlikely to recognize that he is missing anything” (Blumer, 1969)

### Symbolic interactionism – Social theory

- Framework used for this theory (but not all GT)
- Premises:
1. People act toward things [incl. ideas] on the basis of the meanings things have for them.
  2. The meaning of such things is derived from social interaction with others and with self.
  3. Meanings are handled, and modified through, an interpretative process in dealing with the things individuals encounter.

### Example: Refining the research question

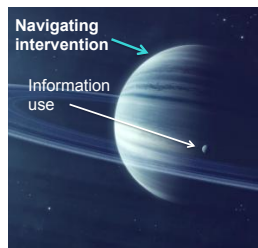
*How do parents find and use information that informs their attitudes and decision making about intervention for their child?*



### Example: Refining the research question

Initial version:  
*How do parents find and use information that informs their attitudes and decision-making about intervention for their child?*

Refined:  
*How do parents navigate intervention? How does information fit into this process?*



## ANALYTIC FINDINGS

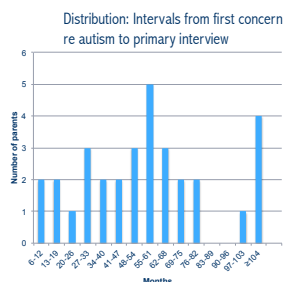
### Sample

45 x 90-minute interviews

- 32 mothers (3 mother-father pairs)
- 9 professionals

Variation in experience:

- Geographic location
- Urban - rural
- Socioeconomic
- Child age: 2.5–18 yrs



### Complexity

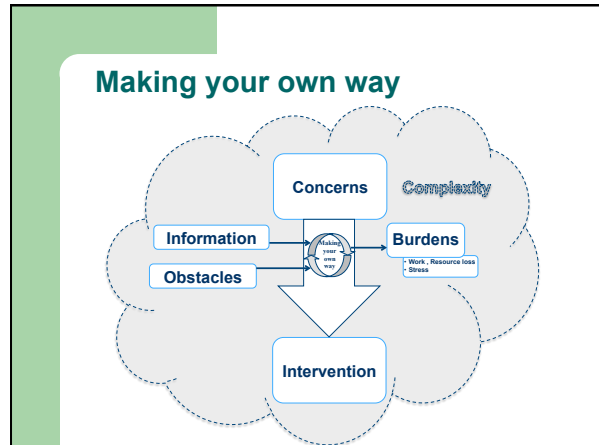
Pervasive characteristic of...

- Information
  - About autism, about intervention
- Concerns (that parents define and respond to)
  - Autism itself, related concerns
- Intervention
  - Health and other systems; public or private
- Skills
  - For pursuing information or intervention

## Concerns → Interventions

<ul style="list-style-type: none"> <li>• Social</li> <li>• Communication</li> <li>• Sensory</li> <li>• Comorbidities (eg, seizure, infection)</li> <li>• Motor</li> <li>• Sleep</li> <li>• Problem behavior</li> <li>• Nutritional, digestive</li> <li>• Toileting, eating</li> <li>• Peer – community integration</li> <li>• Mental health (anxiety, depression, happiness)</li> <li>• Self-care skills</li> <li>• Academic</li> <li>• Vocational, life success, fulfilled potential</li> <li>• Independence (adult)</li> <li>• Parent mental health</li> <li>• Parent financial</li> <li>• Parent marital</li> <li>• Family function, crisis</li> </ul>	<ul style="list-style-type: none"> <li>• Educational-behavioral therapy (ABA, IBI)</li> <li>• Medical (medications, specialist care)</li> <li>• Speech and language therapy</li> <li>• Occupational, sensory therapy</li> <li>• Social opportunities, community activities</li> <li>• Screening, assessment, testing</li> <li>• Diet, nutrition, digestion (GF-CF-SF)</li> <li>• Biomedical (HBOT, chelation, antimicrobe,...)</li> <li>• Alternative therapy (horseback, music)</li> <li>• Technology (iPad, communication device, social learning software)</li> <li>• Academic</li> <li>• Genetic counseling</li> <li>• Respite (funding, care options, camps)</li> <li>• Financial relief</li> <li>• Parenting strategy, approach</li> <li>• Parent training</li> <li>• Marital therapy</li> <li>• Etc...</li> </ul>
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**Concern:** any circumstance or condition attributable to a child's autism that the parent perceives as problematic enough to warrant taking personal action to address—can affect the child, parent, family.



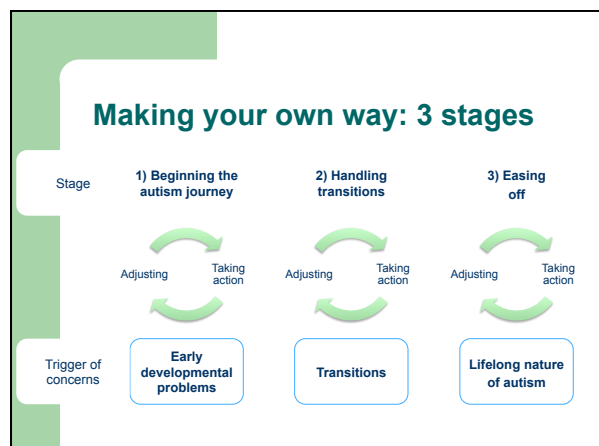
## Adjusting & Taking action

**Making your own way**

**Adjusting:** construct understandings of their situation, respond emotionally, and define options for action; prepares or motivates parents for *taking action*.

**Sub-processes of *adjusting***

- *Defining concerns* related to autism
- *Informing oneself* through active and passive interactions with varied information sources
- *Seeing what is involved* in taking action to address concerns
- *Emotionally adapting* to implications parents see for themselves and their child after reflecting on aspects of their situation and the process they are engaged in
  - Further sub-processes



### Going into high gear

- Response to own sense of *urgency* about child
  - Enter a prolonged mode of intense motivation for *taking action* to pursue intervention
  - Can expend vast amounts of personal time, energy, and financial resources
  - Taking action at a rate that is unsustainable in the long term
- Extreme case of engaged, proactive behavior – informative for understanding motivation

### Urgency

- Drives *going into high gear*
- Def: Subjective sense of intense motivation for *taking action* to avoid or achieve an outcome, and do so quickly before an opportunity is lost
- Cognitive, emotional, physiological (~stress)

*"For me it was like, you get that cold thing in your chest, like, [inhaling] 'Oh my God!' right. But I was also like, 'I have to do something.'"*

- Two consequences: → Action → Thinking

### Urgency: Transcending limits to action

→ Unhesitating eagerness to take action...

#### Increased willingness...

- Lower threshold for action (lower expected chance of success required)
- Willingness to sacrifice more resources (time, energy, money)

#### Ignoring personal limits...

- Of expendable personal resources
- Of limited skills (constraining self-efficacy)
- Comfort zones

### Urgency: Influence on thinking

→ Cognitive engagement, arousal...

Evidence of shift towards **rapid intuitive thinking**:

- Deciding about lines of action rapidly and intuitively; decisions resembled unified ideas re best action to take, integrating broad range of considerations; rather than a deliberative choice between options
- Knowing when to question advice of professionals, rely on own expert knowledge of child to define action
- Occasionally engaging in rash decision making, action, neglecting info or slower deliberative analyses

- Motivation – engagement
- Patient-centeredness

## IMPLICATIONS AND GENERIC RELEVANCE

### Generic transferability

Elements of the experiences and processes found here, where parents become motivated to self-reliantly and proactively pursue intervention, may be applicable to other healthcare consumer groups who must navigate systems of care that lack capacity to provide fully sufficient support to help them address their concerns.

**Limitations:**

- Among parents of children with autism: Insufficient representation of fathers, northern Ontario regions, ESL, parents of adult children
- Challenge to identify and compare to analogous research in non-autism healthcare consumer groups

### Relevance: Patient-centered care

Importance of understanding consumers' meaning-making more deeply when defining appropriate, patient-centered care.

For supporting parents of children with autism:

- Suggest aspects of personal/family situations for professionals to explore in depth when defining appropriate care
- Become sensitive to parents' readiness to be engaged in care (more support very early, and later on)

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