

# 3rd meeting: Lived Experience

## ***LECTURE 3:*** **Siblings and Extended Family**

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## ***1. Sibling's feelings and roles***



## ***2. Mediating factors and theoretical framework***



## ***3. Intervention for siblings***



## ***4. Extended family roles***

# ***Outline***



# QUALITATIVE RESEARCH ON TDSIBS OF CHILDREN WITH ASD

- Semi-structured interviews, exploring the experiences of TDsibs of children with ASD about their relationship with their siblings and the effect it has on their lives.

## Sibling roles

- Caregivers
- Parents' and sibling's helpers
- Entertainers
- Rescuers when sibling is aggressive  
(Angell, Meadan, & Stoner, 2012)

## Emotional Aspects

- Love and affection towards siblings
- Minimal sibling disagreements
- Enjoyment from joint recreational activities  
(Angell, Meadan, & Stoner, 2012)

- Awareness of their ASDsibs physical, intellectual and behavioral differences
- Recognition of their talents and needs
- Sense of pride for their achievements

(Gorjy, Fielding, & Falkmer, 2017; Petalas et al., 2009 ; Angell, Meadan, & Stoner, 2012)

# QUALITATIVE RESEARCH ON TDSIBS OF CHILDREN WITH ASD

- Concerning personality characteristics research results show that TDsibs of children with ASD are:
    - Compassionate
    - Empathetic
    - Patient
    - Persistent
    - Tolerant towards their ASDsibs and individuals with disabilities in general
- (Gorjy, Fielding, & Falkmer, 2017; Angell, Meadan, & Stoner, 2012)



# QUALITATIVE RESEARCH ON TDSIBS OF CHILDREN WITH ASD

- Negative aspects of sibling relationship according to TDSibs:
  - Challenging behaviors of ASDsibs, including aggressiveness, loud outbursts, meltdowns and inappropriate behavior in public places (Gorjy, Fielding, & Falkmer, 2017; Petalas et al., 2009 ; Angell, Meadan, & Stoner, 2012).
  - These challenging behaviors lead to feelings of self-blame, stress and trepidation (Gorjy, Fielding, & Falkmer, 2017).
  - Embarrassment for sibling's peculiar behaviors in public places
  - Anger and anxiety about the public's judgement, prejudice or misunderstanding towards their sibling (Gorjy, Fielding, & Falkmer, 2017; Petalas et al., 2009 ; Angell, Meadan, & Stoner, 2012).
  - Lack of acceptance → limited opportunities for social outings and family recreational activities and tension between acceptance of their ASDsib and longing for change so their family appears normal (Gorjy, Fielding, & Falkmer, 2017; Petalas et al., 2009).



# QUALITATIVE RESEARCH ON TDSIBS OF CHILDREN WITH ASD

- Social relationships of Tdsibs:
  - Fear that their peers, who react negatively to their ASDsib, will reject them
  - Anxiety about finding friends who understand their different life situation
  - Desire to have more friends in general and friends who understand ASD in particular  
(Petalas et al., 2009; Angell, Meadan, & Stoner, 2012)
- Family role:
  - Increased responsibilities are sometimes viewed as unwanted pressure
  - Craving for additional parental attention
  - Anxiety about their sibling's future if they don't acquire necessary life skills  
(Gorjy, Fielding, & Falkmer, 2017; Petalas et al., 2009 ; Angell, Meadan, & Stoner, 2012)



# QUALITATIVE RESEARCH ON TDSIBS OF CHILDREN WITH ASD

- Coping strategies of TDsibs:
  - Isolation and withdrawal → response to sibling's challenging behaviors
  - Social support from family, friends, online or other support groups
  - Extending support to others and educating them about ASD
  - Physical exercise and respite care
  - Presence of other TDsibs in the family → sharing of responsibilities
  - Learning techniques that minimize ASDsibs' challenging behaviors. These include preventing bad experiences, redirecting direction, encouraging social behavior and teaching new skills.

(Angell, Meadan, & Stoner, 2012; Gorjy, Fielding, & Falkmer, 2017; Petalas et al., 2009)



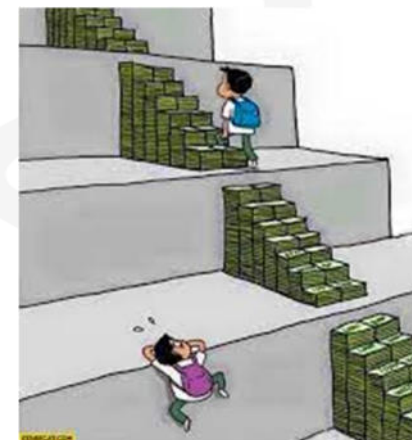
# QUANTITATIVE RESEARCH ON TDSIBS OF CHILDREN WITH ASD

- Shivers, Jackson and McGregor (2019) conducted a meta-analysis of 69 studies reporting on the emotional, psychological, behavioral and social functioning of TDsibs of children with ASD.
- Their analysis revealed that TDsibs of people with ASD have significantly worse outcomes across all types of functioning than comparison groups.
- Worse internalizing behavior problems
- More negative beliefs about disability, but not self-concept
- Worse psychological functioning
- More negative sibling relationships
- Greater impairments in social functioning
- No significant difference in areas of:
  - Adjustment
  - Coping
  - Family functioning
  - Attention/Hyperactivity
  - Externalizing behavior problems
- Psychiatric symptoms and behavior problems analysed together → more symptoms and behaviors related to anxiety/depression and ADHD than comparison groups.

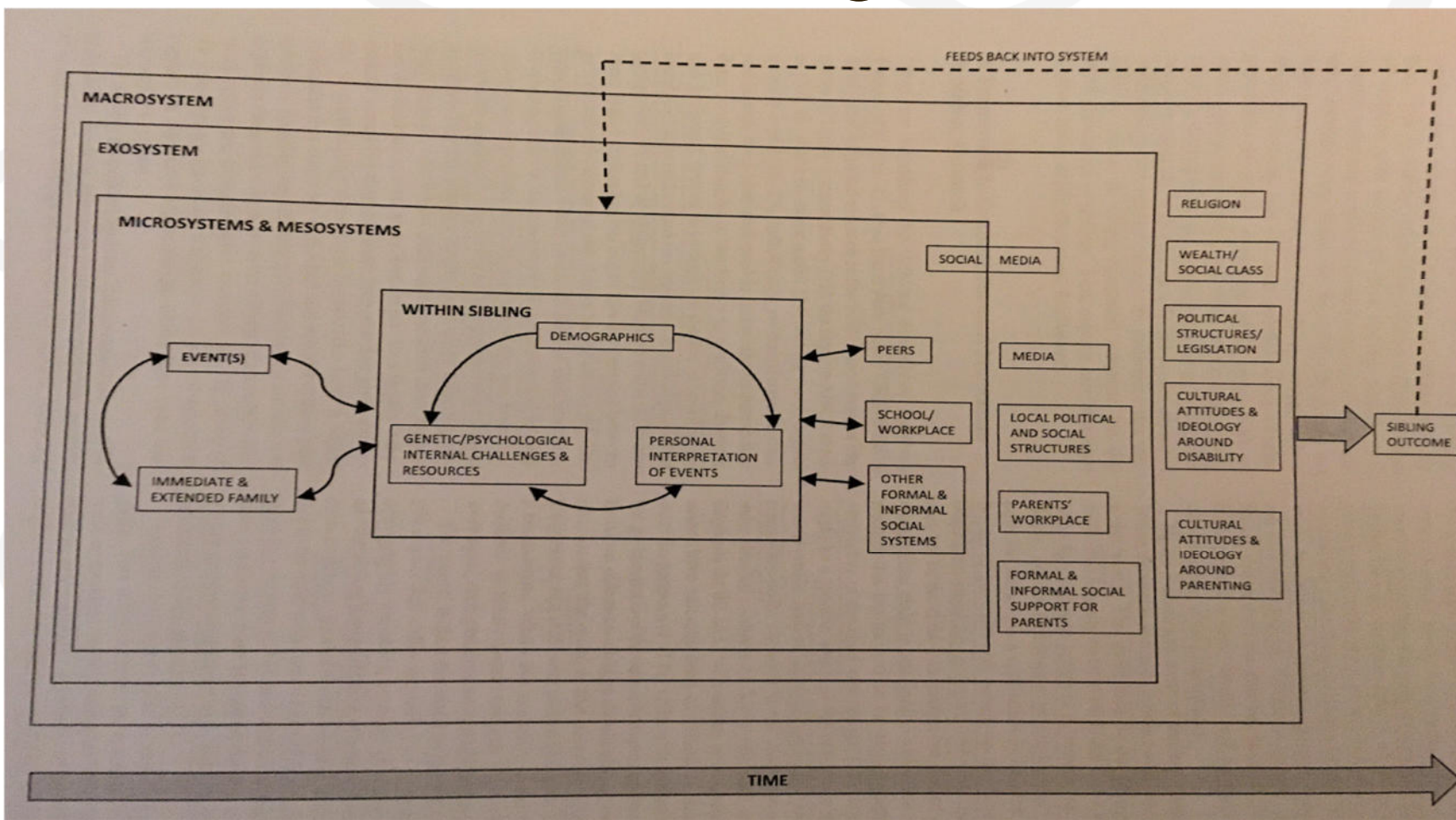


# MEDIATING FACTORS OF TDSIBS OUTCOMES

- Socioeconomic status
- Level of social support
- Demographic factors such as gender of TDsibs, number of siblings in the family, birth order of siblings
- Severity of symptoms of ASD
- Negative effects experienced by other members of the family – mainly, parental stress
- Parents' coping styles
- Presence of Broader Autism Phenotype in siblings or parents.



# THE SIBLINGS EMBEDDED SYSTEMS FRAMEWORK



# INTERVENTIONS FOR TDSIBS OF CHILDREN WITH ASD

- Shivers & Planick (2015) reviewed 17 studies that reported on the results of TDsibs as agents of intervention, either by teaching them various behavioral techniques to use with their ASDsibs or by modeling desired behaviors or skills in video or in vivo.
- Children with ASD showed increases in skill acquisition and/or decreases in behaviors of concern.
- Nearly all of TDsibs demonstrated acceptable levels of implementing the intervention.
- Most siblings and their parents reported positive changes in their everyday lives and moderate to strong satisfaction with the intervention.
- Important to keep in mind the characteristics and needs of TDsibs and developmental changes in abilities and desires to participate in interventions.



# INTERVENTIONS FOR TDSIBS OF CHILDREN WITH ASD

Support groups:

- Increase of TDsibs knowledge about ASD
- Improvement in self – concept and decrease in negative self-esteem and interpersonal problems
- Changes in adjustment and emotional problems - decrease in depressive symptoms and anxiety
- More positive sibling interactions
- Enjoyment for having the opportunity to share experiences, express feelings, problem solve, learn about autism and have fun

(Smith & Perry, 2005; Mavropoulou & Baloyianni, 2007; Brouzos, Vasilopoulos & Tassi, 2017; Kryzak et al., 2015)



# THE ROLE OF THE EXTENDED FAMILY

- Mothers of children with ASD engaged in more leisure activities with extended family members compared to mothers of typically developing children but at the same time reported equal level of satisfaction with leisure (Tunali & Power, 2002).
- Informal social support, such as help from family and friends can significantly decrease depression among parents of children with ASD (Benson, 2006; Dunn et al., 2001, Ekas et al., 2010).
- Family support was associated with increased optimism in mothers of children with ASD. This increased optimism in turn predicted lower levels of depression, negative affect and parenting stress (Ekas et al., 2010).
- Negative social support is associated with increasing levels of depressive symptoms and negative affect (Smith, Greenberg & Seltzer, 2012).



# THE ROLE OF THE EXTENDED FAMILY

## Grandparents:

- They assume hands-on caregiving roles (Park et al., 2005; Margetts et al., 2006).
- Work alongside experts and parents and become members of a “child focused multidisciplinary team” (Margetts et al., 2006).
- Role models of social support within the family (Lee & Gardner, 2010; Kahana et al., 2015).
- Not all grandparents are willing or able to assume supporting roles in the family context due to practical, emotional, cultural reason and difficulties in communication between them and their children (Sullivan et al., 2012; Baydar & Brooks-Gunn, 1998; Katz & Kessel, 2002; Lee & Gardner, 2010; Glasberg & Harris, 1997; Hillman, 2007; Fingerman, 2001).
- Research focused on interventions for custodial grandparents has yielded positive results concerning their skill acquisition and competence and these educational programs could serve as models to enhance all grandparent support capabilities (Kahana et al., 2015).





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# THANK YOU!



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