

# Autism and Family Dynamics

20<sup>th</sup> March 2024

# Programme

1. Accommodating autism at home
2. Friendships
3. Intense emotions
4. Passionate interests
5. Stages of autism through the lifespan
6. Effects on the family of having several autistic children
7. A mother or father with autistic characteristics
8. Sibling rivalry

# Prevalence of Autism

- Centers for Disease Control and Prevention
- **One in 36** 8-year-old children are autistic
- Male: Female ratio 4:1
- However, the adult ratio is 2:1
- Prevalence excludes those diagnosed as teenagers and adults
- **59% IQ in the normal range**

# Recurrence Rates

- Brian et al *Autism* 2016, Vol. 20(7) 888-892
- Older sibling diagnosed with ASD
- Recurrence rate for a subsequent sibling at age 9 years
- **35%**



# Parents Occupation

- Dickerson: *Research in ASD* 8:9
- Fathers in technical fields more likely to have an ASD child
- Engineering: Twice as likely
- Finance: Four times
- **Health care (medical): six times**
- Higher risk of severe autism if both parents are in technical fields

# Parental Mood Disorders

Schnabel et al (2020) *Autism* 24 26-40

Meta-analysis of studies

- 33% had **anxiety disorders**
- 31% had **depressive disorders**
- No significant difference between mothers and fathers

# Accommodating Autism at School: Camouflaging

- **Observing, analysing and imitating**
- Learning social and friendship rules
- Suppress autistic characteristics and avoid being rejected and bullied
- Surface sociability but a lack of social identity
- Socializing is a source of anxiety and stress
- Inconspicuous at school, so autistic burnout is not noticed

# The Mask

- *Emily masks in public and will meltdown the second she is out of the situation.*
- Dr Jekyll and Mr Hyde
- *I can dance. I can dance with anyone who wants to dance with me, but it is always their choreography.*





# Friendship: Stage 1 3-6 Years



# Strategies: An Adult 'Acting' As a Friend

- Observe the natural play of the child's peers, learn the games and rules.
- Learn '**child**' **speak**.
- **Turn taking**.
- **Ask for help**.
- **Video** replay of social play scenes at school.
- **Pause button**.

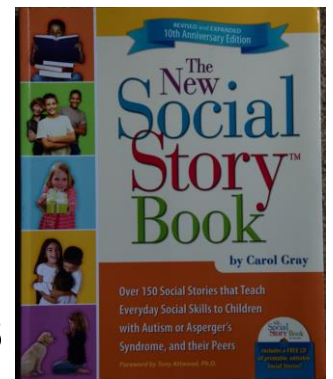
# Social Stories



- Sometimes children help me. They do this to be friendly. Yesterday, I missed three math problems. Amy put her arm around me and said, “ It’s okay, Juanita.” She was trying to help me feel better. On my first day at school, Billy showed me my desk. That was helpful. Children have helped me in other ways. Here is my list:
- I will try to say, “thank you” When children help me.

# Two-Person Hugs

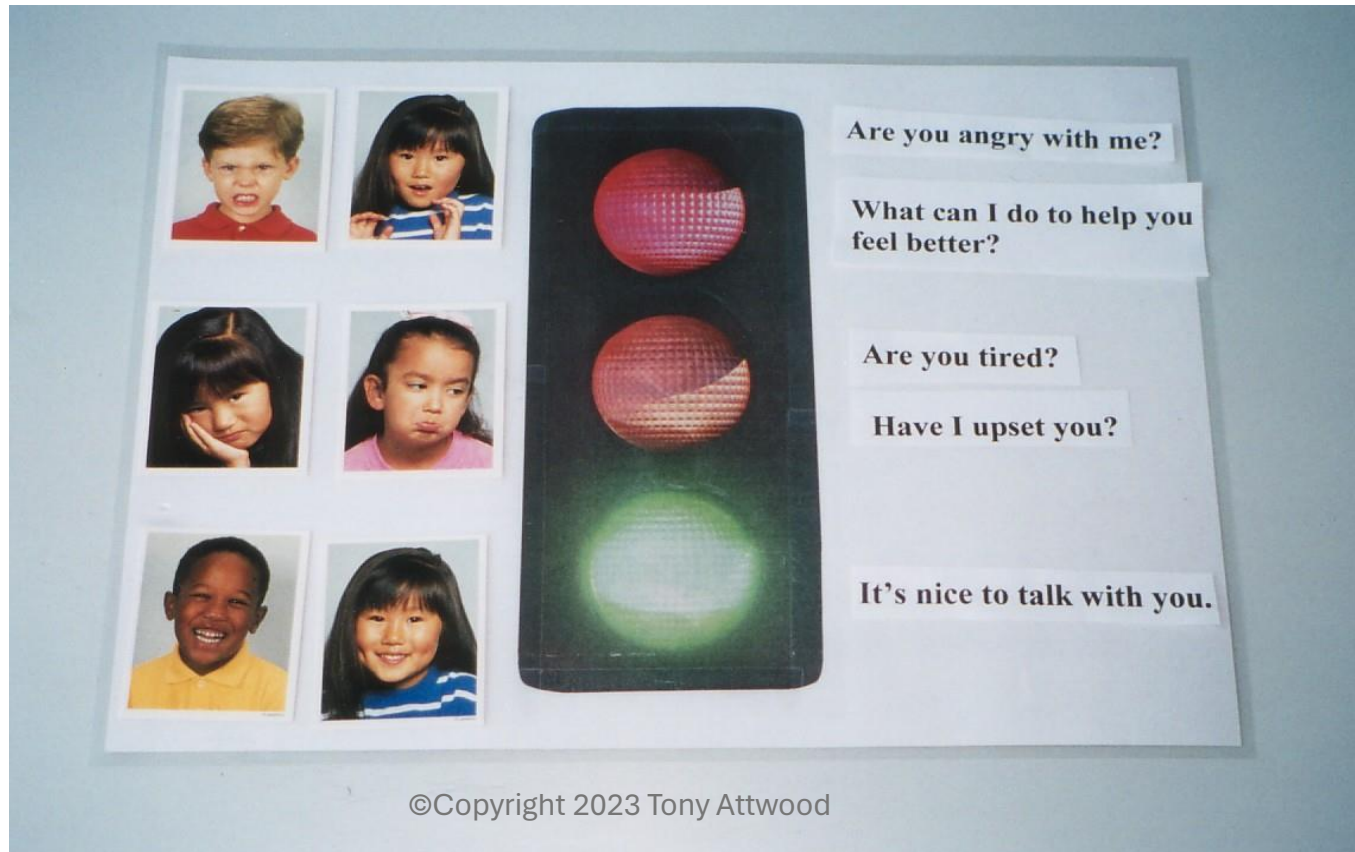
- Sometimes two people hug one another. It's a two-person hug when both people hug at the same time.
- A two-person hug often means *hello* or *goodbye*.
- Sometimes, people use two-person hugs to share their feelings. These hugs may mean, *I love you*, *We are both happy*, or *We are both sad*
- When two people hug each other at the same time, they often:
  - Stand close facing each other
  - Wrap one or two arms around the other person
  - Squeeze a little but not a lot
  - The hug ends when either person begins to relax their arms



# Stage 2 6-9 Years

## Social Signals

- Road signs: Traffic lights





# Ability to Attribute Social Meaning

- Noticing objects and facts rather than thoughts, feelings and intentions.





Descriptions of pictures and events may not include thoughts and feelings.

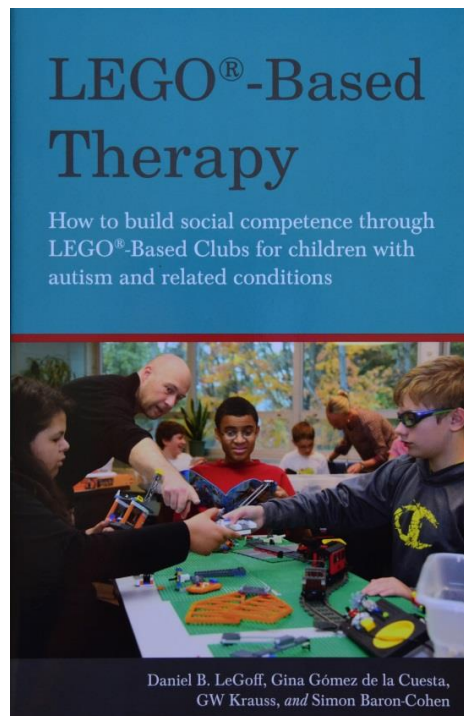






# Friendship Opportunities

- Develop friendships through the **special interest**
- Lunch and after school **clubs** based on special interests such a movie trivia, computer games
- Lego Therapy and Minecraft



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# Stage 3: Friendships

- **Social ability gap** with peers increases with each grade
- Less able to rely on intuition , must rely more on cognitive abilities to process social situation
- Peer interactions confusing, overwhelming and sometimes **aversive**
- Experience **bullying, teasing, rejection and humiliation**
- Not having a **friend to repair or refute derogatory comments and restore a sense of trust**
- Difficulty in friendship situations that have **not been seen before or rehearsed**
- **Criticized by peers** for making a simple social error

- Animals as friends
- Internet friends



# Stage 4 Friendships Age 13+

- Recognition of **not being popular**
- *I wasn't rejected but did not feel completely included*
- *I was supported and tolerated but not liked*
- **Blame themselves** or being **autistic** for peer rejection
- Affects self-esteem, self-identity, mood and perception of autism

# Autistic Friendships

- Anxious about making a **social mistake**
- *I live in constant fear of performance anxiety over day-to-day social encounters*
- Before falling asleep **reviewing the social experiences** of school – ruminating on social performance
- Conscious retreat into solitude
- *I'd rather just be alone, but I can't handle the loneliness*

# Autistic Friendships

- Yearning for a sense of **connection**
- Experience **rejection** from popular friendship groups
- Accepted by **marginalized teenagers** that engage in activities and interests that cause concern for parents
- Alcohol and drug use, eating disorders
- The group ‘adopt’ the autistic teenager
- A **new intense interest** in information valued by the group

# Friendship Encouragement

- **An autistic friend**
- Find each other on the **periphery** of social activities
- Similar interest **groups** such as robotics, computer programming, science projects, playing music and singing together
- Sitting beside each other, drawing
- Comic Book, Cosplay and fan conventions



# Friendship Activities for Parents

- **Puzzling Peers**
- *Peers congregating and talking about nothing of substance or about boys*
- *Someone talking about her experiences and opinions and thinking that I (and others) would be interested*
- **Awkward situations**
- *You walk into class late and everyone turns to look at you*
- *A friend says “I’m so fat” and looks at you for a comment, probably anticipating a ‘white lie’*



# Meltdowns



- *Two types of meltdown*
- *Outward directed and 'blind rage', try to strike out and destruction **Explosion***
- *Inward directed, despondent, a depression 'attack' **Implosion***



# Managing a Meltdown

- **Do**

- Stay **calm**
- **Affirm and validate** the child's emotion
- **One person** dealing with the situation
- Confirm **the feeling will go**
- Keep **other people away**
- **Minimal speech**
- **Special interest** as an 'off switch'
- Seek a **safe place for solitude**

- **Not Do**

- **Interrogation**
- Focus on **punishment and consequences**
- *When I'm upset, the last thing I want to do is talk to someone*
- *I can hear but my brain can't process what people say*
- Try not to **jolly up** or use **comfort and affection**
- *Human comfort has always been a mystery*

# Special Interests (Passions)

- **Thought blocker** anxiety
- **Knowledge overcomes Fear** (Liliana and spiders)
- **Source of pleasure** (superior to interpersonal pleasures, - addiction?)
- **Means of relaxation** calming
- Source of **friendship**
- **Explore an emotion or experiences** watching movies with a related theme

# Special Interests

- **Attempt to achieve coherence** Putting things in order, categorizing
- **Understand the physical world** Science and the natural world (psychology)
- **Comforting** Certainty of facts and information
- **Create an alternative world** from dinosaurs to science fiction and fantasy worlds in literature and Internet role-playing games
- **Sense of identity** The interest defines who you are, being proud of achievements, Superheroes (Harry Potter) and respect

# The Stages of Autism Through the Lifespan: Puberty and Adolescence

- Anxiety (all types)
- Depression
- Eating disorder
- Situational mutism
- Self-harm
- Borderline Personality Disorder
- Gender Dysphoria

# Autistic Adult Well-Being: Maja Toudal Survey

- To not be disturbed
- Not having to act a certain way just because it is supposedly normal or appropriate
- Having my own place to hide
- Being able to express and be understood
- Being able to excel in what you love to do

# Autistic Well-Being: Maja Toudal Survey

- Space to pursue interests/hobbies
- Daily engagement with special interests
- Freedom from excess sensory pain/disturbance
- Having a purpose in life
- Accepting my autism and working with it to create harmony in my life instead of difficulties

# Ageing and Autism

## Research conducted by Berthine Ommensen

- Ten mature autistic adults
- Mean age 63.3 years
- Intensive interviews
- Analysis identified four overlapping themes
  1. Autistic identity
  2. Emotional regulation
  3. Social instinct
  4. Positive outlook



# Ageing: Emotional Regulation

- Anxiety and depression
- **Recovery from depression was slow and lengthy**
- Experienced mental health problems since their teenage years, but not understanding what they were going through
- **7/10 reported that as they had grown older, they had experienced an improvement in their mental health**
- Stress of work and *working for a boss who has no ethics*

# Ageing: Emotional Regulation

- Being stressed and overwhelmed by **relationship difficulties**, including **perceived failure to meet the emotional needs of their partners**
- Distrust and disdain for most forms of treatment and **health professionals**, particularly medical doctors
- Not listened to or understood
- Unfairly judged or misrepresented by health professionals
- *They were not interested in me. They're interested in the drugs they can sell*
- **Aversion to medication** a common theme (side effects)

# Ageing: Emotional Regulation

- **Coming up with strategies themselves** through reading and experimentation rather than advice from health professionals
- Exercise, self-talk “you can manage this”
- Mindfulness, meditation, spiritual and physical activities such as gardening for emotion regulation
- Enjoyed as solitary pursuits
- *I can be a bit kinder to myself*
- Stoicism, toughness and lack of self-pity



# Ageing: Social Instinct

- Feeling drained by socializing
- Socializing is effortful
- Remained a lifelong problem
- Awkward social interactions, fraught relationships and solitariness

# Ageing: Positive Outlook

- *I can look back now and cut myself a bit of slack*
- **Being comfortable with who they are**
- *I've become more accepting of myself*
- New rewarding activities, volunteer work, community groups, and work schedules that suit them without concern for negative judgement
- No pressure to conform to society's standards, focus on activities that bring pleasure and a sense of fulfilment
- Sense of humour

# Several Autistic Children

- **Different levels** and profiles of autism – even in identical twins
- **Compatibility:** Magnets that attract or repel
- All need **personal space**
- **Crisis management** - ‘putting out fires’
- **Parental exhaustion**
- Effect on a **non-autistic child**

# Maintaining the Relationship for Parents of an Autistic Child

Sim et al (2019) *Research In ASD* 58, 39-51

*We are in this together*

## **1 Shared Beliefs**

- Acceptance
- Focus on the positives
- Existential meaning

# **Maintaining the Relationship for Parents of an ASD Child**

## **2 Teamwork**

- Nurturing the family
- Nurturing self
- Nurturing the relationship

## **3 Shared Experiences**

- Communication
- Humour
- Emotional support



# Divorce Rates

- **Freedman et al 2012 JADD 42:4**
- Media implies a divorce rate of 80%
- Survey of 913 families
- **No evidence to suggest a greater risk of divorce**
- Symptom severity was not a factor
- There was **lower marital satisfaction**



# Being an Autistic Mother

Pohl et al (2020) Molecular Autism 11:3

355 autistic mothers, 132 control

## **More likely to:**

- Experience both **prenatal and postnatal depression** (60% had postpartum depression)
- Feel the birth had not been adequately explained to them
- Find motherhood as an isolating experience

# Being an Autistic Mother

- Feel that their parenting was being **judged**
- Unable to ask for support when they needed it
- Report they were not coping

## **More concerned about**

- Multi-tasking demands of parenting and domestic responsibilities

# Being an Autistic Mother

- Creating **socializing opportunities for their child**
- Felt they should be offered extra support because of their diagnosis
- **Difficulty communicating with professionals** about their child
- Greater anxiety when needing to interact with a professional
- Feel **misunderstood by professionals**, which could result in conflict

## Equally able to:

- **Prioritize their child's needs above their own**
- **Seek opportunities to boost their child's self-confidence**

# Clinical Experience: Support group for NT children

## • **Qualities of an Autistic parent**

- Helping with homework but pedantic and long winded
- *Practical and he helps us with fixing things*
- *He is very good in emergency situations*
- Great memory for facts and information
- *He took up windsurfing and practiced till he could sail perfectly*
- *He is a great inventor, only he has ideas but they don't go anywhere*

# Issues for the Autistic parent

- **Understanding natural childhood abilities and behaviour.**
- **The role and responsibilities** of being a parent.
- Wants the children to succeed but **using criticism not compliments.**
- **Discipline- marital conflict**
- Not understanding why children **need so many friends**

# Siblings

- Conflict resolution (alternative perspective)
- Sabotage programmes
- Could feel neglected, having to be well behaved, not wanting to burden a parent with their problems
- Autistic child's jealousy for social siblings



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- **25 Online courses** that can be downloaded and available for up to 60 days on:
- Friendships
- Emotion management
- Relationships
- Autistic burnout
- Autism and ADHD
- PDA
- Autistic girls and women
- Employment