

# Cross-disciplinary working in autism to promote positive outcomes

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# Greetings from the University of Northampton



Photo: Dr Stuart Moussir-Harrison

# Content of this presentation

- Why is it important that professionals work successfully in partnership with families of children with autism?
  - and with each other to support them?
- Present systemic model of understanding family interaction with sources of informal and formal support
- Identify factors that contribute to effective cross-disciplinary/partnership working to support families



Parents and professionals, São Carlos, Brazil

# The take-home message

- Effective cross-disciplinary work is vital
- But too often it is not happening
- Important that current and future professionals work together positively, imaginatively and in innovative ways to support people with autism and their families

# Potential impact of autism on the family



- Lifelong condition affecting about 1% of population, characterised by difficulties in social communication, restricted interests, sensory sensitivities
- Overwhelming evidence that autism can significantly affect family functioning and quality of life
- Wide range of challenges including:
  - Eating, toileting, self-care
  - Inappropriate social behaviour
  - Sleep issues
  - Impact of fixed routines
  - Behaviour problems
- Impacts on parents/siblings, relationships with wider family, and on individual on autism spectrum
- Families may experience anxiety, stress, isolation and stigma

(Preece & Jordan, 2007; Rao & Beidel, 2009; White & Hastings, 2004)

# Heightened vulnerability

- Traditional/typical parenting strategies will probably not be effective (Glazzard & Overall, 2012)
  - ‘hidden’ nature of autism/inconsistent skill profile can lead to judgmental attitudes (naughty children, inadequate parents)
- Typing ‘autism +’ into Google (Jan 10 2020):
  - autism + **treatment**: 207,000,000
  - autism + **cure**: 25,300,000
- Helpful information on internet – but lots of unreliable, unproven and sometimes dangerous approaches and ‘cures’

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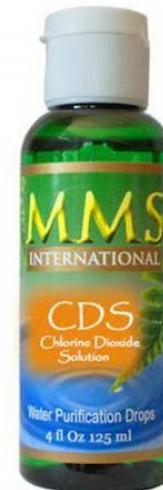
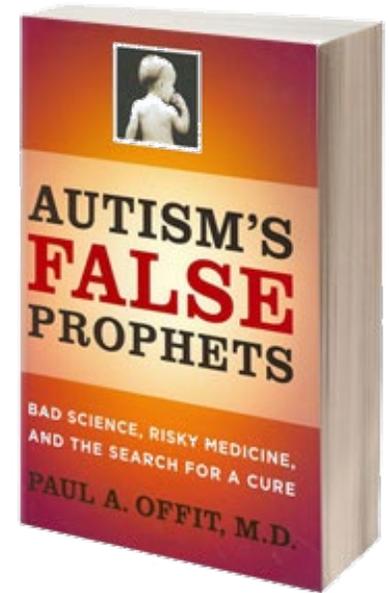
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# What impacts upon family stress?

- Housing
- Family finances
- Employment
- Informal support from family and friends
- Support from service providers
  - education
  - Health/medical
  - social care

(Ekas *et al.*, 2010; Johnson *et al.*, 2011; Lu *et al.*, 2018)

- **BUT...**
- Families living with autism may receive limited informal support (Preece, 2014; Preece & Jordan, 2007)
- So effective support from professionals – can be crucial



# However...

- Relationships with professionals remain a major stressor for families living with autism.
- Problems occur across all professional areas – health, education, social care etc.
- Problems arise from both parent-professional interactions and interaction between professionals



# Parents' voices – Living with autism in rural coastal areas of England (2018-20)



- We've had such a terrible experience. Parents seem to be being treated like dirt sometimes, and it's almost as if their views are not taken in. It's almost as if professionals won't believe them, can't believe them, just don't believe them (*Autistic mother of autistic teenager, Cornwall, England*).
- What's the point? We've been discussing the same thing to 10 different social workers over the last 2 years and nothing changes. It gets more severe. But there is no help. And I'm wondering what stage we have to get to where something literally goes "pop" and then they will say, "*Oh, we should have done that...*" (*Single mother of 4 children, including autistic son and disabled twins, Norfolk, England*).

# Parents' voices – Equity and Social Inclusion through Positive Parenting (ESIPP) (2015-18)

- *How would you describe the support you get from the system, from kindergarten, experts? Are you satisfied?*
- S: No (laughter). You have to do everything by yourself. I didn't know occupational therapy existed. Our paediatrician is an OK lady but she never gave us any support. You have to do everything by yourself (*Mother of child with autism, Croatia*).
- Support system? That is the first time I have heard that. We do not have that at all. We are left alone. Grandma and Grandpa help a lot. But there is not a support system here. Perhaps in Skopje, but here in Veles there is nothing else but school (*Mother of child with autism, Macedonia*).



## Teachers' voices – Autism Spectrum Disorders-Empowering and Supporting Teachers (ASD-EAST) (2018-20): working with parents

- Very often parents don't want to listen to professionals. As parents they want the best for their child and feel they know best what is good for them. But professionals may have some other opinion about what would be best for the child and look at things from another point of view (*Teacher, Croatia*).
- We teach something at school, and then we show parents how to move it home. But school is to be at school. So unfortunately, they do not always want to follow our recommendations at home, or they do things that cause the therapy to break down (*Teacher, Poland*).
- We have many unrealistic parents and we cannot fight them. In our country they are always right (*Teacher, Macedonia*).

# Teachers' voices – Autism Spectrum Disorders-Empowering and Supporting Teachers project (2018-20): working with other professionals

- Our contacts with clinics are limited to the exchange of documents, and these should be joint actions, ideas, solutions. Many students remain in the care of not only neurologists, but also psychiatrists. Cooperation with them is almost non-existent. But it is necessary to cooperate, for example, to design a therapy, or to know what the effects of drugs may be (*Teacher, Poland*).
- Sometimes, doctors often do not consider the opinion of teachers and psychologists, and they really have lack of knowledge in special education field. There are often problems with teamwork: certain professions think that their opinions are more important than others (*Teacher, Croatia*).
- As special education teachers working in special school we sometimes have problems in work with psychologists and speech therapists where we have some similar tasks. Some professionals like to think that children's achievements are all due to them – not the whole team working together (*Teacher, Macedonia*).

# Benefits of effective partnership working

- Improved focus on the individual situation
- Better outcomes for service-users
- More effective/efficient use of services
- Improved communication
- Shared information – leading to better decisions
  
- Opportunities for professional development and growth
- Better relationships
- Increased personal satisfaction

(Douglas, 2008)



# Challenges

- Different worldviews of the individuals involved (Shaw *et al.*, 2007)
- Professional identity and importance (Robinson & Cottrell, 2005).
- Differences in perspectives, funding and priorities between organisations (Frederickson and Cline, 2009).
- Impact of disagreements on families (Abbott *et al.*, 2005a).
- Lack of joint training (Sims, 2011).



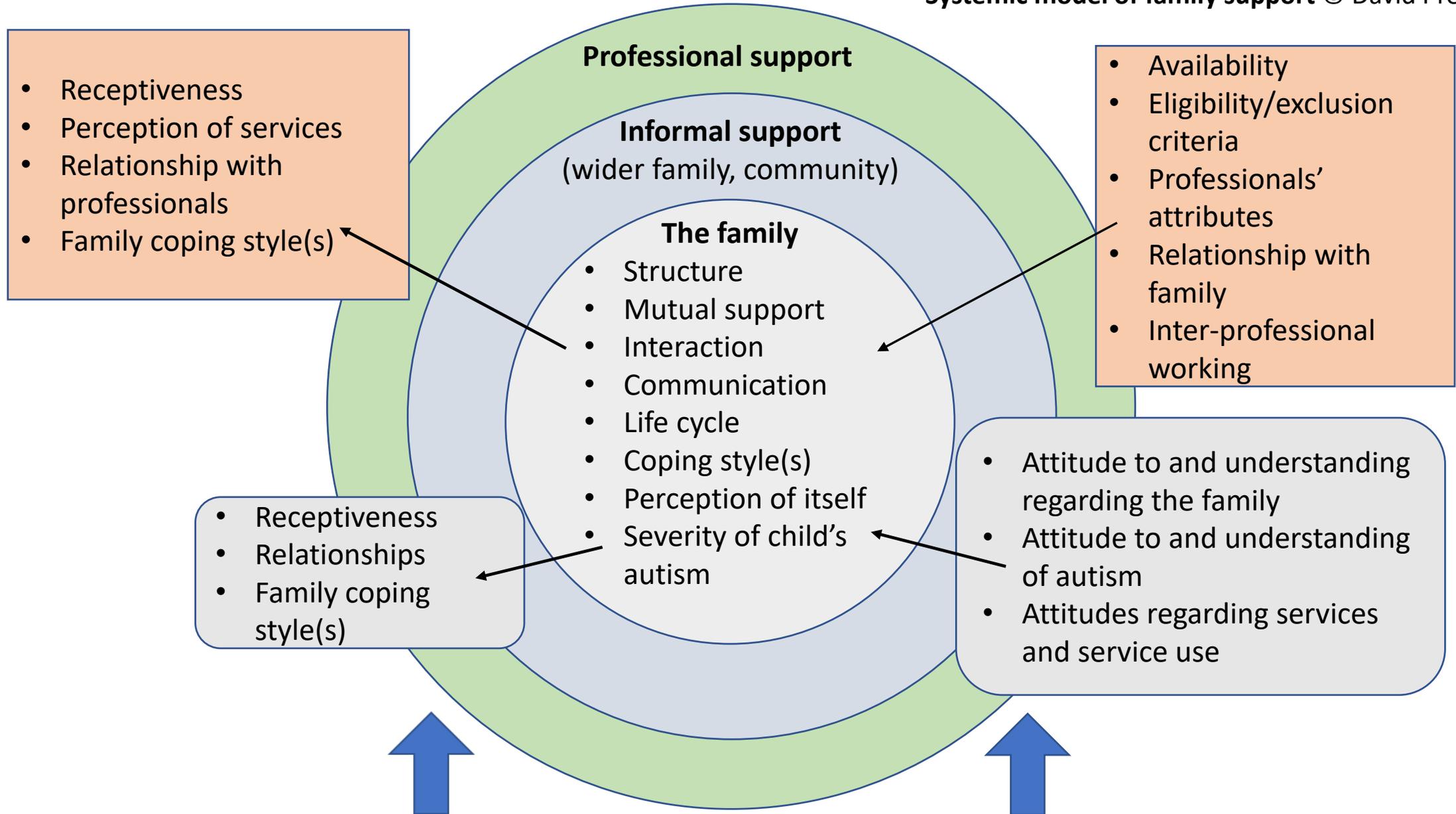
# Models of partnership working

- Generic models, e.g.
  - Family Partnership model (Hilton Davis)
  - Family systems intervention (Carl Dunst)
  - Families with disabilities (Naomi Dale)
- Autism-specific models, e.g.
  - TEACCH (Schopler/Mesibov)
  - SCERTS (Prizant)
- Different models but:
  - Many similarities
  - Borrow from others
  - Used in conjunction with each other (and other approaches)



# Some issues with models

- One-way delivery of professional expertise still dominates interaction of some professionals with families
- Models do not necessarily take account of e.g. parenting style, family relationships, resources, values, cultures (societal, family, professional)
- ‘Consumer’ models– can be unrealistic where there are e.g. limited service options, financial constraints
- Fail to take account of multiplicity of perspectives (within family and between professionals)
- Suggest interactive systemic model which acknowledges roles of nuclear family, wider family/friends, professionals and broader underpinning factors.



Competing demands: budgetary pressures, understanding of autism, prevalence, diagnosis, philosophical arguments, etc.

# What helps develop meaningful cross-disciplinary working?

- Four consistent key factors impacting on effective partnership working with families:
  - Workers' personal attributes, including their professional competence
  - Shared training
  - Working to a shared agenda
  - Appropriate, individualised support:
    - Understanding family's experience
    - Minimising time constraints
    - Developing family skills



# 1. Personal attributes



- Theo Peeters and Rita Jordan (1999):
  - imaginativeness
  - adaptability regarding communication/social interaction
  - teamwork
  - flexibility
  - humility
  - as well as being 'bitten by the bug of autism'
- Professionals who:
  - understand each other's perspectives, experience, skills and constraints
  - acknowledge the limits of personal and professional competence
  - engage in multi-professional problem solving
  - are willing/able to be innovative

## 2. Shared training

- Helps to develop shared value base
- Helps develop a common language and perspective
- Helps to defuse myths and misunderstanding
- Reduces sense of 'other'



# 3. Shared aims and objectives

- Many barriers to effective partnership working – institutional/personal
- Need shared focus on positive outcomes for child/family
- Parents/family members may share some thinking styles/characteristics of autism (Whitaker & Preece, 2013)
  - but so may some professionals
- Key issues
  - Acknowledging family perspectives
  - Supporting family to identify which concerns take precedence
  - BUT – ensuring these priorities are realistic/achievable



## 4. Appropriate individualised support



- Professional support for/partnerships with families must be individualised to take account of their strengths, needs and situations, e.g.
  - Some families may have a limited understanding of autism, while others may be extremely well informed (which can be challenging for professionals).
  - Some families may be resilient, while others may be highly vulnerable.
- 4.1 Professionals must have insight into and empathy with all family's experience (parents, individual with autism, siblings), not just on what they see as 'optimal outcome' from their own professional perspective.

## 4.2 Acknowledging time as a factor for families and children

- *Parents think of time as a daily routine, they also see the care of their child as an ongoing, lifelong, ever-evolving commitment, not a short-term educational or therapeutic contact. This is a significant difference in time orientation that should be highlighted for professional understanding of families (Brotherson & Goldstein, 1992, p523)*
- Key barriers to effective use of family time when interacting with professionals:
  - Inability of professionals to coordinate their daily activities among themselves
  - Overwhelming number of tasks parents are asked to complete by professionals
  - Lack of local/accessible services
  - Lack of flexible, family-centred scheduling of services

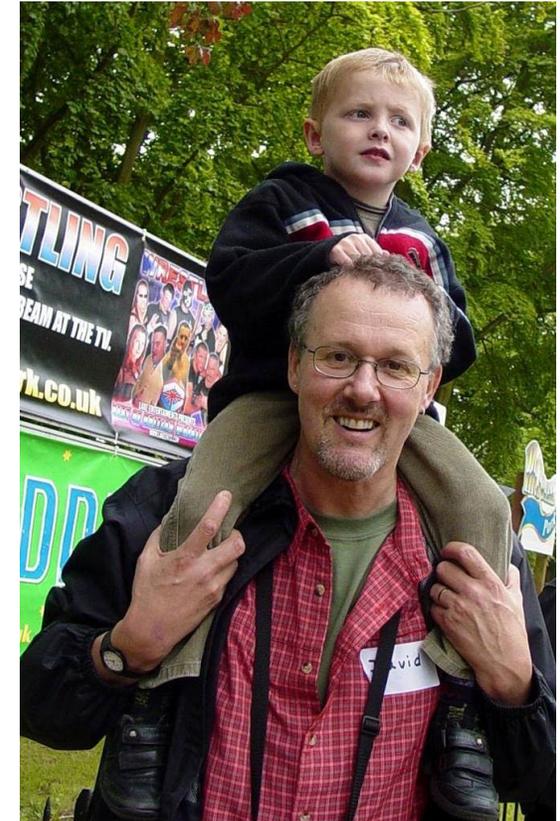
# 4.3 Supporting the family to develop their skills

- What do families need to know?
- The same as professionals:
  - accurate information about autism
  - current evidence-based 'good autism practice'
  - positive strategies to work effectively with their children
- Range of appropriate supports:
  - Group education
  - Individual support



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TEACCH workshops: UK

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