



Supporting families of adults with autism

# **Autism with Complex Needs**

**Tom Wightman**

# Some Alarming Facts:

- A transition handled badly
- A parent not treated with respect and dignity

# Person-Centred Plan

- The Support Plan needs to be written
- The Plan must be implemented
- It must be kept up-to-date
- It has to be read by everyone who deals with the person to ensure they understand the person's needs

# Person-Centred Plan

- Cost is not the driver
- What a person needs, is the driver
- Delivery should be with respect and dignity
- Least restrictive environment
- People need a life with opportunities, variety and social interaction

# Incidents of Anxiety

- Incidents of Anxiety should be recorded, as well as incidents of Aggression
- These need to be investigated and not passed over as just behavioural problems and certainly not punished
- These could be signs of a physical problem: environment or pain
- Sorting the problem could prevent further incidents

# Use of Medication

- Correct Diagnosis is Critical
- Medication can result in extremes of both mood and conduct
- Very low doses of medication can work
- Build-up of toxins from high doses can cause dangerous behaviour, obesity, catatonia

# Training

- Autism training is required for everyone dealing with people with autism
- Learning Disability training only, is not acceptable – and potentially dangerous
- Ideally everyone needs to be trained in autism, those giving the care and those in charge of the finances

# Training

- Oversight and enforcement should be provided by a dedicated group within the Local Authority
- Not an Add-On to another job
- Enforceable Authority
- Quality Treatment
- Consistent Procedures
- Best Use of Finances



# Delivery

- Dignity and Respect for all
- Living a Good Life
- Timely Provision of Needs
- Stop Wasting Money with Bureaucracy
- Better Outcomes

# Accommodation

- More appropriate accommodation is required now
- Even more is going to be required in the future as the age of both the carers and the people with autism increases
- Service models are available – e.g. Morpeth
- These are not prisons or temporary accommodations, these need to be homes 10

# Accommodation

- Not just a room
- Not in a hospital environment
- Permanence
- Safe and secure

# Accommodation

- It's not just a building that's required
- Well trained, sympathetic staff
- Well trained, sympathetic management
- Activities
- Good Management is the key

# Transitions

- What transitions?
- Who should be involved?
- Must be timely

# Complaints and Appeals

- Clearer Complaints procedure
- Clearer and more rapid Appeals procedure is required
- Who could be the subject of a complaint?
- Who should be responsible – where does the buck stop?

# Complaints and Appeals

- The complaints procedure is fraught with potential personal criticism of the complainant
- Complaints agreed upon, yet not properly addressed
- Complaint out-of-date
- Threats
- Bureaucracy

# Diagnosis

- Just because someone has a diagnosis of something else, it doesn't mean that they don't have autism as well
- Accordingly, if someone has autism, it doesn't mean that they should not be tested for other problems or conditions



# What needs to Change

- A transition handled badly
- A parent not treated with respect and dignity

# What Can You Do To Make A Difference!

- Build appropriate accommodation in the community according to need.
- Move the people with autism and complex needs out of NHS and into the community.
- Employ carers and managers who are empathetic towards people with autism.
- Ensure that training is completed and that it has been understood.
- Set up Groups to oversee delivery of services and training.