

Care Pathways & Clinical Services for Adults with ASC

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Overview

- Prevalence
- Clinical Issues
- Service Issues
- Drivers for Change/Policy Context
- Key Challenges
- Specialist ASC Teams
- Care Pathway
- Towards Social Inclusion?

Epidemiology

- First ever national epidemiological study estimated overall prevalence of 1% for ASC (Brugha et al, 2009)
 - 1.8% men & 0.2% women meet diagnostic criteria
 - No data on numbers of people with Asperger Syndrome
- Historically, many adults with AS are undiagnosed
 - Lack of local prevalence data
 - Difficult for commissioners to plan services

Clinical issues

- People with ASC are an extremely heterogenous group, who face a variety of challenges, including:
 - Profound difficulties relating to other people, and to the world in general – ‘social world’
 - Very high levels of social exclusion - ‘doubly excluded’
 - Low rates of employment
 - Many live with parents well into adulthood
 - High rates of psychiatric co-morbidity
 - Often denied access to needed services

What do people with ASC need?

- A job
- A nice place to live
- Enough money
- Friends/partners
- Essentially, access to the same range of opportunity as anyone else
- But, there are currently significant obstacles to this...

Service Issues

- People with AS are currently excluded from accessing MH/LD services
 - Unable to obtain diagnosis
 - Only able to access services at point of crisis
 - Unhelpful & expensive
- If a person with autism does manage to access mainstream services...
 - Significant competency gap amongst frontline staff
 - Needs likely to be poorly understood
 - Potential for ineffective, inappropriate and potentially harmful interventions

Drivers for change

- Recent increase in awareness thanks to:
 - Local/national activism
 - Media
 - CAMHS graduates
 - Complaints to PCTs
- Potential for cost savings – NAO report (2009)
 - Reliance on independent provision/crisis intervention = expensive
- Unprecedented focus on ASC by policymakers

Policy Context

- **Autism Act (2009)**: first ever piece of disability-specific legislation in the UK
- **National Autism Strategy** - *“Fulfilling and Rewarding Lives”* (DH, 2010)
- **Statutory Guidance** - *“Implementing Fulfilling and Rewarding Lives”* (published December 2010)

Previous situation where nobody took responsibility for providing services for adults with ASC becoming increasingly untenable

Key Challenges

- DH very clear about two things:
 - There will be no new money
 - The majority of the needs of people with ASC should be met within existing services

But...

- Mainstream services lack skills and experience re. how to work effectively with people with ASC
- Existing services will not be able to provide diagnostic assessment & preventative intervention

How to solve this problem?

- GPs to diagnose?
- Online assessments?
- ASC directorate to go alongside MH & LD?
- ?

Specialist ASC Teams

- South West SHA developing commissioning guidance, due to be published early 2011
- Sets out care pathway & strongly recommends development of multi-agency, jointly commissioned specialist ASC teams in each PCT/LA area
- Need to be compact & cheap, but able to have disproportionate impact

Remit of Specialist Teams

- Two broad areas of activity:
 - **workforce support** to agencies across the care pathway (including health, social care and voluntary sector organisations) involved in providing services to this client group.
 - **direct work with people with ASC** who are not able to access existing provision due to the absence of significant psychiatric co-morbidity and/or learning disability

Workforce support

- Provision of comprehensive, ongoing **programme of training** and awareness-raising to front-line staff across care pathway, targeted to meet the specific training needs of different organisations
- **Supervision clinic** to enable professionals in secondary mental health/learning disability services to properly diagnose & manage people with ASC

Workforce support

- **Consultation/liaison service** to local social care & voluntary sector agencies working with people with ASC, to enable them to obtain:
 - Ongoing, specialist advice about specific cases
 - Support to adapt their services to enable them to be more appropriate and accessible to people with ASC
- **Partnership working** with relevant stakeholders to develop and implement a range of local initiatives to improve the quality of life of people with ASC, and reduce levels of social exclusion

Direct work with people with ASC

- **Diagnostic service**, accessible from primary care
- Comprehensive package of **post-diagnostic support** for people with ASC and their families/carers
- Holistic **assessment of need** across health, social care, housing, employment, education etc, and **signposting** to agencies who can help with this
- **Range of preventative interventions** to help avoid unnecessary contact with mental health services, and promote social inclusion/independence – i.e. development of self-directed social support networks, “social skills training” etc

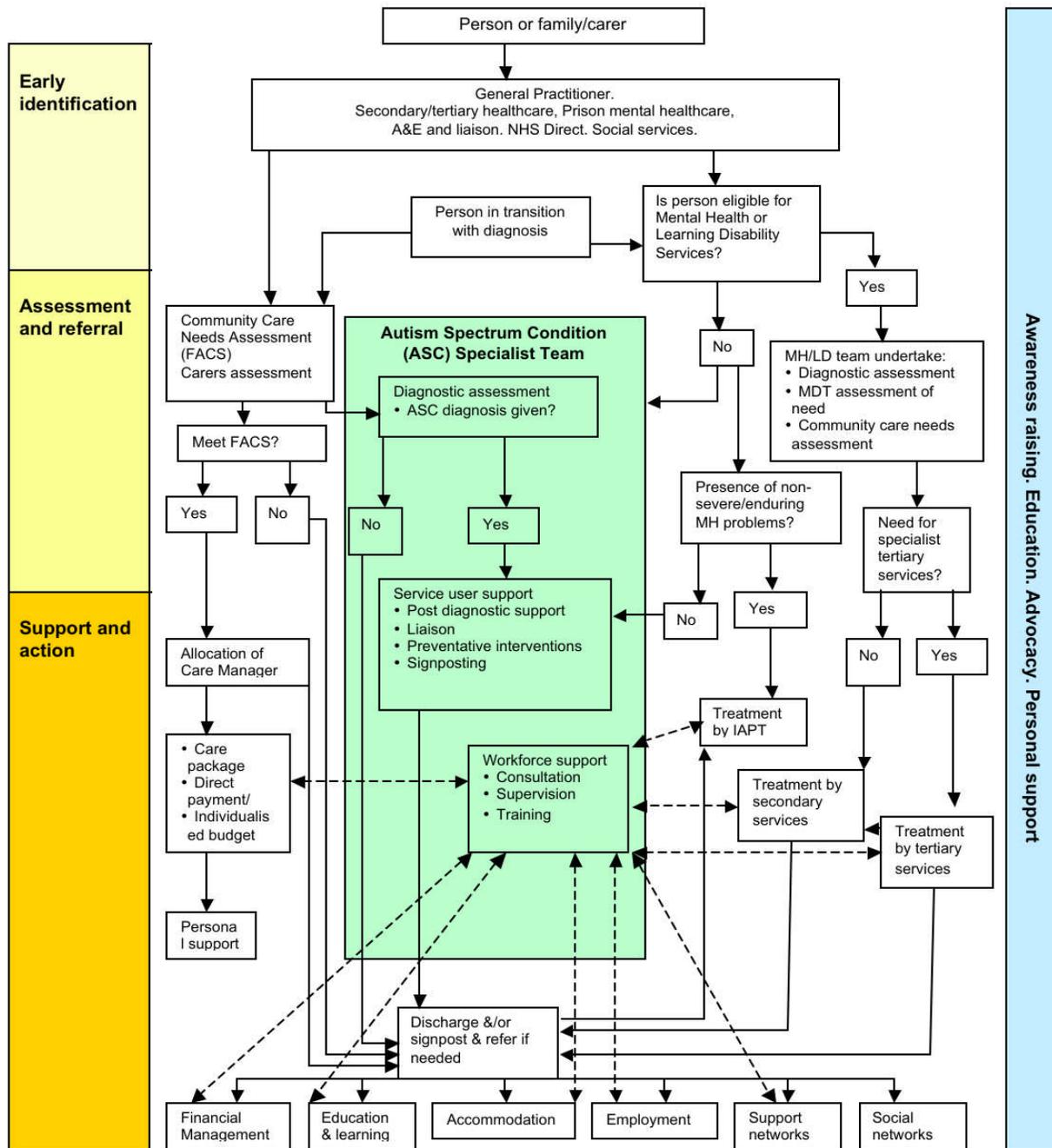
Specialist ASC Teams

- Idea is not to become the people who provide all the services for people with ASC
- This would not be sustainable & would locate all the expertise in a small part of the care pathway
- Role of specialist ASC team is essentially a facilitative one – to liaise with mainstream services to help them work better with people with autism

Specialist ASC Teams

- However, for people who are not eligible for mainstream services, there is a need for specialist teams to have capacity to provide a range of direct services
- This includes:
 - Diagnostic clinic
 - Post-diagnostic support
 - Preventative group interventions
 - Signposting

Autism Spectrum Condition Adult Care Pathway



Key points from care pathway

- In terms of access to diagnosis – first question we ask: “is the person eligible for MH/LD services?”
- If so, it’s the responsibility of these services to diagnose, with support from specialist team
- Same applies to social care assessments
- Not the team’s job to undertake these – their role is to train & liaise with generic adult social care teams to enable them to do it better

Key points from care pathway

- Once assessments done, team signpost people with ASC towards agencies across care pathway to access appropriate support
- All these agencies can access the same level of training & support as health & social care providers
- NB. Training alone is insufficient – the thing that changes practice is being able to access 1:1 supervision

Key points from care pathway

- Therefore, if a person with ASC identifies needs around employment, they will be signposted to an employment service, who will have access to ongoing training & liaison from specialist team
- Likewise, if “low-level” mental health needs are identified, the person will be signposted to IAPT, who will similarly have access to specialist training & supervision

Key points from care pathway

- Specialist teams should only diagnose if there's nobody else who could do it
- If a person is in secondary services, it's their responsibility to diagnose/manage, with supervision & training from specialist team
- Care coordination/management remains with referring agency
- Teams can accept referrals for supervision/training from anyone in care network

Key issue: Social Inclusion

Q: How do we include one of the most socially excluded groups in the country?

A: We help them get:

- Meaningful, real jobs
- Good quality housing
- Enough money
- Social networks
- Access to the same range of opportunity as anyone else...

Key challenges

- How to do this with no new money
- How to develop sufficient local expertise – general lack of experienced skilled clinicians
- How to enter into partnerships with neighbouring PCTs/LAs to commission sustainable services
- How to pool resources & develop proper, sustainable jointly commissioned services

The End

- Thanks very much for listening
- Feel free to contact me to discuss further c/o:

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