



## Presentation to Members of the European Parliament

March 2014



This project has been funded with the support of the Lifelong Learning Programme of the European Union.  
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### Agenda

- Introduction
- Women living with autism
- Principle issues
- Action to ensure the respect of rights
- Discussion and Questions



## Introduction to Autism

- Autism is a spectrum condition
- Autism is a **lifelong developmental condition** which affects the person's ability to
  - communicate
  - interact socially
  - think and act flexibly
- It affects
  - the person's sensory experience of the world
  - the way in which information is processed in the brain
- **one in a hundred people**



## Introduction to Autism

- In society, people with autism are often stereotyped
  - 'Rainman'
  - the geeky eccentric
- Long held belief that autism mainly affects boys and men
- But, there are more women with autism than we thought
- In reality neither women nor men with autism consistently conform to stereotypes

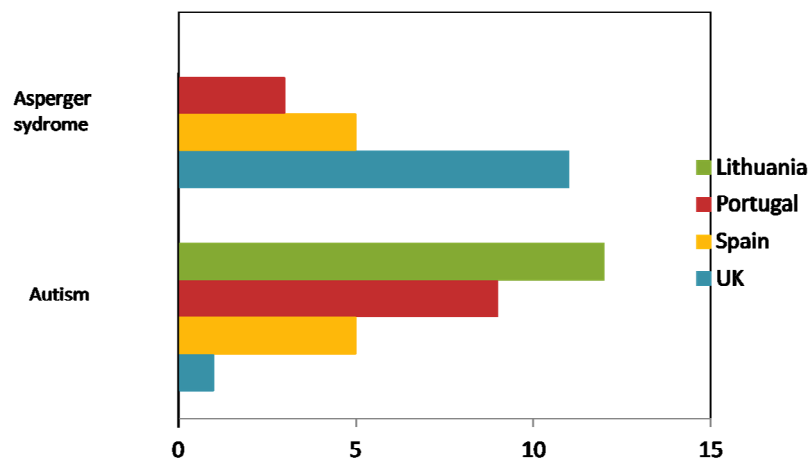


## Introduction to Autism in Pink

- Project funded by the **EU Lifelong Learning Programme**
- Learning about women with autism through workshops and interviews
- Production of materials to be made available to a wider audience
  - for women with autism and those who care for them
- Participant countries are
  - UK
  - Lithuania
  - Spain
  - Portugal
- 10-12 'women with autism' volunteers from each country
- Diagnosed with anything classed as being on the **autism spectrum**, including Asperger syndrome



## The Autism in Pink participant diagnoses



## Introduction to Autism in Pink

- We are women with autism but
  - we are individuals with our own personalities, outlooks and circumstances
- Actual effects of autism on individual lives are hugely variable
- Some themes have been emerging in the public domain
  - The Autism in Pink findings amplify these themes
- We would like to talk about the project findings
  - And contrast these with our rights as laid out in the [United Nations Convention on the Rights of Persons with Disabilities](#)



## Sofia's story

### Sofia is a woman with Asperger syndrome

- *Sofia is a bit of a loner at school, but she gets by OK academically*
- *Her hobby is drawing*
- *Sofia goes on to further education*
  - *but keeps changing course*
  - *changes establishment to be nearer home and continue living with her parents*
  - *she passes her course but takes twice as long as everyone else*
- *She gets a part-time admin job after being unemployed for a year*
  - *she stays in same job for 4 years but sees people promoted around her*
  - *she never socialises with colleagues*
- *Sofia has had same boyfriend from age 18*
  - *moves in with him when she gets her job*
- *She doesn't really have any friends*



## Sofia's story

- Her doctor is treating her for depression
- Her Mum reads something online about Asperger syndrome and tells her
- After 2 years of trying, Sofia is diagnosed
- She tells her employer about her diagnosis
  - nothing much changes
  
- How have Sofia's human rights, as laid out in UNCRPD been breached?



## Sofia's story

- Education and health system fail to consider autism for a long time
  - Diagnosed with depression
- No **diagnosis** = no support in education
  - coping with academic and sensory challenges at same time
  - restricted by need to live with parents
- Difficult to fulfil **potential**
  - affects her future job role and pay
  - passed over when it came to promotion
- After diagnosis, Sofia and employer don't know how to change things

UNCRPD Article 25, Health: ...States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive

UNCRPD Article 24, Education: ... Persons with disabilities receive the support required, within the general education system, to facilitate their effective education and ...Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion

UNCRPD Article 27: Work and Employment: States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.



## Sofia's story

- Limited ability to develop social skills
  - affecting inclusion
  - isolated at school and out of school
- Unable to leave abusive boyfriend
  - No one to tell / talk to
  - Doesn't want to be alone

UNCRPD Article 3: principle of full and effective participation and inclusion in society

UNCRPD Article 30: participation in cultural life, recreation, leisure and sport

UNCRPD Article 16: Freedom from Exploitation violence and abuse.  
States Parties shall take all appropriate [ ] measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects



## Linda's story

Linda is a woman with autism

- *Linda is bullied and isolated at school, and struggles academically*
    - *after 2.5 years she is referred for assessment*
    - *she is diagnosed with autism*
    - *2 years later she receives official support for some academic areas*
  - *She goes on activities and holidays with her parents*
  - *She does not have friends*
  - *She tries to further her education after finishing school*
    - *she is not accepted on the courses that she wants*
    - *she is accepted on a course and passes it*
  - *She is unemployed*
  - *She receives disability benefits and lives at home with her parents*
- How have Linda's human rights, as laid out in UNCRPD been breached?



## Linda's story

- Delayed and inadequate support in education
  - Leading to lack of ability to fulfil potential
- Holidays and activities
  - sometimes unable to disclose diagnosis
- Poor standard of living on benefits
  - no option but to live with parents
  - stress from benefit procedures

UNCRPD Article 24, Education: ...States Parties shall ensure an inclusive education system at all levels and life long learning directed to: the full development of human potential....

UNCRPD Article 3: principle of Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

UNCRPD Article 28: ... Adequate standard of living and social protection

UNCRPD Article 19: Living independently: and being included in the community: ...Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement



## Principle issues

- From these stories we can see how UNCRPD does not offer adequate support or protection to women with autism in Europe
- The principle issues are:
  - **Under diagnosis**
  - **Employment**

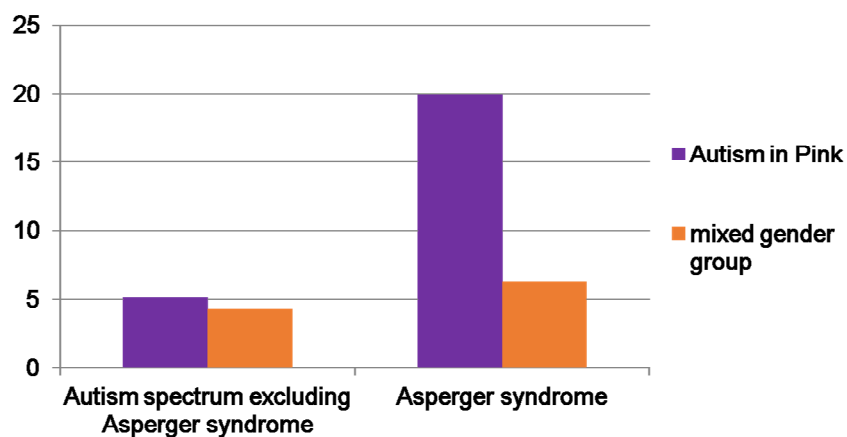


## Principle issues – under-diagnosis

- It's different for girls...
  - autism is associated with males
  - autism presents differently in females
  - females mask symptoms better than males
- Resulting in
  - Failure to consider autism by education and healthcare professionals
  - If referred, failure to diagnose - methods skewed to males
  - Inconsistent diagnosis country to country and within countries



## Average Age at diagnosis for Autism in Pink group compared with mixed group





## Principle issues – employment

- Difficulties
  - lack of recognition of skills and strengths of people with autism
  - communication issues and lack of social skills make interviews challenging
  - lack of appropriate support from employers
  - lack of knowledge on part of autistic women of legally required 'reasonable accommodation'
- Resulting in:
  - 90% of people with autism in Europe are unemployed
  - difficulty gaining employment because of inequality towards women, disabilities, autism
- What needs to be done?



## Action is urgently required to

- Look at specific disabilities especially autism in depth
  - gender differences
  - range of effects
- Raise awareness of
  - education and health professionals
- Reduce **under-diagnosis and misdiagnosis** of women with autism
- Raise awareness of
  - employers and benefit decision makers
- Increase awareness of women with autism about 'reasonable accommodation'

EDS 2010-2020 List of Actions 2010-15:  
'Raise disability awareness and specific knowledge among health professionals considering specific needs of female and male patients'. (pg 14, Health)

EDS 2010-2020 List of Actions 2010-15:  
'Focus on what people can do and persuade potential employers with convincing arguments and support to employ people with disabilities' (pg 10/11, Employment)

'Develop models of good practice on reasonable accommodation and good quality jobs'  
'Provide employers and policy makers with information on positive measures'  
'Promote labour market training relevant to people with disabilities' (pg 11/12, Employment)



## Specific recommendations

- Monitoring and implementation of UNCRPD
- Ensure EDS 2010-2020 is harnessed to raise awareness of autism and autism in women
- Ensure the review of EDS 2010-2020 planned for 2016 addresses the gender dimension in disability and autism in particular
- Raise a parliamentary question asking how the issue of under-diagnosis of autism in women and girls can be addressed.

Thank you for listening



## Discussion and Questions



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