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Ensuring health equality for all women and girls

The role of Annual Health Checks in addressing sexual and reproductive health issues experienced by women and girls with a Learning Disability and/or Autism

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Context

- CDC are Strategic Partner to the Learning Disability & Autism (LD/A) CYP Programme at NHSE
- Strand around health inequalities: STOMP STAMP and Annual Health Checks (AHCs), specifically for women and girls
- Output: a report for NHSE, with recommendations, looking at how AHCs could be more effective at meeting needs of this cohort

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Why?

- People with a LD and/or autism often experience worse physical and mental health outcomes and die younger than other people
- Women and girls face a double disadvantage when it comes to health inequalities
- 18 year lower life expectancy for females with a LD than general population, 14 year lower life expectancy for males with a LD (NHS Digital, 2017)
- More focus in recent years on sexual & reproductive health issues experienced by women & girls in general

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Key questions

- What are some of the specific issues experienced by women & girls with a LD and/or Autism?
- Do AHCs effectively address these issues? If not, should they be addressed in the AHC or elsewhere (e.g. in education?)
- What needs to happen next to implement the recommendations? (e.g. guidance, training etc.)

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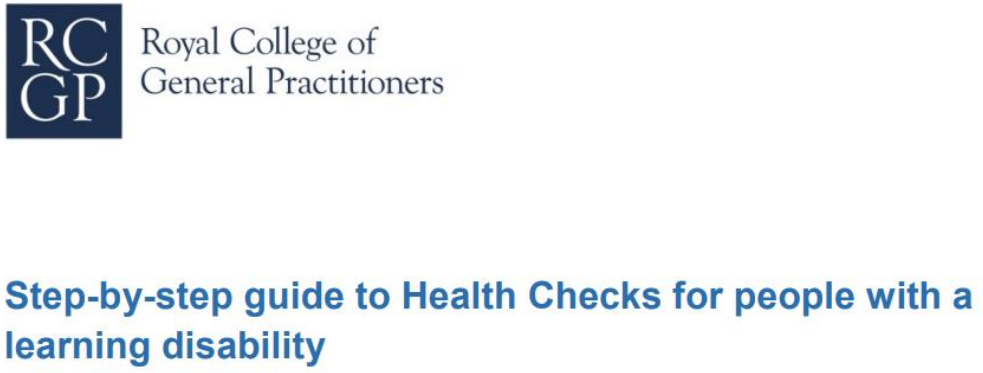
Method

- Research of academic literature, guides for professionals (NHSE, RCGP), easy-read guides about the AHC produced by charities/LAs
- Focus groups with young women:
  - CDC focus group with 5 young women, aged 19-24
  - Commissioned Ambitious about Autism to run a group with 6 autistic young women, aged 16-20
- Consulted with expert organisations from across the sexual health, LD/A and women's sectors
- 2x focus groups for experts in the field

Scope

- AHCs are for anyone 14+ with a LD. Plans to extend to autistic people without a LD
- Broad remit- sexual & reproductive health in its widest sense
- Age – 14-25 great period of physical and emotional change
- Needs and abilities – often the YP with most complex needs won't be able to engage in traditional structure of AHC, but will be most at risk of health inequalities
- Gender identity – inclusive definition, Cass Review report
- Ethnicity - triple disadvantage

1. What are the issues, and what does the RCGP Guidance tell us about them?



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What are the sexual and reproductive health issues relevant to this cohort?

Based on research & conversations with YP and experts, we identified a number of issues that fall under 2 broad themes:

- Physical health
- Sexual health and relationships

Physical health

- Screening (breast and cervical)
- Breast and pelvic examinations
- Menstrual issues
- HPV vaccinations
- Pregnancy (not a focus for this report but requires consideration & further research)
- Menopause (not a focus of this report but requires consideration & further research)
- Miscellaneous (e.g. eating disorders, chronic pain disorders, UTIs)

Physical health – what does the Guidance say?

- Screening not relevant to this cohort, but unclear Guidance around breast examinations. Should these be taking place at a younger age for this cohort?
- Cervical screening not part of AHC but women should be advised to have one
- Pelvic examinations should only take place 'if needed'
- Effects of start of menstruation can present significant issues (e.g. heavy bleeding, painful periods, increased seizures and behavioural disturbances). PMS more prevalent in autistic women, who may take longer to learn 'practical skills to manage…as well as appropriate social behaviours'
- Effects of menstruation on gastro-intestinal issues and bowel habits – should this be included in the AHC?

Physical health – what does the Guidance say?

- Unclear whether HPV vaccine would be delivered during AHC. Currently only administered via injection – what about those young people with needle phobia (especially prevalent amongst autistic young people)?
- People with anorexia more likely to be autistic, anorexia can result in irregular/no periods
- Chronic pain disorders (e.g. endometriosis) disproportionately affect women and girls
- Higher hospital admission risk for adults with a LD with a UTI
- Migraines, rheumatological and musculoskeletal pain (e.g. fibromyalgia) seen more frequently in women

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Sexual health & relationships

- Contraception
- Sexually Transmitted Infections (STIs)
- Relationships and Sex Education (RSE)
- Domestic violence and sexual abuse/exploitation

The right to romantic and sexual relationships

- We all have rights to seek romantic & sexual relationships if 16+ and have capacity to consent– enshrined in law
- Health service has important role to play in upholding these rights
- Most with LD/A can engage in safe & fulfilling relationships if they are given sufficient social support and accessible RSE
- BUT negative stereotypes still persist

"It is a presumption that there's no sexual activity for learning disability... I find it so frustrating and insulting to the population, you know, to just presume that that that won't be a factor" (Expert)

Sexual health & relationships – what does the Guidance say?

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- Main focus is on contraception – recognises understanding may vary & that easy read info should be available.
- Stresses that women should not be given contraception because they are thought to be 'at risk' of pregnancy or abuse – emphasises choice
- No reference to sexual health screening despite higher rates of unsafe sex and pregnancy - face to face testing options essential
- References to many elements of RSE throughout Guidance (e.g. contraception, period management, sexual abuse/exploitation)
- Particular issues around LGBTQ+ YP in this cohort
- Prevalence of 'masking' amongst autistic women

Sexual health & relationships – what does the Guidance say?

- YP with LDs at higher risk of sexual exploitation
- Disabled people also experience higher levels of domestic abuse
- Reasons are complex and include poor RSE, tendency towards overprotection, not knowing how to report abuse and poor police response, lack of training for professionals, lack of appropriate support services for this cohort
- Guidance encourages professionals to look for signs of being 'at risk of sexual abuse or sexual exploitation' and to provide 'guidance on safety and abuse prevention'
- Emphasises importance of 'listening carefully' to views of women around contraception in particular and supporting them to make own decisions

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2. What did the young people tell us?

- Wide range of mental and physical health issues are important (especially domestic abuse checks)
- Comfortable talking to a doctor about: periods, changes to breasts
- Not comfortable talking to a doctor about: sex & contraception, domestic abuse, STIs
- Feelings of judgement and shame - YP prefer to go to sexual health clinics
- Overwhelming preference for female doctors and nurses

- YP want to get advice & support from qualified people, as and when they need it
- All YP wanted to be able to prepare for AHC
- Wide range of methods (talking to someone in person beforehand, online, booklets, videos, home visits, easy-read)

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Would you feel comfortable talking to your doctor about...

Personally I wouldn't like to talk to a male doctor about my period as it embarrassing

For years I have been talking to my doctor about my periods because they were absent

Talking to doctors about period has been helpful

Your period

GPs referring to specialist for lots of things

I am very scared of doctors so would struggle to talk to them about any topic, but if i bring my friend to help me explain, i would feel much more comfortable to talk about it

i have a gynaecologist for that

Might be comfortable talking to a female doctor, but need support to talk about it

Wouldn't mind a male doctor, more about how their personality comes across

it depends on the charterer rather than gender for me more

Not to a doctor- can be slow at sorting things out

Would you feel comfortable talking to your doctor about...

DA helplines are not accessible so would not know where to physically go (would not go to a hospital and cannot talk on the phone)

Would prefer to talk to support worker or social worker who know me better, my family situation, who would be better placed to deal with issue and keep me safe

Domestic abuse

With autism, risk of people not being taken seriously (misinterpreting social situations)

No, because I would be scared

If I was in that situation, the emotions would be too bad to talk about it or make thoughts come together- would not be able to say it very cohesively

Would go to a friend who knows how I talk and who can understand what I say

i wouldn't i don't trust them that much these situations is partly why I am getting aac so I can reliably communicate

sometimes the doctors have been quite harsh to me as their temper is short

2. The role and purpose of Annual Health Checks

4 key purposes

- Promotion of screening
- Physical examinations and administration of vaccines
- Referrals to other services (sexual health clinics, domestic abuse charities)
- **Provision of education/messages** (e.g. around self-examination, cervical screening and RSE) – should start well in advance of woman becoming eligible:

"You can't just introduce (cervical examinations) at 25 to a population" (Expert)

3. Key reflections

- The need for differentiation according to age
- The need to promote choice and control
- The importance of consent
- Balancing management of risk with allowing young people to develop healthy and fulfilling sexual relationships:

"We're not going to protect young people with learning disabilities from the things that might go wrong with sex by telling them not to have sex... there are lots of ways that we could approach that with GPs, even very small bits of training like information sessions of maybe an hour or even written stuff" (Expert)

4. Recommendations

4 categories:

1. Changes to the AHC itself
2. Training and resources for professionals
3. Information and resources for women and girls and their families
4. Further research

Changes to the AHC itself

- Accessibility (female nurse/doctor as standard practice, bringing a friend, less jargon, more training around MH and Autism)
- Co-locating AHCs in education settings (would require better link up between education and GPs and improved info sharing)
- Modelling approaches (e.g. female relatives having cervical exam at same time, social stories)
- Signposting to other services (sexual health clinics, charities)

Training & resources for professionals

- Gender and age specific guidance
- More detailed guidance – current guidance could be seen as 'tick-box exercise'
- More training and resources for professionals (clarity around safeguarding, national forum for practitioners, new RSE requirements, local sexual health services, providing reasonable adjustments, Autism)

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Information and resources for women and girls and their families

- Preparation is key for young people
- Videos
- Websites and social media
- Detailed easy read guides
- Role of education settings (e.g. teaching about AHCs during PSHE time)
- Champions in sexual health and wellbeing

Further research

- Pregnancy and associated issues
- Menopause
- Gender identity
- Race, ethnicity and culture

"Nobody wants these people attending these annual health checks to feel that it's a tick box exercise. It has got to be meaningful" (Expert)

Question

- Did anything from the research surprise you/ stand out to you?

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Thank you!

- Any questions?
- If you have any thoughts or comments, please email mhunt@ncb.org.uk