Establishing a Level 2 Sexual Health Service for people with Learning Disabilities

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Introduction
A local needs assessment undertaken by the FPA in 2013 on behalf of Public Health Kingston demonstrated an unmet need for sexual health services amongst young people with learning difficulties (LD) mainly because both the young people themselves and their carers were unaware of existing services.

Young people with LD requested a familiar venue that was private and where other people with LD would also be present. They wanted experienced staff that they could trust, who would listen, not interrupt or be ‘bossy’ and took time to explain things so they understood. They also expressed an indirect preference to see female staff.

Public Health Kingston commissioned:
• A specialist level 2 sexual health service for young people with LD aged 13-25years, initially for a 15 month pilot period. The Wolverton Centre for Sexual Health was successful in bidding for the service.
• Outreach support from the FPA (an experienced FPA consultant in LD & sexual health) for a 26 month period to help establish the sexual health service in the community, provide outreach support to young people with LD and also training for staff.

Establishment of the LD Service

Bearng in mind feedback from young people with LD, the Commissioners chose a community clinic for children’s services as the location for the new service (Moor Lane Clinic, Chessington) as it was already familiar to the clients.

A consultant in sexual health and service manager from the Wolverton Centre supported the service.

The service commenced in April 2014.

Service details
Clinic time: 00.00-00.00pm once a month
Staff: Specialty Dr, Band 6 nurse, Band 3 technician
Reception team from the children’s centre

Clinical provision:
Sexual health screening (GC/CD NAATs, Syphilis, HIV, Hep B serology, other tests as indicated)
Full range of contraception incl. co-eds and implants
Hep B immunisation
Sexual health advice, sex education
Safeguarding/CSE (all clients are discussed within the Vulnerable Persons MDT held at the Wolverton Level 3 site)

Publicity
The service was launched on the 24th March 2014 and was attended by over 25 people from local LD organisations, schools, Kingston Learning Disability nursing team, Kingston Learning Disability Parliament and social services.

Staff training
The Connect clinic staff received training in assessment of capacity to consent, sex and the law, learning difficulties and autistic spectrum disorder, managing young people with LD etc. General awareness training in LD was provided for all Wolverton staff and local professional staff and carers.

Outreach
This was an important part of establishing the service. All key stakeholders were contacted and sent information about the service. The FPA consultant visited all local schools including the 3 local Special Schools, youth groups and LD services as well as specific transition events hosted by RBK and an evening event called ‘Boogie Nights’ for people with LD.

School visits
Arrangements were made with one of the local Special Schools for pupils to visit the Connect Clinic as part of their PSE programme. They were run as fun informal sessions to improve the young peoples’ awareness of sexual health issues and the service. 50 young people attended in the first year.

Changes during the pilot period
The clinic was moved in April 2015 to the Level 3 sexual health service at The Wolverton Centre, Kingston Hospital and the clinic session changed to a weekly service on a Wednesday afternoon from 3.00-5.00pm.
The community setting was found to be too isolated with poor clinical and reception support and no IT access. Microsoft was not available.

Both staff and clients found a monthly clinic too infrequent to infrequent to meet timely needs. A Friday afternoon was a difficult time to manage urgent safeguarding issues and referrals and pathology transport was unreliable. Clients and their carers were happy with this arrangement particularly as the Wednesday afternoon was a quiet day with no other clinics running.

The age limit (<25 years) clinic was removed so people with LD of all ages could attend. This was in response to referral of older adults by Kingston LD Nursing Team and a specific request from the Kingston Learning Disability Parliament.

Key Findings for the period April 2014 – March 2016

Demographics
• There were 62 attendances by 19 clients (14 female; 5 male)
• The age range was 16 years to 40 years.
• Learning difficulties – wide range of diagnoses often multiple: Autistic spectrum disorder, Asperger’s syndrome Downs syndrome, cerebral palsy, epilepsy etc
• 9 clients were in education; 3 employed; 3 unemployed
• 2/19 were heterosexual; 2/19 were homosexual
• 1/19 were sexually active or had sex previously

Source of referral
• The main sources of referral were from the family and social services (Total 58%)
• 15/19 clients attended with a support worker (7), family member (6) or partner (2)

Reason for attendance
• 42% attended for contraception
• 42% attended with symptoms or concerns re their sexual health

STI screens
11/12 clients that were sexually active had a STI screen incl syphilis, HIV & Hep B

Infections diagnosed
Chlamydia 3
TV 1
PID 2
1st episode HSV 1
BV 2
candida 1

Other services
Hep B immunisation 1 dose
Cervical cytology 1
Pregnancy tests 4

Safeguarding concerns
• High prevalence reported sexual assault
• 4 current cases
• 4 historic cases
• 8/9 cases sexual assault were in females
• 2 cases occurred in an 11 & a 12yr old – their first sexual experience

Conclusion
Small number of clients attended the service but all were complex with multiple needs. Although intended initially for young people with LD under the age of 25 years, 53% clients were older than this indicating an unmet need in all age groups. They are a highly vulnerable group with high rates of STIs, child sexual abuse and safeguarding concerns.

Tips for providing a sexual health service for people with learning difficulties
• Setting up specialised sexual health services for people with LD is to be encouraged as they are a highly vulnerable group with complex needs, who are poor at accessing services.
• It is important to engage with all stakeholders including the clients in the initial service development process.
• Consider using an expert in LD and sexual health (we were fortunate to have a LD consultant in sexual health from the FPA to help us) to facilitate engagement with people with LD.
• Publicity and bespoke information leaflets and resources are important - we created our own.
• Ensure on going regular outreach work.
• Staff involved with the service need additional training in LD, sexual health and the law and undertaking capacity assessments.
• It is important that the staff should have an interest in LD and be well supported as it can be emotionally demanding.
• Ensure there are robust local governance processes for managing clients with safeguarding concerns.
• Consider incorporating services for LD within existing level 3 sexual health services rather than stand alone community sites due to the lack of local support required.

Footnotes:
*Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies
†Prevalence of child sexual abuse among children with learning disabilities: a systematic review
‡Prevalence of child abuse among children with intellectual disabilities: a systematic review
#Prevalence of child abuse among children with learning disabilities: a systematic review