

# Needs Assessment with Staff Supporting Relationships and Sexual Health for Adults with Learning Disabilities in NHSGGC

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## FINAL REPORT

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## Abbreviations

HSCP	Health and Social Care Partnership
LD	Learning disabilities
NHSGGC	NHS Greater Glasgow & Clyde
SSKAAT-R	Socio-Sexual Knowledge and Attitudes Test – Revised
SNA	Support Needs Assessment
STI	Sexually Transmitted Infection

# Summary

## Introduction and Background

People with a disability should have the same human rights as everyone else, including the right to express their sexuality and to form and maintain relationships. Adults with learning disabilities are under-represented at the Sandyford sexual health service. NHSGGC therefore wished to explore current staff practice and identify areas of improvement. Traci Leven Research was commissioned to undertake a needs assessment, engaging with staff across the NHSGGC area who work directly with adults with learning disabilities to assess their levels of knowledge and confidence in discussing and responding to sexuality, sexual health and relationships for adults with learning disabilities, and seek the views of staff on how best to improve service delivery on this topic.

## Method

A total of 62 staff members engaged in the research across health, social work and third sector providers, covering each of the six HSCPs in the NHSGGC area. Engagement was via one-to-one interviews (via telephone and video) and video group discussions.

## Current Practice

Across all sectors and all areas, there was recognition that work around sexual health and relationships is nearly always reactive rather than proactive – i.e. providing support or an intervention when an adult with a learning disability was either displaying inappropriate sexualised behaviour or finding themselves in risky or vulnerable situations.

Staff within all settings spoke about initial assessment protocols to identify clients' needs and to set goals:

- **Health Assessments** - Across HSCPs, standard practice is that anyone referred to the nursing LD team will receive a nursing assessment which includes a section on relationships and sexual health. However, a large proportion of adults with learning disabilities will never be referred to the health team.
- **Social Work Assessments** - Across social work teams in the HSCPs, there was recognition that assessment tools do not explore needs relating to sexual health and relationships.
- **Transition** - Across each of the HSCPs, staff said that levels of knowledge and awareness or needs around sexual health and relationship were not routinely explored at the stage of transition from children's to adult services.
- **Day Centre and Third Sector Care Provider Assessments** - Staff in day centres and third sector care providers also spoke about carrying out initial interview assessments with users to establish needs and to set goals. The issue of relationships and sexual health was not a standard part of these assessments, and goals relating to relationships were rarely, if ever, a feature.

With the exception of East Renfrewshire, who have focussed on delivering person-centred individual support, all HSCPs indicated they had historically run group courses for adults with learning disabilities on sexual health and relationships. Most of these had been nurse-led. Some areas had developed new courses and were delivering them (or about to deliver them) when the pandemic forced group work to cease. All areas also provided one-to-one support as required, tailoring interventions to the needs of individuals. Day centre staff, third sector

care providers, service officers and healthcare assistants spoke about 'low level' support which was delivered more organically as part of their routine work and day-to-day support for adults with learning disabilities.

Historically, Sandyford offered a sexual health service specifically for adults with learning disabilities called the *Feeling Good* service. This had been highly valued by HSCP staff supporting adults with learning disabilities, and many expressed regret at the cessation of the service. Currently, there is a small Sandyford Inclusion Team which includes a specialist sexual health nurse and a consultant gynaecologist. The team is dedicated to supporting users of Sandyford services who have vulnerabilities, including adults with learning disabilities. Most referrals to the Inclusion Team come internally from clinicians within Sandyford. However, there is a separate telephone line for the Inclusion Team which is open to external referrals from, for example, community LD nurses, social workers etc. However, none of the staff consulted as part of the needs assessment were aware of the Inclusion Team.

Dates N Mates is a third sector national organisation providing opportunities for adults with learning disabilities to meet up in organised social events and meet other people, giving them opportunities to establish friendships and/or romantic relationships. Adults with learning disabilities can join the organisation as members in order to access these opportunities. In addition, they have recently developed a relationships and sexual health course to deliver to their members. There were many staff across the HSCPs who had only a vague awareness of Dates N Mates without knowing what they offered, or who had no knowledge of Dates N Mates at all. There may additionally be other independent third sector organisation who provide opportunities for adults with learning disabilities to meet one another socially and form relationships.

## Barriers and Facilitators to Providing Support and Advice around Relationships and Sexual Health

The identified barriers to providing a support and advice around relationships and sexual health are:

- **Parents/families** - It was said that parents often tend to infantilise their adult children with learning disabilities, conflating their intellectual developmental age with their level of sexual maturity, and not recognising that their child may have sexual desires or wish to pursue personal relationships. Parents/families could be reluctant for staff to discuss issues around sexual health and relationships with their adult child through a desire to 'keep them safe' and avoid them entering relationships.
- **Levels of knowledge and confidence among staff** - Many staff members felt that they did not have the knowledge or confidence to address issues around sexual health and relationships, thus leading to them avoiding the subject or feeling that they could not adequately provide effective support.
- **Fears of staff** - There was a fear for some staff (particularly those who provided day-to-day support and care) that initiating conversations on this topic could lead to safeguarding questions being raised or investigations about their conduct.
- **Lack of appropriate resources** - Overall, standard resources available for working with adults on learning disabilities on the topic of relationships/sexual health were felt to be inadequate, not meeting communication needs and not up-to-date.

- **Lack of referrals** – Lack of referrals from social work to health teams was a reason why some areas had ceased offering group support, particularly in areas where social work and health worked more independently.
- **Lack of venues** - In North East Glasgow, a lack of available venues for providing group support was a practical barrier to delivering such a service.
- **Attitudes of other Health and Social Care Colleagues** - It was recognised that some staff may be prone to de-sexualise adults with learning disabilities, trivialise issues around relationships, or try to suppress sexual behaviour. Some pointed to misconceptions that adults with learning disabilities will not be sexually active.

The identified facilitators to providing a support and advice around relationships and sexual health are:

- **Staff with interest in sexual health/relationships** – Staff with a particular interest in, and passion for, providing support around relationships and sexual health are instrumental in developing resources, delivering courses, and generally ensuring that sexual health and relationships are on the agenda within their team.
- **Development of bespoke resources** - Several HSPCs have produced bespoke resources for providing group sessions on sexual health and relationships. These are a facilitator to providing support and also raise the visibility of available support.
- **Training** – Where staff have been trained to provide support around sexual health and relationships, this has led to increased knowledge and confidence and a readiness to address relevant issues when they arose.
- **'Asking the right questions' and the relationship between health and social work teams** - Staff in the areas where referrals from social work to health (for sexual health/relationship support) were high attributed this to 'asking the right questions' in order to identify needs. Also, a key facilitator was felt to be where health and social work were co-located and integrated.
- **Gender of staff** - A facilitator to having discussions on these issues in a natural way, is where staff have a relationship of trust with a client of the same gender. Many staff pointed to the low numbers of male staff, but having male staff could be advantageous for delivering sexual health and relationship interventions to men.
- **Staff Viewed as external experts** - Although the value of a long-standing relationship of trust between service user and carer/professional was recognised, staff in day centres and service providers recognised that there was also value in health staff coming in to deliver interventions on sexual health and relationships – health staff being viewed as 'experts'.

## Knowledge and Confidence

Many staff across all sectors reporting feeling ill-equipped to provide support, information and advice around sexual health and relationships. Few staff had received any training specifically for supporting sexual health and relationships, with most saying they relied only on common sense and their own life experiences when supporting adults with learning disabilities. There were, however, some staff who had received training to deliver support around relationships and sexual health, most commonly in preparation for delivering group courses. Where staff had been trained with a view to delivering group courses, they found training also benefited them in their more routine interactions with service users or providing one-to-one support around sexual health and relationships.

## Resources

Staff mentioned a number of standard resources being used within HSCPs when supporting relationships and sexual health with adults with learning disabilities: *The Big Question*, *SSKAAT-R*, *Sex & The 3 Rs*, and *Ready, Willing and Able*. Overall, most staff feel existing resources are often not suitable for the communication/comprehension needs of adults with learning disabilities and are somewhat out of date, particularly relating to staying safe online and regarding LGBT+ identities.

Several HSCPs have developed their own bespoke resources or made significant adaptations to existing resources to accompany group courses. These bespoke/adapted resources are also available to staff to use for one-to-one support with service users. The available bespoke/adapted resources are:

- The updated course developed in Glasgow South (originally based on *Ready, Willing and Able* but updated and now incorporating some materials from *Sex and The 3Rs* and other bespoke materials).
- Glasgow North West social work team retain the resources acquired to deliver group work a number of years ago, including useful models and tactile materials.
- Resources to accompany the 12 week bespoke sexual course for women in Renfrewshire which used *Sex and The 3Rs* as the basis for development: a 150 page flexible, modular resource (largely visuals) was produced.
- The bespoke resources for a 13-week course in Inverclyde, including a workbook.
- The resources for the course developed in West Dunbartonshire (not yet delivered), which may be similar to, some of the Glasgow South materials.
- The resources for the course developed by Dates N Mates.

A number of staff members, particularly Community LD Nurses, have frequently resorted to making their own resources to support individual clients. BoardMaker was the most frequently mentioned tool for developing bespoke resources.

## Examples of Good Practice

Examples of good practice identified are:

1. **Inverclyde Resources and Courses:** Key health staff developed a workbook and 13-week course to deliver support to adults with learning disabilities. Staff received training to deliver the course. Prior to the pandemic, the team were delivering the course three times per year. The workbook, completed over the course, is available to participants at the end. The course is interactive in nature. Both the course and the workbook have been designed to be used flexibly.
2. **Renfrewshire Resources and Courses:** A Community LD Nurse and a Speech and Language Therapist in Renfrewshire together developed resources and a 12-week sexual health course for women with learning disabilities. *Sex and The 3 Rs* was used as the base for developing bespoke resources to support the course. The speech and language therapist ensured the course met the communication and comprehension needs of women with learning disabilities, adding colour to the resources and making them more accessible. Additions were further exploration of relationships, aspects of physical health and mental health, and staying safe online. All sessions in the group course were reinforced through resources for the participants to take away. The resource developed was a 150-page book, mostly visuals.

3. **East Renfrewshire approach to identifying and addressing needs:** The social worker from East Renfrewshire who contributed to the research said that in assessments/reviews she would always explore client's needs and expectations around sexual health and relationships, refer to health colleagues for an intervention to ensure that the client had appropriate information and support around navigating relationships, and link with external organisations to facilitate a client exploring opportunities to form relationships.
4. **Dates N Mates – Service and sexual health and relationships course:** Dates N Mates is a third sector national service in Scotland providing social opportunities for people with learning disabilities to meet to create friendships and relationships. All staff at Dates N Mates have recently received training to support relationships and sexual health and a subgroup of staff have subsequently developed their own course to deliver sexual health and relationship education/support to their members. The training, and the course subsequently developed, covered topics such as boundaries, consent, public and private spaces, sexual health and wellbeing, contraception and STIs. The course and associated materials have been developed in-house specifically for the needs and circumstances of adults with learning disabilities

### **Staff's Views on Needs**

Staff frequently expressed shock at the lack of understanding and awareness around sexual health and relationships among the adults they worked with which they felt should have been worked on more at an earlier stage. It is recognised, however, that provision in children's/education services is not in the scope of this needs assessment.

The two key needs identified through the consultations for staff across all sectors were:

- Better resources for delivering interventions or information about sexual health and relationships for adults with learning disabilities
- Training for staff to raise awareness and understanding of the relevant issues and to build confidence and skills to have discussions around sexual health and relationships and to identify and address needs. There was an appetite for training among all staff consulted.

Across all staff groups, it was health staff who were most commonly identified as being best placed to lead interventions on sexual health and relationships. Some social workers were also keen to take a lead role in developing and delivering interventions. Other staff groups were also keen to be involved by way of supporting and re-enforcing the messages. Staff in third sector care providers, day centres and other social work staff also felt that they were well placed to identify service users who could benefit from courses or other interventions on relationships and sexual health. There was an appetite among staff working directly on a day-to-day basis with adults with learning disabilities to have training to provide 'low-level' support and everyday conversations around sexual health and relationships. In day centres and third sector providers whose staff structures have 'champions' or 'ambassadors' for particular topics, it was felt that having champions/ambassadors for sexual health and relationships would be appropriate and feasible.

Some health staff advocated having more focus in nursing assessments on sexual health and relationships. Many social work staff and day centre staff saw scope for routinely including sexual health and relationship needs and goals during assessments and care and support planning. Transition from children's to adult services was a point at which many staff felt there was scope to include assessment of needs around sexual health and relationships,

including an assessment of levels of knowledge and awareness and identifying where education/interventions are required.

## Recommendations

### 1. Develop resources

A clear message from the research is the need to develop new resources on relationships and sexual health which better meet the communication and comprehension needs of adults with learning disabilities and which provide up-to-date relevant information. Specific recommendations are:

- The starting point for developing new resources should be a review of existing resources developed in the HSCPs.
- The content should also include appropriate and up-to-date information around online conduct/internet safety, and LGBT+ issues.
- The resources should be modular and be able to be used flexibly.
- Speech and language specialists should be key partners in developing the resources.
- Use similar language/terms or images from resources used in education.
- Parents/families/carers and service users should be involved in reviewing resources or directly contributing to their development.
- Resources should be available and accessible to all staff throughout all HSCPs.
- Consideration should be made regarding licensing and copyright issues.
- Review and revise resources at appropriate intervals.

### 2. Develop and Deliver Group Courses

It is recommended that courses are developed alongside the resources. Recommendations for the development and delivery of the course are:

- Interactive group activities should be used to engage participants, including tactile props (e.g. of bodies/body parts, etc).
- Where possible, the composition of participants within groups should ensure that participants have similar levels of disabilities, needs and experiences.  
Groups may most likely be run by community LD nurses, but could also involve social workers or other key, trained staff – but they would benefit from involvement from those having more routine day-to-day involvement (care providers; day centre staff) who can support learning and reinforce messages.
- Groups may be delivered in settings such as day centres, residential settings etc where those using the services can be invited to participate; other groups could be run in community/health facilities as appropriate.
- Consideration should be given to running groups centrally (e.g. at Sandyford), perhaps staffed with community nurses from across the HSCPs on a rotational basis.

### 3. Develop and Deliver Staff Training

The development new resources and courses would have to be supported by staff training. The needs assessment findings suggest that an appropriate model would be to have training and staff roles at two different levels:

1. Broad training for staff across all sectors (including health, social work, day services, care providers, etc) to be trained to:

- Have an awareness and appreciation the rights of adults with learning disabilities to express their sexuality and form and maintain relationships;
  - Have conversations with the people they support about sexual health and relationships, ensuring that this aspect of their wellbeing is not overlooked as part of their care;
  - Provide routine advice and information as required on the topic (with use of some of the resources as appropriate);
  - Identify and refer service users who would benefit from a group or one-to-one intervention from specialist ('level 2' trained) staff.
2. Training for staff with a particular interest in supporting relationships and sexual health. At this level, staff would be trained to:
- Deliver interventions to adults with learning disabilities through group courses and one-to-one work, using the new resources and courses developed and available throughout the NHSGGC area;
  - Become 'champions' for relationships/sexual health, supporting other staff members to provide day-to-day support on the topic, promoting the available resources, groups etc, and potentially delivering the 'level 1' training to staff through a cascade training model.

#### 4. Incorporate Relationships and Sexual Health into Assessments and Care Planning (and acting on identified needs)

It is recommended that, where possible, relationships and sexual health become more routinely part of assessments and care planning and embedded into the required forms etc. These interviews should identify current needs regarding sexual health and relationship support and/or future aspirations. Where, for example, assessments identify an interest in pursuing personal relationships or set a goal of having a boyfriend/girlfriend, this can be followed up as appropriate by staff:

- assessing levels of awareness and understanding around relationships and sexual health;
- delivering or referring to specialist staff for interventions where required (in groups or one-to-one) with the aim of providing service users with the information and skills to pursue and navigate relationships safely and appropriately;
- advising on opportunities to facilitate meeting other people with a view to forming relationships.

#### 5. Involving Parents, Families, Carers

Recommendations are:

- Involve parents/families/carers in the development of new resources and courses on sexual health and relationships.
- Widen reach of the 'level 1' training to parents/families/carers where appropriate.
- Encourage staff to talk to parents/families/carers about the reasons for providing this type of information and support, and seek co-operation.
- As part of the resources developed, have information leaflets specifically for parents/families/carers.

## 6. Awareness Raising and Partnership Working Across Staff Groups

The recommendation is:

- Ensure appropriate means of sharing available support, resources, referral routes etc with staff working with adults with learning disabilities throughout the NHSGGC area.

## 7. Publicise Sandyford Inclusion Service

The recommendation is:

- Provide information about Sandyford services and how and when to make referrals to the Inclusion Team within the training to staff.

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# 1. Introduction

## Introduction

This document presents the findings from a needs assessment with staff supporting relationships and sexual health with adults with learning disabilities across the NHS Greater Glasgow & Clyde (NHSGGC) area. The research was overseen by a steering group led by Jo Zinger, Health Improvement Lead – Sexual Health, Adult and Communication, Sandyford. The steering group comprised representatives from each of the six Health and Social Care Partnerships (HSCPs) including staff working in both health and social work. The research was undertaken by Traci Leven Research, with Traci Leven as the lead researcher (and author of this report), and assisted by Bobby Jones who conducted some of the research interviews. A total of 62 staff who worked with adults with learning disabilities contributed to the research.

## Background

Across Scotland there are 23,584 adults with learning disabilities known to local authorities<sup>1</sup>. Key statistics from Learning Disability Statistics Scotland show that of those adults with a learning disability:

- 62% lived in mainstream accommodation
- 15% lived in supported accommodation
- 31% lived with a family carer (with 78% of these living with a parent carer).

Across Scotland, the number of adults with a learning disability per 1,000 population is 5.2, although there is considerable regional variation. In the six Health and Social Care partnership (HSCP) areas in Greater Glasgow and Clyde, the rates per 1,000 adult population are:

- Inverclyde – 7.6
- West Dunbartonshire – 6.2
- East Renfrewshire – 5.7
- Renfrewshire – 5.6
- East Dunbartonshire – 5.3
- Glasgow City – 4.1

People with a disability should have the same human rights as everyone else<sup>2</sup>. Adults with a learning disability have human rights to express their sexuality and to form and maintain relationships.

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<sup>1</sup> <https://www.sclد.org.uk/wp-content/uploads/2019/12/Learning-Disability-Statistics-Scotland-2019.pdf>

<sup>2</sup> <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

A health needs assessment of people with learning disabilities in Scotland in 2017<sup>3</sup> found that adults with learning disabilities can face barriers to expressing their sexuality or accessing education and support. Adults with learning disabilities may find that they are assumed to be asexual by society and/or by their caregivers and they may therefore not be offered the required education, information or support to make appropriate choices about forming and maintaining relationships and/or sexual activity. There is evidence that adults with learning disabilities are at increased risk of gender-based violence and abuse.<sup>4</sup>

A literature review and primary research conducted in 2019 for NHSGGC and NHS Lothian for the health needs assessment of LGBT+ people<sup>5</sup> highlighted that LGBT+ identities may be more likely among those with learning disabilities (particularly those on the Autistic Spectrum), but that it was difficult for many to be out about their identity, to connect to the LGBT+ community or to receive an appropriate diagnosis of gender dysphoria which could be conflated with autistic traits.

Adults with learning disabilities are under-represented at the Sandyford sexual health service, and that recent changes to structure and integration of services may have impacted levels of joint working. NHSGGC therefore wished to explore current staff practice and identify areas of improvement.

## The Needs Assessment

The stated aim of the project was to undertake an engagement process with staff across the NHSGGC area that work directly with adults with learning disabilities to assess their levels of knowledge and confidence in discussing and responding to sexuality, sexual health and relationships for adults with learning disabilities, and seek the views of staff on how best to improve service delivery on this topic.

The objectives were:

- Across the six health and social care partnership areas (HSCPs), establish the level of current practice staff working directly with adults with learning disabilities provide around relationships and sexual health, with a description of the barriers and facilitators to this topic.
- Define and describe the levels of knowledge and confidence, of those who work directly with adults with learning disabilities and seek the views of staff on how best to maintain or improve these competencies.
- Describe examples of good practice that may exist that could be shared across the health and social care system.
- Define and describe across the six HSCPs, if staff working directly with adults with learning disabilities use any resources to support learning on relationships and sexual health. Staff opinion is sought on the suitability of any resources and of any resource gaps.

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<sup>3</sup> <https://acppld.csp.org.uk/system/files/people-with-learning-disabilities-in-scotland.pdf>

<sup>4</sup> <http://www.healthscotland.scot/media/2846/gender-based-violence-and-learning-disability.pdf>

<sup>5</sup> <https://www.stor.scot.nhs.uk/handle/11289/580258>

- Seek the views of staff on how best to improve sexual health service delivery for adults with learning disabilities.
- Identify gaps and recommend opportunities, to develop good practice for responding to sexuality, sexual health and relationships for adults with learning disabilities.

## Method

### Topic Guide Development

A topic guide was developed by the lead researcher and approved by the steering group lead. The topic guide sought to ensure that each interview/group discussion with staff addressed each of the project objectives (see above). The topic guide can be found in the appendix.

### Recruitment of Staff

The project aimed to engage staff working across each of the six HSPCs who provided support directly to adults with learning disabilities. This included staff working in social work, health and third sector care providers. An online form was developed via Limesurvey for staff to express an interest in participating in the needs assessment. The form asked for:

- Name
- Sector (health, social work, third sector, other)
- Name of organisation
- Geographical area/areas work in
- Contact details (email/phone)
- Contact preferences
- Work patterns/availability
- Participation preferences (phone interview/video interview/video group discussion/other)
- Optionally – open ended question on comments on supporting adults with learning disabilities with relationships and sexual health, and 2 questions on how much information/knowledge they have on the topic, and how confident they feel in supporting clients on the topic.

Steering group members from the HSCPs ensured that the link to the form and information about the research was disseminated to staff in relevant teams and organisations. This was augmented by the researcher attending some online team meetings to further introduce the research and invite participation. An online flier was also posted on Twitter with links to the online form, and this was shared by the researcher as well as some of the HSCPs.

Those who completed the online form or made contact directly with the researcher were invited to take part in a one-to-one interview or group discussion. Some further staff were subsequently recruited to group discussions by staff who had initiated contact.

### Numbers of Staff Contributing

A total of 62 staff members participated in the research during July and August 2021. The breakdown by HSCP and sector is shown in the following table.

HSCP	Health	Social Work	Third Sector Providers	Total
Glasgow	10	10	2	22
East Dunbartonshire	1	1	0	2
West Dunbartonshire	4	3	1	8
Renfrewshire	4	7	0	11
East Renfrewshire	6	1	0	7
Inverclyde	3	0	0	3
Wider area across NHSGGC	1	0	8	9
<b>Total</b>	29	22	11	62

Within Health, most contributors were Community Learning Disability Nurses, but there were also speech and language therapists, physiotherapists and healthcare assistants who participated.

Within Social Work, most were social workers who managed cases, but some worked in day centres or as service officers in community services.

The consultations comprised 20 one-to-one interviews and 12 groups.

**Group Conduct, Analysis and Presentation of Findings**

The topic guide (see appendix) was used to ensure that all relevant topics were explored in the course of the discussion, but conversations were allowed to flow naturally and participants could raise and discuss other pertinent issues around the broad topics.

With consent, all interviews and group discussions were digitally recorded and transcribed. The qualitative data from transcripts were then sorted thematically – the needs assessment objectives (see above), forming the top-level themes, with sub-themes emerging, noting areas of commonality and difference between and across HSPCs and sectors.

The subsequent chapters of this report present the findings by theme/objective:

- Chapter 2: Current practice
- Chapter 3: Barriers and facilitators
- Chapter 4: Knowledge and Confidence
- Chapter 5: Resources
- Chapter 6: Examples of Good Practice
- Chapter 7: Staff’s Views on Needs

The discussion on findings and recommendations are presented in Chapter 8.

**Validation**

An earlier draft of this report was shared with the project steering group and with a wider group of research participants from across the NHSGGC area from health, social work and third sector providers. An online validation event was held in September 2021 at which these participants had the opportunity to discuss and comment on the findings and

recommendations presented. This ensured that the descriptions of current practice are accurate and that the recommendations are appropriate and actionable. Following the validation event, some minor changes were made before finalising this report.

## 2. Current Practice<sup>6</sup>

### Reactive, Not Proactive, Interventions

Across all sectors and all areas, there was recognition that work around sexual health and relationships is nearly always reactive rather than proactive – i.e. providing support or an intervention when an adult with a learning disability was either displaying inappropriate sexualised behaviour or finding themselves in risky or vulnerable situations. Within social work, staff said that often clients were identified as having needs when they were alerted through the police or it became an Adult Support and Protection issue.

*"My feeling is discussions on sexual health and relationships are not happening at all unless it's a crisis or it's been sexually inappropriate behaviour, or they've done something inappropriate and it's coming in through the Police or ASP. But I don't think anyone is having routine conversations about what are people's sexual needs. Where are they getting their advice and guidance from? So it's almost like it's not on people's radar".*

Social Work Services Manager

*"Situations have happened where we've got to a crisis point – for example someone had a partner who was a gentleman without a learning disability, and he was taking photos of her and putting them online – it's when it gets to a crisis point and you realise...that wasn't a relationship, that man has abused her".*

Service officer (social work)

Social workers, day centre staff and third sector care providers all provided examples of working with service users to provide support when crises occurred or issues arose around sexual health/relationships. However, the most common practice appears to be making referrals to the community LD health team. In East Dunbartonshire, Renfrewshire, Inverclyde, West Dunbartonshire and East Renfrewshire, the community LD team is an integrated and co-located service with social work and health working together. In these areas, referrals to the team would be examined and cases would be distributed based on individual need – with community LD nurses usually being allocated to referrals for sexual health and relationship support. In Glasgow, social work and health teams across two of the localities (South and North West) are not co-located. While social work staff can make referrals to the health team, there appears to be more variation in the extent to which referrals are made by social work for issues around sexual health and relationships.

A common issue reported by staff across all sectors in all HSCPs was the risks posed by adults with learning disabilities using social media and the internet, including online dating sites and in particular sharing images of themselves without an understanding of the risks and how to conduct themselves appropriately online. While this has been a continually growing issue, this has been accelerated by lockdown during which many service users have been online

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<sup>6</sup> The unusual nature of service delivery during 2020 and 2021 means that much of the descriptions of 'current' practice relate to practices prior to the Covid pandemic.

much more or have been using technology for the first time – many services themselves moved online and some issued tablets to facilitate this.

Possibly the most frequent issue which staff were asked to address was masturbation. Often health or social work staff were alerted by families or care providers to service users masturbating in inappropriate places. Some health staff pointed to referrals to their team for this issue sometimes being unnecessary and could perhaps often be addressed by care providers if they had some training or improved confidence in how to talk about this. Health staff and social work staff often did one-to-one work to educate service users on public and private places.

Although a number of HSCPs had developed and delivered group courses on sexual health and relationships (see below), those recruited to the groups were those for whom referrals had been made due to issues/problems arising around sexual health and relationships, rather than providing general information/education with a more pro-active intention.

Although staff generally acknowledged that current practice is reactive rather than proactive, there was an appetite among many members of staff to develop more proactive practices around sexual health and relationships and several were already considering how to do this.

## Assessments, Care Planning and Goal Setting

Staff within all settings spoke about initial assessment protocols to identify clients' needs and to set goals.

### Health Assessments

Across HSCPs, standard practice is that anyone referred to the nursing LD team will receive a nursing assessment. Regardless of whether the nature of the referral was related to relationships or sexual health, the nursing assessment will include a section on needs in this area. Thus, the health assessment affords an opportunity to identify needs relating to sexual health and relationships which can be followed up as appropriate by the health team. However, it is recognised that a large proportion of adults with learning disabilities will never be referred to the health team, and needs picked up opportunely during health assessments will be missed if referrals are not made for other reasons.

Although nursing staff in all HSCPs said that there was a sexual health section included in all nursing assessments, there was some variation in the attention paid to this – some nurses said that this was a critical section and any needs identified would be followed-up, while others said that the section was not adequate for exploring all needs (particularly around relationships) and that it was often overlooked or not given adequate importance:

*"On our nursing assessment there is a women's health/men's health section on it – like are you sexually active, have you ever had STD screens, things like that – but there's nothing about relationships. I would say that a lot of people, I think don't follow it up a lot – everything else takes priority over that – it takes a back seat".*

Community LD Nurse

### Social Work Assessments

Across social work teams in the HSCPs, there was recognition that assessment tools do not explore needs relating to sexual health and relationships.

*"When you're going to assess people, more than likely you've just picked them up, you're just getting to know them. With SNAs, there's a relationship section in that, but it's not something generally we'll refer to – see sexual relationships, that's not something you would naturally think about when you're doing a needs assessment, it's more kind of family relationships or friends. I don't know what my colleagues would say about that, but certainly when I've been doing SNAs, I've never really thought about sexual relationships as part of it".*

Social worker

*"When we do assessments we talk about mental health, physical health, we don't specifically talk about relationships and sexual health, I think because it's taboo in a lot of ways, and also you're not sure what people know or understand. We talk about relationships in general – like personal relationships, friendships that type of thing. To be fair, I haven't raised the 'do you have a boyfriend/girlfriend' type of thing. Sometimes people might tell me that that's what they want as part of that assessment. But I hadn't thought about it until you asked: I should be asking about that. It's just not something I've included".*

Social worker

Nonetheless, a number of social workers felt that although it was not formally part of the paperwork associated with assessments, there could often be opportunities for clients to talk about relationships if it was relevant to them or they felt it was important to share that information.

### **Transition**

A common theme across many of the consultations with staff was concern that people with learning disabilities were generally leaving children's services without appropriate levels of knowledge and awareness of sexual health and relationships, and the perception was that sexual health and relationship education was not adequate in special needs schools and children's services. However, across each of the HSCPs, staff said that levels of knowledge and awareness or needs around sexual health and relationship were not routinely explored at the stage of transition to adult services. Such issues would only be raised at transition if there had been concerns about, for example, inappropriate sexualised behaviour during their engagement with children's services.

### **Day Centre and Third Sector Care Provider Assessments**

Staff in day centres and third sector care providers also spoke about carrying out initial interview assessments with users to establish needs and to set goals. Again, the issue of relationships and sexual health was not a standard part of these assessments, and goals relating to relationships were rarely, if ever, a feature. However, there were sometimes opportunities to discuss these issues at assessments if the service user raised them:

*"I did a garden visit the other week for a young lady coming into our service on transition, and the first thing she told me was 'my boyfriend's coming here and we hold hands at lunch time'. So it's obviously important for her to tell me that, but it's not on any of my paperwork! I didn't ask the question, but she found it important for me to know".*

Day centre staff

## Development and Delivery of Sexual Health and Relationship Courses

East Renfrewshire has focused on delivering person-centred individual support to address needs around sexual health and relationship support and has not offered any group work.

Each of the other HSCPs have developed and delivered courses to groups of adults with learning disabilities. These are summarised below, but two are highlighted in more detail in Chapter 6 (examples of good practice).

- **North West Glasgow:** Historically, group courses on sexual health and relationships had been offered through the social work team. This was developed following staff training and in-house development of a course and collation of appropriate resources. Following restructure a few years ago, the remit for delivering sexual health/relationships interventions was moved to the health team, who with social work involvement, had been delivering courses pre-pandemic.
- **North East Glasgow:** The health team in the North East received training and, finding the *Ready, Willing and Able* resource inadequate, developed their own resources to deliver a course. (They described this as 'scrambling together' a course). Only one course has run due to lack of interest and difficulties securing a venue.
- **South Glasgow:** In South Glasgow, the *Ready, Willing & Able* resource had been used to develop and run a 12-week programme which was delivered to groups of adults with learning disabilities. This was subsequently improved and updated to make the resources more appropriate for adults with learning disabilities, include more contemporary information (e.g. around internet safety), and shortened to an eight week course. Some resources/images from *Sex and the 3Rs* were included in the revised course resources. However, since redevelopment, low numbers of referrals has meant the new course has not been run and the new version remains untested.
- **East Dunbartonshire:** East Dunbartonshire have historically run group courses, led by community LD nurses, adapted to the needs of adults with learning disabilities from a standard (mainstream) course over six to ten weeks. As group-work begins to be offered again post-pandemic, sexual health and relationships has not presently been identified as a topic for group work due to a lack of referrals or demand for such interventions; other topics are taking a priority as demand dictates (e.g. weight clinic, blood clinic). Current practice on relationships/sexual health is focused on delivering one-to-one support where required.
- **Inverclyde:** A bespoke 13-week course was developed in Inverclyde around 5/6 years ago and (pre-pandemic) has run three times per year – see Chapter 6.
- **Renfrewshire:** A bespoke 12-week course for women was developed and run in Renfrewshire, the first group being curtailed by the pandemic – see Chapter 6. A men's group (with a wider remit than sexual health/relationships, but which explored this topic) was also run by a male nurse within a local day centre.
- **West Dunbartonshire:** Health staff in West Dunbartonshire developed their own course which was based on the course offered in South Glasgow. The course was ready and about to run in 2020 when the pandemic forced it to be cancelled.

Due to low numbers of referrals to the health teams in Glasgow on the topic of sexual health and relationships, there was an attempt to seek referrals from across Glasgow to a group run by staff in the South but this has not yielded a group.

In addition, Dates N Mates, a third sector organisation has recently received staff training and developed their own relationships and sexual health course for adults with learning disabilities who use their service (see chapter 6).

There were also a few examples of service providers and day centres who had historically provided some group information/ support in day care settings which focussed on, or included, sexual health and relationships. These had been led by service staff, but some had input from health staff. In East Dunbartonshire, a social worker mentioned a local-authority run group in a community centre for adults with learning disabilities which runs regular information programmes including topics around sexual health and relationships such as personal space and consent. In one of the day centres in West Dunbartonshire, male staff, pre-pandemic, had run a men's group incorporating 'The Traffic Life Game'<sup>7</sup> exploring relationships, and this had been well received. However, changes to operational models meant that they would no longer be providing support in groups in this way.

## Individual Support

Referrals are made for interventions around sexual health and relationships to community LD health teams in each of the HSCPs from day services, service providers, social work, families, GPs and others. Usually interventions involve one-to-one support from a community LD nurse, in some cases assisted with speech and language services. In the areas which have developed courses and resources for group support, often the same resources are used for one-to-one support as required, usually in a modular way rather than delivering a whole course -i.e. choosing the topics most relevant to the individual. Most staff providing individual support ensure a person-centred approach, often adapting resources or creating bespoke resources specifically for the client depending on both the particular topics in which they need support and their own communication and comprehension needs. Several staff spoke about using Talking Mats as a tool to explore relevant topics.

Day centre staff, third sector care providers, service officers and healthcare assistants spoke about 'low level' support which was delivered more organically as part of their routine work and day-to-day support for adults with learning disabilities. It appears that many staff who had day-to-day contact with adults with learning disabilities are reluctant to initiate conversations on the topic of relationships/sexual health (see Chapter 3 – barriers), but there were many examples of staff providing advice when situations or conversations arose in the course of their work.

## Sandyford Services

Historically, Sandyford services, both centrally at their main service in Glasgow and at local clinics throughout the NHSGGC area, offered a sexual health service specifically for adults with learning disabilities called the *Feeling Good* service. This had been highly valued by HSCP staff supporting adults with learning disabilities, and many expressed regret at the cessation of the service.

Currently, there is a small Sandyford Inclusion Team which includes a specialist sexual health nurse and a consultant gynaecologist. The team is dedicated to supporting users of Sandyford services who have vulnerabilities, including adults with learning disabilities (also adults with mental health conditions, involved in prostitution, victims of gender based violence etc.). The

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<sup>7</sup> <https://www.trafficlifegame.com/>

Inclusion Team will consider and recommend adaptations to the service depending on the needs of the patient which, for someone with a learning disability may include:

- Putting a discrete alert on the system to alert clinicians to communication needs
- Fast-tracking appointments where required (e.g. if there is a need for contraception but the learning disability impacts on their ability to reliably use condoms until a standard appointment is available)
- Ensuring a support worker attends with the patient where this was required
- Where required, communicating with support workers about follow-up appointments
- Ascertain the best ways of communicating results of tests, exploring whether a support worker should be involved in sharing results
- Providing longer appointment times to accommodate additional needs
- Contacting the community LD nursing team to ask for follow-up support if required.

Most referrals to the Inclusion Team come internally from clinicians within Sandyford – so an adult with a learning disability would have to attend first before being flagged as requiring support from the inclusion team. However, there is a separate telephone line for the Inclusion Team which is open to external referrals from, for example, community LD nurses, social workers etc. It is notable though, that none of the staff consulted as part of the needs assessment were aware of the Inclusion Team or that they were able to make direct referrals to it.

Few of the health or social work staff consulted tended to make referrals to the Sandyford service. Rather, if a need for services such as contraception or STI screening was required, it is more common for staff to recommend attending the Sandyford service, often asking support workers/service providers to make the arrangements. However, some health staff had made direct referrals and generally they were pleased with the level of service and the appropriateness of the appointments in dealing with communication or other support needs for adults with learning disabilities. There were also support staff who said they had accompanied service users to Sandyford appointments and again views were positive. There were, however, a few concerns raised by staff regarding Sandyford services, as discussed below.

Community nurses in Inverclyde had supported some clients to attend the Sandyford service and found that the preparatory work and role of the community LD nurse was not recognised by the Sandyford services:

*"With contraception, we would do the sex education part and then support to the Sandyford, but then you find that the Sandyford nurses have got to do their questions, but we've already done that to get to this point. They (the client) have chosen their method of contraception and we've done all the work with them and then at the Sandyford they get a wee bit confused because they're asked the same questions but in a different way. They ask about relationships and have they been tested for HIV and so on, and it's quite a lot of information. Some go alone to those appointments and some don't, it just depends. This year I've supported three appointments for a change of the (contraceptive) implants. There's a big delay for that. When we go with a client to an appointment, a lot of people assume we're carers rather than nurses. Quite a lot of folk don't know what a learning disability nurse is- they think we're carers and don't realise we've done the work already. It would be good if people knew, whatever the service, that we've*

*done the work to get the client there and they're ready to get whatever service it is that they're there for".*

Community LD Nurse

In this instance, the community LD nurses in Inverclyde contrasted this current situation to when the Feeling Good clinics were running and there was a dedicated sexual health nurse to this service with whom a professional relationship could be developed with the community nurses, offering a more seamless service.

There were also a further two LD nurses who felt that communication could be improved in terms of receiving feedback from Sandyford after referrals had been made.

### Dates N Mates and Other Independent Third Sector Organisations

Dates N Mates is a third sector national organisation providing opportunities for adults with learning disabilities to meet up in organised social events and meet other people, giving them opportunities to establish friendships and/or romantic relationships. Adults with learning disabilities have to join the organisation as members in order to access these opportunities. In addition, they have recently developed a relationships and sexual health course to deliver to their members. The services provided by Dates N Mates are described in Chapter 6 (examples of good practice).

There were some staff in various settings who mentioned Dates N Mates. Some said that they had or would recommend Dates N Mates to service users who expressed a desire to explore relationships. These included, for example, service officers in Renfrewshire and one of the Community LD Nurses in South Glasgow, and a social worker in both East Dunbartonshire and East Renfrewshire. One social worker also said they had been asked to provide references for service users who had applied to join Dates N Mates confirming their learning disability and setting out needs. However, there were many more staff who had only a vague awareness of Dates N Mates without knowing what they offered, or who had no knowledge of Dates N Mates at all.

There may additionally be other independent third sector organisation who provide opportunities for adults with learning disabilities to meet one another socially and form relationships. One mentioned in West Dunbartonshire is Golden Friendships – an independent unregulated service tackling isolation and giving opportunities for people to meet at events and form peer relationships.

### Sexual Health and Relationships Specialists within Organisations

In some larger service providers (e.g. CrossReach) and day services (e.g. a day centre in Renfrewshire), a model is used in which staff with a particular interest in certain topics take on the role of 'champions' or 'ambassadors' for the topic (e.g. dementia, older people, mental health, etc), but the needs assessment did not find any day services or service providers who had roles for champions/ambassadors for sexual health and relationships – though there was a view that there would be scope to develop such roles (see Chapter 7).

Another large service provider, Enable, has a different model in which a Practice Development Team (comprising practice development nurses with experience across health and social care roles) receive referrals from staff across the service who have service users needing additional support – this may include support around sexual health and relationships. The practice development team feel well placed to deliver such support, but recognise that such referrals

are dependent on staff recognising the need (which may not always happen), and also feel that wider staff would benefit from training on sexual health and relationships.

Within some learning disability teams, there are some community LD nurses with a particular interest and specialism in sexual health and relationships and these individuals can be key to driving the development of local programmes and ensuring sexual health and relationships is a topic on the radar of wider staff (see Chapter 3 – facilitators).

### 3. Barriers and Facilitators to Providing Support and Advice around Relationships and Sexual Health

#### Barriers

##### **Parents/Families**

In the course of discussions with staff across all sectors, parents/guardians/family carers were identified as one of the most common barriers to providing support and advice around relationships and sexual health. It was said that parents (particularly older parents) often tend to infantilise their adult children with learning disabilities, conflating their intellectual developmental age with their level of sexual maturity, and not recognising that their child may have sexual desires or wish to pursue personal relationships. Parents/families could be reluctant for staff to discuss issues around sexual health and relationships with their adult child through a desire to keep them safe and avoid them entering relationships. However, many staff pointed to the need for adults with learning disability to be given knowledge *in order to* keep them safe because being naïve about sex made them particularly vulnerable to abuse:

*"Sometimes parents of adults with a learning disability are scared for them to have this knowledge – treating them like a child, thinking they're too vulnerable to know this – but actually not knowing makes them **more** vulnerable. It's about kind of working with the parents or guardians to support and explain to them that you'll assess their level of what they need to know, but if someone's got a certain level you wouldn't go beyond that. I've got somebody just now that I'm working with and it's about working with the parent – I'm saying any resources that I use, I'll show you so that you know exactly what I'm doing. Me doing that has allowed them to actually agree for me to do the work I need to do".*

Community LD Nurse

Where adults with a learning disability do not have a legal capacity to consent, staff are unable to undertake any intervention without the permission of the legal guardian (often the parent/family member).

Several staff members from health and social work pointed to families asking them to do some work with their adult children to address masturbation, teaching them about public and private spaces, but often families only wanted that particular issue addressed without any wider input around sexual health and relationships.

Some staff also said that attitudes of parents/families can be reflected in a reluctance among service users themselves to engage in discussions about relationships or sexual health - e.g. if they are 'not allowed' to have a boyfriend/girlfriend, they will not engage with discussions with professionals on this topic.

##### **Levels of Knowledge and Confidence among Staff**

Levels of knowledge and confidence among staff were varied across all sectors and HSCPs, but many felt that they did not have the knowledge or confidence to address issues around

sexual health and relationships, thus leading to them avoiding the subject or feeling that they could not adequately provide effective support. This is discussed further in Chapter 4.

### **Fears of Staff**

Apart from feeling ill-equipped to support service users on sexual health and relationships, there was also a fear for some staff – particularly those who provided day-to-day support and care, that initiating conversations on this topic could lead to safeguarding questions being raised or their being subject to investigations about their conduct:

*"When I've been having these conversations, I think 'Oh, I'm going to get pulled into the office, there's going to be a phone call about me' justifying why you're bringing up subjects, why you're talking about certain things. I think that's why we kind of avoid it unless we have to – you do just skirt round it because you feel vulnerable".*

Service officer, Social Work

### **Lack of Appropriate Resources**

Overall, standard resources available for working with adults on learning disabilities on the topic of relationships/sexual health were felt to be inadequate, not meeting communication needs and not up-to-date. A discussion on resources used across NHSGGC and the views of staff is provided in Chapter 5. However, the lack of appropriate resources can act as a barrier to providing effective interventions.

Those who had run group courses on relationships and sexual health indicated there were difficulties in securing good quality props for use in the groups.

### **Lack of Referrals**

The next section in this chapter on 'facilitators' highlights the value of integrated teams such as Renfrewshire in health teams picking up referrals of social work clients who require input on sexual health/relationships. The converse was seen in areas where health and social work operated somewhat more independently e.g. in Glasgow where, on the whole, there appears to be much less conversation between the health and social work teams. Indeed, in South Glasgow where work was done to revise the resources and course for delivering group support, no groups have been run with the new resource due to a lack of referrals. However, social workers in South Glasgow appear to be unaware that group support is available, and unsure of what the criteria would be to make a referral for an intervention from the health team with regards to sexual health and relationships.

In areas where interventions such as group courses were not being routinely offered (usually due to a 'lack of referrals'), there seemed to be a somewhat circular relationship where referrals were not coming through because social workers, service providers and others were not aware of any available interventions. There was also an awareness that perhaps there was a lack of conversation or discussion around relationships or sexual health which could identify needs and yield referrals.

*"We're not planning to do any groups on sexual health and relationships at the moment. In terms of referrals that come through, since I've been here there isn't a demand for that – but then again, is it because we need to start probing a wee bit more around some of these questions?"*

Community LD Nurse

## **Lack of Venues**

In North East Glasgow, a lack of available venues for providing group support was a very practical barrier to delivering such a service. During the one course which had been offered in the area, the venue had to change part-way through the course, and a new venue for any forthcoming courses has not been identified.

## **Attitudes of other Health and Social Care Colleagues**

Within care settings such as day centres, it was recognised that some staff may be prone to:

- De-sexualise adults with learning disabilities, assuming that they do not have desires or sexual needs;
- Trivialising issues around relationships;
- Not recognising sexualised behaviour or desires as legitimate/trying to suppress sexual behaviour.

*"We have a young man and a young lady who are on-and-off boyfriend and girlfriend, they like to sit and hold hands – but then she can decide she doesn't want to go out with that person and go out with this person and dumps him. It can sound quite insignificant, almost a joke – but the backlash of that for that other man is he can cry, go home miserable – he's got mental health problems. The anxiety – he couldn't understand the reasons, nobody had spoken to him about falling in love and people not wanting to see you any more. Some staff can think 'it's just them two at it again', but I think they need to be aware how serious that is for their emotions, especially when mental health's involved".*

Day centre staff member

*"We have had a few staff who have this attitude..like there is a young man with autism who has a specific fancy to certain ladies (service users). He can have quite sexualized behaviours, and staff are very uncomfortable with that. We've had to say he's a young man - he's 19, he fancies that lady and that's okay as long as he's giving her space, not doing anything he shouldn't be – I think they (staff) want to give him into trouble – but he's allowed to fancy somebody! It's about letting staff know there are certain things that are and aren't okay, and how they approach it, rather than thinking it's this big bad negative thing – oh my goodness you're not allowed to do that – getting that point across that why not? He's 19, that's okay".*

Day centre staff member

Although not mentioned frequently by staff, there were some who pointed to a misconception among wider health staff, including GPs that adults with learning disabilities will not be sexually active and therefore will not require cervical smear tests or HPV injections etc. Community health staff felt that if GPs are advising care providers that these procedures are not required, it undermines their efforts to ensure patients had access to appropriate care.

## Facilitators

### **Staff with Interest in Sexual Health/Relationships**

There are certain staff members in health and social work teams who have a particular interest in, and passion for, providing support around relationships and sexual health. Such staff are instrumental in developing bespoke resources, developing and delivering courses, and generally ensuring that sexual health and relationships are on the agenda within their team. Some community LD teams (e.g. Inverclyde and Renfrewshire) include a particularly enthusiastic Community LD nurse who lead on this topic. There can be a tendency when allocating referrals that those referred for sexual health/relationships input will be allocated one of the nurses with a particular interest in the topic, but equally such nurses are keen to volunteer to take on such cases.

### **Development of Bespoke Resources**

Several HSPCs have produced bespoke resources for providing group sessions on sexual health and relationships. These provide staff with appropriate resources which can also be used modularly for one-to-one support. The availability of such resources is a facilitator to providing support and also raises the visibility of available support to those who may make referrals (e.g. care providers).

### **Training**

Where staff have been trained to provide support around sexual health and relationships, this has led to increased knowledge and confidence and a readiness to address relevant issues when they arose. Where health and social work staff had been trained with a view to deliver group support sessions, even where group support has not been delivered or groups have ceased, staff are able to draw on the learning from their training to deliver one-to-one support.

### **'Asking the Right Questions' and the Relationship between Health and Social Work Teams**

In Renfrewshire and Inverclyde HSCPS, for example, courses have been developed and delivered in direct response to a large volume of referrals to the health teams on the topic of sexual health and relationships. Conversely, in East Dunbartonshire and Glasgow, the reason given for not delivering courses on this topic was that the low volume of referrals did not merit it. Staff in the areas where referrals were high attributed this to 'asking the right questions' in order to identify needs. Also, a key facilitator was felt to be where health and social work were co-located and integrated:

*"I think that Renfrewshire, from my experience of other health boards, do seem to be unique in the relationship between health and social work. We're sharing the office, we're talking about it. Social work – they're dealing with issues around sex and sexual health day in, day out with their clients. Because we're hearing those conversations, sharing in those conversations, that's maybe why the referrals come in. There's just that close working".*

Community LD Nurse

## **Gender of Staff**

An issue which emerged in several of the consultations with staff members was the relevance of whether the staff member and service user were both of the same gender. Some staff said that they feel particularly uncomfortable discussing sexual health and relationship issues with clients of the opposite gender and/or they sense the discomfort of clients in these situations. A facilitator to having discussions on these issues in a more natural way, is where staff have a relationship of trust with a client of the same gender. A male healthcare assistant described a patient disclosing that he would like a girlfriend and what he hoped to get out of a relationship during a 'man-to-man chat' – a telling phrase, and indicative of the importance of having staff of the same gender when having routine conversations which may lead to disclosures and expression of needs in this area.

In Renfrewshire, there is one female nurse and one male nurse who have a particular interest in supporting sexual health and relationships, and the tendency when referrals come to the team on this topic is that the female nurse will support women and the male nurse will support men. The female nurse led the development and delivery of the women's group (see Chapter 6), and the male nurse had historically delivered a men's group within a day centre.

Generally staff felt that for adults with learning disabilities, having a staff member of the same gender was a facilitator to having open discussions on the topic of sexual health and relationships in a way that might not be as significant for the those without learning disabilities.

Many staff pointed to the low numbers of male staff working in health, social work and other care roles, but having male staff could be advantageous for delivering sexual health and relationship interventions. In East Dunbartonshire, a social worker gave a historical example of having a male psychology student on the team who ran a groupwork programme together with a temporary male social worker on relationships for a group of men who had been identified as having relationship difficulties. This provided an opportunity to run a men's group which would not have worked with female staff.

*"A lot of our clients will relate a lot better over certain things to a male worker than they will to a female one. And sometimes when you've got that developmental thing going on and people's hormones are going a bit crazy, they can start focussing on female staff as well, which can be tricky".*

Social Worker

## **Staff Viewed as External Experts**

Although the value of a long-standing relationship of trust between service user and carer/professional was recognised, staff in day centres and service providers recognised that there was also value in Health staff coming in to deliver interventions on sexual health and relationships – health staff being viewed as 'experts' and even their uniform giving them gravitas that elicited respect from service users who were perhaps more inclined to listen to the advice given.

*"The difficulty I've noticed through working here – see when someone comes in with the uniform on, our service users can act quite differently. If we were trying to get support for somebody with Talking Mats around menstruating or whatever, she would just sit and avoid the subject and be all giggly and talk about other things – but as soon as a nurse comes in*

*and they see the uniform and they know they're in for a specific task, you'll see a different side to that person – they'll do what they're asked. As much as I think we've got a better rapport and we know the person we're supporting a lot better, there's something about the uniform that definitely works for us – they'll be like right, they mean business, they've brought (nurse) in".*

Day centre staff member

## 4. Knowledge and Confidence

### Quantitative Measures of Knowledge and Confidence

Staff members who completed the online form were given the option of answering two questions about their levels of knowledge and confidence in relation to supporting adults with learning disabilities with relationships and sexual health.

Of the 48 members of staff who answered the question on how much information/knowledge they had around supporting adults with learning disabilities with relationships and sexual health:

- 8 (17%) said a lot
- 35 (73%) said a little
- 5 (10%) said none.

Of the 47 members of staff who answered the question on how confident they felt in supporting adults with learning disabilities in relationships and sexual health:

- 5 (11%) said very confident
- 23 (49%) said quite confident
- 18 (38%) said not very confident
- 1 (2%) said not at all confident.

It is noted that levels of knowledge and confidence varied widely between staff members in all sectors and it is recognised that those who expressed interest in taking part in the needs assessment are likely to over-represent those with an interest and knowledge in relationships and sexual health.

### Views on Knowledge and Confidence

Staff in social work and third sector care providers frequently referred to health team colleagues as the 'experts' they would refer to for sexual health and relationship advice and support. However, within health teams only a small number of staff with a particular interest in sexual health and relationships felt that they were in any way 'expert'. Many staff across all sectors reporting feeling ill-equipped to provide support, information and advice around sexual health and relationships.

Within social work some staff said that they could feel awkward or embarrassed and they lacked confidence when talking to clients on the topic of sexual health and relationships:

*"There was a chap I was working with and I got quite hot and flustered about the whole thing, I got quite embarrassed....I could feel myself going pink, because I think it is something that needs a bit of practice. Interestingly, we get training in talking about mental health or suicide even, and those conversations get people a bit unsettled and nervous about saying the wrong thing, but they train us how to do it so we have more confidence. There isn't that kind of training on how to talk about sexual health that I've come across".*

Social Worker

One area which many staff felt they lacked appropriate knowledge was around LGBT+ identities.

*"I've found over the years we're getting more and more people that are exploring their sexuality or identity and they're coming to us looking for more information. Just now I've got a patient who is looking to transition to being a female. I don't feel that I have all the skills that I should have- I don't want to do our patients a disservice, I want to have all the right skills and tools. It's the language as well and all the new names of things...things are changing all the time...I just feel that I don't want to say the wrong things, and I'm very aware of my language. Me and (colleague) think we both need more training on it".*

Community LD Nurse

## Training

### **Drawing on Individual Experience Rather than Training**

Few staff had received any training specifically for supporting sexual health and relationships, with most saying they relied only on common sense and their own life experiences when supporting adults with learning disabilities:

*"You just rely on your individual experience. The Sandyford used to run sessions for people with learning disabilities, so quite often the referrals would come to us and we would signpost to the Sandyford groups that were already up and running. They disbanded, so it was coming back into LD nursing – which is fine, but I've personally not had any training, any formal courses or even just how to SSKAAT, how to use The Big Question, how to use Sex and The 3Rs. We've got all these resources but never had any training on how to use them. You work through them and work it out yourself. I certainly don't think we're experts by any manner of means".*

Community LD Nurse

*"Basically you are just taking it from your own life skills because it's not anything that's taught. Sometimes it can be a bit daunting that you're giving this person information and how they interpret the information, and how they behave following that, that can be quite daunting".*

Community LD Nurse

*"If I pick up someone under Adult Support and Protection, my purpose is to manage the risk and support the adult. At those points I feel I can speak to them about what's happening for them and build that relationship and give them advice on how to keep themselves safe – but I feel like that's just my own values and my own experiences, what I've picked up about how to manage a sexual relationship – I've never had any formal training around how to support adults with sexual relationships. So it's just going off on your own".*

Social Worker

### **Experience of Training**

There were, however, some staff who had received training to deliver support around relationships and sexual health, including:

- Health staff in NE Glasgow had received training around five years ago to deliver sexual health and relationship support based on the *Ready, Willing and Able* resource.
- Some Social Work staff in NW Glasgow had been trained many years ago to do interventions based on *The Big Question*.
- Health staff in Inverclyde had received training prior to developing their resource and course.
- Staff at Dates N Mates had been trained to deliver relationship and sexual health support by Informing Choices NI, a Northern Irish sexual health charity.
- All staff at RNIB (third sector care provider) in West Dunbartonshire had received training on sexual health awareness. The training was delivered through someone at the Scottish Drugs Forum, covering topics such as sexual health and the law, healthy and unhealthy relationships, what/why/where and how of relationships, pornography, different types of relationships etc. This was followed up with refresher training in direct response to a service user uploading explicit photographs online and working out how best to support him.
- Some staff at a day centre in West Dunbartonshire had booked a three-day training course on supporting adults with learning disabilities on sexual health, but this was cancelled when the pandemic started. The staff due to attend were those who had been delivering a men's and a women's health group, which included elements of sexual health and relationships.

Where staff had been trained with a view to delivering group courses, they found training also benefited them in their more routine interactions with service users or providing one-to-one support around sexual health and relationships.

## 5. Resources

### Standard Resources

Staff mentioned a number of standard resources being used within HSCPs when supporting relationships and sexual health with adults with learning disabilities.

#### **The Big Question**

The Big Question is used in East Renfrewshire, NE Glasgow, South Glasgow, East Dunbartonshire and the Sandyford services as an assessment tool to explore individuals' level of understanding of topics around sexual health and relationships and provide information to address gaps in knowledge.

#### **SSKAAT-R**

SSKAAT-R (Socio-Sexual Knowledge and Attitudes Test – Revised) is a resource to assess knowledge and attitudes of people with learning disabilities, and was mentioned by staff in West Dunbartonshire and Inverclyde.

#### **Sex & The 3 Rs**

Health staff in NE Glasgow said they had recently acquired Sex and the 3 Rs, but had not yet familiarised themselves with it or begun using it. It is one of the tools available to health staff in East Dunbartonshire and Renfrewshire (where it has been adapted for a bespoke local resource).

#### **Ready, Willing and Able:**

The resource *Ready, Willing and Able* is used across Glasgow; in South Glasgow it was used as the basis for a course delivered to groups.

### Limitations of Standard Resources

Overall, most staff who are aware of, or use, existing resources feel that they are limited in their usefulness. A common view is that the resources are often not suitable for the needs of adults with learning disabilities – either having too many words or using unclear line drawings to illustrate and communicate messages.

*"I think for some individuals The Big Question works really well. For those with more complex disabilities where it's about talking about a picture, I think some of the images are pretty poor and people don't actually know what you're trying to present by it. It's like – what's that meant to be, and you get to the point where you have to tell them what it is, and they're like, 'that's not what it looks like'. So I think there's work to be done on the images".*

Community LD Nurse

Staff in North East Glasgow who received training to deliver group support were disappointed in the Ready, Willing and Able resource which was provided to accompany the course. The resource was felt to be inadequate and inappropriate for the needs of adults with learning disabilities. They then struggled to produce bespoke resources before running a group:

*"We did a two day course...it was an introduction to the subject matter. It looked at various different things – risk, contraception, all sorts of things relating to sexual health. There was somebody commissioned to develop a tool we could use to run groups, so we had a number of meetings where we inputted. But it was poor what came – it was the Ready, Willing and Able tool. It's poor – too many words, not enough pictures. We spent half the time preparing the groups looking for pictures, but they would be banned because they were sexual content, from the health service you couldn't get onto them. So it was quite frustrating".*

Community LD Nurse (NE Glasgow)

A further common view is that existing resources are somewhat out of date, particularly relating to staying safe online and use of social media. Another area where resources are felt to be dated is that they do not include adequate or up-to-date information about LGBT+ identities.

Those who had used the SSKAAT-R tool felt it was often preferable to the Big Question for many adults with learning disabilities.

### Adapted and Bespoke Resources

As highlighted in Chapter 2, several HSCPs have developed their own bespoke resources or made significant adaptations to existing resources to accompany group courses. These bespoke/adapted resources are also available to staff to use for one-to-one support with service users. The available bespoke/adapted resources are:

- The updated course developed in Glasgow South (originally based on *Ready, Willing and Able* but updated and now incorporating some materials from *Sex and The 3Rs* and other bespoke materials).
- Glasgow North West social work team retain the resources acquired to deliver group work a number of years ago, including useful models and tactile materials.
- Resources to accompany the 12 week bespoke sexual course for women in Renfrewshire which used *Sex and The 3Rs* as the basis for development: a 150 page flexible, modular resource (largely visuals) was produced.
- The bespoke resources for the 13-week course in Inverclyde, including a workbook which is completed by participants throughout the course.
- The resources for the course developed in West Dunbartonshire (not yet delivered), which may replicate, or be similar to, some of the Glasgow South materials which were used as reference.
- The resources for the course developed by Dates N Mates.

A number of staff members, particularly Community LD Nurses, had frequently resorted to making their own resources to support individual clients. BoardMaker was the most frequently mentioned tool for developing bespoke resources.

*"A lot of available resources are quite complicated when it comes to health – really long and complicated. So I tend to make my own to meet the*

*individual needs of that person. If you wanted to do relationships, for example and say it was inappropriate to have a relationship with your support worker, I haven't been able to find a document that pinpoints how to explain that in a very easy way. Some easy-reads are called easy-reads, but I actually find them quite complicated. In my last job I think it was called BoardMaker, and in this one I think it's called PictureSymbol. Other than that – it depends because some of the individuals I support don't want pictures because they don't want to feel like it's a child's kind of thing – and other people, I just try to find images that aren't copyrighted. So just all different ways to meet what the individual needs are”.*

Community LD Nurse

Indeed, several staff stressed that it would be difficult to prepare any generic resource that would be appropriate for a wide range of adults with learning disabilities, and that adaptations would frequently be required.

### Features of a good resource:

Staff who contributed to the needs assessment were asked for their opinions on what makes a good resource for adults with learning disabilities. Key features of good resources are considered to be:

- Easy-read formats ('true' easy read – as some resources marketed as easy-read are not considered as accessible as others)
- Pictorial formats, using clear images – preferably photos, avoiding ambiguous line drawings or abstract representations
- Videos are helpful for many
- Tools to facilitate users to express how they feel
- Tactile, true-to-life, 3D resources such as models of body parts etc (particularly for group work)
- Flexible, adaptable formats

## 6. Examples of Good Practice

This chapter highlights four examples of good practice in local areas which appear to work well to identify needs and provide support around sexual health and relationships for adults with learning disabilities. They include the bespoke resources and courses developed by Inverclyde and Renfrewshire, but these are not the only examples of local areas developing or adapting resources and offering courses (as noted in Chapter 5), and a review of all available local resources is recommended (see Chapter 8).

### Inverclyde Resources and Courses

One of the community nurses in Inverclyde has a keen interest in sexual health, having undertaken a university qualification in family planning. She, together with two Band 5s in her team developed a booklet and a 13-week course to deliver support around sexual health and relationships to adults with learning disabilities. This was in direct response to the team receiving multiple referrals from different agencies about sexual health and relationships.

The staff received training (though they could not remember who offered it) around 5-6 years ago. They had looked at *The Big Question* which they were aware had been used as the basis for interventions in Glasgow, but they did not feel that resource would best suit the needs of their patients, and decided to develop their own booklet and course.

Prior to the pandemic, the team were delivering the 13-week course three times per year for people referred for sexual health and relationships (not all referrals were put onto group courses – some referrals would merit one-to-one work). The booklet which the team produced is a workbook which is completed throughout the course and taken away at the end. The team also offer refresher sessions subsequently, depending on comprehension and ability needs.

Participants were put into groups of around four or five for the course. The approach has been to match suitable people together for the groups, assessing needs and levels of understanding to ensure that, where possible, participants were at similar levels:

*"We try to match people up to be in the group. There's no point in matching up people who's experiences or abilities are different. That can be quite challenging at times, but we try to do that because we find that even though we've got a 13 week programme, some might start at week 4 because when we've looked, they've had body awareness and other things they're able to understand and have a good knowledge of. So we try to match up, and the only reason we can do that is myself and (other two nurses) have worked here for a long time so we know who the patients are".*

Community LD Nurse

A key feature of the course that was developed is that it is interactive, ensuring that participants are actively involved (e.g. when talking about body parts - drawing around someone's body and putting labels on it, etc).

All groups have been run with two nurses – ensuring that if anyone became upset or made a disclosure, there was one nurse who could deal with the individual and the other could

continue facilitating the group. (When running the groups, no disclosures had been made, but the practice ensured that both the staff and participants were safeguarded).

Sessions last around two hours, including breaks. The course consists of:

#### Session1 – **Introduction and ground rules**

Session 2 – **Body parts**: This includes the development from birth to adult, changes to bodies inside and out, genital parts. This session is useful to establish language and terminology used by participants, and teaching the correct names for body parts (it was noted that people with learning disabilities did not always use standard terms for body parts which could make it difficult to communicate boundaries).

Session 3 – **Hygiene**, for both men and women, including a hygiene quiz etc, and also **self-esteem**.

Session 4 – **Thoughts and rights about sexual relationships** – what that means, what rights are, what support is available if they want a sexual relationship, what the law says.

Session 5 – **Sexual well-being, sexuality** (including straight, gay and bisexual), **common myths**. This session discusses stereotypes and genders.

Session 6 – **Social Media and Dating**, including how to stay safe online, and discussion on pornography.

Session 7 – **Effects of drugs and alcohol and risky behaviour**, looking at the effects on sexual wellbeing and relationships.

Session 8 – **Relationships** including what people want, the different types of relationship you can have with people, what people want from a sexual relationships, when it is safe and not safe.

Session 9 – **Adult support protection training**, including looking at the law and the Adult Support Protection Act, and how this keeps people safe from harm – so participants have a plan if they are experiencing any form of harm and they know how to report it; they take away a care plan with people they can contact.

Session 10 - **What sex is**, including discussion on masturbation, sexual activity, types of contraception, safe sex.

#### Session 11 – **Pregnancy and parenthood**

Sessions 12 & 13 are used for recapping previous sessions and reinforcing key messages.

Some groups have been run as all-female or all-male groups, while others have been run with a mix of male and female participants. Staff felt that both approaches had worked well.

The booklet and course are felt to be flexible – they have been used in different ways for different people, including one-to-one interventions as well as courses, and have been used with couples. The booklets have also been shared with children’s services for young people to use. A key consideration, when developing the resource, was the need for it to be used flexibly in person-centred ways:

*"When we did the booklet – we didn't do it as having notes that said you need to follow it this way. We did it in a way where the patient and the*

*nurse can look at it together and there's different ways you can work it. There's not just one way we do it. With our experience – and that's why we did it that way – we were confident enough that if we deliver it, we might not deliver it the same way for everybody, but they're getting the same information. So we followed the format, but the delivery would be different for different people. Also, the booklet – I've been able to offer it to children's services. One of the children's social workers has asked me for it for a couple of the children's homes- they had a couple of young men who were at the age of masturbation and didn't have a lot of education. So they've used it and I've gone through the booklet with them, but they've used it slightly differently but been successful".*

Community LD Nurse

A key feature of the resource is that it is 'communication friendly' – with few words and a lot of pictures. The aim when developing the resource was that it would be possible to ascertain the messages from the pictures, but also that it would be meaningful to those with higher literacy and comprehension skills:

*"We don't have a lot of words in it – there's a lot of pictures. It's communication friendly. If you look at the pictures, you can tell the story of what's going on. So we made it that if you were able to read the words, if your comprehension was good it wasn't going to make you feel silly looking at it – but also if you couldn't read or write, you could still understand some information".*

Community LD Nurse

The courses and resources, including one-to-one bespoke interventions offered by the health staff in Inverclyde appear to be well known, and health staff report that they continue to receive many referrals from service providers, day centres, social workers, families, GPs etc.

## Renfrewshire Resources and Courses

A Community Learning Disability Nurse and a Speech and Language Therapist in Renfrewshire together developed resources and a 12-week sexual health course for women with learning disabilities. The rationale for developing this was the nurse had noticed an increasing volume of referrals (from various sources including social work, GPs, families, support providers and day centres) for young women to receive sexual health information. At the same time, the speech and language therapist felt she was seeing many clients who did not appear to have knowledge or understanding of relationships. The aim was to provide appropriate information in a proactive way to avoid crises or difficulties relating to sexual health and relationships:

*"I really enjoyed delivering sexual health – it was something I was good at, got a good rapport with my clients. We decided to create a 12-week sexual health group for women. We had a rationale for it, and it was agreed within the health team that that was needed based on the referrals that were coming through. Often they came through after an incident – which I would like to think, if the knowledge was there, could have been avoided. So it was like were reacting instead of being proactive – with that group we wanted to be proactive. We wanted to give people the opportunity to have this information that maybe they didn't get at school –*

*of maybe it wasn't given fully, given in an accessible format, or just avoided".*

Community LD Nurse

The resource used locally in Renfrewshire had been *Sex and The 3 Rs*, and this was used as the base for developing bespoke resources to support the course. The value of having a speech and language therapist to develop the resource was recognised, ensuring that it met the communication and comprehension needs of women with learning disabilities. The speech and language therapist made visuals, added colour to the resources and made it more accessible.

There was only one initial group run with four women, but the group was curtailed by the pandemic and the last few sessions were completed online. Although the motivation for developing the course was taking a more proactive approach, the initial group was run with women who had been referred to the nursing team for sexual health/relationship information and support in response to incidents, issues or behaviours meriting intervention. Some considerations when setting up the first group were:

- Securing an appropriate venue where participants would feel comfortable
- Developing an inviting information letter and information booklet for those invited to attend, including appropriate visuals and a photograph of the staff running it
- Arranging snacks/refreshments to make the experience welcoming and appealing
- Deciding whether it was appropriate to allow participants to attend with a carer (one asked to bring a carer, but it was decided that having a carer would not be appropriate because it may inhibit the comfort or levels of participation from the others).

While the course had been developed with *Sex and The 3Rs* as the basis, this was built on further in terms of exploring relationships, aspects of physical health (including cancer screening checks etc) and mental health. There was an emphasis too on staying safe online.

*"For me, it's not just looking at the mechanics of sex, which Sex and the 3Rs is, but taking it further to – how can you identify a good relationship or a bad relationship. What kind of relationships you have – professionals, carers, family, friends – when you're thinking about having romantic relationships, and helping people distinguish the difference between that. That's not covered in Sex and the 3Rs. We've (traditionally) been giving people sexual health information and they're not actually able to process that it's not appropriate for them to have sex with their carer!"*

Community LD Nurse

*"Another big difference between Sex and the Three Rs and ours was – in the safeguarding respect, sending pictures to people and if you view other people's pictures. I think everybody we worked with had sent and received pictures. But they weren't aware of the implications for them but also if they're viewing other people's pictures – like if they're viewing children that's a criminal offence. And passing them on and showing their friends*

*pictures they got sent – where that left them - which wasn't talked about, and really needed to be talked about".*

Speech and Language Therapist

All sessions in the group course were reinforced through resources for the participants to take away. All together the resource developed was a 150-page book, mostly visuals.

The first group session had very positive feedback from the participants who appreciated the informal feeling in the group, saying it was not 'teachery', and the group appeared to benefit particularly from peer support, discussing each of the topics openly together.

Although the pandemic is still curtailing their ability to deliver more groups, thought is being given to how to take this forward in future. Some considerations are:

- Now the resources are developed, the speech and language therapist sees less need for her continued involvement and envisages this will be taken forward by the nursing team.
- There are issues to be resolved with BoardMaker (the tool used to develop the resources) to obtain a license for wider use.
- They would like to explore delivering the groups in day centres (a men's group had also been run previously in a local day centre by a male nurse in the team).

Since delivering the first course, the resources have been used when providing one-to-one support to individual patients – usually on a modular basis, using visuals from the resource on particular topics as required.

## East Renfrewshire Approach to Identifying and Addressing Needs

From the consultations with staff, East Renfrewshire appears to be the only HSPC in which social work assessments will routinely explore needs and goals around sexual health and relationships<sup>8</sup>. The social worker from East Renfrewshire who contributed to the research said she would always explore client's needs and expectations around sexual health and relationships, refer to health colleagues for an intervention to ensure that the client had appropriate information and support around navigating relationships, and link with external organisations to facilitate a client exploring opportunities to form relationships:

*"We would always have the discussion with an individual as we are developing a relationship. My previous role was in a provider as a service manager, and (sexual health and relationships) would never be in that paperwork. But definitely in East Ren it is very much a discussed topic and we would always discuss that. I'm working with someone who, during the planning day, said 'I just want a wife'. I was like, 'Okay, how do we support that?'. With the support staff – the provider – it was very much a 'that's just never been broached and that's not part of his plan, or his goal' – it had never been discussed. But when we had our planning day, that*

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<sup>8</sup> Note: only one social worker in East Renfrewshire was included in the research. There may be a variety of individual approaches to social work assessments within and across HSCPs.

*was facilitated. He did have the option of being able to say this is what my end result is: I'm happy, I'm settled and I have a wife. So it is definitely something that I'll be working on with him. I'll speak to the health team and get support around supporting him to understand relationships as well as different organisations we can tap into – Dates N Mates and things we would look into. Definitely the starting point would be his understanding of that because he does have a moderate learning disability, so it's picking out what does that mean to him – does it mean him actually moving in with a wife and being married, or is it the kind of friendship thing – just more to do with loneliness and feeling isolated, or does he understand what marriage is and he wants a wife. I would definitely go to our health colleagues for that”.*

Social Worker

Those in the health team in East Renfrewshire indicated that while referrals for sexual health and relationship input are not very common in their area (perceived to be because of a lack of need among the population they work with), they are equipped with *The Big Question* and can adapt resources as required to provide one-to-one support for patients who need information around sexual health and relationships.

### Dates N Mates: Service and Sexual Health and Relationships Course

Dates N Mates is an independent third sector national service in Scotland providing social opportunities for people with learning disabilities to meet to create friendships and relationships. Adults with learning disabilities join the service as members in order to access these opportunities. They work independently from HSCPs – i.e. they do not provide a service on behalf of social work services; however in some areas (not in NHSGGC), members have used Self Directed Support to pay for their membership. Within the NHSGGC area, the two areas in which Dates N Mates operates are Glasgow and Renfrewshire, and this is postcode-specific, dependent on funding. However, they accept members from other areas with the understanding that they would have to travel into Glasgow or Renfrewshire (or other areas they operate, such as Falkirk) in order to attend the social events and activities they offer. Indeed, the consultations with staff in East Renfrewshire, East Dunbartonshire and West Dunbartonshire found that there were service users within each of these areas who were known to be members of Dates N Mates.

All staff at Dates N Mates have recently received training to support relationships and sexual health and a subgroup of staff have subsequently developed their own course to deliver sexual health and relationship education/support to their members. At the time of interview (July 2021), they were planning to deliver their first group sessions on this.

The training, and the course subsequently developed, covered topics such as boundaries, consent, public and private spaces, sexual health and wellbeing, contraception and STIs. The course and associated materials have been developed in-house specifically for the needs and circumstances of adults with learning disabilities including:

- Ensuring that all communication including the handouts are in easy-read and accessible formats
- Including sections on human rights and the law specifically about people with learning disabilities

- A focus on the circumstances of people who live in residential settings and in shared housing.

The sessions are planned to be participative with exercises to do as well as information being shared.

Prior to delivering the course, staff already have conversations with members around relationships continually, and to a lesser extent, sexual health. The course has been developed with consideration to many of the questions that have already been asked and situations members have found themselves in.

## 7. Staff's Views on Needs

### Sexual Health and Relationship Education for Children

When staff were asked for ideas on how to better improve sexual health and relationships service delivery for adults with learning disabilities, one of the most frequent answers was improving sexual health and relationships education given in schools, particularly special needs schools or other children's services for those with learning disabilities. Staff frequently expressed shock at the lack of understanding and awareness around sexual health and relationships among the adults they worked with which they felt should have been worked on more at an earlier stage. It is recognised, however, that provision in children's/education services is not in the scope of this needs assessment.

### Development of Resources and Training

The two key needs identified through the consultations for staff across all sectors were:

- Better resources for delivering interventions or information about sexual health and relationships for adults with learning disabilities
- Training for staff to raise awareness and understanding of the relevant issues and to build confidence and skills to have discussions around sexual health and relationships and to identify and address needs. There was an appetite for training among all staff consulted.

### Roles in Delivering Support on Sexual Health and Relationships

Across all staff groups, it was health staff who were most commonly identified as being best placed and the most appropriate to lead interventions on sexual health and relationships. Some social workers were also keen to take a lead role in developing and delivering interventions. Other staff groups were also keen to be involved by way of supporting and re-enforcing the messages:

*"I think it would be for health staff to do courses on sexual health and relationships, but it would be good if we were still part of it to know what's said to take it on, follow it through and be part of the journey and pick up the bits afterwards, maybe re-enforce things that have been discussed".*

Service officer (social work)

Staff in third sector care providers, day centres and other social work staff also felt that they were well placed to identify service users who could benefit from courses or other interventions on relationships and sexual health.

*"I think there maybe needs to be almost a tiered system in relation to relationships and sexual health. We've got a lot of people who attend daycare and day services. We've got a lot of third sector providers. I think staff there should have a baseline knowledge and be able to have some of these basic conversations with our service users – and then create more of an 'expert' team in health. So day service staff, housing support staff, third sector, are able to have the basic conversations around it and support people with some of the more basic parts of it – and then if things are a bit more complicated, or feel a bit more risky, then referring into*

*health or social work for a more comprehensive assessment, a different type of education or work around it. But people in general who work with people with learning disabilities need to have some degree of skill in relation to having these conversations. I know it's difficult because some people just don't like talking about it, and it's everybody's individual thoughts on it.. but I think there needs to be blanket training across the board".*

Nursing Lead

There was an appetite among staff working directly on a day-to-day basis with adults with learning disabilities to have training to provide 'low-level' support and everyday conversations around sexual health and relationships.

*"I think the staff here should be trained – at the least we should be having the initial conversation, talk about it comfortably and then maybe if they felt that wasn't enough, then we could refer to the nurses – but I know the nurses workload is very busy – so I would rather, if we could, do some early intervention before it got to a big issue. That could only be a better thing to do".*

Day centre staff member

In day centres and third sector providers whose staff structures have 'champions' or 'ambassadors' for particular topics, it was felt that having champions/ambassadors for sexual health and relationships would be appropriate and feasible.

## Incorporate Relationships and Sexual Health Plans into Assessments and Care Planning

Some health staff advocated having more focus in nursing assessments on sexual health and relationships. Although existing nursing assessments focus on sexual health needs (e.g. around contraception and STD screening), some staff felt there may be inadequate inclusion of wider needs around relationships, and overall a need to have further emphasis on the importance of assessing sexual health and relationship needs at assessment stage.

Many social work staff and day centre staff saw scope for routinely including sexual health and relationship needs and goals during assessments and care and support planning.

*"Coming into adult services, it should just be part of the support plan that we offer – would you like to travel independently etc and what do you think about having a boyfriend or a girlfriend?... It needs to be just as important on support plans as the other parts".*

Day centre staff member

*"Improvements are needed to the needs assessments- none of these questions (around sexual health and relationships) are asked. There's not even a question about their sexuality- it's not taken into account. It needs to go right back to the start, so that people are given an opportunity to discuss that. If these types of questions are added in at the start, then parents and carers will come across them as standard questions and the subject can be discussed and any support that's needed can be put in place*

*from the start. If you're not asked about it, you're not going to tell about it. If parents thought we were open to hear about these topics, it might take away a bit of their fear about broaching it".*

Day centre staff member

Transition from children's to adult services was a point at which many staff felt there was scope to include assessment of needs around sexual health and relationships, including an assessment of levels of knowledge and awareness and identifying where education/interventions are required.

*"The transition nurse just gets an overall health perspective and the social worker would look at anything we'd need going forward and reviewing their care plan and how that would work, make sure their guardianship is in place because a lot of people don't know to apply for that prior to them becoming an adult -so they would look at those more technical things. It would be really good if it was seen as a norm to be discussing sexual health and relationships on a regular basis..at transitions and other assessments".*

Community LD Nurse

*"I think there's scope to get (sexual health and relationships) into assessments. I think if we could start to have conversations earlier on when we're doing that kind of work, it will become more commonplace. Maybe some of the places we should be starting at is at transitions. You can have a couple of years with a transition with someone moving from children's over to adult services. So we could be having those conversations at an earlier stage and that could be part of our transitions work. So if we get it in there, that would be really good".*

Social Work Services Manager

## 8. Discussion and Recommendations

### Develop resources

A clear message from the research is the need to develop new resources on relationships and sexual health which better meet the communication and comprehension needs of adults with learning disabilities and which provide up-to-date relevant information. The research has found numerous examples of teams and individuals across different HSCPs who have already undertaken work to develop new resources ranging from individual nurses 'scrambling' to put together materials to support a patient to teams who have developed resources to provide comprehensive courses. There has undoubtedly been duplication of effort as staff across HSCPs within NHSGGC have independently sought to develop resources to meet the needs of their service users.

It is recommended that a group should be formed to take forward the development of new board-wide resources to support relationships and sexual health with adults with learning disabilities. The recommendations for developing new resources are:

- The starting point for developing new resources should be a review of existing resources developed in the HSCPs – particularly the resources to support the women's course in Renfrewshire, the course in Inverclyde and the newly revised course in South Glasgow. It is likely that a new central resource could borrow heavily from these.
- While the topics covered are likely to include all those in existing standard resources (e.g. Sex and the 3Rs, The Big Question and Ready Willing and Able), the content should also include appropriate and up-to-date information around online conduct/internet safety, and LGBT+ issues.
- The resources should be modular and be able to be used flexibly. The resources should be able to be used to provide a comprehensive programme as a 'course' either delivered in groups or one-to-one settings, but it should also be able to be used for interventions on individual topics as required. Also, within each topic there should be various options for formats for providing the information (e.g. easy-read leaflets, videos, Talking Mats, etc), so that provision can be tailored to the needs of individuals.
- Speech and language specialists should be key partners in developing the resources to ensure appropriate communication tools are used.
- It may be prudent to review the resources used for sexual health and relationship education with children with learning disabilities in education and children's services, and where possible use similar language/terms or even the same images in the new resources developed. This would ensure a continuity of approach for adults requiring support at, or shortly after, the transition to adult services.
- Parents/families/carers and service users should be involved in reviewing resources or directly contributing to their development.
- Resources should be available and accessible to all staff throughout all HSCPs.

- Consideration, and if necessary investment, should be made regarding licensing and copyright issues.
- Given that existing resources are recognised as being somewhat out of date, it would be important to review and revise resources at appropriate intervals.

## Develop and Deliver Group Courses

Where delivered, group courses with adults with learning disabilities to support relationships and sexual health appear to have worked well. They have, however, been limited due to low levels of referrals in some areas and also practical constraints including venue availability. Group courses appear to be an effective way of providing opportunities for offering information and support (including peer support) around sexual health and relationships, and in particular moving towards more proactive, rather than reactive support.

It is recommended that courses are developed alongside the resources. Over the course of several weeks, courses would deliver the information contained within each of topics in the resources. Recommendations for the development and delivery of the course are:

- Interactive group activities should be used to engage participants, including tactile props (e.g. of bodies/body parts, etc).
- Where possible, the composition of participants within groups should ensure that participants have similar levels of disabilities, needs and experiences.
- Groups may most likely be run by community LD nurses, but could also involve social workers or other key, trained staff – but they would benefit from involvement from those having more routine day-to-day involvement (care providers; day centre staff) who can support learning and reinforce messages.
- Groups may be delivered in settings such as day centres, residential settings etc where those using the services can be invited to participate; other groups could be run in community/health facilities as appropriate.
- Consideration should be given to running groups centrally (e.g. at Sandyford), perhaps staffed with community nurses from across the HSCPs on a rotational basis. This may prove effective where interest/referrals were not sufficient to merit running more local groups. However, the efficacy of this approach would depend on whether participants were able or willing to travel to attend the groups.

## Develop and Deliver Staff Training

The development new resources and courses would have to be supported by staff training. The needs assessment findings suggest that an appropriate model would be to have training and staff roles at two different levels:

1. Broad training for staff across all sectors (including health, social work, day services, care providers, etc) to be trained to:

- Have an awareness and appreciation the rights of adults with learning disabilities to express their sexuality and form and maintain relationships
  - Have conversations with the people they support about sexual health and relationships, ensuring that this aspect of their wellbeing is not overlooked as part of their care
  - Provide routine advice and information as required on the topic (with use of some of the resources as appropriate)
  - Identify and refer service users who would benefit from a group or one-to-one intervention from specialist ('level 2' trained) staff.
2. Training for staff with a particular interest in supporting relationships and sexual health. Given the current arrangements within HSCPs, they are likely to be largely community LD nurses, but there are also social workers interested in taking on this role. There may also be staff within day services and third sector care providers who would be interested in receiving this training and taking on a remit for relationships and sexual health support within their organisation. At this level, staff would be trained to:
- Deliver interventions to adults with learning disabilities through group courses and one-to-one work, using the new resources and courses developed and available throughout the NHSGGC area
  - Become 'champions' for relationships/sexual health, supporting other staff members to provide day-to-day support on the topic, promoting the available resources, groups etc, and potentially delivering the 'level 1' training to staff through a cascade training model.

Given the value of providing sexual health and relationship support by staff members who are the same gender as the client, effort should be made to ensure that staff trained at 'level 2' adequately comprise staff of both genders where possible.

It is recognised that the release of staff for training will require buy-in from managers and existing workloads, demands and current levels of staffing should be considered.

Once training opportunities are established and available, local authorities may consider new contracts with service providers to include a requirement for staff to have attended relationships and sexual health training.

## Incorporate Relationships and Sexual Health into Assessments and Care Planning (and acting on identified needs)

The findings from the needs assessment show that questions about relationships and sexual health are not routinely asked at key review points such as assessments and care and support planning. It is recommended that, where possible, relationships and sexual health become

more routinely part of these conversations and embedded into the required forms etc. These interviews should identify current needs regarding sexual health and relationship support and/or future aspirations. Where, for example, assessments identify an interest in pursuing personal relationships or set a goal of having a boyfriend/girlfriend, this can be followed up as appropriate by staff:

- assessing levels of awareness and understanding around relationships and sexual health
- delivering or referring to specialist staff for interventions where required (in groups or one-to-one) with the aim of providing service users with the information and skills to pursue and navigate relationships safely and appropriately
- advise on opportunities to facilitate meeting other people with a view to forming relationships. Dates N Mates has been highlighted here as a potentially beneficial organisation for this who are also seeking to provide support around relationships and sexual health in courses– there may be other social organisations locally.

Assessing levels of awareness and understanding among those who show an interest in pursuing relationships/sexual activity affords an opportunity to identify those who may benefit from interventions rather than reactively providing interventions for those who are at risk or exhibiting inappropriate behaviours.

It is recognised that introducing sexual health and relationships during assessments/goal setting may face objections from parents/families – particularly where there is a welfare guardianship in place and where parents/family members have the role as guardian. It is therefore critical that appropriate dialogue and agreement is sought with parents/families, as discussed below.

### Involving Parents, Families, Carers

It is important to address the role of parents, families and carers as potential barriers or facilitators of providing education and support around relationships and education. Recommendations are:

- Involve parents/families/carers in the development of new resources and courses on sexual health and relationships
- Widen reach of the 'level 1' training to parents/families/carers where appropriate, so they can be more informed of the rights of adults with learning disabilities, and equipping parents/families/carers themselves with the information, confidence and tools to have conversations with the adults they care for and ask professionals for more support where required
- Encourage staff to talk to parents/families/carers about the reasons for providing this type of information and support, and seek co-operation.
- As part of the resources developed, have information leaflets specifically for parents/families/carers.

## Awareness Raising and Partnership Working Across Staff Groups

The research highlighted that many staff groups were unaware of what support was available in different sectors within their HSCP – for example some social work staff were unaware of the support provided/available from their health colleagues; many staff were unaware of independent third sector organisations such as Dates N Mates or what support they offered. Moreover, staff in each HSCP were largely unaware of practices or resources developed in other HSCPs within the NHSGGC area. The recommendation is:

- Ensure appropriate means of sharing available support, resources, referral routes etc with staff working with adults with learning disabilities throughout the NHSGGC area.

## Role of Sandyford Inclusion Service

Across the HSCPs, virtually no community nursing or social work staff were aware of the availability of the Inclusion Service at Sandyford or that they could make direct referrals for adults with learning disabilities. The recommendation is:

- Provide information about Sandyford services and how and when to make referrals to the Inclusion Service within the training to staff.

It should be noted that the Inclusion Service is currently a small team with limited resources, and wider publicising the service is likely to increase demand. Resourcing should be a consideration.

## Appendix A : Topic Guide

### **Needs Assessment with Staff Supporting Relationships and Sexual Health for People with Learning Disabilities**

#### **Draft Topic Guide**

#### **Role and Current Practice**

Could you summarise what your role is and what you currently do – if anything – with regards to supporting adults with learning disabilities around relationships and sexual health.

Probe: What is done:

In groups or individually

As a 'course' or as ad-hoc/responsive to needs and circumstances

To provide appropriate referrals to sexual health services

How does your organisation fit in with the learning disability services infrastructure locally?

#### **Barriers and Facilitators**

We are keen to explore both the barriers and facilitators to providing support and advice in the areas of relationships and sexual health. What either helps or hinders you in this aspect?

Probe:

Role of parents/guardians/carers

Available resources

Available referral routes or external sources of information/advice/support

Levels of knowledge and/or confidence in you/your team

Requirements specific to learning disabilities/types of learning disability

Pressures/demands of time, priorities etc.

#### **Knowledge and Confidence**

How would you rate your knowledge and your confidence with regards to providing information and support around relationships to adults with learning disabilities?

Have you received any training regarding this? (Probe for details)

What (else) has contributed to your knowledge and/or confidence in this area?

How could your knowledge and/or confidence be improved?

### **Resources**

Do you use, or are you aware of, any resources for providing information/support around relationships and sexual health?

How would you rate these in terms of usefulness and appropriateness when working with adults with learning disabilities?

Have you/your team/others adapted any resources or used them in different ways? (Probe for details)

What further resources are needed, or how could existing resources be improved?

Probe: Format, content

### **Examples of Good Practice**

We are keen to find and share examples of good practice – from your experience, what has worked well with regards to providing support and information to adults with learning disabilities around relationships and sexual health?

Are there example of good resources on topics outside of sexual health and relationships that are good for using particularly with adults with learning disabilities – things we could learn from?

### **Improvements**

What is needed to better improve sexual health service delivery for adults with learning disabilities?