

IT'S MY LIFE - MAKING IT OUR REALITY

Best practice guidelines for health, social care and education practitioners regarding relationships and sexuality education programmes for children and young adults with intellectual disabilities



RESIDE

RELATIONSHIPS AND SEXUALITY IN
INTELLECTUAL DISABILITY EDUCATION

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EXECUTIVE SUMMARY

WHAT ARE THE ISSUES?

Children and young people with intellectual disabilities experience specific and distinct barriers regarding developing and sustaining relationships and in the expression of their sexuality. However, while some Relationships and Sexuality Education (RSE) programmes do exist for this population, it is unclear what content is currently being delivered in special schools and if and how it is evaluated. RSE programmes should be consistently evaluated to ensure they effectively meet the needs of children and young people with intellectual disabilities and address the concerns of parents.

WHAT DID WE DO?

A total of eight special schools across England, Northern Ireland (NI), Scotland, and Wales, participated in the study. In-depth qualitative and focus group interviews were undertaken including children and young people, parents, health, social care and education practitioners collectively referred to as 'professionals', who consented to participate. A total of 37 pupils with intellectual disabilities aged between 12 and 19 years participated in an individual or group interview. Semi-structured individual interviews took place with 11 parents of children and young people with intellectual disabilities, and seven with healthcare and other professionals. Two focus groups took place with nine healthcare and education professionals.

The findings and experiences of good practice and methods of programme delivery were used to develop best practice guidelines for professionals regarding RSE content and delivery to meet the needs of children and young adults with intellectual disabilities.

WHAT WE FOUND OUT?

- Children and young people with intellectual disabilities want education and information to develop their knowledge and understanding regarding friendships, relationships and the expression of their sexuality.
- Parents of children and young people with intellectual disabilities recognise the need for their children to have access to education that is tailored and specific to their individual needs.
- A range of professionals are involved in the development and delivery of RSE programmes, adopting creative teaching and learning approaches.

WHAT NEEDS TO HAPPEN NOW?

- The best practice guidelines should be used to enable health and other professionals to develop, implement and evaluate RSE programmes specific to the needs of children and young people with intellectual disabilities.
- All RSE programmes need to be developed and delivered around clearly defined learning aims, objectives and outcomes.
- A formal evaluation of the impact and outcomes achieved as a result of participation in a RSE programme should be undertaken.



RECOMMENDATIONS

The findings from the in-depth qualitative interviews and focus group interviews with pupils with intellectual disabilities, parents of children and young people with intellectual disabilities, and healthcare and other professionals informed eight main evidence-based recommendations:

RECOMMENDATION 1

A structured, evidence-based RSE programme needs to be developed, tested and implemented within special schools for children and young people with intellectual disabilities.

RECOMMENDATION 2

RSE programme development needs to be flexible and adaptable and delivered for all levels of intellectual disability, age and ability across special school settings.

RECOMMENDATION 3

Defined aims, objectives and outcome measures for the delivery of relationships and sexuality education need to be developed and implemented for RSE programmes.

RECOMMENDATION 4

Evaluation mechanisms before, during and after delivery need to be developed and integrated within all RSE programmes.

RECOMMENDATION 5

There is a need to develop and implement a support network for professionals involved in the development, delivery and evaluation of RSE programmes.

RECOMMENDATION 6

Longitudinal follow up studies are required to identify the impact and outcomes achieved through the delivery of RSE programmes.

RECOMMENDATION 7

Further research is required which adopts a lifespan approach on the RSE needs of adults with intellectual disability to ensure they have evidence-based information to make informed choices and decisions.

RECOMMENDATION 8

There is a need to scope and develop a RSE programme to address the specific needs of adults with intellectual disability living in the community.



DEFINITIONS

HIV

Human immunodeficiency virus

RSE

Relationships and sexuality education

PROFESSIONALS

Health, social care and education practitioners for example, school nurses, teachers, teaching assistants, education managers.

STIs

Sexually transmitted infections

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THE PARTICIPANTS

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**“One size doesn’t fit all
... you can’t roll out the
same thing to everyone
because it has to be
person-centred really”.**



INTRODUCTION AND CONTEXT

BACKGROUND

An intellectual disability refers to a significant impairment of general intellectual and adaptive functioning that originates in childhood (Cooper et al., 2014). Approximately 2.5% of the UK population have an intellectual disability, equating to some 1.5 million people. Of this there are 286,000 children - 180,000 boys, 106,000 girls - age 0-17 with an intellectual disability (Emerson & Hatton, 2008; Lenehan, 2017). The population of children and young people with intellectual disabilities is increasing and ageing, with more living into adulthood with a range of neurodevelopmental, physical, behavioural and mental health needs (Huang et al., 2016). The increase is due to improvements in neonatal intensive care and health care services and access to care and support (Jarjour, 2015). Children and young people with intellectual disabilities often have more complex support needs than other children to understand, learn and remember new information and skills. They may need additional support with everyday activities such as communicating, keeping safe and undertaking everyday tasks. Many will require specialist services at some point in their lives (Emerson & Hatton, 2008).

There have been significant policy changes and developments over recent decades regarding the education of children and young people with intellectual disabilities with moves to inclusive education (Buchner et al., 2021). Parents of children with intellectual disabilities may wish their child, where possible, to attend the same school as typically developing children. Some, due to their specific learning and support needs may attend a blend of mainstream and special education provision (Klang et al., 2020). For some children, particularly those with the most complex of education and support needs, full-time attendance at special education provision may be appropriate (Florian, 2019). Despite their additional needs, all children and young people with intellectual disabilities have the right to have their needs recognised and promoted, their voices heard and receive education, care and support to enable them to reach their full potential, set within the context of the United Nations Convention on the Rights of the Child (UNICEF, 1989). Despite these aspirations and the positive developments, children and young people with

intellectual disabilities experience specific and distinct barriers regarding developing and sustaining relationships and in the expression of their sexuality.

Existing literature recognises the rights of people with intellectual disabilities to have fulfilling lives and to make their own life choices (Simpson et al., 2006; World Health Organisation, 2015). People with intellectual disabilities want friendships, meaningful relationships and some want intimacy (Box & Shaw, 2014). However, the expression of sexuality is an area where potential freedoms are often limited and restricted, compared to typically developing young people (Jahoda & Pownall, 2014). People with intellectual disabilities are often misperceived as being either asexual, hypersexual or sexually immature (McCann & Brown, 2018). Additionally, several studies have highlighted issues related to autonomy versus vulnerability, exploitation or risk of harm (Conder et al., 2015; Fisher et al., 2016). There is a need to develop the understanding of families and professionals in education, social care and health services that many people with mild and moderate intellectual disabilities are interested in and actively engage in sexual relationships (Brown & McCann, 2018; Frawley & Wilson, 2016). However, they may possess less knowledge about relationships and sexuality, display more inappropriate sexual behaviours and often do not understand the consequences of engaging in unprotected sex when compared to their typically developing peers (Ballan, 2012). Many practice unsafe sex, are less likely to use contraception, have an increased risk of having an unplanned pregnancy, and have greater exposure to the human immunodeficiency virus (HIV) and sexually transmitted infections (STIs), compared to typically developing young people (Jahoda & Pownall, 2014; McCarthy, 2014). Young people with intellectual disabilities who are sexually active are at greater risk of sexual abuse and exploitation. This contributes to the increased risk of mental health conditions such as anxiety, depression and low self-esteem. Some also experience difficulties in forming and maintaining relationships resulting in loneliness and social isolation (Baines et al., 2018; McDaniels & Fleming, 2016). Current research evidence indicates that young people with



intellectual disabilities may not have proper access to suitable relationships and sexuality education programmes (McCann & Brown, 2018). While some Relationships and Sexuality Education (RSE) programmes do exist for this population, most focus on knowledge acquisition regarding sexuality and sex, lacking a focus on healthy relationships, informed choices and decision-making (McDaniels & Fleming, 2016). Furthermore, potential RSE programmes should involve young people with intellectual disabilities, parents, and professionals involved in their education, care and support. However, despite these issues, there remains a definitive gap in the delivery of RSE programmes that specifically address relationships and sexual needs and concerns for this population (Brown & McCann, 2018).

Rationale

There is no evidence-based best practice guide for healthcare and other professionals regarding addressing the RSE needs of children and young people with intellectual disabilities. It is unclear what is currently being delivered in special schools and if what is delivered is taught and evaluated consistently and in a way that meets the needs of children and young people with intellectual disabilities whilst also addressing parental concerns. Therefore, limits in consistency of provision and delivery ultimately impacts on life choices and places the health of children and young people with intellectual disabilities at risk, and may increase their vulnerability to harm, abuse, sexually transmitted infections and unintended pregnancy. Healthcare and other professionals have important health education roles in meeting the needs of young people with intellectual disabilities, including those related to relationships and sexuality. They are therefore well placed to work with children and young people with intellectual disabilities and their parents to ensure that relationships and sexuality education needs are identified and effectively addressed.

This study therefore sought to identify the contributions of healthcare and other professionals in the provision of RSE programmes in exemplar schools in England, Northern Ireland (NI), Scotland and Wales. Key stakeholders, including children and young people with intellectual disabilities, parents, school and sexual health nurses, teachers and other professionals were involved to identify current provision and best practice to inform the development of this best practice guideline to inform content and delivery in the special school setting. This work has led to the development of best practice guidelines to inform practice and future RSE delivery.

ETHICAL CONSIDERATIONS

Ethical approval to conduct this research was received from the Faculty of Medicine, Health and Life Sciences Research Ethics Committee, Queen's University Belfast prior to commencing the study. An amendment to the original application was sought, and approved, to expand recruitment to include England and Wales, and allow for online participation.

Information on the study was provided by the research fellow to the gatekeeper on each site for distribution to pupils, parents and professionals. The gatekeeper shared details of those interested in participating with the researcher to arrange a qualitative semi-structured interview or focus group. In advance of interviews and focus groups taking place, all participants received an information sheet and returned a completed consent form. Parents/carers of pupils who expressed interest were also sent an information sheet and asked to complete a consent form.



DEVELOPMENT OF BEST EDUCATION PRACTICE GUIDANCE

AIM AND METHODS

The aim of the study was:

To develop best practice guidelines for intellectual disability and other nurses on relationships and sexuality education (RSE) for children and young people with intellectual disability.

A project advisory group was established comprising professionals involved in RSE programmes for children and young people with intellectual disability, who had an interest in the work. A total of eight special schools across England, Northern Ireland, Scotland, and Wales, were approached and invited to participate in the study. In each participating school, the principal or a designated teacher, acted as a gatekeeper to identify pupils, parents and professionals who would be willing to take part in interviews and focus groups. These individuals were then issued letters of invitation and information about the study. Members of the nursing profession were approached through existing contacts of the research team.

The research fellow liaised with the gatekeeper in each school to arrange interviews with the pupils. Interviews and focus groups with parents and professionals were organised by the researcher following direct contact with those who expressed an interest in participating.

In-depth, qualitative semi-structured interviews and focus group interviews took place with all participants who agreed to take part in the study. A series of open-ended questions were asked to identify current best practice in RSE provision.

What was the response?

During a period of 13 months from February 2022 to February 2023, 90 expressions of interest were received which comprised 47 pupils with intellectual disabilities and 16 parents. The remaining 27 responses were received from health, social care

and education practitioners (for example, school nurses, teachers, teaching assistants, education managers) and will be collectively referred to as 'professionals' for the purpose of this report.

A total of 64 individuals subsequently participated in an interview or focus group. Figure 1 shows the geographic locations of expressions of interest across the United Kingdom. Table 1 shows the breakdown by group of those who participated. The remaining 26 who were unable to take part included 10 pupils who became ill, or parents did not provide consent; and 5 parents and 11 professionals who were contacted on a number of occasions and did not respond.

A total of 37 pupils with intellectual disabilities aged between 12 and 19 years participated in an interview with the research fellow. A Microsoft Teams online interview took place with 13, and face-to-face individual interviews took place with 4, some of whom also had a member of teaching staff present. Each interview lasted between 10 and 22 minutes. The remaining 20 pupils took part in two focus groups from one school consisting of an all-boys or all-girls group. Each focus group had a number of education staff present for additional support. The boys' focus group had a total of 12 participants and lasted 34 minutes; while the girls' focus group had a total of 8 participants and lasted 39 minutes.

Semi-structured individual interviews took place with 11 parents of children and young people with intellectual disabilities and 7 professionals. Each interview lasted between 14 and 51 minutes for parents, and 26 to 66 minutes for professionals. Interviews took place via Microsoft Teams, telephone, or in person in the school or parent's home.

Two focus groups, facilitated by the researcher, with 5 teaching professionals in group one and 4 teaching,



nursing and management professionals in group two, took place online via Microsoft Teams and lasted 53 and 33 minutes respectively.

Conversations during all pupil, parent and professional interviews and focus groups explored:

- Experiences and understanding of relationships, sexuality and consent
- Experiences of RSE programmes
- Identifying topics for inclusion in an RSE programme
- Collecting examples of good practice and methods of delivery

All interviews and focus groups were audio recorded and transcribed verbatim by the research fellow. All identifiable information was removed and each participant was allocated a pseudonym.

Table 1: Participant groups across the United Kingdom

REGION	PUPILS	PARENTS	PROFESSIONALS	TOTAL
England	5	3	5	13
Northern Ireland	24	6	8	38
Scotland	5	0	1	6
Wales	3	2	2	7
TOTAL	37	11	16	64



Figure 1: Distribution of expressions of interest across the United Kingdom



WHAT DID WE FIND

There was overall positivity from all participant groups that RSE should be taught to children and young people with intellectual disability. Participants felt that, like all young people, those with intellectual disability also have relationships and friendships and require knowledge and information to help them make better informed choices and decisions.

The data showed parents were supportive of their children learning about RSE rather than preventing or limiting it. However, we are aware that some parents might feel uncomfortable in broaching RSE topics with their children and acknowledge that those taking part in this research may be those who are in favour of RSE provision.

There was a clear rationale and context for teaching RSE to young people with intellectual disability. It was recognised that they have equal rights as children to lead a full and rewarding life, and should be provided with appropriate information relevant to their needs.

The importance of keeping safe and healthy was an important component and was reflected in the narratives of pupils, parents and professionals.

DATA ANALYSIS

All transcripts were read independently by the research team to gain an understanding of the participants' views and experiences and identify themes and sub-themes. Following this the transcripts were discussed collectively by the research team to identify and agree the final sub-themes and themes across and within the data. As a result of this process, three main themes with associated sub-themes (Table 2) were identified and described below.

Table 2: Themes and sub-themes relating to participants' experiences of RSE programmes

MAIN THEME	SUB THEMES
Initial Planning and Preparation	<ul style="list-style-type: none"> • Learning styles and learning needs • Age and ability • Communication
Delivery of RSE	<ul style="list-style-type: none"> • Delivery modes • Who delivers? • How is it delivered?
Evaluation of RSE	<ul style="list-style-type: none"> • Programme evaluation • When to deliver again?



“It’s on the child’s level as well, which is really important. You’ve got to use the language and the actions that they understand”.

“They don’t talk about it, not enough, so, I think they should talk about it more ... I think it is just a bit late to start it, because other schools do it in Year 8 and Year 9, and we’re doing it in Year 11”.



THEME 1: Initial Planning and Preparation

LEARNING STYLES AND LEARNING NEEDS

Parents and professionals were keen that young people with intellectual disabilities, irrespective of the child’s level of disability, should be afforded the same opportunity to learn about relationships and sexuality as typically developing children:

“You can’t go in and have a lesson with somebody like my [daughter] who is completely non-verbal and has a severe learning disability and give the same lesson to a child who will go home and say oh mammy guess what we were chatting about today. It has to be aimed at that child’s level”. Parent 3.

However, it was recognised that this brought challenges to delivering the topic with the general consensus that a specific tailored and accessible programme should be developed. In addition, the RSE programme should be tailored to suit the level of the child’s understanding:

“One size doesn’t fit all ... you can’t roll out the same thing to everyone because it has to be person-centred really”. Professional 13.

Irrespective of the person’s level of intellectual disability, it was deemed important that a learning needs assessment would be conducted before any teaching was delivered on an individual basis or within a classroom setting:

“There needs to be that discretion or ability to make sure it’s individual to the individual nature of the child, young adult or person growing up”. Parent 5.

AGE AND ABILITY

There was an overwhelming agreement particularly amongst pupils and parents that RSE should be



introduced into the curriculum at an earlier age and stage and built upon over time, as developmental changes commence, particularly for girls as young as nine or ten years old, and curiosity increases:

“They don’t talk about it, not enough, so, I think they should talk about it more ... I think it is just a bit late to start it, because other schools do it in Year 8 and Year 9, and we’re doing it in Year 11”. Pupil 33.

“I think it’s essential that it is taught in school because these children have a lot of learning to do around this. It is something I would say should be started at a young age. Now when they are a young age, you are just talking very simple things. But I think it is something that has to progress with them”. Parent 4.

“They should be taught at an earlier age because they forget that wee girls can take their period from an early age ... I am just glad that I was opened enough to notice that she was fully developed from she was about nine, ten, years old”. Parent 8.

Other challenges highlighted particularly by professionals regarded pitching their teaching at the right level to make it accessible and relevant for the individual pupil. This became increasingly difficult when there was a mixed ability and understanding within the same group of pupils. It was considered

important that the young people understood the “foundations” of the “complexities of friendships and relationships” before moving onto sexuality education and the safeguarding elements.

These challenges were also recognised by parents; however, they wanted their children to be taught about relationships and sexuality at the appropriate time as they were mindful they would develop into fully functioning and more independent adults irrespective of their age or level of intellectual disability:

“The mechanism for delivery is completely different depending on who you’re working with, age range, ability wise, an important message”. Professional 11.

“Whether it’s done at a slightly later age range depends on the ability of that class. But it should still be delivered just as it is in a mainstream school because I don’t understand why it’s not. Maths is taught in all different schools, both special and mainstream. English is taught in mainstream and special, as is PA [physical activity]. So, is this not something that should also be taught because children with need will go on to be, they’re not always going to be a child with additional needs, they will be an adult with additional needs”. Parent 2.



COMMUNICATION

Professionals recognised the need to consider and incorporate individual communication styles and what would potentially work best for each pupil when preparing RSE programme content and delivery:

“It’s very pupil led and everything is based around their sensory needs and their kind of regulation”. Professional 1.

“It’s on the child’s level as well, which is really important. You’ve got to use the language and the actions that they understand”. Professional 8.

In addition, the need for effective communication and a positive relationship with parents in the development, planning and preparation stage was recognised by many professionals as paramount:

“There’s a certain relationship needs to be developed between parent and school that’s conducive to the learning, again of the young person. Because anything that we do, we send home to the parents as well ... we believe that there’s the triangle ... the individual, there’s the parent care, and there’s any other professional involved in their life ... young people need to be getting the consistent message”. Professional 11.

To support teachers and maintain consistency and accuracy in the information being delivered, all parents clearly articulated their need to be kept informed. They did not want to be involved in programme delivery, rather they wished to be made aware of when the subject was being delivered to their children and the content and topics being taught:

“Talk to us, about what it is specifically that you’re covering, because we can mirror that at home ... if you’ve got any resources, send them home ... and you have some activities, let us know what they are ... so that they’re getting the same information from all of the people that they trust and that they can see that we’re working together on it. And we’re not confusing them because if they are learning in a very specific way at school about something and then we might come home and have different terminology or a different value or a different take on it and we’re saying oh, actually, no, do it like this, then we are just further confusing the issue for them”. Parent 1.

“I knew that Tuesday afternoons were likely to be a little bit bumpy and I knew that in the afternoon at home time, to kind of clear my work diary a little bit because my son might have needed to have offloaded. And that was really, really helpful”. Parent 11.



Some professionals were proactive in the involvement of parents and had invited them to workshops held in the school to discuss and share information and details about the RSE programmes. This was viewed as an important part of any RSE programme delivery which needs to be incorporated and planned for from the outset:

“We have done at least two parent workshops where the parents have come in and we have explained to them about our programme and about the barriers and obviously trying to allay the parents fears and anxieties about teaching sex education to their really special child and just trying to get it across, that we are not encouraging them to go out and have sex, we are not encouraging them to be sexualised. But that is a journey, and just in my experience from A to where we are now, B, all those years later, we have come miles and miles”. Professional 6.

Some parents were apprehensive about the in-depth details and had no desire to be involved in the delivery of the programme, whilst another parent was keen to be involved on some level:

“I don’t know if I would feel comfortable with all the detail. I do think it’s better for him [son] being taught by a teacher because he associates the teacher with learning. Yeah, but I would like him to know that he could come and speak to me about things, which I don’t think he ever would, or ever will to be honest, because he sees me as mummy, and that’s not something that you talk about with your mummy”. Parent 7.

“I would be fully on board with it, and I would want to be there, participating, be in the room when they are doing the lesson so that I can see what they are teaching [daughter] so that I can take that home and teach her the same thing. I think we all need to be on the same level when it comes to that, definitely. Because school can’t teach them one thing and then me teach them something completely different”. Parent 3.



“Feel very safe like because I know the safety of online safety, so if something happens, then I know what to do. I need to block the person”.

“We learned so much from [teacher] and she will keep us safe no matter what and she makes us happy about it. She will let us be happy and enjoy it ... It’s about keeping you safe. It’s about being aware of the world out there because my mum said there’s some bad people that might make you feel uncomfortable”.

“You can’t go in and have a lesson with somebody like my [daughter] who is completely non-verbal and has a severe learning disability and give the same lesson to a child who will go home and say oh mammy guess what we were chatting”.

“There needs to be that discretion or ability to make sure it’s individual to the individual nature of the child, young adult or person growing up”.



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“I felt like it was a good course and it kind of taught you what’s right and what’s wrong”.



THEME 2: Delivery of Relationships and Sexuality Education

DELIVERY MODES

The setting and environment in which RSE was delivered was mainly in a school classroom. Within this context, in addition to learning in a whole group or classroom, there were alternative modes of delivery which included small group work and gender specific delivery to enable learning to take place at an appropriate pace and level of understanding:

“We try to have boys and girls together, rather than separate boys’ and girls’ groups, and any more personal questions that either gender wants, [female learning support assistant] will deal with the girls and I’ll deal with the boys. Such as periods, and masturbation with the boys, et cetera. So, separate that, otherwise we try and keep it all as neutral gender groups and have everyone together”. Professional 2.



Delivery on a one-to-one basis was also used on occasion, either for initial education on a specific topic or as a follow-up, to enable learning to take place at an individual's pace and level of understanding. The time allocated for each lesson was important recognising that flexibility was required to enable discussions with the pupils to come to a natural end rather than having to stop when the 'bell rings', which could lead to unanswered questions and increased anxiety. Novel approaches were facilitated to overcome this:

"I can rob from science and then when I am finished this is when I can finish the RSE, then I can use the RSE time to go back to science ... it works very well". Professional 15.

Interaction with peers and internet searches are frequently used as a mode of learning for neurotypical young people, and there was evidence that some pupils in this study were searching the internet and also asked friends for information to quell their curiosity:

"I get my information from online, [teacher], or anyone else willing to teach me ... I learn from other people". Pupil 2, age 15.

"I learned about like proper consent from YouTube videos". Pupil 13, age 17.

Whilst the pupils generally felt safe using social media and accessing the internet, there were concerns from parents and professionals as to inherent risks and potential danger of the internet and social media, including accessing unreliable and inaccurate information and being a potential target of exploitation by hint of their intellectual disability:

"Feel very safe like because I know the safety of online safety, so if something happens, then I know what to do. I need to block the person". Pupil 9, age 13.

"We had a horrific experience with an online predator ... you have all the parental controls, every time I think about it, it just makes my head explode ... we contacted the police, and it was all sorted out. It was all dealt with very, very quickly, but it was absolutely terrifying. It was awful, just what could have happened". Parent 4.

"For my son a lot of his learning will come from YouTube and things like that, which is always my worry because there's so much rubbish on there. And although we've restricted it, it doesn't matter because you still get some really awful things that come through". Parent 11.

"The random, silly things that you and I might google, and some of our people can't access the internet. Or when they do access the internet, they get into all sorts of messes". Professional 16.

WHO DELIVERS?

There was an eclectic mix of educators delivering RSE to the young people. Primarily this involved teachers and teaching assistants from within the school who had varying levels of knowledge and expertise in the subject. To assist with the delivery in schools, external educators were occasionally engaged. These ranged from school nurses and social workers from local Health and Social Care services to trainers from independent agencies specialising in relationships and sexuality education:

"There's a number of teachers I can think of that absolutely are terrified whenever I come in and they just don't want to be in the classroom, or they go out giggling ... because they can't cope with it. So, how are the pupils supposed to be engaging if they see their teachers going on like that ... and then they're [pupils] telling the teachers to wise up. They're saying it's nothing to be embarrassed about, wise up". Professional 12.

Irrespective of who delivered, the need to set the context and build rapport with the young people was vital and was especially important when an outsider was coming in to meet the young people and deliver topics:

“They came in the first time, and they just introduced themselves and they spent a bit of time just talking about something non-related to sexual education, talking about preferred programmes or whatever. We introduced that individual and they were able to just develop a bit of a relationship initially, and then we think it wasn’t until week two or week three that we actually started to roll out a wee bit of education. I think in terms of that, but that’s a very difficult thing to be able to do and spend that time for every individual and the difference between a specialist service and if you’re going to roll this out in educational services is quite hard in schools”. Professional 13.

There was a consensus among the professionals that collaboration and partnership with parents and families was vital to successful delivery and reinforcement of content at home which was articulated well by one parent:

“I think more than other curriculum areas, that splits very much into a parent responsibility and a teacher responsibility. Teacher responsibility is about the knowledge transmission to the individual student, child. The parent responsibility is the sensitisation of that knowledge to their individual child”. Parent 6.

Parents were also proactive in teaching their children especially where the school had not yet introduced a topic and they considered the information was necessary, for example regarding menstruation:

“Slowly I sort of slipped wee things in to her. Told her, showed her what a sanitary towel was. Told her how to use it”. Parent 8.

“Coming up to her period, how I got her ready for that is I would have started putting wee pads on her and got her used to having the panty liners on her ... when I would have been on my period, I would have brought her into the bathroom, and I would have showed her this is completely normal ... I had no bother with her when the periods arrived because I had that all put in place before ... it wasn’t a shock to her”. Parent 3.

However, parents recognised that not all would be confident or feel comfortable talking to their child about RSE:

“It would be something a lot of parents would have to take a back seat. Cause the same as any other child, there’s a level of embarrassment ... or there’s certainly likely to be at least with some children. You don’t want your parents to be involved ... when you are learning about that kind of thing”. Parent 10.

Irrespective of who delivered RSE there was evidence of embarrassment and awkwardness experienced by all pupils, parents and professionals:

“I just don’t like talking about it”. Pupil 5, age 14.

“Some of the words I didn’t like out of it. So, I don’t really say the words I don’t like ... Just freezes me out if I say them”. Pupil 31, age 14.

“A lot of the work that I’m doing with my son is that these are not things to be embarrassed or ashamed of, but it’s about there is a time and a place. And I think this is where we struggle a bit because they don’t really talk about that in school and that would be really, really helpful. It’s that extra layer of those unwritten rules that my child doesn’t understand. So, it’s not about making them a secret, but it’s about recognising when it would be ok to have those conversations and that is tricky”. Parent 11.

“Some of the older ones [pupils] who are more aware in the class find it quite embarrassing ... and it’s making them feel comfortable so that they can be really open to what we’re going to be learning”. Professional 5.



HOW IS IT DELIVERED?

In addition to traditional classroom-based approaches such as PowerPoint and group discussions, professionals were creative in their use of resources when delivering RSE and included activities such as drama, photographs, and worksheets. Parents were equally creative in how they delivered information to their child and at times used opportunistic life experiences to introduce or build on certain topics:

“I think a bit of drama helps a long way as well and keeping it very informal. And it’s not me standing at the front of the board, going through slide and slide and slide”. Professional 14.

“Trying every which way you can until it finally works ... discussion and talking and talking and talking and let them talk and listen to each other, and doing it practically”. Professional 6.

“Sometimes it is about creating those opportunities when they happen ... incidental learning is a really big part of it. So sometimes it’s about developing conversations and being led by him [son]”. Parent 11.

Visual tools and practical activities such as lifelike dolls, condoms, sanitary towels and photos were often used by parents and professionals as this was deemed to be more engaging and significantly increased understanding:

“There is no point just talking to them about it, it has to be visual and it has to be so simple and factual and it’s nothing that you have to understand this to do this. It doesn’t matter about that, this is right, this is not right, this is what happens, this is what we do ... don’t tell them what not to do, tell them what they have to do”. Parent 4.

“Visual and practical definitely, because that’s a good focus for our pupils. Anything like hands on, things that they can see is a lot better for their learning needs”. Professional 7.



Social stories based on real life scenarios were also considered important aspects of delivery and discussed within groups, as well as using books designed specifically for children and young people with intellectual disabilities:

“Social stories or visual and light touch introduction, and then maybe reminders and sort of encouragement after it”. Parent 5.

“I got a book on Amazon about what’s happening to Tom and what’s happening to, I forget, it’s the girl book, and it’s very descriptive in it, a lot of visuals for my autistic kids. And there was giggles and laughs but I want to be extremely open”. Parent 9.

“I think the books Beyond Words stuff through Barry Carpenter has been good because there’s no actual written words in the books. There’s a story and the pupils are telling that story and they’re empathising and they’re sharing into that”. Professional 4.

Additionally, practical workbooks and word searches were useful teaching resources although the time involved in preparing them was immense:

“The booklets are made taking into account the pupils special needs and for each of the tasks that they have to do, there’s two or three different ways of doing it. It helps cater for kind of different learning styles, kinaesthetic learners like to do a cut and stick maybe, visual learners will maybe perhaps like to copy something across, or things like this ... it took a lot of work at home as well but it’s worth doing”. Professional 15.

Across pupils’ narratives there was a preference for a visual and practical approaches in the delivery of RSE with opportunity provided to interact and discuss topics with their peers and teachers:

“I would rather start with the video”. Pupil 10, age 19.

“Working together ... trying to figure out the problems on each sheet”. Pupil 20, age 12-19.

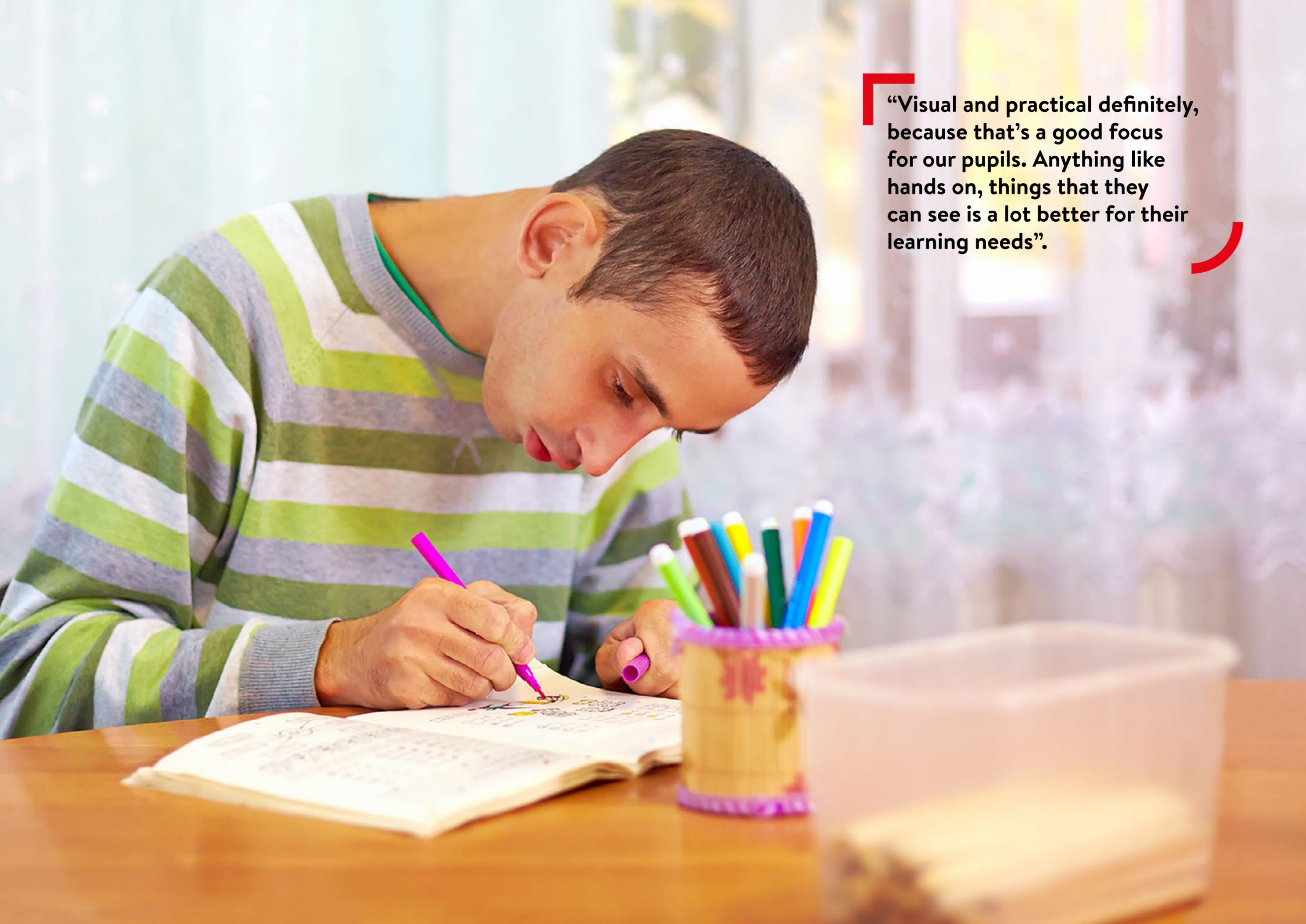
“Putting yourself in the deep end and just kind of going for it”. Pupil 32, age 14.

Overall, the pupils were accepting and appreciative of those who educated them, and valued the information they were being given:

“It is just interesting learning about sex education ... it is just great to know all this stuff because it can come in useful”. Pupil 2, age 15.

“We learned so much from [teacher] and she will keep us safe no matter what and she makes us happy about it. She will let us be happy and enjoy it ... It’s about keeping you safe. It’s about being aware of the world out there because my mum said there’s some bad people that might make you feel uncomfortable”. Pupil 25, age 12-19.

“I felt like it was a good course and it kind of taught you what’s right and what’s wrong”. Pupil 32, age 14.



“Visual and practical definitely, because that’s a good focus for our pupils. Anything like hands on, things that they can see is a lot better for their learning needs”.

“You still need that education and what might be relevant to somebody when they leave school, mightn’t be relevant to them five, six years down the line, so the education needs to be continued and the programmes need to be run”.



THEME 3: Evaluation of Relationships and Sexuality Education

PROGRAMME EVALUATION

Although considerable effort went into the initial planning and preparation of relationships and sexuality education, there was little evidence of formal evaluation taking place of the programme content or delivery. One teacher had taken the initiative and sought feedback on the RSE resources they had prepared for the pupils, from an external healthcare professional and some internal teaching staff which reassured them:

“It wasn’t like I just went off and did my own thing. I sort of did it and had sort of two internal people seeing what I was doing and then an external person because it is always good to have input from others”. Professional 15.

Evaluation and extent of learning were not routinely built into RSE programmes. However, the professionals were mindful that the content and delivery had to be effective and wanted to ensure the young people understood the information being given:

“It’s those kind of lower end that we are just going, is this an effective programme, how can we make this better for them”. Professional 4.

During the interviews and group discussions some pupils provided positive feedback which on occasion was directly aimed at the teacher or classroom assistant who was also in the room with them:

“We learned it from our best teacher ever ... I was happy with [teacher] telling me because it made me more knowledgeable on it”. Pupil 28, age 12-19.



WHEN TO DELIVER AGAIN?

The amount of time allocated to RSE, and the age it was taught differed between each school. This was dependant on the preference of the school and the teacher assigned to deliver the subject; no standard approach was apparent. In some schools there was a 'one-off' programme of delivery, whilst in others it was delivered over several years, with each year reinforcing and building on the previous learning:

“Generally those first couple of sessions are like ease in sessions. Like something that’s not too much for them to handle initially. So, they get comfortable and then you can start to explore those kind of deeper things a little bit, but definitely initially for those first couple of years we just talk about it in their own sex, but maybe they’re learning about the other body, but they’re not learning it with them there. And then they’ve got a bit of confidence by the time they hit that kind of older age group”. Professional 4.

A resounding message that came through the narratives of the pupils, parents and professionals, was that teaching of RSE should not stop for young people with intellectual disabilities when they leave school. Rather, it should continue and be incorporated into Adult Services as it is only when these young people are experiencing the different situations as they grow older, that the learning has more meaning and impact:

“It shouldn’t really stop there [leaving school] because there might be more stuff that school doesn’t teach you that you should know”. Pupil 31, age 14.

“For our children who don’t necessarily follow a chronological learning path, for things like that to suddenly stop and fall off a cliff once they’ve left a full time, you know at 19, once they leave full time school situation, is doing them a disservice ... it’s something that should be there for whatever it is that they’re doing, whether it’s a college, or vocational, or some other kind of care facility, after school, it should be a constant thread ... it’s one of the most valuable things that is going to help them go forward in their life ... to kind of just fall by the wayside once they leave the school building, just really does them a disservice”. Parent 1.

“You still need that education and what might be relevant to somebody when they leave school, mightn’t be relevant to them five, six years down the line, so the education needs to be continued and the programmes need to be run”. Professional 12.



“We learned it from our best teacher ever ... I was happy with [teacher] telling me because it made me more knowledgeable on it”.



OVERVIEW OF FINDINGS

The qualitative interviews with pupils, parents and professionals from across the four countries of the United Kingdom revealed the importance and value of teaching RSE in special education schools.

Our UK-wide qualitative study showed that the young people already possess some knowledge and understanding and want more information on friendships, sex, contraceptive use, and abusive relationships while parents were concerned about safety both in-person and online, the importance of respecting boundaries and consent. Both the young people and parents want to learn about relationships and mental health.

It was deemed important by the educators to ensure that learning had taken place before moving on to the next topic within a RSE programme. At times this required information to be repeated with more explanation or in accessible terms, or a pause placed on the programme to enable the pupils to process

the information received. The young people were keen to learn about relationships and sexuality and embraced the many different delivery approaches utilised. They learned at a level and pace conducive to their needs which subsequently made them feel valued as young persons:

“I really thought it was useful to learn about it [RSE] ... I think it’s very useful for life and going forward in relationships like what you are going to do when you’re older and your own choices”. Pupil 33, age 15.

“I reckon it’s [RSE] so important because like, it can be too late and then a baby comes. Then practically your childhood’s ruined because you have a baby and all your friends are going out to clubs or whatever, and you’re sitting in the house minding a baby”. Pupil 33, age 15.

RSE PROGRAMME MAP – WHAT TO DELIVER

The aim of the RSE Programme Map is to provide the professionals delivering the education with guidance and inspiration to assist them in the development and delivery of comprehensive relationships and sexuality education for all pupils within their remit.

The suggested content of the RSE Programme Map was identified through analysis of the data from the study participants which pupils, parents and professionals identified as the most important to include. These are grouped as falling under one of three themes: relationship; sexual; and 'cross-cutting'. Each theme is considered an interlinking piece of a jigsaw, with one informing the other, as shown in Figure 2:

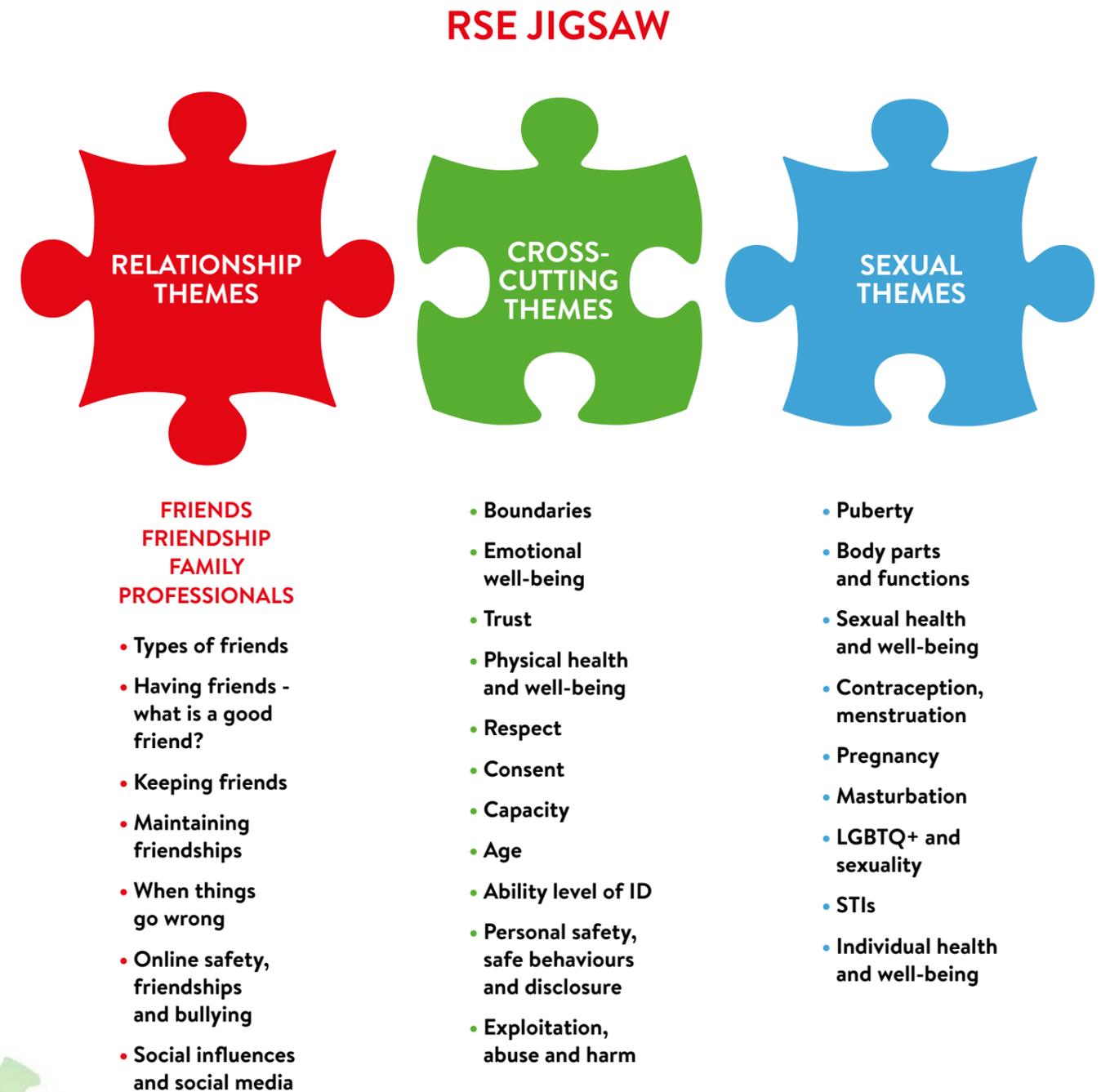


Figure 2: RSE Jigsaw Programme Map

Clearly defined learning aims, objectives and outcomes for the programme and each session within should be articulated at the outset.



“The mechanism for delivery is completely different depending on who you’re working with, age range, ability wise, an important message”.



USEFUL RESOURCES

AMAZE

An online platform to provide sexual health education to children and young people, educators, health care providers, parents and guardians, mainly through the use of videos.

<https://amaze.org>

BARRY CARPENTER

<https://barrycarpentereducation.com/category/research-2/>

BODYSENSE INSTRUCTIONAL DOLLS

Three dolls to assist teaching sexual health education to students with intellectual disabilities.

Two of the dolls are anatomically correct adult dolls. To teach about the human body, hygiene and social interactions. The third doll has female genitalia and internal reproductive organs to teach anatomy, menstruation, hygiene, masturbation and reproduction.

<http://bodysense.org.uk/wordpress/>

BOOKS BEYOND WORDS

<https://booksbeyondwords.co.uk>

CCEA (Council for the Curriculum, Examinations and Assessment), Northern Ireland
Relationships and Sexuality Education

<https://cea.org.uk/learning-resources/relationships-and-sexuality-education-rse>

CENTRAL SEXUAL HEALTH

NHS Forth Valley's website which provides additional support needs resources for use by a range of professionals.

<https://centralsexualhealth.org/professionals/learning-disabilities/>

CHALLENGING BEHAVIOUR FOUNDATION

<https://www.challengingbehaviour.org.uk>

CHANGE PEOPLE UK

A range of accessible resources for people with intellectual disabilities are available to buy on friendships, relationships, sexuality, LGBTQ, sex, safe sex, contraception, masturbation, pregnancy, parenting and sexual abuse.

<https://www.changepeople.org/shop/products>

CIRCLES SOCIAL SKILLS UTILITY™

An app that simplifies sexuality by teaching about social relationships, intimacy and boundaries. A pilot study found an improvement in user's understanding of social boundaries after using the app, particularly where physical contact should be minimal or not at all (Faight et al., 2020).

<https://www.circlesapp.com/>

Useful Resources contd. over/

USEFUL RESOURCES contd.

COMMON YOUTH

<https://commonyouth.com>

DEPARTMENT FOR EDUCATION IN ENGLAND

Support and training materials for schools to help train teachers on relationships, sex and health education.

<https://www.gov.uk/guidance/teaching-about-relationships-sex-and-health#train-teachers-on-relationships-sex-and-health-education>

DOWN'S SYNDROME ASSOCIATION

<https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/relationships-and-sex-education/>

DR RANJ SINGH

How to Grow Up and Feel Amazing! The No Worries Guide for Boys

In this book Dr Ranj explains everything you ever wanted to know about puberty - plus lots more.

ELIZABETH SCHMIDT RESOURCES

<https://ekschmidt.com/resources/>

FAMILY PLANNING ASSOCIATION

Useful RSE information and resources.

<https://www.fpa.org.uk/our-views/>

FUMBLE

Your handy guide to sex.

<https://fumble.org.uk>

INFORMING CHOICES NI

Deliver Relationships and Sexuality Education (RSE) programmes.

<https://informingchoicesni.org/education>

JIGSAW

Teaching resources to help teachers confidently teach a well-being curriculum.

<https://jigsawpshe.com/home>

JUST THE TWO OF US

Big questions and short answers on sex, Down Syndrome, and sexuality.

https://justthetwoofus.org/?_ga=2.185697260.45255485.1676291197-2011108130.1676291197#toggle-id-15-closed

KEEPING CHILDREN AND YOUNG PEOPLE SAFE:

An Online Safety Strategy for Northern Ireland 2020-2025

<https://www.health-ni.gov.uk/sites/default/files/publications/health/online-safety-strategy.pdf>

MENCAP

Advice and support about sexuality and relationships for those with a learning disability.

<https://www.mencap.org.uk/advice-and-support/relationships-and-sex>

MIDDLETOWN CENTRE FOR AUTISM

Designs and delivers training programmes cognisant of the needs of parents, education professionals and those who traverse these groupings.

<https://www.middletownautism.com>

NSPCC

PANTS resources for schools and teachers.

<https://learning.nspcc.org.uk/research-resources/schools/pants-teaching>

PUBERTY AND SEXUALITY FOR CHILDREN AND YOUNG PEOPLE WITH A LEARNING DISABILITY (NHS, 2009).

A sexual health teaching pack for children and young people with disabilities aged 9-18 years including children with severe intellectual disabilities.

<https://s3-eu-west-1.amazonaws.com/leedssexualhealth.com/downloads/Puberty-Sexuality-Pack.pdf>

RAPE CRISIS SCOTLAND

Useful resources on sexual violence for young people.

<https://www.rapecrisisscotland.org.uk/resources/?cat=3>

RSHP (Relationships, Sexual Health and Parenthood)

The RSHP resource has been developed by a partnership of local authorities and health boards, with advice from Education Scotland and the Scottish Government. The resource can be used in early learning settings, schools, colleges and community-based learning. It is organised to sit within Curriculum for Excellence. A network can be joined and subscription includes being kept informed of any developments in the delivery of RSHP education.

<https://rshp.scot>

SANCTUARY FILM, BLUE TEAPOT COMPANY, GALWAY, IRELAND

A film made with actors and advocates with intellectual disabilities to highlight relationships and sexuality.

http://blueteapot.ie/our_performances/sanctuary-film/

Useful Resources contd. over/

USEFUL RESOURCES contd.

SEX AND THE 3R'S:

Rights, Risks and Responsibilities: A sex education pack for working with people with learning disabilities

A resource that offers a framework for professionals to facilitate sexual health education to adults with intellectual disabilities that is inclusive of LGBTQ. Possible issues are identified, as well as suggestions on how to work around them. The topics include consent, safer sex, sexting, pornography and sexual abuse.

<https://www.pavpub.com/learning-disability/sexual-health/sex-and-the-3-rs-rights-risks-and-responsibilities>

SEXUALITY AND INTELLECTUAL DISABILITY:

A Guide for Professionals

A book on gender and sexuality for professionals working in the intellectual disability sector. Provides guidance and toolboxes on dating, sex education and LGBTQ inclusion.

<https://www.routledge.com/Sexuality-and-Intellectual-Disabilities-A-Guide-for-Professionals/Triska/p/book/9781138231023>



SHEPHERD SCHOOL, NOTTINGHAM, UK

A video of best practice showing the delivery of a sexual health education programme to young people with intellectual disabilities.

<https://online.clickview.co.uk/exchange/channels/32366675/teachers-tv/videos/36769760/sex-and-relationship-education>

SUPPORTED LOVING UK

A website advocating for the rights of people with intellectual disabilities to have relationships and provides a range of resources for people with intellectual disabilities, parents and staff.

<https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving>

TALKABOUT

A structured programme for teaching and measuring social skills. It is a whole scheme of work which helps assess, teach and measure work easily.

<http://alexkelly.biz/alex-work-and-talkabout/>

THE CENTER FOR PARENT INFORMATION AND RESOURCES

A website with a range of sexual health education resources for educators to use with children and adults with disabilities. This includes sexual development, sexuality, dating, healthy relationships, sexual self-advocacy, and information for parents and resources for specific disabilities.

<https://www.parentcenterhub.org/sexed/>

THINGS ELLIE LIKES AND THINGS TOM LIKES

Accessible books about sexuality, puberty and masturbation for boys and girls, and young men and women, with autism and related conditions.

https://uk.jkp.com/products/whats-happening-to-ellie?_pos=2&_sid=204e978de&_ss=r

TODD PARR

It's Okay to be Different.

<https://www.toddparr.com/todd-parr/todd-parr-the-traveling-its-okay-to-be-different-tour/>

FINAL CONCLUSION AND RECOMMENDATIONS

What is evident from the wider international research literature and the findings from our study is that children and young people with intellectual disabilities want education and information to develop their knowledge and understanding regarding friendships, relationships and the expression of their sexuality.

Parents of children and young people with intellectual disabilities recognise the need for their children to have access to education that is tailored and specific to their individual needs. They have concerns about potential exploitation and targeting by other young people and potential predators. Parents recognise that education and information is empowering for their children and they want to be involved and informed about the content of RSE programmes, what is being taught and when.

A range of professionals are currently proactively involved locally in the development and delivery of RSE programmes, adopting creative teaching and learning approaches. There is a need for formal evaluation of the impact and outcomes achieved as a result of participation in a RSE programme. There is currently little formal evidence that the children and young people can and do generalise their learning more effectively in different situations.

There is also limited evidence of the long-term outcomes achieved on issues such as forming and maintaining friendships, forming and developing relationships, consent and decision making, unplanned pregnancy, reduction in sexually transmitted infections and reduction in safeguarding concerns and exploitation.

Therefore, arising from the findings from our study a number of evidence-informed recommendations are made:

RECOMMENDATION 1

A structured, evidence-based RSE programme needs to be developed, tested and implemented within special schools for children and young people with intellectual disabilities.

RECOMMENDATION 2

RSE programme development needs to be flexible and adaptable and delivered for all levels of intellectual disability, age and ability across special school settings.

RECOMMENDATION 3

Defined aims, objectives and outcome measures for the delivery of relationships and sexuality education need to be developed and implemented for RSE programmes.

RECOMMENDATION 4

Evaluation mechanisms before, during and after delivery need to be developed and integrated within all RSE programmes.

RECOMMENDATION 5

There is a need to develop and implement a support network for professionals involved in the development, delivery and evaluation of RSE programmes.

RECOMMENDATION 6

Longitudinal follow up studies are required to identify the impact and outcomes achieved through the delivery of RSE programmes.

RECOMMENDATION 7

Further research is required which adopts a lifespan approach on the RSE needs of adults with intellectual disability to ensure they have evidence-based information to make informed choices and decisions.

RECOMMENDATION 8

There is a need to scope and develop a RSE programme to address the specific needs of adults with intellectual disability living in the community.



PROJECT DISSEMINATION

The findings of the study will be shared with the participating schools and a range of other organisations across the United Kingdom. Dissemination of findings will also take place via local and international events and publications including:

- An event in Northern Ireland
- Visits to schools
- Pupil webinar
- Journals



REFERENCES

Baines, S., Emerson, E., Robertson, J. & Hatton, C. (2018).

Sexual activity and sexual health among adults with and without mild/moderate intellectual disability. BMC Public Health, 18(667), 1-2.

<https://doi.org/10.1186/s12889-018-5572-9>

Ballan, M. (2012).

Parental perspectives of communication about sexuality in families of children with autism spectrum disorders.

Journal of Autism and Developmental Disorders, 42, 676-684.

<https://doi.org/10.1007/s10803-011-1293-y>

Box, M. & Shaw, J. (2014).

The experiences of adults with learning disabilities attending a sexuality and relationship group: I want to get married and have kids.

Journal of Family Planning and Reproductive Health Care, 40(2), 82-88.

<http://dx.doi.org/10.1136/jfprhc-2012-100509>

Brown, M. & McCann, E. (2018).

Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. Research in Developmental Disabilities, 74, 124-138.

<https://doi.org/10.1016/j.ridd.2018.01.009>

Buchner, T., Shevlin, M., Donovan, M.A., Gercke, M., Goll, H., Šiška, J., Janyšková, K., Smogorzewska, J., Szumski, G., Vlachou, A. and Demo, H. (2021).

Same progress for all? Inclusive education, the United Nations Convention on the rights of persons with disabilities and students with intellectual disability in European countries.

Journal of Policy and Practice in Intellectual Disabilities, 18(1), 7-22.

<https://doi.org/10.1111/jppi.12368>

Conder, J.A., Mirfin-Veitch, B.F. & Gates, S. (2015).

Risk and Resilience Factors in the Mental Health and Well-Being of Women with Intellectual Disability. Journal of Applied Research in Intellectual Disabilities, 28(6), 572-583.

<https://doi.org/10.1111/jar.12153>

Cooper, V., Emerson, E., Glover, G., Gore, N.J., Hassiotis, A., Hastings, R., Knapp, M.R.J., McGill, P., Oliver, C., Pinney, A. & Richards, C. (2014).

Early intervention for children with learning disabilities whose behaviour challenges.

Challenging Behaviour Foundation. Available at:

<https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/Briefing-Paper.pdf>

REFERENCES cont.

Emerson, E. & Hatton, C. (2008).

People with learning disabilities in England: CeDR Research Report.

Centre for Disability Research. Available at:

https://www.lancaster.ac.uk/staff/emersone/FASSWeb/Emerson_08_PWLDinEngland.pdf

Fisher, M.H., Baird, J.V., Currey, A.D. & Hodapp, R.M. (2016).

Victimisation and social vulnerability of adults with intellectual disability:

A review of research extending beyond Wilson and Brewer.

Australian Psychologist, 51(2), 114-127.

<https://psycnet.apa.org/doi/10.1111/ap.12180>

Florian, L. (2019).

On the necessary co-existence of special and inclusive education.

International Journal of Inclusive Education, 23(7-8), 691-704.

<https://doi.org/10.1080/13603116.2019.1622801>

Frawley, P. & Wilson, N.J. (2016).

Young people with intellectual disability talking about sexuality education and information.

Sex Disability, 34, 469-484.

<https://doi.org/doi:10.1007/s11195-016-9460-x>

Huang, J., Zhu, T., Qu, Y., & Mu, D. (2016).

Prenatal, perinatal and neonatal risk factors for intellectual disability:

A systemic review and meta-analysis.

PLoS ONE, 11(4), e0153655.

<https://doi.org/10.1371/journal.pone.0153655>

Jahoda, A. & Pownall, J. (2014).

Sexual understanding, sources of information and social networks;

the reports of young people with intellectual disabilities and their non-disabled peers.

Journal of Intellectual Disability Research, 58(5), 430-441.

<https://doi.org/10.1111/jir.12040>

Jarjour, I.T. (2015).

Neurodevelopmental outcome after extreme prematurity: a review of the literature.

Pediatric Neurology 52(2), 143-152.

<https://doi.org/10.1016/j.pediatrneurol.2014.10.027>

Klang, N., Göransson, K., Lindqvist, G., Nilholm, C., Hansson, S. & Bengtsson, K. (2020).

Instructional practices for pupils with an intellectual disability in mainstream and special educational settings.

International journal of disability, development and education, 67(2), 151-166.

<https://doi.org/10.1080/1034912X.2019.1679724>

Lenehan, C. (2017).

These are our children.

Council for Disabled Children. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/585376/Lenehan_Review_Report.pdf

McCann, E. & Brown, M. (2018).

The inclusion of LGBT+ health issues within undergraduate healthcare education and professional training programmes: A systematic review.

Nurse Education Today, 24, 204-214.

<https://doi.org/10.1016/j.nedt.2018.02.028>

McCarthy, M. (2014).

Women with intellectual disability: Their sexual lives in the 21st century.

Journal of Intellectual and Developmental Disability, 39(2), 124-131.

<http://dx.doi.org/10.3109/13668250.2014.894963>

McDaniels, B. & Fleming, A. (2016).

Sexuality education and intellectual disability: Time to address the challenge.

Sexuality and Disability, 34, 215-225.

<http://dx.doi.org/10.1007/s11195-016-9427-y>

Simpson, A., Lafferty, A. & McConkey, R. (2006).

Out of the shadows: A report of the sexual health and well-being of people with learning disabilities in Northern Ireland.

Family Planning Association. Available at:

<https://pure.ulster.ac.uk/en/publications/out-of-the-shadows-a-report-on-the-sexual-health-and-wellbeing-of-3>

UNICEF. (1989).

The United Nations Convention on the Rights of the Child.

Available at:

<https://www.unicef.org.uk/wp-content/uploads/2016/08/unicef-convention-rights-child-uncrc.pdf>

World Health Organisation. (2015).

Sexual health, human rights and the law.

Geneva: World Health Organisation. Available at:

https://apps.who.int/iris/bitstream/handle/10665/175556/9789241564984_eng.pdf

“I really thought it was useful to learn about it [RSE] ... I think it’s very useful for life and going forward in relationships like what you are going to do when you’re older and your own choices”.





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