



# 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



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin



University  
of Glasgow



# WELCOME



# PROGRAMME



Opening Address

Human Rights Commission and RSE

Why RSE matters - a parent's perspective

Question Time - pupil views on RSE

Background to the study

What we did

What we found and what needs to happen

Open forum

Closing comments

Lunch





# RESIDE

RELATIONSHIPS AND SEXUALITY IN  
INTELLECTUAL DISABILITY EDUCATION



# OPENING ADDRESS



**Professor Christopher Scott**

Acting PVC for Research

*MHLS Faculty,  
Queen's University Belfast*







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# HUMAN RIGHTS COMMISSION AND RSE



NORTHERN IRELAND  
HUMAN RIGHTS  
COMMISSION

**Lauren Shaw**

Policy and Research Officer

*Human Rights Commission*



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# WHY RSE MATTERS - A PARENT'S PERSPECTIVE



Mark



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# QUESTION TIME - PUPIL VIEWS ON RSE



## Knockevin Senior School

Castlewellan Campus





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# BACKGROUND TO THE STUDY



## RSE Research Team



# RESEARCH TEAM

## **QUEEN'S UNIVERSITY BELFAST, School of Nursing and Midwifery**

**Prof Michael Brown**, Professor of Nursing and Director of Graduate Studies

**Dr Mark Linden**, Reader and Director of Research

**Dr Lynne Marsh**, Senior Lecturer in Learning Disabilities

**Dr Freda McCormick**, Research Fellow

## **UNIVERSITY OF GLASGOW, Scottish Learning Disability Observatory**

**Dr Maria Truesdale**, Senior Lecturer in Intellectual Disabilities

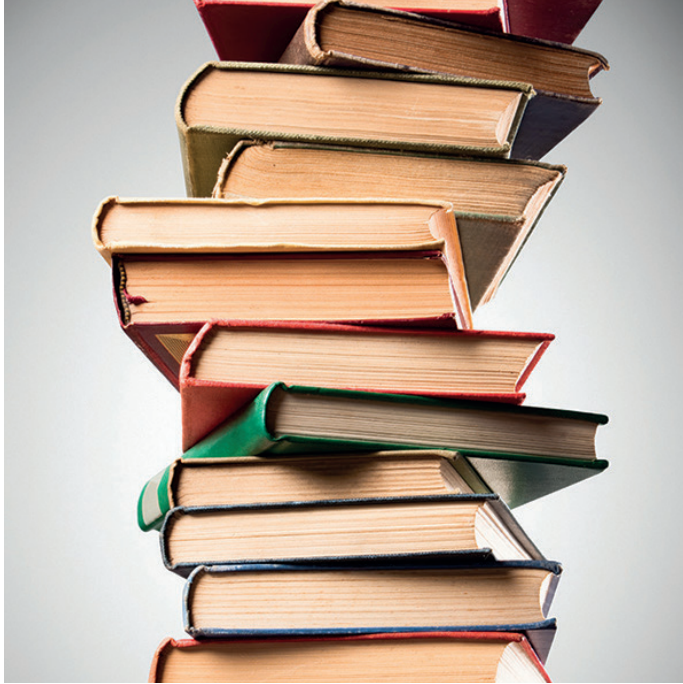
## **TRINITY COLLEGE DUBLIN, School of Nursing and Midwifery**

**Dr Fintan Sheerin**, Associate Professor in Intellectual Disability Nursing  
and Head of School of Nursing and Midwifery





# ACKNOWLEDGEMENTS



- Burdett Trust for Nursing, the study funder
- The parents, pupils and professionals who participated in the interviews and focus groups
- The Project Advisory Group who provided advice and guidance throughout the study
- Compass Advocacy Network for easy read content
- Garry Gilmour at EH6 Design for creating the marketing materials and RESIDE logo



# BACKGROUND

- Approximately 1.5 million of the UK population have a learning disability of which 286,000 are children and young people aged 0-17 years.
- CYPLD experience specific and distinct barriers regarding developing and sustaining relationships and in the expression of their sexuality.
- People with learning disabilities want friendships, meaningful relationships and some want intimacy but are often limited and restricted.
- Often misperceived as being either asexual, hypersexual or sexually immature.
- Increased risk of unplanned pregnancy, mental health conditions, sexual abuse and exploitation.
- Need to develop the understanding of families and professionals in education, social care and health services.



# SYSTEMATIC LITERATURE REVIEW 2019

Original Article

## People with intellectual disabilities, relationship and sex education programmes: A systematic review

Edward McCann<sup>a</sup>, Lynne Marsh<sup>b</sup> and Michael Brown<sup>b</sup>

<sup>a</sup>School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland

<sup>b</sup>School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

### Abstract

**Objective:** The aim of this systematic review was to examine the research evidence concerning the views and experiences of people with intellectual disabilities regarding their participation in and the effectiveness of relationship and sex education programmes.

**Methods:** A systematic search of relevant electronic databases was conducted using defined inclusion criteria. All papers reviewed were from October 1998 to October 2018. PRISMA guidelines were followed in the design and reporting of the systematic review.

**Results:** A total of eight studies published in English were included in the review. Data were analysed and the key themes identified were (1) designing and developing relationship and sex education programmes, (2) participating in relationship and sex education programmes and (3) perceived benefits of relationship and sex education programme participation.

**Conclusion:** This review identified that people with intellectual disabilities are accessing relationship and sex education programmes and appear to find them helpful. Further research is required to investigate the extent to which programmes impact on long-term behaviours that enable the development of sustainable relationships and reduce the unintended consequences of sexual activities. Implications for policy, practice and future research developments are discussed.

### Keywords

Intellectual disabilities, programmes, sex education, sexuality education, systematic review

## HEJ

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Eight papers selected from a total of 1,685

Three themes identified - designing and developing, participating in, and perceived benefits of RSE programmes

RSE programmes appear to be helpful

Need to investigate long term impact

Implications for policy, practice and future research



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# SYSTEMATIC LITERATURE REVIEW 2020



International Journal of  
Environmental Research  
and Public Health



Review

## The Design, Content and Delivery of Relationship and Sexuality Education Programmes for People with Intellectual Disabilities: A Systematic Review of the International Evidence

Michael Brown <sup>1,\*</sup>, Edward McCann <sup>2</sup>, Maria Truesdale <sup>3</sup>, Mark Linden <sup>1</sup> and Lynne Marsh <sup>1</sup>

<sup>1</sup> School of Nursing and Midwifery, Queen's University Belfast, Northern Ireland BT9 7BL, UK; m.linden@qub.ac.uk (M.L.); l.marsh@qub.ac.uk (L.M.)

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**Abstract:** There is growing empirical evidence regarding the relationship and sexuality experiences and needs of children, young people and adults with intellectual disabilities. A total of twelve papers met the inclusion criteria regarding relationship and sexuality education (RSE) programmes specific to the needs of this population. The preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines were followed and quality appraisal undertaken. The four themes identified were principles informing RSE programme development, design and content of RSE programmes, delivery of RSE programmes and evaluation of RSE programmes. The discussion presents areas that need to be addressed to ensure that people with intellectual disabilities, their families, carers and professionals are fully involved in the design and delivery of RSE programmes. Further research is required to identify the impact of the programmes and the sustained outcomes achieved. Recommendations are made regarding the activities required to enable the development of evidence-based and person-centred approaches to relationship and sexuality programmes.

**Keywords:** intimate relationships; sexuality; programme content; programme delivery; intellectual disabilities

Twelve papers selected from a total of 1,033

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Four themes identified - principles informing RSE programme development, design and content, delivery, and evaluation of RSE programmes

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Areas need to be addressed to ensure that people with intellectual disabilities, families, carers and professionals are involved in design and delivery of RSE programmes

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Need to identify programme impact and sustained outcomes



# THE STUDY



- Funded by the Burdett Trust for Nursing
- Developing Best Practice Guidelines for health, social care and education practitioners regarding relationships and sexuality education programmes for children and young adults with intellectual disabilities
- 12-month study
- Qualitative design
- Special schools in England, Northern Ireland, Scotland and Wales





# THE APPROACH



## Education required to support practice innovation and RSE needs

- Established Project Advisory Group
- Identified school sites across four regions
- Qualitative interviews
- Focus groups
- Data analysis
- Development of best practice guide and project report
- Dissemination and publications



# THE TIMELINE



- Study commenced November 2021
- Ethics amendment approval granted January 2022
- Established PAG - February 2022
- Recruitment and data collection – February 2022 to February 2023
- Data analysis - January to April 2023
- Project report and best practice guide - May to September 2023
- Report and best practice guide launch - October 2023

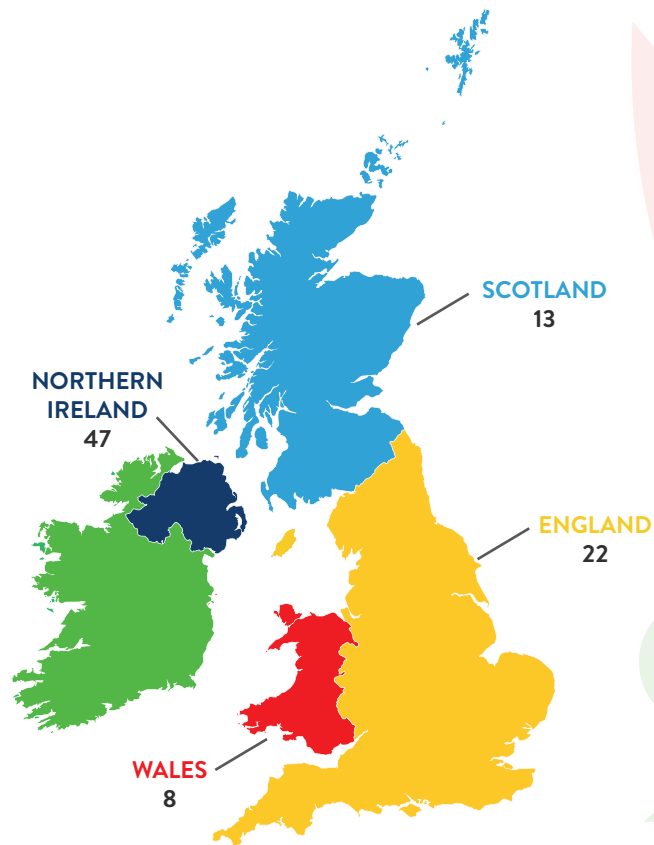
# WHAT WE DID



## RSE Research Team



# EXPRESSIONS OF INTEREST ACROSS THE UNITED KINGDOM



# PARTICIPATION 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
<b>TOTAL</b>	<b>37</b>	<b>11</b>	<b>16</b>	<b>64</b>

# PUPIL INTERVIEWS



- Aged between 12 and 19 years
- 13 online via Microsoft Teams
- 4 face-to-face
- 12 in a boys' group
- 8 in a girls' group

# PARENT AND PROFESSIONAL INTERVIEWS AND FOCUS GROUPS



## PARENTS

- 11 interviews

## PROFESSIONALS

- 7 interviews
- 9 professionals over 2 focus groups



# DATA ANALYSIS



# THEME 1



## INITIAL PLANNING AND PREPARATION

- Learning styles and learning needs
- Age and ability
- Communication

# THEME 2



## DELIVERY OF RELATIONSHIPS AND SEXUALITY EDUCATION

- Delivery modes
- Who delivers?
- How is it delivered?

# THEME 3



## EVALUATION OF RSE

- Programme evaluation
- When to deliver again?

# WHAT WE FOUND AND WHAT NEEDS TO HAPPEN



## RSE Research Team





# OVERVIEW OF STUDY FINDINGS



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.

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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.

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Concerns about potential exploitation and targeting by other young people and potential predators.

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A range of professionals are involved in the development and delivery of RSE programmes, adopting creative teaching and learning approaches.



# RSE PROGRAMME MAP - WHAT TO DELIVER



## FRIENDS FRIENDSHIP FAMILY PROFESSIONALS

- Types of friends
- Having friends - what is a good friend?
- Keeping friends
- Maintaining friendships
- When things go wrong
- Online safety, friendships and bullying
- Social influences and social media



- Boundaries
- Emotional well-being
- Trust
- Physical health and well-being
- Respect
- Consent
- Capacity
- Age
- Ability level of ID
- Personal safety, safe behaviours and disclosure
- Exploitation, abuse and harm



- Puberty
- Body parts and functions
- Sexual health and well-being
- Contraception, menstruation
- Pregnancy
- Masturbation
- LGBTQ+ and sexuality
- STIs
- Individual health and well-being

## RSE Jigsaw

# USEFUL RESOURCES



# WHAT NEEDS TO HAPPEN

- 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.



# NEXT STEPS

Funding has been received from the Medical Research Council, Public Health Intervention Development (MRC PHIND) and the Northern Ireland Research and Development Fund to:

- Co-develop a RSE programme for children and young people with intellectual disabilities
- Test the acceptability of this programme with children and young people, parents and teachers
- Develop a future funding proposal to test the feasibility and effectiveness of the newly developed programme.





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# OPEN FORUM







# RESIDE

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# THANK YOU



The study report  
**IT'S MY LIFE -  
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can be accessed here:





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