Scottish Learning Disabilities Observatory

Welcome to the 2025 Scottish Learning Disabilities Conference

This document contains information about today's event, including session details, speaker bios, and important information about the venue.

Programme:

Time	Session	Speakers
9.30-10.00	Registration, tea and coffee	
10.00 -11.05	Session 1	Chair: Deborah Cairns
10.00 - 10.10	Welcome	Deborah Cairns (SLDO)
10.10 - 10.35	25 years of learning disabilities research at the University of Glasgow	Andrew Jahoda (SLDO)
10.35-10.45	A message from the Minister for Social Care and Mental	Tom Arthur and Amanda McCarren, Scottish Government
10.45- 11.05	Wellbeing Celebrating partners and collaborators. SLDO film preview	Deborah Cairns (SLDO)
11.05 -11.30	Coffee Break	
11.30 - 13.00	Session 2	Chair: Maria Truesdale
11.30 - 11.50	Pain related medication in adults with learning disabilities	Christine Pacitti (SLDO) and Sarita Soni) (NHS Greater Glasgow and Clyde)
11.50-12.15	Smart Bra for Cancer Detection	Deborah Cairns (SLDO) and Yang Wei (Nottingham Trent University)
12.15 - 12.35	Research for Everyone	Fiona Barlow (SLDO) and Aaron Hume



12.35 - 13.00 13.00 - 14.00	Supporting neurodivergent young people into employment Lunch and Poster Session	Craig Melville (SLDO), Lily Meehan, Lorraine Waddell and Audrey Dickie (University of Glasgow)
14.00 - 15.15	Session 3	Chair: Craig Melville
14.00 - 14.25	Future Friendships: Codesigning a programme to support the friendships of young people with a learning disability across the transition from secondary school	Amanda Gillooly (SLDO), Catherine Dempsey (ARC Scotland), and Leeanne Clark
14.25 - 14.50	BEATIt 2: A story of collaboration	Katrina Bannigan (SLDO) and Jenny Miller (PAMIS)
14.50 - 15.15	Supporting healthy lifestyles for people with learning disabilities	Arlene McGarty (SLDO) and Michael McEwan
15.15 - 15.30	Comfort Break	
15.30-16.30	Session 4	Chair: Arlene McGarty
15.30 - 15.55	Working together in partnership to improve diabetes education for adults with learning disabilities in Scotland.	Maria Truesdale (SLDO) & Scott Taylor (NHS Lothian)
15.55 - 16.20 16.20-16.30	Positive Behaviour Support (PBS) at the University of Glasgow: Developing a PBS Pathway in NHS Forth Valley Closing remarks	Anne MacDonald (SLDO) and Ginny Avery (NHS Forth Valley) Deborah Cairns
10.20 10.00	Ciosing i cinariks	Deporari Carris



Poster session (in the Byres Hub) - in alphabetical order by first author:

Nada Alhozaimy - The Inclusive schooling in Saudi Arabia: experiences of typically developing students

Deborah Cairns et al - Research for Everyone

Marie Murphy et al - Improving access to cancer screening among people with learning disabilities: development of a complex intervention

Shylet Musabayana – Exploring the lived experiences of Black African families of adults with learning disabilities living at home in the UK.

Christine Pacitti - Investigating Pain Related Medication Use in Adults with Intellectual Disability: A Systematic Literature Review

Jingyuan Sun - Physical activity in children with and without disabilities

Laura Ward - Cancer incidence and mortality among adults with learning disabilities in Scotland

Presentation summaries (in order of the programme):



Understanding Pain and Medication Use in Adults with Learning Disabilities: Why Working Together Matters

Christine Pacitti and Sarita Soni

This presentation explores how pain is recognised and treated in adults with learning disabilities, and why this matters for their health and wellbeing. People with learning disabilities often live with

multiple health conditions and take several medications, but pain can be missed or misunderstood, especially when communication is difficult.

The talk is based on a research project that reviewed existing studies on pain-related medication use in this group. One key finding is that pain often goes under-treated, even though many people are prescribed



multiple medications. In contrast, psychotropic medications (used for mental health or behaviour) were more commonly prescribed, sometimes without a clear diagnosis. This raises important questions about how pain is recognised and managed, and whether better pain care could reduce the need for other medications.

The presentation also highlights the importance of working together. Bringing together researchers, doctors, pharmacists, carers, and people with lived experience could help us to better understand pain challenges and improve care for people with learning disabilities. We will discuss real-life relevance and how shared working can help reduce health inequalities and improve quality of life. Find out more via https://bit.ly/3ZwVH4f

Smart Bra for Cancer Detection

Deborah Cairns and Yang Wei

A recent study by the Scottish Learning Disabilities
Observatory (SLDO) found that women with learning
disabilities are more likely to die from breast cancer compared to women
without learning disabilities. Women with learning disabilities are less
likely than women without learning disabilities to take part in breast
screening. Breast screening can lower breast cancer deaths.

A recent 'Cancer Research UK' <u>study by the SLDO team and Cancer</u>
<u>Behaviour Research Group</u>, <u>at the University of Glasgow</u>, found that
women with learning disabilities, carers and health professionals reported
that some women with learning disabilities found it difficult or simply not
possible to use the mammography machine, which is what is used for
breast screening. This is an important research finding and explains why
some women with learning disabilities do not take part in breast
screening. We want to make it easier for women with learning disabilities
to have breast screening. We are working with Scientists at Nottingham
Trent University, and people with learning disabilities, to make a 'Smart



Bra' that will be able to identify if someone has breast cancer. The 'Smart Bra' will make breast screening much easier to do. The 'Smart Bra' may also help to detect breast cancer at an early stage, and this could lead to better health outcomes for all women, with and without learning disabilities. Find out more via https://bit.ly/smartbranews



Research for Everyone

Aaron Hume and Fiona Barlow

The aim of Research for Everyone was to make complex health research easier to understand for as many people as possible. This project was led by people with learning disabilities and researchers at

the University of Glasgow. Through facilitated workshops, we translated two complex health studies published by researchers from the University of Glasgow's College of Medical, Veterinary and Life Sciences – one study was about the link between heading the ball in football and neurodegenerative disease, and one was about the impact of living with cancer on mental health. Our group created three outputs per study: an animation, an infographic and a podcast episode.

The outputs reached over 150,000 people online within 6 weeks. We received positive survey responses about how useful the outputs were and the importance of making research easier to understand for as many people as possible. University of Glasgow colleagues have since used an adapted version of the Research for Everyone model to support their work and a new University of Glasgow training resource is being developed to support researchers to engage ethically with underrepresented groups, influenced by the feedback from researchers about this project.

We hope this inclusive approach to creation of novel research communication tools can address some of the barriers to accessing research and help more people to engage with science that is relevant and



important to them. Find out more, including where to watch and listen to the animations and podcast episodes via https://bit.ly/Research4Every1



Supporting neurodivergent young people into employment

Craig Melville, Lily Meehan, Lorraine Waddell and Audrey Dickie

The Scottish Government policy called <u>No One Left Behind</u> provides a framework to support neurodivergent and disabled people to find paid employment. Universities, hospitals and other public sector settings can support this policy. Although there are obstacles, we want to talk about the positive impact that working with Lily has had on the School of Health and Wellbeing, and our plans to work with Project Search, run by Glasgow City Health and Social Care Partnership, to offer internships to neurodivergent young people.

Session 3



Future Friendships: Co-designing a programme to support the friendships of young people with a learning disability across the transition from secondary school

Amanda Gillooly, Leeanne Clark and Catherine Dempsey

The transition from secondary school can be challenging for many young people with learning disabilities. Previous research indicates that friendships can be difficult to maintain during this transition. We conducted workshops with young adults with learning disabilities, family carers, and teachers to find out what helps people to develop and sustain friendships when they leave school and what makes this difficult. We worked together with young adults, family carers and teachers to co-



design a programme to support the friendships of young people across the transition from school.

The programme sessions focus on different topics which people told us were important in making and sustaining friendships. This includes exploring common interests, building confidence, keeping in touch digitally, and social activity planning. This programme is currently being piloted in schools to find out if this is feasible to deliver and if it is helpful for young people and their families. Find out more https://bit.ly/3UUXIDG



BEATIt 2: A story of collaboration

Katrina Bannigan and Jenny Miller

A researcher and a leading expert will present together to provide an overview of Beatlt2 to highlight that depression is a common problem for people with severe to profound learning disabilities. Yet, there is no research about psychological help for adults with severe to profound learning disabilities who have depression.

Behavioural activation is a psychological therapy that is about helping people to improve their mood by having more purposeful activity in their lives. BeatIt2 is an adapted version of this approach for people with severe to profound learning disabilities. BeatIt2 was adapted with the help of PAMIS, drawing on their 33 years' experience of solely supporting people with profound learning disabilities and their families. A feasibility study is underway to assess whether this adapted intervention is effective and acceptable to people with severe to profound learning disabilities and their families and carers, and whether it can be delivered by community services.

Find out more about Beat It2 via https://bit.ly/4ohXiUy





Supporting healthy lifestyles for people with learning disabilities: the importance of working in partnership with people with lived experience

Arlene McGarty and Michael McEwan

In this presentation we will discuss inclusive lifestyle behaviour change programmes. For example, programmes that try to improve physical activity levels and diet. We will cover some key findings and ways to help support people to lead healthier lives. We will discuss the role of partnership and including people with lived experience in the process of understanding how lifestyle programmes work.

Session 4



Working together in partnership to improve diabetes education for adults with learning disabilities in Scotland Maria Truesdale and Scott Taylor

Adults with learning disabilities are at least twice as likely to develop type 2 diabetes and often face barriers to getting the education and support they need. DESMOND-ID is an adapted version of the DESMOND (Diabetes Education and Self-management for Ongoing and Newly Diagnosed) programme, made more accessible and inclusive for this group. It is currently being tested in a UK-wide research study. This presentation will describe how the programme is being delivered in Scotland, and how working in alliance with NHS Lothian supported participant recruitment, data collection, and delivery. Key learning will highlight inclusive and collaborative ways of working to improve diabetes care for everyone. Find out more via https://bit.ly/43F8fgt





Positive Behaviour Support (PBS) at the University of Glasgow: Developing a PBS pathway in NHS Forth Valley

Anne MacDonald and Ginny Avery

Some people with learning disabilities who have complex support needs may be living in inappropriate places such as hospitals or institutions. Scottish Government are working alongside people who work in local government, housing, health and social care to try and stop this, and to help people come home to their own communities. One approach that can help people get the right support is Positive Behaviour Support (PBS). The University of Glasgow has developed a course that will teach staff about PBS.

In this presentation we tell the story of one NHS Board that has developed an approach to using PBS. We will describe the different levels of PBS and what this looks like in the work we do. We will talk about how nurses who have completed the PBS course at Glasgow University use their skills to support people differently. We hope this approach will improve the lives of people with learning disabilities who have complex support needs, their families and carers.

Speaker Biographies (in alphabetical order by surname)

Ginny Avery



Dr Ginny Avery is a Consultant Clinical Psychologist and Head of Learning Disability Psychology in NHS Forth Valley. She has worked in Learning Disability Services for over 20 years and remains passionate about supporting individuals, their families and carers to access high quality health care. She has interests in working with people who have experienced trauma and those who have forensic needs. As well as delivering psychological interventions herself she continues to



enjoy supporting the wider workforce to deliver psychological care through training, supervision, and the development of clinical pathways.

Katrina Bannigan



Katrina joined the Scottish Learning Disabilities
Observatory in 2024 as a Research Assistant to work
on the Beat It 2 study which is testing the feasibility of
behavioural activation for depression in adults with
severe learning disabilities. As an occupational
therapist, she is passionate about the value of
occupations—our everyday activities—for health. Her
past research has predominantly focused on evidence

synthesis to support the development of complex interventions. Her interest in evidence synthesis grew out of the research she conducted for her PhD thesis which focused on the evidence-based practice within the allied health professions.

Fiona Barlow



dissemination.

Fiona is the Impact and Communications Officer with the Scottish Learning Disabilities Observatory and leads on strategic communications and public engagement work, supporting the team with knowledge exchange and pathways to impact generation. With over 10 years working in Higher Education, Fiona is particularly interested in innovative approaches to knowledge exchange, inclusive research practices and accessible research



Deborah Cairns



Deborah is the Director of the Scottish
Learning Disabilities Observatory and
Professor of Health and Neurodevelopmental
Conditions, in the School of Health and
Wellbeing, at the University of Glasgow.
Deborah is passionate about her research

which aims to improve the health of people with learning disabilities and their families. She has worked on many different projects about people with learning disabilities including: cancer incidence, cancer screening, multi-morbidity (having two or more health conditions), oral health and COVID-19, to name a few. She has also worked on projects about the physical and mental health of family members who support someone with a learning disability. Deborah is committed to conducting research that has impact and works closely with self-advocates with learning disabilities, family carers and third sector organisations who are pivotal in all of her work and who have a shared vision of ensuring the human rights of all people with learning disabilities are recognised, supported and upheld.

Leeanne Clark



Leeanne is a business founder and owner of Not Lost Anymore, which aims to meet the specialist needs of people with learning disabilities, lifelong conditions, the care system and those who have been through trauma and abuse. In her role, she is a Lived Experience Trainer and Consultant. Leeanne is also an RSA Fellow and author of 'My Journey Through Life - The Real Me!'

Over the years, Leeanne has been a campaigner for people with lived experience and has participated in various projects and panels.



Catherine Dempsey



Catherine is Head of Programmes and Learning for ARC Scotland. She leads ARC's work involving people with support needs, including the National Involvement Network and training co-designed and co-delivered by people with lived experience of the subject. She also leads ARC's consultancy offer, designing and delivering solutions for social care organisations. Catherine is a voluntary

Board Director and funding Assessor. She has a particular interest and background in improving the experience and aspirations of young disabled people moving from school to adult life, including facilitating large group Person Centred Planning (The Big Plan) with young people and families across Scotland.

Audrey Dickie



Audrey joined the School of Health and Wellbeing in July 2013, working directly with the Head of Professional Services to support 7 individual research units spread across 10 sites. Audrey has worked across a number of key admin areas, including organising and managing events, staff training, managing equipment for staff and being

involved with Athena Swan activity from the 1st application to achieving and renewing Gold. Audrey also helped in the successful move to the Clarice Pears building. Audrey is now the Events Coordinator for the School, managing and organising a wide range of events and seminars.



Amanda Gillooly



Amanda is a Research Associate at the University of Glasgow. She is interested in research promoting the mental health and wellbeing of people with intellectual disabilities and their families. Since joining the School of Health and Wellbeing in 2019, Amanda has worked on clinical trials focused on adapting and evaluating psychological therapies for

people with intellectual disabilities. Prior to working at the University of Glasgow, she completed a PhD at the University of Strathclyde, examining the social experiences of children and young people with Williams syndrome. Amanda also previously worked as a Research Associate at the University of Edinburgh, working across studies with children with intellectual disabilities and their families.

Aaron Hume



Aaron is a researcher, student, and disability rights campaigner from West Lothian. He lives with cerebral palsy, autism, and a moderate learning disability. Aaron is currently studying for an HNC in Social Services at West Lothian College. His research involvement includes collaborations with universities across the UK and Europe, and he works closely with several third-sector

organisations and the Scottish Government on projects focused on human rights, digital accessibility, and upcoming legislation such as the Human Rights Act and the Learning Disability, Autism and Neurodiversity Bill. Aaron is really passionate about using his lived experience and the power of humour to break down the stereotypes and barriers in order to educate future healthcare professionals helping them truly understand the meaning behind the social model of disability, so they can see no person is the same as the next person. With the Scottish Learning Disabilities



Observatory, he has worked as a project advisor on inclusive initiatives such as the This Is Me campaign and Research for Everyone project.

Andrew Jahoda



Andrew Jahoda is a Professor of Learning
Disabilities in the School of Health and Wellbeing at
the University of Glasgow. He also has an honorary
position as a consultant clinical psychologist with
NHS Greater Glasgow and Clyde. Andrew has
worked at Glasgow University since 1998. His
research interests concern the mental health and
wellbeing of people with intellectual disabilities.
This includes work about the impact of stigma and
ways of promoting inclusion. Another strand of

Andrew's research is about adapting psychological therapies like CBT and behavioural activation for people with learning disabilities, to make them more accessible and sensitive to people's lived experience.

Anne MacDonald



Anne is the Lead for Learning, Teaching and Scholarship for the Observatory. She is a Senior Lecturer in the School of Health and Wellbeing at the University of Glasgow. In this role she leads on developing and delivering postgraduate qualifications in Positive Behaviour Support for the health and social care workforce, with a focus on people with learning disabilities and behaviours that challenge. Prior to this,

Anne worked for nearly 20 years with a third sector social care provider where she managed the organisation's Positive Behaviour Support team.

Anne also works part-time as a Professional Advisor for Complex Needs in the learning disability policy team at the Scottish Government. As part of this role, she wrote the Scottish Government's Coming Home report



which focused on out-of-area placements and delayed discharge from hospital for people with learning disabilities and complex needs.

Michael McEwan



Michael is a freelance Journalist who does work for BBC Radio/TV. He recently worked on a radio documentary on BBC Radio Scotland called "Disability with Attitude", covering changing perceptions of disability in the past 40 years. He was also commissioned to do a documentary for Radio Scotland for the

Paralympics in Tokyo 2024 call the "Pride of Scotland", focusing on some of the athletes who represented team GB from Scotland. Michael is also a disability campaigner and has worked with numerous disability organisations across Scotland.

Arlene McGarty



Arlene is a Research Fellow at the Scottish Learning Disabilities Observatory. Arlene is interested in lifestyle behaviours (for example, physical activity and sedentary behaviour) and how these impact the health of people with learning disabilities. She is also interested in finding ways to change these behaviours to help people with learning disabilities lead healthier and happier lives. Some of the projects that Arlene works on include:

School-based "active play" for children with learning disabilities.
Understanding walking opportunities in adults with learning disabilities.
Increasing motor development skills in children with learning disabilities.
Measuring energy expenditure in adults with learning disabilities.



Lily Meehan



Lily joined the University of Glasgow in 2022 before starting a full-time position as an Administration Assistant. Lily enjoys working with the Admin team in the School of Health and Wellbeing and feels it's a very friendly and supportive environment here in the Clarice Pears Building. Lily's responsibilities include supporting the admin team with various tasks such as uploading images to the CMS, trimming videos, uploading them to YouTube, and preparing transcripts. Lily also helps to cover reception during lunch breaks

and assists with any emergencies that may occur at reception.

Craig Melville



Craig is a Professor of Neurodevelopmental Psychiatry in the School of Health and Wellbeing at the University of Glasgow. His work focuses on using evidence from research to inform the development of interventions and policies to improve the health of people with neurodevelopmental conditions. Craig has worked on clinical trials of complex interventions, such as

psychological therapies, weight management and health checks in primary care. Evidence from epidemiological research has been central to the development of these clinical trials and his work with SLDO centres on how to use Scotland's national datasets to understand and tackle the health inequalities experienced by people with neurodevelopmental conditions.



Jenny Miller



Jenny is the Chief Executive Officer (CEO) of Promoting a More Inclusive Society (PAMIS). PAMIS is a third sector organisation working solely with people with profound learning and multiple disabilities (PMLD) and their family carers. Jenny's role includes amplifying their voices to ensure they are included in research, policy and education locally, nationally and internationally. Jenny's

leadership and practice have been strongly influenced by lifelong education from people with PMLD as expert educators teaching us how to communicate, act with compassion, make human connections and work together.

Christine Pacitti



Christine is a doctoral student with research interests in health inequality, inclusive research, and optimising health care and prescribing for adults with learning disabilities. Her PhD research is examining the treatment of pain and painful conditions experienced by adults with learning disabilities focusing on any health inequality that may emerge from this project. Christine is a clinical pharmacist, with expertise in mental health,

and has practiced professionally within community, hospital and mental health settings. Prior to commencing her doctoral studies, Christine worked within NHS learning disability psychiatry multi-disciplinary teams providing support with medication for people with learning disability and complex health needs. Christine is an experienced carer of a family member with learning disability and complex health needs.



Sarita Soni



Sarita has worked as a Consultant in Learning Disabilities (LD) in Glasgow, and as Honorary Senior Clinical Lecturer at the University of Glasgow since 2007. Her special interests include epilepsy and dementia. Previously, Sarita completed general psychiatry and LD training in Ireland and England and she is a member of the Royal College of Psychiatrists. She gained a PhD from Cambridge

University looking at the psychiatric phenotype of Prader-Willi syndrome (PWS). Sarita has been involved in other research projects including a trial of a nurse-led clinical service to improve outcomes for people with epilepsy and LD, a PWS neuroimaging study, and a study of behavioural phenotypes in Coffin-Lowry syndrome.

Scott Taylor



Scott is proud to be a Registered Learning
Disability Nurse who works within NHS Lothian as
a Consultant Nurse and is also Co-chair of the
Scottish Learning Disability Lead Nurse Group.

Previously Scott has worked with Edinburgh Napier University, Scottish Government, and NHS Fife working on wide range of initiatives, projects

and studies.

Current work activities stretch across the four practice pillars – expert practice, facilitating learning, leadership, and research. With key focus being the annual health check, acute hospital services, service redesign, and building research capacity.



Maria Truesdale



Maria is a Senior Lecturer with the Scottish Learning Disabilities Observatory. Her goal is to improve the physical and mental health and wellbeing of people with learning disabilities and their carers through the evaluation, development and testing of complex interventions using gold standard methodology and inclusive research.

Maria has conducted a number of trials using complex interventions in physical and mental health for people

with learning disabilities and has played a central part in the development of a randomised control trial of the clinical and cost-effectiveness of the DESMOND-ID structured education programme for adults with learning disabilities and type 2 diabetes. Maria also supports the teaching and delivery of the PGT Positive Behaviour Support programme and contributes to the supervision of MVLS Postgraduate courses.

Lorraine Waddell



Lorraine is an Administrative Assistant to Public Health, Byres Community Hub Admin Support and SHW Operations team assistant, contributing not only to the smooth running of the Clarice Pears Building but also to the wider community and School of Health & Wellbeing.

Her outreach activities have helped strengthen networks for the Hub and SHW research team in the East End, building meaningful relationships

that support ongoing collaborative work. As a champion of An Inclusive Community, Lorraine has been recognised in a commendation from the MVLS EDI Awards for her involvement in the Chancellor's Fundsupported BSL classes and the Deaf social group in the Byres Hub.



Yang Wei



Yang Wei is a Professor of Wearable Technology at Nottingham Trent University, where he leads the Advanced Textiles Research Group (ATRG). His research drives innovation at the intersection of textiles, electronics, and digital health, focusing

on smart, lightweight, and integrated textile systems for healthcare, defence, and industrial applications, with a strong emphasis on clinical translation and regulatory standards.

He has led major projects funded by EPSRC, NIHR, Innovate UK, Wellcome Leap, and Cancer Research UK, delivering significant advances in cancer monitoring, respiratory sensing, and rehabilitation technologies. At NTU's Medical Technologies Innovation Facility (MTIF), he contributes to national initiatives in e-textiles and digital health, supporting the development of next-generation wearable systems.

Please remember to complete the evaluation at the end of the event. You can find it online via this QR code, or there are paper copies available on the day. Thank you.



