LEARNING DISABILITY PROFESSIONAL SENATE
2026 LISTEN AND LEARN EVENT

“Healthy lives together - listening and learning to improve health for children, young people and adults with a learning disability”



Learning Disability Professional Senate Listen & Learn Event

17.9.2026

Dr. K. Courtenay

National Clinical Director for Learning Disability and Autism

Mental Health Learning Disability Neurodevelopmental Conditions Programme

NHS England

kenneth.courtenay@nhs.net

Learning Disability and the 10-Year Health Plan

Neighbourhood

- Roll out of 24/7 neighbourhood health centres
- Supporting Mental Health Act implementation:

  Guidance on commissioning community services for people with a learning disability and autistic people

  Tool for ICBs to understand people impacted by changes to the detention criteria

Digital

- Rollout of the Reasonable Adjustments Digital Flag across health and social care
- NHS UK web-team research on people with learning disability and easy-read information
- Project to understand experience of people with a learning of screening digital processes

Prevention

- Learning disability Annual Health Checks & Health Action Plans
- Vaccinations – deep dive
- Keyworking Minimum Standards published
- Professional guidance on identifying learning disability in Primary Care to add people to the GP Learning Disability Register

Thank You

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GIG CYMRU NHS WALES | Perfformiad a Gwella Performance and Improvement

National Update Wales

LEARNING DISABILITY PROFESSIONAL SENATE

LISTEN AND LEARN EVENT

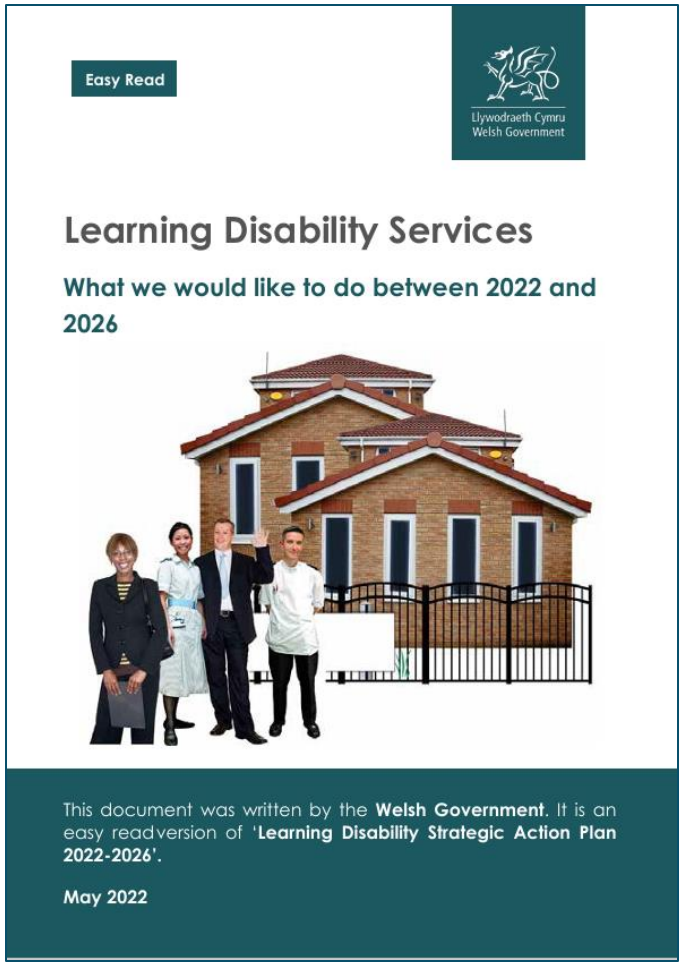
Lara Homan RNLD
Quality Performance Improvement Manager
NHS Wales Performance & Improvement
Lara.homan2@wales.nhs.uk

Learning Disability Strategic Action Plan 2022–2026

A shared national direction

The Learning Disability Strategic Action Plan set out the Welsh Government's strategic priorities for improving outcomes for people with learning disabilities between 2022 and 2026.

The plan was co-produced with the Learning Disability Ministerial Advisory Group (LDMAG),stakeholders and people with lived experience, and is aligned to the Programme for Government and Well-being of Future Generations Act.

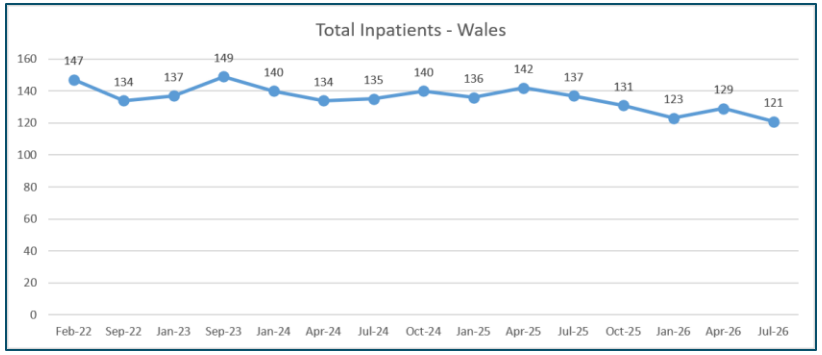


Welsh Government — Learning disability strategic action plan 2022 to 2026 ↗

Examples of Progress made

DATA + TRANSPARENCY

- Introduction of a quarterly learning disability inpatient census.
    - Median length of stay reduced.
    - Delayed discharges reduced.
    - Total inpatient numbers reduced



Introduction of Metrics measuring:

- Annual health checks uptake,
- Health Equalities Framework implementation.

WORKFORCE DEVELOPMENT

80,000+

NHS staff completed Paul Ridd Foundation Learning Disability Awareness Training since April 2022.

Training expanded into social care, with an enhanced programme for staff who have more intensive contact with people with learning disabilities.

IMPROVING PHYSICAL HEALTH

Learning disability annual health checks became part of the GP contract in April 2025.

QUALITY + RESTRICTIVE PRACTICE

Work is underway to adapt and roll out the Reducing Restrictive Practice Framework across Wales in 2026–27.

From strategy to transformation

Three-year integrated service transformation

In January 2026 the Labour Minister for Mental Health and Wellbeing supported a three-year integrated learning disability service transformation Programme across health, social care and housing, from April 2026 to March 2029 in line with the Homes not Hospitals review of community and inpatient provision.

Three major developments announced

In July 2026 the Plaid Cymru Deputy minister for Social Care, Mental Health and Women's Health announced three major developments to improve outcomes, strengthen accountability and help people live independently and close to home. They also connect learning disability transformation to Wales's wider Integrated Community Care System (ICCS), centred on prevention and seamless community support.

1. National inpatient data: a new baseline

First Wales national dataset

The Welsh Government has published the first national dataset on Welsh residents with learning disabilities receiving specialist inpatient care in Wales and England. The data is derived from the quarterly inpatient census undertaken by NHS Wales Performance and Improvement and published by Digital Health and Care Wales (DHCW).



KEY PURPOSES

- Improve transparency and accountability.
- Better understand need and service demand.
- Monitor hospital admissions and discharge performance.
- Track progress in reducing unnecessary inpatient care over time.

Next step: Further work will enhance data collection in Wales and use these insights to improve services.

2. One quality framework across Wales



Integrated Quality Statement

The Welsh Government will publish an Integrated Quality Statement this month establishing a national framework for improving the quality, consistency and experience of care and support across Wales.

THE QUALITY STATEMENT

Shared vision — provides national expectations.

Co-produced — informed by people with lived experience, families and professionals.

Integrated — promotes collaboration across health, social care and housing.

Outcome-focused — ensures services work together around individual needs.

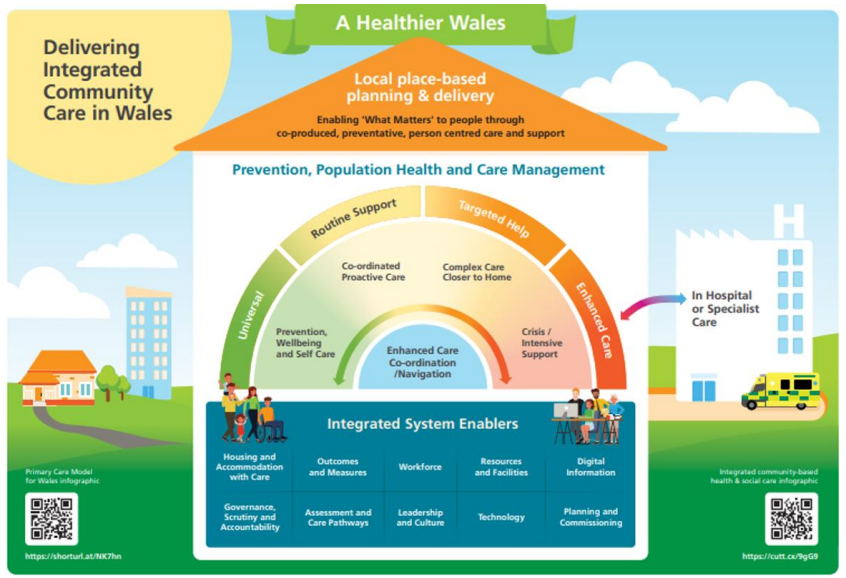
3. A three-year transformation programme for system-wide change

Learning Disability Transformation Programme

2026–2029

The programme will deliver system-wide change through Regional Partnership Boards and align with Wales's Integrated Community Care System (ICCS)—a preventative approach joining up health, social care and third-sector support so people can stay well at home.

Scheduled Welsh Government launch: 23 September 2026.



DELIVERY PRIORITIES

- Delivering integrated community support through ICCS.
- Improving access to information and advice.
- Developing integrated models of community care.
- Improving inpatient pathways.
- Ensuring the right support, at the right time, in the right place.
- Preparing services for future Mental Health Act reforms.
- Strengthening partnership across health, social care and housing.

THE PROGRAMME AIMS TO

- Reduce unnecessary hospital admissions.
- Improve discharge arrangements.
- Shift the balance of care from hospital settings to community support.
- Help people live independently and well within their local communities.

Welsh Government — ICCS position statement; improving outcomes and community support ↗

Learning Disabilities Unit
Complex Care and Rights Division
Mental Health, Social Care and NCS Directorate

Scottish Government
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OFFICIAL-SENSITIVE

We are the Learning Disability Policy Unit

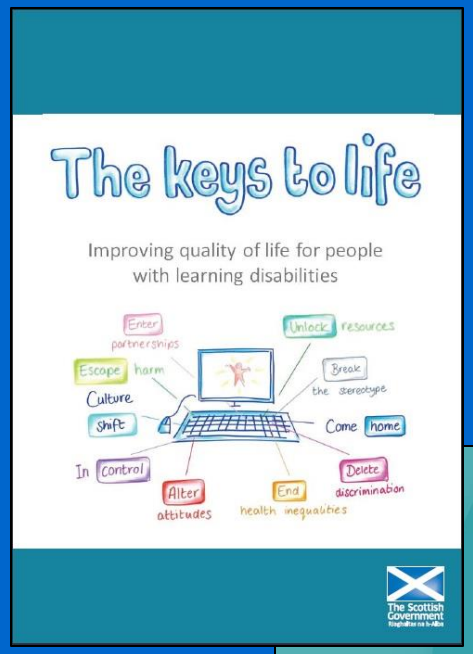
Our vision: To make Scotland a better place to live for people with a learning disability, where people can live healthier lives, enjoy choice and control over the services that they use, and are supported to be independent and active citizens.

To work across government to deliver our vision.

- **To deliver the Coming Home agenda, reducing delayed discharge and ensuring that people with complex needs can live in at home or in a homely environment.**
- **To work across Health and Social Care to address health inequalities and improve the quality of services for people with learning disabilities.**
- **To drive the delivery of Learning Disability Annual Health Checks, ensuring all eligible people are offered a health check annually.**
- **To deliver Changing Places Toilets Fund (2025-26 to 2028-29).**
- **To fund organisations to support people with learning disabilities and their families, e.g. through the Learning Disability Support Fund and our national 3rd sector partners**
- **To fund organisations to support people affected by Fetal Alcohol Spectrum Disorder (FASD).**
- **To evidence the barriers faced by people with learning disabilities and their families/carers and the impact of policy actions.**

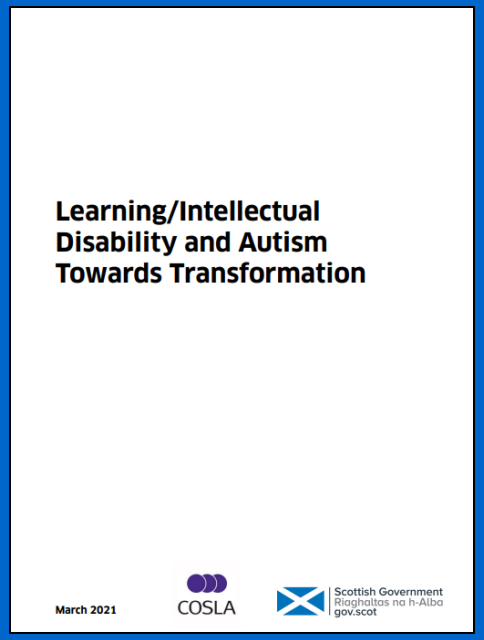
Key partners: COSLA, NHS Boards, IJBs/HSCPs, local authorities, SCLD, PAMIS, Inspiring Scotland, Down's Syndrome Scotland, ARC Scotland, Scottish Learning Disabilities Observatory, The Assembly, People First Scotland, FASD Hub (Adoption UK) and FAAST Team (Uni of Edin) LDSF

Key Policy Drivers



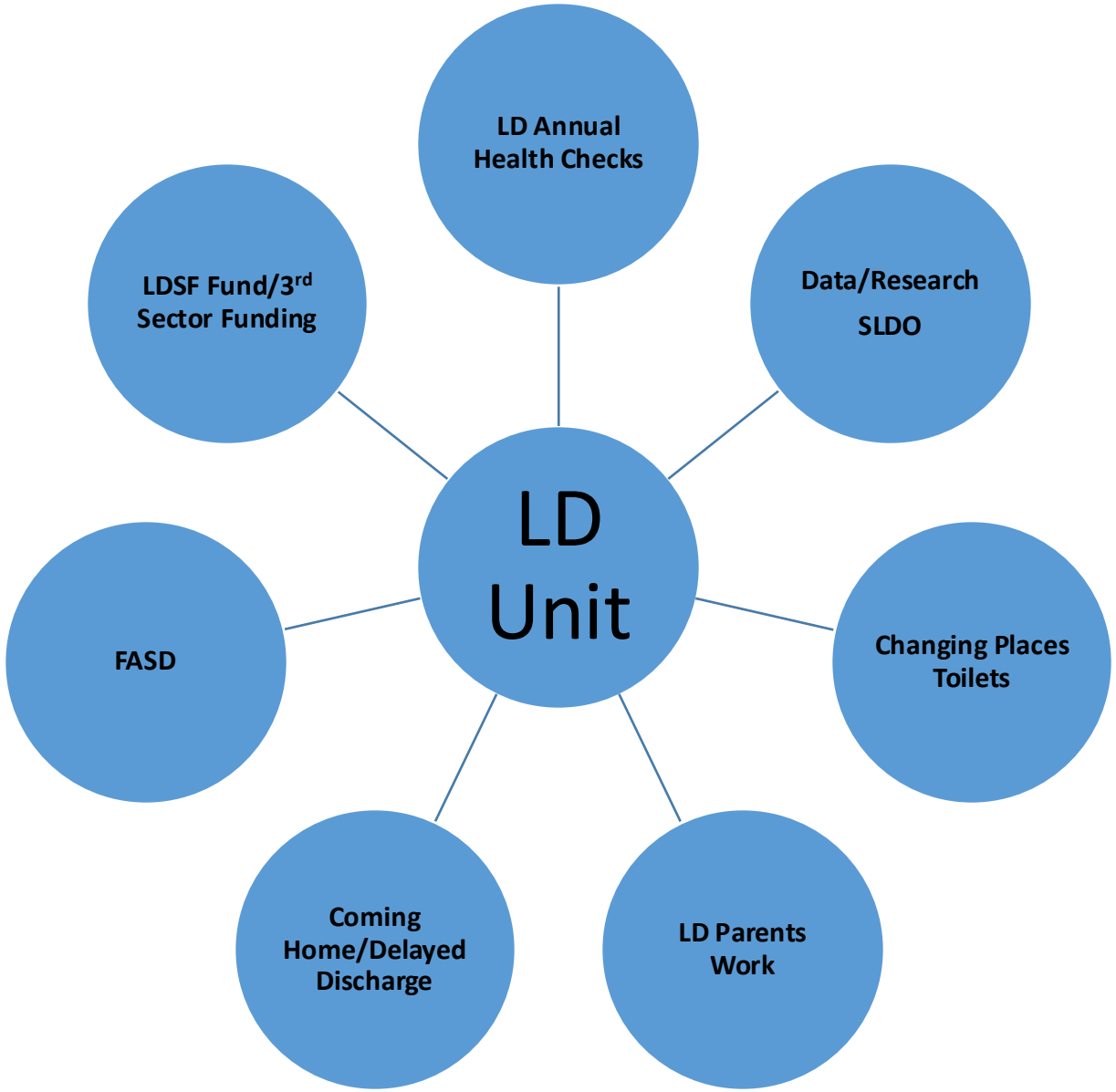








Overview of LD Unit Priorities

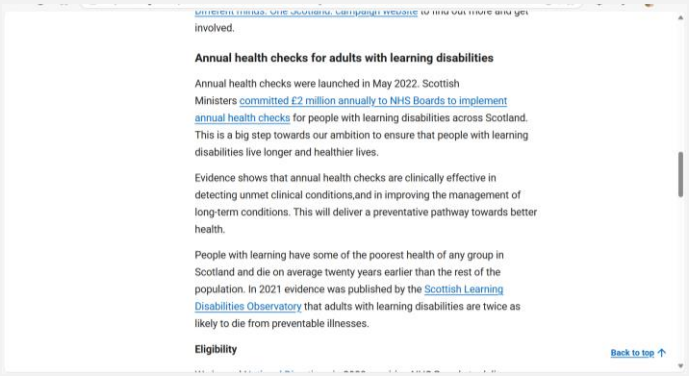


Annual Health Checks for Adults with Learning Disabilities

- Evidence shows people with LD die on average 20 years earlier than the rest of the population and are twice as likely to die from preventable illness.
- LD Annual Health Checks introduced for all people aged 16+ as an effective prevention and early intervention measure.
- Specially designed process includes preparation and delivers health checks in a way that effectively manages complexities e.g. stress, non-verbal.
- National Direction issued to Boards who are provided with £2 million per year to fund delivery.
- Delivery picking up after concerted efforts. In 2025-26 over 8,700 health checks offered (6161 on previous year) resulting in 3287 onward referrals to other services, providing vital opportunities for prevention, early intervention, treatment and support.

Annual Health Checks – Delivery Resources





involved.

Annual health checks for adults with learning disabilities

Annual health checks were launched in May 2022. Scottish Ministers committed £2 million annually to NHS Boards to implement annual health checks for people with learning disabilities across Scotland. This is a big step towards our ambition to ensure that people with learning disabilities live longer and healthier lives.

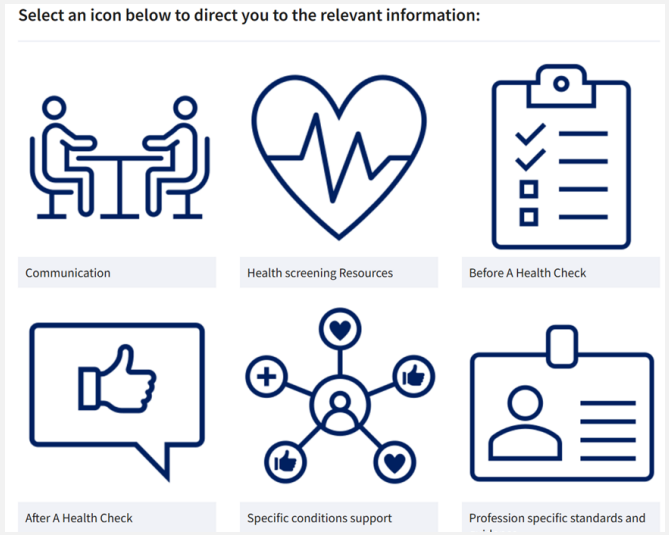
Evidence shows that annual health checks are clinically effective in detecting unmet clinical conditions,and in improving the management of long-term conditions. This will deliver a preventative pathway towards better health.

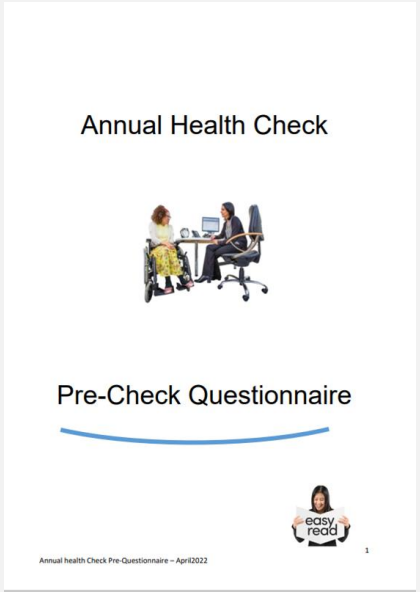
People with learning have some of the poorest health of any group in Scotland and die on average twenty years earlier than the rest of the population. In 2021 evidence was published by the Scottish Learning Disabilities Observatory that adults with learning disabilities are twice as likely to die from preventable illnesses.

Eligibility

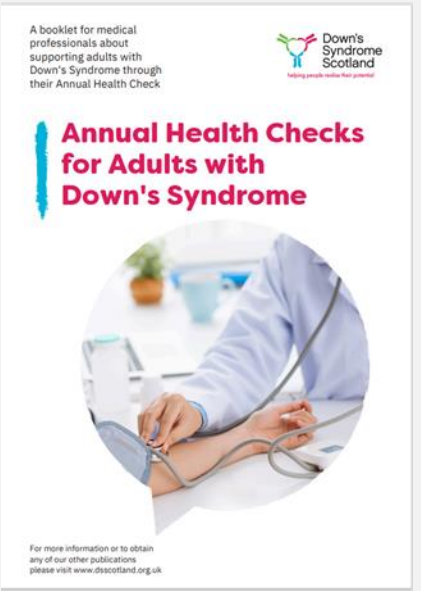
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Annual Health Checks – Lived Experience Engagement

Annual Health Check Involvement Network (AHCIN)

The involvement network was established in November 2025 and is facilitated by Scottish Commission for People with Learning Disabilities (SCLD) as part of their core delivery.

Aim
A co-ordinated mechanism for involvement which engages lived experience directly with the delivery of LD annual health checks and Scottish Government.

Rationale
Streamlined engagement, limitation of siloed working, protect and support people to be involved in a meaningful and mindful way, managing expectations. Supporting the reduction of duplication of work and dilution of impact.

Annual Health Checks – Lived Experience Engagement

Benefits

Direct access to key areas of implementation and delivery of AHC including;

- National Implementation Group
- Data Programme Boards
- Health Boards
- Scottish Government LD policy team and the Minister for Community Cre

Opportunities

- Involvement and engagement – visibility and having your voice heard
- Awareness raising and promotion of AHC
- Contribution to Monitoring and Evaluation of delivery (accountability)/Evidence gathering of impact of AHC
- Contribute to ideas and suggestions as part of a continuous improvement process for delivery and implementation
- Development of new resources and information sharing processes
- Collaborative working, Best Practice Sharing, Peer Support

Coming Home – Delayed Discharge

Jointly owned by COSLA, Coming Home seeks to support people with LD and complex needs to live in the community, close to family and friends.

First phase delivery of SG's 2022 Coming Home Implementation Report:

- Dynamic Support Register – data to improve visibility of people with LD and complex care needs at local/national levels, and a tool to support local planning and decision making.
- Peer Support Network – hosted by HIS, LD professionals from across Scotland meet to share good practice and support one another to plan services for people with very complex care needs.
- National Support Panel – to provide support and oversight of Dynamic Support Register

A short Life Working Group est in 2025 developed an action plan which provides an update on progress to date, addresses the outstanding recommendations from the Coming Home Implementation Report 2022, and sets out further actions required to achieve the Coming Home vision and mission

Coming Home Action Plan and accompanying **Easy Read**, **Coming Home Training Guide** and **Housing Options Guide** published on 19 March 2026 with up to £20 million to support delivery of the action plan via ILF Scotland and **The Independent Living Fund Scotland Coming Home fund.**

Scottish Learning Disability Observatory (SLDO)

The LD unit funds the Scottish Learning Disability Observatory (SLDO) who are a multidisciplinary research group focused on understanding the causes of poor health and health inequalities experienced by people with intellectual and developmental disabilities, and developing, evaluating and implementing evidence-informed interventions to address these challenges. Alongside this, they also deliver a programme of world class, post-graduate teaching.

SLDO develop improved and additional information about the health and healthcare of people with learning disabilities in Scotland, they;

- Generate and translate information into knowledge, that is designed to inform actions, practice and policy to benefit people with learning disabilities;
- Contribute to health improvement by providing information, data and intelligence on the health and healthcare of people with learning disabilities;
- Translate information and data into meaningful health intelligence for practitioners, commissioners, policymakers and the wider community.

Changing Places Toilet Fund (CPT)

- “Where would you go if you could ***only*** use the toilet in your house?”
- Much larger than standard accessible toilets with specialist equipment such as a hoist and adult changing bench.
- Used by people with complex needs and health conditions – from learning disabilities to people with MND, cancer and dementia (and their families/carers).
- Scottish Government initial investment of £10 million in 2025-26 and 2026-27, has funded awards totalling over £7 million for the development of 78 new Changing Places Toilets. Further funding of up to an additional £3 million in 2026-27 budget will take our total investment in CPTs to £13 million.
- A second round of funding opened on 10 August further information on the fund and CPTs can be found via our fund manager Inspiring Scotland’s **website.**

Changing Places Toilet Fund (CPT)

- CPTs are being funded on the Isle of Lewis, in Clackmannanshire where there are currently no Changing Places Toilets and in a range of other venues, such as community and leisure centres, outdoor spaces and well-known venues like the Royal Botanic Gardens, Dynamic Earth and the National Theatre of Scotland.

Fetal Alcohol Spectrum Disorder (FASD)

FASD is a complex condition that can cause lifelong, permanent and irreversible damage, although early diagnosis and tailored interventions can improve outcomes for the child. It is the most commonly known preventable cause of permanent learning disability worldwide.

There is no known amount, type or timing of alcohol that is safe in pregnancy. Avoiding alcohol during pregnancy and when contemplating pregnancy is the only way to be sure that the baby will not be affected by FASD. The advice of Scotland's Chief Medical Officer is therefore to avoid alcohol completely when pregnant or trying to conceive - No Alcohol No Risk.

SG published an Alcohol Framework (2018) which set out a commitment to increase awareness of FASD and support improved diagnosis; SG made a commitment within the 2018 Programme for Government to "increase support for children and families affected by FASD"

Over the last four years, we have provided almost £2 million specifically to improve understanding of and support for FASD. £620,000 in 25/26 includes funding for:

The FASD Hub in Scotland (Adoption UK Scotland), which provides support, training and advice to families, carers and professionals supporting children affected by FASD, this is the first of its kind in the UK.

The Fetal Alcohol Advisory Support and Training Team (FAASTT) at Edinburgh University to allow the delivery of training to improve knowledge, attitudes and confidence in professionals working with individuals with FASD.

Learning Disability Support Fund (LDSF)

The Learning Disability Support Fund (LDSF), managed by Inspiring Scotland, is a multi year fund providing funding to 9 charities who have a support approach that improves the lives of people with learning disabilities. The fund is aimed at supporting organisations' efforts to create a society where people with learning disabilities can lead fulfilling, independent, and active lives as equal citizens.

Objectives of the fund are; a more inclusive society, improved health outcomes for people with learning disabilities and people with learning disabilities have a social network and safe relationships

The 9 charities receiving funding are; Get2gether, People First Scotland, Values Into Action Scotland (VIAS), The Scottish Assembly, Ydance, Dates n Mates, Neighbourhood Networks, Project Ability, National Involvement Network (NIN – ARC Scotland)

Parents with Learning Disabilities

- People with learning disabilities have the same rights to be parents as those without disabilities. It is essential that families remain together as a complete family unit, wherever possible
- Support should be timely and effective, placing parents with learning disabilities and their families, firmly at the centre and in control.
- Improvement requires person centred approaches, early interventions and co-ordinated multi agency working
- Scottish Government are working with Scottish Commission for People with Learning Disabilities (SCLD) to review and refresh the Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities.
- These guidelines will help services to improve their support for parents with a learning disability and their children, increase the chances of children of parents with a learning disability to continue to live with them in a positive and supportive environment that meets the children's needs and increase the chances of avoiding family breakdown, which has enormous social and financial consequences

NORTHERN IRELAND LEARNING DISABILITY SERVICE MODEL



Debbie Murray

Head of Learning Disability Unit

DoH
www.health-ni.gov.uk

NI Context

- Population – 1.93 million
- NHS = Health and Social Care (HSC)
- DoH – policy and commissioning
- 5 HSC Trusts - service providers

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Context - Learning Disability

- Adult learning disability services currently support approximately 9,000 adults and their families who are known to social services.

- Learning disability is the third largest programme of care by cost, approx £500 million per annum.

Service Model Vision

- Developed in collaboration with Trusts, independent sector providers and people who use HSC services.
- Grounded in HSC values of working together, excellence, compassion, and being open and honest.
- Delivery underpinned by these values and principles.

Key Ambitions

- Life Changes
- Health and Wellbeing
- Carers and Families
- Meaningful Lives and Citizenship
- Home
- Mental Ill Health and Behaviours of Distress or Concern

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Service Delivery Plan

HSC

Working together · Excellence · Openness & Honesty · Compassion

Department of Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

We Matter

Service Delivery Plan

Learning Disability Service Model
"We Matter"

August 2025

DoH
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Implementation: Service Delivery Plan

- 3 year roadmap for transforming learning disability services in Northern Ireland.
- A regional approach to the management of Learning Disability services.
- Ensuring equity across the region.
- Better commissioning of the right level and blend of services to support people in the community at an earlier stage

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www.health-ni.gov.uk

Public consultation

- 5 regional in-person and online webinar engagement events.
- 345 people attended the 5 roadshows held in each Trust area.
- Consultation closed 25 November 2025.

Roadshow themes

- Timescales for implementation
- Access to mainstream services for this cohort
- Unmet needs of those with complex needs
- Transitions planning
- Cross-Departmental working
- Workforce planning
- Respite/Short Breaks

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Roadshow themes

- Day Opportunities/Day Care
- Digital Solutions eg Health Passport
- Data collection
- Transport
- Care for Carers
- Direct Payments
- Governance and Accountability

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Consultation findings

- 264 responses to the consultation through Citizen Space, Easy Read questionnaires and by email.
- Initial analysis of the Citizen Space responses shows overall support for the direction of travel.
- Initial quantitative summary of responses to the consultation report on the Departmental website in January 2026.

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Next Steps

- Full qualitative analysis report of the consultation feedback is nearing completion and will be submitted to Minister by the end of September.

- A comparative analysis exercise taking account of consultation feedback and the Muckamore Abbey Hospital Inquiry recommendations, against the SDP actions, is currently underway.

Next Steps

- We hope to finalise the Service Model and associated Delivery Plan by the end of October, subject to work pressures and other competing priorities.

- The service delivery plan will form the basis for an action plan which will determine ownership of actions, timeframes for delivery and priorities for the next 3 years.

Next Steps

- Once agreed by Minister, decisions required on how services need to be reconfigured, and any additional investment required.

- The ambitions outlined within the LDSM will only be realised if the Department is able to secure the necessary funding to support implementation.

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Next steps

- Roadshows feedback highlighted an urgency for change
- Some actions already progressing such as the Transitions Protocol under Life Changes ambition.

Next steps

Some areas where implementation arrangements are to be determined –

- LD Workforce Review,
- review of high-cost cases,
- review of inpatient bed provision,
- planned review of legislation, and
- governance structures for oversight and implementation.

Interdependencies

- Some actions being addressed by other workstreams -

  - joint Transformation bid with DfE on improving transitions
  - Direct Payments exercise led by CSWO
  - Non- Emergency Transport Strategy review
  - Equity of Access Report implementation

- These clearly align to the direction of travel for the service model and there is a need to build effective relationships across relevant workstreams

RNLD INPUT

Key ambitions for Health and Wellbeing in the LDSM are closely aligned to the Equity of Access Report -

- annual health checks
- hospital passport
- healthcare facilitation with specific references to LD Nursing around individuals receiving holistic assessment and care and being supported for timely discharge from hospital
- timely access to RNLD's intervention with appropriate skills and level of expertise, working as part of the wider interdisciplinary team

Contact details

learningdisabilityunit@health-ni.gov.uk

Thank you for listening

DoH
www.health-ni.gov.uk

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

Unlocking the Determinants of Health and Wellbeing for People with an Intellectual Disability as They Age

Evidence from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

Prof Mary McCarron
Professor of Ageing and Intellectual Disability, School of Nursing and Midwifery
Principal Investigator, IDS-TILDA
Director, Trinity Centre for Ageing and the Life Course in Intellectual Disability
Executive Director, The National Intellectual Disability Memory Service, Tallaght University Hospital

Thursday, 17th September 2026

@MccarrmMary
@ageingwithID

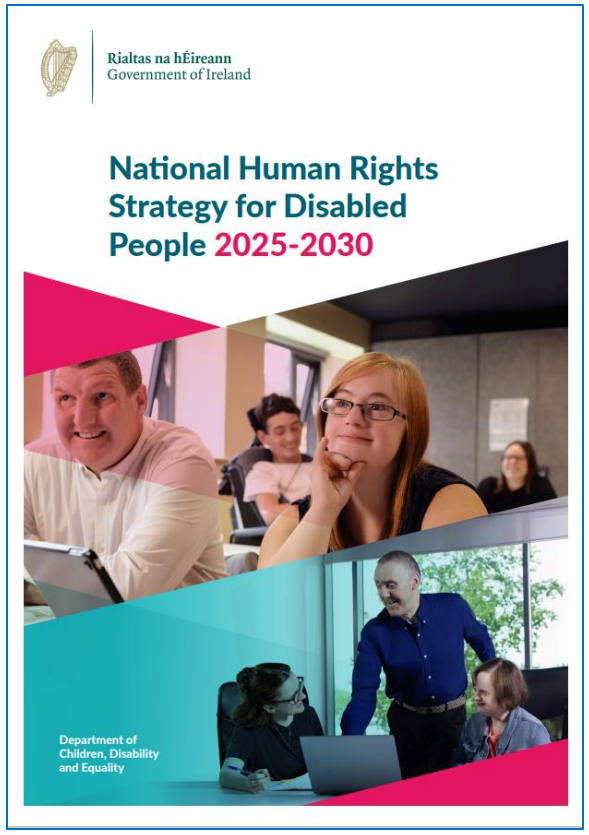
National Human Rights Strategy for Disabled People 2025-2030

A transformative strategy to realise the rights of disabled people in Ireland, with health equity at its core.

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

Trinity Centre for Ageing and the Life Course in Intellectual Disability

Step Change in Disability Policy: Grounded in the UN Convention on the Rights of Persons with Disabilities (UNCRPD)



Right to the highest attainable standard of health, without discrimination

Commitment to inclusive, integrated, accessible health services for all

Human rights focus led by disabled people themselves

CRPD CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES







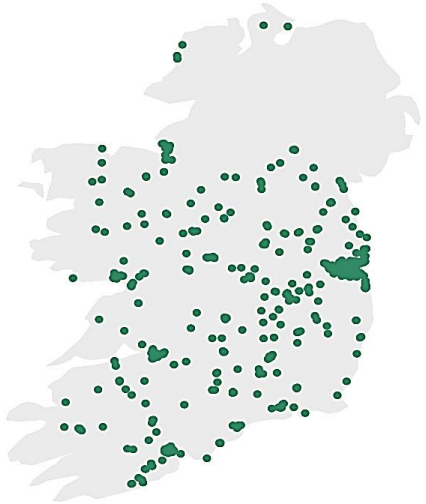
Mortality Disparities in People with Intellectual Disability: Urgent Need for Better National Data

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)



Mortality higher in women across age groups.
Average age of death 19.07 years earlier than for the general population.
Greater attention has been paid to closing the gap.

However, evidence that this being achieved is limited by the dearth of longitudinal national data.





Wave 6

First nationally-representative longitudinal study on ageing with an intellectual disability comparable to the general population

IDS-TILDA

Conceptual Framework: A New Perspective

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)



PPI in IDS-TILDA

by people with an intellectual disability

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)



Inputting on protocols



Training fieldworkers



Disseminating results



Translating Findings

Research is everybody's business… including people with an intellectual disability

Under-50s Intergenerational Change

Residential Profile

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Residence profile change




Fewer living in residential care **(7.7%)** compared to Wave 1 **(44.8%)**

More living in independent/family setting **(46.4%)** compared to Wave 1 **(21.2%)**

	Wave 1		Wave 5	
	n	%	n	%
Independent/family	61	21.2%	85	46.4%
Community group home	98	34.0%	84	45.9%
Residential	129	44.8%	14	7.7%

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

Multimorbidity and Physical Health Trajectories in People with Intellectual Disability

Self-Reported Health

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Despite the prevalence of chronic health conditions, most adults appraised their health as excellent, very good or good at **88.5%.**

For those aged 50 and over, this statistic is **91.4%** higher than reported by TILDA for the general population **at 81%**



Multimorbidity and Chronic Health



Research in Developmental Disabilities
Volume 34, Issue 1, January 2013, Pages 521-527

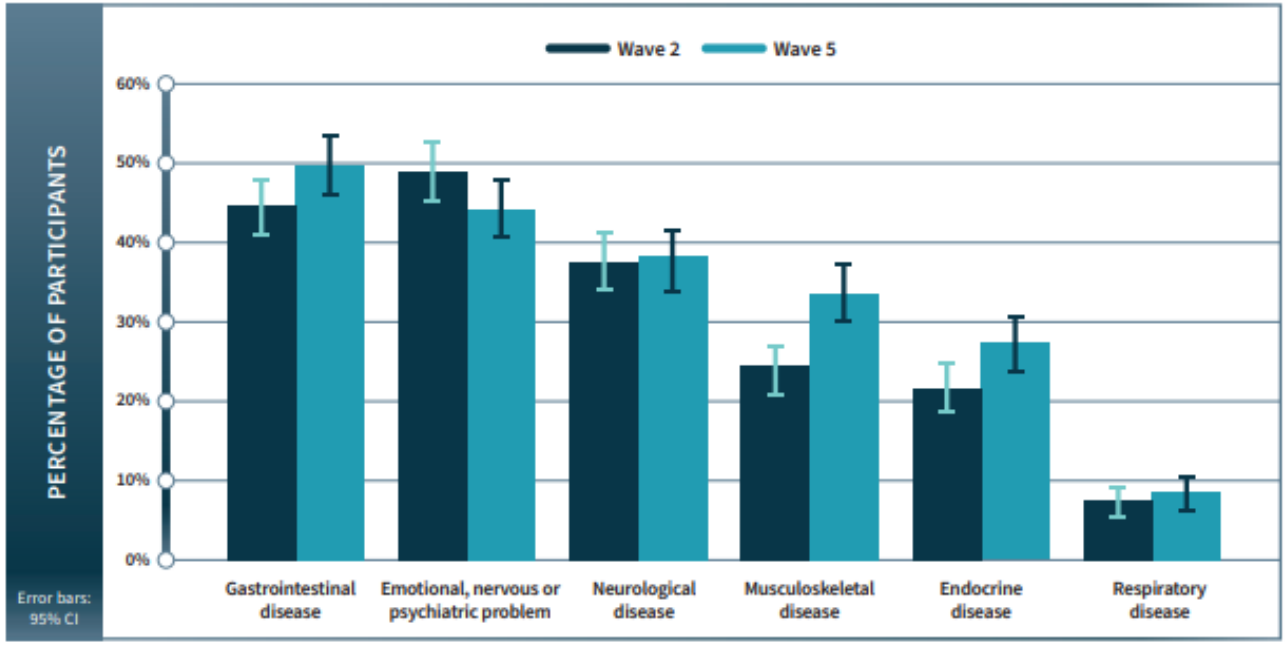
Patterns of multimorbidity in an older population of persons with an intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA)

Mary McCarron [a], Janet Swinburne [a], Eilish Burke [a], Eimear McGlinchey [a], Rachael Carroll [a], Philip McCallion [b]



IDS-TILDA	TILDA
Gastrointestinal	Cardiovascular
Mental Health	Respiratory
Neurological	

Chronic health classification at Wave 2 and Wave 5



Patterns of chronic health conditions continue to differ to those reported by TILDA for the general population.



Osteoporosis and Osteopenia

Suboptimal screening patterns

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Wave 5

19%

doctor diagnosed osteoporosis

Compared to **32%**

Objectively measured

A further **29.4%** within the **osteopenia** range



Wave 2

17.3%

Attendance at DXA

Wave 5

36.9%

Successfully Completed Echolight scan (n=81/84)

96.4%

65.5% (n=53/81) had compromised bone health who previously were unaware

Suboptimal screening patterns





Is DXA always the appropriate screening method?

Alternative screening devices and reasonable adjustments?



Radiofrequency Echographic Multispectrometry

(REMS Technology)

- Diagnostic & monitoring device
- No ionising radiation
- Portable
- Takes approximately 2 minutes
- Doesn’t require the patient to lie in exact position for long periods
- Instant read out results
- Reasonable adjustments can be provided

Echolight website

YouTube

ESCEO
EUROPEAN SOCIETY FOR CLINICAL AND ECONOMIC ASPECTS OF OSTEOPOROSIS, OSTEOARTHRITIS AND MUSCULOSKELETAL DISEASES

FDA U.S. FOOD & DRUG ADMINISTRATION

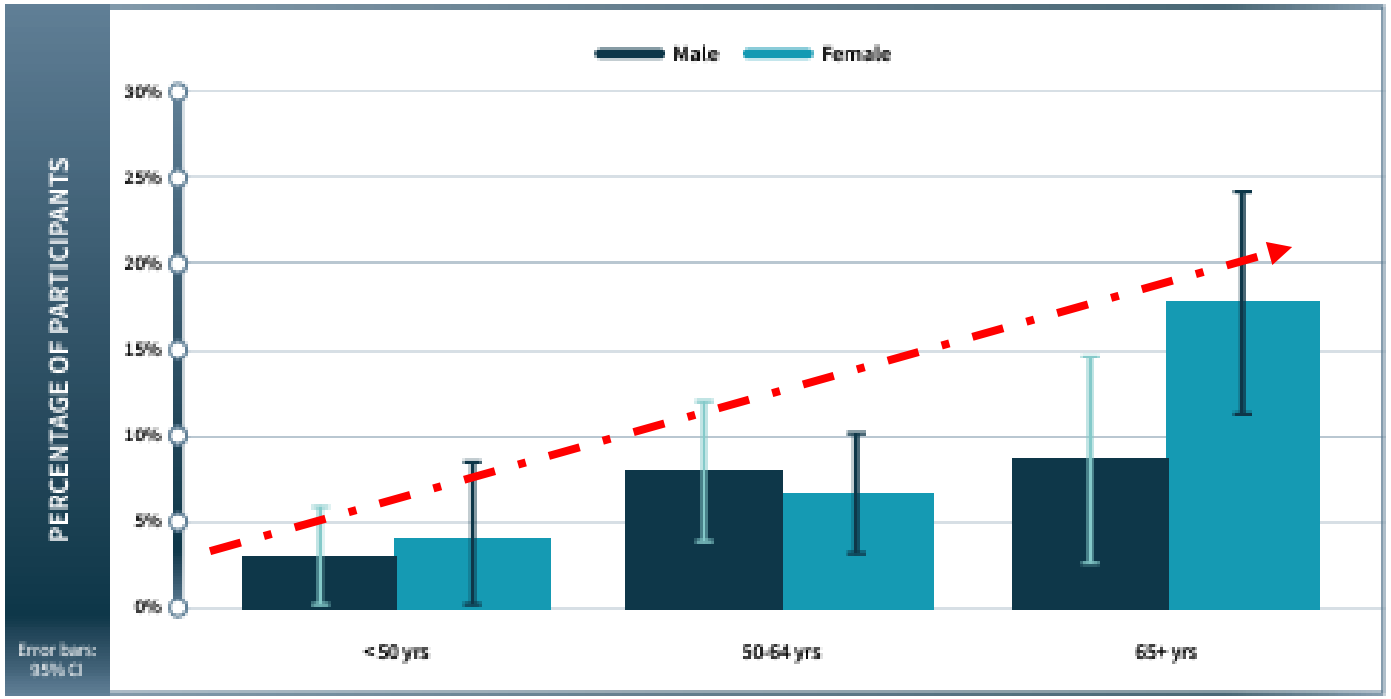


Fracture, falls and fear of falling

Reported fragility fractures

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Fragility fracture only – wrist, vertebra & hip



Prevalence increases with age
4% - 6.6% - 17.8%

Higher levels observed among women

Double the 1 in 10 reported by TILDA for those >65yrs.

Foot Health

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Most participants **(89.8%)** rated their foot health as excellent, very good, or good.



16.3% reported **pain** in their feet



55.6% reported foot pain **impacted** their **ability to walk**

Participants' objective levels of foot risk measured using the Brunswick Foot Risk Assessment Form

	Low	Moderate	High	Urgent
Skin (n = 473)	41.6%	56.7%	1.7%	0%
Nails (n = 472)	64.6%	33.9%	1.5%	0%
Structure/anatomy (n = 473)	62.6%	37.2%	0.2%	0%
Sensation (n = 364)	99.2%	0.8%	0.0%	0%
Vascular (n = 469)	88.5%	6.4%	5.1%	0%
Footcare (n = 473)	91.1%	7.8%	1.0%	0%
Footwear (n = 473)	96.2%	3.0%	0.2%	0%

84% had at least one moderate or high risk for poor foot health

About **97.4%** of participants with **Down syndrome** had at least **one moderate risk**, with **only two** showing **low risk** in all categories. This corresponds to **early-onset** foot health issues reported in this population.

Significantly More Adverse Health Concerns for Older Adults with a Severe/Profound Intellectual Disability

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Comparing participants with severe/profound ID to mild, moderate:

Those with severe/profound ID are **more multimorbid at 90.7% (p<0.05)** VS **(56.1%** mild ID, **75.3%** moderate ID).

41.3% have joint disease (p<0.05) VS **(27.8%** mild ID, **34.9%** moderate ID)

79.1% have gastrointestinal disease (p<0.05) VS (**31.2** mild ID, **50.3%** moderate ID)

58.7% have emotional, psychiatric, or mental health problems. (p<0.05).VS **34.6%** mild ID, **43.9%** moderate ID)

57% have neurological disease (p<0.05). VS (**24.9%** with mild ID, **38.5%** with moderate ID)



A care pathway for the management of chronic conditions is needed for all people with intellectual disabilities, particularly those with severe and profound disabilities.

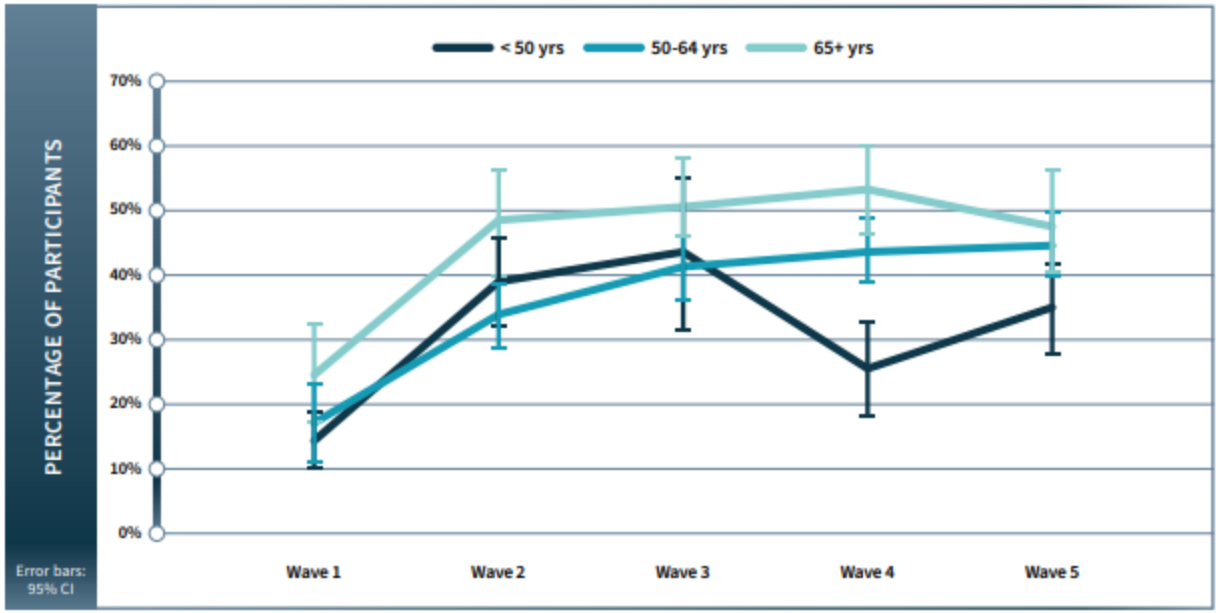


Constipation: Learning from IDS TILDA



The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Constipation stratified by age, Wave 1 to Wave 5





Constipation is highly prevalent and has increased considerably over the lifetime of IDS-TILDA

17.3% in Wave 1 to **42.8%** in Wave 5

Rate of progression almost **triples** after 5 years.

In the under 50's the prevalence rose from **14.6%** at Wave 1 to **34.4%** at Wave 5.

Similar trends were observed for those in the 50–64-year-old group rising from **16.9%** to **44.4%** and the 65 and over year group from **24.6%** to **47.2%.**

Exploring Frailty

Tallaght University Hospital | Ospidéal Ollscoile Thamhlachta
An Academic Partner of Trinity College Dublin

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

	TILDA	IDS-TILDA	IDS-TILDA >50
Total n(%)	4961 (100%)	745 (100%)	462 (100%)
Gender			
Male n(%)	2272 (45.8%)	332(44.6%)	191 (41.3%)
Female n(%)	2688 (54.2%)	413 (55.4%)	271 (58.7%)
FI Scores			
FI Score Min.	0.00	0.00	0.00
FI Score Max	0.64	0.59	0.59
FI Score Mean	0.12 ± 0.09	0.19 ± 0.11	0.21 ± 0.12
FI Score Median	0.09	0.16	0.19
Frailty Categories			
Robust	28.89%	21.74%	16.2%
Pre-Frail	45.43%	51.68%	50.3%
Frail	24.68%	26.58%	33.4%



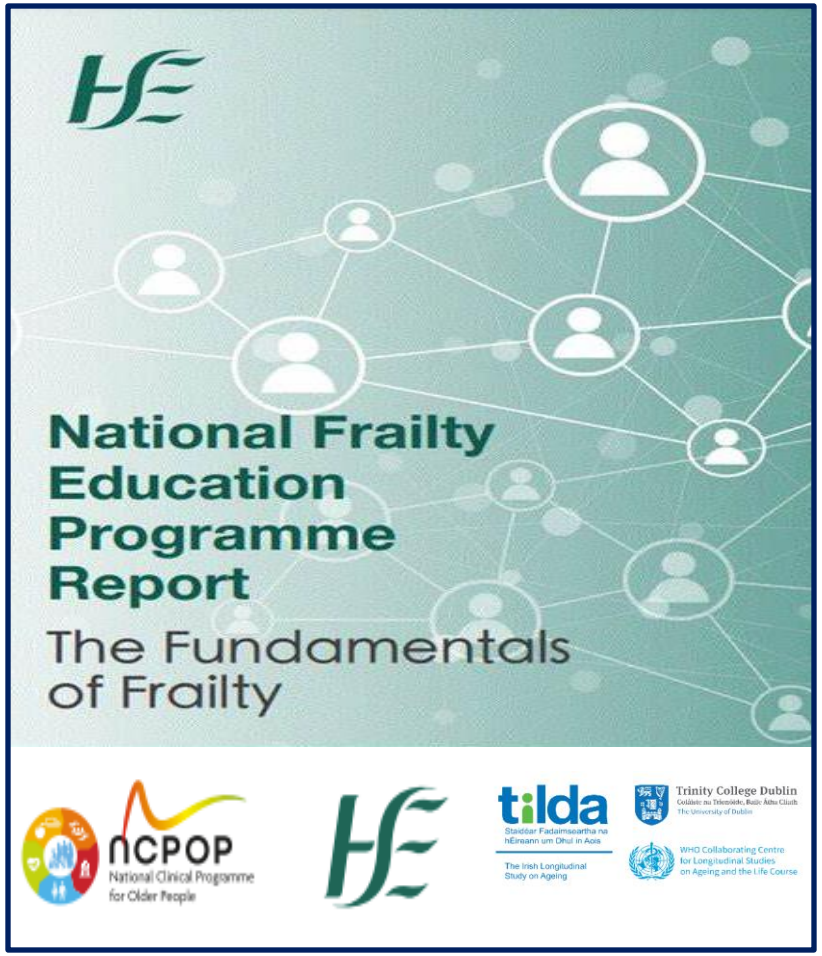
Frailty Scores: The Intellectual Disability population has higher mean and median frailty scores.
These scores increase with age.

Robustness and Frailty: There is a smaller proportion of people classified as "robust" in the Intellectual Disability population, especially those over 50. There is a higher proportion of individuals classified as "frail" in the Intellectual Disability population.



Adaptation of the National Frailty Education Programme (NFEP) for People with Intellectual Disabilities

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)



- Fundamentals of Frailty
- Comprehensive Geriatric Assessment
- Delirium
- Cognition
- Mobility Falls and Bone Health
- Polypharmacy & Falls
- Continence



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The University of Dublin

Oral Health





Oral Function

Modified Oral Status Survey Tool (MOSST)

Edentulism

19.3% edentulous

72.1% IDS-TILDA participants who were edentulous reported that **they did not have** dentures.

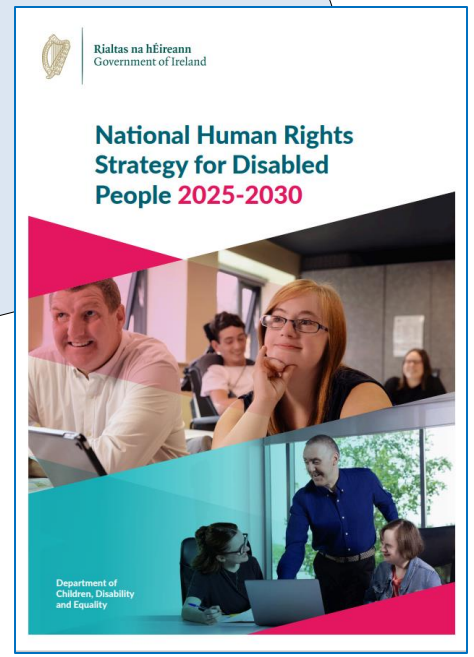
This compares to just **5.2%** edentulous participants in TILDA.

From clinical measurements, **over 70% did not** possess a functional dentition; rising to over **95%** among those with **severe to profound** intellectual disability

'Priority Actions 2025-2026 include:

19.1 Publish the National Oral Health Policy Implementation Plan 2025-2027. (Department of Health)

19.2 Address poorer levels of oral health, particularly among those with intellectual Disabilities'



Advancing Inclusion: Translating Research to Practice and Education

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)







https://youtu.be/qQj0ajzomZk

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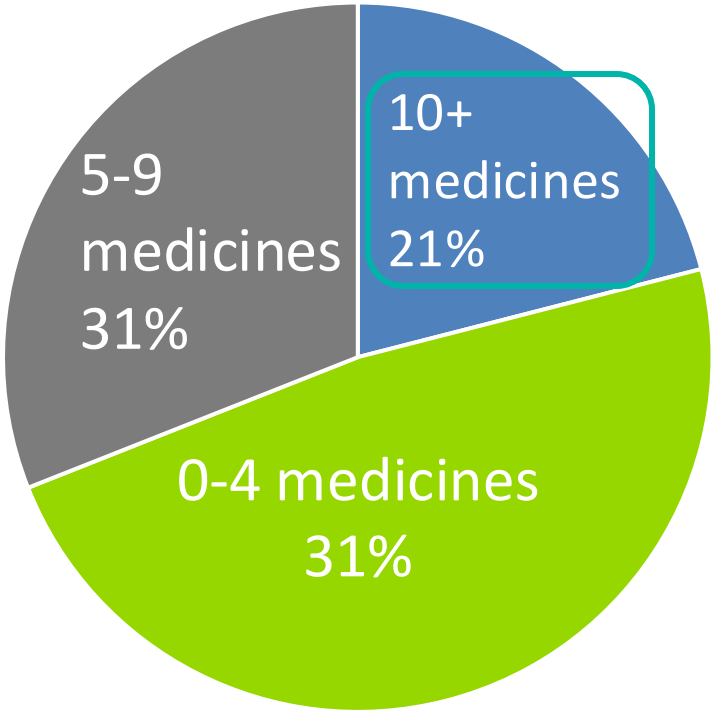
Medication Use




Polypharmacy and Excessive Polypharmacy

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

IDS-TILDA (n=736) (40+ years)



TILDA (Irish General Population 50+ years, n=8038) (Richardson et al 2012)	
5-9 medicines	19%
10+ medicines	2%

Classification

- **No Polypharmacy: 0-4 medicines**
- **Polypharmacy: 5-9 medicines**
- **Excessive Polypharmacy: 10+ medicines**

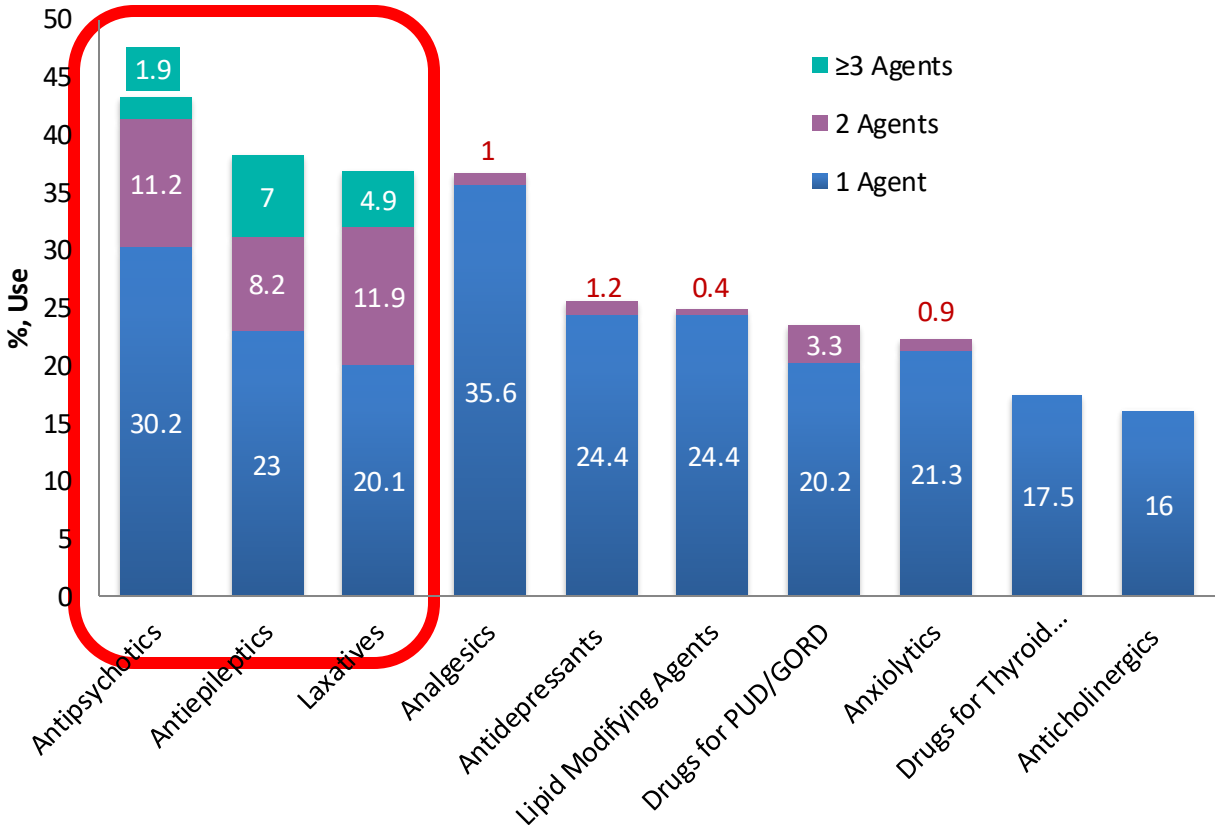




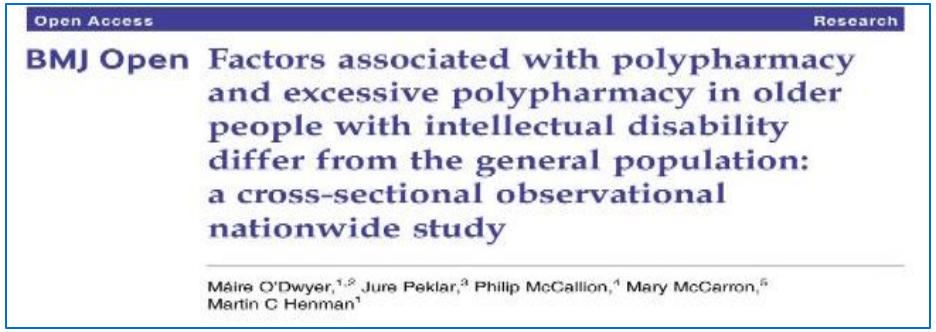
Frequently reported medications

IDS-TILDA vs TILDA

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)



Three Most Frequently Reported Therapeutic Drug Classes TILDA (Richardson et al., 2012)	
Drug Class	**Frequency**
Lipid Modifying Agents	33 %
Agents Acting on the RAAS	26 %
Anti-thrombotic Agents	25 %



Open Access Research

BMJ Open Factors associated with polypharmacy and excessive polypharmacy in older people with intellectual disability differ from the general population: a cross-sectional observational nationwide study

Máire O'Dwyer,[1,2] Jura Peklar,[3] Philip McCallion,[4] Mary McCarron,[5] Martin C Henman[1]



Psychotropic Medication Use: Key IDS-TILDA Findings

60%
of IDS-TILDA participants take a psychotropic medication

40% Antipsychotic Prevalence
Most commonly prescribed psychotropic over 10-year period

26.2 → 31.8%
Antidepressant use **increased**

Anxiety & Sleep Medicine use **decreased**

40-49 year olds

Lower use of antipsychotics in 2020 compared to 2010

⚠ Support Gap

Among participants with behaviours that challenge **without mental illness**:

- **35.5%** received a psychotropic medicine
- Only **40%** had access to key non-pharmacological supports

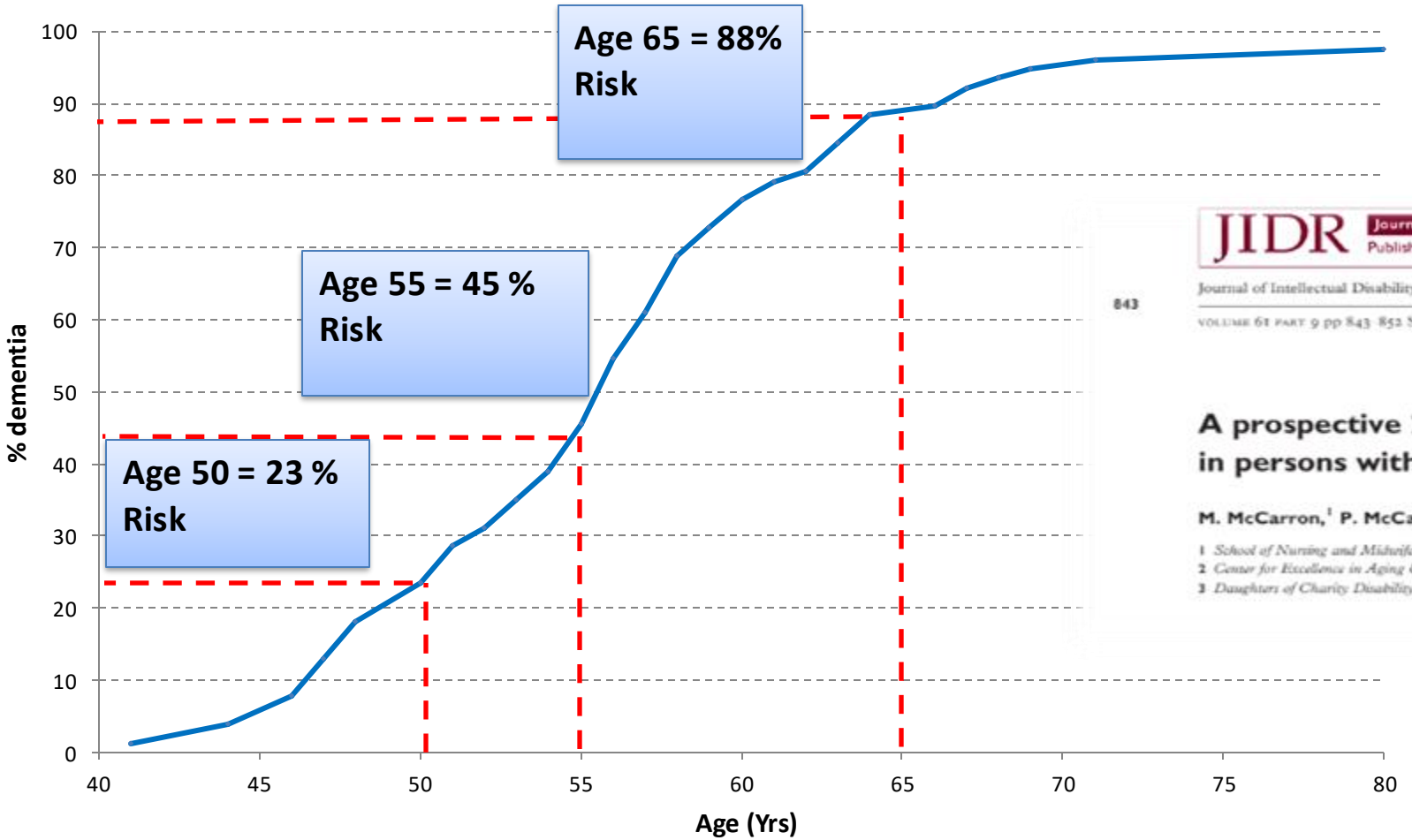
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Psychological Well-being and Cognitive Health

Ageing with Down Syndrome

Risk Trajectory By Age – Dementia in Persons with Down Syndrome

The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)





JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Journal of Intellectual Disability Research doi: 10.1111/jir.12390

VOLUME 61 PART 9 pp 843–852 SEPTEMBER 2017

843

A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome

M. McCarron,[1] P. McCallion,[2] E. Reilly,[3] P. Dunne,[3] R. Carroll[1] & N. Mulryan[3]

1 *School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland*
2 *Center for Excellence in Aging & Community Wellness, University at Albany, Albany, NY USA*
3 *Daughters of Charity Disability Support Service, Dublin, Ireland*

IDS TILDA: Translation and Policy Impact
National Intellectual Disability Memory Clinic

National Intellectual Disability Memory Service

Trinity Centre for Ageing and Intellectual Disability

Memory Service Now Funded on a Permanent Basis

Following a pilot period, the memory service has now been **incorporated into the national health budget** on a permanent basis.

This will mean that people with intellectual disability in Ireland can be **assured of permanent diagnostic service for dementia** into the future.



Potentially Modifiable Risk Factors for Dementia

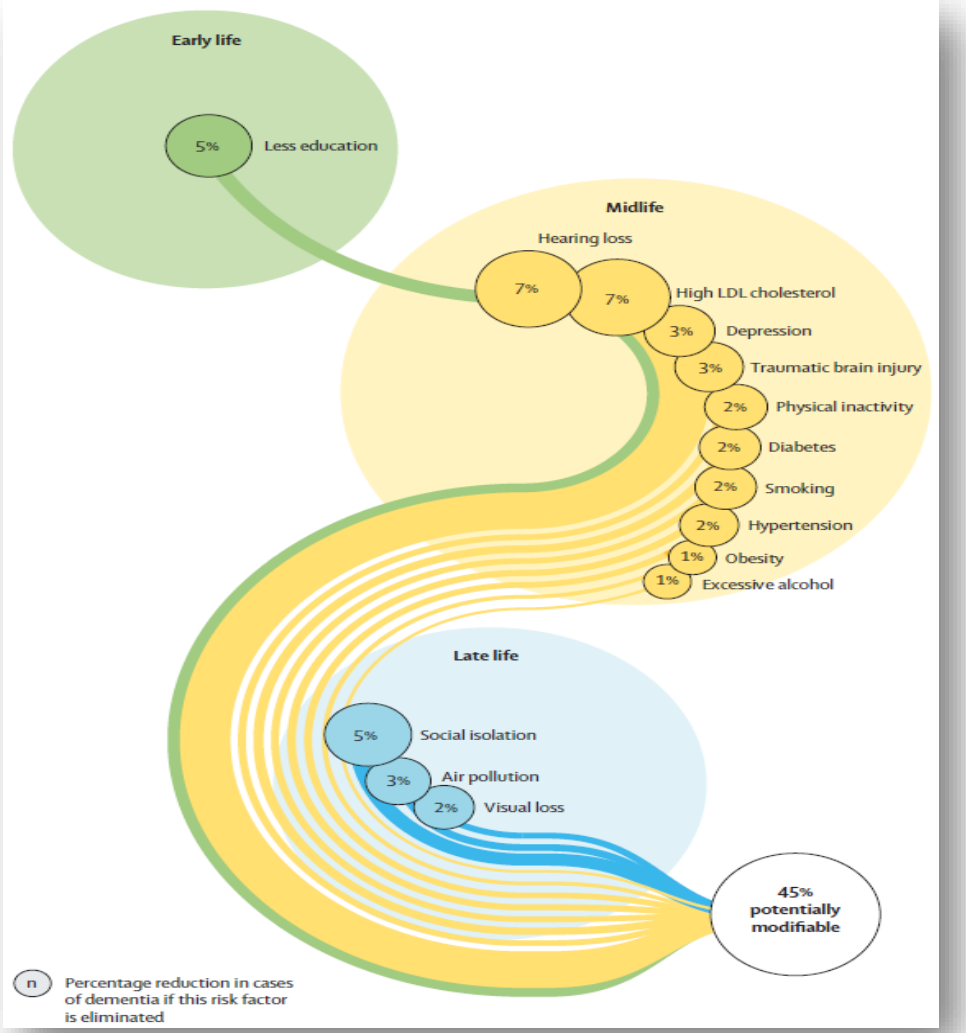
Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission

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Indicates that **nearly half of all dementia cases worldwide could be prevented or delayed by addressing 14 modifiable risk factors.**





THE LANCET

Include the voices of people with Down syndrome in the conversation on dementia

Trinity Centre for Ageing and the Life Course in Intellectual Disability

"Like everybody here, I have dreams for the future. There are things that I want to do, and I know dementia might play a part of my life too.

So, when you start talking about dementia, I want to be included in that conversation. I want to be included in the conversation about my future.

I want to be empowered so that I can choose how to reduce the risk of dementia"

- Dr Mei Lin Yap, Ambassador Liaison Officer







From Guidelines to Biomarkers: Enhancing Care in Intellectual Disability & Dementia

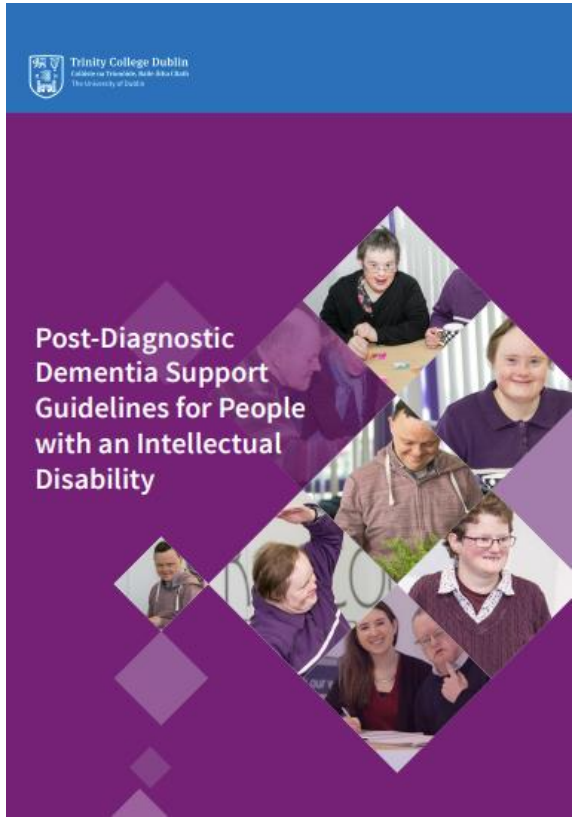
Trinity Centre for Ageing and the Life Course in Intellectual Disability

Biomarkers in the identification of Alzheimer's Disease in people with Down Syndrome (Bio-MinDS)



HRB: Emerging Clinical Scientist Award - *"We are entering a new era in AD treatment– for the first time there are therapies that can slow disease progression. Frustratingly, people with Down syndrome have been routinely excluded from AD drug trials, despite urgent clinical need in this population."*

- **Dr. Antoinette O'Connor**







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Social Determinants of Health: Choice, Interpersonal Relationships and Community Participation

Choice and Decision-Making Support

Opportunity to further develop decision agreement plans

There was an **increase in self-choice** scores for each age category, with the biggest increase among under-50s.

Younger men and women living independently/with family with mild/moderate intellectual disability had the **highest level of personal choice** in all aspects of daily living.

One-third of the sample had a **formal written decision agreement** plan in place, and a further **18.7%** had an agreement under development.

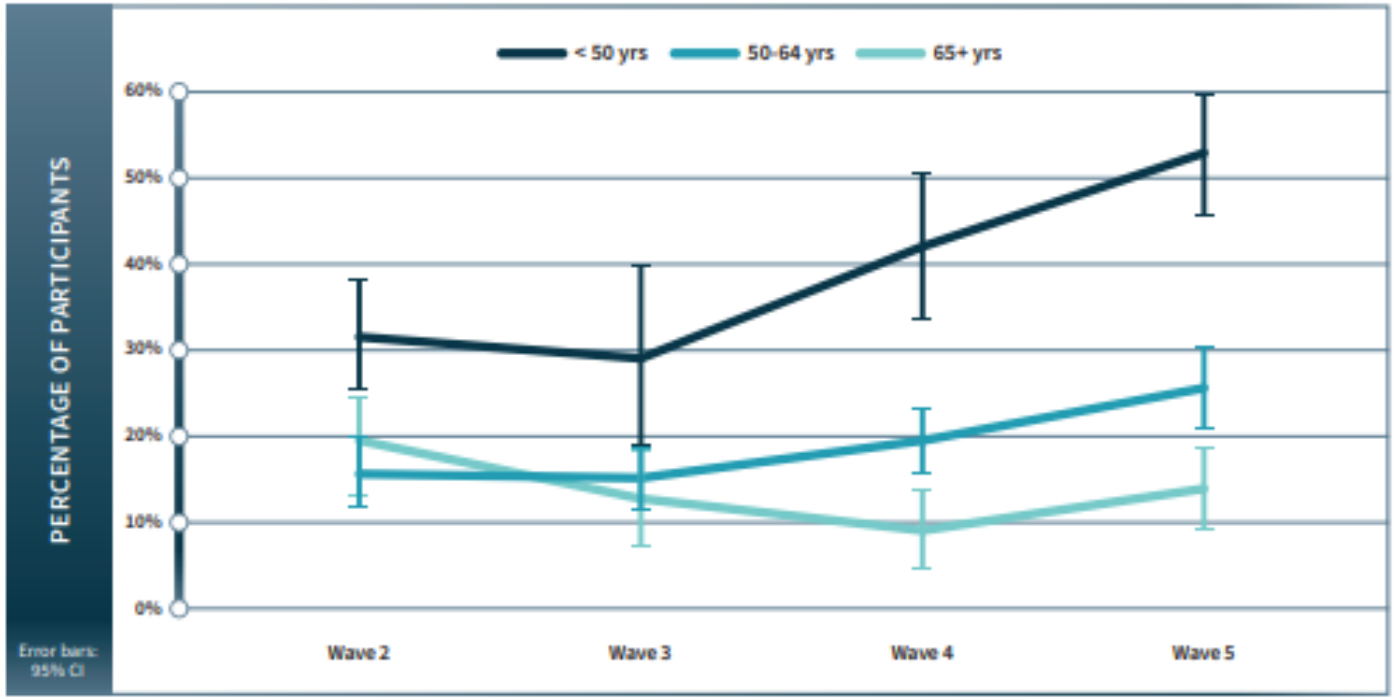
Thirteen people reported having an **advanced care directive**.



Interpersonal Relationships – Family Proximity

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Proportion of participants who lived close to family stratified by age, Wave 2 to Wave 5



96.2% had family, the most common being sisters (75.1%), brothers (70.7%) and nieces/nephews (46.6%).

Still <1% had **spouse/partner or children** of their own.

Number of participants **living close to family** increased from 20.3% in Wave 2 to **29.3%** in Wave 5.

The **biggest increase was for the under-50s**, whose proximity increased from 31.6% to 53%.

However, the trend was reversed for **participants aged 65+, with fewer living close to family** (W5 13.6% Vs W2 19.5%).

Interpersonal Relationships – Friendships

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Most participants had friends **(93.8%)**, and **60.5%** had a **best friend** – **both increased** since previous waves.

Nine in ten self-reporting participants had at least one close family member **(88.4%)**, and one close friend **(90.8%)**.

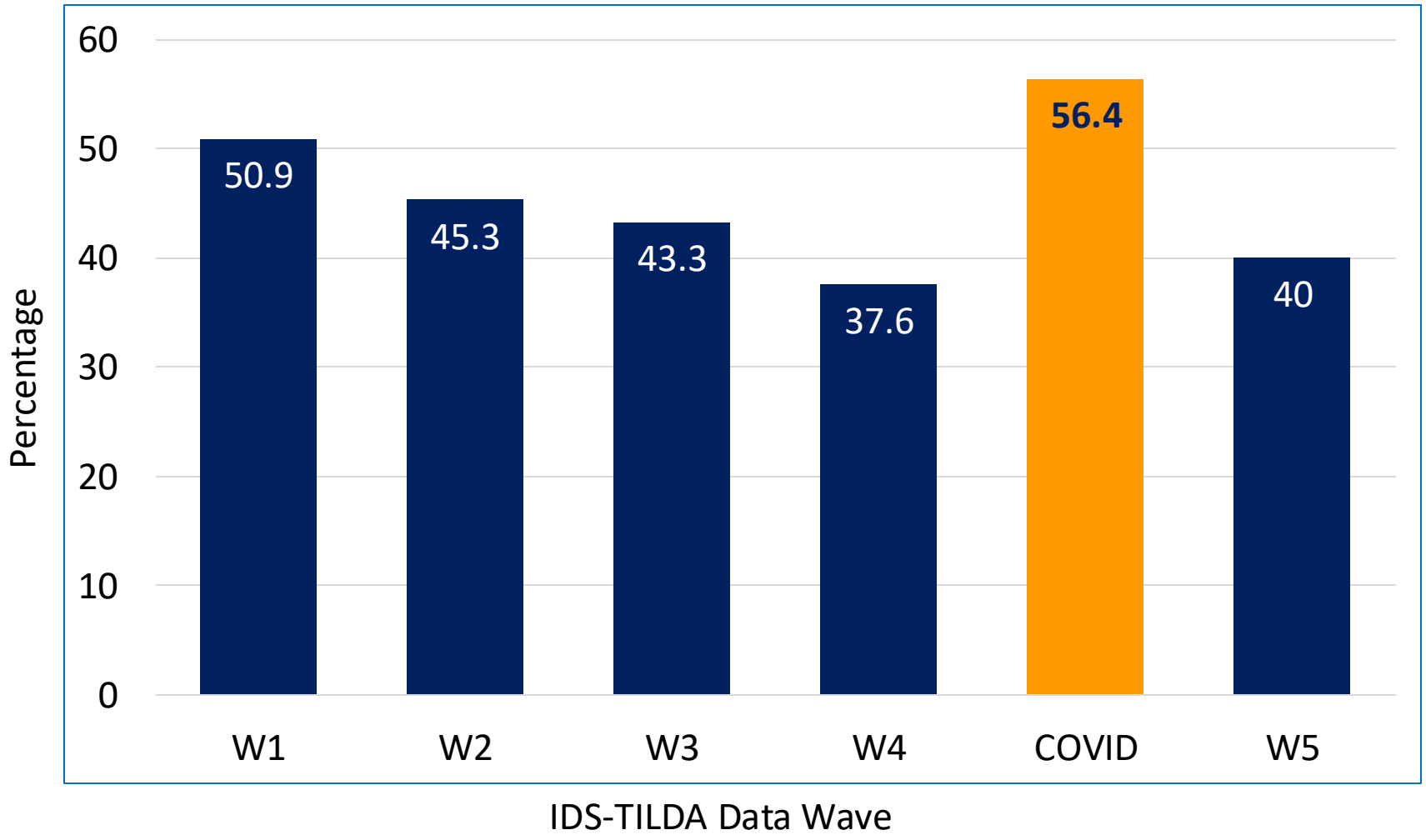
Co-resident friends were most common **(60.5%)** and highest in residential **(75.2%)** and group homes **(73.5%)**



Peers with an intellectual disability were the **most common type of best friend** at (62.6%), followed by **support staff** (18.1%).

Do you ever feel lonely? (Yes)

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)



40% still report **feeling lonely**

More **women** (45%) experienced loneliness than men (38%)

Loneliness and the loss of emotional support

The hardest and most bitter form of loneliness

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Losses include:

- **Loss of family members**
- **Loss of staff**
- **Loss of friends**

Participants unable to adjust to the new context after loss

Because they have no replacement relationships

Loneliness is concealed during the day by activity and is felt most intensely at night.

I lost my friend last year I was very close to her. It was terrible.

No, the two of them only talk to me. Rest have no interest

What make me feel very lonely is when for the last couple of months one of the girls was avoiding me.

I gets lonely after my mother and father and my two brothers

"Mostly at night when I'm sitting here and there'd be times, I'd love to have somebody to kind of say, oh that's very funny on that television. Or that you should see the view out there it's gorgeous."

Night time, it's terrible at night time

The consequences of loneliness

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Loneliness makes people hypervigilant





A heightened state of alert

Disrupting sleep

Raising Systolic Blood Pressure

Creates a distrust of others

Remembering more negative events



Key factors associated with inclusion & participation (IDS-TILDA)



Multiple factors shape experiences of inclusion / exclusion

Responses to supporting inclusion must be individualised

The Challenge

Improving social inclusion and community participation

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Inclusion & Participation is Multidimensional & Multifactorial.

Requires an individualised person-centred approach.

✓ Evidence ✓ Policy (✓)





IDS-TILDA shows some positive patterns over the past 15 years

But…
Slow change.
Little change for some (NB key factors)





What can you do to influence modifiable factors of inclusion?



The commission on Care for Older People



gov.ie News

Press release

Ministers for Health announce appointment of members of Commission on Care for Older People

From Department of Health
Published on 29 February 2024
Last updated on 29 February 2024

Determine the **effectiveness, adequacy and efficiency** of the care and supports which are currently provided within the health and social care system, including the **plans for their further development**, in meeting the **evolving care needs** of the increasing diversity of older people within the context of the ageing population.



Keep up to date with TCAID

Trinity Centre for Ageing and the Life Course in Intellectual Disability

https://www.tcd.ie/tcaid/

https://www.linkedin.com/company/trinity-centre-for-ageing-and-intellectual-disability/?viewAsMember=true

Save the date

17-20 August 2027

IASSIDD 2027 Congress

18th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities

Taking place at the **Convention Centre Dublin**, the event will feature Pre-Conference Academy Workshops on **Monday 16 August**, followed by the main conference from **Tuesday 17** to **Friday 20 August 202**7.



17-20 August 2027
IASSIDD
Dublin, Ireland
Inclusive Futures: Bridging Science, Policy and Lived Experience

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Thank You

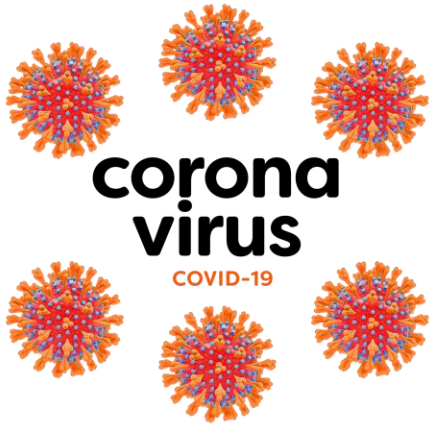
https://www.tcd.ie/tcaid/

https://idstilda.tcd.ie/

@ageingwithID

#ageingwithID

How we Survive & Thrive



How We Survive and Thrive: The People with Learning Disabilities Pandemic Inquiry

Hello!

Robert Garlinge



Dreenagh Lyle



Rachael Hall



We are some of the commissioners

Rachael helps manage the project

Why we are here today:

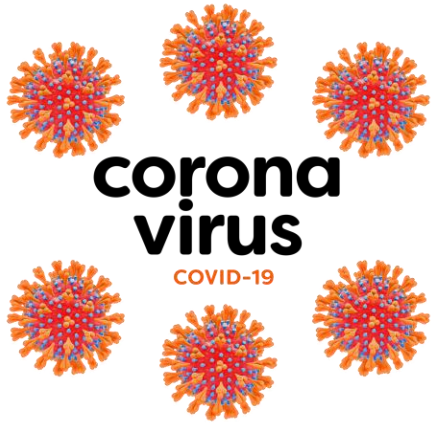
How we Survive & Thrive



- We are here to tell you about our project
- We are nearly finished our work and wanted to share an update and give you a sneak peak!
- We hope you will support our work when its finished

Rob

What is our project about?





- **How We Survive and Thrive** is an inquiry into people with learning disabilities experiences during the covid pandemic.
- It is led by people with learning disabilities and families
- We wanted to understand what happened to people and their families
- We wanted to take that learning and make sure everyone knows what needs to change

D

The inquiry is chaired by Andrew Lee and Philippa Russell.

Alongside them there are 10 commissioners, including 6 people with learning disabilities and 4 family members



Rob

Why are we doing this work?



- People with learning disabilities faced significant inequalities before the pandemic.
- The pandemic made many inequalities worse, and many people still haven't returned to the same quality of life they had before.



- We should not ‘go back to normal’ when normal was not working
- There will be other health emergencies, disasters or crises. We want to help everyone be prepared if or when they happen

Rach

Why are we doing this work?



- We are worried people with learning disabilities haven't been heard by the UK Covid Inquiry.
- We know some people submitted written statements and some organisations and researchers were asked to share evidence.



- We think its important to hear directly from people with learning disabilities and families about what is important to us.

D

Why are we doing this work?





- Through this project we wanted to put people with learning disabilities and families at the centre.
- We wanted their voices to be prioritised
- We wanted to be the ones making the decisions about what the project did and what we focused on

Rob

With thanks to our partners and funders

Manchester Metropolitan University

University of Birmingham

MacIntyre
Providing support...your way

CERTITUDE LONDON
FOR THE LIFE YOU WANT

Brandon
Live free
the learning disability charity

dimensions

Choice Support

United Response
support that changes with you

LDE
Learning Disability England

Rach

Our big question is….



What needs to happen for people with learning disabilities to be in the best place to survive and thrive if there is another pandemic?

Rob

How have we heard from people?





We heard from people in lots of different ways

- Surveys
- Workshops, online and in person
- Workshop in a box
- People shared their research and reports, videos and case studies

Worsening Inequality



The pandemic did not create inequality.

It exposed and intensified inequalities that already existed.

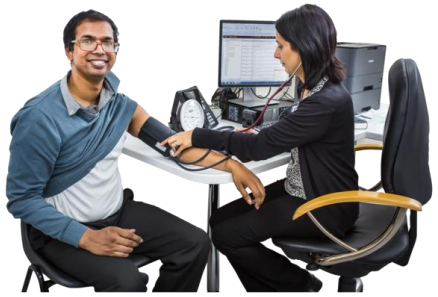
This affected people who:

- Don’t have full rights
- Don’t have good support and opportunities
- Aren't supported to make decisions about their lives

Rob

What people told us





We found that because people with learning disabilities were overlooked in planning, communication, decision-making and service delivery:

- support was reduced or withdrawn when people needed it most
- health inequalities had a profoundly negative impact

D

What people told us



- information was often inaccessible, confusing or arrived too late



- many people with learning disabilities and families had little influence over decisions affecting everyday life



- many people became isolated and lost confidence, sense of purpose and opportunity.

D

Prevention





We need to:

Take action to make sure people are living good lives now

Plan well for future pandemics and national crises

All this preventative work will make sure people are in the best position to survive and thrive in a crisis

Rach

Some of our recommendations

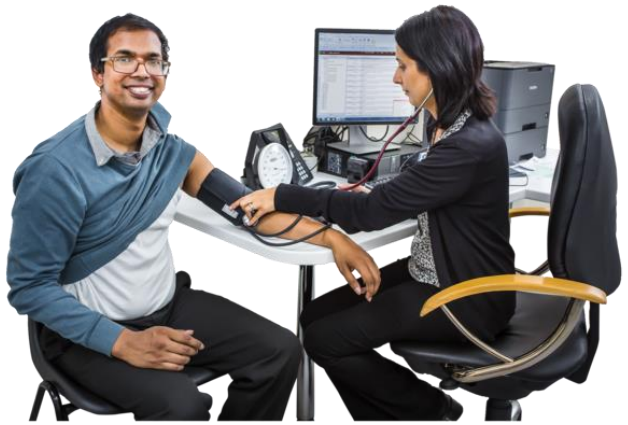


Government must support an independent national voice for people with learning disabilities.

It must be resourced to influence policy, action this Inquiry's recommendations, press for better practice and hold decision-makers publicly accountable.

D

Some of our recommendations



Health services must deliver proven support for people with learning disabilities

Like annual health checks and learning disability liaison nurses in hospitals.

They must collect and share information about different outcomes and health inequalities affecting people with learning disabilities.

Rach

Some of our recommendations



During a national crisis, government, councils, and support and housing providers must keep supporting people or given them more support if they need it.

They must not reduce or withdraw support.

Social Care must be stronger

D

Some of our recommendations

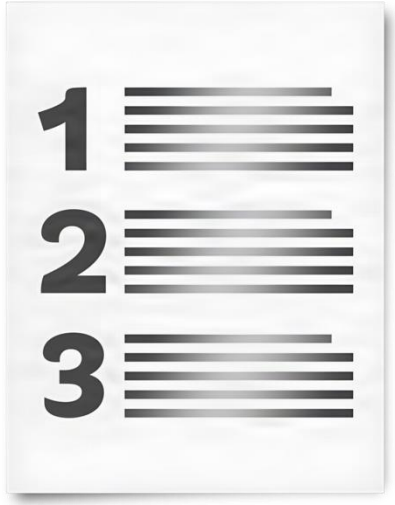


National and local leaders must ensure all people with learning disabilities are recognised as a priority group in all national and local health plans, strategies and service frameworks.

This must include people from minoritised communities and people with profound and multiple learning disabilities

Rach

Some of our recommendations



Before making major decisions, government and councils must set out how these will affect people with learning disabilities, including those who face other disadvantages.

Rob

Some of our recommendations



Government and councils must set policies and work with employers and community organisations to increase opportunities for work and inclusion.

Then people will be better connected before any future crisis.

Rob

Making change happen



- We are looking to make practical recommendations to make change happen
- We know the system is already under pressure
- Much of what we heard was about basic good practice.
- Sometimes it was obeying the law.
- We want to make sure everyone can live a Good Life!



Rob

Sharing our work



- We are finishing our reports at the moment.
- There will be an easy read and full report
- There will be policy briefings to help us all think about what action we need to take
- There will also be online events, a launch and discussion sessions. Join us!

Rach

Can you help share our recommendations?





We really need your help to make sure everyone hears about this work. We are going to ask people:

- To share the report amongst your organisations and networks.
- To speak to care support providers, schools, local authorities and healthcare providers about the report and its recommendations.
- To ask people to write to your MP to tell them about the report and the recommendations.

D

Keep in touch



Email info@LDEngland.org.uk

Of sign up to our newsletter to hear about when we launch our report:



Rob

HEALTHY LUNGS

Co-producing a respiratory health education programme with people with a learning disability from minoritised ethnic communities

Learning Disability Professional Senate • Healthy Lives Together • September 2026

Esther Smith Advanced Clinical Practitioner – All Age Learning Disability Service LSCFT
esther.smith@lscft.nhs.uk
Tracey Hartley-Smith Clinical Nurse Consultant – Mental Health, Intellectual and Developmental Disability Service Gold Coast Health Queensland
tracey.smith20ed97@health.qld.gov.au

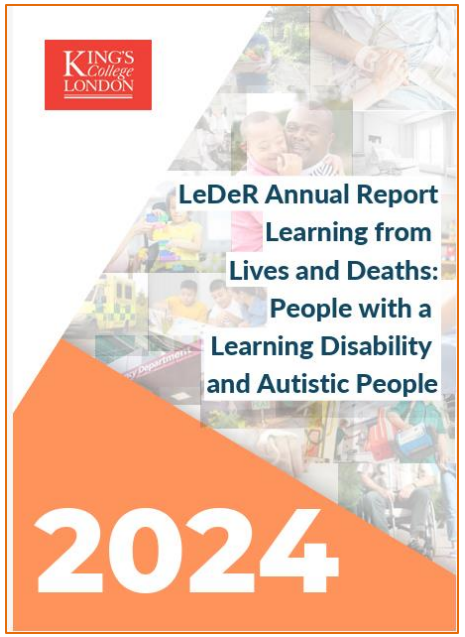
Why we couldn’t ignore this

Respiratory disease remains a leading cause of death for people with learning disabilities.

For people from minoritised ethnic communities, disadvantage can overlap:

- Learning disability
- Ethnicity
- Poverty & access
- Communication

The result can be late recognition, delayed treatment and poorer outcomes.





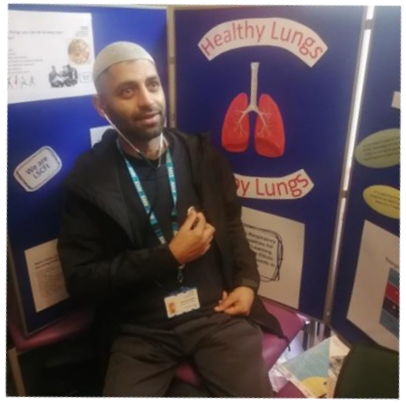
LeDeR + We Deserve Better gave us a clear challenge: prevention had to reach people differently.

OUR STARTING POINT

We started by listening — not by assuming









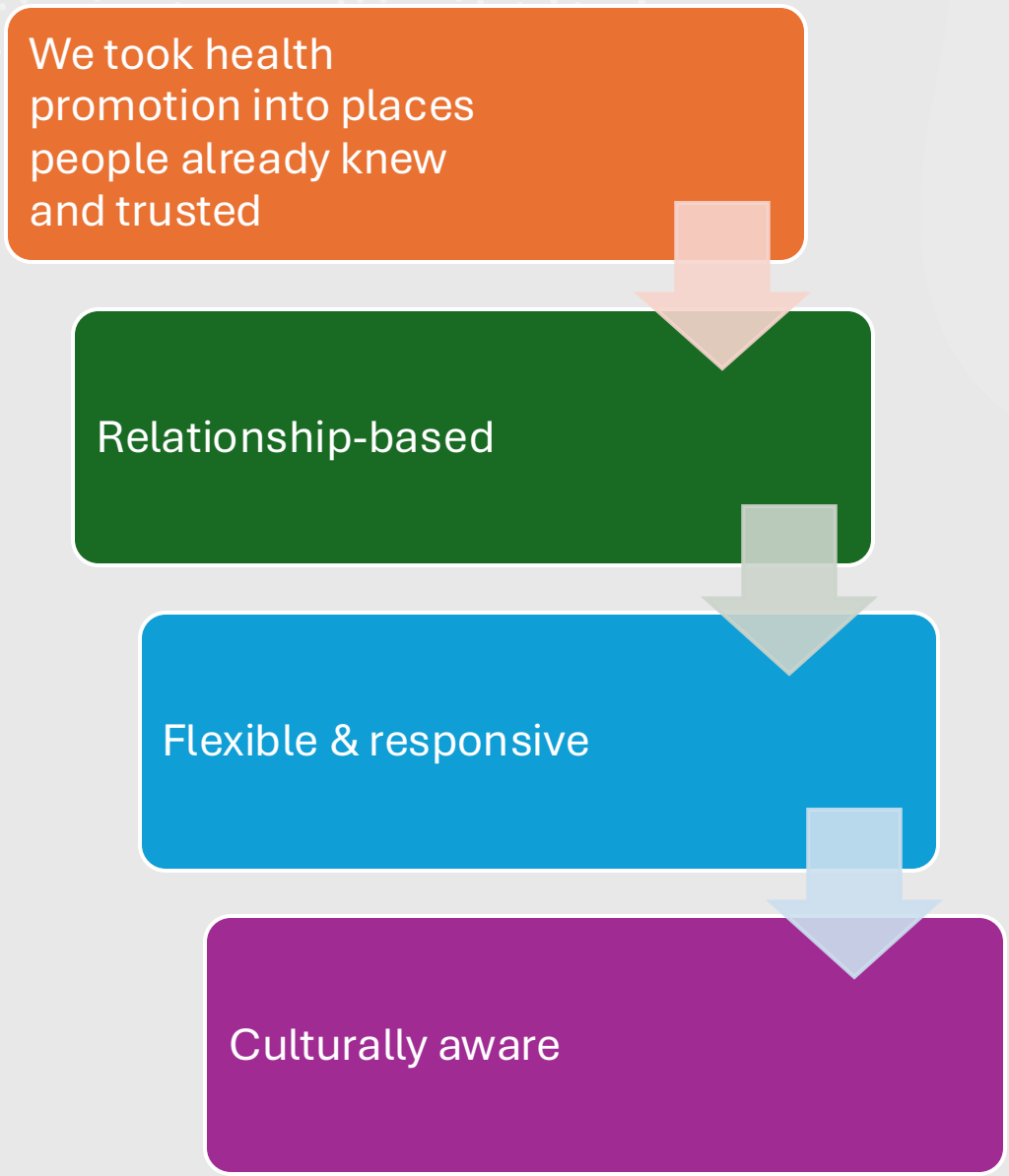
Coffee mornings. Carers' groups. Community leaders. Faith venues. Self-advocates.

We listened before designing, tested the workshops, and adapted as we went.

Co-production was not a stage of the project — it was how the project worked.

We stopped expecting communities to come to healthcare

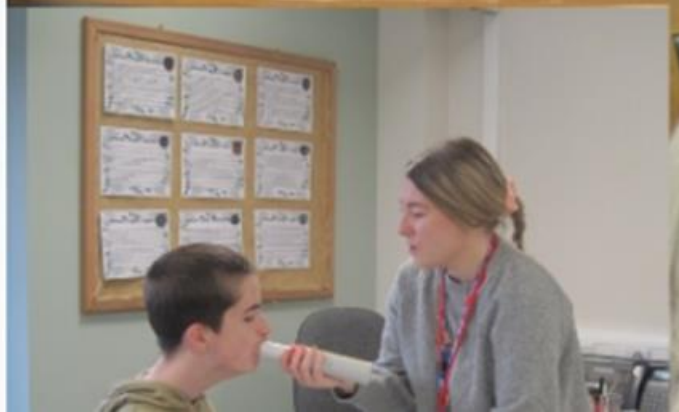
The intervention began with relationships












Healthy

What happened when we did that?

26+

community workshops

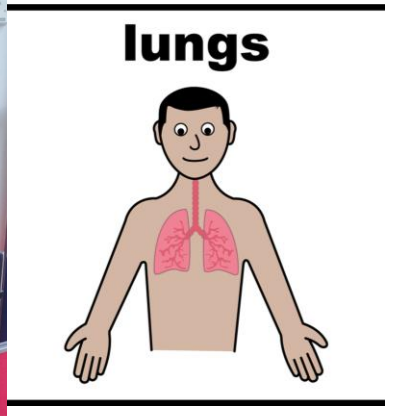
400+

participants reached









Accessible resources • culturally tailored information • practical education • early recognition • knowing when and how to seek help

ONE FAMILY'S EXPERIENCE

The numbers mattered. This mattered more.

**"At appointments I felt rushed.
Here, I had time to understand."**

Parent attending through a carers group

She had been seeking help for ongoing health concerns, including breathing difficulties.

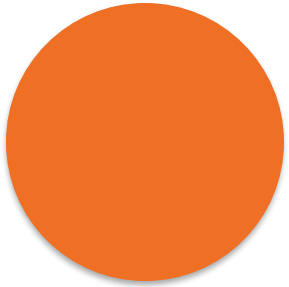
- The workshop created time for clear, accessible explanation and discussion.
- **She felt listened to, understood what action to take, and reported a significant improvement in her child's health.**

Access is not only about whether a service exists. It is also about whether people can understand, trust and use it.

Did we ‘reduce inequality’?

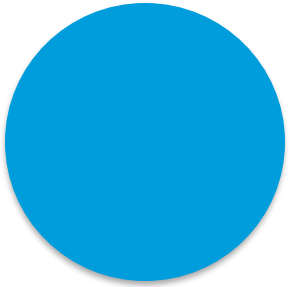
We should be careful not to claim that a short project closed the inequality gap.

What we did change were some of the conditions that help inequalities persist:



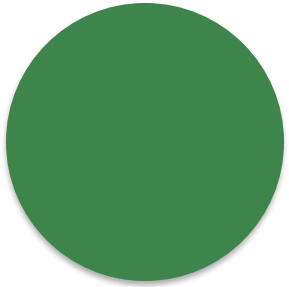
Awareness

of respiratory health



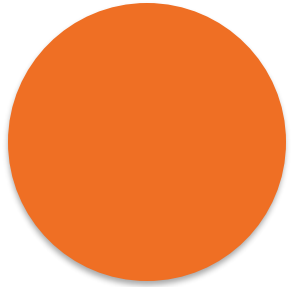
Confidence

to manage health



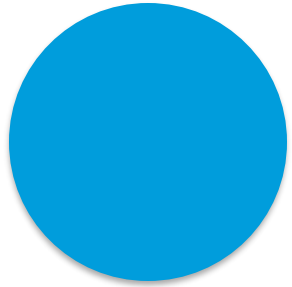
Engagement

with services



Trust

between communities and teams



Help-seeking

earlier recognition and action

And the work continued beyond the initial project through ongoing delivery and pathway development.

WHAT WE'D TELL ANYONE
TRYING TO DO THIS ELSEWHERE

Don't call communities "hard to reach".

Ask whether our services are hard to reach.

1. **Listen first**
2. **Go where people are**
3. **Build relationships first**

Healthy Lungs showed us that meaningful prevention starts with humility, trust and co-production.

https://vimeo.com/1099429767/a14eab7bac

Reducing Health Inequalities through Early Community, Based Intervention.

NHS
East London
NHS Foundation Trust

Simone Mingay, Clinical Nurse Manager
Services for People who have a Learning Disability (SPLD)



Ask about the #ELFTPromise

We care
We respect
We are inclusive

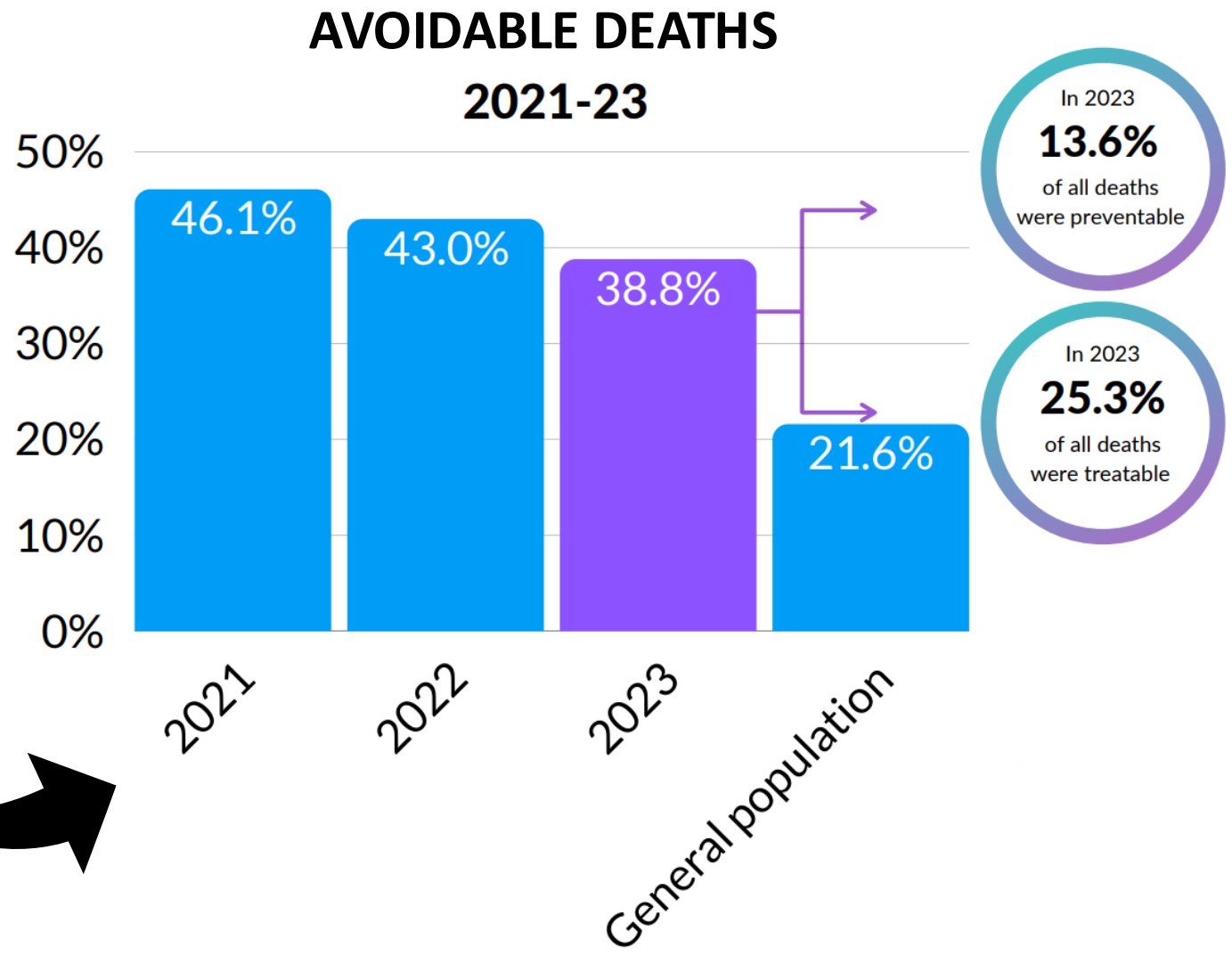
Why does equity and physical health matter?

NHS East London NHS Foundation Trust

Compared to the general population:

- People with a learning disability die **~20 years younger**
- Avoidable deaths are nearly double the rate

This mortality gap exists because prevention happens too late, or not at all.



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We care
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We are inclusive

Source: White et al., 2024. https://www.kcl.ac.uk/ioppn/assets/pdfs/leder/leder-annual-report-2023.pdf

Local challenge to Acute and Primary Care

NHS East London NHS Foundation Trust



There was a high rate of emergency hospital admissions among individuals with a learning disability.

→ Hospital stays were often longer for this group compared to the general population.



This trend has significant implications, not only in terms of financial cost to the health system, but also due to its emotional and mental health impact on individuals and their families.

This was a system responding to crisis rather than preventing it

Service User Experience and Feedback

NHS East London NHS Foundation Trust

'People with learning disabilities often feel excluded and unheard. They want to be fully part of our society, not marginalised or forgotten'

Valuing People, 2001

'She was agitated (due to being unwell) and without him (the home manager) being on the ward to intervene, she would have been prescribed sedation without understanding that she was distressed and feeling unwell'

Home Manager, Case Study F

'Pharmacy delays the discharge process, by 24 hours at least and this can be avoided if ward staff notifies pharmacy on medication needs beforehand. This happens on most discharges'

Carer Experience 2024

'We felt that if we were not present at the hospital, my sister would not have survived'

Sister/ Carer 2024

'Staff were not listened to- we have more than one machine to read the ketones, however Paramedics ignored staff concerns and refused to take him'

Home Manager, Case Study R

Ask about the #ELFTPromise

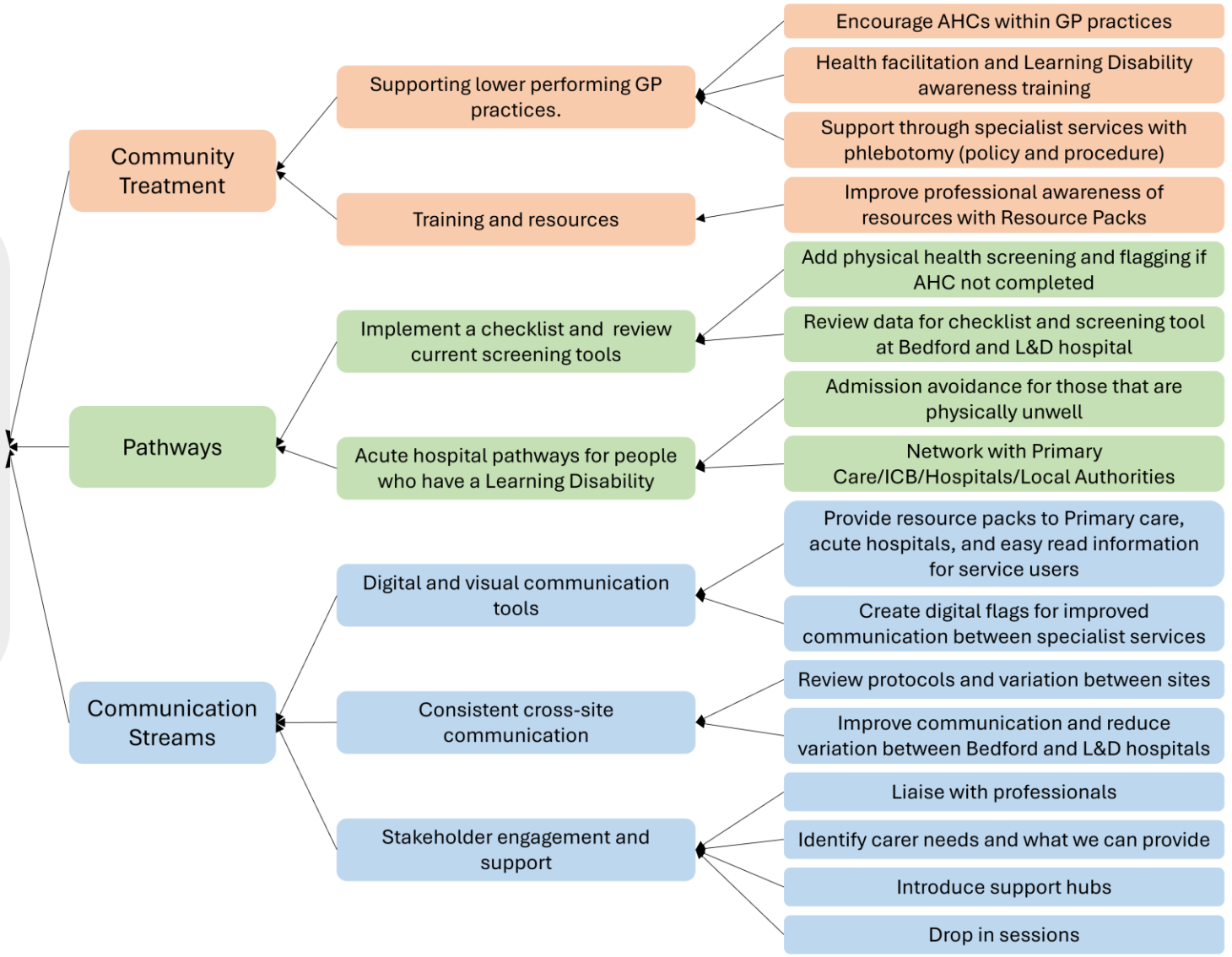
We care
We respect
We are inclusive

Aim and Approach: Prevention upstream, before A&E, before deterioration, before admission

East London NHS Foundation Trust

AIM

Reduce avoidable acute hospital admissions in Bedfordshire for people with a Learning Disability by 40%, by July 2025.



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elft.nhs.uk

Change Ideas Tested

NHS East London NHS Foundation Trust

Targeting lower performing GP Practices:

Promoting Annual Health Checks.

Training to Primary Care colleagues.

Awareness of available community resources.

Checklist and screening tools:

Digital flagging on acute systems.

Physical health considerations in MDT's.

Triage checklist within acute settings.

Pathway development:

Acute and community pathways.

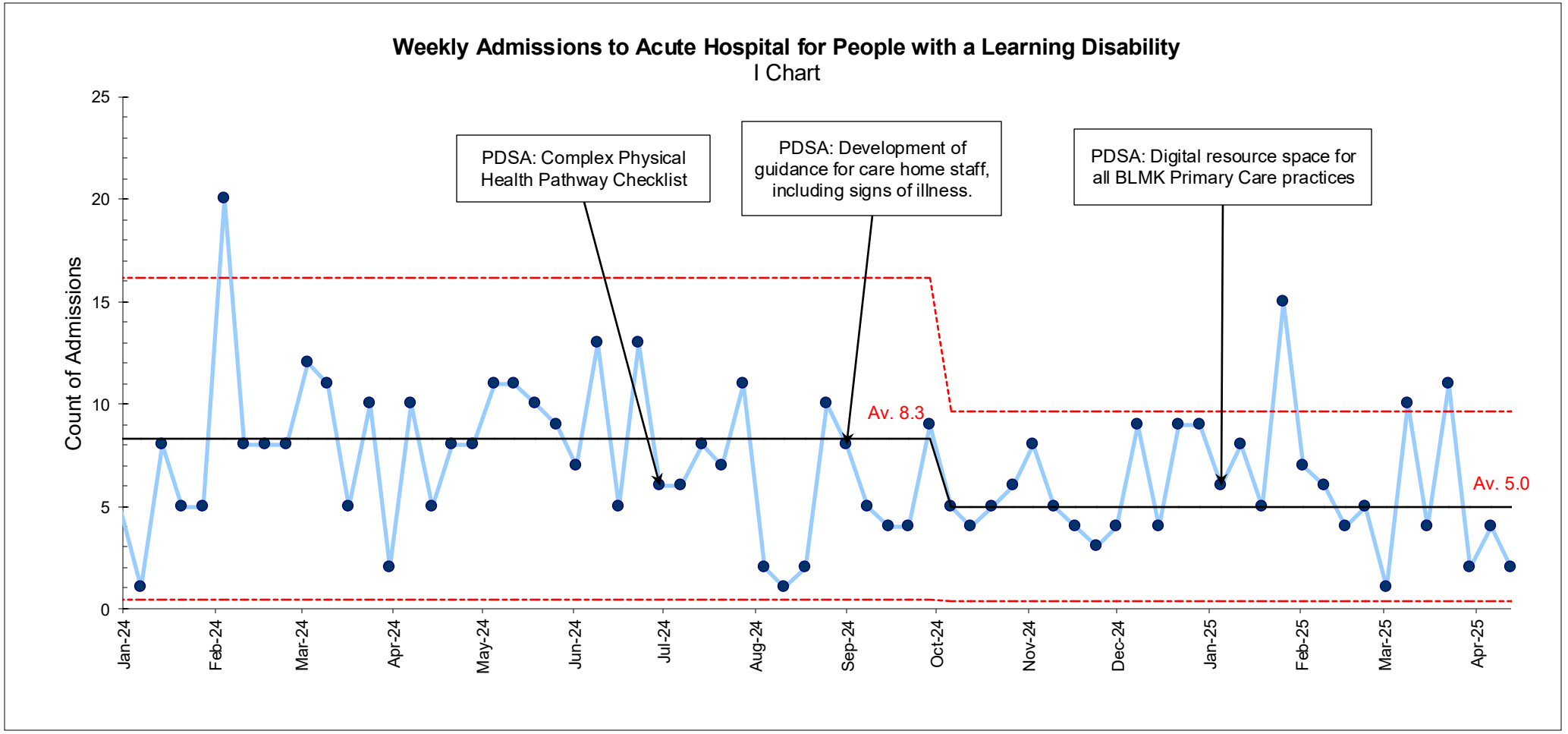
Collaborative admission avoidance policy

Collaborative discussions with stakeholders.

Digital resource space:

BLMK wide digital resource space to enhance access to accessible information, guidance and tools to deliver high quality care.

Impact and Outcomes: Acute Admissions



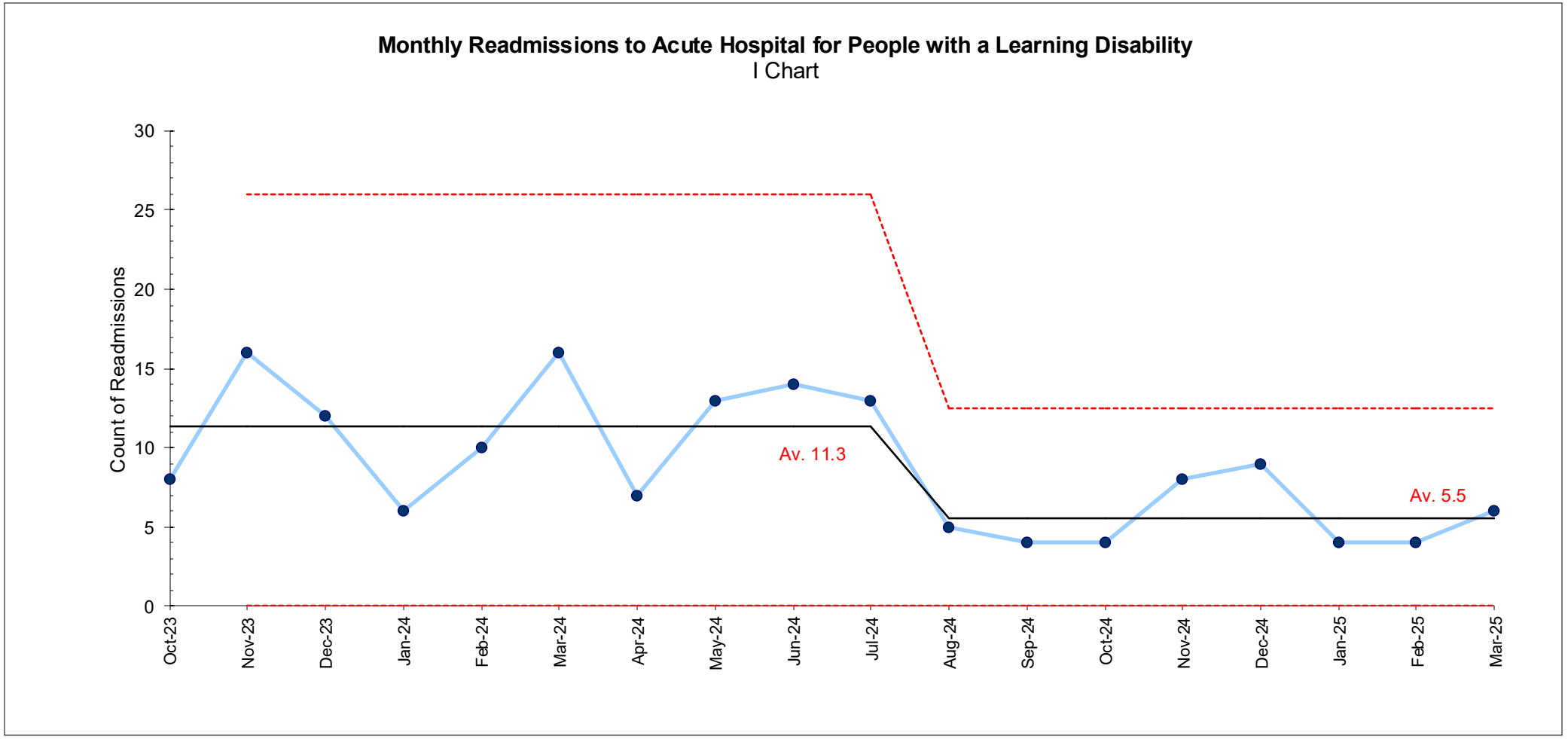
40%

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Impact and Outcomes: Acute Readmissions



55%

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Impact and Outcomes: Financial Savings

East London NHS Foundation Trust

Average cost of an acute bed per day*: (excluding any treatment costs)	£350
Average Length of Stay:	10 days

Average Weekly Admissions: (***before*** interventions)	8.3
Average Weekly Admissions: (***after*** interventions)	5

Weekly cost of admissions **before** interventions

£ 29,050

(8.3 admissions x 10 days x £350)

—

Weekly cost of admissions **after** interventions

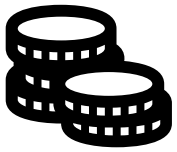
£ 17,500

(5 admissions x 10 days x £350)

=

Weekly Cost Avoidance

£ 11,550



Cost avoidance of over £600,000 per year, excluding treatment costs

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*Average cost of an acute bed per day is an estimate based on 2020/21 National Cost Collection Data. Source: UK Parliament (2023) *Written questions and answers - Written questions, answers and statements - UK Parliament*, *Parliament.uk*. Available at: https://questions-statements.parliament.uk/written-questions/detail/2023-03-14/165361.

Post Project Service User Feedback

East London NHS Foundation Trust

"They helped us avoid another hospital stay, which was a big relief." (Carer)

It stopped me from panicking and going to A&E.
(Service User)

"Because of the team, I didn't have to go into hospital."(Service User)

I liked that people listened to me about what I wanted. I feel more confident about my health now."
– Service user

"They worked well with my GP and social worker — everyone communicated really well."
Service User

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Preventing Avoidable Admissions: David's story

NHS East London NHS Foundation Trust

PROBLEM

- 19-year-old with moderate learning disabilities and autism
- 3 hospital admissions in 6 months for aspiration pneumonia
- Referred to Learning Disability Specialist Healthcare Team (SHCT)

INTERVENTION

- Multidisciplinary plan co-produced with GP, SHCT, SLT, and carers
- Medication review to ensure antibiotics in home
- Carer training on early warning signs of infection
- Weekly health monitoring with clear escalation pathway
- Updated Annual Health Check and hospital passport

OUTCOMES

- **Zero** hospital admissions in 3 months
- Improved hydration
- Increased carer confidence and skills
- Stronger collaboration between primary care and community team



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Lessons Learned

NHS East London NHS Foundation Trust

Proactive	Early MDT working prevents crisis	Monitor data for patterns and trends
Training	Carer training	Empowerment of service users
Tools	Use simple tools (Restore2, SBARD)	Improve Communication
Reasonable adjustments	Carer understanding of reasonable adjustments	Professional understanding of reasonable adjustments

Ask about the #ELFTPromise

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We respect
We are inclusive

- **Scaling This Model Nationally**
- Model can be replicated across:
  - Primary Care Networks (PCNs)
  - Integrated Care Systems (ICSs)
- Key components for scaling:
  - Co-production embedded in design and delivery
  - Standardised training for primary care
  - Strengthened Learning Disability Registers
  - Community-based outreach model
- Low-cost, high-impact approach:
  - Reduces hospital admissions
  - Improves patient experience
  - Addresses health inequalities
- Opportunity:
  - Development of a Learning Disability Friendly GP accreditation model

Future Directions and Call to Action

NHS East London NHS Foundation Trust

- **Scale approach** across Bedfordshire, Luton & Milton Keynes
- **Share learning** via care home forums and primary care training
- **Continue monitoring data** for sustainability and cost-effectiveness



Together, we can make hospital admissions *the exception*, not *the expectation*.

Constipation management in people with intellectual disability

Tooba Bukhari

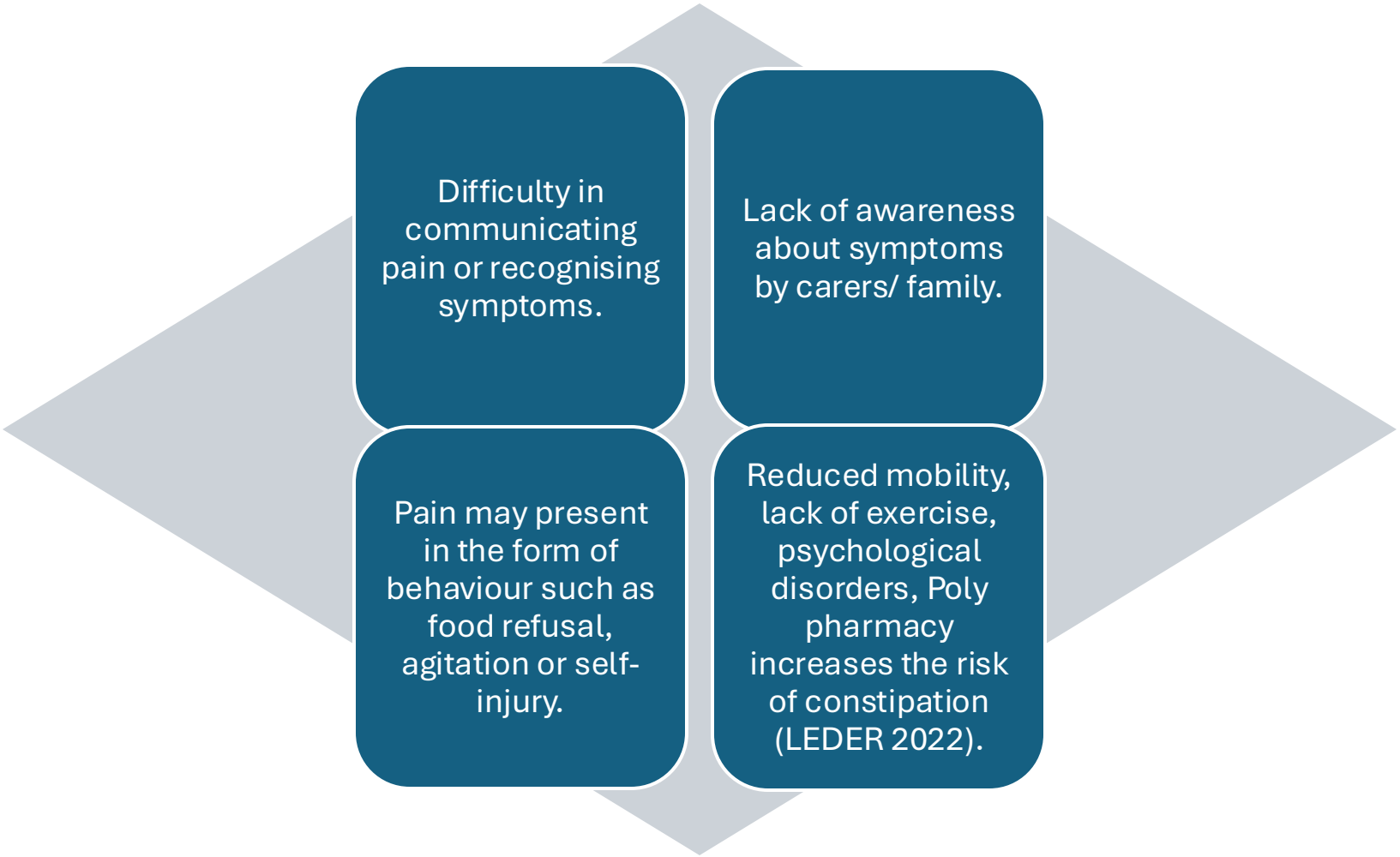
Learning disability Physiotherapist

Constipation in People with Intellectual disability

Prevalence and mortality:

- Between 33% and 50% of adults with intellectual disability experience constipation.
- Higher rate of 60% reported in non ambulatory adults and people with profound intellectual disability.
- 23% deaths in people with ID vs 10.1–15.3% deaths in general population due to constipation (Heslop et al., 2020)(Barberio, 2021).

Health inequalities

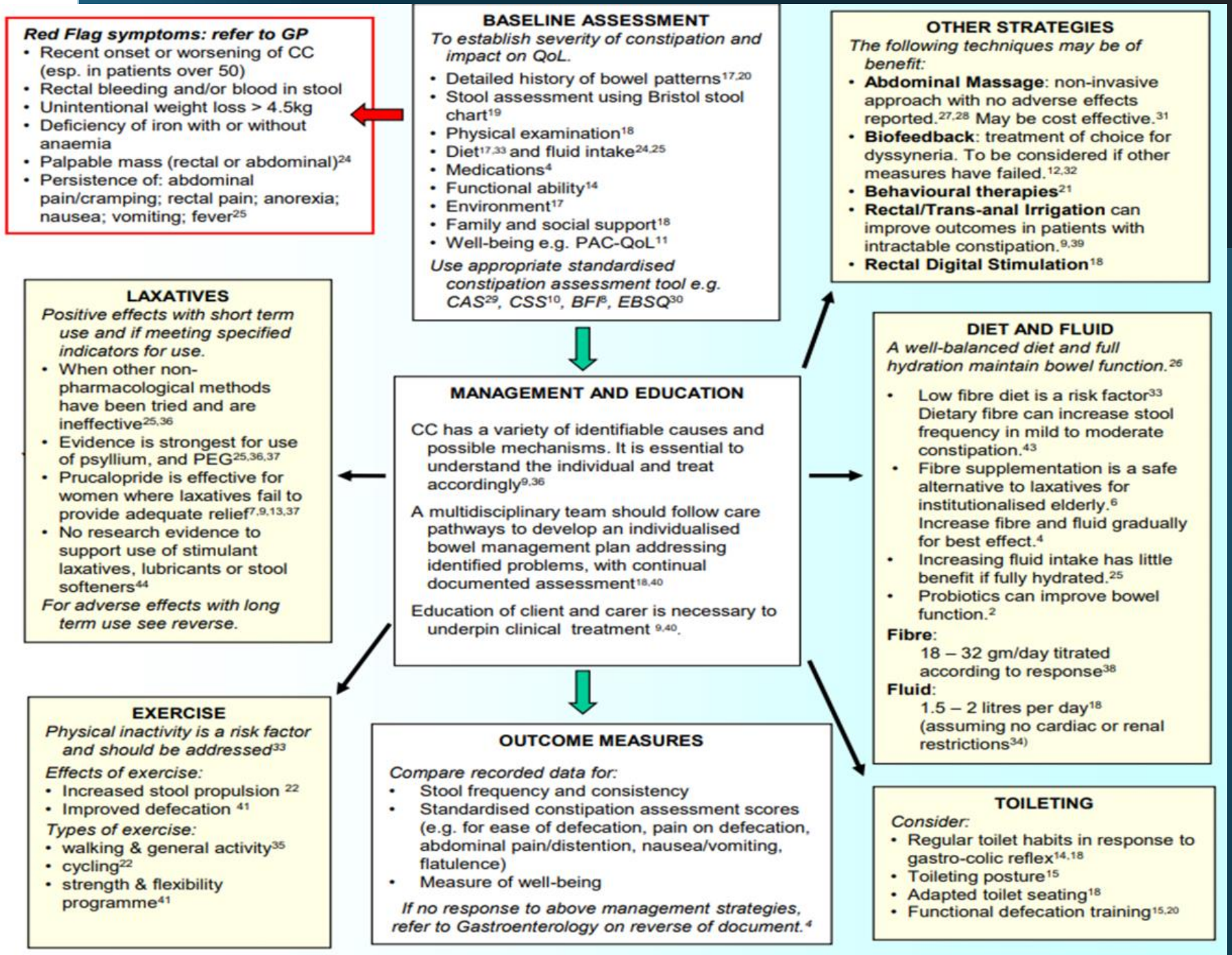


Richard’s story

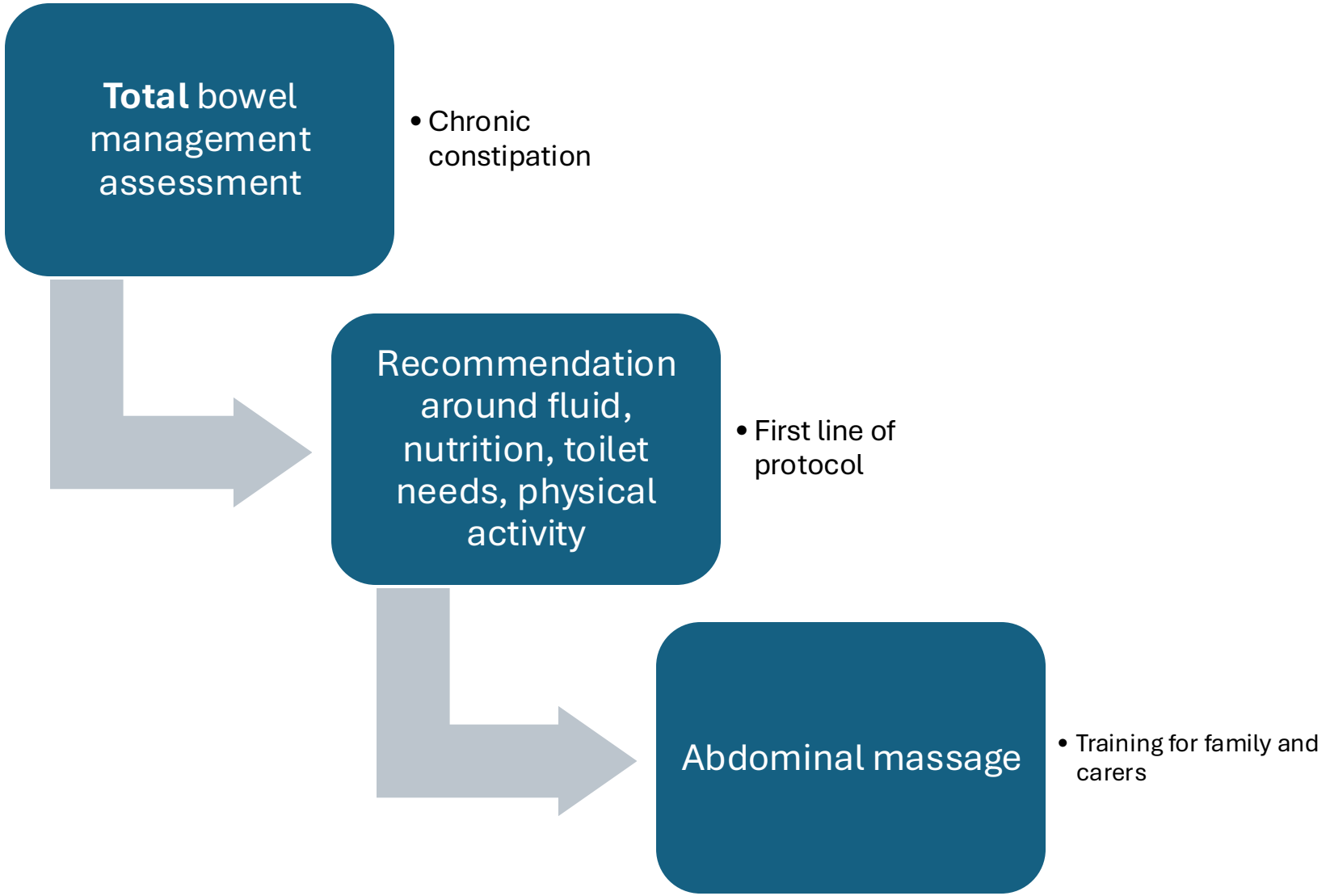
- 33-year-old
- Constipation was a long-term condition requiring regular monitoring and support.
- Bowel health monitoring reduced over time, and support staff had limited bowel health training.
- Changes in behaviour and increasing distress were attributed to mental health rather than possible physical health problems.
- Severe faecal impaction was not recognised despite contact with multiple health and social care professionals.
- Serious failings were identified across health and social care services.
- Richard died from complications of untreated constipation, a largely preventable condition.

Public Health England - A multiprofessional approach – Pathway

Authors: Marian Emly, Anna Marriott



CWP – Pilot work



Prevention is better than treatment

Key to prevention

Healthy diet **Plenty of fluids** **Regular exercise**

Good toilet habits

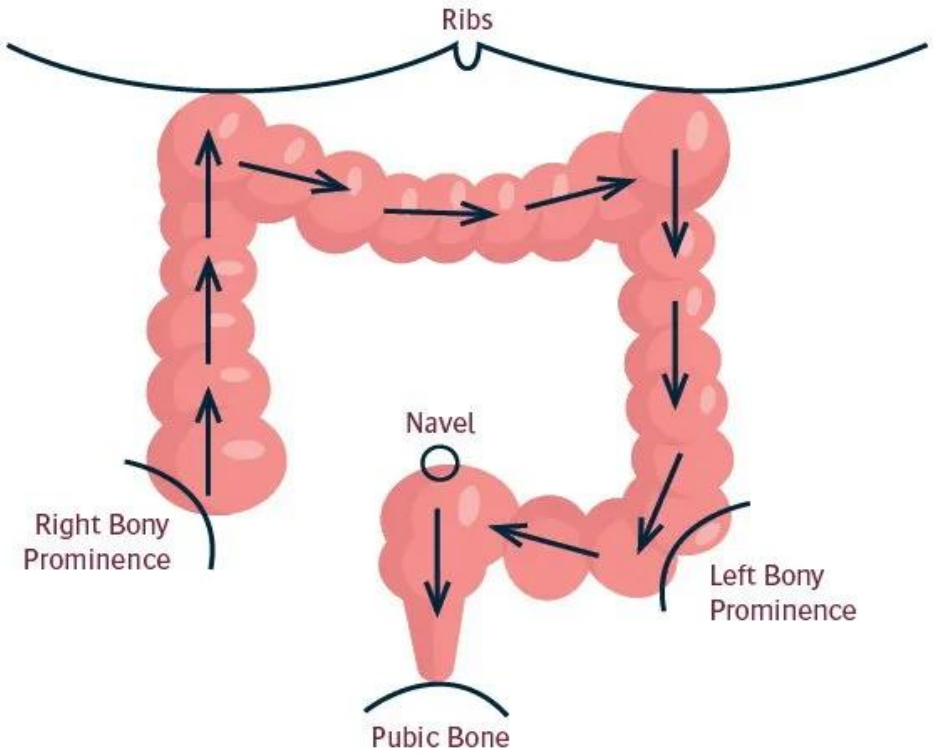
- Encourage regular habits.
- Suggest raising the feet onto a low stool as this relaxes the pubo-rectalis muscle and facilitates complete emptying of the rectum
- Advise on abdominal massage where appropriate.
- While privacy is important, don't allow this to put someone at risk – it is more important to be able to keep an accurate bowel chart.



Annual Health Checks

- Ask about constipation.
- Review the poo book or bowel chart.

Abdominal massage



- **Moss, Smith et al. 2007**

5 participants, aged 4 to 9 years, severe to profound LD

20 min of massage at least twice daily for 24-35 weeks

Impact: stools of 'normal' consistency increased in three of the five participants.

- **Bromley et al. 2014**

25 children, 3 months to 19 years with physical and LD

6 weeks, 20 minutes once a day for 6 weeks

Impact: 87.5% parents considered it effective. Reduction in use of laxative in 58% children.

- **Connor M et al 2014**

181 residents, severe LD

Daily or weekly abdominal massage and laxatives

Impact: Relieve discomfort and pain.

- **Finlayson et al 2026**
- 31 adults with intellectual disability
- 6- week period
- Feasible nonpharmacological intervention.

Looking Forward - Priorities



EMBED PROACTIVE BOWEL HEALTH MONITORING ACROSS HEALTH AND SOCIAL CARE SERVICES.



IMPROVE STAFF, CARER, AND FAMILY AWARENESS OF CONSTIPATION RISKS AND EARLY WARNING SIGNS.



PROMOTE HEALTHY LIFESTYLES, INCLUDING HYDRATION, NUTRITION, PHYSICAL ACTIVITY, AND TOILETING ROUTINES.



STRENGTHEN ANNUAL HEALTH CHECKS AND HEALTH ACTION PLANS TO INCLUDE BOWEL HEALTH AND PREVENTION STRATEGIES.



IMPROVE COMMUNICATION AND SHARED RESPONSIBILITY ACROSS SERVICES TO REDUCE DIAGNOSTIC OVERSHADOWING.

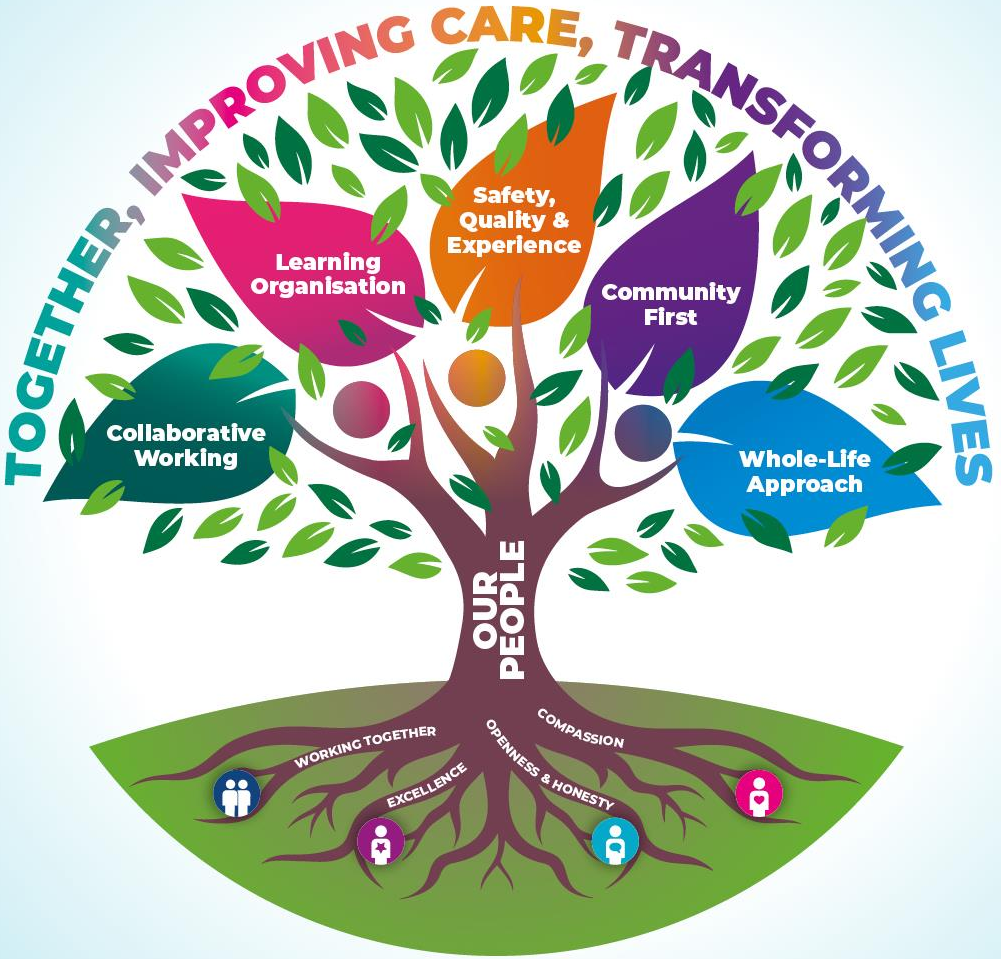

THANK YOU!

“Value versus Challenge in Early Intervention: A group-based therapeutic intervention”

CAMHS ID
Southern Health and Social Care Trust
Northern Ireland

Emma McDermott
CAMHS ID
Early Intervention Lead
September 2026





HSC Southern Health and Social Care Trust
TOGETHER, IMPROVING CARE, TRANSFORMING LIVES

CAMHS ID Southern Health & Social Care Trust

Specialist Practitioner & Manager

Consultant Psychiatrist / Clinical Lead

Step 3/Specialist

3 Senior Practitioners

3 Practitioners

Speciality Doctor

Occupational Therapist

CAMHS Nurse

Medication Monitoring
Senior Nurse Practitioner

Early Intervention/Step 2

Senior Practitioner

CAMHS Nurse

3 Assistant Practitioners

Prevention and Innovation

- "Healthy Me": a pilot group based mental health promotion programme adapted for young people with intellectual disabilities; a successful programme delivery and collaboration with Action Mental Health MensSana (third sector/community sector NI)
- Public Health Agency Partnership working Group: Special Schools Partnership Pilot N.I
- CAMHS ID Parent Therapeutic Intervention Group (TIG): Parents co-produce a PBS plan for their children



- **Mental Health Strategy 2021–2031:** This ten-year plan sets out regional priorities to ensure children and young people with intellectual disabilities have equal access to mental health services. Challenging Behaviour Fo...
- **Regional Consistency:** The strategy addresses historical variations in trust-level delivery by building a joined-up regional network. Health and Social Care ... +1
- **Funding Priorities:** Developing dedicated CAMHS-ID teams is a recognized funding priority to reduce inpatient admissions and provide early intervention. www.health-ni.gov.uk +1

Early intervention creates an opportunity to influence what happens next

Southern Health and Social Care Trust

TOGETHER, IMPROVING CARE, TRANSFORMING LIVES

The Adapted “Healthy Me” Programme: group based mental health promotion programme

- Healthy Me’, was originally a collaboration between Action Mental Health (AMH) MensSana, Child and Adolescent Mental Health Services (CAMHS) in the Southern Health and Social Care Trust and the Royal College of Psychiatry (RCPsych) in Northern Ireland in 2014. Adapting ‘Healthy Me’ for delivery in special schools was recommended in evaluation of this pilot programme.
- Funding via R&D SHSCT in 2020-2022 for a co-produced pilot adapted ‘healthy me’ programme, for young people with ID, taken forward by Action Mental Health (AMH) MensSana and Intellectual Disability Child and Adolescent Mental Health Service (ID CAMHS) in the Southern Health and Social Care Trust (SHSCT).
- Unmet Need: The need to develop effective evidence based psychoeducational and practical intervention services has been well described in a range of research and policy documents. This includes very early interventions.
- The ‘Healthy-Me’ programme was found to be feasible to deliver in a special school setting into the Personal development and mutual understanding (PDMU) section of the curriculum
- Service evaluation: presented at RCPsych International Congress

CAMHS Child & Adolescent Mental Health Services

amh menssana

HSC Southern Health and Social Care Trust

TOGETHER, IMPROVING CARE, TRANSFORMING LIVES

Public Health Agency (PHA) Partnership working Group: Special Schools Partnership Pilot N.Ireland

- PHA work is focused on prevention → early intervention → reducing inequalities → improving population health → partnership working → better outcomes regionally here in NI.
- 2023: This initiative aimed to improve outcomes for Children with Special Educational Needs and Disability through creating and testing a model of Partnership and Engagement across Special Schools in N.I., initially engaging 7 Special Schools in local partnerships with key stakeholders across sectors and professions, in a Hub and spoke network model, overseen by a Strategic Special Schools Collaboration/ SEND Transformation Programme Board.
- Cross sectoral collaboration, with involvement of parents, children and young people, will ensure a child centred and outcomes- based approach, enable shared learning and training, shared resources (spaces, programmes, services, finance) and enable us to measure improved outcomes for children, families, staff and schools.
- CAMHS ID Training to Donard special school-pilot in August 2025
- RCPsych going to be delivering training to staff 2026/2027: Crash Course in Mental Health for teachers & school staff, special school version.

HSC Southern Health and Social Care Trust

TOGETHER, IMPROVING CARE, TRANSFORMING LIVES

Parent/Carer Therapeutic Intervention Group (TIG)

2018 Launch of Early Intervention including TIG

Senior Practitioner/Assistant Practitioners (AP) direct delivery
Face to Face locations across SHSCT, 12 weeks
Directly recruit to group from service waiting list/based on referral information

2020 Impact of Pandemic

Adapted content for virtual delivery/staff changes
Use of videos to model/teach/demonstrate
Changed/Increased Individual AP support alongside group delivery
Comprehensive new patient assessment prior to allocating to Early Intervention/Group

2026 Currently

Mix/Blend of Face to Face and Virtual session delivery, 7 weeks
MH Nurse
Sensory Needs/Sensory Processing/Skills building led by Occupational Therapist
Consider pilot in special school alongside AHPs/Teaching staff

HSC Southern Health and Social Care Trust
TOGETHER, IMPROVING CARE, TRANSFORMING LIVES

Where does Parent/Carer Therapeutic Intervention Group (TIG) **fit?**

A TARGETED INTERVENTION WITHIN CAMHS-ID

UNIVERSAL

Information
Health promotion
General advice

↓

TARGETED

Parent/carer therapeutic group

Early therapeutic intervention
Emerging needs

↓

SPECIALIST

Individual / intensive intervention
Complexity • risk • persistence



Children's Mental Health Matters!

The challenge

WHEN SUPPORT STARTS TOO LATE

Emerging difficulty

↓

Uncertainty & worry

↓

Families try to cope

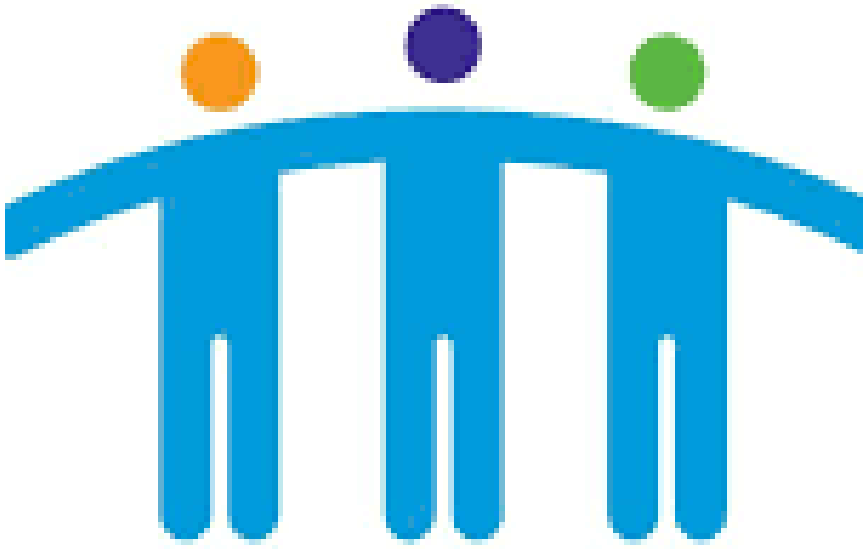
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Distress escalates

↓

Crisis / intensive intervention

Where can we change the trajectory?



RIGHT CARE

RIGHT TIME

RIGHT PLACE

Parent/Carer Group

PARENTS & CARERS ARE THERAPEUTIC PARTNERS

- Know the young person best
- Notice changes across everyday settings
- Recognise patterns and early warning signs
- Support emotional regulation and communication
- Can practise and reinforce therapeutic strategies
- Help transfer learning into everyday life



****We don't just work with the young person.**
We work with the system around the young person.**

Children's Mental Health Matters!

Why a group?



THE GROUP IS MORE THAN A DELIVERY FORMAT

LEARN

Therapeutic knowledge and psychoeducation

SHARE

Experiences, ideas and problem-solving

PRACTISE

Try strategies in a supported environment

CONNECT

Reduce isolation and build confidence

NICE guidelines:

- Involved family members/carers in developing and delivering intervention plan
- Recognise the impact of living with/caring for a person with LD
- Clear focus on the person and their family/carers
- Information provided in a format that is easy to understand
- Provide skills training and emotional support to families/carers

Therapeutic intervention + peer support + shared learning

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What it is / what it isn't

A CLEAR CLINICAL POSITION

IT IS	IT IS NOT
Proactive	A replacement for individual assessment
Preventative	One-size-fits-all
Therapeutic	Parent-blaming
Skills-focused	About changing the young person's identity
Family-centred	A guarantee difficulties won't recur
Adapted for ID	“Just a parenting course”

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What makes it CAMHS-ID?

ADAPTATION IS NOT AN ADD-ON

Therapeutic support needs to reflect:

Development
Communication
Emotional understanding
Sensory needs
Family context
Everyday environments

Same therapeutic principles

Different route to understanding and applying them

IDCAMHS
giving hope by working for and with the child

CAMHS
Child and Adolescent Mental Health Services

ParentsPlus
Empowering Professionals to Support Families

Parent LineNI™
Call Parentline NI today for advice, support or guidance.
0808 8020 400

STRIVE NI

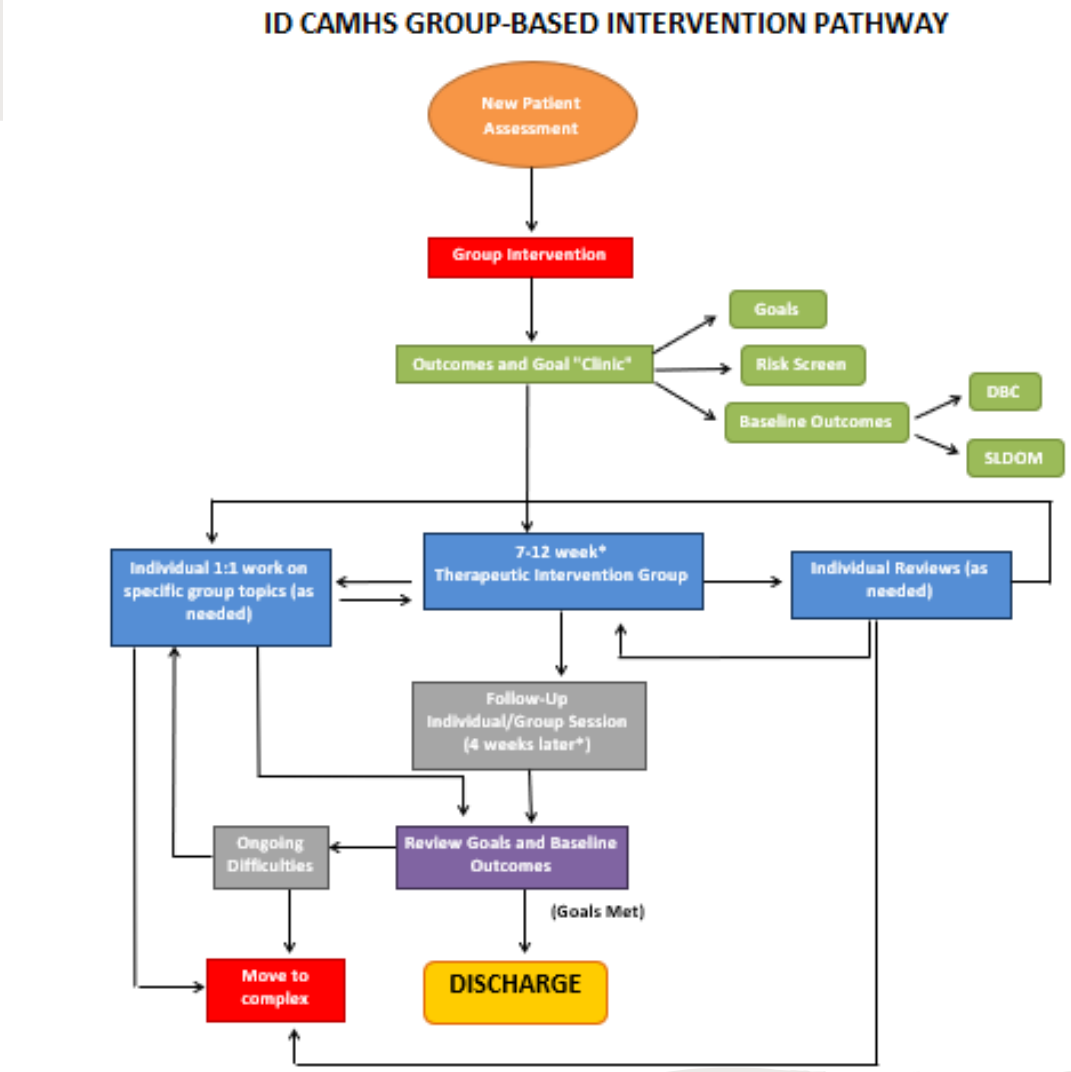
CYPSP
Children & Young People's Strategic Partnership



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Pathway/Snap-shot of Early Intervention Cases

- 5 year old boy, Autism, ID, frequent night wakening, hyper/disruptive behaviour, poor eating, not yet toilet trained
- 7 year old boy, Autism, ID, query ADHD, PICA, long standing sleep difficulties
- 8 year old boy, Trisomy21, mainstream school (Learning support unit), sleep difficulties, intolerant of younger children
- 9 year old boy, ASD and ADHD, parent health needs/anxiety, aggressive in school, spitting and picking at his gums and toes
- 9 year old girl, Trisomy21, history of constipation, difficulties with transitions, query Autism and ADHD
- 11 year old girl, Trisomy21, mainstream school (Learning support unit), awaiting autism assessment, odd thoughts of death, lots of refusal
- 15 year old girl, ID, IDIC 15 (a rare chromosome disorder), cerebral visual impairment and epilepsy. Extremely disturbed sleep, occasional aggression, excessive/persistent talking and limited social skills.



Initial assessment

Goal setting, information gathering, further assessment

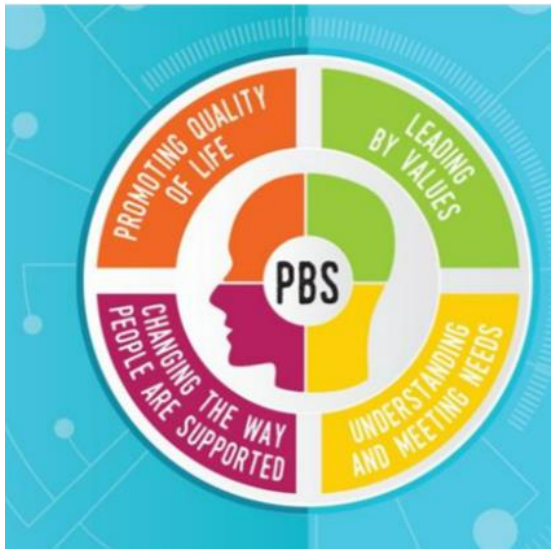
Intervention

Group/Individual

Brief PBS Plan

Review

Discharge





- Early Intervention: Staff skills & Training
- Positive Behaviour Support (PBS)
- Sleep Action
- Role specific/Professional training
- Makaton/PECS/Talking Mats/Intensive Interaction/Total communication approach
- Parent Plus Special Needs
- Skill development: relaxation, emotional regulation, Play, ADLs
- Sensory Integration
- PICA awareness/support
- ARFID, Sensory Eating
- Epilepsy/First Aid
- Autism/ADHD Assessment and Intervention
- Eye Movement Desensitisation Reprocessing (EMDR)
- Trauma Informed Practice
- Introduction to CBT



29/04/2024

Dear Parent/Guardian,

Please find information enclosed about our group-based **Therapeutic Intervention Programme**. This is an education and skill-building programme for parents to help parents to better understand and support their child's behaviours of concern and providing them with practical strategies and advice around topics such as strengthening their relationship with their child, communication and visual strategies and sleep difficulties.

We ask you to all approximately 2 hours for each session. The sessions will be virtual via Microsoft Teams, I will send you a link by email.

We have scheduled virtual sessions for:

Friday 10th May 10am
Friday 24th May 11.30am
Friday 31st May 10am
Friday 7th June 10am
Friday 21st June 10am
Friday 28th June 10am

The topics are:

Parent self-care & attachment
Understanding behaviour & behaviour support planning/Anxiety
Sleep/behaviour
Physical health
Communication & social stories
Goal setting & teaching new skills/sensory needs & sensory processing
*We can consider the need for any further sessions and recap/review

Please note, your child is **not required** to attend these sessions.

I would appreciate if you would get in touch f you need to make other arrangements or if you no longer feel this intervention is needed, our telephone number is 028 38360680

Best wishes

Emma McDermott

Senior Practitioner / Early Intervention Manager

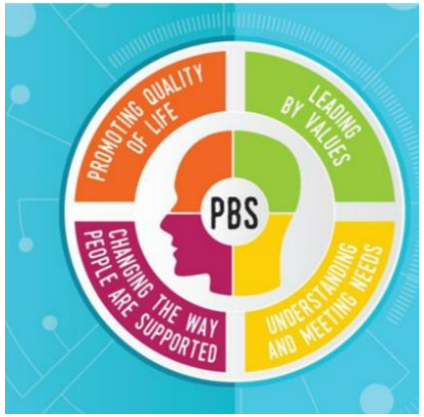
ID CAMHS

Therapeutic Intervention Group (TIG)
Self-care & Attachment
Understanding behaviour & behaviour support planning
Anxiety
Sleep (Sleep Action)
Physical Health
Communication & Social stories
Goal setting & Teaching new skills
Sensory Needs & Sensory Processing
Recap/Review

Understanding Behaviour and Behaviour support planning

- Understand the ABCs of behaviour and how to record these
- Know how to identify triggers for behaviours of concern
- Begin to understand how to identify the function of your child's behaviour
- Understand what reinforces behaviours
- Begin to understand what you can do to differently when your child presents with behaviours of concern





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What happens in the group?

FROM UNDERSTANDING → TO THERAPEUTIC SKILL

UNDERSTAND
Emotions, distress and behaviour

↓

RECOGNISE
Triggers and early warning signs

↓

COMMUNICATE
Needs, feelings and preferences

↓

REGULATE
Coping and emotional regulation

↓

PRACTICE
Therapeutic strategies

↓

APPLY
At home, school and in the community



THE THERAPEUTIC WORK DOESN'T END WHEN THE GROUP ENDS

LEARN

↓

PRACTICE

↓

ADAPT

↓

USE AT HOME

↓

REVIEW

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Mia's Positive Behaviour Support plan

ID CAMHS
October 2023

Background
Mia is an 11 year old girl who lives in Kilkeel with dad Joe, mum Lina, and dog Elsa. Mia has two older step-sisters, Monika who lives nearby with her own children and Kornelija who is studying in Carlisle. Mia attends St Colman's Primary School, Kilkeel with the support of a classroom assistant and is currently in P7. Mia has Down syndrome, wears glasses and is able to communicate verbally but it can sometimes be difficult to understand, particularly to those not familiar with Mia. Mia is currently awaiting autism assessment. This positive behaviour support plan has been developed by ID CAMHS. Behaviours of concern should always be viewed as Mia's expression of an unmet need and/or anxiety. Consider possible function of behaviours of concern: Discomfort/Pain, Interaction, Escape/avoid, Tangible, Sensory (DIETS).

Recommended Interventions
Reward chart for Mia
Countdown (strip, with hand or and verbally)
I need a break card/symbol
Exercise and meaningful activity
3 x 3 mins a day of focus/time with Mia
Praise
Virtual parent sessions: parent self-care & attachment, understanding behaviour, behaviour support planning and anxiety, sleep, communication & social stories, physical health, goal setting, teaching new skills and sensory processing awareness

Interests/skills/motivators
I-Pad
Swimming
Dolls
Football
TikTok dances

Further consideration to be given to:
Occupational Therapy (has been referred-awaiting input)
Speech and Language Therapy (has been referred-awaiting input)
Autism assessment (has been referred-awaiting assessment)

Behaviours of Concern:

- Reluctance to get ready in morning sometimes (Angry/Aggressive)
- Pulling at tights, picking skin, pulling hair, pick at her finger nails and scratch her back until it is red and sore looking (Anxiety)
- Mia can also become very focused on routine/checking behaviour

Possible triggers for my child:

- Not knowing what is happening next
- Waiting
- Sensory sensitivities – does not like wearing tights
- Peers similar in age (prefers younger children and babies)
- Puberty

When Mia is calm/ relaxed:

- On iPad
- TikTok dances
- Watching movies
- Enjoys swimming
- Happy/content

Proactive Strategies (what will help Mia to stay calm and avoid getting anxious):

- Hugs from mum and dad
- Knowing her routine, what is happening next
- iPad time
- TikTok dances
- Playing with her dolls

Early warning signs:

- Saying or signing specifically that something is wrong or not feeling well
- If she has a bad day at school
- Seeking attention
- Acting silly, pushing boundaries
- Crying
- Tired

What should you do at this time?

- Distraction verbally and practically, redirecting
- Take away the trigger
- Give her time, stop activity and return to it later
- Outdoors before bath time to release energy before calming

If the behaviour escalates, my child may:

- Engage too long in the interaction
- Be hyper
- becoming annoyed or distressed
- Hurt others

What should you do at this time?

- Appear calm
- Give space, parents remain calm, talk in a calm, monotone voice
- Keep language simple – use soft tune/voice
- Do not make prolonged eye contact
- Be aware of your own body language
- Don't make demands of Mia or continue to talk to her
- Safety first, remove self or others from situation, ensure she doesn't hurt herself or others

If Mia is trying to get your **Attention** by engaging in negative behaviours:

- Teach her how she can get your attention/the attention of others in a more appropriate way. This could be by teaching her a sign, a symbol, a vocalisation or to gently tap your hand/arm
- Make sure you notice when she is trying to get your attention appropriately and respond as soon as you can. This will help to reinforce the behaviour you want
- Interact with Mia regularly, giving her plenty of opportunity to get positive attention
- Where possible ignore the negative behaviour

If Mia is engaging in a negative behaviour to **Escape/Avoid** something or someone:

- Give her an effective way to stop something she doesn't like; to remove her from a situation or person she doesn't don't like. This could be a sign/word or photo card to say "Finish" "I need a break" or "Home"
- Teach her to make choices and a way to say "yes" and "no"
- Introduce her to a situation/activity gradually to help her become used to it
- Use humour as a way to distract her
- Notice when she is displaying 'early warning signs' that she may be becoming unhappy or anxious
- Change the way you ask her to do something

When Mia engages in negative behaviour to get something **Tangible:**

- Teach her how to communicate she wants a snack/toy etc.
- Give her what she has asked for as soon as she has requested appropriately. Give lots of praise. Make sure she has regular access to what he needs
- Teach her how to get something for herself where possible.
- Make sure she is not left without food or drink for too long, or without something meaningful to do (offer these regularly)
- As far as possible ignore the negative behaviour
- If the situation escalates and people are at risk give her what she wants

Where Mia engages in behaviours of concern to get her **Sensory** needs met:

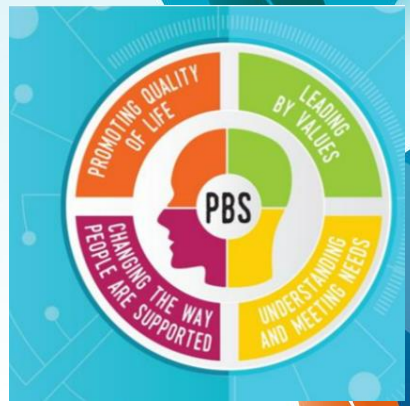
- Awaiting Occupational Therapy input
- Try out different objects to see which she prefers, then use these to create new activities
- Use preferred items to help you engage with Mia
- Make sure Mia can get her sensory needs met but in a way that will not isolate her further or leave her engaging in a self-stimulatory behaviour for too long. Try and support her to have at least some meaningful routine/structure in her day, so that the self-stimulatory behaviour doesn't 'take over'

When my child has calmed, he/she may:

- Need reassurance and comfort
- May be tired

How to support my child when he/she is calm:

- Give time on her own with adult present
- May need a movement break
- Give verbal praise and let her know of the positive or negative outcome of the interaction



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What changes for parents and carers?

“I DON'T KNOW WHAT TO DO” → “I HAVE A PLAN”

BEFORE	AFTER
Uncertainty	Understanding
Feeling overwhelmed	Increased confidence
Reacting to escalation	Recognising early signs
Trying strategies alone	Shared learning
“What is happening?”	“What might be driving this?”
Isolation	Connection

What changes for the young person?

CHANGING THE RESPONSE AROUND THE YOUNG PERSON

Earlier recognition of distress

↓

More consistent adult responses

↓

Better opportunities for communication and regulation

↓

Greater opportunity to practice coping strategies-Proactive skills building

↓

Potentially less escalation



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Prevention

CHANGING THE TRAJECTORY

Early signs

Stress • worry • avoidance • sleep change • communication difficulties

↓

Early therapeutic response

Understanding • strategies • support

↓

Increased confidence & consistency

↓

Potentially reduced escalation

Prevention doesn't mean preventing every difficulty

It means intervening before difficulties become more challenging/established

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Measuring impact

WHAT DOES SUCCESS LOOK LIKE?

YOUNG PERSON

Wellbeing • coping • communication • participation

FAMILY

Confidence • understanding • strategy use • stress • experience

SERVICE

Engagement • outcomes • discharge/onward referral • escalation/Step up

FROM	TOWARDS
Reactive	Proactive
Crisis	Prevention
Individual	Family/system
Late intervention	Early intervention
Expert-led	Partnership

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"I love the scheduling, I think this will really help Charlotte and me and may well ease the talking and questioning every minute of the day. It is very helpful having the girls out working with Charlotte"

"I have put the idea behind social stories into action at the weekend in describing to our son what to anticipate on a day out which helped him understand what was going on and made the outing much more enjoyable for the whole family"

"All the ideas each week we covered were helpful. Especially schedules and learning to listen more. Love the 3 mins each day one. I do it more now and also the advice on sleep"

"No content of course was just right. We weren't overloaded with anything, sometimes you can become overwhelmed with information but not this one, Emma and Karen were very good at explaining everything"

"Facilitator included everyone in the group and made us feel very comfortable in a virtual room with strangers. By the end of the first session, I felt I knew everyone well and was looking forward to the following sessions"

"The facilitators created a lovely inclusive environment for the group without judgement where our lived experiences as parents were valued and listened to"

"listened and wasn't overbearing. The overwhelming message I got from her is that she understands how tough and isolating it can be parenting a child with additional needs"

"I know it isn't always practical but it would have been nice I think to have had the course face to face in a room with the other parents, but the facilitators excelled to themselves"

The voice of families

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Three key messages

EARLY INTERVENTION MATTERS

Families shouldn't need to reach crisis before therapeutic support begins

PARENTS & CARERS ARE THERAPEUTIC PARTNERS

Building caregiver knowledge, confidence and skills can influence what happens around the young person

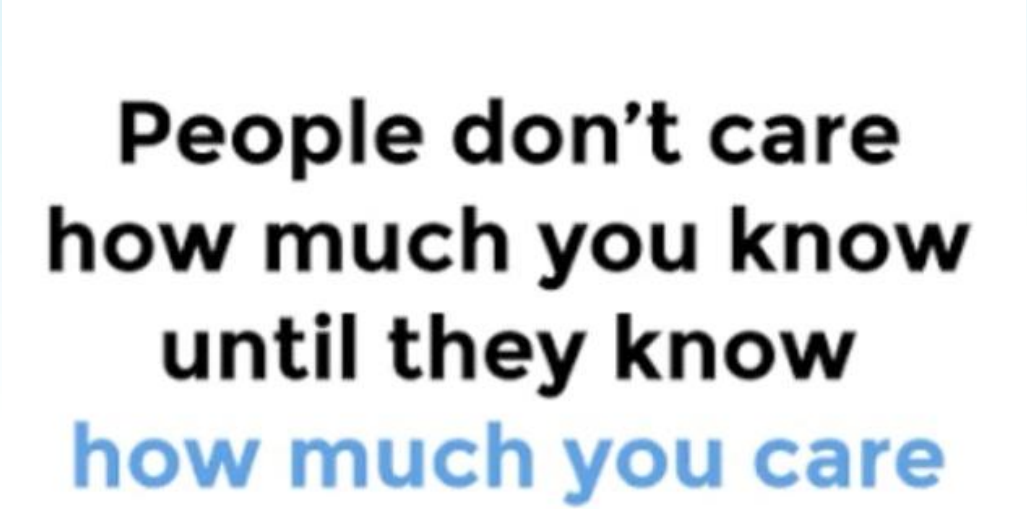
GROUP-BASED INTERVENTION HAS A PLACE IN CAMHS-ID

It offers a potentially scalable route between universal support and intensive intervention.

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Thank you



My Contact details

Emma.McDermott@southerntrust.hscni.net

CAMHS ID Senior Practitioner/Early Intervention Lead

SHSCT N Ireland

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Scaling and Replicating Community Physical Activity and Health-Connecting Interventions

How, why and to what extent does partnership-based working contribute to the Five Ways to Wellbeing for people with a learning disability?

Vicky Romilly | Sarah Needham | Stella Elliott | Liz Fletcher

Nottinghamshire Healthcare NHS Foundation Trust • YMCA Newark & Sherwood • Boccia England • Sport for Confidence

Healthy lives are built in communities.

Why physical activity belongs in the learning disability health inequalities conversation

The health gap is stark. The opportunity to move, take part and belong is unequal too.

LEARNING DISABILITY HEALTH INEQUALITY

19 years

Adults with a learning disability die, on average, 19 years younger than adults without a learning disability.

LeDeR 2024

39% vs 21.1%

Deaths rated avoidable — adults with a learning disability compared with the general population.

LeDeR 2024

WIDER DISABILITY PICTURE: PHYSICAL ACTIVITY INEQUALITY

39.5% vs 20.2%

Physically inactive (fewer than 30 minutes a week) — disabled adults compared with non-disabled adults.

Sport England, 2025

52% vs 74%

Feel they have the opportunity to be as active as they would like — disabled vs non-disabled people.

Yet 67% of disabled people want to do more physical activity.

Activity Alliance 2025–26

Physical inactivity is not a side issue. Access to movement, community participation and belonging is part of the health inequalities challenge.

Sources: LeDeR Annual Report 2024 (published July 2026); Sport England, Inclusive practice makes business sense (2025); Activity Alliance, Annual Disability and Activity Survey 2025–26.

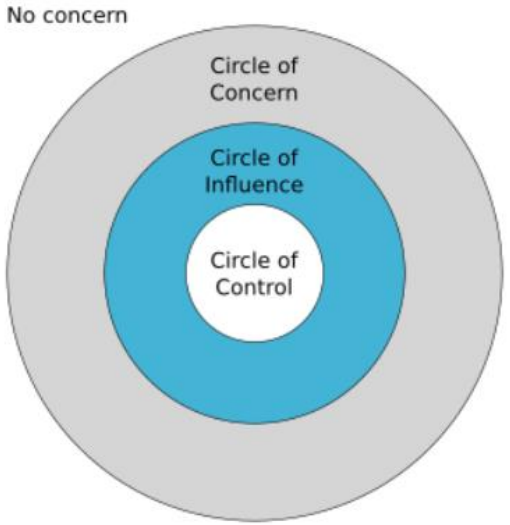
Why did we need to do something differently?

The policy direction is clear: people with a learning disability should live well in their local communities.
The reality of access is much harder.

The Five Ways to Wellbeing

1. Connect with others
2. Be physically active
3. Learn new skills
4. Give to others
5. Take notice / be present

Circle of Concern, Influence and Control



Awareness, Action, Advocacy



References: Aked J, Marks N, Cordon C, Thompson S. Five Ways to Well-being: The Evidence. London: New Economics Foundation; 2008. Covey SR. The 7 Habits of Highly Effective People: Powerful Lessons in Personal Change. London: Simon & Schuster; 1989. Dougall D, Buck D. My role in tackling health inequalities: a framework for allied health professionals. London: The King's Fund; 2021.

Realist evaluation: Our programme theory and background to the project

- People have a right , and policy supports access to community-based leisure services
- Difficulties relate to access including adjustments and inclusivity
- Feeling excluded can have a negative impact
- Community leisure providers want to be able to offer accessible service
- Specialist health services manage stretched services and need to find innovative solutions to offering specialist care that can align to the five ways to wellbeing
- Partnership work might support the exploration of prevention led pathways



What we wanted to build…

A community-based pilot at the YMCA Newark & Sherwood Community and Activity Village

Health Inequalities Framework



An interactive partnership-based model

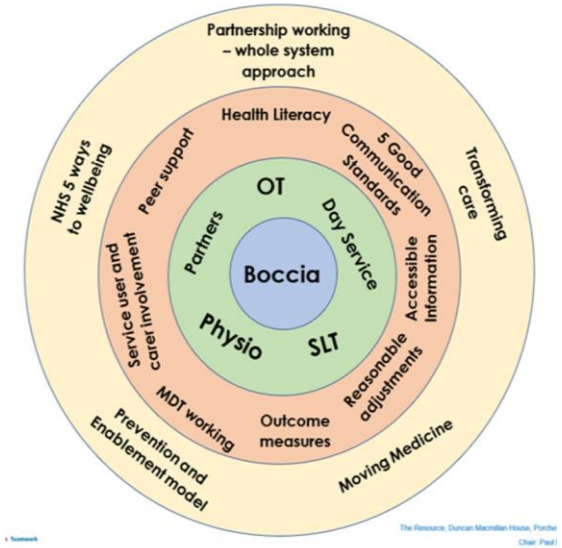
People and Partners

Coach-led activity

AHPs alongside the sport sector

Adjust in real time

Boccia used as a therapeutic modality



The intention: move from "referral to an activity" towards supported access to ordinary community life.

Sources: Dougall D, Buck D. My role in tackling health inequalities: a framework for allied health professionals. London: The King's Fund; 2021. Boccia partnership model graphic supplied by project team.

What did it look like in practice?







“The best day of my week”

What changed for people?



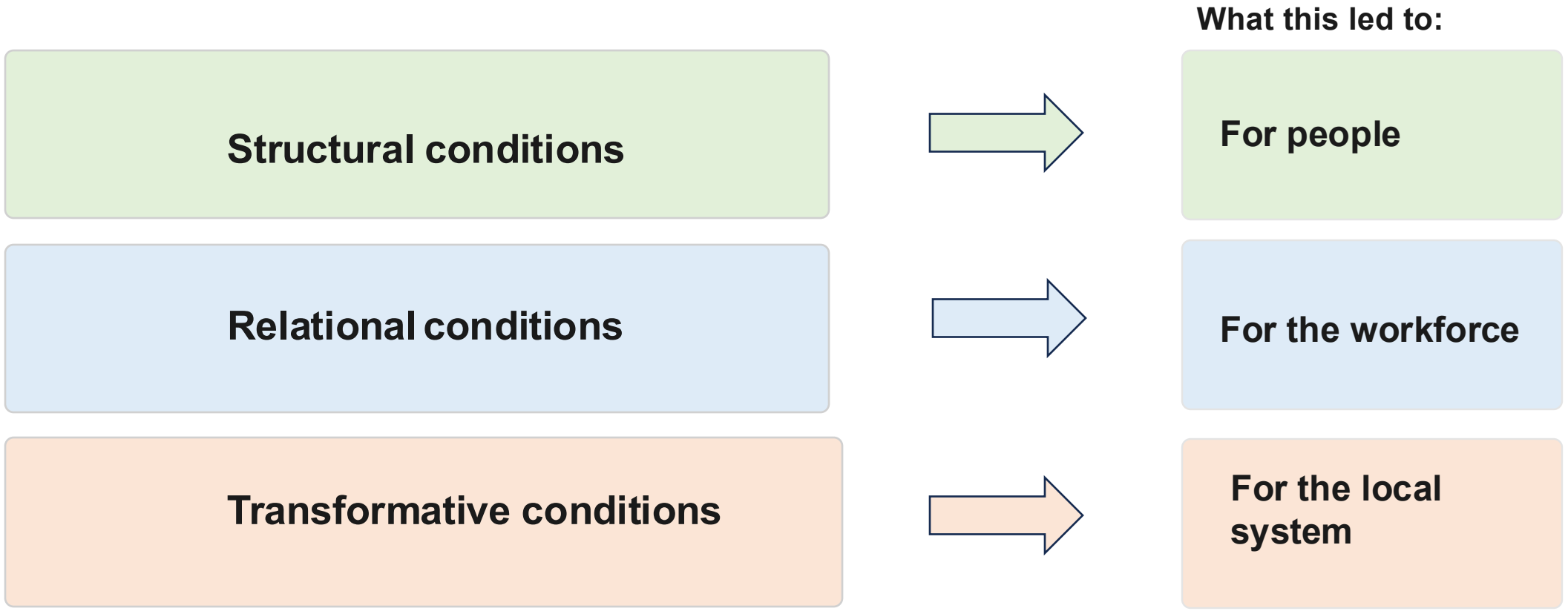




"Normally we work solitary… the bond we have together, a trust of each other and learning… we're getting to learn each other's roles."

What changed for the workforce and wider system?

A systems change lens helps show how change happened across structures, relationships and ways of thinking.



Source: *Adapted from a systems change lens: structural, relational and transformative conditions.*
Kania J, Kramer M, Senge P. The Water of Systems Change. FSG; 2018.

What did the realist evaluation help us understand?

The same activity will not produce the same outcome everywhere. What matters is the context and the mechanisms it triggers.

CONTEXT
- Community setting
- Senior leadership support
- Coach-led delivery
- AHPs working alongside
- Existing local relationships
- Flexibility to adapt

MECHANISMS
- Trust
- Psychological safety
- Feeling welcome
- Shared ownership
- Confidence / capability
- Belief that change is possible

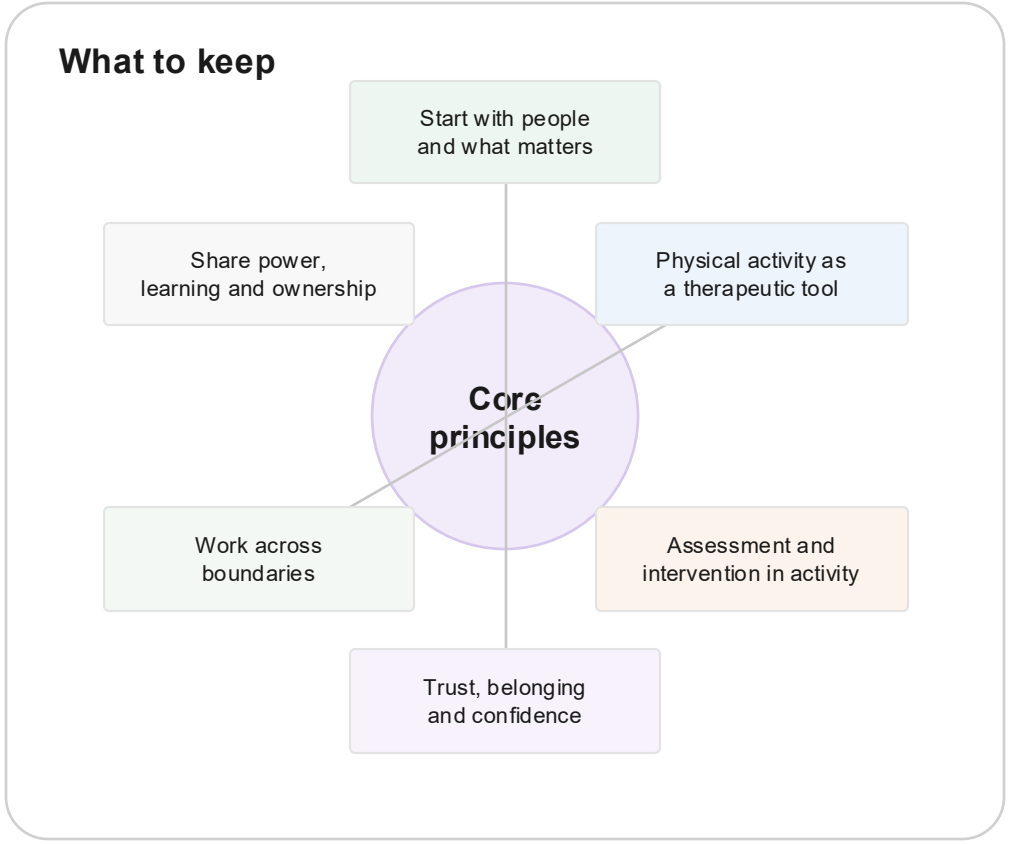
OUTCOMES
- Participation
- Belonging
- Wellbeing
- Self-management
- Workforce learning
- More inclusive local provision

The community environment and **diversity of support** built **connection** for all
The project enabled inclusivity which impacted positively on **health outcomes**
Collaborative leadership enabled **community change**
Encouraged **self management** and **community belonging**
Clinical **therapy became embedded in activity**
Barriers to change are overcome through **strategic influence**

Realist evaluation framework: Pawson & Tilley (1997).

So what does this mean for sustainability and spread?

A “lift and shift” model is unlikely to work. Copy the principles, but adapt the model to local place, neighbourhoods and systems.





The transferable part is the way of working — not a fixed activity, venue or delivery route.

From project to system: the opportunity

The aim is not to create more specialist activity programmes.

The aim is to make ordinary community opportunities work better for people with a learning disability.

Three questions to take away

Who in your local sport and leisure system do you know?

Where could clinical expertise build community capability rather than parallel provision?

What would need to change for this to become part of the system — not a project?

We would like to build a blueprint for collaborative leadership and learn with other areas about how these principles can transfer.

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Contact Details and Resources

Contact Details

Contact Us:

Liz Fletcher OT and National Lead SfC
Liz@sportforconfidence.com

Senior Physiotherapist

Sarah Needham Physiotherapist
Sarah.Needham@nottshc.nhs.uk

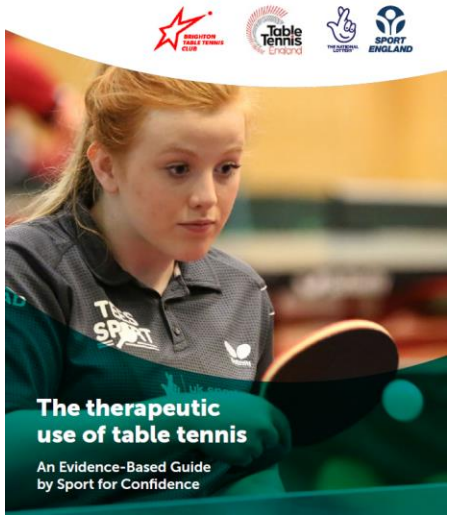
Senior Speech Therapist

Stella Elliott Speech Therapist
Stella.Elliott@nottshc.nhs.uk

Resources of interest: www.sportforconfidence.com Explore the Learning Arena














The Challenging Behaviour Foundation

What Matters to Me

Involving people with severe, profound and multiple learning disabilities in decision-making processes

Jacqui Shurlock, Marie Baker and Taylor Anderson

The Challenging Behaviour Foundation
making a difference to the lives of people with severe learning disabilities

The Challenging Behaviour Foundation: Who We Are



Our **mission** is to make a difference to the lives of people with severe learning disabilities, whose behaviour challenges, and their families, working together to:



Champion their rights



Ensure timely information and support



Raise awareness and understanding



Promote and share best practice

What Matters to Me

- Built on existing good practice around improving the way we involve and take account of the **views, preferences and experiences** of people with severe or profound and multiple learning disabilities.
- Adopts a **mixed method approach** to **engage creatively** and in an **individualised way**, including **family carers and people who know them best**
- Raising awareness of the **value and importance** in adapting engagement methods so that services and support **accurately reflects their wants and needs**.



It is possible to find out what matters to people with severe or profound and multiple learning disabilities!

It is possible to use what matters to make a difference!

"Every person, every child, every young person is entitled to be able to give their views and their opinions, to be able to tell us what they like, what they dislike, what they want, what they need. And just because it can be difficult to obtain these from children and young people, doesn't mean that we really shouldn't try."

Family Carer - What Matters to Me



What Matters to Me – Influencing communities



Video clip taken from **What Matters to Me – Using What Matters: The Circles of Influence.**

To watch this and other videos, and to find out more about What Matters to Me, please go to:

https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/what-matters-to-me/

What Matters to Me – Influencing communities

Young people trialled a group hydrotherapy session and demonstrated through body language, facial expressions and vocalisations, what they gained from it

Impact:

- Providers changed their offer — group hydrotherapy is now open to all service-users
- Over 200 young people now take part, with transition swims booked months ahead by 5–8 families per session

"It's so important for young people like Fenton to be supported and listened to. It's their right. They deserve it.

They just need to be listened to, and time taken out to hear what they've got to say, because they all have something to say and give."

Family Carer - What Matters to Me

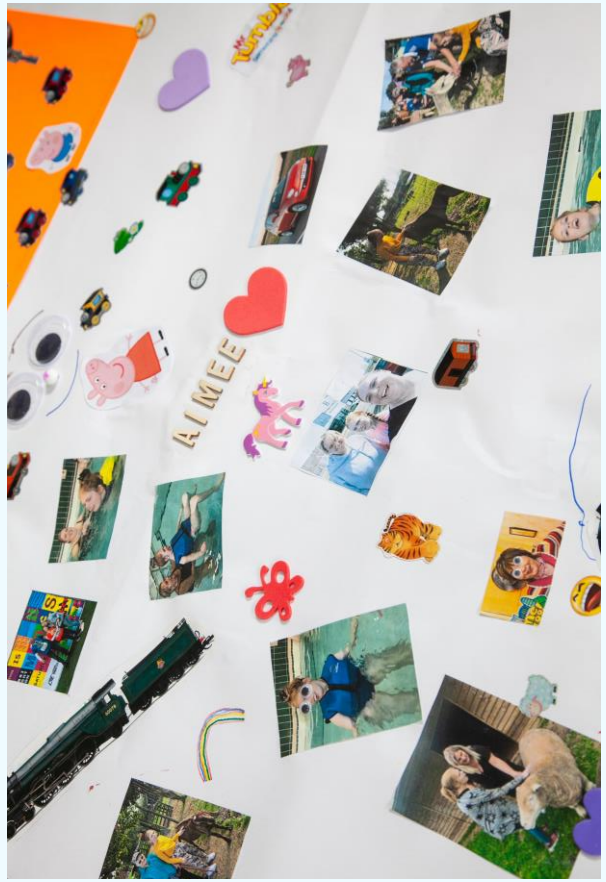


What Matters to Me – Family Carer Experiences









What Matters to Me – Family Carer Experiences

Why the What Matters To Me project worked:

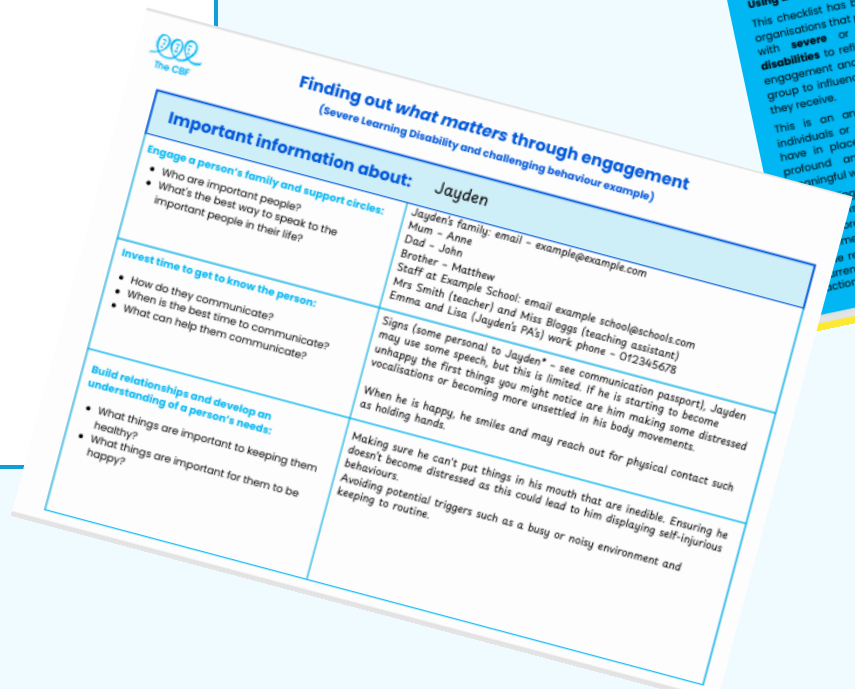
- ❖ Taking the time
- ❖ Not being scared
- ❖ Seeing 'no' as a positive
- ❖ Seeing the whole family

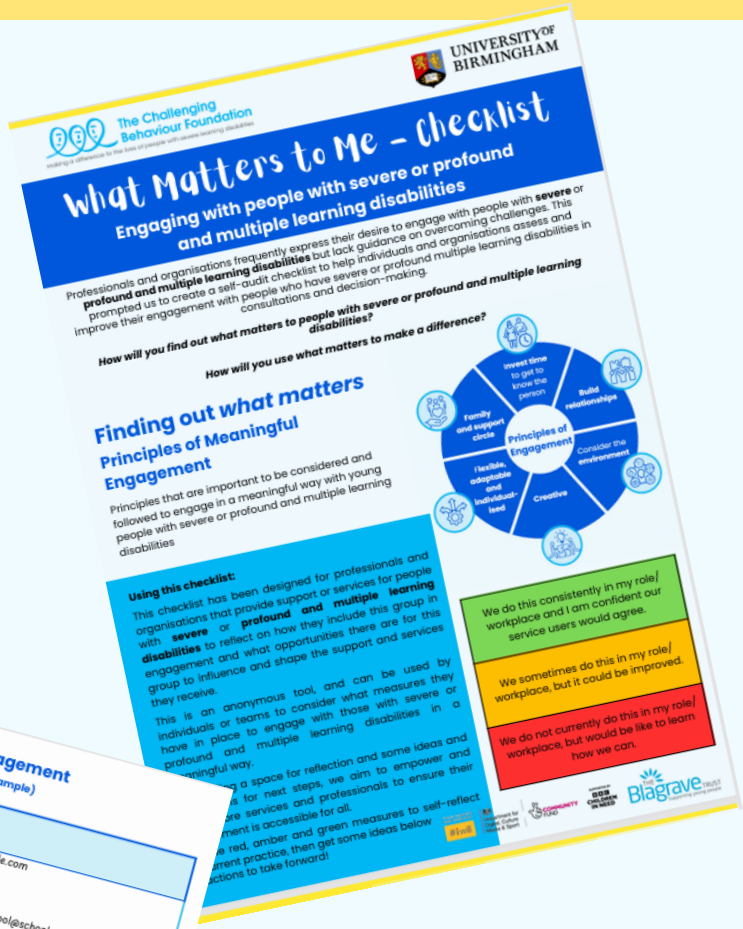
What Matters to Me – A Practical Toolkit

What Matters to Me: A Practice Toolkit

Provides materials and resources that can be used by both professionals and families to improve how people with severe or profound and multiple learning disabilities are consulted with and engaged in processes that impact their lives.

- Reflection Checklist
- Presentation Template
- Finding out what matters through engagement – individual recording document
- Consultation template
- Socal media content





What Matters to Me – Network and Next Steps

Making it Matter:

no voice but a lot to say

COMMUNITY FUND

The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

SCAN HERE

Join the network for project updates

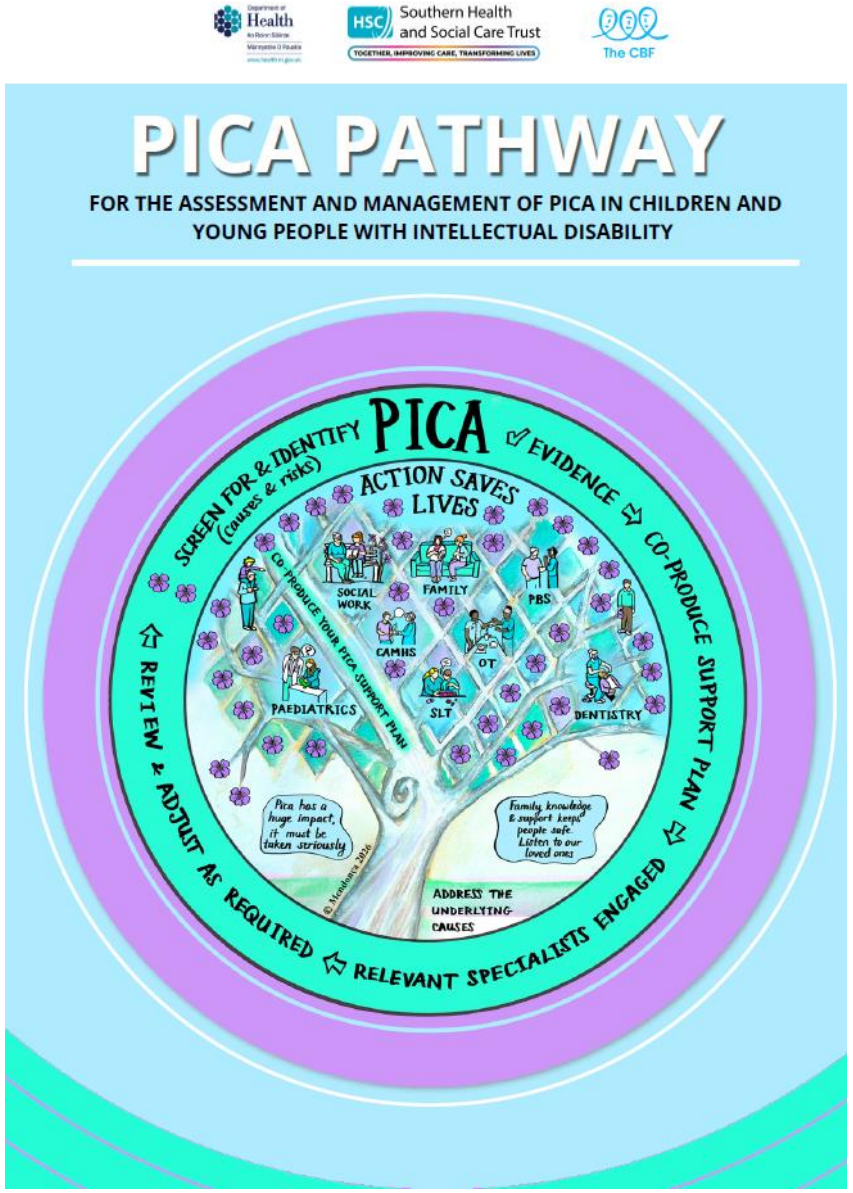
makingitmatter@thecbf.org.uk

Co-producing a pica pathway for children and young people in Northern Ireland

Dr Lizzy Donaghy, Consultant Psychiatrist Child and Adolescent Psychiatry/Psychiatry of Intellectual Disability

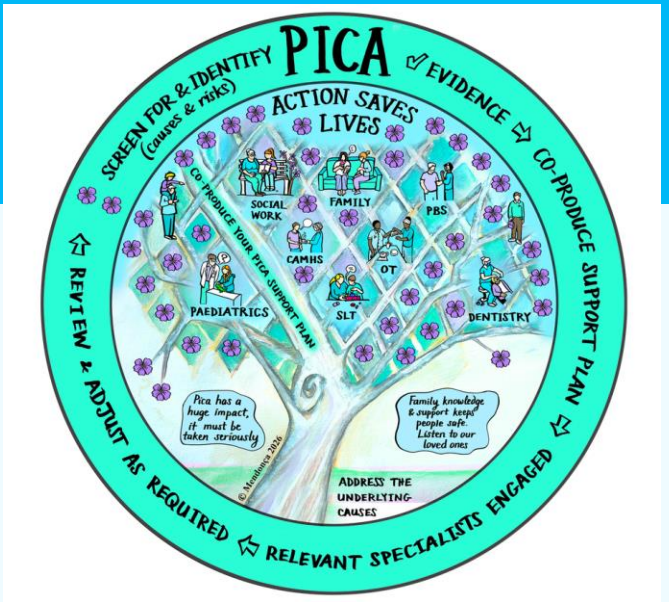
Kate Sanger, Creator of mycommpass.com

Challenging Behaviour Foundation



Outline of Presentation

- What is Pica and why is a Pica Pathway needed?
- What sort of Pathway? – Key Principles
- The Pica Pathway: Using the Pathway and Pathway Sections
- Co-production
- Example pica support plan
- Summary



What is Pica and why do we need a pathway?

- Pica is the regular consumption of non-food items or ‘non-nutritive substances’
- Pica is common in children with intellectual disability, previously reported to occur between **5% and 25% of children with intellectual disability**
- **PICA CAN BE LIFE THREATENING and cause significant health issues– it must be taken seriously**

Pica is frequently **under-identified**, **under-reported**, and **under-treated**.

No current pathway in Northern Ireland in practice for assessment and management of pica in children and young people with intellectual disability.

What sort of pathway? – Key Principles

- **Evidence-based: best practice recommendations**
- **Co-produced**
- **Multi-disciplinary approach, with joined up working – with family carers as valued partners**
- **Clinical guidelines – robust assessment and management**
- **Focused on outcomes and actions -** leading to timely information, support and services – and a good quality of life for the person
- **Regional and deliverable**

To include:

- The causes of pica (likely multi-factorial)
- The consequences of pica – diverse and pica can be life threatening
- A holistic pica support plan

Using/Moving along the Pathway

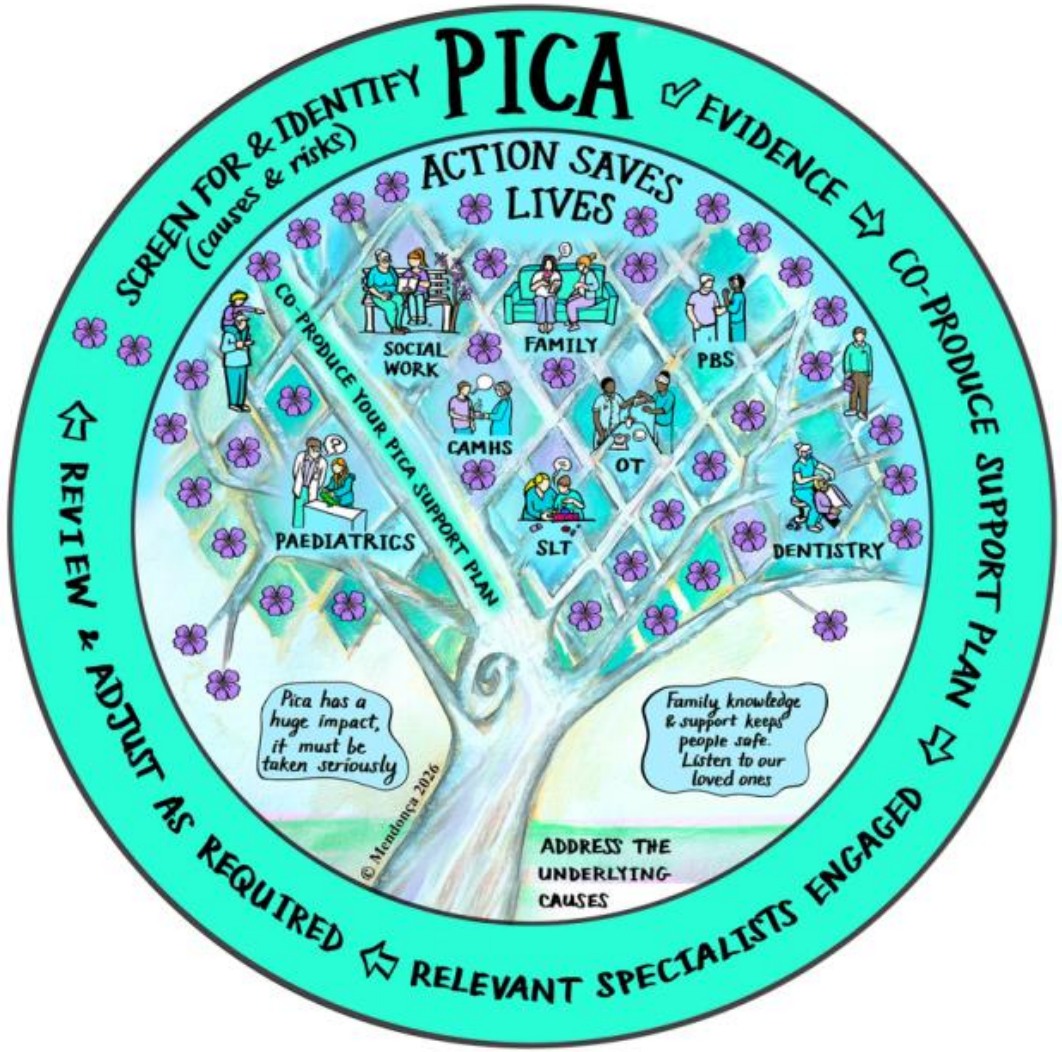


Specialist Input

Key Messages

Assessment,
Interventions and Support

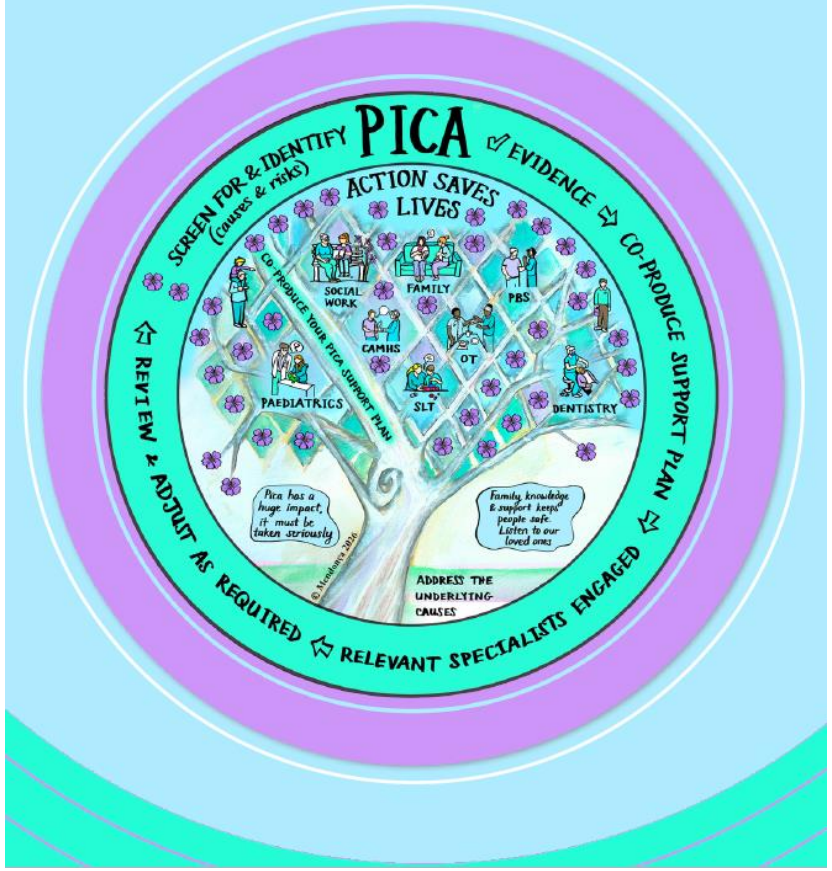
Actions



Department of Health | HSC Southern Health and Social Care Trust | The CBF

PICA PATHWAY

FOR THE ASSESSMENT AND MANAGEMENT OF PICA IN CHILDREN AND YOUNG PEOPLE WITH INTELLECTUAL DISABILITY



Contents:

P3 **1.Introduction:** What is pica and why we need a pathway

P4 **2.Overview and key principles of the pathway**

P8 **3.Gathering evidence:**

P8 **a)** Screening for pica

P10 **b)** History taking tool and family input

P12 **c)** Safety advice and what to do if there are urgent concerns

P13 **d)** Developing a pica support plan

P15 **4.Specialist input**

P15 **a)** Paediatric medicine assessment, interventions and support

P24 **b)** Dental assessment, interventions and support

P26 **c)** CAMHS assessment, interventions and support

P33 **d)** Positive Behaviour Support assessment, interventions and support

P42 **e)** Occupational therapy assessment, interventions and support

P44 **f)** Speech and language therapy assessment, interventions and support

P46 **g)** Social work assessment and support

P48 **5.Review, reflect and adjust**

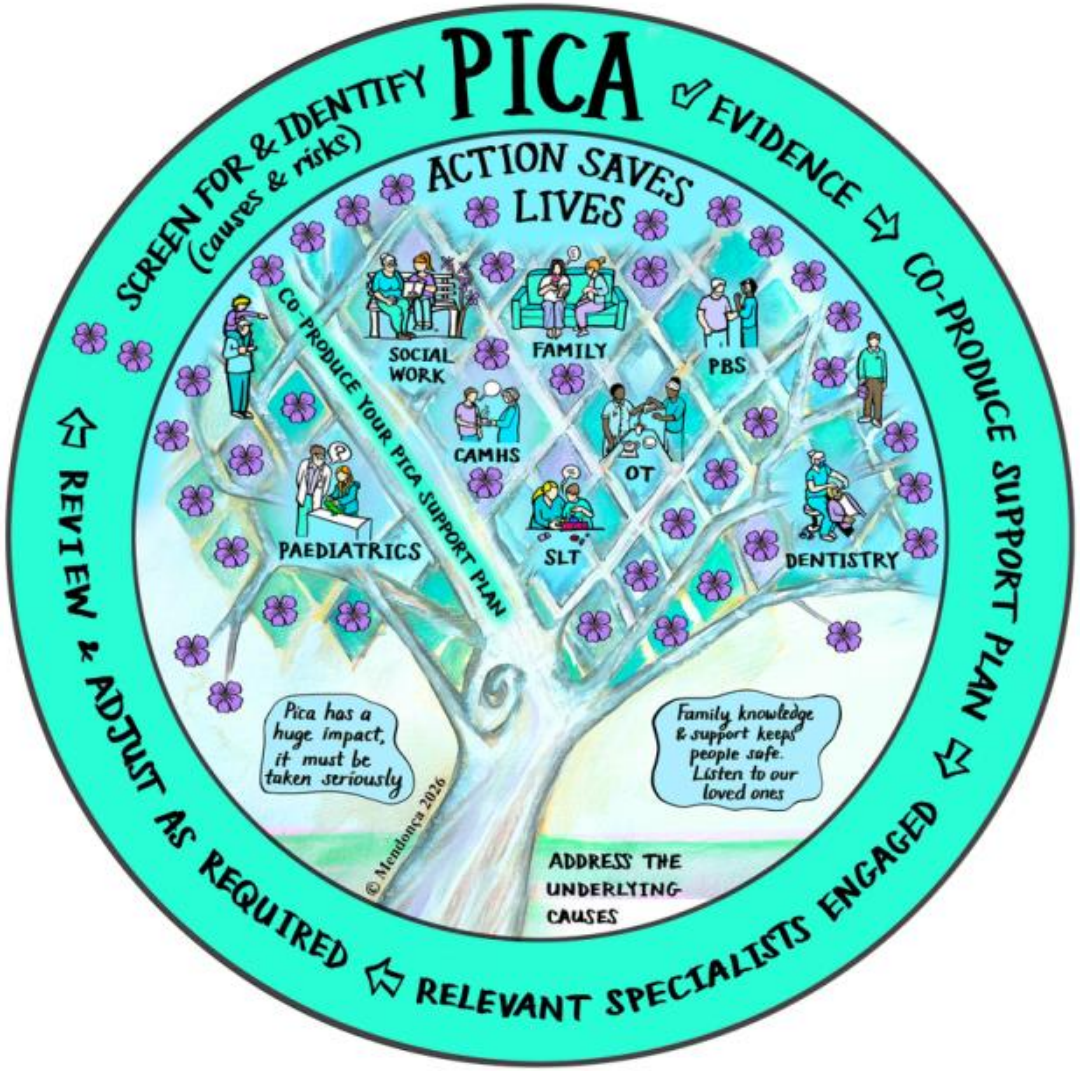
P50 **6.Appendices and templates**

P83 **7.References**

Co-production: Multidisciplinary working group

Who is involved:

- Family carers
- Paediatric Medicine
- Dentists
- CAMHS
- Positive Behaviour Support
- Occupational Therapy
- Speech and Language Therapy
- Social Work
- Early intervention
- Education specialists



Co-production: Family Carer Focus Groups

Key themes from Family Carer Focus Group

1. Understanding Pica – Prevalence and Contributing Factors
2. Multi-Disciplinary Involvement – “everyone’s issue”
3. Family Expertise and Lived Experience
4. Challenges in Current Systems and Services
5. Risk, Safety and Safeguarding
6. Screening, Early Identification and Medical Monitoring
7. Practical Tools and Behavioural Approaches
8. Emotional Impact on Families

Example PICA Support Plan

Poppy Fae



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Pica and the Dangers

Poppy has Pica which means that Poppy might try to eat inedible objects. Mostly:

- Materials
- Threads
- Bedding
- Bandages
- Plasters
- Glass

WARNING

Poppy has already had emergency surgery to remove a bandage which Poppy ate during a stay in hospital

WHAT IS PICA?

PICA is characterised by the habit of injesting inedible objects.

RISKS include:

- Vomiting
- Constipation
- Infections
- Blockages in gut and intestines

Sometimes surgery is needed to remove the object from the gut or to repair damaged tissues.

Poppy will eat her bed linen, please check



Poppy needs one-to-one support at all times. Never leave Poppy unattended as this puts her in

DANGER

The CBF

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Why does Poppy's Pica Behaviour happen?

I kept a diary to see:

1. when Poppy's pica behaviour occurred
2. when it was at its worst and
3. what was happening when she didn't engage in Pica

- Anxious, frustrated, bored, sensory issues.
- Over expectation of Poppy's abilities.
- Group dynamics.
- Low-mood.
- Feeling unwell, pain.
- Carers attitude and experience.
- Carers approach, tone of voice and body language







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What is Poppy Doing When She Doesn't Engage in Pica

- Poppy is happily engaged in the task at hand and shows no sign of anxiety



- Poppy will be chatty and engage with her peer group



- Poppy's body language will present as relaxed and not chewing furiously on her beads.
- Poppy will use her I-PAD and sing happily to herself



- Poppy will lay her weighted doll with chewy beads aside and appear relaxed in her task



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Why Vigilance is Important for Supporting Poppy

- Poppy may see an opportunity where you may not and she is very quick.
- Poppy will eat a range of inedible objects.
- Because you didn't see her do it, don't assume it didn't happen.
- Poppy can be persistent at removing small threads.
- If you ask Poppy 'where is the....? She will point to her mouth to indicate she has eaten it
- Poppy doesn't understand the consequences of her Pica; therefore, it is up to all those involved in her support to ensure her safety but still allowing her the chances to lead a fully engaged happy life.



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How Symptoms of Pica Can Present for Poppy

Poppy may present as quite well even though she is ill, in trouble or needs medical attention

- Quiet, less active
- Loss of appetite/weight loss
- Constipation/diarrhoea
- Vomiting (severe continuous retching)
- Hiccups
- Body language - something has changed in her demeanour that gives cause for concern
- Blood in stools
- Physical/behaviour change, agitated, frown lines
- Reaction to pain
- Distended abdomen
- Sleep problems

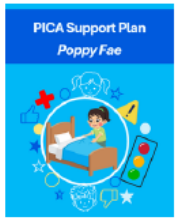
Remember all pica behaviour is HIGH RISK

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Proactive Strategies

Everyone involved in Poppy's support is aware of her Pica Behaviour, and has read her **Communication Passport**.

All staff involved in Poppy's support must read and ensure they understand the importance of her **Pica support plan**.



Follow the information in her Passport about **keeping Poppy in your vision** whilst not crowding her.

Read Poppy's **body language**, see her anxiety or boredom

Make sure Poppy has her **weighted doll** with the **chewy beads** attached as this helps her regulate her anxiety . Make sure the beads are sterilised and replaced as necessary.



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Reactive Strategies

Always **report near misses** or if you suspect she has eaten something she should not have

If you think she is about to put something in her mouth, **use distraction, never shout** as this will lead to her eating it

If you think or know she has eaten something and she is showing signs of being unwell (as described in her plan) **seek medical help**

If you have attended hospital, **do not be fobbed off** by medical staff not seeing the seriousness of Pica

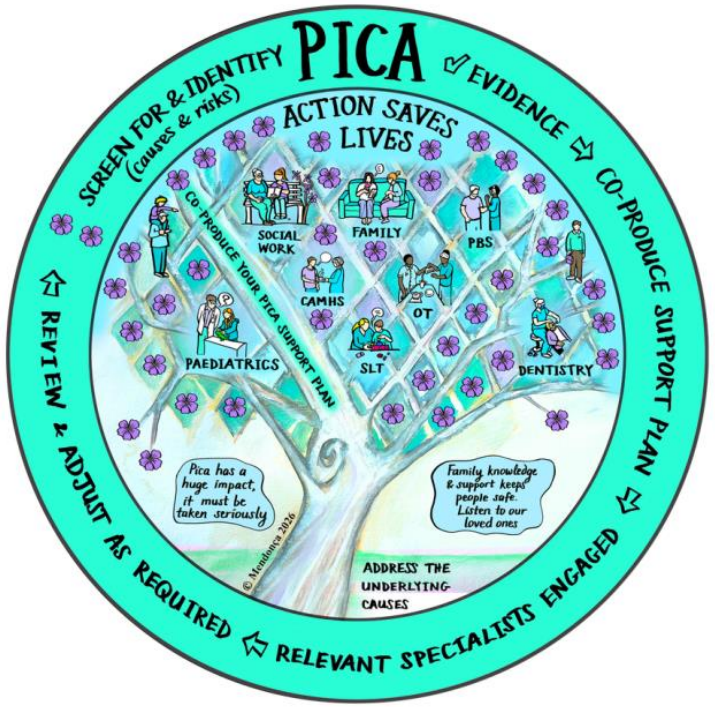
Make sure hospital staff read her **MEDICAL ALERT** page in her Communication Passport

All staff please read Poppy's **Pica Support Plan**

IMPORTANT! If there are threads or material coming out of Poppy's bottom, **NEVER pull them out**, run a bath and sit Poppy in the bath.
If they are still visible dry Poppy carefully and put her nappy back on and seek advice from Mum or a Nurse at the surgery.

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A useful tool……leading to positive outcomes



- Pathway structure: key messages and key actions
- All contributing to the pica support plan (and multi-component therapeutic plan where indicated)
- Co-ordinated support, identified lead
- Regular review
- Awareness raising (specific for the individual- and more generally)
- Accessible format

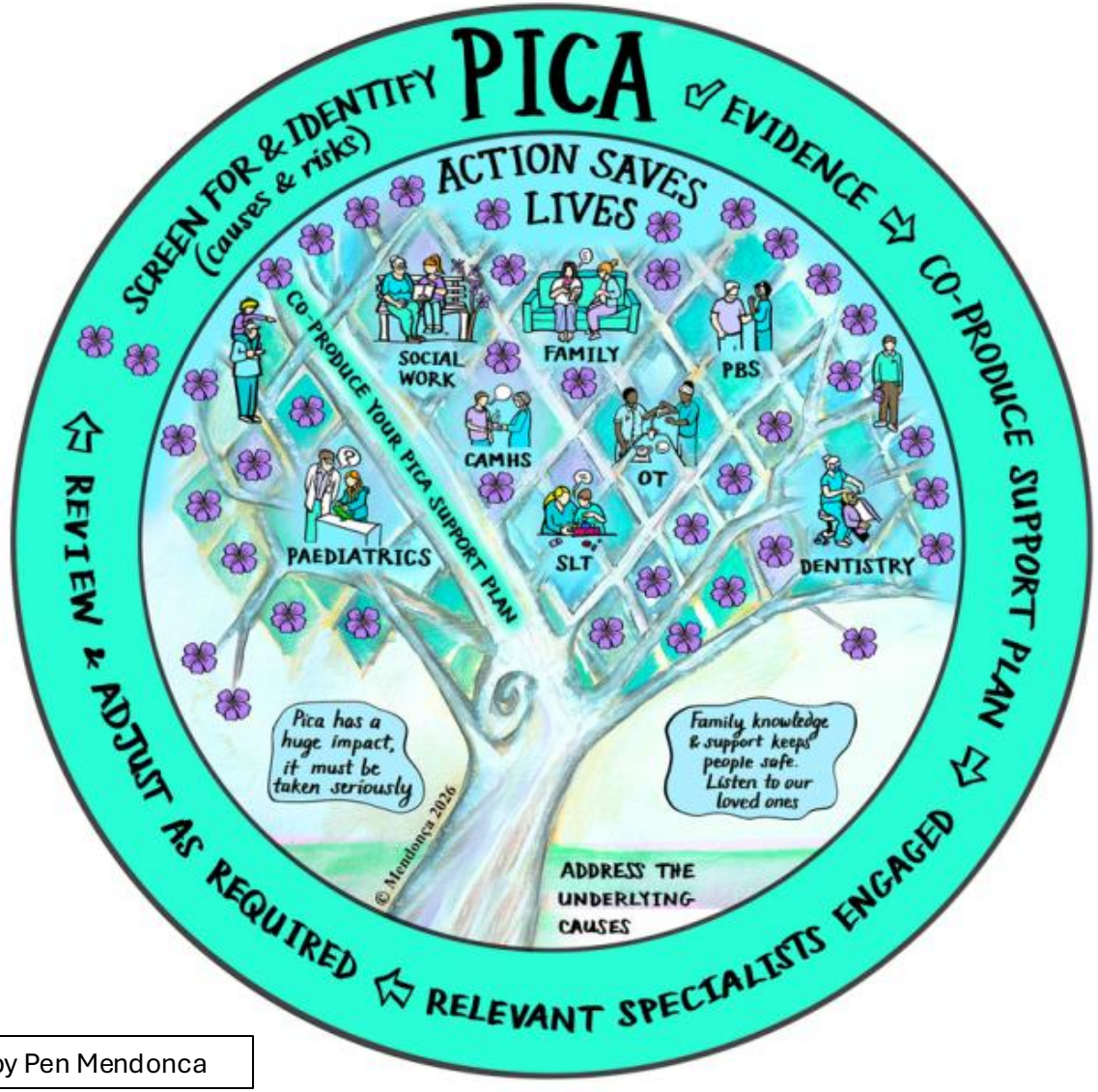
Acknowledgements and Thanks

Authors:

- Dr Lizzy Donaghy, Dr Heather Hanna, Vivien Cooper OBE, Jessica Agnew, Dr Robyn Bailey, Prof Peter Baker, Orlagh Butler, Dr Trish Carolan, Victoria Craig, Dr Susie Gibbs, Dr Linda Hume, Dr Beata Kowalewska, Emma McDermott, Dr Kathryn McKenna, Rachael McMaster, Dr Sarinda Millar, Elaine Mooney, Kate Sanger, Dr Louise Sharkey, Dr Fionnuala Williams.

Special thanks to:

- Lindsay Gollogly, Kelly Mullan, Louise McConville-Clancy and to the other family carers who provided valuable input and insight as we co-produced the pathway; Prof Billy Bourke, Dr Evelyn Ervine, Dr Claire McKenna, Jackie Shurlock, Prof Benjamin Thomas, Ruth Walker, Becky Wetherly.



Credit: Original artwork by Pen Mendonca

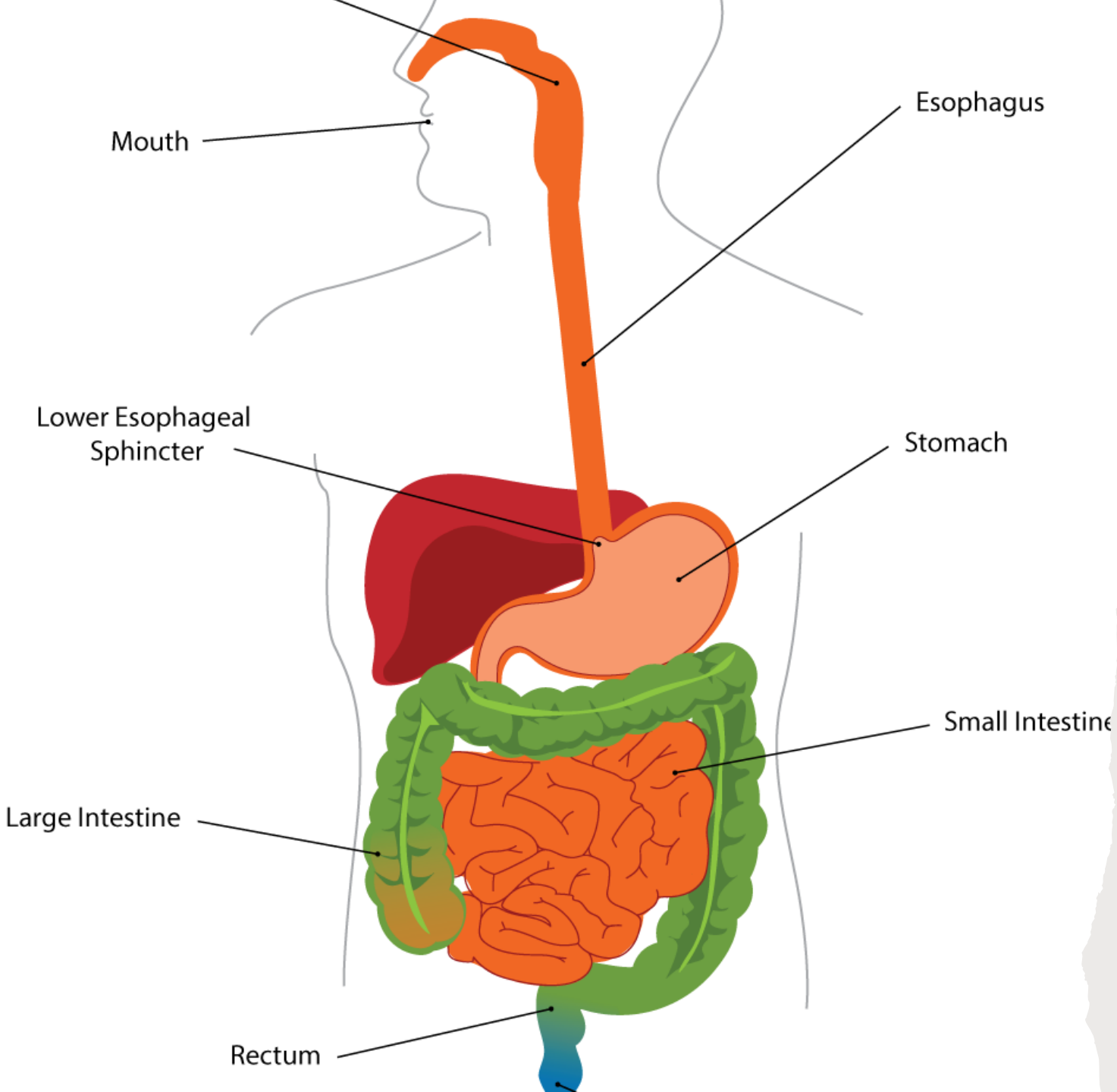
Pica

Camden Learning Disabilities Service (CLDS)



Risks





What are the risks?



What are the risks?



CONSTIPATION



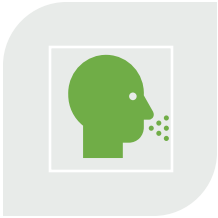
VOMITING



INFECTIONS



BLOCKAGES



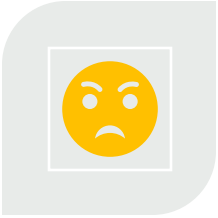
CHOKING



POISONING



DAMAGE TO TEETH



BOC



WEIGHT CHANGES



CUTS

Management and Role



Pica management

The type of management depends on the cause or motivation

Potential causes:



Sensory



BOC



Deficiencies



Oral stage

MDT Working



Occupational therapy:

- Functional ax including sensory ax
- Sensory toys
- Active support
- Capable environments



Nursing/SSW:

- Medication review
- Diet advice
- Monitoring
- MH monitoring
- Hunger
- Health access



SLT:

- Dysphagia
- Choking risk
- Visual supports
- Form of communication?
- Choice making



Psychology:

- PBS Plan
- QOL ax
- Self soothing
- Due to trauma or mental illness?
- Underlaying unmet need



GP/Other:

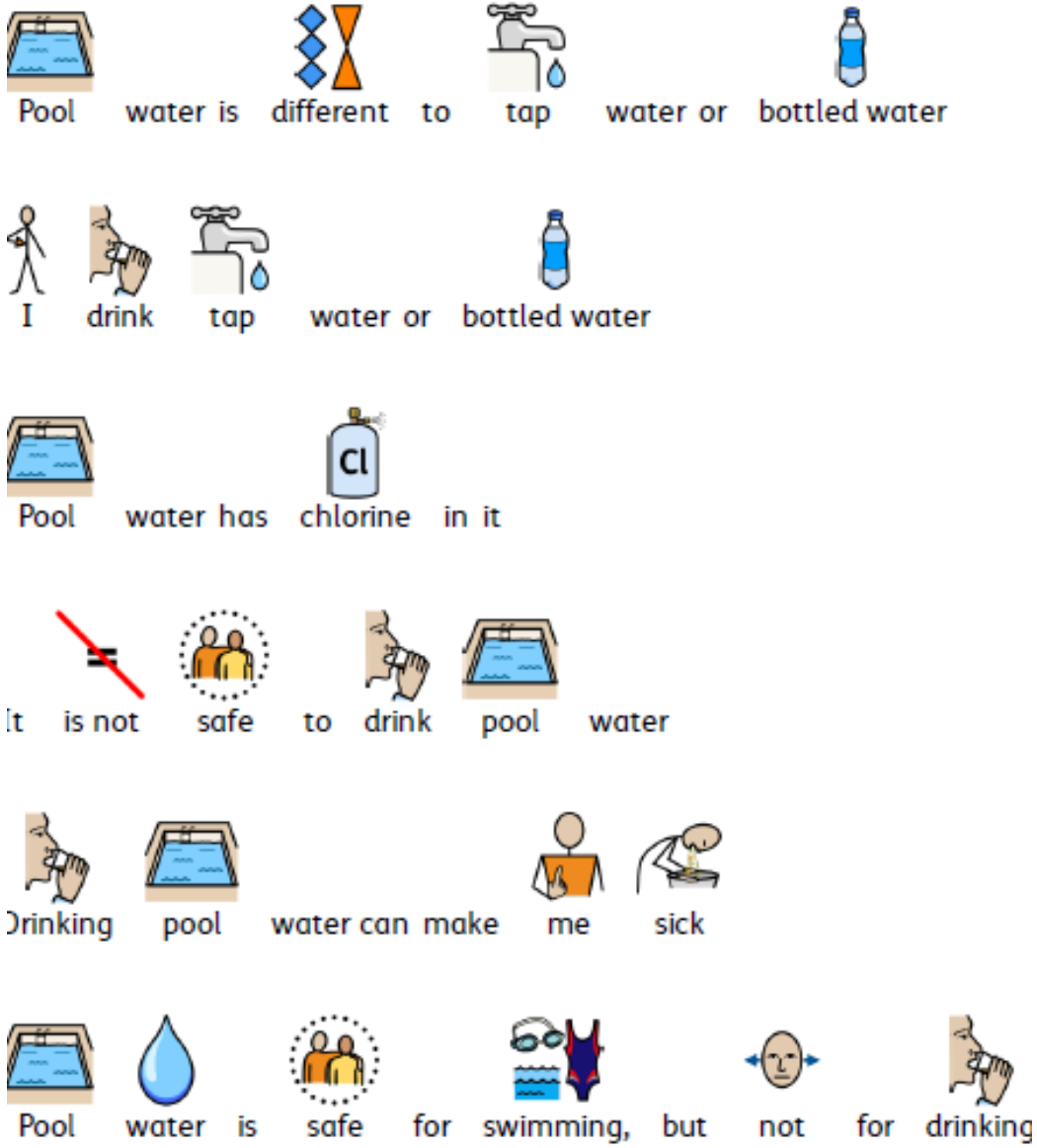
- Blood test
- Abdominal exam
- Dental review
- Nutritional supplements

Quality of life



Person-Centred Planning

- Does the person understand that pica can be dangerous?
- How to communicate this?
- How to involve the person in their care?
- How to make sure the person doesn't miss out on preferred activities?
- Education



Risk vs. QOL





CLDS Care Plan

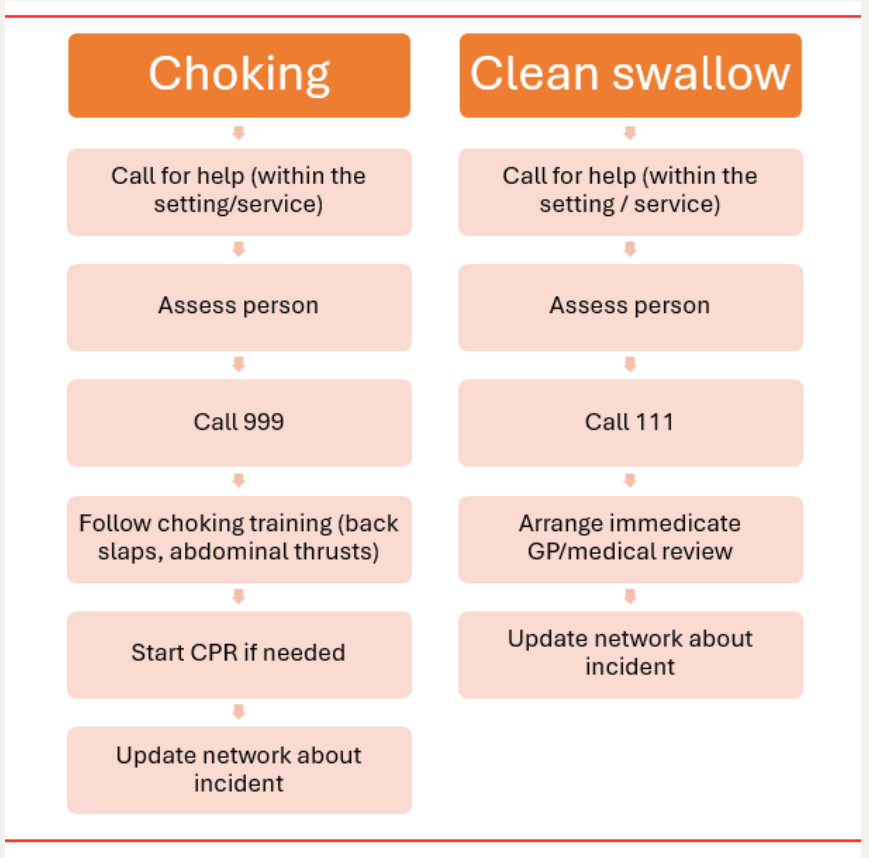


Capacity: XXX does not have capacity to make decisions around his eating, drinking and swallowing. He is not able to communicate information about this decision.

Items XXX may attempt to eat	Potential short- and long-term risks	Risk Management Plan
Please note: XXX is not exclusively drawn to specific non-food items. The list below includes items XXX has been observed eating or mouthing; however, he may also ingest items not listed here. **Dust:** *XXX may eat dust found on floors or surfaces. He has previously swallowed dust.* **Hair and Clothing Fibres:** *XXX may eat hair or fibres found on floors or surfaces.* **Paper:** *XXX may rip paper into small pieces and chew them.* **Electric Cables:** *XXX may chew the plastic coating of electric*	- **Infections or poisoning** from consuming items that are found on the floor, items with chemicals in/on, or from bodily excrement - **Cuts** in the mouth, throat, intestines or when passing item. - **Constipation** and **blockages** in the gut and intestine from larger items or harder items attempting to pass through. - **Stomach distention** or **perforation** due to	**1. 1:1 supervision** - XXX should be supported 1:1 (including during personal care) to ensure he can be redirected from picking up non-food items he is known to consume. XXX responds very well support from staff he knows well, and 1:1 support appears to significantly reduce XXX's attempts to consume non food items. - Prevent him from putting these items in his mouth. Verbally and gesturally prompt to put items down - Provide support if he does put items in his mouth **2. Clean / tidy environment** - Keep environment clean and tidy to prevent dust build up and items on the floor and surfaces. - In rooms where XXX will be left alone for any period (E.g. bedroom) remove all unnecessary cables or keep cal… hidden or covered with covers/trunking. - Check any wiring regularly for damage and remove if… **3. Meaningful/sensory activities** - XXX's PICA behaviours appear to be linked to sensory seeking, when he is under stimulated.

cables and may be unaware of the associated risks. **Plant Matter:** *XXX may rip leaves into small pieces, chew them, and may spit them out. There is a risk he may accidentally swallow plant material.* **Live Animals:** *XXX may put small animals, such as slugs or caterpillars, into his mouth.* **Soil:** *XXX may pick up and eat soil when in the community.* **Faeces:** *XXX may touch and eat dog faeces in the community or his own faeces after bowel movements. He may also pass stool in the shower.* **Urine:** *XXX may touch and taste his own urine, particularly during urination in the shower.* **Sharp Objects (Broken Glass/Broken Pottery):** *XXX has been observed breaking glass and bringing shards toward his mouth. While XXX may not show a particular interest in sharp objects, he remains at risk of ingesting them if available.*	consuming hard and sharp items. - **Choking** from consuming spherical, larger items and items not meant for consumption (e.g. latex gloves). - **Electric shock** from live wires (risk of electric burns, neurological damage, internal organ injury, cardiac arrest) - **Fire hazard** from damaged wiring being used after being chewed - **Damage to teeth** if biting hard items. - **Behaviours of concern** if physical health difficulties arise whilst consuming or passing an item.	- Prevent boredom: Provide enough stimulation throughout the day with preferred / varied activities - Scheduled Sensory time: Build regular sensory breaks into XXX's daily schedule, particularly including opportunity for full body movement (jumping, running, walking) - Sensory activities XXX enjoys: - Jumping - Running/walking - Massages - Using a body sock - Rocking (in a suitable chair) - Showering / water play - XXX benefits from access to safe ways to access similar sensory stimulation he is seeking with Pica behaviours - Long shaped silicon chewy - Bubble blowing - Textured snacks (e.g. melt in the mouth crisps, small pieces of seaweed – see eating, drinking and swallowing care plan for further advice to ensure foods are safe for Shirwa). **4. Emergency response** - **If choking:** Call for help within the setting, assess the person, and dial 999 immediately. Follow choking first aid procedures (back slaps, abdominal thrusts), start CPR if necessary, and update the care network after the incident. - **If clean swallow (no choking):** Call for help within the setting, assess the person, and contact 111. Arrange an urgent medical or GP review, and update the care network about the incident.

Functions or reasons for the Pica behaviours	
Sensory needs	- XXX presents with high levels of sensory-seeking behaviour, including rocking, vocalising, jumping, running, and tactile exploration. He also shows an interest in strong smells (e.g. faeces) and appears to enjoy eating and often attempt to continue beyond satiety if not prompted. - These behaviours suggest a strong drive to seek sensory input. XXX's Pica may be primarily motivated by the oral-tactile feedback he receives from mouthing or consuming non-food items.
Behaviour needs	- XXX most often engages in Pica when under-stimulated or without access to structured, meaningful activity. His college tutor reported no incidents of Pica observed, suggesting that when XXX is actively engaged in meaningful activities, the likelihood of Pica behaviours decreases. Taken together with his sensory profile, this indicates that the primary function of XXX's Pica is sensory stimulation, which he particularly seeks during periods of under stimulation or boredom. - There is currently limited evidence to suggest that XXX's pica behaviour functions to gain interaction with other when under stimulated, though this should continue to be monitored.
Eating and drinking needs	- There is no evidence to support that XXX has a physical dysphagia. - He doesn't have weakness or incoordination to the muscles of the mouth and throat involved in eating, drinking, and swallowing. - XXX does have some difficulties pre-orally in terms of being able to adequately prepare and modify foods (e.g. cutting) but this is accommodated for day-to-day by his Carers and family. XXX's difficulties around mealtimes are also characterised by changes in mood and behaviour whereby he can eat at a very fast pace, put more food in his mouth before swallowing the previous mouthful, eat foods items which are larger in size and not chew foods as thorough if distracted, distressed etc. These factors increase XXX's risk of aspiration, choking and ill-health as it means there is additional strain on his body in those moments. XXX can also eat non-food items, as this plan outlines which has the same potential risks. There has been a choking incident reported in the past where XXX consumed some stringy cheese and this got lodged in his throat. He required first aid interventions to remove the item. See eating, drinking and swallowing care plan for more information.



Emergency process

Pica is not always avoidable


Hospital admission


Scans


Monitoring


Surgery

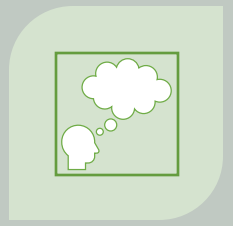

Aftercare


Review care plan

To end



Pathway reflections



SUPPORT WHERE IT IS NOT PICA



IMPROVED QUALITY OF AHC



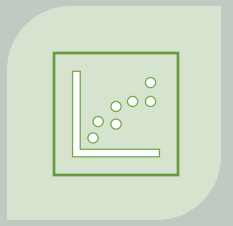
IMPROVED CONFIDENCE



SYSTEMIC CHANGES

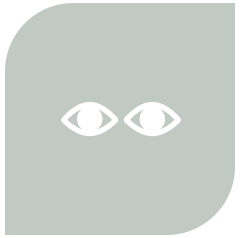


“LIFE CHANGING”



DATA COLLECTION

Key points



BE VIGILANT



FOLLOW THE CARE PLAN



COMMUNICATE WITH THE NETWORK



BE ASSERTIVE AND PERSISTENT: PROFESSIONALS MAY NOT FULLY UNDERSTAND



YOU PLAY A CRUCIAL ROLE IN THE PERSON'S SAFETY

Shared points of the pica pathways

Evidence-based

Co-produced

Multi-disciplinary approach – with family carers as valued partners

Clinical guidelines – robust assessment and management

Focused on outcomes and actions

Plans: NI regional pathway to be shaped within local Trusts; Camden pathway to be shared outwards with other London areas

Thank you

Any questions?



The Development of Global Mental Health Assessment Tool– Intellectual Disability and Neurodevelopmental Disorders: GMHAT/Full -ID/NDD

Dr Niranjani Gadgil

ST6 in Psychiatry of Intellectual Disabilities

CANDDID

Background - Health Inequalities, and Comorbidities in people with Intellectual Disabilities (ID) &/or Neurodevelopmental Disorders (NDD)



Approximately 25–40% of adults with intellectual disabilities experience co-occurring mental health problems

Around 3–5% of people accessing mental health services have co-occurring autism spectrum disorder (ASD)

Among children and young people:~36% with intellectual disabilities experience mental health conditions compared with ~8% of children without ID



Common co-occurring conditions :Mood and anxiety disorders, Psychosis, Catatonia

Higher rates of Mental health needs in people with ID and/or NDD

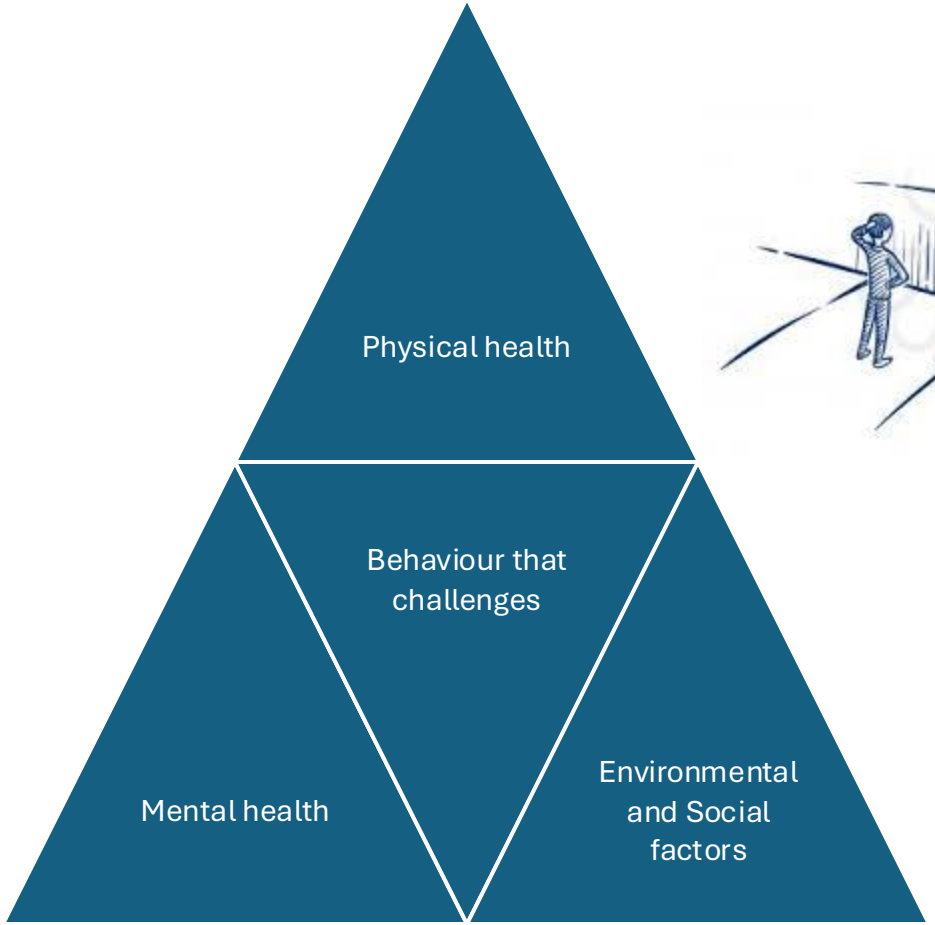
Co-occurrence of multiple neurodevelopmental conditions



Health inequalities: People with intellectual disabilities die on average 15–20 years earlier than the general population.

Mental health problems contribute significantly to barriers in accessing appropriate health and social care

Understanding behaviour in people with ID





- **Communication barriers**
Difficulties expressing internal experiences can limit recognition of distress using standard assessment approaches

- **Behaviour as communication**
Distress may be expressed through changes in behaviour rather than verbal report

- **Diagnostic overshadowing**
Symptoms may be attributed to intellectual disability or neurodevelopmental diagnosis rather than recognised as treatable mental health conditions

- **Autistic perspective**
Differences in sensory processing, communication, and emotional expression can alter how mental health difficulties present and are understood

Consequences of unrecognised needs

Needs often go unrecognised as a result of significant barriers in people with ID.

This can lead to needs not being addressed appropriately as physical health needs can be misconstrued as behavioural or mental health needs and vice versa

This can lead to:

- Crisis presentations
- Placement breakdown
- Carer burnout
- Hospital admission
- Social isolation
- Increase in morbidity and mortality



Need for a structured tool

Good-Quality Assessment has the potential to support community living by:

Identifying:
Support needs early
Reasonable adjustments
Risks

Supporting:
Stable placements
Meaningful activity
Better MDT coordination
Person-centred care

Enabling:
Prevention and early intervention
Continuity of care across services
Reduced avoidable hospital admissions



CANDDID

What is GMHAT (Global Mental Health Assessment Tool)?

- A **computerised, standardised** clinical assessment tool
- Clinically validated and **aligned with ICD-10**
- Designed for **routine clinical** practice
- Supports **holistic**, needs-led assessment
- Can be used by a wide range of **healthcare professionals** within an MDT, with appropriate training

<u>GMHAT Versions:</u>

Has adapted versions designed to meet the needs of specific populations and different care settings.

- Primary care: GMHAT-PC
- Secondary care: GMHAT/Full; GMHAT/Full-ID/NDD; GMHAT/Full-CYP

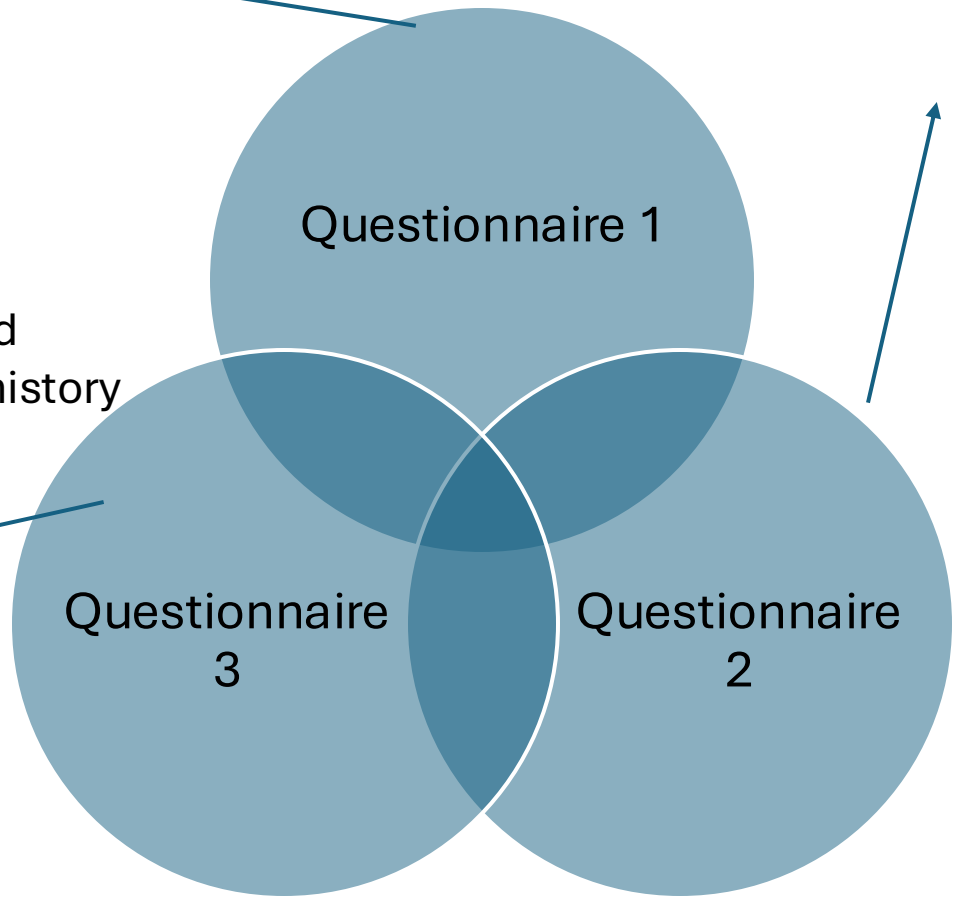
GMHAT/Full- ID/NDD - Tool structure

Background and History

- Presenting concerns and reason for referral
- Personal and social history
- Physical health and past mental health history
- Developmental and neurodevelopmental background
- Substance use and medication history

Needs, Quality of Life, and Risk

- Identification of unmet needs across key life domains
- Exploration of quality of life
- Assessment of risk and vulnerability, including safeguarding concerns



Structured Mental Health Assessment

- Mental State Examination
- Covers a broad range of symptoms including Mood, Anxiety, Psychosis, Orientation etc.
- Uses behavioural equivalents and informant information where verbal report is limited

Takes about 60 – 90 minutes

CANDDID

Key Features of GMHAT/Full-ID/NDD

Integrated

Embedded within the electronic system

Previous information can be pulled through

Flexible

Adaptive questions open only when relevant

Not all fields compulsory

Allows free-text input

Supports clinical quality and judgement

Quantitative scoring and qualitative prompts

Prompts areas MDT members may not routinely consider

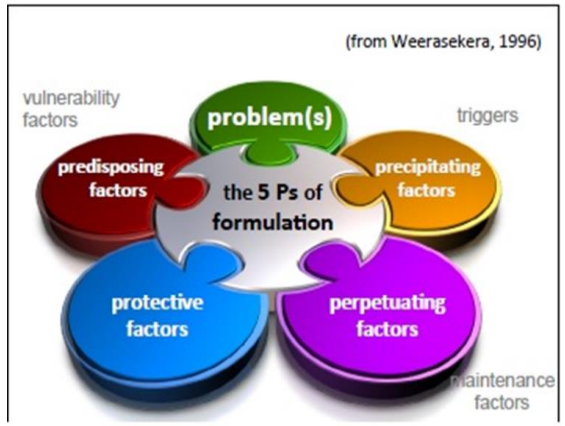
ID/NDD-adapted

Supports carer / informant responses

Uses Behavioural equivalents

CANDDID

Holistic Formulation



Summary document

- Can be generated following assessment
- Provides a clear overview of Key findings and Identified needs
- Can be edited to remove sensitive or confidential information
- Can be shared across MDT, GPs, carers, and other services
- Supports continuity of care

Formulation

- Problem – What issues does the patient have?
- Precipitating – What triggers have led to the problems
- Predisposing – Family history, genetics, past experience
- Perpetuating – Social, environment, peers, carers
- Protective – personal strengths, resources, coping strategies

CANDDID

Roll out and training resources



Roll out

- Piloted across Cheshire and Wirral Partnership NHS Foundation Trust ID services around end of 2022.
- Standard operating procedure (SoP) for a graded rollout developed
- Delivered Face-to-face training sessions with hands-on use of the tool on the electronic system using test patients

Training resources

- Pre-recorded training videos covering all aspects of GMHAT Full ID/NDD developed

CANDDID

Planned evaluation

Evaluation

- Initial feedback sought through Participation and Engagement leads and audit completed
- Further evaluation planned to support learning, refinement, and consistency in practice.
- Initial step includes a survey and focus group seeking feedback from professionals who conduct assessments using GMHAT across community and inpatient intellectual disability teams in the Trust.



Contact information

Dr Niranjani Gadgil
ST6 in Psychiatry of Intellectual Disabilities
Cheshire and Wirral Partnership NHS Foundation Trust, UK
Email - n.gadgil@nhs.net

Centre for Autism, Neurodevelopmental disorders and Intellectual Disabilities (CANDDID)
CANDDID :: Cheshire and Wirral Partnership NHS Foundation Trust

Acknowledgements

Rachel Mills[12], Dr Ceri Woodrow[12], Prof Sujeet Jaydeokar[123], Prof Mahesh Odiyoor[123]

Affiliations:

[1] Cheshire and Wirral Partnership NHS Foundation Trust, UK

[2] Centre for Advanced Neurodevelopmental and Developmental Intellectual Disabilities (CANDDID), UK

[3] Chester Medical School, University of Chester, UK


THANK
YOU

Improving access to blood tests for people with learning disabilities: the story so far

Jenny Pratt – Strategic Health Facilitator LSCFT
Learning Disability Health Facilitation Team

Sarah Duffin - Senior Lecturer, Pre-Reg Nursing
University of Cumbria



The Initial Pilot - from an idea to a collaborative pathway.



NHS University Hospitals of Morecambe Bay NHS Foundation Trust

NHS Lancashire & South Cumbria NHS Foundation Trust

The Lunesdale Surgery

Carnforth & Milnthorpe Primary Care Network

How it all began

Primary Care • Pathology • Learning Disability services

Dr Karen Perkins, Dr Julia Smith, Dr Tom Jamieson, Sarah Duffin Trainee ACP and the Bay CLDT

A small pilot that established the foundations for a new approach to blood sampling.

THE START OF THE TAP JOURNEY

One pathway • shared expertise • a patient-centred approach to alternative blood sampling

Pilot outcomes

20

patients

in the initial pilot

Clinically important findings identified and funding enabled a plan for wider roll out across the Bay



1 patient

Non-diabetic hyperglycaemia

Elevated HbA1c identified — high risk of developing Type 2 diabetes.



1 patient

Raised cholesterol

Cardiovascular review arranged following the result.



2 patients

Abnormal thyroid function

Results enabled diagnosis and adjustment of thyroxine dose.

The pilot demonstrated that accessible blood sampling can identify previously unmet clinical need.

TAP MicroSelect: At a Glance

Touch-activated capillary blood collection from the upper arm

A quick overview of how TAP works, who may benefit and the key limitations to consider.

1 What is it?

A patient-friendly device designed to simplify blood collection using capillary sampling from the upper arm.

2 How does it work?

- Gentle touch-activated vacuum
- Micro-needle technology
- Collects blood just below the skin surface
- Designed to minimise discomfort

3 Who could it be used for?

Patients at home • people with learning disabilities

Older people • fragile veins

Multiple unsuccessful venepunctures

Severe burns • needle phobia

4 Benefits

✓ Painless experience

✓ Can support collection at home

✓ Minimal red blood cell breakdown

✓ Fast and efficient collection

5 Limitations

- Collection may occasionally fail
- Sample volume is limited
- Not suitable for every blood test

6 Not suitable for

FBC testing

Tests requiring larger sample volumes

High-precision tests or those affected by tissue-fluid contamination

Key message: TAP offers a less invasive alternative to venepuncture for selected patients, while recognising sample-volume and test limitations.

What can the TAP test for?

Available tests and sample prioritisation

SAMPLE PRIORITY

1 **Most important test**

Number requested tests in priority order.

Prioritise sample collection by numbering tests from 1.

Leave tests blank if they are not required.

Only the tests shown in the table are currently available using TAP devices.

TAP blood collection – please prioritise sample collection by numbering from 1 (1 indicating the most important test). Leave blank any tests not required.			
HbA1c		Prolactin	
Lipids (total cholesterol, LDL, HDL, triglycerides)		Cortisol	
Liver function test (ALP, total protein, albumin, total bilirubin and ALT)		Thyroid function test (TSH and FT4)	
Renal Profile (Creatinine, sodium and urea, eGFR). Please note we are unable to offer potassium by this method.		**Please note there are no other tests currently available using TAP devices**	
Bone profile (Albumin, adjusted calcium and phosphate)			
Folate			
Vitamin B12			
Ferritin			

Prioritisation helps ensure the most clinically important tests are attempted first when sample volume is limited.

The roll out across the Bay - who is it used for?

Targeting capillary sampling where it adds the most value



ELIGIBILITY **On the Learning Disability register AND coded as having needle phobia**

Approximately 20% of people on the Learning Disability register may need this method of blood sampling.

TAP or an equivalent device can support:

- **Recommended screening — e.g. thyroid testing in Down syndrome**
- Investigation of symptoms
- Drug monitoring — e.g. antipsychotic medication
- **Annual Health Checks**

Not everyone needs regular blood testing — the pathway is targeted to clinical need.

Access through Primary care – how we embedded it

PRIMARY CARE

1 Identify Patient
Suitable patient identified
Code as needle phobic

2 Plan Blood Tests
Request TAP device • Schedule test
Order TAP-specific t-Quest codes on EMIS

3 Prepare
Correct sample labelling & documentation
Consider reasonable adjustments

4 Complete TAP
Complete in Primary Care
Home visit / carer support if appropriate

5 Record & Evaluate
Send sample to laboratory
Provide patient/carer questionnaire

Can the patient tolerate TAP in Primary Care?

NO

YES → Complete TAP

COMMUNITY LEARNING DISABILITY TEAM

6 Additional Support
Support desensitisation and reasonable adjustments
Coordinate with the GP Practice

7 Exceptional Circumstances
LD Team undertakes TAP only where Primary Care is unable to complete the procedure

IMPORTANT
The GP must request the blood tests and prioritise which tests are required before sampling.

What patients and carers told us

The impact in their own words

"I am looking forward to my next blood test"

"Could not believe how easy that was… just amazing"

"Feels just like something sucking"

"It was like having a big cloud removed"

"It was WOW!"

"TAP process is a major step forward for our son who will not give blood unless under GA"

"We are no longer able to go to the paediatric ward to have blood samples taken, so this is great"

"This is life changing. It reduces my worries about her for the future if she can have blood tests done so easily"

Patient and carer feedback highlights reduced anxiety, easier access and the potential for genuinely life-changing care.

60 patients accessed over period April ‘25 to April ‘26

- **37 %** patients have NEVER been able to give a routine venepuncture blood sample

- **58 %** patients have never been able to give a blood sample by venepuncture or only in an acute/outpatient setting

time since last blood test	number of patients
1 year	1
2 years	13
3 years	1
4 years	3
5 years	6
never	22
only on acute admission	10
only in outpatients	3
total	**59**
plus 1 contemporary venepuncture obtained ? Need for TAP	

Clinical outcomes following retrospective questionnaire

Key Measure	Current Total
Responses received	30
Successful TAP procedures	14
Partially successful procedures	15
Unsuccessful TAP procedures	1
New diagnosis / clinical finding reported	14
Medication change reported	7

Other Impact / Patient or Carer Benefit

- Reassurance. Normal TFT and iron levels in patient with Down Syndrome and Coeliac Disease
- I only have used TAP twice but the pt was much more willing and not as anxious, its really great, thanks to all involved.
- Mum was happy son could have a less evasive procedure to have his bloods done prior to referral. Previous work was done under GA which is very stressful for the family. It was reassuring that there is a option for bloods screening to rule out certain diagnosis.
- Previous attempts for venepuncture on this patient had been unsuccessful as they would not allow needles near to them but TAP was tolerated well once initially applied.
- Reassured that bloods are normal, good for building confidence with TAP
- Part of investigations for changes in behaviour and weight loss, able to refer to gastro as bloods were taken and normal
- Has been putting weight on and able to reassure carer that no concerns with bloods
- Reassured that bloods normal as behaviour had changed
- Reassured that TFT remains in satisfactory boundaries
- Carers happy that sample can now be taken without causing upset
- Mum over the moon that TAP can be used
- Carers amazed that TAP was tolerated
- Lifestyle changes recommended to Mum

ICS roll-out – what's next

Replicating the Bay model safely across Lancashire

A staged approach from laboratory engagement and validation through to routine Primary Care use and results access.

1



Engage laboratories

Work with laboratories in the three other Acute Trusts across Lancashire.

2



Validate locally

Each laboratory needs to compare venous and capillary samples in a small patient cohort.

3



Test in GP Practices

Three Practices in each area test venous vs capillary samples on approximately 20 patients.

4



Replicate the Bay model

Use the established Bay approach as the basis for wider implementation.

5



Embed in Primary Care

TAP devices sit within Primary Care and GPs request tests via T-Quest.

6



Return results

Results return to the GP; LD Services access via LPRES or by contacting the Practice.

The aim is a consistent, validated pathway that can be adopted across the ICS while retaining local laboratory governance.

Benefits realisation

What successful implementation can deliver



Benefits span patient experience, clinical quality, workforce efficiency and strategic priorities.

Patient outcomes & experience

- Improved access to diagnostics for underserved populations
- Reduced anxiety, trauma and avoidance of care
- Enhanced dignity and autonomy

Workforce & system benefits

- Increased confidence for clinicians
- Consistent phlebotomy pathways across services
- Reduced failed appointments and repeat attempts

Clinical quality

- Earlier detection of diabetes, thyroid disease, renal & liver dysfunction
- Improved medication safety monitoring
- Reduced risk of advanced disease and emergency admissions

Strategic alignment

- Meets CORE20PLUS5 objectives
- Delivers Equality Act compliance
- Supports NICE and PHE guidance

The value extends beyond successful blood collection — improving access, safety, experience and system efficiency.



Current position & ambition

Priorities for wider implementation

1. **Funding secured**
   Further investment is needed to support full roll-out across Lancashire.

2. **New capillary sampling device**
   Three alternative devices have been tested to date, including options that allow bottles to be changed while using a single device.

3. **Acute Trust leadership**
   Biochemistry leads are required at each Acute Trust to support local validation and implementation.

4. **Additional programme support**
   Support is now secured from North West Coast Innovation and NHS England Diagnostics/Pathology, strengthening the programme and wider implementation.

5. **National ambition**
   Develop a national pilot for 2027–2028.

Ambition: sustainable Lancashire roll-out → national pilot 2027–2028

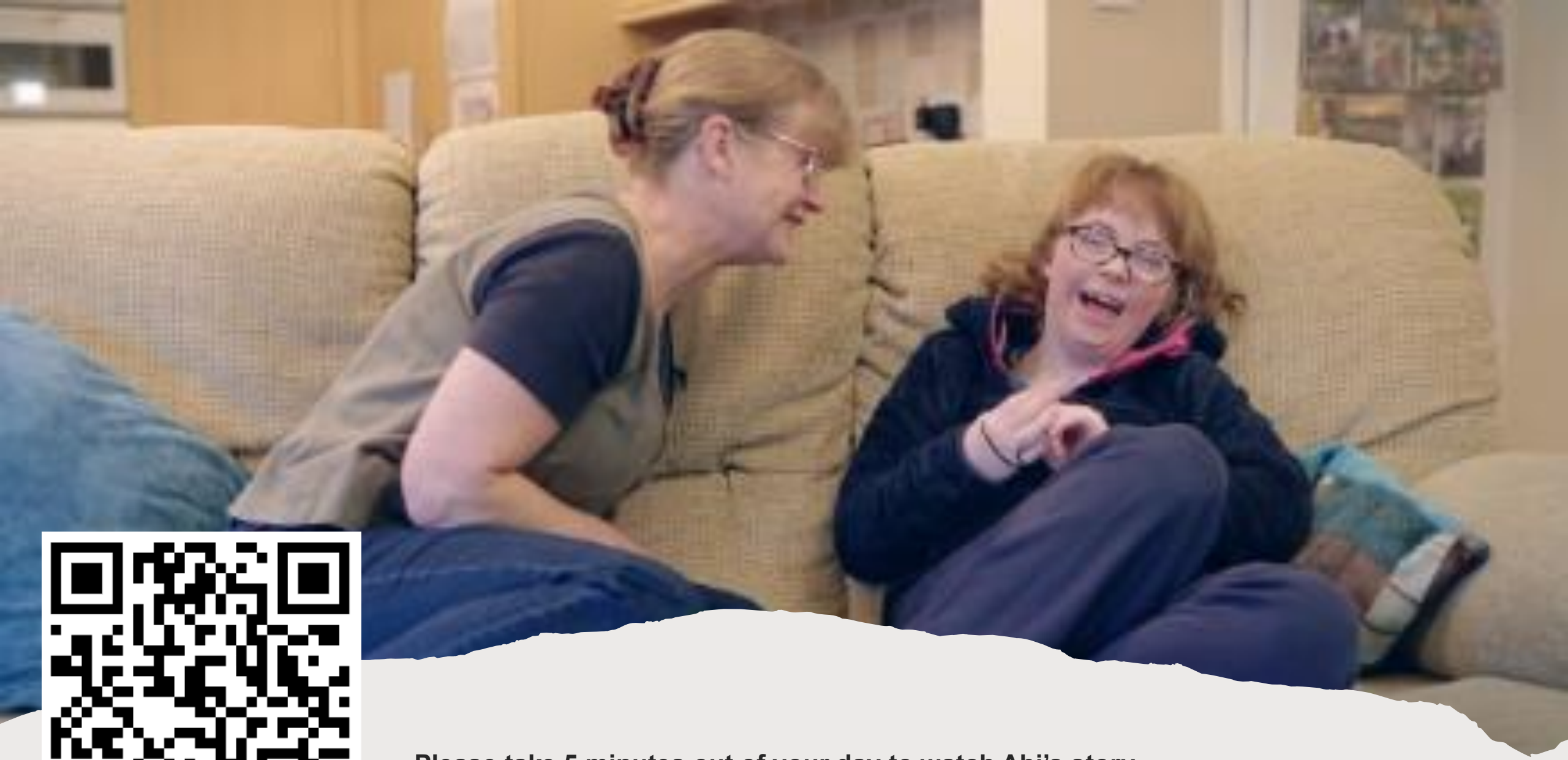
Finally...

If we can make it work for people with learning disabilities, we can make it work for all those who need it.

“What reasonable adjustments in the NHS should look like.”

Thank you for listening

Consent obtained for sharing of all photographs used in this presentation.



Please take 5 minutes out of your day to watch Abi’s story

TAP Bloods - Abigail's Story | Videos & Movies on Vimeo

Further information



OPEN ACCESS | Research Article | 20 August 2026

Comparison of a capillary blood collection device and standard venepuncture for routine clinical biochemistry assays: developing reasonable adjustment phlebotomy for patients with learning disabilities

Authors: Karen Perkins, Joanne Kilkenny, Andrew Brown, Thomas Jamieson, Sarah Duffin, Jennifer Pratt, and Julia Smith | AUTHOR INFO & AFFILIATIONS

Publication: Journal of Patient Centricity

Comparison of a capillary blood collection device and standard venepuncture for routine clinical biochemistry assays: developing reasonable adjustment phlebotomy for patients with learning disabilities

Link to webinar:

https://www.youtube.com/watch?v=Tcq4GkBR6EI

Accelerated Multimorbidity in Adults with Learning Disabilities

What have we learned and what should we do?

Healthy Lives Together
Listening and Learning to Improve Health for People with a Learning Disability
17th September 2026

Thomas Jun (g.jun@lboro.ac.uk)
Professor of Sociotechnical System Design, Loughborough University

Satheesh Gangadharan (s.gangadharan1@nhs.net)
Consultant Psychiatrist, Leicestershire Partnership NHS Trust

DECODE

https://decode-project.org/

NIHR-funded research
April 2022 – August 2026







Loughborough University
NHS Leicestershire Partnership NHS Trust
University of Leicester
Swansea University Prifysgol Abertawe
King's College London
De Montfort University Leicester
The University of Nottingham
University of Plymouth

Summary Description - DECODE

Real World Data in Electronic Health Records

↓

AI-Ready Clean Data

↓

Clinically Significant Patterns

↓

Accessible Knowledge

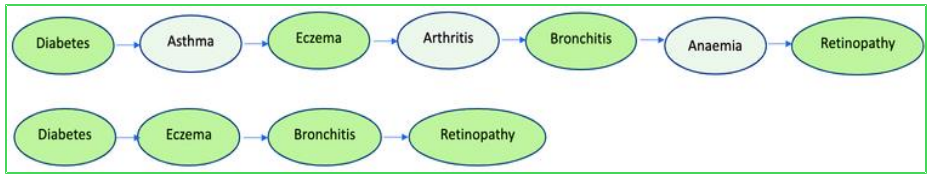
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Actionable Use Cases

CPRD (England)
(20,646adults)

SAIL (Wales)
(13,650adults)

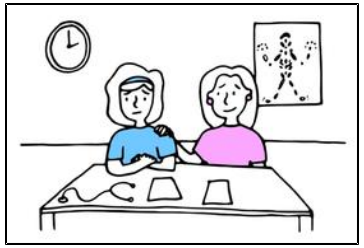
Year 2000 onw ards



Disease trajectories



Interactive dashboard



Accessible visual narratives



Context analysis



Primary Care Use Case



Health Information Use Case



Public Health Use Case

Policy Briefing – to be shared after the event







Why this matters for implementation

DECODE is not a case for creating a wholly separate service. It is a case for redesigning existing systems so that prevention, neighbourhood care, population health management and integrated pathways reflect the actual disease trajectories of people with learning disabilities.

What Have We Learned?

What Should We Do?

People with Learning Disabilities

Die around **19 years younger** than the general population (LeDeR report)

Multiple Long-term Conditions (Multimorbidity) in this population

1. Close to universal and it **starts young**.
2. The **age offset** is measurable.
3. It is **not simply** old age arriving early.
4. The **consequences** are already visible in **service use**

1. Close to universal and it **starts young**

- **86%** of the English and Welsh DECODE cohort had two or more.
- Some had as many as **12**
- Number of long-term conditions was…
  - **3.5 below the age of 45**
  - **5.4 at 45 and over**

2. The **age offset** is measurable

- **Early onset diabetes and hypertension, mental illness and anaemia** emerging in the **45-64 age band** (England data, DECODE)
- **Comorbidity at ages 20-25** → comparable to that of **50-54 year old** in general population (Scotland data, Cooper et al, 2015)
- **20-30 year offset**

3. This is **not simply** old age arriving early.

- Enduring **mental illness** is the most prevalent (30.9%).
- **Epilepsy and chronic gastrointestinal conditions (reflux disorder) are prevalent.**
- **Younger men:** the dominant cluster is **neurological with cerebral palsy, dysphagia, epilepsy, chronic constipation and pneumonia.**
- **Clusters** differ markedly **by age and sex**

4. The **consequences** are already visible in **service use**

Across **62,243 hospital admissions** from the Welsh population

- **Epilepsy** featured around **39% of** admissions in both sexes**.**
- **Mental illness** were associated with a small number of **very long stays**
  - 934 admissions of **129 days or more**
- **Longer stays** are associated with greater socioeconomic deprivation, obesity, lower physical activity, **a higher count of long-term conditions**

What Have We Learned?

What Should We Do?

Policy Implication – NHS England and ICBs

1. **Different age threshold** for people with learning disability for **national screening programmes and health check and**, from the general population whose morbidity arrives two decades later.
2. NICE guidelines on Multimorbidity (NG56) should **name this group as a high-risk group** which needs proactive identification.
3. **Joint strategic needs assessments** should carry **accelerated multimorbidity in this group as a named inequality to explore** in the local population.

Service redesign- ICBs and NHS Trusts

1. Enhanced **Annual Health Checks** using multimorbidity risk prediction and prevention
2. Service reconfiguration based on **observed clusters**
    - **Young men**: neurological–dysphagia–epilepsy–constipation–pneumonia constellation
    - **Women**: mental illness–reflux–chronic pain–thyroid constellation
3. Pathway reconfiguration
    - **Epilepsy** as the dominant driver of hospital admission
    - **Mental illness** as the driver of the longest hospital stay
    - **Explicit routes for people with LD** in existing pathways for **diabetes, cardiovascular, respiratory and renal conditions**.

Clinical practice

1. **Frailty assessment** should be considered in **mid-life** in this population.
2. **Structured medication review** should be routine well before the 15-medicine threshold is reached
3. Clinicians should actively seek the conditions that are under-recognized and burdensome in this population – dysphagia and aspiration risk, chronic constipation, reflux, epilepsy control, thyroid disease and anaemia.

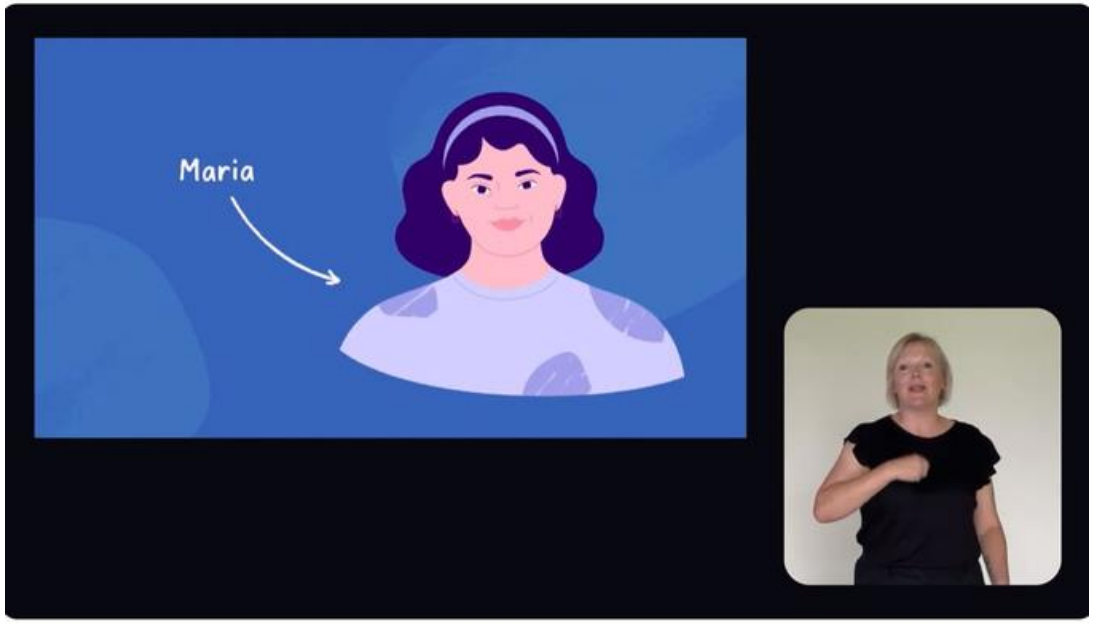
Accessible Information for Carers/PwLD

- Maria's story (3min)



https://youtu.be/Q8an4ZV5Vcs?si=XnlA92pkZltNgqS4

- With Makaton signs



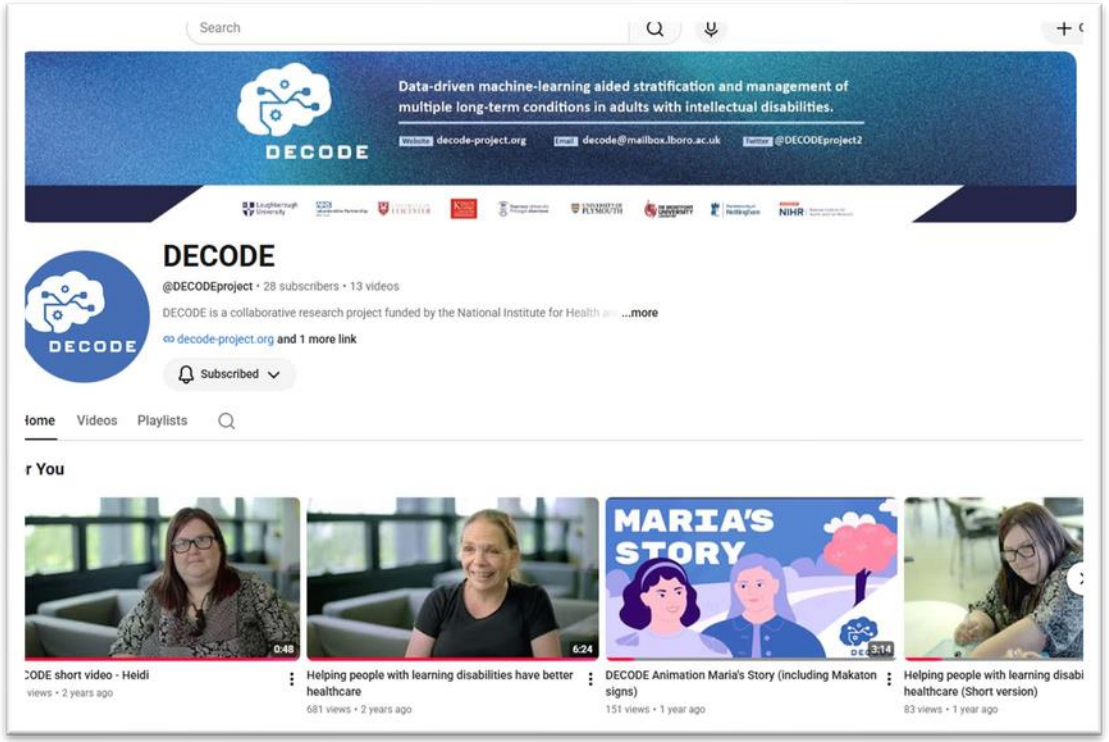
https://youtu.be/vb3rDrc-Wvo?si=4QofCHWg32QfU0zP

Project website



https://decode-project.org/

Youtube channel



www.youtube.com/@DECODEproject

Contacts
Thomas Jun(g.jun@lboro.ac.uk)
Satheesh Gangadharan (s.gangadharan1@nhs.net)

Scottish Learning Disabilities Observatory

CANCER RESEARCH UK

Early detection of breast cancer in people with learning disabilities through Smart Bra.



Professor Deborah Cairns & Professor Yang Wei

Scottish Learning Disabilities Observatory

Background Research

- Cancer incidence and deaths in people with learning disabilities
- Improving access to cancer screening among people with learning disabilities
- New study: Smart Bra for cancer detection

The Baily Thomas Charitable Fund

CANCER RESEARCH UK

NTU

UofG

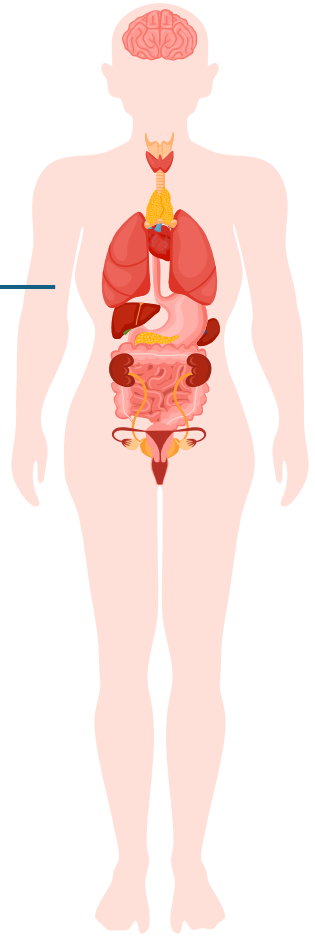
Cancer incidence and deaths among adults with learning disabilities in Scotland

The most common cancer in women was Breast Cancer:

- 23% for women with learning disabilities
- 24% for women without learning disabilities

Breast cancer

- Less likely to be diagnosed with breast cancer (SIR=0.75)
- More likely to die from breast cancer (SMR=1.58)



What does this mean?

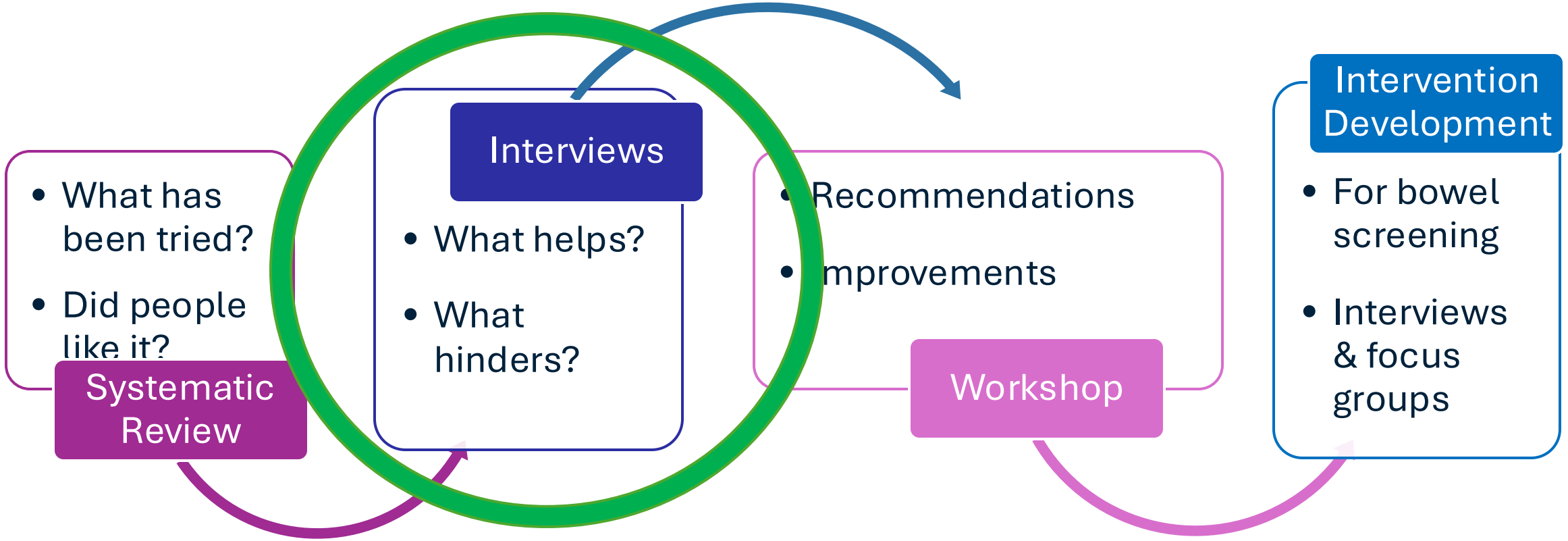
- We know from research that women with learning disabilities are less likely to attend breast screening and so early signs of breast cancer may be missed.
- If early signs are missed, the cancer can spread and possibly lead to death.

The Baily Thomas Charitable Fund

Ward, L. M., Cooper, S. A., Sosenko, F., Morrison, D., Fleming, M., McCowan, C., ... & Cairns, D. (2024). Population-based cancer incidence and mortality rates and ratios among adults with intellectual disabilities in Scotland: a retrospective cohort study with record linkage. *BMJ open*, *14*(8), e084421.

Scottish Learning Disabilities Observatory

Improving access to cancer screening among people with learning disabilities



CANCER RESEARCH UK

Project leads: Professor Katie Robb & Dr Marie Murphy
Main researcher: Dr Lauren Fulton

Scottish Learning Disabilities Observatory

Improving access to cancer screening among people with learning disabilities

Participant group	Participants with learning disabilities	Carers of people with learning disabilities	Participants in professional roles
Scotland	9	6	13
England	6	2	23
Wales	6	1	11
Northern Ireland	8	0	8
Total	**29**	**9**	**55**



CANCER RESEARCH UK

Improving access to cancer screening among people with learning disabilities

One issue with low uptake of breast screening was that some women with learning disabilities were unable to use the mammography machine.

We decided to investigate this further.....



(Health professional)

Scottish Learning Disabilities Observatory

A new era of breast cancer detection

Project: Early detection of breast cancer in people with learning disabilities through Smart Bra

Start date: 01-11-2025

End date: 28-02-2027

Duration: 16 months

SMART BRA

NTU

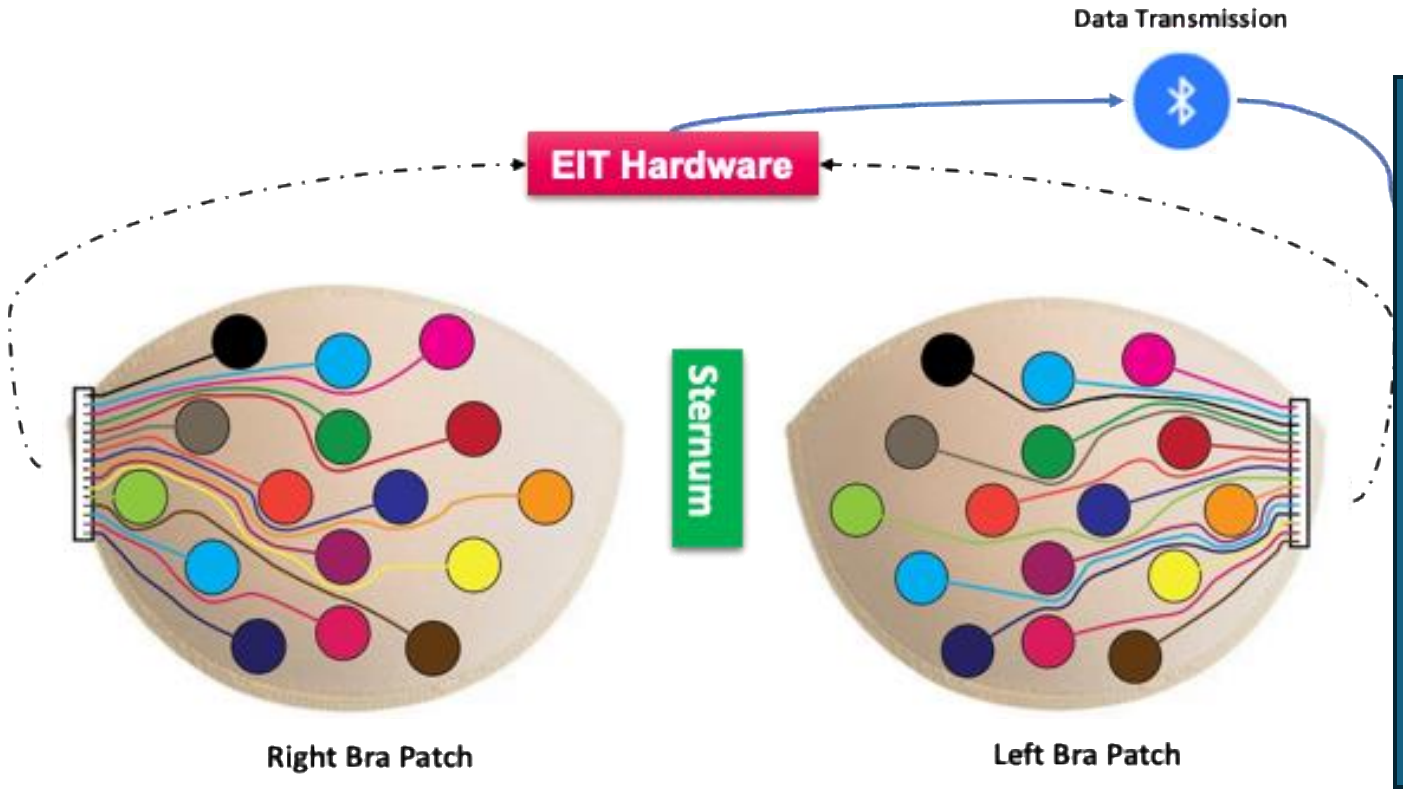
UofG

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Scottish Learning Disabilities Observatory

Our vision:

- Develop a smart bra that can detect and monitor breast cancer
- To capture data within minutes on a digital device



What is Electrical Impedance Tomography (EIT)?

A safe, non-invasive imaging method that maps the internal electrical conductivity and impedance of a body part using surface electrodes

CANCER RESEARCH UK

Preliminary validation studies

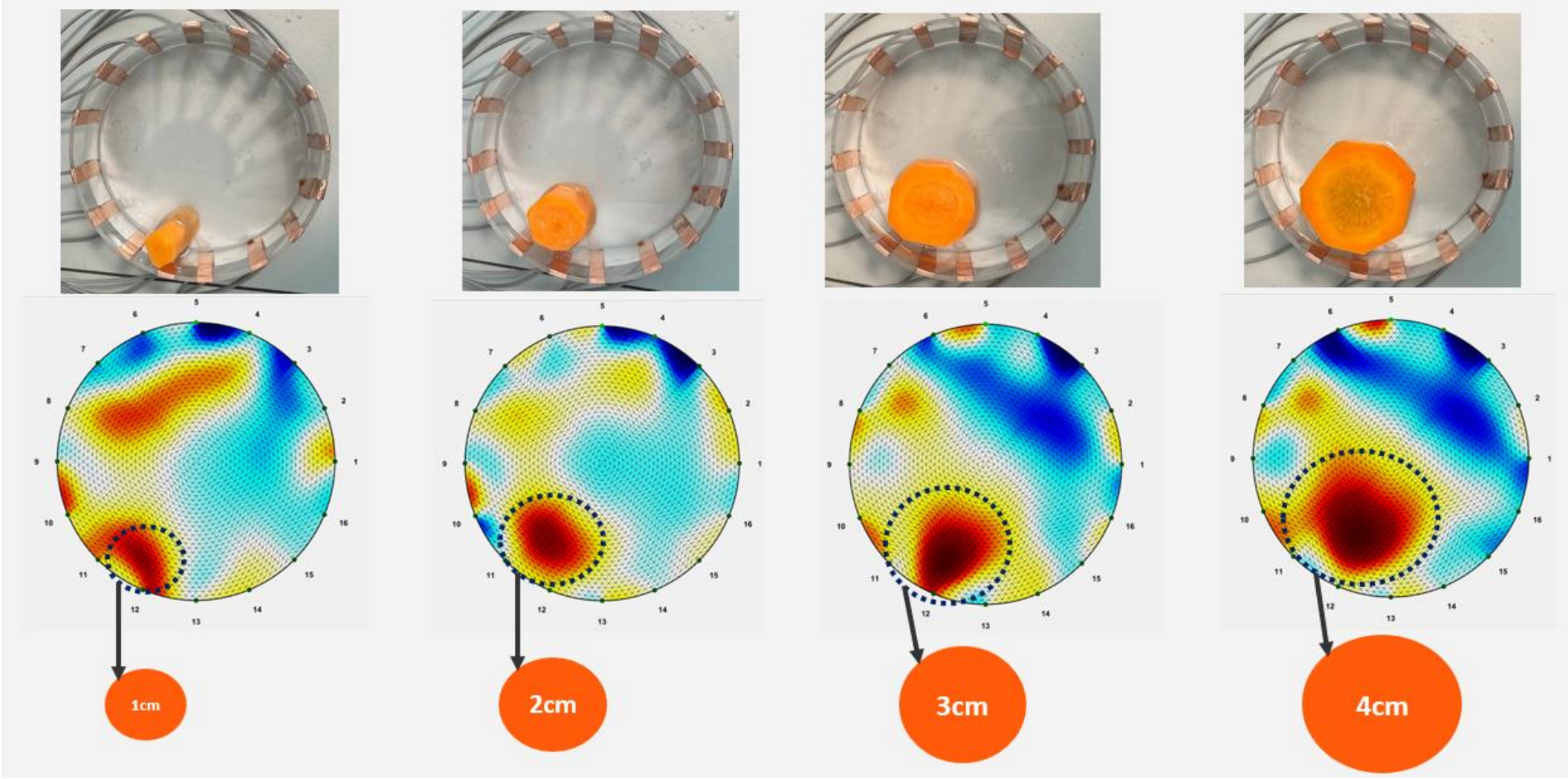
Can EIT detect breast cancer?....



- Carrots are frequently used in biomedical engineering and radiology as "tissue phantoms" to mimic the dense, solid properties of breast cancer tumours.

Scottish Learning Disabilities Observatory

Size validation (1cm – 4cm ‘tumour’)

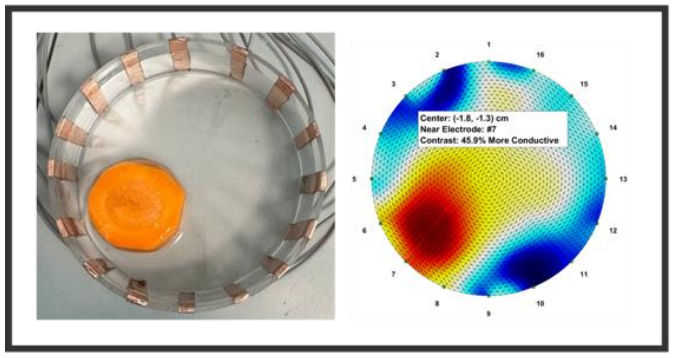


NTU

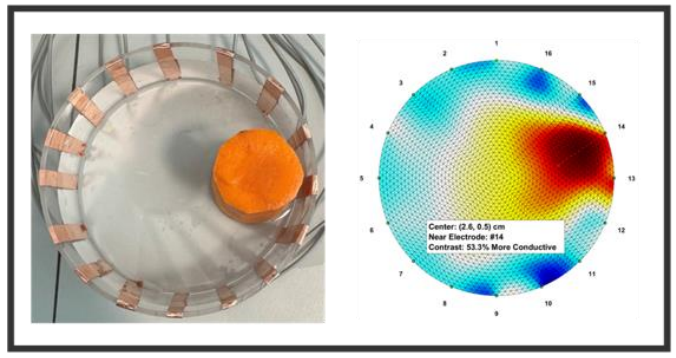
Scottish Learning Disabilities Observatory

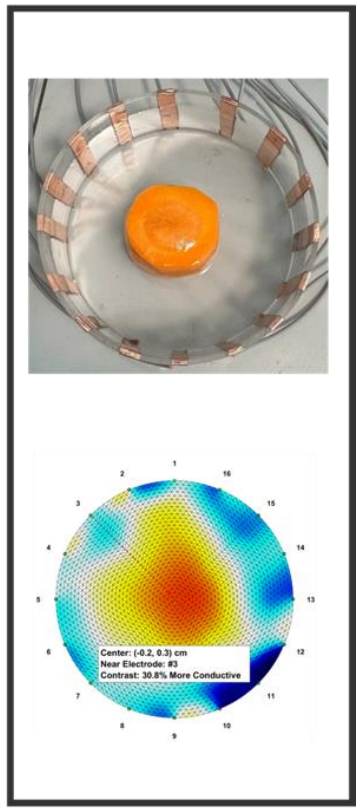
Position validation

Near Electrode: #7

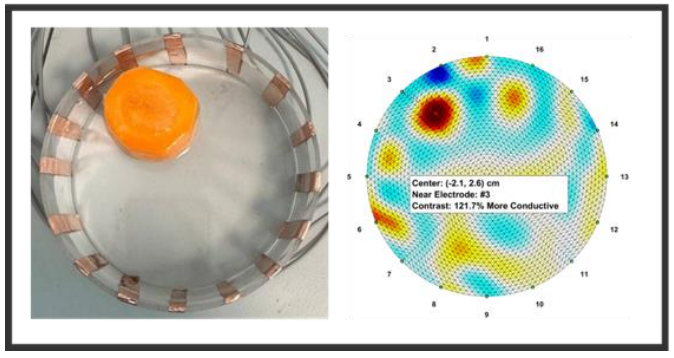


Near Electrode: #14

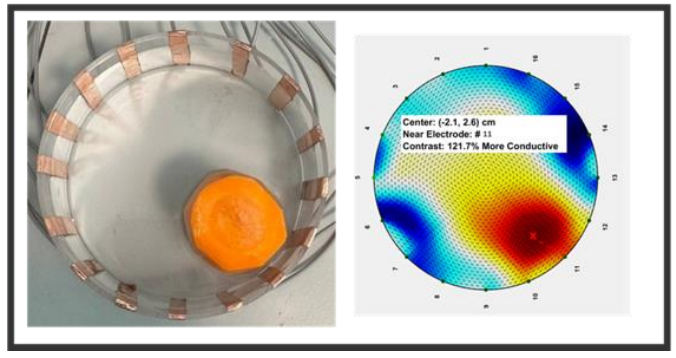




Near Electrode: #3



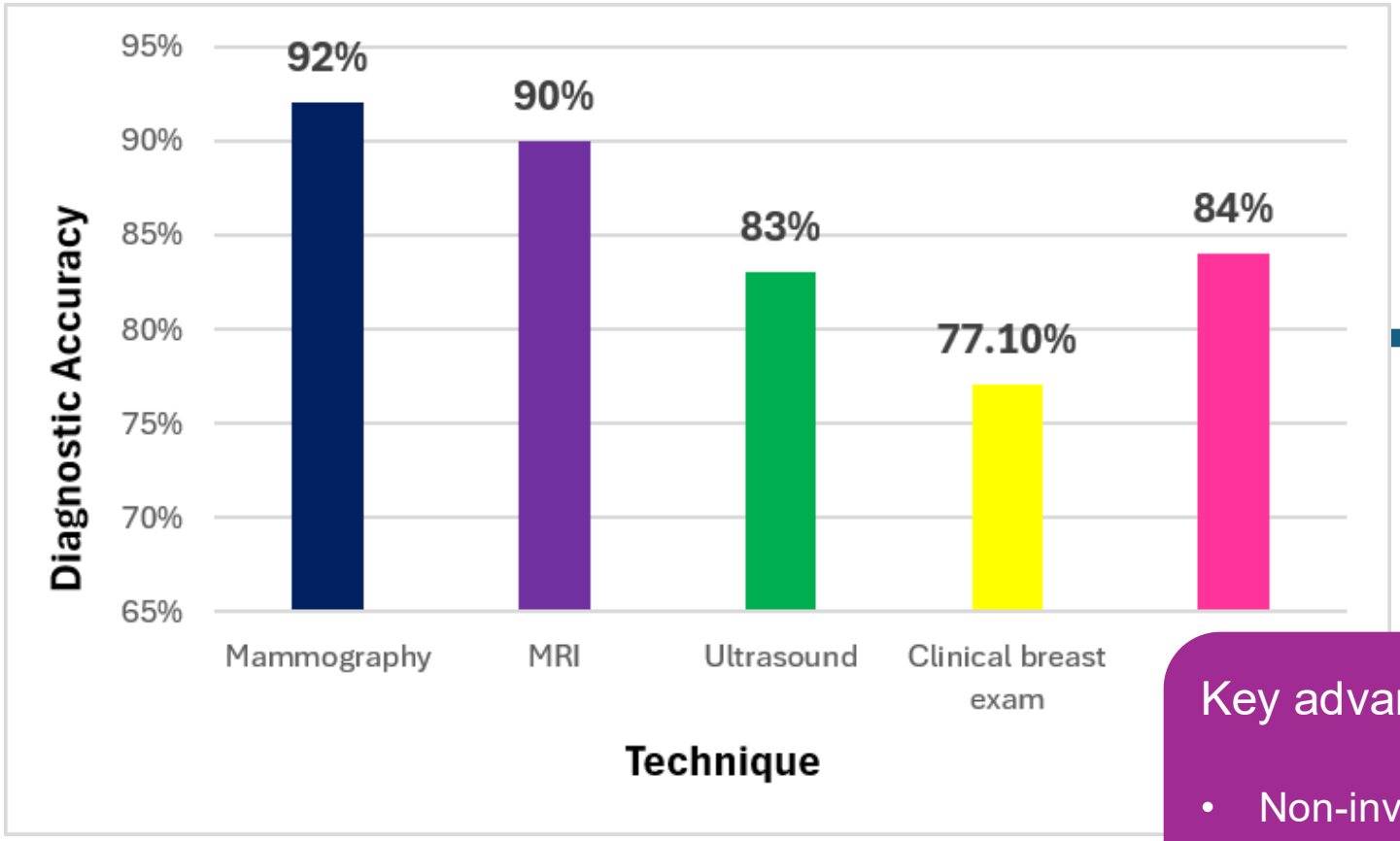
Near Electrode: #11



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Scottish Learning Disabilities Observatory

How good is EIT in comparison to existing diagnostic devices?



Promising + Wearability

Key advantages

- Non-invasive & Radiation-Free
- Low-Cost & Portable
- Suitable for Frequent Monitoring

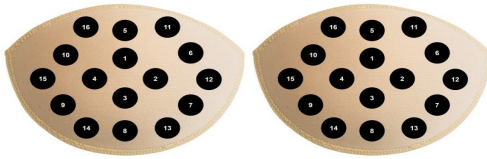
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Smart Bra development

Workshops at the University of Glasgow

Co-development of Smart Bra with:

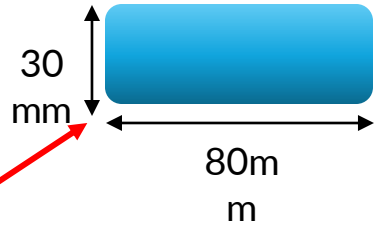
- Adults with lived experience
- Parent carers
- PAMIS
- Fortune Works
- People First





PCB Hardware

- Form factor : Ruler design





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NTU

University of Glasgow

pamis
promoting a more inclusive society

fortune works

People First (Scotland)

Completed Version_1 Design

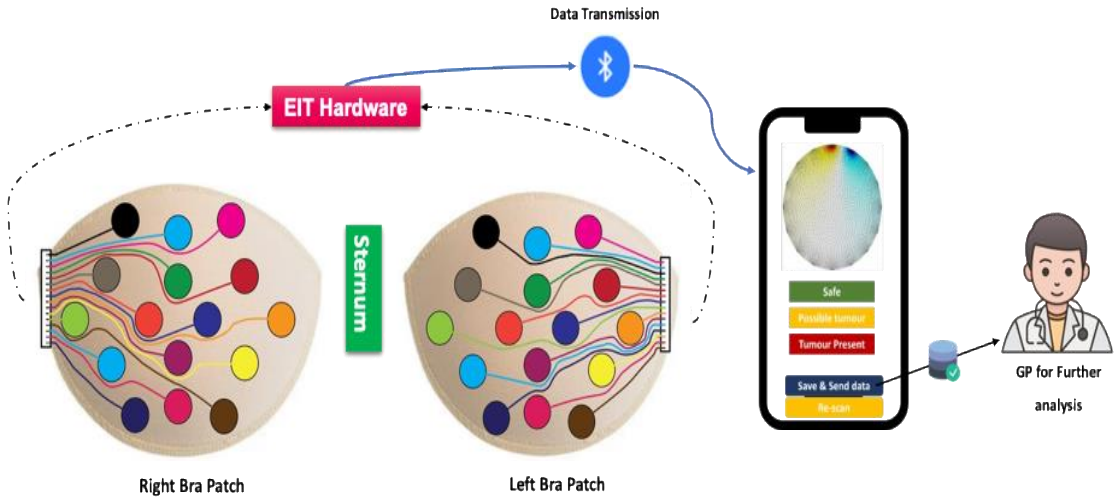




NTU CANCER RESEARCH UK University of Glasgow

Scottish Learning Disabilities Observatory

The future....



Possible outcome:

- Used by the NHS as an alternative breast screening device for women unable to use to the mammography machine

Benefits:

- Increase in screening participation for women with learning disabilities and women unable to use the mammography machine
- Pain-free breast screening device
- Breast screening results sent to digital device within minutes

Questions for us all to consider...

- **Do we want to be able to use the Smart Bra at home or should it only be used only in healthcare settings?**
- **Would you want to have access to this information on your digital device, or should the results only be seen by health professionals in the first instance?**

CANCER RESEARCH UK

Scottish Learning Disabilities Observatory

The team

University of Glasgow

Prof Deborah Cairns (Lead)

Prof Katie Robb

Dr Lauren Fulton

Nottingham Trent University

Prof Yang Wei (Lead)

Prof John Hunt

Prof Katherine Townsend

Shadrack Aboagye

Eloise Salter

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Scottish Learning Disabilities Observatory



Thank you

Deborah.Cairns@glasgow.ac.uk

CANCER RESEARCH UK

Pain Chek In Learning Disability Service



www.enfield.gov.uk

What is Pain Chek ?

- PainChek is a digital pain assessment tool that uses AI-assisted facial analysis and structured behavioural observation.
- Designed to support assessment of pain, especially when people cannot reliably self-report.
- Combines facial indicators with observations of voice, movement, behaviour and body signs.
- Produces a pain score and supports longitudinal monitoring.

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THE PAINCHEK® UNIVERSAL APP

AI Based Micro-facial Pain Expression Analysis:

- 3 second scan of patient face
- Recognises 9 micro-facial expressions indicative of pain

Guided Digital Questionnaire Checklist:

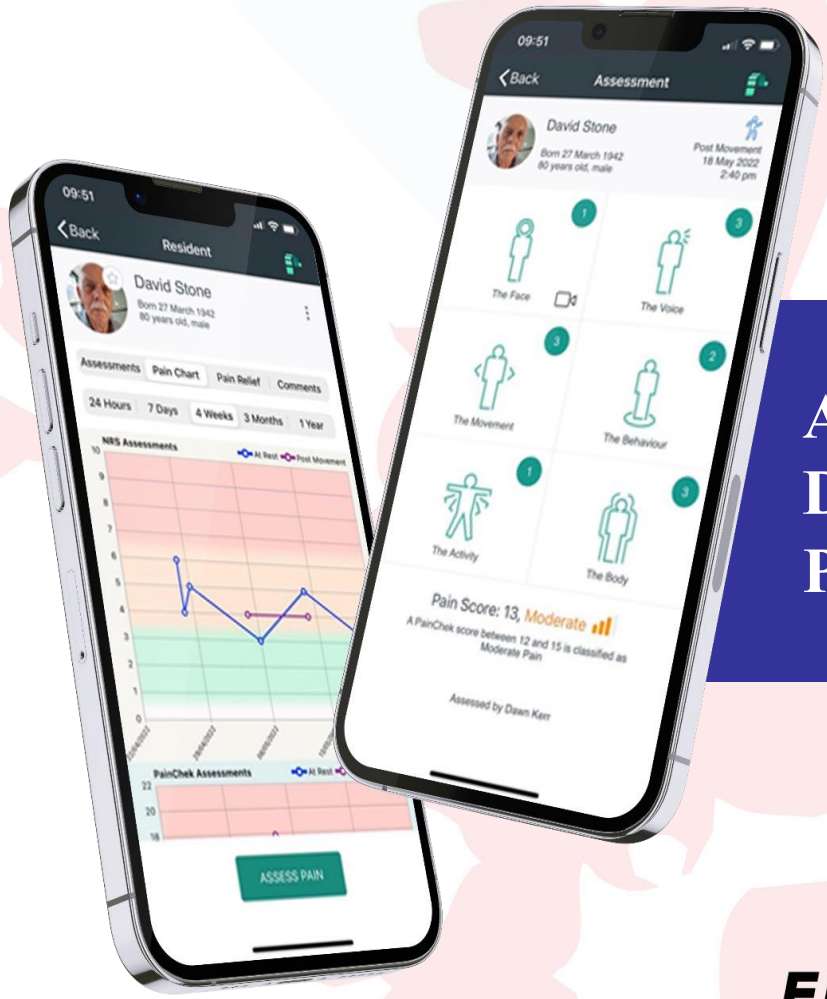
- Guides the carer in other pain assessment factors e.G. Movement, vocalization etc.
- Questions with Yes/ No decisions

Automated Pain Assessment Score:

- 42 test points
- Generates overall pain severity score
- No pain, mild, moderate or severe and pain profile of the resident

Documented Via Cloud Backend:

- Pain trend line and monitoring of treatment
- Capability to integrate into resident medical records
- Data analytics capability for audit and accreditation

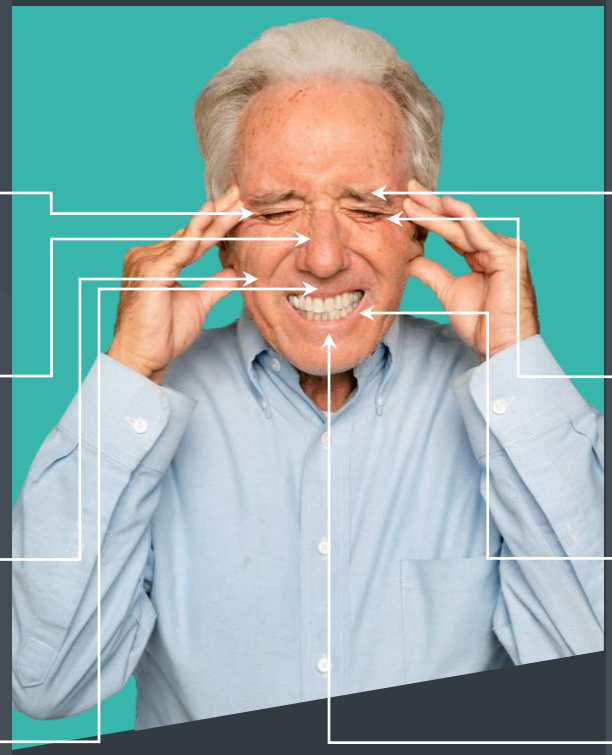


A Medical Device In Your Pocket

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PAINCHEK® ASSESSING FACIAL INDICATORS OF PAIN

PainChek's AI Analytics Is Based on Facial Action Coding System (FACS)



FACS Research Ongoing Since Original Publication In 1978 By Prof. Paul Ekman

What is FACS?

- A catalogue of facial muscle movements that are indicative of facial expressions of pain (Action Units)
- Different combinations of these expressions have been found to indicate pain
- PainChek scans the face for 3 seconds to identify and document the presence or absence of these nine expressions
- This is the first step in the the PainChek® pain assessment process

THE EVOLUTION OF PAIN ASSESSMENT

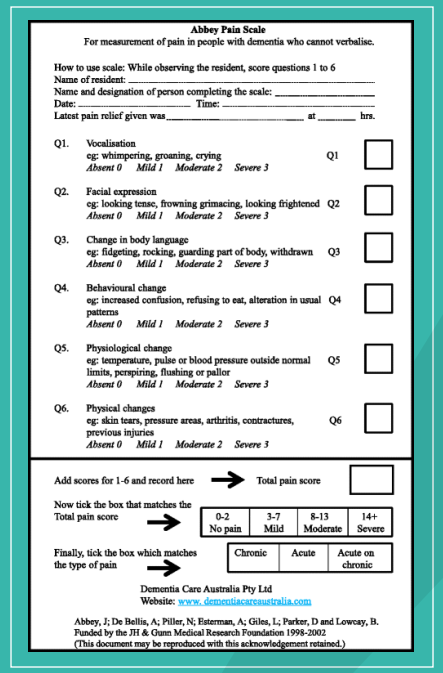
The PainChek App

Which I see as a welcome evolutionary development of my past work, was introduced to improve pain management practices by ensuring an **evidence-based** assessment of pain could be made at the **point of care,** and digitally linked to other systems.

This would make **information quickly available to prescribing physicians,** for example, as well as guiding nursing staff in dispensing PRN medication.

Dr Jennifer Abbey,
Creator of the Abbey Pain Scale

Legacy Pain Assessment Tools



Abbey Pain Scale
For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6
Name of resident: .....
Name and designation of person completing the scale: .....
Date: ..... Time: .....
Latest pain relief given was ..... at ..... hrs.

Q1. Vocalisation
eg: whimpering, groaning, crying Q1
Absent 0 Mild 1 Moderate 2 Severe 3

Q2. Facial expression
eg: looking tense, frowning grimacing, looking frightened Q2
Absent 0 Mild 1 Moderate 2 Severe 3

Q3. Change in body language
eg: fidgeting, rocking, guarding part of body, withdrawn Q3
Absent 0 Mild 1 Moderate 2 Severe 3

Q4. Behavioural change
eg: increased confusion, refusing to eat, alteration in usual patterns Q4
Absent 0 Mild 1 Moderate 2 Severe 3

Q5. Physiological change
eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor Q5
Absent 0 Mild 1 Moderate 2 Severe 3

Q6. Physical changes
eg: skin tears, pressure areas, arthritis, contractures, previous injuries Q6
Absent 0 Mild 1 Moderate 2 Severe 3

Add scores for 1-6 and record here → Total pain score

Now tick the box that matches the Total pain score →

0-2 No pain	3-7 Mild	8-13 Moderate	14+ Severe

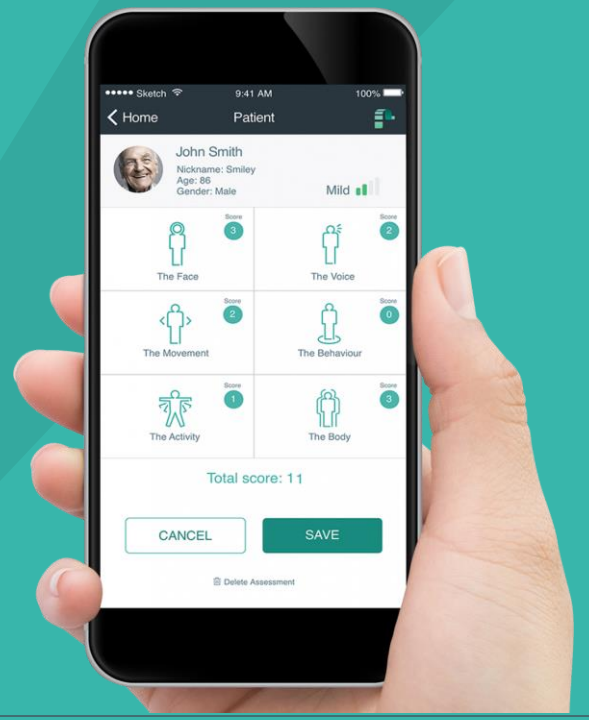
Finally, tick the box which matches the type of pain →

Chronic	Acute	Acute on chronic

Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B. Funded by the JH & Gunn Medical Research Foundation 1998-2002
(This document may be reproduced with this acknowledgement retained.)

PainChek®



Abbey Pain Scale & Similar Manual Systems Were The Standard Of Care In Developed Countries For Assessment Of Pain In People Who Cannot Verbalise. It Significantly Relies On Subjective Measures That Can Vary Greatly Between Practitioners/Carers.

1 Dr. Jennifer Abbey AM (of the Abbey Pain Scale) is on the PainChek advisory board & supports the transition from APS to PainChek

How to use Pain Chek



- Observe the person at rest or movement.
- Use smartphone/tablet to assess facial expressions.
- Complete behavioural checklists.
- Review pain score alongside clinical judgement.
- Reassess after interventions to monitor response.

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WHY PILOT PAIN CHEK IN LEARNING DISABILITY SERVICES?



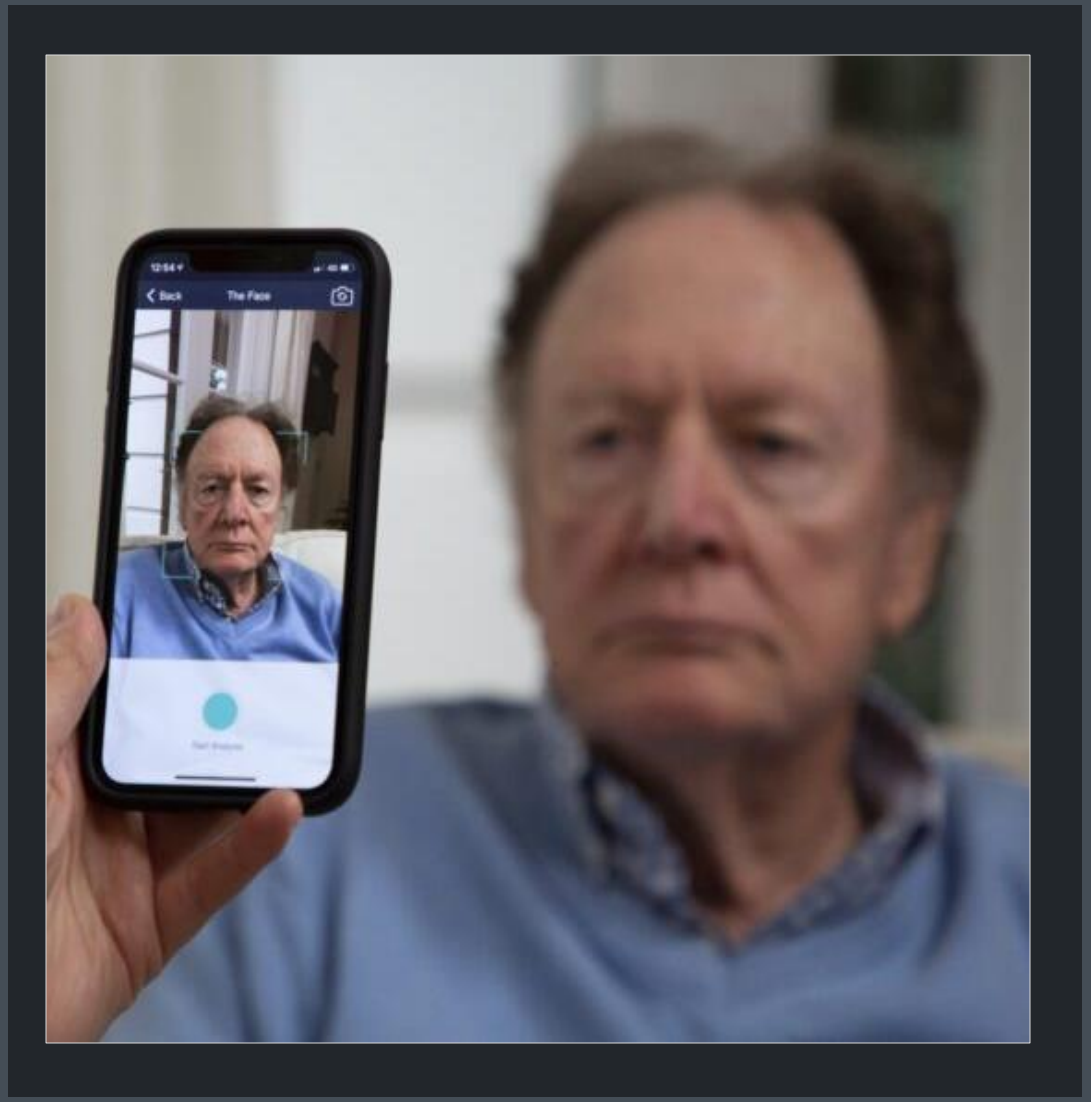
Evidence in learning Disability



- Many people experience communication difficulties.
- Pain can present through behaviour, facial expression or changes in function.
- Diagnostic overshadowing can delay recognition of health problems.
- Structured pain assessment helps identify change earlier.

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SUPPORTING EVIDENCE



PainChek in England

Orchard Care Reduces Significant Injuries with PainChek
Orchard Care Reduces Safeguarding Incidents with PainChek
Orchard Care and PainChek joint peer-reviewed research paper
UK Health and Social Committee Statement
Sunday Times Article - KYN & Loveday
Oakland Care - BBC Article on PainChek
Bedford Luton Milton Keynes ICB Video - Methodist Homes
Dovehaven Care Homes - Safeguarding and Benzodiazepines
B&M Care Homes - Falls & Placement Breakdowns
We Care Group - Caring Times PR
Agecare - Improving Diagnosis of Pain
Harbour Healthcare - PCS/PainChek Case Study
CQC Regulator Case Study

PainChek in Scotland

PainChek appeared on Scottish TV News
Renaissance Care - Innovation in Care
Elder Homes Case Study
Elder Homes PR - Caring Times
Cluny Lodge Inspection Report
Scottish regulator supports PainChek
Care Inspectorate - Best Practice Case Study
Abbey Healthcare - Website PR

PainChek in Wales

Shaw Healthcare - Website PR
Life Sciences Hub Wales - Website PR
PainChek Gwent Project Video - Showcasing outcomes

Enfield Pilot project with Supported Living



- **Aims of the project**
  - To implement Pain chek into a supported living provider with a minimum of 30 clients
  - To increase the number of proactive pain assessments and establish baseline assessments
  - To reduce the number of hospital attendances relating to unmet needs
  - To reduce the use of prescription pain medication
  - To improve staff recognition of signs and symptoms of pain
  - Improve communication between services and systems
  - Increase confidence in caring ability with families

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Why Pain Chek ?

- Improve pain recognition for people with communication difficulties.
- Strengthen person-centred care and health outcomes.
- Support consistent practice across teams.
- Provide structured evidence during MDT, GP and specialist discussions.
- Generate local data to evaluate impact and inform future decisions.

- Pain Chek had been trialled locally in older people's services
- Pain Chek were very supportive of exploring the Learning Disability client g



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Progress



- Identified agreed cohort of 31 service users
- Consent and capacity assessments
- Staff training
- Awareness session for families
- Regular meetings with Pain Chek
- Identifying super users

Progress

- 31 service users assessed over ~9.5 months.
- 3,560 assessments completed by 91 assessors.
- Assessments used routinely, not only during pain events.
- Repeated assessments helped build individual pain profiles



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Outcomes

88.4% of assessments recorded no pain, helping establish baseline patterns.

413 assessments identified mild, moderate or severe pain.

83% PainChek assessments and 40% completed post movement.

Changes from baseline often provided the most useful clinical information.

Case study 1

- Female client
- Regular use of prescription pain medication with no clear pattern
- Able to self vocalise pain and request pain medication
- Gave consent to join the pilot project
- One month into the project prescription reduction in the use of prescription pain medication
- Pain management care plan updated
- Improved relationship with staff team

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Case study 2

- Male client
- Non verbal communication care plan in place
- Displaying signs and vocalisations of pain
- Changes in presentation, withdrawn, refusing to engage in activities
- Regular pain check assessments alongside carer assessments
- Knee pain identified and client supported GP review and treatment.
- Constipation-related discomfort identified and monitored.
- Breakthrough pain recognised despite regular analgesia.
- PainChek complemented verbal self-report in abdominal discomfort episode.

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Findings



PainChek supported the team to recognise the early signs of change in the client .



Aided documentation and evidence for escalation and treatment decisions.



Supported review of what works for the client, paracetamol does not suit everyone.



Did not replace professional judgement, observations or clinical as

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Next Steps

- Regular training
- Feedback sessions
- Improvements to the App specifically for use with people with a learning disability
- Explore the interface with Whzan and other digital tools that improve communication with primary and secondary care
- Expand to other providers

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Contact details

- Sarah Pope, Clinical Lead, Enfield Integrated learning disatbility service

T: 0208 379 5039

E: sarah.pope5@nhs.net or sarah.pope@enfield.gov.uk

- Yasin Syed, Pain Chek, Account Manager

M: +44 (0)7539 255 874

E: yasin.syed@painchek.com

https://www.painchek.com/

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