

Accessibility of Annual Health Checks for Young People (14-17-year-olds) with learning disabilities in Surrey Heartlands

A qualitative research

March 2024

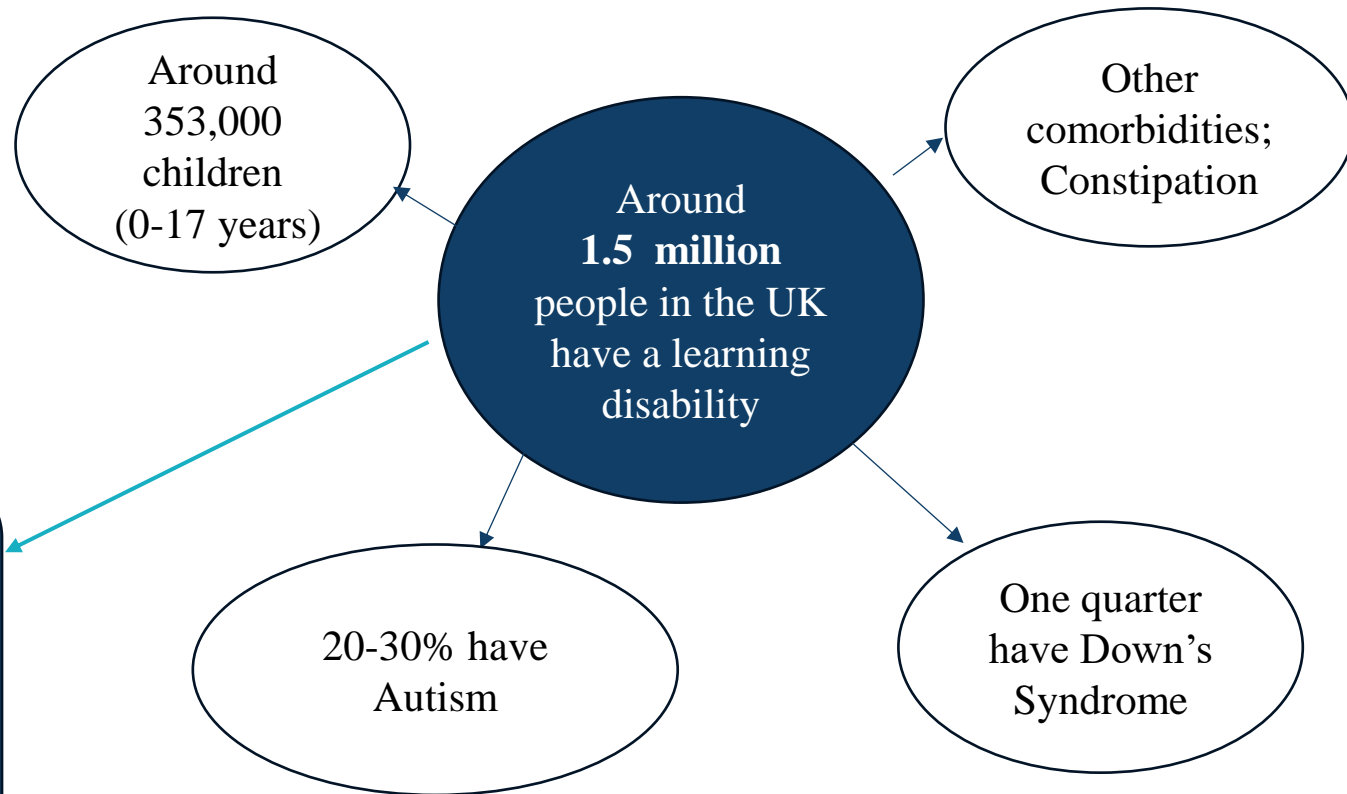
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Learning disability

- A lifelong condition
- Affects learning and social skills
- Mild, moderate, severe and Profound

Surrey

- 21,800 adults with LD
- **7,000 children and young people with special education needs**



i) Shorter life expectancy

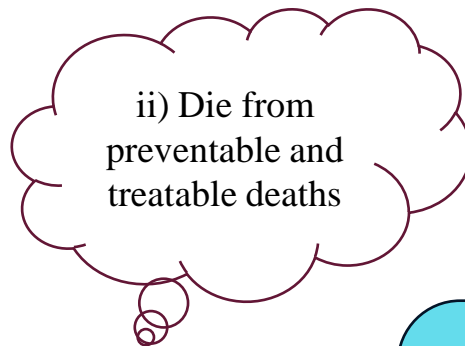
- ❖ **Four times** likely to die than the general population.
- ❖ LD from the marginalised communities are **six times** more likely to die than their counterparts.

On average, people with LD die over **20 years** younger than the general population.

In Surrey:

- ❖ Women with LD live 22 years fewer than their counterparts without LD
- ❖ Men with LD live 11 years fewer

(Surrey Heartlands LeDeR, 2021)



- ❖ Respiratory
- ❖ Circulatory
- ❖ Cancer



iii) Access to health and care services

In Surrey, a proportion is known to Health & Social Services

Healthcare outcome measures in 2021/22 for Young People with LD in Surrey

Health outcome measures in 2021/22

Obesity

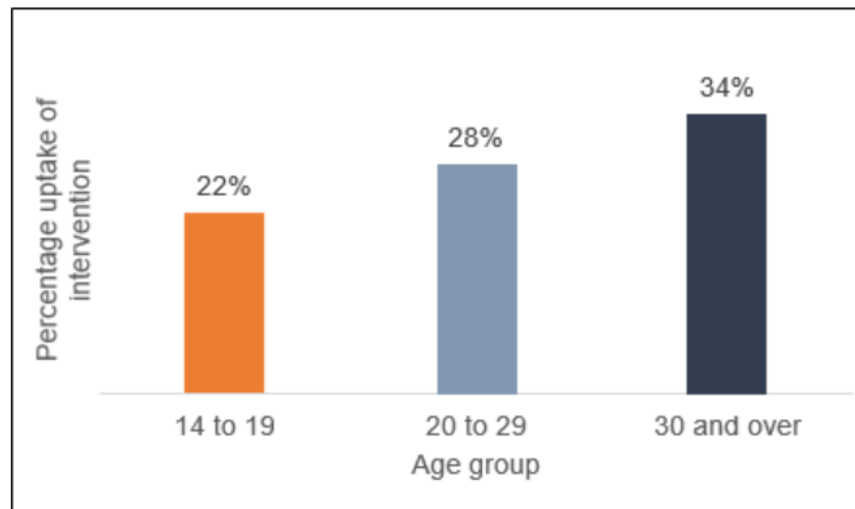
Significant high increase of BMI \geq 25:

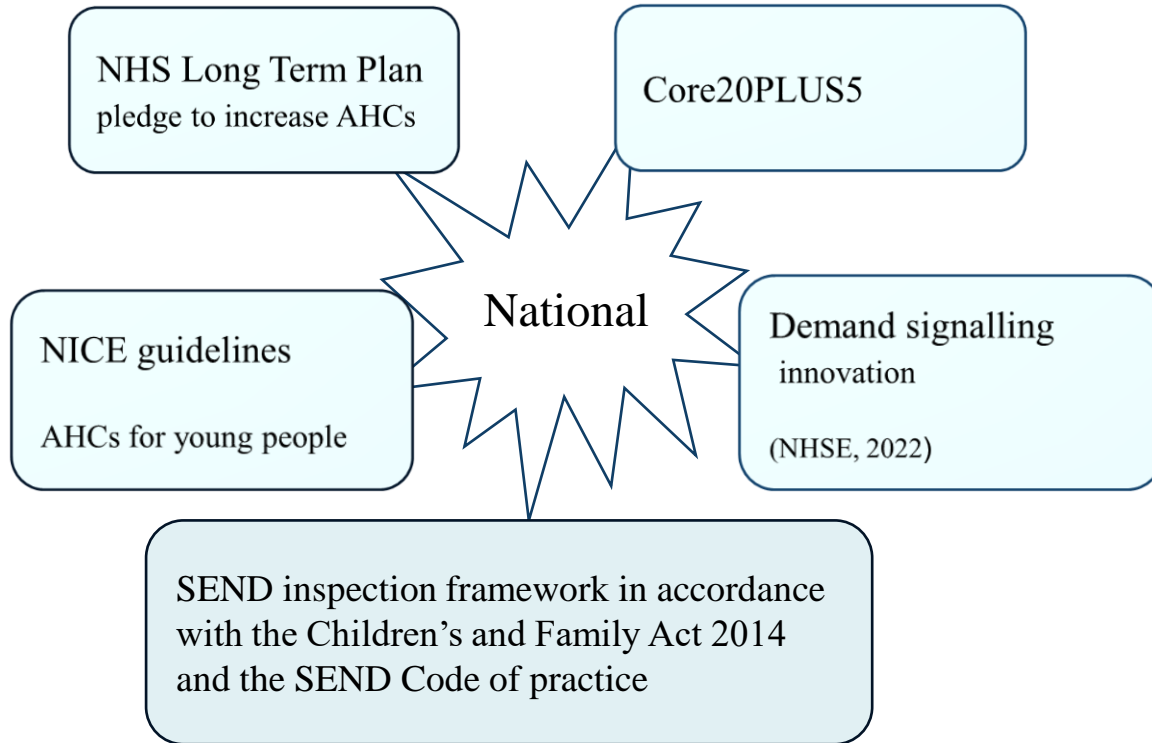
- ❖ 14-19 age group - 32%
- ❖ 20-29 age group – 51

- High risk – Women

* Highest **health outcome** across four ‘places’ in Surrey Heartlands

Intervention: Assessment of nutritional status, diet, and level of activity in Surrey by age group, 2021/22





Local policies

- Surrey's Health and Wellbeing Strategy
- Surrey Heartlands ICS
- Surrey Heartlands LeDer Review
- All Age Autism Strategy

What is an Annual Health Check (AHC)

AHCs was introduced in England for people with learning disabilities i.e.,

- ❖ 2008 - Adults 18+ with LD
- ❖ 2014 - Young people (14-17-year-olds) support transition
- ❖ A free 'top to toe' health check performed **ANNUALLY** by a GP and/nurse
- ❖ Lasts between 45-60 minutes

GP practices maintain a learning disability register for people with LD.



Who is eligible?

'anyone' with a learning disability aged 14+ is eligible for an AHC



Health Action Plans :

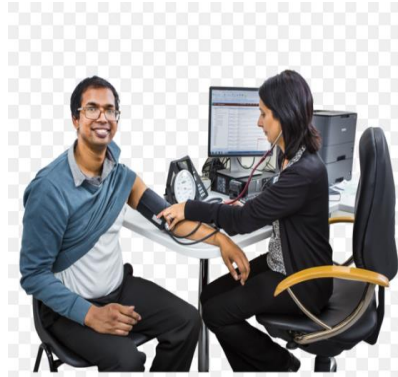
- ❖ Produced after AHCs
- ❖ Supports EHCPs during reviews for 14-17-year-olds



Evidence-base on the effectiveness of Annual Health Check

Prevention and health improvement

- ❖ Early detection of health conditions
- ❖ Increasing screening uptake for sexual health, cancer
- ❖ Treatment – medication review
- ❖ Onward referrals e.g., to lifestyle weight management, mental health
- ❖ Relationship building with GPs



Health outcomes achieved:

- ❖ Identification of previously undetected illnesses
- ❖ Less hospital admissions
- ❖ Increased secondary referrals
- ❖ 26,954 people with LD reported reduced mortality for Down's syndrome and autistic people linked to AHCs (Kennedy et al., 2022).

Why Annual Health Checks for 14-17-year-olds in Surrey Heartlands

April 2022 – Sept 2023

14-17-year-olds with LD in Surrey Heartlands

- 65% had AHC compared to 82% of adults with LD
- 271 young people – on the Learning Disability Register**
- 30 – Annual Health Checks delivered
- 16 – Health Action Plans completed



- 14-17-year-olds are RELUCTANT to take AHCs**



Aim

To identify barriers and enablers from a Multi stakeholders' perspectives on how to make AHCs more relevant and accessible to young people (14-17 years old) with learning disabilities in Surrey Heartlands

Objectives



1. To understand the barriers to AHCs for 14-17 years old with learning disabilities from professionals and parents/carers for young peoples' perspectives.
2. To identify enablers/ facilitators and understand what is currently working well.
1. To understand what can be done to improve the uptake

Qualitative research (1:1 interviews and Focus groups)

Researchers	Participants	Research method	Recruitment	Challenges
a) Lighthouse research consultancy	<ul style="list-style-type: none"> Parents/carers of young people (14-17-years-old) with LD 	<ul style="list-style-type: none"> 1:1 interviews Own home 	<ul style="list-style-type: none"> Advertised widely: 3rd sectors, schools, internal and external. 	<ul style="list-style-type: none"> Challenges recruiting participants on the LD register. <p>*Only 3 were on the LD register</p>
b) Public Health Lead	<ul style="list-style-type: none"> SEND/Education, Health and Social Care professionals 	<ul style="list-style-type: none"> Focus groups Virtual via Teams 	<ul style="list-style-type: none"> Internal networks <ul style="list-style-type: none"> ➢ Emails ➢ Meetings ➢ Word of mouth 	<ul style="list-style-type: none"> No challenges encountered

Discussion guide / Objectives:

- Awareness and knowledge of AHCs (beliefs and misconceptions)
- Barriers, motivations and triggers towards AHCs
- AHCs delivery
- Enablers and improvements to increase the uptake

- Stimulus used to educate parents with no prior knowledge of annual health checks (nine parents) about what they were, to allow for their hypothetical views on barriers and motivations.

Phase 1: Sample profile: demographics parents/carers of 14-17-years-olds

Demographic 14-17-years-olds

Learning disability - severity*	No		Age of YP	NO
Mild	5		14	2
Moderate	3		15	4
Severe	4		16	4
			17	2

Gender	No		Provision	No
Male	7		Mainstream	2
Female	4		Specialist	10
Non-binary	1			

Total number of participants (parents/carers) = 12

Annual Health Check status

YP on the LD Register	No
Yes	6
Don't know/ No	6
Annual Health Check Status	No
Parent and YP attended AHCs in the last 2 years	3
Parents/YP not heard of AHC's and not attended practices	9
Parent and YP invited for an AHC but did not attend (due to cancellation by GP)	1

* None of the participants were from the marginalised population

Key barriers to low uptake of annual health checks from parents/carers

Negative experience for
parents

Unable to see the benefit

HCP's / schools not
talking about AHCs so
low priority

Lack of information/
promotion /
experience suggesting
that not important

Unawareness
e.g, 9 out of 12 parents
unaware of AHCs



NHS Surrey Heartlands			Surrey County Council		
No.	Profession	Provision	No.	Profession	Provision
2	SEND Designated Clinical Officers		2	SEND Managers	
2	Learning Disabilities Nurses		2	Children Social Workers	
4	GPs		1	Family Support Worker	
4	Special School Nurses	Special schools	1	SENCo	Mainstream school
			1	SENCo	Special School

- ❖ Total number of professionals – 19
- ❖ Places : East Surrey, Surrey Downs, Northwest Surrey, Guildford and Waverley

Unawareness

- Thought to be 18+
- Confusion with NHS Health Checks
- Importance/ impact on young people
- Eligibility / initiation

Identification / diagnosis

- Gap in diagnosis - Suspected LD cases in services.
- GPs and LD diagnosis
- Inaccurate registers
- Agencies not communicating
- **Complex needs prioritised:**

Specialist services
 ➤ Special schools
 ➤ Have EHCPs
 ➤ Social Services
 ➤ Community LD nurses

• Prioritisation

- Pressures in primary care – other issues prioritised
- Non- essential
- Delivered in the last quarter, not on YP's birthday
- Multiple services - older adults prioritised
- Not in practice areas/ schools/ out of county
- Realistic for GPs in care homes versus schools

Communication / recording

- YP unresponsive to invitations
- Complex referrals from services
- Different recording systems by services
- Arden system not user friendly for Health Action Plans
- Inaccessible information to promote AHCs
- Lack of central conduct for YP

YP's parents/carers needs

- Exhausted parents
- Family composition: Have 2/3/4 children. 4 out of 12 parents had another child with a disability
- Single parenthood, low income
- Reliance on parents - YP do not have the loudest voice

Enablers/ what is working well / strengths from both research

AHCs training offered
to the GPs

Reasonable adjustments
in place

Any Health Care
Professional can deliver
AHCs

Relationship built with
parents

Information on
Local Offer and Healthy
Surrey websites

- Routine** - appts every year / setting a ritual (same time of year)
- Flexibility**
- Waiting area, waiting time
- Preparation** prior appointment; social stories
- Invitation with information stating purpose
- Can part of the appt be done online/ at weekends/ at school

Targeted Communication strategy

For 14-17-Year-Olds

- ❖ Clarity on importance of AHCs
- ❖ Raise awareness of AHCs and Health improvement:
 - School's bulletins, SEND Networks
 - NHS links and SCC websites
 - Parental forums, 3RD sector, Leaflets
 - Webinars, events, Social stories



Young people seen by other services

- ❖ AHCs to be incorporated in health checks/ annual reviews

Improvement on LD diagnosis

Clear guidelines on eligibility

Understanding of professional roles & Communication

- ❖ E.g., GPs, Education
Psychologist, paediatricians. .

Personalisation

- ❖ Embed AHCs to EHCPs
- ❖ Embed AHCs to Children Social Care Systems for assessments and reviews.

Health Action Plans

- ❖ Simple standardised HAP across Surrey Heartlands

Oliver McGowan training

Integrated teams

- ❖ A tiered approach - one system:
A document or digital – Medii App

Improve access and support positive transition. Consideration for:

- ❖ Pilot Special School nurses to deliver AHCs in Special Schools.
- ❖ Nurse consultant
- ❖ Health Facilitation Team
- ❖ LD Liaison Nurses for 14-17-year-olds

Quality Assurance

- ❖ Feedback from parents/ YP