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NHS North West Learning Disability and Autism Operational Delivery Network

Development of the Physical Health Workstream

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Helping people to be
the best they can be

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What are we trying to address?

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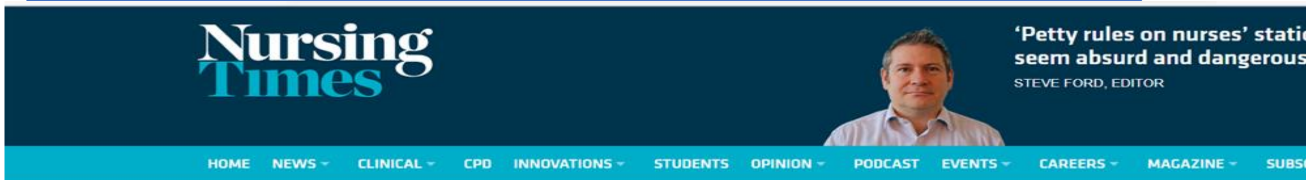
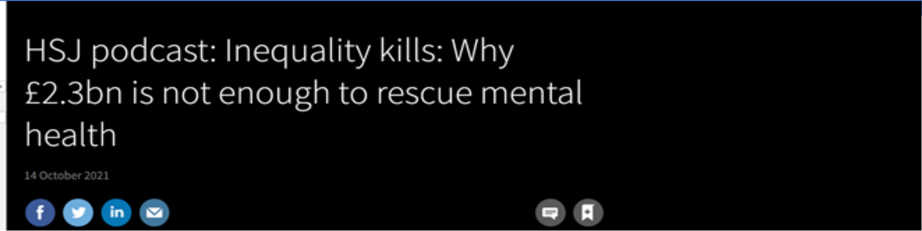
People with intellectual disability (ID) die much younger than the general population



LEARNING DISABILITY

'Shocking' rates of avoidable death among people with learning disabilities

Higher level of morbidity than the general population



Preventing avoidable deaths of people with a learning disability: Is LeDeR enough?

December 6, 2018

Health inequalities

SEARCH enter keywords...

NEWSLETTER enter email address SIGN ME UP

Latest LeDeR report highlights 'persistent' and 'shocking' inequalities

SAVE & READ LATER

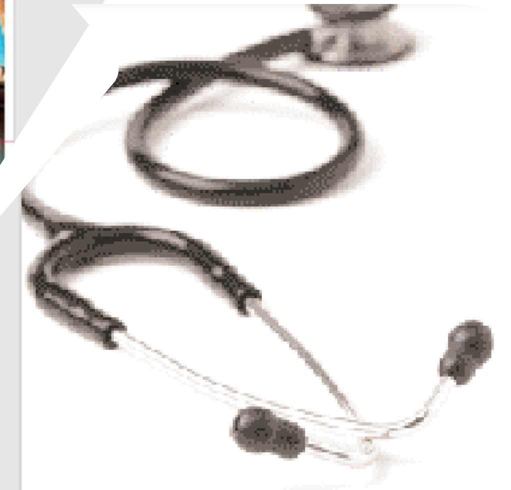
Lauren Nicolle

News, 15 July 2022

NHS
England

Health Inequalities - background

- Treat me Right: Better healthcare for people with a learning disability 2004
- Death By Indifference 2007
- Death By Indifference 74 deaths and counting 2012



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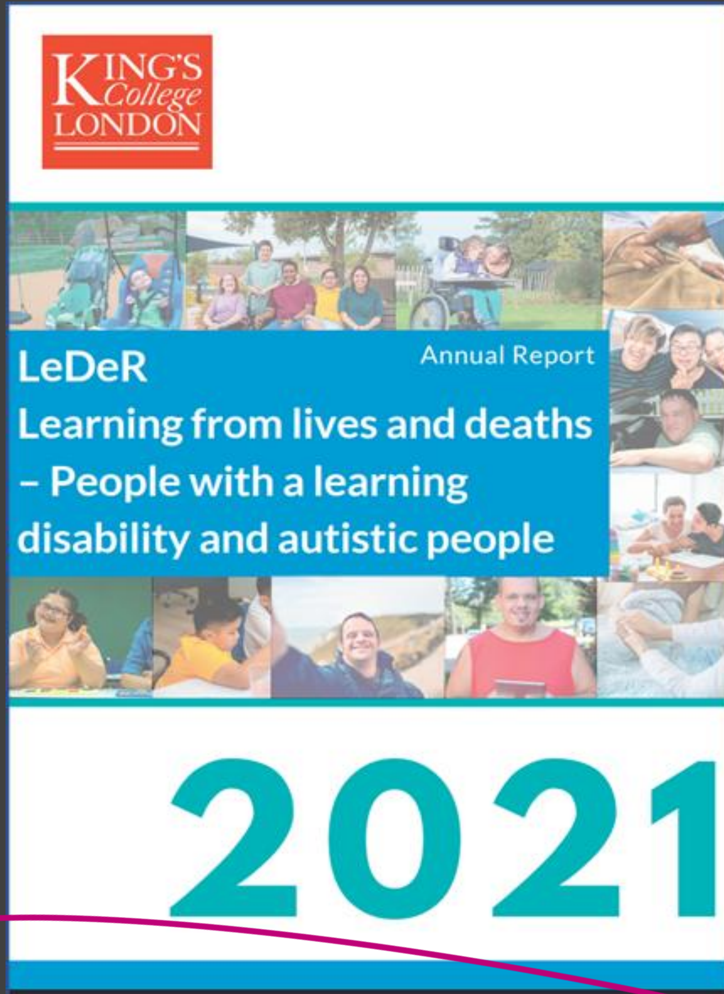

Most common causes of death

- COVID-19
- Diseases of the Circulatory System
- Diseases of the Respiratory System
- Cancers
- Diseases of the Nervous System

Frequently reported long term health conditions for people who died in 2021

- Epilepsy (33%, n=364)
- Cardiovascular conditions (33%, n=357)
- Mental health conditions (32%, n=355)
- Sensory impairment (25%, n=269)
- Dysphagia (23%, n=250)

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Key findings

6 out of 10 people with an ID died before the age of 65

On average, males with a learning disability die 22 years younger than males from the general population, and females 26 years younger than females form the general population.

In 2021, the average number of long-term health conditions per person was 2.45 (standard deviation = 1.56).

49% of people with an ID who died were avoidable compared to only 22% in general population

People of Black, Black British, Caribbean or African, mixed ethnic group and Asian or Asian British ethnicity died at a younger age in comparison to those of white ethnicity

LeDeR – findings from NW rapid review project

NHS England

Learning from LeDeR Rapid Reviews (March-April20)

Carrying out a review of 126 rapid reviews for deaths which took place in March and April 2020.

LeDeR	Testing	Diagnosis	PPE
Lack of specific guidance for pandemic	Lack of testing in early stages Lack of access to testing Validity of testing	Diagnostic overshadowing Not all other diagnosis explored whether COVID or not	Lack of PPE for care homes/supported living Conflicting guidance around correct use of PPE

Health monitoring	Communications	Specialist Support
Lack of access to equipment & training by care staff to carry out the more than routine observation (signs and symptoms of hypoxia)	Inconsistent use of hospital passports People with severe learning disability particularly impacted in terms of communication needs and new environments.	Some patients receive one to one support in the community and contractual arrangements did not allow staff to follow the person
Cause of death / death certification	**Public Health**	**DNACPR**
Some death certificates had Down's Syndrome identified as the cause of death.	High volume of people with a learning disability have co-morbidities including underlying conditions such as obesity, high cholesterol and diabetes.	High use of DNACPR. Decision to put a DNACPR in place did not always include the family/carers

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Alan's story - part 1

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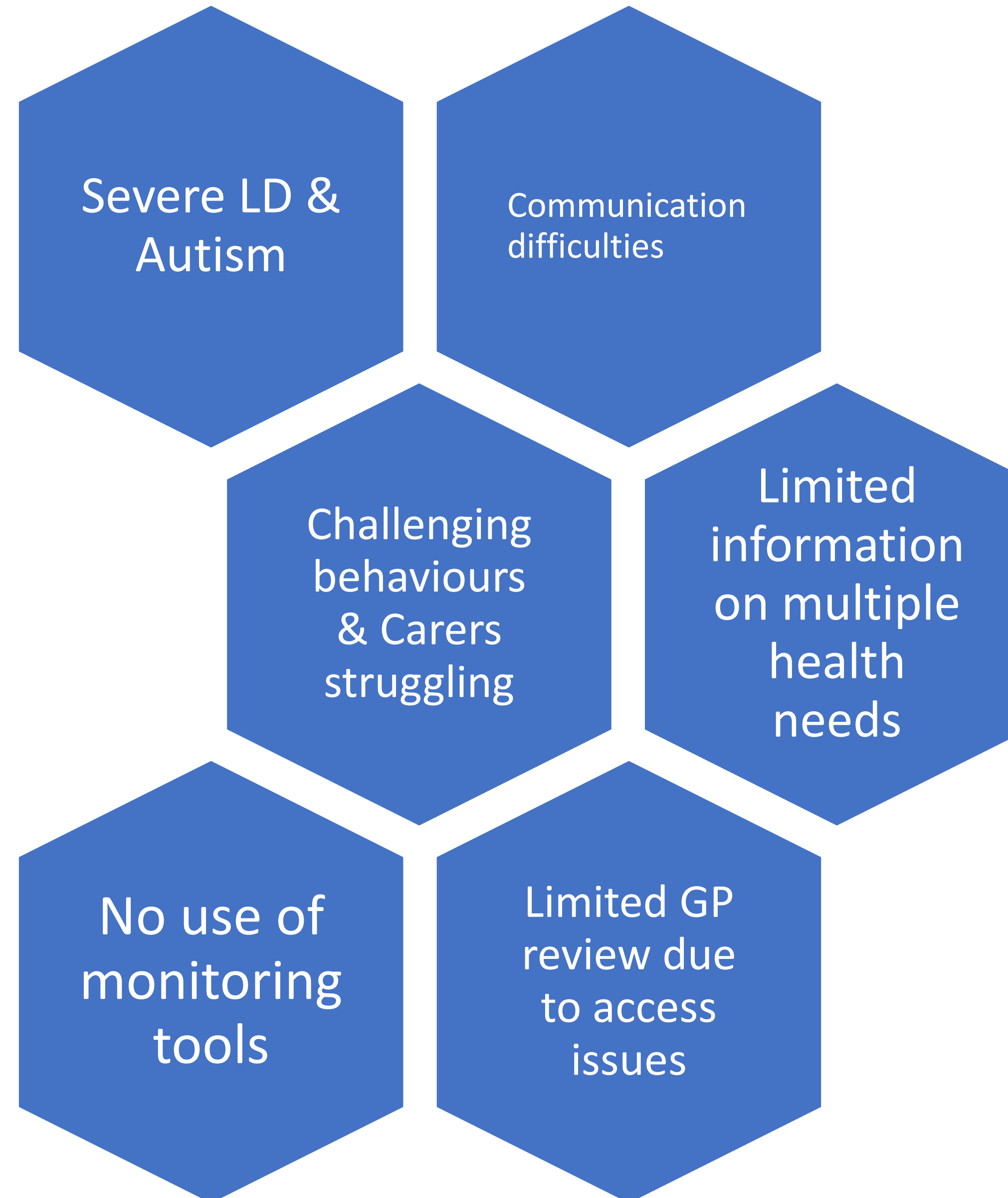
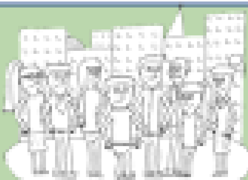


Learning Disability and Autism Programme

Improving quality of care for people in hospital settings

Reducing the number of people in hospital



Improving provision of community services

Improving outcomes for children & young people

Improving health outcomes and access to health care

Improving outcomes for autistic people

Building a capable workforce

NHS England and NHS Improvement

Developing the 3 year strategy – National priorities 20/21

- Respiratory conditions
- Seasonal flu vaccination
- Cardiac care
- Identifying deterioration/sepsis
- Diabetes
- Constipation
- Cancer
- Epilepsy

Management of medical conditions

- DNACPR – Do Not Attempt Cardio Pulmonary Resuscitation
- End of life care
- Reasonable adjustments (RA)
- Annual Health Checks (AHCs)
- STOMP-STAMP (medication)*
- Inequalities for people from minority ethnic communities

Changing how we work

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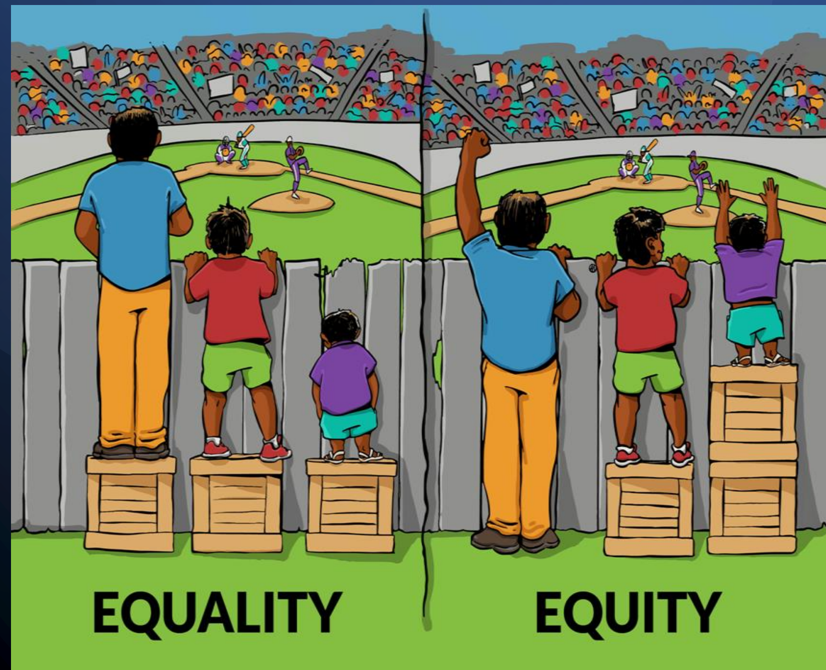
Population Health Management and equity of outcomes



Population health

The health outcomes of a group of individuals, including the distribution of such outcomes within the group.

Population health management

The approach used to achieve measurable improvements in the health outcomes of a population.

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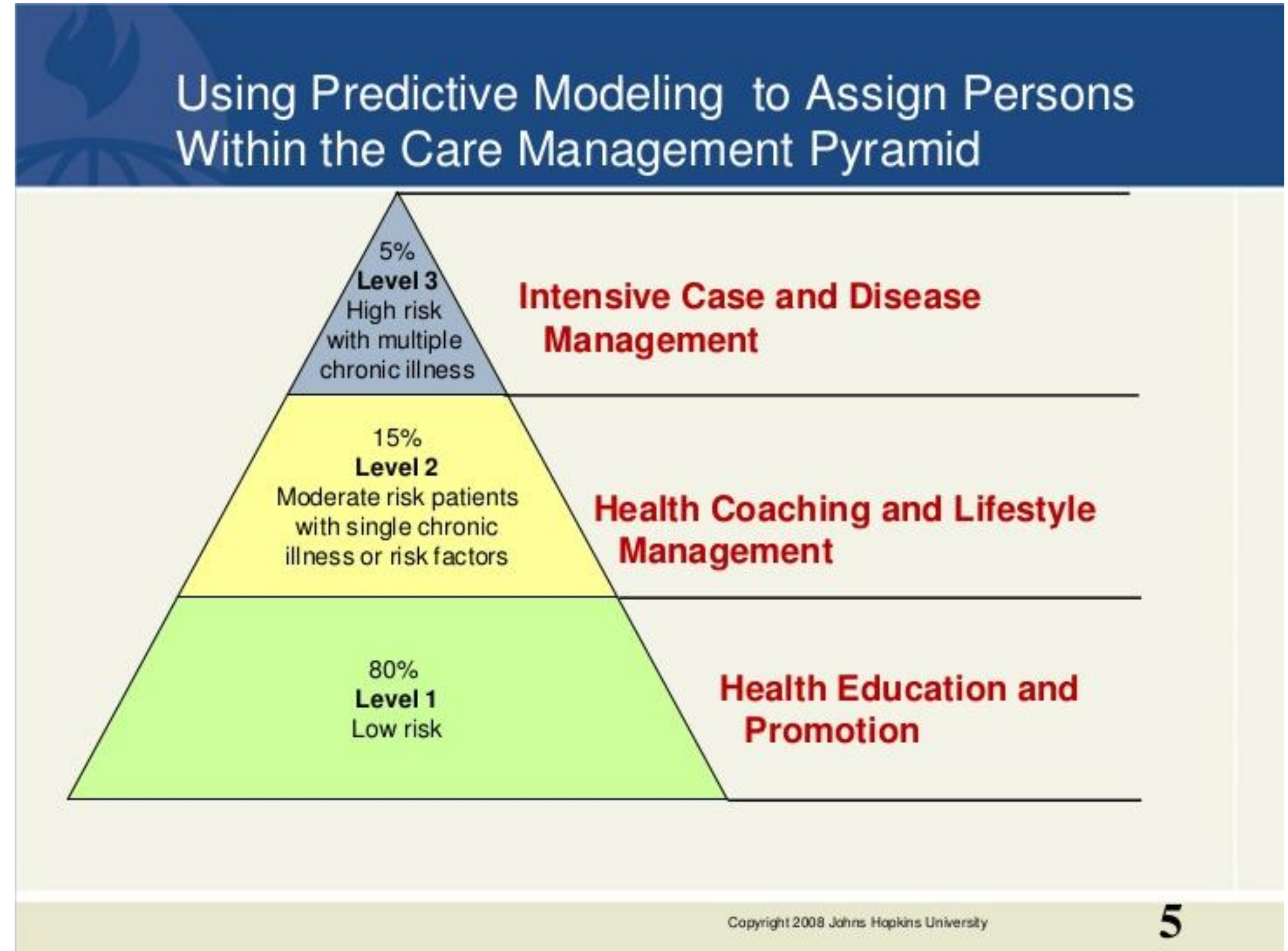
Needs Stratification

- Cornerstone of population health management
- It improves quality and experience without costing more or even by reducing costs
- However, it needs good predictive accuracy and approach to consider false negatives.



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Population Health Management Approach

Aggregation of patient information data across various services

Analysis of the data into single actionable record and actions

Improve both clinical and financial outcomes

Seeking to improve health outcomes of a group by monitoring and identifying individual patients in that group

Population Health Management

NHS
Cheshire and Wirral Partnership
NHS Foundation Trust

Macro-level: Population level data with strategies that work across the range of services e.g. vaccination programmes

Maso-level: Different strategies for different populations eg. population segmentation or risk stratification e.g. shielding etc

Micro-level: Intensive case management; disease management

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Proposed aims of the workstream

Short and medium terms aims:

- Understand the range of activities around physical health in NW
- Agree a regional stratification process
- Agree a SoP to address needs
- Agree quality standards – quality of care plan
- Implement the above across the NW region

Longer term aims

- Develop and pilot a model of intensive input for very high risk individuals (e.g: physical health intensive support services)
- Trial physical health care and treatment reviews
- Develop specialist roles within primary, secondary and tertiary care

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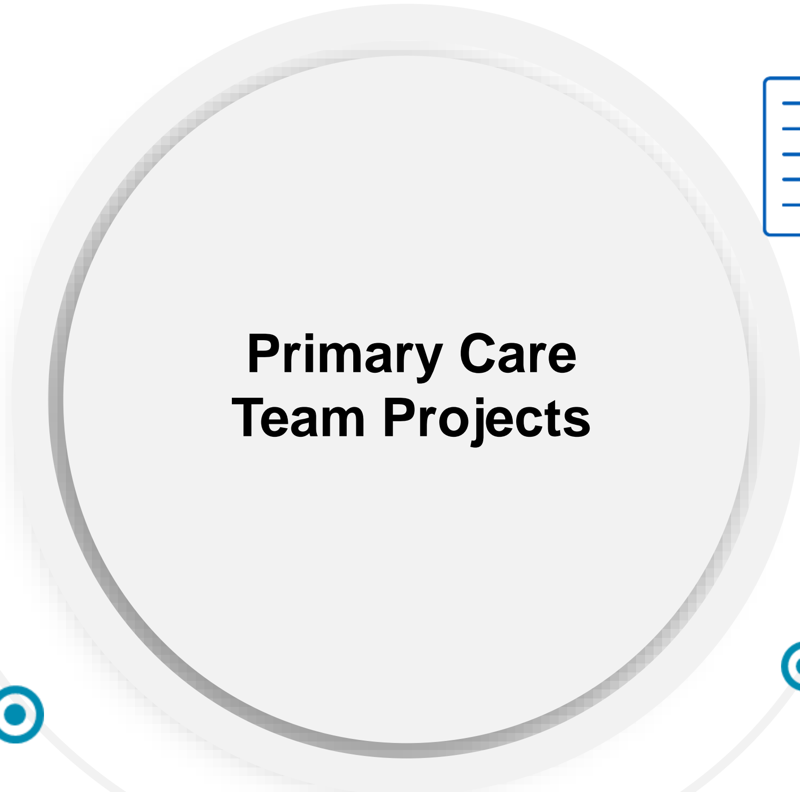
Potential evaluation of outcomes

Short and medium terms outcome evaluation:

- Reduction in admission
- Reduction in A&E attendance
- Quality standards – quality of care plan
- Appropriate use of MCA
- Appropriate use of DNACPR
- Service user and carer experience
- Experience of health staff

Longer term outcome evaluation: in addition to above

- Reduction in premature mortality and preventable deaths



Primary care review
Programme of work over the next 12 months to review the whole pathway around the AHC in primary care, including improvement of the Learning disability register

Immunisation and vaccination
Working with the vaccine team to review uptake of the vaccine by people with a learning disability, campaigns, easy read documentation and local/regional work to improve access to and uptake of

LeDeR
Supporting the LeDeR team by providing information and evidence which supports the development of the LeDeR Annual Report

DNA CPR
Working with the palliative care team to review the situation experienced by people with a learning disability in respect of DNACPR

Children and Young people – Annual Health checks
Working with CYP team to join up EHCP and AHC - using EHCP to inform a discussion around AHC for 14-17 year olds. Work with CYP team on SEND agenda as well

Autism specific AHC
Working with the Autism team to support the development of the Autism specific health check
Working with NAS to capture information relating to Autism specific health check from communities

HEE – AHC Primary care training platform
Develop a primary care platform where all training around AHC will be captured for all primary care roles

ARRS- workforce – AHC/HAP
Looking to develop training and support for ARRS roles and their inclusion in AHC work, support people to attend, delivery of aspects, support of community inclusivity to deliver HAP

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Potential regional stratification process

Take a population health management approach to identify people with intellectual disability who are at an increased risk of premature mortality/preventable death

Development and evaluation of a tool looking at relative risk rather than absolute risk, dependent on combination of dynamic and static factors

Dynamic Support Tool for Physical health (DST-PH) - refer to www.canddid.nhs.uk/DST-PH

Project funded by NHSE/I

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Who could use the Decision support tool?

Any health professional working with people with LD should be able to complete the tool.

It can be used in primary care as well as secondary care

It is based on individual’s current presentation

The ratings change according to changes in underlying conditions or the person’s circumstances

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What does this allow us to do?

It is quick to use – either in primary care or in CLDT

It takes into account a range of potential risk factors

Objectively identifies level of risks

Will allow focussed interventions at individual and system level

Facilitate development of innovative solutions

Inform commissioning intentions

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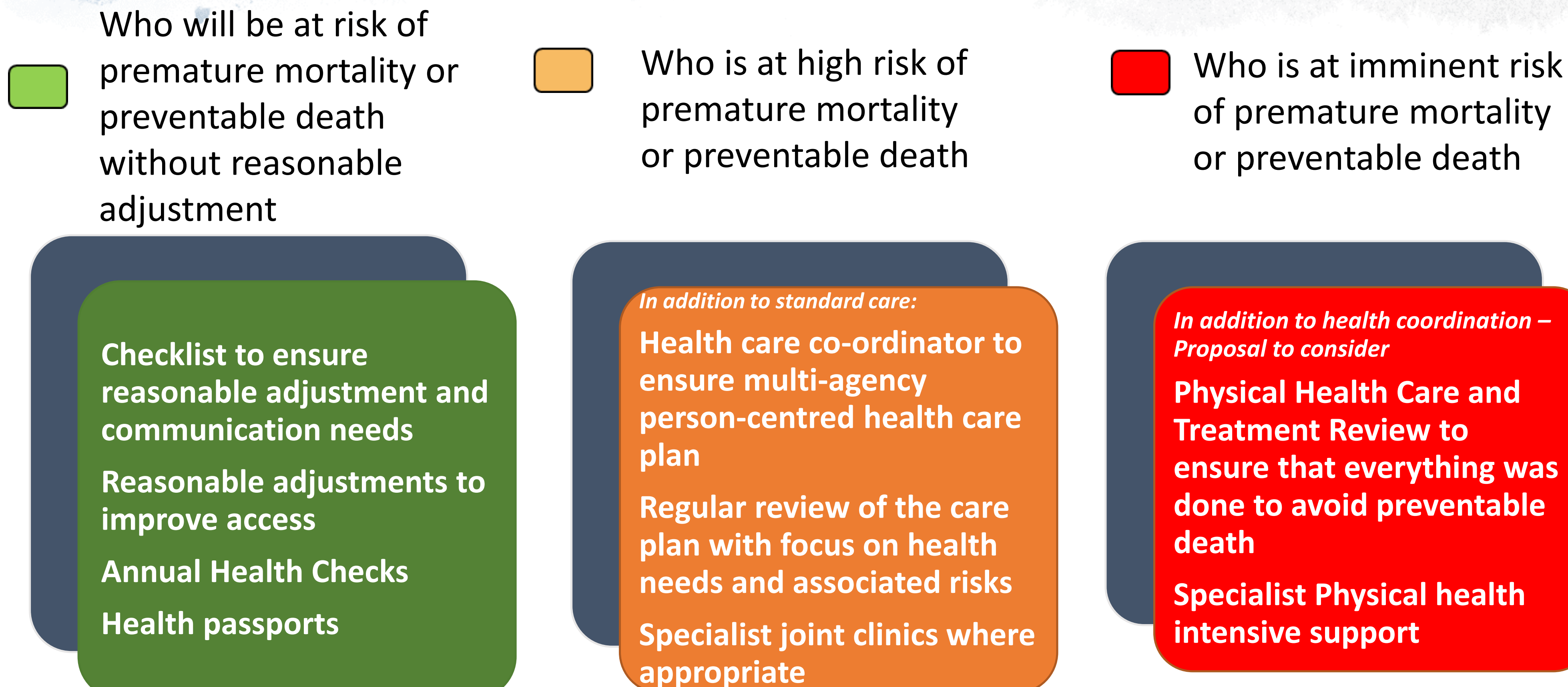
Management strategies based on needs stratifcation



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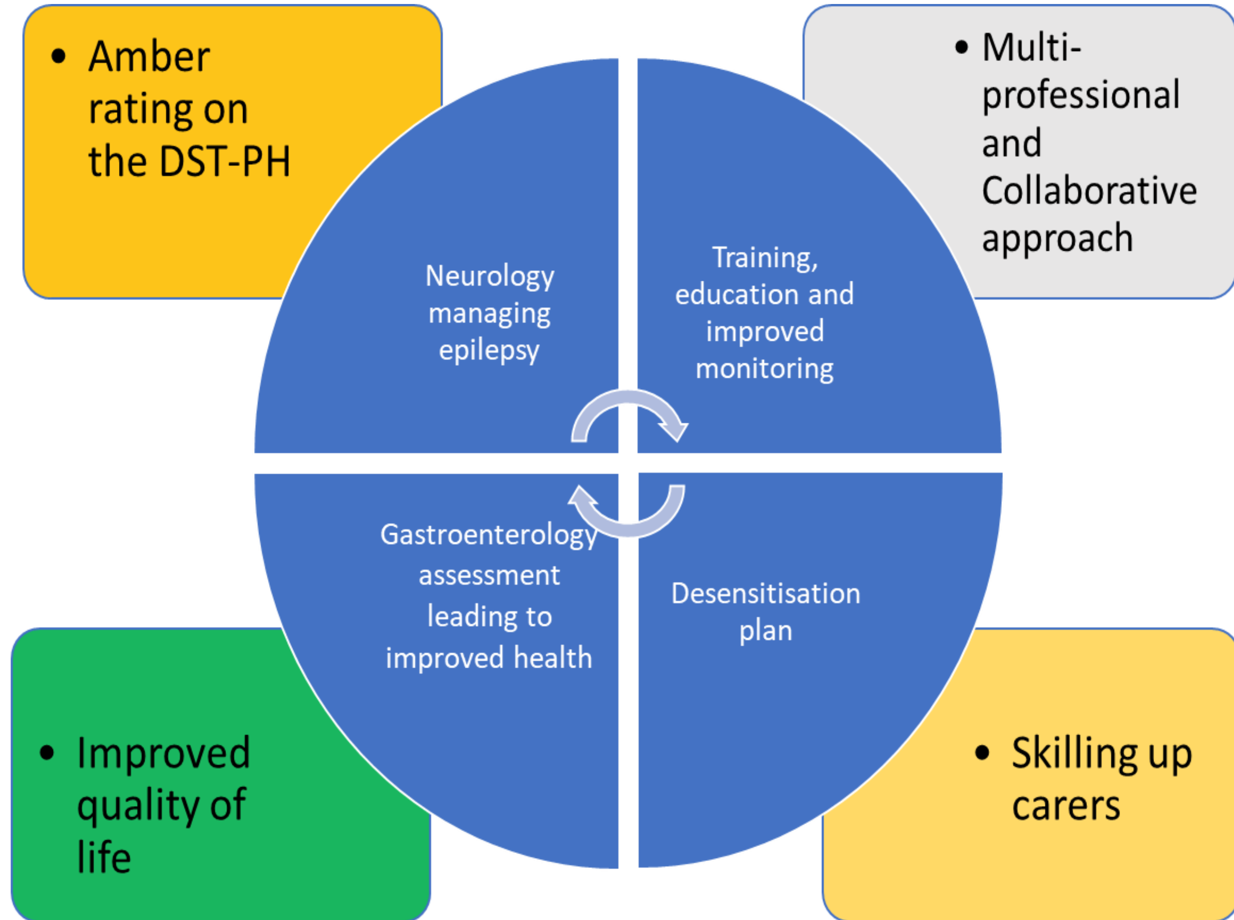
Alan's story - part 2



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