

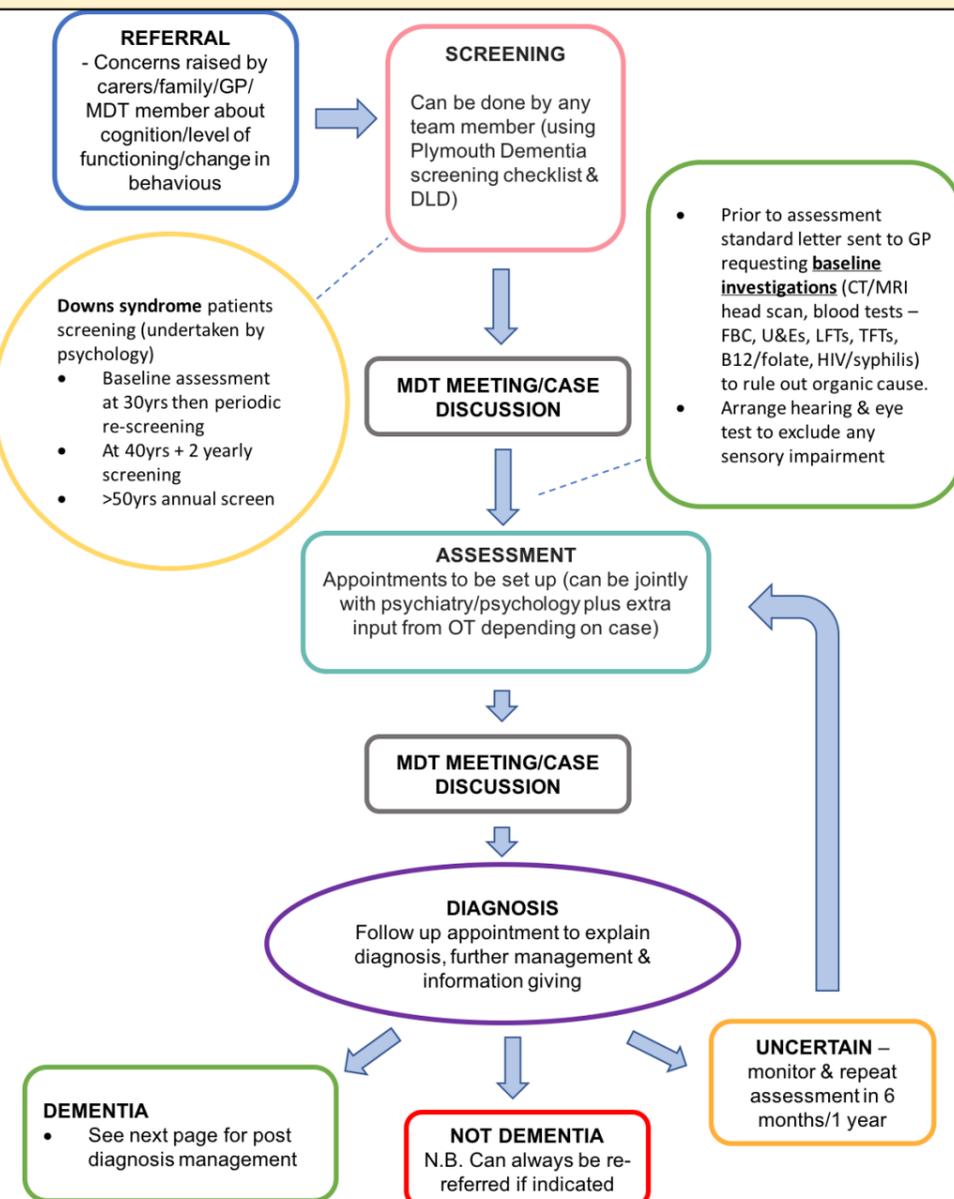
Development of a dementia diagnostic & management pathway within the Hackney Intellectual Disability Service

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Aims:
To develop a dementia diagnostic & management pathway for those with intellectual disability within the Hackney Intellectual Disability Service

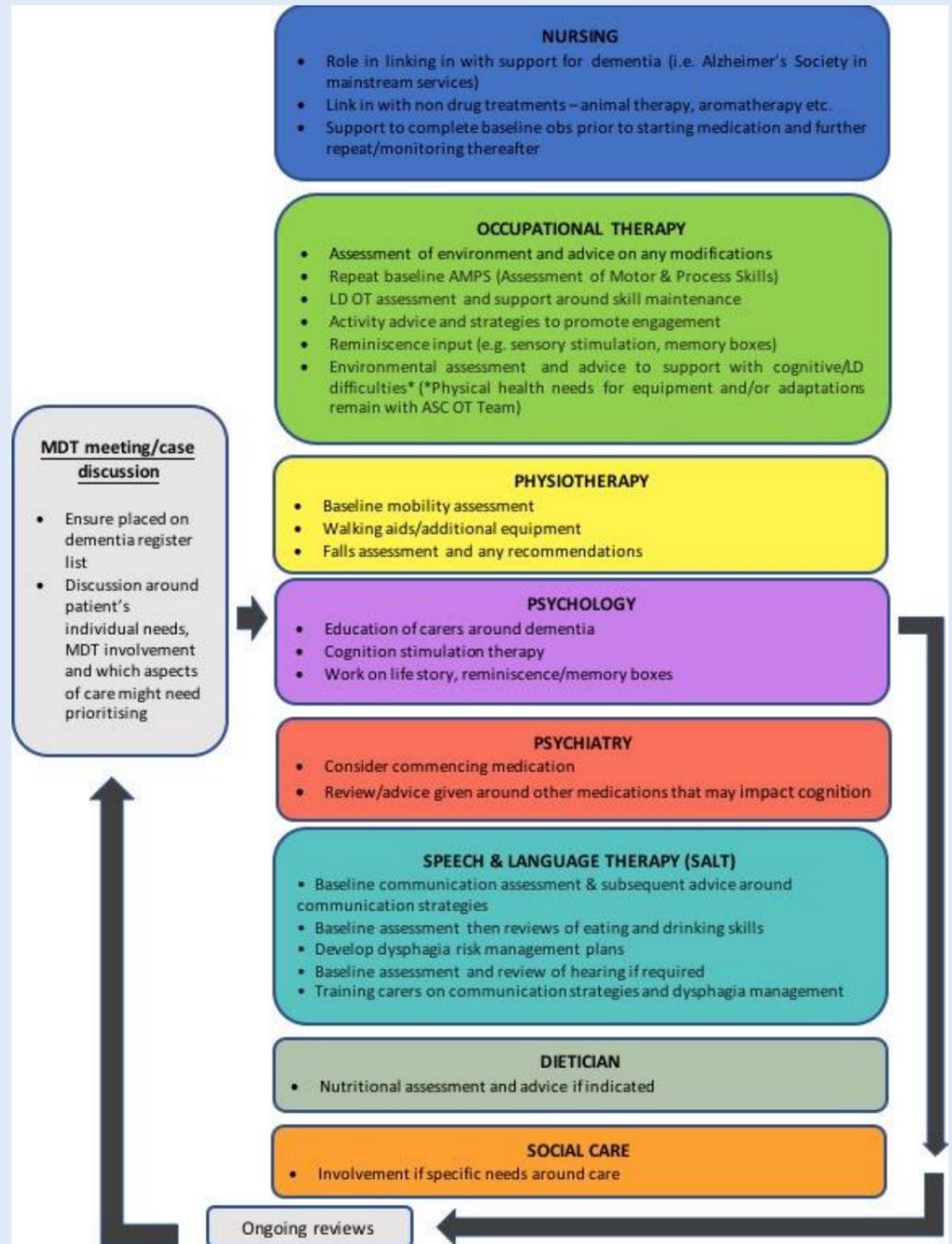
Background:
People with intellectual disability (ID) are more likely to develop dementia compared to the rest of the population. The risk is significantly increased in those with Down's syndrome who are more likely to develop Alzheimer's type dementia ⁽¹⁾.
In addition to this the increasing life expectancy of those with intellectual disability means they are more likely to develop cognitive decline/dementia in their lifetime ⁽¹⁾.
In 2009, the Department of Health launched the first ever National Dementia Strategy for England called 'Living Well with Dementia' ⁽²⁾.
Despite this the needs of those with intellectual disability have not always been sufficiently addressed as highlighted by the report 'Hidden in Plain Sight' ⁽³⁾.
Whilst mainstream services have established memory clinics, those with intellectual disability who need assessment for possible cognitive decline will be assessed within intellectual disability services and there are not always formalised pathways.

Figure 1: Hackney ILDS Dementia Diagnosis Pathway



Methods:
- Information gathering looking at best practice guidelines and dementia pathways used by other ID teams. We observed that they all use a multidisciplinary team (MDT) approach but with slightly different set up depending on resources available.
- Set up regular dementia pathway meetings with key stakeholders within the team to get viewpoints from all MDTs members. This generated discussion around current knowledge base and anticipated roles within a dementia pathway

Figure 2: Hackney ILDS - Post Diagnosis Management of Dementia in Intellectual Disability



Results:
MDT agreed on the following:
- A formalised screening, assessment and diagnostic pathway (Figure 1)
- Initial framework for post diagnostic management with roles of each MDT member (Figure 2)

Conclusions:
Ongoing process to establish pathway, but next steps identified as follows:
- Reviewing pathway steps in practice and adjusting accordingly
- Establishing links with mainstream dementia services to ensure ID clients have equal access to support available
- Addressing training needs of team as a whole

References
(1) Dementia and People with Intellectual Disabilities. Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia. *The British Psychological Society* 2015
(2) Department of Health. Living well with dementia: a National Dementia Strategy. London: HMSO; 2009.
(3) Hidden in Plain Sight - Dementia and Learning Disability. Need2Know. Burke, Christine; Macdonald, Millie; Dodd, Karen; Satinsky, Emily; Kousoulis, Antonis. *Foundation for People with Learning Disabilities* 2018