

Developing Dementia Services for People with Learning Disabilities (LD)

Dr Hannah Kiddle (Clinical Psychologist)

Paul Crabbe (Senior Intensive Support Nurse)



Providing care all of us would recommend to family and friends

What we're here to talk about...

- Dementia in people with LD
- Best practice & our practice
- What we do well
- What we need to improve
- Pilot Memory Café



Providing care all of us would recommend to family and friends

What is a LD?

In order to meet diagnostic criteria for a LD the individual must:

1. Have significantly impaired intellectual functioning (IQ < 70)

and

2. Have significantly impaired social and adaptive functioning

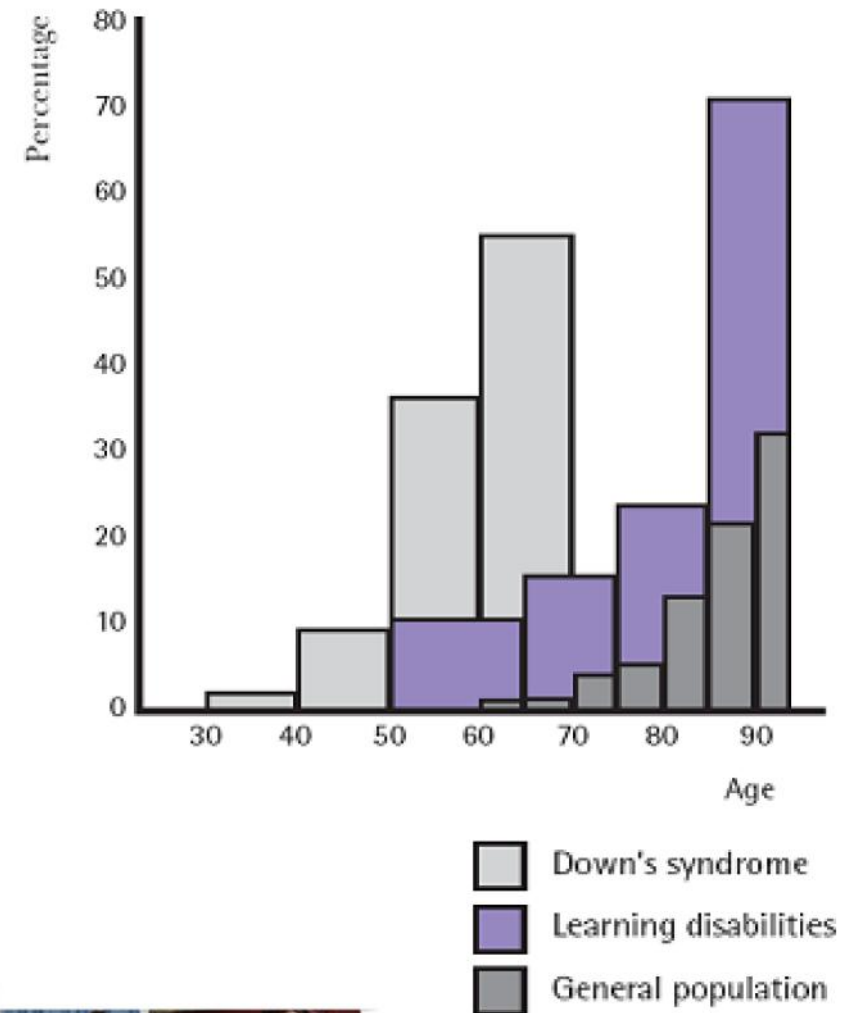
and

3. These difficulties must have been evident in childhood



Dementia in People with LD

- Increased risk of dementia
- People with Down syndrome:
 - Increased risk of Alzheimer's disease
 - Earlier onset and faster progression
 - 80% develop seizures



Providing care all of us would recommend to family and friends

Challenges in Assessment

- Pre-existing cognitive impairment & floor effect
- Diagnostic overshadowing
- Communication & sensory impairments
- Changes due to social or emotional difficulties
- Effect of early institutionalisation
- Effect of support and living environment
- Medical and physical health problems



Providing care all of us would recommend to family and friends

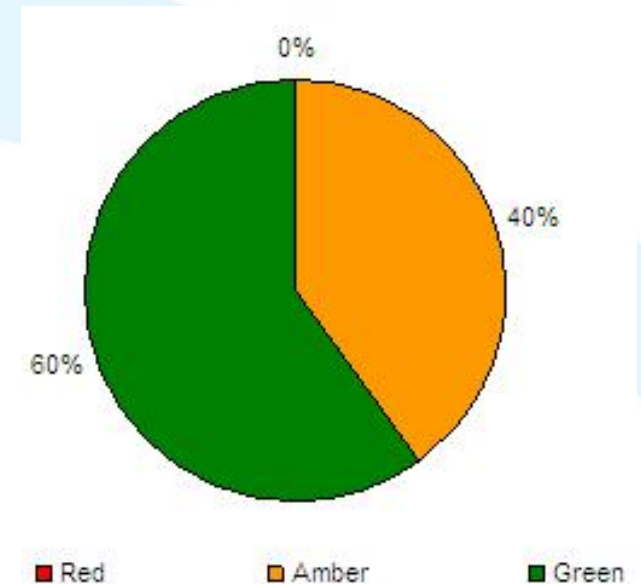
Standards of Good Practice (2009)

1. Legal framework & guidance
2. Population
3. Multi-agency dementia strategy
4. Care pathway
5. MDT approach to assessment, diagnosis & support
6. Assessment & diagnosis
7. Person centred dementia care
8. Care management & review
9. Interventions
10. Dementia friendly environments
11. Dying in place
12. Choices and rights of people with LD & dementia
13. Support to family carers
14. Capable workforce
15. End of Life (EoL) care



Audit of Current Practice*

- 60% of standards rated green (standard met)
- 40% amber indicating partially meeting standard
 - One standard relates to care homes and day centres
- 0% red indicating there are no areas in which there are significant gaps in service



Providing care all of us would recommend to family and friends

*Tanskanen, S. & Kiddle, H. (2013)

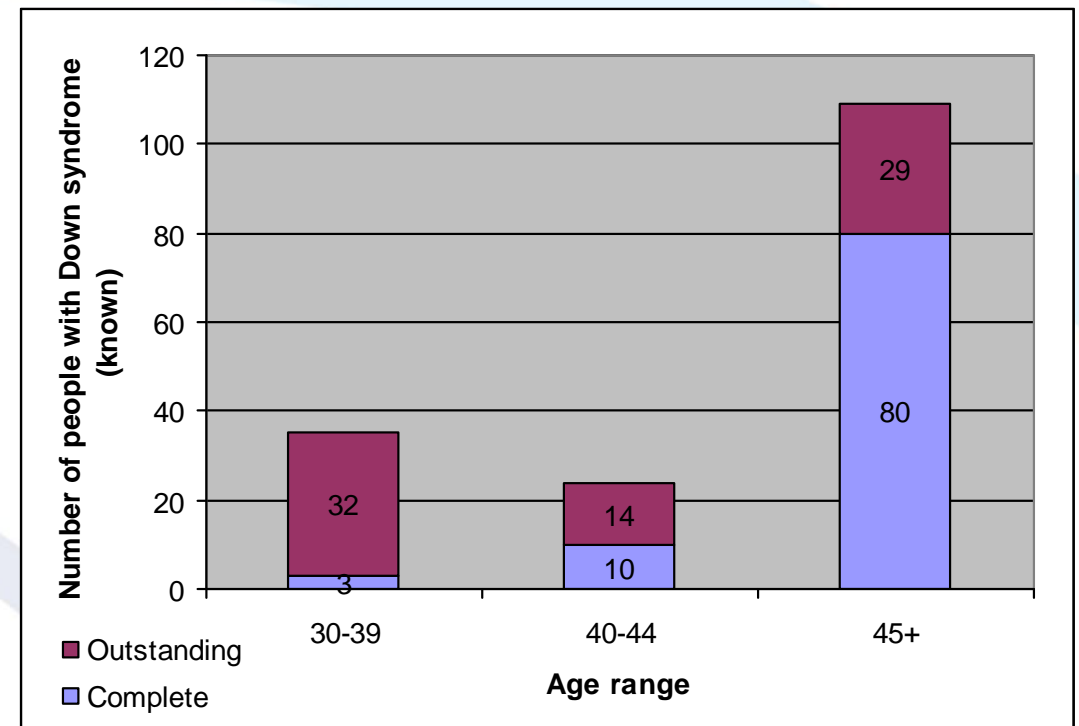
What we're doing well...

- Increased awareness of dementia in LD
 - Training for all LD service staff
 - Dementia resource packs in every CLDT and IST
 - Liaison with mainstream services to incorporate LD into care pathways
 - Attendance at Dementia & Dignity and Dementia Partnership Board meetings
 - Liaison with mainstream Dementia Facilitators to add dementia & LD to GP training
 - Dementia information added to good practice notice boards in CLDTs and outpatients (easy read)
- Improvement of services for people with LD & dementia
 - Learning Disabilities and Dementia Working Group
 - Dementia Champions in all Community and Intensive Support Teams
 - Regular reviews by care managers of placements, day activities etc



Down Syndrome Baseline Project

1. Database of people with Down syndrome
 - 189 on GP database (March 2013)
 - 184 on Down syndrome database (known to LD Service in March 2013*)
2. Baseline cognitive assessments



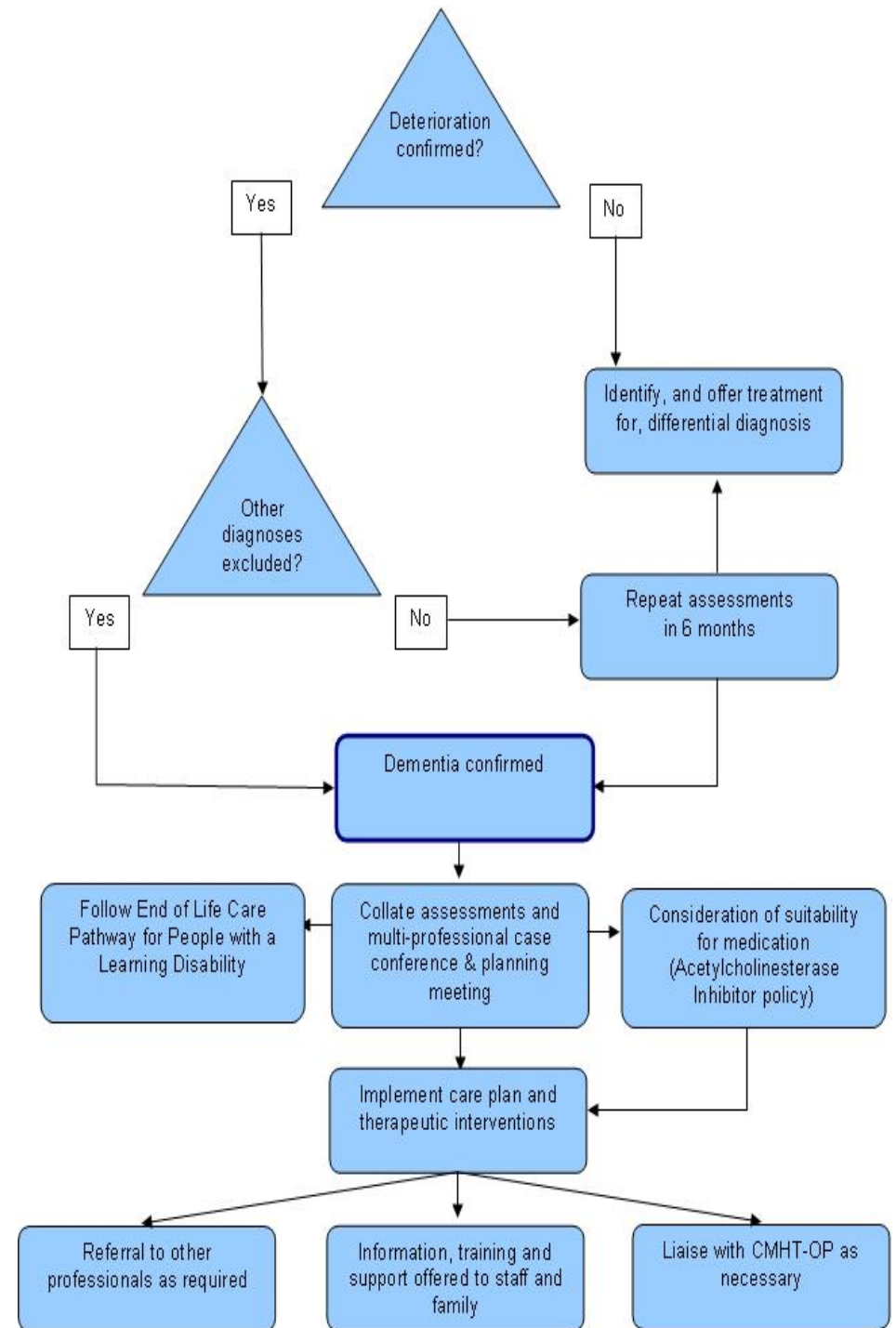
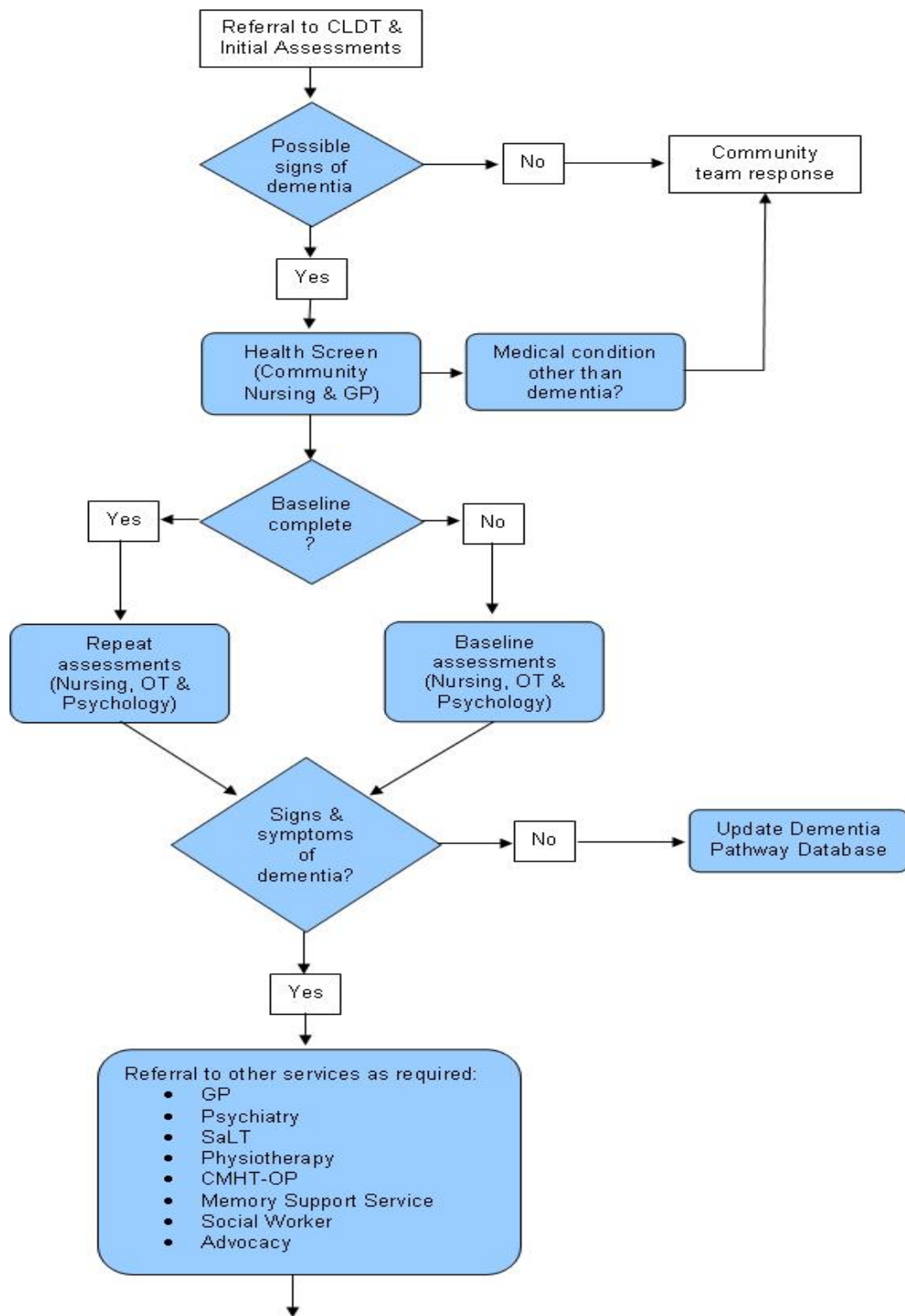
Providing care all of us would recommend to family and friends

**some now deceased/out of area*

Care Pathway

- Implementation of care pathway for dementia assessments in East Dorset
- Includes Community Nursing, Psychology, Psychiatry and Occupational Therapy
- Agreed battery of assessments
 - NAID
 - CAMCOG-DS
 - DLD
 - HALO
- Referrals to other services as required
- Link to EoL care pathway
- LD services are now referred to in mainstream care pathways





What we need to improve...

1. Sharing dementia diagnosis & information

- Easy read versions of dementia assessments as standard
- Access to easy read information about dementia and medication
- Discuss the development of a protocol for sharing dementia diagnosis with the individual and support network

2. Carers' education

- Memory Café pilot will include education session
- Training for care providers to be developed for Poole and Bournemouth Boroughs (already established in Dorset)
- Bespoke training by CLDT for individuals with LD & dementia as appropriate
- Carers' assessment to be completed for non-professional carers as standard



Providing care all of us would recommend to family and friends

What we need to improve...

3. End of Life

- EoL care plans for individuals diagnosed with dementia as standard
- Support “dying in place”
- Develop staff skills and knowledge in EoL & awareness that dementia is a life-limiting disease
- Develop links with palliative care

4. Dementia friendly environments

- Provide care homes/residential units with information and guidance
- Improve outpatient departments at Community Team bases



Providing care all of us would recommend to family and friends

Memory Café

Memory Cafés and People with LD

- People with LD are able to attend mainstream cafés
- Challenges in accessing:
 - Pre-existing cognitive and social impairment
 - Stigma attached to LD, especially Down syndrome
 - Age of onset is younger
 - Communication difficulties
 - Effect of early institutionalisation
- Adaptation needed to enable people with LD to access mainstream cafés
- No evidence as to
 - The benefits of memory cafés for people with LD
 - What needs to be adapted

Pilot Memory Café (September 2013)

- Adapted from mainstream memory café
- To include intensive Interaction & sensory integration
- Includes presentation for carers by professional (30 minutes)
- Aims of pilot:
 - Establish what aspects need to be adapted for people with LD & what works well
 - Evaluate use of intensive interaction & sensory integration
 - Establish whether carers' education & support is effective
 - Liaise with mainstream cafés on adaptation for people with LD



Questions?

Contact us at:

Hillcrest, 31 Slades Farm Road, Bournemouth, BH10 4EU

01202 636166/636158

hannah.kiddle@dhuft.nhs.uk

paul.crabbe@dhuft.nhs.uk



Providing care all of us would recommend to family and friends