

# Bradford Ageing Learning Disability & Dementia (BALDAD)



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### Introduction

BALDAD is a multi-professional and carer group who meet bi-monthly. The purpose of which is to update on development and consider suggestions on improving the care and early detection of dementia in this hard to reach group of people; particularly within mainstream mental health services. In optimising opportunities for health, participation and security in order to enhance quality of life as people age (WHO 2002), it also develops training, awareness and care pathways with other services. The work is underpinned by research from the International Association for the Scientific Study of Intellectual Disabilities (IASSID) and its Special Interest Research Group on Ageing and Intellectual Disabilities (SIRGAID).

### Planning

People with learning disabilities and in particular those with Down's syndrome are more at risk of developing dementia than the general population. They also develop it at a much younger age. Due to this group of people already having an impaired cognitive functioning it is more difficult to detect, particularly in the earlier stages. The BALDAD group was therefore formed to look at ways in which we could identify people suffering from dementia at a much earlier stage and develop care pathways to provide timely and effective services. Our aims were:

- To raise awareness about the needs of the older person with an LD and those with dementia in collaboration with generic services.
- To carry out baseline assessments in capturing a true picture of a person's skills and abilities before any deterioration takes place.
- To look at the current resources available and their future capacity to meet the needs of this growing population.
- To gather information and data to inform future planning of services.
- To enable people to continue living in their own home for as long as possible by increasing knowledge, support and flexibility of services.
- To provide carer support.
- To provide access to expertise, training and resources in line with NICE guidelines, National Dementia Strategy and other evidenced based research.
- To look at good practice in other areas that could be adapted to our practice.

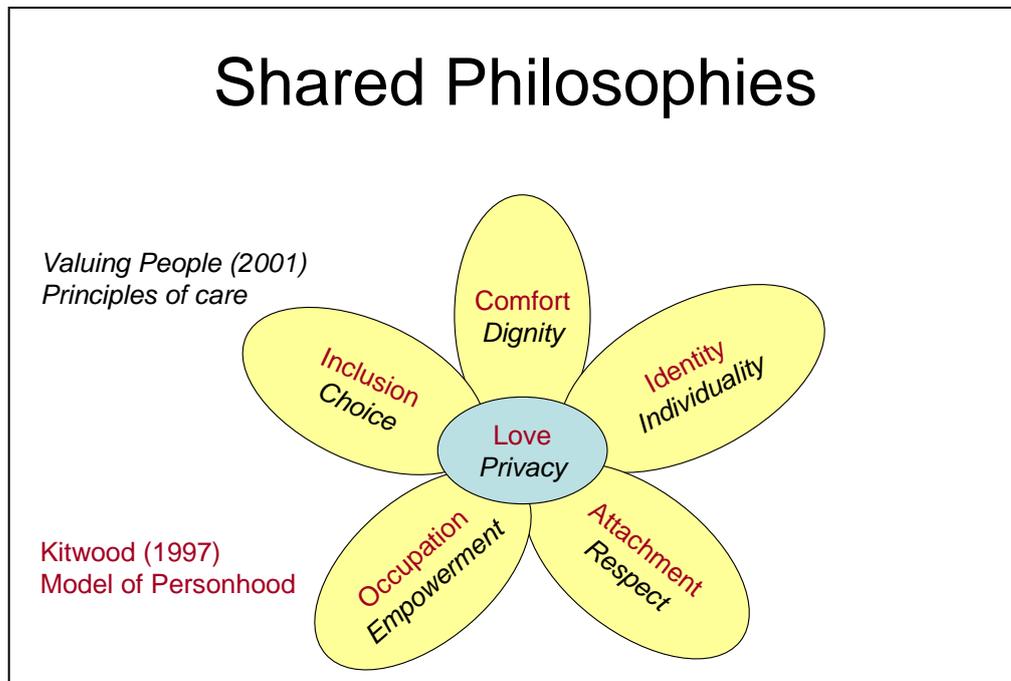
### Implementation

In June 2007 the Health Care and Wellbeing (HCW) of the older adult with LD training package was developed to deliver awareness and knowledge to staff working in LD services. This training enabled staff to carry out baseline assessments of people's skills and abilities by using a Cognitive & Behavioural skill (CAB's) checklist to help detect deterioration at an earlier stage. It also provided a health screening tool to rule out other conditions that can mimic dementia and a DisDAT Distress tool to monitor for pain or other reasons for distress. A dementia care pathway was developed and included in the training package.

The training was delivered in two full day sessions. The first session focuses on the usual bio/psycho/social signs and symptoms of ageing, discusses age related diseases and conditions and how they may affect people with LD; especially the link with challenging behaviour and pain due to communication difficulties (Kerr et al 2006). The second session is on dementia in general, how it affects people with LD

and highlights differences with the general population. For example, epilepsy is a known 2<sup>nd</sup> stage feature of Alzheimer's in people with DS (Janicki et al 1995) and there is evidence to suggest that dysphagia may also be a 2nd stage feature (Regnard 2006).

In March 2010 the HCW training package was updated and the dementia session links shared philosophies between dementia and learning disabilities by marrying Kitwood's (1997) Model of Personhood with Valuing People's (2001) Principles of Care.



The training package has been designed to be delivered inter-agency and community mental health staff are now attending the training. The BALDAD group continue to meet on a bi-monthly basis to share knowledge, research evidence and discuss how best to manage the care of individual cases.

## Results

In May 2009, an audit was undertaken providing both quantitative and qualitative evidence on LD service users diagnosed with dementia. Table 1, provides demographic information on where people with LD diagnosed with Dementia are living. The audit projected future trends and service requirements and identified a lack of adequate services for people with LD & Dementia. In line with the Bradford Changing Lives through Real Partnership Learning Disability Programme (O'Neill 2009), it was agreed that pathways into generic Mental Health Services would need to be developed to address the additional needs of this group of people and reduce inequalities. Professionals from Mental Health Services were invited to join the group to progress this development.

**Table 1. Stage of Dementia/Accommodation**

	Family	Resi.	LD nursing homes	Supported Acc.	EMI units
Possible	4		2	2	
Early	1	1	1	3	
2nd					2
2 <sup>nd</sup> -3rd			1	2	
Advanced			5		1
<b>Other Neurological</b>	4	1		2	

Since the HCW training package was introduced over 70 staff and 20 people who are either carers or from other agencies have attended the training. To our knowledge 21 CAB's baseline assessments have been completed and this figure is likely to be much higher. Raised awareness of dementia in people with LD means we are receiving more timely referrals for more in depth assessment and the completion of the CAB's assessments has provided a very useful baseline for our LD Psychologists to use in their more in depth assessments; resulting in an earlier probable diagnosis of dementia. The May 2009 audit identified that within two years there had been a 3 fold increase in the number of people being diagnosed with dementia, to the previous six year period in which only 10 people had been diagnosed.

Our LD Psychiatrist is now treating a number of service users with Donepezil medication and monitoring their progress. Managers of the daycare centres that provide a service for the older adult with LD have made changes to the environment and introduced appropriate therapeutic activities for the service user as a result of knowledge gained from attending the BALDAD group. Supported Accommodation Managers have introduced the use of Telecare aids and other adaptations to enable service users with dementia to continue living in their own homes for as long as possible and having attended the training, supported accommodation staff have a greater awareness in meeting the needs of this population.

More recently mental health staff have been attending the training, promoting good interaction and collaboration between LD & mental health staff and shared learning takes place that identifies similarities as well as differences. This is important in creating pathways in line with Greenlight for Mental Health and the National Dementia Strategy.

## Conclusion

The results show that a multi professional and carer group such as the BALDAD has been very beneficial in raising awareness and helping to reduce health inequalities for this hard to reach group of people, by providing information, knowledge from current research, training and support. However, there is much work still to be done in training staff in all agencies, informing commissioners and educating services and independent providers about what is required to meet the additional needs of people with LD & Dementia.

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June 2010

## References

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