Report for

Faculties of Old Age Psychiatry

& Learning Disability

TRAVELLING ALONE OR TRAVELLING TOGETHER?

THE INTERFACE BETWEEN LEARNING DISABILITY

AND OLD AGE PSYCHIATRY.

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Background

Research suggests that between 30% and 50% of people with learning disabilities (LD) may exhibit behaviours that are caused by communication difficulties, physical illness and mental illness (Emerson, 1995). Recent research into the epidemiology of mental illness in adult populations with LD suggests prevalence rates between 20.1% - 22.4% (Taylor et al., 2004; Cooper et al., 2007). In comparison with the general population, people with LD show evidence of decline earlier than expected in relation to adaptive behaviours and physical abilities. The mean life expectancy has increased from below 20 years in the 1930s to well over 60 now (Braddock 1999).

Earlier research noted that, generally, older people with LD have higher levels of functional abilities, lower levels of challenging behaviours and lower rates of epilepsy than they did in the past (Moss 1991, Maaskant et al 1996). However, as the life span continues to increase, a number of age related health issues have emerged.

The prevalence of dementia is higher in people with LD even when those with Down syndrome are excluded (Strydom et al, 2007). Moreover there is a high prevalence of both physical and psychiatric morbidity in the older population with LD (Cooper 1997).

Against this background an editorial in the British Medical Journal in 2000 'Mental Health Services for People with Learning Disabilities: a complete overhaul is needed with strong links to mainstream services', suggested that:

'mental health services in the United Kingdom are set for dramatic restructuring in the light of recent government initiatives to improve quality of care and equity of provision... But little thought has been given to the well documented mental health needs of people with learning disabilities'. (Hassiotis, Barron and O'Hara, 2000).

Valuing People, the Learning Disability white paper published in 2001, emphasized the need for people with LD to access mainstream services (Department of Health, 2001). The vulnerability of this group was highlighted in Everybody's Business (Care Services Improvement Partnership, 2005), and Valuing People Now, a three year strategy published in 2009, further emphasized the health inequality that exists in people with LD (Department of Health, 2009a).

Alongside these documents, the National Dementia Strategy (Department of Health, 2009b) was launched in 2009, following the NICE Dementia guideline (NICE, 2007a) and the amendments to the NICE guidance on the anti-Alzheimers drugs (NICE, 2007b). Unfortunately the National Dementia Strategy failed to address the needs of people with LD and dementia.

Despite these policy documents, this report suggests that we have still not articulated what quality of care and equity of service provision for people with LD and mental health problems might look like. This was the basis for the survey of service provision reported here.

Method

The method involved a two-stage process: firstly a pilot survey of members of the Executive Committees of the Faculties of Old Age Psychiatry (OAP) and LD, and secondly a survey of all members of both Faculties.

Pilot project

In late 2005, acknowledging the lack of services for people with LD who had dementia, or other mental illnesses associated with old age, a Royal College of Psychiatrists' working group was set up to look at the interface between old age psychiatry and the psychiatry of learning disability. It was chaired by the Chair of the LD Faculty and included two representatives from the Faculty of OAP.

The aim of the group was threefold, to look at the assessment and management of dementia in learning disability; to identify principles of diagnosis and management of dementia in learning disability; and to look at what services were needed and how they should be accessed.

In order to establish an overview of current service operation and provision, a questionnaire was sent to members of the Executive Committees of both Faculties. Open questions, inviting comments and descriptions were asked about the services for people with LD over the age of 65, and people with LD of all ages who had dementia. Respondents were asked to describe what services existed; what positive experiences they had had dealing with these groups of people; what gaps existed in the current service provision; and whether there were any particular problems in accessing or providing services. Respondents were also asked about the interface between the two faculties and how it could be improved.

The pilot questionnaire was reviewed and revised to develop the questionnaire circulated to the membership of both Faculties in the full Faculty survey.

Full Faculty survey

A postal questionnaire was circulated to the members of the Faculties of Old Age Psychiatry and Learning Disability in late 2008. Two mailings were carried out using mailing lists for both faculties as supplied by the College.

The responses on the questionnaires were transcribed and entered into a software analysis tool (NVivo) for thematic analysis. NVivo is a qualitative data analysis tool (QDA) computer software package produced by QSR International. It has been designed for qualitative researchers working with very rich text-based and/or multimedia information, where deep levels of analysis on small or large volumes of data are required. More information is available at: http://www.qsrinternational.com/products_nvivo.aspx.

Results

Pilot project

A total of 21 replies were received: 15 from learning disability consultants, and 6 from old age consultants. Five respondents worked in Primary Care Trusts, 12 in Mental Health Trusts, two in Health Boards, one in a joint organisation with Social Services, and one in an acute and community Trust.

Responses to the pilot questionnaire showed that services for people with LD and dementia, or old age mental illness were patchy and depended on individual interest and development in local services. Specialist old age services saw people with mild LD, but had difficulty in managing people with moderate or severe LD. Specialist memory clinics for people with LD were few, and run by LD services. Old age psychiatrists felt that LD services focussed more on people with severe LD, but that people with moderate LD were too disabled for the OAP services. Down syndrome patients were managed within LD services. There was general agreement that the varied provision patterns for LD and OAP services, which sometimes involved them being in different Trusts, exacerbated difficulties, and that more communication and cooperation would help.

As a result of this survey it was decided to focus on five areas: joint meetings between the Faculties of OAP and LD, joint research activities, medical student teaching (to be addressed through local mechanisms), sharing of good practice, and a full survey of both Faculties to provide detailed information on service provision and consultants' views.

Faculty survey: Quantitative Overview

942 questionnaires were mailed out using a membership list for both Faculties supplied by the Royal College of Psychiatrists: 53 were returned as unknown/ retired or ineligible and 444 analysable questionnaires were returned. 415 of these were returned by consultants (15 by academics, 12 by SAS doctors and 2 others).

66% of respondents were working in an OAP service and 31% in LD services.

68% were working in Mental Health Trusts, 9% in Primary Care Trusts and 5% in LD Trusts. A further 6% were working in joint organisations with Social Services and 2% in Community Trusts.

52% of respondents said they had access to a memory clinic for people with LD. 41% said they had no memory clinic access and 7% didn't know.

The majority of memory clinics were run by the old age psychiatry service (76%) but a sizable minority (21%) took place within the LD service, and a small number 2% were described as run by both.

In patient care was under the LD service (42%), under old age psychiatry (23%) and under both (34%).

59% of respondents agreed that there is a need for super-specialised services for PWLD and functional mental health problems over the age of 65. 33% didn't agree and 5% were unsure.

With regard to special services for PWLD and dementia 81% didn't agree that there was a need for super-specialised services for this group (only 13% agreed).

Full Faculty survey: Qualitative analysis

Older people with LD and functional mental health problems

In response to a question asking what services existed in their area for people with a learning disability and functional mental health problems 31% of 342 comments fell into the category of didn't know or nothing specific available: "we rarely see them on OAP. LD is a separate Trust with whom we do not have much contact." 24% of comments referred to LD services, eg "LD service generally keeps own patients." 12% of comments referred to the availability of inpatient and outpatient care, eg "standard outpatient and inpatient options in LD and OA provided when appropriate on a case by case basis". Tailoring services to need was a theme addressed in 8% of comments: "if mild would have all the usual OA facilities. If more severe tend to be seen by PLD services."

Respondents were also asked to comment on gaps in services for this group. Of 270 comments, 38% referred to the lack of an appropriate specialist service: "they need specialised services however at the present moment are being accommodated elsewhere which is not appropriate for both client groups"; "I don't think anyone has a particular interest". Another 18% were confessions of ignorance: "the fact that I know nothing about LD services locally probably says it all"; "in 13 years as a consultant OPMH I have not been asked to see these patients." 13% highlighted the lack of a specific area of service, mainly housing options and day care.
Problems in accessing LD and OAP services for this group attracted 301 comments. Although 52% fell into the category of none or not applicable this was not necessarily good news: "I don't think there are more 'gaps' than for anyone else". 12% of comments addressed difficulty in accessing LD services, 7% territorial disputes and 6% difficulty in accessing old age services. 8% highlighted a specific area where access was difficult eg housing, residential care, social services.

When asked how people with LD and functional mental health problems in later life are best cared for the greatest number of comments (29% of 366) referred to joint working, followed by references to the LD service (27%). According to need was the theme of 18% of comments, and only 15% saw the best option as care within a super-specialist service.

People with a dementia and a LD

In response to the question asking what services exist for this group in their area 27% of 399 comments referred to no specific/ no specialist service. 18% referred to LD services and 16% to a particular service element eg outpatient care, respite, day care. 9% of comments addressed use of a memory service.

The comments relating to gaps in services for this group covered a broad range: 16% (of 238) referred to staff training/ resource issues, 14% to the need for specialist accommodation, 13% to their being no specific service (implying a need for one existed) and 12% of comments referred to the ignorance of respondents concerning this group eg "I don't have a working knowledge of what services are available"; "LD now in a different Trust."

The survey specifically asked about gaps in service provision for people with LD and dementia below the age of 65 and this question elicited similar responses. Of a total of 239 comments, 21% fell into the category of don't know/ can't comment: one respondent helpfully suggested "please ask local LD service". 19% were references to the lack of a specified service element, particularly day care and long term care options. 16% referred to the lack of a specialised service eg "LD may not have sufficient OA expertise, OAP may lack sufficient LD experience, no dedicated resources for either". 13% commented that there was no service for anyone under 65 with a dementia.

In response to a question about difficulties in providing a service for people with LD and a dementia, 26% of 303 comments fell into a category of service access and capacity eg "we do what we can with existing services". 16% referred to staffing difficulties and 16% replied none. The lack of a specialist service featured again (11%) and another theme was 'not applicable as have had no referrals' (10% of comments).

Respondents were asked to comment on problems in accessing the other service (ie LD psychiatrists commented on access to OAP services and vice versa). Most comments fell into the category of none (48% of 197 comments). Problems with OA service featured in 11% of comments (eg "old age psychiatrists do not take people with LD") and problems with LD services 6% (eg "contact with LD very difficult – at a different site"). The theme of access to appropriate resources featured in 12% of comments and 'I don't see these patients' was the theme in 8%.

Positive experiences

172 comments came under the question about positive experiences in dealing with older adults with LD and functional mental health problems. 49% related to good joint working and liaison (eg "good work done partly by us and them") and 16% to a positive treatment outcome. 21% of comments came under none, very little or 'don't see these patients'.

164 comments were categorised under the question about positive experiences in dealing with LD and dementia irrespective of age. Joint working and service provision accounted for 62% of comments and 19% covered no positive experiences and 'don't see these patients'.

Discussion

Qualitative data gathered from an initial survey of LD and OAP Faculty Executive Committee members showed that the service models that exist to meet the needs of older people with LD are highly variable, with some services having well established LD and OAP services providing access to people with LD with or without dementia with clearly agreed protocols. In other services there is no clarity on which service should meet the needs of this group. There were a number of good practice examples. These include the following: generic OAP services providing good access for older people with LD, excellent working relationship between LD, OAP services, primary care and voluntary sector, and services with a clear dementia care pathway and protocol for the use of anti dementia medications.

However the picture is highly variable across UK.

Everybody's Business (Care Services Improvement Partnership, 2005) and Raising the Standard (Faculty of Old Age Psychiatry, 2006) made a number of recommendations about the care of older people with learning disabilities and mental health problems including:

- better information on services
- joined up working between primary care, OAP and LD services
- joint training
- consideration of joint teams
- support for family carers
- involving people using services in planning, monitoring and delivering services
- special attention to the needs of people from black and minority ethnic groups
- jointly agreed protocols
- routine cognitive assessments for adults with Down Syndrome

Valuing People (Department of Health, 2001) recommends that people with LD are able to access mainstream services and, while recommending this, the document acknowledges the support that people with LD would need from specialist LD services as well as the flexibility in approach that services have to provide.

In the light of these recommendations the findings of this survey are disappointing: there is agreement on the service required to meet the needs of people with dementia and LD or for people with LD who develop other mental health problems in later life. This theme runs through many of the responses. Respondents commented that there are only small numbers of people in this interface area so it is hard to justify a service and that the need for a service is not recognised by commissioners. It also appears that in many areas the two specialist services are geographically and/ or organisationally separate, which leads to each service lacking knowledge of the other service and challenges in trying to work together.

The people who do see patients who fall into this interface area generally report their experiences as positive and rewarding.

The findings of this survey need to be used to stimulate further debate and discussion about how to meet the needs of this vulnerable group and we recommend a joint conference to publicise the survey and highlight a variety of service models.

Ethnicity plays a major role in influencing care giving practices, carer stress and help seeking behaviour in people with dementia and their carers. In people with learning disabilities there is research evidence suggesting significant differences in the nature of care giving, carer stress and carers' psychological and physical burden between main stream and minority ethnic communities (McGrother et al, 2002, Devapriam et al, 2008, Gangadharan and Bhaumik, 2008). Contrary to the popular view, very few people belonging to BME population, enjoy the support of extended family networks (Hatton et al, 2002). Material disadvantage, lack of informal networks and high need for services are some of the key issues related to people with learning disabilities from an ethnic minority background (Hatton et al, 1998).

Needs of carers, caring for people with LD and dementia from BME groups, are unlikely to be met fully and the problems are compounded by the lack of availability of culturally appropriate respite and home care provision. Lack of awareness of services and language barriers may prevent people from ethnic minority communities from receiving appropriate levels of support. This can result in significant distress for both the person with learning disabilities and their carer.

The plan of action developed from this survey needs to address the needs of BME carers and service users, including the following actions: developing cultural competence for clinical staff; developing partnerships with community and voluntary organisations; inclusion of people with LD and their carers in consultation processes for service development and delivery; all provider organisations to improve staff support for service users and carers; and further research to understand the views of people with learning disabilities with dementia from BME communities and their carers about culturally appropriate ways of meeting the needs of the ageing population.

Conclusion

It is clear that significant gaps exist in service provision for older adults with LD. Although there are positive practice examples, these are few and far between. Recommendations for the way forward are:

1. Clear guidelines on interface working between specialist LD and OAP through the development of care pathways involving both services. This will enable people with LD to access the most apropriate service for the needs that they present with.

2. Skills development for both groups of professionals through joint training opportunities. Both Faculties should encourage joint CPD events at local as well as national levels.

3. The competency framework for higher specialist trainees in both services should include skills in assessment and management of mental health problems in older people with LD.

3. Working with health and social care commissioners to raise awareness of the need to develop a range of services that would meet the needs of this population (inpatient provision for people with dementia and functional disorders; community support that is available over 24 hours; flexible, crisis support; short break provisions; residential facilities with nursing care etc). This should be undertaken with a systematic needs assessment of the population and involvement of older people with LD and their carers.

4. Development of interface protocols that include agreement on referral between services, availability of joint clinics, and joint working arrangements for people with complex needs.

5. The College needs to alert other mental health and social care professionals to the needs of older people with LD and dementia or functional mental illness. Other health and social care professionals may need to consider training in this area.

6. Specific work is needed to clarify and develop service models for older people with LD and dementia or functional mental illness from BME communities and their carers.

7. Those LD psychiatrists who are interested in older people and those old age psychiatrists who are interested in LD should be encouraged to develop and share their expertise with each other and with other relevant professionals.

8. Both LD and OAP services should ensure that they include users and carers from this interface area in service planning and improvement projects.

It is important to focus on all mental health problems in this population, and not to concentrate solely on dementia.

At present, across most of the UK, LD services and OAP are pursuing their own separate paths. If we are to address the needs of people with LD and dementia or other mental health problems of later life, we need to travel together, not alone.

Acknowledgements

**APPENDIX: SURVEY QUESTIONNAIRE FOR INTERFACE GROUP
BETWEEN LEARNING DISABILITY FACULTY AND
PSYCHIATRY OF OLD AGE FACULTY**

Grade of Responder: SAS Doctor ☐ Consultant ☐ Senior Lecturer/ Professor ☐ Other ☐

Nature of Service Provided :   Adult Learning Disability Services   ☐

Lifespan Learning Disability Services   ☐

Old Age Psychiatry Services   ☐

Other   ☐   Pls specify …………………………….

Type of Organisation: Mental Health Trust ☐   Learning Disability Trust   ☐

Based on PCT   ☐   Community Trust   ☐

Joint Organisation with Social Services   ☐

Other   ☐   Pls describe …………………

**1. Please describe what services exist for people with <u>learning disability and
functional mental health problems</u> over the age of 65 in your area, e.g. inpatient,
outpatient, DV, day centre, respite care**
……
…………………………………………………………………………………………………..

Are there any special services for them?   YES ☐   NO ☐
Please give details …………………………………………………………...

Inpatient care: Under LD service ☐   Under OAPry service ☐ Under both ☐

Do you think there is a need for special services for them?   YES ☐   NO ☐

What gaps are there in services for people <u>***over 65***</u> with LD and functional mental health
problems?
……
……

What problems have you had in accessing old age psychiatry/ LD service for patients with
learning disability who are over the age of 65 and suffering from functional mental health
problems?
……
……

How do you think people with LD and functional mental health problems in later life are best
cared for?
……
……

**2. Please describe what services exist for <u>people with dementia (PWD) who have a
learning disability *irrespective of age*</u> in your area, e.g. assessment unit for dementia,
day care, respite care etc.**
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…………………………………………………………………………………………………..

Who looks after PWD & LD: LD service ☐   OAPry service ☐

Do they have access to a Memory Clinic service: YES ☐   NO ☐

If YES, who runs the Memory Clinic: LD service ☐   OAPry service ☐

Are there any special services for PWD & LD?   YES ☐   NO ☐
Please give details …………………………………………………..

Do you think there is a need for special services for them? YES ☐   NO ☐

What gaps are there in services for PWD & LD?
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……

Please describe any gaps that exist in the current service provision for people with learning disability and dementia **below the age of 65**
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What difficulties do you have in providing services for people with learning disability and dementia?
…….
…….

What problems have you had in accessing old age psychiatry service/LD service for your patients with learning disability who are suffering from dementia?
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3a. Please describe any positive experience you have had in dealing with people with learning disability over the age of 65 who have <u>functional mental health problems</u>
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3b. Please describe any positive experience you have had in dealing with people with learning disability and <u>dementia, irrespective of age</u>
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4. We would like to identify areas of <u>positive practice</u> in this area of work. If you know of any, please could you give brief details below (AND contact information in case we need more details)
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