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Learning Disability Psychiatry

Newsletter of the Faculty of the Psychiatry of Learning Disability

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View from the Chair

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Dear Readers,

Welcome to the first edition of the 2009 Faculty newsletter. Since the last newsletter (September 2008), the Faculty has made significant progress in many areas but at the same time has faced some challenges. Among the several achievements, I wish to mention a few for your information. The College Research and Training Unit has already rolled out the 360° appraisal for psychiatrists working in learning disability and is looking for members to join the pilot process. We would appreciate your input so that your feedback will help us in making the appropriate changes.

The quality standards for adult in-patient units in learning disability services are almost ready and are likely to be rolled out in the early months of 2009. The joint guideline with the British Psychological Society for assessment and management of dementia in people with learning disability is now ready and will be sent for approval by the Society and the Royal College of Psychiatrists in the very near future. The first two meetings of the working group on the future role of psychiatrists in learning disability have been held and we hope to produce a draft version of the document in 2009 for members' comments.

I also wish to mention several individual achievements by Faculty executive members. I congratulate Dr Roger Banks on being bestowed the Honorary Fellowship of the Royal College of General Practitioners. Roger has built effective bridges, not only with primary care but also with voluntary organisations such as Mencap. His contributions are highly valued by our Faculty and the College.

Dr Paul Winterbottom and myself will be leading the next stage of the Lord Darzi review for learning disability in the south-west and the East Midlands regions respectively. In addition, Paul will be leading the next stage review for mental health in the south-east.

Along with these achievements there have been some challenges as well, the most recent being the change in the criteria for eligibility for the Member of the Royal College of Psychiatrists (MRCPsych) examination. It is no longer a requirement to have an experience of at least 6 months in psychiatry of learning disability or child and adolescent psychiatry, as this has been replaced with achievement of competencies. This change has taken place in line with the globalisation of the MRCPsych examination, but it poses a significant threat to recruitment to our specialty training posts. Dr Jo Jones, Chair of Psychiatry of Learning Disability Faculty Education and Curriculum Committee,

and myself are in dialogue with the President and the Dean regarding this and are proposing solutions to this problem. I will keep you posted regarding developments in this area.

The Faculty is also preparing itself for the future challenges of revalidation and recertification. There have also been some threats, particularly in relation to academic posts in psychiatry of learning disability (one such post has recently been lost at very short notice due to withdrawal of funding from a trust). I am currently dealing with this situation and I am also aware that this threat is apparent for many academic posts in psychiatry, not just for our specialty alone. In this regard we wish to work closely with the Academic Faculty of the College to ensure that the future of academic psychiatry, including that of learning disability, remains secure.

Finally, I wish to make you aware of international developments. We have recently held the first-link meeting in the presence of a number of psychiatrists from various faculties. Also present was Dr Rachel Jenkins, Chair of the International Board of Affairs. This is an attempt on my part to pull together under one umbrella all the projects in learning disability currently being undertaken internationally, including those in the Indian subcontinent, Africa and Europe, to improve the workforce resources for such projects. Support and advice will also be available from the International Board of Affairs.

Many thanks to all those who have returned the survey form on workforce. A report will be published in the very near future by Dr Regi Alexander and myself.

I wish to thank you all for remaining involved and interested in Faculty activities. My thanks also go to the Executive Committee members for their continuing hard work. ■

Letter from the Editor

Angela Hassiotis

Dear Colleagues,

Welcome to the first issue of our newsletter in 2009. Apart from the credit crunch (see Janet McPherson's update on Northern Ireland, pp. 6–7), the update from our Chair also makes for sober reading, particularly around the impact of changes in training for the psychiatry of learning disability. The articles published reflect a number of topics of concern to our members such as transition and care programme approach. I am particularly pleased that we have been able to host an interesting perspective on the rationale and work on the service users' group.

Finally, congratulations to the 2008 winners of the Alex Shapiro oral and poster presentations, Dr Devapriam and Dr Kiani.

I would like to thank all contributors and ask our membership to consider submitting articles or comments on articles that are published. Please email your contributions to: a.hassiotis@ucl.ac.uk.

Authors may be approached directly for furhter discussion about any aspect of their work. ■

Disclaimer

The views expressed in this publication are the personal views of the authors and do not necessarily reflect the College's position.

From long-stay hospital into the community: an outcome study of quality of life in people with learning disability and enduring mental health or behaviour problems

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Alec Shapiro Oral Presentation Award, 2008

Following the recommendations of the White Paper *Valuing People* (Department of Health, 2001), Leicestershire Partnership Trust closed its last long-stay hospital (Gorse Hill Hospital) which had about 60 individuals with learning disability. A significant proportion of these individuals have enduring mental health and behaviour problems.

The majority of the studies evaluating the impact of deinstitutionalisation on service users' quality of life show a significant improvement following a move into the community. However, a small number of studies suggest that this is not always the case. The impact of the move on people with learning disability and enduring mental health problems or challenging behaviour is far from clear and it is possible that there are shortfalls in the current provision of community support for this group.

Aims

1. To compare the quality of life before and after the re-provision.
2. To explore the areas of quality of life which are more likely to show change following re-provision.
3. Explore the relationship of changes in quality of life with behaviour and mental health problems, level of support and access to services.

Method

This study uses a prospective design to compare the quality of life of individuals before and after the move into the community, using a questionnaire by Cragg & Harrison (1986) that has been validated in people with learning disability. There are three assessment points at baseline and subsequently at 6 and 12 months after the move. Data were collected by a multidisciplinary team, which included psychologists, psychiatrists, nurses, physiotherapists, occupational therapists, speech therapists, and health and social service managers. The data were analysed using SPSS version 11 for Windows.

Results

A significant improvement in quality of life was noted in most individuals at 6 months follow-up in most areas (activity, relationship, access, choice, dignity and individuality). The pattern was noted to be similar but not significant at 1-year follow-up. Interestingly, there was a significant improvement in the dignity domain, but deterioration in the relationship domain at 1-year follow-up.

Discussion

The study shows a significant improvement in quality of life 6 months after the move, which is consistent with the existing evidence. The follow-up 1 year after the move reveals that the improvement in quality of life is maintained. The study will explore the changes in dignity and relationship domains further.

Absence of any further improvement after the 6 months assessment may point to over-reliance of the quality-of-life instruments on the observable changes in the lifestyle and the environment. A major drawback in the quality-of-life assessment of people with learning disability (especially moderate to profound degrees of learning disability) is lack of subjective accounts. ■

References

Cragg, R. & Harrison, J. (1986) *Living in a Supervised Home: A Questionnaire on Quality of Life*. West Midlands Campaign for People With Mental Handicap.

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Department of Health.

Urban–rural differences in the nature and prevalence of mental ill health in people with intellectual disability

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Alec Shapiro Poster Prize, 2008

Studies in the general population have shown that there is a higher prevalence of mental ill health in urban areas

compared with rural areas. However, to date no such study has attempted to explore this issue in people with intellectual disability.

The main aim of our study was to compare the prevalence of psychiatric and behaviour disorders in adults with intellectual disability who lived in Leicester (city) with those who lived in the county.

Method

Data were collected on demographic and socio-economic characteristics, with information on ICD–10 diagnosis of mental illness, autism-spectrum disorder and behaviour disorder in adults with intellectual disability registered with the Leicestershire Learning Disability Service between 1 January 2001 and 31 December 2006. City and county status were determined by mapping each individual's postcode to their corresponding ward.

Any differences between city and county were evaluated using the χ^2-test.

Results

The study group were 2713 adults with a diagnosis of intellectual disability (IQ ≤70); 1217 (44.9%) were living in the city and 1496 (55.1%) were living in the county. A significantly greater proportion of people from ethnic minority groups were residing in the city (38.7 *v.* 5.5% living in the county) and urban status was significantly associated with socio-economic deprivation ($P<0.001$).

Although there was no significant difference between the rates of common mental illness by place of residence, the study revealed that the prevalence of behaviour disorder and autism-spectrum disorder was higher in people living in the county (20.7 and 9.8% respectively) compared with those living in the city (18.8 *v.* 7.6%). One possible explanation for these findings could be the presence in the city of a higher number of ethnic minority groups who have difficulty in accessing the services and are also known to under-report the symptoms of behaviour disorder and autism. The other possibility might be the development a of higher number of specialist placements in the county to accommodate people with autism and behaviour disorder.

Conclusion

More research projects in other parts of the UK are needed to develop an appropriate service provision for people with intellectual disability who live in diverse geographical areas.

Accessible care programme approach toolkit

Sue Martin, Ian Hall, Edd Carter, Magda Pearson and Angela Hassiotis

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A longer version of this article will be published in Advances in Mental Health Learning Disabilities

The care programme approach (CPA) was introduced in the early 1990s to coordinate the community management of service users with mental health problems and to reduce their disengagement with services. New guidance aims to improve the outcomes of CPA such as increasing satisfaction with services, ownership of the care plan and improving inter-agency communication.

Camden Learning Disabilities Service and Islington Learning Disabilities Partnership have been using CPA for many years for service users with mental health problems. One of the targets of our services' communication plan was to improve the accessibility of the CPA meetings to service users. In 2006, a multidisciplinary group of professionals from the Camden Learning Disabilities Service met to review the services' CPA processes with a view to making them more person-centred. This group included representatives from psychiatry, speech and language therapy, care management, community support and outreach and community nursing.

The group started by reviewing what was and what was not working within the existing process. In that context, they explored service users' experiences of CPA meetings and sent out a questionnaire to all care coordinators for completion.

The outcome of this work provided clear information about how service users and care coordinators would like to see the CPA processes change. Service users reported that they frequently did not understand what had been discussed at the reviews; they felt intimidated and isolated by the process and at the end of the review were disempowered and stressed out. One of the main concerns of the care coordinators was the limited time they had available to make the CPA process accessible for service users.

It was agreed that to address these issues there were two main areas that the group needed to overhaul – the structure and the documentation of the CPA reviews.

CPA structure

The structure was broken down into four stages. Stage 1 is a planned meeting between the service user and care coordinator at which the service user prepares an agenda for the review meeting. This meeting is facilitated by the use of a photo-symbol resource (www.photosymbols.co.uk) made available to all care coordinators and an agenda document accessible to the user. The purpose of the meeting is to prepare the service user in advance of the review so that they have a clear picture of what is going to be discussed. It also helps to generate a feeling of ownership and control over the process.

During the review meeting the service user is encouraged to chair the meeting (stage 2). A format that follows the agenda is suggested, possibly including A0 flipcharts, headed with photo-symbols that correspond to those on the accessible agenda, to facilitate a 'what is working/not working' exercise for each of the items. To allow for the meeting to be run in an accessible way, all CPA meetings are given a 90 min time slot.

Following the review, the care coordinator completes the accessible care plan (stage 3) and meets with the service user for a debriefing session (stage 4). During this session, they check that the service user understood what had been discussed at the review. A copy of the accessible care plan is left with the service user as their record of the meeting, its actions and outcomes.

Documentation

Three new documents were developed. All used a universal set of photo-symbols and followed guidance on making documents accessible. The first to be developed was a leaflet titled 'What is CPA?' which explained the process and what service users might expect to happen.

The second document was an accessible agenda plan. It systematically goes through the key areas that may be discussed at the review and enables the service user to consider what they would like to say in relation to these areas.

The final document is an accessible care plan. Based upon the content of the CPA form, this document presents the action of the CPA review meeting in accessible format. A crisis plan with contact details is also provided.

Care coordinators can tailor these documents to service user's individual needs using a data bank of relevant photo-symbols. The statutory documents of the foundation trust continue to be used but are now enhanced by accessible versions as described. ■

Professional experiences of transition (workshop held at the annual meeting of the Faculty of the Psychiatry of Learning Disability)

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During the Faculty residential meeting I had the great pleasure of contributing to a workshop that aimed to explore issues at transition from child to adult services. Part of the workshop included a brainstorming session about transition to adulthood, which I had hoped would enable us to gain an overview of what transition looked like for other psychiatrists working across the UK. What emerged instead was a wider discussion about many of the attendant issues.

The group itself was composed of one general adult psychiatrist and psychiatrists of learning disability, some of whom worked in children's services and others within adult services. During the workshop, group members were asked to brainstorm about their local experiences of transition and, if possible, any good practice examples. There was a wide variety of experience and opinion within the group. These experiences ranged from one clearly defined transition clinic to the use of care programme approach to coordinate transition.

In brief, the transition clinic was attended by young people during the 2 years prior to transition to adult services; therefore, any difficulties were identified sooner and adult social services were alerted to the need for service provision at a later date. The care programme approach seemed to be used as a way to hand over care from child to adult services. The clinician who described this approach explained some difficulties relating to the information gap that occurred in this context, in particular around the way that the severity of intellectual disability was recorded or measured. This could mean that individuals required further assessment of their abilities. Many members of the audience shared their experience in interpreting the information that they had received from the child services, in particular relating to severity of disability.

Of particular note was the confusion about eligibility criteria for adult services. This confusion centred around two aspects of eligibility, age and ability.

Age

Some services commence at the age of 16 and others at the age of 18. One participant explained that the difficulty

is shared by child services which are also not aware of a date/age of transition, particularly for those with neurodevelopmental diagnoses. The workshop group discussed the relevance of age to the process of transition or potentially its irrelevance, given that people reach adulthood at their own pace and that this can be highly variable in all sections of the population. Indeed, one group member reflected that whereas for the general population transition is a natural process that happens by itself, for people with learning disabilities this was framed as an artificial process that takes place as the individual makes additional transitions from child to adult-orientated services.

In the UK, many good practice guidelines published by the government and the Department of Health have moved away from imposing a date for transition. Transition is described, ideally, as a seamless process that attends to all the medical, social, educational and personal needs of the individual. This would suggest that transition would take place over a number of years rather than happening as a simple hand-over.

Ability

The use of IQ tests to determine eligibility for specialist services was roundly criticised by the group, although its utility as reproducible measure was acknowledged. It was reported that IQ is no longer used in Scotland (!) as a criterion for assessing the level of intellectual disability. The criticisms of IQ tests covered three territories: lack of meaning, loss of borderline intellectual functioning group and resource issues. The IQ tests lack meaning to both service users and professionals who often find that they do not provide an indication of level of need. This was encapsulated by the statement that 'the most severe IQ you can have is 71'. Although couched in humorous terms, this statement seemed to resonate with the experience of the group as a whole and the shared anxiety that is felt about the duty of care owed to those individuals who have borderline intellectual disabilities, who often have significant mental health and social care needs, have been well known to children's services and who on reaching adulthood have no service that meets their needs. It was felt that if such service users were assessed using a different approach, they would indeed be eligible for specialist services.

The workshop group preferred the idea of 'holistic formulations' of an individual's disabilities and strengths that could be used to determine a young person's eligibility for adult services at the time of transition to adulthood. This ideal was tempered by acknowledgement of the need for professionals to create transition plans that are based in real life and are mindful of the available resources.

Conclusions

The participants were sceptical about the idea that transition is a finite experience that can be defined by age or ability and that the current widely diverse approaches for the management of transition often exclude those who are most in need. There was a general consensus that the need for a clear idea of eligibility is important at transition as at any other time and that this should take the form of a formulation of both strengths and weaknesses of the individual.

The participants would like to have access to a nationwide survey of how different services approach this issue. ■

Update on Northern Ireland

Janet McPherson

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Faculty events

A successful faculty conference was held in the City of Derry Hotel in June 2008. The first evening's theme was forensic issues in learning disability. Among the speakers was Dr Siobhan Keating, Forensic Clinical Psychologist. The chance to hear from this acknowledged local expert was most welcome. She was ably assisted by Specialist Registrar Dr Arun Subramanian.

The next day, no fewer than five managers from various health trusts presented their views of the future for learning disability services in their areas. The Faculty much appreciated the time so willingly given by the managers. This meeting was timely, as the administrative changes as a result of Review of Public Administration were almost complete and it was an ideal time to do some planning for the future.

This meeting also said goodbye and thank you to Dr Caroline Marriott, previous Faculty Chair, for her formidable work for learning disability in general and the Faculty in particular.

The autumn saw the annual All Ireland Institute of Psychiatry meeting. This is a joint meeting with colleagues from the Republic of Ireland. One afternoon was given over to specific faculty meetings. The theme for the learning disability part was new service provision, organised by Drs Marietta Cunningham and Aideen Morrison. Speakers from the North and South provoked lively debate. It was good to meet with the Southern psychiatrists and we wish them well for their new Irish College.

Training

Dr Damien Hughes was unanimously agreed to be the new Learning Disability Programme Director. He has taken up

his new post with enthusiasm, notwithstanding the myriad of educational changes happening at present.

Our small but dynamic training scheme continues to flourish and recently welcomed Drs Holly Greer and Maggie McGurgan at specialist trainee 4 level on a job share basis. Presently five trainees are training in learning disability at this level or above, with one trainee, Dr Helen Corbett, on secondment to placement in London.

Service and planning issues

The Review of Public Administration has been taking place over the past couple of years to streamline the administration of public services in the province. It meant reducing the number of health service trusts to five. There was much upheaval at managerial level, which hopefully is settling now with most personnel in post. The current issues are largely those of finance with severe budgetary constrains being imposed upon the health service. The traditional 'Cinderella services' such as learning disability with a history of under-funding feel these cutbacks particularly keenly and some difficult choices have to be made about service provision. There are many patients in learning disability hospitals in Northern Ireland who have finished their treatment and are awaiting resettlement into the community. Existing community services are also stretched. Community services for children with a learning disability and services for forensic patients continue to be patchy.

One bright spot on the horizon is a new eight-bed assessment and treatment unit for children with learning disability and challenging behaviour in Belfast which is on course to open in 2010. This will replace the existing children's ward on the Muckamore site.

Of note for the future is the National Service Framework for mental health services in Northern Ireland, a draft of which is presently being prepared. The latest draft has nine core standards for the provision of services, with the aim of standardising and improving services across the province. This should be published by the Department of Health later this year. Learning disability is also represented on the child and adolescent mental health services group of the National Service Framework by Dr Paula McLorinan, the province's first jointly trained child and adolescent and learning disability psychiatrist who took up post in the summer of 2008.

In conclusion, the Learning Disability Faculty of Northern Ireland continues to develop. However, this is against a backdrop of severe budgetary constraints which will restrict service provision and particularly service improvement for patients. ■

Development of the service user group

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Ray Jacques is the Faculty lead for service user involvement

A service user group was established in June 2006, as the Learning Disability Faculty's response to the College's plan to increase the involvement of the College with users and carers. The formation of the group had followed a significant period of debate within the Faculty as to the best way to engage service users. In the development of national strategy and local service delivery the involvement of service users had become the norm and most of us now experience it within our work settings. However, as a Faculty there was little in the way of direct user involvement and there was considerable debate as to how, or indeed if, such involvement was to happen.

In researching the development of the group it became clear that service user engagement over the past 10 years has become increasingly sophisticated, as had the skill base and experience of service users who participate. Indeed, the development of any mental health policy without service user engagement had become unacceptable. Philosophically, the case for engagement of service users in how we think of ourselves as professionals is a strong one, but it is also politically important if seeking to influence others. It was out of these discussions that a service user group was formed and funding agreed, initially for a 2-year period. This period has now ended and agreement reached for the continuation of the group in 2009. The experience of the group and the thinking behind its development is what I would like to reflect on here.

Setting up the service user group

It was felt important that the group consisted of service users from as wide a geographical spread as the Faculty representatives. The group consisted of four service users, one each from Northern Ireland, Scotland, Wales and England, with Roger Banks and myself as the Faculty representatives. If the group was to attract people with experience and talent, then it quickly became clear that we needed to tap into the network of service user groups and that we needed support to do that. We have therefore enlisted Mencap Cymru to help facilitate the service user group and recruit members.

One of the key questions in setting up the group was about the process of user involvement. Although there were various models available to pick from, we wished to avoid those we considered tokenistic and find a way of

functioning for the group which fitted with what we were trying to achieve. A lot of attention therefore was paid to how meetings were structured.

Beginnings

The service users met the evening before the first group meeting to review the agenda and tasks for the next day. They were joined by the Faculty members for the initial group meeting and for one of the other meetings. This opportunity to socialise with the group was very useful and enjoyable, and it helped the group to function better and get up to speed quickly.

The morning of the main meeting, the service users met with the Mencap Cymru facilitator. The user friendly papers were presented and discussed along with the agenda for the afternoon. The format of the meetings was established in the first session, which proved really helpful. Flash cards were used by all group members to ask questions, have things explained further and to take turns to speak.

Lunch was held with the College members of the group and the joint meeting was held in the afternoon. The group decided on a rotational chair chosen from among the service users and all group members have had the opportunity to take this role. One of the College members took notes and the Mencap facilitator supported the group.

The format of the meetings was flexible, depending on the tasks of the meeting, such as consultation on specific topics (involving power point presentation) or the key issues, and points following discussion were recorded.

The initial meeting included a tour of the Royal College of Psychiatrists and an introduction to the roles and functions of the College. This proved invaluable in orientating the group (including myself) into what the College did and how it functioned. An informal welcome lunch took place with the then President (Sheila Hollins) and Lord Rix. The service users were also able to share details of their previous experience of user groups and to share their own agenda for the group.

Further developments

At subsequent meetings, a particular topic or area was discussed. This included consultation with the Faculty working group about copying letters to patients; consultation on the use of medication in challenging behaviour; and the legal rights of people with learning disability. The major focus of the group was on the experience of users as recipients of services. This led to the development of the workshops and teaching sessions on consultation skills at the Belfast residential conference in October 2007.

In addition to the above tasks, the group also developed a range of topics they felt strongly about and wanted to further work on. This list is extensive but clear themes emerged. They focus on the service user–professional interface and the actual experience of this interface, the skills base, communication styles of professionals, the use of medication and people's choice and rights concerning this. This agenda evolved throughout the course of the meetings and has mapped out a significant plan for future work.

My perspective

Personally, the involvement with the group has been one of the key learning experiences of my professional life. It has helped me not only to think about my own practice and skill base but has prompted deeper reflections into the nature of our work and what we are hoping to achieve. It was also useful to know that the concerns of psychiatrists are not different from those whom we seek to help. Development of evidence-based practice, research and training were all shared concerns. Ensuring that systems of care are fit for purpose, that the rights of the vulnerable are protected, that service users are involved and empowered in making decisions about their treatment and have the right to expect those treatments to have a scientific rationale are areas that need further work. They constitute the salient topics for us as a professional body, as well as for our patients.

In conclusion, service user involvement in the work of the Faculty will continue to present challenging issues for psychiatrists. There is an ongoing debate as to how and why service users should be involved, which for me makes it all the more obvious that service user involvement is essential to the healthy working of the College and the Faculty. Otherwise, we are in danger of increasingly talking to ourselves about ourselves, which I am sure is what we as psychiatrists would strongly advise our patients against!

Finally, many thanks to Olcay, Joan, John Paul and Gary for all their hard work and help. ■

Faculty service user group

John Paul McClusker

Dr Ray Jacques

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Olcay Ucurel

Gary McIntre