



The
British
Psychological
Society

The Same As You? 2000 -2012

British Psychological Society response to the
Scottish Government Consultation report

September 2012

About the Society

The British Psychological Society, incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. We are a registered charity with a total membership of almost 50,000.

Under its Royal Charter, the objective of the British Psychological Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge". We are committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research.

The British Psychological Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

Publication and Queries

We are content for our response, as well as our name and address, to be made public. We are also content for the Scottish Government to contact us in the future in relation to this consultation response. Please direct all queries to:-

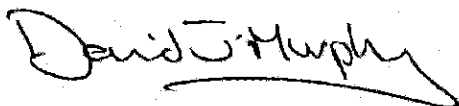
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About this Response

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We hope you find our comments useful.



David J Murphy CPsychol
Chair, Professional Practice Board

CONSULTATION QUESTIONS

Progress and Challenges

Q.1. Do the findings of the evaluation broadly reflect your views about services for people with LD/carer?

Yes No

Yes, the Society believes that evaluation broadly reflects the successes and challenges applied psychologists have experienced across Scotland in relation to services for people with LD. The document pulls together all the key pieces of work that had been recommended or indeed inspired by the Same as You (SAY) over the past ten years.

The picture that is revealed for people with learning disabilities (LD) in the document is significantly better than it once was. The more detailed evaluation reports which underlie the consultation document could have been made more easily available as they contain a lot of useful detail to help the respondent understand the needs of the population and some of the things which have been achieved.

Sampling Issues

We note that the sample of 50 people used to inform the evaluation was not quite as large as intended and has an overrepresentation (twice the number planned) of those living in the community, with fewer ex-hospital residents and people living in restricted circumstances than planned (half the number). Additionally, the sample did not include any young people under early twenties. Other than this it seemed to represent a wide range of people and it was good to see ethnic minorities represented.

The SAY related to people with a learning disability, as well as those with autistic spectrum disorder (ASD) (including those without a LD). The Society would find it helpful to have greater clarity with regards to whether this consultation also refers to people with ASD who do not have a LD.

We continue to use the term learning disability across health and social services in Scotland and are concerned that one or two parts of the evaluation refer to "learning difficulties" which refers to some different client groups with more specific cognitive differences and needs, and less significant social needs, than those with a LD. We are aware that the term Intellectual Disabilities is now recognised and internationally understood.

Q. 2. Can you give examples; either locally or nationally, of what you think has worked well over the last 10 years of *The same as you*?

Since the launched of SAY there appears to have been a fundamental shift in attitudes towards individuals with a learning disability, amongst the general public, professionals and people with LD and their families. This has been underpinned with equality and diversity policies, as well as anti-discrimination legislation, adult protection legislation and the Incapacity Act. The SAY work has helped people see those with LD as independent individuals, with their own needs, wants, talents and ambitions, rather than as a homogenous group to be contained in long-stay wards. For a lot of people, it was the first time that they have heard the voices of

people with LD and understood the need for change.

A continued national change is the reduction in bed numbers in hospitals for people with LD since there is no evidence that hospital is the best place to treat or intervene or manage their difficulties. However, there is still work to be done to identify and implement best practice in managing complex needs of a variety of kinds (both physical, psychological and behavioural) in the community (Department of Health, Mansell, 2007). It can still be extremely slow to secure funding and implement a suitable package of care when an individual is discharged from hospital, particularly when this person's original care package has ceased following admission. Often patients in a hospital may not be considered a priority as they pose less risk than individuals in a crisis in the community.

Often what works best for individuals with complex needs is a service with specialist understanding of the nature of the person's specific difficulties and a well-managed, supported and informed staff team, rather than a hospital ward, as well as an understanding of the long term nature of many of these needs. Thus models of care based on psycho-social needs rather than a biological illness model can be most useful (Hatton & Taylor, 2005; Kinderman, 2005).

Living Arrangements

Specific examples of things that work well across Scotland include the choices people with LD can make over where and how they would like to live, including in some areas, joint health and social care provision for those whose needs are extremely complex. A range of different options, from single tenancies to shared living, are now available and we can meet almost all needs by working closely across public and a range of independent service providers.

However, while the evaluation reports numbers living more independently in various living arrangements there is a lack of information about how they feel about where they live, and whether this is similar to experiences of the general population.

Scottish Consortium for Learning Disabilities (SCLD) and South East Scotland LD Managed Clinical Network (MCN)

Both of these organisations have made very useful contributions to the development of services and to the involvement for people with a LD as well as learning from each other. Their profiles do not appear to be as evident across the whole of Scotland, and across all services and sectors as they might be. LD NHS services are relatively small and these national and regional groups provide essential reference points and for sharing good practice and supporting small specialist groups of professionals. It would be useful to encourage more working together, or to host a joint conference to allow services right across the country, including the north, to benefit from the learning to date and ongoing activity.

Additionally the national Forensic Network has achieved a great deal in terms of sharing good practice and the work of their LD work stream could be more explicitly shared and linked to these LD organisations. The LD MCN are considering a regional development for women with a need for a low secure in-patient service as currently many women have to be admitted to hospitals south of the border or within private establishments. We therefore believe it was unwise to close beds in The State Hospital before suitable community and low secure services for both men and women with LD had been developed.

Health

The Health Needs Assessment Report for People with LD published in 2004 has

been extremely helpful in promoting a greater understanding of the health needs of this population and highlighting current service delivery gaps. The recent health evaluation review commissioned by SCLD/Scottish Government is helpful in updating progress in these areas (Allan, Brown, Brown, & Stevenson, 2012).

Much of the progress has focused on individuals' access to physical healthcare, identification of physical conditions, and supporting acute and primary care services to improve their service in order to benefit people with a LD. Quality Improvement Scotland (QIS) assisted in ensuring continued progress. South of the border there is a Public Health Observatory specifically designed to monitor the health of people with a LD. It is unclear as yet how the Scottish Public Health Observatory will address the needs of specific or indeed overlapping populations.

Mental Health

As noted in the recent SAY health review, mental health and emotional wellbeing have been somewhat neglected in this agenda, in which health is often assumed to refer to physical health. Michael Matheson, Minister for Public Health, in his introduction to the recent Mental Health Strategy for Scotland 2012-2015, states:

"Key challenges are to continue the good work that has already been started to deliver on our commitments to offer faster access to specialist mental health services for young people and faster access to psychological therapies. These targets are world leading in setting expectations for access to mental health services. They demonstrate how in Scotland we truly give mental health parity with other health services in what we do as well as in what we say."

We strongly believe that such aspirations must also apply to people with a LD who have psychological, behavioural or mental health difficulties. Services for people with a LD have had the advantage of adopting a psycho-social model many years ago, and thus the recovery model now used widely in mental health services is easy to understand, but this should not be a barrier to receipt of specialist therapy, delivered by suitably trained people when it is indicated.

Psychological Interventions

Encouragingly a modest increase in research to improve the evidence base for psychological therapies such as Cognitive Behavioural Therapy (CBT) for anger management has continued over the last decade, but support for further research is crucial (Taylor, Novaco, Gillmer, Robertson & Thorne, 2005; Willner, Jones, Tamsy & Green, 2002; Scottish Government, *The Matrix*, 2011).

There is a long-established evidence base for behavioural analysis and individualised behavioural interventions based on an analysis of the function of behaviour. In 2010 NHS Education Scotland (NES) funded the pilot of a training programme for Positive Behavioural Support (PBS) for LD nurses in Scotland. Clinical Psychologists assisted in the selection of educational provider and had a major role in providing clinical supervision to participants applying their learning in the workplace. Further development of this training could enhance the skills of the LD workforce and ensure that people with a LD receive evidence based effective support. (Harvey, Boer & Evans, 2009; Scottish Government, *The Matrix*, 2011).

Services in NHS Scotland are supporting the developing evidence base for a number of other psychological approaches and interventions for individuals, carers and families. These include an adapted version of the Clinical Outcome Research Evaluation (Booth-Willis & Marshall, 2009), Behavioural Family Therapy (Marshall, & Ferris, 2011), and Cognitive Analytic Therapy (CAT) (Kirkland, 2010; Breckon & Simpson, 2011). It is crucial that research into effective psychological

interventions receives support and that evidence based interventions are delivered by the right staff with the right qualifications at the right time and with appropriate clinical supervision in line with *The Matrix: A Guide to Delivering Evidence-based Psychological Therapies in Scotland* (2011). It is essential that such interventions are understood and supported by a capable workforce (*Review of Learning Disabilities Nursing*, DoH, Welsh Government, Scottish Government, 2012)

Q. 3. Can you give examples of issues in current work and/or policies that still need to be addressed?

Improved Interagency Working

Greater collaboration, coordination and sharing of resources within and across agencies could further improve and enhanced the provision of seamless services for people with a LD. Work continues on improving transition from childhood (education, health, accommodation, care, benefits) however this has been discussed for over twenty years and continues to be highly unsatisfactory for many families. The Society response to the consultation on the NHS Scotland Quality Strategy emphasised the need for clear communication and explanation about conditions and treatment, and effective collaboration between clinicians, patients and others. It remains the case that some people with a LD are supported by independent sector care staff that may have had little or no training. Clinical Psychologists invest considerable time in training staff groups to help them understand what this means for their client/patient/service user and how they need to adapt their communication and expectations specifically in relation to individual needs. Clinical Psychologists are also spending increasing amounts of time informing assessments of capacity to understand various aspects of life in order to inform medical opinions.

Supported Employment, Training and Further Education Opportunities

We believe these could be improved and were disappointed by the reduction in part time college places for people with LD last year. Performance targets for schools may have had an indirect effect for children with LD who previously remained in school for much longer than is often the case today. We believe it is important that these young people do not become excluded from both systems due to the barriers they present to organisations meeting specific performance targets. Meaningful employment opportunities are critical to help people live lives free of poverty and without the risk of social exclusion and encouraging individuals to self manage in relation to employment has been shown to promote self determination (Rusch & Dattilo, 2012).

Choices / Independent Living. Many Clinical Psychologists believe that there is a need to commission more 'core and cluster' services. This model can offer a flexible and more robust support plan that fosters independence whilst allowing easy access to staff support at short notice. This would offer greater scope to meet the needs of some service users who have the skills to live independently but may be vulnerable at times.

Choices / Day Opportunities. We believe that service users would benefit from

increased efforts to make links with voluntary sector organisations that offer creative opportunities that are inclusive of a range of service users. Excellent examples of services in Glasgow are Indepen–dance and Project Ability. These organisations offer opportunities to develop creative interests with skilled support whilst also breaking down prejudices and social barriers. Other creative options should be encouraged and greater links forged with local 'Arts initiatives'.

Equality in Improving Access to Psychological Interventions

The Scottish Government Mental Health Division has undertaken a great deal of work over the past four years to develop a set of standards and governance around NHS delivery of evidence based psychological interventions. This ensures that staff are appropriately informed and trained, and that services make appropriate delivery plans to facilitate the provision of interventions at all levels using skill mix, and that people receive a timely service. However, the application of these approaches and targets by NHS Boards has been patchy across Scotland, particularly for smaller groups with more specific needs such as people with LD. We believe that the NHS Boards Psychological Therapies Groups should address the needs of people with LD and other developmental disorders, not just mental illness, anxiety and depression in the mainstream population.

Incapacity Certificates (for medical treatment)

Clinical Psychologists are competent to assess capacity to make various decisions but have no statutory duty to contribute or issue certificates. Currently they have to request a certificate to deliver their own intervention from the GP who very often asks a Clinical Psychologist for their opinion about such matters. We believe that this is a waste of resource and should be reviewed.

Clinical Psychologists are frequently required to provide specialist assessment of capacity in relation to complex decisions regarding ability to make decisions where responsible medical staff need expert advice in relation to the *Adults with Incapacity (AWI) (Scotland) Act (2000)*. The absence of Clinical Psychologists from the list of professionals who are able to provide a Section 47 Certificate for psychological treatment they provide would therefore appear to be a significant anomaly, leading to unnecessary time and expense resulting from referrals to GPs (who may subsequently seek advice from the psychologist regarding the assessment of capacity). It should also be noted that the increasing demand on specialist LD psychology services which has resulted from AWI is a significant factor in increasing waiting times for psychology referrals.

Good Practice – Organisations

Q. 4. Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?

The British Psychological Society has published the following documents to support, guide and set standards for applied psychologists and organisations working with individuals with LD:

- *Good Practice Guidance for Clinical Psychologists when Assessing Parents with a Learning Disability* (2012) Baum, S., Gray, G., and Stevens, S. (Eds)
- *Commissioning Clinical Psychology services for Adults with LD* (2011). Guidance for commissioners and senior managers on the role of Clinical Psychologists who work with adults who have a Learning Disability.
- *Dementia and People with Learning Disabilities* (September 2009). Guidance on the assessment, diagnosis, treatment and support of people with LD who develop dementia.
- *Challenging Behaviour: A Unified Approach* (2007). This report was published by a joint working party across the Society, the Royal College of Psychiatrists and the Royal College of Speech and Language Therapists. It outlines a number of ways in which the quality of life of people whose behaviour challenges services can be improved through direct clinical interventions, developing capable environments and creative commissioning.
- *Good Practice Guidelines* (Updated Dec 2005) for UK Clinical Psychology Training Providers for the training and consolidation of Clinical Practice in Relation to People with Learning Disabilities.
- *Learning Disability: Definitions and Contexts* (2000).
- *Challenging Behaviours - Psychological interventions for severely challenging behaviours shown by people with Learning Disabilities* (2004).

Good Practice - Individuals

Q.5. What have you done, as an individual, to make positive changes within your local area?

Applied Psychologists have taken significant leadership roles in a number of areas. Some examples are listed here:

- In several NHS services, Clinical Psychologists have led multi-disciplinary working groups to develop a dementia diagnostic care pathway.
- In several areas clinical psychologists have led the development of multi-disciplinary evidence based diagnostic pathways for assessing ASD and providing post diagnostic support.
- Clinical Psychologists across Scotland have worked collaboratively with challenging behaviour nurse specialists to develop tiered services for those with severe challenging behaviour.
- In Fife, a Clinical Psychologist has been developing and evaluating work with parents with a LD over a number of years. A multi-agency assessment pathway is currently being developed to ensure that timely evidence based multi-disciplinary assessments inform the best support for parents with a LD, and the support and protection for their children. Also in Fife, a Forensic Psychologist has led the adoption of the 'Good Lives Model' within the Fife Forensic LD Service (Ward & Stewart, 2003). This emphasises the function of offending behaviour in meeting normal needs and requires the service to support service users to meet these needs more adaptively.
- In South Glasgow LD Teams, a care pathway to ensure the use of Adults with Incapacity (Section 47 Part 5) certificates has been developed. This has heightened professionals' awareness of our need to consider clients' capacity to consent to treatment, or to refuse treatment. The pathway offers a clearer framework to enhance consistency across GP practices so that clients get a more consistent service. They have also been set up a transitions pathway to ensure that service users and families are offered continuity of support in the transition from child services to adult services have linked with palliative care with the aim of enhancing our service by establishing an end of life plan for service users with palliative care needs.
- At the University of Edinburgh, several doctoral trainees have been supported to complete research with people with LD or ASD, their staff or their families. A Clinical Psychologist supports a government funded research programme into improving standards of diagnosis of adults with ASD.
- At the University of St Andrews, a Senior Lecturer in the School of Psychology and Neuroscience acts as a consultant to the Joint Improvement Team (JIT), the Psychological Interventions LD sub-groups and serves on the Boards of the SCLD and PAMIS. This ensures that account is taken of evidence when developing policy and involving service users.
- At the University of Glasgow several studies are being carried out to evaluate the processes and outcomes of adapted psychological therapies for people with a LD. In collaboration with colleagues in the Glasgow UCEDD and elsewhere in the UK, a randomised control trial of group anger management has been established and is delivered by service staff that are trained and supervised by Clinical Psychologists. This was a major trial involving 179 participants with LD and their workers and carers. A small

open trial of adapted Behavioural Activation for depression in Glasgow has provided promising results and led to HTA funding for a randomised control trial across sites in Scotland, England and Wales that will start in 2013. A feasibility study of challenging behaviour training for family carers is being led in Glasgow. In addition to outcome treatment outcome studies, funding has been obtained to examine key processes that underpin the delivery of CBT, this includes the perceptions of individuals with LD who are receiving therapy. Research examining psycho-social factors that contribute to the inter-personal and emotional well-being of people with LD is also underway. This includes work on frequent aggression and investigating the areas of depression, anxiety and young people's developing sexuality.

- The development, implementation and evaluation of child, adolescent and adult intellectual disability screening tools to help identify those who are likely to have an intellectual disability in community, health, criminal justice and educational settings.
- Society members have various other clinically relevant research going on e.g. emotion recognition in children with LD and ASD project with schools in Lothian, examining factors which influence the likelihood of parents and carers facilitating a healthy diet in those they support. An influential project is the LD screening tool work and the adoption of this tool across the UK, Europe, Australia, New Zealand, Japan and Hong Kong. The adult version has been piloted and recommended for use in criminal justice services by the Department of Health and the child version has been recommended for use by education for children aged 14 upwards to help inform transition services.

Future Priorities - Healthcare

Q.6. What still needs to be done to ensure that people with LD have access to better and more appropriate healthcare?

Workforce Issues

At a recent presentation for the Joint Improvement Team and Mental Health Division, Dr Michael Brown, Consultant Nurse, emphasised the increasing range of complex needs presenting due to the changing nature of the population of people with LD.

In terms of the need for trained health practitioners he said, "The role and function will be one of knowledgeable and expert practitioner who can educate, assess, plan, coordinate, safeguard and deliver evidence-based interventions for a population with high and complex care needs".

Applied psychologists would be in full support of the work developed by Tommy Stevenson, in his workforce planning role with NES, and the ways in which development of information sharing, learning and professional development must underpin services to people with a LD. We would like to see this work made more visible to NHS Boards and local authorities (Cheseldine, McCue, Brown & Kwiatek, 2011). See presentation made at JIT/MHD Regional Event, Beardmore Hotel and Conference Centre, *Glasgow Complex Needs Supports Working Together*.

However, there is a large body of evidence about the impact of staff training and development and this must be utilised in development of any further initiatives. Simply making training packs available is inadequate. Surveys of clinician/ staff confidence in delivering interventions are as important as evaluations of knowledge

change (Cochrane, 2011).

Applied Psychologists have considerable expertise in developing and delivering staff training, and of doing so in a manner which can be delivered within a working week, e.g. in repeated or regular 'bite size' chunks. They also have the skills in delivering clinical supervision around psychological therapies and in other activities related to the clinical governance thereof.

However, it is not only the NHS workforce who must be considered. Michael Matheson stated in his introduction to the Mental Health Strategy Scotland 2012-2015:

"People...have a greater desire to control how they access help and support. Self help, self referral, self directed, self management and peer to peer are all concepts that will only grow in importance and which demand a different mindset and approach to service design. The system of the future must develop to embrace and adopt these approaches alongside the more traditional approaches to service delivery, which will also continue to be necessary."

Applied Psychologists working with people have a long tradition of sharing their skills with nurses, families and support workers. "Self directed" for people, with a LD often means with support. Those family or paid carers offering that support must also be well informed about the nature of LD and the many co-existing physical and mental health issues their client may experience. Commissioned services must build standards in ensuring adequate knowledge and capability in their staff.

Service Development and Outcome Measurement

The Society urges that use is made of the skills and expertise of applied psychologists when considering service development and outcomes assessment. This would be in keeping with the vision of how Applied Psychologists can assist both the NHS and other services achieve their objectives, set out in the report *Applied Psychologists and Psychology in the NHS* (Scottish Government, 2010), and would ensure best use of the expertise of psychology as a profession.

General Healthcare

The health care patterns of need for individuals with LD have been shown to differ from the general population. This is the case for both physical and mental health. Individuals with LD are more likely to experience health inequalities (Cooper, Melville & Morrison, 2004).

Epidemiological studies have consistently reported a significant association between poverty and the prevalence of intellectual disabilities (Emerson, 2007). The increased risk of poorer health of children and adolescents with LD is associated with the greater risk of socio-economic disadvantage (Emerson, & Hatton, 2007). Poverty accounts for some of the health and social inequalities experienced by individuals with a LD and this should be taken into consideration during policy writing.

Health care staff require training in accessible and effective communication. Health promotion messages need to be repeated, and must be consistent and engaging. People with LD may need to hear the same message several times, and need support to understand the implications for their own behaviour around health.

The Society believes that consideration needs to be given to staff training in areas of healthcare need which are being developed at a general level, e.g. weight management, palliative care, and which have a health psychology component.

Health Psychologists who may have limited experience of working with people with a LD could develop this experience with the support of clinical psychology colleagues and/or LD specific services.

Many psychology services now offer a considerable degree of support in relation to dementia through standardised assessments to aid diagnosis, training workshops for carers and contribute to multidisciplinary baseline assessments for all adults with Down Syndrome when they reach an agreed age (Jones, Hathaway, Gilhooley, Leech & MacLeod, 2010).

It would be useful to continue the monitoring of the Quality Indicators developed and reported during the last decade. These would provide an excellent baseline against which to measure continued improvement with an appropriate emphasis between adults, children, physical health and complex needs of various kinds.

Mental Health

There has been a great deal of progress with work still to be done on physical health needs for people with LD. The recognition of work by NES and JIT towards improving practise in work with challenging behaviour is welcomed and must be built upon. LD services have adopted a psycho-social model many years ago whilst emphasising 'ordinary lives' as the priority.

Some mental health services for people with LD still use a predominantly medical model however, and this can be a disadvantage. Broader psycho-social understanding of mental health difficulties can be less stigmatising (BPS, 2010). In *England the Mental Health Act (1983) Approved Clinician (General) Directions (2008)* and the *Mental Health Act (2007) New Roles Guidance (NIMHE, October 2008)* determined that not only medical practitioners could be Responsible Medical Officers for those detained in hospital or the community, but also Consultant Nurses and Clinical Psychologists with the new title of Approved Clinician. In a LD service this is particularly appropriate since many admissions to hospital relate to behaviour rather than illness (Beail, 2010) and in pilot sites this arrangement seems to work well. The Society has supported this initiative via training and accreditation of these new Approved Clinicians.

It is well evidenced that mental health needs are greater in people with LD (Cooper, Smiley, Morrison, Williamson & Allan, 2007). Same as You, the QIS reviews of LD services and the current evaluation have failed to emphasise this. The reasons for this higher prevalence is due both to organic brain differences, as well as higher prevalence of distressing life experiences such as bullying and sexual and physical abuse, as well as disability itself. Diagnosis can be more complex when compared to mainstream patients and there are difficulties delivering suitably adapted interventions and support in mainstream mental health wards (Simpson, Whoriskey & McCue, 2007).

A stronger emphasis on joint working between mainstream mental health services and LD services would be welcomed as recognised in the *Mental Health Strategy for Scotland 2011-2015 - A Consultation*, Scottish Government (2011) and *Promoting Health, Supporting Inclusion*, Scottish Government, (2002).

Increasing Evidence Base for Psychological Interventions

The Scottish Government have recently commissioned and published a review of the evidence base on psychological interventions (Scottish Government, *The Matrix*, 2011). This document was developed in response to requests from health boards for advice on commissioning services in local areas.

"The Psychological Therapies 'Matrix' is a guide to planning and delivering

evidence-based Psychological Therapies within NHS Boards in Scotland. It provides a summary of the information on the current evidence base for various therapeutic approaches, a template to aid in the identification of key gaps in service, and advice on important governance issues."

There is a significant evidence base that supports the use of PBS (Harvey, Boer, & Evans, 2009) and the evidence base for the application of CBT is growing for this population (Taylor, Novaco, Gillmer, Robertson, & Thorne, 2005; Willner, Jones, Tamsy, & Green, 2002). Training in approaches such as PBS and CBT has been made available to staff in LD NHS services, and to LD staff in forensic services respectively.

These training packages should be encouraged across both sectors and standards regarding appropriate trainers and ongoing supervision during the programmes communicated to Boards for its delivery. Boards may need to consider best use of integrated approaches between mental health and LD services to ensure specialist services are only utilised when really necessary.

Interventions should be measured by acceptable outcome measurement tools – acceptable in terms of adaptability for people with LD, affordable for services and meaningful when summarised centrally. The Society's, DCP Learning Disabilities Faculty, have recently published (2012) an outcome study in relation to assessment and intervention for individuals who present with challenging behaviour and this recommends and provides access to some outcome measures.

Child Mental Health/Psychological Needs

We believe that clarity is required in relation to specialist services for children with developmental disorders of various kinds, as well as LD more broadly, in terms of how these specialist services relate to general Child and Adolescent Mental Health Services. Consideration needs to be given to the benefits of very specialist services as opposed to giving children access to mainstream services. Decisions are required about integration with local authority and social care organisations.

Support for Families and Carers

The Society is extremely concerned to read that parents were still being given negative messages by health and social care staff following the birth of a disabled child within the last three decades. However, we are aware that there have been publications supporting this evidence, albeit with reference to those now in their teens (Myerson, 2009; Mencap, 2001). Any information SCLD have from their research should be passed on and action should be taken within the relevant health areas, ensuring that current maternity and paediatric teams have had training in breaking the news of a disability diagnosis, with a view to offering appropriately constructive follow up and support.

The evaluation clearly recognises the impact that caring can have on mental well-being but there clearly continues to be a need to offer support to carers in this area to promote the maintenance of good mental health e.g. work carried out in Ayrshire using WRAP© training for carers, or utilising Local Area Coordinators to help identify services.

As people in general are living longer there appears to be an increase in older carers. (Walker & Walker, 1998). Often a crisis situation occurs (e.g. parental death) prior to care packages being commissioned. Commissioning strategies need to develop evidence about local needs in this respect and plan accordingly, working proactively with families and people with LD, as often happened in the early days of community care.

The recession has had an impact on the availability of care packages and individuals with LD may be waiting for longer to move into appropriate accommodation, with very uncertain timescales. Welfare reform and reviewing benefits adds to such uncertainty. This has an impact on families' ability to plan their lives, increasing stress and decreasing a sense of control and wellbeing. A means of monitoring carer demographics needs to be considered. Although census data tells us that as individuals get older they are more likely to take on more responsibility as carers, this information is not currently captured in eSAY returns.

Relationships

The Society's response to the consultation on Mental Health Strategy emphasised the importance now placed on the effect of poor childhood attachment experiences in the development of complex mental health problems such as personality disorder (Bentall, 2009). Services should place greater weight on the security continued relationships with professionals and care staff can provide, and this should be considered in workforce planning, and in staff training. Such an emphasis on the relational is being increasingly considered within forensic services using the cognitive analytic model to help staff understand the way in which their patients have developed patterns of relating which can manifest as behavioural difficulties, and the way in which staff responses are crucial in assisting patients to develop more adaptive responses.

Psychological health is very dependent on support from a variety of relationships (Cohen, Gottlieb & Underwood, 2000). Clients with a LD may report feeling lonely, particularly during weekends and evenings and one of the negatives of decommissioning of large sites has been that loss of contact. Further work to develop places people with LD can meet together if this is what they wish should be considered, as well as integrated social opportunities (McConkey & McGinley, 1990).

From clinical experience this seems particularly pertinent for people who have had packages of care that involve 24 hour support and therefore are not funded to access shared day services (McCorkell, 2012).

Often those discharged from long stay hospitals have not been supported to keep in touch with those they were friends with whilst in hospital. Work with care providers to encourage more creative ways of linking up individuals in the community could be a way forward. A consistent environment and network allows those with LD to form stable relations enhancing opportunities for social interaction (Peck et al., 1997).

Criminal Justice

The Society welcomes the development of medium and low secure services for people with LD and forensic needs however the other parts of the criminal justice section of the consultation document is not entirely clear. These services still have the problem of delayed discharges and difficulties funding and moving people on to the community safely. Very few beds for women were developed and women continue to be sent south of the border regularly to the detriment of their family relationships and continuing care. Men who need medium secure beds are also still being referred south of the border. The South East and Tayside (SEAT) MCN project considering "models of care for those with the most complex needs" (MCN paper, 2012) drew together much of the information related to development of further tiers of service for those with most complex needs and which may help inform government about the needs in this area.

There have been recent publications indicating that the percentage of individuals with LD in prisons is much higher than previously thought (Xenitidis & Powell, 2008). With prison mental health services being transferred over to NHS it will be interesting to see how this impacts upon prisoners with LD and emotional health needs, given no funding was transferred from prison to NHS for psychology services. Forensic Psychologists continue to be employed directly by prisons to deliver offence related assessment and interventions, but not mental or emotional related therapy.

Perhaps prison staff training needs to be addressed as a priority.

Forensic Matrix

The forensic matrix meetings are considering how to deliver low intensity interventions across the forensic estate (including LD). It will be interesting to see how services ensure that this is implemented on an equal footing within LD services.

Priority Themes

In light of the expected future population changes and an increase in older adult representation it is key that we give priority to this group of individuals.

With regard to ageing and dementia, the consultation simply suggests services 'plan' for an ageing population. The Society would emphasise the need for staff training in health and dementia related issues for people of older age and a LD. The BPS/RCPsY (2009) *Dementia and People with LD. Guidance on assessment, diagnosis, treatment and support of people with LD who develop dementia (CR155)* also highlights the need for good quality assessment, diagnosis and support and those guidelines have been helpful in helping services develop to meet the increasing needs of this client group. Early assessment, functional modifications to living environment, staff education and long term flexible services are required (Janicki, 2011).

Additionally commissioning of care should be determined by person centered approaches regardless of age. Relationships between general practice, primary care and LD should continue to be developed to ensure joined up health care and good communication in complex cases.

Future Priorities - Education

Q.7. What still needs to be done to ensure that people with LD have access to better educational opportunities?

The Society believes it would be very helpful if educational services would identify children with a LD at the earliest possible stage. There are still far too many young people leaving school where their needs remain unclear to adult services, requiring assessment in their late teens. Often they have been labeled with a number of different diagnoses none of which make it clear they have broad and significant cognitive and social impairments which constitute a LD.

We would advocate a culture of expectation of and support for educational attainment for people with LD.

Working closely within the Additional Support for Learning Procedures, schools must be clear whether cognitive or social factors are impacting on learning in order to ensure the most appropriate interventions and supports in preparing for transition to adult services.

We believe it is important to ensure that college places are available on a full and part time basis, to anyone with a LD who wants to attend further education. There is good evidence of a more general link between education and employment success, including income levels. People with LD who are able to achieve qualifications will be better placed to find meaningful employment.

Additionally, education and further education can support people with LD in developing wider life skills, social skills and a greater degree of independence and confidence. It is therefore essential that there are enough accessible college places, that schools support young people to achieve entrance requirements for mainstream college places where appropriate and that we support parents and families in understanding the importance of education for all young people.

Future Priorities – Independent Living

Q.8. What still needs to be done to ensure that people with LD are able to live independently?

The definition of a LD implies that a person requires at least some level of support in their life. We believe suggest that it is important to distinguish autonomy with independence. No member of society is entirely independent, but most desire autonomy at various levels. Many of those who find it hardest to speak for themselves still require considerable support and will never be completely independent.

Professionals could support people in positive risk-taking to a greater extent than at present, through a culture of enablement (and in some cases, re-ablement). However, this cannot be done without support providers being very informed about the nature of people's disability and cognitive difficulties to ensure expectations are sensible and effectively and ethically implemented.

We recommend that those offering support should be enabled to understand why there are ways of delivering their service which will work best for the individual and increase the likelihood of achieving greater independence. Stable staff and carers also increase the likelihood of service users developing their skills and confidence over long periods of time.

The Society would welcome research, investment in and development of new technology to support independence (Taber-Doughty, Shurr, Brewer, & Kubik, 2010) whilst retaining a strong ethical framework to increase independence (Perry, Beyer & Holm, 2009).

More LD awareness raising for transport planners and transport providers could well make further impact in terms of equality and independent living.

Future Priorities – Employment

Q.9. What still needs to be done to ensure that people with LD have access to better employment opportunities?

The Society has no comment to make on this aspect of the consultation.

Future Priorities

**Q.10. What other future priorities do we need to focus on?
(Please list these in order of importance with the most important first)**

- Improved and joint commissioning of services for people with LD ensuring those delivering services are knowledgeable and capable in the specific ways required by their individual clients.
- Increased partnership working with the independent sector to meet a diverse range of need with tailored solutions.
- Continued development of joint working between health and social services, service users and communities.
- Research into demographic changes, and into how we achieve the best possible outcomes for people with increasingly complex needs.

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