

CONSULTATION QUESTIONS

Progress and Challenges

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

Yes No

Please provide any comments, evidence and/or examples here

This is a readable and comprehensive overview of the overall experience for people with learning disability and carers today and is a useful reminder of the real progress that has been made over the past ten years both in providing support and enabling people with a learning disability to support and organise for themselves.

The report clearly aims not only to highlight these improvements but to list the challenges that remain. It recognises the significant variation across areas in progressing such a wide agenda and the difficulties in drawing clear conclusions for a national picture. The authors often do not provide any analysis as to why progress has not been made and where particular agencies have been inactive or ineffective. Whilst this is not intended to be an 'inspection' report it does mean that the concluding priority actions are therefore necessarily rather global and tend not identify who should be doing what - talking in terms of 'agencies' and 'public authorities'. This is unlikely to trigger action or reinforce responsibility with individual readers/agencies in terms of ownership of the action plan.

We were unsure around the methodology used for the evaluation. SCLD is an estimable organisation with considerable achievements. However it is a charity with a number of influential partners not part of Scottish Government. SAY originated from government and established SCLD as a catalyst and champion for progressing SAY. Part of evaluating SAY would be evaluating the effectiveness of SCLD - something which may have been done separately - and there may have been a case for this evaluation being carried out by a more independent researcher. This is not a comment on professionalism or integrity of SCLD. The Scottish Government set up the evaluation team has not followed its normal practice of listing the members of the report team aside from those named within the acknowledgements to the full reports who we assume were members of the team.

The sample sizes for both people with learning disabilities and carers were relatively small compared to the total population and when divided further into categories would have made it difficult to draw firm or meaningful conclusions which would therefore need to be treated with some caution. This we assume was more a reflection of the limited resources made available to the researchers rather than a methodological decision. This does mean that it is not always possible to distinguish as to whether this report is a policy evaluation or a stand-alone research exercise meaning that it tends to fall between these stools.

The report is not placed within the current and projected economic climate or explicitly deal with the 'elephant in the room' of the very limited and ever-shrinking resources available to statutory and voluntary agencies. Hard areas around eligibility, targeting resources and rising expectations from service users and carers are not addressed. Whilst government cannot dictate how authorities spend their money this does not facilitate delivering the action plan provided. Consideration should be given to national targets along the lines of HEAT.

In many of the areas dealt with – such as transport, employment and education - the difficulties identified are not exclusive to people with learning disability and again a wider context would have prompted discussion around specialist projects versus mainstream services which is a constant theme at local level.

There could also be a more sophisticated analysis of desired outcomes. Whilst there has certainly been a massive change from institutionalised care to community-based support in many cases this has led more to narrow domestic routines largely with paid staff rather than real integration into local communities, peer support and user empowerment.

Nevertheless the report - and in particular its consultation with people with a learning disability and carers - is a very welcome catalyst for prompting and re-energising our efforts to sustain and further improve our response.

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*?

Please provide any comments and/or examples here

- closure programme of long-stay hospitals and relocation of former residents into community-based accommodation
- creation of joint learning disability team within East Dunbartonshire which is well-established and co-located within a building accommodating primary care, mental health and all social work community care teams and thus providing the full range of clinical support
- increased visibility of people with a learning disability and some improved integration via expansion of further education and (to a lesser extent) employment opportunities
- major shift within East Dunbartonshire with most eligible adults utilising our dedicated residential respite facility rather than as previously having to travel (in some case long distances) to respite provided elsewhere. This resource has very much become part of the local village community assisted by recruitment of many of its staff/manager from the immediate area

- move from structured centre-based day activities to more person-designed flexible activity - locally we retain a sizeable centre (albeit one with excellent Care Inspectorate ratings) but the content and location of delivery has been transformed and we are moving to a more decentralised approach around 'community hubs' with aspirations for a significant SDS element - successful 'social club' model locally
- improved and targeted health promotion/health check activity from the joint learning disability team - including an innovative response to periodically screening people with Down's Syndrome anticipating possible dementia onset and local agreement with GPs around prevalence and enhanced surgery appointments
- developments in availability of advocacy - locally commissioned single advocacy project which works with all adults including those with a learning disability with excellent links into Social Work and the JLDT
- implementation of progressive and principle-based legislation to both protect and promote the rights of those with a learning disability as well as other mental disorders - Adult Support & Protection, Mental Health Care & Treatment - positive local examples of use of ASPA to benefit adults
- access to SCLD for information, advice and joint working - locally SCLD were commissioned to complete a small piece of action research with service users who had been subject to adult protection processes
- move towards a more person-centred, outcome-focused approach to social work assessment and support management - locally we have
 - longstanding access to staff trained in delivering Person-Centred Planning
 - implemented an outcome-based framework for drawing up and reviewing support plans alongside service users and carers (see case study on IRISS website)
 - continually adapted assessment format used by JLDT to incorporate developments such as SDS and an outcomes focus
 - producing easy-read formats as required
- response from palliative care services has generally been very positive locally from specialist nurses working alongside JLDT nurses who have had relevant training

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

Please provide any comments and/or examples here

Expand use of easy-read formats at a national and local level - not just relating to learning disability-specific materials but generically for official publications e.g. routine use of visual prompts on letterheads

Central and co-ordinated assistance to local areas around the funding and management of high-cost support packages - probably the single biggest challenge facing adult social care and one that we all struggle with - including if possible an agreed model (?with CoSLA) for a resource allocation framework - need for national forum as well as clear guidance

Acknowledging the current and anticipated financial constraints and the difficult decisions being made and that will have to be made as budgets continue to contract

Communicating this to parents/carers locally and nationally given their rising expectations and the advocacy and ever-increasing range of purchasable service provided by key voluntary agencies

Need to review models of support/care which in many cases were developed speedily to meet the needs of those discharged from long-stay hospitals but where the infrastructure is no longer fit for purpose - in particular to support young people in transition and older people with increasing needs - growing proportion with complex needs/challenging behaviour now being managed in community settings where the onus falls mainly on care providers employing staff with limited training on low wages

The undoubtedly more tolerant response from the community could be tested if support packages have to be shaved by budget limitations - year on year savings now being sought by local authorities from care providers

Evaluate new models of day activity and benefit to adults

- does the scope of community-based activity over months or years replicate the range of activity possible within a well-run centre?

- ensuring not prompted by cost savings or ideology without an evidence base including views of service users - avoiding 'throwing the baby out with the bathwater' and using measurable outcomes

Transition for young people into adulthood/adult services - remains a problematical area -- fundamental issues around move from relatively well resourced children's services (including health) to much more limited adult resources - managing whilst trying to meet parental expectations in an era of eligibility and resource allocation - how can we work better in partnership

with parents? - need to properly sort pathway between children's and adult services across social work, education, psychology which we are attempting locally

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?

Please provide any comments and/or examples here

See Q2

Good Practice - Individuals

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

Please provide any comments and/or examples here

N/A

Future Priorities - Healthcare

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

Please provide any comments and/or examples here

- strengthen 'observatory' role nationally through consistent GP role in LD registers
- improve epilepsy care pathways
- management of health-related aspects of transitions from child to adult care for those with complex needs
- dementia post diagnostic support
- meeting HEAT target for access to psychological therapies
- strengthen role between local learning disability teams and acute health
- strengthen interface between community care providers and health teams to ensure cohesive delivery of care plans
- workforce planning for learning disability teams
- undertake Equality Impact Assessment in acute services with a focus on meeting the needs of people with learning disability
- access to health improvement interventions that are tailored to meet population needs
- delivery of programmes of health screening that are relevant to population needs
- support to adults whilst within acute settings in relation to communication around diagnosis, stages of treatment etc. and social support
- problems around discharge when care providers not contacted in advance to inform when adult returning home - preparing the adult, ensuring supports in place
- need for accessible information for adults with a learning disability from primary care and health promotion

- maximise access to clinical services within the person's local community

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Future Priorities - Education

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

Please provide any comments and/or examples here

Further education courses for adults with a learning disability now contracting due to budget cutbacks - objectives need to be reviewed so that

- more educational emphasis over and above social benefits
- less emphasis on 'life skills' which are more appropriately taught within schools or creative day activity programmes
- colleges are self-sufficient in providing additional support needs rather than relying on cash-strapped local authorities to provide this
- more outcome-focused - even physical activity should have a clear purpose around health benefits

Development of on-line resources to maximise both educational and social networking opportunities.

Review balance between mainstream and specialist schooling

- change in educational psychologist remit as caused difficulties in early and accurate evidencing a learning disability to enable additional support and future planning
- we would query the usefulness of the SG stats quoted on page 16 that two-thirds of children with additional support needs attend mainstream schools - would need to be broken down by 'learning difficulty' and diagnosed learning disability - also in many cases students would be based within a specialist unit within a mainstream school limiting interaction

Future Priorities – Independent Living

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

Please provide any comments and/or examples here

- recognise the spectrum of 'independent' living from minimising the personal support required (via regular reviews, avoidance of a risk-averse approach and creative use of assistive technology) for more able adults through to looking at alternatives to 24/7 support within a singleton tenancy (which can unintentionally limit the adult's main contact to paid staff) via models of multiple living (e.g. separate facilities for one or more adults with challenging behaviour within a communal facility)
- review existing supported accommodation provision to allow for more flexible use and open up to younger adults - tackle the issues around tenancy (rights of individual, financial incentive from housing benefit) versus ability to make best use of extremely scarce resources - review 'models of care/support'
- how do we move away from the focus on filling 'voids' within established multiple (and scarce) properties and focus more on the needs and aspirations/expectations of the adults/parents including young people in transition?
- continue to increase the proportion of children or adults utilising self-directed support options - move to 'individual budgets' even for those not on a direct payment - balance the issues around risk/exploitation for SDS users with the benefits from choice and control
- build on local area co-ordinator model recognising that a preventative approach (including small grants to individuals) can obviate the need for formal intervention and promote access to mainstream activities/facilities

Future Priorities – Employment

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

Please provide any comments and/or examples here

- current economic climate and level of unemployment further militates against people with a learning disability obtaining formal or meaningful employment - at the same time as welfare benefit reforms are likely to significantly increase the number of people (including those previously on DLA or ESA) expected to look for work
- public sector could do a lot more to create employment opportunities - again difficult at a time when organisations struggling to retain current staff - but need to be more imaginative e.g. trend towards creation of 'community hubs' as a route in for all council services provides scope both for user participation in facilities (e.g community cafes) and a point for social activities devolved from a formal day centre
- disjointed local planning around employability schemes disadvantages adults with a learning disability - schemes funded to focus on those with 'additional needs' but may lack expertise or motivation to be inclusive for those who have a learning disability when dealing with number of others struggling to find work
- again raises issue of specialist versus mainstream projects but clear need for dedicated staff who can both provide appropriate support and constantly 'sell' to potential employers the real benefits of taking on someone who may well offer reliability, be suited to particular types of work and come with a 'mentor' for a period of time.

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)

Please provide any comments and/or examples here

Comments in italics

- refocus SAY National Implementation Group with clear remit, co-production approach and cross agency membership that can be accountable for progress
- establish a clear monitoring framework for the next phase of SAY based on outcomes and align data requirements accordingly.

National focus engendered by SAY1 has somewhat dissipated and needs to be re-energised with clear priorities and guidance to areas to ensure consistency and more joined-up working (in particular around education and employment)

- joint commissioning of appropriate local support to improve outcomes for people with learning disabilities whose behaviour challenges services
- capacity planning for future needs, including increasing numbers of young people with complex needs and older people with increased health needs e.g. dementia.

Unsustainable pressure on social work-commissioned community-based supported accommodation for increasing number of adults with highly challenging behaviour operated by care providers struggling to maintain levels of competent staffing with local authority-required cost savings coupled with a reduction in NHS-run units

Need to review nationally and across authorities the impact of economic factors (reduced government spend, impact of welfare reform on ability to charge for services further reducing local government revenue) on sustainability of high-cost support packages and produce clear central guidance on use of resource allocation frameworks and models of support - need to invest in action research to inform this - relatively small research activity in this field compared with other community care groups

- continue to support people to participate in community life in order to improve awareness and public understanding through greater interaction.

Need for national government-sponsored campaigns (equivalent to mental health campaigns such as 'See Me') to raise the community profile of people with a learning disability (?building on Paralympics)

- health improvement services must address the specific needs of people with learning disabilities.

Local response to the evidenced health risks to people with a learning disability needs to go beyond GPs to incorporate clear strategies and interventions from health promotion teams

- invest in timely information and support for families, including respite and short breaks, to enable them to plan for the future.

Work required locally (and nationally in terms of models) around expanding range and choice of 'short breaks' (to complement rather than replace high quality structured respite) with emphasis on agreed outcomes, choice and control (including SDS) for the adult as well as support for carers

- address eligibility criteria for access to employability support that exclude some people with learning disabilities

See Q9

- build on the work of the Transitions Forum to improve joint working and provide choices for individuals.

All areas are struggling to manage this in a fair and transparent manner in reconciling increasing demand, parental/user expectations and eligibility/declining budgets and the 'step' from children's to less resourced adult services. . Central guidance with pathways, models, consistency around eligibility and a clearer role for key voluntary campaign/advocacy organisations who are also major care providers would assist.

- ensure that adult support and protection legislation is working effectively and appropriately

This would be assisted by unequivocal central guidance based on legal advice that ASPA applies in its entirety to people who may lack mental capacity even they are unable to themselves consent to intervention to avoid the current inconsistency across Sheriffdoms

Other comments

- *clear link required between SAY2 and the Scottish Strategy for Autism to ensure a consistent approach, avoid unnecessary duplication around strategies and ensure that people with a learning disability who also have autism receive the same priority and investment as others with autistic conditions*
- *operationally people with autism and a diagnosed learning disability are directed along the same pathways for assessment and eligibility within learning disability services to ensure consistency across the 'transitions' group*

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