

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

All the groups that informed the consultation on the day indicated that, in relation to people with Learning Disability and Complex Needs - no, people are not in agreement.

We agree with the evaluation that there remain patchy areas in Education, further Education and Employment. There is a real need to link to outcomes for individuals.

There is a lack of vocational skills training – the person will express need but lack of college placements and lack of support in F.E. places. Very patchy, depends upon individual colleges. Cutbacks in F.E placements and too many changes in this setting with changing courses. Need to give people opportunities to follow interests. Allocation of Individual Budgets may be an option.

Need to change expectations by looking at what is possible and happens elsewhere; other countries seem to get people with LD into employment as that is the expectation. What is different?

When a person is in an assessment and treatment setting, it may be in a different geographical location from their own/ family home and so interests/activities may not be able to be reciprocated in their own locality. Expectations in colleges need to change and not use as a 'day centre'.

Statutory organisations could take a lead in offering placements and jobs, also the Voluntary Sector commissioned services.

The report says very little regarding complex needs. Limited synthesis of contributing reports. A small reference group was used to inform the recommendations. How appropriate is it for SCLD – an organisation developed as a result of SAY – to evaluate? Is there not a conflict of interest in this?

The case loads of Community learning disability teams are heavily weighted towards working with individuals who have complex needs - yet the views from this service area appears to be missing from evaluation.

We would suggest there has been a lack of consultation with professions and service providers up to now. The document is so broad, it does not really get into depth we would have liked. How far are findings reported, so far today inclusive of complex needs services? - very small sample. Limited information on children.

The "Same as You 2 " needs to reflect the complexity of people with complex needs as they are on the increase.

One group commented that people with ASD don't want to be 'The Same as You'

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?*

A number of groups all reported that the facilitation of the move out of hospitals into community, leading to a significantly increased community presence, has been and continues to be a huge success.

There remains a danger of creating mini institutions where some people are still stuck in hospital and SAY 2 needs to consider how to encourage a focus on delivering better outcomes for this group of people. This may be due to lack of affordability – new ways of joint commissioning, pooling of resources, flexible working patterns for staff, supporting people with complex needs.

One group suggested that there is a need for continuing hospital care for a very small number of people. However, as a balance to this we need to remember that sometimes a person's reputation has been used as a barrier to moving on, but when given the opportunity they have very successful community lives.

One group agreed that the expectation that people should hold is for everyone to have the opportunity to live in the community, and that this should always be taken as the starting point for everyone with complex needs. It should have to be demonstrated why this is not appropriate for a particular person – and the alternative argued for very carefully.

A downside of success is the lack of a transferrable formula to make success consistent, but personalised responses to each individual is the key to success.

One group felt that the evidence of good practice and what has worked well will more naturally be reported from local responses to the consultation.

There are a lot of people with complex needs being supported well by Community Learning Disability Teams (CLDT), but challenges remain around the management of and response to real crises. An example provided from Fife was of very robust local services for forensic cases – good infrastructure. Also good project (joint) for people ready to move out from hospital.

Ayrshire – there is a local health improvement strategy within the public health strategy. Example of 'Bridge to Vision' project with local organisation spreading nationally.

The development of liaison learning disability nurses in acute

services in a number of areas was recognised by all as a welcome and effective initiative.

East Dunbartonshire – joint CLDT – works well, also integrated teams in Forth Valley.

Local area co-ordination good – but not impacting significantly on the lives of those with more complex care and support needs.

Development of relevant legislation – huge impact. Adults with Incapacity Act (AWIA) , Adult Support & Protection Act (AS&P) , Mental Health (Care and Treatment) Act.

Other examples included:

- Commissioning process in Tayside (although different in 3 areas of Tayside). Get it Right for People as in Partnership. Some care providers cannot cope with levels of challenge, so criteria for commissioning is quite complex - Castlebeck is half empty just now.
- There is not enough variety of service provision opportunities in between failed community places and the likes of Castlebeck.
- Joint working is crucial. (across Health, Social Care, Carers/ Families/ Third Sector and with the individual themselves).
- Need to stop thinking about buildings as services. Services could be anything.
- National facility at Morpeth Hospital:- £420K pp; people stay for 18 months intensive treatment therefore they benefit from this and are able to move on; not quite at forensic level; We need a Scottish version; support workers are really good and know individual well so keeps person stable.
- Some people might like to live in more rural areas but not accessible to some staff.
- Tayside are going to be using a 4 bed house with different specialists to help. It was discussed that people with PMLD would need consistency in staff.
- Difficult to organise and implement discharge plans when person is out of area.
- Change Fund help.
- MCN as a model
- Person centred approaches
- Life plans
- PAMIS – adult changing facilities and toilets
- Specialist LD nurses
- Improved information
- SCLD – user involvement
- People with LD getting involved in schools
- QIS, reviews
- Recognising the Human Rights of people with disability
- Autism has moved forward

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

The right and entitlement to ordinary life experiences for all people with learning disability and additional complex needs.

Services need to re-design budgets, but there is lack of willingness to 'give up' budgets. Perhaps "Integration" will tackle this.

Transition experience is patchy – can work very well but question why this is not universal. The move from Children's Services to Adult Services throws up huge changes for individual and family – should be seamless, but requires organisational structural change. It seems to more consistently work well where the support of the transition is a specific role, as opposed to being in addition to other duties.

More consultation with families – lack of carer involvement can cause further difficulties as it reduces the opportunities for maximising the understanding of the person with learning disability.

Personalising services and training is key. Both the care and the accommodation need to be right in care setting.

Some people with learning disability and severe autism are still stuck in hospital – carer involvement in these situations needs to be ongoing. Today's commitment from the Minister was received as very encouraging.

There is a need for investment in housing, and environmental issues, need particular consideration for people with complex needs – learn from best practice.

Equity – eligibility criteria for people with high functioning autism. Where is it appropriate?

There remain capacity issues regarding AWIA, in regard to the capacity of clinicians to appropriately consider and implement the duties under the Act. This is also exacerbated by remaining anomalies – e.g. clinical psychologist's are often heavily involved but not able to sign Section 47 certificates.

High use of A&E by some individuals with learning disability–services need to understand this more thoroughly and improve experiences and access for people.

Parenting issue - anecdotal evidence would suggest that there appears to be an increasing number of children taken into care.

Need for agreed resource allocation framework. Input of socio-economic level on resource allocation?

There is still need for huge improvement in acute care.

Assessment and treatment units for inpatients with learning disability, some people remain hidden as they are long stay patients in the wrong environments. We need to address the situation of people whose discharge is delayed.

Private care providers – there is a perception that the standard not good enough for people with LD

There is more pressure across all services with the increase in the number of people requiring service, and an increase in the complexity of the care and support needs of these individuals.

Quality of support workers - how can we support continuous professional development across the breadth of the workforce.

High cost placements, particularly with out of area placements
Monitoring out of area placements - is this as robust as we would wish?

Why are we paying so much? We should focus on repatriation, with provision of services either in region or locally. The current range of providers available in local areas restricts the opportunities to bringing people back

Women with learning disability and forensic needs, of which there are small numbers, but their needs are not currently appropriately met within Scotland and this needs to be addressed

There appears to be an expectation in some areas that cheaper care packages can be commissioned, without real consideration given to the implications for both the supported person and the support staff.

A wee bit like you – on the way to the Same as You!

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?

Lessons could be learned from changes within Youth Justice services.

Many examples of good practice with specific transition workers. For example CAMHS to Adult Services – transition work.

Contribution of person centred planning over course of SAY timescale.

Contribution of voluntary/third sector organisations in community living placements. However we need to recognise that there is often support provided from CLDT teams and it is the combination that is successful.

Access to Health is better and more person centred.

The experience of patients and their carers/families where support has been available from a Learning Disability Acute Liaison Nurse, or similar service, has been significantly more positive than experiences where this level of support is not yet routinely available.

Partnership working has improved across the board. Integrated working developing.

Positive Behavioural Support - a Complex Needs resource. Need for research into practice and evaluation of this. Think big change in profile of LD into other services. Big improvement in service user involvement.

Some improvement in service governance at local level (but more doubtful nationally). 'Equally Well' funding very welcome and the subsequent projects that arose from it are having a positive effect and acting as change agents across the country.

Autism strategy positive – need to link to this.

The continued development of the LD MCN very positive.

Supporting people who offend – services and links most other agencies – especially Police.

Challenging behaviour MCN training programme

Epilepsy

Dementia

Down's Screening

Additional support team – crisis management and support

Provision of advocacy services, but need more

Integrated care pathways

OSS autism

PCPs in local area co-ordination

Person centred plans

Modernising LD nursing review

Autism diagnostic service in Forth Valley

Dementia; Diagnostic service and care pathway in Forth Valley

Good Practice – Individuals

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

People clearly felt unable, unwilling to advertise their own achievements in such a forum, however some of the examples that were forthcoming included:

Positive changes to local communities by community presence of people with LD and complex needs.

We have gone to our work every day and done our best to make a difference !!!

Trying to do our best

We care

We have been doing it together for 10 years

Joint Borders integration strategy and Commissioning strategy

Training and retaining a skilled workforce

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?

There were a number of suggestions and recommendations about continued efforts to train and education the workforce and carers about the different requirements and health patterns of people with learning disabilities.

Some of these suggestions were:

- Health professional should have knowledge of conditions and how someone with learning disability and complex needs and/or autism may react.

- Autism is prevalent (undiagnosed) so should be more awareness.
- Raise the profile of health issues and learning disability with support providers.
- Educate GPs on LD health issues.
- Inequity – people are defined by their autism or LD rather than their right to equity of healthcare and required treatments.
- Train the trainer packs for providers.
- Generic basic skills – to help someone's anxiety, communication etc., the same way applies to everyone, and crosses boundaries, so what applies to one group can apply to another.
- Specific examples of training required continues to focus on Adults with Incapacity Act and associated duties; plus Adult Support and Protection; the range of issues to be vigilant about, and what to do if you have concerns.
- Funding for WRAP training (Wellness Recovery Action Planning) for parents and people with Learning Disability (mental health).

Issues were raised and discussed about the support and initiatives required to enable people with learning disabilities and complex needs to have healthy physically active lives.

For example:

Allocation of funding in Ayrshire for an integrated rugby team!.

There was a lot of discussion about the importance and key role delivered by Primary Care and GP Practices.

A number of groups picked up the need to build on the Enhanced services initiatives and

- Need good anticipatory care planning
- Improve data from GPs on LD.
- Influence the GP contract.
- Build into the QOF.
- Work collaboratively with GPs to get them to buy in.
- Annual healthcare reviews for people with learning disability known to the services.

Healthcare in acute healthcare settings was also discussed and the following suggestions for continued improvement/ focussed improvement work were made from the groups:

- Liaising nursing between primary care and acute. More liaison nurses required.
- An example from Ayrshire, of joined up thinking, regarding provision of anaesthesia for people with learning disability undergoing dental operations – they identified the potential to link with other surgeons therefore if other treatment required it could be done at same time, thus negating the need for multiple general anaesthetics.
- Integrated support network around the person can link with admitting wards to advise staff of particular needs of the person with complex needs – positive advocacy.
- General hospitals – legal procedures, treatment and compliance. Consent to treatment. Consent to screen. Complex issues become

more complex where the adults are assessed as not having capacity.

Knowledge, information and awareness raising were seen to be underpinning pieces of work that would support people with learning disabilities to understand about healthcare issues, be more likely to engage with the services, and, if the awareness raising was aimed at staff and carers as well; perhaps they would be more likely to ensure the person with learning disability received appropriate and equitable healthcare.

Specific areas suggested were for better information to be made available about : gastric healthcare; respiratory risks and implications.

There is a need to ensure that public campaigns are “learning disability friendly”, that health promotions and health screening for the general public is fully inclusive of people with learning disability. This is not the current experience.

The changing profile of the learning disability population was discussed and questions raised:

We need to ensure/consider how we are going to look at older people with LD. Do we have the right range of LD specialists? Do we need to educate colleagues across Medicine of the Elderly services and social care service workforce for older people in order to ensure they can appropriately meet the need so older people with learning disability?

It was also suggested that it would be helpful to have an alert card – e.g. for people with autism, that the individual could use to help people understand their individual needs.

Future Priorities – Education

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

There are FE colleges which have specific LD student support . Is this model affordable and deliverable on a larger scale? We need to develop appropriate courses with progression.

All children should have access to opportunities. Positive destinations should be the ambition for all Scotland's children, and this should be fully inclusive of all children with disabilities.

Education to help people with day to day living along side having a vocational focus.

Work with children early enough to identify future requirements of flexibility of FE institutions.

SDS will be a real opportunity to tailor what people want. Adequate diagnosis in childhood will assist with transition into adulthood with appropriate understanding of an individual's needs, wishes and support requirements.

Education providers - the perception of respondents was one of poor quality and poor value, these placements fill peoples' time but with no real outcomes.

Purpose of education – vocational. Difficult for people with complex needs, especially with the current competition for jobs.

Alternatives – non college alternative. Use SDS to achieve their need.

What does it mean for people with complex needs? Employment pathway, but it is a challenge.

Ayrshire: the re-design of what they are providing in specialist provision – continued.

Communication needs/ difficulties can be considerably higher for people with additional complex needs and need particular adaptations to assist. Education might not lead to employment, but will develop the individual. Mainstream employment may not be a reality, but created employment activities maybe an answer.

We think F.E. are missing an opportunity in developing better services and support for people with learning difficulties and with complex needs. Could they get into partnership with Local Authority and Voluntary Sector to develop support teams? We would welcome a central expansion of the approach of positive destinations to young people with learning difficulties.

There is a strongly held perception that the experience of sending so many children to out of area educational placements is directly increasing the risk of continuing adult out of area placements.

Future Priorities – Independent Living

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

People with complex needs require to be given the opportunity to be supported to live independently. Increasing opportunities for this will be enhanced through:

Co-ordinated approach across agencies and coordinated application of resources

Joint Model/ sharing of expertise

Holistic planning to ensure all an individual's needs are considered and included in the planned package of care and support.

Developing capacity and infrastructure, e.g. encouraging more specialist services to deliver locally

Managing people within their own community with "as required" support from specialist services

Development and maintenance of a flexible and skilled and supported workforce.

Involving person and family in designing support packages. Continuing to raise the standard of support to people with complex needs.

The market for providers is quite combatative/competitive, rather than collaborative.

Buy-in from senior managers across agencies and SGHD to ensure any savings by re-designing services are re-invested to provide better, appropriate services and support.

By supporting the person in the right environment/support, this can lead to less dependency/more independence.

We need to look at models of service delivery, for example; effective core and cluster to reduce isolation and deliver some economies of scale.

We need to bring in real person central planning.

We need to look at all sensory aspects.

We need to look at needs-led housing design.

Should there be training for planners, housing, in relation to LD and needs?

Self-directed support – needs to be clear thought regarding promotion and governance. We need to acknowledge that an individual's opportunity for a successful, inclusive life is dependent upon the appropriate utilisation of the SDS package.

There needs to be acceptance of risk enablement.

Issue of individual care and network of support. We need to address

the risk and implications of isolation.

Importance needs to be given to a focus on the quality of life experiences rather than domestic issues.

Services need to focus on psychological wellbeing.

Future Priorities – Employment

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

Employment opportunities are not the only goal for people with complex needs.

Getting people life ready.

One group proposed that the key to maximising opportunity: better co-ordination between the multitude of agencies with interest in this area.

More work with employers.

Good practice in employment – an example given was Winconscin in America.

Also, wide range of employment options important, offered in a manner that provides maximum flexibility to ensure people with the widest range of abilities and support needs can have some manageable experiences of employment.

Link with some multi-national companies to develop specific support and staff awareness and create jobs. (Possibility of a TV programme in relation to this). The example of project search is good, although very expensive – can it be developed to include people with complex needs?

Pre-vocational settings must have arrangements for through-put, but preferably with positive destinations for those that are graduating onto the next phase of their life/ learning.

Social Work and Health have failed to lead the way!!!

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 find below the list of suggestions for future priorities that were submitted from the groups.

Please note – as this response is a collation of a range of views, these are not arranged in any order of priority.

- Appropriate accommodation – some sort of central day care type place for people to gather.
- Acknowledgement of the cost and continued need for 24 Hour support in a flat for people, both individually and in groups.
- Need to engage with housing departments to ensure the development of a range of housing options and accommodation in correct environments.
- We need to get better at considering and applying Telecare and security in properties.
- National care standards to be reviewed in relation to what care provider should be delivering –and the opportunities and outcomes experienced by people with learning disability and additional complex needs. .
- Training for care workers – there continue to be inconsistent approaches depending on what care provider they are with.
- Healthcare; entitlement and human rights
- Multi-agency approach; integrated services
- Have a GIRFEC approach to adults > care; multi agency care co-ordination
- Meaningful occupation opportunities for all
- We need to build on the continuing contribution of person centred planning – to ensure that everyone's gifts and contributions are explored and found.
- Understanding of individual needs. Educate the public and other professionals to understand needs of people with learning disabilities and autism. Specially trained carers. Consult the families always. National campaign, e.g. 'See Me' for LD and complex needs.
- Outcomes not outputs – what are people/professionals contributing to person's outcomes? We should each individually be able to answer this on each and every occasion – otherwise – why are we involved in that person's life?
- Relevant, needs based, on the job education – especially support workers (e.g. complex needs module).
- Explore supporting people with LD to undertake the role of Health Champions.
- Targeting values and attitudes of school-children – education about diversity of care and support needs
- Improve transition at last! Should there be more of a cradle to grave service?
- Is there a need for learning disability physicians?

- Need to focus specialist health on children with complex needs (e.g. nursing, psychology, SALT).

General Comments

- Lots of focus on children and older people but not so much on the middle.