

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

In relation to people with Learning Disability and Complex Needs - No

Agree with patchy areas in Education, further Education and Employment. Real need to link to outcome. 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 people's expectations by looking at what is possible; other countries seem to get people with LD into employment as that is the expectation.

When a person is in an assessment and treatment setting, it may be in a different location from their own 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.

Findings of evaluation: says very little regarding complex needs. Limited synthesis of contributing reports. Small reference group for recommendations. How appropriate is it for SCLD – an organisation developed as a result of SAY – to evaluate? Community learning disability teams – who do bulk of work with complex needs - virtually missing from evaluation. Lack of consultation with professions and service providers up to now. May not have been most effective way to put out consultation – but also may come from current consultation. Document is so broad, 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.

Did not reflect issues for people with complex needs. Some areas a lot has happened, but in others, not much.

Small numbers – the evaluation does not reflect the complexity of people with complex needs.

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

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*?

Moving out of hospitals into community, leading to community presence. There remains a danger of creating mini institutions where some people are still stuck in hospital. 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. Is there a need for continuing hospital care for a very small number of people? Sometimes a person's reputation has been a barrier to moving on, but they have very successful community lives. The group agreed that the expectation that people should have the opportunity to live in the community 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.

Downside of success is the lack of a formula to make success consistent, but personalised response to the individual is key to success.

This will come from local responses . Example – positive example of some hospital closure, e.g. Lennox Castle. Closure programme generally worked well (apart from long-stay hangover). Gave some areas chance to build community care infrastructure – but some challenges about sustainability due to political changes. There are a lot of people with complex needs being managed well by CLDT's, but challenge around real crises. Example from Fife of very robust local services for forensic cases – good infrastructure. Also good project (joint) for people ready to move out. Already established jointly funded project. Ayrshire – local health improvement strategy with public health strategy. Example of 'Bridge to Vision' project with local organisation spreading nationally. Development of liaison learning disability nurses in acute services in a number of areas. East Dunbartonshire – joint CLDT – works well. Integrated teams Forth Valley. Local area co-ordination good – but not impacting on complex needs. Development of relevant legislation – huge impact. AWIA, AS&P, Mental Health Act.

- 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 in between failed community places and the likes of Castlebeck.
- Joint working is crucial.
- 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 so benefit from this and are able to move on; not quite at forensic level; 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 discharge plans when person is out of area.
- Change Fund help.
- Small amounts of money
- LD local area co-ordination – help signposting and benefit
- MCN as a model
- Hospital closures
- Person centred approaches
- Life plans
- PAMIS – changing toilets
- Specialist LD nurses
- Improved information
- Work on
- SCLD – user involvement
- People with LD getting involved in schools
- QIS, reviews
- Recognising the Human Rights of people with disability
- Adults Support & Protection legislation
- Adults with Incapacity Act
- 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 complex needs. Need to re-design budgets, but lack of willingness to 'give up' budgets. 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. Family member (with LD) in hospital is being well cared for, staff well trained in challenging behaviours – this level of training requires to be replicated in community setting. Personalising services and training is key. Both the care and the accommodation need to be right in care setting.

Some people with severe autism still stuck in hospital – carer involvement in these situations needs to be on-going. Commitment from Minister very encouraging. 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? Difference between Health & Social Care. How effective and skilled staff are and impact of this on out of area placements.

Equality of skilled workforce.

Transition.

Capacity issues regarding AWIA. Also, anomalies – e.g. clinical psychologists heavily involved but not able to sign Section 47 certificates.

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

Parenting issue appears to be increasing in number of children taken into care.

Need for agreed resource allocation framework. Input of socio-economic level on resource allocation? Still need for huge improvement in acute care.

Assessment and treatment inpatients, hidden as they are long stay

Standard of care in sheltered housing

Private care providers - standard not good enough for people with LD

More pressure with increase in the number of people requiring service

Quality of support workers

Lack of confidence

High cost placements, particularly with out of area placements

Monitoring out of area placements

Why are we paying so much? We should focus on repatriation, with provision of services either in region or locally.

Women with forensic needs, small numbers, but need to be addressed
Expectations of cheaper care packages
Can't bring them back – services not available locally
The current range of providers available in local areas – restrict bringing people back
Need to address delayed discharges
Development forensic issues
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 to be learned from changes within Youth Justice services.
Many examples of good practice with specific transition workers.

Contribution of person planning over course of SAY timescale. CAMHS to Adult Services – transition work.

Contribution of voluntary/third sector organisations in community living placements.

Access to Health better and more person centred.

Example of when person in third sector placement goes into hospital, this is allocated to Acute Team.

Support that Voluntary Sector receives from CLDT teams.

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

Positive Behavioural Support - 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 projects from it.

Autism strategy positive – need to link. Development of MCN very positive. Supporting people who offend – services and links most other agencies – especially Police.

Liaison nurses in Lothian

Challenging behaviour MCN training programme

Epilepsy

Dementia

Down's Screening

Autism

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?

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

Michael has retired! (allegedly). 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?

- Need good anticipatory care planning
- Would be good to hold relevant notes on someone who accesses services regularly – only GP can do this?
- People should be treated properly
- Health professional should have knowledge of conditions and how someone may react.
- Would be helpful to have an alert card – autism – so people know situation.
- 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.
- Autism is prevalent (undiagnosed)so should be more awareness.
- Children with complex needs are reviewed annually so shouldn't this translate to adults?

- Inequity – people are defined by their autism or LD. Need to ensure/consider how we are going to look at older people with LD. Do you have right range of LD specialists? Demand has increased workload and AWI was discussed and adult support protection. Need awareness training on how to recognise.
- People, for whatever reason, will not engage with Health professionals, so are not getting appropriate services.
- Refer to a specialist team if fail to engage. Need multi-disciplinary input.
- Need to define outcomes first and how you're going to measure this – pathway. Effective interactions – joint working.

LD observatory is the central focus. Provide detail, analyse evidence. Inform and shape systematically, plug gaps. Improved health promotion. Uptake of screening will improve with additional support. Raise the profile of health issues with support providers. Training issue of support works. Educate GPs on LD health issues. Improve data from GPs on LD. Influence the GP contract. Build into the QOF. Work collaboratively with GPs to get them to buy in.

Incentives to pick up health promotions. Observatory help long term agenda. Identify and make (get on) primary care agenda. Evidence outcome right and link. Acute Care FA1 still happening, one example in England. Health care passport – info on each individual.

Liaising nursing between primary care and acute. More liaison nurses required. Better information on: gastro; respiratory. Targetting a resource knock-on, getting it right for people with LD. Information: Electronic systems and access to them. Delayed Discharge – improve Model of Care – outcome Tier expect Planning discharge at admittance Assessment and treatment Consistent model regardless of where they are in care. Plan to discharge early. General hospitals – legal procedure, treatment and compliance. Consent to treatment. Consent to screen. Complex when adults are incapacity.

More understanding of needs of people with complex needs. 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. Also, similar approach with Police. All relevant people need to sign up to risk management plan – collective decision making.

Issue of not being able to speak to GP if person is over 16 unless guardianship.

Healthcare – more training for staff. Still inequity in liaison nursing nationally. Investment in CLDT's. Example from Ayrshire regarding

anaesthesia for dental operations – potential to link with other surgeons therefore if other treatment required it could be done at same time. Funding for WRAP training (Wellness Recovery Action Planning) for parents and people with Learning Disability (mental health). Better training for all NHS staff. Train the trainer packs for providers. Need for support for physical activity. (Example of funding in Ayrshire for integrated rugby team!).

Future Priorities – Education

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

- Examination process should ensure they include how to deal with LD and autism.
- There are FE colleges which have specific LD student support – need to develop appropriate courses with progression.
- Shouldn't be a big gap in services from leaving school to moving on to FE.
- All children should have access to opportunities.
- Education to help people with day to day living.
- Allow people to access education at home – more feasibility.
- Work with children early enough to identify demand.
- SPS will be a real opportunity to tailor what people want.

Educational opportunities. Identify them at school and plan.
Adequate diagnosis in childhood to transition into adulthood.
Difficulty with Educational needs.

Challenging behaviours cause difficulties.

18 Drop off

Support through schools.

Education providers - poor quality, fill their time but no outcome – poor value – somewhere to go but no outcome.

Purpose of education – vocational. Difficult for people with complex needs.

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: re-design what they are providing in specialist provision – continued. Resource Centres – group profound, can't envisage employment or educational development.

Service: Communication level very low with people with additional complex needs. Education might not lead to employment, but will develop the individual. Employment may not be a reality, but unrealistic in this day and age. Created employment activities maybe an answer, but not mainstream.

F.E. missing an opportunity in developing better services and support for people with learning difficulties and with complex needs. Could get into partnership with Local Authority and Voluntary Sector to develop support team. Expand approach of positive destinations to young people with learning difficulties.

Better experiential learning rather than class based. Avoid repetitive courses. How well has additional support for learning worked? Needs to be person-centred asset-based approach. Should stop sending so many children to out of area educational placements as this increases the risk of promoting 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
Co-ordinated approach across agencies
Co-ordinated resources
Holistic
Joint Model
Sharing of expertise
Holistic package
All statutory agencies
Specialist services to deliver locally
Bringing people back
Capacity and infrastructure
Managing people within their own community with specialist services

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 of service people 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.

Adopt models of care. More flexibility within provisions. Develop natural supports. Use of Telecare. Enhance CLDT. Need to look at effective care and cluster to reduce isolation and economies of scale. Need to bring in real person central planning. Need to look at all sensory aspects. 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. Needs to be acceptance of risk enablement. Needs to be supportive scrutiny and evaluation of range of services. Issue of individual care and network of support. Risk of isolation. Aggregation.

Importance of quality of life focus rather than domestic issues. Need to focus on psychological wellbeing. Target service on needs based, rather than wants (but taking desires into account).

Future Priorities – Employment

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

Adult Education Centre – sheltered employment – back to the future – don't want to go back.

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

Getting people life ready.

Re-employ as an example in recession – this is – should be supported to work. Life skills.

Live independently – these courses are getting cut, but there was no development.

Key, better co-ordination: employers; education; supported employment; agencies.

More work with employers.

Employment – Winconsin in America, area of best practice.

Also, wide range of employment options important.

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). Example of project search – is good – can it be developed to include people with complex needs? Pre-vocational settings must have arrangements for through-put. 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)

Future Priorities – Question 10 of Consultation

- Appropriate accommodation – some sort of central day care type place for people to gather.
- 24 Hour support in a flat for people – individually – groups.

- Have a range of housing options.
 - Need to engage with housing departments.
 - Telecare and security in properties.
 - National care standards to be reviewed in relation to what care provider should be delivering.
 - Training for care workers – inconsistent depending on what care provider they are with. Some care workers need training and education at a basic level.
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- Health
 - Integration
 - Multi-agency approach
 - GIRFEC model
 - Have a GIRFEC approach to adults > care
 - Reflect the GIRFEC principles
 - Education and employment for people with complex care is difficult to manage expectations
 - Meaningful occupation
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- Continuing contribution of person centred planning – to ensure that everyone’s gifts and contributions are explored and found.
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- Understanding of individual needs. Educate the public and other professionals to understand needs of people with learning disabilities and autism. Accommodation in correct environment. Specially trained carers. Consult the families always. National campaign, e.g. ‘See Me’ for LD and complex needs.
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- 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?
- (Should it be a developmental disabilities agenda rather than just LD?)
- Relevant, needs based, on the job education – especially support workers (eg complex needs module).
 - People with LD as Health Champions.
 - Targeting values and attitudes of school-children.
 - 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.
- PMLD – age is just a number so why does someone with PMLD have to move from children’s services at 18?