

## 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.

***Note: this response has been prepared by the Learning Disability Care Group on behalf of NHS Forth Valley.***

There are mixed views as to the findings of the report and therefore the majority view is the evaluation does not cover the full range of need.

The report recognises some improvement but this is not clearly defined. We note the size of the sample is small and that only four Local Authorities were involved.

Improvements are not quantified, not measured, not defined and are largely anecdotal.

There appears to be an arguing of both sides i.e. that employment and activity has improved yet a third are not in full five day per week activities. It would have been helpful to have consulted with statutory services in advance of release of the report for consultation.

Note that there is a loss of Carers Allowance for older carers at 65 years of age that is of concern.

We consider the impact of the eligibility criteria is still to be fully realised.

People with complex needs including mental health; substance misuse; and forensic needs are not well represented in the report.

**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

The closure of Institutions and move towards integration of Health and Social Care Services has resulted in closer joint working and partnerships between statutory agencies.

The development of Assessment and Treatment In-patients units for people with a learning disability with complex healthcare needs has provided effective and timeous treatment for individuals. However, challenges remain regarding long term patients and delayed discharges.

Integration of Services including Integrated Community Learning Disability Teams and improved partnership working amongst agencies to meet the needs of people with learning disability and complex needs.

Development of the Learning Disability Managed Care Network in South East Scotland has increased joint working arrangements, education and training opportunities, addressed specialist clinical areas such as forensic and increased opportunities for shared learning.

The development of a regional Forensic Unit in Fife and the regional approach to the Models of Care project focussing on sustainable future models of accommodation and care support.

The allocation of health change fund monies to address the health needs of people with learning disability. The Equally Well projects assisted in addressing some of the deficits in service provision.

Approaches to address health needs included interfaces with In-Patient Services, Community Learning Disability Teams and main stream services- Primary Care, Social Work / Local Authority and third sector.

Noted increase in the use of care programme approach to have been effective in supporting people with complex needs.

Legislation including AWI, ASP and MHA has improved working in a positive way across LD Services.

Note concern that there is no regular external scrutiny of the use of AWI guardianship orders.

**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

Delayed Discharges for people with learning disability still requires to be addressed as hospital stays are longer than clinically necessary.

Single IT system across statutory agencies.

Educational Psychologist are not assessing children at school for learning disability and referring on to Adult Services at transition. This impacts on Adult Clinical Psychology Services to assess and determine whether the person has a learning disability or not. It would be advantageous if Educational Psychology would undertake this function at an earlier stage so that the child's strengths and areas for development can be identified and services appropriately tailored to meet their needs.

**Legislation – areas of concern:**

- Power of Attorney – open to abuse;
- The Adult Support & Protection Act – NHS responsibilities & impact
- ASP Code of Practice – requires more detail regarding self-harm
- Guardianship – lack of regular scrutiny of Welfare Guardianship

- Adults with Incapacity Assessments – referrals to psychology for assessment of capacity related to an ASP concern have increased significantly in relation to application of ASP legislation
- Private (family) requests for reports for guardianship applications

All of the above represent a resource issue in terms of clinical staff time to apply the legislation appropriately.

Finance remains a significant issue particularly where complex care packages and / or specialist support is required.

Although some areas are targeting higher costed care packages some lower level needs and proactive input may reduce potential problems at an earlier stage and prevent crises.

We note there has been some recent activity regarding immigration and people with learning disabilities in arranged marriages.

Noted increase in children with learning disability and complex health needs – requires a resource response – specialist clinical services.

Transition for children remains challenging and use of specialist services in out of area placements is expensive.

Detailed support plans and implementation of care packages;

- Positive if joint working between agencies to support implementation
- Negative if not implemented
- Impact on client and care provider if the package is not supported
- Placement breakdown and repeated failures
- Impact on health and wellbeing of individuals
- Impact on assessment treatment available beds
- Improvements in contractual arrangement; care management and care co-ordination; interfaces between agencies; approved quality of training for staff and guidance and support for staff required.
- Speech and Language Therapy and implications regarding the communication strategy and accessible information.
- More supports required for parents with a learning disability
- Digital inclusion and risks particularly around internet and the vulnerability of client group
- The Scottish Government should be promoting research in learning disability and research funding.
- Person centred planning requires time to undertake but can be overtaken by resource issues and other priorities. Some investment in person centred planning aligned with self directed supports could assist people to develop individualised appropriate support packages.
- Agreed ethical standards required – multidisciplinary review, risk assessment and risk management.

### **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

Integrated Health & Social Care – Joint NHS and Local Authority  
Community Learning Disability Teams x 3  
Assessment and Diagnostic Service for ASD established.  
Two year Anticipatory Care Project  
Dementia Memory Clinic established.  
Shared Care Protocol between Adult Mental Health, Learning Disability and Older Peoples Services  
User Involvement Pathway and Care Planning and Delivery  
Operational Policies and referral pathways; generic integrated care pathway learning disability  
Participation and contribution to the Managed Care Network – training and development programmes established; significant numbers of staff undertook programme, education courses, seminars; Psychiatry and on call Psychiatry on a regional basis.  
Increase in Advocacy Services in Forth Valley for people with a learning disability  
Consultant Psychiatrists undertaking training for new trainees in Adult Mental Health raising awareness of LD Services.  
Re-design of Community Residential Services – separation of accommodation from care support. Improved user choice in care support; users with secure tenancies. User's now legal tenants.  
Adult Support & Protection Partnership across five agencies recently completed a multi-agency audit.  
Development of Acute Liaison post in Forth Valley Royal Hospital.  
Joint Policies and Procedures with Adult Mental Health, Learning Disability including Observation policies, Time off Ward, ECT Protocols. Wider NHS Forth Valley policies developing around Adult Support & Protection.  
Forensic Multi Area Forum and agreed information sharing protocol.  
Joint Commissioning Work between Local Authorities and NHS Forth Valley and additional Models of Care project across the Managed Care Network looking a long term sustainable accommodation and support models.  
Development of Loch View Assessment Treatment unit and enhancement of Community Learning Disability teams at the point of RSNH closure.  
Development of user friendly accessible information/resources.

**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

Response in group / Learning Disability Care Group collective response on behalf of NHS Forth Valley.

## 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

There needs to be greater recognition that Specialist Services are necessary for some people with learning disability and complex health and social care needs. Particularly people with additional mental health needs, challenging behaviour, forensic needs, complex health needs, people with profound and multi disability and people on the Autism Spectrum.

Children at transition to adulthood and transfer from Paediatrics to Adult Services. Medical Management Transition Group is being developed and a pathway required to guide GP's.

Specialist services specifically geared towards children with learning disability is inconsistent across Scotland and fails to recognise the mental health needs of children with a learning disability. We are not getting it right for every child. Children with learning disability and additional mental health needs are severely disadvantaged as they do not have access to appropriate specialist support at an early age. Educational Psychologies lack of early diagnosis of learning disability fails to assist in identifying the child's development needs, strengths and therefore impacts on services ability to be accessed and or to respond.

Additional supports required for parents with learning disability.

More needs to be done regarding provision of adequate Psychological Therapies Services in all areas.

Specialist Learning Disability teams are under resourced and have seen cuts in services at a time when the client population is rising, complex needs are increasing and more evident; people are living longer. An uplift in specialist services including Psychiatry, Nursing, Allied Health Professions in addition to earlier statements regarding clinical psychology is urgently required.

Further attention to Dementia and supports for client's in community settings and additional community resources.

Prisoner healthcare is having a notable impact on Forth Valley's healthcare services with three prisons in the area. Full impact of this has still to be felt.

## 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

Ensure educational opportunities are individualised. Educational Psychology to assess for learning disability at school is crucial so that identified needs and support to access appropriate services is available. Stronger links required with local services.

Make 'out of area' placements the exception and encourage local schools to build capacity in the local area working with statutory agencies do so.

Colleges we suggest should consider developing an improved range of options. It is unclear what the focus is in recent years. Query is it employment or education?

Need a range of vocational/employment/educational courses.

Transport subsidies have been cut in some areas impacting on users.

Consideration be given to extending the options to include more pragmatic learning experiences for example, personal care and group work such as relationships, keeping safe that would build on users skills and independence.

Shared educational support on site costly to have each individual with their own support worker.

### **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

Enhanced Learning Disability Teams / Specialist Services to address complex healthcare needs adequately.

Recognise some people with learning disability and complex needs require access to specialist and mainstream services not either or. Recognise health and social care needs vary over time and services have to be flexible to respond. Person centred care supports. Integrated community services.

Care providers who will work with statutory agencies to ensure robust care packages are in place. Reduce repeated placement breakdown.

Wider services including local area co-ordination and employability support to access appropriate activity.

Use of technology to assist people to stay at home. Training and awareness of assisted living technology.

Self directed support to be managed carefully and creatively. Also though would require careful monitoring to ensure client was in receipt of the

agreed supports.

Concern regarding internet use and client vulnerability on social networking sites.

## **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

Education important to prepare for employment.  
Employability Project appears to struggle to get people into employment and opportunities are few. Percentages getting supports in practice approximately 20%

Users are competing within a difficult job market and employers are reducing posts.

The benefits system includes challenges around being fit for work. Any loss of benefit or reduction in benefit for people with learning disabilities taking up employment may be detrimental to the individual. It is challenging to secure employment at a level that would provide an income greater than benefits.

## **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

Increase in specialist clinical service resources including psychiatry, learning disability nursing, clinical psychology, neurology, Allied Health Professions; nursing liaison posts.

Multi agency and multidisciplinary assessment, intervention and support will deliver better outcomes for individuals with complex needs. Additional resources required to achieve this and recognition of increasing number of people with learning disability and complex needs.

Transitions from children to adulthood working better on behalf of the young person and family - both healthcare and independent living context.

Further integration of health and social work services and their role in providing specialist support for sustaining people in their community.

Careful management of implementing self directed support.

Clear role for Health Improvement Scotland and Care Inspectorate.