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

Yes, The City of Edinburgh Council, Health and Social Care, agree that the findings set out in the evaluation largely reflect the views of those working in supporting adults with Learning Disabilities and their Carers.

The discussion around the Evaluation results noted positively an increase in health care provision and joint working generally. Improved staff ratios matched to need and generally better support models were seen as significant over the 10 year period. The move from large buildings based day services have lead to better communication with carers and day to day contact that has meant meaningful relationships based on individual need.

There are however areas in the evaluation that we believe are perhaps optimistic.

- In Edinburgh very few people are in paid employment.
- The numbers involved in volunteering seems high
- The figures relating to the number of people with partners seem high.
- People rely heavily on paid workers for friendship, often ‘friends’ are ex paid workers.
- Some Carers, particularly those in an older age group, still prefer day services to reflect safe education type provision particularly from specialist providers
- The need for more Speech and Language Therapy

Areas for further work for us were noted around:
- Listening further
- Targeting support to need across the priority areas including prevention
- Managing risk

In all discussion however there was a theme of fear for the future and the belief that the current Welfare reform, removal of ILF and the whole criteria agenda would be to the detriment of individuals. Optimism has dropped.

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

Having the SAY has been of huge benefit in communication direction, increasing standards, expectations and assisting in setting the scene for negotiation at local government level. It raised the profile and brought the various organisations together with a common purpose. It assisted in promoting:

- Cultural shift around day service support to community based services
- Move towards new models of housing support – more independent living leading to Care home registering and more core and cluster housing services designed to meet individual needs
- Short breaks in the community developed to offer good alternative to residential institutional respite
- Development of Local Area Co-ordination has been key to major change in the delivery/provision of Day Services based on developing individuals independence skills, developing new friends and social supports and generally assisting with improved quality of life
- Improvement in joint working across the various agencies –Voluntary Sector and NHS
- Advocacy development
- Councils being more aware and consulting with Carers and Carer organisations
- Carers participating more in the planning and delivery of services
- Carers involved in design of service specifications, carer assessment tools, carer information etc
- Raising the profile of the need for meaningful employment opportunities
- Improvement to Health care and Health outcomes
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

- Developing social contacts and networks away from a reliance services and paid carers
- Guidance and practice/knowledge to support placement of older people with learning disabilities in Care Homes linked to staff training and development of understanding about the effects of aging on those with learning disabilities
- Development of local plans for autism in services for people who do not have a learning disability
- Knowledge/policy data re black and ethnic minority, autism and learning disability issues particularly relevant for young people in transition
- Promotion of community short breaks
- Continued work on all agencies working together
- Awareness and action around the effect of Welfare reform on the future strategy and the impact on individuals
- Ensuring that SDS is for all and not just those who have capacity or competent carers
- Accessible toilets and changing rooms for those with complex physical needs
- Access to FE given the current changes and limits in this area
- More personalised support to older carers of people with learning disabilities
- Wide range of flexible respite and short breaks options for carers and those they care for

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

SAY has had a role in helping to secure new resources each year to meet demographic growth in Learning Disability. This has allowed us to develop our response to the strategy in an imaginative and significant way.

- Dedicated Transition Team for children moving into adult services to ensure a smooth transfer and to develop support that meets need based on funding allocation rather than a one size fits all service
- Development of the Transition Team to work with those with High Functioning Autism and those with Physical disabilities to bring the same forward looking person centred culture to these areas
- Local Area Co-Ordination Team which has transformed day services for those with needs, up to a moderate level, and developed respite alternatives based on friendships and a good quality experience for the individuals not just carers.
- Development of the LAC team to work with those with Physical disabilities offering the same opportunities for development of skills, friendship and independence.
- Support worker for parents with a learning disability to support them in parenting skills and maintaining their family as a unit.
- Development of "Pathways Courses" in conjunction with Telford College.
- Use and development of person centred approaches.
- Development of End of Life Planning for Carer support.
- Care planning based on individual need and aspirations.
- Health Improvement initiatives through the LAC team and NHS.
- Extensive consultation and co-production of the Edinburgh Learning Disability Plan.
- Joint health and social care reviews of care packages for older people with learning disability living in Care Homes.
- Strategy development for older people with learning disabilities in relation to Day Support and Accommodation planning and support.
- Children and families are now offering more direct payments to sustain children in the community and to cater services to individual needs.
- Smoother transitions to adult services this is aided by now having a dedicated Disability practice team.
- Respite for children is being reviewed, so that there is better parity with adult services to aid with transition and to have clearer pathways for this, using the GIRFEC model.
- Implementation of a Joint Carers Strategic Action Plan, Towards 2012, five year action plan- Children and families are now offering more direct payments to sustain children in the community and to cater services to individual needs.
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

This is covered in question 4

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

- Improved training and understanding of needs by GPs and General Nurses
- Improved models/contracts to ensure GPs actively address the needs of those with Learning Disabilities
- Support for those with low needs to ensure health issues are monitored and followed up i.e. chiropody, annual health checks
- Further integration of NHS and H&SC staff
- Ensure all aspects of preventative health input/screening have easy read leaflets explaining the procedures
- Put in place systems locally to ensure plans are made about what happens in the event of a carer no longer being able to care in emergency situations
**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

- Over the past years good models of practice and activity were developed with FE colleges which sadly have now started to deteriorate given the change of FE funding and focus. Work needs to be done to address the current crisis nationally and locally to develop good models of learning that reflect those with a learning disability and the likely needs and outcomes in relation to employment and general life long learning strategies.
- Positive destinations/GIRFEC should apply to people with disabilities leaving school and college
- Address school exclusions due to support needs
- Continue to provide quality carer training courses
- Improved training for teachers to support Inclusive Education
- Increase independence skills at school particularly in relation to travel training
- Positive messages from an early stage about work possibilities rather than day services being the best to be expected
- Prepare individuals for work by skills development

**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

- Resourcing complex needs accommodation and care services from joint funding models that reflect the complexity as well as medical needs
- Continue to move individuals to community setting from NHS settings ensuring appropriate funding sources and Healthcare houses close and resources transfer to support people in the community.
- Develop more autistic specific services in the local area
- Up-skill social workers so better awareness of autism
- Promote more realistic expectations of families so they know what to expect when their children run into adult services.
- Transition service planning together with schools and families from an early stage ensuring that the messages from schools do not reflect institutional thinking based on out dated models of support.
- Imaginative use of Telecare support for travel, safety and
independence generally
- Improved information on options for housing and support
- Improve quality of life for those living independently in relation to social life, friendships, work opportunities etc
- Provide quality carer support to allow carer’s needs to be met

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

We believe most authorities have under achieved in this area. Initiatives in Edinburgh have focused on young people with no destinations from school but little focus on those with Learning disabilities. There needs to be a much greater focus at all levels to embed the principle of employment for those with Learning Disability to be supported to work through out the education system and a much more pro active approach from large employers such as Local authorities, NHS and Civil Service to provided employment opportunities.

Suggested areas of activity would be:

Promote value/contribution of people with a learning disability in workplace
Employment champion – nationally
Focus of the Job Centre and responsibilities on them to assist and develop the area -Is this really a Social Care agenda?

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

- Outcomes based assessment so the person with LD is at the heart of the assessment.
- Housing care and provision – investment to meet demographic trends.
- Opportunities for life skills development and preparing to live on own. To replace/add to activity previously carried out by colleges and day
- Centres
- Provision of local service choices for those with Complex care needs/Autism.
- Bringing back individuals where appropriate from out of area placements
- Building neighbourhood networks thereby reducing dependence on paid staff.
- National drive to encourage statutory agencies to employ people with learning disabilities
- Establish a framework for FE college courses to move forward learning and developing from good practice
- Establish appropriate support network to make SDS work for those who need support to achieve support this way
- A new performance reporting model which allows us to track progress in addressing the gaps identified in this consultation, as well as moving towards reflecting outcomes at individual level. We recognise that the latter is challenging and may need to be done through use of case studies etc, rather than being incorporated into a traditional performance framework
- Prevention-focused activity recognised as essential activity
- Life planning for carers
- Increase LAC activity
- Integration will provide a variety of opportunities, all be it they will be different for each Local Authority, but will for Edinburgh mean a look at how current NHS and LA activity can be improved
- Improve the knowledge and understanding of staff in care homes for older people about the health needs of people with learning disabilities
- Undertake joint health and social care reviews of care packages,
- Need to consider how general/acute hospital services could up-skill staff or supporting wards to care for those with learning disabilities and their needs in hospital.
- Emergency plans for carers of people with learning disabilities