

## CONSULTATION QUESTIONS

### Progress and Challenges

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

Yes  No

Please provide any comments, evidence and/or examples here

- The numbers of people with a learning disability and their carers who were interviewed seems disproportionate to the numbers of PWLD in Scotland. How much time was dedicated to people with complex communication needs? Do carers views properly represent the views of the cared for person?
- Gathering consultation views is now disseminated to others to gain a broader view but organisations and carers may not undertake to do this on behalf of the government.
- People still have less access to single tenancy as a choice; it seems more people have to share in order to be able to justify costing. A lot of the time people have little or no control over who they share with. SDS may support this in the future.
- Would agree totally with the findings regarding adult access to college courses
- With regards to accessing public transport this can be a "negative or unhelpful" experience due to the attitude of some transport staff. A stressful unhappy incident can greatly affect someone's confidence and may put them off travelling far from home in the future. This is an identified training need for public transport staff.
- "Access to services" - the report mentions that some families/carers felt they had to fight to find out and or get the services they want. We would agree with carers and would suggest that some local authorities still haven't got it right when it comes to supporting people with learning disability to move from children's to adult services. As a provider we are often approached too late in the process and asked if you can "fit someone in" to services, despite at least 2 years transition planning time.
- 'Access to Services'- there are still concerns that L.A's seem to be directing users and carers to use their own services rather than those of their choice. The reason given to families is that their finance package is tied to the L.A run services.
- We would agree with future priorities that while some aspects of services and delivery are better than 10 years ago, we still have lots more to do. Obviously we do wonder how the advent of Health and Social Care Integration, SDS, reductions in benefits and resources influence future priorities.

**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 large long stay units which were used as dumping ground for those people with varying support needs.
- Recognition of the complexity of needs which may require very person centred approaches
- The start of a move to service users having some control i.e. Direct Payments. Self Directed Support (SDS). Although this has some way to go as some L.A's are still pushing their own services removing real choice from users and carers.
- Organisational support provided to users to help engagement at policy and strategy levels.
- Local Area Co-ordinators are valuable however are too low in numbers with some L.A' s saying 'it never quite worked for them'. Why not?
- Recognition of the need for person centred approaches to individuals is greatly improved however this has raised the expectations of PWLD and carers and does not always balance with the resources available.
- Funding for Independent Advocacy Services is good but still not enough of them and not enough emphasis on how we advocate for people who have more complex needs.
- SCLD idea was good in principle but I think the purpose and role of the Consortium needs reviewed in line with all the changes.
- Lobbying Alliance groups have given people with a Learning Disability a stronger voice.
- There has been a big improvement in the joining up of the Sensory Strategy with the Learning Disability Strategy. However there is still some way to go in working across the various strategies to avoid vulnerable groups 'falling between two stools'.

**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

- SDS is being introduced differently across the local authorities' areas. That is different time scales, different forms, different information formats. There appears to be a lack of consistency and communication with the third sector across the board.
- Lack of transparency in relation to charges applied to service users by local authorities - different levels of criteria, different rates of charges. A postcode lottery is developing in terms of charges for what

and how much. This can have a major impact on the amount of money someone may have to access their local community and activities. Seems that there is no point in having the ability to be part of your community if you have no resources or support staff to do so.

- It may be that reduced financial and human resources make it difficult or unsafe for PWLD to live in their own homes. Could this mean that elderly parent carers will still be left caring for an adult son or daughter until a crisis situation develops?
- Transition from children's services and education is difficult for parents and young people to negotiate. Integration of health and social care services may offer improvement in terms of a holistic and more joined up service. There still appears to be hurdles to cross with education and the teams involved in the journey from child to adult care services.
- Children and young people attending special education schools generally have access to local authority sensory impairment teams or acute services if a problem is identified. Although the incidence of undetected, significant vision and/or hearing loss is high, particularly in those with complex needs, there is no statutory intervention to offer specialist screening to all children and young people who have a learning disability.
- Workforce training should include awareness of sensory impairment as essential training. Without the ability to see and/or hear properly, particularly if undetected; information gathering, communication and mobility are affected. This in turn affects self determination and ability to make informed choices.
- Transport is often a difficulty for people who access support services but are still living with parents/carers. The person may have a Motability vehicle but in many cases this is being used by parents/carers whilst the person is being cared for elsewhere. A legal requirement for the vehicle to be used to support the person with the disability would improve access to services, provide greater access to community activities and would frequently reduce the cost of care packages which often include a charge for transport already provided.
- Sensory needs are often 'hidden' or viewed as the part of the person's learning disability which is a problem. Government policy and strategy does not always feel joined up. e.g. Autism/sensory loss, Dementia/sensory loss, LD/Sensory Loss etc There needs to be improved synergy across strategy.
- There seems to be an unfair power imbalance that local authorities hold when commissioning services with 3rd sector - tendering for services does seem to be weighted towards driving down the salaries/standards of social care staff in the 3rd sector.

- Continue to professionalise the social care sector through registration with SSSC to ensure best practice from qualified/motivated workforce
- Treat more harshly those who are found guilty after criminal proceedings of abuse/neglect of vulnerable adults.

### 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

- Delivered a personalised quality service that is recognised by Care Inspectorate grading's - however this comes at cost as quality services must be properly resourced and some local authorities will not fund or commission specialist services.
- We have developed training for the workforce to essentially 'pave the way to optometry' for the people they support, ensure that an eye test is undertaken, but more importantly ensure that any results from the eye test are understood and embedded in the future care planning for that person, building capacity ensuring sustainable services in the future.
- We are currently rolling out a 'Vision Champion' model of training across Scotland which equips professionals with the necessary knowledge, skills and awareness to recognise sight loss where this might otherwise be overlooked. This training can cut across all clients groups and as well as evidencing good partnerships working offers a sustainable service for the future at a relatively low cost.
- We have developed training accredited by Caledonian University in Vision and Learning Disability for health and social care professionals.
- We have developed CET accredited training for Optometrists to support them with alternative testing methods for PWLD.
- We now have a service user group that we consult with regarding service development and practice, government legislation, policy & procedures. This group have spoken at conferences and fringe events and have membership on RNIB Scotland Committee..
- Created a carers forum to support parents/carers to address shared problems and offer mutual support to each other.
- We have seen tremendous results in supporting people with complex needs to eye care; picking up those 1 in 3 people with a learning disability that we know are likely to be living with undetected sight loss. Our projects are evidencing substantial results, not only in the prevention of sight loss for the people we support, but also an increase in their independence, inclusion and quality of life.

*We won the COSLA award for raising awareness of the need for people with a learning disability to have access to community eye care.*

*We won the Care Accolade for the 'Most Innovative/imaginative training'.*

*We have won the Herald Society Award for our Optometry training.*

*We have been shortlisted in two categories for our Dementia partnership working and also our Vision and Dementia training*

All of the above improves services, improves access to community services and increases independence for each individual who crosses our path.

### 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

- Developed and lead a team of dedicated staff who have supported me in raising awareness of undetected sight problems in people with a learning disability not only in Scotland but across the UK
- Shared our knowledge, skills and experience with others though the assessment tools and training we have developed something which is unique
- Commented on Government policy and strategy papers
- Continued to keep practice and knowledge up to date
- Contributed to various LA strategy meetings.
- Influenced government strategies

### 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

*An estimated 579,000 adults with learning disabilities in the UK have refractive error and an estimated 53,300 adults with learning disabilities have **severe** refractive error" Emerson & Robertson. 2010. CeDr.*

*People with learning disabilities are at much greater risk than members of the general population of ocular and visual defects, including refractive errors.*

*People with learning disabilities may not have the ability to self-refer for primary eye exam or be able to communicate their sight loss to carers.*

- Review access to supplementary eye tests for people with learning disability or more complex needs. Currently patients are unable to access a supplementary test if the first test is unsuccessful as a

result of for example refusal/behaviour.

- Recognition at national and commissioning level of the link between sight loss and learning disability - without this the wrong support/care plans can be produced either over or under estimating costs/resources needed. This links directly to SDS plans which do not always give enough consideration to the health needs of people with learning disabilities.
- That a formal vision assessment is undertaken as part of all social work and health needs assessments of people with a learning disability in Scotland.
- That young people with a learning disability have a formal vision assessment on leaving school to ensure that undetected sight loss does not adversely impact on their transition
- Health improvement planning that really reaches vulnerable groups.
- There are good practice examples of 'Health Checks' being carried out by highly trained L. D. nurses who have had additional 'Sensory' training. This supports in the recognition of previous undetected sight problems.
- There is recognition that people with learning disability are more susceptible to certain health concerns - Dementia, certain cancers GP's may not always be the most appropriate people to carry out those initial health checks.
- Improved training for NHS staff in the needs of people with learning disability, or other complex needs such as Dementia. Training in sensory awareness, communication, allowing time that may be needed for individual consultation/support/care. So often we read of traumatic experiences of people entering the realm of NHS care and being neglected, ignored, or at worse receiving sub standard treatment and care.
- Review Care Inspectorate standards to include sensory needs and a link to training basic grade staff in awareness. 'People don't know what they don't know' often undetected visual difficulties are blamed on behaviour that challenges others.
- Sensory training for Care Inspectors to support them in their role in advising others.
- Develop a module on sensory needs that could be included in the training of LD nurses, Social Workers, OT's Psychologists, speech and language therapists etc raising awareness at the point of training.
- Invest to save!

## 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

- Stop the cuts to colleges for their special need courses - there seems to be disproportionate cuts to these courses being implemented in comparison to other courses.
- Ensure college teaching staff have experience of supporting people with learning disability and other needs including sensory and that they are not the staff who cannot perform properly and are being redeployed to cover these courses in a tokenistic way.
- Ensure that courses undertaken have an outcome which has demonstrable value and meaning to the person. E.g. skills for independent living, work or volunteer placement. It would help if realistic expectations and realistic outcomes were achieved. (SMART)
- Improved link with personalised plans and measurable outcomes.
- A question would be 'how is the content of course decided' ? are users consulted?

## 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

- Better joined up working when people are moving from child to adult services - it seems many parents/carers go through a real period of stress as when guided by social work personnel they seem to be scrabbling around for services at the last minute
- Recognition that when consulting with carers for services that there answers/wants/needs may be very different from the people they care for.
- Ensure that packages of care link to personalisation and SDS and of course sensory needs.
- Ensure money is available for 3rd sector to ensure ongoing access to training to support with independent living.

- Access to independent advocacy

### **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

- Realistic work training opportunities which are properly supported and not viewed as tokenistic 'tried and failed' experiences.
- It would be helpful for people to be given 'taster' sessions for employment opportunities.
- Perhaps being able to use volunteers or personalised budgets to offer initial work shadowing and support.
- Realistically there is a shortfall in employment opportunities for whole generations of young people at the moment so there is a mountain to climb for PWLD.
- At present there is a hurdle to overcome in terms of the benefit system.

### **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

- Sensory needs are often 'hidden' or viewed as the part of the person's learning disability which is a problem. Government policy and strategy does not always feel joined up. e.g. Autism/sensory loss, Dementia/sensory loss, LD/Sensory Loss etc There needs to be improved synergy across all the strategies.
- More monitoring and accountability of local government in relation to the personalisation agenda. There seems an unfair power imbalance that local authorities hold when commissioning services with 3rd sector organisations. This can be weighted towards driving down the salaries/standards of social care staff in the 3rd sector.
- Review access arrangements for supplementary eye tests for people with learning disability or more complex needs. Currently patients are unable to access a supplementary test if the first test is unsuccessful



as a result of for example refusal/behaviour or if it is refractive error.

- That a formal vision assessment is included/ undertaken as part of all social work and health needs assessments of people with a learning disability in Scotland.
- That young people with a learning disability have a formal vision assessment on leaving school to ensure that undetected sight loss does not adversely impact on their transition
- Review Care Inspectorate standards to include sensory needs and a requirement to training staff in sensory awareness. 'People don't know what they don't know' often undetected visual difficulties are blamed on behaviour that challenges others
- Funding and training for Independent Advocacy Services for people who have more complex needs.
- Develop a module on sensory needs that could be included in the training of LD nurses, Social Workers, OT's Psychologists, speech and language therapists etc raising awareness at the point of training for future health professionals.
- Although there has been great progress it is essential (and challenging) to consult in greater numbers in a meaningful and comprehensive way with people who have a learning disability - especially those who have complex communication needs.
- Perhaps part of the curriculum should be devoted to educating young people about how they can influence service provision and legislation.
- Review the purpose and role of the L.D. Consortium in line with all the changes
- More education in schools about the diverse natures of people that make up our communities to combat discrimination.
- Invest to save!