

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

While this seems to broadly reflect the successes and challenges we have experienced in Fife, the actual sample making up the service user and carer evaluation under represented both people under early twenties, as well as those previously in hospital or in restricted environments. Thus middle aged people living independently or with families were over represented. Other than this it seemed to evaluate the experience of a wide range of people with a learning disability.

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?*

What has worked well to enable all of the developments we have made is the more fundamental shift in attitudes amongst the general public, professionals and amongst people with learning disabilities and their families. The SAY work made people see those with learning disabilities as independent individuals, with their own needs, wants, talents and ambitions, rather than as a homogenous group-many of whom were contained in long-stay wards. For a lot of people, it was the first time that they heard the voices of people with learning disabilities and understood the need for change.

The most obvious examples from Fife are the significant reduction in bed numbers at Lynebank Hospital, including closure of all long stay beds, the review of day time activities, the review of commissioning for those with complex needs and development of a joint strategy, as well as the development of a wider range of accommodation solutions and care providers with expertise in a variety of fields. For those people who have to go in to hospital for treatment of mental health or psychological problems new environments have been developed to improve quality and person centred care.

Specific examples of things that work well in Fife include the choices people with learning disabilities can make over where and how they would like to live, including joint health and social care provision for those whose needs are extremely complex. We have developed a range of different options, from single tenancies to shared living, and we can meet almost all needs within Fife, by working closely with a range of independent service providers.

In Fife, in addition to meeting the recommendations in relation to the needs

of people with a learning disability, the SAY? Report initiated a focus on the needs of people with an Autism Spectrum Disorder (ASD), whether with or without a learning disability; with evidence of local action and developments being collated and reflected within Fife's Partnership In Practice (PIP) Agreement. The PIP has ensured that all key partners within Fife have worked together to take forward SAY? Recommendations.

It became apparent over the initial years that a closer focus on the needs of, as well as services for, people with ASD was needed; Fife, so an ASD Co-ordinator co-ordinator post was created in 2008 with this post being jointly funded by Fife Council and NHS Fife. In line with the SAY? Report, the post took on a 'cradle to grave' approach; with raising the profile of ASD and building capacity, within both community and public service settings, seen as a priority and central to ensuring that interventions are both effective and appropriate.

Over the past ten years, since the launch of the SAY? Report, we have grown to appreciate the distinct differences between learning disabilities and ASD. However, there exists a significant range of parallel issues and overlap in approaches and models of intervention. Therefore, in 2009, to reduce the likelihood of duplication in addressing these issues, Fife extended the Learning Disability Strategic Implementation Group to include ASD. This group exists to support delivery of actions within local policy, plans and strategy in relation to learning disabilities and/or ASD.

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

Supported employment, training and further education opportunities for people with learning disabilities / autistic spectrum disorder could be improved as meaningful employment opportunities are crucial to help people live lives free of poverty and without the risk of social exclusion.

There are significant planned changes in the Further Education sector. It will be important therefore that, in collaboration with our further education college colleagues, we will need to address reductions and changes in relation to further education college places for people with learning disabilities

The strategy for jointly commissioning services for those with complex needs should improve the delivery of care which is more individualised and effective using evidence based approaches. Clearly developments in the integration of health and social care will be significant in this respect. Service users and carers represented at the Learning Disability and ASD Strategic Implementation Group in Fife are very clear that integrated services (from assessment, to delivering care, to budgets) are the way ahead.

Jointly commissioned services for people with learning disabilities / ASD will

need to ensure that care/support staff are well trained in not just generic care standards but the specific needs of people with learning disabilities who may also have other needs such as mental health, physical health and behavioural needs. Management of such services will need to be aware of best practice with specific groups of people building on work done by the Joint Improvement Team.

In relation to health improvement: the population of adults with an ASD remain under-diagnosed, whether with or without a learning disability. Therefore, in comparison to that of adults with a learning disability, research in relation to health needs for adults with an ASD is less advanced. A similar themed action plan to that initiated through Fife's Learning Disability Health Improvement Strategy, may be beneficial to people with ASD; whether with or without a learning disability.

Following a snapshot exercise within Fife's Mental Health (Community) service a project has been initiated to look into numbers of adults with ASD, accessing existing services including housing and older people's services. It is anticipated that during this process, some adults who 'may' have an ASD will be identified; and, perhaps, benefit from an assessment.

Linking with this project, both Social Work and Housing data collation systems have been adjusted to ensure that they capture numbers of those with an ASD; whether as a primary or secondary referral component. Additionally, running in parallel, the development of an ASD assessment and diagnostic pathway for adults is being progressed.

It would also prove beneficial to have clarity in relation to numbers of those accessing services with both a learning disability and ASD. This may allow Fife to be in a better position to more accurately reflect local data within the e-SAY Dataset; as well as address planning of future services for those with learning disability and/or ASD.

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

Significant work has been done in Fife to improve services and access to services over the last ten years. Our services now are barely recognisable in comparison to those of the previous decade. However, although we have had a lot of successes in small and larger scale projects and developments, it is the underlying approach that has made the difference and improved our services. We have worked in partnership across Fife, via our Learning Disability / ASD Strategic Implementation Group, to ensure that we offer choice, quality and often ground-breaking services.

It is not only the services for people with learning disabilities that are

accessible. We have worked hard to make all public facing services as accessible as possible to people with a range of additional needs.

A few examples of the things we have achieved via our partnership approach include:

The provision of health and social care on a single site for people with complex needs in Dunfermline. This joint care facility allowed people to move out of long stay hospital with some of the most complex health and social care needs. This model is being further developed in relation to the very few long-term patients in Lynebank hospital to reflect lessons learned from the service described above. A service provider has been identified and the joint specialist service is currently under development.

We appointed an ASD Coordinator in 2008. The post was recently evaluated, showing that we have made services far more accessible to people with ASD, and that we have increased awareness of their wide-ranging needs with our staff and members of the public. A number of initiatives and projects were borne as a result of collaborative working across agencies; least of all in tackling waiting lists for assessment of children and adolescents, by increasing the number of diagnostic teams for children and adolescents; with some now based within the community setting. Work continues in key areas i.e. a diagnostic pathway for adults, self-help options and the forthcoming development of a One Stop Shop; which will provide a number of community-based services, to be determined via a process of co-production. This service will be available for people across the Autism Spectrum, including those with a dual diagnosis of Learning Disability, and their families

Through our own in-house provision, and through independent sector provision, we are able to provide a range of community living options, while partnership with NHS Fife has allowed a network of community treatment, rehabilitation and care services to wrap around the individual.

We established a Transitions Scrutiny Panel, bringing together cross party elected members to examine in detail all the Council services available to young people in transition and from that we have developed a very ambitious action plan that will support a more wrap-around approach to young people in transition to ensure they and their families get the best possible support at what can be an anxious time.

We recently completed the development of a joint commissioning strategy for learning disability / ASD, focusing on how we can best commission services for people with complex needs. The strategy is currently being implemented and tested across Fife, and we will consider rolling out the successful aspects of this approach to other groups of people.

Good Practice - Individuals

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

We have established the Learning Disability / ASD Strategic Implementation Group (LD/ ASD SIG) for Fife, bringing together service users, families and carers and the statutory and voluntary agencies involved in providing services. This group has championed the rights of people with learning disabilities/ ASD and their families, with staff, with politicians and with the wider population of Fife. We have seen potential, ability and individual people first, and disability second and have worked hard to shift from institutional solutions and mind sets to the inclusive, responsive services we see in Fife today.

Most significantly, the Implementation Group has ensured that the people who use the services and their families are at the heart of strategic decision making about these services. We have done this by making sure that they are key members of the LD/ ASD SIG and that their voices are heard and their contributions respected. The group has worked to drive the hospital discharge programme forward in Fife, finding innovative solutions and putting people with learning disabilities in control of their own lives.

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?

Health promotion messages need to be repeated, and must be consistent and engaging. People with learning disabilities may need to hear the same message several times, and may need support to understand the implications for their own behaviour around health.

Further developments such as the healthcare passport will refine the progress made to date and NHS Fife employs one Primary Care Liaison Nurse in order to keep this work going.

Assessment and diagnosis of dementia and ASD need to become better established and post diagnostic sign posting needs to be robust, involving service users and carers in evaluating the benefits.

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

It is important that irrespective of the changes which are taking place within further education that college places are available on a full and part time basis, to anyone with a learning disability /ASD who wants to attend further education. We know there is a more general link between education and employment success, including income levels. People with learning

disabilities/ASD who are able to achieve qualifications will be better placed to find meaningful employment.

In partnership with the further education colleges, Fife Council Social Work Service developed a support service called Fife In College Support Service. Fife Council provides a budget to each college in order to deliver support to students with additional support needs on a one to one basis or a group basis. This service was initially established in 2005 and it is hoped that this service will continue to support students in the future, however it is anticipated that changes within Further Education may lead to changes in availability of college courses for students with additional support needs.

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

We would like to see investment in and development of new technology to support independence, whilst acknowledging the need for assessment of needs on an individual basis so that appropriate support and input is provided to each person.

Professionals could perhaps support people in positive risk taking to a greater extent than at present, through a culture of enablement (and in some cases, re-ablement).

People and their families need to be clear what level of support they can expect and about decision making processes about these levels of support so they can plan their lives appropriately.

We need to maximise independence within the abilities of the person. Any risk assessment needs to take into account people's skills/potential but also needs to recognise their support needs.

Increased opportunities to develop individual capacity via self-help options including tapping into existing community-based resources and building the capacity of resources to better cater for the needs of people with learning disabilities /ASD.

Education: emphasis on meaningful lives through addressing individual capacity to develop healthy relationships with others; including, age appropriate, focus on sexual well-being as well as individual rights and responsibilities. This may also include input from the criminal justice sector; as people with learning disability / ASD may become a victim of crime.

Future Priorities – Employment

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

Better training and education, targeted at employability. Employers beyond the public sector could be supported to understand the value that people with learning disabilities could bring to their organisation. They need to hear a clear message, essentially that there is no such thing as People With Learning Disabilities / ASD as a homogenous (and somewhat anonymous) group, but rather that there are individual employees and prospective employees, people with skills, talents, training needs and a contribution to make, some of whom may also have a learning disability.

When they are employed, support needs must be taken into account, but their employment must be on equal terms with any other employee in relation to salary and benefits. It is about a fundamental shift in attitude, and it can be achieved, just as we have moved from institutional to community care.

In Fife, the draft Supported Employment Strategy for Fife was discussed at the Opportunities Fife Strategic Group (OFSG) in May 2012. The OFSG Chairperson welcomed the renewed emphasis on the skills and employability needs of disabled people particularly in light of the welfare reform agenda. It is further proposed that this would form a central focus for a newly constituted Opportunities Fife Health and Employability Programme Delivery Group.

Multi-disciplinary and agency approaches to employment can contribute specific skills in ability assessment, job analysis and activity adjustment (for example occupational therapists). This can help address potential achievements as valued employees rather than focus on impairments.

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

Improved commissioning of services for people with learning disabilities / ASD.

More consultation, more involvement and engagement with the wider community, e.g. community councils and community planning groups – people with learning disabilities / ASD can become much more visible within their communities, and have their voices heard.

Increased partnership working with the independent sector to meet a diverse range of need with tailored solutions.

Continued development of joint working between health and social services.

Research into demographic changes, and into how we achieve the best possible outcomes for a growing population of people with increasingly complex needs.

Ensuring people in prison with a learning disability are known about and receive equal and accessible services for managing offending behaviour as well as health and social care.

The planned programme of welfare reforms as this will almost certainly increase the levels of poverty, hardship and employment chances of people with learning disability and their carers.

The impact of these reforms may well mitigate our commitment to develop the SAY vision because there will be a need to re-focus resources in response to the impact of the welfare reforms.

The specific changes to DLA in 2013 and how the Personal Independence Payment will be implemented will be crucial issues for people with learning disabilities and for those who provide the services they rely on in future. Disability Living Allowance (£84 million) and Incapacity Benefit (£47 million) are amongst the highest benefit payment areas in Fife. Other large aggregated claimed benefits are Income Support (£48 million), Job Seekers Allowance (£33 million), and Attendance Allowance (£27 million).

Thank you for taking the time to read the consultation document and taking the time to respond to the question. Your continued input and support is vital in ensuring that we continue to close the inequality gap that people with a learning disability face daily.

All completed questionnaires should be returned to Sarah Grant either by e-mail or at the address below. The closing date for responses is 30th September 2012.

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