

DUNDEE CITY COUNCIL

REPORT TO: SOCIAL WORK AND HEALTH COMMITTEE - 24 SEPTEMBER 2012

REPORT ON: THE *SAME AS YOU ?* 2000-2012 CONSULTATION RESPONSE

REPORT BY: DIRECTOR OF SOCIAL WORK

REPORT NO: 354 - 2012

1.0 PURPOSE OF REPORT

1.1 The purpose of this report is to seek agreement regarding a proposed response to The same as you ? 2000-2012 Consultation Report, Scottish Government. The *same as you ?* is the policy which belongs to people with learning disabilities in Scotland.

2.0 RECOMMENDATIONS

It is recommended that members :-

2.1 Endorse the National Consultation Report

2.2 Note the contents of this report which includes the proposed consultation response

2.3 Agree the proposed consultation response prior to submission to Scottish Government.

3.0 FINANCIAL IMPLICATIONS

3.1 None

4.0 MAIN TEXT

4.1 The *same as you ?* was launched by the Scottish Executive in May 2000. The report related to a review of services available at that time for people with learning disabilities and people on the autistic spectrum. The report contained 29 recommendations which were aimed at improving services and were underpinned by principles recognising the individuality and worth of every person with a learning disability and/ or autism and their right to have a control over how they choose to live their life.

4.2 In 2010 the Scottish Government set up an Evaluation Team to look at how people's lives had changed since the launch of the *same as you ?*. The aim was to identify what improvements had been made and what challenges still remain. The results of this evaluation will inform further policy and service development for people with learning disabilities and/ or autism both nationally and at a local level.

4.3 The *same as you ?* principles and recommendations of 2000 have formed the basis of the development of local services and supports in Dundee and it is felt that much progress has been made in supporting individuals in more personalised ways as opposed to more institutional forms of care and support.

4.4 The evaluation has highlighted that nationally further work is required in Healthcare, Education, Housing and Employment. Some of the consultation questions centre on these areas.

- 4.5 Dundee's Learning Disability Strategic Planning Group has compiled the attached consultation response. There is a well established consultation and involvement process in place which supports strategic planning for people with learning disabilities and/ or autism in Dundee. The Strategic Planning Group would wish overall to endorse the outcome of the evaluation and the content of the National Consultation report.
- 4.6 Following the 2000 The same as you report? there have been annual consultation activities to gain the views of adults with a learning disability as well as their family members and carers. The main focus of these events is the annual Partnership-in- Practice review which has focused on different priority areas over the years and highlighted progress and developments. Front line staff have also had opportunities to contribute their professional opinions as well as providing additional insight into the views and opinions of family members. Advocating Together (Dundee) is the one of the main agencies who help support this consultation as well as providing opportunities for ongoing involvement of local people who have a learning disability. In Dundee we believe we may be unique in offering permanent (rather than sessional) employment to adults with a learning disability who are employed as 'Say Reps' and have through dedication and hard work gained the confidence of their peers allowing them to confidently and appropriately represent others views in planning groups and other committees.
- 4.7 It is suggested within the response that the consultation report does not address the area of direct services for carers. There is also a view the local carers' supports and services, in particular those for carers who are older, need to be evaluated to ensure that we are offering appropriate support for carers as well as for the person they care for.
- 4.8 The consultation area which refers to independent living is suggested in the proposed response as misleading and could cause alarm for some people. The use of the term community living has been suggested with reference to appropriate supports being in place for people.
- 4.9 Although the report makes some reference to public attitudes to people with a learning disability, overall greater education and awareness is needed in order to shape public understanding of the rights and responsibilities of people with learning disabilities and their family members and informal carers. Local people with a learning disability have taken an active role in public education through drama initiatives and other work. A recent initiative has involved Learning Disability Services and the Dundee Rep Theatre. More of these types of initiatives are sought to emphasise the individuality of each person and their right to be heard and have their opinions respected.
- 4.10 It should be noted that an integrated Learning Disability Health and Social Work Team has been developed in recent years and has benefited Service Users by: encouraging better communication and minimising duplication of plans.

5.0 POLICY IMPLICATIONS

- 5.1 This Report has been screened for any policy implications in respect of Sustainability, Strategic Environmental Assessment, Anti-Poverty, Equality Impact Assessment and Risk Management. There are no major issues.
- 5.2 An Equality Impact Assessment has been carried out and will be made available on the Council website www.dundee.gov.uk/equanddiv/equimpact/.

6.0 CONSULTATIONS

- 6.1 The Chief Executive, Director of Corporate Services and Head of Democratic and Legal Services.

7.0 BACKGROUND PAPERS

7.1 EQIA

7.2 *Same as you ?* Review Report, Scottish Executive, 2000.

7.3 *Same as you ?* 2000-2012 : Consultation Report.

Alan G Baird
Director of Social Work

DATE: 12th September
2012

The same as you? – Consultation



The same as you? is the policy belonging to people with learning disabilities in Scotland. It was launched by the Scottish Executive in May 2000 and reviewed the services available at that time to people with learning disabilities and people on the autism spectrum. It contained 29 recommendations intended to drive a change programme which would improve services. The recommendations were underpinned by principles recognising the individuality and worth of every person with a learning disability in Scotland; their right to be included in, and contribute to, society and their right to have a voice, support and to live the life of their own choosing.

In 2010 the Scottish Government set up an Evaluation Team to find out how the lives of people with learning disabilities and/or on the autism spectrum and their families have changed since the launch of *The same as you?*

What improvements have there been and what challenges still remain?

The results of the evaluation will be used to inform priorities for further policy and service development.

The evaluation process highlighted a number of areas where further work was still required, for example:

- Healthcare
- Education
- Housing
- Employment

We would now like to hear your opinions on the outcome of the evaluation and how we can improve things in the future. This is important as your opinions, along with the outcomes of the evaluation, will be taken forward to inform, develop and produce a new policy document for people with learning disabilities.

A new national learning disability strategy group will be formed to work on this new policy during 2012.

The following questions ask about your opinions and experiences so we would appreciate it if you could take the time to respond as we only have a limited amount of funding to do this work so we need to make sure we are spending this on the right areas.

The same as you? – Consultation

RESPONDENT INFORMATION FORM

Please Note this form **must** be returned with your response to ensure that we handle your response appropriately

1. Name/Organisation

Organisation Name

Dundee Learning Disability Strategic Planning Group

Title Mr Ms Mrs Miss Dr *Please tick as appropriate*

Surname

Mitchell

Forename

Arlene

2. Postal Address

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3. Permissions - I am responding as...

Individual

Group/Organisation

Please tick as appropriate

(a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

(b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

Please tick ONE of the following boxes

Yes, make my response, name and address all available

Yes, make my response available, but not my name and address

Yes, make my response and name available, but not my address

(c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site). Are you content for your **response** to be made available?

Please tick as appropriate Yes

No

(d) We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate

Yes

No

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 x No

Please provide any comments, evidence and/or examples here

We identify with the findings of the evaluation and believe that these are consistent with the views expressed by our local population.

More specifically we appreciate the inclusion of life planning as a critical part of peoples lives. Recently consultation in Dundee has demonstrated that people are now keen to live healthy and active lives.

We believe that inclusion, citizenship and having safe relationships with others are areas that might merit more attention in future. From recent research it is clear that Hate Incidents and Hate Crimes should also be addressed on a zero tolerance basis.

We also think that in Scotland we should give more consideration to equality characteristics that people experience, as well as learning disability, and look at how people might be discriminated or negatively impacted upon within the population of people who have a learning disability.

The evaluation is more limited in it's content about services for carers per se however this is not thought to be inappropriate. It is acknowledged that carers will be affected by services for the person they care for and in this aspect the evaluation is adequate and appropriate.

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

In Dundee as an outcome of SAY and other policies in the last 10 years people have progressed from institutional care towards more personalised supports and services.

Some people who might previously have been hospitalised are now well supported by universal services (either alone or with support to access these). While there will continue to be a need for care settings where people will receive support alongside others it is thought that perhaps it is not the only or the most effective way for all those who currently receive such provision to receive their support. We recognise that there are still a significant number of people who have not achieved their full potential and are still over reliant on institutional provision. We believe that people could be enabled to access mainstream services and have a lifestyle more like their peers. We identify that locally we are still in a process of transition towards more people being supported by mainstream/universal services either with support or independently.

Partnership -in-Practice Agreements in Dundee have supported strong partnership working across agencies including Health and Social Work Services and this partnership approach has supported local developments. Community capacity building activity and determination to develop effective and responsive user involvement practices have enabled adults with learning disability to gain permanent employment as 'SAY reps' who have the skills, confidence and knowledge to represent their peers and attend meetings on equal terms with professionals.

Recent local consultation has demonstrated that people are now interested in having healthy lifestyles and in learning activities, demonstrating that local and national work in these areas has been successful.

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

In Dundee joint commissioning for social care and health care has been effective in achieving positive outcomes and we will seek to increase the use of this model. This model has been identified as particularly useful in developing alternatives to institutional care for more people with a complexity of need including behaviour which challenges service providers. Effective alternative community provision must be increased in order to make progress towards eliminating the need for long term hospital care and joint commissioning is thought to be the most effective and preferred route for this.

It is anticipated that Self Directed Support (SDS) legislation will add increased vitality to the process of personalising individual services and supports locally . We will need to ensure that these processes are clear, effective and accessible in order to support individuals to get the best support for them.

Alongside SDS for people who require care and support we need to continue to develop ways for people to access preventative or lower level support that helps them avoid crisis. Citizen Leadership, capacity building, self-advocacy , mutual support, peer support and inclusion are vital to maintain individuals who are not requiring or eligible for higher levels of support.

We need to increase effective use of technology and Telecare to support people in ways that are unique to their circumstances.

It is thought that there is a need to manage the challenges of access criteria for learning disability health staff intervention along with Social Work Department access criteria. National Guidance could help support local solutions. It is thought that referral criteria should be adapted to be more needs led and more responsive to those for whom diagnosis is complex. Also for conditions that span different health or social work services like Autistic Spectrum Disorder and dual diagnosis like Down syndrome and dementia.

Further work is needed to develop the right services for people with Autistic Spectrum Disorder. It is also recognised that further work is needed to support family members, in particular parents of adult children, to have a life of their own and be confident that services and supports for their loved ones are the best they can be.

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

A vital improvement in service delivery resulted from the integration of Health and Social Work/Care Services and the identification of a single manager for Learning Disability Services in Dundee.

We have taken steps towards modernising services to meet the needs evidenced by assessment processes and expressed by people in care planning and in consultation.

Examples of improvements made include- the development of a Learning Disability Providers Forum, amalgamating learning disability employment services with mainstream supported employment, and partnership working with Dundee College.

Approaches to providing care are less institutional and there has been a rise in people's expectations about the care provided. This has resulted in a reduction in numbers wanting/accepting Nursing Home Care.

A number of these "new" institutions locally became untenable and the local response to this was to seek other models of care provision rather than seek to create new institutions or move people to similar provision elsewhere. We have developed a number of community/independent living models to respond to individual needs of these former residents. The closure of some

Nursing and Residential Care Homes and Units was sometimes something Social Work and Health staff had little say in. The responses (although sometimes rapid) have been planned to be more responsive to individual need.

Attention has been paid in Tayside to the application of simple, timeous and effective communication between members of the Integrated Learning Disability Team, family and paid care givers. This has provided more effective, efficient care and support and contributed to reducing stress to family members and carers at critical times.

In Ninewells Hospital there has been considerable improvement to person centred care following developments where the Acute Liaison Learning Disability Nursing Service and the Acute Services staff share knowledge and promote cohesive support to learning disabled adults with complex health issues admitted for unscheduled care.

These improvements have included establishing proactive links with the Acute Services to plan and anticipate adaptations in advance of planned out patient and in-patient admissions e.g. arranging pre-out patient visits for individuals with ASD and altering the times and locations of clinic appointments accordingly.

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

Many individuals have worked together in partnership with people with learning disability and their families to progress development in Dundee.

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 has been successful local work which has made demonstrable improvement in access to Health Care, this work needs to continue both locally and nationally. Specialist learning disability staff have shared knowledge and skills with colleagues in health care professions to improve understanding and accessibility as well as supporting people to expect the health care to which they are entitled. Specialist staff have shared skills and knowledge to train and support social care staff to provide appropriate care in the community.

A local Downs Syndrome Clinic has been initiated leading to early identification of health care needs for people within this group.

It is essential that Health Care professionals recognise the value of each individual to reinforce positive attitudes to accessing health care. Attitudes to disability need to be at pre-birth as well as early years. The attitude to possible disability in the unborn child must be non-judgemental allowing parents to gain a balanced view of the future.

Achieving change in public attitudes to disability, especially learning disability is a priority and projects like the local drama initiative "Inform Theatre" support public awareness and understanding. Changing public perception is vital as it influences those who promote access to health care e.g. the GP's Receptionist, the public around (in waiting areas etc) when people with a disability attend local hospitals.

In Dundee there have been education initiatives provided to medical staff in training regarding learning disability and more specifically Profound or Multiple Learning Disability (PMLD). Consideration should be given to mirroring this in other areas as well as looking at similar initiatives for all types of staff.

Further work is required to examine the results of the current pilot of the P.A.R.C. (pre appointment recording chart) tool developed with Keep Well funding and specifically aimed at the Profound and Multiple Learning Disability service user group. Fundamentally it aims to act as a means of enhancing the sharing of clear clinical information between carers and GPs in respect of individuals with PMLD . By furnishing GPs with a greater breadth of accurate information on the PARC prior to a consultation appointment, the GP should be able to make more accurate and timeous diagnostic decisions for such a complex group with many co-existing and complex medical issues.

Work is needed to explore the development of an accurate and regularly updated electronic register of known Learning Disabled individuals in Primary Care. This register, populated with specific information, would electronically flag pertinent information to out of hours Accident & Emergency and NHS 24 services when emergency contact is instigated. Critically, this would underpin local and nationwide healthcare access in support of daily living, relocation and holiday opportunities.

Research and input is needed to determine and develop the skills, training and competency framework required to support paid care staff to safely address the complex healthcare tasks required to support current and future service users. This would ensure that learning disabled children, adolescents and adults requiring invasive procedures such as home ventilation, respiratory suction and enteral feeding could have these care tasks carried out consistently

across all spectrums of their daily life unhindered by skills barriers. Often this is reported as a source of frustration for family carers, when they discover that the invasive tasks which they carry out cannot be done by all paid care staff.

Specialist Health staff should explore the potential role of Learning Disabled adults functioning as peer healthy lifestyle coaches to underpin key health messages and work alongside LD health staff. This is wholly applicable in a range of health promotional areas from diet, alcohol and drugs to relationships and parenting skills.

In partnership with key trans agency stakeholders, such as Community Midwifery and Child & Family Services, there is a need to develop ante natal pathways of support for learning disabled parents and explore creative mechanisms to support and advice new parents of babies with disabilities during post natal care.

Future Priorities - Education

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

Schools have made progress towards ensuring access to Education (Additional Support for Learning) (Scotland) Act 2009 has supported this. Attitudes to and opportunities for learning post school continue to require attention.

With direction from 'Partnership Matters' Dundee College have been exceptional in working in partnership to develop educational opportunities. However, there is still a small group of people who see going to school as a life long activity and not a development phase and this needs to be addressed.

Although 'education' is a vital part of the jigsaw it is our opinion that for adults we need to extend the range of learning experiences for adults. We need to work hard to make sure we have the right model and right range of opportunities. Traineeships are needed with time at college and time in a work placement. Scottish Government needs to look at 'modern apprentice' schemes and consider if 'supported apprentice' could be sponsored in more practical areas like car valet work, hotel work etc and ways that supporting people in employment could be cost-neutral to an employer.

Again public awareness is important to support these changes and the public need to understand the value of each individual.

Future Priorities – Independent Living

Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?

There are people who can live independently without formal planned support. In order to facilitate this for those who are able we must ensure that these individuals know how and where to get support when needed and an increase in "drop-in" type services is needed if people are to have fewer formal supports.

For many people the preferred model would be living as part of a local community rather than 'independently' as this creates a vision of managing without external help and may increase isolation which in turn can create vulnerability.

We need to support parents and other full time 24/7 care givers and see them as part of a whole family unit. Often previous 24/7 carers are still the main carer for their loved one after they leave the family home and front line services need to maintain a balance between the rights of the individual and working in partnership with their main carers.

We must promote ways of forming and maintaining safe relationships and avoid isolation. For many people who have left formal services they need to be encouraged to keep up with the friends they have made.

We need better ways to support parents too through transition to the person they have cared for living away from the family home. We also must recognise the mutuality of family relationships and make sure the person living away from the family home gets appropriate support in their role in family life e.g. the person may be a carer for mum and dad. Appropriate bereavement support also needs to be more available for people.

We must find ways to achieve Best Value in resource meet needs and share the cost of 'independent living'.

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

The outcomes of benefits reform are still not fully known. There need to be models of supporting people financially during a transition to work. Models of training , work placements etc need to be flexible and suitable for individuals to allow them to test employment without receiving a lower income.

Overall it is recognised that more work placements are needed, paid or voluntary depending on individual circumstances.

The current economic climate makes overall work opportunities difficult. However employers, through education of the general public, need to learn that employing someone with a disability can be a positive action and a positive contribution to their workforce.

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

The ESAY statistics provide a valuable benchmark across Scotland and building up information over subsequent years will be helpful.

We need to increase the capacity of our communities to support each other allowing people whatever their needs, to support others and to benefit from the support of others.

We have supported those with lower level needs to effectively be part of communities but need to support those with complex needs and/or complex circumstances, which will always be a challenge.

Self-Directed Support as a genuine support needs to enable people to be employers and be in as much control as they can in a Scotland in which difference is celebrated and valued.

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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