

**Summary of Feedback from Speakeasy  
Sessions held in the Western Health and  
Social Care Trust area during March –  
April 2017**

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## 1 Introduction

There are about 1800 families who have an adult member with learning disability living in the Western Health and Social Care Trust (WHST) area. There is dissatisfaction with current arrangements and use of resources among both families and the WHST. There is a genuine desire to do things differently and to put in place the conditions that will improve the quality of life for individuals and their carers.

In 2016/17 the Western Trust will implement a plan to spend £3m on new services for Learning Disabled adults. The focus of this work is to consider how a further £5m might be best invested going forward.

The Trust announced additional £2.5m investment 2017/18 of the outstanding £5m underfunding. Carers did not agree to this programme. The focus of our work needs to address the full £8m annual investment deficit since the underfunding was announced in March 2016, including the investment shortfall over that period.

## 2 Terms of Reference

The terms of reference for this engagement were agreed with Mr Chris Matthews from the Department of Health (DoH) in March 2017 and are stated below (the paragraph numbers refer to the original documents detailing terms of reference from earlier discussions with the former Minister of Health, Ms Michelle O'Neill in October 2016 and which were clarified with WLDAG and the SWCF in February 2017 to confirm that the engagement process was to be with all carers in the WHST area).

- 1.3 *The Trust is preparing to draw up plans for additional investments in this area and these plans must be drawn up in partnership with families and carers.*
- 2.2 *However, there is an urgent need to develop the plan for the increased investment; therefore it is proposed that the facilitation and the work on the plan should take place in parallel.*
- 3.2 *In view of need for urgency in the creation of the service development plan, it is proposed that the main vehicle for this should be a series of facilitated workshops in the locality, run under the Personal and Public Involvement (PPI) scheme, for families and carers to work with the Trust to develop a set of priorities for the increased investment.*
- 3.3 *These workshops will be used both as means of restoring trust and confidence and to develop an agreed investment plan.*

At a policy level, the Northern Ireland Assembly had drafted the new Programme for Government (PfG) in 2016 based on an outcomes approach. At least three of the PfG outcomes are particularly relevant to adults with a learning disability:

1. *'we enjoy long, healthy active lives'*
2. *'we are an innovative creative society where people can fulfill their potential'*
3. *'we care for others and help those in need'*

Learning disability is not an individual, family or even health and social care issue. It is a societal issue. This is because the factors that impact on an individual's wellbeing and quality of life are determined by issues such as money, housing, transport, friendships, social life, recreation and interests.

The task is to develop an agreed plan in partnership with the individuals and their families about how to make outcomes meaningful in real terms in their day to day lives and hopes for the future.

A shared sense of what needs to be put in place will be the basis for developing a holistic plan. This is likely to involve other partners and players besides the families and the WHSCT, who need to buy in and commit to taking up their role in delivering results.

### **How should this be done?**

The Personal and Public Involvement (PPI) approach is critical to how this process is to be conducted, i.e. increasing a sense of ownership, equalising power, reducing inequalities and improving patient/carers and staff morale.

Three principles are:

1. Respect for each other's roles and expertise/experience, and for the process
2. Reciprocity, i.e. everyone gives something and gets something in exchange
3. Responsibility in how we treat information, follow through on commitments

A definition of PPI<sup>1</sup> is set out below:

*Personal and Public Involvement (PPI) is the active and effective involvement of service users, carers and the public in health and social care (HSC) services.*

*People have a right to be involved in and have an active role in the decisions that affect their health and social care. We know that when people are meaningfully involved in decision making about their health and social wellbeing or listened to when they complain or raise concerns this leads to improved quality and safety.*

*PPI is a statutory duty for HSC organisations. It is a two-way process and not solely to be used when we want to hear the views of service users and carers when we bring something to them for their consideration.*

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<sup>1</sup> "Setting the Standards, Personal & Public Involvement (PPI), Involving you, Improving Care" Public Health Authority 2015

*Involvement can range from one to one clinical or social care interaction with service users and carers to larger engagements to assess needs, design services and influence commissioning priorities and policy development.*

Carers who attended the Speakeasy Sessions think that the term ‘involvement’ needs to be fully explored in the context of establishing an exemplar of PPI practice in Adult Learning Disability services. The HSC Guidance describe **involvement** as *‘more than consulting with and includes meaningful engagement, active participation and partnership working which includes being part of the decision making process and final agreed way forward’*<sup>2</sup>.

This will be addressed in the development of an agreed model of PPI going forward which will be set out in Section 6 of this report.

### 3 Methodology

This section describes the methodology that was agreed with the DoH for the engagement process.

#### 3.1 Work Plan

##### *Step 1 – Promote the Process (March 2017)*

- a. Communicate widely to let people know what this conversation is about
- b. Explain how to participate
- c. Work with naturally occurring groups and services to engage people
- d. Organize logistics, i.e. transport/access/support/expense
- e. Set up registration for the conversations

##### *Step 2: Start the Conversation (March 2017)*

- a. Convene six x 2 hour Speakeasy sessions across the area, e.g. Enniskillen, Omagh, Strabane, Londonderry/Derry (two morning and evening sessions) and Limavady (scheduled over 2-3 weeks)
- b. Run these as a facilitated conversation to hear people’s answers to the questions
- c. Seek nominees from each conversation group to be part of an analysis team when the conversations are complete to pull a plan together

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<sup>2</sup> <https://www.health-ni.gov.uk/publications/personal-and-public-involvement-ppi-dhssps-guidance-hsc/> HSC (SQSD) 29-07 Guidance on Strengthening Personal and Public Involvement in Health Care

### ***Step 3: Agree the Plan (April - June 2017)***

- a. Analyse the feedback to determine the outcomes that people want, the measures of progress to delivering the outcomes, assessment of current performance, analysis of reasons behind the performance, identification of partners who can help
- b. Develop the strategy for the next 12 months that will deliver tangible results, including low cost/no cost solutions
- c. Secure the buy-in of partners
- d. Share the plan with all who attended the conversations

### ***Step 4: Commence Implementation of the Plan (July 2017 – February 2018)***

- a. Prepare detailed implementation plan
- b. Design the data collection for evaluation
- c. Implement the actions
- d. Gather data on the difference that it is being made
- e. Present a regular report which is public
- f. Hold an open session detailing feedback on progress at the five locations

### ***Step 5: Review Progress and Plan Next 12-18 months (March 2018)***

- a. Carry out an annual review and next steps planning
- b. Use data, measurement and feedback to spur ongoing improvement and learning, and avoid a 'blame game'
- c. Make improvement opportunities everyone's focus
- d. Continue to publicise progress and results to be agreed with carers/family groups prior to release

## **3.2 Communication**

The Communication of the Speakeasy events was done through the media: newspapers, radio and the Facebook pages of the carer groups WLDAG and SWCF. There was a delay in confirming the Speakeasy process which was not finally signed off by the Department until mid-February 2017, after the NI Assembly had been stood down.

The first round of Speakeasy Sessions commenced on 20<sup>th</sup> March 2017 and the last one was held on the 12<sup>th</sup> April 2017. The details of communication are set out below:

Media outlet	Date of Advert
Londonderry Sentinel	w/c 13 <sup>th</sup> March
Derry Journal	w/c 13 <sup>th</sup> March
Limavady Sentinel	w/c 13 <sup>th</sup> March
Derry Journal (County Ed)	w/c 20 <sup>th</sup> March
Co. Derry Post	w/c 20 <sup>th</sup> March
Strabane Chronicle	w/c 20 <sup>th</sup> March
Strabane Weekly News	w/c 20 <sup>th</sup> March
Impartial Reporter	w/c 20 <sup>th</sup> March
Fermanagh Herald	w/c 20 <sup>th</sup> March
Tyrone Herald	w/c 20 <sup>th</sup> March
Ulster Herald	w/c 20 <sup>th</sup> March
Tyrone Constitution	w/c 20 <sup>th</sup> March
Londonderry Sentinel	w/c 3 <sup>rd</sup> April
Derry Journal	w/c 3 <sup>rd</sup> April
Derry News	w/c 3 <sup>rd</sup> April
Entire Q Network	11 Day campaign
Q 102. 9 (Derry based)	7 <sup>th</sup> to 12 <sup>th</sup> April
Radio Foyle via Trevor Millar	14 <sup>th</sup> March 2017 Mark Patterson Show for March sessions 6 <sup>th</sup> April 2017 Mark Patterson Show for evening session on 12 <sup>th</sup> April 2017

- Statutory Daycare managers within WHSCT - sent notification home with clients attending the Centres (all sectors)
- Statutory Respite managers (Beltany – Omagh; Cottages – Londonderry)
- Reception at Lakeview Hospital

Due to the short turnaround for the northern sector sessions an invitation was also emailed to following Independent providers on 14<sup>th</sup> March and 15<sup>th</sup> March 2017:

- Glenshane Care
- Destined
- Faughanvale Daycare
- Mencap - Cookie Company and Age Appropriate
- Mencap Employment Services
- LCDI
- New Horizons
- WLDAG – Lucy Brown
- SWCF – Caroline Kelly
- Foyle Parents & Friends
- Cathy Magowan, Carers Co-Ordinator
- Limavady Health Centre
- Evening session on 12<sup>th</sup> April 2017 – sent to WHSCT Development Officer for

Derry City and Strabane councils to go through their community updates – they were sending out to their six neighbourhood areas (Strabane through to Limavady)

### 3.3 Participation

70 people (66 carers and four service users) attended the Speakeasy Sessions across the five locations. The findings from each of these sessions will be summarised in section 4.

### 3.4 Future Planning and Implementation

This process achieved Steps 1-3 of the original work plan. Section 6 of this report will set out the proposals for developing a model of PPI that will ensure that service users and carers have the opportunity and choice to be involved in service planning and design at different levels. Steps 4-5 of the work plan are for the implementation phase which begins in July 2017.

## 4 Main Issues Arising from Speakeasy Sessions

The population of adults with learning disability in the western area who are registered with the Western Health and Social Care Trust numbers approximately 1824 (see the Table below for the age distribution).

Age range	Number of Adults with Intellectual Disability registered with the WHSCT
18-24	402
25-29	242
30-34	267
35-39	173
40-44	153
45-49	159
50-54	124
55-59	115
50-64	93
65+	214
TOTAL	1824

The level of disability ranges from 'mild' to 'profound'. People's needs vary depending on a range of factors. The issues raised by carers and individuals who were able to attend reflects this diversity. Future planning must take account of how best to increase the quality of life given the resources that the WHSCT can deploy or secure in partnership with other providers and organisations.



#### 4.1 Money

- a. There has been a significant breakdown in trust between carers and the WHSCT over the underfunding issue; this came up at every Speakeasy Session. People were explicit that at the heart of this breakdown is not understanding how decisions are being made or the reasons for the deficit underfunding in learning disability, particularly since differing explanations have been provided to them by the WHSCT and the HSCB. This ongoing controversy is a stumbling block to establishing a meaningful PPI process.
- b. Carers have queried if the additional £3m in 2016 -2017 is 'new money' and represents a recurrent uplift in the deficit in the WHSCT ALD resource. They are also unsure if the remaining £5m (spilt over the next two years: 2017 - 2018 and 2018 -2019) has been secured.
- c. Some carers at the Speakeasy groups wished it to be stated that they had **not agreed** to the £3m expenditure plan as presented by the Trust, and challenged WHSCT's presentation of the of the £3m expenditure in 2016 -2017. (The SWCF attendees at the Speakeasy sessions requested that it be noted that no one who had attended meetings with the WHSCT since the start of 2016 ever agreed to the details within the Trust's £3m expenditure plan)
- d. Allocation of resources has been a key issue at all the sessions. Core to this is the provision of reliable data and information. People would like transparency about how additional money has been used and be involved in how the budget overall is allocated. This will require better accountability systems in the WHSCT and DoH about how money is used as well as acknowledgement of the constraints on information sharing due to conflicts of interest or breaking individual confidentiality. However, where possible, the norm should be that access to information about the service funding and reports, etc. should be made easily available to service users on the WHSCT website.
- e. Carers state that consultation does not equate to involvement. They want to be meaningfully involved in prioritising how finances are used in the ALD programme. They are aware of the constraints on finance and be involved in a wider debate about the funding of services in the future.

(Since the start of the Speakeasy Sessions the WHSCT has put information as requested on its website relating to budgets and spend, as well as publishing other information and reports:

<http://www.westerntrust.hscni.net/services/3472.htm>

This has been welcomed by carers groups.)

#### 4.2 Meeting Needs

- a. Access to a social worker is necessary for everyone to have a current and relevant needs assessment completed; currently there are 24 social workers in community based Learning Disability teams across the WHSCT which means a case load of approximately 35-50 individuals each. Carers highlighted that there needs to be regular reassessments for individuals as their situation changes, particularly during life stage transitions.

- b. Individual needs assessment information can be aggregated up to inform a comprehensive audit of needs which is the basis for service planning in the western area.
- c. Participants at the Speakeasy Sessions think that the numbers of individuals who are diagnosed with autism in the WHSCT area is probably an underestimate, and that there is hidden need.
- d. Support packages for individuals can range from £1 per week to £7/8000 per week; it is important that there are adequate resources to meet these needs.
- e. It was suggested that there needs to be a Regional Commissioner for Learning Disability (like the Children's Commissioner) who can advocate at a regional level for the changes that are necessary to improve quality of life and well being.
- f. Carers want an 'evidence based' assessment of need which would involve mapping all current services and resources across the continuum of care and reflecting this distribution against the audit of population need; this would indicate where there are gaps and potential duplication in provision, or where resources need to be reconfigured to be more effective in achieving better outcomes for individuals and their families.
- g. The Department of Health sets policy direction and eligibility criteria for programmes of care; HSCTs have to assess need at an individual level and then balance population needs against budgets; processes for prioritising resources allocation across a population such as in the western trust area need to involve service users and carers so they can understand the process.
- h. Carers perceive that service solutions for individuals are driven by the resources that are available in the ALD programme of care and that the level of unmet need is not properly captured as a basis for advocating for more resources in the western area; the voice and experience of the carers needs to be included in an overall assessment of needs for future planning.

#### 4.3 Personal and Public Involvement

- a. A priority going forward is to develop a new way of working in line with the principles of PPI and co-production. There is a strong desire for 'meaningful involvement' between the WHSCT and carers. What this means in terms of changes in culture, behaviour, and mind-sets' needs to be made explicit by all involved to generate observable differences in interaction and decision making; the process may need to be facilitated for a period of time to mediate any conflicts and restore goodwill.
- b. A proposal on how this might go forward will be discussed with carers at the workshop to be held on the 6<sup>th</sup> June 2017(see Section 6. The key issues that carers seek involvement in are: meeting needs, identification of the numbers of adults with learning disability who have challenging needs and transparency in decision making about the deployment of money and resources, as well as the evaluation of services.
- c. Nevertheless, there is a genuine desire to make the West an exemplar of how co-production and partnering should be done; there were requests to source best practice models from elsewhere to inform how we do things here as well

- as applying the current development of co-production and PPI approaches being developed by the DoH and the PHA; the resources required to support this is necessary for it to work as it would require 2-3 designated information officers to support its development (like the model used in Co-operation for Children which has dedicated information analysis and GPS mapping support).
- d. It was recommended that the WHSCT set up a comprehensive database and provide a regular newsletter as a way of communicating directly with service users and carers. This was highlighted frequently as being a reliable method to ensure that the same verified information gets through to everyone. It was felt that the WHSCT is best placed to issue this regularly.
  - e. Some people stated that there are too many different groups each issuing their own information which causes confusion. Simplifying to a shared information channel would help to alleviate the sense that some people are more 'in the know' than others.

#### 4.4 Purpose and Social Activity

- a. Access to a greater range of '**evening and weekend**' as well as day opportunities is necessary; the quality of life and wellbeing of adults with learning disability and their carers is greatly enhanced by having a social life, with opportunities to develop relationships beyond the family, as well as being able to enjoy family occasions such as having a meal out.
- b. Some people said that 'buddy' and befriending schemes had worked well in the past while recognising that appropriate safeguarding mechanisms need to be in place for safety assurances.
- c. 'One size does not fit all' in terms of provision given the location, variety of needs and levels of autonomy; this means there needs to be a 'system wide' review of what can be provided across the wider public sector including housing, transport, local government, education as well as community, faith based and voluntary organisations; this should include looking at being able to access facilities 'out of hours'.
- d. While there is a lot of training provided, there are few work placements; the WHSCT and other big employers across the area might be able to help with this by providing protected work opportunities. Carers said that '**meaningful not monotonous**' work and volunteering opportunities give a structure to the week as well as increasing self esteem and empowerment of the individuals who are able to engage in these activities.
- e. Carers said that more imagination and creativity is needed to design and deliver a wider range of activities and opportunities. This has implications for utilising a wider panel of community volunteers (with adequate safeguards) who can offer a wider range of activities as well as developing staff skills sets and new models of practice.
- f. Social farming opportunities are seen as a positive outlet and there is a desire to see more examples of this kind of provision. The psychosocial and therapeutic benefits to individuals are seen to be important.

#### 4.5 Supported Housing

- a. The need for a wider range of independent living options was highlighted as important as individuals are older and need their independence as well as reducing the pressure on families
- b. In particular there is a shortage of choice for supported housing in local locations so that individuals are not separated from their family and friendship networks

#### 4.6 Transport

- a. The opportunities available to increase wellbeing are restricted by difficulties with independent travel and transport; the problems with transport options causes additional pressure on carers. Taxi fares are expensive. Some community based schemes such as Destined Taxis in Derry are being piloted and could be part of a wider solution.
- b. Travel and transport are an important issue especially in rural areas; it was suggested that a reduced-fare bus pass would be introduced as this would create parity with the travel pass provided for those with sight loss.
- c. Transport issues and travel arrangements to day opportunities need to be reviewed so that staff are not out on buses when people arrive at the centres; there needs to be better timing and scheduling of activities, as well as the refurbishment of some facilities. Some carers say that the size of the buses are too large and therefore restrict more flexible use of vehicles.

#### 4.7 Staffing, Roles and Engagement

- a. There is a need to review tasks and skills mix to develop new roles/address staff recruitment issues in some areas for example to provide personal assistants with the increase in self directed support; futures planning taking a longer term lifestyle approach; providing support to carers as they age with planning carer support and engaging in meaningful co-production at the individual as well as at Trust levels.
- b. It was suggested that centres establish a model like school governors made up of parents/family members who can have an active role in the decision making process in the running of their centre to develop their range of services and that this would provide more meaningful involvement. The current role for parents and friends is mainly as fundraisers. There is a concern among older carers about the low number of 'younger' carers coming forward to get involved and contribute their views.
- c. Carers said that they would like to participate in a training needs analysis with staff as they would like to contribute their views and ideas on emerging areas of practice, for example in new technology, social media and use of computers to be able to engage younger adults in co-designing meaningful programmes of activity. Some carers are already involved in training staff which should be built on as well as carers being able to avail of training and education about new evidence where relevant.
- d. Carers think it would be wise to engage staff in the process of planning changes to, for example, day centre programming and activities to increase their ownership and commitment to changing the culture in the ALD services and how *'things are done.'*

- e. Service users and carers should be involved in the evaluation of service providers and the quality of service as external contracts are being reviewed with providers (where there is no conflict of interest).

#### **4.8 Ageing**

- a. Given the ageing demographics there is a need for an older people's specialism within adult learning disability services with a specific focus on learning disability and ageing; better integration with mainstream services means raising awareness in general health and social services about the specific needs of older adults with learning disability and their carers.
- b. More effective ways to engage older carers need to be used for example through television and radio. This group are liable to become very isolated and disempowered in terms of accessing support.
- c. Future planning is an important issue giving the demographics; and the provision of a personalised 'pathway' of progression about what to expect and how to plan for including the risks associated with developing more chronic health conditions such as Diabetes Type 2.
- d. Carers would like to see a review of the options for ageing adults and carers and how transitions are anticipated and managed to avoid a crisis situation and breakdown of arrangements, which is distressing.

#### **4.9 Inclusion**

- a. There needs to be a culture of proper inclusion to reduce isolation. Adults who have profound needs and their carers need emotional and physical support for respite and to feel inclusion.
- b. Innovation has been happening through learning disability centres being set up in the community, promoting social inclusion and inclusion in the community plan; but more needs to be done in this regard so as to avoid the institutional situation just being transplanted into the community.
- c. Opportunities to increase inclusion in public and civic spaces and facilities needs to be addressed with local government and prevent discrimination. This should be raised with local government through the community planning mechanism.

#### **4.10 Facilities**

- a. There needs to be an entire assessment of all the facilities and determine fitness for purpose.
- b. Some buildings need refurbished, e.g. Glenside and Iona in Strabane and other facilities need modernised and better use made of floor space to avoid overcrowding and facilitate a wider range of activity; promote better staff/client ration to allow for smaller groups of like ability and hence enhance person centred programmes and more flexibility.
- c. More joined up thinking between statutory, community and voluntary organisations to make the best use of resources and to be able to access different funding streams, e.g. People in Communities; Out of Hours use of centres; a one stop shop.

#### 4.11 Respite

- a. There are a variety of forms of respite. Bed respite in the north west consists of seven beds between 100 people. Carers said that the method for allocation lacks transparency or predictability and there needs to be a formula or statistical equation that is fair and equitable. There are three beds in the Omagh area which is not considered adequate for the level of need.
- b. People tend to want respite when they need it. Inevitably there is high demand at certain times of the year. The WHSCT state they could use double their current provision as currently only 66% of assessed need is met. Alternative forms of respite might be needed to increase the range of what can be provided such as commissioning respite beds, direct payments, short breaks.
- c. There is a need for crisis respite as a resource when, for example, a carer dies or falls ill unexpectedly.
- d. Planning for and managing transitions is an important area for improvement; some carers have not had positive experiences and feel that more forward planning and prevention could have avoided unnecessary worry and actual disruption.
- e. Carers referred positively to holidays and summer breaks that used to be available through the HSCT but are no longer provided. The reason was due to staff concerns about professional and ethical risks arising from the behaviours of some individuals. However, these opportunities are missed and carers asked for this to be reviewed. One carer said *'ALD is difficult because it is difficult'* so don't stop because of problems: find solutions, recruit more volunteers; the HSCT to consider reinstating their past involvement as well as possibly considering if this can be provided by the voluntary or community sector through social enterprise.
- f. Agreed approaches to risk assessment and risk management need to be understood as carers feel that the HSCT is too risk averse: *'keeping things safe does not mean doing things well'*, while the Statutory sector are obliged to ensure safeguarding of vulnerable adults.

#### 4.12 Empowerment

- a. Some service users who attended stated that there should be a philosophy of **'empowerment'** not **'baby sitting'** in regard to how support and services are provided.
- b. Many carers and adults with learning disability want a new approach: a 'whole of life' personal life course planning and use a 'think family' approach to involve the wider family system in planning support in the present and for the future and in making lifestyle decisions.
- c. Some groups would value technical help or support from Trust staff in preparing bids and proposals as well as recruiting volunteers, (e.g. LCDI – Be Safe Be Well) and simplify the Self Directed Support process.



#### 4.13 Physical and Mental Health Care

- a. More opportunities for physical activity and outdoor activities are needed; adults with learning disability tend to lead sedentary lifestyles, which can lead to health issues.
- b. Health issues and access to proper medical treatment and oversight was raised frequently with issues ranging from enabling a fast track system for appointments (reduce waiting stress), capacity to make informed decisions about medical treatment; medical staff need to have a better understanding of how to help an individual make an informed decision; better access to Ophthalmic Services, Physiotherapy, Occupational Therapy and Speech and Language therapy.
- c. Co-morbidity of different conditions creates additional complexity for individuals, carers and health care professionals; person centred treatment planning is critical to ensure that medication regimes are complementary.
- d. Adults with learning disability experience the same issues as other adults their age; while it is policy that they use mainstream services, carers report that mainstream services are not always 'tuned in' to the particular needs and understanding of adults with LD. This highlighted the important and value of liaison nurses and support who can link with specialist services on behalf of Adults with LD. Out of hours access is an issue and this is being worked on.
- e. Adults with Learning Disability can have mental health problems, e.g. depression and would benefit from access to psychology services as well as psychiatric treatment.
- f. More prevention investment and activity will support individuals and their carers better as well as saving money by avoiding unnecessary escalation of issues, deterioration of health or crises.
- g. It was highlighted that small amounts of funding can make a big impact, e.g. funding a minibus or seven seater people carrier to centres for flexibility of small group travel to enable travel to training for the Special Olympics.

#### 4.14 Carers' Needs

- a. Carers find delays in decision making and respite applications frustrating and puts their lives on 'hold'. The core part of this problem is the very poor provision of respite that needs to be addressed as a matter of urgency.
- b. Carers state they can see that social workers themselves are under pressure which means that some carers may not offload their worries or needs as they think their social worker is not able to act as an advocate for them.
- c. Carers are 'time poor'. It is important that health and social care professionals maximise their time by advising them in advance of the agenda in preparation for meetings, forwarding them relevant information, reading the relevant background information about the individual, and avoiding unnecessary waiting and delays in appointments.
- d. Carers find that they have a lot of form filling and 'red tape' bureaucracy – not just for the HSCT but for other government agencies; the recent welfare

changes from DLA to PIP and fitness to work assessment is stressful, unnecessary and time consuming as it requires endorsements from their GP most of whom are helpful but not always easy to access.

- e. Carers who wish to go out to work and have a career have few choices for support to facilitate this.
- f. A number of people have talked about a 'role swap' to increase mutual understanding between carers and health care professionals.
- g. Some carers asked how services are evaluated and the results shared. They requested better ways to provide knowledge so as to 'educate' carers about current thinking, best practice, innovation and the future options they may have, particularly given the spread of different age groups and needs. Is it possible to be informed of comparators across N Ireland through SLA monitoring?

In conclusion, most carers recognise the constraints that staff in the WHSCT work under, and are seeking a 'culture change' of meaningful PPI involvement.

## 5 Pilot Wellbeing Questionnaire

During the Speakeasy Sessions, participants were asked to complete a simple 'wellbeing' questionnaire about themselves (if a service user) or their loved one. This was based on the Social Wellbeing Framework and the Patient Client Council Report (2015). It was further refined through consultation with carers. It is currently online<sup>3</sup> and available for piloting as a way of "needs assessment" and capturing feedback from carers and service users.

The survey lists a number of aspects of everyday living for adults with learning disability. It asks the respondent to rate each aspect in regard to 'how important' it is and 'how well' it is currently provided. The rating is 0-5, where 0 = low and 5 = high. The questions relate to:

- Independence and autonomy
- Purpose and meaning
- Relationships and belonging
- Safety and security

This section will summarise the completed questionnaires from the Speakeasy Sessions (total = 51). The questionnaire was not completed by everyone who attended. These questionnaires are based on the original version which has since evolved, and so does not contain some of the additional aspects which are included in the current final version which is currently online at [https://www.surveymonkey.co.uk/r/ALD\\_Wellbeing\\_Survey](https://www.surveymonkey.co.uk/r/ALD_Wellbeing_Survey)

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<sup>3</sup> [https://www.surveymonkey.co.uk/r/ALD\\_Wellbeing\\_Survey](https://www.surveymonkey.co.uk/r/ALD_Wellbeing_Survey)



The purpose of the Wellbeing survey is to show the difference between the “importance” scores and the “how well” scores as an indicator of priorities. The tables in Appendix Two show the number of people who rated an aspect of wellbeing as 4-5 ‘importance’ to them and a score of 0-1 indicating ‘how well’ it is currently provided. Where someone rates an aspect of well being as 5 i.e. high importance but 0 in terms of how well it is provided, this negative difference highlights the need for improvement.

**The greater the difference the score the higher the priority it is to address this issue.**

The table below summarises the rating scores from each of the Speakeasy Sessions. For example, while 40 people rated health needs as high importance by rating it as 5/5, no one scored how well it was being delivered as 5/5.

Well Being Aspect	How Important = 5	How well = 5	Difference 5-5
Health needs	40	0	40
Carers needs	42	3	39
Day opportunities	38	0	38
HSC staff and support	36	0	36
Futures planning	38	4	34
Needs assessment	36	4	32
Location of Services	36	6	30
Respite and short breaks	35	6	29
Physical exercise	36	7	29
Behaviour support and advice (therapeutic services)	30	4	26
Transitions	24	0	24
Ageing and frailty	32	8	24
Leisure	31	8	23
Work opportunities and placements	21	1	20
Supporting housing and independent living	26	7	19
Further education and training	15	15	0
Shopping	16	16	0

There are consistent priorities emerging as were discussed at the Speakeasy Sessions and many of the issues are interlinked: access to health care services, carers needs, day opportunities, access to staff and support, future planning which is linked to ageing and frailty.

These results are not statistically representative of priority needs as a much larger sample would be required. The piloting of this approach may be one way in the future for services users and carers to provide feedback on their most important needs and the current quality of provision. Over time it is a way of measuring if service quality and user experience is improving. This can inform local and area wide service evaluation and planning in the future.

There are no surprises in this list. The WHSCT have been developing strategies to address respite and day opportunities. The Speak Easy sessions and the pilot survey results highlight the urgency of putting arrangements in place to alleviate pressures on carers and increase the quality of life of Adults with Learning Disability.

Not all of these priorities require new resources. Instead they may require different ways of working or new models of practice. For example, 'futures' planning is a method of working to enable families to anticipate the issues that will arise as service users and carers age so they can develop plans for future eventualities and minimise crises.

## 6 Developing an Exemplar Model of PPI

Developing a future mechanism for PPI in Adult Learning Disability Services in the WHSCT was an important aspect of the terms of reference for this process. Much work and thinking on this had already taken place prior to this process. The break down in trust arising from the finance and underspend issues had derailed the process for carers.

What it would take to develop PPI in ALD and how it would work was discussed at meeting with carers, WLDAG and SWCF at meetings on the 09.05.17, 18.07.17 and 19.05.17. Joint workshops were held on the 06.06.17 and 19.06.17 between carers, the WHSCT senior managers and professional staff, representatives from the Department of Health, the HSCB and the regional PPI leads from the PHA to discuss a way forward and address the following issues

- a. Clarify carers' concerns about how the financial underspend is being addressed<sup>4</sup>
- b. A model of PPI and co production for Adult Learning Disability services with agreed terms of reference, MoU and governance arrangements
- c. Communication and information sharing for all carers and service users in the WHSCT s that they can be directly provide with information
- d. Develop an involvement plan
- e. Interim arrangements to prioritise WHSCT in year spend for additional monies during 2017 – 2018 based on a comprehensive assessment of needs

This section will summarise the main outputs of the PPI discussions and the action plans for the next steps.

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<sup>4</sup> *The DoH convened a meeting with WHSCT, HSCB and carers representatives from WLDAG and SWCF on 06.07.17 to clarify financial questions. As noted in Section 4.1, the issues about money had been a 'red line' for carers through the Speakeasy process and a stumbling block to progressing with PPI. The proposed financial investigation could provide some independent authority but this cannot proceed in the absence of a Minister of Health.)*

## 6.1 Vision for PPI

The vision for an effective model of PPI model in ALD was described as:

- a) Evidence of good, meaningful involvement by the Western Health and Social Care Trust (WHST) with carers
- b) Better relationships between everyone involved with caring for adults with learning disability.
- c) Improved capacity and capability of both carers and WHST to engage in PPI
- d) Evidence of change in behaviour, attitudes, culture and relationships
- e) “Coming clean” on the past and moving forward on a basis of trust
- f) Agreed understanding by the WHST of what carers mean by “involvement”
- g) Communication is addressed so that all 1800+ families have the choice to be informed
- h) Design an architecture, model and process for PPI that clarifies purpose, roles decision making etc and sets out an agreed PPI work plan for the development of the Adult Learning Disability (ALD) service to improve services and address gaps in service provision
- i) Create an equal partnership in which partners are involved in planning rather than presented with a “fait accompli”

***Ultimately, this must lead to better outcomes and quality of life for adults with learning disability.***

The “ground rules” to help everyone fully participate in the process were agreed as:

- |                       |  |
|-----------------------|--|
| a. Transparency       | g. No hidden agendas   |
| b. Openness           | h. Commitment to stay with the process (even if it’s difficult, frustrating ...) |
| c. Honesty            | i. Clarify meaning and understanding   |
| d. Trust              |  |
| e. “Say it – mean it” |  |
| f. Equality of voice  |  |

Michelle Tennyson and Martin Quinn (regional PPI leads, Public Health Agency) presented the PPI principles and approach at the workshop on the 06.06.17 to help guide the thinking. The main points arising from the discussion are summarised below:

- a. Constraints on PPI will always be there and need to be worked with, around or resolved where possible. Constraints may include policy, time, resources, understanding, knowledge and culture. The key message is to “take control of what you can do”. M Tennyson described the Neurology Network as an example of co-production in Social Care.
- b. Carers’ previous experiences will inevitably affect their levels of trust and readiness to engage with health and social care; carers highlighted that a demonstrable change in culture is necessary and carers’ perspectives and experience need to be factored into future planning
- c. A PPI structure, governance and process is necessary to provide a PPI mechanism for addressing the current ‘red line’ issues to do with

communication, information sharing, involvement in decision making and future planning; this structure, governance and process does not yet exist; the PHA PPI leads advised that it is important to start putting structures and process in place and “learn by doing”

- d. A comprehensive assessment of need/unmet need is the basis for future planning and “co-commissioning” of services (this is likely to become the responsibility of Health and Social Care Trusts in future); social worker assessments are key to this
- e. The Public Health Agency (PHA) PPI advised that a new PPI structure and mechanism should work to achieve some “early wins” to build confidence and a sense of achievement; this does not mean ignoring the more challenging issues; a parallel short term/long term process is necessary.

## 6.2 Going Forward: Different Views

In light of the PPI discussion of the issues, groups were asked to propose next steps.

The SWCF emphasised that they felt unable to agree to structures at this point. They described a set of “pre-components” that need to be in place before deciding PPI structures:

- a) Transparency of information sharing
- b) Effective communication systems
- c) PPI shown to be endorsed and led from “top down” in the WHSCT
- d) Enabling informed decision making by clarifying ‘numbers, needs and money’
- e) Defensiveness stops and there is ownership of decisions and actions

In contrast, based on the advice of the PPI leads, WLDAG proposed moving ahead to put mechanisms in place to enable decision-making and planning. These are summarised below:

- a) Set up a Trust wide PPI structure to lead on strategy, commissioning, long term planning and keep up to date with current developments
- b) Set up local PPI structures in the northern and southern sectors to focus on local issues, tailoring local services and exploiting local opportunities.
- c) Set up a Service User PPI forum, possibly clustered around the day centres to ensure that service users have a voice and strong influence on planning, direction, service evaluation and future developments
- d) Include a role for service providers in the PPI structure to ensure that services meet the needs and are also shaped by experience of service deliverers
- e) Develop a PPI structure with wider community and voluntary organisations as well as local government to increase inclusion and increase community based opportunities
- f) An agreed Memo of Understanding (MoU) would set out clearly how the range of PPI processes would work, particularly in regard to representation and appointments to different roles

- g) In regard to information sharing, the WHSCT in conjunction with carers, to map out each of the areas, identify “numbers, needs, money” and services in each area; determine how to ensure a flow of information (horizontally and vertically) so that everyone has access to appropriate information and ensure it is a two-way flow

The WHSCT highlighted that the key principle for them is equality for service users and carers to improve outcomes for adults with learning disability. The WHSCT committed to developing a PPI two-way communication and involvement plan with the 1800+ families. This requires some short-term immediate action as well as the need to develop robust structures in the longer term and for PPI at Trust wide and local levels. PPI training and awareness raising is necessary for staff and carers. An independent chair to facilitate the new PPI structure and processes was proposed.

There is a planning task to map assessed need against current provision and use a service improvement methodology to address these and plan for the future. The Social Work pilot initiative for service improvement in WHSCT will provide one vehicle for doing this.

At the follow up meeting on the 19.06.17 plans for communication, involvement and sharing interim spending intentions with carers were proposed. These are set out in the next steps section.

## 7 Next Steps

This group of carers who are a mix of WLDAG and SWCF are acting as an “advisory group” to help the WHSCT design the communication and involvement plans which will shape the PPI structure, Memorandum of Understanding and governance processes going forward. (It is understood that it is not a PPI representative group.)

### 7.1 Communication and Information Sharing

The aims of the communication and information-sharing plan are to:

- a) Achieve 100% contact with all carers and service users
- b) Invite carers for adults with Learning Disability to register on the Trust carers’ database
- c) Explain the PPI rationale and involvement plan and opportunities for them to participate at different levels in addressing issues that matter to them: money needs and services

The proposed action plan for achieving this is set out below:

ACTION	WHO	WHEN
--------	-----	------

1. Identify the ALD carers within the overall WHSCT carers' database	AG/GH	July/August 2017
2. Send out information about registering with the PPI carer database to all carers known to social workers and day centre members seeking their consent to register; staff to promote the initiative	CB/MD	July/August 2017
3. Compare the ALD Carers Database with the MPI list and identify ALD carers who are missing	AG/GH/CB/MD	September 2017
4. Write to this group using the MPI contact details as per option 1	AG/GH	September 2017
5. In parallel, co-design and take forward public awareness and publicity campaign using range of media and primary care/GP venues to inform public about the drive to register ALD carers on the PPI Trust Carers database	RH/WHSCT comms/carer organisations	September/October 2017
6. Regularly review and update and migrate information to PARIS system in 2018	RH/MD/CB	November 2017

A similar parallel process to develop an ALD service users' database should also be carried out.

The creation of a WHSCT ALD Carer Database and ALD Service Users Database is the foundation for PPI as it enables direct two-way communication between the WHSCT and carers.

It was emphasised that staff need to be informed so they can encourage carers and service users to register. It will require time, skills and resources to be dedicated as a specific, integral PPI task and not be seen as an "add on." This requires the ALD service to ensure that ALD Carers are clearly identifiable on the Trust carers' database for two way communication and information sharing purposes. It is acknowledged that some carers may wish not to be included on the database.

Two other inputs are required for the ALD carers' database:

- a. Someone must ensure that information details are accurate, kept up to date and properly used in accordance with data protection legislation. In law this is the role of the Trust. Rosaleen Harkin is the information asset owner for adult learning disability. The WHSCT has an

Information Governance Structure in place to oversee the appropriate use of information in line with Data Protection Principles.

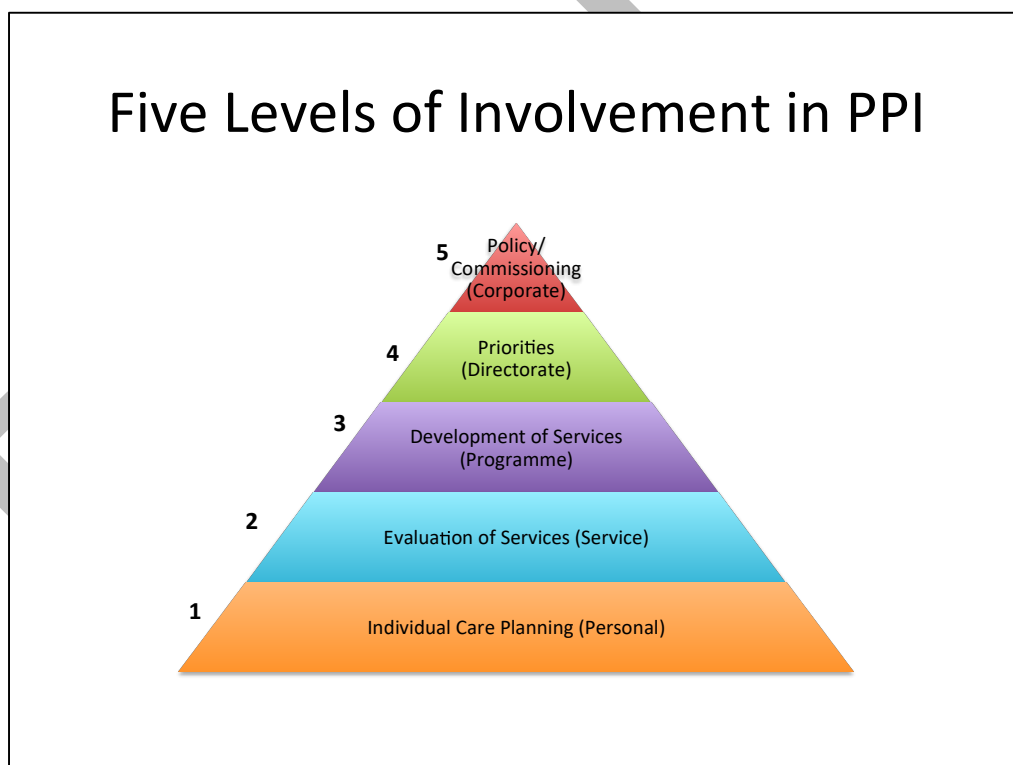
- b. Advice on language, messaging, content and channels from carers' groups. The key communication messages are that this is PPI for ALD; the rationale and need for PPI in ALD; that this is an opportunity to address issues, resolve problems, evaluate service quality and input into future development.

The output from this process is the PPI ALD databases for

- a. Service users and
- b. Carers aligned with the Trust Carer's database

## 7.2 Involvement Plan

In addition to the Communication and Information Sharing Strategy, it was agreed that the WHSCT through its PPI Lead Siobhan O'Donnell, working with the Service Managers Margaret Dolan and Carina Boyle and carers, develop an involvement plan for how the five levels of PPI will be implemented in Adult Learning Disability. The five levels of PPI were discussed (see the model below)



The aim is for the WHSCT to put in place robust mechanisms with service users and carers that facilitate meaningful involvement at all five levels:

- Level 1: A person is actively involved in determining their needs, setting goals and agreeing their support/care plan with their social worker
- Level 2: Services users and carers are involved in evaluating the services that are being provided to them
- Level 3: Service users and carers are involved in the development of services
- Level 4: Services users and carers are involved in setting priorities and allocating resources for the future at service directorate level
- Level 5: Service users and carers are involved in commissioning and policy development at an organisational or regional level

Not all carers or service users wish to be involved at all levels. The WHSCT has a responsibility to put in place an involvement plan that enables service users and carers to have the choice to be involved, to put in place mechanisms and supports that facilitate involvement and to develop their skills and ability if they wish to be involved at the different levels.

The WHSCT will develop an involvement plan at all the five levels over the next 6-12 months. This is predicated on the need for clarity on scope and roles to set the scene for positive engagement from all parties to enable a PPI plan to be developed and implemented.

This work can build on the proposals for involvement mechanisms and governance arrangements provided by carer groups. At service evaluation and service development levels this means mapping what already exists, identifying gaps and/or developing new mechanisms, which are offered to carers as ways of being actively involved. A PPI structure and mechanisms for priority setting in the WHSCT should be in place for 2018-2019.

### **7.3 Interim Arrangements for Spending**



An interim temporary arrangement is required in the 2017-2018 financial year for carers to input into the WHSCT spending intention for ALD services. The process for doing this was agreed as follows:

- a) The carers who have attended the 6<sup>th</sup> June and 19<sup>th</sup> June 2017 meetings and any who attended the Speakeasys be invited to discuss priorities and proposed spend. The priorities and needs would be informed by WHSCT information derived from a variety of sources including carers' and needs assessments from social workers and the feedback report from the Speakeasy process
- b) It was noted that carer input on the WHSCT plan would not constitute "agreement" to financial spending as from a legal perspective this is not permissible. However, it is permissible for carers act as an advisory group.
- c) There is no legal requirement for a 12-week public consultation process. However, it was suggested that the WHSCT share the proposed spending plan through a series of targeted focus groups for example across the 6 day centres.

This process should be completed by September 2017. This is a tight timescale given the holiday period during July and August with day services closures across the Trust.

#### 7.4 Summary Action Plan WHSCT Next Steps

It is the WHSCT's role to take forward the plans which have been described in this section. The action plan below was discussed at the final meeting with the Facilitator for the process on 04.07.17.

TASK		TIMEFRAME	LEAD
1	<b>Finalise Communication Plan</b>	<b>21/7/17</b>	<b>Rosaleen Harkin</b>
	<ul style="list-style-type: none"> <li>• Quality Assure communication for service users and carers</li> </ul>	<b>14/8/17</b>	
	<ul style="list-style-type: none"> <li>• Send out and include notification of information sessions on involvement and interim spending plan 17/18 (need to involve Communications Dept.)</li> </ul>	<b>17/8/17</b>	
2	<b>Interim Spending Intention</b> <ul style="list-style-type: none"> <li>• Document the areas of spend and share evidence base and the rationale</li> <li>• Share with carers</li> </ul>	<b>18/8/17</b>	<b>Senior Management Team (ALD)</b>

	<ul style="list-style-type: none"> <li>Advisory Group QA (1 week)</li> </ul>		
	<ul style="list-style-type: none"> <li>Share and Explain at Speak Easy Sessions</li> </ul>	<b>End of September</b>	
<b>3</b>	<b>Develop Involvement Plan</b> <ul style="list-style-type: none"> <li>Including Local Engagement Partnership at Level 3</li> <li>Agree at Speak Easy Sessions – (a number of tools can be used to support involvement eg delegated democracy)</li> </ul>	<b>Sept – Nov 17</b>	<b>Senior Manager Team (ALD)/ SO'Donnell, EQIA Martin Quinn, PHA</b>
	<ul style="list-style-type: none"> <li>Communicate the Involvement Plan</li> </ul>	<b>Nov – Dec 17</b>	
	<ul style="list-style-type: none"> <li>Implement the Involvement Plan</li> </ul>	<b>Jan – Feb 18</b>	

## 8 Conclusions

It is important to maintain the momentum over the next few months. Everyone involved has shown energy and commitment to the process. There needs to be a focus on implementing the plans that have been agreed and accountability for following through on commitments.

Putting the PPI arrangements in place will be supported by Siobhan O'Donnell, the WHSCT PPI lead and Martin Quinn the regional PPI lead. It is recommended that a programme management approach is deployed to drive this initiative forward. This will require an additional post for 12 – 18 months to establish the relationships, structures, governance systems and processes that have been discussed and need further development.

This process is likely to take 2-3 years. It needs leadership and the involvement of carers and staff who have key roles in making the PPI model in ALD a success. The ultimate goal is to improve services and outcomes for adults with learning disability.

Anne McMurray  
07.07.17

DRAFT