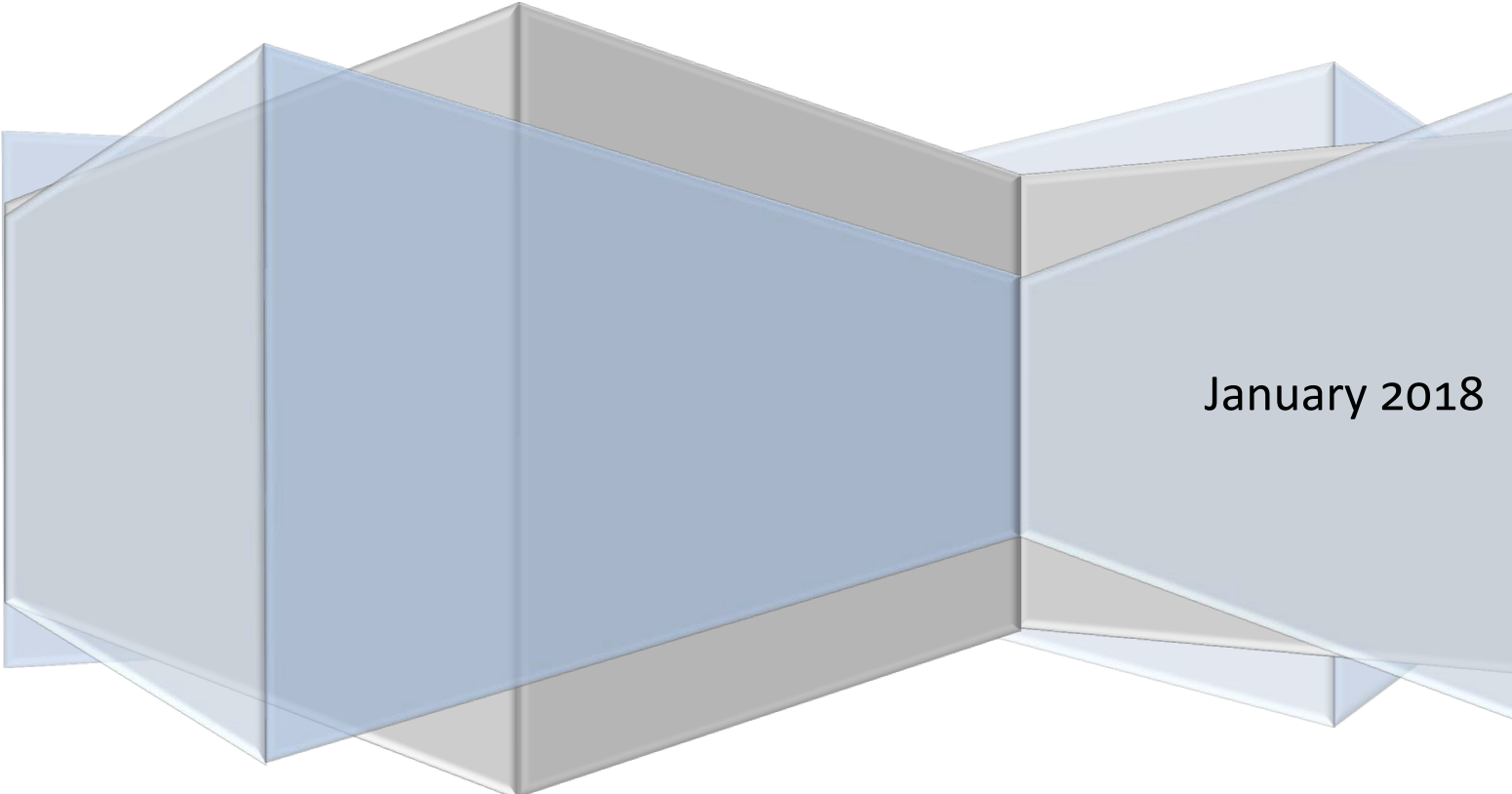


PPI Information Sessions: Feedback Report



January 2018

Background

Personal and Public Involvement (PPI) is described by the Public Health Agency (PHA) as ‘the active and effective involvement of service users, carers and the public in Health and Social Care (HSC) services’. This means giving the people who use our services, their carers, and the local community a say in how services are planned, delivered, and evaluated. PPI is a legal requirement for all Health and Social Care (HSC) organisations, and the Western Health & Social Care Trust Adult Learning Disability Service has been working with service users, carers, and the public to develop a model for effective involvement.

Locality Engagement Meetings

The Western Health & Social Care Trust Adult Learning Disability Service held six public locality engagement meetings to engage directly with service users, carers, and local members of the public about their Personal and Public Involvement plans. These meetings took place in Strabane, Derry/Londonderry, Limavady, Omagh, and Enniskillen. All of the meetings followed the same format: an introduction from a local member of the public; short presentations on PPI and the proposed model of involvement from Trust and Public Health Agency (PHA) representatives; small break-out group sessions with facilitators; a question and answer session; and closing remarks from a local member of the public. Easy-read documents and cards were made available to facilitate engagement.

Details of the meetings and attendance numbers are provided below:

Date	Location	Number Attending
Monday 23 rd October 7-9pm	Fir Trees Hotel Strabane	63
Wednesday 25 th October 7-9pm	Waterfoot Hotel Derry/Londonderry	20
Thursday 26 th October 10am-12pm	Waterfoot Hotel Derry/Londonderry	37
Tuesday 7 th November 7-9pm	Roe Park Hotel Limavady	29
Thursday 9 th November 10am-12pm	Omagh Enterprise Centre Omagh	44
Thursday 9 th November 7-9pm	Killyhevlin Hotel Enniskillen	38

The locality engagement meetings were widely promoted via the following mediums:

Means of communication	Dates	Responsible person
Getting Involved Leaflet to Service Users & Carers on MPI (1900 in total) WLDAG SWCF	w/c 9/10/17	BSOs
Trust Statutory Day Services Trustwide	w/c 9/10/17	BSO
All staff / service areas within Learning Disability programme	w/c 9/10/17	HOS & Managers
Londonderry Sentinel	17/10/17	Comms Dept
Derry Journal	17/10/17	Comms Dept
Co Derry Post	17/10/17	Comms Dept
Strabane Chronicle	19/10/17	Comms Dept
Strabane Weekly News	19/10/17	Comms Dept
Tyrone Constitution	25/10/17	Comms Dept
Fermanagh Herald	25/10/17	Comms Dept
Impartial Reporter	26/10/17	Comms Dept
Ulster Herald	26/10/17	Comms Dept
Fermanagh/Omagh Community Support Newsletter	w/c 23/10/17	Fermanagh & Omagh Council
WHST website	w/c 9/10/17	Comms Dept
Facebook	w/c 16/10/17	Comms Dept
Twitter (reminders)	1-2 days before each event	Comms Dept
Radio Advertisement for broadcast Trustwide on Q101.2/Q012/Q97	20/10/17 – 8/11/17	Comms Dept
Radio Interview for Trustwide broadcast	19/10/17	Rosaleen Harkin
WHST Local Implementation Day Opportunities Group	19/10/17	MDolan/L Coyle

Feedback Overview

During the breakout sessions, attendees were asked to consider three questions:

1. How should we communicate with service users and carers?
2. How can we make sure that everybody's voice is heard?
3. Would the model shown meet your needs for involvement?

The responses to these questions are summarised below.

Communication

In relation to communication, the consensus across all six sessions was that this must be transparent, consistent and timely, tailored to need, and two-way. There was strong support for the implementation of a newsletter, or local newsletters, created in collaboration between carers, service users, and the Trust. Many felt that this would be the most effective means of information dissemination, providing that it was circulated consistently. Other preferred forms of communication included:

- Post/letters
- Text messages and phone calls
- Emails
- Website
- Public meetings
- Politicians
- Social media (including Facebook and Twitter)
- Communication via Day Centres
- Communication via Social/Key Workers
- Communication via local groups
- IT links
- DVDs

It was commonly agreed that communication could not follow a 'one size fits all' approach: the way in which information is presented (i.e. the use of images, the use of language etc.) should cater to the individual's level of need. For example, some service users may feel infantilised by the use of pictures, whilst others may find images helpful, or require the use of Makaton. As such, individuals should be given the option to choose both their preferred form of communication, and their preferred style.

One of the most common suggestions across all six sessions was that there is a pressing need to compile up-to-date databases for service users and carers in order to facilitate effective and comprehensive communication. Concern was expressed that not all individuals with a learning disability have been accounted for, and several carers stated that they have not been receiving correspondence via post. In order for communication to be as far-

reaching as possible, it was commonly agreed that these databases are of paramount importance going forward.

The majority of groups suggested that Day Centres and social/key workers could be key points of contact and information sharing; however, it was noted that due to workforce pressures and gaps in social/key worker allocations, this means of information sharing is currently not as effective as it could be. It was agreed that if social/key worker allocations were consistent and long-term, this particular avenue of communication would be invaluable. Several groups suggested that a hotline or helpdesk would be useful to have in times of crisis, and to function as a central point of information sharing when a social/key worker cannot be contacted.

It is important to note that many groups emphasised that they really appreciate the work of social/key workers, and wish to see them better supported and involved in PPI.

Ensuring Voices are Heard

It was unanimously agreed that service users and carers must have their voices heard in order for PPI to be successful, and it was also widely acknowledged that comprehensive engagement with such a geographically diverse population can be a challenge. In addition to implementing the solutions put forward in the communication section above, in order to ensure that all voices are heard the following suggestions were made:

- Several groups suggested that introducing and explaining PPI at the point of transition would be a helpful way of ensuring engagement with as many service users as possible going forward
- It was generally agreed that public meetings are an effective way to engage in a two-way conversation, and several groups indicated that the breakout sessions in particular were valuable ways of enabling individual voices to be heard
- It was noted that not all service users and carers can attend public meetings for a range of reasons, and as a result these voices can be 'lost'. Most groups agreed that a concerted effort must be made to reach out to these 'lost' voices. They made the following recommendations:
 - It was suggested that social/key workers could play a key role in this by, for example, using review meetings to encourage involvement and signpost access to transport etc. to facilitate attendance
 - Many groups expressed that they would like to see the Trust come out to more rural areas and host meetings in local venues. They felt that this would be an effective way to engage a wider range of people who may not have the means or time to travel to larger meetings

- Several groups observed that large public meetings can be intimidating to some service users and carers, and suggested that smaller focus groups within day centres or local clubs beyond the five major 'spokes' of Limavady, Enniskillen, Omagh, Strabane, and Derry/Londonderry City could be useful in engaging with and hearing from a wider range of individuals. Coffee mornings were also put forward as a more relaxed alternative to formal meetings
- One group suggested that the use of sign language interpreters at public meetings would be helpful, and could encourage involvement from service users whose views may otherwise not be represented at public meetings

Suitability of PPI Model

The general opinion of the proposed PPI framework was largely favourable, and the majority of attendees agreed that it would meet their needs for involvement. The hub and spoke model was commonly highlighted as a particularly useful tool for engaging with local areas; however, several groups suggested that it would be even more beneficial to add another layer of smaller 'sub groups' from more rural localities, which could feed up more unique priorities to the five main 'spokes'. Groups from these localities expressed feeling isolated or 'forgotten', and indicated that reaching out 'beyond' the five main centres would be an effective means of engaging with and hearing these voices.

Many groups noted that it is crucial for senior managers to believe in and actively champion the PPI process, and emphasised that PPI must be a visible priority at all levels. It was also widely agreed across the six sessions that the instatement of an independent PPI facilitator/co-ordinator would be a key element in moving PPI forward, and in the right direction.

Some attendees expressed reservations about the proposed PPI framework, suggesting that the model is vague, and that they haven't been given enough information about what involvement at the different levels of the pyramid – particularly beyond level three – will actually look like. Several groups raised the concern that the model as it stands might be too 'high level', and as such may not fully represent unique, local issues and priorities. Involvement must be issue- and geography specific, and be flexible enough to represent a wide range of complex needs. It was also suggested that the hub and spoke model has the potential to elevate some voices over others, and create a culture of inequality amongst parents and carers.

The overall consensus, however, was that service users and carers are willing to trial the new PPI framework. It was strongly agreed that the success of the model will depend heavily on a culture of two-way communication and transparency, and the majority of groups indicated that a system of frequent evaluation and feedback – going both ways –

would be crucial in moving the project forward. Many expressed the view that this trial period is an opportunity for the Trust to build trust and mend fractured relationships, and agreed that this could only be done if promises are kept, and tangible, measurable progress is made. As one carer summed up:

“This could really work, if we make it work”

Areas of Interest/Concern

During the six sessions attendees had the opportunity to ask questions and raise general areas of concern that they wish to be addressed going forward. The main issues raised were:

- Underfunding
- Access to respite/short breaks
- Social/key worker allocation
- Transport
- Need for more nurses
- Future planning
- Transitions
- Access to carer assessments

These are the common issues raised across the five localities. Area specific issues are outlined below.

Individual Sessions: Feedback Summaries

Monday 23rd October: Fir Trees Hotel, Strabane

In addition to the issues noted in the overview, the main themes arising from the Strabane session were:

- A key concern was the lack of Learning Disability nurses in Strabane. Several attendees indicated that there is currently only one nurse in the locality
- Several attendees noted that not all service users, carers, and families are engaged with equally: it was suggested that there is already a ‘hierarchy’ amongst carers. These attendees stated that this hierarchy needs flattened in order for everyone to feel fully involved
- It was noted that more must be done to involve families and siblings

Wednesday 25th October: Waterfoot Hotel, Derry/Londonderry (morning session)

In addition to the issues noted in the overview, the main themes arising from the Derry morning session were:

- A desire to see resources more 'fairly' distributed outside larger areas
- One group indicated that they would like to have more parent/carer meetings organised with local groups. In a similar vein, another group expressed that they would like to see the Trust engage with more rural community organisations
- Several groups suggested that they would like more help navigating Self Directed Support (SDS) and changes in Disability Living Allowance (DLA)

Thursday 26th October: Waterfoot Hotel, Derry/Londonderry (afternoon Session)

In addition to the issues noted in the overview, the main themes arising from the Derry/Londonderry evening session were:

- Several groups suggested that the Trust should work more closely with schools and the Education Authority
- One group suggested that the Trust should look to existing groups, like the Western Learning Disability Action Group, as successful models for effective communication
- Several groups indicated that they would like help understanding and navigating SDS
- One group stated that much more needs to be done to involve the service user separately from the carer
- One group expressed interest in understanding the needs of other areas in the Trust

Tuesday 7th November: Roe Park Hotel, Limavady

In addition to the issues noted in the overview, the main themes arising from the Limavady session were:

- It was noted that Limavady currently has a shortage of social workers. Trust staff assured attendees that these posts are being filled
- Several groups noted that they would like to see better Autism services in place in the area
- One group noted that they would like local day centres to interact more closely with carers and service users to disseminate information
- One group indicated that liaising closely with local schools and bringing students into day centres would have a positive mutual impact
- Several groups noted that, going forward, it is important to reinforce that PPI is separate from the issue of underfunding, and is an opportunity for a positive new start

- One group indicated that there is a need for Out of Hours provision in the area
- Several groups suggested that lines of communication in the area need to be clarified: some carers do not know who to contact in various situations
- Concern was expressed over the use of bank staff in day centres

Thursday 9th November: Omagh Enterprise Centre, Omagh

In addition to the issues noted in the overview, the main themes arising from the Omagh session were:

- Several attendees noted that they did not receive correspondence about the sessions in the mail. They expressed concern that there is a gap in communication in the area
- Access to annual health checks was raised as a common need in the area
- One group noted that volunteers should be celebrated and supported
- One group suggested that looking to the structures of local groups and organisations further afield for learning would be helpful
- One group expressed the need for better connections between the Education Authority and transitions in the area
- One group indicated that Bamford recommendations must be followed moving forward
- One group noted that the mental health of carers needs to be given much more consideration
- A parent who was involved in the Speak Easy sessions provided the Trust with a vision of what a Short Break & Wellness Centre would look like in the Omagh area

Thursday 9th November: Killyhevlin Hotel, Enniskillen

In addition to the issues noted in the overview, the main themes arising from the Enniskillen session were:

- More/better access to family support workers was raised as a common issue in the area
- One group expressed the desire for Adult Learning Disability to use an assessment tool more in line with that of the children's service, which takes a more holistic approach to the needs of the service user
- One group suggested that bringing speakers in to local groups to share information and answer questions would be very useful
- Several groups noted that SDS is a concern: they suggested that it isn't 'sold' in the correct way, and as a result service users and carers do not understand it. They

recommended that dedicated drop-in centres/helplines would be helpful ways to provide this information

- Several service users and carers noted that they did not see or receive an invitation to the session, but instead learned of it through word of mouth. They expressed concern that there is a gap in communication for the area

Future Directions

The Adult Learning Disability Service has taken the feedback from the six sessions on board, and is currently working alongside the PHA, the South West Carers Forum, the Western Learning Disability Action Group, carers, service users, and families to address the issues raised and suggestions submitted going forward. The current plans in progress are:

- The Western Trust and PHA have provided a resource for a PPI facilitator, and work is ongoing to put together a detailed job specification for this role going forward
- The Learning Disability Service has resourced a Communications Officer, and is committed to ensuring that all service users, carers, and families receive timely information in their preferred style and medium
- Work is ongoing to collect information from all returned expression of involvement interest forms, and to put together a database for service users and a database for carers with this information
- Regular involvement meetings continue to take place to ensure true co-design and co-delivery of the PPI framework