Developing an exemplar Model of Involvement for Adult Learning Disability Services in the Western Trust area.

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1. Purpose of report

In November 2017, the WHSCT, on the advice and request of the Adult Learning Disability Advisory Group, commissioned an independent facilitator to drive forward the development of a Hub and Spoke model of Involvement for Adult Learning Disability services which had been outlined and agreed by the WHSCT and communities of interest through a series of workshops.

This role was to facilitate the meetings to ensure objectivity and impartiality, facilitate the identification and agreement of clear roles and objectives, to outline the governance arrangements of the model and to manage the relationships within the group to ensure progress would continue at a steady pace.

As the need for this role would suggest, the relationships and trust within the group in November 2017 were fractured, agreement on shared goals and priorities could not be reached and understanding and expectations of what being involved would mean practically, differed greatly from member to member. Despite this, the members were clearly committed to completing the 'job in hand' and continued to come to the table in the hope of forging agreement on the best way forward, the one underlying and unifying factor being the determination to improve the lives and experiences of service users and carers.

This report seeks to describe the development of the Involvement model, honestly reflecting the complexities, challenges, disappointments and successes, and making recommendations for the next step of the journey – the implementation phase. This report will share learning and provide guidance to other groups and directorates who wish to improve outcomes for their service users through adopting and embedding a model of meaningful Involvement .

2. Introduction and background

At present there are approximately 1824 adults with learning disability in the western area who are registered with the Western Health and Social Care Trust. This information is held on the Master Patient Index, a database, managed by Trust staff and governed by Data Protection legislation.

The level of disability ranges from 'mild' to 'profound' and the level of services needed to support each individual vary according to this need. It must be acknowledged, that even with the best of support, some individuals will never be able to personally contribute to or be involved in this process due to the level of their Learning Disability, and in this situation it is essential that carers or advocates are able to speak on their behalf (MENCAP 2015)[1].

Following the well-documented and public controversy regarding underfunding of Adult Learning Disability in the Western Trust area, which caused a significant breakdown in trust between service users and carers and the WHSCT, the WHSCT committed to embark on a significant programme of work which would see meaningful 'Involvement' of service users and carers integrated into the planning processes of the Western Trusts Adult Learning Disability Services.

The aims of this approach were to: improve relationships and restore trust; ensure openness and accountability with regards to future development of services and allocation of resources; champion a cultural and behavioural change in actively embracing Personal, Public Involvement (PPI), or simply 'Involvement' into every day planning processes within Adult Learning Disability services, and ultimately to improve the lives of service users and carers at home, within their communities and when accessing services.

Following discussions with Mr Chris Mathews (DOH) and former Health minister Michelle O Neill in 2016 the direction given was two-pronged: 1. An independent investigation into the underfunding would take place (this has been put on hold with the collapse of the Stormont Assembly); 2. An Adult Learning Disability Advisory group was convened to inform and guide the development of a model of Involvement within Adult Learning Disability services to ensure this situation would not happen again.

3. **Personal Public Involvement.**

Personal and Public Involvement (PPI) is a process whereby service users, carers and the public are empowered and enabled to inform and influence the commissioning, planning, delivery and evaluation of services in ways that are relevant and meaningful to them. People have a right to be involved and increasingly they expect to be actively involved in decisions that affect them.

PPI is a statutory responsibility as detailed in the HSC (Reform) Act (NI) 2009 through the Statutory Duty to Involve and Consult. Each Health and Social Care organisation, to which the legislation applies, is required to involve individuals in the planning and delivery of Health and Social Care (HSC) Services. Specifically, sections 19 and 20 of the above legislation require that service users and carers are involved in and consulted on:

1. The planning of the provision of care

2. The development and consideration of proposals for change in the way that care is provided

3. Decisions that affect the provision of care. (HSC 2012)[2]

By June 2018, 274 carers and service users expressed interest in becoming involved, the majority of these at a local level:

Derry – 84

Strabane – 37

Omagh – 44

Limavady – 43

Enniskillen - 66

- **The Co-design/ Co-production/ Co-commissioning conversation**

In addition to the PPI Strategy, a number of conversations have begun to develop and gather some momentum over the recent years.

A number of policy and strategy documents have underpinned the development of these conversations.

The phrasing has shifted from 'involvement', to 'co-production', 'co-design' and more recently 'co-commissioning'. Kelly and Kennedy 2018 [3], suggest that the rationale for this could be that, arguably, traditional models of Involvement could be seen to perpetuate power imbalances and tokenism and have failed to make any real change.

However, while the language differs in organisations and forums at difference times, and while some of the phraseology would indicate a greater level of involvement, the terms seem to be, for the most part, fluid and interchangeable.

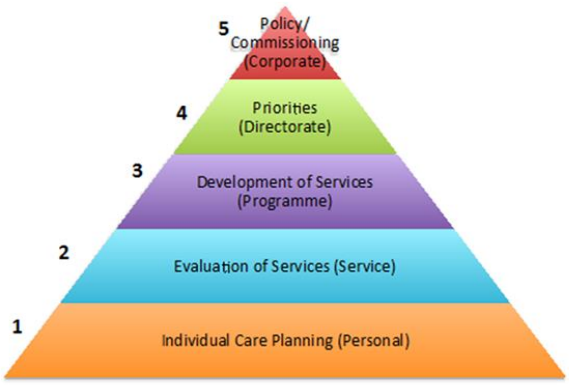
The conversation about co-commissioning in N.I seems to be in early stages and requires a level of legislative protection which does not yet exist, coupled with an organisational culture and system change that is unrealistic in the short-term, and which needs to begin with getting basic 'involvement' right.

This is not to say that co-commissioning isn't an ideal to aim for - when legal protections, guiding principles and organisational culture and structures are aligned and tested.

Members of the Advisory group felt that these conversations were at times confusing the agenda, raising expectations unrealistically and 'muddying the waters' in terms of moving the focus and discussion away from 'Personal, Public Involvement' and hindering the progress of the group. *Following discussion the Advisory group decided to focus on PPI or simply 'Involvement', the rationale for this decision being if we are able to implement a model of true and meaningful Involvement, many of the other terms will naturally grow from this process*.

- **Levels of Involvement**

During the workshops in 2017 and again in 2018, similar opinions were expressed around the 5 Levels of Involvement which were reflected in the workshops and shown below:



While this model is useful at an academic, business planning and measurement level, many of the service users and carers (not all) felt that this model was vague and difficult to understand and also had quite a hierarchical structure to the way in which it was presented which suggested that all the “important” people would be operating at the top.

The facilitator felt that for this stage of the process, what was missing for potential participants was the ‘practical feel’, in other words, how would this theory look in practice? What will Involvement mean for me? One way to do this was to ensure that the triangular model was ‘flattened’ to ensure that the top, ‘strategic’ levels would ‘feel’ as accessible to all service users and carers as the bottom ‘local’ levels.

With the agreement of the Advisory Group, the model was simplified to ‘Strategic’ and ‘Local’ involvement, described below:

Local level

At a local level the groups will meet in Derry, Strabane, Limavady, Omagh and Fermanagh. Each group will strive to involve and gather the views of members from

their area who have more complex needs and cannot attend the meetings, and also those who live in rurally isolated areas.

- The Local Involvement group will identify and discuss issues to be addressed in the local area to improve life for service users and carers.
- The Local Involvement group will enable information to be shared widely within the community and will identify issues and areas of service improvement to be discussed at the Strategic Involvement Group.
- The Local Involvement Group will have regular feedback from the Strategic Involvement Group about the progress of issues brought to it and will have the opportunity to discuss, deliberate and influence, in a timely manner, any policy and service developments that will affect service users and carers locally.

The Local Involvement Group may discuss things like:

- Service user, Carer and advocate ideas for their health, care or treatment
- Service users experiences of services
- The Trust's plans and staff experiences
- What aspects of services may need to change
- What service users and carers want from services and staff
- How to make the best use of resources
- How to improve the quality and safety of services.

Strategic level

At a Strategic Level, one Western Trust- wide group will meet regularly. The members of the Strategic group will consist of WHSCT LD and finance staff at AD or Director level, WHSCT PPI rep, 2 representatives elected from each Local Involvement group and reps from PHA and HSCB.

- The Strategic Group will debate and address the issues brought to them by the Local Involvement Groups
- The Strategic Involvement group will ensure that the issues and ideas generated by the Local Involvement groups are fully debated and considered in the planning, development and commissioning of services.

- The Strategic Involvement group will ensure an open and two-way dialogue with each Local Involvement group to ensure each group is kept abreast of developments which will impact Learning Disability Services, service users and carers.
- The Strategic Involvement Group will oversee the development of the Local Involvement groups and will be accountable to ensure the agreed Involvement process.

The Strategic Involvement Group will be informed by the Local Involvement Groups as well as policy and strategic directives, and taking all this into account may discuss and make decisions about things like:

- What and how, aspects of services may need to change
- What service users and carers want from services and staff and how to deliver this
- How to make the best use of resources
- How to improve the quality and safety of services for service users and carers

It is anticipated that this Hub and Spoke Model will provide a safe forum and structure that will enable service users and carers to challenge, influence and advise on the commissioning and delivery of Adult Learning Disability services.

Although it may seem to be implicit, it is important to reiterate that, “at both levels, it will be essential that the professional input of the planner and HSC professional is equally factored into the decision making process, alongside other key considerations such as statutory obligations and resource availability.” (HSC 2012)[4].

We need to be open, honest and realistic about the limits of involvement.

The detail of what Involvement means for each member should be discussed at an early stage to establish agreed vision and expectations.

A Planning Session was held to look at what Involvement means for carers and service users. The responses were noted below.

What we agree Involvement is:

- Discussion about service user and carers needs
- Taking into account that the professionals have an overview of all the services and interfaces
- A place to share information and ideas
- A place to influence how services work
- A place to talk about what doesn't work
- Encourage local solutions to solve local problems
- An opportunity to get together with local people to hear their views and ideas about how to develop services and do things better
- Knowing we are all working towards a better life for everyone with a Learning Disability
- Honesty and transparency on all sides
- Working in a partnership
- Transparency of decision making and how decisions were made
- People with Learning Disabilities will become more aware and involved with what is going on
- Having access to information to help form opinions
- To have a voice
- To have it heard
- To listen to others voices

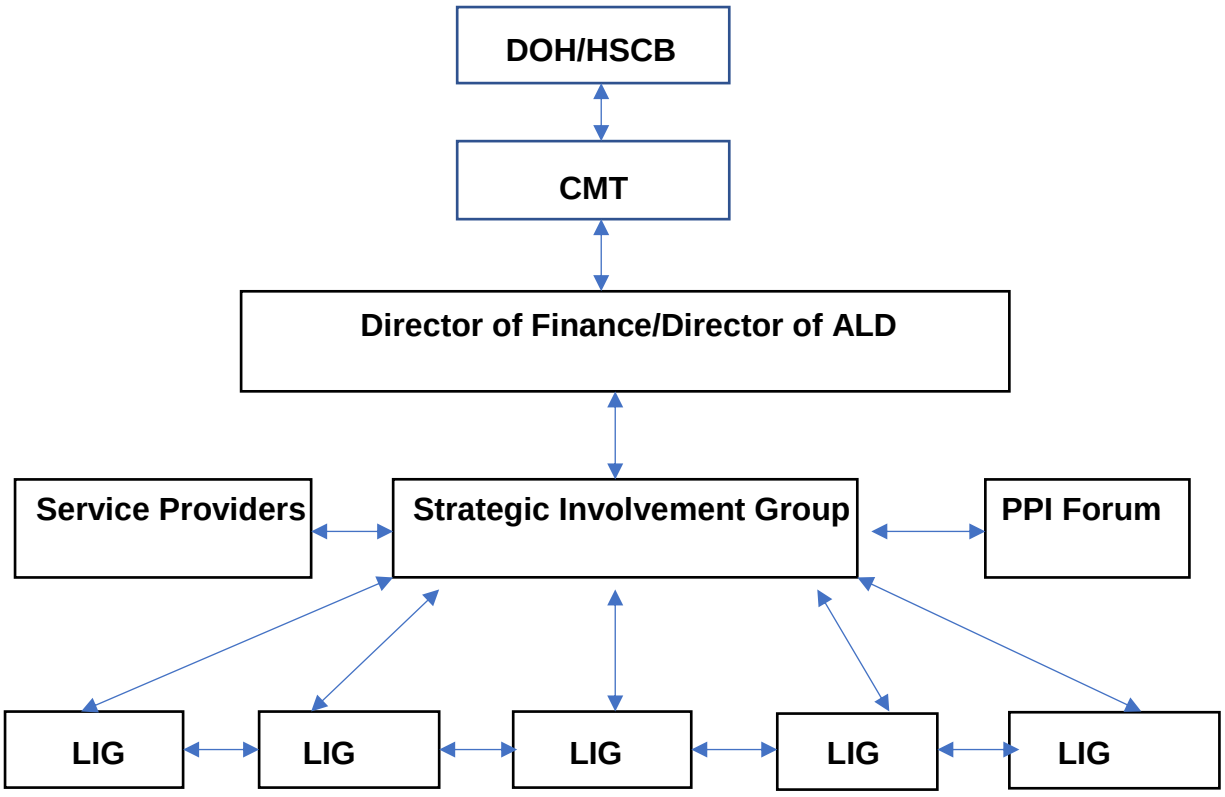
- To accept that there will be other voices, opinions and ideas that are just as important as mine
- Share experiences and ideas
- All carers and service users can air their point of view at the table
- Agendas will be focused and based on what service users and carers want to discuss
- Working in partnership with Trust, service users and carers in shaping and planning services for Adults with Learning Disability
- Ensuring service users and carers input influences the priorities for investment and care
- Influencing
- Shaping
- Listening
- Respect
- Ownership
- Able to make decisions for ourselves as individuals
- Listening and being allowed to act on how we can do better by bringing together those who have expertise through work experience and lived experience

What we agree involvement is not:

- Pretending to listen or care but then doing what you were going to do anyway
- Being ignored
- Being told we are valued and then nobody recognising my contribution
- Not being fixed on things having to happen in a certain way
- Blaming
- A place to bring personal complaints
- A place for high level business processes
- Hearing about decisions that have been taken without our knowledge when there was time for discussion
- Saying yes to everything
- Ignoring learning and expertise
- People making decisions that you want to make for yourself

- Not about 1 voice or those who shout the loudest
- Commissioning/procuring
- Taking away from the role of the WHSCT
- Dominating or pushing own agenda
- Being closed to others views
- Individual cases
- People at the table having more info than others
- Asking local people to accept statutory responsibility for decisions and budgets
- Not a forum for specific complaints
- Not a forum for procurement of services
- Should represent the views of all Adults with a Learning Disability and carers as a community and not personal agenda
- Making decisions without carer and service user input
- Not taking on board issues presented by parents and service users

Where will we sit in the system? What structures will we influence within?



4. The Advisory Group

This group has been in existence since January 2017.

The purpose of the group was to work in a spirit of partnership with the WHSCT to provide advice and guidance on the development of an exemplar 'Hub and Spoke Model of Involvement' which will improve services and the experience of services for service users and carers.

The group was to agree and clarify the purpose, structure and governance of the Model for Involvement and support the development and initial implementation of the Model.

Membership of the group were: Carers drawn primarily from local communities of interest i.e. the Western Adult Learning Disability Action Group from the northern sector of the Western Trust and South West Carers Forum from the southern sector of the Western Trust; senior WHSCT staff working in Adult Learning Disability services (who would be tasked with embedding the process within the system); WHSCT PPI representative and Public Health Agency PPI staff.

Due to the initial fragility of the relationships and trust between members, an Independent facilitator was employed early in 2017 to facilitate the first steps and to deliver a report which would guide the future direction of travel. A series of 6 workshops was held in each district council area, attended by 66 carers and 4 service users. The information, issues and ideas raised at these sessions informed the findings and recommendations reflected in the Ann Mc Murray report (2017) which provided an initial guide for the work of the Advisory Group.

It needs to be said that with the collapse of our government, this document was never officially signed off by the Department of Health which caused a difficulty within the Advisory group as the direction of travel was interpreted differently by different members of the group.

By November 2017, the group continued to face a number of fundamental challenges to successful partnership working and a second independent facilitator was commissioned in Nov 2017 to facilitate the work of the group.

➢ ***The challenges:***

- It was clearly voiced that members of the group had issue with the manner in which these workshops were organised and in how the target population were informed, feeling that they were not properly involved in the planning and content of the workshops. Members of the group felt that the workshops had been used by the WHSCT as an opportunity to push a WHSCT agenda.
- Members of the Advisory group were concerned that knowledge and understanding of PPI or 'Involvement' had not reached all relevant WHSCT staff within Adult Learning Disability services and were unhappy that they could not see any tangible moves by the WHSCT to address this through training.
- It was clear that the group, while making some progress, had unresolved fundamental differences in terms of priorities and approaches which slowed the pace of work and created 3 separate 'factions' i.e. SWCG, WALDAG and WHSCT.
- Chair and Co-chair had not been appointed by the group, and a Code of Conduct was not in place. Setting of the Agenda was viewed with suspicion and mistrust.
- Terms of Reference had been suggested in Ann Mc Murray's report however, this was implied and open to interpretation. A Terms of Reference had not been put on the table for discussion and agreement, the meetings were unstructured and difficult to control, and the role and purpose of the group continued to be debated in circles.
- It was clear that some of the members continued to direct blame and anger at a personal level towards other members of the group and this behaviour was compromising the development of good relationships.
- The financial position of underfunding, which was the catalyst for this work, and which was outlined in the DOH report as an issue which should be debated and influenced by this group in the short -term proved to be a contentious issue, with some members of the group refusing to give the issue space on the agenda. Some members felt that this was an issue which should not be debated until the 'Involvement Model' was in place and working well. However, others felt that this was an issue to be addressed simultaneously,

as directed by Chris Mathews and the Health Minister. These members felt that unless efforts were made to include them in the redressing of the financial issues that any attempt at developing an Involvement process would be tokenistic.

- A potential conflict of Interest was raised by a number of members as two of the members of WALDAG were also employed by a local service provider. This raised dissatisfaction among a number of members of the group but this had not been openly addressed around the table.
- A number of carers had unrealistically high expectations of being involved and constantly pitched the discussions at this level, espousing a top- down approach which seemed to defeat the purpose of true involvement. These carers had an expectation to go directly and prematurely to Level 5 involvement (before levels 1-4 are established and working well) and to 'hold the WHSCT (work and staff) to account'.
- A number of carers were unable to listen to or respect the point of view of others around the table and unwilling to concede their position in any debate in order to progress the work. This approach caused division within the group and a stop- start situation.
- A fundamental lack of trust existed for some members of the Advisory group and being 'stuck' in this position harboured suspicion and lack of tolerance and respect for colleagues around the table. This manifested in a belief that the WHSCT staff were not being honest in their motives and membership of the group, that the independent facilitator was not independent and was in fact pushing a Trust agenda, and that the Advisory Group would be defunct without them.
- An issue also existed around the creation of a database of Service users and Carers to improve communication and 'involvement'. This had become confused with updating the Master Patient Index which had been a recommendation of the Anne Mc Murray report. However, the reality of this is that the contents of this database are subject to Data Protection regulation and it would not be appropriate, in fact it would be a breach of GDPR, for any non-trust employee to have sight of this database.

- ***Addressing the challenges***

- In addressing the challenges the Independent facilitator adopted the chairmanship of the group, setting the agenda before each meeting with input from the group. Although this caused contention on occasion, the facilitator was careful, in the interests of equality, to ensure that all members requests and concerns were addressed at the table as an agenda item.
- To ensure openness and transparency and foster trust, the facilitator was careful not to undertake to address concerns 'off' the table and ensured that difficult or contentious conversations took place in the public forum of the group.
- Three planning sessions were held to discuss and address outstanding and contentious issues.
- The ' Conflict of Interest' issue was discussed and resolved.
- The development and adoption of a 'Code of Conduct' for the group was facilitated
- Two co-chairs have been nominated by the group.
- A series of workshops took place which gathered the wider views of service users and carers and would directly inform the Terms of Reference, Governance and Underpinning Principles of the Model for Involvement
- In March 2017 a definite shift in the positivity and focus of the group was apparent. In order to facilitate the growing pace and intensity of the work, a number of sub-groups were set up so that identified areas of work could develop simultaneously:

1. The Communications sub-group
2. The Terms of Reference sub-group (Terms of Reference included as appendix)
3. The Induction sub-group (Welcome and Induction Pack included as appendix)
4. The High Cost cases/ Unmet need sub-group

- The Trust employed a communications officer in Jan 18 to dedicate time and expertise to improving communications, through the development of a web-site, newsletter and a Communication Strategy to guide the Involvement work into the future.

Unfortunately, it became clear that during this process, the expectations of a number of members of the group were so high as to be unlikely to be met within the purpose and context of this Advisory Group and disappointingly, at time of reporting, had expressed their dissatisfaction to parties outside of the Advisory Group and withdrew from the group for an unspecified period of time.

In managing this situation the remaining members of the Advisory Group were disappointed that members did not address their concerns at the table and they were left in the dark as to what the exact concerns were. They clearly expressed that 'the experience of a few was not the experience of all', and they felt that work was progressing well and the outcomes of the meetings and relationships had greatly improved since Nov 2017.

They also felt that in terms of progress towards developing a Model of Involvement, that this withdrawal had come at a critical time. The group agreed that expectations had been raised among service users and carers and it was essential to continue the work. At this point, *274* service users and carers had expressed interest in becoming involved and were waiting for the next step.

To ensure representation from all geographical areas the decision was taken to identify and invite appropriate representatives from the Omagh and Enniskillen area onto the time-bound Advisory Group.

The group also agreed a Code of Conduct/ Guiding principles for the Advisory Group to provide some guidelines for the remainder of this groups existence which is anticipated to be active to March 19. All members and new members are required to sign and abide by this document.(The Code of Conduct/ Guiding principles are included as appendix).

The structure and process for decision - making and accountability should be clearly defined

5. Workshops 2018 / Local voices informing the Involvement Model

Following the Involvement workshops for Adult Learning Disability services held in March and April of 2017 and the subsequent reporting of the issues and recommendations, the Advisory group were tasked with oversight of the development of a Hub and Spoke Model of Involvement for Adult Learning Disability services.

On appointment, the brief of the independent facilitator was to ensure the model was in place by March 18. However, soon after appointment it became very clear that this time-frame was unrealistic due to the fact the group was still stuck in the 'storming' phase of its development, and thus this timeframe would not allow the space to discuss and agree the values and principles which would underpin the model.

It was also apparent that further work needed to be undertaken to ensure that local communities and potential representatives understood what involvement would mean for them and that the views of Adults with Learning Disabilities and their carers would shape and influence the Terms of Reference, the Values and Principles and the Governance arrangements of the Involvement model.

Between February 18 and March 18 a series of 6 workshops were held in each district council area across the Western Trust (with 2 being held in Derry).

The workshops were led by the Independent facilitator and supported by the Communication manager who was simultaneously developing a Communication strategy which would be crucial in supporting the involvement process.

The purpose of the workshops was to gather experiences, views and suggestions about how involvement would make a difference to service users and carers lives in real terms, and which would influence the detail and direction of the Involvement Model.

The workshops were attended by a total of **97** participants. At each workshop the participants addressed:

- The guiding principles and purpose of the local groups (Membership and Terms of Reference, Recruitment process onto the local groups)
- The levels of involvement – what it will look like practically and what measures we can put in place to ensure that it is happening at each level and making a difference to you
- The communication channels
- The support that will be required to enable this to happen inclusively

*It should be noted that the outcomes of these workshops have **directly** informed and influenced the Communication strategy, the Terms of Reference and the Induction and Welcome Pack (included in the appendices).*

There should be a balance in numbers of service users/carers in any involvement meeting

Workshop Outcomes

How will our group work? Practicalities and governance.

- We will be open and welcoming – balance focus and work with informal approach
- We will foster and nurture good relationships
- We will keep it simple! Common languages and processes
- We will speak for those who can't speak for themselves
- We will overcome communication problems
- We will work together
- Everyone will have their say
- Our members should live in the local area
- Our meetings should be no longer than 11/2 hours
- We will vote for the person we want to take the lead
- We will expect to have situations, problems and solutions clearly explained to us
- We will have ability/ power to resolve issues at local level
- We must have personal and practical experience of Adult Learning Disability services (experts by experience) either as a service user or a carer and service users will be over 18 years of age
- Although service providers will not be part of our core group, we may include stakeholders beyond carers and service users…. Co-optees (rules set and conflicts of interest identified and managed)
- We will work with Local Trust reps
- We will meet at least every 2 months
- We will communicate and advertise successful outcomes locally and centrally to encourage new members to become involved
- We will create links with Children's services
- More than 1 person will be elected from our local group to sit on strategic group.
- Administrative support will be provided by WHSCT

What support will we need to become and stay involved?

- We will see positive change and improvement in our lives
- The level of support needed will be assessed individually
- We will meet at a time suitable for all our group and will alternate venues and times if needed
- We may run our meetings alongside social activities for loved ones/ run group in same premises as other events
- We will set the meeting dates in advance
- We will have a meaningful Induction and ground rules
- We will have a clear Terms of Reference and understand our role
- We will have Easy read, timely, agenda and papers
- Service users will be able to include an appropriate person to accompany them to meetings
- We will have our expenses reimbursed
- We may have additional direct payment hours to cover time to attend meetings
- We will have access to transport where needed
- We will have access to a sitting service where needed to enable us to attend meetings
- We will have a break during meeting to help with attention span and concentration
- We may have a mentor where needed to keep member involved and included during meetings/ ensure conduct is respectful and inclusive
- We will have a budget for each group so that we can make our own decisions

What difference could being involved make to our lives – Measures- How will we know involvement is working?

- I will have access to a social worker who has up to date knowledge and have an assessment at regular intervals
- I will have a personalised goal plan
- I will have access to direct payments so I can make decisions about my own day to day life and activities
- I will have access to information which will give me reassurance and enable me to make informed decisions
- I will be able to access services, programmes and activities which cater for my individual level of need and develop my personal abilities.
- I will have information about programmes and activities in my own community
- I will have equal access to opportunities no matter where I live
- All carers will have a carers assessment completed
- Key front-line staff will undertake involvement training
- I will have a seamless transition from Children's services to Adult services, being transferred immediately to the MPI database for Adult Learning Disability
- I will have access to speech and language therapy and physiotherapy throughout my lifespan
- The services that were important to support me until the age of 18 will continue after I am 18
- I will feel empowered, knowledgeable and confident that my involvement is making a difference for others.

Common themes and Discussions

A number of common threads and themes were discussed across all workshops.

- Participants felt strongly that the title or brand for this work as ‘PPI’ was both confusing (sharing its initials with Payment Protection Plan) and uninspiring. We were asked to refer to the model simply as the ‘Involvement’ model.

- Participants suggested that we must be sensitive and careful as to how we advertise and communicate the involvement message and to be mindful of personal concepts of disability. In other words, we should encourage involvement which does not label or identify people as different. We should ensure our involvement model is framed in a positive way and aim to build on individual, group and community strengths.

- A recurring discussion was the possibility of supporting Service User only groups as some service users wished to take part separately from their parents or carers. This was due to issues of over protectiveness and a wish to express ideas and issues that they would not discuss in front of their parents or carers.

- Participants suggested that the 5 Local Involvement Groups should meet on an annual basis to celebrate achievements and share information and best practice. It would also give them an opportunity to identify and align issues to plan together.

- Participants stressed that the Local and Strategic Involvement Groups must have a patient and respectful approach and strive to overcome communication difficulties using practical and creative methods to ensure participation and involvement of all service users

- Participants felt that the Local and Strategic Involvement Groups must move at the pace of the members. Members should set the pace and approach of the meetings and not be expected to meet in a Health Service management like manner or be integrated into the culture of Health and Social Care meetings.

The strategic Involvement group must be as accessible to service users and carers as the local group.

A person-centred approach should be taken to ensure service users and carers are supported to attend the meetings

6. Towards changing a culture/ the WHSCT commitment

This has been a particularly challenging involvement process for the WHSCT due to the circumstances from which it was born. It should be acknowledged that the individual staff involved, work within a multi-faceted organisation in which the cogs grind very slowly when it comes to organisational and cultural change. It is within this context that the staff have been charged with developing an exemplar Model of Involvement. The staff fully recognise the difficulties of this within their own organisation, however they also recognise the potential huge rewards and benefits of this process and are fully committed to improving outcomes for service-users and carers.

The WHSCT staff members are equal members around the table of the Advisory group but have (along with others) faced anger and distrust from other members from the outset which has been aimed at a very personal level on occasions.

The WHSCT staff are fully aware of the frustrations and anger and are committed from the Chief Executive level down through to service managers to ensure this process will operate in real and meaningful terms and the situation of underfunding will not happen again.

The relationship between the Assistant Director, Service managers and other members of the group have improved and the majority of the Advisory group feels that they have been dealt with open and honestly at the table. However, the members also feel that there is a disconnect between the work of the Advisory group and the WHSCT Finance Directorate in that they feel that financial decisions are still presented as a ‘fait accompli’, despite the best efforts of the ALD Assistant Director to make this connection.

The Advisory Group members recognise that a cultural shift within Health services will take time and that flexibility and a willingness to ‘stay with it’ is needed in this process. They are committed to doing this, so long as they feel the conversation with the WHSCT is honest and that they can see that real attempts are being made to embed involvement.

Any programme of training and induction should present 'Involvement' as a positive and rewarding approach to improving outcomes for service users.

The WHSCT are currently developing a Corporate PPI strategy. This process of developing a Model of Involvement in Adult Learning Disability will inform and influence this strategy and action plan.

The WHSCT have employed a communication resource to improve communications to support the Involvement Model. This has seen the development of a brand and logo for Adult Learning Disability services, the publication of a newsletter and the development of a web-site to inform and support service users, carers and the wider public. This was supported through the advisory group members at the Communication sub-group and was also directly informed by the feedback from the workshops.

A communication strategy has also been developed to support the Involvement Model into the future .

The WHSCT have committed to employing a dedicated resource to facilitate the implementation and embedding of the Involvement Model. It is hoped that this resource will be on the ground by September 18.

In creating a viable solution to addressing the database issue, while ensuring data protection legislation is upheld in relation to the MPI, the WHSCT staff have created a database for service users and a database for carers, seeking the explicit consent of individuals to be added.

Through the WHSCT PPI corporate strategy which will need to be resourced, the Adult Learning Disability Directorate will be enabled to roll out Involvement training for a range of front-line and management staff.

In championing this work within the WHSCT, the Assistant Director has facilitated a number of meetings between the Advisory group members and Chief Executive, and also with the Director and Assistant Director of Finance to agree direction and discuss the process.

However, the caution in all this work which has been very positive, is that the financial situation is not yet redressed and the opportunity must be taken by the WHSCT to strengthen the connectedness in the planning processes to ensure openness and transparency in the allocation of finance and ensure this situation never happens again.

Close links must be maintained with Childrens Learning Disability Services to improve the experience of transition from Children to Adult services.

7. Towards a Communication Strategy

Following the appointment of a communications facilitator the approach to Involvement has been has been 2- pronged, in recognition of the close relationship between communication and involvement processes.

A Communications Sub-Group was set up and established in January 2018 led by the communications facilitator.

This group was established to plan and implement a robust and efficient communications strategy for ALD Services which would be informed and shaped by service users and carers.

In a few short months, following the workshops which gathered information from service users and carers about how they would like to be communicated with and what they would need to know, intensive input from the members of the communication sub-group and feedback from the Advisory group a number of practical actions were achieved.

- The development of branding for ALD services
- The establishment of an online hub presence providing information, help and support in a visually appealing and user-friendly manner, across a range of topics which were highlighted by carers, service users, staff and members of the Communications Sub-Group. The online system will build a database of contact details to assist information distribution.
- The development and distribution of a Newsletter/Ezine for distribution of news and information . The first issue was distributed to over 2,000+ addresses held on the MPI & Carers Databases and also posted online on the new-look website section.
- A Communications Strategy for ALD services (to be signed off by the Advisory Group in August 2018 and launched in September 2018)

8. Short-term Implementation Plan for Hub and Spoke Model/ Advisory Group

Time-frame	Actions
July 18	• Letter from Advisory group to WHSCT • Report signed off by WHSCT • Easy read literature • Initial letters out to all interested individuals/ support needed • Advisory group meeting • Communication strategy agreed/ launch agreed
August 18	• Publication of 200 induction packs • Recruitment process update • Advisory Group meeting • Initial facilitation of Local Implementation groups agreed (who?) • Venues booked
September 18	• Letters of invite sent • Practical support arranged • Launch of Local Involvement groups agreed • 1st meeting of each group/ mentorship agreed where appropriate/ induction
October 18	• Advisory group meeting/ Agree TOR/ code of conduct/ Induction pack for Strategic Involvement group • Admin of meetings/ easy read/ 2 weeks in advance/
November 18	• 2nd meeting of Local Involvement groups • Initial nomination of service users and carers to Strategic Group • Admin of meetings/ easy read, 2 weeks in advance
December 18	• Advisory Group meeting • Letters of invite to SIG/ • Practical supports arranged • venue booked

January 19	• 3rd meeting of local involvement groups • 1st meeting of Strategic Involvement Group/ mentorship agreed where appropriate/ induction • Admin of meetings/ easy read, 2 weeks in advance
February 19	• Advisory group meeting/ exit strategy
March 19	• 2nd meeting of Strategic Involvement group • Admin of meeting/ easy read, 2 weeks in advance • Final Advisory Group meeting

These practical actions may need the continuity of an independent resource or champion to ensure the momentum is built upon and to support the WHSCT and Advisory Group to drive the process forward within the time-frame.

9. Conclusion

It is important to say that while the process has been and continues to be challenging, requiring a strength of personal leadership qualities in all those involved, that the tangible outcomes are successfully manifesting.

The web-site is now live and will be well advertised through a launch and the Terms of Reference, Code of Conduct and Induction Pack has been developed.

The process is now in a crucial stage of 'pre-implementation' and it is essential that the WHSCT continue to resource independent facilitation of the process to drive the process forward, to continue to provide advice and practical support to the Advisory Group and to ensure the actions are implemented within the expected time-frame (until the WHSCT Involvement 'resource/ post' is in place).

The over-arching learning in this process is that the business of true and meaningful involvement in Adult Learning Disability services comes with its own unique challenges.

For those who become and stay involved, it is important to recognise the limitations of influence and involvement and also that to change the culture of an organisation takes time and patience and is characterised by a 'chipping away' at old practices and beliefs and a series of small changes or 'wins'.

As with many partnerships and collaborations, the strength of the relationships will dictate the pace and direction of work and it is essential for each member to exercise personal responsibility in choosing to nurture this for the best outcomes possible.

Finally, the shared belief that through Involvement we can improve the day- to -day lives and choices of People with a Learning Disability and their Carers, has remained the underpinning belief that has driven this process through seemingly insurmountable difficulties.

10. Recommendations

1. The Advisory Group to continue to oversee and drive the implementation of the Local and Strategic Groups until March 19.

2. The Advisory Group to be the group which is recognised, resourced and endorsed by the WHSCT to carry out this work.

3. The Adult Learning Disability Involvement work to inform and closely align with the WHSCT Corporate PPI Strategy and Action Plan.

4. The financial directorate to be represented at the Advisory Group to provide expertise and advice and to build upon relationships

5. The financial allocation to Adult Learning Disability and the allocation in relation to High Cost Cases and Unmet Need must be addressed simultaneously to this process and remain on the Agenda of the Advisory Group.

6. The Advisory Group to work together to co-produce a paper for CMT which will articulate unmet need.

7. The formal relationship should be defined between the Local and Strategic Involvement Groups, the WHSCT PPI Forum, the WHSCT Adult Learning Disability Directorate and the WHSCT Financial Directorate.

8. This work is at a crucial stage of development and requires the continuation of independent facilitation to drive the process forward. The post of 'Involvement Facilitator' must be given priority by the WHSCT to be in place by Sept '18 if possible.

9. The set-up and facilitation of the Local Involvement Groups and of the strategic Involvement group should be supported and facilitated by the 'Involvement Facilitator' for the first year and not by Adult Learning Disability staff. This will encourage positive group development, a consistent approach and provide an overview of local discussions which will inform the direction of the Strategic Involvement group.

10. Each Local Involvement Group should have a budget to allow each area to creatively encourage maximum involvement at a local level.

11. The role of Service Providers should be discussed and agreement reached how they can be involved while ensuring accountability and integrity of the process.

12. The WHSCT must roll out Involvement Training to all staff working in the arena of Adult learning Disability. 'Involvement' should be a key item on the JD, Person specification and induction of WHSCT staff in Adult Learning Disability.

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2. *HSC (2012). Valuing People, Valuing Their Participation. A Strategy for Personal and Public Involvement for the Public Health Agency and Health and Social Care Board*
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4. *Grove, N. See What I Mean – guidelines to aid understanding of communication by people with severe and profound learning disabilities. Charge applies: download an order form from the BILD website (www.bild.org.uk)*
5. *DOH (2017). National Involvement Standards. 4PI Involvement for Influence*
6. *DHSSPS (2016). 'Health and Wellbeing 2026. 'Delivering Together'.*

Appendices :- Involving You, Improving Lives.

Adult Learning Disability Involvement Advisory Group

Code of Conduct/ Guiding Principles

Aim

The purpose of this Code of Conduct is to ensure clarity and openness of process and procedure to safeguard the integrity and reputation of the work of the Advisory group and its members.

1. This group is a partnership of Adults with a Learning disability, their representatives and Carers, Senior WHSCT staff working in Adult Learning Disability and Personal Public Involvement Staff who provide leadership, advice and guidance in the specialism of Personal, Public Involvement.

2. Members will adhere to meeting etiquette, showing respect and consideration for other members values, beliefs and points of view.

3. To ensure openness and transparency of this group, members of the group have been asked to declare any conflict of Interest. Two of the current members who are represented on the group are also employees of a local service provider 'Destined'. The Advisory group have discussed the management of this interest and are agreed that the Advisory Group is advisory only and time-bound, and no commissioning or service development decisions will be made at this table. It is agreed that the knowledge, experience and ability to harness the views of many service users and carers will positively contribute to the work of this group.

4. This group is temporary and time-bound and was established to assist and advise on the development of an exemplar hub and spoke model of involvement.

5. While there is no exact time-frame for the group it is likely to cease in around Dec 18 - March 19 at latest.

6. Being temporary and focused the group consists of original members. Additional members must be invited to the Advisory group meetings with prior group agreement.

7. In the event of a member/s leaving which would leave an area or community of interest unrepresented around the table, the group can agree to target new members.

8. Members will ensure that their contribution is genuinely representative of the wider community of Adults with Learning Disability and their Carers.

9. The group should nominate a Chair and Co-chair role who will ensure that all business is carried out in a structured manner and that all views are heard. Every member should be given the opportunity to express a view and have it considered.

10. All members will participate in an honest and open manner. To achieve openness, it is important for members to feel able to share information and express their opinions and concerns freely in meetings.

11. Members will be expected to be responsible when sharing the groups' discussions to ensure that their feedback is above-board, accurate and fair to all those present.

12. Members will bring any criticisms or concerns they might have about the value, role and functioning of the Advisory Group to the meeting for discussion, to provide the Advisory Group with an opportunity to address them. These items should be shared with the chair and co-chair prior to the meeting to be added to the agenda.

13. Members will keep confidential any information that has not yet been made public and/or is provided in confidence, nor use confidential information for their individual personal advantage or for anyone known to them or to disadvantage or discredit the Advisory Group or anyone else.

14. All members will disclose any potential conflict of interest on joining the Advisory Group. If at a meeting a particular issue arises that could give rise to a potential conflict of interest then the member should again disclose their interest to the chair and co-chair and, if appropriate, withdraw from any further discussion or consideration of the matter.

15. All members will give timely apologies to the meeting. In the event that apologies are not given, they will not be noted.

16. Absence without apologies for 3 consecutive meetings will be regarded as withdrawal.

17. Members who decide to resign from the group must do so formally through the Chair or co-chair in writing.

18. Minutes, papers and notes of discussions arising from the meetings will only be shared with active members of the group who have signed the Code of Conduct.

19. All members will sign this agreement confirming that they will comply with the conditions set out in the Code of Conduct for the Advisory Group.

Signature ……

Date……

Western Trust Area, Adult Learning Disability

Local Involvement Group

Welcome and Induction Pack

Contents **Page**

1. Welcome and thank you for getting involved

Welcome to the Local Involvement Group.

Your colleagues on this group are adults with a Learning Disability, carers, representatives and Trust staff.

This group will discuss every-day, local issues that affect service users and carers, and will strive to put forward ideas and solutions about how to improve services. The group will also share knowledge about programmes and events taking place in the local community to raise awareness and encourage inclusivity.

You may be asked to speak about your 'lived experience'. This might be about the impact of having a learning disability on your life. It may be about the impact of being an informal carer. It might also be of your experience of using and engaging with Adult Learning Disability services as a user or carer. What is important is that you are able to bring your own knowledge and experience to the process.

You do not need specialist knowledge as others in the room will have that.

Please know that there is no such thing as a stupid question or suggestion so we welcome and encourage you to keep asking questions and making suggestions to keep people thinking.

We will strive to use plain, straightforward language and avoid jargon.

We will also provide the support you need to become and remain involved.

We recognise that some service users have more complex health needs than others and attending meetings may be difficult for some. However, each and every service user and carers voice is equally important , so, if you cannot take part in bi-monthly meetings you can still contribute to the discussion in other ways.

Finally, we hope that Involvement in this process will be a rewarding and enjoyable experience for you.

2. What is PPI ?

Personal and Public Involvement (PPI) is a process whereby service users, carers and the public are empowered and enabled to inform and influence the commissioning, planning, delivery and evaluation of services in ways that are relevant and meaningful to them. People have a right to be involved and increasingly they expect to be actively involved in decisions that affect them.

*To keep language simple we will call PPI "**Involvement".***

Involvement is a statutory responsibility as detailed in the HSC (Reform) Act (NI) 2009 through the Statutory Duty to Involve and Consult. Each Health and Social Care organisation, to which the legislation applies, is required to involve individuals in the planning and delivery of Health and Social Care (HSC) Services. Specifically, sections 19 and 20 of the above legislation require that service users and carers are involved in and consulted on:

1. The planning of the provision of care

2. The development and consideration of proposals for change in the way that care is provided

3. Decisions that affect the provision of care.

Service users and carers can be involved at a ***local*** or a ***strategic*** level:

Local level

At a local level the groups will meet in Derry, Strabane, Limavady, Omagh and Fermanagh. Each group will strive to involve and gather the views of members from their area who have more complex needs and cannot attend the meetings, and also those who live in rurally isolated areas.

- The Local Involvement group will identify and discuss issues to be addressed in the local area to improve life for service users and their carers.

- The Local Involvement group will enable information to be shared widely within the community and will identify issues and areas of service improvement to be discussed at the Strategic Involvement Group.
- The Local Involvement Group will have regular feedback from the Strategic Involvement Group about the progress of issues brought to it and will have the opportunity to discuss, deliberate and influence, in a timely manner, any policy and service developments that will affect service users and carers locally.

The Local Involvement Group may discuss things like:

- Service user, Carer and advocate ideas for their health, care or treatment
- Service users experiences of services
- The Trust's plans and staff experiences
- What aspects of services may need to change
- What service users and carers want from services and staff
- How to make the best use of resources
- How to improve the quality and safety of services.

Strategic level

At a Strategic Level, one Western Trust- wide group will meet regularly. The members of the Strategic group will consist of WHSCT LD staff, 2 representatives elected from each Local Involvement group, PHA, HSCB.

- The Strategic Group will debate and address the issues brought to them by the Local Involvement Groups
- The Strategic Involvement group will ensure that the issues and ideas generated by the Local Involvement groups are fully debated and considered in the planning, development and commissioning of services.
- The Strategic Involvement group will ensure an open and two-way dialogue with each Local Involvement group to ensure each group is kept abreast of developments which will impact Learning Disability Services, service users and carers.

- The Strategic Involvement Group will oversee the development of the Local Involvement groups and will be accountable to ensure the agreed Involvement process.

The Strategic Involvement Group will be informed by the Local Involvement Groups as well as policy and strategic directives, and taking all this into account may discuss and make decisions about things like:

- What and how, aspects of services may need to change
- What service users and carers want from services and staff and how to deliver this
- How to make the best use of resources
- How to improve the quality and safety of services for service users and carers

Each of these groups may co-opt members to inform the discussion around particular areas. These may be representatives from Public, Private or Community and Voluntary sector organisations. In the case of Learning Disability Service Providers, due, recordable consideration must be given by each group to the management of both conflict of interest and equality of representation.

3. Why is Involvement worthwhile?

Involvement is underpinned by a set of values and principles, but at its core, is the drive to achieve truly person-centred services. Delivering Health and Social Care services where service users, carers and the public are fully engaged in a partnership based approach to health and wellbeing, whether that is at the strategic, or individual level of care planning and provision.

The impact of Involvement has been demonstrated in a range of areas including increased efficiency and effectiveness, tailoring services to need, reducing wastage and duplication, improving quality and safety, and increasing levels of self-responsibility for one's own health and wellbeing.

- It is your right to be involved in influencing the planning, design and commissioning of services

- It is your right to receive timely information in an honest and understandable way
- It is your right to know how public money is being spent

4. Why should I get Involved?

- Improving day to day life for people with LD and their carers
- To speak for those with more profound and complex disability
- Empowerment and ownership
- Sense of community and comradeship
- A vehicle to speak collectively
- Building personal skills and knowledge
- Access to training and information

5. How will my involvement help?

- Help to influence change and improvement in areas that concern people most
- Identify what services are important to fund. This may be different from the services
  that commissioners think are important
- Influence how services are planned, designed and commissioned
- Improve the lived experience for people with learning disabilities and carers through influencing the services ie: what services, where they are and how they are carried out
- Making sure that people get good quality information, provided in user-friendly ways and publicised widely so that the wider public get to hear about it
- Influence the evaluation of services, by suggesting measures that are important to people who use service (these may be difference to those that have been used by service planners)

6. Our values and principles

- We will ensure that the work is meaningful, enjoyable and rewarding
- We will foster a sense of community, belonging and a collective voice
- We will find creative and practical ways to ensure participation
- We will be committed to Involvement and active inclusion
- We will recognise and appreciate the individual skills, talents and knowledge of all members
- We will work in the spirit of Partnership
- We will ensure Equality, mutual respect and co-ownership
- We will recognise, listen to and respond to **You** as 'Experts by experience'

7. Who else will be involved?

- Adults with a learning disability
- Carers and families who are or have been engaged with Adult Learning Disability Service
- Appropriate representatives as agreed by members within the parameters of the Terms of Reference and Code of Conduct
- WHSCT Learning Disability staff
- Co-optees as agreed by members within the parameters of the Terms of Reference and Code of Conduct

8. The support you can expect

- Tailored to individual needs
- Buddy system/ mentor
- Induction and training
- Easy read, understandable, accessible, relevant information
- Reimbursement of expenses (define)

- Transport
- Respite or sitting service
- Cost covered for care support
- Additional direct payment hours to cover time spent at meetings

9. What we expect from you

- To commit to the spirit of partnership, loyalty and mutual respect
- Willingness to listen to, understand, respect and consider, different views
- The ability to commit to time for meetings and resulting work
- The ability to commit to training
- The commitment to prepare for meetings by reading information, which will normally be sent to you in advance
- The ability to express your views at meetings attended by a range of professionals (it is ok if you need help to do this)
- The ability to keep asking questions until you get enough information or an explanation to understand fully what people are talking about
- An ability to challenge current thinking in ways that are both creative and supportive
- To give a commitment to maintain confidentiality about meetings attended
- To give a commitment to share information as agreed by all members of the group
- To act as a champion for PPI and Involvement ensuring positive information sharing and culture change

10. How our group will work

- We will be respectful and inclusive
- We will address communication barriers
- We will speak for those who cannot speak for themselves
- We will meet every 2 – 3 months
- We will arrange meetings 1 year in advance
- We will hold short meetings – maximum 1- 1.5 hours
- We will have clear roles and responsibilities
- We will keep numbers balanced – half of the members will be service users, carers and representatives
- Numbers must be balanced to make decisions (a quorum)
- We will have a focused agenda and decide what we will discuss
- We will have administrative support
- We will keep language plain and simple
- Where appropriate we will have a buddy system
- Each group will have a person who is a ‘point of contact’ this will normally be the chair/ co-chair. However, in the initial stages of set up this will be another nominated person.

11. Information and training

Information and Training will be provided on an ongoing basis and will be determined by the needs of each Local Involvement Group. We will ensure you have access to the information and knowledge you need to feel fully informed and confident in contributing to discussions.

Through the Induction and throughout the process we will build your knowledge and understanding about:

- Western Health and Social Care Trust and Community Learning Disability services
- The Health and Social Care system and how it works
- Involvement – levels, values and practicalities
- Your role and responsibilities
- How to prepare for, participate and chair or co-chair meetings

So that you know what to expect, here is an example of how the first few meetings may happen.

1st meeting – Welcome/Getting to know each other – informal/ Introduction/ Involvement

2nd meeting – Induction Pack/ TOR/How our group will work practically/ Website

3rd meeting - What happens in our local area/ what issues do we want to address on our agenda – identify knowledge needed to address these particular issues – identify chair and co-chair

12. Communication and feedback – how will we know our involvement is making a difference

- How will we know we have been listened to and our contribution acted upon

Reimbursement of costs/ travel form

Process for Complaints

Register of Interests

Adult Learning Disability

Local Involvement Group

Draft Terms of Reference

1. Introduction

This is a partnership of service users with a Learning Disability, their families, carers and service user representatives and WHSCT staff from Learning Disability services who will work in partnership to improve the lives of adults with a Learning Disability and their carers in the Western Trust area.

The title given to this work is Personal, Public Involvement (PPI Strategy) but we will simply refer to it as "Involvement".

This document outlines the rules about what we will do and how we will do it.

2. Aim

This group has been established to:

a) Ensure the openness and accountability of the spending of public money in the area of Learning Disability services
b) Ensure the involvement and influence of service users and carers in the development, improvement and provision of services
c) Nurture a culture and spirit of Partnership and Involvement between WHSCT, Service users, Carers and Communities.

This process will involve adult service users with a Learning Disability and their families and carers, in conversations with the WHSCT so that they can together identify where and how services need to change.

Open and transparent communication will ensure that this partnership of carers, service users, and WHSCT staff will influence the planning and delivery of services and the allocation of resources.

3. Values and Principles

- We will ensure that the work is meaningful, enjoyable and rewarding
- We will foster a sense of community, belonging and a collective voice
- We will find creative and practical ways to ensure participation
- We will be committed to Involvement and active inclusion
- We will recognise and appreciate the individual skills, talents and knowledge of all members
- We will work in the spirit of Partnership
- We will ensure Equality, mutual respect and co-ownership
- We will recognise, listen to and respond to ‘Experts by experience’

4. What we might discuss

We will discuss the things that are important to us in Adult Learning Disability Services. These could be things like: Local Community and Voluntary events and programmes, transport, day care, respite and short breaks, future planning, access to social workers, transition planning, living options, mental and emotional wellbeing, physical health and well-being physiotherapy, employment, education, speech therapy and nurses, transition planning, access to carer assessments and Self- directed support or other areas that you may identify as important to you.

5. Objectives

- We will share local information and identify gaps, priorities and opportunities for improvement to be shared with the Strategic Hub
- We will influence how resources are allocated
- We will actively contribute to the Communication strategy and action plan
- We will commit to sharing best practice and celebrating success
- We will promote the work of the group to other people with Learning Disabilities and their families and carers within their local areas
- We will actively seek to attract new members onto the local group
- We will actively seek to share the views and opinions of local service users and carers experiences of a range of services and their ideas about how things could be changed for the better
- We will have our discussions and decisions represented at the Strategic Involvement Group
- We will identify opportunities and target groups for 'Involvement' training
- We will review TOR, membership and recruitment process at regular intervals as the process evolves.

6. Membership of the group

- Service users and their family or carer or appropriate representatives (advocates) who are over 18 and have experience of Adult Learning Disability services and have consented to be involved.
- WHSCT staff working locally in front line ALD services
- Half of the members should be service users and carers and/ or appropriate representatives (advocates)
- Quorum of members should be present to make significant decisions
- Members can join the group be to address particular pieces of work at any time of the year
- All new members will be provided with Induction and training opportunities to ensure they have the knowledge and confidence to contribute

7. How we will work

- We will strive to ensure that this work is enjoyable and fulfilling for all members
- We will balance focus and work with informal approach to accommodate all needs and nurture relationships
- We will hold short, focused meetings to accommodate health and concentration needs
- We will keep it simple and strive to use common languages and processes
- Chair and Co-chair election
- WHSCT will have responsibility for co-ordinating and servicing the meetings
- We will send easy read papers well in advance of each meeting
- We will make decisions only if a Quorum are present
- Half the members will be service users and family or carer representatives
- We will clearly document voting and decision- making processes

- We will provide members with induction and ongoing training
- We will meet every three months
- We will hold meetings during day or evenings to suit local members
- We will have refreshments at each meeting
- We will set the dates a year in advance if possible, to help with planning
- We will identify a mentor or contact person for carers and service users who request this to support them to fully participate
- We will have rules such as putting up hand to speak and careful chairmanship to ensure voice of service users heard
- We will agree rules about sharing of contact information and appropriate contact times
- We will agree Confidentiality, code of conduct and public messages

8. What our group is not

- A place to raise individual complaints about staff or treatment
- A token gesture

9. Supports

- Reimbursement of out of pocket expenses
- Additional direct payment hours to cover time to attend meetings
- Induction and training
- Easy read documents
- Mindful chairmanship
- Mentorship role
- Access to a sitting service
- Accompanying person to the meeting
- Suitable meeting venues
- Transport
- Text message reminders

10. Accountability of the group