



Welcome

to your

Local Involvement Group

Western Trust Area, Adult Learning Disability

Personal and Public
Involvement (PPI)



Involving you,
improving care

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Welcome and Introduction 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. We welcome and encourage you to ask questions and make 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 them. However, the voice of each and every service user and carer 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.

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;

- 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;
- Have regular feedback from the Strategic Involvement Group about the progress of issues brought to it;
- 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 user's 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 Involvement Group will consist of Western Trust Learning Disability staff, 2 representatives elected from each Local Involvement Group, Public Health Agency and the Health and Social Care Board.

The Strategic Involvement Group will:

- Debate and address the issues brought to them by the Local Involvement Groups;
- 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;
- Ensure an open and two-way dialogue with each Local Involvement Group to ensure they are kept abreast of developments which will impact Learning Disability Services, service users and carers.

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.

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 spent.

A Planning Session was held to look at what Involvement means for carers and service users.

What we agreed Involvement is:

- Bringing together those who have expertise through work experience and lived experience to respectfully discuss how we can do things better;
- Representing the views of all Adults with a Learning Disability and carers as a community and not a personal agenda;
- Discussing service user and carers needs;
- Sharing information, ideas and solutions;
- Influencing how services work;
- Discussing what doesn't work;
- Working together with local people in a spirit of partnership to hear views and ideas about how to develop services and do things better;
- Working in a spirit of honesty and transparency on all sides;
- Ensuring people with Learning Disabilities become more aware of and involved with what is going on in their area;
- Having a voice and listening to others;
- Accepting that there will be other voices, opinions and ideas that are different from mine but just as important.

What we agreed involvement is not:

- Being ignored;
- Being told we are valued and then nobody recognising my contribution;
- Being fixed on things having to happen in a certain way;
- Blaming or accusing;
- A place to bring personal complaints or discuss individual cases;
- Hearing about decisions that have been taken without our knowledge when there was time for discussion;
- Saying yes to everything;
- Pretending to listen or care but then doing what you were going to do anyway;
- Making decisions without carer and service user input;

- Dominating or pushing own agenda;
- Being closed to others views;
- Keeping information from others or sharing it too late to inform discussions;
- Asking local people to accept statutory responsibility for decisions and budgets;
- A forum for procurement of services.

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'.

Why should I get Involved?

- Improving day to day life for people with Learning Disabilities 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.

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 different to those that have been used by service planners).

The support I can expect

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

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 and co-optees as agreed by members within the parameters of the Terms of Reference and Code of Conduct.
- WHSCT Learning Disability staff.

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).
- 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 Involvement.

How will my group work?

- We will be respectful and inclusive.
- We will address communication barriers.
- We will be a voice for those who cannot speak for themselves.
- We will meet every 6-8 weeks.
- 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.

What information, training and support will be provided?

Information and Training will be provided on an ongoing basis and will be determined by the needs of each Local Involvement Group. We also have 2 Local Involvement Facilitators who will meet with you before you join the group to take you through the induction and support you at each meeting. 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 during the process we will build your knowledge and understanding about:

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

Further information

For more information contact the Local Involvement Team at ALD.Involvement@westerntrust.hscni.net .