

Learning Disability Day Support National Learning Event | December 2021

As part of the New Models of Learning Disability Day Support Collaborative, ihub are hosting a series of National Learning Events. This event shared learning from the Collaborative so far, the work and experiences of the National Involvement Network and the viewpoints of a variety of stakeholders through a round table discussion.

New Models of Learning Disability Day Support Collaborative



Ashleigh Spalding - Improvement Advisor

National Involvement Network Members



- **Katrina Merrilees** With special thanks to **ARC**
- **Michael Connolly** **Scotland** for supporting this presentation and discussion
- **Tom Mitchell**

Round Table Discussion

- **National Involvement Network Members**
- **Arlene Johnstone** – Highland HSCP
- **Andrew MacDonald** – Scottish Government
- **Mark Mulhearn** – East Renfrewshire Carers Centre
- **Alan Stevenson** – Talking Points, East Renfrewshire HSCP
- **Rodger Watt** – Scottish Government

Participant feedback

“The points raised mirror support needs across the whole community with Covid raising the need for collaborative work and community based responses”

“Overview of Phase 1 was complex and covered a lot of ground, but first rate. NIN presentation was great, presenters showed a lot of courage.”

The following is a summary of the key learning points for participants during the event’s three sections:

Involving Service Users

- Staff capacity and skills impact on the extent to which service users are involved decisions
- Staff and service users can be limited by their experience of how budgets can be used in the design of care support plans
- Improving engagement strategies and approaches to involving people is crucial in the re-design/development processes

Insight into Service User experiences

- The right level of service input and support is essential to people with a learning disability being able to live their lives and overcome barriers.
- A lack of involvement in decision making processes impacts negatively on a service user’s wellbeing
- Where challenges cannot be overcome in the short term, good communication is key to ensuring the service user feels involved and can influence the decision making process

Ideas to consider locally

- Signing up to the Charter for Involvement
- Red Rules/Blue Rules – challenging organisational norms
- Mutual gain between service users and communities
- Improving terms and conditions of staff having a knock on effect on conditions for both people with support needs and their families



New Models of Learning Disability Day Support Collaborative – Phase 1 Learning

Utilising the [Scottish Approach to Service Design](#) we used a number of tools, engagement methods and evidence gathering activities to determine the key issues in developing day support services.

See the list of tools and resources, and other content shared in the session, opposite.

Through the analysis of the contextual ISM data and outcome measures for this collaborative, the national team identified a number of key learning points for the re-design of learning disability day support in Scotland:

Tools, resources and reports

- Review of [National focus group findings](#), previous local engagement, experience of engagement and resulting strategies
- Use of the [ISM](#) (Individual, Social, Material) behavioural model
- Critical review of engagement against the [Ladder of Coproduction](#)
- [Red/Blue Rules](#) barrier analysis – a review of strategic and policy barriers to service development
- [Phase 1 Learning Report](#)
- [Phase 1 Learning Report \(easy read\)](#)
- [Phase 2 Evidence Review](#)

Project teams need to have the capacity to undertake re-design work, multi-disciplinary input to address numerous areas of process, and the opportunity to build relationships to work together effectively.

Discovery is not a quick process even where project teams do meet the above criteria. Current user engagement and involvement strategies need to be understood and improved for an effective discovery phase.

Learning disability is a complex area where no one solution will meet the needs of everyone, nor address every part of the system which needs to change. The key areas for development give a high level overview of where change is needed, but each is underpinned by numerous individual aspects of services which need to be re-designed or improved.

The key area for development of changing the hearts and minds of communities has additional complications as it requires change in public perceptions and activity. While there is an element of this around re-designing or improving HSCP support for communities to engage in the topic of learning disability, there is also need for something more widely influential, perhaps similar to the Dementia Friendly campaign.

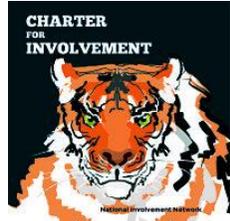
Inequalities have a huge impact on people with a learning disability, particularly people with profound and multiple learning disabilities. However, there is a lack of data around this at both a local and national level. In turn, this impacts on local team's understanding of inequalities in their area and makes accessing and using relevant data to inform their service planning difficult.

National Involvement Network

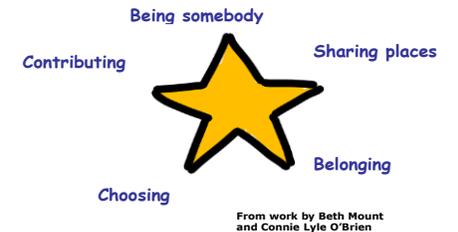
The National Involvement Network (NIN) is a large group of people with support needs from across Scotland. They started meeting in 2007, and now have local groups in different areas. The groups come together to share their ideas and experiences of involvement.

Charter for Involvement

- The [Charter](#) was written by NIN members to communicate how they want to be involved in decisions about the support they receive
- The Charter is all about people who get support being listened to and respected
- The Charter has 12 statements which fit with human rights
- 85 organisations have signed up to putting the Charter into practice
- NIN members encouraged the audience to read the Charter and sign up to putting it into practice



5 Valued Experiences



What involvement means

- NIN members spoke about what involvement means to them and the impact it can have on people living better, more fulfilling lives
- The audience were encouraged to think of things that they are involved in, how this made them feel, and what it would feel like to not be involved
- NIN members reflected that involvement training is needed for both people who provide services to understand why it matters, and people with support needs to think about getting more involved
- NIN members deliver “Being Involved” – training on involvement

Lived experience during the pandemic

- Reflecting on experience of support before and during the pandemic, the impact that a loss of choice and control can have on a person was significant
- These experiences were expanded in feedback from other NIN members who were struggling with a lack of support due to staffing and restrictions, and frustration with decisions being made without speaking to them first

To sign up to the Charter or find out more on the NIN please contact [ARC Scotland](#).

“They need to stop making decisions about our support without asking us first”

Key resources and links

- [The Charter for Involvement](#)
- [National Involvement Network](#)
- [Local Involvement Networks](#)
- [National Involvement Network \(Facebook page\)](#)
- [We're all in this together \(survey of social care workforce\)](#)

Round Table Discussion

The final part of the event was dedicated to a round table discussion with a focus on two of the Collaborative's key areas for development.

The following is a summary of the key points made for each area.

"how organisations can support and empower practitioners, processes, frameworks to be creative and innovative in providing support - really examine those myths of what you 'can't' do, really listen to the voices of those people who need support and find ways to have really good conversations where peoples needs/priorities/risk priorities differ"

Staff Empowerment

- Organisational rules and policy can be a barrier to creatively meeting peoples needs
- It can be helpful to explore barriers within organisations to better understand how working differently can overcome them
- Staff perceptions of what support can look like for the person can be limiting – particularly how support budgets can be used
- Carers feel that improving the terms and conditions for paid carers will improve the impact and sustainability of the overall sector - it has to be made "an attractive sector to join."

Supporting families to take a break

- Supporting families to take a break is inherently linked to the supported person's needs and support planning
- Sometimes these needs can conflict with each other, e.g. if a service user wishes to move away from traditional 9-3 building based support can impact on carers, such as going to work
- Perceptions of risk are important, the supported person must be safe and happy, but potential risks can affect judgement of what is safe
- Both carers, and the people they support can be affected by not having knowledge of what they can do with their support budgets

Service user perspective

Choice:

- Importance of having options
- People need to be listened to with personal preferences taken into account
- Communication of circumstances when options/access to preferences are limited

Respect:

- Listening and communication are essential to people feeling respected - *"I don't feel respected when not listened to by staff"*
- Not being offered the same opportunities as peers – *"felt like why is this happening? I've done nothing wrong"*

Safety:

- Service users can have similar concerns around safety as carers
- Concerns for safety travelling alone at night
- Being in a vulnerable position when meeting people without a learning disability

Next steps

- Participants feedback will be used to identify areas for future work and opportunities. If you have any additional comments, please email his.peopleledcare@nhs.scot and a member of the team can follow up with you.
- Our next National Learning Event will take place on **15 March 2022**

"I feel that I will take parts from each area of the event, it also reminded me to take time out to attend the events which are important to the work we do"