



Healthcare  
Improvement  
Scotland

# **An Equality Impact Assessment of**

**New Models for Learning Disability Day Support Collaborative**

**March 2023**

## 1. Introduction

Healthcare Improvement Scotland is required to assess the impact of applying a proposed new or revised policy, against the needs of the general equality duty, namely the duty to:

- Eliminate unlawful discrimination, harassment and victimisation and any other conduct prohibited by the Equality Act 2010;
- Advance equality of opportunity between people who share a protected characteristic and people who do not share it; and
- Foster good relations between people who share a protected characteristic and people who do not share it

The relevant protected characteristics are:

- age
- disability
- gender reassignment
- pregnancy and maternity
- race
- religion and belief
- sex
- sexual orientation
- marriage and civil partnership (relates to the elimination of discrimination only)

The recommendations made in this report seek to improve equality and to help meet the specific needs of people with the relevant protected characteristics, where possible.

Our impact assessments also consider if the New Models for Learning Disability Day Support Collaborative has the potential to impact on health inequalities.

Health inequalities are disparities in health outcomes between individuals or groups. Health inequalities arise because of inequalities in society, in the conditions in which people are born, grow, live, work, and age.

Health inequalities are influenced by a wide range of factors including access to education, employment and good housing; equitable access to healthcare; individuals' circumstances and behaviours, such as their diet and how much they drink, smoke or exercise; and income levels.

The potential impact of the New Models for Learning Disability Day Support Collaborative on an individual's human rights has also been considered.

Giving due regard to these factors is also intended to help Healthcare Improvement Scotland to meet its duties under the Fairer Scotland Duty, which requires public bodies to reduce inequalities of outcome caused by socioeconomic disadvantage.

## **2. Aim/Purpose of the New Models for Learning Disability Day Support Collaborative**

The review and redesign of day support for adults with learning disability has been an important agenda for many Health and Social Care Partnerships (HSCPs) for some time. At a strategic level, the Same as You (Scottish Government, 2000<sup>i</sup>) paved the way for a wholesale shift in thinking and approach to services for people with learning disabilities. The Keys to Life (Scottish Government, 2013<sup>ii</sup>) recognised that further work was required to reach the aspirations of a truly person-centred network of service provision and opportunities.

How support is provided not only has significant impact on those accessing the service, but also on their carers and families who often use this as a means to access a short break/respice. Pre COVID-19 the Collaborative Communities team were in discussion with several Health and Social Care Partnerships (HSCPs) around the redesign of day services with support requested to enable a co-designed and co-produced approach to exploring a shift from building based to community models of support.

During COVID-19, lockdown measures in Scotland resulted in the closure or significant reduction of building based day services for adults with complex needs in many areas. Some providers had adapted their services to provide support for people within the home environment and there have been early indications that some people are thriving with this approach. However, we found evidence that people with profound and multiple learning disabilities have been more adversely impacted than those with less complex needs, including a reduction in access to allied health care practitioners.

In these cases, alternative (e.g. digital) approaches have not resulted in better outcomes. Rather, people have lost confidence, skills, mobility and social connections – impacting on emotional wellbeing.

The closure or reduction of building based day services has had significant impact on people and carers during COVID-19<sup>iii</sup>, with many families taking on significantly increased caring roles. At the same time there has been a reduction in carer support available from provider organisations and also from wider family due to lockdown measures. This has further highlighted the importance of providing opportunities for short breaks/respice and ensuring the needs of carers are met within any future models of day support.

All of this aligns to the Scottish Government's reform of adult social care<sup>iv</sup>, which has as one of its key elements, a focus on developing new models of care. Any work done to explore new models of day support is of keen interest as are any policy or regulatory changes required to enable such models.

The key drivers for reviewing and redesigning day support opportunities at this moment in time therefore include:

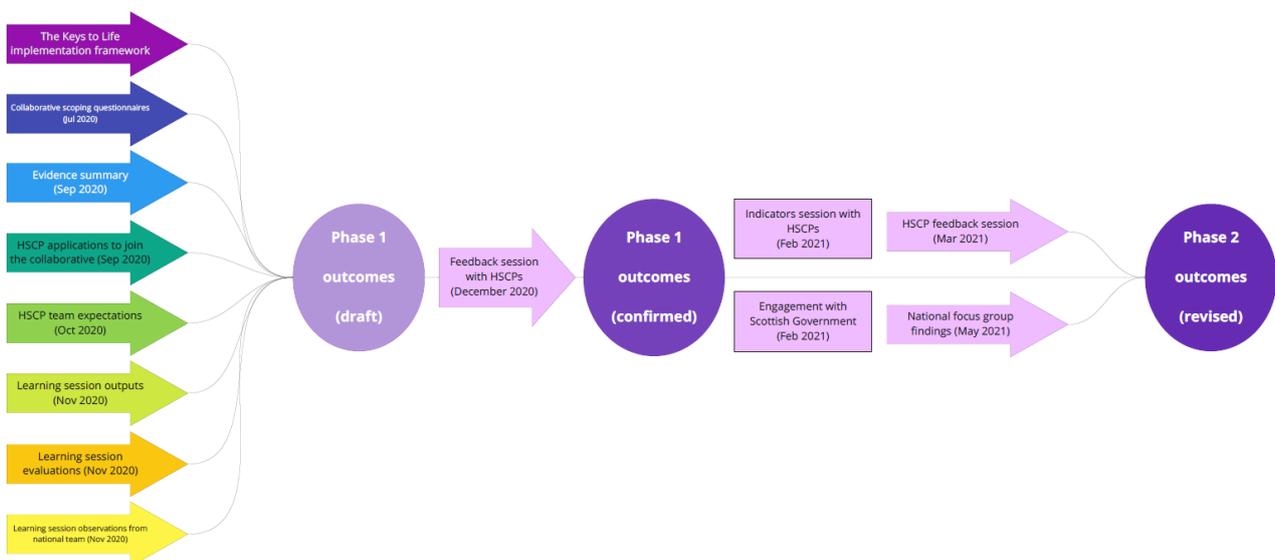
- Ensuring a range of support options are available to enable adults with a learning disability to have choice and control as outlined in the values of Self-Directed Support, which underpins the reform of adult social care in Scotland.
- A request for support from HSCPs to enable a co-produced approach to the review and redesign of day support.

- The needs of unpaid carers have been further highlighted during COVID-19, including the importance of building based day support. Family/carers seek confidence in services that are accessible for their family member and the person they care for. There is also a link to the provision of short breaks/respite.
- COVID-19 has seen the temporary closure of building based day support with an opportunity to learn from the degree of replacement with more individualised alternative support.
- Some services remain at reduced levels of operation or have not resumed at all. Rationale has included workforce challenges, compliance with COVID-19 restrictions (particularly during and exiting from earlier 'lockdown' periods). Stakeholders have identified significant variation in reinstating/reopening of services and noted a gap in meeting compliance with national policy on such.
- People accessing support have had some insight into other options with indications of this being a positive experience for some, yet at the same time, many community based services and settings are no longer available.
- Anxiety from people who access services about re-opening building based services and bringing numbers of people together during periods where COVID-19 variants were prominent.
- Indications from various forums that a review of day support will be included in commissioning strategies going forward.

The following outcomes have been coproduced with the HSCP Project Teams, drawing from the following sources:

- Keys to Life (2013)
- Pre-collaborative questionnaires (July 2020)
- Collaborative applications (October 2020)
- Feedback from the introductory and learning sessions (November 2020)
- Engagement with the HSCP Project Teams (December 2020)

The outcomes have been refined in phase two:



<b>Short-term outcomes (what is learned and gained)</b>
S1 Increased knowledge and skills in respect to involving people who use services, parents, families and carers in service design and improvement processes
S2 Insight gained into best practice, innovation and alternative models of support across Scotland and beyond, including learning from working through COVID-19
S3 Increased knowledge, skills and confidence in applying the use of SAAtSD and QI to support coproduced delivery
S4 Project Teams provide each other with peer appraisals and draw on wider learning from other areas/sectors as means of understanding best practice
S5 Greater understanding of national organisation strategies, expectations and supports available
S6 Insight gained into the opportunities and challenges to implementing national strategy at a local level

<b>Medium-term outcomes (what will be done differently)</b>
M1 The views of people who use services, families and carers contribute to discovery and define activities at a local level to create co-designed services
M2 Redesign and improvement work is undertaken using a systematic framework to manage change projects
M3 Day support models are developed with and peer input from other HSCPs
M4 Health, Social Care, independent and 3rd sectors develop a greater understanding of their current system (stakeholders, strengths and weaknesses and factors that influence local context).
M5 Knowledge of opportunities and challenges to implementing national strategy at a local level is used to inform Scottish Government strategy and policy

<b>Long-term outcomes (the difference made)</b>
L1 The needs and personal choices of people with learning disabilities, their families, and unpaid carers are at the centre of change ideas within organisations who deliver support.
L2 People with learning disabilities have greater choice in how and what opportunities they access, and are enabled to do this within in their local community
L3 Day support models are based on strong evidence/good practice and informed by policy and strategy
L4 Both organisations and the workforce are enabled to work in a way which promotes flexibility and choice for people with learning disabilities.
L5 National level strategy, policy and resources are structured in a way which promotes and supports organisations and the workforce to be flexible and responsive to the needs and choices of people with learning disabilities accessing support.

## Scope

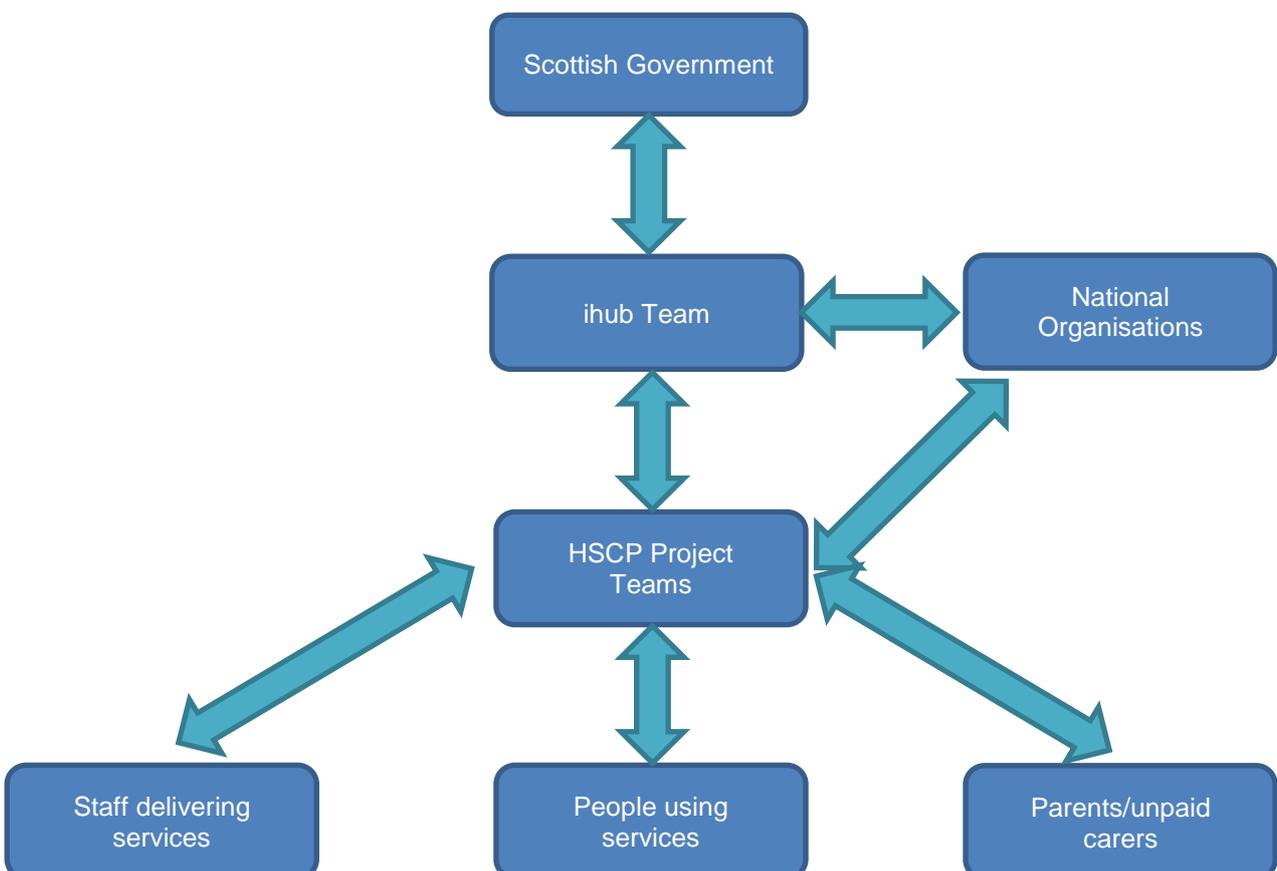
This project focussed on the delivery of day support for people with learning disabilities across Scotland. This includes those with profound and multiple learning disabilities. The initial programme was to last at total of 6 months and work with eight HSCPs, supporting them to discover, plan and implement new strategies to deliver support opportunities for people with learning disabilities. The ihub team also sought evidence in the form of literature reviews, learning from the collaborative and facilitating the communication of this learning to wider networks at both a local and national level.

The ihub team had no direct contact with service users or their families/unpaid carers. The responsibility of involvement was held by local HSCP Project Teams.

Although the ihub team did not have a direct impact on the experience of service users or their families/unpaid carers, it was necessary to consider how HSCPs, who are facilitating this change locally, identify and address inequalities and meaningfully involve people in their local improvement activity.

Engagement with national stakeholders identified significant inequality for people with profound and multiple learning disabilities, including the impact of the pausing of services, the lack of access to remobilised services and examples where the communication of this was lacking (e.g. no communication or letters sent in an inaccessible format).

### Flow of Impact and learning (Fig. 1)



### 3. Assessment of impact

The groups of people who might be impacted by this work include:

- adults with a learning disability who currently access day opportunities
- adults with a learning disability who do not currently access day opportunities
- parents, families and other unpaid carers who support adults with a learning disability, and
- staff who deliver services.

Having a learning disability is a protected characteristic in itself but there is the potential for further protected characteristics to be relevant within this group of people.

To ensure day support services are equally available to all adults with a learning disability and there is awareness / good relations around a range of different needs, it would be helpful to gather evidence and learning about the specific needs of disabled people and unpaid carers in relation to age, gender, sexuality, ethnicity, religion and any health conditions or impairments a person may have. For example, the needs of LGBT people can often be overlooked within learning disability, while cultural appropriateness may determine whether someone from a minority ethnic background feels able to access the service. Any access barriers that may be rooted in poverty could also be a cross-cutting consideration.

People with learning disabilities and unpaid carers will both be protected from discrimination under the Equality Act – either by being disabled according to the definition, or by the potential to experience discrimination by association with someone who has the protected characteristic.

The ihub team have been assessing the Collaborative’s consideration of, and impact on equalities throughout each phase of the programme. During Phase 1 of the work (Oct 2020 – May 2021) it was recognised that while the ihub team did not have a direct role in engaging with supported people and their families, consideration should be given to how the HSCP project teams who make up the Collaborative are addressing equality impact.

The ihub team assessed this through review of local Strategic Plan documentation, EQIA documentation in the relation to the plans, or anything specific to the re-design of day services which may include such an assessment. Our findings are demonstrated in the table below.

Partnership	Strategic Planning Reference to LD?	Completed EQIA for Plan?
Argyll & Bute	<a href="#">Yes</a>	
Edinburgh	<a href="#">Yes</a>	<a href="#">Yes</a> (specific to the re-design of Day Services)
Falkirk	<a href="#">Yes</a>	
Highland		

Partnership	Strategic Planning Reference to LD?	Completed EQIA for Plan?
North Ayrshire	<a href="#">Yes</a>	<a href="#">Yes</a>
Perth & Kinross	<a href="#">Yes</a>	<a href="#">Yes</a>
Renfrewshire	<a href="#">Yes</a>	<a href="#">Yes</a>
West Lothian	<a href="#">Yes</a> specific commissioning plan	<a href="#">Yes</a>

The findings from Phase 1 suggested a need for greater understanding of inequalities for people with a learning disability and how this could be improved upon through the individual team's work was a potential outcome for the Collaborative. The ihub team therefore increased the focus on inequalities throughout Phase 2 and measured it as an emerging outcome.

In Phase 2 of the work (June 2021 – March 2022), the number of core project teams was reduced to 4, Falkirk, North Ayrshire, Perth & Kinross, and West Lothian. Each project team completed an application to continue working with the Collaborative in which they were asked to detail any EQIA work undertaken locally, and, in relation to the Service Design approach, “what would you plan to focus on in the Discovery phase of the work? Include how you would ensure that the voice of supported people and unpaid carers is evident from the start of this process.”

The Phase 2 application process also included the condition of 1 member of each team participating in a regular “Inclusion Group”. This space allowed representation from each project team to come together and discuss the issues, opportunities, and any gaps in knowledge with each other, the ihub team, and a HIS Equalities and Diversity Officer. It also allowed the ihub team to gather insight into what could be offered from the Collaborative based on the knowledge gathered from the group.

The final alteration to Phase 2 was the involvement of people with lived experience in Collaborative events. The ihub team engaged with the People Led Policy Panel through Inclusion Scotland and the National Involvement Network who supported their members to contribute to national conversations. The team also continued to build on their Phase 1 relationship with PAMIS to ensure the voices of people with more complex disabilities, and their families were captured and heard in the Collaborative's work. Phase 3 started with the involvement of one of the Perth and Kinross team members who has Downs Syndrome in the delivery of the Collaborative's Learning Disability Week event. For all of these activities, consultation and feedback with participants, and personal reflections from the team, are reviewed on an ongoing basis.

The ihub team worked with PAMIS, ARC Scotland, and SCLD to create Design Personas which capture a range of individual people's experiences with inequality. The use of these will be monitored throughout the year alongside qualitative feedback on their use. There is also scope for the creation of carer Design Personas and the inequality they face in their role.

In phase 2 we invited the Scottish Learning Disability Observatory to present on the significant health inequalities that people with a learning disability experience. This includes:

- Premature death – die 20 years earlier, inequality greater for women and people are dying from preventable conditions
- Poor health – 43 times more likely to report poor health, inequality greater in younger age groups
- Pattern differs from general population – significant difference in morbidities with non learning disability population
- Complex and multiple health needs
- Invisible – lack of disaggregated data, often included in disability data

Phase 3 takes place from April 2022 – March 2023, with equality impact being assessed as described for Phase 2.

In this phase the national team has continued to emphasize the need for user involvement in the HSCP project teams whilst exploring how people with lived experience can participate in, and contribute to, national events.

The learning to date has highlighted the significant level of inequalities within inequalities.

## **Evidence**

### Phase 1

The Evidence & Evaluation for Improvement Team (EEvIT) conducted an evidence review in September 2020. The full report is included here:

<https://ihub.scot/news/evidence-summary-for-new-models-for-learning-disability-day-support-collaborative/>

The ihub team gathered the views of HSCP project teams throughout Phase 1 (October 2020 – May 2021). The purpose of this was to capture what was happening at the time within these services, what is working, what is not working, and what are their aspirations for the future. A variety of service design tools were used to gather and record this data, including, but not limited to, ISM Behaviour Model, Ladder of Participation, SWOT analysis and User Journey Mapping.

Evidence gaps include demographics of people who access day services and their carers, including information around protected characteristics. In phase 1 of this work the ihub team connected with People First and SCLD to learn from them and, in the care of People First, hold a focus group with users to inform our evaluation of need in this area.

As a means of combining best practice the ihub team will also run a National Learning Event to spread learning of best practice at a much wider level.

Learning during phase 1 has shown that there is limited information on Equalities Data in respect to learning disability services across the project teams. Only one team had

undertaken any form of specific equalities monitoring around the re-design of Learning Disability services, for all others this is something which is incorporated into Equalities Monitoring for their wider Strategic Plans. This would be examined in the Equity and Inclusion Group (recommendation 3).

## Phase 2

The Evidence & Evaluation for Improvement Team (EEvIT) conducted an evidence review in November 2021, followed by a presentation to the Inclusion Group. This evidence review included a specific question around inequalities data for people with a learning disability. While the report does give a high level picture of the impact of inequalities, it was difficult for EEvIT to go into more detail as data available often could not be disaggregated enough to inform beyond the high level overview. The full report, accompanying presentation and recording of the presentation are included here:

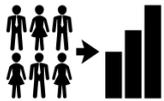
<https://ihub.scot/news/turning-evidence-into-action-phase-2-evidence-summary-for-new-models-for-learning-disability-day-support-collaborative/>

In March 2022 SLDO presented at our National Learning Event, sharing their data around health inequalities for people with a learning disability, which received great feedback from the audience on its usefulness. SLDO's slides are included in the presentations from the event:

<https://ihub.scot/news/national-learning-event-new-models-for-learning-disability-day-support-collaborative-mar-2022/>

People with lived experience of having a learning disability and unpaid carers have been enabled to have their voices heard through the National Learning Events and National Connections Group over the course of phase 2. Regardless of who has been involved the key themes for improvement in the eyes of the people use services is communication and involvement. The way we currently structure things in our organisations creates barriers to both people's involvement in their own support planning, but also in respect to having their voice heard when being consulted regarding service design and delivery.

The ihub team have continued to gather the views of HSCP project teams throughout Phase 2, through the Inclusion Group, baseline data templates requesting further information on demographics and protected characteristics of service users, and prompting discussions amongst teams when planning their Discovery work.

	<p><b>What do you know about the demographics of the people who access services?</b></p> <ul style="list-style-type: none"> <li>• What are their <a href="#">protected characteristics</a>?</li> <li>• Where do they live?</li> </ul>	
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*Extract from Baseline Data Questionnaire*

The Inclusion Group and the baseline data templates reinforced the evidence that there is a lack of robust data on the impact of inequalities for people with a learning disability locally. However, conversations with the Inclusion Group did provide anecdotal evidence of the impact on service users, and highlighted a previously unexplored impact of safeguarding (e.g. Adult Support and Protection) on people's ability to have intimate relationships.

The evidence from conversations with teams around the planning of their Discovery work suggests that project teams have made significant progress towards better understanding their roles in addressing inequalities within the Collaborative. All teams are exploring this slightly differently, but all have recognised that if they want to co-design with their users, they need to consider and actively change their communication methods to enable people to participate, rather than perpetuating existing inequalities in organisational participation and involvement strategies/methods.

The ideas teams are testing out or exploring are around;

- Easy Read communication
- Accessible and friendly spaces for engagement
- Communication tools such as talking mats to gather service user stories

One team has also recruited a team member who has Down Syndrome and have been going through ongoing learning over the past year to ensure their teammate can participate as an equal partner in their project. This has involved the creation of team member profiles, altering meeting formats and content, and focusing on individual strengths and assets to managing the work between themselves.

Considering what the ihub team have learned through gathering the views of project teams and hearing the voices of those with lived experience, inequalities will be a continued focus for the Collaborative throughout phase 3, to better understand their impact, and what good practice in respect to equality means for co-designing with this user base. (Recommendation 4)

Finally, our wider stakeholder base seem to have been inspired around the Collaborative project team's work around easy read documentation. In our final National Learning Event of Phase 2 they requested that Collaborative outputs are published in easy read alongside their full length counterparts. This is something the ihub team have already undertaken without seeing evidence of these documents being made use of. Current documents available for download in easy read are related to describing the Collaborative and disseminating high level learning from it. The ihub team therefore need to consider what information is it that the wider stakeholders really want in easy read, is it the learning from the Collaborative, or is it translating approaches into easy read? (Recommendation 5)

### Phase 3

In phase 3 we introduced a number of service design approaches, with accompanying narrative and scenario to explore inequalities:

- **User Journey Mapping** ([ihub.scot/user-journey-mapping](https://ihub.scot/user-journey-mapping)) – Based on learning from our exploration into inequalities the example draws on a situation that many with a learning disability may face. Exploring relationships, safety, risk-aversion

and the perspectives of the person, parents and staff.

In coaching sessions with project teams the sessions drew out the concerns of parents and the inequality that people with a learning disability face in an everyday part of life.

Sessions attendees estimated that the scenario would typically take a statutory service 6-8 weeks to reach the end goal for the service user. A participating third sector provider noted that they would be able to turn this around “almost instantly, certainly within a week”.

- **User Outcomes** ([ihub.scot/user-outcomes](http://ihub.scot/user-outcomes)) – This tool was tested and adapted with the HSCP Project Teams and sessions framed on challenging the views of service leads and owners against the perspectives of users and carers. The tool supported these conflicts being ‘put onto the table’ to challenge the views held by service owners, providing a space for the carer voice.

By extension, this tool can be used to emphasize the need for user involvement. In sessions, statutory staff were challenged on making assumptions, e.g. “in my opinion ...” and recommended that they involve people who access services to ascertain what their expectations actually are.

- **Generating ideas** ([ihub.scot/generating-ideas](http://ihub.scot/generating-ideas)) – This tool supports groups to generate a high volume of change ideas to a particular scenario or problem.

The approach we took provides six prompts to guide the ‘ideation’ stage of service design. We included a prompt for ‘ideas that reduce inequalities’ as it is intersectional in its relevance to the experiences and lives of service users.

The emphasis in this prompt is to generate ideas that will address the scenario or problem whilst contributing to an overall reduction in inequality faced by people with a learning disability.

The sites we worked with have involved people in a number of inclusive ways:

- **Storytelling** – Open discussion with people who access services and carers rather than traditional surveys or closed questions.
- **Inclusive methods** – Use of Makaton and Talking Mats in gather user feedback.
- **Design methods** – Use of art and design, including game design in user engagement in a day centre.
- **Alternative approaches** – Evening planning sessions with a group of 26 people (service users and their circles of support) to plan for better transition processes for young people.

- **Addressing inequalities** – The three sites have developed a relationship with PAMIS (see below) who are supporting them to explore how people with a profound learning and multiple disabilities are involved in inclusive life-long learning opportunities, recognising their right to purposeful and meaningful activity. Exploring how this is enabled through inclusive communication e.g. PAMIS digital passports ([PAMIS Digital Passports | PAMIS](#)) and multisensory story telling ([Storytelling | PAMIS](#)) as well as ensuring accessible environments e.g. changing places toilets ([Changing Places Toilets \(changing-places.org\)](#)). There are examples of impact emerging, e.g. through the Connecting Together Group in Falkirk a music venue is exploring adding a changing places toilet to their facility.

We facilitated user and carer representation in our national work in phase 3 through:

- A presentation from **PAMIS**, led by a carer, emphasizing “choice not chance” for people and that a building base is essential for people with profound and multiple learning disabilities.
- [Presentations](#) from staff from the **Inspired Community Enterprise Trust** with lived experience of learning disability on their employment journey, exposing and exploding myths about employment and sharing their roles in delivering services, including mentoring and developing more inclusive employment opportunities.
- A presentation from the **Perth & Kinross HSCP Project Team**, co-delivered by a member of the team with lived experience, on the launch of their discover activity.

See the [event summary](#) and [launch video](#) for more information.

We also heard from South Ayrshire Council on their **League of Champions** in a national learning event. In the session we heard how the process of involving people has changed significantly with learning at each stage, resulting in the development of the local strategy and the group continuing to oversee its implementation.

In our work with sites and our HSCP Learning Network Drop-in sessions we heard from services that:

- Eligibility criteria for access to services is often for “substantial and critical need” only, risking a ‘lost generation’ of people who cannot access services.
- In resuming services after and through the COVID-19 pandemic, not all people have returned to the same level of service (in days) that they previously received in a day centre. Reasons include the decimation of the workforce (both in terms of retention and recruitment issues) but also that in the earlier stages of service remobilisation, the reduced number of service users on site (to comply with physical distancing requirements) had led to improved outcomes for those people. Some services have recognised this in planning services and have stated that offering a higher ratio of staff to service user in a service has been a key learning point in the pandemic.

In contrast to the above, feedback from national stakeholders confirms that people, particularly those with profound or multiple learning disabilities have lost confidence, skills and the social connections and friends they gained through accessing service models previously.

Across phases 1-3 we have introduced speakers to present on alternative models of support, to share the user and carer voice and to allow HSCPs to make connections with national stakeholders and representative bodies. This has included:

- [ARC Scotland](#)
- [bOunceT](#)
- [Camphill Blair Drummond](#)
- [Care Inspectorate](#)
- [Community Brokerage Network](#)
- [Cornerstone](#)
- [East Renfrewshire Carers Centre](#)
- [Enable](#)
- [Gig Buddies](#)
- [Inclusion Scotland](#)
- [The National Development Team for Inclusion \(NDTi\)](#)
- [The National Involvement Network](#)
- [PAMIS](#)
- [People First \(Scotland\)](#)
- [The People-Led Policy Panel](#)
- [The Scottish Commission for Learning Disability](#)
- [The Scottish Government](#)
- [The Scottish Learning Disability Observatory](#)
- [The Scottish Social Services Council \(SSSC\)](#)
- [Senscot](#)
- [Shared Care Scotland](#)
- [Shared Lives](#)
- [Social Work Scotland](#)
- [Talking Points East Renfrewshire](#)
- [The Usual Place \(part of Inspired Community Enterprise Trust\)](#)
- [Uppertunity](#)
- [Values Into Action Scotland](#)

## 4. Recommendations for change

The following actions are recommended following the conclusion of Phase 3:

### 1. Documenting and sharing good practice in respect to user involvement in the service design process,

The approaches and tools used in the Collaborative can be of relevance to **people working in learning disability day services, other social service provision, service design and engagement staff.**

These can be found at: [ihub.scot/improvement-programmes/people-led-care/collaborative-communities/new-models-for-learning-disability-day-support-collaborative/tools-and-resources](https://ihub.scot/improvement-programmes/people-led-care/collaborative-communities/new-models-for-learning-disability-day-support-collaborative/tools-and-resources)

### 2. When undertaking service design, establishing a stakeholder group that can provide perspective and advise on equality matters is essential, as is the terms of their engagement.

A stakeholder group should include representation and/or allow input from organisations with specialist topic knowledge, unpaid carers and people who use the services.

Methods should be inclusive and the terms of engagement agreed with the group.

Local services should consider the connections made, and list of national and local organisations outlined earlier in this document. The list should not be considered definitive and should account for local context.

### 3. Place an emphasis on the exploration and understanding of inequalities.

To ensure that user experience and the inequalities within are explored and understood, a focal point for this is recommended in order to avoid summary observations and assumptions overlaying user experience.

In the Collaborative we arranged an Inclusion Group of which membership was mandatory for participating teams. Through this approach and the dedicated exploration of the inequalities we were able to frame our approaches and tools with a deeper relevance of user experience.

The work of the group was supplemented by an [evidence paper](#) on alternative models with a focus on inequality. Such an approach is recommended in order to avoid assumptions made from disaggregated data and assumptions that people inevitably make through lack of experience or unconscious bias.

Services should consider how the dimensions of inequality can be examined, who can contribute to this and how they will ensure the user voice is included.

#### **4. Document our own learning from the involvement of service users in Collaborative activities**

This final version of the EQiA documents our learning, including the elements we learned that we had been blind to when the work was started. It has been an informative and impactful journey and the approach has proved its worth, impacting on our approaches and the design of our outputs (coaching sessions and tools).

#### **5. Where meaningful, create easy-read versions of the Collaborative's outputs for wider stakeholders to share with their service users**

Our learning reports, and presentations of these have been made available in easy read format. The introductions to the design personas was also made available to suppliers in easy read for sharing with participants.

This approach has been examined carefully with due care and attention paid to what and when – e.g. the learning reports and the summary of the collaborative are vital to ensuring that the work is introduced properly to people who use services.

In this topic area we learned that they may have had negative experiences of involvement which accentuated the need for clear communication.

Of note to similar programmes of work – key stakeholders at a national level, with user representation included are often participating in the Cross Party Groups at the Scottish Parliament. Involving these stakeholders in early discussions about your work will reduce the risk of misconceptions about the role of the programme or project.

#### **6. Make better use of existing networks and stakeholder relationships**

A key learning for all national programmes and services is to ensure that as early as possible, there is engagement with stakeholders.

At a national level, the topic area of a programme may interconnect with the subject matter of the [Cross Party Groups](#) at the Scottish Parliament.

Reaching out to stakeholders will undoubtedly identify other networks, involvement structures, evidence and user experience. The following are examples in this subject area:

- a. The [People Led Policy Panel](#), a diverse group of people who all have lived experience of adult social care support, including unpaid carers.
- b. The [National Involvement Network](#), a network of people with additional support needs who seek to promote involvement, emphasising the [Charter for Involvement](#).
- c. [The Assembly](#), a growing number of individuals who support and facilitate accessible politics and active political engagement for Scotland's community of people with learning disabilities and/or autism.

- d. The Disabled Children and Young People Advisory Group (DCYPAG) - As part of the DCYPAG, a sub-group was established to consider in more detail how disabled children and young people with complex support needs and alternative communication, should be engaged to influence and inform the design and development of the National Care Service (NCS). [The ALLIANCE will be sharing the Knowledge Exchange online from May.](#)

It is not believed the above recommendations will create any new, adverse, impacts. However, for services to overlook these recommendations will risk further exacerbation of the inequality people face.

## 5. Monitoring and review

This EQIA was reviewed on a monthly cycle at Project Team meetings.

Phase 2 also involved direct engagement with people who use services, their families, and staff working in services. The EQIA was updated to reflect this.

### Updates

Date	Recommendation	Update	Status and next steps
May 2021	1. Include a question on equalities in the application form for phase two	Question included:  <b>3.3 Healthcare Improvement Scotland requires that any organisation wishing to submit their application to join the collaborative provides assurance and demonstrates that it is compliant with the requirements of the general equality duty, as set out in Section 149 of the Equality Act 2010. Please outline how you have considered the potential equality impact of your project (minimum 100 words). Alternatively, please attach your Equality Impact Assessment document with this application.</b>	Complete.  Review responses in application assessments.
	2. Put in place a stakeholder group that can provide perspective and advise on equality matters for the Collaborative	Scope changed to "National Connections Group" that will facilitate engagement and connections with people with lived experience and organisations that represent them and national organisations (including Scottish Government) with a locus in this work.  Three meetings in phase two.	Arrange meetings.  Consider external speakers and how people with lived experience can be included.  Complete.
	3. Put in place an Equity and Inclusion Working Group, drawing from HSCP Project Teams	Renamed to Inclusion Group.   Microsoft Word 97 - 2003 Document  Three meetings in phase two.	Arrange meetings.  Consider external speakers.  Complete.
June 2021	1. Include a question on equalities in the	Responses varied, ranging from quoting that there is policy in place and no return of an impact assessment to one return of the assessment.	Raise poor responses in feedback meetings with leads.

Date	Recommendation	Update	Status and next steps
	application form for phase two		Raise in first Inclusion Group meeting.  Complete.
<b>Sep 2021</b>	2. Put in place a stakeholder group that can provide perspective and advise on equality matters for the Collaborative	National Connections meeting 1 took place on 21 September.  Presentations from: <ul style="list-style-type: none"> <li>• Scottish Government on their Towards Transformation Plan (LD and Autism) and how people will be “drivers” for leadership</li> <li>• Camphill Blair Drummond on their service model and the impact of the pandemic on people</li> <li>• PAMIS on impact of pandemic on people with profound and multiple learning disabilities</li> <li>• Social Work Scotland on Self Directed Support (SDS)</li> </ul>	National Connections Sessions have brought in the voice of lived experience and examples of alternative models of support.  Complete.
	3. Put in place an Equity and Inclusion Working Group, drawing from HSCP Project Teams	Lack of responses and poor responses to question in phase two applications referenced to representatives.  Exploratory conversation took place considering the protected characteristics. This highlighted the following: <ul style="list-style-type: none"> <li>• <b>Age</b> – reference made to difficulty in people “retiring” from day support.</li> <li>• <b>Gender</b> – A feeling that “majority of clients are aware of genders”. Example of learning resource that supports women with a learning disability to understand their bodies, rights and choices and to protect emotional and physical wellbeing.</li> <li>• <b>Marriage and civil partnership</b> – Example of support for someone seeking divorce after difficulties in choosing to get married where an incapacity decision was in place. Significantly more difficult that for someone without.</li> <li>• <b>Physical disability</b> – lack of dedicated equipment in “mainstream” gyms for people who need physiotherapy, hence need to retain day centres</li> <li>• <b>Race</b> – Lack of data, sense that groups are underrepresented.</li> <li>• <b>Religion and belief</b> – Adult safety and protection issues with recruitment of people with learning disabilities to particular</li> </ul>	Meeting content to be reviewed for potential improvement projects.  Meeting topics included impact of pandemic and the inequalities that people with learning disabilities face.  Complete.

Date	Recommendation	Update	Status and next steps
		<p>sects. One area has a condensed personal plan that covers religion and belief.</p> <ul style="list-style-type: none"> <li>• <b>Sexual orientation</b> – Many barriers for people, “people identified by their condition”. Examples shared of safety and sex education programmes and of opportunities in other areas that the teams might aspire to (drag queens, gender non-conforming dressing).</li> </ul> <p>Other general points included:</p> <ul style="list-style-type: none"> <li>• Difficulty accessing the demographic data on people who access services and utilise SDS</li> <li>• Importance of community relationships</li> <li>• Importance of training for outcome-focussed assessments and that the pandemic is affecting demand and capacity – “taking focus away from outcome-focussed assessments”</li> <li>• Recognition locally that the EQIA (or equivalent) process was not always returned to after initial form completion.</li> </ul> <p>Session was a helpful opportunity to discuss service development, learn from other areas and reflect on own services</p>	
<b>Dec 2021</b>	2. Put in place a stakeholder group that can provide perspective and advise on equality matters for the Collaborative	<p>National Learning Event presentation from National Involvement Network (NIN) members and participation in Round Table Discussion with service leads.</p> <ul style="list-style-type: none"> <li>• Promotion of NIN Charter for Involvement which resulted in several HSCPs signing up to be part of the work</li> <li>• Highlighted the importance of enabling people to participate in conversations about their care and support – “nothing with me, without me”</li> <li>• Introduced the challenge supporting the safety of people with a learning disability without putting up barriers to their equal participation in society, e.g. going out at night.</li> </ul>	<ul style="list-style-type: none"> <li>• Continue to stay connected with the NIN.</li> <li>• Monitor further uptake of the Charter for Involvement as much as possible.</li> <li>• Continue the conversation around supporting positive risk taking through project team coaching sessions, and in other Collaborative activities such as problem tree mapping and design personas.</li> </ul> <p>Complete.</p>
	3. Put in place an Equity and Inclusion Working Group, drawing from HSCP Project Teams	Based on findings from the above Inclusion Group we have commissioned three organisations to produce personas (a tool used in service design) that will facilitate a stronger focus on the inequalities people face.	Use design personas in team coaching sessions in 2022:

Date	Recommendation	Update	Status and next steps
		<p><b>ARC Scotland</b></p> <ul style="list-style-type: none"> <li><a href="#">Aron persona</a></li> <li><a href="#">Casper persona</a></li> <li><a href="#">Karen persona</a></li> </ul> <p><b>SCLD</b></p> <ul style="list-style-type: none"> <li><a href="#">Grace persona</a></li> <li><a href="#">James persona</a></li> <li><a href="#">Robin persona</a></li> </ul> <p>The first 6 personas were shared with HSCP Project Teams at the December 2021 Collaborative Session. They were well received, with initial feedback from the attendees as follows:</p> <ul style="list-style-type: none"> <li><i>Good.</i></li> <li><i>They push thinking.</i></li> <li><i>The example of not liking art compared to a story locally where someone had said “everyone likes art”, assuming that everyone doing art (and crafts) therefore liked it. Similar to the line about not liking everyone at a service but having to spend time with them regardless – this aggregation of people.</i></li> <li><i>Very positive. Will use and share.</i></li> <li><i>Not used personas before. The frustrations box really hit home. Parallel learning for other services, e.g. older peoples services. Highlights what needs to change and improve.</i></li> <li><i>All personas so different, so complex and everyone has different needs. So much variation, shows the work that we need to do.</i></li> </ul>	<ol style="list-style-type: none"> <li>How do these experiences reflect the findings of your discovery activities?</li> <li>Is there further engagement you need to carry out? (service users, staff, families, providers)</li> <li>Are there any changes you would make to policy, process or service design?</li> </ol> <p>Personas to be shared on website (tools and resources).</p> <p>Personas to be used in design phase.</p> <p>Complete.</p>
<p><b>Mar 2022</b></p>	<p>3. Put in place an Equity and Inclusion Working Group, drawing from HSCP Project Teams</p>	<p>Based on findings from the above Inclusion Group we have commissioned three organisations to produce personas (a tool used in service design) that will facilitate a stronger focus on the inequalities people face.</p> <p><b>PAMIS</b></p> <ul style="list-style-type: none"> <li><a href="#">Miss F persona</a></li> <li><a href="#">Mr J persona</a></li> <li><a href="#">Miss L persona</a></li> </ul>	

Date	Recommendation	Update	Status and next steps
<b>May 2022</b>	4.Document our own learning from the involvement of service users in Collaborative activities	Lessons learned meetings established for the ihub project team on a regular basis to capture what works in the Collaborative delivery	Complete (documented in this EQIA).
<b>March 2023</b>	5. Where meaningful, create easy-read versions of the Collaborative’s outputs for wider stakeholders to share with their service users	<p>Easy read descriptions of persona design undertaken in phase 2.</p> <p><a href="#">Phase 3 easy read descriptor</a> updated and included in March 2023 National Learning Event papers.</p> <p>Easy read of phase 3 learning report (including final National Learning Event) commissioned (will be published with main report after conclusion of the Collaborative).</p>	Complete (pending final publication).
	6. Make better use of existing networks and stakeholder relationships	Recommendation made for national programmes.	<p>Documented in EQIA.</p> <p>Complete.</p>

## 6 Who carried out the impact assessment

The impact assessment of New Models for Day Supports for People with Learning Disabilities Collaborative was carried out by Alan Bigham and Ashleigh Spalding.

**EQIA completed by:** Ashleigh Spalding and Alan Bigham

**EQIA reviewed by:** Rosie Tyler-Greig

## 7. Contact Information

If you have any comments or questions about this report, or if you would like us to consider producing this report in an alternative format, please contact our Equality and Diversity Advisor:

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## Sources

<sup>i</sup> <https://www.webarchive.org.uk/wayback/archive/3000/https://www.gov.scot/resource/doc/1095/0001661.pdf>

<sup>ii</sup> <https://keystolife.info/>

<sup>iii</sup> <https://www.scottishhumanrights.com/media/2102/covid-19-social-care-monitoring-report-vfinal.pdf>

<sup>iv</sup> <https://www.gov.scot/policies/social-care/reforming-adult-social-care/>