

Supporting Carers – The Role of Integration

Thursday 7th November, Galashiels Volunteer Hall

Introduction

This event, hosted by [the Health and Social Care Alliance Scotland \(the ALLIANCE\)](#), gave attendees the chance to share their views on the support that is available to carers in the Borders. Discussions focused on carers' experiences of health and social care integration and the Carers Act. Both were identified as important themes in the area during early conversations with the ALLIANCE's local partners.

The ALLIANCE partnered with [Borders Care Voice](#), the [Borders Carers Centre](#), the [Coalition of Carers in Scotland](#) and the [Carers Trust Scotland](#) to plan and deliver this event.

This report will provide an outline of each partner's presentation, the table discussions that were had around each theme and the learning that the ALLIANCE's [Integration Support](#) team can take forward for future events.

Speakers

Jenny Smith, Chief Officer, Borders Care Voice – Local Experiences of Integration

Jenny began the day by providing an overview of the work of Borders Care Voice – a membership organisation that represents people who use services, unpaid carers and third sector organisations that are relevant to health and social care.

Borders Care Voice facilitate and attend a number of groups which allow them to hear carers' views. As members, carers can also sit on the organisation's board and attend events throughout the year.

Through these channels, Borders Care Voice have been able to gather local views on integration. They have found that carers do not generally have a great awareness of integration or its mechanisms. They are more interested in the services at the point they receive them, and the quality of them when they do.

However, Jenny added here that 'if integration is working well, carers don't need to know about it. It should be seamless.'

From the conversations they have had with carers in the Borders, however, health and social care services in the area are not seamless. Carers have called for information sharing and communication between providers to be improved, particularly between the Scottish Borders Council and NHS Borders. These issues

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can extend to the third sector too and are also common within parts of a single organisation. For example, between primary and secondary care within the NHS.

She gave the example of one carer who was tired of having to repeatedly retell their story: 'The GP didn't know I was a carer, even though the hospital does.'

However, Jenny highlighted four projects that are working well to support carers in the Borders:

- What Matters (Community Led Support) Hubs
 - The Scottish Borders Council's social work department lead these drop-in sessions, also staffed by the British Red Cross and the Borders Carers Centre. These sessions provide advice for carers about support available in their area.
 - These have reduced waiting lists for social work assessments, as many people can be supported without waiting for a full assessment.
- The Borders Carers Centre
 - The Borders Carers Centre has been commissioned locally to carry out Carer Support Plans, removing the burden from the Scottish Borders Council and opening doors for carers to access new services.
 - The Carers Centre also advocate on behalf of carers, or the person they care for, in order to get them the support they need.
- Cheviot
 - The Cheviot locality comprises Kelso, Jedburgh, St Boswells and the surrounding area. Before the Public Bodies (Joint Working) Act came into effect, Cheviot was an early test site for a number of integrated approaches.
 - As well as setting up a multi-disciplinary Community Health Team comprising physios, occupational therapists and nurses, they also co-located the social work team into Kelso Community Hospital.
 - Poynder View Resource Centre's Mental Health Older Adults Team provides community based specialist mental health support for people who have a diagnosis of Dementia in the Eastern Borders with input from psychiatrists, psychologists, occupational therapists and other allied health professionals. Carers in the Borders have reported positive experiences of this service and Borders Care Voice have noted greater involvement in their Dementia Working Group as a result.
- And the Joint Learning Disability Service
 - This service has been run by a multi-disciplinary team for many years, comprising social workers, nurses, physios, speech and language specialists and psychologists. This approach works well and is valued by carers.

Despite these success stories, Jenny said that the progress of integration has been slow in the Borders – making a comparison between the Scottish Borders Council, NHS Borders and a pair of tankers:

'Trying to change the course of the twin tankers (the Scottish Borders Council and NHS Borders) was never going to be a quick task. However, legislation for

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integration came at a time when those tankers were also tasked with operating with a smaller crew and less fuel.’

Nonetheless, integration has the potential to provide carers with the support they require and ‘further integration can only help when resources are tight and duplication of effort needs to be reduced.’

Shubhanna Hussain-Ahmed, Partnership Development Officer, Coalition of Carers in Scotland – Supporting Carers – The Role of Integration

Shubhanna provided a national perspective of carers’ experiences, speaking about what carers should expect from integrated health and social care services.

Her presentation provided a link between the morning and afternoon session – with the first half discussing carers’ experiences of health and social care integration and the second half discussing the Carers Act.

Shubhanna began with a reminder that one of the main intentions of integration was ‘to improve services for patients, carers, service users and their families.’ However, in order to achieve this, it is crucial that carers and people who use health and social care services are able to play a role in the planning and commissioning of integrated services.

Shubhanna then spoke about the Carers Collaborative, which is a peer support network that the Coalition of Carers in Scotland coordinate. The aim of the Carers Collaborative is to provide a forum for Integration Joint Board (IJB) Carer Representatives across Scotland to meet regularly and to share their experiences of being on IJBs. The Carers Collaborative reports annually on the progress that has been made in terms of carer involvement on IJBs. This year, the Carers Collaborative published their [third annual report](#).

She acknowledged that whilst it is an issue that carer representatives do not have any voting rights on their IJB, the focus should really be on whether the involvement of carers is meaningful and effective.

Over the last three years, carer representatives on IJBs have reported some improvement and progress in terms of being included. More areas are providing training for carer representatives, but this isn’t yet available across the board. Some IJBs lack ongoing mentoring to allow people to take part. And there is a real lack of consistency in terms of expense policies. This was a particular problem in the two years following the implementation of the Public Bodies (Joint Working) Act, where each IJB took a different approach. There is still no clear guidance around expense policies for carers, however the Coalition of Carers in Scotland plan to focus on this issue over the next year.

Shubhanna explained that a lack of time to prepare for meetings is also hindering carers’ involvement on IJBs. Carers lead very busy lives and are often sent 200-500

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page documents to read with very little notice prior to meetings. Carers have also highlighted their lack of influence in terms of bringing items to agendas.

Shubhanna then spoke about carers' experiences of the Carers Act, which came into effect in April 2018. The Coalition of Carers in Scotland carried out [a survey in November 2018](#) which found that:

- Only 16% of the carers knew what the Carers Act was and the rights it offered to carers;
- Around one third (33%) had heard of the Carers Act, but were not really sure what the legislation was about;
- Around half of all carers (51%) who responded to the survey had never heard of the Carers Act.

This lack of awareness is mirrored in carers' local experiences in the Borders. The Coalition of Carers in Scotland found that 70% of carers in the Borders had never heard of the Carers Act, 13% had heard about the Act but are not sure what it means and only 17% were fully aware.

Similarly, a clear majority of respondents in the Borders had never heard of the right to:

- Be involved in the planning of any carers' services that local authorities and health boards provide;
- Be involved in the hospital discharge planning of the person(s) that you are caring for, or plan to care for;
- Have your views taken into account when local authorities are assessing the needs of the person that you are caring for;
- Access support if your needs meet the local eligibility criteria for carers;
- Be involved in any assessment of your own needs for support;
- Access a Young Carer Statement if you are a young carer (under the age of 18) caring for a family member or friend;
- Access an Adult Carer Support Plan if you are an adult (aged 18+) and providing care to a family member or friend;
- Receive information and advice, including information about your rights as a carer.

Shubhanna ended the session by sharing some of the preliminary results from a follow up survey the Coalition of Carers in Scotland are currently undertaking, to gauge whether carers were any more aware of their rights under the Carers Act this year. It would appear that at a local and national level, carers are far more aware of their rights now. However, despite the increase in awareness of their rights, many carers are still reporting that those rights are not being implemented or realised in practice.

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Scott Lafferty, Development Manager, the Carers Trust Scotland – Network Partner Experience of the Carers Act

Scott provided another national perspective on carers' experiences of the Carers Act.

The Carers Trust Scotland engage with local carer centres across Scotland to investigate the practical experiences and implications of the Carers Act.

The Carers Act promotes a more holistic, person-centred approach and, from the experiences of the Carers Trust's network partners, has encouraged NHS and Health and Social Care Partnership staff to work far more collaboratively.

It has also encouraged digital development and engagement, with a lot of carer centres now using apps to engage with younger carers.

However, the Carers Act has brought unintended consequences. One carer who has been in touch with the Carers Trust has lost £3000 a year as a result of the Carers Act. And another has waited a year for an assessment.

Since the Act came into effect, the number of people contacting carer centres has increased, raising expectations. This has led to an increase in administrative work for carer centres, stretching staff's capacity. One member of staff at a local carer centre told the Carers Trust that they feel like a 'factory worker' as a result of the number of carer support plans they were asked to produce.

Jargon is another barrier that has arisen from the Carers Act, preventing people from accessing support.

And the Carers Trust have also found that inconsistent eligibility criteria are another key frustration for carers. Across Scotland there are 32 different sets of eligibility criteria and 32 different carer strategies. Whilst it is important that each local authority is able to tailor services to their communities, this is leading to a variation in carers' experiences of services across Scotland.

Debbie Rutherford, Information & Training Officer, Borders Carers Centre – The Carers Act – Where Are We Now?

Debbie began her presentation by saying that she would like to talk about the human side of the Carers Act.

She spoke about the duties placed upon both the Scottish Borders Council and NHS Borders in terms of implementing the Carers Act. The Borders Carers Centre works in partnership with both organisations to ensure these duties are met and that carers' views are taken into account.

The Borders Carers Centre engage with carers via Carers First, previously known as the Scottish Borders Carers Advisory Board. Carers First is a proactive forum of carers who are really helping to drive forward change in the Borders.

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Prior to the implementation of the Carers Act, the Carers Centre raised awareness of the Act's provisions by training professional staff as well as engaging with carers to explain the Act. This was followed up by an event following the Act's introduction to measure the progress that had been made. Carers were asked:

- If they had noticed any changes in the Borders?
- What is working well for them as a carer?
- What are the main challenges faced?
- What services have they used and what were the benefits?
- And what are the priorities for carers going forward?

To raise awareness amongst staff, they have also delivered Carers Act training to 1200 professionals across health and social care services. This appears to have made a real difference, as the Carers Centre have seen a 25% increase in referrals and a 30% increase in carers support plan completions.

They also worked in partnership with the Scottish Borders Council as well as the Scottish Government to design carer support plans. The Carers Centre's expertise ensured that these plans were comprehensive and met carers' needs.

As well as this, the Carers Centre supports the Scottish Government by collecting local data for the National Carers Census. This ensures that the Scottish Government has a clear idea of the pressures that carers are facing in the Borders, including the extensive nature of caring tasks, hours spent caring and the difference that support can make.

The Carers Centre also worked in partnership with the Scottish Borders Council to develop clear and accessible [eligibility criteria](#) for carer assessments as well as a [short breaks statement](#) and [local carer strategy – 'Carers Living Well.'](#)

Over the last year, they have also begun to deliver respite to carers in partnership with Shared Care Scotland. Together, they have provided holidays, short breaks and gifts to the equivalent value of £15,128 to 43 carers ranging from 'massages and free lunches to fantastic holidays and nights away.'

They also offer 'Time to Live' applications, which enable carers to apply for up to £300 towards a break which would help them feel supported. This can be used for a range of reasons, such as accessing a gym, taking a short weekend away to recharge batteries or buying a piece of equipment to help make life a bit easier.

In addition to these ongoing services, over the last 18 months they have introduced a free counselling service and a free carers legal surgery.

A crucial aspect of each of these projects is the Borders Carers Centre's commitment to partnership working. These initiatives would not have been as successful without the expertise of each partner, illustrating the importance of integrated approaches.

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Table Discussions

To cover both subjects the day was split into two halves, giving delegates the chance to share their experiences of integration in the morning and the Carers Act in the afternoon.

Integration Stories – Carers’ Experiences of Integration

Question One: What is working well? How are organisations working well together in the Borders to support local carers?

Attendees highlighted the Borders Carers Centre as a standard for local organisations to follow. The organisation’s in-house ‘Time to Live’ fund, which is able to top up carers’ budgets where necessary, was highlighted as a particularly successful local initiative.

This was used recently to support a man whose priority in the carer assessment he received was to keep his wife out of a care home. To do so, he had been given a budget by social services to access respite. Using his fund to book a golfing trip, the Borders Carers Centre were then able to top this up with money for food and drinks. This in-house fund was crucial in terms of overcoming any financial barriers he may have faced, ensuring the man was able to take respite and, in turn, keep his wife out of a care home.

Borders Care Voice were also praised during discussions for their ability to ‘give carers a voice’ and work collaboratively with the Borders Carers Centre. It was argued that, with the limited resources at their disposal, local organisations are doing great work engaging with carers, working in partnership and signposting carers onto relevant services.

Elsewhere, the East Ayrshire Carer Centre and Dundee Carer Centre were highlighted as examples of good practice further afield. The former for their work supporting social work to carry out carer support plans and the latter for their website, which was noted as being up to a very high standard in terms of information sharing and awareness raising.

Question Two: What could be improved? Could integrated health and social care services do more to support local carers?

It was noted that both the Borders Carers Centre and Borders Care Voice would be able to achieve more but are limited as a result of funding constraints.

One attendee said that this lack of funding has a knock-on effect on the services that are available to carers: ‘We’re always told that there’s no money for services. So we shouldn’t be surprised that there is none for carers.’

Communication between partners was highlighted repeatedly as something to be improved upon. Carers were frustrated at the number of times they have to repeat

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themselves when speaking to different health and social care staff. Better communication between partners would address this complaint, with one attendee suggesting a 'central database for all services.' However, it was noted that GDPR may make this difficult to achieve. GDPR was highlighted by a number of attendees as a barrier which prevents organisations from sharing information with one another and fully integrating.

People also described a lack of transparency within integrated health and social care services. Carers do not feel as if they are given a chance to share their views and meaningfully shape services and, as a result, services do not feel person-centred.

As well as feeding into services, carers need to hear more from organisations about what is available to them – and this information has to be as accessible as possible.

Attendees highlighted eligibility criteria and carer assessments as two subjects carers would like more information about.

When asked at one table if anyone had seen the eligibility criteria for support in the Borders, everyone answered no. In the words of one carer, carer assessments are similarly 'illusive.' During discussions, people were unsure what assessments involved or where to go to receive them. Amongst those with an awareness of carer assessments, there was a concern that these aren't always followed up: 'Carer assessments are in place but then there are no services to pick up the needs identified afterwards.'

It was also noted that the Carers Act has raised expectations amongst carers in the Borders, with services facing increasing pressure as a result. The Borders Carers Centre, for example, have been inundated with requests for carer support plans since the implementation of the Carers Act.

Question Three: How involved are carers in the planning and delivery of these services?

Carers in the Borders did not feel involved in the planning and delivery of integrated services. Attendees said that carers are invited to meet to discuss existing plans but are not involved in strategic changes.

There is a feeling that services involve carers reactively rather than routinely, despite an appetite for carers to have more say in 'what takes place on the ground.'

Question Four: To what extent would you say carers are aware of integration?

The vast majority of attendees believed that carers are not aware of the process of health and social care integration, with one carer saying that their first exposure to integration had been this event.

It was argued that carers are too busy, with too many responsibilities to keep up to date with policy developments such as integration. Integration is seen as 'just

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another change,' which 'doesn't feel linked to the day to the day experiences of carers.'

Other attendees were aware of integration but did not believe it was taking place. One carer said that they could not think of a single practical example that illustrated the positive effect of integration.

There was a feeling amongst other attendees that Scotland has been talking about integration for 20 years with little progress having been made, which has led to jadedness and cynicism.

Question Five: How are organisations working together to raise awareness of integration amongst carers? What more can be done?

Attendees said that conflicting organisational cultures within the NHS, the Scottish Borders Council and the third sector are preventing organisations from working together to raise awareness of integration.

IJBs have the potential to raise awareness amongst carer representatives. However, it was suggested that carers are not being given the support they need to take part in IJBs and, as a result, feel undervalued.

The Carers Act – Where Are We Now?

Question One: How are organisations working together in the Borders to deliver the Carers Act?

During discussions, the Borders Carers Centre and Borders Care Voice were highlighted as two organisations that are working together very successfully in partnership to deliver the Carers Act. The Borders Carers Centre also have good links to the Scottish Borders Council.

'What Matters Hubs' were praised for providing a community connection for carers in the Borders, encouraging organisations to work together, raising awareness of carers' experiences and signposting carers to services that may improve their health and wellbeing.

Attendees also highlighted Community Link Workers' role in terms of signposting – a role which is seen as crucial if organisations are to work together to deliver the Carers Act.

Outwith the Borders, East Ayrshire Council were praised for the information they provide about the Carers Act. Their information on young carer statements was highlighted as being particularly eye catching.

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Question Two: How dependent is the Carers Act on integrated working?

The general consensus amongst people in attendance was that the Carers Act was very dependent on integrated working. When asked at one table if the Carers Act could succeed without integration, everyone said that it could not.

It was suggested that by working together, organisations could create a single point of contact for carers. This would reduce the need for carers to continually retell their story, instead promoting information sharing across organisations.

It was argued that different partners bring different skills. And that utilising different organisation's networks creates more avenues to raise awareness of the services that are available to carers.

Question Three: Are you aware of what support has been made available to carers through the Carers Act? And, in your experience, are carers receiving this support?

Attendees agreed that whilst organisations with an interest in health and social care in the Borders were aware of the Carers Act, ordinary people and carers were not: 'If you asked people on the street, they'd have no idea what you were talking about.'

Jargon and inaccessible terminology are seen as barriers to people fully understanding the Carers Act.

Amongst those who did have some awareness of the Act, there was uncertainty about the rights it offers and what it means specifically for people living in the Borders.

Question Four: What more could be done to raise awareness of the Carers Act?

Attendees agreed that there is a lot more that could be done to raise awareness of the Carers Act. Potential engagement ideas included:

- Hosting more events such as this one, for carers to offer feedback;
- Empowering carers to engage through training with the Borders Carers Centre;
- National awareness campaigns;
- A 'carers line' that offers support at the right time;
- Using underutilised networks such as Community Councils;
- Third sector organisations (such as the British Red Cross);
- Social media (such as Facebook);
- Radio and TV;
- Word of mouth, family and friends;
- And local mail-outs (if GDPR compliant).

GDPR was mentioned as an unintended barrier which hampers information sharing and signposting and makes engaging with carers more difficult.

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The Scottish Government also have a responsibility to raise awareness in the area. As do elected members, Health and Social Care Partnerships (HSCPs) and Third Sector Interfaces (TSIs).

Extra support for carers would also free them up to attend physical engagement events such as this one. However, identification of carers was highlighted as a difficult issue without an easy solution.

There was a strong feeling that organisations are continually failing to engage with carers and that a change of approach is required: 'If we are rejected continually, we need to learn from this.'

One table agreed unanimously that the answer was to pay carers to engage with organisations. Carers in attendance felt that it was unfair that, whilst professionals from third sector and health and social care organisations are compensated for attending consultation events such as this one, carers are not. Carers lead very busy lives and there was resentment during this discussion that their time is not valued as highly as professionals.

New approaches will be required to engage with carers and raise awareness of the Carers Act in the Borders.

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Evaluation Feedback and Learning for Future Events

From evaluation feedback forms returned to ALLIANCE staff members, learning was gathered for future events.

Attendees referred to the event as 'very positive' and were happy to have been given a platform to share their views.

People particularly enjoyed the day's table discussions and felt very comfortable sharing their views with 'everyone being able to speak without any pressure.' As a result, people felt able to speak openly, 'honestly and frankly.' This created a 'down to earth' atmosphere where participants were more willing to discuss problems and barriers they are facing: 'It looked at all of the real issues, without avoiding challenges and issues.'

Attendees valued the opportunity to network and meet new people whose views they would not normally hear. The range of people in attendance was praised, with representatives from local carer services, national carer organisations, third sector organisations, the Scottish Borders Council, NHS Borders and the Scottish Government in attendance, alongside carers.

There was also praise for the range of speakers who provided a variety of perspectives. Attendees were also pleased with the range of information available. Information stands were placed throughout the hall for attendees to browse at the beginning of the day and during breaks. Both the information stands and speakers' presentations were seen as a valuable means of hearing more about the Carers Act and health and social care integration: 'I have a greater awareness as a result of attending.'

In terms of room for improvement, people in attendance felt that the venue could have been better. There were comments that the room was cold and that it was too large, which made hearing speakers' presentations from some parts of the hall difficult. The ALLIANCE will need to ensure that venues for future events have a good sound system and are generally up to an acceptable standard.

There was disappointment that a carer who was planning to deliver a presentation was unwell. However, attendees understood that this was unavoidable.

There were also suggestions that there could have been more carers in attendance for table discussions, with a better balance between carers and professionals from the third sector and health and social care. Whilst the aim of the day was to gather as wide a range of perspectives from different backgrounds as possible, and many carers were able to attend on the day, more could be done to support greater carer attendance at future events.

Their caring role makes it difficult for carers to attend events such as this. Many already struggle to balance their work commitments, caring responsibilities and time for themselves. This issue was touched upon in response to the fourth question during the afternoon's discussions, with suggestions that carers should be better compensated for their time.

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It may be worth considering the inclusion of the ALLIANCE's Digital Coordinator during planning for future events. Doing so would enable carers to attend remotely by streaming the event live or watching a recording in their own time. Carers could also potentially deliver presentations from the comfort of their own homes.

Overall, people commented that they would be interested in attending a similar event in the future. However, the ALLIANCE would have to ensure that all of the feedback given above is taken into account.

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Information Stands

- The ALLIANCE
- Borders Carers Centre
- Borders Care Voice
- Children's Health Scotland
- Scottish Health Council

Organisations Represented During Discussions

- Ability Borders SCIO
- Borders Carers Centre
- Borders Care Voice
- Brothers of Charity
- Carers Trust Scotland
- Central Borders Citizens Advice Bureau
- Children's Health Scotland
- Coalition of Carers in Scotland
- East Ayrshire Carers Centre
- East Ayrshire Health and Social Care Partnership
- Encompass
- Fetal Alcohol Spectrum Disorders (FASD) Scotland
- Life After Caring
- Lilliesleaf Ashkirk & Midlem Community Council
- NHS Borders
- Scottish Borders Community Councils' Network
- Scottish Borders Council
- Scottish Borders Social Enterprise Chamber CIC
- Scottish Government
- Scottish Health Council
- St. John's Nursing Home
- Quarriers

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Resources

[The Borders Carers Centre, Borders Care Voice, Scottish Borders HSCP: Living Well in the Scottish Borders](#)

[The Coalition of Carers in Scotland: Awareness of the Carers \(Scotland\) Act](#)

[The Coalition of Carers in Scotland: Equal, Expert and Valued](#)

[The Scottish Borders Council, Scottish Borders HSCP: Short Breaks Statement](#)

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For more information, please contact:

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About the ALLIANCE

[The Health and Social Care Alliance Scotland \(the ALLIANCE\)](#) is the national third sector intermediary for a range of health and social care organisations.

The ALLIANCE has over 2,900 members including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing unpaid care.

Many NHS Boards, Health and Social Care Partnerships and Primary/Community Care practices are associate members and many health and social care professionals are Professional Associates. Commercial organisations may also become Corporate Associates.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.