



We're Here Too!

Participation and older people

Empower,
Involve,
Include

About the events

Outside the Box and Scottish Care held a series of events in late 2014, to look at ways to ensure that older people who have additional support needs are able to have their say and be part of their community. This grew out of work on Making Choices, which is a project developing ways for older people to benefit from the greater flexibility that Self-directed support brings.

- Older people, including those who need extra support such as people living in care homes or sheltered housing and people who get home care, say they want to make choices about the support they get.
- They want to participate in shaping the services they get and helping the organisations that provide support to have good quality services.
- They want to be able to continue being part of their communities for as long as possible. This includes making a contribution as well as taking part in activities organised by other people.
- They want to have a range of different services and community opportunities available to them, so they can choose the combination that reflects their interests.
- They want to be part of making choices and decisions that affect everyone in their community, not just be involved in issues that mostly affect older people.
- They want other people to remember that they are part of the community, just like everyone else.

This report summarises what we discussed at the events and the possible solutions we identified for the problems that come up in many places.

- Slides and photographs from most of the presentations are on the website: www.otbds.org/werehere.
- There is also a fuller set of notes from the discussions.

Main messages

There are some barriers to some older people with higher support needs having their say and making a contribution in their communities. In other places people do not face these problems, or it has less impact.

People have come up with solutions to every actual and perceived barrier.

- Sometimes it is about changing attitudes towards older people with higher support needs and making the effort to listen.
- Sometimes it is about practical arrangements.
- Sometimes it is about reviewing processes that are getting in the way.

Often other people have experience of working in partnership with older people who need more support. Talking to other people and learning how they are doing things helps a lot.

What happens next?

There were 2 messages in almost every set of discussion notes: "Start the conversation" and "One size does not fit all". This report is part of starting the conversation.

- We will be circulating this report and hope other people will share it with people you know.
- We are gathering more examples of what people are doing to support and encourage participation by older people who need more support.
- People at the events went away with each other's contact details. We would like to hear how you got on sharing ideas and giving each other some advice and encouragement.
- People said they want to meet up again. We will arrange a follow up event in summer 2015.

"It has spurred me on to ask questions about service user involvement at every integration event I attend." (Feedback after the day)

Issues and possible solutions

Participation and older people

“It’s involving the right people at the right time in the right way.”

People said that they wanted older people’s voices to be heard. It is useful to think about why people are not participating. Then we can tackle all the barriers.

- The biggest barrier is when people don’t think their views matter – when they have low confidence and self-esteem.
- Another is older people having low expectations of participation when it has not led to change in the past.
- The practical barriers such as inappropriate venues and asking in unhelpful ways are important, but can get fixed when the right attitude is there.

Reaching people

- Get out and talk to people. Everywhere we can be asking people ‘what do you think?’
- Take notes of conversations, rather than give out evaluation or consultation forms.
- Digital inclusion can give more options for some older people.
- Connect with the community – friends, family, neighbours – as another way to reach older people who services think of as hard to reach. For example, get teenagers to ask their grannies and granddads about what they think.
- Public services can use opportunities to engage with people – such as talking to people who attend GP surgeries.

- Go to where people are – hairdressers, barbers, teasops, opticians, chemists, post offices, mobile library, community groups and the like.
- Use staff like link workers who are on the ground.

Everyone needs to remember about older people who can get excluded when we don’t take enough notice of the other circumstances in their lives.

- It includes older people who have dementia.
- It also includes people who have other mental health problems.
- People from BME (black and minority ethnic) communities may have different experiences and are less likely to be in touch with the same networks as other older people.
- Older LGBT (lesbian, gay, bi-sexual and transgender) people will have had different experiences when they were younger which may mean they are not certain of feeling welcome, and may have different views and priorities.

“Start where people are. Talk, ask, find out what matters to them, listen.”

“Have conversations – tea and a blether can be a better way to encourage older people – and most other people – to contribute.”

“Give staff the permission to talk to people.”

Encourage people to be involved

- Be clear what you are asking people to engage about and what you want to achieve.
- Make it relevant for the people you are asking.
- Do consultation with people, not at people. Include opportunities for people to tell you about what is important to them.
- Know your audience. Ask them what will work for them.
- Use plain English.

- Always work through the full process: Ask, Listen, Act, Feedback to people on what has been done.
- Allow more opportunities for people to share their knowledge and experience.

Make it a good experience for the people taking part and treat them well.

- Provide lunch, or tea and cakes.
- Arrange transport if needed.
- Make sure the venue is fully accessible.
- Set timings of meetings or discussions to suit the target audience.

How services respond is also important

- All staff can help change the way services listen and respond. If it's not feedback about your work or department, pass it on to the people for whom it is relevant.
- Recognise that listening is a skill. Not everyone is good at it. People can learn the skills once they accept this.
- Get cleverer about describing and evidencing the need for the types of services older people say they want.
- Build in hearing older people's voices to impact assessments when public bodies are looking at services or policies.

"The one change that could have the biggest impact is staff in services starting to really listen to what older people are saying."

Build up skills around participation

- Raise awareness of engaging with older people throughout organisations.
- Learn from organisations and people in other settings - the third sector has a lot of experience of participative service evaluations, for example.
- Demystify the 'formal consultation' - there is more than one way and time to get people's participation.
- Build up engagement skills, so staff in public bodies and providers do not think that focus groups and surveys are the only methods of participation.
- Build up community engagement networks in your area.

"Get together with people from different backgrounds and maybe also different views. Share the learning."

Presentations

Collective voices of older people

Highland Senior Citizens Network is an independent Highland-wide network of local participation groups and for individual older people.

Make it Happen - Falkirk District Forum is a way for people aged over 50 to get involved and have their say in community life. The Forum had support from Outside the Box while checking out if older people did want a forum and while getting started and it is now becoming a constituted group.

Grey Matters in Helensburgh is a collective voice for older people. It began in 2011 and there are now over 160 members.

Example of what an independent collective group can do:

- Grey Matters contributes to consultations and shaping services for older people.
- It also provides activities that older people want, such as talks on topics of interest and trips away. People have fun and enjoy each other's company as well as being a forum to discuss ideas and raise concerns.
- It now has services that give peer-based support to older people, such as timebanking and practical help with collecting prescriptions and the like when people come home from hospital.

"We start from the view that older people have got a lot of experience and have a lot to give."
(Member of Grey Matters)

"In other countries the elders run the village. Here, people assume that the elders need to be looked after."
(Member of Grey Matters)

There is a list of local groups led by older people across Scotland, with contact details, at: www.otbds.org/werehere

Points from the presentations

The Aberdeen Golden Games involved older people from the outset. This started off as planning a specific project but has extended to shaping strategic planning.

The Dementia-friendly communities in North Lanarkshire are shaping policies across Council activities, as well as changing perceptions of older people and getting more practical support for people.

More information

The Scottish Health Council has examples of good participation. SHC give advice and support to NHS Boards, which will also be useful with Integration.

www.scottishhealthcouncil.org

The Wisdom in Practice resources include discussion papers on inclusion of older people from BME communities and older LGBT people. www.wisdominpractice.org.uk/useful-resources/

Participation and co-production

People described how older people can look for support but find that the available services do not offer the support that they want. Co-production is one way of creating services that do reflect what people want as well as need.

It helps when people understand what is involved in good partnership working:

- Recognising it is about everyone's priorities and not just the public sector.
- Focussing on the role of older people as service users and of the voluntary sector, not just focussing on what happens between the NHS and Council.

The outcome of older people's contribution can be a range of things:

- Different ways of doing the current service – where, when, how it is presented, and lots more.
- A spin-off activity linked to or part of the first one.
- More contribution from older people in the current activities.
- An idea for a new service – doing something else.

Co-production can find more solutions to problems that affect many people and services.

- It can bring in more ideas around knotty problems such as transport for older people, especially in rural areas.
- Better understanding of co-production sits alongside changing the way we assess and commission services.
- The quality standards should still meet the vision that older people have.
- There is scope for co-production in making more use of existing services and resources, as well as starting new services.

More information

Outside the Box published 2 reports on co-production with older people as part of the Wisdom in Practice project:

- The experiences and ideas of people across Scotland who took part in an event.
- A review of the research literature and good practice, looking at what makes for effective co-production with older people, by the National Development Team for Inclusion.

www.wisdominpractice.org.uk/co-production

Creating and supporting community-based services and supports

Presentations

Get Together Groups in East Renfrewshire

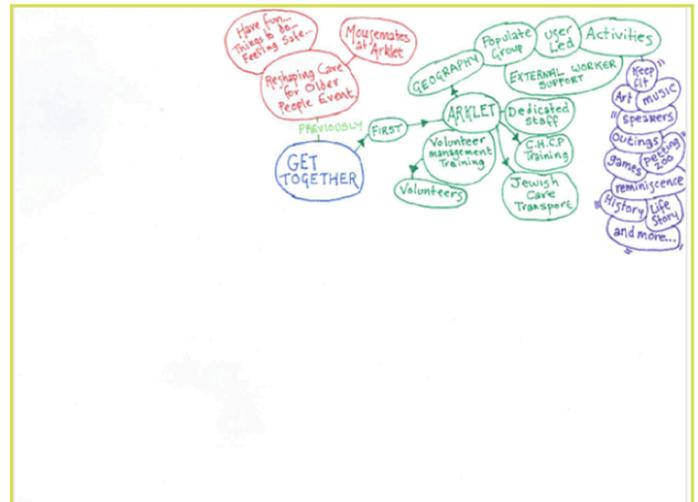
These show how listening to what a few people want led to good outcomes for them and to activities that gave other people more choices.

The groups were developed as a way for people referred for day services in East Renfrewshire to get together with other people who lived nearby. People said they wanted to have fun, have things to do and to feel safe.

The first place that the service approached was a residential care home, to ask if they could base some activities in their building for residents and others in the area. After discussions with the residents and management, they said Yes.

- Older people said what they were interested in.
- People from the local area who were attending were supported by staff to explore transport supports.
- Partnership staff helped them get groups and activities started.
- Other organisations contributed help in kind such as volunteers, training for those involved and transport to enable more people to come along.

This is how the project grew between September and October 2014. There were over 300 places in activities by older people.



How much did it cost?

- The venues and refreshments were all provided by the partners.
- Transport was provided by other partners.
- The speakers who gave talks to older people or provided training also covered their own costs.
- When people decided to go to an activity that had a cost, people paid their own way and some reduced rates were negotiated.

The feedback from the older people is very positive.

- 90% said they felt happier.
- 70% were less isolated.
- 96% said they were looking forward to the group.
- It gave a break to carers of people living at home (who were often older people themselves).

We looked at why community activities are happening in some care homes, but not in others. These are steps that help support good partnerships and have better outcomes for the older people living in the care homes.

- Start with something that is time-limited. Don't ask for a long-term commitment at the start – it could be just one day.
- It seems to be easier to start small. Try a joint or reaching out activity with a few people, or one part of a care home.
- Have simple, clear agreements when a community group is working with a care home (or with a public body or any other bigger care provider). List out what is happening and who is responsible for what. It only needs to be one page.
- There needs to be good leadership from managers and from the committee at the community group.
- Build the confidence of the staff at the care home.
- Also build the confidence of people at the community group or facility.
- Give everyone access to training, and ideally shared training or each group of people training the others. That way everyone gets more skills and they understand each other better.
- Start with the aim of it being win-win for everyone.
- It helps when everyone understand that it matters, and that community activities and links will benefit the older people involved.
- Be clear about the benefits to the care home or service provider – such as contributing to their Care Inspectorate grading.
- Try lots of activities, so people living at the care home can find what is right for them. Accept this means that the care home is involved with lots of community groups.
- Learn how to include and support people who have extra difficulties.
- Plan for the activities to be self-financing after any initial setting up costs.

Supporting people's community connections

People agreed that community connections are important for people, but that often older people who need more support drift away from their communities as contact with services increases.

- Plan to maintain and build on the connections people already have, or had, before focussing on trying to find new ones.
- People who are older and need more support benefit from contact with the community.
- In each community there are people who want to welcome them. The starting point is to encourage people to offer and be willing to ask.
- Mapping services is useful, but it is good to remember that people can start making connections while that is going on, or even manage without it.
- Think differently about the resources that are in the community – buildings, businesses, people's skills, churches and their buildings and congregations, youth organisations, music groups and more.
- Ask people what their skills are and who they know.
- Staff in public services can find out about how community groups keep people safe – from training for volunteers to making sure that vulnerable people are not at risk of abuse. Most groups are applying common sense and good practice, and have a good track record.
- It helps when you build in ways for older people to be making a contribution. That way community supports have a mutual support ethos.
- We could create more services for older people if it was easier for community groups to have access to buildings such as health centres and council offices when they are not being used at evenings and weekends.
- There would also be more support if it became easier for people to use their own homes, local hotels and cafés and the like.

"If people could get together as partners and think what each one can offer – practical stuff, not just money – then we could increase the overall capacity."

"Share the problem with the community and they will come up with solutions."

"There's more to a pub than alcohol."

"It's wrong that we are now talking about 'giving communities permission to care'. They were pushed away by services saying or implying that only trained workers had the skills."

Building a Dementia-friendly Community in North Lanarkshire

"This began with the NHS listening to what people with dementia were saying about what was important to them. They told us that they wanted everyone to understand dementia and how it impacts on ordinary life."

- It began in Motherwell in 2012.
- All 6 North Lanarkshire towns are now involved.
- By October 2014 73 businesses and organisations had signed up.
- People with dementia are involved and feed back on whether it is making a difference.
- Dementia features regularly in the local media in positive ways.
- They are sharing the learning with other parts on Scotland and now in other countries.
- There is a Dementia-friendly Community Toolkit on the Alzheimer Scotland website.

- This approach also fits with current policies on links between health and social care, co-production and community capacity building, as well as better results for individual people.

A dementia friendly community is composed of the whole community - shops, public services, faith communities, organisations, businesses, emergency services, transport and community leaders - who are committed to work together and help people with dementia to remain a part of their community and not become apart from it.

Older people going out and about

Living Streets is a UK-wide voluntary organisation that works to improve opportunities and safety for pedestrians.

Community Street Audits are a tool developed by Living Streets to enable community members to assess the walking environment from the perspective of the people that use it every day. Audits are community led, involving local people and officers working together to make improvements.

Living Streets supported residents in 2 care homes in Perth and Kinross to do audits of the streets near them.

- The aim was to find routes that residents could use for walks – which it did.
- They involved other people in the community, such as school children and parents.
- The audits benefited other people too and build relationships between the people living in the care homes and others in their community.

Points from presentations

The care homes and sheltered living service described ways they are supporting people to be active in their community, such as Wheatland supporting people to get involved with the Bo'ness Railway.

The forums are doing activities that support older people to make a contribution and show them doing this.

The Aberdeen Golden Games showed older people across Aberdeen being active and keeping well.

Tackling barriers to people getting care

Many older people and their relatives only contact services when it is an emergency.

- It would help if there was information for people on how and when to contact services, and encourage people to start talking to the local authority about support earlier and plan ahead more.
- Older people and frontline workers can help write the leaflets.

The media portraying older people as a burden and needing high levels of services does not help here.

- We need to challenge the assumptions and images of older people, including those with higher support needs.
- An underpinning issue is the values – older people not being valued and their contributions not recognised.

The type of care that is provided can also be a barrier. Making this meet what older people see as good quality will make a big difference:

- Continuity in services – consistency of staff, being reliable and being there at the same time and place.
- How care is presented – supporting people to keep well and have a life, rather than 'doing to' people who cannot cope.

We can recognise that people's needs change.

- Build in the ways people's social networks support them, rather than continuing to base future planning mostly on a medical model and around formal services.
- Respond quickly when someone needs more support – for example have quick access to OT assessments when someone ends a bit more equipment to enable them to stay at home.
- Do not assess people too soon after a fall, for example, or at least build in reviews early enough to recognise the ways in which people can recover and rebuild their skills and confidence.

"Waiting lists for assessment are a real problem. It would help if the Scottish Government set a time limit for this – like cancer treatment waiting times."

"Have positive images and examples of what people with dementia can do. Get a positive message over to people."

"Listen. Have higher expectations of older people and of how services can support us."

"It will help if the public gets more involved, saying what our expectations are and asking questions. What we expect from care homes should be supporting people to live as normal a life as possible."

"Older people can make this an election issue."

More information

Over the Fence is a website with information for people looking for support for themselves or for someone they care about. There is a page with local sources of information and advice for each council area in Scotland. www.overthefence.org.uk

The Scottish Government has a website with information for people receiving support, family carers, and for staff providing services. <http://www.selfdirectedsupportscotland.org.uk>

Age Scotland has material on older people's participation in the electoral process: www.ageuk.org.uk/scotland/get-involved/campaign-with-us/guide-to-lobbying/

Enabling risks

People at each event talked about risks and how this is often given as a reason for limiting older people's choices.

- The definition of risk is different for different people and organisations. But professionals are seen as the 'experts'.
- Organisations such as local authorities seem 'risk averse'. The policies around risk seem to be there to protect the organisations' interests rather than to protect people's interests.
- It feels as if there are confused, mixed messages coming from the Scottish Government to local authorities.
- 'Risk' can be used (or appears to be used) as an excuse for not doing some things that are new or seem difficult.
- It is not clear what is appropriate training to help staff reduce risk and enable older people to do the things they want to do.
- There is still a culture for participation of older people in some services.
- We need to understand more about the older person's perception of risk and how this is formed.

"We've lost sight of what risk assessments are for. It is to identify the potential problem so we can avoid or minimise them. It shouldn't be about creating barriers."

"Listen to what people are saying. Most older people are aware of risks. If they say they want to do something, they may have already taken account of the risks and know where they put the balance."

These are steps that help solve the problems.

- It helps when people remember what it is the person wants to achieve. Start with being person-centred and taking a holistic approach.
- Having a 'can do' attitude makes a big difference. In turn, this leads to demonstrating that activities can be done.
- Have an open a dialogue with all the partners.
- Use examples of best practice and share them locally and nationally – which then shows what is possible.
- Allow people opportunities to explore and define risk, so we understand what it means.
- Have an agreement on training and have multi-disciplinary training. It will help if there is more understanding of what people in different roles are trained to do.
- Use Cost-Benefit Analysis to demonstrate that the benefits outweigh the apparent risk.
- Take a holistic approach to managing and providing care.
- Use the skills and experience of all the staff inside the service and in partners. There will be someone who knows how to reduce a risk or make something safer.

Be specific – which risks, at which times and situation. For example, if the fear is that someone might have a fall, don't respond by stopping them doing anything.

- Look at where they are walking, how to reduce risks by walking aids, right footwear.
- Look at the environment, lighting, somewhere to sit for a rest, how to make the place safer for them.
- Look at how they can build up their balance and confidence.

The culture of the organisation makes a difference. Positive aspects are:

- A culture of promoting innovation and community links within organisations.
- Getting back to common sense.
- Explaining the risks of not doing something.
- Enough buy in from partners and from elected members and senior staff.
- Participation and support of older people, to say that we want risk enablement and not being stopped from having a life.
- Support from families and carers, who have been part of the conversations.
- Public understanding.

The processes for commissioning providers also need to reflect innovation and risk enablement:

- What is commissioned – focus on the service or the outcomes, how traditional the service is.
- How tenders are drawn up.
- How providers are assessed.

“Get staff to think and apply the standards at work to their own lives. What would it be like to they were too risk averse?”

Supporting people to be active

“Have you ever been on a long-haul flight, when you are cooped up in a seat for 9 hours, watching a film that you didn’t choose and not able to get up and move very much? How did you feel after it? Imagine being in a seat for 9, 10, 12 hours and more every day. That’s what happens to many older people living in care homes.” (Denise Fagg, Volunteer Activity Co-ordinator, Luncarty House Care Home)

Supporting people to be physically active is a good way to help people have a better quality of life, have a say in what they do, and increase their links with the community.

Perth and Kinross CHAN – Care Home Activity Network – is sharing ideas and skills among care homes to enable older people to be more active, and so improve their physical and mental well-being. Older people are involved in the planning at all stages and levels – planning what was needed at the start, setting the overall approach and what goes on at each care home.

The outcomes for residents have been very positive.

- People enjoy getting outside and doing more.
- Balance and movement are improving for many people.
- People’s physical and mental wellbeing are improved.
- There is lots to talk about and do in between the walks or swimming sessions etc.

“Ladies get out, keep out and get your muscles going.” (Resident from Perth, when interviewed on television)

“When in the water I feel like I am flying – I can move around freely, it’s exhilarating.” (Gentleman who finds walking difficult, after going swimming)

The Aberdeen Golden Games came from Aberdeen Council looking at ways to increase physical activity among older people, to keep people well.

- Older people were part of the planning at the outset and at every stage since then.
- In 2011 this was a 2-day event with free taster sessions at Aberdeen Sports Village, which 80 people attended.
- The next stage of the developments meant finding a different way to fund the games, to develop more skills among staff and to reach out to the most frail and most isolated people.
- The 2012 games were much bigger and the scale has grown since.
- Aberdeen Football Club have been involved since the beginning. They now provide a range of activities for older people throughout the year.

The value and impact are high.

- The Games are challenging stigma about what older people can and want to do.
- It gives older people opportunities to try new activities and shape the longer-term activity that is offered in Aberdeen City.
- It supported the establishment of greater partnership working between Aberdeen City Council, Sport Aberdeen, Aberdeen Football Club Community Trust, and Paths for All.
- There are now more activities developed by the partners specifically for older adults, including those receiving care at home, in sheltered housing complexes or in care homes.
- There are more links between older people living in all settings and other people in their community.

"We now feel part of the community again. It helps us keep moving and stay active." (Older person in Aberdeen)

Build in ways to promote innovation and ways to learn from each other

Innovation and learning from other people and places came up in almost every discussion.

- Self-directed support gives good opportunities to be innovative.
- Public services can understand more about what helps people be innovative – learning how people have done things, as well as what they did.
- We need realistic expectations of what innovative services can do: sensible timescales to get things going and then to see the impact, proportionate monitoring and feedback.
- Plan ways to try things, learn from what doesn't work as well as what does.
- Value small and local. Scale out when something works, don't assume it always means scaling up.
- Get systems in place to track the changes that innovative approaches make on the factors that matter to older people as well as on money and the impact for public services.
- We can build in more ways to learn from what other people are doing if we all take responsibility for sharing what we do.

"The money seems to be tied up in the wrong places. We hope that we can use the new strategic commissioning to help with this."

"It helps where individual people are willing to try things and are good at calculating the balance between risks, actions to reduce them, and the risks of being too safe. There is a craft of innovation and enabling risk, which people can learn."

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Contact us

Outside the Box

Outside the Box provides community development support for groups that want to develop an idea into a practical response:
www.otbds.org

We have projects developing the way older people and others who use social care services and community supports get what they need.

- Over the Fence gives information and advice for people starting to get support:
www.overthefence.org.uk
- Making Choices is developing information for older people, and there will be a companion resource for staff working in care services.
- Getting There supports the work of smaller, user-led organisations that also provide support:
www.gettingtheresds.com/

Wisdom in Practice has been supporting the development of services led by older people. It is funded by the Scottish Government through the Equalities Fund from 2012 - 2016:
www.wisdominpractice.org.uk/

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Scottish Care – People as Partners

Scottish Care represents the largest group of independent sector health and social care providers across Scotland. Amongst its aims Scottish Care works to ensure that those who use services in their own home or those who live in residential care are as fully involved as possible in making decisions which affect them, their lives and their home. We work with providers, better able to participate, make their voice heard and communicate their issues of concern and comment.

One of the projects Scottish Care manages is the People as Partners project, which over the last two years has been working with providers to get them ready for the new Self-Directed Support Act (SDS) which started in April 2014.

www.scottishcare.org
www.scottishcare.org/people-as-partners

